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Joint Committee on Human Rights

Implementation of the Right of Disabled People to Independent Living

Twenty–third Report of Session 2010–12

Report, together with formal minutes

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Joint Committee on Human Rights

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In the footnotes of this Report, references to oral evidence are indicated by ‘Q’ followed by the question number. Oral evidence is published online at http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/publications/. References to written evidence are indicated by the evidence reference number as in ‘IL 12’. 
# Implementation of the Right of Disabled People to Independent Living

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Summary

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, the Convention) is the newest treaty in the human rights framework, and was ratified by the UK in 2009. This Report examines the UK’s implementation of the right to independent living for disabled people, as enshrined in Article 19 of the UNCRPD.

Independent living as a right

Despite the UK having ratified the UNCRPD, independent living does not currently exist as a freestanding, justiciable right in UK law. This Report argues that the existing matrix of human rights, equality and community care law, while instrumental in the protection and promotion of the right to independent living, is not sufficient. The right to independent living should be added as an outcome in any forthcoming Bill on adult social care in England.

We also recommend that all interested parties, governmental and non-governmental, immediately start work on assessing the need for and feasibility of free-standing legislation to give more concrete effect in UK law to the right to independent living. The Government should publish their assessment of the need for and desirability of such legislation in the light of the forthcoming first report of the UN Committee on Disabilities.

The Government have characterised the obligations assumed by under the Disabilities Convention as “soft law”. This Report regards this as indicative of an approach to the treaty which regards the rights it protects as being of less normative force than those contained in other human rights instruments. The UNCRPD is hard law, not soft law, and the Government should fulfil their obligations under the Convention on that basis, and counter any public perception that it is soft law.

The impact of current reforms

While we recognise the exceptional economic circumstances facing the UK, we conclude that there is a risk of retrogression of the UK’s obligations under Article 19 as a result of the cumulative impact of spending cuts and reforms. There has been particular concern about the effects of reductions in funding for local authorities, changes to Disability Living Allowance under the Welfare Reform Bill, caps on housing benefit and the closure of the Independent Living Fund, and the way in which these might interact to restrict enjoyment of the right to independent living.

Many local authorities are restricting eligibility criteria for social care support. We argue that this risks breach of Article 19. We recommend that the Government’s forthcoming Disability Strategy includes measures to monitor the impact of restrictions on eligibility for adult social care on disabled people’s access to independent living.

Many of our witnesses expressed concern over the proposed change from Disability Living Allowance to Personal Independence Payments (PIP). During the course of this inquiry, the Government decided that disabled people in residential settings should continue to be eligible for the DLA/PIP mobility component. We welcome this. However, we recommend that the new assessment system and eligibility criteria must not create a disincentive to using
implementation of the right of disabled people to independent living

aids and adaptations, should be independently reviewed with the involvement of disabled people’s organisations before being rolled out nationally, and must continue to be based on the fundamental principle that this is a benefit based on the additional costs of impairment, and not based on medical diagnosis.

we argue that the closure of the independent living fund to new applicants, with no ring-fenced alternative source of funding, may severely limit the ability of disabled people to participate in society. the government should address this issue in their consultation paper on replacement funding to be published in early 2012 and ensure that this change in policy does not result in retrogression as far as article 19 is concerned.

the range of reforms proposed to housing benefit, disability living allowance, the independent living fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people. some disabled people risk losing dla and local authority support, while not getting support from the independent living fund, all of which may force them to return to residential care. as a result, there seems to be a significant risk of retrogression of independent living and a breach of the uk’s article 19 obligations.

we therefore recommend that the office for disability issues, the devolved administrations and local authorities, monitor the impact of reform and spending decisions on the right to independent living and report on the extent to which reforms to the ilf, dla and housing benefit are enabling the government and local authorities to deliver their article 19 obligations.

policy development and decision making

the uncrpd imposes obligations on the government to ensure compliance with the convention across the whole of the uk, to develop policy by assessing the impact of decisions with the convention in mind, and to do this with the involvement of disabled people.

the devolved administrations have taken different approaches to delivering the right to independent living. we commend the scottish government and the welsh government for their respective plans to promote independent living, but note with disappointment the lack so far of an equivalent strategy in northern ireland. although the uk government should not seek to direct the devolved authorities or local authorities in the exercise of their powers, we argue that they should acknowledge their responsibilities under the convention to ensure its implementation across the whole of the uk.

we also received evidence that compliance with the convention by public authorities has not been uniform, and we are unclear how the government are meeting their obligation to ensure this compliance, especially in the light of localism and changes to public authority duties in england under the equality act 2010. we argue that the government should work with the devolved administrations, the independent mechanisms, regulators and disabled people’s organisations to promote awareness and understanding of the convention among public authorities.

we are concerned that the uncrpd does not appear to have played a central role in the development of policy and recommend that the government make a commitment to parliament that they will give due consideration to the articles in the convention when
making new policy and legislation.

We also received evidence that impact assessments of current reforms were not adequately carried out, and did not take into account the likely cumulative impact of reforms on disabled people. We therefore argue that the Government should publish a unified assessment of the likely cumulative impact of the proposals on independent living.

The UNCRPD specifically requires disabled people to be involved in the implementation of the Convention, and in this context we are disappointed that the English specific duties under Section 149 of the Equality Act no longer encourage the involvement of disabled people. We argue that this is a retrogressive step.

Other issues

A number of other issues relevant to the enjoyment of independent living were raised during the course of our inquiry.

We welcome the Government’s intention to consider introducing portable assessments for care needs. However, we are concerned that this may be insufficient to ensure the enjoyment of rights under Article 19, in particular the right to choose one’s place of residence and where and with whom one lives on an equal basis with others, and urge the Government to consider whether further action is required.

Independent living also applies to people in residential settings. We therefore argue that the Government should include in their Disability Strategy a commitment to enable disabled people living in residential settings to access their full Article 19 rights. We also urge the Government to take action to enable people in residential homes to retain a greater proportion of money they earn from paid work.

We argue that the Government should monitor disabled people’s access to information, advice, and advocacy services, continue to support and develop the role of Disabled People’s User-Led Organisations, and implement the advocacy provisions in sections 1 and 2 of the Disabled Persons Act 1986 when reforming community care legislation.
1 Introduction

1. We launched our inquiry into the right to independent living for disabled people in February 2011. We sought to examine various aspects of the right to independent living within the framework of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, or “the Disabilities Convention”). The UNCRPD is the newest treaty in the UN human rights framework, and was ratified by the UK in 2009. It builds on existing human rights treaties including the International Covenant on Civil and Political Rights and the International Covenant on Economic Social and Cultural Rights. Its purpose is to "promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” The very existence of the Disabilities Convention is premised on the acceptance by the international community that governments need to take positive steps to remove the obstacles which all too often prevent people with disabilities from enjoying the human rights to which they are entitled.

2. The right to independent living is specifically enshrined in Article 19 of the UNCRPD, which states that “State Parties to this Convention recognise the equal right of 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”. However, as the UK Government acknowledges in its first compliance report which it recently submitted to the UN Committee on the Rights of Persons with Disabilities (“the UN Disabilities Committee”), independent living underpins the rights set out in many of the other articles of the Convention. The UK’s approach to independent living therefore “goes well beyond the right as described in Article 19 and encompasses increasing choice and control, removing barriers and inclusion in the community.”

3. Independent living, described by the Office for Disability Issues as being “about disabled people having the same level of choice, control and freedom in their daily lives as any other person”, was placed at the heart of the last Government’s policy on disability. Each of the three main political parties expressed its approval for the Independent Living Strategy, which the then Government published in 2008, which set out actions aimed at improving the choice and control disabled people had over the services they needed to live their daily lives. In June 2010, the current Government explained that they were looking at ways of taking the Independent Living Strategy forward. The Government’s Disability Strategy, which the Minister for Disabled People told us would build on the Independent Living Strategy, is due to be published later this year. In December 2011, the Government published a discussion document, Fulfilling Potential, in order to receive feedback from disabled people and disabled people’s organisations on realising aspirations, increasing

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1 The UN Disabilities Committee is the body responsible for monitoring states’ compliance with their obligations under the treaty.


3 Q 246
individual control and changing attitudes and behaviours. However, this document does not invite feedback on human rights or other legislative rights for disabled people.\(^4\)

4. This inquiry was conducted during a period of fundamental reform to many of the arrangements which underpin independent living in the UK, and in the context of significant reductions in public spending. Important developments in the area of independent living include the rolling out of the previous Government’s replacement of Incapacity Benefit with Employment and Support Allowance and the introduction of a Work Capability Assessment, and the current Government’s Welfare Reform Bill,\(^5\) which introduces Universal Credit, replaces Disability Living Allowance with Personal Independence Payments and makes changes to the housing benefit system. Other developments include the closure of the Independent Living Fund, changes to the provision of adult social care, and various reforms in the name of the “Big Society” and “localism”. These changes will all affect disabled people and may, both individually and cumulatively, have a significant impact on the ability of disabled people to enjoy independent living as protected by the Disabilities Convention generally and by Article 19 in particular.

5. The Disabilities Convention is innovative in promoting a model of “subsidiarity” with respect to implementation and monitoring, whereby the traditional approach to treaty monitoring is augmented by requiring States to establish a domestic framework to promote and monitor implementation of the Convention\(^6\) including designated leadership within the Government, an independent framework to promote, protect and monitor implementation, and the active involvement of civil society—and disabled people’s organisations in particular—in both implementation and monitoring. This model is designed to encourage a domestic dialogue regarding implementation of the Convention and to promote mainstreaming.

6. Effective parliamentary oversight has an important role to play in giving effect to the principle of subsidiarity. It is first and foremost for the national authorities to determine what measures the state is required to take in order to implement the obligations it has assumed in the Convention, and Parliament plays an important role in scrutinising the adequacy of the steps which have been taken by the Government and testing the justifications for taking apparently backward steps or for not going further to implement the obligations. Those exercises in parliamentary scrutiny at the national level help to ensure that scrutiny of states’ compliance reports by the international treaty bodies is properly informed and, where appropriate, pays due respect to the outcome of national democratic processes. The democratic legitimacy of the international system for the protection of human rights increasingly depends on national parliaments taking this role seriously.\(^7\)

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\(^4\) Fulfilling Potential: a discussion document, Office for Disability Issues, 1 December 2011

\(^5\) See also our Report on the Bill, Legislative Scrutiny: Welfare Reform Bill, 21st Report 2010–12, HL 233 HC 1704

\(^6\) Article 33

\(^7\) The Inter-Parliamentary Union has published a very useful Handbook for Parliamentarians on the Disabilities Convention, From Exclusion to Equality: realizing the rights of persons with disabilities (2007) which is designed to assist parliamentarians to perform their important task of seeking to give practical effect to the rights recognised in the Convention.
7. By holding this inquiry we have sought to build on the work of our predecessor Committee in this respect. That Committee examined the Disabilities Convention during its inquiry into the human rights of adults with learning disabilities, and recommended that the UK ratify the Convention. It also scrutinised the Convention itself, prior to its ratification, and subjected the Government’s proposed reservations and interpretative declarations to rigorous parliamentary scrutiny. The UN Convention requires the Government to take steps to ensure that reforms and spending decisions are consistent with its obligations. In our inquiry we have sought to examine the degree to which such steps have been taken and identify the potential implications of the reforms for disabled people’s right to live independently and to be included in the community. In addition to informing domestic developments, our Report is also intended to make a parliamentary contribution to the forthcoming scrutiny of the UK’s performance by the UN Disabilities Committee.

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2 Independent living as a human right

What is independent living?

8. The Government, adopting wording originally proposed in 2002 by the Disability Rights Commission, have defined independent living as “all disabled people having the same choice, control and freedom as any other citizen—at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations”\(^{11}\).

A personal account of independent living

John Evans gave a personal account of the meaning of independent living in evidence to us:

“What does independent living mean to me? I think that is a very deep, life changing question and it means a lot of things. I suppose I could say it has changed my life and I know it has changed the lives of many other disabled people whom I have come into contact with [...] It is very hard I think to get that message across to people who perhaps are not dependent on others to support them in their day-to-day living. But it has provided me with a life, my work—I have worked widely—and the opportunities and the choices to do the things I want, like you do. I think with the restrictions somebody like myself has, with the kind of severe impairment I have, it is freedom. It is the freedom for me to be able to do what I want to do, when I want to do it, in a way, because I have people around me who can support me to do that.”\(^{12}\)

9. Independent living is as relevant to people living in residential care as it is to someone living in their own home, and as relevant to people with significant cognitive impairments as to a university graduate. In its inquiry on the rights of adults with learning disabilities, our predecessor Committee supported independent living as a basis for Government policy, explaining that, as a concept, it was important that independent living did not mean leaving people without support:

“When we refer to independent living, we refer to the Disability Rights Commission interpretation, which promotes choice and autonomy for people with disabilities in their daily lives. This may mean different things for different people. It should not be confused with situations where people with learning disabilities have been moved to supported living in the community without adequate support. One of the first things that we learned in this inquiry was that a ‘one size fits all approach’ was not appropriate.”


\(^{12}\) Q 78
We consider that the principles of independent living and promoting the participation of disabled people in community life are core themes of the UN Disability Rights Convention. It has a clear basis in other human rights standards and principles, such as freedom, equality and autonomy.”

10. Independent living, in short, is freedom for disabled people. Individual freedom has long been cherished by our common law tradition. The Disabilities Convention simply recognises that for some people positive steps have to be taken in order to secure that freedom.

Relevant provisions of the Disabilities Convention

11. The UNCRPD’s stated purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” It reaffirms the existing human rights of disabled people and sets out the practical action that is required to remove barriers and put in place the support to make the human rights of persons with disabilities an everyday reality. The key articles for understanding the right to independent living as enshrined by the Convention are Articles 3, 4 and 19. The effect of these three crucial provisions is summarised below. Their full text is included in the Annex.

12. Article 3 of the Convention sets out a number of general principles which are intended to guide States in their interpretation of the subsequent provisions of the treaty. These include:

- Respect for the inherent dignity, individual autonomy (including the freedom to make one’s own choices), and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

13. Article 4 of the Convention sets out the range of obligations which are assumed by States which choose to ratify the Disabilities Convention. The general obligations set out in Article 4 are extensive. Significantly, they explicitly recognise that States are under an obligation to take positive actions in order to comply with the Convention. The obligations recognised in Article 4 include (most relevantly for the purposes of our inquiry) the following:

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13 See Seventh Report of 2007–08, paras 72–73
14 Article 1
15 In a recent statement, the Children's Commissioner has expressed concerns about the impact of the Welfare Reform Bill on children, citing Article 4 of the UN Convention on the Rights of the Child, which imposes similar obligations.
• To ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability;¹⁶

• To adopt all appropriate legislative, administrative and other measures for the implementation of the rights in the Convention;¹⁷

• To take all appropriate measures (including legislation) to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;¹⁸

• To take into account the protection and promotion of human rights of persons with disabilities in all policies and programmes;¹⁹

• To ensure that public authorities and institutions act in conformity with the Convention;²⁰

• To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise;²¹

• To take measures to the maximum of its available resources with a view to achieving progressively the full realisation of the economic, social and cultural rights in the Convention;²²

• To consult closely with and actively involve persons with disabilities, through their representative organisations, in the development and implementation of legislation and policies to implement the Convention, and in other decision-making processes concerning issues relating to persons with disabilities.²³

14. Article 19 of the Convention is a key provision: it deals with living independently and being included in the community and is of such importance to this inquiry that we set it out in full:

“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, including by ensuring that:

a) 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;
b) 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;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

15. Article 19 has been interpreted as a logical extension of the right to equal recognition before the law in Article 12 of the Convention, in the sense that recognition of legal capacity restores the “power of persons with disabilities to decide about their own lives, while the right to independent living paves the way for persons with disabilities to choose how to live their lives.” Article 19 can be seen as what lawyers call a “lex specialis”, that is, a more specific or concrete expression of a general underlying norm when that norm is given effect in a particular context. It gives more specific meaning to the general rights to liberty and security of person and to private and family life in the particular context of disabled people and their living arrangements. Of particular importance is the elimination of living arrangements that segregate and isolate people with disabilities (e.g. institutionalisation), unless that choice is made by the disabled person. Article 19 thus requires States Parties to ensure that people with disabilities are able to live in the community with accommodation options equal to others, and that these options support the inclusion and participation of people with disabilities in the life of the community. Article 19 requires that States ensure that disabled people have the opportunity to choose with whom they live on an equal basis with others.

16. In order to realise these freedoms, States Parties are obliged to ensure that disabled people have access to a range of support services that they may require in order to live freely in the community, and to avoid isolation and segregation from the community. The Convention also requires that steps are taken to ensure that mainstream community services and facilities must be available to disabled people on an equal basis with others and responsive to their needs.

