

Equality and human rights in residential care in Wales during coronavirus

October 2020

About us

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Introduction

- 1. The coronavirus pandemic has had a profound impact on those who live in residential care and raised serious questions about the value we place on older and disabled people's lives. There is evidence that equality and human rights standards have not been upheld, including in key decisions about care home admissions, visits and access to critical care. As we prepare for the next wave of the pandemic, we have an important opportunity to examine how these decisions were made and what more needs to be done to safeguard older and disabled people's rights.
- 2. Now more than ever our equality and human rights laws should be at the heart of decision-making. These laws set out the government and service providers' obligations to protect people's lives, dignity, wellbeing and freedoms. They provide a practical framework to navigate decisions about maintaining and balancing our full range of rights, helping to assess the impact of restrictions and whether they are proportionate and appropriate to individual needs. One of the important principles of equality and human rights law is that every effort should be made to involve people in decisions that affect them. Listening to and learning from the lived experiences of older and disabled people is crucial as we move forward.
- 3. This briefing describes the key issues that have arisen in care homes, and sets out the equality and human rights framework that should be applied to prevent them happening again and to improve practice. It is intended to support decision-makers and providers to comply with their obligations and embed equality and human rights considerations in the ongoing response to the pandemic. Throughout the briefing we use 'care homes' to refer to all types of residential social care for adults, including provision for older people and disabled adults of any age. This information relates to Wales. We have also published a briefing on coronavirus in care homes in England.

Issues that have arisen in care homes¹

Deaths from COVID-19

- 4. Almost 19,400 care home residents across England and Wales died with COVID-19 up to 12 June, accounting for nearly 40 per cent of all deaths from the virus.² Overall, care home deaths have increased by almost 66 per cent in Wales compared with previous years.³ Deaths from COVID-19 in care homes were initially not included in official reports.⁴
- 5. There have been disproportionate deaths among some groups, including those aged 65 and over,⁵ those from Black and Asian groups⁶ and men.⁷ Almost half of care home residents who died had dementia or Alzheimer's disease.⁸ Data gaps persist in Wales and it has not been possible to break down deaths for all protected characteristics.

¹We held a roundtable discussion with a range of stakeholders on 9 September 2020 to gather evidence on the issues that emerged during the first wave of the pandemic and views on the practical recommendations needed to mitigate these in future. Stakeholders included: Social Care Wales, Alzheimers Society, Older People's Commissioner for Wales, Macmillan Cancer Support, Age Cymru, Wlesh Senate for Older People, Royal College of Nursing, Care Inspectorate Wales and Disability Wales. We engaged separately with the Welsh Local Government Association and Care Forum Wales. Where the evidence in our briefing is drawn from this engagement, we cite 'EHRC Wales stakeholder engagement' in subsequent footnotes.

² The most recent analysis of the impact of coronavirus on the care sector is for the period up to 12 June. ONS (3 July 2020), 'Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)', figure 2; and ONS (23 June 2020), 'Comparison of weekly death occurrdences in England and Wales: up to week ending 26 June 2020', figure 1. In this period there were 46,425 deaths involving COVID-19 reported in England, including 18,562 among care home residents (39.8 per cent) and 2,370 deaths involving Covid-19 reported in Wales, including 826 among care home residents (34.9 per cent). This includes care home residents who died in care homes and in hospitals. The ONS definition of 'involving COVID-19' is where COVID-19 was mentioned anywhere on the death certificate, whether as an underlying cause or not.

³ Bell, D. et al. (29 August 2020), 'COVID-19 mortality and long-term care: a UK comparison', International Long Term Care Policy Network. The analysis compares the number of deaths during the pandemic to average weekly deaths during the previous 5-year period, as a measure of 'excess deaths'. This approach deals with misdiagnosed deaths and deaths that have other immediate causes but would not have occurred without the pandemic.

⁴ Blackall, M. (18 April 2020), '<u>UK Care Home Covid-19 deaths 'may be five times government estimate</u>', The Guardian.

⁵ ONS (3 July 2020), '<u>Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)', figure 8.</u>

⁶ Wider evidence across England and Wales suggests people from some ethnic groups are at a higher risk from COVID-19, see ONS (7 May 2020), 'Coronavirus (COVID-19) related deaths by ethnic group, England and Wales: 2 March 2020 to 10 April 2020'.

⁷ ONS (3 July 2020), '<u>Deaths involving COVID-19 in the care sector</u>, <u>England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)</u>', figure 5.

⁸ ONS (3 July 2020), '<u>Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)',</u>

Admissions and testing

- 6. In the first stages of the pandemic, the Welsh Government instructed Local Health Boards to discharge all patients deemed medically fit so they could free up NHS capacity to treat COVID-19 patients.⁹ Some individuals were discharged from hospitals into residential care but there was no requirement for testing prior to admission.¹⁰ This has been identified as a potential factor in the spread of coronavirus to care homes.¹¹ Welsh Government has since issued guidance that requires testing of all indivduals being discharged from hospital into care homes, regardless of whether or not they were admitted to hospital with COVID-19.¹² Despite more recent improvements in testing capacity,¹³ providers have continued to report difficulties on the ground and delays getting results.¹⁴
- 7. Requirements for residents to isolate in the absence of tests or confirmed results can have a significant effect on their mental and physical health. One care home manager in Wales reported that isolation has a "huge impact on mental health and well-being", resulting in decreased mobility and people eating and drinking less.¹⁵

Personal protective equipment (PPE)

8. There were widespread reports of insufficient access to PPE in care homes during the first wave of the pandemic.¹⁶ The Welsh Government is responsible for providing PPE supplies to local authorities, and directors of social service manage and co-ordinate distribution to care providers in their areas.¹⁷ Our stakeholder engagement found care providers experienced difficulties getting sufficient PPE

⁹ Welsh Government and Public Health Wales (April 2020), 'COVID-19 Hospital Discharge Service Requirements (Wales)'.

¹⁰ See e.g. Bell, D. et al. (29 August 2020), '<u>COVID-19 mortality and long-term care: a UK comparison</u>', International Long Term Care Policy Network.

¹¹ Ibid.

¹² Welsh Government (7 May 2020), 'Care homes testing policy' [accessed 12 October].

¹³ The Welsh Government has committed to regular testing of care home residents and staff. Welsh Government (2 May 2020), '<u>Written statement: Coronavirus testing in care homes</u>' and Welsh Government (7 May 2020), '<u>Care homes testing policy</u>' [accessed 12 October].

¹⁴ Older People's Commissioner for Wales (June 2020), '<u>Care home voices: A snapshot of life in care homes in Wales during Covid-19</u>'. This point was also evidenced in our own stakeholder engagement.
¹⁵ Ibid.

¹⁶ Welsh Parliament, Health and Social Care Committee, 'Inquiry into the impact of Covid-19 outbreak, and its management; on health and social care in Wales: report 1', Older People's Commissioner for Wales (June 2020), 'Care home voices: A snapshot of life in care homes in Wales during Covid-19'; see also Jones-Berry, S. (6 May 2020), 'No PPE masks left for care homes or homecare staff', NursingStandard; and Savage, M. (9 May 2020), 'UK care homes scramble to buy their own PPE as national deliveries fail', The Guardian.

