

Disabled Families in Flux: Removing barriers to family life

Disablism Audit 2009



In association with



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About cerebral palsy.
For disabled people achieving equality.

Acknowledgements

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This report and our Scope Family Survey were produced in association with **National Family Week: www.nationalfamilyweek.co.uk**

Surveys of families with non-disabled children conducted by Tickbox.

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Introduction

Family life is an important aspect of social life¹. For many it is the context in which we learn about social relationships, access community activities and build and test our identities. Families come in different shapes and sizes and play different roles for family members over their lifetimes². Whatever form a family takes it can offer on-going support, guidance and comfort for family members. Past research has shown, however, that families with disabled children are often put under significant pressure as they do not receive the services they need³. As a result, this has led some to describe many families with disabled children as being at '*breaking point*'⁴.

Over the past decade legislation and policies have been introduced to better support the needs of disabled children. Despite this focus on disabled children⁵, many families with disabled children in the UK still experience lack of opportunity, marginalisation and discrimination. As such, the everyday life experiences of disabled families are characterised by disablism.

Scope defines disablism as: '*discriminatory, oppressive or abusive behaviour arising from the belief that disabled people and their families are inferior to others*'. Disablism manifests itself in many different ways; from a lack of opportunity to participate in community activities to an exclusion from interacting with peers. Studies have consistently shown that disablism remains a pervasive part of the nation's psyche and informs many of the decisions that have a negative impact on the lives of disabled children and their families⁶.

The impact of disablism was comprehensively documented by the Prime Minister's Strategy Unit's report in 2005 entitled *Improving the Life Chances of Disabled People*⁷. The report, for the first time, acknowledged that existing policy and approaches to date had not effectively met the needs of disabled children and their families and as such had negatively impacted on their life chances. In response to the report, the Government committed to taking the necessary action to ensure that: '*By 2025 disabled people [and their families] should have the same opportunities and choices as non-disabled people and be respected and included as equal members of society*'. Achieving this goal is all the more urgent, given the changing demographics of Britain.

Recent estimates have put the number of disabled children under 16 in Britain at 770,000⁸ and the number of children with Special Educational Needs (SEN) at 1.6

¹ Cabinet Office (2008) Families in Britain: An evidence paper:

http://www.cabinetoffice.gov.uk/media/111945/families_in_britain.pdf

² Silva, E. B. & Smart, C. (1998) *The New Family?* London: Sage

³ McLaughlin, J., Goodley, D., Clavering, E. & Fisher, P. (2008) *Families Raising Disabled Children: Enabling care and social justice*, Basingstoke: Palgrave Macmillan

⁴ C.f. Mencap (2006) *Breaking Point: Families still need a break*:

<http://www.mencap.org.uk/document.asp?id=297>

⁵ DfES / HM Treasury (2007) *Aiming High for Disabled Children: better support for families*:

<http://www.everychildmatters.gov.uk/files/64301A568B221580F3F449A098CB3CE9.pdf>

⁶ Demos (2004) *Disablism: How to tackle the last prejudice*, London: Demos

⁷ PMSU (2005) *Improving the Life Chances of Disabled People*:

<http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

⁸ IPPR (2007) *Disability 2020: opportunities for the full and equal citizenship of disabled people in Britain in 2020*:

million, out of a population of 11.8 million children⁹. By 2020, the total number of children is projected to drop to 10.8 million, but it is widely suggested that the proportion of disabled children will increase¹⁰. If the same rate of increase that occurred between 1975 and 2002 was to be observed between 2002 and 2029, there would be over 1.25 million disabled children by 2029¹¹. Advances in medical science and technology mean that many more disabled children born with complex impairments are reaching adulthood¹². As such, we are likely to see a significant rise in the number of families bringing up disabled children in the medium term.

Despite this projected rise, little has changed on the ground for families with disabled children in the four years since the Government's commitment in *Improving the Life Chances*. On 3rd October 2008 the *United Nations Committee on the Rights of the Child* criticised the UK Government for failing to meet international standards around the treatment of disabled children and young people¹³. In their concluding observations the Committee noted that the UK does not have a clear strategy in place to fully include disabled children in society. This lack of national strategy has meant that both disabled children and their families remain at a significant disadvantage and are frequently unable to overcome the barriers they face in society.

This report offers an opportunity to investigate in more detail the barriers families with disabled children face as we move towards the Government's ambitious target of equality for disabled people and their families by 2025. This report, the second in Scope's annual Disablism Audit series, represents the culmination of a piece of research which has elicited the views of over 500 families with disabled children and focus groups with families. The starting point for the report is the concluding words of Scope's Disablism Audit 2008 report which assert the importance of research into this area:

*'If we do not undertake this project and challenge the disablist society in which we live, then disabled people [and their families] will never achieve equal citizenship or have the freedom to have choice and control over their lives.'*¹⁴

The purpose of this report is to draw on the experiences of families with disabled children in the UK today, to represent their lives on a day-to-day basis and suggest areas for future policy consideration.

<http://www.ippr.org.uk/publicationsandreports/publication.asp?id=531>

⁹ Audit Commission (2002) *Special Educational Needs: A mainstream issue*: <http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/D3265D20-FD7D-11d6-B211-0060085F8572/SEN-briefing.pdf>

¹⁰ IPPR (2007) *op. cit.*

¹¹ ONS (2004) *Living in Britain: results from the 2002 General Household Survey*: http://www.statistics.gov.uk/downloads/theme_compendia/lib2002.pdf

¹² C.f. ONS (2003) *Persistence, Onset, Risk Factors and Outcomes of Childhood Mental Disorders, Follow-up survey to the 1999 National Survey of the Mental Health of Children and Adolescents*:

http://www.statistics.gov.uk/downloads/theme_health/PMA-ChildPersist.pdf

¹³ UN Committee on the Rights of the Child (2008) *Concluding Observations: United Kingdom of Great Britain and Northern Ireland*:

http://www.timetogetequal.org.uk/core/core_picker/download.asp?id=471

¹⁴ Parnell, R. & Bush, M. L. (2009) *Unequal Citizenship?: The personal is political! (The Scope Disablism Audit 2008)*:

http://www.timetogetequal.org.uk/core/core_picker/download.asp?id=503

The launch of this report coincides with the inaugural **National Family Week**¹⁵, an initiative that celebrates family life in the UK. Scope is supporting **National Family Week**, and publishing this report during it, to recognise the important contribution that families with disabled children make to their local communities and British society.

Scope's Disablism Audit Series

This year's Disablism Audit has its roots in the work Scope conducted between 2004 and 2006 attempting to understand disablism as a concept and to indicate areas of society where disablism is still rife. *Disablism*¹⁶ and *Disablist Britain*¹⁷ examined a selection of official statistics about disabled people's lives, looking at key indicators of equality in order to examine disabled people's progress towards equal rights and opportunities.

Scope's Disablism Audit Series are annual reports that will provide a more robust examination of disablism in Britain today. Each year, we ask disabled people about their own perceptions of their lives and reflect on our findings. From this we hope to construct a picture of disablism in British society and understand how this affects disabled people's day-to-day reality. This can then be used to explore what else is needed, in relation to policy, legislation and even social marketing, if the Government is to achieve its ambitious aim of equality by 2025.

Our 2008 publication, *Unequal Citizenship?*¹⁸, explored the experiences of disabled adults and their perceptions about choice and control in their lives. The report examined disabled people's opportunities to have relationships and be involved in community life and what the personalisation agenda meant for disabled people's equality. The report concluded that policy needed to take a new approach to tackle the barriers which prevent disabled people from becoming equal citizens.

This year's report has been divided into three substantive sections, which reflect the themes underpinning families' experiences in modern Britain. The first of these sections, **Understanding Family Experiences**, explores the aspects of family life that characterise the experiences of families with disabled children. The second section focuses on **Factors Affecting Family Life**, including a consideration of family finances, opportunities to take up paid employment, access to information and levels of support for families. Finally the third section, **Family Journeys**, considers families' responses to the factors affecting their life and the impact this has on their outlook and aspirations.

The data that informs this report is taken from four main sources – a comprehensive literature review, the results of the Scope Family Survey 2009, a survey of families with non-disabled children conducted by Tickbox, and a number of focus groups of families with disabled children. For further details of the research methodology, please see the **Methodology** section of this report.

¹⁵ For more information about the week see <http://www.nationalfamilyweek.co.uk/>

¹⁶ Demos (2004) *Disablism: how to tackle the last prejudice*, London: Demos

¹⁷ Scope et al (2006) *Disablist Britain: barriers to independent living for disabled people*, London: Scope

¹⁸ Parnell & Bush (2009) *op. cit.*

Chapter 1 – Understanding Family Experiences

The idea of the family has always attracted significant scrutiny¹⁹ from policy-makers and those interested in social change. The need to reorganise family life to participate in industrial activities²⁰ was considered crucial to the success of the industrial revolution, while religious social reformers²¹ have consistently viewed the family as the ideal platform for moral development. The family has long been considered the fundamental building block of society, and though its structure, size and activities have developed over time, what characterises the family is that, irrespective of its make-up, it offers close-knit support mechanisms which better enable family members to become contributing members of society²².

Despite this, many studies of family life over the last decade or so have tended to focus on either the views of children and young people or on the power relations of parents²³. There has been a particular emphasis placed on parental choice and satisfaction in recent Government policy around social reform²⁴. Many have advocated and championed the perspective of children *or* parents, an approach which results in the unnecessary fragmentation of family members' perspectives²⁵. Both aspects of family life (children's voices and parental perspectives) are vital to the development of effective social policy.

Whilst it is important that the voices of children are represented, '*families, and particularly parents, are the key to children's wider horizons*'²⁶. This fragmentation of familial viewpoints hides the experiences and complexity of family life. Recent research has called for a (re)focus and (re)aggregation on children as part of their families, rather than merely as individuals²⁷. Where studies have taken a *whole-family approach*, the concluding narratives on family experiences have tended to be restricted to ideas about family breakdown²⁸ or unstable modern families²⁹. This section attempts to adopt a *whole family* approach, understanding and providing a snapshot of the multiplicity of experiences that families with disabled children have in their everyday lives.

¹⁹ Anderson, M. (1995) *Approaches to the History of the Western Family, 1500-1914*, Cambridge: Cambridge University Press

²⁰ C.f. Smelser, N. J. (1967) 'Sociological History: The industrial revolution and the British working-class family' *Journal of Social History* 1(1): 17-35

²¹ C.f. Turmel, A. (2008) *A Historical Sociology of Childhood: Developmental thinking, categorization and graphic visualization*, Cambridge: Cambridge University Press

²² Casey, J. (1989) *The History of the Family*, Oxford: Blackwell

²³ May, V. & Smart, C. (2007) 'The Parenting Contest: Problems of ongoing conflict over children' in M. Maclean (ed) *Containing Conflict*, Oxford: Hart Publishing

²⁴ Goodley, D. & Tregaskis, C. (2006) 'Storying Disability and Impairment: retrospective accounts of disabled family life' *Qualitative Health Research*. 16(5): 630-646

²⁵ Social Exclusion Taskforce (2007) *Reaching Out: Think family*:

http://www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/think_families/think_families.pdf

²⁶ Widdows, J. (1997) *A Special Need for Inclusion; Children with disabilities, their families and everyday life*, London: The Children's Society

²⁷ Scott, J., Treas, J. & Richards, M. (2007) *The Blackwell Companion to the Sociology of Families*, Oxford: Blackwell

²⁸ C.f. Centre for Social Justice (2006) *Breakdown Britain: Fractured families*:

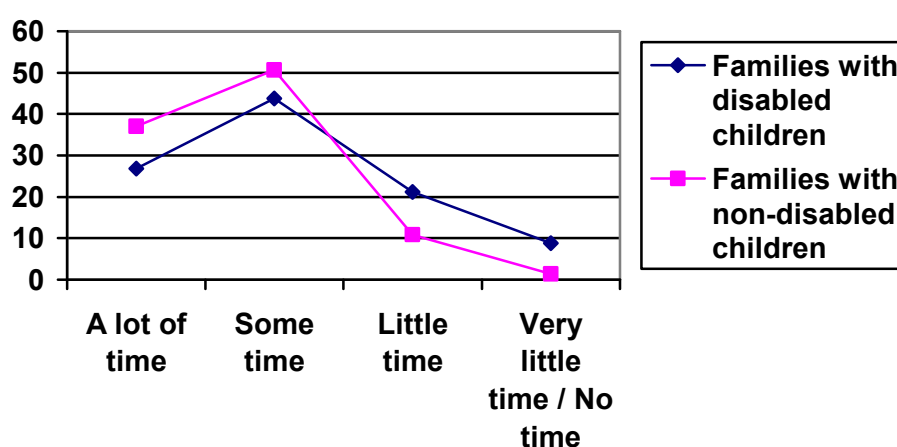
http://www.centreforsocialjustice.org.uk/client/downloads/BB_family_breakdown.pdf

²⁹ C.f. Ipsos MORI (2009) *Families in Britain: the impact of changing family structures and what the public think*: <http://www.ipsos-mori.com/assets/pdfs/families%20report.pdf>

Family Experiences

Academic research has suggested that disabled children in general spend more time within the family home than their non-disabled peers³⁰. As such, opportunities for them to experience quality time within the family – whilst important for the social and emotional well-being of any child³¹ – are particularly significant for disabled children and their families. The findings from our Scope Family Survey 2009 suggest that there are differences in the amount of quality time that families with disabled and non-disabled children get to spend together. Families with disabled children reported that they spent less quality time together; with just under a third (29%) of families with disabled children having very little or no quality time together. On all of the responses on quality time, families with disabled children answered at least 7% more negatively than their non-disabled counterparts.

