

# The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?

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*This paper reviews the emerging international and domestic recognition of the right to independent living and its potential impact on disabled people in Europe. The analysis commences with a brief overview of the UN Convention on the Rights of Persons with Disabilities, for which independent living is both a central theme and a specific provision. The paper then considers the nature of the right to 'independent living' and its recognition in other international and national provisions. It argues that there is an emerging European consensus that such a right already exists and that in consequence the Disability Rights Convention is likely to have a significant impact on the community living and deinstitutionalisation movements.*

## **Introduction**

On the 13<sup>th</sup> December 2006 the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities (abbreviated in this paper as 'the Disability Rights Convention'). The Disability Rights Convention was opened for signature in March 2007 and came into force on the 3<sup>rd</sup> May 2008 following the 20<sup>th</sup> ratification (by Ecuador). As at July 13 2008 129 states have signed the Convention (including all European states) and it has been ratified by 29 (including Croatia, Hungary Slovenia and Spain) <sup>1</sup>. The UK government indicated its intention to ratify by the end of 2008<sup>2</sup> and it is likely that other EU

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<sup>1</sup> United Nations Enable [www.un.org/disabilities/](http://www.un.org/disabilities/), accessed July 14<sup>th</sup> May 2008

<sup>2</sup> House of Lords, House of Commons, Joint Committee on Human Rights, *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*, Seventh Report of Session 2007-08, HL Paper 40-I, HC 73-I, 27. In its response to this report the Government provided details of the issues that needed to be addressed before ratification could take place (*Government Response to the Joint Committee on Human Rights: A Life Like Any Other? Human Rights of Adults with Learning Disabilities* may 2008, Cm 7378, page 4). Ratification of the Disability Rights Convention by the UK will not incorporate it into domestic law – to do so would

states will follow suit. Such widespread ratification will strengthen the growing jurisprudence in member states and in Strasbourg regarding the rights it protects and promotes, not least a right to independent living.

The Disability Rights Convention includes a range of civil and political, as well as economic, social and cultural, rights, covering areas in which disabled people have been discriminated against such as access to justice; participation in political and public life; education and employment.<sup>3</sup> Article 19, entitled “Living independently and being included in the community” requires governments to take action to facilitate disabled people’s ‘full enjoyment’ of this right and their ‘full inclusion and participation in the community’.

The United Nations Handbook for Parliamentarians, *‘From Exclusion to Equality, Realizing the Rights of Persons with Disabilities’* stresses that the Disability Rights Convention is not intended to create new rights rather it ‘complements’ existing human rights treaties and:

‘...clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities’.<sup>4</sup>

Thus while the Disability Rights Convention is the first international human rights treaty that expressly recognises ‘the equal right’ of all disabled people<sup>5</sup> to live in the community, Article 19 has not created a new right. Rather it is intended to provide a clarification of the obligations on States to ensure disabled people’s full and equal enjoyment of this right.

#### *What is meant by ‘independent living’?*

Generally the term ‘independent living’ (also referred to in mainland Europe as ‘community living’) has been regarded as a concept rather than an issue requiring precise legal definition. It has been described as a philosophy which underpins the work of disabled people to achieve ‘self-determination, equal opportunities and full participation in society as equal citizens’<sup>6</sup>. In the UK some attempt has been made to define independent living, which emphasises that it is

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require action separate domestic legislation similar to the Human Rights Act 1998 (which incorporated most parts of the European Convention on Human Rights into UK law).

<sup>3</sup> For an overview of the Convention and its formulation, see Kanter, A (2007) *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities* Syracuse Journal of International Law and Commerce Spring 2007 34, 2 pp 287-321.

<sup>4</sup> No 14 – 2007, United Nations, October 2007:

[www.un.org/esa/socdev/enable/documents/ipuhb.pdf](http://www.un.org/esa/socdev/enable/documents/ipuhb.pdf). See also Article 1.

<sup>5</sup> This paper refers to ‘disabled people’ rather than ‘persons with disabilities’ as this is the term used more commonly in the UK. The Disability Convention provides a broad definition of disability: ‘...includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

<sup>6</sup> European Community Living Newsletter Issue No. 2 Jim Elder-Woodward, ‘From the Rolling Quads to Direct Payments’, November 2006 p 3 [http://www.community-living.info/documents/Newsletter\\_no\\_2\\_06.pdf](http://www.community-living.info/documents/Newsletter_no_2_06.pdf)

not about disabled people living in 'splendid isolation' but supporting people to live their lives as equal citizens:

'all disabled people having the same choice, control and freedom as any 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.'<sup>7</sup>

Although the Disability Rights Convention provides no definition of independent living, the core values of independent living, such as personal autonomy, freedom and equality, are reflected throughout its text.

