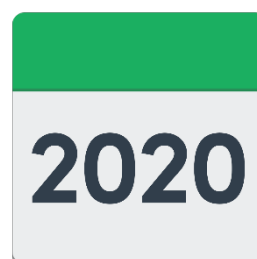
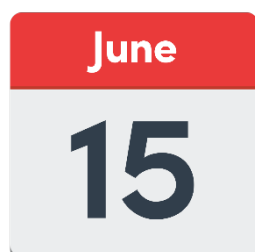


# **An Easy Read report about a Zoom meeting held on 15 June 2020 with families shielding from coronavirus**

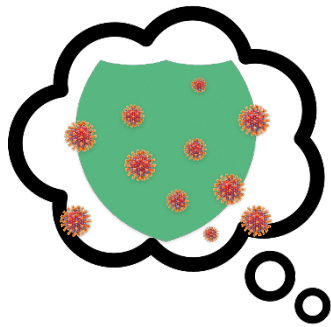


**NHS England and NHS Improvement**



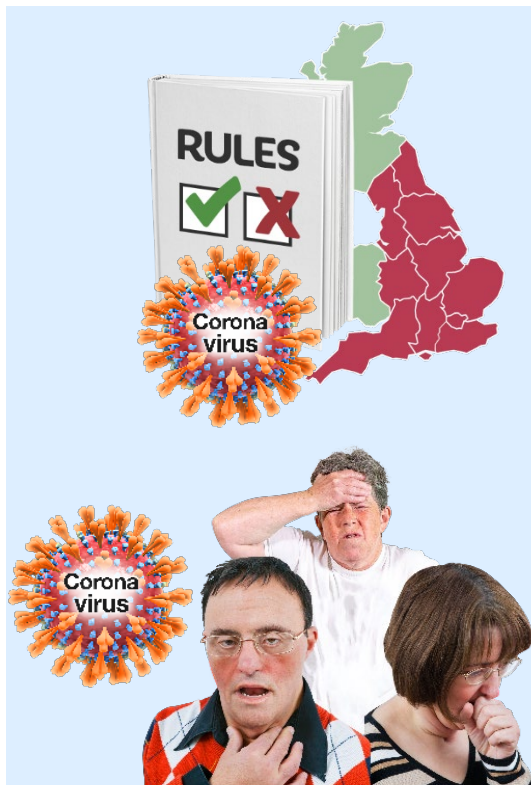
# Introduction

NHS England and NHS Improvement



**NHS England and NHS Improvement** worked with an organisation called **Bringing Us Together**

to find out what families felt about having to **shield** during **lockdown**.



**Lockdown** is when everyone in the UK follows rules about **coronavirus**.

**Shielding guidelines** help to protect very vulnerable people who could get very ill if they catch **coronavirus**.



On **15 June 2020** we held a second parent carer group

**11**



with **eleven families** who were shielding.



**Eight people** from this group took part in a meeting held on **15 June 2020**.



All comments made at the meeting were private.

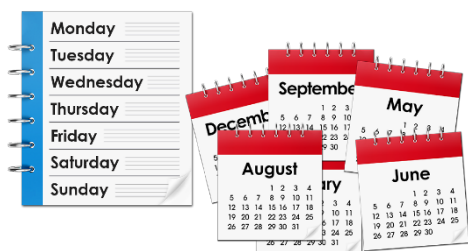


This group was asked:

- things they found **difficult**



- what has been **good**



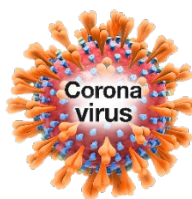
- What will happen in the next few **weeks** and **months**?



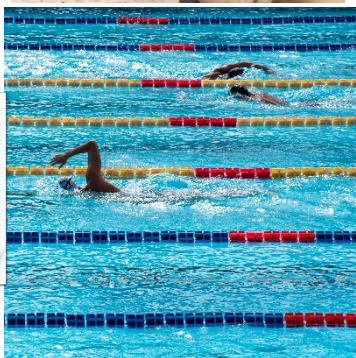
## What did you find difficult?



## A fear of getting coronavirus



Several people said because **coronavirus** cannot be seen it is scary and difficult to shield from.



"My autistic son used to go swimming **8 times** a week.



Because he could not go swimming, he went out for a **run**.





He got worried when cyclists got too close to him and said:



"What happens if I bring **coronavirus** back home?"



**Getting enough food and getting the right food**



"We had a box of food delivered for **1 person** on Tuesdays.



But we need to feed **4 people**.

