



One Place East
Where disability matters

RESEARCH REPORT: PANDEMIC IMPACT ON ADULTS WITH A LEARNING DISABILITY

Redbridge and East London

July 2021

Supported by the London Community Response Fund

Contents

Introduction.....	2
Taking Part.....	3
Impact of Pandemic	7
Contact with Friends and Family	7
Daily Life.....	9
Lockdown	10
Digital Exclusion.....	10
Observations and Potential Risks	13
Day Centres and Day Services.....	14
Activities cannot do anymore.....	16
Accessing Healthcare, Medicine and Vaccines	17
Information and Government Guidance	18
Vaccination.....	19
Employment and Money	19
Financial Impact.....	20
Recovery, Conclusions and Recommendations	21
Requirements for Recovery.....	21
Conclusions	23
Recommendations	25

Introduction

One Place East exists to enable disabled people and those with health conditions in Redbridge and across East London to have choices and improved lives. We:

- ➡ Provide accessible information and advice
- ➡ Improve access to services
- ➡ Provide advocacy and support individuals to have a voice
- ➡ Provide services so people are healthy, happy and part of the community
- ➡ Creating sustainable models of peer support

We are run by and for disabled people, people with lived experience of mental ill health, long-term conditions, dementia and people with a learning disability or autism.

Adults with a learning disability, their parents/carers have contacted One Place East during the first lockdown in 2020 to express their frustration and anger about their treatment during the crisis. Many lost their support, services and social contact, even when living in supported housing.

Our staff and volunteers reported unprecedented levels of loneliness and anxiety amongst this user group.

We successfully applied and secured a grant from The London Community Response Fund (LCRF) to engage adults with a learning disability in a research project exploring their lived experience of the crisis and future support needs.

The research and report is aimed to inform recovery planning, shape local commissioning and prevent further exclusion.

Our goal was to include at least 25 adults with a learning disability in the research. Due to communication barriers we filmed some contributions abiding by social distancing regulations and risk assessments.

We have produced a film that captures the research findings, lived experiences and recommendations for change. This will be published online to extend the reach and impact of this project.

Taking Part

43 adults with a learning disability participated in our research project, exceeding our target of 25.

By working with partners, we succeeded in engaging a diverse group, who lived in a range of settings and not all were existing One Place East service users. 68% of those participating usually receive care and support following a social care assessment.



Participation

participation methods included online survey, paper questionnaires, one to one meetings (virtual), filmed contributions



COPRODUCTION



Members of our Learning Disability User Group helped design and test the survey

people took part who lived independently, with family/carer or supported living



Learning Disability User Group Members

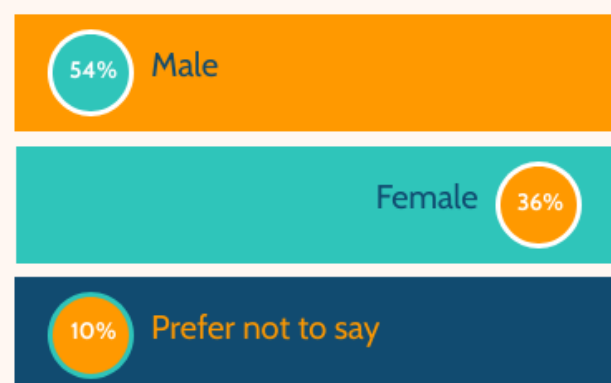


Gender

INTERESTING MIX



We were pleased that so many men took part, as usually more women than men use One Place East's services



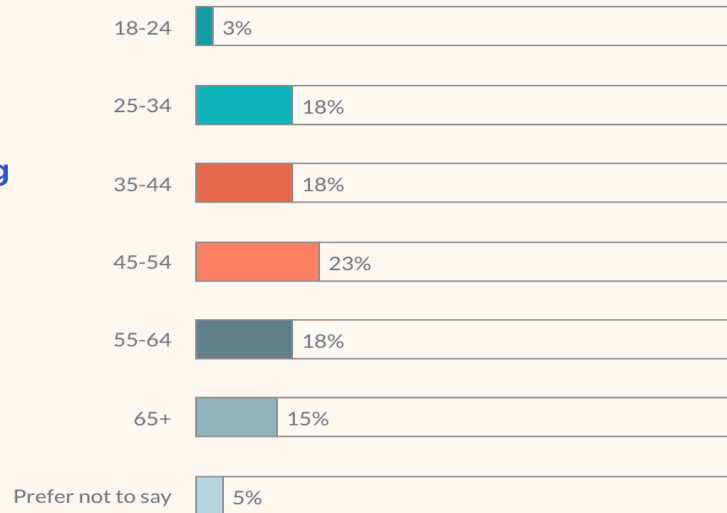


Age

ADULTS



79% of those taking part were of working age

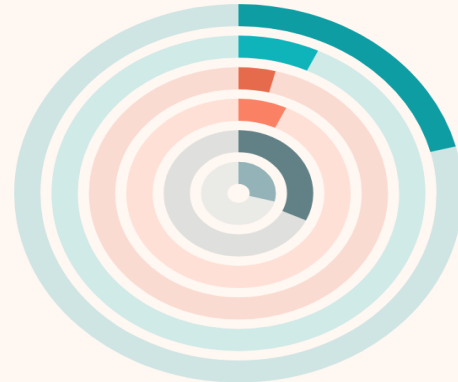


Disability

INTERSECTIONAL DISADVANTAGE



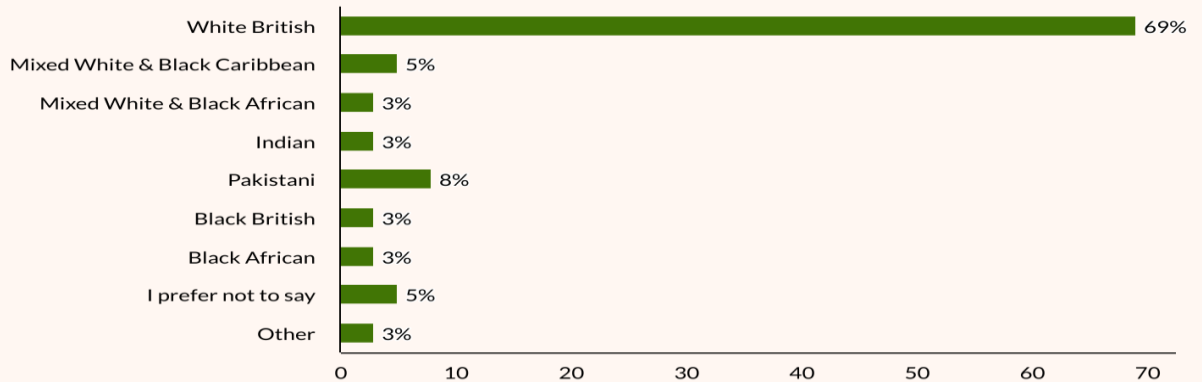
As well as a learning disability, people also identified mental ill-health, epilepsy, panic attacks and high blood pressure as other long-term conditions



Physical disability (21%) Autism spectrum disorder (7%)
Visual impairment (4%) Deaf or hard of hearing (7%)
Long term health condition (32%) Other (29%)



Ethnicity



DIVERSITY IS GOOD



Outreach and collaboration helped ensure an ethnically diverse group participated in the research 26% were black or people of colour

