

employers

For Childcare

charitable group

Childcare for All?

Consulting Families of Children with
Disabilities and/or Special Needs about
Childcare and Employment



Report compiled and written by
Sarah Lowndes & Nora Smith
Employers For Childcare Charitable Group
September 2011

Employers For Childcare Charitable Group

Foreword

As Chief Executive Officer, I am delighted and proud to welcome this report. It is widely acknowledged that the dearth of childcare provision within the region restricts parents' abilities to access the labour market. However the situation for parents of children with disabilities and/or special needs is even more challenging.



The aim of this research is to provide a voice to those parents, with a view to enhancing our awareness and understanding of the issues and barriers they experience on a daily basis.

The vision of Employers For Childcare Charitable Group is to make it easier for parents with dependent children to get into work and to stay in work. We view childcare as a longstanding barrier to employment and during our lifetime we have produced many research publications which centre on the importance of childcare services, both as a labour market and as an economic issue.

As a working mother of two boys, both of whom have special needs, I identify with the challenges and frustrations that many of the parents in the report have shared with us. Although my position has changed in that my sons are now teenagers and childcare is no longer a personal concern, access to appropriate childcare for all remains an issue that is close to my heart.

I hope that through this report policy-makers and politicians will recognise the importance of investing in affordable, accessible, appropriate and quality childcare services for all.

Marie Marin

A handwritten signature in dark ink, consisting of a large loop followed by a series of overlapping strokes.

Chief Executive Officer
Employers For Childcare Charitable group

Disability Action

Foreword

In recent years there has been little research and policy focus on the particular challenges faced by families of children with disabilities and/or special needs when trying to access appropriate childcare services within Northern Ireland.



Access to appropriate childcare services for families in general remains patchy across Northern Ireland. For families with children who have disabilities and/or special needs, the situation is even more daunting, which often makes the barriers to work-life integration overwhelming and for many impossible.

This report illustrates the frustrations that a lack of access to childcare services presents for families. One of the key consequences is that parents have to make major compromises in both their family and working lives.

As a result, employers, and indeed the local economy, may lose the benefit of these parents' valuable experience, knowledge, and skills when they cannot marshal the support they need to care for their children with disabilities and/or special needs while they work. The report also points to the strong reliance on the extended family, most notably grandparents, in providing the much needed childcare support.

My many years spent working with disabled children and adults have proved to me the need to advocate for inclusion, to influence Government policy and to work to change attitudes in partnership with disabled people. Therefore I am delighted to endorse this report. The research provides us with insights into the barriers that families face, and points to the absolute need for Government to ensure that all families here have access to appropriate childcare services.

Monica Wilson

A handwritten signature in black ink that reads "Monica Wilson".

Chief Executive
Disability Action

Acknowledgements

We owe particular thanks to Contact a Family, the Special Educational Needs Advice Council (SENAC) and Tor Bank Special School for assisting us in circulating the survey. We would also like to take the opportunity to thank the parents of the support group that participated in our focus group who so openly shared their experiences with us.

Contents

Contents	Page
Glossary of terms	viii
Figures and tables	xii
Executive summary	xiii
1. Introduction	1
1.1 Methodology	2
1.2 Limitations	3
2. Background	5
2.1 Legislative context	5
2.1.1 <u>International Legislation</u>	5
<i>United Nations Convention on the Rights of the Child (UNCRC) 1991</i>	5
<i>United Nations Convention on the Rights of Persons with Disabilities (UNRPD) 2006</i>	7
2.1.2 <u>Northern Ireland and UK Legislation</u>	8
<i>Children (NI) Order 1995</i>	8
<i>Disability Discrimination Act 1995</i>	8
2.2 Policy context	10
2.3 Statistical data on the prevalence of disability in Northern Ireland and the UK as a whole	16
2.3.1 <u>Disability registers</u>	16
2.3.2 <u>The prevalence of disability</u>	18

2.4 Policies and legislation affecting children with disabilities and/or special needs in England, Scotland and Wales	19
2.5 The realities for families of children with disabilities and/or special needs in the UK	23
2.5.1 <u>The role of grandparents</u>	26
2.5.2 <u>Knowledge of and access to financial support</u>	27
2.6 The challenges for families in Northern Ireland	28
2.6.1 <u>Conclusions</u>	30
3. Results	32
3.1 Family profile	32
3.1.1 <u>Location of respondents</u>	32
3.1.2 <u>Marital status and family size</u>	33
3.1.3 <u>Types of disability</u>	33
3.1.4 <u>Employment status of parents</u>	34
3.2 Use of childcare	35
3.2.1 <u>Main form of childcare used</u>	35
3.2.2 <u>Additional childcare usage</u>	37
<i>Formal childcare used</i>	37
<i>Informal childcare used</i>	38
3.2.3 <u>Childcare challenges throughout the year</u>	39
3.2.4 <u>Awareness of approved home childcare</u>	41
3.2.5 <u>Childcare use by county</u>	43
3.2.6 <u>Hours childcare is used</u>	44
3.2.7 <u>Childcare use according to household type</u>	45
3.2.8 <u>Reasons for not using childcare</u>	45

3.3 Views on quality of childcare provision	51
3.4 Cost of childcare	54
3.4.1 <u>No childcare costs</u>	55
3.5 Knowledge of benefits and help received	55
3.6 Information on childcare	58
3.7 Employment and childcare	60
3.7.1 <u>Employment status and household type</u>	60
3.7.2 <u>Reasons for not being in employment</u>	61
3.7.3 <u>Taking time off work to care for their child</u>	64
3.7.4 <u>Employment patterns</u>	65
3.7.5 <u>In employment but not using childcare</u>	66
4. Conclusions	69
5. Recommendations	75
6. References	77

Glossary of terms

Approved Home Childcare Scheme: An approved home childcarer may also be known as a nanny. In Northern Ireland, nannies are not required to be registered by Health and Social Care Trusts. The scheme was introduced to Northern Ireland in 2006 to enable such carers to be approved and therefore regulated by the Trusts. An approved home childcarer works in the family's home, caring for their child or children and is subject to suitability checks

The scheme was first introduced in England in 2005. In 2007, the Ofsted Childcare Register replaced the Childcare Approval Scheme. The Childcare Register has two parts, a compulsory part and a voluntary part. Some childcare providers, such as nannies, are not required to register with Ofsted, however they can choose to join the 'voluntary' part of the Childcare Register.

Care Package: This process involves assessing the client's needs, planning for care, and coordinating and later reviewing the services recommended. Care packages are provided in the form of places in nursing and residential homes as well as domiciliary care in an individual's own home. A care package could also include provision of a home help and meals on wheels, or a place in a day care centre.

Childcare voucher schemes: The childcare voucher scheme is a Government initiative which operates through employers. The scheme allows parents to pay for registered childcare from their pre-tax salary, thus making a significant saving in tax and National Insurance Contributions. The childcare voucher scheme is available to both parents, provided they can access it through their employer. This means there is the potential for a family to double their saving. Childcare vouchers are accepted by all forms of registered childcare.

Contact a Family: Contact a Family is a UK-wide charity providing advice, information and support to parents of all disabled children.

Daycare Trust: The Daycare Trust is the national childcare charity which has been working since November 1986 to promote high quality affordable childcare for all families. The Trust helps families to make the right decision about childcare for their child through its information, research and services. It also carries out campaigning work to lobby Government on childcare related issues.

Direct payments for disabled children: Direct payments allow a parent to arrange care and services themselves instead of receiving them directly from their Local health and Social Care Trust. Direct payments can be made to parents and carers aged 16 or over. This includes people with parental responsibility for a child with disabilities.

Disability element of Child Tax Credit: This is an element of the Child Tax Credit which a family may receive for any child in the family who gets Disability Living Allowance (DLA), or who is registered blind or who has been taken off the register in the last 28 weeks. The element still applies if DLA has stopped because the child is in hospital. It is paid in addition to the child element for that child (Child Poverty Action Group, 2010: 1284).

Disability Living Allowance (for a child): Disability Living Allowance (for a child) is a tax-free benefit for disabled children to help with the extra costs families may have because their child is disabled. It is not based on the disability but on the needs arising from it.

Family Information Service: A network of Family Information Services (FISs) operates in England, Scotland and Wales, with one in each Local Authority Area. Until March 2011, a national helpline and website existed to direct parents to their local information service. However, due to funding cuts families must now contact their Local Authority directly. Since 2008, FISs have provided a range of information on all services available to parents to help them support their children up to their 20th birthday (or 25th if the child has a disability).

Formal childcare: The definition of registered formal childcare provision as stated in the children (NI) Order 1995 is as follows:

People running day care services, used by children aged under twelve and open for more than two hours a day. Day care services include facilities such as day nurseries, play groups, out of school clubs, holiday schemes and crèches. People who run these schemes are required to register whether or not they receive payment. Childminders who look after children aged under twelve for more than two hours a day in a private house for reward.

Grandparents Plus: Grandparents Plus is the national charity which supports the vital role of grandparents and the wider family in children's lives, in particular when they take on the caring role in difficult family circumstances.

Home Start: Home Start offers support, friendship and practical help to parents with young children in local communities throughout the UK. They recruit and train volunteers who are usually parents themselves to visit families with at least one child under five, at home, and offer them informal, friendly and confidential support.

Informal childcare: Informal childcare is generally defined as care arranged by the child's parent either in the child's home or elsewhere, and is provided by relatives, friends, neighbours or babysitters and is unregulated. It is referred to as informal care because the arrangements are not formalised with contracts or employment rights (OECD Family Database) and are not registered with the appropriate authority.

Parental leave: Provided they qualify, parents of disabled children are entitled to up to 18 weeks parental leave, which is the statutory minimum (for non-disabled children it is 13 weeks). Normally leave must be taken in blocks of one week or more, up to a maximum of four weeks per year. However, parents of disabled children can take leave in multiples of one day. Leave can be taken up to the child's 18th birthday.

Respite care: Temporary or short-term home care of a child that is provided, either for pay or on a voluntary basis, by adults other than the birthparents, foster parents, or adoptive parents that the child normally resides with, which is designed to give the parents some time away from the child, and even the child some time away from the parents, to allow them to emotionally recharge and become better prepared to handle the normal day-to-day challenges of parenting.

Severe Disability Element of Child Tax Credit: A family may receive a severe disability element for each child in their family who gets the highest rate of the care component of DLA. The element still applies if DLA has stopped because their child is in hospital. It is paid in addition to the child element and disability element for that child (Child Poverty Action Group, 2010:1284).

The Childcare Act 2006: The Childcare Act, which passed into law on 11 July 2006, is applicable to England and Wales. It is the first piece of legislation exclusively concerned with early years and childcare. Measures in the Act formalise the important strategic role Local Authorities play through a set of duties including ensuring that there is sufficient childcare for working parents.

Working Tax Credit: Working Tax Credit is designed to help people on lower incomes who meet certain conditions and who are employed or self employed. The amount received depends on various factors, including hours worked and annual income. Working Tax Credit may also include support for eligible childcare. The childcare element currently enables parents to claim up to 70% of the cost of eligible childcare. The current maximum amounts of eligible childcare are £175 per week for one child and £300 per week for two or more children.

Figures and tables

Figures	Page
Figure 1: Types of disability and/or special needs	34
Figure 2: Main form of childcare used in the last 12 months	35
Figure 3: Types of formal childcare used within the last 12 months	37
Figure 4: Types of informal childcare used within the last 12 months	38
Figure 5: Hours of childcare used in an average week	45
Figure 6: Cost of Childcare in an average week	54
Figure 7: Employment status according to household type	61
Figure 8: Employment status of respondents by gender	66
Figure 9: Employment status of respondents that do not use childcare	67

Tables	Page
Table 1: Breakdown of respondents by county	32
Table 2: Reasons for not using childcare	46
Table 3: Awareness and uptake of benefits	56

Executive summary

The aim of Employers For Childcare Charitable Group is to help parents with dependent children to get into work and to stay in work. It is our belief that it is the right of all families to be able to access quality, affordable, appropriate and flexible childcare. Given the fragility of our current economic climate, the sustainability of childcare provision is of crucial importance. The Government's focus on eliminating child poverty and the introduction of the Welfare Reform agenda in order to promote more people back into work needs to be supported by childcare provision which adequately supports the needs of families in Northern Ireland. Employers For Childcare Charitable Group continues to lobby Government to recognise that childcare is both a labour market and an economic issue.

This research report highlights the particular challenges faced by families whose children have a disability and/or special needs in accessing appropriate childcare.

Aims

The aim of this study was to consult with parents of children with disabilities and/or special needs in Northern Ireland about their childcare and employment arrangements. In particular, this study explored the following:

- The use of childcare for children with disabilities and/or special needs and the factors which determine choice
- Experiences and perceptions of childcare
- The cost of childcare
- Employment and childcare

Methodology

This research was carried out in three stages:

1. Desk research consisted of a literature review of current research relating to childcare policy for children with disabilities and/or special needs, relevant legislation and a review of similar studies that have been carried out in Northern Ireland and the UK as a whole.
2. A parent survey was launched online and in hard copy in October 2010 and 235 responses were generated from parents across Northern Ireland. The survey was largely modelled on the Daycare Trust's 2007 survey distributed to families in London (Daycare Trust, 2007).
3. In February 2011 a focus group was conducted with a parent support group whose children have disabilities and/or special needs.

Key findings

The results obtained from our parent survey and focus group reveal a number of important findings, which are highlighted below.

Families of disabled or special needs children that participated in the survey are strongly reliant on informal childcare provision, in particular grandparents.

- The main source of childcare for families whose children have a disability and/or special needs is informal provision (66%), with grandparents being the most common choice (35%).
- 30% of respondents said that they prefer family/friends to provide childcare for their children because they know them and 25% said they prefer this option because it comes at either no financial cost or a lower financial cost.
- Parents recognise that informal provision is not always an ideal choice and that the child's needs may be compromised.

- Parents expressed particular concern about the extra strain being placed on grandparents.
- A number of those that work stated that if they did not have the childcare support from their parents, they would have to give up work altogether.

A high proportion of families that participated in the survey do not use any form of childcare provision.

- 39% of the respondents reported that they do not use any form of childcare provision (formal or informal), with the majority indicating a preference for looking after their child(ren) themselves (44%). This desire was interlinked with their concern or perception that there are no childcare settings to meet their child(ren)'s needs (36%).
- A high proportion of respondents in employment do not use childcare (45%).

There is a lack of specialised childcare for children with disabilities and/or special needs.

- Although respondents remarked on the high cost of childcare, there are a number of other intervening factors affecting parents' choices.
- Only 34% of respondents use formal childcare provision, which indicates a shortage of specialised, appropriate childcare.
- Of those respondents that use grandparents as their main choice of provision, the qualitative data revealed that the lack of suitably trained staff to manage their child's needs was the main motivation behind this choice.
- 16% of respondents said that childcare providers will not accept their child because of their disability.

Many parents are forced to make a number of compromises in relation to their childcare choice and its suitability for their child.

- Some parents of disabled or special needs children are deprived of choice and feel they often have to prioritise factors such as safety or parental convenience, for example, over the specific developmental needs of their child.
- Almost the same proportion of parents are using unregistered childminders and registered childminders (10% and 11% respectively) as their main form of provision, which is a concern. Even in the Northern Health and Social Care Trust area, which covers most of County Antrim and which has the largest number of registered childminders in Northern Ireland (DHSSPS, 2009: 41), 68% of respondents in the county use informal provision (42% of which is Grandparents) and only 10% use registered childminders.

Families that participated in the survey face a number of challenges relating to their childcare throughout the year.

- Conflict between care and work frequently arises for parents because of the often unpredictable nature of their child's needs and disability.
- Parents of disabled and/or special needs children find school holiday periods to be the most difficult time of the year to access childcare (94%).
- Summer holidays, in particular, were cited to be a significant challenge for those who work, but those not in work also expressed concern about the interruption to their child's routine, the lack of structure and the added strain placed on those grandparents who would also provide the care during these periods.
- Within the qualitative responses, some parents indicated a reluctance to ask employers for support, with both parents often adjusting their work patterns to meet the needs of their child.

Approved home childcare has the potential to be a valuable form of provision for many families.

- Awareness of approved home childcarers/registered nannies was low amongst respondents. 54% stated that they were unaware of this type of provision and only 2% use a home approved childcarer as their main form of provision. Indeed much of the qualitative feedback obtained from both the survey and focus group demonstrated that there is a desire for this form of provision to be more accessible.

There is a lack of access to appropriate advice and information to enable parents to make informed decisions in relation to childcare and employment.