*The right to independent living and the Disability Rights Convention*

The idea of a 'right to independent living' owes much to the philosophical approach of the social model of disability which stresses that people with impairments are disabled by the physical and attitudinal barriers within today's society. Those promoting the right to independent living seek to address the long-standing and pervasive negative attitudes towards (and resulting discrimination against) disabled people. This is also the goal of the Disability Rights Convention, which has been described as:

'...a major step towards altering the perception of disability and ensuring that societies recognize that all people must have the opportunity to reach their full potential.'<sup>8</sup>

Independent living is integral to achieving this paradigm shift. Article 19 highlights the importance of independent living (albeit referring to disabled people living independently rather than 'independent living'). It requires States to recognise, and take effective and appropriate measures to facilitate, disabled peoples' full enjoyment of the right 'to live in the community, with choices equal to others', for example by ensuring that disabled people have the opportunity to 'choose their place of residence', 'are not obliged to live in a particular living arrangement' and have access to a range of community support services 'including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'.

While Article 19 makes express provision for 'living independently and being included in the community' these are also core themes of the Disability Rights Convention. For example, the general principles set out in Article 3 include 'the freedom to make one's own choices', and 'full and effective participation of

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<sup>7</sup> Office for Disability Issues, *Independent Living: A cross-government strategy about independent living for disabled people*, February 2008, p 29.

<sup>8</sup> Kanter, A (2007) *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities* Syracuse Journal of International Law and Commerce Spring 2007 34, 2 p 288.

persons'. The purpose of Article 9, which requires States to take action to make a range of areas accessible to disabled people (such as the physical environment, public services and information), is to enable disabled people 'to live independently and participate fully in all aspects of life'. Similarly, Article 26, which deals with rehabilitation services, seeks to enable disabled people 'to attain and maintain maximum independence, full physical, mental social and vocational ability, and full inclusion and participation in all aspects of life'.

### *Institutionalisation versus independent living*

Although the concept of independent living is not just about disabled people being able to live in their own homes, this is a crucial factor for many disabled people. In the UK there is concern that disabled people are being required to move into residential accommodation because appropriate housing and support is not available<sup>9</sup>. A research report published in 2007 found that across 25 of the European countries included in the study<sup>10</sup> nearly 1.2 million disabled people were living in residential establishments.

In many parts of Europe the predominant provision for disabled people (children as well as adults) continues to be institutionalisation (often for life). Over the last decade reports have highlighted serious concerns about the situation of disabled people placed in long stay institutions in Central and Eastern Europe. The reports identify substantial human rights abuses, such as involuntary placements subject to no independent review; appalling living conditions (for example poorly maintained buildings, lack of heating, malnutrition and unhygienic sanitation); the lack of privacy and the absence of rehabilitative or therapeutic activities.<sup>11</sup> However, concerns about human rights abuses in institutional settings are not confined to Central and Eastern Europe. By way of example, in 2006 an investigation into the care and treatment of people with learning disabilities in the UK found that there had been 'unacceptable restrictions' on the residents and years of abusive practice. The report concluded that 'institutional abuse was widespread'.<sup>12</sup>

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<sup>9</sup> Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*, January 2005 (Department of Health, London).

<sup>10</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, p 25. The study included all 27 European Union Members and Turkey. The relevant information was not available for Austria, Germany and Greece.

<sup>11</sup> See for example, Amnesty International (2003) *Bulgaria, Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities*, London, Amnesty International and Mental Disability Advocacy Center (MDAC) (2003) *Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries*, Budapest, MDAC.

<sup>12</sup> Commission for Social Care and Inspection and Healthcare Commission, *Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*, July 2006: see also The Healthcare Commission (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust* and The House of Lords, House of Commons, Joint Committee on Human Rights (footnote 2 above) which reached similar conclusions.

Independent living identifies a fundamental objection to institutionalisation and with it a recognition that the unjustified segregation of disabled people in institutions is in itself a human rights violation<sup>13</sup>. However good the environment and quality of care, placement in an institution is likely to represent a grave interference with an individual's human rights, in particular the right to private and family life. Studies of institutions in France, Hungary, Poland and Romania have, for instance, shown many similarities such as the low numbers of residents receiving weekly visits from their families or being able to go out to meet friends.<sup>14</sup>

Institutionalisation is, additionally, contrary to the policy objectives of both the European Union and the Council of Europe, which seek to ensure that disabled people are able to live as equal citizens.<sup>15</sup> The Council of Europe's Disability Action Plan 2006 – 2015 states:

People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community<sup>16</sup>.

The emphasis on independent living and disabled people's participation in the community shows that it is not enough to challenge the serious human rights abuses that occur, too frequently, in institutions. States must also take action to enable disabled people to live in the community. This has led to debates on 'deinstitutionalisation' (a term that encompasses the closure of institutions following the development of a range of alternative community based services). The concept of independent living is however broader in its aims and offers a guide on how alternative services and support must be developed:

Untold amounts of money have been used to build and maintain institutions. Deinstitutionalisation challenge us to re-engineer social support to ensure that it does not become a gilded cage. In practical terms, this means a commitment to the ideal of community living and the provision of the means to make it happen.<sup>17</sup>

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<sup>13</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, p 2.

<sup>14</sup> Freyhoff G, Parker C, Coue M, and Grieg N (2004) Included in Society, Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People, Brussels 2004

<sup>15</sup> Equal opportunities for people with disabilities: A European Action Plan COM(2003) 650 final

<sup>16</sup> Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, Recommendation Rec(2006)5.

