Parents or carers about their experience of maintaining the healthcare needs of their children under 5 years old December 2023 – February 2024 - Full report

healthwatch
Brighton and Hove

Table of Contents

This project was led and the report written by Michelle Kay.

For further information contact
info@healthwatchbrightonandhove.co.uk

Executive summary

Healthwatch Brighton and Hove (Healthwatch) were commissioned to speak to parents and carers, about their experience of accessing healthcare services on behalf of their child/ren aged five years and under. We aimed to connect with some lesser heard groups and worked with local VCSE partners to identify people from these groups.

These included:

1. Parents with a child with special educational needs (SEN) and/or disability
2. LGBTQ+ parents
3. Parents from ethnic minorities; and
4. Fathers.

Healthwatch engaged with parents and carers through a survey distributed through partners, our own mailing list and through social media. The survey was mostly quantitative closed-end questions with two open-ended questions. This achieved 117 responses. We also carried out 19 interviews. All interviewees were asked to complete the survey prior to interview, to enable the interviewer to probe further and to find out some of the context and explanation behind the survey responses. The survey questions, interview discussion guides and interview summary template can all be found at Appendix B.

Analysis of the survey responses and interview narratives provided insight into the experience of parents accessing healthcare services for their young children. The **key findings** are shown below:

- Challenges with accessing appointments: booking GP and dental appointments.
- Lengthy waiting lists for specialist referral appointments and neuro-diverse assessments.
- Difficulties with attending services: due to having a child with special needs or feeling unwelcome or not catered for (e.g. dads, LGBTQ+ parents, or neuro-diverse families attending parent groups).

- The importance of good customer-service of staff: GP receptionists and consultants' secretaries, as well as healthcare staff including dentists being caring and thorough in treating children.
- Poor quality advice: from GPs and consultants and not responding to parents' concerns or taking their opinions into consideration.
- Costs associated with attending appointments and parenting support groups, including travel costs.
- Lack of available information: on parenting support groups, about emotional support etc. for new parents.
- Lack of consideration for emotional support offered to new parents, including dads.
- Support for emotional wellbeing either not tailored to specific need and/or not provided for long enough.
- Lack of joined up maternity services between hospital, GP, and community services (mid-wife and health visitors).
- The lack of awareness about what The CQC do and the benefits to parents of contacting them.

From the above findings, we proposed **recommendations** around the following themes. For the full list of recommendations please see *Section 7: Recommendations*.

- Access: improve access to appointments for GP, dental and specialist/referrals. Decrease waiting lists for neurodiverse assessments.
- Customer-service: improve flexibility and friendliness of reception staff
- Quality of care: Medical staff should take parents' views into account and all staff should be trained to respond to children with additional needs.
- Parent support services: improve access to support groups, including offering specific services for LGBTQ+ parents and neurodiverse families.
- Emotional support: ensure new parents, dads as well as mums, are asked about emotional as well as physical wellbeing and are signposted towards these services.

- Joined-up care: Ensure GPs and community services (midwives and health visitors) are made aware of challenging birth situations for new mums (and dads).
- Inclusive services: Ensure LGBTQ+ inclusion in maternity services; create opportunities for free services for parents from geographically deprived areas.
- Better promotion of the CQC: Ensure the general public know who they are, what they do and the reasons why service users should contact them.

Methodology

Healthwatch engaged with parents and carers through a survey distributed through partners, our own mailing list and through social media. The survey was mostly quantitative closed-end questions with two open-ended questions. This achieved 117 responses. We also carried out 19 interviews. All interviewees were asked to complete the survey prior to interview, to enable the interviewer to probe further and to find out some of the context and explanation behind the survey responses. The survey questions, interview discussion guides and interview summary template can all be found at Appendix B.

Working with already established partnerships

Healthwatch worked with the following VCSE organisations to connect with parents/carers from lesser heard groups.

- Bridging Change
  A local VCSE which aims to create a more equal and diverse society with positive outcomes for Black Asian and minoritised ethnic people.

- Sussex interpreting Services
  A local VCSE which works with service users from a minoritised ethnic background, and with English as a second language.

- Amaze and PaCC.
  Amaze is a local VCSE, which provides support to parents & carers of children & young people with special educational needs and disabilities in Brighton and Hove.

PaCC, the Parent Carers' Council, hosted by Amaze, offers support to parent carers of children with additional needs to receive the best care from the health and social care services available to them.

- Mothers Uncovered.
  This local VCSE supports women in matrescence, a term meaning the transition of a woman into motherhood. Recorded figures show post-natal illness affects up to 100,000 women in the UK every year. However, many are unable to admit to feelings of depression, anxiety and loneliness and suffer in silence. Mothers Uncovered provides the opportunity for mothers to come together and talk about these painful experiences in a relaxed facilitated environment.

- East Brighton Food Cooperation
  A local VCSE which co-produces a daily meals on wheels service across the more deprived areas of East Brighton. EBFC helps prevent malnutrition and social isolation, through tailored meals that consider dietary requirements and offering social contact with recipients.

- Maternity Voices Partnership Sussex
  An NHS working group that brings together a team of service users and their families, commissioners, and providers (midwives and doctors) to work together to review and contribute to the development of local maternity care using lived experience to contribute to transforming maternity care.

Participant profile

Healthwatch Brighton and Hove always aims to recruit a diverse group of people within our projects, including those who represent a range of ages, sexual identity, and ethnic diversity. Note that in this study we deliberately recruited a high proportion of women to fulfil the objectives of the research.

For complete information on the profiles of survey respondents and interviewees, please see Appendix A. This also includes information on the gender and age of parents' children. A summary follows below:

Survey

Our survey received 117 respondents and 53% (62 people) responded to our demographic questions. Of those who answered these demographic questions, the majority (81%, 50) were women, with 97% (60 people) identifying as the same gender as they were assigned at birth. Most parents (81%, 50) were heterosexual/straight. Survey respondents aged from 25 to 51 years old with the majority (47%, 27 people) between the age of 30-39 years old.

The survey was distributed Sussex-wide, with the majority from Brighton and Hove (46%); 31% from West Sussex and 23% from East Sussex. While most parents (77%, 47) did not have long-term conditions, 16% of parents did. The majority of parents (82%, 51) were "white" and most parents (51%, 31) defined themselves as having "no religion". Most parents (69%, 42) did not have additional responsibility for caring for someone other than their children. However, a high minority of 26% (16 people) cared for someone else.

Interviews

The CQC were also keen to hear from a diverse group of parents and as such, Healthwatch proposed that we would try to enlist parents by working with Voluntary, community and social enterprises (VCSE) partner organisations where possible. The CQC set a minimum of 15 interviews. However, we were able to conduct 19 interviews. Having purposefully selected parents for interview that represented a diverse data set, the percentages for diversity are higher than average.

From the 19 interviews we conducted, ages ranged from 28 to 46 years. Most interviewees were from Brighton (9 parents) with 6 parents from East Sussex and 4 from West Sussex. The majority of interviewees (16) were heterosexual. Most interviewees (14) did not have a long-term condition. Most of our interviewees (15) identified as "white", with four identifying as "non-white". The majority of interviewees (12) had "no religion". Most parents did not provide care for anyone other than their children.

Findings/key themes

The following are findings from the collated experiences of both survey respondents and the 19 interviewees.

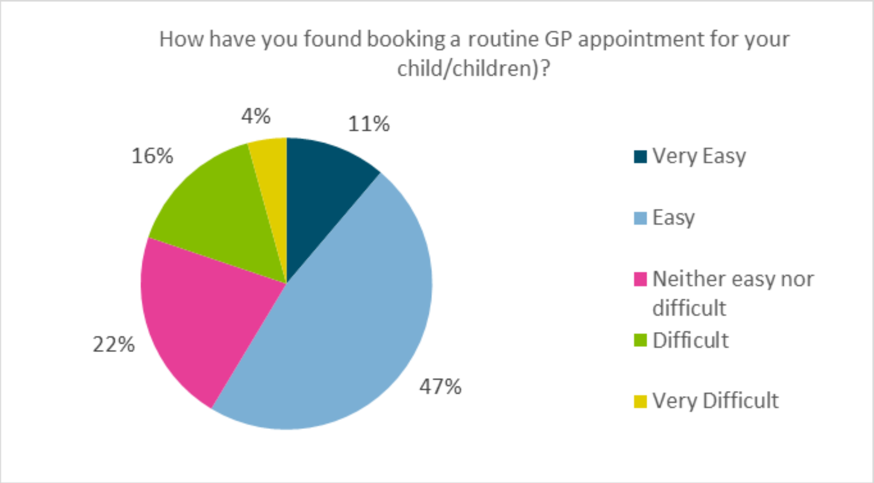
Findings are divided by themes that arose from the analysis. They are presented broadly in the order they were explored in the survey questionnaire and interviews. Each theme firstly presents the findings from 117 survey responses. These are mostly quantitative, using percentages (and numbers of participants) for each question. Charts and tables are used to visually represent the data. Survey responses are followed by findings from the interviews, which are mostly qualitative and include direct quotes, in speech marks, from interviewees.

A. GP Services access

This section covers access to routine GP appointments (those booked in advance), and appointments classified as urgent as they are booked on the day of need.

Routine appointments

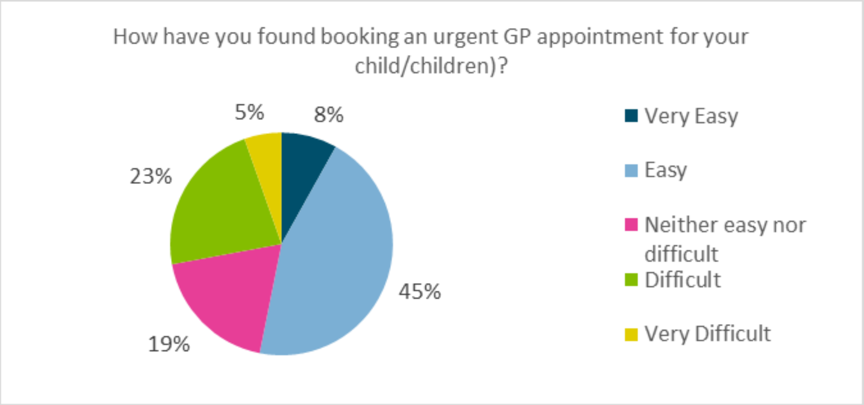
Survey respondents were asked to think about their overall experience as regards to caring for their child/children and how easy they had found booking a routine GP appointment (including for child immunisation).



Most **survey** respondents found it either easy or very easy (59%). However, one fifth of respondents (20%), found booking an appointment to be difficult or very difficult.

Urgent appointments

Survey respondents were asked to think about their overall experience of booking an urgent GP appointment.



Just over half of **survey** respondents (53%, 59 people) found it either easy or very easy to book an urgent GP appointment. However, 28% (31 people) found booking an appointment to be difficult or very difficult.

There were notably more people who found it difficult to book an urgent appointment compared to those that found it difficult to book a routine appointment.

Interviewees

The following reflects the experiences of the 19 parents we **interviewed** and provides some context of the survey findings given above.

Good experience:

Interviewees who found booking an appointment (either routine or urgent) easy to do, said it was easy to get through to the surgery, and they were able to get an appointment *on the same day* as the booking was made. Other reasons that made access easy, was the friendliness of staff, the convenience of the appointment time and in some cases, seeing the GP or nurse in person. However, some interviewees who found it easy to access their surgery were happy to receive a phone call from the GP too. One person received a mixture of remote and in person contact with the GP and commented that they were contacted “out of hours” which added to their positive experience.

The GP is “very good at seeing or calling back on the day if an emergency.” *Mother of four-year-old.*

Booking for routine vaccinations was easy: “I was just given a time and a date to go for these which was convenient” and surgery staff appeared “friendly and competent.” *Father of one-year-old.*

”I made an initial call, after 8am, saw the GP in person, who made the referral to an eye specialist.” *Mother of four-year-old.*

“Think I’m quite lucky compared to other mums. We have had access to everything.” She has “called up at 2.30pm and got an appointment at 4.00pm”. The surgery has “friendly, customer facing (reception) staff.” *Mother of child below one-years-old.*

“Our experience of GP services has been very positive- access is easy and when we call up, we have had a quick response in most cases.” *Father of four-year-old.*

Poor experience

Interviewees who found it difficult to book an appointment (routine or urgent) explained their experiences. These parents complained that it was very difficult to get through on the phone to book an appointment, that when they did the reception staff were not helpful and acted as barriers to the booking system. Several people mentioned the challenge of having to call at a certain time (usually 8/8.30am) and even when they did this would not guarantee an appointment on the same day. One interviewee felt that the lack of permanent staff at the surgery contributed to the problems.

Where the call was an urgent one, some parents explained the surgery would try to arrange an appointment for them on the same day. However, even in an urgent case, some parents had experienced difficulties seeing a GP on the same day.

"Called at lunchtime with an urgent reason, to be told no appointments that day." The interviewee mentioned increased use of locums, which she thinks contributes to delays and inefficiencies. *Mum of five-year-old.*

"I may need to redial 50 or 60 times to get through…Sometimes I just walk into the surgery to request an appointment." *Mother of two-year-old speaking about needing to make an urgent appointment that day.*

"We were forced to move from our existing nearby GP practice without our consent because it was 'over-subscribed.' We now have to attend a practice that is 5 miles away, and my wife [who] does not drive, has to take two buses with our children to attend the new practice." *Father of one-year-old and five-year-old.*

"Trying to get past the reception to see the GP is very difficult…can spend an hour on the phone…in urgent cases I can usually get seen the same evening [but] if it's non-urgent I can wait 6-12 weeks!" *Mother of two-year-old and five-year-old.*

"I have to get up at 8am and get to the phone for an appointment." *Mother of three-year-old.*

Case Study Interviewee IR07 –
Mother of child under one and another child of two-years-old

Mother IR07 told us about her mixed experience of booking appointments (routine and urgent) at her GP practice. The service *"is very easy, quick, and attentive. I have sent over pictures with an email and had an instant response"* to her concerns. However, one of the receptionists at the GP surgery is *"really obstructive and unhelpful".*

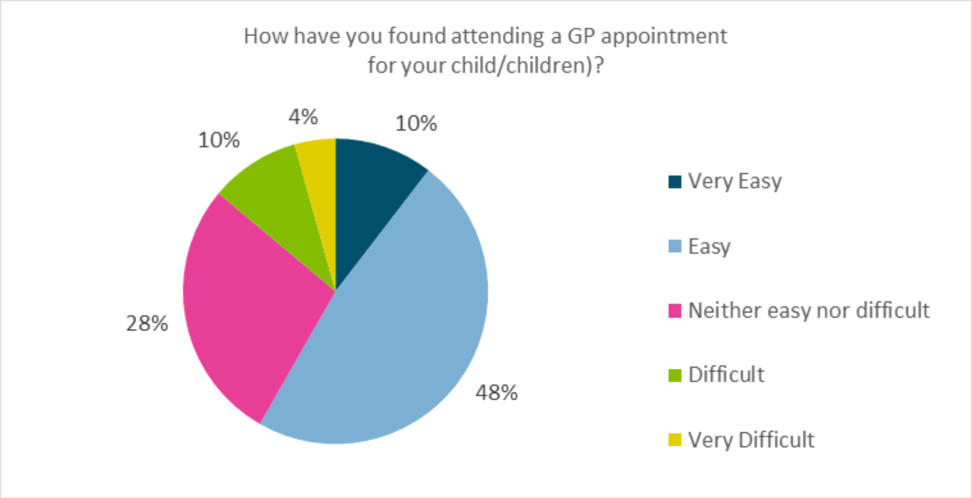
"The hardest part that I've had is just getting through to reception, and then it kind of depends on who you get through to! Provided that the obstructive lady doesn't answer, it is SO fast, SO helpful."

B. GP Services – Attending appointments

All appointments (both routine and urgent)

While the previous section was about accessing and booking appointments, this section focuses on attending appointments and by inference it also covers the quality of the care within the appointment.

Survey respondents were asked to think about their overall experience of attending either a routine or an urgent GP appointment, either remotely or in-person for their child/children. Two people said this did not apply to them i.e. they had not attended any GP appointments with their child/ren. Therefore, the chart below shows results from 115 respondents who had attended a GP appointment.



Over half of all **survey respondents** found attending an appointment either easy or very easy (58%, 57 people). One third of respondents (27%, 32 people) found it neither easy nor difficult and a smaller number (14%, 16 people) found attending an appointment to be difficult or very difficult.

Interviewees

Speaking to interviewees provided further detail on the reasons for these responses.

Good experience

Interviewees who found attending an appointment easy explained that the good quality of care made it a positive experience. In each case, appointments were in person, which may have added to the overall positive experience. Interviewees commented on medical staff being attentive, thorough, and responsive to their child's needs, taking the parent's concern seriously, and sometimes making an extra effort to provide care.

"Whether it's been a GP or a nurse for immunisations, they have been SO good – so quick, so responsive, so attentive, they haven't dismissed me… I feel like the care from them has been really great." *Mother of two-year-old.*

"It really stood out to me how helpful they were. I have to say, I know the doctor made time to see me, it was out of hours and there was no one left at the surgery at that time but because of what was going on at the time [STREP child deaths scare] he made an extra effort". *Mother of four-year-old.*

GP is "always very thorough…always takes it very seriously…really good." *Mother of two-year-old.*

"My experience of our GP and Surgery is mostly positive overall – very helpful when being seen and GP is very natural around babies and children." *Mother of one-year-old.*

When we had a vaccine appointment "the nurse was amazing – so good and quick at her job." *Mother of three-year-old.*

Poor experience

Interviewees who had poorer experiences of attending appointments complained that the GP could be dismissive of their concerns about their child's health, or inexperienced in dealing with their child's condition. One parent felt the service was affected by seeing a different doctor each time. One parent had a poor experience during the Covid lockdown.

"Although caring, the doctor appeared inexperienced in dealing with our child's ear infection. We did not receive the right advice, and unsure as to whether the nature of my child's problem was fully understood." *Mother of four-year-old.*

"There's no easy access to health visitors any more…my youngest has [an issue that] the nursery noticed but the surgery just brushed me off. I always feel rushed – the GP just didn't listen to my concern." *Mother of five-year-old and two-year-old.*

"Every time I go to the GP now it seems I have to fight – 90% of time they don't seem completely sure what is wrong." For example, suspected scarlet fever was ignored until Mum pushed, and turned out child was positive for scarlet fever. *Mother of three-year-old.*

"You always see a different doctor, unlike the nurses with whom we have a nice relationship." *Mother of two-year-old and child under one-years-old.*

Case Study Interviewee IR01 –
Mother of three-year-old and five-year-old.

Mother IR01 told us about several poor experiences she had had with her GP surgery. During lockdown she took her youngest to see the GP. She was concerned about how lethargic her child was and with the context that her child had been a premature baby. The GP agreed to see her child in the car park. Mum IR01 felt this was both an inappropriate location as well as feeling that her child was being given a "poor assessment". Mum IR01 was told to go to the hospital and the by the time she arrived her child "was unconscious and very sick".

Mother IR01 had another poor experience with her older child who "complained of abdominal pains". The mother saw the locum GP at the surgery. The doctor "*was very dismissive and didn't listen to my concerns. They wouldn't prescribe anything to help.*"

As a result, "*I've lost faith in the GP's ability to assess.*"

Case Study – Interviewee IR19 – Mother of three-year-old.

Mother IR19 shares an experience with us regarding trying to get treatment for her child. She explains how her own background, of having a history of anxiety, should have been taken into consideration by the GP who consulted her on her child's condition. Her experience also demonstrates a lack of caring by the GP and an unwillingness to take the mother's concerns seriously, especially when the resulting diagnosis proved the mother had been correct in her concern.

"Last year, I thought my son had scarlet fever. He had a temperature and rash, and I called the GP. He wouldn't see us. He asked me if I was 'sure that you haven't any little beasties in the house?' This sent me into a panic as I suffer from anxiety. As a result, I cleaned the house from top to bottom! After a few more days, I was still concerned, and I rang the doctors again. This time, I was given a next day appointment. The SAME GP now confirmed that it WAS scarlet fever!"

"I have a history of anxiety and depression. When you are not listened to by the GP, it can send you right back. People in power need to consider both parent and child at the same time – taking the parent's background into account when talking to them about their child's condition."

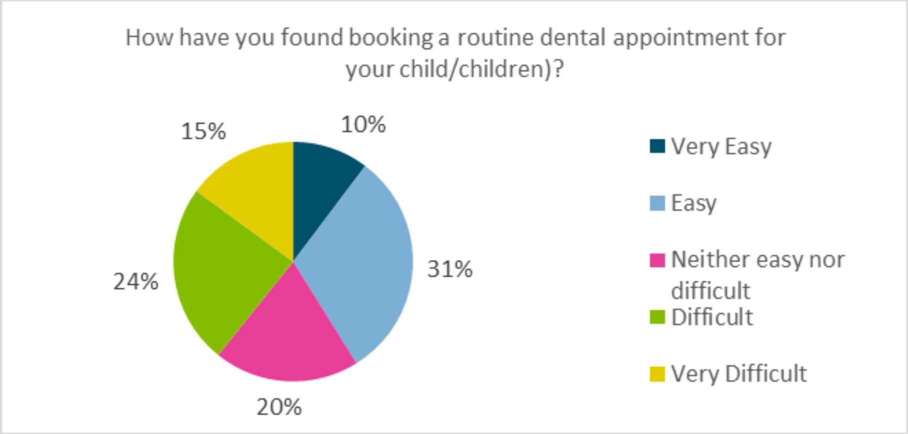
"It's not good not having an assigned GP as this doesn't help them to understand the context of both parent and patient."

