

United Nations Convention on  
the Rights of Disabled People

# Westminster Government Civil Society Shadow Report

**March 2022**

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# UN Convention on the Rights of Persons with Disabilities (CRDP)

The CRDP is an international treaty which identifies the rights of Deaf and Disabled people as well as the obligations on government to promote, protect and ensure those rights. It aims to ensure that Deaf and Disabled people enjoy the same human rights as everyone else and can participate fully in society through the same opportunities as others. The CRDP is divided into 50 “Articles” covering a wide range of areas including education, health, employment, accessibility, independent living, access to justice and freedom from discrimination.

By ratifying the CRDP in 2009, the UK agreed to be examined by the UN Disability Committee every five years. During this examination the Committee looks at how well the CRDP is being implemented and makes recommendations for improvement. The Equality and Human Rights Commission and Deaf and Disabled People’s Organisations have a role in the examination process. This role is called shadow reporting. It is where we have a say on how well we think the Government is following the CRDP.

Inclusion London has a [dedicated web area for the CRDP](#) where you can see all [50 Articles of the CRPD](#) as well as various other resources. The CRDP is also available in [easy read](#) and [BSL](#).

# Glossary – explanation of terms used in this report

Committee	United Nations Committee for the Convention on the Rights of Disabled Persons
Concluding Observations	Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, adopted on 29 August 2017
Deaf and Disabled people	The term “disabled people” covers people with physical impairments, mobility impairments, sensory impairments, learning disabilities/difficulties, people who are neurodivergent and people living with mental distress, energy-limiting chronic illness or other long-term health conditions. Deaf people (with a capital “D”) refers to people whose first language is sign language. In Britain we use “disabled people” instead of “people with disabilities” according to the social model of disability.
Energy Limiting Chronic Illness	ELCI is an umbrella term to describe long-term health conditions in which severe fatigue – or rather energy impairment – is a key disabling feature
Learning difficulties	This is the term preferred by user led self-advocacy groups, as opposed to “learning disabilities”
Mental Distress	This is the term generally preferred by people labelled with mental illness

Neurodiversity	Neurodiversity is the diversity of human brains and minds, the infinite variation in neurocognitive functioning within our species. People who are neurodivergent may be labelled as autistic, and/or of having ADHD, dyslexia, bipolar, personality disorders.
No Recourse to Public Funds	Many migrants live in the UK with permission to stay for a limited time and with the condition that they cannot access mainstream benefits and housing assistance.
Optional Protocol	This is an additional part to the CRDP. By signing up to it, governments are allowing the Committee to investigate complaints brought to them about possible breaches of the CRDP. The UK is signed up to it.
People providing unpaid care	Sometimes referred to as “carers”. The words “care” and “carer” have negative connotations for DDP due to experiences of abuse and power imbalances in settings labelled as “care”. They are also inconsistent with the social model of disability.
Special Inquiry	Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention
White Paper	White Paper (2021) on Reforming the Mental Health Act
Work Capability Assessment	This is the benefit assessment used to test eligibility for Employment Support Allowance (ESA)

# Summary

Our report addresses a series of themes concerning implementation of the United Nations (UN) Convention on the Rights of Disabled People (CRDP) by Westminster Government. The themes were identified from evidence gathered within the earlier stages of our consultation process and then confirmed and enhanced through further consultation and data gathering. For our full methodology see [Appendix 2](#)<sup>1</sup>.

The themes detailed within the report concern:

- 1.** Intersectionality: disadvantage and barriers are compounded, for example for Disabled women, Black DDP and DDP from racialised minorities DDP who are LGBTQ+, asylum seekers, refugees or have No Recourse to Public Funds
- 2.** Continued retrogression: worse conditions across many aspects of DDP's lives
- 3.** Institutionalisation: a specific aspect of retrogression that reinforces, and is underpinned by Theme 6 on our lives being undervalued
- 4.** Silencing DDP: the further marginalisation of DDP and our voices, in the face of continued retrogression
- 5.** Disaster Planning and Humanitarian Emergencies: failures to consider DDP in fundamental aspects of public policy development
- 6.** Lives less worthy: the response to the pandemic, and other policy responses that under value DDP's lives

Our key conclusions drawn from evidence across all themes are that:

- There has been continued regression since the last public examination of the UK under the CRDP in 2017

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<sup>1</sup> p. 112

- Westminster Government (WeG) has adopted progressive initiatives in discrete areas but has not addressed the fundamental issues affecting DDP's lives
- The COVID-19 pandemic response discriminated against DDP and violated our equal right to life
- Disability equality and human rights approaches towards disability have been further undermined since 2017
- There is insufficient monitoring and promotion of the CRDP by WeG

# Introduction

- 1.** This is the civil society shadow report covering implementation of the United Nations Convention on the Rights of Deaf and Disabled People (CRDP) by Westminster Government (WeG).
- 2.** The work putting together this report has been led by Deaf and Disabled People's Organisations (DPPOs). These are organisations fully run and controlled by DDP. We have also welcomed input to this report from non-user led allies. For a full list of contributors see [Appendix 1](#)<sup>2</sup>.
- 3.** The project steering group overseeing the work consists of DDPO forums and networks across England and operates in partnership with DDPOs within each of the three devolved nations. Inclusion London is the named lead organisation. For a full methodology outlining how this report was put together see [Appendix 2](#)<sup>3</sup>.
- 4.** This report follows the social model of disability. This is consistent with human rights approaches underpinning the CRDP.
- 5.** WeG is the national Government for England. According to the latest available figures, DDP make up 22% of the English population<sup>4</sup>. This works out as around 12.44 million people out of a total population of 56.55 million. There is wide regional variation with DDP making up 27% of the population in the North East of England but only 14% in London<sup>5</sup>.
- 6.** WeG also retains “reserved powers” over certain areas of legislation and policy-making covering the devolved nations of

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<sup>2</sup> p. 109

<sup>3</sup> p. 112

<sup>4</sup> Figures for 2019/20. DWP (2021). *Family Resources Survey: financial year 2019 to 2020*. [online] 25 March. Available at: <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#disability-1>

<sup>5</sup> DWP 2021



Northern Ireland, Scotland and Wales. The extent of these reserved powers is different for each nation.

- 7.** This report does not cover British Overseas Territories. We have no contact with DDP in these areas due to lack of funding and capacity to investigate. We are not aware of any monitoring by WeG regarding compliance with the CRDP and the rights of DDP in the Territories. This situation also applies to the Crown Dependencies of Jersey, Guernsey and the Isle of Man. This is a concern for us.
- 8.** This report is one of four covering implementation of the CRDP by each of the four governments that make up the UK. For submission to the Committee these four reports will be sent as annexes to one single UK-wide report. That UK-wide report will contain a set of questions that DDPOs suggest for the Committee to ask the UK Government.
- 9.** The Committee is likely to set its questions – known as a “List of Issues” – for the UK Government at its session in March/April 2023. The UK Government will have one year to write its response to those questions. Their answers will then be examined by the Committee. At that stage DDPOs will again have a chance to have our say, in response to what the Government has told the Committee.

Reservations are where a government is not signed up to full implementation of an Article of the Convention.

- 10.** DDP and DDPOs represented by this report call on WeG to remove its current reservations on Articles 18 (Liberty of Movement and Nationality) and 24 (Education). Reservation 18 means that WeG has no obligation to uphold rights under the CRDP of DDP without settled status. Currently Deaf and Disabled asylum seekers and refugees do not have access to the full range of support they need. People are subject to the disabling impacts of detention centres which exacerbate existing conditions and cause new impairments particularly associated with mental distress<sup>6</sup>. Similar UK reservations within both the Convention on the Elimination of All

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<sup>6</sup> See Annex A, p. 147

Forms of Discrimination Against Women (CEDAW) and Convention on the Rights of the Child (CRC) have been withdrawn. The reservation on Article 24 allows WeG to continue to expand segregated education provision as outlined below.

# Report

## Theme 1: Intersectionality

20. DDP experience extra barriers if we have additional protected characteristics. Intersectionality is routinely overlooked in policy planning which heightens the levels of risk that DDP are exposed to. This was a serious omission in WeG's National Disability Strategy (NDS)<sup>7</sup>.
21. Policy-making to address non-disability equalities issues is generally inadequate in how it includes issues relevant to DDP. The Tackling Violence Against Women and Girls Strategy and Domestic Abuse Act are examples of this<sup>8</sup>. Consultations on non-disability specific issues are not automatically accessible and engagement needs to be initiated and pushed by DDPOs. An easy read consultation on the introduction of tenant satisfaction measures was only published following complaints more than a month after the original document<sup>9</sup>. The consultation document for a Bill of Rights to replace the Human Rights Act was only published in full easy read twelve days before the closing date and two months after it opened<sup>10</sup>. This

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<sup>7</sup> DDPO30

<sup>8</sup> DDPO33

<sup>9</sup> Consultation on the introduction of tenant satisfaction measures published on 9 December 2021. Easy read version added 19 January 2022. Regulator of Social Housing (2022). *Consultation on the introduction of tenant satisfaction measures*. [online] Available at: <https://www.gov.uk/government/consultations/consultation-on-the-introduction-of-tenant-satisfaction-measures#full-publication-update-history> Accessed on: 15.03.22

<sup>10</sup> MoJ (2021). Human Rights Act Reform: a Modern Bill of Rights. *consult.justice.gov.uk*, [online] 14 December. Available at: <https://consult.justice.gov.uk/human-rights/human-rights-act-reform/> Accessed on: 15.03.22

consultation is of particular concern to all DDP who want to ensure the Bill does not water down existing rights<sup>11</sup>.

22. Disaggregated disability data is needed<sup>12</sup>, for example on sexual violence experienced by women and girls who are Deaf and/or Disabled, numbers of DDP affected by other forms of hate crime, unmet social care needs among Black people and racialised minorities and LGBTQ+ communities<sup>13</sup>, on Disabled parents and child protection proceedings, and in relation to modern slavery<sup>14</sup>.
23. Intersectional issues included in the evidence we received have been incorporated throughout this report under relevant themes. Where possible these have been cross-referenced with wider evidence. Where these relate to individual personal testimonies and where there is a lack of research data, this is indicated.

## Theme 2: Continued Retrogression

19. Evidence of further retrogression relates to areas covered by the Special Inquiry, namely independent living and being included in the community, work and employment and adequate standard of living and social protection. It also relates to multiple other areas as outlined below.
20. In 2018 the EHRC warned that “Britain’s most at-risk groups of people are in danger of being forgotten and becoming trapped in disadvantage...This inequality risks becoming entrenched for generations to come, creating a two-speed society where these

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<sup>11</sup> OO6; CBCE27

<sup>12</sup> As identified by the UN Expert Group on Disability Data and Statistics, Monitoring and Evaluation

<sup>13</sup> DDPO30; DDPO33; OO1

<sup>14</sup> Lambert, M. (2021). *Does it matter that gangmasters are targeting people with disabilities?* The Clewer Initiative, [online] 4 June. Available at: <https://theclewerinitiative.org/blog/does-it-matter-that-gangmasters-are-targeting-people-with-disabilities> Accessed on: 15.03.22

groups are left behind in the journey towards a fair and equal country." These groups consist of Disabled people, some ethnic minorities, and children from poorer backgrounds for whom "Prospects... have worsened in many areas of life." Disability inequality was becoming entrenched before the pandemic. The impacts of the pandemic both exacerbated and were exacerbated by that existing inequality.

24. Support for DDP living in the community has decreased further since 2017. This not only reflects further regression under article 19 (Living independently and being included in the community) but has now led directly to breaches of a number of other articles, including 6 (Women), 7 (Children), 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment), 16 (Freedom from exploitation, violence and abuse), 20 (Personal mobility), 21 (Freedom of expression and opinion, and access to information), 23 (Respect for and the family), 26 (Habilitation and rehabilitation), 27 (Work and employment), 29 (Participation in political and public life), and 30 (Participation in cultural life, recreation, leisure and sport). Without adequate support, many DDP are unable to participate in multiple areas of life covered by the CRDP while being at greater risk of crime, exploitation and abuse.
25. WeG effectively delegates responsibility for Article 19 rights to Local Authorities (LAs) but without making sure LAs are aware of those rights and without any monitoring of their implementation. This was picked up by the Committee in 2017<sup>15</sup>, yet WeG has done nothing to rectify the situation, instead allowing the situation to worsen.

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<sup>15</sup> Paragraph 44 and recommendations 45 c).

CRDP Committee (2017). *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*. [online]. Available at: <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhspCUnZhK1jU66fLQJyHlkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2BldQaLP31QDpRcmG35KYFtgGyAN%2BaB7cyky7>. Accessed on: 15:03:22

## Article 6 – Disabled Women

26. Disabled people and women are among the groups who were due to lose the most through welfare and tax changes between 2010 and 2022. EHRC analysis found that women lose on average considerably more than men – about £400 per year on average compared to only £30 for men. On average, disabled lone parents with at least one Disabled child fare even worse, with average losses of almost £10,000 per year<sup>16</sup>.
27. Under UC, anyone unable to earn enough through paid work is not entitled to benefits if living with a partner who earns above a certain threshold. This prevents couples from living together and having an equal right to family life<sup>17</sup>. It also has the potential to trap Disabled women within abusive relationships through lack of financial independence<sup>18</sup>.
28. Disabled women are more likely to experience sexual violence than non-Disabled women<sup>19</sup>. Official figures show that sexual violence against Disabled women in England and Wales more than doubled between 2015 and 2021<sup>20</sup> yet overall prosecution rates for this type

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<sup>16</sup> Portes, J. and Reed, H. (2018). *The cumulative impact of tax and welfare reforms*. [online], Equality and Human Rights Commission, p184. Available at: <https://www.equalityhumanrights.com/sites/default/files/cumulative-impact-assessment-report.pdf> Accessed on: 15.03.22

<sup>17</sup> SR131

<sup>18</sup> WPC (2018). *Universal Credit and domestic abuse*. HC 1166, [online] 1 August.

Available at:

<https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/1166/1166.pdf>

Accessed on: 15.03.22

<sup>19</sup> HM Government (2021). *The end-to-end rape review report on findings and actions*. CP 437, [online] June, p.4. Available at:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1001417/end-to-end-rape-review-report-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1001417/end-to-end-rape-review-report-with-correction-slip.pdf) Accessed

on: 15.03.22

<sup>20</sup> ONS (2021). *Sexual offences victim characteristics, England and Wales: year ending March 2020*. [online], 18 March. Available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/articles/sexualoffencesvictimcharacteristicsenglandandwales/march2020>. Accessed on: 15.03.22

of crime have sharply decreased since 2016/17<sup>21</sup>. The Government itself has described the situation as “totally unacceptable”<sup>22</sup>. There is a paucity of disaggregated data in this area<sup>23</sup>.

29. DDPOs report how police fail to take seriously Disabled women reporting sex crimes<sup>24</sup>. The Government recognises that it needs to address lack of confidence in the police and CPS among Disabled victims<sup>25</sup>.
30. Disabled women are more likely to experience domestic abuse – according to the ONS in 2018, 16.8% of Disabled women were subjected to domestic abuse compared to 6.3% of non-Disabled women<sup>26</sup> – yet there is a shortage of support exacerbated by cuts<sup>27</sup>. This includes an absence of accessible refuges and safe accommodation and lack of mainstream domestic abuse support services equipped to work with Disabled women. A BBC investigation in 2018 found that just one in ten domestic violence refuge spaces in the UK is accessible to Disabled people with physical impairments<sup>28</sup>.

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<sup>21</sup> HM Government (2021), p.3

<sup>22</sup> HM Government 2021, p.4

<sup>23</sup> DDPO33.

<sup>24</sup> DDPO33. Also: Bateman, C. (2021). Sexual violence allegations brought by disabled women 'not going to court', campaign group says. *Sky News*, [online] 1 August. Available at: <https://news.sky.com/story/sexual-violence-allegations-brought-by-disabled-women-not-going-to-court-charity-says-12368315> Accessed on: 15.03.22

<sup>25</sup> HM Government 2021, p.38

<sup>26</sup> ONS (2018). *Domestic abuse: findings from the Crime Survey for England and Wales: year ending March 2018*. [online], 22 November. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/articles/domesticabusefindingsfromthecrimesurveyforenglandandwales/yearendingmarch2018> Accessed on: 15.03.22

<sup>27</sup> DDPO33. Also: Ryan, F. (2019). 'I'm tired and desperate' – a disabled victim of domestic violence on her struggle to survive. *The Guardian*, [online] 19 September. Available at: <https://www.theguardian.com/lifeandstyle/2019/sep/19/disabled-victim-of-domestic-violence-on-her-struggle-to-survive> Accessed on: 15.03.22

<sup>28</sup> BBC News (2018). Why disabled women can't access all refuges. *BBC.co.uk*, [online] 28 November. Available at: <https://www.bbc.co.uk/news/uk-46371441> Accessed on: 15.03.22

31. A new programme commissioned by LAs and run by the charity “Pause”<sup>29</sup> uses coercion to influence Disabled women’s reproductive choices.<sup>30</sup> The charity website lists 27 different areas within England where they work<sup>31</sup>. Women experiencing distress receive support conditional on use of long-lasting contraception. The charity describes its approach as one where they encourage women to “take responsibility for their actions”<sup>32</sup>. One woman was told by her social worker she could not have contact with her children unless she agreed to participate in the programme<sup>33</sup>. Scottish politicians have voiced opposition to the programme’s extension into Scotland on the grounds that it is contrary to a human rights approach<sup>34</sup>.
32. The UK has signed but not ratified the Istanbul Convention (Action against violence against women and domestic violence)<sup>35</sup>.

## Article 7 – Disabled children and young people (CYP)

33. Lack of adequate and accessible services has led to a sharp contrast between the lives of Disabled and non-Disabled CYP<sup>36</sup>. Pre-pandemic economic analysis showed an annual funding gap of £2.1 billion for health and social care for Disabled CYP and their families<sup>37</sup>. Support services for Disabled CYP and their families

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<sup>29</sup> Run by the charity ‘Pause’ which aims to “encourage women to take responsibility for their actions”. See: <https://www.pause.org.uk/>

<sup>30</sup> DDPO33; OO8

<sup>31</sup> See: <https://www.pause.org.uk/what-we-do/where-we-work/>

<sup>32</sup> See: <https://www.pause.org.uk/what-we-do/the-pause-model/>

<sup>33</sup> DDPO33

<sup>34</sup> Logan, C. (2019). Warning over Pause project that only supports women using contraception. *The National*, [online] 23 June. Available at: <https://www.thenational.scot/news/17724137.warning-pause-project-supports-women-using-contraception/> Accessed on: 15.03.22

<sup>35</sup> DDPO33

<sup>36</sup> OO4

<sup>37</sup> OO13



stopped or reduced during the pandemic and were slow to return<sup>38</sup>. This included services run and commissioned by LAs as well as charities, and was impacted by easements to the Children and Families Act introduced by WeG.<sup>39</sup>

34. Disabled children and their families are hit by similar issues to adults in terms of burdensome benefit re/assessments and loss of entitlements due to harsh application of eligibility criteria.<sup>40</sup>

## Article 9 – Accessibility

35. Digital exclusion remains a significant issue for DDP<sup>41</sup>. This is a growing barrier across all areas of life including bill payments, medical tests, parking charges as well as the benefits system<sup>42</sup>. The cost of digital technology for those on benefits and low incomes is one aspect of this, lack of support to use technology is another. Initiatives such as digital skills training are unable to help groups of people who require ongoing physical, mental or cognitive support when navigating the internet. There is also regional variation with the North East of England having the highest proportion of internet non-users in the country, standing at 12.1% for the region in 2018<sup>43</sup>. DDP in rural areas face additional barriers due to patchy broadband availability and distance from public library provision<sup>44</sup>.

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<sup>38</sup> DCP (2021). *Then There Was Silence*. [online]. Available at: <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/10/Then-There-Was-Silence-Full-Policy-Report-10-September-2021.pdf> Accessed on: 15.03.22

<sup>39</sup> See p.45 below

<sup>40</sup> OO4

<sup>41</sup> CBCE6, CBCE7, CBCE13, CBCE17, CBCE27; DDPO43; D.DP36; OO6, OO9, OO11. SR331.

<sup>42</sup> As footnote above.

<sup>43</sup> Better ConNEcted (n.d.) *Local Authority Briefing on Digital Exclusion*. [online]. Available at: [https://4a76708f-a1a4-410f-b467-4623329c3481.filesusr.com/ugd/a73b2d\\_6a663a8699d24e0898e890798c1275a2.pdf](https://4a76708f-a1a4-410f-b467-4623329c3481.filesusr.com/ugd/a73b2d_6a663a8699d24e0898e890798c1275a2.pdf) Accessed on: 15.03.22

<sup>44</sup> DDPO43

36. Before the pandemic 67% of benefit claimants<sup>45</sup> were Deaf or Disabled yet Universal Credit (UC) was designed to be digital by default. WeG never considered how many DDP would be disadvantaged by this and might require reasonable adjustments or support to be able to navigate the digital system<sup>46</sup>. Inaccessibility and digital by default were issues examined by the UN's Special Rapporteur on Poverty in a report dismissed by WeG in 2018<sup>47</sup>. [Appendix 7](#)<sup>48</sup> summarises information from the Independent Case Examiner (ICE) concerning incidences where the digital by default system has created difficulties.
37. There has been no progress in improving access to communication support for Deaf BSL users. This impacts negatively on Deaf people's education, employability, ability to access complaints procedures and to participate in the community<sup>49</sup>. A new private members' British Sign Language bill currently going through Parliament promises new guidance on the "promotion and facilitation" of BSL but not a right to BSL that Deaf campaigners have fought for. It will not address the shortage of BSL interpreters, the adverse impact of national framework agreements and closures

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<sup>45</sup> Edmiston, D., Baumberg Geiger, B., de Vries, R., Scullion, L., Summers, K., Ingold, J., Robertshaw, D., Gibbons, A., and Karagiannaki, E. (2020). *Who are the new COVID-19 cohort of benefit claimants?* Rapid Report 2, Welfare – at a Social Distance, [online] September, p.2. Available at: <https://hub.salford.ac.uk/welfare-at-a-social-distance/wp-content/uploads/sites/120/2020/09/WaSD-Rapid-Report-2-New-COVID-19-claimants.pdf> Accessed on: 15.03.22

<sup>46</sup> See lack of direct answer to Written Parliamentary Question on this subject. Cordova, M. (2018). Universal Credit: Disability. *UK Parliament: Written Question*, 3 September, UIN 169883. Available at: <https://questions-statements.parliament.uk/written-questions/detail/2018-09-03/169883/> Accessed on: 15.03.22

<sup>47</sup> Alston, P. (2018). *Statement on Visit to the United Kingdom*. [online]. Available at: [https://www.ohchr.org/Documents/Issues/Poverty/EOM\\_GB\\_16Nov2018.pdf](https://www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf) Accessed on: 15.03.22

<sup>48</sup> p.137

<sup>49</sup> FG6. See Annex A, p.147

of Deaf clubs on the BSL profession that are necessary for BSL's users' rights under the CRDP are to be met<sup>5051</sup>.

38. Individuals who are neurodivergent experience poor awareness of their access needs within both the private and public sector and by employers<sup>52</sup>.
39. There are ongoing barriers to accessing public transport and the built environment with insufficient engagement of DDP and DDPOs.<sup>53</sup> The Equality Act 2010 is inadequate as a means of protecting DDP rights to access as it relies on individuals to enforce.<sup>54</sup> DDP report that parking designated for use by Disabled people is not enforced as strictly as in other countries and British police will not intervene<sup>55</sup>. Anecdotally the British approach is followed within British Overseas Territories such as Bermuda<sup>56</sup>.
40. Rail passengers who use wheelchairs have voiced health and safety concerns over assistance to board trains<sup>57</sup>. Many rail stations lack

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<sup>50</sup> West, E. (2018). Why is there a shortage of Sign interpreters? *British Deaf News*, [online] 7 August. Available at: <https://www.britishdeafnews.co.uk/why-is-there-a-shortage-of-sign-interpreters/#:~:text=A%20spokesman%20for%20SignHealth%20confirmed,forced%20down%20by%20government%20policy.Accessed> on: 15.03.22

<sup>51</sup> OO7; OO11

<sup>52</sup> D.DP34, D.DP35.

<sup>53</sup> CBCE6, CBCE7, CBCE9, CBCE14, CBCE18, CBCE27, CBCE28, CBCE31, CBCE33; DDPO32, DDPO36, DDPO43; D.DP2, D.DP14, D.DP28, D.DP31, D.DP35; OO9, FG1, FG4. SR35, SR36, SR40, SR80, SR134, SR159, SR176, SR239, SR274, SR279, SR284, SR314, SR315, SR323, SR329.

<sup>54</sup> House of Lords Liaison Committee (2021). *The Equality Act 2010: the impact on disabled people Follow-up report*. [press release], 9 September. Available at: <https://committees.parliament.uk/committee/187/liaison-committee-lords/news/157367/key-provisions-in-equality-act-2010-not-implemented/> Accessed on: 15.03.22

<sup>55</sup> DDPO32

<sup>56</sup> As footnote above

<sup>57</sup> Pring, J. (2021). Regulator probes train ramp safety failings at rail operators across Britain. *Disability News Service*, 16 December. Available at: <https://www.disabilitynewsservice.com/regulator-probes-train-ramp-safety-failings-at-rail-operators-across-britain/> Accessed on: 15.03.22

step free access and passenger assistance is notoriously unreliable. Rail operators have said that “substantial” government investment is needed to make train stations accessible.<sup>58</sup> Many smaller stations now lack platform staff to provide rail assistance while railway companies are moving towards Driver Only Operated trains without guards, leading to more stations becoming inaccessible to passengers who require assistance to board and dismount from trains.<sup>59</sup>

41. DDP report barriers in using other forms of public and specialist transport provision. Only one wheelchair user can travel on a bus at a time<sup>60</sup>. The supreme court ruled that wheelchairs take priority over prams<sup>61</sup>, but this is difficult to enforce in practice<sup>62</sup>. Dial-a-Ride can be unreliable and limit where they will take passengers<sup>63</sup>. Taxi-cards provide eligible DDP with a set number of reduced price journeys per month but the number is dependent upon individual LAs and is subject to a postcode lottery<sup>64</sup>. DDP report mixed experiences using taxis with individual reports of taxi drivers not using health and safety procedures for transporting wheelchair users and of unwillingness to take Disabled passengers<sup>65</sup>.

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<sup>58</sup> Steen, B., McCarthy, H., Mhonda, J., Lucey, G., Vey, J., Ilic, N. (2021). Inclusive Transport Strategy Evaluation: Baseline Report. Department for Transport, [online]. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1042358/inclusive-transport-strategy-evaluation-baseline-report.odt](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1042358/inclusive-transport-strategy-evaluation-baseline-report.odt)  
Accessed on: 15.03.22

<sup>59</sup> DDDPO43

<sup>60</sup> CBCE18

<sup>61</sup> *FirstGroup Plc (Respondent) v Paulley (Appellant)* [2017] UKSC 4. Available at: <https://www.supremecourt.uk/cases/docs/uksc-2015-0025-judgment.pdf>. Accessed on: 15.03.22

<sup>62</sup> CBCE6, CBCE18

<sup>63</sup> CBCE18

<sup>64</sup> CBCE18

<sup>65</sup> D.DP28

42. Emotional assistance animals do not have any legal recognition or standing in the UK unlike the US<sup>66</sup>. For example, Under the USA's federal Fair Housing Act (FHA), an emotional support animal is viewed as a "reasonable accommodation" in a housing unit that has a "no pets" rule for its residents<sup>67</sup>.
43. Access was negatively impacted by COVID through the outside dining areas on pavement and the suspension of Blue Badge parking.<sup>68</sup> There are also examples where the pandemic has been used to permanently take forward retrogressive measures. A temporary access exclusion for DDP to York city centre has been made permanent<sup>69</sup>. This is being challenged in the high court.
44. The pandemic caused isolation for many DDP<sup>70</sup>, particularly those who are digitally excluded. For others, mainstream adoption of remote technology led to an unprecedented degree of inclusion for certain groups of DDP in areas including education and study (article 24)<sup>71</sup>, medical appointments and health (25)<sup>72</sup>, work (27)<sup>73</sup>, benefit assessments and tribunals (28)<sup>74</sup>, participation in politics and public life (29)<sup>75</sup>, and culture and leisure activities (30)<sup>76</sup>. The ELCI community particularly benefited. Pre-pandemic 72% of survey respondents with ELCI reported having had remote access requests

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<sup>66</sup> Society for Companion Animal Studies (2022). Emotional Support Animals (ESAs) in the UK. *scas.org.uk*, [online] 19 January. Available at: <https://www.scas.org.uk/pets-and-mental-health/emotional-support-animals-esas-in-the-uk/#:~:text=As%20it%20currently%20stands%2C%20Emotional,Animals%20do%20have%20additional%20rights>. Accessed on: 15.03.22

<sup>67</sup> DDPO32

<sup>68</sup> CBCE13, CBCE16, CBCE28, FG2, DDPO36

<sup>69</sup> CBCE31, DDPO36

<sup>70</sup> CBCE11, CBCE27; DDPO26; D.DP25; SR23, SR351

<sup>71</sup> FG1

<sup>72</sup> CBCE10; SR346

<sup>73</sup> D.DP13; SR195, SR329, SR331

<sup>74</sup> SR183

<sup>75</sup> CBCE25

<sup>76</sup> DPPO15

denied<sup>77</sup>. DDP report that this level of access has not been adopted as a ‘new normal’, rather the gains are now being removed<sup>78</sup>.

45. The implementation of ‘colourful crossings’ in an attempt to attract customers back to urban centres post-pandemic renders pedestrian crossings inaccessible to certain groups including those who are visually impaired. DDPOs were not consulted beforehand<sup>79</sup>. In response to campaigning, the Mayor of London imposed a moratorium upon installation of the crossings on routes controlled by Transport for London and requested London LAs do the same<sup>80</sup>. WeG’s Department of Transport chose not to make similar requests of LAs outside London<sup>81</sup>.

## Article 16 – Freedom from exploitation, violence and abuse

46. Disability hate crime has risen both on- and off-line. Prosecutions are infrequent and organisations supporting Deaf and Disabled victims report poor responses from the police.
47. Reports of disability hate crime rose by 9% between 2019 and 2020<sup>82</sup> and by 14% from 2017 – 2019<sup>83</sup>. Disability hate crime in

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<sup>77</sup> DDPO15

<sup>78</sup> FG1; DDPO15, DDPO36; SR74, SR331

<sup>79</sup> D.DP2

<sup>80</sup> Transport for All (2021). *Success as Mayor of London agrees to “pause” installation of new Colourful Crossings*. [press release] 3 November. Available at: <https://www.transportforall.org.uk/news/success-as-mayor-of-london-agrees-to-pause-installation-of-new-colourful-crossings/> Accessed on: 15.03.22

<sup>81</sup> Pike, F. (2021). Letter to Pip Jackson of The Access Association, 4 October. Available at: <https://accessassociation.co.uk/wp-content/uploads/2021/10/DFT-20211004.pdf> Accessed on: 15.03.22

<sup>82</sup> Home Office (2020). *Hate crime, England and Wales, 2019 to 2020*. [online], updated 28 October. Available at: [www.gov.uk/government/publications/hate-crime-england-and-wales-2019-to-2020/hate-crime-england-and-wales-2019-to-2020](http://www.gov.uk/government/publications/hate-crime-england-and-wales-2019-to-2020/hate-crime-england-and-wales-2019-to-2020) Accessed on: 15.03.22

<sup>83</sup> Home Office (2019). *Hate Crime, England and Wales, 2018/19*. [online], 15 October. Available at:

London soared by 20% in 2019/2020 with around half classified as violence<sup>84</sup>. One in four DDP feel unsafe to travel on public transport due to negative attitudes from other passengers<sup>85</sup>. A Parliamentary inquiry into online hate crime against Disabled people heard how DDP were leaving social media due to abuse and found that “Self-regulation of social media has failed disabled people”<sup>86</sup>.

