

# Annex A:

## Our Voices

This annex contains the voices and experiences of Deaf and Disabled people, our organisations and allies who contributed to the development of the Westminster Government civil society shadow report.

Extracts have been chosen to illustrate the themes that came up most often within the evidence we received. Annex C and D contain our analysis of event notes, submissions we received in response to our call for evidence and our survey. For a full methodology see appendix 2 to the main report.

Where counter-points to any themes have been submitted these are included below.

The extracts included below are just a sample of voices on each subject and the lists are by no means exhaustive. The full range of evidence (minus a couple of submissions that contained personal information) and all survey responses are publicly available on the Inclusion London website:

[www.inclusionlondon/uncrdp](http://www.inclusionlondon/uncrdp).

# Contents

<b>1. Intersectionality</b> .....	<b>5</b>
Balancing support.....	5
Discrimination against Disabled women’s parental and reproductive rights .....	6
Intersectional harassment and hate crime.....	6
Disability and migration.....	7
Intersectional discrimination in education .....	8
Multiple Discrimination .....	9
Violence and abuse against women and girls .....	10
<b>2. Continued retrogression</b> .....	<b>11</b>
Barriers to education .....	11
Barriers to healthcare .....	14
Criminal Justice System – inaccessible, inappropriate, inhumane .....	16
Cumulative impacts of retrogression.....	17
Cuts to community DPPOs and community organisations .....	19
Digital exclusion .....	20
Discrimination in the workplace.....	21
Distress and trauma caused by benefit assessments.....	22
Employment barriers.....	27
Good practice examples.....	28
Inaccessible and unsuitable housing .....	30
Inadequately funded independent living support.....	31
Lack of progress in access to transport.....	33
Mental Health System.....	34
Pandemic access gains.....	35
Poverty.....	37
Social care charging .....	38
Social Care cuts and failings.....	39
Social care recruitment crisis.....	43

Case Study 1: From an email from a live-in social care agency, June 30th 2021.....	45
The burden of Direct Payments.....	47
Unequal right to parenthood.....	48
<b>3. Institutionalisation.....</b>	<b>49</b>
Abuse and restraint.....	49
Forced detention and compulsory treatment.....	50
Medical model.....	51
Mental capacity and deprivation of liberty.....	52
<b>4. Silencing Deaf and Disabled People.....</b>	<b>54</b>
Blocking access to justice.....	54
Engagement with organisations run <i>for</i> not <i>by</i> Deaf and Disabled people.....	55
Failings of the Equality Act 2014 to protect Deaf and Disabled people’s rights.....	57
Lack of UNCRDP implementation.....	58
Restricting right to peaceful protest.....	59
<b>5. Disaster Planning and Humanitarian Emergencies.....</b>	<b>60</b>
Climate change.....	60
Forgetting Deaf and Disabled people.....	60
<b>6. Lives less worthy.....</b>	<b>62</b>
COVID-19 response.....	62
‘Clinically Extremely Vulnerable’ (CEV) List.....	62
Disproportionate deaths.....	63
Educational Disadvantage.....	64
Expendable lives.....	65
Inaccessible environments and transport.....	67
Isolation and distress.....	68
Lack Of Personal Protective Equipment (PPE).....	72
No £20 uplift to legacy benefits.....	72
Reductions in support.....	73
Restricted access to healthcare.....	74

Unlawful use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders and treatment rationing .....	76
Vaccinations .....	77
Unsafety measures .....	78
Where is the interpreter? Lack of clear, accessible information and guidance .....	79
Hostility and feeling the effects of damaging narratives.....	81
Lack of parity in hate crime law .....	84
Serenity Integrated Mentoring (SIM).....	85
The experience of being disbelieved .....	86
Treatment of people with ‘Medically Unexplained Symptoms’ .....	87
Unequal timeframes for pregnancy termination.....	88
Spectrum 10k .....	89
Photos.....	90

# 1. Intersectionality

## Balancing support

“Although I desperately wish to try my best to help my son, juggling my health condition, caring roles and lack of services which are promised but never delivered left me overwhelmed and not able to deal with the huge amount of paper work. Hence the University has got away with discrimination, inequality and abusing my son’s human rights.” D.DP42

“They don’t accept you as a service user and a carer – and many of us are both. That’s been my biggest barrier, especially with a hidden disability.” SR352

“During my breast cancer journey, I was not recognised as a carer for my youngest son and my husband and this had a huge impact on my health, well-being and financial circumstances. I had to work part time as a result.” D.DP42

“X’s son was a child who was in care because she was a parent with hidden disabilities and due to lack of support she could not cope with the impact of the stress which led to the breaking of relationships with her son. She was physically and mentally burnt out as a mother and she had no choice but to put her son in care. He had hidden disabilities and was told only verbally and not in writing that her son had Asperger’s, as a result of this he was not given the support he desperately needed and was misunderstood and excluded in school. He was not statemented or diagnosed as a child. As a result of his vulnerabilities and his hidden disability not recognised, he was unjustly put into prison twice.” D.DP42

“disabled people having to jump through hoops just to access the most basic healthcare but also having to support other disabled people who do not know or are not able to speak up for their rights even though we have limited energy or experiences of trauma ourselves – is so overwhelming – rapidly worse over the past year” FG1

“I suffer immobility and brain issue,... my wife battle cancer already lost bladder, she [my] only carer 24/7. even sleep in lounge ensure I'm safe.” D.DP22

## **Discrimination against Disabled women’s parental and reproductive rights**

“Disabled parents, and in particular disabled mothers in the UK face discrimination within the family courts and the child protection system. Stay Safe East has been supporting disabled mothers who have been victims of domestic abuse since 2010. It has found a consistent pattern with a strong gender bias – abusive fathers are offered support so they can care for their children, non-abusive disabled mothers are refused support and faced with care proceedings and often lose their children. Psychological reports fail to take account of the impact of trauma. We have worked with women who have had four or five children removed and at no time have they been offered appropriate, accessible support that takes account of the different parenting strategies that might be used by disabled mothers. The only option offered to them is the PAUSE programme which is being promoted by many local authorities, and requires participants to ‘voluntarily’ accept a contraceptive implant. One client was told by her social worker she could not have contact with her children unless she agreed to participate in Pause.”

DDPO33

“Most [people with difficulties] whose children are removed from them, receive no post-loss support at all. One of the consequences arising from the anguish and sense of bereavement experienced by these parents, is that parents often go on to have another child to ‘replace’ their lost child and that child is then also removed.” OO8

## **Intersectional harassment and hate crime**

“I have been quite disgusted about lack of understanding about why during the pandemic travelling communities have needed to be in XXXXX if they have family members at X hospital – some of the scapegoating against disabled people may have been ameliorated through the pandemic and Mutual Aid groups but none of that has been passed on to GRT communities.” CBCE10

“Intersectionality used to demonise. Daily Mail on a mega-scale.”  
CBCE6

“Disabled people...experience hate crime a result of a combination of these characteristics. Galop, an organisation which provides support to LGBTQ+ victims of hate crime people carried out the ‘Stop Online Abuse Survey 2016’ and reported how for example: ‘One respondent reported abuse containing disability slurs and pathologising her gender identity as part of her mental health condition.’” DDPO42

## Disability and migration

“English people dont know about us. They think we came here to take. We came just to get better life. We need them to think we are human beings. We came here for a reason. Some of them think we are criminals. Doctors dont help. Lost something in the street that cant get back. cant smile. No life when living on the street.” [person with No Recourse to Public Funds] FG2

“still has no accessible bath tub or shower. The council say that they cannot make it accessible until she gets migration status. In the meantime she has to use the sink.. The house does not belong to the council. So they cannot make it accessible. If she got migration status then she would be moved. So the council pay for a carer to help her wash and for the house but they do not enable her to wash herself. People are benefiting from the lack of access – the carer is being paid, the owner of the house is being paid, so others are benefiting, while she gets less than £6 a day” [person awaiting asylum decision] FG2

“she met another woman in detention who had broken her spinal cord and was still detained for one year and six months” FG2

“when an asylum claim is refused people get no money, no house, no healthcare but may be unable to return to their country of origin” [person whose asylum claim had been refused] FG2

“The lack of transparency about asylum decision making means that many people do not dare to speak out in case it jeopardises the future. no access to information about the asylum claim. Just waiting for years. No power. It is actively disabling.” FG2

“people are only able to bring their family once their asylum claim has been successful. If family members then arrive there is no entitlement to bigger accommodation. One family shares a single bedroom father mother and adult child who has learning difficulties. There is no prospect of getting bigger accommodation because the child is not entitled to it.” FG2

“the operation was cancelled when she was already in the hospital because hospital staff were told that her asylum claim had been refused. This meant that she was not entitled to secondary healthcare. She therefore was sent home, unable to walk, because the operation had been cancelled. She then had no money for food and no means of getting to places of support” [person whose asylum claim has been refused] FG2

“shops want you to use a bankcard but she is only provided with cash from the local authority. Before Covid she went to local drop-in centres for food but many of these have closed because of Covid. She now has 6 pounds a day for everything. at the beginning of Covid buses stopped taking cash. She was therefore not able to travel. The shame of being refused use of the bus she felt like someone seeing your nakedness” [person awaiting asylum decision] FG2

## **Intersectional discrimination in education**

“I remember my mum was advised ‘don't speak your language at home her because it will mess up her English.’ My mum didn't listen, but for many of the people I grew up with, their parents listened. So they only spoke English at home.” DDPO46

“I spoke with three speech and language therapists and a doctor. His speech and language therapist said ‘don't confuse him by sending him to a nursery where they speak Hebrew. It'll delay his language development even further.’ Her boss (an expert in bilingual children) said ‘send him to the Hebrew-language nursery. He'll learn both languages even if it delays him a bit.’ The speech and language therapist at Binoh said that most children with learning disabilities cope fine with a bilingual approach, although some can't. The doctor was of Indian heritage and supported me in sending M to a Hebrew-

language nursery. She said that her parents had refused to teach her what she referred to as ‘my language’ and only spoke English to her, for fear she would find it difficult to assimilate into English life, and that she deeply regretted not being able to communicate with extended family in India.” DDPO46

“I am Nigerian. I grew up in Hackney. At home sometimes I would use my hands. If I tried to do that in school that would not be the norm. For eating. Using that as an example. In the school it could have been I was being naughty, because I chose to use my hands to eat. Those are the kind of what is the norm or what is sort of like seen as [the] norm, understanding different cultures.” DDPO46

“If you look at some of the issue[s] that still continue to impact on children from Caribbean and African families. For example, children are not supposed to look at elders in the eyes when they are speaking with each other. Children apply this practice at school. Some schools consider this behaviour as being naughty or the child doesn’t understand instructions/conversation, etc.” DDPO46

“I have been denied an interpreter as Social Worker doesn't think child wants to speak our native NZ language and they are going to compromise and put a poster up at school of Maori words instead. Only daughter can't read and no one else at school speaks this language.” D.DP5

## Multiple Discrimination

“I don’t see much evidence about multiple discrimination being tackled. There’s a lot of talk about people being racist, but otherwise no.” DDPO29

“I’m black, disabled, male and a long-term user of mental health services. I’d be perceived as a triple threat. I have three identities. I go in as a mental health service user, so I have to drop my race, my disability - I’m in a wheelchair. Although we talk about being a whole person, that’s not what we receive. We are seen through the lens of siloed thinking. There are massive implications of this for mental wellbeing. You have to see the whole person.” DDPO29

“People also don’t understand that we’re also fluid in our identities’. That adds issues.” DDPO9

## **Violence and abuse against women and girls**

“in 2021, Stay Safe East evidenced the pressing need for a strategy on violence against disabled women and girls (VAWG), the disproportionately high levels of abuse against disabled girls and women and the multiple forms of discrimination experienced when seeking safety, justice or recovery. The published VAWG strategy , whilst recognising some aspects of violence against disabled women, failed to identify any specific actions to address those issues . nor does it recognise the intersectional aspects of violence against a significant percentage of disabled women and girls.” DDPO33

“failure to include any significant outcomes regarding Deaf and disabled women in the Violence Against Women and Girls Strategy, where this group is marginalised from the category of ‘woman’ and restricted to the category of ‘disabled’ through the claim that all disabled women’s needs will be met in the upcoming National Disability Strategy.” DDPO33

“We have also witnessed a distinct failure to inspect Assessment and Treatment Units (ATUs) which means that disabled women, who are often survivors of abuse, are essentially abandoned in ATUs run by private companies, unmonitored. The increased risk of abuse in these cases is especially alarming considering the fact that the average length of time people spend in ATUs is more than 5.5 years , despite their alleged purpose being for short-term stays.” DDPO33

“We are discriminated against [within the benefits system] on the basis that looking after children means we must be fit for work, or our caring disproves that we have support needs ourselves.” DDPO37

“When women are raped on psychiatric wards, it’s not reported. You don’t want to cause trouble, because, if you do, things will be worse for you.” DDPO29

## 2. Continued retrogression

### Barriers to education

“The non-speaking kids were dragged around and restrained – tiny Year Fours being pinned down by massive security guards. I did do whistle-blowing for that but I heard nothing about it. [Mainstream] schools I think are better in my experience for Disabled young people because at least they are around other young people who will advocate them if they need to... it’s pupils without support who are targeted for exclusion. It’s got a lot worse over the past five years and I have taught in a lot of schools in [the region]. There is a lack of accessibility but then if a pupil is seen as needing extra accommodations or needing more work then management starts to target them. There is a complete misunderstanding of what being autistic is. I have seen them not allowed noise cancelling headphones or baseball caps for light and they are expected to act as perfectly neurotypical and if they can’t they are labelled as problems. I have seen this hundreds of times. Support has been cut so many times there is literally nothing for them. There are no school counsellors or anymore and the kids have no one to speak to at all.” CBCE10

“[My son] was devastated as not only was he prevented from continuing with his Adult Nursing Degree, but he used all his savings earned from his apprenticeship, to pay the fees for a service from the University which was not adequately delivered and there was a breach of contract as his Needs Assessment was not adequately adhered to. [He] is a young man who was working hard in hospitals, helping and supporting people... but after this unjust negative experience at University he is questioning if he can even do the smallest task properly.” D.DP42

“My child needed full time support and when they didn't have it, school became impossible and they were only allowed in for an hour a day, which was very traumatic to take them there for that and interesting at the time, they were isolated in a room on their own, or with the support worker, or in a corridor, not doing anything that anyone else in the class was doing... I don't know why I kept taking

him in for that, at that point my son was absconding, destroying furniture, attacking me when he got home. He was so distressed.”  
DDPO46

“Are children are more excluded from school more units built to keep are children separated from,ther mainstream peers” SR285

“segregated provision for my own child was entirely a result of poor practices in mainstream schools. We had no choice in the end but to go for this. Local authorities could do a lot more to hold schools to account – but even if they did, so many schools are no longer under local authority control, this would be difficult.” DDPO46

“Post 16 there are no options. For us, a special school seems to be the best choice available.” DDPO46

“Generally, education is not set up for having big electric wheelchairs and walkers in mainstream school.” DDPO46

“My child attended mainstream school and the long-term trauma he experienced will impact him for a long time. He is now attending a special needs provision that is designed for his needs. I feel there needs to be better understanding and collaboration with professionals, parents, carers, and young people to meet needs and more accountability when this is not working and when schools, health, social care, and transport are in breach of human rights.”  
DDPO46

“His breaches of the rules seem fairly minor but there was an accumulative effect – wearing socks that were the wrong colour, eating food in an area of the school where it was banned and ‘gross defiance’ against staff... In the end he was excluded seven times in total, on the final occasion for five days... After a two-day hearing, a judgment issued last month criticised the school for applying its behaviour policy rigidly and failing to make reasonable adjustments for Hayden because of his disability.” DDPO46

“The feeling I get is that they don’t really understand that inclusion goes beyond accepting disabled children. It means changing the way the schools function, across the board, so that disabled children aren’t singled out or marginalised. Inclusion can’t be bolted on but

needs to be built-in to everything that happens throughout the day. That's going to need deep commitment from school leaders and from teacher trainers." DDPO46

"Many local authorities do not always feel a child's needs can be met in a mainstream school" DDPO46

"So what they were saying was that my son's budget for autism, if it was going to be that much care, if he was going to need full time support, instead he would need to go somewhere special." DDPO46

"Examples of students who had packages before being denied on reapplication, and personal costs being chased up." FG1

"meant to have [an interpreter] for group work in college but that didn't always happen – at start of course not in place so had to wait... took ages for college to get back to me and could I start the course. Finally I went and the interpreter came... and the teacher had said you know this may not be suitable for you and I felt I was being discriminated against, I felt my confidence was lost, made to feel I was not good enough, so I went to a different college and I started to do IT – gave up my dream of the design course and I went and I did an IT course" FG6

"N recently enrolled on to a level 2 English course as at an adult learning college in Halifax, she was first told that there would be a BSL interpreter that they would provide and pay for, as there was another student in the class that needed BSL, this was then taken away when the other student left the class. N was told they didn't think they could find another interpreter to assist, so Nadia found one herself for the college to use and pay for. After a few weeks of attending N and her mother were called in for a meeting which they believed was to discuss how they could assist N further in her education, but it was actually a meeting to advise that the college wouldn't be able to pay for a BSL interpreter or the additional support that N needed in class. The college also told N that she would need to go down by two groups, because they believed that her English was not at level 2, despite completing English level 1 and recently being assessed to confirm which level she should be at.