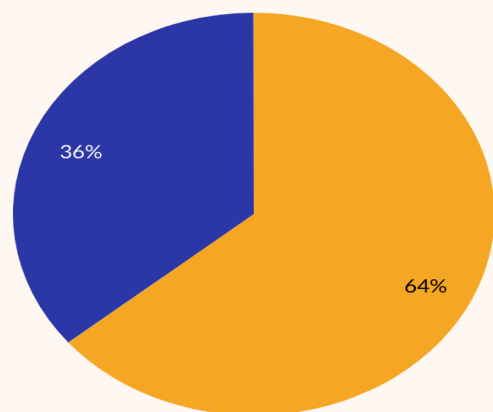


Where people live

NORTH EAST LONDON



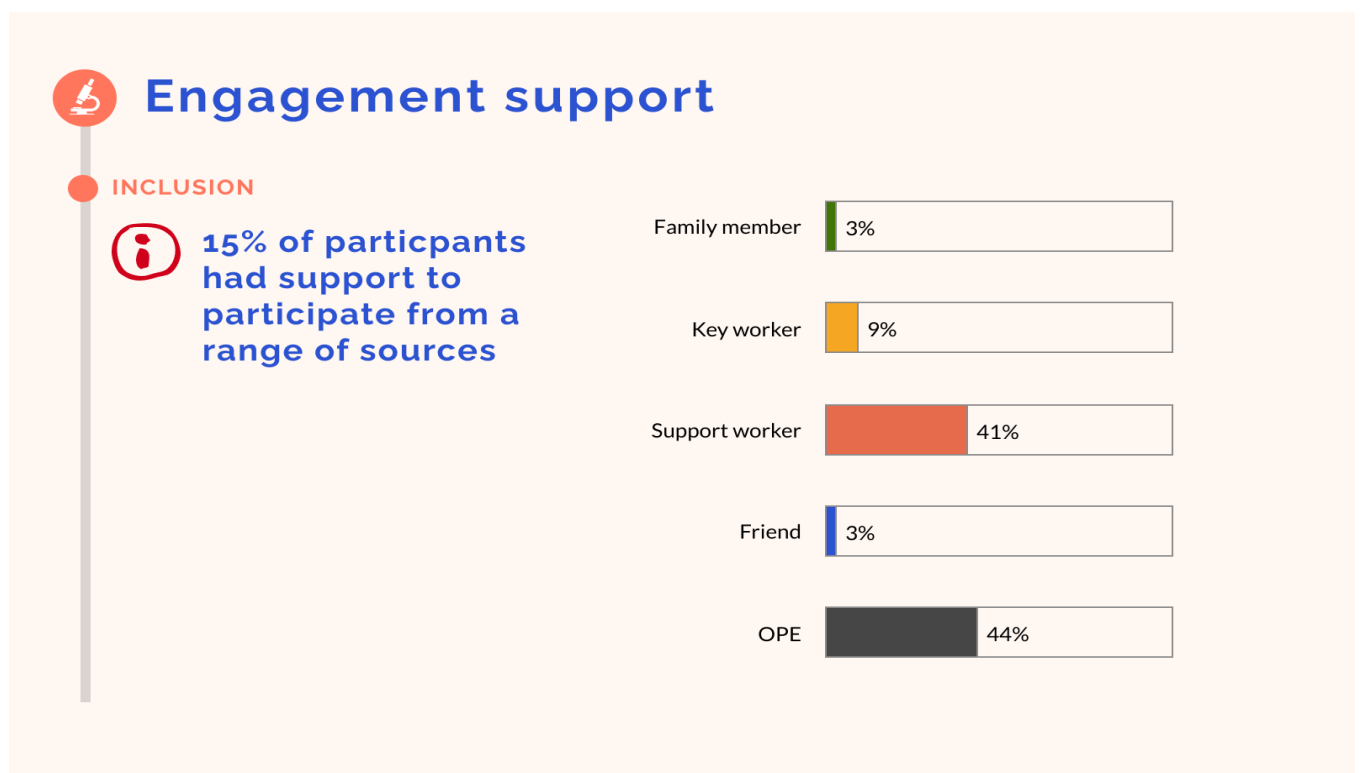
OPE supports people in Redbridge and surrounding boroughs



Redbridge (64%) Waltham Forest (36%)

Diversity, inclusion and equality are core values of One Place East. The research project aimed to support as many people as we could to overcome barriers to participation. As well as having a range of methods to participate; we also worked with partners to put in place the required support for people to have a voice.

Engaging people with a learning disability who live in a range of settings; some with other additional needs, helped us assess if there were different experiences of the pandemic.



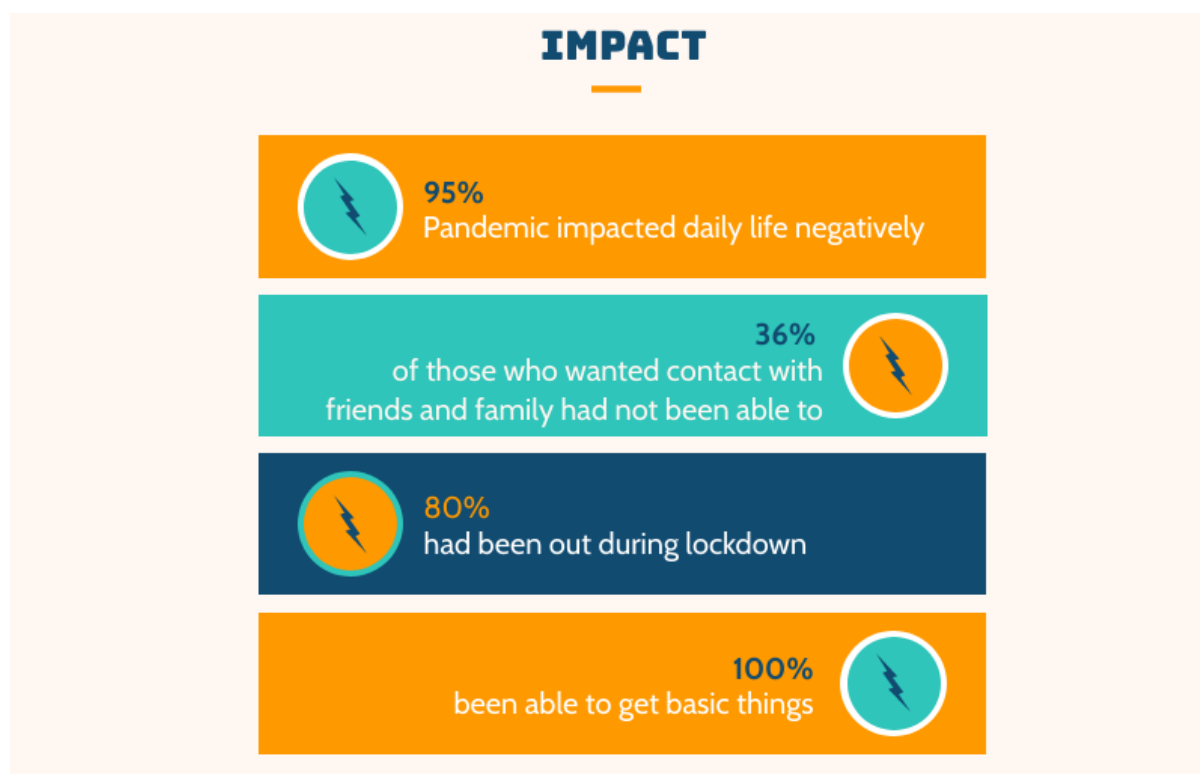
We would like to thank everyone who took part in the research. Including those who helped someone share their experiences, complete the questionnaires and filmed contributions.

