

Greater Manchester Disabled People's Panel

GM Big Disability Survey: Covid-19

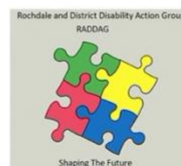


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Executive Summary

The Greater Manchester Disabled People's Panel is a Greater Manchester wide, pan-impairment Panel, made up of 14 Disabled People's Organisations (organisations that are majority led and staffed by disabled people), and is convened by the Greater Manchester Coalition of Disabled People. From the outset of the pandemic, member organisations of the Panel have been working to support disabled people, many of whom have been isolated from information, support and access to basic provisions. The Panel has met on a weekly basis since mid-March, sharing information and resources and inputting, wherever possible, the voice and experiences of disabled people. Having recognised the impact digital exclusion and isolation would have from the onset of the pandemic, the Panel sought to make the Community Hubs more accessible, known and available to disabled people. Throughout the initial crisis stage, when working to improve the situations most affecting disabled people, the Panel was asked for the evidence it had of disabled people's experiences.

To support the existing lived experience, knowledge and expertise of the Panel, two surveys were therefore commissioned to evidence the impact of the pandemic on disabled people across Greater Manchester. In order to make this gathering of information and data accessible, many Panel member organisations supported disabled people to complete the survey, including over the phone. For the same reason, the Panel also produced two versions of the survey – a standard version and an easy read version. 936 people completed the survey; 677 people took part in the standard survey, and 259 participants completed the easy read (60% of whom identified that they were learning disabled).

In addition to the Panel members widely circulating the surveys amongst their members and networks, the surveys were hosted on gmconsult.org, shared through social media, included in mainstream media press releases and circulated through partner agencies in order to hear from a wide variety of disabled people.

Key findings

Once the survey was closed, GMCA provided an impartial analysis of the data. The findings of the survey confirmed the Panel's assertion that disabled people were being disproportionately affected by the pandemic. The survey confirmed that disabled people are experiencing social isolation, reduced social care support, issues

relating to access to food, medicine and information, and a severe impact on mental health.

Shielding and non-shielding disabled people

The initial government-set criteria was a very narrow list of people who were told they needed to shield. This set of criteria was used to inform many of the systems set up to support people, determining who was entitled to access this support to enable them to safely self-isolate. This left many disabled people, who knew that they should be taking extra precautions, unable to access food, medicine and support – many of these disabled people went on to receive letters as the weeks progressed, evidencing and validating their need to shield from the outset of the crisis. The findings of this survey demonstrated this: 20% of the standard survey participants received a letter from the Government to indicate that they were in the ‘high risk’ group for the Covid-19 outbreak. Of the 80% who did not receive this letter, **57% reported having support needs of whom only 19% are getting all of their needs met.**

Community Hubs

The Panel found that many disabled people across GM were unaware of the Community Hubs, and that many disabled people were unable to access the Hubs. The survey highlighted that 31% of respondents to the standard survey were **not at all aware** of the Community Hubs, and that accessibility of the Hubs varied slightly by impairment with those who identified their impairment as ‘hearing’ having the highest proportion of respondents who found the Hub not accessible at all. Some disabled people who were aware of Community Hubs had been unable to access support from them due to not meeting the shielding criteria.

Disabled People’s views on government and local authority

The Panel found that many disabled people felt they were not a priority for the government. This was compounded by the initial language used to reassure the nation of the effects of Covid-19 in February and March – that the general population need not be too concerned, as it predominantly only seriously affected the so-called ‘vulnerable’: the elderly and those with underlying conditions. This language, combined with the delay in setting up support mechanisms for those needing to shield pre-national lockdown, resulted in many disabled people feeling abandoned and that their lives were not valued. The survey demonstrated that a third of disabled people believe that their local authority is not doing anything significant, whilst **76% of disabled people are dissatisfied with the help**

provided by the government. A third of disabled people believe that the government is neglecting disabled people.

The statistics from this report provide an insight into the plight of disabled people during this crisis period. Issues around accessing PPE (56%), cancelled health appointments (62%) and concerns about housing (37% in inaccessible/partially accessible housing) were all touched on. The free text comments offer a real insight into the human costs of this, and were an outpouring of fear, isolation and people in crisis. The disproportionate impact of Covid-19 on disabled people has been significant - not only with regards to accessing food, provisions, information and support, but the drastic impact of the added stress, anxiety and level of self-advocacy needed to try to survive. It is unsurprising therefore that **90% of respondents said that the pandemic has had a negative impact on their mental health.**

This report therefore provides an insight into the lived experience of disabled people during the initial stages of the pandemic, and explores the impact of exclusion, inaccessibility and inequality. The Panel has provided recommendations as to how to improve existing practice, as well as what measures need to be implemented to ensure that this does not happen again as we move into the next stages of this pandemic.

The positive to take from this report is that changes can be made. The experiences of disabled people during this pandemic were not inevitable or unavoidable. By implementing real, tangible changes we can prevent it from happening again. The Panel are offering their expertise, knowledge and guidance on how to make real and substantial changes - but we need to be heard and supported by those in a position to effect change, if we are to “build back better” with disabled people.

1. Introduction

- 1.1 The Greater Manchester Disabled People's Panel wanted to evidence the effect that Covid-19, and the related lockdown, has had on disabled people living within Greater Manchester.
- 1.2 The Panel understood that many of the pre-existing inequalities and issues disabled people face were compounded by the pandemic, and that additional challenges were introduced on top of these inequalities. The survey aimed to expose these challenges, and evidence how disabled people are coping with the changes that have been implemented since the Covid-19 outbreak, capturing their views and experiences.
- 1.3 The Panel commissioned two surveys - one in easy read, to ensure accessibility, alongside the standard version. The questions focused on similar themes and analysis of both will be included in this report. The focus of the report was around social support, with some additional themes included, aiming to give a comprehensive overview of the experiences of disabled people in Greater Manchester since the Covid-19 outbreak.
- 1.4 In addition to the Panel members widely circulating the surveys amongst their members and extensive networks, the surveys were hosted on gmconsult.org for one month, shared through social media, included in mainstream media and circulated through partner agencies in order to hear from a wide variety of disabled people.