- Though, as stipulated in the Children (NI) Order (1995), there is a requirement placed on each Health and Social Care Trust to open and maintain a register of children with a disability, to the best of our knowledge this requirement has still not been fulfilled by all of the Trust areas. Furthermore, those that do maintain a register differ in how the data is collected and indeed in how they define disability. As a consequence, there is a lack of understanding of the extent of need in each Trust area. In turn, there is insufficient information available on suitable childcare for children with disabilities and/or special needs and families therefore face a constant battle in accessing the information they need.
- The majority of respondents were in receipt of Disability Living Allowance (DLA) and Child Benefit (72% and 87% respectively). However, despite 70% of respondents being in employment, knowledge and take up of other financial assistance such as that of the childcare element of Working Tax Credit, childcare vouchers and Direct Payments, was low.
- Parents that participated in the focus group had a negative experience of Direct Payments. Two families were not entitled to Direct Payments as their children were considered 'too sick'.

Accessibility to this form of financial assistance appears to be an issue for parents whose children have complex medical needs associated with their disability.

The lack of suitable and affordable childcare has an impact on parents' employment status and employment patterns.

- 50% of respondents from lone parent households were not in employment, compared to only 18% of respondents from two parent households.
- 70% of respondents not in employment stated that this was due to caring responsibilities relating to their child(ren) with disabilities and/or special needs.
- Within two parent households only 27% of such families were in a situation where both parents work full time.
- For those respondents that do work, managing work and childcare is an enormous challenge. A high proportion of employed respondents do not use any form of childcare (45%). This is because childcare is often shared between parents by adjusting work patterns to enable one or both parents to look after the child(ren). This makes it possible for them to avoid childcare costs altogether. Parents also chose this route because they perceived that formal childcare provision would not meet the specific needs of their child.
- 96% of respondents stated that that they have had to take time off work in the last 12 months to attend hospital or clinical appointments associated with their child's disability and as a consequence expressed concern about their job security.

Recommendations

- An integrated childcare strategy which addresses the childcare needs of children with disabilities and/or special needs is urgently required. This needs to be implemented with clear leadership and accountability from the Northern Ireland Executive.
- There is a need to place childcare services on a statutory footing similar to that which exists in the rest of the UK.
- There is a need to recognise the role of the extended family, in particular grandparents, in policies that directly impact on families in order to support their work-life options.
- There is a need to increase the uptake of childcare among families whose child(ren) have disabilities and/or special needs by improving the appropriateness and accessibility of services.
- Investment needs to be made to train childcare providers to care for children with disabilities and/or special needs. In particular, there is scope for the Approved Home Childcare Scheme to be an attractive option for families of children with disabilities and/or special needs if sufficient training is given.
- The Children (NI) Order (1995) requires Trusts to keep a register of children with a disability. A review of this obligation is urgently needed. There does not appear to be a consistent and coherent approach across the Trusts and within the relevant Government departments. We would recommend that a scoping exercise is carried out on existing information systems to ascertain how the information could best be co-ordinated and streamlined. A partnership approach amongst the relevant Government departments and agencies would lead to an integrated system. This, in turn, would facilitate service planning, monitoring, delivery and ultimately improved outcomes for children with disabilities and/or special needs. Funds saved through this exercise could then be used to deliver and expand on existing services.
- Investment in Advice and Information Services that raise awareness of potential help and support available to assist parents in making informed choices is required. Direct payments are

currently a 'minority service' in Northern Ireland. Awareness of this financial support needs to be raised to allow uptake to increase and to enable more parents to enter the labour market.

- Awareness of other forms of financial assistance such as childcare vouchers and Tax Credits also needs to be raised.
- It is important that Universal Credit works to the betterment of families in Northern Ireland. In particular, our politicians need to seek clarification on how childcare costs will be supported and to ensure that there will not be a reduction in financial assistance available.

1. Introduction

In 2010 Employers For Childcare Charitable Group conducted the first Childcare Cost Survey for Northern Ireland (Employers For Childcare Charitable Group, 2010). The results revealed the many challenges that childcare presents for parents to enable them to access and stay in work. Whilst undertaking the Childcare Cost Survey we recognised the need to conduct a separate piece of research which focused specifically on families whose children have a disability and/or special needs in order to ascertain the particular challenges that they face in accessing appropriate, affordable childcare to enable them to manage their work/life demands.

Stiell *et al* (2006) point out that few studies have explored the experiences and attitudes of parents of disabled and/or special needs children that are either trying to or wish to combine work and caring responsibilities. Therefore the focus of this report is to explore the childcare challenges of families of children with disabilities and/or special needs up to the age of 18 in Northern Ireland. Although we recognise that care can extend beyond the age of 18 for many families, this is an issue which would need to be addressed in a separate research report. The focus of this report is therefore to consider the childcare challenges that families experience in Northern Ireland and how they impact on their employment opportunities.

It is well documented that childcare provision in Northern Ireland is sparse, but this problem is even more evident and significant for families of children with disabilities and/or special needs. As Geraghty and Sinclair state, '[h]istorically, disabled children have been accorded a low priority by public services in Northern Ireland, with parents experiencing services as 'limited, piecemeal and fragmented' (2007:5). Even in England, where childcare policy and legislation is more advanced than that of Northern Ireland, 'finding suitable and affordable childcare for disabled children and children with special educational needs can be incredibly difficult' (Daycare Trust, 2009:4).

1.1 Methodology

The purpose of this research was therefore to identify the existing needs and challenges families of children with disabilities and/or special needs in Northern Ireland face in accessing childcare and employment. The research was carried out in four stages:

1. Desk research consisted of a literature review of current research relating to childcare policy for children with disabilities and/or special needs and a review of similar studies that have been carried out in Northern Ireland and the UK as a whole. The research reviewed informed the questions addressed in our survey and focus group.
2. Pilot survey: A pilot of the survey was circulated through Contact a Family's contacts and networks in September 2010. Contact a Family is a UK-wide charity providing advice, information and support to parents of all disabled children. The feedback received informed the final version of the survey.
3. Parent survey: The parent survey was launched online and in hard copy in October 2010 and 235 responses were generated from parents across Northern Ireland. The survey was distributed through Contact a Family, online forums, childcare partnerships, a range of media, charities, the women's sector, the childcare sector and the disability sector including disability champions within local councils and special schools. The survey was largely modelled on the Daycare Trust's 2007 survey distributed to families in London. A range of disability organisations were targeted in order to obtain responses reflecting a broad range of disabilities. The survey requested information on the profile of the family, childcare usage, views on provision, childcare costs, information/support available and employment.
4. Focus group: In February 2011 a focus group was conducted with a local parent support group which meets every three weeks. We established contact with this group through Contact a Family. The group comprised of three mothers and one family support worker

who provides support on a voluntary basis. Two of the mothers in the support group had children with complex medical needs associated with their disability and were not in employment, while one of the mothers was in full time employment. The focus group lasted approximately one hour and the discussion was transcribed verbatim.

1.2 Limitations

- In the survey, respondents were asked to specify the type of disability or disabilities of their child(ren) from a range of options, namely hidden, learning, physical, mental health and sensory. It was evident from the responses that some respondents classified the same disability differently. For example, while some respondents selected 'learning' for Autism, others selected 'hidden'. For this reason, it was not possible to fully examine how the type of disability had an impact on childcare choices and employment. Furthermore, we were unable to ascertain the number of children that had multiple disabilities as some parents classified one disability under two types.
- Given that the majority of the participating families' children were of school age, the results of our survey are likely to underplay the true extent of difficulty faced by families.
- The distinction between 'respite care' and 'childcare' may have caused confusion for respondents. To limit the risk of respondents telling us about 'respite care' rather than 'childcare', a definition of what we mean by 'childcare' at the start of the survey would have provided clarity on this issue and eliminated confusion.
- The most up to date statistics on the number of households whose children have a disability and/or special needs in Northern Ireland date back to 2007. However, given the way in which they were classified geographically, we are unable to draw comparisons with our results in order to ascertain whether our sample is representative.

- The views of childcare providers were not considered in this report. We recognise the need to consult childcare providers on the barriers they face in providing childcare to such children. Childcare providers will therefore be consulted in a separate but related piece of work.

2. Background

This section sets out the legislative, policy and research background by reviewing previous research into childcare services for children with disabilities and/or special needs and the challenges parents face in juggling work and childcare. This section also encompasses an examination of the policies and programmes that exists in the other regions of the United Kingdom, most notably England.

2.1 Legislative context

This subsection sets out the relevant legislative and policy context that has directly or indirectly impacted on childcare services for children with disabilities and/or special needs.

2.1.1 International legislation

There are a number of international conventions that influence domestic legislation, namely the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities. An overview of their relevance within the context of the rights of such families to accessible appropriate childcare is first considered.

United Nations Convention on the Rights of the Child (UNCRC) 1991

The United Nations Convention on the Rights of the Child (UNCRC) is a comprehensive, internationally binding agreement on the rights of children, adopted by the UN General Assembly in 1989 and ratified by the UK in 1991. The UNCRC's relevance to families' rights to accessible childcare is considered in a number of Articles.

Article 2 lays out the foundation that no child should be treated unfairly on any basis, Article 3 considers the best interests of the child and Article 4 outlines the protection of rights as fundamental. In particular, Articles 18 and 23 recognise the importance of family life and place an obligation on the state to support parents and guardians in their role and also to

develop the necessary mechanisms to provide such support. Article 23 makes a specific reference to children with disabilities and their right of access to appropriate services.

Article 18 (2)

...the purpose of guaranteeing and promoting the rights set forth in the present convention, state parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.

Article 18 (3)

...state Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

Article 23 (1)

States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

Article 23 (2)

States Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006

The United Nations Convention on the Rights of Persons with Disabilities (UNRPD) was adopted by the UN in December 2006. The Convention came into force in May 2008 and was ratified by the UK in June 2009.

There are eight guiding principles that underlie the Convention and each of its specific Articles, namely:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
2. Non-discrimination.
3. Full and effective participation and inclusion in society.
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity.
6. Accessibility.
7. Equality between men and women.
8. Respect for the evolving capacities of disabled children and respect for the right of disabled children to preserve their identities.

Article 7 of the UNCRPD relates specifically to children with a disability, stating:

...all necessary measures to ensure the full enjoyment by disabled children of all human rights and fundamental freedoms on an equal basis with other children. States Parties shall ensure that disabled children have the right to express their views freely on all matters affecting them.

2.1.2 Northern Ireland and UK legislation

This section reflects on both Northern Ireland specific and UK wide legislation affecting families whose children have a disability and/or special needs.

Children (NI) Order 1995

Volume 5 of the Order relates to children with disabilities and lays out the obligation of Health and Social Care Trusts to ensure that services for disabled children and young people are fit for purpose. Specific areas of

the Order relating to the training of childcare providers, the quality of childcare services and the monitoring of disabilities will be addressed where relevant throughout this report.

Disability Discrimination Act 1995

The Disability Discrimination Act 1995 (DDA) gives disabled people rights in accessing goods, facilities and services. Paragraph 4, Schedule 1 of the Act defines a disability as 'a physical or mental impairment which has a substantial and long-term adverse effect on [a person's] ability to carry out normal day-to-day activities'. However, in May of this year an amendment to paragraph 4, schedule 1 of the DDA was made when the Autism Act (NI) 2011 was passed. This amendment was made in order to rebalance the DDA's remit to cover not just physical and mental disability but also individuals with a social and communication disability such as Autism. In order to achieve this objective, the following phrases were added:

- (i) taking part in normal social interaction; or
- (j) forming social relationships

As a consequence of this amendment, disability legislation for Autism in Northern Ireland now surpasses the Equality Act (2010) in the rest of the UK. The Autism Act (NI) 2011 is also the first legislation in Northern Ireland that includes a statutory duty for Government departments to work together.

The DDA covers discrimination by service providers and section 19 (1) states the following:

- It is unlawful for a provider of services to discriminate against a disabled person—
- (a) in refusing to provide, or deliberately not providing, to the disabled person any service which he provides, or is prepared to provide, to members of the public;

(b) in failing to comply with any duty imposed on him by section 21 in circumstances in which the effect of that failure is to make it impossible or unreasonably difficult for the disabled person to make use of any such service;

(c) in the standard of service which he provides to the disabled person or the manner in which he provides it to him; or

(d) in the terms on which he provides a service to the disabled person.

Within the context of childcare providers, the charity Working Families states:

“The Disability Discrimination Act (DDA) covers childcare providers. They must make reasonable adjustments for disabled children and they are not allowed to discriminate. They are allowed to charge extra if they need to employ extra staff or limit their provision to fewer children, but they are only allowed to charge for the extra costs incurred. Reasonable adjustment can mean that they change their practice to accommodate a disabled child’s needs.

(Working Families, 2010)

There are circumstances in which the Act permits justifiable discrimination. For example, ‘[i]t would not be reasonable to expect a childminder to make the degree of alterations to her home that you could expect a Local Authority to make to a school or a nursery’ (Working Families, 2010).

Section 49A of the Disability Discrimination Act 1995 (as amended by the Disability (NI) Order 2006) places a duty on public authorities to promote positive attitudes towards people with a disability and encourage participation by people with a disability in public life.

Section 75(1) of the Northern Ireland Act 1998, the Special Educational Needs and Disability Order NI (1995) and the Child Poverty Act 2010 are considered within the policy context.

2.2 Policy context

Responsibility for childcare is spread across Government departments in Northern Ireland which means that ownership does not lie within one department. The Department of Education (DE) has responsibility for Early Years policy (0-6) and extended schools services, the Department of Health, Social Services and Public Safety (DHSSPS) has responsibility for the regulation and inspection of childcare settings and the Office of First and Deputy First Minister (OFMDFM) has responsibility for children and young people. A number of other departments including the Department of Agricultural and Rural Development (DARD) and the Department of Social Development (DSD) provide funding for childcare settings through various programmes and initiatives.

Childcare is multi-dimensional and requires an integrated approach. However, the current ad hoc and piecemeal approach employed in Northern Ireland has led to a disjointed service, resulting in a decline in the number of childcare places in recent years. In particular, childcare services for children with disabilities and/or special needs have received little policy attention.

Given the current arrangement of childcare services in Northern Ireland, it is extremely difficult to map out the range of policies and services that both consider and meet the needs of families of children with disabilities and/or special needs, specifically in relation to childcare services. However, we will step through some of the key policy developments that have either directly or indirectly impacted on childcare services for children with disabilities and/or special needs in Northern Ireland to date.

Children First (1999), the first and only childcare strategy to be produced in Northern Ireland, makes reference to the development of childcare services for all families 'including those where children have special educational needs or disabilities' (DHSS, 1999: 15). DHSSPS commissioned Capita to review the Strategy in 2005. However the full

recommendations put forward in this review still remain relevant and have yet to be implemented.

Pre-school places were introduced to Northern Ireland in 1998/99. Since then nearly £58m has been invested in creating and supporting over 10,000 new pre-school education places (DE, 2011). Places have been created through the building of new nursery schools and units in the statutory nursery sector and the funding of places in the voluntary and private sectors.

In 2004, Kilkelly *et al* conducted research on behalf of the Northern Ireland Commission for Children and Young People (NICCY) and identified that there are insufficient resources to enable some pre-school programmes to adequately deliver to children with special educational needs. This is because some pre-school programmes do not have the additional support needed, such as classroom assistants, to assist delivery to such children (Kilkelly *et al*, 2004: 124).

In 2006, the Children and Young People Funding Package provided £13.25 million for extended schools. In 2008, DE announced that the outworking of the Budget 2007 process would result in a considerable reduction in the resources available for the Extended Schools programme, from a 2007/08 allocation of £10 million to an allocation of £5.826 million in 2008/09. The Department also introduced new and more stringent eligibility criteria. Extended schools services include a range of activities such as breakfast and afterschool clubs provided on school premises. These are often referred to as 'wraparound' childcare services.

Section 75(1) of the Northern Ireland Act 1998 requires public authorities, in carrying out their functions relating to Northern Ireland, to have due regard for the need to promote equality of opportunity between certain individuals and groups. DE commented:

“In the context of the pre-school phase, the purpose of the assessment will be to investigate whether there are any inequalities among the groups listed in section 75 in accessing funded places. Although section 75 lists 9 categories, the Department considers that only 4 of them - religion, race, gender and disability – are relevant to pre-school children.”

(DE, 2004:47)

The implementation of the Special Educational Needs and Disability Order (NI) 2005 addresses some of the concerns raised by families of children with disabilities and/or special needs. It places a statutory requirement on schools to improve physical accessibility, access to the curriculum and access to information in alternative formats. They also have a duty to make reasonable adjustments to ensure pupils with disabilities are not put at a substantial disadvantage compared to others. Although this legislation is directly related to access to education services, it is also relevant to the context of extended schools services.