C. Dental services

This section shows findings from the survey for both routine and then urgent dental appointments. This is followed by the findings from our interviews concerning dental appointments.

Access to Routine appointments

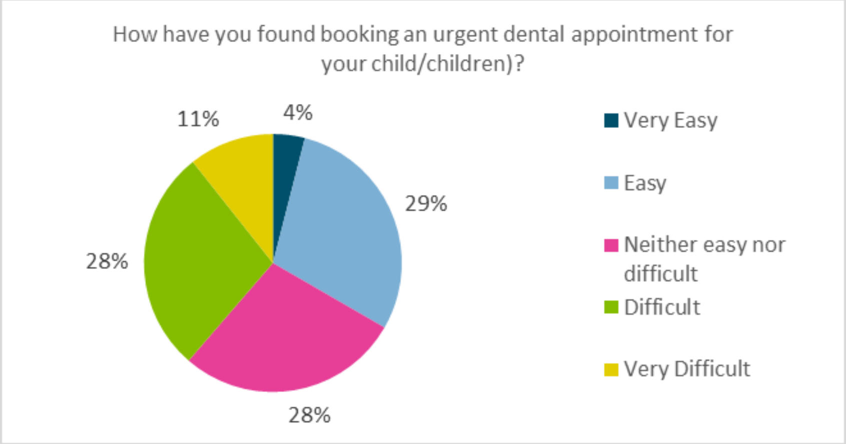
Survey respondents were asked to think about their overall experience of booking a routine dental appointment (i.e. a check-up) for their child/ren. Ten people said this did not apply to them i.e. they had not tried to book a routine dental appointment for their child/ren. The chart below shows results from 107 respondents who had tried to book an appointment.



A total of 41% of **survey respondents** (44 people) found booking a routine dental appointment easy or very easy. However, 39% (42 people) found this process to be difficult or very difficult. One fifth (20%, 21 people) found it neither easy nor difficult.

Access to Urgent appointments

Survey respondents were asked the same question about their overall experience of booking an urgent dental appointment for their child/ren. Forty two people said this did not apply to them. The chart below therefore shows results from 75 respondents who had tried to book an urgent appointment. This is a surprising number of respondents who had experienced trying to book an urgent appointment. This might reflect the difficulty experienced in trying to book a routine appointment, which led to some of these bookings becoming urgent.

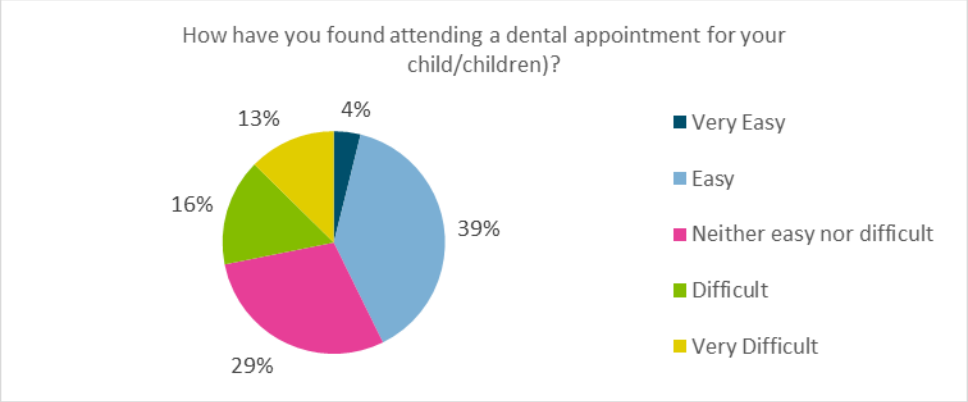


A slight majority of **survey respondents** (39%, 29 people) found it difficult or very difficult to book an urgent appointment. This compares to 33% (25 people) who found it easy or very easy to book this type of appointment. A minority of 28% (21 people) found it neither easy nor difficult to do so. Comparing the two appointments, people found accessing routine appointments easier than urgent ones.

Attending dental appointments (both routine and urgent)

As with the section above on GP appointments, this section covers attendance at dental appointments and by implication the quality of the care within those appointments.

Survey respondents were asked to think about their overall experience of attending either a routine or an urgent dental appointment, either remotely or in-person for their child/children. 13 people said this did not apply to them i.e. they had not attended any dental appointments with their child/ren. One person did not respond to this question. The chart below shows results from 103 respondents who had attended an appointment.



A total of 43% (44 people) found it easy or very easy to attend dental appointments. However, just over one quarter of respondents (28% 29 people) found this difficult or very difficult and almost the same number again (29%, 30 people) found it neither easy nor difficult to attend the appointment.

Interviewees

Some of **our interviewees** had not tried to access a dentist for their child. But for those who had, experiences were mixed for both accessing and attending an appointment. Their experiences provide context to the survey findings above.

Good experiences

Some interviewees had found it easy to gain access to dental appointments at the same dental practice where the parents had already registered, even if this meant waiting until their child was a certain age.

"No issues with access and pretty easy to get an appointment." *Mother of four-year-old.*

"Children go free provided we have twice yearly check-ups." *Mother of two, aged two-year-old and five-year-old, respectively.*

"Our son is registered with our dentist for NHS treatments but will not be seen until age 2." *Mother of (just) two-year-old.*

"Daughter recently had first check up at 8 months." *Mother of a child below one-year-old.*

Two parents told us about their positive experiences of attending appointments. In both cases, this was the first appointment for their child and the parents remarked on the kindness of their respective dentists towards their child.

"The dentist was pretty good with my [older] child who has SEN" at a recent routine check-up. However, future appointments will likely be with "a specialist dentist". *Mother with two children, a three-year-old and another child younger than one.*

"The dentist was really kind *at the first appointment to* get him used to the dentist…I have nothing bad to say about dentists and the routine appointments are easy to get." *Mother with child aged three.*

Poor experience

For some parents **we interviewed**, experience of the dentist was not positive. Several parents complained that they had difficulty finding a dentist that would register them, with one parent registering her children at a dentist she had previously seen in London. Other parents complained about penalties for arriving slightly late (five minutes) or being de-registered due to their child's illness.

"If you're late for just five minutes, they cancel! It's a nightmare! This is difficult to manage when collecting children from school and getting through traffic." *Mother of four-year-old.*

"Forced to register child with our old dentist in London – trips are expensive but a day out!" *Mother of two children, one aged below one, the other two years old.*

"We tried nine dentists and eventually found one that would take us. However, travelling to the dentist is not easy as it is out of the local area." *Father of two, aged five years old and below one.*

"When my daughter was born, I looked into getting her on a list and was told there was a four year wait!" *Mother of one-year-old.*

One parent also gave an example of the poor experience of attending an appointment, whereby the quality of care caused the child to be distressed.

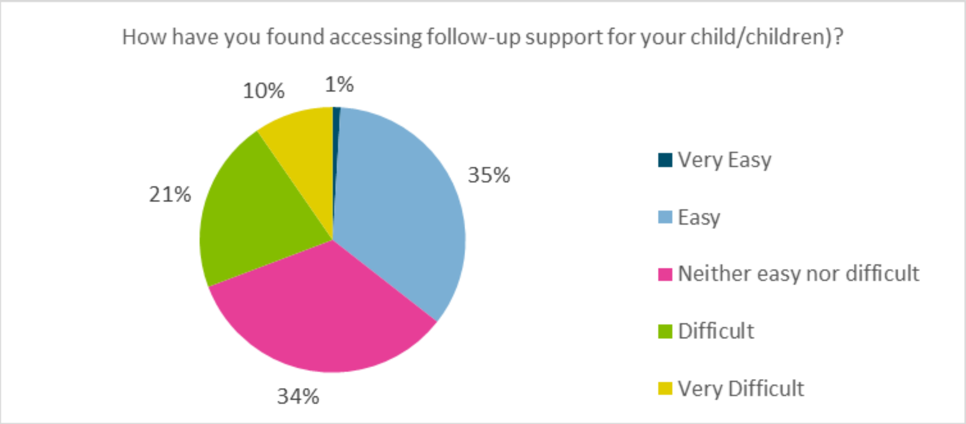
"The dentist was in a rush for the first appointment for my child. She was really anxious and ended up in tears. Another occasion, I had to cancel an appointment for both children due to Chicken Pox…the receptionist then took them off the books and since then I cannot get another appointment!" *Mother of two, aged five and two.*

D. Specialist / Referral Services

This section provides findings from the **survey** about access to specialist services. This is followed by findings from the **interviews** that cover both access and quality of service when attending a specialist appointment.

Survey

Survey respondents were asked to think about their overall experience of accessing follow-up support. The question provided the example of a referral to a specialist or further tests. Thirteen people said this did not apply to them, i.e. they had not tried to access follow-up support for their child/ren. Therefore, the chart below shows results from 104 people who did try to access this support.



Results from the 104 **survey respondents** were similar between those that had found it easy or very easy (36%, 37 people); parents who had found it difficult or very difficult (31%, 32 people); and those that had found it neither difficult nor easy (34%, 35 people). Only one person found it very easy to access, whereas 10 found it very difficult to do so.

Interviewees

Not all our interviewees had needed to use this service. But where they had, the experience was mixed. Good and poor experiences below concern **access** to the service, as well as **quality of care** when attending the service.

Good experience

Interviewed parents who had a good experience of the booking service, felt the referral was made easily and quickly.

"The referral was made, and an appointment found reasonably quickly." *Mother of four-year-old.*

One parent commented that although he had not needed to use this service for his child, he "would like to feel that I could access specialist support quickly if and when this was needed." *Father of one-year-old.*

Parents who had attended an appointment, felt they were taken seriously and the advice they received was useful. Parents complimented medical staff including consultants' secretaries.

"They are understaffed…but the care that we got I can't really fault." *Mother of two, aged five and three.*

"Absolutely excellent care…secretaries were wonderful…taken very seriously as a parent." *Mother of two-year-old.*

"We had a 6-week programme of 'speech support' with the health visitor, provided through the children's centre. This was about parents not stressing about this and about supporting the child at home. It was really good – I found it really helpful." *Mother of three-year-old.*

Poor experience

Interviewed parents who felt their experience had been poor, often described long waiting lists for the referral. In some cases, parents had to follow-up a referral themselves to ensure it took place.

"You rely on doctors to set up specialist referrals and if they don't, then you are back to square one." *Mother with two, one below a year old, the other three-years-old.*

"My [five-year-old] daughter has waited 2.5 years and has another year of waiting to see a speech therapist and this has impacted her confidence and ability to make friends." *Mother with two, five-year-old and three-year-old.*

"I was told there was a 46-week waiting list for him to be seen." *Mother with three-year-old.*

Some parents spoke about poor quality of service during a specialist appointment. One parent was told to "wait and see" if the condition goes away (it didn't). Another parent was given advice that did not relate to their child's condition and sought better advice when on holiday abroad. Another parent was almost forced into agreeing to a procedure for their child.

"I took him to an ENT specialist; they left it to me to decide whether to operate or not (to remove tonsils) – I'm not the expert!" *Mother with three-year-old.*

"When referred to a specialist pediatrician I had to make follow up calls as this was forgotten about. When we attended the appointment, the advice received from the hospital team was for a different condition and therefore irrelevant. This compared to very focused, helpful advice we received while abroad." *Father with two children, a five-year-old and a one-year-old.*

"We must have been seen by about six different professionals, who all gave us different opinions on whether or not she had tongue-tie." *Mother with child under one year of age.*

"The specialist was a bit dismissive, you know, 'well you need to have it done and if you don't then I'm taking you off the list.' He didn't give us the opportunity to air our worries and think about it." *Mother of a four-year-old.*

E. Parenting support services

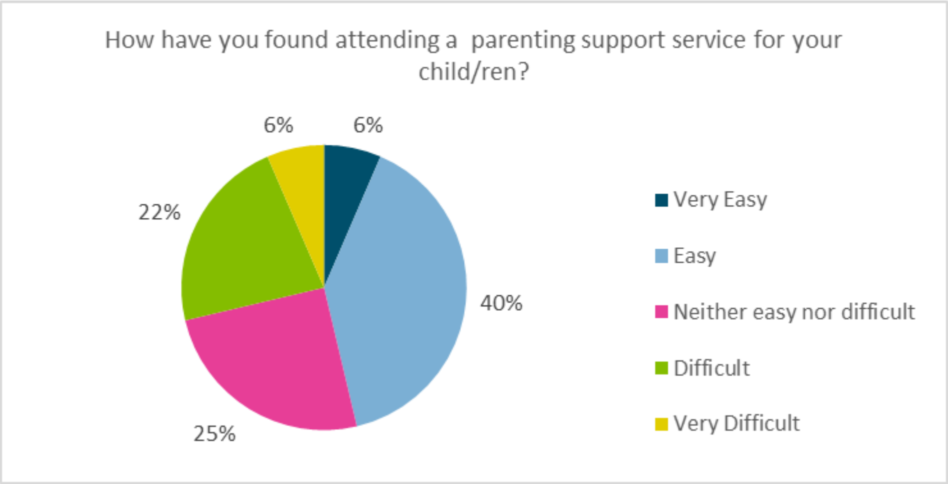
This section shows findings from the survey, regarding **attending** parenting support services and whether available services had been **free or paid for**. This is followed by findings from the interviews in which parents responded to a number of questions about parenting support services.

Survey

Attending the service

Survey respondents were asked to think about their overall experience of *attending* a parenting support service. We defined a parenting support service as being 'a baby or toddler group or other parenting support, not including childcare service'.

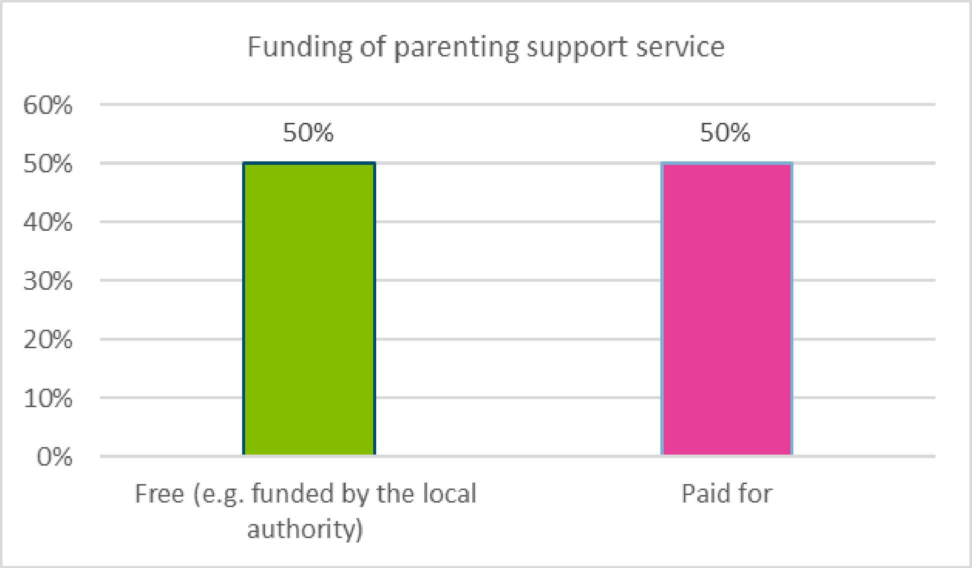
Nine people said this did not apply to them, i.e. they had not tried to access a parenting support service for their child/ren. Therefore, the chart below shows results from 108 people who did try to access this support.



The majority (46%, 50 parents) found the experience of attending a parenting support service to be easy or very easy, while 29% (31 parents) found attending a support service to be difficult or very difficult. One quarter found it neither easy nor difficult.

Free or paid?

Survey respondents were also asked to indicate if most of the parenting support services they had attended were free or paid for. We gave the example of free being funded by the local authority.



88 survey respondents had used a support service, and exactly 50% indicated they had mostly paid for these services while the other 50% had mostly received the service for free.

Interviewees

When we spoke to interviewees, we asked them several questions about parenting support services, which included questions around accessing the service as well as their experience of attending the service. In response to these questions, some parents shared with us the need for emotional support which is sometimes offered informally through these services. We have included these comments later in *Section H. Emotional Support*.

Specifically, interviewees were asked the following questions about parenting support services:

- Have you been to a parenting support service?
- How was it?
- Was it easy to find out about/to access?
- Was it free or paid for?
- Are you still attending? Why? Why not?

Good experience

Interviewed parents who had a positive experience found it easy to access, often free (although this was not always the case) and the friendliness of the service provision. Parents also mentioned the benefit of connections with other parents. Most of the following quotes cover the experience of accessing the service as well as attending. One quote is only about attending.

"Very easy to access but paid for. She likes the social interaction with other parents and our daughter finds the sessions very enjoyable." *Father talking about his wife's attendance at parenting services. They have a One-year-old and a five-year-old.*

"I did a 6-week group with Mothers Uncovered - it was free, really good peer support – I found them through a friend with a connection." *Mother with one-year-old.*

"Have tried various groups – mixture of paid for and free where the best is the Brighton Library singalong sessions which are a lifesaver. The main problem is there are very few free or cheap services in central Brighton and very hard to find out about – I use a Mum's WhatsApp group, or word of mouth." *Mother with four-year-old.*
"I use the toy library which is council run and free of charge; it's really good." *Mother of two-year-old and baby under one year old.*

"These mother and toddler groups are so important to make connections for both your child and yourself." *Mother with five-year-old and baby under one year old.*

Poor experience

Interviewed parents shared several frustrations with parenting support services. These included the difficulties they had found with accessing the service, such as services being unavailable or hard to find out about.

Some **interviewees** shared their frustrations at the lack of local services. Other parents shared the difficulties they found with finding out about services in the first place.

"Hard to contact and even more difficult to attend- with nothing really local." *Father of one-year-old.*

"I wasn't given anything…after three weeks, here's the phone number if you need anything." Mother explaining that she had to research parenting groups herself. *Mother of one-year-old.*

"It is not so easy to find out about these services in the first place and we pay for these…luckily we have supportive relatives who live close who have similar age children that our kids can play with." *Father of two, one-year-old and four-year-old.*

Where parents had attended services, some parents had found the experience to be unwelcoming.

Lack of access to free services

Some parents complained that available services had to be paid for.

"It can be expensive and stressful booking –getting tickets for 'music with mike' felt like getting tickets for Glastonbury! *Mother of three-year-old.*

"All playgroups in the area that the parents know about are paid for!" *Father of one-year-old.*

Lack of access as service is unavailable

One parent spoke about a service that wasn't available anymore.

"Used an excellent online class called 'Family First' (or similar) which was free of charge (council run) and focused on parenting issues. Absolutely phenomenal but I don't think they run this anymore! *Mother of two-year-old and baby under one-year-old.*

Lack of access during Covid

Two parents talked about the difficulties of accessing services during lockdown.

"Limited options during lockdown but did attend good local groups - at first, free, but then paid for. *Mother of four-year-old.*

"My experience was mostly during Covid – had access to some groups online, had to pay for them, but had to find them on my own, via social media networks and word of mouth. no referral from council or NHS." *Mother of three-year-old.*

Some **interviewed parents** spoke about being made to feel unwelcome at parenting support services. One of these parents felt it wasn't the right place for her and her same sex partner, another parent felt the service wasn't suitable for neurodiverse parents or children, and another found the other parents were unfriendly.

"It wasn't a space where we felt comfortable." *Mother talking about visiting local toddler groups and an NHS-funded parenting support group with her wife. Mother of four-year-old.*

"Would appreciate more support groups for parents that are struggling with health issues and neurodivergent…and make more accessible." *Mother of four-year-old.*

"The atmosphere is friendly and supportive, but each visit feels like a 'one-off,' and connecting with other parents does not really happen…also there is always a waiting list and it's paid for." *Mother of two, three-year-old and one-year-old.*

Also, everything is very baby centric, not really useful for me and the other Mums seem to know each other so I didn't feel welcome in their group." *Mother of three-year-old.*

F. Barriers to access and/or use - Survey responses only

This section is about barriers to accessing or using services without relating to any one service. This question was only asked in the survey. Therefore, this section only shows findings from the survey respondents.