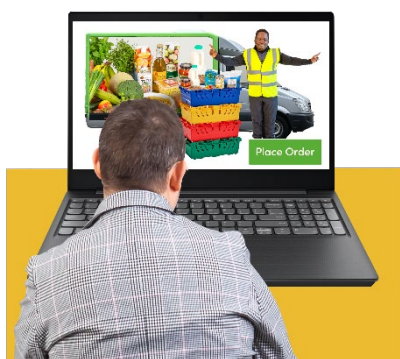
Not everyone has family and friends close by to help."



"It has been difficult to get food for my teenage children.



My son has a glucose-free diet.



Our GP registered us for online grocery shopping and after some time we could shop at 2 supermarkets.



But I could not get the **glucose-free food** I needed for my son."



## Mental health issues



"I cannot remember when I had any **time** to myself.



I only get time to myself when I go to the **toilet**."



## Feeling stressed and tired



"As **lockdown** ends it would be better for (**my child's**) mental health if they stayed at home.





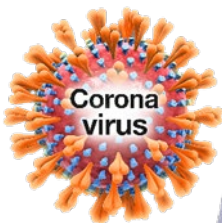
I have to do everything for them. I am very **tired** and cannot sleep well but I need to keep going."



"Some days you do not feel like getting out of **bed**. But you have to carry on.

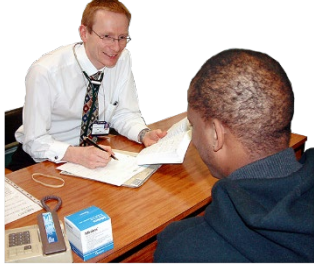


By the end of the day you are very tired, and I do not sleep well. Everything is difficult."

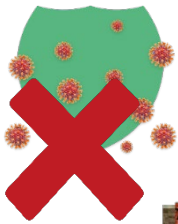


Several family members said:

- information about **coronavirus** and for people who are shielding was **confusing**.



- the government and health professionals like GPs said different things.



"Our house was not big enough for **1 person** to **shield** away from other family members.



But we **did not** get **clear information** about what to do."



"It was very **stressful** for me to shield



and for both of my sons to have their **exams cancelled**.



My GP told me "you **do not** need to **shield**."



Then I got a letter saying I **did** need to **shield**."



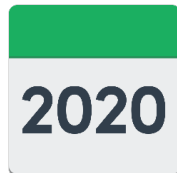
**Worried because the family is high risk**



"I live with **3 teenagers** who are not enjoying **lockdown**. But we are lucky because we have a nice house"



"It is difficult to stay in now that others are going out.



Since **March 2020** I have not seen:



- my autistic son who is in supported living
- my grandchild."



Some people thought they had been let down by health services

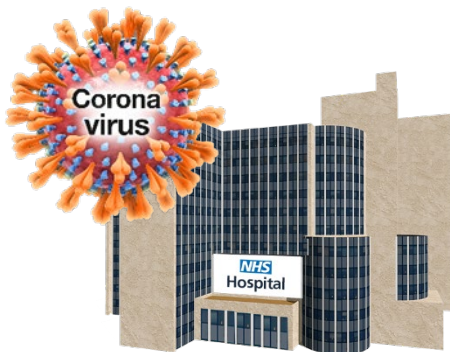


Some people thought after they read the **shielding letter** they should not contact health services.



"I feel that I could be wasting my GPs time if I called them.

The **NHS** doesn't understand what it is like to **shield**."



"It was difficult to get a blood test for my child.

I worried that I would have to take her to **hospital** where she could get **coronavirus**.



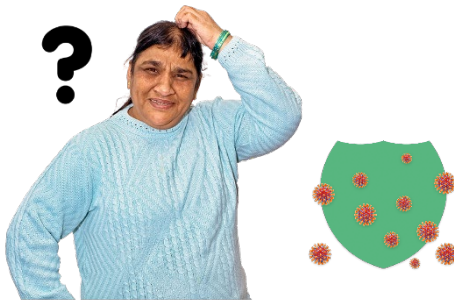
Then the **NHS** agreed that she should be **shielded**."





Family members said:

- we did not get much **support**



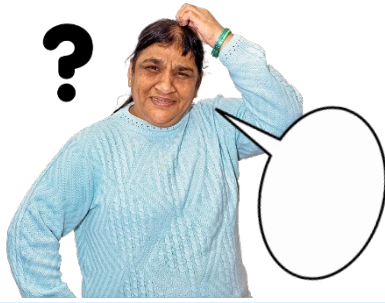
- people who are not shielding do not understand what it means to **shield**



- we are not included in the advice from the government



- we feel that others are judging us.



"People do not understand **hidden disabilities**, so they say:



**Hidden disabilities** cannot be seen, for example **hearing loss** or **mental health issues**.



'Why don't you **go out for a walk** or let your children go to the shops?'"