How much quality time are you able to spend together as a family (%)?



Given the fewer opportunities that families with disabled children have to spend quality time together, it was worrying to see the importance these families placed upon it. As one family told us; *'family time is very important to us - we spend a lot of time together'*. A child, during one of our focus groups told us that: *'I like it best when we sit down and watch films together as a family'*. Many families put in extra effort to ensure that they could spend time as a family, despite the time pressures on their day-to-day lives. As one focus group member recalls: *'at home we do lots of rough and tumble, that happens a lot with the boys. And eating together...communal eating with all different dishes...eating together at home can be a lot of fun'*.

The importance placed on positive family activities and the lack of opportunity to enjoy these has a negative effect on the level of happiness that families reported. Whereas the significant majority (89%) of families with non-disabled children told us that they often or very often felt happy and content as a family, only two thirds of families with disabled children felt the same way.

Many parents of disabled children reported that they found it difficult to find time, within their daily routine, to engage in positive familial activities. This reflects other

³⁰ C.f. Beresford, B. & Rhodes, D. (2008) *Housing & Disabled Children*: <http://www.jrf.org.uk/sites/files/jrf/2208.pdf>

³¹ Christensen, P. (2002) 'Why More 'Quality Time' is not on the Top of Children's Lists: the 'qualities of time' for children' *Children & Society* 16: 77-88

commentator's observations about a general decrease in quality family time in modern society³². However, unlike these general narratives, our research suggests that the low level of quality family time was in large part due to the temporal pressure families faced in meeting the needs of disabled children. As this mother notes: '*due to the demands of physiotherapy (2 ½ hours each night) there is very little time left for anything after school*'. This was particularly the case in families who said they had fewer support networks and mechanisms around them. Furthermore, a number of parents reported that quality time was not always accessible and as such parents felt obliged to choose between differentiated family activities. As one parent reflects; '*I now have a step-family and things that entertain them do not always include my daughter fully*'.

Despite these restrictions on quality time, both in and out of the house, many families with disabled children reported having high levels of fun (76%), though this was still considerably lower than their non-disabled counterparts (91%). Approximately 9% of families with disabled children reported having very little or no fun in their lives. This is significant as sociality is a key part of family life and if families do not have the opportunity to spend quality time and have fun together then family members can become marginalised and feel isolated. As one parent expresses:

'Due to the nature and extent of my daughter's needs [my] family [has] become two separate units. Myself, my partner and son at home with my daughter living elsewhere 24/7 52 weeks. We have not spent any quality time together as a family for seven years now!'

The Family Home

As previously suggested, many family experiences take place within the household³³. The home is increasingly the context where children spend much of their spare time and for many children it is the first place in which they are able to exert some control over their lives³⁴. However a plethora of studies have illustrated that the majority of houses do not meet the needs of disabled children and their families³⁵.

Rob Imrie has argued that the socio-geographical structures of communities are not inclusive and unwittingly exclude disabled children and their families³⁶. This sentiment is reflected in the results of our family survey. Over a third of families with disabled children classed their home as quite unsuitable or very unsuitable. This is extremely concerning given that the overwhelming majority (90%) of families of non-disabled children report that the family home was quite suitable or very suitable for their needs. As two parents who filled in our survey explain:

³² DeVault, M. (2003) 'Families & Children: together, apart'. *American Behavioural Scientist*, **46**(10): 1296-1305

Alanen, L. & Mayall, B. (2001) *Conceptualising Child-Adult Relations*. London: Routledge

³³ DCLG (2009) *Local Index of Child Wellbeing*:

<http://www.communities.gov.uk/documents/communities/pdf/1126232.pdf>

³⁴ Lincoln, S. (2005) 'Feeling the Noise: Teenagers, bedrooms and music' *Leisure Studies*, **24**(4): 399-414

³⁵ Beresford, B. & Rhodes, D. (2008) *op. cit.*

³⁶

Imrie, R. (2004) 'Disability, Embodiment and the Meaning of Home' *Housing Studies* **19**(5): 745-763

See also: Gleeson, B. (1999) *Geographies of Disability*, London: Routledge

'We recently had our house assessed for adaptations for our daughter who has cerebral palsy. Some of the adaptations they said could not be done as our house was 'too small'. The rest of the adaptations would take a minimum of two years to apply for. When I asked how I was going to get my daughter up the stairs when she would be nearly five, they replied that I would have to put her bed in the dining room with a baby monitor and a commode. As we felt this would compromise her dignity, we feel we have little choice but to sell.

This has also been the situation for friends of ours whose son also has cerebral palsy. We recently asked [our local] council to provide us with a disabled bay. We have joined another two hundred people on their waiting list. Recently we found out that this list is not, and possibly will never, go down because [the council] have pulled the funding for these bays... I could go on about everything we have encountered which has made our lives a more difficult struggle... but I won't as I think that you will get this from all of the other thousands of families you are asking.

*'I am separated from my wife and the three boys visit here alternate weekends and some weeknights and we both work to make sure that they are not disadvantaged by the situation... The rented property I live at is a one bedroom house which is not ideal for one adult and three children, particularly when one of the children has sleep difficulties. My general feeling is that approaches [to help the family] are unimaginative and mainly a repetition of what's been done in the past... **I may have been unlucky, unfair or expect too much.**'*

Previous research has reported a number of barriers to access to domestic spaces for disabled children and their families. These access barriers include the physical design of the home; for example level access showers or toilets located on the entrance level of the structure³⁷. Similarly, the respondents to our family survey suggest that unsuitable housing has a direct impact upon quality time and quality of life. For example parents wrote that:

'Staying at home together and all spending time in the living room doing games, watching TV or eating is difficult as space is very limited.'

'I feel we are forced to live in unacceptable circumstances (i.e. no living room because disabled child needs it for a bedroom and no downstairs facilities for bathing our disabled child).'

This evidence clearly demonstrates that a new approach is needed to enable all families with disabled children to spend quality time together in their homes. This is particularly important given the extent to which an inaccessible home and low levels of quality time can have a significantly negative impact upon the quality of family life³⁸.

³⁷ Heywood, F. (2004) 'The Health Outcomes of Housing Adaptations' *Disability & Society* **19**(2): 129-143

Heywood, F. (2004) 'Understanding Needs: A starting point for quality' *Housing Studies* **19**(5): 709-726

³⁸ Clarke, H. (2006) *Preventing the Social Exclusion of Disabled Children & their Families*: <http://www.dcsf.gov.uk/research/data/uploadfiles/RR782.pdf>

Leisurely Families

Many of the families participating in this year's research voiced concerns about the barriers that they faced in spending time together outside the private confines of their homes. Access to leisure opportunities is an important aspect of community life and can enable families to access formal and informal support networks. Our family survey found that whilst 80% of families with no disabled children said they found it easy to access leisure activities, only 58% of families with disabled children could access these activities. Respondents cited various issues in relation to physical barriers and a lack of local accessible activities for their family to participate in.

'To take our child to the swings is an issue as there are no swings for a 10 year old disabled child to go on in our area - we have found one which is 10 miles away. There are lots of things we would love to do but are not accessible for a child in a wheelchair.'

'Difficult to access local walks due to kissing gates, stiles etc which has hindered our family activity of walking as routes are not wheelchair or special needs buggy accessible.'

The multitude of responses to our survey that highlight leisure reflects the extent of the problems families with disabled children face in attempting to spend time together in the public sphere. We feel that it is important to recognise that *'everyday life extends beyond the things we enjoy doing – joining clubs, meeting friends and family socially. It includes those activities, such as shopping, that are part of the ordinary family routine'*³⁹. This was reflected in one parent's response to our survey; *'there are many external things especially when it comes to leisure activities that are impossible for us to access as a family as they are not suitable for someone with complex physical needs'*.

Leisure activities outside of the home hold importance for family life and individual family member development. They constitute a part of quality time that families may spend together and are vital for community inclusion and participation, a feeling of belonging⁴⁰, and the growth and development of children⁴¹. When leisure is inclusive, it can lead to a feeling of belonging in a variety of settings. Previous research has intimated that the importance of leisure activities remain largely similar for both 'disabled' and 'non-disabled' children⁴².

The importance of leisure activity for disabled young people is heightened in instances when they are excluded from accessing fully-participatory education or employment, meaning more emphasis is placed on leisure pursuits⁴³.

³⁹ Widdows, J. (1997) *A Special Need for Inclusion; Children with disabilities, their families and everyday life*, London: The Children's Society

⁴⁰ Murray, P. (2002) *Hello! Are You Listening!: Disabled teenagers' experiences of access to inclusive leisure*: <http://www.jrf.org.uk/sites/files/jrf/1842630873.pdf>

⁴¹ Feinstein, L., Bynner, J. & Duckworth, K. (2006) 'Young People's Leisure Contexts and their Relation to Adult Outcomes' *Journal of Youth Studies* 9(3): 305-327

Aitchison, C. (2003) 'From Leisure and Disability to Disability Leisure: Developing data, definitions and discourses' *Disability & Society* 18(7): 955-969

⁴² John, A. & Wheway, R. (2004) *Can Play, Will Play: Disabled children and access to outdoor playgrounds*, London: National Playing Fields Association

⁴³ C.f. Kelly, D. (2005) *Inclusive Leisure Opportunities: For children and young people aged 8-16 with Special Educational Needs and/or disability in South East England*:

A lack of inclusive leisure opportunities for disabled children and young people can lead to boredom and loneliness, and can potentially impact upon their present quality of life and wellbeing⁴⁴. Where families with disabled children find it difficult or impossible to access such activities it will inevitably impinge on their ability to spend quality time outside of the home together.

Families in the Community

The United Nations Convention on the Rights of the Child (UNCRC) states that all children have the right to participate in their local communities. Similarly the Government's *Aiming High for Disabled Children*⁴⁵ states that support for families with disabled children should enable children and their families to be a part of their community. Despite this right and commitments from the Government, many families with disabled children feel excluded from the societies in which they live. Only 32% of families with disabled children felt that they were accepted by their local communities, compared to 48% of families with non-disabled children. Additionally, 19% of families with disabled children did not feel safe and secure in the local community at least some of the time; compared to 11% of families with non-disabled children.

Low levels of participation in the community have an adverse affect upon families' opportunities to develop as active individuals in society. To achieve inclusion for families with disabled children means tackling the barriers families with non-disabled children do not encounter. This includes equality of access and opportunity, and a non-discriminatory environment⁴⁶. Disabled children need as many opportunities as possible to get involved in the community as this gives them a full range of experiences and the chance to be treated as an equal member of society.

