Briefing paper

Strengthening the right to independent living

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# Introduction and executive summary

## About us

The Equality and Human Rights Commission (EHRC) is Great Britain’s national equality body and accredited by the United Nations as an ‘A status’ national human rights institution. We operate independently as a statutory public body established under the Equality Act 2006. We have been given powers by parliament to advise government on the equality and human rights implications of laws and proposed laws, and to publish information or provide advice on any matter related to equality, diversity and human rights. Find out more about our work on [our website](http://www.equalityhumanrights.com/).

## Executive summary

The right to live independently as part of the community is enshrined in Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). At its heart, it is about ensuring disabled people have the same choice and control over their lives as others, with equal value and dignity. It is integral to disabled people’s enjoyment of their full range of human rights.

This right to independent living is binding under international law and the UK Government is expected to reflect its requirements in laws, policy and guidance. However, the right has not been fully incorporated into domestic law, meaning that disabled people have no redress in the UK courts if it is breached. In our view, the absence of effective legal protection for the right to independent living significantly limits disabled people’s full and equal participation in society.

Across many areas of life, there is evidence that disabled people in Great Britain are not provided with the same choice, control and opportunities as others. Disabled people experience significant disparities in education and a persistent employment and pay gap. There is a chronic shortage of accessible housing and those with care needs often cannot access vital support. Thousands of disabled people are detained in institutions, out of sight and at risk of restrictive treatment or abuse. The coronavirus (COVID-19) pandemic and the response to it have exposed and exacerbated many of the inequalities disabled people face.

A two-tiered society is not inevitable – with the right support, safeguards and protections, disabled people can participate fully and equally in society.

This paper presents evidence of the barriers that disabled people face and, based on that evidence, details the action needed to ensure disabled people can enjoy the same freedoms, autonomy and opportunity as the rest of society. We recommend that the right to independent living is incorporated in domestic law, and we have developed a proposed legal model to achieve that. We also recommend a number of other changes to law and policy that would support the right to independent living, remove barriers and improve the lives of disabled people. Taken together these steps represent a blueprint for a society where disabled people are treated with equal dignity and value.

## Introduction

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty adopted by the UK Government in 2006 and ratified in 2009. It protects disabled people’s rights across a range of areas, including education, health, work and culture, and covers rights that are also enshrined in the Human Rights Act 1998, such as the rights to life, liberty and privacy. By ratifying the CRPD, the UK Government has agreed to protect and promote the rights of disabled people by taking practical steps to ensure the full realisation of disabled people’s fundamental rights and freedoms.

Article 19 of the CRPD sets out that disabled people have the right to live independently as part of the community. This right is about ensuring disabled people can exercise choice and control over decisions that affect their lives on an equal basis with others, and have the maximum level of self-determination and independence. This includes having equal choice and control about living arrangements, daily activities and access to services.[[1]](#footnote-1) At its heart is the principle that disabled people have equal value and dignity to non-disabled people. It is an integral human right for disabled people and has many interdependencies with other specific CRPD rights, including to equality and non-discrimination, accessibility, personal mobility, habilitation and rehabilitation, and an adequate standard of living and social protection.[[2]](#footnote-2)

**UN Convention on the Rights of Persons with Disabilities – Article 19**

‘States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.’

The right to live independently as part of the community, as enshrined in Article 19 of the CRPD, comprises three core elements, which we address separately in turn:

* Section 1 – equal choice and control about where to call home
* Section 2 – access to support services
* Section 3 – equal participation in society.

## Scope of this paper

Due to devolution, there are different contexts in the policy and legislative frameworks related to independent living across England, Wales[[3]](#footnote-3) and Scotland.[[4]](#footnote-4) This paper focuses on the realisation of the right to independent living in England and action taken by the UK Government to respect, protect and fulfil this right. This paper is designed to provide advice to the UK Government, parliamentarians and policy makers on the steps required to address barriers to the right to independent living.

While the CRPD creates obligations to promote and protect the rights of disabled people specifically, older people share many of the barriers faced by disabled people in realising the right to live independently as part of the community, and we have sought to highlight this throughout the paper. Older people are also more likely to experience disability. In 2018/19, 44% of people of state-pension age reported a disability, compared to 19% of working-age adults and 8% of children.[[5]](#footnote-5) It is important that older people also have choice and control over decisions affecting their lives, on an equal basis with others.

## Incorporating the right to independent living in domestic law

By signing and ratifying the CRPD, the UK has agreed to ensure that legislation, regulations, policy and practices protect and promote the rights included in it. As with all the rights in the CRPD, the UK Government has a binding obligation under international law to fulfil the right to independent living. However, the right to independent living has not been incorporated in domestic law, which means that disabled people have no redress in the UK courts if it is breached.

The UK has ratified the CRPD Optional Protocol, which enables individuals or groups to complain to the UN Committee on the Rights of Persons with Disabilities about any violation of the CRPD. This Committee can make recommendations in response to such claims, but their recommendations are not legally enforceable and they cannot force governments to implement them. Under the Optional Protocol, this Committee can also make inquiries into countries where there is reliable information indicating grave or systemic violations of the CRPD.[[6]](#footnote-6)

The UN Committee on the Rights of Persons with Disabilities undertook an inquiry into the UK that was completed in 2016 following evidence of grave or systemic violations of:

* the right to live independently as part of the community (Article 19)
* the right to work and employment (Article 27), and
* the right to an adequate standard of living and social protection (Article 28).[[7]](#footnote-7)

In recent years, the UN Committee on the Rights of Persons with Disabilities found evidence of regression in the right to independent living in England.[[8]](#footnote-8) We have previously recommended that the UK Government should incorporate the CRPD as a whole into domestic law so that individuals can effectively challenge rights violations and access redress.

However, given the centrality of the right to independent living, and concerns about regression on the realisation of this right, we also support specific, targeted measures to incorporate Article 19 rights and bring domestic law into line with international requirements. In collaboration with stakeholders, we have developed a legal model for incorporating the right to independent living into UK law. Our proposals have been endorsed by the UN Committee on the Rights of Persons with Disabilities as well as UK Parliament’s Joint Committee on Human Rights (JCHR).

Our full proposed legal model is set out in the appendix to this paper. The key elements are:

1. **a statutory** **Public Sector Inclusion Objective** that puts a duty on public bodies to act with the objective of meeting the requirements of CRPD Article 19
2. **a presumption on public bodies to provide accommodation, care and support in the community,** unless this is not in line with the person’s wishes
3. **recognition of the primacy of disabled people’s views in decisions about accommodation, care and support,** including a right to decline care
4. **a prohibition on the establishment of further institutional accommodation**
5. **a duty on public bodies to assess the level of unmet need for accommodation in the community, and care and support to enable community or home living,** and report on what they will do to meet that need, and
6. **effective enforcement mechanisms and provision of guidance on implementation** to help ensure the right to independent living is upheld in practice.

