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## CHAPTER 7

# Disabled People and the European Union: equal citizens?

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### **Introduction**

2003 was a significant year for disabled people in the European Union (EU). It marked the tenth anniversary of the United Nations' *Standard Rules on the Equalisation of Opportunities for Disabled People* (UN 1993) which gave international recognition for a social model or rights based approach to disability. The *Standard Rules* provided impetus for a more social model-oriented EU disability strategy, the language of which is dominated by a focus on citizenship, accessibility and barrier-removal. Furthermore, the year was designated European Year of Disabled People with the clear aim of raising awareness of disability issues in general and particularly of the environmental, social, economic, procedural and attitudinal barriers disabled people face. The intention was to generate a more concrete political commitment to promote disabled people's inclusion within mainstream European law and policy.

Central to the mainstreaming of disability issues has been a focus on the extent to which disabled Europeans can actively apply and develop their Union Citizenship. Disabled people, their organisations and allies have argued strongly that disabled people are in effect 'invisible citizens' within the EU, absent from European legislation and without adequate protection from discrimination by substantive EU law (EDF 1995). While more recent developments such as the 1997 Treaty of Amsterdam (which extended the protection of EU nationals against nationality-based discrimination to a range of other grounds, including race, sexual orientation, age, religious beliefs and disability (Article 13 EC)), mark an important advancement in the formal status of disabled citizens, concern still exists around the

accessibility and scope of the rights and obligations implicit in the notion of Citizenship of the Union.

In order to frame our discussion of disabled people's status at Community level, it is important, to identify from the outset what, exactly, we mean by Citizenship of the Union, both in a formal legal as well as a practical sense.

### ***Defining Citizenship of the European Union***

Citizenship in a national context is traditionally allied with the exercise, to varying degrees, of civil, political and social rights. It also commonly denotes the legal and social relationship between individuals within a community and their relationship with the State. To what extent, therefore, does EU citizenship espouse these notions? Moreover, how many of us would really celebrate our status as a citizen of the Union? What, if anything, makes us identify and engage as individuals with EU membership? And to what extent does disability alter our conception and experience of EU membership? In responding to these questions, it is useful to consider, first of all, the formal legal definition of Union citizenship.

The concept of Citizenship of the Union attained formal constitutional status following the 1992 Treaty of Maastricht. This stated quite simply that all nationals of the current 15 Member States are to be regarded as citizens of the Union by virtue of Article 17 (formerly Article 8) of the EC Treaty. But how does the status of the EU citizen differ from the actual practise of EU citizenship – in other words, to what does this status give rise in terms of substantive rights? Very generally, the EC Treaty provides that all EU nationals 'shall enjoy the rights conferred by this Treaty and shall be subject to the duties imposed thereby' (Article 17(2)). This includes a set of (albeit modest) political rights and, more significantly, 'the right to move and reside freely within the territory of the Member States' (Article 18 EC).

The link between active EU citizenship and the exercise of free movement between Member States is, therefore, firmly established in this provision and has been pivotal to the development of substantive rights under Community law over the past thirty years, opening up access to a range of welfare and employment-related rights for those who migrate to other Member States (D'Oliveira 1995; Ackers 1998; Shaw 1998). This led one commentator to suggest that free movement is 'the central element around which our other rights crystallise' (D'Oliveira 1995:65).

The symbiotic relationship between EU citizenship and the free

movement provisions implies that our rights as citizens of the Union are only really meaningful in the context of intra-union mobility making it for many European citizens a 'hollow concept'. As Ackers and Dwyer assert:

in the absence of mobility, Citizenship of the Union contributes little to the social status and day-to-day experience of Community nationals (2002:3).

This conception of EU citizenship is particularly exclusive of those with neither the means nor the inclination to move to another Member State, for example, because of disabling barriers. Even if an individual does wish to move, they must satisfy certain criteria in order to qualify under the free movement provisions and obtain access to the panoply of social rights in another Member State. These criteria can be summarised as follows: you have to be an EU national and you have to be economically active (i.e. in work) or economically self-sufficient (that is, not dependent on welfare benefits). If you are neither of these, you can migrate as a dependent family member (that is, as the spouse, child or parent) of the migrant worker.