<sup>17</sup> Gerard Quinn, Editorial, European Coalition for Community Living Issue No 1, July 2006 [http://www.community-living.info/contentpics/236/Newsletter\\_no\\_1\\_06.pdf](http://www.community-living.info/contentpics/236/Newsletter_no_1_06.pdf)

## **Independent living and international human rights instruments**

Although the right to independent living and community participation is not specifically referred to in any of the existing United Nations core human rights treaties<sup>18</sup>, the last 15 years has witnessed an increasingly assured recognition within the UN human rights agencies that such a right exists. An early and tentative affirmation of the right is found in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the UN General Assembly in 1993 which states that disabled people:

... are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services.

In similar terms the 1994 the Committee responsible for overseeing States' compliance with obligations under the International Covenant on Economic, Social and Cultural Rights (ICESCR) issued its General Comment on 'Persons with Disabilities'. This states that the right of everyone to the enjoyment of the highest attainable standard of physical and mental health implies the right to have access to, and benefit from, medical and social services that will help disabled people to:

'become independent, prevent further disabilities and support their social integration...such persons should be provided with rehabilitation services which would help them "to reach and sustain their optimum level of independence and functioning"'.

## **The Disability Rights Convention and independent living**

As noted above, Article 19 of the Disability Rights Convention specifically addresses the right to independent living:

State Parties to this 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:

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<sup>18</sup> International Covenant on Civil and Political Rights (1966), International Covenant on Economic, Social and Cultural Rights (1966), Convention on the Elimination of All Forms of Racial Discrimination (1965); Convention on the Elimination of All Forms of Discrimination Against Women (1979); Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984), the Convention on the Rights of the Child (1989), and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (2003).

- 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 responsible to their needs.

### *States' obligations under Article 19*

Article 19's emphasis is on the provision of services and support, traditionally seen as economic, social and cultural rights. It is therefore subject to the concept of 'progressive realisation', introduced by Article 4(2), whereby governments agree 'to take measures to the maximum of their available resources ... with a view to achieving progressively the full realization of these rights'.

However, the Committee tasked with monitoring compliance with the Disability Rights Convention<sup>19</sup> may follow the approach taken by the Committee that monitors compliance with the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>20</sup> This Committee considers that while the full realisation of rights may be achieved progressively:

... steps towards that goal must be taken within a reasonably short time after the Covenant's entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possibly towards meeting the obligations recognized in the Covenant.<sup>21</sup>

The Committee has also stressed that although the ICESCR provides for progressive realisation and acknowledges the constraints due to the limits of available resources, some obligations take effect immediately. One such example is the guarantee that rights will be exercised without discrimination. This is explicit in Article 4(2) of the Disability Rights Convention which states that the progressive realisation of economic, social and cultural rights is 'without prejudice to those obligations contained in the present Convention that are immediately applicable to international law'.

Article 19 also has a civil and political rights dimension. The right of disabled people 'to choose their place of residence' engages the right to liberty of movement protected by Article 12 of the International Covenant on Civil and

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<sup>19</sup> The Committee on the Rights of Persons with Disabilities (Article 34).

<sup>20</sup> The Committee on Economic, Social and Cultural Rights.

<sup>21</sup> The Committee on Economic, Social and Cultural Rights General Comment 3, 14/12/90

Political Rights (ICCPR) and 2 of the 4<sup>th</sup> Protocol to the European Convention on Human Rights (ECHR). This is of relevance not only to individuals who are placed in institutions due to the lack of alternative community based services but also where local funding arrangements for community support services (or special educational needs) impair or entirely negate disabled people's right to liberty of movement. Such arrangements, where a local council or municipality is responsible, are not generally portable. Accordingly a disabled person wishing to move into another authority's area, may be unable to do so, if the new authority has entirely different funding arrangements (for example where the arrangements are materially less favourable or the disabled person is required to meet a 'local connection' or 'habitual residence' type test).

### The UN Convention as a catalyst

International convention rights of this nature have the potential to energise latent domestic provisions – in effect a form of legal 'combination therapy' where two imperfect provisions combine to produce an effective treatment. In the UK this takes the form of an interpretive obligation (where possible, to construe ambiguous domestic provisions so as to conform with our international obligations and in South American states this interaction has been termed the 'interconnection doctrine'.<sup>22</sup> A number of domestic and international examples exist of how an analogous treaty – the UN Convention on the Rights of the Child (UNCRC) has been exploited in this way. In *SP v. UK* (1996)<sup>23</sup>, for instance, the question arose as to whether a lawyer could bring a complaint on behalf of young children in municipal care – even though he had not been formally instructed by them to do so. The ECHR is silent on this question – although the case law on article 6 (the right to a fair court hearing) suggested that this was not possible. The Commission rejected the UK's argument that the lawyer had no such right, relying on the UK's ratification of the UNCRC since this effectively estopped the UK from denying that children had rights in relation to legal representation (article 12). The UNCRC has also had an energising impact on the interpretation of the International Covenant on Civil and Political Rights (ICCPR).<sup>24</sup>

### Independent living as a facet of the right to privacy and home

The freedom to exercise choice and control over our own lives is a core component of Articles 5 (right to liberty) and 8 (right to private and family life) of

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<sup>22</sup> See Courtis, C. (2008) 'The right to life and the right to health of children with disabilities before courts: some Latin American examples' p198 in Clements L and Read J (eds) *Disabled People and the Right to Life* Routledge, Oxford.