¹⁷ See Older People's Commissioner for Wales (June 2020), '<u>Care home voices: A snapshot of life in care homes in Wales during Covid-19</u>'.

during the early stages of the pandemic.¹⁸ We therefore welcome Welsh Government's recent announcement which reaffirms their commitment to providing free PPE to care homes, and sets out the approach of the Care Homes Action Plan that a service level agreement has been put in place between the Welsh Local Government Association and NHS Wales Shared Services Partnership to provide PPE for social care within local authority areas, including private, independent and third sector providers.¹⁹

Withdrawal of healthcare

- 9. Healthcare resources were reprioritised during the first wave to meet the immediate impact of the pandemic, resulting in the withdrawal of GP and other routine healthcare services from care homes.²⁰ Evidence suggests this has had a broader impact on residents' health, potentially contributing to the number of 'excess' death in this period.²¹
- 10. Extremely concerning reports emerged that 'do not resuscitate' notices were applied in a blanket way to older and disabled people's care plans without consultation.²² The Chief Medical Officer and Chief Nursing Officer subsequently issued a joint letter stating that age, disability or long-term conditions should never be a sole reason for issuing a 'do no resuscitate' order against an individual's wishes.²³

Restrictions on visits

11. Blanket restrictions were put on visits to care homes during the first wave of the pandemic, which were only lifted when Welsh Government wrote to care homes on 5 June advising on how they may facilitate outdoor visits and published

¹⁸ Ibid.

¹⁹ Welsh Government (2020), 'Care Homes Action Plan: Summary of Progress'.

²⁰ Older People's Commissioner for Wales (June 2020), '<u>Care Home Voices: A snapshot of life in care homes in Wales during Covid-19</u>'. Amnesty International (October 2020), '<u>As If Expendable: the UK Government's failure to protect older people in care homes during the Covid-19 pandemic</u>', p. 23; Alzheimer's Society (13 May 2020), '<u>Care homes 'left to fend for themselves' against coronavirus</u>'.

²¹ Bell, D. et al. (29 August 2020), '<u>COVID-19 mortality and long-term care: a UK comparison</u>', International Long Term Care Policy Network. We discuss the impacts in more detail in the section on the right to health.

²² BBC News (2020) '<u>Coronavirus: GP surgery apology over 'do not resuscitate' form</u>'. See also: OPC/EHRC (July 2020) <u>Statement</u>. See also: Welsh Parliament, Health and Social Care Committee (July 2020) '<u>Inquiry into the impact of Covid-19 outbreak, and its management; on health and social care in Wales: report 1</u>'

²³ Chief Medical Officer and Chief Nursing Officer (17 April 2020). '<u>Joint letter from the Chief Medical Officer and Chief Nursing Officer on "do not resuscitate" notices</u>'.

guidance on 25 June.²⁴The guidance to care homes provided more detail on considerations for facilitating outdoor visits, and advice to facilitate indoor visits in exceptional circumstances and on compassionate grounds. We welcome recent Welsh Government Ministerial statements and advice to care homes that any decisions to restrict visits are made only when absolutely necessary and should involve multi-agency teams.²⁵ We remain concerned, however, that local coronavirus restrictions are resulting or will result in further blanket suspensions of care home visits across those areas.

The equality and human rights framework

12. The equality and human rights framework for care homes during the pandemic comes from the Equality Act 2010, the Human Rights Act 1998, international human rights treaties and provisions in health and social care legislation. Many of the issues that have arisen in care homes will engage multiple overlapping rights.

The Equality Act 2010

13. The Equality Act 2010 ('the Equality Act') protects individuals from discrimination and promotes a fairer and more equal society. While COVID-19 poses unprecedented public health challenges, the Equality Act has not been amended or repealed. All duty-bearers with obligations under the Equalty Act must therefore continue to act lawfully, taking necessary steps to prevent unlawful discrimination and deliver services with users' needs in mind.

Protected characteristics

14. The Equality Act protects people from discrimination on the basis of nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.²⁶ Most care home residents will meet the Equality Act definition of disability.²⁷ Most will be in older age groups, although a number of working age and younger disabled people also live in these settings.

²⁴ Welsh Government (2020) Visits to care homes: guidance to providers

²⁵ Welsh Government (2020) Wriiten Statement: update on care homes visiting

²⁶ Equality and Human Rights Commission (8 January 2019), 'Protected characteristics' [accessed 7 October 2020].

²⁷ Section 6 of the Equality Act defines disability as a physical or mental impairment that has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities. Many older people in residential care will meet this definition. For example, Age UK reports that an estimated 70 per cent of people in care homes in the UK live with dementia, 75 per cent have hearing

Preventing discrimination

- 15. The Equality Act prohibits both direct discrimination (where someone is treated differently because of a protected characteristic) and indirect discrimination (where a policy applies 'neutrally' to all groups but puts a particular group at a disadvantage). Direct discrimination (except age discrimination) cannot be justified and is always unlawful unless a specific exception applies.²⁸ Indirect discrimination may be justified (and therefore lawful), but only if it is a proportionate means of achieving a legitimate aim.²⁹
- 16. The Act also prohibits discrimination arising from disability (where a disabled person is treated unfavourably rather than less favourably than another or put at a disadvantage because of something that relates to their disability). Discrimination arising from disability is only lawful if it is a proportionate means of achieving a legitimate aim.³⁰
- 17. Employers, service providers and those carrying out public funcitons have a duty to make reasonable adjustments so that disabled people can access services, so far as reasonably practicable, as easily as non-disabled people.³¹ The duty has three parts:
 - Changing a policy or the way something is done for example, changing the way care is provided to someone who has different needs to other residents. This includes providing information in accessible format.
 - Making changes to the built environment for example, ensuring that public spaces are accessible to all residents and necessary adjustments for individual residents have been made
 - Providing auxiliary aids and services for example, introducing new
 equipment like a hearing loop, or extra support (auxiliary services) where
 someone else is used to assist the disabled person, such as a reader, sign
 language interpreter or support worker, and providing information in an

loss and 60 per cent have mental health conditions. Age UK (May 2019), '<u>Later life in the United Kingdom 2019</u>'.

²⁸ Equality and Human Rights Commission (1 September 2014), 'Equality Act 2010: summary guidance on services, public functions and associations' [accessed 8 October 2020].

²⁹ Equality and Human Rights Commission (25 November 2019), 'What is direct and indirect discrimination?' [accessed 8 October 2020].

³⁰ Equality and Human Rights Commission (18 February 2020), '<u>Disability discrimination</u>' [accessed 8 October 2020].

³¹ Ibid.

- accessible format such as large print or audio. The costs of a reasonable adjustment must not be passed on to the service user.
- 18. There is evidence that some older and disabled people in care homes were put at greater risk of harm by decisions taken in response to coronavirus. For example, there is a risk of asymptomatic transmission if the policy is to use PPE only with symptomatic residents.³² While this would affect all residents (and staff), those at greater risk of infection or serious illness, such as people with dementia³³ and those from ethnic minorities,³⁴ may be particularly disadvantaged. These groups may also be disproportionately affected by limited testing capacity and policies allowing admissions to care homes without effective testing.
- 19. As well as the risks from the virus itself, decisions to manage the spread are likely to affect people with protected characteristics differently. For example, enforcing isolation and testing may be particularly distressing for someone with learning disabilities or autism and those with dementia.³⁵ Similarly, PPE can cause issues for certain groups for example those with hearing loss who rely on lip reading, and people with dementia who may be distressed if they cannot read emotional cues through a mask.³⁶

Public sector equality duty (PSED)

20. The PSED seeks to mainstream equality considerations in public authorities' day-to-day decision-making.³⁷ The duty requires public authorities to have due regard on an ongoing basis to the need to (a) eliminate unlawful discrimination, (b) advance equality of opportunity and (c) foster good relations between those who share protected characteristics and those who do not.³⁸ In the context of social

³²Older People's Commissioner for Wales (June 2020), '<u>Care home voices: A snapshot of life in care homes in Wales during Covid-19</u>'.

