

Listening to parents of disabled children about childcare

NATIONAL CHILDCARE CAMPAIGN

daycare
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Listening to parents of disabled children about childcare executive summary

Key findings

Use of childcare varies greatly between parents of disabled children, and the type and level of the child's disability may be a factor affecting their use. Some parents of children with severe and complex additional needs who we spoke to used very little or no formal childcare, instead becoming full time carers themselves and/or relying on Direct Payments to employ care workers in the home. Use of childcare was also low among parents of autistic children we spoke to who felt that childcare settings are generally not appropriate for their children whose needs are distinct from those of other disabled children. Many felt that childcare opportunities are not equal among parents, with some having access to places that other parents have not.

Reasons given for not using childcare included: a lack of appropriate places for disabled children; a lack of suitably trained workers to deal with disabled children; and a lack of appropriate facilities for disabled children.

Many parents of disabled children felt very strongly about the benefits that childcare can have both for themselves and their disabled

children – particularly socially and developmentally. It also provides parents with the opportunity to focus attention on their non-disabled children. However, the wrong childcare situation can have negative consequences, and this is very much influenced by the experience and confidence of the workers at a setting. Parents need to feel their child is welcome at a childcare setting before they will leave their child there, and they need to feel trust and confidence in that provider. Many parents felt that their disabled children are especially vulnerable in childcare. Some parents spoke of feeling guilty about using childcare in case their child was taking up the place of another potentially more needy child. A common theme among all parents consulted was the perception that accessing information and places is a constant battle and struggle.

Parents reported numerous gaps in childcare provision for their disabled children that represent considerable barriers to the take up of childcare. The lack of specialised childcare, tailored to the individual's needs was perceived as a significant issue for these parents. Other gaps in provision felt by the parents were: settings where they could place both their disabled and non-disabled children; provision for their own emotional wellbeing as parents of disabled children, particularly when their child is first diagnosed; appropriate settings for their disabled children as they got older; and transitional care from child to adult services.

For many parents who did not use childcare, cost was certainly a factor. Many parents felt that they are not provided sufficient financial assistance for their disabled children's childcare provision. Some argued that as their childcare choices are so limited, they should be allowed extra incentives. The additional costs associated with providing the extra support required for their children meant childcare options were limited and often unavailable to them. The high cost of childcare during the school holidays was another issue for many parents – those working as well as those who were not.

Many parents of disabled children want to work and/or study for a variety of reasons, but they face numerous and complex barriers in their efforts to do so. The benefits of work were recognised by most parents, however they felt it requires a balance of being able to access the right childcare and having an employment situation that is flexible enough to allow them to meet the demands of their disabled child. This is an extremely delicate situation, as even parents with the seemingly right job and childcare situation, can be vulnerable to the high demands of their disabled child, to the detriment of their job. Difficulties are exacerbated at holiday time when finding appropriate and affordable childcare is crucial to the parent's ability to continue working or studying.

Awareness of entitlements and initiatives set up to assist parents of disabled children was quite low among many parents. They often rely exclusively on other parents for information on childcare and spoke of feeling frustrated by what they perceived as a complete lack of any accessible, official source of information. They spoke of feeling uninformed and the worry that they may be missing out. Very few parents were aware of Children's Information Services and among those who were aware, use was limited.

Key Recommendations

1. Increase the uptake of childcare among families with disabled children by making services more accessible and more appropriate to their needs by:

- increasing subsidies for childcare places for disabled children and extending funding to pilot programmes to increase services to families of disabled children;
- formalising a disability childminding network of approved and qualified childminders.

2. Increase the number of childcare places available to disabled children and upskill the workforce to enhance the quality of that provision by:

- creating a national disability childcare fund to develop a skilled workforce;
- making base-line disability training compulsory for all childcare training courses;
- considering schemes to increase uptake of childcare training among parents of disabled children;
- ensuring that Disability Equality Training is provided in every setting; and that specialist training is provided to all staff when a disabled child has been accepted to that setting.

3. Make all childcare settings inclusive and increase the childcare options available to disabled children by:

- ensuring that every childcare setting in London is disability-friendly.

4. Increase parents' confidence in the quality and safety of childcare settings by:

- promoting more widely the benefits of good quality childcare, provided by qualified, registered childcare workers, especially in terms of the social, educational and developmental outcomes for disabled children;
- allowing parents to observe childcare settings prior to committing to using the service.



5. Increase staff retention by improving the status and pay of the profession by:

- producing good practice guidance and benchmarks on pay and progression, particularly for Early Years Professionals;
- requiring all paid staff counting towards ratios to be qualified to Level 2 by 2011 and Level 3 by 2015. After 2015 they should be qualified to Level 3 within two years.

6. Ensure that every parent with a disabled child automatically receives the practical and emotional support required by:

- assigning a key worker to every parent when their child is first diagnosed with a disability. The key worker should provide information, support and practical assistance, including help with applying for help with childcare costs, allowances such as the Disability Living Allowance, and accessing childcare places. The key worker should remain in place during the disabled child's transition from child to adult services.

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7. Increase the provision of childcare that meets the needs of families with disabled children by:

- ensuring sufficient, affordable childcare for disabled children during school holidays;
- ensuring that settings increase the flexibility of hours of operation;
- increasing the provision of emergency or ad hoc childcare for disabled children, for instance through a Sitter Service.

8. Improve and increase the provision of appropriate care for older disabled children and young people by:

- conducting more research with disabled teenagers on their preferences for care provision;
- providing funding to local authorities to address the gaps in provision of care for disabled teenagers;
- considering schemes to upskill the childcare workforce to competently work with older disabled children.

9. Make childcare more affordable for, and increase the uptake of help with childcare costs among, families with disabled children by:

- continuing to fund the Childcare Affordability Programme (CAP),

currently led by the London Development Agency and consider extending the principle to other cities and regions in order to: subsidise costs and fund more free places in London, other high cost areas, rural areas and for disabled children;

- making information on childcare entitlements more accessible to all parents of disabled children and modify the Working Tax Credit system to increase benefits to these families;
- increasing the upper limit of eligible childcare costs under Working Tax Credit for families with a disabled child to £300 per week;
- increasing the help available through tax credits so that parents of disabled young people aged 16-18 can claim for the childcare element of Working Tax Credit.

10. Make it easier for parents of disabled children who want to work, train or study to do so by:

- providing more support to parents returning to work or study, including allowing parents to trial childcare arrangements prior to starting work or study;
- increasing awareness of parental leave rights. Currently parents are entitled to 18 weeks leave for disabled children up to the age of 18;
- introducing paid parental leave for all parents including those with children over six;
- ensuring that the recently announced increase in childcare funding for students adequately covers the needs of parents of disabled children wishing to study;
- developing a Pathways to Work scheme for parents of disabled children.

11. Make disabled children's medical requirements less of a deterrent to their parents working by:

- ensuring the provision of more emergency/ad hoc provision for disabled children, preferably in their own home.