The Sure Start programme was introduced to Northern Ireland in 2000/01. Initially the Department of Health, Social Services and Public Safety (DHSSPS) carried responsibility for the programme but responsibility was transferred to DE in 2007. Funding for Sure Start programmes has been significantly lower than that in the other regions of the UK. Sure Start works on the principle of meeting the needs of the families it serves. A number of Sure Start programmes in Northern Ireland have developed programmes to meet the needs of children with disabilities and special needs. However given the limited resources invested into such programmes, Sure Start is severely restricted in the services that it is able to provide to families of children with disabilities and/or special needs in Northern Ireland.

The Approved Home Childcare Scheme was launched in 2006 by DHSSPS. The benefits of this particular type of childcare service for children with disabilities and/or special needs has yet to be explored. Positive Futures, a Northern Ireland charity that supports children, young people and adults

with a learning disability, ran a project funded by the Department of Agricultural and Rural Development (DARD) under the Rural Childcare Funding Programme between April 2010 and March 2011. The initiative aimed to develop this type of childcare provision to facilitate the childcare needs of families whose children have a learning disability in the western Trust area. Employers For Childcare Charitable Group is also currently conducting a piece of research into this form of provision.

There is also an array of community and voluntary organisations that work to support families of children with disabilities and/or special needs by providing a range of services, funded under a number of programmes. For example, Mencap provides childcare places for children with learning disabilities in Belfast. Currently 50 children avail of this service and they also have a waiting list of 51 children. However, due to the recent funding cuts they now face a number of challenges in continuing to provide these childcare places in the future.

Contact a Family provides advice and information services to families of children with disabilities. One of their key activities is signposting parents and raising awareness of the services available to them, including those relating to childcare. However, as a result of the recent DHSSPS budget cuts, the role of the Information and Development Officer no longer exists. This role provided an invaluable service to families of disabled children for over 11 years and its termination will no doubt be a huge loss to an already vulnerable and isolated group of carers.

The Child Poverty Act 2010 requires the Northern Ireland Executive to develop a Child Poverty Strategy to address how it will meet its target to end child poverty by 2020. The Child Poverty Strategy entitled *Improving Children's Life Chances for Northern Ireland* was launched in March 2011. The Strategy does not detail specific plans or programmes for childcare services, however we are hopeful that the delivery plans will recognise the value of childcare services as an essential component for parents to be able to access and stay in work. The Government has recognised that work is the best route out of poverty. Research shows that '[f]amilies

with disabled children are much more likely to be in poverty because of the higher costs associated with bringing up a child with a disability, and, in some cases, the loss of income involved when a parent has given up work to care for the child' (Monteith *et al*, 2009).

The draft Early Years (0-6) Strategy was launched for consultation in June 2010 by DE. At the launch of the Strategy, the then Minister stated that '[i]t will reflect the drive for cohesion in the policies and services affecting early years so that children and parents get the best outcomes possible'. However the draft Strategy failed to consider or address the need for families to have access to affordable, appropriate childcare services.

Universal credit, which is due to be introduced across the UK in 2013, will see the integration of six existing benefits:

1. Income support
2. Jobseeker's Allowance
3. Employment and support allowance
4. Housing Benefit
5. Working Tax Credit
6. Child Tax Credit.

The new system will subsume all the benefits within a common framework of rules by working to simplify the existing welfare and benefits system and by ensuring that there is a financial incentive to entering employment. The reforms' aims are to help and encourage families to use work as a route out of poverty. Essentially Universal Credit will work on the principle that benefits will reduce as income increases, and increase as income falls. However, there are a number of concerns surrounding some aspects of the welfare proposals.

A recent report from Every Disabled Child Matters (EDCM) highlighted the particular concerns for families who receive Disability Living Allowance (DLA):

“Currently, low income and out of work families who receive Disability Living Allowance (DLA) are entitled to a ‘disability addition’ worth £52.08 per week in 2010/11. Families with a child in receipt of the high rate care component of DLA also receive a ‘top up addition’ worth an additional £21 per week. However proposals under the Universal Credit will see lower benefit ‘additions’ drop by over 50%. Although existing claimants will be transitionally protected, in the future up to 63% of those children qualifying for DLA will potentially be affected by this reduction.”

(EDCM, 2011)

There are also concerns about support for childcare costs under Universal Credit. The Government has already cut childcare support for working families. Since April 2011 households claiming the childcare element of Working Tax Credit can now only claim 70% of eligible childcare costs, which is a reduction from the previous 80%. Under the new system, reforms will, for the first time, help parents working fewer than 16 hours to pay for childcare. However, the Government has said that it will not contribute more financial support for childcare than it currently does, despite more parents being eligible for support. As a consequence, many parents will receive less support towards their childcare costs. The proposed policy changes will have huge financial implications for families, in particular for families of children with disabilities and/or special needs as their entitlement to financial support will be reduced.

At the time of writing this report an economic appraisals option on the future of childcare had been prepared for the Executive. The report was finalised in June 2010, however it has yet to make it onto the Northern Ireland Executive’s agenda. A question was submitted to the Northern Ireland Assembly as to why it has not been considered, and was met with the following reply:

“We hope to bring a paper, relating to the policy and economic appraisal report on Childcare, to the Executive before the end of March this year. This paper will outline the report’s key findings and

once a way forward is agreed the next phase of the work, on the development of a Childcare Strategy, will begin. It is our intention that a lead department for this policy area would be identified shortly by the Executive and that the childcare strategy would be developed with lead from that department, in collaboration with the relevant Ministerial Sub-Committee and the Child Poverty sub-group.”
(NI Assembly, 7th March 2011)

In March 2011 a commitment was given during an Assembly debate to ring fence £12 million for the development of a Childcare Strategy.

Clearly this is a time of significant change which brings with it opportunities for the Executive to address the needs of children with disabilities and/or special needs and their families.

2.3 Statistical data on the prevalence of disability in Northern Ireland and the UK as a whole

A number of researchers have reported on the difficulty in defining disability. Haywood remarks that ‘a consistent definition of disability’ does not exist because ‘social care, education and health all differ in their definitions and criteria for categorising disability’ (Heywood, 2010: 2). This factor makes it difficult to measure and report on the prevalence of disability across the UK.

The difficulty in defining disability is also, in part, due to the fact that on both a national and local level, there is a lack of data available on the number of children that actually have a disability.

2.3.1 Disability registers

The lack of data available is even more significant in Northern Ireland. Although schedule 2, paragraph 3 of the Children (NI) Order (1995) places a requirement on Trusts to open and maintain a register of children with a disability in their area, to the best of our knowledge this has not

yet happened within all the Trust areas. For example, according to NICCY (2008: 20) the Northern Health and Social Care Trust does not yet maintain a register 'due to a number of technical and operational difficulties'. Furthermore, DHSSPS's plan to develop a Northern Ireland wide register of disabled children has not yet taken place (NICCY, 2008: 20). The requirement stipulated by the Order is designed to help service planning and monitoring. The Order states:

Requirement for Trusts to keep a register of children with a disability and to initiate discussions with the parents about services. Trusts to liaise with education and library boards to facilitate early identification of disability.

(DHSSPS, 1995: 3)

The Children with Disabilities Strategic Alliance (CDSA) states that '[d]espite a full regional project report having been completed a number of years ago on the disabled children register, the Health and Social Care Trusts have not moved forward on this matter' (CDSA, 2007: 7). Indeed, Children's Commissioner, Patricia Lewsley, recently commented that '[o]ne of the greatest barriers is the lack of statistical data on children and young people with disabilities' and called for the Northern Ireland Executive 'to develop and implement a strategy for the inclusion of children with disabilities in Northern Ireland' (NICCY, June 2010). The absence of a Northern Ireland wide register therefore makes it difficult to ascertain the number of children with disabilities in each Trust area in Northern Ireland.

In England and Wales, local authorities are required to keep a register of children with disabilities '[i]n order to identify the extent and level of services needed to comply with their general duty towards children with disabilities' under the Childcare Act 2006 (Contact a Family, 2010). Children are not automatically placed on the register. This is at the parent's discretion and failure to have a child placed on the register does not mean they will not receive services. However, 'registration can help local authorities and other agencies plan the right level and mix of

services in [each] area and may be used to provide...information about support and services' available (Contact a Family, 2010).

Similarly, the Order in Northern Ireland stipulates that '[t]here is no corresponding duty on parents to agree to registration', meaning that it is a voluntary register. Parents may not wish to have their child's details placed on the register due to the stigma often associated with disability. Furthermore, if children themselves were consulted they may also choose not to be placed on the register. Therefore, given the right to choice, the register may not be representative. This, in turn, undermines its usefulness for service planning and monitoring.

It is important to note that although there is no central register in Northern Ireland, there are a number of other information systems that hold data about children with disabilities and/or special needs. These include Soscare (Social Services Client Administration and Retrieval Environment) and Module V of the Child Health System. Parents may favour the latter because the data is held under health rather than social care. The Order does suggest that Trusts can build upon existing databases such as the aforementioned. However, there appears to be a lack of co-ordination between Trusts and a streamlining exercise may well be all that is required in order to make the information held more useful in facilitating service planning and monitoring, as stipulated in the Order. This is also true of the relevant Government departments, in particular DE and DHSSPS, who could develop a better system of sharing information to inform the childcare needs of families whose child(ren) have a disability and/or special needs.

2.3.2 The prevalence of disability

The Department of Work and Pensions *et al* (2005: 20) states that there are 770,000 disabled children under the age of 16 in the UK, which, according to Contact a Family (2011), equates to 7% of all children or one child in 20. Despite the absence of a register to establish the number of children with a disability in Northern Ireland, it is reported that the region

has a higher incidence of disability than the other regions of the UK (Kilkelly *et al*, 2004). According to the Office of National Statistics (2004) 'it is estimated that 10 in 10,000 children in Northern Ireland have a severe disability compared to 8 in every 10,000 in England' (as cited in Kilkelly *et al*, 2004:21).

According to the Northern Ireland Statistics and Research Agency (NISRA), 6% of children living in private households in Northern Ireland have a disability (NISRA, 2007:6). In 2006-2007, there were 381,100 children (up to the age of 16) in Northern Ireland (NISRA, 2007a). If 6% of these children had a disability, this equates to 22,866 children. This report also gives a geographical breakdown of disability, although not in terms of county. This means we cannot match the geographical breakdown presented in this report with our results, which are broken down by county.

Based on the figures above for Northern Ireland in 2007 (381,100 children, of which 22,866 have a disability), this equates to one in 16.6 children in Northern Ireland having a disability. Thus, disability is even more prevalent in Northern Ireland than the rest of the UK.

2.4 Policies and legislation affecting children with disabilities and/or special needs in England, Scotland and Wales

In order to assess the level of investment in childcare services for children with disabilities and/or special needs, it is important to consider and highlight the particular policies and initiatives that exist in the other regions of the UK.

Improving childcare services for families of disabled children was both a local and national priority for the Labour Party Government, with a drive to expanding service provision and choice for parents who wanted to balance work and family life.

The Childcare Act, a pioneering piece of legislation that was introduced in 2006 in England and Wales, places a statutory duty on local authorities to ensure that there is ample childcare provision in their area to meet the needs of local working parents. It is their responsibility to plan, support and commission childcare. Section 6 (2) of the Act placed an important statutory duty on local authorities to give particular consideration to the provision of childcare services suitable for disabled children when assessing adequacy and availability in their area.

The Aiming High for Disabled Children (AHDC) programme, which was launched in May 2007, was set up as a transformation programme for disabled children's services in England. As part of the AHDC programme, an additional investment of £35 million was used for the Disabled Children's Access to Childcare (DCATCH) initiative. This signified a major change in the provision of childcare services and how they would be delivered. In this initiative ten pilot areas were used to test out ways of achieving better access to childcare for disabled children and young people. The initiative focused on childcare for disabled children that are currently least likely to access services, including older children and children with complex needs.

Enfield Council, one of the ten pilot areas, allocated its funding towards training childcare providers 'to ensure that all childcare providers within the Borough have the skills and knowledge to confidently include and support disabled children and young people, so their parents have the same range of childcare options available as any other parent' (London Borough Council of Enfield Council, 2010:3). An evaluation of the success of the initiative is not yet available from the Council.

The success of the pilot initiative was exemplified by the fact that DCATCH funding was made available to all local authority areas in England in April 2010 to enable them to improve service delivery and information for families of disabled children. Local authorities could choose to work on the following areas of improvement:

- Better data: estimating demand and monitoring take up
- Participation and feedback: consulting with families
- Improving information for families
- Supporting families to make choices
- Workforce development
- Increasing capacity, inclusion and improving quality
- Initiatives to meet particular childcare needs
- Affordability and cost

(Together for Disabled Children, 2010: 3)

This funding ended in March 2011, leaving the future very uncertain. Indeed, the threat of the withdrawal of the DCATCH initiative led to a petition being launched online by parents, calling on the Government to save the initiative:

“We would strongly contest that there is every case for this service to remain in existence as a pioneering way forward for those in our situation who would like to have the opportunity to continue to work, pay our taxes and contribute to the local economy and NOT be reliant solely on the benefits system to be able to afford to exist.

We feel that our children, who require extra care and support owing to their extra special needs/disabilities, benefit hugely from the support DCATCH provides, so that we may have some semblance of a normal life and their needs should not inhibit our ability to work just like parents who have children without those needs. If this service is removed, a lot of parents will be forced to give up work to care full time for their children as the childcare costs for disabled/special needs children is enormous.

The duress that a child with special needs puts on a family cannot ever be fully explained – experience is the only way to understand. DCATCH have been trained in an exceptional way to handle the parents, children and their families stress. They are a formidable force and it should be known that without their intervention and

help, a lot of what has been achieved in the last year would never have been possible.”

(Petition Online, 2011)

Despite this petition, DCATCH funding was not extended in the recent budget.

Scotland and Wales have also recognised the importance of addressing the needs of families with disabled or special needs children within their policies and strategies. For example, Scotland's *Early Years Framework* (Scottish Government and COSLA, 2008) recognises the need to increase the level of support for families of disabled children with a view to enabling parents to access employment. This approach is very much in line with their philosophy that investing early will have a positive impact on the economy in the long term. In addition, *For Scotland's Disabled Children* (FSDC), a charity established in 2007 to secure rights and justice for disabled children, young people and their families in Scotland, is currently working to ensure that all families with a disabled child have access to affordable and suitable childcare. There are currently 50 organisations in the coalition project. FSDC has recently launched a campaign to trace the 'missing millions' (estimated to be approximately £34 million) that is supposed to be invested in children with disabilities and/or special needs. In 2007, the Scottish Government received £34 million to invest in children and young people with disabilities for the next three years. However, because this money was not ring-fenced, local authorities were able to spend it on their own priorities without any accountability. FSDC has launched this campaign to ensure that the final £11.3 million is spent on children and young people between 2010-2011. Childcare is one of the campaign's priorities (FSDC, 2011). FSDC also has a childcare task group which is exploring how best practice models in England can be utilised in Scotland.

In 2007, the *Disabled Children Matter Wales* campaign also set up a task group called 'Rights into Action for Disabled Children and Young People' to address the needs of such children and collaborate closely with their

families. In 2011 the Welsh Assembly Government announced a new pilot project to help ensure families with disabled children claim the benefits they are entitled to. The £500,000 pilot scheme will look over the next two years at the best ways to increase the household incomes of families with disabled children by working closely with Citizens Advice Cymru to ensure families are getting comprehensive advice about their entitlements (Disabled Children Matter Wales, 2011).

In Northern Ireland no such commitment has been expressed. As Contact a Family states, 'there has been no priority given to childcare provision for disabled children' in Northern Ireland (Contact a Family, 2009:27).

Contact a Family has urged the devolved Governments in Scotland, Wales and Northern Ireland to learn from and fund similar initiatives to that of DCATCH (Contact a Family, 2009:28). Although Scotland and Wales are showing evidence that they recognise the value of the DCATCH initiative, Northern Ireland has not stated its policy position on this matter.

2.5 The realities for families of children with disabilities and/or special needs in the UK

Research shows that families of children with disabilities and/or special needs face a number challenges in accessing childcare and employment:

"[T]he barriers to getting and keeping paid work can often appear insurmountable for parents of disabled children. Lack of suitable and affordable childcare, inadequate support services, non-inclusive after-school activities, inflexible working conditions, schools and nurseries that do not understand or meet their child's needs, time consuming hospital appointments, inflexible school transport arrangements and poorly paid part-time jobs all combine to make work financially and practically impossible."

