Exploring the Effectiveness of Media in Communicating Public Health Messages to People with Learning Disabilities During the Pandemic

Abstract: The article aims to explore mass and social media's role in communicating public health messages in Britain during the COVID-19 pandemic. The article presents findings from a realist mixed methods study analysing data collected from 137 participants who have a learning disability and/or autism. Our study discovered that participants reported that social media only led to confusion because of contradictory messages being presented on COVID-19. Although people with learning disabilities and/or autism preferred gaining information from TV news, they also reported that this information was often confusing and inaccessible. Participants drew on family members, and social care professionals, to explain and help them negotiate the complexities of public health messages during the global pandemic. The study concludes by suggesting the need for accessible information and health communications to effectively contend with any future global pandemic or health emergency to reduce the health risks for people with learning disabilities and/or autism.

- Our study explores how successful TV, the Internet and radio were in communicating public health messages to people with learning disabilities and/or autism.

- The research illustrates that public health messages presented on TV, the Internet and radio confused participants.

- The findings highlight that it was parents, friends, and/or partners who helped explain public health messages communicated from the mass media to people with learning disabilities and/or autism.

- Our study demonstrates that public health authorities in Britain did not do enough to effectively communicate health messages on COVID-19 to these minority groups.

- Our study shows the need for accessible public health information to reduce risks for people with learning disabilities and/or autism for any future health emergency.

Introduction

The article explores how effective health communications of COVID-19 lockdown measures were during the global pandemic. This commences by exploring the impact that COVID-19 had in Britain and the important role that mass and social media played in communicating public health messages to the nation. This study illustrates how disabled people, particularly people with learning disabilities and/or autism, were disproportionately affected by COVID-19. As will be discussed, people with learning disabilities had a significantly higher hospitalisation and mortality rate compared to the general population across Britain. The article draws on a one-year mixed methods study on how accessible mass media and social media were in communicating government lockdown measures and risks to health from the COVID-19 virus. The research discovered that participants with a learning disability and/or autism primarily received most of their public health information from the news and the daily government briefings in particular. Although participants suggested that TV news was more reliable than social media, they also stated that information available on TV was widely inaccessible when attempting to understand or negotiate the complexities around COVID-19 lockdown measures. Participants reported that without the support of family members or professionals, this information would have been inaccessible to them, leaving them at risk of becoming infected with COVID-19 or resulting in them breaking lockdown measures. Our study concludes by suggesting that the National Health Service (NHS), Public Health England, and the government did not take into consideration the importance of accessible information for people with learning disabilities and/or autism, and in doing so led to increased anxieties, barriers, and greater risks of mortality for this minority population. Regarding terminology used throughout this article, the authors are not suggesting that learning disabilities and autism are synonymous but many of our participants had intersecting identities. This study primarily collected data from people with learning disabilities but many participants identified as having a learning disability and autism in the qualitative stage of the research. Thus, the quantitative survey was aimed at people with learning disabilities and autism, hence the terminology used throughout this paper will be people with learning disabilities and/or autism.

Understanding the Spread of COVID-19 Across the United Kingdom

On January 29, 2020, a 23-year-old Chinese international student and his mother reported symptoms of a sore throat, a fever, muscle cramps, and a dry cough to the National Health Services in York, England. The mother had recently flown in from Wuhan, China. At this point, there had been 500 confirmed cases of COVID-19 globally and 17 recorded deaths from the virus. This turned out to be the first confirmed case of COVID-19 in Britain and would signal that a global pandemic had reached the shores of the British Isles. This would radically transform the lives of British residents, resulting in two years of home confinement, restrictions on social interaction, the wearing of face masks, the closing of the British economy, and the resignation of the then Prime Minister Boris Johnson due to a breach of COVID-19 rules. At the start of the pandemic, there was no cure or treatment for COVID-19 and the British government implemented social distancing procedures intended to develop herd immunity, without implementing national lockdown measures (O'Grady, 2020). However, due to infectious disease modelling it was predicted that a herd immunity strategy would result in significant strain on the NHS, and this strategy was quickly replaced with national lockdown measures to curb the spread of infection across the four nations (O'Grady, 2020; Tatlow et al., 2020).

As the British government was slow to act (Anderson et al., 2020), COVID-19 restrictions were not introduced until 23rd March 2020 (Tatlow et al., 2020). Two weeks before this date, the World Health Organisation on March 11th had officially declared COVID-19 a global pandemic as there were 48,000 confirmed infections and 3000 deaths because of the virus (Khan et al., 2021). Yet on the same day that the World Health Organisation had officially declared COVID-19 a global pandemic, the Cheltenham Festival, an annual horse racing event, was held where just under 70,000 people attended in close proximity. Football matches proceeded as normal up until March 13th (Stott et al., 2020) and Westminster seemed reluctant to bring in any restrictions which risked damaging the British economy. Britain’s geographical isolation seemed to have led to overconfidence, as the population had not experienced a global flu pandemic since the Spanish flu outbreak in 1918 (Khan et al., 2021). As Anderson et al. (2020) illustrate, the speed at which the British government moved to implement lockdown legislation failed to slow the rapid spread of COVID-19 across the British population. As they illustrate, earlier restrictions would have significantly reduced rapid transmission, decreasing morbidity and mortality (Anderson et al., 2020).

