

Domino effect: Discussing the knock-on effects of COVID-19 for parents of children with SEND in Westminster

August 2020

Discussion with
Make it Happen, as part of
Healthwatch Central West
London's 2020 COVID-19
engagement.

Introduction

In January 2020, Healthwatch Central West London (HWCWL) launched our [Small Grant](#), a first of its kind project for our organisation. We wanted to reach people in Westminster and Kensington & Chelsea who are under-represented in conversations about health and social care, and we awarded the recipients £500 to complete engagement with groups from these communities.

The five organisations who received the grant were selected in April, just as the national health conversation was turning towards the Coronavirus outbreak. We decided to offer an additional fund to the selected groups, so that they could conduct focus groups, with HWCWL, which focused on the COVID-19 outbreak and response.

In this report, HWCWL shares the main themes from the first group. This was held in May 2020 with 14 members of [Make it Happen](#), a support group for parents of children with disabilities and complex needs, which works to improve services in Westminster. Make it Happen organised and promoted the group, and HWCWL facilitated the discussion.

This report is our latest document¹ sharing local experiences of the COVID-19 pandemic, and it is the first detailing conversations on key issues. Because the participants in this group all share the experience of caring for children with special educational needs and disabilities (SEND), their experiences of COVID-19 are explored within this context.

The questions for this session were adapted from a [survey](#) produced by Healthwatch Central West London. Some of the case study quotes in this document have been edited for clarity, but have been approved by the participants who shared these views.

¹ You can read the full list of our published COVID-19 work in the Appendix.

Method

Our focus groups bring people with similar backgrounds or common experiences together to discuss specific topics of interest. This produces qualitative research that captures the diverse experiences of different NHS service users.

We ask group members about their lived experiences. This could relate to using particular services or living with a particular health condition. We base our questions on what people have already told us through our local engagement on health and care services, or from what we have been told through our surveys.

Listening to **what** people tell us (the content), helps us see the breadth of their experiences. Noticing **how** they talk about their experiences (emotive language, for example), helps us to understand more about why people make the choices they make, what they think about the support they receive, and where there might be gaps. It can help us to understand common themes in their experiences or to identify exceptions that might otherwise be missed.

This helps organisations that commission or provide services, such as the NHS or local councils, to better plan, design and run quality services that meet the needs of local people.

Themes

From the questions relating to the participants' experiences of COVID-19, we have identified some key themes.

Most of these were related to services, information, and additional support for children with SEND and their carers, which had been complicated by the COVID-19 outbreak and the measures implemented in response to the pandemic.

The issues raised included:

- NHS Communications
- Links between health and education
- Explaining changes to children with SEND
- Knowing what they were entitled to
- Value of support groups
- Using video communications
- Concerns about funding
- Shielding and appointments

NHS Communications

Almost every parent participating in the group expressed the need for clarity and forward-planning in every aspect of their child's care, owing to the complexity of their child's needs. In these comments, we can see how existing challenges for the parents have been exacerbated by the period of uncertainty and instability that has been felt by people of all backgrounds.

Case Study

“This lack of planning for the whole picture is a problem now and probably will be for the next year”

“Both of my children use health services at the moment, and I have found the uncertainty and lack of communication extremely challenging, mentally, because we do not really know what the next step is.

“We are used to waiting lists - my son is disabled, so we know waiting lists - my son has had a problem with his tooth, since before Christmas, this is the struggle of our lives, we are used to it.

“So, when people tell me something will take six months, it is challenging, but what's worse, is not knowing whether a wait will be six months or six years.

“There has been health and support available, but sadly, not early enough. For all of March and early April the health services were confused. I don't think anyone was happy to discuss or talk about anything that is non-COVID-19 related. This lack of planning, this not thinking of the whole picture, is a problem now and probably will be for the next year, regarding waiting lists.”

Links between health and education

We held this group in late May and parents were concerned about school closures. This group's perspectives add an important dimension to the discussion of schools and COVID-19: while they shared the same fears of infection as other parents, they also rely on schools for a number of health-related support services for their children. Occupational Therapy (OT) was mentioned throughout this session, as were concerns about when certain specialist staff would be returning to work.

Discussion

“Even if this is a health discussion, for our families, health and education are very closely linked.”

“What should schools be doing now, and what kind of resources are they still going to have? Will there be enough school nurses?”

“We get very little support as it is, so I suppose I want to know if it is going to be worse when this all starts going back to normal.”



“My child is still at school, because he is so vulnerable. It is hard to reach the Westminster autism outreach team, possibly because they are attached to schools, and my child goes to school out of borough, so in terms of autism I have had no support; when services are given in isolation, and not holistically, gaps form and people like myself, who are only known to one team, fall through them.”



“Will there be enough therapists? Some of them are not in the country, some are redeployed to the Nightingale... how will this affect our children?”

