The past decade has seen significant developments in policy and practice for disabled children and their families. In particular there is a new focus upon access and inclusion, with increasing awareness of the need to see disabled children and families as active partners within policy development and implementation. There is growing awareness of the implications of disability discrimination legislation across children’s services and of the importance of improving arrangements for early identification and intervention to maximise disabled children’s participation within mainstream services. The National Service Framework, the advent of Children’s Trusts and a new Special Education Needs (SEN) Action Programme, together with the introduction of direct payments, give encouraging messages about multi-agency working and a strategic and ‘joined up’ approach to childhood disability. However, many disabled children and their families continue to experience discrimination, poverty and social exclusion. The challenge for the Government is to ensure that disabled children are ‘mainstreamed’ across all policy initiatives and to recognise the talents and ambitions of disabled children and their families in service design and implementation. Copyright © 2003 John Wiley & Sons, Ltd.

Introduction

[The key Government objective is] to ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed (Department of Health (DoH), 2001).

The past decade has seen significant changes in attitudes towards disabled people. The implementation of the Disability Discrimination Act 1995 and the creation of the Disability Rights Commission in 2002 challenge all services to think pro-actively about the rights and needs of disabled people. The quality of education, health and social care has generally
improved (although there are wide variations in eligibility and availability). There is
general recognition that disabled children are entitled to be valued and have the same
chance to succeed and participate in society as their non-disabled peers.

However, there is a compelling body of evidence from research and inspection reports that
many disabled children and their families continue to face multiple discrimination, low
expectations and many physical and social barriers to full participation in society.

Such barriers may include:

- Insufficient family support, practical help in the family home and too few breaks (with
  the most severely disabled children frequently receiving the least help because they may
  be viewed as ‘too disabled’ for local services);
- The high additional costs of disability;
- The lack of key workers to ensure well coordinated services planned to meet individual
  family needs;
- Frequent delays in identification, diagnosis and provision of support;
- Lack of good accessible information on available services;
- Inequalities in access to health and other services;
- Limited expectations of children’s educational achievements;
- Insufficient accessible sport, play, leisure and cultural activities;
- Lack of opportunities for young people moving to adult services;
- A limited range of culturally appropriate services for families from minority ethnic
  groups.

Disabled children and their families face a high risk of social exclusion if they do not
receive appropriate multi-agency support, in many cases throughout their lives. It is
estimated that there are currently around 320,000 disabled children aged between birth
and 16, with 110,000 children severely disabled. However, the Department of Work and
Pensions (DWP) Household Survey suggests that there are around 1 million young people
16–24 with a disability (as more broadly defined in the Disability Discrimination Act 1995).
There are an estimated 1.7 million pupils in schools with special educational needs (SEN),
of whom some 250,000 have statements of SEN.

Over the past decade, there has been a marked change in the population of disabled
children. More disabled children are surviving with complex multiple disabilities and rare
conditions because of improvements in neonatal and medical care. Many parents are
caring at home for children with complex health needs who, a generation ago, might not
have survived and half a generation ago would probably have ‘lived’ in hospital or other
institutional care on a long-term basis. There is also a marked reported increase in the
numbers of children with autistic spectrum disorders and Attention Deficit Hyperactivity
Disorder (ADHD) across the UK.

Families of disabled children incur considerable additional expenditure on heating,
housing, clothing, equipment, and other items. Although their need may be greater,
families with disabled children are less likely to own a car or a telephone than families
with non-disabled children. It is estimated that four out of five 12–14 year old disabled
young people need significant help with self-care (such as feeding, washing, dressing,
toileting, etc). A third of parents with a disabled child under two use more than three
pieces of equipment daily to provide basic care.
Housing presents many problems for families. A series of studies (Beresford, 1995) identify the challenges. Beresford and Oldman (2002) and Beresford and others (2000) report that nine out of ten families (in a survey of 3,000 families with a disabled child) report some difficulties with housing. Parents of children with a wide range of disabilities reported lack of space for play, care, equipment storage and carrying out therapies. Over one third of families found the location of their home unsuitable because it was either unsafe for their child or because of problems with neighbours. Four out of ten families said that their homes were cold, damp and/or in poor repair.

