

The Daycare Needs of Disabled Young Children in Northern Ireland

Teresa Geraghty and Ruth Sinclair
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Research Report

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NCB promotes the voices, interests and well-being of all children and young people across every aspect of their lives.

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FOREWORD

Childminding is an important resource for children aged 0–14 years and is currently the most popular form of full-time daycare for working families in Northern Ireland. For disabled children and their families, childminders are ideally placed to offer these children a high-quality, non-stigmatised, childcare service. Childminders, like other early years workers, have a huge influence on the early learning and development of children. A childminder can not only help the disabled child to develop their self-esteem and expectations about what they can achieve, they can also help children without disabilities to learn to value and have respect for those disabled children.

Unfortunately, the childcare needs of disabled children in Northern Ireland have not been given the priority that they deserve. This report highlights the very real dilemma facing parents who have disabled children – that access to appropriate childcare is much more difficult for a whole range of reasons and that much needs to be done to improve the situation if we are not to discriminate against those children and their families.

There are many benefits to developing childminding as a resource for disabled children. Childminding can offer a non-stigmatised childcare service that is inclusive for the whole family, with all the siblings being cared for in the same setting. Childminders care for small groups of children, so they are able to offer individual care, taking into account the particular requirements of a specific child as well as working in close partnership with the parents.

What is very clear from the report is that any strategy for developing childcare services needs a partnership approach, with professionals and parents being key to the effective planning and implementation of future services.

The report has certainly provided us with information about the current provision of childcare services for disabled children as well as an improved understanding and awareness of the role of childminding as part of the wider children's services planning agenda. I would like to thank NCB Northern Ireland, specifically Teresa Geraghty and Ruth Sinclair, for taking this piece of work forward on NICMA's behalf and for producing a report of such quality and clarity. The input of the Project Advisory Group must also be acknowledged in bringing the perspective of both statutory and voluntary agencies working with disabled children. I would also wish to thank the Baily Thomas Charitable Fund for their financial support of the project.

I look forward to NICMA's future involvement in developing childminding services for disabled children and their families.

Bridget Nodder
NICMA Director



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An advisory group guided us throughout the project and we would like to record our appreciation of their help and encouragement.

Bridget Nodder and staff at NICMA supported us all the way and we are grateful for their help. Deena Haydon helped get the project off the ground.

Finally, Edna Colhoun, our office manager, has been an invaluable member of the team, providing administrative input and keeping the office running smoothly throughout.

Teresa Geraghty and Ruth Sinclair
September 2007

Executive summary

Introduction

This scoping study was commissioned by NICMA (the Northern Ireland Childminding Association) and carried out by the National Children's Bureau (NI) in 2006–2007.

The study explores the daycare needs of disabled young children under the age of five in Northern Ireland, taking into account the views of parents, childminders and other professionals in both the voluntary and statutory sectors.

The overall aim of the study is to inform the development of a strategic framework for the provision of daycare services for disabled young children in Northern Ireland.

Background

This is a time of change – and hence of opportunity – for childcare services in Northern Ireland. The new devolved government, the Review of Public Administration and the Comprehensive Spending Review will impact on every aspect and level of policy-making and service delivery, including early years services and those for disabled children.

Since the launch of both the Pre-school Expansion Programme in 1998 and Children First in 1999, there has been a growth in services for young children in Northern Ireland. Although more parents use childminding than any other form of non-family care (making up 76 per cent of all full daycare provision and 44 per cent of all childcare provision) the expansion of early years services has been in group care.

Despite this growth, there is still a shortage of childcare places in Northern Ireland. Indeed, Northern Ireland has one of the lowest levels of early years provision in Europe. Research points to an unmet need for 5,500 places. In addition there are 11,000 unregistered childminders currently providing daycare in Northern Ireland.

The childcare situation for parents who have disabled children is even more stark. Although there is limited up-to-date information on the prevalence of disabled children in Northern Ireland, it is estimated that there are 35 disabled children per 1,000 children under 16, a rate that is higher than the rest of the UK. Between 3 and 4 per cent of children using daycare are disabled, with over one in five disabled children going to a childminder.

Historically, disabled children have been accorded a low priority by public services in Northern Ireland, with parents experiencing services as 'limited, piecemeal and fragmented'.

There is growing evidence that childminding networks help raise standards among childminders. Until 2003 NICMA operated the Children Come First Childminding Network for disabled children. Despite very positive evaluations, there was no funding available to maintain the service.

From its everyday work, NICMA is very aware of the continuing need for good childcare services for disabled children and their families. The result is this scoping study.

The study

Information was gathered indirectly and directly. Indirect information included a review of relevant research, service reviews and documents such as local statistical returns and children's services plans.

The views and experiences of relevant people were gained directly from interviews or group discussions. In total 13 childminders, 26 parents and 15 professionals from across Northern Ireland participated in the study.

Although the style of interview differed for each group of participants, they covered similar topic areas, including:

- perceptions of the daycare needs of disabled young children and their parents
- current daycare provision for disabled young children: type, number and location; gaps; factors determining use of services; factors inhibiting use of services; suggestions for improvement and future development
- services provided by 'specialist' childminders: type, number and location; skills, experience and training required; support required; quality of existing services; suggestions for improvement and future development.

Findings from the study

The impact of the current context

This research took place at a time of significant change in Northern Ireland: most pertinently, the move of early years services from the Department of Health, Social Services and Public Safety (DHSSPS) to the Department of Education (DE); the drafting of an early years strategy by DE, and the introduction of a special early years curriculum for two-year-olds.

The four 'old' health and social services boards had engaged in children's services planning (CSP) for children in need. While disabled children are legally recognised as children in need, the extent to which their needs were being addressed through the CSP process varied. Likewise, the degree to which the four childcare partnerships have been effective in meeting the daycare needs of disabled children varied both between and within areas. Following the reorganisation of health and education bodies with the RPA (Review of Public Administration) the children's services planners have recommended one

regional children's services plan for all children, although no decision has yet been taken.

There were mixed reactions to some of these developments from respondents, particularly the transfer of early years to education, though in the main respondents prefaced their comments with the fact that while it is still too soon to make a judgement, they saw this as a huge opportunity.

Daycare needs of disabled young children

...being the parent of a disabled child means that you just [get] a kind of life sentence of having to fight for services and you either do that and you get something or you don't and you get nothing... (Professional).

This quote reflects a prevailing view among most parents and professionals in the study.

Two main types of daycare were identified: respite and full daycare. Working parents needed full daycare, while parents who did not/could not work (due to their child's condition and the lack of suitable childcare) needed respite. Whichever type of care was required, real difficulties were experienced in finding appropriate services, especially for children with complex and/or medical needs. These difficulties arose from: the general shortage of childminders and home care workers; different ages of children in a family; cost and location of services; and a lack of willingness to mind a disabled child.

Participants in this study discussed the advantages and disadvantages of mainstream or specialist services. All acknowledged that disabled children had the same right to services as other children, but also that the particular needs of each child should be catered for appropriately.

Quality and quantity of early years services

Despite an increase in early years services in NI in recent years, there is still a lack of childcare provision. The situation is much worse for disabled children:

I don't think there is a service for disabled children ... I don't have a childcare facility at the minute and I've exhausted every single avenue that I possibly can ... it's appalling (Parent).

Among the factors parents and professionals identified as important to them in using a service was confidence in the service:

... having confidence in the service and the people offering support (Professional).

... it is reliable or trustworthy, that it is well thought out and that people are qualified to deal with your child (Parent).

Also important was knowing the service was there for the benefit of their child and that it was child-centred:

... anything to help Andrew out ... he was just so content to be there ... he absolutely loved it (Parent).

... knowing that your child's liked and valued is actually really important (Parent).

Several barriers to accessing services were identified. These included:

- lack of information about what services exist and what their child is entitled to
- lack of transport, especially in rural areas and outer city estates
- physical access to buildings because of wheelchairs or other necessary equipment.

I have to carry a suction machine, a kangaroo feed, his own bag, my bag and depending if he's not well, oxygen has to come along, boxes of tissues, you just don't ever travel lightly ... his chair is slightly bigger than a pram and it's just, it's not easy to get round (Parent).

Quality and quantity of childminding services

As well as considering childcare services in general, the study looked specifically at childminding services. Participants raised the following issues:

- Shortage of childminders: the sheer difficulty in finding a suitable childminder who is willing to take a disabled child and who has sufficient competence and confidence.
- Barriers to accessing care: parents felt that childminders discriminated against disabled children – or lacked the confidence to care for a disabled child.

... they [carers and childminders] lack confidence in looking after the young child with disabilities (Professional).

- Although some trusts do operate a specialist childminders service, this is not widespread and not well recognised. Some participants noted the potential for this sort of service to be developed.
- There is an economic cost to a childminder looking after a disabled child. They may have to reduce the number of children they care for in order to meet the needs of a disabled child. It was suggested that this problem might be addressed by a grant scheme, protected funding from H&SS (Health and Social Services) budgets or the use of subsidies.

It doesn't pay as a childminder ... you know, you would need like a one-to-one with that child and your £2.60 an hour would not cover that (Childminder).

- For many families, all the above barriers come together to create cumulative difficulties.

Training, skills and experience of childminders

Almost all participants highlighted the need for adequate and appropriate training of childminders: not just basic childcare training, but also generic disability awareness training and an understanding of specific conditions. Some noted the need for anti-discrimination training:

I have never had difficulty getting childcare for my other two [able-bodied] children, but I have had major difficulties getting childcare for David. It's almost discriminatory I think (Parent).

There were many suggestions as to how such training might be delivered: placement type training in a child's home; the model of using paediatric nurses to train non-medical carers; training via specialist childcare services.

Evidence was given to suggest that training, in itself, might not actually increase the willingness of childminders to care for disabled children. Differing views were also expressed about the necessity of childminders having experience before caring for disabled children, with some respondents stressing attitude and a willingness to learn were equally important.

Support for childminders

The majority of respondents felt that childminders who cared for disabled children needed some form of support. This could be through statutory partnerships, organisations such as NICMA, through childminding networks or through the support groups specific to particular disabilities. At a minimum, childminders need to liaise with other professionals involved in the child's care such as speech and language therapists or social workers.

Childminders mentioned the need for support in terms of getting advice about dealing with particular conditions or behaviours.

There is growing evidence of the value of childminding networks. In this study, childminding networks were regarded positively, in terms of the potential they have to address both full daycare and respite needs and in offering a more sustainable service.

I am a very strong believer in the use of childminding networks and particularly for children with a disability ... it would have to be properly resourced, properly trained and a service that is locally available, locally accessible (Professional).

Infrastructures and multi-agency working

One of the clearest messages from the research is the need for multi-agency and partnership working. Statutory services do not have the capacity to deliver on all of the needs of disabled children and their parents, and some voluntary

agencies have specialist expertise. There was consensus that the way forward is through partnership, including partnership with parents.

... people really need to shift their mind away from the disability to the [child], and really all professionals, education, medical, clinical and social worker, do really [need to] come together much more effectively and stop being fragmented in their responses (Professional).

Key messages

This study has highlighted the struggle endured by families with disabled young children trying to access daycare services. Four key messages emerge:

1. Matching needs and services

There is a real mismatch between the needs of disabled children and their parents and the services that are currently available to them. There is a lack of childcare services and of registered childminders willing and capable of caring for disabled children.

There is a mismatch between where children live and the location of providers. There is unexplained variation in services in different trust and board areas.

There is a mismatch between the needs of disabled children who require more intensive care and the childminders' need to make a living.

Parents require more flexibility and choice, especially if they are to meet the needs of their disabled child alongside those of the whole family.

2. Enhancing the quality of services

Among many pointers to the qualities required in services, two predominate:

First, that of confidence: parents need to have confidence in the service provided, and carers need to be confident in their ability to care for a disabled child.

Second, there is a need for both initial and ongoing training among childminders, both specialist training to meet the needs around specific disabilities and general training around confidence building and disability awareness.

3. Role of childminders

There is huge potential for childminding to meet some of the unmet needs of disabled children and their families. This was seen as a valuable resource and viable option within daycare services.

There is widespread support for a network to support parents and boost the confidence of childminders.

Childminders could be linked into developments such as Sure Start, new children's centres and extended schools, as pilot projects in England are proving.

4. Planning to meet identified need

Early years and disability professionals and parents need to come together in partnership to plan how services for disabled young children will be developed and delivered.

There is a range of documented service models that could meet the daycare needs of disabled children and their parents. There is a need to explore all of these options, recognising that families with a young disabled child require flexible and accessible services. Some may need more than one service option to meet all their needs, preferably through service models that provide a wide range of facilities.

This is a time of great possibilities in service development that needs to be actively embraced if the needs of disabled young children and their parents are to be addressed.

1. Introduction

This scoping study, commissioned by NICMA (the Northern Ireland Childminding Association) and carried out by the National Children's Bureau (NI), explores the daycare needs of disabled young children under the age of five in Northern Ireland. It takes account of the views of parents, childminders and other professionals in both the voluntary and statutory sectors.