48. Only one in 62 cases of disability hate crime received a charge in 2019 – 2020<sup>87</sup>. DDPOs supporting victims report poor responses from the Metropolitan Police across London which reflects experiences reported across the UK<sup>88</sup>.
49. Hate crime did not stop with the pandemic. There were 420 disability hate crimes recorded in Cheshire 2020-2021, which represents a 22% increase<sup>89</sup>. Almost a fifth of victims were aged

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[assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/839172/hate-crime-1819-hosb2419.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/839172/hate-crime-1819-hosb2419.pdf) Accessed on: 15.03.22

<sup>84</sup> Clarke, H. (2020). Disability hate crime rates soar in Hackney. Hackney Gazette, [online], 6 November. Available at:

<https://www.hackneygazette.co.uk/news/crime/disability-hate-crime-rates-in-hackney-soar-6547226> Accessed on: 15.03.22

<sup>85</sup> Coffey, H. (2018). One in four disabled people don't use public transport due to negative attitudes from other passengers, new research finds. *Independent*, [online] 10 October. Available at: <https://www.independent.co.uk/travel/news-and-advice/uk-disabled-travel-accessibility-public-transport-report-trains-buses-a8577211.html> Accessed on: 15.03.22

<sup>86</sup> Petitions Committee (2019). *Online abuse and the experience of disabled people*. HC 759, 22 January. Available at:

<https://publications.parliament.uk/pa/cm201719/cmselect/cmpetitions/759/759.pdf> Accessed on: 15.03.22

<sup>87</sup> Leonard Cheshire (2020). *Reports of violent disability hate crime continue to rise as number of police charges fall again*. [press release], 8 October. Available at: <https://www.leonardcheshire.org/about-us/our-news/press-releases/reports-violent-disability-hate-crime-continue-rise-number-police> Accessed on: 15.03.22

<sup>88</sup> Inclusion London (2021). *Poor Police Response*. [online]. Available at:

<https://www.inclusionlondon.org.uk/news/poor-police-response-report-disabled-victims-of-hate-crime/> Accessed on: 15.03.22

<sup>89</sup> BBC News (2022). Cheshire hate crime rise sees more disabled people targeted. *bbc.co.uk*, [online] 26 January. Available at: <https://www.bbc.co.uk/news/uk-england-merseyside-60138262> Accessed on: 15.03.22

under 15. There was also a significant rise in online hate crime towards DDP and concerns in particular about a form of hate crime known as “doxxing”<sup>90</sup>.

50. DDP with identities under more than one protected characteristic are subject to harassment and hostility on multiple and intersecting levels. In the evidence we received we heard about bullying of CYP from GRT communities at school<sup>91</sup> and about hostility experienced by DDP who are asylum seekers and refugees<sup>92</sup> and from GRT communities<sup>93</sup>. There is no offence in law of intersectional hate crime<sup>94</sup>.
51. DDP continue to see a link between increased experiences of hostility and government rhetoric and media representations concerning benefit cheats<sup>95</sup>. DDP experienced a new layer of demonisation during the pandemic when “the vulnerable” were blamed for the economic harm caused by lockdowns within political messaging (implicitly) and public debate (more explicitly)<sup>96</sup>. Positive media campaigns relating to disability tend to focus on the Paralympics and individual achievements in “overcoming challenges” to succeed in society<sup>97</sup>, rather than promoting a positive image of disability linked to the realities of our daily lives which, despite progress – some of which can be linked to the pandemic<sup>98</sup>, remain largely misunderstood.

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<sup>90</sup> CBCE19.

<sup>91</sup> DDPO38

<sup>92</sup> FG2

<sup>93</sup> D.DP43

<sup>94</sup> CBCE10; DDPO41

<sup>95</sup> CBCE6, CBCE8, CBCE9, CBCE11, CBCE13, CBCE14, CBCE23, CBCE27, CBCE28, CBCE31, DDPO14, DDPO42, D.DP29, D.DP44, FG1, FG2, SR14, SR72, SR83, SR124, SR129, SR130, SR145, SR149, SR168, SR180, SR193, SR222, SR264, SR303, SR309, SR315, SR324, SR327, SR331

<sup>96</sup> SR18, SR129, SR142, SR177

<sup>97</sup> CBCE16, CBCE23, DDPO46

<sup>98</sup> SR303



# Article 19 – Living independently and being included in the community

## Social Care

52. The crisis in social care funding and provision continues to have an adverse impact on DDP's right to independent living. Real-terms LA spending on social care was £700 million below what it was in 2010/11.<sup>99</sup> The EHRC warned that funding caps to social care support could force Disabled people into care homes in potential breach of their human rights<sup>100</sup>. NHS organisations revised their policies in response to threats of legal action<sup>101</sup> but individual support packages funded by both LAs and the NHS are still subject to cuts and decisions in breach of Article 19 rights. Anecdotal reports have increased of DDP's threatened with moves to residential care against their wishes due to costs of community-living support<sup>102</sup>.
53. Hundreds of thousands of DDP are not getting the support they need due to cuts, delays and lack of entitlement. In November 2021 a survey by the Association of Directors of Adult Services found that: almost 400,000 people are now waiting for an assessment of

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<sup>99</sup> The King's Fund (2019). *More people asking for social care support but fewer getting it as demand leaves social care system at crisis point*. [press release], 26 April. Available at: <https://www.kingsfund.org.uk/press/press-releases/social-care-system-crisis-point> Accessed on: 15.03.22

<sup>100</sup> Ryan, F. (2017). NHS cost cutting leaving disabled people 'interned' in care homes. *The Guardian*, [online] 25 October. Available at: <https://www.independent.co.uk/news/uk/home-news/disabled-people-interned-care-homes-nhs-cost-cutting-a8019906.html> Accessed on: 15.03.22

<sup>101</sup> EHRC (2018). *NHS u-turns on discriminatory policies*. [press release] 31 May. Available on: <https://www.equalityhumanrights.com/en/our-work/news/nhs-u-turns-discriminatory-policies> Accessed on: 15.03.22

<sup>102</sup> People are too afraid of retribution – having their support removed – to go on record even anonymously

their needs or service<sup>103</sup>. Age UK has estimated that 1.5 million disabled older people in England are not getting the social care support they need<sup>104</sup>. Between 2015/16 and 2019/20, 120,000 more people requested social care support but around 14,000 fewer people received either long- or short-term support.<sup>105</sup> Inadequate social care provision has led to the phenomenon of “bed-blocking” within the NHS, where patients well enough for discharge have to stay in hospital until social care support can be agreed and set up<sup>106</sup>. It was estimated that lack of social care provision led to 2.5 million lost bed days over the course of 917 days from 8 June 2017 and 12 December 2019, and at a cost of £587m to the NHS<sup>107</sup>. Key reasons for delayed discharge from institutional units reported in monthly NHS digital Assuring Transformation data are lack of social care and lack of suitable housing<sup>108</sup>.

54. There are a number of groups of DDP who are not covered by the way entitlement for social care support is decided, for example disabled parents<sup>109</sup> and people who are neurodivergent<sup>110</sup>. As a consequence they have significant unmet needs. Support from both the NHS and LAs often falls short of the Autism Act 2009<sup>111</sup>. People who need access to Augmentative and Alternative Communication (AAC) are calling for a fully funded, easy to understand system for acquiring AAC technology together with comprehensive teaching

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<sup>103</sup> ADASS, (2021). Snap Survey reveals a rapidly deteriorating picture of Social Care Services. *Press Release*, 29 November. Available at: <https://www.adass.org.uk/snap-survey-nov21-rapidly-deteriorating-social-services> Accessed on: 15.03.22

<sup>104</sup> Age UK. Written evidence submitted by Age UK [ASC 055]. Available at: <https://committees.parliament.uk/writtenevidence/25880/html/> Accessed on: 15.03.22

<sup>105</sup> Bottery, S. and Ward, D. (2021). *Social care 360*. [online]. Available at: <https://www.kingsfund.org.uk/publications/social-care-360> Accessed on: 15.03.22

<sup>106</sup> D.DP23. See also Annex A, p.147

<sup>107</sup> *BMJ* (2019). Lack of social care has cost the NHS 2.5 million bed days since last election, charity says. *bmj.com*, [online] 5 December. Available at: <https://www.bmj.com/content/367/bmj.l6870> Accessed on: 15.03.22

<sup>108</sup> OO13

<sup>109</sup> CBCE6, CBCE27; DDPO16, D.DP44, OO8

<sup>110</sup> D.DP34; SR150

<sup>111</sup> D.DP35, D.DP42

on how it<sup>112</sup>. People with learning difficulties should not be denied access to AAC based on pre-judgements that they can't learn to use it<sup>113</sup>.

55. The sustainability of the social care support system is in question. More than 1.5 million hours of commissioned home care could not be provided between August and October because of a lack of staff, despite record growth in provision. One in two councils has had to respond to a care home closure or bankruptcy over the past six months<sup>114</sup>. The social care workforce is significantly undervalued. The average pay for support workers in England who assist people to live independently in the community is £17,695 or £9.05 per hour – 45p per hour below the Real Living Wage<sup>115</sup>. Many support workers would be paid up to 39% more if they held equivalent roles within other public funded sectors and the sector loses 34% of its workforce every year<sup>116</sup>. Support for DDP to manage Direct Payments and directly employ PAs has been taken away.<sup>117</sup> WeG has repeatedly turned down invitations to meet with DDPOs concerning the development of our own vision for future independent living support<sup>118</sup>.
56. Many of England's 152 LAs responsible for social care introduce year on year budget savings within their disability spend, often justifying cuts of millions of pounds using progressive headings such as "promoting independence" and "working more efficiently". Cheshire West and Chester Council, cut its disability services by

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<sup>112</sup> DDPO38

<sup>113</sup> DDPO38

<sup>114</sup> ADASS, (2021). Snap Survey reveals a rapidly deteriorating picture of Social Care Services. *Press Release*, 29 November. Available at: <https://www.adass.org.uk/snap-survey-nov21-rapidly-deteriorating-social-services> Accessed on: 15.03.22

<sup>115</sup> Community Integrated Care (2021). *Unfair to Care: understanding the social care pay gap and how to close it*. [online] Available at: <https://www.unfairtocare.co.uk/wp-content/uploads/2021/07/Unfair-To-Care-Summary-Report-Single-Pages.pdf> Accessed on: 15.03.22

<sup>116</sup> Community Integrated Care 2021

<sup>117</sup> CBCE7, CBCE8, CBCE22; FG1, FG3

<sup>118</sup> CBCE27; DDPO5; FG4

£1.3 million in their 2021-22 budget<sup>119</sup>. In March 2022, Bristol City Council voted through cuts of £11 million to adult social care as part of an overall savings package designed to meet a budgetary shortfall of £19.5 million<sup>120</sup>. Such figures are typical. Since 2018, three English LAs have become bankrupt with another 25 reportedly on the brink.<sup>121</sup> In October 2020 the Health and Social Care Committee estimated an additional £7bn per year is required for social care by 2023/24 as a starting point to cover demographic changes and raise staff pay in line with the National Minimum Wage.<sup>122</sup> This leads to DDP reliant on social care support living in constant anxiety as they face regular reviews aimed at reducing their support<sup>123</sup>.

57. The shortage of social care staff was exacerbated by both EU withdrawal and the pandemic<sup>124</sup>. DDP living in the community and

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<sup>119</sup> DDPO6; DDPO9

<sup>120</sup> Bristol City Council (2022). *Full Council – Supplementary Information – Wednesday 2 March 2022*. Public Document Pack, [online] 24 February, STATEMENT PS 47, p.49. Available at: <https://democracy.bristol.gov.uk/documents/b30042/Public%20Forum%20republish%20-%20Statements%20received%20at%2015th%20Feb%20first%20budget%20meeting%2002nd-Mar-2022%2014.00%20.pdf?T=9> Accessed on: 15.03.22

<sup>121</sup> NAO (2021). *Local government finance in the pandemic*, HC 1240 [online] 10 March. Available at: <https://www.nao.org.uk/wp-content/uploads/2020/08/Local-government-finance-in-the-pandemic.pdf> Accessed on: 15.03.22

Butler, P. (2021). Swingeing cuts on cards as councils in England face funding crisis, watchdog warns. *The Guardian*, [online] 10 March. Available at: <https://www.theguardian.com/society/2021/mar/10/swingeing-cuts-on-cards-as-councils-in-england-face-funding-crisis-watchdog-warns> Accessed on: 15.03.22

Butler, P. (2021). Slough goes bankrupt after discovery of £100m ‘black hole’ in budget. *The Guardian*, [online] 2 July. Available at: <https://www.theguardian.com/society/2021/jul/02/slough-goes-bankrupt-after-discovery-of-100m-black-hole-in-budget> Accessed on: 15.03.22

<sup>122</sup> Health and Social Care Committee (2020). *Social care: funding and workforce*. HC 206 [online] 22 October. Available at: <https://committees.parliament.uk/publications/3120/documents/29193/default/> Accessed on: 15.03.22

<sup>123</sup> CBCE6, CBCE7, CBCE10; DDPO6; FG1; SR245

<sup>124</sup> CBCE7, CBCE10, CBCE14, CBCE16; DDPO26; D.DP4; FG1; SR155; SR337

acting as individual employers for Personal Assistants (PA) – a group of around 70,000 DDP in England – seem to have been entirely omitted from pre-Brexit preparations. DDP campaigners were told in a meeting with the Migration Advisory Committee that WeG had only alerted them to potential issues with social care workers employed by agencies and had omitted to make them aware of the existence of PA users<sup>125</sup>. In September 2021, the National Care Forum warned that the sector is facing the “most acute recruitment and retention crisis” in its history, with more than 110,000 vacancies.<sup>126</sup> DDP who are LGBTQ+ face additional barriers within social care where being “out” can lead to discrimination and recruitment of PAs is more difficult<sup>127</sup> DDP in rural areas also face additional barriers to recruitment since travel time is not included within support packages and potential workers may be put off by longer unpaid journey times between visits<sup>128</sup>.

58. Social care charging is having an increasingly detrimental impact on the incomes of DDP, forcing some to go without support while others are trapped in debt<sup>129</sup>. According to charging rules, LAs need to leave DDP with a set minimum income. The minimum income level has stayed the same for the past five years while inflation has risen<sup>130</sup>. LAs have steadily introduced harsher charging policies. In 2020, the high court ruled that Norfolk County Council’s new policy discriminated against “severely disabled” people under the European Convention on Human Rights because the council would be charging those with the highest support needs proportionately

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<sup>125</sup> Meeting between DPAC and MAC on 01.04.2021

<sup>126</sup> Delahunty, (2021). Care sector facing 'most acute recruitment and retention crisis' in its history, not-for-profit organisations warn. *Thirdsector.com*, [online] 29 September. Available at: <https://www.thirdsector.co.uk/care-sector-facing-most-acute-recruitment-retention-crisis-its-history-not-for-profit-organisations-warn/management/article/1728476> Accessed on: 15.03.22

<sup>127</sup> CBCE22; DDPO30

<sup>128</sup> CBCE7, CBCE9, CBCE16, CBCE23; DDPO2, DDPO26, DDPO27; D.DP34; OI1; FG2; SR180, SR326.

<sup>129</sup> DDPO3 p.54; CBCE5; CBCE8; CBCE16; CBCE22; D.DP1

<sup>130</sup> D.DP1

more than those with lower support needs<sup>131</sup>. Other DDP in the same situation need to initiate their own individual challenges against their respective LAs in order to access their rights under this ruling.<sup>132</sup> Many DDP, especially those with the highest support needs who are most likely to be affected, may not be aware of the ruling or have the knowledge or support to initiate such a challenge and continue to be discriminated against.

59. Recent figures from six LAs indicate that there could be more than 100,000 Disabled people in social care debt across England<sup>133</sup>. A previous investigation in 2018 found over 166,000 people in arrears on their social care payments. More than 78,000 of these had debt management procedures started against them for non-payment<sup>134</sup>. The true figure is likely to be higher as not all LAs responded and there is no central monitoring by WeG.
60. When social care needs are not met there are extreme consequences. Research published in 2021 found that for the five years from 2010, the loss of social care funding caused 23,662 additional deaths<sup>135</sup>. It is likely this trend continued after the years under study up until the pandemic as cuts only worsened over that period.

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<sup>131</sup> SH, R (On the Application Of) v Norfolk County Council & Anor (Rev 1) [2020] EWHC 3436 (Admin) (18 December 2020) Available at:

<https://www.bailii.org/ew/cases/EWHC/Admin/2020/3436.html> Accessed on: 15.03.22

<sup>132</sup> CBCE8

<sup>133</sup> Pring, J. (2022). Tens of thousands driven into debt by care charges, new figures show. *Disability News Service*, [online] 17 February. Available at:

<https://www.disabilitynewsservice.com/tens-of-thousands-driven-into-debt-by-care-charges-new-figures-show/> Accessed on: 15.03.22

<sup>134</sup> GMB Union (2018). *At least 166,000 trapped in social care debt*. [press release] 4 June. Available at: <https://www.gmb.org.uk/news/least-166000-trapped-social-care-debt>. Accessed on: 15.03.22

<sup>135</sup> Martin, S., Longo, F., Lomas, J., Claxton, K. (2021). Causal impact of social care, public health and healthcare expenditure on mortality in England: cross-sectional evidence for 2013/2014. *BMJ Open*, vol. 11, issue 10. Available at:

<https://bmjopen.bmj.com/content/11/10/e046417> Accessed on: 15.03.22

61. There is a major shortage of advocacy services. Independent advocacy is a crucial aspect of assessments and care planning for many who have ‘substantial difficulty’ taking part in Care Act processes. In one case, a person was told that the local authority ‘no longer commissions advocacy support’<sup>136</sup>.
62. Unprecedented numbers of cases are investigated by the Local Government and Social Care ombudsman (LGSCO) who finds “the adult social care system is progressively failing to deliver for those who need it most.”<sup>137</sup> See [Appendix 4](#) for a summary of recent Ombudsman complaints.<sup>138</sup>
63. During the pandemic, social care support was reduced or suspended<sup>139</sup>. Anecdotally, we heard that LAs would not increase funding to help DDP requiring extra support due to lockdown conditions<sup>140</sup>. Many PAs could not go to work in DDP’s own homes because of lack of access to PPE or because they were self-isolating. This contributed to the 50% rise in deaths among DDP living in the community in receipt of social care support from April 2020 – March 2021. Of the 25,000 deaths, data suggests only 8.7% were COVID-19 related.<sup>141</sup> From January – July 2020, a total of 345 non-COVID patients died of thirst across all settings, a 48 per cent increase on the previous five-year average of 232. Age UK explained that Disabled older people stopped drinking because they feared they could not get to the toilet.<sup>142</sup>

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<sup>136</sup> OO1

<sup>137</sup> LGSCO (2021). Failing social care system reflected in relentless rise in Ombudsman’s upheld complaints. *lgo.org.uk*, [online]. Available at: <https://www.lgo.org.uk/information-centre/news/2021/sep/failing-social-care-system-reflected-in-relentless-rise-in-ombudsman-s-upheld-complaints> Accessed on: 15.03.22

<sup>138</sup> p.124

<sup>139</sup> CBCE13; OO4, OO6, OO13

<sup>140</sup> For related case studies see Annex A, p.147

<sup>141</sup> Gayle, V., Hamada, R., Boutaud, R. (2021). Revealed: Thousands more deaths in home care during pandemic. *The Bureau of Investigative Journalism*, [online] 10 May. Available at: <https://www.thebureauinvestigates.com/stories/2021-05-10/revealed-thousands-of-pandemic-deaths-in-home-care> Accessed on: 15.03.22

<sup>142</sup> Nelson, N. (2020). Thirst killed 345 non-COVID patients in hospitals and care homes during first lockdown. *Mirror*, [online] 13 December. Available at:



64. The Coronavirus Act 2020 introduced easements on the Care Act 2014 allowing LAs to suspend duties to meet the social care support needs of DDP. The easements affected duties to assess needs, carry out financial assessments and make support plans. Only eight LAs officially used these powers with only two making use of the most significant easement suspending the duty to meet need. By the end of June 2020 all of them had reversed their decision to operate the easements. WeG then dropped the provision for easements from April 2021, one year after they were passed.<sup>143</sup> DDP nevertheless experienced long assessment delays, difficulties contacting social services and reduced support provision from care providers throughout the pandemic.
65. WeG Health and Social Care bill focuses on social care support as an older person's issue and there has been a complete absence of engagement with DDPOs. When DDPOs wrote to the Secretary of State for Health and Social Care asking to meet he was too busy.<sup>144</sup> There was not one social care user among the 43 "leaders and experts" he assembled for a health and social care reform summit.<sup>145</sup> The Care Services Minister admitted she is unaware of the views of DDPOs on WeG's social care reforms.<sup>146</sup>

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<https://www.mirror.co.uk/news/politics/thirst-killed-345-non-covid-23158070> Accessed on: 15.03.22

<sup>143</sup> Carter, C. (2021). Government scraps coronavirus provisions allowing councils to suspend key Care Act duties. *Community Care*, [online] 25 March. Available at: <https://www.communitycare.co.uk/2021/03/25/government-scraps-coronavirus-provisions-allowing-councils-suspend-key-care-act-duties/> Accessed on: 15.03.22

<sup>144</sup> See Appendix 8, p.140

<sup>145</sup> D.DP29. Also see: Pring, J. (2021). Minister invited 44 'leaders' to care summit, but not one disabled people's organisation. *Disability News Service*, [online] 14 October. Available at: <https://www.disabilitynewsservice.com/minister-invited-44-leaders-to-care-summit-but-not-one-disabled-peoples-organisation/> Accessed on: 15.03.22

<sup>146</sup> Pring, J. (2018). Care minister admits ignoring views of disabled people on government's reforms. *Disability News Service*, [online] 7 October. Available at: <https://www.disabilitynewsservice.com/care-minister-admits-ignoring-views-of-disabled-people-on-governments-reforms/> Accessed on: 15.03.22 ; Pring, J. (2021). Government 'ignored DPOs' in drawing up social care white paper. *Disability News Service*, [online] 9 December. Accessible at: <https://www.disabilitynewsservice.com/government-ignored-dpos-in-drawing-up-social-care-white-paper/> Accessed on: 15.03.22



66. Of the £5.4bn of new funding for social care from 2022-2025, only £1.7bn will go towards the wider system; the rest will be spent on implementing a new social care cap<sup>147</sup>. The cap limits the amount that any individual will need to pay towards the costs of social care within their lifetime. The cap is contrary to the system originally legislated for, but never implemented, in the Care Act 2014. It will mean people with lower levels of assets will need to spend the same as wealthier people before reaching the cap. The new funding is being raised via a Health and Social Levy raised through National Insurance contributions and will slightly increase poverty rates, from 16.2% to 16.3%<sup>148</sup>.

## Housing

67. There is significant unmet housing need. In 2018 there were 365,000 DDP living in unsuitable properties while the average waiting time for an accessible property was 25 months<sup>149</sup>. Unsuitable conditions include DDP unable to bathe or leave their homes.<sup>150</sup>
68. WeG policy does not adequately address the lack of suitable housing<sup>151</sup>. DDP are disproportionately reliant on social housing.

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<sup>147</sup> Foster, D. (2021). *Proposed reforms to adult social care (including cap on care costs)*. Research Briefing, [online] 11 February. Available at: <https://commonslibrary.parliament.uk/research-briefings/cbp-9315/> Accessed on: 15.03.22

<sup>148</sup> Institute for Social and Economic Research (2021). *How will the new Health and Social Care Levy impact on household incomes*. University of Essex, [online] 20 September. Available at: <https://www.iser.essex.ac.uk/2021/09/20/-health-and-social-care-levy> Accessed on: 15.03.22

<sup>149</sup> EHRC (2018), *Housing and Disabled People*, [online]. Available at: <https://www.equalityhumanrights.com/en/housing-and-disabled-people-britain%E2%80%99s-hidden-crisis> Accessed on: 15.03.22

<sup>150</sup> See above. Also case studies in Ryan, F. (2019) *Crippled: Austerity and the Demonization of Disabled People*. London: Verso, p.107.

<sup>151</sup> MHCLG (2021). *The charter for social housing residents: social housing white paper*. [online]. Available at: <https://www.gov.uk/government/publications/the-charter-for-social-housing-residents-social-housing-white-paper/the-charter-for-social-housing-residents-social-housing-white-paper> Accessed on: 15.03.22 ; Pring, J. (2019).

According to the latest figures from 2019, one-quarter (24.7%) of disabled people rented social housing, compared with just 8.2% of non-disabled people<sup>152</sup>. Private renting can be unsuitable for a number of reasons including discrimination by landlords, inability to make up the shortfall between housing benefit payments and market rents, and the need for security of tenure. The Equality Act 2010 does not provide sufficient safeguards against housing discrimination. According to the housing charity Shelter, Black, Asian and Disabled tenants are disproportionately likely to face discrimination looking for a home, and to end up inhabiting shoddy, unsafe and unsuitable accommodation<sup>153</sup>.

69. WeG housing policy does not address the need for more accessible social housing and training in disability equality for social housing workers<sup>154</sup>. The NDS included proposals to encourage home ownership among DDP and invest in the building of more segregated “supported housing”<sup>155</sup> with nothing to address the substantive issue of accessible social housing stock. The Social Housing green paper only mentions disability in relation to supported housing and the following white paper committed WeG merely to “look at how we can improve access to suitable homes for disabled people”. There is only “fleeting” mention of the housing needs of Disabled people in the government’s National Planning Policy Framework and little or no guidance for councils that makes

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Government faces legal action threat over accessible housing failure. *Disability News Service*, 19 September. Available at:

<https://www.disabilitynewsservice.com/government-faces-legal-action-threat-over-accessible-housing-failure/> Accessed on: 15.03.22

<sup>152</sup> ONS (2019). *Disability and housing, UK: 2019*. [online] 2 December. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandhousinguk/2019> Accessed on: 15.03.22

<sup>153</sup> Butler, P. (20). Black, Asian and disabled tenants ‘more likely to face housing discrimination’. *The Guardian*, [online] 26 May. Available at: <https://www.theguardian.com/society/2021/may/26/black-asian-disabled-tenants-more-likely-face-housing-discrimination> Accessed on: 15.03.22

<sup>154</sup> Need for more accessible housing: CBCE7, CBCE8, CBCE9, CBCE10, CBCE13, CBCE14, CBCE16, DDPO36, D.DP28; FG1; FG2CBCE10Need for specifically social housing: Need for disability training for housing workers: CBCE8; D.DP28

<sup>155</sup> NDS 2021, pp.38-39.

clear the need for accessible housing and their duties to plan for it<sup>156</sup>. The Framework is undermined by the de-regulation of planning for Permitted Development – where commercial premises are converted for residential use<sup>157</sup>. Research commissioned by WeG but only published following Parliamentary intervention found that new housing created through permitted development rights is more likely to be characterised by worse quality residential environments than housing created under the full planning permission process<sup>158</sup>.

70. Problems with housing are compounded by LA and Housing Association failures to carry out repairs and maintenance<sup>159</sup>, as exposed by news reports and an ITV documentary entitled “Surviving Squalor: Britain’s Housing Shame”<sup>160</sup>. Conditions such as water penetration, damp, mould and pest infestations exacerbate existing impairments while creating others. Outsourcing practices

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<sup>156</sup> Pring, J. (2019). Government faces legal action threat over accessible housing failure. *Disability News Service*, [online] 19 September. Available at: <https://www.disabilitynewsservice.com/government-faces-legal-action-threat-over-accessible-housing-failure/> Accessed on: 15.03.22

<sup>157</sup> LGA (2021). *LGA submission to the Ministry of Housing, Communities and Local Government on the National Planning Policy Framework and National Model Design Code*. [online] 26 March. Available at: LGA submission to the Ministry of Housing, Communities and Local Government on the National Planning Policy Framework and National Model Design Code Accessed on: 15.03.22

<sup>158</sup> The Bartlett School of Planning (2020). Government publishes UCL-led research on permitted development housing quality. *ucl.ac.uk*, [online] 21 July. Available at: <https://www.ucl.ac.uk/bartlett/planning/news/2020/jul/government-publishes-ucl-led-research-permitted-development-housing-quality> Accessed on: 15.03.22; Clifford, B., Canelas, P., Ferm, J., Livingstone, N., Lord, A. and Dunning, R. (2020). *Research into the quality standard of homes delivered through change of use permitted development rights*. MHCLG, [online]. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/902220/Research\\_report\\_quality\\_PDR\\_homes.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/902220/Research_report_quality_PDR_homes.pdf) Accessed on: 15.03.22

<sup>159</sup> CBCE16; D.DP22; OI1

<sup>160</sup> *Surviving Squalor: Britain's Housing Shame* (2021). [TV programme] ITV, 12 September: 22.15.

Hewitt, D. (2021). Britain's Housing Shame: A story of shocking conditions and tenants' despair at a lack of action. *itvNEWS*, [online] 12 September. Available at: <https://www.itv.com/news/2021-09-12/britains-housing-shame-shocking-conditions-and-despair-at-a-lack-of-action> Accessed on: 15.03.22

contribute to building failures including the Grenfell disaster. Grenfell survivors describe how, as the LA outsourced contracts to private companies to work on their estate, complaints were left unanswered<sup>161</sup>. The good practice example set by Bournemouth Council in bringing their building works back in-house in order to improve building quality has not been followed by other LAs<sup>162</sup>. According to the BCP Council website, Bournemouth Building and Maintenance Limited (BBML) is an operating company wholly owned by BCP Council providing maintenance for Bournemouth Borough Council's owned housing stock customer. Their satisfaction ratings are consistently over 98%, some of the highest ratings ever recorded for social housing providers in the country<sup>163</sup>.

## Mental Health Support Services

71. Pre-pandemic both child and adult mental health services were over-stretched and facing escalating demand set against funding cuts. Professionals described Child and Mental Health Services (CAMHS) as “not fit for purpose”, citing how CYP were not being seen by services until multiple suicide attempts.<sup>164</sup>
72. There is a lack of choice in mental health treatments with what is on offer rooted in the medical model of disability<sup>165</sup>. There is an emphasis on pharmaceuticals while therapeutic availability is limited to short term interventions based on a CBT model<sup>166</sup>. This is not appropriate for everyone, as the NHS website states, but it is very

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<sup>161</sup> Tucker, P. Outsourcing is killing local democracy in Britain. Here's how we can stop that. *The Guardian*, [online] 2017. Available at: <https://www.theguardian.com/commentisfree/2017/aug/10/outsourcing-killing-local-democracy-britain-stop-it> Accessed on: 15.03.22

<sup>162</sup> BCP Council (n.d.) Bournemouth Building and Maintenance Ltd. [online]. Available at: <https://www.bournemouth.gov.uk/Apply/Counciljobs/BBML/BournemouthBuildingMaintenanceLtdVacancies.aspx> Accessed on: 15.03.22

<sup>163</sup> BCP Council n.d.

<sup>164</sup> BBC News (2018). Child mental health: Camhs 'not fit for purpose'. *BBC.co.uk*, [online] 24 September. Available at: <https://www.bbc.co.uk/news/health-45607313> Accessed on: 15.03.22

<sup>165</sup> CBCE16, CBCE24; DDPO28, DDPO29, DDPO33; D.DP36; SR199

<sup>166</sup> Evidence references DDPO27; DDPO33; D.DP36

difficult to obtain access to anything else – especially for more complex mental health needs – except for those with the resources to access private provision<sup>167</sup>. Potential side effects of medications are not made accessible to patients<sup>168</sup> and people with mental distress report iatrogenic harm<sup>169</sup>. The Mental Health Act White Paper does not provide sufficient emphasis on MH community services to be in line with a human rights approach<sup>170</sup>. People with mental distress have had positive experiences with social prescribing<sup>171</sup>. This is included in the NHS Long-term Plan 2019 but for the benefits of this provision to be rolled out it needs sustainable funding directed at independent, community-based organisations<sup>172</sup>.