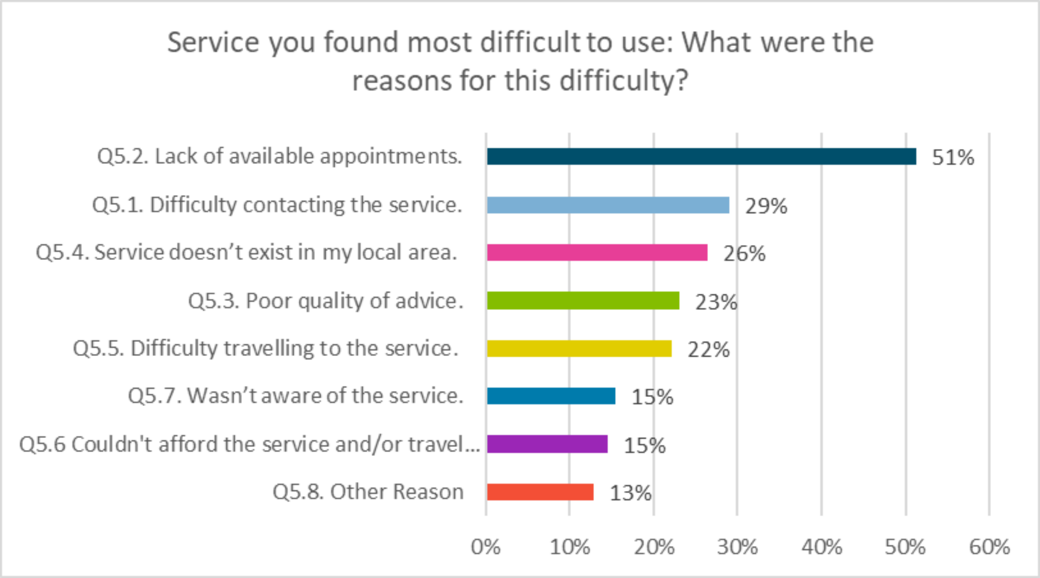
It is worth noting that interviewed parents also reflected on barriers in response to questions about a specific service, and these are included in the previous sections relevant to that service.

Survey respondents were asked about barriers to services. Parents were asked to think about all the services above, namely:

- accessing and attending GP appointments.
- accessing and attending dental appointments.
- accessing follow-up support/referral services.
- attending parenting support services.

We asked parents to think about ***the one that they had found the most difficult to use*** and to select from a list of possible reasons, as to why they found it difficult. Parents were not asked to list the service used, so ***responses could relate to any of the services above.*** Therefore, the chart below gives *a general idea* of the most common barriers to accessing these health services.

Parents were able to tick ***as many reasons as they felt applied***, including selecting "other reason" as one of these options. The percentages in the chart below represent what percentage of 117 people chose this barrier as (one of) the reason(s) as to why they found access or use of a service to be difficult. Therefore, the percentages below total more than 100%.



Most common barriers

The most common barrier to access and/or use of a service was **lack of available appointments**; over half of parents (51%, 60) chose this as one of their barriers. The second most common barrier to access/use (chosen by 29%, 34 parents) was **finding the service difficult to contact**. One quarter (26%, 31 parents) said the service didn't exist in their local area. 23% of parents (27) had received **poor quality advice** and 22% (26 parents) had **difficulty travelling to the service**. Just over 15% (18 people) were **not aware of the service**, and just under 15% (17 people) **couldn't afford** the service itself or travel to the service.

Other reasons for barriers to access

Within the survey, we gave the option for "other reasons" for barriers to accessing or attending services.

There were 15 parents who selected "other reasons" for barriers to access or use of a service. Of these, 13 parents provided 14 comments (one parent provided two comments on different reasons). The comments were as follows.

Lack of available NHS dentists

Four comments related to dentists

“There are no dentists locally taking NHS patients. My daughter has never been to the dentist.” *Mother of a 4-year-old.*

“No NHS dental provision for children in my area.” *Mother of five-year-old.*

Waiting lists

One comment was about the service running late; another comment related to very long waiting lists for specialist support.

“Massive waiting lists for specialist support, with hoops to jump through and constant chasing up before given any access to the service.” *Mother of a 5-year-old.*

Lack of a suitable service

Five comments related to the lack of a suitable service. One parent said the service was only offered in person and at ten weeks’ post-birth, and she was unable to get there. Another parent said she was not offered a referral that would “actually address the problems raised”. A third parent commented that she was not offered a suitable service for her child with additional needs. The fourth parent spoke about the lack of services available during Covid. A fifth parent said it was hard to access playgroups “as a single parent with twins”.

“Breastfeeding service said I had to attend in person after 10 days, I could barely leave the house for 6 months. I had to pay privately online and didn’t get the support I needed.” *Mother with three-year-old twins.*

Restricted availability

Two comments related to services being difficult to access as they were only available during restricted times/days.

“In case of immunisations, surgery dictates when appointment will be. There is no leeway if time/day unsuitable.” *Mother of baby below one-years-old.*

“I tried to get a flu vaccination appointment, but they only did them in the morning once a week, which meant taking time off work and him missing nursery to attend.” *Mother of five-year-old.*

Unable to access

Two further comments mentioned services that they had been unable to access.

“I have found health visiting hard to contact - have not been followed up even though I was earmarked for extra support due to a difficult birth.” *Mother with baby below one-year-old.*

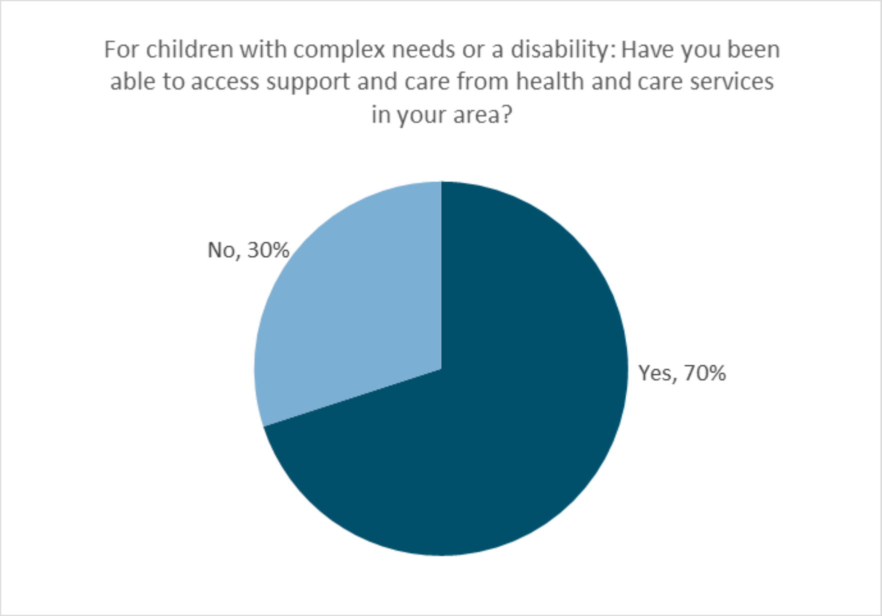
“It’s very difficult to be seen by a GP especially a good one.” *Mother of one-year-old.*

G. Children with complex needs – access to support

This section is about access to services only. Findings from the survey are shown first, followed by findings from the interviews.

Survey

Surveyed respondents were asked to indicate if their child had complex needs or a disability and whether they had been able to access support and care from health and care services in their area.



60 respondents indicated that they had a child with complex needs or a disability. Of these respondents, 70% (42 parents) had been able to access the support they needed. However, 30% (18 parents) had not.

Interviewees

There was mixed experience amongst the parents that we interviewed. Some had found it easy to access the specialist services they needed. Others had found it very difficult.

Good experience

"My child was checked out by a speech therapist when little, and this was easy to access." *Mother of four-year-old.*

"We accessed child psychology. This was relatively easy to access, via the GP and very useful." *Mother of four-year-old.*

Poor experience

"Finding it really difficult to get a follow-up appointment with the GP to discuss referral to an allergy specialist." *Mother with four-year-old.*

"Been on CAMHs waiting list for a year …told it could take 2 – 3 years for assessment which is awful. Meanwhile no support." *Mother of five-year-old and two-year-old.*

“It took eight attempts to get the GP to identify and refer” their child for recurrent ear infections and hearing issues. “It was Potluck that on the eighth, I got a GP who understood and we have a referral.” *Mother of five-year-old and two-year-old.*

We look in more depth at the experience of parents with complex needs in *Section 6: Specifically targeted groups*.

H. Emotional support

In our **survey**, we asked parents several questions about access to services for emotional support. When we spoke to parents in the **interviews**, we asked similar questions. The following is therefore a summary of the findings from both combined under sub-headings related to the question asked.

Did not need support

Parents were first asked if they ever *needed* emotional support for being a parent/carer.

In the survey, 22 respondents indicated they “did not need emotional support” and one respondent did not answer this particular question.

When we spoke to the **interviewees** and asked a similar question, two of the interviewed parents provided the following comments:

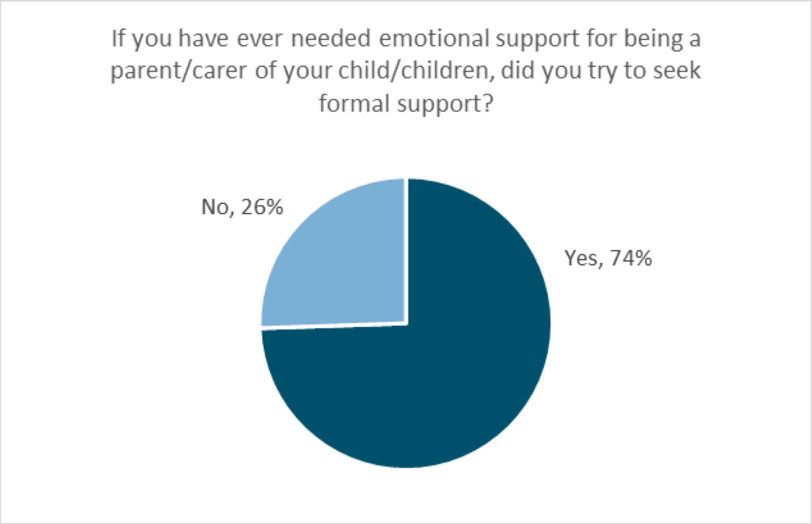
“I would imagine that emotional support is pretty important for (some) first time parents trying to cope with their new-born between birth and six months. It can be difficult when they are at an age when they are not able to tell you what they want. The three of us (my wife, mother-in-law, and myself) are able to support and reinforce each other.” *Father of a one-year-old.*

“We never needed emotional support. Mine and my wife’s extended family have been very supportive.” *Father of a one-year-old and five-year-old.*

Needed - did you seek formal support?

The remaining **94 survey respondents** indicated that they had needed support at one time.

We then asked these 94 **survey** parents if they had tried to seek formal support. By formal support, we gave the example of via their GP or health visitor and in the form of counselling, or a wellbeing service.



Of the 94 **surveyed** parents, 74% (70 parents) tried to seek formal support, while 26% (24 parents) did not.

Did not seek support

Speaking to some of the interviewed parents, some provided comment about why they did not seek support. Reasons included not knowing how to access this support or using social groups as an "informal" way to meet the need for emotional support. Parents also mentioned to us that parenting support services often provided a place to find informal support which avoided the need for seeking more formal support and we have included these quotes here.

Access

“I do feel the need for emotional support, but I don’t know how to access it.” You get lots of support when they are small – health visitor, weigh-ins etc. but less help or advice regarding behaviours and development when they are toddlers.” *Mother of a four-year-old.*

Informal support sought instead

Several parents who were interviewed talked about the importance of seeking connections with other parents. Sometimes this came informally through a parenting support service which avoided the need for formal emotional support from health services.

“I didn’t seek anything professionally. Instead, I went to mother and baby groups and chatted to other people in similar situations rather than access healthcare professionals.” *Mother with child below one-year-old.*

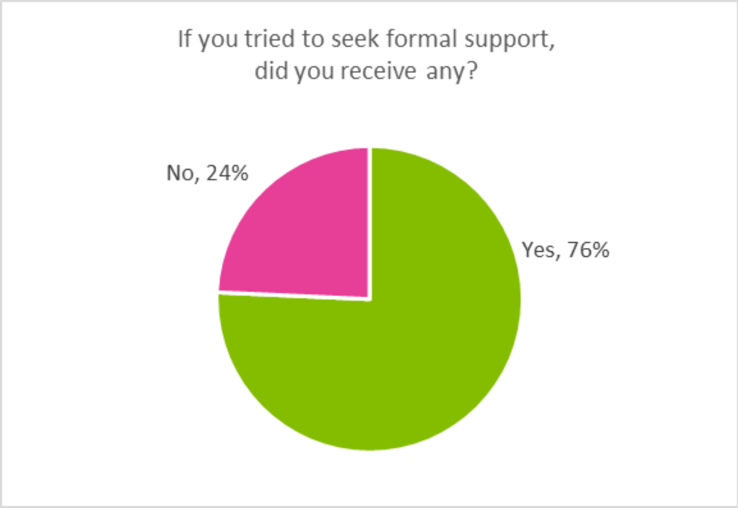
“The group leader of the baby class would talk to me if she saw I was having a bad day. I also get plenty of support from family and friends.” *Mother of a five-year-old and two-year-old.*

“There is informal, mutual support through the mother and baby group – just chatting to other people in similar situations - rather than accessing healthcare professionals.” *Mother with child under the age of one.*

“Pre-Covid I used to go to a Baby and Me group. It was really GOOD! The Health Visitor attended and there was a different topic every week. However, since Covid there is nothing for the youngest. We have to rely on friends with children for support. Now the only services have to be paid for.” *Mother of a five-year-old and two-year-old.*

Needed and sought - did you get it?

In the **survey**, we asked those parents that tried to seek support, whether they were successful in receiving support.



The majority of **survey respondents** (76%, 53 parents) were successful in receiving formal support. However, 24% (17 parents) were not.

Sought support but did NOT receive it

From those parents we **interviewed**, we received the following comments about *seeking but not receiving* support:

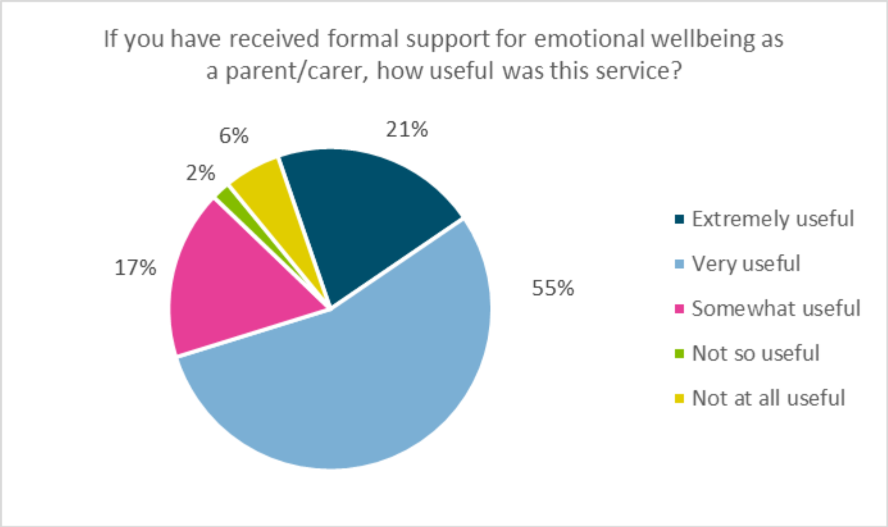
"I struggled after my youngest was born with the events that unfolded following premature birth and the fact that I was on my own when she was born and when I tried to access support, well I didn't get any and I asked several times." *Mother of five-year-old and three-year-old.*

"Difficult to ask for help when standing in an open-plan GP reception area and the receptionist is not being very helpful." *Mother of a two-year-old.*

"When my baby was a few months old I was feeling very down and contacted the GP – who didn't offer anything. I just wanted to talk to someone – not a talking therapy – just reassurance at that time." *Mother of one-year-old.*

Received Support – how useful was it?

Of the **survey respondents** who received the support (53 parents as above), we asked them whether they felt the support had been useful. We provided a five-point scale, from “Extremely useful” to “Not at all useful”.



The large majority of **survey respondents who had received support** (76%, 40 parents) found the service they used to be either very or extremely useful. 17% (nine parents) found it to be somewhat useful. A small minority of four parents (shown as 8% in the chart above) found it was either not so useful (2%, 1 parent) or not at all useful (6%, 3 parents).

From those **parents we interviewed**, some shared with us their experiences of seeking support and receiving it.

Received support – Positive experience

Some parents we interviewed, had good experiences of receiving emotional support. The service was helpful, providing well needed listening, advice, and supportive connections with other parents. In the case of one father, the service prompted a positive life change.

> “Used two excellent services referred by the Health Visitor. ‘Mummy Shock’ provided a free 10-week course and ‘Mothers Uncovered’ offered a free 6-week writing and arts course during which Mums chat about shared experiences. Both provided invaluable support for new

mums, tackling taboo subjects and topics about being a Mum.” *Mother with baby under one-year-old.*

“The most supportive thing was a group therapy service called "Mummy shock’ – a free of charge 10-week therapeutic course. An invaluable way to share your experiences with the group and talk about your body, your career, your relationship etc. I was referred by the health visitor, and it was free but I’m not sure if you have to pay for this service now.” *Mother with two-year-old and baby under one-year-old.*

I received formal support from health professionals based at the Children’s Centre, about a year after the birth of my first child. I was referred via the GP and through hospital pediatric services. These free support initiatives included the ‘Time for Me’ programme and ‘Small Beginnings.’ I was also allocated a key worker though the Children’s Centre. I found all three sources of support very helpful.” *Mother with three-year-old and baby under one-year-old.*

“The support I received prompted me to make a change.’ *Father of four-year-old and one-year-old.*

“I have a history of anxiety and depression and had post-natal depression and found a talking therapy service through a wellbeing source. It was free, lasted 20 weeks and was really helpful. I loved it – it was fantastic!” *Mother of three-year-old.*

Received support - not suitable or not enough support was provided
Other parents we interviewed, did not receive the support they needed. Some explained that the service offered was not suitable for their needs; Others explained the service was good but did not last long enough to meet their needs.

> "I was initially offered CBT but this wasn't the right service for me – just the only service available at the time. Then the Health Visitor referred me for three sessions at BrightPIP which was really amazing…but would have been great to have had more…it was not enough time. My post-natal depression should have been picked up earlier – a bit more of an eye should be kept on parents to see how they are doing." *Mother of two-year-old.*

Case Study – Interviewee IR 03 – Mother of four-year-old.

Mother had difficulty during lockdown when child was first born, as "most of these services were cancelled during lockdown". She is also chronically ill and finds it very difficult to access services generally as she finds it hard to get out of the house. She was referred to BrightPIP mental health charity via the Health Visitor. The service offered three telephone sessions with a psychiatrist which she found was "good and made access easier as it was via telephone". The service is also free. However, there was no follow-up service provided and she would have liked (and felt she needed) additional support. She is currently being assessed for neurodiversity and generally suffers from poor mental and physical health. She does try to participate in WhatsApp groups but overall access to health services is difficult.

Case Study – Interviewee IR10 – Mother of four-year-old.

"The mental health services have never met my needs. I have previously been on toxic mental health medication. I have suffered from mental health issues since childhood and I believe I have ADHD. I have been referred a few years ago to a neurologist (at a hospital outside Sussex) but there was no firm diagnosis made or any follow-up."

"The Brighton-based 'rapid response mental health team' have not been supportive when I have encountered mental health crises. I am still waiting

for a formal mental assessment to identify appropriate mental health support but I think I am low priority."

After birth, Mum IR10 had support from the Perinatal Mental Health team after the birth. However, she believes that she was misdiagnosed with post-natal depression and that her depression actually related to her struggle to 'create a life around her new family' and the death of a close relative around the time of her child's birth. She was placed on CBT courses with other post-natal depression mothers and she asserted that "putting me in a PND box was not appropriate". Mum IR10 feels that mental health services need to be more "joined up" in order to effectively support the multiple mental health issues she asserts she has. She believes the services are "very fragmented" and comments:

"I am one person and one body and should be seen as such by the various agencies and medical teams that attend me."

Currently, Mum IR10 pays privately for a therapist to help her manage her own "neurodivergency" and has done since a year after her child's birth. This was recommended by friends.

I. Other services

During **the interviews**, parents spoke to us about other services they had used and provided additional feedback. Some parents mentioned maternity services and other parents mentioned hospital emergency departments.

Maternity services

Feedback from **interviewees,** reflected positively on the care received by staff in and out of hospital. However, several parents gave observations about the lack of joined up maternity services between hospital, GP, and community services (health visitors or midwives). One parent talked about the lack of LGBTQ+ inclusion in maternity services.

“I received excellent service during pregnancy and childbirth from the midwives and had a successful home birth.” *Mother of baby below one-year-old.*

Lack of joined-up services

“My child was in intensive care in Brighton, but my local midwife seemed unaware of this.” *Mother with five-year-old and three-year-old.*

After premature birth, “the health visiting service was amazing when we got home, but the hospital assumed we would receive ongoing contact from the health visitor and this didn’t happen.” *Mother of two-year-old.*

Lack of support

“There was very minimal contact with the allocated health visitor after the birth of either of our children; didn’t feel they listened to us either.” *Father of four-year-old and one-year-old.*

“Support was very scattered in early days of childbirth. I didn’t really know where to go for certain issues and kept bouncing around between people. In contrast I was really happy with the midwife care treatment in hospital.” *Mother of one-year-old.*

Lack of specific support

> “Not a lot of NHS pregnancy and health related staff and groups are very LGBTQ+ inclusive but thankfully Rainbow families exist.” *Mother of four-year-old.*

Hospital Emergency Departments

Some of the **parents we interviewed** talked about their experiences of attending hospital emergency departments with their children. We have included some of their experiences here. Most parents were very positive about their experience and the care they had received, feeling the staff made them feel at ease and took time to reassure them. We have also included a case study from a parent who visited the emergency departments at two different hospitals, for both of their children at different times. Her experience was very mixed, due to how her family was treated by the staff at each hospital.

