# Westminster Civil Society Shadow Report

# Survey Analysis

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## Summary

This is a detailed analysis of the 351 responses received to a survey intended to inform the development of an Westminster civil society shadow report. The specific aim of the survey was to provide descriptive statistics and to sense check themes identified from an initial analysis of event feedback and evidence submissions.

The survey was published online in 13 December 2021 and was open until 5pm on 24 December. BSL clips were embedded into the survey and hard copies and easy read format were also available. A phone number was provided so that people could answer the survey questions by telephone.

The survey was disseminated by the DDPO networks on the England Steering Group to their contact networks which include not only DDPOs but also disability and equalities third sector organisations, individuals, academics, trade unions, public sector bodies and local authorities. They did this both through direct mail out and social media posts. DDPOs were encouraged to in turn disseminate the survey link to their members. We estimate that through this dissemination our potential pool of respondents was in excess of 100,000 people.

Participation was not restricted to Deaf and Disabled people although the subject would have been most likely to interest those with personal or professional experiences of disability. The short time that the survey was open for and this being just before Christmas when many DDPO staff would have started their annual leave and individuals may have been busy with festive preparations may have limited participation. We also did not have capacity to give advance warning which could have meant coverage within more DDPO newsletters and increased the attention that the survey received.

The survey was anonymous in order to reassure respondents that they were free to share their views without fear of being identified and repercussions. Despite this lack of personal information, it is possible to discern diversity among respondents in terms of geography, impairment, age and employment status.

The prominence of certain issues across responses is significant given the breadth and diversity among respondents. At the same time, no issue has been overlooked. The survey was open for a relatively short time and there were limitations in its reach. Issues raised by only one or two respondents were not discounted but also incorporated into the analysis.

### Question 1: Since 2017 do you think life for Deaf and Disabled people has: got better; stayed the same; got worse?

In response to Q1, 89% of respondents expressed the view that things have got worse, 9% that things have stayed the same and only 2% said they think things have got better.

### Question 2: How have Deaf and Disabled people’s lives got better since 2017?

90% of respondents answered this question but only 34% named an improvement. The majority (67%) either replied that there haven’t been any, provided examples of how things have got worse, skipped the question or said they don’t know.

Only five answers (or 1% of respondents) cited examples of government initiatives that they consider positive. The majority of responses cited greater disability awareness and visibility and/or improvements in the lives of Deaf and Disabled people that came about as the result of the pandemic. Positive examples were frequently qualified, for example that increase in awareness has been offset by decrease in support from the State or how despite gains in access to the built environment, there is still a long way to go.

### Question 3: In your experience, what areas of Deaf and Disabled people’s lives have got worse since 2017?

The longest free text contributions were received in answer to this question. Responses covered a wide base of issues relevant to all areas of Deaf and Disabled people’s lives.

The two biggest headings were COVID (190 mentions / mentioned by 54% of all respondents) and hostility towards Deaf and Disabled people (188/54%). The two are closely connected with many respondents expressing the idea that the treatment of Deaf and Disabled people during the pandemic is linked to a lack of worth placed on our lives.

Other key issues raised by multiple respondents included the benefit system, inadequate support to live in the community, pre-pandemic barriers to healthcare, poverty and inadequate incomes, retrogressions in accessibility, lack of suitable housing, limitations of support from mental health services, barriers to and discrimination within employment, barriers to inclusive education and rising segregation, barriers to justice, intersectionality, increasing barriers to social and family life, rising inequality, silencing Deaf and Disabled people and increasing barriers to democracy and political participation.

Answers to this question also included factors that, along with hostility towards Deaf and Disabled people, can be considered to provide explanations for retrogressive policy making. For example, austerity measures and cuts, lack of engagement with Deaf and Disabled people, disregard for the human rights, lack of awareness, Brexit, and failure to understand the social model of disability. Of the five responses that mentioned Brexit, the specific consequences they mentioned were higher cost of living due to rising inflation and decreased availability of medication.

### Question 4: Are you aware of any areas of good practice where the lives of Deaf and Disabled people have been made better through action taken since 2017: at local authority level; at a regional level?

This question was only answered by 12% of respondents. A higher number used the free text box to state they are not aware of any examples than ticked the box to say that they are. 36 respondents were aware of good practice at local authority level and 11 at regional level. The majority of examples provided for regional level related to engagement with Deaf and Disabled people. Examples at local level covered a number of areas. Most frequently cited were areas linked to engagement, independent living support provision and response to the pandemic.

### Questions 5 – 9: Do you agree or disagree with the themes outlined

There was strong support for the themes overall. On average across the themes there was an 88% agreement rate and 2% disagreement.

Theme 1: Things are still getting worse for Deaf and Disabled people

91% of respondents agreed with this theme and 1% disagreed. This is a higher percentage than ticked to say conditions have worsened for Deaf and Disabled people since 2017 in Q1. The difference can be explained by the fact that they are different questions: question 1 asks about overall conditions facing Deaf and Disabled people whereas Theme 1 relates specifically to retrogression within areas under the government’s responsibility.

Theme 2: Deaf and Disabled people are being stopped from speaking out

90% agreed and 1% disagreed. Two respondents who disagreed gave their reasons. One said that although it is difficult to get our voices heard, they do not think it is getting worse. The other said that it is a matter of objective fact that our ability to express opposition to government measures is being taken away and therefore inappropriate to ask for people’s subjective opinion on.

Theme 3: Institutionalisation of Deaf and Disabled people

84% agreed and 5% disagreed. This was the lowest level of agreement of all the themes, although still strongly supported. Explanations for disagreement can be attributed to respondents lacking awareness of the issues covered in this theme and greater awareness of people living in the community without support. The explanation given within the survey that institutionalisation can also occur within people’s own homes was evidently not clear enough for some respondents to understand what this means.

Theme 4: Deaf and Disabled’s lives are valued less than other people’s

89% of respondents agreed and 1% disagreed. This theme was supported by statements made by respondents within the free text boxes throughout the survey.

Theme 5: The impacts of wider issues on Deaf and Disabled people getting overlooked

87% agreed and 3% disagreed. The main reason given for disagreement was that individual respondents did not see the relevant of climate change to Deaf and Disabled people.

### Question 10: If you disagreed with any of the themes please say why.

This question was answered by 25% of respondents. A higher number used the text box to either restate agreement with the themes or to add information in support of them, than answered with an explanation of why they had disagreed with a theme. Of these nine explained they had no personal experience of the issues covered within the theme and therefore felt unable to agree, and eight expressed an actual disagreement with a specific theme or issue included within the theme.

### Question 11: Is there anything missing?

This question was answered by less than half of respondents – 44%. Where respondents answered, some added issues missing from the from the information under each of the themes as presented within the survey. Others used the text box either to re-stress the issues of most importance to them or to make general points about the situation facing Deaf and Disabled people and to express feelings of despair.

In conclusion, the fact that so many people completed the survey within such a short time and the volume of information entered into the free text boxes illustrates the importance of the shadow report to Deaf Disabled People and the urgency with which people feel their voices need to be heard.

There is significant consistency between responses despite the wide range of information provided and the diversity of respondents. There is strong agreement with the idea of continuing retrogression since 2017. This picture is further strengthened by the lack of response to questions asking about areas of improvement and examples of good practice. There were five free text boxes and therefore five chances for each respondent to give examples they regard as positive. Across 1,755 text boxes just six examples are named that relate to measures introduced by central government. Statistically this is 0%.

The high level of support shown for all of the themes represents significant correlation between the evidence submitted, largely by organisations, and the survey responses from individual Deaf and Disabled people. This provides a strong basis from which to go on and develop the shadow report.

In some cases, respondents gave answers that offer explanations for continued regression. The shadow report will need to engage with these bigger picture issues relevant to implementation of the UNCRDP alongside listing examples of how current policy and practice is in breach of respective Articles of the Convention.

Lastly, the experiences and feelings expressed through the survey responses make clear that are high levels of unmet need, that Deaf and Disabled people across the country are experiencing hardship, anxiety and distress, and that these are therefore highly sensitive issues. The report and how the shadow reporting process is treated needs to be considerate of this situation.

## Introduction

This is a detailed analysis of the 351 responses received to a survey intended to inform the development of an Westminster civil society shadow report. It is just one of a number of ways that Deaf and Disabled people and allies had to feed in to the report. The specific aim of the survey was to provide descriptive statistics and to sense check themes identified from an initial analysis of event feedback and evidence submissions.

The shadow report work is led by the Deaf and Disabled people’s Organisation (DDPOs), Inclusion London, and a Steering Group made up of a number of DDPO networks including National Disabled People Against Cuts, Our Voices Disability Rights UK, Reclaiming Our Futures Alliance, and The DPO Forum. Kate Summers, Fellow in Methodology at London School of Economics, and the Centre for Applied Human Rights at York University also sit on the steering group to provide added expertise from allies.

## Methodology

A call for evidence to feed into the development of the shadow report was launched on 20 October 2021. Wide-ranging evidence was received including notes from 17 consultation events held between 20 October and 15 November. Initial analysis of this evidence produced six themes.

On 13 December an online survey was published (see Appendix A). An easy read and paper copies were also available. A phone number was provided so that people could answer the survey questions by telephone. The survey was open until 5pm on 24 December 2021. 351 responses were received.

The survey was disseminated by the DDPO networks on the England Steering Group to their contact networks which include not only DDPOs but also disability and equalities third sector organisations, individuals, academics, trade unions, public sector bodies and local authorities. We estimate that it reached reached over 100,000 organisations and individuals.

The survey provided another format for people to contribute to the shadow report for whom none of the other opportunities had been suitable. The survey asked respondents their views on the general situation facing Deaf and Disabled people in the present time compared to 2017. It asked about areas where progress has taken place and good practice examples. It also suggested themes drawn from consideration of the evidence submitted to date. The aim of this was to check back in with Deaf and Disabled people and DDPOs on our initial analysis and to find out what issues we were missing.

The survey was anonymous in order to reassure respondents that they were free to share their views without fear of being identified and repercussions such as withdrawal of support. It was made clear to respondents that their answers will be publicly available and quotes may be used within the final shadow report. One of the most commonly mentioned issues in the survey responses is hostility towards Deaf and Disabled people. A guarantee of anonymity was therefore important in order to encourage participation. The project steering group also emphasised the need for the survey to be as short as possible both for accessibility reasons as well as for the benefit of those suffering consultation fatigue and disillusionment having contributed views in the past without being listened to. A decision was taken not therefore not to collect personal information about respondents.

Despite this lack of personal information, it is possible to discern diversity among respondents. Individual responses refer to a number of regions and local authority areas including Bristol, Cambridge, Cheshire, Ealing, Greater London, Greater Manchester, Greenwich, Hammersmith and Fulham, Hampshire, Haringey, Hull, Leeds, Nottingham, Kirklees, Oldham, South Norfolk, Tynemouth and York. One respondent lived in Pembrokeshire and there are a couple of mentions of Scotland, although it is not clear if the individual resides there or is just aware of Scottish government policy. Given that our shadow report will also cover reserved issues it was not a problem to have respondents from the devolved nations.

Individual responses refer to lived experience of a number of different impairments and access needs including neurodiversity, mental health, ME/CFS, physical and mobility impairments, visual impairment and deafness, also use of British Sign Language and of wheelchairs. Paper copies of easy read surveys were received back from respondents with learning difficulties.

Individual responses also indicate a diverse age range and employment status. For example, one mentions having recently completed school GCSEs while another explains a recent move from benefits to a pension. Numerous responses refer both to being in employment and to being on out of work benefits, while other respondents share lived experience as family members and/or providing unpaid support to Disabled people.