<sup>23</sup> *SP, DP & T v. UK* (1996) 22 E.H.R.R. CD 148; [1996] EHRLR 526.

<sup>24</sup> S Joseph, J Schultz and M Castan (2004) *The International Covenant on Civil and Political Rights*; Oxford University Press, Oxford at p625.



the ECHR. The Strasbourg Court ‘considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.’<sup>25</sup>

The decision to institutionalise a person against his or her wishes (or without informed consent<sup>26</sup>) represents a clear interference of that person’s personal autonomy. Where this amounts to detention, Article 5 will be engaged. The Strasbourg Court has emphasised that individuals may be deprived of their liberty notwithstanding (a) that they did not resist their institutional placement<sup>27</sup> (particularly so where they lack sufficient capacity to give informed consent to the arrangement<sup>28</sup>) and (b) that they are not ‘locked up’: that detention may exist even where there are no formal barriers.<sup>29</sup> Large numbers of disabled people (particularly those accommodated in institutions) may, on this definition of ‘detention’ be deprived of their liberty contrary to Article 5. In the UK, for example it has been estimated that on any one day over 22,000 patients are ‘detained’ informally (i.e. without compliance with the procedural requirements of Article 5(1))<sup>30</sup> in psychiatric units and if one takes into account other settings – particularly residential care homes the figure may amount to 50,000.<sup>31</sup>

Whilst coercive institutionalisation may not always constitute a deprivation of liberty for the purposes of Article 5, Article 8 jurisprudence will be relevant to all restrictions placed on individual liberty: particularly to restrictions on social interaction, the ability to establish and develop relationships, educational and other personal opportunities as well as those that impair an individual’s ‘physical or psychological wellbeing’.<sup>32</sup>

Decisions by the Strasbourg Court demonstrate the relevance of Article 8 in such instances, particularly its emphasis on the importance of personal autonomy. The Court has stressed that there must be a clear justification for interfering with a person’s chosen lifestyle, ‘even where the conduct poses a danger to health, or, arguably, where it is of a life-threatening nature’.<sup>33</sup> Article 8 has the potential therefore to extend to situations of passive institutionalisation – essentially where the care regime is constructed in such a way as to make institutionalisation the default option, for example where there are little or no services or support available to people who wish to live in their own homes.

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<sup>25</sup> *Pretty v the United Kingdom* (2002) 35 EHRR 1.

<sup>26</sup> *H.L. UK § 90* (2004) 40 EHRR 761.

<sup>27</sup> *De Wilde, Ooms and Versyp v. Belgium* (judgment of 18 June 1971, Series A no. 12, §§ 64-65.

<sup>28</sup> *H.L. UK § 90* (2004) 40 EHRR 761.

<sup>29</sup> *Ashingdane v UK* (1985) 7 EHRR 528 at §§ 24 and 42 – the key issue being, it appears, whether or not the individual is ‘free to leave’ – see *JE v DE and Surrey County Council* [2006] EWHC 3459 (Fam); (2007) 10 CCLR 149.

<sup>30</sup> *R v. Bournewood Community and Mental Health N.H.S. Trust, ex parte L* [1999] 1 A.C. 458 at 481.

<sup>31</sup> A figure of 48,000 was advanced by the Department of Health on behalf of the UK government in *Bournewood* (ibid).

<sup>32</sup> See for example *Tysiāc v Poland* (2007) Application no. 5410/03 § 107.

<sup>33</sup> *Pretty v United Kingdom* (2002) 35 EHRR 1.

Whilst ‘even a minor’<sup>34</sup> (state imposed) restriction on a person’s liberty requires justification under Article 8(2), few cases concerning this question have been examined by the Strasbourg Court. In *Storck v. Germany* (2005)<sup>35</sup> the Court declined to consider the Article 8 complaint on the basis that in substance it repeated the Article 5 complaint, for which it had found a violation.<sup>36</sup> In *HM v Switzerland* (2002)<sup>37</sup> where such an analysis would have been informative, no separate complaint had been made concerning Article 8 and presumably for this reason the court decided not to venture into this difficult territory. Judge Loucaides in his much admired dissenting opinion in *HM*<sup>38</sup> unfortunately restricts his analysis to the issue of detention (the applicant had placed in the foster home against her will) and of the ‘unique importance’ of ‘physical freedom’.

*HM* may therefore be seen as an example of the Strasbourg courts restrictive vision in this domain: of its failure thus far to conceive of Article 8 as embodying a principle of independent living. If this is so, then the Disability Rights Convention should ensure that such a fundamental question is no longer overlooked. We consider below the extent to which we believe the new Disability Rights Convention will lead to a re-evaluation of the role of the substantive obligation inherent in Article 8 in such cases.