A big shout out goes to members of our Learning Disability User Group for helping design the questions and test to see if our systems worked. You were amazing!



Impact of Pandemic

We explored with people how the pandemic had affected their daily lives and how they had adapted.



In the qualitative interviews conducted people described how they enjoyed the first 3-6 weeks of lockdown but then got depressed. Others described how they felt the last year was distressing.

“there is only so much music you can listen to or TV you can watch.”

Due to physical illnesses some people also had to shield. As a result, they have not been allowed out for a year. One person also became physically ill as a result of not being able to do the usual physical exercise that keeps him well, adding to the mental and physical trauma of the pandemic.

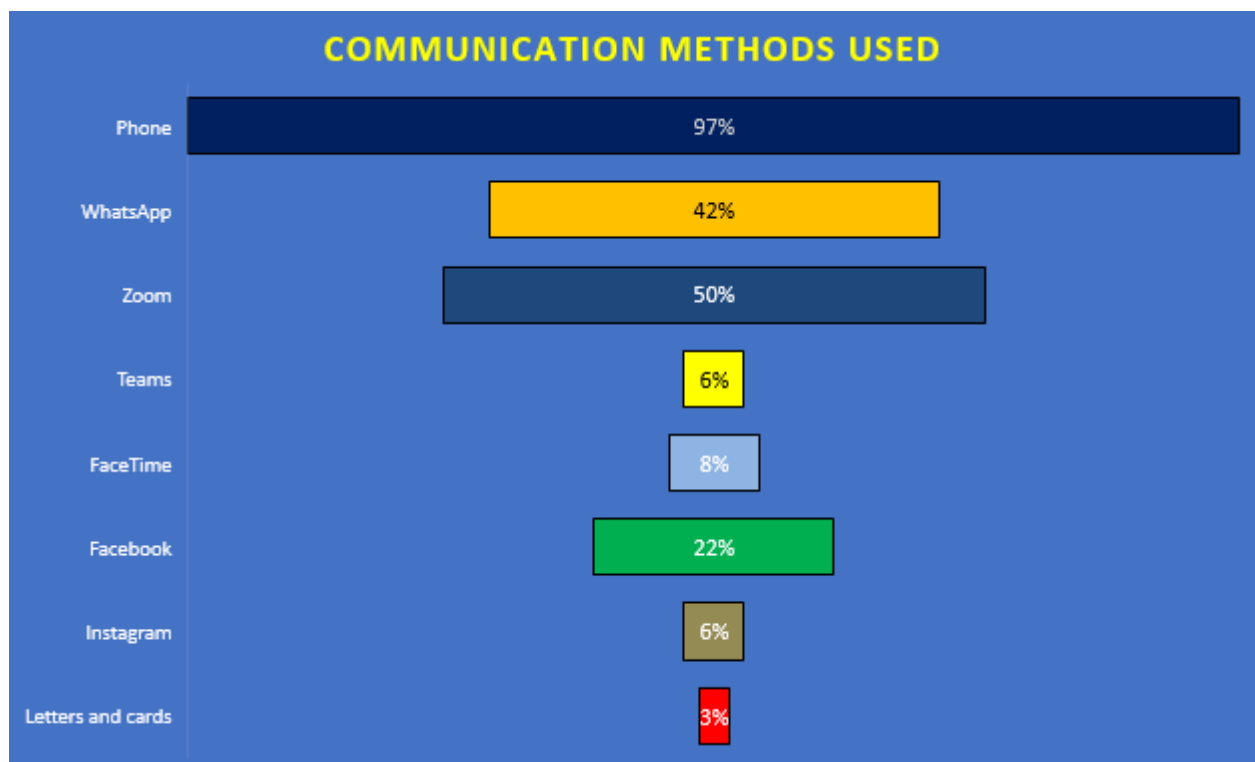
Contact with Friends and Family

95% stated they were getting on well with the people they were living with during lockdown/pandemic.

36% of participants who wanted contact with friends and family has not been able to. The barriers to contact were identified as:

- Regulations on contact, travel and social distancing
- Can't use social media
- Fear on contracting COVID

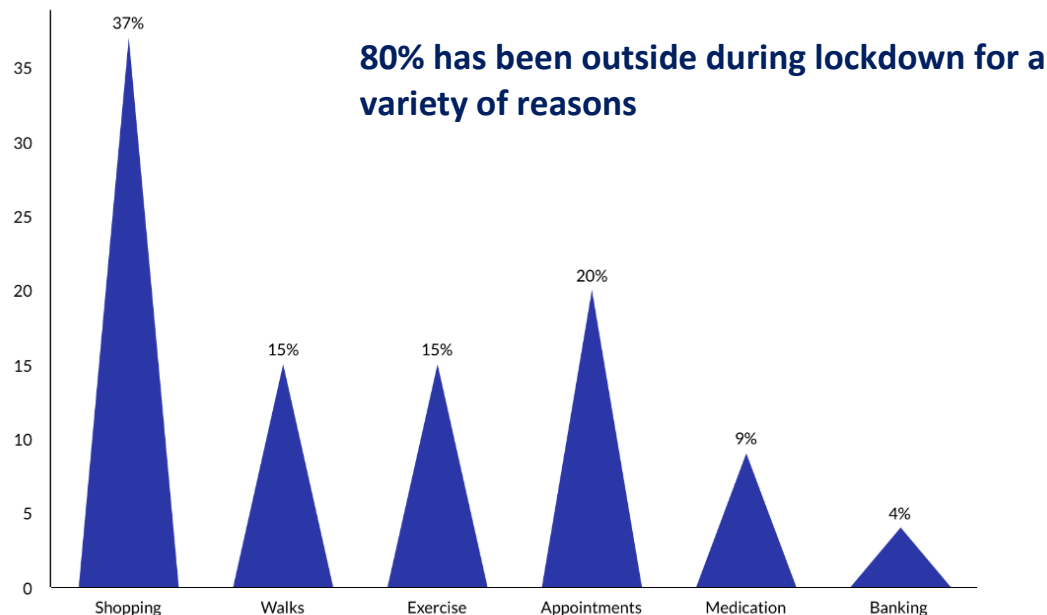
There were a variety of methods used to keep in contact with people during lockdown. By far the most popular was the telephone, used almost twice as much as digital tools.