The report starts by setting out the context for the study, looking at the evidence, from research and practice reviews, on how the daycare needs of this group of children are met. This includes discussion of the current policy context for early years services for children and for disabled children in particular. This context review then considers the role of childminding, of NICMA and the Children Come First Childminding Network, which operated previously to support a group of specialist childminders looking after disabled children. This discussion sets the context for the study and will be useful in helping to interpret the findings and to draw out their implications for future service planning.

Section 3 of the report focuses on the specifics of the study: its aims and objectives and how it was conducted.

Findings from the research are reported in Section 4 under the following seven themes:

- Impact of the current context
- Daycare needs of disabled young children and their families
- Quality and quantity of early years services
- Quality and quantity of childminding services
- Training, skills and experience of childminders
- Support for childminders, including networks
- Infrastructure and multi-agency working.

The implications of the research findings will be fully considered and reported as summary conclusions in Section 5, under the following four headings:

- Matching needs and services
- Enhancing the quality of services
- Role of childminding
- Planning to meet identified need.

This report seeks to serve two objectives: more immediately, to enable NICMA, with the help of the Project Advisory Group, to draft an action plan on developing services to support families of disabled young children; and second, to help inform children's services planners in the new commissioning agency as they plan to meet the needs of this important group of children.

2. Research and policy context of the study

The current context for childcare services in Northern Ireland can be characterised as a time of change and hence of opportunity. These changes – such as the prospect of devolved government, the Review of Public Administration and the Comprehensive Spending Review – will impact on every aspect and level of policy-making and service delivery. Some relate to all children and all aspects of their lives, such as the Ten-year Strategy for Children and Young People in Northern Ireland. Some are more specific to the subject of this review, namely early years and disabled children, for example the move of responsibility for early years from the Department of Health, Social Services and Public Safety to the Department of Education; the Review of Pre-school Education; the Children's and Young People's Funding Package, and the Every Disabled Child Matters campaign.

In setting the context for this study we will review briefly what is known about the needs and current service provision, first, for young children in general, including childminding, and then for disabled young children. We shall draw on evidence from research and service reviews, and examine the policy environment, highlighting key policy issues that have been identified.

Childcare services

Since the New Labour government came to power in 1997, childcare has been a stated priority, a position that has been replicated in Northern Ireland.

From the time of the launch of both the Pre-school Expansion Programme in 1998 and Children First: the Northern Ireland Child Care Strategy in 1999, there has been a growth in services for young children in Northern Ireland. Children First sought to:

- raise the quality of childcare
- make childcare more affordable
- improve access to childcare.

A 2005 review of Children First points to some positive changes in each of these areas, although the lack of a baseline makes it difficult to demonstrate this evidentially (DHSSPS 2005). Many policy documents (e.g. OFMDFM (Office for the First Minister and Deputy First Minister) 2006b; OFMDFM 2006a) highlight government investment in expanding childcare in Northern Ireland. Statistics indicate that the majority of this investment and growth has been in day nurseries, which have increased by 66 per cent in the period 1999–2004. The corresponding figures for childminders showed an increase of 4.8 per cent (DHSSPS 2005). More recent figures for childminders show a *decrease* of 14 per cent in the period 2003–2006 resulting in a 19 per cent reduction in childminding places (DHSSPS 2006).

This emphasis on group care for children has received more attention recently with the introduction of extended schools, which aim to provide a 'wraparound'

service of 8am–6pm daycare as well as teaching. While the initiative is only starting in Northern Ireland, £10 million has been allocated from the Children and Young People's Package, a one-off government funding package for children's services (DE press release 6 June 2006).

Despite these initiatives, there is still a shortage of childcare places in Northern Ireland. Indeed, Northern Ireland has one of the lowest levels of early years provision in the UK and Europe (NICMA 2003; Concordia 2006). A major report into the availability, use and demand for daycare suggests that the number of day nursery places available to under-fives in Northern Ireland is less than half that in England (Gray and Bruegel 2003).

A recent report by the Concordia group (2006) highlights evidence that a lack of affordability and access to suitable childcare is a major barrier to the employment of mothers in Northern Ireland. This report also highlights the gaps in childcare funding and policy in Northern Ireland in comparison to the situation in England; a situation made worse by the greater level of child poverty in Northern Ireland. Concordia have called for legislation comparable to the Childcare Act (2006), which will come into effect in 2008 in England.¹

Childminding

Within the spectrum of early years services, childminding offers a crucial resource to children and their families. It is a service usually provided in the childminder's home, where the childminder is self-employed and works under a contract with parents. The Children (NI) Order 1995 established the framework for registration and inspection of childminders which, in Northern Ireland, is currently the responsibility of the 11 health and social services trusts. This responsibility remains with the trusts despite the recent transfer of early years policy from Department of Health, Social Services and Public Safety to Department of Education.

More parents in Britain use childminders than any other form of non-family care (Dillon and Statham 1998). In Northern Ireland, childminding places account for 76 per cent of full daycare provision and 44 per cent of all childcare provision. At present there are around 3,600 childminders registered in Northern Ireland providing over 17,000 places for children (DHSSPS 2006). The great majority of children placed with childminders are there because their parents are working. In Northern Ireland this is true of a higher proportion of children (82 per cent) than is the case in England (74 per cent) (Gray and Bruegel 2003).

In their study about childminding in the 1990s, Mooney and others (2001b) found that childminding is mainly undertaken by women when their children are young. This enables them to contribute to the household income while caring for their own pre-school children. While more than half of those surveyed perceived childminding to be a long-term career or route into related work, others viewed it as a phase in their employment. Despite defining themselves

¹ Some sections also relate to Wales.

as professional childcare workers, they did not consider the need for training and qualifications to be important.

The survey by Gray and Bruegel also noted the growth in the use of unregistered childminders in Northern Ireland, estimated to be around 11,000. The proportion of unregistered childminders in Northern Ireland is 'strikingly high' compared to England (Gray and Bruegel 2003). This is a matter of some concern, given that the quality of such care is not regulated or monitored.

All the evidence from this survey points to a shortage of childminders within Northern Ireland. This leads the authors to conclude that 'the number of childminders would need to expand by 20 per cent to meet current demand' (Gray and Bruegel 2003). In all, this suggests a demand for childcare places of almost 39,000, leading to unmet need for 5,500 places, in addition to the 11,000 unregistered childminders currently providing care (NICMA 2005).

Sponsored childminding

Although most childminding services are a direct contract between parents and carer, in a small proportion of instances sponsored childminders will be provided, mainly by social services departments. In these instances the role of the childminder may be perceived differently: rather than catering for the needs of working parents, sponsored childminders will be expected to meet the more specialist welfare needs of the children referred to them. Sponsored childminders is one of the options available to social services when exercising their responsibilities to children in need, such as disabled children.

Unfortunately, information on sponsored childminders in Northern Ireland is scarce as this is not included among the Key Indicators of Health and Social Services. However, a report on the Children Order in 2006 reported over 180 sponsored childminders providing over 780 childminding places (DHSSPS 2006).

Recent surveys of sponsored childminding suggest that these carers offer limited hours and the time spent as a sponsored childminder is usually short. Some sponsored childminders may receive extra support, but research suggests most would like more (Cameron and Statham 1997; Dillon and others 2001).

Childminding networks

Increasingly childminders in England are developing formal networks at a local level and joining approved schemes organised by the National Childminding Association. There is evidence that real benefits can be gained from operating childminding networks. According to a review of childminding networks, effective networks:

... are making a significant contribution to the quality of childcare offered by childminders; increase the status of childminding in the eyes of childminders and parents; provide a powerful mechanism in support of childminders; and show signs of helping retention of childminders (Dawson and others 2003).

Additional benefits identified include: increasing diversity in the provision of early years education; offering a mechanism for career progression for childminders; and reassuring parents as to care standards.

A more recent study of networks by Owen (2005) reported that both childminders and network coordinators saw improved access to training via the network as leading to improvement in the quality of service provided for children. Many networks develop training courses in partnership with education, health and social care providers, and voluntary and community organisations.

Community networks can be particularly useful in providing extra support and specific training to those providing places for disabled children (Evans and Lyons 2006). Networks also offer support to childminders, which increases their level of personal confidence, contributes to a sense of belonging to a wider professional grouping, and helps to retain childminders (Owen 2005).

In their review of childminding networks in England, Dawson and others (2003) identified the key elements of successful networks as:

- a strong belief in childminding and networks, ideally with a champion
- coordinators with a deep knowledge of childminding, a proactive and flexible approach to network development, and the necessary skills and attributes
- close synergy between the network and the local authority
- strong, clear lines of communication between stakeholders
- appropriate training and support for coordinators
- a patient and multi-stranded approach to recruiting childminders to the network
- emphasis on the distinctive benefits of belonging to a network (support, personal development, tailored training, recognition, professionalism, dedicated resources)
- a flexible approach to assessment and monitoring, and use of the NCMA Toolkit
- integration of the network into the entirety of local childcare, including promotional activity.

Another way in which childminders link with other children's services is working through Sure Start or through children's centres. Following implementation of the Childcare Act 2006, the latest Sure Start Practice Guidance points to the key role of childminders and childminding networks within Sure Start children's centres (DfES and DH 2006). A recent report into children's centres work with childminders showed that the vast majority are working with registered childminders in their area, and seven out of 10 children's centres had links with childminding networks (NCMA 2006).

There are also opportunities for childminders in initiatives such as extended schools, as experience from England illustrates. In York registered childminders provide a vital element of the wraparound service for a local school and operate alongside other providers such as nurseries (NCMA website accessed 3 January 2007). Similarly there is currently a pilot project in Kent involving 15 registered childminders who are working with a local school to provide before- and after-school care as part of an extended schools package (*Guardian Education* 5 December 2006).

Much has been made by the Northern Ireland government of their investment in extended schools and Sure Start projects. This model of supporting childminders by linking them with Sure Start children's centres and extended schools is promoted by Concordia as a way forward in Northern Ireland, by providing real choice for parents and children and particularly disabled children (Concordia 2006). However, the Audit Office has indicated that the majority of children's centres in England do not reach families with disabled children (National Audit Office report 2006). Caution may need to be exercised in assuming that the expansion of children's centres will address the needs of disabled children, without a clear and determined effort to do so.

NICMA

The Northern Ireland Child Minding Association (NICMA), founded in 1984, is a charity and membership organisation which works to support and develop registered home-based care. Currently about 2,600 childminders are members of NICMA, almost 70 per cent of all registered childminders in Northern Ireland. Among the services it provides, NICMA operates a quality assurance scheme for childminders, a training programme and advice about matters such as insurance and contracts with parents. Local childminding networks offer support services to childminders as well as providing information to parents about childminding vacancies in their areas and running toy/equipment libraries (*Children Come First* booklet NICMA undated).

Disabled children

Up-to-date information on the prevalence of disabled children in Northern Ireland is not readily available. In 1992 a Policy, Planning and Research Unit (PPRU) survey identified 14,600 children under 16 in Northern Ireland with some degree of disability, 2,600 of whom were within the most severe category. This gave a prevalence rate in Northern Ireland of 35 disabled children per 1,000 children under 16 (compared to an equivalent rate in Great Britain of 32 disabled children per thousand children under 16).

Historically, disabled children have been accorded a low priority by public services in Northern Ireland. The needs of disabled children were not recognised in legislation until the late 1980s (Monteith and others 1997). In 1995 the Children (NI) Order recognised disabled children as *children* first and included them within the broad definition of 'children in need'. The Order set out

the range of support services likely to safeguard and promote the welfare of children in need, and the quality standards applicable to those services.

However, research suggests that services to disabled children in Northern Ireland are 'limited, piecemeal and fragmented' (Monteith and others 2002). In a summary of research findings on support to disabled children and their families Monteith and Kelly (2003) identify many shortfalls in services. They note that since the introduction of the Children (NI) Order, 'the prevailing focus on protective rather than preventive services has limited the development of support services for disabled children and their families' (Monteith and Kelly 2003: 1).

The study by Monteith and colleagues also identified the strong association between disabled children and family income levels (Monteith and others, 2002). Families of disabled children face up to three times the costs of families with no disabled children, yet benefits do not take into account the additional costs of caring for a disabled child (Dobson and Middleton 1998). Nor do benefits take into account the cumulative costs of having more than one disabled child in a family (Tozer 1999; see also Horgan 2006). Parents of disabled children are more likely to be unemployed or on low incomes, in insecure jobs or working below their skill levels because of the need to find work that is compatible with the requirements of caring for their child (Daycare Trust 2005; Kagan and others 1998).

Daycare for disabled children

The childcare situation for parents who have disabled children is even more stark than is the general childcare picture. In Northern Ireland Gray and Bruegel (2003) estimate that between 3 and 4 per cent of children using daycare are disabled, with over one in five disabled children going to a childminder. Their survey of parents suggests that at least 15 per cent of families had at least one disabled child.