Although the British government has been criticised for being slow to act and contain the spread of COVID-19 compared to other European countries, after the World Health Organisation officially announced COVID-19 as a global pandemic, the British government started to announce restrictive measures to curb the spread of the disease. On 16 March 2020, the British government called an end to mass gatherings and suggested that, where possible, people should work from home. On 21 March the British government officially closed venues and businesses across the country including ‘cinemas, restaurants, bars, cafés, theatres, nightclubs, bingo halls, concert halls, museums and galleries, casinos, betting shops, spas, parlours, indoor skating rinks and fitness studios, gyms, swimming pools and other leisure centres’ (Tatlow et al., 2020 p. 10). Businesses could operate where employees could work from home and restaurants and cafés were allowed to trade only in takeaway services. On 23 March all British residents were required to stay at home and could only leave the house once a day for exercise. People could go shopping but only for essential goods such as food or medicines (Tatlow et al., 2020). Across Britain, schools, except for vulnerable children and children of essential workers, were closed and teaching was moved online. Universities and other educational institutions were also required to close and move to online learning (Tatlow et al., 2020).

On 25 March 2020, the British government passed the Coronavirus Act 2020 which gave emergency powers to the four nations, England, Scotland, Wales, and Northern Ireland, to implement policies to prevent the spread of COVID-19 across the population. At the start of the pandemic, all four nations, England, Scotland, Wales, and Northern Ireland implemented similar lockdown measures, but by May 2020 different nations had eased lockdown measures at varying rates, whereby Scotland had the most stringent rules, Wales and Northern Ireland sat in the middle ground, and England had the most lenient (Tatlow et al., 2020). Through this legislation, British police services were granted new powers to prosecute any individual breaking the stringent lockdown measures (Stott et al., 2020). Although the British government eventually brought in strict lockdown measures, these did not prevent the rapid spread of COVID-19 across Britain, resulting in 24,259,240 infections and 216,255 confirmed deaths by 2023 (PHE, 2023).

The Role of the Media in Communicating Public Health Messages to Prevent the Spread of COVID-19

During the COVID-19 pandemic, the media played a significant role in disseminating public health messages and government guidelines which were aimed at reducing infection, hospitalisation, and mortality rates. In each of the four countries across Britain, party leaders presented health messages alongside senior health officials, i.e., the daily briefing, which was broadcast by the five leading TV channels. In Britain, and globally, the media has always played a fundamental role in promoting public health messages and wellness education (Mheidly and Fares, 2020). From a public health perspective, the media is a powerful institution that raises awareness of health and has the potential to change public attitudes concerning harmful unhealthy behaviours. During the pandemic, the role of media channels internationally and locally kept the public up to date with infection rates, vaccine development, hospitalisation, and mortality rates (Mheidly and Fares, 2020). In Britain, the daily briefing conveyed up-to-date health information, alongside COVID-19 guidelines and restrictions which were being implemented by the government. The national media aimed to bring quick, accessible, and accurate information to the general public to help reduce the rapid spread of the virus. Thus, accurate health communication was seen as a leading strategy to combat the spread of COVID-19 and reduce hospitalisation and mortality rates (Mheidly and Fares, 2020). As Vaughn and Tinker (2009) have argued, the need for effective, inclusive forms of information is the first principle of pandemic preparedness, avoiding the escalation of rumours, and enabling the trust needed to work together in harmony.

Although the media has always played a fundamental role in the development of public health in Britain and globally, what was unique about the COVID-19 global pandemic was that it occurred during the age of social media (Hossain et al., 2020). Within Britain, there are five leading media channels, which have their own news programmes, that were effectively used to relay accurate health communications to the general population. This was supplemented by the tabloid and broadsheet press illustrating the key public health messages daily. These messages aimed to represent accurate health information and were regulated by the press standards. Yet alongside these regulated sources of information was the unregulated information being presented on social media platforms such as Facebook, Google, Twitter, TikTok, YouTube, etc. (Mheidly and Fares, 2020). Although social media platforms are occasionally an accessible means of finding reliable information, they also became a significantly powerful platform to disseminate misinformation quickly and on a global scale. Another factor that made the COVID-19 pandemic unique was that by the time of the outbreak social media was often the dominant source of news for many communities, and younger people, in Britain and globally (Hossain et al., 2020).

Although the government and public health departments were quick to post health guidelines and government instructions, these information sources could very quickly become distorted and misrepresented on social media (Hossain et al., 2020, Mheidly and Fares, 2020). Examples of this can be seen concerning the ‘anti-vax’ movement, where misinformation around the effectiveness and harm caused by taking vaccines quickly took momentum. Although the anti-vax movement already had a substantial impact on the use of vaccinations globally (Larson, 2018), it was during this global pandemic that this movement started to have a significant impact on public health messages. Thus, falsehoods on COVID-19 were published on social media, shared very quickly, and began to have a global reach. These falsehoods were very difficult to spot and were often a mixture of accurate information and misinformation. As social media is primarily unregulated, this form of communication had a considerable impact on public health messages in Britain and globally (Hossain et al., 2020) undermining the pandemic imperative of trust and causing confusion (Vaughn and Tinker, 2009). Thus, because of the rise of social media, negotiating the complex messages presented on different media platforms became a significant problem for many communities across Britain during the global pandemic.