In our view, strengthening legal protections for the right to independent living would help ensure the protection and fulfilment of disabled people’s human rights more broadly.

## Involving disabled people in decisions that affect their lives

Under the CRPD, the UK has an obligation to ‘consult with and actively involve’ disabled people and their representative organisations (organisations that are led, directed and governed by disabled people) in the development and implementation of legislation, policies and other decision-making processes relating to disabled people’s lives.[[9]](#footnote-9) The UN Committee on the Rights of Persons with Disabilities makes clear that consulting with and involving disabled people should be considered a mandatory step prior to the approval of laws, regulations or policies.[[10]](#footnote-10) This is in keeping with the position of the disability movement that there should be ‘nothing about us, without us’. It recognises that disabled people are experts in identifying and promoting solutions to address the problems and barriers they face.

### Recommendation

In taking action to address our recommendations in this paper, the UK Government should ensure that as a key principle they fully and actively involve disabled people in decision-making processes, as this is in itself essential to fulfilling the right to independent living.[[11]](#footnote-11)

# Equal choice and control about where to call home

UN CRPD – Article 19(a):

‘[States Parties shall ensure that] Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement’

Under Article 19 of the CRPD, disabled people have the right to choose, on an equal basis with others, where, how and with whom they live. Many disabled people live in restrictive institutional settings, away from friends and family, often as a result of insufficient support to live independently as part of the community. Living in institutional settings can impinge on disabled people’s liberty, family life and full participation in society. It can also restrict disabled people’s autonomy, choice and control about the lives they want to lead, including their daily activities and routine, the types of social and leisure activities they would like to engage in, connection to family and friends, and their participation in the wider community.[[12]](#footnote-12)

The COVID-19 pandemic has led to further restrictions on the human rights of people living in institutional settings, including the right to liberty, the right to health and the right to respect for private and family life, and has created specific risks to the right to life.[[13]](#footnote-13)

## Detention and treatment of people with learning disabilities or autism

Many adults and children with learning disabilities and / or autism are held in long-term secure settings. Typically this is because there is not enough support available in the community or in other less restrictive residential settings. We, the JCHR,[[14]](#footnote-14) the UN Committee on the Rights of Persons with Disabilities[[15]](#footnote-15) and other stakeholders, including the Care Quality Commission (CQC),[[16]](#footnote-16) have expressed long-standing concerns about ongoing inappropriate detention and treatment in institutional settings. This suggests a systemic failure to protect the rights to liberty, to a private and family life, and to live independently.

Long-term secure settings often cannot meet the needs of their residents. Evidence shows a high incidence of restraint and other restrictive interventions,[[17]](#footnote-17) which can be traumatising and may be contrary to human rights standards.[[18]](#footnote-18) Some institutions apply blanket restrictions that impinge on people’s human rights and freedoms.[[19]](#footnote-19) There have been a number of reports of inhuman or degrading treatment in institutional settings, such as the shocking physical and psychological abuse of patients with learning disabilities at Whorlton Hall (an independent hospital in County Durham) exposed by the BBC’s Panorama programme in 2019, and at Winterbourne View (a private hospital near Bristol) in 2011.[[20]](#footnote-20)

The UK Government has made several commitments to transform health and care services so that more people with learning disabilities and / or autism can live in their communities. In 2015, the UK Government committed to a 35–50% reduction in inpatient care, with no more than 1,700 people still being cared for in such settings by March 2019. Subsequently, the NHS Long Term Plan commits to a 50% reduction on 2015 levels by March 2024.[[21]](#footnote-21)

However, targets have been missed repeatedly.[[22]](#footnote-22) At the end of December 2020, there were still 2,055 people with learning disabilities and / or autism living in inpatient units in England, 59% of whom had been detained for over two years,[[23]](#footnote-23) often far from home.[[24]](#footnote-24) In February 2020, we triggered a legal challenge against the Secretary of State for Health and Social Care over the repeated failure to move people with learning disabilities and/or autism into appropriate accommodation. [[25]](#footnote-25) Our work on this matter continues.

Data suggests the use of restrictive interventions in inpatient settings, including physical, chemical and mechanical restraint, seclusion and segregation, has increased during the coronavirus pandemic. For example, there was an increase from 3,590 instances of restraint (including 605 on children) during February 2020, to 4,020 (including 730 on children) in November 2020.[[26]](#footnote-26) The pandemic has also exacerbated challenges in accessing community care, increasing the risk that discharges will be further delayed.[[27]](#footnote-27) There has been a disproportionate number of COVID-19 related deaths among people with learning disabilities and/or autism who access care, including those who live in inpatient settings, which raises concerns about their safety during the pandemic and more broadly. For example, the CQC reported a 134% increase in deaths among those receiving care from learning disabilities and/or autism services between 10 April and 15 May 2020 and Public Health England found that the death rate for people with a learning disability was at least 4.1 times higher than the general population in the spring of 2020.[[28]](#footnote-28)

## Mental health detention

The Mental Health Act allows people who are experiencing mental distress to be detained for the purposes of assessment and compulsory treatment. There were almost 51,000 detentions recorded in 2019–20, although the total will be higher as not all providers submit data.[[29]](#footnote-29) We are concerned that the legislation does not adequately support disabled people’s right to independent living under CRPD Article 19, which includes the right to autonomy over decisions affecting their lives.

Evidence suggests the Mental Health Act does not sufficiently empower people to be involved in decisions about their treatment. The CQC has reported that over a fifth of mental health patients were not involved in their care planning,[[30]](#footnote-30) and there is evidence that advance decision making is not used routinely or considered binding.[[31]](#footnote-31)

Insufficient early and preventative mental health support in the community means there is more scope for people to reach crisis point, resulting in detentions that could otherwise be avoided.[[32]](#footnote-32) There has been increased investment in community mental health services and crisis support in recent years.[[33]](#footnote-33) But demand is rising. For example, an NHS study of children and young people in England found that the proportion with a probable ‘mental disorder' had increased significantly from one-in-10 in 2004 to one-in-six by 2020.[[34]](#footnote-34) This means the level of need continues to outstrip the support available, with, for example more than 63% of children and young people with a diagnosable mental health condition unable to access NHS-funded mental health services.[[35]](#footnote-35)