12. Ensure that all families with disabled children can easily access all necessary information on childcare by:

- improving the consistency and reliability of information provision by encouraging all Local Authorities to share information and allow easier movement of childcare users between settings in different boroughs;
- extending the remit of Children's Information Services (CIS) to provide more information and support relevant to families of disabled children, extending their 'brokerage service', and ensuring a disability information officer is in place at every CIS;
- assigning a key worker to every family with a disabled child.

1. Listening to parents of disabled children about childcare background

'Families with disabled children face a constant struggle to access affordable and appropriate childcare. This research by the Daycare Trust is welcome in providing further evidence of the challenges families face. Listening to families will help service providers and Government understand what they need. As well as listening, Government needs to act, both to increase the supply of appropriate childcare places and to provide extra funding so that families can afford to pay for childcare for their disabled children.'

Steve Broach, Campaign Manager, Every Disabled Child Matters (ECDM) www.edcm.org.uk

Disabled children and childcare use

Around seven per cent, or 777,000, of all children in the UK are disabled.¹ According to the Every Child Matters Campaign (ECDM), 29 per cent of disabled children live in poverty². Access to the right childcare for disabled children can have positive consequences for the family as a whole, particularly by enhancing opportunities for the

parents to work or train, which is key to lifting disadvantaged families out of poverty. A Working Families 2006 report which explored the experiences of parents with disabled children of working, or not working, through a series of case studies found that for many parents the benefits of working outweigh any negative effects, offering an economic boost, boosting self-esteem, and providing a sense of personal satisfaction³. Access to good quality, affordable childcare for all children, including those with disabilities is key if the government is to achieve its goal of halving child poverty by 2010 and eliminating it by 2020.

There is also much evidence to support the premise that high quality childcare enhances the developmental, social and educational prospects of children. For instance, The Effective Provision of Pre-School Education (EPPE) project found that: 'pre-school experience, compared to none, enhances children's development and; disadvantaged children in particular can benefit significantly from good-quality pre-school experiences, especially if they attend centres that cater for a mixture of children from different backgrounds'⁴.

Use of childcare among families with disabled children tends to be lower than that of families with no disabled children. Research conducted by the National Centre for Social Research in 2005 found that children statemented with a special educational need were less likely to have received formal childcare than other children⁵. A survey in 2002 by Contact a Family Childcare found that (out of 1870 respondents with disabled children), 94% of families thought that it was more difficult to find appropriate childcare for disabled children and 90% thought there was not enough choice in childcare for disabled children. In addition, 79% said they found it difficult to combine work with childcare⁶.

Government recognises the role that childcare plays in improving the prospects of families with disabled children. The Childcare Act 2006 places a duty on local authorities to ensure sufficient childcare for all families, including those with disabled children, that is high quality, accessible, affordable, sustainable and flexible. Sure Start has provided £21.8 million in 2004-05 to local authorities for special educational needs and disability, including early intervention,

¹ Census 2001

² www.everychildmatters.gov.uk

³ Working Families (2006) Make it Work for You

⁴ Sylva, K., Melhuish, E., Sammons, P., Siraj-Blatchford, I., Taggart, B., Elliot, K. (2003) The Effective Provision of Pre-School Education Project: Findings from the Pre-School Period

⁵ Bryson, C., La Valle, I., O'Shea, R., and Barnes, M., (2005) Use of Childcare Among Families with Children who have Special Educational Needs, NatCen

⁶ www.cafamily.org.uk

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childcare support and training for Special Educational Needs Co-ordinators. Government has also recently announced £340 million additional funding specifically for support for disabled children. This includes: £280 million over the next three years to fund short breaks for disabled children; £35 million for accessible childcare (to be piloted in ten Local Authorities), promote training, and tackle other barriers to accessing childcare; £19 million for a Transition Support Programme to ease transition from child to adult services; and £5 million to involve parents in shaping local services.

Key issues affecting childcare use among families with disabled children – as identified in current research

There is an abundance of evidence to suggest that, even with the current drive to improve services to families with disabled children, they still face considerable challenges when it comes to childcare.

EDCM claim that families with a disabled child pay five times more towards childcare costs than families with no disabled children⁷. A Contact a Family web-based survey in 2004, aiming to investigate how many parents were incurring large costs for childcare, found that 89% found it more expensive to arrange childcare for disabled children, with 17% of families with disabled children spending between £7.50 and £20 an hour on childcare, while 9% spent more than £20 an hour. Financial help with childcare in tax credits was cited as the most effective way for the Government to help them use childcare. Over half of the respondents who were currently not working claimed that having the childcare they need would enable them to start looking for work, while 66% claimed they might consider further education or returning to study⁸.

According to research conducted by Action for Carers & Employment (ACE) in 2006, families with disabled children are at almost double the risk of living in poor households, for example 34% live in families where there is no adult in paid work compared with 18% of children who are not sick or disabled. Finding the right job and childcare arrangements can benefit the whole family⁹.

Much of the recent consultative research suggests that families with disabled children feel that there are simply not enough appropriate places for their children and in many cases, that this becomes an even bigger issue as the child gets older. A report by the Audit Commission in 2003 found that there was 'a lottery of provision, inadequate planning, confusing eligibility criteria, and that families were subject to long waits and had to 'jump through hoops' to get



support'¹⁰. Contact a Family research also suggests that: there is insufficient supply of childcare provision for families with disabilities and special educational needs; and that there are insufficient specialist nurseries and childminders with accessible premises and appropriate training and expertise. In a 2004 survey, they found that 82% of families with disabled children felt that 'the right childcare is simply not there for (their) disabled child'¹¹. Daycare Trust's 2007 Childcare Costs survey supports this, suggesting that services decrease as disabled children get older. Forty one percent of the Children's Information Services (CIS) in England that responded said there were not sufficient services for disabled 0-13 year olds in their area and 32% said they were unsure. For services for 14-18 year olds, 46% of CIS's in England said there were not sufficient services and 39% said they were unsure. A 2005 NatCen report found that respondents with children with special educational needs were more likely to be unable to find the type of childcare they want

when they need it and were more likely than the general parent population to say they found it hard to get their current provider⁷. The Daycare Trust Everyone Counts project (2004) involving focus groups and questionnaires with hundreds of parents and childcare professionals around the country, found that few initiatives had explicitly addressed the needs of children with disabilities and that many families found that flexible and appropriate childcare was not available. It also found that 69% of parents of disabled children found it hard to find appropriate childcare. In 2004 the National Audit Office reported that many childcare providers who said they were able to accommodate children with disabilities were found to offer only one such place⁸. In a mystery shopping research exercise conducted by Mencap in 2006, it was found that although six out of 20 local authorities sent information about childcare providers, in only one instance was the provider able to care for a disabled teenager.