Most survey respondents used the free text questions to name multiple issues within each text box. In analysing the survey data, each separate issue was noted down. The number of times an issue was mentioned under each question was recorded. For multiple choice questions, the percentage of survey respondents answering each way was calculated. Percentages have been rounded up to the nearest whole number, hence totals slightly exceed 100%. Quotations extracted from responses to illustrate views expressed through the survey have been copied exactly as written.

The prominence of certain issues across responses is significant given the breadth and diversity among respondents. At the same time, no issue has been overlooked. The survey was open for a relatively short time and there were limitations in its reach. Issues raised by only one or two respondents were not discounted but also incorporated into the analysis.

## Findings

### Question 1: Since 2017 do you think life for Deaf and Disabled people has: got better; stayed the same; got worse.

* Question answered by: 350
* Skipped: 1
* **89%** (310 out of 351 respondents) expressed the view that things have got worse
* **9%** (32 out of 351 respondents) expressed the view that things have stayed the same
* **2%** (eight out of 351 respondents) said they think things have got better

### Question 2: How have Deaf and Disabled people’s lives got better since 2017?

* Answered by: 316 = 90%
* Skipped: 35 = 10%
* Naming an improvement: 119 = 34% of all respondents to the survey
* None (or not much/very little): 129 = 37%
* Highlighting negative issues or how things have worsened: 65 = 19%
* Don’t know: 3 = 1%

A higher percentage of respondents (37%) used the free text box to state that nothing has improved than named an example of progress. Only 34% of respondents answered the question. Another 19% either cited areas where they think things have gone backwards and/or stated that things have got worse rather than improved.

The biggest reported area of improvement relates to greater disability awareness, understanding and visibility. There were 61 responses on this subject, representing 17% of all respondents who raised this as an example of progress. The second biggest area relates to improvements in Deaf and Disabled people’s lives that came about as a result of the pandemic. There were 31 examples given that fall within this category by 9% of respondents. 20 answers/5% of respondents referred to access improvements unrelated to the pandemic covering transport, buildings and communications. 13 answers/4% of respondents mentioned community support and a strengthening of solidarity. Three respondents shared personal examples of improved circumstances within their lives. Two of these were hard won and indicative of difficulties faced when attempting to secure access to what should be given by right.

“Public perception of disabilities has gotten, maybe 3% more positive, people seem more sensitive to it. That's about it.”

“Para-oympics were well televised and well publicised this year and increased favourable opinion of disabled people (although generally only a specific type of disabled person)”

“Maybe less stigma as everyone is disabled by Covid 19.”

“I can’t think of any with the possible exception of the lack of face-to-face assessments because of Covid! They are highly stressful events!”

“Perhaps better accessibility in some venues for things like gigs, theatre, etc but it's not everywhere and it's come from not-for-profit organisations doing the work, not the government”

“More subtitles, some attention to written material on public transpirt”

“The Disabled community has increased its solidarity and awareness of Disability rights has improved”

“School was inclusive as teacher assessment meant I was allowed to take GCSE English literature rather than me being removed. I got a grade 6.”

Respondents who gave examples of improvements were quick to qualify their responses, stressing the limitations of the positive examples they had given.

“Increase in awareness offset by decrease in support from the state.”

“While there may be greater awareness of some conditions/disabilities, there is greater discrimination too.”

“Accessibility of public transport and spaces has improved overall, but there are still significant gaps and failings.”

“General levels of awareness of need althoughPerhaps not translated into practical actions.”

“better recognition and less stigma of mental health conditions (but still not enough support or accessible treatments)”

“Voluntary organisations (Shelter, Salvation Army etc) are helping Deaf and Disabled people's lives get better and always have done. But they are not being funded and that is the issue.”

Respondents who mentioned improvements experienced during the pandemic highlighted that these were only temporary.

“With the pandemic there have been positive changes in accessibility for people with energy limiting chronic illness/energy impairment. The move to more working from home and online remote access has been a silver lining that should become a protected reasonable adjustment going forward.”

“The pandemic briefly brought inclusion to some people who can’t get out much by putting life online.”

“They haven't. Any improvements were shirt-lived and then actively repealed.”

Greater awareness and representation were not attributed to government initiatives but to Paralympics coverage, to high profile individuals such as Rose Ayling-Ellis, Jack Thorne and members of the Royal family and the pandemic as well as initiatives by business and individual organisations. There were two mentions of the Sunflower Scheme which is a private initiative to raise awareness of invisible impairments. Of six policy measures cited as examples of progression, two of these relate to Scottish government initiatives.

“Increased awareness of certain disabilities in the public consciousness has been welcome, but this is largely in spite of government policy rather than because of it”

“I think awareness has been raised and elevated particularly with mental health and TV awareness. Also physically with the olympic games and the 2 princes raising awareness Rose on Strictly has also raised awareness for the deaf community.”

“Focus on vulnerable people because of the pandemic - not much of a focus, but something. Also Jack Thorne's McTaggart Lecture calling for more representation of disabled people in the media. I'm hoping this will counteract the often negative way disabled people are portrayed in the media.”

“Public awareness of DWP abuses has increased,”

“The sunflower scheme is helping to raise awareness of invisible disabilities”

“Scotland introducing their own benefit system”

“BSL Act 2015 in Scotland.”

Out of 351 respondents only six provided an example of progress that relates to deliberate legislative or policy measures by Westminster government. Noticeably fewer words were used to provide these examples than other responses. The NICE guidelines change was hard won by campaigners over a number of years and in the face of significant opposition from professionals. “Oliver MacGowan” training is another example of a gain won through campaigning and is now included within the National Disability Strategy.

 “implementation of the care act”

“PBH (Personal Health Budgets were introduced giving people more control of what they need”

“Social prescribing”

“The NICE guidelines changes for ME/CFS and this has improved care”

“Oliver McGowan learning disability and autism [training] for all healthcare staff”[[1]](#footnote-1)

“Contactless payment £100”

Improvements

|  |
| --- |
| **Improved disability awareness and understanding** |
| Greater awareness of disability in general | 29 |
| Greater awareness of: |  |
|  | Invisible disabilities | 5 |
|  | Neurodiversity | 3 |
|  | Mental health | 3 |
|  | Mistreatment by the DWP | 3 |
|  | Communication needs | 2 |
|  | Respiratory bugs and how they spread | 1 |
| Greater understanding and awareness due to: |  |
|  | COVID-19 | 2 |
|  | Paralympic coverage | 3 |
| Greater representation of Deaf and Disabled people in: |  |
|  | Media and advertising | 10 |
|  | Arts and culture | 3 |
| Total | 61 |
| Improvements resulting from the pandemic |
| Greater inclusion and access, eg home working and studying, access to healthcare, remote participation and non-disabled people being in the same situation | 20 |
| Temporary social security measures such as cessation of face-to-face assessments and Universal Credit uplift | 9 |
| Improved medical treatment due to challenging of poor medicalcare and greater understanding by doctors | 2 |
| Total | 31 |
| Accessibility |
| More accessible facilities – buildings, transport and toilets | 11 |
|  | Changing Place toilets | 1 |
|  | Wheelchair access to trains | 1 |
|  | Bus ramps | 1 |
| Communications including sub-titles and written materials | 2 |
|  | Sub-titles on TV | 1 |
|  | Signing more mainstream | 1 |
|  | More use of written materials on public transport (not just audio) | 1 |
|  | Closed captions | 1 |
| Total | 20 |
| Stronger community |
| Stronger Deaf and Disabled community - more online groups,greater peer support, stronger campaigning voices and better understanding of benefit entitlements | 9 |
| Greater solidarity from outside the Deaf and Disabled community | 1 |
| Support from charities and voluntary sector organisations | 3 |
| Total | 13 |
| Specific Legislative/Policy measures  |
| BSL Act in Scotland | 1 |
| Devolution of social security to Scotland | 1 |
| Implementation of the Care Act 2014 | 1 |
| Personal health Budgets (PHB) | 1 |
| Revision of NICE guidelines to remove Graded Exercise Therapy for patients with ME/CFS | 1 |
| Social prescribing | 1 |
| Contactless payments raised to £100 | 1 |
| Oliver MacGowan learning disability and autism [training] for all healthcare staff  | 1 |
| Total | 6 |
| Personal Positive Experiences |
| Moved over from benefits to a pension and is now better off Financially | 1 |
| One person related a positive experience at school as the outcome Of an assessment that led to them being able to take GCSE English Literature | 1 |
| One person was awarded disability benefits after two years of struggle | 1 |
| **Total** | **3** |
| **Total examples of progress given** | **134** |

The majority of respondents replying to this question (127 or 36% of all respondents) answered that there have been no improvements or that they are not aware of any. One answered that “very little” has changed and one answered “not much”. Seven people responded to the effect that there has been no improvement in terms of hostility towards Deaf and Disabled people.

“Cannot think of anything”

“I can't think of anything that has improved although personally I moved from benefits to a DWP pension which is slightly more”

“Nothing”

“I do not believe it has, services have been cut to the core.”

A significant number of respondents (65 out of 351 respondents or 19% of the total) chose to either deny there has been any improvement and then detail areas where they see things going backwards (11 out of 351 or 3%), or to emphatically state that conditions are worsening and, in most cases, go on to explain how (54 out of 351 or 16%).

“Nothing. Everything has got worse. I’m still poor and nobody will give me a job.”

“GP services and ability to contact them have been cut. At work ‘Coronavirus’ is commonly used as a reason to not give accessibility, and colleagues can get away with ableism without consequence.”

“Now we have even less help and the statutory authorities like mental health services, our GP’s and social workers leave us less help and fewer clinical interactions since the pandemic. It’s been so hard.”

“State support (social services, NHS medical services, Housing, etc has become more and more threatening, rationed and unhelpful to the point where I simply cannot engage with these agencies any longer.”

|  |  |
| --- | --- |
| **How things have got worse**  | **65** |
| Hostile attitudes towards disabled people | 20 |
| Discrimination |  | 3 |
| Support services |  | 17 |
|  | Independent living | 2 |
| Pandemic - how disabled people's lives were disregarded | 13 |
| DWP/benefit system |  | 10 |
|  | Removal of the UC uplift | 2 |
| Money/income |  | 9 |
| Access to healthcare |  | 3 |
| Accessibility |  | 2 |
| Stress |  | 2 |
| Everything |  | 1 |
| Limitations in support for people with ME/CFS/Chronic Lyme |  | 1 |

### Question 3: In your experience, what areas of Deaf and Disabled people’s lives have got worse since 2017?

* Answered by: 341 = 97%
* Skipped: 10 = 3%

The longest free text contributions were received in answer to this question. Many responses contained multiple examples of how respondents consider things to have got worse for Deaf and Disabled people since 2017. Those examples were grouped into 22 headings and 71 sub-headings. There are then another 119 specific examples that fall within those sub-headings.

The two biggest headings were COVID (190 mentions / mentioned by 54% of all respondents) and hostility towards Deaf and Disabled people (188/54%). The two are closely connected with many respondents expressing the idea that the treatment of Deaf and Disabled people during the pandemic is linked to a lack of worth placed on our lives.

Factors linked to COVID cover multiple areas. Those mentioned the most were disproportionate deaths and associated factors such as care home deaths, treatment rationing, unlawful use of Do Not Attempt Cardio-Pulmonary Resuscitation orders (DNACPRs) and poor access to healthcare (30/9%), isolation (29/8%), attitudes that Deaf and Disabled people’s lives are expendable (27/8%), pandemic response that overlooked Deaf and Disabled people (24/7%), and adverse impact on finances (22/6%).

