

## APPENDIX 2: COVID-19 UPDATE

## CASE STUDIES OF BRENT RESIDENTS DEALING WITH IMPACT OF COVID

## My Health, My Choice – Covid 19 case study

### Background

John\*, 62, has a learning disability along with other physical disabilities. John attends our User involvement service group – My Health, My Choice in Brent. John has been an active member of the group for 2+ years and is very keen for his voice and others to be heard regarding health and accessing services.

### Issue

John lives independently within the community in his own home and has support staff visit his home daily to support with day to day care duties.

However, during lockdown John felt isolated, he was unaware of the services available to him as a vulnerable individual. John does not have access to digital technology, so he must rely on others for information about services available in his community. John is finding this difficult as he is beginning to realise that most services are facilitated online.

Due to the nationwide Covid 19 lockdown, John stopped attending group sessions within the community and therefore his social circle become reduced and is spending more time at home not being very active. John is concerned about his health regarding weight gain and lack of exercise.

John's main concern was contracting the Covid 19 virus as he had different support staff entering his home daily and reached out to The Advocacy Project, via the 'My Health, My Choice' project to find out how to proceed with getting tested.

My Health, My Choice project provided John with the details to his local testing centre. John made his way to the centre and proceeded to have the test administered. John experienced that the NHS testing service in Harlesden is self-administered, meaning that the individual would test themselves using the testing kit.

This was a difficult process for John due to his physical and learning disabilities, there was no reasonable adjustments such as 'easy read' literature made available for John regarding:

- instructional direction
- opening of the packaging
- administering the test
- gaining his test results

John was unable to provide an email address to receive his results and was informed he would have to ring a dedicated telephone line along with a reference number to gain his results.

John has had a difficult experience with gaining his results as the 'test and trace' dedicated phone line **119** is computer operated. There is no human contact, therefore if you have a query you cannot get through to anyone to get your results.

John was unable to provide an email address to receive his results and was encouraged by the testing service to source one (either his own or a third party) to access the service.

## Process

We were able to gain access to this story of events by having regular contact with John to discuss health options, accessibility and services within Brent.

During our conversation, we were able to discuss why, where and what to expect for the testing process from the information provided by NHS.

John was very keen to get the test administered even though he was not displaying any symptoms, due to having many care workers entering his home. John was also keen to see if the service was accessible to people with learning disabilities and is eager to voice his experience.

We supported John with the experience by providing him with a telephone number, address of the location and discussed the process of testing. We offered to send through the literature of the NHS service in the post to which John stated he would be ok with the information provided. It was agreed once John completed the test, he would be in contact with us to communicate his experience.

## Outcome

The outcome of the test is still unknown John is unable to obtain his results, we also tried to contact the delegated telephone number and we were not able to talk with anybody regarding the difficulties to which John was experiencing and after all the options have been listed the phone line is cut dead. Therefore, John's initial goals have not been met using the NHS service.

John has stated that he feels 'let down' by the NHS testing service and he felt that 'it was not safe to give out personal information which are private to another person'. This is regarding the service manager suggesting that John provide an email address of someone else to gain his results. John feels that he should not have to do this being that he does not have an email address.

It appears if you do not have a digital device or accessibility, services are not catering to those who cannot access them or have enough knowledge on its use and purpose.

John is now weary about using the service in the future if he were to display symptoms if a second wave does shut down the community again.

## Systemic issues

The biggest impact experienced by John getting testing is the digital divide/isolation he is experiencing. John has said he will think about getting a 'tablet' or mobile phone but has stated

he would not know how to use it if he did. Also due to his physical disabilities, he would not be able to 'walk and have a mobile phone as my priorities are keeping my balance'. Therefore, John will require the support to use a digital device before purchasing one. Other service users have shared this same viewpoint.

It would be beneficial for NHS services like this to provide an alternative accessible way for people without digital accessible to still be included, as John is still without his test results. Also, the staff on site at that testing centre should be available to support people who have identified as having a disability or those who appear to be struggling. In this case John did ask for help and was told the service is self-administered, this could be discrimination to those who are vulnerable. \*identity changed for confidentiality.