

Submission of evidence:

Coronavirus (Covid-19) and the unequal impact on disabled people

Submission to The Women and Equalities Committee: Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics

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Centre of Resilience for Social Justice www.brighton.ac.uk/crsj/index.aspx

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Blackpool HeadStart <https://sites.google.com/seaside.blackpool.org.uk/mock/home>

on behalf of the Resilience Revolution <https://www.boingboing.org.uk/resilience/resilience-revolution-resources/>

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Introduction:

In this submission we draw on our collective organisational and personal experiences, relating them to policy and practices associated with COVID 19 and equalities more generally. We are a community of academics, students, practitioners, parents/carers and young people working together to beat the odds and change the odds, as and with disadvantaged communities. Many of us have our own complex life challenges including physical and learning disabilities. Some of us are clinically vulnerable or extremely vulnerable to COVID-19 and/or have caring responsibilities for those that are. A wide range of voices are especially important to consider due to the diversity of disabilities, and disability supports.

This submission follows on from our previous submission of evidence on '[The disproportionate impact of COVID-19, and the UK government response, on people with disabilities](#)' dated 30th April, 2020. Although we acknowledge much of these initial recommendations have been upheld, we suggest improvements to their functionality and acceptability for disabled people. These are considered under 5 main themes: consider the most relevant and accurate data, consider the broadest definition of vulnerability, provide clearer guidance for disabled people and their supporters, work in partnership with disabled people to explore innovative solutions and, celebrate the contributions of disabled people. We conclude with a list of immediate and long-term recommendations.

1. Consider the most relevant and accurate data

In this section we review the available data surrounding COVID-19 and disability and suggest areas for improvements.

In our previous submission, we called for a review of the impact of the Coronavirus Act 2020 on disabled people to take place in 6 months' time. We are grateful for your action on this recommendation in the form of the inquiry ([Unequal impact? Coronavirus, disability and access to services](#)). However, we have found that many data sets linking to Coronavirus mortality and infection rates exclude consideration of disability in full or in part. Reviewing and responding to criticisms of the Coronavirus Act 2020 with insufficient, incomplete and inaccurate data perpetuates inequality. It does not offer clarity to policy makers. It does not provide clarity or transparency to disabled people, or to their supporters.



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Some data sets omit data associated with disability in full. For example, ONS data sets associated with '[Coronavirus \(COVID-19\) infections in the community in England](#)' do not consider disability status. Thus, disabled people and their supporters are unable to consider their relative risk and protect themselves accordingly. We are also thus unable to consider changes in infection rates over time relevant to disability. This additionally limits evaluation of the effectiveness of strategies introduced to protect those considered vulnerable as the result of disability and/or ill health (e.g. Shielding initiatives). ONS COVID-19 infection data sets consider other protected characteristics such as age, gender and ethnicity (e.g. August 2020, July 2020). Thus, it is unclear why disability considerations have been omitted.

The ONS report, '[Coronavirus \(COVID-19\) related deaths by disability status, England and Wales: 2 March to 15 May 2020](#)' suggested young disabled people and disabled people of working age were at heightened risk of death compared to the general population. In this age group, disabled men were 6.5 times more likely to die and, disabled women were 11.3 times more likely to die than their non-disabled counterparts. The use of census data to measure disability brings into question the accuracy of the results here because many were likely to have developed disabilities since the last census was conducted. A subsequent ONS report '[Coronavirus \(COVID-19\) related deaths by disability status, England and Wales: 2 March to 14 July 2020](#)' was published September 18th 2020. This similarly used census data to define disability. It found disabled people made up 59% of COVID-19 related deaths in this period. No further reports have since been released on mortality and disability by ONS in consideration of disability. Thus, the available data- provided only at the height of the pandemic- may be misleading. It is likely to aggravate anxieties in particular amongst households with disabled children, young people and those of working age. This does little to help these households feel safe to return to education and/or employment. This has led to anxieties, and to some excluding themselves and/or their households from educational and/or employment opportunities. Thus, poor data practices associated with COVID-19, can be said to perpetuate employment and educational inequalities for disabled people.