Research also indicates that families with disabled children often face inadequate information about childcare and that this further impacts on their up-take of childcare. Daycare Trust's 2007 Childcare Costs Survey found that only 13% of CIS's in England said they had a designated disability officer. In the Contact a Family Childcare Costs for the Parents of Disabled Children 2004 survey, 88% of respondents said they found it 'hard to find information about childcare for disabled children' in their area and this was one of the most common reasons cited for not using childcare⁹. The Every Child Matters Audit Commission 2003 reports that families 'have to struggle through a maze of services to track down essential information and then have to jump through a series of hoops to try and gain access to support'. It also reports that 'Service provision is rarely based on the priorities and needs of individual families. What is provided is often too little and too late to make the best possible improvement to their everyday lives. For example, many families still miss out on their full entitlements to benefits because services don't pass on key information at the right time'.

⁷ Every Disabled Child Matters campaign briefing: Between a rock and a hard place.

⁸ www.cafamily.org.uk/ChildcareCosts.pdf

⁹ ACE (2006) Managing More than Most: A statistical analysis of families with sick or disabled children

¹⁰ Audit Commission (2003) Services for Disabled Children: A review of services for disabled children and their families, www.audit-commission.gov.uk/disabledchildren/reportchild.asp

¹¹ www.cafamily.org.uk/ChildcareCosts.pdf

¹² Use of Childcare Among Families with Children who have Special Educational Needs', 2005, The National Centre for Social Research

¹³ National Audit Office (2004) The Early Years: progress in developing high quality childcare and early education accessible to all

¹⁴ www.cafamily.org.uk/ChildcareCosts.pdf

Listening to parents of disabled children about childcare – background, aims & methodology

Listening to families is a three-year research project that Daycare Trust is conducting, exploring the experiences of, views on, and needs for childcare among families in the UK today. *Listening to parents of disabled children* is a strand of this project, with the aim of consulting with parents of disabled children on the following:

- Use of childcare for their disabled children and the factors that influence this
- Experiences and perceptions of childcare
- Gaps and needs in childcare provision for disabled children
- Working and childcare affordability
- Information on childcare for disabled children.

Questionnaires were used to obtain quantitative data from a wide population on general childcare use and views; and seven interviews (five focus groups and two individual interviews) were conducted to obtain qualitative data. In total, 89 parents were consulted.*

Questionnaires were distributed and promoted through a number of disability support and advocacy groups and through Daycare Trust's own website and correspondence. A total of 110 completed questionnaires were returned from parents of disabled children throughout England.

Focus Groups were conducted with support groups for parents of disabled children around London. The views of workers and managers were also sought in these groups.

Definitions

'Disability'

According to the Disability Discrimination Act (1995), a person is disabled if they have a 'physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities'. The term 'disability' is therefore used in this research to encompass all physical, mental or special educational needs.

'Childcare'

In this research, 'childcare' is defined as any childcare arrangements made for people to look after children, apart from family and friends and so includes childminders, nurseries, playschools, pre- and after-school clubs etc.

* The same data was used to produce a report for the London Development Agency (LDA) who part-funded this strand of the project. See *'Listening to parents of children with disabilities and special educational needs'* (2007), LDA.

2. Listening to parents of disabled children about childcare findings

2.1 Use of childcare

Childcare use among the parents of disabled children who we spoke to varied greatly. While many of the focus group participants spoke of having benefited from various forms of childcare, with after-school clubs being particularly popular, a considerable number of them reported using little or no formal childcare at all. Likewise, over a third (38 per cent) of the 110 questionnaire respondents reported having used no childcare in the previous three months. What was common among all virtually participants though, was a desire to use more childcare for their disabled children.

In particular, parents of children with severe disabilities, such as cerebral palsy, reported having very little access to appropriate childcare and subsequently relying strongly on informal childcare provision, or other types of care such as home help through Direct Payments. Parents accessing home help spoke about restrictions to 'normal' family life that this can cause, particularly for those who were required to remain in the home with the carer at all times, according to the rules of care agency they used.

Some of these parents had used nurseries in the past but stopped using them as they felt that the necessary one to one care was not always available, which compromised the quality of care. Many of them wanted to make more use of holiday clubs and respite care in particular, but found these too expensive and out of reach. All but one of the participants in this group were lone parents, and two of them worked.

There are places that offer that (after school) but they can't offer the one to one, they can't meet their needs. (Their) daughter was going to an evening club. She has her food at regular intervals through her gastrostomy (through a tube in to her stomach). This has to be at particular times every day. She has medication that she has to take before her food so the time had to be exact. She had to be dropped off first on the way home and they couldn't do that for a number of reasons. In the end it was too difficult – she couldn't go over her time before she had her medication and her food and in the end she decided she had to stop going.

(Worker speaking about a family known to her)

They (disabled children) are too high demand.

(mother of two disabled children, on why she doesn't use childcare)

Parents of autistic children also reported that the difficulties they encounter when trying to access appropriate care for their children often preclude them from using any childcare at all. Four out of the five parents of autistic children that we spoke to used no childcare at all due to the lack of appropriate care available to autistic children, who the parents felt, required one to one attention with a worker who is experienced in dealing with autism.

With a child with special needs, I've struggled with specialists who lack...never mind if they're qualified, lack an understanding and patience to deal with them (autistic children).

(mother of 6 year old son with autism)

The whole level of understanding about autism doesn't seem to be there and for us, there's nowhere to access a list of, okay these are people you can call on, be they a childminder, an after-school club or a holiday club where they would have people who understand ...there doesn't seem to be anything like that at all.

(mother of 8 year old son with Aspergers syndrome)



At the moment I don't use any childcare. How do I manage? ...It's not a satisfactory childcare situation at all.

(mother of 11 year old daughter with autism)

Overall, one of the strongest findings from the focus groups was the disparity evident among parents when it comes to availability of appropriate childcare. Some parents felt that getting the right place was often a matter of luck – for instance by having someone who understands your position to help you or by living in the right area. As one parent speaking about finally getting a nursery place for her child said:

*It took one person recognising that (son) needed to be in nursery everyday – if it hadn't been for that person you're *** because not everyone sees it like that. I might get one person, you might get another'*

(mother of four sons, two with disabilities)

On differences of provision between London boroughs, one mother said:

*One of the things I've learned through the campaigning and going and talking nationally in London, is how **** it is elsewhere. I really wouldn't move. It really is **** in a lot of areas – I'm talking about nothing! Parents can't believe I can access three after school clubs a week in (borough).*

(lone mother of daughter with profound multiple learning disability)

Barriers to childcare use

Key barriers to childcare for disabled children identified by parents were a lack of places appropriate to disabled children's needs and a lack of trained workers competent to care for disabled children. Other issues affecting the uptake of childcare among disabled children included the complex medical requirements that many disabled children have, and other logistical difficulties such as transport and competing needs of non-disabled siblings.

Almost every parent who participated in the focus groups spoke of their frustration at the lack of appropriate childcare places for their disabled children. Many parents recalled occasions when they had been given lists of childminders who, when contacted, said they could not care for their disabled child. Others claimed that while childcare places are sometimes made available to their children, they do not provide the level of support that they felt their children require, and so are not appropriate for their needs.