The limitations inherent in these criteria have, by now, been well documented, particularly in respect of their disproportionate marginalisation of women and children (Scheiwe 1994; Lundström 1996; Moebius and Szyszczyk 1998; McGlynn 2000; Ackers and Stalford 2004) same-sex and cohabiting couples (Stychin 2000; Wintemute and Andenaes 2001) and third country nationals (Peers 1996). The more recent lobbying efforts of national bodies, network NGOs and Commission-affiliated organisations such as the European Disability Forum (EDF) have stimulated more critical discussion on the deficiencies of free movement legislation and wider EU-policies in respect of disabled people. However, there is relatively little academic discussion on this issue - one exception is the paper prepared by Waddington and van der Mei (1999) for the EDF - and very little literature challenging the accessibility of European Citizenship in this context.

We turn now to identify and critique the definition, scope and application of the free movement of persons provisions as the principal trigger of European social rights and, indeed, European citizenship. Specifically the paper will address the implications of the hierarchical nature of entitlement for disabled people with particular reference to debates around disability, dependency and work. This discussion will enable us to question the extent to which disabled people can enjoy active citizenship of the Union outside the context of free movement.

This concern has been recently re-articulated by the European Network on Independent Living (ENIL) (2003), the first European Congress on Independent Living held in Tenerife (2003) and the European Congress on Disability in Madrid (2003).

### ***Disabling barriers to mobility***

Waddington and van der Mei, in their discussion of the free movement provisions suggest that 'Community law does not (intentionally) seek to deny this right to people with disabilities' (1999: 8). In practice, however, the interpretation attached to concepts such as 'worker' and 'dependent family member', which are so central to accessing free movement rights, act as additional barriers to disabled people's mobility. This is quite apart from the physical barriers to migration and the impact of the disparity between disability related support available in different Member States. Let us look at these two concepts in more detail.

### **The concept of 'worker' under the free movement provisions**

The concept of work under EU law is central to the operation and enjoyment of the free movement provisions but it is not clearly defined in any of the Treaties or secondary legislation. It has, instead, been left to the European Court of Justice (ECJ) to articulate and develop its meaning. The traditional rationale underpinning the mobility entitlement of workers was primarily economic: that they would be contributing to the development of the market economy by transporting valuable labour and skills resources between the Member States.

The essential criteria for qualifying as a Community worker under the free movement provisions have now been clearly established by the ECJ in *Lawrie-Blum* (1986) as entailing the performance of services, for or under the direction of another (separate rules govern the self-employed), in return for remuneration. While initially these criteria implied a full-time, male breadwinner who was making a discernible economic contribution to society, the ECJ has demonstrated an increasing readiness over the past twenty years to construe the term more broadly to encompass a wider range of working patterns. This has coincided with and, indeed, precipitated a gradual departure from a strict assessment of the tangible economic value of the activity towards one that is more subjective and looks at the value of the activity to the life of the individual him or herself.

As such, the ECJ has reaffirmed the right of all workers in all Member States to pursue the activity of their choice within the Community,

irrespective of whether they are permanent, seasonal, temporary, part-time or full-time (*Levin* 1982), and regardless of whether they are supplementing their income by recourse to welfare benefits (*Kempf* 1986). The only limitation imposed is that the work must be 'genuine and effective' and cannot be carried out on such a small scale as to be regarded as marginal and ancillary to other activities carried out by the individual in the host state, such as studying or tourism, which are governed by different, more restrictive rules (*Raulin* 1992). One of the principal reasons behind these limitations on free movement entitlement is to protect Member States against the threat of so-called 'welfare tourism' whereby EU nationals may be motivated to move to other Member States under the pretext of carrying out 'work' but, in reality, in order to take advantage of more favourable welfare provision.