Reductions incommunity support during the coronavirus pandemic have led to significant unmet need. For example, 42% of people with pre-existing mental illnesses reported that their mental health had declined during the early part of the pandemic due to reduced support from mental health services.[[36]](#footnote-36) The CQC reported this was resulting in a higher risk of detention and other ‘coercive pathways’ into mental health care.[[37]](#footnote-37) As community support was reduced, there was an increase in the proportion of first-time admissions under the Mental Health Act.[[38]](#footnote-38) Going into the second wave of the pandemic, mental health providers predicted a 20% increase across their services, at the same time as an estimated 10–30% reduction in capacity to care for patients.[[39]](#footnote-39) The Centre for Mental Health has predicted that up to 10 million people will need either new or additional mental health support as a result of the pandemic,[[40]](#footnote-40) and the NHS Confederation has expressed concern about high levels of staff burnout and exhaustion in the mental health workforce.[[41]](#footnote-41)

We have raised concerns that changes in the operation of mental health tribunals during the pandemic could reduce people’s ability to challenge their detention and treatment.[[42]](#footnote-42) They include remote working, suspension of pre-hearing examinations, extending the time allowed to list certain hearings, and allowing cases to be heard by a single judge rather than a panel. The CQC has found that some of these ‘major procedural changes’ are ‘likely to impact on patient safeguards and experience’.[[43]](#footnote-43) Additionally, as at April 2021,[[44]](#footnote-44) the Department of Health and Social Care (DHSC) and NHS England’s legal guidance on the operation of mental health services continues to allow ‘temporary departures from the [Mental Health Act] Code of Practice’.[[45]](#footnote-45) This represents a potential significant erosion of a pathway to challenge detention. Any postponement or suspension of rights should be limited in duration as much as possible. We remain concerned that this guidance relaxes important safeguards against unnecessary detention for an undefined period.

On 13 January 2021, the UK Government launched its white paper on reforming the Mental Health Act for consultation, following an independent review that reported in 2018. The review looked at rising rates of detention, the disproportionate detention of people from ethnic minority groups, and concerns that the law is out of step with a modern mental health system. It made recommendations for reform to reduce detention rates and ensure that mental health care is provided in the least restrictive setting, with people free to choose when, where and how they receive treatment.[[46]](#footnote-46) The white paper proposes a ‘wide range of changes to rebalance the Mental Health Act, to put patients at the centre of decisions about their own care and ensure everyone is treated equally’.[[47]](#footnote-47) While the white paper contains several positive measures designed to minimise institutionalisation, it does not reference or explicitly recognise the right to independent living. Our response to the white paper recommends that a new Mental Health Bill include provisions to achieve better realisation of disabled people’s right to live independently as part of their communities.[[48]](#footnote-48) However, a new mental health bill is not expected until 2022.[[49]](#footnote-49)

People detained under the Mental Health Act continue to be at significant risk of restraint and other restrictive interventions,[[50]](#footnote-50) including chemical, mechanical and physical forms of control, coercion and enforced isolation.[[51]](#footnote-51) In 2019–20, there were a total of 131,338 restrictive interventions in England, including 12,318 uses of prone restraint and 11,594 instances of seclusion.[[52]](#footnote-52)

In November 2018, the Mental Health Units (Use of Force) Act received royal assent.[[53]](#footnote-53) The Act is designed to reduce the use of force and restraint in mental health hospitals by improving accountability, training and monitoring. However, at the time of writing, more than two years after receiving royal assent, the Act has still not been brought into force.[[54]](#footnote-54)

## Mental Capacity (Amendment) Act

It is important that disabled people’s right to live independently as part of the community is not undermined if they are deemed to lose or lack mental capacity. Support for people to express their wishes and preferences, including through timely access to appropriate and effective advocacy, and the use of advance decision making, is crucial to ensure they retain choice and control over their living arrangements.

In May 2019, the Mental Capacity (Amendment) Act received royal assent.[[55]](#footnote-55) The Act introduced a new model in England and Wales for authorising deprivations of liberty – the Liberty Protection Safeguards – to provide care or treatment to individuals who lack capacity to consent to those arrangements. This responded to widespread concerns about the existing Deprivation of Liberty Safeguards, including a Law Commission recommendation that these ‘should be replaced as a matter of pressing urgency’.[[56]](#footnote-56) The implementation of the Liberty Protection Safeguards has been delayed until April 2022.[[57]](#footnote-57)

### Recommendations

* The Department of Health and Social Care (DHSC) should continue to increase and embed oversight of the Transforming Care programme, develop accountability measures and consider implementing structural changes to ensure it meets targets on moving patients from inappropriate inpatient care to community-based settings, and reduce the reliance on inpatient care for people with learning disabilities and/or autism.
* The UK Government should bring forward reforms to the Mental Health Act without delay, and implement non-legislative measures, including providing sufficient preventative and community-based support, to ensure people with mental health conditions, learning disabilities and autism can access care in the least restrictive setting possible and avoid unnecessary detention. The UK Government should take into account any increased mental health needs arising from the pandemic.
* The UK Government should implement the Mental Health Units (Use of Force) Act 2018 without delay and work with partners to reduce the use of restraint and restrictive interventions, including by promoting use of our human rights framework on the use of restraint.[[58]](#footnote-58)
* The UK Government should implement the Mental Capacity (Amendment) Act 2019 with clear statutory guidance that is centred on the principles of choice and control and that respects, protects and fulfils the UK’s wider human rights obligations under the CRPD.

# Access to support services

**UN CRPD – Article 19(b):**

‘[States Parties shall ensure that] Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’

Under the CRPD, the provision of personalised support services to enable independent living and inclusion in the community must be considered both as a right in itself and a precondition for independent living. Disabled people have the right to choose services according to their individual requirements and personal preferences, and services should be flexible to meet their needs. However, there is evidence that many disabled people face increasing barriers in accessing the support and care they need.

## Provision of adult social care

The Care Act 2014 aimed to provide a more personalised approach to care, with a greater emphasis on promoting wellbeing and independence – the wellbeing principle of the Act intended to cover the key components of independent living, as expressed in Article 19 of the CRPD.[[59]](#footnote-59) However, the adult social care sector in England is under significant pressure, which means that many disabled and older people are left without the vital support they need to live independently as part of the community.[[60]](#footnote-60)

Since 2010, rising demand and substantial reductions in government funding have led to increased levels of unmet need.[[61]](#footnote-61) Requests for adult social care in England increased by 5.7% between 2015–6 and 2019–20, while the number of people receiving support reduced by 18,000.[[62]](#footnote-62) In 2019, Age UK estimated that 1.54 million older people in England were not getting the care they wanted or needed.[[63]](#footnote-63) Real-terms local authority spending on social care in England was approximately £400 million lower in 2018–9 than in 2010–1.[[64]](#footnote-64)

Having insufficient care arrangements in place can increase the risk that disabled adults and older people with care needs cannot access essentials, including food and water, medicines, clothing, hygiene and exercise, with immediate and long-term implications for wellbeing.[[65]](#footnote-65) Furthermore, the UN Committee on the Rights of Persons with Disabilities ‘observed that the reduction in the provision of support services at the local level has curtailed the ability of persons with disabilities to take part in community life’.[[66]](#footnote-66) Following concerns about the adequacy of care needs assessments, and the lack of transparency in assessments and decision making, we are considering using our statutory powers to examine how the social care system can better uphold human rights and equality.