Other COVID related issues relate to removal of/reductions in social care support (9/3%), lack of access to food (8/2%) adverse impacts on mental health (6/2%), difficulties obtaining priority vaccinations (6/2%), inaccessible environments and communications caused by one way systems, social distancing and mask wearing (5/1%), employment (over-representation in redundancies and Disabled people being forced into work when unsafe – 4/1%), difficulty getting on the CEV list for shielding (4/1%), easements to legislation (3/1%) and Long Covid (3/1%).

70 responses/20% of respondents mentioned a general trend of worsening hostility towards Deaf and Disabled people and disability hate crime. Another 40/11% referred specifically to hostility towards us from the Government and another 32/9% to hostility from the DWP. Professionals in general (2/1%), and social workers (2/1%) and local authorities (1/<1% specifically were also mentioned as sources of hostility. Negative portrayals in the media were also mentioned (24/7%) with three people citing lack of interest in disability from the media and one person highlighting the portrayal of Disabled people as “vulnerable” under COVID as a negative.

“It seemed there was little or no consideration to the survival of those vulnerable or shielding.”

“Accessibility at vaccination centres has been poor for those who rely on others for transport,”

“Covid has effected people mental health and I feel disabled people have been forgotten.”

“The gains in inclusion brought about by the pandemic were pretty much forgotten and abandoned as soon as it was possible to do stuff in person again”

“People with underlying health conditions seen as acceptable deaths in the pandemic, 60% of deaths being disabled people.”

“Government sees disabled people as lesser: deaths of vulnerable people seen as less important; no uplift in disability related benefits; DNRs imposed without consent; treatments eg cancer treatments withdrawn.”

“The response to the Covid-19 pandemic had an eugenic undercurrent.”

“During the Covid-19 pandemic we have been treated appallingly. Policy-makers and general public are seeing us as disposable,”

“for deaf people no translator at government press conferences.”

“We were left behind closed doors to cope with no extra help or support.”

“People left off CEV Covid list and not prioritised for vaccines or food delivery.”

“Long Covid dismissed as ‘anxiety’.”

“The infection control in residential institutions during the pandemic.”

“Deaf and Disabled people have also been subjected to rising Disability Hate Crime and hate inciting rhetoric and propaganda.”

The next biggest headings were the benefit system (162 responses or 46% of all respondents) and inadequate support (115/33%) including the social care crisis and retrogression in Deaf and Disabled people’s right to independent living, barriers to healthcare pre-pandemic (81/23%), poverty and inadequate incomes (73/21%), and retrogressions in accessibility.

Responses relating to the benefits system include the general inadequacy of the system, the damaging impacts of the benefit assessment process on the mental health of claimants, “lies” in assessment reports, DLA/PIP and ineligibility for Motability cars, and Universal Credit. Specific points made about UC include removal of the £20 uplift, calculation of income by household, no support for students and the removal of Severe Disability Premium.

“I had a distressing experience of the PIP process transferring from DLA. The assessor denied my lived experience… I’d describe it as incentivised lying. Under mandatory reconsideration I went from no award to high rate mobility, standard care.”

“application process for ESA and PIP completely degrading and creating further vulnerabilities and mental health issues”

“The PIP claim process is particularly unfit for certain illness or disability”

“Dwp have answered callers & then hung up half way through customer talking, when I call again they say ther is no record of the previous call.”

“universal credit leaves disabled people worse off”

“People losing disability benefits and having to go through the trauma of appeal.”

“children are getting g the disability benefit too untill you appeal.”

Increasing barriers to independent living are highlighted in a number of responses covering social care cuts (45/13%), removal of lack or removal of support (22/%), social care charging (12/6%), the recruitment crisis (10/3%), cuts to individual care packages (9/3%), and the social care crisis (6/2%). The stress of repeated assessments, councils rolling back duties, cuts to children’s support, lack of ongoing support, lack of equipment and increased reliance on families are all mentioned, as is the focus of support on those who are in work and how social care support is not available for Disabled people with certain conditions.

“What's called contribution to home care cost are charges that's really costing us huge amounts of money”

“endless, inane interrogations by every aspect of supposed 'care' for disabled people. Barely a week goes by without 'an assessment', none of which improves the quality of my life,

“services for disabled have been cut back to the bare bones”

“Hampshire shorts breaks funding has been sliced to over a third in the last ten years alone meaning there are lots of Deaf and Disabled children in Hampshire you can no longer access support, including supported swimming sessions”

Pre-pandemic barriers to healthcare include difficulties accessing physiotherapy, hydrotherapy, chiropody, dentistry, mobility aids and equipment, wheelchairs and treatment for ME/CFS. One person each mentioned difficulties obtaining medical evidence for the DWP and essential items not being available on prescription. One point overlapped with intersectionality concerns in highlighting the extra barriers to healthcare faced by those with additional protected characteristics.

“GPs do not take us seriously when we come to them with legitimate concerns especially if we are black, female or queer.”

“Much reduced access to GPs and health services (before pandemic),”

“disabled individuals make do i.e. waiting 3 months to have access to a bath/shower after months on an OT list.”

Responses concerning poverty and inadequate income largely centred around rising costs of living against inadequate benefit levels. One person specifically mentioned failure to take into account Disability Related Expenditure.

“Cost of living has risen, disability benefit has not. Disability related expenditure is still high and largely unrecognised.“

“Benefits don’t cover the cost of living or extra needs”

“The cost of living has risen and benefits haven’t kept up.”

Examples of access barriers cited by respondents cover communications, environment and transport. Communication points relate to digital exclusion (4/1%) and lack of accessible TV programmes, as well as difficulty accessing public services, inaccessible information, and lack of interpreters. Under inaccessible environments, lack of toilets and parking were mentioned as well as Councils’ failure to enforce the Equality Act and to consult. 8 responses (2%) referred to worsening access to public transport with one person specifically raising removal of staffing from trains.

“Subtitles in TV programmes are allocated by cost. Once a channel has achieved its target figure, subtitles cease.”

“The community and the built environment: LTNs, cycle lanes and pedestrian only zones have been brought in without consideration or consultation with disabled people,”

“Parking is worse as disabled places are often all taken now.”

Other sub-headings extracted from responses to Question 4 include lack of suitable housing (20/6%), mental health services (20/6%), employment (16/5%), education (15/4%), barriers to justice (10/%), intersectionality (8/%), increasing barriers to social and family life (6/2%), rising inequality (5/1%), silencing Deaf and Disabled people (4/1%) and increasing barriers to democracy and political participation (3/1%). 13 respondents (4%) simply answered that all or everything has got worse. Four respondents (1%) referred to a lack of hope for the future.

Alongside general references to a lack of suitable housing (10 respondents or 3% of all respondents), specific examples of poor housing provision include landlords not allowing housing adaptations, lack of accessible housing, revenge evictions, housing associations neglecting tenants, problems with council tenancies, Deaf and Disabled people are priced out of the housing market and new housing not accommodating the needs of Deaf and Disabled people. Bad treatment of residents in care homes and the damaging impacts of poor housing on families are also cited.

General inadequacy of mental health services was raised by seven respondents (2%). The failure of police to understand mental health (3/1%) and mental distress escalating due to cuts (2/1%) are also mentioned alongside lack of treatment options, long waiting lists, provision of drugs over access therapy, damage called by psychiatric medication, lack of ongoing support, assaults by staff, the SIM programme and the failure of the Mental Health Act review to take a human rights model approach.

“I've been on the waiting list for 3 years waiting for a adapted bungalow.”

“Housing Associations neglect severely disabled tenants, community services disappeared.”

“Care homes/facilities for people with special needs are appalling”

“reduction in ability to access to mental health services nothing really targeted at the chronically Ill apart from cbt which I consider damaging”

“Traumatic practice and police intervention in mental health have become a huge problem.”

“In mental health hopes were dashed when the Mental Health Act Review was headed by and heavily influenced by mainstream psychiatry. There was no compliance to the UNCRPD on human rights. People in the mental health system (including those who are autistic and sectioned) are not given their human rights and are forced to accept incarceration and treatments they did not agree with.”

“Lack of therapy as opposed to medical model pills.”

“From my own experience as a registered mental health nurse with disabilities, discrimination in the NHS is much worse than I expected and so is bullying for speaking out.”

“Access to Work more difficult to access, many disabled people desperately want to work and cannot without the support they need.”

“Are children are more excluded from school more units built to keep are children separated from,ther mainstream peers.”

“Understanding and support for disabled children in schools has got worse. Mainstream schools don’t have the resources or training budget to fully be inclusive. Same for employers.”

“ability to keep engaged with friendships”

“Trains remain very difficult to access without giving 48hrs notice.”

“Lack of hope that things will change.”

“I no longer have the energy to write about all the shitty things that happen towards us.”

Answers to this question include factors that, along with hostility towards Deaf and Disabled people, can be considered to provide explanations for retrogressive policy making. There were 34 responses (from 10% of all respondents) citing austerity measures and cuts. Of these 17 (5%) referred specifically to cuts to third sector services. Other factors include lack of engagement with Deaf and Disabled people (12 responses or 3% of all respondents), disregard for the human rights (10 or 3%), lack of awareness (7/2%), Brexit (5 or 1%), and failure to understand the social model of disability (2 or 1%). Of the five responses that mentioned Brexit, four referred specifically to higher cost of living due to rising inflation and one to a lack of availability of medication.

“Continued negative effect of austerity measures on access to public buildings, services, and funds”

“Cuts to CAB free advice service to fight wrong decisions and get the support needed”

“not enought working with disabled to find what needs addressing”

“They disregard any obligation to engage with Deaf and Disabled people's own Organisations instead of a mixture of charities and business and just one or two "tame" DDPOs.”

“Poor representation in positions of power, e.g. politics, business”

“I used to buy medicines but because of Brexit, these are no longer available.”

“The impacts of Brexit and covid19 have disproportionately affected those on low income who do not possess the financial flexibility to adapt to the problems caused.”

