National contexts affecting the lives of disabled children in Denmark, France, Germany, Ireland, Italy, Sweden and UK (England and Northern Ireland)

Volume 1

Kay Tisdall

Editor: Allan Colver

Commissioned by the SPARCLE research project which studies the quality of life and participation of children with cerebral palsy in Europe

Funded by European Union Research Framework 5 QLG5-CT-2002-000636

July 2006

Published by University of Newcastle upon Tyne
Robinson Library, Newcastle NE2 4HQ

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Acknowledgements

This review needed the assistance of many people who provided literature, suggestions, and contacts. Their number is too large to list fully but their contributions were most welcome.

Kathryn Faulkner, Michael Gallagher, Alaina Greenman, Sandy Gulyurtlu, and Heike Tarara were employed to locate and assess relevant literature, while Paul Norris undertook statistical analyses and Mark Priestley provided consultancy advice. These people’s help is gratefully acknowledged and their work is reflected in this report.

The SPARCLE partners assisted the gathering of local information and answered numerous questions. They are Allan Colver, Kathryn Parkinson and Heather Dickinson, Newcastle University, Newcastle, UK; Eva Beckung, Göteborg University, Göteborg, Sweden; Jackie Parkes, Queens University, Belfast, UK; Jérôme Fauconnier, Université Joseph Fournier, Grenoble, France; Vicki McManus, Enable Ireland, Cork, Ireland; Susan Michelsen, NIPH, Copenhagen, Denmark; Giorgio Schirripa (deceased) and Marco Marcelli, ASLV, Viterbo, Italy; Catherine Arnaud, INSERM, Toulouse, France; Ute Thyen, Luebeck, Germany

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FOREWORD

This review brings together for the first time factors relevant to the lives of disabled children which operate at national level in seven European countries. It is a unique collation, although the review does not cover all EU countries and will inevitably become out of date.

The review was commissioned to inform a European research study (SPARCLE[1]) across seven countries and is published here as a stand alone document so as to:

- raise the profile of childhood disability
- emphasise opportunities for environmental adjustment to reduce disability as a balance to the emphasis, especially in childhood, of medical and therapeutic interventions to improve function
- be a resource for developers of social policy
- be an example of a report that could be adopted by the EU for regular collation and updating across all EU countries

The content of the review will be incorporated in to the SPARCLE project in two ways:

- by comparing such national context with the actual experience of disabled children and their parents
- by assisting with qualitative and quantitative interpretation of results

The report is primarily a resource and is not set out or edited to be read cover to cover. It is in two volumes, with chapters by context domain in the first volume and by country in the second. Each of the country chapters is set out in the same way with a Table about each context domain starting each section.

Kay Tisdall

Allan Colver

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[1] www.ncl.ac.uk/sparcle/
protocol at: www.biomedcentral.com/1471-2458/6/105

Chapter One: Introduction

This review forms part of a larger study called SPARCLE that aims to identify which environmental factors, if improved, will yield the greatest benefits for disabled children[1] and their families.

The SPARCLE study is funded by Research Framework 5 of the European Union. The study involves partners from seven countries, Denmark, France (2 centres), Germany, Ireland, Italy, Sweden and the UK (England and Northern Ireland) that have regions with population based registers of children with cerebral palsy. Each register covers all children with cerebral palsy in a defined geographical area. 818 children with cerebral palsy and their families were visited.

Cerebral palsy is the most common cause of significant motor impairment in childhood and associated with cognitive and sensory impairments. Children with cerebral palsy are at considerable risk of being disadvantaged with respect to social relationships, education and employment prospects, even though there are infrastructures and systems in place in all seven countries to respond to the child's and family's needs. Such arrangements form some of the environmental factors included within the International Classification of Functioning, Disability and Health (World Health Organisation). Environmental factors are defined as the physical, social and attitudinal environment in which people live and conduct their lives.

This review seeks to identify environmental factors at a national, macro level across the seven countries. The review's remit was to consider the existing literature in European publications (European Union and Council of Europe), international reports and academic research. **This introductory chapter begins by setting the**

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[1] Terminology is contentious within disability studies and the disabled people's movement. In the UK, there has been a strong demand for 'disabled people' rather than 'people with disabilities'. The former phrase is seen as emphasising the "structural and cultural location of disability, as a form of social oppression residing outside the person" (Priestley 2001: xvii). Yet, in North America, the phrase 'people with disabilities' has been preferred because it emphasises people first and disability is but one characteristic people may have. These debates are further complicated by translation and working across countries.
In this review, the phrase 'disabled people' (and disabled children, disabled adults etc.) will be used except when making a direct quotation.

scene in relation to: current theoretical conceptualisations of disability and childhood; key rights documents in relation to disability and children at United Nations and European levels; and comparative welfare regime research. The chapter ends by describing the methodology for this review.

Disability and Childhood Studies – conceptualisations

The 'social model' of disability has been central to the academic development of disability studies. Developing out of the disability movement, writers such as Abberley (1987) and Oliver (1990) attacked the dominance of the individualised model of disability that equated disability with impairment and located the 'problem' within the disabled person. Instead, such writers advocated redefining disability as social oppression experienced by those who were labelled as different, whether in their bodies, minds or both. Disability is caused by societal and structural barriers – whether they be environmental such as inaccessible buildings, institutional such as segregated schooling, or attitudinal.

The social model, as originally expressed, has not been without its critics. For example, it has been criticised for failing to take adequate account of differences by gender and people with learning difficulties. It has been criticised for ignoring impairment altogether and writers such as Crow (1996) and Thomas (1999) have sought to reintroduce and integrate the notion of impairment with disability. The social model also has been criticised for being based on an adult model and not paying sufficient account to children and childhoods. Oliver (1990), for example, theorised 'disability' as a creation of the capitalist mode of production, with disabled people defined as non-productive in the work force and by dominant ideologies. This sits uneasily with the Western assumption that *all* children are not in the work force. Are all children, then, to be considered disabled by society?

Childhood studies have an even more recent theoretical development, in the 'new' sociology of childhood. **Fundamentally, childhood is recognised as a variable of social analysis, along with other categories such as class, gender, ethnicity – and disability.** Childhood is a social construction, as described by this much-quoted sentence: “A child’s immaturity is a biological fact: but how this immaturity is understood and how it is made meaningful is a cultural one” (Prout & James 1990: 7). Children are not seen as passive objects owned by their parents but rather as social actors in their own right, contributing in various ways (whether recognised or not by adults) to their families and their communities. In other words, children should be seen as ‘human beings’ and not just ‘human becomings’ (Qvortrup 1994). In the 1990s, the sociology of childhood set itself up against past theories of child development, which were criticised as falsely setting up the ‘gold standard’ of adulthood and reifying developmental ‘norms’.

Disability studies and childhood studies thus have a number of key similarities. They both question key biological differences – impairment or age – and instead point to the social constructions of disability and childhood. This leads to the recognition that society can create barriers to disabled adults and children that prevent them from being recognised as citizens, to participating fully, to being valued. Both approaches pose questions about the assumptions that children or disabled people are necessarily incompetent. They question setting up a false ‘norm’, whether it be the norm of a non-disabled person in contrast to the ‘abnormal’ disabled person or the norm of an adult in contrast to the deficient child. And both disability and childhood studies have been influenced by, as well as contributing to, the rights policy agenda for disabled people and children respectively.

International and European Policy Context

At international level, there are 3 key policy contexts for disabled children[2]:

- UN Convention on the Rights of the Child (UNCRC)
- UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN Standard Rules)
- World Health Organization’s International Classification of Functioning, Disability and Health (ICF)

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[2] For other binding and non-binding international documents, see http://www.un.org/esa/socdev/enable/disovlf.htm (6.6.04) and Hodgkin and Newell (2002)

The UN Convention on the Rights of the Child was passed by the UN General Assembly in 1989. It became an internationally agreed standard of minimum rights for children. States that ratify the Convention are committed to translating its principles into law, policy and practice. The Convention contains 54 Articles concerning civil, economic, social and cultural rights. Article 1 defines the child under the UNCRC as "every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier". The Convention has four key principles:

- Article 2: All rights guaranteed by the Convention must be available to all children without discrimination of any kind
- Article 3: The best interests of the child must be a primary consideration in all actions concerning children
- Article 6: The inherent right to life and the State's obligation to ensure the child's survival and development
- Article 12: Children's views must be considered and taken into account in all actions concerning children, subject to the children's age and maturity

Beyond the generality of the UNCRC, two articles are of particular importance for disabled children. The first is Article 2, which prohibits discrimination. Disability is specifically mentioned as a ground. The second is Article 23, which addresses the rights of disabled children. The full article is included on page 15. This Article begins with a clear statement of intent: "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, self-reliance, and facilitate the child's active participation in the community". It then proceeds to concentrate on provision: assistance for 'special care', which should be free of charge where possible. Such assistance should aim to ensure the disabled child has effective access to a range of services – education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities. Again, the UNCRC strongly words how such assistance should be given: "in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development".

The UNCRC is the most ratified of any international Convention. This may be because the UNCRC has relatively weak enforcement powers. Ratifying States must report regularly to the UN Committee on the Rights of the Child, which is composed of experts from different countries. States must report the first time after two years and then every five years. The Committee comments on, and discusses with states, the reports; it also can visit countries to learn more and disseminate information on the Convention.

The seven countries in this review differ on the legal power of the UNCRC once a country has ratified it. At one extreme is France, where ratification and publication of the UNCRC resulted in it taking precedence over domestic law. At the other extreme are Ireland, Italy, and the UK, where ratification of the UNCRC did not incorporate it into domestic law. Domestic law must be changed in order for the UNCRC to have legal effect. In between are:

- Denmark: once ratified, the UNCRC did not automatically become part of domestic law. It is applicable to courts and administrative authorities.
- Germany: once ratified, the UNCRC became part of German law and the UNCRC would be taken into account in interpretation of Germany law and ordinary statues
- Sweden: once ratified, Sweden translated the UNCRC into enforceable law. With this done, the UNCRC could be evoked in decisions about domestic law. (Children's Rights Information Network 2004)

The UN Standard Rules were adopted by the UN General Assembly in 1993 (resolution 48/96). The introduction to the Rules clearly sets out the requirement for 'equalization of opportunities':

- The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for planning of societies and that all resources must be employed in such a way to ensure that every individual has equal opportunity for participation. (para 25)

There are 22 Rules, which are divided into four parts (see page 21 for Rule titles). Children are specifically mentioned in a number of Rules:

- Rule 1 (8-9): awareness-raising should be part of the education of disabled children as well as for all children
- Rule 2 (3 and 5): disabled children should receive the same level of medical care as other people and appropriate advice should be given to parents
- Rule 4 (5): assistive devices and equipment should consider the special requirements of disabled girls and boys in design, durability and age-appropriateness
- Rule 9 (3): changes are required to negative attitudes in regards to marriage, sexuality and parenthood of disabled people, especially of girls and women with disabilities

There is a rule specifically on education, which relates to children as well as adults. This rule requires the education of disabled people to be part of the general education system; compulsory education should apply to disabled children along with all children. 'Integrated' education should be encouraged and mainstream schooling must have adequate accessibility and support services, clearly stated policies, flexibility in curriculum and quality materials and teaching. Parents' groups and organisations of disabled people should be involved.

The Rules are not binding on states but, unusually for such instruments, have a monitoring remit. A Special Rapporteur is appointed, along with a panel of experts, whose role is to promote and monitor the implementation of the rules. This Special Rapporteur is required to send out questionnaires to States, UN and other organisations, to monitor implementation plans. Degener and Quinn (2002) note with some criticism that the monitoring body was placed under the UN Commission for Social Development rather than under the Commission on Human Rights. Disability organisations are advocating for a full Convention, which will have greater force than the non-binding Rules. It is proposed that there would be a specific article on the rights of children with disabilities.

The UNCRC and the UN Standard Rules are both set within the broader human rights context of the UN. They are special because they consolidate rights expressed in other human rights instruments and, vitally, focus particularly on children and disabled people respectively. The creation of their own reporting requirements and structures arguably gives a new impetus for lobbying and change at a national level, as well as at an international level.

They have similarities. They are both concerned not only with protection and provision but also with participation. Article 12 in the UNCRC was a radical addition to other texts including the rights of children. Similarly, the UN Standard Rules put forward definitive statements about the involvement of disabled people in decisions about themselves individually, as well as organisations of disabled people being involved in decisions more generally.

Both documents promote ideas of inclusion and/ or normalisation of disabled children and young people, and their involvement in their own communities. Neither the UNCRC nor UN Standard Rules, however, precludes segregated provision or, in particular, segregated schooling. The Standard Rules addresses this directly: “In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered” (Rule 6 (8)). States should aim towards integrating special education into mainstream education. But an exception remains: deaf and deaf/ blind people may have their communication needs more suitably provided for in special schools or classes (Rule 7 (9)).

The UN Standard Rules apply to children just as the UNCRC applies to (young) disabled people. However, both have been criticised for not fully addressing the rights of disabled children. In a UN report commenting on the Standard Rules (2002), it was stated that disabled children are inadequately considered, along with gender, certain groups such as those with developmental and psychiatric disability, and housing. Lansdown (2001) criticises the UN Convention on the Rights of the Child, for the limits of Article 23: “By focusing exclusively on individualised provision of ‘special needs’, the text reaffirms traditional presumptions that the child is in some way ‘deficient’, and can only be helped by services to overcome the deficiency” (18). In the requirements for reporting, Article 23 is grouped with other articles on health and welfare; Lansdown critiques this for continuing to place disabled children within a welfare or medical model of disability. Government reports to the UN Committee on the Rights of the Child were said to provide little attention to disabled children's rights (Lansdown 2001).

The UN Standard Rules make explicit mention of the **World Health Organization's 1980 classification of impairment, disability and handicap.** The Rules themselves recognise the criticisms of the WHO classification, as being too medical and too centred on the individual. It does not satisfactorily deal with the interaction between societal conditions or expectations, and individuals' abilities (see para 20). With these trenchant criticisms from the disability movement, the classification was revised through considerable consultation and a new classification – the **International Classification of Functioning Disability and Health (ICF)** – was agreed by the World Health Assembly in 2001. The classification is described as follows (WHO 2001: 10):

- Part I: Functioning and Disability
    - Body Functions and Structures
    - Activities and Participation
- Part 2: Contextual Factors
    - Environmental Factors
    - Personal Factors

These and other concepts are further defined. For example:

- Impairments are problems in body function or structure such as significant deviation or loss.
- Activity limitations are difficulties an individual may have in executing activities.
- Participation restrictions are problems an individual may experience in involvement in life situations.
- Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

The three key international policy contexts described above have had a considerable impact on European policy, both in the European Union and in the wider Council of Europe. Numerous European Union resolutions have paralleled the provisions of the UNCRC or the Standard Rules. For example, in 1990 a resolution of the Councils and Ministers of Education was agreed concerning 'integration of children and young people with disabilities in ordinary systems of education'. The European Commission adopted a policy statement based on the UN Standard Rules in 1996, which was followed by the resolution by the Council of Ministers later that year. The Council of Europe made a recommendation in 1990, supporting the UNCRC.

The European Union's competencies are set by its treaties and its historical origins in employment and trade concerns have limited the attention to children and disability issues. This is amply evidenced by the statement in the European Action Plan on disability: "employment remains the most critical factor for social inclusion" (2003: 3). In 1997, the Treaty of Amsterdam included Article 13, which allowed for appropriate action to combat discrimination on a range of grounds, including age and disability (see chapter 3 for further discussion). Article 13 thus brought greater attention to these issues in the European Union.

This gradual expansion is evident in the *Charter of Fundamental Rights of the European Union*, introduced in December 2000. At present, the Charter is not binding but the draft European Constitution (2004) incorporates the Charter. Amongst the Charter's 54 Articles are particular rights to services (e.g. education, social services, health care) and a right to good administration (Article 41). There is a general article on children's rights to protection and care, to express their views freely, that their best interests should be a primary consideration in all actions relating to children, and their right to maintain contact with their parents unless this is contrary with children's best interests (Article 24). Article 26 states that the Union will respect and recognise the rights of disabled people to benefit from measures designed to ensure "their independence, social and occupational integration and participation in the life of the community".

The Council of Europe has had a considerable focus on children's issues, with several collaborative programmes and a number of legal initiatives (such as the European Convention on the Exercise of Children's Rights, the European Convention on Human Rights (ECHR) and the European Social Charter). The Council is also active on disability issues. A recommendation in 1992 sets out the need for a coherent policy for people with disabilities. Numerous resolutions have picked out particular policy areas, such as the introduction of universal design in training curricula (2001) and equal opportunities for pupils and students with disabilities in education and training (2003). The ECHR covers predominantly civil and political rights and has system of judicial enforcement through the European Court of Human Rights. Within the Convention is an anti-discrimination article, Article 14 (see Chapter 3). The European Social Charter contains other economic, social and cultural rights. The Charter was redrafted in 1996. Principle 15 states that disabled people have "the right to independence, social integration and participation in the life of the community". The subsequent Article 15 addresses, in particular, education and vocational training, access to employment, and full integration and participation into communities by measures such as technical aids, and enabling access. The enforcement mechanisms are considerably weaker than those for the European Court, however, with periodic reporting to a Committee. A new enforcement mechanism permits a non-governmental organisation with a particular status to lodge a 'collective complaint' with the European Committee of Social Rights.

The European Year of Disabled People (2003) co-ordinated and encouraged activities both at the European and national levels. One of the results is a European Action Plan in relation to equal opportunities for people with disabilities (Commission 2003). This describes forthcoming work: a European Union Anti-Discrimination Programme, the National Action Plans on social inclusion, and a Green Paper on future strategy to combat discrimination.

Comparative Research

Creating and disputing classifications of welfare regimes are popular activities within social policy; **it is taken for granted that welfare states *can* be grouped around certain distinct regimes** (Abrahamson 1999: 394-395). Esping-Andersen catalysed recent developments, with his publication in 1990, *The Three Worlds of Welfare Capitalism*. He identifies three types of welfare regimes divided by their extent of 'decommodification'[3] and welfare state stratification. The three types are:

- Liberal welfare states: means-tested assistance, modest universal transfer or modest social insurance plans predominate. e.g. Australia, Canada, Ireland, New Zealand and the UK.
- Conservative-corporatist states: social rights are deeply enshrined but preserve status differences. Private insurance and occupational fringe benefits are marginal. Important roles are maintained for the church and the family. e.g. Austria, Belgium, Finland, France, Germany, Italy, Japan, the Netherlands, and Switzerland.
- Socio-democratic states: universalism and de-commodification are extended to middle-class people, with the family and the market playing minor roles. e.g. Denmark, Norway and Sweden. (based on Esping-Andersen 1990; Hill 1996; Kleinman 2002)

Others have discussed where particular countries should be placed; or whether the classification should be changed. (Castles and Mitchell (1993), Scruggs and Allan (2004)). For example, it is disputed how to place southern European countries – are they simply underdeveloped welfare regimes, modifications of a type, or a particular welfare type on their own? Ferrera (1996) makes an argument for the later. They have four main characteristics: they are highly fragmented and corporatist in their income maintenance system, with internal polarization; their national health services, in contrast, tend to be based on universalistic principles; there is a mix between public and non-public actors and institutions in welfare; and clientilism persists.

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[3] De-commodification occurs when a service is rendered as a matter of right, and when a person can maintain a livelihood without reliance on the market. (Esping-Andersen 1990: 21-22)

With the popularity of classification comes criticism. It is noted that Esping-Andersen may have spread his system widely but it is reliant on particular measures – predominantly income maintenance. Other systems around different policy areas and therefore look very different to Esping-Andersen's.

Major criticisms are presented by feminist scholars who argue that services must be considered as well as cash (Daly and Lewis 1998). Annttonen and Spilila (1996) suggest a four-part division: abundant social care services; scarce social care services; abundant services for elderly people but scarce services for children; abundant services for children but scarce services for elderly people. A comparison of some of systems for this review's seven countries, is given in Table 1.1.