2. Demographics Information of Respondents

- 2.1 The Panel is a pan-impairment Panel, which includes anyone facing disabling societal barriers due to their impairments or conditions. This includes physical, sensory, mental health, hearing or visual impairments, learning disabled people, neurodiverse people, and those with chronic illness or fatigue. 677 people took part in the main survey and 630 (93% of respondents) of these identify as disabled people. In terms of impairments, 378 people described them as physical (60%), 276 as mental (44%), 102 as hearing (16%), 56 as seeing (9%), 141 as learning (22%), 137 as neurodiversity (22%), 282 as chronic illness (45%) and 52 as other (8%); respondents could choose more than one category to describe their impairment and therefore the percentages exceed 100%. On average, the number of impairments identified by participants was two. **This reflects one of the reasons it is important to take a pan-impairment approach, as many disabled people may have multiple access requirements.**
- 2.2 259 participants took part in the easy read version of the survey and 60% of these identified as having a learning disability.
- 2.3 Participants were spread across all ten boroughs in Greater Manchester, with the largest proportion living or receiving support in Manchester (234 people) and the smallest proportion in Oldham and Bury (39 people in each) (see Figure 1). Due to the small participant numbers in some boroughs and the different demographic groups, this analysis will not necessarily be representative of the views of all disabled people across individual boroughs, but the findings at a Greater Manchester wide level can be used to identify trends in the views of disabled people during the Covid-19 outbreak.

Figure 1: Pie chart showing proportion of respondents living in each borough. Bolton 4%, Bury 6%, I don't live in Greater Manchester 8%, Manchester 25%, Oldham 4%, Rochdale 6%, Salford 8%, Stockport 10%, Tameside 9%, Trafford 6%, Wigan 13%, blank 1%.

- 2.4 Participants were asked to define their gender. There was a large variety of different answers in response to this question as respondents were asked to self-define. In order to analyse these

responses, the data was collated into groups and is illustrated in Figure 2.

Figure 2: Pie chart showing proportion of respondents in each gender category. Female 56%, Male 37%, non-binary 2%, blank 3%, other 2%.

2.5 The ages of respondents ranged from 18 to 64. Older people were well represented, with 22% aged 45-54, 19% aged 55-64, and younger respondents aged 18-24 came in at 11% of respondents. Breakdowns can be seen in Figure 3.

Figure 3: Pie chart showing proportion of respondents in each age category. 18-24 11%, 25-34 16%, 35-44 15%, 45-54 22%, 55-64 19%, 65+ 10%, under 18 6%, blank 1%.

2.6 Respondents were also asked to self-define their ethnicity which led to a large variety of responses. These were grouped into more commonly used ethnicity groups in order to provide more usable data. The variety included in the self-definition did highlight however that commonly used ethnicity groups often do not necessarily provide an accurate/comprehensive indicator of ethnicity.

2.7 8% of the sample (69) defined themselves as an ethnicity commonly included in 'BAME' and these were grouped together (see Figure 4).

2.8 The small number of participants in the 'BAME' category means that any further analysis of this group is difficult. For example, it is not possible to compare amount of worry about housing across 'BAME' participants and their white counterparts because not enough 'BAME' people responded to this question. This highlights an important intersectional issue, where the experiences of 'BAME' disabled people has not been successfully captured in this survey

in a meaningful way, even by a pan-impairment, GM borough wide Panel, including with the support of VCSE networks and mainstream media advertisement.

Figure 4: Stacked bar chart showing proportions of respondents in each ethnic group. BAME 8%, White 77%, Other 15%.

3. Respondents who are classed as “High risk”

- 3.1 20% of participants who completed the standard survey received a letter from the government to indicate that they were in the ‘high risk’ group for the Covid-19 outbreak. However, of the other 80% of respondents, who did not receive a letter indicating that they were ‘high risk’, 57% reported having support needs, for example with obtaining food or medicines (please note: this question was not included in the easy read version of the survey for accessibility reasons). The responses reflected the understanding/experience of Panel members regarding the number of disabled people who had underlying conditions which warranted support, but did not fit within the government-set criteria.
- 3.2 The large proportion of disabled people who did not fit the initial government-issued shielding criteria but had support needs is significant and confirms what the Panel knew from its members and networks. Of these participants, only 19% rated themselves as having all of their needs met, with 10% saying that they were having none of their needs met (see Figure 5). From the Panel’s experience, many disabled people knew that they should be taking additional precautions from their own understanding of their impairments and health, but also, for many, this was corroborated by their GPs. Many of these disabled people did not meet the initial shielding list, and did not receive the initial letter. This left disabled people, who knew that they should be taking precautions, unable to access the support being implemented for those with the shielding letter. Many of these disabled people subsequently went on to receive letters advising them to shield, weeks after the initial letters were distributed. The large group of people who were not officially shielding but who still have support needs is a significant confirmation from this survey of the difficulties disabled people face.
- 3.3 For the 20% of participants who did receive a letter to indicate that they were ‘high risk’, respondents were more likely to be getting all their needs met compared to those that did not receive a letter; yet still **only a quarter of respondents in the high risk category were getting all of their needs met.**
- 3.4 This varied slightly across all of the boroughs, ranging from less than 10% who were getting all their needs met to 35% in one borough.

- 3.5 The only real difference in terms of proportion of support needs being met across these two groups (officially high risk and not high risk but still requiring support) was in the 'all needs being met' category (see Figure 5).
- 3.6 A lot of respondents mentioned the particular difficulty in accessing food delivery slots from supermarkets:

"I usually get supermarket deliveries, but because I'm not on the 'extremely vulnerable' list have been totally unable to access this, and had to increase pain, fatigue and exposure risk by going to supermarket in person, and using some of my personal care time for PA to accompany me."

"Supermarkets are harming disabled people, in collaboration with the government, by refusing to deliver to those of us who are housebound but don't qualify for shielding. I've been trying to get a slot for a month but none are available, they won't prioritise me because none of my official diagnoses put me at high risk from the virus"

Figure 5: Two stacked bar charts with the first showing the proportion of support needs being met by those registered high risk with the government (26% of respondents are getting all their needs met, 34% most, 19% some, 13% a few, 8% none). The second stacked bar chart shows the proportion of support needs being met for those not registered as high risk with the government (21% are getting all their needs met, 32% most, 20% some, 17% a few, 10% none).