The legal status of the relevant standards in the Disabilities Convention

17. In the course of our inquiry it became apparent that Government ministers were under an unfortunate misapprehension as to the legal status of the Disabilities Convention. In oral evidence to us the Minister for Disabled People expressed her view that the Convention was ‘soft law’: “Is it hard law or soft law? [...] the UN Convention is soft law— if one uses those terms—because it is a Convention that does not have legal standing, but it is very much a Convention which every Department is signed up to [...] it does drive at the heart of our approach although technically [...] it is a soft law approach.”

18. “Soft law” is the term generally used to describe standards which do not have the status of being legally binding on the State in international law, such as declarations, minimum principles and similar internationally agreed documents. Treaties, however, are legally

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24 Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, European Foundation Centre, October 2010

25 Q 232
binding on the state in international law. A violation of a treaty obligation is an internationally wrongful act which has serious consequences for the State in international law. Obligations contained in treaties are always “hard law”.

19. The UK Independent Mechanisms\(^{26}\), in supplementary evidence, gave the following assessment of the legal status of the Convention: “As a matter of international law the CRPD, in its totality, is binding international law—i.e. “hard” law. It is an international treaty which has been entered into by State Parties and is subject to the law of treaties and the principle of \textit{pacta sunt servanda}. That is the principle, codified in the Vienna Convention on the Law of Treaties, that States enter into international agreements and implement those obligations in good faith. The CRPD was ratified by the UK Parliament on 8 June 2009. Since that date the UK has had “hard” international law obligations under Article 19 of the CRPD.”\(^{27}\) This analysis is clearly correct.

20. In addition to its status as an international treaty which is legally binding on the UK, the Convention also has a degree of more direct legal effect in the UK’s legal system, through the Human Rights Act 1998 and the European Communities Act 1972. The European Court of Human Rights has begun to take note of the Convention in the context of its interpretation of the European Convention on Human Rights.\(^{28}\) The UK Courts are required by the Human Rights Act 1998 to take account of ECtHR jurisprudence and the Government is bound by its judgments in cases against the UK. The Convention also has a particular status in EU law. The EU, as a “regional integration organisation” has ratified the UNCRPD requiring it to interpret EU law and regulation compatibly with the Convention, providing the basis for consistent interpretation of EC (now EU) secondary law including Regulations, Directives, Decisions, Recommendations or Opinions.

21. What the Minister may have had in mind when describing the Disabilities Convention as “soft law” is that fact that it has not been incorporated into UK law and is therefore not directly justiciable in UK courts: that is to say, an individual cannot go to a UK court to complain about a breach of any of the rights in the Convention. Implementation of the UN human rights treaties is generally supervised by the “treaty bodies”, which are independent expert committees established under each of the treaties, through a system of periodic State reports and, under some of the treaties, petitions from individuals. The UNCRPD requires its parties to report periodically to explain the extent of State compliance. The responsible treaty body will then examine the report, together with submissions of NGOs and others, and will issue Concluding Observations highlighting positive and the negative aspects of the State’s level of compliance, and will make recommendations for appropriate changes to law or practice accordingly. These conclusions and recommendations are not strictly speaking legally binding, but provide an authoritative interpretation of the individual treaty obligations which are legally binding. All of this is correct but it does not make the treaty “soft law”.

\(^{26}\) Article 33 of the Convention requires states to establish an “independent mechanism” to promote, protect and monitor implementation of the Convention. In the UK, the independent mechanism is jointly the Equality and Human Rights Commission, the Scottish Human Rights Commission, the Northern Ireland Human Rights Commission and the Equality Commission for Northern Ireland.

\(^{27}\) IL 122

\(^{28}\) See for example Stanev v Bulgaria (2012) in which Bulgaria was held to have violated the rights of a man with mental health problems to liberty, to a fair trial and not to be subject to degrading treatment. http://echr.coe.int/ECHR/homepage.en
22. The Minister may also have had in mind that the nature of some of the obligations imposed by the Convention are of a different kind from those imposed by treaties such as the European Convention on Human Rights, in that some of them are subject to the principle of progressive realisation. The precise nature of the legal obligations imposed by the Disabilities Convention, and by Article 19 of that Convention in particular, is considered in detail below. It is true that the nature of some of the legal obligations imposed by the Disabilities Convention is different from those imposed by other international human rights treaties such as the ECHR. But this difference in the nature of the legal obligations does not reduce the status of those obligations to “soft law”.

23. We are concerned that characterising the obligations assumed by the Government under the Disabilities Convention as “soft law” is indicative of an approach to the treaty which regards the rights it protects as being of less normative force than those contained in other human rights instruments. The UNCRPD is hard law, not soft law. The Government should fulfil their obligations under the Convention on that basis, and must counter the public perception that it is soft law.

The nature of the legal obligations under the Disabilities Convention

Obligations to respect, protect and fulfil

24. Like all international human rights treaties, the Disabilities Convention imposes three distinct types of legal obligation on States: obligations to respect, protect and fulfil the rights contained in the Convention.

25. The obligation to respect means that States must not interfere with the enjoyment of the rights of people with disabilities. For example, they must respect their right to education by not excluding them from school on the basis of their disability and must respect their right to health by not carrying out medical experiments on them without their free and informed consent.

26. The obligation to protect means that States must take positive steps to protect the rights of disabled people against violation by third parties, including private individuals and organisations. For example, the State must protect people with disabilities against inhuman and degrading treatment by privately run prisons or care homes, and must protect their right to work by ensuring that private businesses cannot discriminate against employees on grounds of their disability.

27. The obligation to fulfil means that States must take appropriate actions (including legislative, executive, administrative, budgetary, and judicial actions) towards the full realisation of the rights in the Convention. For example, the State must fulfil the right not to be abused or mistreated by taking positive steps to ensure that adequate training and information are provided to health professionals, police and prison officers, and must fulfil the right of disabled people to take part in the life of their community by taking steps to enhance accessibility.
Obligations of “progressive realisation” and “non-retrogression”

28. As we pointed out in our recent Report on the Welfare Reform Bill, where international human rights treaties protect social, economic and cultural rights, the State is under a particular type of legal obligation: it must take deliberate, concrete and targeted steps towards the realisation of those rights “to the maximum extent of their available resources.”

29. The availability of resources is therefore of central relevance in assessing the degree to which the UK is meeting its obligations under such human rights treaties. However, the duty of progressive realisation entails a strong presumption against retrogressive measures. In its General Comment on the scope of the UN Committee on Economic Social and Cultural Rights (ICESCR) right to an adequate standard of living and to social security, the ICESCR explained:

“There is a strong presumption that retrogressive measures taken in relation to the right to social security are prohibited under the Covenant. If any deliberately retrogressive measures are taken, the State party has the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant, in the context of the full use of the maximum available resources of the State party. The Committee will look carefully at whether: (a) there was reasonable justification for the action; (b) alternatives were comprehensively examined; (c) there was genuine participation of affected groups in examining the proposed measures and alternatives; (d) the measures were directly or indirectly discriminatory; (e) the measures will have a sustained impact on the realization of the right to social security, an unreasonable impact on acquired social security rights or whether an individual or group is deprived of access to the minimum essential level of social security; and (f) whether there was an independent review of the measures at the national level.”

30. So, while the principle of progressive realisation within available resources affords States a degree of flexibility in achieving the objectives of the Convention, it does not absolve States of the responsibility to take active steps to protect and fulfil those rights. “Retrogressive” measures, that is, measures which represent a backwards step in terms of the realisation of the rights concerned, require strict justification and even then are not permissible if they are incompatible with the “core obligations”. Although States are free to secure their minimum obligations through a variety of means, those obligations have a “minimum core”, and any failure to meet the minimum standards envisaged will be in violation of the international standards which the United Kingdom has accepted.

31. In its recent General Comment on the scope of the right to social security in the International Covenant on Economic, Social and Cultural Rights, for example, the UN Committee on Economic and Social Rights explained:

29 General Comment No 19, The Right to Social Security, (2008), paragraph 42.
30 Joint Committee on Human Rights, 21st Report of 2010–12, HL Paper 233 HC 1704, para 1.30
“The right to social security is of central importance in guaranteeing human dignity for all persons when they are faced with circumstances that deprive them of their capacity to fully realise their Covenant rights.”

“To demonstrate compliance with their general and specific obligations, States parties must show that they have taken the necessary steps towards the realisation of the right to social security within their maximum resources, and have guaranteed that the right is enjoyed without discrimination and equally by men and women.”

“Violations include, for example, the adoption of deliberately retrogressive measures incompatible with the core obligations [...] the formal repeal or suspension of legislation necessary for the continued enjoyment of the right to social security; [...] active denial of the rights of women or particular individuals or groups. Violations through acts of omission can occur when the State party fails to take sufficient and appropriate action to realise the right to social security. In the context of social security, examples of such violations include the failure to take appropriate steps towards the full realisation of everyone’s right to social security; the failure to enforce relevant laws or put into effect policies designed to implement the right to social security [...]”

32. Similarly, in its General Comment regarding the right to housing, the UN Committee asserted that “a general decline in living and housing conditions, directly attributable to policy and legislative decisions by the States parties, and in the absence of accompanying compensatory measures, would be inconsistent with the obligations under the Covenant”.

33. The UN Committee has also emphasised the particular responsibility on states to ensure that the most vulnerable do not bear a disproportionate burden at times of public spending cuts:

“The Committee wishes to emphasize, however, that even where the available resources are demonstrably inadequate, the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances. Moreover, the obligations to monitor the extent of the realization, or more especially of the non-realization, of economic, social and cultural rights, and to devise strategies and programmes for their promotion, are not in any way eliminated as a result of resource constraints [...] Similarly, the Committee underlines the fact that even in times of severe resources constraints whether caused by a process of adjustment, of economic recession, or by other factors the vulnerable members of society can and indeed must be protected by the adoption of relatively low-cost targeted programmes.”

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31 General Comment No 19, The Right to Social Security, 4 February 2008, E/C.12/GC/19, para 1. The Committee on Economic Social and Cultural Rights is the relevant Treaty Monitoring Body for this treaty. The purpose of these General Comments is to provide clear guidance to States and others as to the Committee’s approach to the interpretation of key issues in the ICESCR.

32 Ibid. para 62

33 Ibid. paras 64–65

34 General Comment No. 4, The right to adequate housing, para 11

35 General Comment No. 3, paras 11–12.
34. As we indicated above, the Disabilities Convention does not recognise any new human rights for people with disabilities, but is intended to complement existing international human rights treaties by spelling out in more detail States’ obligations to respect, protect and fulfil the human rights of people with disabilities. It is intended to assist States by clarifying the steps that States need to take in order to ensure that disabled people enjoy their human rights to the same extent as other people. Like the UN Convention on the Rights of the Child, the Disabilities Convention therefore draws on all of the existing international human rights treaties, and includes a mixture of civil, political, social, economic and cultural rights.

35. The right to live independently and be included in the community in Article 19 of the Disabilities Convention embodies this synthesis of civil and political, economic, social and cultural rights. Article 19 (a) in particular concerns self-determination, a recognisably civil and political right. Yet its realisation is strongly dependent upon the availability of options, as envisaged by Article 19 (b) which confers economic, social and cultural rights, and upon access to mainstream community services and facilities as envisaged by Article 19 (c). Ensuring equal access to and responsiveness of community services and facilities in turn depends upon measures to combat disability discrimination, including reasonable adjustments in the context of goods, facilities and services.

36. A rigorous analysis of Article 19 is important because, as we explained above, different types of rights impose different legal obligations. Compliance with the obligations imposed by Article 19 will therefore require the State to take a variety of different actions and measures.

- Article 19 (a) implies rights to self-determination in relation to matters affecting where and with whom a disabled person lives and the means by which disabled people are involved in decisions affecting them. This suggests a need for legal and/or administrative mechanisms which protect and promote choice and control regarding where and with whom disabled people live.

- Article 19 (b) appears to recognise social and economic rights of disabled people and as such obliges a contracting State to “take measures to the maximum of its available resources with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”.36

- Article 19 (c) is more in the nature of a civil and political right to non-discrimination in relation to accessing goods and services, including the duty to make reasonable accommodations, legislative measures for which are required with immediate effect, but which in practice (such as in relation to making premises accessible) may take time to be realised in practice.

37. The precise nature of these legal obligations must always be borne in mind when considering the extent to which the UK has implemented the right to independent living.

36 Article 4(2) of the Disabilities Convention.
and when making recommendations about the sorts of action which the State should be taking in order to fulfil its treaty obligations in that respect.
3 Progress so far

38. Significant progress has been made in the UK towards protecting and promoting disability rights and the right to independent living in particular. This allowed the UK to play a leading role in negotiating the UNCRPD and speedily to ratify it in 2009. This chapter provides a brief overview of some of the more significant areas of progress in recent years.

Legislation and policies in recent years

The Disability Discrimination Act 1995 made it unlawful to discriminate against disabled people in connection with employment, the provision of goods, services or facilities or the disposal or management of premises. It introduced a duty for service providers to make “reasonable adjustments” to allow disabled people to take advantage of their services. This might include provision of equivalent services. The DDA 1995 was subsequently amended by secondary legislation such as the Disability Discrimination Act 1995 (Amendment) Regulations 2003 and by primary legislation such as the Special Educational Needs and Disability Act 2001 and the Disability Discrimination Act 2005. These amendments extended the scope of the Act. The 2005 Act also introduced a Disability Equality Duty which obliged public authorities to take a more proactive role in promoting the equality and inclusion of disabled people.

The Community Care (Direct Payments) Act 1996 enabled local authorities to provide direct payments to disabled people to allow them to commission their own services.

The Human Rights Act 1998 requires that all public authorities act in a manner which is compatible with the rights set out in the European Convention on Human Rights. If public authorities fail to meet this duty, people who are affected by the breach may ask the courts for a remedy. Public authorities include central Government, local authorities, NHS Trusts, and most providers of public services.

Most recently, the Equality Act 2010 sought to streamline UK anti-discrimination legislation. For Great Britain (but not Northern Ireland) it repealed and replaced the DDA (as amended). The Act extended the protection of disabled people from discrimination, but also made changes to the specific duties of public authorities with respect to the involvement of disabled people in policy decisions.

The Welfare Reform Act 2009 introduced the Right to Control (see below), while the Health Act 2009 introduced personal health budgets, both of which would extend disabled people’s choice and control over their supported services. These are both currently being piloted in some areas of the country.

39. The previous Government also took other non-legislative measures in the area of disability policy. These included the establishment in 2000 of the Disability Rights Commission (which was subsequently replaced by the Equality and Human Rights...
Commission) and the establishment of the Office for Disability Issues in 2005 to coordinate disability policy.

40. The previous Government’s 2005 cross-departmental report, Improving the Life Chances of Disabled People, set a goal that by 2025 “disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society”. In particular, it aimed to help “disabled people to achieve independent living by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services.”

One of the recommendations of this report was the setting up of the Office for Disability Issues and the establishment of a body, Equality 2025, to advise the Government on how to achieve the aims of the report by 2025. Equality 2025 was created in 2006.

Independent Living Strategy

41. The Independent Living Strategy (ILS) was a cross-government project, coordinated by the Office for Disability Issues. It was published in 2008 and aimed to fill the gap “between national policy and people’s real experiences”.

The Strategy included commitments to:

- Promote a shared understanding of the principles and practice of independent living
- Strengthen the evidence-basis to inform policy development; redeploy resources from professional assessment to user-led support; create a regional initiative to determine how to invest in independent living for older people in residential care, or at risk of moving into care
- Maximise disabled people’s housing opportunities
- Consolidate progress made in training, information and accessibility of public transport, and enhance the mobility of those whose needs could not be met by public transport
- Enhance the understanding of health services’ contribution to independent living, to enable disabled people to have choice and control over their non-acute healthcare needs, and to enable them to manage their own long-term conditions
- Enable individuals to remain in employment when they acquire an impairment or when an existing impairment or condition deteriorates; ensure that benefit and charging systems do not create unnecessary barriers to independent living
- Promote personalisation, through ensuring that every disabled person in receipt of social care, and/or related funding, has the opportunity to have choice and control over the state funding they receive
- Provide universal information, advice and advocacy service for people who need support in their lives

37 Improving the Life Chances of Disabled People, Prime Minister’s Strategy Unit, 2005.
38 Office for Disability Issues, Independent Living: A cross government strategy about independent living for disabled people, 2008, p.9
• Promote a co-ordinated, strategic approach to investing in independent living for older disabled people, and will also seek to ensure that older disabled people’s voices are heard and that they are enabled to participate in the development and delivery of services.