There is clear evidence of high levels of social exclusion, unmet need and dissatisfaction with limited access to service provision such as therapy, child care and short-term breaks. Many families report poor coordination of services and problems in accessing information. Families from minority ethnic groups may be in ‘double jeopardy’ because of the absence of information, advice, lack of awareness of their cultural needs and limited interpretation services. Notwithstanding the implementation of the Disability Discrimination Act 1995, many disabled people and their families report continuing discrimination and negative attitudes in accessing services.

Difficulties in accessing appropriate services can have significant impact upon the quality of life of disabled children, siblings and families and can in turn increase the risk of subsequent challenging behaviour, exclusion from school, poor educational attainments and limited life chances in terms of accessing further or higher education, vocational training and employment. Lack of appropriate and flexible family support services can lead to family break down. The past decade has seen a marked increase in 52 week residential education.

There is widespread evidence of additional disadvantage and social exclusion for disabled children from minority ethnic communities. Valuing People (DoH, 2001), Emerson and others (2001), Shah (1997), Hussain and Ahmad (2002) and Flynn (2002) clearly document the double discrimination relating to lack of effective information and communication about available services, a shortfall in appropriate family support services and the impact of racism and low income in many communities. Data from the Family Fund Trust indicates significant lower rates of take-up of Disability Living Allowance (DLA) and other disability allowances amongst families from minority ethnic groups.

However, looking positively to the future, the Government has begun to address the disadvantages faced by disabled children through a range of new legislation and policies. The Special Educational Needs and Disability Act 2001, the Carers and Disabled Children Act 2000, the Children (Leaving Care) Act 2000 and new programmes—for example, Quality Protects, NHS Plan and National Service Framework, Valuing People (DoH, 2001) and the new SEN Action Programme offer real opportunities for positive change and development.

**Addressing poverty and social exclusion in families with a disabled child**

The Government acknowledges and is committed to the eradication of child poverty. However, the true and additional costs of caring for a disabled child are not necessarily fully acknowledged in public policy. The Office of Population and Census Surveys (OPCS) studies (1986) and subsequent re-analysis confirms the major financial consequences for families who care for a disabled child at home. Parker (2000) concluded that 55 per cent of
families with a disabled child are living at or on the margins of poverty and households with a disabled child had (and probably still have) a *greater* likelihood of living in poverty than other disadvantaged social groups such as lone parents or families with disabled adults.

Parents of disabled children face on average three times the costs of parents of non-disabled children (Parker, 2000; Dobson and Middleton, 1998). It costs (1998 figures) on average £125,000 to bring up a child with significant disabilities (that is £7,355 per annum) in comparison with an average of £37,394 (£2,100 per annum) for a non-disabled child.

Most parents do not receive the maximum benefits because of lack of information or problems in making applications. This is particularly true of families from black and minority ethnic communities. Moreover the benefit system does not take account of the *cumulative* costs of having more than one disabled child in the family (Dobson and Middleton, 1998; Tozer, 2000).

The absence of affordable and appropriate child care for disabled children is a major factor in the financial disadvantage experienced by many families. Data from the Family Fund Trust (personal communication) demonstrates the difficulties experienced by families of disabled children in getting into, or retaining, employment (Table 1).

The Council for Disabled Children’s survey (2003) of the child-care needs of parents with a disabled child found that 85 per cent of over 2,000 parents wished to work full or part-time. But the majority either incurred considerable additional expenses or were unable to locate or afford appropriate child-care arrangements. Parents of older children or those with behaviour difficulties or complex disabilities reported the greatest difficulty in identifying appropriate and affordable care.

In implementing its commitment to ending child poverty, the Government could regard disabled children as a ‘target group’ for demonstrating *how* child poverty might be eradicated. Disabled children are an easily identifiable group. Their families frequently show great resilience and imagination in managing their own and other resources flexibly and effectively. Regular monitoring of the take-up of the new tax credits, disability-specific benefits such as DLA and their sufficiency to address the additional *current* costs of disabled children would give important messages as to *how* families might be better supported. Such a review could also explore regional variations in take-up, and access to child care for families from minority ethnic groups.