Disabled people and older adults with care needs can also face significant barriers in challenging decisions when their care needs are not met. Research by Independent Age in 2019 found that just one-in-five councils had an adult social care appeals process, meaning many service users had to rely on drawn-out complaints procedures.[[67]](#footnote-67)

There are an estimated 6.5 million unpaid, informal carers across the UK, with an estimated 1.34 million people providing more than 50 or more care hours per week.[[68]](#footnote-68) The reliance on informal, unpaid carers further suggests that disabled people do not have full choice and control over the type and level of care that they receive. The principles of individualised support services mean that disabled people have the right to choose services and service providers according to their individual requirements and personal preferences.[[69]](#footnote-69)

## Closure of the Independent Living Fund

The Independent Living Fund was a national resource dedicated to the financial support of disabled people, enabling them to choose to live in the community rather than residential care.[[70]](#footnote-70) The Independent Living Fund closed to new claimants in 2010 and was definitively closed in June 2015. In England these funds transferred from central administration to local authorities, but the funding was not ring-fenced.[[71]](#footnote-71)

There is evidence that the closure of the Independent Living Fund had a significant impact on many disabled people’s care packages. A survey carried out by the Independent Living Strategy Group in 2016 found that 41% of former fund recipients had seen their support decrease.[[72]](#footnote-72) During its 2016 inquiry of the UK, the UN Committee on the Rights of Persons with Disabilities found that ‘former Fund claimants have seen the support they received from local authorities substantially reduced, to the extent that their essential needs in areas such as daily personal care are not sufficiently covered’.[[73]](#footnote-73)

## Reduced social care provision during the pandemic

The coronavirus pandemic has pushed the already struggling adult social care sector to crisis point, posing a significant threat to the right to independent living. The Coronavirus Act 2020 permitted local authorities in England to suspend or ‘ease’ their duties under the Care Act 2014 to assess and meet a person’s needs for care and support, to review care plans and carry out financial assessments,[[74]](#footnote-74) downgrading the level of care to which an individual is entitled and allowing scope for adult social care services to deteriorate.

These easements were not widely triggered, with only eight English local authorities triggering them between the end of March and July 2020, and the CQC has reported that since 3 July 2020 no local authorities in England are operating under the easements.[[75]](#footnote-75) But local authorities could still reduce provision in the short term due to coronavirus-related staffing absences by ‘applying flexibilities’ to change, delay or cancel services, without having to formally trigger easements or notify the Department of Health and Social Care (DHSC).[[76]](#footnote-76)

In the early months of the pandemic, a number of disabled people’s organisations reported that local social care provision was significantly reduced (one found 54.6% of people with care support needs it surveyed were no longer receiving health or personal care visits at home),[[77]](#footnote-77) with little or no information or transparency about how local authorities took these decisions. [[78]](#footnote-78)

In a survey of directors of adult social services in England in autumn 2020, 60% reported that domiciliary care providers in their area had closed down, ceased trading or handed back local authority contracts since the beginning of the pandemic, affecting 3,309 people in total.[[79]](#footnote-79) This is particularly concerning at a time of increased demand for adult social care; the survey indicated that the pandemic has led to a significant shift in the type of care and support people seek, with increasing numbers choosing to remain in their own home with domiciliary care, making use of direct payments to employ personal assistants or accessing other forms of community support.[[80]](#footnote-80)

There is a risk more disabled adults and older people are being left without the vital care and support necessary to realise the right to independent living.[[81]](#footnote-81)Increased demand for adult social care coupled with decreased supply also risks placing a higher burden on family members or unpaid carers. Research estimates 4.5 million people have been forced to become unpaid carers during the pandemic, and these unpaid carers are disproportionately likely to be women and/or living in poverty.[[82]](#footnote-82)

## Equality and human rights in care settings

Both the House of Commons Women and Equalities Committee and the Health and Social Care Committee have found that the pandemic has exacerbated many of the existing problems within the social care sector and that urgent reform is needed.[[83]](#footnote-83) The Women and Equalities Committee has recommended specific sector-wide reforms, including measures to:

* improve the quality and personalisation of care and support for working-age disabled people across all social care settings
* address workforce issues across the sector, including low pay, poor career progression and high turnover, and
* more effectively integrate services and achieve parity of esteem across health and social care as a single system.[[84]](#footnote-84)

Care homes provide important support for older and disabled people with care needs, but they can also curtail rights and freedoms, including those of disabled people to live as independently as possible. There is evidence that equality and human rights standards have not been upheld in residential care settings during the pandemic, including in key decisions about care home admissions, visits and access to critical care.[[85]](#footnote-85) Restrictions to visits and daily living activities – put in place to protect the right to life – have led to restrictions of other human rights, including the right to independent living, respect for private and family life, and the right to liberty.[[86]](#footnote-86) We have also received concerning intelligence that some care home have continued to operate blanket or unduly restrictive policies even when visits should have been permitted under national guidance.[[87]](#footnote-87)

Existing equality and human rights laws and standards, including Article 19 of the CRPD, provide a practical framework to navigate decisions about fulfilling people’s full range of rights, helping to assess the impact of restrictions and whether they are proportionate and appropriate to individual needs.[[88]](#footnote-88) Equality and human rights laws should be at the heart of decision making, both in the ongoing response to the pandemic and any future reform of the social care system.

### Recommendations

* The UK Government should ensure that any planned reforms to the adult social care system are fully compliant with Article 19 of the CRPD, in line with our proposed legal model for incorporation of Article 19 into domestic law (see appendix), and other equality and human rights laws.
* The UK Government should commit to sustained resourcing of social care services, during and after the pandemic, and provide sufficient funding to each local authority to meet the independent living needs of disabled people in their area through mechanisms (such as ring fencing) that ensure the funding is used for that purpose.
* The UK Government should continue to take urgent steps to ensure disabled people are involved in, and consulted on, decisions about their care and treatment. Decisions should be supported by clear, accessible and consistent guidance that fully complies with human rights standards, including the principles of individual autonomy and non-discrimination.
* The Department of Health and Social Care should ensure that any restrictions established in residential care settings in response to the coronavirus pandemic – both in policy and in practice in individual care homes – are compliant with Article 19 of the CRPD and other equality and human rights standards. Restrictions should be kept under review and updated to allow further relaxations to be introduced as soon as it is safe.