### *Positive obligations and independent living*

Notwithstanding the Strasbourg Court’s frequent observation that the boundaries between a state’s positive and negative obligations under Article 8 do not lend themselves to precise definition,<sup>39</sup> it is clear that the principles that regulate both obligations are not dissimilar.<sup>40</sup> The court has, for instance, held that Article 8 embodies many (if not all) of the core components of the right to independent living: a right to positive measures to ensure ‘the development, without outside interference, of the personality of each individual in his relations with other human beings’<sup>41</sup>; a state obligation to avoid interferences with a person’s development of their ‘social identity’<sup>42</sup> and a right (where the state bears responsibly for the applicants predicament<sup>43</sup> – or if s/he has significant impairments<sup>44</sup>), to positive measures to address inappropriate living conditions.

<sup>34</sup> *Storck v Germany* § 168 (2005) 43 EHRR 96.

<sup>35</sup> *Storck v Germany* § 142 (2005) 43 EHRR 96.

<sup>36</sup> *Storck v Germany* § 142 (205) 43 EHRR 96.

<sup>37</sup> Application no. 39187/98: 38 EHRR 314.

<sup>38</sup> A dissenting view that appears to have become the majority view in *HL v UK* (2004) 40 EHRR 761.

<sup>39</sup> See for example *Odièvre v. France* (2003) Application no. 42326/98 § 40 and *Mikulic v. Croatia* (2002) Application no. 53176/99 § 58).

<sup>40</sup> *Ibid.*

<sup>41</sup> *Botta v. Italy* (1998) 26 EHRR 421: Application no. 153/1996/772/973.

<sup>42</sup> *Mikulic v. Croatia* (2002) Application no. 53176/99.

<sup>43</sup> *Moldovan and others v. Romania* (No. 2) (2005) Applications nos. 41138/98 and 64320/01 § 105 – a case of such severity that Article 3 was engaged.

<sup>44</sup> *Marzari v Italy* (1999) decision, no. 36448/97.

It places a duty on the state to take action to ‘the greatest extent feasible to ensure that [disabled people] have access to essential economic and social activities and to an appropriate range of recreational and cultural activities’ to ensure that their lives are not ‘so circumscribed and so isolated as to be deprived of the possibility of developing [their] personality’.<sup>45</sup> Such compensatory measures, as Judge Greve observed in *Price v. UK* (2001)<sup>46</sup> are fundamental to disabled people’s Article 8 rights.

Whilst the established jurisprudence may recognise the core components of the right to independent living within Article 8, the European Court of Human Rights has imposed a procedural check, by requiring that applicants demonstrate a ‘direct and immediate link’ between the measures sought and their predicament.<sup>47</sup>

The ratification by a state of the Disability Rights Convention may however lead to a reversal of the onus in such cases. As one commentator has suggested, ‘how could a State possibly argue that it would be unreasonable to expect it to adopt a particular measure, if the State has already agreed to adopt that measure by agreeing to other international agreements’.<sup>48</sup> In similar terms the generally wide margin of appreciation accorded to states over such matters may well be constrained by such a ratification – by the emerging European consensus on this issue, a point we address below.

### **Institutionalisation as unlawful discrimination**

Article 19 of the Disability Rights Convention embodies not only the principle of personal autonomy entrenched within Articles 8 of the ECHR and 17 of the ICCPR but also the principle of non-discrimination, referring as it does to the ‘*the equal right of all persons with disabilities to live in the community*’. Article 4 of the Disability Rights Convention is the underpinning provision in this respect, requiring ‘the full realization’ of the Convention’s rights freedoms ‘for all persons with disabilities without discrimination of any kind on the basis of disability.’

The Strasbourg Court has, of late, shown a radical new approach to the interpretation of the Convention’s prohibition of unlawful discrimination under Article 14 – particularly in relation to marginalised and oppressed communities. Whilst these recent developments have been restricted, in general, to severe

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<sup>45</sup> Per Commissioner Bratza (as he then was) in *Botta v Italy* (1998) 26 EHRR 241 and cited by Munby J in *R (A & B, X & Y) v. East Sussex County Council* [2003] EWHC 167 (2003) 6 C.C.L. R. 194 at para 102 and see also *R (T, D & B) v Haringey LBC* [2005] EWHC 2235 (Admin) 21st October 2005

<sup>46</sup> Times 13 August: 34 E.H.R.R. 1285.

<sup>47</sup> *Botta v. Italy* (1998) 26 EHRR 421 § 34; ‘*the existence of a special link between the situation complained of and the particular needs of [the applicant’s] private life.*’ and *Sentges v. Netherlands* (2003) Application no. 27677/02 p6.

<sup>48</sup> See De Schutter O. (2005) *Reasonable Accommodations and Positive Obligations in the European Convention on Human Rights* in *Disability Rights in Europe: From Theory to Practice* Lawson L & Goolding C (eds): Hart Publishing, Oxford (page 48)

violations (for example those engaging articles 2 and 3) the court has also envisaged the application of Article 14 in relation to the qualified rights – as for instance Article 9 in *Thlimmenos v Greece* (2000)<sup>49</sup> and Article 2 protocol 1 in *DH v Czech Republic* (No. 2) (2007).<sup>50</sup>

With the widespread ratification of the Disability Rights Convention it is not improbable that the Court may be prepared to consider Article 14 complaints alleging discrimination on the basis that there is no objective (for example economic or social) justification for the disproportionate numbers of certain categories of disabled people living in institutions compared to non-disabled people. Indeed, adopting the principles identified in *Thlimmenos* it may be prepared to take its investigations further – to require especial vigilance (and investigation) by states where credible evidence is advanced that the difference in treatment is based solely on disability.<sup>51</sup>