In our previous submission, we considered employment trends in regards to disability. We highlighted that disabled people may be at increased risk of exposure to COVID-19 as they may be more likely to work in key worker positions. The omission of disability as a consideration in the July 2020 ONS data limits the ability of researchers to aggregate disability data against employment type. It may be possible that disproportionate COVID-19 mortality rates amongst disabled people may be linked to relative modes of employment. However, important opportunities for these considerations have been missed because disabled people were not considered. Further to this, we are entering what [The World Bank \(9th June 2020\)](#) has predicted as one of the worst global recessions, with a rise in unemployment one of many negative outcomes predicted. A lack of data around disability, employment and COVID-19 is a detriment to policy makers tasked to consider what, where, and if any employment related initiatives should be introduced specifically to support disabled people. Thus, improvements around data collection and reporting are vital to enable disabled people and their supporters to feel comfortable engaging in employment and accessing health care. Equally, they are important for the design and evaluation of support packages.

In our earlier submission, we called for a review surrounding the disproportionate death rates of those with pre-existing conditions. We acknowledge that pre-existing conditions was considered in mortality rates between March-June (see Sec 6. ONS, '[Deaths involving COVID-19, England and Wales: deaths occurring in June 2020](#)'). Of deaths linked to COVID-19, here it was reported 91.1% of individuals had at least one pre-existing condition. The report acknowledges further research is



required, yet stated this would be delayed for some months. Again, this approach to data management and reporting is likely to cause anxiety and distress for disabled people and their supporters. Again, only data from the height of the pandemic is available to them. Yet, there is evidence that this data is and has been calculated throughout the pandemic. For example, the existence of pre-existing health conditions are often reported in the news along with COVID-19 mortality rates. Providing alarming statistics only to delay exploring them will likely increase distrust and disengagement. Furthermore, the consideration of disability and access to health care would benefit from a review of this data. It may provide a more accurate and complete consideration of disabilities in relation to COVID-19 and outcomes (including mortality) than has previously been available. It will provide clear information surrounding what sub-sections of the disabled population may benefit most from additional supports. Lastly, a longitudinal review of this data will aid in exploring if/how patient prioritisation policies impact mortality rates.

We suggest researchers use universally accessible data collection tools to improve inclusivity relating to knowledge generating systems. We recommended this in a previous submission to last year's '[Inquiry into the experiences of disabled students in higher education](#)'; noting that many existing online data collection tools are not accessible to individuals with some disabilities. At the time of that Inquiry, we recommended current [regulations surrounding web and app accessibility](#) be expanded to include digital surveys and operating systems. The experience of this pandemic has suggested that further work in this area is of considerable importance.

We additionally recommend the inclusion of two additional questions in research studies associated with COVID 19, disability and access to care, education and employment. These include:

- 1) Are you or have you ever been considered extremely clinically vulnerable to COVID 19?
- 2) Are you living in a household with someone who is or has ever been considered extremely clinically vulnerable to COVID 19?

The relevance of these questions is explained in the following section.

2. Consider the broadest definition of vulnerability

This section begins with a consideration of vulnerability as specified in policies and guidance related to COVID-19 and considers this against relevant disability legislation.

The culmination of guidance and policies such as the BMA's '[COVID-19 – ethical issues. A guidance note](#)', [The Coronavirus Act 2020](#) and guidance such as, "[COVID-19: guidance on shielding and protecting people defined on medical grounds as extremely vulnerable](#)" has in effect, created new categories of vulnerable people: those clinically and/or extremely clinically vulnerable to COVID 19. The recent publication "[Working Safely during coronavirus \(COVID-19\) outbreak](#)" extends this group of vulnerable people to include those "living with someone who is clinically extremely vulnerable" under the section: 'Supporting clinically extremely vulnerable workers returning to work'. As such, not all those made vulnerable due to illness and/or disability will be protected under the [Equality Act 2010](#). For example, more than one of the authors of this paper is considered clinically vulnerable to COVID 19, but not all fit the definition of disability under the Equality Act 2010.

The Equality Act (2010, Section 6) states:

“(1) A person (P) has a disability if—

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities”.

