



## Kindred Advocacy

### Covid-19 and Families of Children with Complex Medical Needs



October 2020

*I heard that we are in the same boat.  
But it's not that.  
We are in the same storm, but not in the same  
boat.*

Damian Barr, 2020

## **Acknowledgments**

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## Executive summary and recommendations

Even in this small survey respondents spoke of a wide range of experiences directly related to the pandemic in addition to caring for a child with very high level medical needs. Some had struggled with their own medical treatment while others have lost relatives to Covid-19 and to other conditions. They had experienced difficulties with basic needs such as shopping and getting medications. Almost all reported exhaustion and fear of a 'second wave'.

The recommendations included below are intended to be realistic and achievable, and aim to make a difference to families while recognising a limit to statutory resources.

### The impact of the pandemic

The pandemic has had a devastating impact on the lives of parents of children with exceptional healthcare needs. In our survey and interviews, parents spoke powerfully of being plunged into situations which stretched them beyond their capacity to cope, physically and mentally.

**Recommendation:** the impact of the pandemic on families of children with complex needs and serious medical conditions needs to be publicly acknowledged. This could be achieved with a statement from Scottish Government and a letter to families.

### Communication and information on shielding

Families appreciated information from Scottish Government, although some reported that they found it difficult to interpret because of the complexity and volume of information. Shielding letters caused quite a lot of unintended stress, with some respondents anxious about not getting a letter, while others did not want the constraints of receiving a letter. Parents found it very helpful to discuss their circumstances and decision-making with health, education and social care professionals. Conversely, they were upset when professionals did not get in touch and this had a negative impact on their experience. Parents needed more help and morale support to cope with physiotherapy and other treatments. Professionals may have been unaware of the valuable role they could play in providing ongoing support and guidance.

**Recommendation:** Scottish Government should consider whether the decision to shield should be given to parents and key professionals, rather than issue further shielding letters in the event of a second lockdown. Professionals should be encouraged to keep in touch with parents to give them the chance to discuss their personal circumstances. Charities should be funded to provide peer support for parents through social media and telephone conversations.

### Loss of respite care

The survey revealed that over a third of parents received no respite care before the pandemic. This dropped to sixty per cent after the start of the pandemic. This highlights the importance of schools in supporting parents and giving them a break from caring. A number of parents were completely unaware of their entitlement to an assessment of their child's needs by social work (Section 23 assessment) or of their own needs (a Carer's Assessment). Parents are coping with levels of sleep deprivation that will clearly put them at risk of having accidents and also put their children at risk. Many parents described getting five hours of broken sleep each night. There is a need for more research into the impact of sleep deprivation on carers of children with complex needs. Parents should be informed of their entitlement to assessment for respite support. A recent focus on the rights of children may detract attention from the rights of parents to get a good night sleep. Yet the sleep deprivation of parents may be the single most negative impact on care of children with the highest level of medical needs in Scotland.

**Recommendation:** The needs of families for respite should be taken into consideration with regard to special schools. Scottish Government should consider whether to keep special schools open in the event of a second lockdown and to provide additional resource to enable this to happen. In the longer term, Scottish Government should enquire into the impact of sleep deprivation on carers of children with exceptional healthcare needs and consider whether the current state of provision constitutes a breach of human rights.

### Shopping and medications

Respondents reported difficulties with shopping and medication. This caused additional stress. They also experienced difficulties in accessing PPE.

**Recommendation:** supermarkets and pharmacies may be unaware of the stress caused to families of children with exceptional healthcare needs. These retailers could be contacted to ask what measures they will put in place in the event of another lockdown. This information could then be fed back to parents and would help to reduce anxiety about the impact of lockdown.

### Siblings

Respondents were fearful of the impact on siblings and some spoke of the trauma which brothers and sisters had experienced. Worry about other children and home schooling was high on the list of concerns expressed by parents. At the same time they were proud of their non-disabled children and many siblings appear to be playing an active role as 'young carers'.

**Recommendations:** siblings should be prioritised for support from school Hubs in the event of a second lockdown. Charities should be supported to provide activities and support for young carers. Self-Directed Support should be available for adult siblings to be paid as carers within the home in the event of another lockdown. This was agreed in some local authority areas, but needs to be agreed across the country.

## 1. Introduction

The Covid-19 pandemic has had a dramatic impact on all of our lives, but families of children with exceptional healthcare needs are certainly amongst those most affected. Many of these families were struggling to cope prior to the pandemic. Lock down led to a dramatic loss of care and support. The families who took part are particularly reliant on the support which they receive from schools which provide therapeutic support and care as well as education during the day. They also lost support from respite care, carers coming to the home, and from relatives such as grandparents.

Since 2017, Kindred has been funded to run the Exceptional Families Project (EFP), specifically aimed at giving 'a voice' to the families of children with exceptional healthcare needs. A group of parents formed the steering group for EFP which meets regularly and a wider group of parents who couldn't attend meetings feed in their comments and thoughts to the Project Lead, a specialist facilitator. The Project Lead meets with parents in focus groups and in their homes to capture their experiences, interests and concerns. This feedback is shared with practitioners through a series of events, seminars and training sessions across the country.

Part of the project's remit is to foster a stronger connection between parent carers and the NHS managed clinical network for children with exceptional healthcare needs ([www.cen.scot.nhs.uk](http://www.cen.scot.nhs.uk)) established in 2009. The network's role is to improve co-ordination, understanding and practice amongst practitioners working with these families and be an on-line resource for both professionals and parents. The project works with the definition of exceptional healthcare needs as described in the CEN network's assessment criteria –

### **The CEN criteria: Children with Exceptional Healthcare Needs**

The criteria relate to six impairment categories:

1. learning and mental functions
2. communication
3. motor skills
4. self-care
5. hearing
6. vision

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they:

have severe impairment recorded in at least 4 categories together with enteral/parenteral feeding

OR

have severe impairment recorded in at least 2 categories and require ventilation/CPAP

AND

the impairments are sustained and ongoing or expected to last for more than 6 months.

Our research on the Covid-19 Pandemic is based on an online survey and telephone interviews. Many of the 42 families who participated are known to Kindred through our advocacy work and this prior relationship helped us to gain additional insight. We have also drawn on our wider experience of providing advocacy to parents of children with complex needs through the pandemic.

The following report provides an insight into the experiences of families across Scotland. Parents told us about the additional challenges of the pandemic, but also spoke about factors which helped them to cope. In conclusion we identify those practices that are supportive and essential to the well-being of these families as we adapt to this crisis and eventually come through the pandemic.

## 2. Methodology

In early August 2020 we invited parents and carers of children with exceptional healthcare needs to complete a survey about their experiences of 'shielding'. 42 parents responded to the survey, of whom sixteen agreed to take part in a telephone interview lasting around half an hour. The survey and interviews were conducted during August 2020. The purpose of the survey was to interview parents of children who met the CEN criteria and were either ventilated and/or tube-fed.

Kindred has also provided advocacy support to 110 families of children who meet the CEN criteria since 1<sup>st</sup> April 2020. The research has drawn on our experience as an organisation supporting families through the pandemic.