Table 1.1: Welfare State Regime Typologies, by 7 Countries

	Denmark	France	Germany	Ireland	Italy	Sweden	UK
Esping-Anderson (1990) Income maintenance							
Liberal welfare state: means testing, modest universal transfers or social insurance, strict entitlement rules, state encouragement of market	Low	Medium	Medium	Low	Medium	Low	Medium
Conservative corporatist state: strong state welfare orientation, minimal private insurance, family central	Medium	**High**	**High**	Medium	**High**	Low	Low
Social democratic welfare state: state is the principle way to relaise social rights, graduated universal insurance system, full employment commitment	**High**	Low	Medium	Low	Low	**High**	Medium
Sainsbury (1994) Adding family welfare orientation, state support for women working, payment of family benefits to women							
Protestant social-democratic welfare states	✓					✓	
Protestant liberal welfare states							✓
Advanced Christian Democratic welfare states (often but not necessarily Catholic)		✓	✓				
Late female mobilisation welfare states				✓	✓		
Annttonen and Sipila (1996)							
Abundant care services	✓					✓	
Scarce social care services			✓	✓			
Abundant care services for older people but scarce service for children							✓
Abundant care services for children but scarce services for older people		✓			✓		

What about disability and childhood? Just as feminist writers criticised mainstream writers for failing to incorporate caring and gender in their analyses, so feminist and mainstream writers might be criticised for treating disabled people and children as dependants and failing to consider them as units of analysis. Disability is, by its very definition, a test of society and its associated systems. Who is included or excluded by particular services and provisions? Certain groups of disabled people tend to be high users of services. Children and young people are high users of services as well. Disabled children thus combine these factors – they are litmus test for society and services as well as being high users of services.

Feminist research referred to above has considered child care for younger children but this has predominantly been in relation to the gendered division of labour rather than from a child's perspective. Some work has considered welfare regimes in relation to children. For example, Ditch and colleagues (1998) considered the child benefit package and the cost of having children in 15 European Union countries. Their clusters looked like:

- Most generous provision – Belgium, France, Germany, Luxembourg
- Middling provision – Austria, Denmark, Finland, Sweden, UK
- Low levels of provision – Greece, Ireland, Italy, the Netherlands, Portugal, Spain

Such work has been updated and extended by Bradshaw and Finch (2002), which is reported in Chapter 5. There is a considerable amount of work classifying aspects of education policy, and special educational policy. This has been held somewhat separately from the mainstream social policy literature and will be discussed in Chapter 4.

Hurst (1995) provides a three-part division of European countries based on disability issues. First, there are the Nordic countries and the Netherlands who have a "long reputation of human rights and equality of opportunity for all their citizens". This results in financial commitments by the state to service provision and the inclusion of consumers in consultation processes. There are high levels of integrated education and disabled people are not institutionalised. Second, countries such as France, Germany, Spain and UK are labelled as ‘colonial’. They have less and more varied provision than the first category. Their common characteristic is the charity ethic. The concept of consultation is novel, if recognised at all. Third, under-developed countries share this charity ethic and a separatist attitude. Disabled people’s organisations are weak. Greece, Ireland, Italy, and Portugal are included here. The basis of Hurst’s division is not based on systematically analysing data but rather her own views based on the above characteristics of disabled people’s voice, segregation, and provision.

The literature[4] warns to take care in comparative research. For example, country-by-country analysis can ignore differences within countries and falsely present a consensus that in fact does not exist. They can mistake similar labels for similar concepts. The influences of religion, other values and historical developments can be ignored, which can give a policy particular meaning. Further, a focus on one policy can ignore how it interacts with other policies – and then how these are ultimately experienced by people living in those countries.

The present review can not escape these difficulties. It is predominantly a publications review, on publicly-available sources available in print or on the web. It acknowledges that it focuses on national policy, while looking for information on regional differentiation. It will benefit from being paired, in due course, with the systematic data being gathered from parents and disabled children themselves in the wider SPARCLE study. This will help address how policy is actually experienced and combined in practice.

Methods

The project started by seeking to identify the ‘ideal’ analytical framework to consider policies that affect disabled children, aged between eight to 12 years, in the seven European countries. It emerged from three sources:

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[4] For example, see Ackers and Stalford 2004; Ainscow and Haile-Giorgis 1998; Booth and Ainscow 1998; Kleinman 2002

(1) The priorities that disabled children and their families themselves have identified, from other research studies here in the UK and elsewhere, that affect their quality of life now and in the future. Two examples of such studies are cited below:
In Beresford and Sloper's (2000) study, young people with chronic illness and physical disabilities wanted the following information:

- dealing with negative emotions
- living with physical symptoms
- living with unanswered questions
- dealing with parents
- dealing with peers
- managing other social situations
- living with restrictions on lifestyle
- maintaining a positive attitude
- planning for the future
- managing at school

Mitchell and Sloper (2000) list topics that parents have prioritised for information. These parents were carers of children with 'severe' disabilities:

- Benefit entitlements
- Different forms of child care available and respite provision
- Opportunities when young people leave children's services
- Support for the whole family
- Support groups
- Friendships, relationships and sexuality
- A particular disability or condition
- Help in dealing with behavioural and emotional problems
- Knowing your rights and how to complain
- Housing options and adaptations
- Leisure activities

These were added to, in the SPARCLE project, with data collated from focus groups with parents of disabled children in the 7 countries of the study.

(2) Contributions from service and environmental analyses in disability and childhood studies. This predominantly drew upon the 3 key international context described earlier, i.e. the UN Convention on the Rights of the Child, the UN Standard Rules, and the ICF, concentrating on the listed environmental factors.

(3) Key elements of policy analysis should be added, such as questions about eligibility, gatekeepers and gate keeping, universality versus targeted services, legal

basis and enforceability, and costs/funding. Consideration was given in each area to key elements identified in that particular comparative literature.

This resulted in the framework on page 22 of this chapter, modified after consultation with SPARCLE partners. The framework began with the idealised view that it could consider policies across three groups – all children, disabled people, and disabled children. This proved too substantial a task: either because too little information was available or extensive information was available on issues that were marginal for disabled children aged 8 to 12 years such as incapacity benefit. Therefore, it was decided to concentrate on the particular group for this study – disabled children, aged 8 to 12, with a range of physical and learning impairments – and on the seven countries in the study. A policy questionnaire was then produced, modified and finalised. It was used in two ways:

- it was sent to SPARCLE partners for their contributions
- it was used to identify and sort information gathered.

Information was gathered through the following means:

- Networking: contact with relevant personnel at the European Union (e.g. the Unit for Integration of People with Disabilities), Council of Europe (e.g. Committee on the Rehabilitation and Integration of People with Disabilities) and European Centres and Fora (e.g. European Disability Forum); contact with relevant networks, such as the European Forum for Child Welfare and the European Network on Disability Studies; and contacts through the SPARCLE partners.
- Website search: an extensive web search was undertaken, based on searching for key words and following up links. For a list of websites found useful for more than one country, see Appendix.
- Publications search through general literature and key journals. The following journals were consulted over their past 5 years:

    Disability & Society
    European Journal of Special Educational Needs
    Journal of European Social Policy
    Childhood

Children & Society

Certain resources were idiosyncratic to countries while other sources provided coverage across countries. Examples of these kinds of sources are :

- State reports to the UN Committee on the Rights of the Child, NGO reports, and the Concluding Observations of the UN Committee
- National reports following the World Summit on Children (2002)
- Reports of the European Committee of Social Rights on State Submissions
- The Clearing House on international developments in child, youth and family policies provides policy summaries across a range of different topics http://www.childpolicyintl.org/
- European Observatory on Health Systems and policies contains summaries on national health systems
- Eurybase and European Agency for the Development of Special Educational Needs (EADSNE) websites contains country summaries on education policy generally and special educational needs in particular
- Mutual Information System on Social Protection in the Member States of the European Union (MISSOC) maintains comparative tables on social protection (primarily income maintenance). It also undertakes comparative analysis on other aspects of social protection, such as a recent review on health policy.
- Social Security Online provides summaries on social security by country

When gaps were identified in completing the questionnaire, particular efforts were made to fill them. Translation was undertaken of key documents and information in French, German and Swedish – this is noted in any references within the subsequent reviews. The publications review was predominantly undertaken from June 2003-April 2004, with some subsequent updating.

Each policy area was considered in light of the standards set internationally by the UNCRC and the UN Standards and particular analytical frameworks developed in the policy area. These are referred to in the respective chapters.

Information was patchy. Education reached a level of saturation where new sources stopped revealing new information. Other areas sometimes relied on few or even one source – although some were presumably factually correct as they were provided by national governments. Reviews across countries tended to have at least two deficits for this particular study: their level of reporting tended not to contain the specificity desirable for close legal analysis; and/or they were not concentrated on particular issues for disabled children. This was notable, for example, in some of the thorough and recent work done on anti-discrimination legislation (e.g. Brunel University 2002; Degener and Quinn 2002). This work does not systematically address coverage of children and policy areas particular to children. Their case studies tended to focus on employment or pension issues – adult issues, not children's.

A particular objective was to search for comparative statistics. European and international sources were considered. Three main sources were eventually used:

- Eurobarometer statistics on social attitudes towards disabled people
- OECD statistics on public expenditure and special education provision
- Bradshaw and Finch's 2001 study of child benefit packages across 22 countries

These also had their limitations for this review, which are addressed in the respective chapters which follow. Other household surveys were considered (e.g. the Luxembourg Income Study) but they added little useful insight because they only interview people above the age of 15 on a regular basis; and they ask if households have a disabled family member but do not specify which family member this is.

Article 23 of the UNCRC

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

I. Preconditions for Equal Participation
1. Awareness-raising
2. Medical care
3. Rehabilitation
4. Support services

II. Target Areas for Equal Participation
5. Accessibility
6. Education
7. Employment
8. Income maintenance and social security
9. Family life and personal integrity
10. Culture
11. Recreation and sports
12. Religion

III. Implementation Measures
13. Information and research
14. Policy-making and planning
15. Legislation
16. Economic policies
17. Coordination of work
18. Organizations of persons with disabilities
19. Personnel training
20. National monitoring and evaluation of disability programmes in the Rules
21. Technical and economic cooperation
22. International cooperation.

IV.Monitoring Mechanism

Framework for Policy Questionnaire

A. Consider 3 groups under each subject area:

- all children
- disabled people
- disabled children, particularly those with cerebral palsy

B. Consider key policy elements under each subject area, e.g.:

- What is available?
- What is the legal basis for such services? (e.g. legislation, service standards, social insurance system)?
- Structure of services
    - what level of government (national, regional, municipal – or none) is responsible for setting a particular service policy?
    - what level of government (national, regional, municipal – or none) is responsible for deciding the details of a particular service policy?
    - what organisation provides the service? What type of organisation is it - public, private, or voluntary?
    - how is the service monitored externally in terms of performance indicators and inspection? Are services available based on demand or on assessed need?
- Are services equally available across geographical areas?
- Does service supply meet service demand?
- Eligibility (are their age limits, what definition of disability, how decided etc.)
- How is it paid for? Is it free at point of use or is there a charge? If there is a charge, is it means-tested? What proportion does a family pay of the cost?
- What is the extent of choice for the child and/ or family members?

C. Subject areas

- Health and therapeutic services

    for all children

    specialised provision

- Communication and assistive technology
- Caring for children
    - child care
    - work life balance
- Social services, care and assistance
    - support in the home
    - parent/ sibling support
    - child living away from home
    - child protection disability awareness
    - personal care and assistance
- Transportation
    - public transportation and accessibility
    - special provisions
- Leisure and recreation
    - local amenities
    - holidays
- Environment
    - local planning
    - housing
- Social attitudes

  children's attitudes

  awareness raising
- Advocacy
    - structures
        - children
        - disabled people
        - disabled children
    - children's rights in legislation
    - disability rights in legislation
    - information distribution
- Antidiscrimination legislation
    - by age
    - disability

- Social security
    - for children
    - for disabled children
- School education
    - for all children
    - for disabled children
    - policy on school inclusion
- Services structure
    - service responsibility
    - co-ordination

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CHAPTER TWO: ATTITUDES

Within the social model of disability, both social and physical barriers have been recognised as obstacles to inclusion. Indeed the notion of inclusion, in relation to schooling, emerged at least partially because of the realisation that physical integration is not enough: a child might be physically sitting within a mainstream classroom but that does not mean that they are included (Sebba and Sachdev 1997).

Social barriers are recognised by the UN Standard Rules on the Equalization of Opportunities (Standard Rules) in Rule 1 on Awareness-Raising. Along with provision of information, there are requirements for awareness raising through information campaigns, mass media, public education programmes and professionals' training, to ensure a positive view of disability and disabled people. This is captured by what is required for information campaigns: "conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation" (Rule 1). The connection is clearly made between positive attitudes and future removal of barriers.

Statistical information is available at a European level on attitudes towards disabled people in:

- Eurobarometer study 54.2
- Attitudes of Europeans to Disability (2001)
- The European Year of People with Disabilities (2004)

The surveys are particularly useful for this review as they cover all 15 member states of the EU at that time, including the seven in this review. Eurobarometer surveys are intended to help monitor social and political attitudes across all EU member States using an identical set of questions in each nation. All respondents are interviewed face-to-face so as not to discriminate against non-phone owners. However, the surveys are dependent on the respondents' willingness to answer questions on sensitive issues. The typical Eurobarometer sample is 1000 respondents per country with certain exceptions: Luxembourg (600 respondents), Germany (1000 respondents in each of the former East and West Germany) and the UK (1000 respondents in Great Britain and 300 respondents in Northern Ireland). The small number in Northern Ireland means that it is not possible to have significant results on Northern Ireland alone. The fieldwork for the 54.2 study was undertaken in January and February 2001 while the subsequent study's fieldwork was undertaken in September 2003.

There are two particular issues concerning the use of Eurobarometer data for this review. First, respondents were all over the age of 15. No parallel study has been done of children's attitudes and there is no equivalent national data across countries. Second, the study asked whether respondents had a disabled family member. The respondents were not asked, however, to say which family member was disabled or indeed whether they had more than one disabled family member. Hence, the survey does not allow for consideration of responses from those who have a disabled child in their family, separate from those families who solely have a disabled adult family member.

There some further issues of interpretation which can only be briefly mentioned:

- the 'average scores' presented
- how non-responses were handled
- how categories of contact with disabled individuals were re-formulated
- the information presented is based on representative samples rather than surveying the whole population, so that the 'true' figure can be expected to be within three percentage points of the figure reported (using a 95% confidence interval).
- Following the survey convention, results from East and West Germany are reported separately.

Ease and awareness

Respondents were asked ”In general, do you feel completely at ease, somewhat at ease, somewhat uneasy or very uneasy in the presence of people with disabilities?” Average scoring is used here, as well as percentages, so that: ‘very uneasy’ is scored at 1; ‘somewhat uneasy’ scored at 2; ‘somewhat at ease’ scored at 3; ‘completely at ease’ scored at 4. From these results, **people in all seven countries would seem quite at ease with disabled people** (see Table 2.1).

Table 2.1: Ease when in the presence of disabled people 2001

	Completely at ease %	Somewhat at ease %	Somewhat uneasy %	Very uneasy %	Average Score
European average	48.1	34.6	14.9	2.4	3.28
Denmark	73.8	18.7	7.0	0.5	3.66
France	41.5	37.1	18.7	2.7	3.17
E Germany	30.1	40.1	26.3	3.5	2.97
W Germany	33.0	38.4	26.0	2.6	3.02
Ireland	65.9	21.1	9.9	3.1	3.50
Italy	37.7	44.6	15.2	2.5	3.17
Sweden	67.0	25.8	6.2	0.9	3.60
UK	72.5	20.7	5.8	1.0	3.65

Some countries’ average scores are below the European average while others are above. East and West Germany are considerably lower (2.97 and 3.02). Both France and Italy are less easy than the European average at 3.17 each, while Sweden (3.60), the UK (3.65) and Denmark (3.66) are well above the European average score. Sweden’s results are lower than the UK and Denmark primarily because of a lower number ‘completely at ease’ than these other two countries, rather than having more who are ‘somewhat uneasy’ or ‘very uneasy’.

Did these results differ by whether respondents personally know a disabled person? There is a significant relationship, as shown in Table 2.2.

Table 2.2: Ease when in the presence of disabled people by personally knowing a disabled person?

	Don't know any disabled people (%)	Yes, an acquaintance (%)	Yes, a family member (%)	Yes, I consider myself disabled (%)	Total (%)
Completely at ease	37.0	49.5	61.6	62.2	48.1
Somewhat at ease	39.2	34.9	27.7	29.1	34.6
Somewhat uneasy	20.7	13.5	8.8	7.3	14.9
Very uneasy	3.1	2.1	1.8	1.3	2.4

Pearson chi-square: 712.48 ($p<0.001$) Gamma statistic = -0.287 ($p<0.001$)

People who do not know any disabled people are more likely to be somewhat uneasy or very uneasy than other people; equally, those who have a disabled family member or are themselves disabled are more likely to feel completely at ease in the presence of disabled people. It would seem that closeness of personal contact and/ or relationships with disabled people does make people feel more comfortable in the present of disabled people in general. Note, however, that even those who considered themselves disabled do not all feel completely at ease with disabled people.

This comparison is considered by country in Table 2.3. From the gamma statistics, it would suggest that the relationship in Sweden and Denmark is less strong than for the other countries.

Table 2.3: Gamma Statistics for Ease when in the presence of disabled people by personally knowing a disabled person by country

Country	Gamma statistic
Denmark	-0.162 ($p<0.001$)
France	-0.260 ($p<0.001$)
E Germany	-0.315 ($p<0.001$)
W Germany	-0.370 ($p<0.001$)
Ireland	-0.226 ($p<0.001$)
Italy	-0.225 ($p<0.001$)
Sweden	-0.120 ($p<0.05$)
UK	-0.307 ($p<0.001$)

In the UK, then, not knowing a disabled person has a considerable impact on how uneasy people feel in the presence of disabled people: i.e. about one in 10 of those who do not know a disabled person feel either somewhat uneasy or very uneasy. In Germany, the results are more pronounced: i.e. about four in 10 of those who do not know a disabled person feel either somewhat uneasy or uneasy. Conversely, being disabled had a considerable impact on how easy people felt: in the UK, over three-quarters of disabled people feel completely at ease; whereas four out of 10 in West Germany and just over one-half in East Germany.

Concerning children with cerebral palsy, their parent's awareness of cerebral palsy is of potential interest. Respondents were given the choice of 'fairly aware', 'fairly unaware' and 'don't know'. This question was repeated in the 2003 survey. The percentages are described in Table 2.4.

Table 2.4: Awareness of cerebral palsy, 2001 and 2003

	Fairly aware (%)		Fairly unaware (%)		Don't know (%)	
	2001	2003	2001	2003	2001	2003
European average	30.5	40.0	63.3	55.5	6.2	4.5
Denmark	13.8	22.5	65.8	67.6	20.4	9.9
France	27.5	34.1	70.5	63.9	2.0	1.9
E Germany	25.4	32.7	67.0	62	7.6	5.3
W Germany	24.0	33.1	65.9	60.2	10.1	6.7
Ireland	30.9	67.2	63.7	30.0	5.4	2.8
Italy	18.8	24.8	72.3	71.7	8.9	3.5
Sweden	32.1	45.3	62.9	52.1	5.0	2.6
UK	40.4	73.5	51.9	23.3	7.7	3.2

Awareness of cerebral palsy was low in 2001, according to these results. None of the countries, nor the average across European countries, had over 50% of respondents saying that they were 'fairly aware' of cerebral palsy. Two out of five respondents in the UK reported being fairly aware, which was the highest across the countries, while Denmark was the lowest at 14%. Denmark was exceptional in the number of 'don't knows' from respondents.

Awareness of cerebral palsy would appear to have improved considerably in some countries and in Europe overall, between 2001 and 2003. The European average, of those who say they are fairly aware, has risen to 20%. A larger leap can be found in Ireland and the UK. Both of these countries now have over half of respondents who say they are fairly aware of cerebral palsy. This now differs even more from Denmark and Italy, where less than one in four people are aware of cerebral palsy. The number of ‘don’t know’ has decreased in five out of the seven countries (although still large for Denmark) between 2001 and 2003.

Community participation for disabled people

Access to public services is a key demand for disabled people. Rule 5 of the UN Standard Rules stipulates that: “States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society”. Article II-26 of the proposed European Constitution states: “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.”