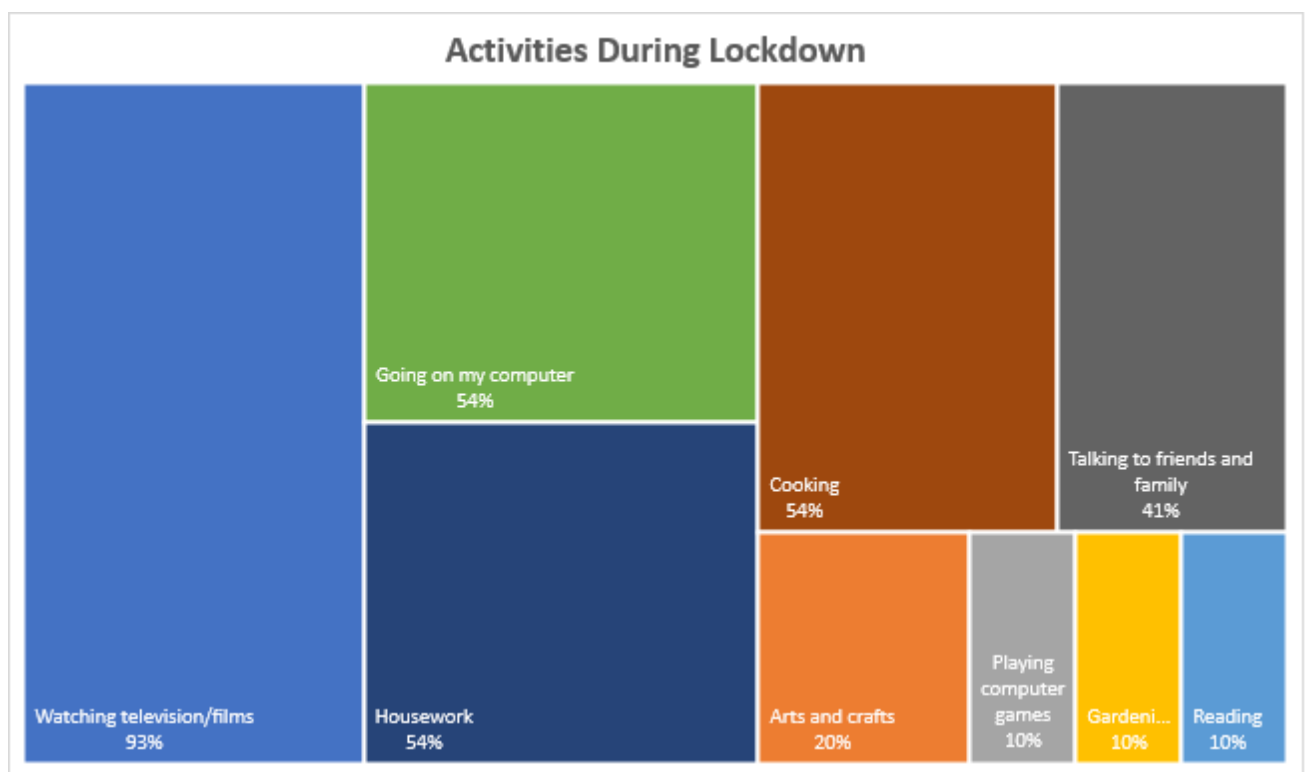
One person described how talking to his friends online daily is what kept him going, as he was unable to go to work.

Daily Life

95% reported the pandemic has impacted their daily life negatively but everyone had been able to access basic things such as food.



Several people highlighted how the walks or shopping trips had only been possible due to support from local organisations. Otherwise they would have been unable to fulfil these basic tasks.



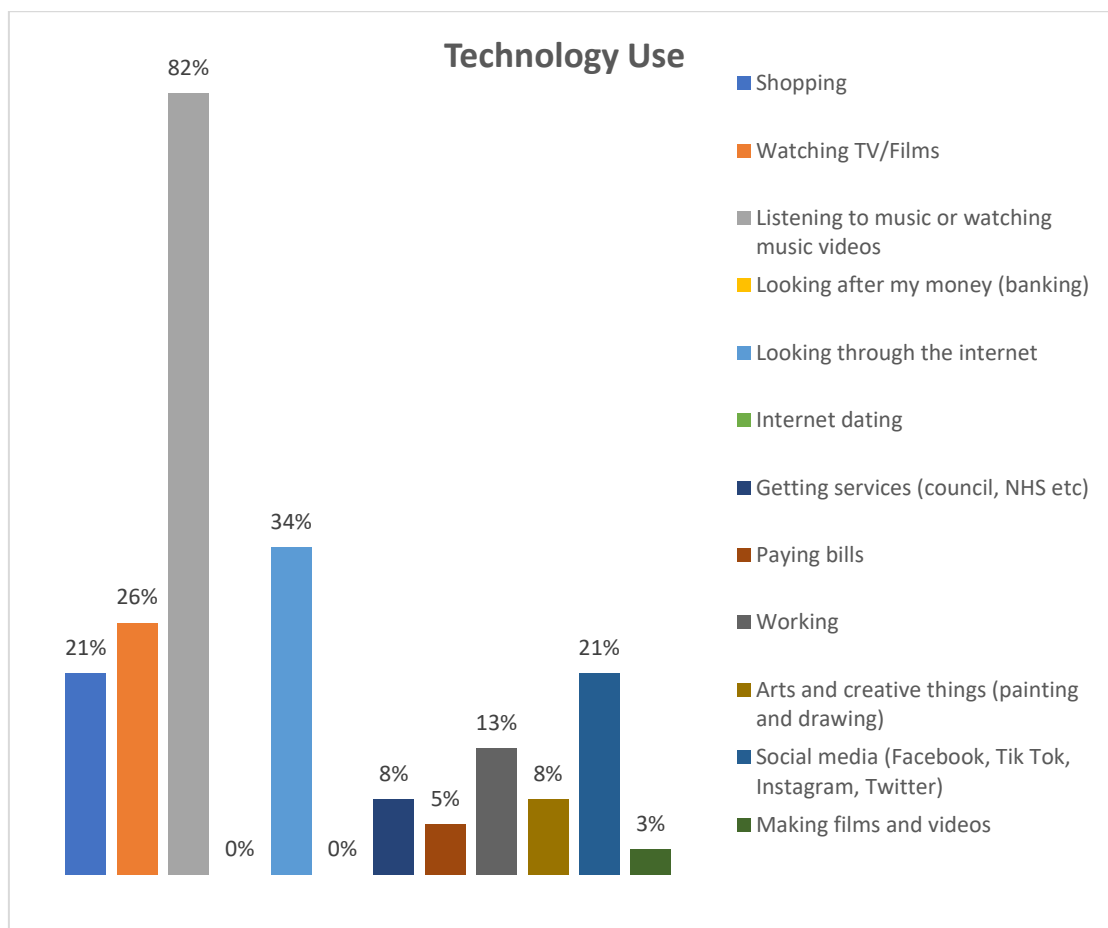
We asked people to identify the positive and negative things about lockdown.

[illegible][illegible]

The research identified a higher use of technology than expected but the profile of use and other factors enable more insight into the findings.

- Impact of Pandemic on Adults with a Learning Disability – OPE 2021 Page 10

- 34% use technology just to browse the internet
- No respondents use technology to manage their money
- No respondents use technology for internet dating
- Only 5% pay their bills online
- Only 8% access public services online
- Only 8% use technology for arts and creativity
- One Place East provided some of the respondents with tablets and digital support during the lifetime of the pandemic distorting those reporting the use of technology and without purpose
- 8% also stated the online activity was with support worker assistance
- Of those who shopped online 59% had not been able to get what they wanted
- There was evidence of people gambling online



The data masks the support required to enable people to utilise their technology. One Place East provided substantial support to help people to go online and utilise the technology they had. They also provided equipment and data to ensure the most vulnerable were not excluded digitally.