“Got worse - understanding about social model of disability”

One single response denied that there have been any retrogressions:

 “I have not noticed anything getting worse since 2017”

|  |  |
| --- | --- |
| **Accessibility** | **54** |
|  | Inaccessible communications |  |  |
|  |  | Digital exclusion | 4 |
|  |  | TV | 2 |
|  |  | Lack of interpreters | 1 |
|  |  | Public services | 1 |
|  |  | Information | 1 |
|  | Inaccessible environment |  | 29 |
|  |  | Toilets | 1 |
|  |  | Councils not enforce equality | 1 |
|  |  | No consultation on LTNs | 1 |
|  |  | Parking | 1 |
|  |  | For the housebound | 1 |
|  | Inaccessible transport |  | 7 |
|  |  | Unstaffed trains | 1 |
|  | Pandemic access gains removed |  | 3 |
| **All** | **13** |
|  | All/everything |  | 13 |
| **Austerity** | **34** |
|  | Austerity |  | 12 |
|  | Cuts |  |  |
|  |  | Cuts to third sector | 17 |
|  |  | Public services harder to access | 4 |
|  |  | Support replaced with phone support = less accessible | 1 |
| **Benefit system** | **162** |
|  | Benefit system |  | 51 |
|  |  | Cruelty/punitive approach | 4 |
|  |  | Carers benefits | 2 |
|  |  | Poor treatment of claimants | 1 |
|  |  | Harder to get & to keep | 1 |
|  |  | Inaccessible | 1 |
|  |  | Conflicting advice | 1 |
|  |  | Cuts | 1 |
|  |  | Child benefits | 1 |
|  |  | Benefit deaths | 1 |
|  |  | Gov failure to investigate benefit deaths | 1 |
|  |  | Sanctions | 1 |
|  | Benefit assessments |  | 39 |
|  |  | Anxiety and impact on mental health/health | 15 |
|  |  | Lies in assessment reports | 8 |
|  |  | Initial claims fail | 1 |
|  | Blue Badges |  | 3 |
|  | DLA/PIP |  | 8 |
|  |  | Penalise ppl in work | 1 |
|  |  | Not suitable for ppl with ME/CFS | 1 |
|  |  | Motability cars | 3 |
|  | Universal Credit |  | 5 |
|  |  | £20 cut to Universal Credit | 4 |
|  |  | Household calculation of finances - not able to live together | 2 |
|  |  | No support for students | 2 |
|  |  | Removal of SDP | 2 |
|  |  | Disabled ppl financially worse off | 1 |
|  |  | No increase in savings limits for years | 1 |
| **Brexit** | **5** |
|  | Inflation/impact on those on low incomes |  | 4 |
|  | Medicines no longer available |  | 1 |
| **COVID** | **190** |
|  | Disproportionate deaths |  | 14 |
|  |  | DNACPRs | 9 |
|  |  | Poor access to healthcare | 5 |
|  |  | Care home deaths | 1 |
|  |  | Treatment rationing | 1 |
|  | More isolated |  | 29 |
|  | Attitude that dis ppl's lives are expendable |  | 22 |
|  |  | Gov attitude | 3 |
|  | Disabled people neglected & overlooked |  | 23 |
|  |  | Gov approach overlooking Disabled ppl | 1 |
|  | Finances and lack of UC uplift |  | 22 |
|  | Inaccessible communication |  | 3 |
|  |  | Difficulties for Deaf/deaf ppl eg masks for ppl who lip-read, social distancing for partially sighted BSL users | 4 |
|  |  | Gov announcements confusing & inaccessible, eg no BSL | 5 |
|  | Social Care /support reduced/removed |  | 9 |
|  | Lack of access to food |  | 8 |
|  | Adverse impact on mental health |  | 6 |
|  | Vaccinations (difficulty getting) |  | 6 |
|  | Inaccessible environments |  |  |
|  |  | Blue badge parking removed | 2 |
|  |  | One way systems in shops…etc inaccessible for VI people | 1 |
|  |  | Town centres | 2 |
|  | Employment |  |  |
|  |  | Disproportionate redundancies | 2 |
|  |  | Forced into work when unsafe | 2 |
|  | Shielding list |  | 2 |
|  |  | Too narrow | 1 |
|  |  | Challenge to get put on | 1 |
|  | Legal easements |  | 3 |
|  | Long COVID |  | 3 |
| **Discrimination**  | **17** |
|  | Discrimination in general |  | 15 |
|  |  | Screening/genetic testing | 1 |
|  |  | Ppl who are MH/neurodiverse | 1 |
| **Education** | **16** |
|  | More segregation/rolling back on inclusion |  | 14 |
|  |  | Difficulty getting ECHPs | 1 |
|  |  | High cost for training and education | 1 |
| **Employment** | **15** |
|  | Employment |  | 5 |
|  |  | Difficulties with Access to Work | 2 |
|  |  | Lack of employment opportunities | 2 |
|  |  | Discrimination at work in NHS | 2 |
|  |  | Lack of rights, eg statutory sick pay | 1 |
|  |  | Workplaces exclude autistic ppl | 1 |
|  |  | Lack of BSL interpretation for interviews | 1 |
|  |  | Not getting reasonable adjustments at work/ management attitude | 1 |
| **Engagement** | **12** |
|  | Lack of engagement with Deaf and Disabled people |  | 10 |
|  |  | DDPOs ignored | 2 |
| **Equality**  | **5** |
|  | Things becoming more unequal |  | 3 |
|  |  | Equality Act unenforceable | 1 |
|  |  | Pandemic highlighting existing inequalities | 1 |
| **Healthcare (pre-pandemic)** | **81** |
|  | Lack of access/impact of cuts |  | 65 |
|  |  | Lack of mobility aids & equipment | 2 |
|  |  | Lack of access to OTs | 1 |
|  |  | Lack of choice over equipment | 1 |
|  |  | Lack of access to physio & hydro | 1 |
|  |  | Lack of access to wheelchairs | 1 |
|  |  | No affordable chiropody or dentistry | 1 |
|  |  | Treatment for ME/chronic illness | 1 |
|  |  | Essential items not on prescription | 1 |
|  |  | Difficulty getting evidence for DWP | 1 |
|  | Access to diagnosis |  |  |
|  |  | Waiting times all time high | 4 |
|  |  | Waiting times for autism diagnosis | 1 |
|  | NICE guidelines |  |  |
|  |  | Not listening to people with lived experience [Lyme disease specifically] | 1 |
| **Hostility** | **188** |
|  | Hostility and hate crime against dis ppl |  | 70 |
|  |  | Online | 1 |
|  | Gov attitude |  | 40 |
|  |  | Introducing legislation that worsens dis ppl's lives | 1 |
|  |  | Due to poor visibility of dis ppl in Westminster | 1 |
|  |  | "Eugenics" | 5 |
|  | Hostile attitude from DWP |  | 32 |
|  | Negative portrayals of dis ppl - media |  | 23 |
|  |  | Lack of media interest in disability | 3 |
|  |  | Idea of dis ppl as "vulnerable" through COVID | 1 |
|  | Hostile attitude from professionals |  | 2 |
|  |  | From social workers | 2 |
|  |  | From local authorities | 1 |
|  | Lack of disability awareness |  |  |
|  |  | Media | 3 |
|  |  | Hidden Impairments | 2 |
|  |  | ME/CFS | 2 |
|  |  | Fibromyalgia | 1 |
|  |  | Poor representation in high places | 1 |
| **Housing** | **20** |
|  | Lack of suitable housing |  | 10 |
|  |  | Not allowing housing adaptations | 2 |
|  |  | Lack of accessible housing | 1 |
|  |  | Revenge evictions | 1 |
|  |  | Housing associations neglecting tenants | 1 |
|  |  | Problems with council tenancy | 1 |
|  |  | Disabled ppl priced out of the market | 1 |
|  |  | New housing not taking needs of dis ppl into account | 1 |
|  | Bad housing damaging families |  | 1 |
|  | Care homes - bad treatment of residents |  | 1 |
| **Human Rights** | **10** |
|  | Violations and dismantling Human Rights Act |  | 10 |
| **Intersectionality** | **8** |
|  | Lack of awareness |  | 3 |
|  | Discrimination |  | 2 |
|  | Need for culturally appropriate services |  | 1 |
|  | Requirement to have been in UK for past 12 months in order to be eligible |  | 1 |
|  | Local services not meeting needs of certain groups |  | 1 |
| **Justice** | **10** |
|  | Cuts to legal aid and barriers to access to justice |  | 9 |
|  | Prison - inaccessible and not meeting needs of disabled prisoners |  | 1 |
| **Lack of disability awareness** | **7** |
|  |  | Poor representation in high places | 2 |
|  |  | Hidden Impairments | 2 |
|  |  | ME/CFS | 2 |
|  |  | Fibromyalgia | 1 |
| **Mental Health** | **20** |
|  | Inadequate MH services |  | 7 |
|  | Police not understanding MH |  | 3 |
|  | Mental distress escalating due to other cuts |  | 2 |
|  |  | Lack of treatment options | 1 |
|  |  | Long waiting lists | 1 |
|  |  | Drugs over therapy | 1 |
|  |  | Drug damage | 1 |
|  |  | Lack of ongoing support | 1 |
|  |  | Assaults by staff | 1 |
|  |  | MH Act review and failure to take a human rights model approach | 1 |
|  |  | SIM programme | 1 |
| **No Hope** | **4** |
|  | Life is harder than ever |  | 4 |
| **Politics and democracy** | **3** |
|  | Voting being inaccessible |  | 2 |
|  |  | Introduction of voter ID | 1 |
| **Poverty and inadequate incomes** | **73** |
|  | Low incomes and rising cost of living |  | 72 |
|  |  | Disability Related Expenditure - largely unrecognised | 1 |
| **Social Model of Disability** | **2** |
|  | Lack of understanding and implementation  |  | 1 |
|  |  | NHS ignorance of | 1 |
| **Silencing Disabled People** | **4** |
|  | Barriers to peaceful protest |  |  |
|  |  | Police and Crime bill | 3 |
|  | Lack of transparency |  |  |
|  |  | FOIs ignored | 1 |
| **Social Life – decreasing** | **6** |
|  | Less access to a social life and friends |  | 3 |
|  | Less access to family life |  | 1 |
|  | Less access to leisure activities |  | 1 |
|  | Less access to exercise |  | 1 |
| **Support** | **115** |
|  | Social care cuts /independent living regressions |  | 45 |
|  |  | Cuts to social care packages | 9 |
|  |  | Social care funding crisis | 6 |
|  |  | Stress of social care assessments | 3 |
|  |  | Councils rolling back duties | 1 |
|  |  | Children and young people's services | 1 |
|  |  | Care industry in crisis | 1 |
|  | Lack of support |  | 22 |
|  |  | No ongoing support | 1 |
|  |  | Lack of equipment | 1 |
|  |  | What support there is focused on those in work | 1 |
|  |  | Support not available for some groups eg ppl who are autistic | 1 |
|  |  | Need to rely on family | 1 |
|  | Social care charging |  | 12 |
|  | Social care recruitment crisis |  | 10 |

### Question 4: Are you aware of any areas of good practice where the lives of Deaf and Disabled people have been made better through action taken since 2017: at local authority level; at a regional level?

* Answered by: 41 (12%)
* Skipped by: 310 (88%)
* Regional good practice: 11 (3%)
* Local authority good practice: 36 (10%)

If you answered yes, please say where and give a brief description.

* Answered by: 84 (24%)
* Skipped: 267 (76%)

41 out of 351 respondents (12%) ticked that they were aware of good practice at regional or/and local level since 2017. 36 responses - just over three quarters of all responses relating to good practice - affirmed good practice at a local level and 11 at a regional level. 88% of respondents did not answer this question, presumably because they are not aware of good practice examples. A higher number (47/13%) used the text box to state this. 10 respondents (3%) used the text box to instead highlight poor practice.

The regional question did not apply to all respondents, only those living within combined authority areas under an elected Mayor. This contributed to the low number of responses to this question. The majority of positive responses to this question related to engagement with Deaf and Disabled people. The most progressive examples in terms of equality and human rights were given in response to this question, for example staff training in the social model of disability, engagement with Deaf and Disabled people (rather than charities) and following the CRDP.

“Helped set up a care co-operative Mayor listens”

“There have been some improvements to provision and support for Disabled people from TfL - with staff trained in the Social Model, the Please Offer Me A Seat badge, and announcements around priority seating for those with 'invisible' impairments.”

“Andy Burnham in Greater Manchester is the only Mayor and voice for disabled people.”

“Greater Manchester on co-production but also looking into how to follow the UN CRDP and adopt the vision set out in the National Independent Living Support Service.”