4. Awareness and Accessibility of Community Hubs

- 4.1 31% of respondents to the standard survey were not at all aware of the Community Hubs, which have been set up in each borough to coordinate food parcels, medicine and other forms of support.

Figure 6: Awareness of Community Hubs by Borough Stacked bar chart showing proportion of people that were aware of the community hubs in each borough. In Bolton, 9% were extremely aware, 13% very aware, 34% somewhat aware, 16% not so aware, 28% not at all aware. In Bury 13% were extremely aware, 23% very aware, 31% somewhat aware, 8% not so aware, 26% not at all aware. In Manchester 9% were extremely aware, 10% very aware, 32% somewhat aware, 18% not so aware, 31% not at all aware. In Oldham 4% were extremely aware, 24% very aware, 20% somewhat aware, 16% not so aware, 36% not at all aware. In Rochdale 2% were extremely aware, 15% very aware, 22% somewhat aware, 22% not so aware, 39% not at all aware. In Salford 14% were extremely aware, 19% very aware, 32% somewhat aware, 10% not so aware, 25% not at all aware. In Stockport 11% were extremely aware, 11% very aware, 36% somewhat aware, 14% not so aware, 27% not at all aware. In Tameside 6% were extremely aware, 9% very aware, 23% somewhat aware, 23% not so aware, 40% not at all aware. In Trafford 8% were extremely aware, 16% very aware, 18% somewhat aware, 18% not so aware, 39% not at all aware. In Wigan 8% were extremely aware, 16% very aware, 32% somewhat aware, 21% not so aware, 24% not at all aware.

4.2 Awareness varied slightly across the 10 boroughs, with the greatest awareness in Salford and the least awareness in Tameside (see Figure 6). Digital exclusion was a prevalent and persistent issue. Awareness of community and voluntary services was low, potentially an interconnected factor.

The Panel had been made aware through its membership and the people we support that multiple individual disabled people across Greater Manchester had been left completely without access to food, some going days without it. The Panel had also been made aware of individuals who should have been shielding not having access to support, and therefore travelling on public transport and entering shops and pharmacies in order to access food and medicine. The regularity of these experiences, taking place across the boroughs and being raised by multiple disabled people's organisations/Panel members, was a recurrent phenomenon.

4.3 Across all types of impairments, there were a similar proportion of people in the standard survey who had used a Community Hub.

This varied from 41% of those who identified their impairment as 'seeing' to 48% of those who identified their impairment as 'learning'.

- 4.4 Those who identified their impairment as 'hearing' had the highest proportion of respondents who found the Hub not accessible at all (see figure 7). It should be noted that these were the smallest sample (95 respondents), so the results may not be representative. It is also important to note, however, that the disproportionate impact on accessing vital support, while a smaller minority of disabled people, is still a critical indicator of the level of impact and exclusion which occurs when systems set up to provide support are inaccessible from the very first entry point.
- 4.5 Those who identified their impairment as 'learning' had the second highest proportion of people who found the Hub not accessible at all (47%). One of the factors the Panel has raised with Community Hubs during the crisis phase has been the lack of a script available which indicates what information the individual is going to need to have to hand in order to access support. This guidance not being available not only impacted on the accessibility for disabled people themselves, but also prevented the people assisting disabled people to access support from being able to make the call on their behalf, especially if they did not live with them.
- 4.6 The average across impairments was 43% who stated that the Community Hubs were not accessible at all.

Figure 7: Accessibility of Community Hubs by impairment category Stacked bar chart showing proportion of respondents that found the community hubs accessible by impairment category. 37% of those with a physical impairment found the hubs not accessible at all, 4% very difficult, 4% difficult, 44% neither easy nor difficult, 5% easy, 7% very easy. 41% of those with chronic illness found the hubs not accessible at all, 4% very difficult, 3% difficult, 38% neither easy nor difficult, 7% easy, 7% very easy. 52% of those with a hearing impairment found the hubs not accessible at all, 5% very difficult, 2% difficult, 29% neither easy nor difficult, 7% easy, 5% very easy. 47% of those with a learning impairment found the hubs not accessible at all, 3% very difficult, 5% difficult, 33% neither easy nor difficult, 5% easy, 8% very easy. 45% of those with a neurodiversity impairment found the hubs not accessible at all, 2% very difficult, 2% difficult, 42% neither

easy nor difficult, 5% easy, 5% very easy. 39% of those with a seeing impairment found the hubs not accessible at all, 9% very difficult, 0% difficult, 43% neither easy nor difficult, 0% easy, 9% very easy. 42% of those with a mental impairment found the hubs not accessible at all, 3% very difficult, 2% difficult, 39% neither easy nor difficult, 6% easy, 8% very easy.

4.7 Figure 8 shows the accessibility of Community Hubs by borough. There is some variation amongst different Greater Manchester boroughs, with those in Rochdale finding the Community Hubs the most accessible: 23% people found it easy or very easy. There were, however, a large proportion of people across most of the boroughs who found the Community Hubs neither easy nor difficult to access.

4.8 The borough where people had the most difficulty accessing the Hub was Tameside, where 76% had difficulty.

Figure 8: Accessibility of Community Hubs by Borough

Stacked bar chart showing proportion of people that found the hub accessible in each borough. In Bolton 53% found it not accessible at all, 40% neither easy nor difficult, 7% easy. In Bury 45% found it not accessible at all, 5% very difficult, 40% neither easy nor difficult, 10% easy. In Manchester 37% not accessible at all, 7% difficult, 42% neither easy nor difficult, 3% easy, 10% very difficult. In Oldham 38% found it not accessible at all, 50% found it neither easy nor difficult, 13% found it easy. In Rochdale 50% found it not accessible at all, 5% found it very difficult, 23% found it neither easy nor difficult, 18% easy, 5% very easy. In Salford 35% found it not accessible at all, 9% very difficult, 48% neither easy nor difficult, 9% very easy. In Stockport, 33% found it not accessible at all, 3% very difficult, 45% neither easy nor difficult, 12% easy, 6% very easy. In Tameside 63% not accessible at all, 13% difficult, 13% neither easy nor difficult, 13% easy. In Trafford 35% found it not accessible, 6% difficult, 47% neither easy nor difficult, 12% easy. In Wigan, 33% not accessible at all, 2% very difficult, 5% difficult, 37% neither easy nor difficult, 5% easy, 7% very easy.