(Scope *et al*, 2007:2)

Families of children with disabilities and/or special needs face many challenges in their daily lives and strive for an existence that is as close to

'ordinary' as possible (Heywood, 2010). It is well documented that families affected by disability are at a greater risk of persistent poverty, largely because such families are less likely to be in employment:

"The additional costs of disability push many families into poverty – it costs three times as much to bring up a disabled child as it does a non-disabled child. Parents in such families are less likely to work and when they do they are more likely to be in low paid employment."

(Barnardo's, 2006: 7)

It is therefore not surprising that due to the constraints of bringing up a child with a disability or special needs, those parents who do work 'often seek work locally in order to be near their child during the day, and may end up employed significantly below their skill level' (Bryson *et al*, 2005:5). Stiehl *et al* followed the experiences of parents of children with disabilities over a four year period and found that where parents have been unsuccessful in reducing their working hours or adjusting their working patterns to accommodate their child's needs, 'many feel forced to look for a different type of work or to change their jobs' (Stiehl *et al*, 2006:iii). Indeed, Contact a Family *et al* (2006) state:

"Employment is a key government strategy to end child poverty. Yet for many parents (and in particular mothers) of disabled children, employment remains a difficult and unreliable route out of poverty...The reason that these families experience barriers to employment is that childcare is neither fit for purpose nor affordable."

(Contact a Family *et al*, 2006:1)

The cost and availability of childcare for such children is also a significant barrier:

"Childcare gives parents the opportunity to take up employment, which can help families lift themselves out of poverty...Finding the

right childcare is a challenge for all families but for parents with a disabled child this is even more problematic.”

(Contact a Family, 2009: 27)

In 2009, Contact a Family reported that ‘[f]amilies with disabled children pay 5 times more towards childcare costs’ (Contact a Family, 2009: 27). A recent national survey by Contact a Family which explored the financial reality for families of disabled children revealed that 22% of respondents had to go without childcare because of a lack of money (Contact a Family, 2010a: 5). The majority of the respondents were not in employment (60%) and of those that were using childcare, 45% reported paying more for childcare for their child with disabilities and/or special needs. Similarly, the Daycare Trust (2007) carried out a survey on parents of children with disabilities and/or special needs in London and found that 40% of respondents that did not use childcare claimed cost was a factor, with 14% stating that this was the most important reason for not using childcare (Daycare Trust, 2007: 35).

A number of research studies have been carried out which indicate that parents with children who have disabilities and/or special needs do want to work but simply cannot work (Contact a Family, 2010a). Indeed, for those that do work, managing work and childcare is an enormous challenge:

“Lack of affordability is not the only barrier to parental participation in the labour market...Parents often need significant flexibility in their working lives in order to take their child between key (and sometimes distant) locations, or to respond to emergencies at little notice.”

(Bryson *et al*, 2005: 5)

Bryson *et al* (2005) found that childcare use varied according to the disability or special need of the child. In general, children with a mental disability were less likely to be looked after by formal carers, perhaps

reflecting a need for more formal, specialised provision or support for carers (Bryson *et al* 2005:2).

A small-scale study conducted by the Daycare Trust (2007a) also found that a number of families of children with disabilities used little or no formal childcare. In particular, parents of children with severe disabilities such as Cerebral Palsy reported having very little access to appropriate childcare, either relying on informal provision or utilising direct payments to give them some respite.

2.5.1 The role of grandparents

Research shows that grandparents are playing an increasingly important role in supporting the childcare needs of families in general:

“In the UK around one in three mothers in paid work receives help with childcare from grandparents... Grandparents are likely to act as “a reserve army” filling in gaps to meet childcare needs.”

(Ghaser *et al*, 2010:6)

Research also reveals that due to the extra demands and stress placed on families of disabled or special needs children, grandparents are often a major source of support, particularly with regard to childcare (Ghaser *et al*, 2010). Gray and Bruegel (2003) also found this to be the case within the context of Northern Ireland. According to Ghaser *et al* (2010:4), formal childcare often fails to meet the needs of such families, and as a result ‘grandparents may play a particularly important role for working mothers with disabled children’.

Sam Smethers, Chief Executive of Grandparents Plus, the national charity which supports the vital role of grandparents and the wider family in children’s lives, expresses concern over the increasingly heavy reliance on grandparents as carers:

"Grandparents raising a disabled child save the taxpayer billions of pounds a year in care costs, and for many that caring role won't end when the child reaches 18. We are worried about the impact of welfare reform and spending cuts on this group."

(Children and Young People Now, 18 January 2011)

Indeed, a recent study by The Family Fund (2011) found that 89% of grandparents were providing more than 50 hours of care per week to their disabled grandchildren.

2.5.2 Knowledge of and access to financial support

Knowledge and take-up of certain benefits for families of children with disabilities and/or special needs can be low. In Contact a Family's survey on the financial struggles faced by such families across the UK, 95% said they were claiming Disability Living Allowance (DLA) for their child (Contact a Family, 2010a). 34% of respondents found out about DLA from another parent rather than from a professional or statutory authority, which is a concerning statistic:

"It is worrying that parents are finding out about financial help in such an unstructured way as there is the risk that they will go without for years."

(Contact a Family, 2010a: 9)

Almost 80% of respondents said they find the benefits system difficult or fairly difficult to navigate.

Direct payments are a form of financial support for families of children with disabilities and/or special needs. The direct payment scheme was introduced as a more flexible means of support for families and was part of the Government's plan to empower families to make choices specific to their needs:

“Direct payments can be used to buy in services for your child following an assessment of need from your local authority. Direct payments can be used to pay for a home carer, nursery place, childminder or out-of-school club. You can also use direct payments to pay a relative to look after your child, provided that person does not live at your home and they are considered to be the most suitable person.”

(Daycare Trust, 2010:22)

However, ‘take-up is low and a number of local authorities do not promote direct payments despite this being a legal requirement (Scope *et al*, 2007:3). Indeed, in Scotland and Northern Ireland in particular, take-up is reported to be extremely low:

“In Scotland and Northern Ireland, despite some unease over the principle of the direct payments, the impact on existing services and future commissioning was minimal. Direct payments remained a ‘minority service’ and the number of users was rarely high enough to prompt any restructuring of existing services.”

(Riddell *et al*, 2006:12)

In Northern Ireland, Direct Payments are governed by the Carers and Direct Payments (Northern Ireland) Act 2002 which made an amendment extending direct payments to include the care of children in section 9 (DHSSPS, 2004).

Very little has been documented about direct payments within the context of Northern Ireland. Awareness and current use of this scheme is therefore explored within the survey and the focus group.

2.6 The challenges for families in Northern Ireland

Research shows that families of children with disabilities and/or special needs in Northern Ireland are at greater risk of financial hardship (Contact a Family, 2010a). The lack of appropriate childcare provision for such

families and the high rate of unemployment therefore exacerbate already existing struggles. Very little research has been carried out in the area of childcare provision for children with disabilities and/or special needs in Northern Ireland. The most recent study by Geraghty and Sinclair (2007) focused predominantly on childminding services.

Gray and Bruegel's study in 2003 reviewed the provision of childcare services in Northern Ireland for children up to the age of 14 and considered how gaps in provision and the cost of childcare can be a barrier to employment. They carried out a survey on childcare providers and parents, concluding that 'children with disabilities are under-represented in formal childcare provision' (2003:35). Gray and Bruegel 'estimate that between 3% and 4% of children placed in childcare have disabilities' (2003:37). Amongst the responding families who had a child with a disability, the employment rate of mothers was only 61%, compared to 80% where there was no disabled child (Gray and Bruegel, 2003:39).

Research shows that families of children with disabilities and/or special needs often experience an unwillingness or reluctance from childcare providers to look after their child (Geraghty and Sinclair, 2007). This is largely due to a lack of training. The Children (NI) Order 1995 specifically addresses this issue:

"Some intending providers or child minders may be reluctant to take on the responsibility of caring for a child with a disability because they are concerned about their capacity to provide adequate care. This needs to be handled sensitively."

(Children (NI) Order 1995, Chapter 8, paragraph 10)

Indeed this reluctance has been identified and explored in Geraghty and Sinclair's (2007) study on childminding. Geraghty and Sinclair identified two main types of care, respite care and daycare, the former being for those that do not work and the latter being for those that do (Geraghty and Sinclair, 2007). Their study focussed predominantly on childminding

services in Northern Ireland and highlighted the shortage of childminders that are both willing and sufficiently experienced and confident enough to look after their disabled child. Participants also raised that the attitude of childminders was a barrier to accessing care – they either discriminate against their child or do not have the confidence to care for them.

Their study revealed that Health and Social Care Trusts do operate a specialist childminding service but that 'this was not widespread and not well recognised' (Geraghty and Sinclair, 2007:8). The 'economic cost' to a childminder who looks after a disabled child was also noted as sometimes minding such a child means they have to reduce their quota in order to ensure the needs of the child are met. It was found that for many families of children with disabilities and/or special needs, all of these barriers merge to create 'cumulative difficulties' (Geraghty and Sinclair, 2007:8).

Gray and Bruegel's (2003) study of the daycare needs of disabled children identified that one in five disabled children went to a childminder (registered and unregistered) and less than 3% to a day nursery. Furthermore, almost half of those children with disabilities who were using childcare were looked after by grandparents and other relatives, sometimes in conjunction with part time formal care.

2.6.1 Conclusions

Legislation exists to ensure that children with disabilities and/or special needs are not discriminated against through the provision of services, in particular childcare services.

Although policies and schemes are in place in the rest of the UK to provide such children and their families with these services, as indicated in section 2.4, Northern Ireland has placed little emphasis on services for such families. This is a concern given the high levels of children with disabilities in the region.

Research shows that the difficulties such families face in accessing employment is further exacerbated by the complexities of finding available, appropriate and affordable childcare services.

The next section explores the specific experiences and challenges faced by families of disabled and/or special needs children in relation to childcare and employment which were raised in our survey and focus group. It is to these results that the report now turns.

3. Results

In order to ascertain the current challenges faced by families and indeed to assess whether the situation has improved since Gray and Bruegel's research in 2003 and Geraghty and Sinclair's research in 2007, we conducted a survey and focus group to explore the experiences of families of disabled and/or special needs children in Northern Ireland with regard to accessing childcare. We sought information on the type of childcare used by families and considered this within the context of employment status, family profile and the cost of childcare in order to build a picture of the daily challenges experienced by such families.

3.1 Family profile

This section outlines the profile of respondents who participated in the survey in terms of location, family size, gender, range and types of disability and the employment status of parents.

3.1.1 Location of respondents

235 respondents took part in the survey. We received responses from a range of parents across Northern Ireland. The majority were from County Antrim (45%), followed by County Down (27%), Derry/Londonderry (9%), Fermanagh (7%), Armagh (6%) and Tyrone (6%).

Table 1: Breakdown of respondents by county

County	Percentage
Antrim	45%
Down	27%
Derry/Londonderry	9%
Fermanagh	7%
Armagh	6%
Tyrone	6%
Other	1%

It is difficult to ascertain whether this sample is representative as a geographical breakdown of the number of families who have children with a disability or special need in each county does not exist in Northern Ireland. As noted in section 2.3, the most detailed account of the number of children with a disability dates back to 2007, and states that 6% of children living in private households in Northern Ireland have a disability (NISRA, 2007:6). The report does give a geographical breakdown of disability, although not in terms of county. For example, it groups Antrim, Ards, Ballymena, Banbridge, Craigavon, Down and Larne all together. Therefore, we are unable to match the geographical breakdown presented in the NISRA report with our results.

3.1.2 Marital status and family size

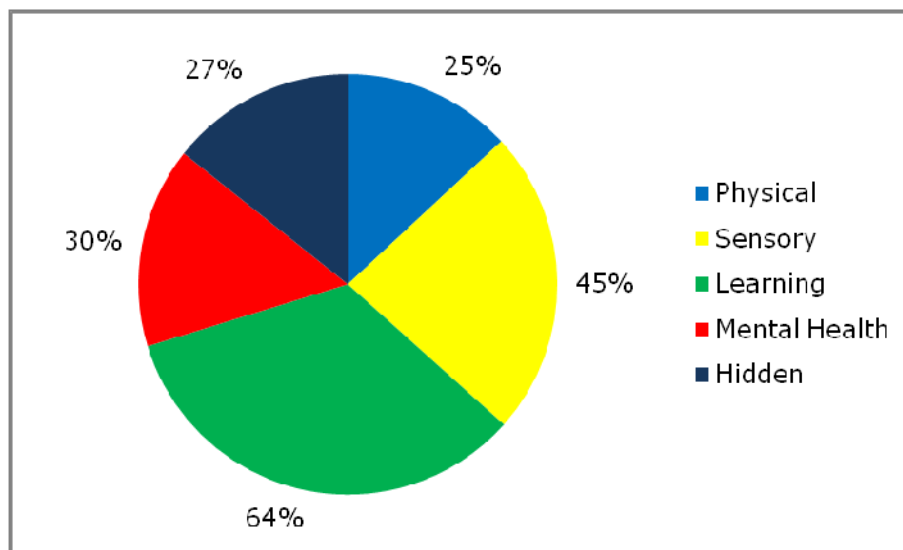
The majority of respondents were female (81%) and came from two parent families (72%). 28% of the respondents were lone parents. Research shows that lone parent families are more likely to report having a disabled child than two parent families (McKay and Atkinson, 2007:1).

The largest percentage of respondents have two children (35%), with one child having a disability and/or special need (81%). 16% of families have two children with a disability and 3% have three children with a disability. In addition, the majority of families in the survey have a child with a disability and/or special needs aged between 5-11 (61%).

3.1.3 Types of disability

We asked respondents to tell us what type or types of disability or special needs their children have. The majority of children had a learning disability (64%), followed by sensory (45%), mental health (30%), hidden (27%) and physical (25%).

Figure 1: Types of disability and/or special needs



Almost half of the respondents' children had one type of disability and/or special need (47%). Just over a third of the children had disabilities and/or special needs that fell within two categories (31%), 13% had three and 9% had four. None of the respondents' children had disabilities and/or special needs that fell within all five categories. A range of disabilities were cited in the survey. The most common disability was Autism. Others included Down's Syndrome, Epilepsy, Dyslexia, Hyperthermia, Attention Deficit Hyperactivity Disorder, Cerebral Palsy and Spina Bifida.

In the survey 72% of families had a child with a disability that was sufficiently severe that disability living allowance was received for the child.

3.1.4 Employment status of parents

The majority of respondents were in employment (70%), with 46% working full time and 24% working part time. 25% were not in employment, 3% were studying and 2% were involved in voluntary/unpaid work. The correlation between employment status and childcare choice is explored in the final section of the report.

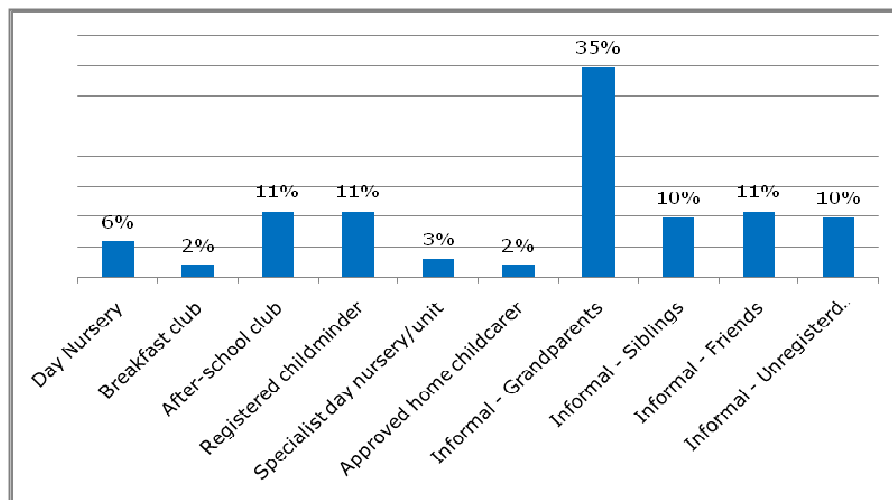
3.2 Use of childcare

In the survey we made a distinction between formal and informal childcare provision in order to obtain a picture of all childcare usage for families of children with disabilities and/or special needs in Northern Ireland. The survey results revealed that 61% of respondents use some form of childcare (formal or informal), while 39% do not use any form of childcare.

3.2.1 Main form of childcare used

When asked what their main form of childcare was, the majority of respondents said grandparents (35%). This was followed by registered childminders, after-school clubs and friends (each 11%). 10% of respondents use unregistered childminders as their main form of provision, which is almost equal to that of registered childminders (11%).