**‘Fulfilling lives’: key messages from young disabled people**

‘Fulfilling lives’ are a key theme within the *Valuing People* (DoH, 2001) objectives for disabled children and Quality Protects. However, the aspirations and ambitions of

<table>
<thead>
<tr>
<th>With disabled children</th>
<th>Without disabled children</th>
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<tbody>
<tr>
<td>3% working full-time</td>
<td>22% working full-time</td>
</tr>
<tr>
<td>13% working part-time</td>
<td>39% working part-time</td>
</tr>
<tr>
<td>84% not working</td>
<td>39% not working</td>
</tr>
</tbody>
</table>

*Table 1: Patterns of employment in mothers with (and without) disabled children (Family Fund Trust, 2003)*
disabled children have often been overlooked in wider consultations with young people. Over the past decade there has been increasing interest in consulting disabled children and young people about their lives and the services they would like to support them. Powerful and consistent messages emerge from a wide range of studies (Morris, 2001; Ward, 2001), in particular the wish to participate in ordinary community activities with their peers, to have access to play and leisure, to look forward to employment and a home of their own and to be respected in local communities.

A Disability Rights Commission survey (2002b) survey of the views and ambitions of 305 young disabled people aged 16–24 clearly demonstrates the barriers to social inclusion (and entry into adult life and employment) experienced by young disabled people. The young people were ambitious for well paid jobs, travel, their own home and family and access to continuing education. But they saw reality as lower incomes and continuing dependency upon families for support and a social life.

Current Government policy places great emphasis upon the active participation of all children and young people both within their own assessments, education and care and within wider service planning, development and review. There are exciting examples of young people directly contributing to the design of services and developing their skills as community leaders. But much more needs to be done to promote similar participation by disabled children and young people. Importantly, 74 per cent of the young people in the Disability Rights Commission (DRC) survey felt that the Government had limited awareness of their needs and rarely listened to their views. They did not yet feel that they were ‘active citizens’ in their local communities.

To improve active participation, it will be crucial that disabled children and young people are fully included and appropriately supported within the further development and implementation of the Children and Young People’s Unit (CYPU) Strategy for Children and Young People. This in turn will necessitate the planned development of the capacity and competence of statutory and other services to communicate individually and collectively with disabled children and young people.

**Educating for equality: access to education**

Education plays a pivotal role in the lives of all children and young people. For disabled children in particular the capacity of schools to provide a safe, supportive environment with a positive ethos and an interesting and stimulating broad curriculum, including Personal, Health and Social Education (PHSE) and Citizenship, will be essential. The past decade has seen many positive developments in the education of disabled children. The Department for Education and Skills (DfES) is consulting on a new SEN Action Programme, which will further develop the education agenda for pupils with disabilities or SEN within an SEN Framework, which actively promotes achievement and inclusion for all learners. The implementation of the disability duties in education under Part 4 of the Disability Discrimination Act 1995 (DDA) should ensure that disabled pupils are progressively and positively included in the whole life of their schools.

However, the Disability Rights Commission within its ‘Educating for Equality Campaign’ has highlighted significant challenges, in particular the importance of addressing the
current under-achievement of many disabled students. Disabled people are currently only half as likely to attend further or higher education as non-disabled people and are twice as likely to leave school with no formal qualifications. In many cases, the lack of opportunity relates to uncertainty about a range of issues including risk management, communication strategies and in some cases a lack of awareness of the potential of disabled students. Currently only 23 per cent of primary schools and 10 per cent of secondary schools are fully accessible.

The Disability Rights Commission (DRC) concerns are mirrored within the Audit Commission report (Special Educational Needs: A Mainstream Issue, 2002). The Audit Commission found wide variations in the level of support available for individual pupils; considerable parental concerns about ‘fighting for resources’ and variable attitudes to disabled pupils in mainstream schools, together with a lack of clarity about schools’ delegated budgets safeguarding the interests of children with disabilities or SEN. The Audit Commission also noted that currently 87 per cent of pupils permanently excluded from primary schools and 60 per cent from secondary schools, have SEN (including disabilities).

