



People, not budgets

Valuing disabled children

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SUMMARY

- There are 49,000 severely disabled children in Britain. The great majority (91%) of them live at home, imposing great strains on family life.
- The level of support given to these families by social services is often extremely poor. The system is bureaucratic, has little sense of responsibility and is fuelled by ideological theories that have little relevance to everyday life.
- 48% of families receive no support whatsoever from outside the family; a further 30% received less than two hours help per week with care tasks in the home; 80% say that health and social services are not properly co-ordinated; another 37% of families have been in contact with eight or more professionals; and respite and residential care are scarce.
- Families living in these circumstances tend to know what they need. They would also usually much rather choose care services themselves than receive insufficient help from local authorities. Unfortunately, the rigidity of the current system does not give families any personal choice.
- Of the £540 million that is spent by social service departments on disabled children, £140 million (26%) is spent on ‘assessment and commissioning’ tasks.
- Recent Government initiatives, while well-intentioned, have aggravated the already poor levels of care. For example, the Care Standards Act 2000 has added a substantial burden of

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regulation and costs on providers of care. 2,000 Care Homes have closed in the last five years.

- Advances in medicine mean that more disabled children are being born and are able to live longer. The number of severely disabled children in need of care is therefore set to increase in the coming years.
- Other countries are able to provide a far better level of care to disabled children. In particular, Austria could provide an excellent model on which to base reform.

Recommendations

- The money currently spent on social service commissioning should be allocated directly to disabled families. This would be a non-means-tested payment paid in addition to current benefits. It would be paid directly to every family providing care at home (and would, at current expenditure levels, be worth £115 a week). Families would be free to decide how to spend the money on the care of their choice.
- In addition, “Care Assessment Teams” would be established as a “one-stop shop” for disabled families.
- The supply of respite and residential care homes should also be liberated by modernising the regulatory approach (through the adoption of the ISO 9000 quality control system) and by providing a more attractive fiscal regime.
- These proposals would require substantial change to the way in which social services respond to the needs of disabled children. They could provide a template for the wider reform of social services.
- The proposals are consistent with the broad direction of public sector reform: they are based on giving greater choice to disabled families and greater freedom to suppliers of care to respond to that choice.

PREFACE

THE BIRTH OF A PROFOUNDLY DISABLED CHILD is an event that rocks any family to its foundations. It tests the bonds of relationships and the strength of parents to the point of failure. Those families who manage to overcome this trauma and somehow keep going deserve the greatest respect.

Despite the hardships faced by disabled families, successive Governments and their agencies have failed to provide these most needy citizens with an acceptable level of service. Instead, disabled families have to learn to cope with a bureaucracy that has little sense of responsibility; to cope with a system fuelled by ideological theories that have little relevance to the everyday life of the disabled; and to cope with a Government that hides behind a language of denial.

Recognising the existing traditions and strengths of the family in providing care to disabled children is crucial for any reform to work. This recognition must be based on creating a needs-led benefit system. Yet today, most services are provided by local authorities through a budget-led system, of which 26% – or £140 million – is wasted on ‘assessment and commissioning’ tasks.

This money should be used to boost the cash available for disabled children and their families. Parents should be awarded direct funds to spend as they choose on care and equipment. For the first time disabled families would then be in charge of their own welfare, and would acquire a sense of initiative. Parents would be able to develop their own individual plans for their child, without further constraint by the state. Individual choice

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would be to the fore, backed up by responsive Care Assistance Teams helping disabled families make informed choices and decisions. In addition, the Care Industry should be freed of excessive standardisation and regulation; and the vigour of the market should be restored through investment and taxation reform.

These proposals are radical and will require substantial change to the way in which social services respond to the needs of disabled children. When successfully implemented, they might well provide a template for the wider reform of social services.

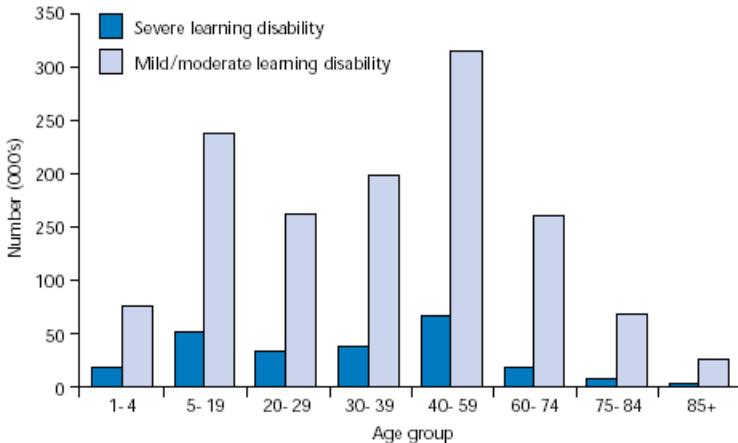
But while they are radical, they are also consistent with the broad direction of public service reform. All the major political parties now advocate the benefits of more choice for parents and patients over schools and hospitals. The proposals made here are based on the same principles: greater choice and control for the disabled family; and more incentive for suppliers to respond to the demands of the disabled. It is this combination that will create the conditions which will help disabled families to regain control over their lives.

CHAPTER ONE

LEARNING DISABILITY IN THE UK

ACCORDING TO A RECENT WHITE PAPER, about 210,000 people suffer from a severe or profound learning disability in England.¹ These people suffer from multiple developmental disabilities including physical, cognitive, psychological, sensory and speech impairments. In many instances, the cause of the disability is not known. Of the 210,000, about 65,000 are children, 120,000 adults under pensionable age and 25,000 older people.²

Learning disability in England by age group



¹ *Valuing People: A Strategy for Learning Disability for the 21st century*, TSO, 2001. This report is also the source of the data in the Chart.

² *Ibid.*

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The number appears to be on the increase, although changes are hard to evaluate due to the general lack of data on this issue. For example, in 1988, according to Mencap, there were 25,000 children and adults with a profound and multiple learning disability. By 2001, this had risen to 40,000.³ One probable cause of this increase is that recent advances in paediatric care have resulted in more profoundly disabled children surviving and living longer lives.⁴

On average, each year six children are born with a severe or profound learning disability for every 1,000 births. With about 800,000 live births a year, 4,800 babies with severe or profound learning disabilities are born each year – that is about 90 babies a week.⁵ However, it is hard to assess the numbers of disabled individuals in Britain over the last few years, because despite an obligation on Local Authorities to keep a register of disabled persons in order to enable better long-term planning, few Local Authorities or other bodies have complied with these rules.

Estimated disability level distribution for severely and profoundly disabled people in England and Wales

Disability Levels	Children 0-19	Adults 20+	Total
Severe	37,500	112,500	150,000
Profound	11,250	33,750	45,000

Source: Collated from Mencap, Scope and National Statistics data.

Profoundly disabled children are not able to lead independent lives. They are fully dependent on carers, usually parents, for their every need. They receive social care in their own homes, or occasionally in care homes.

³ Mencap, *No ordinary life*, 2001.

⁴ B Carpenter, "Sustaining the Family", *BJSE*, November 2000.

⁵ Learning Disability Helpline Document, Mencap, 30 March 2000.

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Care distribution for children with severe learning disabilities

Care at Home	91.2%
Care with a relative	0.5%
Foster Carers	2.3%
Boarding School	4.4%
Permanent Care away from Home	1.5%

Source: D Gordon et al., *Disabled Children in Britain*, TSO, 2000.

There are more profoundly disabled women – 58.7% of the total – than men – 41.3% – especially as patients get older.⁶ Separate gender distribution figures for people younger than 60 are not available but numbers of male and female patients are generally about equal and uniformly distributed across socio-economic groups.

The multiple developmental disabilities suffered, affecting amongst other areas locomotion, personal care, seeing, hearing, and speech, create the need for constant help from the parents. This takes up at least 10 hours of a parent's day and can also involve night-time care.⁷ 75% of profoundly disabled people visit a hospital up to ten times a year, and at least 50% are in contact with a healthcare professional almost every day.⁸

⁶ *Disability in Great Britain*, Department of Social Security, Research Report No. 94, DATE.

⁷ Mencap, *No ordinary life*, 2001.

⁸ *Valuing People: A Strategy for Learning Disability for the 21st century*, White Paper, March 2001.

CHAPTER TWO

THE DISABLED FAMILY

An everyday task

Caring for a profoundly disabled person is an exceptionally demanding task. A fitting analogy is that of having to look after a new-born baby, not just for a few months but for years on end. Waking up several times a night to feed, change or help them through a fit is part of the everyday business of being the parent of a profoundly disabled child.

In most families, the day-to-day care of disabled children is performed by the mother. Fathers generally offer moral and financial support to their spouse and help with the more physically demanding tasks.⁹ However, there are many cases of fathers being sole-carer.

The full-time care of a profoundly disabled child at home prevents at least one of the parents from holding down a job and can lead to severe financial problems. Due to the lack of external support services, families cannot find a viable alternative to this situation at the moment. All too often, having a profoundly disabled child will lead parents into poverty.