Two reports from the Daycare Trust, reviewing evidence on childcare and disabled children, suggest that childcare services are not responsive to the needs of disabled children and their families (Daycare Trust 2001; 2005). The key issues identified include:

- lack of recognition of the additional costs of childcare for a disabled child
- lack of accessible and appropriate childcare places, particularly for young children, young people or those who do not use verbal communication
- lack of flexibility or regular provision of care at weekends or overnight
- lack of confidence or resources for specialist training/equipment in nurseries and among childminders
- lack of adequate transport to and from provision.

There is strong research evidence to show that parents of disabled children find it difficult to access local childcare provision that would enable them to gain paid employment (Monteith and others 2002). In Northern Ireland the employment rate of mothers in families with a disabled child was only 61 per cent compared to 80 per cent in families that had no disabled child (Gray and Bruegel 2003). Employment is not seen as a choice for many parents of disabled children who wish to work for both financial and psychological reasons such as satisfaction, self-esteem, having an identity outside the 'caring' role, feeling that they are active citizens and not just recipients of benefits or services (Kagan and others 1998). Parents who try to combine paid work with caring for a disabled child require flexible and supportive employment arrangements, but what they experience is poorly coordinated services and inadequate systems (Monteith and others 2002). Without good quality, affordable childcare disabled children are missing out on educational and social benefits, and their parents are unable to study, train or work – or gain respite from their caring responsibilities. This can lead to financial hardship and increased stress (Daycare Trust 2001; 2005).

Childminding and disabled children

Childminding can be an important resource for disabled children or those with complex needs and their parents. As Evans and Lyons (2006: 53) point out, 'children with disabilities often benefit from the smaller group and continuity of care offered by childminders, as well as a flexible service that can include respite care and taking the child to therapy sessions'. Horgan too found that parents of disabled children did not necessarily want institutionalised respite care. Instead they would prefer free childcare places and after-school clubs or more personal assistance in caring for disabled children and young people (Horgan 2006).

Children Come First Childminding Network for disabled children

NICMA operated the Children Come First Childminding Network for disabled children in the South and East Belfast Trust and Ulster Community and Hospitals Trust from March 1999 until September 2003. They recruited and trained quality assured childminders who could be matched to families' individual needs, providing 'a choice of flexible "tailor made" childcare arrangements ... in the family's own home' (NICMA *Childminding Network for Children with Disabilities/Special Needs: Childminders Flyer*). This led to childminding services of different types being offered (full time, part time, weekend, evening, respite and holiday cover) for children with a range of disabilities (including autism, communication/physical/learning/global delay, muscular dystrophy, bowel and feeding problems, hydrocephalus, Down's syndrome, speech difficulties, ADD, visual impairment, sensory and respiratory difficulties).

NICMA identified the benefits to childminders of joining the network as:

- quality assurance (opportunity to work within a recognised quality assurance scheme)
- support (dedicated network coordinator, additional support such as a telephone helpline for registered childminders caring for disabled children)
- training (specialist training to help care for disabled children)
- filling vacancies (children and their families matched with childminders by the coordinator)
- toys and equipment (Network Toy and Equipment loan scheme, providing access to a range of play opportunities specifically for disabled children as well as specialised equipment)
- professionalism (support of the coordinator and commitment to the NICMA Quality Childminding Charter, promoting childminding as a professional form of daycare) (NICMA *Childminding Network for Children with Disabilities/Special Needs: Childminders Flyer*).

An evaluation of the Network over the four years it operated demonstrated that:

- There is a need for this type of flexible childcare.
- Childminding networks can be 'reactive' to parents' needs and the geographical areas of demand rather than 'prescriptive' in the care offered.
- Childminders joining the Network were keen to attend training; indeed this attracted them to join.
- Parents and childminders valued the partnership approach. On referral visits to the child's home, a detailed personal information form on the child's individual needs was completed in partnership with the parent and the network coordinator. All 'information gathering' was shared and the coordinator, childminder and parents adhered to a confidentiality policy.
- Opportunities for inclusion in a 'non-stigmatised' setting were important to parents, the minded child and siblings who could all access the service together if they wished. (Often children with 'special needs' are cared for away from their siblings.)
- Parents preferred to go through the Network process; to access quality assured childminders who were trained, willing to attend ongoing training in partnership with the parent and able to offer specialised care for children with additional needs.
- Opening service provision to the child's own home helped make the service accessible. (NICMA 2002; NICMA 2004)

The Children First Network was created through short-term funding from BBC Children in Need (March 1999 to April 2001). Subsequent funding by the Eastern Childcare Partnership between July 2001 and September 2003 enabled NICMA to continue operating the Network for this period. With no other funding forthcoming, the Network ceased operation at this point.

Given the evidence of the value of networks in supporting childminders and raising standards of care, it is not surprising that they have continued to develop as an important feature within early years service provision, particularly within

the new Sure Start children's centres. As a model, childminding networks seem to be particularly relevant in supporting childminders in caring for disabled children.

Policy issues

This brief review points to many positives in recent years in the implementation of early years policies in Northern Ireland, leading to an increase in both the quantity and quality of services. However, these are not as evident in respect of services for disabled young children. There would appear to be several key policy issues still to be addressed, in particular the role of daycare for families with a disabled child and making services accessible and affordable for families with disabled children.

This review suggests that disabled young children are at an intersection between early years and disability in terms of policy, practice and research. The discourse on early years is different to that on care for disabled children and mostly takes place in separate arenas. The former is firmly focused on the economic world of work, especially for mothers, and views childcare as necessary in order to fulfil the government's economic, welfare and taxation targets. For example, the introduction of the Working Families Tax Credit and the voucher system is meant to encourage the use of registered childcare.

When considering disabled children, the emphasis tends to be on giving carers a break through services such as respite care. Yet many parents of disabled children express a wish for early years services that would enable them to both meet the needs of their child and to gain employment.

Two key policy issues remain to be addressed: the limited access to suitable daycare services, including childminders, for disabled children; and funding the additional cost of providing care to disabled children.

It is issues such as these that have led to the campaign Every Disabled Child Matters (see www.edcm.org.uk). The EDCM campaign initially focused on the Every Child Matters initiative in England, but has since been taken forward in all parts of the UK, including NI. Many government initiatives within the Every Child Matters – Change for Children Agenda, such as the Child Care Act 2006 are widely welcomed. However, the EDCM's campaign believes that this 'will fail to deliver the promise for [disabled] children without additional funding to make childcare places both available and affordable'.

They identify several reasons why current strategies around childcare are likely to fail to meet the needs of disabled children – and these are also likely to be true in a Northern Ireland context. These include:

- lack of inspection of the supply of childcare places for disabled children
- no funding stream to increase the volume of childcare for disabled children

- lack of coordination between national and local childcare strategies and initiatives aimed at supporting disabled children and their families
- local authorities not planning childcare based on increased numbers of disabled children
- families with disabled children not being consulted about their childcare needs
- current tax credit ceilings and rules that make childcare unaffordable for families with a disabled child (Every Disabled Child Matters 2006).

3. The study

This study has been commissioned by NICMA to help inform the development of its services. From its everyday work, NICMA is very aware of the need for good childcare services for disabled children and their families. It is also aware that the closure of the Children Come First Childminding Network caring for disabled children has reduced the range of services available to families with disabled children in Northern Ireland. NICMA is keen to develop services that will address these needs, but before embarking on any new development, NICMA wished to undertake an assessment of needs and to gather the views of relevant groups. This scoping study has been commissioned to assist with that process.

Aims and objectives of the study

The overall aim of the scoping study is to inform development of a strategic framework for the provision of daycare services for disabled young children in Northern Ireland.

To achieve this overall aim the study was designed with the following objectives:

- to map current policy and practice regarding provision of daycare for disabled children aged 0–5 in Northern Ireland, including specialist childminding services
- to identify the daycare needs of disabled children and their parents, including the quantity and assessed quality of current childminding services and any perceived gaps
- to identify the requirements of childminders caring for disabled children (e.g. training and qualifications, knowledge, skills)
- to review the operation of the Northern Ireland Children Come First Childminding Network for disabled children for evidence about supply and demand, and lessons to be learnt regarding service delivery
- to assess infrastructure and other resource requirements needed to ensure quality childminding services for disabled children
- to facilitate multi-agency collaboration and consideration of key issues, through membership of the Project Advisory Group and participation within the study
- to inform development of recommendations regarding future progress
- to disseminate findings.

Outcomes from the study

The immediate output from the study will be a report from the researchers to NICMA. Working with members of the Project Advisory Group and children's services planners, NICMA will then consider the implications of the findings

from the study and develop an action plan to develop appropriate daycare services for disabled children.

The intended outcomes of the study are:

- increased knowledge about current provision of daycare services for disabled children in Northern Ireland, including specialist childminding
- improved understanding about whether there is a need, and if so, how to develop specialist childminding services in the future
- increased awareness of childminding as part of the agenda for children's services planning in Northern Ireland.

How the study was conducted

Information was gathered indirectly and directly. Indirect information included a review of relevant literature, research and service reviews, and an analysis of documents such as local statistical returns and children's services plans. Direct views and experiences were gained from interviews or group discussions with three groups of people: childcare managers and planners, parents and childminders.

Below we describe the way in which participants in each group were identified and recruited, together with details of the sample of participants in each group.

The study sought to cover all board areas within Northern Ireland, so early contact was made with relevant people in each board to inform them of the study and to gather information on their children's services plans and planning processes. It was not feasible, however, in this small study to make contact with relevant staff in each trust area. One trust from each board area was chosen to represent all trusts in terms of contact with the statutory services. The trusts which responded most speedily to a request for information were selected. These were:

- Eastern Board: South and East Belfast Health and Social Services Trust
- Western Board: Foyle Health and Social Services Trust
- Northern Board: Homefirst Health and Social Services Trust
- Southern Board: Craigavon and Banbridge Health and Social Services Trust.

Within the trusts, contact was made with both the early years and the disabilities teams.

Participants contacted via voluntary sector agencies were not restricted to these trusts, and represented all four board areas.

Participants in the study

Childminders

The original plan was to interview 20 childminders, five from each board area, with 40 per cent being selected from the list of registered childminders held by the trusts and the remaining 60 per cent from childminders who were members of NICMA.

Eight letters, together with information sheets, were sent to a relevant trust contact within each of the four identified trusts to be distributed randomly to 24 registered childminders. A similar letter and information sheet were sent directly to six further childminders in each board area, 24 in total, randomly selected by NICMA from trusts across Northern Ireland.

Despite several reminders to contacts, this process yielded only 13 childminders willing to be interviewed. All but one of the health and social services trust areas were represented. Two of the childminders had experience of the Children Come First Childminding Network.

Parents

To assess the daycare needs of disabled children, it was planned to hold semi-structured interviews with parents from 20 families (either a mother or father or both) who had a disabled child aged 0–5. Information sheets on the study were prepared for parents. As agreed, 15 sets of letters, together with information sheets, were sent to the disabilities team in each trust area identified earlier for random distribution to parents known to have disabled young children.

The response rate using this method was slow, so contact was also made with a number of voluntary sector organisations from both the early years and disability fields, such as Contact a Family, Sense, Sure Start, Disability Action and Mencap, as well as NICMA. These agencies were able to facilitate further requests for interviews to parents. In addition a focus group was convened of parents whose children attend Segal House, a specialised day-nursery for disabled children.

In total, 19 individual parents participated in the research as well as seven parents who took part in a focus group arranged through Mencap. All seven of the parents in the group discussion were from the Eastern Health and Social Services Board area, mostly from the two Belfast trusts and Down and Lisburn Trust.

As can be seen from the following table, all health and social services board areas of Northern Ireland were represented by the individual parents who participated, apart from the Southern Board.

Table 1 – Individual parent participants by health and social services board and trust areas

Health and social services board area		Health and social services trust area	
Eastern	8	South and East Belfast	1
		Down and Lisburn Trust	3
		Ulster Community & Hospitals Trust	2
		North and West Belfast Trust	2
Western	7	Foyle	7
Northern	4	Homefirst	4
Total	19	Total	19

Professionals

Professionals were identified and recruited via children’s services planning groups in each of the four health and social services board areas as well as disability and early years teams within social services, childcare partnerships and the voluntary sector.

In total 15 professionals were interviewed. The table below shows a breakdown of these participants by geography (health and social services board area or regional organisation), specialism and sector.

Table 2 – Professional participants by area, specialism and sector

Area	Specialism	Sector
Eastern Health and Social Services Board 2	Disability 6	Statutory 7
Northern Health and Social Services Board 2	Early years 6	Voluntary 8
Western Health and Social Services Board 2	Children’s services planning 3	
Southern Health and Social Services Board 2		
Regional 7		
Total 15	Total 15	Total 15

As can be seen, despite some initial difficulties, the study succeeded in gathering the views and opinions of a wide range of professionals and parents. All had a great deal to contribute and we thank them for taking the time to share their views with us.