Where there are concerns that the social care, health or education systems are geared towards placing disabled people in institutional care rather than providing support in the community, there is clearly potential for European Convention arguments to be framed in analogous terms to those considered by the US Supreme Court in *Olmsted v LC* (1999)<sup>52</sup>. The case concerned a care planning regime in the State of Georgia, which skewed funding arrangements to favour institutional placements, rather than community based independent living placements. The Court considered that such arrangements contravened the Americans with Disabilities Act 1990 which (amongst other things) proscribes discrimination in the provision of public services. Whilst the Court emphasised that the financial resources of States' were relevant factors in determining their policies, it stressed the importance of policies being rational and fair and of the basic principle that “unnecessary institutionalization” should be avoided if possible. In the view of the majority:

The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, and

confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

In terms of the ECHR, such an argument would need to rely on a domestic non-

<sup>49</sup> Application no. 34369/97.

<sup>50</sup> Application no. 57325/00.

<sup>51</sup> Essentially migrating the approach adopted in *Nachova v Bulgaria* (No. 2) (2005) Applications nos. 43577/98 and 43579/98 and *Šečić v. Croatia* (2007) Application no. 40116/02 to Article 8 and disability.

<sup>52</sup> *Olmstead v LC*, 527 US 581 (1999)

discrimination provision and seek its interpretation in a way that is compliant with Articles 8 and 14 – a point to which we return below.

### **The development of the right to independent living within European and domestic law**

The Council of Europe, as with the Strasbourg Court, has shown an increasing interest in human rights, equality and disability issues: notably in 2006 publishing its disability action plan which identified independent living is a key goal.<sup>53</sup> The European Commission too was active in supporting the development of the Disability Rights Convention and is now a signatory.

Article 26 of the European Union Charter of Fundamental Rights (2000) provides that disabled people should benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.’ Article 13 of the Treaty of Amsterdam authorises the European Union (EU) to take action to combat discrimination based on a range of grounds, including disability. This has led to a number of measures including the Equal Treatment Framework Directive 2000/78/EC<sup>54</sup> as well as the introduction of an action plan, which aims to ‘develop concrete actions in crucial areas to enhance the integration of people with disabilities’.<sup>55</sup>

The recognition of a right to independent living is not a purely international phenomenon. In many European jurisdictions, campaigns by disabled people to promote independent living have resulted in domestic action – particularly in the realm of non-discrimination legislation. Degener<sup>56</sup>, in 2005 listed 45 states (of which 14 were European)<sup>57</sup> that had introduced specific disability discrimination legislation – and of course the impact of the Equal Treatment Framework Directive 2000/78/EC is that all 27 EU states now must have such legislation albeit (at present) restricted to the realm of employment.

Domestic European legislation to protect the rights of disabled people has not been limited to outlawing discrimination. It appears that a number of EU states,

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<sup>53</sup> *Member states will continue to work within anti-discriminatory and human rights frameworks to enhance independence, freedom of choice and the quality of life of people with disabilities and to raise awareness of disability as a part of human diversity.* Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015

<sup>54</sup> Whilst the Directive does not extend to independent living opportunities for disabled people its reach may prove to be significantly wider than initially envisaged – even without further extension of the Amsterdam principles - see for example *Coleman v Law* Case C-303/06; London Employment Tribunal case no 2303745/2005 where it is argued that the protection afforded by the Directive may extend to the family / unpaid carers of disabled people.

<sup>55</sup> Equal opportunities for people with disabilities: A European Action Plan COM (2003) 650 Final.

<sup>56</sup> Degener, T. (2005) ‘Disability Discrimination Law: A Global Comparative Approach’ in Lawson L & Gooding C (eds) *Disability Rights in Europe: From Theory to Practice* Oxford: Hart Publishing.

<sup>57</sup> The states being Austria, Finland, France, Germany, Hungary. Ireland, Luxemburg, Malta, Netherlands, Portugal, Spain, Sweden, Switzerland and the UK.

when implementing the Directive, took the opportunity to enact more expansive disability rights measures. Kanter<sup>58</sup> cites the Czech Republic as such an example and it appears that Bulgaria and Romania have also adopted this course. In Romania the 2006 legislation<sup>59</sup> specifically addresses the right to independent living (articles 29 and 50) and is underpinned by a set of guiding principles including (at Article 3) the right to "the freedom of choice and control or decision about one's life, services and the type of support one receives" and the requirement to choose "the least restrictive option when determining the assistance and support needed". In Bulgaria the relevant 2005 enactment<sup>60</sup> provides for (amongst other things) the social integration and support of people with disabilities, and this has been fleshed out by the National Strategy for the Equal Opportunities of People with Disabilities, which in essence creates a presumption against the institutionalisation of children with disabilities.