The effect on the family

Family life is invariably profoundly affected by the presence of a disabled child in the home. Having one, or two, parents caring for a disabled child full-time can create strains in couples and lead to

⁹ J Read and L Clements, *Disabled Children and the Law*, Jessica Kingsley, 2002.

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major family crises. Carers often feel guilty about not being able to look after their other children properly because they are so focused on the disabled individual.¹⁰

In many cases, life becomes a fight for survival, especially if the carer has to look after other children at the same time. “Quality time” together, often taken for granted by other families, is usually non-existent. It is, therefore, easy to understand that as many as eight in ten of these families have reached the end of their tether, as Mencap reveals in its *Breaking Point* survey.¹¹

As a result of the extra pressure in their everyday lives, parents of disabled children are more likely to split up,¹² leaving a larger than average number of disabled children to live in single parent households. The lone parent – often the mother – caring for a disabled child often lacks moral and financial support, making the conditions even harder to bear.

Services Needed

Department of Health Policy¹³ has identified the most important priorities for disabled children and their families to be:

- a named social care manager;
- a key worker to co-ordinate support services;
- access to advice;
- clear criteria for entitlement to services;
- aids, equipment and home adaptations;
- respite care;
- support from Health Visitor or GP.

¹⁰ Mencap, *No ordinary life*, 2001.

¹¹ Mencap, *Breaking Point*, 2003.

¹² See B Beresford, *Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child*, Policy Press, 1995.

¹³ Department of Health Social Care Group, *Disabled Children Directions for their Future Care*, HMSO, 1998.

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Care and support can be grouped into three sections: domiciliary care, respite care and residential care.

Domiciliary Care

Under the current system, disabled people and their families are entitled to an assessment of their needs by their Local Authority. Social workers visit the family, assessing their living environment and the family's needs. The family is then allocated a certain number of hours of domiciliary care and equipment, subject to budgetary restrictions, and availability of appropriately trained staff. Despite the individual assessment however, most of these care plans are very similar as they rely on a limited choice of services. Only the amount, rather than the type, of services provided changes.

Families living in these circumstances tend to know what they need. They would also usually much rather choose services themselves than receive unnecessary and insufficient help from their local authorities. Unfortunately, the rigidity of the current system does not give the families any personal choice. Few people can afford services out of their own pocket on a regular basis.

Families are therefore frequently reduced to begging for services which are often poorly delivered, if at all. Mencap has provided clear evidence that the attitude of many Local Authorities towards parents is often disgraceful:¹⁴ for example, 48% of people interviewed by Mencap were receiving no support whatsoever from outside the family while a further 30% received less than two hours help per week with care tasks in the home. These parents inevitably find it difficult to find the time to clean the house properly or cook decent meals for their children, thus leading to poor living conditions.¹⁵

¹⁴ Mencap, *No ordinary life*, 2001.

¹⁵ Mencap, *No ordinary life*, 2001; Survivors, BBC Panorama, February 2003, *Where do you think you're going?*, John Grooms, 2003.

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Respite Care

Many families could better manage caring for their disabled child at home if only they could occasionally take some time off. Short breaks – respite care – are a good way of achieving this, enabling carers to leave their children at a specialised care centre or at a foster family’s home, usually for the weekend or slightly longer, and enjoy a well-earned break.

However, the shortage of provision of these short breaks is making life unbearable for many families, bringing them to breaking point:

One Sunday morning my husband turned to me and said it was him or Duke, our disabled grandson. In the end I told my husband I had made my choice. I couldn’t give Duke up. He needed me more. My marriage was over. And all because nobody would give me a little bit of help with Duke.¹⁶

A BBC Panorama programme shown in February 2003, aptly named “Survivors”, illustrated a moving example of such a case. Barbara Riley is a single mother with three children, two sons and her disabled daughter Asia. She does not have a job. She is on the verge of crisis due to the lack of help from her local authority.

Barbara’s husband left her when Asia was very young, saying he could not cope with their daughter’s severe disability. Barbara had to give up running a pub to care for Asia and her two other children full-time. She earns £14 a week from a paper round and is limited to a maximum of only £20 if she is to receive carer benefits. When the programme was screened she had not had a night away from Asia for over a year.

In the programme, Barbara asked for some extra help as her care package was not being delivered and she was finding it hard to cope after caring for Asia for so long without a break.

¹⁶ “Emily’s story”, Mencap, *Breaking Point*, 2003.

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All I want is one weekend a month, that's all I'm asking.

She got one night a month and a “reduced” care package. Sadly, this is the case with most carers asking for respite care. Very few short breaks are provided for disabled individuals and their families, despite the growing demand. Government figures show that only one in five families with a disabled relative are getting short breaks and 34% of these are receiving fewer than the previous year.¹⁷ Nine out of ten local Social Service departments have a respite care waiting list and for a third of these lists, people are having to wait longer than a year to get a break.¹⁸

Residential Care

Residential care for the profoundly disabled is funded either by local authorities or the NHS and can be provided by both local government and private Care Homes. Also, the number of profoundly disabled people who occupy NHS beds – an inappropriate placement for most – is unknown.

There is a high demand for places in residential care and nursing homes, as well as for special needs residential schools. For various reasons, parents may not want to, or are unable to, look after their child at home and would like to see their child looked after in a more appropriate environment. However, many fail even to get on to waiting lists as places are scarce and cost between £50,000 and £100,000 a year depending on care levels provided.¹⁹

A common reason given for wanting to place a child in residential care is not being able to cope anymore, be it physically

¹⁷ *Making Change Happen, The Government's First Annual Report on Learning Disability*, TSO, 2003.

¹⁸ B Prewett, *Short-term break, long-term benefit: family-based short-term care for disabled children and adults*, University of Sheffield, Joint Unit for Social Services Research, 1999.

¹⁹ Mencap, *Breaking Point*, 2003.

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if a child has grown too heavy, or mentally as seen in the Mencap Breaking Point research. This pressure is only increased by the inability of Local Authorities to provide suitable care packages to support the family.

Another family featured on the *Survivors* programme were the Myersons. The Myersons also have three children: Emmy, their disabled daughter, and a younger daughter and son. On the verge of a breakdown, the Myersons have decided they would like their eleven-year-old daughter Emmy to attend a specialised school nearby. This would allow them to lead a more normal family life, to spend time with their other children while knowing that Emmy is being looked after properly and reaching her full potential, all within a few minutes from their home.

However, despite strong recommendation from the school, the council decided that Emmy's needs would not be met by the specialised school.

This was not a decision based on need, it was a decision based on budget. For heaven's sake what are we supposed to do?²⁰

On top of having to care for Emmy day and night, the exhausted Myersons now have to fight with their Local Authority to obtain any form of help. They appealed against the decision – a follow-up Panorama programme in July showed that the situation had been reviewed and their request was rejected once more.

Sadly, this is not an isolated case. Around the country, those who need help most are being rejected by their local authorities because it would cost too much to provide the care they need.

If respite care facilities were to be properly funded, strategically developed, and more readily available, more families would be able to cope better with caring for their disabled children at home – often their preferred choice. Consequently, there would be less demand for full time residential care.

²⁰ D Myerson, *Survivors*, BBC Panorama, February 2003.

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The law in action

There is a vast array of laws, regulations and guidance notes that determines not only whether disabled children and their carers receive a care package, but also the quality and nature of that care package.²¹

However, many disabled children and their families experience severe problems because local professionals and policy makers fail to appreciate the relevant legal obligations and duties that exist.²² In addition to the complexities of the law, there is also a level of confusion as to which particular agency is responsible for service provision.

There is an explicit duty for agencies to co-operate in the Children Act 1989, the NHS Acts of 1977 and 1999, the NHS and Community Care Act 1990, the Housing Act 1996, the Education Act 1996 and the Disabled Persons (Services Consultation and Representation) Act 1986. Despite this, complaints about service delays caused by inter-agency disputes made to the ombudsman have resulted in repeated criticism of those authorities “for allowing disabled children and their families to suffer while they squabbled over their respective obligations”.²³

The early years and the law

Under the current system, the law is failing disabled children at their time of greatest need: in the first years of a disabled child's life. When a disabled child is first diagnosed, it is the responsibility of the GP to help patients and parents to gain access to other branches of the NHS. At this time parents will be very anxious and distressed as they fight to come to terms with their situation. They are frequently left without adequate information and help with the physical problems of looking after their disabled child, as the

²¹ See the Appendix for a summary of all relevant legislation.

²² J Read and L Clements, *op. cit.*

²³ *Ibid.*

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support systems both within the NHS and Social Services are often limited to crisis management.²⁴ At this time of great confusion and trauma, parents need to have immediate and responsive help with their problems.

After the initial medical diagnosis, parents frequently find that professionals simply fade away and leave the family on its own. This silence from the Community Care industry is disgraceful. Often it is only when parents start to come to terms with their new way of life and to understand how the system should be helping them, that the system responds.²⁵ Indeed, it becomes apparent to many parents that the only way to get the service that meets their needs, rather than the local authorities budget, is to develop their own expert and detailed knowledge of their rights, and the legal responsibilities of the statutory authorities – and to fight for them.