There's only one place in (borough) that you can send your child where you feel happy to leave your child, trained staff, good ratio of children to staff... and the fact that there's only one that I know of in (borough) and you still have to pay for it...It is a postcode lottery isn't it...if you're in the area you can go...

(mother of two children, one with special needs)

It's just not available. To the point that there just seems to be nothing...And so often we're told there's not enough places basically. You're always working in that situation where you think you're very lucky to find something that works, it's not realistic. There's not much chance you'll get everything you're entitled to because it's not an ideal world. When I went to the local childminders group and said 'is there such thing as childminders for autistic children' and was told 'childminders don't want to handle autistic children'. As if that was alright!

(mother of 11 year old daughter with autism)

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Some parents felt that there had been occasions when places had been made available to their disabled children but the facilities were not adequate and so they had not taken up the places.

I also think that some places accept the children...they say 'we can accept your son for a couple of hours so long as he doesn't soil his trousers'. If there're stairs they can't get up then they can't access that service either. So there are a lot of places that are not disability-friendly.

(mother of 17 year old disabled son)

The perception that childcare workers are not adequately trained in how to deal with disabled children is a considerable barrier to these parents accessing childcare. Many spoke of occasions when they had felt a worker was not experienced enough to handle their child, and some felt that workers did not understand their child's disability, or disabilities in general.

They can't care for their (disabled children's) daily needs so straight away...it cuts your scope down.

(mother of 17 year old disabled son)

They need to educate all nurseries – it shouldn't be just special needs (settings). Everyone should be qualified in special needs and that way you wouldn't have to fight (to get your child a place).

(mother of four sons, two with disabilities)

Parents spoke of how their disabled children's medical requirements were a barrier to accessing childcare due to settings not being able to, or not wanting to, cater for those requirements.

I said to one of the carers 'can you give him two lots of this medication?' and she looked at me as though I'd asked her to eat the contents of his nappy. Sheer repulsion. And she said 'no we can't do that here' and it was all on prescription and I'd filled out the medical book. It was just some powder you added to his drink. (In the end they agreed).

(mother of son with Down's syndrome)

One mother spoke of how she had to take her child out of a main-stream childcare setting because it could not meet his medical needs and had to find a place at a special needs setting instead.

He was seizing before going to nursery and they said they



couldn't take him because they didn't know how to administer his medication and if he did seizure while at nursery they'd have to call an ambulance and they could do nothing for him until the ambulance arrived. They don't give any form of medication...

(mother of two children, one with special needs)

Other difficulties experienced by parents in accessing appropriate care for their disabled children included: the need for referral to some settings; problems in getting the child to and from the setting; and the need to 'juggle' their time to also meet the needs of their other children.

As one father with a 13 year old son with Down's syndrome said:

If I have the support to take him to a place, I will take him. Sometimes he can't attend something because there's nobody to take him there... So he's not able to go to them unless I'm at home and I can take him but I'm not always at home... I'd have to remain with him also, which is another issue.

Then if you're a working parent you have to get annual leave just to be able to get that child to the centre in the morning and come back in the afternoon so you're wasting annual leave. A lot of children don't access this because the parents don't have the time or the means to get these children to these places. All the time that you bring your child here you've got to stay with him...if you've got other children you've got to juggle that too. It's very, very difficult. It's okay to make a centre but what resources are there?

Recommendations

Increase the uptake of childcare among families with disabled children by making services more accessible and more appropriate to their needs by:

- increasing subsidies for childcare places for disabled children and extending funding to pilot programmes to increase services to families of disabled children;
- formalising a disability childminding network of approved and qualified childminders.

Increase the number of childcare places available to disabled children and upskill the workforce to enhance the quality of that provision by:

- creating a national disability childcare fund to develop a skilled workforce;
- making base-line disability training compulsory for all childcare training courses;
- considering schemes to increase uptake of childcare training among parents of disabled children;
- ensuring that Disability Equality Training is provided in every setting; and that specialist training is provided to all staff when a disabled child has been accepted to that setting.

Make all childcare settings inclusive and increase the childcare options available to disabled children by:

- ensuring that every childcare setting in London is disability-friendly.

2.2 Views on childcare

Many parents spoke very highly of their childcare settings and of the benefits the right childcare can have for disabled children and their parents. Having childcare for their disabled children can also provide parents with an, often much-needed, opportunity to spend time with their other children. On the other hand, parents also spoke of the negative aspects of childcare provision for disabled children. For instance, many parents felt that their disabled children are not always welcome and wanted at childcare settings and that their disabled children are particularly vulnerable in childcare. Some claimed that informal childcare support is not available to them to the same extent as it is to parents of non-disabled children, forcing them to rely more heavily on formal childcare, which is not always available or adequate. On getting a childcare place, some parents spoke about feeling guilty about potentially taking the place of another more needy child. Many of these parents also face additional transport difficulties due to their children's disabilities.

Parents also spoke at length about the 'battles' and 'struggles' they felt they faced when trying to access appropriate childcare settings; the additional difficulties faced by those less able to fight; the feeling of desperation among some parents resulting in them simply giving up the fight; and of problems associated with applying for the Disability Living Allowance.

Benefits of the right childcare both for parents and children

Many parents spoke very highly of their childcare provision, citing benefits for themselves as well as their children.

His nursery has helped him a lot...when the childcare is right, it's good for the parents, the child, for everyone. If you get good childcare at the beginning, hopefully it's going to help with their future. When you have special needs you need extra looking after but they managed to get funding from the national lottery. He's doing fantastic. He's coming on a lot.

(mother of 3 year old daughter with speech difficulty and partially sighted son with learning disability)

It's a very close and loving relationship that we have but she's bored with me you know at times. And if we're not going out and about, and I can't do that everytime we're home together because I've got to do the washing, cleaning up or whatever, fill out forms...so the three days a week of after school clubs and holiday clubs is (daughter's) social time.

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It's focused on her needs, I have to say, an excellent service we get here...She gets a social life, she gets to mix with teenagers and do something other than school...She gets to have fun, she goes to the cinema, she goes bowling, swimming... She went abseiling, I couldn't believe it, she really did!

(lone mother of daughter with profound multiple learning disability)

If you've got a child with special needs you need some time without any children just to recuperate...give the mother a break.

(mother of two children, one with special needs)

The main thing is you can switch off knowing your child is safe somewhere...the child also...he's always near you...he wants to be able to do something with somebody else at times...so he can socialise...grow strong...and be a part of society.

(father of 13 year old son with Down's syndrome)

Many parents felt that having appropriate childcare for their disabled children allowed them to spend much needed time with their other children.

It just gives him some stimulation during the holidays and gives us, more than anything, not so much a break for me, but time with my other child.

(mother of 13 year old autistic son)

Often the parents feel like they need a break from the disabled child so they can spend time with their non-disabled children so that's another reason people look for childcare, there's no doubt about that.