4.9 Respondents were asked if the government and the local authority are doing enough to help disabled people. A third of disabled people

believe that their local authority is not doing anything significant (see Figure 9).

More people expressed satisfaction (38%) with the local authority help in comparison to Government help for disabled people.

- 4.10 The vast majority of respondents expressed dissatisfaction (76%) with the help provided by the Government, but to varying degrees.
- 4.11 A third of disabled people believe that the Government is neglecting disabled people.

“My confusion with the guidance lies in the fact that the Govt (sic) is not providing a [British Sign Language] BSL interpreter at their press conferences. I either have to rely on broken subtitles or interpreters live streaming an interpretation voluntarily.”

“I want to emphasise how hard to understand government briefings are if you're autistic - they are not clear at all! The language used is very hard to understand.”

“I don't think the government is doing enough to support people with disabilities. They are not making sure people with health issues/disabilities are ok at this time. It is making it lots harder for those of us who are parents too and do not have any help looking after their children when they need to constantly self isolate. I have a toddler and find this every (sic) difficult.”

Figure 9: Satisfaction with government help and local authority help Two stacked bar charts showing proportion of people that are satisfied with 1. Government help and 2. Local authority help. 33% of people believe that the government are neglecting disabled people, 18% that they are harming disabled people, 25% that they are not doing anything significant, 18% that they are doing some good things and 6% that they are doing everything they can. In terms of local authority help, the second of the charts shows that 22% believe that local authorities are neglecting disabled people, 5% that they are harming disabled people, 34% that they are not doing anything

significant, 28% that they are doing some good things, 10% that they are doing everything they can.

5. Access to Personal Protective Equipment

- 5.1 506 participants remarked on their access to Personal Protective Equipment (PPE). 57% of respondents had experienced some difficulty sourcing PPE if it was needed (see Figure 10) whilst 35% found it neither easy nor difficult and only 8% said that it was easy to obtain PPE.
- 5.2 A comparison of this across the Greater Manchester Boroughs shows that those in Tameside have reported the greatest difficulty, where 68% of respondents found sourcing PPE either difficult or impossible.
- 5.3 In comparison, Oldham and Bury respondents reported the least difficulty accessing PPE, however half of respondents still said that they found accessing PPE either 'difficult' or 'impossible'.
- 5.4 For those who took part in the easy read survey, they were asked whether their carers had been wearing gloves and masks and washing their hands. Although a lot of the respondents did not have carers, for 98 people this question was relevant, 88% of these answered yes.
- 5.5 Panel members were aware that many disabled people who use personalised independence payments (PIP) to employ PA's directly (as opposed to employed through social care) struggled to access protective equipment, as they were not recognised as needing it.

Figure 10: Access to PPE by Borough Stacked bar chart showing how easy it was for respondents to access PPE in each borough. In Bolton 10% found it easy, 33% found it neither easy nor difficult, 38% difficult, 19% impossible. In Bury 20% found it easy, 30% found it neither easy nor difficult, 27% difficult, 23% impossible. In Manchester 6% found it easy, 35% found it neither easy nor difficult, 44% difficult, 15% impossible. In Oldham 10% found it easy, 40% found it neither easy nor difficult, 35% difficult, 15% impossible. In Rochdale 8% found it easy, 33% found it neither easy nor difficult, 32% difficult, 28% impossible. In Salford 4% found it easy, 39% found it neither easy nor difficult, 39% difficult, 17% impossible. In Stockport 2% found it easy, 43% found it neither easy nor difficult, 36% difficult, 19% impossible. In Tameside 8% found it easy, 24% found it neither easy nor difficult, 40% difficult, 28% impossible. In Trafford 7% found it easy, 41% found it neither easy nor difficult, 41% difficult, 10% impossible. In Wigan 11% found it easy, 38% found it neither easy nor difficult, 32% difficult, 19% impossible.

6. Access to Services

- 6.1 There has been a significant reduction in health visits during the coronavirus outbreak, with 62% of respondents from the standard survey experiencing one or more health visits that had stopped due to the Covid-19 outbreak and a further 26% reporting that the amount of health visits had reduced. Likewise, in the easy read survey, 46% of respondents had had a medical appointment cancelled and several remarked within the free text boxes that many of their health visits have stopped or reduced. It is important to note the impact that this will have had on some disabled people's ability to maintain their current level of impairment. By being unable to access their usual healthcare (for example physiotherapy), some disabled people may have experienced a decline in their health and wellbeing, and therefore an increase in their support requirements/decline in their impairment. This is important, because it demonstrates an additional impact of Covid-19/lockdown on some disabled people.
- 6.2 Figure 11 shows the breakdown of changes to health visits for those who took part in the standard survey.

Figure 11: Reduction in health visits Stacked bar chart showing proportions of people that have experienced changes to their health visits. 39% if people said that their personal assistant had stopped, 30% that it had reduced and 31% that it had stayed the same. 46% said that a health or personal care professional had stopped, 30% reduced, 24% stayed the same. 58% of people found that their mental health team had stopped, 26% reduced and 16% stayed the same. With district nurses, 48% had stopped, 24% reduced and 28% stayed the same.

“Therapy and mental health (sic) team appts (sic) are over the phone and this is driving me potty and making me feel more alone.”

“I've had no support due to career (sic) self isolating with her family and had to rely (sic) on my teenaged daughter to get my medicine”

7. Mental Health and Wellbeing

- 7.1 90% of respondents to the standard survey said that the pandemic has had a negative impact on their mental health (see Figure 12).
- 7.2 In the easy read survey, respondents were asked about their mood and could tick multiple boxes. Figure 13 shows a breakdown of their responses. 36% of respondents said that they felt low in mood.
- 7.3 Respondents to the standard survey were very concerned about the impact of continued self-isolation. If they have to self-isolate for another month from when they completed the survey, 87% of disabled people said that they were concerned about their mental health. Of these, 40% said that they were very concerned.
- 7.4 Those who received a letter to indicate that they were high risk reported that they were more worried about contracting Covid-19 than those who did not receive a letter, with 47% of those in the official high risk category expressing that they were worried 'a great deal' compared to 29% of those not officially in the high risk category.