“I do want to praise Pimlico Nursery; my son never missed a day this whole time. They are so helpful and so supportive.”

“We want to see that we are being involved, and that things are being put in place to help us. Communication is key, and if you involve us in your journey to that goal, then it will help us as parents or carers see that you are trying to put plans in place.”

Explaining Changes

A prominent theme in this group was how different services would explain changes to individuals with SEND. Many of the parents, whose children have forms of autism or global delay, had used visual narratives (“Social Stories”) to illustrate certain situations.

They were also accustomed to some services displaying accessible images to aid understanding and limit discomfort. The extract below is from a discussion of how service providers might help parents of children with SEND to navigate changing health

Discussion

“I’d like to know how social stories are going to be used to explain what we need to do, whether through videos or images.”

“My daughter needs appointments for hearing aids and an MRI. I developed a social story for her to go to the dentist, which helps to prepare her for what is expected of her in a social situation. They are for children who are entering a new environment, or one that has changed.”

“I think the bigger question is what interactions are going to be allowed, and what type of appointments are going to be allowed moving forward.”

“Yes, [for example] are they going to create hospitals and practices with non-infectious places, where only non-infectious people can enter?”

“or is there a way to send the photo of the doctor before you go to see them?”



“St Thomas does brilliantly in this area, every paediatric clinic lays out who these people are, what they do, they have a big visual on the wall of all the steps that will take place in the appointment. The environments might look different because of COVID-19, but some people should have this step-by-step to help them if they have seeing, hearing difficulties etc.”

Knowing your entitlements

“You have to get really feisty before you get any sort of help.”

The participants had existing challenges within the health and social care services, in particular with knowing what their child was entitled to. The uncertainty surrounding COVID-19 measures had exacerbated the feeling of having to fight for these entitlements.

The participants wanted open communications from the relevant local services, with one commenting: **“I think there needs to be a change in culture [in Westminster], as they don’t seem to feel that it is important to communicate with families. I feel that CCGs and Public Health England should have policies like in education, where there is a policy to listen to service users. Of course, they are listening, but they are stretched.”**



The value of Support Groups

When we asked how the COVID-19 outbreak had affected their relationships, one participant highlighted that being a member of a support group had helped her during an emotionally challenging period. This sentiment was echoed by other members, who credited Make it Happen with being their primary informative resource and a place where they felt understood and supported by people who shared their experiences.

This resonates with recent HWCWL research, which shows that people who are active in their communities report better wellbeing than those who are not. That study also noted that people from Black, Asian or Minority Ethnic (BAME) communities were less likely to be part of such groups than their White neighbours. Most of the women in this group are from BAME backgrounds, indicating the importance of using different research methods to gain an accurate insight into the role of community networks in BAME communities.

Case Study

“She was the therapist, she was the friend, she was the teacher”

“I am glad you asked this because I have been depressed. I have three children, two of whom are autistic. Hend (Make it Happen) was my family that I didn't have in this country, she was always calling me to make sure that me and my children were okay. When I told her about the letter, she advised me. [She] helped me mentally and everything.

“What seems easy for other families, we can't take for granted. Social distancing is not something that our children can understand. Having our children has taught us about coping with hard times and with isolation: having a child with disabilities can be isolating.”

Other comments

When we asked where the participants receive their information about changes to health and social care during COVID-19, every participant said Make it Happen. This was a credit to the group, as well as a flaw in information sharing among different services: it was hard for parents to keep up with every separate NHS or local authority service's updates.

“Make it Happen shares local information that helps parents, between people you trust on WhatsApp. I get update emails from the council, but reading them makes me feel stressed.”

“Groups and services need to connect with support or patient groups, or at least know where are, as good practice. If they aren't connecting them, it is so important to identify those gaps.”

“It is a frustrating journey, and these groups are invaluable. People should get their information from schools, from doctors, from autism outreach, but it takes so long to find information that people shouldn't have to be digging for. That information should all be in one place.”

Using video communications

Part of the conversation turned to how access to video conferencing tools had been a positive influence on the participants' access to health and social care, as well as to their engagement with Make it Happen.

The participants said that it was unhelpful to assume that video conferencing and other digital tools were readily available to everyone. However, for those who did use them, they proved to be an important direct line to services that supported their family's wellbeing.

Discussion

“Social media and these video conferences have really helped me, for quick responses and knowing that people are going through the same things you are. Hend (Make it Happen) has been sharing the conferences, speeches, and language groups. This has helped me, socially.”

“We also ran five sessions on mental health topics. I was looking forward to it every week.”

“If we could have other zoom conferences with, say, GPs or OTs, this could be a big help, because we don't know how long things will be like this for.”

“Couldn't they be more pragmatic about video calls and other resources that could be used for pharmacy and GP meetings?”