The Eurobarometer survey asked respondents, across a range of community activities, whether access was ‘very difficult’ (4) ‘fairly difficult’ (3), ‘not very difficult’ (2), ‘not at all difficult’ (1). The respondents were asked to consider their responses across groups: two groups are considered here, ‘physically disabled people’ and ‘intellectually disabled people’. Average scoring is used on the results. For physically disabled people, the results are described in Table 2.5

Table 2.5: Community participation for physically disabled people

	Public transport	Other public services	Restaurants hotels etc.	University or school	Workplace	Sports events	Cultural events
European	3.36	3.21	3.04	3.02	2.99	2.95	2.93
Denmark	3.56	3.27	3.27	3.06	3.22	3.09	2.99
France	3.56	3.41	3.23	3.26	3.28	3.24	3.22
E Germany	3.19	2.98	2.90	2.89	2.96	2.81	2.75
W Germany	3.23	3.02	2.96	2.81	2.97	2.78	2.74
Ireland	3.60	3.46	3.18	2.99	3.14	3.14	3.04
Italy	3.38	3.29	2.91	2.92	2.98	3.04	2.96
Sweden	3.11	2.74	2.76	2.47	2.67	2.65	2.50
UK	3.45	3.32	3.17	2.83	2.98	3.02	3.00

A low average score indicates more accessibility while a higher score indicates less accessibility, as perceived by the respondents. The average score for all the activities is above 2, showing respondents on average feel that access is generally difficult across all the services asked about.

Public transport is perceived as less accessible than other activities with the highest average both for the EU countries overall as well as the seven countries considered here. Responses by country are more mixed for the most accessible activities. The lowest average (meaning more accessible) across the EU countries is cultural events 2.93 but that is only true for Denmark (2.99), East and West Germany (2.74 and 2.75), and France (3.22). In contrast for Denmark, Sweden, and the UK, University or schools are the activity with the lowest average score. Still, no score is below 2 and thus all activities are, on average, seen as fairly or very difficult in all seven countries.

For intellectually disabled people, the average scores across activities and across countries are shown in Table 2.6

Table 2.6: Community participation for intellectually disabled people

	Public transport	Other public services	Restaurants, hotels etc.	University or school	Workplace	Sports events	Cultural events
European	3.27	3.27	3.18	3.16	3.08	3.07	3.02
Denmark	3.01	3.06	3.14	3.27	3.35	2.87	2.92
France	3.34	3.43	3.32	3.56	3.51	3.38	3.43
E Germany	3.10	3.03	3.00	3.32	3.25	2.90	2.88
W Germany	3.24	3.17	3.14	3.34	3.36	2.96	3.02
Ireland	3.03	3.07	2.88	3.16	3.18	2.90	2.97
Italy	3.31	3.33	3.16	3.42	3.45	3.23	3.28
Sweden	2.74	2.73	2.77	2.93	2.99	2.59	2.60
UK	3.15	3.14	3.00	2.9	2.93	2.82	2.91

Again, respondents feel that access is generally difficult across all the activities asked about. Looking at the European average scores, public transport and other public services are tied for the least accessible for intellectually disabled people. Cultural events remain the most accessible but at a higher score (3.02 for intellectually disabled people compared to 2.93 for physically disabled people).

Across all countries besides the UK, public transport is no longer consistently perceived as the least accessible activity. Rather, the least accessible activities are seen as University or schools for France and East Germany and the workplace for other countries (Denmark, Ireland, Italy, Sweden and West Germany). The most accessible activities are sports events (Denmark, Sweden, UK, and West Germany), restaurants, hotels etc. (France, Ireland, Italy) and cultural events (East Germany).

Attitudes to inclusive education

The responses described above refer to perceptions of existing access to particular activities. The survey also asked respondents *where* they thought disabled children should go to school. Respondents were asked to ‘strongly agree’ (4), ‘somewhat agree’ (3), ‘somewhat disagree’ (3), or ‘strongly disagree’ (1) with the following statement: ‘Children with disabilities should be taught in the same schools as other children’. The results are shown below in percentages and in average scores in Table 2.7.

Table 2.7 Disable children should be taught in the same schools as other children

	Strongly agree (%)	Somewhat agree (%)	Somewhat disagree (%)	Strongly disagree (%)	Average Score
European average	42.2	35.8	16.4	5.5	3.1
Denmark	43.7	37.8	13.5	4.9	3.2
E Germany	34.8	39.8	19.4	6.0	3.0
W Germany	43.1	35.4	16.1	5.4	3.2
France	39.7	34.6	20.6	5.0	3.1
Ireland	48.3	31.2	14.8	5.8	3.2
Italy	53.0	35.6	8.4	3.0	3.4
Sweden	41.4	41.5	13.1	3.9	3.2
UK	41.3	38.2	15.1	5.4	3.1

The majority of respondents in all countries support disabled children being taught in the same schools. The average scores are all quite similar but the breakdown by categories shows a notable minority of respondents who do not support this statement. East Germany and France have the highest percentage, with one in four respondents either somewhat disagreeing or strongly disagreeing. Ireland, the UK and West Germany follow closely behind with about one in five respondents somewhat or strongly disagreeing. Italy has the least, with just over one in ten (11.4%) either somewhat or strongly disagreeing. These differences do seem to have some relationship with the different policies that countries have on segregated education: policy in Italy seeks to include almost all pupils within mainstream education and they have the least respondents disagreeing; education policy in France and Germany maintain a multiplicity of approaches across mainstream and special needs education and have the highest proportion of pupils of the seven countries in special education (for more discussion see Chapter 4 on education).

Overall community participation

Table 2.8 compares the average score for all services, for intellectually disabled people and physically disabled people.

Table 2.8: Average score for community participation for physically disabled people and intellectually disabled people, by country

	Physical Disabled People	Intellectually Disabled People
European average	3.07	3.15
Denmark	3.21	3.08
France	3.31	3.42
E Germany	2.92	3.07
W Germany	2.93	3.17
Ireland	3.22	3.03
Italy	3.06	3.31
Sweden	2.70	2.76
UK	3.11	2.98

Again, the average scores for the EU show a high level of perceived inaccessibility to activities, for both physically disabled people and intellectually disabled people – and indeed, worse for intellectually disabled people in four out of seven categories. The countries differ on whether they are below or above the European average. This is shown in table 2.9, listed in descending order.

Table 2.9: Comparison of average score by country with European average, for average score for community participation for physically disabled people and intellectually disabled people

	Physical Disabled People	Intellectually Disabled People
Less accessible than the European average	1. France 2. Ireland 3. Denmark 4. UK	1. France 2. Italy 3. West Germany
More accessible than the European average	5. Italy 6. West Germany 7. East Germany 8. Sweden	4. Denmark 5. East Germany 6. Ireland 7. UK 8. Sweden

Denmark, France, Ireland and the UK all report answers on average above the European average for physically disabled people, while Italy is just below, followed by West and East Germany, and Sweden considerably below. France has the highest average for both intellectually and physically disabled people (and thus perceptions of less accessible activities) while, conversely, Sweden has the lowest average (and thus perceptions of more accessible activities). Some countries are perceived as less accessible for physically disabled people than intellectually disabled people (Denmark, Ireland, and the UK) while the opposite is true for other countries.

Improved access over the past 10 years regarding public places

The questions so far have covered perceptions of current activities. The survey also asked about respondents' perceptions of improved access over the past 10 years – although the question asked about public places and not activities: 'On the whole, would you say that over the last 10 years access to public places for people with disabilities has improved very much (4), somewhat improved (3), not very much improved (2) or not at all improved (1)?' The results are described in Table 2.10.

Table 2.10: Improvement to access to public places for disabled people over the past 10 years

	Improved very much %	Somewhat improved %	Not very much improved %	Not at all improved %	Average
European average	10.9	48.2	32.9	8.1	2.62
Denmark	9.2	48.1	36.0	6.7	2.57
France	7.8	43.2	39.5	9.5	2.49
E Germany	8.2	51.0	35.7	5.0	2.62
W Germany	10.5	53.6	30.3	5.7	2.71
Ireland	16.1	53.1	22.7	8.2	2.77
Italy	5.7	39.0	44.9	10.4	2.41
Sweden	19.2	61.5	15.8	3.4	2.97
UK	17.7	59.9	18.7	3.7	2.91

All seven countries, as well as the overall European average, show that the people on average perceive that access has improved – even if it is 'not very much'. The countries are quite closely grouped. Sweden and the UK have the two highest average scores – in part because of the high numbers who think access has 'improved very much' and the low numbers who do not choose 'not at all improved' – and Ireland and West Germany also have an above average European score. East Germany is equivalent to the European average score. Denmark, France and Italy are all lower than the European average score. So it would appear that respondents in Sweden and the UK perceive more improvement than the other countries, and particularly in comparison to France and Italy.

Along with their perceptions of improvement and current access, respondents were also asked to react to a statement about what should be done; they were asked if they 'strongly agree' (4), 'somewhat agree' (3), 'somewhat disagree' (2) or 'strongly disagree' with the following statement: 'Something should be done to involve people with disabilities more in society e.g. by facilitating their access to public spaces'. The results are shown in Table 2.11 by percentages and average score.

Table 2.11: More should be done to involve disabled people in society

	Strongly agree (%)	Somewhat agree (%)	Somewhat disagree (%)	Strongly disagree (%)	Average
European average	71.5	27.1	1.2	0.2	3.7
Denmark	74.7	22.7	2.3	0.3	3.7
France	77.7	21.8	0.4	0.1	3.8
E Germany	65.6	32.4	1.9	0.1	3.6
W Germany	64.2	33.8	2.0	0.0	3.6
Ireland	86.3	13.4	0.1	0.2	3.9
Italy	76.3	22.8	0.5	0.4	3.7
Sweden	79.5	18.9	1.2	0.4	3.8
UK	68.1	30.2	1.4	0.2	3.7

The results are notable in the high level of support for more being done to involve disabled people in society; the average score for all EU countries is 3.7 and an even higher average is expressed in France, Sweden and Ireland. Even those countries, whose respondents report a higher than average access to particular services (e.g. Sweden), think that more should be done.

The responses do relate to the extent of people's personal contact with disabled person (see above). The relationship is strong for France (Gamma Statistic = -0.269, $p<0.001$) and Italy (Gamma Statistic = -0.274, $p<0.001$): i.e., respondents who do not know any disabled people are more likely to disagree strongly with the statement while respondents who are disabled are more likely to agree strongly. This relationship is also significant ($p<0.05$) for the other seven countries, although the gradient is less. It is worth noting, however, that the percentages of those who somewhat or strongly disagree are small across all countries.

Conclusion

The Eurobarometer studies provide useful comparative data between countries. They do, however, leave gaps in knowledge which are common across much of European data. For example, the respondents are all over the age of 15 so equally robust attitudinal data is not available from young people below that age, either as a 'snap shot' or longitudinally. The survey did not ask which family member has a disability, so that respondents with a disabled child cannot be disaggregated from the survey results. Robust statistics are thus not available for this particular group, at a European comparative level. Even if snapshot statistics were available, surveys like the Eurobarometer have been invested in over time, so that longitudinal information can be considered. Yet, how attitudes, circumstances and other information change over time is not known for disabled children and their families. **These gaps perhaps in themselves demonstrate an attitudinal barrier to disabled children – there are surveys of disabled people and surveys about children, but there is little robust comparative statistical information on disabled children and virtually none that have disabled children as respondents.**

Despite these gaps, the attitudinal studies do provide some thought-provoking results.

- First, there is a general picture of fairly positive attitudes towards disabled people, as shown by the high percentages of people who feel completely and somewhat ease with disabled people and the considerable support for more being done to involve disabled people in society. **However, there is also a fairly low reported awareness of cerebral palsy, although an increase has occurred between 2001 and 2003.**
- Second, there is some consistency on results across certain countries. For example, Sweden tends to have more positive results than the average European scores for questions examined here. Respondents from this country are more likely to: feel at ease in the presence of disabled people; perceive services as reasonably accessible, for both intellectually disabled people and physically disabled people; and think that access to public places has improved over the past 10 years. France consistently has more negative results than the average European scores, for these same questions. Italy has more negative results in three out of the four areas.
- **Third, the average scores across both individual countries and for Europe as a whole display a perception of inaccessible services, for both physically disabled people and intellectually disabled people**. Public transport is seen as more problematic than other services to access, for people with physical disabilities.

- Fourth, there does seem to be some relationship between the extent of contact a respondent has with a disabled person and their responses to other questions considered here. The closer the acquaintance with a disabled person (from not knowing a disabled person to being disabled oneself), the more likely the respondent is to feel at ease in the presence of a disabled person. It could be suggested that familiarity with disabled people does lead to more inclusive and positive attitudes - an argument against segregation and for inclusion often made by the disability movement (e.g. Oliver 1996).

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CHAPTER THREE:

- **EQUALITY AND ANTIDISCRIMINATION**
- **ADVOCACY AND INFORMATION**

How countries report on their ‘social protection for disabled people’ can be classed in three ways:

- anti-discrimination (i.e. focusing on preventing discrimination and/or sanctions for discrimination)
- promoting equal opportunities
- social provision or compensation

This chapter concentrates on the first two types of social protection, with Chapters 5 and 6 providing further detail in relation to social provision and compensation.

Countries take forward these approaches in different ways such as through legislation focusing on duties, powers and individual rights, national plans which may well have the backing of legislation; and they monitor or enforce these in different ways. Such differences are considered below.

Children generally have not been central to anti-discrimination or equal opportunities legislation and policy. Certainly, particular cases affecting children have been publicly highlighted and addressed by anti-discrimination policy. Children have frequently been seen as an important vehicle for changing societal attitudes, with initiatives to promote positive attitudes towards racism, gender and now disability in schools. Children may well be covered by anti-discrimination legislation and policy either because the laws and policy are framed so as to apply to all citizens or because such issues are gradually being incorporated. But the adult-centred nature of the laws and policy has a legacy: for example, disability definitions that require proof of ‘enduring’ or ‘permanent’ incapacity which can be difficult, if not undesirable, to determine for younger children.

Anti-discrimination and equal opportunities legislation and policy have tended to be driven by adult concerns. This is evident, for example, in the focus on employment, as stated by MISSOC's overview of social protection for disabled people: "Employment constitutes the main approach for the integration of people with disabilities" (2003: 4). Some countries, such as Sweden, have an anti-discrimination law in employment but not equivalent legislation in key areas for children, such as education. The European Union's Directive in 2000[1] requires EU countries to prohibit direct and indirect discrimination – but only in the areas of employment or occupation and memberships of certain organisations.

The European Directive arose from Article 13 of the European Union's Amsterdam Treaty, which specifically mentions age. Article 13 allows (but does not require) the European Community to take a proactive approach towards the elimination of discrimination based on sex, racial or ethnic origin, religious and belief, disability, age or sexual orientation. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules) requires national legislation to include the rights and obligations of disabled people and to remove conditions that may adversely affect their lives (Rule 15, see details below).

Similarly, Article 14 of the European Convention on Human Rights (ECHR) requires that enjoyment of all of the ECHR rights should not be subject to discrimination on any grounds such as "sex, race, colour, language, religion, political or other opinion, association with a national minority, property, birth or other status". 'Other status' has been determined as including the criterion of age. Kilkelly (1999) argues that the European Court of Human Rights has given tacit approval for the inclusion of such grounds as disability and sexuality, as they have been considered the basis for discriminatory treatment.

Article 14 of the ECHR does have limitations. First, alleged discrimination does not contravene Article 14 if there are "reasonable and objective" grounds for treating children differently (see Tisdall 2000). Second, the Article applies only in respect of

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[1] Council Directive establishing a general framework for equal treatment in employment and occupation, 2000/78/ EC of 27 November 2000

the other articles of the ECHR. This may change, should Protocol No. 12 be accepted. Article 1 would extend the non-discrimination to "any right set forth by law". Thus, a public authority should not discriminate against anyone, on any of the grounds, whether or not the specific right is covered by the ECHR.

Further, the proposed European Constitution takes this wide approach to anti-discrimination in Article II-21. The Article echoes Article 13 of the Amsterdam Treaty, in explicitly prohibiting discrimination on the grounds of disability or age, amongst other characteristics. However, these rights are limited to the activities and law of the Union (Article II-51).

All seven countries have also ratified the UN Convention on the Rights of the Child, which contains its own anti-discrimination article. Article 2 (1) stipulates that:

- States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Interestingly, age is not specifically mentioned but presumably would be considered under 'other status'. The Convention has an overall tendency towards a developmental approach to children's views. For example, Article 12 (1) states that children's views should be given "due weight" in accordance with the "age and maturity of the child". Similarly, states should support parental responsibilities and rights and the wider family, to provide guidance "in a manner consistent with the evolving capacities of the child" (Article 5). Both the ideas of 'maturity' and 'evolving capacities' could potentially limit the decision-making contribution of children with, say learning difficulties, who may be deemed by adults as neither mature nor having sufficient capacities.

The seven countries differ in what ratification of the UNCRC means for their domestic law. In Germany, Ireland and the UK, for example, ratification does not automatically mean that the Convention becomes domestic law. It must be incorporated piece by piece into domestic law to have that effect. Sweden passed a Government Bill in 1999, which approved a strategy to implement the UN Convention.

Information and advocacy are central to the claiming of rights, whether the approach to social protection is through equality, anti-discrimination or provision. The complexity of legal and service systems in the seven countries can lead to an unmet demand for useful information – from both parents and children (Beresford and Sloper 2000; Mitchell and Sloper 2002; Morris 1999). Advocacy groups can assist parents and disabled children individually, to access information, provision and rights. Advocacy and other groups can provide support. Beyond individual support and advocacy, groups can also ensure that the views and needs of parents and disabled children are integrated into policy and service decisions.

The Standard Rules recognise the importance of such information and advocacy. Individually, disabled people and their families require up-to-date information and access to the media (Rule 1 and others). Further, professionals and the general public should receive good information and public education and the media should ensure positive portrayals of disabled people (Rule 1 and others). The Standard Rules are permeated by the requirement for the involvement of disabled people's organisations, in the development of relevant services and policies.

The UNCRC, European Social Charter and the proposed European Constitution are all less explicit than the Standard Rules on the right to information and advocacy. The UNCRC, for example, addresses access to appropriate information in Article 17 but the Article predominantly deals with the mass media. Children should have the right to freedom of association (Article 15) and to have their views considered (Article 12) but no mention is made of advocacy organisations.

Legislation on the basis of age

All seven countries have agreed to the UNCRC, ECHR and the Amsterdam Treaty and thus the generality of their anti-discrimination provisions. Certain countries also prohibit discrimination and/ or promote equality in their constitutions. The Italian Constitution, for example, states in Article 3:

- All citizens posses an equal social status and are equal before the law, without distinction as to sex, race, language, religion, political opinions, and personal or social conditions.
- It is the duty of the Republic to remove all economic and social obstacles which, by limiting the freedom and equality of citizens, prevent the full development of the individual and the participation of all workers in the political, economic and social organization of the country.

Germany's and Ireland's Constitutions similarly provide a general guarantee of equality before the law (see country chapters). The Irish Equal Status Act 2000, though, explicitly excludes children under the age of 18 from the 'age grounds' for discrimination protection (Section 3(3)).

Northern Ireland is unusual, in the UK as well as elsewhere, in addressing age discrimination for children. The Northern Ireland Act 1998 places a statutory duty on public authorities to give due regard to the promotion of equality of opportunity – and that includes differences by age (for more details, see UK chapter). The Northern Ireland Human Rights Commission (see NIHR 2002) has stated that the age grounds include children. However, there is no legal remedy for individuals alleging discrimination on grounds of age.

In short, the concept – and subsequent legal provisions – of discrimination against children on the basis of age have largely not been accepted by any of the seven countries. Disabled children may well be protected from discrimination, though, on the basis of disability.

Legislation and policy on the basis of disability

All seven countries are subject to the European and UN requirements on discrimination by disability. Over recent decades, many countries have undergone significant changes in their domestic law on disability. Degener (2003) reports that 43 out of 189 UN Member States have adopted some kind of anti-discrimination law for disabled people. She notes that there were two models for these domestic laws: the Americans with Disabilities Act 1990 and the UN Standard Rules on the Equalization of Opportunities. Rule 15 of the Standard Rules requires that:

- National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens.
- Legislative action may be needed to remove conditions that may adversely affect the lives of disabled persons, including harassment and victimization. Any discriminatory provisions against disabled persons must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principles of non-discrimination.