The expansion of the concept of work and worker has significant implications for disabled people, large numbers of whom are engaged in part-time, intermittent work (*Sly* 1996). According to recent EU figures, 15 per cent of the working age (16-64) population report disability, with 10 per cent reporting 'moderate disability' and 4.5 per cent 'severe disability' (Eurostat 2001). Within this group 46 per cent of 'moderately disabled' and 24 per cent of 'severely disabled' people are engaged in some form of work. However, as Barnes notes, disabled people's participation in the labour market tends to be characterised by their employment in 'poorly paid, low skilled, low status jobs which are both unrewarding and undemanding' (1991:65). Consequently, disabled people are more likely to experience lower levels of career advancement and under-utilisation of their skills and training when in work (*Thornton and Lunt* 1995:2). Thus, while the free movement provisions may open up to a greater proportion of disabled people of working age the prospect of working and living in other Member States they by no means represent a panacea for existing inequalities at national level.

### ***The status of job-seekers***

Case law also exists in relation to the status of unemployed Community migrants in pursuit of employment. In *Antonissen* (1991), for instance, the Court stated that jobseekers retain the status of worker and the right to move to another Member State to seek employment but that this right is not unlimited. For example in *Lebon* (1987) the ECJ held that 'those who move in search of employment qualify for equal treatment only as regards access to employment'. In other words, they can move to another country

in order to look for work but will not enjoy all the social and tax advantages attached to the status of worker until they have actually found work. This finding is problematic for those disabled people who require support systems (which may include statutory support or benefits) to be in place to enable them to seek and obtain employment. This dilemma is mitigated to a certain degree by the existence of EU legislation (Regulation 1408/71 supplemented by Regulation 574/72) which entitles jobseekers to maintain benefits in their country of origin for up to three months while they are abroad looking for work, although certain benefits such as the provision of equipment may be restricted. A further disincentive for potential disabled migrants is that, on returning to their 'home' Member State, they may have to undergo a new assessment before they can recover any further benefits or forms of social support.

### ***The status of voluntary workers***

Some forms of voluntary work are held to constitute 'work' under Community law. In *Steymann* (1988) a German national, resident in the Netherlands, was refused a residence permit by the relevant authorities on the basis that his contribution to the life of a religious community could not be regarded as 'economic' for the purposes of Community law. In return for his contribution, the community provided him with accommodation and 'pocket money'. The ECJ concluded that *Steymann* did, in effect, provide services of value to the religious community which would otherwise have to be performed by someone else (and presumably paid for) and, on that basis, he qualified as a worker.

The ECJ found that *Steymann's* contribution to the community via some plumbing work, general housework and participation in the external economic activities of the community (running a disco and laundry service) were indirectly remunerated through the provision of accommodation and modest living expenses. This decision is significant for the increasing number of disabled people engaged in user-involvement, in-service provision or in the organisation and running of user-led service providers, where they may be involved in irregular or less formalised types of consultation and training for which some sort of remuneration other than cash is made (Barnes 2003).

While decisions such as that of *Steymann* advance disabled people's opportunities and status as Community migrants, it is interesting to note that the majority of ECJ cases considering the concept of work and the definition of 'Community worker' do not explicitly refer to disability or

take account of the specific barriers disabled people encounter when seeking to participate in the labour market. In one of the few cases concerning a disabled person's claim, that of *Bettray* (1989), the Court rejected the claim of a disabled German man employed in a sheltered environment to be considered as a Community worker. *Bettray* was employed by a special Dutch scheme which aimed to 'maintain, restore or develop the capacity for work' of those who are able to undertake some form of economic activity but who are not in a position to undertake regular employment either because of disability or substance misuse. The ECJ held that such schemes could not constitute 'genuine and effective' work as the activities were tailored to fit the individual and were specifically aimed at rehabilitation and reintegration into the mainstream labour market. The ruling in *Bettray*, therefore, significantly enhances the worker status of over 300,000 disabled people in sheltered employment (Samoy 1992), because as Waddington and van dei Mei (1999) point out, contrary to the image of sheltered employment depicted in *Bettray*, the work of most sheltered workshops can be considered equally as 'genuine and effective' as that of most mainstream jobs.