In Germany the goal of independent living is enshrined in a series of statutes<sup>61</sup> which establish that this objective should be supported by the provision of care services in priority to institutionalisation. The statutory regime in Denmark is analogous with the promotion of supported living opportunities and the abolition of institutions for disabled people, explicit underpinning aims of the relevant legislation.<sup>62</sup> In the UK too, although there is no express legislative statement in favour of independent living, it has been argued that it is already an underpinning principle of the national social care legislation.<sup>63</sup>

In Sweden the goal of independent living has reached its fullest European expression.<sup>64</sup> As early as 1954<sup>65</sup> Swedish legislation advocated 'open care' from which it has steadily developed to the stage that the promotion of independent living is now a concrete state obligation<sup>66</sup>.

In addition in many European states, legislation has been enacted to enable disabled people to receive financial payments in lieu of the care support services.

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<sup>58</sup> Kanter, A (2007) *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities* Syracuse Journal of International Law and Commerce Spring 2007 34, 2 at p 310.

<sup>59</sup> Law 448/2006 'Concerning the protection and promotion of the rights of people with disabilities' at [www.anph.ro/admin/doc/upload/serviciu/Lege%20nr.448-2006.doc](http://www.anph.ro/admin/doc/upload/serviciu/Lege%20nr.448-2006.doc) (last visited 5<sup>th</sup> January 2008).

<sup>60</sup> The Law on the Integration of People with Disabilities, which entered into force on 1 January 2005.

<sup>61</sup> The Sozialgesetzbuch IX, the Social Code Volume 9 as amended in 2001 (in conjunction with the Behindertengleichstellungsgesetz 2002 (the "Equal Opportunities for Disabled People Act") and the Allgemeine Gleichbehandlungsgesetz 2006 (the "General Act on Equal Treatment")).

<sup>62</sup> See in particular, the Consolidation Act on Social Housing, etc 2006 para 105 and the Consolidation Act on Social Services 2007 (first adopted in 1998) paras 107 and 108. In this context, see Center for Ligebehandling af Handicappede (2002) 'Danish disability policy - Equal opportunities through dialogue' at <http://www.clh.dk/index.php?id=909> viewed 19 May 2008

<sup>63</sup> See for example Clements L and Thompson (2007) *Community Care and the Law*. Legal Action, London § 4.44 et seq.

<sup>64</sup> See for Ericsson, K (2002) *From Institutional Life to Community Participation Ideas and Realities Concerning Support to Persons with Intellectual Disability* Uppsala Universitets Förlag.

<sup>65</sup> The Act on Education and Care of Some Mentally Subnormal Persons (*Lag om undervisning och vård av vissa psykiskt efterblivna*) 1954.

<sup>66</sup> The Act on Support and Services for Some Disabled Persons (*Lag om stöd och service till vissa funktionshindrade*) 1993.

Direct payment services of this kind are seen as important elements in the promotion of independent living and have been introduced in (amongst other jurisdictions) Sweden, the UK, Belgium<sup>67</sup>, the Netherlands<sup>68</sup>, Austria and Germany<sup>69</sup>.

The fact that such legislation has been introduced does not, of course, mean that it is being implemented. However the existence of a legislative commitment to the promotion of independent living (even if largely rhetorical) will materially reduce a state's margin of appreciation if it sought to argue the inapplicability of such a right within its particular jurisdiction.

### The domestic impact of the Disability Rights Convention

The above analysis suggests that the incremental development of disparate domestic 'independent living' provisions – spurred on by Directive 2000/78/EC – has resulted in a European consensus on the existence of such a right. The obverse may however prove to be the more compelling formulation of the principle, namely that disabled people should not be placed in institutional care if it is practicable for them to be cared for in their own homes. This is not to gainsay the relevance of cost constraints or to deny that for many disabled people such a right is largely theoretical – in that in many European states community based services are in short supply and, where they do exist, of inferior quality.

As to costs, it is the case that institutions with minimal (or no) amenities offer states exceedingly inexpensive ways of 'caring' for disabled people. Such austere institutional arrangements are ceasing to be legally tenable, given the European Court of Human Rights' preparedness to set the bar for an Article 3 violation lower for disabled or elderly people<sup>70</sup>; and to classify institutional conditions as degrading<sup>71</sup> and to articulate the obligations on the state in the language of dignity.<sup>72</sup> Accordingly bare cost justifications for institutionalisation are unlikely to carry the day.

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<sup>67</sup> Social Care Institute for Excellence (2007) *Choice, Control and Individual Budgets: emerging themes* SCIE, London.

<sup>68</sup> In the Netherlands the 'individual-bound budget' (*persoonsgebonden budget*) arrangements are governed by the General Act on Special Disease-related Expenses (*Algemene wet bijzondere ziektekosten*), the Health Insurance Act (*Zorgverzekeringswet*) and the Act on Community Support Services (*Wet maatschappelijke ondersteuning*).

<sup>69</sup> Organisation for Economic Co-operation and Development, *Policy brief: Ensuring quality long-term care for older people*, 2005

<sup>70</sup> See for example *Price v. UK* (2001) § 24.

<sup>71</sup> The Court's recent robust approach – see for example *Dybeku v. Albania* no. 41153/06 18 December 2007 – should be contrasted with the Commission decision in *Hilton v. UK* (1981) 3 E.H.R.R. 104 where a regime that had reduced a prisoner to an 'animal like state' was not considered to violate Article 3.