Colin Barnes & Geoff Mercer argue that, '*human beings, regardless of the nature, complexity and/or severity of impairment, are of equal worth, and have the right to participate in all areas of mainstream community life*'⁴⁷. The development of social and community networks for disabled children is particularly important in the family context, because of their continued exclusion from particular areas of life that non-disabled people often develop networks through⁴⁸.

A number of the families that we consulted told us that they had negative experiences within their local community. Indeed the stories that they told imply that many families with disabled children continue to find themselves unable to play a full part in their local communities. A number of parents said that people's intolerance of a child's behaviour presented a barrier to their active participation in the community. As this mother recalls: '*I have a son who has Asperger's syndrome and pathological demand avoidance syndrome... Often when he has had an autistic moment the general public have been rude or nasty, this impacts on the quality of my family life*'.

<http://www.efds.co.uk/documents.asp?section=476%A4ionTitle=Disability+sport+research+papers>

⁴⁴ Sloper, P. (2000) *Meeting the Needs of Disabled Children*:

<http://www.keele.ac.uk/research/lcs/makingresearchcount/briefings/pb6.pdf>

⁴⁵ DfES / HM Treasury (2007) *Aiming High for Disabled Children: better support for families*:

<http://www.everychildmatters.gov.uk/files/64301A568B221580F3F449A098CB3CE9.pdf>

⁴⁶ Middleton, L. (1999) *Disabled Children: Challenging social exclusion*, Oxford: Blackwell

⁴⁷ Barnes, C. & Mercer, G. (2006) *Independent Futures: Creating user-led disability services in a disabling society*, Bristol: Policy Press

⁴⁸ Shakespeare, T. (2006) *Disability Rights and Wrongs*, London: Routledge

In a more extreme example of stigmatisation from one of our focus groups the following situation was highlighted:

Child: 'There are some kids where we live. Sometimes they'll be out and sometimes they won't be out...'

Child 2: One time they were calling out of the window with their mates. They were calling us spastics.

Mother: There were about six children calling out that they were spastics from their house across the street. And if I could hear them from my house their parents would have been able to hear them.'

Our research did however highlight a number of families who participated in and experienced positive community involvement. These positive community experiences tend to be closely related to the demographics of the area that these families lived in; for example in rural setting and village locations. These provided closer community structures where children were often well known to local people, and the family experienced significant support through these structures. As a number of these focus group and survey respondents show:

'We live in a tiny village and everybody knows [our son], mainly because he escaped hundreds of times when he was little, and he used to turn up in other people's houses. Everybody knows [our son] and everybody looks out for him. He's actually at the park with someone tonight walking their dog'

'We are an integral part of our local community/village which is mainly upper middle class white, where we lived previously which was heavily multicultural and we were targets of both race and disability hatred.'

In contrast, families frequently came into contact with their local community when they were forced to fundraise for their child's need – usually equipment needs. As these two testimonies illustrate:

'We live in a rural community in a very small town where there are limited resources available but the local community helps in whatever way they can in providing activities for my child.'

'[Our daughter] has become part of the community due to our fundraising for various bits of equipment for her and whenever people see her they ignore us and go straight to her.'

This exploration has shown that family experiences tend to be restricted both within the family home and in relation to the wider community. The pressures of family life mean that families with disabled children can have little quality time together and this can result in lower levels of happiness. The isolation and marginalisation from community life and leisure activities felt by families, led one of our survey respondents to reflect: *'Sometimes I feel that our family life is like a house of cards-move the slightest thing and the whole lot will come crashing down!'* What this section clearly demonstrates is that for the majority, family experiences (for those families with disabled children) can be isolating both physically and socially. As a consequence, policy makers have unwittingly allowed families with disabled children to become extremely vulnerable to social exclusion.

Chapter 2 – Factors Affecting Family Life

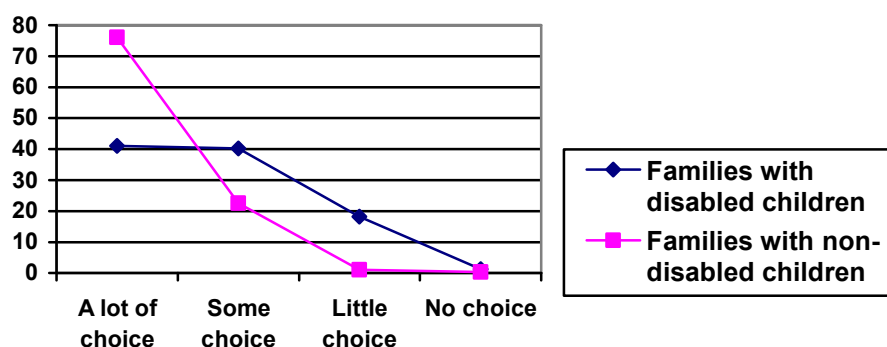
So far, this report has observed that families with disabled children have restricted opportunities to spend quality time together and participate in positive activities in their local communities. It has suggested that whilst families with disabled children place a high value on home life, a number of factors negatively affect their ability to have positive family experiences at home; many of which relate to the physical environment. Similarly, when families with disabled children attempt to access leisure activities or community activity outside of the house they tend to be marginalised or excluded. In some cases, particularly those in smaller close-knit communities or where families come into contact with people through fundraising for their child's need, disabled children and their families become integrated into community life. This Chapter aims to build upon this by looking closer at the factors which affect family life, particularly in relation to employment, finance, choice and control, information and support mechanisms.

Families, Choice and Control

Over the past 12 years there has been a steady shift towards personalising public services, particularly the services that disabled people receive. A Government discussion paper argues that an implication of pursuing personalisation is the need to '*support and encourage people to collaborate with services to meet their own needs [or those of their family]*'⁴⁹. In order to exercise greater choice and control over their lives, families with disabled children need to receive more personalised services which allow them to choose the services they receive⁵⁰.

We asked families about their perceptions of choice and control in their everyday lives. On the surface, our findings show that the majority of families felt they had at least some choice over the things they did as a family: 81% with disabled children and approximately 99% of those with non-disabled children. This does, however illustrate an 18% gap between the experiences of the family types. Similarly, when asked about their perceptions of control, 91% of families with disabled children and approximately 99% of families with non-disabled children felt they had at least some control over decisions that affected family life. This represents a smaller, yet still significant difference of 8% between families.

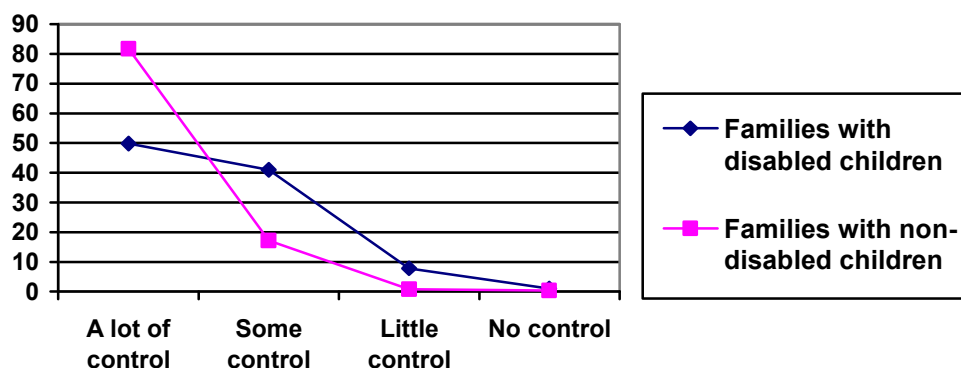
How much choice do you have over the things you do as a family (%)?



⁴⁹ Cabinet Office (2008) *Realising Britain's Potential: Future strategic challenges for Britain*: http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/strategic_challenges.pdf

⁵⁰ Barnes, C. & Mercer, G. (2006) *Independent Futures: Creating user-led disability services in a disabling society*, Bristol: Policy Press

How much control do you have over decisions that affect your family (%)?



These statistics suggest that although families with disabled children are self-reporting high levels of choice and control over their lives, they still have less choice and control than their non-disabled counterparts. Furthermore, whereas families with non-disabled children felt they had equal levels of choice and control in the lives, families with disabled children felt they have 10% less choice over their lives than they had control. This suggests that families with disabled children are likely to report that they have control over their lives, even if there is substantive restriction on their choices.

These findings are similar to those we found last year when we asked disabled and non-disabled adults about the same issue⁵¹. Last year disabled adults reported high levels of choice and control, however when we explored this trend in further depth, we saw that these high levels were contradicted by reported low levels of choice and control in relation to specific aspects of their lives. Similarly, if we look back at the findings from Chapter 1 they imply that families with disabled children in actuality have much lower levels of choice and control than responses to this direct question suggest. As we move to look at other issues that impact on families' lives and experiences we see this disparity between reported choice and control and actual choice and control widen.

Financing Families

The UK Government has pledged its commitment to eradicate child poverty by 2020, yet in 2009 many families in the UK still face high levels of poverty and social exclusion. Living on or under the poverty line has a direct adverse effect on families' everyday lives, leading to negative social and health outcomes⁵². Research has suggested that families with disabled children are one of the social groups most likely to live in, or be at risk of living in, poverty⁵³. Tricia Sloper and Bryony Beresford⁵⁴ have suggested that around 55% of families of disabled children live in poverty and have been described as '*the poorest of the poor*'. Using a standard income measure

⁵¹ Parnell, R. & Bush, M L. (2009) *op. cit.*

⁵² Ridge, T. (2006) 'Childhood Poverty: A barrier to social participation and inclusion' in K. Tisdall, J. Davis, M. Hill, & A. Prout, (Eds) *Children, Young People and Social Inclusion: Participation for what?* Bristol: Policy Press

⁵³ EDCM (2007) *Disabled Children & Child Poverty: Briefing paper.*

http://www.edcm.org.uk/pdfs/disabled_children_and_child_poverty.pdf

⁵⁴ Sloper, T. & Beresford, B. (2006) 'Families With Disabled Children' *BMJ* 333(4): 928-929

of poverty, Government data from 1994–2005 demonstrates that families with disabled children face a 30% risk of poverty⁵⁵.

Our family survey found that over half (52%) of families with disabled children only had enough money some of the time, rarely or never. This compares to 49% of families with non-disabled children. In these financially turbulent times, on the wave of a recession, all families are at an increased risk of financial problems and in part this is reflected in our findings. However, given the higher risk of families with disabled children living in poverty, effective financial support mechanisms are needed now more than ever to ensure those who are most financially vulnerable do not slip into poverty.

Peter Townsend⁵⁶ argues that:

'Families... can be said to be in poverty when they lack the resources to obtain the types of diet, participate in the activities, and have the living conditions and amenities which are customary, or are at least widely encouraged and approved, in the societies in which they belong.'

As such, families who are unable to participate in particular activities or experience living to the same standard as that of the wider population can be considered to live in poverty. The financial needs of families with disabled children have been notably overlooked in policies which consider social exclusion and inclusion. As Harriet Clarke⁵⁷ observes, considerations in this area have lacked emphasis on the importance of poverty in relation to the exclusion of families with disabled children⁵⁸. Indeed research has suggested that families with limited disposable income, particularly families with disabled children, are more at risk of social exclusion⁵⁹. Elements of choice and control that relate to money are integral areas for discussion when considering the experiences of any families, particularly as poverty can be passed down through the generations⁶⁰.

A small number of the families in our research claimed that they had enough money to live on. However their comments indicate that they spend minimal amounts of money on family activities such as days out and holidays. As two families participating in focus groups told us:

'Obviously everyone always wants more but we do OK...we may be well off because we don't go anywhere, we don't go on holidays.'

'We're comfortable, we're OK...we're not the sort of family that goes out a lot because it's difficult, you know what I mean?'