Section 6 of the Equality Act 2010 may be problematic in relation to Section 18/20 of the Coronavirus Act 2020. In these sections, care for disabled people and/or support of carers respectively may be legally reduced and/or withheld. Thus, many with pre-existing impairments may now be experiencing adverse effects in regard to performing “normal” day-to-day activities. Thus, the policies themselves may be disabling. As such, the definition of disability in the Equality Act 2010 is not sufficiently flexible or inclusive enough to respond to barriers outside of the pre-defined norm, e.g., an unprecedented global pandemic. This is worrying because policy should aim to protect the most vulnerable citizens under any and all circumstances, not just the circumstances they define as fit to respond to. This suggests that the Equality Act 2010 may not be sufficient to protect disabled people in times of crisis. The Government of Canada for example, may work to a more all-encompassing definition. It defines disability as a,

“physical, mental, intellectual, learning or sensory impairment- or a functional limitation- whether permanent, temporary or episodic in nature, that, in interaction with a barrier, hinders a person’s full and equal participation in society” ([Proposed Accessible Canada Act – Summary of the bill, Definitions, June 2018](#)).

Thus, comparatively to other countries, the definition of disability of the Equality Act 2010 is limited.

The need to reconsider the Equality Act 2010 is directly related to the disproportionate impacts of COVID 19 on disabled people. Here, it specifically relates to unequal access to care. Unequal access to treatment for disabled people was justified by some professional bodies citing Section 19 (1) of the Equalities Act that allows for ‘a proportionate means of achieving a legitimate aim’. The Coronavirus Act 2020 (Section 30) includes the suspension of some coroner’s obligations associated with inquests surrounding suspicious deaths. As such, disabled people may be denied treatment resulting in death, yet have no rights to wrongful death investigations. Increasing this risk, is a previous court ruling between R (on the application of Antoniou) and Central And North West London NHS Foundation Trust (1), The Secretary of State for Health (2) and NHS England (3) ([Case No: CO/7495/2011](#)). Here, it was ruled that “equality of opportunity "between persons who share a relevant protected characteristic and persons who do not share it" can only apply as between the living” (Section 110). Thus, the enactment of government policies, patient prioritisation guidance, disproportionate mortalities and legal rulings, suggest the Equality Act 2010 may be insufficient in protecting disabled people in the face of a health pandemic. A review of the Equality Act 2010 in partnership with disabled people and their supporters is recommended.

A global review of disability definitions and equality related policies may inform this review. As was recommended by the [Equality and Human Right Commission \(18.01.2018\)](#), a review of UK Human Rights laws may also reconsider Universal Design as outlined within the United Nations ‘[Convention on the Rights of Persons with Disabilities](#)’. A Universal Design approach to health services may improve access to care for disabled people by improving their functionality and acceptability.

However, in consideration of intersectionality, the concept of Universal Design may be extended here to include considerations of relative functionality and accessibility of strategies, services and products across all protected groups.

In considering relative definitions of disability, we found here that other countries may consider protected characteristics more broadly than we do. For example, [the Canadian Human Rights Act 1985](#) outlines 13 protected characteristics including “colour” and “national or ethnic origin” - things that are currently not protected under the Equality Act 2010. This consideration may be of interest in consideration of submissions to the [‘Unequal Impact? Coronavirus and BAME people’](#) inquiry. Disabled people are not a homogenous group and an intersectional approach to any and all policy reviews is recommended. An intersectional approach should also explicitly include the views of young disabled people (see for e.g. [‘The Economic Impact of Covid-19 on Young People’](#) submission to [Youth Affairs APPG’s Economic Impact Inquiry Opens Call for Evidence](#) and [‘COVIDUnder19 - Global Children’s Consultation’](#)).

A review of the Equality Act 2010 may additionally be prioritized before the UK leaves the EU in consideration of 2016 headlines suggesting that, post-Brexit, “Theresa May’s plans to scrap human rights laws facing legal challenge” ([Independent, 29.12.2016](#)). Little clarifications have been provided to disabled people and their supporters surrounding potential impacts of leaving the EU on human rights and protections. However, there is a danger here that Universal Design- a principle not fully ratified into UK law- may be less likely to be considered when the UK leaves the EU.

3. Provide clearer guidance for disabled people and their supporters

In our previous submission we called for clearer guidance to be available to disabled people and their supporters, specifically recommending a dedicated web page including employment advice for shielding households. We appreciate that these recommendations were upheld. We appreciate that work in the area of the provision of accessible and timely information is an ongoing endeavour and encourage that it continue.