Nadia also found that her teacher was impatient and not helpful.”  
CBCE4

“Experienced discrimination by other students regarding the support she received” CBCE7

“My disabled son has no identity outside of his disabilities (in the eyes of others). Positive futures are not imagined, individual preferences and choices neither sought, recognised, nor valued.”  
DDPO46

“Educational needs of children are being ignored; they are told they are stupid or lying. Parents are threatened or abused.” CBCE8

“Disabled people have no choice but are forced to have special education. Not inclusive. Schools are not built for disabled children.”  
CBCE8

“There is no accountability. There is under-funding, children are being excluded because their needs are not being met. The government wants special schools and not mainstream, accessible education.” CBCE8

“university official told S she would be unable to become a teacher and undertake the workload. S left due to the (unsupported) workload and did teach. Also experienced other students who expressed S would “not be pulling her weight”. This was left unchallenged by the tutor.” CBCE7

## **Barriers to healthcare**

“Experience of being a disabled person in hospital – not being given the same care as non-disabled people. They were not treated equally, but also, things that would have helped, like having carers in before visiting hours, was not allowed. Carer hours did not fit around visiting hours so the only time they could leave the ward was when a friend (who was able to push a wheelchair) could take them out.”  
CBCE31

“X has a history of an eating disorder and even though this was unrelated to the issue they were in hospital for, this history really

skewed the way they were treated. They were seen as a ‘pain’ and made to feel like a ‘pain’. They don’t believe that would have been the case if they didn’t have that history.” CBCE31

“You can’t criticise NHS because it’s a national treasure. In terms of sickness/physical health it’s great but in terms of neurodiversity, spirituality, mental health they don’t have a clue. It’s overwhelming that people can see you suicidal, depressed off your medication and not do anything immediately.” CBCE24

“Certain diagnoses and histories impact on how people have been treated, or been refused treatment” CBCE31

“Funding cuts in NHS services seen a reduction in access to things like physio and hydrotherapy, reduction in ability to access to mental health services nothing really targeted at the chronically ill apart from cbt which I consider damaging” SR51

“Expensive treatments were now being refused and peoples’ health issues were not being dealt with properly.” CBCE33

“being a woman and also being young has had a significant impact on how seriously X has been treated by doctors, even female doctors. Before an endometriosis diagnosis, they had a 6 month period, bleeding non-stop for 6 months, but it was difficult to get a medical professional to take that seriously. There’s so much sexism in medicine” CBCE31

“Medical gaslighting was identified as a real problem – changing the tone of ‘why are you experiencing this’ to ‘you are not experiencing this’ because things can be very difficult to diagnose. The dismissal of people’s lived experience of their own bodies is a big problem.” CBCE31

“growing up in a rural area, the notion that healthcare should be accessible everywhere is absolutely laughable. Austerity has completely decimated healthcare around here: two hospitals closed, one A&E closed.” CBCE31

“As my physical disability is degenerative the access to medical support has worsened. Every 2 years the GP’s leave so there is no

continuity of care. The situation has worsened since my GP was taken over by an American private health company. I can empathise with the GP's leaving as their well being is compromised. You can see and sense how unhappy they are" SR19

## **Criminal Justice System – inaccessible, inappropriate, inhumane**

"I had hospital admissions in September 2003 and again in 2009 (3 sections) after unnecessary interrogations by Essex Police who sent me to the top of a carpark ready to end my life. They ignored my request for a doctor. They failed to follow their own procedures." D.DP8

"People had had traumatic experiences with the police e.g. distress caused by handcuffing, having a knee on their neck in A&E, being dragged down a corridor. Police are the first call when someone is in distress but they do not have the training or empathy to respond." CBCE24

"disabled prisoners also need support" CBCE7

"Access to justice, in particular being disabled in prison is an awful experience. Those in wheelchairs are often restricted to their cells, those with limited or no vision are often left to identify a suitable 'carer' and access to appropriate medication and community hospitals is problematic in favour of prison security and a lack of staff." SR250

"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?" SR250

"Police forces lack training in how to properly communicate with Deaf and disabled people. Training that exists is often short and infrequent, with very little chance for updating knowledge." DDPO33

"[disability hate crime] area of horror. Real and appalling; police not interested." CBCE8

“disabled clients are unwilling to report domestic abuse to the police not only because they have no confidence that this will keep them safe but because they fear that their Black partner will end up dead in a police cell, as had happened to a substantial number of Black men, most of whom had mental health issues.” DDPO33

“The justice system in England does not adequately support disabled people to fully engage in the justice process and many barriers exist beyond those mentioned above. More disabled people would benefit from the use of intermediaries in court and advocates throughout the entire justice process to fully ensure both their participation and that their rights are properly upheld. However, despite these roles existing, they are not frequently or consistently utilised by the police, the Crown Prosecution Service, or the courts.” DDPO33

“Accessing courthouses in Britain is extremely difficult for disabled people . The number of police stations has decreased significantly in recent years, and those that remain are not all accessible to people with mobility impairments, and often lack information in accessible formats, such as Easy Read or Braille. Unless advance notice is given, it can be difficult e to ensure that BSL interpreters, ‘appropriate adults’, and intermediaries are available, which impedes ability to report crimes such as abuse, violence, and sexual assault and to get justice. Additionally, it is currently legally permissible for the police to interview Deaf and disabled people without ‘appropriate adults’ or interpreters if delays would “result in harm to people, property or evidence.” DDPO33

“how many routine or key court information leaflets... are available in Easy Read? [We] wrote over 2 years ago to the Home Office asking for a copy of “Sarah’s Law” leaflet in Easy Read. We have yet to receive it, despite occasional reminders.” OO8

## **Cumulative impacts of retrogression**

“It feels like a constant attack. Getting back to normal agenda is about getting back to taking away things that help disabled people eg public toilets, pavements.” CBCE6

“Spending your whole time trying to get your basic needs met makes you ill-er.” FG1

“The future looks dark and desperate.” SR101

“I am too ill and tired and exhausted to be able to join in with protests against all these things that are wrong even though I want to.” FG3

“I find keeping going so exhausting that I make mistakes and forget things and then end up in debt. For example, I had a hospital appointment that my husband drove me to and I forgot to sort the Congestion Charge out so we got a fine that we can't pay and the bailiffs came round last week. They were so hostile to my husband the way they treated him. I have three jobs – I had four at one point.”FG3

“Having to prove again and again that you are disabled is such hard work, always having to collect the evidence and GPs charging for the evidence. I have to do my Blue Badge again but I keep forgetting. And with everything it's up to you chase up each person – chase up this one and chase up that one. Especially with hidden impairments you have to prove again and again. I have lost hope.” FG3

“Financial and social support (including benefits), underfunded services, making ends meet and getting support is harder than ever, mental health, recklessness towards our human rights - it feels like it's more of a battle than ever to stay well and stay alive, and often that fight is with the state and statutory services.” SR24

“We are more excluded than ever. I'm struggling financially, emotionally, physically and mentally. We are treated like 3rd class citizens.” SR36

“Every person I've met who struggles with disabilities can attest that the lack of proper services available exacerbates their problems.” SR121

“Everything access to public services, health, food, work, social care, family life, leisure, daily life, democracy, justice - everything that was

already sliding away in terms of quality of life and equality of experiences and expectations is now moving away at speed.” SR219

“No access or little access to appropriate health care, no access or in appropriate access to social services, nearly died because of covid, now pay for all health care in particular mental health care as the nhs has completely broken and I have had to make official complaints, which they don't take seriously because they are relying on me not being able to. Afford legal advice, and to be honest I'm just not well enough to do anything about it. I am no longer doing any paid work, I was doing permitted work under ESA regulations before the pandemic. I no longer volunteer I'm. Too tired from long covid. If I have the vaccination I might have more health problems and I don't have anyone to look after me so I am mostly staying at home. I am really isolated, so are a lot of my disabled friends. I am finding hard to travel long distances on public transport. I don't really have much to hope for in the future. If I think about it too much I get really depressed. I am trapped.” SR298

“People with Autism are unemployed or underemployed. DLA has been replaced with PIP. Low income people affected by high inflation. Lack of hope that things will change. Effects of the Government's response to Covid.” SR28

“I personally do not feel discriminated against or forgotten Things are moving forward not backwards” SR90

## **Cuts to community DPPOs and community organisations**

“People generally felt the Government didn't listen to their voices and that vital Self Advocacy projects to help to protect people's rights and disabled persons user led organisations that support people to come together as a community were closing and not being properly funded” CBCE28

“Funding for independent advocacy cut.” FG1

“Loss of disabled people's community organisations” SR324

“Even when you know your rights it is difficult to get them met and there is no advocacy available to use especially as many DDPOs have lost funding.” CBCE32

“Not enough people are informed enough about their rights. Local Disabled People’s Organisations that used to provide this service have all closed or have too little capacity” FG1

## Digital exclusion

“Now everything is online [Council] staff are refusing to call or leave Voice Notes. Someone from the Council could call but they won’t. Information is online but [my friend] has only recently lost her sight and can’t get support to learn how to access information online. It’s really nasty.” CBCE10

“Digital exclusion – a lot of health, social care and housing information and systems going online.”CBCE27

“A lot went online without phone numbers” CBCE8

“I think it’s a direct tactic – you drive down the needs when people don’t know what their rights are. I think it’s got worse over the past five years. I think it’s intentional over ignorance. Since being a County Councillor and assuming they want to do the right thing and then finding out the worst, I am convinced it’s a tactic they do use. If they can’t find it, they won’t ask for it.” CBCE10

“Huge pockets of poverty and rural deprivation where tech doesn’t exist” CBCE10

“My mum and dad both have learning disabilities as does my younger brother... Information from school comes through the internet. My mum and dad can’t use the computer and wouldn’t really be able to read it anyway. If my teachers had really understood what my life is like, I think I would have had better support and achieved more.” OO8

“People without access are those most in poverty who don’t have digital access.” CBCE6

“In my work as a Community Engagement Officer I worked with elderly and disabled people over the lockdown who would usually go to day centres so they weren’t isolated but many could not use or have access to the technology. So much is online now, for example the GPs.” FG3

“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.” SR107

## **Discrimination in the workplace**

“Furlough made it easier to get rid of disabled staff who were struggling due to lack of reasonable adjustments.” CBCE10

“Worked for the NHS for 12 years – became unwell and had a supportive team. However, a new manager questioned her ability to travel for the role – X resigned and has been unable to work after COVID. Advised by trade union to challenge the disability discrimination. Feels that people are allowed to get away with disability discrimination.” CBCE7

“I think it is more different for people with hidden impairments... But people at work don’t see all these. I am expected to do a lot of over-time. I get bullied at work and go home really upset. It brings my blood pressure up and had to have stress leave. There is no sympathy for me as a disabled person. I get laughed at more. And this you have to understand is in the NHS. I work for the NHS. I get mocked for always having something wrong with me and being off sick and management don’t understand. I have a colleague with Crohns disease and she was told she was not allowed to use the toilet except on official breaks.” FG3

“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.” SR206

## **Distress and trauma caused by benefit assessments**

“We supported a refugee woman who survived genocide and being shot, who needed to be spared the WCA interview where you have to go over what happened to you. The assessor company, the Centre for Health and Disability Assessments (CHDA) — Maximus — dismissed as insufficient, a letter from the clinical physiotherapist referring her to the Pain Clinic and verifying shrapnel in her body from surviving a bomb blast. An in-depth report on her trauma from the PTSD lead doctor at the local hospital was similarly discounted. The doctor complained to Maximus that she is called as an expert witness in court cases and her professional opinion had never been dismissed before. After intensive advocacy, we were able to secure exemption from interview.” DDPO37

“The assessor companies pressure women and girls to undergo interviews when this is too stressful and many want a paper-based assessment. Medical evidence by doctors much more qualified than the assessor (who can be a physio or ambulance man) is often dismissed. Often, assessors only make a token effort to reach doctors and practitioners for their opinion to accompany the paper assessment. Hence they often don’t reach them and make decisions based on ignorance and bias.” DDPO37

“I had to pay a NHS practitioner privately for a report to support my benefits claim - I was no longer part of her clinic, but needed her written report. 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).” SR214

“processes for assessing someone’s welfare benefit entitlements are intensive, require significant investment of time, and can be very distressing; for Simon, this is often the cause of extreme distress in advance of an assessment, when assessment paperwork arrives,

when seeking clinical and professional evidence, when being reassessed and whilst waiting to receive the outcome. This happens once every 18 months and attributed distress can last around 6 months. Although there are times when Simon experiences less distress, his ASC and ADHD are permanent conditions for which he cannot receive appropriate care. The disability benefits review processes convey a systemic lack of understanding of the nature of ASC, the life changing impact it has on someone's ability to work." D.DP35

"Assessors had not read the forms already submitted so did not know the full extent of their medical conditions and asked invasive and inappropriate questions that left them feeling embarrassed and depressed about their personal situations." CBCE11

"application process for ESA and PIP completely degrading and creating further vulnerabilities and mental health issues" SR51

"Attendees felt it is too difficult to get any help and support and that they had to 'jump through many hoops' and it shouldn't be that difficult. They felt it was deliberately designed to put disabled people off applying for benefits / social care or other support because it is so difficult, many disabled people give up as they cannot 'fight' anymore or suffer with their mental health because of the assessment." CBCE11

"I have done this more than once but nothing changes so I will no longer waste my time raking up how awful anything to do with [Department for Work and Pensions] is, it is too distressing" D.DP37

"There are so many bureaucracies that you must go through to get any help. Do they think you are in a wheelchair for a laugh. I was asked if I could walk 50 metres, I am visually impaired so how do I know how far that is". CBCE11

"National Federation of Blind access to support or mobility and skills training: squeezed out of social care. Far fewer people working here and negative impact on lives." CBCE8

"any form of rehabilitation under severe pressure" CBCE8

“Appalling that disabled people have to pay for letters to confirm our medical conditions.” FG1