It was difficult to carry on with education and social care.



“Education and Health Care Plans can stop when someone is **19 years old**,



Our son moved from children’s services to adult services.



But now we don’t know what will happen to **him** when **shielding** ends.”



“Our son used to stay at a college from **Monday to Friday** and was home at weekends.



He is **22 years old** so he needs to move from children's services to adult services.



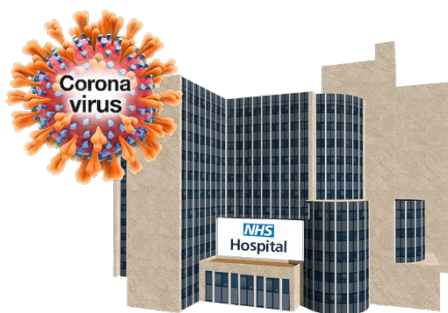
As we are **shielding** we don't know what will happen in the future."



**Worrying about a shielded person with serious health problems or disabilities.**



"My daughter tries to understand the news and asks me lots of questions.



I worry that I cannot go to hospital with her. If she got **coronavirus** I don't think she would survive."



## What was good or helpful?



Some family members said they did a lot of their **work at home** and found new ways to work.



"It was good to find out I could work from home and **be at home more**.



And I **did not** have to take the kids to lots of **different activities**."





"Life can be calm. I'm lucky I have **a kitchen that works** and people can sit in different rooms."

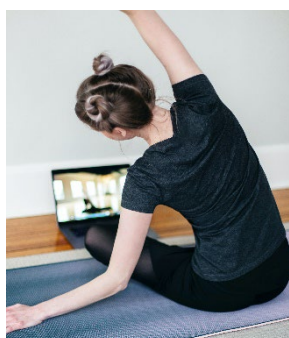


**More family time**



"I have had a lot of time with my family."

We used to do a lot at the weekend and the rest of the week was **stressful**.



And **my child** is exercising at home too."



**Time to do activities and learn new skills**



"It is difficult to feed **2** hungry boys on a low income.



Now we have more time for cooking. My youngest is learning how to help in the kitchen."



**Shielded family members got better support as the Personal Assistant could not visit**



"His brother is very skilled at supporting **his brother/sister**, which is not easy."



## Support for shielding families



"We **did not** get the support we needed from:

- **social services,**



- **schools**



- the **council.**"



"Our council rang us to see if we needed **help**. We wanted to take rubbish to the tip.



After hours of **emails** and phone calls they could not help."



"At first it did not matter.

**3 or 4 months later** it feels like we have been forgotten."



**For some the support was very good.**



"My support agency made small changes and ran a **very safe service.**"



"The **Personal Assistants** have been very good at keeping everyone safe and using computers to offer support."



## What next?



Two **reports** have been sent to:



Department  
of Health &  
Social Care

- Department of Health and Social Care



Ministry of Housing,  
Communities &  
Local Government

- Ministry of Housing, Communities and Local Government





The reports helped to change **Government guidance** that came out



at the **end of June**.

**160**



So far **over one hundred and sixty people** have taken part in the groups:



- younger people



- **Black And Minority Ethnic** people



**Minority ethnic** groups are people from different cultures.



- **people with** high support needs who are shielding



- people with a learning disability and autistic people



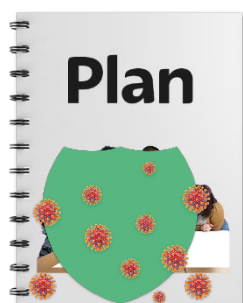
- parents, carers and families



- people with health problems.



## Going forward



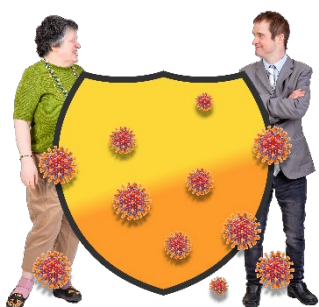
One person from the group wanted a clear plan for families who carry on shielding.



A lot of people were scared and unhappy.



"I do not expect to see a clear plan because lockdown has been handled badly."



People who are **shielding** will not get support if they have not been supported before."



"I worry that our support will stop



because there is not enough money to pay for it."



"It could get worse as we are moving out of **lockdown** when it is not safe.



Everyone will think we worry too much.



"We would worry less if there was better **information** from the **government** about shielding:



- for the **public**



- for the **people who are shielding.**"



"We should talk more about:

- what people who are shielding need to do



- what families with **hidden disabilities** and illnesses need to do.





Thank you to everyone who took part in the groups set up by the organisation called **Bringing Us Together.**

**Contact details?**