I feel personally responsible for educating at least eight social workers.²⁶

However, many parents cannot master the complexities of the law and simply resign themselves to the day to day routine of caring for their child, virtually unaided.²⁷

Social Services don't tell you what you are entitled to. You need a degree to understand their manuals. GPs don't have the time to tell you about other things.²⁸

²⁴ Ibid.

²⁵ Ibid.

²⁶ Scope, *The Direct Approach*, 2003.

²⁷ L Clements, *Community Care and the Law*, Legal Action Group, 2000.

²⁸ Mencap, *No ordinary life*, 2001.

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This is yet another grey area, where budgetary restrictions often lead to unfair practice, and many parents and carers are simply told there is no money available to pay for their care package making their assessment a paper exercise.

For those who are lucky, some services will be provided. However, Social Services can, and usually do, charge for the services they provide under the Children Act 1989.²⁹ If parents receive income support, working family tax credit or disabled person's tax credit, no charge can be made.

Despite the clear legal obligation to provide care to children identified as being disabled, and due to the constant misinterpretation of the law described above, many disabled children reach school age with little or no help from Social Services, NHS or Education Authorities.³⁰

School and the law

With little or no help during the first five years of their child's life, parents then have to deal with the education system. Indeed for most disabled children it is the education department through LEAs that is the lead agency from the age of five to 19 years. However, those children with complex health needs will continue to have contact with the NHS, and parents will be continuing their battle with Social Services to get more help.

The Education Act 1981 introduced an emphasis on disabled children being educated within mainstream schools. The Act also required that children should be provided with an individual "statement" of their educational needs. The child's Local Education Authority (LEA) is obliged to provide any services required by this "Statement of Education Need". In the 1990s, a

²⁹ However, it is questionable whether there is power to charge for services provided to a disabled child under the Chronically Sick and Disabled Persons Act 1970.

³⁰ J Read and L Clements, *op. cit.*

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series of reports³¹ highlighted that, in practice, children experience lengthy delays for both the formation of the Statement and its subsequent implementation.

Parents and their disabled children are again forced into fighting for small concessions from their LEA. The Education Act 1996 has sought to speed up the process of assessment and implementation, but despite this, the process remains “perplexing and stressful for very many children and their parents. Those who wish to challenge any aspect of the assessment find it particularly taxing and frustrating”³². The fact remains, as Read and Clements report,³³ that there are too many different agencies, with too many separate agendas, effectively preventing disabled children from gaining access to the services they need.³⁴

Budgetary issues and constraints are to the fore throughout the statementing process. It is the responsibility of the LEA to undertake the Statement, and it also holds responsibility for the provision of the services required by this Statement. There is therefore often a great reluctance on the part of the LEA to agree to parent representation in decision-making processes. Where services such as speech and language therapy, physiotherapy and occupational therapy, are required, the LEA and NHS often shuffle bewildered parents from one department to another in an attempt to avoid the financial responsibility of service provision.³⁵ Throughout this bureaucratic exercise, disabled children are being denied both education and basic health care.

³¹ See, for example, *Getting in on the Act*, Audit Commission, HMSO, 1992; and B Beresford, *Expert Opinions, A National Survey of Parents Caring for a Severely Disabled Child*, Policy Press, 1995.

³² J Read and L Clements, op. cit.

³³ Ibid.

³⁴ Mencap, *No ordinary life*, 2001.

³⁵ J Read and L Clements, op. cit.

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Transition into adulthood

As a child grows older, the agencies providing help often change too. A disabled person has to deal with the National Health Service, the Social Services, the LEA, and Benefit Agency and the Housing Departments, as well as coping with the transition from child orientated teams to adult teams.

The law recognises that difficulties exist with a child's transition into adulthood. The Disabled Persons Act 1986 requires that education authorities consult Social Services authorities to establish whether a child over the age of 14, who has been "statemented" under Part IV Education Act 1996, is likely to require support from the Social Services department when he leaves school. This duty is reinforced by the Education (Special Education Needs) Regulations 1994, which requires the contribution of Social Services departments and others to the transitional plan.

Research by Barnardo's³⁶ shows that current community care policies mistakenly assume that young people with disabilities will continue to stay at home as they move into adulthood, and that parents will continue to act as the main carer. However, this is often not the case as young people seek independence as parents grow older.

Local authorities are required to produce transitional plans, but with limited budgets and options, these are often absent or inadequate. It is therefore not surprising that disabled children develop into adulthood continuing to be largely segregated from normal life. By remaining dependent on Social Services and Income Support, a disabled adult will have very few opportunities to gain any control over his or her life.

Complex laws and regulations and a budget-responsive service delivery system keeps disabled children and their parents segregated from the general population and increasingly dependent on inadequate care services.

³⁶

Barnardo's Policy Development Unit, *Transition into Adulthood*, 1996.

CHAPTER THREE

WHAT IS AVAILABLE?

Domiciliary Care

Domiciliary Care, provided in the home, has been steadily increasing over the last few decades. While this is mainly a result of the crisis in the residential sector, caused by restricted budgets and over-regulation, it is also government policy to help “everyone move out of long-stay homes to somewhere better”.³⁷ However, domiciliary care is not always the better option.

Unfortunately, there is a large gap between current policy objectives and actual service delivery. Instead of being given more choice over their lives, numerous disability charities report that people are getting trapped in their homes with no choice over their care services.

Although Social Services are legally bound to provide care for the disabled, the level of service is directly linked to the Local Authority disability budget. In far too many instances, the Local Authorities are failing to deliver: for example, although there is a legal requirement for the Local Authority to review the needs of carers, Mencap research has found that six out of ten families have never had a Carer’s Assessment.³⁸ Half the families involved have not seen a review of their care packages within the last year. Similarly, reports over the years show that disabled children, and

³⁷ *Making Change Happen, The Government’s First Annual Report on Learning Disability*, TSO, 2003.

³⁸ See Mencap, *Breaking Point*, 2003.

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parents of disabled children, tend to be highly dissatisfied with the services provided by their local authority:³⁹ Mencap found that 48% of people interviewed were dissatisfied with the services they had received.⁴⁰

Interactions with family support services tend to be time-consuming and frustrating and often result in multiple and duplicate assessment without a clear purpose.⁴¹ This is usually due to the complexity of the different organisations: according to Mencap, 37% of families have been in contact with eight or more professionals.⁴² These different government and voluntary organisations often fail to communicate and co-operate: 80% of families of disabled children report that health and social care services are not being properly co-ordinated, resulting in delayed and inefficient service delivery for many people.⁴³

Service users also find that some workers may be judgemental, ignoring their views and those of their families and treating them inappropriately. Often there is not a named social worker assigned to a specific individual, there is no link, no relationship, between social services, disabled children and their parents.⁴⁴ However, these grievances are only being discovered thanks to the hard work of disability charities such as Mencap, Scope and many others, and are not being monitored by any national or local authorities.

³⁹ J Read and L Clements, *op. cit.*

⁴⁰ Mencap, *No ordinary life*, 2001.

⁴¹ Social Security Inspectorate.

⁴² Mencap, *No ordinary life*, 2001.

⁴³ Mencap, *No ordinary life*, 2001 and J Read and L Clements, *op. cit.*.

⁴⁴ J Read and L Clements, *op. cit.*

WHAT IS AVAILABLE?

Direct Payments

Introduced by the Conservative Government in 1996, direct payments allow disabled individuals to choose between direct service – such as help from social services – or the value of the service as a direct payment. The legislation regarding these direct payments was modified in April 2003, allowing access to funds for carers of disabled children under the age of 16. Access to direct payments cash relies on the individual having already been assessed by Social Services and having an agreed care package already funded, thus still representing a budget-led, rather than a needs-led, system. Furthermore, the payment can only be used for specific areas of care and is too low to cover any form of residential care.

However, direct payments do have advantages. Unlike domiciliary care provided at the discretion of the social services, they bring choice and control to the patients, who can employ a regular, trustworthy and committed carer, chosen and paid for by themselves. This reduces the amount of struggle, allows more flexibility and thus generally improves the morale and quality of life of disabled children and their families.⁴⁵ In addition, direct payments can be used to fund the substantial demand for respite care for the families of disabled children.

According to government guidelines, an individual is eligible if “he is a person who appears to the responsible authority to be capable of managing a direct payment by himself or with such assistance as may be available to him”.⁴⁶ The number of disabled patients identified as “needing a service”, however, depends on the Local Authority and its financial resources. Many areas are not extending direct payments to children with learning disabilities as

⁴⁵ Community Care (Direct Payments) Act 1996; *Draft Policy and Practice Guidance Consultation*, Scope Response, November 2002.

⁴⁶ Community Care, Services for Carers and Children’s services (Direct Payments) (England) Regulations 2003.

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they have not unlocked the necessary resources.⁴⁷ In addition, the goalposts for these criteria are being moved further and further away from patients due to lack of funding.⁴⁸

Although the direct payments system has improved the quality of treatment and life of some disabled individuals by giving them choice, many eligible service users are not benefiting from this scheme. Indeed, the exact number of potential beneficiaries is not known as many Local Authorities have no idea how many needy disabled people live in their area.⁴⁹ This is due to lack of information provided by social workers and local authorities. In 2003, the Government has recently set up a scheme to help promote direct payments in association with charities, to train social workers and inform patients about direct payments. The success of this scheme has yet to be evaluated.

