Good practice in working with parents of disabled children

Workshop overview

Workshop programme

9.00	Registration and coffee
9.30	Welcome, introductions and overview
10.00	Examining what works well
10.30	Understanding the experience of families
10.50	Similarities and differences with other families

11.00	**Break**

11.20	Themes from research
11.40	The challenges of linking evidence and practice

12.30	**Lunch**

1.15	Listening to parents
1.30	Key messages
2.15	Examples from practice

2.45	**Break**

3.00	Feedback from practice groups
3.40	Evaluation and close

4.00	**Depart**

Workshop aims

- To focus on what we know from both research and experience based learning to support parent carers to achieve better outcomes for their families
- To increase knowledge and confidence to understand the needs of parents and families caring for disabled children
- To provide an overview of key themes emerging from the evidence base about effective ways of working with parents of disabled children.

Learning outcomes

By the end of the workshop you will be able to:

- Understand the context in which families are caring for disabled children
- Reflect on ways of supporting parents that help create positive outcomes for disabled children and their families
- Explore ways of translating the messages from the evidence base into practice in your own settings.

Briefing paper
Kim Aumann and Carrie Britton

Key messages

Section One Definitions

Parent carers: recognising two roles in one term

Disabled children: who do we mean?

Family diversity

Section Two What we know about the population

Introduction to this section

Demographic data about disabled child population and their families

The outcomes dilemma

Section Three The wider context of disability and disadvantage

Introduction to this section

Disability and disadvantage

Unique journey

Dealing with lack of opportunity

Getting through the maze – experience of conflict

Section Four Five keys to getting it right

Introduction to this section

Early support

Transition times

Continuity and key working

Skills and attitudes

Parent carer participation

This briefing paper provides an overview of some of the chief experiences and topics of concern for parents of disabled children for a wide range of participants, including new practitioners, experienced managers from the community and voluntary sector, health, education, social care or integrated teams, and commissioners. We scope the main topics with an emphasis upon what parents of children with disabilities tell us matter most.

Please note, that due to decades of under investment in research activity, there is a current lack of comparable evidence and research data in this field. Therefore, an examination and comparison between the effectiveness of different types of service provision and support programmes for parents of children with disabilities is not yet possible. The authors were not commissioned to conduct a literature review however, we do indicate key messages and markers of good practice, and tips for effective partnership working with parents gained from over 35 years frontline experience. *September 2009*

Section One
Definitions

1.1 Parent carer: recognising two roles in one term

Many would agree that parenting is one of the most rewarding yet challenging roles for adults in all societies. While we may share an understanding of the terms parent and parental role, there is wide cultural and lifestyle diversity in the delivery of the parenting role. Every Child Matters programmes for Change are based upon the assumption that parents have the greatest influence upon the outcomes for their child. Similarly each of the eleven standards of the National Service Framework for Children, Young People and Maternity Services highlight the role of parents in accessing care and services for the child and those parents are key partners to decision-making. Government has prioritised parenting support as a central tool to enhancing children's life chances as set out in Every Parent Matters.

However in the context of disabled children, it is important to recognise the additionality that is inherent when parenting a child or young person with a disability. To do this we use the term 'parent carer' to distinguish the added complexity and challenge that is experienced when parenting in this situation. Caring for a disabled child makes demands on families over and above those usually expected of other families.

For these parents, the carer role impacts both daily life and the experience of parenting so an overview of this topic must include evidence from the studies about both 'caring' and the journey of parent carers in particular. The 'parent carer' term and role is not yet widely used or understood, and some parents would not necessarily choose the term 'parent carer' nor recognise their additional carer work because perhaps the child's difficulties are not fully diagnosed or acknowledged, or they have absorbed the extra work of dealing with their child's additional needs without labelling it.

A key challenge in this arena is that data collected about disabled children and their families is patchy, inconsistent and limited. So while it is difficult to identify an abundance of research that pinpoints clear outcomes and substantiates best practice, the overwhelming majority of studies consistently evidence that disabled children and their families face numerous barriers to both accessing timely, appropriate and sufficient support, and to participating in society like other families. Their outcomes and life chances in the main are restricted.

In this briefing paper we indicate where research evidence and/or long years of practical experience of working with a wide range of families over time indicates key ways of making the journey easier and achieving outcomes valued by families of disabled children and young people.

1.2 Disabled children: who do we mean?

There needs to be clarity about the terms used because disabled children are not one homogenous group and different institutions, policies and practices deploy language that can be interpreted differently. Children with disabilities usually refer to children with physical or learning disabilities. The Disability Discrimination Act 1995 definition is 'a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities'. This includes complex health needs, learning disability, autistic spectrum disorders, sensory impairment, physical impairment and emotional and behavioural disorders.

Children with Special Educational Needs (SEN) may have medical, behavioural, learning or physical needs but are not necessarily disabled. Children with emotional or mental health difficulties are commonly overlooked. The terms additional or special needs are used by different people to mean different things. In many Children's Trusts the term 'disabled children' is often used to include children with special educational needs, disabilities and those with the other forms of additional needs.

Children with additional needs is a wider term that can include children with all the above challenges, while the term SEND (Special Educational Needs and Disabilities) is being used in the latest publications from the Department of Children Families and Schools.

Other key terms

There are no clear shared definitions about other key terms used such as severe, complex, multiple, profound, and their usage varies in different services and has also changed over time. In this paper we use the following terms to mean:

- Impairment = this broadly means functional limitations, which are typically categorised as physical, sensory and cognitive.
- Children = children and young people.
- Parents = all those with parental responsibilities including adoptive parents, foster or step parents, kinship carers.
- Family = at least one parent living in the same household with at least one dependant child.

Over the last 30 years, the life accounts and stories of disabled children and adults has helped to shape our understanding of disability. People often talk about the medical and social models of disability which can engender heated debate, but it's important to have an understanding of the controversy involved and the terms used when engaging with this area of work.

The medical model of disability views disability as a characteristic of the person, caused by disease, a health condition, syndrome or trauma for which medical intervention is needed to correct the problem. Through this lens, a disabled child is seen as faulty and their impairment becomes the focus of attention, requiring diagnosis and labelling and specialist assessments and services take priority over ordinary needs of childhood. Many dispute and reject this view in favour of the social model of disability, which views disability as a socially created problem caused by inaccessible environments and discriminatory social attitudes. Through this lens, the child is seen as valued, their strengths and needs are defined and inform an outcome based programme of support where resources are made available, training for parents, carers and professionals is offered, relationships are crucial and diversity is welcomed. Developed largely by disability activists in the 1980's, this view argues that providers had been too concerned with changing the child and not worried enough about reducing the negative impact of social barriers and the disabling

nature of structural problems. "Impairment is what we have. Disability is what we experience" (John and Wheway 2004).

In the early 1990's, a transformational shift away from a medical model of care began with the emergence of family-centred care: a model that accepted the family as central in a child's life. This model recognises the family's values and priorities as central to the child's care and incorporates the parent and family as active collaborants in care planning and effective intervention (Ahmann1994).

1.3 Family diversity

Personal experiences and expectations of what being a parent means and the values and beliefs related to parenting vary. Disabled children, like other children, are raised by parents from a variety of family backgrounds, cultures and experiences. Different cultures and different family compositions may address things in different ways and give them different meanings. Inclusive language can be a powerful way of showing respect for difference especially when working with parents from minority groups such as fathers, lesbian and gay parents, or parents from black and minority ethnic (BME) communities. The most pressing problems affecting some disabled children from BME backgrounds are poverty and social disadvantage. These factors appear to have a greater influence on the prevalence and impact of disability than ethnicity.

The overwhelming majority of disabled children live at home with their families. Estimates range from 85% to 99% (Buckner and Yeandle 2006; Kagan et al 1998). Mothers carry the main responsibility for their care (Atkin 1992; Beresford 1995; Read 2000) and compared to the general population, a greater proportion are lone parents (Beresford 1995). 32% of disabled children live in lone parent families compared to 22% of other children (Buckner and Yeandle 2006; Emerson and Hatton 2005). Around 2% of disabled children live outside their family home in long term foster placements, with relatives, in residential schools or health care and hospital settings (Pinney 2005). Having a disabled child cuts across socio economic, geographical, gender and ethnic divides, although as is explained in the next section, a high proportion of disabled children are living in the poorest neighbourhoods.

Section Two
What we know about the population

2.1 Demographic data about disabled child population and their families

The government estimates that there are around 770,000 disabled children in the UK (HM Treasury and DFES 2007). Until quite recently, many policy makers and organisations were operating on the understanding that this figure was as low as 320,000. The 2003 Audit Commission Review of Services for Disabled Children in the UK described services as 'a lottery of provision, too little provided too late, a jigsaw puzzle of services' (pp 2- 4). This picture was echoed in the Prime Minister's Strategy Unit's 'Improving the Life Chances of Disabled People' report (PMSU 2005). During the 2006 Aiming High for Disabled Children Cross Party hearings, the Children's Commissioner for England, Professor Sir Al Aynsley-Green, stated that 'the evidence was known, policies were in place but delivery was lacking' (HM Govt 2006). Quite recent investment in research and more accurate data collection and analysis has enabled service design and delivery to begin to be more evidence based.

Clear understanding about the demographics of the disabled child population is vital for the effective planning and delivery of services. It is equally important to examine the data about the families of these children and who's doing the caring, if we are to develop services that lead to good outcomes for disabled children and their families. However, recent knowledge review reports compiled by the Centre for Excellence and Outcomes on the theme of disability (C4EO 2009) confer with others (Buckner and Yeandle 2006, Langerman and Worrall 2005) and find that the data available about disabled children is inconsistent and often unreliable. This is due to a lack of consensus on how to define disability, an absence of robust schemes that identify and record disabled children, incomparability of different data sets due to differences in age range or the impairments classified as disabilities and the reluctance of some families to label their children as disabled. We have identified four surveys and data analysis exercises conducted in the last 10 years, that provide considerable information about the numbers, incidence, prevalence, distribution and trends of this population group (DWP 2004, Walker 2002, Emerson and Hatton 2005, Gordon et al 2000), all of which significantly help service providers to identify and anticipate need.

Incidence and prevalence of childhood disability
Both the incidence and prevalence of childhood disability is growing. For the period between 1990 and 2000, more babies were born with impairment and more children per thousand were diagnosed with a disability. For example, the Office of National Statistics report that the incidence of severe disability increased from 6 to 8 per 10,000 population and the incidence of mild disability increased from 17 to 18 per 10,000 per population (Nessa 2004). For the period between 1975 and 2002, the number of disabled children increased by 62%, from 476,000 to 772,000 under 16 years (PMSU 2005).

The increase is thought to be due in part to population increases, but also to a number of other factors like changes in diagnostic practice, increases in multiple births following IVF treatment and medical advances that assist children to survive events like premature births and major trauma such as injuries from road traffic accidents. Medical technologies, like feeding lines and breathing assistance, are also assisting disabled children to function more effectively and extend their life expectancy (Ludvigsen and Morrison 2003; Nessa 2004).