One Place East:

- ➡ Supported 58 people with digital assistance
- ➡ Delivered 174 technology support sessions
- ➡ Provided 500 telephone wellbeing checks that often included technology support

Training and supporting people with a learning disability to use technology virtually presented many challenges. Even those who did use technology only managed to utilise it for basic functions, few accessing services, banking or shopping online.

Barriers to Access and Inclusion

30% of people who use day services were unable to benefit from online activity during lockdowns when it moved online.

A range of reasons were identified to evidence the exclusion and inequality experienced when it comes to the use of technology.

- No use of technology apart from tv
- Requiring support to go online
- Getting services had been difficult, couldn't work out how to do it
- No access to a computer or tablet
- No access to smart phone or data
- Lack of confidence and skills to use the required apps

Value of Access

For those who had the skills to use technology and had access to equipment and data; the benefits were evident.

- ✓ Keeping in touch with family and friends
- ✓ Play online games
- ✓ Able to access faith activities
- ✓ Access to information on health issues, Covid-19
- ✓ Ability to make medical appointments
- ✓ Attending different Zoom meetings to have a voice and feed into planning
- ✓ Being able to follow exercise sessions

The outcomes of digital inclusion:



Observations and Potential Risks

The research identifies some risks that the increased use of technology during the pandemic has created or amplified. Increased access to equipment without the skills and full understanding of safe use, paired with a lot of free time identified issues that One Place East and our partners need to address.

- Safeguarding and ensuring people with learning disabilities have at least a basic understanding of how to use technology safely
- Risk of gambling with associated financial and addiction impacts
- Risk of scamming and exploitation
- Potential exposure to bullying, hate crime and trolling

Repeated and extended lockdowns, social distancing, less connection with services as well as family and friends are all clearly impacting on the wellbeing of those participating.

People felt safe from catching the virus in lockdown where they lived. However, there were feeling and emotions consistently identified that impact on a person's wellbeing in several ways.

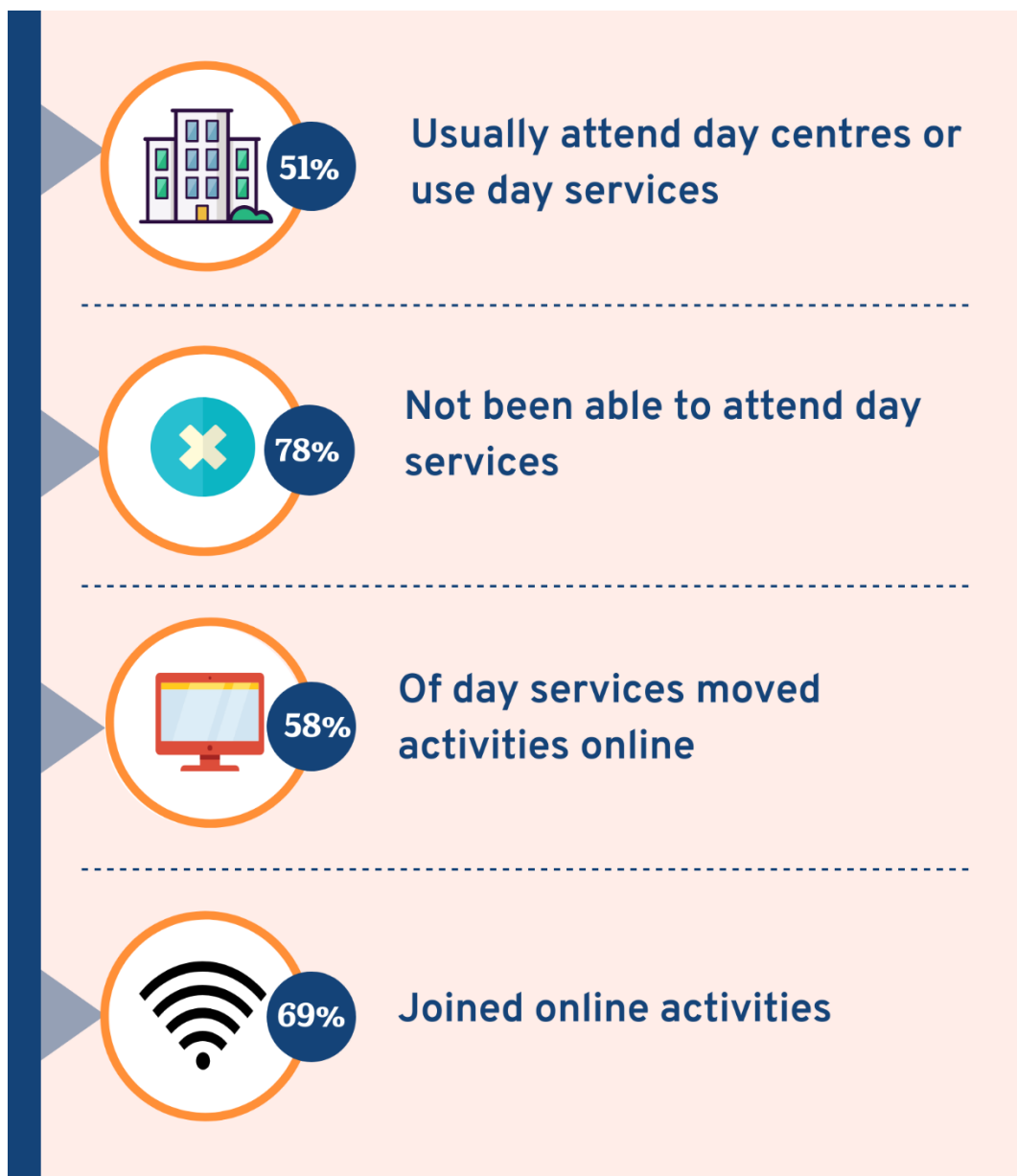
- Loss of social connections and support networks
- Isolation and loneliness
- Anxiety and depression
- Loss of social skills and confidence
- Less positive outlook

Day Centres and Day Services

We wanted to gain some insight into the impact of the pandemic on day services and day activities for adults with a learning disability.

78% had not been able to attend their day services, further exploration found that these were the people with greatest need. Many had not been able to get any day services since March 2020. Accessing day services seemed to be a very hit and miss experience.

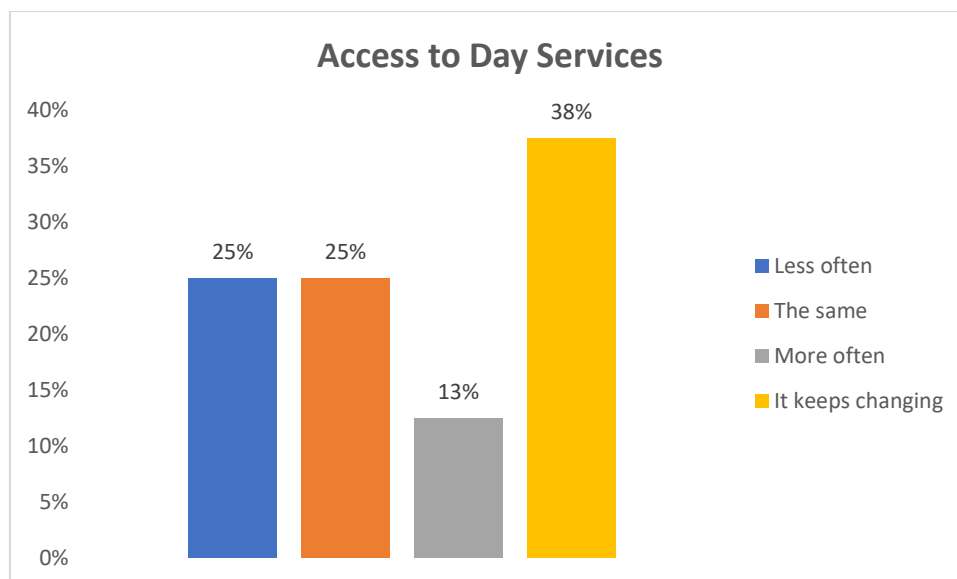
The research also provided interesting information about what people do during the day and which elements they miss most.