Inadequate monitoring of the system is also causing many problems for service users, as they are given no chance to re-evaluate their position or even give up direct payments. This ought to be an integral part of the system, as service users may have originally underestimated the costs of finding personal assistants, training them, and providing beds for them if they are needed overnight. Rejected applications for direct payments (and a range of other services) generally go unrecorded. This means that local authorities have no evidence of the amount of “unmet need” patients for whom no viable system is in place.⁵⁰ Although monitoring and support feature in the government’s guide to direct payments, they are often not enforced.⁵¹

⁴⁷ Scope, *The Direct Approach*, 2003.

⁴⁸ Ibid.

⁴⁹ Social Services Inspectorate, *Annual Report*, 2001.

⁵⁰ Scope response, 2002.

⁵¹ Scope, *The Direct Approach*, 2003.

WHAT IS AVAILABLE?

Social Services didn't give me any information. It was Mencap that supplied me with all the information.⁵²

Residential Care

Few severely disabled children gain access to residential care: in 2002, only 2,300 of the 49,000 (or 4.7%) severely disabled children were in residential care. Another 57,000 non-disabled children were in care.⁵³

Access to residential care for the severely disabled is restricted by the shortage of local authority funding, the small number of available beds around the country, and the increasing regulatory burden placed upon the care industry – which as a whole saw a 5% reduction in the number of beds between 1997 and 2000.⁵⁴ Most residential care is funded by the child's Local Authority while some are also supported by the NHS.

Respite Care

Respite care can be delivered in several different formats. Often it is provided by a residential care institution or a children's hospice. Disabled children may also stay with a foster family overnight, or for a weekend. On average a disabled child in respite care costs between £50 and £150 per night.⁵⁵

Unfortunately, respite care is extremely hard to obtain for profoundly disabled children and their families. The lack of provision of this service, is in part due to lack of forward planning

⁵² Scope, *The Direct Approach*, 2003.

⁵³ See Department of Health website.

⁵⁴ *Community Care Statistics 2001*, Department of Health. The fall in the number of beds has probably continued since 2000 as the regulatory pressures and costs of the Care Standards Act 2000 have come into play.

⁵⁵ Mencap, *Breaking Point*, 2003.

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and also, the low remuneration for foster families. Over-regulation and a shortage of funds has also contributed to the low number of beds available.

Children's hospices play an important role in the provision of respite care for disabled children and their families. Families appreciate the non-clinical environment, the friendliness of the staff and the good facilities.⁵⁶ However, the growing demand for short breaks in hospices is putting them under great pressure and patients are having to join waiting lists once more.

Research by the Joseph Rowntree Foundation⁵⁷ has shown that hospices provide respite care for children that is unavailable elsewhere. In a survey of four hospices the average accommodation given to children was for 20 days in a year. According to this research, families are keen to use hospices for three main reasons:

- a positive recommendation by another family or by a professional;
- poor personal experience of other respite care services, such as hospital wards and local authority residential services;
- a lack of suitable alternative facilities, particularly in areas where the adopted policy prohibits sick children from entering Social Service establishments.

However, this situation is putting undue pressure on hospices, who provide charitable services to all and thus have a limited amount of resources.

⁵⁶ Joseph Rowntree Foundation, June 1999.

⁵⁷ Ibid.

WHAT IS AVAILABLE?

The Care Standards Act 2000

The Care Standards Act 2000 (CSA 2000) was intended to modernise social care with a particular emphasis on service quality and client protection. This was to be achieved by:

- the formulation of the National Care Standards Commission (NCSC), which is required to regulate all Care Homes and a range of Social Care services in line with National Minimum Standards;⁵⁸
- the formation of the General Social Care Council, which is required to control the training and work standards of the 1 million-strong social care workforce;
- the formation of the Training Organisation for Social Services, which is required to improve the quality and quantity of learning opportunities for social work students;
- the formation of the Social Care Institute for Excellence, which is required to act as a “knowledge base” and to promote best practice in social care services.

The Department of Health website claims that the CSA 2000 was necessary in order to “eliminate inequalities in social care, to provide a system that is convenient to use, and responds quickly to emergencies”. The Department of Health also claims that “some social care services were not of a good enough quality or

⁵⁸ Shortly after the launch of the NCSC, the Care Industry was told that plans were being made to replace the commission by two new super-regulators, consisting of the Commission for Health and Care Audit and Inspection (CHAI) and the Commission for Social Care Inspection (CSCI). The CHAI is broadly responsible for inspecting the NHS while the CSCI has taken over most of the NCSC’s duties and those of the Department of Health Social Services Inspectorate.

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suited to the needs of the user”.⁵⁹ For Anne Parker, the NCSC Chair, “the overwhelming priority for the NCSC is to protect people who receive care services”.⁶⁰

However, for many in the Care Industry and, more importantly, for those people who receive its services, the CSA 2000 has been a disaster. David Arculus, Chair of the Government Better Regulation Task Force, has admitted that a key concern has been the unintended consequences that new regulations have had on the Care Industry, which “had perversely resulted in the sale and closure of Care Homes and the resulting bed shortage.”⁶¹

The NCSC has added a substantial and often unjustifiable burden of new regulation onto the providers of care services and their employees. Frank Ursell, of the Registered Nursing Homes Association, has commented that “the increase in regulatory burden has been the main cause of closure for many... care homes”.

It is widely accepted that the drive to develop National Minimum Standards for the care sector has also added a substantial extra cost to providing services. Martha Trust Hereford, a small charity which provides nursing care for profoundly and multiply disabled young people, has documented evidence that implementation of the Care Standards Act has added an extra 3% to its annual costs. Martha Trust Hereford believes that:

The introduction and implementation of the Care Standards Act has not added to the quality of care [Martha Trust Hereford provides] and has actually diverted managerial resources away from the business of caring for its residents and into satisfying the National Care Standards Commission’s desire to micro manage [the Trust’s] business.⁶²

⁵⁹ Department of Health Website www.doh.gov.uk

⁶⁰ *Caring Times*, June 2003.

⁶¹ *Caring Times*, June 2003.

⁶² Private interview with Martha Trust Hereford manager.

WHAT IS AVAILABLE?

The NCSC has also enforced a 20% increase in the annual cost of registration. Care homes had no choice but to pay up or be put out of business. This increase is difficult to justify and has contributed to the closure of care homes, many of which operate on very tight budgets: the leading analyst of the sector estimate that 5% of homes closed between April 2002 and October 2003.⁶³

Other regulations in the CSA 2000, such as guidelines requiring staffing levels to be increased, have been delayed, sometimes indefinitely, in view of spiralling costs which would have caused yet more damage to the industry. Room size and other building regulations required by the Act have also been shelved for existing homes. As Frank Ursell of the Registered Nursing Home Association comments, “one has to question the competence of the Government here”.⁶⁴

The Criminal Records Bureau

The Criminal Records Bureau (CRB) was established under Part V of the Police Act 1997. The Care Standards Act 2000 currently requires all Care Home staff and others who have unsupervised access to children and vulnerable adults to submit a Criminal Records Bureau check. The check will enable employers to have wider access to criminal records information through the disclosure process and to successfully filter out undesirable applicants.

Prior to the establishment of the Care Standards Act 2000, Care Homes who were responsible for children obtained a police check service on employees through their local NHS Trust. Under the new rules, the employee must have a CRB check in place before starting work – and therefore before having a salary. This expense is proving to be a strong disincentive for people entering

⁶³ Laing and Buisson www.laingbuisson.co.uk

⁶⁴ *The Care Crisis*, Stephen Evans and Greg Clark, Conservative Policy Unit, 2002.

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the Care Industry. Care Homes are now having to foot the bill in order to encourage job applicants.⁶⁵

Due to the well-publicised chaos at the CRB, checks on 700,000 existing care workers for 2003 were delayed until June 2004. In addition, all Agency Nurses, Domiciliary Care Agency personnel and foreign workers were temporarily exempted from CRB checks. The deadline has since been extended again to the end of October 2004.

At the same time, the CRB sent care homes a request for details of the 700,000 existing staff to be delivered to the CRB in October 2003, ready for the new June 2004 deadline. Frank Ursell from the Registered Nursing Home Association (RNHA), commented that:⁶⁶

Many of us will see some staff changes in the intervening nine months, at £24 or £29 a time I will certainly be unwilling to commit myself until a lot nearer the June deadline.

The worries about the cost and impracticality of CRB measures was voiced in the August 2003 RNHA Newsletter:

The National Care Standards Commission has today released new guidance on CRB checks for staff which, effectively, have every chance of bringing the sector to its knees.

Furthermore, the quality of CRB checks and of disclosures made to employers is doubtful. One case involved the CRB not passing the record of an employee's prison conviction to the employer because "it was felt by CRB staff not to be relevant".⁶⁷ In this case, the conviction was already known to the Care Home but this could have led to serious consequences in another situation.