³³ Dementia and Alzheimer's disease are among the underlying conditions that affect the mortality rate for Covid-19. Raleigh, V. (19 August 2020), 'Deaths from Covid-19 (coronavirus): how are they counted and what do they show?', The King's Fund.

³⁴ Wider evidence across England and Wales suggests people from some ethnic groups are at a higher risk from Covid-19, see ONS (7 May 2020), '<u>Coronavirus (COVID-19) related deaths by ethnic group, England and Wales: 2 March 2020 to 10 April 2020</u>'.

³⁵ Alzheimer's Society (2020), '<u>How care homes have been affected during the coronavirus pandemic</u>' [accessed 9 October 2020]; British Geriatrics Society (2020), '<u>COVID-19</u>: <u>Managing the COVID-19</u> <u>pandemic in care homes for older people</u>' [accessed 12 October].

³⁶ Some care homes have since provided PPE with clear panels to overcome these issues. See Older People's Commissioner for Wales (June 2020), 'Care Home Voices: A snapshot of life in care homes in Wales during Covid-19'.

³⁷ Alzheimer's Society (2020), '<u>How care homes have been affected during the coronavirus pandemic</u>' [accessed 9 October 2020].

³⁸ Equality Act 2010, s.149.

- care, the PSED applies to public authorities (such as Government departments, local authoriries and NHS bodies) and those who exercise public functions (for example where a local authority contracts out a service).³⁹
- 21. Having due regard to advancing equality involves: removing or minimising disadvantages suffered by people due to their protected characteristics; taking steps to meet the needs of people from protected groups where these are different from the needs of other people, including taking account of disability; and encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.⁴⁰ Fostering good relations means tackling prejudice and promoting understanding between people from different groups. Compliance with the duty may involve treating some people more favourably than others.
- 22. To comply with the duty, public authorities and care providers should assess the impact of policies as they are being developed and monitor the actual impact as they are implemented.⁴¹ Every effort should be made to involve people in decisions that affect them, and the greater the significance of a decision, the greater the effort should be.⁴² These steps are critically important in preventing discrimination, advancing equality and tackling disadvantage, and supporting a culture of transparency and accountability.⁴³
- 23. Assessments should be based on the best evidence available. If public authorities and care providers do not have the evidence they need to meet the duty they must take steps to fill the gaps, including collecting new sources of data and commissioning external advice or analysis. Where normal data gathering methods have been disrupted during the pandemic, public authorities should innovate to find alternatives.⁴⁴ Involving service users and other affected groups can also be

³⁹ More information is available in our technical guidance on the PSED. Equality and Human Rights Commission (19 February 2019), '<u>Equality Act technical guidance</u>'.

⁴⁰ Equality and Human Rights Commission (20 April 2020), 'Public Sector Equality Duty' [accessed 9 October 2020].

⁴¹ More information is available in our technical guidance on the PSED. Equality and Human Rights Commission (19 February 2019), '<u>Equality Act technical guidance</u>'.

⁴² Equality and Human Rights Commission (19 February 2019), '<u>Equality Act technical guidance</u>', para 5.27.

⁴³ Obligations to report on how the PSED has been complied with apply across England, Wales and Scotland, though the specific requirements are different in each country. Equality and Human Rights Commission (20 April 2020), 'Public Sector Equality Duty' [accessed 9 October 2020].

⁴⁴ Equality and Human Rights Commission (2020) <u>'Rebuilding a more equal and fairer Wales: focus on the unequal impact of the coronavirus pandemic'.</u> EHRC (2020) <u>'Rebuilding a more equal and fairer Wales: focus on the unequal impact of the coronavirus pandemic'.</u>

- a key way to understand the potential equality impact and the disadvantages different groups face.
- 24. It is important in meeting the PSED to consider the cumulative impact of a series of decisions that on their own may seem relatively small but coincide to create a serious problem. For example, when taken together, restrictions on family visits, changes in normal care routines and reduced access to primary care services may have a significant impact on individuals' physical and mental health and a disproportionate impact on some groups.⁴⁵
- 25. It is not clear from the evidence available how some national, regional and local decisions about the response to COVID-19 in care homes were reached and whether the equality impact was considered. This may have resulted in failures to comply with the PSED. We are concerned about whether sufficient data is being collected to understand and mitigate the potential or actual impacts of ongoing policy frameworks and service delivery decisions at all levels.⁴⁶

The specific duties

- 26. There are number of specific equality duties in Wales that support bodies to comply with the PSED. Most relevant are the requirements to engage with affected groups (regulation 5), ensure a robust evidence base (regulation 7) and publish equality impact assessments (EIAs) in an accessible format (regulation 8(1)(d)). These requirements still apply in the context of coronavirus.
- 27. Feedback from our stakeholders suggests engagement with older and disabled people was lacking, and that their voices and stories were not heard or reflected in policy decisions.⁴⁷ They also told us that communications were sometimes confusing or unclear, contradictory or mistimed.
- 28. During the first wave of coronavirus, the Welsh Government failed to provide and publish robust equality impact assessments to demonstrate that its approach was proportionate and effective measures were in place to mitigate any discriminatory impact. A number of equality impact and integrated impact assessments have

⁴⁵ Alzheimer's Society (2020), '<u>How care homes have been affected during the coronavirus pandemic</u>' [accessed 9 October 2020].

⁴⁶ Care home deaths were not included in official reports until 29 April, and currently, the latest analysis of Covid-19 in the care sector is up to 20 June 2020. ONS reporting does not include ethnicity data or a breakdown of disability by impairment type. See Raleigh, V. (19 August 2020), 'Deaths from Covid-19 (coronavirus): how are they counted and what do they show?', The King's Fund; ONS (3 July 2020), 'Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)'; ONS (6 October 2020), 'Deaths registered weekly in England and Wales, provisional: week ending 25 September 2020'.

⁴⁷ EHRC Wales stakeholder engagement.

since been published retrospectively. While this is welcome, and makes a difference in demonstrating how appropriate evidence has been considered and suitable mitigation measures have been identified, we have noted a number of common themes for improvement. These relate to when they were published, mitigating actions, evaluation and engagement. We have included recommendations in these areas to help improve practice.

Human Rights Act 1998

- 29. The Human Rights Act 1998 (HRA) sets out the fundamental rights and freedoms to which everyone is entitled. It incorporates the European Convention on Human Rights into UK domestic law. Furthermore, the Government of Wales Act 2006 and the Wales Act 2017 stipulate that Senedd Cymru/Welsh Parliament and Welsh Government cannot make decisions or laws that do not comply with human rights legislation. Public bodies and other bodies carrying out public functions must not act in a way that is incompatible with the rights set out in the HRA, whether they are involved in designing policies and procedures or directly delivering services. This includes care home providers who are delivering care arranged or paid for by the local authority, either directly or indirectly, partly or in full.
- 30. Human rights have been described by UN bodies as 'indivisible and interdependent'.⁵¹ This means they are interrelated and that one set of rights and freedoms cannot be fully enjoyed without others. During the coronavirus pandemic, it is important for Government to understand the wider impact of decisions and seek to protect our full range of rights wherever possible.