The study questions

Although the style and emphasis of the semi-structured interviews differed for each group of participants, each covered similar topic areas, as did the focus groups with parents. The topics covered included:

- perceptions of the daycare needs of disabled young children
- perceptions of the daycare needs of parents of disabled young children
- current daycare provision for disabled young children and their families: type, number, location, process for allocation to families; gaps; factors determining use of particular services; factors inhibiting use of particular services; suggestions for improvement; suggestions about future development
- services provided by 'specialist' childminders: type, number and location; skills, experience and training required; support required; quality of existing services; suggestions for improvement; suggestions about future development.

All interviews, bar one, were recorded, as was the focus group's discussion. The tapes were then transcribed and analysed using a thematic framework. The outcome of this analysis forms the basis of Section 4: 'Findings' of this report.

Project support and accountability

NICMA convened a Project Advisory Group, which met three times during the study. The group was useful in promoting the study and making contact with key informants. Furthermore, it is hoped that this Group will be instrumental in taking forward the findings from the study through to the development of an action plan.

4. Findings

The findings from the study are presented in this section of the report. A thematic framework was used to report the findings, rather than representing the views of each of the different participant groups separately. Where there is any marked divergence of view between or within groups, this has been noted. Analysis of the data pointed to seven key themes, as listed below. More detailed findings are reported within this broad framework.

- Impact of the current context
- Daycare needs of families with disabled young children
- Quality and quantity of early years services
- Quality and quantity of childminding services
- Training, skills and experience of childminders
- Support for childminders, including networks
- Infrastructure and multi-agency working.

Impact of current context

This research took place at a time of significant change in Northern Ireland.

Early years services moved from the Department of Health, Social Services and Public Safety (DHSSPS) to the Department of Education (DE) in November 2006. The DE also commenced the drafting of an early years strategy during the research period. In addition, a special early years curriculum for two-year-olds is to be implemented (currently the early years curriculum is for three-year-olds). There are mixed reactions to some of these developments, particularly the transfer of early years to education, though in the main respondents prefaced their comments with the fact that it is still too soon to make a judgement on this development:

It is such early days at the moment ... [with] the Department of Education ... In terms of developing a new childcare strategy, we certainly do see it as an opportunity ... but the ... difficulty will be the time it will take because we are starting from scratch almost ... they are talking about a one-year turn around for the early years strategy. I think that is very ambitious (Professional).

... because the shift has now gone over to education ... what does that mean for you as a childminder, so that you don't actually disadvantage your child. And also ... who will be doing the inspecting? ... Whether it's a joint inspectorate or if education is going to get [involved] in that ... (Professional).

... we just saw something at the ... meeting this morning – it was ... supposed to be for the two-year-old programme ... but there was nothing specialist about the under-twos, it was just normal training that an NVQ person would do (Professional).

The years 2006–7 have seen an expansion of some early years services such as Sure Start with 25 Sure Start programmes in existence throughout Northern Ireland by March 2007.

The boundaries of health and social services boards and trusts were redrawn following the Review of Public Administration (RPA), though the new trusts did not 'go live' until April 2007. As part of this reorganisation, services for disabled children have moved from disability teams (with a primarily adult focus) to children's services from April 2007. Generally there was optimism among research participants of the opportunities that the RPA represented, especially in terms of planning to include disabled children and in terms of simplifying the infrastructure:

... I think under RPA generally this is a great opportunity for everybody to sit back and look at infrastructure, and look at the needs of children ... and that ... children with disability have a clear voice, and have access to the services they require (Professional).

... I just think that ... with the RPA and the new change in social and political climate ... it's an opportune time to really profile children with disabilities (Professional).

Each of the four 'old' health and social services boards had engaged in children's services planning (CSP) for children in need (as defined by the Children (NI) Order 1995) for some years prior to the research. While disabled children are legally recognised as children in need, the extent to which their needs (and specifically daycare needs) are being addressed through the CSP process varies from one board area to another. Likewise, while there are four childcare partnerships (one in each HSSB area), the degree to which they have been effective in meeting the daycare needs of disabled children varies both between and within areas:

... well I know with the ... report that we would do for the childcare partnership ... childminding would be looked at and they would be looking at for example rural areas, where it needs to be developed, looking at issues with regards to ethnic minority groups. You know you are constantly trying to develop those areas and then at the Board we would have various meetings with regard to new development of services, childminding would feature as well [but] ... I suppose when people look at it they tend to look at it generically [i.e. not in terms of children with disabilities] (Professional).

... we have looked at general gaps in rural areas and [X area and Y area] ... are two areas that are not well catered for in terms of early years services, so I am sure that applies even more so for children with disability, there is nothing there at all so they are even worse off than having services that you can't access (Professional).

... one of the objectives of the Childcare Partnership is to provide more appropriate childcare provision for children with a disability ... [with] this objective ... we are doing bits but we haven't completed the work (Professional).

... the Wrap-Around² process is working well, in the areas that it [has] affected and parents do seem to get a lot out of it and that's about trying to put all the services in one place that seem to make it reasonably accessible for parents ... and certainly the parents who are not in a Wrap-Around area want to be in a Wrap-Around area but it is really only the beginning (Professional).

The children's services planners have recommended that there is one regional children's services plan for all children following the reorganisation of health and education bodies with the RPA (paper presented to Mr David Sissling, the Chief Executive Officer Designate of the Health and Social Services Authority, January 2007). Ultimately the decision lies with the Minister for Children.

The Northern Ireland Assembly elections took place in March 2007 resulting in a new Assembly being elected. This resulted in devolution being restored, with the new Assembly due to operate from 8 May 2007. It is still too early to say what the impact of the change from direct rule will mean.

Daycare needs of families with disabled young children

... being the parent of a disabled child means that you just [get] a kind of life sentence of having to fight for services and you either do that and you get something or you don't and you get nothing ... (Professional).

This quote from one of the professionals interviewed for this research summarises the experience of many, if not all, of the parents in this study. Professionals and childminders are also aware of the daily struggle that parents of disabled children face.

Type of care

In terms of the daycare needs of disabled children and the needs of their parents the interviews identified two main types of care that parents required: One is respite care, the other is full daycare. Working parents identified the need for both full daycare (for pre-school children) and part-time care (for school age children) while parents who did not or could not work (due to their child's condition and the lack of suitable childcare) identified the need for respite care.

² Wrap-Around is a programme for disabled children and their families run by the Southern Health and Social Services Board, initially funded by the Executive Programme Fund for Children, which has now been brought into the mainstream.

Respite care is usually needed to give parents a break from caring, is short term and for under-fives usually means the child is cared for in their own home or perhaps by being taken out to an activity by a person other than his/her mother or father for a couple of hours. Full or part-time daycare means the child is cared for either in his/her own home, in a childminder's home or in a group care facility such as a day nursery. Full daycare can be for up to nine hours or perhaps even more depending on the work and shift patterns for parents. While some of the parents who participated in this study were employed and needed full daycare, others felt that they could not take up employment due to their child's condition and the lack of services which they thought met the needs of their disabled child. Therefore the needs of both these groups and their children are quite distinct in many ways.

Professionals who participated in the study were aware of these differing needs:

I think the first thing is in terms of respite care and the second thing is actual daycare for parents who go to work which is just like the daycare needs that ... all parents that are working [have] and the added difficulties therein trying to care for a child with a disability, particularly if it is quite a severe disability, finding daycare that can actually deal with their needs (Professional).

The need for respite care (as opposed to full daycare) for parents was also something that several of the respondents identified. Respite care is seen not as a luxury, but as something that is essential for the mental and emotional well-being of both parent and child:

Clearly daycare for many of the parents equates to respite for them, it gives them the opportunity to get on with their daily living and ... it is an essential element to support these parents ... (Professional).

I think they [parents] need respite, they definitely need respite. I think it makes looking after the child bearable – if that's the right word – I mean they are all lovely children but just sometimes they get to the stage where they can't take any more ... (Childminder).

Just the fact of getting a break ... having a bit of me time and have somewhere for him to go (Parent).

... the idea of respite is an important one and certainly many parents I have spoken to are saying that the form of respite that they need would be in relation to short breaks. Short breaks enable them to go off and do something else so that they can with confidence leave their child with someone, even just to go shopping or get their hair done so ... very short breaks like that are important (Professional).

Respite care is also seen not only as a necessity during the day but also in the evenings, therefore requiring childminders or carers to be flexible in their availability:

... the parents ... maybe need a bit of time in the evenings but the minders need to be flexible ... Well ... my own experience of a family that has disabled children ... it is ... they need support in the night time as well (Childminder).

... [there is a need for a] babysitting-type service in the evening to enable parents to have a social life and there is no family support to enable that to be done (Professional).

There was a difference of opinion in relation to whether parents wanted the respite care in their own home or away from it:

... I think parents often would want [respite] care delivered in their own home (Professional).

... [respite care services] are domiciliary based and most parents are now looking for children to be taken out and stimulating them. And obviously in a preschool age group we also have to take cognisance that education is ... a right and therefore inputting respite should have some stimulatory developmental or educational function ... (Professional).

However, the real difficulties of finding any appropriate respite care were also mentioned by both parents and professionals, especially for children who have complex and/or medical needs:

Whenever he [child] is just out of the hospital he is really hyper and so at that stage ... I would need a break ... but ... we are waiting on a nurse coming from Belfast to provide respite ... (Parent).

... the fact that there is an absence of any domiciliary specific support, for example, if a child is trachy³ ... or oxygen dependent, there is no service apart from paediatric nursing that could provide respite. There's no domiciliary service that provides that, unless we can train up on an individual basis for a particular kid, and generally they're high cost packages (Professional).

... they have a thing called Care and Share where a person would come into the house and take Stephen⁴ somewhere for two hours. Now he is not at that stage yet because he can't cope with half-an-hour of doing anything, never mind somebody taking him out of his own environment for two hours ... I didn't think it was suitable for him ... they [social services] have offered me two hours a week at £4 an hour ... to try and find somebody to look after him and there's nobody trained that's going to take £4 an hour to come in and look after a child for two hours ... I mean that's just a non-starter (Parent).

³ Has a tracheostomy.

⁴ All names have been changed to preserve anonymity.

As mentioned above for parents who wish to work, full or part-time daycare for their child or children is needed. However, several parents struggled to find appropriate daycare for their child or children. Difficulties included:

- the general shortage of childminders and home care workers
- different ages of their children
- cost
- location
- a lack of willingness to mind a disabled child.

... I want to go to work and provide a ... quality of life for my children ... [but Alan, aged 11] doesn't need a childminding service any more. He's outgrown that service. Because he was in a house there recently with babies and toddlers, and they came first because obviously they were the priority. And they needed more attention, and then he would get a bit bored ... they had lots of toys and stuff but most of it wasn't appropriate for his age (Parent).

... well I have to [work]. I am a single Mum. My husband's dead, so ... I have to work ... thankfully I have a big family ... [but] ... I must have went to see at least eight different childminders and they're all very, very positive until they met him. And actually when they met him he was as good as gold and ... I got a phone call half an hour after leaving the home saying, I'm sorry, we have to look after our business (Parent).

... I've ended up getting somebody into the house [through a nanny agency] and she didn't have any experience with disabled children ... but she's just a lovely, kind girl and ... it's working out very well (Parent).

... I am a working parent and ... I need someone to come into my home five afternoons a week because of the ages of my other two older sons [11 and 14 years] ... both of them are too old to go to a childminder but they are too young to be coming into the house on their own so I need to have an adult who will be in the house caring for Emma and then being a presence in the house for them coming in from school (Parent).

Inclusion versus specialist services

Any discussion of how to meet the needs of disabled children raises debate about the advantages and disadvantages of mainstream or specialist services. That was true of the participants in this study.

To some extent there was consensus among parents, childminders and other professionals about the daycare needs of disabled young children. In each of the three groups, respondents emphasised that disabled children have the same needs as other young children and that they should have the same access as other children to daycare services:

I think it's good for special needs children to be around the other children plus the other children being around special needs children. There should be very little a difference made between them (Childminder).

Well, we just really need to know that she is in an environment with hopefully combining being with her peer group and being with other little kids but also having therapy done with her that is appropriate to her needs (Parent).

I think that young children with disabilities should have the same right of access to daycare as those children without disabilities. Our experience is ... that the more disabled the child, the more difficult it is to access mainstream services like childminding [or] day nursery placements ... (Professional).

I think they [the needs of children with disabilities] go ... in a line with what other children with no disabilities need. So they have play and stimulation and conversation and toys and all of that stuff (Parent).

Whilst acknowledging this same need, many respondents were also conscious that enabling equal access to daycare for disabled young children meant taking deliberate steps to achieve this or to acknowledge that some children will require very specialist care that is not part of a mainstream service:

... parents of disabled children should be able to have their choice of daycare settings for their children, that's the first bit. The second bit is that means those settings have to be appropriately supported for those children and from what I have learnt over the years is that what that means is that staff in those settings need to have training and support to include disabled children (Professional).