Disabled children now represent 5% of all children and their life chances to successfully reach adulthood are noticeably improved. Disabled children and their families are managing multiple and changing impairments, mostly within the family home whereas earlier generations of children were cared for in hospital or residential settings. Identifying and analysing the rise in both absolute numbers of disabled children, and increase in severity of impairments is challenging. There are thousands of disorders and conditions (Casswell 2004) that make it difficult to quantify categories of disability while some children have no diagnosis at all. However, there are common trends emerging from the data that are worth noting. These are:

- mobility, communication and learning difficulties are the most common areas of significant difficulty recorded by the Department for Work and Pensions' Family Resources Survey (DWP 2002).
- learning disability, autism and cerebral palsy are the three most prevalent conditions recorded by families applying for Family Fund grants, which sets their criteria at the more severe range (Family Fund 2004).

Differences in incidence between gender and ethnicity of disabled children

There are more disabled boys than girls. In the period from 1990 to 2000, the Office of National Statistics reports that the incidence of severe disability in boys increased but fell slightly for girls. For boys the increase was from 7 to 11 per 10,000 population while for girls the decrease was from 6 to 5 per 10,000 population (Nessa 2004) and this pattern seems to be increasing. The DWP estimates that 400,000 disabled children are boys and 300,000 are girls. Unfortunately, very little data exists on the ethnicity of disabled children (Emerson and Hatton 2005) and there is no evidence to suggest an increased link between the two. However, it's possible that some ethnic groups (Indian, Pakistani, Bangladeshi and Chinese) are less likely to report disability (PMSU 2005).

2.2 The outcomes dilemma

The key features of the Every Child Matters (ECM) programme were the arrangement in a triangular hierarchy of universal, targeted and specialist services. The second feature was the focus of service delivery on five outcomes for individual children.

- Being Healthy
- Being Safe
- Enjoying and Achieving
- Making a Positive Contribution
- Economic Wellbeing

The five ECM outcomes are usually considered of equal significance to children and young people, and therefore to service providers, commissioners and assessors. However, recent national research (Beresford et al 2007) recommended important adaptations to these outcomes in relation to services for disabled children. The rationalle for these adaptations are as follows:

- Overall, the five outcomes are relevant for disabled children but crucially they omit communication, a fundamental capacity, so this needs to be added as a sixth outcome. Greater attention to communication is fully endorsed by findings from the recent Bercow Inquiry into speech and language

provision, the Aiming High for Disabled Children hearings (HM Govt 2006), and echoed consistently by local parent carers' views.

- The outcomes themselves mean something very different to disabled children and their parents compared to other families of fit and well children.

- The outcomes need to be used in order of their relevance to disabled children and their parents. The research team recommend a hierarchy as illustrated in the figure below.

Every Child Matters: Outcomes framework adapted for children with complex health needs and disabilities

Highest priority

- Being healthy, including emotional wellbeing
- Being able to communicate (new item)
- Staying safe

- Enjoying and achieving
- Making a positive contribution
- Economic wellbeing

Lowest priority

There are real problems and complexities with measuring and interpreting outcomes for disabled children. For example:

- The comparator data derives from child development trajectories of ordinary healthy children. The development of disabled children does not necessarily fit the sequence, stages or nature of these data sets.

- There is a scarcity of research evidence about some common and longstanding interventions and therapies.

- There is little published data that compares different approaches and their efficacy, especially those carried out within a community setting rather than in-patient environment. Although there are studies about particular subgroups of conditions, for example about different approaches for children with autism, we have little evidence across the disabilities about which interventions work best for different groups of families. And some studies are of uncertain quality.

- While there is evidence from other countries, particularly the USA, this may not be relevant enough because of cultural differences and differences in the way services are provided in the UK.

- Service provision was previously focussed upon meeting child and family needs, rather than designed with a focus on the impact of interventions on child outcomes. Hence the information collected is often about resources, activities and the experience of using services which may only provide a partial picture of outcomes.

- Researchers have noted the significance of maintaining quality of life, sometimes in the context of deterioration of abilities, findings which concur with studies with older service users, and reinforce the importance not just of outcomes but also the way in which the service is delivered. Service-users have long argued that the impact of the way in which services are delivered can be as important as the outcomes of the service, and the way in which something is done can undermine or contribute to quality of life outcomes. Monitoring and evaluating individual practitioner interaction with parent carers and disabled children is not systematically collected.

- There is a complex debate about whose outcomes should be considered (child and/or family, child and/or parent, practitioner or family defined outcomes) and how inputs can be monitored and evaluated. Parent carers and practitioner views can vary about which interventions or services have greatest impact or value. This often stems from the difference in the outcomes families or practitioners focus upon.

- An area of consensus is the value of early intervention, and prevention of crisis. However it is difficult to prove that preventative intervention is cost effective although there are some examples of economic comparisons. One report estimates that if a disabled child needed to be placed in a residential setting or with a foster carer due to family breakdown, it would cost an average of £2,236 per week or £486 per week respectively (Copps and Heady, 2007). These figures do not of course reveal the emotional, behavioural or relational consequences of interventions; however they do highlight that support for families before they can no longer cope is less costly and emotionally preferable to looking after children following a family breakdown. Providing appropriate childcare that enables parents to work is similarly economically beneficial.

- It is difficult to measure non-economic outcomes such as children and family well-being and parent carer capacity to cope and respond resiliently to the extra demands of caring for disabled children.

While there is only a partial and poorly developed research evidence base in this arena, and no conclusion about best practice to achieve optimum positive outcomes for child, parent and family, the need to define outcomes for service interventions, and to provide greater systematic transparency about the outcomes sought through interventions with individual children, is clear. The progress map summaries published by the Centre for Excellence and Outcomes (C4EO 2009) recognise the need for more attention to setting, monitoring and evaluating outcomes. There are examples of ways to monitor the impact of social care practice on family quality of life outcomes (Bamford et al 1999) and Together for Disabled Children have produced a document with guidelines for adopting an outcomes approach (TDC 2009).

Section Three
The wider context of disability and disadvantage

3.1 Introduction

Despite a raft of policy initiatives and government guidelines introduced over the past two and three decades to improve the life chances of disabled children, they and their families have continued to meet obstacles to achieving ordinary and reasonable quality lives.

In 2003, the Audit Commission conducted a review of services for disabled children and their families which, while painting a very critical picture of the situation for families at the time, resulted in visionary recommendations for the direction for future government initiatives. The key features were that services should meet families' needs; that families should be enabled to participate in everyday life; that services recognise that children grow and move on and that they recruit and develop the right workforce. Since then, with the involvement of parent carers and significant campaigns organised by leading voluntary sector groups such as the Council for Disabled Children, Contact a Family and Mencap to name just a few, key initiatives have been developed. These include the following:

Prime Minister's Strategy Unit's 'Improving the Life Chances of Disabled People' which made recommendations across four areas: independent living; early years and family support; transition to adulthood and employment (PMSU 2005).

Every Child Matters (ECM), and the subsequent Children Act 2004, built on the recommendations of the Laming Inquiry (DoH/Home Office 2003) and set out policies to protect children and to maximize their potential through five outcomes – being healthy; being safe, enjoying and achieving, making a positive contribution and economic wellbeing – which were then developed into a national framework for change which informs policy development, assessment, inspection and delivery at both national and local levels. ECM's focus includes: supporting parents and carers; early intervention and effective protection; accountability and integration of services; workforce reform.

National Service Framework (NSF) for Children, Young People and Maternity Services which sets out national standards for the first time for children's health and social care. It's a 10 year programme for improving children's health and well-being through eight standards. The focus of Standard 8 is on disabled children. It provides that children who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, promote social inclusion and, where possible, enable them and their families to live ordinary lives. It also provides that local authorities and Primary Care Trusts ensure all children and their families who are assessed as having needs that can be met by short term breaks are offered, without undue delay, a range of services from which to choose (DoH 2004).

In the summer of 2006, the HM Treasury and the Department for Education and Skills jointly announced a review of children's services, designed to make recommendations to the 2007 Comprehensive Spending Review. One of the three strands of the children's review focused specifically on services for disabled children. A cross-party panel of MPs was established to hold hearings on services for disabled children which focused on early year's services, family support and children's services and transition to adulthood.

As a result, an additional £340 million is being invested in short breaks, parent participation and transition work. Launched as Aiming High for Disabled Children (AHDC): Better support for families, in 2007, the programme is the newest plan that sets out to improve and transform services for disabled children and their families. (HM Treasury/DfES 2007) Its three priority areas are: access and empowerment; responsive services and timely support; and improving quality and capacity. Key to making the changes envisioned is a Core Offer and a disabled children's national indicator. The core offer sets out expectations about how children and families will be informed and clarifies their entitlements which covers information, transparency, assessment, participation and feedback.

Alongside other improvements such as Valuing People: A Strategy for Learning Disability for the 21st century (DoH 2001) and, Removing Barriers to Achievement (DfES 2004), which sets out the Government's vision for the education of children with special educational needs and disabilities, and the Disability Discrimination Act 2005 (DDA), the hope is that disabled children and families will begin to experience a real change and shift in the effective provision of support services and their capacity to enjoy an equal opportunity to lead ordinary lives.

3.2 Disability and disadvantage

So what do we know about the lives of families with disabled children? Parents of disabled children come from a huge variety of family backgrounds, cultures, social groupings and experiences. Wide-ranging research consistently shows that families of a child with disabilities are more likely than others to experience poverty, (PMSU 2005) relationship breakdown, (Beresford 1995; Higgins et al 2005) general health and mental health issues, (Barlow et al 2006; Oelofsen and Richardson 2006), unsuitable housing (Beresford and Rhodes 2008) and problems associated with employment, like finding suitable childcare (Stiell et al 2006).

A quick glimpse of the following statistical data illustrates real ways in which the life chances and positive outcomes for disabled children and their families are compromised.

55% of families with a disabled child are living in, or on the margins of poverty (Gordon et al 2000).

There is ample evidence that links poverty and disability. While genetic conditions do not appear to be associated with poverty, low income families are more likely to have low birth weight babies and these babies have a higher risk of health problems leading to disabilities (PMSU 2005). There may also be a significant link between children with moderate learning difficulties and lower socio-economic status (DoH 2001). What emerges most strongly from the available data is the causal link between disability and poverty – having a disabled child leads families into poverty.

It costs three times more to raise a disabled child compared to raising a child without a disability (Dobson and Middleton 1998). Additional costs include for example, clothing, bedding, laundry, trips to hospital, equipment, heating and housing adaptations. One study estimates that families need an extra £105 per week over and above their incomes, to meet their child's extra needs (Wooley 2004).

10% of families with disabled children care for more than one disabled child (Sharma and Dowling 2004). Families with two or more disabled children are more likely to be single parent families, less likely to be in paid employment or live in their own homes and more likely to be reliant on income support (Lawton 1998; Tozer 1999).

The level and take up of disability benefits is inadequate. Not enough families are claiming their entitlement. Estimates in 2006 suggest that only 50% of disabled children under 16 were receiving some level of Disability Living Allowance (DWP 2006). This financial strain is further compounded by the level of debt family's experience. One figure reports 31% of families with disabled children are in debt, compared to only 18% of other families (Emerson and Hatton 2005) while another suggests this figure is as high as 84% (Kempson 2002). Studies on the cost of caring indicate that benefits need to be increased by 20-50%, depending on the child's age and impairment (Dobson and Middleton 1998).

Families are more likely to be managing on one income or living on benefits. 32% of families with a disabled child have no parent working over 16 hours per week, compared to 16% of other families. Depending on whether you have one or more disabled children, only 11 to 16 % of mothers and 51 to 63 % of fathers were in the workforce compared to 61% of mothers and 86% fathers without a disabled child (Emerson and Hatton 2005).