Figure 12: The impact of the pandemic on mental health
Stacked bar chart showing how people felt the pandemic had affected their mental health. 10% none at all, 24% a moderate amount, 24% a little, 18% a lot, 25% a great deal.

Figure 13: Mood of participants taking part in the easy read survey
Bar chart showing mood of participants that took part in the easy read survey. 22% felt depressed, 25% down, 6% low in mood, 30% ok, 3% happy, 20% something else, 26% scared.

“My mum is doing all my care and I wonder how long she can keep this up as my dad also depends on her as he has dementia and she is very tired”

“Self-isolation is a normal way of life for many disabled people. It is unusual to be asked now about our mental health and how we are managing!”

“I’m struggling because I live alone and my anxiety won’t let me go out much so I’ve been having half a tin of beans or spaghetti with 2 slices of toast every day because I couldn’t get access to home deliveries until today. I’ve spent 3 days in the dark

because I couldn't get out to get electric because of my mental health condition. COVID just adds to that anxiety"

"I have a disability, plus my son has autism, and with his school closed, I have been having to care for him 24 /7 and meet his support needs at home while his dad works, which has taken a huge physical toll on my physical and mental health. I think it has been overlooked that there are people with multiple disabilities and caring responsibilities in the same family coping without school childcare and support."

8. Housing

- 8.1 In the standard survey, 32% of the respondents are worried about their housing situation (see Figure 14).
- 8.2 19% of disabled people, who answered the standard survey, live alone. This could further compound the impact of social isolation and lack of access to support for these participants during the period of lockdown.
- 8.3 The survey also asked if their housing was accessible and had the adaptations that they need. Although this is not necessarily directly related to Covid-19, it reflects the continuing difficulties that disabled people experience within their housing, which is only exacerbated by the pandemic. **37% said that their housing was not accessible or only partially accessible.** The impacts of inaccessible housing include reduced independent living, increased need for social care, more reliance on carers and family members, an increase in accidents (including those that are life-changing or fatal) and avoidable hospital admissions.

Figure 14: Worry about housing within the standard survey Stacked bar chart showing how worried people are about housing. 68% are not at all, 10% a moderate amount, 13% a little, 4% a lot, 5% a great deal.

9. Digital Exclusion

- 9.1 The standard survey asked participants if they used a digital device. 11% of disabled people (70 respondents) answered that they do not use a digital device.
- 9.2 An exploration of the reasons for this (Figure 15) shows that 24% (17 respondents) needed support to help them to access a digital device, and that this is not available.

The most popular digital device amongst the respondents to the standard survey was a smart phone, with 74% of the respondents owning one, followed by 52% having a laptop. Panel members, their organisations and disabled peers were encouraged to assist people to fill in the survey, many doing so via telephone. The Panel did what it could to bridge the digital divide, but recognises that there will be digitally excluded people whose experiences have not been captured by this survey. This is particularly the case for those who reside in boroughs without a local disabled people's organisation which can provide support. Additionally, disabled people who live in institutions and care homes are unlikely to have accessed the survey, due to the segregated nature of these institutions.

9.3

Figure 15: Reasons why respondents do not use a digital device. Stacked bar chart showing reasons why respondents do not use a digital device. 24% need support that isn't available, 21% don't like them, 9% because of their visual impairment, 13% other, 10% can't understand how to use them, 10% impairment related, 6% rely on family, 4% have no home internet.

10. Accessing information

- 10.1 Figure 16 shows a breakdown of where respondents access news and information. It shows that most people who responded to the standard survey accessed information via the internet (72%) and on television (71%).
- 10.2 Within the easy read survey, 68% of respondents stated that they access information from the television and 15% through the internet. Those who took part in the easy read survey relied heavily on their family or support staff to access information, with 36% and 26% of respondents respectively. This demonstrates the

importance of support to access vital information and provision, and highlights how quickly and easily disabled people without this important support can suffer negative consequences, becoming segregated not only from services and provision, but also basic information.

Figure 16: How respondents of the standard survey accessed news and information bar chart showing the places where respondents access news and information. Less than 10% use the red button on tv, community sources, charities and NGOs. Around 30% use family, 25% the radio. By far the most popular are the internet and television which over 70% of respondents use.

11. Care plans

11.1 Respondents of the standard survey were asked if they had a care plan and, if so, did they find it satisfactory pre-Covid-19 and after the outbreak. Figure 17 shows a comparison of the results. It is clear that disabled people are less satisfied with their care plan during the pandemic. For example, 58% of disabled people were satisfied or very satisfied with their care plans before Covid-19, but after the outbreak this is only 35%.

Figure 17: Comparison of satisfaction levels in relation to disabled peoples care plans Bar chart comparing the way people thought about their care plans before covid 19 and after the outbreak. Significantly more were satisfied with their plan before than after (around 37% before and only 25% after). Likewise, more people are very dissatisfied with their care plan after the outbreak (24% compared to 10% before).

12. Conclusion

- 12.1 From the onset of this global pandemic, disabled people have faced multiple areas of disadvantage, exclusion and unnecessary risk. Unequal access to food, medical supplies, support and information created crisis situations for many disabled people, which compounded the issues of the pandemic itself. The pandemic has come on top of the existing structural and societal exclusion, discrimination and inequality facing disabled people. It is not the virus that has caused these experiences of disabled people throughout the crisis highlighted in this report; it is the epidemic of our society's structural exclusionary and discriminatory treatment of disabled people.
- 12.2 Disabled people across Greater Manchester are being significantly impacted by Covid-19 through lack of Hub accessibility, inability to access PPE, difficulty getting online food slots and reduction in health visits. The vast majority of respondents believe that neither the government nor local authorities are doing enough for disabled people. Disabled people are not satisfied with their care plans, since the outbreak of Covid-19 and the pandemic is having a considerable impact on the mental health of disabled people in the region, with 90% responding that the pandemic was having a negative impact on their mental health.
- 12.3 Recurring testimony in the free text boxes evidenced accessing food as a critical issue, particularly amongst those who did not meet the initial narrow shielding criteria. Many of these people were left without access to food due to not meeting the criteria to access support, but they were also unable to source a slot via online supermarket services due to heavy public demand.
- 12.4 In many of the free text comments a theme of family support highlighted that many disabled people are still having to rely on family and are unable to access support to live independently. While this support prevented some people from entering a crisis situation, the precarity and risk of family support was a cause of anxiety, with many carers themselves also having impairments.
- 12.5 The pandemic was a crisis that came upon an already existing crisis of austerity that had created what the UN called a 'human catastrophe' for disabled people in the UK. The pandemic has acted as a catalyst to further sharpen the inequalities, exclusions, and higher excess

fatality rates of disabled people (see ONS Deaths related to the coronavirus (COVID-19) by disability status).