While the extension of the Community concept of work and the definition of what constitutes a Community worker to include less traditional forms and patterns of work often undertaken by disabled people is to be welcomed, a sizeable proportion of disabled people are not, for various reasons, active in the labour market in any sense. In fact, according to 2001 Eurostat figures, 46 per cent of 'moderate' and 61 per cent of 'severe' disabled people are reported as being economically 'inactive'. This begs questions as to the availability of an alternative status that triggers access to the freedom of movement provisions: the status of a dependent family member.

### ***The status of 'dependent' family members under the free movement provisions***

The second group to enjoy certain rights by virtue of the free movement provisions is the families of Community migrant workers. This group encompasses many disabled family members who do not, for various reasons, undertake paid employment, such as disabled children and young people, and (increasing numbers of) older disabled people. Family members who move with a migrant worker can access the same welfare-related (including disability benefits) and other social benefits in the host state as the worker and, in that sense, derive a highly privileged status from their

relationship with the worker (*Michel S* 1973). However, limitations are placed on who may claim these derived rights by the way in which Community law defines who and what constitutes 'family' and 'dependency'. Again, in much the same way as the definition of work and 'worker' has evolved, these definitions and, perhaps more noteworthy, the ideologies and presumptions underpinning them have significant implications for disabled people.

### ***The Community definition of 'family' under the free movement provisions***

Currently, Community law specifies that the only family members who are entitled to move with the migrant worker and have access to the range of social and tax benefits in another Member State are: the worker's spouse (legally married, heterosexual); their children who are under the age of 21; any other children who are over the 21 but who are dependent; and dependent relatives in the ascending line (Regulation 1612/68, Article 10). It is the interpretation attached to dependency that impacts most significantly on disabled people generally.

### ***Defining 'dependency' under the free movement provisions***

A dependent relationship is, to a large degree, presumed in relation to children under the age of 21 and to the older parents of Community workers. However, the ECJ has so far failed to provide any clear guidelines as to what exactly constitutes dependency. It mostly clearly associates the state of dependency with financial dependency. For example in the case of *Inzirillo* (1976), the ECJ ruled that the son of an Italian migrant worker was entitled to claim a French disability benefit based solely on his financial dependency on his parent. However, financial dependency is not taken to require residence with the migrant worker. The ruling in *Diatta* (1985) held that a 'dependent' family member is not required to live in the same household as the migrant worker as long as some form (however superficial) of financial dependency can be demonstrated. Ironically, the financial dependency required for a family member to claim social entitlement may be extinguished once that claim is realised, making dependency 'a matter of initial [qualifying] fact' (Ackers and Dwyer 2002:44).

More appropriate in the context of disability would be a broader interpretation of dependency by the ECJ to encompass relationships of physical and emotional support, which are often of greater significance to those concerned than financial support, as this would

open up derived rights to a large number of disabled (and non-disabled) family members.

The way in which dependency is construed within this context is particularly problematic from a social model perspective. A central tenet of the disabled people's movement has been a rejection of a presumed automatic link between impairment and dependency with a focus instead on less physically based notions of independence (Morris 1993; Shakespeare 2000). This is encapsulated in the philosophy of independent living which distinguishes between the physical doing of an act for oneself (such as dressing or feeding) and exercising choice and control over how these activities are undertaken. Adopting an independent living approach to dependency involves recognising that:

no one in a modern industrial society is completely independent, for we live in a state of mutual interdependence. The dependency of disabled people, therefore, is not a feature which marks them out as different in kind from the rest of the population but as different in degree (Oliver 1989: 83-4).

Defining 'family' (and indeed 'work') to account for the interdependence between family members (and therefore the contribution that all family members make however financially or physically dependent they may be perceived to be) would have significant implications for the accessibility of the free movement provisions. It may also have implications for the hierarchical nature of entitlement as it would be difficult to sustain a privileged position for workers if other aspects of family life were recognised as equal to the breadwinning role.

### ***Adopting a rights-based approach to European Citizenship***

While the free movement of persons provisions, and particularly the extension of the concept of worker, have achieved much in enhancing the migration potential of disabled people, it is important to note their limitations. First of all, the social and economic rights arising out of free movement are based firmly on an ethic of non-discrimination. In that sense, they do not create additional social rights but merely provide migrants with access to these rights under the same conditions as nationals in the Member State to which they migrate. Consequently, the nature and level of benefits (for example, those yielded by social welfare systems) are only as good as those already available to disabled nationals within the host state. Attaining EU migrant worker or family status does not, in that sense, address

the inequalities already inherent in national laws and policies affecting disabled people.