Three out of four families with disabled children live in unsuitable housing (PMSU 2005). 40% of parents in one survey reported problems with cold, damp and poor repair in their homes (Beresford and Oldman 2002). Poor quality or inaccessible housing is hugely damaging to a child's quality of life, especially given the barriers disabled children face in accessing ordinary activities outside of the home.

- Only 1 in 13 disabled children receive a regular support service from their local authority (CSCI 2005) and there is a lower take-up of services and benefits from BME families (Audit Commission 2003, Chambra et al 1999).

- Childcare for disabled children is extremely inadequate, often due to a lack of worker expertise and homes and buildings that are hard to access (Daycare Trust 2001). The National Audit Office found that in 2004 only 10% of childminders offered services for disabled children (NAO 2004) and while finding the right childcare is a challenge for all families, a recent Contact a Family report found that it is more problematic for parents with disabled children (Bennett 2009). The majority of mothers in one study reported that they were unable to return to paid employment because of the need to care for their child (Curran et al 2001).

- Encouraging families to take up Direct Payments (cash payments from the local council which can be used by the service user to buy services from an organization or employ somebody to provide assistance) in lieu of services may deliver choice but the reality check is that there is a paucity of appropriately trained workers available to work directly with families. Direct Payments require supervision and responsible employer practice that adds to the carer burden for many parents, and is not the panacea many believe it to represent. (For evidence about this debate see p47 of the full report: Parliamentary Hearings on Services for Disabled Children, October 2006 HM Govt 2006).

- While there are no clear UK studies that establish a connection between having a disabled child and relationship breakdown, there are a number of extensive parent surveys that illustrate the strain on families (DH/DfES 2004) and the 'breaking point' many are living with on an ongoing basis (Contact a Family 2004; Mencap 2003 and 2006).

- Managing the extra demands of bringing up disabled children is tough. Being a 'carer' is widely accepted to be stressful, isolating and likely to impact negatively on carer health and wellbeing. Stress related illnesses such as anxiety, depression and neurotic symptoms are widespread amongst parents of disabled children (Carers UK 2004; Hirst 2004; Wallander and Varni 1998; Singleton et al 2002). Stress on families is cited as one of the causes of children going into residential placements, either in the care of social services or to a residential educational establishment (DoH NSF 2004). Increased levels of stress double the chance of illness or injury for carers (Shared Care Network 2006).

- In the seminal research of Strauss and Corbin (1988) the work load inherent in becoming a carer begins to attract serious attention and supporting the carer is seen as a key to better outcomes for the person being cared for. Mencap's 2006 survey of 353 families with caring responsibilities for children with severe or profound learning disabilities found that: 8 out of 10 families had reached breaking point and 1 in 3 had experienced a cut in their short break services in the last year; 7 out of 10 families provided more than 15 hours of care every day and 5 out of 10 provided care during the night; 7 out of 10 family carers who were in poor physical health and 9 out of 10 in poor mental health, said it was because of the amount of care they provided.

- Brothers and sisters of disabled children are at risk of negative psychological effects and many struggle to cope (Rossiter and Sharpe 2002; Opperman and Alant 2003). About one third of young carers in the UK are siblings of disabled brothers or sisters (Dearden and Becker 2004).

- Disabled children are 13 times more likely to be excluded from school (CAF 2009).

- Children with special educational needs (many of whom will be defined as having a disability) are more likely than their peers to be bullied (DCSF 2009; Office of the Children's Commissioner 2006; Reid and Batten 2006; Mencap 2007). The Mencap survey found that 8 out of 10 children with learning disabilities had been bullied and 6 out of 10 had been physically hurt.

- Disabled children are at greater risk of abuse and neglect than non-disabled children. While there is a lack of UK research, one American study reports the risk as high as 3.4 times higher (Sullivan and Knutson 2000).

In conclusion

These statistics paint a bleak picture and they strongly shape both the experience and social perception of disability. The negative impact of a build up of adversity and deprivation is widely documented in the child development literature of the last 30 years. Bringing up disabled children cannot be seen in isolation from these wider influences and challenges and in fact they provide clues for ways of effectively supporting families so that parenting capacity is not diminished.

Practical and emotional support helps parents to better meet their child's needs (PMSU 2005) and there are things that can be done. For example, the home is the hub of family life. For disabled children, whose lives can be held back by poor services, poverty and unwelcoming public attitudes, it ought to be a place of safety, so improving homes and creating outdoor play spaces is a real way of bettering their quality of life. Assisting families to take up their benefit entitlements and improving their access to childcare so those who want to work can, contributes to lifting children out of poverty. Short break care, extra support to help families have fun together and access to other parents and counselling services all help to decrease stress and improve parents capacity to care for their children. Disability awareness training and guidance on ways of dealing with situations in public places are useful ways of working with negative social attitudes.

3.3 Unique journey: core themes and stages

While parents of disabled children have diverse individual backgrounds, resources and preferences, studies have shown that they share in common a distinct set of experiences irrespective of the child's diagnosis that set them apart from parents of children without disabilities (Gammon and Rose 1991; Russell 1991; Worthington 1994). The themes of the parent carer journey need to be clearly understood by commissioners, managers and individual practitioners, because external factors such as how services are designed, where they are targeted and the skill and attitude of individual practitioners are known to impact the nature of the journey parents travel.

Service provision can be effectively organised and delivered that addresses these core experiences in place of a clinically diagnostically segregated and categorised approach. (Stein and Jessop 1982).

Parent carers tell us that having a disabled child impacts on every aspect of their lives. Most are presented with a huge learning curve and are met with obstacles as they seek to acquire information and knowledge about their child's disability or condition and the support available for them. Parent carers manage varying degrees of loss and disappointment as their children reach regular developmental milestones differently from their siblings and peers.

In a recent family survey where 615 families were asked what makes them stronger, almost 70% said that understanding and acceptance of disability from their community is poor or unsatisfactory; over 60% said they were not listened to by professionals and over 60% said they don't feel valued by society in their role as carers (Bennett 2009).

Celebrating ordinary experiences can become more difficult. Well-meaning professionals can intervene and unintentionally de-skill parents, failing to involve them respectfully as partners in the decision making about their children's lives. Without any warning or training, parents are called upon to negotiate the maze of services and support. They are required to meet with different professionals, repeat their stories and

evaluate progress and provision throughout the child's life. A large number of parents are unable to develop restful sleep patterns on consecutive nights: they have little access to breaks as friends and family support dwindles while only limited childcare or short break opportunities are available.

The significance of providing the conditions that support parents to bring up their children and help them and their children to cope with stressful situations are widely acknowledged. Research studies credit the resilience of some socially disadvantaged children who succeed despite adversity, to their child-centred parenting and their parent's interest in and hopes and goals for their education (Desforges and Abouchaar 2003; Osborn 1990; Pilling 1990). Much can be learned from the research on building resilience (Hart and Blincow 2007; Aumann and Hart 2009) and there are studies of multiple deprivation that also suggest that the quality of parenting is liable to be a powerful feature in children's development (Kolvin et al 1990; Utting et al 1993).

Journeys to diagnosis

Family surveys consistently report parents saying that one of the times of greatest challenge was the search for and hearing about the child's diagnosis. For example from research published in 2002 parents said:

'Our trust towards doctors has gone, which affects the rest of your lives.'

'Worry, anxiety, nobody listened or seemed to believe us as to how bad she was.'

'We were devastated. Even talking about it now upsets me. It was like a dark, dark pit and you're on your own.' (Britton and Moore 2002)

Research over many years by Knafl et al (1986, 1995, 2002) reported that the families' experiences during the route to diagnosis can have a significant impact on their subsequent relationship with practitioners and service providers. They advised practitioners to listen to the parents' account of the journey to date, to demonstrate that the parent 'has been heard', and to negotiate with parents their priorities for how they want to communicate and relate to service providers.

Cyclical grieving (chronic sorrow)

Within coming to live with the child's disability, one important element is the phenomena of cyclical grief. This dynamic long term occurrence is a core experience for many parents and was first called 'chronic sorrow' by Olshansky in 1962. His work has been more fully explored and contributes to our understanding of the long term impact of becoming a parent carer and evidences why models of linear grief, such as first described by Kubler-Ross (1973), are not appropriate in this setting (Gravelle 1993; Teel 1991; Worthington 1994). The key features are unhappy or depressed feelings that come and go in intensity without warning, as unexpected events and moments such as other children meeting normal developmental milestones set off intense feelings of sadness (sometimes more intense than at the time of diagnosis) about the loss of expectations of what the child could have done or been.

Stress: a central experience of parent carers

Different researchers confirm that chronic stress is a major challenge for parent carers (Eiser 1994; Beresford 1995). The daily effort to meet the child's basic and additional needs is emotionally and physically costly for parents. For example in a group of studies by the team at the Department of Psychosocial Research into Rheumatic Disease, at Coventry University, a focus group approach was used to investigate the views of children with chronic arthritis and of their parents. The mothers and fathers interviewed reported that their experiences were characterised by guilt, anxiety, anger, frustration helplessness, powerlessness and isolation (Barlow et al 1998). These parents, like hundreds of others throughout similar research, felt that their sources of stress were as follows:

- Monitoring health status of child (symptoms, side effect
- Treatment regimes (adherence, time required, complexity)
- Lack of information
- Lack of opportunity for discussion with professionals
- Physical, psychological and social impact of disease on child
- Balancing the needs of the child with those of the family
- Social barriers (accessing leisure activities, friendships)
- Lack of time for oneself
- Guilt

Concepts of family normalcy and normalisation

The way families cope with finding out about and dealing with the additional demands of caring for a disabled child will be influenced by many factors including for example: their internal, built in capacity to manage challenges; the external support and resources available to them; family support; their pattern of communication and problem sharing; their value and belief systems; and the extent of the adversity they face (Anderson 1981; Stein & Jessop 1982; Knafl and Deatrick 2002).

Since the 1960s, researchers have explored carer families' journeys and the key processes that interact as family members learn to accommodate the child, their condition and the implications of therapy or treatment, into daily family life. The idea of family 'normalcy' was first described by Olshansky in 1962, and its key concept is that rather than view families as having individual abnormal responses to crises and challenges, families in general respond similarly to such events. Parents sometimes describe their determination and efforts to get back to or maintain 'normal' family life (Gravelle 1993). This complex ongoing process has been referred to as normalisation (Purssell 1994) or adaptation and is illustrated in the figure below.

