healthwatch
Liverpool

The Covid-19 Pandemic and Mental Health in Liverpool

What Disabled People Told Us

Contents

Introduction

In March 2020, Liverpool, along with most of the world, went into lockdown as a response to the Coronavirus/Covid-19 pandemic.

The impact was felt in many ways and will continue to be felt for many years to come – economically, socially, politically and personally. Physically and mentally.

As the reality of lockdown became clear, Healthwatch Liverpool decided to ask people about how the changes to their lives were affecting their mental health. And, over several months, we continued to ask people about the longer-term mental health impacts of Covid-19, and their concerns for the future.

We developed an online survey based on feedback from local people of all ages, and we ran it from June 2021 to January 2022. In total we received input from 343 individuals.

We have grouped what people told us into a series of reports (covering 'Executive Summary and Recommendations', 'Key Findings', 'Children and Young People', 'Disabled People', 'Case Studies' and 'Additional Data') all of which can be found on our website www.healthwatchliverpool.co.uk/Covid-MH-Report.

As part Healthwatch Liverpool's wider survey about the impact of Covid-19 on local people's mental health we wanted to make sure that we listened in more depth to how clinically vulnerable disabled people coped during the pandemic. We wanted to know what things helped them, and what prevented them from maintaining good mental health and emotional wellbeing. We did this because we wanted to make sure that their opinions were heard by the people who design and provide mental health services in Liverpool.

To produce this report, Healthwatch Liverpool worked in partnership with Harriet Brignal, an MSc student in Global Health at the University of Glasgow School of Social and Political Sciences. Thanks to Harriet, and the University of Glasgow, for allowing us to include work from Harriet's dissertation within this report.

What We Did

This work was informed by Healthwatch Liverpool's initial findings[1,2] that disproportionately higher numbers of people with a disability felt that their mental health had been affected by the pandemic, compared to the wider population. This finding backs up evidence from across the country which shows that disabled people have cited Covid-19 more frequently than non-disabled people as having a harmful impact on their mental health (46% for disabled people and 29% for non-disabled people) (ONS, 2021).

This study involved in-depth interviews with 8 disabled people, looking at:

- How the Covid-19 pandemic impacted on their mental health and wellbeing

- How the Covid-19 pandemic affected their access to healthcare or wellbeing services

- What strategies they have developed to improve their wellbeing and reduce the impacts of the pandemic

The participants were recruited via local disability support organisations and networks and were interviewed via Zoom or telephone. They ranged in age from early twenties to over eighty. Some lived alone, others with partners and some with family. Five identified as male, three as female, and all identified as White British.

Please note: some of the quotes in this report are composites, based on input from more than one person, to increase their anonymity. This was agreed with the participants as part of the study.

[1] www.healthwatchliverpool.co.uk/report/2020-07-22/coronavirus-survey-interim-report-april-may-2020
[2] www.healthwatchliverpool.co.uk/report/2020-11-25/coronavirus-survey-interim-report-may-august-2020

What We Found Out

1) Pandemic Effects which have impacted on the Mental Health and Wellbeing of Disabled People living in Liverpool

a) Experiencing Clinical Vulnerability during the Covid-19 Pandemic

Four of the eight participants spoke in depth about having a long-term health condition that contributed to them being clinically vulnerable to Covid-19, and how they found their general wellbeing and mental state impacted by this experience:

"When the virus started hitting these shores, I said to my boss 'I'm gonna go home until we figure out what's going on'. There was some data that was coming out which was worrying and anybody over 60 wasn't being given a ventilator. If you were 60 and you had a condition, say like mine, I'd be last in the queue, seriously. It's terrifying, and for me, worry is the worst thing I could possibly do."

This reflects the feelings of participants during the early months of the pandemic when there were rising concerns about patient prioritisation in triage assessments due to excessive strain on hospitals, resulting in bed and ventilator shortages.

Participants felt that their health concerns were heightened at this time, resulting in anxiety around ableism (discrimination against people with disabilities) within decision-making, and assumptions about the 'quality of life' of disabled people. Participant accounts of this period highlight the stress that individuals at greater risk from Covid-19 experienced. This was linked to the additional concerns of some for whom stress was a risk factor causing further harm to their physical wellbeing, highlighting the complex impacts the pandemic has had on the lives of those at greater risk from the virus.

b) Shielding Status: Confusion and Fear

Of those who were clinically vulnerable, three spoke of being given 'shielding patient' status and spending from six months to over a year shielding at home. These participants discussed the mental impacts of the shielding process:

"I found it hard to deal with. I got letters off the doctor because I was under the hospital, then I got a letter off the council, and I think I got another letter off the GP. It scared me a fair amount to be honest. I was getting it from every direction, all saying 'stay in, don't go out, you'll die if you leave the house!' and that is actually pretty terrifying you know? It did have a definite impact receiving constant letters from all these different sources, constant texts, phone calls… I did actually reach a point about 6 months in where I did get up one morning and my partner was like 'Oh hiya, do you want a cup of tea?' and I just burst out crying."

