



Illustrations by Martine d'Ellard
Martine is mother to an autistic teenager

Findings from the research into the free childcare offer for disabled children

About the research

Contact a Family, the Council for Disabled Children and the Family and Childcare Trust ran an online survey for parent carers between 6 July and 21 September 2015. This was promoted via the charities' networks.

The aim of the research was to find out more about parent carers' experiences of accessing the free childcare offer of 15 hours for disabled children (this includes children with special educational needs, health conditions or developmental delay).

The following findings are based on 268 responses from parent carers/guardians of 291 disabled children.

About the respondents

36% of respondents are in either part time or full time paid work and 53% of respondents are not in paid work due to caring role.

62% of respondents say their partner is in either part time or full time paid work while 9% of respondents say their partner is not in paid work due to caring role.

1. Findings from the research

Disability status of children

76% of children are in receipt of Disability Living Allowance (DLA)

48% of children have a statement of special educational needs (SEN) or Education, Health and Care (EHC) plan

Family income

24% of respondents are receiving Income Support

53% of respondents are receiving Child Tax Credit and/or Working Tax Credit and have an annual income under £16,190

Amount of free early education accessed

60% of respondents receive full free entitlement of 15 hours per week for 38 weeks, compared with 97% uptake of full free childcare offer amongst the 3-4 year old demographic as a whole

15% receive some of the free entitlement - on average 9 hours per week, based on open responses.

25% of respondents receive none of the free entitlement

The type of setting used to access free offer

32% private, voluntary or independent setting

32% state nursery class or state nursery school, including those run by children's centres

22% pre-school offering part-time early education sessions

15% nursery or pre-school for disabled children

4% childminder

1% childminder for disabled children

Informal childcare

23% of respondents also use additional/secondary childcare provided informally by relatives or friends

Reasons given why parents are accessing less than the full entitlement of childcare for their disabled child

(Based on 53 responses, parents could pick more than one option)

36% were only offered a limited number of hours by the nursery/carer

32% say one-to-one care (or other additional support) is not available at all times their child needs it (for example, for longer than three hours a day)

27% choose not to use their child's full early education and childcare entitlement

22% say funding for one-to-one care (or other additional support) does not cover all the hours their child is entitled to

10% say the nursery/child carer that they use offers the free hours in blocks/days/times that do not meet their child's needs

7% say the nursery/child carer that they use offers the free hours in blocks /days/times that are not convenient for their family

Open responses

4 respondents say that their child is too ill or cannot cope with attending the full 15 hours of childcare per week

3 respondents say that childcare staff are not sufficiently trained to provide the support that their child needs

3 respondents report suitable schools being fully subscribed or too difficult to get to

2 respondents say that there is no available funding to provide the one-to-one care that their child needs for 15 hours per week

2 respondents report being charged extra to access one-to-one care for the full 15 hours per week

2 respondents say that childcare providers refuse to offer the full 15 hours as their child is too difficult

Responses given why parents are accessing none of their free entitlement for childcare for their disabled child

(Based on 36 responses, parents could pick more than one option)

38% do not think that available provision can care for their child safely

30% do not think that available provision has staff that are adequately trained

28% do not think that available provision is inclusive and supports their child to participate in activities alongside their peers

33% do not think that available provision can meet their child's special or additional needs

25% said the nursery/child carer refused a place or excluded their child because of their disability or special education need

20% did not know that their child was entitled to the free early education

18% say there was no childcare or nurseries with any vacancies

18% say the nursery/child carer asked them to pay for additional hours or services and they could not afford this

15% could not find a place that was convenient for their family

Open responses

4 respondents refer to the lack of available one-to-one care that their child needs

2 respondents say they are in the Education, Health and Care plan application process

2 respondents refer to a lack of adequately trained staff

Reason given if child refused a place or excluded from a nursery childcare setting

(Based on 45 responses, parents could pick more than one option)

49% say their child has been refused a place at/ excluded from a setting because they say they cannot meet the child's additional needs

47% say their child has been refused a place at/ excluded from a setting because the child needs one-to-one care (or other additional support) which is not available/ affordable

34% say their child has been refused a place at/ excluded from a setting because they say they cannot manage the child's behaviour

30% say their child has been refused a place at/ excluded from a setting because they cannot meet the child's medical needs

23% say their child has been refused a place at/excluded from a setting because they say they are not trained to care for the child

15% say their child has been refused a place at/excluded from a setting because the physical environment is not accessible