Research findings are based on:

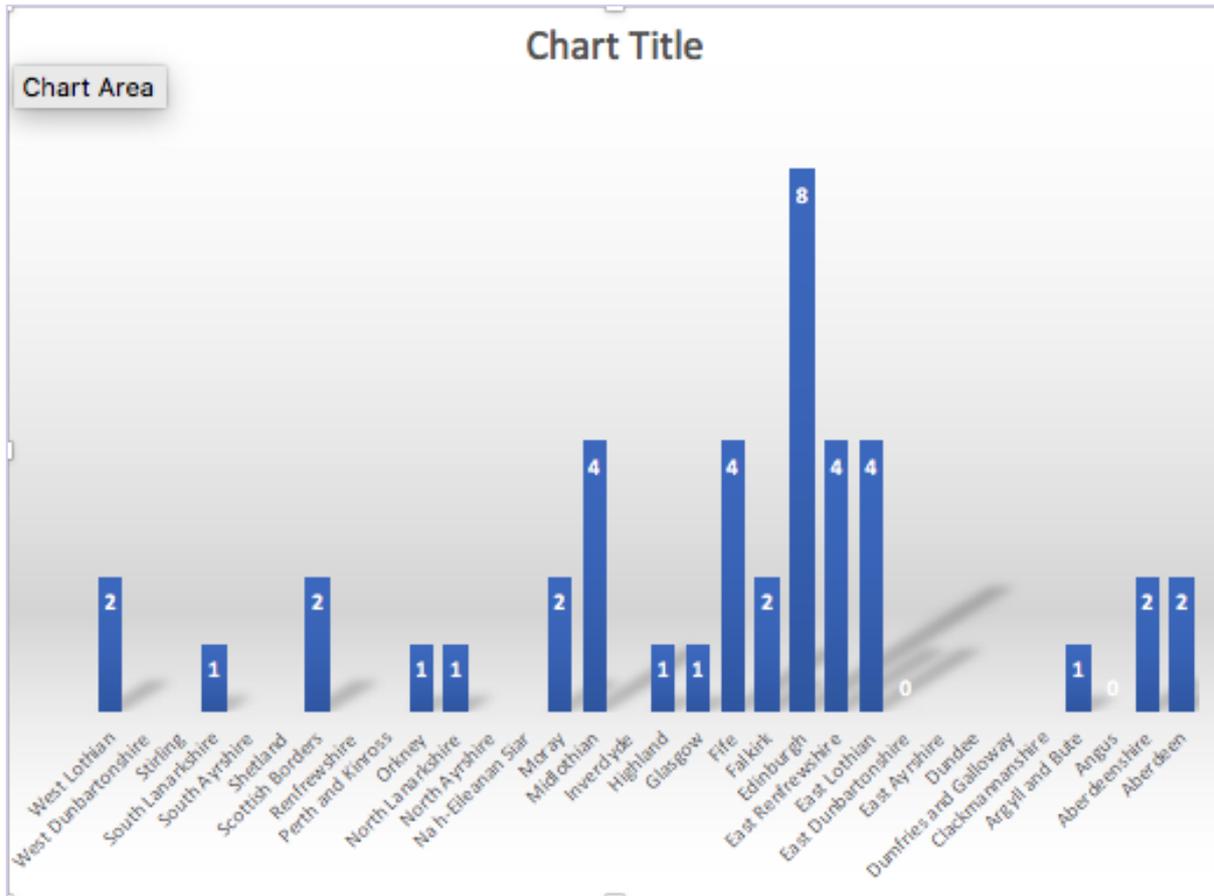
- 110 families provided with advocacy support by Kindred since 1 April 2020. Information from this work is used to design the survey and telephone interview.
- 42 parents complete the online survey.
- 16 parents who took part in the online survey are followed up with a semi-structured telephone interview lasting around 30 minutes.

For a small sample size, the group is quite representative geographically and in terms of other demographics. Parents from 17 local authority areas participated in the survey, with children of ages ranging from under 1 to 19 years old.

- The 42 respondent came from 17 different local authority areas.
- The local authority area with the highest number of participants was Edinburgh, with 8 parents taking part. This is predictable due to the location of Kindred's core services.
- 8 out of 42 respondents were single parents (around a fifth)
- 3 families had more than one child with exceptional healthcare needs
- 5 children/young people are ventilated (all CPAP/BiPAP overnight, none requiring 24 hour ventilation)

- 28 are tube-fed (two thirds)
- 1 has a tracheotomy
- 26 have seizures/a diagnosis of epilepsy (half the children/young people)
- 34 were shielding at the time of the survey (almost three quarters)
- The children/young people's ages were: 12 in the age range 0-5 years, 16 aged 6-10 years, 12 aged 11-15 years, 5 aged 16-19 years.

**Figure 1: distribution of respondents by local authority**



There were some additional factors which should be noted. Twelve of the respondents did not meet the NHS criteria for exceptional healthcare needs. However, their responses indicated that these are parents of children who have significant care packages. For example, parents mentioned overnight care packages and respite care with CHAS, and eight were shielding. As these families appear to have equivalent needs to those who meet the CEN criteria their responses have been kept in the data.

A further twelve parents responded to the first part of the survey completing 11 questions, but stopped abruptly when asked the question 'Have you been shielding your child with exceptional healthcare needs?'. Unfortunately it seems that the question caused unintended anxiety and the parents withdrew from the survey because they felt that their responses to the question about shielding might be judged negatively. Eight respondents said that they were not shielding their child and did not seem to experience any qualms about completing the rest of the survey.

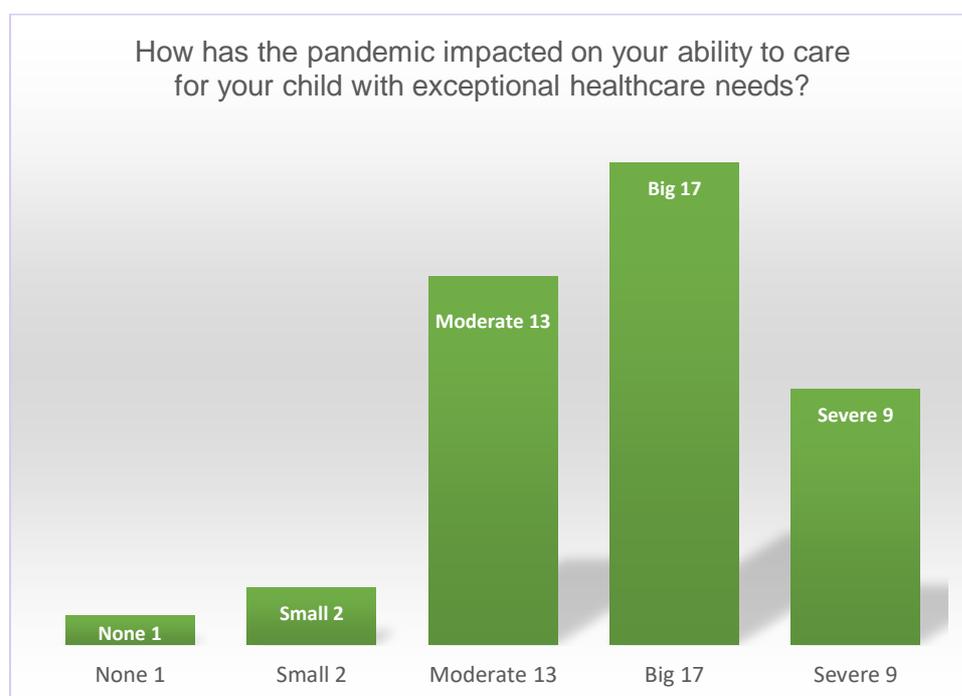
The fact that 11 parents withdrew when asked about shielding suggests that we have to be careful about the messages conveyed to parents. Parents who are shielding may be getting more media attention and this may mean that parents who have chosen not to shield feel unable to speak about their experiences.