Whilst the specifics of the difficulties encountered by each participant when shielding varied, depending on factors such as personal living situation or interpersonal relations at home, all three accounts agreed that the time spent shielding was detrimental to their wellbeing due to worry, boredom or spending what they felt was an unhealthy amount of time indoors. Participants also all discussed finding information about their personal shielding status to be confusing and disorganised, leading to uncertainty about how to ensure their safety.

c) Adjusting after Shielding

When discussing their concerns for the future, those who had experienced clinical vulnerability disclosed further anxieties about the prospect of adjusting to life after lengthy periods of shielding:

"Now my problem is a mental one, rather than a physical one. I'm gonna have to go back to work in September and I'm still avoiding going to the shops? I think it's all a bit too quick personally... I think maybe their thought process is, well, less people are dying now, because it's already kind of ripped through the older generation and people who've had more significant health issues, but the hospital admissions and the death toll is rising again..."

Participants still felt a lack of protection as social distancing guidelines began to ease, leading to expectations from employers that individuals should return to work.

Two participants highlighted the mental impacts of the pressure to return to a busy workplace following extensive periods of shielding from a virus that was still a present and ever-developing threat to their health. They felt that as sub-par protections (as they saw them) dissipated and discussions turned to a return to 'normality', their future was overshadowed by remaining health concerns and that a 'one size fits all' approach took no account of their individual circumstances.

d) The experience of the Covid-19 pandemic for those with an existing mental health condition

Three of the research participants discussed the challenges of negotiating daily life throughout the pandemic with mental health diagnoses such as obsessive-compulsive disorder, post-traumatic stress disorder and chronic depression; and the worsening of symptoms that they experienced. Lockdown could be more worrying to these participants than the virus itself.

"I don't do well in enclosed spaces so being stuck in the same four walls is practically torture. It's a lot of pressure, especially with mental health issues. I felt like I was in a whirlwind to be honest. Like I was in a washing machine. I felt like I was losing my mind."

Participants discussed aspects of the pandemic that they felt made their mental health conditions worse, such as experiencing a loss of social contact or having

an extreme change in daily routine. Whilst each participant faced individual stressors and responses to them, participants' experiences centred around feeling an intensified loss of control over their circumstances and a lack of availability of support.

e) Feeling Socially Isolated

One of the most concerning themes was the impact of social isolation:

"I think for me it was just not socialising with people in general, you know? With me not really having any sort of contact with my family and that, erm, I felt very isolated. I found it very hard. I'd say it wouldn't of been too bad if I'd had another person with me, it's not nice not having any support. I think that lockdown made a lot of people ill. The lockdown itself. When you're by yourself it can be boring. Your mind starts overthinking and that causes a lot of problems when you've got nobody else to communicate with. It's 18 months or more when you think about it. It's a long time to not be mixing with people and just doing normal things…"

Five of the eight participants discussed the effects of having limited social contact with others. Some lived alone throughout the research period, or for certain parts of it, and some found it increasingly hard to reach out to others as they were having a difficult time coping. One participant described the challenges of having no family support system, being clinically vulnerable to the virus and living with chronic pain. Another felt isolated living within supported independent living, having no connection with others in their home. Some lived with family but found the overall experience of living under lockdown restrictions to be socially isolating due to loss of work and socialisation, and others experienced acute social isolation.

f) Experiencing Little Change

A sub-theme emerged from one interview in which the participant reported having experienced very little change in their day-to-day life during lockdown, stating that the social conditions of the lockdown itself had no impact on their wellbeing as they were already accustomed to staying at home because of restricted mobility:

"I really, honestly can't say that it has impacted upon me at all. I really, really mean that. I mean, probably because I've accepted that I can only do a certain amount anyway, erm, I just live with that in my mind…"

This participant went on to describe the positive impacts of the pandemic on their life, such as the local supermarket introducing a specific priority service for digitally isolated older people shielding at home (this participant did not use the internet), and the wave of offers of support from the local community. This person's experience demonstrates the levels of social exclusion that some individuals already faced prior to the pandemic.

g) Experiencing Positive Change

Another participant highlighted how, despite it being a very difficult time, lockdown conditions had benefitted them in certain ways:

"I'm not a very social person. I don't particularly like people. Erm, so if anything, the lockdown did me a world of good in that respect because I don't have to speak to anyone. I don't have to leave the house to see people. Erm, so it's kind of a good thing in that way but you can't live life that way. It's not healthy. To live like that."