# Equal participation in society

**UN CRPD – Article 19(c):**

‘[States Parties shall ensure that] Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.’

The right to be included in the community under Article 19 of the CRPD necessitates ensuring disabled people’s full and effective inclusion and participation in society, on an equal basis with non-disabled people. The CRPD makes clear that there are a number of preconditions to enable disabled people’s full and equal participation in society. These include the provision of:

* inclusive and accessible education, employment and healthcare
* an adequate standard of living and social protection, and
* accessible community facilities, goods and services.[[89]](#footnote-89)

However, disabled people still face persistent barriers in all areas of life that prevent their full and equal participation in society: in the education system, in the labour market, and in accessing appropriate housing, public transport, healthcare and other public services. The coronavirus pandemic has also created and exacerbated barriers to disabled people’s full and equal inclusion in society, including unequal access to healthcare, the failure to provide public safety information in accessible formats, and new challenges in accessing vital food and medicines.

## Inclusive education

The right to an inclusive education is guaranteed under Article 24 of the CRPD and is inherently linked to disabled people’s full and equal participation in society. The UN Committee on the Rights of Persons with Disabilities has made clear that inclusive education plays an important role in ‘building the strengths, skills and competencies necessary’ for disabled people ‘to enjoy, benefit from and contribute to their communities’.[[90]](#footnote-90) In England, the Children and Families Act 2014 attempted to address long-standing concerns about the provision of support for children and young people with special educational needs or disabilities (SEND),[[91]](#footnote-91) including the introduction of education, health and care (EHC) plans. But sufficient progress has yet to be made, and concerns continue to be expressed about delays, long-term funding, poor information and communication, and dissatisfaction on the part of parents.[[92]](#footnote-92)

Disabled children and adults continue to face a number of educational disparities.[[93]](#footnote-93) For example, children with SEN continue to have significantly lower attainment than children without SEN. In England, the difference in the percentage of pupils who achieved grades 9–4 in English and maths in 2018–9 was very large between pupils with SEN (26.7%) and those without (71%). Children with SEN are also more likely to be excluded from school.[[94]](#footnote-94)

In recent years, there has been a consistent increase in the number of children with SEN being educated outside mainstream schools: between 2019 and 2020, the number of pupils in state-funded special schools increased by 5.3%, continuing an upward trend since 2006.[[95]](#footnote-95) Recent announcements by the UK Government to create more special school places[[96]](#footnote-96) will do nothing to reverse this.[[97]](#footnote-97) Evidence also suggests that special educational needs are often the reason for moves to home education.[[98]](#footnote-98) We are concerned that this trend is inconsistent with the right of disabled children to access inclusive, good quality education.[[99]](#footnote-99)

The UK currently has two ‘reservations’ or interpretive declarations against the right to an inclusive education (Article 24 of the CRPD).[[100]](#footnote-100) The reservations alter or restrict the UK’s obligations by qualifying what it has agreed to. The first reservation says that the UK defines a ‘general education system’ to include both mainstream and special schools. The second says that the UK reserves the right to send disabled children to special schools outside their local community. These reservations are contrary to the purpose of the CRPD as they reinforce the segregation of disabled children in education, and the UN Committee on the Rights of Persons with Disabilities has stated that inclusive education must be understood as full inclusion of disabled children in mainstream schools.[[101]](#footnote-101) A fully inclusive education system, in which disabled children and non-disabled children are educated together, can play a valuable role in breaking down stereotypes, prejudice and harmful practices towards disabled people. The need to combat such attitudes and behaviours, and promote awareness of disabled people’s capabilities, is covered by CRPD Article 8.[[102]](#footnote-102)

The challenges affecting SEND provision in schools have been exacerbated by the coronavirus pandemic.[[103]](#footnote-103) Staff shortages, social distancing rules and the need to concentrate resources on the health emergency have led local authorities to reduce SEND provision, in some cases ceasing it altogether.[[104]](#footnote-104)

The Coronavirus Act (2020) amended Section 42 of the Children and Families Act 2014 to provide ministers with the power to temporarily modify the legal obligation on local authorities and health commissioning bodies to provide the support listed in a child’s EHC plan. Following this decision, local authorities and health bodies in England were only required to make ‘reasonable endeavours’ to discharge their duties.[[105]](#footnote-105) New regulations also relaxed timescales for conducting EHC assessments and issuing EHC plans, stipulating that local authorities and other bodies must do so ‘as soon as reasonably practicable’. These temporary changes have now ceased.[[106]](#footnote-106)

While changes were in force, stakeholders raised concerns that some local areas used the change in the law to effectively cease SEND provision altogether.[[107]](#footnote-107) Stakeholders also reported inconsistencies in the way in which local authorities interpreted the ‘reasonable endeavours’ duty.[[108]](#footnote-108) This risked compounding the already difficult situation faced by many families who looked after children with SEND at home during the periods of school closures, including for those who did not receive adequate support with specialist equipment, additional tutoring, accessible learning resources and social care.[[109]](#footnote-109)

Although the temporary changes to EHC plans have now ceased, challenges remain for local authorities in dealing with the backlog of assessments and support provision.[[110]](#footnote-110) There is also the possibility that EHC plan modifications could be reintroduced if the pandemic were to worsen again. Ongoing reductions in support create a real risk that increased numbers of disabled children could reach crisis point and be admitted to inpatient units or held in restrictive settings, in breach of the right to live independently in the community. Children in these settings are no longer receiving support normally provided in schools or community services.[[111]](#footnote-111)

## Equal access to employment

Disabled people’s right to work (under CRPD Article 27 and International Covenant on Economic, Social and Cultural Rights Articles 6 and 7) is closely linked to their enjoyment of the right to independent living as part of the community. Employment can support disabled people’s equal social and economic inclusion and, as for many people, be an important source of personal fulfilment.

In 2017, the UK Government published a strategy to increase employment rates and improve support for disabled people to gain and remain in employment, with a target of getting one million more disabled people into work by 2027.[[112]](#footnote-112) Between 2017 and 2019, the number of disabled people in employment increased by 404,000.[[113]](#footnote-113)

However, despite this progress, disabled people of working age remain at a distinct disadvantage in the UK labour market. Between April and June 2020, only 53% of disabled people were in employment compared with 81.7% of non-disabled people[[114]](#footnote-114). Disabled people are also more likely to work part-time, to do lower skilled jobs, and to earn less than non-disabled people on average.[[115]](#footnote-115) These are key factors that contribute to the disability employment and pay gaps.