“I am not sure if my experiences can help at all but I feel compelled to so that things can hopefully change... The 'nurse' they had doing the interview (ATOS) tried leading questions nearly all the time but the worst part of that interview was being asked to explain all my previous suicide attempts. (I have CPTSD from an abusive childhood mainly but adulthood was also... fraught) she had me explain each and WHY they failed. Going into detail of what I tried, when and why... finally when I had detailed each attempt she hit me with "Do you really think you were that depressed though?" I was confused... I had just detailed several attempts to take my own life... she followed up with "I mean if you had really been depressed and wanted too you would have succeeded!" She pretty much told me that I failed at living and also that I failed at dying. On top of all the things in that interview I had to painfully admit I couldn't do she made me feel like absolute crap for not doing society the favour of ridding myself from it... I have now lost PIP altogether because due to these experiences its actually become a fresh new trauma trigger for me... that undid a lot of progress made in therapy and still has implications even now” D.DP5

“Ms A, who has PTSD from abuse, agoraphobia and serious physical health conditions, has suffered repeated stressful reassessments and being wrongly cut off multiple times.” DDPO37

“people are being put through unnecessary trauma to claim their benefits.” CBCE28

“the process to the tribunal feels like being criminalized. The process has exacerbated current health conditions and M developed rheumatoid arthritis.” CBCE7

“I am working with clients who have moved from DLA to PIP and gone from being on FULL DLA to zero PIP. Trying to get DWP to give the right amount of benefit.” CBCE8

“My son has autism. He cannot cope with the online ESA process; then questions. Received £150 compensation after complaining;

process not accessible; assumes everyone can do it; does not give correct information.” CBCE8

“Ms C is aged 17 and her mother applied for PIP on her behalf after it was suggested by Great Ormond St Hospital. She was asked to travel to a face-to-face assessment by IAS despite her PTSD, physical disabilities and having had COVID three times due to low immunity. IAS eventually agreed to a paper-based assessment in November 2021. However, the DWP decision-maker (DM) seemed to seize on minor improvements against a background of Ms C being severely incapacitated by her immune system illness and after being hospitalised. She was refused PIP, the DM scoring her only a handful of points, saying there was no evidence of need. The doctors treating Ms C are horrified and said they had not been contacted for their opinion. Ms C’s mother has put in for mandatory reconsideration and meanwhile is skipping meals and using her own PIP to pay for her daughter’s disability expenses. She says: “. . . the whole year that passed after an application was made has been a nightmare for us”. DDPO37

“J, a severely disabled woman in the East Midlands was cut off benefit for “failure to attend” a home visit. The appointment times allocated by Capita were before she could get herself ready in the morning. She told us that the CAB said nothing could be done and made her feel bad that it was her own fault. She had gone over the age to make a fresh PIP claim, and Attendance Allowance for older people has no mobility component. She lost the first-tier tribunal which upheld the “failure to attend”, which she could not go to as it was in another town and she is virtually housebound. With help from the CPAG Upper Tribunal Project, we made a disability case about her ill-health to the Upper Tribunal judge as to why her appeal should be heard late. She was granted £10,500 arrears and ongoing PIP benefit.” DDPO37

“R is a Disabled Asian woman with cancer in XXXXXXXX, she found WinVisible online after a bad experience with advice locally. She had been similarly cut off by the DWP after problems with Capita, and due to illness she struggled to submit her appeal papers. These arrived to the tribunal one day after deadline, and the clerk said they would have to consider whether to accept her appeal. We couldn’t

tolerate uncertainty or her waiting ages for appeal, and we contacted the DWP directly. She got £11,500 in PIP and severe disability premium payments. She said: “While some of the benefits staff were kind, most couldn’t care less. I was close to a complete breakdown, and if it weren’t for [WinVisible’s] help, I don’t know how I would have survived.” R was cruelly cut off when she needed benefits the most. We don’t know whether racism was a factor as well as sexism and disability discrimination, as officials often assume women are exaggerating illnesses. Being labelled unco-operative and cut off for ‘failure to attend’ interviews when we are ill, in mental distress or in hospital treatment is a huge problem.” DDPO37

“S had to give up waged work. With an invisible disability, her interview for disability addition to Universal Credit was deemed ‘inconclusive’ and she was told she had to wait until face-to-face interviews restarted. She was bounced between DWP Universal Credit, the assessors Maximus, and her GP who declined to provide more medical evidence. We used welfare rights guidance to challenge unreasonable delay and she won £4,000 arrears. She said: “Thankfully after what felt like a never-ending nightmare, I have finally got what I had been entitled to. I feel so relieved that I can now afford the diet that I should have been on, I can focus on my health and my children without Jobcentre breathing down my neck about being sanctioned, me having to keep asking for sick notes from my GP and them pushing me to go back to work. I would like to continue with WinVisible support group to help others in any way that I can from my own personal experiences.” DDPO37

“I am a member of a Facebook group for PIP claimants and when I read all these stories from people who are bed bound being asked to go to assessment centres, I realise how lucky I am. Several people in this group have been bed bound for years and the DWP hounds them to go to assessment centres.” FG3

“My friend’s husband was found fit for work even though he had a heart problem. So he went back to work and about an hour after arriving he collapsed and died. That was about 2018.” FG3

## Employment barriers

“I tried really hard, worked so hard for it and I felt the job centre really weren’t that interested in me, .... You have to show evidence you are making an effort to find a job and I felt really let down by the system. Sometimes Deaf people are shoved aside. I’ve had enough of it really. The job centre in particular I think... It’s about setting up systems so Deaf people can have interpreters when we need them. Without them we become stuck, we are held back in life... I think for Deaf people there is so much discrimination it is hard to come back after those knocks, especially when you are looking for employment, it is a hard thing. I feel like I am down here and all the jobs are up here. I have a brother and he has a job, he has had a good education, he has had a lot more chances than me because he is hearing and he hasn’t had the same barriers to education and access to information and he manages to get jobs...a real inequality between myself and my sibling.” FG6

“My experience with a lot of Deaf people has been that they give up their jobs because of the communication barriers/language barriers at work. We encourage Deaf people to have their dreams but it doesn’t become a reality for them because of the barriers that they face.” FG6

In the 1990s there was work going on where Deaf people were advising jobcentres on how to be more inclusive. It’s like it’s gone backwards. Why do we have to keep fighting? It’s really worn us out.” FG6

“It is ironic that the system and process implemented to support and accommodate disabled people [Access to Work] into work is unsupportive” CBCE7

“In large public organisations, staff with disabilities are bullied and do not get the accommodations they need to do their job successfully.” SR133

“A staff member she managed found the Access to work process mortifying and difficult, with significant barriers including time delays, bureaucracy, unclear expectations on the sourcing and delivery of equipment” CBCE7

“You have to fight for [Access to Work] – lots of people have quit; many people don’t have the support mechanisms or resources - very damaging to health” CBCE7

“Employers are more frugal now – everything is about money even for needs that were not a problem before to meet.” FG1

“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. The equalities officer did negotiate reasonable adjustments for mandatory training. It's the enormity of it, everything is a battle.” SR324

“Employment tribunals - 3 months and one day is far too short a time and is a timeframe that can be impossible for people to meet in a number of circumstances, for example if they are hospitalised or having a breakdown – putting all their energy into surviving with none to spare at that time to take a case.” FG5

“I think things are definitely getting worse. When I had a work station assessment at work this time round, I had a massive battle to get the equipment I need. They argued that because I only work at this job one day a week I can hot desk. I challenged the outcome of the assessment and was ignored. So I referred myself to Occupational Health and they bought me a chair and a footstool and the equipment I needed.” FG3

“employment situation has improved I believe” SR225

## **Good practice examples**

“We are working closely with our allies in the Greater Manchester Coalition of Disabled People and the Greater Manchester Mayor’s Disabled People’s Panel to organise regionally across local authority and unitary authority boundaries in order to maximise DDPO knowledge and expertise-sharing, and our collective campaigning capacity.” DDPO7

“Oliver McGowan report: mandatory training of staff in LD and autism. A pilot in South Gloucestershire was well produced. Example of good practice.” DDPO7

“Greenwich delivered PPE to all shielding Direct Payment users in the Borough despite poor Gov guidance.” SR326

“Haringey has opened up a few new services (Disability Action Haringey and Actually Haringey) which help people directly and are run by disabled people.” SR123

“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” SR91

“My local council has been brilliant with free or reduced cost activities, or swimming and exercise sessions.” SR209

“The sunflower scheme is helping to raise awareness of invisible disabilities” SR214

“PBH (Personal Health Budgets) were introduced giving people more control of what they need” SR29

“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.” SR214

“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.” SR74

“Contactless payment £100” SR90

“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.” SR99

“Hammersmith and Fulham Council on co-production 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.” SR331

“Oliver McGowan learning disability and autism for all healthcare staff” SR334

“In Leeds uk are doing some very good work for people and whoever looks after them with learning disabilities and autism and their carer” SR334

“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.” SR258

## **Inaccessible and unsuitable housing**

“I know someone in [xxxx] and they are the carer for their brother and they have been in a flat that is not only inaccessible but also bad for them and there is no way to get anyone to listen that they have rights.” CBCE10

“I became disabled through illness in March 2019, effectively becoming housebound in a rented flatshare in Camden as I could no longer climb the stairs. I was admitted to hospital in May 2019, and filled in a homeless application via Camden council in July 2019. In September 2019 I was essentially forced to accept unsuitable temporary housing upon being discharged from hospital, where I was trapped due to inaccessibility for two years, where I was not able to access the bathroom. D.DP28

“When he came out of hospital he was put in a nursing home for older people and people in palliative care. It was very bad for mental health” FG2

“People also felt that they have less choice about where they live due to shortages in housing” CBCE28

“[my son] has been "prescribed" adaptations to this house to make it safe for him to use his wheelchair and enable him to get out, but the landlord, council and support agencies have made this impossible and refused to follow the law. The injuries my son received from his fall were never treated and although the broken bones have healed he can no longer use his hand properly or walk safely. When I began complaining about this my Landlord "punished us" by first trying to evict us and make us both 'street' homeless and then by cutting off my heating and hot water completely.” SR107

“there are still problems with accessible housing – still battling with the Local Authority who are unhelpful about damp” CBCE7

“Lack of social housing. Disabled young people having to live in care homes for the elderly because no accessible accommodation.” FG1

“[local authority] thousands wasted on adaptations to improve life, still years on forced live in cell 11x11ft, the misuse grant monies was beyond belief,... Basic the company used to make wet room safe follow fall, failed,... but then the massive issue's began, electric wire's left bare...rat infestation... sleep in lounge” D.DP22

“This argument between [the Council] and me went on for nearly 3 years... I then decided to use my student finance allowance to help... All this time the water was still gushing and coming through the floors boards in the kitchen making it perilous to enter for an abled bodied person let alone someone who is unsteady on his feet and prone to falling down...because of the stress that he was under and the constant high [Blood Pressure] that he was having for several years (even prior to the water gushing under the floor boards in the kitchen) that he had a stroke.” O11

## **Inadequately funded independent living support**

“I know someone whose son died who had Down’s Syndrome. He had to take laxatives on a regular basis and avoid certain foods due to his intestinal problem and that poor man died with 25lbs of faeces in his intestinal tract because it ended up rupturing and that was

because there was no one making sure he took his medication on time. They didn't want him to live in a care home setting so he was in supported housing and he enjoyed the freedom but should also have been getting the support." CBCE10

RB is a young adult who attended a specialist school until the age of 16. They had a series of subsequent placements in supported living accommodation, all of which broke down due to ongoing behavioural and addiction issues which were not adequately addressed by their funded level of care. We raised safeguarding concerns with the local authority. Their response was that RB had capacity to make unwise decisions. RB eventually became homeless, despite desperate attempts by their mother to secure further support to safeguard them. Living on the streets, RB became target for local drug gangs. We supported RB to secure urgent council accommodation pending further needs assessments under the Care Act 2014. We raised multiple safeguarding concerns with the local authority about the urgent nature of risk to RB. The local authority did not put in place adequate interim support pending assessment, and RB again fell victim to local drug gangs and "mate crime". RB became suicidal, making attempts on their life. RB was eventually admitted to hospital." OO1

L is a young adult with Downs Syndrome and learning disability who used to attend a day opportunity for 3 full days per week. He lives in residential care. L has recently been told that the day opportunity cannot meet his continence needs without 1:1 support to assist him. Requests from L's family to the local authority for appropriate support to continue to meet L's needs during the day have not been responded to. L's four friends, whom he lives with, continue to travel to the day opportunity but L has to stay at his care home. He does not have additional 1:1 support to leave the care home to explore any other community-based activity. He is unable to leave his care home Monday to Friday. We are currently advising L on a range of rights, including his right to liberty. OO1

T, a 36-year-old man, lived in a London Borough receiving care and support in his supported living accommodation. Towards the end of 2019, his needs for care and support increased when his mother died. The funding panel turned down his social worker's application

for additional hours to meet his increased need. The situation spiralled and T was admitted to hospital following self-harming. He lost his accommodation. On discharge from his local hospital ward, he was allocated council accommodation and offered a limited and inadequate number of 'outreach' hours to help him go shopping every week. His council accommodation was a basement flat within a larger block, and only had one very small window in the bathroom which did not open properly. T was not supported adequately, and regularly urinated over his home, was not able to clean effectively and lived in squalor by the time he was referred to us. He urgently required an uplift in care and support, which had it been implemented in 2019, would have avoided significant inhuman and degrading treatment." OO1

## **Lack of progress in access to transport**

"trains cause huge travel anxiety, as wheelchair users are getting left on trains. We felt this was linked to stereotypes about disabled people not having work to get to, or having more time so if their time is wasted it doesn't matter – things that would be unthinkable for non-disabled people. There needs to be some real work around this to make progress." CBCE31

"Our local bus service First York have been clear that they will not install audio-visual systems into their buses until they have new buses which they cannot currently afford." CBCE31

"Accessible Public transport reduced" SR274

"Lack of truly disabled and deaf friendly public transport" SR314

"Another participant leaves so much extra time which means travel takes double or triple the time that it does for non-disabled people. They had an experience of needing help to get on and off a train to the airport. The lift in York was broken but they were not told or supported until they asked for assistance. They finally managed to get onto the train. At the other end they were thankfully getting off at the end of the line. Nobody came to get them off the train, they couldn't raise any alarm and it was only when the cleaners came to the carriage that they were able to get off the train. Even after

allowing for these things to happen, they still nearly missed their flight on that occasion. It is very disempowering and incredibly stressful if they are using public transport alone. If they have a carer or friend with them, they can jump off the train to get help, but if they are on their own, they can't do that, so they have no power in this instance." CBCE31

"Accessibility of public transport and spaces has improved overall, but there are still significant gaps and failings" SR159

## **Mental Health System**

"The psychological recovery of survivors is certainly not ensured when examining the lack of timely therapeutic services available, which has been brought more sharply into view in post-pandemic numbers, with 2021 figures showing that 21% of patients have waited longer than six months for treatment. From the experience of DDPOs working with clients navigating the psychiatric system, the pattern seems to be that the first port of call, regardless of what the patient is presenting with, is a short course of Cognitive Behavioural Therapy (CBT). Not only is this hugely inappropriate for patients presenting with Complex PTSD or other trauma from domestic or other abuse, but having to try CBT first delays joining the lengthy waiting list for trauma-informed care, constituting a lack of appropriate measures to promote [their] psychological recovery." DDPO33

"I have been suicidal for over two months but was not given any support when I was discharged from the psychiatric hospital" SR72