COVID-19 and its Impact on Disabled and Neurodivergent Communities

Although the pandemic had a significant impact across the population, it was disabled people or people with long-term health conditions who were most affected by the spread of COVID-19 and the lockdown restrictions (Watson and Shakespeare, 2023). Figures from the Office for National Statistics (ONS, 2020) measured the early impact that COVID-19 had on disabled people. This data revealed that disabled populations accounted for 22% of the population infected by COVID-19, but the mortality rate for this group was at a staggering 59% of the overall death rate during this period (ONS, 2020; Watson and Shakespeare, 2023). Furthermore, a report published by Public Health England (2020) revealed that mortality rates for adults with a learning disability aged 18 to 34 were 30 times higher than the general population. From a global perspective, disabled people have been disproportionately affected by the global pandemic. The COVID-19 Disability Rights Monitor Coordination group (Brennan et al., 2020) found that during the global pandemic, violations of human rights emerged, for example, homeless disabled people were forced into institutions, disabled children were denied access to appropriate forms of education, and disabled women and girls were at particular risk of experiencing domestic violence (Brennan et al., 2020; Mladenov and Brennan, 2021). There was a universal failure by residential institutions to protect disabled people from the spread of COVID-19. Lockdown measures which were meant to protect disabled people within these institutions failed and became incubators for the spread of the virus across many disabled populations (Brennan et al., 2020; Watson and Shakespeare, 2023).

Lockdown measures also led to restrictions or the end of vital services for disabled people living in the community. Many disabled people could not access personal assistants, basic goods such as food, and access to therapeutic services (Brennan et al., 2020; Mladenov and Brennan, 2021; Dai & Hu, 2022; Shakespeare, et al., 2022). Thus, many disabled people globally were denied access to basic and emergency treatment because of their impairments. Mladenov and Brennan (2021) suggest that global policy responses to the pandemic primarily medicalised and pathologised disabled people drawing on a strong biomedical model response that significantly restricted their human rights globally. These public health responses have overemphasised the notion of pathological vulnerability which has led to forced institutionalisation and, in some cases, restricted emergency healthcare. Mladenov and Brennan (2021) suggest that many of these policy responses have been more harmful to disabled people than the risk of death caused by COVID-19, for example, the impact of loneliness and isolation, the disappearance of therapeutic services, the increased likelihood of catching COVID-19 within an institution, the disappearance of community care services and a lack of access to medical services beyond COVID-19 services.

Yet it is people with learning disabilities who have been disproportionately affected, even when compared to other disabled groups, during the global pandemic and lockdown measures. Examining COVID-19 hospital and mortality rates in the general population illustrates that people with learning disabilities were five times more likely to receive hospital treatment and eight times more likely to die from a COVID-19 infection (Courtenay and Cooper, 2021; Williamson et al., 2021). The NHS was already aware that people with learning disabilities, due to health inequalities, were at significant risk of hospitalisation and death because of influenza. Living conditions for people with learning disabilities have put them at particularly high risk of contracting influenza and COVID-19. People registered as having a learning disability often live in supportive living or residential care (Williamson et al., 2021; Hughes and Anderson, 2022). As people with learning disabilities often have access to carers, professional traffic in and out of the home is amplified, impacting people's ability to socially isolate and distance (Hughes and Anderson, 2022; Shakespeare, et al., 2022). Many people with learning disabilities have other risk factors such as living in poverty, epilepsy, diabetes, and obesity which again increased the likelihood of mortality due to COVID-19 (Williamson et al., 2021; Hughes and Anderson, 2022).

Although people with learning disabilities are more likely to die from COVID-19, health services seem to apply a eugenic approach to rating the worth of a person's life based on their intellectual ability/disability (Abrams and Abbott, 2020; Courtenay and Cooper, 2021). At the start of the pandemic, health services and local authorities, rather than administering extra support for this at-risk disabled community, responded by administering a blanket 'Do Not Attempt Cardiopulmonary Resuscitation' order if they were hospitalised because of COVID-19 (Courtenay and Cooper, 2021). Similarly, nondisabled people were offered vaccinations before people with learning disabilities. There was also a hierarchy created between different disabled communities, where young people with physical or sensory impairments were prioritised over young people of the same age with a learning disability (Courtenay and Cooper, 2021).

Although disabled groups were at higher risk of hospitalisation and death, getting targeted public health messages out to this group also seemed to be a significant problem. As Abraham and Abbott (2020) illustrate, public health messages were not aimed at disabled populations. The discourses which emerged at the beginning of the pandemic, rather than specifically focusing on at-risk groups, served to justify and play down the mortality rate of COVID-19 within the general nondisabled populations. The general message which emerged from Public Health England was that of not to worry, you are only at risk of death if you have a long-term health condition. Public health communications on death rates, i.e., messages such as '91% of people dying with coronavirus have an underlying health condition', were used to reassure the public, rather than target disabled at-risk populations (Abraham and Abbott, 2020, p. 168). These disablist health discourses reinforced the message that disabled people's lives, and in particular people with learning disabilities, were worth less than the nondisabled 'healthy' populations. It is not surprising that many disabled populations felt high levels of stress and anxiety when trying to negotiate British government guidelines and health communications presented in the media. Thus, as people with learning disabilities and/or autism are often 'key members of the digital underclass' with a wide range of pre-existing unmet communication needs (Wilde, 2022, p. 12; Shakespeare, et al. 2022) there is an urgent need to examine their experiences of the pandemic health communications which is the focus of this study.