• Seek to ensure a seamless transition into adulthood for young disabled people

• Promote more joined-up working between health, education and social care to provide timely and flexible support where this is needed by families affected by parental disability

• Monitor the progress on the aims of the Strategy, in particular through the Equalities Public Services Agreement (PSA)

42. Along with the publication of the Strategy, the Independent Living Scrutiny Group was established with a remit to report annually on the implementation of the strategy.39

Valuing People

43. In 2001, the then Government launched a strategy for people with learning disabilities, Valuing People.40 This was followed in 2009 in by Valuing People Now,41 which proposed a three-year strategy to take account of developments since 2001 and was accompanied by a further response to our predecessor Committee’s Report, A Life Like Any Other? The Human Rights of Adults with Learning Disabilities.42 In response to that Report, Valuing People Now adopted human rights as one of the four key guiding principles underpinning the strategy.

Right to Control

44. The Welfare Reform Act 2009 introduced the “Right to Control”. The Right to Control was produced in close consultation with disabled people. Under the current Government, pilot schemes (the “Right to Control Trailblazers”) were introduced by means of the Disabled People’s Right to Control (Pilot Scheme)(England) Regulations 2010. In the Right to Control Trailblazers areas43 disabled people are able to combine the support they receive from different sources in order to decide how best to spend the funding.

Political consensus

45. Progress so far with independent living was achieved with a general consensus that the organising principle of public service design and delivery should be to optimise choice, control and participation, in general accordance with the approach envisaged in Article 19 of the Convention.

39 An independent group of disabled people that offers the Government its views on progress on delivery of the Independent Living Strategy. It is chaired by Baroness Campbell of Surbiton, a member of this Committee.

40 Valuing People, DoH March 2001;

41 Valuing People Now, DoH 19 Jan 2009


46. The major UK political parties have made commitments to this approach. The previous Government instigated the ILS and the present Government have endorsed the tenets of the ILS. In evidence to us, the Minister for Disabled People, Maria Miller MP, said “we want to remove barriers to create opportunities for disabled people to be able to fulfil their potential and be fully participating members of society, very much building on the Independent Living Strategy”. The current Government have also continued the work of their predecessors in regard to the Right to Control.

47. We welcome the Government’s continued commitment to removing barriers and creating opportunities for disabled people, and consider this to be entirely consistent with their obligations under Article 19 UNCRPD. The UK has an established position as a world-leader on disability rights and in relation to independent living in particular. We strongly encourage the Government to make every effort to maintain and build upon this status.

The current situation

48. Although progress has been made on implementing the right to independent living, recent assessments have indicated that there is still work to be done. The second annual report by the Independent Living Scrutiny Group, published in February 2011, says “As we move to the midway point of the five year strategy, we would expect to be seeing indications of the positive impact of the action plan. Unfortunately, this has not really been the case”. It noted that direct payments and personal budgets for adult social care had increased choice and control for those disabled people receiving them, and advocated the continuing development of personalisation. However, it raised concerns about the impact of funding cuts and benefit reform, and about continuing barriers faced by disabled people in terms of access to housing, transport and employment.

49. The most recent evidence, from the ODI’s Life Opportunities Survey, confirms that this remains the case. The Survey found that 16% of adults with impairments experienced barriers to education and training, 57% experienced barriers to employment (compared with 26% of those without impairments), 75% experienced barriers to using transport (compared with 60%), 44% of households with at least one person with an impairment experienced barriers to economic life and living standards (compared with 29%) and 82% experienced barriers in leisure, social and cultural activities (compared with 78%).

50. We note the significant disadvantage to disabled people which persists in relation to choice and control and levels of participation in economic and social life and the impact this has on their economic and social well-being, and on what many of our witnesses considered to be their enjoyment of basic human rights. We therefore welcome the Government’s recognition that more progress is required to promote disabled people’s right to independent living.

51. The Government should continue their commitment to delivering independent living by ensuring that the forthcoming Disability Strategy sets out a clear plan of
action to make progress with regard to independent living as defined by Article 19, with
milestones and monitoring mechanisms. The Disability Strategy should build on and
update the outcomes framework set out in the current Independent Living Strategy.

**Legislative underpinning of the right to independent living**

52. The right to independent living is not currently underpinned by specific legislation.
Instead, a matrix of related legislation and policy exists, which does not fully provide
disabled people with the rights to self-determination in relation to matters affecting where
and with whom they live, or choice and control over how their support needs are met.

53. In evidence to us, Scope argued that a “basic enforceable right is crucial for sustaining
progress towards ensuring independent living for all disabled people”.47 The Social Care
Institute for Excellence told us that the fact that disabled people do not enjoy choice and
control is not a failure of policy but of implementation: “Making the right to independent
living legally enforceable at an individual level, so that each disabled person has a clear
entitlement to independent living and the services required to support it, would build on
the body of policy work in a useful way”.48

54. Article 4 of the Convention requires the Government to take measures to the
maximum of its available resources to achieve progressively the full realisation of
economic, social and cultural rights. But successive governments have not incorporated
economic, domestic and social rights into domestic law. In this context the ICESCR is
relevant. In 2007, the previous Government’s 5th report to the UN Committee on
Economic, Social and Cultural Rights, stated that “the ICESCR has not been and is not
expected to be incorporated into domestic law. This means that the rights contained in the
Covenant are not directly enforceable by domestic courts”.49 In 2009 the UN Committee
urged “the State party [the UK] to ensure that the Covenant is given full legal effect in its
domestic law”.50

55. On four occasions in the last Parliament, Lord Ashley of Stoke introduced a private
member’s bill with the intention of establishing a legal right to independent living, but
none of the bills was taken up by the previous Government, and they were consequently
not passed.51

56. Successive governments have argued that the principles and objectives of the
Convention are implemented through the policies, laws and practices of the welfare state.
This raises the question as to whether the provision of housing options, support services
and access to general services are subject to the discretion of the State, rather than being
constitutional rights. The Scottish Human Rights Commission argued that “the failure as
yet to incorporate the Disability Convention does limit the opportunities to enforce the
right […] to independent living”.52 Independent Living in Scotland argued that the

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47 IL 85
48 IL 42
49 Fifth Periodic Report from the United Kingdom, July 2007 E/C.12/GBR/5, paras 74–5
50 Concluding Observations of the Committee on Economic, Social and Cultural Rights, 22 May 2009 E/C.12/GBR/CO/5,
para 13
52 IL 81
Implementation of the Right of Disabled People to Independent Living

Convention was “not part of domestic UK or European law and as such is not 'justiciable' in the domestic or European Courts. Given the inequalities and issues in accessing justice that disabled people face, we feel it is essential that the UK bring the rights in the UNCRPD into domestic law at the earliest possible opportunity.”

57. In England and Wales, the law regarding adult social care is currently undergoing a process of review, with the possibility of new legislation in the next parliamentary session. In this context, the Law Commission has recently produced a proposal to consolidate the law on adult social care, describing the current situation as “a confusing patchwork of conflicting statutes”. The Law Commission’s report recommends a unified adult social care statute for both England and Wales, and states that the new statute should establish that the overarching purpose of adult social care is to promote or contribute to the well-being of the individual. The statute would require the Secretary of State and Welsh Ministers to make regulations prescribing the eligibility framework for the provision of community care services, which local authorities would be required to use to set local eligibility criteria.

58. The report also recommended that in defining in statute the concept of "well-being", the following outcomes should be taken into account:

- health and emotional well-being;
- protection from harm;
- education, training and recreation;
- the contribution made to society; and
- the securing of rights and entitlements.

The Social Care Institute for Excellence suggested in evidence to us that "independent living", as defined by the Convention, should be added to the list of outcomes.

59. The Law Commission rejected the idea that a principle based on independent living should be included as a means of establishing enforceable legal rights to services. They concluded that “a principle based on an assumption of home-based living would not be suitable to be included as a principle in the statute. The key issue should be the person’s wishes and feelings, and in effect this principle could skew choice in one particular direction.” This conclusion appears to be based on the assumption that independent living equates to “home-based living”. Article 19 makes clear that disabled people should “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”, and that the option that should be made available to people should include “in-home, residential and other community support services”.

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53 IL 30
54 Law Commission, Adult Social Care, 10 May 2011, HC 941
55 Ibid, p. 8
56 IL 42A
60. The Right to Control programme has provided disabled people assessed as eligible for public service support with a right to an individual budget. However, as yet this exists only in the eight “Trailblazer” areas. Any extension of the project will depend on the results of those pilot schemes, and the Government making appropriate regulations. Further, the Right to Control does not provide disabled people with a right to support.

61. The Equality Act 2010 is of critical importance to independent living. It prohibits discrimination in relation to access to goods, facilities and services, including public services and requires service providers to make reasonable adjustments proactively where not to do so would place disabled people at a substantial disadvantage.

62. The Public Sector Equality Duty, under section 149 of the Equality Act 2010, requires public authorities to have due regard to eliminating discrimination, advancing equality of opportunity and fostering good relations. This duty is a “process duty”—that is, questions of lawfulness concern the degree to which public authorities are able to account for having shown “due regard” and not in respect of the resulting degree of equality or inequality. A series of high profile cases have featured the consideration of the Duty in respect of local authority decisions to tighten social care eligibility criteria, including in Birmingham and the Isle of Wight. In these cases, the actions of the local authorities were found to be unlawful because they had failed to demonstrate that they had taken account of the impact the decision would have on disabled people, and had failed to consult. The decisions themselves were not at issue.

63. The Right to Control is a welcome step towards establishing independent living as a right. If the evaluation of the “Right to Control Trailblazers” is positive, the Government should make regulations to roll out the scheme nationwide in both social care and primary health care.

64. We note that while the UK has made progress in developing a rights-based approach to the design and delivery of public service support to disabled people, disabled people in the UK do not enjoy a right to independent living in domestic law.

65. We regret that the Convention has not been incorporated into UK law and no underpinning legislation exists specifically to protect and promote the right to independent living. While we consider the existing matrix of human rights, equality and community care law to be instrumental in the protection and promotion of the right to independent living, we do not consider it sufficient. The right to independent living (as defined by Article 19) should be added as an outcome in any forthcoming Bill on adult social care in England.

66. Our inquiry has revealed that the current legal framework for giving effect to the right of disabled people to live independently and be included in the community is inadequate to ensure the effective enjoyment of that right in practice. Significant gaps have been shown to exist in the existing patchwork of laws and we have made a number of specific recommendations in order to fill those gaps, for example by implementing the right to control, and including independent living as an outcome in reformed community care law.

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58 R (on the application of Rahman) v Birmingham City Council (2011); R (on the application of JM and NT) v Isle of Wight Council (2012)
67. We remain concerned, however, that merely filling in the gaps in the current legislative framework will still not accord the right to independent living the legal status that its fundamental importance deserves. We hope that the Commission on a Bill of Rights will consider the arguments for and against expressly recognising the right of disabled people to independent living in any Bill of Rights for the UK. In the meantime, we recommend that all interested parties, governmental and non-governmental, immediately start work on assessing the need for and feasibility of free-standing legislation to give more concrete effect in UK law to the right to independent living.

68. Such legislation could be specifically designed to implement the rights recognised in Article 19 of the Disabilities Convention. Like the Child Poverty Act 2010, which achieved cross-party consensus at the time of its passage through Parliament, such a statute could set clear outcomes for government and public authorities to work towards, and to which they should have due regard when making both policy and spending decisions. This framework of nationally agreed outcomes would also help facilitate the portability of assessments between different local authority boundaries. The legislation could require national and local government to publish an independent living strategy at regular intervals, and provide for progress against that strategy to be monitored by an independent expert body. Such strategies would also enable government to demonstrate transparently that it is meeting its obligations under Article 4(2) of the Disabilities Convention to take measures to achieve progressively the full realisation of the social and economic rights which are included in Article 19. In developing such strategies, the Government and public authorities would be required to actively involve disabled people, in keeping with their obligations under Article 4(3) of the Disabilities Convention.

69. We recommend that the Government publish their assessment of the need for and desirability of such free standing legislation implementing the right to independent living in the light of the forthcoming first report of the UN Committee on Disabilities following its scrutiny of the UK’s first compliance report.
4 The Government’s approach to implementing the UNCRPD

70. Since the United Kingdom ratified the UNCRPD in June 2009, much of the legal, policy, administrative and financial architecture underpinning the right to live independently and be included in the community has undergone, or is undergoing, significant reform. This chapter will examine the approach the Government have taken to developing and implementing relevant reforms and spending decisions and the role the UNCRPD has played, with particular reference to the General Obligations in Article 4 of the Convention.

Protecting and promoting the right to independent living

71. Implementation of the right to live independently and be included in the community involves the design, implementation, coordination and maintenance of a complex array of legal duties and entitlements, benefits services and social and environmental conditions. A wide range of actors need to be engaged at both local and national level, across different sectors. In evidence to us, the Equality and Human Rights Commission explained Article 19 as focussing on “the development of living options and all associated support services or mechanisms which cumulatively accord disabled people equal opportunities to be included and to participate as fully as they wish in the community.”

72. As a consequence, implementation of Article 19 demands a strategic and “joined-up” approach. The National Centre for Independent Living likened support for disabled people to a house of cards, where removing one card caused them all to collapse. They argued that the closure of the Independent Living Fund was an example of this. They cited the case of a woman who, while still receiving a consistent level of support from the local authority, no longer received the ILF part of her support. This resulted in her life being “very restricted”.  Independent Living in Scotland cited the case of someone who could not get funding for a ramp or a wheelchair, and so was unable to leave her house: “what use is an accessible bus if you cannot get out of your house to get to it?”

73. The College of Occupational Therapists Specialist Section-Housing told us that “the areas of legislation and practice guidance affecting the housing situation and rights of disabled people are multi-factored, and removing such legislation, or elements of it, under the banner of reducing regulation burdens, supporting localism or cutting general public sector costs runs the risk of substantially reducing the rights of disabled people to independent living through the possibly unintended consequences of interacting cumulative impacts.”

74. The nature of independent living strongly suggests the need for coordinated strategy and action at the national and local level, both cross-departmentally, between

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59 IL 62, para 13
60 Q 9
61 Q 28
62 IL 78
the different levels of government, and with non-governmental actors, and for careful consideration of both the independent and cumulative impacts of policy and legislative reform and public spending decisions.

75. We recommend that the Government consider provision of the means to independent living in the round. The complex interconnections between services and benefits mean that changes to one service or benefit may have unintended consequences for another—and for the overall level of outcomes achieved. For instance, changes to housing provision may have significant impacts on the accessibility of healthcare, transport, support networks and other rights and opportunities.

Independent Living Strategy: its effectiveness, and plans for the future

76. Although the Independent Living Strategy (ILS) was an important milestone on the way to establishing independent living at the heart of policy making, the use made of the strategy is unclear.

77. The National Centre for Independent Living told us that the aims of the strategy were fully supported by the organisations they represented. However, they expressed concern over implementation and the fact that, as far as they were aware, the Independent Living Strategy was “currently lying in someone's in-tray waiting for a decision about whether it will be picked up and further work done on it.”

78. Tim Cooper, head of the ODI at the time he gave evidence, said: “One important part of the Independent Living Strategy was getting wider recognition of independent living being not just about where you live but about all the changes to society and the support services that helped you to live a fulfilled and independent life [...] There is probably more that we can do to help them to understand that, if they change one area of policy in their department, there may be knock-on effects for a sister department down the road. That kind of brokerage is part of ODI’s role.”

79. Scope agreed that the Strategy was an important milestone, but criticised it for not addressing independent living as a human rights issue. RNIB and Action for Blind People argued that the ILS no longer appeared the best tool for implementing Article 19 obligations. They suggested that the ILS needed "resuscitation".

80. However, the Social Care Institute for Excellence argued that the failure was in implementation rather than in the policy documentation, that the gap between policy and real people's experiences could be filled by "assiduous day-to-day application of the policies" and that the right to independent living should be made legally enforceable at the individual level.
81. In the light of these comments, we asked the Minister for Disabled People about the future of the ILS. She said that the new Disability Strategy would build on the ILS, and would take “the UN Convention as a starting point”.68

82. We welcome the commitment made by the Minister for Disabled People that the UNCRPD will provide the basis of the forthcoming Disability Strategy. We expect the Disability Strategy to be robust, targeted and deliverable, and co-produced with disabled people. It should cover all aspects of the Convention, including the right to independent living, and be specific in terms of how it delivers the Convention articles in order to aid measurement and transparency. The implementation process should include clear milestones, monitored by an independent body.