(lone mother of daughter with profound multiple learning disability)

The negative impact of not enough, or inappropriate, childcare

Parents spoke of the negative consequences of having the wrong, or inadequate, childcare for their disabled children. Many parents, particularly those with autistic children, felt that their children need consistency both with their childcare workers and settings. Likewise, if a worker does not build a satisfactory and understanding relationship with a disabled child, it can result in the child being frustrated and unhappy.



It takes them (autistic children) a long time to get used to someone so if they start to get used to someone and then they let them down, that sets them back so much...that it's not worth starting...if they get the confidence to get used to someone, to accept another person...it's just not worth it.

(mother of 13 year old autistic son)

These children need continuity. If you start with the child they want to be with that person, build a relationship...oh yeah we'll send someone today, another tomorrow, then that child becomes more aggressive...that is a very big issue. It's better to not have anything than ...you don't know what you're getting tomorrow. This causes more issues for parents.

(father of 13 year old son with Down's syndrome)

Some parents spoke of occasions when they had felt that their children were not welcome or wanted at childcare settings and that this had been a considerable deterrent for them.



They said they weren't sure if they'd be able to take him. And I was going back to work...they said they'd have to meet him to establish whether they could take him. I thought to myself 'well if someone doesn't want my son I don't want to leave him there'.

(mother of son with Down's syndrome)

My son is in a mainstream nursery because at the time I didn't know my son had special needs. At the moment the staff seem to consider him a problem because he doesn't settle very easily there because he cries as many children do. He cries a bit more now because he's got the hang of the fact that I'm going but he's generally harder work than other children. But now when I go in there to drop him off I can see their faces drop – and he's lovely, he's charming and plays with the other children and he's independent once he's happy there... But I think actually he deserves, all children deserve, to have someone that's relating to them. I'm taking him out of that place when and if I can get him place at another nursery.

(mother of son with Global Developmental Delay)

Many participants worried about the vulnerability of their disabled children, particularly as many of them would be unable to express themselves if they were being abused or mistreated.

I have a personal resistance to using over-night respite for a whole variety of reasons. ...A lot of the evidence I've seen around over-night respite care and residential placements for disabled children is actually extremely worrying...A child like my daughter who can't speak, who can't indicate her needs, is actually one of those that is high risk.

(lone mother of daughter with profound multiple learning disabilities)

[Son] came home with marks on his arms and I have no idea how he got them ... We are more worried about the school we send our children to and more concerned about the system that's set up...but...what can we do, spend all our hours sitting at the nursery watching our child? You have to have some faith in these people that they are going to look after our children and at the end of the day, we've got no choice, what are we going to do, keep them at home?

(mother of three children, one with special needs)

Informal childcare support

Some of the parents we spoke to were able to depend on informal support, in particular that provided by family members. However in many cases, parents felt that they couldn't rely on informal support in the same way other families could, as friends and relatives can't, or won't, always assist when it comes to the high demand children.

We had a lot of problems - social issues. I had to go places with him. He always has to have someone with him. For a long time we had to use family members because we did not have childcare.

(father of 13 year old son with Down's syndrome)

We are mums and dads and everything, aunties and uncles...I know that my son and me, I was on my own, literally on my own, my mum and dad didn't want to know, my brothers didn't want to know, so it was only me and my children.

(mother of adult disabled son).

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Obstacles faced by parents

Parents expressed guilt at having childcare, feeling, or in some cases being made to feel, that they were taking the place of another, more needy, child.

Sometimes you feel guilty...my child, I don't find him that difficult and I tend to think there are so many people that need it [childcare place] more than me and I feel a bit reluctant to get it. I think 'oh why am I taking it what there's people that so much need it more than me'.

(mother of 13 year old autistic son)

Or if you do ask and they say but there's a waitlist...or you're told 'it's for more severe special needs, what about all those children that are in hospital?' and then you feel guilty and think I shouldn't even have asked.

(mother of 11 year old daughter with autism)

When parents were asked to describe their childcare situations, they frequently spoke of the 'struggle', 'battle', 'push' and 'fight'.

My argument is, if you've got able-bodied children, you don't need to go through this, you're not begging and clawing and inviting extended family from abroad...you know...paying...vast sums of money privately to fill in the gaps.

(lone mother of daughter with profound multiple learning disability)

And he did need to be statemented and I had to fight for it... and I feel I shouldn't have to fight.

(mother of four sons, two with disabilities)

You have to push for everything.

(mother of two children, one with special needs)...

But that is a very tiring thing to do when you're looking after a child with special needs.

(mother of son with Global Developmental Delay)

Parents spoke of the difficulties faced by other parents of disabled children who they felt were less able to 'fight' or 'work' the system, including lone parents and those with English as a second language.





Especially when you're a single parent or a parent with more than one child. Constantly badgering people is hard work. If you've got a partner who's fighting the same side you are it is easier but my heart does go out to these people...even language problems. People who don't speak our language, I don't know how they do it...my heart really does go out to these people.

(mother of two children, one with special needs)

There is a very large community of people who have arrived to this area recently, English may not be their first language and how on earth they ever find or get access...I think in many cases they don't. Anecdotally you hear about children in other schools who pretty much, they have some undefined special needs, probably autistic, they never get diagnosed or stated, they don't get assessed. They certainly don't get any specialist provision and the parents aren't able to negotiate.

(mother of 11 year old daughter with autism)

It takes a lot of fight to get any of this... Somebody who maybe hasn't got English as a first language, somebody who isn't as confident doesn't get that...

(worker, Scope)

Some parents spoke of simply not being able to continue fighting for information and places for their disabled children and of, at times, giving up.

I had to complain to so many people. I didn't have time to sit down and write a letter. It's just overwhelming...sometimes it's easier to just give up.

(lone father of daughter with profound disabilities)

There is always competition, you always have to struggle, you must fight...I don't need to fight, I'm tired, I'm drained of energy. You have to fight, you have to be loud...if you have a disabled child, things should be thrown at you, you shouldn't have to fight for everything. Like people who are unemployed in this country, they get benefits, they don't have to fight every week for everything. If you have a disabled child your life is already a struggle...

(mother of autistic son)

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Difficulties with the Disability Living Allowance

Participants were extremely vocal in speaking about the difficulties associated with applying for the Disability Living Allowance (DLA). It was viewed as a complex application process and one that requires time and knowledge of how the system works.

We get on average about six to ten requests to help with the DLA per week (at support centre). It goes through phases at certain times of the year...but we'd get at least four or five a week...for one of our worker it takes about four hours – two hours to prepare and two hours to write up but it takes up to six hours and that's for us who are doing it day in day out...

(worker at support centre for families with disabled children)

It gets depressing. You're writing about your son and you have to do it in such a negative way. It took me a week – every morning I'd take him to nursery and then I'd come back to the form...that full week and I was in a cloud of depression for that week that I was filling...