... in relation to daycare, the mainstream services for children ... should be inclusive of all children including children with disabilities ... but ... I have to say I am always pulled between the need for specialist provision versus mainstream provision because having specialist provision sometimes feels like it's run in contrary to the principle of inclusivity or normalisation but I am convinced that some of these children have such specialist needs that you do need a different type of an arrangement for them (Professional).

... they very much have the need for an integrated setting because it [a childminder's house] is the home environment; because it is children of different ages; those children need to feel integrated within that setting and not excluded. So obviously we need to do a lot of work with the adult to make sure that child is fully integrated within that setting (Professional).

... we [parents of children with disabilities] need to have the same choices as everybody else, we shouldn't be penalised because our child is disabled (Parent).

However, other people also pointed out that even with some of those supports, some children would not be able to access the service. Parents of children with life-threatening conditions, in particular, highlighted the need for one-to-one care with a person trained in the specific condition that their son or daughter has to live with:

To me a lot of Chris's disabilities are hidden because he can go into any environment or any situation and for all intents and purposes people are going to look at him and not see any problems. He has very complex and very severe needs ... I feel he needs somebody very trained and highly structured to be able to cope with him ... (Parent).

... As a Mummy of a wee disabled child it's very hard ... you know, you're responsible for them and you don't want to give over that responsibility because he's your child ... he can turn and he has stopped breathing on many occasions and just for them [carers] not to realise his wee signals ... (Parent).

Professionals indicated the need for realism when attempting to meet the needs of children with complex needs in mainstream settings:

... [the needs] are quite significant in the first instance. Obviously with the change in trends, particularly technology and medicine, we are having the survival rate of children significantly increased. Coupled with that we have parents' knowledge base increasing so much so that they want to access mainstream educational facilities and day services for their children. We have found this particularly difficult to achieve because our childminding services generally, there is a dearth of provision that would accommodate children with disabilities (Professional).

The need for one-to-one care was understood by some childminders, but eventually they would like to integrate such children with others in their care:

I think some children really need one-to-one to help them, certainly in the beginning and then at a later stage then they can be introduced to have other children with them. I think it is very good for them to have other children around them, but I think until you see the development in the child and what the child needs, a one-to-one basis is much better (Childminder).

Some professionals pointed out that, regardless of where the child was cared for, he/she would need to be able to follow whatever programme had been agreed for him/her in terms of attending clinics, accessing different therapies or interacting with other professionals:

... if you're a childminder, you're in loco parentis, and that would mean that if there's a particular programme your child is going through that should be carried out by a parent, whether it's speech and language therapy, it might be physiotherapy, well then that would need to come with the childminder as well (Professional).

... we [parents] just really need to know that she is in an environment with hopefully combining being with her peer group and being with other little kids but also having therapy done with her that is appropriate to her needs (Parent).

The disabled child within the whole family

Many respondents highlighted the need to address the needs of the child within the context of the needs of the whole family. Disabled children may be part of families where the other children do not have disabilities. Interventions need to take into account the particular circumstances of the family, whether it is a single- or two-parent family, whether the child has siblings, if the siblings have disabilities or not, and the age of their brothers and sisters:

... I suppose you're hoping it's tailored for the whole family and the parents that they get that support (Professional).

... if there is a notion of specialist childminding it needs to be somebody that has to be attached to a family as opposed to only looking after one [child] because if something happens to them [the other two children] then the person or adult who is responsible is as responsible for them as they are for Emma (Parent).

... you've got to move out of the childminding situation because of age. And for those children I think you need some sort of after-school resource (Parent).

Generally the needs of parents of disabled children were seen as being much the same as the needs of all parents in terms of:

- reassurance from the daycare provider
- the competence of the carers
- a willingness to work in partnership with parents to meet the needs of their child.

Well, I think that the parents need just to really have the knowledge that the childminder or the person who will look after the children does have knowledge and is confident and really will work in partnership with the parents ... and that you really have to show that you are understanding and you have to show the parents that you are listening and that you are totally taking on board what they are saying and that you are doing what they are asking you to do (Childminder).

... what I've come across with the parents, they ... want their children to be treated as individuals but you know as normal children, without saying too much about the disability. They need a lot of reassurance, a lot of parents, especially the first time children with, you know, disabilities, are very anxious about leaving their children. Yes, I would spend more time

settling in and trying to get more information or as much information as possible, just to keep the ... confidence of the parent up when they are needing a childminder (Childminder).

I think parents have the same aspirations for their disabled children as they have for any of their other kids. I think parents of profoundly disabled children perhaps lack confidence in mainstream services ... If a parent feels that their child needs a lot of additional support then they naturally want the best that they can get and in a lot of instances then they perhaps feel that they can only be provided by ... paediatric nursing (Professional).

Well, they need to be reassured that when the children are in those settings that they are safe ... a basic level of safety and they need to know that they are being included and that they are not being discriminated against when they are in those settings, by being neglected or not included in activities, etc. They need to know that the staff in those settings have the expertise to deal appropriately to give their children the daycare that is appropriate to them. That's what they need to know I think. I mean there are also other issues, aren't there? I meant there are transport issues as well for them to daycare settings which are more complicated than for non-disabled children (Professional).

As can be seen from this section, the daycare needs of families with disabled young children vary in terms of care to cover working hours or care for respite purposes. Apart from needing to appreciate the specific condition of a disabled child and its consequences, the needs of a disabled child and their parents are similar to those of any parent and any child. Parents want their child to be well cared for, treated as an individual, and need their other children (if any) to be catered for too. Childminders and professionals are aware that such parents need a little more reassurance about services than is often usually the case, perhaps because they have had a negative experience of mainstream services already.

Quality and quantity of current early years services

The recent past has seen the growth of early years services in Northern Ireland, particularly private day nurseries. Statistics indicate that there has been an increase of 66 per cent in the number of places for children in day nurseries in the period 1999–2004 (DHSSPS 2005). In contrast, there has been a reduction of 14 per cent in childminders between 2003 and 2006 with a corresponding reduction in childminding places by 19 per cent (DHSSPS 2006).

Despite this increase there is still a lack of provision in general and the situation is much worse for disabled children. Parents of disabled children often find it difficult to access early years services either because they simply do not exist in their local area or because the quality of care in such facilities does not tend to factor in disability:

I don't think there is a service for disabled children ... there isn't a service. And even social services provide nothing. They provide you with a list of childminders but they can't provide any service ... I don't have a childcare facility at the minute and I've exhausted every single avenue that I possibly can ... It's appalling (Parent).

While there are some facilities that provide respite care for disabled children on a residential basis, many of these are not open to children under the age of five. For these under-fives community options are the preferred choice of professionals and indeed of many parents too. Often the community options are provided by voluntary sector organisations and are bought in by a health and social services trust:

... we can offer a range of care which offers the family support perhaps in the child's own home, like Crossroads or Barnardo's Choices for Children. Overnight care for pre-school age children is probably quite limited, Crossroads and Home Links maybe offer say one, two to three sessions per week where they'll look after the child, perhaps in either the child's own home or the carer's own home, to give the parents a short break. The other option that we have in the Trust ... [is] the Breakaway scheme. And again Breakaway would be carers who would offer a short break ... a weekend a month, something along those lines ... say from a Friday evening to a Sunday afternoon (Professional).

Early years services for disabled children: specialist or integrated?

In thinking about the qualities of a service, again the issue of segregation versus integration was raised in terms of disabled children accessing specialist services. In interviews parents raised several factors, listed below, that encouraged them to use a service, whether specialist or integrated. These included:

- being reassured by the professionalism of staff
- being recommended by other users
- being registered and regulated
- location
- cost.

In addition, some respondents mentioned the need for specialised equipment, toys or facilities, though these were in the minority.

Confidence in services

Several parents and professionals mentioned the need for parents to have confidence in the service being offered in order to be able to use it:

I think having confidence in the service and the people offering support (Professional).

... I think that parents would be willing to use any service that they had sufficient information about which would reassure them that services could meet their child's needs and would offer stimulation, opportunities, those kinds of things that you hope your child is going to have if you're not caring for them yourself (Professional).

You would use a service if you know it is reliable or trustworthy, that it is well thought out and that people are qualified to deal with your child and that they understand the different levels of intelligence (Parent).

As a parent right now if I was going to choose somewhere to put Robert into ... where the staff were highly trained in speech problems ... have been trained in behavioural problems ... and the staff could actually talk to me about dyspraxia and autism and I actually knew that they actually knew what they were actually dealing with (Parent).

For me it is very much about reputation, Mencap is synonymous with the whole area of learning disability, so it is a case where people who have a proven track record in delivering services to their client groups (Parent).

Something to benefit the child

The service would also need to be beneficial to and enjoyable for the child. Parents, as opposed to any of the other respondents, particularly identified this:

[I would use] any service that is of benefit to my child, this is why I use Sure Start because it gives her a chance at the moment ... Sure Start is a good thing [as] it gets her to be with other children (Parent).

... as I say that Cedar Foundation was great for Tony ... it gives you great encouragement and he enjoyed the thing as well (Parent).

... anything to help Andrew out ... but just to know that ... Andrew was happy to be there and I wasn't worried about [his condition] ... and about him getting on with other children because he is an only child, he was just so content to be there ... he absolutely loved it (Parent).

Child-centred services

Parents and professionals mentioned the need for services to be child-centred as being an important factor, as did some childminders:

It would boil down simply to whether the person offering the service got on well with the child. So many professionals have spent so much time with her; I think we can pick that up pretty quickly now where there is a genuine empathy (Parent).

... knowing that your child's liked and valued is actually really important
... And how does the person respond to your child? (Professional).

... anybody in that field has to love children ... children are so important
... and you need to look after their health and welfare – not just doing it
for the sake of a job (Parent).

... I think if they see the childminder is willing to adapt the environment to
the particular child's needs and not the other way around, expecting the
child to fit in with the childminder, I think if they see [what we] are willing
to do that it encourages them (Childminder).

Barriers to accessing services

Respondents also identified barriers that would prevent or inhibit them from
accessing services in general. There was a great range of these and they
included:

- information
- acceptance of disability
- transport
- physical access.

Information

The need for information was clearly highlighted by interviewees. If parents do
not know what services exist or what their child is entitled to, they cannot be
expected to access those services. In particular positive feedback from other
parents would encourage use of services:

Probably feedback from other users would be the first thing that would
come through. I think secondly ... that they need to be made aware of
what the services are and I think thirdly they probably will also be
encouraged if they are confident that the staff who are running these
services are suitably qualified and that there is effective governance
arrangements in place. Accessing the service is an issue if ... they
require transport ... and ... cost (Professional).

Sharing information, that minders have like a plan drawn up of what they
would do in the day, activities, that sort of thing, healthy eating, that sort
of thing, maybe a wee handout to give to parents ... maybe health
visitors giving out information (Parent).

They should give you the information you're entitled to (Parent.)

Well, first of all they [parents] have to know that it's there. And maybe if
you don't have a lot of other children, because if it's your first baby you
don't know the routes anyway, and you find your way blindly ... it's luck
more than anything else that you actually end up with somebody ... I
think that's even more difficult if your first child is a disabled child. So I
think knowing what's out there is really quite important (Professional).

... I suppose it's always ... other professionals having the right information to be able to give out the good information (Professional).

... I know from our Wrap-Around project that parents being put into contact with self-help groups is very, very important ... They need contacts ... the people that they come into contact with around the disabled children's needs at the hospital, at the Child Development Clinic, the GP, the Health Visitor, those people need to know about self-help groups or about the processes that you need to go through to get support for daycare for a disabled child (Professional).

Acceptance of disability

While some childminders felt that parents not accepting a child's disability might inhibit them from accessing services, none of the parents themselves nor any of the other professionals mentioned this as a factor. This might be because all of the parent respondents in this research have come to terms with their child's disability and/or diagnosis and were more likely to view their children not just in terms of their disability but as children who happen to have a disability.

Transport

Transport or the lack of it was identified as a key factor for parents and children living in rural areas in particular, but also in urban areas where housing tends to be on the periphery of a town and where there is little, if any, public transport, especially that which is accessible for disabled children. In addition, in urban areas the siting of some services, particularly in interface areas (for Protestant and Catholic communities to meet) means they are not accessible to those people who do not feel safe having to cross such boundaries. One professional also mentioned that intra-community paramilitary or political allegiances also were a barrier for some parents within an area.

Physical access

For children with physical disabilities, the need for physical access to buildings where services were based was mentioned. Often services are provided out of old buildings that were not designed for people who have less mobility:

... with Peter I have to carry a suction machine, a kangaroo feed, his own bag, my bag and depending if he's not well, oxygen has to come along, boxes of tissues, you just don't ever travel lightly ... his chair is slightly bigger than a pram and it's just, it's not easy to get round ... we put ... off [going to the clinic] as often as possible unless ... he was sick and he had to go, because it wasn't worth the hassle (Parent).

Quality and quantity of childminding services

As well as considering the needs and supply of daycare more generally, this study asked specifically about childminding. The interviews provided rich material on the role of childminders in meeting the needs of disabled children. The key themes raised were:

- shortage of childminders
- barriers to accessing care from childminders
- lack of specialist childminders
- economics
- difficulties multiplied.