"more mental health services are needed. [Child and Adolescent Mental Health Services] is not fit for use. it is a waste of nhs money/resources because it does more harm than good" SR131

"Mental health waiting times have got a lot worse." FG1

"I go from panic to manic to mania - the mania made me try to end it all back in July but i recovered after five days in hospital. I came home and none of the services helped me. I live alone." D.DP7

"There should be choices of non-medical intervention." CBCE24

“1. losing services that provided excellent support in the name of so called "transformation" 2. services discharging patients or providing only a short term intervention for longstanding, complex needs 3. no on-ward support in the community is provided when discharged 4. services are not trauma-informed and the medical model of mental health is prevalent meaning people are prescribed psychiatric drugs instead of being offered a talking therapy” SR199

“Mental health support especially, doctors refer people to charity groups for support, even if those people are on the verge of suicide.” SR121

“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.” SR303

“Participants were members of the Hearing Voices Network which has more advanced outlook than talking services in NHS and come from lived experience. Also an ambassador for Hope Street which does things like social prescribing – things like chats, crafts, choir, and a support network, also part of a Spiritual Crisis Circle. All these things work better than the mental health system AND it is cheaper to socially prescribe than medicate.” CBCE24

“Psychiatry in general is causing more harm than any benefit to many people, especially the way that psychiatrists and other ‘professionals’ can label people with diagnoses based on very brief consultations - and patients have no right of appeal.” SR351

## **Pandemic access gains**

“I have been pleased that doctors have moved to phone and video appointments – inaccessible for some – but has been beneficial for me so I don’t have to commute all the way to the hospital and the staff seem keen to keep it as well. This could be a real positive if it is made more accessible for those that need.” CBCE10

“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.” SR351

“When everyone had to work at home, disabled people were leading because we are very good at finding solutions to problems. Work being able to be done online and people not being dragged to places commuting for short meetings and even on-disabled people are seeing that having to go into the office for a short meeting is a waste of time. So I’m hoping this is a gain we can keep – it won’t be for disability reasons but maybe something we can benefit from!” CBCE10

“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.” SR18

“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. 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” SR214

“Remote access to events dropped when lock down ends” SR74

“Gains [in accessibility from lockdown] being lost as quickly as they came. This is led by politicians – who say outrageous things such as you won’t catch Covid by going back to work, women will lose their careers if they have to work from home...etc” CBCE6

“COVID pandemic has created some opportunities such as remote meetings and remote working which might benefit some disabled people” CBCE11

“Disability student helpline is asking students to return to colleges, even though it’s a reasonable adjustment for them to study from home.” CBCE8

“But access improvements and adjustments gained during the pandemic now being taken away – need to get message across that you need to be doing all of these things all of the time. Access provisions at universities already been taken away. Students allowed

to live abroad and participate remotely but same not permitted for disabled students for disability-related reasons.” FG1

“Greater use of technology has helped to connect and support some people who would normally have found it difficult to engage in particular activities. Some disabled people have benefitted from a new level of community support, with many examples of help provided by local people. Some voluntary, community and social enterprise (VCSE) organisations have found great value in providing online support. They have been able to reach some service users who would not normally have been reached through traditional methods” OO6

“in many cases, disabled workers are benefitting from the increased flexibility offered by working from home arrangements. This helps some disabled people to balance work, health, and caring needs. Disabled people often live with conditions which cause fatigue, pain, and discomfort. Being able to work flexibly at times when the individual feels more able to work is of great benefit to some disabled workers. Working from home has allowed some disabled workers to manage self-care more easily, in the privacy of their own homes.” OO6

## Poverty

“you can’t call a poor person to be part of your group if there is a gap of poverty. You can be friends but you are not equal in the group. Disabled people are given so little money that is a struggle to stay alive,” FG2

“People said that they had not had enough employment choices and that they do not have enough money to live on.” CBCE28

“The benefits were hard enough to live on previously, but since Brexit, Covid lockdown and inflation rising, there has to be a strict regime of what we need and what we can't afford. As a couple, my wife and I go without, as we make sure our growing 15 year old daughter gets what she needs.” SR232

“financial poverty so that choices of eat or heat are everyday reality” SR149

“Disadvantage, poverty and digital exclusion are all being more firmly entrenched” SR331

“Benefits being slashed and people being forced into poverty” SR52

“most disabled people are forced to live in poverty or one step away from losing everything,” SR131

“Disabled people living in Dickensian levels of poverty due to austerity, rising prices of everything, cuts to universal credit,” SR163

“For some of my Good Friends suffering poverty” SR277

“Benefits are being cut so we are struggling with poverty... More disabled people committing suicide due the extreme hardship of deprivation” SR285

“ESA payments have not increased in line with increase in bills. £6000 cap on savings before ESA payments are reduced traps Disabled people in poverty.” SR44

## **Social care charging**

“Social care provision was brought into the conversation noticing that local authorities are charging more, leaving disabled people on benefits to pay more for their support.” CBCE5

“Look at social care. It’s going backwards. Most LAs have introduced charges and these fundamentally disadvantage Disabled people.” DDPO29

“I hate that social care is so separate from the NHS and I hate that the principle you are treated when you need to be is not upheld in social care. As a former GP I have seen this.” CBCE6

“No guidance on financial assessment; all decisions seem discretionary; depends on council and county.” CBCE8

“Some of my friends are having to choose between eating, heating their homes and paying for care because of the charging policy.” CBCE22

“a requirement for their financial contribution... can leave people with disabilities financially challenged and with ongoing, assessed, but unaddressed needs.” D.DP35

“During the financial assessment, he was informed then that judging and looking at his income that he would not need to make any contribution to his care package. However, he was very surprised to see that he had in fact had to pay for his care. Something which to this day he believes that he should not have to pay, especially seeing as that the stroke, the falls that has led to a cracked L1 vertebrae which has caused him is all at fault with the council, especially with housing. If they had only listened to him and me in the first place... None of this would have happened. And now he’s being summoned to court for the outstanding payment which is causing him further anxiety on top of his current circumstances and I fear that he may suffer from another stroke or heart attack which is bad as I do not live at the property, or he may self harm which he has done in the past. He has now been summonsed to court for non-payment. I am truly at my wits end with this and its now causing me sleepless nights.” OI1

## **Social Care cuts and failings**

“The group felt the Government had failed to protect their rights under Article 19 which is the right to Independent Living as many people are living in hospitals and care homes because there is a lack of money and will to support people properly in the community.” CBCE28

“Friend has had repeated attempts to massively cut her care budget – has happened I believe three times over the past seven years. I want to get on the record this is absolutely due to austerity. The Local Council just doesn’t have the budget anymore so they are repeatedly going back to the same people, going through the horror they are not going to get the support they need to stay in their own homes, so three times within a small number of years having to face the horror that they are trying to get her out and force her into a home. She has a care budget and was choosing to use carers that are most expensive than the recommended hourly amount from the Council, she found cheaper agencies were not providing a good

enough service so she chose to go to a more expensive carers on fewer hours and the local authority used that as an excuse to cut her budget to that smaller number of hours but on the same rate as the cheaper local authority and has to find the difference from her own pocket. She is on a zero hours contract as a lecturer so really doesn't have this money. She can't spend as much money on food ..etc as a result." CBCE10

"People with disabilities having to move out of area for support."  
CBCE27

"Fears that if we contacted eg social services [for support] we might be deemed incapable of looking after ourselves and persuaded into living in care homes." SR14

"My daughter had a brain injury. That she had no support or rebilation. Infact as I tried to get her support we had intimidation used against us . I also work in 3rd sector and support families with children with disabilities. That are constantly Gaslighted. Lied to or intimidated by front line professionals when families speak up trying to get support" SR156

"I contacted social services for a review and it took them four months to get back to me." CBCE10

"I lost my Social Services Care budget in 2017 - for my severely disabled bedbound son. I had 4 care staff. It wasn't enough but it was at least that. £45,000 a year. Social Services took it all away without any review and has just left me to care on my own for my son 24/7 without any support. I work 19+ hour days and am often woken in the night so never get a good night's sleep. I do the work of 4 people. I also have to do Occupational Therapy, physiotherapy, social services job too. As an "Unpaid carer" I am treated like I am the scum of the earth... For the first year after the care staff were taken away, he was evicted from his home and spent a year living in a shed in my garden." SR107

"Disabled women with high support needs, and less frequently disabled men, may be left with little 'choice' but institutional care homes after domestic abuse because of a lack of suitable housing and an assumption they cannot cope in the community (or their care

costs too much). Assessment of care needs does not include an assessment of the risk of domestic or other abuse.” DDPO33

“In summary, the under-resourced CQC regularly gives ‘Good’ ratings to homes riddled with abuse, rooted in its focus on compliance with standards rather than ethics, safety, or independent living.” DDPO33

“Health and Social care system which is a ‘Demand avoidant system – many disabled people are at the end of the queue” CBCE7

“Things are moving backwards for disabled people everywhere and especially independent living. There are more cut-backs on the way. I believe that funding-wise disabled people are bottom of the pile.” CBCE6

“No responsibility is ever taken – central government blames local government who blames central government.” CBCE6

“Many disabled people are turned away, hours reduced. £8bn has been removed by the government from social care” CBCE8

“The experiences attendees shared of using Social Care were not good. The Local Authority outsource the service to care agencies and it was felt that they did not give the adequate care to disabled people. The care providers, it was felt, did not take the disabled persons needs or requests into consideration when appointing carers. No fixed time was given for carers to attend which left disabled people in need and unable to plan their day accordingly. When contacted by disabled people, the Local Authority appeared ‘not to care’ by saying there was nothing they could do to help.” CBCE11

“Despite requesting a woman carer to help me wash, I would sometimes be sent a man. Some carers would not help me shower and I could hear them rummaging around in my personal belongings which was very upsetting. I do not feel I could apply for care again in the future if I needed it”. CBCE11

“Recent research emphasises that cuts to social care lower the health and wellbeing outcomes of disabled people and highlights the

impact political decisions have on disabled peoples' lives, and the risk to life that results from health and social care policy that opts for short-term electoral and budgetary advantage over the interest of the whole community" DDPO26

"assessment process [for Augmentative and Alternative Communication] that is that is considered highly discriminatory by many disabled people and their families" DDPO38

"Also Continuing Health Care funding for support with living in the community (article 19) Funding is being cut even more. Some people are losing 50% of their Personal Health Budgets. It is a continuous fight every year to get or keep the support people need and you have to fight over and over again. It is exhausting and many people just give up. All help people need is being restricted and the rules get changed all the time. There are also too many people to deal with rather than just one person who knows you and your conditions," CBCE32

"I have MS, rheumatoid arthritis, heart problems, COPD, I only have one kidney, I have tumorous cancer, Hepatitis from a blood transfusion, cellulitis, a melanoma and edema. I need social care support, having fallen over a number of times, but Newham Council won't provide it because I own my own home where I lived with my husband. I worked all my life – around 38 ½ years - paying tax at the 40% tax-rate, I made thousands of pounds of savings but it all went on adaptations to the house when my husband fell ill... I also took out loans to make more adaptations and those had interest on them and so now I am thousands of pounds in debt. Newham Council say I have to pay for my own social care support but I can't afford it. They say if I sign my house over to them so they get it when I die then I can have social care support from them now. I won't do that. But it means I can't have an operation I needed. I have had 8 mini-strokes and a heart attack and I need an operation. But I wouldn't be able to manage when I came out so I can't have it." FG3

"The Council also takes so long to respond to requests for support. Our GP asked for a social worker and equipment and incontinence pads. That was in the February. We heard nothing. We finally heard

back from Newham social services in March – a few weeks after my husband had died.” FG3

“Simon has always had the impression that obtaining a diagnosis for his dual diagnosis of Autism and ADHD, would be a gateway to obtaining the support he needed to enable him to manage his life and have the opportunities that other people have. Unfortunately, Simon has experienced that this is not the case and he has spent many years, since diagnosis, trying to manage, trying to co-ordinate his own care, trying to communicate his needs and fighting for the system of Health and Social Care to meet his assessed needs.”  
D.DP34

“XXXXXX Council cut disabled people’s services by 1.3 million in the 2021-22 budget . These cuts included a £31,000 cut to the council’s Equalities and Diversity budget, and the closure of three respite care homes. The ruling XXXXXX Party group members seek to obfuscate the reality and scale of the cuts, by referring to them as “efficiency measures”, “streamlining of service”, “rationalisation”, “savings,” and similar politically preferred language. In April 2021 local members of the XXXXXX Party were instructed by senior party role holders not to refer to the cuts as “cuts.” XXXXXX Party councillors—including disabled councillors—are ‘whipped’ to vote through the cuts. Voting against the cuts would result in disciplinary action, including the threat of having the ‘whip withdrawn’ i.e., suspension from the XXXXXX Group / Party. In April 2021 two XXXXXX Party councillors told two town councillors they would be “reported” for raising the cuts to disabled people’s services at a town council meeting, and that they should remain quiet as speaking out would “worry disabled people.” One of the [local] councillors told members they were “proud” of the budget. This behaviour is illustrative of a local political culture which is institutionally hostile to disability rights activism, with widespread ignorance of disabled people’s rights, and of the social model.” DDPO7

## **Social care recruitment crisis**

“Everything is going wrong. Impossible to get personal assistants. Social care is not valued as a profession. It used to be. Horrendous now.” CBCE8

“I’m having major difficulties trying to get PAs. Part of the difficulty is the pay is so bad but if I want to pay more I get less PA time.”  
CBCE22

“There's nobody wants to go into care work. They blame it on the pandemic but I don't think it is.” CBCE22

“Rise in LGBT-phobia makes it harder for LGBT service users to hire respectful/non-discriminatory PAs” CBCE22

“Brexit – much more difficult employing Personal Assistants and pressure people into having to use agencies.” FG1

“As I’m sure you are aware Brexit and loss of freedom of movement coupled with the pandemic has quickly led to a major and growing staffing crisis in social care and support for independent living for disabled people. The low pay and low status of social care work is yet a further issue affecting recruitment post- Brexit as in rural areas especially it is possible to earn much more as cleaners or in the hospitality sector.” D.DP4

“The key findings [from our research] indicated that LGBTQI+ Disabled People using self-directed support reported many positives from having more choice, control and power. However there were concerns that ‘coming out’ to social care would jeopardise support. The difficulties in recruiting and retaining good PAs, the difficulties in securing support for ‘social hours’ could lead to social isolation.”  
DDPO30

**Case Study 1:**  
**From an email from a live-in social care agency,**  
**June 30th 2021.**

“In the last week, the number of carers who want to work has plummeted. Some carers want a break, some carers are doing something else, some are cancelling their booked work with their clients to have a rest.

Is this happening elsewhere?

Yes. I have talked to about 15 of my competitors, and they are seeing exactly the same thing.

What does this mean to you?

It means that we are extremely short of carers. If a carer is ill or has a family emergency, we will find it extremely hard to find the replacement you'd like (though we are confident that we will find a replacement if needed). We will do our best.

I am sorry about this. The situation has moved unimaginably fast. Last week we had 40 spare carers. This week we have none. In the 11 years I have been at xxxxxx Care I have never seen such a fast change in carer availability.”

**Case Study 4** - I also only had one interviewee March 2020 (who was not really suitable in terms of driving & attitude but I had no choice but to take her on) she has recently walked out, after verbally abusing me, hence recent recruitment with just one applicant who I have taken on.

**Case Study 5** - I'm really struggling with hiring suitable PAs and have found out this week that one has been sharing personal information with her other clients and family and telling some of the most awful lies

about me. She has done this in text messages so I have screenshots of what she said. Since then, I don't want to see anyone, talk to anyone, eat, sleep and feel deeply humiliated, ashamed and embarrassed.

