# healthwatch
Waltham Forest

Key Findings:
COVID-19, Disability and Health and Social Care in Waltham Forest

Nov. 2021

introduction: In March 2021, Healthwatch Waltham Forest (HWWF) started working with other Healthwatch groups in North East London to survey the impact of COVID-19 on the accessibility of health and social care services that disabled people use. HWWF expanded the study to three into parts: 1.) analysis of local data from the regional survey; 2.) local interviews with disabled people and carers of disabled people from Waltham Forest; and 3.) co-producing recommendations with interview participants. This report highlights the key findings and insights from the study.
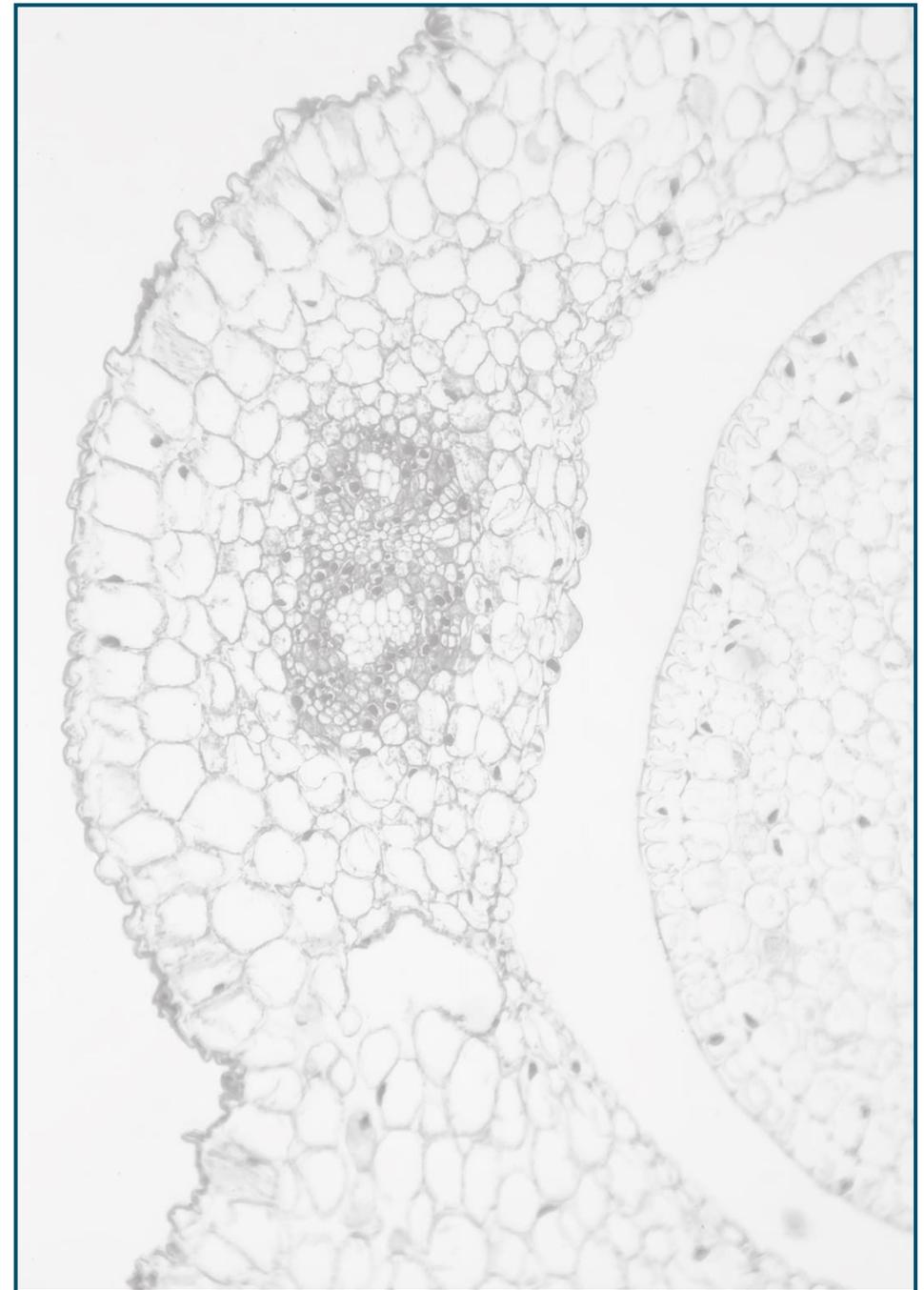
background 1: Research shows some disabled people are more likely to experience severe medical outcomes from COVID-19 than non-disabled people[1,3]. Some disabled people are also at increased risk of being infected if they receive personal or residential care or cannot socially distance[2]. Disabled people are more likely to report increased harm to wellbeing, psychological distress and feelings of loneliness[1,3] and more likely to report access to healthcare, food and essentials has become worse during the pandemic[3].