⁶⁵ Private Interview with Care Home Manager.

⁶⁶ RNHA Newsletter, 18 August 2003.

⁶⁷ Private Interview with Nursing Home.

WHAT IS AVAILABLE?

Staff Training and National Vocational Qualifications (NVQs)

The task of training improvements, set in the Care Standards Act 2000, is to be achieved through the offices of two organisations: the General Social Care Council; and the Training Organisation for Social Services. In addition, the National Care Standards Commission has produced standards requiring Care Homes to have set proportions of their workforce with NVQ2, 3 or 4, as appropriate, by 2005.⁶⁸

Although appropriate training is always welcome, the concern is that the scale of the new training regime is so far-reaching that it will inevitably further damage the Care Home Sector, by adding yet more costs that cannot be recouped from care purchasers.

Care assistants tend to be drawn from two separate parts of the national workforce. They are either young and looking for their first jobs; or they are returning to work after their own children have become independent. A substantial proportion of the care assistant workforce is part-time.

With 50% of all care assistants required to have NVQ2 by 2005, Care Home owners are encountering a new problem. For a variety of reasons, many care assistants are reluctant to undertake NVQ2 training.⁶⁹ The main criticism is that all NVQs rely on a paper-based assessment system, while many care assistants would be much more receptive to an appropriate practical assessment.

Younger care assistants often use this first job as a springboard for other careers, such as nursing, and do not feel it appropriate to study for NVQ2. The older care assistants often feel demotivated by having to “go back to school” to learn how to look after children, after having spent so many years themselves raising a family. The rigidity of the regulations, and the failure to appreciate the nature of the workforce, further undermine the ability of the Care Home Sector to meet the needs of disabled children.

⁶⁸ NVQ2 is designed for care assistants, NVQ3 for persons with supervisory responsibilities and NVQ4 for Care Home Managers.

⁶⁹ Private Interview with Martha Trust, Hereford 2004.

CHAPTER FOUR

GLOBAL BEST PRACTICE

MANY DIFFERENT SUPPORT SYSTEMS for the disabled can be found around the world, with large variations in their outcome. The evidence suggests that high levels of patient satisfaction are proportional to the amount of choice given to the patient. Examples of how three countries offer the severely disabled some choice in the services that are provided are presented below, in order of increasing consumer choice and satisfaction.

New Zealand

Disabled people in New Zealand are given a lot more choice than in Britain, especially when it comes to formal domiciliary care. However, this choice does not extend to funding residential care or informal domiciliary care.

An estimated 28,900 adults and 13,000 children with learning disabilities receive disability care at home in New Zealand. Another 3,500 people receive care in residential settings.⁷⁰ Institutional and community support is financed by the State.

Although similar to the British model, where the needs of the disabled are evaluated by the state, there is a much greater emphasis on individual choice than in the UK as well as much greater freedom of supply.

Once their assessment has been completed, disabled people then have a choice of a personal assistant from different agencies, whose fees are reimbursed by the state as a Disability Allowance.

⁷⁰ Statistics New Zealand, *Disability Survey*, Snapshot 8.

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Disabled individuals usually choose a carer from a nearby agency, but choice can be extended further if need be. If the client is not happy, he or she can choose to change carer.

Under the New Zealand system, disabled individuals have a much greater say in who helps them on a daily or weekly basis than in the UK. The care received is much more personal and being individually tailored, is achieving high levels of satisfaction.⁷¹

The Disability Allowance reimburses people for the ongoing regular costs that they incur due to their disability. It is means-tested and the amount of allowance paid is variable, depending on a person's needs as defined by their doctor and individual financial situation. There is a fixed ceiling for every different category of applicant.

Disabled children and their families receive a Child Disability Allowance which can be additional to the disability allowance and is a non-taxable, non means-tested payment of NZ\$36.30 (£13.25) per week. This payment is usually given to the parent or guardian of a disabled child who lives at home and requires constant care and attention. The allowance is also available when the child lives in a residential setting and the family is required to contribute to his or her maintenance costs.⁷²

Disabled people with urgent needs, such as a new wheelchair, can also receive a Special Needs Grant, which is a one-off payment. If disabled people find themselves in financial difficulty during a period of particularly bad health, for example, they are entitled to a Special Benefit, which can help meet living costs for a short time while their situation is being resolved.

⁷¹ National Audit Program for Disability Support Services, *Home Based Services*, 1999.

⁷² www.workandincome.govt.nz/documents/brochures/disability-allowances.pdf

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Another way of getting help is by using an Advance Payment, which is basically a loan, to help purchase something that would normally have taken a long time to save up for.⁷³

However, although disabled people in New Zealand are given choice in formal domiciliary care, the importance of family support has not been taken into consideration. While families with disabled children get an allowance for caring for their children, this disappears when the child reaches adult status, even though the family often continues caring for him. Furthermore, institutional care is not an option for most people, even when desperately needed, as the Disability Allowance thresholds are generally too low to cover residential care fees.

In terms of residential care, in New Zealand there are only 3,500 people with learning disabilities living in care homes, private hospitals or mental health units, of which 2,500 are under pensionable age. This represents an enormous decrease in numbers since 1996, as New Zealand, in common with other western economies, has adopted a policy of encouraging community care over residential care.⁷⁴

United States of America

About 1.2 million people in the US receive disability care at home through state programmes.⁷⁵ Institutional and community

⁷³ Ibid

⁷⁴ Statistics New Zealand, Disability Survey, Snapshot 8.

⁷⁵ A Leblanc, M Tonner and C Harrington, "State Medicaid Programs Offering Personal Care Services", *Health Care Financing Review*, vol. 22, no. 4, summer 2001; and M Kitchener and C Harrington, *Medicaid, Home and Community Based Waivers: Program Data 1992 - 1999*. University of California, 2001. This number can only be an estimate as census figures do not take account of people using services from more than one programme.

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support is provided for people with disabilities by Medicaid,⁷⁶ a federal funding program. The federal government provides the basic framework and about half the funding; individual states then customise their programmes and provide the other half of the funding from their own resources.

The two main programs available are the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and the Home and Community Based Services (HCBS) waiver, which also cover the elderly and disabled.

Expenditure for these services was \$10.9 billion for ICF/MR in 2002 and \$16.4 billion for HCBS. 70% of the total Medicaid expenditure is on institutional care, but this percentage is progressively decreasing as money is being directed towards consumer choice programs,⁷⁷ which allows care to be given at home.

However, as in Britain, this structure has many shortcomings. Typically, nurses and/or social workers assess their client's disabilities and care needs and develop a care plan. Despite the individual assessment, most of these care plans tend to be very similar as they rely on a limited choice of services. Only the amount, rather than the type, of services provided changes.

Under the HCBS scheme, care managers can choose between various authorised care agencies, which then bill Medicaid, to provide attendant care and other services. They can also send patients to one of their 11,400 Care Homes (called Hospices in the US).⁷⁸ However, the recipients do not get any choice over which Personal Assistance Services (PAS) they will use and have little recourse to getting better services if they are dissatisfied with their current provision.

⁷⁶ Centers for Medicare and Medicaid Services, www.cms.gov

⁷⁷ www.hcbs.org/data/2002LTCExpenditures.doc

⁷⁸ National Centre for Health Statistics, Home Health and Hospice Care Fastats. www.cdc.gov/nchs/fastats/homehosp.htm

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Various new initiatives are being trialled in the US. A pilot scheme, the “Cash and Counselling” programme, has been developed in three states – Arkansas, Florida and New York – thanks to a private initiative from a charity, the Robert Wood Johnson Foundation.⁷⁹ This provides cash benefits as an alternative to Medicaid services, in order to maximise consumer choice for people using PAS, giving people more control over their own lives. The care managers’ role is to check eligibility and financial needs, but the choice of the personal assistant is made by the patient. Furthermore, the money can also be spent on other disability-related needs such as transport, home and vehicle modifications and respite services. Money can be carried-over from month to month, allowing the patient to save up for a special purchase or for emergencies. Spending is monitored to make sure the money is spent on disability-related needs, and unusual purchases need prior approval.⁸⁰

This programme has been applied with rigorous research methodology over the last seven years, comparing the behaviour and costs of patients following the usual procedure and those using the consumer-orientated program. It is now clear that Cash and Counselling programme users receive a better quality of care than those having institutional care.⁸¹ The timing and reliability of their care is much more satisfactory and unmet need is being reduced. It has also allowed a reduction in the number of carers looking after disabled individuals and resulted in more personalised care. There has been no additional cost: indeed, the need for hospital and nursing home care has been reduced for people on this programme.

⁷⁹ See www.rwjf.org

⁸⁰ P Doty, *The Cash and Counselling Demonstration: An Experiment in Consumer-Directed Personal Assistance Services*. US Department of Health and Human Services, 1998.

⁸¹ See www.healthaffairs.org

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In terms of residential care, much has changed for disabled adults over the last 20 years. Until 1980, most residential services for people with profound and multiple learning disabilities were provided by large, state-owned institutions. New legislation, giving states more flexibility, heralded a fundamental change in the way residential patients were cared for. People could now be cared for in community settings such as small homes, special flats or their own homes. This option was taken up by most states and the number of beds in large institutions has halved in the last 20 years to just over 46,000. Nine states do not have any large institutions at all. Today, 80% of Medicaid recipients, both under the HCBS and the ICF/MR services, are served in the community.