There is a terrible shortage of PAs and carers in my area. I have called. The main disability charity hub and they confirmed how it is.

### **Case Study 6:**

Had a job advertised one month only two people applied both didn't turn up.

### **Case Study 7:**

In over 20 years of employing PA's this has been the worst time ever. Have 1 PA who left awhile back have been unable to recruit. Now another has left (long story) but situation was difficult. I have tried Facebook job pages, indeed, gumtree. We are quickly using up the good will of remaining PA's who are having to cover shifts.

### **Case Study 8:**

So my agency hasn't found any staff to cover shifts and are looking for nursing home placement - what happens if i don't want to go ? Can my care hours get reduced?

### **Case Study 9:**

Well, I've been running a job advert since July, about 8 weeks ago, and had about 5 applicants, 3 were unemployed pressing the button just to keep getting their benefits, 1 the shifts didn't suit him and the

other couldn't drive. Didn't get to the interview stage. I'm just lucky my other 2 PA's are covering the extra shifts for the time being, but it's not worth them doing tbh as the extra they earn, half of it is taken in tax.

### **Case Study 10: from PA Pool a PA introduction agency**

PA numbers have been declining significantly since Brexit. In the month of January this year we had 280 new PAs join the website. This has reduced to a mere 48 in the month of August [2021]. PA User numbers have been steadily increasing which suggests people are struggling to recruit and trying all avenues open to them.

## **The burden of Direct Payments**

“Trying to cut back on direct payments – very worrying. Will put people more at risk than they already are. Already hard enough to find Personal Assistants.” CBCE6

“Direct payments are a ‘cop-out’. You must be the employer and do all the work.” CBCE8

“I end up spending more of the money for PAs on trying to sort out direct payments. Sometimes I think I’d be better without direct payments!” CBCE22

“I don’t think there’s anything wrong with direct payments – the problem is we don’t get any support. They give this support to lots of disabled people who haven’t been employed themselves and expect them to be able to handle it. I remember when we had more proper DDPOs who were there to help people run their packages and we haven’t got that anymore.” CBCE22

“I used to do all the administration and management of my Mum’s direct payments, all the paperwork. It was so much work, such hard work.” FG3

## Unequal right to parenthood

“Parents only get sign posted for the wrong reasons, such as when parents are struggling and desperate to help their child and are wrongly suspected as the cause of the child’s distress instead of getting the support to meet their child’s needs.” D.DP42

“Disabled mothers with young children being taken into care because easier than giving them the support they need to manage. Upsets me being a disabled Mum who brought up children. I was lucky, the system didn’t help me, but friends did.” CBCE6

“It has been opinionated that I have Autism (Aspergers) by a psychologist and therefore can't understand the emotional needs of my child. Child is 6 and we have an exceptionally close emotional bond. Psychologist hasn't seen me interact with child. Child has been removed.” D.DP5

“attitudes to parenting including ivf, pregnancy, adoption.” SR23

“In 2007, England could have been described as a European leader in this field, having published the seminal, Good Practice Guidance on working with parents with a learning disability... Regrettably, this is no longer the case; indeed, governments in Scotland and, more recently Wales, have, in stark contrast to England, demonstrated and continue to demonstrate a clear commitment to ensuring the rights of these families are respected.” OO8

“In 2013, [we] asked the Department of Health to update the Good Practice Guidance, as although the fundamental principles remained unchanged, there had been a number of relevant new laws and policies since 2007... The DoH declined to do so on the basis of insufficient resources to do the work... there has still been no attempt by the Department of Health and Social Care to take on any responsibility for this Guidance.” OO8

### 3. Institutionalisation

#### Abuse and restraint

“People also felt that people with learning disabilities were more at risk now from being abused, tortured and treated with less dignity and respect. people talked about the abuse scandal at Whorlton Hall and how many other hospitals and care setting have been rated inadequate and staff found guilty of abuse but yet care companies have been allowed to keep contracts, Cygnet who owned Whorlton Hall being one of them who have still got contracts... some [event participants] do not feel free and safe in care homes and hospitals” CBCE28

“Over the past 5 years, there have been reports after report all affirming that psychiatric hospitals subject inpatients to brutal and inhumane treatment that the Government refuses to address by mandating a programme involves moving everyone out of such institutions into the community with the ultimate goal of ending institutionalisation of disabled people” DDPO5

“People with learning disabilities are still being locked away in institutions (Assessment and Treatment Units) and continuing to be treated badly and isolated from families (Winterbourne View and many others).” CBCE27

“All the independent reports affirm that people with learning difficulties and autistic people detained in hospital are routinely subjected to chemical and physical restraint leading to inhuman and degrading treatment.” DDPO5

“The conditions in these mental health institutions have not changed since Panorama’s exposure of Winterbourne View Hospital scandal first broadcasted during 2011. People with learning difficulties and Autistic People are still routinely being abused, treated inhumanity and dying in state-sanctioned institutions.” DDPO5

“2000 autistic and learning-disabled people are locked up in inappropriate institutional settings. Government has failed to move them into community-based support.” CBCE8

“This country has a long history of institutionalising people just because they’re seen as different.” DDPO29

“the government continues to authorise both the use of restraint on grounds related to mental distress” DDPO28

## **Forced detention and compulsory treatment**

“Particularly difficult for black males currently. The UN guidelines don’t get down to ground level. You can quote the UN in a tribunal and say that coercion is against their belief system but in reality having your rights upheld is difficult because the law in the UK doesn’t support human rights.” CBCE24

“Private mental health hospitals are keeping people there because it’s a cash flow issue.” DDPO29

“In the case of people judged to ‘have capacity’ who are not consenting to ECT, ECT could still be allowed if the Responsible Clinician regards it as necessary to save a person’s life, or to prevent serious deterioration, and if court approval has been obtained. In the case of people judged not to ‘have capacity’, ECT will still be allowed if both the Responsible Clinician and a Second Opinion Appointed Doctor (SOAD) agree that it is required.” DDPO28

“Detaining people is not care. One time, my son was sectioned and, because he cannot stand sounds (he has autism and so gets agitated) he said to me: ‘If you don’t get me out, I will stay here for life’. It’s just so sad. Two of my clients have been abused in hospital - when they were sectioned there. It’s left to them to prove it. How can they when they’ve been traumatised?” SR352

“The worst thing I felt was you had no power and they could do what they liked to you.” DDPO29

“demise amongst brutal issues from psychiatry” SR277

“I was only in for eight days and I was totally traumatised.” DDPO29

“There need to be a move toward autonomy - coercive and forced medication left me depressed and suicidal.” D.DP27

“our rights to believe what we want, and to religious freedom. But if you say you hear the voice of God or experience something unusual the first port of call is to drug you. This approach is not trauma informed and doesn’t take a person’s life experience into account.” CBCE24

“A participant had experienced coercion of medicine – this was traumatic” CBCE24

“My daughter suffered from psychiatric abuse.” SR78

“One participant described himself as a black gay man under CTO, who has been brutalised and traumatised by the mental health system” CBCE24

“Sectioning experience is traumatic – ‘I’m quite well spoken/eloquent but many people aren’t who are suffering at the hands of the Government and NHS.’” CBCE24

“there is a problem with the whole idea of someone doing something to you ‘in your best interests’ and giving you no choice. I’m against forced mental health treatment in all forms, whether it’s CTOs or sectioning. Institutionalising people in care homes or hospitals causes irreparable damage. The whole psychiatric system is coercive and controlling. I would prefer non-hierarchical support because I do find mutual aid helpful.” SR351

## Medical model

“the Government has failed to ensure that law and policy addressing issues for people in mental distress enshrines the human rights model of disability. Instead, we are very much regarded still as people who need protection against ourselves and clinical treatment.” DDPO28

“The government’s not doing [a human rights approach in mental health]. Fundamentally, they’re talking about doing it, but on the ground there’s not much evidence of it. There’s a lot of rhetoric, but it’s the medical model that’s happening.” DDPO29

“There’s a basic, underlying problem. Our starting point about equality and human rights is still viewed through the lens of impairment and medically.” DDPO29

“Services see people as their impairments, or their health conditions.” DDPO29

“The government’s approach is patriarchal – about looking after us.” DDPO29

“They’re sticking with the medical model. They put people in boxes.” DDPO29

“The Human Rights Act and the Equality Act are not compatible with the CRDP. Yet the government’s even talking of replacing the Human Rights Act with its own Bill of Rights. Erosion of human rights will continue under this government.” DDPO29

“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.” SR3

## **Mental capacity and deprivation of liberty**

“The Mental Capacity (Amendment) Act enacted in 2019 has weakened legal safeguards for people lacking capacity. The LPS will now cover hospital or care home and anyone being cared for in any domestic setting, such as supported living, shared lives schemes, or even within their own homes. Care commissioners, funders and providers will be placed under the duty to conduct LPS assessments, authorisations and renewals covering person’s capacity, mental disorder and deprivation of liberty justification. No longer will LPS decision makers are required to consider the disabled person’s best interests.” DDPO5

“Changing Perspectives have no confidence in the system that allows a conflict of interest, where the Care Commissioners, funders

and providers involved in the LPS authorisation process whilst being in receipt of financial arrangements. Disabled people lacking capacity and their advocates who want to challenge LPS decisions must use expensive court of protection arrangements on a very limited income means.” DDPO5

“The Mental Capacity (Amendment) Act does not include the state’s duty to promote disabled person’s liberty which is incompatible with promoting their UNCRPD rights.” DDPO5

“Deprivation of Liberty Safeguard concerns are also a commonly occurring theme in our casework. This may involve a failure by a local authority to follow correct procedures around standard authorisations, or in some cases not following them at all.” OO1

“We are particularly concerned that due to severe budget constraints, some local authorities are suggesting that individuals be deprived of their liberty, rather than appropriate support be put in place. In one case, this involved a local authority suggesting that individuals could be locked in their bedrooms rather than have waking night support.” OO1

## 4. Silencing Deaf and Disabled People

### Blocking access to justice

“All happening within the context of same government having dismantled access to justice, to appeals and rights. They are trying to remove access to judicial review. They’ve already taken away legal aid. The ability to challenge is being taken away so there’s nothing we can do.” CBCE6

“Legal Aid and Advocacy was taken away, attendees felt this was done with the intent to stop disabled people appealing decisions and complaining.” CBCE11

“Lack of redress via the law - few law centres, advice organisations, legal aid decimated” SR324

“So many Law Centres have also closed now. In those organisations that still survive the ones doing the work have more and more to do and are more and more up against it. There aren’t enough people to do the work.” FG1

“Over-arching problem is not just lack of legal aid but disabled peoples’ rights are not respected. Always bottom of the pile” CBCE8

“UN should know about the Norfolk case: disproportionately high charges for care for a severely disabled person found to be discriminatory. My situation is exactly the same. I want to be the second person to win. But no access to legal aid because I used my benefits to buy my home. If home costs £100k, no legal aid. Discrimination against those who cannot work.” CBCE8

“our options for challenging things are getting smaller - criminalisation of protest; proposals to limit judicial reviews; failure to reverse changes to legal aid as some examples.” SR331

“Judicial reviews (JR) are the only legal method for challenging hospital blanket policies. JRs can only be initiated by lawyers by patients in receipt of legal aid and it can be a lengthy process. Independent advocates and other advocates have no power to

legally challenge such policies. It's for this reason why hospitals have got away with just having blanket policies that are most of the time are left unchallenged. So, there is no real effective way of challenging hospital blanket policies that are blatantly unlawful. Even when lawyers challenge hospital policies, the management soon backs down and will do the right thing, to consider each case on its merit so the case does not get heard by judges. So, in the majority of cases, people with learning difficulties and autistic people are continuous being subjected to unlawful practices whilst detained under the MHA 1983." DDPO5

"Simon has been told repeatedly that he needs to take legal action to escalate his case against the local authority and NHS regarding omissions in his care. He has only recently been able to secure legal advice regarding improper use of the Care Act after many years of searching for representation, but cannot secure legal advice related to inequalities issues. Tackling unequal access to health and care, and improper use of the legislation in place to protect the wellbeing of people with ASC is essential but impossible for those on limited incomes." D.DP35

## **Engagement with organisations run *for not by* Deaf and Disabled people**

"National strategy group – they are toothless, what are they doing?, where is our representation?, we are experts in our own experience, they need to get the right representation, they don't have the right people so they fail, has been failure after failure" CBCE6

"National Disability Strategy – insufficient consultation by the government. Used their own consultation networks which aren't good enough and don't have enough Deaf and disabled people involved. Worked out as something like 25 people per region but these include charities as well as DDPOs, so probably not more than 5 Deaf or Disabled people per region." CBCE6

"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." SR331

“Disabled People and our representative organisations are not being involved by Government as equal partners in the co-design of policy and services that affect us. A number of examples of this include the Government establishing a Disabled People’s Organisation (DPO) Forum, of which we were a member. This ‘forum’ met on two occasions, but government did not listen our suggestions to co-design a meaningful National Disability Strategy. Instead, government cancelled future meetings.” DDPO26

“When the government develops laws and policies, it must closely consult and involve us. It doesn’t.” DDPO29

“Lack of voice - Government talk to disability charities not DDPOs who represent us.” SR172

“The representation of DPOs needs looking at. There are big issues around the government’s use of charities – people speaking for us instead of involving organisations of us.” DDPO29

“There needs to be a fundamental shift in knowledge and awareness-raising about the CRDP. More people with lived experience need to be used to formulate policy.” DDPO29

“The absolute failure to meaningfully engage with disabled people and our organisations in the development of the published National Disability Strategy has resulted in a group of disabled campaigners taking the Government to court on the grounds that consultation was so poor as to be unlawful.” DDPO26

“Government is not recognising the distinction between large nationally based disability charities ‘for’ disabled people and DPOs as representative organisations ‘with’ disabled people. Government regularly meets with the Disability Charities Consortium, made up of national charities as ‘the voice’ of disabled people, when in reality these organisations may speak on behalf of disabled people, but cannot represent us.” DDPO26

“When disabled people raised issues with the government about lack of accessibility and issues with the national disability strategy survey, the government refused to budge. They also never thought

to get feedback on proposals – just had the survey and then brought out the green paper not for consultation.” CBCE6

“More of a sense of disabled people being gas-lit and set up against other groups in a competition for funding.” CBCE6

“Local government – used to be more representative and better engagement.” FG1

“disabled people aren’t consulted/involved in topics about us” SR131

## **Failings of the Equality Act 2014 to protect Deaf and Disabled people’s rights**

“People felt that businesses and organisations are not being taken to court enough under the Equality Act.” CBCE28

“People get away with disability discrimination” CBCE7

“inadequacy of EQUALITY ACT 2010 in protecting rights.” CBCE8

“UK government thinks the Equality Act is sufficient. But there’s nothing to enforce and disabled person must pick off offenders one by one, for example, we if don’t have access to an accessible toilet.” CBCE8

“No enforcement or inspection. Not a day goes by at DR UK without a story of being thrown out of a club or restaurant. See Israel Minister’s experience at COP 26.” CBCE8

“Goodwill needed. If there was information about accessibility within business rates, people would be keen to get it right, but there’s no information. Has anyone tried to use the Equality Act? Painful because it means two parties have fallen out and difficult to mend (example of case of discrimination against children). Tried to use law to improve matters, but relationship breaks down. Hard to use in employment and schools.” CBCE8

## Lack of UNCRDP implementation

“Overall participants attending the focus group sessions recognised the implementation of the UNCRDP hasn’t been felt by those present. The overall feeling was that there is a long way to go for deaf and disabled people in the UK to feel their rights are met.” CBCE5