background 2: Researchers and campaigners argue the COVID-19 pandemic is intensifying pre-existing health, social and economic inequalities between disabled and non-disabled people[1,2,4]. Campaigners argue wider non-clinical risks to disabled people from isolation and unmet care needs caused by emergency COVID-19 measures are not recognised[2,3]. These measures include relaxation of local authorities' legal duty of care and protections under the Mental Health Act. Researchers argue these measures also shift even more care responsibilities onto unpaid carers – most of whom women[5].

healthwatch
Waltham Forest

methods 1: This study took place in three parts: 1.) North East London regional survey about COVID-19 and changes to health and social care services; 2.) Interviews with Waltham Forest residents who were disabled (n=2) or carers of disabled people (n=2), and a local expert on care (n=1). 3.) Recommendations by interview participants based on experiences of local health and social care services. Recommendations were summarised by the researcher, sent to participants for approval and finally grouped thematically in this report.

methods 2: Meanings of disability are extremely diverse. In this study, 'disabled people' are defined as those with a disability according to the Equality Act[6]. This includes d/Deaf, Disabled, or neurodiverse people and those who live with HIV/AIDS or a long-term mental or physical health condition. It is important to highlight many people protected by the Act view being d/Deaf or Disabled as a social, cultural or political identity. However, not everyone with a legally recognised disability considers themselves disabled – including some d/Deaf people.

2.

survey finding 1: This study reports responses from Waltham Forest (n=23) from the regional dataset (n=570). This means the data in this report is not statistically significant as Waltham Forest survey sample is too small. White English, Welsh, Scottish or Irish and some Black ethnic groups were overrepresented. South Asian and other white ethnic groups were underrepresented (Chart 1). Adults aged 50 to 65 years old were more likely to take part than those aged over 65 years (Chart 2). This means older adults were underrepresented, as nearly half of disabled people are of pension age (65+)[7].

survey finding 2: A large majority (82%) of respondents said they had access to key information on staying safe during the pandemic. However, fewer said they had access to inform about changes to services (65%), with changes to social care the area with the lowest reported level of information access (Chart 3). Most respondents said they would prefer to receive information about the vaccine by email (82%) or another mode of contact. Respondents who only selected one communication preference chose either email (9%) or letter (4%).

healthwatch Waltham Forest

Chart 1. Ethnicity of survey respondents versus local population

Categories (top to bottom):
- Asian: South Asian
- Black: African
- Black: Carribean
- Black: Other
- Mixed: White & Asian
- Mixed: White & Black African
- Mixed: White & Carribean
- Mixed: Other
- White: English, Welsh, Scottish or Irish
- White: Other
- Other Ethnic Groups