Article 2: the right to life

31. The right to life is 'non-derogable', which means it must be maintained even in times of emergency.⁵² Public authorities have positive obligations to protect life, including a duty to prevent avoidable deaths and to investigate deaths for which the State or a public authority may be responsible.⁵³ Public authorities should also

⁴⁸ Senedd Research (4 April 2017), 'In brief: a quick guide to human rights in Wales'.

⁴⁹ Public functions are defined as 'functions of a public nature'.

⁵⁰ See Care Act 2014, s. 73.

⁵¹ See e.g. UN Human Rights Office of the High Commissioner (undated), <u>'What are human rights?'</u> [accessed: 12 October 2020].

⁵² Council of Europe (7 April 2020), 'Respecting democracy, rule of law and human rights in the framework of the COVID-19 sanitary crisis: a toolkit for member states', pp. 4-5.

⁵³ This duty is often fulfilled by inquests, police investigations or public inquiries.

- consider the right to life when making decisions that could put people in danger or affect their life expectancy.⁵⁴
- 32. A number of decisions in the COVID-19 response may have resulted in failures to adequately protect the right to life, including decisions about hospital discharges, admissions to care homes, prioritisation of testing and access to necessary healthcare and treatment. Representative groups have described how the combination of decisions in the pandemic response either ignored care home residents or treated them as expendable.⁵⁵ In Wales, the First Minister commissioned a focused and independent expert rapid review of the operational experience in care homes between July to September which was published in October 2020.⁵⁶

Article 3: freedom from ill-treatment

- 33. Article 3 protects people from torture and inhuman or degrading treatment. It is an absolute right, and like the right to life it must be maintained at all times, including in emergencies. Lack of resources can never be used as a defence for ill-treatment.
- Torture is defined as deliberate infliction of very serious and cruel mental or physical suffering.
- Inhuman treatment is that which causes intense physical or mental suffering, including serious physical or psychological abuse in health and care settings.⁵⁷ It covers both deliberate abuse and neglect.
- Degrading treatment is that which is extremely humiliating and undignified.
 Whether this threshold is reached depends on a number of factors, including the duration of the treatment, its effects and the health or 'vulnerability' of the individual. Degrading treatment covers both deliberate abuse and neglect.
- 34. The European Committee for the Prevention of Torture (CPT) has stated that older people's exposure to coronavirus and "extreme level of suffering" may be found

⁵⁴ Equality and Human Rights Commission (15 November 2018), '<u>Article 2: right to life</u>' [accessed 7 October 2020].

⁵⁵ Silver Voices (6 May 2020), "Ignored and expendable": what are older lives worth? (briefing 30/20)' [unpublished]. See also Amnesty International (October 2020), 'As If Expendable: the UK Government's failure to protect older people in care homes during the Covid-19 pandemic' and Older People's Commissioner for Wales (June 2020), 'Care Home Voices: A snapshot of life in care homes in Wales during Covid-19'.

⁵⁶ Welsh Government (2020), <u>'Rapid review for care homes in relation to COVID-19'</u>.

⁵⁷ Equality and Human Rights Commission (15 November 2018), '<u>Article 3: Freedom from torture and inhuman or degrading treatment</u>' [accessed 7 October 2020].

incompatible with the UK Government's Article 3 obligations.⁵⁸ Reductions in access to routine and critical healthcare, and the mental and physical impact of isolation (including due to restrictions on visits and issues with testing capacity or delays) all have implications in this context. The CPT is clear that "an inadequate level of health care can lead rapidly to situations falling within the scope of the term 'inhuman and degrading treatment'."⁵⁹

- 35. Reduced oversight while inspections are paused and visits are restricted also heightens the risk of Article 3 breaches and care homes operating as closed services.⁶⁰ The advice and regulatory flexibility provided by Care Inspectorate Wales during this time has played an important role in ensuring the wellbeing of residents.⁶¹
- 36. The pressure on care homes in this period, the distress to residents and the challenges in implementing infection controls may result in increased use of restraint. However, there is no robust data on restraint in these settings so it is not possible to make an assessment or identify trends. Restraint is any act carried out with the purpose of restricting an individual's movement, liberty and/or freedom to act independently.⁶² It includes chemical, mechanical and physical forms of control, coercion and enforced isolation. The use of restraint on people in care homes may amount to inhuman or degrading treatment if it is not proportionate in the situation and strictly necessary to prevent harm.⁶³ Restraint is more likely to amount to inhuman and degrading treatment when it is used on groups who are at particular risk of harm or abuse.⁶⁴

⁵⁸ Council of Europe (7 April 2020), 'Respecting democracy, rule of law and human rights in the framework of the COVID-19 sanitary crisis: a toolkit for member states', p. 5.

⁵⁹ Ibid.

⁶⁰ Care Inspectorate Wales suspended routine inspections on 16 March and has since moved into a 'recovery phase', using remote ways of working as far as possible. Care Inspectorate Wales (2020), '<u>Latest information on Novel Coronavirus (COVID-19)</u>' [accessed 9 October 2020].

⁶¹ Welsh Government (7 October 2020), 'Rapid review for care homes in relation to COVID-19'.

⁶² EHRC (2019), <u>'Human rights framework for restraint'</u>. Segregation that amounts to solitary confinement (defined as 22 hours a day or longer without meaningful human contact) is contrary to human rights standards as established by the Mandela Rules. United Nations Office on Drugs and Crime (2015), <u>'Standard Minimum Rules for the Treatment of Prisoners (the Nelson Mandela Rules)</u>'.

⁶³ Equality and Human Rights Commission (March 2019), '<u>Human rights framework for restraint'</u>.
⁶⁴ Ibid

Article 5: right to liberty

- 37. Article 5 protects individuals from arbitrary detention and provides a right to challenge detention that may be unlawful. Some people who need support, for example those with dementia, may not have capacity to make decisions about their care and treatment, including decisions about whether they move into a care home and what happens when they are there for example, their routine and whether they are allowed to leave. In these cases, restricting the person's freedom could amount to an unlawful deprivation of liberty if appropriate safeguards are not in place.
- 38. The deprivation of liberty safeguards (DoLS) under the Mental Capacity Act 2005 respond to this by creating a series of checks to make sure any restrictions are necessary, appropriate and in the individual's best interests. The Act provides that people should be supported to make decisions as far as possible, including through access to advocacy, and that any limits on their freedom should be the least restrictive option available.⁶⁶
- 39. Some measures introduced to manage COVID-19 in care homes could create new restrictions on people's freedom for example requirements to isolate, social distance or undergo testing. We are concerned that policy-makers and providers may not be considering the impact of these restrictions, whether there is a less restrictive option and what is in the individual's best interests. More generally, we are concerned that providers may be departing from DoLS requirements during the pandemic. The Court of Protection has reported a "striking and troubling" drop in DoLS applications and a significant reduction in referrals to advocacy services, ⁶⁷ although it is worth noting that this has not translated into a significant decrease for applications for DoLS to Care Inspectorate Wales. Without support for decision-making, people may not be able to make their own decisions about care and treatment, including end-of-life planning.

⁶⁵ Equality and Human Rights Commission (30 November 2018), 'Article 5: Right to liberty and security' [accessed 9 October 2020].

⁶⁶ Office of the Public Guardian (2007), 'Mental Capacity Act 2005: Code of Practice', p. 19.