73. Between 2015 and 2020 there were 56 mental health-related deaths in England and Wales where coroners identified a lack of staffing or service provision as a “matter of concern”, meaning they believed “there is a risk that future deaths could occur unless action is taken”<sup>173</sup>. Bed shortages were cited in a number of the cases. In the case of Julian Gaunt, the senior coroner was particularly concerned that people with less serious problems could receive treatment from the local wellbeing service faster than those with more complex conditions<sup>174</sup>. This is consistent with national

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<sup>167</sup> NHS (n.d.) Overview – Cognitive behavioural therapy (CBT). *nhs.uk*, [online] Available at: <https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/cognitive-behavioural-therapy-cbt/overview/> Accessed on: 15.03.22

<sup>168</sup> DDPO29; D.DP36; FG4

<sup>169</sup> CBCE27; DDPO22, DDPO29; D.DP36; SR199

<sup>170</sup> DDPO28; SR3

<sup>171</sup> D.DP24; SR214

<sup>172</sup> Buck, D. and Eubank, L. (2020). What is Social Prescribing. Available at: <https://www.kingsfund.org.uk/publications/social-prescribing>. Accessed on: 15.03.22

<sup>173</sup> Jayanetti, C. (2021). Coroners warned of mental health care failings in dozens of inquests. *The Guardian*, [online] 5 September. Available at: <https://www.theguardian.com/society/2021/sep/05/coroners-warned-of-mental-health-care-failings-in-dozens-of-inquests> Accessed on: 15.03.22

<sup>174</sup> Whymark, B. (2019). Mentally ill father’s death could spark review into psychological treatment services. *Eastern Daily Press*, [online] 30 April. Available at: <https://www.edp24.co.uk/news/gaunt-inquest-norfolk-nsft-prevention-future-deaths-report-1388008> Accessed on: 15.03.22

prioritisation for the funding of short-term interventions aimed at reducing the cost burden of lost working days due to anxiety and depression<sup>175</sup>.

74. During the pandemic many MH support services were closed or reduced. Anecdotally we know of one acute ward that was emptied at short notice for COVID patients. We received evidence relating to a lack of step down support from secure settings into the community, one leading directly to suicide<sup>176</sup>.

## Community sector

75. As public services have withdrawn, DDPOs and the voluntary sector have tried to fill gaps while facing growing threats to their own survival. Between 2016 and 2019, 124 user-led groups – more than a quarter (26 per cent) of one national network were forced to close. Two years later, a further 33 had gone.<sup>177</sup> During the pandemic many organisations stepped up in an attempt to mitigate the harm and disruption during the pandemic while dealing with their own difficulties<sup>178</sup>.

## Article 20 – Personal mobility

76. DDP's mobility has been adversely affected by loss of disability benefits through harsher eligibility requirements such as the PIP 20

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<sup>175</sup> See: Layard, R. (2015). *A New Priority for Mental Health*. Centre for Economic Performance, [online]. Available at: <https://cep.lse.ac.uk/pubs/download/EA035.pdf> Accessed on: 15.03.22

<sup>176</sup> CBCE10; SR72

<sup>177</sup> Pring, J. (2021). Government's strategy fails to support DPOs, as more close due to 'hostile environment'. *Disability News Service*, 5 August. Available at: <https://www.disabilitynewsservice.com/governments-strategy-fails-to-support-dpos-as-more-close-due-to-hostile-environment/> Accessed on: 15.03.22

<sup>178</sup> DDPO30



metre rule.<sup>179</sup><sup>180</sup> As of January 2020, 102,000 Motability customers had lost PIP awards that entitled them to vehicles to facilitate travel and mobility.<sup>181</sup> DDP who do not meet the eligibility criteria may be unable to access public transport, especially those living in rural areas with infrequent bus services and unstaffed rail stations.

The introduction of Low Traffic Neighbourhoods (LTNs) was taken forward during the pandemic without adequate engagement. Criticisms of LTNs include lack of information and longer journey times for DDP making travel much more difficult.<sup>182</sup>

## Article 23 – Respect for home and the family

77. Too often children are removed from Disabled parents instead of providing them with the support they need to fulfil their parental role<sup>183</sup>. Child social work teams commonly view possession of an impairment as a risk factor in and of itself. Adult teams do not challenge this nor put in place support to address the unmet need

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<sup>179</sup> For a more detailed explanation see: DPAC and Inclusion London (2017). *Follow Up Submission: Response to UNCRPD Inquiry Report and UK Government Response*. [online], p.49. Available at:

<https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.inclusionlondon.org.uk%2Fwp-content%2Fuploads%2F2017%2F03%2FUN-inquiry-response-DPACIL-Final-1.doc&wdOrigin=BROWSELINK> Accessed on: 15.03.22

<sup>180</sup> For figures relating to PIP and Motability losses calculated 2017-2018 see: UK DDPO UNCRDP Monitoring Coalition (2018). *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland – Annual Alternative report from civil society*. [online], p.33. Available at: <https://www.inclusionlondon.org.uk/wp-content/uploads/2021/10/Final-DDPO-UNCRPD-alternative-12-month-follow-up-report-2018-.doc> Accessed on: 15.03.22

<sup>181</sup> Disability Rights UK (2020). Over 100,000 DLA Claimants Lose Motability Vehicles After PIP Reassessment. [disabilityrightsuk.org](https://www.disabilityrightsuk.org), [online]. Available at: <https://www.disabilityrightsuk.org/news/2020/january/over-100000-dla-claimants-lose-motability-vehicles-after-pip-reassessment> Accessed on: 15.03.22

<sup>182</sup> Transport for All (2021). *Pave The Way: the impact of Low Traffic Neighbourhoods (LTNs) on disabled people, and the future of accessible Active Travel*. [online]. Available on: <https://www.transportforall.org.uk/wp-content/uploads/2021/01/Pave-The-Way-full-report.pdf> Accessed on: 15.03.22

<sup>183</sup> DDPO33; OO8

that is the actual risk factor. Anecdotally, judiciary say that over 50% of parents before them in care proceedings appear to have some form of learning difficulties whether diagnosed or not<sup>184</sup>.

Independent advocacy for people with learning difficulties in child protection cases is not statutory despite evidence of its importance and courts do not produce documents in easy read to help parents know what to expect. Organisations working with parents report that most receive no support following removal of their children. DHSC has not responded to requests to update and promote guidance for working with Disabled parents. The most recent guidance from WeG was 2007<sup>185</sup>. NDS did not include Disabled parents despite consultation responses requesting this<sup>186</sup>. Additionally, Disabled women have restricted access to parenting options such as IVF and adoption<sup>187</sup>.

78. The practice of sending Disabled adults many miles away to institutional placements denies a right to family life and disrupts relationships. The LGSCO found that Croydon Council's failure to support an autistic man and his mother led to 'stress, anxiety and breakdown in family life'<sup>188</sup>.

## Article 24 – Education

79. There is severe and deliberate retrogression of DDP's right to inclusive education in line with WeG's continuing reservation on this article.

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<sup>184</sup> 008

<sup>185</sup> 008

<sup>186</sup> 008

<sup>187</sup> SR23

<sup>188</sup> Turner, A. (2021). Council's failure to support autistic man and mother led to 'stress, anxiety and breakdown in family life'. *Community Care*, [online] 21 December. Available at: <https://www.communitycare.co.uk/2021/12/21/ombudsman-croydon-council-failure-support-autistic-man-mother-stress-family-breakdown/> Accessed on: 15.03.22; LGSCO (2021). *Investigation into a complaint against London Borough of Croydon*. Reference number: 20 003 686, [online] 04 November. Available at: <file:///C:/Users/User/Downloads/REPORT%2020%20003%20686%20LB%20Croydon.pdf> Accessed on: 15.03.22



80. Placements in segregated “special schools” compared to mainstream education have increased steadily since 1999. Between 1999 and 2021, the percentage of children in England with an EHCP attending “mainstream” education fell from 64.6% to 50.4%, while those attending “special schools” and other forms of segregated education rose from 35.4% to 49.6%<sup>189</sup>. In 2021 there was an additional 11,655 pupils without an ECHP educated in segregated settings.
81. Abuse scandals within such settings appear in the media but much more goes on that is not exposed with use of physical restraint and seclusion rooms common practice.<sup>190 191</sup> The Independent Inquiry into Child Sexual Abuse (IICSA) has called for tougher inspection and oversight of residential special schools<sup>192</sup>.
82. To date WeG has invested in “59 new free special schools for children with complex SEND” and “a further 75 are in the pipeline”<sup>193</sup>. The Chancellor’s Autumn 2021 budget included a pledge to invest £2.6 billion for Disabled CYP in England. Previous SEND capital grants went either to fund new special school buildings or segregated units either within or acting as satellite

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<sup>189</sup> ONS (2021). *Special educational needs in England*. [online] 24 June. Available at: <https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england> Accessed on: 15.03.22

<sup>190</sup> Titheridge, N. (2021). Pupil abuse in special school secure rooms filmed on CCTV. *BBC News*, [online] 14 October. Available on: <https://www.bbc.co.uk/news/uk-58885635> Accessed on: 15.03.22

Hattenstone, S. and Allison, E. (2019). ‘He was covered in bruises’: the vulnerable children being harmed in special schools. *The Guardian*, [online] 6 July. Available on: <https://www.theguardian.com/society/2019/jul/06/he-was-covered-in-bruises-the-vulnerable-children-being-harmed-in-special-schools> Accessed on: 15.03.22

<sup>191</sup> See Annex A p.147

<sup>192</sup> Independent Inquiry into Child Sexual Abuse (2022). *Residential schools investigation report*. HC 1131, [online] March. Available at: <https://www.iicsa.org.uk/key-documents/28486/view/iicsa-residential-schools-investigation-report-march-2022.pdf> Accessed on: 15.03.22

<sup>193</sup> NDS, p.66.

provision (ie not on the same site) for mainstream schools. This new money could expand special school placements by 30,000.<sup>194</sup>

83. Declining support in mainstream schools means families too often feel they have no choice but to opt for special education.<sup>195</sup> According to the most recent published figures, Disabled pupils without an EHC support plan are five times more likely to receive a permanent exclusion than non-Disabled pupils. For Disabled pupils with an EHC support plan the figure is 2.5 times more likely.<sup>196</sup>
84. The high court found that SEND cuts proposed by Bristol LA were unlawful<sup>197</sup> <sup>198</sup> but the SEND crisis is ongoing<sup>199</sup>. In 2020, SEND tribunal panels upheld LA decisions in only 193 of 3,770 hearings – an LA success rate of only 5%, and the worst on record<sup>200</sup> <sup>201</sup>. Families are having to go through expensive, time-consuming and stressful tribunals to get legal rights enforced.

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<sup>194</sup> Keer, M. (2021). New Budget funds for SEND capital spending. But how did LAs spend previous cash? We checked.... *Special Needs Jungle*, [online] 28 October. Available on: <https://www.specialneedsjungle.com/new-budget-funds-for-send-capital-spending-but-how-did-las-spend-previous-cash-we-checked/> Accessed on: 15.03.22

<sup>195</sup> DDPO38

<sup>196</sup> Department for Education (2021). *Permanent exclusions and suspensions in England: 2019 to 2020*. [online] 29 July. Available at: <https://www.gov.uk/government/statistics/permanent-exclusions-and-suspensions-in-england-2019-to-2020> Accessed on: 15.03.22

<sup>197</sup> Keer, M. (2018). Legal victory for Bristol parents against SEND cuts – what does it mean for other areas? *Special Needs Jungle*, [online] 6 August. Available on: [www.specialneedsjungle.com/legal-victory-bristol-parents-against-send-cuts-what-mean-other-areas/](http://www.specialneedsjungle.com/legal-victory-bristol-parents-against-send-cuts-what-mean-other-areas/) Accessed on: 15.03.22

<sup>198</sup> DDPO4

<sup>199</sup> Smith, J. (2021). Bristol Send Crisis Shows Little Signs of Improvement for Families. *Chopsy Bristol*, [online] 6 October. Available on: <https://chopsybaby.com/magazine/bristol-send-crisis-shows-little-signs-of-improvement-for-families/> Accessed on: 15.03.22

<sup>200</sup> Keer, M. (2020). 95% of decisions in favour of parents, but nobody wins at the SEND Tribunal. *Special Needs Jungle*, [online] 11 December. Available on: [\(https://www.specialneedsjungle.com/95-decisions-favour-parents-nobody-wins-send-tribunal/](https://www.specialneedsjungle.com/95-decisions-favour-parents-nobody-wins-send-tribunal/) Accessed on: 15.03.22

<sup>201</sup> DPPO38; OO13

85. Racism and intersectional oppression continue to present significant barriers for DDP in education. Factors such as poverty and unsafe family environments all act as a multiplier effect and contribute to higher rates of exclusion<sup>202</sup>. These additional factors are also amplified for certain communities, for example, people in Black and Minority Ethnic families are between two and three times more likely to be in persistent poverty than people in White families<sup>203</sup>. According to the latest official figures on permanent exclusions for 2019/2020, a Black Caribbean boy on Free School Meals (FSM) and with an EHCP has a 74.75% chance of permanent exclusion; for a Black Caribbean boy on FSM who is Disabled but does not have an EHCP his chance is 149.5%<sup>204</sup>. Pupils who are Gypsy or Roma have the highest rate of exclusions being more than three times likely as a White British child to be excluded<sup>205</sup>. Exclusion rates vary between LAs: in some areas Black Caribbean pupils are 5-6 times more likely to be excluded than White pupils<sup>206</sup>.
86. Life outcomes for excluded pupils are poor. According to one study, the proportion of excluded children who experience mental distress is likely close to 100 per cent even though this is not reflected in

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<sup>202</sup> HM Government (2020). *Timpson Review of School Exclusion*. CP92, [online] May, p.34. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/807862/Timpson\\_review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/807862/Timpson_review.pdf). Accessed on: 15.03.22

<sup>203</sup> Social Metrics Commission (2020). *Measuring Poverty 2020*. [online]. Available at: <https://socialmetricscommission.org.uk/wp-content/uploads/2020/06/Measuring-Poverty-2020-Web.pdf> Accessed on: 15.03.22

<sup>204</sup> Statistics derived from analysis of: Department for Education (2021). *Permanent exclusions and suspensions in England: 2019 to 2020*. [online] 29 July. Available at: <https://www.gov.uk/government/statistics/permanent-exclusions-and-suspensions-in-england-2019-to-2020> Accessed on: 15.03.22

<sup>205</sup> Department for Education 2021

<sup>206</sup> Analysis of Department for Education exclusions statistics, 2018-19. McIntyre, N., Parveen, N. and Thomas, T. (2021). Exclusion rates five times higher for black Caribbean pupils in parts of England. *The Guardian*, [online] 24 March. Available at: <https://www.theguardian.com/education/2021/mar/24/exclusion-rates-black-caribbean-pupils-england> Accessed on: 15.03.22

official figures<sup>207</sup>. Pupils officially excluded from school at age 12 are four times more likely to be in prison by age 24<sup>208</sup>. David Lammy MP is quoted as saying, “The relationship between pupil referral units [a type of alternative provision maintained by the local authority] and the criminal justice system has become symbiotic, and the rise of exclusions is creating a pipeline of young people into our prison system. There is no fiscal or moral case to go on like this.”<sup>209</sup>

87. Students who are Deaf/Disabled face entrenched barriers to higher education. A number of universities have faced criticism for disability discrimination over recent years<sup>210</sup>. A report published in 2020 by the independent Higher Education Commission concluded that Disabled students are often forced to interrupt their studies because of the “financial burden, a lack of support, and struggling to fully access their teaching and learning”, while the complaints process creates further barriers<sup>211</sup>. The report called for reform of the Disabled Students Allowance (DSA) system. We heard about Deaf and Disabled students denied access to their chosen courses

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<sup>207</sup> Gill, K, with Quilter-Pinner H. and Swift, D. (2017). Making the Difference: breaking the link between school exclusion and social exclusion. London: Institute for Public Policy Research. [online], p.16. Available at: <https://www.ippr.org/files/2017-10/making-the-difference-report-october-2017.pdf> Accessed on: 15.03.22

<sup>208</sup> The Edinburgh Study of Youth Transitions and Crime (2016). Study links school exclusion to prison. [press release] 6 April. Available at: <https://www.ed.ac.uk/news/2013/exclusionprison-280213> Accessed on: 15.03.22

<sup>209</sup> Weale, S. (2017). School exclusions data in England only 'the tip of the iceberg'. *The Guardian*, [online] 17 October. Available at: <https://www.theguardian.com/education/2017/oct/10/school-exclusion-figures-date-england-only-tip-iceberg> Accessed on: 15.03.22

<sup>210</sup> Pring, J. (2020). Disabled students ‘face appalling barriers’ at latest university to face discrimination claims. *Disability News Service*, [online] 13 August. Available at: <https://www.disabilitynewsservice.com/disabled-students-face-appalling-barriers-at-latest-university-to-face-discrimination-claims/> Accessed on: 15.03.22

<sup>211</sup> Higher Education Commission (2020). *Arriving At Thriving: Learning from disabled students to ensure access for all*. [online] 6 October. Available at: <https://www.policyconnect.org.uk/research/arriving-thriving-learning-disabled-students-ensure-access-all> Accessed on: 15.03.22; Pring, J. (2020). Disabled students call for strict new rules for universities that fail on access. *Disability News Service*, [online] 5 November. Available on: <https://www.disabilitynewsservice.com/disabled-students-call-for-strict-new-rules-for-universities-that-fail-on-access/> Accessed on: 15.03.22

due to lack of access and support provision as well as prejudice and lack of awareness by educational professionals<sup>212</sup>. Pandemic access gains for students who require participation are anecdotally being taken back<sup>213</sup>.

88. The Coronavirus Act 2020 introduced an easement to the Children and Families Act 2014 which lessened the legal obligations for provision of support for Deaf and Disabled CYP.<sup>214</sup> This, combined with the fact that online learning is not accessible to all, meant that many simply went without education during lockdowns and/or shielding.<sup>215</sup> Due to the intersection between poverty and disability lack of digital technology within households was an additional factor preventing remote learning.<sup>216</sup>

## Article 25 – Health

89. Access to NHS services and treatment is increasingly difficult, including GP and specialist consultant appointments, dentistry, chiropody, physiotherapy, and occupational therapy<sup>217</sup>. This affects everyone but has a disproportionate impact on DDP, due to both increased reliance as well as access needs. There are additional barriers for those subject to intersecting oppressions. For example: there is a need for culturally competent and accessible services for Black DDP and DDP from racialised minorities communities<sup>218</sup>; for Deaf BSL users who are Black people and from racialised minorities, English may only be a third or fourth language and therefore access to fully skilled interpreters and face-to-face interpreting is even more important<sup>219</sup>; DDP who are refused asylum

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<sup>212</sup> CBCE4 (unpublished due to inclusion of personal data); FG4

<sup>213</sup> FG1

<sup>214</sup> DDPO38

<sup>215</sup> DDPO38; CBCE10

<sup>216</sup> CBCE10

<sup>217</sup> CBCE32; SR51, SR105, S107, R1SR222, SR234

<sup>218</sup> DDPO33

<sup>219</sup> FG1; FG6

can be denied secondary healthcare<sup>220</sup>, unless they meet certain criteria<sup>221</sup>.

90. Factors including tightened eligibility for accessing mobility aids and equipment have led to unprecedented numbers of DDP using crowdfunding sites to beg for money to purchase essential such items as wheelchairs. leading to a strengthening of the charity model of disability.<sup>222</sup>
91. Diagnosis assessment waiting times are at an all-time high while anecdotally DDP are blocked at the first hurdle by GPs from even beginning the process<sup>223</sup>. Diagnoses are required in order to access support.
92. DDP labelled with “Medically Unexplained Symptoms” (MUS) often report iatrogenic harm (harm caused by medical treatment)<sup>224</sup>. In October 2021 NICE revised their guidance on ME/CFS to reflect changes that people with ELCI have spent years campaigning for. These include removal of Graded Exercise Therapy, which has been proven to cause harm to patients, and CBT. People with ELCI have spent years fighting for their own accounts of their illness to be listened to and for the physical basis of their conditions to be recognised and treated. The Royal College of Psychiatrists and other physicians wrote criticising the changes, reflecting continuing dismissal of DDP’s lived experience<sup>225</sup>. There is already evidence of people experiencing Long COVID becoming subject to similar disbelief when requiring adjustments at work<sup>226</sup>. DDP call both for a

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<sup>220</sup> FG2

<sup>221</sup> Namely, that they receive support from the Home Office under section 4(2) of the Immigration and Asylum Act 1999 or from a local authority under section 21 of the National Assistance Act 1948 or Part 1 (care and support) of the Care Act 2014.

<sup>222</sup> Ryan, F. (2017) Need a Wheelchair? Pay for it yourself. *The Guardian*, [online] 19 July. Available at: <https://www.theguardian.com/society/2017/jul/19/wheelchair-pay-yourself-disabled-people-crowdfunding>. Accessed on: 15.03.22

<sup>223</sup> SR74; SR92; SR109; SR111; SR209

<sup>224</sup> DDPO12

<sup>225</sup> See SR210 for an individual account relating to NICE guidelines and Lyme Disease.

<sup>226</sup> TUC (2021). *Workers’ experiences of long COVID – A TUC report*. [online] Available at: <https://www.tuc.org.uk/sites/default/files/2021->

rebalancing of power to bring health service provision in line with human rights approaches and for greater investment in biomedical research<sup>227</sup>.

93. WeG avoided the large scale medicine shortages that were predicted as a result of EU withdrawal<sup>228</sup>. Individual DDP have nevertheless been adversely impacted by lack of availability of specific medicines key to their health and well-being<sup>229</sup>.
94. It is complicated and difficult to obtain from health professionals the medical evidence required for benefit re/assessments. GPs commonly charge anywhere up to £200<sup>230</sup>. Due to long waiting lists, specialists, psychiatrists and community mental health teams commonly discharge DDP between acute crises meaning there is no named professional able to provide current evidence. Anecdotally, this is frequently interpreted by benefit assessors in contravention of their own guidelines to mean that the person's condition no longer limits their ability to take part in daily life/ is no longer subject to disabling barriers.

## Article 26 – Habilitation and Rehabilitation

95. Concerns regarding shortages and understanding of the need for specialist rehabilitation services have been reported<sup>231</sup>. There is a lack of accessible data on availability of vision rehabilitation officers. Healthwatch Birmingham investigated local visual impairment rehabilitation services in response to reports from people of

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Accessed on: 15.03.22

<sup>227</sup> CBCE8; DDPO12; D.DP10, D.DP30

<sup>228</sup> Dayan, M. (2021). What happened to those Brexit medicines shortages?

*NuffieldTrust.org.uk*, [online] 29 September. Available at:

<https://www.nuffieldtrust.org.uk/news-item/what-happened-to-those-brexit-medicines-shortages> Accessed on: 15.03.22

<sup>229</sup> CBCE32; SR107

<sup>230</sup> DDPO37; FG1, FG3

<sup>231</sup> OO9



difficulties getting care and support for sight loss and visual impairment<sup>232</sup>. In response to their recommendations the Council committed in March 2022 to recruit an additional Visual Impairment Rehabilitation Officer<sup>233</sup>.

## Article 27 – Work and employment

96. DDP and DDPOs report increasing barriers to both finding and sustaining employment. WeG has claimed a reduction in the disability employment gap but research by leading academics shows that, once increased numbers in the workplace identifying as Disabled people are factored in, the disability employment gap hasn't changed since 2013<sup>234</sup>, and has even widened since the pandemic<sup>235</sup>.
97. Disabled workers earn one fifth (20%) less than non-Disabled workers. Disabled women face the biggest pay gap, paid on average 36% (£3.68 an hour, or around £6,700 a year) less than non-disabled men.<sup>236</sup> DDP are over-represented in insecure work

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<sup>232</sup> healthwatch Birmingham (2020). What challenges do people with sight loss face accessing vision rehabilitation services in Birmingham? [online] 21 September. Available at: <https://healthwatchbirmingham.co.uk/report/what-challenges-do-people-with-sight-loss-face-accessing-vision-rehabilitation-services-in-birmingham/> Accessed on: 15.03.22

<sup>233</sup> healthwatch Birmingham (2022). *Improving services for people with vision impairment*. [press release] 4 March. Available at: Accessed on: 15.03.22

<sup>234</sup> Wass, V. and Jones, M. (2020). MEASURING DISABILITY AND INTERPRETING TRENDS IN DISABILITYRELATED DISADVANTAGE. *Disabilityatwork.co.uk*, [online]. Available at: <https://www.disabilityatwork.co.uk/wp-content/uploads/2020/08/Briefing-Note-disability-measurement-.pdf> Accessed on: 15.03.22

<sup>235</sup> Pring, J. (2022). Ministers 'should admit figures show zero progress on disability employment'. *Disability News Service*, [online] 24 February. Available at: <https://www.disabilitynewsservice.com/ministers-should-admit-figures-show-zero-progress-on-disability-employment/> Accessed on: 15.03.22

<sup>236</sup> TUC (2020). Disabled workers earning a fifth less than non-disabled peers – TUC analysis reveals. *TUC.org.uk*, [online], 31 October. Available at: <https://www.tuc.org.uk/news/disabled-workers-earning-fifth-less-non-disabled-peers-tuc-analysis-reveals> Accessed on: 15.03.22



98. Disability discrimination in the workplace is a major issue. DDP report workplace bullying in large public sector organisations such as the NHS, LAs and government departments. DWP lost more disability discrimination cases at employment tribunal than any other employer in Britain between 2016 and 2019.<sup>242 243</sup> It lost a

further six between 2020-2021.<sup>244</sup> This is despite signing a legally binding agreement with EHRC to improve equality and diversity in the workplace.<sup>245</sup> Many disability discrimination cases do not make it to tribunal. Barriers include the three month one day time limit for bringing cases and the need to prove you are Disabled in order to be covered by the law. This particularly impacts on people who are neurodivergent and may never have received a formal diagnosis.<sup>246</sup>

99. DDP report that WeG's Access to Work disability employment scheme has become increasingly difficult to access since 2013<sup>247</sup>. To be eligible, DDP must work over a certain number of hours and earn over a certain threshold. DDP in self-employment must be able to show a viable three year business plan. There is a cap on individual support packages which limits DDP with high support needs from career progression to senior roles. After initiation of a legal challenge, WeG raised the cap so that fewer DDP would be affected<sup>248</sup>.
100. Disabled workers were over-represented among redundancies during the pandemic. From July to November 2020, 21.1 per thousand Disabled workers were made redundant compared to 13.0 per thousand who are non-Disabled<sup>249</sup>.

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<sup>244</sup> Pring, J. (2021). DWP admits losing six more disability-related employment tribunals. *Disability News Service*, [online] 25 November. Available at: <https://www.disabilitynewsservice.com/dwp-admits-losing-six-more-disability-related-employment-tribunals/> Accessed on: 15.03.22

<sup>245</sup> EHRC (2020). DWP signs legally binding agreement to improve equality and diversity in the workplace. [press release], 17 December. Available at: <https://www.equalityhumanrights.com/en/our-work/news/dwp-signs-legally-binding-agreement-improve-equality-and-diversity-workplace> Accessed on: 15.03.22

<sup>246</sup> See point regarding assessment delays, p.46.

<sup>247</sup> Hale, C. (2017). *Barriers to Work: A survey of Deaf and Disabled people's experiences of the Access to Work programme in 2015/2016*. Inclusion London, [online]. Available at: [https://www.inclusionlondon.org.uk/wp-content/uploads/2017/10/Barriers-to-Work\\_InclusionLondon\\_Oct-2017-1.pdf](https://www.inclusionlondon.org.uk/wp-content/uploads/2017/10/Barriers-to-Work_InclusionLondon_Oct-2017-1.pdf) Accessed on: 15.03.22

<sup>248</sup> McVey, E. (2018). *Access To Work Scheme*. Statement UIN HCWS563, [online] 20 March. Available at: <https://questions-statements.parliament.uk/written-statements/detail/2018-03-20/HCWS563> Accessed on: 15.03.22

<sup>249</sup> ONS (2021). *Coronavirus and redundancies in the UK labour market: September to November 2020*. [online]. Available at:

101. DWP runs WeG's flagship disability employment scheme, Disability Confident. It is not clear what tangible difference the scheme has made. By September 2019, 13,600 employers signed up to the scheme had promised to provide 8,763 new paid jobs and 1,903 traineeships for DDP people between them, making an average of 0.78 jobs and traineeships each despite including some of the largest employers in the country.<sup>250</sup>
102. Anecdotally we still hear reports that DWP work coaches do not have sufficient Deaf and disability awareness and that DWP advisors repeatedly communicate with Deaf and Disabled claimants in non-accessible ways<sup>251</sup>. A claimant-led project is calling for community-based employment support that is removed from the DWP and separate from the benefits system<sup>252</sup>.
103. DDPOs and allies have called for flexibilities in the qualification requirements for entry to apprenticeships in order to include people with learning difficulties<sup>253</sup>.
104. Thousands of DDP on out of work benefits are subject to mandatory work search requirements under threat of sanctions (having their benefits stopped or reduced) for non-compliance. Sanctions have been linked to benefit deaths and harm caused to DDP<sup>254</sup>. They have also been found to discriminate against DDP compared to

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<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/articles/labourmarketeconomicanalysisquarterly/december2020#redundancies-among-different-groups-of-employees-and-industries> Accessed on: 15.03.22

<sup>250</sup> Pring, J. (2019). 'Dismal' job figures show failure of Disability Confident, says de Cordova. Disability News Service, [online] 10 October. Available on:

<https://www.disabilitynewsservice.com/dismal-job-figures-show-failure-of-disability-confident-says-de-cordova/> Accessed on: 15.03.22

<sup>251</sup> FG6

<sup>252</sup> DDPO47

<sup>253</sup> DDPO46; OO13

<sup>254</sup> CBCE7, CBCE16. See for examples Appendix 6, p.134, deaths of Elaine Morral, Danielle Obeng and Brian Bailey whose suicides were linked to conditionality and sanctions.

non-Disabled job-seekers<sup>255</sup>. Research found that conditionality for Deaf and Disabled job-seekers is itself literally “mad-making” and is supported by a volume of robust evidence that it moves DDP further from employability<sup>256</sup>. A DWP whistleblower recently exposed that DDP waiting for their WCA and clearly not able to safely engage in work-related activity are being forced to attend weekly job centre meetings.<sup>257</sup> WeG has consistently ignored calls to end conditionality for this group. DDPOs are concerned by anecdotal evidence that new claimants are not being made aware of their right to undergo assessment through a WCA for exemption from conditionality due to disability<sup>258</sup>. Due to a lack of disaggregated data under UC we are not able to see how many DDP are affected in this way.

## Article 28 – Adequate standard of living and social protection

### Poverty

105. EHRC research into the cumulative impact of welfare reform and tax measures since 2010 found that negative impacts are particularly large for households with more Disabled members, and individuals with higher support needs.<sup>259</sup> Nearly half of those in poverty, 6.8

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<sup>255</sup> Geiger, B.B. (2018). A Better WCA is Possible. London: Demos, p.17. Available at: [https://demosuk.wpengine.com/wp-content/uploads/2018/02/2018\\_A\\_Better\\_WCA\\_is\\_possible\\_FULL-4.pdf](https://demosuk.wpengine.com/wp-content/uploads/2018/02/2018_A_Better_WCA_is_possible_FULL-4.pdf). Accessed on: 15.03.22

<sup>256</sup> Mehta, J., Clifford, E., Taggart, D. and Speed, E. (2018). When your mental health disappears overnight: Constant anxiety of benefit sanctions is toxic for mental health of disabled people. *Clinical Psychology Forum*, (312), 4-6.