“Government should be asking Deaf and Disabled people which out of all the recommendations from 2017 are most important to address and also how.” CBCE6

“the government has failed either to promote general awareness of the UNCRDP, or to provide the scale of funding which would enable DDPOs to do so on the comprehensive scale needed” DDPO28

“in a concerning development, the application of the term ‘autonomy’ to people in mental distress diverges from the usual sense of the word. That is because the Mental Health Act White Paper proposes only some increase in choices available to us, together with a reduction in numbers and lengths of detention, but not an end to detentions as such, nor to community treatment orders. The government is opposed to making more fundamental changes to the detention criteria which would mean that people whom it thinks need the Act’s ‘protection’ can no longer be sectioned. A further issue is the plan to have a two-tier system which gives stronger rights to people who are judged to ‘have capacity’.” DDPO28

“the government continues to authorise... The overall usage of Tasers has also increased and has done so despite evidence that people from racialised communities are disproportionately affected” DDPO28

“Overall, disabled people did not feel that the Government had made much clear progress on the Convention rights and did not feel confident for the future.” CBCE11

“As a signatory to the Un CRDP, the UK Government should have incorporated the CRDP definition into law but they didn’t. This has a real-world impact. For example, whenever you complain to a tribunal, you have to prove whether you are disabled or not. This is a

degrading experience that entails reducing yourself down to the things you are unable to do. It is very medical model and is a particular issue for people who are neurodivergent. It means that a lot of people's cases get thrown out of people don't bother making them in the first place. If you do take a case, it is then the luck of the draw who is running the tribunal as to whether you will be considered genuinely disabled or not." FG5

## **Restricting right to peaceful protest**

"Community and activism have been central to my well being and these are up for reform by the UK policing bill." D.DP27

"The Government and police have even actively attacked disabled people and their disability equipment to try to disenfranchise, prevent and dissuade their participation in climate actions and protests." CBCE33

"The attack by state and police on our Right To Protest together with the building of Super Prisons with disabled accessible cells, plus increased stop and search powers and powers of arrest and imprisonment, removes deaf and disabled people's rights, freedoms and liberties, as well as affect their confidence and ability to stand up, speak out and fight for justice, rights, access, equality, fairness, and lives." SR239

## 5. Disaster Planning and Humanitarian Emergencies

### Climate change

“Measures brought in to reduce climate impact discriminating against disabled people, eg e-scooters dangerous on the pavement but if they were effective in cutting car use couldn’t they be used on the roads?” CBCE6

“The community and the built environment: LTNs, cycle lanes and pedestrian only zones have been brought in without consideration or consultation with disabled people, resulting in reducing already severely limited access due to cuts to pavement and road repairs and lack of dropped kerbs, etc” SR239

“Local and national government responses to the climate crisis, such as LTNs and pedestrianisation, without the necessary discussion and inclusion, let alone any consideration of the impacts on deaf and disabled people, without seeking or including or enabling the expertise and input and views of the user led deaf and disabled organisations that are led by and representing us, have resulted in further marginalising and excluding deaf and disabled people and in reducing disabled accessibility and inclusion within the community.” CBCE33

“Issue of reducing carbon emissions and measures to do that being adopted without thinking about impact on disabled people, eg “whole swathes of London where you can’t stop a black cab”; eg heat pumps need houses that are properly insulated and so many disabled people can’t afford this; traffic calming measures adopted with no consultation or thought to safety of disabled people or equality impact assessment.” FG1

### Forgetting Deaf and Disabled people

“Because they don’t have disabled people telling them, and it’s all done by non-disabled people, they don’t understand. Disabled people should be included in emergency planning.” CBCE6

“No inclusion of disabled people or our issues in disaster planning – it’s not that they don’t know, it’s that they don’t care” CBCE6

“disabled people are still afterthoughts” SR133

“The current government doesn't even know that disabled people living in our own homes receiving support exist as a group.” SR331

## 6. Lives less worthy

### COVID-19 response

#### **‘Clinically Extremely Vulnerable’ (CEV) List**

“Six months ago he became labelled as clinically extremely vulnerable because he has post polio syndrome. But before that he was not included among those shielding.” FG2

“Many left off[f] shielding list” SR74

“People also commented by putting people more at risk by not putting them on the 'vulnerable person' register and people not being able to get shopping. Some people couldn't queue up for food.” CBCE28

“From a Carers perspective there was a variance in getting those with learning disabilities on to the vulnerable list.” CBCE5

“Not being on CEV list – suggestion that you are malingering if you shielded while you weren't on it.” FG1

“Example of only receiving notification to shield a couple of weeks before shielding officially ended.” FG1

“ ‘I seem to be in a category where I'm not vulnerable enough to get help with essentials like food shopping, but too vulnerable to catch Covid and survive.’ – Woman in Wales, living with fibromyalgia and stenosis of the spine.” DDPO11

“ ‘I'm on the 'vulnerable' list but not the 'extremely vulnerable' list - I am concerned about the possible effects of coronavirus on me but there is no support available with things like shopping. As a younger person with no visible disability I fear I wouldn't be allowed to use shopping hours dedicated to vulnerable people.’ – Woman in London, living with ME” DDPO11

“ ‘We have lost both our incomes, and we were already using foodbanks before the lockdown. We can't access them now, and

nobody has been in touch from the various services that were in contact with us. I am very concerned about accessing food as I cannot stand for long at all and queuing would be out of the question at supermarkets.’ – Woman in Scotland, living with fibromyalgia.” DDPO11

“ ‘I am housebound and one of the forgotten ones. I feel very isolated, frightened, anxious, lonely, hungry, very tired, hopeless. I am hungry due to the fact I need home delivery groceries and it's a three-week wait. I am nearly down to my last scrap of food from my freezer and I don't know what I am going to do. I sleep a lot lately, very tired probably because of my high dose of medications and very little food.” – Woman in Northern Ireland, living with arthritis, complex regional pain syndrome (CRPS), dystonia, fibromyalgia, degenerative disc disease (DDD), heart condition.” DDPO11

“ ‘When I told the supermarkets how I rely on delivery to get basics, they responded with a script about the government’s ridiculously limited list of vulnerable groups each time. I was completely brushed aside.” – Woman in East Midlands, living with ME, polycystic ovary syndrome (PCOS), Irritable Bowel Syndrome.” DDPO11

## **Disproportionate deaths**

“Disabled people are held responsible for our own deaths from Covid.” CBCE6

“Government continually referred to disable people in care homes and over a certain age as older rather than disabled people whereas a high percentage of people in this age group are disabled – a way of hiding the disproportionate impact on disabled people.” CBCE6

“People with underlying health conditions seen as acceptable deaths in the pandemic, 60% of deaths being disabled people.” SR74

“As of November 2020, disabled people accounted for 60% of all deaths in the UK from Covid, leaving disabled people feeling unseen, unimportant and forgotten” DDPO26

“More health inequality in system; mental health and distress. In relation to Covid, 18–34-year-old disabled people 6X more likely to

die; never mind life expectancy far lower than for rest of population.”  
CBCE8

“Recent findings by investigative journalists on people receiving homecare in their own homes – found deathrate increased enormously but only 9% due to Covid. Significant number probably due to not getting the treatment or therapy they needed – very worrying statistics.” CBCE6

“During the coronavirus pandemic disabled people have been particularly hard hit. Two thirds of deaths in the UK have been disabled people or those with 'underlying health conditions'. The phrase 'underlying conditions' has been used repeatedly and in a pernicious way to suggest that disabled people's lives matter less and that 'normal' and 'fit' people need not worry about or take precautions to avoid spreading coronavirus because the only people dying are those who were already ill or disabled - 'they would have died soon anyway'.” D.DP25

“local councils and the government refuse to accept responsibility for the deaths of disabled people during the pandemic” SR131

## **Educational Disadvantage**

“During the pandemic most disabled children had no access to digital provision – families reliant on a single phone owned by Mum and having to share between all children for accessing education. During pandemic only small percentage of children from wealthier homes did homework – none of the disabled children did.” CBCE10

“Many disabled children and young people have had little-to-no participation in mainstream education for over 18 months because they have not accessed the necessary education, health, and social care support or that remote education has not been accessible for various reasons such as having adaptive technology, assisted software, or differentiated and accessible curriculum materials.”  
DDPO46

“We strongly believe that the practical outcome of the Children and Families Act easements and non-implementation of the Equality Act’s

reasonable adjustment duties has resulted in many disabled students' human rights to mainstream education being violated by the state under UNCRPD Article (24).” DDPO46

“some disabled students, because of their impairments and health conditions, may not be able to participate in learning without accessing therapeutic interventions, the use of learning mentors, specialist teaching, and communication facilitation. In addition, schools represent a site of more than just education for some disabled children and young people. For instance, without physiotherapy and occupational therapy, which can be delivered in the school setting, for many disabled students their physical health deteriorates” OO6

“as a result of the Children and Families Act’s S(42) easement, many disabled students are without education support. Whilst the COVID-19 guidance suggested therapy sessions ought to be provided via Zoom and other virtual platforms, ALLFIE has found that local authorities had made no effort to secure online or other SEND provision for disabled students with education, health and care plans (EHCPs) once the Secretary of State for Education gave notification at the beginning of May.” OO6

## **Expendable lives**

“Attitudes changed around disabled people during the pandemic – suddenly being seen as people who can be 'sacrificed', who can be made to stay inside so that non-disabled people could get on with their lives.” CBCE31

“Being a disabled person feels dangerous on a daily basis. I feel expendable.” SR219

“We are considered by the government to be expendable. Second class citizens. Our lives are expensive to support, so maybe we are collateral damage. If more of us die, it will eliminate that drain on the public purse.” SR327

“Covid we were treated as nothing, expendable and if we die we die, the uk govt do not like disabled people” SR335

“Deaf and disabled people are subject to eugenics and seen as expendable, collateral damage and are an afterthought, if at all” SR239

“Disabled people have been expendable during the COVID-19 pandemic, which has highlighted the general public and governments distain when it comes to the disabled community.” SR145

“We are regarded as expendable by the UK Government in relation to Covid, we are always third or fourth thought at best. We are regarded as a financial burden so if we die from Covid it saves the government money.” SR258

“The Covid-19 pandemic showed us that the Government did not see disabled people as important at first. It felt like we were at the bottom of the list and had to fight for ‘our right to life’.” CBCE27

“Excess deaths and pandemic – negative attitudes within the medical profession have become a lot more entrenched. – view of disabled people as expendable.” FG1

“There is utter disregard for D&DP in every avenue of life. The response to the Covid-19 pandemic had an eugenic undercurrent” SR15

“ ‘I was very upset to see that because I need a carer, the NHS considers me too frail for ventilation and my life not worth saving. Hard to live with this hideous, soul-crushing disease knowing the NHS doesn’t consider me worth saving. Not sure I’ll ever trust the NHS again.’ – Woman in London, living with ME.” DDPO11

“It seemed there was little or no consideration to the survival of those vulnerable or shielding.” SR103

“ ‘I feel the whole 'management' of the pandemic by central & local governments has been discriminatory as we have been completely overlooked.’ – Woman in East Midlands, living with fibromyalgia, Sjogren’s syndrome, osteoarthritis, spondylitis, sleep apnea, depression, disassociation disorder, PTSD.” DDPO11

“ ‘I feel a bit like the experiences of disabled and chronically ill people have been at once co-opted and erased. We are experts in isolation yet we've been ignored/told we are expendable.’ – Woman in Scotland, living with fibromyalgia, c-PTSD, PCOS, Hashimoto's disease.” DDPO11

“ ‘Politicians not talking to, but talking about, disabled people (when they remember us) has been quite painful to experience. The 'oh, it only kills people with a pre-existing condition,' as though that doesn't include anyone they think is listening. It's never 'your life is valuable and we're doing all we can to support you' - it's often in the third person.’ – Woman in East England, living with a thyroid condition.” DDPO11

“ ‘The marginalisation of people whose disabilities makes them literally the most vulnerable to a novel virus is richly ironic. I have particularly experienced this in work/educational settings: for instance where concern is expressed 'for those whose loved ones and family may be more vulnerable', rather than those who may be more vulnerable themselves.’ – Woman in London, living with Behçet’s disease.” DDPO11

## **Inaccessible environments and transport**

“Shopping has become more awkward as disabled parking bays were closed because of Covid distancing. Parking has become very difficult.” FG2

“In York we have been having a battle with the council about Blue Badge holder access to the city centre for the past 18 months. We cannot access, on an equal basis with others, the physical environment of the city centre... made permanent despite passionate pleas from disabled groups and their allies against it...” CBCE31

“One participant described that visually impaired people are more worried about being infected on the bus because people are close to them, rather than worrying if they’re on the right bus going to the right place which was previously the concern.” CBCE31

“Disabled access reduced by use of pavements for outside dining. York City centre access for Blue Badge holders permanently reduced after initial Covid restrictions.” SR44

“Closing down of access - car parks and Blue Badge spaces, no stopping in London for cabs/cars, huge exclusion zones in Central London, York (see current court case) Pavements blocked with tables/chairs and excess street furniture” SR324

### Isolation and distress

“Those in Residential Social Care settings were locked down and reliant on the Care Staff for all of their interpersonal interactions. The rules regulating contact outside of the Residential Home became draconian and Residents were separated from their relatives, friends, and support structures outside of the Homes.” DDPO30

<p><b>July 2020</b> - No longer able to stay in own home due to impact of family isolation – family carer unsupported and struggling to cope</p>	<p>We were contacted about MB's son, LB. LB lived in supported living but was unable to cope with a lack of visits as well as staff wearing face masks (due to significant medical trauma and intervention as a child). MB had no option but to bring LB back to the family home as he was so distressed being in his supported living accommodation. MB is now receiving direct payments but is nervous about recruiting employees to care for LB in case he can return home and will not be able to take his carers with him. MB has reported significant sleep deprivation and is experiencing significant mental health issues as a result.</p>
<p><b>August 2020</b> - Proposed restraint if</p>	<p>We were contacted about AR's daughter, J, prevented from having visitors because she is living in shared</p>

<p>attempting to hug family</p>	<p>accommodation. There had been no individual risk assessment. Additionally, at the time of referral, due to J's Downs Syndrome the provider was also denying visits on the basis that J should have been shielding. Told that if visits outdoors were allowed, J would need 2:1 care to restrain her as she would attempt to hug AR and they would not allow this.</p>
<p><b>August 2020</b> - Suggestion from care provider that if family continue to pursue visits, they will apply for deputyship and remove family ability to support in normal way. No previous capacity issues</p>	<p>Family told that if they keep trying to arrange in person visits to support their daughter in supported living, care provider may apply for deputyship or stop involving the family in her care and support. Family felt that they would be punished if they tried to visit.</p>
<p><b>August 2020</b> - Uncertainty over rules – provider raising concerns</p>	<p>Visiting and visitors - query from provider. What to do if people are coming and going from their home - people want to visit family - including overnight. What are the rules? Can we access testing?</p>
<p><b>August 2020</b> - Provider raising concerns over lack of mental health support available for tenants experiencing extreme distress due</p>	<p>Provider made contact with us directly as they had heard through a solicitor they approached that we were looking at this issue. He supports a cluster of accommodation 16 rooms in total and has been writing to the local MP, central government and newspapers. Some</p>