9% say their child has been refused a place at/excluded from a setting because they do not have the necessary specialist equipment

6% say their child has been refused a place at/excluded from a setting because they must pay for additional hours, which they cannot afford

Open responses

4 respondents report being told there was no space when other children were known to have been accepted

2 respondents report their older children being left with the babies

2 respondents report their children being excluded until statements of special educational needs were obtained

1 respondent reports their child being excluded from a setting as his needs would cause insurance premiums to rise

We asked families to rate the following statements:

57% agree/strongly agree that early education or childcare settings are available in their local area that can ensure their child is safe and healthy (25 % disagree/ strongly disagree)

44% agree/strongly agree that early education or childcare settings are available in their local area that can include their child in activities alongside non-disabled children (34% disagree/strongly disagree)

42% agree/strongly agree that early education or childcare settings are available in their local area that can respond to their child's special educational needs or disabilities and help them progress (36% disagree/strongly disagree)

42% agree/strongly agree that early education or childcare settings are available that will make reasonable adjustments for their child. (33% disagree/strongly disagree)

35 % agree/strongly agree that early education or childcare settings are available in their local area that have a good understanding of their child's special educational needs or disabilities (39% disagree/strongly disagree)

Local Offer

Local authorities now have to publish details about the support and facilities which families can expect to find in their area for children and young people who have special educational needs and disabilities. This is called the Local Offer. It is not a list of services, but is meant to be information about the support that the local authority expects to be available. It covers early years, as well as other services such as healthcare, schooling and social care.

In relation to free early education, did you find the information in the local offer helpful?

27% of respondents found this information helpful or very helpful

21% of respondents found this information unhelpful or very unhelpful

41% of respondents have not viewed the local offer

2. Family case studies

About the case studies

As a follow up to our online survey, Contact a Family spoke with several respondents who had provided their contact details and agreed to provide further information about their experiences of early years childcare and accessing the free childcare offer.

The aim of these case studies is to paint a fuller picture, and gain a more in-depth understanding of some of the experiences and challenges faced by families with disabled children, children with special educational needs or developmental delay, in their efforts to access affordable and high quality early childcare.

We have gathered case studies from seven parents, each with an individual story to tell.

Karen Holland from Islington has a five year old daughter named Keira with Down syndrome, as well as two older daughters, Aleasha, 23 and Jezselle, 22

“When Keira was two, I registered her at the same children’s centre that my two older daughters had attended several years previously. Although I had a very positive experience of this childcare provider previously, I was generally disappointed with the level of provisional care they provided for Keira. While there was a SENCO worker on site, I felt that the staff as a whole were poorly trained regarding disability issues and ill-equipped to cope with my daughter’s additional needs.

“I understood that the ratio of staff required to provide care to individuals with special needs was as follows: ‘children under age of one with a disability, should have one-to-one support with

an allocated keyworker... (and)...from the age of one up to the age of five, among children with special needs, the ratio is set at one staff member to three children.’ In my experience, seeing how the provisional care was delivered at the day care centre, it became clear this standard ratio was not suitable for Keira or for any disabled child, due to safety concerns.

“The provider was either unwilling or unable to provide the one-to-one care that Keira required, citing the high costs of extra staffing, and while I requested several times that they apply for top-up funding from the local authorities to fund this service, this was never followed through. The only solution offered was that I find a childminder that could better cater to Keira’s needs.

“I believe that compulsory training needs to be provided to independent childminders in specific areas such as Makaton language, health and safety, and medication. Additionally, training should also be offered in child protection and disability issues more generally to ensure that every child’s needs are met accordingly, because ‘every child matters.

“As a lone parent, I have been unable to get back to work since Keira was born, due to her medical needs and my lack of confidence in the childcare services available in my local area. I felt that I have had to remain on call for her at all times. Now that Keira is five and has been enrolled in a full time special needs nursery, which, I may add, she loves, is happy and very settled, I have been using my spare time to begin setting up my own cosmetic sales business as an entrepreneur.”

Tara Gool from Dorset County is the mother 17 year old William, 14 year old Sonny who has autism, and 4 year old Lillie-Mae who has Down syndrome

“Lillie-Mae attended nursery from the age of one, and began accessing her 15 hours of free early education at the age of two. I have had a largely positive experience with childcare access for my daughter; however, there have been some disputes over funding which have slightly soured my relations with the nursery.