Methodology

This article presents findings from a study examining the media and health communications for people with learning disabilities and/or autism. The project employed a mixed-method approach (Hesse-Biber and Johnson, 2015) incorporating quantitative and qualitative data collection (De Vaus, 2014). This study was funded by the Independent Social Research Foundation to try to comprehend how COVID-19 health information was communicated to people with learning disabilities and/or autism through different media outlets. This article focuses primarily on the quantitative findings which indicated that COVID-19 guidelines and information were not adequately communicated by health professionals via the mainstream media and social media (Wilde, 2022). Although the survey design used in this paper is predominantly quantitative, it was decided that the team would develop a methodology that would not only incorporate the voices of service users within the qualitative stage but also include their voices within the survey. Hence, qualitative analysis from the survey was included within the data findings in this article to add depth to the quantitative data.

Survey design

The survey applied a mixed method 'exploratory subsequential' approach (Creswell, 2015) in line with a realist disability studies perspective (See Macdonald, et al., 2018). This means qualitative data was collected and analysed, and from this analysis, a quantitative survey was produced. Within the qualitative stage, 34 in-depth interviews were conducted discussing disabled participants' experiences during the COVID-19 pandemic (see Authors forthcoming). From the qualitative analysis, the quantitative survey questions were developed from the lived experiences of people with learning disabilities and/or autism. Thus, the survey emerged from the voices and experiences of disabled people to explore if these experiences were representative of a larger group. When developing the survey, accessibility was at the forefront of our questionnaire design. The team piloted the survey on people with learning disabilities and/or autism who were accessed through several third-sector organisations in the North East of England to improve the design and accessibility of the survey. The team also included a researcher who is an expert by lived experience and has previous experience as a research assistant; she helped design the qualitative and quantitative phases of the research project. Participants' completion times ranged from 5 - 15 minutes, which averaged to less than 10 minutes. As reading speeds differ for adults with learning disabilities and/or autism, we decided to give an approximate 10 to 15-minute completion time on the participants' information sheet. The questionnaire consisted of 30 predominantly closed-ended questions, with an option of adding to these questions with open-ended answers. For participants that had reading and writing issues, our expert by experience recorded each question and closed-ended answers to assist the participant in completing the questionnaire. Questionnaires could be accessed by laptop, tablet computer, mobile phone or by hard copy. Assistive technologies such as dictate, or text-to-speech software could be used to assist potential participants in completing the survey.

Survey sample

The survey was released online in 2022 for three months. The survey was publicised on social media and was sent out to organisations across Britain which supported adults with learning disabilities and/or autism. To collect data on learning disabilities and/or autism, a cross-sectional, mixed-mode method was developed, using a survey that could be completed online (with short videos reading out each question and answer) or with a hard copy (Fricker, 2016). It was distributed in a variety of ways to ensure the inclusion of participants from a wide range of social demographics nationally; particularly to access socially excluded populations. This project had been widely publicised by third-sector organisations, and residents could 'opt-in' to complete the online survey. The survey also appeared on several social media websites which were used by people with learning disabilities and/or autism. The study took place from 2022 to 2023 and produced a sample size of 137 participants. However, only 103 participants took part in the quantitative data that is being presented in this study. The CHERRIES checklist has been used to consider the nature and representation of the sample used in this study (Eysenbach, 2012). Regarding response metrics (i.e., response rates), there was a 20% completion rate, which was calculated by comparing the number of members of the public who viewed the survey with the number of individuals who completed the questionnaire (Eysenbach, 2012). Although this study was anonymous in design, IP addresses could also be viewed on the online survey programme, allowing the team to check if single users had completed the questionnaire multiple times.

Social demographics

Our entire sample consisted of adults (18+) with learning disabilities and/or autism. In total, our sample consisted of 103 participants in the quantitative stage of the research, and 34 adults in the qualitative stage, equating to 137 participants in total. More females completed the questionnaire at 61% compared to males at 29%, and 10% of the sample defined themselves as non-binary. Our sample is predominantly white, at 92%, and cannot be seen as a representative sample of people with learning disabilities and/or autism from black or ethnic minority groups. Regarding age, the sample had a relatively equal age spread ranging from 18 to 76 years old. The largest age group represented in the study were between 25 and 34 years old, at 26%. Interestingly, half of the study defined their neurodivergent identity as a disability and the other half rejected this statement. However, 45% also indicated having another disability or long-term health problem. The majority of the sample reported that they were also employed at 50%, and 39% stated that they were unemployed or in a voluntary position. Regarding their current housing situation, the majority, at 50%, reported living on their own (with or without support), followed by 41% living with their partners, and 16% living with their parents. Only 2% of this study reported living with others in residential care or supportive living environments (see Table 1).