The 78% of people who used to go to a day centre or use day services but have not been at all is higher than the national average *in the* [National Coronavirus and Learning Disabilities Study](#).

The constant changing of guidance and access to services was the most unsettling for people. 38% stated that their access to services kept changing.

For many, having certainty and a familiar structure to days gives security. Routine is important for maintaining positive wellbeing and managing emotions.

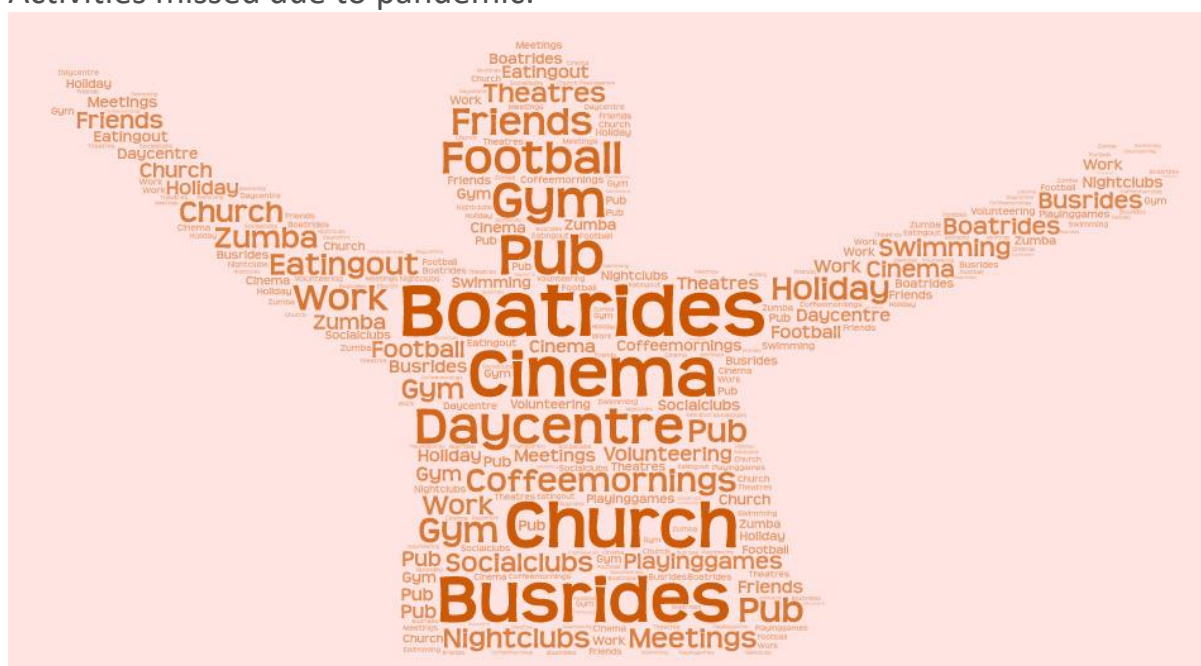


Activities cannot do anymore

Participants identified a range of activities the pandemic had prevented them doing. Many are important for physical health, fitness and mental wellbeing.

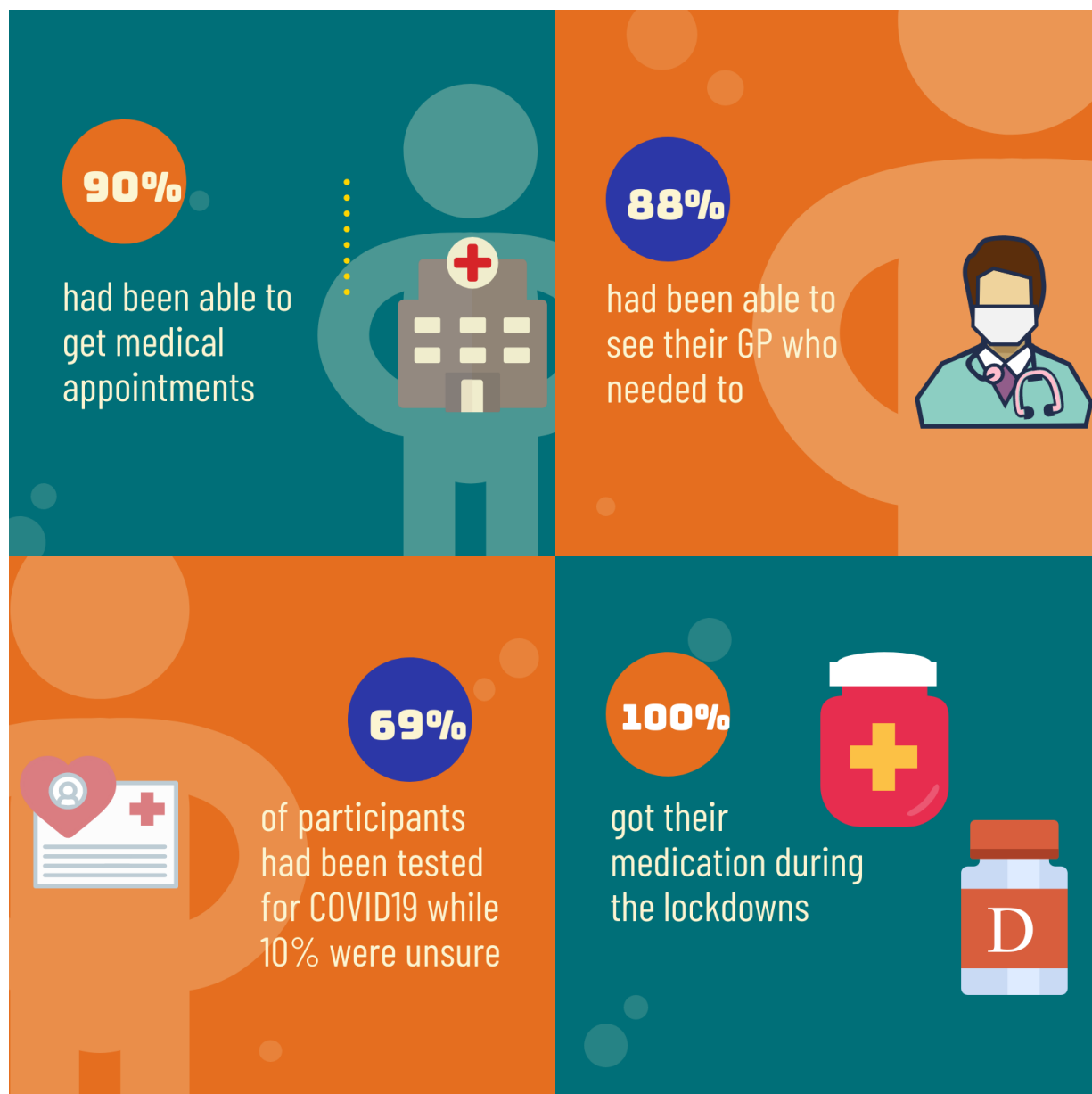
The diversity demonstrates that for many adults with a learning disability they participate in many cultural, social, sport, faith-based, exercise, community and employment activities. Central to nearly all of them is the social contact with other people; something many described as the hardest thing to go without.