(mother of 3 year old daughter with speech difficulty and partially sighted son with learning disability)

If you get it wrong like we got ours wrong when we were filling in on (son's) mobility we got it wrong because what we said he could do was he could hold our hand and take a couple of steps and they thought he could walk. He can walk but he can't walk unaided. He could walk across this room and then he'd have to sit down but yet we worded it so incorrectly that they turned us down.

(mother of two children, one with special needs)

Recommendations

Increase parents' confidence in the quality and safety of childcare settings by:

- promoting more widely the benefits of good quality childcare, provided by qualified, registered childcare workers, especially in terms of the social, educational and developmental outcomes for disabled children;
- allowing parents to observe childcare settings prior to committing to using the service.

Increase staff retention by improving the status and pay of the profession by:

- producing good practice guidance and benchmarks on pay and progression, particularly for Early Years Professionals;
- requiring all paid staff counting towards ratios to be qualified to Level 2 by 2011 and Level 3 by 2015. After 2015 they should be qualified to Level 3 within two years.

Ensure that every parent with a disabled child automatically receives the practical and emotional support required by:

- assigning a key worker to every parent when their child is first diagnosed with a disability. The key worker should provide information, support and practical assistance, including help with applying for help with childcare costs, allowances such as the DLA, and accessing childcare places. The key worker should remain in place during the disabled child's transition from child to adult services.

2.3 Gaps and needs in childcare provision for disabled children

When you've got a child with a disability, your options are usually really, really slim. And I know that mothers all over London will be screaming saying 'it's the same for us' but I have two able bodied children, I know the difference and the difference is wider than the Atlantic Ocean in the difference of choice because the only option I had at that point was (childcare setting), it was the only option in the borough and when that fell apart there was no where else to send her.

(lone mother of daughter with profound multiple learning disability)

Parents felt that the gaps in childcare provision for disabled children are numerous and represent considerable barriers to the take up of childcare. The lack of specialised childcare, tailored to the individual family's needs was perceived as a significant issue for these parents. Other gaps in provision identified by participants were: settings where they could place both their disabled and non-disabled children; provision for their own emotional wellbeing as parents of disabled children, particularly when their child is first diagnosed; appropriate settings for their disabled children as they got older; and transitional care from child to adult services.

Many parents spoke of the need for childcare to be structured around their needs – particularly in terms of timing, the provision of 'wraparound' care, and the type of childcare provided. Having specialised or tailored childcare was especially important to mothers with autistic children. They felt that current childcare settings are not always appropriate for autistic children who need: consistency, both in the care provided and in the carers; structured care; and to be surrounded by people who understand the disorder.

What I want is specialist childcare – but part time. So I suppose childcare that's a single activity, not just sitting around, maybe something that's more structured. If they know what to expect it's a lot easier...socialising is quite difficult for these children...predictability is very important.

(mother of 11 year old daughter with autism)

Parents spoke of a desire to have childcare settings for their disabled and non-disabled children in the same or nearby locations, both for the convenience this would bring, and also for the added sense of security that comes with having their non-disabled child there to keep an eye on their disabled sibling.



I wanted (non disabled daughter) to go to the nursery next to my son's school but I was told no. So where do I send her then, to another school half way across the borough just so I can get her into a nursery and him into a school. Should there not be provision so that you can have siblings, younger or older, so you have got them on the same side.

(mother of two children, one with special needs)

You want your child to be together as brothers so they could go to the same place if they have the right activities... if (other brother) could join in with him that would be a big help...now you have to send this one, one side, this one another side, so you're separating the two. If the older brother was there he would be able to look after (disabled brother).

(father of 13 year old son with Down's syndrome)

Many parents spoke of their own need for support, particularly for their emotional wellbeing. They spoke of the stress that comes with having a disabled child and the need that creates for practical & emotional support.

Someone to check on you because once you've filled out some forms...I think you're forgotten about.

(mother of four sons, two with disabilities)

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Someone you can approach and instead of them telling you what to do, just to listen... You need some sort of listener... for the parents.

(lone father of daughter with profound disabilities)

One mother suggested that parents particularly need extra support when their child is first diagnosed with a disability, both to help them emotionally and also to 'introduce' them to the services available to them.

Parents (who have just found out about child's disability) – they don't want to go out so you have to encourage them to go out, that's what's missing. Giving them a piece of paper... because they have a million things to do and they put it to one side, and they don't follow it up... the child misses out, the parent misses out, the parent becomes depressed... it's a catch 22. It's not just giving the person a date and saying 'you go out and find out something', it's get that person to go there, that's the biggest struggle.

(father of 13 year old son with Down's syndrome)

Many parents expressed fear that even fewer appropriate childcare places will be available to their children as they get older. Some believed that there is a shortage of places for older disabled children because they become more difficult to manage physically as they get older and bigger.

'It's something that I will find harder as time goes on'.

(mother of 13 year old autistic son)

As the child gets older, still there's no proper things set up for them... there was no organisation for children with Down's Syndrome in the borough, that's why we set up, ran our own group. Parents have to get together to start doing these things...

(father of 13 year old son with Down's syndrome)

One mother was concerned about her son's transition from child to adult services and the potential gap in services available to them during that time.

Am I going to be pushing him around in a wheelchair for six weeks... for him, he needs to interact with people, he needs to interact with children who have disabilities the same as himself... I feel that I'm going to be isolated for that time, and (disabled son), no matter how much he loves me and I love him... he'll get fed up of me, he'll go mad.

(mother of 17 year old disabled son)



Recommendations

Increase the provision of childcare that meets the needs of families with disabled children by:

- ensuring sufficient, affordable childcare for disabled children during school holidays;
- ensuring that settings increase the flexibility of hours of operation;
- increasing the provision of emergency or ad hoc childcare for disabled children, for instance through a Sitter Service.

Improve and increase the provision of appropriate care for older disabled children and young people by:

- conducting more research with disabled teenagers on their preferences for care provision;
- providing funding to local authorities to address the gaps in provision of care for disabled teenagers;
- considering schemes to upskill the childcare workforce to competently work with older disabled children.

2.4 Working and childcare affordability

The cost of childcare is a considerable barrier for many parents of disabled children. Of the questionnaire respondents who were not currently using childcare, around 40 per cent claimed that cost is a factor, and for 14 per cent of them, cost is the most important reason for not using childcare.

Most questionnaire respondents were in receipt of the Child Benefit and Disability Living Allowance, however knowledge and take up of other financial allowances such as the Working Tax Credit, childcare vouchers from employers and funding from local authorities and colleges/universities, was extremely low.

Focus group participants also spoke of cost being a factor in their decision to use childcare, with many feeling that because of the extra support required by their disabled children, childcare is more costly and harder to access. Many of their children require a high level of support, and therefore more expensive childcare. This additional cost doesn't usually seem to fall on the parents themselves, but many parents felt that it has a negative impact on the places available. In some cases, parents were unable to take up childcare because the necessary funding to provide the level of support required was not available.