Figure 2: Main form of childcare used in the last 12 months



Only 6% of respondents use a mainstream day nursery and only 2% use a specialist day nursery/unit. These low figures could be explained by the fact that the majority of children are school age. However, use of wraparound care was also low, with 11% availing of after-school clubs and only 2% using breakfast clubs, so it would appear that grandparents are covering the majority of wraparound provision.

Although informal childcare, which encompasses grandparents, friends, siblings and unregistered childminders, was the most common choice of childcare provision (accounting for 66%), some respondents expressed concern over their reliance on grandparents to provide childcare to their disabled or special needs child:

"My son's childcare is great as it is my mother who looks after him when needed, but she is not in any way trained or qualified to do it and undoubtedly he suffers from development needs."

(Full time employed mother of child with Autism, aged 5-11 years)

"My parents provide the childcare and I could not work without them. They love my son but I worry as they get older as my son is very active. He is also very vulnerable so I feel that family best understands his needs."

(Full time employed mother of child with Autism, aged 5-11 years)

"I do not like having to use my parents for childcare and am currently considering giving up my full time job to care for my son as he needs more help than what my 63 year old parents can give but I can't find any other option."

(Full time employed mother of child with Autism and Dyspraxia, aged 5-11 years)

One of the participants in the focus group also expressed concern about her reliance on her parents:

"My mum is 70 and my dad is 80. God forgive if something happened to my dad. I would have to either reduce my hours heavily in work or give up work altogether."

(Full time employed mother of child with gross developmental delay, aged 4 years)

Each of these quotations come from mothers from two parent households where both work full time and highlight the lack of choice and the restrictions parents face in accessing formal provision.

3.2.2 Additional childcare usage

In formulating our survey, we recognised that parents tend to use a variety of childcare settings throughout the course of the year to supplement their main childcare type. The majority of respondents did indeed use a variety of both formal and informal childcare settings in addition to their main childcare type. These are discussed in more detail in the following two subsections.

Formal childcare used

We asked respondents to tell us which types of formal childcare they have used in the last 12 months. Figure 3 shows the range of formal provision available of by families.

Figure 3: Types of formal childcare used within the last 12 months

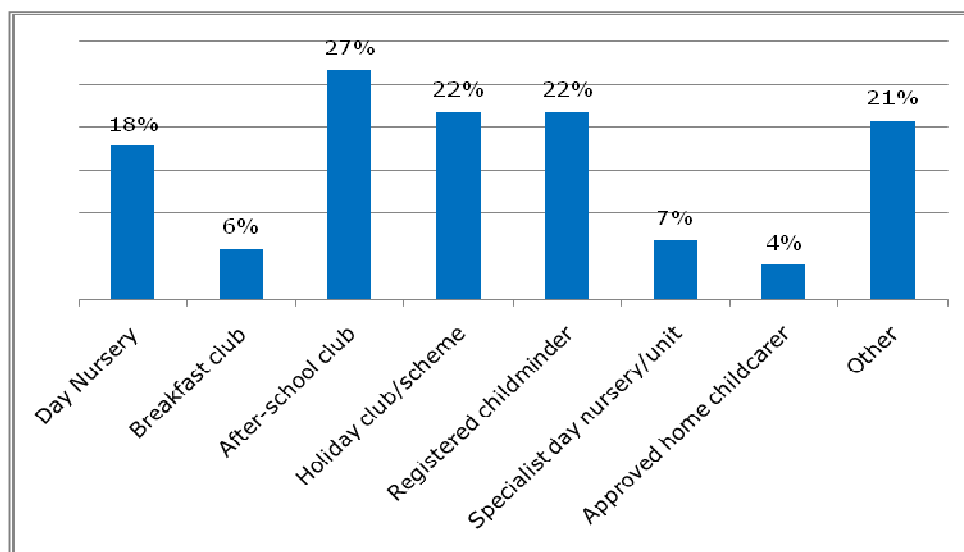


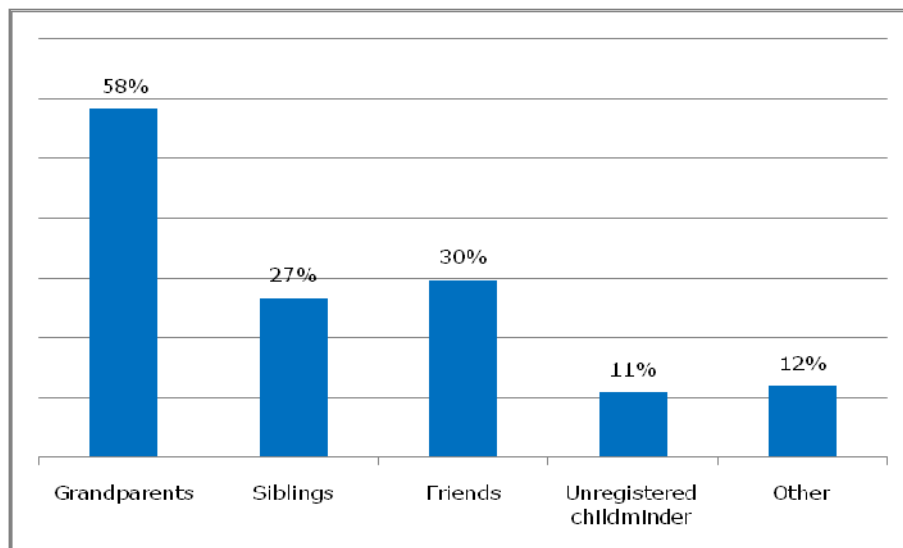
Figure 3 indicates that the use of formal childcare varies significantly among parents of children with disabilities and/or special needs. The most common type of formal childcare accessed by parents is an after-

school club (27%). Indeed wraparound provision (after-school clubs and breakfast clubs) accounts for 33% of formal childcare usage. Given that the majority of the children are school age (age 5-11), wraparound provision is therefore the most appropriate choice of formal provision. This is followed by holiday clubs/schemes and registered childminders (each 22%) and day nurseries (18%). Only 7% of respondents are using a specialist day nursery/unit, the majority of which are in County Antrim. This raises concerns about the lack of specialist childcare available to families and is considered in more detail in subsection 3.2.8 when we come to explore the reasons why families do not avail of childcare. Interestingly, 21% answered 'other' to this question, largely because the type of care they are using is respite care rather than childcare.

Informal childcare used

As subsection 3.2.1 revealed, family members play a key role in the provision of childcare for children with disabilities and/or special needs. The results for informal childcare are illustrated in the figure below.

Figure 4: Types of informal childcare used within the last 12 months



Family members account for 85% of informal childcare availed of, with grandparents being the most common choice within this category (58%). 11% of respondents are accessing unregistered childminders. Those who

selected 'other' used extended family members such as aunts and cousins, and respite care. Gray and Bruegel (2003:23) argue that 'the choice of formal, rather than informal, care depends partly on the ability to pay for it'. This issue will be explored in the section on childcare costs.

3.2.3 Childcare challenges throughout the year

Research has shown that parents of children with disabilities and/or special needs find school holiday periods particularly challenging and that parents feel they would benefit significantly if they could be offered term-time working (Stiell *et al*, 2006). Respondents in our survey were asked whether there is a particular time of the year when they find accessing childcare more challenging. In line with Steill *et al*'s findings, 94% of respondents said school holiday periods were the most challenging, in particular during the summer, and 6% said during term-time:

"Summer is more difficult as the kids are off school and the grandparents have three kids all day including two with disabilities, which is very demanding. We try to arrange our holidays so that they do not have all three kids for many days during the summer."

"All holiday periods [are a challenge]. I need to be able to work, but can only rely on certain people with whom my son is comfortable. I also need to prepare my son for changes to his routine over a period of a couple of days."

"Summer holidays when children are off school have been a particular problem. Indeed, I have had to give up my part time job this year because I could not get any childcare for my son during that time. I have previously contacted registered childminders but always get the same answer - they do not want to take on a child who needs one to one care."

"School holidays, especially summer, [are a challenge]. I don't know how I am going to keep working by then as my mother really struggles to look after my child."

"Summer time, in particular, [is a challenge] but any of the school holiday times are horrendous. The lack of structure and requirement for activity is exhausting. My boys need to be constantly supervised."

The increased cost of childcare over the summer holiday period was also a concern for parents:

"It costs more during the summer holidays as they are there all day."

"My daughter goes to a private day nursery and it is very expensive during the summer months as I work full time."

Therefore, already existing difficulties are exacerbated during school holiday periods.

The lack of synchrony among schools in terms of closure dates during school holiday periods also caused problems for families:

"[My] three boys attend three different schools and the holidays are not synchronised, so, for example, Halloween holidays... might span two weeks for the two schools. This rapidly eats into our leave allowance and I am reliant on my parents, who are both 70, to help me out. If I didn't have them I would probably have to resign. So many parents of children with Autism have had to give up their jobs for the reason that life is so difficult."

(Employed mother of two children with Autism)

This reinforces the important role that family members play in meeting the childcare needs of families of disabled and/or special needs children.

3.2.4 Awareness of Approved Home Childcare

The Approved Home Childcare Scheme was introduced by Government in 2006, enabling parents to employ a childcare provider to look after their child or children in their own home. Approved home childcarers are approved by the Health and Social Care Trusts, enabling families to claim financial assistance through Tax Credits or childcare vouchers when availing of this provision. This form of provision has the potential to be an attractive option for families of children with disabilities and/or special needs, as the demands of the child(ren) can be more easily met within the confines of their own home. Indeed, one of the recommendations put forward by the Daycare Trust following consultation with parents of disabled children was 'ensuring the provision of more emergency/ad hoc provision for disabled children, preferably in their own home' (Daycare Trust, 2007:03). Only 2% of respondents use approved home childcarers as their main form of provision (see figure 2) and only 4% have used this form of provision in some capacity in the last 12 months (see figure 3). Yet a number of respondents drew attention to the importance of their child being looked after in their own home so that interruption to the child's daily routine can be avoided. For example:

"My children would find it difficult adapting to childcare outside of the home. Their safe haven is home."

We wanted to ascertain respondents' level of awareness of this type of provision. 54% said they were unaware of it, 25% had never considered it and 21% said they had considered this form of provision. Only 4% of respondents actually use approved home childcarers in some capacity (see figure 3) and the qualitative data we received indicated a desire to embrace this option if the approved home childcarer was suitably trained:

"I would like to have a more formal childcare arrangement in my own home, but am aware that poor understanding of my child's condition by potential childminders will make this difficult."

A number of respondents expressed the need for provision to be provided on a one to one basis in order to accommodate the developmental needs and demands of their child.

This lack of awareness of approved home childcarers was also apparent in the focus group. Having explained what this form of provision was, we asked participants whether they felt this option would be a solution to their childcare needs:

“I think potentially it would be good but you would have problems with the training of staff because I know the community children’s nurses will refuse to fund it and I know a social worker will refuse to fund it. Then we [the families] will end up paying for the training and a girl might only last three weeks and then give up because she cannot cope.”

“There are very few people in the childcare sector who would be prepared to take on my child and her needs. I know three girls who trained to work with my daughter that are now going down the nursing route. That’s the kind of level of medical attention my daughter needs. It would be fantastic. You see if somebody would come in, a childminder, come into my home and look after my child, that would be amazing but it just wouldn’t happen and it would cost a fortune. That would be first choice rather than having to send her somewhere else. So yes, that would be perfect if you could cross out all the obstacles. I can’t see it ever happening but it would be great.”

Both these respondents have children with complex medical needs related to their disability. Although both admitted that this form of provision would in theory be ideal, they both feel they would never be in a position to be able to use it. Training was perceived by the focus group participants to be a significant barrier to accessing this, and indeed any, form of childcare provision, given the complex medical needs associated with their child’s disability. Employers For Childcare Charitable Group is

currently conducting a separate study into approved home childcare, which will be published later in 2011.

3.2.5 Childcare use by county

In order to determine the types of childcare accessed across the region, we examined the main childcare types utilised in terms of county. The results revealed that there is a greater variety of childcare used in Counties Antrim and Down and the least variety in Counties Tyrone and Armagh. This corresponds with the fact that there is a greater range of childcare in the east of the region than there is in the west (Rural Childcare Stakeholder Group, 2008: 33). It was difficult to explore the distribution of childcare use in Counties Armagh and Tyrone, given that the response rate was substantially lower in these counties. Therefore, it is important to note that the figures obtained for these counties may not be reflective.

It is well documented that formal childcare is sparse in rural areas which leads to a greater reliance on unregistered childcare provision (Joseph Rowntree Foundation, 2001; Gray and Bruegel, 2003). The results revealed that informal childcare is more prominent in County Tyrone (80%), with the most common childcare choice being unregistered childminders (40%). This could indicate that parents are forced to make this choice due to a shortage of registered childminders in the county.

After-school clubs are the most common childcare choice for parents in County Armagh (30%). This could be explained by the fact that the majority of the children in the participating families were school age.

The main form of childcare provision in County Down is grandparents, accounting for 37% of respondents. When the types of informal childcare are considered collectively (grandparents, siblings and friends), informal provision accounts for 59% of childcare usage in the county.

The Northern Health and Social Care Trust, which covers most of County Antrim, has the largest number of registered childminders in Northern

Ireland (DHSSPS, 2009:41). Yet, 68% of parents in the county use informal provision (42% of which is grandparents) and only 10% use registered childminders. This calls into question whether this choice is motivated by a lack of appropriate provision for disabled or special needs children in the county, prompting parents to rely on family members to provide childcare.

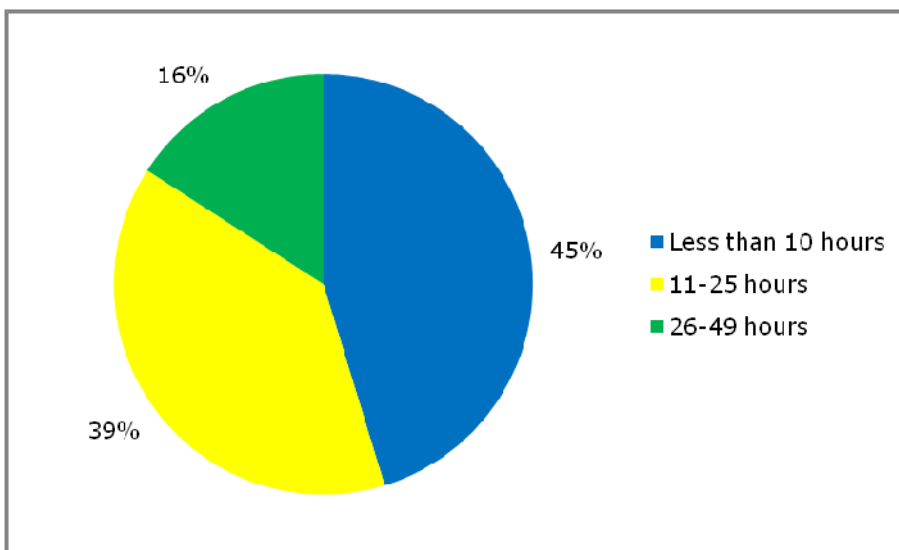
Use of childcare provision in County Fermanagh is more evenly spread. Formal childcare (after-school clubs, registered childminders and specialist day nurseries/units) was used by 56% of parents and the remaining 44% availed of informal provision (grandparents, siblings and friends).

In County Derry/Londonderry, 71% of respondents use a form of informal childcare while only 29% use registered childcare, in this case after-school clubs.

3.2.6 Hours childcare is used

The majority of respondents use childcare for less than 10 hours per week (46%), yet 46% of the respondents work full time. As highlighted earlier, the majority of the children in the survey are of school age which could explain why most parents use childcare for less than 10 hours per week. 39% availed of childcare for 11-25 hours per week. Interestingly, none of the respondents use childcare for 50+ hours per week. These results contrast with the Northern Ireland Childcare Cost Survey 2010, where just over 60% of respondents used over 25 hours of childcare per week compared to only 16% in the disabilities and special needs survey (Employers For Childcare Charitable Group, 2010:13).

Figure 5: Hours of childcare used in an average week



3.2.7 Childcare use according to household type

64% of two parent households use childcare, while 36% do not. For lone parent households 55% are using childcare and 45% are not availing of any form of provision. The main childcare choice for the majority of two parent households was informal provision (63%), with grandparents being the main choice of childcare overall (36%). Informal provision was also the most common choice for lone parent households (81%), with the use of family members being more evenly spread – grandparents (27%), siblings (24%), friends (19%) and unregistered childminders (9%).

3.2.8 Reasons for not using childcare

Given that 39% of the respondents reported that they do not use any form of childcare, we wanted to explore their reasons further.