Activities missed due to pandemic:



Accessing Healthcare, Medicine and Vaccines

We wanted to see if people had been able to get needed healthcare and the level of vaccine hesitancy. Of all the areas covered in the research, accessing healthcare was one of the most consistently positive stories.



Our research only identified a few people who experienced access problems with primary care. These experiences related to not being able to get through on the phone and/or understanding the new procedures.

Issues relating to COVID testing were identified in small numbers for people with complex needs. These related to the trauma caused by this procedure. In specific cases sedation or some level of restraint was needed in order to

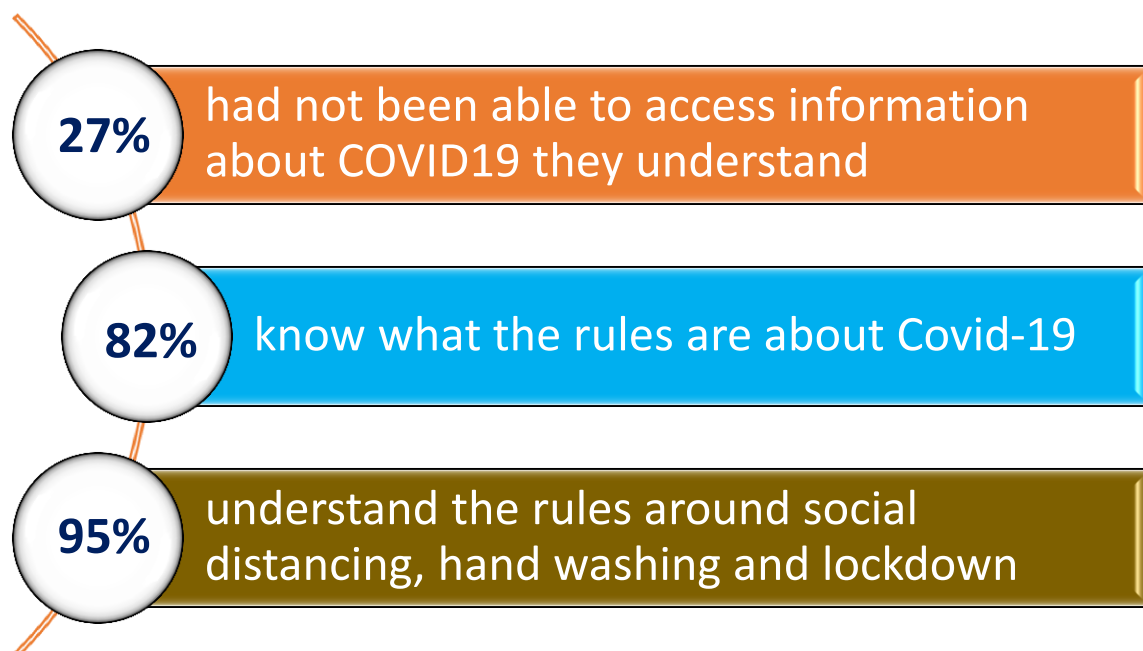
administer the test. The frequency of testing was dictated by the supported living or care home provider. Triggered by family visits and then returning to the group home.

Information and Government Guidance

The language and volume of information, guidance, regulations and laws linked to the pandemic has been overwhelming for many people across the country.

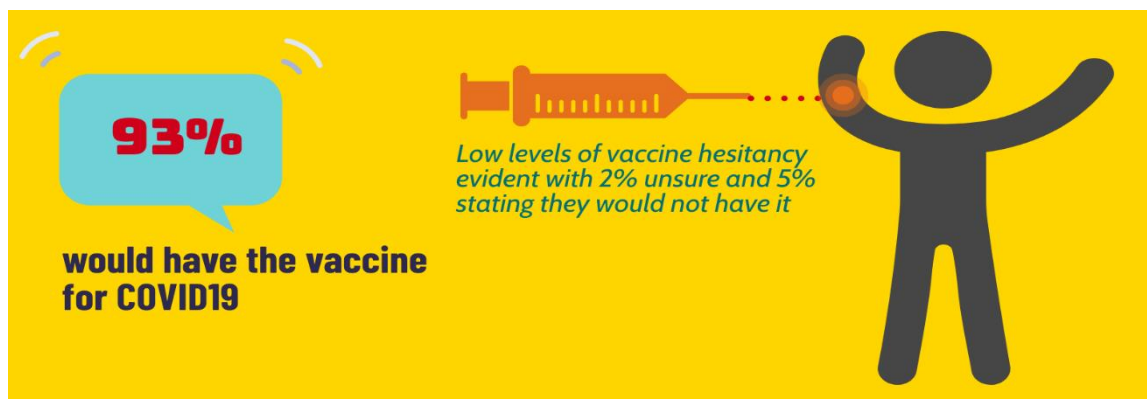
Keeping up with changes to the rules and understanding why they are needed can present additional challenges to people with a learning disability or cognitive impairment.

The biggest issue recorded was not being able to get information in a format that was accessible and understandable with assistance. However, the statistics about knowing and understanding the rules hides the level of work required with many people on a one-to-one basis (phone/online) to ensure comprehension.



The level of understanding of those we engaged in our research is almost in line with the results of 70% in the [National Coronavirus and Learning Disabilities Study](#).

Vaccination



Our research shows that a higher percentage of people would take the coronavirus vaccine than the [National Coronavirus and Learning Disabilities Study](#) results of 80%.

With such small numbers of people cautious about taking the vaccine, we have only been able to identify two reasons for this.

- Fear of needles
- Fear of the link between vaccines and Autism

Employment and Money

Only **22%** of research participants are in paid employment, despite 68% being of working age. A reflection of the historic inequality and exclusion faced by people with a learning disability in the employment market.



Our qualitative interviews provided more insight into the challenges experienced working from home. People described problems getting online or dealing with technology issues when working from home. The level of support that would normally be available in the workplace was lacking at home.

“There were only so many times I could phone work for support in a day, then it became annoying.”

Several participants who worked from home described the additional stress and isolation experienced. Although positive to be still working, the reduced support available appears to have really impacted some.

How employers treated people with a learning disability during the lockdowns needs further investigation. ONE PLACE EAST is concerned that some may not have had access to advice to ensure their rights and entitlements were protected.

The issue is going to be overcoming the fear people described by many about going back out in public again once restrictions are lifted. The barrage of information and constant reinforcement of key messages and restrictions has really scared many people.