A second limitation of the free movement provisions is their emphasis on economic contribution as a basis for entitlement. Essentially, the extent to which disabled people enjoy rights in this context bears direct relation to their level of economic activity. Feminist and, more recently, children's rights critiques of EU citizenship have in particular challenged EU law's devaluation and, thus, marginalisation of economically subordinate groups in its allocation of tangible entitlement (Ackers and Stalford 2004).

These limitations suggest that a shift towards a more coherent rights-based approach to EU citizenship could effectively address the deficiencies of free movement-based conceptions of citizenship. Indeed, citizenship is not just about securing access to social entitlement. It provides an important oratory for enhancing individuals' sense of autonomy and agency and for promoting effective participation. A broader, rights-based approach to citizenship incorporates these more ideological notions of participation, inclusion and equality while acknowledging individuals' contributions as everyday social actors (Cockburn 1998). Lister notes in this respect:

social citizenship rights also promote the 'de-commodification of labour' by decoupling the living standards of individual citizens from their 'market value' so they are not totally dependent on selling their labour power in the market (1997: 17).

Much remains to be achieved, however, to translate these ideologies into more inclusive, tangible entitlement for disabled people. So far, the EU has stopped short of implementing any binding law on Member States in respect of disability issues, opting instead for less controversial, aspirational, non-binding (or 'soft law') initiatives aimed primarily at facilitating the professional integration of disabled people. Even Article 13 of the EC Treaty, by which the 1997 Treaty of Amsterdam extended the long-standing prohibition of discrimination on grounds of nationality to other grounds including disability, has yet to be fully exploited as a legal basis on which to address the specific needs of EU nationals with impairments. Indeed, the European Disability Forum did submit proposals in 1999 for a specific disability directive based on Article 13, similar to that already implemented in the context of race equality. This recommended imposing specific obligations on Member States to take into account the impact of all laws and policies on disabled people, not only in an employment context,

but also in relation to housing, education, welfare and environmental initiatives.

It was not until the end of 2003, however, that the Commission made any real political commitment to act on the proposals put forward by the EDF and other lobbying organisations. On 30 October, it presented an Action Plan to improve and facilitate the economic and social integration of disabled people in an enlarged Europe. The first two-year phase of this six-year plan, which started in 2004, focuses on creating the conditions for disabled people to access the mainstream labour market. This is accompanied by a commitment from the Commission to issue bi-annual reports on the overall situation of disabled people in the enlarged EU as a means of identifying new priorities for subsequent phases of the Action Plan.

Notwithstanding the fact that these measures are targeted primarily at those who have the capacity to engage in full-time, paid employment, it is with some optimism that we might forecast the direction of the wider EU disability agenda, particularly in view of recent constitutional developments. Perhaps one of the most promising portents in this regard is the increasing prominence of human rights at EU law-making level, most notably through the introduction in December 2000 of the *Charter of Fundamental Rights in the European Union* (CEC 2000). This document sets out, for the first time in the European Union's history, the institutions' commitment to upholding and advancing a range of civil, political, economic and social rights in favour of all persons resident in the EU. Most of the 54 provisions contained in the Charter (which are heavily inspired by the provisions of the 1950 European Convention on Human Rights) are of direct or indirect relevance to disability with Article 26 of the Charter explicitly stating that:

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

These measures concern education, vocational training, ergonomics, accessibility, mobility, means of transport and housing as well as access to cultural and leisure activities, giving it a much wider scope than many of the other employment-related initiatives presented previously.

The Charter is currently only of declaratory (non-binding) force, although it has been incorporated in its entirety into Part II of the draft EU Constitution currently under negotiation. The new Article 26 is now

enshrined in Title III of Part II (entitled 'Equality') and is supported by other provisions such as Article 20: 'Everyone is equal before the law'; and Article 21 (1):

Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.