Shortage of childminders

Respondents were aware of the shortage of childminders in general in Northern Ireland. The shortage of childminders (specialist or generic) is seen as a barrier to employment for parents, but also depriving very disabled young children of the opportunity to interact with their peer group:

If someone offered me a job I can't do it, the childminding isn't there for his needs because there is so much going on with him all the time ... So it needs to be somebody that has the patience to actually work with him [on a one-to-one basis] (Parent).

... my husband phoned loads of places because he thought for me to go back and work for a couple of days would ... help ... and he couldn't find anything (Parent).

... my rationale was that Emma would be much better off being with other children, having that stimulation rather than being home with me watching the Tweenies, watching me doing the Hoovering or making the dinner or something like that and for me to have her looked after she would receive better stimulation than she would if she was sitting in the house with me (Parent).

Barriers to accessing care from childminders

Childminders and other professionals were aware that parents of disabled children faced more barriers to accessing childcare than was the case for other parents:

I would think that parents with children with disabilities must find it much more difficult to get their children minded (Childminder).

... I would imagine right across Northern Ireland because we have a shortage of childminders generally and in some areas it is much worse than others, that the choice for parents who have a child with a disability will be much lower because there are so few childminders who are either prepared or who have the knowledge to be able to provide that sort of specialist service (Professional).

... I think there aren't enough childcare places for the parents to go around and pick, it's really a matter of who's available and have they got a place? (Childminder).

Some parents felt that childminders discriminated against their child because of their disability and were unwilling to mind a disabled:

I have never had difficulty getting childcare for my other [able-bodied] two children, but I have had major difficulties getting childcare for David. Both in the childminding setting and also accessing nursery or crèche places ... It's almost discriminatory I think in some ways for the children and also for the parents (Parent).

It may be that this is not intentional discrimination as seen by parents. It may be that childminders do not have the confidence to care for a disabled child and, in fact, have a fear of such children:

... they [carers and childminders] lack confidence in looking after the young child with disabilities (Professional).

... people are nervous of children with disabilities, people are very anxious and awkward around them except for people who either have [disabled children themselves] or experience [of working with disabled children] and the difference between them and others is extraordinary (Parent).

I think the childminders panic, you know a child with special needs, oh, I could never do that (Childminder).

For childminders there is the issue of balancing the needs of the disabled child and any other children who might be minded at the same venue:

I know there was lady who came with a young baby and they were going to arrange for somebody to come and talk to me about the needs of the child, but I decided not to take the child on because I was already looking after a young toddler and the baby was only three months old and I just thought it was too dangerous a situation. If the child I had been minding had of been a year older than that ... I mean, with a toddler you can bring in a normal baby, but a baby with special needs you have to be careful because the toddler doesn't understand (Childminder).

Parents too were conscious of the competing demands that potentially all children make of childminders:

... I don't think one childminder could look after two 'normal' as such children and a special needs child because a special needs child, in my view, needs a one-to-one all the time and somebody who understands the problem, the difficulties we have in doing things that an ordinary child just takes for granted (Parent).

Lack of specialist childminders

Some professionals in the statutory sector were aware of specialist childminders who were employed by some health and social services trusts in

order to provide respite care for disabled children. However, sometimes these childminders were not specifically allocated to disabled children and neither was this kind of service available across all of Northern Ireland:

The Trust does run a specialist childminding service and that is particularly useful and it's particularly in demand as well ... Family and Child Care Services would use it as well and we would use it for children with disabilities (Professional).

... there are one or two sponsored childminders with the Early Years Team ... it is just a general sponsored childminder scheme (Professional).

Specialist childminders have been developed here ... particularly for children from childcare and from child protection but there is not – to my knowledge – any specialist childminders for disability (Professional).

None of the parents and only a minority of the professionals from the voluntary sector were aware of the possibility of specialist childminders as a service option. Interestingly, childminders who participated in this study did not consider themselves to be 'specialist', even if they did take care of disabled children.

Economics

Another key issue is an economic one. Childminders are self-employed and are usually licensed to care for up to six children (three under the age of three and three aged four+). If any child – such as a child with a disability – needs more intensive care or attention than his/her non-disabled peers, this reduces the childminder's capacity. Some childminders have said they do not want to pass on the extra cost to the parent:

Well, I felt that when I was looking after a child with special needs, which I still am, I don't take my whole intake of children. I am allowed six and I would never go over the five. Even though the child has got older, I still need to give that child a lot more attention ... not in a learning way or anything like, but toileting and things like that. I feel that I can't take on my six which affects, obviously, my income but I don't reflect [that] in any of my prices or anything like that (Childminder).

... I know that parents shouldn't have to pay ... anything more than they do. I think it's unfair for parents that have to, you know ... you should only have to pay for a child, one child (Childminder).

Some childminders and professionals did state that one-to-one care would cost more or that to provide such care would not provide a living and therefore was not feasible:

It doesn't pay as a childminder ... you know, you would need like a one-to-one with that child and your £2.60 an hour would not cover that (Childminder).

It would not be cost-effective for a childminder to have a child that needs a lot of extra attention because of disability so there all kinds of problems (Professional).

... I think they [parents] need some extra financial support to help them to get the daycare that they do need because it does cost more ... if they feel their child needs a one-to-one basis they are going to have to pay more for that (Childminder).

However, at least one parent did incur extra childcare costs with a childminder due to her son's disability:

... children with disabilities [are] more expensive ... which did happen with Michael. I paid more than somebody who didn't [have a child with a disability] (Parent).

There were some suggestions as to how the extra costs could be met. These included:

- a grant scheme
- protected funding within social services budgets
- the use of a subsidy scheme.

... perhaps there [could be] some sort of a grant for parents with a disabled child which might assist them in accessing childminding, or if the grant could be paid to a childminder who would agree to take a disabled child, whichever way around. An extension of the Disability Grant Scheme⁵ would be wonderful, so that there's not a financial penalty for either the childminder or the parent (Professional).

... unless ... [the funding] was ring fenced through the likes of our sponsored daycare or something who obviously trains childminders, and signs them off, and does all the quality assurance, unless they had a particular funding stream attached to them, because we, as a disability programme, certainly couldn't ring fence particular money for childminding, because you can't gauge in a year what the need's going to be, and you can't really project or set hours against it then (Professional).

... I think really what is needed is some sort of subsidy, that there is some sort of additional funding that goes with the child that gives the parent a lot more options (Professional).

⁵ The Disability Grant Scheme is a small grant scheme administered by the District Childcare Partnership that enables health and social services trusts to make grants to registered mainstream daycare facilities to assist with the placement of a disabled child.

Only one professional did not feel that childminders who cared for a disabled child should be paid more than those who cared for children who were not disabled – however, it was suggested that perhaps such childminders might ‘do less hours’ if the work is more demanding.

Difficulties multiplied

This section has highlighted the many barriers that families with a disabled child face in accessing childcare in general and childminding in particular. But of course for many families all those barriers come together to create cumulative difficulties.

For example, one professional explained how a lack of confidence in caring for a disabled child plus the economics of the situation can conspire to ensure that childminders do not want to or feel they cannot mind a disabled child:

... I think in many of those [childcare] settings people don't have the confidence and I would say confidence rather than competence sometimes when you are dealing with children with a disability ... and capacity is an issue ... I mean take, for example, childminding: if you are a childminder and you are registered for three children, you require three children to make the funding work for you because you are paid so much per child. Because a child has additional needs you have got to reduce the number of children; unless you are charging the parents of the child with a disability more, you are actually out of pocket so it doesn't stack up financially. So the actual cost of provision for a child with a disability is more by the very nature of the level of need so that is one barrier. Why would a childminder take on a child with a disability if a) they don't feel confident about it, b) then they don't feel competent to deal with it, and c) from an income point of view they are going to lose out? (Professional).

Well there all kinds of problems with finding children with disabilities suitable daycare because of the staff requirement: if they have severe disabilities then they need one-to-one or maybe even just a half-person [more] in place to help staff and that can be difficult. There is no funding really available to cover that. We also require that for the Children Order that they should get the help that they need, but there is no funding to go along with that. Particularly before they have been diagnosed there tends to be problems with the level of staffing and funding (Professional).

While professionals may have highlighted the fact that some disabled children may present challenges to the business side of childminding, several parents whose children have complex needs doubted the ability of childminders to effectively care for their children:

I wouldn't actually let them look after my son if they were just a childminder and ... if they were just being trained and then brought in to my home. I've tried that before with the ... Trust. They had sent me two ... carers that had looked after elderly people ... so they were no help to me really ... they just weren't competent enough, whereas if they had some experience before they came to me, that would have been fine (Parent).

Training, skills and experience of childminders

Participants were asked what they thought childminders needed in terms of skills, experience and training in order to meet the needs of disabled children. This section of the interviews provided a range of opinions on all three aspects.

Adequate and appropriate training

The need for adequate and appropriate training of childminders was something that almost all participants highlighted. As well as basic childcare training, generic disability awareness training was mentioned, but more emphasis was put on understanding specific conditions and their manifestations and consequences:

... I don't think they need any specific training ... but I think they need to know about the condition of the child and how to work with the child and help it really and I don't know if there would be any particular training course that would make them a better carer or a childminder you know, but obviously what they have in place for being a normal childminder is also good enough ... (Parent).

... I suppose in terms of general training, they [childminders] do need a lot of support in terms of disability awareness, integrating children within the home-based childcare setting, inclusion, equal opportunities for all children really, including those with a disability – those would be the sort of generic topics I would like to see included but then maybe some sort of mechanism where you could look at special disability syndromes and ... I would assume that those childminders already have, you know, child development, child protection, business skills – all those sorts of things (Professional).

Well, all of us have an elementary first aid course. If you are dealing with children who have medical needs, I would think you would need to find out a bit more about these needs (Childminder).

Every special needs child is different from, you know, from each other and it will just be really learning from them and also be given a basic training on how to work with special needs (Childminder).

I think it is very much around their ability to have warmth; it is no different to anybody coming into my house and minding my child, somebody who is child-centred. People can be taught to do things but you can't teach someone to enjoy being with children, that is something that is inherently there. I suppose, depending on the complexity of the needs of your child, they may need quite up-to-date first aid training or medical training but ... because every child will be different, they will then be trained in what the specific needs of that particular child is (Parent).

In terms of development you will need what you would expect a childminder to have in relation to parenting and management of children, and your general skills and knowledge you would expect any childminder to have, but enhanced skills and knowledge in relation to the type of disability that you are dealing with – and I think that it nearly has to be done on a child-to-child basis because some of these children, particularly with more complex needs, may have medical conditions like tracheostomy, epilepsy, for the management of that, those individual childminders need to have that kind of knowledge for each individual child (Professional).

... I think it's about skilling up ... all childminders [for] ... any child to be able to access their service ... and it's about ... building up the knowledge ... and skills (Professional).

Of course some children do have very specific needs that can only be met by specific training. This is particularly so for children with life-threatening conditions, but can extend to other conditions too:

Well, they would need basic life support. They would also need to know how to look after a child with a tracheostomy. It's actually nursing skills that they would actually need (Parent).

... well obviously to be able to do all the bits and pieces, suction ... you know, to be able to give oxygen, to do CPR if necessary and to keep cool. No matter what, do not panic, and do not leave the child (Parent).

... I do feel that I need more education regarding [the children's] condition and it is very difficult to get that. I have done various courses; at the moment I am doing a part-time OU⁶ degree in early years but even a course like that doesn't go into special needs in any real depth ... but it doesn't actually deal with autism or any other disability in great depth (Childminder).

I can only speak from his point of view here now obviously ... Makaton trained, which is a sign language they would use for kids who can't communicate verbally, some sort of behavioural type training where they can deal with kids who have very extreme behavioural traits, which he does (Parent).

⁶ Open University.

Sometimes working with specialised equipment was mentioned:

I think training in using the equipment that parents have to use at home (Parent).

Given developments in medicine, science and child development, many parents mentioned the need for training to be constantly updated:

... I think it would be of value that people are [provided] with ... up-to-date information, research on particular areas ... like, for example, behaviour management ... or child development ... (Parent).

Anti-discrimination training and willingness to learn

Parents who felt they and their child had been discriminated against because of the child's disability tended to mention the need for anti-discrimination training. In addition, there was a recognition that childminders did not necessarily have to be medically trained or have other specialised training. Rather, people felt that a willingness to learn how to communicate or treat the individual child was a necessary prerequisite:

... I think these children need to be treated normally within a family ... to see beyond [the disability] ... So unless really there was something medical that was required, that's different ... (Parent).

Somebody that could come in and prove to me that they can work with him ... and have fun with him and be able to communicate with him, which means a wee bit of sign language (Parent).

She [the nanny] hasn't got special training [in working with disabled children], but ... I trust her and she's kind and she's caring and these are the kind of qualities you would like [someone minding your child to have] (Parent).