Degener's review of these 43 laws considers three issues:

- the legal approaches
- the groups protected – whether disability-specific or not
- and enforcement mechanisms

These ideas have been elaborated in 13 principles proposed by Gooding and Casserley (2000). The sections below draw on these frameworks to consider such legislation as it applies to disabled children.

Legal approaches

Degener (2003) finds that anti-discrimination provisions for the protection of disabled people can be regulated by four different legal approaches:

  - criminal law

  - constitutional law,
  - civil law
  - social welfare laws

In the seven countries, only France utilises the **criminal law approach**. An act of discrimination is defined as “any distinction made … on the grounds of health, disability, or a comparable factor” (MISSOC 2003: 55). If such a distinction entails inferior treatment, it is punishable by a fine or imprisonment. Because the law is ‘symmetrical’ (i.e. it applies equally to disabled and not disabled), the law has explicit exceptions to allow for preferential treatment in social, medical and financial support (Malaga 2003: 26).

In contrast, several countries have general equality articles within their **constitutions**. The relevant articles for Ireland and Italy have already been mentioned above. Provisions for equality can also be found in the constitutions of France and Germany.

The civil rights approach has been taken by Germany, Ireland and the UK. Degener (2003) also cites Sweden but the Swedish legislation in 1999 concerns employment. The German legislation in 2002 prohibits discrimination by public authorities, barrier free environments and the use of German sign language (Malaga 2003: 39). Ireland has recently passed three civil rights laws: the Employment Equality Act 1998, the Equal Status Act 2000, and the National Disability Authority Act 2000. The Equal Status Act prohibits direct and indirect discrimination in the provision of services, goods and facilities. The Disability Bill 2004 outlines rights to access public buildings and services. In the UK, the Disability Discrimination Act (DDA) (1995) is the foundational act in all jurisdictions, along with the Equality and Disability Northern Ireland Order 2000. Discrimination is prohibited in the areas of employment, access to goods, facilities and services, and buying or renting land or property. The Act also allows the Government to set minimum standards to assist disabled people to use public transport easily. Change is presently being considered to this legislation, both to the details of the Act and also in the creation of a single equalities bill.

The last approach is through social welfare laws for disabled people. Degener (2003) does not include any of the seven countries in this category. However, if this approach is recast to considering social rights through provision and duties, Denmark, France Germany, Italy, and Sweden could be included here; certainly, this is how these countries respond to cross-European reporting on these issues (e.g. CE 2000; Malaga 2003; MISSOC 2003). Ireland could be added also, with its new Disability Bill 2004.

Danish policy making, until recently, has been very much opposed to the individual litigation approach of civil rights anti-discrimination legislation (Bengtsson 2001; Mabbett 2002). Instead, long-established coalitions of disability advocacy groups have worked with policy makers to develop a sector-by-sector approach. The Danish Disability Council and its affiliate, the Equal Opportunities Centre for Disabled Persons, have the responsibility to ensure implementation of the principle of equal treatment through this principle of sector responsibility. This is defined as making “every sector of society responsible for its own affairs” (OECD 2003: 105).

France, Italy and Sweden all report recent national plans, backed by legislative force, to promote integration of disabled people. Denmark also has a national plan. These plans are explicitly tied to implementation of the UN Standard Rules (see CE 2000 for Italy and Sweden). The Swedish National Action Plan, for example, was passed by the Swedish Parliament and has established goals and monitoring. A Government Action Plan for Disabled Policy has been approved in Italy, in order to “place the provisions” of existing law “on a concrete footing” (MISSOC 2003: 67). The MISSOC report (2003) states that in France, “A programme of concrete measures to implement the integration of disabled people, in particular in daily life” (55) was to be implemented in 2004.

Degener’s overview expresses a clear preference for the civil rights approach over others. The French criminal law approach requires the perpetrator to have acted with bad intentions but: “In reality, however, disability based discrimination is often carried out with the best intentions of the perpetrator” (Degener 2003: 5). Further, Gooding and Casserley (2003) point out that the legal burden of proof is higher in criminal than in civil cases and the prosecution is at state discretion.

Constitutional anti-discrimination approaches have the benefit of being the highest domestic law and thus may lead to reform in disability case law. However, Degener discounts the approach for three reasons. First, some constitutions give no substantive rights to citizens, so that the rights cannot be invoked in court. (This problem, however, is not solely experienced by constitutions, as evidenced by the Northern Ireland Act 1998 on age.) Second, constitutional provisions protect disabled people from discrimination by state entities but not by private employers or providers. Thirdly, the provisions tend to be broad and vague, leaving considerable discretion to the courts.

Degener prefers civil rights approaches because they are more detailed in their scope. They tend to have enforcement provisions and a definition of what counts as discriminatory practice or equality. She states that discrimination provisions in social welfare legislation are usually “less comprehensive and reform-oriented” (2003: 13). Waddington and Diller (2002), however, provide a less clear-cut evaluation. First, some countries have used a civil rights model of disability but superimposed it on existing income support and quota policies, which have used a social welfare view. They have not co-existed easily, being based on different premises. Second, the civil rights model is not the single answer:

Groups Protected

Children are covered to some extent by the anti-discrimination and equality approaches listed above. The employment provisions are largely not relevant, until children reach the legal age to work or they undertake vocational training. The provisions for goods and services, however, would apply to children just as they would for adults. Some countries explicitly include education within their laws and policies: e.g. the Equal Status Act 2000 in Ireland; the new Part IV of the DDA for

England, soon to be added into Northern Irish law; specific mention in the Swedish National Action Plan.

Children may not be excluded explicitly from certain laws and policies but they may be excluded implicitly by the **definitions of disability** used. Take, for example, the definition of disability in Ireland's National Disability Act 1999:

- a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment. (Section 2(1))

This is very similar to that contained in the UK Disability Discrimination Act 1995:

- a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities. (Section 1(1))

The German definition is also similar. These definitions require a longevity – terms such as 'enduring' and 'long-term' – that may difficult to evidence for a child who is growing and developing. This is recognised in Germany: the Federal Ministry of Health and Social Security stresses that the timeframe does not exclude necessary early interventions for disabled children (2003: 3). And, as Degener (2003) points out, the definitions are medically oriented in relying on impairment. This too can be problematic for children, when it can take considerable time before a diagnosis is made and some diagnoses are medically controversial (e.g. Attention-Deficit/ Hyperactive Disorder).

Such definitions have been criticised for falling back on a **medical model**, which 'blames' and tries to change the individual, in contrast to the 'social model' of disability, which focuses on removing societal barriers (physical or attitudinal) instead. France has no definition of disability within its Criminal Code and instead has relied upon the WHO International Classification of Disability to create "statistical nomenclatures of disability" (MISSOC 2003: 48). This is further described by Bolderson and Mabbett (2000) as: "the severity of impairment is measured by looking at its disabling effects; in other words, disability provides a unified concept for scaling and combining diverse impairments" (16). The MISSOC report (2003) states that there has been "some progress" (48) away from a medical approach. Similarly, the Italian constitution does not contain a definition of disability but its 1992 Law does:

- anyone with a stabilized or progressive physical, mental or sensorial disability giving rise to learning, relational or occupational problems and a situation of social disadvantage or marginalization. (art. 3)

Denmark and Sweden explicitly advocate non-categorisation of disability. However Sweden does have a definition of disability within its anti-discrimination employment legislation. And in Denmark there are thresholds in social service legislation: e.g. a child must have a "severe and permanent physical or mental impairment" to be entitled to the supplementary costs allowance (MISSOC 2003: 22).

Legislation differs further in the range of people it covers (taken from Degener 2003). The UK, for example, is exceptional across the seven countries in protecting people who have been disabled in the past (Sweden does also in its anti-discrimination employment legislation) and those who have been victimised because of making a complaint about an act of discrimination. Ireland's legislation extends to discrimination on the basis of association as well as future, past and imputed disabilities (Gooding and Casserley 2003). Countries also differ on the type of discrimination that is covered. Ireland and UK define discrimination as 'unfavourable treatment' while France uses 'unjustified differentiation'. Indirect discrimination is covered in Ireland and the German 2002 Act but not in the UK's Disability Discrimination Act (DDA). While constitutional approaches may produce a wide coverage of public services, the civil rights and criminal approaches in France, Germany, Ireland and the UK all have notable gaps. For example, the UK DDA allows for minimum standards for buses to be specified but if a disabled person is refused entry the person cannot make a claim of discrimination (Gooding and Casserley 2003). The German 2002 Act covers public authorities but not the private sector.

Enforcement and sanctions

The growth in civil rights approaches has been paralleled by concerns about their enforcement. Gooding and Casserley (2003: 3) outline three principles:

- groups of and for disabled people should be able to take enforcement action;
- sanctions should be proportionate, effective and dissuasive
- there should be national independent body to promote and enforce disability rights

A civil rights approach tends to have the clearest and most specific enforcement and sanctions procedures attached. Independent bodies have been established in Ireland (Equality Authority[2] and the Human Rights Commission), Northern Ireland (Equality Commission) and the rest of the UK (Disability Rights Commission) in relation to disability. These bodies can assist people in making individual complaints as well as providing advice, information, policy input etc. The legislation lays out legal routes for cases and outlines sanctions that can be made by the respective tribunals and courts. Independent bodies can also usually undertake investigations that do not rely on an individual complaint.

Constitutional approaches are typically the vaguest, as noted above. The French Criminal Code requires an individual case, at the criminal level of proof. The MISSOC report (2003) states that associations for disabled people can help enforce individual people’s rights, with their or their guardian’s permission. Social welfare approaches differ on their enforcement mechanisms and sanctions. Sweden has a monitoring system set up for its National Action Plan. Individual complaints can be taken to the Office for the Disability Ombudsman. In Germany, disabled people’s rights are set out in the Social Code and the 2002 Act. Associations recognised by the Federal Ministry can support individuals in making a complaint/ court case; such associations can also take cases forward at their own behest. Penalties can be built into target agreements for barrier-free environments. In contrast, the Italian Government’s report to the UN Committee on the Rights of the Child notes

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[2] Note that the National Disability Authority in Ireland has a policy promotion role but is not involved in enforcement (NDA 2002).

weaknesses in implementation of the 1992 Framework Law, with considerable geographical differences (1998: para 393).

It is unclear how well enforcers such as Ombudsmen and Commissioners work when there is more than one in a particular country: for example, how effectively do the Ombudsman for Disability and the Ombudsman for Children deal with complaints by or on behalf of disabled children?

Advocacy and Information

All seven countries have organisations that promote the rights of children and of disabled people, but they differ in their powers and standing (see Table 3.1). A general trend is the establishment of Ombudsmen and/ or Commissioners. These are already established in most of the seven countries or are being proposed. For children, the exception is Germany, where a federal children's commissioner has been rejected by the federal government. For disabled people, the exceptions have been France and Italy.

Such positions and their offices tend to have statutory backing and statutory powers, giving them an independence from governments. These powers can differ, however, across offices and countries. For example, not all Ombudsmen and Commissioners can handle individual complaints nor carry out formal investigations. Denmark is consistent in not granting such powers to its national statutory bodies. Other countries differ between bodies: for example, the Swedish Ombudsman for Disabled People can handle individual complaints whereas the Ombudsman for Children cannot.

Most countries have national bodies that bring together policy-makers with non-governmental organisations and other representatives of parents and/ or disabled people. Some countries have flourishing non-governmental or voluntary sectors, with organisations representing children, their parents and disabled people. It should be noted, however, that organisations *of* (rather than *for*) children remain relatively rare. Several countries are experimenting with various types of children or youth parliaments, with France having one of the most established through school councils.

Ombudsmen and their equivalents tend to have a remit to disseminate information on rights. Other organisations can also have a remit to provide information, such as non-governmental organisations. Certain countries have sought to ensure a co-ordination of information, such as the Comhairle organisation in Ireland or the Citizens' Advice Bureau in England. Nonetheless, a common finding across countries is the difficulties for parents and disabled people to receive co-ordinated and pertinent information.

Table 3.1: Organisations that promote the rights of children and disabled people

	Is there a statutory body to protect the rights of children?	Is there a statutory body to protect the rights of disabled people?	Are there (other) standing national bodies to provide policy advice?
Denmark	Yes. National Council for Children	Yes. Danish Disability Council and the Equal Opportunities Centre for Disabled Persons	• Council of Organisations of People with Disabilities
France	Yes. Défenseure des Enfants	*Unknown*	• Federal Council for the Association for the Rights of the Child • National Consultative Commission on Rights • Inter-ministerial delegation for people with disabilities • National Consultative Council of Persons with Disabilities
Germany	Partially. Most Länder have appointed a child welfare officer or children's commissioner	Yes. Federal Commissioner for Disabled People	• Parliamentary Children's Commission • Federal Youth Panel • Working party for youth welfare • Council for Participation of Disabled People
Ireland	Yes. Ombudsman for Children and Human Rights Commission	Yes. Equality Authority and Human Rights Commission	• National Children's Advisory Council • National Children's Parliament • Council for the Status of People with Disabilities
Italy	Partially. Office for Public Defender of Childhood in 4 regions; legislative proposals for national Defender	No	• National Documentation and Analysis Centre for Children and Adolescents • Parliamentary Commission on Children • National Observatory on Children and Adolescents • National Committee for Disability Policies • Consultation with organisations of disabled people and their families
Sweden	Yes. Office for Children's Ombudsman	Yes. Office for Disability Ombudsman	• Parliamentary Children's Committee • Child & Youth Advisory Committee • Government Disability Advisory Panel
UK	England – Proposed Northern Ireland – Yes Commissioner for Children & Young People, the Equality Commission and the Human Rights Commission	Yes England - Disability Rights Commission Northern Ireland - the Equality Commission and the Human Rights Commission	Government committees and advisory groups at various times. Parliamentary committees, including the Joint Committee on Human Rights, House of Lords/ House of Commons Westminster

Conclusion

The seven countries have taken diverse approaches to disability anti-discrimination and equality legislation and policy, which are summarised in Table 3.2

Table 3.2: Approaches to Disability Anti-Discrimination/ Equality Legislation and Policy

	Approach	Definition of disability	Enforcement
Denmark	Social welfare	✗	Danish Disability Council and the Equal Opportunities Centre for Disabled Persons oversight Folketing Ombudsman for individual complaints and formal investigations, in relation to public authorities
France	Constitution Criminal	✗	Through courts
Germany	Constitution Civil rights Social welfare	Constitution - ✗ Civil rights - ✓ Social welfare - ✓	Through courts
Ireland	Constitution Civil rights Social welfare	Constitution - ✗ Civil rights - ✓ Social welfare - ✓	Constitution and civil rights - through courts Social welfare – complaints and appeals procedure, ultimate appeal to courts
Italy	Constitution Social welfare	Constitution - ✗ Social welfare - ✓	Equality Authority
Sweden	Social welfare	✗	Office for Disability Ombudsman Monitor National Action Plan
UK	Civil rights	✓	Disability Rights Commission (England) Northern Ireland Equality Commission

Disability analysts quoted in this chapter have emphasised the civil rights approach, as closest to the social model of disability and more clearly delineated and enforced than other approaches. However, the approach still tends to fall back onto a definition that inherently includes and excludes, that tends to rely on the medical model of impairments, and relies on proof of long-term effects that may be difficult to provide for children. The constitutional approach may be laudable in its general principles but appears to be weak in its translation into practice. The criminal approach sets a high threshold for enforcement. All approaches that utilise the courts may create barriers for disabled people, who may find it difficult to access them (Clements and Read 2003), let alone for children (who may not be considered to have legal capacity and thus would be reliant on others for enforcement).

The consensus in the literature is that countries do not have to take just one approach: for example, Denmark now incorporates a civil rights approach alongside its social one aligned with sectoral responsibility. Using more than one approach may be the most desirable solution: the constitutional approach for its overarching nature; the civil rights approach for its specificity, enforcement and protection of individual rights; and a social welfare approach, appropriately updated, to ensure a proactive and monitored strategy and provision.

Hitherto, in general, the rights of children have not been central to approaches based on criminal or civil law; rather children's needs have been addressed in social welfare approaches. Their age is treated as a developmental concern rather than a potential characteristic for discrimination. Age discrimination against children is not a strong concept in domestic law in any of the seven countries and has been weakly interpreted by the European Court on Human Rights. Disabled children have considerably stronger rights not to be discriminated on the basis of their disability than on their age.

There is a trend across countries to establish independent organisations with statutory powers, to promote and protect the rights of children and of disabled people. This is hastened by official support for such organisations from the United Nations and the European Union. The powers of these organisations, however, can differ substantially: from being predominantly advisory and promotional to having enforcement powers in relation to individual complaints and/ or formal investigations. As required by the Standard Rules, countries seek to include the views of disabled people's organisations; representatives are frequently included upon national advisory bodies. Consultative arrangements are also common with children's and parents' organisation.

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CHAPTER FOUR: SCHOOL EDUCATION

International and European requirements

School education is an international priority. The right to education has long been stated in international documents such as the 1948 Universal Declaration of Human Rights Article 26 and the International Covenant on Economic, Social and Cultural Rights Article 13(2). Goals towards universal primary compulsory education were set by the World Summit for Children in 1990 and re-stated in 2002. Further, the World Declaration on Education for All, with its revised 2002 framework for action, has set the goal of achieving universal primary education and 50% improvements in adult literacy levels by 2015.

The United Nations Convention on the Rights of the Child (UNCRC) has two articles dedicated to education.

- Article 28: The child’s right to education, and the State’s duty to ensure that primary education at least is free and compulsory. Administration of school discipline to reflect the child’s human dignity.
- Article 29: The State’s recognition that education should be directed at developing the child’s personality and talents, preparing the child for active life as an adult, fostering respect for basic human rights and developing respect for the child’s own cultural and national values and those of others

Further, Article 23 addresses specifically the rights of disabled children, and states that disabled children should receive special assistance (free of charge whenever possible) to ensure “ the child has effective access to and receives education in a manner conducive to the child’s achieving the fullest possible social integration and individual development”.

Education is also addressed in the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules).

- Rule 6. States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system.

The Rule thus goes further than the UNCRC in recommending integrated settings. Support for integrated or mainstream settings was declared the preferred setting by the 'Salamanca Statement', another international statement from government representatives and international organisations (UNESCO 1994). The Standard Rules, though, do allow for special education when "the general school system does not yet adequately meet the needs of all persons with disabilities" (Rule 6(8)) and acknowledges that separate instruction may respect the communication needs of deaf and deaf/ blind persons (Rule 6(9)). The Rule makes further specifications that include:

- Inclusion of both genders and all levels and kinds of disabilities
- Special attention should be directed to: very young children; pre-school children; and disabled adults, particularly women.
- Parents' groups and organisations of disabled people should be involved in education processes
- Integrated settings must have suitable support and accessibility

Education is also mentioned within the European Convention on Human Rights. Article 2 of the First Protocol states that:

- No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions.

This Article notably differs from the UNCRC and the Standard Rules, because it is negatively phrased. In other words, a child would not have a right to education under the ECHR but rather they cannot be denied access to education that is provided to other children. While children are arguably the consumers of education, it is parental convictions that are respected rather than children's.

The European Social Charter has a positive right to education, in Article 17. Parties should take "all appropriate and necessary measures" to provide children and young people with "a free primary and secondary education as well as to encourage regular attendance at school". Parental rights and duties are to be taken into account in providing children and young people with the education and training that they need. Discrimination is prohibited in training opportunities, under the Charter, but no specific mention of disabled people's right to education is made.

The proposed European Constitution combines all three elements: it has a proactive right to education; it applies to everyone and is thus inclusive of children and disabled adults; and it mentions parental rights:

- Everyone has the right to education and have access to vocational and continuing training.
- This right includes the possibility to receive free compulsory education.
- The freedom to found educational establishments with due respect for democratic principles and the right of parents to ensure the education and teaching of their children in conformity with their religious, philosophical and pedagogical convictions shall be respected, in accordance with the national laws governing the exercise of such freedom and right (Article II-14).