⁵⁵ DWP (2006) *Households Below Average Income: An analysis of the income distribution 1994/95–2005/05*

⁵⁶ Townsend, P. (1979) *Poverty in the United Kingdom*, Penguin: Harmondsworth

⁵⁷ Clarke, H. (2006) *Preventing the Social Exclusion of Disabled Children and Their Families*: <http://www.dcsf.gov.uk/research/data/uploadfiles/RR782.pdf>

⁵⁸ See also: Preston, G. (2005) *Helter Skelter: Families, disabled children and the benefit system*, London Centre for Social Exclusion (LSE)

⁵⁹ Contact a Family (2004) *Flexible Enough? Employment patterns in families with disabled children*: <http://www.cafamily.org.uk/pdfs/FlexibleEnough.pdf>

⁶⁰ C.f. Social Exclusion Taskforce (2007) *op. cit.*

However the overwhelming majority of families reported monetary worries. Many families told us about the problems they encountered in getting funding for basic equipment or reasonable adjustments to their home which would significantly improve their quality of life. A lack of joined up working in local authorities was consistently cited as one of the main reasons for families' financial problems. A lack of financial support from the state left many families having to use their own savings to pay for expensive equipment. In extreme cases lack of financial support led to significant pressure being placed upon the family structure. As this father who answered our survey told us:

'My wife, daughter and son have not been home since my son's incident two years ago. We get practically no professional help, do not know to date what it is we are entitled to and nobody seems accountable for anything. All we want is the ability to be a family again in a position to chart our own future as we see fit. All we want is help to adapt our family home in order that my son, together with us as a family will get back to living!

Because our local authority have been dragging their feet for over a year to award us £30,000 [Disabled Facilities Grant], my son remains in rehab from which he should have been discharged in April 2008. Because he remains in rehab we cannot even apply for a vehicle on Motability and cannot therefore go on family outings! Because he is there, we get no financial help. I have been living at home on my own since April 2007 and yet the council refuses to give me a discount of council tax. My wife had to stop working and as a result, irrespective of decades in employment she apparently does not even qualify for additional benefits! We need HELP!!!

Familial Employment

This risk of poverty becomes ever more acute when we take into account, parents of disabled children's ability to engage in paid work. Our survey found a marked difference between families with disabled children, and those with non-disabled children, in terms of their perception of how having a family had impacted on their opportunity to work. 55% of families with non-disabled children felt that any impact had been positive. This is in stark contrast to the two thirds of families with disabled children who described the impact as negative. This was reflected in comments from our survey, as one family wrote: *'holding down a part-time job makes us all feel really stretched as a family unit.'*

A number of studies⁶¹ explore the range of difficulties that parents of disabled children have in accessing paid employment due to caring responsibilities and lack of accessible childcare. A number of parents in the focus groups told us that whilst they welcomed new measures that ensure employers give people time off for caring responsibilities, they were concerned that this tends to be unpaid and as such parents cannot afford to take time off.

⁶¹ C.f. Scope et al (2007) *Making Work Work for Parents of Disabled Children*: http://www.workingfamilies.org.uk/asp/main_downloads/makingWORKwork.pdf
Contact a Family (2004) *op. cit.*

Jenny Watson⁶² notes that carers often have to reduce hours of work or – in the most extreme cases – leave work completely to fulfil their role in the family. The families in our research noted a range of ways in which family life impacted upon adults' opportunities for gaining paid employment, particularly in relation to the type of work which they could engage in and the impact of home responsibilities on career progression. As these parents reflected in their survey responses:

'My husband's career has been put on hold due to the pressure on our family life and I have had to give up a very well paid job, not even managing part time work to be a full-time carer.'

'I am sad that my friends who I went to university with and whose careers were on a par with mine when I had my son are now in more exciting and demanding roles while I am left scrabbling round for little bits of work at a lower rate of pay than I could reasonably expect were I able to even work half time hours.'

It was often the case that, whilst one parent could no longer work because of caring responsibilities for a disabled child, the other had to change jobs, work away from home, or for longer hours to support the financial needs of the family. A number of families explained that this impacted upon family life where the main breadwinner for the family could only spend limited time at home, subsequently seeing less of their family, and hindering their opportunities to support the other parent in their caring role. As these responses from our survey illustrate:

'I was the breadwinner but have been unable to return to work since the birth of my twins... My husband has therefore had to take a better paid job working away but that means he only comes home for the weekend and is always very tired.'

'As a father it is impossible to earn a living wage whilst still being able to support my family which included a little girl... If I support the family... then I don't earn enough. If I earn enough I can't support the family physically and emotionally. I feel like I'm being torn in two the whole time and making no one happy especially myself.'

Where the impact of work on family life is significantly negative, respondents reported increased levels of stress, both for the working parent, their spouse or partner and their children. As we have noted previously, research has found that parents of disabled children often experience greater stress than parents of non-disabled children⁶³. This, often ongoing, stress puts increased pressure on family members which impacts upon the experiences of the family and quality of life of its members⁶⁴.

⁶² Watson, J. (2006) Whose Rights are They Anyway?: Carers and the Human Rights Act: <http://www.carerswales.org/Policyandpractice/Research/ResearchLibrary/Whosrightsaretheyanyway-carersandthehumanrightsact.pdf>

⁶³ Contact A Family (2006) *op. cit.*

⁶⁴ C.f. Mencap (2006) *op. cit.*

Informed Decision-Making

Another significant consideration of family life is the importance of being able to access information on what services and support mechanisms are available⁶⁵. Effective information sharing is an integral aspect of supporting choice and control in service provision. Previous research has argued that families with disabled children often cannot access the information they need or only had access to information which was generally out of date, used poor terminology, and put forward negative representations of their child⁶⁶.

Our family survey showed marked differences between families with disabled children and those with non-disabled children in relation to their perceived access to information for decision-making. A staggering 61% of families with disabled children felt they could not access information to make informed decisions about their family's life. This is in marked contrast to families with non-disabled children, where the majority (86%) found it easy to access information.

Without appropriate, accessible and timely information, families with disabled children cannot make informed decisions and as a consequence have less choice and control over their family's life. As one survey respondent explained: *'Having to find out about things that you don't even know exist is hard. No one is there to tell you what to look for. Sometimes if you don't find out by mistake services pass you by e.g. sports, short breaks, funding, aids, health and education...'* Lack of information is also exacerbated by families' concerns about the future. As one survey respondent wrote:

'[My] disabled children are approaching transition - this is the most worrying time that we have had in 15 years of disabled life!!! It is like a black hole heading towards us.'

Where accessing information was difficult, the families in our research often resorted to gathering information via their own methods. As this dialogue from one of the focus groups illustrates:

'Mother 1: The internet, forget anyone official telling us, the only way you find anything out is to find it out yourself. [To others] did you know you can get free bus travel?

Mother 2: Yes.

Mother 3: No!

Mother 1: It gives them and their companion free bus travel. We went on it this evening.

Mother 3: I didn't have any idea. Well this answers the question – this is how we find out, by talking to each other.'

Having access to information, or knowing the right avenues through which to seek such information, is vital for families with disabled children. Unless you have access to the right information you cannot make informed decisions about services provision and support mechanisms⁶⁷.

⁶⁵ ODI (2008) Improving Provision of Information to Disabled People: Application of the five principles: <http://www.odi.gov.uk/docs/wor/imp/improving-provision.pdf>

⁶⁶ Goodley, D. & Tregaskis, C. (2006) *op. cit.*

⁶⁷ EDCM (2009) *Making Disabled Children Matter Locally*: http://www.edcm.org.uk/mdcm1_april09.pdf

Despite the fact that information sharing is a core aspect of parental policy⁶⁸, policy reform needs to be more sensitive to the needs of the whole family to improve access to suitable information on the ground.

Family Support Networks

Access to appropriate support services is important both in terms of enabling family life and in terms of meeting the needs of individual disabled children. Many families require assistance from third parties to support day-to-day tasks and a disabled child's inclusion in the life of the family, to keep healthy or to enable them to take short breaks from caring responsibilities⁶⁹. Choice and control over services is a vital aspect of empowering families to enjoy a high quality of life. However only 16% of families with disabled children who responded to our survey felt that they got the support and help they needed to have a full family life. In contrast families with non-disabled children were three times more likely to have access to the support they needed (44%).

Comments from both our survey respondents and focus groups participants suggest that families with disabled children are often unhappy about the level of formal support that they receive. Examples of the frustrations families experienced ranged from instances where support packages were not forthcoming, to the nature of the overly-complicated benefit application processes. As this parent expresses: *'[We are] still advocating [and waiting] after 11 years for paid awake night time care to give parents a rest and two nights of unbroken sleep per month.'*

Many families reported having to fight with statutory agencies to get the support services they need. A significant number of families said that they had been put in this position by their local authorities and as a consequence had taken up a lot of family time and energy battling for the services they needed. This can be clearly seen in the experiences of respondents:

'What hurts the most is the fighting we have to do just to get our daughter what she should be, and is entitled to. I really believe and nobody will convince me any different at the moment, but local councils and especially the government, do not really care for disabled children or their families. If they did it would not be such a rigmarole to get what we are entitled to, when entitled to it. Instead there is so much 'red tape' and downright bureaucracy that it has destroyed the faith we as a family have in our local [Primary Care Trust] and the government. Nothing we have received for our daughter, has not had to be argued and fought for.'

'My life is taken up with appointments, letters, complaints and generally fighting his corner. Luckily as a social worker I have inside knowledge of the system but even I struggle to get my head around the number of professionals involved (22 at this point!).'

'Each year I think it's going to get easier and... each year the fight gets harder.'

⁶⁸ C.f. Lamb, B. (2009) *Lamb Inquiry: Special educational needs and parental confidence*: <http://www.dcsf.gov.uk/lambinquiry/downloads/Lamb%20Inquiry%20Review%20of%20SEN%20and%20Disability%20Information.pdf>

⁶⁹ Watson, J. (2006) *op. cit.*

It is clear from these responses that formal support systems for families with disabled children are currently often failing to meet their needs. Where appropriate support is lacking the families explained that there were a range of subsequent impacts on family life. This situation had an adverse effect on family members' and their quality of life. The disabled child had limited independence from their family, their parents/guardians became socially vulnerable and excluded due to caring responsibilities, and any non-disabled siblings had less quality time to spend with their family.

When families were successful in challenging local authorities, their everyday lives and family experiences significantly improved. As one parent in a focus group explains: *'The direct payments have been fantastic...we've got an 18 year old boy and he's absolutely fantastic...he takes him out to the field and plays football with him with the local boys'*.

A lack of information about services and a lack of access to state-funded services means that families with disabled children are overly reliant on the support networks of their extended family, friends or local community. Despite this, many families told us that their extended support networks were unable or unwilling to look after the disabled child. For many families this leads to marginalisation and a restricted amount of choice and control in their lives. Although this disempowers many families, some drew strength from the closeness that this situation brought to their family. As this family recounted in our survey:

'Our son is autistic, and having a [disabled] child has changed all our lifestyle and priorities. We don't have any other family here (they live abroad), and only a small circle of friends who are happy to accept us as we are. We are a close family, but having a disabled child you need to plan everything like a military operation. But we love each other, and that's what matters.'

This lack of formal or informal support results in families with disabled children having very restricted opportunities to act spontaneously, try new things or spend time with those they enjoy spending time with. Whereas 69% of families with non-disabled children were often able to do new things and have new experiences, only 44% of families with disabled children were able to do things. Only 34% of families with disabled children found it easy to do things spontaneously, compared to 63% of families with non-disabled children. As a result, only 60% of families with disabled children regularly see people that they enjoy spending time with, compared to 82% of families with non-disabled children. A number of families reported that they did not regularly spend time with people they enjoy spending time with because those people did not understand their families experiences and/or needs. As this survey respondent illustrates: *'Our friends with children and family don't really understand the world that we operate in. A day out is planned months in advance and we always need at least one other adult with us.'*

Choice and control in terms of support is an integral aspect of overcoming the barriers faced by disabled children and their families in their everyday lives⁷⁰. The evidence presented here suggests that local authorities need to radically change the ways that they work with individuals and their families; ensuring that families have the information and services they need to exercise genuine choice and control over their lives. The findings of our research strongly suggest that changes to support mechanisms are not happening fast enough for families on the ground. Moreover, support which is tailored to the needs of the individual disabled child or those of their carer in isolation, without a consideration of the wider familial context, inevitably lacks the complexities and sensitivities needed to support family life as a whole.