<sup>257</sup> Pring, J. (2022). DWP is forcing distressed claimants to attend weekly meetings, says whistleblower. *Disability News Service*, [online] 10 March. Available at: <https://www.disabilitynewsservice.com/dwp-is-forcing-distressed-claimants-to-attend-weekly-meetings-says-whistleblower/> Accessed on: 15.03.22

<sup>258</sup> D.DP38

<sup>259</sup> Portes and Reed 2018

million people, are from families in which someone is Disabled.<sup>260</sup> WeG has pushed on with the roll out of UC despite evidence of severe hardship caused to claimants and dismissed concerns raised by the UN Special Poverty Rapporteur.<sup>261</sup>

106. Low incomes set against rising inflation is a big concern for DDP. 21% of respondents to our survey (72 out of 351) raised this issue with some attributing it to Brexit<sup>262</sup>. The four year benefit freeze (2016 – 2020) affected 27 million people while sweeping another 400,000 into poverty.<sup>263</sup>
107. Use of foodbanks and homelessness have both increased amongst DDP. More than six in ten (62%) working-age people referred to food banks in early 2020 were Disabled. Of those households referred to food banks over this period, those affected by disability were generally in greater levels of debt. 23% households referred to food banks were losing more than a quarter of their income on repaying debt or loans, compared to 14% among households not affected by disability. 41% of Disabled people were in debt to the DWP.<sup>264</sup> From April to June 2021, there were 30,900 homeless households containing a Disabled member. This represents a rise of 10.95% compared to the same three month period in 2019. These figures only pertain to households eligible for temporary housing from authorities.<sup>265</sup>

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<sup>260</sup> Social Metrics Commission (2019). Measuring Poverty 2019. [online]. Available at: [https://socialmetricscommission.org.uk/wp-content/uploads/2019/07/SMC\\_measuring-poverty-201908\\_full-report.pdf](https://socialmetricscommission.org.uk/wp-content/uploads/2019/07/SMC_measuring-poverty-201908_full-report.pdf) Accessed on: 15.03.22

<sup>261</sup> Alston 2018

<sup>262</sup> SR3; SR142; SR217; SR232

<sup>263</sup> Barnard, H. (2019). End the Benefit Freeze to Stop People Being Swept into Poverty. *Joseph Rowntree Foundation*, [online] 9 March. Available at: <https://www.jrf.org.uk/report/end-benefit-freeze-stop-people-being-swept-poverty> Accessed on: 15.03.22

<sup>264</sup> Trussell Trust (2021). *The state of hunger: it's not right that disabled people are being forced to turn to food banks*. [online]. Available at: <https://www.trusselltrust.org/2021/06/28/the-state-of-hunger-its-not-right-that-disabled-people-are-being-forced-to-turn-to-food-banks/>. Accessed on:

<sup>265</sup> DLUHC (2021). *Statutory Homelessness: Detailed local authority-level tables – April to June 2021, England*. [online] 28 October. Available at:

108. Assessment criteria for Personal Independence Payments (PIP) – a benefit intended to cover the extra costs of disability – are unsuitable for people with certain conditions and needs, for example people with fluctuating conditions such as ELCI and mental distress<sup>266</sup>.
109. In March 2020, WeG introduced a temporary increase to UC of £20 per week<sup>267</sup>. This was not applied to over 2.2 million legacy benefit claimants, three quarters of whom are Disabled. Many of these needed to shield and as a result their essential expenditure increased considerably during the pandemic, for example, for the purchase of PPE, through increased energy costs and due to online delivery fees.<sup>268</sup>
110. In a survey of 1,800 benefit claimants more than three quarters (78%) said their financial situation was ‘worse’ compared to at the start of the pandemic; half (52%) were spending ‘significantly more’ on household bills and utilities than they were before the pandemic; 67% were struggling to eat a balanced diet, 67% were struggling to pay bills and just under half (46%) were falling behind on rent or mortgage payments<sup>269</sup>. Personal testimonies shared by legacy benefit claimants included experiences from families unable to wash or do laundry regularly.<sup>270</sup>

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1028995/DetailedLA\\_202106.ods](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1028995/DetailedLA_202106.ods) Accessed on: 15.03.22

<sup>266</sup> DDPO13; D.DP8

<sup>267</sup> CBCE6, CBCE7, CBCE16, CBCE33; DDPO26, SR38, SR74, SR117, SR136, SR142, SR170, SR202, SR203, SR205, SR226, SR232, SR242, SR251, SR331

<sup>268</sup> See: Disabled People Against Cuts (2021). *#20More4All - Why the £20 per week uplift to Universal Credit must be applied to legacy benefits: testimonies, stats & facts*. [online]. Available at: <https://dpac.uk.net/2021/03/20more4all-testimonies-stats-facts/> Accessed on: 15.03.22

<sup>269</sup> Disability Benefits Consortium (2021). *The Millions Missing Out*. [press release] 26 August. Available at: <https://disabilitybenefitsconsortium.com/2021/08/26/test-post/> Accessed on: 15.03.22

<sup>270</sup> Disabled People Against Cuts (2021). *#20More4All – Why the £20 per week uplift to Universal Credit must be applied to legacy benefits: testimonies, stats & facts*. [online].



111. The Chancellor of the Exchequer explained that this was because the uplift was for people “in work”<sup>271</sup>. This fuelled a view among DDP that WeG does not value their lives<sup>272</sup>. The Chancellor responded to an interview question from ITV’s Martin Lewis about extra help for those on legacy benefits by saying: "The original rationale for doing the temporary uplift in universal credit was to help those on low incomes. People who were in work but whose incomes were going to be affected by the crisis. It's universal credit and working tax credit that are the benefits that capture the vast, vast, vast majority if not all of those people. The legacy benefits don't do that."<sup>273</sup>
112. Even after the uplift, UC represented just 43.4% of the minimum income required for a decent standard of living, and 33.9% without.<sup>274</sup> Despite widespread opposition, WeG removed the uplift on 30 September 2021.<sup>275</sup>

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Available at: <https://dpac.uk.net/2021/03/20more4all-testimonies-stats-facts/>. Accessed on: 15.03.22

<sup>271</sup> *The Martin Lewis Money Show* (2021). [TV programme] ITV, 5 March: 20:30

<sup>272</sup> Direct references to disability hostility and feelings that the Westminster Government does not value Deaf and Disabled people’s lives: CBCE6, CBCE8, CBCE9, CBCE13, CBCE14, CBCE27, CBCE28, DDPO42, D.DP29, FG2, SR15, SR22, SR100, SR114, SR134, SR145, SR148, SR180, SR182, SR188, SR190, SR208, SR224, SR258, SR266, SR284, SR289, SR293, SR327, SR333

<sup>273</sup> Money Saving Expert (2021). Martin Lewis grills Chancellor Rishi Sunak on self-employed income support, stamp duty, benefits help & more. *moneysavingexpert.com*, [online] 5 March. Available at: <https://www.moneysavingexpert.com/news/2021/03/martin-lewis-interviews-chancellor-rishi-sunak---the-key-questio/> Accessed on: 15.03.22

<sup>274</sup> Joseph Rowntree Foundation (2021). *Planned cuts to Universal Credit will hit incomes of millions of households unable to afford a minimum living standard*. [press release] 14 July. Available at: <https://www.jrf.org.uk/press/planned-cuts-universal-credit-will-hit-incomes-millions-households-unable-afford-minimum> Accessed on: 15.03.22

<sup>275</sup> Jones, H. (2021). Six ex Tory ministers call for Universal Credit increase to become permanent. *Metro*, 4 July. Available at: <https://metro.co.uk/2021/07/04/six-ex-tory-ministers-call-for-universal-credit-increase-to-become-permanent-14871676/> Accessed on: 15.03.22

113. One of WeG's reasons for not extending the uplift to legacy benefits was that DDP could just move onto UC. This overlooks the fact that many DDP are worse off under UC. Neither the Severe Disability Premium nor the Enhanced Disability Premium exist under UC. Two disabled men won a legal challenge against WeG concerning the loss of £180 per month for DDP in this situation<sup>276</sup>. DWP resisted fully compensating DDP for their losses resulting in a further three high court hearings, all of which WeG lost.<sup>277</sup> The ruling will affect up to 50,000 people and will involve sums of up to £150 million over a six-year period to put right.

## Benefit Assessments

114. Benefit assessments are still a major issue for DDP with the same issues that DDP have been reporting for years. When the Work and Pensions Committee (WPC) held an inquiry into ESA and PIP assessments they received such an unprecedented volume of evidence that alongside the inquiry report and recommendations,<sup>278</sup> they brought out a second publication of claimants' testimonies.<sup>279</sup>
115. Despite five independent reviews of the Work Capability Assessments and two for the PIP assessment, too little has changed. Speaking to a Parliamentary Committee, one of the reviewers described "systematic bias" within the operational side of

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<sup>276</sup> Leigh Day (2022). *Severely disabled benefits claimants win legal challenge over loss of income caused by move on to Universal Credit*. [press release] 21 January. Available at: <https://www.leighday.co.uk/latest-updates/news/2022-news/severely-disabled-benefits-claimants-win-legal-challenge-over-loss-of-income-caused-by-move-on-to-universal-credit/>. Accessed on: 15.03.22

<sup>277</sup> Leigh Day 2022

<sup>278</sup> WPC (2018a). *PIP and ESA Assessments*. HC 829, 2017-2018 [online] 14 February. Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/82902.htm> Accessed on: 15.03.22

<sup>279</sup> WPC (2018b). *PIP and ESA Assessments: claimant experiences*. HC 355 [2017-2018], 8 February. Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/355/35502.htm>. Accessed on: 15.03.22



the DWP and that “things just haven’t been taken forwards.”<sup>280</sup> He said “I think it would be useful to have another review, absolutely. If one were to do that I would go back and not just look at the Work Capability Assessment but look more fundamentally at the whole concept of what we are doing.”<sup>281</sup>

116. DDP live in constant anxiety about being called up for reassessment. This has a detrimental impact on people’s mental health<sup>282</sup>.
117. DDP told us about the complexities of the assessment process which requires lengthy form filling, gathering recent medical evidence and attendance at assessment<sup>283</sup>. Not all assessment centres are accessible and can be many miles from a person’s home<sup>284</sup>. Lateness counts as a no-show; missing an assessment is punished with benefits stoppage. Claimants have no control over the time or the date of their assessment. Home visits are difficult to obtain.
118. During the pandemic face to face assessments were replaced with telephone assessments or decisions made on the basis of the written evidence that was submitted<sup>285</sup>. This was not suitable for all but for many others represented a significant improvement in their lives.

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<sup>280</sup> UK Parliament (2021). *Experts questioned on flaws in assessments for disability and health-related benefits*. [press release] 30 November. Available on: <https://committees.parliament.uk/committee/164/work-and-pensions-committee/news/159277/experts-questioned-on-flaws-in-assessments-for-disability-and-healthrelated-benefits/>. Accessed on: 15.03.22

<sup>281</sup> WPC (2021). *Oral evidence: Health assessments for benefits*, HC 604, [online] 1 December, Q4. Available on: <https://committees.parliament.uk/oralevidence/3122/pdf/>. Accessed on: 15.03.22

<sup>282</sup> CBCE11, CBCE17, CBCE28; DDPO27, DDPO47; D.DP5, D.DP8, D.DP35; FG1, FG3

<sup>283</sup> DDPO3, DDPO37; D.DP5, D.DP8, D.DP14; FG1

<sup>284</sup> DDPO3

<sup>285</sup> CBCE5; SR183, SR331

119. Disabled people are carers too<sup>286</sup>. 62% of carers have some form of impairment<sup>287</sup>. Insufficient attention is paid to this overlap within policy-making, including the cumulative burden on families going through multiple assessments.
120. Interaction with benefit assessors can be highly distressing, for example due to insensitive questions such as asking claimants with mental distress why past suicide attempts have failed, insisting claimants participate in physical examinations that cause them pain and hostile attitudes. 8 respondents to our survey used the word “lies” to describe assessment reports. This theme was picked up by the WPC inquiry who commented in their report that: “Central to the lack of trust are concerns about the ability of the Department’s contractors to conduct accurate assessments.”<sup>288</sup>
121. DDP have for many years called for audio recordings of assessments to be provided by default (with an opt out option), believing that this would improve the accuracy of assessment reports. We welcome moves towards this but DWP has been slow to implement<sup>289</sup>.
122. The quality of assessment reports has been a constant issue since they were introduced. WPC found evidence of “systematic poor quality”.<sup>290</sup> Government figures released in May 2018 suggest that tens of thousands of ESA benefit claims could have been decided

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<sup>286</sup> D.DP42

<sup>287</sup> Statista (2019). Share of illnesses or disabilities, if any, of carers in England in 2018/19. [online], June. Available at: <https://www.statista.com/statistics/535320/distribution-of-ailments-of-carers-in-england/>

<sup>288</sup> 2018a, p.3

<sup>289</sup> DWP (2021). *Shaping Future Support: The Health and Disability Green Paper*. CP 470, [online] p.40. Available on: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1004042/shaping-future-support-the-health-and-disability-green-paper.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004042/shaping-future-support-the-health-and-disability-green-paper.pdf)  
Accessed on: 15.03.22

<sup>290</sup> WPC (2018). *PIP and ESA Assessments*. HC 828, 2017-2019 [online] 14 February, p.3  
Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf>  
Accessed on: 15.03.22

by civil servants on evidence from assessment reports that should have been rejected because their quality was “unacceptable.”<sup>291</sup> This has a direct impact on DDP through wrongful decisions which find no eligibility for benefits. The rate of assessment decisions over-turned at appeal stood at 75% for both ESA and PIP in quarterly statistics for June – April 2019.<sup>292</sup>

123. Data gaps under UC make it more difficult to understand the current situation. For example, we no longer have information about how many Disabled claimants are being found “Fit for Work”. New benefit applicants go onto UC where data is not disaggregated by disability. For further examples see [Appendix 8](#)<sup>293</sup>.
124. In 2013, WeG introduced an additional stage to the assessment process called “Mandatory Reconsideration” (MR) which claimants must go through before they can appeal against being turned down for benefits/having benefits reduced after re-assessment. There is no set timeframe for MR. The claimant is not eligible to the benefit while going through MR, although if found eligible at appeal would then receive a back payment. The majority of MRs rubber stamp the original decision<sup>294</sup>. The introduction of MP has undoubtedly discouraged claimants to go to appeal. In 2020, the High Court

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<sup>291</sup> Pring, J. (2018) DWP figures on ‘unacceptable’ WCA reports cast doubt on decisions made on tens of thousands of ESA claims [online] Disability News Service. Available at: <https://www.disabilitynewsservice.com/dwp-figures-on-unacceptable-wca-reports-cast-doubt-on-decisions-made-on-tens-of-thousands-of-esa-claims/>. Accessed on: 15.03.22

<sup>292</sup> MoJ, (2019). *Tribunal Statistics Quarterly, April to June 2019 (Provisional)*. [online]. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/830965/Tribunal\\_and\\_GRC\\_statistics\\_Q1\\_201920.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/830965/Tribunal_and_GRC_statistics_Q1_201920.pdf). Accessed on: 15.03.22

<sup>293</sup> p.140

<sup>294</sup> Between 2013 and 2018, only 11% of MRs for ESA over-turned the original decision whereas at Appeal 60% of decisions were over-turned; for PIP the figure was 19% over-turned at MR and 63% at Appeal. WCA 2018a p.7.

ruled that forcing claimants to go through MR for ESA was unlawful<sup>295</sup>. It remains in place for PIP.

125. Once claimants reach appeal stage and before their case is heard by tribunal, they are eligible for a standard rate of ESA if their doctor sends a note saying the person is unfit for work. In 2018 it emerged that DWP had been writing to doctors instructing them not to issue the notes, thus leaving claimants with no income while waiting for their appeal to be heard. In January 2019 the Chair of the WPC wrote to the Minister for Disabled People asking about this.<sup>296</sup>
126. Reassessment puts DDP under threat of having all or a substantial part of our income stopped. DDP unable to navigate the complex assessment process and without support are put in situations of high risk. Despite this, WeG does not accept a safeguarding duty for benefit claimants. They have continuously declined to call for an inquiry into benefit-related deaths. According to the current Secretary of State for Work and Pensions, safeguarding is the responsibility of local agencies such as social services departments and doctors' surgeries.<sup>297298</sup>

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<sup>295</sup> *Connor, R (On the Application Of) v The Secretary of State for Work And Pensions* [2020] EWHC 1999 (Admin) Available at:

<https://www.bailii.org/ew/cases/EWHC/Admin/2020/1999.html> Accessed on: 15.03.22  
For an explanation of what the judgement means and who it applies to, see: Disability Rights UK (2020). High Court rules mandatory reconsideration requirement for ESA claimants unlawful. *Disabilityrightsuk.org*, [online] 11 August. Available at: <https://www.disabilityrightsuk.org/news/2020/august/high-court-rules-mandatory-reconsideration-requirement-esa-claimants-unlawful> Accessed on: 15.03.22

<sup>296</sup> Field, F. (2019). Letter to Sarah Newton, Minister for Disabled People, 11 January. Available at: <https://old.parliament.uk/documents/commons-committees/work-and-pensions/FF-SN-ESA-GP-letters-17-19.pdf> Accessed on: 15.03.22

<sup>297</sup> WPC (2020). *Oral evidence: DWP's response to the coronavirus Outbreak*. HC 178, [online] 30 September, Q230. Available at: <https://committees.parliament.uk/oralevidence/963/default/> Accessed on: 15.03.22

<sup>298</sup> UK Parliament (2021). *Disabled people's experiences of the benefits system: Work and Pensions Secretary given 'final chance' to publish report*. [press release] 16 December. Available on: <https://committees.parliament.uk/committee/164/work-and-pensions-committee/news/159956/disabled-peoples-experiences-of-the-benefits-system-work-and-pensions-secretary-given-final-chance-to-publish-report/> Accessed on: 15.03.22

127. A survey conducted in association with a Channel 4 documentary on benefit deaths found that of 3,500 survey respondents, 13 per cent said they had attempted suicide as a result of interacting with the DWP<sup>299</sup>. A third said it had caused them to plan suicide, while 61 per cent said the way the system is implemented led them to have suicidal thoughts<sup>300</sup>.
128. An inquest into the death of Philippa Day in 2021 identified 28 instances where “systemic errors” by both the DWP and the assessment provider contractor had led to failures in the handling of her benefit claim.<sup>301</sup> In December 2021, another coroner wrote to the DWP calling for urgent action after a severely ill benefit claimant died as a result of being told by DWP that he had to leave hospital to attend a benefits appointment in person or his claim would be stopped.<sup>302</sup> Five bereaved families have more recently called for a public inquiry to be held into benefit deaths<sup>303</sup>. [Appendix 6](#) lists benefit deaths that have occurred since 2017<sup>304</sup>.

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<sup>299</sup> Smallman, E. (2021). The truth about disability benefits: ‘People are killing themselves because of this system’. *iNews*, [online] 16 December. Available at: <https://inews.co.uk/news/long-reads/the-truth-about-disability-benefits-people-killing-themselves-system-1353558> Accessed on: 15.03.22

<sup>300</sup> Smallman 2021

<sup>301</sup> Clow, G. (2021). *Regulation 28: REPORT TO PREVENT FUTURE DEATHS Philippa Jane Louise Day (died 16 October 2019)*. [online] 12 February. Available at: <https://www.judiciary.uk/wp-content/uploads/2021/02/Phillipa-Day-2021-0043.pdf> Accessed on: 15.03.22; Leigh Day (2021). *Conclusion of inquest into death of Philippa Day*. [press release] 27 January. Available at: <https://www.leighday.co.uk/latest-updates/news/2021-news/conclusion-of-inquest-into-death-of-philippa-day/> Accessed on: 15.03.22

<sup>302</sup> Hayes, S. (2021). *ANNEX A – REGULATION 28: REPORT TO PREVENT FUTURE DEATHS (1)*. [online] 3 December. Available at: [https://www.judiciary.uk/wp-content/uploads/2021/12/Terence-Talbot-Prevention-of-future-deaths-report-2021-0419\\_Published.pdf](https://www.judiciary.uk/wp-content/uploads/2021/12/Terence-Talbot-Prevention-of-future-deaths-report-2021-0419_Published.pdf) Accessed on: 15.03.22

<sup>303</sup> Express and Star (2021). Bereaved families call for public inquiry into deaths of benefits claimants. *expressandstar.com*, 20 July. Available at: <https://www.expressandstar.com/news/uk-news/2021/07/20/bereaved-families-call-for-public-inquiry-into-deaths-of-benefits-claimants/> Accessed on: 15.03.22

<sup>304</sup> p.134

129. WeG has expanded the terminal illness "six month rule" to twelve months in response to the threat of legal action. This is welcome. Figures revealed that more than 100 terminally ill people were being turned down for PIP each month despite having less than six months to live.<sup>305</sup> However, we have learned that the cost of this concession will be off-set by WeG reneging on its pledge to limit reassessments for those with unchanging or degenerative conditions<sup>306</sup>. Policy costings attached to the 2021 Autumn Budget estimate that the combination of these two measures will make a projected saving of £70 from 2022/3 – 2024/5.
130. DDP are concerned that recent proposals to merge benefit assessments for ESA and PIP will tighten eligibility and could undermine the non-means-tested nature of PIP by linking it to ESA which is an out of work disability benefit.<sup>307</sup> The Health and Disability Green Paper mentions the need for an “affordable” benefits system in several places.<sup>308</sup> DDP fear that that WeG proposals to limit access to judicial review<sup>309</sup> are intended to prevent legal challenges against future attempts to limit eligibility and deny benefits to DDP who need them.
131. Nothing has been done to bring benefit assessments in line with a human rights approach and they continue to be underpinned by the Waddell-Aylward biopsychosocial model of disability which is contrary to this<sup>310</sup>.

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<sup>305</sup> APPG for Terminal Illness (2019). *Six Months To Live?*[online] Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/all-party-parliamentary-group-for-terminal-illness-report-2019.pdf> Accessed on: 15.03.22

<sup>306</sup> HM Treasury (2021). *Autumn Budget and Spending Review 2021: Policy Costings*. [online] October, p.54. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1029980/Policy\\_Costings\\_Document\\_FINAL.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1029980/Policy_Costings_Document_FINAL.pdf) Accessed on: 15.03.22

<sup>307</sup> DWP 2021

<sup>308</sup> DWP 2021, p.37; p.56; p.57; p.61; p.67.

<sup>309</sup> As below – p.65

<sup>310</sup> For confirmation of the role of the BPS model within welfare reform see comments to Parliament made by Lord Freud. Hansard HL Debate, 17 January 2012, col. 496.

## Theme 3: Silencing DDP

132. Opportunities for DDP to get our voices heard and to challenge inequality and discrimination are diminishing. WeG has been criticised for appearing not to listen to criticism by numerous bodies including the National Audit Office<sup>311</sup>, Parliamentary committees<sup>312</sup> and the UN Special Rapporteur on Poverty<sup>313</sup>.
133. It is well established that DDP die earlier than non-Disabled people<sup>314</sup>. This trend has been exacerbated by austerity and WeG's response to COVID where DDP died disproportionately<sup>315</sup>. DDP are dying who have experience of living in the community and speaking up on disability justice issues, while the younger generation are being segregated out of sight in places where they are spoken *about* and *for*<sup>316</sup>.

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Available at: <https://hansard.parliament.uk/lords/2012-01-17/debates/12011740000437/WelfareReformBill> Accessed on: 15.03.22

For a good explanation of how the Waddell-Aylward model is contrary to a human rights approach see: Shakespeare, T., Watson, N., & Alghaib, O. A. (2017). Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. *Critical Social Policy*, vol. 37, no. 1, pp. 22–41. Available at: <https://doi.org/10.1177/0261018316649120>.

<sup>311</sup> National Audit Office (2018). *Rolling out Universal Credit*. HC 1123, 2017–2019, [online] 15 June, p.8. Available at: <https://www.nao.org.uk/wp-content/uploads/2018/06/Rolling-out-Universal-Credit.pdf> Accessed on: 15.03.22

<sup>312</sup> WPC (2019). *Universal Credit and "survival sex"*. HC 83, [online] 16 October, p.43. Available at: <https://publications.parliament.uk/pa/cm201919/cmselect/cmworpen/83/83.pdf> Accessed on: 15.03.22

<sup>313</sup> Alston 2018, p.5

<sup>314</sup> CBCE7, CBCE16, CBCE27, DDPO28

<sup>315</sup> See p. 88

<sup>316</sup> Through rising special school provision as described above p.41



## Article 13 – Access to Justice

134. In 2018, a report by the EHRC found: “access to justice has deteriorated”<sup>317</sup>. WeG’s long-awaited LASPO review and associated Action Plan were disappointing in that they offered no immediate improvement to this situation<sup>318</sup>. Nothing was included about reinstating legal aid for initial welfare advice and employment claims despite clear evidence that the lack of support to resolve legal issues has negative impacts on emotional, social, financial and mental health.<sup>319</sup> WeG committed to reviewing thresholds for legal aid but there is no guarantee they will up them.
135. Financial eligibility rules for legal aid funding prevent discrimination cases from going forwards. An inquiry by the EHRC found that “Victims of discrimination are being denied their fundamental right to justice and perpetrators are going unchallenged because of the current legal aid system.”<sup>320</sup>
136. The availability of community care lawyers to challenge LA decisions in breach of the Care Act 2014 has been badly impacted as a consequence of legal aid cuts<sup>321</sup>. LA complaints procedures are

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<sup>317</sup> EHRC (2018). *Is Britain Fairer? The state of equality and human rights in Britain*. [online], p.5. Available at: <https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-accessible.pdf> Accessed on: 15.03.22

<sup>318</sup> MoJ (2019). *Post-Implementation Review of Part 1 of the Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO)*. CP 37, [online] February. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/777038/post-implementation-review-of-part-1-of-laspo.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/777038/post-implementation-review-of-part-1-of-laspo.pdf) Accessed on: 15.03.22; MoJ (2019). *Legal Support: The Way Ahead – An action plan to deliver better support to people experiencing legal problems*. CP40, [online] February. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/777036/legal-support-the-way-ahead.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/777036/legal-support-the-way-ahead.pdf) Accessed on: 15.03.22

<sup>319</sup> EHRC (2019). *The impact of LASPO on routes to justice*, research report 118. [online]. Available at: <https://www.equalityhumanrights.com/sites/default/files/the-impact-of-laspo-on-routes-to-justice-september-2018.pdf>. Accessed on: 15.03.22

<sup>320</sup> EHRC (2019). *Access to legal aid for discrimination cases*. [online]. Available at: <https://www.equalityhumanrights.com/sites/default/files/access-to-legal-aid-for-discrimination-cases-our-legal-aid-inquiry.pdf> Accessed on: 15.03.22

<sup>321</sup> See section on Access to Justice, p.63.



difficult to navigate for many DDP and the appeals process under the Care Act has never been introduced. Once LA complaints procedures have been exhausted, complainants can take their case to the LGSCO who has spoken out against “the general erosion to the visibility, capacity, and status of complaint functions within councils.” The LGSCO annual review for 2020-2021 showed that investigations are increasingly finding systemic problems rather than one-off mistakes with local government services<sup>322</sup>.

137. DDP and DDPOs are concerned that WeG proposals to limit access to judicial review (JR) will make it even more difficult to challenge and over-turn discriminatory legislative and policy measures<sup>323</sup>. [Appendix 3](#) lists key disability-related JRs that have taken place since 2017 and which evidence the need for continued access<sup>324</sup>. DDPOs would rather see expanded access through extension of the time-limit and ability for organisations to bring JRs, removing the pressure on individuals who are personally affected to act as claimants.
138. DHSC officially supports the Act, Listen, Do principles and yet in practice people with learning difficulties report inaccessible complaints procedures and challenges to being heard<sup>325</sup>.

## Article 21 – Freedom of expression and opinion, and access to information

139. DDP’s ability to peacefully protest is undermined by the passing of information from police to DWP<sup>326</sup>. On the grounds that ability to

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<sup>322</sup> LGSCO (2021). *Ombudsman annual review highlights widening cracks in council complaints systems*. [press release] July.

<sup>323</sup> *Judicial Review and Courts Bill*. 2022. HC 198 2021-2022. [online] Available at: <https://bills.parliament.uk/bills/3035> Accessed on: 15.03.22

<sup>324</sup> p.119

<sup>325</sup> D.DP35

<sup>326</sup> Pring, J. (2019). Police force admits agreement to share information about protesters with DWP. *Disability News Service*, [online] 25 July. Available at:

protest indicates ability to work, protestors have then been called up for benefit reassessments under threat of losing their incomes<sup>327</sup>. In Lancashire in 2018 Disabled anti-fracking protestors were apparently targeted by police actions that put them at risk of injury<sup>328</sup>.

140. The new Police, Crime, Sentencing and Courts Bill threatens to restrict the public's ability to peacefully express opposition to WeG measures that adversely impact on DDP. Under the new legislation, police will have new powers to stop protests in England and Wales if they are deemed too noisy and disruptive and large protests in or near Parliament will be prohibited<sup>329</sup>.

## Article 29 – Participation in Politics and Public Life

141. DDP continue to face unequal access to voting<sup>330</sup>. Voting provisions for people who are blind and visually impaired were ruled unlawful in May 2019 with Mr Justice Swift describing them as “a parody of the electoral process”<sup>331</sup>. Provisions remained unchanged for the

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<https://www.disabilitynewsservice.com/police-force-admits-agreement-to-share-information-about-protesters-with-dwp/> Accessed on:

<sup>327</sup> Pring, J. (2018). Police force admits passing footage of disabled protestors to DWP. *Disability News Service*, [online] 20 December. Available at:

<https://www.disabilitynewsservice.com/police-force-admits-passing-footage-of-disabled-protesters-to-dwp/> Accessed on: 15.03.22

<sup>328</sup> Pring, J. (2018). ‘Kicked, punched, knocked unconscious, tipped out of wheelchairs’: Campaigners describe repeated police targeting of disabled anti-fracking protestors. *Disability News Service*, [online] 13 December. Available at:

<https://www.disabilitynewsservice.com/kicked-punched-knocked-unconscious-tipped-out-of-wheelchairs-campaigners-describe-repeated-police-targeting-of-disabled-anti-fracking-protesters/> Accessed on: 15.03.22

<sup>329</sup> Police, Crime, Sentencing and Courts Bill. 2022. HL 95 2019-21; 2021-22. [online]. Available at: <https://bills.parliament.uk/bills/2839> Accessed on: 15.03.22

<sup>330</sup> OO9, OO13

<sup>331</sup> Andrews, R (On the Application Of) v Minister for the Cabinet Office [2019] EWHC 1126 (Admin) Available at: <https://www.localgovernmentlawyer.co.uk/governance/396->

December 2019 General Election in which 87% of blind respondents surveyed by RNIB were unable to vote independently and in secret<sup>332</sup>. People with learning difficulties are discouraged from voting by inaccessible elections information and lack of awareness concerning their right to vote<sup>333</sup>. The introduction of a requirement to produce photographic identification at polling stations will create additional barriers for DDP wishing to vote in person<sup>334</sup>. A new Voter Card will be available for those who do not have any of the accepted forms of ID<sup>335</sup>, but this will require an application process which entails an additional step between those who are marginalised and their vote. This will inevitably lead to reduced participation.

142. The combined impact of rising barriers to mainstream education, digital exclusion, inadequate incomes and lack of support to participate in the community mean that DDP remain under-represented within public and political life<sup>336</sup>. Accessibility gains through increased use of remote participation in the pandemic are being taken away again<sup>337</sup>.
143. A Government report concluded that Disabled politicians face a “multitude” of barriers and that equalities legislation has been

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[governance-news/47386-high-court-hears-judicial-review-over-voting-provisions-for-blind-and-partially-sighted-people](https://www.governance-news/47386-high-court-hears-judicial-review-over-voting-provisions-for-blind-and-partially-sighted-people) Accessed on: 15.03.22

<sup>332</sup> RNIB (2019). *Turned Out 2019: the latest research into voter experiences*. [online] Available at:

<https://www.rnib.org.uk/sites/default/files/RNIB%20Turned%20Out%202019.pdf>

Accessed on: 15.03.22

<sup>333</sup> OO13

<sup>334</sup> OO13; SR326

<sup>335</sup> DLUHC (2022). Protecting the integrity of our elections: Voter identification at polling stations and the new Voter Card. Policy paper. [online] 6 January. Available at: Accessed on: 15.03.22

<sup>336</sup> Evans, E. and Reher, S. (2021). *Barriers to elected office for disabled people*.

Government Equalities Office, [online] 21 July. Available at:

<https://www.gov.uk/government/publications/barriers-to-elected-office-for-disabled-people/barriers-to-elected-office-for-disabled-people> Accessed on: 15.03.22

<sup>337</sup> See below, p.68

broken<sup>338</sup>. Just six out of 650 MPs openly identify as Disabled. MPs are still unable to job-share which is a barrier to Disabled candidates<sup>339</sup>. Information obtained through FOIs revealed that the House of Commons refused to take action after Disabled members of staff, MPs and peers raised concerns about their safety during the COVID-19 pandemic<sup>340</sup>.

144. Actions included in the recent NDS such as permitting Deaf jurors<sup>341</sup> and reinstating a support fund for standing for elected office<sup>342</sup> are welcome but will not address wider socio-economic and attitudinal barriers.