Purssell's Model of Normalisation for Families with Chronically Ill Children (1994)
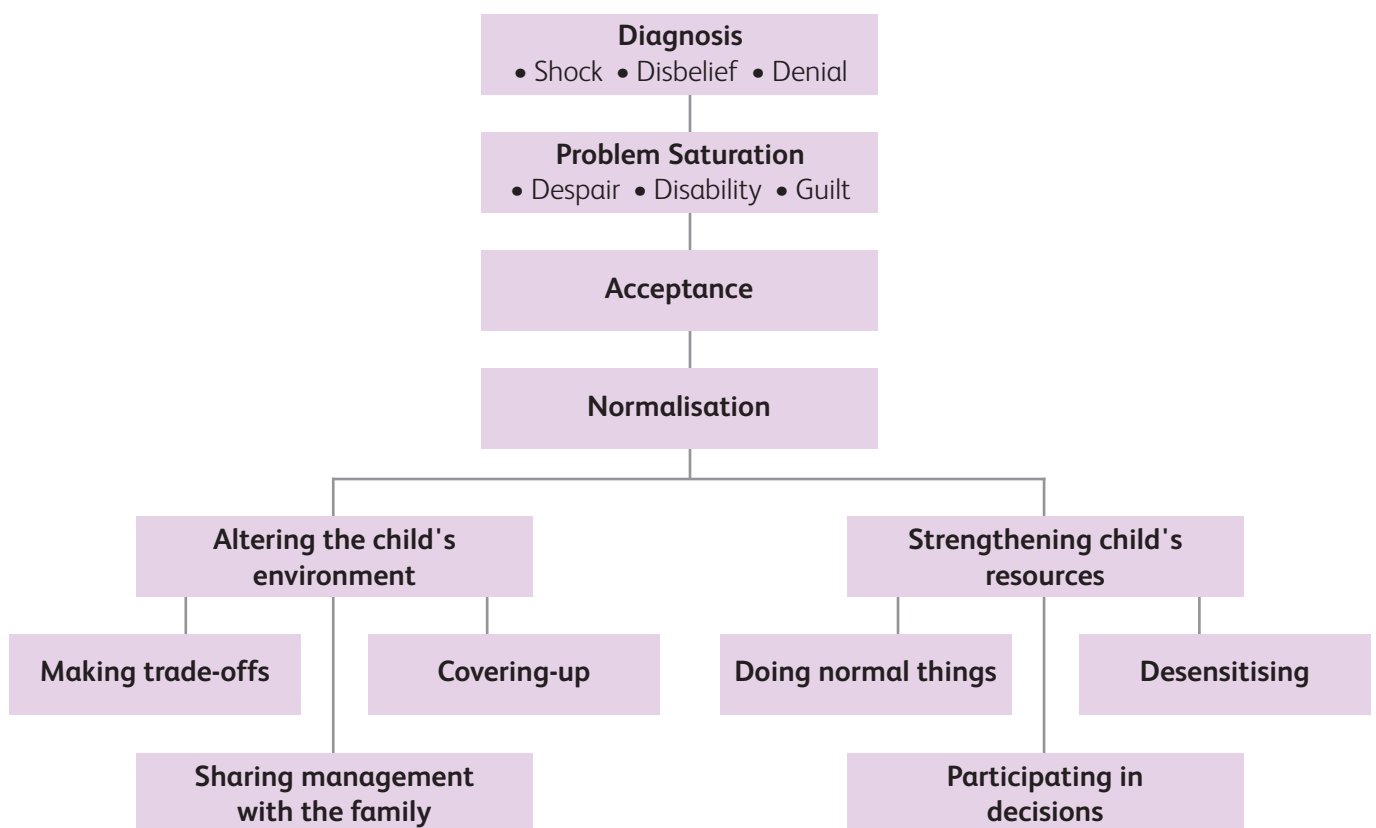
Understanding family normalcy provides us with reference data concerning the common responses by most families and so may broadly indicate families' need for support and assistance and also help us to recognise problematic or idiosyncratic responses by some families so that additional intervention or support can be made available.

While living with a disabled child affects all families, there will be some who need services more and some who need them less. Unfortunately, what we don't know is whether or not some groups of families would benefit more than others from having access to different types of support.

Facilitating positive movement along parent carers' journey
Within the general population many view disability as a potentially damaging and even 'tragic' life

event. But with the necessary support and enough helpful interventions, having a disabled child can be compatible with a healthy and good life. When working with families there is a balance to be struck - between avoiding taking a position in relation to disability that is inevitably negative and encouraging parents to approach the journey positively without minimising the problems they and their children face. Identifying both the factors which create difficulties and the services and other support arrangements that alleviate the strain and unlock positive opportunities is key.

A more recent development of the normalisation model comes from Kearney and Griffin (2001) which has been adapted by Britton and illustrated below. This model gives practitioners a reflexive guide to helping parent carers emotionally travel from a sense of helplessness and despair, to one of strength and hope.

Insiders' Guide model of Parental Experience (Carrie Britton, 2005 adapted from Kearney + Griffin, 2001)

Despair Helplessness

Defiance Strength

Sorrows
- Finding out
- Isolated
- Fears + worries
- Grief
- Hard work of becoming carer
- Stress
- Not knowing

Tension

Confusion

Doubt

Ambiguity

Joys
- New values eg. kindness
- New strength
- New perspective
- New knowledge

No hope

Hope

Summary of stages in learning to manage
A brief summary of the parent carers' journey is outlined below:

Early stage
- Anxiety and effort to secure diagnosis – route to diagnosis impacts how they relate to professionals later, for example speedy route to diagnosis and treatment leads to greater trust, but if diagnosis delayed, missed or incorrect, families less likely to trust professionals later
- Shock and feelings of helplessness and powerlessness about child's diagnosis and treatment – completely unfamiliar territory for parent
- Eagerness to put child in hands of experts who have solutions
- Isolation – do not know other people who live with this situation, dislocation with family and friends
- Actively seeking information and people who can help
- Feeling of crisis and that life will now always be different

Middle stage
- Clearer understanding about child's individual experience of condition and individual needs
- Coping with conflicting advice – having to choose who to believe
- Realising things cannot always be fixed or changed
- Trying to do everything that is advised –unsustainable emotional and physical effort –finding resource limits
- Learning about the future and impact on each family member
- Emergence of chronic sorrow (cycles of grieving) and clinical chronic stress which can become permanent
- Learning to 'fit into community' – inclusion issues arise
- Navigating different education, health, social care and benefit systems

Later stage and ongoing
- Search for and reframing of 'normality' – each family's unique sustainable pattern for daily life
- Developing confidence about own expertise, child and family's limitations
- Finding individual family solutions to challenges
- Drawing on range of different expertise including own and professionals
- Connecting with and finding others who live similar lives
- Learning to advocate effectively, negotiate or fight to have child's needs met
- For a minority, willingness to campaign so that other families do not experience such a difficult journey

3.4 Dealing with lack of opportunity

Without doubt, disabled people face extensive barriers to leading ordinary lives. Research consistently highlights the gap between the experiences and expectations of disabled and non-disabled people (Hirst and Baldwin 1994; Morris 1995; Oliver 1996). The Government's report 'Improving the life chances of disabled people' clearly sets out in quantifiable terms the disadvantage disabled people experience, compared with non-disabled people. For example, they are more likely to live in poverty, less likely to have educational qualifications, less likely to be in work, more likely to experience hate crime or harassment, and more likely to encounter problems with housing and transport (PMSU 2005). Some of the most restrictive features in the lives of disabled people and children are not necessarily to do with the demands of their impairments.

For many parents, having a disabled child can be their first experience of disability and their first exposure to disability discrimination. They may have had little or no contact with disabled people and find themselves having to reconcile issues related to difference, stigma, prejudice – equality of opportunity and dilemmas about choosing special or mainstream provision and schooling.

Since 1997, Government policy and guidance has been driving inclusion and the principle, now enshrined in law, enables children with special educational needs to be educated in mainstream schools as a right (where this is what parents want). Accessing good quality education means different things for different children. While a flexible education system that recognises and responds to the diversity of learning needs amongst pupils is ideal, there is evidence to suggest that there is a way to go before all children have such an equality of opportunity (OFSTED 2004 and 2006; Warnock 2005). As Wedell, Emeritus Professor of the Institute of Education, University of London points out, this is not surprising when we consider the challenges involved in identifying the nature and consequences of the learning difficulty and how best to help; the dilemma deciding if disabled children should learn the common curriculum and whether it is broad enough to meet their needs, and whether or not disabled children should learn in ordinary or separate classrooms (Wedell 2008).

Parents are not one homogenous group. They hold complex and conflicting views about inclusion and whether and how they engage with the disability movement's civil rights agenda. Many are likely to have different and changing responses as they are confronted for example, with barriers to their children's participation, lack of support, inflexible services and hostile or negative attitudes to disability.

Parents face quite difficult choices when trying to assess the best education provision for their child. While many are wholly committed to mainstream schooling, some believe special schools provide the learning environment needed and others are committed to one or the other at the outset but change their minds in the light of disappointing experiences or the process of negotiating the detail of provision. Research evidence that compares children in special and mainstream settings has yet to find clear signs that either lead to better educational outcomes (Lindsay 2003).

Whilst parents continue to seek out welcoming, protective and safe environments for their children, there is a need to offer choice, as finding the route to achieve the services and support that will offer individual disabled children equality of opportunity is likely to vary.

3.5 Getting through the maze: parent's experience of conflict

Fighting for services

As well as managing the practical and emotional demands of caring for a disabled child, most parent carers, by virtue of their situation, find themselves engaging with a vast array of services and practitioners by necessity. A common theme to parent carers' reports over the last twenty years has been of having to fight to secure the services their child and family need (Beresford 1995; Sloper at al 2006, PMSU 2005). A national survey conducted back in 1995 reported that parents felt that dealing with service providers was one of the most stressful aspects of bringing up a disabled child (Beresford 1995). This was followed a few years later with a further study revealing that substantial numbers of families reported a 'constant battle' with the multiplicity of agencies and professionals involved, the lack of co-ordination between different agencies and the burden of multiple contacts (Sloper et all 1999).

While good services and more recently integrated and co-located provision will surely help to shift this view and mediate the stress, parents continue to report difficulties. There are tensions that seem active across the breadth of services and geographical areas that matter greatly to parent carers and play a large part in many aspects of their experience. An NHS study looking at children's services reported that parent carers' experiences of services were poor:

'Parents repeatedly used the term fight to describe their dealings with health care professionals. They were perceived as battle-hardened veterans of the system and there was a genuine sense of them and us between parents and health care professionals'. (NHS QIS 2004 p7).

This experience of 'conflict' or 'battle' is likely to stem from different experiences for different parents. It could be due to power imbalance, gate keeping and resource control issues, absence of joint planning and co-ordination or services not focussing on developing their user interface. Perhaps decisions made about equipment, toys, room use and layout within the family home, who visits the home, which nursery or school the child can attend, which care package and so on, are taken by professionals or service managers unknown to the family. Dealing with this level of daily intrusion into normal family autonomy is again part of the experience of being a parent carer. It explains why the relationship with service providers can be tense and different from that of parents who are not also carers. Many parents talk of their dissatisfaction and anger about having to fight to get for their children basic things and ordinary opportunities that others routinely take for granted.

Issues of power imbalance
It is easy to see that there is an inherent tension in the system for delivering support and services for disabled children and their families. Many hard working professionals and parents know only too well the limitations on resources, the problem with assessments led by the availability of provision, the challenge of distributing support fairly and equitably and the responsibility to do the best one can for individual children.

These tensions contribute to difficulties and stress for service providers and users alike so resolving this experience of 'having to fight' should be the focus of supporting parent carers and service reform in the future. Specialist training for managers, practitioners and parent carers could help develop a shared sense of values, and practices that facilitate shared problem solving for the long term.

Issues related to power and the parent-practitioner relationships are complex and require careful analysis. For examples patterns of power balance vary in different branches of medicine, depending upon historical factors within similar units and communication and personality interactions between individual practitioners and individual patients. Specific characteristics of this imbalance are described by Michelle Mason, a long standing educator, writer and active campaigner in the disability movement (training communication 1997):

'The main difference between parents, patients and professionals is one of power. Professionals act within a system, backed up by laws, regulation, colleagues, and resources, training, status, clerical support, large offices, long words and emotional distance. Parents only have their love for their child, and their desire that that child should be given the best possible chance to have a good life. How is partnership possible in such an unequal state of affairs? It is only possible if everyone involved is willing to examine the values and beliefs that lie behind all our actions.'