Financial Impact

Only a very small percentage (3%) had experienced a negative impact on their finances from the pandemic. Additional pandemic supplements to Universal

Credit had led to 15% having more money than before. Restrictions meant that most had been unable to spend any money of it.

95% had not tried to get new or more benefits during the last year, despite One Place East delivering over 500 telephone welfare and befriending checks. The remaining 5% did not know.



Recovery, Conclusions and Recommendations

Requirements for Recovery

When considering the recovery from the pandemic, our research highlights a series of common themes:

- Anxiety about going out and the risks
- Fear about being able to keep safe once restrictions lift
- A desire for everyone to follow the rules
- A request for clearer information and guidance
- Support to address the mental health impact is needed
- Exercise activities to help improve physical and mental health
- Wearing of masks and handwashing continues

This word cloud captures what people felt are required to ensure a positive recovery from the pandemic.



Conclusions

The pandemic response by all partners in Redbridge needs to be recognised for its success in mobilising organisations and residents to ensure the most vulnerable in the borough were prevented from crisis.

The transformation of services to meet evolving needs in super-fast time required immense energy, creativity, people power and resources. One Place East responded to meet the needs of adults with a learning disability by:

- Closing all face to face services and moving them to telephone, email or digital delivery within a week
- Increasing digital information content, e-newsletters and social media
- Providing telephone welfare checks and befriending
- Providing a WhatsApp based peer support group 7 days a week, 12 hours per day
- Creating challenges and competitions to provide activities for people to do at home
- Providing telephone and online digital support and training
- Providing laptops and tablets for those in need to prevent exclusion
- Running online workshops, support groups, meetings and classes
- Delivering practical support and assistance where required including shopping, transport to essential appointments, data bundles, energy top-ups, collecting prescriptions
- Supporting online Comedy Club Laugh-Able
- Live streaming events and discussion groups
- Fast tracking referrals from the Redbridge Coronavirus Hub

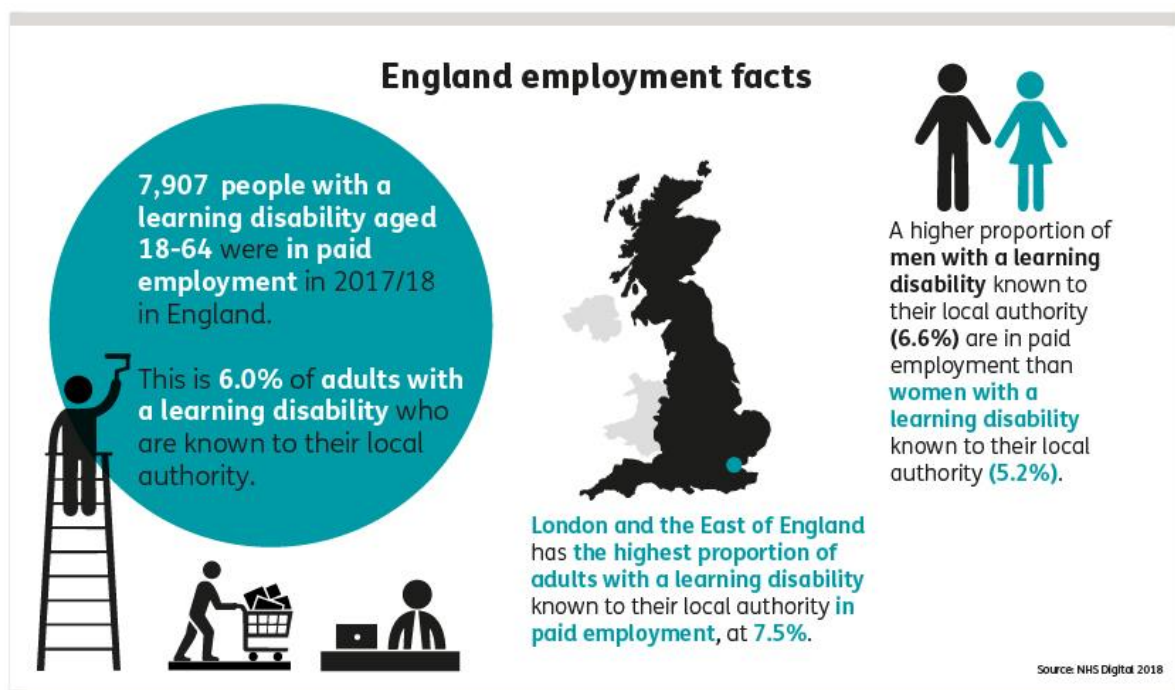
We are extremely pleased with the level of participation in this research. This was achieved partially through the support of partner organisations and our committed staff and volunteers.

One of the things the last eighteen months has highlighted is the existing levels of inequality, exclusion and discrimination experienced by people with a learning disability across society. The pandemic merely acted to amplify these factors; especially for those with the greatest, most complex needs or those without support networks.

Uncertainty, removal of routines and changing guidelines has impacted many people's mental health and sense of wellbeing. The inability to see friends, family or access valued day services has added to the challenge and in some cases caused mental distress and illness.

The fact that only 22% of working age adults with a learning disability participating in our research are in employment, signifies the exclusion from the labour market. This finding is far higher than the national average and reflects the profile of people we were able to engage in this exercise.

Government data on employment for people with a learning disability truly demonstrates the level of inequality and exclusion.



Our findings demonstrate the efforts the NHS and its providers have made to ensure people with a learning disability could access the healthcare and medications they required.

Vaccine hesitancy amongst our participants appears very low. We hope an indicator of high levels of uptake once eligibility was announced.

Digital exclusion has been a constant battle throughout the pandemic and our findings suggest this is likely to continue without further investment and collaborative working. Technology is playing a greater role in everyday life for things like accessing services, banking, shopping, learning and employment; in many cases it's use has been speeded up by the pandemic. So that existing inequality and exclusion is not further embedded, it's everyone's responsibility to ensure no one with a learning disability is left behind.

Friendships, social connections and access to support networks are so important for people with a learning disability as our research has found. More ways to meet this basic human need should be explored that increases inclusion in wider society, culture and community activities.

In order to ensure a fair and equitable recovery for all, the needs of people with a learning disability need to be considered thoroughly. There is real anxiety about going out again and a return to 'normality' without the protections of masks, distancing and handwashing. The factors could inhibit our community feeling the full benefit of a recovery. This could potentially further amplify existing exclusion and inequality.

Recommendations

One Place East has carefully considered our recommendations and with our User Group identified the ones which need the most attention. Some recommendations focus solely on recovery from the pandemic, others on the longer-term changes required to address long standing inequality and exclusion.

1. Partner agencies work together across the public and voluntary sectors to **support people anxious about going out or returning to normal activities** once all lockdown measures are eased in July 2021.
2. **Investment is put into addressing the mental health impact of the pandemic on adults with a learning disability.** Historically, tailored mental

health and wellbeing support has been difficult to access for this segment of our community.

3. Work to **address the inequality and exclusion in the labour market** for people with a learning disability is increased.
4. Interventions to **address digital exclusion** are planned and commissioned for adults with learning disability. This should also include involvement of users in the coproduction of services and transformation programmes locally to increase inclusion to services and support.
5. New **approaches to build friendships, social connections and community support networks** are explored that will increase inclusion in wider society, culture and community activities.

As part of this work, participants have done a short accessible film which you can see via our website www.oneplaceeast.org