> “It was the perfect balance of – you’re not being stupid, and we didn’t feel that we were overreacting, but equally they didn’t over worry us, so it was a perfect balance.” *Mother with child below one year old.*
>
> “100 per cent! The quality of care has been really, really wonderful.” *Mother with child below one year old.*

> “After a stressful experience with private healthcare, we were referred to an NHS surgeon at the Royal Alexander Hospital. We were seen straight away. The Alex staff were really reassuring and once there the situation was not at all stressful.” *Mother with one-year-old.*

Case study – Interviewee IR15
Mother with five-year-old and two-year-old.

Mother IR15 spoke to us about two different experiences she had with each of her children, both of whom have different conditions whereby it was necessary to visit the hospital emergency department.

“Getting the right information seems to depend on where you go. I am midway between Brighton and Worthing and can use either. However, the advice is not always the same or consistent.

“My youngest has an immune condition and we have visited Worthing several times. The staff at Worthing said everything was fine and there was nothing to worry about. However, the one time we decided to go to Brighton, the staff there referred us to a specialist immediately and came up with a plan. There was only three weeks between referral and seeing the specialist. We had one and a half-hour appointment with the specialist and they did a thorough examination and they listened to the history of everything before providing us with advice.

“I didn’t feel listened to in Worthing, so will now always go to Brighton.

“I and my other child have the same condition and I know to be concerned if I recognise symptoms showing in my child. We initially visited Worthing but they just didn’t seem concerned and I felt like I was wasting their time. The GP we saw there, admitted they didn’t know enough about the condition and the appointment lasted no more than 10 minutes. We had to go back to our GP and start again.

“My confidence in Paediatrics at Worthing is zero. I would possibly go to Worthing if a child broke their arm, but not for a more complicated problem.

“Sometimes I feel caught in a battle between services.”

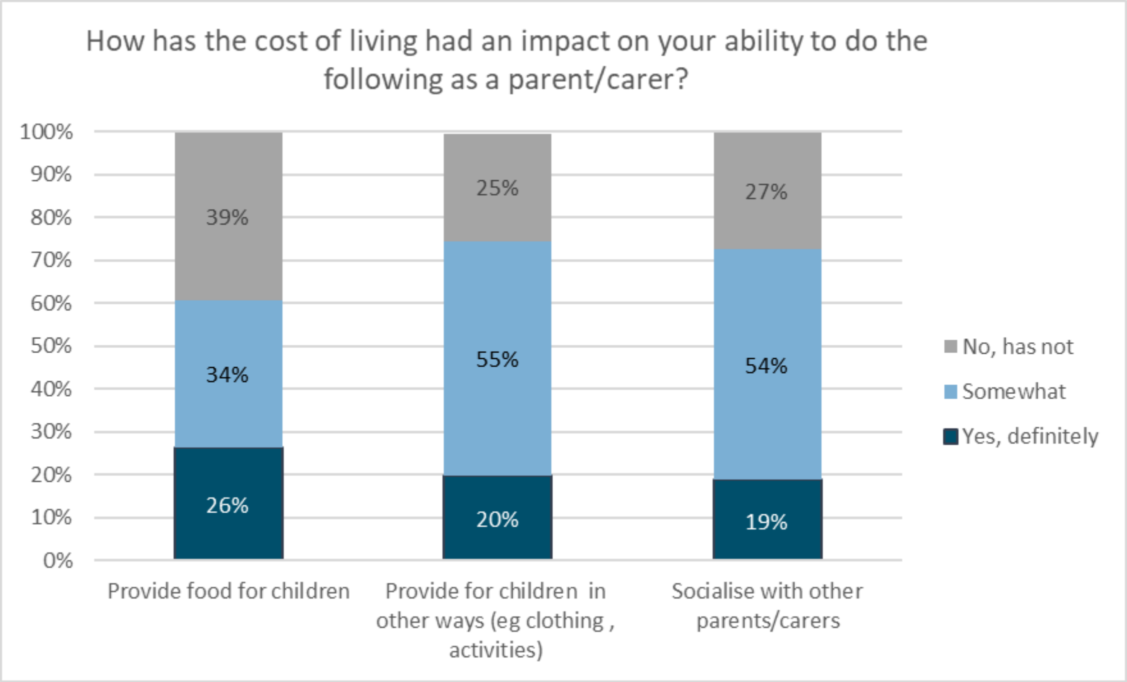
J. Cost of living

In 2023/24, there was a national cost of living crisis, and the CQC wanted to find out to what extent this had affected parents and carers. This section shows findings from the survey and then findings from the interviews.

Survey

Healthwatch asked parents in the survey whether the cost of living had impacted on their ability to do the following:

a) provide food for their children;
b) provide for their children in others was such as clothing and activities; and
c) to socialise with other parents/carers.



Providing food

71 **survey respondents** advised that the cost of living had impacted on their ability to provide food for their child/ren, with 26% (31 parents) definitely affected and 34% (40 parents) somewhat affected. 39% (46 parents) said the cost of living had not affected their ability to provide food.

Providing clothing & activities

87 **surveyed parents** advised that the cost of living had impacted on their ability to provide things other than food (e.g. clothing and activities) for

their child/ren. 20% (23 parents) indicated they were definitely affected and 55% (64 parents) were somewhat affected. 25% (29 parents) said the cost of living had not affected their ability to provide non-food items for their children.

Socialising with other parents/carers

85 parents who **responded to the survey** advised that the cost of living had impacted on their ability to socialise with other parents, with 19% (22 parents) definitely affected and 54% (63 parents) somewhat affected. 27% (32 parents) said the cost of living had not affected their ability to socialise.

Interviewees

Speaking to **parents we interviewed**, we found that most of the interviewees had been impacted in some way by the challenging cost of living situation. Some **interviewed parents** were managing, through family support or through making some difficult decisions. Others were finding it very difficult, and this was affecting their ability to parent.

Family and friends' support has helped

Some interviewees had friends or family who offered support, for example, grandparents who helped with childcare.

"We are very lucky that both of us work, and my mum helps with childcare, so the impact has been minimal." *Mother with five-year-old and three-year-old.*

"Our mortgage increased and there has been a significant increase in childcare costs. However, due to an arrangement with the child's grandmother, this has lessened the impact on the cost of living for us." *Father with one-year-old.*

"Was lucky to get hand me downs from friends so relatively little was spent on clothes in year one." *Father with four-year-old and one-year-old.*

Difficult decisions have made it manageable

Some parents made difficult decisions in response to the cost of living situation. Parents spoke about economising and prioritising essential expenditure as well as taking on extra paid work.

"I am juggling several jobs and went back to work. We are lucky that my partner has a good job, but we still find ourselves overstretched more often (just not maxed out)." *Mother of one-year-old.*

"Moving out of Brighton - Housing is more affordable." *Mother of child under one year old.*

"Bills have gone up, but we are just about managing. Our main frustration is not being able to take our child to more groups and activities. We've had to prioritise food and we are quite thrifty so get most things second-hand." *Mother of two-year-old.*

"I'm not going to sit in a cold house. I am coping by cutting back in other areas, socialising for example, and buying secondhand clothes etc." *Mother of a five-year-old and two-year-old.*

"Sometimes we need to make difficult choices, but our children eat well, and their free school dinners really help with our food budget." *Father of a five-year-old and one-year-old.*

Some are really struggling

Some parents were very honest with us about how difficult things were. One mother talked about having to re-mortgage, another about buying "cheap", and a third Mum talked about being in debt.

"You have to go to the cheapest supermarket and pick the cheapest foods." *Mother with a four-year-old (and older teenager).*

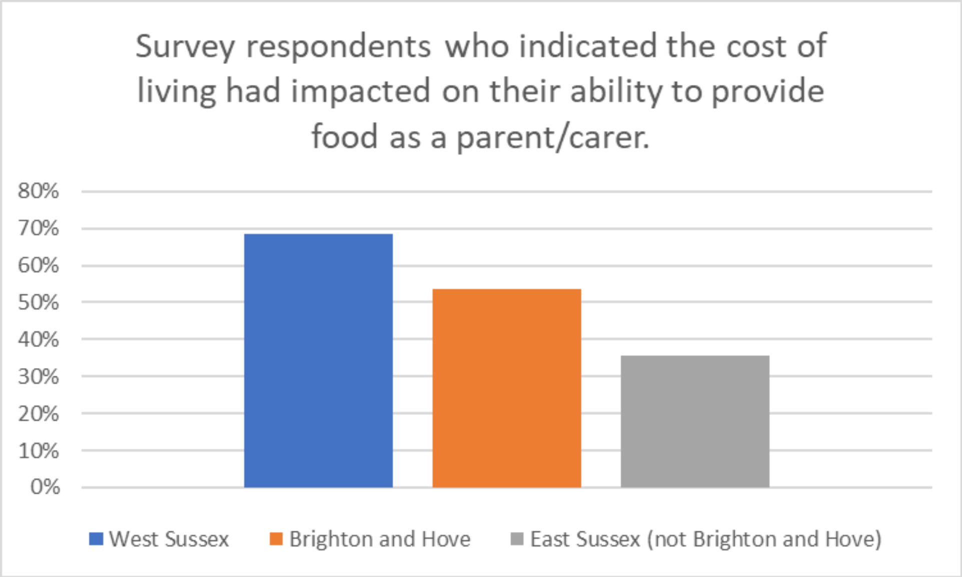
"We're quite in debt to the energy supplier. But we've got so much going on that dealing with it is not a priority." *Mother of a four-year-old.*

"We had to re-mortgage last year. I have changed career to bring in more money." *Mother of a three-year-old.*

Geographical difference in the cost of living crisis

Sussex has a mixture of areas of deprivation and areas of affluence. This is equally reflected in a mix of deprivation and affluence within Brighton and Hove specifically (and East and West Sussex specifically). East Sussex is slightly more affluent than Brighton and Hove. West Sussex has slightly higher levels of deprivation than the other two areas. See Appendix C for maps showing areas of deprivation for Sussex.

We compared the numbers of **survey respondents** who answered "yes" to the question of "Has the cost of living impacted on your ability to provide food for your children?" West Sussex had the highest numbers of "yes" to this question (68%) with only 32% of survey respondents saying the cost of living had not affected their ability to provide food. Over half of Brighton and Hove respondents (54%) said they had been affected in this way; 46% said they had not. East Sussex were less affected by the cost of living in providing food for their children: 36% said they had been affected, 64% said they had not.



The CQC – awareness amongst parents

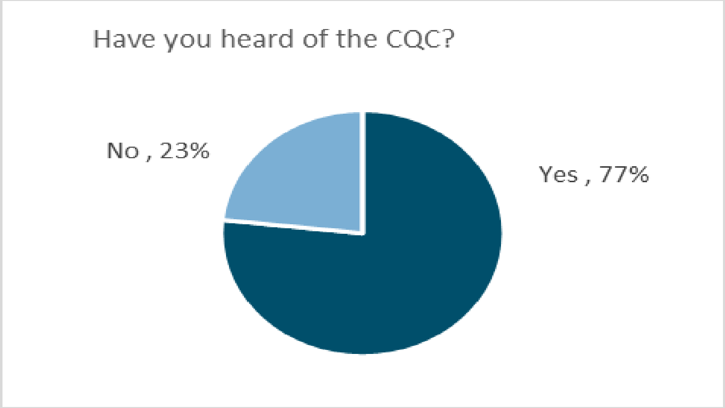
The Care Quality Commission (CQC) were interested in whether parents had heard of the CQC and if they had tried to contact them. Healthwatch asked parents in both the survey and the interviews about their knowledge of the CQC and whether they had contacted the CQC on behalf of themselves or their child.

This section provides findings from the survey and interview and follows the order of questions asked.

Heard of the CQC?

Survey findings

In the **survey**, we asked parents if they had heard of the CQC.



The majority of parents (77%, 89) had heard of the CQC; only 23% (27 parents) had not. One person did not respond to this question.

Interview findings

Speaking to **interviewees,** these parents gave us some further context as to whether they had heard of the CQC and understood the role it played in health services. Some interviewees thought the CQC had a provider role or were involved in governance, although some were also unsure about the role of the CQC. One interviewee had only heard about them due to her work.

“Sort of think I know who they are – are they like a governing body?” *Mother of three-year-old.*

“Are they to do with the hospital, or the community?” *Mother of four-year-old.*

“I don’t really know what they do. Are they a group of GP practices?” *Mother of four-year-old.*

“I think I’ve heard of them but I’m not really sure what they do.” *Father of four-year-old and one-year-old.*

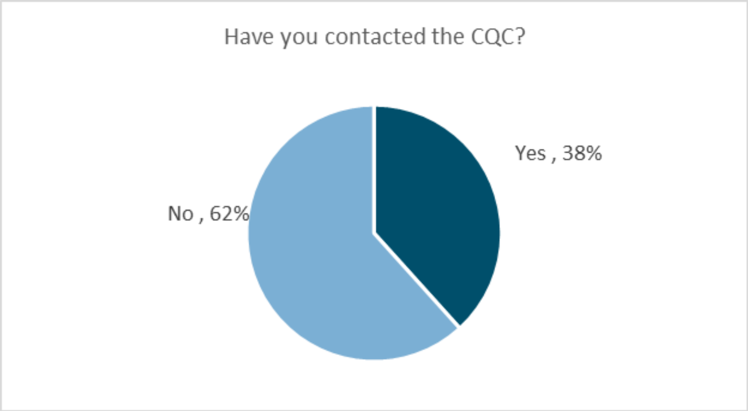
“I haven’t heard of them.” *Mother of two-year-old and baby below one-year-old.*

“I’ve not heard of them in a personal context, only through my work in the healthcare sector but then again, I have only heard of a ‘CQC Report’ but that's all I know about them.” *Mother of baby below one-year-old.*

Have you contacted the CQC?

Survey findings

In the **survey**, we asked those parents who had heard of the CQC, if they had contacted the CQC by telephone, or in writing or having filled out a form online.



While many parents (62%, 71) had not contacted the CQC, 38% (44 parents) had tried to contact them.

Interview findings

Speaking to **interviewees**, they provided reasons why they had or had not contacted the CQC or would/would not consider doing so. Some parents had contacted the CQC through their professional work, on behalf of other service users but had not contacted them for personal reasons. One parent had contacted the CQC to make a personal complaint as a service user.

Contacted the CQC for myself

"Yes, I have contacted the CQC, regarding a complaint about a hospital for myself." *Mother of a five-year-old and two-year-old.*

Contacted the CQC on behalf of others

"I have contacted them professionally through work but not personally." *Mother of a two-year-old.*

Intends to contact the CQC

“I haven’t yet but would like to complain about the nature of my health problems that have been repeatedly misdiagnosed by local services.” *Mother of a four-year-old.*

Would not contact the CQC

“I work for the local authority and am aware of the CQC and its role. However, I would not think of contacting the CQC first if I had a complaint about the health services.” *Mother of a one-year-old. “*

“I wouldn’t contact the CQC. I would contact other more local agencies and organisations first.” *Mother of a three-year-old and a baby below the age of one.*

Ideas of how the CQC can engage parents

Interview findings

For those **parents we interviewed**, we also asked how they thought the CQC could engage parents in their work.

Better awareness

Some parents felt the CQC needed better promotion to begin with before they could effectively engage with parents. One parent was unsure what to suggest.

"The CQC should probably make people more aware of them but they wouldn't be the first place I would think of." *Mother of a two-year-old.*

"I would contact the CQC (if and when needed) if I was made more aware of them. It would be good if when a parent goes with their child to the GP or nursery, they promoted the CQC – let people know that there is a regulation service." *Mother of a one-year-old.*

"The CQC needs to use GPs more to promote what they do." *Mother with child aged three-years-old.*

Specific ideas of how to engage

Some parents we spoke to suggested methods the CQC could use to involve parents in their work, for example surveys and discussion groups. One parent suggested that GPs could support the promotion of these methods. Another parent suggested the CQC could target specific groups, such as the LGBTQ+ community.

"What about a parents' portal? Must be user friendly. Perhaps ask parents directly for their opinions of services?" *Mother of a two-year-old.*

"Send out a survey on the parenting experience." *Mother with baby below one-year-old.*

"Quick surveys would be the more realistic option." *Mother of a one-year-old.*

"Share written information and reports and asking us parents for feedback; I have found it good to talk about my experiences today and would happily do so again." *Father with child aged five-years-old.*

"I would suggest emails and text messages and then phone calls and face to face where more detail can be captured. Also, surveys, discussion groups and interviews. However, only if it is advertised well.” *Mother with five-year-old and two-year-old.*

“GPs could ask parents relevant questions linked to CQC themes. GPs could publish results in their surgery. A survey would be helpful – if it went out every year at the same time – showing that the results matter by feeding them back to patients.” *Mother with child aged three-years-old.*

Share written information about its work and projects and ask parents to feedback on this. *Father of a child below one-year-old.*

“Ask parents more about their parenting experiences at a local level and how they think more joined-up, localised services and projects for families could be developed.” *Father of a child aged one-year-old.*

“Consult with LGBTQ+ people about their parenting experiences and the issues and concerns they had.” *Mother of a four-year-old.*

K. Specifically targeted groups

The focus of this report was on achieving a wide range of diversity amongst the group of parents we surveyed and spoke to. We targeted several different groups of parents. These included:

v. Parents with a child with special educational needs (SEN) and/or disability;
vi. LGBTQ+ parents;
vii. Parents from ethnic minorities; and
viii. Fathers.

In addition to the previous findings we have shown, this section carries out a ‘deeper dive’ of how specific circumstances can affect a parent’s experience of accessing health services for their child.

i. Children with Special educational needs (SEN) and/or disability

Our earlier section focused on access to services for parents who had a child with complex needs. Here we show the complexity of life with a child who has additional needs, through the eyes of three parents. Often this is mixed with other needs within the family. Parents shared with us difficulties with getting GP and specialist referral appointments, the challenge of attending appointments with an SEN child who draws negative attention from other parents. Some parents also mention that GPs do not seem to understand their child's condition or the challenge of parenting their child and their advice is not always appropriate.

Parental ill health as additional context

Two parents shared with us the additional challenges they experience by having to manage their own health needs in addition to their child's special educational needs. One parent's experience was more positive than the experience of the second parent.

Interviewee Mother IR10, with a four-year old, explained how her own and her partner's health issues have been challenging to manage. However, they have "found access to services relatively easy for our child who is neurodivergent (sensory-related)".

Another interviewee, Mother IR03 explained in detail the challenges she has faced in accessing services for herself and her child:

Case Study Interviewee IR 03 - Mother with four-year-old.

Mother IR03 has had various difficulties accessing health services, for both herself and her children. One of her children is aged 10 and therefore not within the remit of this project. However, the mother's experience of trying to access services for both children reflects the scale of the difficulties she has experienced.

"It is really difficult to get follow-up appointments for allergy-related specialist for one child."

Mother IR03's younger child is waiting for an assessment for ADHD. The mother explains the frustrations of trying to access this service.

"We were only offered out of hours doctors' appointments to discuss potential ADHD assessment for my other child. I was told to call back in two weeks' time to make an appointment."

Mother IR03 felt this was unsuitable as it did not provide continuity of care.

Mother IR03 also explains how her own poor health prevents her from accessing childcare support and health services.

> “I suffer from mental and physical health issues, and this makes it difficult to attend appointments and children are not accessing specialist services as a result.”

She would like to see further support.
“I would appreciate more support groups for parents that are struggling with health issues and neurodivergent…and make more accessible to all.”

Medical understanding of child’s condition

The following interviewee IR13 talks about the difficulties of accessing services with a SEN child, and the relationship with the doctors at her GP practice who while kind, did not seem to understand her child’s condition or the affect it has on the family.

Case Study – Interviewee IR13 – Mother of three-year-old and one-year-old.

Mother IR13 has two children and is in a relationship with a partner in full-time work, which effectively means she is parenting alone during the week.
“The kids are usually in bed when he gets home.”

Mother IR13 has a toddler below one year of age and her three-year-old has special educational needs, where he doesn’t speak and has comprehension difficulties.

She has found booking appointments easy.

> “The GP staff are always really friendly. Whenever I ring for an appointment for my son, even though there are never any ‘officially available,’ they always find me an appointment space as soon as I explain I have a child with special needs.”

However, attending appointments is difficult.

> “While it is very easy to book the GP, attending with the children is very difficult. This is because my son needs 1-1 attention and monitoring at all times. I cannot attend any external appointments with both children.”

Also, Mother IR13 doesn’t feel the GP understands her child’s condition.

> “The GP shows concern and listens to me but unfortunately, the quality of advice and support has not been good. The GP makes recommendations to me, that are hard to carry out. They do not necessarily understand what the key behavioural/health issue actually is and do not take my child’s SEN sufficiently into account when making recommendations for his management and care.”

Her son has needed support from educational psychologists and counsellors. But accessing follow-up support and specialist referrals is also very difficult.

> “There is always a delay when I have a concern about my child’s ongoing treatment or health care. You flag things up and then there is a long wait before anything happens. It has been difficult to keep waiting before we can move on to the next service.”

In addition, her child was prescribed ‘Melatonin’ as he has particular difficulty settling and sleeping at night and has been taking this for a while. However, recently she has experienced difficulties with getting the medication.