Thus, the international and European documents show certain themes. Integrated (now more commonly termed 'inclusive') settings are preferred, although not required. School education should be provided to all and compulsory education should be free. Education rights are not only about children but contain an element of parental rights – most strongly seen in the European documents, but also through other articles in the UNCRC around parental guidance etc..

Organisation

Most of the European countries have experienced devolution of school responsibilities, over recent decades. Sweden exemplifies this. The Swedish Parliament and the Government are responsible for the general management and goals for schools, while operational responsibilities are devolved to municipalities and schools. While differing in detail, educational policy is set in Denmark, England/Northern Ireland, Ireland and Italy at central government level while varying elements of discretion and decision-making are devolved to smaller regional bodies. Germany is the exception, in its 16 Länder having long-standing responsibility for educational policy. Nationally, Länder ministries come together to agree national standards and other matters. The Federal Government does have some reserved powers in relation to education, such as vocational education.

The countries differ in how far responsibilities and discretion are devolved to schools. Italy, for example, has a highly decentralised structure; the Law no. 59 of 1997 widened schools' autonomy over financial, administrative and organisational matters and gave schools considerable independence in taught content and teaching approach (Gruppo 2003: 59). While in England, central government has taken over responsibility for the National Curriculum in the 1980s, it has decentralised other aspects such as funding from the regional local authorities down to schools. Northern Ireland has five types of schools with differing relationships to the five Education and Library Boards in relation to management and funding.

France has decentralised its educational system since 1982 but the central government retains a considerable role. It continues to set educational choices and curricula and is responsible for staff recruitment, training and management. Different levels of territorial authorities are now responsible for education – with over 36,000 communes responsible for primary schools. Local bodies now have more control in the daily running of schools. (Eurydice France 2004)

In some of these countries there are exceptions to the increased devolution. For example, in Northern Ireland the maintained integrated schools have their recurrent costs met by central government, the Department of Education in Northern Ireland. In Sweden, Saami schools (for Saami-speaking children in the North of Sweden) and special schools for deaf and hard of hearing pupils remain centrally managed (Sweden 1998: 452). In Denmark, the 14 counties retain responsibility for special educational support for children whose “development calls for special and extensive consideration and assistance” (Egelund 2000: 89) while the 269 municipalities are responsible for other special educational assistance for children and young people under the age of 18 and pre-school institutions, primary and lower secondary schools (Egelund 2000:89).

How might such devolution impact on disabled children? It could have the advantages of ensuring that local services take responsibility to meet the educational needs of disabled children and that they plan and provide services to meet the particular needs of their populations and communities. The other side of flexibility can be inequity, so that children living in one part of the country may not receive the same services that they would if they lived in another part of the country. Devolved funding means that each fund is smaller, which can lead to budget pressures should a particular child require specific expensive services. Economies of scale can be lost, so that specialist expertise is not widely available. Denmark, for example, organises for such specialist expertise to be available through municipal authorities to call upon county or national specialists (Denmark 1993: para 217).

Educational legislation in all countries includes disabled children. For some countries, this is established in their respective Constitutions: e.g. Article 34 of the Italian Constitution (“Schools are open to everyone” (34(1)), the Basic Law of Germany in its equality Article 3, and Ireland’s Constitution require the state to ensure that “the children receive a certain minimum education, moral, intellectual and social” (Article 42.3.2). All countries have education that covers all children, whether or not they have disabilities.

Countries also differ in regards to curricula. All counties have some form of central guidance (Germany at secondary level). Certain countries, like Denmark, Italy and Sweden, have centrally set goals and curriculum guidelines by subject are issued. Danish local authorities and Danish and Italian schools are able to adapt the curriculum locally. German curricula are predominantly set at Länder level. England/ Northern Ireland, France, and Ireland have more prescriptive national curricula.

Having a national curriculum, in which all pupils disabled or not must participate, provides potential equality. All children have the right to be educated on the same subjects to a sufficient standard. In Sweden, for example, if children do not reach the attainment goals in 5th year, this would be a reason for resources to go towards their special needs (Persson 2004). On the other hand, most countries with a defined national curriculum tend to make exceptions for disabled children. For example, Ireland has separate curriculum guidelines for students with mild and moderate learning disabilities. So does Germany for pupils with learning difficulties or who are mentally handicapped – although it is not clear what the difference is. Schools can offer a reduced course of study in Sweden. More flexible curricula render issues of “exceptions” unnecessary. Denmark, for example, has no special curriculum guidelines for disabled pupils. Pupil progress in Italy is to be mapped regularly through an individual education plan.

Costs of school education

All countries provide compulsory schooling free of charge. The countries differ, however, in the extent of payment for independent schools. At one extreme are Denmark and Sweden; their systems are based on parental choice. Parents can choose to send their child to an independent school and receive state funding (in Denmark, only 80% of the costs are paid). In Germany, state funding goes to independent schools; in return, such schools cannot charge fees that increase social segregation and hence they tend either to be free or subsidised. In England, Northern Ireland and Ireland, state funding goes to a range of schools, some of which are not managed by the state. The parents of disabled children in these countries can have additional rights to choose an independent school: if a child is assessed to have special educational needs (SEN), and a particular school is identified as important to meet those needs, the state will fund that placement.

The countries also vary in the coverage they give to incidental costs of attending schooling. For example, Denmark, Germany, Sweden, the UK and Italy (at primary school level) and usually French municipalities, provide free books and education materials. Other countries work on the basis of grants, such as Italy for transport and meals and Ireland for school transport, text books and uniforms. France provides a special education allowance, which is meant to offset the additional expenses associated with educating a disabled child in the family. The amount depends on the seriousness of the disability.

School setting

Fitting with the Salamanca Statement advocating mainstreaming schooling (see above), all the countries officially support inclusive schooling. The countries differ, though, in the extent of exceptions to a mainstreaming principle and segregation/ separation within mainstream schools. EADSNE (2003) suggests a classification for these different approaches:

- One-track approach: policies and practices include almost all pupils within mainstream education. Italy and Sweden are included here.
- Multi-track approach: a multiplicity of approaches to inclusion is maintained, with a variety of services between the two systems (i.e. mainstream and special needs education systems). Denmark, France, Ireland and the UK are included here. Germany is described as moving from a two-track to a multi-track approach.
- Two-track approach: two distinct systems are maintained. Pupils with SEN are usually placed in special schools or special classes and do not follow the mainstream curriculum. None of the seven countries are included here.

The OECD (2003) sought to compile equivalent statistics in relation to SEN, using comparable definitions. This information remains limited for this review, as not all of the seven countries submitted information for all the issues, and the statistics are from 1999. France, Italy, Sweden and the UK did provide comparable information on the educational location of pupils.

Italy represents one extreme at 98.3%: since the 1970s, it has supported full 'integration' of disabled pupils in ordinary schools. France represents the other extreme in the seven countries. The right of disabled children to be school in ordinary schools was recognised in legislation as early as 1975 and has since been reaffirmed in subsequent legislation. It retains, though, an extensive system with both special schools and segregated/ separate provision within ordinary schools. France's overall 29.7% is composed of 17.2% of these students being in special classes in regular schools and 12.5% in regular classes. In 2003 the European Commission of Social Rights noted that the number of children integrated into mainstream education remains substantially lower than the number attending special schools.

Sweden's percentage at 42.4% is high given their support for 'a school for all'; since the date of these statistics in 1999, Sweden has closed many of its special schools and/ or changed them into resource centres. England/ Northern Ireland, Germany and Ireland explicitly assert the need to retain a continuum of provision, often with encouragement for pupils to move between the types of provision. Recent or proposed legislation has sought to strengthen the rights of children with SEN to mainstream education; although there are still exceptions such as if it was incompatible with the provision of efficient education of other children (Eurydice Ireland 2003, Eurydice UK 2003).

Despite the advocacy of inclusion, commentators from most countries note that there are difficulties in practice. The report from the Italian Save the Children (Gruppo 2003) commented on recent cuts in staffing expenditure, architectural and physical barriers; and the Government itself reported that the rights of disabled pupils are not met in all areas of the country (1998: para 486). Similar concerns about lack of resources are expressed in England/ Northern Ireland (Kilpatrick 2004), France (EADSNE 2003), Germany (EADSNE), Ireland (Children's Rights Alliance 1997), and Sweden (Persson 2004). Numbers of children in segregated settings are small in all the countries (EADSNE 2003: 10): Italy, less than 1%; Denmark, Ireland, Sweden and the UK, between 1-2%; France, between 2-4%; Germany, between 4-6%. Concern is expressed, however, that in some countries, numbers of children in special schools are growing (e.g. Egelund 2000, referring to Denmark; Lundahl 2002, referring to Sweden).

All countries place a legal responsibility on the respective state body, to provide support for children with SEN (however defined). All countries have a range of support services and educational interventions to provide such support. Additional teaching support or assistance is common across all countries.

All countries but Denmark and Italy have mandatory teacher training on SEN within initial training. In Denmark, all teacher training colleges must offer a module on 'children with different needs' but participation is not mandatory (Egelund 2000: 94). When Danish Folesckoles are to have a disabled child attending, the teachers there must receive continuous training (Council of Europe (CE) 2003). Specialist training is available for Italian support teachers but not for all teachers (Eurydice Italy 2004). Other countries may only have a small proportion of initial mandatory training on special needs (e.g. see EADSNE France 2003). Such training for all may assist pupil inclusion.
Specialist teacher training is available in all countries.

Should it be identified that a child needs special support, all seven countries have a system of individual assessment by professionals, which (if deemed necessary) leads to an individual plan for the particular child. These assessments are usually the gateway to additional support. However, the countries differ substantially in their use of categories and the formal rights within the system. Denmark and Sweden both officially work to a non-categorical system of SEN and both have the least legally-bound system. In Denmark, teachers and the head of the school, the school health service or their parents can all ask for an assessment. The assessment is undertaken by the Pedagogical Psychological Advice Office in the municipality. The subsequent report gives recommendations, whether for special education or for other types of assistance. The office or school head can only overrule the parents' wishes with 'strong arguments' if the parents do not agree with the need for special education (EADSNE Denmark 2001). The Office monitors the development of such pupils, at least once a year. Similarly, in Sweden the Education

Act stipulates that pupils in need of special support must have written plans of development set up in co-operation with the pupils, parents and professionals. Local authorities are obliged to meet the pupils' needs for education.

Italian law (Framework Law 104/92) requires individual education plans for children with learning difficulties. These plans extend beyond education to include co-ordination with health and welfare services, cultural associations and sports and recreational facilities (EADSNE Italy 2003). France also has an assessment system than goes beyond educational planning. If recognised as 'disabled' under the Guideline law no. 75-534 of 30th June 1975, a child may become eligible for financial aid, measures of guidance and special education and/or the need for full time care or accompanying specialised medical social services. To be recognised as 'disabled', a child must be assessed by regional commissions of special education. They rely on multidisciplinary technical teams (doctors, special educators, psychologists, social assistants) who analyse each case before giving their decision. A disability card may be allocated if the child is judged to have 80% or more incapacity (France 2004 translation). The decisions of the Commissions can be appealed against.

The French system has relied upon the WHO International Classification of Disability (MISSOC 2003:48). The MISSOC report states that there has been "some progress" (48) away from a medical approach. Armstrong and colleagues (2000) note that assessment now incorporates observations of children to assess their 'developmental potential' but does not think this represents progress towards a more social approach. Greater emphasis is placed on the child's performance and projected future development, and less on the 'origin' of their difficulties. This view, while seeming to take into account the importance of context in evaluating a child's development, still places the origins of such difficulties within the child. In effect, it positions the professional gaze even more powerfully than ever before in relation to disabled children and their families (66).

England, Northern Ireland Germany and Ireland and also have a set category, special educational needs. It differs from the French, though, as being specifically linked to educational needs. While interagency assessments are encouraged, the plan does not cover the breadth of the French and ‘SEN’ overlaps but does not equate to the definitions of disability provided in other areas of legislation (e.g. social services, social security, or disability discrimination). Educational psychologists in England, Northern Ireland and Ireland have a pivotal role in these systems (as they do in Denmark), in co-ordinating the assessment. The assessment results in a “Statement”, which should specify resources and school placements. Various parts of the assessment process and statement can be appealed against by parents. The systems thus differ on several strands:

- Whether assessments primarily focus on education (Denmark, England/ Northern Ireland, Germany, Ireland, Sweden) or are ‘holistic’ assessments (France, Italy)
- Whether assessments rely on a medical classification (France) and, to a lesser extent, Germany or a circular one of ‘SEN’ (other countries)
- While all systems emphasise professional assessment, the emphasis on non-categorical systems in Sweden and Denmark is aligned with a less formal bureaucratic rights for parents (and children) in comparison with England/ Northern Ireland, Germany and Ireland.

Conclusions

Distinct patterns can be observed across the seven countries, in relation to education.

The majority of the European countries have experienced devolution of school responsibilities, over recent decades. Countries with greater devolution report positive effects for inclusion (EADSNE 2003). These effects, however, have not been systematically tested to concur with these reports. Greater local flexibility can exist alongside greater inequity, as is frequently remarked in UN Committee Reports on these countries (see individual country chapters).

All seven countries include disabled children within all children’s entitlements to education. This extends in all countries to access to the curriculum. However, those countries with a more prescriptive curriculum tend to make exceptions for disabled children. Several countries have recently expanded the SEN teaching in initial teacher training; Denmark and Italy are the exceptions in not having such training mandatory.

Officially, policy is pro-inclusion for disabled children. Countries differ, however, on the extent of separate special education provision they maintain. At one end is Italy, which has very little segregated special education, in contrast to France and Germany, which have a considerable network of institutions. All of the seven countries do continue with at least some special schools. The divisions between mainstream and special schools are becoming less distinct in several countries, with specialist classes being located within mainstream settings and special schools being changed into resource centres for mainstream teaching.

In each country, a state organisation is required to provide support for children with SEN. A range of support services and educational interventions are available. All countries have developed a system of assessment, with an individual plan for children with SEN.

Comparable statistics are difficult to obtain in this area, due to considerable differences in definitions within nations let alone across them. Denmark is one extreme, because it officially does not use a definition of disability. With no such official category, it did not submit information to the OECD (2003) publication on SEN.

The extent to which children are truly ‘included’ in so called inclusive settings requires in-depth consideration. For example, disabled children may be placed within a mainstream school but actually may have little academic or social inclusion within that school.

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CHAPTER FIVE: SOCIAL SECURITY

The term ‘social security’ will be used in this chapter. Different countries use different terms to describe financial support provided by the State, or other organisations, to individuals to ensure adequate standard of living. In continental Europe, the term ‘social protection’ is preferred. The terms vary somewhat with respect to the elements included: from support through the private sector, to pensions, cash benefits and/or tax credits and allowances.

This chapter relies largely on 3 sources of data:

- Bradshaw and Finch’s comparison of child benefit packages (2002)
- Mutual Information System on Social Protection in the EU (MISSOC) database
- Country-specific information from available documents.

This chapter cannot by itself provide a full picture of State or other socially-available support for families with disabled children, which could be translated into a financial value. Like all the chapters, it should be understood in the context of the whole policy review and the information available to it.

International and European requirements

Social entitlement to an adequate standard of living, social assistance and social security are enshrined in international and European documents, for children, disabled children and disabled people.

The UN Convention on the Rights of the Child (UNCRC) sets out the child’s right to an ‘adequate standard of living’ (Article 27) and to benefit from social security (Article 26). Article 27 begins by requiring States to “recognise the right of every child to a standard of living adequate for the child’s physical, mental, spiritual and moral development” (27(1)). Parents, and others responsible for the child, have the primary responsibility but States should take appropriate measures to assist parents and other carers to do this. Article 26 does not give children the right to social security but rather the right to *benefit* from social security. This is justified by children's economic security being bound up with their caregivers, so that receipt of social security is contingent in Article 26(2) on a carer's lack of resources (Hodgkin and Newell 2002: 379). Also relevant is the particular recognition of the "special needs" of a disabled child to "special care" and assistance, so as to ensure social integration, which is outlined in Article 23.

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules) also contain provision for income maintenance and social security. Rule 8 is largely adult-oriented with its focus on employment and earned income. For example, States must provide "adequate income support" to disabled people but this is for those who have temporarily lost or received a reduction in income or have been denied employment opportunities (8(1)). Rule 8, however, is applicable to children in two ways: first, States should not exclude or discriminate against disabled people in their schemes (8(2)) and, second, States must provide income support and social security protection to "individuals who undertake the care of a person with disability" (Rule 8(3)). Notably, Rule 8(3) does not set the standard of 'adequate' income support as Rule 8(1) does for adults. In his 2002 Report, the Special Rapporteur on the Standard Rules recognised that an adequate standard of living and poverty alleviation had not received sufficient attention in the Standard Rules and required further elaboration.

Both the UNCRC and the Standard Rules are set within wider international requirements for social security and poverty alleviation, such as Article 9 of the International Covenant on Economic, Social and Cultural Rights and recommendations from the World Summit for Social Development (Copenhagen, 1995).

Article 12 of the revised European Social Charter applies equally to children and adults. This article sets out requirements for a social security system at a minimum level. Also relevant is Article 30, which outlines the right to protection against poverty and social exclusion. Article 16 then sets out requirements on States to promote the "economic, legal and social protection of family life" by benefits and fiscal arrangements.

The proposed European Constitution (Article II-34) puts forward a strong case for the entitlement to social security benefits and social services, in accordance with Union law and national laws and practices. Member States of the European Union produce National Action Plans for Social Inclusion (NAPs) and there is a five-year Community Action Programme (2002-2006) to encourage co-operation in the fight against social exclusion (ATD Fourth World 2004). Children were identified as a target group for action against social exclusion, but Euronet (2002: 7) declared that few countries have identified a concern for child poverty and social exclusion in their National Action Plans.

There are strong statements, therefore, within International and European documents on the social rights of children and disabled people in regard to social security and adequate standard of living/ alleviation of poverty. However, this strength is qualified by the status of these documents, as discussed in Chapter 1.

Comparing social security systems

Comparisons of social security systems have been a central component of comparative social policy. As discussed in Chapter 1, Esping-Anderson's seminal work in the 1990s, for example, suggested three models of welfare regimes – liberal welfare, conservative-corporatist, and socio-democratic. Table 1.1 in Chapter 1 shows the classification of the seven countries considered in this project. The countries differ considerably. Denmark has a high level of collective and public service consumption (Kleinman 2002). As Hill (1996) describes, in Scandinavian countries: "Schemes of social insurance come so close to being universal that one wonders whether the term 'insurance' is really appropriate". This contrasts with France and Germany where the principle of insurance is clear. France is described as focusing on "corporate rather than national solidarity, horizontal rather than vertical distribution, occupationally based welfare" (Kleinman 2002). France has long prioritised family policy and this has a dominant role within the social security system. It is a fragmented system, occupationally based and in which local municipalities have considerable control of the means-tested social assistance. Ireland and the UK both have national systems, which have some universal benefits but have moved to targeted allocation. There is debate around the status of Southern European countries such as Italy. Italy is seen as having a “clientalistic” system, where particular groups are able to lobby for benefits (Kleinman 2002). Some analyses regard this as incomplete or immature examples of the corporatist model while others argue for a distinctive category of Southern European welfare (see Kleinman 2002 for further discussion).

Hölsch and Kraus (2004) considered European social assistance systems, with a narrow definition of social assistance that did not include categorical assistance (i.e. cash benefits for specific groups). Of interest here is there typology based on how centralised the social assistance systems were:

Table 5.1: Classification of social assistance systems by centralisation/ decentralisation

Degree	**Description**	**Countries**
High decentralisation	Benefits funded by municipalities Benefit levels established by regional or local authorities and vary across regions	**Germany, Sweden**, Spain, **Italy** and Austria
Medium centralisation/ decentralisation	Benefits funded by regional or local authorities Benefit levels set by central government and largely uniform across regions	Belgium, **Denmark, France** and Finland
High centralisation	Benefits funded by central government Benefit levels set by central government and uniform across regions	**Ireland, the UK** and the Netherlands

Source: Hölsch and Kraus (2004): 150

Hölsch and Kraus (2004) asked which systems led to greater distributive efficiency and redistribution. Their data, however, only applied to Finland, France, Italy, Germany and the UK. They found some evidence that very centralised systems such as the UK were better at redistribution than decentralised systems such as Italy – but this was only true at the extremes. A medium degree of centralisation as in France resulted in a better distributive efficiency than extremes.