⁷⁰ DH (2008) A Guide to Receiving Direct Payments From Your Local Council: A route to independent living:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083561

Chapter 3 – Family Journeys: Responses & Aspirations

This report has looked at the barriers families with disabled children face in being able to enjoy fulfilling family life on their own terms. In the previous chapter we explored this in more depth, focusing specifically on the barriers that families face in relation to family finance, opportunities to take up paid employment, access to information and effective support mechanisms. This final section develops this theme further by looking at how families respond to these restrictions on their family life and the impact this has on their outlook and aspirations.

Responses from families with disabled children

Families respond to the pressures of bringing up a disabled child in different ways. Some of these responses are more productive and have more positive outcomes than others. Through an analysis of contributing families' experiences, we have identified three broad responses that families have to their family experience. These are **Empowered**, **Unempowered**, and **Disempowered** approaches. Below we have outlined a broad synthesised profile identified from our evidence.

1. Empowered Families

Family Life:

- Proactive in seeking opportunities which enable them to spend quality time together;
- Are optimistic in overcoming any barriers faced by their family and/or child;
- Where barriers cannot be overcome they actively negotiate them so that their needs as a family are met.

Family Experiences:

- Have successfully accessed appropriate service and had positive experience of them;
- Employer/employers are supportive of their family's needs;
- Feel fully informed about options and support opportunities (may also be supported by a close-knit family or friend-based network).

Family Outlook:

- Positive and optimistic outlook, confident that they can tackle and overcome any barriers when they arise, and are happy to take risks and put themselves in unfamiliar situations.
- Feel well supported and do not feel the need to plan in detail for the future but employ a 'take it as it comes' approach.

Family Response: *Empowered*

Illustration:

'We have an amazingly complex family life...It's very difficult at times but we hold it together with help from Social Services. We all feel very happy with our life together. We have some wonderful times and experiences. We enjoy our family and make the best of every situation. We try new things and adventure into all sorts of activities

with fun... We play a lot of sports. Football and golf, it's a bit of an obsession with [my son]. The way I've always thought about it is whatever [my son's] potential is I want him to achieve it. Whatever his goals are we'll help to open the doors. Whatever it is you want to do there's no reason why not.'

2. Unempowered Families

Family Life:

- Proactively seek opportunities to spend quality time together, however are frustrated and pessimistic if/when this is not achieved;
- Generally spend time at home as a family because some past experiences of going out together have presented insurmountable barriers;
- Time spent together tends to revolve around the needs of their disabled child because of lack of support;
- Any activity spent outside the home is planned for in advance because of little spontaneity in family life.

Family Experiences:

- Often one parent works long hours whilst the other takes on a caring role. Working parent may feel unsupported by employer/feel uncomfortable discussing home life with them. Caring parent often feels isolated and unsupported in their role;
- Find it difficult to access information for decision-making;
- Feel attached to specific communities, e.g. in relation to school or impairment specific support groups, but not necessarily to their own local community.

Family Outlook:

- Swings between positive and negative outlook, but pessimistic about the future and their ability to control what happens to their family. Previous negative experiences restrict their future ambitions for their family and make them reluctant to put themselves in unfamiliar situations;
- Feel constant anxiety over the potential for the family to become disempowered;
- Feel the need to plan in detail before undertaking family activities which serves to limit their opportunities for spending time together outside the family home;
- Carefully plans for, and because of lack of information, worries about their child's future.

Family Response: *Unempowered*

Illustration:

'We are a close family, but having a disabled child you need to plan everything like a military operation. Every time you try to have fun outside the house as it were, it's almost too much like hard work. There are lots of things we would love to do but are not accessible for a child in a wheelchair...It takes about three months of planning before my husband can go bike riding with one son. [When we go out] we always end up with one parent with one son and the other looking after our disabled son. We just like being at home together really. ...communal eating with all different dishes...eating together at home can be a lot of fun. ...it is impossible to earn a living wage whilst still being able to support my family...If I support the family then I don't

earn enough. If I earn enough I can't support the family physically and emotionally. I feel like I'm being torn in two the whole time and making no one happy especially myself. The only viable help and information I ever get is through the tried and tested experience of other parents... Sometimes I feel that our family life is like a house of cards – move the slightest thing and the whole lot will come crashing down!

3. Disempowered Families

Family Life:

- Family may not be living together because family home is unsuitable for their needs;
- Time spent having fun together is minimal;
- Families may take part in leisure/holiday in separate locations or not at all.

Family Experiences:

- Lack relevant information with which to inform the decisions that they make. May feel that their views are not listened to or that support services are unreachable;
- Tend to see the child's needs as the cause of family problems;
- Generally do not receive any support from local authorities and/or there is no extended family nearby to assist;
- Many have extreme demands on their financial resources and some live in poverty as a result;
- Feel detached from any form of community life and therefore may feel socially isolated.

Family Outlook:

- Resigned and exhausted. Feel they have lost the battle and are now resigned to the fact that they are powerless to control what happens to their family. Believe that there is no point in fighting because it does no good. Feel that they have 'burnt out' in terms of 'fighting' to access support services;
- Adopt a 'getting through the day' approach and rarely feel positive about their situation.
- Know that they are in need of help but feel they cannot access the support that they need/don't know where to try.

Family Response: *Disempowered*

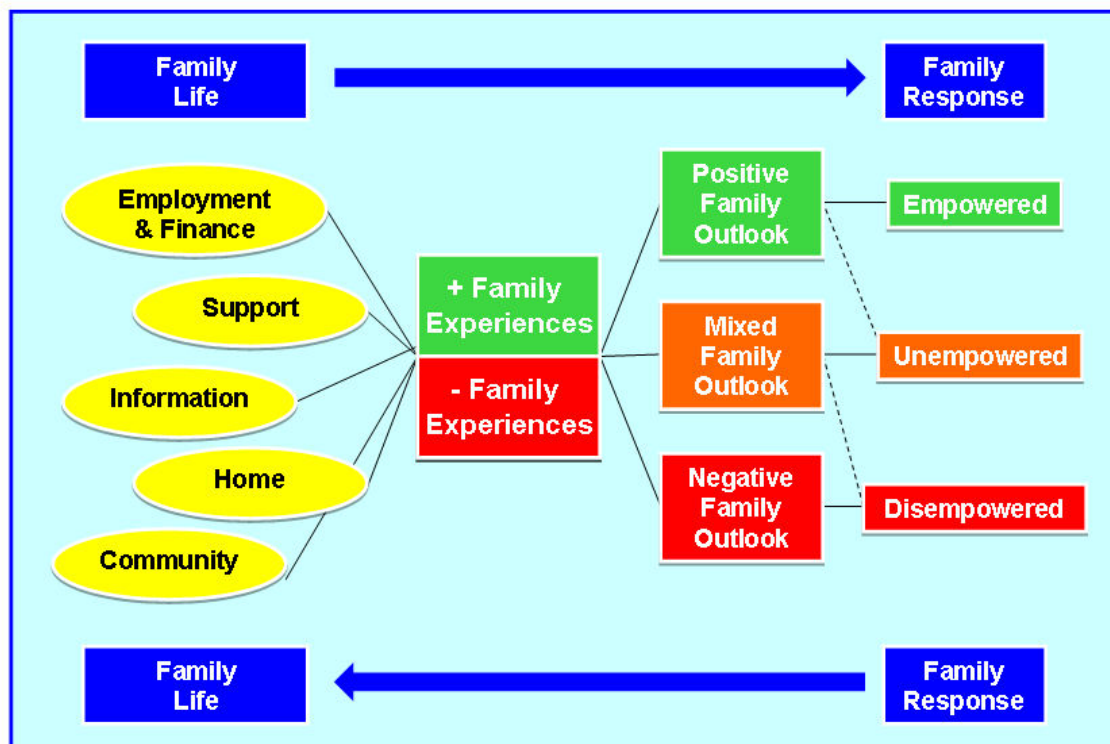
Illustration:

'Due to the nature and extent of my daughter's needs we are unable to function as a family and have become two separate units. Myself, my partner and son at home with my daughter living elsewhere 24/7 52 weeks. We have not spent any quality time together as a family for seven years now! When we did live together I felt we were forced to live in unacceptable circumstances (i.e. no living room because disabled child needs it for a bedroom and no downstairs facilities for bathing our disabled child)... We were often restricted or isolated. Some of this was due to us not having the energy or right 'frame of mind' to face the challenge of doing something outside of the home, not necessarily the attitude of others. I have an opportunities group near but it's hard for me to get there as I don't have a car so I don't see anyone who is going through the same thing as me. We no longer take holidays as a

family, my husband takes a holiday with friends etc, I take a holiday with family/friends and my daughter takes holidays with school. The support from social services is, at best, slow and unreliable and at worst non-existent.'

Family Journeys

The profiles outline the interconnectivity between possible family responses. For the *unempowered* families in particular there is an anxiety present in the profiles towards slipping into disempowerment. The diagram below illustrates the journeys different families go through in their lives and the effect this has on their experiences and responses.



In creating this framework for understanding families with disabled children we are not suggesting that the family outlook or response reflects all family members at any one moment; individuals are too complex for this reduction. We are, rather, describing an indicative reported state of the family at any given time. Statistically, the majority of families placed themselves in the *unempowered* category across our family survey.

These family responses are not distinct categories but rather indicative phases that families pass through. In many cases during our research we found that families had displayed all of these responses at some point during their life and that movement between these categories is common. As such we need to understand and

conceptualise family lives as not static but rather fluidic and cyclical⁷¹. Family response necessarily affects family life and the experiences of family members. These new life circumstances and experiences then inform the family outlook and consequently the families' new response.

As such, this framework of understanding both allows for complexity and variation within the families and offers an avenue for hope. Addressing more effectively the needs of the *unempowered* group of families we can ensure families are empowered to have choice and control over their lives. Similarly, through researching what causes families to slip from *unempowerment* to *disempowerment* we can better understand a *whole family* approach to supporting family life. Furthermore we can generate family-led and family-focused social policy. We recommend that policy makers and decision makers adopt this approach when generating new policy and evaluating existing policies that impact on the lives of families with disabled children.

Family Aspirations & Futures

Ultimately a family's response to their life and experiences will determine the aspirations they have about their futures. Our survey found that 71% of families with disabled children think about, and plan for, their family's future. This was approximately the same level reported by families with non disabled children (72%). However, when asked how confident they felt that their family would be able to achieve the things that they hoped for in the future, families with disabled children had significantly lower expectations. Whilst 32% of families with non-disabled children felt very confident that they would achieve their ambitions for the future, only 6% of families with disabled children felt the same way. This represents a shocking disparity of 26%. In total 45% of families with disabled children felt not very confident or not confident at all about achieving their hopes for their future. If we relate this back to the high levels of reported choice and control by families we can once again conclude that in reality many families are only able to exercise limited control and choice over their lives and futures.

The outlook of families in terms of their aspirations and future planning reflects their position in relation to empowerment. *Empowered* families in this sense often lived in the moment, approaching the future with a positive outlook framed in its unpredictability. They were proactive about future planning activity when necessary and consistently championing positive and aspirational outcomes for family members. The most important and most visible instances tended to be the transitions from early years to primary, primary to secondary education and secondary to further education or other learning / employment opportunities.

In stark contrast, *disempowered* families felt that they were unable to plan for the future and were often anxious about what it held for the disabled child and the family. They were extremely disillusioned about the support services that would be available to them in the future and most commonly suggested low outcomes for family members. As these two survey responses illustrate:

'My child will be going from child to adult services and I am not looking forward to getting even less support than I do now.'

⁷¹ Allan, G. (1999) *The Sociology of the Family: A reader*, Oxford: Blackwell

'We both worry about our children's futures each day and that in itself causes our health to be more at risk.'

Somewhere between these two extremes are *unempowered* families. These families often tended to consider the options for their child or family in a more structured way, however tended to be less aspirational than *empowered* and used a language of *pragmatism*. As a consequence they were more likely to aim for lower outcomes for family members than *empowered* families, however did not yet feel (or had not yet experienced) the level of pessimism displayed by the *disempowered* families, as these two focus group accounts show:

'Facilitator: What do you hope for in the future?