> “I was informed that the surgery could no longer prescribe this medication in ‘this geographic catchment area’”.

Effect on family environment

Our final case study, interviewee IR05, continues the theme of challenges with bringing up a child with additional needs. Mother IR05 talks about the negative views of other parents, the long waiting lists and lack of support while waiting for referral, as well as the negative impact on the rest of the family.

Case Study – Interviewee IR05 - Mother of five-year-old and two-year-old (as well as an older child with ADHD).

Mother IR05 has three children, two who are five and two respectively, and an older child who is on the CAMHS waiting list for an ADHD assessment. Although her seven-year-old son is older than the remit of this project, which focused on children aged five and below. Mother IR05 gives us insight into the effect on herself and her other children, of having a child with additional needs.

Mother IR05 received formal support when her son was young, due to his behaviour and the way it was affecting her.

> “It was the way I was feeling about myself as a Mum. I was not coping with the constant criticism from everybody. I had to pay for this support because there wasn’t anything else available. The problem is that parents are just meant to suck it up.”

She tried to engage in parenting groups with her son and daughter.

> “I am self-employed, so it is hard to work and engage with parenting support groups. Also, I found that my son was quite challenging and whenever I did take him and my middle child to places, I found it very difficult, because his behaviour was not welcomed by a lot of other parents. So, I stopped going.”

Mother IR05 also found the nursery to be unhelpful.

> “We have used the same nursery for all my children and have had a mixed experience. With my son I was constantly being told what he had done wrong, this was every day I picked him up. The nursery did get someone in to assess him, but it didn’t lead to any help or support. I think they were only looking for autism. It was like ‘there is something wrong with your child, but we can’t suggest anything’.”

Her experience with school has been better.

> “School on the other hand have been fantastic and have sent his teacher on an ADHD course which has been a big help.”

Her son is waiting for an assessment from CAMHS but this took a long time.

> “My son is currently on the CAMHS waiting list for an assessment. They think it is most likely ADHD. When he was younger, we had an appointment at the hospital and I deduced that they were assessing him for the possibility of autism but concluded that ‘there was no further investigation needed.’ After that, there was nothing for a long time. He had to be six before CAMHS would even speak to us. Our request was not even acknowledged, and we were left in complete silence until I phoned. The waiting list is 2-3 years which is just awful.”

Meanwhile, she has carried out her own research to understand him and his needs.

> “I have also done a lot of my own research, as standard parenting doesn’t work. It is challenging where other parents judge and assume you are not discipling your child. It is a real minefield between what you need to do and what society expects you to do.

However, she comments on the negative impact on her middle child.

> “The impact on my younger child who is only two years younger than him, is that she has had to bear the brunt of a lot of his behaviour. She has had to put up with a lot from him.”

She also comments on the negative impact on the family of waiting so long for an assessment.

> “I guarantee that parents are falling apart while people are on waiting lists for help with their child because it is so stressful at times.”

ii. LGBTQ+ parenting experiences

We spoke to three mothers who identified as LGBTQ+. One Mum had a mixed experience of the health services, which seemed unrelated to her being part of the LGBTQ+ community. Another Mum had experienced mental health challenges and we are aware that there are higher numbers of mental health challenges amongst the LGBTQ+ community when compared to the general population.[1] A third mother shared with us her negative experiences of the health services that directly related to her being part of this community. Perhaps when we consider these different accounts, they provide an accurate illustration of mixed experience from the LGBTQ+ community.

---

[1] For more details on this, see: https://www.mentalhealth.org.uk/explore-mental-health/statistics/lgbtiq-people-statistics#:~:text=Mental%20health%20problems%20such%20as,among%20people%20who%20are%20LGBTIQ%2B.

Mixed experience and unrelated to LGBTQ+

Interviewee mother IR06 had a mixed experience of the health services. Her daughter required emergency treatment in hospital when very young and Mum IR06 remembers the following.

> “It was a very good, prompt service and easy to access. My concerns were taken seriously, my daughter received a thorough examination and we were sent home with medication.”

However, when her daughter had suspected tongue-tie, mother IR06 experienced a very different service.

> “We must have been seen by about six different professionals, who all gave us different opinions on whether or not she had tongue-tie.”

Mental health issues

Interviewee mother IR03 lives with her same sex partner and their four-year-old child. Mother IR03 needed mental health support after giving birth but her experience was mixed.

> “I received formal support from various organisations for my mental health postpartum. Brightpip was great but was only three sessions. So, they referred me to the wellbeing service. My experience with them was awful.

She explains how due to a previous trauma, she rated high on the PTSD assessment. However, the Wellbeing service was not able to support her, and instead referred her to a social worker.

> “They then also said they can't give me any support because they can only support veterans with PTSD, not survivors of domestic abuse. They said I must refer myself to another service and get on a multiple year long waiting list. This experience did me a lot of harm.”

She was later able to access therapy through a women’s centre.

> “That was great. But also, only 12 sessions. A lot better than three, but not enough to deal with complex PTSD, and the struggles of parenting with neurodivergence.”

Mother IR03 sums up her challenges as a lack of continuity of care.

> “There have been no follow-ups or further referrals made to try to actually address the problems raised”.

Judged for LGBTQ+ and long-term conditions

For interviewee Mother IR10, her experience with health services has been predominantly influenced by how she has been judged, partly related to her LGBTQ+ status.

Mother IR10 is married to her same sex female partner, and they have a four-year-old child.

Mother IR10 describes her negative experience of the health services as being largely influenced by judgement on her personal choice and situation.

"Being from a LGBTQ+ group has been the predominant influencing factor in terms of how we have been perceived and supported. Sadly, a lot of our experience of society generally has been negative."

Mother IR10 perceives the midwifery aspect of her pre-natal care as undermining and judgmental.

'We were torn apart by the hurdles and barriers we faced, particularly before the birth. It was an intrusive violation of our lives by social services."

Her and her partner were also judged by others.

"We were regularly confronted with comments from the general public such as: 'Who is the father'? – 'you look alike-you must be sisters'."

Mother IR10 suffers from mental health and believes she is neurodiverse. Her wife is recovering from an operation and needs to manage this condition carefully. Rather than support, they were judged by the midwife and their ability to parent was called into question.

> “I found it disgraceful that my wife and me were flagged up to social services on our first appointment with the midwife who judged us after a 15-minute consultation. My wife has a life limiting condition. I was inaccurately diagnosed with some mental health conditions as I was currently experiencing a family bereavement. We were treated like a statistic. We are amazing parents… yes, we have disabilities, but we know what we can manage and do and put a lot of planning and support to make sure we would be the parents any kid deserves.”

Mother IR10 feels that the judgement was not just related to their health but also to the life choices.

> “The implication was always; are you ready to start a family as a same sex couple?”

Later on, they found support through “an amazing health visitor” and informal support through Rainbow Families[2]. However, she feels that processes and protocols in the health services are failing same sex couples.

> “Not a lot of NHS pregnancy and health related staff and groups are very LGBTQ+ inclusive but thankfully Rainbow families exist.”

---

[2] http://www.rainbowfamilies.org.uk/

iii. Black, Asian and minoritised ethnic groups and those who do not speak English as a first language

Of the 62 parents who responded to our questions about ethnic diversity, 11 people indicated that they came from a “non-white” background; four of these were interviewed. While a small group, these numbers reflect positively against the average of 6% of Black, Asian and minority ethnic groups represented in Sussex.[3] Some of these parents provided comments or took part in an interview.

We found that their experiences were mixed. One person had experienced racism by her midwife, and she also talks about her experience as a single Mum of twins; another parent felt her ethnic diversity was only an advantage for connecting with other diverse parents. Some parents who identified in this group did not highlight any experience that was connected with their ethnicity.

> “I am from a Middle Eastern background, but this doesn't affect anything. I've always found the GP to be excellent, especially in providing appointments when they know it’s for a child under 5.” *Arab Mother of four-year-old.*

> “I came from South Africa as a child so have seen people with very little and a lot.” *South African Mother of five-year-old and two-year-old.*
>
> “We have a mixed household with my husband and I from slightly different cultures. It has so far been a benefit to us to encourage diversity and be open to other parents who are also diverse in their outlook. I have not experienced any difficulties with the health services because of the colour of my skin or otherwise. We speak three languages at home, but our primary language is English. I have always found this a positive thing, encouraging diversity and our

---

[3] https://www.sussex.ics.nhs.uk/wp-content/uploads/sites/9/2022/08/Sussex-BAME-Population-Needs-Review.docx.pdf

children to experience difference in the household." *South African and Portuguese Mother of five-year-old and baby aged below one-year-old.*

"There is a slight language barrier for me due to my accent (although I speak English fluently). Sometimes I feel a bit excluded in group situations as people chat quickly." *British Chinese Mother of four-year-old.*

"Being a single mother of twins is a disability and should be recognised as so. I experienced so much racism from midwifery service and health visitor that I am scared to seek support. There is only one GP that I trust, and it has taken me around two years to get to see her. The Breastfeeding service said I had to attend in person after 10 days, I could barely leave the house for six months. I had to pay privately online and didn't get the support I needed. Playgroups and playgrounds and libraries are not suited to a single parent with twins." *British Indian Mother with twins aged three years old.*

"It's very difficult to be seen by a GP especially a good one. At the moment there are not enough dentists or appointments at the GP. Queues are long and when you finally do get through, the advice is not always useful." *British Indian Mother with four-year-old and one-year-old.*

iv. Dad's experience

We interviewed three fathers about their experiences of accessing support on behalf of their child(ren). We also heard from one mother about her husband's experiences. Two fathers provided some comments through the survey. The experience of being a Dad, is often similar to that experienced by mothers, such as waiting for access to services, and the need for physical and emotional support from friends and family and this was the case for some of the fathers who responded to our survey and to whom we spoke. However, some fathers found that some of these challenges are particularly difficult for fathers as they go unrecognised.

Similar experiences of healthcare services

One surveyed father mentioned the lack of accessible services.
"Emergency medical services often do not answer the phone." Father of a four-year-old and two-year-old.

One father had not experienced any difficulties with accessing health services but talked about the importance of accessing specialist services if and when needed.

> “While I have not needed to access specialist referral for my child, I think it is important that we, as parents, can feel confident about our child’s care in the future and, that if we needed to access specialist services then we could do so quickly.” *Father of a one-year-old.*

Another father told us about the difficulties he had experienced accessing primary care because of travel difficulty.

> “We were forced to move from our existing nearby GP practice without their consent because it was ‘over-subscribed.’ We asked if there was any way we could avoid moving but were told that we needed to make a written request, but this did not make a difference. We now have to attend a practice that is five miles away from our home. My wife does not drive and has to take two buses with our children to attend the new practice-we just have to put up with it.” *Father of five-year-old and one-year-old.*

This same father has also found challenges with getting medical attention for his one-year-old daughter.

> “My daughter wasn’t eating and had a consistently high temperature. It was difficult to get an appointment for his child even though she did appear to be quite ill. The GP practice team appeared caring and thorough with checking symptoms, but they advised a ‘wait and see’ approach and if there seemed to be any rapid deterioration in the daughter’s condition to take her to A&E. It seemed as if the surgery were trying to keep me and my daughter

at bay and they were reluctant to prescribe any antibiotics or other medication for her.”

One father from our survey mentioned the additional challenges of being a working parent.

> “Sometimes we don't have time to take our kids for tests.”
> *Father of a four-year-old.*

Emotional struggles for fathers too.
One of our interviewees spoke about the need for emotional support for parents.

> “I would imagine that emotional support is pretty important for some first-time parents trying to cope with their new-born between birth and six months. It can be difficult when they are at an age, when they are not able to tell you what they want.” Father of a one-year-old.

For him, support comes informally through the family.

> “The three of us - my wife, mother-in-law (who helps out with childcare) and myself - are able to support and reinforce each other.”

Another interviewee (Mother IR15) mentioned that her husband could have benefited from emotional support in the early days of childcare.

> “My Husband has really struggled. He has mental health issues. He is very hands on as a dad but there isn’t much support for dads. Parenting groups such as library events are very female orientated. The only Dads group is for those with kids 5-13 years old. We have set up a WhatsApp group for parents and the dads are pretty active.” *Mother of a five-year-old and two-year-old.*

Interviewee Father IR17 comments on the emotional support that he needed during Covid soon after the birth of his daughter, and more recently. He has two children, aged four-years-old and one-year-old.

> “Our experience has been mostly positive although we have had very minimal contact with the allocated health visitor after the birth of either of our children. The health visitor did not give us a huge amount of information/advice on caring for newly born children.”

During Covid, access to parenting groups was very restricted.

> “Difficult to access with work commitments and availability at inconvenient times.”

Father IR17 was also working at home and bringing up their first child was not easy.

> “I needed support during Covid when I was working from home, as I found it really difficult to balance – there was no boundary between home and work life.”

He received initial support through his GP who prescribed medication, but

> “The really helpful development was being referred to a ‘Health in Mind’ course and later a ‘Work in Mind’ programme which was facilitated by an excellent key worker. It took this to realise how much I hated my job at the time and prompted me to make a change.”

This support programme was free and really helpful. However, he comments that it would be good if there was more support for fathers.

> “I would have liked to have been made more aware via my GP and the hospital of more touch points for himself (and his wife) about how to access social and community-based activities. For example, Father groups that would enable me to connect with other parents and experience a sense of community and solidarity.” This is still the case today, as we would still like to be more involved in community groups which could connect my wife and I socially with other parents.”

v. Does age matter?

Some of the parents we interviewed felt their age was a factor in their experience.

One 28 year old Mum with a four-year-old “felt like a very young mother with my first child”.

Another interviewee now 29 years old, with a five-year-old and one-year-old reflects on her young age as being an advantage.

> “I was in my 20’s with my first and I also look very young. So, whenever I go to children and parent groups, I attract other young mums who want to socialise with me, which is great. I have always had a very positive experience.”

At the other end of the age range, an interviewee who is currently aged 45 years old, with a two-year-old, felt her older age could have been a factor in some of her experiences with other mums.

> “Maybe age – most of my friends have had children some time ago – although I have managed to make a couple of new mum friends of similar ages.”

Conclusion

Healthwatch Brighton and Hove (Healthwatch) were commissioned to speak to parents and carers, about their experience of accessing healthcare services on behalf of their child/ren aged five years and under. We aimed to connect with some lesser heard groups. These included parents with a child with special needs; LGBTQ+ parents; parents from ethnic minorities; and fathers. We worked with local VCSE partners to identify people from these groups.

Healthwatch engaged with parents and carers through a survey that achieved 117 responses. We also carried out 19 interviews which provided some context and explanation behind the survey responses. There was a range of experiences across the parents we engaged with, some having accessed services easily and found the service to be of good quality and provide appropriate care and advice, others experiencing the opposite.

Parents from the lesser heard groups also had mixed experiences, with some having the same success or challenge as other parents we spoke to. However, it is recognised that parents from these lesser heard groups found accessing some services harder than other parents and sometimes their specific needs go unrecognised. Consequently, healthcare providers need to provide opportunities for tailored services for these groups, specific training to healthcare staff to enable appropriate care, as well as provide information to parents from these groups, about the specific services available to them.

Some additional observations were as follows:

- There was a higher than expected number of parents (28%) who found it difficult to access urgent GP appointments. This suggests that due to difficulties gaining a routine appointment, these became urgent.

- Many parents spoke about the lack of signposting for new parents (to parent support groups for example). These provide vital early support for parents. Considering a huge majority of our parents (81%) felt they needed this support, it should be recognised that an increase in these services, as well as wider publicity, may prevent the need for accessing more formal emotional support later on.

- A surprising number of parents (29%) found attending these support groups difficult. Therefore, making these groups more accessible to all parents is important in light of the above comment.
- A large majority of those that sought emotional support found it to be helpful. Therefore, where formal support is sought, it should be easily accessible. This is in contrast to 24% of our parents who had sought this service but had been unable to access it.
- Some parents mentioned that medical staff had not paid attention to their view on what was wrong with their child. Often this related to hereditary conditions and family context. It is worth noting that time could be saved, and a more accurate diagnosis made, if medical staff responded to parents with interest and respect.
- In a similar vein, better joined up services between hospital, GP and community (midwives and health visitors) would avoid service users re-telling their story (of a difficult birth for example) as well as alerting community services to provide proactive support to vulnerable parents.
- Speaking to parents from lesser heard groups, demonstrated that not all of these parents will undergo negative experiences of the healthcare services. However, this doesn't negate the benefit of tailored services as well as the important by-product of enabling connections between parents within these groups.
- Many parents talked about lengthy waiting lists. It goes without saying that to decrease waiting times for specialist services and neuro-diversity assessments, would enable parents to get the help they need for their child and in some cases, reduce the call on healthcare services as a result. 30% of our parents had not been able to access these services.
- The majority of parents we heard from were affected by the cost of living crisis, including impacting on their ability to provide food (60%) and clothing (75%) for their children. Considering this context, the need for free and accessible services is more important than ever.

This is in stark contrast to our survey findings where 50% of parents were paying for parenting support services they attended.

- Although most of the parents (77%) we spoke to had heard of the CQC, many were unsure about the role of the organisation, or the benefit to parents of contacting them. If the CQC plan to work more closely with parents, they need to promote themselves clearly and widely, demonstrating the benefits to parents of contacting them (as opposed to contacting the healthcare provider, in the case of a complaint). It would be beneficial to promote the organisation through GP surgeries, hospital departments and the staff within to help them promote themselves.

- While it is recognised the CQC have limited ability to increase waiting lists or create additional services, through their fundamental standards they have influence on the provision of these services. These can be summed up in the five standards of Safe, Effective, Caring, Responsive and Well-Led provision of services.[4] If this influence is successful, it can be shared with parents through better promotion of the CQC.

---

[4] https://www.theaccessgroup.com/en-gb/blog/cqc-standards-the-cqc-fundamental-standards-and-cqc-5-standards/#:~:text=The%20CQC%205%20Standards%20are,each%20of%20the%205%20Standards.

Recommendations

These recommendations are based on the findings from the survey and the interviews we conducted with parents. Our first set of recommendations are for the health and social care services. By implication, they are also for the CQC in light of inspections and ongoing monitoring of these services.[5] We have placed these recommendations under sub-headings according to the type of service. Our second set of recommendations concern improving the CQC's relationship with the service user as suggested by interviewed parents.

Recommendations for the Health and Social Care Services – in line with CQC fundamental standards

GP Services

- Improve access to GP appointments. Ensuring the telephone number is easy to get through to and there is someone to answer the phone. Providing same-day appointments for urgent appointments. Provide a call-back service when the phone line is particularly busy.
- Improve the customer-service at GP practices, including training reception staff to be polite and helpful to service users.
- Improve the quality of care in GP appointments, ensuring staff are friendly, attentive, and respond to the child's condition and take the parent's concerns seriously.
- Improve the consistency of care for GP patients i.e. ensuring patients have access to the same doctor.
- Ensure healthcare staff in GP practices are trained in all conditions and provide peer-to-peer support to widen knowledge of less well-known conditions.
- When caring for a child, take the family context into account e.g. anxiety in the family, other conditions, neurodiversity in parents.
- Promote better understanding (through training) of complex needs and neurodiversity.

---

[5] See https://www.bma.org.uk/advice-and-support/gp-practices/the-cqc/what-the-cqc-do#:~:text=The%20role%20of%20the%20CQC,that%20standards%20are%20being%20met.

- Provide separate sessions for parents with children who have special needs, to make it easier for these families to attend appointments.

Dental practices

- Improve access to services, enabling every service user to be able to access a dental appointment annually.
- Improve the quality of care – ensuring all staff are kind and caring, particularly towards children, and especially when it is the first dental appointment for the child.
- Improve the customer service of reception staff, allowing flexibility around parents arriving late when appointments are immediately after school. Also, allowing for appointments to be postponed for unforeseeable reasons such as illness (instead of de-registering patients as a consequence).

Specialist / Referrals

- Decrease the waiting times for referrals to specialist services.
- Decrease the waiting times for CAMHS assessments.
- Improve the quality of care – ensuring all staff take parents seriously and respond appropriately to their concerns.
- Support the above with staff training.

Parent Support services

- Increase access to free services for all parents, and particularly those on a lower income.
- Provide specific services for LGBTQ+ parents and neurodiverse families.
- Decrease the barriers to access, by ensuring information on parenting support services is provided to all new parents (via the GP and midwife).
- Provide better access to these services for parents with multiple births (twins etc.).

Emotional support for parents

- Ensure all new parents are provided information on emotional support services (via GP and midwife).
- Ensure parents have access to a 'safe' place to discuss any emotional support they might need.

- Ensure GPs are aware of any challenging birth situations for new mums and ask about any emotional support needed.
- Provide longer-term emotional support and an alternative to CBT through the Wellbeing Service.
- Provide specific support for neurodiverse parents; parents who have experienced trauma; and LGBTQ+ parents.
- Treat the whole person rather than specific conditions.
- Ensure emotional support is available to fathers as well as mothers.
- Ensure GPs are aware to ask about fathers need for support as well as mothers.

Other services

- Joined up maternity services between hospital, GP, and community services (health visitors and midwives).
- LGBTQ+ inclusion in maternity services.
- Provide training and encourage LGBTQ+ inclusion in all areas of health services.
- Provide consistency of care between hospital settings (for example, Brighton and Worthing), providing the right information and ensuring staff are listening to parents about the concerns they have for their child.
- Provide training to all staff on anti-racism behaviour.