Social security for children

From the perspective of children, the typologies again differ as do the distribution of countries across them. Bradshaw and Finch (2002: 13) identify the following divisions, in relation to comparing child benefit packages:

Leaders	Austria, Luxembourg, Finland
Second rank	**France, Sweden, Germany, UK**, Belgium, **Denmark**, Norway, Australia
Third rank	**Ireland**, Israel, Canada, USA and **Italy**
Laggards	New Zealand, Portugal, Spain, Japan, the Netherlands and Greece

Bradshaw and Finch (2002) based their table in July 2001 on these 14 elements:

- Gross earnings
- Employee social security contributions
- Non-means-tested child benefit
- Net housing costs
- Net local taxes
- Health charges/ benefits
- Guaranteed child support
- Income tax payable
- Income-related child benefit
- Gross housing costs
- Gross local taxes
- Net childcare costs
- Education charges/ benefits
- Other – e.g. social assistance paid to low earners

Country respondents were asked to provide this information, based on eight income states (e.g. one earner working 16 hours per week for a minimum wage; two earners, one on average male earnings and one on average female earnings; no earners) and nine family types (e.g. lone parents with different numbers and ages of children; couples with different numbers and ages of children; comparisons with households with no children). These decisions were based on the accumulated knowledge, from previous work.

Bradshaw and Finch (2002) conclude that non-income related child benefits and the income tax system are the main ways that the child benefit package is delivered for families with school age children.

Education and health costs, in most countries, do reduce the value of the child benefit package but not greatly. In Table 5.2, the child benefit package structure is compared between the ‘average family’ case – a couple plus two children with one earner on average male earnings – and the ‘social assistance’ family case – a couple on social assistance plus one child.

The table shows that:

- Denmark is a clear leader in redistribution for families on social assistance, with the UK, Ireland and Sweden following behind. Italy is dramatically lower, with families on social assistance disadvantaged compared to both average families and childless couples.
- When considering the differences between the average family and the social assistance family case, it becomes evident that the child benefit package does more for the average family in Germany, Italy, Sweden and France than it does for the social assistance family. This is not the case in Ireland, the UK and Denmark; Table 5.2 shows that this relates to the amount of social assistance provided, which composes a substantial part of the child benefit package for these families.
- Germany has the narrowest range of benefits, relying solely on social assistance, income tax, and income related child benefit for these two family types. Sweden is unusual amongst the seven countries, in having a substantial contribution from the ‘non tax and benefit’ package – most notably in rent and school benefit costs. For the social assistance family case, the net disposable income moves from a negative figure (as compared to a childless couple) to a positive figure following the net rent contribution.

While Bradshaw and Finch (2002) comment that there is a general trend towards supporting families through the tax system, Denmark and Sweden do not have any tax concessions for children except for child care. Ireland is also reported as not having general tax allowances but the income threshold for paying taxes varies by the number of children. Germany, by contrast, has moved over the last decade to supporting families primarily through the tax system.

Table 5.2: Structure of the child benefit package for the 'average family' and 'social assistance' (SA) case
The amounts are the differences in income from a childless couple at this earnings level in £ ppps (purchasing power parities)

	Social Assist.	Income tax	Income related child benefit	Non-income related child benefit	Net rent	Net local tax	School costs/ benefits	Health costs	Other	Net after taxes and benefit[1]	Net after all[1]
Denmark											
Average	0	0	0	110	23	0	0	0	0	**110**	**133**
SA	389	-151	0	55	13	0	0	0	0	**289**	**302**
France											
Average	0	38	28	72	0	-7	16	-2	0	**138**	**144**
SA	66	0	14	0	29	-6	0	0	0	**79**	**102**
Germany											
Average	0	189	0	0	0	0	0	0	0	**189**	**189**
SA	11	0	95	0	0	0	0	0	00	**105**	**105**
Ireland											
Average	0	43	0	116	-6	0	-22	-18	0	**159**	**114**
SA	108	0	0	58	-16	0	-6	0	0	**166**	**143**
Italy											
Average	0	28	97	0	0	0	-28	5	0	**125**	**102**
SA	-153	0	0	0	0	0	-5	0	0	**-153**	**-159**
Sweden											
Average	0	0	0	130	0	0	42	0	0	**130**	**172**
SA	-85	0	0	65	137	0	21	0	0	**-20**	**138**
UK											
Average	0	43	0	112	0	-21	0	0	0	**155**	**134**
SA	132	0	0	67	0	0	21	0	0	**199**	**220**

Source: based on information from Tables 9.3 and 9.5 of Bradshaw and Finch 2002

[1] Net disposable income

How does the child benefit package relate to the average earnings within each country? Bradshaw and Finch make such a comparison in Table 5.3. They seek to create a more 'representative' selection of family types and earning levels, as the family cases described above over-represent low income families.

Table 5.3: The value of the child benefit package, as a percentage of average earnings

	After tax and benefits	After housing costs	After services	After all
Denmark	6.2	8.7	5.3	7.7
France	10.4	12.3	8.9	10.9
Germany	9.0	9.8	7.6	8.3
Ireland	15.2	14.0	8.0	6.9
Italy	4.8	4.8	1.9	2.0
Sweden	6.7	9.2	7.7	10.2
UK	11.6	10.9	8.2	7.5

Source: Table 11.4 Bradshaw and Finch (2002)

Bradshaw and Finch (2002) determine that these variations are *not* due to: a country's wealth (i.e. Gross Domestic Product (GDP) per capita); characteristics of the country's labour market, such as minimum wage or women's employment; level of earnings. Child benefit packages tend to be more generous in countries with high expenditure on family benefits and services per capita; and high social expenditure as a percentage of GDP and per capita.

Table 5.4 below shows social expenditure, under certain general categories, for the seven countries and the European average:

Table 5.4: Public expenditure by function (as a percentage of GDP)

Category	**Denmark**	**France**	**Germany**	**Ireland**	**Italy**	**Sweden**	**UK**	**EU**[1]
Family[2]	3.8	2.8	1.9	1.6	1.0	2.9	2.0	2.2
Health[3]	7.1	7.2	8.0	4.9	6.3	7.4	6.1	6.1
Housing[4]	0.7	0.9	0.2	0.5	0.0	0.6	1.5	0.4
Incapacity[5]	3.9	2.1	2.3	1.4	2.1	5.2	2.5	2.9
Education	8.0	5.9	4.5	4.4	4.5	7.8	4.5	5.3
Pre- Primary	0.7	0.7	0.4	0.0	0.4	0.6	0.4	0.4
Primary	1.7	1.2	0.7	1.4	1.0	2.1	1.1	1.3
Secondary	3.0	2.9	2.1	1.6	2.1	3.0	2.1	2.2
Post Secondary	2.3	1.0	1.2	1.3	0.9	2.2	0.9	1.4
Other	0.3	0.1	0.2	0.1	0.1	0.0	0.0	0.1

Source: Figures relating to Family, Health, Housing and Incapacity refer to expenditure in 2001 and are taken from the OECD Social Expenditure Database 1980-2001, OECD (2004a). OECD definitions are included in the footnotes (OECD 2004b). Figures for Education refer to the financial year 1999-2000 and are based on UNESCO data available at http://portal.unesco.org/education

[1] In calculating average Education expenditure for the EU all data used is for 1999-2000.

[2] Family include expenditure which supports families (i.e. excluding one-person households). This expenditure is often related to the costs associated with raising children or with the support of other dependants. Expenditure related to maternity and parental leave is grouped under the family cash benefits sub-category.

[3] Social expenditure data in the health policy area is taken from the OECD Health database (OECD, 2003). All public expenditure on health is included (not total health expenditure): current expenditure on health (personal and collective services (HC.1 to HC.7 in the ICHA) and investment (HC.R.1). Expenditure here includes in-patient care, ambulatory medical services and pharmaceutical goods.

[4] Rent subsidies and other cash benefits to the individual to help with housing costs.

[5] Disability cash benefits consist of cash payments on account of complete or partial inability to participate gainfully in the labour market due to disability. Sickness cash benefits related to loss of earning because of the temporary inability to work due to illness are also recorded. This excludes paid leave related to sickness or injury of a dependent child which is recorded under family cash benefits. All expenditure regarding the public provision of health care is recorded under health. Social expenditure on services for the disabled people encompasses services such as day care and rehabilitation services, home-help services and other benefits in kind.

Ireland has less spending than the European Union average whereas Denmark, France, and Sweden consistently spend more than the European average. Public expenditure on housing is generally low, but UK is considerably above other countries and the European Union average. Italy by contrast reports no public expenditure on housing.

Importantly, Bradshaw and Finch conclude that child benefit packages do impact on child poverty rates: the more generous the package the lower the child poverty rate. Bradshaw and Finch use a poverty rate determined by the US poverty line, which is derived from budget standards. The same approach is found in the UNICEF (2000) report; the following percentages of children live in households with incomes below this poverty line:

Denmark	5.1%
France	10.7%
Germany	12.5%
Ireland	21.4%
Italy	35.1%
Sweden	5.3%
UK	29.1%

This information is from 1997, and thus different from the 2001 date for information on the child benefit package.

Social security for disabled children

Bradshaw and Finch (2002: 49) explicitly exclude consideration of disability from their analysis, both for disabled adults and disabled children. Thus the calculations do not represent benefits or income that relate to disability – and most countries do have a complex system of supplements and additions. Further, some of the assumptions made within the 14 elements above are not likely to apply to many disabled children. For example, Bradshaw and Finch assume that transport will not be required to and from school, family members each visit the general practitioner once a year, and the family receives one antibiotic prescription per year.

The MISSOC database contains information for disabled children but it is typically spread across three sections (family benefits, invalidity and long-term care). The information is insufficient to provide a solid comparison of disability-specific benefits: comparative information was not found across categories such as age limits, financial amounts, nor eligibility definitions; there are considerable gaps in coverage, as other benefits were identified through other sources. A compilation of the MISSOC and other information is contained within Table 5.5 at the end of this chapter. The table shows at least three different types of additional financial support, for disabled children, across the seven countries:

- Supplements or extensions to general child benefits/ family allowances
- Benefits for caring costs
- Benefits based on a child being disabled

Most countries make some changes to general child benefits and family allowances to recognise a child's disability. Italy, for example increases the level of annual family income, which is eligible for child benefit. Parents in the UK have additional amounts added to their tax credits. Germany does not pay additional cash benefits beyond the regular family allowance but does extend the age limits for entitlement to family allowance – unlimited if a child is disabled. An extension of age limits is also available in Ireland, Italy and Sweden. It is not available in Denmark or the UK. Denmark is unique in not modifying its general child and family provisions to take account of disability.

It is a common feature to provide allowances for caring. All but Italy have an allowance paid to those responsible for caring, on an on-going basis. France and Sweden have provisions for parents who need to take care of a disabled child on a temporary basis. Other countries have forms of parental leave, unpaid or paid, which are not covered within the MISSOC database and are not included in Table 5.5at the end of this chapter. Such provisions are discussed further in the country chapters.

Another route to financial support is through specific benefits to cover the costs of disability. Countries differ on whether children are included within the general disability benefits available to adults of working age as well as children, or whether they have benefits for disabled children only. France, for example, has the special education allowance (Allocation d'éducation spéciale) for children. Ireland's Domiciliary Care Allowance is only for children and their families. Germany and the UK take a different approach, including disabled children within the general disability benefit provisions. So, for example, in Germany there are no age limits for those being cared for, in regard to statutory long-term care insurance or social assistance for caring.

The UK does not provide certain additional benefits for disabled children at young ages (age three for the higher rate of Disability Living Allowance (DLA) mobility, age five for the lower rate of DLA mobility). The argument is that very young children require considerable care, whether disabled or not (Zeitzer 1995). While such age limits are not explicit for the Swedish assistance allowance, they seem to apply in practice:

- Even small children can have assistance, but it is hard to get assistance allowance for babies, because they need so much care taking anyhow (Ingmanson 2003 translation: 98).

Certain disability-specific benefits are 'passport' benefits. If a child or family member is judged to be eligible for these benefits, they then become eligible for other benefits. An example of this is the UK, where receipt of certain levels of the DLA renders the family eligible for extra child tax credits and other benefits.

Conversely, if the child is disabled but under the threshold to gain the DLA, the child does not have access to these other benefits. This has both advantages and disadvantages: one eligibility category aids simplicity but may mean an ‘all or nothing’ approach to benefits, with some disabled children and their families just missing the threshold for DLA and thus the associated benefits as well.

Conclusion

The rights of children and disabled people to an adequate standard of living, and inclusion within social security system, are established within international and European documents. There has been considerable comparative attention to social security systems internationally and more specifically in Europe. Within this comparison, there has been an on-going strand that has analysed the financial impact of the social security system for children. What is missing, however, is the same quality of comparative information – both in what is available and in analysis – on the social security system for disabled children. International studies show that prevalence rates of childhood disability are increasing for children living under the absolute poverty line (LeRoy et al. 2000).

The generosity of social security systems vary with the social group considered. The typologies of welfare regimes put forward by authors such as Esping-Andersen (1990) look very different if considered for instance from the perspective of women, or from the perspective of children. Recent work on child benefit packages places the seven countries considered here in the middle ranks of countries, with France in the lead and Italy at the end. These ranking are based on a judgement of ‘representative’ families. When families who have no earners and receive social assistance are considered, Denmark becomes the leader, with the UK, Ireland and Sweden following behind. Italy, though, remains dramatically lower, with families on social assistance receiving considerable less than ‘average’ families and childless couples.

Bradshaw and Finch (2002) report a general trend towards supporting families through the tax system. But out of the seven countries considered here, Denmark and Sweden do not have any tax concessions for children except for child care and Ireland does not have general tax allowances per se. Education and health costs do reduce the value of child benefit package but not substantially. Countries differ on the eligibility basis for benefits: for example, Table 5.2 shows how, for the average family and the social assistance family cases, France, Germany and Italy use income-related child benefits while Denmark, Ireland, Sweden and the UK do not. All but Germany and Italy have a non-income related child benefit and this is a substantial contribution to the child benefit package in the other five countries.

The benefit package for disabled children can be divided into three types: supplements or extensions to general child benefits; benefits for caring costs, frequently in terms of replacement wages; and benefits for the extra costs of having a disability. The first type can be found across all seven countries except Denmark. The second type is also popular, but not found in a permanent form in France nor Italy. There are countries that have child-specific benefits for disabled children and their families, and those that include children within the disability provisions for adults.

Universal benefits are most frequently described as the "pinnacle of desirability" for social rights as they avoid the problems of the other principles. However, Mabbett writes that:

- Universal systems bring with them a heavy emphasis on other principles of allocation, often involving the exercise of professional power such as the delineation of a disability category (2002: 45).

This criticism would seem to apply to some non-income related benefits for disabled children but not others. Child benefits are determined by an age category but otherwise universal benefits do not involve much professional power in deciding eligibility. Benefits based on disability, though, typically do involve considerable professional or administrative discretion in determining eligibility. This difference is perhaps due to the uncontested presumption of child dependency and of the salience of age, while disability is more contested and problematic.

Table 5.5: Benefits and allowances for disabled children and their carers[1]

Category	**Denmark**	**France**	**Germany**	**Ireland**[2]	**Italy**	**Sweden**	**UK**[3]
Within general child/ family provisions	No	Yes	Yes	Yes	Yes	Yes	Yes
Extend age limit for disabled young person?	No	No	Yes no age limit	Yes up to age 19	Yes no age limit	Yes extended	No
Other details		Tax reduction for households with a dependent child who has a disability card.		*Incapacitated Child Tax Allowance*: claimed by parent/ guardian for child who is permanently incapacitated before reaching age 21 or while in full time education or training	Increase in the level of annual family income which is eligible for child benefit, increased to €7,230 per year	If child is attending special schools for the mentally handicapped up to the age of 23[4]	*Child Tax Credit* (introduced in 2004): an extra amount is added if a child is registered blind or receives DLA (3623€). If at the higher component of DLA, a further amount added (1131€)[5]. The money to the family will depend on family gross annual income.
Outwith child benefit/ family allowance	Yes	Yes	Yes	Yes	No	Yes	Yes
Carers' allowance	Income replacement benefit for domiciliary care of a handicapped child.	Allocation de presence parentale *Complement d'allocation spéciale*	*Statutory long term care insurance* pays for pension insurance contributions for caring family members. Also provides for	*Carer's Benefit* full-time carers for up to 65 weeks *Carer's Allowance* means tested payment for carers Respite Care Grant		*Care allowance* for parents of disabled or seriously ill children[6]. It aims to compensate for the extra care and for additional costs caused by the	*Carer's Allowance*

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[1] Source for exchange rates http://europa.eu.int/comm/eurostat/newcronos/queen/display.do?screen=detail&language=en&product=LT&root=LT_copy_1031680375681/yearlies_copy_221546607827/d_copy_874392991452/db_copy_326658639582/dbc_copy_455814982301/dbc10512_copy_638912660396 (3.9.04)

[2] Payments for the Ireland are typically given per week. These were converted to monthly figures using the formula (weekly figure x 52)/12

[3] Payments for the UK are typically given per week. These were converted to monthly figures using the formula (weekly figure x 52)/12

[4] Information from Clearing House, Section 1.3 Table 1.32. Also international reform monitor http://www.reformmonitor.org/index.php3?content=docview,2626 (14.5.04), http://www.ssa.gov/policy/docs/progdesc/ssptw/1999/sweden.htm (1999)

[5] The exchange rate here has been calculated for 2004

[6] Information from Ingmanson 2003 translation

Category	Denmark	France	Germany	Ireland[2]	Italy	Sweden	UK[3]
			short-term substitution of carer and short term care. *Social assistance* provides for costs occurring to the carver, adequate allowances and payments for adequate old age provision	*Incapacitated Child Tax Allowance*		disability and for loss of income. Temporary parents' allowance	
Amounts		Allocation de presence parentale 3 levels, ranging from 238.74 €/month to 477.78 €/month, dependent on level of work, and increased by 1/2 if a single parent family[7]. *Complement d'allocation spéciale* – supplement to the special education allowance 897€/month	*Substitution of carer and short term care* (insurance only) 1432€	*Carer's Benefit* 605.37€/month for 1 person; 908.27 €/month for > 1 person *Carer's allowance* maximum 442 €/month for 1 person; maximum 663 €/month for > 1 person. *Respite care grant* for one eligible person 508 €/year		Individual assessment. 4 flat rate bands based on degree of incapacity. Maximum 865€/Month.	132.99 €/month An additional amount is added for a dependent spouse or other carer.
Conditions	For parents caring at home for children under age 18 suffering from severe and	Allocation de presence parentale Any person who stops work or works fewer hours when	*Substitution of carer* (insurance only) for maximum of 28 days/ year, if	*Carer's Benefit* meet insurance contributions; carer 16-65; addition for child under 18		*Carer's allowance*. For children who require special supervision or care for at least 6 months	Carer must be age 16-65. Care for at least 35 hours per week and earn less than 114€ per week and not be in full time

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[7] Information from MISSOC 2002 France

Category	Denmark	France	Germany	Ireland[2]	Italy	Sweden	UK[3]
	permanent physical or mental impairment or a chronic or long-term illness.	the child they are responsible for has a serious illness, accident or disability requiring constant supervision or substantial care. APP for a period of 4 months can be renewed twice in one year.	carer away on holiday or for illness *Short term care* (insurance only) for maximum of 28 days/ year	*Carer's allowance* not eligible for Carer's Benefit; means-tested, carer 18-65; addition for child under 18 *Respite care grant* – those in receipt of DCA (see below) eligible		due to illness or disability; until the disabled child is 19. A child must be resident in the family. If at an institution, a vocation care allowance can be paid when a child is staying with the family[8]. *Temporary parents' allowance* – e.g. when the disabled child is ill or contagious, the regular caretaker is sick, has to be taken for treatment or to learn how to take care of the child or visits to the child's doctor or schools. Until the disabled young person is aged 23[9].	education.[10]
Assistance with the costs of caring/ disability	*Supplementary costs allowance* – to compensate for the additional costs and expenses resulting from disability. Personal	*Allocation d'éducation spéciale (AES)* for parents caring for a child with a permanent incapacity	*Statutory long term care insurance* *Social assistance* (for those who are not eligible for statutory insurance)	*Domiciliary Care Allowance (DCA):* for home care of disabled children		*Assistance allowance* paid to disabled person who need personal assistance in everyday life. Additional assistance is available, if there	*Disability Living Allowance* - Care Component, 3 bands of payment dependent on level of help needed. Low some time during day. Medium either day or night High both day and night. Mobility Component lower band