Data analysis

It should be noted that the authors are influenced by a critical realist philosophy regarding disability and impairment, hence the authors classify 'disability' as disabling cultural, structural and economic barriers and 'impairment' as a biological/neurological variation (Macdonald and Deacon, 2020). The data was analysed using descriptive statistics in the form of a frequency test to examine the frequency distribution of cases and a descriptives test to rank the Likert scale data. Correlations were examined between the social demographic variables using a crosstabulation and a chi-square statistic (χ^2) to discover whether variables (i.e., social demographics × media information on COVID-19 = improved health information for people with learning disabilities and/or autism) were statistically independent or whether they are associated (De Vaus, 2002). Where the *expected count* fell below five in the data analysis, a *Fisher's Exact Test* was used to confirm statistical significance. The data were analysed using SPSS in the form of single variable analysis (univariate), and where data were calculated to be significant ($P \leq 0.05$) bivariate analysis was applied (De Vaus, 2002). The data analysis indicated that there was no significant bivariate/multivariate data in this study. For this reason, univariate analysis, using frequency tables, will represent the data analysis in this study. The qualitative survey data were analysed using a thematic analysis that was collected during the questionnaire phase of the research. Qualitative interview data which was collected during the interview phase of the research will be presented in a follow-up article to represent the lived experiences of participants with learning disabilities and/or autism (see Authors forthcoming).

Findings: Clarity of Information Presented by Different Media Sources on COVID-19

When exploring the leading source of health information concerning COVID-19 lockdown measures and infection rates, most participants reported watching the daily briefings on TV or online during the pandemic. Therefore, 62% reported that the daily briefing was their primary source of information about COVID-19 lockdown rules and the pandemic (see Table 2). When exploring further how clear health professionals and politicians were on the daily briefing, only 20% of participants reported they were clear on the messages presented in this daily health communication broadcast (see Table 2). What this data seems to indicate is that although most participants with learning disabilities and/or autism watched the daily briefing, only one-third of this population found it accessible and understood the health messages being presented by this media source. This is explained by one participant who suggested the daily briefings kept him up to date, but this information had to be explained by his mother as it was often difficult to follow. As John states '*My mother, she watched all the reports, kept me up to date on everything to do with data, rules, studies etc., and supported me through all vaccinations'.* As this participant illustrates, although John recognises the importance of Britain's daily briefings, he also found this health information at times inaccessible or contradictory.

Other than the daily briefing, the study explored what were the other most useful sources of media information concerning COVID-19 and the pandemic. The greatest media source of information reported by participants, at 36%, was TV news (see Table 2). Thus, just over a third of participants agreed that the TV news presented a clearer set of messages concerning COVID-19 and the pandemic compared to other sources of information. As Jude stated, *'probably the TV news as it told me the rules of what was going to happen'*. Another participant stated it was the TV which kept her most up-to-date, but this was often unclear and confusing. As Sophie suggests, the '*TV kept me updated with what rules we have to follow, but I wouldn't say it was good information because the rules weren't clear, so I had to search online'.* Participants also acknowledged the importance of official and accurate data in understanding the lockdown measures. Thus, although TV was identified as the most important source of information, participants also illustrated the importance of radio news, at 33%, and newspapers, at 30%, which were an important source of health information during the pandemic (see Table 2). For people with learning disabilities and/or autism, social media, at only 13%, was the least helpful source of reliable information reported by participants (see Table 2). As one participant stated regarding social media, *'I like official stuff as opposed to theories and gossip'.* Another participant, Ocean, suggests the worst sources of information came from the Internet, with *'people sharing obviously fake news on Facebook [and] thankfully there were few people I know who did this'*. Thus, for participants with learning disabilities and/or autism, social media was reported to be the most unreliable and unclear source of health information concerning COVID-19 lockdown measures or infection rates.

Feelings of Anxiety Concerning National Lockdown Measures by People with Learning Disabilities and/or Autism

During the pandemic, there were several discussions in the press which emphasised that people with learning disabilities and/or autism were at significant risk of death during the COVID-19 pandemic (Courtenay and Cooper, 2021; Williamson et al., 2021). This study explored people's knowledge of these risks and how anxious people were about going outside after the easing of lockdown conditions. Levels of anxiety emerged in the quantitative analysis, as 71% of participants expressed high levels of anxiety during and after COVID-19 measures were enforced and then relaxed (see Table 3). Other anxieties manifested themselves concerning breaking lockdown rules, as 38% reported being extremely worried about getting in trouble with the police by not following government guidelines and lockdown conditions (see Table 3). As Michael states '*I was worried the police would arrest my parents*.' Several participants illustrated their fears about being criminalised within the qualitative data. One participant also illustrated that they were fearful of police power because of a video they had watched on social media:

> I was anxious that the police may have abused their power to get me into trouble even though I knew I wasn't breaking any rules. This is because I [have] seen on

> YouTube and other news programs just how bad some police treated people during the pandemic.