“A zoom appointment would reduce anxiety, all that anxiety, even unrelated to coronavirus.”

“However, there is a presumption that all of us can use the internet and the services that are being offered as alternatives now. We need to not isolate people who can't use it - there will always be families who can't use Zoom or Teams, for many reasons.”

Funding

“Please include our concerns about potential funding changes to our local services.”

When asked about losses to income, some of the group were forthcoming about their household finances, but more of them said that they were especially fearful of how an economic downturn would affect their access to health services.

“We are also worried about the future economy, what will be cut? Even if you didn't personally have a loss of income, it will eventually catch up with you.”

“As the services find ways of balancing their budgets, what kind of guarantees are we going to get about not receiving a drop-in service? Obviously, some things can be done over video, but drop-in services were [already difficult].”

Shielding and appointments

Most of the participants in this group were on the “shielding list”, meaning that they had to take extra measures to isolate from the public during the COVID-19 lockdown period. For some parents, as seen earlier in this document, their child was able to attend school because they would receive more specialised support in the school than they would be able to if they had to self-isolate.

As with the wider public, the group’s participants mentioned having had treatment delayed and appointments cancelled, adding strain to their already challenging experiences with accessing care for their children.

As with other themes of information and communication covered in this report, the group’s participants felt that communications regarding shielding could be categorised as either insufficient or overwhelming. The case study below provides an example of the resulting confusion.

Case Study

“My manager called me saying she had COVID-19 and told me to self-isolate. My daughter had a temperature, she is autistic but does not have any other needs.

“I didn’t contact my GP to be honest, [in my experience] GPs make you feel as though you are paranoid, a very worried parent, as if it is easy when you have children with SEND in the house. We received the shielding letter, so her school said they couldn’t have her in school, but her behaviour has been very challenging: she needed to go outside.

“The school said I needed a letter from the GP to say whether she was able to go back to school. The GP said they didn’t know why the NHS sent [the letter], but they said that it sounded like we had had COVID-19. They said we might qualify for the test, and eventually emailed the school and gave permission for my daughter to return to the classroom. It was a bit confusing to be honest, it was not like a normal time, but i do feel like the NHS did overwhelm the parents at times, or they didn’t at all. I was getting letters and messages; I didn’t use any of the services to be honest.

“It is good that they were providing health and stuff, but it was very confusing. It was really overwhelming. But I am glad that i had a chance with CAMHS, my son is high functioning, he is a young boy, and he was having a call with a psychotherapist for an hour every Tuesday. He has anxiety and autism, and she was calling to make sure he was stable and to talk to him about his mental health. I know some parents have not had a good experience with CAMHS, but i am glad they have been helpful to me.”

Appendix

Appendix 1: Questions

As with our public survey, [Your Experience Matters](#), we developed broad questions that could elicit a range of different experiences. These formed the basis of a semi-structured conversation with 14 members of Make it Happen.

1. **Do you have an experience from the outbreak that you would like to share?**
 - How has it affected you?
 - Did you find anything difficult during this time?
 - What was helpful during this time?
2. **Did you have COVID-19 symptoms and have to self-isolate because you were classed as being part of the “vulnerable” group?**
3. **Would you like to share how COVID-19 has affected your relationships with others?**
 - How are you communicating with others?
 - How have you all found living together?
4. **Did you have to see a doctor for a non-COVID-19 issue?**
 - For example, did you have any appointments booked before March until now, which were cancelled?
5. **Where do you find your information, and in what format would you prefer to read it?**

Appendix 2: HWCWL published findings (COVID-19 engagement)

May 2020

[How is Coronavirus affecting you and your loved ones? \(Infographic\)](#)

July

[Bridging the Gap: Young people’s experiences of mental health before and during the COVID-19 outbreak - Young Healthwatch Mental Health engagement \(update document\)](#)

August

[BAME Responses to Your Experience Matters \(update document\)](#)

About Healthwatch Central West London

Healthwatch was established under the Health and Social Care Act 2012 to understand the needs, experiences and concerns of people who use health and social care services. We deliver the statutory Healthwatch provision for Kensington & Chelsea and Westminster, and we previously delivered this work for Hammersmith & Fulham. Our research and local engagement puts local people's views at the centre of decision making about health and social care.

We make this happen by:

- Helping to improve the quality of local health by sharing what people need from their care with those who commission, run, and make decisions about NHS and social care services.
- Listening to what people like about services and what could be improved.
- Monitoring how changes in the healthcare system affect local people.

Contact us

If you would like to contact HWCWL about this report, or about our other research and local engagement in Westminster, you can get in touch with us here:

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You can add your voice to this ongoing survey here:
<https://www.surveymonkey.co.uk/r/YourExpMatters>

You can request a paper version of the survey via any of the contact details above.