... somebody who is willing to learn. It is very much about a group of people who have a willingness to work constructively with these children. Just because somebody has a qualification in childcare doesn't mean that they could necessarily care for children ... I need someone who is committed and consistent ... Somebody who is willing to give their commitment, who [is] prepared to be with you for the foreseeable future (Parent).

Delivery of training

There were many suggestions as to how such training might be delivered. Some respondents mentioned placement-type training, either in the child's own

home prior to the commencement of the childcare contract or in another setting such as a special school. In addition, the expertise of parents was also recognised:

... it would be useful if I had been taken to the home of somebody who had a child with special needs so that I could talk to the parents and identify the needs of the children and get a bit of practical experience of looking after them to know first-hand whether I would be able to do that because it's all right in an imaginary situation, but when you have the children with you maybe for eight or nine hours, it is often different from what you had anticipated (Childminder).

They would need to obviously do hands-on training like in daycare centres or even in special schools and let them see how ... to be around a child. They need to be taught properly (Parent).

... if there was like a placement-type scheme where they could gain some experience of just working with disabled children. Because I think it's very difficult to imagine if you've never had experience of working with an ill or disabled family member just what the impact of that is going to be, and perhaps more people would be willing to volunteer if they could see that maybe it's not that difficult after all. I don't think that there's any theory substitute for that (Professional).

... I suppose the best training would be actually from the mothers, you know, the mothers and fathers or the carers that look after the child (Childminder).

... if the childminder could be linked in if the child goes to another setting ... We would be happy enough in a sense to let the childminder maybe even come up and see the child in this environment and have a chat with the staff and things like that (Professional).

Another possible model that could be used is based on the training that paediatric nursing staff have been able to give to non-medical carers for children with complex needs in some of the health and social services trust areas:

... we have had children with medical conditions in hospital ... and we ... have developed care arrangements for them coming out of hospital and ... in a couple of cases we have trained care staff ... they are ordinary people ... with ordinary skills like parenting skills and childminding skills, we have trained them up in the needs of that particular child and they know what to do in an emergency or sudden [change] in the child's condition (Professional).

Does training increase capacity?

However, training in itself will not necessarily guarantee an increase in the number of childminders willing to accept disabled children. During the lifetime of NICMA's Children Come First Childminding Network for disabled children over 150 places were filled on training sessions, yet only 27 childminders were recruited, minding a total of 44 children from 13 families (NICMA Annual Report 2002–2003). During the research one of the professionals also reported a similar pattern in her health and social services trust area:

... we would find that you would get some childminders agreeing to come to the sponsored childminding training ... You know, you would invest the money in the funding and they maybe wouldn't then take on a child with special needs (Professional).

There could be a variety of reasons for childminders not accepting disabled children following completion of training. For example, they may feel it is no longer for them now that they know more about what it entails; they may have been motivated to do the training for their own professional development; they may feel that they will lose money by taking a disabled child if they cannot fill their quota of places (in the event that a child needs one-to-one attention).

Is experience necessary?

In terms of experience, there tended to be two schools of thought among our participants. One is that experience of childminding and life itself is vital before undertaking childcare with disabled children. The second one is that experience of minding children without disabilities is not necessarily a prerequisite, or even necessarily a good thing, if it is merely a matter of repeating poor practice or being resistant to new ideas:

... you need a bit of experience behind you. There's no point in 17- and 18-year-olds going in. They need to be experienced in childcare, I think (Parent).

I am not a great believer in experience, I think experience just often means you repeat mistakes ... One of our therapists is 19 or 20 at Queens and is studying psychology so basically she gets to do fieldwork three times a week and she gets paid for it, and I mean her enthusiasm and excitement and energy is brilliant, uplifting, and she's got no real experience at all. But other than that, she knows what she is doing, she is very well mentored, she knows exactly what she is supposed to be doing. So I am not worried about experience (Parent).

... you're going to have somebody who is not one bit experienced who is absolutely fantastic and somebody who has loads of experience and isn't. So experience isn't a necessity for me because you can't learn until

... somebody's given you a chance. Skills, empathy and all the usual skills, a very caring attitude [are more important] (Parent).

It's two-sided ... I think in his case, and I can only say this from experience, because the ones that have had lots of experience actually seem to be able to work with him better, but at the same time I have actually had a girl in, she has just left university, she did her psychology degree and she worked really well with him. So I don't really think you can give a definite answer to that, it depends on the person (Parent).

The 'Catch 22' situation was also mentioned in terms of how people would not necessarily have experience in caring for a disabled child prior to them being requested to do so by parents:

Experience would be a difficult one, because if they hadn't had a [disabled] child [to mind] they are not going to get the experience, but that doesn't necessarily mean that they wouldn't be a suitable person (Professional).

In addition, there was a feeling among some parents that what was needed for successful minding of their child was that the carer was confident and that it was possible for them to learn to carry out quasi-medical procedures or deal with a particular condition. After all, many parents have had to learn to use equipment or carry out procedures in order to keep their child alive; some have trained other family members to do likewise:

I think [you need] confidence. I mean if you don't have the confidence and you're not sure of yourself. Although, saying that, if someone had probably said to me at the beginning, 'You'll have to do all these things', I'd have been like, aye get on, but I, it grows on you, and it's like all our family, they can all do the things [now]. When you have to do it, you'll do it (Parent).

In reality it appears that childminders who express an interest in caring for a disabled child will rarely be 'new' childminders. Sometimes they may have a disabled relative from whom they learnt something of the needs of disabled children:

... usually what happens is that nobody comes forward for specialist childminding unless they have been looking after children for some period of time so, I think they would need at least two to three years of ... general childminding duties ... Anybody doing specialist childminding doesn't come forward unless they have a real desire and a real interest and a will to provide that sort of service because it is not hugely paid so they need to have a real interest in it and we found too quite a number of people had within their extended families somebody with a disability or special need and that is where the interest came from (Professional).

Support for childminders, including networks

The majority of respondents felt that childminders who cared for disabled children would need some form of support. This could be through statutory partnerships, organisations such as NICMA or through childminding networks.

At a minimum it was felt that childminders would need to liaise with other professionals involved in the child's care such as speech and language therapists or social workers:

Depending on each child, they will need certainly support from the social worker who is managing the situation or whether it is the health visitor or a specialist nurse. They need that kind of professional support on an ongoing basis and they will come across issues that they need to be able to refer to people and know that they have somebody that they can talk to about how the situation is going and how it can be managed ... they will probably need ... support from some form of childminding coordinator who will ensure ... the possibility of fully updated training and who will take responsibility for monitoring their practice because somebody needs to do that. So from my point of view this has to be part of service rather than individual childminders going on about their business (Professional).

... I think social services or the health board or whoever ... the childminding people are organised through [need to provide] ... a back-up if they have a query or problem they can go to them and know that the support was there for them and the back-up was there (Parent).

... access to speak to somebody if they weren't sure, like I would have the community paediatric nurse. Even something as simple as the tube being blocked or machines not working and that. Just somebody, like a 24-hour call, as in somebody who can give advice in all areas of a disabled child (Parent).

I think the capacity to link into named professionals in terms of a support structure, whether that be through the identified social worker working with the family or the child with the disability, whether it be dealing with the specific specialist around, whether it be physiotherapy, occupational therapy, speech and language therapy, paediatrics, but that they do have access to these people for advice as required (Professional).

I would say it would be a very stressful job, so yes I would say they probably would need a shoulder to cry on (Parent).

Childminders themselves mentioned the need for support in terms of getting advice about dealing with particular conditions or behaviours. Some specifically mentioned organisations like NICMA or social services early years teams, while others spoke about self-help groups, either for childminders or for carers or parents of children with specific disabilities:

I think they would need just someone at the end of the phone anyway, you know, to talk to them in confidence about any problems you would have had. ... NICMA ... have an advisory thing, if you have problems they are very good ... and my social worker is very good and if I have any problems I can ring her in confidence and she will ... give me general advice and tell me where to go for help (Childminder).

... if they are able to join ... these voluntary groups ... generally talk to other parents or carers, drop-in centres or something like that (Parent).

[Childminders need] ... support ... for mental strain and for just to be able to guide you in what activities, what's best for the child, what's best for their needs (Childminder).

... I think they could come and keep like a regular visiting pattern so that you know how to deal with the child's stage of development and that ... When ... somebody come to the house with me for that child and I thought that was a great advantage because she had already worked on a one-to-one with the child so when they left then it was up to me just to follow it through then to the next session to help that child (Childminder).

Some parents and professionals did not feel that childminders who cared for disabled children would require any more support than those who cared for children without disabilities, though these were in the minority:

I think it is a case, yes, there can be a network there for them to be involved in the normal support network, whether that be through training courses or befriending or mentoring schemes for childminders [but] I would say if somebody is not coping with the child that they are looking after, then should they be looking after that child in the first place? (Parent).

... if they're going to be trained and skilled enough, they should be in the position to provide the support for the parent ... I mean they'll obviously have their own organisation or whatever whereby they can get appropriate work support, but I don't really think they should need anything additional (Professional).

Others thought that support groups specific to the type of disability might be more useful than generic support groups:

... I just think the range of special needs is so vast that while ... I would support a network, I think that perhaps the support of the groups specific to that disability might be more beneficial if it is appropriate (Professional).

Some parents had some specific ideas about how support might be offered, some of which was based on their experiences with other service providers:

... I think also for parents it [would be] fantastic to know that mentors or managers were actually coming to visit the childminder working on site. I think that is just such a confidence boosting part of it. You know you have got a childminder and once a month someone comes in and spends an hour ... observing ... just literally observing, writes a little report, you sit down and discuss it with the childminder – brilliant, gives you lots of confidence that they are not operating on their own, other people are giving a few ideas (Parent).

Have support groups that can get together and discuss any problems and concerns you might have and also ideally if you had a [childminders] and toddlers group nearby and children could be welcomed as part of the group too and it would give the carers a chance to get out and mix with other people and see the children they are caring for hopefully mingling with other children, otherwise it could become very isolated (Parent).

Childminding networks

Two childminders in the study had experience of the Children Come First Childminding Network that NICMA had run from 1999–2003. One of these commented that the Network had been beneficial to her:

... I had a lady come out to talk to me about it and she trained me and everything (Childminder).

A minority of parents had had contact with the Children Come First Childminding Network in the past. There were mixed reactions to the Network and to childminders accessed through it:

... two of them [childminders] were in the Network for specialised child minding. But ... there wasn't training that I saw that was available for them, and they were anxious of course ... it was very difficult ... to get people to come on board with specialised childminding (Parent).

Childminding networks are regarded by some as being positive, especially in terms of having the potential to address both full daycare and respite needs and being sustainable – for both parents and childminders:

I am a very strong believer in the use of childminding networks and particularly for children with a disability. I have looked at how they have been used elsewhere and I think it is about trying to provide a dedicated service that is fairly flexible in terms of its provision; you can have full daycare needs met, you can have respite needs met and be supported properly, and also in terms of the proper accreditation of people, just basic registration requirements, accredited status, a quality mark that would be available to actually give parents a lot more confidence in the service. The fact that it is resourced would also be a very important one,

it would have to be properly resourced, properly trained and a service that is locally available, locally accessible (Professional).

I think the idea of a network [is good], that it is not just a small number of individual independent childminders operating on their own, that you have it coordinated in some way that can actually ensure that you have the best use of that service in terms of acceptability and availability (Professional).

I think in an area like [this one] ... there is the opportunity to develop one or two childminding networks that would increase the availability of respite care but it has to be flexible and ... It requires support, it requires to be established as a scheme and as a service in its own right, properly managed, properly supported and properly resourced (Professional).

Infrastructure and multi-agency working

One of the clearest messages coming from the research is the need for multi-agency and partnership working. Professionals from statutory services are certain that those services do not have the capacity to deliver on *all* of the needs of disabled children and their parents. Some of this is to do with the wide range of disabilities and the need to have specialist knowledge and expertise. Some voluntary sector organisations are specialists and work in very specific areas. This specialism could be 'bought in' by commissioners of services:

... I don't believe that it is just statutory sector service and there is a real role for disability voluntary sector organisations (Professional).

... first of all there should really be a good cross-section of people ... parents, childminders as well as people from the voluntary and professional agencies, but I think the parents and the childminders really are the people who are going to be using the service and providing the service, and they should have a strong say in how it's going to be run. I think they all should have good access to guidance, also maybe look at if there have been other good examples of good practice ... (Professional).

There is a degree of consensus among parents, professionals and childminders that the way forward in addressing the daycare needs of disabled children and their parents' needs is through partnership, including partnership with parents:

... I have a ... plan for Robert to help with the ayspraxia and autism and [I need] someone ... [who] could sit down and say we'll work with you and we will see what we can do here ... and somebody that's willing to work with you and liaise with you because it has to be there (Parent).

... I think the key thing is partnerships. I think if you ... can make other organisations see that it is in their own interest to try to plug this gap and

that you want to do it as a proper sort of formal arrangement, then that's got to be the right thing to do (Parent).