A DoH report which captures the outcomes of patient and public involvement makes an interesting observation about the role of values in health care settings: "The diversity of values that inspire those who are committed to involvement work can be a source of strength, but little attention is paid to these values and the ways in which they influence the practice of involvement" (DoH 2004 p28). The report comments that while it is likely that there will be differences in attitudes and values, what matters is that these differences are explored, so that the principles (altruism, democracy, community , partnership, consumerism) that underpin the way practitioners work with patients and the public, are debated and made clear.

Parent carer/practitioner relationships over time

Practitioners' training usually concentrates upon the child or young person with less attention on developing evidence based expertise on ways of working with parent carers. Practitioners who only see children at a particular stage or age are less likely to be aware of the longer term impact of their intervention or their style of practice. For example practitioners who mainly work with preschool children will be more used to overtly directing and advising parents in the early stage because parents may not yet have developed confidence in their own expertise as either parents or carers. In contrast, a practitioner working with older children will be more used to incorporating the child's wishes and negotiating with more experienced parents.

Feedback from parent carers prioritises the need for much further training and specialism, together with a respect and understanding of the parent carers' expertise about their child. (EDCM 2009).

This is especially true where children have complex or enduring health needs and practitioners deploy a medical model approach that can view parents as passive receivers of professionals' expertise rather than as key partners. Just as children develop, the carer/practitioner relationship evolves too and a policy devised for one stage will not necessarily fit another stage, but a consistent feature is respecting the parent carers' role and input. Anticipating a child's future and thinking about where they may want to spend their time living, working, learning or socialising as adults and how they will develop a sense of belonging for example, can help inform the decisions and support offered now.

Families can be anxious about providing feedback about services to managers, through formal engagement processes, informal mechanisms, or complaints procedures. It can often feel too risky when they know that their children are likely to face ongoing challenges that will require continuous dialogue with practitioners. A common aspect of the user/provider relationship is the tension between managers who naturally prefer to affirm positive news of their service in contrast to parent carers' delivery of the message that far more needs to change.

Section Four
Five keys to getting it right

4.1 Introduction

A starting place to examine good practice guidelines that should form the basis for working with families of disabled children is outlined in the Common Core of Skills and Knowledge for Children's Workforce (DfES 2005). This prospectus sets out required knowledge and skills to practise at a basic level in six areas of expertise. These are:

- effective communication and engagement
- child and young person development
- safeguarding and promoting the welfare of the child
- supporting transitions
- multi-agency working
- sharing information

The document states:
'Good communication is central to working with children, young people, their families and carers and is fundamental to the Common Core. It involves listening, questioning, understanding and responding to what is being communicated by the child, young person and those caring for them.

Effective communication requires the involvement of children, young people and those caring for them in the design and delivery of services and decisions that affect them. It is important to consult with them and consider their opinions and perspectives from the outset. A key part of effective communication and engagement is trust, both between the workforce, children, young people and their carers, and between and within different sectors of the workforce itself.

To build rapport with children, young people and those caring for them, it is important to demonstrate understanding, respect and honesty. Continuity in relationships promotes engagement and the improvement of lives.' (p6)

This document also outlines a basic summary of the relevant legislation that impacts children's services (pp 27-28) – reminding us all that behind guidelines for good practice is a legal imperative. This includes the Duty to Involve legislation: Section 242 of the NHS Act 2006.

4.2 Early support

Providing information at the time when parents are first discovering their child has a disability, whether at birth or much later, is crucial, as is the way the information is delivered. Even when parents have been the first to suspect something unusual and professionals have not responded, the way in which these early contacts with professionals take place can have a huge significance for both the early stages and later on in the lives of families. It's a key time for providing the right support.

A review of a range of parent surveys identified that the services most valued by parents are ones that are able to provide:

- support at time of diagnosis
- access to information and advice
- assessment that takes on board family views
- effective and stress-free service coordination
- an efficient and not over-prolonged statementing process
- a service that considers and meets the needs of the whole family
- targets and developmental milestones to work towards
- evidence of achievements
- rapid and obstacle-free access
- ideas and suggestions for activities
- a knowledge base on which parents can rely for informed treatment options
- help to enable parents, especially mothers, to enter or return to work
- skills to parents. (King et al 1999; Li et al 2003; Robinshaw and Evans 2001; Jennings 2008; Bennett 2009)

Good early intervention improves children's health and social and cognitive development. And while key worker strategies are relevant throughout a disabled child's lifespan, effective key workers are particularly valued at the early stages. Evaluation of the Parent Advisor Model developed by Hilton Davis and his colleagues (Davis et al 2002) suggest the benefits for families and the importance of training and support for this role.

All families with new children experience an adjustment period and are likely to try and test different types of support and child rearing approaches to find out what works well for them. There is considerable evidence to suggest that when a new child is disabled, many parents feel extreme anxiety as they try to find ways to cope with the situation. They report feeling isolated, unsupported and ill informed (Sloper and Turner 1992) and need allies. Parents of pre school disabled children appreciate support at this time, particularly from practitioners who can help with their child's development, such as portage workers, health visitors, speech and language therapists and physiotherapists (Hall 1997; Beresford et al 1996).

Early education is positively associated with learning and development outcomes for all children. It can tackle some of the social and physical barriers faced by disabled children (DfES and DoH 2003 – Together from the Start) and delaying intervention can result in loss of function such as the ability to maintain posture, or reduce the effectiveness of the interventions such as speech and language therapy. (DoH 2004 NSF).

However, research conducted by the C4EO (2009) found that a 'one size fits all' approach may not benefit all children equally. While the quality of education is important and makes a difference to the longer term outcomes throughout primary education (Mitchell et al 2008, Sammons et al 2008, C4EO 2009), it is important for intervention programmes for disabled children to be clear about what specific outcomes they seek. For example, the research found that more highly structured programmes performed better and the longer and more intense programmes had larger effects. But the data did not support the notion that the earlier you start an intervention the better and nor was parental involvement always essential for success. Interestingly, the successful outcomes for children were partly dependent on the capacity of services to compensate for the problems that the most disadvantaged families were facing. The current evidence suggested that better resourced families were benefiting most from services and

families low in social capital due to illness, poor functioning, family structure, or poverty, especially where families had children with severe impairments, were less able to take advantage of these services. So, while individual teaching methods were important, they were less important than service structure, resourcing and reliability if aiming to reach particular groups of families.

Not surprisingly, the same report pointed out that dealing with the larger problems such as poverty and lack of support might be more important to the child's outcomes. There is a very clear link between child achievement and poverty. Children living in poverty make slower progress and the gap begins early. Their health, self-confidence and social skills are poorer than other children. As poverty affects families with disabled children disproportionately and these children are living with impairments likely to compromise their achievement of development milestones and their functioning in general, it is particularly important for early childhood educators to invest in ways of reaching less resourced families.

A further C4EO research report (2009) makes a number of recommendations for early childhood educators regarding reducing the negative influence of poverty on children's outcomes including: supporting learning activities at home with families; focusing on language and literacy development; strategies and procedures that help children to make a positive transition to early years provision so they have a good start in learning; building stronger links between the home and the early years provider to ensure positive experiences as early as possible.

4.3 Transition times

There are a number of key transition periods in the lives of families with disabled children that time and again generate additional strain and stress (Baldwin and Carlisle 1994). The Every Child Matters, Common Core of Skills and Knowledge (DfES 2005) document sets out why each period of transition is a time of challenge for service users and providers, and particular steps are needed to achieve effective transitions without inducing severe parental stress or anxiety. While these points can vary depending on a child's age or development or personal circumstances, the common critical stages where things change significantly for most disabled children and families include:

- discovering the child's impairment
- entering the education system and moving from nursery to primary to secondary settings
- starting to live more independently
- changing from children's to adult services

As one mum put it during a recent parent carer training event:

'I climbed a mountain when we found out about his illness and when we coped with the total change to our family. But I never thought I'd have to climb another mountain when he got to school and another one when he went to big school. Does it ever get any easier?'

It's not hard to see that adjusting to different circumstances, changed services, new environments and unfamiliar people can increase the vulnerability parents and children feel. The need to be able to adapt to changing demands can be overwhelming and can undermine parent's sense of competency and know-how. Acquiring new knowledge, getting and absorbing the information needed and navigating the path isn't easy. Parents frequently report not knowing what they have to do or who they should talk to. They say they feel like the stakes are high and that they have to get it right, if their child is to make the transition successfully, settle into their new situation and make progress. Offering useful and positive interventions at these particular points can help to smooth the way.

Of significant importance is the transition stage from childhood to adulthood. National research shows that many disabled young people find this change the most stressful, and often the most negative period of their lives (Williams 2003; Heslop et al, 2002). Preparing for life after school brings new challenges for all young people but if you're disabled, the transition can be a time of extreme stress and anxiety. Young people tell us that as they embark on adulthood they face a bewildering change in services, care and learning provision and the services they received as a child are frequently not available to them as adults. They also identify friends, rather than formal services, as the single most important factor in their emotional support (Williams and Heslop 2005).

The need to improve transition arrangements for disabled young people and achieve the right to be included in mainstream society and opportunities, is firmly placed within the context of national legislation and guidance including for example the National Service Framework (DoH 2004), Valuing People (DoH 2001) and the Quality Protects Programme (DoH 2001). And there are a number of documents and directives pushing local authorities to set standards for disabled young people to access support to smooth this process.

Consistent messages from national studies reveal that young people are facing real barriers to accessing suitable college or work placements, leisure opportunities and maintaining friendships or relationships. This lack of opportunity, which other young people take for granted, often triggers mental health problems including anxiety, depression and more complex forms of emotional distress. For those young people who need professional help, getting it is difficult because the pathways to support are vague or uncoordinated, there are often long time delays to access assessment and interventions, and they're shunted between mainstream and specialist services or don't "fit in" anywhere (www.valuingpeople.gov.uk).

All the more reason for commissioners, managers and practitioners to recognise the importance of getting in early, because transition to adulthood is a time likely to be hazardous if the need for information and support is ignored.

4.4 Continuity and key working

Families with disabled children have contact with an average of ten different professionals, and visit hospitals and clinics over 20 times a year (Tarleton and Macaulay 2002).

Parent carers say that 'Navigating their way through the maze of services is a frustrating, time-consuming, repetitive and distressing process' (PMSU 2005) so it's no surprise that the NSF emphasises the value of key working as a way of co-ordinating family support. It states that disabled children and children with complex health needs should 'receive coordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and , where possible, which enable them and their families to live ordinary lives' (DoH 2004).

Keyworker schemes aim to offer a main point of contact for families, providing information, linking services and coordinating packages of care. While they may differ in their size and structure, all employ key workers who act as a single point of contact with services and help parents to navigate the bewildering system. A number of schemes have been developed over recent years and while only small numbers of families are in receipt of a service - around 8,000 reported by the Shared Care Network in 2005 (Greco et al 2005) and the data on the cost and impact of schemes is limited, parents using key workers consistently report the benefits including a greater 'peace of mind', reduced stress and less isolation.