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[8] Information from Ingmanson 2003 translation

[9] Information from MISSOC 2002 Sweden

[10] Contact a Family (2004) Benefits, Tax Credits and other financial assistance, http://www.cafamily.org.uk (10.5.04)

Category	**Denmark**	**France**	**Germany**	**Ireland**[2]	**Italy**	**Sweden**	**UK**[3]
	assistance (see Chapter 6)					is a temporary enlarged need. *Car allowance* – for those who cannot use transportation because of disability.	child needs help to walk in unfamiliar location, higher band child is unable to walk without assistance. Lower band can be paid from 5 years old, higher band from 3 years old.
Amounts	Costs over DKK 6000 compensated and a standard monthly amount of DKK 2000 is discounted. Not means tested and not liable to tax[11].	107 €/month (not means tested) Supplement for children with an incapacity degree of 80% or 50 - 80% when taken into care by a specialised institution: Category 1 - 80 €/month Category 2 -241 €/month Category 3 - 897 €/month	Home care Category 1- 205 €/month Category 2 -409 €/month Category 3 -665 €/month In kind benefits for basic care and housework: Category 1- 383 €/month Category 2 -920 €/month Category 3 - 1917 €/month *Social assistance* Cash benefits for home care same. Benefits up to amount of need for basic care and housework Also aids and appliances	*DCA* maximum 149 €/month per disabled child		*Assistance allowance* 20.70€/month[12] *Car allowance* 6751€. Additional max subject to income test 4500€. Costs for adaptation to car covered without limit.	*Disability Living Allowance.* 2 Parts. Care Component three different payment levels exist: Low approx 99€/month Medium 251.33€/month High 359.66€/month. Mobility Component two different rates: Low 99.66€/month High 260€/week

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[11] Information from Denmark 1993: para 212
[12] Information from Ingmanson 2003

Category	**Denmark**	**France**	**Germany**	**Ireland**[2]	**Italy**	**Sweden**	**UK**[3]
Conditions	Severe or permanent physical or mental impairment	For children with a permanent incapacity of at least 80% or with a permanent incapacity of at least 50% attending special educational scheme recommended by CDES. Parent stopped work or a third person must be needed. Supplementary allowances – for children whose disability requires particularly costly expenses or assistance from an outside person or continuing care of a highly technical nature. Until the disabled young person is 20 years		*DCA* – means-tested on child but not on parent; home care of disabled children, if child not at home pro rata payment when visiting home; up to age 16. Children in residential care who go home at weekends or holidays may receive a pro rata payment based on a per nightly rate		Assistance must be needed for more for more than 20 hours/ week. The regional social insurance office makes the decision. 4 bands refer to different levels of handicap 25%, 50%, 75%,100%	

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CHAPTER SIX: SUPPORT AND CARE SERVICES

The division between public and private responsibility for care has been changing in European countries (Daly & Lewis 1998). In the past women were expected to take care of family dependents and their care was unpaid. If families were unable or unwilling to care for their dependents, then their dependents might be institutionalised. The dependents frequently had little control over their care, whether within their families or in institutions. There is also change in how dependents are perceived, with more emphasis on service users as clients and consumers of welfare provision, whose rights and wishes should be considered and respected (Carmichael and Brown 2002; Daly & Lewis 1998).

As discussed in Chapter 1, welfare regime theory would divide the seven countries into different types in the areas of social care. The tradition of family care is strong in countries like France, Germany, Ireland and Italy whereas there is greater state provision in social-democratic welfare states like Denmark and Sweden. The UK is described as a Protestant liberal welfare state, which tends to have means-tested state provision. However, the studies cited in Chapter 1 do not address social care of disabled children; Annttonnen and Sipila (1996) for example consider childcare for young children and services for older people but not home support for disabled children.

The division between social assistance/security and care services is more distinct in certain countries than others. At one extreme are countries like the UK, whose social assistance is centrally decided and administered. Support and care services are set within a national framework but local councils are responsible for delivering the services. Thus there is a distinction between social assistance and care services. At the other extreme are countries like France, where the focus is on financial assistance and where social workers spend a considerable amount of their time providing financial aid (Madge and Attridge 1996). This review has separated out social assistance and care services but the potential overlap is relevant.

International and European requirements

Particular rights to care and community opportunities are set out within international requirements. Both the UN Convention on the Rights of the Child (UNCRC) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules) promote community inclusion rather than institutionalisation.

Article 23 of the UNCRC requires States to facilitate a disabled child's "active participation in the community". Assistance must be provided to the child and those responsible for the child's care. Whenever possible, such assistance should be free of charge or take into account the financial resources of those caring for the child. As Article 2 prohibits discrimination under any articles of the UNCRC, disabled children should have:

- Article 12: The right to express their views and for these to be given due weight.
- Article 18: The right to state support for their parents and the development of institutions, facilities and services for the care of children. This includes childcare services and facilities for children of working parents.
- Article 20: The right to special protection if they were deprived of their family environment and to have appropriate alternative family care or institutional placements.

The Standard Rule 4 sets out strong requirements for support services. Such services should aim to increase disabled people's "level of independence in their daily living and to exercise their rights". The requirements include that States should ensure the provision, development, distribution and servicing of assistive devices and equipment, as well as provision of personal assistance and interpretation. Disabled people should be involved and the special requirements of disabled boys and girls should be considered in regard to assistive devices and equipment. Specifically, Rule 9 says that disabled people should be enabled to live with their families. Respite care and attendant care should also be made available.

European documents, such as the European Social Charter, echo the requirements of the Standard Rules. Article 15(3) of the Social Charter requires State Parties:

- To promote disabled people’s full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.

Article 16 of the Charter requires families to have an adequate standard of living. This is interpreted to include adequate child care services which meet families’ needs and are affordable, accessible and of a high standard. Article 27 obliges States to promote child day care services and stipulates that both parents should have the possibility for parental leave.

In summary, all these documents strongly put forward disabled people’s right to live and participate within their communities, and to be supported by the State to do so. The UNCRC sets out that, for children unable to live with their families, the State must provide them with ‘appropriate’ alternative care.

Childcare

The seven countries differ in the extent of State involvement in childcare. Of the seven countries, Sweden gives parents the strongest right to childcare. Denmark is moving in this direction, with municipalities providing a ‘child care guarantee’. France also has a long tradition of pre-school provision (Dialogue with Citizens 1999). Italy does not guarantee childcare for all children but Law No. 104 of 1992 does guarantee a crèche place for all disabled children under the age of four. Similarly, Germany and the UK give a broader right to childcare for disabled children than they do for children in general. Ireland does not have a developed system of childcare or legislative requirements for it. Childcare, however, has been identified as an investment priority in Ireland’s National Development Plan 2000-2006 (Clearing House Ireland 2004).

Denmark, Sweden and the UK all use definitions of childcare that extend into the age group of children involved in this rreview. For example, the duty of Danish municipalities to provide day care extends from 0-17 years, in different types of facilities. After school, most children aged 6-9 years go to a public after-school centre (Pruzan 1998 quoted in Clearing House Denmark 2004). Municipalities must also provide after-school clubs for children aged 10-14 years and evening youth clubs for young people aged 14-18 years. Sweden similarly sets a duty on municipalities to provide childcare, although only for ages 1-12 years (Sweden 1998: 72). The UK similarly uses the age of 12 to define its after-school services, although often ‘under-8s’ services are grouped together.

Bradshaw and Finch (2002) provide summary information, as of July 2001, on out of school arrangements across 22 OECD countries. Eurostat provides data on service provision use. Table 6.1 summarises information for the seven countries considered: Germany and Ireland would seem to have low coverage of out-of-school provision, relying on parents to make private arrangements. The other countries have more developed out-of-school provision.

Specific provisions give particular rights and services to disabled children. Legislation in Sweden gives young people over the age of 12 the right to short-term supervision. Children under 12 have a right to take part in an ‘ordinary’ after-school centre and to receive support there (CE 2003: 343). If disabled children have needs that cannot be met within regular day care services, the Danish municipality can refer the children to the country authority for provision (Denmark 2003a: 57). A system of integrated leisure centres has been piloted in France and is now being extended (Loisirs Pluriel 2004 translation). Disabled children under UK children’s legislation have a specific right to out-of-school provision.

Table 6.1: Out of school childcare arrangements

Country	School hours	Most prevalent f/t formal out of school childcare [or out-of-school-hours care]	Fees	Reduced	How reduced	% of all children using childcare provision compulsory school age up to age 12 (year; %)
Denmark	Primary: 8-12.00 Secondary: 8-14.00	After school clubs	Yes	Yes	Low income	2000; 75% (out of school care only)
France	8.30-11.30 13.30-16.30	Centre de loisir sans hebergement	Yes	Yes	1.childcare highly subsidised, and usually free for low income 2. childcare tax credit for children under 7	No information
Germany	8-15.00	Kinderhorte	Yes	Yes	1. highly subsidised: costs depend on income and number of children in childcare 2. 90% costs are financed at local and federal level	1998; 13%
Ireland	Primary: 9-15.00 Secondary: 9-16.00	None	N/a	N/a	N/a	1997; 8% (data for children aged 5-9 using childminders)
Italy	Primary: 8-12.30 Inter: 8-13.00 Secondary: 8-14.30	Catholic oratori (places of sociability)	No or very low	Yes, if charges	Locally arranged. If any charges, children in households on social assistance are generally exempt	1998 (service users source); 47% (excludes centre-based care)
Sweden	8.15-15.00	Municipal school care Ages 6-12	Yes	Yes	Reduced for number of siblings in care, fees income-related	2001; 36%
UK	9-15.30	Out of school clubs	Yes	Yes	Tax credit (formal childcare only)	2002 (service users source); 81%

Sources: Table E.2, Bradshaw and Finch (2002): 218; Summary Table pages 29-30, Eurostat (2004)

Support in the home and in the community

Governments of all seven countries state their intention to support disabled people within their families and to promote their inclusion or integration within their communities. For example, the Italian Government reports on the decreasing institutionalisation of disabled children since its 1992 legislation (1998: para 398). The Irish Government states its policy to assist disabled children to live with their families (1996: para 306). For some countries, such as the UK, this policy is given legal backing in statute.

The countries differ in how they seek to support disabled children living in their families, in several ways:

- the balance between financial and in-kind assistance
- whether the assistance is through child or disability policy
- eligibility requirements
- involvement of parents and disabled children in decisions

The focus of French policy is on financial assistance, to reimburse the costs of disability and of caring (see also Madge and Attridge 1996). For example, the special education allowance (Allocation d'éducation spéciale (AES)) addresses the costs of disability (see France Chapter). Costs can include technical aids for the home, training costs for family members, costs for special holidays, and extra costs of transport and clothing (Ministry of Employment and Solidarity 2002 translation). Income replacement for caring is provided through the parental presence allowance (Allocation de presence parentale (APP)).

By contrast, countries such as Denmark and Sweden provide financial assistance but they also have extensive rights to services set out within legislation. Sweden, for example, has an Act concerning Compensation for Assistance (LASS) and the Act Support and Services for Persons with Certain Functional Impairments Act (LSS). Disabled people with more serious disabilities can receive a host of different types of support under these Acts:

- Counselling and support
- Escort and companion services
- Contact persons
- Relief services in the home
- Short-term stays away from home
- Short term supervision for school pupils over the age of 12
- Accommodation in family homes or in housing with special services for those children needing to live away from the parental home

Other supports are also available for disabled people. Of particular note in Denmark and Sweden are the rights to personal assistance. If the eligibility criteria of Italian Law 104 of 1992 are met, disabled people are entitled to a range of services, such as: home help, personal assistance, personal care services, and extra-curricular activities. A similar range is available under German legislation. The UK also has a range of services that should be provided to disabled children and their families, under their children's legislation. However, there have been concerns about the limited implementation of this legislation (Audit Commission 2003) and the lack of contact, let alone support, between families and social work services (Griffiths 2002; Hunt 2002).

Ireland would seem to have the least developed system for social care support, with the power but not the obligation to provide it. Thus disabled children do not have the right to in-kind support services, although their parents may have a right to financial assistance. This will change with the Disability Bill, should it become law, as disabled children (and their advocates) will have the right to request an independent assessment of service need. Any such assessment and subsequent service statement can be legally enforced.

Parents of disabled children frequently value flexibility of support services in the home, and sensitivity to their family needs (Beresford et al. 1996). One method of creating this is to give power to families by giving them the funds to buy the care that they need. Direct payments, as they are called in the UK, are now available to parents of disabled children. The payments through the French system also provide a form of direct payment or reimbursement. Paragraph 15 of the German Social Code, Book IX introduced the right of disabled people to buy their own services through a personal budget, although this is noted by Boeltzig with Clasen (2002: 69) as atypical. UK research on direct payments for disabled adults points out some problems with the approach. With more control can come more responsibility, as employers, and administration and co-ordination can be burdensome (Carmichael and Brown 2002). Disabled adults may have the money but the services may not be available to buy. Such ‘supply-side’ problems are noted in Sweden, with difficulties in recruiting personal assistants and high turnover of these assistants (Lindqvist 2001: 41), and in Germany, where the use of young men involved in community service has led to turnover and a lack of female staff (Büchner 1997 translation).

Countries differ in whether support for disabled children is provided primarily through disability or child policy – or a combined policy that covers both disability and children. In Italy and Sweden it is through disability policy, in Ireland and UK through child policy and in Denmark, France and Germany through both.

Disability policy The primary legislation for support services in Italy and Sweden is for disabled people, both children and adults. Specific mention of children is made at particular points such as a disabled children’s right to a crèche place, from the ages of 0-3 years in Italy. Otherwise, disabled children and adults have the same rights under this legislation.

Child policy Ireland and the UK take a different approach. The primary legislation for support services is children’s legislation. This relates only to in-kind services in the UK as financial reimbursement for the costs of disability are through the Disability Living Allowance (see Chapter 5 for more information). Ireland’s position will change with the Disability Bill, bringing it into the ‘disability’ category.

Combined policy Support services for disabled children in Denmark, France and Germany are provided under generic legislation. Thus, the Danish Social Service Act covers provisions for all children and young people, disabled people and particular provisions for disabled children and their families as well. The French Social Security Code similarly covers all groups, with the specific provisions for AES and APS included. The German Social Code and Social Assistance Act have particular sections for families and for disabled people, with specific mention of services for disabled children and their families at particular points.

Do the differences in approach matter? In the UK, it was argued that children should be included within the more general childcare legislation, to recognise that disabled children were children first and foremost. Yet, research and inspections of services continue to show a lack of provision of support services and a lack of disability expertise amongst child social services departments (Audit Commission 2003). Nor does disability legislation ensure children’s needs are met. Both the Swedish National Board of Health and Social Welfare (2003) and the Children’s Ombudsman (BO 2002) note that disabled children have not been sufficiently visible within disability legislation. The conclusion could be drawn that, whatever the approach, provision for disabled children risks being a low priority and marginal to more general services.

All countries have eligibility requirements for support services. Countries differ, though, in how they balance medical and social definitions. These are summarised in Table 6.2. Denmark and Sweden’s policies explicitly emphasise a social rather than medical approach to disability, in order to access support services (Bengtsson 2001: 13; Lindqvist 2001: 24). However, the Danish definition includes an element of individual impairment and not solely the identification of social barriers or opportunities (Bengtsson 2001: 13).

Table 6.2: Eligibility for support services

	Definition	**Assessment**
Denmark	"reduced physical or psychic functional ability" followed by reference to the Standard Rules	Municipal authority assessment (which may include recommendation to county)
France	Medical although incorporating social elements	Medical certificate and family questionnaire Professional assessment CDES
Germany	Three tiers of disability under the Social Code. At the first tier, the definition of disability is "People are disabled if their physical or mental capacity or psychological health very probably differs from the condition typical of their age for a period exceeding six months and if their participation in social life is therefore impaired" (MISSOC 2003: 24). Three types of disability under the Social Assistance Act	This depends on the service route. For social assistance, family application to social services, typically followed by Medical assessment
Ireland	1. No definition in Child Care Act 1991 2. Definition in Disability Bill. Substantial restriction in capacity to carry out employment or participate in social and cultural life, due to enduring impairment.	1. Health board 2. independent assessors
Italy	Impairment followed by social exclusion	Joint assessment health and social services
Sweden	No explicit definition of disability	Professional assessment, which can include medical certificates and/ or examinations
UK	Blind, deaf or dumb or suffering from mental disorder of any kind or substantially and permanently handicapped by illness, injury or congenital deformity or such disability as may be prescribed (Children (NI) Order S.2(2); Children Act 1989 17(11))	Professional assessment by social services, frequently combined with health

The Italian definition of disability similarly begins with the notion of impairment and proceeds to social barriers:

- A disabled person is anyone who has a physical, mental or sensory impairment, of a stable or progressive nature, that causes difficulty in learning, establishing relationships or obtaining employment and is such as to place the person in a

> situation of social disadvantage or exclusion (Article 3(1), translation from Discapnet).

Germany takes a similar approach but has a more complex system of assessment and provision depending on whether families are eligible for social insurance through health care or for social assistance. Combined assessments between health and social services are undertaken in Italy, and encouraged in the UK. In Ireland, health boards have responsibility for services for disabled children.

Definitions of disability in Ireland and the UK are the same as those used within social security legislation – and not those used, for example, in disability discrimination legislation (see Country Chapters for more details). In the UK, this results in a medicalised definition. In Ireland, eligibility for services is enhanced if people have a ‘medical card’. Eligibility criteria in the French system are based around comparisons with non-disabled children and whether the disabled children require more supervision and care.

A more ‘social’ definition does not preclude a medical assessment. For example, in Sweden an application must be first made by an individual for support services, under LSS. The law does not require medical certification as professional observation and investigation by non-medical professionals is sufficient under law. However, Lindqvist reports that medical certificates and examinations are increasingly being used to determine eligibility and subsequent categorisation (2001: 25-26).

Four countries – Denmark, Germany, Sweden and the UK – require parents’ and children’s views to be incorporated in decision-making for some services. For example, the German Social Code requires both children’s and disabled people’s views to be considered in service decisions. Ireland’s Disability Bill asks assessors to facilitate disabled people’s involvement but does not require children’s and parents’ views to be incorporated into the assessment and decision-making. Thus, not all countries ensure that requirements of the UNCRC and Standard Rules are protected legally.

Support for family members

All countries would seem to have under-developed policies for supporting carers in their own right. Payment for care is common across the countries (see Chapter 5), although more flexible and extensive in some than others. Support and counselling for carers is part of the package available under some social support legislation, such as the Swedish LSS and the German Social Code/ Social Assistance Act. The UK has instituted a carer's assessment, so that carers can be assessed in their own right for services and support. Carers have the right to an assessment – but not to subsequent services. If support for carers is under-developed, support for siblings of disabled children is a rare feature in official policy. If siblings groups are available, they are frequently not on long-term funding and available throughout the country (e.g. Germany, Ireland and the UK). Siblings do not necessarily wish to go to groups (Connor and Stalker 2003) but a common finding in the UK is that they often want to have more information about their sibling's impairment and associated current and future impacts (Banks et al. 2001; Connors and Stalker 2003). In Germany, a website[1] for siblings of disabled children goes some way to provide such information, as well as providing contact with other young people. Italy does allow, under Law No. 328 of 2000, for all household members to apply for assistance at home. The municipalities have considerable discretion when making decisions on this (Italy 2005).

Short-term breaks can be beneficial to disabled children, their carers and other family members. All countries have some provision for these breaks, although they differ in the breadth of what is provided. Ireland, for example, provides a respite grant for families receiving Domiciliary Care Allowance but the limits of available respite are noted by the Children's Rights Alliance:

- A number of respite programmes exist, but operate on a project basis with no permanent funding. Moreover, where residential respite services are appropriate for older children they should be developed and provided in centres and environments which are appropriate for children (1997: 38).