The needs of children with profound learning disabilities, however, are generally not covered by any of these programmes. In fact, a court order is required in many states before a child can gain a place in an ICF/MR. Paying privately for these residential services is very rare due to the high cost of care – private insurance policies only cover care in the home. Nursing home places for children are extremely rare too, and are only given to children with life-limiting disorders, similar to hospices in the UK. The only provision of residential care for children with multiple and profound disabilities in the US is delivered by special needs schools.

Austria

In Austria, the state provides money which is given directly to the disabled individuals or to their families. This maximises consumer choice. The recipients can choose to spend it as they wish, thus giving them more control over their own lives. Whether they spend the money at home, sharing it informally with their family or purchasing services from a professional carer, or whether they buy respite care or full-time residential care, is up to them.

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This direct cash benefit, or “Pflegegeld”, has recently been extended to cover all of the 300,000 disabled people in Austria.⁸² These include people physically and/or mentally disabled by war, accident or from birth. The Pflegegeld comes in seven different amounts, depending of the hours of care needed per week. It is not counted in income tax assessments and is not means-tested. Amounts range from €145 (about £87) per month for basic assistance at home to €1,532 (about £920) per month for residential service users. The average monthly amount received is €405 (about £243).⁸³ In addition, if the disabled person needs the use of a specially equipped car to travel around, the state will pay back any necessary car modifications costing up to about €18,168 (about £11,000).

After the assessment of the disabled person’s needs and delivery of the Pflegegeld, spending is not monitored. Disabled people and their families are trusted to spend their allowance on the needs they were assessed for. There has been no evidence of bad practice in this area.⁸⁴

For disabled children and their parents, information and help is provided by mobile support units in six major Austrian towns. These units consist of a team of professionals including child doctors, psychologists and psychiatrists. The team provides confidential information on all available help in the area and advice on how to access it. It helps parents find special schools for their children and provides tips and even some basic training for informal care at home, as well as counselling when pressure builds up. The doctors present can also provide a check-up for the children, and if necessary send them to their GP for treatment.

⁸² Bundesministerium für soziale Sicherheit, Generationen und Konsumentenschutz (BMSG), www.bmsg.gv.at

⁸³ BMSG, www.bmsg.gv.at

⁸⁴ C. Nemeth and E. Pochobradsky, *Qualitätssicherung in der Pflege*, Bundesministerium für Soziale Sicherheit und Generationen, 2002.

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Furthermore, the team gives advice and support at crucial times in the child's life, such as starting at a new school or changing from child to adult status.

Because it is a mobile unit, the team comes to different areas only on specific days. However, it can be contacted by telephone at any time during the week, and travel to people's homes if need be.

Mobile units appear to be restricted to disabled children and their families. Moreover, they can only be found in six large towns in Austria, and many disabled people do not have access to these useful sources of help and information. Despite their success, a quality survey⁸⁵ has shown that information is still insufficient for many families, making it clear that mobile units need to be extended to the whole of the country, and made accessible to any disabled person who needs help.

This model had been used successfully for the provision of long-term care to the elderly in Austria and is now being extended for disabled people. Results of a recent quality study of the Austrian Pflegegeld system did not find any cases of poor hygiene or outright neglect for people with high levels of care. In fact the levels of attendance, hygiene and health were rated good or excellent for all those using the Pflegegeld programme.⁸⁶

The evidence suggests that Pflegegeld users receive a better quality of care than in the UK and other European countries. The timing and reliability of their care is much more satisfactory and unmet need is not an issue. It allows more personalised care and acknowledges the crucial role of family members in the provision of informal care. Overall, it has expanded the choice between different care services, developed home and community care and freed up institutions, allowing people with the most severe conditions to use residential care services.

⁸⁵ OECD, *Ad Hoc Group Report*, 2003.

⁸⁶ BMSG, www.bmsg.gv.at; and C Nemeth & E Pochobradsky, *op. cit.*

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Prevention of Fraud and Inappropriate Spending

It is remarkable that a recent study of the Austrian Cash Allowance for Care – a system that goes further than in other OECD countries towards leaving choice to service users and their families to find appropriate care – did not find any cases of very poor hygiene or open neglect when surveying the condition of 700 people over the age of 65 with care needs above 120 hours per month.⁸⁷ There is no indication of older persons being neglected when relying on consumer-directed rather than agency based care. Apparently, the informal support and surveillance from relatives and others in the community is sufficient to avoid this.

Within the US, exploitation of the system by relatives was also very rare in Cash and Counselling schemes. Cases where people attempted to enrol their relatives in the scheme to obtain the allowance for their own use were identified at the time of the initial counsellor home visit and referred to adult protection services before an allowance was paid. US authorities found that periodic telephone calls and visits are adequate to ensure that recipients of the allowance are not exploited as their situations change.⁸⁸

⁸⁷ Ibid.

⁸⁸ Phillips et al., *Lessons from the implementation of Cash and Counselling in Arkansas, Florida and New Jersey*, Mathematical Policy Research, Inc, 2003.

CHAPTER FIVE

RECOMMENDATIONS

SUCCESSIVE GOVERNMENTS have neglected the needs of children with profound and multiple disabilities. No plans are being made to change a system in desperate need of an overhaul.

The problems faced by these children and their families are now so severe that they can only be addressed by reforming both the supply and the demand sides of the disability care industry.

Principles for Demand Side Reform

Allowing children with profound learning disabilities and their parents to make their own choices will put an end to the state's failed attempts to plan other people's lives. New policies should:

- allow individuals to regain control over their own lives by being able to choose their own care support systems;
- enable people to make their own choices by allocating resources directly to the individual;
- open up the choice of services beyond government organisations;
- provide disabled people with vital information about their care options.

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A Care Allowance Scheme

Disabled people's choice and control over the care they receive would be maximised by giving them a direct cash benefit. A Care Allowance could be spent on any type of care desired. Its value would vary according to the level of disability. It could be spent on formal home care, especially if they live alone, chosen from any agency of care workers. Or it could be shared with family and friends who are providing informal care. Recipients could also choose to purchase goods and services other than personal care, such as assistive technologies and vehicle modifications, which would increase their independence by reducing the need for personal assistance. Alternatively, the money could also be spent on respite care; and for the profoundly disabled, the Care Allowance would also cover residential care costs.

The crucial principle is that it would be disabled people, and their families, who would have the power of choice. The aim would be to enable them to receive the type of care fully tailored to their own individual needs; and to develop long-term relationships with informed and attentive carers.

How would a Care Allowance Scheme work?

Assessments to determine levels of care are currently carried out by the Local Authority. However, the individual's opinions and the family's experience are often not taken fully into account under this system. As one parent has commented:

The way they deal with carers is appalling – they don't show respect for relatives. They don't respect carers for the knowledge they have gained over the years.⁸⁹

Once the individual gets his assessment, it is unlikely to be properly monitored, let alone correctly implemented. Most children are stuck with their original care plan, even though their

⁸⁹ Quotation taken from Mencap, *No ordinary life*, 2001.

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needs may have changed. Doctors witness the family's struggle but are unable to do much about the situation in practical terms.

The amount of care given to different disabled people is hard to quantify. It is given as a number of hours of care, which, as has been seen, are often not fulfilled. And care provision varies from Council to Council, depending on each Local Authority's financial resources. This support system is extremely rigid and often fails disabled children and their families.

Assessment of how much care an individual requires should be evaluated not by reference to a Council's budget but by medical need. To achieve this simple goal, the assessment process should be carried out by a team specialised in disability (a "Care Assistance Team"). The disabled person would then receive a fixed amount of money, pre-defined on a national level, corresponding to his or her needs.

Under this policy, the Care Assessment Team would fill in a single form, after having medically assessed the person's disability level and care needs. This process would take place during a single consultation at a local facility and would result in the provision of the appropriate Care Allowance.

To minimise bad practice, the Care Assistance Teams should be regularly reviewed by an independent review board, who would countercheck the information provided on Assistance forms to maximise public accountability. Complaints from service users would also be investigated by this board. It is envisaged that the Care Assistance Teams would be modelled on the Austrian units, and would consist of professionals including a doctor, a paediatric nurse, a physiotherapist, and an information specialist. The Care Assistance Team would not only conduct the care assessment but also provide continuing help and support to disabled children and their families. Disabled children and their parents should be able to turn to the Care Assistance Team for anything from information to counselling to help with finding a carer or a school. This would give people access to help and information when they decide they need it.

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The Care Assistance Team would give disabled children regular medical check-ups in order to monitor their situation and adapt their Care Allowance accordingly. All disabled children would then have an approach tailored to the specific needs of them and their families.

Modern regulation required for Care Homes

The Care Standards Act 2000 is an over-prescriptive piece of legislation which leaves little room for care providers to interpret what is required of them. Its one-size-fits-all quality control system has led to large cost increases, and this has contributed to significant care home closures: in the last five years, 2,000 Care Homes – with a total of 61,300 beds – have closed.⁹⁰ The needs of the disabled are being sacrificed to meet the needs of the regulator.

