

The daycare needs of disabled young children in Northern Ireland

Research summary

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.

Teresa Geraghty and Ruth Sinclair
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The full report is available from www.ncb.org.uk

About NCB

NCB promotes the voices, interests and well-being of all children and young people across every aspect of their lives. As an umbrella body for the children's sector in England and Northern Ireland, we provide essential information on policy, research and best practice for our members and other partners.

NCB aims to:

- challenge disadvantage in childhood
- work with children and young people to ensure they are involved in all matters that affect their lives
- promote multidisciplinary cross-agency partnerships and good practice
- influence government policy through policy development and advocacy
- undertake high quality research and work from an evidence-based perspective
- disseminate information to all those working with children and young people, and to children and young people themselves.

NCB has adopted and works within the UN Convention on the Rights of the Child.

NCB works in partnership with Children in Scotland (www.childreninScotland.org.uk) and Children in Wales (www.childreninWales.org.uk).

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