■ Survey Respondents ■ Waltham Forest Population

Chart 2. Age of survey respondents

Categories (top to bottom): 65+, 50 - 65, 25 - 49, 18 - 24, Under 18
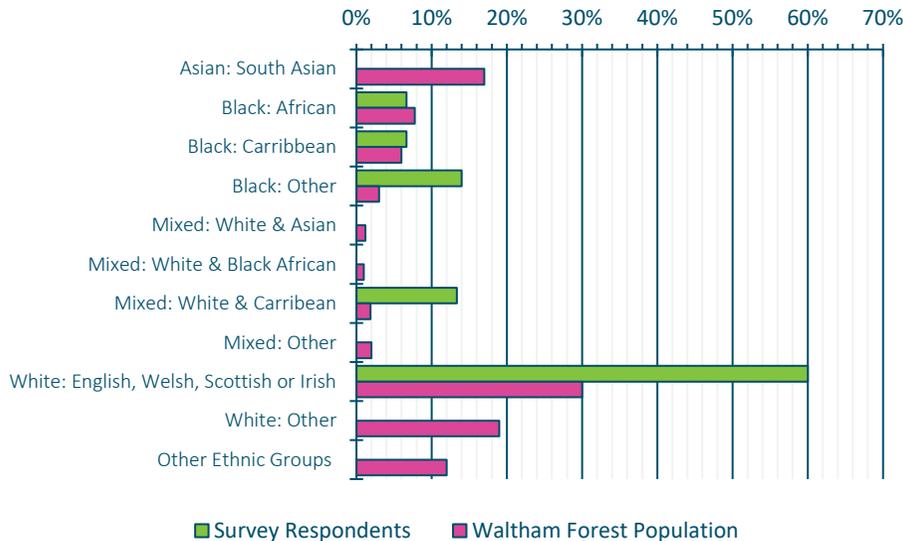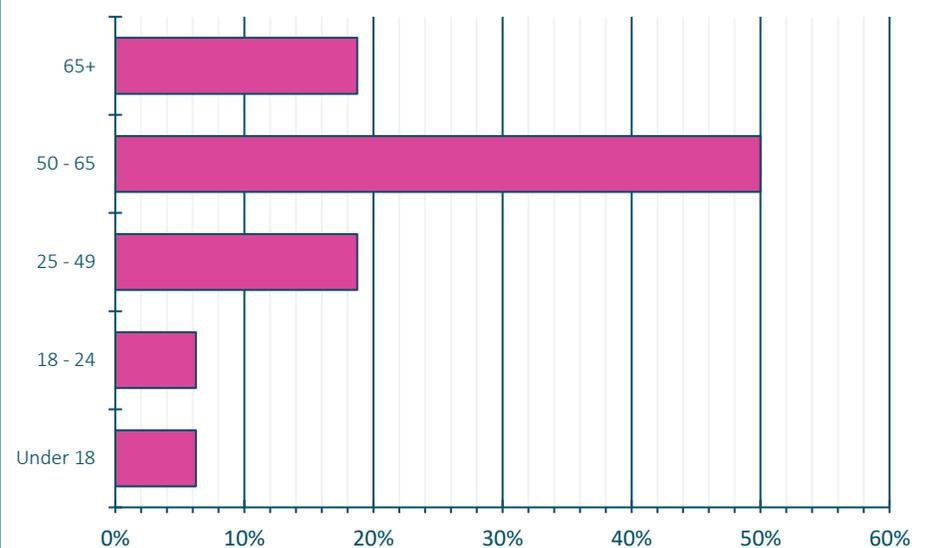
survey finding 3: Most participants said access to their GP had become harder during the pandemic (53%) (Chart 4). A minority said they found online appointments were easy to access and could be more convenient to attend than in person. Most respondents said access to hospital specialists had become much harder (70%). Most respondents said their regular hospital appointments were cancelled (75%). Among these respondents, a large majority said cancellations had affected their health and wellbeing (83%), most of whom said it affected them 'by a great deal' (55%).

survey finding 4: In open ended questions, most respondents said the COVID-19 pandemic had affected their health and wellbeing. A significant group of respondents said the pandemic had negatively affected their mental health. However, none of these respondents said they had accessed mental health services so far during the pandemic. Most respondents in this group said this was because they believed they didn't need mental health services.

healthwatch Waltham Forest

Chart 3: Respondents' Access to Information about Social Care

- ■ No info
- ▨ Info: difficult to access and understand
- □ Not sure
- ▨ Info only for carer
- ■ Info: easy to access and understand

30%
43%
13%
9%
4%
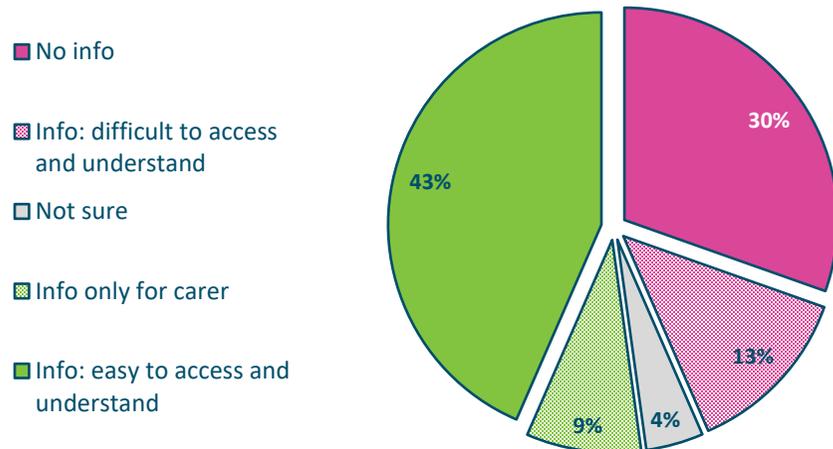
Chart 4. Access to healthcare specialists during the pandemic