We do however wish to raise concerns surrounding the clarity of information for the supporters of disabled people, including their employers and educational establishments. For example, the document [“Working Safely during coronavirus \(COVID-19\) outbreak”](#) states that the advice surrounding ‘Supporting clinically extremely vulnerable workers returning to work’ also “applies to workers living with someone who is clinically extremely vulnerable”. However, provided [risk example templates](#) do not appear to consider household vulnerabilities within their assessments. Thus, due to inconsistencies between workplace guidance and exemplars, employers may not be doing due diligence in regards to protecting households vulnerable to COVID-19. This may lead to some disabled people and/or their carers excluding themselves from employment because protections for them are limited. Thus, these individuals are facing employment insecurity partly as a result of unclear guidance. Indeed, evidence suggest that disabled people are facing increased employment insecurity more generally. In August 2020, Citizen’s Advice released the report [‘An Unequal Crisis: why workers need better enforcement of their rights’](#) suggesting disabled people and their carers have disproportionately been impacted by redundancies.

We have heard of many examples where disabled people and/or caregivers of disabled people have seemingly faced employment discrimination and/or abuse from colleagues. These stories have increased since August 2020, when shielding was ‘paused’. We have also heard from many from

vulnerable households that they are reluctant to support their children's return to school due to safety concerns. We have suggested that the lack of recent data around disability health outcomes in relation to COVID-19 is problematic here. However, we have heard reports from parents of vulnerable children that their GPs say that they are unable to give specific advice around schools leaving them feeling like they have no choice, but to deregister their children. Thus, disabled children may be excluded from education (and potentially future employment) due to lack of information and advice. Health Professionals may additionally have their clinical capacities reduced in order to provide letter and/or individual advice to vulnerable children and families. Thus, families have little information aside from news sources to base their assessment of risk. With regards to education, this lack of COVID-19 specific information and advice has been compounded by changes introduced by the [‘Special Educational Needs and Disability \(Coronavirus\) \(Amendment\) Regulations 2020 \(the ‘Amendment Regulations’\)](#) which has relaxed timescales for assessment of need with regards to Education, Health and Care (EHC) planning. This has the potential to affect both individual children and their families, in addition to the availability of accurate information and data from which policy decisions may be informed.

Some news stories are likely to cause alarm and further perpetuate reduced access to care, employment and education by perpetuating disengagement. Headlines such as, “Florida confirmed 9K new COVID-19 cases among children within 15 days as schools reopen” ([The Hill, 25.08.2020](#)) do little to calm anxieties for households with disabilities. In this story, the exact numbers of infections tied to primary, secondary and higher education students and staff is still under debate. According to press outlets, the initial report from The Department of Health was removed for further accuracy reviews days after first publication (e.g. [The Hill, 25.08.2020](#) / [News Service of Florida 25.08.2020](#)). None the less, this information was and is being shared across a variety of social media platforms. With schools reopening and the national pause of shielding, now more than ever vulnerable children, their families and supporters need access to clear, accurate and consistent information from reputable government sources. Moreover, and given the unhelpful messages in the mainstream and social media, the people with learning disabilities in our community have looked to Government messaging for clarity. They have experienced this as highly confusing which has increased their sense of confusion and anxiety. We have found this to unacceptable in the extreme and call on the Government to provide clear messaging that is as unambiguous as possible. This should be provided in accessible language and easy read guides provided for people with neuro-diverse needs.

Thus, the culmination of lack of information, inaccurate, incomplete and inaccessible information does little to facilitate equitable outcomes nor ease the concerns of disabled people and their supporters. Rather, they are likely to adversely damage disabled people's trust in government, government agencies and employers. Immediate changes are needed here to prevent exclusions and disengagement.

4. Work in partnership with disabled people to explore innovative solutions:

Some innovative practical solutions have been suggested in the UK and internationally that warrant further exploration in partnership with disabled people. Some of these have originated within disabled and clinically vulnerable to COVID-19 communities.