 “Unaware of who regional mayor may be.”

|  |
| --- |
| **Regional** |
| **Engagement**  | **5** |
|  | Greater Manchester Disabled People’s Panel | 3 |
|  | Mayor who listens | 1 |
|  | Use of technology to enable participation | 1 |
| **Access**  | **2** |
|  | Public transport | 2 |
| **Equality and human rights**  | **2** |
|  | Looking into implementation of UNCRDP | 1 |
|  | Social Model of Disability training | 1 |
| Independent living  | 2 |
|  | Support for local care co-operative | 1 |
|  | Looking into adoption of Deaf and Disabled people’s vision for a national independent living support service | 1 |

Of all respondents only 10% were able to think of good practice they are aware of at local level. The majority of responses related either to engagement with Deaf and Disabled people or to initiatives supporting Deaf and Disabled people living in the community. Five good practice examples of responses to the pandemic were given. Other examples cover benefits, access, employment and justice. One person shared a positive personal experience and another instead provided an example of good practice at national government level.

“Leeds City Council coordinated support for vulnerable people and continues to do so - food deliveries, medication deliveries and other forms of support,”

“Cambridgeshire County Council has a good application form for Blue Badges that asks about fatigue, pain, breathlessness & hypermobility, all of which are hard to get recognised for PIP to qualify, and were completely missed off when they opened Blue Badges up to invisible conditions like mental health and autism. This should be standard everywhere.”

“I applied for and had my local council tax totally waived”

“Promotion of changing places, please offer me/happy to give you a seat campaign (Nottingham), taking a range of disabled people views for example in new/renovated council buildings and streetscapes”

“In Leeds uk are doing some very good work for people and whoever looks after them with learning disabilities and autism and their carers”

“Haringey has opened up a few new services (Disability Action Haringey and Actually Haringey) which help people directly and are run by disabled people.”

“My local council has been brilliant with free or reduced cost activities, or swimming and excercise sessions”

“Greenwich delivered PPE to all shielding Direct Payment users in the Borough despite poor Gov guidance.”

“South Norfolk Council - Help Hub and community prescribing. I have had amazing support from a mental health and culture organisation called The Restoration Trust. I was referred to The Restoration Trust by South Norfolk's Help Hub.”

“Only thing the council did was to use corvid hardship fund to cover our council tax last two years”

“Hull City Coucil [continues to support and promote Direct Payments and to fund an independent Direct Payment Support Service run and controlled by disabled people.”

“One small positive is council more interested in contacting those deemed vulnerable”

“It’s beneficial for various Disabled people that there are now remote appointments. I do find it helpful myself that I don’t have to travel now and I’d like to continue to have remote appointments offered, but I think there should be a choice of both.”

“Wider consultation”

“£20 universal credit uplift but barely touches the sides and not given to legacy claimants”

|  |
| --- |
| **Local authority** |
| **Engagement**  | **8** |
|  | Disabled People’s Commission [Hammersmith and Fulham] | 1 |
|  | Disabled people’s panel [Cheshire] | 1 |
|  | Consultation eg on accessible buildings/environments such as streetscapes and council buildings [Nottingham] | 1 |
|  | Continued to support local DPO with funding and regularly worked in partnership [Hull] | 1 |
|  | Supporting set up of new disabled people led services and DDPO [Haringey] | 1 |
|  | Working towards a local Disabled People’s Forum [Cambridge] | 1 |
| **Independent Living**  | **8** |
|  | Community prescribing | 1 |
|  | Free of reduced costs for activities | 1 |
|  | Fund an Independent Direct Payment Support Service run and controlled by disabled people. | 1 |
|  | Help Hub signposting to local services | 1 |
|  | Integrated Care Systems are trying to use a holistic approach to support people with learning disabilities and mental distress | 1 |
|  | Promote Direct Payments | 1 |
|  | Support for disability sports organisations | 1 |
|  | Work with people with learning difficulties, people who are autistic and people who provide unpaid support | 1 |
| **Pandemic response**  | **5** |
|  | Support such as food deliveries, medication deliveries [Leeds] | 1 |
|  | CEV list was helpful for getting priority shopping. | 1 |
|  | Contacting “vulnerable” people | 1 |
|  | Providing free PPE for Direct Payment users [Greenwich] | 1 |
| **Benefits** | **4** |
|  | Council Tax covered for Disabled people | 2 |
|  | Benefits form filling service | 1 |
|  | Blue Badge application form appropriate for neurodiversity and mental health; | 1 |
| **Access**  | **2** |
|  | Promotion of Changing Place toilets  | 1 |
|  | Please offer me/happy to give you a seat campaign | 1 |
| **Employment**  | **1** |
|  | Employing Disabled staff | 1 |
| **Justice**  | **1** |
|  | Creation of a coalition of local justice groups | 1 |
| **Personal experience**  | **1** |
|  | Made sure cat was looked after while in hospital | 1 |
| **National government** | **1** |
|  | £20 Universal Credit uplift | 1 |

47 respondents (13%) answered “none” or that they were “not aware of any” good practice.

“No improvements, government never make funds available to improve the services.”

“I wouldn't say they have. Most have had to deal with huge cuts due to ongoing austerity. They neither have the power nor the financial resources to help.”

 “Honestly, I spent a while thinking about this and I can say I can think of no good practice since 2017”

“I simply cannot think of any scheme run by the local council (Kirklees), which has benefit myself or others I know who are disabled.”

“No, and there appears to be no intent or propect of this happening.”

“They haven’t. They don’t care about the disabled”

 “SADLY . Can't see any improvements.”

 “Don’t know if any :(“

 “None that I'm aware of, but hopefully there is some.”

Two respondents instead provided alternative sources of good practice:

“By individuals efforts and resources.”

“Can’t think of any other with the exception of what BRIL [local DDPO] are doing.”

One respondent explained that a lack of improvement at regional and local level is down to lack of support from national Government:

 “No improvements, government never make funds available to improve the services.”

There were also negative issues raised within the text box for positive examples of regional and local practice. These mainly related to inadequate attention to disability related issues and lack of support. One person used the text box to highlight limitations in local NHS provision and another two to adverse impacts of national government policies.

“not seeing anything re [Mayor] and disabled.”

“I work a council with a directly elected mayor the astro turf the involvement of disable people and don't do equality assessment for anyone.”

 “The guy who hung the fire doors drilled through my electric cable

 “I have found they are not willing to provide the help you ask for because you need it at the social services level.”

 “No my local authority don’t care and would rather I left them alone to help other people who only need short term support. No stair lift finding available so they would rather I don’t ask.”

“Here in Oldham the NHS System is not receiving good support in helping both Deaf and Disabled people.”

|  |  |
| --- | --- |
| **National Government** |  |
|  | Harmful impacts of national policy on Deaf and Disabled people | 2 |
| **Regional** |
|  | Mayor not addressing **Disabled** people’s issues | 1 |
|  | Not able to help as is remit of social services | 1 |
| **Local authority** |  |
|  | Lack of equality impact assessments | 1 |
|  | Not giving access to Direct Payments | 1 |
|  | Not responding to housing repairs issues | 1 |
|  | No funding for housing adaptations | 1 |
|  | Tokenistic engagement of Deaf and Disabled people | 1 |
| **Local NHS** |  |
|  | Inadequate help for Deaf and Disabled people | 1 |

### Questions 5 – 9: Do you agree or disagree with the themes outlined

Theme 1: Things are still getting worse for Deaf and Disabled people.

For example: in social care; education; employment; mental health services; housing and benefits; with Covid sometimes used as a reason for not meeting our needs. Disabled people were also more likely to die from Covid even after accounting for health and age factors.

Theme 2: Deaf and Disabled people are being stopped from speaking out.

For example: making protesting illegal; plans to limit legal challenges against the government; less involvement of Deaf and Disabled people, inaccessible complaints procedures; greater bureaucratic burdens for lower amounts of support; cuts to funding for our organisations as well as other services we need such as advice and advocacy services and Law Centres; changes to Legal Aid; more barriers to contacting local Councils; and, less disability data collection by government.

Theme 3: Institutionalisation of Deaf and Disabled people.

This means placing people in segregated settings and taking away their rights through for example forced detentions and inappropriate use of restraint. It can also happen in people’s own homes where their support needs are not being met. Institutionalisation affects both children and adults

Theme 4: Deaf and Disabled people’s lives are valued less than other people’s.

This has been shown during the pandemic. For example: patients with Covid discharged into care homes; disabled people not getting treatment when the NHS is over-stretched; unlawful use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders; inaccessible information and communications; not consulting with Deaf and Disabled people. Babies who will be born disabled can still be terminated later than other babies. Hate crime law is still not equal for disability.

Theme 5: The impacts of wider issues on Deaf and disabled people get overlooked.

For example climate change and the treatment of refugees.

\_\_

The below summary treats responses to all five theme-based questions. Six themes had been identified from initial feedback and evidence submissions. Unfortunately, the online and easy read surveys only contained five themes. The theme that was omitted, on intersectionality, was only asked to two of the telephone respondents who both expressed agreement.

* 351 respondents were presented with five questions each, one per theme.
* 88% (1548 out of 1755 answers) were in agreement
* 10% (166 out of 1755 answers) answers were skipped
* 2% (41 out of 1755 answers) expressed disagreement with one of the themes

There was strong support for the themes.

Percentage of survey respondents who agree there has been continued retrogression since 2017 **(Theme 1)**

* 91% agreed
* 1% disagreed
* 8% did not answer

Percentage of survey respondents who think that government measures are stopping Deaf and Disabled people from speaking out **(Theme 2)**

* 90% agreed
* 1% disagreed
* 9% did not answer

Percentage of survey respondents who agree that institutionalisation of Deaf and Disabled people has been a growing problem since 2017 **(Theme 3)**

* 84% agreed
* 5% disagreed
* 11% did not answer

Percentage who agree that Deaf and Disabled people's lives are valued less than non-disabled people's (Theme 4)

* 89% agreed
* 1% disagreed
* 9% did not answer

Percentage who agree that the impacts of wider issues on Deaf and Disabled people get overlooked. For example, climate change and the treatment of refugees (Theme 5)

* 87% agreed
* 3% disagreed
* 10% skipped

### Question 10: If you disagreed with any of the themes please say why.

* Answered by: 86 (25%)
* Skipped: 265 (75%)
* Number explaining a disagreement: 21 (6%)
* Number using to text box to express agreement and/or adding information in support of a theme: 53 (15%)

29 respondents used the text box not to provide the requested information, but instead to express agreement with the themes. 24 respondents used the text box to add information in support of the themes and to explain why they had agreed, although this information was not requested.

Of those respondents who used the text box to give further information in support of the themes, most highlighted discrimination and less favourable treatment of Deaf and Disabled people. Nine respondents highlighted lack of support with responses covered a number of different areas including social care, financial support, resources for inclusive education, mental health support and support for carers; eight respondents highlighted hostility and stigmatisation mentioning a variety of perpetrators including the Government and social workers and taking a number of forms including hostility related to demonisation of Disabled people as benefit scroungers and related to the view that Disabled people’s lives are expendable.

Other issues raised included Deaf and Disabled people not being listened to, the need for better support for refugees and asylum seekers, adverse impacts caused by welfare reform, social care charging, housing, digital exclusion, use of restraint on disabled prisoners, mental capacity and lack of communication.

“You've got it absolutely spot on! Sadly”

“I agree with the themes disabled people are still afterthoughts.”

“my life”

“Because I have experienced many of them! Especially service cuts/health care/mental health care cuts and the impact of covid meaning I may not be able to get any care at all for issues that cause disability.”

“I believe Climate & our Environments should be looked after & I believe in making sure Citizens suffering asylum should be given sanctuary & care .”

“I agree with everything you’ve said I’ve found that everything is geared up to non disabled only and we are just not cared about at all. No accessible communications are still prevalent on most utilities and things we all need to deal with. It’s just so unequal and uninclusive… and very inhumane :(“

“I wholeheartedly agree with all identified themes.”