The current over-regulatory approach should be replaced with a reliable quality control system which would give care providers the flexibility to meet their clients' needs and which would provide a reliable means of service inspection and assessment. Most British industry uses International Standards such as ISO 9000 as the basis for their quality control systems. The concept of ISO 9000 is for the service provider to construct a quality system that suits their particular industrial sector. It enables versatile, manageable and customer-friendly quality systems to be created, by allowing the integration of high quality policy with lower level workplace best practice instructions, creating a manageable and deliverable integrated quality system.

Care Home operators should be able to choose whether to implement their own Quality System and use independent nationally accredited inspectors, or to stay with the National Care Standards Commission for Inspection. Giving Care Home operators such a choice would promote best practice in Quality Control and lead to better value for money from Care Home operators, by reducing regulatory costs.

⁹⁰ Laing and Buisson www.laingbuisson.co.uk/longtermcare.htm

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Currently Care Homes often receive duplicated Inspections. Care Homes can be inspected by Local Authorities one week, by the NCSC the next week, and yet again by an Environmental Health Inspector the week after that. The Health and Safety Executive (HSE) may also duplicate work undertaken by other inspectors. Duplicated inspection should be avoided and clearer guidance given to bodies such as the HSE.

Taxation and Investment Reform

The mass closure of Care Homes shows that investment in the Care Home sector has long been neglected and it will take many years for the capacity of the industry to be at a level that meets the needs of users. More investment is required. This will be stimulated by a reform of the tax system that will encourage investment in each of the three main sectors involved in the Care Industry: the voluntary and charitable sector; the small- and medium-sized business sector; and the large public companies sector. Reforms should be properly tailored to meet the different needs of all three sectors.

Enterprise Investment Scheme (EIS)

The Enterprise Investment Scheme (EIS) was introduced in 1994 to encourage individuals to invest in small higher risk trading companies as a means to help alleviate the problems faced by such companies in raising equity finance. The scheme provides income tax relief for new equity investments by external investors and business angels in qualifying unquoted companies, and capital gains tax exemption on disposal of shares. In April 1998 capital gains tax reinvestment relief was merged with EIS to create a new unified scheme so that individuals and some trustees can defer the capital gains tax arising on any chargeable gain by investing the gain in qualifying companies.

In March 1998, “nursing or residential care homes” were specifically excluded from the EIS. The scheme should be amended to bring the Care Home Sector within the EIS. The

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upper investment threshold should be removed, thereby allowing larger investments to qualify for the 20% income tax relief. Shareholdings would only need to be held for two years to retain their income tax relief in full and capital restrictions on the value of the company should also be substantially increased. The EIS would help smaller Care Homes in particular, by presenting them with a welcome source of investment capital.

Care Homes Modernisation Tax Credit

Stimulating re-investment within the sector is also necessary. The existence of a Research and Development Tax Credit has helped to encourage investment in future technology and products within the manufacturing sector. This scheme allows for Research and Development expenditure to be charged at 150% in the Profit and Loss Account. This scheme should be used as a blueprint for encouraging re-investment of funds for companies in the Care Homes sector.

Care Home owners should be encouraged to upgrade and modernise existing facilities, by introducing a Tax Credit for repairs. At present all repairs are allowable as a 100% cost to the profit and loss account. Repair expenditure should instead be charged at 150% to the profit and loss account for Corporation Tax purposes. Furthermore, improvements, which are currently deemed to be capital expenditure for Corporation Tax purposes, should be treated the same way as repairs, with the expenditure being charged at 150% to the profit and loss account.

As a result, care home operators would have a great incentive to invest money into the repair, modernisation and upgrading of their facilities. Those companies which were not trading profitably (and which therefore would not be able to make full use of the Care Home Modernisation Tax Credit) could use the tax credit against any trading profits they may have made during the last six years, which would result in a tax repayment.

The Care Home could also take the option, if it were not trading profitably, of having a cash back refund of 16% of the

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actual Care Home modernisation cost. This would be paid directly to them by the government.

Accelerated Capital Allowances

The Care Home Industry also needs greater incentives to build new Care Homes. Under the current system Care Homes are not eligible for tax allowances on the cost of their buildings.

To encourage companies to acquire and invest in new properties, the treatment for tax purposes of capital expenditure on the acquisition of new buildings and the development of new building sites should be reformed, provided the buildings are either newly-built or existing premises which weren't previously used as Care Homes.

The definition of Industrial Buildings should be amended to include Care Homes, thus ensuring that Care Homes are entitled to receive Industrial Buildings Allowance. An initial first year allowance of 40% of the new build costs should be introduced and have a subsequent writing down allowance of 4% per annum.

Charitable Sector Care Home Operators

The charitable sector also need incentives to increase its capacity for looking after the most vulnerable. The special tax dispensations enjoyed by the charitable sector mean that it would not be incentivised by the above taxation reforms.

However, the principles of the Care Home Modernisation Tax Credit could be developed for the charitable sector. Any new charitable investments in modernising existing care facilities, building new facilities or redeveloping facilities which are not currently being used as Care Homes, should result in a tax credit or a one-off payment from the Government, as applicable, on completion of the project equal to the amount of credit a non-charity would have received under the Care Home Modernisation Tax Credit for the expense incurred.

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Children's Hospices

Hospices provide free, charitable services to patients yet receive only small contributions from the NHS or Local Authorities. They are therefore heavily reliant on charitable fundraising to pay for revenue expenditure. They should have the same benefits as other charitable providers with regards to tax incentives for the upgrading or creation of new facilities.

Monitoring

The quality of information available on disabled children and the care services they receive is extremely poor. No clear, reliable data exists on the number of disabled children, the amount of care they receive, where they receive it and the efficacy of that care. Any reform to the way in which care is delivered must be accompanied by far more effective monitoring. This can be conducted by the Care Assistance teams.

CHAPTER SIX

COSTINGS OF POLICY RECOMMENDATIONS

Currently Social Services spend £540 million on disabled children: of this sum, £140 million is spent in assessment and commissioning. If this money were given directly to disabled families, on top of all the other benefits they currently receive, then they would achieve a far greater degree of independence and control over their lives.

General assumptions

To calculate how the proposals would work, the following assumptions have been made:

- the overall level of available funding has not been increased. Whether or not this is desirable is, of course, a matter of political will. It might be noted, however, that on average, current social services spending is about £11,020 year per disabled child. This compares to the average cost of juvenile prisoners of around £36,000 a year;⁹²
- the care that a disabled child is currently receiving would continue indefinitely. These proposal are supplementary to that which children are already obtaining;

⁹¹ See *Valuing People: A Strategy for Learning Disability for the 21st century*, White Paper, March 2001.

⁹² See Hansard, 3 June 2003, Column 98W.

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- the benefits for domiciliary and day care will not be means-tested and will be universal;
- the calculations here present a snapshot of what would happen if disabled families did not greatly change the way that they used care services. In reality, of course, it is probable that disabled families would wish to take advantage of more respite care; and some would wish to use more residential care. The degree to which this would be possible would depend on the amount of money that central government decided to spend on disabled children;
- similarly, the costs of providing respite and full-time residential care are based on today's prices. However, with a more modern regulatory regime, and a more favourable fiscal regime, it is reasonable to expect the level of supply to increase.

Cost of Care Assistance Teams

It is assumed that each Care Assistance Team will have a Doctor, a Paediatric Nurse, a Physiotherapist, a Care Specialist and an Information Specialist as Team members. Each Team will cost about £280,000 per annum to run.

It is estimated that each care assistant Team would be able to see 20 children a week; and that each disabled child would need to be seen annually. Each Care Assistance Team would thus be able to provide care for about 750 disabled families.

With 50,000 severely disabled children in England and Wales, there would therefore be a need for 65 Care Assistance Teams. At an average cost of £280,000, the operating cost of 65 Teams would be about £18 million a year.

Cost of Care Allowance Scheme

The Care Allowance will be graded into four levels :

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- domiciliary and day care;
- respite care with foster families;
- respite care in a Care Home;
- full-time residential care.

Proposed value of benefits

Domiciliary and Day Care	£16.50 per day
Respite Care with Foster Family	£55 per day
Respite Care in Care Home	£210 per day
Full-time Residential Care	£210 per day

Take-up and Costs

	Value/Day £	Uptake Days/Year	No. of Users	Cost/Year £ 000s
Domiciliary & Day Care	£16.50	365	27,500	165,618
		295	15,000	73,012
		325	5,000	26,812
Respite Care with Foster Family	£55	70	15,000	£57,750
Respite Care in Care Homes	£210	40	5,000	£42,000
Full-time Residential Care	£210	365	2,500	191,625
Total Cost of Care Allowance Scheme				£556,817

Adding together the cost of the Care Assistance Teams and the Care Allowance Scheme gives a total proposed expenditure in the region of £575 million. This compares with a current Social Services spending on disabled children of £540 million.