Coordinating implementation of the Convention across government departments and the devolved administrations

83. Article 33 of the UNCRPD requires States to implement a domestic framework to implement and monitor the Convention. This includes the designation of “one or more focal points” within government and encourages the designation of a “coordination mechanism” within government to “facilitate related action in different sectors and at different levels”. In response to UN Human Rights Council Resolution 10/7, Human rights of persons with disabilities: national frameworks for the promotion and protection of the rights of persons with disabilities, the previous Government advised that the Office for Disability Issues was both the focal point and the coordinating mechanism within the United Kingdom Government. It went on to say that “in the United Kingdom, some policy areas are now the responsibility of the Devolved Administrations in Scotland, Wales and Northern Ireland. The ODI will therefore work with focal points in each of those Administrations on issues around implementation, monitoring and reporting.”69

84. The UK response placed particular emphasis on the following mechanisms: “The ODI works with the Minister for Disabled People and with a cross-Government Ministerial group. ODI is overseen by the Disability Equality Delivery Board which is made up of senior officials from a range of other Government Departments. The Board also has three external members who bring expertise from outside Government and represent the specific experiences of disabled people of all ages and bring useful information to the decision making of the Board. The Board reports to the Improving the Life chances of Disabled People Ministerial Group, which is chaired by the Minister for Disabled People.”

85. Tim Cooper, of the Office for Disability Issues, said that ODI had worked with Departments to ensure they were aware of the provisions of the Convention.70 He pointed to the Right to Control initiative as having brought together the Department for Work and Pensions, the Department of Health and the Department for Communities and Local
The Minister for Disabled People highlighted contact with the devolved administrations: “even in areas like DWP where we have benefit and employment policies which are not devolved: we still work together on areas where we can join up our policy”. However, the Minister for Care Services told us that the Department of Health did not dictate to the devolved administrations how they should be discharging their duties in terms of the Convention. Article 4 of the UNCRPD makes clear that “the provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions”, but it does not offer any guidance as to how conformity with the Convention should be achieved across devolved or “federal” government. Any adverse finding by the UNCRPD Committee regarding failure to implement Article 19 would relate to the UK as a whole, even if the failure related to the jurisdiction of just one nation within the UK.

Although responsibility for the UNCRPD resides with the State (the United Kingdom) most of the measures required to make the rights under Article 19 practicable and real will be implemented by local or devolved rather than national government. Article 4 requires States “to ensure that public authorities and institutions act in conformity with the present Convention”. The Convention does not specify the means by which such conformity should be achieved. Nevertheless, it clearly implies an obligation of conduct, and the Government should be able to explain the means by which they comply with this requirement and how the arrangements for such compliance achieve their “obligations of result”. The delegation of powers by central government to devolved or local government to take decisions regarding the allocation of resources relevant to the realisation of Article 19 does not amount to a delegation of responsibility to ensure the progressive realisation of the Article (or other Articles in the Convention).

While we acknowledge that the Government should not seek to direct the devolved authorities or local authorities in the exercise of their powers, the UK Government should acknowledge their responsibilities under the Convention to ensure its implementation across the whole of the UK. Ultimately, the repercussions of any breach of the Convention will rest with the UK Government.

We recommend that the Office for Disability Issues updates and expands upon its response to Human rights of persons with disabilities: national frameworks for the promotion and protection of the rights of persons with disabilities, explaining its approach to coordinating implementation of the Convention across Whitehall, the devolved administrations, public authorities and other sectors. This could usefully be done in the context of the forthcoming Disability Strategy.
Implementation of the right to independent living by the devolved administrations

90. The devolved administrations have each taken their own approach to implementing the right to independent living. In Scotland, the Scottish Government, the Convention of Scottish Local Authorities (COSLA) and Independent Living in Scotland issued in 2009 the joint statement “Independent Living—A Shared Vision”. It aims to ensure that disabled people across Scotland will have equality of opportunity at home and work, in education and in the social and civic life of the community, based on the principles of choice, control, freedom and dignity. During the course of our inquiry the Welsh Government announced that it would develop a framework for independent living in Wales. Northern Ireland does not appear to have made progress on developing a strategy of its own. The independent mechanisms for Northern Ireland (Equality Commission for Northern Ireland and Northern Ireland Human Rights Commission) told us that the Promoting Social Inclusion Disability Working Group (PSI Working Group) reported to the NI Executive in December 2009 recommending that the NI Executive undertake a review of independent living and place it at the centre of its focus on disability issues. The NI Executive has not responded to this.

91. We were made aware several times in evidence that the situation in Northern Ireland presented complications because the Equality Act 2010 does not apply there. One particular difference between disability legislation in Northern Ireland and the rest of the UK stems from the 2008 decision of the House of Lords in Malcolm v LB Lewisham which overturned the “disability-related less favourable treatment” principle, which still stands in Northern Ireland. In the rest of the UK, section 15 of the Equality Act 2010 reintroduced the principle through the provision of “discrimination arising from disability”.

92. The Equality and Human Rights Commission told us that it was “not sure that each of the devolved Governments has necessarily realised that there is a right of independent living”. The Equality Commission for Northern Ireland argued that people in Northern Ireland were disadvantaged relative to those in Great Britain and that it was entirely within the competence of the Northern Ireland Executive and Assembly to amend the disability legislation in the way that has been done in Great Britain.

93. We commend the Scottish Government and the Welsh Government for their respective plans to promote independent living. We note with disappointment the lack

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75 http://www.scotland.gov.uk/Publications/2010/03/29164308/1
76 See, for example, IL 124. In May 2011, the Welsh Assembly Government was renamed as the Welsh Government. We received written evidence from the Welsh Assembly Government in April 2011, before the name change (IL 61), which is labelled as such. For simplicity, in the body of this Report, we refer to the “Welsh Government” throughout.
77 The PSI Working Group was established in 2004 to identify the main barriers to participation experienced by people with disabilities and to make recommendations on how these could be removed. The Working Group was made up of representatives from various disability organisations, the Equality, Children’s and Human Rights Commissions and officials from Government Departments.
78 London Borough of Lewisham v Malcolm (2008)
79 Q 41
80 Q 47
81 Q 55
so far of an equivalent strategy in Northern Ireland. It is regrettable that the Northern Ireland Executive has not yet responded to the proposals of the PSI Working Group made in 2009.

94. The Northern Ireland Equality Act should be amended to address the effects of the House of Lords judgment in Malcolm v Lewisham, ensuring parity of protection between disabled people in Northern Ireland and Britain.

Ensuring that public authorities comply with the Convention

95. For some, the advent of localism and changes to the specific duties in England under the Equality Act 2010 call into question the extent to which the independent living agenda can be carried out effectively at the local level. In England, the specific duties related to the Public Sector Equality Duty no longer explicitly require public authorities to carry out equality impact assessments or to involve disabled people in the process of meeting the Duty, unlike the predecessor Disability Equality Duty. Many witnesses reported a lack of joined-up thinking and a lack of awareness at local level of independent living and the Convention.

96. The Local Government Group told us that the joining up of individual initiatives had not worked as well as it might, and that “the best way to improve locally is to ensure local government involves users of services as much as possible in the design of those services”.82 Their representative, Bob Collins, said the lack of cross-cutting thinking at both national and local level had been his “greatest frustration” during his time as a councillor. However, he argued that the situation was improving and that councils were better at linking different services than Government.83 Scope told us that “Government and local authorities have a very mixed approach on their understanding of independent living [...] people from a health background particularly find it more difficult to understand the social barriers”.84

97. Witnesses were concerned about the impact that localism might have on the consistency of service provision. Housing Options and National Development Team for inclusion (NDTi) said that, in the absence of national performance indicators and a lack of clear entitlement to housing and care there was a risk of localism resulting in a “postcode lottery”.85 The RNID were concerned that different local authorities would adopt different priorities for delivery of social care,86 while MENCAP argued that localism, in conjunction with reductions in local authority budgets, would result in non-statutory services “suffering greatly”.87

98. Scope argued that, in the social care context, there was a danger that localism might result in fragmented provision and lack of effective scrutiny. They were particularly concerned that no mechanism was in place to ensure that the extra £2 billion of un-ring-
fenced funding, announced in the 2010 Comprehensive Spending Review, would be spent on social care.\(^8\)

99. Many of our witnesses suggested that there was a lack of awareness of the Convention among service providers.\(^9\) The Surrey Coalition of Disabled People argued that the Government should legislate to ensure that public bodies received mandatory awareness training.\(^9\) The Wallsall Alliance for Independent Living recommended that the Government should take steps to ensure that civil society in general was aware of its obligations under the Convention.\(^9\)

100. We are unclear how the Government are meeting their obligation to ensure compliance with the Convention by public authorities, especially in the light of localism and changes to specific duties in England under the Equality Act 2010.

101. The Government, led by the ODI, should work with others including the devolved administrations, the independent mechanisms, regulators and disabled people’s organisations to promote awareness and understanding of the Convention among public authorities, especially local government, and to monitor its implementation.

Impact assessments

102. Article 4(1)(c) of the Convention requires states to take account of the impact of policy on disabled people. "Quick start guidance" from the Home Office states that the English specific duties under the Equality Act 2010 "do not require public bodies to prepare or publish equality schemes, equality action plans, equality impact assessments, or separate annual reports on equality".\(^9\) In Wales and Northern Ireland public authorities continue to be required to conduct equality impact assessments. Scotland has yet to finalise its specific duties, but the Scottish Government’s consultation indicates its intention to retain the requirement.\(^9\)

103. Karen Ashton, of Public Law Solicitors, suggested that there was a conceptual misunderstanding in the Government’s thinking about the new public sector equality duty and specific duties, arguing that the public sector equality duty was by its nature an extremely important process duty. Reducing the bureaucracy involved did not necessarily improve its effectiveness.\(^9\)

88  IL 85
89  RNIB IL 25; Disability Rights Partnership IL 116
90  IL 52
91  IL 77
93  Consultation on revised draft Regulations for the public sector equality duty specific duties, Scottish Government, 9 September 2011.
94  Q 66. See also D and S vs Manchester City Council[2012] EWHC 17 (Admin) Case No: CO/5169/201 ' para 67 There is a theme to the submissions made by the claimants which is that the evidence they seek and which they submit is absent is that of decisions made to promote equality of opportunity and steps taken in that regard i.e. practical measures. That is not the same as having due regard. The duty is to have due regard not to achieve results.
104. Witnesses criticised the quality of equality impact assessments of recent legislation.\textsuperscript{95} RNIB and Action for Blind People discussed the proposal to remove the DLA mobility payment as a threat to Article 19 and the Independent Living Strategy which yet nonetheless "seemed to pass through any screening process [...] The proposal was accompanied by an Equality Impact Assessment but there now appears to be very little reference, if any at all, to the aims of the Independent Living Strategy".\textsuperscript{96}

105. Others noted the absence of any consideration of human rights in impact assessments. Disability Alliance criticised consultation exercises for a general lack of reference to the Convention, arguing that this pointed to a lack of awareness among policy makers of its requirements.\textsuperscript{97} We note that the Government have given a "clear commitment" to Parliament that it will give due consideration to the UN Convention on the Rights of the Child Articles when making new policy and legislation, and in so doing will always consider the recommendations of the UN Committee on the Rights of the Child, but that no equivalent commitment has been given to Parliament in relation to the UN Disabilities Convention.\textsuperscript{98}

106. The Scottish Human Rights Commission told us that the development of an integrated human rights and equality impact assessment would provide a means to ensure that the rights of disabled people were taken into account. They also suggested that a fully participatory impact assessment process would "ensure that the cumulative impacts of a range of different policies and programmes rather than their discrete impacts can be understood through the lived experiences of individuals."\textsuperscript{99} The Lord Chancellor and Secretary of State for Justice, Rt Hon Kenneth Clarke MP, indicated his willingness to consider the impact assessment methodology being developed by the Scottish Human Rights Commission to see if it holds any useful lessons for Whitehall departments in the way in which they assess the human rights impact of laws and policies.\textsuperscript{100}

107. In evidence to us, Ministers defended the Government’s use of impact assessments. The Minister for Disabled People told us that the Government had:

“published a full impact assessment in April 2011 around the housing benefit changes [...] That included the impact on disabled people. The way we considered the Article 19 requirements in terms of independent living was part of that full impact assessment. It was clear from the impact assessment that there was impact across the board on people, but that that did not disadvantage any particular group”.

She added:

\textsuperscript{95} The consultation and impact assessment process on the DLA reforms have recently been criticised in a report, widely known as the “Spartacus Report”, by Dr SJ Campbell and others. The report argues that the impact assessments did not appear to take account of the views of respondents, and that the consultation process breached the Government’s own guidelines, in particular in not being open for the standard 12 week period, and in concluding two weeks after the Welfare Reform Bill was introduced in the House of Commons. Responsible Reform, SJ Campbell et al, January 2012.

\textsuperscript{96} IL 25

\textsuperscript{97} IL 106A

\textsuperscript{98} Sarah Teather MP, Minister of State for Education, Written Ministerial Statement on the Children's Commissioner Review, HC Deb 6 Dec 2010 col 7WS.

\textsuperscript{99} Q 51

\textsuperscript{100} Oral evidence, 20 December 2011, HC1726-i, Q34.
“We have had that impact assessment looked at, at a judicial level, and it was found to be a very fair and correct way of assessing the needs” 101

The Minister for Care Services said that “[i]n terms of social care, we had an extensive debate about the impacts of inadequate funding of social care [...]” 102

108. In our legislative scrutiny Report on the Welfare Reform Bill we noted criticisms of the impact assessment process for that Bill. Equality impact assessments were not published by the Government until the Bill was in Committee in the Commons, and, while equality impact assessments have now been published for distinct parts of the Bill, these do not attempt to assess the cumulative impacts of multiple provisions in the Bill on particular groups with protected characteristics. This is of concern, since at least some individuals will experience these changes cumulatively, and their impact needs to be understood in this way. For example, a disabled person may find that they lose their lower rate DLA, and therefore become subject to a cap on their housing benefit such that they cannot afford to remain in their home. Moving may disrupt informal patterns of care and support at the same time as they have increased reliance on these supports.

109. The Equality and Human Rights Commission suggested that, when the UN Expert Committee on the UNCRPD examines the UK’s implementation of the Convention, “a failure to be able to demonstrate having accounted for the likely cumulative impact of policy and spending decisions may leave the Government exposed to serious criticism”. 103

110. We are concerned that the UNCRPD, and Article 19 in particular, does not appear to have played a central role in the development of policy. Inadequate attention has been paid to the impact of relevant policy on the implementation of the UNCRPD, in contravention of Article 4(1) and 4(3). We recommend that the Government make a clear and unequivocal commitment to Parliament, equivalent to that which it has already given in relation to the UN Convention on the Rights of the Child, that they will give due consideration to the articles in the UN Disabilities Convention when making new policy and legislation, and in doing so will always consider relevant recommendations of the UN treaty monitoring bodies.

111. However, if properly carried out, equality impact assessments provide an important mechanism through which to ensure policy achieves desired goals and avoids unintended consequences, and help to demonstrate transparency and accountability. We recommend that they should be produced early in the policy-making process with the full involvement of those likely to be affected by the policy.

112. Given the breadth of the current reforms, the Government should publish a unified assessment of the likely cumulative impact of the proposals on independent living, and set out any relevant mitigations through the Disability Strategy. The relevant strategies in the devolved administrations should also include such mitigation plans.

101 Q 236
102 Q 236
103 IL 62
113. We regret the exclusion from the English specific duties under the new Public Sector Equality Duty of the requirement to conduct equality impact assessments. The Government should either revise the duties accordingly, or promote equality impact assessments as a matter of good practice, with the assistance of other expert bodies such as the Equality and Human Rights Commission, Scottish Human Rights Commission, Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission. We welcome the willingness of the Secretary of State for Justice to consider the impact assessment methodology being developed by the Scottish Human Rights Commission and we look forward to the outcome of that consideration.

114. Our evidence suggests that equality impact assessments have not played an important part in assessing the impact of recent policy on disabled people in the context of the UNCRPD, because of poor quality, or untimely, EIAs. There also appears to be some confusion over the requirement to conduct EIAs, which the Government should clarify.

115. The Equality and Human Rights Commission, Scottish Human Rights Commission, Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission should monitor and publish an assessment of the degree to which due regard appears to have been paid to Article 19 in the most relevant policy developments and decisions in this Parliament. The findings should feed into the development of the Disability Strategy and relevant plans for each jurisdiction.

Consultation and involvement of disabled people

116. The UNCRPD specifically requires the Government to involve disabled people in the implementation of the Convention. The Disability Discrimination Act 2005 introduced the Disability Equality Duty which, among other things, required public authorities to involve disabled people in decision making in meeting their duty. The new specific duties under section 149 of the Equality Act 2010 do not require English bodies to involve disabled people, unlike the equivalent duty in Wales.