This participant discussed the experience of being autistic and feeling relief from social stressors, and also reflected on an underlying concern that their increasing self-isolation was unhealthy. This finding, and the one above, highlight how the mental challenges experienced by some cannot be generalised as applicable to all due to the scope of individual experiences. Whilst some found reduced social contact to be the greatest factor impacting their mental wellbeing, others already accustomed to less social contact experienced a range of other stressors such as barriers to healthcare and further difficulties.

h) Financial Worry

A further sub-theme highlighted by one participant was the impact of financial worry faced by many throughout the pandemic:

"…there was a whole sector of people who were completely forgotten about. I don't know what I'd of done if I'd been completely on my own, I really don't. Because everything went, absolutely everything and I wasn't entitled to claim anything apart from when my doctor recommended that I went for the ESA and I didn't get that for about the best part of a year really… but that was only about 150 quid every few weeks or something, it doesn't pay your rent or your bills or anything…"

After losing three sources of income due to the continued extensive lockdown conditions, this participant expressed frustration at feeling failed by the UK welfare system. They fell under immense financial strain and found it mentally challenging being left financially dependent on their partner.

As can be seen above, there have been a multitude of impacts on life for the individuals involved in this project that have contributed to stress and feelings of reduced wellbeing. In addition to the many disruptions to day-to-day life, participants also discussed how they faced complex barriers to healthcare and wellbeing support services, further contributing to stress, anxieties, and mental burden.

2) Impacted Access to Healthcare and Wellbeing Support Services

All eight participants discussed experiencing impacted access to healthcare or wellbeing support services in the form of delays, cancellations, restricted access or over-stretched care. Many felt anxious or experienced a deterioration of their health and wellbeing due to disruptions to routine appointments or planned surgeries and some described feeling pressure to manage and monitor their own care due to the strain on services.

i) Disruptions to Routine Appointments

"...even down to stress and anxiety because I had, also, hospital appointments in different clinics, so they were all cancelled because of Covid which causes you anxiety and that. I was supposed to have trigger-point injections in my neck and my shoulders in December and because of the Covid I couldn't have them, so I've suffered with chronic pain. I begged the hospitals and all that, that causes stress and all that. Not being able to get in touch with people because of the Covid, you know. I never even got a letter to say we'll make another appointment and that, so those appointments have been missed, yeah."

Disabled people and those with long-term health conditions are often in contact with a range of services to maintain and support their physical and mental health. Disruptions to service provision have, therefore, had a profound impact on this group. Three participants discussed experiencing prolonged pain due to the cancellation or delay of treatments or surgeries because of the pandemic, which also caused great distress.

j) Overwhelmed Services

Participants described stressful experiences of struggling to navigate overwhelmed essential services, and concerns about worsening health during this period:

"I have to have my bloods done every three months for diabetes checks and it was a struggle trying to book appointments. My blood sugar was high before we went into lockdown and I was getting no exercise, so that was really worrying me. You have to phone up and at one point, whoever was on reception was lifting the phone up and putting it down again. I went down in my car, and she said come in and while I was waiting the phone was ringing and she was doing it in front of me. I think they were understaffed but I'm not sure."

k) Inaccessibility of Remote Healthcare Appointments

One participant further described difficulties relating to navigating the sudden changes to care provision.

"…I get trigger finger. I've got locked fingers if I'm pressing, right… that gets frustrating. When people go 'oh, we'll let you know by text' and I say 'no, can I have paperwork or hard-copy?' It's been difficult getting around some of the (CBT) coursework as well by using a phone because I haven't got a pad. I haven't got an iPad or a computer, so it's been a challenge for me… because it's not a face-to-face thing now, which it would have been if there wasn't the Covid."