Cost of living

- Create more opportunities for free services and consider different geographical areas of deprivation.

CQC Guidelines

- Provide guidance for all of the above in line with the CQC's Fundamental Standards.[6]

---

[6] https://www.cqc.org.uk/about-us/fundamental-standards

Recommendations for improving the CQC's relationship with the service user as suggested by interviewed parents.

- Better promotion of the CQC. Ensure the general public know who they are, what they do and the reasons why service users should contact them.
- Use a variety of methods to reach out to parents. For example, distribute surveys and invite parents to take part in interviews and discussion groups.
- Share information with parents and carers and ask for their opinion, via a parent's portal.
- Use both online and face-to-face methods of contact.
- Partner with health services (GP, hospitals) to help promote the CQC.
- Ensure all health services display the CQC rating and locate information on how to access the CQC (next to the rating).

Implications for further research

Healthwatch have some comments on implications for further research.

The focus of this report was on achieving a wide range of diversity amongst the group of parents we surveyed and spoke to (in the interviews). While a strength of the report, this also meant that each type of inequality was represented in small numbers within the survey and even smaller within the interviewees. For example, of the 62 parents who responded to our questions about ethnic diversity, 11 parents identified themselves in the survey as "non-white", which became four parents who were interviewed.

The CQC set a minimum of 15 interviews; Healthwatch conducted interviews with 19 parents.

To expand this research further, Healthwatch advise a more targeted project that focuses specifically on one group of parents, for example, ethnic diversity. To conduct this targeted approach, it would be advisable to partner with a voluntary or charitable organisation who had direct access to this specific group of people. Methods of approach could include small working groups and in a face-to-face format to achieve richer narrative. However, this would require greater resources including time, than was feasible within this current project.

Appendix A: Participant profile

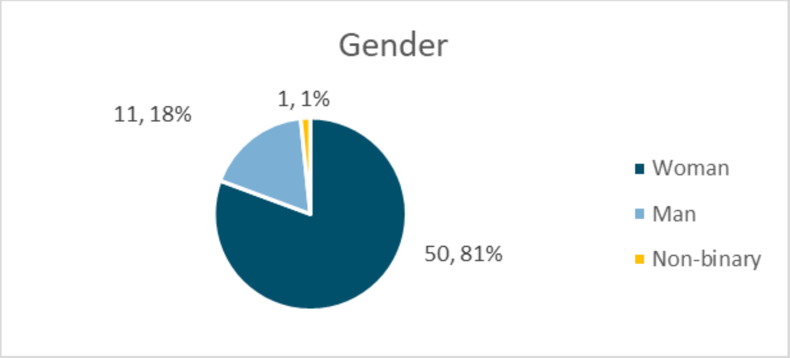
Healthwatch Brighton and Hove always aims to recruit a diverse group of people within our projects, including those who represent a range of ages, sexual identity, and ethnic diversity. The CQC were also keen to hear from a diverse group of parents and as such, Healthwatch proposed that we would try to enlist parents that represent seven different groups, working with Voluntary, community and social enterprises (VCSE) partner organisations where possible.

Survey Respondents

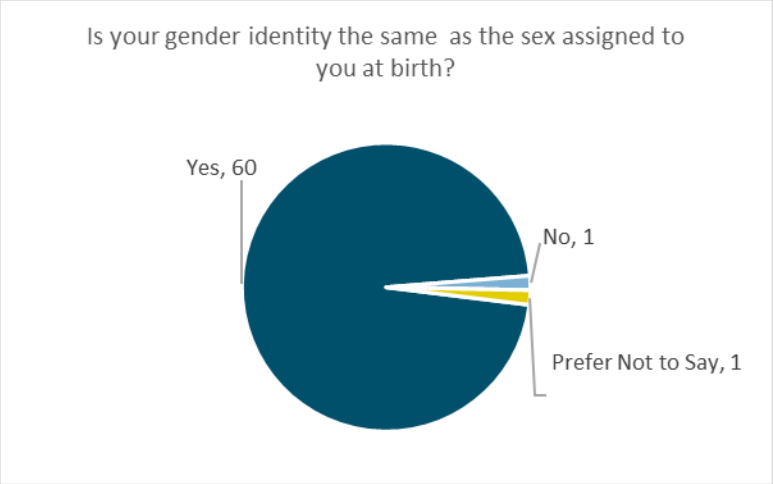
There were **117 respondents to the survey**, including **19 people we interviewed** in more detail. The following profile data is based on all of the survey respondents including the interviewees. For a separate profile of the interviewees, please see the end of this section.

The survey included demographic questions based on protected characteristics. Survey respondents could choose if they wanted to answer these questions; 62 people (53%) did so, while 55 people (47%) chose not to.

Gender

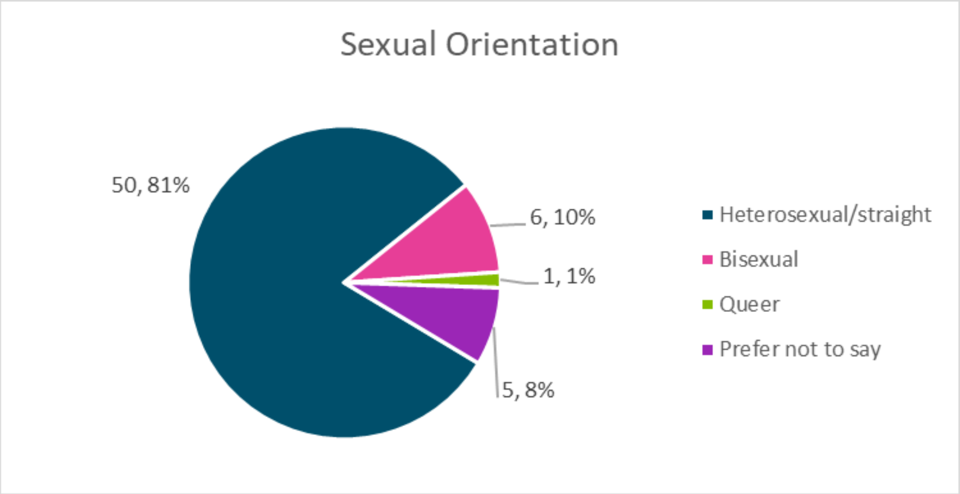


Of the 62 people who responded to these questions, 81% (50) were women; 18% (11) identified as men; and one person identified as non-binary.



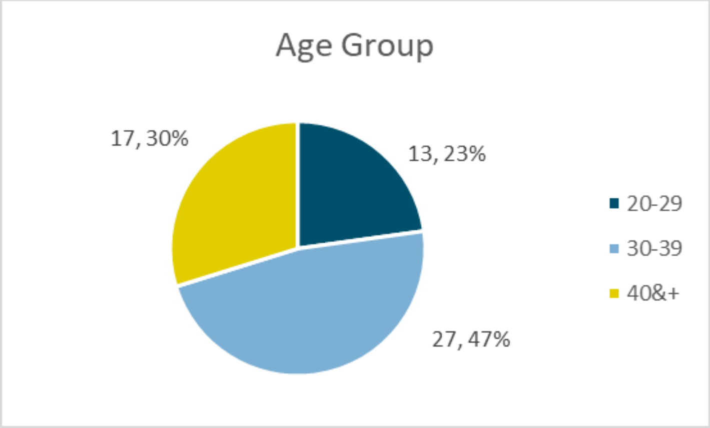
The majority of parents (60, 97%) identified as the same gender as they were assigned at birth. One person did not identify as the same sex assigned at birth and one person preferred not to say.

Sexual orientation



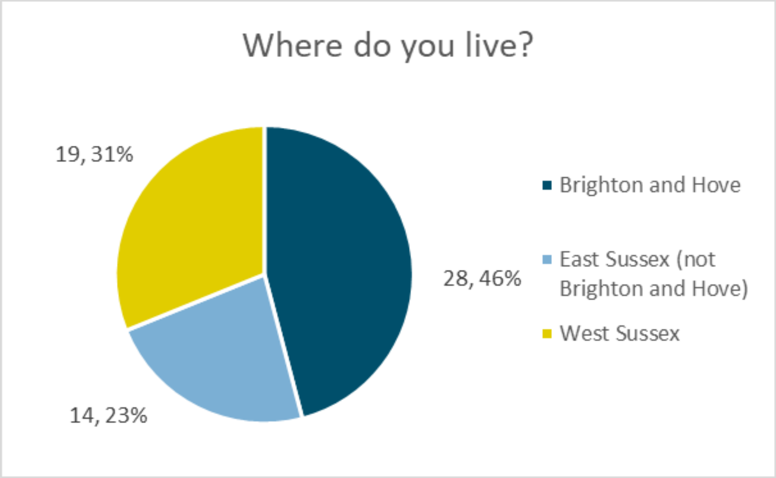
Most parents (81%, 50) identified as heterosexual / straight. 10% (6 people) identified as bisexual, 8% (5 people) preferred not to say, and one person defined themselves as queer. Nobody identified themselves as lesbian/gay woman.

Age



Survey respondents ranged in age from 25 to 51 years old. The majority (47%, 27 people) were between the age of 30 – 39 years old. 30% of parents were in their 40's (with one person aged 51). The minority of parents (23%, 13) were aged in their 20's. Five people did not respond.

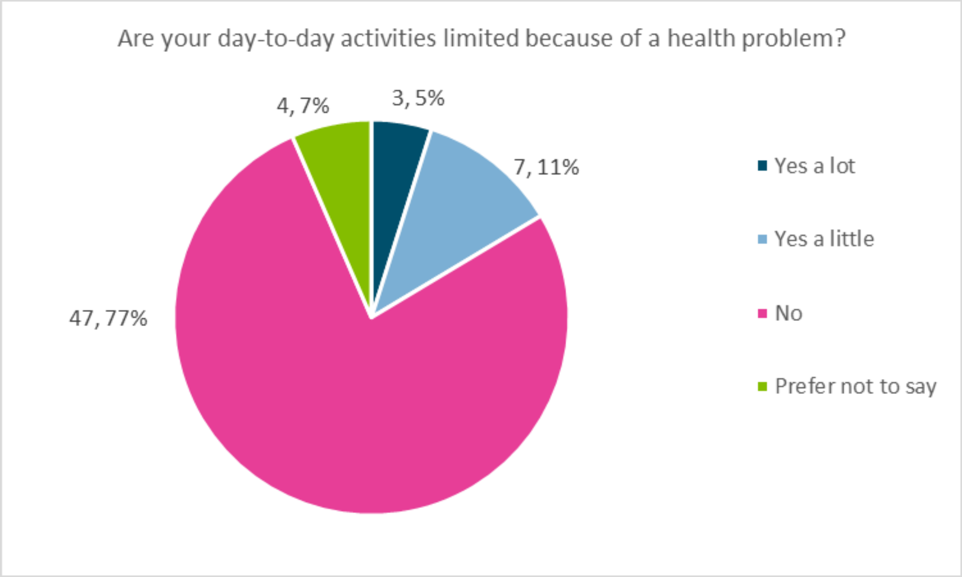
Geographical location



The CQC were happy for us to speak to parents across Sussex. Most parents (46%, 28 people) were from Brighton and Hove; 31% (19 parents) were from West Sussex; and 23% (14 people) were from East Sussex. One person did not respond to this question.

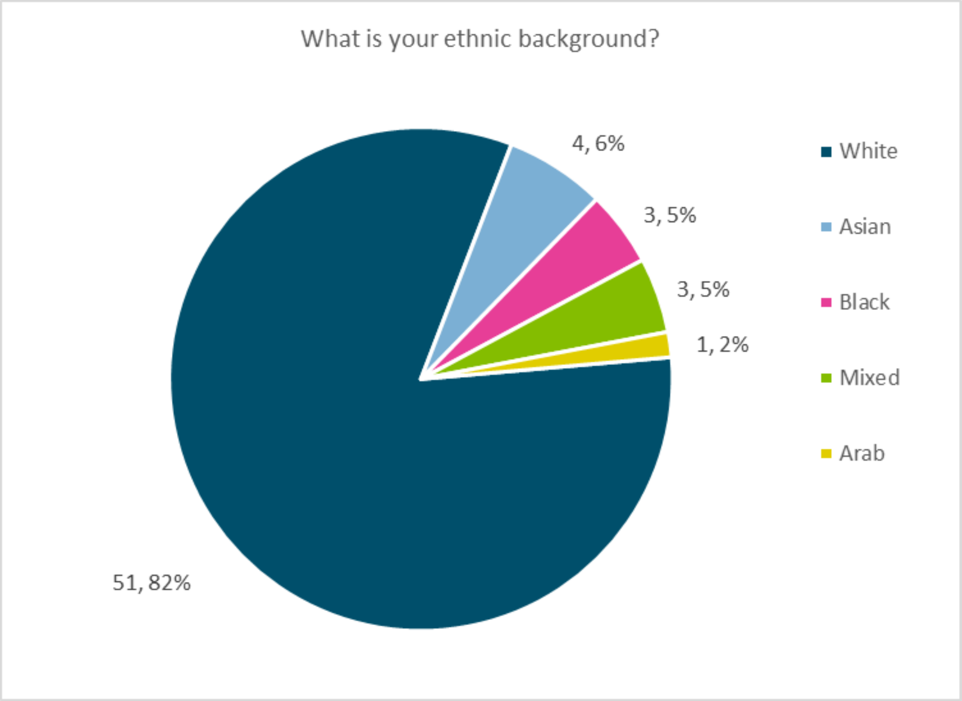
Long-term conditions

We asked parents if their day-to-day activities are limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months.



Most parents (77%, 47) did not have a long-term condition that affected them on a daily basis. However, 16% of parents did, with three affected "a lot" and seven affected "a little". Four people preferred not to say and one person did not respond to this question.

Ethnic background

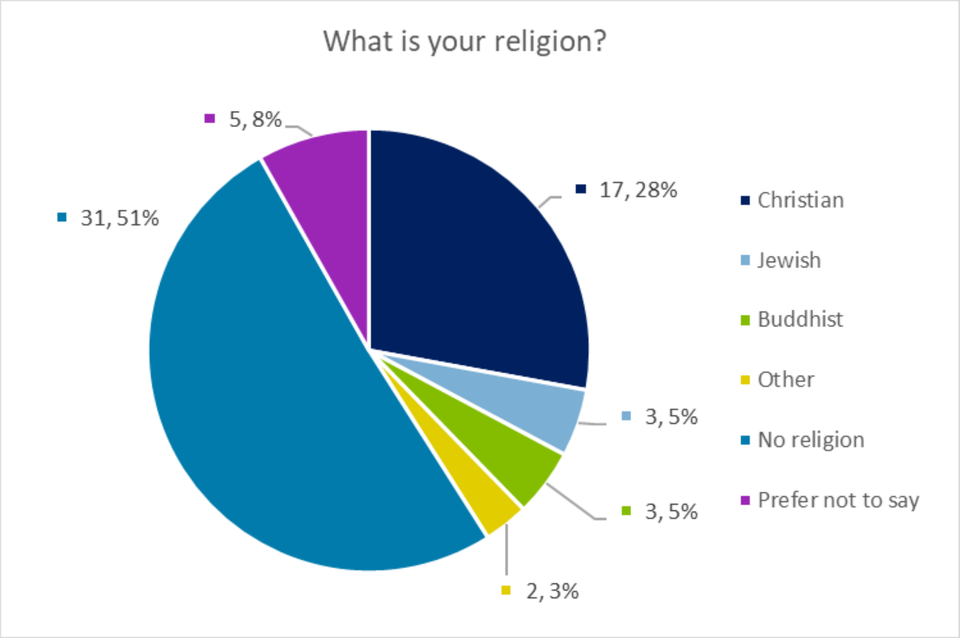


Most parents who responded to this question (82%, 51) described themselves as "White", either "White: English, Welsh, Scottish, Northern Irish or British" (71%, 44); "White: Irish" (3%, 2); or "Any other White background" (8%, 5).

Four people defined themselves as "Asian". Three of these were "Indian" and one person was "Chinese". Three people defined themselves as "Black, Black British, Caribbean or African" with two people who were "Caribbean" and one person who was "African".

Three people described themselves as mixed, with two people describing themselves as "White and Asian" and one person identifying as "White and Black African". One person described themselves as "Arab". There were no "other" ethnic groups.

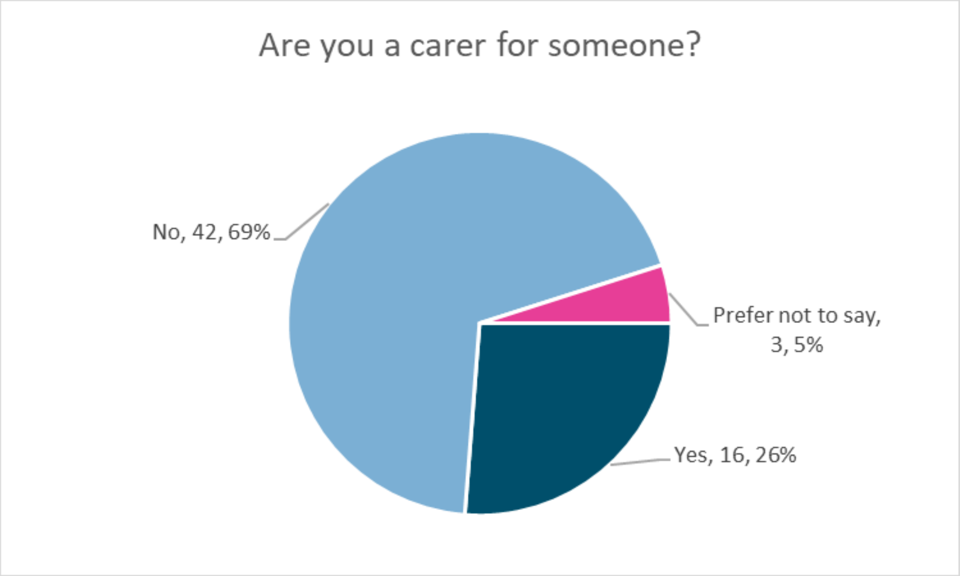
Religion



Most parents (51%, 31) defined themselves as having “no religion”. The next largest group were Christian (28%, 17). Other groups were smaller: 5% (3 parents) were Jewish and the same number were Buddhist; 3% (2 people) were “other”, with one person “spiritual” and the other “quaker”. Five people preferred not to say. No parents were either Sikh or Muslim.

Carers

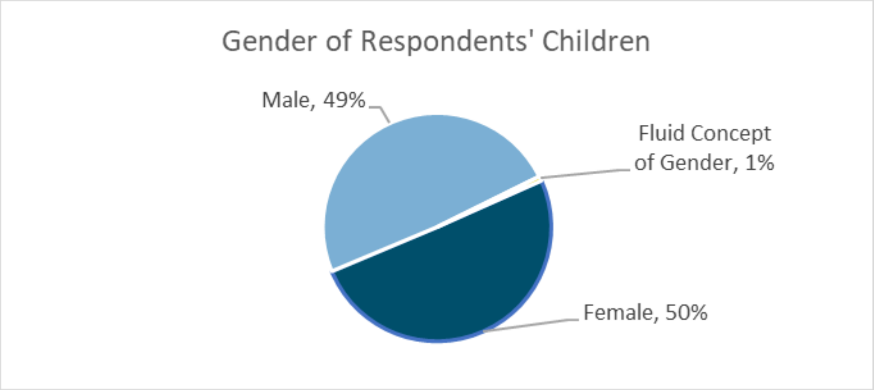
As specified by the NHS "A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid."



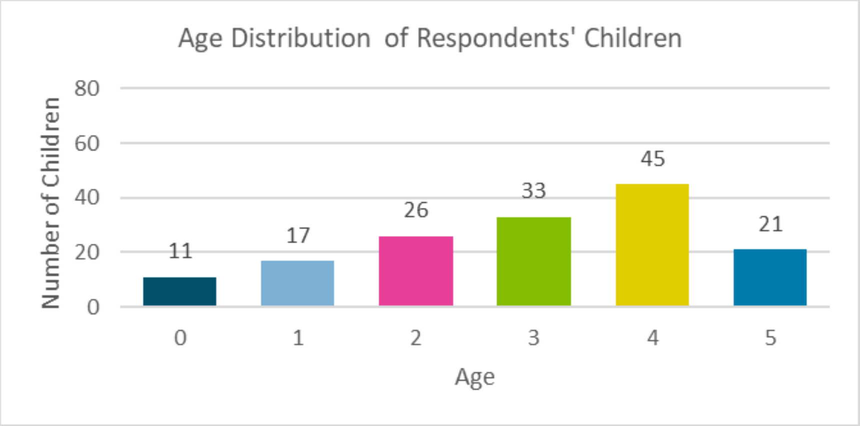
Most parents (69%, 42) were not caring for anyone (other than their child(ren)). However, over one quarter of parents we spoke to did care for someone else (26%, 16). Three people preferred not to say, and one person did not respond to this question.

Gender and age of Children

In addition to the demographic questions tied to protected characteristics, we also asked survey respondents to describe the age and gender of their child(ren).