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For example, Judith Keith, a parent with clinical vulnerabilities, [change.org petition](#) asks, “Let kids from Shielding families go back to school in smaller, safer ‘Shielding Bubbles’. Here, the idea is that those limiting their risks could be collectively grouped; thus reducing the risks to vulnerable students. Should universal mask wearing be introduced, shielding bubbles may enable students and teachers that are mask exempt to safely continue their education and employment.

In Canada, news outlets have reported that students and families are given the option to register for either face-to-face or online learning in the 2020-21 academic year (see e.g. [CBC, 08.06.2020](#)). Here, school boards are mandated to provide online training for all families that make this decision. It must however be recognised that the Ontario Ministry of Education already had in place an [e-learning strategy](#) pre-pandemic. Thus, one barrier in the UK in regards to providing online education is the lack of infrastructure for its provision. This can and should be addressed in the long term, however in the short-term a more creative approach may be required.

One challenge to the provision of e-learning in the UK thus far has related to socio-economic barriers (i.e. some families simply cannot afford computer equipment etc.). However, the UK governments’ ‘Eat Out To Help Out Scheme’ ([House of Commons Library, 26.08.2020](#)) demonstrated that businesses are willing to be reimbursed by the UK government for expenses incurred by individual citizens. A similar partnership between government and digital and technology providers may enable vulnerable children and families to purchase computers and other essential learning aids at a highly discounted rate and/or for free. This approach may aid in reducing resource delays and enable the most disadvantaged to access e-education and/or work from home. This may be made specifically available to disabled and/or extremely clinically vulnerable individuals in recognition that they would be disproportionately unlikely to benefit from other government schemes (see for e.g. our previous submission).

Coronavirus has provided a unique opportunity to advance UK based understanding around e-learning. The exploration and provision of e-learning may be specifically supported by qualified and trainee education and health providers. Currently, Higher Education Institutions are challenged in the provision of safe placement opportunities for vulnerable students; such as those in teacher training, trainee school nurses, trainee social workers, etc. On-line and e-learning options may further enable these students to complete higher education and enable their future access to employment. Enabling qualified teachers with vulnerabilities to become e-mentors would enable them to work from home safely whilst continuing to contribute to education. Here, their skills and expertise would aid in enabling vulnerable University students to complete their education and enter the workforce. These collaborations may form the vanguard for e-learning in the event of future outbreaks and/or school closures.

Few examples could be identified that suggest innovation employment solutions for disabled people following the COVID-19 pandemic. However, some more generalist ideas may be considered here. For example, increased thought and consideration should go into apprenticeship opportunities for disabled people at the strategic level. England may wish to follow the lead of the Welsh government and devise their own ‘[Disability action plan for apprenticeships](#)’. Partnership with businesses that have publically committed to supporting disability inclusion may prove beneficial such as with members of ‘[The Valuable 500](#)’ (a group of businesses that have committed to disability inclusion within their leadership agendas). We may wish to extend the provision of undergraduate internships for disabled people to include post-graduate students. Here, expansion to the [Change 100](#) programme offered by [Lenard Cheshire](#) may be considered. The specific introduction and

continuance of scholarships and/or fellowships for disabled students and/or graduates may be especially important. Further to this, new initiatives such as the youth employment scheme [KickStart](#) could be advanced to better support disabled young people. For example, additional incentives and/or supports may be provided to employers that make employment opportunities available to disabled young people, and/or reducing the number of young people an employer must take on to be eligible for the scheme providing they make specific efforts to recruit disabled young people (see for e.g. [‘The Economic Impact of Covid-19 on Young People’](#) submission).

These are but some ideas. It is important that a wide spectrum of disabled people be involved in designing and implementing novel approaches to disability support and in the design of any policies and/or policy reviews.

Celebrate the Contributions of Disabled People

Many disabled people and their supporters report experiencing increased stigma and social judgments at this time. It is important to counter this narrative with one that celebrates the contributions of disabled people.

In our previous submission, we cited the [Office of National Statistics \(2019\)](#) report suggesting that disabled people are more likely than non-disabled people to be in ‘Caring, Leisure and Other Service Occupations’, ‘Sales and Customer Service Occupations’ and ‘Elementary Occupations’. We speculated that it was therefore highly likely that a disproportionate number of disabled people were keyworkers throughout the pandemic. Although data omissions surrounding disability and employment make it challenging to confirm these suspicions, there is evidence to suggest that disabled people may have contributed to inventions that enabled society to stay home and stay safe.