	Much Harder	Somewhat harder	About the same	Somewhat easier	Much easier
Hospital	47%	7%	33%	13%	
GP	21%	32%	16%	16%	16%

0%   20%   40%   60%   80%   100%

■ Much Harder   ▨ Somewhat harder   □ About the same   ▨ Somewhat easier   ■ Much easier
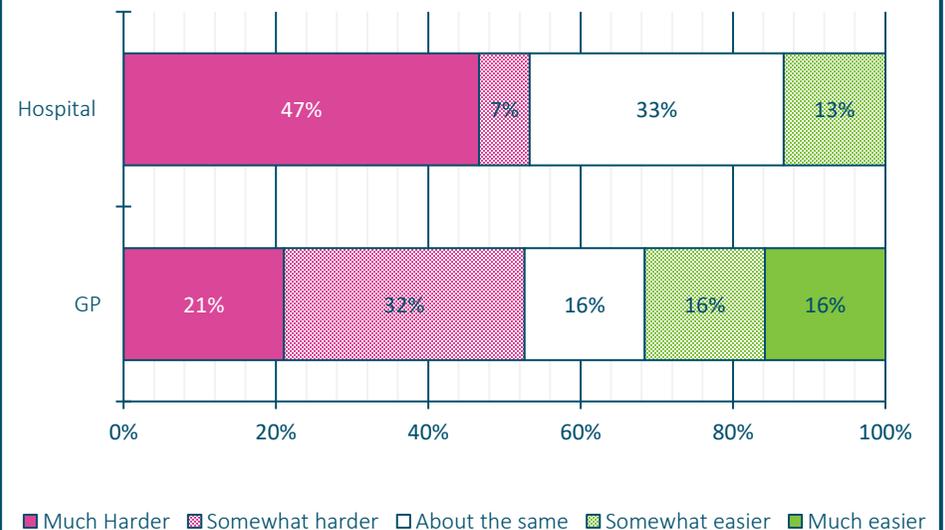
interview finding 1: Most participants said they found general information about COVID-19 safety and guidelines easy to find. Participants said they received information online, in letters sent to their home or through social or traditional media. One participant said they saw COVID-19 information in local food takeaways, which they said helped them to stay informed. However, participants said up to date and local information about services was much harder to find – such as information on local vaccination centers and on changes to local services.

interview finding 2: Most participants said accessing their GP had become much harder during the pandemic. Some participants said their GP would not provide them information and advice about the COVID-19 vaccine. One participant said their GP didn't contact them about the vaccine, which meant the person they cared for did not have their second jab until three months after their first. Some participants believed GPs preferred to see fewer patients, and that the COVID-19 pandemic gave surgeries an 'excuse' to reduce in-person appointments.

healthwatch
Waltham Forest

interview finding 3: Interview participants said communicating with health practitioners had become harder during the pandemic. Some participants said they found using e-consult and remote consultations difficult to use. Participants who had accessed these services said they felt could not use these channels to effectively communicate their health concerns. Some participants also said remote communication increased bureaucracy and could be hard to manage. One participant said they were discharged from a service after they missed a telephone consultation.

interview finding 4: All participants said they were expected to use 'digital-by-default' to access at least some services. Some said felt this expectation had increased during the pandemic. Participants who were not digitally confident found digitization could be a significant barrier to accessing essential services. Other participants felt using digital platforms increased their access to socialising and information during the pandemic. However, one digitally confident participant still found using the Universal Credit platform difficult to navigate because of slow responses from administrators.

interview finding 5: Participants said there were not enough mental health services for people with acute conditions. Carers said people with a high level of mental health need could only get hospital treatment by being detained under Mental Health Act. One participant said this waiting period could be very dangerous for people with complex and volatile behaviour and the people that care for them. They said the policy to provide care in the community was 'farcical', as there were 'clearly' not enough appropriate out-patient services to support people with complex and acute needs.