This participant had been awaiting a twenty-week Cognitive Behavioural Therapy (CBT) course prior to the pandemic and as face-to-face services became suspended, they found the move to remote facilitation frustrating as the course materials were only made available online, meaning they had to use their mobile phone due to having no access to a computer. Although this participant discussed finding the CBT course to be very helpful, despite being somewhat inaccessible, for others this might have acted as a deterrent from continuing or a complete barrier.

l) Delays to Planned Surgery

Two participants discussed the impacts of experiencing extensive delays to planned surgeries, resulting in prolonged pain, reduced mobility, and emotional distress:

"I was expecting quite soon that I was going to be given a date to have this operation done not long after the beginning of October. Covid came onto the scene and all the operations for what my sort of operation was called were put on hold… I remember the next appointment I had was on the 29th of January and there again I went as though I was a new patient altogether. I didn't hear anything for quite a while. Only to realise that Covid had taken over yet again… So I felt, well, good grief. I'm never going to have this hip done. So now we're talking into early 2021. I remember saying to the registrar when I'd seen him on the last occasion, 'would it be worth considering going privately?' …and this registrar said to me, 'to be perfectly honest, at this point in time, it'll hardly make any difference'. They had to get round a long list of people. It's just been so drawn out, it really has…"

One participant waited for a total of twenty-one months for a hip surgery, leaving them living alone with reduced mobility, in pain, and unable to leave the house. By the time they were given a date for surgery they had been further diagnosed with breast cancer and were entirely exhausted by the process. The NHS continues to face the severe effects of Covid-19 on planned surgery in the UK and millions of people remain on waiting lists with little idea of when they will be seen.

m) Waiting for Mental Health Services

Four participants disclosed having sought some form of support for their mental health throughout the pandemic and two participants spoke in detail about the wellbeing impacts of experiencing extended waiting periods after seeking support:

"I've had a terrible time. All the services got overloaded, so I couldn't get any counselling. I'm still on counselling waiting lists because of the backlog of Covid. You offload everything onto one person about everything that's going on, and they write all that down in a little assessment and then you've got to wait weeks before you see someone else to tell them the whole stuff again."

This person said their mental health had been *"Massively"* impacted by this delay. Both participants raised an important point about the mental impact of opening up about their mental health to service providers during assessments and through referral processes to then be left to wait for months before being offered any formal support. This was particularly concerning as both participants mentioned finding it hard to reach out to others. Both described this process as a deterrent from seeking help and one linked waiting times to a greater likelihood of presenting to emergency services in crisis.

One of the two participants discussed eventually making the choice to seek private mental health care after feeling increasingly unable to cope:

"I've been fortunate enough to be able to afford to go private, but some people couldn't afford that…"

This quote summarises widely raised concerns that the Covid-19 pandemic has widened pre-existing (mental) health inequalities within the UK.

Overall, the limited access to healthcare and support services experienced by participants as a result of Covid-19 was felt to have left individuals feeling anxious and emotionally drained. Some experienced pain or functional decline and others felt pressure to develop strategies to manage their own physical and mental wellbeing in place of strained or suspended services. The strategies developed by participants to cope with the stressors of the pandemic are discussed below.

3) Strategies to Support Wellbeing throughout the Covid-19 Pandemic

n) Developing Mental Health Care

All the research participants involved discussed feeling a need to devise their own means of wellbeing support to ease the impacts of the pandemic, some in response to a lack of availability of care. One participant discussed having to develop their own mental health care in response to receiving talking therapy which they found unhelpful:

"I rang up eventually, after feeling really low. I told them erm, 'I'm gonna pull out of this because it's not helping me'. I got a phone back from my therapist because I'd recently

told her, you know, I was feeling quite down and not seeing the point in life, and she just said, 'can you do a quick survey about us before you go?'. I thought she was going to ask me how I felt? Or why I was leaving? But I remember in that moment feeling like I'm just a stat. I'm just a stat. OCD has nowhere near enough recognition. I read three books over lockdown, and I discovered exposure and response prevention where you have to expose yourself to your fears... I really kind of discovered myself from receiving very bad therapy. I'm very clued up on my disorder."

This person felt unable to access appropriate mental health support throughout the pandemic. In response, they found a form of therapy that helped them. However, this again raises the critical issue of how the strain on mental health services may be impacting individuals with pre-existing mental health conditions who were already more likely than their peers to experience barriers in accessing mental health services.

o) Developing Strategies for Wellbeing

Participants described using a range of methods to maintain or improve their wellbeing. The following examples reflect the helpful strategies for mental health and wellbeing utilised by participants, but also reflect the inequalities that some may have faced in being unable to engage with such strategies. For example, some participants highlighted the benefit of creativity and arts for wellbeing:

"That sense of achievement when you have learnt something new, or done something by hand, it does give you a bit of a buzz, and that's what I'm trying to project. My belief in the power of the arts for health and wellbeing is just unquestionable."