Respondents were asked to specify their reasons from a range of statements, which are cited in the following table in order of preference:

Table 2: Reasons for not using childcare

I'd rather look after my child(ren) myself	44%
I can't find childcare to meet my child(ren)'s needs	36%
I prefer to use family/friends because I know them	30%
I don't require childcare	30%
Childcare is too expensive	28%
I prefer to use family/friends because this comes at either no financial cost or a lower financial cost	25%
There are no childcare providers I feel I can trust	22%
Childcare is not available when I need it	19%
Childcare providers will not accept my child because of their disability or special needs	16%
Lack of transport	13%
I can't find a childcare place in a convenient location	11%
Childcare does not reflect my culture	6%

The majority of respondents indicated a preference for looking after their child(ren) themselves (44%). This desire was interlinked with their concern or perception that there are no childcare settings that would meet their child's needs (36%):

"My child requires strict routines because of his condition and does not adapt well to change, becoming very distressed, and because of his level of need, I can't find childcare to meet my needs."

(Father of child with Autism and severe learning difficulties, aged 3-4 years)

"My children would find it difficult adapting to childcare outside of the home. Their safe haven is home. I have had to give up work to be able to do this."

(Mother of a child with Asperger Syndrome and another recovering from aggressive cancer, both aged 5-11 years)

“Our daughter has got so used to me looking after her at home 90% of the time. I wanted it this way as I wanted our daughter to grow up feeling secure and loved. I only ever leave her with my two sisters and that way I can relax knowing she is in good hands.”

(Mother of child with Autism, aged 5-11)

“Because of my children’s difficulties/disability, most childcare providers will not accommodate my children as they are not qualified nor trained to work with children with these problems and so will not accept them.”

(Mother of two children with Autism and learning difficulties, aged 3-4 years and 5-11 years)

One particular couple who have three children with Autism aged between 5-11 have both opted to work part time in order to share the care of their three children and eliminate the need to use a childcare provider:

“We have adjusted our working hours to ensure one parent is always available for our children.”

16% of respondents stated that childcare providers will not accept their child because of their disability:

“Because of my children’s difficulties/disability, most childcare providers will not accommodate my children as they are not qualified nor trained to work with children with these problems and so will not accept them.”

(Mother of two children with Autism and learning difficulties, aged 3-4 years and 5-11 years)

A number of respondents experienced reluctance from childminders in particular to take on the care of their child:

“I can't find childcare to meet my child’s needs. My daughter needs a wheelchair and needs a lot of attention. Because of this

childminders I have asked can't take her because they don't have the time to look after her as well as the other children they are minding."
(Single unemployed mother of child with Congenital Muscular Dystrophy, aged 3-4 years)

"We have found it extremely difficult to find appropriate childcare for our son. The majority of childminders we contact from the NICMA list are not interested or feel he is too much to take on and unfortunately if the new childminder we have found cannot look after him I will have to reconsider my working arrangements which will have a big impact on our family."

(Employed mother of child with Down's Syndrome, aged 3-4years)

Some respondents also reported that childcare providers had turned their child away because they were unable to cope with their disability:

"We cannot access formal childcare for my children because of their disabilities. The last day nursery they attended they were asked to leave after three days because staff could not manage. We as their parents have to care for our children and had to reduce our working hours to care for them given we had no other alternative."

(Part time employed mother of child with Autism, aged 5-11)

Employment and childcare use is explored in more detail in section 3.7.

This lack of acceptance appeared to be correlated with the perception that childcare providers are not suitably trained to look after children with disabilities and/or special needs.

Concerns around training as well as the reluctance from childcare providers to mind children with complex medical needs, were also expressed in the focus group. One participant, a mother of four children, one of which has Cerebral Palsy and complex medical needs, said:

“My daughter needs oxygen all the time. If you mention oxygen to a childcare provider you know...they obviously have to have training. We can't train them ourselves. We have to ask the Children's Support Nurses. They have to train them and sign them off. Who's going to pay for that? The Community Children's Nurses won't.”

The focus group also brought to light the sympathy that parents often have towards childcare providers, given that there is little or no investment in training childcare providers to deal with the needs of such children:

“They couldn't do it and I wouldn't expect them to. It's too much.”

This respondent also said she would feel 'guilty' if her child was looked after by a childcare provider because she is so demanding that the other children would lose out. The Daycare Trust also found this to be the case when they surveyed parents in the greater London area (Daycare Trust, 2007: 13).

The focus group revealed that for many parents of disabled and/or special needs children, it is matter of *having* to look after their child(ren) themselves because realistically there is no other option:

“We're struggling to get a care package [for our daughter] which we need 7 days a week. That's a necessity for us as a family...to check my daughter's temperature every ten minutes to make sure that she's sleeping. That's a necessity but we're not even getting that.”

Therefore, given that some families are struggling to get the necessary care package in place to meet the needs of their child, being in a position to consider childcare is deemed to be a luxury.

30% of respondents stated that they prefer to use family or friends because they know them. This reason was interlinked with the issue of

trust, where 22% reported that they did not feel they could trust childcare providers to look after their child:

“My child needs 24/7 care and not everyone can see or meet his needs, never mind understand his disability. I would have no trust leaving him with [childcare providers] who these days have a very limited understanding of disabilities as a whole, never mind Autism.”
(Unemployed single mother of one child with Autism, aged between 5-11 years).

“I can only rely on certain people with whom my son is comfortable.”
(Single mother, studying, of one child with Asperger Syndrome, aged 12-14 years)

A large percentage of parents not using childcare therefore perceive that formal provision would not meet their child's needs.

For many of the respondents that do not use childcare, cost was certainly a factor that influenced this choice. 28% of respondents said childcare was too expensive and 25% said they preferred to use family or friends because this comes at either no financial cost or a lower financial cost:

“Childcare is too expensive. I cannot afford to pay the cost of childcare as the majority of my wages are used on every day living expenses.”
(Full time employed mother of a Down's Syndrome child aged 5-11)

It is interesting to note that 'lack of transport' and 'I can't find childcare in a convenient location' were the least common reasons for not using childcare (12% and 11% respectively). 50% of those that do not use childcare are from County Antrim, the most urban county in the region, which could go some way to explaining why location and transport were the least common reasons for not using childcare. Other researchers have

identified transport as a major barrier to accessing childcare in rural areas (Rural Childcare Stakeholder Group, 2008).

The needs of the child are clearly of significant concern to parents. Indeed, it is notable that 72% of those that do use childcare have a child with a disability that is sufficiently severe that the family receive Disability Living Allowance for the child. Access to and knowledge of benefits is explored more fully in section 3.5.

3.3 Views on quality of childcare provision

Quality childcare is fundamental to all families. For those families that use childcare, we wanted to explore their views on the quality of provision on offer. Overall, feedback on quality was very encouraging. For example:

- 92% of respondents either agreed or strongly agreed with the statement 'The childcare provision I use is safe and secure'.
- 71% either agreed or strongly agreed that 'The provision was of a high quality'.
- 60% either agreed or strongly agreed with the statement 'Staff are well qualified in terms of appropriate skills and experience'.

Given that the majority of respondents are using informal provision, these statistics relate predominantly to informal childcare. Although the areas of safety, quality and the training of staff were rated highly, the qualitative data revealed that parents have had to compromise on other aspects of their child's care. This means that where one area of the provision is strong, another area may be weak. For example, the following respondent acknowledges that although her child is safe and well looked after, her childcare provider, an approved home childcarer, is not suitably trained to look after her child:

"Acquiring specially trained childcare is difficult and expensive! I compromise certain aspects of childcare that I would like (sensory

activities etc) for the knowledge that my child is safe and well looked after.”

(Employed mother of one child with Autism, aged 5-11)

In this case the safety and security of the child takes precedence over developmental needs as it is perceived to be too costly to use a specially trained childcare provider.

While 60% either agreed or strongly agreed that their childcare provider was well qualified in terms of skills and experience, it is interesting to note that in contrast those who do not use childcare cited lack of suitably trained staff as a reason (see subsection 3.2.8).

The statements that respondents were most negative about were specific to the needs of their child’s disability. For example:

- 30% either disagreed or strongly disagreed with the statement ‘There is a range of activities for my child’.
- 16% either disagreed or strongly disagreed with the statement ‘Provision meets my child’s needs’.
- 14% either disagreed or strongly disagreed with the statement ‘Staff are well qualified in terms of skills and experience’.

23% also either disagreed or strongly disagreed that provision is flexible. One respondent remarked on the need for more flexible childcare in terms of costs and notice periods:

“Whilst [my childcare provider is] flexible, a five week notice period is required. With the volume of medical appointments that my child is required to attend, I end up paying for a lot of childcare that I don’t actually need.”

However, it is important to note that more respondents were positive than negative about each of these statements.

Some respondents drew attention to the fact that their choice of formal childcare meets their needs in terms of work demands rather than their child's needs:

"Whilst the childcare provision I have meets my needs in terms of reliability and flexibility - I can get out the door in the morning and get to work - it is difficult for my childminder to meet all of my child's needs as they are quite diverse. [My son] needs assistance with all aspects of his personal care [and] he has to be supervised very closely [for his own safety]."

(Employed single mother of one child with Global Development Delay and Epilepsy, aged 5-11)

"My main childcare provision is utilised as it is convenient rather than specific for the needs [of my child]."

(Unemployed mother of three children with Autism, each aged 3-4, 5-11 and 12-14)

Both these respondents use registered childminders.

Clearly, the childcare needs of disabled or special needs children and their families are highly complex and significantly challenging. Parents' accounts of their experiences of accessing childcare reveal a mixture of both positives and negatives. Indeed, although feedback on the quality of provision was encouraging, 42% of respondents either agreed or strongly agreed that there are aspects of their childcare that they would like to change.

Thus, while parents feel that their childcare provision is safe, secure and of a good quality, some parents recognise that the specific needs of their children are not being sufficiently met. Due to a lack of access to appropriate childcare provision, parents are forced to make compromises in relation to their childcare choice. Safety and the practical needs of the parent therefore can take precedence. Parents acknowledge that this is neither ideal nor appropriate and many therefore either adapt their

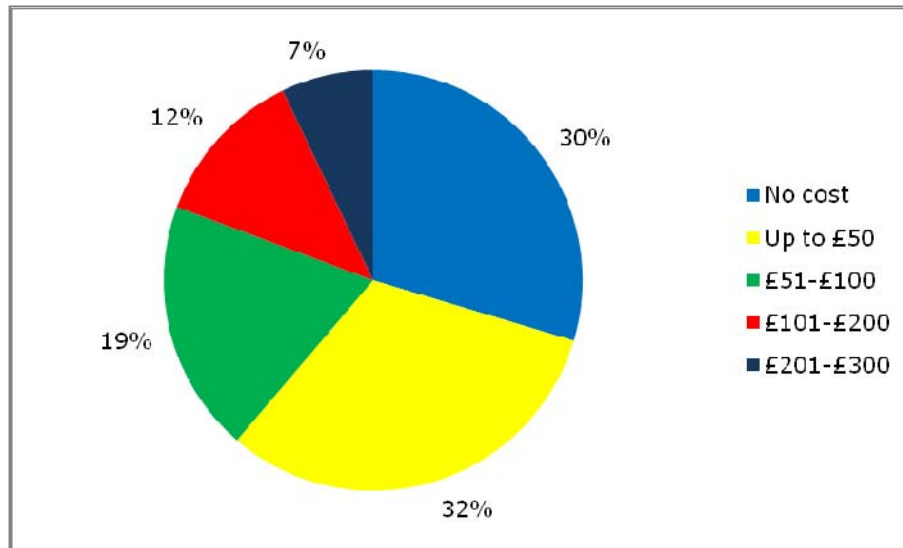
employment patterns around their childcare needs, leave employment altogether or turn to grandparents and other family members.

Employment status and childcare choice will be explored later in section 3.7.

3.4 Cost of childcare

Access to affordable childcare is a concern for many families and indeed as subsection 3.2.8 demonstrated, one of the reasons that some families do not use childcare is because they perceive it to be too expensive. For those that do use childcare, the results revealed that the majority of respondents pay up to £50 per week towards childcare (32%). This was closely followed by 30% stating that they had no childcare costs, perhaps because the most common form of childcare used was grandparents. 19% reported that they paid between £51 and £100 per week, 12% between £101 and £200 and only 7% between £201 and £300 per week.

Figure 6: Cost of childcare in an average week



The costs reported were substantially lower than those reported in the Northern Ireland childcare costs survey (Employers For Childcare Charitable Group, 2010). This is most likely due to the fact that the majority of respondents use childcare for less than 10 hours per week (46%) and because grandparents are the main childcare choice for

parents. Another intervening factor is the adjustment of work patterns to accommodate their childcare needs. This factor is fully explored in section 3.7 on employment.

3.4.1 No childcare costs

Given that a substantial number of respondents incurred no costs for their childcare (30%), we decided to explore this issue further. 94% of respondents in this category are using informal provision as their main form of childcare, with grandparents accounting for 67% of this total. It is also interesting to note that of those that incurred no childcare costs, 74% were actually in employment. Thus, the use of informal provision explains why a high proportion of families are encountering no costs. It is interesting to note that 24% of those that encountered no costs are receiving Direct Payments, which could go some way to explaining why the remaining 6% using formal provision experienced no costs.

The low costs reported in the survey can be explained by two intervening factors, the main choice of childcare and the hours of childcare used. The majority of families are using informal provision, in particular grandparents, and are therefore incurring little or no cost, and the hours of childcare are low given that the majority of children are school age.

3.5 Knowledge of benefits and help received

Tax credits and benefits play an important role in helping families manage their household budgets. We asked respondents to tell us about their knowledge of benefits and the level of support they receive. The following table illustrates the level of awareness amongst respondents on potential assistance that is available to them as well as the number of respondents that are actually in receipt of these subsidies:

Table 3: Awareness and uptake of benefits

	Receive	Know about	Don't know about
Childcare element of Working Tax Credit	24%	52%	24%
Childcare vouchers	10%	42%	48%
Child Benefit	87%	10%	3%
Child Tax Credit	50%	40%	10%
Working Tax Credit	27%	57%	16%
Disability element of Child Tax Credit	36%	21%	43%
Severe Disability element of Child Tax Credit	20%	27%	53%
Disability Living Allowance (for your child)	72%	16%	12%
Direct Payments	19%	25%	56%

Disability Living Allowance (DLA) and Child Benefit are the most well known and widely received financial allowances among respondents. 72% of respondents receive DLA for their child(ren) and 87% receive Child Benefit.

The disability element of Child Tax Credit was only received by 20% of respondents and 43% were unaware of it.

56% of respondents said they were not aware of Direct Payments as a form of financial assistance and only 19% actually receive this form of help. Those parents who participated in the focus group expressed enormous frustration over Direct Payments:

“I have talked about Direct Payments until I am blue in the face and it is like talking to a brick wall. I have asked my social worker who tells me my daughter is too sick for Direct Payments...I would love to get Direct Payments because I would be able to pick whatever care I want.”

Another participant also reported that insurance is a problem if Direct Payments are to be used to pay for provision in the family home:

“I was told Direct Payments weren’t an option for us for insurance reasons. Who is going to pay for the insurance and who is going to train them? It’s all about money. A childminder [approved home carer] isn’t going to want to take on the cost of the insurance.”

Thus cost and training are clear obstacles for families who require financial assistance towards care provided in their own home. These obstacles may go some way to explaining why only 19% of the participating families in the survey actually receive Direct Payments.

53% of respondents said they were unaware of the Severe Disability element of Child Tax Credit. Families who are receiving the highest rate component of Disability Living Allowance would qualify for this assistance (Daycare Trust, 2010:4).

The childcare element of Working Tax Credit and childcare vouchers are the two forms of financial assistance that exist for working parents to help with the cost of childcare. Given that 70% of the respondents are in employment, the number of respondents in receipt of either the childcare element of Working Tax Credit or childcare vouchers is quite low (24% and 10% respectively). However, the majority of families are using informal rather formal provision (66%), meaning that eligibility for financial assistance will be low. Awareness of childcare vouchers is also extremely low, with 48% stating that they were unaware of this form of financial assistance.

Respondents were given the opportunity to tell us about other help and support they receive not listed in the questionnaire. A number of respondents mentioned that services such as the Home Start initiative and Positive Futures are a vital support:

“I receive some ‘services’ rather than monetary support from Positive Futures Family Support Service for one of my sons. This will equate to activities approximately once a week, however this has been reduced recently again because of reduced funding to the service,

which happened again before CSR [Comprehensive Spending Review].”

Concern over the recent Comprehensive Spending Review, in particular cuts in benefits, was also echoed in other responses:

“One of my boys attends a two week summer scheme run by his special school. This was cut to one week last year and was only reinstated after elected representatives intervened. This was before the Comprehensive Spending Review and I fear that we will be first in line for cuts as we were last year.”