“I agree with them all. Targets now come before people, profits before integrated care and the language borrowed for the worst intentions——levelling-up!”

“Nope all spot on!! Thank you for doing this! You are a ray of light.”

“disabled people are being penalised if they can't use a computer,read or write or use IT equipment. It puts them at risk.“

“Thee are also a lot of lonely and isolated people with health issues not being supported, apart from charitable organsisations.”

“In prison, the use of restraint and control policies on those with disabilities is not uncommon. I have seen a man in a wheelchair slumped forward with his hands secured behind his back in handcuffs. Was this necessary, or even lawful?”

|  |  |  |
| --- | --- | --- |
| **Discrimination – 14** |  | **11** |
|  | Unequal access to healthcare | 3 |
| **Hostility towards Deaf and Disabled people – 11** |  | **4** |
|  | Government response to the pandemic | 3 |
|  | Expendable lives  | 2 |
|  | As benefit scroungers | 1 |
|  | From social workers | 1 |
| **Independent living – 8** |  |  |
|  | Lack of social care support | 3 |
|  | Lack of suitable housing | 1 |
|  | Lack of support for carers | 1 |
|  | Mental capacity – too often presumption against | 1 |
|  | No support for autistic people | 1 |
|  | Social care charging | 1 |
| **Engagement – 3** |  |  |
|  | Deaf and Disabled people not listened to | 2 |
|  | Lack of communication | 1 |
| **Benefit system – 2** |  |  |
|  | Stress and anxiety | 2 |
| **Intersectionality – 2** |  |  |
|  | Need for support for refugees and asylum seekers | 2 |
| **Mental health services – 2** |  |  |
|  | Inadequate support/withdrawal of treatment | 2 |
| **Poverty – 2** |  |  |
|  | Lack of financial support | 2 |
| **COVID – 1** |  |  |
|  | Poverty and inadequate social care led to disproportionate deaths | 1 |
| **Education – 1** |  |  |
|  | Lack of support for pupils with Special Educational Needs and Disability | 1 |
| **Justice – 1** |  |  |
|  | Use of restraint on disabled prisoners | 1 |
| **Retrogression – 1** |  |  |
|  | Worsening conditions for Deaf and Disabled people overall | 1 |

21 reasons were given for a “disagree” response. Only eight expressed an actual disagreement with a specific issue. Nine of the reasons given were that the individual respondent had no personal experience of a particular issue and therefore did not feel qualified to comment. Of the remaining four, one cited unclear wording, one highlighted the absence of any mention of Disabled people who are from Black Asian and Minority Ethnic Communities, one expressed a view that the survey was biased and another considered the theme (of Deaf and Disabled people being silenced) to be objective fact and therefore inappropriate to be treated as a matter of subjective viewpoint (as suggested by the agree/disagree framing). The person who considered the survey to be biased may have missed the introductory information which explained how the themes have been identified from evidence submitted by Deaf and Disabled people and DDPOs.

At least one of the respondents had missed the point that institutionalisation can occur in people’s own homes where they are not provided with adequate support and are likely to have agreed rather than disagreed had they picked this up. This may apply to other respondents who disagreed but did not leave an explanation. A few respondents explained that they had disagreed with the institutionalisation theme because they have not personally seen or experienced it while acknowledging this does not necessarily mean it isn’t happening. The point about institutionalisation is that it involves segregation from the rest of the community so it makes sense that respondents might be least familiar with this option.

A few of the disagreements related to climate change and whether this is relevant to disability, however other respondents used the text box to voice support in favour of including this issue.

There was one disagreement over the issue of abortion and whether Disabled people should be challenging time limits and one disagreement that Deaf and Disabled people are being stopped from speaking out.

“I personally do not feel discriminated against or forgotten Things are moving forward not backwards”

“Q9. Unclear wording.”

“I simply don't know about greater impact of climate change on DP (in the UK at least)”

“Institutional I agree somewhat but not something I have much experience in, I'd have preferred a don't know option. I expect it does happen but not as big issue for me as others”

“7. Haven’t heard about it, tho doesn’t mean it’s happening”

“I disagreed mainly because I hadn’t really noticed things deteriorating in that area overall”

“I disagreed as it's simply true. I know this from social media groups and personal contacts, if the said person was to go on a legal demonstration, get arrested they would be put under pressure and fear a loss of benefits. I haven't witnessed this myself, but many have quoted this, and one instance may be exaggerated but many can't all be lying.”

“I agree that there is increase segregation in society but not that this is linked to force restraint etc. This has, does and should not happen. Its linked to poor practices, limited resources and lack of scrutiny. It affects a relatively small number of people massively.”

“I'm not sure that the impact of climate change specifically on disabled people is being ignored, I feel its just being ignored in general”

“I haven’t seen it happen, but I could be wrong.”

“I don’t agree with the abortion point, I believe it is the woman’s right to choose”

“Failed to mentioned the theme related to BAME with a disability.”

“I do not agree that disabled people are often institutionalised, quite the opposite. I feel that a great many have been left to cope with the rigours of everyday life, but without the necessary resources to do so.”

“I am not sure d&d people are being stopped from speaking out. Although it is still difficult”

|  |  |  |  |
| --- | --- | --- | --- |
| **Theme** | **Number of disagreements** | **Percentage of respondents** | **Percentage of all disagreements** |
| Continued regression – things are still getting worse for Deaf and Disabled people | 2 | Less than 1% | 5% |
| Shutting down challenge and redress – Deaf and Disabled people stopped from speaking out and accessing justice | 4 | 1% | 10% |
| Re-institutionalisation – inadequate support to live in the community, Deaf and Disabled people | 19 | 5% | 46% |
| Life less worthy – Deaf and Disabled people’s lives are valued less than non-disabled people’s | 5 | 1% | 12% |
| Wider issues – how Deaf and Disabled people are ignored in responses to wider humanitarian issues | 11 | 3% | 27% |

### Question 11: Is there anything missing?

* Answered: 155 (44%)
* Skipped: 196 (56%)

The majority of respondents did not answer this question. 12 respondents entered “no” or equivalent in the text box.

Where respondents answered, some added issues missed from the examples given under each theme. Others used the text box either to re-stress the issues of most importance to them or to make general points about the situation facing Deaf and Disabled people and express feelings of despair.

“It's the enormity of it, everything is a battle.”

“Sadly, every part of our lives has been challenged and the rights we fought so hard for in the 80’s and 90’s are now being eroded.”

“I think you have covered everything.”

“Yes the fact that disabled people are left to rot like they don’t matter is a sad predicament.”

“D&D people are disadvantaged by our government even where actually it would be cheaper not to do so. Our value as scapegoats is high.”

“The whole emphasis of benefits needs to change, any money a disabled person gets goes straight back into the economy for lots of reasons. This message needs to be put out in all different ways.”

“The future looks dark and desperate.”

“Government departments and councils should be leading by example, and currently they aren't.”

“I’m struggling financially, emotionally, physically and mentally. We are treated like 3rd class citizens.”

“Disabled people in uk are treated awfully by the state.”

“Not really, but I want to say how isolating it is to have a physical and/or mental disability. Isolation leads to mental health problems, but mental health services are being cut, and if you are isolated in the first place it's hard to find out what support is out there.”

“It feels like the government are trying to kill disabled people.”

Key issues raised by respondents that had not been covered within the information presented under each theme included:

* Access to the built environment, public transport and to communication
* Criminalisation of Deaf and Disabled people due to failure to meet needs
* Decreasing access to social networks and social and leisure activities for Deaf and Disabled people
* Digital exclusion
* Direct hostility towards Deaf and Disabled people and disability hate crime – in particular direct hostility shown by the Government towards Deaf and Disabled people
* Examples of where the Government is failing to take a human rights approach and the social model being undermined
* Failures of the Equality Act 2010 to protect the rights of Deaf and Disabled people
* Genetic screening studies – Spectrum 10K in particular
* Issue of inadequate support specifically for those Deaf and Disabled people who are unable to leave their homes
* Lack of reasonable adjustments within the criminal justice system including courts and prisons
* People providing unpaid support (“carers”)
* Specific examples of how Deaf and Disabled people are denied an equal right to family life, including how incomes are calculated on a household basis under Universal credit and discrimination within access to IVF and adoption
* The impacts of the pandemic on access including both how increased barriers to accessing services have been retained, and in some cases, made permanent and how the pandemic provided unprecedented access gains to some Deaf and Disabled people which are now being removed
* The importance of intersectional approach and areas where individuals with identities that fall under more than one protected characteristic face multiple barriers

“Accessibility!”

“Transport still shockingly inaccessible eg underground and rail network in London still many stations are not step free. Low traffic neighbourhoods preventing disabled people’s essential car journeys”

“In mental health there needs to be a human rights approach instead of forced medication and Electroconvulsive Therapy.”

“discriminated by the courts as they don’t follow guidelines for adjustment neither does any other public body Inc the police and local council in fact everytine I’ve asked for an adjustment it’s like I’ve asked for Gold !”

“Digital disenfranchisement/isolation The refusal by local authorities to make "reasonable adjustments" in communication with disabled and the move to everything being digital has further led to disabled vulnerability. If you cannot use a mobile phone, or cannot afford one; or a computer; you are completely cut off now - you cannot access a doctor, get Covid vaccines, source food or support. We are become a 4th class - the digitally disenfranchised who are being totally ignored and unsupported. It comes with heavy financial penalties too.”

“No mention of those of us who are retricted to our homes/beds and rely entirely on Social Care. Our thoughts, concerns and needs are ignored and brushed under the carpet. We are told 'No' and 'Can't be done' and 'No funding' far too often. When will we hear 'Yes' or 'We'll try' for once?”

“Want to say we are not 'vulnerable' we are oppressed”

“Only to link the lives of unpaid carers with this survey.Often forgotten yet in their millions taking care of a wide spectrum of adults and children with disabilites Every aspect of this survey also affects them.They are frequently unable to access what they need to take care of the disabled individual because of the impact of decades of austerity politics which continues to this day and is harming and taking the lives of carers and the disabled”

“How the uk benefit system forces disabled people to stay single or lose benefits.”

“The pandemic has seen a return to purely medical understanding of risk and vulnerability leaving millions at risk from factors not considered… Impairment specific campaigns are increasing and this dangerous for disability rights and justice”

“The launch of the Spectrum 10k study by Simon Baron Cohen has been proven to be unethical and seeking pre-natal screening of Autistic babies. The Autistic community has the largest unemployment percentage in the UK despite many people being fit to work, autistics are met with extreme discrimination and Cohen's study wants to further segregate autistics from society by dividing them into low/high functioning.”

“my disabilities make certain persons think I couldn't surely be intelligent enough to know what I am speaking about.”

“criminalisation of people with mental health, learning disabilities, neurodiversity or communication needs for disability related issues where criminal law is being stretched to create crimes due to lack of care/failure to meet needs.”

“Accessibility in society has got worse, especially as the world became a little more accessible for us during the pandemic, disabled and deaf people were able to work from home or go through education at home. Now as things return to slight normality all of these things are being taken from us. Including financial help, while the pandemic continues.”

“Nobody wants us. The whole of society sees us as burden upon their money and taxes. To be hated is awful. 35% of the given population surveyed by channel 4 said they saw disabled people as a burden on society. That’s a a lot of hate to contend with.”

“Herd immunity was the government’s way to tackle covid - by throwing disabled people under the bus as ‘it only really affects people with underlying conditions’, the implications being that it’s fine for those people to die. A Sentiment that has been picked up and repeated by the public.”

“Contempt shown to disabled people even within the NHS this is worse for females and black minorities. Conditions that effect women more than men are treated with less compassion or research.”