⁶⁷ Judiciary of England and Wales (4 May 2020), <u>Correspondence from Mr Justice Hayden, the Vice President of the Court of Protection, dated 4 May 2020</u>. The CQC has made clear that safeguards remain in force during the pandemic, and that deprivations of liberty should be avoided unless absolutely necessary and proportionate to avoid harm in the individual case. CQC (26 May 2020), 'Working within the Mental Capacity Act during the coronavirus pandemic' [accessed 7 October 2020].

Article 8: right to a private and family life

- 40. Article 8 protects the right to respect for a private and family life, home and correspondence.⁶⁸ It includes a right to physical and psychological integrity⁶⁹ and to create and maintain social relationships.⁷⁰ Public authorities can interfere with this right to pursue a legitimate aim, including to protect health, but any interference must be lawful, necessary and proportionate.⁷¹
- 41. Restrictions on visits and requirements to supervise visits are likely to interfere with people's Article 8 rights. Blanket restrictions are unlikely to be compliant with human rights standards. While these restrictions were introduced to help protect the lives and health of care home residents, the wider impact on their rights and health should be carefully weighed.
- 42. Not seeing family and friends has potentially serious implications for mental and physical health, particularly over a prolonged period.⁷² For those with dementia (who account for at least 70 per cent of care home residents in the UK)⁷³ it can result in cognitive and other skills deteriorating rapidly, including communication skills and the ability to recognise family members.⁷⁴ The Joint Committee on Human Rights heard evidence of the significant distress the absence of visits was causing young people with learning disabilities and autism.⁷⁵ The British Geriatrics Society has warned of the "real risk" of physical deconditioning due to isolation.⁷⁶ Care home residents may also rely on family members to provide important

⁶⁸ European Convention of Human Rights, Article 8 (1).

⁶⁹ See European Court of Human Rights: Osman v UK (Application no. 23452/94), paras. 128-130; Bevacqua and S. v Bulgaria (Application No. 71127/01), para. 65; Sandra Janković v Croatia (Application No. 38478/05), para 45; A v Croatia (Application No. 55164/08), para 60; Söderman v Sweden [GC] (Application No. 5786/08), para 80.

⁷⁰ See European Court of Human Rights: X. v Iceland (Application No. 6825/74), pp. 86-87; McFeeley et al. v UK (Application No. 8317/78) para. 82.

⁷¹ <u>European Convention on Human Rights</u>, Article 8 (2). The European Court of Human Rights has held for any interference to be 'necessary' it must correspond to a pressing social need and be proportionate in pursuit of a legitimate aim, See The Sunday Times v UK (Application No. 6538/74), para 59.

⁷² Age UK (22 September 2020), 'Visiting in care homes: where now?'.

⁷³ Alzheimer's Society (September 2020), 'Worst hit: dementia during coronavirus', p. 13.

⁷⁴ See <u>written evidence submitted by Alzheimer's Society (DEL0115)</u> to the Health and Social Care Select Committee's inquiry on 'Delivering core NHS and care services during the pandemic and beyond'.

⁷⁵ Joint Committee on Human Rights (12 June 2020), '<u>Human Rights and the Government's response to COVID-19: The detention of young people who are autistic and/or have learning disabilities, fifth report of session 2019-21'.</u>

⁷⁶ British Geriatrics Society (30 March 2020), '<u>COVID-19</u>: <u>Managing the COVID-19 pandemic in care homes for older people</u>' [accessed 7 October 2020].

- aspects of their care.⁷⁷ While for some care home residents the risk of exposure to COVID-19 from visits outweighs the benefits, in many cases there are strong welfare reasons to allow visits to help reduce distress and ensure care needs are not neglected.⁷⁸
- 43. The risks associated with visits can be significantly mitigated by providing care home visitors with appropriate access to PPE and regular testing (which may allow for physical contact), and facilitating outdoor or socially distanced visits where necessary. These measures would also help avoid the need for supervised visits. A balanced approach can protect the right to life while maintaining the right to a private and family life and the right to health, ensure that care home residents' quality of life does not diminish.

Obligations under international human rights law

- 44. The UK Government has signed a number of international human rights treaties which are binding under international law. These treaties are not directly enforceable in the UK courts, but by ratifying them the UK Government has agreed that their requirements will be reflected in laws, policy and guidance. They can also be used to interpret the rights protected under the Human Rights Act. Welsh Government is required to respect, protect and fulfil human rights found in international law, which in practice means refraining from interference, ensuring protection against abuses and taking positive action to facilitate their enjoyment.⁷⁹
- 45. We highlight two key rights under these treaties, beyond those already identified through the HRA, that are particularly relevant to care homes during coronavirus: the right to health, and disabled people's right to live independently. The Government is required to respect, protect and fulfil human rights found in international law, which in practice means refraining from interference, ensuring protection against abuses and taking positive action to facilitate their enjoyment.

Incorporation of international treaties

46. The Welsh Government has incorporated some of the rights protected in international treaties into domestic legislation. For example, the Social Services and Well Being (Wales) Act requires Welsh Ministers to have due regard to the UN Principles for Older Persons and the Convention on the Rights of Persons with

⁷⁷ Alzheimer's Society (9 July 2020), '<u>An open letter to the Government – allow family carers key worker status</u>'; Age UK (22 September 2020), '<u>Visiting in care homes: where now?</u>'.

⁷⁸ British Geriatrics Society (30 March 2020), '<u>COVID-19: Managing the COVID-19 pandemic in care homes for older people</u>' [accessed 7 October 2020].

⁷⁹ UK Government,(2006) 'Government of Wales Act 2006'

Disabilities. Other areas of Welsh Government policy reference how treaty obligations will be taken forward at a devolved level, for example the Welsh Government's 'Action on Disability: The right to independent living framework and action plan' sets out its vision for taking forward implementation of the CRPD in Wales.

The right to health

- 47. Under Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) the Government is required to recognise everyone's right to 'the highest attainable standard of physical and mental health', including by treating and controlling epidemic diseases. 80 The UN Committee on Economic, Social and Cultural Rights (CESCR), which reviews states' compliance with ICESCR, has highlighted that the right to health is closely related to and dependent on the realisation of other rights, including the right to life and the prohibition of torture, inhuman or degrading treatment.81
- 48. In fulfilling the right to health, CESCR has emphasised the importance of understanding both freedoms and entitlements, such as the right to be free from torture and non-consensual medical treatment, and the entitlement to a system of health protection that provides equality of opportunity to enjoy the highest attainable standard of health.⁸² CESCR has also highlighted the right to timely and appropriate healthcare⁸³ and the need to ensure that healthcare facilities, goods and services and available in sufficient quantity, of good quality, accessible to all without discrimination and sensitive to different cultures.⁸⁴
- 49. The UN Secretary General has made clear that difficult decisions about the provision of treatment to older people must be guided by 'a commitment to dignity and the right to health', under which every life has equal value.⁸⁵ Policies to the contrary, including blanket restrictions on critical care and use of 'do not resuscitate' notices without consent, may violate the right to non-discrimination

⁸⁰ International Covenant on Economic, Social and Cultural Rights, Article 12.

⁸¹ Committee on Economic, Social and Cultural Rights (2000), <u>CESCR General Comment No. 14:</u> The Right to the Highest Attainable Standard of Health (Art. 12), para. 3

⁸² Committee on Economic, Social and Cultural Rights (2000), <u>CESCR General Comment No. 14:</u> The Right to the Highest Attainable Standard of Health (Art. 12), para. 8. Para 19 also emphasises 'equality of access to health care and health services'. <u>ICESCR</u> Article 2 stipulates that State Parties 'undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind'.