The coronavirus pandemic risks further exacerbating the disability employment and pay gaps. Disabled people are at particular risk of unemployment, under-employment and redundancy as a result of the pandemic. Citizens Advice has reported that one in four disabled people face redundancy, compared with one in six of the working population as a whole.[[116]](#footnote-116) A summer 2020 survey commissioned by Leonard Cheshire found that 21% of disabled people in the UK had worked reduced hours during the pandemic; 20% had lost out on income; and 40% felt at greater risk of redundancy due to their employer judging them based on disability.[[117]](#footnote-117) Throughout the pandemic, disabled employees have reported that their employers have failed to provide reasonable adjustments so that they can work effectively. It appears from reports to the Equality Advisory and Support Service that in some cases disabled people have been made redundant, despite government initiatives such as the Coronavirus Job Retention Scheme, either because employers believe this is in an employee’s best interest or have struggled to meet their obligations to make adjustments under equality or health and safety law.

## Adequate standard of living and social protection

The realisation of the right to live independently and be included in the community requires an adequate level of income protection, which can be secured through social security and employment.[[118]](#footnote-118)

Disabled people are more likely to live in poverty and material deprivation than people who are not disabled. Research by the Joseph Rowntree Foundation found that 31% of disabled people in the UK lived in poverty in 2017–8, compared to 20% cent of non-disabled people.[[119]](#footnote-119)

Our analysis of the tax and welfare reforms introduced between May 2010 and January 2018 revealed that their cumulative impact on disabled people by the 2021/2 tax year will be significantly regressive. It is estimated that households with at least one disabled adult and a disabled child will lose over £6,500 a year (over 13% of their net income) and disabled lone parents with at least one disabled child will lose almost £10,000 of their annual net income.[[120]](#footnote-120) Following its 2016 inquiry into the UK, the UN Committee on the Rights of Persons with Disabilities reported evidence of grave and systemic violations of the right to independent living and the right to an adequate standard of living and social protection.[[121]](#footnote-121)

Evidence suggests that benefit sanctions have had no tangible positive effects in moving disabled people closer to paid work and that the use of sanctions may have exacerbated many disabled people’s existing illnesses and impairments, especially for those with mental health conditions.[[122]](#footnote-122) Our review of recent social security reforms also indicates that sanctions do little to change claimant motivation, but encourage hostility towards support services and worsen relationships with job centre staff.[[123]](#footnote-123)

Research shows that disabled people are among the groups most likely to be affected by the expected rise in poverty during and following the coronavirus pandemic.[[124]](#footnote-124) Disabled people are at a greater risk of experiencing a reduction in earnings through redundancy, a reduction in hours, or being furloughed from a job in a shut-down sector.[[125]](#footnote-125) They are also more likely to have fallen behind on essential bills during the pandemic.[[126]](#footnote-126) For example, one analysis shows that in July 2020 19.5% of disabled people in Britain had struggled to pay their bills, and 21.3% had to borrow money or rely on credit in the last seven days, compared to 13.4% and 18.2% of non-disabled people respectively.[[127]](#footnote-127)

Social security provides an important safety net for many households and is of increasing importance through the pandemic. However, concerns remain around the sufficiency of support, the accessibility of the system and the impact of sanctions and conditionality.[[128]](#footnote-128) There have also been widespread concerns that people in receipt of legacy benefits (including Jobseeker’s Allowance, Employment and Support Allowance, Personal Independence Payment and Income Support) – mainly disabled people and carers – have been unfairly excluded from the temporary £20-a-week uplift in universal credit allowance during the pandemic.[[129]](#footnote-129)

## Accessible housing

Accessible housing is a cornerstone of independent living,[[130]](#footnote-130) and disabled people should have choice and control over their homes and communities. Yet many disabled people live in homes that do not meet their requirements. Our 2018 inquiry into housing for disabled people found a chronic shortage of accessible and adaptable homes across all tenure types in Great Britain.[[131]](#footnote-131) In 2019, it was estimated that 91% of homes did not provide the four features required under Part M of the building regulations for even the lowest level of accessibility – a home that is ‘visitable’ (to most people, including wheelchair users). These four features are: level access to the entrance, a flush threshold, sufficiently wide doorways and circulation space, and a toilet at entrance level.[[132]](#footnote-132) The Housing Made for Everyone (HoME) coalition estimates that some 400,000 wheelchair users are living in homes that are neither adapted nor accessible.[[133]](#footnote-133)

Local authorities are not ensuring the construction of enough accessible homes to meet demand.[[134]](#footnote-134) Our 2018 inquiry found that only 28% of local authorities across Britain set a percentage target for accessible homes.[[135]](#footnote-135) Disabled people also often face unacceptable bureaucracy and delays when they require housing adaptations – such as the installation of grab rails, stairlifts, or wet rooms – to meet their basic living needs.[[136]](#footnote-136) Section 36 of the Equality Act 2010, which states that the duty to make reasonable adjustments applies to the common parts of rented accommodation, has not yet been fully implemented.[[137]](#footnote-137) Furthermore, the provision of advice, support and advocacy for disabled people living in unsuitable accommodation is patchy.[[138]](#footnote-138)

## Accessible transport

Accessible, affordable transport underpins disabled people’s ability to participate in all aspects of social and economic life, and to live independently. In recent years, there has been an ongoing commitment to improve the accessibility of public transport to make travel easier for disabled people. For example, in 2018, the UK Government published a strategy that set out plans to improve the accessibility of public transport.[[139]](#footnote-139)

However, disabled people continue to face barriers to accessing public transport, and efforts to improve the situation have been slow and piecemeal. Those barriers vary depending on the person’s particular impairment. For many, including wheelchair users, it is simply the physical inaccessibility of the infrastructure that prevents them from accessing transport – a particular problem on the rail network.[[140]](#footnote-140) The lack of accessible information, such as not having audio-visual announcements on all buses, also presents challenges. Despite recent efforts, more regular and consistent staff training is still required; there is clear evidence that helpful and supportive staff make a significant difference to the travelling experience of disabled passengers.[[141]](#footnote-141)

Disabled people who use wheelchairs still face specific barriers accessing taxis and private hire vehicles, including a shortage of wheelchair accessible vehicles.[[142]](#footnote-142) A decade on from the passing of the Equality Act 2010, a number of sections of the Act in relation to taxis and private hire vehicles are not yet, or are only partially, in force.[[143]](#footnote-143)

Disabled people can face particular barriers in reporting complaints when transport accessibility regulations are breached. Passengers are often not aware of their rights, or what constitutes discrimination on public transport. The variety of different regulators and complaint-handling bodies across the transport sector can be confusing, and complaints processes may not be provided in accessible formats for a range of impairments.[[144]](#footnote-144)