interview finding 6: Most participants believed health and social care services did not have enough capacity to keep up with demand during the pandemic. Some believed the COVID-19 had a worsening effect on services which were already struggling. Some believed that emergency measures to roll back health and social care services were part of a long-term trend and would ultimately be permanent. Many of these participants experienced cuts and closures to local services in the years leading up to the pandemic. Most references to cuts spoke about closure of day centres and associated impacts.

healthwatch
Waltham Forest
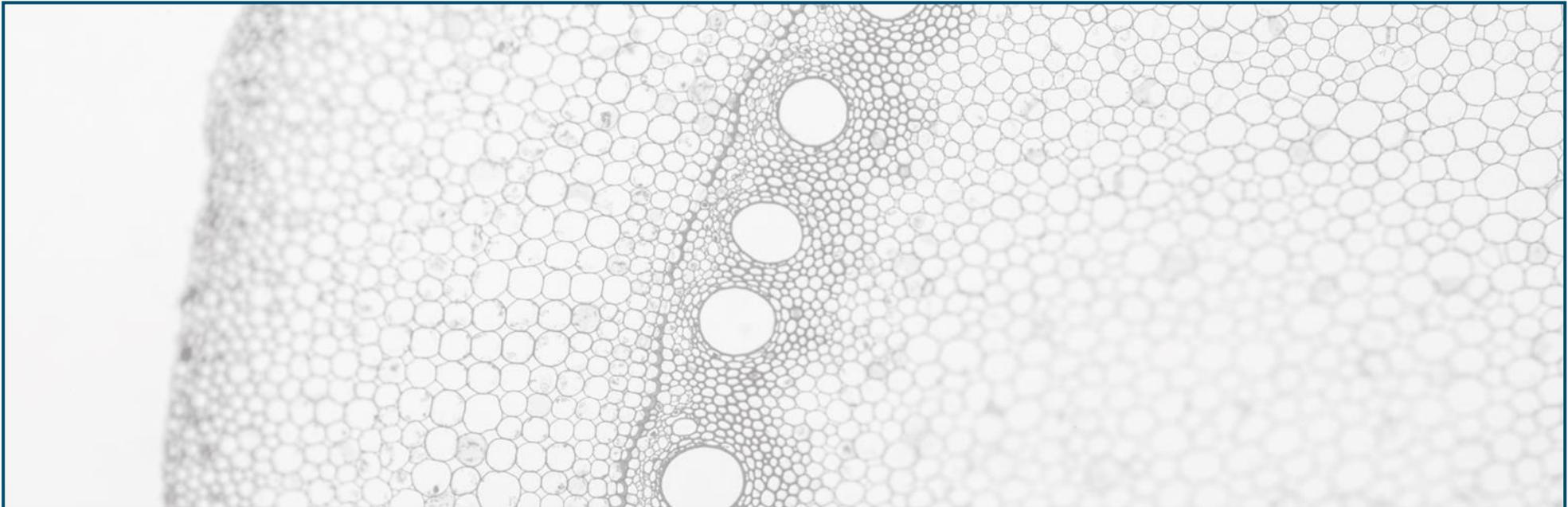
recommendation 1: Respond to diverse information and communications needs of disabled people and carers of disabled people.

Participants said care providers should: provide a mix of in person and digital services; provide an interpreter when requested; ask patients and service users about their communication needs; make it easier for people to digitally and non-digitally make appointments; make it easier to log an enquiry with a GP.

recommendation 2: Actively promote disabled peoples' rights to make decisions about their care.

Participants said care providers should: practitioners should speak directly to disabled patients and service users; inform them of their condition, treatment options respect their communication needs; actively enable disabled patients to challenge their care or treatment.

healthwatch
Waltham Forest

recommendation 3: Build integrated information networks between the Volunteer Community Sector (VCS) and care sectors.

Participants said care providers should: integrate information networks in the local care economy between VCS, Local Authority NHS and local care providers; share best practice and forward planning across the local care economy.

recommendation 4: Make the complaints procedure more accessible for disabled people and carers of disabled people.

Participants said care providers should: make the complaints procedure easy to access, clear and transparent; make it easier for carers to make a formal complaint about the treatment of the person they care for.

recommendation 5: Increase availability and increase accessibility of mental health services for people with acute needs.

Participants said care providers should: expand the availability of meaningful activities for people with acute mental health needs; provide meaningful activities for people with acute mental health needs who are inpatients or sectioned.

recommendation 6: Reduce patient and service user bureaucracy for disabled people and carers of disabled people.