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Supply Side Reforms

The Enterprise Investment Scheme, the Care Homes Modernisation Tax Credit and the Accelerated Capital Allowances would all incur some further costs to the Treasury. However these costs are expected to be offset by demand-side cost reduction resulting from deregulation of the Care Home sector and small efficiency savings (in particular, the freeing up of beds) within the NHS, Department of Health and other regulators.

CHAPTER SEVEN

CONCLUSION

BRITISH CHILDREN WITH LEARNING DISABILITIES, and their families, have been failed by successive governments. Government figures on learning disability are very few and far apart, reflecting the lack of concern for, and monitoring of, this situation. The current Government has set up several schemes under its *Making Change Happen* programme in order to reassure learning disability advocacy groups. However, while yet more money is being spent on committees and task forces, disabled children are still being denied basic health and social care.

The bureaucracy that is responsible for failure should be swept away and resources channelled directly to the disabled children and their families. Control and choice would be given back to disabled children and their families by giving them a Care Allowance with which they could purchase the care they need, when they need it. For the first time, disabled people would have unrestricted access to information and medical support thanks to the creation of mobile Care Assistance Teams.

The Care Industry must also be freed from the worst aspects of the Care Standards Act 2000. The cost of these rigid regulations has resulted in the closure of many care homes. The Care Industry should be revitalised by allowing the adoption of ISO 9000 as a quality standards framework.

While the regulatory burdens imposed on the Care Home Industry have increased, so have the incentives to open new establishments been dramatically reduced. Tax credits should be reintroduced as an incentive for existing care homes to refurbish

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and modernise their establishments, and to encourage the creation of new care homes by introducing an Accelerated Capital Allowance. By rejuvenating the Care Industry, more care home beds and respite care facilities should be available, giving disabled children and their families a genuine choice of care services, valuing and enhancing their lives together.

Government should not attempt to micro-manage the lives of its citizens, even the most disabled. Rather it should trust the disabled to be able to exercise the right of choice. And it should allow the market to respond to that choice.

APPENDIX

A SUMMARY OF THE LAW AND DISABLED CHILDREN

THE LAW RELATING TO DISABLED CHILDREN could best be described as a patchwork of statutes that have been enacted in the last 55 years. In some areas, it is complex and has sections that are unresolved and controversial. As areas of interpretation are clarified by the courts, new questions arise.⁹³

In addition to the statutes, there are endless statutory instruments, departmental circulars and guidance notes to be taken into account, all adding to the general confusion and uncertainty regarding disability legislation.

This situation has led to Local Authorities and the NHS, as purchasers and sometimes providers of care, often misinterpreting their duties. This in turn often interferes with the delivery of a service, the final result being that disabled children are not getting the level of community care they need and deserve.

In addition to those Laws that apply in England and Wales, there are a number of European and International human rights-based laws or civil liberty documents that impact on the care of the disabled. These include international covenants and conventions that have emerged from the United Nations, such as the UN Convention on the Rights of Children (1989), which are not enforceable but act as international standards to the rights of children.

⁹³ See L Clements, *Community Care and the Law*, Legal Action Group, 2000 and J Read and L Clements, *op. cit.*

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Major Laws that relate to Community Care and the Disabled⁹⁴

National Assistance Act 1948

Chronically Sick and Disabled Persons Act 1970

Local Authority Social Services Act 1970

Health and Social Services and Social Security Adjudication Act 1983

Disabled Persons (Services, Consultation and Representation) Act 1986

The Children Act 1989

National Health Service and Community Care Act 1990

Carers (Recognition and Services) Act 1995

Human Rights Act 1998

Care Standards Act 2000

The Carers and Disabled Children's Act 2000

Education Acts (Various)

The National Assistance Act 1948

An important part of Beveridge's proposals was the National Assistance Act 1948. The Act abolished the poor law system that was in place at the time and in Part III tackled the needs of vulnerable people. Amongst other things, it required local authorities to provide residential accommodation for elderly and disabled people.

The Act also required that disabled people should have access to the advice and guidance, occupational activities and facilities needed to overcome communication or mobility disabilities.

The Chronically Sick & Disabled Persons Act 1970 (CSDPA)

Alf Morris MP introduced the CSDPA as a Private Members Bill. The strength of the Act is that it made the provision of services under The National Assistance Act 1948 S29 mandatory rather than discretionary. This Bill was the first of many attempts to ensure that care for disabled persons was needs-based rather than budget-based.

⁹⁴ This table is derived from L Clements, *Community Care and the Law*, Legal Action Group, 2000.

A SUMMARY OF THE LAW AND DISABLED CHILDREN

The receipt of high quality services for disabled people as a right was, and still is, viewed as a luxury that cannot be afforded. A leading analyst has comments that “community care has been resource- rather than rights-oriented”.⁹⁵ He further notes “that we are witnessing feats of impressive judicial gymnastics as the courts endeavour to equate the simple “needs-led” language of section 2 of the Act with the complexities of severe resource shortages.”

Local Authority and Social Services Act 1970

This statute created Social Services Authorities by the reorganisation of various welfare departments as recommended in the Seebohm Report (Cmnd. 3703). Social Service departments are permitted to undertake certain functions under this Act and the list is regularly updated. This includes needs Assistance and provision or purchasing of care packages for disabled children.

Health and Social Services & Social Security Adjudications Act 1982

Under provisions within this Act, local authorities can charge for both community care services and equipment where the recipient of these can afford to repay them. These provisions have led to tens of thousands of elderly people being forced to sell their homes.

Disabled Persons (Services, Consultation and Representation) Act 1986

The Act, another Private Member’s Bill, gave disabled persons and their carers the right to request an assessment of their needs. It is only after an assessment of needs has been undertaken by Social Services that a decision is made - also by Social Services - as to the quantum of service that should be provided. This conflict of interest is at the root of the current budget-led care system.

⁹⁵ See L Clements, *Community Care and the Law*, Legal Action Group, 2000 and J Read and L Clements, *op. cit.*

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The Children Act 1989

The Children Act 1989 is British legislation that also contains broad civil liberty provisions, in particular for disabled children or children in need. This includes “the best interests principle”, which states that a child’s best interest should be of the greatest importance and that delay in making decisions about a child’s care is harmful to the child’s interests.

Social Service authorities are also under a general duty to safeguard and promote the interests of children “in need”.

The provisions of the Children Act 1989 are stated in general terms and the duties are described as “target duties”. For this and other reasons the Children Act can at times have a difficult legal relationship with other legislation, leading to confusion.

National Health Service and Community Care Act 1990

The National Health Service and Community Care Act 1990 redefined community care in a number of areas. Its roots are in the Griffiths Report of 1988 entitled *Community Care – Agenda for Action*, which was succeeded by a White Paper *Caring for People* (1989 CM 849).

A policy of closing all NHS long-stay wards and a large proportion of local authority-run accommodation led to a huge increase in social security costs for private nursing and residential home fees. The Act sought to effectively limit this expenditure by transferring budgets to local authorities, thereby taking a budget-led, rather than needs-led approach to community care.

Carers (Recognition and Services) Act 1995

The National Health Service and Community Care Act 1990 failed to provide support for carers so it was left to yet another Private Member’s Bill to make up for the shortfall. The Carers (Recognition and Services) Act 1995 requires Social Service authorities to assess the needs of the carer as a separate activity. The Act recognises the importance of carers as the main providers of social care in the community.

A SUMMARY OF THE LAW AND DISABLED CHILDREN

Human Rights Act 1998

The European Convention on Human Rights has been incorporated into British domestic law through the Human Rights Act 1998. It states that “*no one shall be subjected to torture or to inhuman or degrading treatment or punishment*” and generally influences all aspects of the way disabled individuals are treated.

Care Standards Act 2000

The aim of the Care Standards Act 2000 was the modernisation of social care. There is a particular emphasis on service quality and client protection. The Act established the National Care Standards Commission as the regulator.

According to Ann Parker, Chair of the National Care Standards Commission, “the overwhelming priority for the National Care Standards Commission is to protect people who receive care services.”⁹⁶

To deliver this, the Care Standards Act 2000 has a multitude of prescriptive standards aimed at every detail of the Care Industry from the design of care homes, to staff training, to very specific care regulations.

The Act also stipulates the use of the Criminal Records Bureau (CRB), which is tasked with checking the police records of employees for their employers. The CRB experienced a chaotic start to its life and failure to deliver has met with much criticism.

The Care Standards Act 2000 has been extremely costly for the Care Industry to implement and has been quoted as the main cause for many recent care home closures. It has not been welcomed by service providers, who regard it as an exercise in micro-management which will result in many more care home closures in the months and years to come.

Consequently the Government delayed some of the provisions within the Act, and has now exempted existing care homes of many of the CSA regulations. However, a great amount of damage

⁹⁶ *Caring Times*, June 2003.

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has been done as many existing homes closed in the face of over-regulation before this decision was made.

The Carers and Disabled Children's Act 2000

This Act further adds to the rights of carers. In certain cases the Act allows carers and disabled children to receive direct payment in lieu of the provision of services, to receive vouchers for respite care, as well as giving them further rights to assistants and services.

However, Social Services can charge for services provided under this Act.

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