- 12.6 Digital exclusion has hardened instead of being reduced. With many emergency systems inevitably – and understandably - relying on information technology, this did create substantial risk factors in who was excluded, including factors such as disability, age, ethnicity, and poverty.
- 12.7 Disabled people broadly felt government messaging and response left them marginalised or forgotten, leading to anxiety and anger. The initial reassuring guidance pre-lockdown was that the general public need not worry, it was only “the elderly and the vulnerable” that really needed to be concerned. What was missing from the outset, having recognised some of the groups who would need to take extra precautions, was the support, guidance and information for these people, who ended up being – predictably and disproportionately – heavily affected by Covid-19. The survey particularly highlighted the lack of consideration and support given to those who did not fit the initially narrow government group of those who needed to shield.
- 12.8 The Panel recognises the huge effort and dedication it took to shift an entire country to an online and remote existence in the space of a couple of weeks. The Panel also recognises that this was done with the intention of providing access to support and to services in a way which fell in line with the necessary quarantine. The Panel must also make clear however, that the pre-existing inequalities which were prevalent pre-Covid-19 were predictably going to be exacerbated by the pandemic. This is important to note, not because it is inevitable that these inequalities exist, but that services and providers do not consider sufficiently disabled people (and other groups who face systemic inequalities) throughout their planning. The Community Hubs are but one example of this. In its inception, this system was telephone based only, with no indicator of what information you would need to have to hand to access support, which automatically excluded many from accessing support. Many disabled people – as evidenced by the survey – who did manage to contact Community Hubs were turned away without accessing any support. **The Panel asks – what was expected to happen to these people?**
- 12.9 The information contained within this survey should not come as a surprise. It was predictable, avoidable and caused by pre-existing socio-economic and health inequalities. The pandemic has not been

the great leveller, it has been a stark spotlight on the drastic social, economic and equalities divide in this country.

The experiences of many disabled people left seeking support and provisions added avoidable and unnecessary stress and anxiety, which exceeded what the general population was experiencing as a result of the pandemic. If changes are not urgently made to address these issues, this impact will continue to perpetuate and accelerate health and socio-economic inequalities, and have serious long-lasting implications.

- 12.10 The positive to take from this report is that **changes can be made**. The fact that the negative experiences of disabled people during this pandemic were not inevitable or unavoidable means we can prevent it from happening again. The Panel are offering their expertise, knowledge and guidance on how to make real and substantial changes - but we need to be heard and supported by those in a position to effect change in order to see real results.

13 Recommendations

The survey and this report have explored the experiences of disabled people during the initial crisis phase. As we ease out of this phase of lockdown, disabled people are at significant risk of being further marginalised and excluded.

In order to combat the effects of some of these issues, the Panel makes the following recommendations.

13.1 Equality Impact Assessments

Although the Equality and Human Rights Commission has suspended Public Sector Equality Duty reporting obligations during the Covid-19 crisis, the Equality Act 2010 remains in force and Greater Manchester Public Authorities must continue to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation.
- Advance equality of opportunity between different groups.
- Foster good relations between different groups.

The most effective way to illustrate that these equality implications have been considered and assessed is to undertake an Equality Impact Assessment.

Guidance produced by the Equality and Human Rights Commission states “While there is no explicit legal requirement under the general equality duty to engage with people with different protected characteristics, the general equality duty requires public authorities to have an adequate evidence base for their decision-making, and engagement can assist with developing that evidence base. Engaging with stakeholders and employees will help public authorities to base their policies on evidence, rather than on assumptions.”

The recommendation to engage with stakeholders mirrors the policy of the disability movement: “Nothing about us without us”. The establishment of the GM Disabled People’s Panel has allowed Greater Manchester to make progress towards this ideal. The Panel, however, cannot replace the need for public bodies to engage with Disabled People’s Organisations in their locality. They will be the experts in their area. An example of good practice during the pandemic is the involvement by Rochdale Borough Council of one of the Panel members - Rochdale and District Disability Action Group (RADDAG) – in its Equality Impact Assessments of the Rochdale Emergency Response Hub and more recently its walk through test centre.

The Panel therefore recommends that all public bodies providing services to disabled people in Greater Manchester should undertake Equality Impact assessments of their Covid-19 responses and involve disabled people in the assessment of these. The recommendations from these assessments must then be actively put in place, to ensure the recovery phase and any future peaks do not further negatively impact on disabled people.

13.2 The Panel recommends that digital exclusion be recognised as a key issue during this pandemic, and that digital inclusion is an urgent priority

Digital exclusion is generated by multiple factors including age, disability, poverty and language. Digital exclusion is not just those who do not have access to a device – it includes issues such as:

- The accessibility and cost of the device.
- The additional costs of purchasing access technology solutions.
- The support and training needed to set it up and learn how to use it.
- The on-top costs of the data and broadband.

The Office for National Statistics, in its March 2019 report, found 56% of digitally excluded adults are disabled people. Given the crisis response is relying upon digital platforms, the Panel is concerned that not enough action is being taken by public bodies to reach people with no internet access or IT abilities due to accessibility or poverty.

The Panel recommends the provision of digital devices to enable digital inclusion. The panel also recommends that the device itself will not solve digital exclusion, but that the costs of

data/broadband and the support and training must also be included for the successful inclusion of disabled people.