Disabled people have had a hand in developing many of our more modern communication tools. For example, [Vint Cerf](#) helped pioneer Internet and e-mail technologies. [Haben Girma](#) has championed digital accessibility and inclusivity alongside industry. Text messaging, speech-to-text software (e.g. dictation software), text-to speech technologies (e.g. screen readers), voice activated technologies and many more inventions now used by the majority, were developed with disability in mind (see for e.g. <https://incl.ca/the-evolution-of-assistive-technology-into-everyday-products/>). A precursor to the typewriter was said to be invented to assist [Countess Carolina Fantoni da Fivizzon](#) to write letters irrespective of visual impairments. Mabel Hubbard secured funding enabling her then teacher, Alexander Graham Bell, to go on to invent the telephone (see for e.g. <https://content.govdelivery.com/accounts/TXGOV/bulletins/a89c33>). These tools enabled wider society to work from home, limit face-to-face contact and access information quickly and remotely. Yet the past and present contributions of disabled people towards these tools and technologies has not been celebrated. They, like data linked to disability and COVID 19, have been omitted from government narratives. This undervalues disabled people, perpetuates stigma and increases the likelihood of disengagement and discrimination. Thus, efforts should be made to celebrate the contributions of disabled people and to encourage and enable future contributions to innovation and enterprise.

Summary of Recommendations:

Within 3 Weeks’ Time:

- 1) We recommend all data collected in relation to COVID-19 moving forward specifically considers disability and clinical and household vulnerabilities to COVID 19. Retrospective



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reports considering pre-existing health conditions and impacts associated with COVID 19 should be generated to compensate for previous failures in data capture. This data will aid in advancing our understanding of vulnerability and potential links to inequalities. This will aid in practice and policy decision making. Providing a summary of available data sets and reports in various accessible formats will enable disabled people and their supporters to make informed choices on their health and wellbeing. In the interest of intersectionality, summaries of data sets relevant to other protected characteristics may also be made available.

- 2) We recommend further updates to advice given to employers- including all exemplars. Make it clear how vulnerabilities and household vulnerabilities can and should be measured. Make it clear how employers can best support disabled and vulnerable employees AND employees with caring responsibilities for disabled and/or vulnerable people. Consider how government initiatives and support packages can enable employments and provide safety nets for those who cannot continue in their current roles due to health risks.
- 3) Publicly acknowledge the contributions of disabled people in regard to tools and technologies that enabled much of the general population to stay home during this pandemic. Work with disabled people to identify and share these stories and acknowledge contributions. The learning from this can later be used to inform [Disability History Month](#) celebrations. This learning may also inform future reporting of the experience of COVID 19 in the national curriculum.

Within 6 Months' Time:

- 1) We suggest a governmental review of data collection processes relating to protected characteristics and COVID 19 be conducted. This should include disability. The learning from this exercise will prevent future data omissions.
- 2) Convene a Disability Task Force to continue efforts in collecting, reporting and providing clear and accessible information on/by and for disabled people. Universal Design principles may be helpful here. The task force should include disabled people and their supporters. It should also seek to identify contributions of disabled people, include a global review of definitions around disability and human rights law, identify practice-based solutions and critique existing policy and regulations (e.g. [regulations surrounding web and app accessibility](#)). A sub-committee of this task force may consider if policies associated with disability and COVID 19 may have contributed to disabled people being denied equal access to health care during the pandemic and, if so, if wrongful deaths were thus likely to occur. The Coronavirus Act 2020 limits investigations into individual deaths. However, it should not limit investigations to explore factors relating to disproportionate death rates associated with protected characteristics, such as disability.
- 3) We suggest a formal review of the Equality Act 2010 take place prior to the next 6 monthly review of [The Coronavirus Act 2020](#). We strongly recommend that an intersectional approach be taken to this review, that disabled people and their supporters be heavily involved, and that the broadest definition of vulnerability be considered. A global review of definitions of disabilities and human rights laws may inform this review. Information around equality provisions should be provided to disabled people and their supporters prior to leaving the EU.