Mother: [Daughter] wants to be an RSPCA inspector. And I've told her, well, there are going to be some jobs that she can't do, but then there are going to be some jobs that she won't want to do...some adaptations may have to be made but if you put your mind to it, like she has done with her walking, I don't see why she can't achieve it.'

'[Our son] is going to be a plumber with his brother...obviously he won't be able to go with him a lot but he'll take him on a few jobs...and [son] would like to sweep floors at the airport.'

In light of this, the *unempowered* family becomes an important site for the identification, analysis and elimination of disability within family lives. Social policy has tended to focus on those families who are the most marginalised; and rightly so. However this has been to the detriment of an equal focus on those in *unempowered* families. Current policy frameworks seem to reproduce the conditions that allow families with disabled children to slip into *disempowerment* and in extreme cases poverty and family breakdown. This sentiment is reflected in the answers we received from survey participants in relation to what they felt their families' quality of life would be like in five years time. The majority of families with disabled children (59%) reported that their quality of life would be either the same or worse than it is currently. This compares to only 37% of families with non-disabled children.

Conclusion

What this report has clearly demonstrated is that without support, all families with disabled children are currently fated to remain at a disadvantage. Families with disabled children still face substantial barriers in their everyday family lives. These range from a lack of quality time and unsuitable houses, to marginalisation from community activities and a lack of support networks. By addressing these barriers which stop families meaningfully exerting choice and control over their lives, we can tackle the systemic disability which underpins the lives of many disabled families in Britain today.

Our research suggests that the ability to have positive family experiences, a positive outlook, aspirations and an empowering family life is dependent on the level of choice and control families have⁷². When barriers to choice and control are placed in front of families, in particular lack of support, they respond in broadly three ways. Firstly, using past positive experience they retain a positive outlook, high ambitions

⁷² Following DfES / HM Treasury (2006) *Parliamentary Hearings on Services for Disabled Children*: http://www.edcm.org.uk/pdfs/parl_hearings_reportamended.pdf

and proactively *empower* themselves to address the barrier. In contrast, many families do not have the networks, resources or positive past experiences to tackle barriers to choice and control and as such become *disempowered*. Alternatively, the majority of families remain *unempowered*. When faced with a barrier to their choice and control, these families are uncertain because they do not have, or only have limited, access to the information or support they need to overcome the barriers. Consequently, many report that they take a pragmatic stance, but without the necessary knowledge to act pragmatically, it results in a hit and miss approach. This approach sometimes produces positive and sometimes negative outcomes for the family.

Our report argues that the *unempowered* family is key to understanding what causes families with disabled children to become *disempowered*. When these families move from being *unempowered* to *disempowered* they become further alienated from the life skills, support mechanisms and outlook needed to improve their family life. As such, many become trapped in a vicious cycle as the more they perceive themselves to lose choice and control over their lives, the less support they receive and the more of a reality it becomes. We believe that policy needs to safeguard against families remaining in this *unempowered* state, as well as providing support to those already *disempowered*, enabling them avenues to become *empowered*. A closer focus on *unempowerment* will clarify at what levels and with which means we can best support families with disabled children. This will also clarify the effectiveness of current interventions in families' lives by the state as well as offer new or strengthening existing ones.

We can only truly support families to have choice and control over their lives if we ensure it is the whole family, and not individual members, who are the focus of our policy and practice. This is crucial as the complexity of the family is bound up in interdependency. This means that we need to rethink the emphasis placed on parental satisfaction as the primary measure of successful service provision. It means also that we need to think holistically when we are designing service provision, as equipment or short break services, for example, do not just affect the child or the parent, but the lives of the family as a whole and how they interact with those around them. There are resource implications in adopting this approach, however *empowered* families cost the Government in the medium to long term less, as they sustain employment, enrich their local communities and improve family wellbeing.

In association with the launch of **National Family Week** we were keen to celebrate the very real positive contribution that families with disabled children make to British society. It has given us, however, an additional opportunity to highlight the progress that still needs to be made to ensure that all families, irrespective of need, can make a contribution to our society. If, as the Government suggests, we want families of disabled children to have equal opportunity and choice by 2025, then we need to take a closer look at how we can eliminate the barriers that families face in exercising choice and control over their lives. Families are resourceful, yet they need appropriate, accessible and timely support in order to thrive. As one of our focus group participants expressed:

'[If] people do a proper job and provide the help they're supposed to do, the quality of a disabled family's life could improve tenfold instantly.'

Methodology

This research has focused on the experiences of families with disabled children. In order to produce this report we have analysed four data sets.

Literature Review

First, a comprehensive **literature review** was undertaken to stimulate discussion and ground the findings of the data collected. This review was based on the three themes which form the report: *choice and control*, *quality family time at home*, *community relations*. The review involved systematic searches of online academic databases (including Web of Knowledge and ASSIA), government policy documents, and third sector publications online.

The Scope Family Survey 2009

Secondly, **Scope's Family Survey** was launched in February 2009 and ran for 12 weeks. An online survey (hosted by Snap Surveys), this recorded the responses of 500 families with disabled children from all over the UK. It posed questions in relation to key themes of interest arising from the literature review (*choice and control*, *support*, *community*, *leisure* and *family aspirations*). Within the sample, approximately 21% of families responding to this question comprised single parent households and approximately 8% of parents classed themselves as 'disabled'.

The demographics of the survey were as follows:

Number of disabled children per family

1:	83.4%
2:	9.6%
3:	1.2%
4:	0.4%
No response:	5.4%

Ethnicity of family members

White or White British:	92%
Mixed Heritage:	3.0%
Black or Black British:	2.6%
Asian or British Asian:	0.8%
Other:	0.6%
No response:	3.6%

The Tickbox Survey of Families with Non-Disabled children

Third, a **comparison survey** of families with non-disabled children was commissioned by Scope and run by Tickbox. This has enabled a consideration of the differences and similarities between familial perceptions in relation to our key themes. This survey received 1000 responses.

Family Focus Groups

Fourth, a series of **focus groups** were commissioned which sought the views of families, enabling the development of their views in relation to the three prominent themes discussed above. This method of data collection provided families with opportunities to give their views in a semi-structured way, thereby adapting the agenda to capture their own experiences.

Qualitative Analysis

A range of analytical approaches were employed in order to represent the findings of each method of data collection. Frequencies were drawn from the survey data, and a selection of cross-tabulations elucidated further upon these themes. Thematic analysis was applied to the open responses from the survey. The focus group discussions were recorded for further interpretation and clarification, and recurring themes were tallied. Anonymous verbatim quotes (written and oral) are used throughout to further inform the discussion and maximise the voices of the families themselves.

Ethical Considerations

Scope is committed to the highest ethical standards in research, evaluation and consultation⁷³. The overriding ethical basis of this research has been that of protection, alongside the responsibility which must be held by researchers to ensure the well-being of those participating. Steps were taken to ensure best practice in research ethics, equality, diversity, informed consent, confidentiality and data protection.

⁷³ Ethical considerations were informed by:

British Sociological Association (2004) *Statement of Ethical Practice for the British Sociological Association*:

http://www.britsoc.co.uk/user_doc/Statement%20of%20Ethical%20Practice.pdf

Dench, S., Iphofen, R. & Huws, U. (2004) *An EU Code of Ethics for Socio-Economic Research*: <http://www.respectproject.org/ethics/412ethics.pdf>

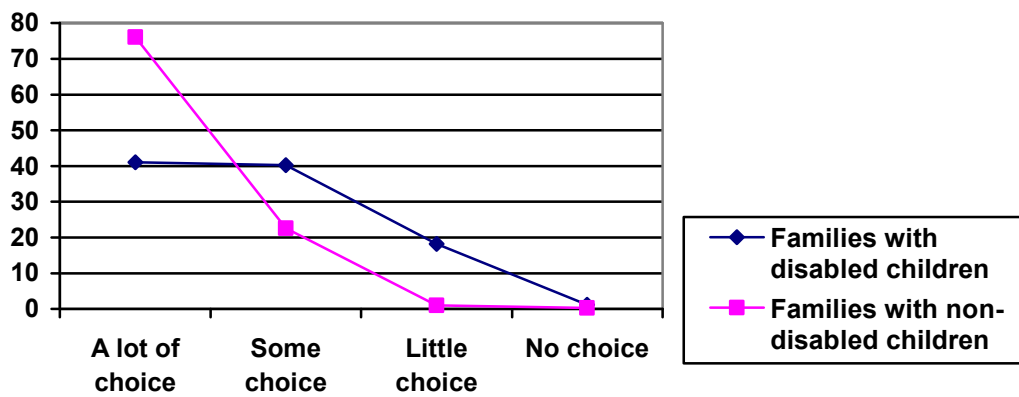
Government Social Research Unit (2005) *GSR Professional Guidance: Ethical assurance for social research in government*:

http://www.gsr.gov.uk/downloads/professional_guidance/ethical_guidance.pdf

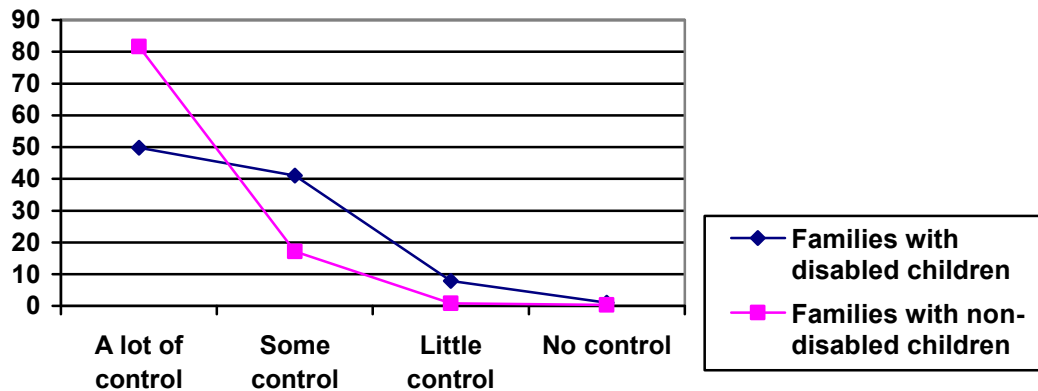
Social Research Association (2003) *Ethical Guidelines*: <http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf>

Appendix A – Survey Responses

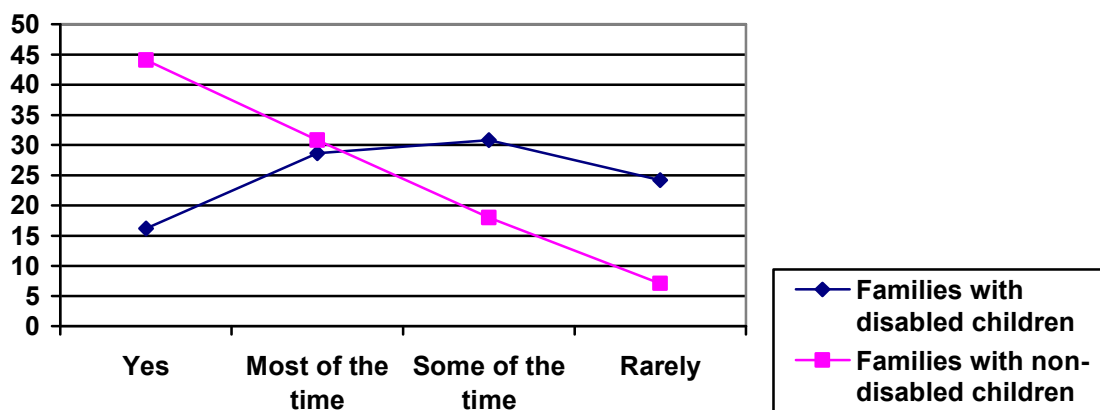
Q1. How much choice do you have over the things you do as a family (%)?