13.3 The Panel recommends that accessible information be implemented and produced consistently

Access to information is vital to enable disabled people to make informed choices about their lives. Public health information and government guidance in particular must be concise, accessible and clear, to enable disabled people to make informed choices to ensure their safety. The emergency support systems set up in Greater Manchester on a telephone-only basis excluded many disabled people, including people who are Deaf/hard of hearing, people who are non-verbal, people with speech impairments and learning disabled people. Other particular gaps have been information not being available in easy read and British Sign Language (BSL).

The Panel recommends that information should be provided in an accessible format to every disabled person (as per Accessible Information Standard). Accessible formats include easy read, large print, braille, audio and BSL.

13.4 The inclusion of disabled people and disabled people's organisations in all planning

Disabled people and our organisations must be involved in the development of systems and policies from the very onset, and at local, regional and national levels. It is crucial that lessons are learnt from the initial stage of the pandemic. In order for people not to experience the same isolation from services provision and support in the future, systems need to be put in place now to ensure no one falls through the gaps in future peaks/crises. The situations faced by disabled people in Greater Manchester and nationally exposed the lack of consideration and inclusion of disabled people in national emergency planning.

To ensure that during the recovery, transition and aftermath of this pandemic these issues are not perpetuated, the Panel recommends that disabled people's organisations are included in all levels of decision-making.

13.5 Isolation, Safety and Mental Health

Prior to the pandemic, mental health services were already heavily impacted by austerity, leading to widespread shortages in mental health support services. The various factors outlined in this report have had a significant impact on many disabled people's mental health. It is critical that disabled people – and others experiencing mental health distress – are able to access support.

Mental Health issues are being exacerbated and created by isolation and the pandemic. Isolation represents an increased risk of domestic violence, therefore additional resources need to be allocated to help disabled people currently having to isolate in accommodation with abusive family members.

Food insecurity is also a significant issue and anxiety about this is an issue for many disabled people; moreover people with eating disorders are at risk of relapse and need support to secure supplies to reduce anxiety.

Additional issues to factor in, in terms of mental health, are addiction services which need to assist people staying at home but needing help to manage their condition. We are also concerned that children are not getting access to Child and Adolescent Mental Health Services (CAMHS).

The Panel recommends, in order to combat some of these issues, that there is an urgent prioritisation of funding and resourcing mental health support.

13.6 Support independent living for disabled people

In addition to factors such as independence, control and choice, the pandemic highlighted additional reasons for disabled people to be supported to live in the community. The concentration of disabled people in institutional settings and care homes presented a vast infection vector risk. Long term strategy must be developed to support independent living in the community, reversing the effects austerity has had on disabled people's rights to live their lives in a place of their choosing, with access to the required support.

The Panel recommends a re-prioritisation of independent living, and that this needs to be recognised as an equal, vital right, in

accordance with Article 19 of the UN Convention on the Rights of Disabled People.

13.7 Personal Assistance / Carers

Due to personal assistants/care workers (PA'S) having to self-isolate if symptomatic, local authorities should give disabled people blanket pre-emptive permission to pay family members and friends in order to have support in place during the crisis period. This is allowed for in Care and Support (Direct Payments) Regulations 2014, Regulation 3, and section 17A Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, Regulation 11.

If personal assistants/care workers (PAs) are self-isolating when symptomatic, we are concerned that disabled people will not have emergency access to PAs/carers from other sources. Local authorities and providers should create a process to share or pool PAs/carers as a short-term measure and following all the recommended safety guidance. Extra funding should also be allocated for disabled people who have to hire PAs at short notice to cover shifts as people fall ill.

Local authorities should also confirm to disabled people that they can pay for PPE with their care budgets. Flexibility should be given in using direct payment budgets to pay different people (including different rates), or to buy equipment as needed during the pandemic.

Many disabled people employ, or rely on, formal and informal care. Personal Protective Equipment (PPE) is not being routinely supplied to PAs / carers. Avenues for disabled people to access PPE are needed, and PAs should have easy access to Covid-19 testing.

The Panel recommends that these measures be put in place to prevent current crisis situations for disabled people as we move into the recovery phase, and to improve the emergency planning should there be future peaks or crisis situations.

13.8 Statutory Standards, Social Care Assessments and Health Care

The Coronavirus Act 2020 reduces legal duties for social care while leaving powers intact, and the ethical framework & easements have also been published. Taken together, this means that local authorities can choose to maintain social care to Care Act 2014 Standards. It is important that the Care Act 2014 standards continue to be kept as the minimum required standards, as has been confirmed to the Panel.

After threat of Judicial Review, the NICE guidelines for critical care were revised to protect the rights of neurodiverse people, learning disabled people and those with poor mental health from discrimination in access to critical care. Health providers should ensure that all healthcare staff continue to abide by the revised NICE guidelines regardless, if a future peak occurs, and should also utilise 'health passports' so that they do not misunderstand a person's impairment, their steady state of health, and support needs. The Panel can provide examples of good practice health passports.

Many disabled people, and people with long term health conditions, who required medical equipment / supplies at home experienced shortages, and there was an initial lack of information from Clinical Commissioning Groups (CCGs). In the event of future peaks, clear guidance and information should be published on how priority groups can fast track access to medical supplies and equipment. Clear guidance should be provided for people who have appointments in clinics and hospitals and are worried about attending.

The Panel was made aware that disabled people were not getting access to health care and treatments for long-term conditions that are not Covid-19 related, such as medication, injections and therapy. Member organisations have reported that alternative, less effective treatments are being used.

The Panel has been informed that, during the crisis stage, disabled people have experienced contact and reviews unexpectedly, adding an unnecessary level of stress and concern.

If a future peak occurs GP's surgeries should not send out pre-emptive DNR letters to people that they deem higher risk (while the Panel has not been made aware of any specific instances in GM, there is evidence that it did occur in other parts of the UK). All patients should get a fair

chance of treatment, alongside everyone else, at the time of needing the healthcare.

Disabled people have told us that the guidance provided for testing for Covid-19 is very confusing, and some have been unable to correctly self-administer the tests due to their impairments. The test, track and trace system has also reportedly struggled to accommodate multiple communication and access needs. Both of these measures need to improve on their accessibility in order to ensure disabled people have equal access to keeping themselves safe.