Quotations from the survey and interviews have been used throughout this report but all names have been changed.

### 3. The impact of the pandemic

Parents who spoke to us in telephone interviews tended to put a 'brave face' on their situation, often describing themselves as 'lucky'. However, as the interviews progressed a different story emerges. At some point in the interviews, almost all indicate that they have been stretched to their limit and their comments reveal the devastating impact of the pandemic on their lives. Parents who responded to the online survey tended to be more blunt. This suggests the need to be cautious about initial responses.

**Figure 2: The impact of the pandemic**



Names and details quoted have been changed to ensure anonymity throughout this report.

*It's all the little things. The constant care is exhausting. The children are quite young.*

*It has been utter hell. The worst experience of my life to deal with my daughter alone at the most stressful of times. I tried to care for myself at the start but there just wasn't time and I ran out of energy. I am now exhausted mentally and physically. I have put on a lot of weight and lost fitness. My anxiety and depression has felt far more prominent than it has in a long time and I feel like I have completely lost myself.*

*It's the whole uncertainty. Our daughter has had four respiratory arrests in the past and ended up in A&E. We were dreading this during Covid. We have been more watchful than usual.*

*My life didn't change. I'm already isolated. Naebody comes. During this pandemic I have learned to do my own things. Because naebody actually cares. You are gonna do extra and I am gonna do less. When Maya is at respite I want her nails cut and her showered. When I went and visited and I didn't have to check the monitors, change her pads, weigh her pads. I could just play with her. I watched them 2:1 with Maya and that's when I realised how knackered I am. I'm meant to do that myself and they got two people doing that.*

*I feel like having to deal with my child has had a huge negative impact on my mental health as I had to become full time carer again and it means less focus on being a mum.*

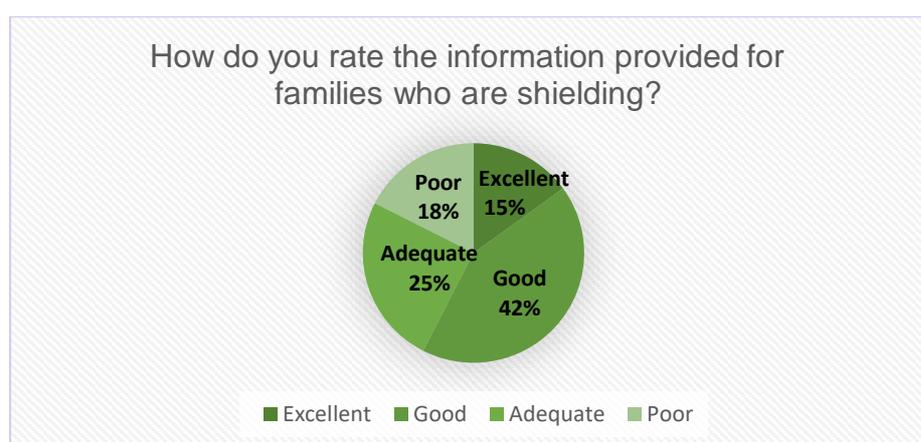
#### 4. Communication & Information on shielding

##### 4.1 General information provided by Scottish Government

There was a lot of anxiety over information in the weeks before lockdown, with many families saying that they took their children out of school before the schools closed.

During lockdown, many parents felt the information from Scottish Government was excellent or good although some said they needed help to interpret the information, or had to spend time themselves interpreting the messages. Over half of the survey respondents (57%) said that they thought the information provided by Scottish Government was 'Good' or 'Excellent', with a further 25% saying that it was adequate

**Figure 3: information**



Comments included the following:

*I thought the shielding information was clear and I appreciated the regular updates. Tables of information were clear, well laid out and easy to read.*

*The anxiety of the whole thing had a big impact. It was the amount of decision making with limited information and trying and get it right. For example, who to let in house. I think we were pretty much abandoned to make those decisions. No one would take responsibility for the decisions we make. We pulled them out of school on 16<sup>th</sup> March, a week before schools closed. I talked about it to the teachers.*

*Excellent information. We got a letter from NHS explaining shielding to us. It was very straightforward. We were given guidelines and stuck to them. Every letter gave us all the information we needed. We got a letter two weeks after lockdown. I feel completely supported by the NHS and Government. Within the first week we had a phone call from our consultant. We said we had not received a shielding letter and they said we will take care of that for you. We had phone calls from our physio, OT, and school, all saying the same thing. We are part of big group and I've always had that kind of back up in Aberdeenshire.*

*The briefings helped and watching them myself. People could read them in different ways. I was listening from the shielding perspective. We shut down a week before everyone else did. We did get text messages from Scottish Government.*

#### 4.2 Shielding letters

There was a range of experiences regarding 'shielding letters', from those who were very appreciative of the information in the letters, to those who did not receive a letter and felt all the more excluded and isolated in having to make decisions without individual guidance about their child's condition.

If a family received a shielding letter, this was appreciated and validating of the high level needs of the child. A shielding letter also provided access to priority slots for shopping.

Parents were keen to mention that they had 'got their letter'. However many families had started shielding before they received a letter. Conversely, many parents said that they did not get a letter, often because the child's condition was so rare that they did not fall under a category for shielding. Some children had multiple conditions, resulting in a high level of vulnerability, but none of their diagnoses on its own met the criteria for shielding. Some parents took a robust attitude and this was even a bit of a 'badge of honour' – that their child was too unique to receive a letter. However, for many who did not receive a letter there was an added anxiety of feeling that that they had not been given a clear steer on the issue of shielding, whatever their own views. The issue of whether or not a letter had been received resulted in a lot of discussion in online support groups.

*We got a letter from our neurologist, and decided he should stay on shielding list. But if you are asking about day to day decisions, we make them ourselves.*

*The information provided has been poor. We didn't get a letter. I had to phone the paediatrician. I felt very guilty phoning a respiratory consultant. No one was sure if she would be on the shielding list. I've had to say to the school that I want her to be treated as very vulnerable. We did receive lots of information from X charity. My fear is not that she will get Covid. It is that she will not be intubated.*

The charity named by the parents supports families of children with a rare condition across the UK.

#### 4.3 Communication with professionals

Parents found it helpful to have a telephone conversation with a 'lead professional' early on during the pandemic, particularly if this clinician was familiar with their particular circumstances. Parents also appreciated regular contact from other professionals.

Conversely, they felt extremely isolated if they did not receive support and this also led to them feeling anxious and even guilty. It is clear that parents wanted help to talk over their situation so that they could think through decision-making. Contact from key professionals early on in the pandemic seems to have been key to parents over all experience of decision-making regarding shielding.