“I feel so upset with the hostile attitude of the DWP, councils and even some charities”

“A judicial system which is frequently discriminatory against Disabled people accused of a crime, still more so against Disabled people who belong to racialised communities. All too often, reasonable adjustments are not made either. These factors lead to unfair trials. In addition, prison conditions are often appalling.”

“Along with disability hate crime Fraud is rife in the UK. Often the two are interlinked. Vulnerable means just that - you are "ripe for the picking", we become so desperate to survive we seek support from whoever we can and we will pay anything to 'comply' with the near impossible tasks Local Authorities set us on threat of fines or imprisonment for non-compliance.”

“York City centre access for Blue Badge holders permanently reduced after initial Covid restrictions.”

“Whenever those in power are addressing the harms against marginalised groups, they silo us. This creates an atmosphere of competing for resources. They commit to supporting disabled people, or women, or the Black community, or the LGBT community, but almost never acknowledge or fund systems that are built around the fact that someone can be within all of those communities (and others). This silo approach doesn't work because it particularly fails those at the intersections.”

“Still a very low level of disabled voices in the media. But where there are, they get trolled and abused online or the public lack of awareness leads people to ask "if they can work why can't you?”

“hate crime like violence physical and verbal is getting more frequent towards disabled/deaf people.”

“Society and government do not want the disabled any more.”

Responses also highlighted different aspects of the individual issues included within the themes. A breakdown of the issues and specific points made in relation to these issues can be found in the table below.

The issues appearing most frequently within responses to Question 11 were problems with the current benefits system (28 separate responses/mentioned by 18% of respondents who answered this question); hostility towards Deaf and Disabled people in general or more specifically by the Government, DWP, media, public or professionals, including negative portrayals in the media – 22/14%); barriers to health services for non-COVID patients (21/14%); independent living (21/14%); access (19/12%); mental health (15/10%); discrimination (12/8%); justice (11/7%); intersectional issues (9/6%).

“I have been suicidal for over two months but was not given any support when I was discharged from the psychiatric hospital”

“The gruelling cruel assessments make peoples physical and mental health alot worse.”

“Disabled people cannot get past occupational health required for some degree courses e.g. nursing or for jobs. Universities are still allowed to rescind unconditional offers on the grounds of disability.”

“The issues Concerning The Covid-19 Pandemic has caused alot of other health issues to be put to one side and not receiving the required Support.”

“Refugees are are coming from trauma often getting traumatised by services this need to stop. Poor practice and traumatic practice and coersion are big problems.”

“Mental health services impossible to access. Unless you attempt suicide but even the only if you almost succeeded) or if you threaten someone else. You don't get help.”

“Lack of concern about older people and those living alone… Fears that if we contacted eg social services we might. be deemed incapable of looking after ourselves and persuaded into living in care homes.”

“Recent arguments about the new NICE guidelines echo the ideas of “hysteria” and mental illness instead of physical illness. Some quarters have far too much control over others.”

“The support from social services is shocking. I was asked to sign a form during a social care for personal assistant review, she said to save her coming to visit during the pandemic with the final draft for me to approve and sign. They made lies in the paperwork & missed out key information & have ignored my emails saying I don’t agree with the final report & they won’t re do it.”

“I have a managed account for PA payroll. The council won’t pay the cost of the managed account since the payroll company increased the prices. Due to me only receiving pip the council were to find everything in relation to PA. However the council have failed to find me an alternative company within there budget. The managed account company have been threatening every month for over a year to close the account spontaneously.”

“Kids are literally killing themselves here over the lack of support they get. (See Kidderminster as a recent example) Every person I've met who struggles with disabilities can attest that the lack of proper services availible exacerbates their problems. Mental health support especially, doctors refer people to charity groups for support, even if those people are on the verge of suicide.”

“more mental health services are needed. camhs is not fit for use. It is a waste of nhs money/resources because it does more harm than good”

“In large public organisations, staff with disabilities are bullied and do not get the accommodations they need to do their job successfully.”

“People are dying as a result of government policy. We are burdens to be removed. We are silenced and patronised. I fear, like last time, the UK government will simply ignore your findings. They simply do not care and want us gone”

“There is an institutional mismatch between the health service and the disability benefit service that needs to be rectified. If you are given a diagnosis by the health service you should be recognised as disabled across all state institutions. At the moment the grading of disability for disability benefit excludes most people with diagnoses even quite serious diagnose”

 “They want to stop judicial reviews”

“The DWP blames applicants for not providing correct information in claims, but the NHS won't provide it. It means that we have to pay privately (if we can), and keep appealing our claims. It is humiliating, stressful, and leads to mental health problems (eg self-harm).”

“NHS dentistry access even worse for disabled people than general public as most of the few remaining surgeries are in old, inaccessible buildings”

“Social attitudes around Covid have revealed a lot of discrimination and prejudice.”

“Limited access to healthcare, support assistants and food during Covid has disproportionately affected disabled people. And no one cares.”

“there is a lack of support available and only CBT therapies are offered”

“Continued exclusion from employment, access to work scheme cut, progress in understanding needs of disabled folk has reversed. My workplace NEVER considers my needs when planning away days, training, social events. I am utterly excluded.”

Within the answers there are three examples of good practice. These relate to:

* The benefit system under Scottish Government control
* Changing Places toilets
* Positive support from a third sector organisation.

“Have you looked in the Adult Disability Payment in Scotland? This sounds like a positive change is coming but I don’t know if they just know what to say to make it more acceptable to disabled people.”

“There are more Changing Places which is positive for me but there is a crisis in education and for transport to school for children with special needs.”

“The support I have received from The Restoration Trust has enabled me to access Zoom, which has helped me to be in touch with more people than before the pandemic.”

|  |  |
| --- | --- |
| **Access – 19** |  |
|  | Lack of access | 5 |
|  | Got better in the pandemic, now worse | 1 |
|  | Failure of the Equality Act “to genuinely promote disability” | 1 |
|  | Reduced access due to COVID response including outside dining reducing access on pavements and reduced parking for Blue Badge holders. Access for Blue Badge holders to York City Centre was permanently reduced after initial COVID restrictions. And is now subject to a legal challenge. | 1 |
|  | Introduction of Low Traffic Neighbourhoods | 2 |
|  | Public transport accessibility going backwards | 2 |
|  | Cuts to funding for public transport disproportionately impacting on disabled people  | 1 |
|  | Digital exclusion | 2 |
|  | Digital exclusion - disabled people being made vulnerable to fraud as a result of digital exclusion | 1 |
|  | Digital exclusion – increasingly everything online eg local authorities;  | 1 |
|  | Digital exclusion - increasing card only options excluding disabled people eg parking meters | 1 |
|  | COVID adjustments reducing access, eg telephone only medical appointments, carers not allowed into appointments, lack of support for people on CEV list needing to isolate | 1 |
| **Awareness - 1** |  |
|  | Lack of awareness of invisible impairments | 1 |
| **Benefits System - 28** |  |
|  | Universal Credit £20 uplift not applied to legacy benefits | 2 |
|  | DWP pushing autistic people into unsuitable insecure jobs | 1 |
|  | Forces disabled people to stay single, no respect for family life | 1 |
|  | Tightening of eligibility for DLA/PIP | 2 |
|  | Having to pay for medical evidence | 1 |
|  | Gov plans to bring PIP within UC and undermine its non-means-tested status | 1 |
|  | Health and Disability Green paper and plans to bring PIP within Universal Credit | 1 |
|  | Positive advances in Scotland such as Adult Disability Payment | 1 |
|  | Fear and distress caused by reassessment | 4 |
|  | Need to go through appeals as assessments ignore evidence | 9 |
|  | People with energy limiting chronic illness and fluctuating conditions fall through the cracks | 1 |
|  | Benefit deaths | 1 |
|  | Household calculation of finances – denies family life | 1 |
|  | Surveillance of claimants trapping people at home | 1 |
|  | PIP assessment process inappropriate for people with certain support needs/in certain groups eg autistic/fluctuating conditions | 1 |
| **Climate change - 2** |  |
|  | Climate crisis impacts Deaf and Disabled people disproportionately | 1 |
|  | Adverse impact of environmentally unfriendly policies on disabled people | 1 |
| **COVID response - 6** |  |
|  | Isolation and adverse impact on mental health of Deaf and Disabled people | 2 |
|  | No BSLi at government briefings | 1 |
|  | Disproportionate deaths | 1 |
|  | Difficulties accessing support and food | 1 |
|  | Deaf and Disabled people - after-thought in planning  | 1 |
| **Disability Hate Crime - 1** |  |
|  | Targeting of “the vulnerable” | 1 |
| **Discrimination - 12** | **5** |
|  | Within education | 1 |
|  | Within employment | 4 |
|  | Within IVF provision and adoption – lack of recognition and support for disabled people’s rights to family life | 1 |
|  | Spectrum 10K study – pre-natal screening of autistic babies. Further segregation – dividing into low and high functioning | 1 |
| **Education - 4** |  |
|  | Cuts to school transport provision for disabled pupils | 1 |
|  | Deaf children completely overlooked in mainstream provision | 1 |
|  | Lack of support and understanding for autistics and PDA sensory processing children and parents in schools | 1 |
|  | Lack of Special Educational Needs and Disability support | 1 |
| **Employment - 3** |  |
|  | Lack of support to find employment | 1 |
|  | Understanding of disability going backwards in workplaces | 1 |
|  | Difficulties obtaining Access to Work support | 1 |
| **Engagement - 4** | **2** |
|  | Charities and third sector organisations not independent – too afraid to speak out for fear of losing funding | 1 |
|  | No options to speak out or be listened to | 1 |
| **Freedom of movement - 2** |  |
|  | Migration barred to Deaf and Disabled people | 1 |
|  | Need to ensure refugees and asylum seekers are treated with respect and have support they need | 1 |
| **Health services - 22** |  |
|  | Access to health services has worsened considerably/cuts | 6 |
|  | Increased barriers to health services as a result of COVID | 2 |
|  | Parking charges in hospitals | 1 |
|  | More red tape and difficulties getting NHS wheelchairs | 1 |
|  | Few remaining NHS dentists usually in old and inaccessible buildings | 1 |
|  | More bureaucracy for obtaining wheelchairs | 1 |
|  | People with mental health diagnoses need to take advocates with them in order to be believed | 1 |
|  | Barriers to dentistry | 1 |
|  | Long waits for physio | 1 |
|  | Debates about NICE guidelines and ME/CFS echo ideas of “hysteria” and mental illness rather than physical health | 1 |
|  | NICE guidelines – need to respect and reflect views of people with lived experience | 3 |
|  | Long waiting times for diagnoses - Diagnosis times for autism can be well over 2 years and yet diagnoses are needed in order to receive an y form of support | 2 |
|  | Diagnostic overshadowing – people with MH labels not believed unless have an advocate present | 1 |
| **Hostility - 22** | **7** |
|  | Insufficient representation in the media but those who are in the public being trolled and abused online | 1 |
|  | Government hostility and demonisation | 9 |
|  | Negative portrayal of Deaf and Disabled people in media | 2 |
|  | Media hostility | 1 |
|  | DWP hostility | 2 |
| **Independent living - 21** | **2** |
|  | Lack of support for both children and adults | 4 |
|  | Lack of advocacy support | 2 |
|  | Social care recruitment crisis after BREXIT | 1 |
|  | Social care funding crisis | 1 |
|  | Less funding for charities | 1 |
|  | Lack of support to decreasing access to social life for disabled people | 1 |
|  | Criminalisation of disabled people – criminal law being stretched to cover people who are being failed by lack of support provision | 1 |
|  | Lack of support for unpaid carers | 1 |
|  | Homelessness | 1 |
|  | Lack of proper support from social services for people to manage Direct Payments | 1 |
|  | Lack of support provision in the community and how it results in the long term in higher costs due to people being put into residential care or hospitalised | 1 |
|  | Access to support unequal between different impairment groups, eg lack of support for autistic people; people with energy limiting chronic illness and fluctuating conditions fall through the cracks | 1 |
|  | Health and Social Care Green Paper  | 1 |
|  | Local Authorities not following lawful practices  | 1 |
|  | Inadequate support for people who are unable to leave their homes | 1 |
| **Intersectional issues - 9** |  |
|  | Important to include intersectional issues | 1 |
|  | Need for solidarity from the LGBT+ community | 1 |
|  | Services inappropriate for refugees who are traumatised and coming from trauma | 1 |
|  | Need for female only services | 1 |
|  | Conditions that affect women more than men treated with less compassion or research.  | 1 |
|  | Services and support always silo’ed and divided between different groups rather than recognising intersectionality | 1 |
|  | Some groups of people experience greater barriers to healthcare than others, eg women and people from BAME communities | 1 |
|  | Lack of recognition that disabled people can be both service users and carers | 1 |
|  | Fear particularly among disabled older people of contacting social services for help for fear of being put into a home | 1 |
| **Justice - 11** |  |
|  | Difficulties finding legal support | 2 |
|  | Lack of reasonable adjustments in the judicial system especially for racialised communities leading to unfair trials | 1 |
|  | Inaccessible conditions in prisons | 1 |
|  | Need for training for all prison and probation staff in understanding disability and disabled people’s rights under the Equality Act | 1 |
|  | Courts and police not following the law on reasonable adjustments | 1 |
|  | Proposals to restrict access to judicial review | 1 |
|  | Removing rights to peaceful protest and free speech | 2 |
|  | Government ignores court rulings | 1 |
|  | Human Rights Act – Gov wanting to dismantle | 1 |
| **Mental Capacity - 3** |  |
|  | Misuse of legislation to deny support | 1 |
|  | Advance Directives not legally enforced | 1 |
|  | Presumption of lack of capacity | 1 |
| **Mental Health - 15** |  |
|  | Charities being used to fill gaps in Mental Health provision even when young people are suicidal | 1 |
|  | CAMHS not being fit for purpose/doing more harm than good | 1 |
|  | Controlling and coercive approach within psychiatry | 1 |
|  | Physical health damage by psychiatric drugs | 1 |
|  | Mental health damage through trauma within mental health services | 1 |
|  | Lack of support – even if suicidal | 7 |
|  | No choice of treatment – just CBT or online therapy | 3 |
| **Personal mobility - 3** |  |
|  | Motability card being removed through benefits system | 1 |
|  | Greater difficulties getting blue badges | 2 |
| **Poverty - 6** |  |
|  | Decent standard of living needed – benefits don’t cover rising cost of living | 4 |
|  | Extra costs of disability – having to pay for own aids and equipment | 1 |
|  | Need for support for those who cannot work | 1 |
| **Social Model/human rights approach - 5** |  |
|  | Mental Health Review did nothing to bring mental health system in live with human rights model of disability | 1 |
|  | Medical model reinforced through pandemic - Social model undermined by designation of “vulnerable” through COVID | 2 |
|  | Increasing prevalence of impairment only campaigns | 1 |
|  | Government – lack of human rights approach to disability | 1 |