“As Lillie-Mae’s needs increased as she got older, it was mutually agreed between the nursery management and myself that they should apply for top-up funding from the local council to provide one-to-one care services for my daughter. I believed that she could strongly benefit educationally and emotionally from having one person at nursery that was assigned to her care and whom she could depend on to be there for her at all times. Obtaining the funding was relatively straight-forward but I was disappointed that the one-to-one care that I had been promised never materialised.

“Despite numerous conversations where I expressed a strong preference that one-to-one care for Lillie-Mae be provided, the nursery insisted that it wasn’t necessary as ‘all’ of the staff provided her care and I’m not really sure how the top-up funding was allocated. While I was generally happy with the quality of the care provided at the nursery, I was frustrated at the lack of communication on this matter and that my preferences for my daughter’s care did not seem to be prioritised.

“A further incident arose when the nursery refused to provide care during school holidays, I was informed that they did not have enough staff to cater for my daughter’s needs. No other

children in the nursery had been refused care and I had to make a formal complaint to the governing body of the nursery and to Ofsted on the grounds of discrimination before they agreed to provide care for Lillie-Mae over the summer holidays.

“Lillie-Mae was later moved, part-time, to a smaller nursery where the staff were really excellent and where one-to-one care was provided at all times, without accessing top-up funding.

“I have only been working part-time since my daughter was born, on weekends and evenings, so that my partner and I can juggle childcare responsibilities. Now that Lillie-Mae has started at reception, I will consider returning to full-time work but we will have to do the maths to see if this is economical given the high costs of one-to-one after-school childcare.”

Siobhán Bain from Southwark is the mother of Cillian, age 5 and Fintan, age 3. Fintan has a variety of undiagnosed disorders and has global developmental delay

“I have been discouraged by many of the attitudes that I have encountered while trying to find suitable childcare for my son Fintan. He has been rejected outright by certain childcare providers as soon as his additional needs were mentioned; others have been unable to seek funding for the one-to-one care Fintan requires until he has received his Education, Health and Care plan. Suggestions have been made that Fintan be left in a childcare setting without the one-to-one care that he vitally requires so that his ‘additional needs can be assessed’. I find the idea of deliberately leaving my son in a childcare setting that I know to be wholly unsuitable as a

trial run to be a highly distressing and insensitive suggestion, not to mention dangerous.

“Generally, I am uncomfortable with leaving Fintan in any childcare setting that is merely willing to tolerate his presence as a legal requirement or treat him as ‘a problem that has to be solved’. I am seeking a childcare setting where my son will be treated as an asset to the group, where mainstream children will be encouraged to engage with Fintan and learn about his disabilities rather than fearing them. I believe strongly in the idea of inclusion, but only if it is wholly committed to by all involved and sufficiently funded to be properly workable; conditions which I do not see as existing currently. I feel that I have been discouraged, rather than facilitated, by local service providers at every juncture.

“I currently pay for a full-time nanny for my children rather than take up the government’s offer of 15 hours free childcare per week due to a lack of suitable facilities in my local area. I am extremely lucky to have a flexible well paid job that allows me to do this but I am deeply saddened by the fact that many other parents of children with additional needs will be kept out of work due to lack of access to viable and affordable childcare facilities. No attempt has been made by this government to address the glaring gap in provision of wraparound care and pre-school care for disabled children such as Fintan.”

Sarah Smith¹ from Essex is the mother of 4 children, 3 of whom have additional needs

“Three of my children have additional needs and I have experienced significant difficulties finding

¹ This respondent’s name has been changed to protect her anonymity

suitable childcare for them over the years. My son, who has hypermobility syndrome, global developmental delay, autism, and serious food allergies, was rejected from 17 different childcare providers before he was accepted by a local charity run pre-school. The reasons given usually referenced his food allergies, and how they would cause insurance premiums to rise. Additionally, none of these providers were able or willing to provide the one-to-one care that he requires. I was not aware that top-up funding from the local authority could be sought to cover the costs of providing this service and this was never suggested to me as a possibility by any of the providers I approached.

“I was very happy with the quality of the care he received when I finally found a suitable pre-school where one-to-one care was provided for 15 hours per week. However, I have been told by the provider that the one-to-one care would not be extended to the free 30 hours proposed by the childcare bill and therefore, this piece of legislation would be of no use to us. The extra 15 hours of free care would not apply to children like my son who require intensive care.

“I have noticed some improvements in childcare provision for disabled children since my eldest daughter was a young child. In particular, the availability of extra funding for one-to-one care is a significant advancement. However, I feel that the information regarding these services is not made easily available to those who need it, and a lack of knowledge results in a lack of power to access assistance.