However, anxieties about the police predominantly focused on accidental rule-breaking rather than police corruption. As Josie states *'I was scared my parents would get in trouble for visiting me. … I worried the police would arrest them'.* This data demonstrates a level of uncertainty concerning lockdown conditions and government guidelines for this particular community. Participants also illustrated significant worry, with 78% regarding other people around them breaking lockdown conditions and increasing their risk of being infected by the virus (see Table 3). One of the biggest fears, at 36%, was groups of people congregating in spaces outside (see Table 3). This was followed by a lack of mask-wearing, at 29%, and people invading their personal space at 28% (see Table 3). Interestingly, only 23% were significantly worried about people infecting them with COVID-19 after lockdown conditions were relaxed (see Table 3). Home visits were least likely to cause anxiety, and only 15% were worried about people visiting theirs or other people's homes after lockdown conditions were relaxed (see Table 3).

Although only 23% were worried about being infected by COVID-19, some of our participants in the qualitative literature did raise several concerns about this issue (see Table 3). One participant illustrated his anxiety about starting to go back outside, as this would increase the likelihood of him catching COVID-19. However, his greatest worry seemed to be anxiety about the quality of treatment he would receive in an NHS hospital if he, as a person with autism, were to become ill with COVID-19. As Frankie states '*I hope you're aware that government-issued NHS guidelines to [do not resuscitate] [are] for all autistic people? Yes, really*.' Even though this practice had been abandoned in NHS hospitals by the end of the pandemic, this was still a serious concern for Frankie. This narrative shows that some of our participants with a learning disability and/or autism were aware of the disablist practices that had been implemented in healthcare during the COVID-19 pandemic, and this seems to have had a significant impact on their trust in services after the lockdown was eased. Thus, other participants reported being confused by mixed messages presented both in the media and by health and social care practitioners. This confusion and anxiety are illustrated by one participant who carried on shielding after the lockdown conditions were removed. As Emily states:

> I’m still shielding as not felt safe enough to return yet. Still so unclear [about] what to do as the world says go out [but] makes fun of you for wearing masks. But my GP tells me to still avoid busy and indoor places as I’m so vulnerable and my carers, doctors, and physios still wear masks as that’s their rules too. The messages are so mixed.

As Emily describes, even though lockdown restrictions have been removed and it is no longer a requirement to wear a mask, this participant still feels anxious about going outside due to mixed messages in the media, by politicians, and the actions and messages from healthcare workers. Therefore, this participant has become a prisoner within her own home and is at significant risk of experiencing loneliness and isolation resulting in all of the related health risks and vulnerabilities associated with this form of exclusion and marginalisation (Macdonald et al., 2021; Shakespeare, et al., 2022).

Support with Health Communications from Peers and Health and Social Care Professionals

The importance of family, friends, and health and social care professionals’ ability to make health communications accessible was a central theme in the data analysis. The analysis illustrated that family members and health and social care professionals were central in supporting adults with learning disabilities and/or autism to understand and negotiate the often-complex rules of COVID-19 lockdown measures during the pandemic. Within the data analysis participants often describe not understanding the constantly changing rules presented on TV or in the news. Therefore, to overcome the inaccessible nature of health communications being presented by the media, many participants discussed the importance of family members helping to explain information on COVID-19 and lockdown measures during the pandemic. As Kyle discusses, ‘*My mum gave the best information as she was heavily invested in learning about it and so knew the ins and outs of it’.*

This is supported by the quantitative data which illustrated that the most helpful source of health communication outside of the media was family members at 53% (not including partners) (see Table 4). When exploring this data, it was mothers and fathers who were the most useful sources of information concerning COVID-19 lockdown measures and health information, at 34% (see Table 4). This was followed by brothers and sisters and other family members at 19%. In the qualitative data, several participants explained this further and stated that, although they listened to the news and daily briefings, they struggled to understand the information presented on TV. As one participant stated, *the 'people around me, [my] partner and family, as I didn't understand most of what the rules were'*. Interestingly, adults with learning disabilities and/or autism revealed that the least helpful source of information came from their partners at 13% or their friends and neighbours at 19% (see Table 4). Regarding partners, this may be explained by the fact that their partners sometimes also had a learning disability and/or autism. However, several participants did discuss the importance of partners and neighbours in the qualitative data. As one participant states, my '*partner gave me easy-read documents'* and another participant reports, *'I think it was mostly communication with friends. Some of them had caught it early on and were able to tell me about the symptoms.'*

Participants in this study also reported the importance of health and social care professionals as a source of information concerning COVID-19. The data reveals, at 49%, that health and social care professionals who supported them in the community played a significant role in passing on vital health information to participants in this study (see Table 4). It was social care professionals or advocacy groups that offered the greatest level of support, at 26%, followed closely by health professionals at 22% (see Table 4). Within the data findings, health and social care professionals or third-sector organisations played a significant role in explaining complex information on COVID-19 which was being presented in the media. As Jessica reports, her '*[autism group] organised peer-support groups on Zoom where we could talk about the most recent updates'.* The data illustrates that for people with learning disabilities and/or autism, some health and social care professionals made sense of health communications on COVID-19 presented in the media, to make this information accessible to participants in this study.