### Recommendations

* The UK Government should remove the reservation and interpretive declaration on Article 24 (Education) of the CRPD, and take concrete steps to facilitate genuine family choice and realise the right of disabled children to inclusive education, with the best interests of the child a primary consideration.[[145]](#footnote-145)
* The Department for Education should implement the recommendations made by the House of Commons Women and Equalities Committee**[[146]](#footnote-146)** to address the backlog of EHC assessments and plans to ensure that children and young people with SEND get the support they need within statutory timescales. Should flexibilities in EHC plan duties become necessary again, the Department for Education should also update guidance to local authorities to state that they should publish information setting out the implications of flexibilities on SEND provision in their area and the minimum level of provision that they expect to be able to provide.
* The Department for Work and Pensions should introduce mandatory monitoring and reporting on the recruitment, retention, progression and pay of disabled people for employers with over 250 staff, including mandatory action planning to address the factors contributing to disability employment and pay gaps.
* The Department for Work and Pensions should publish robust time-bound targets to reduce disability employment and pay gaps, and ensure there is clear ministerial accountability in meeting those targets.
* The Department for Work and Pensions should ensure that the social security system is accessible and effective for all, supports the right to an adequate standard of living, and does not contribute to increasing material deprivation and poverty. This should include a review of the time until first social security payment, and the impact of sanctions and conditionality. It should also include the collection and monitoring of data on the protected characteristics of claimants and claim outcomes, and the provision of reasonable adjustments where required.
* Data on reasonable adjustment provision (including anticipatory reasonable adjustments) should be disaggregated by impairment type, including for people with mental health conditions, people with learning disabilities and people with fluctuating conditions.
* The UK Government should identify and monitor the specific economic impacts of the pandemic on groups of people who share protected characteristics, including disabled people. The government should ensure that this insight informs its strategic plans, investment frameworks and public sector contracts at a formative stage.
* The Ministry of Housing, Communities and Local Government (which consulted on raising accessibility standards for new homes in 2020) should ensure there is an adequate supply of new houses built to inclusive/universal design standards and to wheelchair-accessible standards across all tenures, in line with the recommendations of our housing inquiry.[[147]](#footnote-147)
* The UK Government should urgently follow up on its 2018 commitment to implement Section 36 of the Equality Act 2010 to require reasonable adjustments to the common parts of rented accommodation and promptly consult if further consultation is deemed necessary prior to implementation.
* The Department for Transport should review the relevant regulatory framework governing taxi and private hire accessibility, including possibilities for enacting some or all of the outstanding provisions in Part 12 of the Equality Act 2010 and considering whether additional regulations may be needed to address remaining gaps in protections.
* The Department for Transport should undertake or commission research into the barriers that transport regulators continue to face in enforcing accessibility regulations, and take action to support regulators to improve enforcement.
* The Department for Transport should embed compliance with the Public Sector Equality Duty and the wider equality and human rights framework in any new management and governance structures introduced following the independent Williams Rail Review (set up in 2018 to look at the whole rail industry and delivery of passenger services),[[148]](#footnote-148) to ensure that the rail network is fully accessible and supports disabled people’s equal participation in society.

# Conclusion

The right to independent living is integral to disabled people’s enjoyment of their full range of human rights, and their full and equal participation in society. Yet, many disabled people face persistent barriers to the full realisation of their right to live independently as part of the community. As this paper has demonstrated, there is evidence that disabled people in the UK are not provided with the same choice, control and opportunities as others, across many areas of life.

However, a two-tiered society is not inevitable – with the right support, safeguards and protections, disabled people can participate fully and equally in society.

We recommend that the right to independent living is incorporated into domestic law, and we have developed a proposed legal model to achieve that, which is set out in the appendix to this paper. Proposals to strengthen the law on independent living must be fully resourced and take a life-course approach. Disabled people and their representative organisations should be fully involved in the development and implementation of any legislation.

Additionally, throughout this paper we have set out clear and practical solutions to strengthen the right to independent living, remove barriers and improve the lives of disabled people. Taken together, these steps represent a blueprint for a society where disabled people are treated with equal dignity and value.

# Appendix

The UN Committee on the Rights of Persons with Disabilities has recommended that UN CRPD Article 19 should be incorporated into domestic law.[[149]](#footnote-149) We agree with this recommendation. We have previously recommended that the UK Government should incorporate the CRPD as a whole into domestic law so that individuals can effectively challenge rights violations and access redress.[[150]](#footnote-150) However, given the centrality of the right to independent living, and concerns about regression on the realisation of this right, we also support specific, targeted measures to incorporate Article 19 rights into domestic law (in line with international requirements). We have developed proposals for legislative change to strengthen disabled people’s right to live independently and be included in the community in England.[[151]](#footnote-151)

While this model could equally apply to Wales, we are yet to consult extensively in Wales or consider the equivalent Welsh legislation, so at present we have set this out as applicable to England, pending further discussions with stakeholders in Wales.

In developing the position set out in this appendix, we sought views from a range of stakeholders, including the Independent Living Strategy Group (which is made up of disabled people and allies from a range of organisations) and our own Disability Advisory Committee. There was general recognition that there is no single way to incorporate the right to independent living into domestic law, and a mixture of provisions with duties and rights of varying strength, levels and breadth is likely to be required. Our view is that, while the key elements below would ideally be taken forward as a package, incremental progress on even one or two of these elements would be a positive step forward.

## Elements of a proposed model for incorporating the right to independent living

The following key elements, in combination, make up a potential model for incorporating the right to independent living into domestic law:

1. a Public Sector Inclusion Objective
2. a qualified presumption in favour of living in the community
3. the primacy of disabled people’s views
4. a prohibition on the establishment of further institutional accommodation
5. assessment of unmet need, and
6. enforcement and interpretation.

### A Public Sector Inclusion Objective (PSIO)

As the overarching mechanism for giving domestic effect to Article 19, we propose the creation of a statutory ‘Public Sector Inclusion Objective’ (PSIO).

A great many public authorities have functions that can be carried out to further Article 19 in some way. These include local authorities delivering social care and clinical commissioning groups (CCGs) delivering NHS Continuing Healthcare, but also housing associations providing social housing, central government and local bodies providing public transport, planning authorities regulating public spaces and many more.

With that in mind, the PSIO would take the form of an overall duty on all listed public authorities to act with the objective of meeting the requirements of Article 19. A list of relevant public authorities subject to the PSIO would need to be developed and would operate in a similar way to the list in Schedule 19 to the Equality Act 2010.

This creation of an overall duty would have the advantage of capturing all the elements of Article 19 in some way, including those aspects that are not sufficiently specific to form the basis of rights enforceable by an individual. It would be enforceable through judicial review.

The PSIO would not directly make compliance with Article 19 compulsory. But although considerations such as cost could still be used as reasons not to do what Article 19 might otherwise require, public authorities would need to confront and explain the impact of any failure to give effect to Article 19, and to explain their reasoning for such action.