## Article 31 – Statistics and data collection

145. There is a reduction in disability data collection preventing scrutiny. See [Appendix 8](#) for a list of data gaps<sup>343</sup>. The depth and robustness of the evidence that triggered the Special Inquiry can no longer be replicated due to missing information. NDS includes actions to improve data collection but omits social security among these.<sup>344</sup>

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<sup>338</sup> Evans and Reher 2021

<sup>339</sup> CBCE9, CBCE25

<sup>340</sup> Pring, J. (2020). House of Commons failed to act after disabled staff and MPs spoke out on COVID safety. *Disability News Service*, [online] 10 December. Available at: <https://www.disabilitynewsservice.com/house-of-commons-failed-to-act-after-disabled-staff-and-mps-spoke-out-on-covid-safety/> Accessed on: CBCE9, CBCE25

<sup>341</sup> HM Government, (2021). *National Disability Strategy*. CP512, p.26. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1006098/National-Disability-Strategy\\_web-accessible-pdf.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006098/National-Disability-Strategy_web-accessible-pdf.pdf) Accessed on: 15.03.22

<sup>342</sup> NDS, p.27

<sup>343</sup> p.140

<sup>344</sup> NDS 2021, p.95; p.100.

## Article 33 – National implementation and monitoring

146. WeG's NDS was put together with inadequate engagement and consultation with DDP<sup>345</sup>. An online survey that was conducted to inform the NDS asked DDP about their views and lived experience but with no indication of what the proposals for the strategy were. In January 2022 the High Court ruled that WeG had not discharged its duty to consult via the survey and it is therefore unlawful<sup>346</sup>.
147. In June 2021, the Minister for Disabled People shut the DPO Forum he had set up just one year earlier and after only three meetings<sup>347</sup>. In WeG's recent report back to the Committee (in fulfilment of paragraph 73 of the Concluding Observations) there are repeated references to engagement with non-user led charities<sup>348</sup>. This is not consistent with Article 33 obligations and as defined by General Comment No. 7.<sup>349</sup> There is no support for DDPOs through the NDS. WeG recently awarded a large sum of money to the national

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<sup>345</sup> CBCE6, CBCE13; DDPO26

<sup>346</sup> Disability Rights UK (2022). *National Disability Strategy declared unlawful: Disability Rights UK comment*. [press release] 26 January. Available at: <https://www.disabilityrightsuk.org/news/2022/january/national-disability-strategy-declared-unlawful-disability-rights-uk-comment> Accessed on: 15.03.22

To see the judgment: *Binder vs Secretary of State for Work and Pensions* [2022] EWHC 105 (Admin) Available at:

[https://www.bndmans.com/uploads/files/documents/Binder\\_v\\_SoS\\_for\\_Work\\_and\\_Pensions\\_2022\\_EWHC\\_105\\_\(Admin\).pdf](https://www.bndmans.com/uploads/files/documents/Binder_v_SoS_for_Work_and_Pensions_2022_EWHC_105_(Admin).pdf) Accessed on: 15.03.22

<sup>347</sup> DDPO26. Disability Unit (2020). Email to Disability Positive CEO to cancel DPO forum meetings.

<sup>348</sup> Government, (2021). *UK 2021 Follow-up Report*. [online]. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1033032/UN\\_Committee\\_on\\_the\\_Rights\\_of\\_Persons\\_with\\_Disabilities-20pt\\_Large\\_Print.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1033032/UN_Committee_on_the_Rights_of_Persons_with_Disabilities-20pt_Large_Print.pdf) Accessed on: 15.03.22

<sup>349</sup> CRDP (2018). *General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*. CRPD/C/GC/7. Available at: [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD/C/GC/7&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD/C/GC/7&Lang=en) Accessed on: 15.03.22

disability charities as grant funding. This was not offered through due procurement processes and DDPOs were not given an opportunity to bid.<sup>350</sup>

148. WeG did not engage with DDP or our organisations when formulating their response to the pandemic, despite DDP being both most at risk from COVID-19 and worst impacted by measures adopted to contain the pandemic. In their inquiry into DDP's experiences of the pandemic, WEC found that "While Ministers described their engagement with disabled stakeholders during the pandemic as very positive, open and effective, some disabled people and their organisations felt excluded and ignored." They exhorted WeG to "consult widely with disabled people and their organisations on ... genuinely effective mechanisms by which disabled people can influence policies and practices which directly affect them."<sup>351</sup>
149. DDPOs report difficulties accessing information, in particular from the DWP. Inclusion London paid the ONS for employment breakdown figures they were able to calculate within less than half a day after DWP claimed these were too expensive to produce<sup>352</sup>. The Information Commissioners Office (ICO) has needed to intervene on countless occasions for release of information relating to benefit deaths<sup>353</sup>. The NAO found that DWP has no mechanism

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<sup>350</sup> DHSC (2021). Disability charities benefit from £2.4 million fund. *Gov.uk*, [online] 30 March. Available at: <https://www.gov.uk/government/news/disability-charities-benefit-from-24-million-fund> Accessed on: 15.03.22

<sup>351</sup> WEC (2020). *Unequal impact? Coronavirus, disability and access to services*. HC 1050, [online] 22 December. Available at: <https://committees.parliament.uk/publications/4068/documents/40461/default/> Accessed on: 15.03.22

<sup>352</sup> Pring, J. (2018). New job stats raise questions over ministers' boasts on disability employment. *Disability News Service*, [online] 20 September. Available at: <https://www.disabilitynewsservice.com/new-job-stats-raise-questions-over-ministers-boasts-on-disability-employment/>

<sup>353</sup> For example: ICO (2021). *Freedom of Information Act 2000 (the Act) Decision notice*. Reference: IC-48363-C8Q5 [online] 22 March. Available at: <https://ico.org.uk/media/action-weve-taken/decision-notices/2021/2619540/ic-48363-c8q5.pdf> Accessed on: 15.03.22

for tracking or monitoring of recommendations made by internal review processes following deaths of claimants linked to changes to their benefits<sup>354</sup>. Internal reports for cases pre-2015 were not passed to independent teams reviewing the WPC linked to a number of these deaths<sup>355</sup> and records were apparently destroyed<sup>356</sup>. WPC used their Parliamentary powers to publish a report into the experiences of “vulnerable” benefit claimants that WeG refused to release<sup>357</sup>. Although DWP has now conducted a long-promised review of the effectiveness of sanctions, they are withholding the findings<sup>358</sup>. This leads to high levels of distrust from DDP towards DWP which both WPC and officials on WeG’s Social Security Affairs Committee (SSAC) have highlighted<sup>359</sup>.

150. Good practice examples of engagement with DDP/DDPOs at regional and local levels have not been replicated by WeG.

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<sup>354</sup> NAO (2020). *Information held by the Department for Work and Pensions on deaths by suicide of benefit claimants*. HC 79, 2019-20, [online] 7 February. Available at: <https://www.nao.org.uk/wp-content/uploads/2020/02/Information-held-by-the-DWP-on-deaths-by-suicide-of-benefit-claimants.pdf> Accessed on: 15.03.22

<sup>355</sup> Pring, J. (2019). Caxton House cover-up: DWP hid benefit deaths papers from WCA review team. *Disability News Service*, [online] 9 May. Available on: <https://www.disabilitynewsservice.com/caxton-house-cover-up-dwp-hid-benefit-deaths-papers-from-wca-review-team/> Accessed on: 15.03.22

<sup>356</sup> Pring, J. (2020). DWP admits destroying secret reports into benefit-related deaths. *Disability News Service*, [online] 27 February. Available at: <https://www.disabilitynewsservice.com/dwp-admits-destroying-secret-reports-into-benefit-related-deaths/> Accessed on: 15.03.22

<sup>357</sup> WPC (2022). *Disabled people’s experiences of the benefits system: Committee publishes Government-commissioned research*. [press release] 3 February. Available at: <https://committees.parliament.uk/committee/164/work-and-pensions-committee/news/160750/disabled-peoples-experiences-of-the-benefits-system-committee-publishes-government-commissioned-research/> Accessed on: 15.03.22

<sup>358</sup> Butler, P. (2022). Report on effectiveness of benefit sanctions blocked by DWP. *The Guardian*, [online] 27 January. Available at: <https://www.theguardian.com/society/2022/jan/27/report-on-effectiveness-of-benefit-sanctions-blocked-by-dwp> Accessed on: 15.03.22

<sup>359</sup> WPC 2018 p.3; WPC (2021). *Disability employment gap*. HC 189, 2021-22, [online] 22 July, p.67 Available at: <https://committees.parliament.uk/publications/7005/documents/72950/default/> Accessed on: 15.03.22



Examples at LA level include the Disabled People's Commission in Hammersmith and Fulham<sup>360</sup>, and the Disabled People's Panel in Cheshire<sup>361</sup>, and at regional level the Disabled People's Panel in Greater Manchester<sup>362</sup>. Two examples of progressive actions arising from this panel include the reinstatement of the Safer Town initiative in Northwich (Cheshire) in response to rocketing disability hate crime figures and a joint initiative between the metro mayor regions of Greater Manchester and Liverpool to promote safer travel for DDP on local transport. In all examples Deaf and Disabled people are remunerated for their time and co-production is resourced by the authority.

151. At an LA level DDPOs are frightened of speaking out and challenging LA decisions for fear of losing funding and being unable to run user-led services for the benefit of local DDP<sup>363</sup>. Such fears led one DDPO to submit evidence to us for this report anonymously. Lack of funding has forced many organisations to close. In 2019 the National Service User Network reported the closure of 200 user led organisations over the past two years<sup>364</sup>. The consequence is that increasingly we are returning to a situation where DDP are spoken about and for and non user-led charities dominate the disability sector reinforcing the charity model of disability.
152. DDP are concerned that the EHRC is unable to adequately fulfil its role as the National Human Rights Institution for England and Wales, having experienced budget cuts down from £62m in 2010 to £17.4m

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<sup>360</sup> See: <https://www.lbhf.gov.uk/councillors-and-democracy/resident-led-commissions/disabled-people-s-commission/nothing-about-disabled-people-without-disabled-people>.

<sup>361</sup> DDPO6

<sup>362</sup> See: <https://gmdisabledpeoplespanel.com/>.

<sup>363</sup> Pring, J. (2019). Council accused of 'settling scores' after cutting funding from DPO that criticised it. *Disability News Service*, [online] 11 April. Available at: <https://www.disabilitynewsservice.com/council-accused-of-settling-scores-after-cutting-funding-from-dpo-that-criticised-it/>. Accessed on: 15.03.22.

<sup>364</sup> Pring, J. (2019). User-led sector 'faces threat of extinction'. *Disability News Service*, [online] 14 February. Available at: <https://www.disabilitynewsservice.com/user-led-sector-faces-threat-of-extinction/>. Accessed on: 15.03.22



by 2020.<sup>365</sup> EHRC has consistently declined to carry out an independent inquiry into benefit deaths.<sup>366</sup> Recent EHRC consultations have not met good practice accessibility standards<sup>367</sup>. The EHRC Disability Advisory Committee (DAC) is due to be scrapped without an equality impact assessment or consultation with DDPOs<sup>368</sup>. Instead, they plan to discuss future engagement with a range of disability stakeholders<sup>369</sup>. The original EHRC Disability Committee was downgraded in July 2013 against the advice of an independent reviewer and 70% of consultation responses<sup>370</sup>. Findings of the Special Inquiry in 2016, Concluding Observations in 2017, EHRC's own finding of growing disability inequality in 2018 and the disproportionate deaths of DDP due to discrimination during the pandemic are some of the reasons why DDP consider the DAC is still needed<sup>371</sup>.

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<sup>365</sup> EDM 382. *Budget for Equality and Human Rights Commission*. 2016-2017. Available at: <https://edm.parliament.uk/early-day-motion/49634/budget-for-equality-and-human-rights-commission> Accessed on: 15.03.22

<sup>366</sup> Pring, J. (2020). EHRC failed to consult its own disabled advisers before snubbing DWP deaths probe. *Disability News Service*, 2 July. Available at: <https://www.disabilitynewsservice.com/ehrc-failed-to-consult-its-own-disabled-advisers-before-snubbing-dwp-deaths-probe/> Accessed on: 15.03.22

See also DDPO40. This correspondence to EHRC from DDP/DDPOs concerning DDP deaths never received a response.

<sup>367</sup> DDPO39

<sup>368</sup> Pring, J. (2022). New concerns over equality watchdog as it scraps disability committee. *Disability News Service*, [online] 3 March. Available at: <https://www.disabilitynewsservice.com/new-concerns-over-equality-watchdog-as-it-scraps-disability-committee/>. Accessed on: 15.03.22

<sup>369</sup> EHRC (2022). *Statement on our Disability Advisory Committee*. [press release] 9 March. Available at: <https://www.equalityhumanrights.com/en/our-work/news/statement-our-disability-advisory-committee>. Accessed on: 15.03.22

<sup>370</sup> Pring, J. (2013). Equality watchdog to scrap vital disability committee. *Disability News Service*, [online] 19 July. Available at: <https://www.disabilitynewsservice.com/equality-watchdog-to-scrap-vital-disability-committee/>. Accessed on: 15.03.22

<sup>371</sup> Pring, J. (2022). New concerns over equality watchdog as it scraps disability committee. *Disability News Service*, [online] 3 March. Available at: <https://www.disabilitynewsservice.com/new-concerns-over-equality-watchdog-as-it-scraps-disability-committee/>. Accessed on: 15.03.22

153. DDP who are transgender have raised concerns about the EHRC's independence and their position on trans rights issues in line with a wider outcry from LGBT+ organisations seeking to have their "A rating" removed<sup>372</sup>.

## Theme 3: Institutionalisation

154. WeG continues to employ legislation entrenched in a medical as opposed to a human rights approach and which authorises substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders. DDP continue to have no right to independent living enshrined in domestic legislation<sup>373</sup>.
155. Opportunities were lost to achieve compliance with the CRDP through recent/planned legal reforms including the Mental Capacity (Amendment) Act 2019, due for implementation on 1st April 2022, and the White Paper (2021) on reforming the Mental Health Act 1983. This is in contravention of the below articles, of General Comment 1, and Guidance on Article 14 as well as Article 19 and General Comment 5,<sup>374</sup> which are absolutely clear that an end to coercion is fundamental to living independently and being included in the community.<sup>375</sup>

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<sup>372</sup> D.DP39; Brooks, L. (2022). LGBT+ groups call for EHRC to lose international status over trans stance. *The Guardian*, [online] 11 February. Available at: <https://www.theguardian.com/society/2022/feb/11/lgbt-groups-call-for-anti-trans-ehrc-to-lose-international-status> Accessed on: 15.03.22

Siddique, H. (2021). EHRC undermined by pressure to support No 10 agenda, says ex-chair. *The Guardian*, [online] 18 January. Available at: <https://www.theguardian.com/society/2021/jan/18/ehrc-undermined-pressure-support-no-10-agenda-david-isaac> Accessed on: 15.03.22

<sup>373</sup> DDPO26

<sup>374</sup> Sections 15a, 15d, 20, 27, 47, 48, 81, 83 and 98a. As above.

<sup>375</sup> DDPO27

156. The White Paper recognises that neither a diagnosis of autism, nor a learning difficulty alone justify detention under mental health legislation. Detention is still allowed where a mental health diagnosis is also given and deprivation of liberty will remain possible under the Mental Capacity (Amendment) Act 2019. There are concerns that removal of provision from civil sections of the law will lead to more compulsory detentions of autistic people/people with learning difficulties under criminal law<sup>376</sup>.
157. Under the White Paper people at risk of detention will be able to nominate a person to represent them (in place of automatic selection of their nearest relative) but this will be capacity-based. Expansion of the role of Independent Mental Health Advocates (IMHAs) is welcome but the shortage of advocacy provision must be addressed.
158. The White Paper 2020<sup>377</sup> rightly has a strong focus on people in mental distress from racialised communities, CYP, and people who are autistic or have learning difficulties, but is inadequate in its lack of attention to structural inequalities and people who are women, older, LGBTQ+, and have physical and/or sensory impairments<sup>378</sup>.
159. In a review of three safeguarding cases, Sir Stephen Bubb described a “national system of care and support for people with learning disabilities and autism that is wholly inadequate”<sup>379</sup>. He discovered a history of inappropriate placements, ineffective multi agency support and lack of understanding of the problems faced by

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<sup>376</sup> DDPO5

<sup>377</sup> DHSC (2021). *Reforming the Mental Health Act*, CP 355, [online] January. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/951398/mental-health-act-white-paper-web-accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/951398/mental-health-act-white-paper-web-accessible.pdf) Accessed on: 15.03.22

<sup>378</sup> DDPO27

<sup>379</sup> Bubb, S. (2021). *Building Rights: A report to the Keeping Bristol Safe Partnership Board. Review of Bristol's policies and actions for people with learning disabilities and autism*. [online] Available at: <https://democracy.bristol.gov.uk/documents/s62446/02%20-%202021-07-19%20Building%20Rights%20review%20Sir%20Stephen%20Bubb.pdf> Accessed on: 15.03.22

the families, also that families found it extraordinarily difficult to challenge decisions being made about their loved ones. The review identifies serious failings by the police, British Transport Police, criminal justice system (CJS), LA and secure institutions. These include failure to understand needs, abuse, denial of human rights and lack of community-based support.

## Article 12 – Equal recognition before the law; Article 14 – Liberty and security of person

160. Under proposed Advance Choice Documents, people will be able to express choice of treatment if detained but will only carry full weight if the person is judged to have had capacity when drawing up the Document. Even then, a clinician will be able to overrule the person's choices provided they have recorded reasons for doing so.
161. A shortage of Independent Mental Capacity Advocates (IMCAs) means that the right to equal recognition before the law for DDP judged to lack capacity cannot be upheld<sup>380</sup>.
162. There is a major concern over Deprivation of Liberty safeguarding issues and a growing tendency for LAs to suggest/providers to adopt deprivation of liberty measures in place of appropriate support<sup>381</sup>.
163. The Mental Capacity (Amendment) Act enacted in 2019 has weakened legal safeguards for people judged to lack capacity and made it easier to deprive people of their liberty. Liberty Protection Safeguards due to be introduced no longer require the Disabled person's best interests to be considered and removes independent assessments except when a care home manager or a local authority

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<sup>380</sup> 001

<sup>381</sup> 005

decides that the person concerned is objecting. Challenges require going through expensive court of protection arrangements<sup>382</sup>.

164. Over 2000 people with learning difficulties/ who are autistic are in inpatient units where they are at increased risk of abuse and neglect<sup>383</sup>. NHS figures for 2021 report a 10% rise in patients admitted to psychiatric hospitals compared with 2015<sup>384</sup>. The average hospital stay is five years. 100 inpatients have been detained for more than 20 years<sup>385</sup>. 250 CYP with learning difficulties/who are autistic were identified in a mental health hospital in England in February 2019 compared to 110 in March 2015<sup>386</sup>.
165. WeG has missed successive targets for de-institutionalisation.<sup>387</sup> In 2020 the EHRC sent a pre-action letter to WeG arguing it had breached the European Convention on Human Rights for failing to meet targets set in the Transforming Care and Building the Right Support programmes<sup>388</sup>. The latest Government target is to close 50% of inpatient beds by March 2024.
166. Without investment in the development of community social care support services, private institutional settings are too often

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<sup>382</sup> DDPO5

<sup>383</sup> OO13

<sup>384</sup> BBC News (2021). Autism: Number of people stuck in hospital 'national scandal'. *bbc.co.uk*, [online] 14 July. Available at: <https://www.bbc.co.uk/news/uk-england-57722356> Accessed on: 15.03.22

<sup>385</sup> McCubbin, J. and Clegg, R. (2021). 100 people held more than 20 years in institutions. *BBC News*, [online] 24 November. Available at: <https://www.bbc.co.uk/news/uk-59388886> Accessed on: 15.03.22

<sup>386</sup> DDPO5

<sup>387</sup> Salman, S. (2019). 'You can't rehabilitate someone into society when they're locked away'. *The Guardian*, [online] 16 January. Available at: <https://www.theguardian.com/society/2019/jan/16/rehab-centre-learning-disabilities-secure-units-community> Accessed on: 15.03.22

<sup>388</sup> EHRC (2020). *Health Secretary faces legal challenge for failing patients with learning disabilities and autism*. [press release], 12 February. Available at: <https://www.equalityhumanrights.com/en/our-work/news/health-secretary-faces-legal-challenge-failing-patients-learning-disabilities-and> Accessed on: 15.03.22

considered the only viable option<sup>389</sup>. There is insufficient scrutiny of where Disabled people are moved after they leave state-funded ATUs. At one ATU in the two years up to April 2018, almost 50% of residents left to go into privately owned “independent hospitals.” Only around 30% went on to either supported living or residential care in the community<sup>390</sup>. In the case of people detained under the Mental Health Act 1983, disputes over who should provide aftercare have resulted in serious shortcomings<sup>391</sup>.

167. WeG has committed over £400m in capital investment including the building of new institutions as well as refurbishment and modernisation of existing facilities<sup>392</sup>. Mersey Care has received planning permission for a new 40-bed low secure unit for people with learning difficulties/who are autistic using £33m of government funding and on a geographically isolated site next to a recently opened 123 bed medium secure unit and a high secure unit<sup>393</sup>.
168. Above sections concerning a crisis in provision of adequate independent living support<sup>394</sup> are evidence of institutionalisation within DDP’s own homes<sup>395</sup>.

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<sup>389</sup> Mencap, CBF, Rightful Lives, LDE and NAS (2020). Letter to The Independent calling for a robust Action plan for Transforming Care, 6 January. Available at: [www.mencap.org.uk/press-release/letter-independent](http://www.mencap.org.uk/press-release/letter-independent) Accessed on: 15.03.22

<sup>390</sup> Salman 2019.

<sup>391</sup> [https://www.cqc.org.uk/sites/default/files/20210127\\_mhareport\\_printer.pdf](https://www.cqc.org.uk/sites/default/files/20210127_mhareport_printer.pdf).

<sup>392</sup> DHSC (2021). *Reforming the Mental Health Act*. Consultation outcome. [online] 24 August. Available at: <https://www.gov.uk/government/consultations/reforming-the-mental-health-act/reforming-the-mental-health-act> Accessed on: 15.03.22

<sup>393</sup> OO13.

<sup>394</sup> pp.25-33

<sup>395</sup> “nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization” such as “isolation and segregation from independent life within the community; lack of control over day-to-day decisions; ... rigidity of routine irrespective of personal will and preferences;”. CRDP Committee (2017). *General Comment No 5 Article 19: Right to independent living*. [online] 27 October, pp.4-5. Available at: [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en) Accessed on: 15.03.22

## Criminal Justice System (CJS)

169. DDP increasingly face criminalisation as a direct consequence of inadequate support, for example disabled CYP with unmet learning needs exploited by gangs<sup>396</sup>; benefit claimants targeted by DWP fraud surveillance<sup>397</sup>.
170. The CJS is not accessible to DDP and frequently fails to comply with its legal duties under the Equality Act. Courts fail to make reasonable adjustments for Disabled defendants, denying them access to a fair trial<sup>398</sup>. Prisons are ill equipped for meeting the needs of Disabled prisoners<sup>399</sup>. Racism is systemic within the CJS<sup>400</sup>. Although WeG has committed to specific actions recommended by the Lammy Review 2017, there is no given timeframe for when we will start to see a reduction in racial disparities across the CJS<sup>401</sup>.
171. The White Paper gives forensic patients second-class status. Criteria for detaining people who fall under Part III of the current Act will not be amended and their nominated representative will have more limited powers than for other patients. There are plans for supervised discharges for patients in this category.

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<sup>396</sup> Children's Commissioner (2019) Excluded teens are often the most vulnerable – and they're falling through the gap. [online]. Available at:

<https://www.childrenscommissioner.gov.uk/2019/03/27/excluded-teens-are-often-the-most-vulnerable-and-theyre-falling-through-the-gap/>. Accessed on: 15.03.22

<sup>397</sup> SR293; WPC (2021). *Oral evidence: DWP's Annual Report and Accounts 20/21 and Spending Review settlement*. HC 728, [online] 24 November, Q63-Q66. Available at: <https://committees.parliament.uk/oralevidence/3082/html/>. Accessed on: 15.03.22

<sup>398</sup> CBCE8; DDPO33; OO8; SR5

<sup>399</sup> CBCE8; SR5, SR250

<sup>400</sup> D.DP27; DDPO27

<sup>401</sup> Equal (2020). *EQUAL's response to the 'Tackling Racial Disparity in the Criminal Justice System: 2020 update'*. [online] Available at: <https://www.equalcjs.org.uk/sites/default/files/Lammy%20update%20EQUAL%20reponse%20FINAL%2025%2003%202020.pdf>. Accessed on: 15.03.22



## Pandemic response

172. Easements introduced during the pandemic made it easier to detain people under the Mental Health Act, requiring only one rather than two doctors to authorise a hospital detention. Mental Health Review Tribunals were moved online which disadvantaged some patients<sup>402</sup>.

Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment;

Article 16 – Freedom from exploitation, violence and abuse

173. Abuse scandals at a number of institutions have resulted in large-scale criminal proceedings. Undercover filming showed abuse and mistreatment of residents with learning difficulties and autism at Whorlton Hall, England.<sup>403</sup> An investigation was launched into "organised and complex" abuse at a special school in London in 2021<sup>404</sup>.
174. Behind the public scandals are everyday practices that breach the rights of DDP. Growing numbers of patients with learning difficulties are being physically restrained in mental health units, despite ministers telling NHS trusts to use such techniques less often. Staff in NHS mental health hospitals deployed restraint on such patients

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<sup>402</sup> DDPO5

<sup>403</sup> Trigg, N. (2019). Whorlton Hall: Hospital 'abused' vulnerable adults. *BBC News*, [online] 22 May. Available at: <https://www.bbc.co.uk/news/health-48367071>. Accessed on: 15.03.22

<sup>404</sup> Titheradge, N. (2021). Pupil abuse in special school secure rooms filmed on CCTV. *bbc.co.uk*, [online] 14 October. Available at: <https://www.bbc.co.uk/news/uk-58885635> Accessed on: 15.03.22



22,000 times in 2018, almost 50% more than the 15,000 occasions in 2016.<sup>405</sup>

175. A CQC review into restraint, prolonged seclusion and segregation for people who are autistic and/or have mental distress and/or learning difficulties found many people let down by failings.<sup>406</sup> A Parliamentary committee heard evidence of “cruel” and “inhumane” treatment of young people in ATUs.<sup>407</sup> Detention in ATUs leads to long-term trauma and in some cases to additional self harm and suicide attempts<sup>408</sup>.
176. The Mental Health Units (Use of Force) Act 2018<sup>409</sup> is designed to limit physical, mechanical and chemical restraint of detained patients and the use of isolation, seclusion and segregation. It was the result of campaigning and a private member’s bill following the death of Olaseni Lewis, a young Black man who died after 11 police officers restrained him face down in in the Bethlem Royal Psychiatric hospital in London 2010. However, achieving the Act took eight years and, contrary to usual practice, implementation of it took a further 3 years, until December 2021.
177. DDP living in the community without adequate support are made vulnerable to exploitation, violence and abuse. ‘Cuckooing’ is a term used for the practice where criminals take over someone’s

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<sup>405</sup> Campbell, D. (2018). Physical restraint used on 50% more NHS patients with learning disabilities. *The Guardian*, [online] 2 October. Available at: <https://www.theguardian.com/society/2018/oct/02/physical-restraint-used-on-50-more-nhs-patients-with-learning-disabilities> Accessed on: 15.03.22

<sup>406</sup> CQC, (2019). *CQC calls for action to fix the closed system that leads to people with a learning disability or autism being segregated in hospital*. [press release] 21 May. Available at: <https://www.cqc.org.uk/news/releases/cqc-calls-action-fix-closed-system-leads-people-learning-disability-or-autism-being> Accessed on: 15.03.22

<sup>407</sup> Verma, R. (2018). Parents Share Harrowing Accounts of Autistic Young People Locked Up In Secure Hospitals. *Rights Info*, [online] 13 December. Available at: <https://rightsinfo.org/parents-share-harrowing-accounts-of-autistic-young-people-being-locked-up-in-secure-hospitals/> Accessed on: 15.03.22

<sup>408</sup> O05

<sup>409</sup> *Mental Health Units (Use of Force) Act 2018* Available at: <https://www.legislation.gov.uk/ukpga/2018/27/enacted>. Accessed on: 15.03.22

home and use the property as a base for drug dealing and other criminal activity. It has become central to drug operations in England. In January 2022, two teenagers were found guilty of the murder of Leigh Smith, a Disabled man who had become a victim of cuckooing<sup>410</sup>. There is also a significant overlap between modern slavery and disability – in particular learning difficulties and mental health support needs<sup>411 412</sup>. According to figures from Nottingham City Council for 2019/2020, 60% of their clients rescued from slavery were Disabled<sup>413</sup>. There is a need for disaggregated data on a national level: the National Referral Mechanism (for identifying and referring potential victims of modern slavery and ensuring they receive appropriate support) does not currently count Disabled victims whilst it does count victims according to race and gender<sup>414</sup>. The Keeping Control study evidences the extent to which people in mental distress are subjected to hate crime and abuse, including abuse within mental health services<sup>415</sup>.

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<sup>410</sup> Kingsley, T. (2022). Teenagers found guilty of ‘disturbing’ murder of vulnerable man after cuckooing his flat. *Independent*, 21 January. Available at: <https://www.msn.com/en-gb/news/uknews/teenagers-found-guilty-of-disturbing-murder-of-vulnerable-man-after-cuckooing-his-flat/ar-AAT0InW> Accessed on: 15.03.22

<sup>411</sup> The Passage (2020). *The Passage’s modern slavery coordinator contributes to BBC article on connection between disability and modern slavery*. [press release] 17 December. Available at: <https://passage.org.uk/2020/12/17/the-passages-modern-slavery-coordinator-contributes-to-bbc-article-on-connection-between-disability-and-modern-slavery/>. Accessed on: 15.03.22

<sup>412</sup> Kingsley, T. (2022). Teenagers found guilty of ‘disturbing’ murder of vulnerable man after cuckooing his flat. *Independent*, 21 January. Available at: <https://www.msn.com/en-gb/news/uknews/teenagers-found-guilty-of-disturbing-murder-of-vulnerable-man-after-cuckooing-his-flat/ar-AAT0InW>. Accessed on: 15.03.22

<sup>413</sup> BBC News (2020). The Archers tackles the 'hidden' connection between disability and modern slavery. *bbc.co.uk*, [online] 16 December. Available at: <https://www.bbc.co.uk/news/disability-55259019>. Accessed on: 15.03.22

<sup>414</sup> Lambert 2021.

<sup>415</sup> <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12806>

## Theme 5: Disaster Planning and Humanitarian Emergencies

178. The needs of DDP are routinely overlooked within disaster and humanitarian emergency planning. This is despite being among those most likely to be adversely affected (due to the intersection between disability and poverty) and most in need of emergency assistance (due to the disabling barriers we face in everyday life). We also heard about how negative impacts on DDP of actions intended to address climate change are ignored.

### Article 11 – Situations of Risk and Humanitarian Emergencies

179. WeG was not adequately prepared for the pandemic. This had a disproportionate impact on DDP (including Disabled older people) as the group of people most seriously at risk from COVID. The NAO found the pandemic had “exposed” WeG “vulnerability to whole-system emergencies” and WeG lacked detailed plans for several aspects of its response to COVID-19, including shielding, employment support schemes and managing the disruption to schooling<sup>416</sup>.
180. Within pandemic response planning, the needs of DDP were overlooked. Guidance for people who employ their own PAs was published more than five weeks after written advice for the wider social care sector and more than a month-and-a-half after DHSC published its first COVID-19 action plan, and only in response to

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<sup>416</sup> NAO (2021). *The government's preparedness for the COVID-19 pandemic: lessons for government on risk management*. HC 735, 19 November, p.8. Available at: <https://www.nao.org.uk/wp-content/uploads/2021/11/The-governments-preparedness-for-the-COVID-19-pandemic-lessons-for-government-on-risk-management.pdf>

Accessed on: 15.03.22

interventions by campaigners highlighting their existence to WeG<sup>417</sup>. Information PA users urgently needed was about accessing PPE. The guidance set out that this was their responsibility to obtain and purchase, despite the high level of risk they were exposed to, limited availability and spiralling costs.