However, there are positive messages for the future. Disabled pupils are likely to need support from multiple sources. The new SEN Action Programme is strategic, with goals set over a ten year period. Its key themes of early identification, intervention, access and inclusion are applicable to services for disabled children and to the wider group of children regarded as being ‘at risk’.

The new disability duties in education (DDA Part 4), linked to the Government’s inclusion programme and a consultation on the future role of special schools also offer a positive agenda for change. Very importantly the SEN Action Programme recognises the challenge of recognising and celebrating achievement for those pupils who cannot access formal examination systems but nonetheless progress not only academically but in terms of their wider life skills.

New opportunities also include building on the potential of the Extended Schools Programme to promote access and inclusion for disabled children and their families. Accessible schools benefit whole communities (through developing a range of after school and homework clubs, community use of school facilities and child care for disabled children on school sites). Their further development as ‘full-service’ schools with the co-location of health and social services on site has particular significance for disabled children, who are likely to need multi-agency support in accessing education, play and leisure services or child care.

**Improving service coordination and delivery**

The past decade has seen some significant improvements across all services for disabled children and their families. The Quality Protects Programme, designed to improve social services for vulnerable children, has delivered additional ear-marked support for disabled children (£30, million in 2003/4). An analysis of the Year 4 QP Management Action Plans (Council for Disabled Children, 2003) shows encouraging innovative, user focused and ‘joined up’ service development in many authorities.
The SEN and Disability Act 2001 and the new Part 4 duties in the DDA 1995 have created higher expectations of the potential achievements of disabled children and raised awareness in education providers of their duties to promote access and inclusion. The Carers and Disabled Children Act 2001 offers new opportunities for flexible and individualised packages of support through the use of direct payments. *Valuing People* (DoH, 2001), the Government’s National Learning Disability Strategy and the *Valuing People* (DoH, 2001) Implementation Team are encouraging better community based services for young people with learning disabilities and their carers. Many families still report wide variations in the availability of services and support. But there are new and important opportunities for addressing the current lack of coherence in provision for disabled children and their families and for promoting greater inclusion within mainstream services.

**Addressing inequalities in health: The National Service Framework**

Notwithstanding a policy shift towards a social rather than medical model of disability, the majority of disabled children are likely to be multiple users of child health services. Service integration is essential for the well-being of disabled children, who may require a health input into a wide range of provision, including play and leisure, child care, short breaks, behaviour management, provision of equipment, and nursing, domiciliary or palliative care. Without such support, families may be unable to cope and may request residential education or other provision and disabled children’s access to education and other mainstream services may be severely limited.

The National Service Framework (which includes an External Working Group on Disabled Children) is setting standards, to ensure that health, education and social care are delivered as an integrated service. These standards should ensure that disabled children are identified, assessed, and systematically tracked throughout childhood and into adult life.

**Health Act flexibilities and the role of Children’s Trusts**

A key element within effective multi-agency working for disabled children will be the breaking down structural, fiscal and cultural barriers between agencies. Existing mechanisms within Health Act flexibility (for example, pooled budgets) could be actively developed to maximise multi-agency working and avoid duplication. Children’s Trusts offer a major opportunity to model and evaluate new patterns of joint working. A key element within such joint working should be the development of protocols and procedures for the delivery of community and specialist support across a range of inclusive and specialist community settings.

There is widespread support for the pilot Children’s Trusts to demonstrate new approaches to planning, commissioning, financing and delivering accessible and inclusive services for disabled children and to ‘model’ multi-agency approaches to identification, assessment, referral and tracking (IRT). Indeed it has been argued that if Children’s Trusts can ‘work’ for disabled children, then they will be equally effective for the wider range of vulnerable children.
Early intervention and support: reducing risk and social exclusion

Early intervention and appropriate support are crucial to maximise disabled children’s abilities and potential and to ensure that appropriate interventions are made to ensure optimum development. A growing number of Sure Start programmes, Early Years Development and Childcare Partnerships (EYDCPs) and Early Excellence Centres are already developing innovative services for disabled children. A number of early support pilot projects are currently testing out the guidance Together from the Start (DfES and DoH, 2003), with regard to different models for effective multi-agency early identification, intervention and family support. The outcomes from the evaluation of the Early Support Pilot Projects should have immediate benefit in terms of improved evidence based integration of services and initiatives through:

- Developing models for multi-agency early identification and referral.
- Developing and implementing the role of the key worker and the introduction of the multi-agency ‘Family Support Plan’ to avoid duplication of services and encourage multi-agency assessment and provision (having regard to its potential for use within the Integrated Assessment System).