The fact is our children are expensive. You do require often, the children I'm talking about, one to one care...they do often require personal care or a good understanding of challenging behaviour, of autism and how to deal with them...and that carries a cost. The support worker costs way more than the place in the club. You pay £8 or £10 a session in (borough), but how much are you paying a support worker? From 3 o'clock to 6 o'clock you're paying £10 an hour, that's £30 just for the support worker. These are the problems.

(lone mother of daughter with profound multiple learning disability)

Some parents felt that, as childcare options for disabled children are so limited, it should be free to enable them to be 'part of society'.

For disabled children it should be free... to allow them be part of society you know... well other children, you've got a choice on where can send a (non-disabled) child, there's a choice... But when it's a disabled child... you're trying to get them integrated in society, you have to get a safe environment...how are they going to be looked after...so they've got a disadvantage already but now you put the pressure on parents to pay.

(father of 13 year old son with Down's syndrome)



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High cost of holiday-time care

A prominent theme emerging from the focus groups was the difficulties parents of disabled children experienced in finding adequate, affordable childcare during the school holidays. This was an issue both for parents who worked and those who were not working. For parents who worked, the lack of places and the high cost of holiday care meant that they often had to use up all their annual leave during this time. Even when they did this, they generally had fewer days annual leave than their child had days off school. For parents who were not working, they experienced the school holidays as being a difficult time trying to entertain their disabled child, and holiday clubs as being expensive and often out of reach.

You have to budget for the six weeks holidays. Their (children's) needs have increased, they're eating at home so you have to do breakfast, lunch and dinners, and then to go out as well, you can't keep them in for six weeks

(parent of child with severe disabilities)

The other one I know take children for six weeks holiday...I spoke to one of the carers there and they charge for one week with no lunches included, Monday to Friday 8.30 to 3.30 they charge £200 a week. All special needs they deal with, autism, Down's...but £200 a week they charge... the cost of childcare outside term time is astronomical.

(mother of two children, one with special needs)

Working, affordability and other childcare issues

Many of the parents we spoke to, did want to work and/or study for a variety of reasons, but faced numerous and complex barriers in their efforts to do so. The benefits of working were recognised by many participants, however they felt it requires a balance of being able to access the right childcare and having an employment situation that is flexible enough to allow them to meet the demands of their disabled child. This is an extremely delicate situation, as even parents with the seemingly right job and childcare situation, can be vulnerable to the high demands of their disabled child, to the detriment of their job. Difficulties are exacerbated at holiday time when finding appropriate and affordable childcare is crucial to the parent's ability to continue working or studying.

Participants felt that being able to work is especially important for many parents with disabled children, not just for financial reasons,

but also because of the social and emotional benefits for the parent and child. There was even a feeling among some parents that they had to justify themselves for wanting to work.

I also think that whilst a lot of us these days need to work for financial reasons, or maybe just ...it's your personal right if you want to carry on doing your job, it's your right to be a parent and work, I think as somebody who has a child with special needs, there's sometimes an added reason to want to go to work to focus on something else...

(mother of 6 year old son with autism)

There's no doubt that we just want to work but you feel like you just have to justify yourself all the time. It's childcare that's crucial for me because I wanted to work. I feel very passionate about the fact that for us, for mothers in particular who've got disabled children, it's even more important for those of us that want to work than our peer group that have able bodied children... because having a child with profound or severe disabilities in the house...it leads to social isolation, depression amongst mothers, depression for the young person that's got the disability...poverty...

(lone mother of daughter with profound multiple learning disability)

For these parents, finding a balance of the right childcare and a sympathetic employer was very difficult.

I'd have to find a job that would fit in with school hours, plus when you have a child with special needs you find you have to go to a lot of meetings all the time and you'd have to have a job that would allow you to do that.

(mother of 8 year old son with Aspergers syndrome)

Even with the right childcare and a good job, parents can experience difficulties. One mother told of how she used to have a well paid job and managed to pay £410 per week for the right childcare but even then, because of the high demands on her time by her disabled child, she was unable to continue working in that job.

The provision I had was okay so I paid £410 a week from 8 until 6 and it was 48 weeks a year. I could manage that out of my pay packet because I had a good job. There were two weeks in August and a week at Christmas ...I would have to take that time off work. But it would work but they said I had too many nursery appointments and after being back for a week and a half they said 'you can't do your job but we do want to support



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you so we've made you a special projects worker and the first thing you're to do is review everyone's expenses'. Yawn. It was a compromise agreement. So I left.

(mother of son with Down's syndrome)

Participants also spoke of other issues that they face as parents of disabled children wishing to enter the workforce. For instance, because of the high demands of their disabled children, including frequent medical appointments and bouts of sickness, committing to regular working hours is difficult. One mother with a child with Down's syndrome told of the problems she experienced in her job because of having to take time off work due to her son's ill health, saying:

The nursery policy is do not bring your child in if they are unwell. But if they were to look at my child – he has breathing problems, he has reflux...a load of other issues as well...so if I was to look at him and say 'are you well?' You're not well. I'd never take him. I did go back to work for three weeks before work got fed up with me and I was let go...At the moment I have three appointments in the coming week and two appointments next week so in a month I've got 10 appointments so how the hell am I going to hold down a job? It's nearly impossible.

School holiday-time also poses immense difficulties for parents who want to work, as they either have to take time off to care for their disabled children, find appropriate formal care, or depend on informal care.

The only way I've been able to keep working over the years is sadly because my marriage ended. So over the summer holidays and school holidays we've been able to juggle childcare ...I've been able to juggle it, otherwise it's just out of the question.

(mother of 6 year old son with autism)





Recommendations

Make childcare more affordable for, and increase the uptake of help with childcare costs among, families with disabled children by:

- continuing to fund the Childcare Affordability Programme (CAP), currently led by the London Development Agency and consider extending the principle to other cities and regions in order to: subsidise costs and fund more free places in London, other high cost areas, rural areas and for disabled children;
- making information on childcare entitlements more accessible to all parents of disabled children and modify the Working Tax Credit system to increase benefits to these families;
- increasing the upper limit of eligible childcare costs under Working Tax Credit for families with a disabled child to £300 per week;
- increasing the help available through tax credits so that parents of disabled young people aged 16-18 can claim for the childcare element of Working Tax Credit.

Make it easier for parents of disabled children who want to work, train or study to do so by:

- providing more support to parents returning to work or study, including allowing parents to trial childcare arrangements prior to starting work or study;
- increasing awareness of parental leave rights. Currently parents are entitled to 18 weeks leave for disabled children up to the age of 18;
- introducing paid parental leave for all parents including those with children over six;
- ensuring that the recently announced increase in childcare funding for students adequately covers the needs of parents of disabled children wishing to study;
- developing a Pathways to Work scheme for parents of disabled children.

Make disabled children's medical requirements less of a deterrent to their parents working by:

- ensuring the provision of more emergency/ad hoc provision for disabled children, preferably in their own home (as per recommendation in Section 2.3).