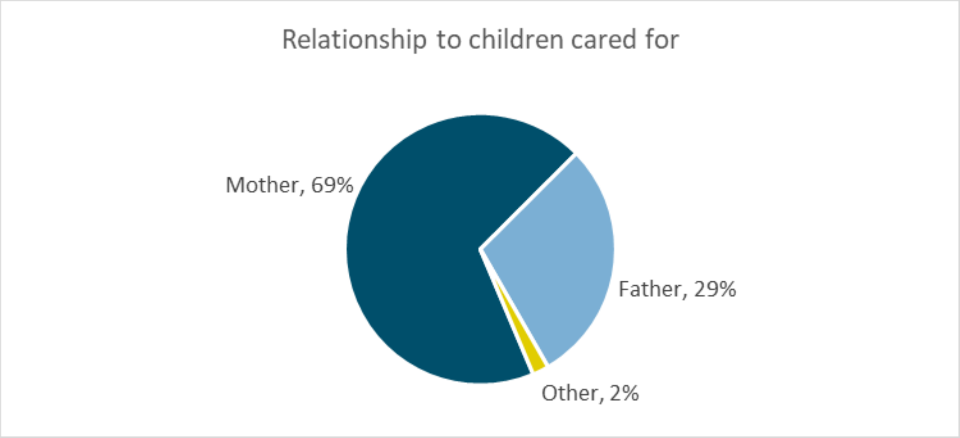
There was almost an even split between male (49%, 75 children) and female (50%, 77). One child was described as having a “fluid concept of gender”. In total, there was 153 children.



Children aged from a few months old; 11 children were “below one year old”). 17 children were “aged from 1 year to below 2 years old”; 26 children were below 3 years old”; 33 children were below 4; 45 children were below 5 and 21 were below 6 years old.

Relationship to child(ren)

We asked parents/carers to tell us what relationship they were to the child.



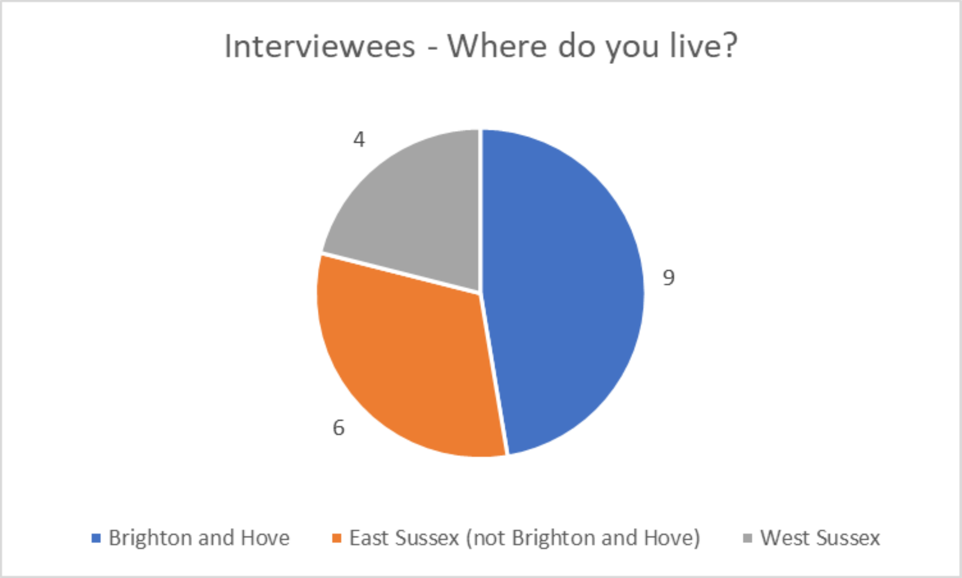
The largest majority of parents were mothers (69%, 71), with a large minority of fathers (29%, 30). There were two “other” parents. One person defined themselves simply as “parent”; the other described their relationship as “Sgo for one, Mother for the other”. Special Guardianship order (Sgo) covers foster-care, adoption, kinshipcare and similar relationships. See Family Lives website for further details.[7]

Interviewee profile

The following provides a summary of the 19 parents and carers who took part in the interviews.

A diverse profile was achieved within the survey in terms of gender, age, ethnicity etc. Through those that volunteered for interview, we purposefully furthered this diversity by ensuring we interviewed three fathers, three non-heterosexual parents, three parents with long-term conditions, and four parents who were not from a "White" background. We also ensured representation from parents whose religion was not "Christian" and three parents who cared for someone in addition to caring for their children.

Interviewees - Geographical location

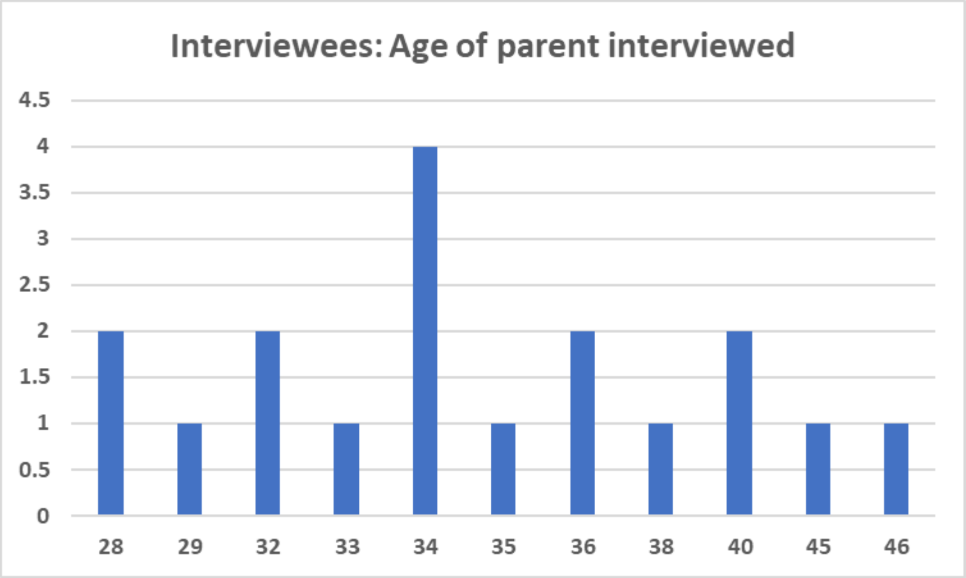


Most Interviewees were from Brighton and Hove (9 parents) while a smaller representation were from East Sussex (6 parents) and West Sussex (4 parents).

---

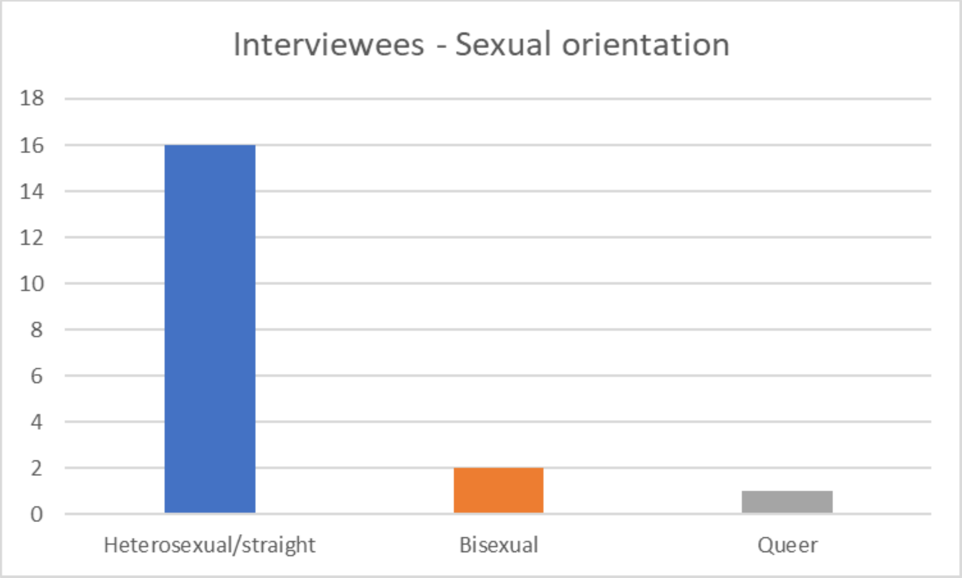
[7] For more details on Special Guardianship order (Sgo), see https://www.familylives.org.uk/advice/your-family/fostering-adoption-kinshipcare/special-guardianship-orders.

Interviewees - Age



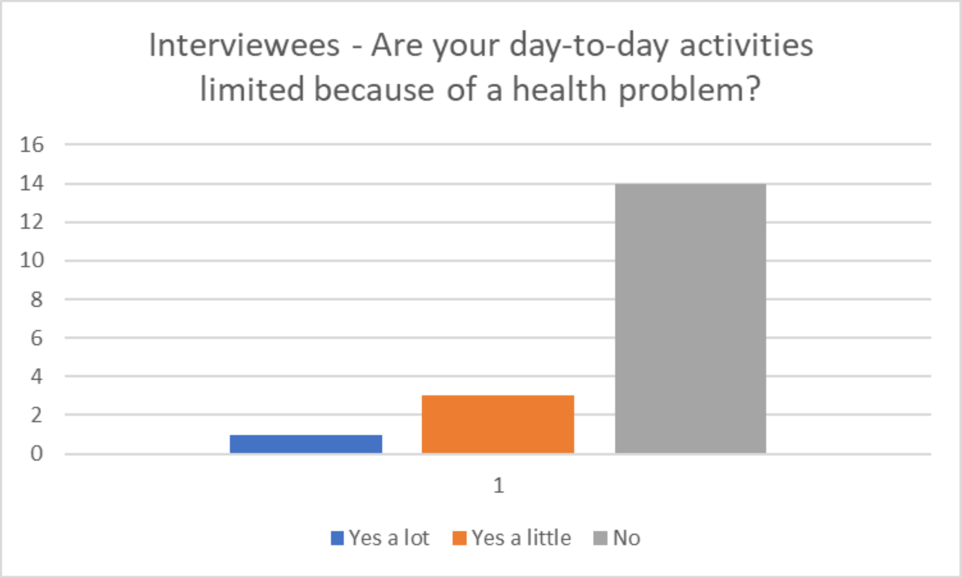
One interviewee did not provide their age. Of the 18 who did, ages ranged from 28 to 46.

Interviewees - Sexual orientation



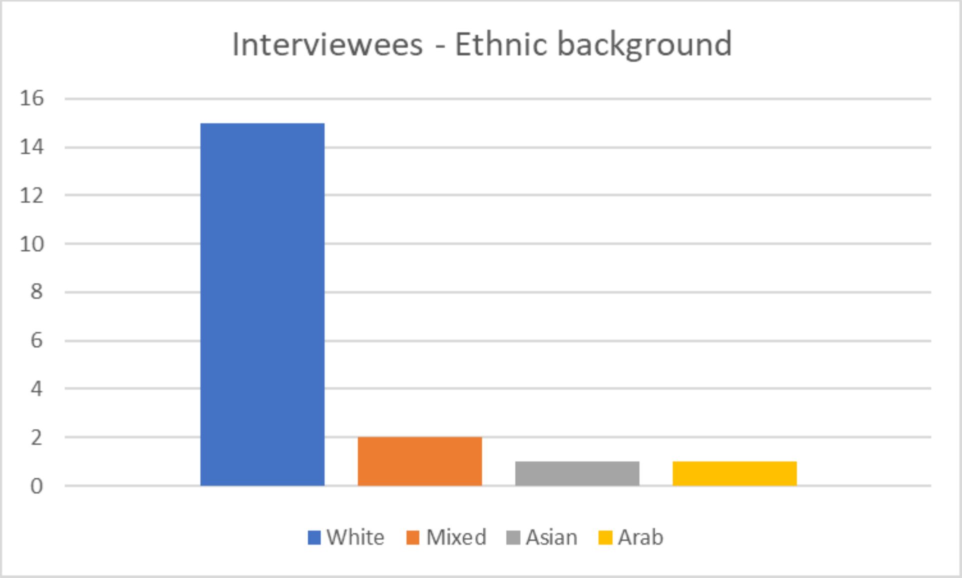
The majority of interviewees were heterosexual (16) with two parents who identified themselves as bisexual and one parent who was queer.

Interviewees – Long-term conditions

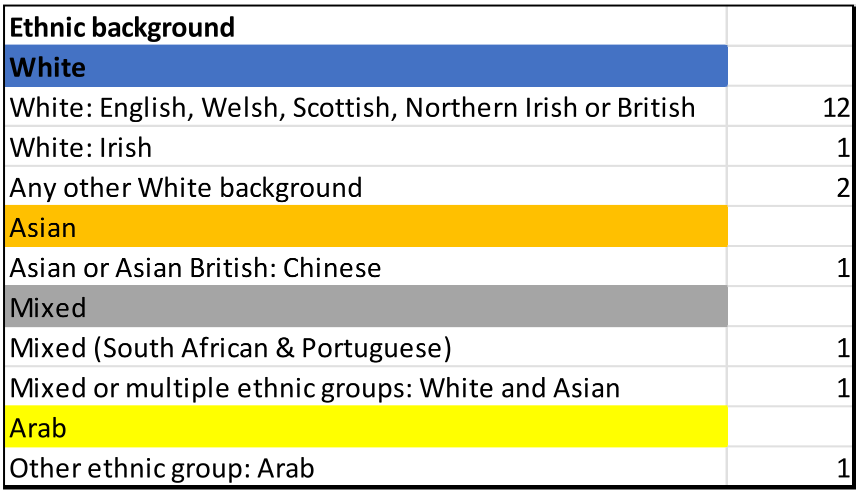


The majority of interviewees (14) did not have a long-term condition. However, one person had a health condition that affected them "a lot" on a daily basis. Another two parents had a condition that affected them "a little". One person did not answer this question.

Interviewees – Ethnic background

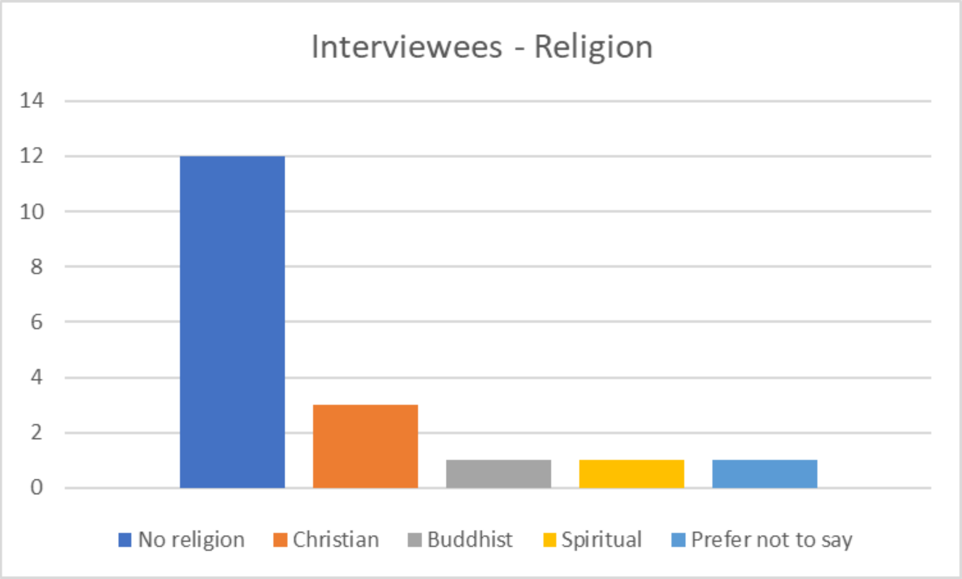


Most of our interviewees (15) identified as "white", two parents identified as "mixed", one parent as "Asian" and another parent as "Arab". The table below shows the ethnic identity of interviewees in more detail.



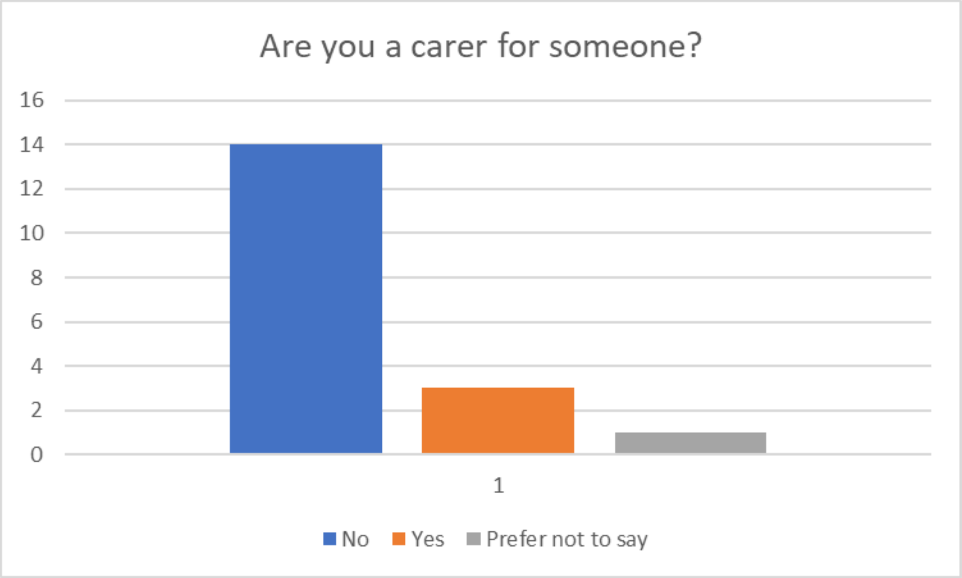
Ethnic background	
White	
White: English, Welsh, Scottish, Northern Irish or British	12
White: Irish	1
Any other White background	2
Asian	
Asian or Asian British: Chinese	1
Mixed	
Mixed (South African & Portuguese)	1
Mixed or multiple ethnic groups: White and Asian	1
Arab	
Other ethnic group: Arab	1

Interviewees – Religion



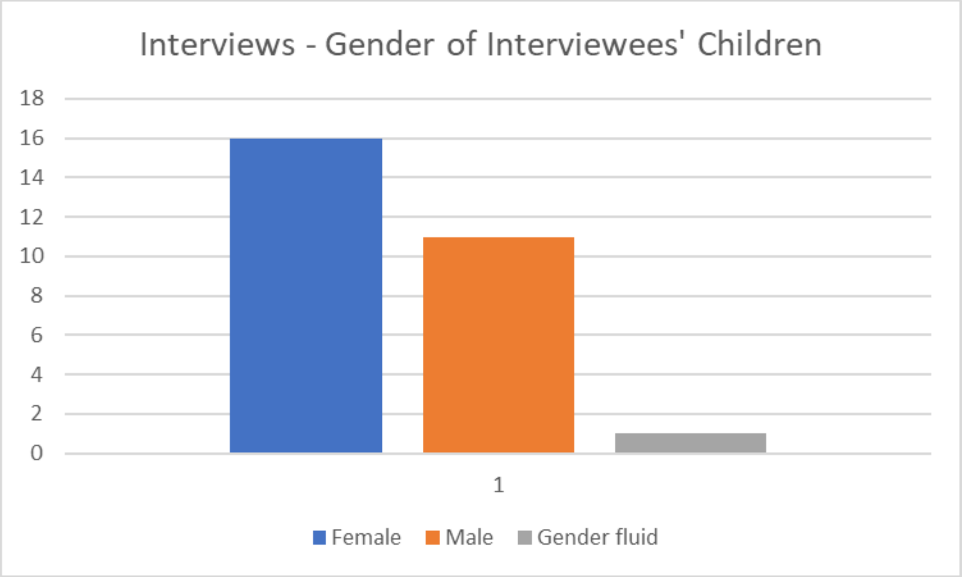
The majority of interviewees (12) defined themselves as having “no religion”. Three parents were “Christian”, one parent was “Buddhist”, one parent “Spiritual”, and another parent chose the option for “prefer not to say”. One other parent did not respond to the question.

Interviewees - Carers

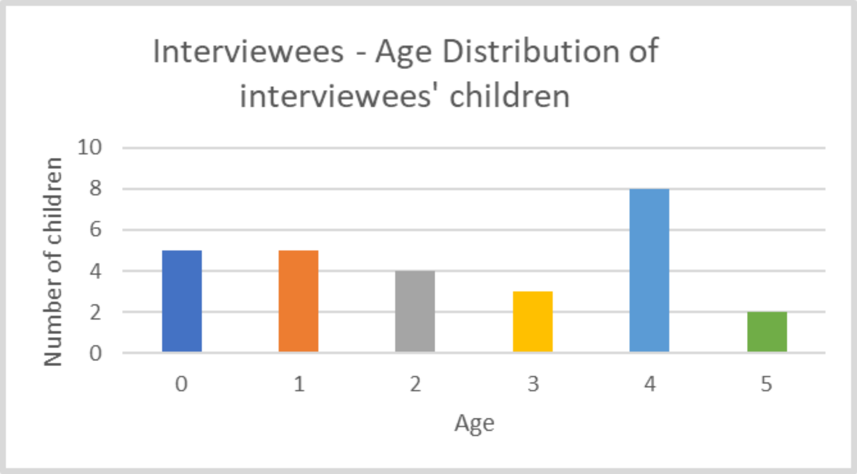


Most parents (14) we interviewed were not carers. However, three parents did care for someone (other than their child/ren) and one person selected the option for "prefer not to say". Another parent did not respond to this question.