<p>to pandemic related isolation</p>	<p>within his service had not seen family during first lockdown. He reported widespread provider confusion about what is possible for providers to facilitate, and additionally insurance concerns. Tenants suffering due to ongoing separation from family are needing additional psychological support and cannot access this.</p>
<p><b>September 2020</b> - Local authority refuses additional support required for an individual experiencing isolation-related distress</p>	<p>LA refusal to uplift 1:1 hours for shared core hours. This is needed because one of the tenants is displaying behaviours that challenge and distress due to the pandemic changes. Other tenants now at risk</p>
<p><b>November 2020</b> - Uncertainty over how to manage services when tenants are discharged from hospital whilst still testing positive</p>	<p>A provider contacted us to ask how to manage cases where local hospital are trying to discharge tenants who are COVID-19 positive back into their own homes. Hospitals are doing this before getting a negative result. They can't see anything in the supported living guidance or regulations that helps them, only discharge to care home provision. They do not have access to testing and they are worried the virus will spread.</p>

“If you are anxious or concerned about what’s happening, it’s treated like a mental health problem. Linked with pretending Covid had gone away. For those still trying to stay safe it’s then a case of being locked away indefinitely.” CBCE6

“My friend had been in hospital during covid-19 where he had experienced two locked downs. My friend had no visits with his mother who has been dying from cancer. Friend’s mother does not know how to use technology and therefore phone contact was only available. My friend was not allowed to go to the shops and had to wait until staff could do his shopping including buying sweets which he hated. During this time the staff cancelled all ward-based activities. Staff with full PPE in the office only doing essential tasks. Friend’s mental health deteriorated – he would shout and ‘kick off’ and was sent to his room to calm down. The hospital staff did not explain the covid-19 situation – it was left me to do it... My friend was only allowed to speak to me once a week between 3 to 4 pm.” DDPO5

“Total visitors ban has had a dire impact upon inpatients health. Inpatients said they had nothing to do on the ward as in-person activities were suspended indefinitely including access to therapy sessions. Inpatients told me there increased incidents of bullying, assault, self-harming behaviour including starvation during long-periods of time being stuck on the ward. As I and others were not permitted onto the ward, it was difficult to ascertain what actually happened.” DDPO5

“Hospital frustrated any contact between inpatients and the outside world. Staff routinely even well into the covid-19 paramedic and locked down restrictions would tell me that they do not know where the technology is, how to set up the technology and no internet connection. Each ward had one computer clearly not enough when all face to –face contact had been suspended indefinitely by the hospital management. I was told on several occasions that inpatient could not have a 1-1 private meeting with me because there was other patient data on the computer. Absolute nonsense. I have a tablet that is set up without access to anything other internet search and social media platforms include skype and zoom and alike. The hospital clearly used technology to block any meaningful contact between inpatient and outside world.” DDPO5

“A Mother sought a legal challenge against a psychiatric hospital for stopping contact visits with her child. She argued that the hospital failed to make Equality Act 2010 disability-related reasonable

adjustments by allowing some kind of face-to-face contact visits to continue throughout covid-19 paramedic. The hospital failed to make any reasonable adjustments including facilitating virtual visits through providing on-line device so that the family are able to maintain some kind of face to face contact during covid-19 paramedic.” DDPO5

“We heard from inpatients that community leave was suspended indefinitely despite professional bodies guidance making it clear that patients should still continue to use their community leave on the same terms as the rest of the population who were not detained under the Mental Health Act. Shopping, out-door exercise, attending medical appointments, visiting families and friends were some of the freedoms that the general population had during locked-down.” DDPO5

### **Lack Of Personal Protective Equipment (PPE)**

“Bristol did better than other areas but still difficulties for people living in their own homes to access PPE for their Personal Assistants.” CBCE6

“Residential Care Staff were put at risk due to several factors, including lack of adequate Personal Protective Equipment, PPE, and the use of vacancies within the sector to relieve the pressure on the NHS beds. As they were put at risk, so too the Residents.” DDPO30

“Disabled People living independently in the community and using Self Directed Support became under increased risk from lack of PPE provided and available.” DDPO30

“The lack of PPE has been a major concern for CEV social care users. It was virtually impossible to obtain not just the protective clothing but also testing for the virus and for the necessary hand washes, aerosol sprays, and surface cleaners needed to maintain a safe home environment. The risk of cross contamination became a major factor in allowing social care staff into the home.” DDPO30

### **No £20 uplift to legacy benefits**

“£20 uplift – came at a time when people not usually on it came onto it. It wasn’t about disabled people but about everyone else they wanted to keep happy.” CBCE6

“Cuts to Disability Benefits and the denial of £20 a week to Disabled People and others on Legacy Benefits further impoverishing Disabled People and making it harder to stand up, speak out and fight for our rights and lives.” CBCE33

“The £20 a week UC uplift not applying to legacy benefits, the majority of claimants being disabled people.” SR74

“60% of disabled people accessing our services reported that their quality of life and health and wellbeing had been negatively impacted by the disproportionate impact of the pandemic, with many disabled people being left without the £20 weekly uplift given to those on Universal Credit. Disabled people, especially those in receipt of personal assistance, have felt like an afterthought during the pandemic” DDPO26

## **Reductions in support**

“I'd rather type this than say it because it's upsetting and about suicide which not everyone is ok to hear about. ... My brother who is also disabled died by suicide this summer because he couldn't speak to the crisis team, they discharged him before he died and didn't follow up soon enough. Mental health and isolation in the pandemic for disabled people has not been taken seriously enough especially for people who have no coping mechanism independently.” CBCE10

“...a woman who due to her PAs getting COVID, having to rely on neighbours to support her and then as a result the local authority tried to pressure her to go into a care home. She knew if she went in, she would never come out.” CBCE10

“Lots of community and resource centres were closed during COVID and have never re-opened. This has led to greater isolation of people and worsening of MH conditions.” CBCE32

“particular issues facing LGBTQI+ Disabled People significantly...LGBTQI+ Disabled People are quite likely to rely on

social care due to geographical separation from childhood support, less likelihood to have children, more likely to experience alienation from biological relatives, and less likely to have friends locally away from LGBTQI+ venues.” DDPO30

## **Restricted access to healthcare**

“Can’t get hospital appointments because of Covid backlog. I’m sick being told it can’t be done because of COVID” CBCE6

“Health appointments were hit and miss. Many routine check-ups and blood tests were cancelled. This put disabled peoples care and health at risk and continues to do so.” CBCE11

“Hospitals and healthcare – so many appointments being cancelled.” FG1

“Lots of people need urgent surgery but no access to GP or consultants for diagnosis. Need to go privately. Why is this worse for disabled people? Most have multiple health needs and are forced to choose which condition can be referred to an expert. Problems of health and social care lead to people collecting MORE disabilities.” CBCE8

“NHS wheelchairs there are still waiting lists of years for an assessment in many NHS trusts. This has got worse due to a backlog due to Covid.” CBCE32

“some very serious impacts that disabled people have experienced such as worsening mental health, worsening physical health due to the disruption to NHS provision, and loss informal support networks.” CBCE11

“NHS dentists were not doing extractions in many areas during the lock down periods and a 3 year backlog of NHS dental treatment has been reported. Some people haven’t been able to see their dentist since 2019 or have had to pay privately.” CBCE32

“The physical health system is so inaccessible for people with mental health support needs and has getting worse through Covid through added layers of bureaucracy that make it difficult to navigate.” D.DP11

“As well as having their participation in the life of society restricted disabled people's access to health care has been limited because many have avoided doctors or hospitals for the last 20 months thinking (correctly) they could be more at risk from catching Covid in those settings. Thus chronic conditions which needed treating were left untreated. In some cases this has led to worsened pain and ill-health. In some it has led to death.” D.DP37

“ Of the respondents under the regular care of a GP or specialist for chronic conditions, 66% [of respondents to our survey] reported disruption to care during the pandemic. This has long-term implications for people’s health and will place increased pressure on the NHS and social care once the current crisis has passed.” DDPO11

“ ‘The lack of access to medical help for anything other than coronavirus is very scary. Plus, if I get the virus will they decide I’m not worth saving because of my conditions?’ – Woman in North West England, living with Graves’ disease, thyroid eye disease, anxiety disorder, depression” DDPO11

“ ‘There has been a major impact on the ability of people with severe chronic illnesses to access support and healthcare. I am extremely concerned about the backlog this is going to cause down the line, as there are already significant waiting times for specialists. The NHS has been underfunded for so long that I am terrified I won’t have any access to this specialist care when the pandemic subsides. Our conditions are not going away and I think the lack of care during this time will cause irreversible damage to many of us and make our conditions even worse. I think policy makers have to understand that many people with chronic and rare diseases already feel like we are forgotten, but there are millions of us and this could cause a tsunami of healthcare problems after the pandemic earthquake.’ – Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.” DDPO11

“‘Diabetes nurse appointment cancelled, diabetes annual review cancelled including eye screening, endoscopy for Crohn’s cancelled, asthma annual review cancelled. I used to have monthly GP review - cancelled, but I can contact by phone for emergency.’ – Woman in

East England, living with diabetes, Crohn's disease, asthma, endometriosis, post-traumatic stress disorder (PTSD)." DDPO11

"Hospital appointments for pain injections, neurologist, infusions have all been cancelled.' – Woman in London living with spinal cord injury, chronic pain, neurogenic bladder and bowel, osteoporosis." DDPO11

" 'I have mental health therapy twice a week; this has been cancelled and nothing has been put in place. All specialist appointments that I've been waiting 9 months for have been cancelled or even discharged.' – Woman in South East England, living with ME, fibromyalgia, POTS, anxiety, depression, costochondritis, asthma, IBS, interstitial cystitis, non-alcoholic fatty liver disease (NAFLD)." DDPO11

" 'I had a text saying not to contact them unless it's an emergency.' – Woman in Scotland, living with ME." DDPO11

"56% of respondents [to our survey] reported that their health had declined since the pandemic began, with a significant number reporting the detrimental impact of increased stress and anxiety." DDPO11

## **Unlawful use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders and treatment rationing**

"Care home in our area that had blanket DNACPRs placed on all residents – largely autistic people – for absolutely no clinical reason" CBCE10

"People were very upset that the Government allowed medics to issue DNR (do not resuscitate) orders on files of people with learning disabilities and Autism." CBCE28

"Disabled people also reported to us that they had received letters from their GP suggesting that they should agree to a Do Not Resuscitate (DNR) order against their name in the event they became unwell with Covid. This naturally caused a huge amount of concern about what would happen to disabled people who needed intensive

care. Reassurances were eventually given by the NHS, but by then, confidence in the treatment disabled people would receive was damaged” DDPO26

“I know of folks who's died of covid in hospital because of not receiving same treatment as none disabled/deaf people.” SR211

“GPs were asking about Do Not Resuscitate Notices on their patients, and some patients were being advised that their care may become palliative rather than acute.” DDPO30

“CQC investigation found many People with learning difficulties had “do not resuscitate” (DNR) orders included in their medical records during the second wave of the pandemic, in spite of widespread condemnation of the practice. GP surgeries had been found enacting DNR blanket policies for specific groups of people, in this case people with learning difficulties during the covid-19.” DDPO5

“The National Institute for Health and Care Excellence (NICE) covid-19 critical care guidance stated that all adult COVID-19 patients should be assessed for “frailty” when admitted to hospital, and that “comorbidities and underlying health conditions” should be taken into account. CFS “frailty” scoring system consist of levels of frailty. Frailty score includes someone needing various help with day to day activities. Anyone with a Personal Assistants or anyone detained under the Mental Health Act would clearly be at disadvantaged when prioritising critical covid-19 life saving treatment. NICE revised and amended covid-19 critical care guidance after Hodge, Jones & Allen lawyers threatened with judicial review proceedings on behalf of disabled people.” DDPO5

## **Vaccinations**

“the Joint Committee on Vaccination and Immunisation (JCVI) failed to recommend that people with learning difficulties are prioritized for covid-19 vaccinations. Both the JCVI and Secretary of State for Health and Social Care failed to take sufficient account of the evidence of the particular vulnerability of people with learning disabilities to Covid-19 if they are residing in institutional settings such as psychiatric hospitals.” DDPO5

“We also had to campaign to be a priority for vaccinations.” CBCE27

“priority list for vaccination being changed at the last minute, leaving off those who’d been told for a year they were vulnerable” SR74

“Disabled people living in their own home with a family member caring for them, had to wait to be vaccinated. Myself and my family members as well as my disabled adult son had our first Covid injections in March 2021. A year too late!! No help on what to do during pandemic and no PPE provided by Social Services until a year and a half after lockdown. Again too little too late!!” OI3

“Disabled children under 12 cannot get a vaccine yet.[December 2021]” SR99

“Accessibility at vaccination centres has been poor for those who rely on others for transport, this not only creates a barrier to vaccination, but consequently creates a barrier to activities which require a 'vaccine passport'.” SR103

“Not everyone is able to have the Covid vaccine. Other countries are locking down at the moment but this government isn’t. No one should be forced to lose their job because the science isn’t there yet for them to have a vaccine.” FG4

## **Unsafety measures**

“Took away Covid restrictions – bunch of people mainly non-disabled people including MPs decided they were sick of them. So disabled people now having to choose between staying safe and taking part in day-to-day life.” CBCE6

“Government haven't identified risk. Mixed messaging regarding safety and isolation etc.” CBCE33

“The right to life of disabled people has been curtailed by the government's refusal to act in the interests of public health during the pandemic, a situation which continues to the present day. The UK government failed and continues to fail to take measures which would reduce viral transmission, eg mandating the wearing of facemasks on public transport and in shops and other indoor public

spaces... The impact of this on me personally and many others who are clinically vulnerable has been to force us to shield indefinitely, to more or less imprison us in our homes. It has not felt safe for many of us who are clinically vulnerable to use public transport... Those of us who either cannot drive because of impairment or don't have a car are particularly hard hit. I am old and do not need to use public transport to get to work but there are many clinically vulnerable people who do and they are put at serious risk... Some disabled people cannot use public transport at the best of times because of inaccessibility, but in the pandemic the situation has got far worse.” D.DP37

“When the government doesn't protect public health, solely relying on vaccination when some have not been vaccinated and the vaccines do not work equally well for everyone, and seemingly deliberately allows the spread of coronavirus the result is that many disabled and chronically ill people are much less able to participate in the life of their communities.” D.DP37

“there is no current Lockdown. The likelihood of increased infection rates, hospitalisation and deaths remain high. There have been variants of the original Covid 19,... Vaccine uptake has been patchy in some locations,... onside uncertainty about the continuing efficacy of the vaccines and boosters, other illness are surfacing, including a particularly virulent influenza.” DDPO30

### **Where is the interpreter? Lack of clear, accessible information and guidance**

“[COVID] for Deaf Sign Language users massive impact on lives and employment. Such a lack of information. Communication based on English. I raised £13,000 through a crowd-funder to take a legal challenge. The ruling was that the government must provide an interpreter either at the same location or through in-vision. Crises or events will happen in our time but they never think about us. Ridiculous to have to do that sort of campaigning. Climate change or coronavirus – they don't even think what we need – we need to think about people's access.” CBCE6

“Access to information during the pandemic has been a huge problem. Lack of interpreters at the covid briefings, lack of easy read versions of advice and the letters sent out by local council. Information was released significantly later for groups who needed alternative communications.” CBCE31

“People felt that their rights had been ignored during the Covid crisis by not providing timely accessible information. They talked about easy read not being available and also the Government not having signers at press conferences which put them at risk as they didn't know what was happening. Some people talked about them having breakdowns and meltdowns because of this and one person had to move into a hospital because he became so poorly.” CBCE28

“participants reported at the beginning there was confusion with regards to disabled people returning to work and a sense the guidance lacked clarity, leaving disabled people feeling vulnerable and confused.” CBCE5

“Also no accessible information about the local situation, eg vaccinations/when the local tip is open/all aspects” CBCE6

“The pandemic has been very stressful, advice from the government was sparse and confusing.” SR103