Other participants talked about keeping busy, having a routine and staying physically active as key ways to stay positive:

"During lockdown, podcasts in particular were very useful in keeping my mind active, keeping me going, and countering feelings of isolation".

"The main thing was, erm, trying to exercise to help myself and bring myself into a better place. I have a routine which I started. Before I even got out of bed, I've got to do stretches and that, to get moving around."

Although exercise was helpful for many, it's important to note that some disabled people have had fewer opportunities to exercise since the start of the pandemic, and one participant noted how they might have coped better if they had been physically able to get out for exercise. Those unable to use exercise to cope discussed other things that contributed towards mental resilience when coping with the impacts of the pandemic, such as having strong religious faith, or drawing on past experience of living under restricted and challenging conditions during military service.

Six participants spoke about the benefits of having direct access to a private or shared outside space, however, this too was a marker of inequality for others.

One participant spoke of struggling to cope within a supported living flat that had no direct access to an outdoor space:

"I'm lucky, I've got a back garden I can sit in. Some people, I don't know how they've done it, in flats or they haven't got anywhere to look out of."

One participant described putting themselves at risk to get outdoors to support their wellbeing.

"Yeah, we were going out all the time, even though you weren't supposed to. Because I can't physically be in the same place all the time".

Participant Reflections

When asked for their final thoughts, participants discussed a number of perspectives and recommendations for the future and talked about their hopes for an inclusive and timely mental health response across Liverpool. Individuals called for less of an *"umbrella style"* approach to understanding mental health and disability, highlighting a need for support for individuals transitioning from shielding, and expressing a desire for better community-based networks for the provision of mental health services. The following quote summarises participant perspectives on the impact of Covid-19 on the mental health of disabled people in Liverpool:

"It seems like they're only starting to consider it now. They're using mental health as a big factor to end lockdown because they know that a lot of people who have mental health issues really want to get out of lockdown. Like, for someone like me, I can't wait to get out of lockdown, but I feel like over lockdown there was barely any support. There was no help. In a pandemic there's people who slip through the cracks who don't get seen to or don't get spoken to. I think they need to sort mental health services out. There's people dying left right and centre that could be alive if they'd sorted it out. It's just all good and well, like, having the service, but it's being able to access the service or not being just palmed off onto waiting lists for months. With nothing in the meantime to help out."

Conclusions

"The trouble is, the whole world is set around an idea of the average person…"

Prior to the pandemic, people with physical disabilities and long-term health conditions already faced disabling barriers constructed within society, health inequalities and disproportionate mental distress. The Covid-19 outbreak has concentrated pre-existing hardship and introduced additional constraints.

This research indicates that such people have experienced a continued lack of consideration across decision making throughout the pandemic. This was highlighted particularly by those who have been clinically vulnerable and have felt that their health has been negatively impacted by efforts to bring society back to 'normal' for the less vulnerable population. Some participants experienced acute social isolation, whereas others found themselves confronted with a pre-existing lack of social contact, as very little changed. Those with mental health conditions found their symptoms to be exacerbated whilst support services became overwhelmed and financial worries increased further for others, leaving participants in distress. Disruptions to healthcare access had a profound impact on those in regular contact with health services, with participants reflecting the knock-on impact that missing regularly required care can have on general wellbeing, particularly for those left in pain. Inaccessibility of mental health services continues to be an issue for participants and those who did seek formal support were left feeling worse-off following extensive waiting periods. Although the participants involved were able to develop some methods to manage the mental health impacts of the pandemic, the ability to do so was recognised as unequal, further highlighting the mental burden experienced by many.

Overall, the findings of this project demonstrate how crucial it is for healthcare providers, policy makers and commissioners to:

• understand the mental health experiences of disabled people throughout the pandemic, and beyond;

• support their inclusion within policy, planning, service delivery and review;

• minimise long-term consequences and prevent further exclusions as Liverpool works to recover from the impact of the pandemic.

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About Healthwatch Liverpool

Healthwatch Liverpool is the independent champion for people who use health and social care services in Liverpool. We're here to make sure that those running services put people at the heart of care.

One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

As part of a national network made up of local Healthwatch organisations in every local authority area of England (and Healthwatch England, the national body) our work contributes to a nationwide perspective on health and social care services.

At Healthwatch Liverpool we also provide a dedicated information and signposting service which helps to put people in touch with services and activities that can help maintain and improve their health and wellbeing.

All our reports about the mental health impact of the Covid-19 pandemic are available online at www.healthwatchliverpool.co.uk/Covid-MH-Report.

If you require a copy of the report in another format or language, please contact us and we will do our best to help.

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healthwatch Liverpool