181. The intersectional needs of DDP were not considered within official responses to the pandemic. For example, Disabled asylum seekers were overlooked except for community initiatives<sup>418</sup>. Under the Immigration Act 2014, people without migration status are not entitled to bank accounts<sup>419</sup> and were therefore left unable to pay for essential goods when shops went over to card payments. Without bank cards, Disabled asylum seekers needing to shield had no way to pay for online deliveries. Their weekly benefits are only £39.63 with no additional element for the extra costs of being Disabled and no right to work. This was not enough to cover online delivery fees. Community organisations providing food and support were closed.
182. Six years ago, 72 people were killed by a fire that broke out in the Grenfell tower in London<sup>420</sup>. Among them were Disabled residents, who due to the chronic shortage of accessible housing, had been housed by their local LA on upper floors with no way to escape in case of fire. Lawyers involved in the Grenfell Tower Inquiry into the

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<sup>417</sup> Pring, J. (2020). Coronavirus: PA guidance is finally published... five weeks late. *Disability News Service*, 23 April. Available at:

<https://www.disabilitynewsservice.com/coronavirus-employers-of-pas-given-just-two-days-to-digest-vital-new-furlough-guidance/> Accessed on: 15.03.22

<sup>418</sup> FG2

<sup>419</sup> Home Office (2016). *Immigration Act 2016, Factsheet – Banks (Section 45)*. [online] July. Available at:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/537220/Immigration\\_Act\\_-\\_Part\\_2\\_-\\_Bank\\_Accounts.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/537220/Immigration_Act_-_Part_2_-_Bank_Accounts.pdf). Accessed on: 15.03.22

<sup>420</sup> Disability Rights UK (2021). Grenfell Tower fire is ‘a landmark act of discrimination against disabled and vulnerable people’. *disabilityrightsuk.org*, [online] 22 April. Available at: <https://www.disabilityrightsuk.org/news/2021/april/grenfell-tower-fire-%E2%80%98-landmark-act-discrimination-against-disabled-and-vulnerable> Accessed on: 15.03.22

2017 fire which killed 72 people described it “as a landmark act of discrimination against disabled and vulnerable people”<sup>421</sup>. 41% of people who died were Disabled and 85% were Black people and from racialised minorities, raising issues of institutional racism as well as disablism<sup>422</sup>.

183. Today DDP are still fighting for protections from fire risks if placed in high-rise housing. Disabled peers in Parliament are currently lobbying for explicit mention of Disabled people within the new building safety bill<sup>423</sup> <sup>424</sup>. DDP are seeking a judicial review of WeG’s decision to award a fire safety contract to consultants who have repeatedly argued against introducing written evacuation plans for disabled residents of tower blocks<sup>425</sup>. According to a fire safety guide written by this organisation, it is ‘usually unrealistic’ to expect landlords to put arrangements in place for DDP to evacuate blocks of flats in the event of an emergency.
184. Among DDP and DDPOs there is a strong commitment towards addressing climate change as a global emergency. There is concern that DDP are in particular danger from natural disasters due to barriers to accessing emergency information and/or physical barriers to evacuation.
185. There are a number of examples where measures aimed at tackling climate change have had an unintended adverse impact on DDP.

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<sup>421</sup> Disability Rights UK 2021

<sup>422</sup> Disability Rights UK 2021

<sup>423</sup> *Building Safety Bill*. 2022. (HC 139, Session 2021-22). [online] Available at: <https://bills.parliament.uk/bills/3021> Accessed on: 15.03.22

<sup>424</sup> Pring, J. (2022). Disabled people will be forgotten again unless ministers change safety bill, say peers. *Disability News Service*, [online] 24 February. Available at: <https://www.disabilitynewsservice.com/disabled-people-will-be-forgotten-again-unless-ministers-change-fire-safety-bill-say-peers/> Accessed on: 15.03.22

<sup>425</sup> Claddag (2022). *Claddag issues proceedings against Home Office over ‘means of escape’ contract*. [press release] 10 February. Available at: <https://claddag.org/2022/02/10/claddag-issues-proceedings-against-home-office-over-means-of-escape-contract/> Accessed on: 15.03.22

These include LTNs<sup>426 427</sup> and the plastic straw ban<sup>428</sup>. Insufficient consideration of DDP and lack of engagement at planning stages mean that DDP are forced to speak out after implementation in order to secure exemptions, giving a false impression of being against tackling climate change in general.

186. DDPOs would welcome improved engagement and consideration of equality impacts of counter-terrorism measures on DDP<sup>429</sup>. For example, removal of blue badge parking to make way for new defences has made York City Centre less accessible to DDP<sup>430</sup>.

## Theme 6: Lives Less Worthy

187. The pandemic starkly highlighted attitudes towards DDP whereby our lives are held to have less value than other people's. Such attitudes were apparent in decisions taken by WeG in their handling of the pandemic; political messaging and public debate concerning lockdown; and, disability discrimination in treatment rationing. These were in addition to existing issues relating to DDP's unequal right to life.

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<sup>426</sup> Transport for All (2021). *Pave The Way: The impact of Low Traffic Neighbourhoods (LTNs) on disabled people, and the future of accessible Active Travel*. [online]. Available at: <https://www.transportforall.org.uk/wp-content/uploads/2021/01/Pave-The-Way-full-report.pdf> Accessed on: 15.03.22

<sup>427</sup> CBCE33; SR134, SR323

<sup>428</sup> DDPO1

<sup>429</sup> D.DP31, D.DP32

<sup>430</sup> Bryant, M. (2021). York's anti-terror measures make centre a 'no go zone' for disabled people. *The Guardian*, [online] 19 November. Available at: <https://www.theguardian.com/uk-news/2021/nov/19/york-anti-terror-measures-disabled-people-blue-badge-parking> Accessed on: 15.03.22

188. The pandemic has seen a return to purely medical understanding of risk and “vulnerability” leaving millions at risk from non-medical factors not considered.<sup>431</sup>

## Article 5 – Equality and non-discrimination; Article 10 – Right to life; Article 25 – Health

### COVID-19

189. The background to COVID-19 is a history of unequal access to healthcare services for DDP.<sup>432</sup> For example: Disabled women have long reported unequal access to health screening and adoption of alternative breast screening techniques for women with certain conditions is slow in the UK compared to other countries<sup>433</sup>; studies evidence Deaf people being unable to access both primary and secondary healthcare on an equitable basis with others<sup>434</sup>; nomadic patients report being removed from health treatment waiting lists while travelling which means that health needs are often not addressed until they reach an acute stage<sup>435</sup>.
190. People who are housebound are often unaware of their rights or report being refused home visits. In a recent survey by Chronic Illness Inclusion only 12% of respondents had ever received a home visit by their GP, fewer than 2% had ever received a domiciliary or sexual health screening service and only 5% had accessed domiciliary dental care<sup>436</sup>.

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<sup>431</sup> Cited by SR219: TourettesHero, (2020). Understanding the Risks. [online]. Available at: <https://www.touretteshero.com/2020/07/03/understanding-the-risks/>. Accessed on: 15.03.22

<sup>432</sup> OO13

<sup>433</sup> D.DP2

<sup>434</sup> OO10

<sup>435</sup> OO5

<sup>436</sup> DDPO12



191. DDP have shorter average lifespans than non-Disabled people linked to multiple issues including inability to travel to appointments, lack of reasonable adjustments to make services accessible, diagnostic overshadowing and lack of staff training. All of these issues took on heightened significance through the pandemic.
192. Recent research has evidenced that people living with mental distress and people with learning difficulties were at a greater risk of deaths relative to the general population before the pandemic<sup>437</sup>. During 2019/2020 people with learning difficulties were three times more likely to die avoidably of a cause which was treatable with good quality healthcare.<sup>438</sup>
193. Numerous deaths of DDP within hospital settings have been directly linked to staff error and to system-wide failings pre-pandemic. Hampshire Hospitals NHS Trust apologised after Disabled campaigner Juliet Marlow died from neglect while in their care in 2018<sup>439</sup>. 75 DDP have died in ATUs since 2015. An independent review commissioned by NHS Midlands into one of these "potentially avoidable" deaths, that of Clive Treacy, found that "system-wide failures" led Clive to experience "an unacceptably poor quality of life" and he was not "kept safe from harm." She recommended that "All the deaths should be re-looked at to ensure they have had proper scrutiny."<sup>440</sup> In 2021, Essex NHS Mental

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<sup>437</sup> Das-Munshia, J., Changa, C.K., Bakolisf, I., Broadbentb, M., Dregana, A., Hotopfa, M., Morgane, C., and Stewart, R. (2021). All-cause and cause-specific mortality in people with mental disorders and intellectual disabilities, before and during the COVID-19 pandemic: cohort study. *The Lancet Regional Health – Europe*, Volume 11, 100228. Available at: <https://doi.org/10.1016/j.lanepe.2021.100228> Accessed on: 15.03.22

<sup>438</sup> OO13

<sup>439</sup> BBC News (2020). Basingstoke hospital 'neglect' over diabetes patient death. *bbc.co.uk*, 6 October. Available at: <https://www.bbc.co.uk/news/uk-england-hampshire-54439184> Accessed on: 15.03.22

<sup>440</sup> Holland, L. and Lucas, R. (2021). Seventy-five people have died in autism and learning disability units in England since 2015, Sky News reveals. *Sky News*, 10 December. Available at: <https://news.sky.com/story/seventy-five-people-have-died-in-autism-and-learning-disability-units-in-england-since-2015-sky-news-reveals-12491903> Accessed on: 15.03.22

Health Trust was fined 1.5 million pounds for a whole catalogue of failures in care over a long period which led to the deaths of 11 inpatients<sup>441</sup>

194. Official figures record that Disabled people accounted for 60% of COVID-related deaths<sup>442</sup>. This is an under-estimate: due to inadequate data, the calculation had to be based on 2011 data when the population of DDP was lower. Campaigners had to fight for mortality data of DDP to be published. *The Every Death Counts* campaign raised funding to threaten WeG with a legal challenge over failure to publish mortality data of people with learning difficulties<sup>443</sup>. Mortality rates were higher for certain groups of DDP. For example, younger people with learning difficulties were up to 30 times more likely to die of COVID than their non-Disabled peers<sup>444</sup>. Mortality rates of those treated under the Mental Health Act 1983 rose significantly during the pandemic<sup>445 446</sup>.
195. Media attention and official responses linked disproportionate deaths of DDP to underlying health conditions and messaging gave the impression of a distinction between these deaths and those of non-Disabled people. There was no public or political outcry against the disproportionate mortality statistics for DDP. A blog post on The Health Foundation website comments:

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<sup>441</sup> <https://www.bbc.co.uk/news/uk-england-essex-57496578>.

<sup>442</sup> ONS (2020). *Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020*. [online] Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020> Accessed on: 15.03.22

<sup>443</sup> See: <https://www.crowdjustice.com/case/every-death-counts/>.

<sup>444</sup> PHE (2020). *People with learning disabilities had higher death rate from COVID-19*. [press release], 12 November. Available at: <https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19> Accessed on: 15.03.22

<sup>445</sup> CQC (2021). *COVID-19 INSIGHT*. Issue 9, March, [online]. Available at: <https://www.cqc.org.uk/sites/default/files/COVID-19%20Insight%209.pdf> Accessed on: 15.03.22

<sup>446</sup> DDPO27

“There has been a surprising absence of analysis of the reasons for this particular inequality... The category of ‘underlying health conditions’ has been used prominently, including in press briefings and analysis, with little reference to ‘disability’... Explaining deaths in terms of underlying health conditions omits reference to co-occurring risk factors”<sup>447</sup>

196. DDP were much more likely to die from COVID-19 even after taking into account factors such as age, underlying health conditions, poverty and risk through living in care homes. Once these factors are accounted for, working-age Disabled women with higher support needs have been about 90 per cent more likely to die from COVID than non-Disabled women of the same age and more-disabled men in the same age group were 74 per cent more likely to have died from COVID-19 than non-Disabled men in the same age bracket<sup>448</sup>. The remaining factor that can explain this discrepancy is unequal access to healthcare and life-saving treatment.
197. Political decisions regarding handling of the pandemic determined DDP’s chances of survival. Had WeG locked down earlier in the first wave of the pandemic, lives could have been saved<sup>449</sup>. The Prime Minister was accused of saying he would rather “let the bodies pile high” than impose a third lockdown<sup>450</sup>. Public debate presented a

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<sup>447</sup> Sayce, L. (2021). The forgotten crisis: exploring the disproportionate impact of the pandemic on disabled people. *The Health Foundation*, 21 February. Available at: <https://www.health.org.uk/news-and-comment/blogs/the-forgotten-crisis-exploring-the-disproportionate-impact-of-the-pandemic>. Accessed on: 15.03.22

<sup>448</sup> Bosworth, M.L., Daniel Ayoubkhani, D., Nafilyan, V., Foubert, J., Glickman, M., Davey, C. et al (2021). Deaths involving COVID-19 by self-reported disability status during the first two waves of the COVID-19 pandemic in England: a retrospective, population-based cohort study. *The Lancet*, Vol 6, Issue 11, E817-E825. Available at: [https://doi.org/10.1016/S2468-2667\(21\)00206-1](https://doi.org/10.1016/S2468-2667(21)00206-1) Accessed on: 15.03.22

<sup>449</sup> Buchan, L. (2020). Coronavirus: Lockdown one week earlier could have halved UK's death toll, says Neil Ferguson. *Independent*, 10 June. Available at: <https://www.independent.co.uk/news/uk/politics/uk-lockdown-coronavirus-death-toll-neil-ferguson-a9559051.html> Accessed on: 15.03.22

<sup>450</sup> Ng, K. (2021). Boris Johnson said he ‘would rather let bodies pile high’ than impose third lockdown, reports claim. *Independent*, 26 April. Available at:

false binary between the lives of “the vulnerable” and the economy and welfare of the majority of the population. Hostility towards DDP rose during the pandemic. DDP felt scapegoated and that their lives are viewed as expendable<sup>451</sup>.

198. Patients with COVID were discharged into care homes to free up NHS beds in the first few weeks of the pandemic. Testing was not implemented until 15 April 2020. WeG has admitted this policy may have directly led to subsequent deaths, as confirmed by a PHE report, but experts say that official figures “underestimate” deaths caused by discharging patients into care homes<sup>452</sup>. According to official figures, 39,017 people died in care homes in England between 10 April 2020 and 31 March 2021<sup>453</sup>. It is estimated that over 4,000 additional deaths occurred before 10 April<sup>454</sup>. A Parliamentary Committee inquiry found that “The Government and the NHS both failed adequately to recognise the significant risks to the social care sector at the beginning of the pandemic” which “had devastating and preventable repercussions for people receiving care and their families and put staff providing social care at risk” and “led to many thousands of deaths which could have been avoided”<sup>455</sup>.

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<https://www.independent.co.uk/news/uk/politics/boris-johnson-dominic-cummings-lockdown-b1837326.html> Accessed on: 15.03.22

<sup>451</sup> CBCE17, CBCE27, CBCE31, CBCE33; DDPO11, DDPO15; D.DP25; FG1, FG2; SR124, SR129, SR144, SR177, SR219, SR239, SR258, SR264, SR327, SR335

<sup>452</sup> O’Dowd, A. (2021). COVID-19: Official figures “underestimate” deaths caused by discharging patients into care homes. *BMJ*, 2 June. Available at: <https://www.bmj.com/content/373/bmj.n1415>. Accessed on: 15.03.22

<sup>453</sup> CQC (2021). *CQC Death Notifications from Care Homes*. [online], 21 July. Available at: <https://app.powerbi.com/view?r=eyJrJoiOGE1YTZlODItYzA2Ni00MmUxLTkyZjQtYjk3OTg0ZmYwMTIyIiwidCI6ImE1NWVjYWI4LWNINjYtNDVIYS1hYjNmLTkyYmMyYjA3YjVhYjY9> Accessed on: 15.03.22

<sup>454</sup> Sabin, L. (2021). England’s COVID care home deaths could be thousands higher than official figures, say providers. *Independent*, 1 August. Available at: <https://www.independent.co.uk/news/uk/home-news/covid-care-home-deaths-higher-b1894592.html?r=28937> Accessed on: 15.03.22

<sup>455</sup> Health and Social Care and Science and Technology Committees (2021). *Coronavirus: lessons learned to date*. HC 92, 12 October. Available at: <https://committees.parliament.uk/publications/7496/documents/78687/default/> Accessed on: 15.03.22

199. Treatment rationing guidance used at times when the NHS is over-stretched discriminates against DDP. A Parliamentary Committee on Human Rights found that: “decision-making relating to admission to hospital, in particular critical care, for adults with COVID-19 has discriminated against older and disabled people”<sup>456</sup>.
200. In March 2020, campaigners secured a revision of the “rapid COVID-19 critical care guideline” produced by the National Institute for Clinical Excellence (NICE). The guideline originally stated that all adults on admission to hospital, irrespective of COVID-19 status, should be assessed for frailty using the Clinical Frailty Scale (CFS) and that comorbidities and underlying health conditions should be considered. Under threat of legal action, NICE updated its guidelines on 25 March to emphasise the need to consider additional patient factors when interpreting the CFS score<sup>457</sup>.
201. This was far short of the reassurance that campaigners were seeking and left DDP completing homemade “hospital passports” from templates supplied by DDPOs<sup>458</sup>. These documents emphasised the valuable roles that individuals play in the community and their contributions to society despite being Disabled. They were to be used to help argue for admission to hospital or access treatment if denied according to the clinical score.

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<sup>456</sup> JCHR (2020) The Government must urgently consider the human rights implications of COVID-19 measures, says Joint Committee on Human Rights. [online], 21 September. Available at: <https://committees.parliament.uk/work/218/the-governments-response-to-covid19-human-rights-implications/news/119291/the-government-must-urgently-consider-the-human-rights-implications-of-covid19-measures-says-joint-committee-on-human-rights> Accessed on: 15.03.22

<sup>457</sup> NICE (2020). NICE updates rapid COVID-19 guideline on critical care. *nice.org.uk*, [online] 25 March. Available at: <https://www.nice.org.uk/news/article/nice-updates-rapid-covid-19-guideline-on-critical-care> Accessed on: 15.03.22

<sup>458</sup> Greater Manchester Coalition of Disabled People [GMCDP] 2020. *COVID-19: Emergency Hospital Passport*. [online]. Available at: [https://gmcdp.com/sites/default/files/GMCDP%20COVID%2019\\_%20Emergency%20hospital%20passport](https://gmcdp.com/sites/default/files/GMCDP%20COVID%2019_%20Emergency%20hospital%20passport) Accessed on: 15.03.22

202. Guidance for doctors published by the British Medical Association (BMA) in April 2020 caused alarm among Disabled people. It stated that, if demand for NHS services outstripped its capacity, doctors “may be obliged to withdraw treatment from some patients to enable treatment of other patients with a higher survival probability”. It also said that, if services become “overwhelmed”, the presence of other health conditions may exclude some patients from eligibility for intensive care or ventilation, while it may even be necessary “to discontinue treatment that has already been started”<sup>459</sup>.
203. It appears that an unpublished age-based frailty score system commissioned by the UK government's Chief Medical Advisor, Professor Chris Whitty was behind the widespread denial of intensive care to over 80s. It also excluded many Disabled people over the age of 60 from life-saving treatment. Testimony by doctors has confirmed that the system was used by medics to prevent elderly patients “blocking” intensive care. A second version of the tool increased the score for specific illnesses but lowered it for age – in other words, made it more targeted at denial of treatment on the basis of impairment as opposed to age. A study comparing the number of COVID-19 deaths on normal wards against the number of intensive care beds said to be available in UK drew the conclusion that intensive care was being overzealously withheld from older DDP<sup>460</sup>. The charity Mencap is aware of cases where people with learning difficulties were denied treatment<sup>461</sup>.

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<sup>459</sup> BMA (2020). COVID-19: ethical issues when demand for life-saving treatment is at capacity. [online] 3 April. Available at: <https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-ethical-issues-when-demand-for-life-saving-treatment-is-at-capacity> Accessed on: 15.03.22

<sup>460</sup> Shovlin, C. and Vizcaychipi, M. (2020) Implications for COVID-19 triage from the ICNARC report of 2204 COVID-19 cases managed in UK adult intensive care units. *Emergency Medicine Journal*, June, 37(6), pp.332-333. [online]. <http://orcid.org/0000-0001-7894-873X> Marcela P Vizcaychipi3,4

<sup>461</sup> Investigations Team (2021). Medical treatment was withheld from people with learning disabilities during pandemic. *Telegraph*, 13 June. Available at: <https://www.telegraph.co.uk/news/2021/06/13/medical-treatment-withheld-people-learning/> Accessed on: 15.03.22



204. Amnesty International received multiple reports of care home residents' right to NHS services, including access to general medical services (GMS) and hospital admission, being denied during the pandemic, violating their right to health and potentially their right to life, as well as their right to non-discrimination despite hospital bed capacity never being reached<sup>462</sup>. Guidelines published by NHS England on its website on 10 April advised that some care home residents "should not ordinarily be conveyed to hospital unless authorised by a senior colleague." The guidelines were withdrawn a few days later but the damage lingered.
205. WeG declined to provide national guidance that would guarantee DDP the same rights to life sustaining treatment as non-Disabled people<sup>463</sup>.
206. Unlawful use of blanket Do Not Attempt Cardio-Pulmonary Resuscitation Orders (DNACPRs) on the medical notes of DDP has been a problem throughout the pandemic<sup>464</sup>. DDP, their families and support workers were also distressed to be contacted by local health professionals encouraging adoption of advance DNACPR

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<sup>462</sup> Amnesty International (2020). *As If Expendable: the UK Government's Failure to Protect Older People in Care Homes during the COVID-19 Pandemic*. [online]. Available at: <https://www.amnesty.org.uk/files/2020-10/Care%20Homes%20Report.pdf>. Accessed on: 15.03.22

<sup>463</sup> Pring, J. (2020). Coronavirus: Hancock refuses to publish treatment guidance. *Disability News Service*, 23 April. Available at: <https://www.disabilitynewsservice.com/coronavirus-hancock-refuses-to-publish-treatment-guidance/>. Accessed on: 15.03.22

<sup>464</sup> CBCE7, CBCE10, CBCE13, CBCE16, CBCE17, CBCE21, CBCE23, CBCE27, CBCE28, CBCE32; DDPO5, DDPO26, CBCE36; FG4; SR12, SR14, SR88, SR111, SR160, SR163, SR191, SR228



directives<sup>465</sup> <sup>466</sup>. Such practices have a history preceding COVID-19. WeG commissioned an independent inquiry from CQC who found inconsistent and concerning approaches to DNACPR decisions requiring improved oversight and reform<sup>467</sup>. Proposed measures do not go far enough to stop the problem.

207. Medical resources were prioritised for COVID patients instead of DDP with existing conditions. One NHS trust told people with muscular dystrophy it was keeping their ventilator filters for COVID patients<sup>468</sup>.
208. Campaigners challenged blanket visitor bans to prevent DDP with communication and cognitive support needs from being admitted to hospitals without support. One in four Learning Disability nurses surveyed said they had seen examples where people with a learning disability have not been allowed to be accompanied by a family member, carer or supporter in hospital<sup>469</sup>. Guidance was revised but left at the discretion of individual NHS Trusts<sup>470</sup>.

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<sup>465</sup> For example: Booth, R. (2020). UK healthcare regulator brands resuscitation strategy unacceptable. *The Guardian*, 1 April. Available at: <https://www.theguardian.com/world/2020/apr/01/uk-healthcare-regulator-brands-resuscitation-strategy-unacceptable>; Investigations Team (2021). People with mental illness and learning disabilities given 'do not resuscitate' orders during pandemic. *Telegraph*, [online] 9 June. Available at: <https://www.telegraph.co.uk/news/2021/06/09/patients-mental-illness-learning-disabilities-given-do-not-resuscitate/>. Accessed on: 15.03.22

<sup>466</sup> DDPO26

<sup>467</sup> CQC (2021). *Protect, respect, connect – decisions about living and dying well during COVID-19*. [online]. Available at: <https://www.cqc.org.uk/news/releases/improved-oversight-reform-needed-pressures-pandemic-shine-light-inconsistent>. Accessed on: 15.03.22

<sup>468</sup> Pring, J. (2020). NHS trust tells people with muscular dystrophy: 'We're keeping your ventilator filters for patients with coronavirus'. *Disability News Service*, 7 May. Available at: <https://www.disabilitynewsservice.com/nhs-trust-tells-people-with-muscular-dystrophy-were-keeping-your-ventilator-filters-for-patients-with-coronavirus/>. Accessed on: 15.03.22

<sup>469</sup> Mencap (2020). *Learning Disability Nurse Survey*. [online]. Available at: [www.mencap.org.uk/myhealthmylife](http://www.mencap.org.uk/myhealthmylife). Accessed on: 15.03.22

<sup>470</sup> Pring, J. (2020). Coronavirus: New NHS guidance 'leaves door open to dangerous discrimination'. *Disability News Service*, [online] 18 June. Available at:

209. DDP were disproportionately impacted by lockdown and shielding due to a lack of access to vital services including medical and dental treatment<sup>471</sup>. Around one-quarter (25%) of Disabled people who were receiving medical care before the coronavirus pandemic indicated they were currently receiving treatment for only some of their conditions (compared with less than 1 in 10 (7%) non-Disabled people<sup>472</sup>. This undoubtedly contributed to high numbers of additional non-COVID-related deaths<sup>473</sup>. 74 out of 100 NHS England GP surgeries refused registration to nomadic patients during the pandemic<sup>474</sup>.
210. Lack of access to food and medicines was a major issue for DDP needing to shield. Supermarkets were unable to identify Disabled customers. Once the CEV list was in operation this had the unfortunate impact of discriminating against DDP unable to leave their homes for pre-existing conditions unrelated to a risk of catching COVID. Survey data show that 60% of disabled people struggled to access essential supplies, including food, in the early months of the pandemic<sup>475</sup>. At least one Disabled man who was not

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<https://www.disabilitynewsservice.com/coronavirus-new-nhs-guidance-leaves-door-open-to-dangerous-discrimination/> Accessed on: 15.03.22

<sup>471</sup> CBCE6, CBCE7, CBCE11, CBCE13, CBCE14, CBCE32; DDPO11, DDPO26, DDPO36; D.DP25; FG1

<sup>472</sup> ONS (2020). *Coronavirus and the social impacts on disabled people in Great Britain: July 2020*. [online]. Available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/july2020>

Accessed on: 15.03.22

<sup>473</sup> See above p.31

<sup>474</sup> Friends, Families and Travellers (2021). *Locked Out: 74% of GPs refused registration to nomadic patients during COVID-19 Pandemic*. [online] 8 July. Available at:

<https://www.gypsy-traveller.org/news/locked-out-74-of-gps-refused-registration-to-nomadic-patients-during-covid-19-pandemic/> Accessed on: 15.03.22

<sup>475</sup> WEC (2020). Unequal impact? Coronavirus, disability and access to services. HC 1050. Available at:

<https://committees.parliament.uk/publications/4068/documents/40461/default/>

Accessed on: 15.03.22

in contact with services starved to death.<sup>476</sup> A Parliamentary Committee found that the pandemic had “profoundly adverse effects” on DDP’s access to services<sup>477</sup>.

211. Safeguarding systems were suspended or reduced during the pandemic. We received evidence concerning safeguarding phone lines not being answered and wrong numbers given out in one LA area<sup>478</sup>. One young man was found days from death having been starved and locked in his mother’s attic over for months over the course of the first lockdown<sup>479</sup>.
212. According to WeG’s approach to the pandemic, those most at risk of COVID were designated as “vulnerable” and advised to shield. WeG pandemic planning revealed a lack of understanding of who DDP are and how our lives are integral to the functioning of the communities within which we live, for example it is not straightforward for frontline workers in insecure employment, parents of school children and with those with unpaid supporting responsibilities to self-isolate.
213. Inadequate consideration was given to the well-being of those who were shielding<sup>480</sup>. In July 2020, Disabled people reported more frequently than non-Disabled people that the pandemic was affecting their well-being because it made their mental health worse (46% for Disabled people and 18% for non-Disabled people), they felt lonely (42% and 29%), they spent too much time alone (36% and 25%), they felt like a burden on others (25% and 8%), or had no one

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<sup>476</sup> DRUK (2020). Disabled man dies due to lack of food during lockdown.

*disabilityrightsuk.org*, [online] 25 June. Available at:

<https://www.disabilityrightsuk.org/news/2020/june/disabled-man-dies-due-lack-food-during-lockdown> Accessed on: 15.03.22

<sup>477</sup> WEC 2020.

<sup>478</sup> D.DP7

<sup>479</sup> itvNEWS (2021). Sheffield mother locked autistic son in attic until he almost starved to death. *itv.com*, [online] 13 January. Available at:

<https://www.itv.com/news/calendar/2022-01-12/mother-imprisoned-autistic-son-in-attic-until-he-almost-starved-to-death> Accessed on: 15.03.22

<sup>480</sup> As above.

to talk to about their worries (17% and 10%)<sup>481</sup>. We heard extensively about the isolation and anxiety that DDP experienced. 10% of respondents to our survey cited shielding and negative impacts on mental health as examples of how things have got worse for DDP since 2017<sup>482</sup>.

214. DDP within institutional and residential settings had fewer freedoms and were subject to greater levels of isolation than non-Disabled people during lockdowns. Under the Coronavirus Act 2020, people detained under the Mental Health Act were exempt from the right to go outside for exercise once a day. The total visiting ban meant ward activities and therapy ceased. Anecdotally, this led to increased bullying, assault, and self-harm and there were no efforts by staff to facilitate virtual contact with friends and family<sup>483</sup>. DDP in residential homes were subject to 14 days self-isolation if they left the home for contact with friends or family<sup>484</sup>. Providers were not clear on guidelines and families were prevented from visiting despite this causing extreme distress to people with learning difficulties/who are autistic<sup>485</sup>. In one case study, a provider insisted on 2:1 staffing to facilitate a family visit so that a woman with learning difficulties could be physically restrained if she broke social distancing rules by attempting to hug her family<sup>486</sup>.
215. The ‘Clinically Extremely Vulnerable’ (CEV) list of those officially told to shield was not wide enough. Anecdotally we know of DDP not on the list, and thus not able to access to the protections it afforded, whose GPs said they needed to shield for medical reasons. We also

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<sup>481</sup> ONS (2020). *Coronavirus and the social impacts on disabled people in Great Britain: July 2020*. [online], 20 August. Available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/july2020>

Accessed on: 15.03.22

<sup>482</sup> See Annex A, p.148

<sup>483</sup> DDPO5

<sup>484</sup> 001; DDPO30

<sup>485</sup> OO1

<sup>486</sup> OO1

know of DDP who only received notification they should have been on the CEV a year or longer into the pandemic.<sup>487</sup>

216. DDP needed to lobby WeG for priority access to COVID vaccines after working age people listed as CEV were initially placed sixth on the priority list<sup>488</sup>. After lobbying this was amended to raise the level of priority<sup>489</sup>. We received evidence about the lack of priority for younger Disabled people and those living with family members, and difficulties accessing vaccinations for those unable to travel<sup>490</sup>.
217. Legal protections for Disabled workers ended on 31 March 2021 when WeG announced an official end to shielding despite COVID rates still being high<sup>491</sup>. Many employers had not respected DDP's right to life before this. Research by disability charity Scope found that 22% of disabled workers faced having to choose between going to their place of work and quitting their job <sup>492</sup>.
218. Official communications about the pandemic were confusing and not made available in accessible formats. WeG refused to provide

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<sup>487</sup> FG1

<sup>488</sup> DHSC (2020). *JCVI: updated interim advice on priority groups for COVID-19 vaccination*. [online] 25 September. Available at: <https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi-25-september-2020/jcvi-updated-interim-advice-on-priority-groups-for-covid-19-vaccination> Accessed on: 15.03.22

<sup>489</sup> DHSC (2020). *Joint Committee on Vaccination and Immunisation: advice on priority groups for COVID-19 vaccination, 30 December 2020*. [online], updated 6 January. Available at: <https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi-30-december-2020/joint-committee-on-vaccination-and-immunisation-advice-on-priority-groups-for-covid-19-vaccination-30-december-2020> Accessed on: 15.03.22

<sup>490</sup> CBCE32; OI3; SR254

<sup>491</sup> DPAC and Black Activists Rising Against Cuts (2021). Joint Press Statement on Safety at Work after the ending of Shielding. [press release] 31 March. Available at: <https://dpac.uk.net/2021/03/joint-press-statement-on-safety-at-work-after-the-ending-of-shielding/> Accessed on: 15.03.22

<sup>492</sup> Faragher, J. (2020). A fifth of disabled workers had work from home requests turned down during pandemic. *Personnel Today*, 23 November. Available at: <https://www.personneltoday.com/hr/a-fifth-of-disabled-workers-had-covid-work-from-home-requests-turned-down/> Accessed on: 15.03.22

BSL interpretation for televised public briefings (which Scotland and Welsh Governments put in place) until forced by a high court ruling<sup>493</sup>. At this point there was only one public briefing left.