... if you build up a good relationship with them [parents] where you inform them what is happening with the child, what sort of activities you are providing for the child ... that encourages them (Childminder).

... somebody who's going to work with children needs to display I think and understand children's developmental needs. They need to be very aware of the holistic picture of children and ... move away from the old, traditional view of a disability first and a child second. It's the other way round. You need to engage with parents around their children's needs as opposed to the disability (Professional).

... we are all working for the one purpose and that's for the child, it's for the child and the parent, and we've all got to stop being protective and saying that one service is better than the other ... and it's about having just something for the parent and the child to ... make it an easier path for them so it's about everyone wanting to work with more people ... it's maybe saying, let's see how we can create the best package for that (child), whether it's here or whether it's somewhere else or whether the child will be better placed in mainstream with the package there, whether they would be here, or a dual place (Professional).

... this is about professionals being different and being prepared to listen to parents and listen to children and young people and being prepared to work with each other (Professional).

I find with any child you know, it is sitting and listening to the parents ... and discussing things ... (Childminder).

... people really need to shift their minds away from the disability to the [child], and really all professionals – education, medical, clinical and social worker – do really [need to] come together much more effectively and stop being fragmented in their responses (Professional).

In terms of infrastructure, professionals felt that specialist childminding needed to be part of a larger childcare plan or even a more general children's services plan, so that it is a service that is built in from the start:

I just think that the specialist childminding service needs to be part of an overall development plan to provide respite care and support for families of children with disabilities. It would be a mistake I think for it to be developed by say, for example, by NICMA in isolation from the commissioning of planning services, it will not work – it is a very difficult area and most definitely needs to be planned for it to work properly. You would need significant communication and resources and support for it to work well and for it to be targeted at those children in greatest need and that is why I think it really needs to be linked in with current services and

become an option and part of the overall continuum of care (Professional).

One possible option would be to use the existing and recently expanded Sure Start programme as a way of incorporating specialist childminders into a more generic service:

... what we would like to see now is the childminding networks that we are developing as part of the Sure Start projects. I would like to see those having an element of specialised childminding within them so that you have possibly a small number of childminders who are prepared to provide a service for children with a range of special needs, not just disabilities, and you provide those individuals with some sort of one-to-one support, relevant training and maybe some financial incentives so that within that Sure Start area you could provide a specialist childminding service as another [available] service... Professional).

However, not all areas of Northern Ireland are covered by Sure Start programmes, so while this might be one option, there may need to be others. Possibilities exist via the childcare partnerships or Regional Children's Services Plan that has been proposed by the children's services planners, to ensure that some areas are not left without a service.

For parents with more than one child and for those whose disabled child is getting older, there is a need for childcare to go beyond the options of childminding, nursery or crèche facilities to encompass supervised after-school and holiday-time activities:

... you've got to move out of the childminding situation because of age. And for those children I think you need some sort of after-school resource (Parent).

I think the difficulty of having just a network specifically for children with disabilities, which is what we did have, is you are excluding general childminding. What do you do with those siblings who don't have a disability? So I think it would be far more inclusive to have specialist childminding services within the current childminding networks, the current infrastructure, that we already have (Professional).

Also mentioned was the need for services to take a more family-oriented view. Often there is so much focus on the disabled child that parents may forget to tend to their own needs as individuals, as partners and as parents to their other children:

... it's not leaving the family out of it, they too need build up, and so they're more resilient for whatever life throws at them ... their [parents] world so much revolves around this one person that the parents can forget that they're parents and have a life, in terms of what does that

mean or in terms of their other children, what does that mean ... working out those kind of relationships is actually difficult for any family. Most of us don't have to look at it too hard, but if you're a parent of a disabled child you have to be looking at the now in terms of how is everybody looking? How are they dealing? How are they doing? But you have to think of the future and prepare everybody for the future in a way that other families really [don't] ... (Professional).

I suppose family support would be the other end. It's looking at siblings because, due to funding and stuff like that, a lot of services will be specifically for the disabled child. And intervention: I suppose where the Mum ... a lot of intervention will come in if there's going to be a breakdown with the Mum, or the Mum needs quite a lot of support. And I suppose if there's family support, and the idea that the whole family can access a service and advice, and information for siblings as much as anything else (Professional).

I think if you have an extended family that's where you need to involve them, so I would say you would see a lot more grannies and a lot more family here than maybe you would in another setting, because they need to know where the child is going ... And quite often they're involved in the programmes – speech and language therapy programmes or physiotherapy programmes (Professional).

It seems clear from the respondents in this study that there is a need for a concerted effort to be made if the daycare needs of families with disabled young children are to be met. No one organisation has all of the resources or expertise to do this. Consequently, partnership within a clearly defined structure is vital. This partnership needs to extend beyond organisations to parents, families and childminders.

5. Summary conclusions

This study has highlighted the struggle endured by families with disabled young children when trying to access services, including daycare services. The points below summarise the key messages coming from the study under the following headings:

- matching needs and services
- enhancing the quality of services
- the role of childminding
- planning to meet identified need.

Matching needs and services

This study shows clearly the real mismatch between the needs of disabled children and their parents and the services that are currently available to them. Parents of disabled children struggle on a daily basis to access appropriate services to meet the needs of their children. This includes access to daycare services.

There is a general lack of childcare services in Northern Ireland, especially a lack of registered childminders. This is even more acute with regard to disabled children.

There is a mismatch between where children live and where there is childcare provision. Some areas of Northern Ireland, particularly the Eastern Board area, have many more registered childminders than other areas.

Geography impacts on all children and their families but this is more acutely felt by disabled children who may be isolated in rural areas. Providing for small numbers of children with complex needs is therefore expensive and difficult, in terms of the skills required to meet the needs of such children.

There is also a mismatch between the needs of parents who might only require respite (as opposed to full daycare) and childminders trying to make a living.

There is a lack of consistency across Northern Ireland in relation to available services with no two health and social services trust areas appearing to offer identical services.

Parents of disabled children want to have choice when it comes to daycare – some want to be able to return to work and therefore require full- or part-time daycare. Of these, some want group care in a mainstream nursery, some want a childminder to care for their child in the childminder's home, while others want the child to be cared for in his/her own home, possibly with siblings.

Other parents who cannot or choose not to work outside of the home require respite care, either at home or away from the child's home. Those who need this type of care would like to be able to choose when and where it occurs.

The separation of early years services and services for disabled children means that children's services planning process and childcare partnerships have had a limited impact on increasing the daycare services available to disabled children in Northern Ireland.

Enhancing the quality of services

The study also provides clear pointers to the qualities required in services for disabled children. A strong theme underpinning this was that of confidence: confidence of the parents in the service provided and confidence of the carers in caring for a disabled child.

There is a need for training, both general and specific. This training needs to be provided on both an initial and ongoing basis. There is a need for adequate specialist training to meet the needs of children with specific disabilities, but in general there is a greater need for more confidence-building training and disability awareness training among childminders.

There is a need for funding to bridge the gap between what parents can afford and what childminders need to earn to make a living while providing intensive care for those children who need it.

There is considerable variation in both the quantity and quality of services between trust and board areas. Parents and professionals are not always clear about what is possible.

There is a need to develop services for disabled children in the context of the whole family and for such services to support both the disabled child's parents and his/her non-disabled siblings.

Role of childminding

There is huge potential for childminding to meet some of the unmet need. This was seen as a valuable resource and viable option within daycare services.

There is widespread support for a network to support parents and childminders. Such a network could boost the confidence of both the childminders and parents.

Childminders could be linked into developments such as the Sure Start expansion, new children's centres and extended schools, as pilot projects in England are proving.

Planning to meet identified need

There is a need for early years and disability professionals and parents to come together in partnership to plan how services for disabled young children will be developed and delivered.

This is a time of great possibilities that need to be actively embraced – as early years becomes the responsibility of the Department of Education and as disabled children become part of children's services following RPA. In addition an early years strategy and a parenting strategy are being developed: both offer a real opportunity to give a central place to disabled children and their families.

There is a need to explore all potential models in order to meet the daycare needs of disabled children and their parents. Existing models include:

- a one-stop-shop service where early years, education and health professionals can be accessed in one setting (e.g. Sure Start; Wrap-Around service; Segal House)
- childminders operating out of their own homes
- childminders caring for children in the child's own home
- an extension of the sponsored childminding model currently operating in some health and social services trust areas to include sponsored childminding for disabled children
- networks of childminders
- networks of childminders linked with extended schools to provide an alternative to large group after-school care.

Meeting the needs of families with a disabled young child requires flexible and accessible services. Many families will need more than one service option to meet all their needs, preferably through service models that provide a wide range of facilities.

Partnership is key to the effective planning and implementation of services for disabled children. This includes both the statutory and voluntary and community sectors in health and education as well as partnership with parents.

6. Action plan

The overall aim of the scoping study is **‘to inform the development of a strategic framework for the provision of specialist daycare services for disabled young children in Northern Ireland, including specialist childminding if appropriate’**.

The scoping study report seeks to serve two objectives:

1. to enable NICMA, with the help of the Project Advisory Group, to draft an action plan on developing services to support families of disabled children
2. to help inform children’s services planners in the new commissioning agency with regard to plans for disabled children.

The key messages of the scoping study fall under the following four headings:

- matching needs and services
- enhancing the quality of services
- the role of childminding
- planning to meet identified need.

These headings have been used to devise a draft action plan.

As the study has been commissioned by NICMA, for the purposes of this action plan, the focus will be on the development of specialist childminding services.

SCOPING STUDY on ‘The daycare needs of disabled young children in Northern Ireland’

Action plan

Aim 1: Matching needs and services

Key Message	Objective	Action	By whom
Lack of registered childminding provision	To have increased the provision of registered childminding.	<ul style="list-style-type: none"> • Gather baseline data for registered childminding provision across NI • Development of NICMA’s Recruitment and Retention Strategy for childminders to include call for a childminder start-up package • Focus of all childminding network coordinators in five Sure Start areas [see Aim 4]. 	<p>NICMA/childcare partnerships</p> <p>NICMA</p> <p>NICMA</p>
Lack of specialist childminding provision	To have developed a pool of childminders willing to provide daycare for disabled children.	<ul style="list-style-type: none"> • Identify and map childminders who: <ul style="list-style-type: none"> – offer a specialised service – have accessed specialist training (either through NICMA or trusts). • Promote specialist childminding to current 	<p>NICMA/trusts</p> <p>NICMA/childcare partnerships</p>

		<p>childminders to encourage interest</p> <ul style="list-style-type: none"> • Map gaps in childminders with specialist training • Develop resources to support promotion of specialist childminding. 	<p>NICMA/childcare partnerships</p> <p>NICMA/childcare partnerships</p>
<p>Improving information for parents about childminding, specialist childminding and daycare provision</p>	<p>To have developed local information systems about availability.</p> <p>To have developed a system for disseminating information/making it more accessible.</p>	<ul style="list-style-type: none"> • The development of a regional information resource/database of childminding vacancies for disabled children or those with special needs. 	<p>Childcare partnerships/trusts</p>

Aim 2: Enhancing the quality of services

Key Message	Objective	Action	By whom
General and specific training	<p>To have increased availability of disability awareness training for childminders and daycare staff.</p> <p>To have established sources of support in relation to specific disabilities.</p>	<ul style="list-style-type: none"> • Identify and cost a range of specialist training currently available for registered childminders from all sources • Clarify whether training is appropriate and meets the needs of disabled children. 	NICMA/childcare partnerships
Addressing barriers to the provision of daycare for disabled children, specifically addressing the economic barriers	To have explored policy issues related to affordability for parents of disabled children (including access to and use of benefits/direct payments).	<p>Consider:</p> <ul style="list-style-type: none"> • Grant scheme • Protected funding within social services budget • Use of direct payments • Further research into matching the needs of disabled children and their families with appropriate services. 	
Whole family approach to service development	To have considered the daycare needs of families to include non-disabled siblings.		NICMA/childcare partnerships

Aim 3: Promoting the role of childminding

Key Message	Objective	Action	By whom
Development of childminding network	<p>To explore options within childminding networks for disabled children.</p> <p>To establish closer links with initiatives such as Sure Start and extended schools.</p>	<ul style="list-style-type: none"> To have integrated the daycare needs of disabled children into planning local Sure Start/extended schools initiatives. 	NICMA/Sure Start
Potential for current childminders to extend service	To encourage current childminders to extend service to disabled children.	<ul style="list-style-type: none"> Using NICMA database and information from trust early years teams, identify and map current specialist childminding provision. 	

Aim 4: Planning to meet identified need

Key Message	Objective	Action	By whom
Partnership approach to the planning and delivery of a range of flexible services	<p>To have developed regional and local partnerships to include key stakeholders, including education, health and social care, DEL, voluntary sector organisations (disability-focused/early years-focused) and parents.</p> <p>To have undertaken a regional/local assessment of need and mapping of available services.</p> <p>To have prepared a regional/local action plan to provide a range of services.</p>		Multi-agency group

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