Participants said care providers should: integrate care services for greater efficiency, in particular between pharmacy and GP services; make it easier to apply for referral to specialist social care services for people with acute mental health conditions.

healthwatch
Waltham Forest
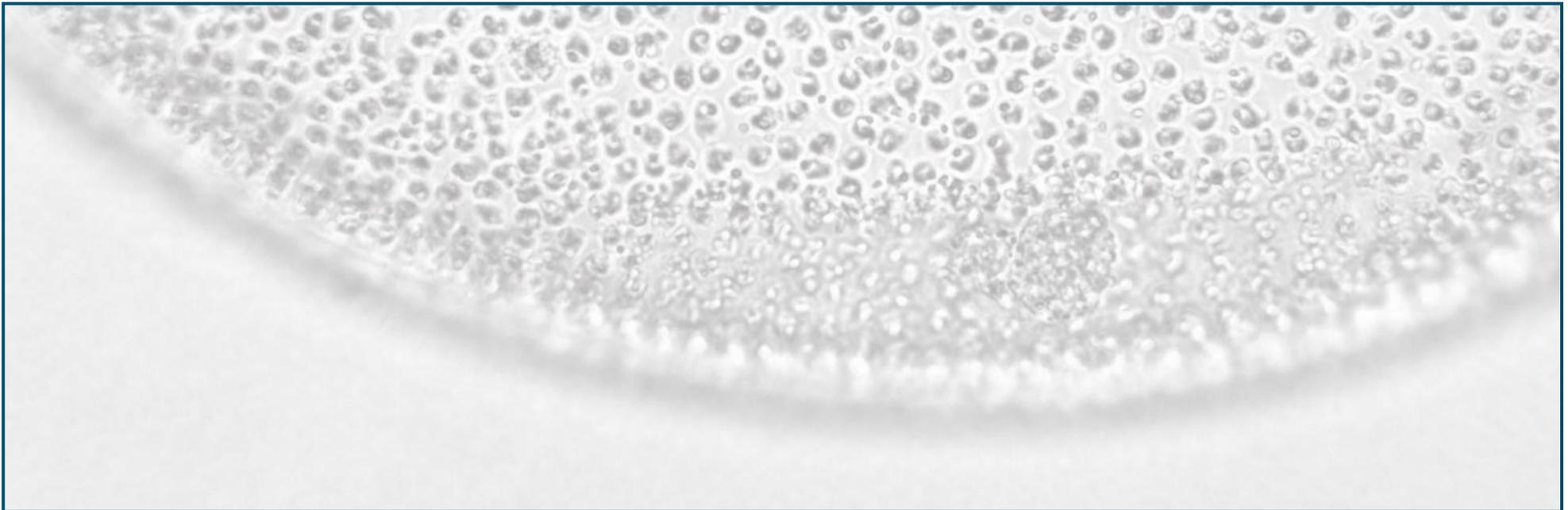
discussion: Changes to health and social care identified in this study supports wider evidence on the impact of the COVID-19 pandemic on services: reduced GP access[8] ; accelerating digital healthcare and digital-by-default, which could amplify health inequalities[9,10,11]; and worsening effect on underfunded acute mental health services[12], with reductions in community care[13] and increased detentions under the Mental Health Act and Mental Capacity Act[14,15,16]. These changes may impact the accessibility of service for could different social groups. However, the risks to disabled people are more severe.

strengths: The survey stage of this study was rolled out across the region, which means the North East London Healthwatch region can analyse and compare from a larger dataset. Interviewing a local expert enabled us to consider the experiences of disabled people and carers who we could not engage with in this study, such as digitally excluded people. Many interview participants said they enjoyed talking about their experiences of care and found having their recommendations recorded and published to be gratifying.

limitations: The study took place during lockdown in early 2021 and all stages of the project were conducted remotely. Delivering in this way may have excluded some disabled groups. Consequently, the data from the survey is both unrepresentative and not statistically significant meaning the findings are not statistically generalisable. HWWF tried to engage local organisations. However, funding was not available to compensate study partners and, anecdotally, VCS capacity was very low at the time. These organisational factors may have also contributed to poor inclusion of disabled groups in this study.

conclusion : Changes to digital healthcare, GP access and acute mental health care are structural challenges to the rights and inclusion of some disabled people. This study has also highlighted the interconnected impacts of these changes to carers of disabled people. However, some local disabled communities may have been excluded from this study because of the way research activities were delivered. Research at Healthwatch Waltham Forest will aim to use an 'evolving set of practices' [17] to improve inclusion by learning and developing from this project and future projects.