“Intersectionality – lack of important pandemic information available in different language, left to charities and grassroots communities – for example family members trying to translate; the more oppressions you experience, the more overlooked you are and the more excluded you are from any policy-making considerations.” FG1

“A lot of government information is difficult to decipher, for example the covid 19 rules, even listening to the prime minister is not helpful, as he doesn't speak clearly and uses confusing language about what is and isn't allowed.” DDPO26

“BSL is an important language and sadly this government in England does not use BSL for example when doing Covid Press Conferences - this creates a sense of isolation and exclusion for hearing impaired and deaf people” DDPO26

“28% of our survey respondents did not know if their chronic condition placed them at higher risk according to government guidance. This showed the need for clearer guidance, both for people living with chronic conditions and the shops and services expected to respond to their needs” DDPO11

“ ‘When I asked if I could check with the GP if I was in the vulnerable group I was told to look online.’ – Woman in Yorkshire and the Humber, living with fibromyalgia.” DDPO11

“the impact of poverty emphasised the digital gap between those who had access to online information and those who for reasons of cost were without. The closure of the libraries reduced public computer access and digital exclusion had a significant impact on education and employment. For many families living within the poverty thresholds, the lack of technology in the form of smart phones or computers, was compounded by the inability to access the internet.” DDPO30

## **Hostility and feeling the effects of damaging narratives**

“It was widely felt that we need a new government as the current Government did not care about people with disabilities, particularly learning disabilities... People said that not feel they have confidence in our current Government and that disabled people have been treated appallingly over the last five years.” CBCE28

“..the hostile environment towards disabled people is a very significant problem with hate crime in the community and on line an ever constant problem. 1 in 4 disabled people feel unsafe to travel on public transport due to the significant rise in the hostile environment towards disabled people in the community.” CBCE19

“Attitudes towards disabled people are getting worse; increasing levels of abuse are being experienced, due to the false media portrayal of disabled people as scroungers and fraudsters, with 66% of disabled people saying that they have experienced aggression, hostility or name calling.” DDPO41

“social anxiety from people who would rather see me suffer than try to help me. This government not bothered about anyone who is unable to cope or needs support” SR293

“I think the government hate us disabled people and have no interest in us other than trying to fit us into the workplace whilst reducing any help to do so. “Useless eaters” that’s all we are ...” SR100

“the way disabled people's lives were devalued in rhetoric and official messaging around Covid-19 contributed to even more blatant hostility and disregard for disabled people's lives” SR331

“There’s been a massive increase in disability hate crime. Government rhetoric hasn’t helped. It’s opened the door to othering us.” DDPO29

“It’s always been an ideology not to assist disabled people. That’s what the Government really think of us” CBCE11

“dehumanisation, hatred and a systemic attempt by the UK government to punish disabled people for trying to live.” SR162

“Many respondents [to our survey] reported experiences of discrimination in shops, the NHS, the media and public conversation. People reported feeling unseen, unheard and unvalued.” DDPO11

“What unsettles me is that we have a government who would gladly drop help to those of us who are disabled while they are in power, all our current efforts can be lost” CBCE7

“The Government and MP’s put negative ideas in non-disabled people’s mind about disabled people, through their comments and attitudes. These ideas then form how people feel about disabled people. They think we are all scroungers, that we could work if we wanted to, that we must not be a good person and we are a burden on the state. This allows the Government to continue to do the things they do to disabled people, to cut services and benefits.” CBCE11

“My own friend said to me, I know you’re not like that but others are”. Meaning disabled people are scroungers and on the take.” CBCE11

“It feels like people hate you more than they did before.” FG1

“the government fuels discrimination of the disabled/sick/refugees/poor” SR72

“There was a real change in tone around 2010 when the government changed. We started to get a lot of rhetoric around disabled people as benefit scroungers, as people who are committing fraud, and who are a burden on the system.” CBCE31

“fear of disbelief or accusation of fraud. People then leave things too late and things deteriorate significantly before they get help.” CBCE31

“The presumption of ‘you’re faking this’ was so pervasive that it took so long for them to overcome this and ask for help. They became disabled while at work and wore splints, started using a wheelchair...and each time they noticed they were being taken less seriously as previously or equal to people on the same level as them at work. They were a good manager but were not being given the same platform within the workplace as a result of their disability.” CBCE31

“Everything the government does is about getting people into employment – never consider those who for whatever reason cannot” CBCE10

“.....all those who can’t work, who receive benefits have nothing, its only if you can work.....not against that but misses out a big group of people. I still get the feeling that people with a disability are perceived as less by this government and that has an impact on the rest of society. It’s clearly a big thing.” CBCE5

“Government messaging leads to attacks and hostility.” CBCE6

“Inclusion London believes that criminal conduct based on a victim’s wrongly presumed lack of disability should be covered by hate crime law. This is because rhetoric, from both the media and the government, have portrayed Disabled people as “scroungers” and ‘benefit cheats’, and perpetrated extremely exaggerated figures around benefit fraud. As a result of this rhetoric, it has been found

that many instances of hate crime have been motivated by the belief that Disabled people are faking being Disabled – it is important that hate crime legislation takes into account this “scrounger” rhetoric and the effect it has had on crimes against Disabled people.” DDPO41

“I’ve been called an ‘it’ many times – ‘what is IT doing?’ ‘Look at the state of THAT’.” DDPO42

“I’ve had remarks about how I look in my wheelchair, and a few times the statements ‘you should have been aborted’, and ‘you don’t deserve to live’.” DDPO42

“Online abuse and physical threats cause distress but also inhibit Disabled people’s daily lives, with individuals too fearful go online or to leave their houses alone.” DDPO42

“Added to this is the Government's "hostile environment" - their insistence that disabled people are just 'lazy' shirkers who could work if they just put their minds to it” SR107

“It’s important for disabled people to accept responsibility for themselves and help portray a more positive image of ourselves.” SR90

## **Lack of parity in hate crime law**

“Disability hate crime is treated differently from other hate crimes. It’s much more difficult to get someone to represent us due to doing away with legal aid, but also making it look like we are worth less than other groups of people who experience hate crime.” CBCE10

“There should be a single Hate Crime Act based on the relevant provisions currently contained in the Crime and Disorder Act 1998 but extending to all categories of crime..., we believe that in any new Act, there should be parity across all strands of hate crime” DDPO41

“the law should be extended, so that stirring up hatred offences towards disabled people or people with a transgender identity are covered, and all protected characteristics are given parity within law. We agree that stirring up offenses be extended to all material. Hate

crime has been stirred up by false rhetoric by politicians about disability benefit fraud, which has been relentlessly amplified by the press so now members of the general public abuse Deaf and Disabled people as benefit fraudsters and scroungers.” DDPO41

“social media companies have a responsibility to proactively seek out and remove content which constitutes a hate crime, and should have penalties applied to them by a new regulatory body if they fail to do so” DDPO41

“The stirring up offences currently contained in the Public Order Act 1986 are particularly relevant to Disability Hate Crime where someone is targeted by groups of people falsely accusing the Disabled person of being a paedophile, inciting prolonged incidents of harassment and threats, sometimes leading to serious crimes” DDPO41

## **Serenity Integrated Mentoring (SIM)**

“We believe SIM is in breach of several articles of the UN convention on the Rights of Disabled People.” DDPO34

“SIM is designed for people who are in contact with mental health services, who are frequently at high risk of suicide and self-harm, and deemed “high intensity users” of emergency services... Specifically, [SIM Response plans] can give doctors and nurses the confidence NOT to treat or respond in ways in which they would have felt compelled to before... SIM explicitly advocates withholding potentially life-saving treatments from disabled people. We strongly believe that this is an act of discrimination on the basis of disability.” DDPO34

“Most concerningly, for me, was the rollout of a program in the NHS called Serenity Integrated Mentoring, which describes itself as a 'coercive' method of correcting behaviour from 'problematic service users' who cause 'an unnecessary financial burden' on public services. The program seems to target mainly women with BPD (also known as Eupd) who are often victims of abuse and/or sexual assault. It allows healthcare providers including the NHS to refuse any care to 'service users', even unrelated to their mental health

diagnosis. 'service users' who attempt suicide too many times can be given criminal charges and sent to prison. It's made me scared to ask for help." SR103

## **The experience of being disbelieved**

"desexualisation of disabled people produces an inability to comprehend the risk of abuse within a culture of disbelief that this group is sexualised." DDPO33

"Women's own descriptions of our needs are routinely dismissed, even if verified by a medical professional. But often the GP factual reports are very skimpy... Women are also made to pay charges for letters which we can't afford. These letters often don't usefully describe needs but simply provide diagnoses which are already available in medical records." DDPO37

"...twice I was offered the same hostel room,... which was completely unsuitable for someone with my disability. However, what was truly terrifying for me, was that both my PA at the time, and the hostel staff, and Camden council, all thought the accommodation was suitable. This caused an enormous amount of stress, not to mention the huge amount of time it took me to gather and submit the asked for evidence to prove that it was unsuitable, only to be offered the same hostel room less than a year later, with huge amounts of stress yet again, and having to get a solicitor from Disability Law to submit evidence at, no doubt, a substantial cost to the government." D.DP28

"Lack of consistency in training can result in a culture of disbelief that crimes such as hate crime, domestic abuse and sexual violence should happen to Deaf and disabled people, especially Deaf and disabled women, despite figures from the Office for National Statistics showing that sexual violence against disabled women has more than doubled since 2014 ." DDPO33

## Treatment of people with ‘Medically Unexplained Symptoms’

“I suffer from ME. 2007 Guidelines have made things worse. Managed to have a remedy. Some Royal Colleges are refusing NICE guidelines and proceeding anyway with CBT.” CBCE8

“Disabled voice ridden over. NICE guidance but threatened with legal action.” CBCE8

“Rated all the research. PACE trial graded low/very low. Why is CBT brought in? £millions spent but no biomedical research on ME. I’m 50 next year and want to campaign on this.” CBCE8

“MUS are typically taken as evidence not of genuine physical illness, but of cognitive or behavioural dysfunction, frequently resulting in psychological therapies, in particular CBT, being used to ‘treat’ MUS, in spite of the lack of evidence that this is effective. In fact, there is considerable evidence that such treatments are harmful to patients.” DDPO12

“Before receiving their diagnosis, four in five respondents [to our survey] had their physical symptoms attributed to psychosocial causes such as stress, anxiety, or being overweight, and half received psychological therapy for their undiagnosed physical symptoms, with 81% finding this therapy unhelpful, and 66% finding it not at all helpful...Many respondents described the experience of having their physical symptoms attributed to psychosocial factors, which did not align with their lived experience, as ‘gaslighting’...Some respondents’ health deteriorated either from the exertion of attending psychological therapies, or as a direct result of interventions such as graded exercise therapy for ME/CFS or Long Covid... Patients’ beliefs and behaviours are often blamed by health care providers for the failure of CBT and other psychological therapies to improve their conditions, leaving patients with MUS feeling worse than when treatment began.” DDPO12

“With medical care I assume I will be disbelieved especially regarding ME & so keep my interactions to a minimum, this means my health care is not adequate.” DDPO12

“I don’t trust health and care providers. My health - both mental and physical - have deteriorated and I have refused to seek help.”  
DDPO12

“I don't trust medical people any more. I try to be optimistic and friendly (or at least to seem to be), but every time I need to see or speak to a GP, I get really nervous and depressed because the normal scenario is that I have asked for help in vain.” DDPO12

“Now when I have concerning symptoms, I don't know if I should seek medical care as I don't know if I'll be believed. So I don't listen to my body or see doctors, even when I have new and significant chest pain, for example.” DDPO12

“I have been traumatised by medical gaslighting to the extent that I frightened to go to the doctor now. When I do go, it takes me days to recover. I have anxiety attacks and become suicidal.” DDPO12

“Long Covid barely talked about despite being a mass disabling event it is not considered in decision making, and sometimes talked of as a new phenomenon, completely invalidating the 250,000 people living with ME / CFS following a virus.” SR74

## **Unequal timeframes for pregnancy termination**

“Hi I am Heidi Crowter. I am 26 years old. I have down syndrome (DS). When i found out that there is discrimination in the womb I was really upset. I contacted a solicitor, Paul Conrathe and he helped me take the UK Government to the High Court. The court case was in July 2021 and we got the verdict on 23rd September. We lost. The judges did not think that it is discrimination. We are now asking the Court of Appeal if we can appeal the decision. I and most of the Down syndrome community think that its wrong that a baby with DS can be aborted up to birth but a baby without DS can only be aborted up to 24 weeks. It is important to me that we should be treated the same in the womb as it makes me feel that my life is not as valuable as anyone else's. In 2020 in England and Wales there were 693 abortions for DS (Ground E) and 14 abortions after 24 weeks for DS. I live with my husband James who I love with all my heart... To be honest I feel shocked that the doctors don’t respect

the parent's decision. I feel distraught and very shocked that this can happen as I am someone who has Down's syndrome and I feel in the light of this law that no one values me or wants me. I love James with all my heart. and I wouldn't change him one bit. I think that they need more education on the condition and see the baby behind the extra chromosome. I think they need to meet people with Down's syndrome and see what impact they have on life." D.DP24

"I am James and I live in Coventry, with my lovely wonderful wife Heidi. I feel emotional, and a bit worried that other people don't value me as I am. because I want people to be valued in life and down syndrome can't hold us back from living a fun and fulfilled life." D.DP24

"My name is Rula Sweby. I feel really horrified about doctors putting pressure on mothers to abort their unborn children who may have the unique condition of Down Syndrome because it's not their business to do so, considering it is actually up to the parents to make that decision themselves. I believe that every baby born with Down Syndrome is unique in its own way just as all babies are. We all have the same human rights. I would say that the main message I want people to know about Down's Syndrome is not to be afraid of talking with and getting to know us." D.DP24

"Everyone should be treated the same... Doctors need to give information and support instead." D.DP24

"I have autism. A friend of mine in her 20s her name is Beth. She's my friend her mum was my drama teacher and she's a actor... She has Down's Syndrome I don't see Down's Syndrome I see a friend!" D.DP24

"I don't agree with the abortion point, I believe it is the woman's right to choose" SR53

## **Spectrum 10k**

"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.” SR144

## Photos



**DDPO18** - People seeking asylum describe the disabling effects of government policy. Under the colourful rainbow, a group of people chat happily. Under the fading rainbow, one man stands with his backpack next to him, leaving a house. On the right, the same man is homeless, crouching in a bush with a black hood shading his face. Without food, shelter or hope for the future, he says asylum policy made him 'lose my mind'. A police officer and a politician stand together ignoring him.



**DDPO23** - People with impairments which make it hard to leave their homes, are often told that it is impossible to join events from home. Yet during lockdown, events from theatre to pub quizzes or university lectures became accessible.



**DDPO24** - A deaf person has arms out signing 'Where?'. In front of her there is a hand with the words, 'Where is the Interpreter?'



**D.DP23** - "My Spinal operation remove to cyst in the spinal cord on the expect me to go home and survive without a care package"



**D.DP15** - "wanted to submit this image to the UN shadow report. The drawing is based upon a scene I witnessed in Cornwall this morning. It involves a son with a Learning Disability shopping with his elderly parents. Many of families members like my mum who look after people with learning disabilities could be elderly. Both Cornwall and the care system continue to ignore "The Looming Crisis" . He was lucky that his parents was able to provide lifelong care ,but other families are not so fortunate. He will probably end up in care home once his parents have passed away,regardless how independent the individual might evolve into. From a person viewpoint it,s scary and upsetting. And we have know about for years and years but yet we prioritise more privileged citizens. "



**D.DP13** - "Cost of travelling to work. There is no public transport alternative. Half a month's wages. The reason why there isn't any more food in the fridge"