*Information was poor. Initially it was very difficult as there was little guidance on shielding for household members of children who are shielding. We had mixed messages from different professionals on what was appropriate and what was not. It felt very isolating and I felt very guilty initially for going for walks with all the precautions but I was glad when we were given advice tailored to Joseph from his community team and doctors who know him after approximately 5-6 weeks.*

*She's a big girl and we don't have family around me. It is literally just us. We didn't really get any check in to see if we were ok. We could have had support over the phone. Check in call from one of the team, like speech and language therapy. We were just left. She has no behavioural problems so they don't think they need to call.*

#### 4.4 The role of social media and support groups organised by charities

Parents said their social media networks which had provided them with opportunities to discuss their individual situations. Some of these networks were facilitated by charities. For other families, social media networks were primarily parents connection up with each other to provide support and advice.

*Having our local charity, Charlie House, providing support, interaction and information really helped us feel less isolated. More money needs to go to these types of services.*

*We could not have the CHAS at home visit and we could not stay at either of the CHAS houses however the staff were very supportive and we spoke regularly.*

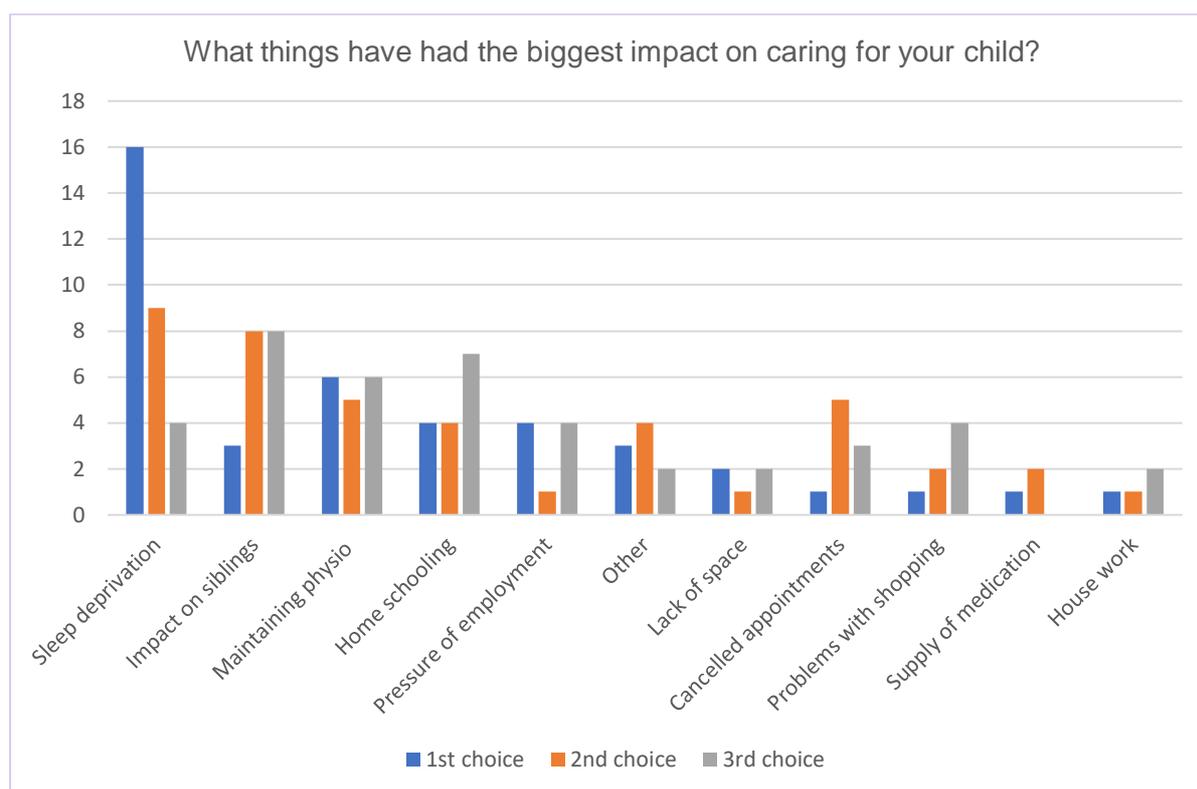
*The Early Years Team, our Community Nurse Emma and CHAS at Home made regular 'check-in' calls and I know I can turn to them especially once my husband is back at work and I am in the house on my own with no garden, continuing with 'shielding'. Victoria at Kindred is 'an angel'. She took on things, and acted as a liaison with services.*

*I probably talked about it on the SWAN network. And communicated via FB messenger with school.*

## 5. Impact on services

Parents of CEN children experienced a dramatic loss of care especially in the first months of the pandemic. Many families have regular overnight care either through their local health board or from Children’s Hospices Across Scotland. They also receive significant care and support through school and after-school clubs.

**Figure 4: respondents were asked to rank the top three factors affecting their ability to care during the first months of the pandemic (from March to August)**



When asked about the factors which had the biggest impact on caring for their child, the most significant factor was sleep deprivation. For sixteen parents, this was the first factor that they named when asked to choose three from a list of ten factors. The impact on siblings and the pressure of home schooling were also high on the list. Parents were clearly concerned about their other children and felt under pressure to try to meet their needs, as well as caring for the child with exceptional healthcare needs.

‘Other’ factors listed by parents, in addition to the ten factors which were included in the question, were: mental health of the child and siblings; being unable to attend community groups; boredom and depression; worry; challenging behaviour; interaction with a partner; and ‘space to have time on my own’.

Parents spoke powerfully about the loss of services.

*There's no break from it at all. No carers, no respite, no school. It's relentless. My child usually has 2:1 care at school and now I am supposed to care, teach, and do his therapies all while working from home and giving my other two children some attention. It's impossible really.*

*We felt unsupported by social work. I was actually told that we did not need help (despite my daughter needing 2:1 support at all times). I was told that I could cope, unlike other families. We received little support or input from school. School took the view that as all the pupils are vulnerable they would not be able to offer support to any. Thus mainstream kids were getting school but the kids in special school weren't. This felt extraordinarily unfair. A local charity made up themed activity boxes for the children. These were tailored to our children (their needs but also their interests and abilities). This was a wonderful scheme. They deserve acknowledgement for this and the idea should be shared more widely.*