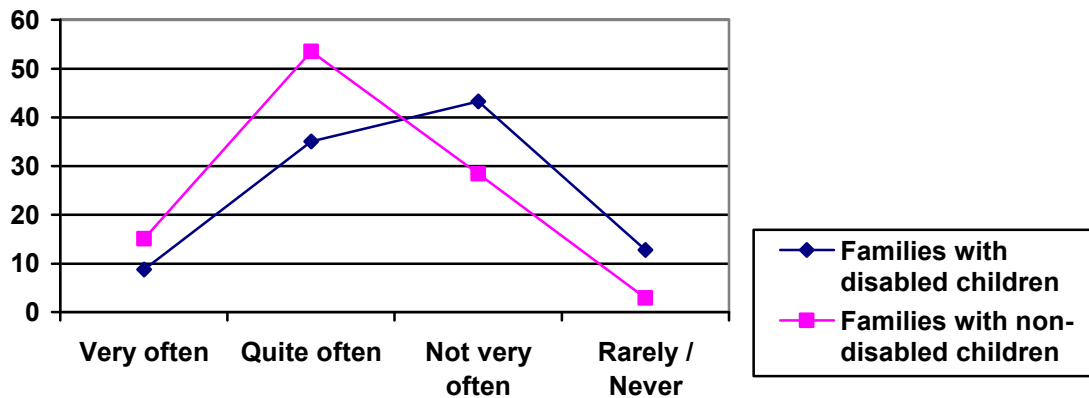
Q2. How much control do you have over decisions that affect your family (%)?



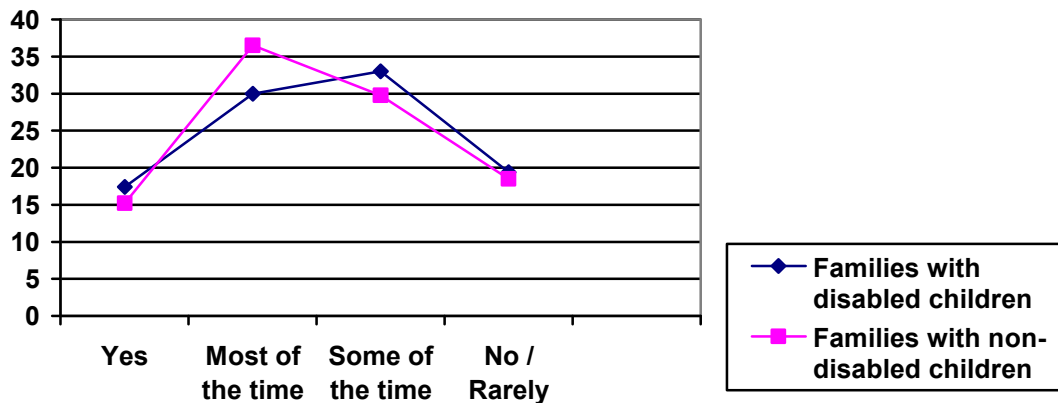
Q3. Do you receive enough help and support from others to have a full family life (%)?



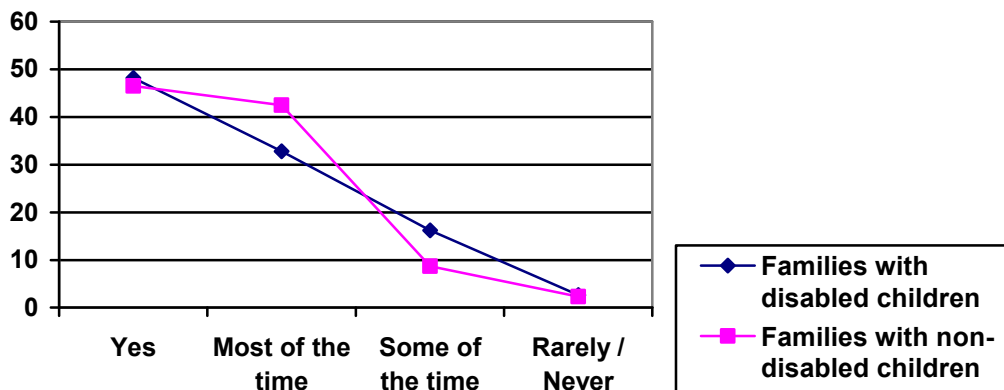
Q4. How often are members of your family able to do new things and have new experiences (%)?



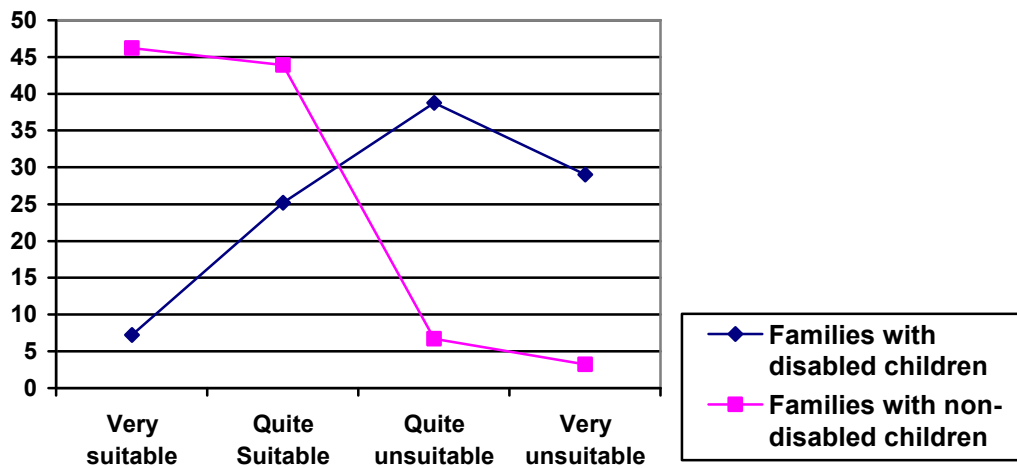
Q5. Do you have enough money (i.e. wages, savings, benefits etc) to buy the things your family needs (%)?



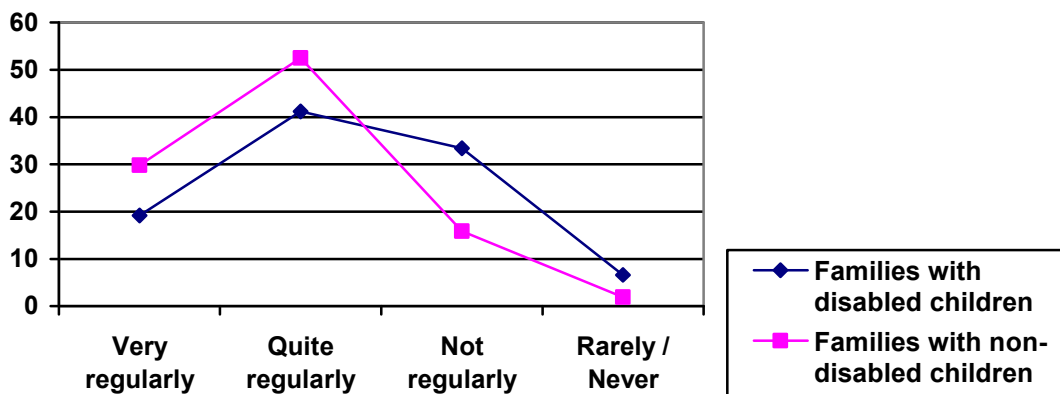
Q6. Does your family feel safe and secure at home and in your local community (%)?



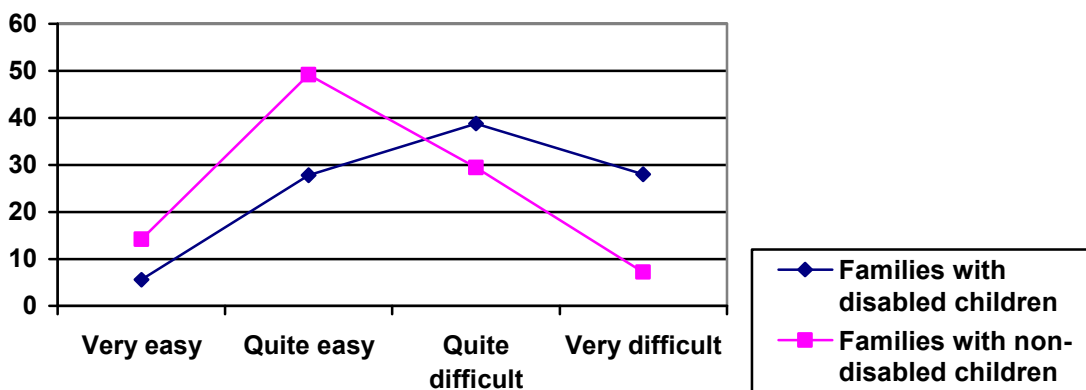
Q7. How suitable is your home for your family's needs (%)?



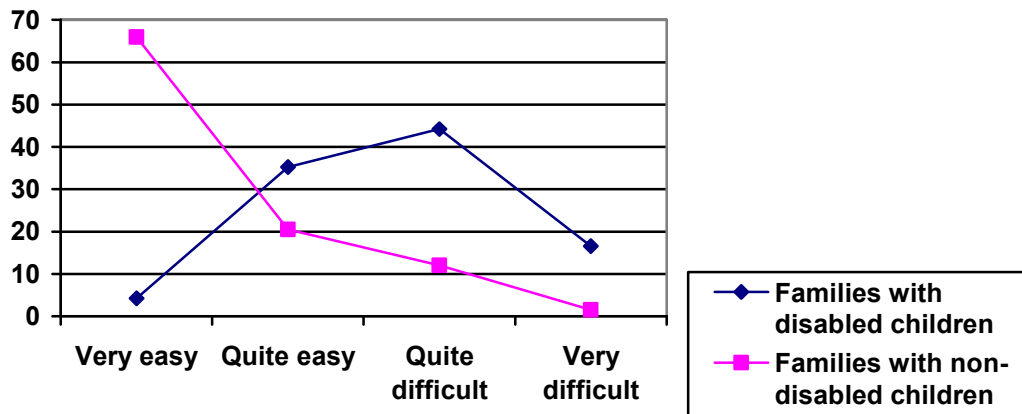
Q8. How regularly does your family see people that you enjoy spending time with (e.g. friends or family members) (%)?



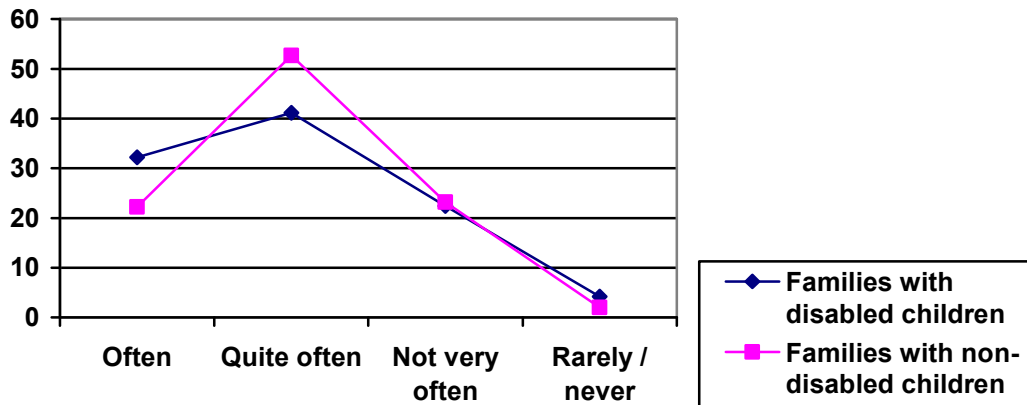
Q9. How easy is it as a family to do things spontaneously (e.g. go out for the day, go on trips etc.) (%)?