healthwatch
Waltham Forest

questions or comments about this report?

want to take part in future projects?

we'd love to hear from you!

contact us:
Research Officer: Sophie De Val

Email 1: sophie.deval@healthwatchwalthamforest.co.uk
Email 2: info@healthwatchwalthamforest.co.uk
Phone: 0203 078 9990 (Office)

Address: Healthwatch Waltham Forest, Waltham Forest Resource Hub (Central), 1 Russell Road, London, E10 7ES

healthwatch
Waltham Forest

References

1. Kavanagh, A., Dickinson, H., Carey, G., Llewellyn, G., Emerson, E., Disney, G., & Hatton, C. (2021). Improving health care for disabled people in COVID-19 and beyond: Lessons from Australia and England. Disability and Health Journal, 14(2), 101050. https://doi.org/10.1016/J.DHJO.2020.1010502.
2. Scope. (2020). The disability report: Disabled people and the coronavirus crisis. https://www.scope.org.uk/campaigns/disabled-people-and-coronavirus/the-disability-report/ [Accessed: 29/11/2021]
3. Office for National Statistics. (2021). Coronavirus and the social impacts on disabled people in Great Britain. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/february2021 [Accessed: 29/11/2021]
4. Trust for London. (2021). Poverty and disability. https://www.trustforlondon.org.uk/data/disability-and-poverty/ [Accessed: 29/11/2021]
5. Power, K. (2020). The COVID-19 pandemic has increased the care burden of women and families. Sustainability: Science, Practice and Policy, 16(1), 67–73. https://doi.org/10.1080/15487733.2020.1776561
6. Equality Act (2010). https://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed: 29/11/2021]
7. Scope. (2021). Disability facts and figures. https://www.scope.org.uk/media/disability-facts-figures/
8. Healthwatch England. (2021). GP access during COVID-19. https://www.healthwatch.co.uk/report/2021-03-22/gp-access-during-covid-19 [Accessed: 29/11/2021]
9. Davies, A. R., Honeyman, M., & Gann, B. (2021). Addressing the Digital Inverse Care Law in the Time of COVID-19: Potential for Digital Technology to Exacerbate or Mitigate Health Inequalities. Journal of Medical Internet Research, 23(4). https://doi.org/10.2196/21726
10. Spanakis, P., Peckham, E., Mathers, A., Shiers, D., & Gilbody, S. (2021). The digital divide: amplifying health inequalities for people with severe mental illness in the time of COVID-19. The British Journal of Psychiatry, 1–3. https://doi.org/10.1192/BJP.2021.56
11. Watts, G. (2020). COVID-19 and the digital divide in the UK. The Lancet Digital Health, 2(8), e395–e396. https://doi.org/10.1016/S2589-7500(20)30169-2
12. Royal College of Psychiatrists. (2018, February 18). Mental health trusts' income lower than in 2011-12. Royal College of Psychiatrists. https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2018/02/21/mental-health-trusts-income-lower-than-in-2011-12 [Accessed: 29/11/2021]
13. Care Quality Commission. (2021). How are people's mental health needs met in acute hospitals, and how can this be improved? . https://www.cqc.org.uk/sites/default/files/20201016b_AMSAT_report.pdf [Accessed: 29/11/2021]
14. Mental Capacity Act , (2005). https://www.legislation.gov.uk/ukpga/2005/9/contents[Accessed: 29/11/2021]
15. Mental Health Act , (1983). https://www.legislation.gov.uk/ukpga/1983/20/contents [Accessed: 29/11/2021]
16. Mukadam, N., Sommerlad, A., Wright, J., Smith, A., Szczap, A., Solomou, S., Bhome, R., Thayalan, R., Abrol, E., Aref-Adib, G., Maconick, L., Aubrey-Jones, D., Tugrul, S., Knowles, M., Menys, H., Sathanandan, S., Moslehi, S., Huntley, J., Liu, K., & Carlos Bazo-Alvarez, J. (2021). Acute mental health presentations before and during the COVID-19 pandemic. BJPsych Open, 7(134), 1–8. https://doi.org/10.1192/bjo.2021.970
17. Nind, M. (2014) What Is Inclusive Research? London: Bloomsbury Academic. http://dx.doi.org/10.5040/9781849668149.ch-001