These measures, which reflect the spirit of Article 13 EC, are further reiterated in Part III Title I of the draft constitution entitled 'The Policies and Functioning of the Union'. Specifically, Article 3 states that:

In defining and implementing the policies and activities referred to in this Part, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

Finally, Part III, Title II acknowledges the institutions' capacity to enact binding laws with a view to combating discrimination on these grounds:

Article 8 (1): Without prejudice to the other provisions of the Constitution and within the limits of the powers conferred by it upon the Union, a European law or framework law of the Council of Ministers may establish the measures needed to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. The Council of Ministers shall act unanimously after obtaining the consent of the European Parliament.

While institutional activity is restricted to the areas of competence articulated by the constitution, if adopted, and implemented, these provisions will provide an important template on which to enact more tailored initiatives in favour of disabled people, thereby detaching tangible rights from the economic imperative of the free movement provisions.

## **Conclusion**

In this chapter, we have aimed to illustrate the way in which Community definitions of the concepts of work, family and dependency have significant implications for the citizenship of disabled people. The evolution of the concept of work to include new forms and different working patterns has opened up the status of Community worker to a larger percentage of disabled people. This ignores, however, the growing tension within disability studies and the disabled people's movement about

the priority afforded to inclusion in the labour market (Barnes 2004). Early social model thinking clearly linked disablement with exclusion from the labour market (Oliver 1990) and therefore argued that reintegration was a precursor to disabled people's full participation and citizenship. Alongside this the independent living movement has adopted a different focus. The movement emerged largely from attempts to replace large-scale residential institutional care with services and support required for disabled people to live independently while emphasising the importance of acknowledging individuals' interdependence.

Furthermore, focusing solely upon paid employment as the precondition for the full exercise of citizenship rights provides a narrow view of contribution. In an economy driven by consumption the consumer plays a 'productive' role. This is particularly pertinent for disabled people around whom a vast 'disability industry' has emerged employing thousands in the direct provision of care and medical support as well as indirectly through the production of aids and adaptations. Likewise, as feminist writers have suggested (Ackers 1998; Lister 2002), unpaid or informal 'care' work undertaken largely by women (including disabled women) plays an important role in both supporting the traditional notion of a single family breadwinner and of dispersing much of the societal costs associated with supporting children, disabled and older people.

Quite aside from these ideological debates, we have identified a range of additional barriers that restrict disabled people's ability to effectively exercise free movement. The disparity between social security systems and welfare provision in different Member States acts as a deterrent to mobility. Moving between Member States may result in the loss of existing benefits in the sending state and there are often qualifying periods before new claims can be made in the receiving state. Moreover, the conditions under which disabled people can export certain benefits are decidedly restrictive. Non-legal barriers include barriers to physical movement especially in terms of inaccessible public transport; in addition to well-documented discrimination in employment, housing, public support, and assistance (Waddington and van dei Mei 1999).

Thus while there may be a growing formal commitment at EU-level to extend full citizenship and its accompanying free movement rights to disabled people (on the basis of non-discrimination), considerable obstacles still exist at national level which hamper their enjoyment and for which the EU cannot currently claim legislative competency. In order to engage disabled people in a more meaningful way in the EU polity, therefore,

active citizenship requires a departure from traditional free movement-based interpretations which, through their elevation of formal employment, inevitably and consistently exclude a large proportion of them.

It is in this respect that a broader rights-based approach to citizenship becomes an important means by which to extend disabled EU nationals' rights beyond the economic imperative of the free movement provisions towards a more inclusive and positive declaration of their specific needs and value. As well as seeking to promote the substance of tangible entitlement, a rights-based model of citizenship provides an important platform not only for promoting individual autonomy and agency but for exposing and crediting disabled people's contribution to society through their formal and informal, direct and indirect participation in the labour market.

The EU has certainly started to adopt a more proactive stance on disability issues in the past decade or so, manifested in a number of subtle budgetary, institutional and legislative developments. However, if European citizenship is to be regarded as more than simply a showcase for modest rights available primarily to economic actors under the free movement provisions, there is an urgent need for a more enforceable and confident declaration of disabled people's status at this level.

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