117. Witnesses regretted this change. Breakthrough UK said “local disabled people who are trying to influence what is happening in the locality and trying to be a part of the Big Society and so on, previously had a way of taking local statutory bodies to task if they were not doing proper consultation. That has been removed”. Scope said that the requirement to involve disabled people had had a great impact in achieving greater equality. They were concerned that these duties had been removed in the name of lightening the regulatory burden.

118. Some witnesses pointed to particular problems with consulting disabled people. Breakthrough UK told us that disabled people as a group had different communication needs, and that consequently effective communication required a certain amount of bureaucracy.

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104 Q 137
105 IL 85
106 Q 134
119. While some witnesses suggested that the Government were good at consulting the “usual suspects”, some suggested that such consultation rarely went any wider, to involve disabled people themselves.\(^{107}\) Leicestershire Centre for Integrated Living advocated greater consultation with user-led organisations.\(^{108}\) Although members of Choices and Rights Disability Forum and North Bank Coalition suggested that consultation did take place, they were concerned that it was not taken into account in decision making.\(^{109}\) Sense argued that deafblind people were rarely involved in consultations.\(^{110}\) In supplementary written evidence, Doug Paulley also argued that consultation should involve “user led organisations instead of charities or other bodies. Charities do not effectively represent their beneficiaries and in any case as service providers themselves have different vested interests than ULOs”.\(^{111}\) KeyRing suggested that there was particular difficulty in enabling some disabled people, for instance those with autistic spectrum disorders or learning difficulties, to take part in community projects. They argued that this risked alienating those most in need of services from the consultation process.\(^{112}\) The Coalition of Neurodiverse Organisations argued that the format of some consultation documents needed to be better designed in order to take the needs of neurodiverse people into account.\(^{113}\)

120. The Government gave examples of the involvement of disabled people. The Minister for Care Services pointed to health and well-being boards within local authorities as “being placed under duties to involve service users right from the outset, and throughout that process” and argued that “the places that are doing best are the places that are involving most; the places that are damaging people the most are the places that are ignoring people the most”.\(^{114}\) The Minister for Disabled People said that Right to Control Trailblazers had been instructive: “there are a couple of things we have learnt already. The first is that co-production with disabled people, right from the beginning, has been a very successful part of this whole process, from policy development through to implementation [...] The other lesson I would draw [...] is how empowering the process is, being able to take the funding streams available and use them in innovative ways”.\(^{115}\) She also noted that 5,000 people took part in the consultation on the reform of DLA and argued that consultation on Personal Independence Payment was “demonstrably influencing policy”.\(^{116}\)

121. The UNCRPD specifically requires disabled people to be involved in the implementation of the Convention, and the Government have acknowledged the importance of such involvement. We recommend that the Government aim to involve disabled people in the development of policy, rather than simply consult them, and to

\(^{107}\) IL 1  
\(^{108}\) IL 24  
\(^{109}\) IL 27  
\(^{110}\) IL 36  
\(^{111}\) IL 117  
\(^{112}\) IL 83  
\(^{113}\) IL 71  
\(^{114}\) Q 243  
\(^{115}\) Q 245  
\(^{116}\) Q 249
ensure that timescales and methods are used which enable a full range of disabled people and their representative organisations to be involved.

122. We are disappointed that the English specific duties under Section 149 of the Equality Act no longer encourage the involvement of disabled people. This is a retrogressive step. The Government should actively promote involvement to public authorities as a means of meeting their Equality Duty and in order to comply with the UNCRPD.

**Awareness of the UNCRPD**

123. The evidence we received suggested that awareness of the UNCRPD among disabled people was low. Disability Action suggested that such a lack of awareness resulted in a weakness in the disability rights movement\(^{117}\) and, referring to work they had carried out for the Equality Commission for Northern Ireland, argued that awareness-raising was essential to ensure adequate monitoring of compliance with the Convention. John Evans argued that the Government should commission disabled people's organisations to carry out awareness-raising and capacity-building sessions.\(^{118}\) Doug Paulley pointed to a particular problem in residential settings, where “empowerment of service users and raising their awareness of their rights can only happen through changing the culture of the institutions where they live”. He argued that “institutional environments consciously or unconsciously train their ‘customers’ into expecting and accepting lower standards of quality of life” and that people in residential care often had “little concept of rights and what might be expected in an independent living situation outside of ‘careland’”.\(^{119}\)

124. Our evidence suggests awareness of the Convention among disabled people is low. It is important that disabled people are aware of their rights in order that they can access them. We recommend that the Government work in partnership with disabled people's organisations in order to increase awareness.
5 Implementing Article 19—issues and challenges

The impact of current reforms

125. Many of the arrangements underpinning independent living in the UK are currently the subject of reform. Chapter 4 examined the extent to which the Government have fulfilled their obligations of conduct with regard to the Convention in terms of process, particularly in the context of these reforms. This chapter will examine the possible impacts of the reforms themselves in more detail. The two issues are closely intertwined. The UN Committee on Economic, Social and Cultural Rights states that any deliberately retrogressive measures require careful consideration. Its General Comment 4 on the right to adequate housing suggests that a “retrogressive measure” might involve “a general decline in living and housing conditions, directly attributable to policy and legislative decisions by States Parties, and in the absence of accompanying compensatory measures”. The State Party must act within its “maximum resources”, so any such reduction must be both necessary, and proportionate to wider reductions in public spending, and also subject to appropriate evaluation. Evidence discussed in Chapter 4 suggests that in terms of impact assessment and consultation, the reforms discussed below may not meet this test.

126. Four developments were of particular concern to witnesses: reduction of social care expenditure at local authority level; the replacement of Disability Living Allowance by Personal Independence Payment (PIP); the closure of the Independent Living Fund; and the cap on housing benefit. Some of these issues were also discussed in our legislative scrutiny Report on the Welfare Reform Bill, and the reduction of social care expenditure is also relevant to the evidence we received about the wider social care policy agenda which is covered below. The following discussion treats each of the four reforms separately, but witnesses were particularly concerned that the overall cumulative impact of the reforms might lead to retrogression of the enjoyment of rights under Article 19. For example, the College of Occupational Therapists told us that current policy proposals “run the risk of substantially reducing the rights of disabled people to independent living through the possibility of unintended consequences of interacting cumulative impacts”, while the Equality and Human Rights Commission said that “the cumulative—even if unintended—effects of DLA reform and cuts in local authority expenditure risk seriously eroding the enjoyment of Article 19 of the Convention”.

127. Many of our witnesses provided examples of how proposed reforms could lead to retrogression. RNIB Action for Blind People reported on a 40% budget reduction made by

123 IL 78
124 IL 62
Norfolk County Council to a Sensory Support Unit for people who had lost their sight. They argued that this would result in people having to move into residential care or becoming more isolated, and also that this would lead to greater costs in the longer term.\textsuperscript{125} The Choices and Rights Disability Coalition reported fears that people might have to move back with parents or family, or into residential care\textsuperscript{126} while David Webdale had concerns about his own situation: “without the ILF I could not continue to employ care staff, so I could not get to work, and as my parents get older my only future would be in some kind of residential care home”.\textsuperscript{127}

**Local authority expenditure**

128. Local authorities are required to assess the care and health needs of their populations, determine which levels of the national “Fair Access to Care Services” (FACS)\textsuperscript{128} eligibility will qualify for services, and to assess the need for care and support of individuals.

**Fair Access to Care Services (FACS) criteria**

FACS is a process to determine eligibility for social care support, based on risks to independence over time. Its aim is to help social care workers make fair and consistent decisions about the level of support needed, and whether the local authority should pay for it. The criteria are as follows:

**Critical**

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken

**Substantial**

- there is, or will be, only partial choice and control over the immediate environment;

\textsuperscript{125} IL 25  
\textsuperscript{126} IL 27  
\textsuperscript{127} IL 34  
\textsuperscript{128} FACS is a national eligibility framework for allocating social care fairly. It consists of four bands based on severity of need, which local authorities use to set their funding thresholds.
Implementation of the Right of Disabled People to Independent Living

and/or

- abuse or neglect has occurred or will occur; and/or

- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or

- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or

- the majority of social support systems and relationships cannot or will not be sustained; and/or

- the majority of family and other social roles and responsibilities cannot or will not be undertaken

Moderate

- there is, or will be, an inability to carry out several personal care or domestic routines; and/or

- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or

- several social support systems and relationships cannot or will not be sustained; and/or

- several family and other social roles and responsibilities cannot or will not be undertaken

Low

- there is, or will be, an inability to carry out one or two personal care or domestic routines; and/or

- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or

- one or two social support systems and relationships cannot or will not be sustained; and/or

- one or two family and other social roles and responsibilities cannot or will not be undertaken

129. Adult social care is both needs-tested through the FACS criteria, and means-tested. Charging for residential care, including the personal needs allowance, is set nationally. People with more than £23,250 in capital are likely to be charged the full cost. Local authorities exercise discretion in deciding whether, whom, and how much to charge for services for people living at home. Overall, local authority budgets face reductions of 28% over the next four years. In the 2010 Comprehensive Spending Review, the Government
announced an extra £2 billion in funding for social care, divided between local authorities and the NHS, although this funding has not been ring-fenced.

130. The Association of Directors of Adult Social Services referred to “underfunding relative to demand” for services. This is in the context of a reduction of £1bn in adult social care budgets for 2011–12 (according to ADASS’s survey of local authority budgets). The Local Government Association told us that local government had been particularly hard hit by reductions in public expenditure and that the additional funding made available for social care was “more than offset by reductions in overall funding for local government”. They stated that “given the expected rise in the annual cost of adult social care we therefore anticipate a multi-billion pound shortfall by 2014–15 and have concerns about this funding gap being met”.

131. The Norfolk Coalition of Disabled People submitted to us a report they had commissioned on the cumulative impact of welfare reforms and reductions in local authority expenditure, with case studies of individual households who were facing reductions in their income together with reductions in local authority services. They argued that, in addition to an anticipated loss of £526 per year for each claimant as a result of central Government reductions, reductions in care services implemented by Norfolk County Council would amount to a further £500 per year reduction.

132. Scope argued that the additional £2 billion for social care in the Spending Review would go some way towards addressing concerns about reductions in local authority funding, but only if it was ring-fenced. They said that, as it was not ring-fenced, it would very likely be diverted into other budgets. Scope also told us that independent living should be seen as a preventative agenda, arguing that long-term costs can be mitigated and that “the Government should seek to shift the focus of the debate from costs towards expenditure on independent living options as an investment that promotes better value for money and improved outcomes for disabled people”.

133. We recognise the exceptional economic circumstances facing the UK and the challenges involved in implementing the stringent cuts in public spending the Government feel are necessary. However, in tackling these economic challenges the Government must give due attention to their obligations under international law.

134. We welcome the additional £2 billion for social care set out in the 2010 Spending Review but are concerned that, without ring-fencing, it will not make up for anticipated shortfalls in social care budgets. Any reduction in care budgets, particularly in the context of rising care costs, presents a serious risk of retrogression in the realisation of the right to independent living.

135. We concur with Scope’s view that expenditure on independent living should be seen as an investment and that such an approach will reduce long-term costs and
promote better outcomes for disabled people and for society in general. We urge the Government to adopt this approach to the funding of adult social care and other budgets which contribute towards independent living.

136. In the light of pressure on local authority budgets, many witnesses complained of a restriction in eligibility under the FACS criteria. The Association of Directors of Adult Social Services told us that 78% of councils now only met substantial or critical needs and 4% only critical. The Independent Living in Scotland Project said that the concentration on critical and substantial need was short-sighted economics, resulting in a bigger and bigger backlog of people whose needs had developed through not being addressed earlier. They also suggested that it would reduce participation in the labour market, thereby reducing people’s ability to contribute financially to society. Karen Ashton, of Public Law Solicitors, argued that a move to critical-only provision might be in breach of Article 19, as it risked denying people personal assistance to prevent isolation or segregation from the community.

137. The Minister for Care Services told us that:

“central government has never had an overarching responsibility for setting national eligibility or for setting an overall direction for how individual local authorities deliver their legal obligations. In the last 12 months we have had reports and recommendations from the Law Commission on how we reform social care law, to make it both clearer and more orientated around outcomes […] and […] recommendations from the Commission on Funding of Care and Support, which has recommended that we examine greater consistency around eligibility [a slightly different point which will be discussed below]”.

He said that the Government were in a dialogue with the sector about how reform could be taken forward and a White Paper would be published in April.

138. We are concerned that the restriction of Fair Access to Care Services eligibility criteria to critical-only risks giving rise to individual breaches of Article 19(a) of the Disabilities Convention and to retrogression in the realisation of the rights in Article 19(b). We recommend that the Disability Strategy includes measures to monitor the impact of restrictions on eligibility for adult social care on disabled people’s right to independent living.

**Disability Living Allowance**

139. The Welfare Reform Bill seeks to replace the Disability Living Allowance with a Personal Independence Payment (PIP). The Government argue that the change is compliant with UNCRPD as PIP is intended to target resources at those who need it most. They believe the changes are justifiable, as they support those most affected by disability and introduce a fairer, more consistent and evidence-based assessment system.
140. The reforms are designed explicitly to achieve a 20% saving, and recent Government figures suggest that 500,000 fewer people would receive PIP in comparison with DLA. Much of the written evidence we received expressed concern that the reform was driven by the aim of reducing expenditure. For instance, the Social Care Institute for Excellence told us that “the aim of targeting (DLA/PIP) is, by definition, to reduce the number of disabled people receiving help towards disability-related expenditure”. 

141. We also received evidence concerning the proposals for assessing eligibility for PIP. Disability Alliance argued that there was a risk the new assessment for the Personal Independence Payment would generate “a perverse incentive for disabled people not to use aids and adaptation. This would impact on the ability to live independently”. Guide Dogs for the Blind Association said that the proposals “would penalise those who used mobility aids, as it meant they were more able to get around and consequently would need less benefit”. Breakthrough UK agreed, arguing that, when assessing mobility, it was important to “take into consideration the wider context of how their mobility equipment interacts with their environment, [and] of how these items are acquired and paid for”. The Government’s most recent assessment of PIP addresses some, but not all, of these issues.

142. We also heard concerns about whether the proposed new assessment would be entirely based on measuring impairment. Scope said that the proposed changes to DLA put an emphasis on impairment rather than extra cost. They argued that there was “very little relationship between the severity of your impairment and the additional costs you face” and that the payments would therefore be wrongly targeted. They referred to:

  “people with Asperger’s syndrome and who have learning difficulties who face substantial barriers in travelling independently, making decisions by themselves and going about their community and accessing leisure activities. These people incur many, many additional costs because of the way that society is structured. Therefore, just because they have a less severe impairment, that does not mean they should be cut out of the system.”

143. The Government initially proposed to remove the mobility component of DLA/PIP for people living in residential care in order to remove overlaps in provision. These issues were recently examined by the Low Review, which “found no evidence of overlap in the support offered by the mobility component of DLA and that offered by local authorities and providers” (Low Review, executive summary). The Government have now announced

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140 IL 42

141 Q 8

142 IL 86.

143 IL 58

144 DWP, Personal Independence Payment: assessment thresholds and consultation, January 2012

145 Q 101

146 Q 105

147 The Low Review was an independent review of mobility in state-funded residential care, commissioned by Mencap and Leonard Cheshire Disability, and chaired by Lord Low of Dalston. It reported in October 2011: Independence, Choice and Control—DLA and personal mobility in state-funded residential care.
that people living in residential care will continue to be eligible for the mobility component of PIP.

144. The Low Review has shown the benefit of working together with disabled people’s organisations to ensure that welfare reform fulfils the Government’s stated aim of promoting opportunities for disabled people’s participation in, and contribution to, society. Inclusion London, together with many other organisations and individuals, told us that “involvement of disabled people in policy development [...] is crucial for disabled people’s independence, choice and control.” The considerable concern that has been expressed about the aims and detail of the replacement of DLA with PIP illustrates the need to involve disabled people’s organisations in the development and implementation of the new benefit. Such involvement is required by Article 4(3) of the Convention.

145. We welcome the Government’s recent decision that disabled people in residential settings should continue to be eligible for DLA/PIP mobility component. However, we recommend that, in order for PIP to play its part in promoting independent living, the new assessment system and eligibility criteria:

a) must not create a disincentive to using aids and adaptations;

b) continue to be based on the fundamental principle that it is a benefit based on the additional costs of impairment, and not based on medical diagnosis; and

c) should be independently reviewed with the involvement of disabled people’s organisations before being rolled out nationally.

