



## Case study

### John: digital access during Covid-19

#### 1 Background

John\* (62) has a learning disability along with other physical disabilities. John is a regular attendee of our user involvement project in Brent, 'My Health, My Choice'. John has been an active member of the group for over two years and is very keen to speak up about health and accessing services.

*\* Identity changed for confidentiality.*

#### 2 The issue

John lives independently within the community in his own home and has support workers visit his home daily for day to day care. During lockdown John felt isolated and was unaware of the services available to him as a vulnerable individual. John does not have access to digital technology, so he relies on others for information about services available in his community. John has found this difficult as he is beginning to realise that most services are now provided online.

Due to the restrictions, John was unable to attend group sessions within the community, and therefore his social circle was reduced. He had to spend more time at home, not being very active. John was concerned about his health regarding weight gain and a lack of exercise.

John had a serious concern about contracting Covid-19 due to the different support staff coming into his home on a daily basis. He reached out to The Advocacy Project, via the 'My Health, My Choice' group, to find out how to go about getting tested. We gave John details of his local testing centre. John made his way to the centre and was told the NHS testing service in Wembley was a self-administering service, meaning that the individual would have to test themselves.

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

- › instructions on how to do the test at home
- › opening the packaging
- › receiving the test results

When returning his test, John was unable to give an email address to receive his results and was told he would have to ring a dedicated telephone line with a reference number to get his results. The dedicated phone line was computer operated and was therefore another barrier to receiving the results.

One of the alternatives suggested to John was to give an email address for a trusted third party, where the test results could be sent on to. John did not feel comfortable doing this.

### 3 The process

We had regular contact with John because of his involvement in the 'My Health, My Choice' group which is set up to discuss health options, accessibility and services within Brent. During our conversations, we were able to discuss why, where and what to expect regarding the testing process, from the information provided by the NHS. John agreed to get in contact with us to share his experience, once he had had the test. This was to help us gather qualitative feedback on how service users with learning disabilities have experienced testing for Covid-19.

### 4 Outcomes

John was unable to get his results as he couldn't get through on the phone line. We contacted the dedicated telephone number on his behalf and at his request, and we were also unable to get through.

John says he feels 'let down' by the NHS testing service. Regarding the service manager suggesting that John gives an email address of someone else to get his results, he said he felt 'it was not safe to give out personal information which is private to another person'. John thinks he should not have to do this because he does not have an email address.

John is now wary about using the service if he were to display symptoms in the future.

### 5 Systemic issues

- ▶ A significant issue highlighted by this situation is the digital divide and isolation that service users with learning disabilities are experiencing. John has said he will think about getting a 'tablet' or mobile phone but was concerned he would not know how to use it if he did. Additionally, due to his physical disabilities, he would not be able to 'walk and also have a mobile phone, as my priorities are keeping my balance'. John would need support to use a digital device before buying one.
- ▶ Health services need to provide an alternative accessible way for people to get tested for Covid-19. Those with disabilities or other support needs who are unable to carry out the tests independently need local testing centres where staff can administer the tests.
- ▶ The process of communicating the test results needs to improve. Those who don't have access to technology are being excluded from accessing their test results.