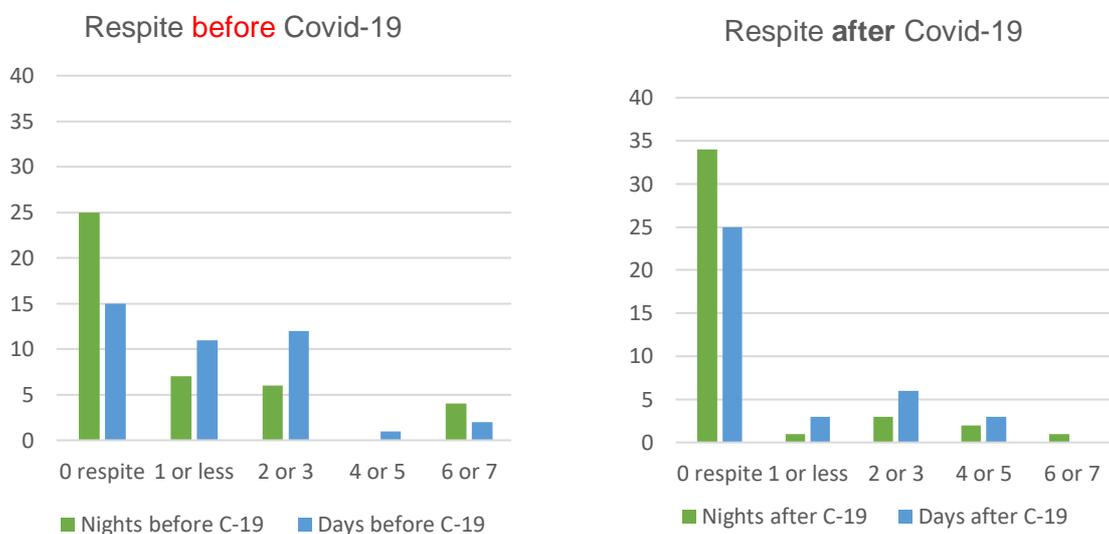
*My role was always unappreciated and difficult, losing my entire support system overnight (online grocery deliveries/ability to go to surgery/pharmacy/shop/ to get what we need and of course access to all usual medical/dental services) was and is totally devastating. We will never recover from this, have lost our home and entire way of life and can never go back - I see a very isolated and lonely future ahead with no chance of proper support or understanding.*

*It actually highlighted the pressures I work through whilst caring and how I'll cope no matter what as this is embedded in a caring role. This was our life before the pandemic whereby feeling isolated and alone where no-one can fully understand or appreciate our lives unless they have first-hand experience themselves or know of others in similar situations. I also felt that while we were initially cut off from all our appointments as a consequence of the pandemic we were still able to seek the support we required when needed and which also made me fully aware of and appreciative of how much we rely on and need our NHS in our little world yet how far themselves and their resources are stretched.*

### 5.1 Loss of respite care

Comments from parents reflect a range of experiences from those who had no respite care, to those who lost all their support, and some who had endeavoured to hold on to care. However, perhaps the most noticeable finding is that many of the families were receiving no respite support at all before the pandemic.

**Figures 5a and 5b: Respite provision**



All five parents who had more than one night of respite care *after* the start of the pandemic had a child who was both tube-fed and had seizures/a diagnosis of epilepsy. Therefore seizures or a diagnosis of epilepsy may be a significant consideration in allocation of respite.

It was difficult to interpret the answers provided in the online survey because parents sometimes see respite in terms of weekends per year, or they may measure their respite in terms of nights per week. There was also some confusion over whether hours of support from a carer counted as respite and whether hours at school or nursery for respite. It was quite easy to resolve these issues over the telephone. Some parents had taken part in both the survey and the phone interviews which sometimes helped with analysing the findings.

*We still had respite care on a reduced level , also we got three dates at the hospice as we were classed as family in crisis*

*We stopped using our respite service while we were shielding, after 4 months we introduced it slowly and now we are back to our normal respite.*

*We lost all help including family help due to our child being in the shielding category.*

*Respite was cancelled and there was no alternative other than hospital and to try and have the shielding removed as that was the only way to achieve respite facilities again! Not an acceptable position.*

## 5.2 Assessment of need

Many parents appeared to be surprised when asked about respite care and had not been informed of assessment processes for support from Social Work. There is a statutory requirement for local authorities to assess a child with a disability (the 'Section 23' assessment) and carers also have a right to assessment of their needs. It appears that families of children with very significant medical needs are not informed of this right to assessment. Parents also commented on the confusion around whether their children would get a place in a school 'Hub' in the early months of the pandemic and the lack of clear guidance on who might be eligible for these places.

*In general entitlement to respite is almost hidden from you. I am so surprised it took us four years. No one said 'do you know what Section 23 is'.*

*I am unsure if we are actually entitled to respite care. I assumed it was only if your child had a life limiting condition. We have an undiagnosed genetic condition, which is still under investigation. However, my child is non-verbal, can only walk short distances in and around the home and garden with help, oral and tube-fed (again reliant on adult support), and in nappies. I never feel like I have a chance to be a parent as my caring roles take over. If anything, lockdown has shown us that our lives are not that much different and very similar to lockdown restrictions in that we are restricted to our home to provide effectively care and support.*

*We don't get any! It's not offered to us and it's frustrating that this is clearly available. It feels like the councils don't make this information known*

*Information is NOT clear as to who could access school place - seemed to be only Social Work referrals for family circumstances. Schools had no say in terms of who is 'vulnerable' and might benefit from continued school-based support.*

### 5.3 The impact on sleep

Sixteen parents ranked sleep deprivation as top of their list of factors which had an impact after their pandemic. A further nine ranked sleep as their second choice and four as their third choice. In all two-thirds of parents listed sleep deprivation in their top three choices.

The comments from parents about sleep describe how and why their sleep is impacted. Some children wake frequently with pain or vomiting. Many of the parents sleep with a SATS monitor to measure oxygen levels close to their bedsides, and describe the sleep disruption caused by beeping and lights. Often the anxiety that their child might need urgent help means that the parent cannot sleep deeply (such as the parent who describes having to be at her son's side in a 'split-second'). If children are tube-fed the parents have to wait until the feeding is finished to ensure that the pipes are not twisted around the child. Parents describe feeling depressed, exhausted and unable to function as parents or in other aspects of their lives. They describe the disruption to family life and to the lives of siblings.

Half of parents who said the pandemic had a 'severe' or 'big' impact on their lives named sleep deprivation as the most significant factor, compared with 18 per cent of parents who said that the pandemic had a 'moderate' or 'small' impact. This suggests that sleep deprivation is a key factor in coping levels.

*The peg feeding is slow. We have to wait till the feed is finished (midnight or 1pm) because the pipe can get twisted around him. I can make it slower but then he is full in the morning and we are trying to maintain his oral feeding. I can also use the monitor but then I have a screen glaring next to me and it impacts on my sleep.*

*[We are] badly sleep deprived. We sleep by 12.30pm but the SATS monitor can be beeping. We are often up in the night. Our only respite was Rachel House. We were there in June for 2 weeks. They give us space.*

*Always difficult to be honest. He uses a ventilator overnight and is often sick. So I have to be with him in a split second. I can hear him if slightly gasps. If he pulls the mask off an alarm goes off. But usually there is a warning noise. We go through stages where it is every night. Tends to be early hours in the morning. For weeks and weeks it can be every night. And then we can be through a phase of him not being sick. It's very unpredictable and manifests in lots of ways. It's stressful, physically tiring, and it saps you mentally. My brain just doesn't function. I am not running at full capacity. Feel mentally slow, on all levels.*

*I never get an unbroken night. Frequently up to him three or four times in the night. Even in my own bed I have a video screen six inches from my head.*

*I never get a full night. I am always waking up at 4pm. I feel I will miss something. It causes anxiety. We forget things and make mistakes. We forget emails or phone calls. You feel drunk sometimes.*

*I have to get up and check that she is not stuck. Have to go in and manoeuvre her. I haven't considered overnight respite. Previously it was horrendous. I'm not really able to catch up on lost sleep. I'm a much better mum when I've had sleep.*