The test of the effectiveness of both Sure Start and the Early Support Pilot Programmes will be the creation of replicable protocols and procedures in place to ensure that disabled children are fully included within all local planning arrangements and policies and procedures.

Transition to adult life: improving the life chances of young disabled people

In recent years, there has been increasing commitment to improving transition planning and support for young disabled people moving into adulthood. But there are wide variations in the quality of local planning arrangements and evidence of a frequent lack of coordination between children’s and adult services. Young people and their families express concern at discrimination in access to further education and training and a range of different, confusing and often inadequate levels of funding support as young people move through education, training and into paid employment.

The use of direct payments and the Independent Living Fund grants for young disabled people are still underdeveloped. There are ongoing problems with the provision and repair of equipment (with wide regional variations). Following education and training, many young disabled people continue to experience barriers to employment, with low expectations of their potential and limited awareness of the Access to Work scheme for younger disabled people. The role of Connexions will be crucial, but needs further development to ensure that there is specialist support and advice in all Connexions Partnerships and that disabled young people benefit from the Government’s proposals for 14–19 year olds.

Disabled young people at transition will be a key ‘marker’ for the success of the process of IRT as set out in the Coordinating Children’s Services Programme. They are likely to have life-long support needs and to receive services from a range of agencies over time. Local authorities, who have been asked to establish effective systems by Autumn 2003, should
be expected to include procedures which ensure that disabled children are central to any tracking arrangements and that there are effective arrangements in place for information exchange and realistic planning.

**In conclusion**

As noted, disabled children and families have benefited from a wide range of Government policies and initiatives. There have been encouraging moves towards greater educational and social inclusion and some innovative community support services. Most encouragingly, there is recognition that disabled children can and do succeed. They are ambitious for ‘fulfilling lives’, but, as noted, they and their families frequently experience discontinuity, fragmentation and poor quality support. There are wide regional variations in the quality and coherence of available support.

Notwithstanding the high risk of social exclusion and disadvantage, services for disabled children are characterised by innovative and effective models for parent and child participation in individual decision-making and as partners in policy making. The role of the voluntary sector is well developed. Despite the double jeopardy experienced by many disabled children from minority ethnic groups, there are positive models for working with families and whole communities around disability and SEN.

IRT and the emphasis upon preventative and well-coordinated children’s services are crucial to the well-being of disabled children. If the Green Paper leads to new and effective early identification, referral and tracking system for children ‘at risk’, then disabled children may well benefit the most.

The challenge for Government policy is that disabled children require a range of services, which may vary over time but might include:

- **Universal services** (for example, education, primary health care)
- **Targeted services** (for example, Sure Start)
- **Specialist services** (for example, Child and Adolescent Mental Health Services (CAMHS), special educational provision, short term breaks)
- **Rehabilitative services** (for example, child protection, secondary or tertiary health care).

The UK is unique amongst its European counterparts in having disability discrimination legislation and a Disability Rights Commission. If we are to achieve the Disability Rights Commission’s goal of: ‘*a society where all disabled people can participate fully as equal citizens*’ then there is an ongoing challenge in ensuring that disabled children are central to all Government policies (perhaps through a ‘disability impact’ statement on all new initiatives). Most importantly, we now know what a good inclusive school, a high quality family support services or good health care should look like for disabled children. But, as noted below, the Government has an ongoing challenge for change:

*Services play a vital role in meeting the needs of disabled children and their families and in ensuring that they are not excluded from the opportunities that most non-disabled children and their families take for granted. A common theme from parents’ and children’s accounts is the desire for an ordinary and reasonable quality of life. Yet, research suggests there is a long way to go before this is achieved.*

Social
attitudes and limited and variable service provision continue to exclude disabled children from many opportunities and to constrain the lives of their families (DoH, 2002, Quality Protects Research Briefings: Meeting the Needs of Disabled Children).

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