219. The rights of Disabled Parliamentarians to continue shielding after Parliament reconvened in person were denied. They were subject to discriminatory comments by fellow politicians. A government minister told MPs shielding from coronavirus that it was their “duty” to return to the House of Commons, even though that could put their lives at risk<sup>494</sup>.
220. A medical model approach taken to the pandemic has obscured human rights breaches. 24 breaches of DDP’s rights by WeG were identified in the first 12 months of the pandemic<sup>495</sup>. A report from Oxford University’s Disability Law and Policy Project and the Bonavero Institute of Human Rights concluded that WeG’s policy-making breached its duties to DDP under both the Equality Act and the Convention on the Rights of Persons with Disabilities (UNCRPD). It called for an “immediate” review of legislation introduced during the crisis, as well as an inquiry to “understand the scale of COVID-19 related deaths and to examine why this group has carried such a heavy burden”<sup>496</sup>.
221. WeG has failed to undertake any rights-based assessment of what happened to DDP during the pandemic. One piece of

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<sup>493</sup> BBC News (2021). COVID: Deaf woman wins claim over lack of sign language at briefings. *bbc.co.uk*, [online] 28 July. Available at: <https://www.bbc.co.uk/news/uk-england-leeds-57998047> Accessed on: 15.03.22

Judgment available here: <https://www.judiciary.uk/wp-content/uploads/2021/07/R-on-the-application-of-Katherine-Rowley-v-Minister-for-the-Cabinet-Office.pdf>

<sup>494</sup> Pring, J. (2020). Concerns growing over Rees-Mogg’s ‘shocking’ comments on shielding MPs. *Disability News Service*, [online] 12 November. Available at: <https://www.disabilitynewsservice.com/concerns-growing-over-rees-moggs-shocking-comments-on-shielding-mps/> Accessed on: 15.03.22

<sup>495</sup> Pring, J. (2021). Government’s ‘shocking’ pandemic rights list of shame. *Disability News Service*, [online] 25 March. Available at: <https://www.disabilitynewsservice.com/governments-shocking-pandemic-rights-list-of-shame/> Accessed on: 15.03.22

<sup>496</sup> Tidball et al 2020.

ethnographically-led research commissioned by the WeG Disability Unit consisted of interviews and qualitative engagement with nine DDP over six weeks within a three month period from July to September to map their individual experiences<sup>497</sup>. Almost no attention has been paid to the discrimination that appears to have led to disabled people dying in disproportionate numbers from COVID-19.

222. The Prime Minister has promised an independent inquiry into the handling of the pandemic but we have no further information such as how to ensure adequate inclusion of disability and human rights approaches. In December 2021 an independent cross-bench Peer, Lady Hallett, was appointed as Chair to the inquiry due to commence in Spring 2022<sup>498</sup>. We await further information such as consultation on the terms of reference for the inquiry.
223. One area of good practice highlighted in the evidence we received concerns WeG's commitment to "Oliver McGowan learning disability and autism for all healthcare staff"<sup>499</sup>. This training initiative is named after a young autistic man who died after admission to Southmead Hospital in Bristol following an epileptic seizure in 2016. Independent review findings published in December 2020 found that the death was "potentially avoidable" and that the initial Learning Disabilities Mortality Review took an "unacceptably prolonged" 17 months to complete and contained a number of inconsistencies<sup>500</sup>.

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<sup>497</sup> Disability Unit (2021). *The lived experience of disabled people during the COVID-19 pandemic*. [online] 28 July. Available at: <https://www.gov.uk/government/publications/the-lived-experience-of-disabled-people-during-the-covid-19-pandemic> Accessed on: 15.03.22

<sup>498</sup> Cabinet Office, Prime Minister's Office, 10 Downing Street, and The Rt Hon Boris Johnson MP (2021). *Prime Minister announces COVID-19 Inquiry Chair*. [press release], 15 December. Available at: <https://www.gov.uk/government/news/prime-minister-announces-covid-19-inquiry-chair> Accessed on: 15.03.22

<sup>499</sup> SR334

<sup>500</sup> BBC News (2020). Oliver McGowan: Health chief apologises for autistic teen's death. *bbc.co.uk*, 2 December. Available at: <https://www.bbc.co.uk/news/uk-england-bristol-55157372> Accessed on: 15.03.22



224. This commitment is included within the NDS which promises that, “Subject to evaluation, DHSC will make training on autism and learning disability available for all 2.7 million health and adult social care staff.”<sup>501</sup> It is important that this training is user led and consistent with the social model and human rights approaches. Given the absence of engagement from DHSC with DDPOs this is a concern. NDS also includes a commitment to working with “disabled people and disability organisations at every stage of social care reform”<sup>502</sup>. DDPOs are excluded.
225. We continue to hear of how difficult it remains for DDP to access health appointments, assessments, tests and treatment following the lift of lockdown rules<sup>503</sup>. As of December 2021, there were nearly 6 million people in England, amounting to 9% of the population, waiting for surgery<sup>504</sup>. Millions of patients have struggled to access dental care since 2019 with an additional 350,000 dental slots needed to clear the backlog at the start of 2022 but insufficient capacity to deliver despite additional funding<sup>505</sup>.
226. Many DDP were concerned by the lifting of all remaining COVID-19 rules in England in February with 6 in 10 saying they are afraid of

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<sup>501</sup> NDS 2021, p.89

<sup>502</sup> NDS 2021, p.87

<sup>503</sup> CBCE14; FG1

<sup>504</sup> Campbell D. and Duncan, P. (2021). Almost 6 million people on waiting lists for hospital treatment in England. *The Guardian*, [online] 9 December. Available at: <https://www.theguardian.com/society/2021/dec/09/almost-6-million-people-on-waiting-lists-for-nhs-surgery-in-england> Accessed on: 15.03.22

<sup>505</sup> Gregory, A. (2022). NHS England plans dental ‘treatment blitz’ to tackle appointments backlog. *The Guardian*, [online] 25 January. Available at: <https://www.theguardian.com/society/2022/jan/25/nhs-england-dental-treatment-appointments-backlog> Accessed on: 15.03.22

socialising<sup>506</sup>. The Prime Minister has ruled out any future full lockdowns.<sup>507</sup>

## Other

227. The law permits terminations at a later stage in pregnancy for foetuses that will be born with impairments which is discriminatory.<sup>508</sup> At the same time there are concerns regarding protection of women's reproductive rights. A young woman with Downs Syndrome, Heidi Crowter, took a legal challenge against the difference in time frames on the grounds of disability discrimination<sup>509</sup>. This was dismissed by the high court at the end of 2021.
228. There have been repeated and ongoing attempts to legalise assisted suicide both through private members bills in Parliament and the courts. Political parties allow their members a free vote rather than setting a party line on the issue. Given the context of regressing life chances and entrenched disability discrimination within our health system DDP are extremely concerned about this. The campaign pushing for legalisation is very well resourced whereas the voices of DDP, who have access to far fewer resources, are rarely if ever included in media, public or political debate on the issue<sup>510</sup>.

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<sup>506</sup> O'Dell, L. (2022). Scrapping of COVID rules in England 'will increase fear and anxiety' for disabled people, charity warns. *The Limping Chicken*, [online] 21 February. Available at: <https://limpingchicken.com/2022/02/21/scrapping-of-covid-rules-in-england-will-increase-fear-and-anxiety-for-disabled-people-charity-warns/> Accessed on: 15.03.22

<sup>507</sup> HC Deb (21 February 2022). vol. 709, col.54. Available at: <https://hansard.parliament.uk/commons/2022-02-21/debates/982A4806-6695-4ECE-9D1C-4BD0E8798306/LivingWithCOVID-19> Accessed on: 15.03.22

<sup>508</sup> D.DP24; see Annex A for personal testimonies from people with Down's Syndrome and feedback on this issue.

<sup>509</sup> BBC News. Woman with Down's syndrome loses abortion law fight. *bbc.co.uk*, [online] 23 September. Available at: <https://www.bbc.co.uk/news/uk-england-coventry-warwickshire-58662846> Accessed on: 15.03.22

<sup>510</sup> Pring, J. (2022). Peer 'makes new bid for assisted suicide legalisation' through health and care bill. *Disability News Service*, [online] 6 January. Available at:

229. Hate crime law is still not equal for disability. Given the rise in disability hate crime this is becoming more urgent. DDP are calling for all protected characteristics including disability to be included in the Public Order Act 1986 under “stirring up offences”.<sup>511</sup> DDPOs also argue the need for anti-hate legislation that captures crimes motivated by reason of a person being Disabled<sup>512</sup>. Currently perpetrators need to have shown hostility towards a person’s disability for it to count as a hate crime which excludes deliberate targeting and exploitation of Disabled people.
230. Lenient sentences for perpetrators of deliberate harm towards DDP contribute to a sense that our lives are valued less. A mother who slowly starved her daughter to death, leaving her surrounded by faeces and mouldy food and with an untreated skin disease that left her face unrecognisable, was recently sentenced to just nine years seven months<sup>513</sup>. A man was handed a nine-month sentence suspended for 18 months for his involvement with his father’s keeping of man with learning difficulties in appalling conditions as a slave for forty years<sup>514</sup>. His father had died before he could stand trial and the man was charged only with paying below minimum wage.
231. DDP report being made to feel like criminals due to benefit fraud investigations triggered by a secret algorithm that campaigners

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<https://www.disabilitynewsservice.com/peer-makes-new-bid-for-assisted-suicide-legalisation-through-health-and-care-bill/> Accessed on: 15.03.22

<sup>511</sup> DDPO39

<sup>512</sup> DDPO41

<sup>513</sup> BBC News (2022). Blackpool mother jailed for starving daughter to death. *bbc.co.uk*, [online] 25 February. Available at: <https://www.bbc.co.uk/news/uk-england-lancashire-60507814> Accessed on: 15.03.22

<sup>514</sup> Sky News (2022). Man 'kept as a slave' for 40 years now enjoys watching football and old World Cups, says charity. *news.sky.com*, [online] 4 February. <https://news.sky.com/story/man-kept-as-a-slave-for-40-years-now-enjoys-watching-football-and-old-world-cups-says-charity-12532461>. Accessed on: 15.03.22

suspect targets Disabled people<sup>515</sup>. Claimants undergo considerable anxiety and stress during investigations that can take up to a year<sup>516</sup>.

232. The introduction of Serenity Integrated Mentoring (SIM) as a model of mental health intervention is contrary to a human rights approach. It was designed in 2013 for people who are in contact with mental health services, at high risk of suicide and self-harm, and deemed “high intensity users” of emergency services. The premise is to create a SIM Response Plan for such individuals which will give health professionals the confidence NOT to treat them or respond in ways in which they would have felt compelled to before. SIM explicitly advocates withholding potentially life-saving treatments from Disabled people.<sup>517</sup>
233. The approach and model of disability underpinning the Spectrum 10k study has also caused concern<sup>518</sup>. The study seeks pre-natal screening of Autistic babies.”<sup>519</sup> Many in the autistic rights movement have criticised the lack of consultation with autistic people or their families and raised concerns related to privacy, scientific ethics and eugenics due to fears of sharing genetic data. This led to the formation of the autistic-led Boycott Spectrum 10K group. The project was paused in September 2021<sup>520</sup>.

**END**

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<sup>515</sup> Greater Manchester Coalition of Disabled People (2022). GMCDP & Foxglove Legal Challenge to the Department for Work and Pensions DWP Fraud Algorithm. *gmcdp.com*, [online]. Available at: <https://gmcdp.com/gmcdp-foxglove-legal-challenge-department-work-and-pensions-dwp-fraud-algorithm> Accessed on: 15.03.22

<sup>516</sup> SR293

<sup>517</sup> DDPO34

<sup>518</sup> SR144

<sup>519</sup> SR144

<sup>520</sup> Chapman, R. (2021). Why Autistic People Are Worried by Spectrum 10K. *Psychology Today*, 25 August. Available at: <https://www.psychologytoday.com/gb/blog/neurodiverse-age/202108/why-autistic-people-are-worried-spectrum-10k> Accessed on: 15.03.22

# Abbreviations

<b>AAC</b>	Augmentative and alternative communication
<b>ADASS</b>	Association of Directors of Adult Social Services
<b>APPG</b>	All Party Parliamentary Group
<b>ATU</b>	Assessment and Treatment Unit
<b>BMA</b>	British Medical Association
<b>BSL</b>	British Sign Language
<b>CBT</b>	Cognitive Behavioural Therapy
<b>CEV</b>	Clinically Extremely Vulnerable
<b>CFS</b>	Clinical Frailty Score
<b>CJS</b>	Criminal Justice System
<b>CPS</b>	Crown Prosecution Service
<b>CQC</b>	Care Quality Commission
<b>DCP</b>	Disabled Children's Partnership
<b>DDPO</b>	Deaf and Disabled People's Organisation
<b>DDP</b>	Deaf and Disabled People
<b>DHSC</b>	Department of Health and Social Care
<b>DLUHC</b>	Department for Levelling Up, Housing and Communities (formerly MHCLG)
<b>DNACPR</b>	Do Not Attempt Cardio-Pulmonary Resuscitation
<b>DSA</b>	Disabled Students' Allowance
<b>DWP</b>	Department for Work and Pensions

<b>EHCP</b>	Education, Health and Care Plan
<b>ELCI</b>	Energy Limiting Chronic Illness
<b>ESA</b>	Employment Support Allowance
<b>EU</b>	European Union
<b>FSM</b>	Free School Meals
<b>GRT</b>	Gypsy, Roma and Traveller communities
<b>ICO</b>	Information Commissioners Office
<b>IMCA</b>	Independent Mental Capacity Advocate
<b>IMHA</b>	Independent Mental Health Advocate
<b>JCHR</b>	Joint Committee on Human Rights
<b>JR</b>	Judicial Review
<b>LASPO</b>	Legal Aid, Sentencing and Punishment of Offenders Act 2012
<b>LCW</b>	Limited Capability for Work
<b>LCWRA</b>	Limited Capability for Work Related Activity
<b>LGBTQ+</b>	Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Allies, Asexual and Pansexual
<b>LGSCO</b>	Local Government and Social Care Ombudsman
<b>MAC</b>	Migration Advisory Committee
<b>ME/CFS</b>	Myalgic encephalomyelitis / Chronic Fatigue Syndrome
<b>MH</b>	Mental Health
<b>MHCLG</b>	Ministry of Housing, Communities and Local Government
<b>MoJ</b>	Ministry of Justice
<b>MUS</b>	Medically Unexplained Symptoms

<b>NAO</b>	National Audit Office
<b>NDS</b>	National Disability Strategy
<b>NHRI</b>	National Human Rights Institution
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Clinical Excellence
<b>NRM</b>	National Referral Mechanism
<b>ONS</b>	Office for National Statistics
<b>PA</b>	Personal Assistant
<b>PHE</b>	Public Health England
<b>PIP</b>	Personal Independence Payment
<b>PPE</b>	Personal Protective Equipment
<b>SSAC</b>	Social Security Advisory Committee
<b>SEND</b>	Special Educational Needs and Disability
<b>TUC</b>	Trades Union Congress
<b>UC</b>	Universal Credit
<b>UK</b>	United Kingdom
<b>VI</b>	Visual Impairment
<b>WCA</b>	Work Capability Assessment
<b>WEC</b>	Women and Equalities Committee
<b>WPC</b>	Work and Pensions Committee



# Evidence Reference numbers

<b>CBCE</b>	Notes from capacity building and consultation events
<b>D.DP</b>	Evidence submission from an individual Deaf or Disabled person
<b>DPPO</b>	Evidence submission from a Deaf and Disabled People's Organisation
<b>OI</b>	Evidence submission from a non-Deaf or Disabled person
<b>OO</b>	Evidence submission from a non-user led organisation
<b>SR</b>	Survey Respondent

# Appendices

## Appendix 1: List of Contributors

Thank you to everyone who sent in evidence and contributed to the development of this report.

All evidence is published online on the Inclusion London website:  
[www.inclusionlondon.org.uk/uncrdp](http://www.inclusionlondon.org.uk/uncrdp).

### **Deaf and Disabled People's Organisations**

Anonymous1

#Queer#Crip Group

Birmingham DRC

Bristol & South West Disabled People Against Cuts

Bristol Independent Living Group

Cambridge and Essex Disabled People Against Cuts

Changing Perspectives

Cheshire Disabled People Against Cuts

Chronic Illness Inclusion

Disability Murals

Disability Positive

Disability Rights UK

Disability Sheffield

Equal Lives

Equality Together  
Greater Manchester Coalition of Disabled People  
Inclusion London  
Liberation  
London, East and South East TUC Disabled Workers' Forum  
National Disabled People Against Cuts  
People First (Self Advocacy)  
Regard  
Sheffield Voices  
Social Power and Mental Health Steering Group  
Sovereign Harbour Disability Association, East Sussex  
Stay Safe East  
StopSIM Coalition  
Suffolk Coalition of Disabled People  
SWARM Collective: Sex Workers Advocacy and Resistance Movement  
TUC Disabled Workers' Committee  
Unfair Debt Group  
Unspoken  
World of Inclusion  
York Disability Rights Forum

## **Ally Organisations:**

Access Social Care  
Centre for Applied Human Rights at the University of York  
Disability Benefits Consortium  
Disabled Children's Partnership  
Disability Politics UK

Friends, Families and Travellers

Just Fair

Mencap

National Union of British Sign Language Interpreters (NUBSLI)

Norah Fry

Royal Association for Deaf People (RAD)

Royal National Institute for the Blind

Unison

## **Individuals:**

Anonymous x 11

Alyson Fisk

Amanda Jacobs

Christopher

George Gale Snr

Haley Jones

Heidi Crowter

Jason Holmes

Julia Cameron

Kenny Thompson

Kimaya Crolla-Younger

Linda Coy

Mia Mantra

Simon Fidler

Simon Smith

Sarifa Patel

## Appendix 2:

# Methodology

This report was put together through a project led by the DDPO Inclusion London and supported by a Steering Group that includes the following national DDPO/DDP-led group networks and allies:

- Disability Rights UK Our Voices
- DPO Forum
- National Disabled People Against Cuts
- Reclaiming Our Futures Alliance
- York Centre for Applied Human Rights
- Dr Kate Summers, Fellow in Methodology, London Schools of Economics
- Ellen Clifford, consultant

The project was underpinned by the following principles:

- Led by Deaf and Disabled People – but with input from allies welcomed.
- Robustly evidenced and methodologically sound.
- Value for money – identifying relevant existing resources to share and co-producing where new ones are required.
- Streamlined – avoiding duplication and excess of information in order to most effectively meet the needs of the UN disability committee.
- Best practice accessibility.
- Meaningful and transparent participation.
- Respectful towards Deaf and Disabled people and organisations taking part, remunerating participation where possible and appreciating strains on time and capacity.

- Widely owned – ensuring inclusion of diverse Deaf and Disabled people.

The work to put this report together was initiated by a tender for funding specifically for CRDP civil society shadow reporting to be undertaken from September 2021 with a final report submitted to the UN by 31<sup>st</sup> March. Funding for civil society shadow reporting was very welcome. However, the tender was not co-produced with DDPOs, was not ring-fenced to user led organisations, did not take adequate account of good practice in relation to access and inclusion relevant to consultation and engagement with DDPOs, and was based on a failure to adequately understand shadow reporting under the CRDP. The funding will not cover involvement of DDPOs within further stages of the examination process. The resulting project relied heavily on DDPOs own resources. We hope that lessons can be learned for future.

A [call for evidence](#) to inform this report was launched on 20 October 2021, open for approximately one month until 15 November 2021 and available in BSL and easy read. It was disseminated through the contact networks of each of the DDPO networks represented on the Steering Group (see Annex D Appendix B), through social media and through DDPO newsletters. An online, accessible event was held to launch the call for evidence with speakers including a member of the current CRDP Committee, a current member of the CRDP Secretariat and a campaigner who was involved in drafting the CRDP.

We received 103 separate submissions from 22 DDPOs, 13 non-user led organisations, including charities and trade unions, 34 DDP and 3 individual allies (family members/friends of DDP). These were in the format of written documents, pictures, tweets and emails. Content ranged from lists of statistics, virtual comment boards, links to reports, copies of entire reports, survey findings and personal testimonies as well as submissions written specifically in response to the call for evidence.

The variety of submissions was welcomed in order to accommodate access needs as well as the multiple strains and barriers experienced by both organisations and individuals wanting to participate. A number of other DDPOs and non-user led organisations wanted to send evidence but were unable to meet the timeframe even with dispensation given for submissions up until the middle of February.

Between 20 October and 31 December 2022, 17 events were held by 15 different DDPOs across England to raise awareness of the CRDP and to gather views for this report<sup>521</sup>. Most events included a number of workshops looking in more detail at specific articles or disability-related issues. These were attended by approximately 270 DDP although event hosts reported that more had signed up to attend than turned up on the day. An additional 31 documents recording the discussions at these events were included as evidence.

Targeted outreach was undertaken to include the voices of: DDP who are Black people and from racialised minorities; DDP living in rural areas; Disabled asylum seekers, refugees and people with No Recourse to Public Funds<sup>522</sup>; DDP who provide unpaid support for other DDP (often referred to as “carers”); DDP who use Augmentative and Alternative Communication (AAC); DDP who live in residential homes; also, DDP who are LGBTQ+, sex workers, low paid workers and in disability-related debt. This involved six focus groups attended by approximately 50 DDP and led to an additional 12 submissions.

More than 1000 pages of evidence was received. Analysis of early submissions and event notes informed the questions developed for an online survey open to DDP and allies from 13 - 24 December 2022. BSL was embedded into the online survey to increase accessibility. The survey was also available in hard copy and easy read paper format and respondents had the option to give their answers over the telephone.

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<sup>521</sup> Fourteen events were advertised publicly for open attendance on the Inclusion London website. All 17 were advertised in mail outs to their members and to other DDPOs in the region, on the host DDPO’s website and social media. Full list of events: <https://www.inclusionlondon.org.uk/uncrdp/full-events-list/events-list/>

<sup>522</sup> NRPF Network (n.d.) Immigration status and entitlements – How immigration status affects eligibility for public funds and other services. [nrpfnetwork.org.uk](https://www.nrpfnetwork.org.uk/information-and-resources/rights-and-entitlements/immigration-status-and-entitlements/who-has-no-recourse-to-public-funds-nrpf) [online] Available at: <https://www.nrpfnetwork.org.uk/information-and-resources/rights-and-entitlements/immigration-status-and-entitlements/who-has-no-recourse-to-public-funds-nrpf> Accessed on: 15.03.22



The survey was disseminated by all England SG members through mail out to contact networks and social media, reaching over 100,000 potential respondents including DDPOs, ally organisations and individuals<sup>523</sup>.

A total of 351 responses to the survey were received. For our analysis of survey responses please see Annex D<sup>524</sup>.

The survey asked respondents their views on the general situation facing DDP in the present time compared to 2017. It also: asked about areas where progress has taken place and good practice examples; suggested themes drawn from consideration of the initial evidence we had received and feedback from the events; and asked if there were areas that survey respondents thought were missing and what those were.

Percentage of survey respondents who agree there has been continued retrogression since 2017

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

Percentage of survey respondents who think that government measures are stopping Deaf and Disabled people from speaking out

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

Percentage of survey respondents who agree that institutionalisation of Deaf and Disabled people has been a growing problem since 2017

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

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<sup>523</sup> See Annex D p.151 for calculating potential respondents

<sup>524</sup> p.151.

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

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

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

- 87% agreed
- 3% disagreed
- 10% skipped

The narrative survey answers and evidence submissions were then analysed using the same set of coding headings. There is considerable overlap between the issues that are covered in both. The findings were written up and cross-referenced with statistical data, research findings and reports collated through a desk top exercise. Relevant quotes and extracts from personal testimonies were then pulled together into Annex A in recognition of the importance of lived experience within the shadow reporting process and the barriers to education and production of “robustly evidenced” reports that the vast majority of Deaf and Disabled people face.

All evidence is publicly available via the Inclusion London website. Each evidence submission and survey response has an individual reference number. These are used in the footnotes to link points made in the text with the specific submissions and responses where they are raised. See abbreviations above for a guide to the reference numbers.<sup>525</sup>

It is important that intersectional issues are taken into account in all policy planning and delivery and that equalities impact assessment consider the full diversity of DDP. There is a dearth of research and disaggregated data in these areas. The lived experience of DDP should nevertheless be listened to. We have therefore extracted examples of intersectional issues

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<sup>525</sup> p.106

from the evidence we received and incorporated within the main body of the report.

A list of suggested questions for the CRDP Committee to send to the UK Government is included within a UK-wide civil society shadow report put together and agreed by the England Steering Group in partnership with the respective Steering Groups for the Scottish and Welsh civil society shadow reports and Disability Action Northern Ireland. This is available on the Inclusion London website.

These questions were informed by our analysis of the evidence we received and considered. They reflect what we think it would be most useful for respective UK governments to provide information on in order for the CRDP Committee to get the best understanding of where implementation of the CRDP is at across the UK.

The UK is not due before the CRDP Committee until March/April 2023 at the earliest on account of a backlog created by the pandemic. Submission of evidence now will reduce the prospect of being pushed back further. Policy developments are fast moving. We therefore plan to send an update further to this report to the Committee once there is a scheduled date for them to consider the UK and adopt a “List of Issues” (LOI).

# Appendix 3:

## List of Disability-Related Judicial Reviews since 2017

### September 2017

[\*Davey, R \(on the application of\) v Oxfordshire County Council & Ors\* \[2017\] EWCA Civ 1308 \(01 September 2017\) \(bailii.org\)](#)

Court of Appeal clarified that the wellbeing principle in the Care Act is complied with if Local authority can demonstrate that it had considered individual's wellbeing. The decision confirmed a significant cut to Luke Davey's care package.

### December 2017

[\*RF v Secretary of State for Work And Pensions\* \[2017\] EWHC 3375 \(Admin\) \(21 December 2017\) \(bailii.org\)](#)

High Court finds 2017 Personal Independence Payment (PIP) Regulations restricting eligibility for the mobility component for people who experience psychological distress unlawful.

### May 2019

Successful legal challenge to government's voting provisions (for blind and partially sighted voters). No judgement available but see:

<https://www.leighday.co.uk/latest-updates/news/2019-news/successful-legal-challenge-to-governments-voting-provisions/>

### November 2019

[\*RR \(Appellant\) v Secretary of State for Work and Pensions\* \[2019\] UKSC 52](#)

The supreme court has ruled against the UK government's attempts to force the bedroom tax on 155 partners of people with severe disabilities, in a decision that will hamper ministerial attempts to water down human rights legislation.

## June 2020

[\*R \(Johnson, Woods, Barrett & Stewart\) v SSWP\* \[2019\] EWHC23 \(Admin\); \*SSWP v Johnson, Woods, Barrett & Stewart\* \[2020\] EWCA Civ788](#)

A successful challenge to the rigidity of the monthly assessment period regime under universal credit (UC) and the way that earned income is calculated for certain claimants. Implementing regulations came into force on 16 November 2020. [View the regulations](#). The adjustment or ‘fix’ provided for by these regulations initially operated manually but, as of August 2021, it now operates automatically.

## January 2020

[\*\(TP, AR & SXC\) v Secretary of State for Work and Pensions\* \[2020\] EWCA Civ 37](#)

The Court of Appeal upholding the findings of both High Court judges to the effect that the Universal Credit transitional provisions constitute discrimination under ECHR, art 14 (read with A1P1) in respect of “severely disabled persons” i.e. people who had previously been entitled to receive the Severe Disability Premium in Legacy Benefits.

## March 2020

[Nice Guidance on Access to Critical Care is amended after threat of JR](#)

## March 2020

NHS England has agreed to change its policy on hospital visitors so that it no longer discriminates against disabled people, [in the face of at least two legal challenges](#).

## January 2020

[\*R \(TD & Ors\) v Secretary of State for Work and Pensions\* \[2020\] EWCA Civ 618; \*R \(TD & Ors\) v Secretary of State for Work and Pensions\* \[2019\] EWHC 462 \(Admin\)](#)

The Court of Appeal found that legacy benefits claimants who had to claim UC after wrong decisions that they are fit to work were discriminated against. Those claimants lost transitional protection and income even after decisions wrongly finding them fit for work were overturned.

## July 2020

[\*Connor, R \(On the Application Of\) v The Secretary of State for Work And Pensions\* \[2020\] EWHC 1999 \(Admin\) \(24 July 2020\)](#)

High Court rules mandatory reconsideration requirement for ESA appeals unlawful.

## July 2020

[No: \[2020\] NIQB 53](#)

High Court holds that special rules for terminal illness, in case where claimant cannot demonstrate their death can be reasonably expected within six months, are 'discriminatory' and 'manifestly without reasonable foundation'

This decision was overturned by the Northern Ireland Court of Appeal, but led to [Westminster Government's commitment to change terminal illness rules](#).

## July 2021

[\*R \(on the application of Katherine Rowley\) -v- Minister for the Cabinet Office\* \[2021\] EWHC 2108 \(Admin\)](#)

Failure to provide BSL Interpreters for Data Briefings was Unlawful Discrimination

## November 2020

[\*R \(Kausar and JL\) v Secretary of State for Work and Pensions\* CO/987/2020](#)

High Court finds DWP unlawfully refused UC to disabled students for 7 years, [only for Secretary of State to change the law to bar them again](#)

## December 2020

[\*SH, R \(On the Application Of\) v Norfolk County Council & Anor\* \[2020\] EWHC 3436 \(Admin\)](#)

The High Court found changes to local authority charging for care policies to be discriminatory against Disabled people with high support needs.

## December 2020

[\*R, \(on the application of\) v The Secretary of State for the Home Department \(Rev 1\) \[2020\] EWHC 3416 \(Admin\) \(14 December 2020\)\*](#)

The high court rules systemic disability discrimination in Home Office Asylum support system.

## March 2021

[Visually impaired woman secures promises from government to change pandemic communications \(on the morning of the JR\)](#)

## March 2021

Errol Graham: Family of man who starved to death after benefits cut off lose High Court challenge against the DWP. No judgment available but see: <https://www.disabilityrightsuk.org/news/2021/march/errol-graham-family-man-who-starved-death-after-benefits-cut-lose-high-court>

## July 2021

DWP to stop ‘cold-calling’ disabled people to make low benefit ‘offers’. [DWP amended its policies and guidance before the JR was heard.](#)

## July 2021

DWP concede new ‘transitional protection’ for disabled people left financially worse off on transfer to UC. No judgment available but see: <https://www.gcnchambers.co.uk/dwp-concede-new-transitional-protection-judicial-review-deadman-and-ryan-v-secretary-of-state-for-work-and-pensions-co-1146-2021-22-july-2021/>

## July 2021

Severely disabled man challenged stop to his PIP after 28 days in hospital. No outcome yet. <https://www.leighday.co.uk/latest-updates/news/2021-news/severely-disabled-man-challenges-halt-to-personal-independence-benefit-payments-after-28-days-in-hospital/>



## August 2021

A disabled swimmer has been granted permission for a JR of the new charging regime for Hampstead Ponds which she claims is discriminatory. No outcome yet.

<https://www.leighday.co.uk/latest-updates/news/2021-news/disabled-swimmer-wins-permission-for-judicial-review-of-discriminatory-charges-at-hampstead-ponds/>

## January 2022

[\*R\(Binder & Others\) v Secretary of State for Work and Pensions\* \[2022\] EWHC 105 \(Admin\)](#)

High Court judgment declaring that the National Disability Strategy is unlawful following a failure to lawfully consult disabled people and others.