*Our child is sedated at night because of seizure activity so actually we sleep. More to the point is the exhaustion of caring for her in the day. I needed increased anti-depressants as I was close to collapse until we were able to use family support. Trying to work too!*

*I never get enough sleep. Pump goes on at 1030 and comes off at 6.30 am and quite often alarms at night. Alice is also sick once or twice a night.*

*I never feel I have enough sleep, every night is disrupted.*

*We had nursing staff for ten years. It is disturbing for her brother who is 11 years old. He has grown up with nurses in the house. It has a huge impact on the family. Her machine is quite noisy. Her brother has been woken in the night by the ambulances.*

*He can't self-settle. One of us gets in bed and cuddles him. He wakes from 11pm onwards and screams out and wakes other children. Our one year old is awake from 3am – 6am. One of us is with each child.*

#### 5.4 Therapy services

Parents struggled with the added burden of having to provide therapies during the pandemic, especially physiotherapy. They felt that professionals sometimes did not believe them when they raised concerns. Almost a third of those who said that the pandemic had a 'severe' or 'big' effect said that they struggled to maintain physiotherapy exercises and other therapies. Eight of this group of families also mentioned cancelled appointments as a problem.

*She was having a lot of pain. GI and Neurology were saying different things. They asked have you contacted your GP. I said there is nothing wrong me, it's a pandemic. That was the worst time ever. Then everyone was dead patronising. She ended up going for a two week assessment. They came back and said it was a pain episode. Six weeks of hell with them telling me I was in denial. They couldn't take my word for it. I had problems with community nursing team. I pretty much fell out with all of them. You could cry. You are absolutely exhausted and suicidal. They say they can't help. Then suddenly when they decide they want to do it they can suddenly whip out two weeks of respite. No one phoned me with an apology.*

#### 5.5 Shopping and medication

Difficulties with shopping and medication did not score highly as challenges (see Figure 1.). However, in the interviews and comments many of the respondents spoke about problems with getting supplies of shopping and medication. They had difficulty getting supermarket slots for deliveries and had to turn to friends and neighbours for help. If they did receive

food parcels, the food was not suited to their needs. Systems for getting medications and Personal Protective Equipment (PPE) were cumbersome. For many respondents, the lack of supportive arrangements for shopping and medications clearly caused lasting stress and a feeling of being disregarded.

*Problem with supply of medication (the local pharmacy is very small). Our health visitor dropped off medication. Shopping was another problem. Social work expect you to give cash.*

*Shopping was nightmare. I couldn't get super market slot. I had to send a shopping list to friend who had to shop for us for 6 weeks.*

*It was a ridiculous rigmarole over getting more medications. They could not have been more unhelpful. It was 'decreed' that gloves should only be available for overnight care. I had to drive to Astlie Ainsley. We are on our own.*

*We were in hospital when lockdown happened, we were discharged with no support but the knowledge we had to shield, so no food at home. A neighbour who works at M&S brought us bread and milk. It was week four before we got a delivery slot. It really was a nightmare.*

*We got phone calls from the Council asking if we were receiving food parcels. It was filling my cupboards with stuff I wasn't using. Eventually I managed shopping online. I did get a priority slot but for a place we don't shop from (Iceland).*

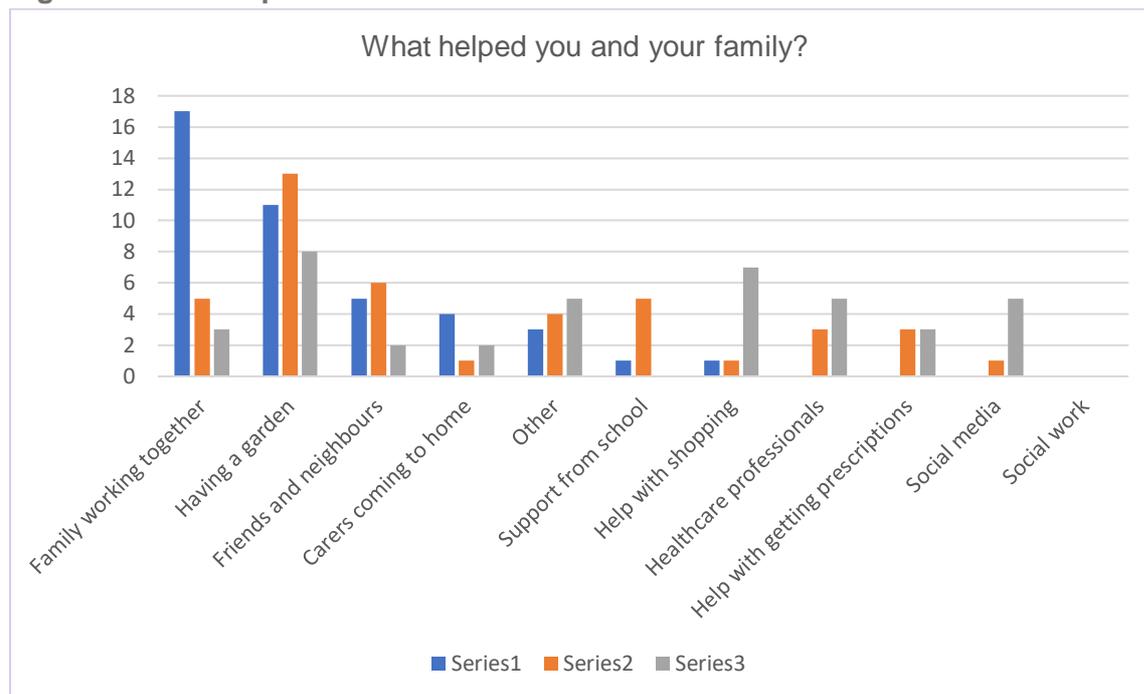
## **6. Family resilience: what helped and what made life more difficult?**

In our online survey parents were asked to rank the top three factors which helped them cope during the pandemic from a list of ten. The results are shown in the chart below.

More than half the respondents (N=25) chose 'working together as a family' as one of their top three responses, with around 40% choosing 'working together as a family' as their top factor. However, the most frequently named factor was 'having a garden' which was chosen by 32 parents (more than 75%). The third most popular choice was support from 'friends and neighbours'. This raises the question of how parents coped if they did not have a garden (or did not rate having a garden in their top three chosen factors). These parents were more likely to identify 'working together as a family' as a key factor. This is a picture in which parents felt very much on their own within their family group and they used terms like 'batten down the hatches' and 'hunker down'.

None of the families mentioned getting support from Social Work. This is a surprising finding since these families have significant care packages and would be in regular contact with a social worker. This finding may need more exploration but is likely to relate to recent pressures on social work budgets with families feeling that they will not get additional help. Child Planning Meetings have been taking place using Microsoft Teams, but this was not mentioned by parents in the survey.

**Figure 6: what helped?**



### 6.1 Family support

Parents who had a partner were appreciative of the mutual support within the family. Amongst this group more than 70% named 'working together as a family' as a factor helping them to cope. However, some parents talked about tensions in the household. A number of parents talked about their own long term health conditions which affected their ability to care for their child and the help that they needed from their partner.