#### Proposed formulation of a Public Sector Inclusion Objective:

In exercising its functions, a public authority must act with the objective of meeting the requirements of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.

A public authority must, in particular, act with the objective of:

* securing that all disabled people are enabled to live in the community with choices equal to others, unless that is incompatible with the wishes of the particular person in question
* offering provision enabling full inclusion in the community for disabled people
* enabling disabled people to choose where they live
* enabling disabled people to choose with whom to live, and
* ensuring that disabled people are not obliged to live in a particular living arrangement.

### b) A qualified presumption in favour of living in the community

As well as that overarching obligation in relation to Article 19 as a whole, we also consider it necessary to give a harder legal edge to those core elements of Article 19 that are framed in more specific terms.

At the heart of Article 19 are particular obligations around living in the community. To give specific effect to those particular obligations, we propose two elements of a qualified presumption in favour of living in the community:

* a presumption (including on local authorities, CCGs, and other public bodies discharging relevant functions, such as those relating to housing) of provision of accommodation in the community, qualified only by the wishes of the disabled person (leaving it open for a person to seek institutional accommodation if that is what they genuinely want), and
* a presumption to secure care and support to enable community or home living, again only when this is in line with a person’s wishes.

Aspects of the right to independent living are subject to the concept of progressive realisation. This requires States Parties to take ‘deliberate, concrete, targeted’ steps’, using ‘all appropriate means’ to the maximum of the resources available in the State, to meet the rights, and to commence these steps ‘immediately or within a reasonably short period of time’.[[152]](#footnote-152) As set out in relevant UN guidelines, reference to the availability of resources ‘reflects a recognition that the realisation of these rights can be hampered by a lack of resources and can be achieved only over a period of time’.[[153]](#footnote-153) We propose that the concept of progressive realisation could be reflected in commencement provisions. For example, commencement could be linked to a requirement on the Secretary of State to publish a plan to meet unmet need in relation to care and support (see below).

A public authority exercising functions relating to the provision of accommodation to a disabled person must secure that the person is accommodated in the community unless that is incompatible with the wishes of the person.

A public authority exercising functions relating to the provision of care or other support to a disabled person must discharge those functions, including providing personal assistance, to enable the disabled person to live in whichever of the following they prefer:

* any accommodation provided for them by virtue of the provisions above on accommodation in the community, or
* their own home.

### A primacy of disabled people’s views

To comply with Article 19, disabled people should be able to decline care (or elements of care), even if others think those care elements are best for their wellbeing, and to have that wish respected.

This is necessary particularly to prevent those wishes being undermined by decision-makers who may seek to block a community placement – for example because they think some elements of care will not be available in the community, while the disabled person considers this a sacrifice worth making for living in their community. This is reflected in the provision below.

#### Proposed formulation of a right to decline

The following provisions apply where a public authority is assessing a disabled person’s need for accommodation, care or support.

A disabled person may decline any particular provision or element of provision, or request different provision, even though other people may consider that giving effect to such a preference would compromise the disabled person’s wellbeing.

The public authority must give effect to a choice falling within the provision.

### d) A prohibition on the establishment of further institutional accommodation

Compliance with Article 19 means that no new institutional accommodation should be created.

This is generally in line with the Transforming Care programme and recent moves by the Care Quality Commission (whose policy on registering new providers of care for people with learning disabilities and autism marks a clear shift towards support in the community).

We received some feedback that a provision on deinstitutionalisation should go further and include an explicit requirement to close down existing institutions. Alternatively, this could take the form of requiring existing institutions to divest themselves of the features of institutions set out in the proposed provisions on interpretation below.

#### Proposed formulation of a provision on deinstitutionalisation

A public authority exercising functions in relation to the regulation or authorisation of residential accommodation shall do so to secure that no existing institutions are permitted to expand and no new institutions are established.

This provision shall not prevent the continuation of maintenance and improvement of conditions at existing institutions.

### e) Assessment of unmet need

To ensure concrete progress towards full realisation of the right to independent living, it is important that authorities understand the extent of the need for accommodation, support and care in the community and the extent to which this is currently being met.

The draft provision below proposes a local duty based on the joint strategic needs assessment regime set out in Section 116 of the Local Government and Public Involvement in Health Act 2007.

Focusing that process only on the obligations in the provisions on accommodation and care and support (under b) A qualified presumption in favour of living in the community, above) directs it to those things that are, in this proposal, the most hard-edged legal obligations.

The element below proposes a linked duty on the Secretary of State to produce a national assessment based on those local needs assessments.

As explained above, the national assessment is in part to inform the process of bringing into force provisions relating to the presumptions in favour of community living and so bring about the progressive realisation of those elements of Article 19.

#### Proposed formulation of duties to report and act on unmet need

A listed public authority must prepare and publish within a year of the commencement of the relevant provisions, and then every two years after that or as directed by the Secretary of State, a report setting out:

* its assessment of relevant needs in its area
* the extent to which those relevant needs are being met, and
* what it will do to meet those relevant needs.

‘Relevant needs’ means all needs for services necessary for it to discharge the duties under the provisions on accommodation and care and support under b) A qualified presumption in favour of living in the community, above.

The Secretary of State must prepare and publish within two years of the commencement of the relevant provisions, and then every two years after that, a report setting out:

* the Secretary of State’s assessment of relevant needs in England
* the extent to which those needs are being met
* what the Secretary of State will do to secure that those relevant needs are met. and
* when they will commence the provisions on accommodation and care and support.

### f) Enforcement and interpretation provisions

To ensure clarity of application and the enforceability of a right to independent living, we consider that the elements above would need to be accompanied by the following provisions:

* **Enforcement:** Provision for an independent body, such as a tribunal (likely to be part of the First-tier Tribunal) to decide whether public authorities have discharged their obligations. Without such provisions, a person would only be able to challenge through existing complaints routes (which are not sufficient for Article 19 compliance purposes) and/or by judicial review (which looks only at the legality of decisions and not their substantive merits).
* **Guidance and definitions:** The provision of guidance, produced through public consultation and with parliamentary approval, will be required to ensure clarity of implementation of the relevant elements outlined above. In addition, it will be important to define key terms. On the latter point, we propose the following interpretation of terms relating to institutions.

#### Proposed formulation of provisions on interpretation

Living or being accommodated in the community means living in, or being provided with, accommodation that is not in an institution.

An institution is residential accommodation where:

* residents are isolated from the broader community
* residents live together with people other than those with whom they have chosen to live
* residents do not have control over their day-to-day lives and over decisions that affect them, or
* the interests of the organisation itself tend to take precedence over the residents’ individualised needs or wishes.

The Secretary of State may by order add additional factors to be taken into account in determining whether residential accommodation is an institution.

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