## February 2022

[\*T & Ors, R \(On the Application Of\) v Secretary of State for Work And Pensions\*, \[2022\] EWHC 351 \(Admin\)](#)

High Court dismissed the claim of legacy benefits claimants that Failure to extend £20 per week COVID uplift to claimants of legacy benefits in line with UC constituted discrimination. The court found that difference in treatment was justified.

## Appendix 4:

# Local Government and Social Care Ombudsman's latest annual review of complaints.

In September 2021, the Ombudsman's annual review of social care complaints was published, covering both councils and independent care providers across England. It found fault in 72% of the complaints it investigated last year, This percentage of upheld cases is greater than the previous year (69%) and shows a relentless rise over the last decade in the proportion of cases in which care users and their families have been let down by local services.

The faults the Ombudsman finds in its investigations are increasingly caused by the measures employed by councils and care providers to mitigate the squeeze on their resources. In 2020-21 the Ombudsman received 2,033 complaints and enquiries about adult social care. This included 270 about independent care providers, where the person arranged and paid for their own care. As in all areas of its casework, last year the Ombudsman received and decided fewer complaints about adult social care than the previous year because of the disruption caused by COVID-19.

The Ombudsman made 1,642 individual recommendations to put things right in adult social care investigations last year, of which around a third (546) were aimed at improving services for everyone.

% of complaints upheld each year:

2015/16	65%
2016/17	54%
2017/18	57%
2018/19	58%
2019/20	69%

## Recent cases:

What follows is a selection of the most recent complaints investigated and upheld by the Ombudsman. Some complaints were not upheld, while others were upheld but the Council had agreed to take action to a suitable remedy so there was nothing further that the ombudsman could achieve by investigating these complaints and they are not mentioned in this document.

## Social Care Charging

**22-Dec-2021** [Cheshire West & Chester Council](#) Miss X complained the Council incorrectly charged her for care that she understood would be free. The Council was at fault for failing to provide financial information to Miss X about her package of care when she left hospital.

**17-Dec-2021** [Liverpool City Council](#) Mr X complained about how the Council managed his late brother, Mr Y's, finances while it was his court appointed deputy. There was fault in how the Council identified and reported a change of Mr Y's circumstances which affected Mr Y's benefits

**15-Dec-2021** [City of York Council](#) Mr K complained about the Council's handling of his father's care funding. He said it took the Council four months to tell him the outcome of the care assessment. As a result, he said he experienced financial loss as the Council asked him to pay the care charges. He also said this caused him and his father distress.

## Assessment and care plan

**21-Dec-2021** [Essex County Council](#) Ms X complained about the way the Council assessed her mother's needs for homecare support. Ms X says this resulted in distress and a delay in her mother's discharge. We found fault with the way in which the Council responded when Ms X and the care home raised concerns about the proposed support at home.

**15-Dec-2021** [London Borough of Croydon](#) We upheld Ms X's complaints about a failure to arrange a timely assessment to enable Mrs Y to have an appropriate care package so she could go home from hospital and about poor care (missed medication).

**15-Dec-2021** [Kent County Council](#) Mrs X complained the Council reduced the support provided to her son, Mr Y, on his care plan without involving him in 2019. There was fault in how the Council reduced Mr Y's care and support without notice and delays in arranging his direct payments in late 2020

## Direct payments

**10-Dec-2021** [East Sussex County Council](#) Mrs Y complained about the way the Council dealt with Mr X's direct payments, and its complaints handling. The Ombudsman has found fault by the Council, causing injustice.

**04-Nov-2021** [Warrington Council](#) Mr X complained about how the Council provided for his, and his son, Mr Q's, social care needs. Based on the information we have seen, there was fault in how the Council calculated and managed Mr Q's direct payments. This caused an underpayment to Mr Q and avoidable frustration, time and trouble to Mr X

**14-Oct-2021** [Nottinghamshire County Council](#) Ms X complained about how the Council assessed her mother Ms Y's care and support needs and about how it handled the financial assessment and Ms Y's financial contribution. The Council was at fault for delays in notifying Ms Y of her contribution, for delays in responding to Ms X and for the way it recouped an overpayment which left Ms Y without sufficient funds to pay for her care.

## COVID

**21-Dec-2021** [Oxfordshire County Council](#) The Council was at fault when Mr X's Care Provider withdrew his home care package with no notice when it decided he and his wife may have COVID-19. The Council was also at fault for delaying in sourcing another care package for Mr X.

**06-Dec-2021** [West Sussex County Council](#) Mrs X complains about a lack of communication from the Burlington Nursing Home, where the Council had placed her father, causing unnecessary distress, and a failure to recognise he was approaching the end of his life, which meant his family could not spend time with him before he died.

**23-Nov-2021** [London Borough of Croydon](#) Mrs X complains the Council failed to provide enough support for Mr Y during the COVID-19 pandemic, leaving her to meet all his needs for several months and unable to work. The Council did not respond promptly or constructively to all Mrs X's requests for support. This left her struggling to meet all Mr Y's needs.

**03-Nov-2021** [MTCARE Property Limited](#) Ms X complains Meavy View Retirement Home (run by MTCARE Property Limited) failed to look after her mother properly while she was living there during the COVID-19 pandemic in 2020. Meavy View did not keep proper records of the care provided for Mrs Y, which may have put her and others at risk of harm

**01-Nov-2021** [Hanford Manor Limited](#) Miss X complains Hanford Manor failed to look after her late father, Mr Y, properly when he stayed there in February 2021. She says this resulted in a rapid decline in his condition and poor infection control, which resulted in him catching COVID-19 from which he died. Hanford Manor failed to produce care plans for meeting Mr Y's needs

**26-Oct-2021** [Essex County Council](#) The Council was at fault when it failed to consider Mr X's requests on behalf of his sister, Ms S, for disability related expenditure. This caused Ms S an injustice because there is uncertainty over whether those requests should have been granted

## Disabled Facilities Grants

**18-Nov-2021** [London Borough of Redbridge](#) The Council's failure to deal properly with Mr X's application for a Disabled Facilities Grant caused avoidable delays of 32 months

## Residential care

**04-Jan-2022** [Barnsley Metropolitan Borough Council](#) Mr X complained his mother's care home billed him for unpaid care charges two and a half years after his mother passed away. Mr X says this situation has caused distress and upset to him and his family. The Ombudsman found fault with the Council for failing to pay Mrs Z's top-up charges despite placing her in a residential care home.

**21-Dec-2021** [Tameside Metropolitan Borough Council](#) Mr C complained about the way the Council, and the care provider it commissioned,

responded to a deterioration of his son's behaviour, which resulted in increasing incidents. We found the Council was at fault for a delay in its response

**21-Dec-2021** [Reading Borough Council](#) Ms X says her mother died in hospital because of poor care she received in a care home. There were admitted failings in the care Ms X's mother received at the care home. But Ms X's mother's death cannot be attributed to poor care at the home through this investigation

**21-Dec-2021** [Charlton Care Group Limited](#) Mrs C complained about several aspects of the care support her father received at the care home he was living. Mrs C said these resulted in distress to her father and herself. We found there were some shortcomings with regards to the support Mr F received

**21-Dec-2021** [Care Plus Group \(North East Lincolnshire\) Limited](#) Mr X complained on behalf of his deceased mother, Mrs Y about the standard of care provided by Fairways Care Home and about an investigation completed after she fell. We find the Care Home delayed in responding after Mrs Y activated her sensor mat.

**13-Dec-2021** [Rushcliffe Care Ltd](#) Mrs X complains about the failure of a care home to administer her mother's medication correctly. There was fault which warrants a remedy.

**10-Dec-2021** [Health & Care Services \(NW\) Limited](#) Mrs X complains about the Care Provider's treatment of her late husband, Mr Y's, funded nursing care payments. Mrs X says this caused Mr Y a financial loss and caused her additional upset and distress while grieving for him.

## Safeguarding

**23-Dec-2021** [Birmingham City Council](#) Summary: Mr B complained the Trust and the Council delayed his late mother's discharge from hospital and kept her in hospital against her will on two occasions in December 2019. Mr B said as a result his mother, Mrs C, contracted a hospital acquired infection and this contributed to her untimely death. We found fault in the way the Trust and the Council dealt with Mrs C's second discharge, and this meant she remained in hospital for longer than she wanted.

**09-Dec-2021** [Warwickshire County Council](#) Mrs D complains on behalf of her late husband (Mr P) about the care he received while in residential care. We found the Council failed to provide a care placement for Mr P which was suitable for his needs. I also consider there were failings by the care home to promptly identify on one occasion that Mr P required medical treatment. There were also delays by the Council in arranging an alternative care placement for Mr P and a failure to properly communicate with Mrs D on this and other issues.

# Appendix 5:

## Copy of DDPO letter to Secretary of State for Health and Social Care with response

16th July 2021

Our ref: KMSJ20210716/Gov

Rt Hon Sajid Javid MP  
Secretary of State for Health and Social Care  
Department of Health and Social Care  
39 Victoria Street  
London  
SW1H 0EU

Dear Secretary of State,

Engaging with Disabled People on Social Care Reform

Many congratulations on your appointment.

I am writing to you on behalf of the Disabled People's movement in connection with the urgent and pressing issue of social care reform. I attach a Statement on Social Care that has been signed by over five hundred Disabled People, disability organisations and allies.

We ask that Disabled People of all ages be placed at the heart of current government engagement on shaping social care reform. It is those of us that draw on social care that should have the biggest say in the future.

We ask that reform proposals are designed to improve the lives of Disabled People, young and old. The support we receive from social care should enable us to live full and active lives, connected to our families, friends and community. Social care should not starve us of the support we need, burden us with charges or institutionalise us against our will.



We need a strengthened framework of rights, which treat those of us that receive social care as full and equal citizens, where our voice is heard and where we co-design the support we need.

Finally, we need to contribute to how social care services are delivered and funded, ensuring that structures, processes and funding do not create a lottery of care, increase bureaucracy, or put undue financial burdens on us.

We would ask that you meet with representatives from the Disabled People's movement to discuss the Statement and how government can put us at the heart of its engagement. This issue affects our lives.

Yours sincerely

Kamran Mallick

Chief Executive Disability Rights UK

[kamran.mallick@disabilityrightsuk.org](mailto:kamran.mallick@disabilityrightsuk.org)

**From:** MB-SOFS <[mb-sofs@dhsc.gov.uk](mailto:mb-sofs@dhsc.gov.uk)>

**Sent:** 01 September 2021 13:07

**To:** Kamran Mallick <[Kamran.Mallick@disabilityrightsuk.org](mailto:Kamran.Mallick@disabilityrightsuk.org)>

**Subject:** POC\_1347162

Dear Mr Mallick,

Sajid Javid has asked me to thank you for your kind letter of 16<sup>th</sup> July, congratulating him on his appointment as Secretary of State for Health and Social Care.

Sajid is incredibly honoured to take up this post, particularly during such an important moment in our recovery from COVID-19. He knows that the position comes with a huge responsibility, and he will do everything he can to deliver for the people of this great country. He is looking forward to working with the brilliant people who have dedicated their lives to our great health and care services, and to ensure that all the tools and talents at our disposal are used to ensure it remains the best health service in the world.

Sajid knows that thanks to the fantastic efforts of our NHS and social care staff, who work tirelessly every day, and our phenomenal vaccination programme, we have made enormous progress in the battle against this dreadful disease. He wants our country to get out of this pandemic and that will be his most immediate priority.

As you will appreciate, the Secretary of State is currently receiving a large number of letters and emails daily and is unable to respond personally to them all at this very busy time. Also, unfortunately, due to the considerable pressures on his diary at the moment, the Secretary of State is unable to meet with you at the moment. However, he is looking forward to working with you in the future, and recommends that you continue with your engagement with Minister Whately and Department officials on the issues you have raised.

Yours sincerely,



Department  
of Health &  
Social Care

**David Davies**

Correspondence Manager for the Secretary of State

Department of Health and Social Care, 9<sup>th</sup> Floor, 39 Victoria  
Street, London SW1H 0EU

E: [mb-sofs@dhsc.gov.uk](mailto:mb-sofs@dhsc.gov.uk)

## Appendix 6:

# Deaths of claimants

There has been a series of high profile cases last year, relating to claimants' deaths and suicides driven by benefit loss, following interactions with DWP.

DWP still refuses to accept that these deaths are part of a wider problem, but their own figures show that DWP has internally investigated 97 deaths since summer 2019 and 27 cases of serious harm. In the last two years alone, the rate of internal investigations by the DWP into deaths and serious harm almost tripled (a 176% rise) with 124 cases since summer 2019, 97 concerned people who have died. And although DWP has put into place a series of safeguarding measures for dealing with “vulnerable” claimants, the latest cases highlight both failures to follow these processes but also the inadequacy of these even when followed properly.

In spite of these structural failings, and an increasing death toll, the Secretary of State for Work and Pensions, Dr Therese Coffey has stated that the statutory safeguarding responsibility to vulnerable claimants falls to councils, social services, doctors and others, but not the DWP

<https://committees.parliament.uk/oralevidence/1630/pdf/>

### List of publicly known benefit deaths since 2017:

**February 2017.** Jodey Whiting took her life after her benefit payments were cut off because she had missed a capability assessment while suffering from pneumonia. The Department for Work and Pensions (DWP) later admitted mistakes were made and paid the family compensation. [Engagements – Hansard – UK Parliament](#)

**February 2017.** James ‘Jimmy’ Ballentine overdosed on prescription drugs after he learned he had mistakenly over-claimed benefits from the Department for Work and Pensions (DWP). It is understood Mr Ballentine made efforts to find out how much money he owed but was unable to get an answer, which sent him in a spiral of depression. [It is a pleasure to serve under...: 24 Apr 2019: Westminster Hall debates – TheyWorkForYou](#)

**September 2017.** Brian Sycamore, took his own life after running out of money because he was having trouble getting UC. He left a suicide note sarcastically “thanking” Universal Credit bosses. [Our crippled brother was judged fit to work, had benefits stopped – then took his own life – Derbyshire Live \(derbytelegraph.co.uk\)](#)

**October 2017.** Amy Nice, a struggling young mum took her own life after she feared losing her benefits under the Government’s Universal Credit scheme, [It is a pleasure to serve under...: 24 Apr 2019: Westminster Hall debates – TheyWorkForYou](#)

**October 2017.** Chris Gold died ‘in hunger’ a few days after a television interview about the difficulty getting Universal Credit. He was heavily in debt and preparing to lose his home.

**November 2017.** Elaine Morrall, 38, was found dead wrapped in her coat and scarf because she could not afford to turn on her heating. Her benefits had been stopped multiple times including when she had not attended a Universal Credit interview because she had been in intensive care. [We may never know how mother found 'frozen in hat and coat' died – Liverpool Echo](#)

**December 2017.** Daniella Obeng was found dead within days of arriving in Qatar to find work when her disability benefits were cut off. [It is a pleasure to serve under...: 24 Apr 2019: Westminster Hall debates – TheyWorkForYou](#)

**June 2018.** Errol Graham, 57, who had a history of mental health problems, starved to death in his Nottingham flat after his benefits were stopped. [Errol Graham death: Nottingham man starved after benefits stopped – BBC News](#)

**June 2018.** Jeff Hayward was 52 when he died of a heart attack in June last year, two weeks before he was due to go to court to challenge a fit for work DWP decision. His family have won his case – seven months after he died. [Man wins fit-for-work appeal seven months after his death | Disability | The Guardian](#)

**July 2018.** Brian Bailey, 59, took his own life after allegedly "becoming overwhelmed" with the pressures that the new benefit system had put on him, feeling that he could not cope with the uncertainty regarding his

payments, and constantly fearing being evicted from his home. ['Universal Credit killed my dad' – grieving daughter slams system after tragic death – Grimsby Live \(grimsbytelegraph.co.uk\)](#)

**December 2018,** [Kevin Dooley](#), a 48 year-old man died by suicide after his benefits were cut and he was declared fit to work. [Chronically ill Leeds dad took own life after DWP stopped his benefits, inquest hears – Leeds Live \(leeds-live.co.uk\)](#)

**January 2019.** [Alexander Boamah](#). Drug overdose after being given 11,000 pounds as backdated payment by DWP. A specific concern from the coroner relates to the potential that individuals, without capacity to manage their finances, may come into receipt of funds which place them at particular risk. [Alexander Boamah | Courts and Tribunals Judiciary](#)

**April 2019.** [Stephen Smith](#), 64, a man with multiple debilitating illnesses who was denied benefits and deemed fit to work, sparking a national outcry over the government's welfare system, has died. [Starving man deemed 'fit to work' at just 6st dies | Metro News](#)

**October 2019.** The inquest into the death of 27 year old [Philippa Day](#) – who had been diagnosed with unstable personality disorder and killed herself after her benefits were wrongly cut off, – found 28 errors in the management of her benefit claim by both the DWP and private contractor Capita. <https://www.judiciary.uk/wp-content/uploads/2021/02/Phillipa-Day-2021-0043.pdf>

**April 2020.** [Terence Talbot](#), died after the DWP ordered him to leave hospital to visit a jobcentre despite being severely ill with a condition that later killed him. Health professionals told the inquest into his death that they had never heard of such a “severely ill inpatient” being told by DWP to leave hospital to make a benefit claim in person. The assistant coroner for Mid Kent and Medway, wrote to work and pensions secretary Therese Coffey last month to warn her that other claimants could die unless urgent changes are made to how DWP deals with such cases. <https://www.disabilitynewsservice.com/coroner-dwp-must-act-after-it-told-severely-ill-patient-to-leave-hospital-to-make-claim/>

In **December 2020**, an inquest heard how [Roy Curtis](#), an autistic man took his own life in November 2018 six days after being told to attend a “fitness for work” assessment, despite DWP being repeatedly warned that its

actions were making him suicidal. [It is a pleasure to serve under...: 24 Apr 2019: Westminster Hall debates – TheyWorkForYou Roy-Curtis-2020-0272\\_Redacted.pdf \(judiciary.uk\)](#)

**December 2020.** [Philip Pakree](#), 49, died in his sleep, after 18 months of problems with his disability benefits and harassment over the Work Capability Assessment he was too ill to undergo [Partner of 'distraught' ESA claimant says DWP drove him to his death – Disability News Service](#)

## Appendix 7:

# Summary of ICE Annual Report (2020-2021) focused mainly on Disabled claimants

Independent Case Examiner (ICE) provides a free independent complaints review service for the Department for Work and Pensions (DWP) and their contracted services. It is a higher level of complaints, when DWP does not recognise liability or maladministration, and when complainants have exhausted the internal complaint process.

ICE's first task in case adjudication is to work out whether there has been 'maladministration', or in simpler terms, whether DWP handled things for a customer as their procedures and processes say they should. According to ICE, 'It seems worth stating that had DWP 'simply' done what it set out to do, there would not have been 484 upheld case findings this year'.

The ICE Annual Report can be found here:

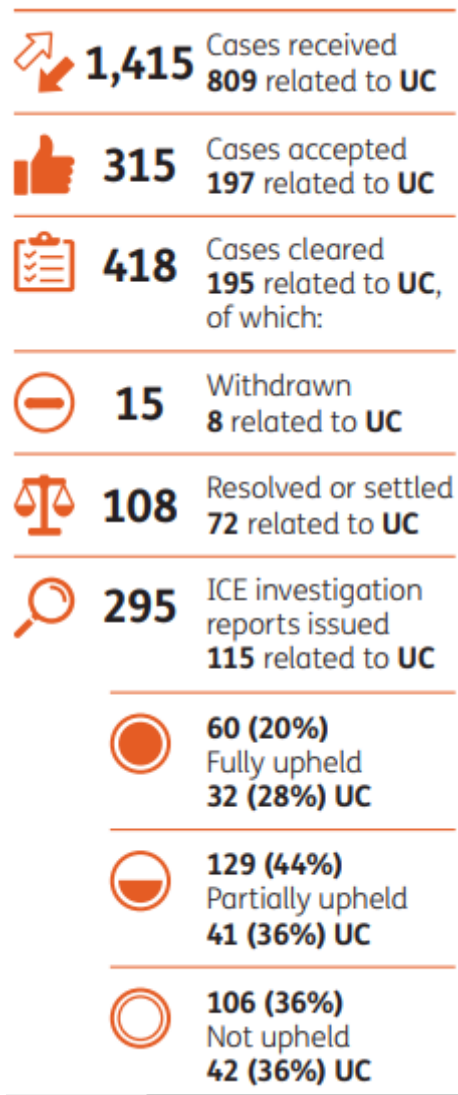
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1026729/ice-dwp-annual-report-2020-2021.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1026729/ice-dwp-annual-report-2020-2021.pdf)

What is repeatedly reiterated in this report, is that each case is extremely technical and complex, which is why they are impossible to summarise easily. In its drive to simplify the benefit system, DWP has prioritised simplification for its own benefit, while forcing claimants to navigate an extremely complex system, digital by default and which is badly understood by DWP staff. Those who are the least likely to navigate successfully this system, Disabled people, people whose English is the second language, older people are being failed disproportionately by DWP. In the words of the ICE report 'significant failings can arise from a series of apparently small errors and oversights'.

See key statistics and case studies below:



## Universal Credit and Disabled claimants



More than half of the Working Age complaints accepted by ICE were from Universal Credit (UC) claimants; UC replaced a number of legacy benefits, not all administered by DWP, including Child Tax Credit, Working Tax Credit, Housing Benefit and Income Related Employment and Support Allowance (ESA). Crucially, those that do claim UC, find they can no longer return to claiming legacy benefits, in particular ESA, a benefit for people who cannot work temporarily or longer term. ICE found people making inappropriate claims in error because of DWP staff confusion or ignorance.

In the 2 case studies used by ICE, one Disabled claimant was wrongly advised to claim UC although he wanted to make a claim for ESA, but was not informed of the existence of New Style ESA. The complainant and his partner made a joint UC claim, but they lost their Child Tax Credits (as UC and CTC cannot be claimed as the same time) and as the claim progressed, they were told that they were not entitled to UC because they had more than £16,000 in savings. Although they were able to make a new claim for New Style ESA, they could no longer be paid CTCs.

The 2<sup>nd</sup> case is even more complicated, and involves again Disabled complainants, and just serves to highlight that UC was devised as a simplified system for one single, young

short term unemployed person in mind and cannot cope with claimants with more complicated lives.

## Disability benefits



The majority of cases seen by ICE this year are from Personal Independence Payment (PIP) claimants. PIP was introduced in 2013 and has gradually replaced Disability Living Allowance (DLA) for people aged 16 to 64. In the main the complaints ICE received concern the PIP assessment process and how medical evidence provided to support a claim had been interpreted, in particular where a claimant may have previously been in receipt of a long term award for DLA, prior to being invited to claim PIP.

The case study used by ICE concerns a failure by DWP to do what they should have in a PIP claim, in respect of a change of appointee.

Without going into the details of the case, DWP's numerous failures over a period of time meant that by the time the claimant died, they had been without ESA for three months and PIP for three weeks. After ICE's intervention, the next of kin was paid more than £10,700 in June 2021

# Appendix 8:

## List of Data Gaps

### Work and Pensions

Since the roll out of Universal Credit (UC), it is more difficult to see what is happening to DDP than under the legacy benefits system it replaced.

- **Work Capability Assessments: Outcomes are only published for Employment Support Allowance claimants, but ESA is now closed to new claims.** Based on the government's own statistics, around 1% of claimants are leaving the Work Related Activity Group (WRAG) each month plus over 1% the Support Group (SG). Most DDP are now claiming UC as the default benefit. ESA assessments are now mainly reassessments and the statistics are very limited in what they can tell us. UC only disaggregates statistics by conditionality, i.e. the level of sanctions which applies to each category.  
<https://www.gov.uk/government/statistics/esa-outcomes-of-work-capability-assessments-including-mandatory-reconsiderations-and-appeals-december-2021/esa-work-capability-assessments-mandatory-reconsiderations-and-appeals-december-2021>
- **Universal Credit: Disabled people don't exist as a distinct group**, but belong to conditionality groups, meaning attracting different levels of sanctions. So disabled people under UC are lumped in with other groups, such as people on income support or single parents, and it is impossible to know how many of them are claiming UC, whether they have Limited Capability for Work (LCW) or Limited Capability for Work Related Activity (LCWRA) and are being sanctioned. The official statistics are supposedly here, but lead to a website where users have to create their own statistics.  
<https://www.gov.uk/government/statistics/universal-credit-statistics-29-april-2013-to-9-december-2021>
- **No statistics on and monitoring of WCA Outcomes for UC claimants.** Although DWP has made it possible to know (through the X-plore tool, which helps you to construct your own tables) the number of claimants found to have LCWRA under UC, and the number of claimants found

to have LCW, DWP has confirmed that the number of DDP found to have LCW were only claimants moved from the ESA WRAG to UC because of a change of circumstances. These claimants have never undergone a WCA under UC. **More importantly**, DWP does not publish the number or % of people undergoing a WCA and found to have neither LCWRA nor LCW, which under the old ESA system meant **being found fit for work**. This is really important, as the ratio between the 3 groups used to be a good indicator of the disability assessment contractors' performance, and evidence of pressure by the government to keep the claimant count down. The number of Mandatory Reconsiderations (MR which is a DWP internal appeal system to challenge a benefit decision) is an overall number and **the publication of the Ministry of Justice on tribunal statistics** no longer differentiates between the different UC claimants. They are all lumped together, disabled and unemployed people, working people, etc. A crucial piece of information has been lost as these figures were previously produced by the MoJ, and not the DWP.

- **Policies introduced are not monitored.** For example, cuts to ESA WRAG. No evaluation of impact on DDP and no evaluation of whether the cuts have incentivised DP into work (which was the government's argument in favour of the cut). No impact assessment has taken place of the removal of the £20 uplift on disabled people on UC during the pandemic.
- **Refusal to publish a report commissioned by the Prime Minister's office** – into the effectiveness of its support for “vulnerable” claimants of Universal Credit. It was eventually published after the Work and Pensions Committee threatened to publish it if DWP did not, but not before the authors of the report were asked to water it down, by removing several references to ‘unmet needs’. The report confirms that the level of benefits is so low that some DDP are still unable to meet essential living costs such as food and utility bills.  
<https://committees.parliament.uk/publications/8745/documents/88599/default/>
- **Refusal to publish an evaluation on the effectiveness of sanctions commissioned in 2019.**  
<https://www.theguardian.com/society/2022/jan/27/report-on-effectiveness-of-benefit-sanctions-blocked-by-dwp>

- **DWP Outcome Delivery Plan:** DWP is only planning to evaluate the impact of policies designed to help people move into work

<https://www.gov.uk/government/publications/department-for-work-and-pensions-outcome-delivery-plan/department-for-work-and-pensions-outcome-delivery-plan-2021-to-2022>

- The **Claimant Service and Experience Survey (CSES)** was last published in 2019 and shows a decrease in satisfaction for ESA and PIP claimants <https://www.gov.uk/government/publications/dwp-claimant-service-and-experience-survey-2018-to-2019--2/claimant-service-and-experience-survey-2018-to-2019>

## Equalities

- **Life Opportunity Survey Data** on how disabled and non-disabled people participate in society. Was discontinued in 2015
- **Fulfilling Potential Outcomes and Indicators** Data measuring indicators in the Fulfilling Potential disability strategy outcomes and indicators framework. Discontinued 2015

## Data Gaps Identified in Evidence Received

- Available numbers of specialist vision rehabilitation workers and impact of cuts. Information is held by individual Local Authorities with no central collation or monitoring<sup>526</sup>.
- Disaggregated disability data on<sup>527</sup>:
  - sexual violence experienced by women and girls who are Deaf and/or Disabled;

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<sup>526</sup> OO9

<sup>527</sup> See p.12 above

- numbers of DDP affected by other forms of hate crime;
  - unmet social care needs among among Black people and racialised minorities and LGBTQ+ communities;
  - Disabled parents and child protection proceedings;
  - DDP who are/have been victims of modern slavery
- Figures on funding for people who require access to AAC<sup>528</sup>

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<sup>528</sup> DDPO38

## Appendix 9:

# List of 24 Breaches of DDP's Rights in first 12 months of COVID-19 Pandemic<sup>529</sup>

1. Ministers failed to offer recipients of so-called legacy benefits such as ESA the same £20-a-week benefit increase [given to those on universal credit](#).
2. The Department of Health and Social Care [took five months to produce guidance](#) that aims to protect disabled people in supported living services during the pandemic.
3. Justin Tomlinson, the minister for disabled people, [failed to carry out meaningful engagement](#) with disabled people's organisations during the early months of the pandemic.
4. DHSC drew up a strategy that allowed patients infected with COVID [to be discharged from hospitals into residential homes](#), as part of a so-called "safe discharge" scheme regulated by the Care Quality Commission.
5. DHSC [released new guidance](#) for those seen as clinically extremely vulnerable to the virus, less than 24 hours before the England-wide lockdown that began in November.
6. Disabled people seen as extremely vulnerable to coronavirus were initially only placed [sixth in the priority list](#) for a COVID-19 vaccine when it was first published in November.
7. After the priority list was altered, following pressure from disabled campaigners, [there were further concerns](#) that hundreds of

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<sup>529</sup> Compiled by Disability News Service:

<https://www.disabilitynewsservice.com/governments-shocking-pandemic-rights-list-of-shame/>

thousands of disabled people with underlying health conditions were still not being treated as a priority for the vaccine.

- 8.** The government failed to provide shielding information in an accessible format to visually-impaired people, as well as failing to provide other information and guidance in an accessible format, [including for BSL-users](#).
- 9.** Government departments, including the Ministry of Justice and the Department for Work and Pensions (DWP), refused to allow many disabled staff to work from home, [forcing them to go into work](#), and also refused other reasonable adjustments.
- 10.** [The emergency Coronavirus Act](#) restricted rights to care and education and the rights of people in mental distress.
- 11.** The first official statistics showing how many disabled people were dying with coronavirus [were not published until late June](#), even though disabled people were being disproportionately affected by the pandemic.
- 12.** Many disabled people who receive direct payments to pay for their personal assistants [were unable to access personal protective equipment in the early months of the pandemic](#).
- 13.** The government only published guidance to help [people on direct payments more than five weeks after](#) it had published guidance for the wider social care sector.
- 14.** NHS England guidance on banning visitors to patients [discriminated against disabled people](#) with high support needs, while NHS England then failed to consult disabled people [on a new version](#) of the guidance.
- 15.** The government's test and trace programme [was not accessible to many disabled people](#).



- 16.** Direct payments users [were given only two days](#) to digest new government guidance if they wanted to take advantage of the government's COVID-19 job scheme for their personal assistants.
- 17.** Shielding MPs were [not able to take part remotely](#) in House of Commons debates.
- 18.** [Delays in testing social care staff](#) led to thousands of disabled and older residents of care homes becoming infected with COVID-19 and losing their lives.
- 19.** Hospital patients were [discharged into care homes without being tested](#) for COVID-19, causing the loss of thousands of lives.
- 20.** The government's Disability Unit [stayed silent on its web page](#) from 2 April to 20 July, while thousands of disabled people were dying from COVID-19.
- 21.** DWP [re-introduced benefit sanctions](#) in early July, while millions of disabled people were shielding from the virus.
- 22.** Social care workers [were omitted from a list of workers](#) exempt from having to self-isolate for two weeks after entering the country, ignoring the support needs of disabled people.
- 23.** Health and social care secretary Matt Hancock [refused to provide guidance](#) that would ensure disabled people had the same rights as non-disabled people to life-sustaining treatment if they contracted COVID-19.
- 24.** The government [introduced lockdown guidance](#) (PDF) that discriminated against many disabled people who needed to exercise more than once-a-day.

# Annexes

## Annex A:

### Our Voices – extracts from personal testimonies and evidence submissions

Check <https://www.inclusionlondon.org.uk/uncrdp/shadow-report/annex-a/>

# Annex B:

## Progress Tracker of 2016 and 2017 Recommendations

Check <https://www.inclusionlondon.org.uk/uncrdp/shadow-report/annex-b/>

# Annex C: Evidence analysis

Check <https://www.inclusionlondon.org.uk/uncrdp/shadow-report/annex-c/>

# Annex D: Survey Findings

Check [https://  
www.inclusionlondon.org.uk/uncrdp/  
shadow-report/annex-d/](https://www.inclusionlondon.org.uk/uncrdp/shadow-report/annex-d/)