“Cuts in benefits are of concern to us as these enable us to work reduced hours to care for our children ourselves.”

The CSR announced by Government in October 2010 laid out a series of changes to welfare benefits for the next four years. These changes are already impacting on families and the current economic climate is clearly exacerbating already existing struggles for families of children with disabilities and/or special needs. This makes it all the more important that families are aware of the benefits that exist and that they are availing of the financial assistance they are entitled to. Table 3 indicates that awareness and uptake of certain benefits is poor.

3.6 Information on childcare

Until March 2011, a national helpline and website was in operation in England, Scotland and Wales to enable families to easily access their local information service and thereby ascertain the childcare provision available in their area. Despite the existence of Family Information Services in England, Scotland and Wales, research shows that accessing information about childcare for disabled children is extremely difficult and often obtained ‘word of mouth’ (Daycare Trust, 2007:23).

A Government funded Family Information Service was never introduced in Northern Ireland, making it difficult for parents to access information on childcare provision, financial help available and possible benefit entitlements. However, Employers For Childcare Charitable Group recognised the need for such a service and has offered a Childcare Information Service and helpline since the charity was founded in 2002. In addition, the Health and Social Care Board for Northern Ireland has recently developed the Northern Ireland Family Support website which gives details of a wide range of organisations that provide help and support to families.

We asked parents to rate how easy or difficult they find accessing information services in Northern Ireland. In terms of how easy it is to find information on help with paying for childcare, the majority of respondents said they found it difficult or extremely difficult (86%), while 14% said they found it easy or very easy. Given that few respondents are availing of the financial assistance available (childcare vouchers, the childcare element of Working Tax Credit and Direct Payments) as indicated in table 3, these statistics would correspond with this finding.

63% said they found it difficult or extremely difficult to access information on childcare in their area, while 37% said they found it easy or extremely easy. One respondent commented:

“Childminders should receive some training in special needs or there should be a register of those that would consider caring for a child with special needs instead of parents having to ring round and try to ‘sell’ their child on its good points, as I felt I had to do.”

A number of respondents commented on the difficulty in accessing information on childcare provision for older children:

“The key issue I find regarding childcare is availability once a child reaches twelve - at this stage many other children could probably be at home on their own after school. My son can't and at this stage

there seems to be very little available. I am going to have to advertise for someone to work from my house next year and am unsure how to do this, what to pay and how to make sure they are suitable.”

The Approved Home Childcarer Scheme could therefore be ideal in such circumstances, yet as subsection 3.2.4 revealed 54% are unaware that this provision exists and only 4% have actually used approved home childcarers in some capacity in the last twelve months.

3.7 Employment and childcare

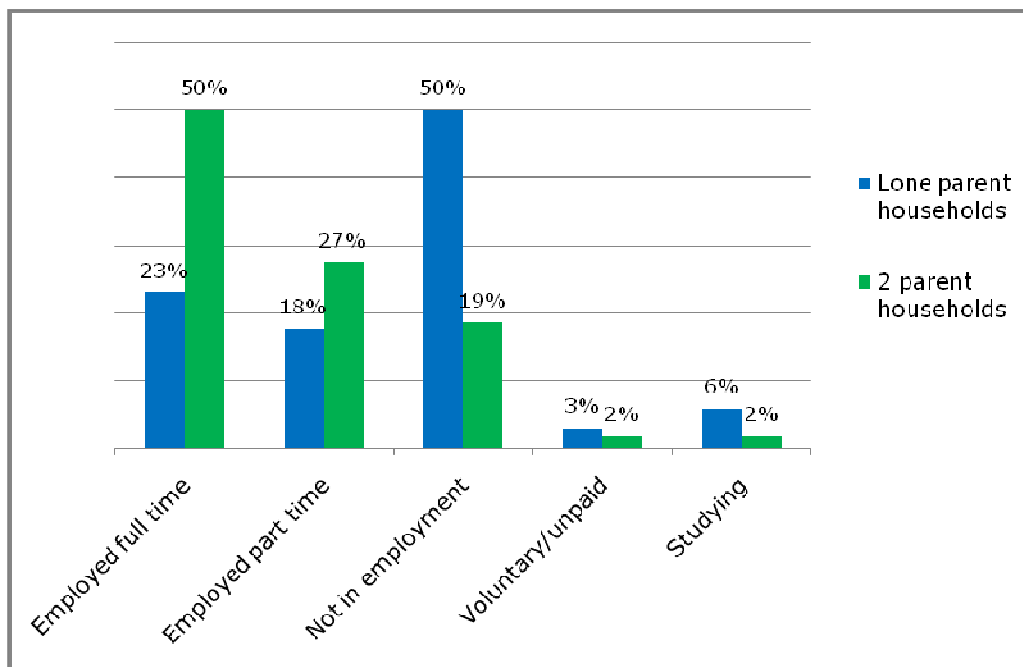
Access to affordable, appropriate and quality childcare enables families to access and stay in work. We therefore wanted to explore respondents’ employment patterns to ascertain whether childcare provision, or the lack of, had a bearing on their choice of employment patterns. Parenthood, in particular motherhood, has an impact on employment choices. In this section we explore employment status in relation to household type, parents’ reasons for not being in employment, the influence of a child’s disability on employment patterns, and the influence of employment status on childcare use.

The majority of respondents were in employment (70%), with 46% working full time and 24% working part time. 25% were not in employment, 3% were studying and 2% were involved in voluntary/unpaid work.

3.7.1 Employment status and household type

Employment status differed according to household type. Within two parent households, only 27% were in a situation where both parents work full time. Figure 7 details the employment status of all respondents according to household type.

Figure 7: Employment status according to household type



Of the respondents from two parent households (72%), 50% reported that they were employed full time compared to only 23% of lone parent households. This contrasts with the childcare cost survey 2010, where 79% of respondents from two parent households and 76% of lone parent households were employed full time (Employers For Childcare Charitable Group, 2010:25). 50% of lone parent households were not in employment, compared to only 18% of two parent households. Therefore there are significant differences in employment status in each family type.

3.7.2 Reasons for not being in employment

“It’s a nightmare for me trying to manage all my children. It’s just really hard. It’s not practical for me to work.”

(Mother of four children, one of which has Cerebral Palsy and complex medical needs)

Respondents not in employment (25%) were asked whether this was due to caring responsibilities relating to their child(ren) with disabilities and/or special needs. 70% said ‘yes’ to this question:

"My son's Autism makes it impossible to hold a regular job."

"I am not in employment currently and recently left full time education due to the constraints of childcare."

Furthermore, substantially more lone parent families than two parent families were not in work due to caring responsibilities (88% and 12% respectively). However, irrespective of family type, it is clear that a lack of adequate childcare is a significant barrier to employment and training for such families.

The extent of the child's disability and medical needs was also a significant barrier for the parents who participated in the focus group. Two of the three participating parents strongly communicated that they do want to work but that they simply cannot work. The following participant has three children with a disability, one of which has complex medical needs associated with her disability:

"Whilst I would like to go back to work, it's the unpredictability of the kids. I don't know any employer where I could go to work and then say 'I'm sorry, I have to go now'. I would need a very accommodating employer....When the Government's pushing you to come back to work they just need to come and live in your shoes so that they can understand why you can't."

This particular parent is so restricted that she would have to work within close proximity to the school because her child's medical needs and disability are so severe:

"We can't be more than 10 minutes away from school. Therefore I would have a 10 minute restriction as to where I could work."

This scenario supports that of Bryson *et al's* findings:

“Lack of affordability is not the only barrier to parental participation in the labour market...Parents often need significant flexibility in their working lives in order to take their child between key (and sometimes distant) locations, or to respond to emergencies at little notice.”

(Bryson *et al*, 2005:5)

Another participant in the focus group whose child has Cerebral Palsy and complex medical needs highlighted that employment is simply not an option for her to consider:

“Going to work would be a luxury for us. It’s just not possible.”

The Family Support Worker currently working on a voluntary basis who participated in the focus group is a major source of information for the families attending the family support group:

“I am aware of the difficulties families face in trying to get through the red tape and legislation. I know people who want to get back to work but there is no specialised childcare. The daycare nurseries aren’t going to take a child that’s tube fed or that needs oxygen and there’s a huge shortage of trying to get somebody that’s willing to take on this kind of care.”

Thus a lack of investment in training childcare providers to look after children with disabilities and complex medical needs and a lack of willingness from childcare providers given this lack of investment are clear barriers to employment for such families.

Some respondents expressed a desire to work but felt their employability was restricted given the level of flexibility an employer would need to demonstrate:

“I would like to have the option of employment but when my son is ill it takes two people to cope with him and the other children. There is no way an employer could afford to employ us when we might be off for weeks at a time.”

3.7.3 Taking time off work to care for their child

Research shows that parents of children with disabilities and/or special needs often need to take time off for hospital or clinical appointments associated with their child’s disability (Daycare Trust, 2007; Scope *et al*, 2007). Respondents in employment were therefore asked whether they have had to take time off in the last 12 months for this purpose. 96% of respondents said ‘yes’ to this question. A number of the respondents expressed concern over their job security due to the frequency in which they have had to take time off work either to care for their child or to take them to hospital appointments:

“We are coping only just. We have lost yet another care worker and we are stranded. I am going to lose my job if I have to take any more leave or time off and my husband is constantly exhausted and worn out. We need to find suitable and reliable and affordable childcare very soon or we will both go under.”

(Employed mother of child with Cerebral Palsy, aged 5-11)

Some parents reflected on the difficulties they face in finding a sympathetic employer:

“Increasingly, there is less scope to have a work-life balance as my employer states business needs take priority.”

Indeed, research by Scope *et al* (2007:6) found that annual leave entitlement was frequently used for this purpose, putting further strain on family circumstances. This was also apparent in our survey results:

“I use my annual leave to look after my daughter when she is ill or attending hospital appointments. My employer does provide carers

leave but it is unpaid and because I am on such a low income I cannot afford to avail of this. Also I am a single parent and cannot afford to work part time. Flexible working hours are not suitable as I have to put my daughter on to the school bus and collect her."

(Full time employed single mother of child with Rett Syndrome, aged 5-11 years)

"I have had so much time off. My holiday entitlement begins in April and I had used it all by June. My employer is so inflexible. I am told to take unpaid leave or reduce my hours, neither of which I can afford to do."

(Full time employed single mother of a child with Asperger Syndrome, aged 12-14 years)

The qualitative data reveals that the logistics of managing childcare and work is clearly extremely complicated and challenging for families of disabled or special needs children.

3.7.4 Employment patterns

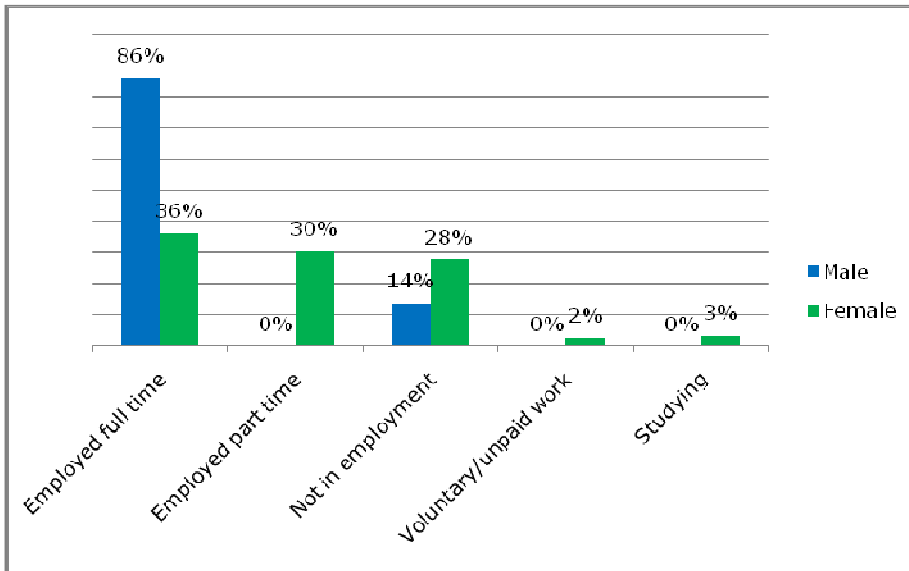
The lack of access to affordable and appropriate childcare appears to influence the employment patterns of households. A number of respondents remarked that they have no choice but to work part time rather than full time due to the lack of affordable and suitable childcare for their disabled or special needs child:

"I can only work part time as the childcare costs are too high and the availability of Autism trained childcare is non-existent."

"I have reduced my working hours to act as main childcarer for my child. I only use an after-school club for about 30 minutes once a week."

When the results were broken down further by gender, it was revealed that 86% of the male respondents worked full time, compared to only 36% of the female respondents. Interestingly, none of the male respondents worked part time, while 30% of the female respondents worked part time.

Figure 8: Employment status of respondents by gender

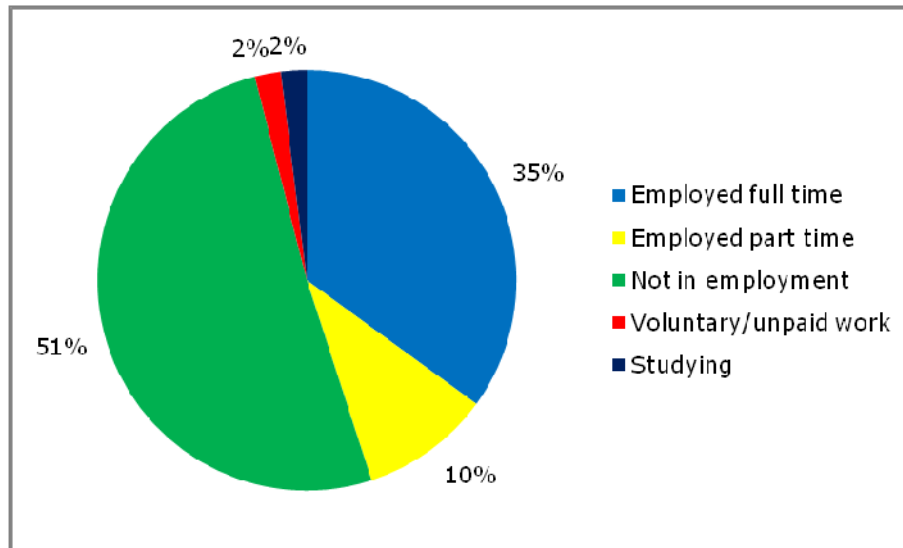


Twice as many female respondents were not in employment (28%, compared to 14% for males), which would indicate that mothers take on the majority of the caring responsibilities.

3.7.5 In employment but not using childcare

Given that such a high proportion of the respondents do not use childcare (39%), we felt it was important to explore the employment status of these respondents to help ascertain whether their employment status had a bearing on this figure.

Figure 9: Employment status of respondents that do not use childcare



It is interesting to note that 45% of those that do not use childcare are in employment (35% full time and 10% part time). This calls into question how families are managing the care of their children while they are out at work.

The qualitative data collected in the survey revealed that a number of respondents in employment but not using childcare have adjusted their working hours to accommodate their childcare needs. Many respondents commented that since there is no appropriate childcare to meet their child’s needs and since childcare is so expensive, they have adjusted their working hours to enable them both to look after their child themselves rather than use childcare:

“My husband cut his hours to work at the weekends and I work during the week. As the cost of childcare was too expensive, nearly all my wages would have gone on childcare.”

“We both have had to work part time because it was so difficult when our children were young to get anyone who would mind a child with special needs, especially the type of disability my children have which is hidden and because behaviour can be ‘bad’, people judge you and your child and it is extremely difficult.”

"My husband came out of work to look after my child full time as my son was attending physiotherapy, occupational therapy etc - we could not juggle both of us working and meeting my son's needs."

"Both my partner and I are self employed so that between us we can negotiate the looking after of our two children who are visually impaired."

"My husband has organised his work hours so he starts at 6.30am and finishes in time for school collection."

These responses indicate that both parents feel the struggle of juggling work and family life, not just the mothers as is typically the case.

4. Conclusions

This report has revealed a number of struggles faced by parents of children with disabilities and/or special needs in Northern Ireland in accessing childcare and employment. Parents are faced with significant challenges because the childcare infrastructure and resources are not sufficient to meet the needs of families in general as a result of the lack of strategic and policy development in the area of childcare. The problems faced by families of children with disabilities and/or special needs are therefore even more significant.

The results obtained from our parent survey and focus group reveal a number of important findings, which are now considered in turn.