Single parents were surprisingly resilient, however seven out of eight single parents named sleep deprivation and tiredness as a factor making it difficult to cope.

Although the survey data shows the importance of family life, the interviews revealed that respondents had faced tragic situations and impossible choices in the early months of lockdown. Several of the respondents had been bereaved during the pandemic and being unable to visit their own parents. It was particularly difficult for parents who have had to weigh up shielding their child against other factors.

*We are very lucky. There are two of us and the other children are getting older. I know there are many parents out there that who don't have this support. If you had a big package and it disappeared that would be much more difficult. We were generally just forgotten. I didn't hear any mention of how we would be supported. I honestly don't know how parents would cope. We didn't request food packages.*

*My mother died of Covid. It was so awful having to decide whether to visit her or not and I couldn't. I am still struggling with this.*

*We had been housebound in the afternoons from the start of the year due to the needs of our child, therefore we missed our two hours in the morning for Fergus's class/ hydrotherapy/ meeting friends. It has been mentally and physically exhausting especially having to deal with the emotional impact of losing a parent during the pandemic.*

*I've been undergoing cancer treatment. I had aggressive treatment last year. I was in hospital and then stayed with my parents for two months. We have all been shielding. My wife is a key worker so my son went to the Hub. My transplant nurse said you have to weigh up the risks. Nursery were running a good system and he was in own room.*

*Only positive from all of this is that family and friends now understand a bit better the reality of our daily life.*

## 6.2 Community Support

Friends and neighbours were high up the list in terms of providing helpful support, and in the interviews many parents also talked about their communities.

*Without the village and community it would have been very difficult. Thankfully had friends who picked up medication and shopping. Because [my child] is so special we didn't get shielding letter for a while. If we didn't have friends we would not have had food or medication for a while. I feel because she was a child we were not first.*

*We are very grateful for all the help and support we have received for not only Cara but also for us a family. The care packages we received, phone calls and deliveries we are so helpful.*

*The community has been amazing. The shop keeper put our shopping over the fence.*

## 6.3 Siblings

The parents who responded to the survey were concerned about other children in the household. When asked about the impact of the pandemic (Figure 4), their concern about the impact on siblings was at the top of the list, coming second only to the impact on sleep. Fourth on the list of concerns was home-schooling. Impact on siblings was mentioned by almost half the respondents and home schooling was a concern for over a third of respondents. In the interviews and written comments, parents talked of their fears about the mental health of siblings. One parent mentioned the support that a sibling had received from a charity and that this had been a big help to the family.

For some siblings, the impact of having a brother or sister with major healthcare issues can have long term consequences. One mother spoke of her non-disabled child being woken frequently in the night by noisy equipment, and the trauma of witnessing paramedics treating their sibling. She felt that this had affected the non-disabled child's sleep patterns and their ability to settle at school.

Several parents had more than one child with a disability. It was particularly difficult for those parents who had a child with a different diagnosis, such as autism, ADHD, a painful joint condition, or brittle asthma. In these cases, parents were stretched to provide support to children who had very different needs. These parents felt that their multiple roles were not understood by statutory professionals and the challenges of caring for two or more very different children were not reflected in the allocation of services and support. Three parents had two children with exceptional healthcare needs and had to juggle the support provided to each child.

Parents also spoke of their 'pride and joy' in non-disabled siblings, especially when talking about the relationships with the disabled child. The affection between siblings is a source of great strength for parents. Even very young children had an awareness of the needs of the child with exceptional healthcare needs and also seemed aware of the parent's need for support. One parent describes her non-disabled six year old providing her with comfort by 'sitting next to her'. There is no mention of siblings feeling resentful of the attention received by the disabled child.

In two households older siblings had been employed through Self Directed Support to work as carers. In both cases, the families had been proactive to make these arrangements and it is likely that other families were not as able to advocate for themselves in this way. These two families spoke of their older children moving on to college or university. This was a cause of pride but there was also a sense of sadness which came from losing that young person from the household, the contrasting prospects of the child with a disability, and a sense of a lost childhood for the sibling who had been a young carer. On the positive side, relationships between older siblings and parents have strong and positive quality. The experience of being a young carer clearly provides life-skills and self-confidence.

*The biggest affect has been mentally on everyone. Sabena starting self-harming. She has never had any health problems. I would never have believed until I saw the evidence on her arms.*

*We have to balance physical health with Emily's mental health. We keep Sam at home and let Emily go to school and shield them from each other. She is only one who can put a smile on his face every time. Sam doesn't have any understanding. Emily has grown up with Sam never giving feedback. It is harder for us as parents not getting feedback. Emily has never known any different. We have (Charity) Family support worker who works really closely with Emily. One on one activities, and gathering for siblings on Zoom.*

*Her brother is very anxious about starting S1. The school know about his younger sister but they are not providing him with support. I am worried he will refuse to go to school.*

*Cara has feeds in the day but sometimes replacement fluids. I'm up until midnight and then Joe is up at 2pm. Nearly every night. On a good night I get 5 hours sleep. Joe attended the resource and Saturday club and has direct payments (10 hours a week). I was offered a Hub space but it caused him more anxiety and it was not worth sending him. Cara was on the shielding list. So I never took up the place. My husband works away. My 6 years old [has no additional needs]. She will sit with me.*

*Because we were shielding, we could not have carers. We were trying to cope and take over the carers shifts. Before the pandemic, I could go to work and Fin had two people with him. We were very lucky because my husband was furloughed and our middle son was supposed to be on year abroad and social work agreed that husband and son could be employed as carers. Our second son felt unable to meet friends because of shielding Fin. So he has moved out to stay with a friend.*

#### 6.4 Work and income

Nine respondents listed pressure of employment as a major stressor (around 25% of the participants). A number of respondents spoke of the relief of being furloughed, or their partner being furloughed.

None of the respondents mentioned concern about their income or worries about having basic necessities such as food or other household items. Some mentioned that employment pressures in the household increased as a result of the pandemic, resulting in greater pressures on time for caring. Others spoke about the flexibility of their employment and the support of employers. Work was an added pressure, but also a form of respite from the caring role.

In summary, the pressures of work were heightened during the pandemic but work was also seen as a positive, and provided a sense of identity outside the caring role. Parents were willing to make great efforts to hold onto their employment.