The study also explored if participants contacted their GP to clarify health information concerning lockdown measures or COVID-19 symptoms/infection during and after the pandemic. The study discovered that one-third of participants, at 29%, had attempted to contact their GPs regarding more information about COVID-19 or lockdown measures (see Table 5). Interestingly, from this group, only 45% had managed to speak to their GPs and 55% of participants could not get through to their GPs (see Table 5). For participants who needed more information concerning being infected with COVID-19, 32% of participants had attempted to contact their GPs for support (see Table 5). From this group, 55% had managed to speak to their GPs about information concerning being infected, whereas 45% had again not succeeded in getting through to their GPs (see Table 5).

Several participants in the qualitative data highlighted their dissatisfaction with GPs and access to information. Many noted the difficulties in accessing a GP since the start of the pandemic As Zach suggested, his '*GP … were awful, no support. If I'd been living on my own, I would have had no information at all. Never clear if my mum could come with me to vaccine centres - very poor info available. So, I went through the whole process by myself, and I was lucky I had a mobile phone to communicate with my mum*'. Participants illustrated that in their GP surgery, there was a lack of information or support available to adequately inform them about the pandemic. This data illustrates two points, firstly up to one-third of participants felt they needed to reach out to their GP for additional information on COVID-19 due to health communications being somewhat inaccessible. Secondly, for participants who reached out to their GPs, these health professionals were not a useful or additional source of information regarding lockdown rules or COVID-19 infections.

Discussion

This article suggests that the inaccessible forms of health communications may have led to the high level of infection and mortality rates for some autistic and learning-disabled communities. Our findings discovered that a significant disabling barrier emerged concerning inaccessible health communications during the global pandemic (see Table 2). Although health communications are a vital way of reaching out to the public to help stop the spread of disease, particularly during a global pandemic, public health messages must be accessible to all members of the public, not just nondisabled communities. Although people with learning disabilities and/or autism attempted to access health communications during the pandemic in different media formats, i.e., the daily briefings, TV news, newspapers, radio, and social media, (see Table 2) the findings in this study illustrate that these messages were generally inaccessible. This has been illustrated elsewhere, particularly with the deaf community, as the daily briefings in England were not communicated by British Sign Language (Shakespeare, et al., 2022).

Within our study, because of ineffective health communications, many people with learning disabilities and/or autism struggled to understand lockdown rules and public health messages (see Tables 2, 3 and 4). Many of our participants indicated high levels of stress and anxiety, in particular, concerns about the spread of COVID-19, or fears that their parents would be arrested for breaking lockdown rules when supporting them within the community (see Table 3). Our findings also illustrate that several key disablist messages did resonate with some participants with learning disabilities and/or autism. Some of our participants illustrated a heightened level of stress and anxiety due to the dominant discourse which was presented suggesting that as long as you have not got a ‘pre-existing’ health condition then you will not die of COVID-19 (Abrams and Abbott 2020). As Abrams and Abbott (2020) illustrate, this message reassured nondisabled populations and constructed a bioethical utilitarian statement rendering disabled lives as less important or that can be sacrificed for the ‘greater’ good of society. This message was internalised by some of our participants resulting in a fear of going to a hospital in case of a ‘do not resuscitate’ order being invoked (Courtenay and Cooper, 2021) or further and unnecessary prolonged experiences of isolation through heightened fears of catching the disease (Williamson et al., 2021; Shakespeare et al. 2022). For many of our participants, these dominant discourses led to further social isolation and a loss of independence, further exacerbating existing inequalities experienced by disabled communities in pre-pandemic life (Macdonald et al., 2018).

Expert evidence presented to the Public Enquiry on COVID-19 by Nick Watson and Tom Shakespeare reported that disabled people were put at significant risk compared with nondisabled populations during the pandemic (Watson and Shakespeare 2023). Due to the financial crisis of 2008, and austerity politics, by the time of the pandemic public spending on social care had fallen by almost 10% across Britain (Watson and Shakespeare 2023). This reduction in social care not only impacted disabled people's experiences of independence but also had a significant impact on effective healthcare responses to the pandemic. Within our study, because of inaccessible health communications and limited support from GPs (see Table 5), we discovered that health, social care, and third-sector professionals played a significant role in making these health messages accessible to disabled groups (see Table 4). People without access to health and social care professionals, often relied on parents or other family members to translate many of these messages into an accessible format (see Table 4). As Shakespeare et al. (2022) illustrate many health and social care services had either been cut, or suspended during the pandemic, which was picked up by family members of disabled people. We discovered that, because health communications were inaccessible, people with learning disabilities and/or autism relied on both parents and health and social care professionals to explain public health messages and lockdown rules. Yet, a key concern here is that disabled people without family support, and with limited access to health and social care professionals, because of a lack of inaccessible health communications have an increased chance of social isolation, marginalisation, and heightened infection rates (Macdonald, et al., 2018; Shakespeare, et al., 2022).

Conclusion

Effective health communications allow a slowdown of infection rates and a reduction in mortality during and after a pandemic (Mheidly and Fares, 2020). Yet this study illustrates how ineffective health communications were during the COVID-19 pandemic for disabled communities. The findings also illustrate the importance of health and social care professionals in communicating public health messages during the COVID-19 pandemic. Studying health communications and how effective these are in including and not alienating disabled populations must be central to future public health responses to the outbreak of infectious diseases. Effective health communications must take place alongside adequately funded health and social care services to support disabled people's independence during any future pandemic (Shakespeare et al. 2022). Inclusive Health communications must be made a priority for public health and media disciplines to make sure that effective health communications are accessible to all and do not convey the disablist messages which alienated many disabled people in this study.