“One problem that has remained constant over the years is a complete lack of access to affordable child minding services for disabled children. Now that my son has started in reception, I would like to consider the opportunity to return to work. However, there is no funding available

to cover my after-school childcare costs, and as he requires one-to-one care, a childminder would cost £30 an hour. Even considering the available tax credits and subsidies, this would remain unaffordable and seeking a job paying close to minimum wage would be uneconomical considering my childcare costs.”

Kelly Brown from Swindon is the mother of 17 year old Tyler and 2 year old Eden who has muscular dystrophy

“My initial experience of accessing free early childcare for Eden was very positive. I managed to find a local nursery that was wheelchair accessible and offered one-to-one care, 35 hours a week at no additional cost. This was all funded by the local council.

“However, with Eden falling ill this summer, and in and out of hospital, she has been withdrawn from nursery temporarily and must be cared for at home to protect her from potential infections. I appealed to have Eden’s 15 hours of free childcare transferred over to an Ofsted approved home carer. However, I was told by local authorities that this would be impossible as funding can only be provided for children who are attending ‘early childcare settings’.

“There is no safety net for families in our situation and now my partner and I have been forced to take several months off work each to care for her. We are eager to return to work soon but this will only be possible if we pay for a home carer entirely out of our own pockets which will put significant financial strain on the family. This money will have to come partially from Eden’s Disability Living Allowance funding which we were hoping to conserve for buying vital equipment and planning for our daughter’s future.

“30 hours free childcare a week will be useless to parents of ill children like Eden if we are unable to access funding for home care. Local rules do not provide equal opportunities if your child is in poor health!”

Nicola Flynn from Westminster has two children, Darragh aged 3 and Aoife aged 2. Darragh has Down syndrome

“I have been unable to access any of the free early childcare entitlement as I don’t feel that any of the locally participating childcare providers would be able to provide the one-to-one support that Darragh needs in a learning environment.

“I am concerned that some of the better quality childcare providers in the area have not chosen to take part in the 15 hours free scheme. Based on stories I have heard from fellow parents of disabled children, I believe that the providers in the area would be ill-equipped to cope with Darragh’s needs and would probably keep him in the baby group rather than letting him interact with peers of his own age. As a result, I opted to hire a childminder for my two children.

“I was very discouraged by the standard of the information provided by the local authorities. The information was not readily accessible and the list of childcare providers was out of date. I felt that the council was not forthcoming with assistance and that I was forced to conduct much of the research for myself.

“With Darragh now enrolling in a local state school that is well equipped to deal with his needs, I will consider enrolling Aoife in a nursery that is taking part in the free early childcare scheme. However, I felt that this wouldn’t have been an accessible or viable option for Darragh considering his additional needs.”

Lisa Evans from Redcar and Cleveland is the mother of 12 year old Reece, 9 year old Darcy, and 2 year old Riley. Riley has chronic lung disease and has a gastrostomy

“I have found accessing childcare for my son, Riley, to be quite a straight forward and positive experience. He was admitted without hesitation to our local private nursery, which was the first childcare provider that I approached. I have found the staff to be helpful and willing to learn about my son’s additional needs. Riley needs to be fed through a gastrostomy tube so when he started at nursery the staff all received the relevant training from a local community nurse. As a result, I have full confidence in their ability to provide safe and good quality childcare for Riley.

“Currently, I am not working due to my caring role; however, when Riley’s free childcare entitlements are doubled to 30 hours per week, this will allow me to return to work. I have had a conversation with the nursery and they have been very accommodating, agreeing to figure out a flexible childcare schedule for Riley that will suit my shifts when I return to work.”

We would like to say a huge thank you to everyone who completed the survey and the families who have allowed us to share their experiences in our case studies. This evidence will help us to campaign for equal access to childcare for disabled children.



Contact a Family

Contact a Family supports families with disabled children across the UK. Whatever the condition, whenever they need us, wherever they are. For advice on any aspect of caring for a disabled child, call our freephone helpline on 0808 808 3555.

www.cafamily.org.uk



Council for disabled children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. Our work impacts on over 800,000 disabled children and their families and our vision is a society in which disabled children's life chances are assured, their needs are met, their aspirations are supported and their rights are respected.

www.councilfordisabledchildren.org.uk



Family and Childcare Trust

The Family and Childcare Trust works to make the UK a better place for families. Our vision is of a society where government, business and communities do all they can to support every family to thrive. Through our research, campaigning and practical support we are creating a more family friendly UK.

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