Interviewees - Gender and age of children



Amongst the interviewed parents, there was a total of 27 children who were five years of age or under. The majority of these were female (16 children), a smaller minority of 11 were male children and one child was “gender fluid”.



Children aged from a few months old to just below six years of age. Five children were “below one year old”; with the same number of children who were “aged from 1 year to below 2 years old”. Four children were below “3 years old”; three children were below 4; eight children were below 5 and two children were below 6 years old.

Some parents mentioned siblings who were older than six years of age, but they were not counted in the data, as they were beyond the remit of this project.

Interviewees – Relationship to child/ren

Most of the interviewees defined themselves as “mother” with three that defined themselves as “father”. All 19 identified as having the same gender they were born with.

Appendix B: Survey questions, and interview discussion guides.

Please find below a copy of the survey questions and the interview discussion guide.

Survey Questions

Parents/Carers of Children 5 years and under

1. Do you have a child who is 5 years or younger?

Healthwatch Brighton and Hove has been appointed by the Care Quality Commission (CQC) to speak to parents and carers of children, aged 5 years or younger. Healthwatch is your independent patient champion. To read more, please visit our website. The CQC is the independent regulator of health and social care in England. To read more, please visit the CQC's website.

We are looking to find out parent/carer experiences of booking and attending GP (doctor) and dental appointments for your child(ren) and attending parenting support groups. The CQC will use your experiences in their conversations with health and social care providers, to help improve the quality of services in your local area.

The CQC would like to know if parents/carers have heard of, and/or used the CQC to feedback on care via their feedback form.

The questionnaire will take less than 10 minutes, and you have a chance to enter a prize draw for one of three £20 high-street vouchers.

All responses are confidential - our privacy policy can be seen here: Healthwatch Brighton and Hove Privacy Policy

If you are interested, there is an option at the end of the survey, to volunteer to speak to a Healthwatch staff member in more detail about your experience.
Many thanks
Healthwatch Brighton and Hove

1. Are you a parent/carer of a child aged 5 years or younger? *

☐ Yes, I am a parent/carer of a child/children aged 5 years or younger.
☐ No, I am a parent/carer of a child/children aged 6 years or older.
☐ No, I am not a parent/carer.

2. Thank you!

Thank you for your interest. However, this survey is only for parents and carers with a child/children aged 5 years and younger. Please keep in touch and we invite you to respond to future surveys that best meet your health and social care experience.

3. Your child(ren) aged 5 years or younger.

2. What is the Gender and Age of your child(ren)?

	Gender	Age
Child 1		
Child 2		
Child 3		
Child 4		
Child 5		

If gender is other than male or female, please specify

3. What relationship do you have to the child/ren you care for?

☐ Mother

☐ Father

☐ Other (please specify):

4. Thinking about your overall experience for your child(ren), how easy have you found the following as regards caring for your child/children?

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	n/a
Book a routine GP appointment (including for child immunisation)	☐	☐	☐	☐	☐	☐
Book an urgent GP appointment	☐	☐	☐	☐	☐	☐
Book a routine dental appointment (e.g. a 'check-up')	☐	☐	☐	☐	☐	☐
Book an urgent dental appointment	☐	☐	☐	☐	☐	☐
Attend a GP appointment (either urgent or routine) – in person or remotely (e.g. phone call)	☐	☐	☐	☐	☐	☐

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	n/a
Attend a dental appointment (either urgent or routine)	☐	☐	☐	☐	☐	☐
Accessing follow-up support (e.g. referral to a specialist, or further tests)	☐	☐	☐	☐	☐	☐
Attend a parenting support service (e.g. baby or toddler group, or other parenting programme), but not including a childcare service	☐	☐	☐	☐	☐	☐

5. Thinking of the service above which you have found the most difficult to use, please select from the following the reason(s) why you have found it to be difficult (please tick as many as apply).

☐ Difficulty contacting the service.

☐ Lack of available appointments.

☐ Poor quality of advice.

☐ Service doesn’t exist in my local area.

☐ Difficulty travelling to the service.

☐ Couldn’t afford the service and/or travel to the service.

☐ Wasn’t aware of the service.

☐ Other (please specify):

6. If you have attended a parenting support service (e.g. baby or toddler group, or other parenting programme), but not including a childcare service, can you indicate if most of these classes have been:

☐ Free (e.g. funded by the local authority)

☐ Paid for

☐ I have not attended any of these classes

4. Child(ren) with complex needs

7. If one of your children/your child has complex needs or a disability, have you been able to access support and care from health and care services in your area?

☐ Yes
☐ No
☐ I do not have any children with complex needs or a disability

5. Seeking emotional support

8. If you have ever needed emotional support for being a parent/carer of your child/children, did you try to seek formal support e.g. through your GP or health visitor and in the form of counselling, or a wellbeing service etc?

☐ Yes
☐ No
☐ I have never needed emotional support as a parent/carer

6. Receiving emotional support

9. If you tried to seek formal support, did you receive any formal support (from counselling or wellbeing service etc.)?

☐ Yes
☐ No

7. Receiving emotional support - part B

10. If you have received formal support for emotional wellbeing as a parent/carer, how useful was this service?

☐ Extremely useful
☐ Very useful
☐ Somewhat useful
☐ Not so useful
☐ Not at all useful

8. Cost of living

11. Has the cost of living had any impact on you as a parent/carer?

	Yes, definitely	Somewhat	No, has not
Impacted on my ability to provide food for my child(ren)	☐	☐	☐
Impacted on my ability to provide for my child(ren) in other ways (e.g. clothing, activities)	☐	☐	☐
Impacted on my ability to socialise with other parents/carers	☐	☐	☐

9. The Care Quality Commission

12. Have you heard of or contacted the Care Quality Commission (CQC)?

	Yes	No
Heard of the CQC	☐	☐
Contacted (by telephone, written to, or filled out a form online)	☐	☐

10. Further comments

13. Do you have any further comments about accessing health services as a parent/carer of a child/children aged 5 years or younger? Please think about any services that have been easy or difficult to use.

11. Further engagement

14. Would you be interested in either of the following?

	Yes	No
An informal chat with a Healthwatch staff member about your experience (approx. 20 minutes via telephone or Zoom meeting)	☐	☐
Entering in for a prize draw to win one of three £20 high street shopping vouchers	☐	☐

12. Contact details for further engagement

15. If you have answered yes to either of the above, please complete your contact details below:

13. About you - invite

Thank you for taking the time to participate in our survey. Healthwatch Brighton & Hove is committed to being a diverse and inclusive organisation, reflecting the community we serve.

We are committed to ensuring our services are accessible to everyone regardless of ethnicity, race, gender, gender identity, religion, belief, sexual orientation or age. These optional questions will, taking a further 2 minutes, help us to assess equality in our services, and to meet our equal opportunities and diversity commitments.

Thank you.

16. Are you happy to answer a few questions about yourself?

☐ Yes, I am happy to answer a few questions about myself
☐ No, I would prefer not to answer these questions

14. About you - questions

17. Are you a

☐ Woman
☐ Man
☐ Non-binary
☐ Prefer not to say
☐ Other (please specify): ____________________

18. How old are you? (please put "prefer not to say" if this applies to you).

____

19. Where do you live?

☐ Brighton and Hove
☐ East Sussex (not Brighton and Hove)
☐ West Sussex
☐ Outside Sussex

20. Is your gender identity the same as the sex assigned to you at birth?

☐ Yes
☐ No
☐ Not sure
☐ Prefer not to say

21. Sexual orientation - Please tick the box that you identify with.

☐ Bisexual
☐ Gay man
☐ Lesbian/Gay woman
☐ Heterosexual/straight
☐ Don't know
☐ Prefer not to say
☐ Other (please specify):

22. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

☐ Yes, a little
☐ Yes, a lot
☐ No
☐ Prefer not to say

23. What is your ethnic background? (please put "prefer not to say" if this applies to you).

☐ Asian or Asian British: Indian
☐ Asian or Asian British: Pakistani
☐ Asian or Asian British: Bangladeshi

☐ Asian or Asian British: Chinese

☐ Any other Asian background

☐ Black, Black British, Caribbean or African: Caribbean

☐ Black, Black British, Caribbean or African: African

☐ Any other Black, Black British, or Caribbean background

☐ Mixed or multiple ethnic groups: White and Black Caribbean

☐ Mixed or multiple ethnic groups: White and Black African

☐ Mixed or multiple ethnic groups: White and Asian

☐ Any other Mixed or multiple ethnic background

☐ White: English, Welsh, Scottish, Northern Irish or British

☐ White: Irish

☐ White: Gypsy or Irish Traveller

☐ White: Roma

☐ Any other White background

☐ Other ethnic group: Arab

☐ Any other ethnic group

☐ Other (please specify):

24. What is your religion? Please say "no religion" or "prefer not to say" if either of these applies to you.

☐ Buddhist

☐ Christian

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ No religion

☐ Prefer not to say

☐ Other religion (please specify):

25. Are you a carer for someone? As specified by the NHS "A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help

because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid."

☐ Yes
☐ No
☐ Prefer not to say

15. Thank you!

Thank you for taking the time to complete this survey. Your responses will be used anonymously and alongside other responses to this survey, by Healthwatch Brighton and Hove. The findings will be written up and presented to the CQC with recommendations on improving services in your area.

Interview discussion guide.

Parents/Carers of children aged 5 years and younger.

For Interviewers (in Italics):
For all Qs, please use prompts such as 'can you tell me more about that?'
The 'whys' and the 'hows' will give us more information than the survey.
Start here: Thank you for agreeing to talk about your experience of services as regards your child or children 5 years and younger. About the recent survey you did, we want to know more about your experience of accessing healthcare on behalf of your child(ren)....

- 30 mins
- Anonymity
- Confidentiality and Safeguarding
- Consent to record – used to listen back and pick out key themes and anonymous quotes.

Before we start do you have any questions?

1. Introduction
How many children do you have aged 5 or under, their sex, check SEN/disability for later Q, check names so you can refer to this throughout e.g. when you took [Alfie] to the dentist etc…, *Also would be useful to find out whether they are in a relationship and does their partner/husband/wife take their child(ren) to appointments too.*

2. Services
The first set of questions is about accessing services, and why you might have found it easy or difficult to access healthcare for your child/ren. We also ask questions about quality of care.

a) GP

I want you to think about a time when you've taken [Alfie] to the GP:

- Has this happened, and what was the reason for the appointment?

Access

- How easy/difficult was it to get an appointment? (Lack of available appointments? Service doesn't exist in my local area. Difficulty travelling to the service? Couldn't afford the service and/or travel? wasn't aware of the service?).

Quality of service

- Was there anything that was particularly positive about the care you/[Alfie] received? What was this appointment for?
- If so, what was positive about the care you received?
- Have you ever had an experience with the care from GP that was not so positive? What was this appointment for? Why was this?
- Did you feel you received the right advice or information? Did this help towards the reason for the appointment?
- Did you feel you were listened to?

If the appointment was routine, please ask them for an example of an urgent appointment. If urgent, then vice versa. With same questions.

b) Repeat above for dentists, noting whether this was routine or urgent – we are interested in both so if they start with a routine example, be sure to ask them about an urgent example afterwards.

c) Did / have you ever needed follow-up support like referral to a specialist for [Alfie]?

- Why was this? What follow-up support was this?

Access

- How easy was it to get this follow-up support?

Quality of service

- How was this experience in terms of the care [Alfie] received?

3. Parenting support services such as baby and toddler groups

- Have you been?
- How was it?
- Easy to find out about it/access?
- Free/paid for?
- Are you still attending? Why? Why not?

4. SEND if applicable – Does your child(ren) have any additional needs?

- Have you received support for [Alfie]?
- How difficult or easy was it to get this support?
- How did you find out about the support?
- Was the support useful for [Alfie]?

5. Emotional support

- Have you ever received emotional support?
- Was if informal (friends/family) or more formal (counselling or therapy)?
- When was this – pregnancy, within one year of birth, or after?

For formal support:

  - ➢ How did you find out about this support?
  - ➢ How useful was this formal support?
  - ➢ Was it free/paid for?
  - ➢ Are you still getting this support, if not why not?

6. Cost of living

- Has the cost of living affected you, if so how?
- Has it affected your care for [Alfie], like seeing other parents, going to activities, childcare, etc, If so, how?
- Has it affected what food you eat, heating, socialising, buying things for [Alfie], etc.

Please ask questions from Section 7 as appropriate - if you can see from their survey that they fit a particular group, please select the relevant question to ask them. If they have not answered the demographic questions, you could ask them a general question about their background

7. Additional questions according to interviewee background (select as appropriate)

- Is there anything about your background or faith that might have influenced your experience?
- Have language barriers ever affected your experience with accessing healthcare services on behalf of your child(ren)?
- Is there anything about being a father that may have affected your experience?

- Is there anything about being LGBTQ+ that may have affected your experience?
- Has parenting alone affected your experience, and if so, in what ways?
- Does having a long-term condition affect your parenting experience as far as contact with the health and social care services?
- Do you think there are any differences in your experience as a younger Mum compared with older Mums?
- FOR THOSE WHO HAVE NOT ANSWERED THE DEMOGRAPHIC QUESTIONS YOU COULD ASK "Is there anything about your background, faith, ethnicity, sexuality etc. that might have influenced your experience?

8. CQC

- Have you heard of the CQC?
- Do you know what they do?
- Have you ever contacted them? Why was this, how did you do this?
- Do you know how to contact them?
- Would you contact them if you needed to?
- If the CQC wanted to involve parents more in how they work, how do you think the CQC should go about it?
    - *Prompts: Sending out a survey for parents to complete? Sharing written information and asking for parents to feedback on this? Inviting parents to take part in either a discussion group or interview (much like this) but directly with the CQC? Or anything else?*

9. Any further comments about you and [Alfie]'s use of the services we've talked about?

10. In addition to the demographic questions (questions about you) that we asked in the survey, to do our complete due diligence there are a couple more. Are you ok for me to ask you these and of course if you do not wish to answer one of them, you can tell me.

10a. Are you married? In a civil partnership?

10b. Are you pregnant? On maternity leave?

10c. Are you currently serving in the UK Armed Forces? (this includes reservists or part-time service, such as the Territorial Army)?

Q10d. Have you ever serviced in the UK Armed Forces?

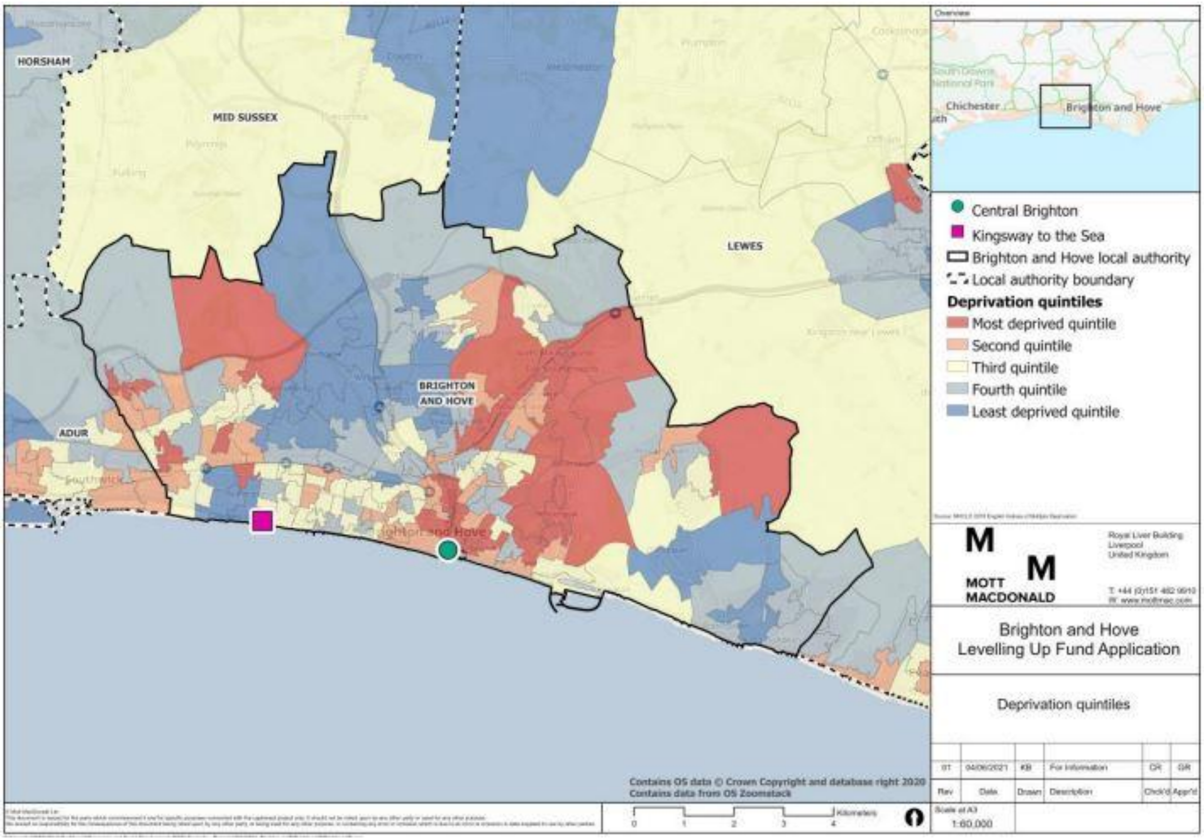
Q10e. Are you a member of a current or former serviceman or woman's immediate family/household?

11. Would you like to be added to the Healthwatch Brighton & Hove mailing list to receive information about any future projects? Would you be interested in being contacted direct by either the CQC or Healthwatch for further information on this project or other projects?

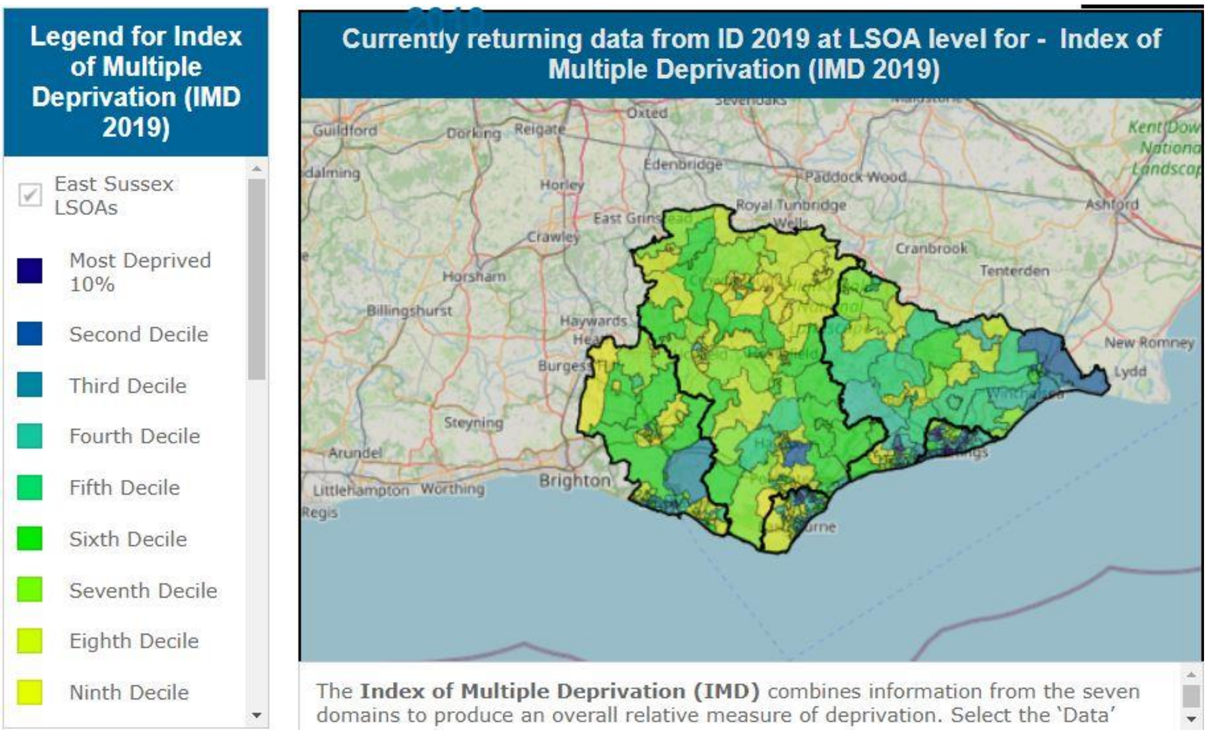
Thank you and check details for voucher (£20 Amazon). *Only if they say “I would prefer not to receive a voucher from Amazon, then offer them a Love2Shop voucher instead).*

Maps showing areas of deprivation for Sussex.

Brighton and Hove



East Sussex



Legend for Index of Multiple Deprivation (IMD 2019)

Currently returning data from ID 2019 at LSOA level for - Index of Multiple Deprivation (IMD 2019)

The **Index of Multiple Deprivation (IMD)** combines information from the seven domains to produce an overall relative measure of deprivation. Select the 'Data'

West Sussex

National Index of Multiple Deprivation (IMD) Deciles (2019) in West Sussex

Notes. Deciles: 1 = most deprived (blue), 10 = least deprived (yellow)