## Conclusion

The fact that so many people completed the survey within such a short time and when capacity to publicise it was relatively low just before Christmas reflects the importance of the shadow report to Deaf and Disabled people and the urgency with which people feel their voices need to be heard. This is supported by the volume of information entered into the free text boxes.

There is strong consistency between responses despite the wide range of information provided and the diversity of respondents. A large percentage – 89% of all respondents - answered that conditions have worsened for Deaf and Disabled people since 2017. An even higher percentage – 91% - agreed with the first theme that there has been continued retrogression across multiple areas including social care; education; employment; mental health services; housing and benefits; with Covid sometimes used as a reason for not meeting our needs.

This picture is further strengthened by the lack of responses given to questions asking specifically for areas of improvement and examples of good practice. A minority of respondents – 34% - responded to Question 2 (How have Deaf and Disabled people’s lives got better since 2017?) by citing an area of improvement. 54% either responded with “none” (or a variation on), or instead described increasing barriers that Deaf and Disabled people are facing, while a further 3% replied “don’t know”. The rest skipped the question. Only four answers mention a measure that can be accredited to government in England. Two answers refer to initiatives of the Scottish government, suggesting that this is where we should be looking for good practice.

Overall respondents appeared to have a good knowledge of relevant legislation, policy and practice, so this suggests that lack of mention is not down to lack of awareness of existing progressive initiatives. Moreover, the test of whether an initiative is truly progressive is whether it positively impacts on the lives of Deaf and Disabled people sufficient for them to be aware of it.

Respondents expressed a high level of support for all themes. Percentages in agreement were 91%, 90%, 84%, 89% and 87%. More than double the number of respondents volunteered additional agreement with the themes or added information in support of them than voiced a disagreement. The theme with the lowest percentage of agreement relates to institutionalisation of Deaf and Disabled people. More respondents explained that they have insufficient awareness of this subject in order to agree than voiced an actual disagreement.

When asked if there was anything missing from the themes, the majority of respondents either replied in the negative or skipped the question. No one provided information relating to an entirely new theme but rather contributed additional issues in support of the existing themes.

There is therefore strong correlation between the evidence submitted and the survey responses. This provides a substantial basis from which to develop the next shadow report.

In some cases, respondents gave answers that offer explanations for continued regression. A feeling of direct hostility from Government towards Deaf and Disabled people is one issue that was not covered within the themes that a significant number of respondents mentioned in response to every question where there was a free text box provided.

Another big picture issue cited in far fewer responses but of importance nevertheless relates to the models of disability underpinning policy and service provision and specifically to how the medical model has been strengthened by the pandemic and the Government’s failure to implement a human rights approach.

The shadow report will need to engage with these bigger picture issues relevant to implementation of the UNCRDP alongside listing examples of how current policy and practice is in breach of respective Articles of the Convention.

Lastly, the experiences and feelings expressed through the survey responses make clear that are high levels of unmet need, that Deaf and Disabled people across the country are experiencing hardship, anxiety and distress, and that these are therefore highly sensitive issues. The report and how the shadow reporting process is treated needs to reflect and be considerate of this situation.

## Appendix A:Copy of Survey (non-easy read)

Thank you for your interest in this survey.

Over the past six weeks, we have been sent lots of information from Deaf and Disabled people and their organisations as well as other with an interest in disability. We are now looking carefully through all of this so that we can write the next “shadow” report for the United Nations Disability Committee.

The report will be about what has been happening to Deaf and Disabled people in England since 2017. You can find out more about this work on the Inclusion London website.

We have also made this quick survey. This is because we want YOUR views on how we should put together the different examples you have sent us.

The survey is anonymous but there is the option to include your name and contact details at the end to stay in contact with this work. The findings from the survey will be made public but no names or identifying information will be included.

If you choose to share your name and contact details at the end of the survey, these will be held by Inclusion London but will not be shared with anyone else.  You can also sign up through the Inclusion London website [www.inclusionlondon.org.uk/uncrdp](http://www.inclusionlondon.org.uk/uncrdp) to stay in contact with this work. Doing it this way means you can keep your survey anonymous.

1. In your view, since 2017 have things for Deaf and Disabled people overall:

Got better

Stayed the same

Got worse

2. In your experience, what areas of Deaf and Disabled people’s lives have got better since 2017?

[max 100 words]

3. In your experience, what areas of Deaf and Disabled people’s lives have got worse since 2017?

[max 100 words]

4. Please tick if you are aware of any areas of good practice where the lives of Deaf and Disabled people have been made better through action taken since 2017:

By local Councils

By regional elected Mayors

If you answered yes, please say where and give a brief description.

 [max 150 words]

5. Things are still getting worse for Deaf and Disabled people. For example: in social care; education; employment; mental health services; housing and benefits; with Covid sometimes used as a reason for not meeting our needs. Disabled people were also more likely to die from Covid even after accounting for health and age factors.

Agree

Disagree

6. Deaf and Disabled people are being stopped from speaking out. For example: making protesting illegal; plans to limit legal challenges against the government; less involvement of Deaf and Disabled people, inaccessible complaints procedures; greater bureaucratic burdens for lower amounts of support; cuts to funding for our organisations as well as other services we need such as advice and advocacy services and Law Centres; changes to Legal Aid; more barriers to contacting local Councils; and, less disability data collection by government.

Agree

Disagree

7. Institutionalisation of Deaf and Disabled people. This means placing people in segregated settings and taking away their rights through for example forced detentions and inappropriate use of restraint. It can also happen in people’s own homes where their support needs are not being met. Institutionalisation affects both children and adults.

Agree

Disagree

8. Deaf and Disabled people’s lives are valued less than other people’s. This has been shown during the pandemic. For example: patients with Covid discharged into care homes; disabled people not getting treatment when the NHS is over-stretched; unlawful use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders; inaccessible information and communications; not consulting with Deaf and Disabled people. Babies who will be born disabled can still be terminated later than other babies. Hate crime law is still not equal for disability.

Agree

Disagree

9. Deaf and disabled people experience extra barriers if they also belong to other equalities groups. Examples include: higher rates of forced detentions and deaths in police cell for Black men with mental distress; extra barriers to healthcare for people from Black and Minority Ethnic Communities; the way the needs of disabled asylum seekers and refugees were overlooked during the pandemic. Disabled women are at higher risk of domestic violence yet the new law on Domestic Abuse was passed without anything in it on carer abuse.

Agree

Disagree

10. The impacts of wider issues on Deaf and disabled people get overlooked. For example, climate change and the treatment of refugees.

Agree

Disagree

10. If you disagreed with any of the themes please say why.

[max 100 words]

11. Is there anything missing?

[max 200 words]

Many thanks for taking the time to fill in this survey. If you would like to stay up-to-date with this project, and are happy to leave your personal details, please enter them here:

12. Name

13. Email address

## Appendix B:Calculating total potential respondents

Networks and organisations represented on the Project Steering group disseminated the survey both through social media and direct mail out to their members. There is overlap between both memberships and social media followers and a combined total would be an exaggeration of the number of potential respondents. Memberships and followers of each network and organisation include a number of DDPOs and other membership organisations who were all encouraged within the communication that went out to forward the survey on to their own contact networks. With the exception of Bromley X by X and TUC Disabled Workers’ Committee who fed back to us confirming they had disseminated the link, it is not known how many other member organisations did so or how far those organisations reach. Inclusion London for example calculates that through its membership of London DDPOs it has a reach of 70,000 Deaf and Disabled Londoners.

Alliance for Inclusive Education

* 300 members
* 5000+ social media

DPAC

* 4300+ members
* 29,500+ social media

Disability Rights UK

* 20,000 members
* 64,000+ social media

Inclusion London

* 1600+ mail outs
* 9,500+ social media

Liberation

* 114 members (excluding individual members involved in the CRDP work)

Reclaiming Our Futures Alliance

* 294 members
* 900+ social media

Experts by Experience Bromley

* 100 members

TUC Disabled Workers Committee members

* 20 members
1. Entered in response to Q.3 but taken with the individual respondent’s other answers it is assumed they intended to include this as an example of improvement [↑](#footnote-ref-1)