⁸³ Committee on Economic, Social and Cultural Rights (2000), <u>CESCR General Comment No. 14:</u> The Right to the Highest Attainable Standard of Health (Art. 12), para. 11.

⁸⁴ Ibid., paras. 12 (a), (b), (c) and (d).

⁸⁵ United Nations (May 2020), 'Policy Brief: The Impact of COVID-19 on older persons', p. 3.

under the ECHR read in conjuction with the right to life.⁸⁶ The UN Secretary General has also emphasised that even where health services unrelated to COVID-19 are scaled back, the right to health requires that older people 'continue to receive integrated health and social care, including palliative care, rehabilitation, and other types of care'.⁸⁷

- 50. During the first wave of the pandemic, access to healthcare not directly related to coronavirus was limited for millions of patients when staff and funding were diverted to meet the needs of those critically ill with COVID-19.88 In care homes, a reduction in access to healthcare and reduced diagnoses of new conditions89 has likely contributed to the high number of 'excess' deaths in in this period.90 The withdrawal of core health services is a direct challenge to the enjoyment of residents' right to health, and should be avoided while the pandemic continues by allowing for face-to-face assessments and treatment were possible, with the use of PPE and other infection control measures.
- 51. Reduction in access to healthcare for the wider population risks a detrioration in health standards that could lead to a greater number of older and disabled people needing residential care in the future.

The right to live independently

52. Welsh Government is required under Article 19 of the UN Convention on the Rights of Persons with Disabilities to respect, protect and fulfil the right to independent living as part of the community. This is a fulcrum right that underpins many others. It means Welsh Government must ensure disabled people can enjoy the same self-determination and independence as everybody else. ⁹¹ The right to independent living includes having choice and control over where you live and who you live with. ⁹² Welsh Government should provide individualised support that

⁸⁶ European Convention of Human Rights, Article 14 and Article 2.

⁸⁷ United Nations (May 2020), 'Policy Brief: The Impact of COVID-19 on older persons', p. 6.

⁸⁸ See e.g. Pigott, P. (6 October 2020) 'Covid in Wales: Routine surgery lists have increased six-fold', BBC News.

⁸⁹ EHRC Wales stakeholder engagement.

⁹⁰ In 2020, up to 12 June, there were 1,210 'excess' deaths in care homes in Wales, compared to the same period in 2019. ONS (3 July 2020), 'All data related to Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)', Table 1. A total of 4,428 care home residents in Wales died between 1 January and 12 June 2020 (including deaths related to COVID-19), compared with 3,218 deaths for the same period in 2019.

⁹¹ UN Committee on the Rights of Persons with Disabilities, <u>General Comment No. 5: Right to independent living</u> (27 October 2017).

⁹² Ibid.

- enables independence and inclusion, and ensure community services that are available to the general population are accessible to disabled people.⁹³
- 53. The right to independent living means that disabled people are provided with all means to enable them to exercise choice and control over their lives, including making decisions about their health, wellbeing, communications and personal relationships. As such, restrictions on visits to care homes from family, friends and healthcare workers, restrictions on people's freedoms, and lack of access to advocacy and supported decision-making may amount to an inference with disabled people's enjoyment of the right to independent living. Other restrictions, such as not being able to leave care homes or restrictions on socialising and leisure activities may also have an effect on independent living.
- 54. The UN Committee on the Rights of Persons with Disabilities has stated that the range of support in the community, including home-care and personal assistance support, and rehabilitation services 'must be ensured and not discontinued as they are essential for the exercise of the rights of persons with disabilities'. ⁹⁶ The UN has warned that the economic impact of the pandemic could lead to future cuts to community-based care that limit the right to independent living in the longer-term. ⁹⁷

Incorportation of CRPD

55. Welsh Government's 'Action on Disability: The right to independent living framework and action plan' sets out a vision for taking forward implementation of the CRPD in Wales, taking account of the UN Committee's recommendations. 98 The framework makes commitments to meaningful engagement with and involvement of disabled people in decisions that affect them, and is underpinned by the concept of co-production, recognising that 'services cannot be improved to fully meet the needs of disabled people unless they are actively involved in the design and delivery of those services.'99 Feedback from our stakeholders

⁹³ Ibid.

⁹⁴ Ibid.

⁹⁵ See, for example, concerns summarised by representatives of Relatives and Residents Association in <u>oral evidence to the APPG on Coronavirus (12 August 2020)</u> ('many of the callers to our helpline have been telling us that the current situation in care homes is now very much like a prison with such restricted visiting, residents unable to leave the grounds of the home and those limited interactions with other residents and staff').

⁹⁶ Chair of the United Nations Committee on the Rights of Persons with Disabilities (April 2020), 'Joint Statement: Persons with Disabilities and COVID-19'.

⁹⁷ United Nations (May 2020), 'Policy Brief: A Disability-Inclusive Response to COVID-19'.

⁹⁸ Note that this does not equate to full incorporation.

⁹⁹ Welsh Government (2019), '<u>Action on Disability: the right to independent living framework and action plan</u>'.

- suggests these commitments have not been met in the experience of older and disabled people in residential care settings during the pandemic, undermining their enjoyment of the right to independent living.
- 56. We have developed a proposed legal model for the full incorporation of the right to independent living in domestic law, 100 which was endorsed by the Joint Committee on Human Rights in 2019. We are concerned that the pandemic could lead to a long-term regression in standards and protections for disabled people. The incorporation of a right to independent living would in our view help prevent this, and would ensure access to redress in cases where disabled peoples' rights have been unlawfully curtailed.

Social Services and Well Being (Wales) Act 2014

57. The Social Services and Well Being (Wales) Act provides a legal framework to ensure that people living in care homes can access advice, information, guidance and advocacy services, and are involved in decision-making and have a voice and control over their care and treatment. Evidence from our stakeholders suggest this was not the reality during the first wave of COVID-19, which has exposed and exacerbated long-standing issues about people's ability to understand and realise their rights in residential care settings.

Wellbeing duty

- 58. Section 5 places a duty on anyone exercising duties under the Act to promote the wellbeing of people who need care and support. Our stakeholder engagement found there has been a marked decline in the wellbeing and quality of life for those living in care homes during the pandemic. For example, Alzheimer's Cymru reported that some residents with dementia experienced clear cognitive decline during the time when visits were suspended. This is supported by the experiences captured in the Older People's Commissioner for Wales *Care Home Voices* report.
- 59. As well as mental well-being, our stakeholder engagement found that older people's physical health had been affected by the suspension of routine

¹⁰⁰ See <u>our submitted evidence regarding adult social care and the right to independent living to the Joint Committee on Human Rights inquiry on the Government's response to COVID-19: human rights implications.</u>

¹⁰¹ Joint Committee on Human Rights (2019), '<u>The detention of young people with learning disabilities and/or autism, Second report of the session 2019'.</u>

¹⁰² EHRC Wales Stakeholder Engagement

¹⁰³ Older People's Commissioner for Wales (June 2020), '<u>Care Home Voices: A snapshot of life in care homes in Wales during Covid-19'</u>.

healthcare appointments during the pandemic. This has led to a backlog of cancelled appointments and undiagnosed health conditions. If this is not addressed, we could face a wider health and social care crisis in the future for which the sector is not prepared.