There is also evidence to suggest key workers improve parents' emotional health, quality of life and sense of coping well (Singleton et al 2002) plus improved relationships with service providers, fewer unmet needs and greater family well-being (Greco et al 2004). A more recent review of the literature (Cavet 2007) reports that:

Key workers improve the quality of life of families by ensuring quicker access to support and benefits, reduced levels of stress and greater empowerment (C4EO 2009). Parent carers valued the regular contact, supportive relationships, a single point of contact and a family-centred, rather than a child-centred approach.

They said good practice was when key workers recognised the families' strengths and represented the families' interests rather than those of their employing agencies.

A further study reports that better outcomes resulted for families when key workers carry out more aspects of the role, had appropriate amounts of contact with families, regular training, supervision and peer support, a dedicated service manager and a clear job description (Sloper et al 2006). Recommendations from the research suggest that key workers must document unmet needs, encourage participation in service development and facilitate smooth inter-agency working. Results also suggest that parent involvement is valuable, but it cannot overcome the disadvantages of key workers not carrying out all the aspects of the role.

4.5 Skills and attitudes

Models of working with parents and families There are many approaches to working with parents and families which can be categorised into five broad groups:

- **Expert model**
  This largely reflects the dynamics of the medical model of care in that the practitioner is seen as the expert and the parent as the passive recipient of information and direction. There is an emphasis on assisting the parent and family to comply with directions and becoming a 'good' user of existing services. Some research suggests that practitioners may individually prefer to use a more partnership orientated approach but that the training they receive, the pressures of work and lack of supervision result in the continuation of directive approach, particularly in newly qualified practitioners.

- **Transplant model**
  Here the parents are expected to carry out programmes and treatments according to detailed and prescribed professionally-given information and instruction. The Portage system of communication training is cited as an example of this model in action. Some research indicates that parents seek involvement and a role within therapeutic programmes but not necessarily to become their child's surrogate therapist.

'Partnership shouldn't mean an escalation of responsibilities. Parents don't want to be another therapist although they do want to be partners,' (Phillipa Russell, Parent and former Director of Council for Disabled Children, speech at 100 Hours conference 1998).

- **Consumer rights model**
  This approach reflects a strongly individualistic political agenda, with parents being the consumers of services. The rhetoric includes 'individual choice', 'individualised packages of care' and a principle that the parent knows best. (Darbyshire and Morrison 1995) writes 'this model can be criticised for its concentration on the individual nature of special need and provision which deflects our attention away from social construction of disability, community and power'.

- **Social network/systems model**
  This approach rejects a deficit view of disability and encourages a diversity of approach and opinion between parents/families and professionals. The practitioners' role is facilitative of the family finding their own way of managing daily life, and is characterised by greater fluidity, flexibility and informality.

- **Partnership model**
  Mutual respect is established for an effective partnership relationship (National Academy for Parenting Practitioners 2009). The partnership model can be summarised as:

  - When the practitioner and parent have expertise that is different but complimentary

  - The parent and practitioner combine their expertise to gain effective outcomes for the family

  - The practitioner follows the lead from the parent, and the parent determines the focus of their work in an interactive collaboration

  - There is an attempt to agree on goals and ways of achieving them, reaching mutual agreement and clarity through open communication and negotiation

  - The practitioner is respectful of inequality of power where it might exist such as the practitioner's responsibility for child protection

- Relational qualities such as respect, trustworthiness genuineness, humility, empathy, personal integrity and enthusiasm are experienced by the parent.

The latter two models have the key markers of empowerment and partnership working in that they actively promote parents' sense of control over decisions affecting their children, a sensitivity to parents' rights to opt into the professional system at the level they choose, and an understanding of the unique adaptational style that each family and social network will employ.

Even when practitioners and parent carers share the same values and have common aims, the process of achieving partnership is a challenge. While parent carers may appreciate the constraints practitioners are managing, their primary responsibility as parents is to represent their child's needs and negotiate provision to meet those needs. The majority of parents are likely to remain carers for their disabled children well into their adult years. Finding ways to build respectful working relationships and meaningful ways of drawing on their expertise, enhances their capacity to care.

Parent carers consistently report the significance of the way in which practitioners relate to them and appreciate, for example: being approached in a straightforward and honest way; do what they say they will do; show that they appreciate the demands and challenges of the caring role; and are informed and willing to find out when they don't know. While these are not surprising features, one extensive research report found that "Health professionals are aware of the importance of good communication with patients, but do not always think through what this means in practice (Farrell 2004 p15). Developing skills in this area is key to effective partnership work.

4.6 Parent carer participation

Beliefs and values of individual commissioners, managers and practitioners may support partnership and empowerment of parent carers as foundational principals of policy and service design. However, parents report policy often fails to deliver an experience of partnership or empowerment.

Confusion about the use of the term 'participation' has long been recognised in the research with some advocates stressing 'being there' and 'taking part' in the event, decision or project, and others emphasising the influence or power users could have in the decision-making process or event itself. The researchers concluded that:

'Whatever perspective trusts took, at this stage the implementation of a formal strategy on participation was mostly an aspiration. This is despite agreement among child service professionals and across sectors that the involvement of users in the design of services would benefit the improvement of frontline services and improve outcomes for families' (DfES and NCB 2005 p9).

The following terms: 'involvement'; 'consultation'; 'participation'; 'partnership'; and 'engagement' are similar in meaning but are often interpreted differently, sometimes incorrectly, by different people and organisations. They sit along a continuum within the process of partnership working, which in this context is between social care and health providers (managers and practitioners) and services users (children, parents, parent carers and the public). The terms are defined below, with additional detail taken from definitions within the Newcastle Participation of Parents & Carers Strategy (2006-2009).

Involvement = the fact or condition of being involved with or participating in something. To involve is defined as to include as a necessary part or result; cause to experience or participate in an activity or situation (Oxford Dictionary of English 2nd edition). This includes taking part in service planning processes, such as interviewing staff.

Consultation = when people are given choices about changes that are going to happen and say what they think about them. This can be conducted for example through questionnaires, open days and discussion events.

Participation = the action of taking part in something. To participate is to share, to be involved or to take part (Oxford Dictionary of English 2nd edition). Being part of the decision-making process and actively influencing change. Building partnerships where people share responsibility for decision-making.

Partnership = the state of being a partner or partners (Concise Oxford English Dictionary). Partnership in sharing power, control and responsibility.

Engagement = interlock, something that engages or binds, commitment. To engage is to pledge oneself, not just in terms of promise to marry (Concise Oxford English Dictionary) . It means to involve people in a way that makes them know their contributions are valued.

There is a growing body of good practice in this arena (for example see www.caf.org.uk, also Children, Young People, Parents and Carers Participation in Children's Fund Case Study Partnerships which is a joint NECF and DfES 2007 report available from http://www.ne-cf.org) that suggests that specific consultation and participation work needs to be developed and implemented within a wider participation strategy. Listening is only half the story – acting on what parents say and working to ensure that parent carers involved in this work know about what action was taken as a result of their input, is as important. Recommendations from recent literature such as the Developing Preventative Services Children's Fund Strategic Plan Framework 2005-2008 include, for example:

- Investing in sustainable engagement processes that include guidelines, toolkits and training
- Strengthening representation and safe participation through elected Parent Carer Councils
- Building a learning environment, that addresses issues such as leadership, reflectivity, honesty and transparency, power differences, insecurity and threats generated by change, training to assist cultural change at all levels.
- Effective monitoring with accountability for ensuring remedial action is undertaken.

While many believe parent carers' involvement in service planning and delivery improves outcomes, there is limited evidence that highlights the added value. Most of the research that does exist comes from the health sector. For example, one report commissioned by the Department for Health (Farrell 2004) reviews 12 different research studies about patient and public involvement and concludes that involving service users influences planning and the delivery of services, increases confidence, understanding and the skills of those who participate and is rewarding for professionals. It also points to the complexities involved and recommends that staff need to experience the benefits of participation work and have access to training in the various ways of involving service users, if their skills and confidence are to increase.

At a time when the views and experiences of disabled children are at last gathering status and being actively and directly sought by service providers, it is prudent to learn from parent participation work and build on the successes so that these lessons can be transferred to the emerging involvement of disabled children in service planning, wherever possible.

In conclusion
Most parents want to do their best for their children and worry about getting it right. The need to be able to adapt to new information and changing demands can be overwhelming when your child is disabled. Parent carers need additional support to raise their children in ways that achieve the best outcomes. Providing services that are responsive and effective relies on us appreciating family need and understanding the problems they face. Listening to parent carers and involving them in the decision making is key. Doing so helps us to know what to provide, where to target and how to co-ordinate and integrate support into family life.

References

Ahmann, E. (1994). Family-centred care: shifting orientation. Pediatric Nursing 20(2), 113-117

Anderson, J. (1981). The social construction of illness experience: families with a chronically ill child. Journal of Advanced Nursing 6, 427-434

Appleton P & Minchom P. (1991) Models of Parent Partnership and Child Development Centres. Child Care, Health and Development 17(1), 27-38

Atkin, K. (1992). Similarities and differences between informal carers. In Twigg,J.(ed.) Carers: Research and Practice. London: HMSO

Audit Commission (2003) Services for disabled children: a review of services for disabled children and their families. London: Audit Commission.

Aumann, K. and Hart, A. (2009) Helping children with complex needs bounce back: Resilient Therapy for parents and professionals. London: Jessica Kingsley.

Baldwin, S. and Carlisle, J. (1994) Social Support for Disabled Children and their Families: A Review of Literature. Edinburgh: HMSO

Bamford, C., Qureshi, H., Nicholas, E. and Vernon. A. (1999) Outcomes of social care for disabled people and carers. York: Social Policy Research Unit, University of York.

Barlow, J.H., Cullen-Powell, L.A. and Cheshire, A. (2006) 'Psychological well-being among mothers of children with cerebral palsy' in Early Child Development and Care 176(3-4), May 421-428

Barlow, J., Harrison, K. and Shaw, K. (1998). The experience of parenting in the context of juvenile chronic arthritis. Clinical Child Psychology and Psychiatry, 3, 445 – 463.

Bennett, E. (2009) What makes my family stronger? London: Contact A Family

Bercow, J. (2008) Bercow Review: Speech, Language & Communication Services For Children And Young People Must Improve, UK. URL: http://www.medicalnewstoday.com/articles/101319.php# [23.10.09]

Beresford, B. (1995). Expert Opinions: a national survey of parents caring for a severely disabled child. Bristol: Policy Press.

Beresford, B. and Oldman, C. (2002) Housing matters :national evidence relating to disabled children and their housing. Bristol: Policy Press

Beresford, B., Rabiee, P. and Sloper, P. (2007) Priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services Social Policy Research Unit, University of York

Beresford, B. and Rhodes, D. (2008) Housing and disabled children. York: Joseph Rowntree Foundation

Beresford, B., Sloper, P., Baldwin, S. and Newman, T. (1996) 'What works in Services for Families with a Disabled Child?', Barnardos.

Boyden, J. and Ennew, J. (1997) Children in Focus: a manual for participatory research with children. Stockholm: Radda Barnen

Britton, C. and Moore, A. (2002) Views from the Inside: Routes to diagnosis – families' experience of living with a child with arthritis. British Journal of Occupational Therapy 65(8), 374-380.

Buckner, L. and S. Yeandle (2006). Managing More than Most: a statistical analysis of families with sick or disabled children. London: Carers UK

Callery, P. (1997) paying to participate: financial, social and personal costs to parents of involvement in their children's care in hospital. Journal of Advanced Nursing, 25, 746-752.