Studying the global pandemic and how this affected disabled populations can allow us to respond more effectively when the next global pandemic occurs, reduce the spread of infection, increase feelings of well-being and trust, and lower mortality rates for disabled populations. As Vaughn and Tinker (2009) suggest, if one group, i.e., disabled people, are left out of effective health communications then not only does this affect this particular group, but it will subsequently affect the entire population and facilitate the rapid spread of a virus during a future pandemic. Thus, we would argue that improved inclusive health communications are not just an issue for disabled people but a concern for the entire population which we must confront now before the next global pandemic.

Appendices

Table 1: *Social demographics*

Characteristics	Per cent	n
Gender	100%	100
Male	29%	29
Female	61%	61
Non-binary	10%	10
Ethnic groups	100%	102
White	92.2%	94
Black	3.9%	4
Mixed ethnic groups	3.9%	4
Age	100%	101
18 - 24	6.9%	7
25 - 34	25.7%	26
35 - 44	21.8%	22
45 - 54	22.8%	23
55 - 64	15.8%	16
65+	6.9%	7
Disability	100%	103
Yes	44.7%	46

No	55.3%	57
Employment	100%	101
Employed	49.5%	50
Unemployed	25.7%	26
Voluntary	12.9%	13
Student	5.0%	5
Retired	6.9%	7
Current residence	100%	100
On my own	35.0%	35
With my partner	41.0%	41
With my parents	16.0%	16
With friends	1.0%	1
Supported living (with others)	2.0%	2
Supported living (by myself)	5.0%	5

Notes: n = participant numbers

Table 2: Clear Information on COVID-19

Clear Information		Per cent	n
Did you watch the daily briefings on TV/online?		100%	103
	Yes	62.1%	64
	No	37.9%	39
Clear Information from the briefings on TV/online		100%	103
	Yes	20.4%	21
	No	79.6%	82
Clear information on television news		100%	99
	Yes	36.3%	36
	No	63.6%	63
Clear information on the radio		100%	94
	Yes	32.9%	31
	No	67.0%	63
Clear information in the newspapers		100%	98
	Yes	29.5%	29
	No	70.4%	69
Clear information on politicians daily briefings		100%	103
	Yes	20.4%	21
	No	79.6%	82
Clear information on social media		100%	96
	Yes	12.5%	12
	No	87.5%	84

Notes: n = participant numbers

Table 3: COVID-19 and feelings of anxiousness

Relaxed lockdown measures		Per cent	n
Anxious about going outside		100%	103
	Yes	70.9%	73
	No	29.1%	30
Were you worried about getting in trouble with the police for not following the rules		100%	103
	Yes	37.9%	39
	No	62.1%	64
Were/are you worried about other people not following the rules		100%	103
	Yes	77.7%	80
	No	22.3%	23
If yes, - lots of people close together in places		100%	103
	Yes	35.9%	37
	No	64.1%	66
If yes - people not wearing masks		100%	103
	Yes	29.1%	30
	No	70.9%	73
If yes - people invading your space		100%	103
	Yes	28.2%	29
	No	71.8%	74
If yes, people infecting you with COVID-19		100%	103
	Yes	23.3%	24
	No	76.7%	79
If yes, people touching you		100%	103
	Yes	15.5%	16
	No	84.5%	87
If yes, - people visiting your home		100%	103
	Yes	7.8%	8
	No	92.2%	95
If yes, - people visiting other people's homes		100%	103
	Yes	6.8%	7
	No	93.2%	96

Notes: n = participant numbers

Table 4: Information on COVID 19

Helpful – Family Members and Peers	Per cent	n
Family Total	100%	103

	Yes	53.3%	55
	No	46.7%	48
Mother/ Father		100%	103
	Yes	33.9%	35
	No	66.1%	68
Sister/Brother/other Families		100%	103
	Yes	19.4%	20
	No	80.6%	83
Health and Social Care Total		100%	103
	Yes	48.5%	50
		51.5%	50
Social Care Professionals/Supporting Organisation/Advocate		100%	103
	Yes	26.2%	27
	No	73.8%	76
Health Professional		100%	103
	Yes	22.3%	23
	No	77.7%	80
Friend/Neighbours		100%	103
	Yes	19.4%	20
	No	80.5%	83
Partner		100%	103
	Yes	12.6%	13
	No	87.4%	90

Notes: n = participant numbers

Table 5: GP Information on COVID-19

Contact with GP		Per cent	n
Did you contact your GP concerning information about COVID-19		100%	100
	Yes	29%	29
	No	71%	71
	Yes - spoke to GP	44,8%	13
	Yes – but could not get through to my GP	55.1%	16
Did you contact your GP concerning information about being infected with COVID-19?		100%	99
	Yes	33.3%	33
	No	66.6%	66
	Yes - spoke to GP	54.5%	18
	Yes – but could not get through to my GP	45.4%	15

Notes: n = participant numbers

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