Voice and autonomy

- 60. Section 6 places an overarching duty on all exercising duties to have regard to:
 (a) the individual's views, wishes and feelings; (b) the importance of promoting and respecting their dignity; (c) their characteristics, culture and beliefs (including, for example, language); and (d) the importance of providing appropriate support to allow them to participate in decisions that affect them.
- 61. Concerns were raised by stakeholders that during the first wave of the pandemic, the views, wishes and feelings of older people (described in section 6 of the Duty) were not considered, even on fundamental areas such as which home they were discharged to, if they wished to have a Do Not Resuscitate notice in place or not, and if they were able to receive visitors. While the pandemic poses unprecedented public health challenges, people should still have choice and control as provided for in the Act, and any restrictions should be strictly necessary and proportionate.

UN Principles for Older Persons

- 62. Section 7 places a duty of due regard to the United Nations Principles for Older Persons adopted by the General Assembly of the United Nations on 16 December 1991.¹⁰⁴ There are 18 principles, grouped into five themes, which are: independence, participation, self-fulfilment, care and dignity.¹⁰⁵ Though distinct from the international human rights treaties, and not binding on states, the Principles provide an important guide as to the direction of international best practice in relation to older peoples' rights.
- 63. It is clear from our engagement with stakeholders that coronavirus has exposed issues of ageism and age discrimination, and that these issues have had an effect on the response to the pandemic. Older people in care homes were perceived to have been overlooked and ignored, which would be in direct contravention of Section 7.

¹⁰⁴ United Nations Principles for Older Persons (Resolution 46/91).

¹⁰⁵ Welsh Government (2015), 'Social Services and Well-being (Wales) Act 2014: Part 2 Code of Practice (General Functions)'.

UN Convention on the Rights of Persons with Disabilities

64. Part 2 of the Code of Practice (General Functions) states that, when exercising social services functions in relation to disabled people who need care and support, local authorities must have due regard to the UN Convention on the Rights of Persons with Disabilities.¹⁰⁶

Information and guidance

- 65. Section 17 requires local authorities to ensure that information, advice and assistance relating to care and support services is available and accessible. As a minimum, this should include: how the care and support system operates, the types of care and support available, how to access care and support services, and how to raise concerns about the well-being of another person who appears to have care and support needs.
- 66. Around a third of all older people do not know their rights and many of those who do are reluctant to 'make a fuss.'¹⁰⁷ We further found that communication to care home staff during the pandemic has been inconsistent and unclear. Care Forum Wales informed us there were significant issues around version control for guidance, which had led to confusion. The Older People's Commissioner report supported this view and found that care home managers and staff faced considerable difficulties in: 'accessing crucial information and guidance to support them in minimising the spread of the virus and protecting residents and staff. Particular issues were highlighted about the amount of rapidly changing information that care homes were receiving, often from multiple bodies, which was often confusing or contradictory.'¹⁰⁸ As one care home manager said, 'We were inundated with paperwork from multiple agencies that was duplicated and sometimes contradictory.'¹⁰⁹

Advocacy

- 67. Section 181 states that local authorities may be required to arrange advocacy for people who are in need of care and support.
- 68. Stakeholders have informed us that lack of advocacy is a longstanding issue within the social care sector, which has been exacerbated under Covid-19. This has led

¹⁰⁶ Welsh Government (30 April 2020), ".

¹⁰⁷ Equality and Human Rights Commission Wales Stakeholder Engagement, Welsh Senate of Older People

¹⁰⁸ Older People's Commissioner for Wales (June 2020), '<u>Care Home Voices: A snapshot of life in care homes in Wales during Covid-19</u>'.

¹⁰⁹ Ibid.

to decisions being taken without older people's understanding, involvement or consent, in direct contravention of the advocacy provisions and principles of voice, control and co-production set out in the Act. The examples provided by our stakeholders were instead characterised by lack of involvement and autonomy for older people in decisions that affected their lives and the services they received, a lack of preventative action through inadequate provision of testing and PPE, and a failure to focus on quality of life and well-being.

Coronavirus Act 2020 and the Social Services and Well Being (Wales) Act

- 69. Stakeholders raised concerns over the provisions in the Coronavirus Act 2020 which enable the suspension of parts of the Social Services and Well-Being (Wales) Act 2014. This means that local authorities no longer have to carry out needs assessments, meet adults' eligible care and support needs, carry out financial assessments, or review care and support plans. Instead, local authorities are able to charge a person retrospectively for any care in certain circumstances and only have a duty to meet needs for care and support in the most serious cases. Whilst Welsh Government have confirmed that no local authorities have actually used these powers, concerns remain that it is present on the statute book and could pose risks to the rights of older and disabled people.
- 70. This is particularly important in light of recent evidence from the British Institute of Human Rights which found that 77 per cent of staff working in health and social care were not provided with legal training or clear information about the use of Emergency Powers under the Coronavirus Act. Similarly, 73 per cent of those surveyed were not provided with legal training or clear information about Human Rights Law,¹¹³ we hope this briefing will go some way to addressing this knowledge gap.

¹¹⁰ Social Care Wales (29 March 2017), 'Overview, Social Services and Well Being (Wales) Act 2014' [accessed 8 October 2020]. See also EHRC Wales Stakeholder Engagement

¹¹¹ Senedd Research (12 May 2020), '<u>Coronavirus: emergency regulations on social care and mental health (updated on 12 May)</u>'.

¹¹² Welsh Government (23 September 2020), <u>Letter to Chair of ELGC committee</u>.

¹¹³ British Institute of Human Rights, (July 2020) <u>The Joint Committee on Human Rights Inquiry into the human rights implications of the UK Government's Covid-19 response: Evidence from staff working in health, care and social work</u>

The Regulation and Inspection of Social Care (Wales) Act 2016

71. This legislation creates a regulatory system centred on the needs of those who receive care and support. Under the Act, Welsh Ministers are required to protect, promote and maintain the safety and well-being of people who use regulated services (including advocacy services) and to promote and maintain high standards in the provision of services. The legislation aims to provide a robust response to the lessons learned from previous failures in the system.¹¹⁴

Welsh Language (Wales) Measure 2011

- 72. This measure requires that services in social care are of the same standard and are as easily and promptly available in Welsh as in English, and should be as wide-ranging and thorough. Organisations should not assume English as the default language when providing their services and Welsh speakers should not be required to ask for a service in Welsh.¹¹⁵
- 73. These provisions are important to ensuring older people who may only be able to communicate their care needs effectively in Welsh receive the same level of care and communication as English language speakers. For many Welsh speakers, language is an integral element of their care, 116 especially for those with additional needs such as people with dementia who often lose their second language or those who have suffered a stroke. 117

Ensuring compliance with equality and human rights standards

74. We recognise that the coronavirus pandemic poses unprecedented challenges for Government, and that important policy changes and guidance were implemented as the pandemic progressed, including Welsh Government's Care Homes Action Plan.¹¹⁸ However, the issues that have arisen in care homes raise real concerns that equality and human rights standards have been breached.¹¹⁹ it is crucial that

¹¹⁴ Social Care Wales (April 2019), 'Overview: Regulation and Inspection of Social Care (Wales) Act 2016' [accessed 7 October 2020].

¹¹⁵ Social Care Wales (September 2020), 'Using Welsh at work' [accessed 7 October 2020].

¹¹⁶ Welsh Government (April 2019) 'More than Just Words: Strategic Framework for Welsh Language Services in Health, Social Services and Social Care: Progress Report – Year 2'.