146. Significantly fewer people will receive PIP in comparison with those currently receiving DLA. DLA was conceived as a means to enable disabled people to meet the extra costs associated with overcoming barriers to independent living. We fear the introduction of PIP will restrict the ability of disabled people to overcome these barriers and enjoy the right to independent living

Independent Living Fund

147. The Independent Living Fund is an Executive Non-Departmental Public Body of the Department for Work and Pensions, which provides discretionary cash payments directly to disabled people so they can purchase care from an agency or pay the wages of a privately employed Personal Assistant. This enables disabled people to choose to live in their communities rather than in residential care. The ILF is now closed to new applicants, but funding for existing users is protected for the life of this Parliament. The Government committed to carrying out a consultation on a replacement for the fund after they had received the report of the Dilnot Commission (which reported in July 2011). In December 2011, the Minister for Disabled People announced that that consultation would take place in the spring of 2012.
148. Many witnesses were concerned about the closure of the Fund. The UK Disabled People’s Council argued that the Government’s decision to close the Independent Living Fund in the future would have “brutal consequences” for many disabled people who might rely on ILF grants to top up their direct payment support.\footnote{151} The National Centre for Independent Living argued that it was too early to assess the full impact of closing the fund. However, while the fund was closed on the assumption that requirements for independent living would be “delivered equitably as part of local authorities’ broader independent living strategies”,\footnote{152} bodies such as the Association of Directors of Adult Social Services were saying that they “simply have not got the money to make up the shortfall”.\footnote{153}

149. Independent Living Alternatives said that “what scares people the most is that that money [from the ILF] is going to end up going into the social services pot and just being lost”.\footnote{154} However, the Independent Living Association reported a mixed response on the issue. Some people raised concerns about funding disappearing into the social services pot, but others suggested that while the ILF was a discrete pot of money it “came with all this baggage of separate reassessments and sometimes not very flexible rules around [its] use”.\footnote{155} The Local Government Association argued that, in general, ring fencing was a barrier to the greater integration of services.\footnote{156}

150. The Association of Directors of Adult Social Services confirmed that the closure of the Fund was having “an adverse impact”. In evidence to us they said that “we are already experiencing people coming to us in adult social care who previously would clearly have gone to the Independent Living Fund” and that “with the majority of authorities having eligibility criteria of substantial or critical, there is little doubt that there will be many people who cannot now be assisted in the way that the Independent Living Fund was able to assist people”.\footnote{157}

151. The Minister for Disabled People told us that “ILF [...] was never designed to replace mainstream care and support. It was clear that it was increasingly becoming a postcode lottery for people who were in receipt of it” and that “we are absolutely clear that people who are currently in receipt of payments under the ILF will continue to receive absolutely the level of support that they would expect on an ongoing basis until 2015. Obviously, beyond the next spending review none of us sitting here can give any further commentary”.\footnote{158}

152. \textbf{We are extremely concerned that the closure of the Independent Living Fund to new applicants, with no ring-fenced alternative source of funding, may severely limit the ability of disabled people to participate in society. We would expect the Government to address this issue in their consultation paper on replacement funding}
to be published in early 2012 and to ensure that this change in policy does not result in individual breaches of the rights in Article 19(a) and retrogression as far as Article 19(b) is concerned.

**Housing benefit**

153. Reforms to housing benefit, such as the proposed cap contained in the Welfare Reform Bill, have caused particular concern for disabled people. Disabled people often live in adapted housing, and rely on local formal and informal support mechanisms, and would therefore likely to be more affected than the general population by any need to move house. Organisations such as the Mental Health Foundation, the RNIB, Leicestershire Centre for Integrated Living all submitted evidence that housing benefit was an important part of the range of support needed by many disabled people and their families. The College of Occupational Therapists argued that “Inappropriate housing is a major barrier to personal independence in the home. It also bars disabled people from ‘full inclusion and participation in the community,’ and from developing and using their skills and potential to the fullest degree.”

154. The College of Occupational Therapists criticised the proposed housing benefit cap, and penalties for those deemed to be under-occupying their property, on the grounds that compelling people to move might reduce access to their support networks. Inclusion London told us that the cap on housing benefit “will disproportionally impact on disabled people because a higher proportion of disabled people live in social housing and are four times more likely to claim Housing Benefit than non-disabled people”. Disabled People Against Cuts argued that forthcoming reductions in the amount of Local Housing Allowance that can be claimed in the private rented sector would severely limit opportunities for those disabled people whose support or equipment needs meant they required a larger property.

155. We also received evidence from the National Development Team for inclusion (NDTi) suggesting that reductions in funding for interest-only mortgages through income support had affected disabled people’s housing opportunities; and we heard from one family of how these changes were restricting their daughter’s access to housing. These changes are also said to be impacting on the Government’s own scheme, Home Ownership for People with Long Term Disabilities (HOLD).

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159 IL 41, IL 25, IL 24
160 IL 78
161 This proposal was defeated in Committee stage of the Welfare Reform Bill in the House of Lords on 14 December 2011, on an amendment proposed by Lord Best. Lord Best’s amendment was rejected, along with other Lords amendments to the Bill, by the House of Commons on 1 February. At the time of writing, the final outcome is unclear.
162 Q118
163 IL 43
164 IL 45
165 IL 47
166 IL 66
167 Mental Health Foundation IL 41, Sue Kirkman, IL 8
156. The Minister for Disabled People told us, with regard to problems of people losing support networks when forced to move, that “our impact assessment looked at the sorts of issues you are talking about, and we recognise what you are talking about. That is one of the many reasons why the Discretionary Housing Payment budget has been increased so significantly [trebled to £190m].”

157. The Minister for Housing told us that the impact of the Housing Benefit cap on disabled people had been taken into account in the Government’s impact assessment, but expressed his view that he did not believe that “anybody in this country has the right to live in any street they want to live in at the cost of the taxpayer.” He pointed out that up to a third of properties within a Local Housing Allowance area would still be available for any individual. The Minister also pointed to the increase in Discretionary Housing Payment, arguing that it would enable local authorities to assist people in not having to move, and that this would very likely be used to support disabled people. With regard to disabled people being forced to move from homes which had been specially adapted for their needs as a result of changes to funding the Minister told us that he did “not want [adaptations to housing] to be made and then for people to be forced to move from homes where those adaptations have been made a great cost, and there is disruption to people’s lives and cost to the taxpayer”. The Government, in their written evidence to us, stressed that those in receipt of DLA or Attendance Allowance would be exempt from the housing benefit cap.

158. In spite of reassurances from the Government that disabled people will be protected from the full impact of the changes to Housing Benefit, the evidence we received demonstrates a large degree of concern among disabled people about the impact of the reform on their ability to enjoy adequate housing provision taking account of their particular needs.

159. We welcome the Government’s statements that they do not wish to see people forced to move from houses which have undergone adaptation, but the interaction between where a person lives and other elements of the right to independent living go further than the issue of adaptations alone.

160. We welcome the increase in the Discretionary Housing Fund, but are concerned that its discretionary nature means it will not provide an adequate guarantee that the right of disabled people to exercise choice and control over where they live will be consistently upheld in the light of reductions in Housing Benefit.

161. The range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing DLA and local authority support, while not getting support from the Independent Living Fund, all of which may force them to return to residential care. As a result, there seems

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168 Q 265. On 14 December 2011 the Government announced a further £30 million increase to this fund: “I am pleased to announce today an additional £30 million that we will add to the discretionary housing payment budget from 2013–14”, Lord Freud, proceedings on the Welfare Reform Bill, HL Deb 14 Dec 2011 Col 1302.

169 Q 257

170 Q 258

171 IL 80
to be a significant risk of retrogression of independent living and a breach of the UK’s Article 19 obligations.

162. We recommend that the Office for Disability Issues, working with the devolved administrations and local authorities, monitor the impact of reform and spending decisions on the right to independent living and undertake to promote innovative ways through which to mitigate their impact. This should include reporting on to what extent reforms to the ILF, DLA and housing benefit are enabling the Government and local authorities to deliver their Article 19 obligations.

**Adult social care**

163. Adult social care is a particularly important policy area in terms of independent living, as it is a key delivery mechanism for support that many disabled people need to go about their daily lives. In addition to concerns about cuts in local authority expenditure a number of issues relating to adult social care were raised in evidence which are relevant to the implementation of Article 19. These include the personalisation of social care to deliver more choice and control; the “portability” of care packages; choice and control in the context of residential care settings; the role of regulation and inspection; and commissioning.

**Personalisation of adult social care**

164. Measures which transfer power to disabled people to exert choice and control over their living arrangements and which provide people with the means to fashion the care and support around their own aspirations are central to the implementation of Article 19. Earlier developments in this area included the establishment of the Independent Living Fund in 1988, the Community Care (Direct Payments) Act 1996 and the piloting of individual budgets in 2007–09. Adult social care is one of the funding streams included in the Right to Control Trailblazers established under the Welfare Reform Act 2009. Current policy in England is to roll out personal budgets to everyone eligible by 2013, with the emphasis on direct payments as the primary form of budget. In addition, the Health Act 2009 introduced personal budgets for non-acute health care in pilot areas.

165. We received evidence which suggested that while some local authorities viewed further personalisation as a way to mitigate the effects of cuts through innovation and greater integration of budgets and services, others were potentially undermining choice and control by imposing restrictions on how personal budgets could be spent as a means of targeting expenditure. For instance, Disabled People Against Cuts told us that in many cases personalisation had not meant an improvement in choice and control over their lives for disabled people but instead a rationalisation of services and a reduction in care funding allocated\(^\text{172}\). A recent report by Demos, funded by Scope, suggested that a growing minority of local authorities were allocating a cash amount in personal budgets lower than the equivalent value of the care previously provided, and stated that there was “a risk the personalisation agenda will be subsumed by the need to reduce costs”\(^\text{173}\).

\(^{172}\) IL 45

\(^{173}\) Coping with the Cuts, Demos 2011, p. 116.
166. The National Association of Adult Placement Services told us that some councils had “tried to impose unnecessary and damaging rules to restrict people’s use of personal budgets or Direct Payments, or have told people they can only have a Direct Payment if their allocation is at least a minimum amount.”

167. While personalisation has the potential to increase choice and control, and may lead to innovative methods of delivering services more efficiently, there is the potential that it might be seen a means to delivering services more cheaply, but not necessarily as effectively as before.

168. National and local government should monitor and actively promote the innovative practices of local authorities which employ personalisation effectively to mitigate the impact of spending cuts. The Government should monitor the extent to which choice and control is being diminished or increased by the roll out of personal budgets, and take action if the goal of increasing choice and control is not being realised.

169. We welcome the Government’s pilot scheme to extend personal budgets to primary healthcare. They should also monitor this scheme with regard to the increase or reduction of choice and control, and take action if there is no increase.

**Portability of care**

170. The Scottish Human Rights Commission was among a number of witnesses concerned about a lack of “portability of care”. These concerns included “variations in eligibility criteria between local authorities, requirements for different assessments in different areas meaning a lack of assurance on similar level of provision and variation in charging for community care meaning that it may be financially unviable for disabled people to move”. They thought that this resulted “in barriers to disabled people accessing work and higher education in other local authorities, as well as generally exercising their right to freedom of movement and choice of residence within the country”.

171. These concerns were endorsed by a number of witnesses. For example, John Evans and Diane Mulligan both told us that a lack of portability was a barrier to accessing Article 19 rights. Inclusion London argued that a lack of portability, coupled with changes to housing benefit, would be a “double whammy” whereby people were forced to move to cheaper areas where their care package might not be preserved.

172. The Personal Care at Home Act 2010, which receive Royal Assent under the previous Government, would have allowed for the full portability of care packages, including both assessment and the receiving authority’s accepting the individual’s existing care package for the first six months until it could be suitably modified to the now socio-geographical environment. The present Government have decided not to commence the Act.
173. The Dilnot Commission, established in July 2010 to examine the funding of care and support, recommended the Government introduce national eligibility criteria and portable assessments in order to ensure consistency. The Government told us that these proposals would feed into the White Paper on funding of adult social care, which is due to be published in April 2012.179

174. However, although this has been welcomed, some organisations suggested it did not go far enough. The RNID said:

“The Government has committed to greater portability of social care assessment, something that we welcome. However, we would like this to go a step further and give assurances that people will be able to move between local authority areas and into more independent living arrangements without changes to their entitlement to care and support”.180

175. **We welcome the Government’s intention to consider introducing portable assessments. However, we are concerned that this may be insufficient to ensure the enjoyment of rights under Article 19, in particular the right to choose one’s place of residence and where and with whom one lives on an equal basis with others. We urge the Government to consider whether further action is required.**

**Residential care**

176. There is sometimes a misconception that the term “independent living” refers only to people living in their own homes and that it does not apply to those living in residential care. However, as stated at the beginning of our Report, independent living means “all disabled people having the same choice, control and freedom as any other citizen”. The detail of independent living, as set out in Article 19, also applies to people in residential settings, namely:

- the opportunity to choose where and with whom you live;
- access to support, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- access, on an equal basis with others, to community services and facilities for the general population.

177. As Sense noted, it is the nature of support which a person receives which determines whether someone is able to access their Article 19 rights: “A person could be living in their own home but if they are receiving little or no support then they will have no choice, control, or freedom. Similarly a person living in a residential setting could have a package of care which enables them to live the life that they choose and to be included in their local community”.181
178. We heard evidence from Mr Doug Paulley, who lives in a residential home. He told us that: “Having choice and control over such things as who supports you and when and how; the ability to get out and about; the ability to access employment and education— these are all very limited, as is some involvement in both the policy setting and your everyday experience, your everyday care provision”.  

179. Recent reports, such as that concerning Winterbourne View care home, indicate that sometimes significant levels of abuse of people’s human rights is taking place in some care homes. The Care Quality Commission told us that when they carried out inspections of a sample of 10% of private home care providers, 12% were “non-compliant” on the outcome of “respecting and involving people” and “28% of them were non-compliant on the outcome on care and welfare”, and thereby proper planning”.  

When asked whether the Government should do more to promote awareness of human rights amongst providers, Louise Guss from the CQC replied: “There can never be enough promotion, in my view, of the human rights of people who use social care and health services.”

180. People First on the Isle of Wight raised particular concerns about a lack of funding for advocacy for people in residential care. Sense provided an example of someone living in a residential home who was not provided with a communicator and who thus had no choice or control in their daily life.

181. The Government should include in its Disability Strategy Action Plan a commitment to enable disabled people living in residential settings to access their full Article 19 rights. It should also set out actions to achieve this commitment, and establish detailed outcomes against which progress can be measured and monitored. The Government should also ensure that residential care home providers are aware of the UNCRPD and of their role in assisting in its implementation.

182. Shaping Our Lives told us of young people, living in residential care, who “want to be in employment and want to have a life that is like the life of their peers who are non-disabled”. They suggested that employment should be considered a right in its own regard. Doug Paulley described the way means-testing affected his freedom to benefit from paid employment. While earned income is not taken into account in means-testing of domiciliary services or direct payments for people living in their own homes, people who are in care homes may only keep a “personal allowance” of £22.60 per week (£23.00 in Wales) of any earned income before the rest is taken to pay for their placement.

183. The Minister for Care Services responded to these concerns by telling us that, if a disabled person could engage in paid employment, then “being in a residential care setting is probably an entirely inappropriate setting for them to be in in the first place”. He told...
us that the issue of personal allowances would be considered in the forthcoming White Paper on adult social care, particularly in the context of whether direct payments and personal budgets should be available to people in residential care. The Minister for Disabled People pointed out that someone in residential care could receive support from Access to Work and also the Work Programme and Work Choice.

184. There appears to be an anomaly in the charging policy for residential care which creates a significant work disincentive, thus impeding access to independent living. The Government also appear not to recognise the extent to which people living in residential care are able to engage in paid work. We urge the Government to take action to remove this disincentive as soon as possible.

The role of inspection and regulation

185. Service providers, whether of residential, domiciliary or community services, have a key role to play in enabling disabled people to have autonomy and access similar opportunities to non-disabled people. The Minister for Care Services told us that requirements under Regulation 17 of the Health and Social Care Act 2008 required providers to “make suitable arrangements to ensure the dignity, privacy, and independence of service users”, and to ensure “that service users are enabled to make, or participate in making, decisions relating to their care or treatment.” He said the Government “would expect the CQC, as part of its ongoing work around inspection, to be making sure that they are satisfied that those standards are being met”.190

186. However, we received evidence from the Mental Health Foundation of a lack of awareness amongst service providers of how, for example, people living with dementia could and should have more choice and control over the support they need.191 The Equality and Human Rights Commission’s recent inquiry into home care services for older people found evidence of a breach of older people’s human rights as a result of poor care practices and a failure to involve people in decisions about the services they received.192

187. The Care Quality Commission told us that for them “it is much harder ... to regulate non-institutional care and home-based models of care” than residential or institutional settings.193 The fact that it took a television programme to expose human rights abuses at Winterbourne View indicates that the inspection regime for institutional settings is not working as well as it should.

188. The Government should, in partnership with disabled people’s organisations, monitor the extent to which regulation and inspection frameworks are promoting independent living in both domiciliary and institutional settings. The Disability Strategy should include the role of regulation and inspection in promoting Convention rights.