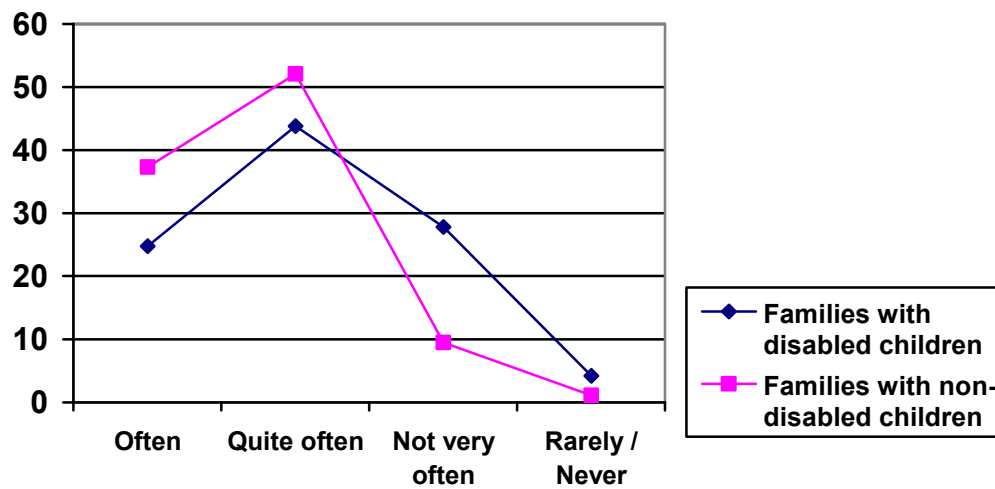
Q10. How easy is it to get the information you need to make informed decisions about your family's future (%)?



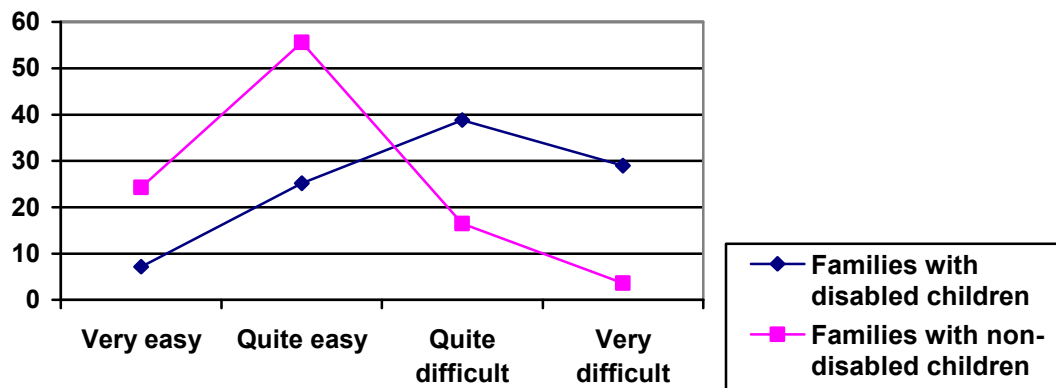
Q11. Do you think about, and plan for, your family's future (%)?



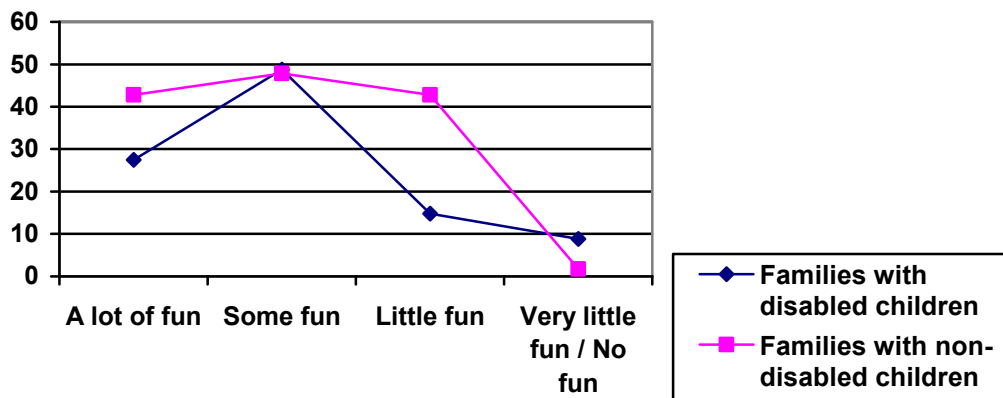
Q12. How often do you feel happy and content as a family (%)?



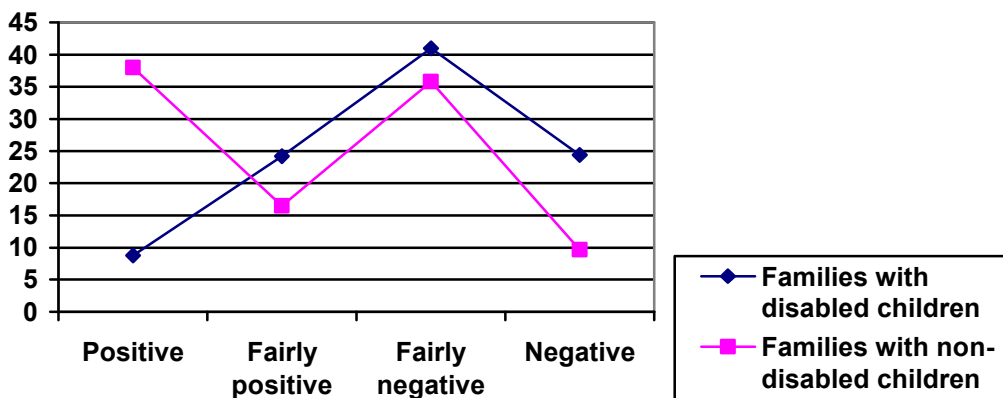
Q13. How easy is it as a family to access leisure activities (%)?



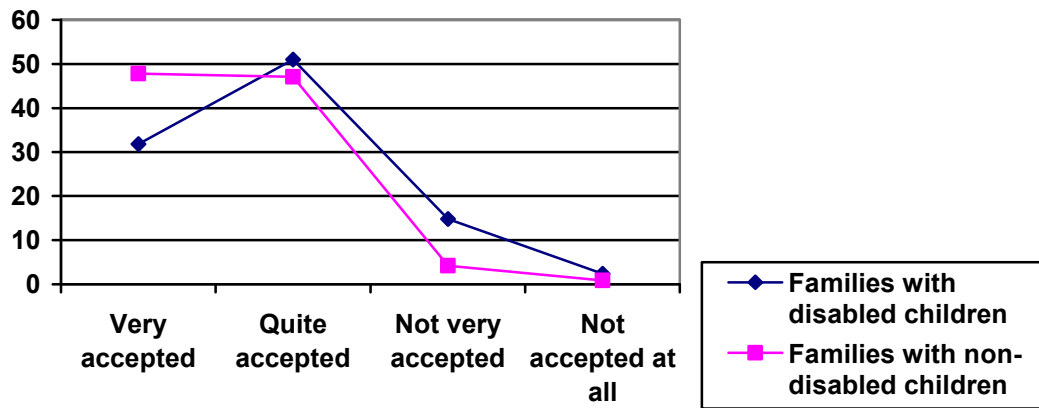
Q14. How much fun do you have as a family (%)?



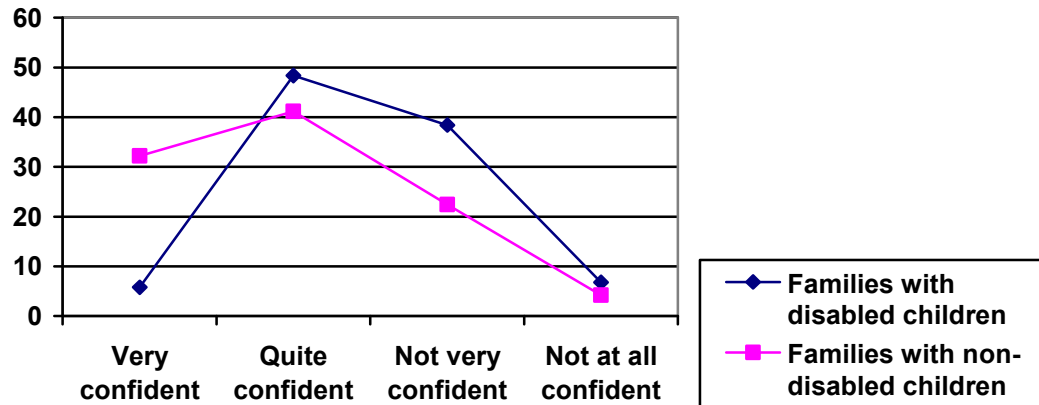
Q15. Do you think that having a family impacts on your opportunity to take up paid employment (%)?



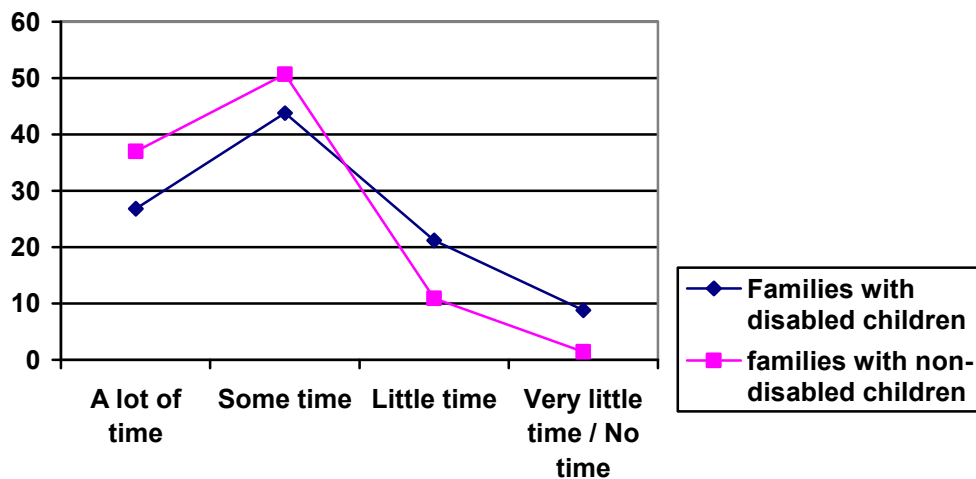
Q16. As a family do you feel accepted in your local community (%)?



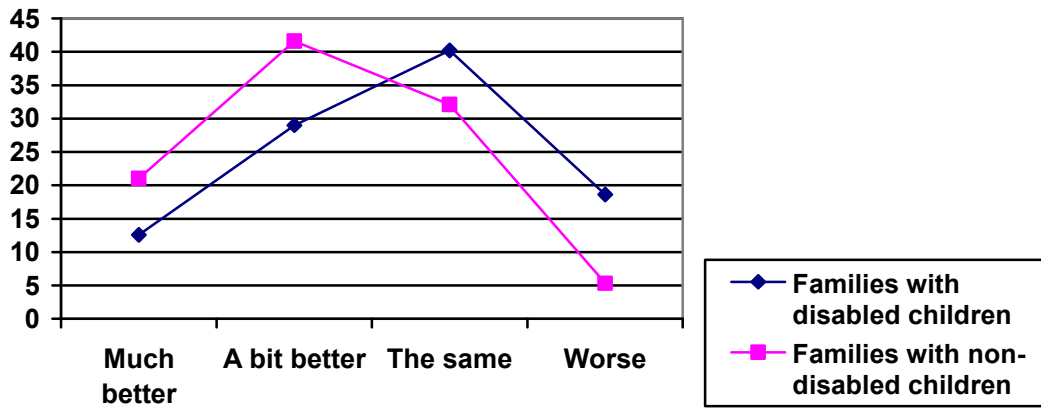
Q17. How confident are you that the aspirations of your family will be realized (%)?



Q18. How much quality time are you able to spend together as a family (%)?



Q19. What do you think the quality of life of your family will be like in five years (%)?



Scope is a national disability organisation whose mission is to drive the change to make our society the first where disabled people achieve equality. We provide information, support and a range of innovative services to disabled people, particularly those with cerebral palsy, across England and Wales.

If you have been affected by any of the issues in this report you can contact Scope Response.

Scope Response is a free and unique service that offers information, advice and support to disabled people, families and professionals.

Visit our website at:

www.scope.org.uk/response

or email **response@scope.org.uk**.

You can also contact Scope Response on **0808 800 3333** or text SCOPE followed by your message to **80039**

Scope and National Family Week are celebrating the important contributions that all families make to British society.

For more information see:

www.nationalfamilyweek.co.uk

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Time to get equal

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About cerebral palsy.
For disabled people achieving equality.