The Panel recommends these measures be implemented to ensure that disabled people do not continue to experience unnecessary consequences, on top of the pandemic itself.

13.9 The Panel recommends the development of a BAME disabled people's organisation

The survey was highly circulated amongst, not only the Panel's members and networks, but various others including the VCSE networks, GMCA, mainstream media and social media. Even with these various channels and connections, the survey had an underrepresentation of 'BAME' disabled people, meaning that their experiences and input have not been captured to the degree that we would have wished. It highlighted the need for an intersectional approach, to ensure the intersections of race and disability, and its societal impacts are not overlooked. As a diverse city region, 'BAME' disabled people should not have been so underrepresented.

The Panel recommends the development of a BAME disabled people's organisation. Panel members offer to support the development and creation of a 'BAME' pan-impairment disabled people's organisation in Greater Manchester.

13.10 The Panel recommends the development and resourcing of a disabled people's organisation in each of the 10 boroughs

The current boroughs without an established local disabled people's organisation (Bolton, Bury, Oldham and Trafford) corresponded with the lowest contributions from disabled people. Given the wide-reaching networks across GM, through which the survey was shared, the low

numbers from these boroughs without a local disabled people's organisation demonstrates the gap and the need.

In order to ensure localities are including disabled people in their decision making it is essential that there is a local disabled people's organisation in each of the 10 boroughs. The Greater Manchester Disabled People's Panel provides a cross-GM perspective, and can highlight wide reaching issues and solutions on a Greater Manchester level. What the Panel cannot do is replace local disabled people's organisations' expertise on local infrastructure, systems and issues.

The Panel recommends the development, resourcing and inclusion of disabled people's organisations within each of the boroughs in which there is currently a gap. There are Panel members who can support this work.

13.11 Employment

While the survey did not include specific questions on employment, it would be remiss of the Panel not to address the issues facing disabled employees as we move into the recovery phase. As lockdown is due to end on 1st August, including for the majority of those who have been shielding, the Government must urgently issue detailed guidance to employers about disabled people's rights to reasonable adjustments relating to Covid-19, including continued remote working. Employers must be actively encouraged and supported to retain their disabled employees, especially in the context of an expected increase in unemployment. There has not been enough clarity and information provided on what constitutes a "COVID safe" workplace, and specifically there has been limited advice on what additional measures must be required to make workplaces "COVID safe" for those who do have underlying reasons as to why the virus is of a higher risk to them.

The Government should make clear that employers must engage with their disabled employees on what their needs and risks are, and consider additional factors such as safely travelling to and from work in their responsibilities in ensuring disabled people are given the appropriate and necessary reasonable adjustments. In order to ensure disabled people can access the required adjustments, Access to Work must be improved to ensure the system is working quickly and flexibly to meet disabled worker's needs.

The Panel recommends that the GMCA, local authorities and other key public anchor organisations in each borough conduct an

urgent EIA as part of their COVID 'return to work' plan and engage with disabled employees to agree reasonable adjustments.

The Panel recommends that the GMCA and GM Employment Charter ensure that clear guidance and standards are developed to ensure disabled employees within all Charter Supporter organisations are supported to return to work.

The Panel recommends monitoring and reporting of Disability employee data.

13.12 Education

The Panel are concerned that children who have an Education Health and Care Plan (EHCP) are not receiving the same level of support. The Panel has been told that some children with EHCP were unable to continue attending mainstream schools, and that little or no support was provided.

The Panel recommends that Greater Manchester should aspire to have a fully supported inclusive education system.

13.13 Utilise the knowledge, insight and value of the lived experience of Disabled People's Organisations

Finally, it should be recognised that the Panel has put a lot of time, effort and resource into creating and conducting this survey. Panel members have supported over 200 digitally excluded individuals to ensure their experiences were included in the survey. While the data and results are important, it cannot be part of the Panel's role to repeat this as a regular exercise. It is important to recognise that the results of the survey provided a confirmation of the Panel's existing understanding, information and knowledge. Panel members - as disabled people's organisations - are not remote from the issues or from disabled people. We have a frontline connection to disabled people in Greater Manchester, and as a collective can ascertain cross borough and pan-impairment issues. The Panel is here to support and advise on how improvements can be best made, but can only do so if it is utilised based on its guidance and insight on lived experience and collective evidence.

The Panel recommends the expertise, advice and guidance that the Panel and disabled people’s organisations can provide be fully utilised, in order to “build back better” with disabled people.

Greater Manchester Disabled People's Panel Members

Breakthrough UK
Disability Stockport
Disabled Staff Network University of Manchester
Embrace Wigan & Leigh (co-opt)
GM Autism Consortium Advisory Group
Greater Manchester Coalition of Disabled People (GMCDP) (convenor)
Manchester Deaf Centre
Manchester Disabled People's Access Group (MDPAG)
Manchester People First
Manchester Disabled People Against Cuts (MDPAC)
National Federation of the Blind UK (NFBUK)
People First Tameside
Rochdale and District Disability Action Group (RADDAG)
Salford Disability Forum

Associate Members

Action Together
Activity Alliance
Better Things
Beyond Empower
Bury Society for Blind and Partially Sighted People
Bury U3A
Change
Communic8te Bury
Lifeshare
Maddchester
Pegasus Riding
Proud and Loud Arts
Rochdale Parent Carer's Voice
RNIB
Seashell
Tameside Autism Group
Trafford Hard of Hearing

Further information:

The full free text submissions from the survey are in Appendix A.

The Panel's first year report can be found here

gmdisabledpeoplespanel.com/year-one-report/

The Social Model of Disability

The Social Model of Disability the Panel operates within the social model of disability, which identifies the way society is organised and the barriers it puts in place for disabled people as the problem, rather than the individual's perceived impairment. These barriers can take organisational, attitudinal and physical forms. The social model states that society is responsible for removing the barriers disabled people face, in order to enable disabled people to be an equal, included and valued part of society.

Under the social model, impairment and disability are not the same:

Impairment

Is when part of a person's body, mind and/or emotions works differently to what is considered 'normal' by society.

Disability

Is the barriers, discrimination and prejudice disabled people face. It is not our bodies or minds which 'disable' us, it is society.