1. Families of disabled and/or special needs children that participated in the survey are strongly reliant on informal childcare provision, in particular grandparents.

Previous research reveals that due to the extra demands and stress placed on families of children with disabilities and/or special needs, grandparents are often a major source of childcare support (Gray and Bruegel, 2003). The results from our survey strongly support this finding. The main source of childcare for families with disabled or special needs children is informal provision (66%), with grandparents being the most common choice (35%). However, the qualitative data received from respondents reveals that parents recognise this is not always an ideal choice and that the child's needs may be compromised. In addition, parents expressed concern about the extra strain being placed on grandparents. A number of those that work also stated that if they did not have the childcare support from their parents, they would have to give up work altogether.

The fact that only 34% of respondents use formal childcare provision indicates a shortage of specialised, appropriate childcare. It is clear that some parents of disabled or special needs children are deprived of choice and feel they often have to prioritise factors such as safety or parental convenience, for example, over the specific developmental needs of their child.

It is a concern that almost the same proportion of parents are using unregistered childminders and registered childminders (10% and 11% respectively) as their main form of provision. In addition, the Northern Health and Social Care Trust, which covers most of County Antrim, has the largest number of registered childminders in Northern Ireland (DHSSPS, 2009: 41). The fact that 68% of respondents in the county use informal provision (42% of which is grandparents) and only 10% use registered childminders, is therefore cause for concern. This finding calls into question whether the prominent use of informal childcare is due to cost or a lack of appropriate, registered provision for disabled or special needs children in the county.

2. There is a lack of specialised childcare for children with disabilities and/or special needs.

Gray and Bruegel (2003: 23) argue that 'the choice of formal, rather than informal, care depends partly on the ability to pay for it'. Respondents to the survey did indeed remark on the high cost of childcare. However, there are clearly a number of intervening factors other than cost which are influencing parents' choices. For example, a high proportion of respondents in employment do not use childcare (45%) and of those respondents that use grandparents as their main choice of provision, lack of suitably trained staff to manage their child's needs was the main motivation behind their choice. It is clear from the qualitative responses obtained from both the survey and the focus group that appropriate provision is not available, and that the lack of specialised childcare leads parents to choose family members, in particular grandparents, to care for their child while they work. Previous research also confirms this (Gray

and Bruegel, 2003). Therefore, Gray and Bruegel's (2003: 35) observation that 'children with disabilities are under-represented in formal childcare provision' is just as apparent today.

3. Families that participated in the survey face a number of challenges relating to their childcare throughout the year.

Our survey results reveal that conflict between care and work frequently arises for parents because of the often unpredictable nature of their child's needs and disability. It was apparent that parents of disabled and/or special needs children find school holiday periods to be the most difficult time of the year to access childcare (96%). This corresponds with Stiehl *et al's* (2006) study where parents expressed that they would benefit significantly if they could be offered term time working to accommodate school holiday periods. Interestingly, they found that when additional care demands arise, most parent carers 'look first to renegotiate roles and responsibilities within their household or extended family' before turning to flexibility rights at work, swapping work days or working from home (Stiehl *et al*, 2006:iv). A similar reluctance to ask employers for support was also evident in our survey results, with both parents often adjusting their work patterns to meet the needs of their child.

Summer holidays, in particular, were cited to be a significant challenge for those who work, but those not in work also expressed concern about the interruption to their child's routine, the lack of structure and the added strain placed on those grandparents who would provide the care during these periods. Therefore, already existing difficulties are exacerbated during school holiday periods.

4. Approved home childcare has the potential to be a valuable form of provision for many families.

Awareness of approved home childcarers was low amongst respondents. 54% stated that they were unaware of this type of provision and only 2% use a home approved childcarer as their main form of provision. Employers For Childcare Charitable Group recognises the scope for this form of provision to accommodate the needs of children with disabilities and/or special needs and their families. Indeed much of the qualitative feedback obtained from both the survey and focus group demonstrated that there is a desire for this form of provision. We are therefore currently conducting a piece of research in the area of home approved childcare, which will be published later this year.

5. There is a lack of access to appropriate advice and information to enable parents to make informed decisions in relation to childcare and employment.

It could be argued that the statutory obligations under the Children (NI) Order (1995) are not being adequately fulfilled. Although, as stipulated in the Order, there is a requirement placed on each Trust area to open and maintain a register of children with a disability, to the best of our knowledge this requirement has still not been fulfilled in all the Trust areas. Furthermore, those that do maintain a register differ in how the data is collected and indeed in how disability is defined (NICCY, 2010). As a consequence, there is a lack of understanding of the extent of need in each Trust area. In turn, there is insufficient information available on suitable childcare for children with disabilities and/or special needs and families therefore face a constant battle in accessing the information they need.

The majority of respondents were in receipt of Disability Living Allowance (DLA) and Child Benefit. However, knowledge and take up of other financial assistance such as that of the childcare element of Working Tax Credit, childcare vouchers and Direct Payments, was low. Extended

family members, most notably grandparents, play a key role in the provision of childcare for such families, yet financial assistance in the form of childcare vouchers and the childcare element of Working Tax Credit cannot be utilised by working parents to pay for such care.

Feedback from the focus group revealed that where a child has complex medical needs associated with their disability, Direct Payments are not even an option for such families. An alarming comment from one parent in the focus group was that their child was deemed by Social Services to be 'too sick for Direct Payments'. Insurance and who pays for it was also raised by another parent in the focus group. Therefore, accessibility to this form of financial assistance appears to be an issue for parents whose children have complex medical needs associated with their disability. Clearly work needs to be done to improve both awareness and accessibility. It is a concern that those most in need are not necessarily receiving or entitled to this help because the infrastructure and resources are not in place to meet the needs of children with complex medical needs.

6. The lack of suitable and affordable childcare has an impact on parents' employment status and employment patterns.

According to DfES (2007: 12) '[f]amilies of disabled children are less likely to have one or both parents in work'. Indeed our survey results revealed that within two parent households only 27% of such families were in a situation where both parents work full time. This, as well as the fact that the majority of the respondents' children are of school age, goes some way to explaining why a high proportion of the participating families only used childcare for less than 10 hours per week and indeed why the childcare costs reported were so low. If parents had access to appropriate childcare, perhaps more would be accessing full time employment.

Research shows that many parents who have children with disabilities and/or special needs do want to work but simply cannot work (Daycare Trust, 2007; Contact a Family, 2010a). Indeed our results revealed that

for those that do work, managing work and childcare is an enormous challenge. The survey results revealed that a high proportion of employed respondents do not use any form of childcare (45%). Upon exploring the qualitative responses from parents, it became apparent that childcare is often shared between parents by adjusting work patterns to enable one or both parents to look after the child(ren). This makes it possible for them to avoid childcare costs altogether. Parents also chose this route because they perceived that formal childcare provision would not meet the specific needs of their child.

In summary, the results obtained from this study reveal that parents are limited in their choices mainly due to the lack of access to specialised provision, the cost of childcare and their insufficient knowledge of the financial help that is available to them. This, in turn, leads many families to make compromises in relation to their childcare choice and employment patterns in order to accommodate their child's needs. These compromises contravene the rights of such children and their families under the UNCRC, UNCRPD, the Disability Discrimination Act 1995 and the Children (NI) Order 1995.

5. Recommendations

- An integrated childcare strategy which addresses the childcare needs of children with disabilities and/or special needs is urgently required. This needs to be implemented with clear leadership and accountability from the Northern Ireland Executive.
- There is a need to place childcare services on a statutory footing similar to that which exists in the rest of the UK.
- There is a need to recognise the role of the extended family, in particular grandparents, in policies that directly impact on families in order to support their work-life options.
- There is a need to increase the uptake of childcare among families whose child(ren) have disabilities and/or special needs by improving the appropriateness and accessibility of services.
- Investment needs to be made to train childcare providers to care for children with disabilities and/or special needs. In particular, there is scope for the Approved Home Childcare Scheme to be an attractive option for families of children with disabilities and/or special needs if sufficient training is given.
- The Children (NI) Order requires Trusts to keep a register of children with a disability. A review of this obligation is urgently needed. There does not appear to be a consistent and coherent approach across the Trusts and within the relevant Government departments. We would recommend that a scoping exercise is carried out on existing information systems to ascertain how the information could best be co-ordinated and streamlined. A partnership approach amongst the relevant Government departments and agencies would lead to an integrated system. This, in turn, would facilitate service planning, monitoring, delivery and ultimately improved outcomes for children with disabilities and/or special needs. Funds saved through this exercise could then be used to deliver and expand on existing services.
- Investment in Advice and Information Services that raise awareness of potential help and support available to assist parents in making informed choices is required. Direct Payments are

currently a 'minority service' in Northern Ireland. Awareness of this financial support needs to be raised to allow uptake to increase and to enable more parents to enter the labour market.

- Awareness of other forms of financial assistance such as childcare vouchers and Tax Credits also needs to be raised.
- It is important that Universal Credit works to the betterment of families in Northern Ireland. In particular, our politicians need to seek clarification on how childcare costs will be supported and to ensure that there will not be a reduction in financial assistance available.

References

- Barnardo's (2006) *It doesn't happen here: the reality of child poverty in Northern Ireland*.
- Bryson, C; Bell, A; La Valle, I; Barnes, M; O'Shea, R. (2005) *Use of Childcare among Families from Minority Ethnic Backgrounds and among Families with Children with Special Education Needs*. National Centre for Social Research.
- CDSA (2007) *Children with Disabilities Strategic Alliance Manifesto*. Belfast: Children in Northern Ireland.
- Child Poverty Action Group (2010) *Welfare benefits and tax credits handbook 2010/2011*. London: Child Poverty Action Group.
- Children and Young People Now (18th January 2011) *Grandparent carers face tough challenges, reveals report*. London: Haymarket Professional Publications Ltd.
- Contact a Family (2009) *What makes my family stronger? A report into what makes families with disabled children stronger – socially, emotionally and practically*. Contact a Family: London.
- Contact a Family (2010) *Disabled Children's Services*. Available at <http://www.cafamily.org.uk/families/rightsandentitlements/disabledchildrenservices/index.html>
Accessed on 01/03/2011.
- Contact a Family (2010a) *Counting the Costs 2010: The financial reality for families in Scotland, Wales and Northern Ireland*. Contact a Family.
- Contact a Family (2011) *Statistics: Information about families with disabled children*. Available at <http://www.cafamily.org.uk/professionals/research/statistics.html>
Accessed on 08/06/2011.
- Contact a Family, Council for Disabled Children, Mencap and Special Educational Consortium (2006) *'Between a rock and a hard place'*. Every Disabled Child Matters campaign briefing.
- Daycare Trust (2007) *Listening to parents of children with disabilities and special educational needs*. London: London Development Agency.
- Daycare Trust (2007a) *Listening to parents of disabled children about childcare*. London: Daycare Trust.
- Daycare Trust (2009) *Childcare Costs Survey 2009*, London: Daycare Trust.

Daycare Trust (2010) *Childcare for disabled children and children with special educational needs*. London: Daycare Trust.

Department of Education (DE) (2004) *Review of pre-school education in Northern Ireland*, Belfast: DE.

DfES (2007) *Aiming High for Disabled Children: better start for families*. London: HM Treasury.

Department of Health, Social Services and Public Safety (2004) *Direct Payments: Legislation and Guidance for Boards and Trusts*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (DHSSPS) (2009) *Children Order Statistical Tables for Northern Ireland (2008/2009)*. Belfast: DHSSPS.

Department of Work and Pensions, Department of Education and Skills and Officer of the Department of the Prime Minister (2005) *Improving the Life Circumstances of Disabled Children*. Cabinet Office - Prime Minister's Strategy Unit.

Department of Health and Social Services (DHSS), Training and Employment Agency (T&EA), Department of Education NI (DENI) (1999) *Children First: The Northern Ireland Childcare Strategy*. Belfast: DHSS.

Department of Health, Social Services and Public Safety (DHSSPS) (1995) *Children (NI) Order 1995 Guidance and Regulations Volume 5: Children with a Disability*.

Disabled Children Matter Wales (2011) *Benefit Uptake Scheme for Disabled children*. Available at http://www.dcmw.org.uk/news_item.cfm?id=52
Accessed 11/03/2011.

Employers For Childcare Charitable Group (2010) *Northern Ireland Childcare Cost Survey 2010*. Lisburn: Employers For Childcare Charitable Group.

Every Disabled Child Matters (2011) *Breaking down barriers: making work pay for families with disabled children*.

For Scotland's Disabled Children (2011) *About the Campaign*. Available at <http://www.fsdc.org.uk/how-can-you-help/find-the-missing-millions/about-the-campaign>.
Accessed 01/03/2011

Geraghty, T and Sinclair, R (2007) *The Daycare Needs of Disabled Young Children in Northern Ireland*. NICMA and NCB.

Ghaseer, K; Montseeat, E R; Waginger, U; Price, D; Stuchbury, R; Tinker, A (2010) *Grandparenting in Europe Summary*.

Gray, D. and Bruegel, E. (2003) *Final Report: The availability, use of, and demand for childcare services among the parents of children aged 0-14 in Northern Ireland*. Families and Social Capital ESRC Research Group.

Heywood, J (2010) Childhood Disability: Ordinary lives for Ordinary Families, in *Community Practitioner*.

HM Government (2006) *The Childcare Act*. OPSI. London: The Stationary office.

Joseph Rowntree Foundation (2001) *Work and Family Life in Rural Communities*. York: Joseph Rowntree Foundation.

Kilkelly, U; Kilpatrick, R; Lundy, L; Moore, L., Scraton, P; Davey, C; Dwyer, C; McAlister, S. (2004) *Children's Rights in Northern Ireland*. Northern Ireland: NICCY.

London Borough Council of Enfield (2010) *DCATCH (Disabled Children's Access to Childcare) Training Programme: Continuing Professional Development for Childcare Providers 2010-2011*.

McKay, S and Atkinson, A (2007) *Disability and caring among families with children: Family employment and poverty characteristics*. Corporate Document Services.

Monteith, M; Casement, E; Lloyd, K; McKee, P (2009) *Taking a closer look: Child Poverty and Disability*. Northern Ireland: Save the Children and Family Fund.

NICCY (2008) *'Who speaks for us?' Review of Advocacy Arrangement for Disabled Children and Young People with Complex Needs*.

NICCY (2010) *Too Many Barriers for Children with Disabilities*. Northern Ireland: NICCY.

NISRA (2007) *The Prevalence of Disability and Activity Limitations amongst Adults and Children Living in Private Households in Northern Ireland*. Belfast: Northern Ireland Statistics and Research Agency.

NISRA (2007a) *Population and Migration Estimates Northern Ireland (2007) – Statistical Report*. Belfast: Northern Ireland Statistics and Research Agency.

Northern Ireland Assembly Debate on Childcare Strategy (7th March 2011). Available at <http://www.theyworkforyou.com/ni/?id=2011-03-07.5.38&m=90290> Accessed 21/03/11.

Petition Online (2010) *Save DCATCH (Disabled Children's Access to Childcare)*. Available at <http://www.petitiononline.co.uk/petition/save-dcatch-disabled-childrens-access-to-childcare/439>
Accessed 22/02/2011.

Riddell, R; Priestley, M; Pearson, C; Mercer, G; Barnes, C; Jolly, D; Williams, V (2006) *Disabled People and Direct Payments: A UK Comparative Study*.

Rural Childcare Stakeholder Group (2008) *Rural Childcare: Investing in the Future*. RCSG.

Scope, TreeHouse, Ambitious about Autism and Working Families (2007) *Making Work Work for Parents of Disabled Children: Achieving a Work/Life Balance with a Disabled Child*.

Scottish Government and COSLA (2008) *The Early Years Framework*. Edinburgh: Scottish Government.

Stiell, B; Shipton, L; Yeandle, S (2006) *Caring for Sick or Disabled Children: Parents' experiences of combining work and care*. Carers UK and Contact a Family.

The Family Fund (2011) *"I wish I could just be grandma": Parenting again when you have a grandchild with a disability*. York: The Family Fund.

Together for Disabled Children (2010) *DCATCH – Information for Parents*.

Working Families (2010) *Disability Discrimination Act and Childcare*. Available at <http://www.workingfamilies.org.uk/articles/parents-and-carers/caring-for-disabled-adults-and-children/disability-discrimination-act-and-childcare>
Accessed 21/03/11.

employers

For Childcare

charitable group

Employers For Childcare Charitable Group
137a Hillsborough Old Road
Lisburn, BT27 5QE

t: 028 9267 8200

f: 028 9267 9200

e: info@employersforchildcare.org

w: www.employersforchildcare.org

Company Registration No: NI43041

Charity Registration No: XR5 7249