190 Q 270
191 IL 41
192 EHRC 2011, Close to home: An inquiry into older people and human rights in home care
193 Q 225
**Commissioning**

189. The Equality and Human Rights Commission’s inquiry into home care services for older people found that commissioning practices too often focussed on a rigid list of tasks, rather than what older people actually wanted, and that ensuring an acceptable quality of care was not given a high enough priority.

190. The Government told us that the Health and Social Care Bill “will place local authorities and GP Consortia under a new duty to agree a Joint Health and Wellbeing Strategy and to agree commissioning strategy based on an assessment of local need” which would amount to “a strengthening of duties and requirements on local organisations to work together, not just on the needs assessment, but also in turning that assessment into a shared commissioning strategy that should underpin their own plans.”  

191. However, the role of Care Quality Commission (CQC) is more limited than its predecessors in terms of regulating commissioning. CQC told us that:

> “the biggest issue is that we no longer comment on the quality of commissioning. We do not comment on the relative weight that commissioners give to home-based care or on their support for independent living. We merely […] focus entirely on the providers themselves and not on how services are commissioned.”

They added that the Health and Social Care Bill currently making its way through Parliament would specifically remove their ability to comment on NHS commissioning.

192. Human rights have been explicitly written in to commissioning strategy in Scotland, a development which was commended by the Scottish Human Rights Commission. The guidance, which was jointly published by the Scottish Government and COSLA, "aims to assist public bodies to make decisions that comply with all applicable polices, European Union and domestic law and human rights obligations".

193. The NHS Commissioning Board should produce guidance for Health and Wellbeing Boards on the need to incorporate human rights into their commissioning strategies, emulating the guidance of the Scottish Government.

194. The Health and Social Care Act 2008 included a provision which ensured private and third sector care homes were defined as carrying out a public function when providing publicly-arranged care, bringing them within the scope of the Human Rights Act 1998. The current Health and Social Care Bill should be similarly amended to extend this definition to provision of care at home.

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194 IL 80
195 Q 223
196 Q 227
197 IL 81
Access to information and advocacy

195. A number of witnesses highlighted challenges faced by people who needed access to advice, information and advocacy if they were to take full advantage of personal budgets and direct payments (for example older people with high support needs and people with learning disabilities.) This is relevant not only to Article 19, but also to Article 12 which requires States Parties to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". Breakthrough UK told us of one person who, on initial assessment for Employment Support Allowance, was deemed ineligible, and was subsequently deemed eligible when she had received professional assistance. They argued that it was difficult for disabled people to access their entitlements without such support. They argued that "advocacy, advice and information, provided by other disabled people […] is a cornerstone, without which independent living cannot become a reality".199

196. Evidence was submitted to us about the importance of independent sources of information, advice and support to use personal budgets,200 and members of our Committee also heard this message on an informal visit to Essex Centre for Independent Living.

197. We received evidence that funding for advocacy was under threat. People First (Isle of Wight) reported that “the local authority has withdrawn funding for advocacy, saying that people need to pay for this from their personal budgets, but the reality is they do not have enough money in personal budgets to be able to pay for advocacy”. They added that a lack of advocacy was of particular concern in care homes, but that it was also necessary to guarantee quality of service provided via personal budgets.201

198. The Government acknowledged that “Local disability organisations can play an important role in providing the assistance that disabled people may need to exercise choice and control over their lives, ensuring that sufficient information, advice and advocacy is available”.202 Sections 1 and 2 of the Disabled Persons Act 1986 established the right to advocacy for disabled people. However, the relevant measures have never been implemented by successive governments.

199. Access to information, advice and advocacy is critical for all disabled people to benefit from personalisation. The Government should:

- monitor access to information, advice, and advocacy services in the context of the roll-out of personal budgets;

- continue to support and develop the role of Disabled People’s User-Led Organisations to enable them to provide independent information, advice, and advocacy services; and
• implement the advocacy provisions in sections 1 and 2 of the Disabled Persons Act 1986 when reforming community care legislation.

Access to housing and to community facilities on an equal basis with others

200. In addition to concerns about changes to housing benefit raised earlier in this Report, and about access to adequate housing being key to independent living, we also received evidence suggesting that there was a lack of suitable housing available. The Spinal Injuries Association told us that this lack was contributing to newly injured people “increasingly being discharged straight from hospital into a Care or Nursing home.”203 The College of Occupational Therapists argued that “inappropriate housing is a major barrier to personal independence in the home. It also bars disabled people from ‘full inclusion and participation in the community’.”204

201. The Minister for Housing said that he had invited the Home Adaptations Consortium to publish a good practice guide with the intention of speeding up housing adaptations.205 However, we also received evidence that there has been a significant reduction in the number of housing adaptations funded since 2008.206

202. Access to housing directly relates to access to other facilities in the community, and we received evidence suggesting that access to transport in particular was a problem. Breakthrough UK submitted evidence that disabled people feel that access to housing, transport and community facilities were an important part of independent living and participation in family and community life: “If there are transport barriers, for example, then people will not be able to make effective use of their support at home or work.”207 Guide Dogs for the Blind Association stressed the importance of accessible public transport, but suggested that cuts to concessionary fares and local public transport services were leaving some disabled people “isolated and unable to travel as and when they need.”208 People First also submitted evidence of reductions in public transport which have “had a serious impact on many individuals and their ability to move about in the community”.209

203. The Government told us that over one in five disabled people had difficulty using transport and that “disabled adults are less likely to use all modes of transport compared with non-disabled adults. This was particularly marked for local trains, the underground, long distance trains and motor vehicles”.210

204. The Disability Strategy should set out how the Government intend to take action on, and measure progress on, disabled people’s access to housing, transport, public space and public services within the context of the right to independent living.

203 IL 87
204 IL 78. The quotation refers to the preamble to Article 19.
205 Q 256
206 AKW Medicare Ltd, IL 60
207 IL 58
208 IL 86
209 IL 67
210 IL 80
Hate crime and abuse

205. Public attitudes towards disabled people, and whether they feel safe in their own homes and in the community, are an important aspect of independent living. The Government told us that “Disabled people are more likely to be victims of crime than non-disabled people at all age groups apart from those aged over 65”. An inquiry carried out by the Equality and Human Rights Commission found that harassment of disabled people was ‘a serious problem’ which, in some cases, has resulted in serious injury, suicide or murder. On 6 February 2012 six of the main disabled charities reported that they are now regularly contacted by disabled people who say that they have been taunted on the street about supposedly faking their disability and expressed their concern that this climate of suspicion could spill over into hate crimes or even violence. The charities say that one of the contributors to this climate of suspicion is the repeated allegations by ministers and civil servants that there is widespread abuse of the disability benefits system.

206. People First recommended that “Each police force should have a disability hate crime strategy that brings in the expertise of disabled people to develop it and support officers to implement it” and that there should be funding for independent reporting centres to support people to report hate crime and to make sure action is taken. The Essex Coalition of Disabled People echoed this in their lived experience report on disability hate crime in Essex. They argued that user-led organisations, such as their own, should work in partnership with the police and Crown Prosecution Service in order to promote understanding of hate crime; develop signposting and support to direct victims to sources of help; educate people; and increase reporting.

207. The Coalition’s Programme for Government included a commitment to improve the recording of hate crime offences against disabled people, which are frequently not centrally recorded. The Government told us that “from April 2011 police forces are collecting and reporting to the Home Office the number of offences that are motivated by hostility towards disabled people”. The Government also told us that they were working to empower disabled people and their organisations to increase reporting of disability hate crime; developing a national, independent disability hate crime reporting centre; providing guidance on minimum standards for such reporting centres; empowering disabled people and their organisations to set up their own reporting centre; and raising disabled people’s awareness of disability hate crime and incidents and how to report them.

208. The occurrence of hate crime against disabled people, and the fear of such crime, is a growing threat to disabled people’s ability to live independently. We welcome the Government’s commitment to reducing hate crime, and in particular the requirement that police forces collect and report data on such offences.

211 EHRC, 2011, *Hidden in Plain Sight: Inquiry into Disability-related Harassment*
212 Scope, Mencap, Leonard Cheshire Disability, the National Autistic Society, Royal National Institute for the Blind and Disability Alliance.
215 Coalition: our programme for government, p.14
216 IL 80
217 IL 80
209. We remind the Government of its obligations under Article 8 of the Disabilities Convention to foster respect for the rights and dignity of persons with disabilities and to combat stereotypes and prejudices relating to such people. The Government should take care to ensure that the justifications it offers for its reforms to the system of disability benefits does not undermine its other work to promote positive perceptions and greater social awareness towards persons with disabilities.

Access to redress and justice

210. Breakthrough UK referred to the importance of “basic legal redress if human rights are denied”\(^{218}\) and Independent Living in Scotland told us that “Enforcement of human rights is also crucial to their implementation yet this continues to be an issue”\(^{219}\). They referred to a survey by Leonard Cheshire which found that “rights in legislation are simply not translating into reality for many disabled people”\(^{220}\).

211. Ill and disabled people make up a 58% of those affected by removing welfare benefits from legal aid.\(^{221}\) Inclusion London argued that the changes to the legal aid system would mean that disabled people would have no support to challenge decisions relating to welfare benefits, housing or employment.\(^{222}\) In 2009–10 people appealing against Employment and Support Allowance decisions were twice as likely to succeed if they had representation.\(^{223}\) Overall, ill and disabled people make up at least 20% of those affected by the planned reduction in legal aid services.\(^{224}\)

212. The Scottish Human Rights Commission submitted evidence of “an inability of disabled people to access justice due to, among other factors, difficulties in accessing appropriate legal representation, and problems accessing legal aid.”\(^{225}\) Disabled People Against the Cuts also expressed concerns that disabled people will find it harder to challenge any abuse of their human rights and argued that there should be monitoring of their access to redress.\(^{226}\)

213. We briefly discussed this issue in our recent legislative scrutiny Report on the Legal Aid, Sentencing and Punishment of Offenders Bill,\(^{227}\) although we did not consider it in great detail. In that Report we noted that the impact assessments of the Bill had reportedly not adequately taken into account the likely effect of its various provisions on disabled people.

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\(^{218}\) IL 58  
\(^{219}\) IL 30  
\(^{222}\) IL 43  
\(^{223}\) Retaining legal aid for welfare benefits appeals: A briefing for Report Stage of the Legal Aid, Sentencing and Punishment of Offenders Bill, Justice for All 2011  
\(^{225}\) IL 31  
\(^{226}\) IL 45  
214. The Government should monitor the extent to which access to redress and justice for disabled people is affected by the provisions of the Legal Aid, Sentencing and Punishment of Offenders Bill, and the effect this has on their right to independent living. The Disability Strategy should include action to be taken to ensure disabled people's access to redress and justice.
Conclusions and recommendations

Independent Living as a human right

The legal status of the relevant standards in the disabilities

1. We are concerned that characterising the obligations assumed by the Government under the Disabilities Convention as “soft law” is indicative of an approach to the treaty which regards the rights it protects as being of less normative force than those contained in other human rights instruments. The UNCRPD is hard law, not soft law. The Government should fulfil their obligations under the Convention on that basis, and must counter the public perception that it is soft law. (Paragraph 23)

Progress so far

Political consensus

2. We welcome the Government’s continued commitment to removing barriers and creating opportunities for disabled people, and consider this to be entirely consistent with their obligations under Article 19 UNCRPD. The UK has an established position as a world-leader on disability rights and in relation to independent living in particular. We strongly encourage the Government to make every effort to maintain and build upon this status. (Paragraph 47)

The current situation

3. We note the significant disadvantage to disabled people which persists in relation to choice and control and levels of participation in economic and social life and the impact this has on their economic and social well-being, and on what many of our witnesses considered to be their enjoyment of basic human rights. We therefore welcome the Government’s recognition that more progress is required to promote disabled people’s right to independent living. (Paragraph 50)

4. The Government should continue their commitment to delivering independent living by ensuring that the forthcoming Disability Strategy sets out a clear plan of action to make progress with regard to independent living as defined by Article 19, with milestones and monitoring mechanisms. The Disability Strategy should build on and update the outcomes framework set out in the current Independent Living Strategy. (Paragraph 51)

Legislative underpinning of the right to independent living

5. The Right to Control is a welcome step towards establishing independent living as a right. If the evaluation of the “Right to Control Trailblazers” is positive, the Government should make regulations to roll out the scheme nationwide in both social care and primary health care. (Paragraph 63)
6. We note that while the UK has made progress in developing a rights-based approach to the design and delivery of public service support to disabled people, disabled people in the UK do not enjoy a right to independent living in domestic law. (Paragraph 64)

7. We regret that the Convention has not been incorporated into UK law and no underpinning legislation exists specifically to protect and promote the right to independent living. While we consider the existing matrix of human rights, equality and community care law to be instrumental in the protection and promotion of the right to independent living, we do not consider it sufficient. The right to independent living (as defined by Article 19) should be added as an outcome in any forthcoming Bill on adult social care in England. (Paragraph 65)

8. We remain concerned, however, that merely filling in the gaps in the current legislative framework will still not accord the right to independent living the legal status that its fundamental importance deserves. We hope that the Commission on a Bill of Rights will consider the arguments for and against expressly recognising the right of disabled people to independent living in any Bill of Rights for the UK. In the meantime, we recommend that all interested parties, governmental and non-governmental, immediately start work on assessing the need for and feasibility of free-standing legislation to give more concrete effect in UK law to the right to independent living. (Paragraph 67)

9. We recommend that the Government publish their assessment of the need for and desirability of such free standing legislation implementing the right to independent living in the light of the forthcoming first report of the UN Committee on Disabilities following its scrutiny of the UK’s first compliance report. (Paragraph 69)

The Government’s approach to implementing the UNCRPD

Protecting and promoting the right to independent living

10. The nature of independent living strongly suggests the need for coordinated strategy and action at the national and local level, both cross-departmentally, between the different levels of government, and with non-governmental actors, and for careful consideration of both the independent and cumulative impacts of policy and legislative reform and public spending decisions. (Paragraph 74)

11. We recommend that the Government consider provision of the means to independent living in the round. The complex interconnections between services and benefits mean that changes to one service or benefit may have unintended consequences for another—and for the overall level of outcomes achieved. For instance, changes to housing provision may have significant impacts on the accessibility of healthcare, transport, support networks and other rights and opportunities. (Paragraph 75)
Independent Living Strategy: its effectiveness, and plans for the future

12. We welcome the commitment made by the Minister for Disabled People that the UNCRPD will provide the basis of the forthcoming Disability Strategy. We expect the Disability Strategy to be robust, targeted and deliverable, and co-produced with disabled people. It should cover all aspects of the Convention, including the right to independent living, and be specific in terms of how it delivers the Convention articles in order to aid measurement and transparency. The implementation process should include clear milestones, monitored by an independent body. (Paragraph 82)

Coordinating implementation of the Convention across government departments and the devolved administrations

13. While we acknowledge that the Government should not seek to direct the devolved authorities or local authorities in the exercise of their powers, the UK Government should acknowledge their responsibilities under the Convention to ensure its implementation across the whole of the UK. Ultimately, the repercussions of any breach of the Convention will rest with the UK Government. (Paragraph 88)

14. We recommend that the Office for Disability Issues updates and expands upon its response to Human rights of persons with disabilities: national frameworks for the promotion and protection of the rights of persons with disabilities, explaining its approach to coordinating implementation of the Convention across Whitehall, the devolved administrations, public authorities and other sectors. This could usefully be done in the context of the forthcoming Disability Strategy. (Paragraph 89)

Implementation of the right to independent living by the devolved administrations

15. We commend the Scottish Government and the Welsh Government for their respective plans to promote independent living. We note with disappointment the lack so far of an equivalent strategy in Northern Ireland. It is regrettable that the Northern Ireland Executive has not yet responded to the proposals of the PSI Working Group made in 2009. (Paragraph 93)

16. The Northern Ireland Equality Act should be amended to address the effects of the House of Lords judgment in Malcolm v Lewisham, ensuring parity of protection between disabled people in Northern Ireland and Britain. (Paragraph 94)

Ensuring that public authorities comply with the Convention

17. We are unclear how the Government are meeting their obligation to ensure compliance with the Convention by public authorities, especially in the light of localism and changes to specific duties in England under the Equality Act 2010. (Paragraph 100)

18. The Government, led by the ODI, should work with others including the devolved administrations, the independent mechanisms, regulators and disabled people's organisations to promote awareness and understanding of the Convention among
Implementation of the Right of Disabled People to Independent Living

public authorities, especially local government, and to monitor its implementation. (Paragraph 101)