¹¹⁷ The Conversation, 2019 <u>Bilingualism and dementia: how some patients lose their second language and rediscover their first</u>

¹¹⁸ This includes the <u>Care Homes Action Plan</u>, <u>Visits to Care Homes: guidance for providers</u>, <u>Guidance for providers of social care services for adults during the covid-19 pandemic</u> and <u>Public</u> Health Wales' guidance for health and social care professionals

¹¹⁹ A recent survey of health, care and social work staff by the British Institute of Human Rights showed half had witnessed human rights violations that involved someone being treated worse than

continuing issues are addressed, good practice is embedded and measures are put in place to prevent problems re-emerging. Building equality and human rights considerations into decision-making at both the national and local level is a key part of this.

Our recommendations

Welsh Government

- (1) Welsh Government should continue to take urgent steps to ensure decisions about the health and care of older people in residential settings - both in individual cases and at the national policy level - are made in collaboration and consultation with older people and their representative organisations. This must be supported by clear, accessible and consistent guidance that fully complies with human rights standards, including the principles of individual autonomy and non-discrimination.
- (2) Welsh Government should ensure that the choice, control and autonomy of care home residents are retained as far as possible during the pandemic, and any restrictions are necessary, proportionate and time-bound.
- (3) Welsh Government should ensure residents of care homes have full and equal access to necessary healthcare, including GP services and hospital treatment, and that consultations are carried out face-to-face wherever possible.
- (4) Welsh Government should ensure 'do not resuscitate' notices that were wrongly applied to people's care plans are expunged.
- (5) Welsh Government should work with providers to ensure older people who lack capacity can access independent advocacy.
- (6) Welsh Government should ensure there is sufficient, reliable and timely testing capacity to ensure that people in care homes are not unnecessarily exposed to coronavirus and do not have to isolate unnecessarily, and can safely access visits from family, friends and healthcare services.
- (7) Welsh Government should ensure measures remain in place to guarantee sufficient personal protective equipment for care homes throughout the

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others because of their identity or a particular protected characteristic. British Institute of Human Rights (August 2020), '<u>The Joint Committee on Human Rights Inquiry into the human rights implications of the UK Government's Covid-19 response: Evidence from staff working in health, care and social work', p. 17.</u>

- pandemic, equipment with clear panels should be prioritised where necessary to mitigate any communication difficulties for disabled people.
- (8) Welsh Government should take steps to facilitate safe visits to care homes by extending care home testing to essential visitors, allowing them the same access to PPE and regular testing that is envisaged for care home staff in the Welsh Government winter plan.
- (9) Welsh Government should amend guidance on care home visits to prohibit blanket restrictions, including in areas where local restrictions are in place, and ensure all decisions are based on individual risk assessments so that visits are only restricted where strictly necessary. The guidance should be promoted publicly to increase understanding among providers, residents and visitors about when visits are allowed, and should be kept under review and updated to allow further relaxations to visiting policies where it is safe to do so.
- (10) Welsh Government should assess whether restraint has increased during the pandemic and work with providers, the NHS and inspectorates to identify what additional support should be made available to avoid its use and ensure transparency and effective monitoring and oversight. Guidance on avoiding the use of restraint should build on existing resources and good practice and reflect the principles set out in the Commission's human rights framework for restraint, which Welsh Government has already referenced in it's guidance. Particular consideration should be given to groups who have impairments or characteristics that increase the risk of harm.
- (11) In line with the UNCRPD and the commitments outlined in the: Action on Disability: The Right to independent living framework and action plan, Welsh Government must:
 - a) provide sufficient funding to each local authority to ensure disabled people's right to independent living is protected during and following the pandemic. Funding should be provided through appropriate mechanisms, such as ringfencing, to ensure the funding is used for that purpose.
 - b) ensure the commitments outlined in the Framework are considered when taking policy decisions relating to disabled people in residential care setting, including the commitments to meaningful engagement, involvement and coproduction, and embed the social model of disability.
 - c) incorporate the right to independent living in domestic law to protect the human rights of disabled and older people during and in the aftermath of the pandemic.

- (12) Oversight of changes to social care provision across local areas should be increased to ensure that recovery planning and national policy decisions are informed by accurate and up-to-date data. The Welsh Government should consider all possible means to ensure that local authorities and care providers are able to meet increased care and support needs during and resulting from the pandemic.
- (13) Welsh Government should ask the UK Parliament to repeal the power under the Coronavirus Act 2020 to suspend the legislative requirements under the Social Services and Well Being (Wales) Act. Welsh Government should use the intelligence and legal framework provided in this briefing to ensure that older and disabled people in residential care settings are provided with the highest standards of care, as intended under the Regulation and Inspection of Social Care (Wales) Act.

Welsh Government and all relevant public bodies

- (14) In line with the specific equality duties in Wales, Welsh Government and all relevant public bodies in Wales should:
 - a) ensure engagement with older and disabled people is undertaken, considered and recorded in developing the Covid-19 response in care homes;
 - b) publish equality impact assessments at the point of completion, with clear data sources (here normal data gathering methods are disrupted or inadequate, new sources and alternative methods should be used to gain insight into potential and actual impacts for different protected characteristics); timescales for planned actions and how these actions will be monitored and evaluated;
 - c) ensure equality impact assessments and any accompanying communication are accessible, clear and appropriate;
 - d) ensure guidance for care homes is easily accessible and the latest version is easily identifiable, with a clear rationale and evidence base for decisions.

Welsh Government, Commissioners, Service planners and Care providers

- (15) Under the Social Services and Well Being (Wales) Act 2014, the Welsh Government, commissioners and service planners and care providers should:
 - a) consider the broader wellbeing areas covered under Section 5 of the Social Services and Well Being (Wales) Act in decisions about the response to the

- pandemic so that quality of life is better understood and considered in future policy decisions.
- b) take steps to involve older people in the decision-making process and capture their stories and experience in order to fulfil obligations under Section 6 and under the duty to have due regard to the United Nations Principles for Older Persons. 120
- c) take action to improve older people's understanding of their rights in residential care settings, as provided under Section 17. This should take account of those who are digitally excluded or who have additional access needs to ensure information sources and support are available to all older people.
- d) ensure advocacy services under section 181 are available, adequately resourced and publicised within all older people's residential care settings. This includes resuming Independent Advocate visits to ensure older people are supported to participate in decisions that affect them.
- (16)The Welsh Government, commissioners and service planners and care providers communicating Covid-19 policy decisions should ensure content is easily accessible in both Welsh and English. Welsh language services should be mainstreamed so they are not an 'optional extra.'

Care Inspectorate Wales

- (17)Care Inspectorate Wales should ensure plans are in place for effective ongoing oversight for care homes throughout the pandemic, expand inspections as far as possible with priority to those services where standards are most at risk (as informed by previous inspections and local intelligence gathering), and reinstate full inspections whenever it is safe to do so. CIW should further consider taking immediate steps beyond existing routes to ensure that residents, relatives and staff can report concerns while visits are restricted.
- (18)Care Inspectorate Wales should fully utilise the powers provided under the Social Services and Well Being (Wales) Act to ensure older people's voice and well-being are at the centre of the regulation of residential care and support services during the pandemic. For example, by actively speaking and listening directly to older and disabled people during complaints and inspection procedures and acting on concerns through both formal and informal mechanisms.

¹²⁰ Social Services and Well Being (Wales) Act 2014, section 6.

Further information

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