*If I have not been furloughed, our family would have not been able to cope.*

*Pleased and relieved [that my child is going back to school]. It is essential for me that my child is back in that environment as well as my being able to work again. I feel far more anxious about my older children as the young generally, being low risk, don't seem to really 'get' the wider risk.*

*I was not furloughed until end of April. Then I was on a flexible furlough. On 1<sup>st</sup> July I went back to one day a week for my own reasons.*

*If I had not been furloughed I would have had to resign.*

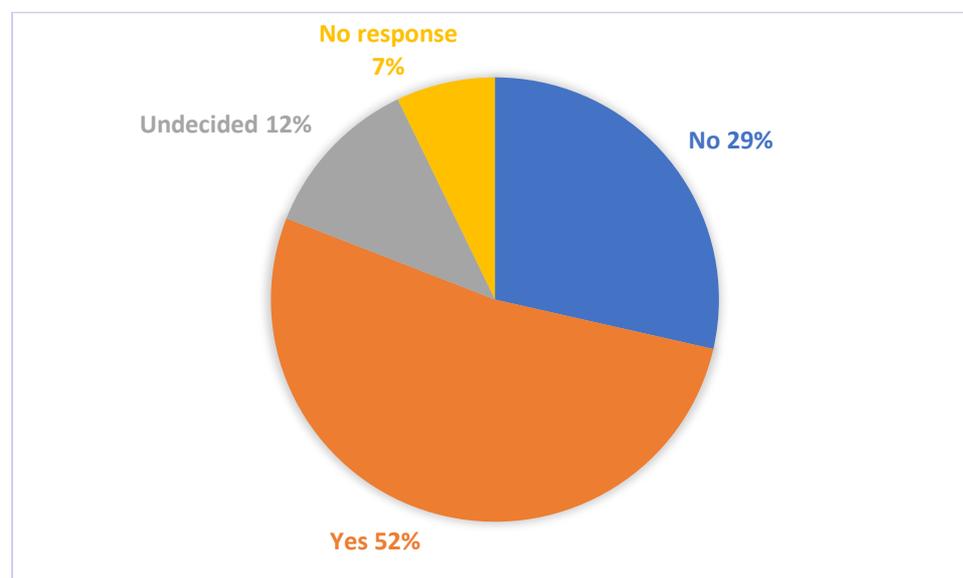
*Key for me was the Carer's Policy of my employer. They are leading the sector and were totally supportive. Without this support I would not have been able to carry on. Even then I was exhausted juggling what I did manage with caring responsibilities.*

*My husband was working longer hours at home than ever at office. Our six year old was needing home schooling and emotional support. We were lucky that we had the support of friends. It hit me hard in the beginning. Never getting a chance to 'mum him' - always making sure his meds are done, making sure he is being moved around. In normal times I get to spend some fun time with him.*

## 7. Looking ahead

### 7.1 Back to school

Figure 6: Will you send your child back to school?



Most of the parents who took part said their child would go back to school. However, of the five parents who said their child was ventilated, none said they would send their child back to school. Parents did a lot of research into their child's particular condition. They were also aware of the negative impact of keeping their child out of school. A number of parents focussed on the evidence that Covid-19 has less impact on children than adults, even for those with underlying conditions. The decision of whether to return to school involved weighing up complex factors. Where parents were able to speak to their child's paediatrician or hospital consultant, this was very helpful and influenced their confidence and decision-making.

Parents found it particularly helpful if they were able to have conversations with school to discuss arrangements for PPE and protective measures that would be put in place for their child. Some children were returning to school situations where they would be more isolated than before. For example, some would be taught alone. But parents still felt that the return to school would be positive for their child's over well-being. Where schools did not make contact, parents felt let down and less willing to send their child back to school.

*I've had lots of meetings with school. I'm happy with measures in place. It's not ideal and I understand why parents with suction and trachy are not happy. Lewis can't go on the floor which limits his time in the nursery. His team are working to help him with the change. He would always use calm room but now that's his main hub. That's for his safety, Covid's no one's fault.*

*I'm ok with it. I have read a lot of literature from around the world. It doesn't seem to affect children nearly as badly as adults.*

*On the one side we think she will love it. I have met the Deputy Head and Educational Psychologist. The negative side is whole process of viruses and bugs. Last time she was in ICU she ended up with other infections. We just don't know. She is supposed to have a full time place (30 hours) in nursery but it's been reduced to 2 days, Thursday and Friday.*

*I feel she needs the social interaction of school. What they are missing out is really important. It is a risk assessment and it is worth the risk.*

*Finished school July 2019. Nightmare with transition [to adult services].*

*She was at mainstream nursery, and then we got a place at local special needs school. She has a 1:1 Personal Support Assistant with medical training. The PSA has been a saviour. I trust her one hundred per cent.*

*My child won't return to school. It is very stressful for parents with children with long term needs, the risk has not gone therefore it is hard to see how we can integrate back to a normal life when this is still the case.*

*I've never got a single call from Isabel's school even about going back. Her brother's school was checking weekly. It's just nice to have someone there.*

*Hopefully with the return to school, normality resuming to a certain extent. But I don't foresee this being the last time we have to go into lockdown.*

*There are only five kids in his class. They have always had hand sanitiser. He will go back to school full time. But I don't think this is the end of it. If we can just get through a few weeks of normality then I think we are a bit more prepared. I think we would continue to keep our carer. The carer we have is single, she lives on her own and shields. We feel confident about her coming into our home.*

## 7.2 A second wave

When asked an open questions ('How do you see the future as we come out of lockdown?'), eight respondents mentioned the possibility of another lockdown. All said they felt anxious or wary and some used stronger language: 'bleak', 'terrifying', 'grim', 'full of uncertainty'. This question revealed the enormous anxiety amongst parents, despite the resilience they showed in coping with the first six months of the pandemic.

The more detailed responses from the interviews show that parents are ready to think things through and weigh up the risks. They appreciate advice and clear information, but they take responsibility for decisions about protecting their children from contracting Covid-19.

*If we got a second wave, we would take our kids out a bit sooner. Stop having our carer again. Would hunker down. Would we stop shielding sooner, possibly.*

*A second lock down will break a lot of families. People [are] starting to get their lives back. Light at the end of tunnel.*

*I find this part harder. The future is difficult, worrying and challenging. It is easier to hunker down and know 'stay safe, stay home'. We are responsible for him and there is a major threat out there to him. The decisions we make may put him at greater risk. We are all really tired. I feel really bad for my other children. His condition is upsetting. I feel we have to move to start moving carers in but we are increasing the risk to him. Figures are down at the moment but I am feeling I have to keep a close eye on that. Probably it's not sustainable that we carry on like this.*

*People are going to get complacent. I have a proper fear for this winter. It seems to me it is all building towards something bad. Our schools are not set up for it.*

*We spent so long counting down until this was all over. Really hard because goal posts kept moving. We had to change our mindset to living like this.*

*Quite anxious but can see there are spikes. Anxious there will be a lock down and back to square one.*

## **8. Conclusion**

It is clear from our survey that parents of children with exceptional healthcare needs will go to extreme lengths to protect their children. It was the norm for these parents to get five hours of broken sleep a night, yet they did not hesitate to take their children out of school in March 2020 at the start of the pandemic. Many took their children out of school before schools closed.

This survey reveals much that is of relevance to the caring role, irrespective of the pandemic. Indeed, a number of parents commented that there was not much different in the lives because they already felt extremely isolated. However, respondents were greatly appreciative of support that they received from professionals and from Third Sector Organisations. The latter were talked of as if they were a wider family, providing comfort and support. Parents referred to key conversations with professionals which had made all the difference to their decision making.

The dearth of respite care available to families means that schools are all the more important in their lives. Schools are not just a source of learning. They are also a source of respite, of therapeutic care, entertainment, social activity and creativity. In the event of a second lock down all this must be considering if it comes to a decision about whether close our special schools.

Parents are the experts in caring for their children. This should not be at the cost to their mental and physical wellbeing. The pandemic has revealed the extraordinary strength of parents of children with exceptional healthcare needs but further exposed the challenges of their everyday lives.

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