<sup>72</sup> See *Pretty v UK* (2001) 35 EHRR 1; *Price v. UK* (2001) Application no. 33394/96; *D. v. UK* (1997) (1997) 24 E.H.R.R.423 Application no. 146/1996/767/964; *Keenan v. UK* (2001) Application no. 27229/95; *Bensaid v. UK* (2001) Application no 44599/98 and *Valašinas v. Lithuania* (2001) Application no. 44558/98.

The difficulty lies at the other end of the spectrum where a disabled person with high care needs seeks an independent living arrangement that is materially more expensive than the state's proposal for an adequately serviced residential arrangement. In such cases, as we have noted, the Strasbourg court has traditionally put the onus on applicants 'to demonstrate the existence of a special link between the situation complained of and the particular needs of his or her private life'.<sup>73</sup> Even if the applicant is able to discharge this requirement, the court has then afforded states a wide margin of appreciation since the question concerns 'the allocation of limited State resources'.<sup>74</sup> Such an approach may now change, with the court commencing from a default position of an obligation to promote independent living – not merely because the relevant state has ratified the Disability Rights Convention (if that be the case) but in recognition of the European consensus concerning such a right.

The proportionality review will then be based upon the reasonableness of the state's assertion that the obligation cannot be discharged in the instant case. No doubt where cogent reasons are advanced the court will afford a reasonable margin of appreciation – but a state's discretion in such cases will not be unlimited and the court will scrutinise with particular care, policies that appear overly general or inflexible or indiscriminate<sup>75</sup> and the onus will have changed: the state will in each case be required to advance rational grounds for its policy position. Since the economic argument in favour of institutionalisation is questionable<sup>76</sup> the process of justification is likely to pose not inconsiderable and new challenges for all States. Whether the Strasbourg Court will always accept a cost difference as sufficient to discharge the onus must be open to doubt. Whilst such an argument would provide the legitimate aim for the purpose of Article 8(2) it does not in itself dispose of the proportionality review – as indeed was the case in the much criticised *Sentges v. Netherlands*<sup>77</sup> decision where the court noted that the State had already made available not inexpensive independent living aids.

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<sup>73</sup> See for example *Sentges v. Netherlands* (2003) Application no. 27677/02 and *Zehnalová and Zehnal v. the Czech Republic* (2002) Application no. 38621/97.

<sup>74</sup> See for example *Osman v. UK* (1998) 29 EHRR 245 and *Sentges v. Netherlands* (2003) Application no. 27677/02.

<sup>75</sup> *Hirst v. UK* (No. 2) (2005) Application no. 74025/01 § 84; *Dickson v UK* (2007) Application no. 00044362/04 and see also *Dybeku v. Albania* (2007) Application no. 41153/06 § 50, where the Court was prepared to analyse a cost argument and reject it as irrational.

<sup>76</sup> See in particular Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Canterbury: Tizard Centre, University of Kent; and additionally Hurstfield J, Parashar U, and Schofield K. (2007) *The costs and benefits of independent living* Office of Disability Issues, London.; Kestenbaum, A. (1999) *The Costs of Independent Living*. Joseph Rowntree Foundation, York and Richardson G, Gravelle H, Weatherly H and Ritchie G. (2006) *Cost-effectiveness of interventions to support self-care: A systematic review*. International Journal of Technology Assessment in Health Care, Vol. 21, No. 4, pp. 423–432.

<sup>77</sup> *Sentges v. Netherlands* (2003) Application no. 27677/02: see De Schutter O. (2005) *Reasonable Accommodations and Positive Obligations in the European Convention on Human Rights* in Disability Rights in Europe: From Theory to Practice Lawson L & Gooding C (eds): Hart Publishing, Oxford.



## Conclusions

It is strongly arguable that a European consensus already exists concerning the qualified right of disabled people to live independently. The case for such a right will become incontestable with the widespread ratification of the Disability Rights Convention. The recognition of such a right brings with it a presumption that independent living will be the default option for disabled people; a positive obligation on the state to promote their social inclusion and an interpretative principle, that domestic legislation will be given a meaning that advances the possibility of independent living and challenges policies that are weighted to produce an institutional outcome.

In this paper we have argued that recognition of the right has emerged, not because of the Disability Rights Convention but as a consequence of diverse legal and policy developments – domestic as well as international – all of which can now be seen as components of the right: a multifaceted right that is both civil and political, and social and economic; that is centred on non-discrimination and the social model of disability and embraces the social inclusion agenda. In the European context, the recent rapid acceptance of the right owes much to the activities of the European Union and in particular the Equal Treatment Framework Directive 2000/78/EC. The Directive and the new interpretive regime attendant upon the widespread ratification of the Disability Rights Convention will inevitably interact and empower all those who seek to convert these largely theoretical rights into concrete realities for disabled people.

The right to independent living is a right that has taken a long time to be recognised. Although the genesis of its recognition can be traced to the days of the anti-Poor Law movement it is a right that (like disabled people themselves) has for the last 200 years been marginalised. Its time has now come: it is a right that can now be openly acknowledged: no longer a policy objective, but a fundamental and universal human right. For the 1.2 million disabled people currently placed in institutions across Europe this is a right that cannot be realised too soon.