Carers UK (2004) In poor health: the impact of caring on health. URL: http://www.carersuk.org/Policyandpractice/Research/Healthimpactofcaring/1201185222/ResearchInPoorHealth.pdf
[4 October 2009]

Casswell, D., ed. (2004) The Contact a Family Directory of specific conditions, rare disorders and UK family support groups. London: Contact a Family.

Cavet, J (2007) Best practice in key working: what do research and policy have to say? (Working in partnership through early support: distance learning text), London: Early Support.

Centre for Excellence and Outcomes (C4EO) (2009) Ensuring all disabled children and young people and their families receive services which are sufficiently differentiated to meet their diverse needs Progress map summary, research review, scoping review. June 2009. URL: http://www.c4eo.org.uk/themes/disabledchildren/diverseneeds/files/c4eo_diverse_needs_progress_map_summary_6.pdf [4 October 2009]

Centre for Excellence and Outcomes (C4EO) (2009) Improving the wellbeing of disabled children (up to the age of eight) and their families through increasing the quality and range of early interventions Progress map summary, research review, scoping review. June 2009. URL: http://www.c4eo.org.uk/themes/disabledchildren/increasingquality/files/c4eo_improving_the_wellbeing_through_early_years_progress_map_summary_4.pdf [4.10.09]

Centre for Excellence and Outcomes (C4EO) (2009) Improving the wellbeing of disabled children and young people through improving access to positive activities: extended services, youth work, inclusive play and leisure opportunities, sports and the arts. Progress map summary, research review, scoping review. URL: http://www.c4eo.org.uk/themes/disabledchildren/positiveactivities/files/c4eo_improving_the_wellbeing_improving_access_progress_map_summary_5.pdf [4.10.09]

Chambra, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) On the edge: minority ethnic families caring for a severely disabled child. Bristol: The Policy Press.

References

Commission for Social Care Inspection (CSCI) (2005) The State of Social Care in England 2004-5.
Contact a Family (2004) No time for us: relationships between parents who have a disabled child. A survey of over 2,000 parents in the UK. London: Contact a Family.

Contact a Family (2009) Information about families with disabled children. URL: http://www.cafamily.org.uk/professionals/research/statistics.html [5.10.09]

Copps, J. and Heady, L. (2007) The financial costs and benefits of supporting disabled children and their families. London: New Philanthropy Capital.

Coyne, I.T. (1995) Partnership in care: parents' views of participation in their hospitalised child's care. Journal of Clinical Nursing 4, 71-79.

Curran, A.L., Sharples, P.M., White, C., and Knapp,M. (2001) Time costs of caring for children with severe disabilities compared with caring for children without disabilities. Developmental Medicine and Child Neurology, 43, 529-533.

Curtis, L. and Netten, A. (2005) Unit costs of health and social care. Personal Social Services Research Unit, University of Kent, Canterbury.

Darbyshire, P. (1992) Parenting in Public: a study of the experiences of parents who live-in with their hospitalised children and of their relationships with paediatric nurses. PhD. Dissertation. Edinburgh: University of Edinburgh.

Darbyshire, P. and Morrison, H. (1995) Empowering parents of children with special needs. Nursing Times, Vol. 91(32) 26-28.

Davey, C. (1988) Paediatric Physiotherapies-Parent Relationships: the Paediatric Physiotherapist's perspective. Physiotherapy. MSc dissertation. Southampton: Wessex Medical Library, University of Southampton.

Davis, H., Day, C. ,and Bidmead, C. (2002). Working in Partnership with Parents: the Parent Adviser Model. London: Harcourt Assessment.

Davis, H., Day, C. and Bidmead, C. (2002b). The Parent Adviser Training Manual. London: Harcourt Assessment.

Daycare Trust (2001) Ambitious for all, rising to the childcare challenge for children with disabilities and special needs. London: Daycare Trust/Contact a Family.

Dearden, C. and Becker, S. (2004),Young Carers in the UK: the 2004 Report. London: Carers UK.

Department for Children, Schools and Families (2005) Commission for Social Care and Inspection: Social Services Performance Assessment Framework Indicators 2004-5. URL: http://www.dcsf.gov.uk/rsgateway/DB/STA/t000541/index.shtml [5.10.09]

Department for Children, Schools and Families (2008) Aiming High for Disabled Children. Nottingham: DCSF. URL: http://www.togetherfdc.org/SupportDocuments/AHDC % 20Programme % 20Plan.pdf [22.10.09]

Department for Children, Schools and Families (2009) Safe from bullying in play and leisure. London: DCSF. URL: http://www.antibullyingalliancetoolkit.org.uk/work_in_the_community/safe_from_bullying.aspx [6.10.09]

Department for Education and Skills (2005) Common Core of Skills and Knowledge for the Children's Workforce Nottingham: DfES.

Department for Education and Skills Publications (2007), Every Parent Matters. www.teachernet.gov.uk/everyparentmatters.

Department for Education and Skills (2004) Removing barriers to achievement: the government's strategy for SEN. Nottingham: DfES. URL: http://www.teachernet.gov.uk/_doc/5970/removing % 20barriers.pdf [22.10.09]

Department for Education and Skills and National Children's Bureau (2005) Children, Young Persons and Parents Participation in Children's Trusts: National Evaluation of children's Trusts Nottingham: DfES.

Department of Health (1976), "Fit for the Future – Report of the Committee for the Child Health Services", The Court Report, London: HMSO.

Department of Health (2000) The Quality Protects Programme: Transforming Children's Services. Local authority circular: LAC (2000)22 : HSC 2000/033. London: DoH

Department of Health (2001) Valuing People. A New Strategy for Learning Disability for the 21st Century. White Paper. London: DoH.

Department of Health (2004) National Service Framework for Children, Young People and Maternity Services. London: DoH.

Department of Health/Department for Education and Skills (2003) Together from the start – practical guidance for professionals working with disabled children (birth to third birthday) and their families. London: DoH/DfES. URL: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4061141.pdf [6.10.09]

Department of Health and the Home Office (2003) The Victoria Climbié Enquiry: Report of an Enquiry by Lord Laming. Cm 5730. London: The Stationery Office

Department for Work and Pensions (Undated) UK Data Archive Study Number 4803 – Family resources survey. UK 2002-03. London: DWP.

Department for Work and Pensions (2004) Carers Allowance Quarterly Statistics August 2004 URL: http://research.dwp.gov.uk/asd/asd1/ca/ca_quarterly_statistics_aug04.asp [7.10.09]

References

Department for Work and Pensions (2002) Family Resources Survey http://www.dsdni.gov.uk/index/stats_and_research/stats-publications/stats-family-resource/family_resources/family_resources_survey_2002-2003.htm [23.10.09]

Department for Work and Pensions Information and Analysis Directorate (2004) Press Release: Estimate of the number of disabled children in Britain covered by the Disability Discrimination Act (1995).

DWP administrative data cited in Preston, G. with Robertson, M. (2006) Out of Reach: benefits for disabled children. London: Contact a Family/Child Poverty Action Group.

Department for Work and Pensions Information Directorate (2006) Work and Pensions Longitudinal Study, Bespoke information request. Analysis based on May 2006 data.

Desforges, C.and Abouchaar, A. (2003) The impact of parental involvement on pupil achievement: A Literature Review. DfES Research Report 433. London: DfES

Dobson, B. and Middleton, S. (1998) Paying to care: The cost of childhood disability. York: Joseph Rowntree Foundation.

Eiser, C. (1994) Growing Up with a Chronic Disease: The impact on children and their families. London: Jessica Kingsley Publishers

Emerson, E. and Hatton, C. (2005) The Socio-Economic Circumstances of Families Supporting a Child at Risk of Disability in Britain in 2002. Lancaster: Lancaster University.

Every Disabled Child Matters EDCM (June 2009) Disabled Children and Health. EDCM: London. URL: http://www.edcm.org.uk/pdfs/edcm_disabled_children_and_health.pdf [22.10.09]

Family Fund (2004) Family Fund Annual Activity Report 2003-2004. York

Farrell, C. (2004) Patient and Public Involvement in Health: The Evidence for Policy Implementation. London: Department of Health.

Franklin, L. (2007) Every Disabled Child Matters Campaign Briefing Disabled Children and Health. London: HM Treasury and DFES.

Gammon, E.A. and Rose, S.D. (1991) 'The Coping Skills Training Program for parents of children with developmental disabilities: an experimental evaluation' in Research on Social Work Practice, Volume 1, 244-256

Gordon, D., Parker, R., Loughran, F. and Heslop, P. (2000) Disabled Children in Britain: A Reanalysis of the OPCS Disability Survey: London: The Stationery Office.

Gravelle, A (1993) Caring for a child with a progressive illness during the complex chronic phase, parents' experience of facing adversity. Journal of Advance Nursing 25, 738–745.

Greco, V., Sloper, P. and Barton, K. (2004) Care coordination and key worker services for disabled children in the UK. York: University of York.

Greco, V., Sloper, P., Webb, R. and Beecham, J. (2005) An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs. Department for Education and Skills Research Report 656. London: Department for Education and Skills.

HM Government (2006) Parliamentary hearings on services for disabled children. London. URL: http://www.edcm.org.uk/pdfs/parl_hearings_reportamended.pdf [22.10.09]

HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families. London: HM Treasury. URL: http://www.togetherfdc.org/SupportDocuments/AHDC % 20 Programme % 20Plan.pdf [22.10.09]

Hall, D. (1997) 'Child Development Teams: are they fulfilling their purpose?' Child Care Health and Development 23(1), 87-99.

Hall, D.M.B. and Prendergast, M. (1990) An integrated health service. BMJ Volume 301, 1341-1342.

Harrison, J. and Woolley, M. (2004) Debt and Disability: The impact of debt on families with disabled children. York: Contact Family & Family Fund.

Hart, A. and Blincow, D. with Thomas, H. (2007) Resilient Therapy with children and families. London: Brunner Routledge.

Heslop, P., Mallett, R. Simons, K. & Ward, L. (2002) Bridging the Divide at Transition. What Happens for Young People with Learning Difficulties and their Families? Kidderminster: British Institute of Learning Disabilities.

Higgins, D.J., Bailey, S.R. and Pearce, J.C. (2005) 'Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder' in Autism, 9(2), 125-137

Hirst, M. (2004) Health inequalities and informal care: end of project report. University of York, Social Policy Research Unit.

Hirst, M. and Baldwin, S. (1994) Unequal Opportunities. London: HMSO.

Hodes, D. T., (2003) The Laming Inquiry. Journal of Clinical Forensic Medicine, 10 (4), 275-277.

Jarbrink, K., Fombonne, E. and Knapp, M. (2003) Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study. Journal of Autism and Developmental Disorders, 33(4) 395-402.

Jennings, J. (2008). Celebrating success across the children's workforce: working with the early support developmental journal for babies with visual impairment, London: RNIB.

References

John, A. and Wheway, R. (2004) Can play will play. Disabled children and access to outdoor playgrounds. London: National Playing Fields Association.

Johnstone, C. and Marder, L. (1994) Parenting a child with a chronic condition: and emotional experience. Pediatric, 20(6) 611-614.

Kagan, C., Lewis, S., and Heaton, P. (1998) Caring to Work: Parents Combining Employment with the Care of Disabled Children. London: Family Policy Studies Centre.

Kempson, E. (2002) Over-indebtedness in Britain. London: Department for Trade and Industry.
Kearney PM & Griffin T (2001) Between joy and sorrow. Journal of Advanced Nursing, 34(5), 582-592.