**Impact assessments**

19. We are concerned that the UNCRPD, and Article 19 in particular, does not appear to have played a central role in the development of policy. Inadequate attention has been paid to the impact of relevant policy on the implementation of the UNCRPD, in contravention of Article 4(1) and 4(3). We recommend that the Government make a clear and unequivocal commitment to Parliament, equivalent to that which it has already given in relation to the UN Convention on the Rights of the Child, that they will give due consideration to the articles in the UN Disabilities Convention when making new policy and legislation, and in doing so will always consider relevant recommendations of the UN treaty monitoring bodies. (Paragraph 110)

20. However, if properly carried out, equality impact assessments provide an important mechanism through which to ensure policy achieves desired goals and avoids unintended consequences, and help to demonstrate transparency and accountability. We recommend that they should be produced early in the policy-making process with the full involvement of those likely to be affected by the policy. (Paragraph 111)

21. Given the breadth of the current reforms, the Government should publish a unified assessment of the likely cumulative impact of the proposals on independent living, and set out any relevant mitigations through the Disability Strategy. The relevant strategies in the devolved administrations should also include such mitigation plans. (Paragraph 112)

22. We regret the exclusion from the English specific duties under the new Public Sector Equality Duty of the requirement to conduct equality impact assessments. The Government should either revise the duties accordingly, or promote equality impact assessments as a matter of good practice, with the assistance of other expert bodies such as the Equality and Human Rights Commission, Scottish Human Rights Commission, Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission. (Paragraph 113)

23. We welcome the willingness of the Secretary of State for Justice to consider the impact assessment methodology being developed by the Scottish Human Rights Commission and we look forward to the outcome of that consideration. (Paragraph 113)

24. Our evidence suggests that equality impact assessments have not played an important part in assessing the impact of recent policy on disabled people in the context of the UNCRPD, because of poor quality, or untimely, EIAs. There also appears to be some confusion over the requirement to conduct EIAs, which the Government should clarify. (Paragraph 114)

25. The Equality and Human Rights Commission, Scottish Human Rights Commission, Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission should monitor and publish an assessment of the degree to which due regard appears to have been paid to Article 19 in the most relevant policy
developments and decisions in this Parliament. The findings should feed into the development of the Disability Strategy and relevant plans for each jurisdiction. (Paragraph 115)

Consultation and involvement of disabled people

26. The UNCRPD specifically requires disabled people to be involved in the implementation of the Convention, and the Government have acknowledged the importance of such involvement. We recommend that the Government aim to involve disabled people in the development of policy, rather than simply consult them, and to ensure that timescales and methods are used which enable a full range of disabled people and their representative organisations to be involved. (Paragraph 121)

27. We are disappointed that the English specific duties under Section 149 of the Equality Act no longer encourage the involvement of disabled people. This is a retrogressive step. The Government should actively promote involvement to public authorities as a means of meeting their Equality Duty and in order to comply with the UNCRPD. (Paragraph 122)

Awareness of the UNCRPD

28. Our evidence suggests awareness of the Convention among disabled people is low. It is important that disabled people are aware of their rights in order that they can access them. We recommend that the Government work in partnership with disabled people’s organisations in order to increase awareness. (Paragraph 124)

Implementing Article 19—issues and challenges

The impact of current reforms

29. We recognise the exceptional economic circumstances facing the UK and the challenges involved in implementing the stringent cuts in public spending the Government feel are necessary. However, in tackling these economic challenges the Government must give due attention to their obligations under international law. (Paragraph 133)

30. We welcome the additional £2 billion for social care set out in the 2010 Spending Review but are concerned that, without ring-fencing, it will not make up for anticipated shortfalls in social care budgets. Any reduction in care budgets, particularly in the context of rising care costs, presents a serious risk of retrogression in the realisation of the right to independent living. (Paragraph 134)

31. We concur with Scope’s view that expenditure on independent living should be seen as an investment and that such an approach will reduce long-term costs and promote better outcomes for disabled people and for society in general. We urge the Government to adopt this approach to the funding of adult social care and other budgets which contribute towards independent living. (Paragraph 135)
32. We are concerned that the restriction of Fair Access to Care Services eligibility criteria to critical-only risks giving rise to individual breaches of Article 19(a) of the Disabilities Convention and to retrogression in the realisation of the rights in Article 19(b). We recommend that the Disability Strategy includes measures to monitor the impact of restrictions on eligibility for adult social care on disabled people’s right to independent living. (Paragraph 138)

33. We welcome the Government’s recent decision that disabled people in residential settings should continue to be eligible for DLA/PIP mobility component. However, we recommend that, in order for PIP to play its part in promoting independent living, the new assessment system and eligibility criteria:

a) must not create a disincentive to using aids and adaptations;

b) continue to be based on the fundamental principle that it is a benefit based on the additional costs of impairment, and not based on medical diagnosis; and

c) should be independently reviewed with the involvement of disabled people’s organisations before being rolled out nationally. (Paragraph 145)

34. Significantly fewer people will receive PIP in comparison with those currently receiving DLA. DLA was conceived as a means to enable disabled people to meet the extra costs associated with overcoming barriers to independent living. We fear the introduction of PIP will restrict the ability of disabled people to overcome these barriers and enjoy the right to independent living (Paragraph 146)

35. We are extremely concerned that the closure of the Independent Living Fund to new applicants, with no ring-fenced alternative source of funding, may severely limit the ability of disabled people to participate in society. We would expect the Government to address this issue in their consultation paper on replacement funding to be published in early 2012 and to ensure that this change in policy does not result in individual breaches of the rights in Article 19(a) and retrogression as far as Article 19(b) is concerned. (Paragraph 152)

36. We welcome the Government’s statements that they do not wish to see people forced to move from houses which have undergone adaptation, but the interaction between where a person lives and other elements of the right to independent living go further than the issue of adaptations alone. (Paragraph 159)

37. We welcome the increase in the Discretionary Housing Fund, but are concerned that its discretionary nature means it will not provide an adequate guarantee that the right of disabled people to exercise choice and control over where they live will be consistently upheld in the light of reductions in Housing Benefit. (Paragraph 160)

38. The range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing DLA and local authority support, while not getting support from the Independent Living Fund, all of which may force them to return to residential care. As a result, there
seems to be a significant risk of retrogression of independent living and a breach of the UK’s Article 19 obligations. (Paragraph 161)

39. We recommend that the Office for Disability Issues, working with the devolved administrations and local authorities, monitor the impact of reform and spending decisions on the right to independent living and undertake to promote innovative ways through which to mitigate their impact. This should include reporting on to what extent reforms to the ILF, DLA and housing benefit are enabling the Government and local authorities to deliver their Article 19 obligations. (Paragraph 162)

**Adult social care**

40. National and local government should monitor and actively promote the innovative practices of local authorities which employ personalisation effectively to mitigate the impact of spending cuts. The Government should monitor the extent to which choice and control is being diminished or increased by the roll out of personal budgets, and take action if the goal of increasing choice and control is not being realised. (Paragraph 168)

41. We welcome the Government’s pilot scheme to extend personal budgets to primary healthcare. They should also monitor this scheme with regard to the increase or reduction of choice and control, and take action if there is no increase. (Paragraph 169)

42. We welcome the Government’s intention to consider introducing portable assessments. However, we are concerned that this may be insufficient to ensure the enjoyment of rights under Article 19, in particular the right to choose one’s place of residence and where and with whom one lives on an equal basis with others. We urge the Government to consider whether further action is required. (Paragraph 175)

43. The Government should include in its Disability Strategy Action Plan a commitment to enable disabled people living in residential settings to access their full Article 19 rights. It should also set out actions to achieve this commitment, and establish detailed outcomes against which progress can be measured and monitored. The Government should also ensure that residential care home providers are aware of the UNCRPD and of their role in assisting in its implementation. (Paragraph 181)

44. There appears to be an anomaly in the charging policy for residential care which creates a significant work disincentive, thus impeding access to independent living. The Government also appear not to recognise the extent to which people living in residential care are able to engage in paid work. We urge the Government to take action to remove this disincentive as soon as possible. (Paragraph 184)

45. The Government should, in partnership with disabled people’s organisations, monitor the extent to which regulation and inspection frameworks are promoting independent living in both domiciliary and institutional settings. The Disability Strategy should include the role of regulation and inspection in promoting Convention rights. (Paragraph 188)
46. The NHS Commissioning Board should produce guidance for Health and Wellbeing Boards on the need to incorporate human rights into their commissioning strategies, emulating the guidance of the Scottish Government. (Paragraph 193)

47. The Health and Social Care Act 2008 included a provision which ensured private and third sector care homes were defined as carrying out a public function when providing publicly-arranged care, bringing them within the scope of the Human Rights Act 1998. The current Health and Social Care Bill should be similarly amended to extend this definition to provision of care at home. (Paragraph 194)

Access to information and advocacy

48. Access to information, advice and advocacy is critical for all disabled people to benefit from personalisation. The Government should:

- monitor access to information, advice, and advocacy services in the context of the roll-out of personal budgets;
- continue to support and develop the role of Disabled People's User-Led Organisations to enable them to provide independent information, advice, and advocacy services; and
- implement the advocacy provisions in sections 1 and 2 of the Disabled Persons Act 1986 when reforming community care legislation. (Paragraph 199)

49. The Disability Strategy should set out how the Government intend to take action on, and measure progress on, disabled people's access to housing, transport, public space and public services within the context of the right to independent living. (Paragraph 204)

Hate crime and abuse

50. The occurrence of hate crime against disabled people, and the fear of such crime, is a growing threat to disabled people’s ability to live independently. We welcome the Government’s commitment to reducing hate crime, and in particular the requirement that police forces collect and report data on such offences. (Paragraph 208)

51. We remind the Government of its obligations under Article 8 of the Disabilities Convention to foster respect for the rights and dignity of persons with disabilities and to combat stereotypes and prejudices relating to such people. The Government should take care to ensure that the justifications it offers for its reforms to the system of disability benefits does not undermine its other work to promote positive perceptions and greater social awareness towards persons with disabilities. (Paragraph 209)

52. The Government should monitor the extent to which access to redress and justice for disabled people is affected by the provisions of the Legal Aid, Sentencing and Punishment of Offenders Bill, and the effect this has on their right to independent
living. The Disability Strategy should include action to be taken to ensure disabled people's access to redress and justice. (Paragraph 214)
Formal Minutes

Monday 6 February 2012

Members present:

Dr Hywel Francis, in the Chair

Baroness Berridge
Lord Bowness
Baroness Campbell of Surbiton
Lord Dubs
Lord Morris of Handsworth

Rehman Chishti
Mike Crockart

Draft Report (Implementation of the Right of Disabled People to Independent Living), proposed by the Chair, brought up and read.

Ordered, That the Chair’s draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 214 read and agreed to.

Summary agreed to.

Resolved, That the Report be the Twenty-third Report of the Committee to the House.

Ordered, That the Chair make the Report to the House of Commons and that Lord Bowness make the Report to the House of Lords.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Written evidence reported and ordered to be published on 3 May 2011, 24 May 2011, 14 June 2011, 21 June 2011, 28 June 2011, 5 July 2011, 25 October 2011, 6 December 2011, and 6 February 2012 was ordered to be reported to the House.

[Adjourned till Tuesday 7 February at 2.00 pm]
Declaration of Lords Interests

Baroness Campbell of Surbiton:

Trustee and co-founder of the National Centre for Independent living. 
Chair of the Government’s Right to Control Advisory Group. 
Co-Chair of the All-Party Parliamentary Disability Group (APPDG). 
Personal recipient of Disability Living Allowance and Community Care Direct Payments. 
Previously acted as consultant to Office of Disability Issues (ODI) in the role of Chair of Independent Living Scrutiny Group (Department of Works and Pensions) 
Former chair of SCIE.

Lord Lester of Herne Hill:

Advised Monica McWilliams on the draft Bill of Rights for Northern Ireland. 

A full list of members’ interests can be found in the Register of Lords’ Interests: http://www.publications.parliament.uk/pa/ld/ldreg/rego1.htm
Witnesses

Tuesday 24 May 2011

Sue Bott, National Centre for Independent Living, Neil Coyle, Disability Alliance, Marije Davidson, RADAR, and Jaspal Dhani and Julie Newman, UK Disabled People’s Council

Jim Elder-Woodward and Pam Duncan, Independent Living in Scotland, Rhian Davies and Paul Swann, Disability Wales

Tuesday 14 June 2011

Mike Smith, Commissioner and Chair, Disability Committee, Equality and Human Rights Commission, Monica McWilliams, Chief Commissioner, Northern Ireland Human Rights Commission, Bob Collins, Chief Commissioner, Equality Commission for Northern Ireland, and Duncan Wilson, Head of Strategy and Legal, Scottish Human Rights Commission

Diane Mulligan OBE, UK Candidate for the UN Committee of Experts on the Rights of Persons with Disabilities, David Ruebain, Solicitor, Former Director of Legal Policy, EHRC, Chief Executive of the Equality Challenge Unit, Pauline Thompson OBE, Co-author, Community Care and the Law (4th Edition), and Karen Ashton, Solicitor, Public Law Solicitors

Tuesday 28 June 2011

Professor Peter Beresford OBE, Centre for Citizen Participation, Brunel University, John Evans OBE, and Doug Paulley

Stephen Lowe, Social Care Policy Adviser, Age UK, Emily Holzhausen, Director of Policy and Public Affairs, Carers UK, Andrew Lee, Director, People First, and Marc Bush, Head of Policy, Scope.

Tuesday 5 July 2011

Lorraine Gradwell, Breakthrough UK, Julia Lim and Kate Sheehan, College of Occupational Therapists Specialist Section: Housing, and Tracy Hammond, KeyRing

Tracey Jannaway, Independent Living Alternatives, Hazel Roper, Independent Living Association, Nadra Ahmed, National Care Association and Adam Penwarden, Turning Point,

Tuesday 12 July 2011

Councillor David Rogers, Chair of the Local Government Group’s Community Well-being Board, Emma Jenkins, Senior Adviser in adult social care, Local Government Group, Linda Sanders, Co-chair of the Association of Directors of Adult Social Services Physical Disability Policy Network, and Jonathan Garden, Policy Officer, ADASS
**Tim Cooper,** Director of the Office for Disability Issues

**Tuesday 25 October 2011**

**Rt Hon Grant Shapps,** Minister of State for Housing and Local Government, Department for Communities and Local Government, **Paul Burstow,** Minister of State, Department of Health and **Maria Miller,** Parliamentary Under-Secretary of State, Department for Work and Pensions.

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## List of written evidence

1. Ruth Abrahams  
2. St Bridget’s Home (LCDisability)  
3. Jackie Postance  
4. Clive Durdle  
5. Barry Taylor  
6. Susan Kirkman  
7. Kevin Kelleher  
8. William Gwyn Chaplin  
9. Action Disability Kensington and Chelsea (ADKC)  
10. Nailsea Disability Initiative  
11. John Curran  
12. Leicestershire Centre for Integrated Living  
13. RNIB and Action for blind people  
14. People First  
15. Choices and Rights Disability Coalition and North Bank Forum  
16. Disabled Persons Transport Advisory Committee (DPTAC)  
17. Changing Places Consortium  
18. Independent Living in Scotland  
19. Shelley Bark  
20. Tabitha Collingbourne  
21. David Webdale  
22. Independent Mechanism for Northern Ireland  
23. Sense  
24. York People First  
25. Sense Scotland  
26. Disability Wales  
27. Disability Wales  
28. Mencap and Leonard Cheshire Disability  
29. Mental Health Foundation  
30. Social Care Institute for Excellence  
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32. Inclusion London
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<td>Disabled People Against Cuts (DPAC)</td>
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<td>NAAPS</td>
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<td>Housing Options &amp; National Development Team for Inclusion (NDTi)</td>
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<td>Housing sub Group of the Gateshead Learning Disability Partnership Board</td>
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<td>Lothian Centre for Inclusive Living (LCIL)</td>
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<td>40</td>
<td>Nicola Sturgeon MSP, Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy, Scottish Government</td>
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<td>Surrey Coalition for Disabled People</td>
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<td>People First Isle of Wight</td>
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<td>Written evidence published anonymously</td>
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<td>C Lloyd</td>
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<td>Coalition of Neurodiverse Organisations including Neurodiversity Internaional, the Autistic Rights Movement United Kingdom (ARMUK), and the London Autistic Rights Movement (LARM)</td>
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<td>Swansea Association for Independent Living (SAIL)</td>
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Article 3—General principles

The principles of the present Convention shall be:

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

b) Non-discrimination;

c) Full and effective participation and inclusion in society;

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of opportunity;

f) Accessibility;

g) Equality between men and women;

h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4—General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;

e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions.

Article 19—Living independently and being included in the community

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, including by ensuring that:
a) 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;

b) 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;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.
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