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2.5 Information on childcare for disabled children

Parents of disabled children face considerable barriers when trying to access information about childcare. Focus group participants spoke of a reliance on word of mouth, and many were simply unaware of sources of childcare information, apart from other parents. They felt that this is an unsatisfactory situation, particularly as many parents of disabled children are isolated and in danger of receiving no childcare information at all.

I think without doubt the concept of networking and finding out information from other people is the most vital source of information.

(mother of 6 year old son with autism)

The key thing for me is where to get information. I find I don't get any unless I speak to other parents.

(mother of son with Global Developmental Delay)

Parents expressed frustration because of the inadequate information provision, which they felt might be preventing them from accessing services and support. The fear of missing out on vital information that could benefit their families was common among many parents.

I still feel that I don't know...maybe this is why I feel I'm struggling so badly because nothing is clear to me, I don't understand, I don't realise or I haven't heard of it. My doubt is maybe I don't know things- that's why it's hard.

(mother of autistic son)

I've never had outreach, I've never had that kind of support, I've always had to fight for it, always had to travel down here (to Centre) or go to other centres for information. It shouldn't be that one person gets it while another doesn't.

(mother of four sons, two with disabilities)

We only found out when we started fighting for (son's) place at [centre] that he needed his statement, but at the time we weren't made aware of that because they said he doesn't need his statement until he's four so that all fell through... if we knew he'd need a statement before he started school we would have had him tested properly. Nappies! I didn't know my son was entitled to nappies until someone told me at nursery.

(mother of two children, one with special needs)





What I'm not being made aware of I feel is the things that are available to me in terms of childcare. So not just 'your child's in nursery fine' it should be 'oh there's a pilot...' Maybe I just need to fight for but ...I don't know the things I've got to fight for yet and I don't know who to ask.

(mother of son with Global Developmental Delay)

Information needs for parents of disabled children

Parents spoke about the need for more straightforward information provision – perhaps from a single source or 'central resource', and for information more pertinent to their individual situations, combined with the offer of practical help where required.

The whole level of understanding about autism doesn't seem to be there and for us, there's nowhere to access a list of, okay these are people you can call on, be they a childminder, an after-school club or a holiday club where they would have people who understand ...there doesn't seem to be anything like that at all. Every one of us has to fight for ourselves don't we...

(mother of 8 year old son with Aspergers syndrome)

I think some sort of central resource base would be a good thing because I do believe that somewhere that this information could be held...because if it's just one person and that link breaks for some reason, your childminder gets ill or something...

(mother of 11 year old daughter with autism)

There's definitely not a main source of income that mothers or fathers can contact if they have a child with special needs.

(mother of two children, one with special needs)

On how they would like to receive information, parents expressed a preference for support and information received from outreach workers and health practitioners; and through the Child Development Team; designated disability information officers; and newsletters.

I used to get someone come to the house and they would give early years education and she would also tell me all the stuff that's going on as well That's how we got into this pilot (scheme for free childcare for disabled two year olds). Everyone should get that...

(mother of 3 year old daughter with speech difficulty and partially sighted son with learning disability)

Really what the Child Development Team should do is set up a parents' forum. And one person a month from the CDT bringing all the mums together that are interested, giving us any new information we're not aware of, updating us on any old information...

(mother of son with Global Developmental Delay)

Specific childcare information officers in each area for disabled children [are needed] and we've already got one...she's based in a centre for children with disabilities 0 to 19 year olds (in hospital), so it's health. It's got consultant paediatricians, consultants, physios, all based there... It's worked very, very well. She produces a newsletter...three times a year or something...you can get her by telephone, you can fax her and you can email her...She helps support families filling out benefit forms like the DLA, she gets referrals straight from the (Children's Centre) so as the children are coming being diagnosed, she gets an immediate referral because that's where she sits, in the Centre with the consultant paediatrician and nurses. So that's excellent. That's a really good place to sit for her. She gets an immediate referral.

(lone mother of daughter with profound multiple learning disability)

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Recommendations

Ensure that all families with disabled children can easily access all necessary information on childcare by:

- improving the consistency and reliability of information provision by encouraging all Local Authorities to share information and allow easier movement of childcare users between settings in different boroughs;
- extending the remit of Children's Information Services (CIS) to provide more information and support relevant to families of disabled children, extending their 'brokerage service', and ensuring a disability information officer is in place at every CIS;
- assigning a key worker to every family with a disabled child (as per recommendation in Section 2.2).



conclusions

Poverty and social exclusion are two challenges faced by families with disabled children, and having access to appropriate, affordable, high-quality childcare is key to addressing these disadvantages. The right childcare can benefit disabled children by improving their social, developmental and educational outcomes. It can also help improve outcomes for the entire family by opening up opportunities for parents of disabled children to work and potentially lift their

family out of poverty; to spend more time with their non-disabled children; and to get a break from their caring responsibilities, potentially reducing incidences of stress or emotional break-downs. The right childcare can also help 'normalise' family life for many of these families by providing outlets for both parents and disabled children to pursue their own interests and to develop as part of society.

In order for the full benefits of childcare for disabled children to be felt though, a number of considerable gaps and needs must be addressed. Currently there are not enough appropriate and affordable childcare places for disabled children. In order to increase the number of places, there needs to be childcare workers at every setting who are suitably trained in working with children with all types of disabilities. Every childcare setting needs to be disability-friendly and local authorities must pursue their target of achieving childcare sufficiency, paying particular attention to the needs of disabled children. More places need to be made available catering to the specific needs of individual disabled children with consideration given to creating childcare environments that are appropriate to the very specific needs of autistic children.

Parents of disabled children must have easy access to practical and emotional support to assist them with all of the additional challenges they face. This should include help with finding out about and applying for help with childcare costs and other initiatives, finding appropriate childcare places, and other issues of daily life, including finding compatible employment opportunities if appropriate. The end result should be that parents with disabled children don't feel they have to continually struggle to achieve a normal life for their family and, can access suitable, affordable childcare when and where they need it.

Other briefing papers from the *Listening to families* research are:

- [Listening to lone parents about childcare](#)
- [Listening to black and minority ethnic parents about childcare](#)

Daycare Trust, the national childcare charity, is celebrating 21 years of campaigning for quality, accessible, affordable childcare for all and raising the voices of children, parents and carers. We lead the national childcare campaign by producing high quality research, developing credible policy recommendations through publications and the media, and by working with others. Our advice and information on childcare issues assists parents and carers, providers, employers, trade unions and policymakers.

Established in 1986, Daycare Trust has seen its campaigning translate into policy change, including the establishment of the national childcare strategy. However, access to quality childcare services is still dependent on where families live and on their income. In our 21st campaigning year, Daycare Trust is uniquely qualified to give a voice to parents facing a multiple range of challenges. Please support our campaign for universal quality affordable childcare.

Daycare Trust offers a range of services, including an information line, consultancy, training and membership. This year we are offering free membership to parents as a celebration of our achievements. Contact us for details of our services or visit our website.

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