King, G., King, S., Rosenbaum, P. and Goffin, R. (1999) 'Family centred care giving and well-being of parents of children with disabilities: linking process with outcome', Journal of pediatric psychology, vol 24, no 1, pp 41–53.

Knafl, K., Ayres, L.M.,Gallo, A.M., Zoeller, L.H. and Breitmeyer, B.J. (1986) Learning from stories: parents' accounts of the pathway to diagnosis. Pediatric Nursing, 21(5), 411- 415.

Knafl, K. and Deatrick, J. (2002) Families and chronic illness, a synthesis of current research. Journal of Family Nursing, 8(3), 178-198.

Kolvin, I., et al (1990) Continuities in Deprivation, ESRC/DHSS Studies in Deprivation and Disadvantage Vol 15, Aldershot: Avebury.

Kubler-Ross, E. (1973) On Death and Dying, London: Routledge

Langerman, C. and Worrall, E. (2005) Ordinary Lives: Disabled children and their families. London: New Philanthropy Capital.

Lawton, D. (1998) Complex numbers: Families with more than one disabled child. Findings. York: Joseph Rowntree Foundation.

Li, Y., Bain, L. and Steinberg, A.G. (2003) 'Parental decision making and the choice of communication modality for the child who is deaf', Archives of pediatrics & adolescent medicine, vol 157, no 2, pp 162–168.

Lindsay, G. (2003) Inclusive education: a critical perspective, British Journal of Special Education, 30 (1), 3-12.

Ludvigsen, A. and Morrison, J. (2003) Breathing space. Community support for children on long-term ventilation. Barkingside: Barnardo's.

Mencap (2003) Breaking Point: a report on caring without a break for children and adults with severe or profound learning disabilities. London: Mencap.

Mencap (2006) Breaking Point –families still need a break. London: Mencap. URL: http://www.mencap.org.uk/document.asp?id=297 [12.10.09]

Mencap (2007) Bullying Wrecks Lives: the experiences of children and young people with a learning disability. London: Mencap URL: http://www.mencap.org.uk/document.asp?id=164# [12.10.09]

Ministry of Health (1959) Report on the Welfare of Children in Hospital, chaired by H Platt. London: HMSO.

Mitchell, L., Wylie, C., & Carr, M. (2008). Outcomes of early childhood education: Literature review. Report to the Ministry of Education. Wellington: Ministry of Education.

Morris, J. (1995) Gone Missing? A Research and Policy Review of Disabled Children Living Away from their Families. London: Who Cares? Trust.

National Academy for Parenting Practitioners (2009) What is Evidence Based Practice? Workshop briefing paper.

National Audit Office (2004) Early Years: Progress in developing high quality childcare and early education accessible to all. London: House of Commons.

National Health Service Quality Improvement Service (QIS) (2004) The Voice of Parents and Carers.

Nessa, N. (2004) The Health of Children and Young People. Chapter 10 Disability. London: Office of National Statistics.

Newcastle Participation of Parents & Carers Strategy 2006 – 2009. http://www.newcastlechildrenservices.org.uk/wwwfileroot/microsites/childrensservices/newfiles/mcs_Parent_Carer_Participation_Strategy_Final.pdf [23.10.09]

Oelofsen, N. and Richardson, P. (2006) 'Sense of Coherence and parenting stress in mothers and fathers of preschool children with developmental disability' in Journal of Intellectual and Developmental Disability, 31(1), March 1-12.

Office of the Children's Commissioner (now known as 11 million) (2006) Bullying Today 11 Million, 2006, Bullying Today: A Report by the Office of the Children's Commissioner, with recommendations and links to Practitioner Tools, London: Office of the Children's Commissioner. http://www.11million.org.uk/content/publications/content_134 [12.10.09]

OFSTED (Office for Standards in Education) (2004), Special Educational Needs and Disability: towards inclusive schools. London: OFSTED.

OFSTED (Office for Standards in Education) (2006) Inclusion: does it matter where pupils are taught? HMI 2535. Manchester: OFSTED.

Oliver, M. (1996) Understanding Disability: from theory to practice. London: Macmillan.

References

Olshansky S (1962) Chronic Sorrow: a response to having a mentally defective child. Social Casework, 43, 190-193.

Opperman, S. and Alant, E. (2003) The coping responses of the adolescent siblings of children with severe disabilities Disability and Rehabilitation 25 (9) 441-454.

Osborn, A. F. (1990) Resilient children. A longitudinal study of high achieving socially disadvantaged children. Early Child Development and Care, Vol. 62.

Pilling, D. (1990) Escape from Disadvantage. Falmer Press.

Pinney, A. (2005) Disabled children in residential placements. London: Department for Education and Skills.

Prime Minister's Strategy Unit (PMSU) (2005) Improving the Life Chances of Disabled People. London: Cabinet Office.

Purssell, E. (1994) The process of normalisation in children with chronic illness. Paediatric Nursing 6(10) Dec 1994, 26-30.

Qureshi, H. and Henwood, M. (2000) Older People's Definitions of Quality of Services, York Publishing Services: York.

Ray, L.D, and Ritchie, J.A . (1993) Caring for chronically ill children at home: factors that influence parents' coping. Journal of Pediatric Nursing, 8(4) 217-224.

Read, J. (2000) Disability, Society and the Family: Listening to Mothers. Buckingham: Open University Press.

Reid and Batten (2006) B is for bullied: the experiences of children with autism and their families, London: NAS.

Robinshaw, H. and Evans, R. (2001) 'Service provision for preschool children who are deaf: parents' perspectives', Early child development and care, vol 168, no 1, pp 63–91.

Rossiter, L and Sharpe, D (2002), 'Siblings of children with a chronic illness: A meta analysis', Journal of Pediatric Psychology.

Russell, P. (1991) 'Working with children with physical disabilities and their families – the social work role' in Oliver, M. (ed) Social Work Disabled People and Disabling Environments London: Jessica Kingsley Publishers.

Sammons, P., Sylva, K., Melhuish, E., Siraj-Blatchford, I., Taggart, B., and Hunt, S. (2008) Influences on Children's Attainment and Progress in Key Stage 2: Cognitive Outcomes in Year 6. London: DCSF.

Sammons, P., Sylva, K., Melhuish, E., Siraj-Blatchford, I., Barreau, S., & Grabbe, Y. (2008). The Influence of School and Teaching Quality on Children's Progress in Primary School. Nottingham: DCSF.

Sharma, N. and Dowling, R. (2004) Postcards from home. The experience of disabled children in the school holidays. Essex: Barnardo's.

Sharpe, D. and Rossiter, L. (2002) Siblings of children with a chronic illness: a meta analysis, Journal of Pediatric Psychology, 27(8), 699-710.

Shared Care Network Straw poll of shared care providers in Norfolk, Essex, Northern Ireland, Leeds, plus 12 Barnardo's schemes. 4th December 2006.

Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R., and Meltzer, H. (2002) Mental Health of Carers. London: Office for National Statistics.

Sloper, P. and Turner, S. (1992) 'Service needs of families of children with severe physical disability.', Child: Care Health and Development 18, 259-282.

Sloper, P. (1999) Models of service support for parents of disabled children: What do we know? What do we need to know? Child: Care, Health and Development, 25, 85-99.

Sloper, P., Greco, V., Beecham, J., Webb, R. (2006) Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families? Child: Care, Health & Development, 32(2), 147-157

Stein, R and Jessop, D. (1982) A noncategorical approach to chronic childhood illness. Public Health Reports, 97 (4) 354-362.

Stiell, L., Shipton, L. and Yeandle, S. (2006) Caring for Sick or Disabled Children: Parents' experience of combining work and care. Sheffield Hallam University: Centre for Social Inclusion.

Strauss, A. and Corbin, J. (1988) Unending work and care: Managing chronic illness at home, Jossey-Bass: San Francisco.

Sullivan P. M. and Knutson, J. F. (2000) Maltreatment and disabilities: a population-based epidemiological study. Child Abuse and Neglect, 24(10): 1257-1273.

Tarleton, B. and Macaulay, F. (2002) Better for the break? Short break services for children and Teenagers with Autistic spectrum disorders and their families. Shared Care Network publication. York: York Publishing Services.

Teel, C. (1991) Chronic sorrow: analysis of a concept. Journal of Advanced Nursing, 16, 1311-1319

Together for Disabled Children (TDC) (2009). Adopting an Outcomes Approach, July 09. URL: http://www.togetherfdc.org/SupportDocuments/AdoptingAnOutcomesApproachV.1.pdf [6.10.09]

Tozer, R. (1999) At the double: supporting families with two or more severely disabled children, National Children's Bureau: London

References

Utting, D., Bright, J. and Henricson, C. (1993) Crime and the Family, Improving Child-rearing and Preventing Delinquency. Family Policy Studies Centre.

Walker, A., O'Brien, M., Traynor, J., Fox, K., Goddard, E. and Foster, K. (2002) Living in Britain. Results from the 2001 General Household Survey. London

Wallander, J.L., and Varni, J. W. (1998) Effects of pediatric chronic physical disorders on child and family adjustment. Journal of Child Psychology and Psychiatry,39(1) 29-46.

Warnock, M. (2005) Special educational needs: a new look, Impact No.11. London: Philosophy of Education Society of Great Britain.

Wedell, K. (2008) Confusion about inclusion: patching up or system change?, British Journal of Special Educational Needs, 35(3).

Williams, V. (2003) 'Looking back at transition', paper presented to the Foundation for People with Learning Disabilities' conference Count Us In: Meeting the Mental Health Needs of Young People with Learning Disabilities.

Williams, V., Heslop, P. (2005) 'Mental health support needs of people with a learning difficulty: a medical or a social model?', Disability and Society, Vol.20, 231-245.

Woolley, M. (2004) Income and Expenditure of Families with a Severely Disabled Child. York: Family Fund.

Worthington, R. (1994) Models of linear and cyclical grief: different approaches to different experiences. Clinical Pediatrics, May, 297-301.

You might be amazed
Quiz

1. What percentage of disabled children live in or on the margins of poverty?

A 20%   **B** 35%   **C** 55%

2. In 2006, what percentage of families with disabled children under 16 were receiving some level of Disability Living Allowance – a non means tested benefit?

A 50%   **B** 25%   **C** 82%

3. What percentage of families of disabled children are caring for more than one disabled child?

A 4%   **B** 10%   **C** 2%

4. For parents without children with disabilities, 61% of mums and 86% of dads are in paid work. What do you think the percentage is for mums and dads WITH disabled children?

Mums   **A** 16%   **B** 26%   **C** 56%

Dads   **A** 43%   **B** 53%   **C** 63%

5. How much more does it cost on average to raise a disabled child in comparison with a child with no disabilities?

A 4x   **B** 3x   **C** 2x

6. In the general population, 22% of all families are lone parents – what percentage of families with disabled children are lone parents?

A 25%   **B** 28%   **C** 32%

7. Out of every four families with a severely disabled child, how many might be living in unsuitable housing?

A 3   **B** 2   **C** 1

8. How many more times is a child with special educational needs likely to be excluded from school compared to other children?

A 13x   **B** 7x   **C** 3x

9. What percentage of families get any regular support from social services?

A 8%   **B** 13%   **C** 30%

10. How many more times are disabled children likely to be abused?

A 2.7x   **B** 3.4x   **C** 4.5x