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[1] http://www.besondere-geschwister.de (8.8.04)

Care outside the home

Countries differ considerably with respect to their provision of residential or foster care. France, for example, has maintained its segregated medical-social establishments for disabled children, and these can be residential or non-residential (Handicap Government France 2004 translation). Italy has sought to decrease the number of children in residential children's homes and increase foster care placements. The Italian Government notes, however, that this policy has not yet been successful (1998: para 244). Germany also would seem to have a fairly high level of institutionalisation (Busse 2000: 72). Problems with sufficient foster placement are reported in other countries, such as Sweden (BO 2002) and the UK (Mooney and Fitzpatrick 2003).

Residential placements were traditionally offered by religious orders in Ireland and then increasingly by lay organisations. Funding for these organisations is now provided either by Health Boards or the Department of Health, with a responsibility on Health Boards to ensure there is an adequate number of residential places. Health Boards must also ensure the quality of foster and residential placements (Ireland 1996; NCO 2003).

In all seven countries, the State has responsibility for ensuring the quality of residential or foster placements by regulation and inspections.

Conclusion

All seven countries state a commitment to including or integrating disabled people into their community and, for children, to support them in their families wherever possible. In this way, they meet the requirements set out in international and European documents.

This commitment is implemented through both financial and in-kind assistance to families. Countries differ in whether they use disability, children or combined policies to do so. For disabled children, access to such assistance is through the 'gate' of eligibility criteria and assessment. Criteria and assessments differ in their balance of medical and social approaches and, in fact, can combine a social definition of disability with a medical assessment. While rights to services may be established in law, they are reported to be subject to budgetary or supply-side constraints. Ireland differs from other countries in having fewer requirements in legislation for childcare and services for disabled children. Most countries devolve responsibility for assessment and provision to local level and this is reported to result in inequities of provision across the country (e.g. Denmark, Germany, Ireland, Italy, Sweden and UK).

In contrast to a needs-led approach, childcare in Denmark and Sweden is demand-led. In Denmark, the childcare service is the most extensive, in that it extends up to the age of 18. In Sweden, the right stops at age 12 (although short-term supervision is available for 'severely' disabled children under LASS). Such a strong right is not available in other countries for childcare.

Families frequently identify flexibility as a key need in support services. Cash payments and flexible in-kind assistance, such as personal assistance, can provide this. Cash payments to purchase assistance, though, bear certain responsibilities for the purchaser and do not guarantee quality and continuity of care. Short-term breaks appear underdeveloped in most countries, with evidence of marked lack of provision reported in countries such as Ireland and the UK.

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CHAPTER SEVEN: HEALTH SERVICES AND ASSISTIVE TECHNOLOGY

Several recent trends in health care systems are noted in the OECD publication, *Social and Health Policies in OECD Countries: a survey of current programmes and recent developments* (Kalisch et al. 1998). Cost containment became a major issue for most OECD countries in the late 1980s and early 1990s as an increased amount of Gross Domestic Product (GDP) was being spent on health care systems. This is evident in Table 7.1.

Table 7.1: Total expenditure on health: percentage of Gross Domestic Product (GDP)

	1970	1980	1992	1997	2002
Denmark	Not available	9.1	8.5	8.2	8.8
France	5.4	7.1	9.0	9.4	9.7
Germany	6.2	8.7	9.9	10.7	10.9
Ireland	4.7	7.6	7.1	6.4	7.3
Italy	Not available	Not available	8.4	7.7	8.5
Sweden	6.9	8.7	8.3	8.2	9.2
UK	4.5	5.6	6.9	6.8	7.7

Source: OECD in Figures (2003)

In the five countries for which there are 1970s data, a distinct increase in health spending (as a percentage of GDP) is evident. Despite the concerns about cost containment, only two countries – Denmark and Ireland – lowered this percentage between 1980 and 2002 (although absolute spending increased). For the other five countries, the percentage increased.

The OECD publication reports that concern has now shifted from cost containment towards the quality of care and the achievement of better health outcomes. Alongside these concerns about quality, cost and efficiency, health care policy frequently has concerns about equity:

- Citizens should have access to some minimum level of health care, and treatment should be based on need for care rather than solely on income. Further, individuals should be offered some degree of protection against the

> financial consequences of falling ill, and payment for this protection should be income-related rather than based on individual risk (OCED 1995 quoted in Kalish et al. 1998: para 328).

A similar ‘citizenship’ model is evident in international documents that establish children’s and disabled people’s rights to access quality health care.

International and European requirements

The UN Convention on the Rights of the Child (UNCRC) establishes a child’s right to health care. This right is developed from more generic documents such as the Universal Declaration of Human Rights and the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights. Article 24 (1) of the UNCRC states: “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.” Article 2 of the UNCRC would apply to health services to ensure children are not discriminated against. Yet, Article 24 (1) finishes with a recommendation’ rather than a distinct right, about equal access: “States Parties shall strive to ensure that no child is deprived of his or her right to access to such health care services.” The article details certain measures, such as reduction of infant and child mortality and ensuring basic child health and nutrition education. Of particular relevance to this Chapter are the requirements to emphasise primary health care and to provide guidance for parents.

Article 23, which concentrates on disabled children, mentions health services. The Article requires States to provide assistance, free of charge where possible, to ensure that disabled children have effective access to, and receive, health care and rehabilitation services. These services should help the child achieve the “fullest possible social integration and individual development” (Article 23 (3)). Along with emphasising the need generally for health care services, the World Summit for Children (2002) also makes specific mention of disabled children. The countries committed themselves to:

- Ensure effective access by disabled children and children with special needs to integrated services, including rehabilitation and health care, and promote family-based care and appropriate support systems for parents, families, legal guardians and caregivers of these children (para 37(17)).

From a disability perspective, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules) address medical care and rehabilitation. Rule 2 begins: “States should ensure the provision of effective medical care to persons with disabilities”. It further specifies:

- Providing programmes run by multidisciplinary teams of professionals, for early detection, assessment and treatment of impairment
- That such programmes should ensure the full participation of disabled people and their families, at an individual level, and organisations of disabled people at a planning and evaluation level
- Local community workers should be trained in early detection, provision of primary assistance and referral
- All medical and paramedical personnel should be adequately trained and equipped.
- Disabled people should be provided with any regular treatment and medicines needed to preserve or improve their level of functioning.
- The same level of medical care should be provided to disabled people as other members of the society.

Two aspects of this Rule relate to children in particular. First, Rule 2(3) stresses that “particularly infants and children” should have access to the same level of medical care as others. Second, personnel should be trained to ensure that appropriate advice is given to parents, so as to ensure options are not restricted for their children.

Rule 3 addresses rehabilitation, beginning: “States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.” Again, the rule stresses the need for national programmes, the participation of disabled people at individual and planning levels, and access to rehabilitation. Services should be available in the local community.

Accessibility to information and communication is considered under Rule 5. States are required to undertake measures to provide access. This includes:

- Full information on diagnosis, rights and available services and programmes
- Strategies to make information services and documentation accessible
- Sign language interpretation services
- Ensuring the accessibility of the media and new computerized information and service systems

Communication needs are addressed in several other rules, such as education (Rule 6) and culture (Rule 10).

The expression of health rights in the European Social Chapter is phrased in terms of protection. Article 11 requires State Parties to take appropriate measures to ensure “the effective exercise of the right to protection of health”. The right to social and medical assistance must ensure protection of people without adequate resources and to ensure those receiving such assistance do not have their political or social rights diminished (Article 13). The provisional European Constitution emphasises access and benefit: “Everyone has the right to access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.” Protecting health is required for Union policies and activities (Article II-35).

Disabled children, then, should have the right to health care and rehabilitation services under these international and European documents. There is particular stress on services and expertise being suitably co-ordinated, on family- and community-based care where possible, and information for professionals, parents and disabled people. The expression of rights differs: the right to health *protection* or the right to *access* available health care services. Arguably, the first expression is stronger than the latter, for it emphasises the end rather than the means; a person could have equal rights to access the available health care, but it may be insufficient to protect the person’s health.

Principles

National health care policy in all seven countries asserts that all citizens (and, in some countries, all people living in the country) should have access to a minimum level of health care. The countries then divide into those that have a national health service – Denmark, Ireland, Italy, Sweden and the UK – and those that have social insurance systems for health care – France and Germany.

Wendt (1999) describes the fundamental differences. The guiding idea of national health systems is the belief that the whole population has a right to health care in case of sickness. In countries where state insurance systems have been institutionalised, the dominant idea is that those who are included in the compulsory health insurance have a right to health care on the basis of contributions. Those who are not employed and do not pay their own contributions only have derived rights in insurance systems.

Children thus have a different position in the two systems. The citizenship model of national health services covers children as well as adults. The social insurance model, being based on labour-market involvement and/ or financial contributions, is not as inclusive of children. Children only have derived rights, through their parents, to health care. Wendt (1999: 9) notes that children of self-employed people and those who opt out of statutory health insurance are not covered by the German statutory social insurance system.

A national health service tends to have three characteristics: a high degree of state intervention; health services that are publicly financed; and health services that are delivered by public employees in provision that is publicly owned. A social insurance system tends to have: less state intervention; health service are financed through compulsory health insurance; and health services are provided by a mix of private and public organisations (Ruxton 1996; Freeman 2000). Variations on these characteristics are evident across the seven countries and are explored below.

Social and private health insurance differ in important respects. Membership of social insurance schemes is compulsory, whereas membership of private schemes is optional (Freeman 2000). The premiums set by private schemes are risk-rated, so that individual payments are typically established by the calculated risks of that individual. By contrast, social insurance schemes reflect the collective risk of insured members. Individuals' payments are unrelated to their particular risk-rating and their payments are unrelated to the amount or cost of care they use (Maarse and Paulus 2003: 117). Thus "… social health insurance is based upon the principle of solidarity whereas private health insurance rests upon the principle of the ability to pay" (Maarse and Paulus 2003: 117).

Freeman (2000) points out that differences between social insurance and tax-based systems are not as great as often described: "Taxation may be thought of as a form of compulsory insurance … while insurance premiums are normally levied as a compulsory payroll tax on employers and employees" (7). Indeed, all seven countries raise public money in a variety of ways to pay for health services, which is further considered below. There are, however, several implications brought out by Freeman (2000) and Kalisch et al. (1998):

- Political. Social insurance systems make the cost of health care more "visible" (Freeman 2000: 3) and thus rises in costs above wages can create political pressure.
- Queuing is less likely in social insurance systems, particularly with fee-for-services, while it is more of a problem in national health care systems (Kalisch et al. 1998: para 348).
- Spending. In social insurance systems, governments are not responsible for health spending. The relatively high degrees of freedom for patients and doctors can result in higher levels of spending. Social insurance systems tend to absorb larger proportions of GDP (see Table 7.1 above) than national health services.

- Consumer satisfaction. The freedom in a social insurance system tends to result in higher consumer satisfaction with health services than national health services.
- Access to specialist services. In national health services, General Practitioners tend to act as 'gatekeepers' to specialist (and thus more expensive) services and there is a focus on primary care. Social insurance systems – particularly in the French system – tend to allow more direct access to specialist services (see also Wendt 1999: 10).

Organisation

Another key difference between the countries is the degree of central control. More centralised health care systems are provided in France, Ireland and the UK whereas decentralisation characterises Denmark, Germany, Italy, and Sweden (see Table 7.2). Proposed changes in Ireland will centralise control even further, with the abolishment of regional boards.

Decentralisation can have particular advantages (see also Chapter 4):

- It allows for local provision to adapt more quickly and specifically to local populations. This can involve more public participation and accountability can be more direct and transparent.
- It has the potential for cost-effectiveness, as those planning and/ or providing services on the ground take responsibility for their own budgets.
- It can facilitate local co-operation and co-ordination across services (Kalisch et al. 1998; Taroni 2003).

On the other hand, decentralisation can have certain disadvantages. One, it can cause problems with 'economies of scale', where needs of small numbers of people cannot be pooled across a larger population and, correspondingly, specialist expertise is difficult to sustain. Two, a major concern reported in health care systems is inequity. The regionalisation in Italy, for example, has raised considerable concerns about the difference between Northern and Southern regions financially. An equalisation fund has been established to ameliorate the larger inter-regional differences but there is an ‘optimistic’ expectation that this will only be for a 13-year transition period. Taroni (2003: 140) believes this expectation is unlikely to be met; the dependence of Southern regions on economic transfers from a few Northern regions is likely to erode the former’s autonomy and will work against equality.

Table 7.2: Overview of health care organisation

Country	**Description**	**Government level that sets policy**	**Government level that sets policy details**	**Organisation(s) that provide the services**	**Who monitors the service?**
Denmark	Decentralised	Central government	County councils and municipalities	Mixed • GPs are self-employed • Public services of municipalities or county councils • Private providers	Central government
France	Centralised	Central government	Central Government	Mixed • Doctors in public hospitals are salaried civil servants • Doctors in outpatient care are self-employed • Private and public hospitals	Central government
Germany	Decentralised	Central government	Corporate – Central and regional government, sickness funds and providers	Mixed • Most hospital doctors are salaried employees • Doctors working in local practice are independent practitioners • Private and public hospitals	Federal Ministry of Health & Social Security and Federal Insurance Office
Ireland – proposed changes	Centralised	Central government	National - Health Services Executive (HSE)	Mixed public and private providers, particularly voluntary organisations	HSE
Italy	Decentralised	Central government	Regional government	Mixed. • Local Health Units • Public hospital trusts • National institutes for scientific research • Private accredited	Regional Government

Country	**Description**	**Government level that sets policy**	**Government level that sets policy details**	**Organisation(s) that provide the services**	**Who monitors the service?**
				providers • Voluntary organisations	
Sweden	Decentralised	Central Government	County councils and municipalities (for their respective provision)	Mostly public sector, although some private providers	Central government
UK	Centralised	Central government	Central government, although regional and local plans	Mixed range of public providers and some private providers	Range of agencies; central and regional

Decentralisation has several meanings: political decentralisation (e.g. Swedish county councils; Danish county councils and municipalities; Italian regions); financial decentralisation (e.g. Denmark, Italy, and Sweden but also devolved budgets in other countries); and service decentralisation. The latter is particularly evident in all the countries, as they have incorporated or further developed some elements of choice and competition within their systems. The UK, for example, has created an 'internal market' in the National Health Service with separation between purchasers and providers. In 1993, Denmark introduced patient choice of hospitals, giving them the right to demand and receive care where they wished (Ruxton 1996: 258). Germany sought to stimulate market competition amongst its social insurance funds in the 1990s (Maarse and Paulus 2003: 123).

Countries differ in the extent that private organisations – profit or not-for-profit – are involved in health care. In France, Germany and Italy, such provision is common. Voluntary organisations are significantly involved in providing services in Ireland. In other countries – e.g. Denmark, Sweden and the UK – provision of core services remains predominantly in the public domain.

Health care systems differ in how services are accessed. General Practitioners are frequently the initial 'gatekeepers' or "guides" to specialist services in national health services. This is true in Denmark, Ireland, Italy, and the UK. Freeman (2000: 33) reports that, in Sweden, patients are allocated a doctor working in a local health centre but may consult specialists directly in hospital outpatient departments. Barriers, however, are being introduced to accessing specialists in this way. In both France and Germany, families can directly access specialists, without a referral.

All countries have specialist services for disabled children. Sweden, for example, is described as having especially advanced health provision for disabled children (Ruxton 1996). A management plan is drawn up for each child and therapies are provided free of charge. France has specialist care for disabled children through the medical-social examination and care centres (CAMSP) and medical educational sector (CMPP) (UNAPEI 2003 translation; European Agency for Development of Special Needs Education (EADSNE) 2003). Italy has hospital services (for diagnosis and assessment), local centres with ambulatory units attached, and residential institutions. The number of residential centres has decreased in recent years (Ruxton 1996). In decentralised systems, arrangements for very specialist services need to cover a large administrative area and population to be economical.

Costs

As discussed above, cost containment was a concern of all countries in the 1990s. A range of methods to contain cost was used, such as: alternative payment systems for hospitals; limiting costs of new technologies and pharmaceuticals; shifting care to outpatient services and community care; and greater accountability, particularly at a local level (Kalisch et al. 1998: 4). Two other methods were : increased 'co-payments' where individual health care users are required to pay a share of costs; and changing a previously free service to one that the individual must pay for.

Private insurance or mutual funds in several countries fill the financial gap for payments. Italy, for example, has the 'ticket' which was introduced to contain pharmaceutical demand and has since been revised and extended (Freeman 2000: 37). Taroni (2003: 141) reports "creeping privatisation" as medical services in Italy, previously covered by minimum national requirements, are "delisted" and thus subject to charges. Healthcare reforms in 1999 provided financial cover for such costs through private insurance or mutual funds; and such provision was available in private markets from public or private providers (Taroni 2003: 141). Kalisch and colleagues (1998) noted that this disadvantaged families with children:

- In Italy, the practice of shifting health care costs to families through the introduction of health care charges is creating imbalances between families of different size as well as between generations. This is because the elderly are more readily exempted from payment on the basis of income than families with young children; moreover, adults with children pay a higher share of health cost through taxation and contributions (para 336).

Wendt (1999) notes that co-payments can be a considerable burden for those who regularly use health services due to poor health or need for health services and for lower-income groups. Certain groups of disabled children, such as children with cerebral palsy, frequently do have a need for more health service provision and support than other children; disability is known to have an adverse effect on family finances in many countries (see Chapter 5). Children, however, are often exempt from health care charges and other payments as are disabled people.

All seven countries provide either free health care for children or the countries mitigate the costs of health care for those families with low-income. A summary of the health costs is provided in Table 7.3:

Table 7.3: Health costs for children

	Charges for Children				**Exemptions**
	Hospital	GP	Dentist	Prescription	
Denmark	✗	✗	✗	✗	
France	✓	✓	✓	✓	Income-related
Germany	✗	✗	✗	✗	
Ireland	✓	✓	✓	✓	Means-tested
Italy	✗	✗	✓	✗	For children under 6 income-related
Sweden	✗	✗	✗	✓	Over yearly maximum costs prescriptions free
UK	✗	✗	✗	✗	

Source: Bradshaw and Finch 2002, Table 6.1

Bradshaw and Finch (2002) conclude that health care costs are not a significant drain on the child benefit package in these countries, except for Ireland. But Bradshaw and Finch do not include in their analysis the health care and associated medical costs for disabled children.

Assistive technology

A recent European study (Deloitte & Touche 2003) investigated access to assistive technology. This study was undertaken in eight European countries in 2002, including six countries in this project (Denmark, France, Germany, Italy, Sweden and the UK) but not Ireland. Methods included: desk research; interviews with key stakeholders; visits to national organisations; and interviews and questionnaires with disabled people, their representative organisations and suppliers. No special attention was given to disabled children. Key findings include:

- There are wide variations in the delivery systems for Assistive Technology. The responsible health and social care systems, which organise and regulate the provision, tend to be complex.
- More involvement is required of end-users in the selection of the technology.
- Assessments are not uniform in procedure or results. For example, a dissatisfied disabled person in Germany could go to other doctors or rehabilitation centres until the person is satisfied with the results.
- Most producers and distributors of the technology are medium to small enterprises, except for mass-produced items such as basic hearing aids and wheelchairs.
- Information exchange is poor in certain countries and good information is unduly dependent on chance encounters. Sweden and Denmark have central and national resource centres which play a “vital role” (108) in the delivery of information.

User involvement

If a service user is dissatisfied with a service in some countries, he can ‘exit’ and shift providers. This gives an incentive to providers to meet the needs and wishes of service users so that the users do not exercise their power to ‘exit’. One goal of competition and choice in health care systems is to improve the quality of care for service users, as well as greater efficiency. All seven countries have some degree of consumer choice (see Table 7.4)

Table 7.4: Examples of consumer choice

	Choice of GP	**Direct access to specialist**	**Choice of hospital**
Denmark	✓	Most require a referral from a GP	✓
France	✓	✓	✓
Germany	✓	✓	✓
Ireland	✓	✗	✗
Italy	✓	✗	✓
Sweden	✓	✓ hospital out-patient	✓
UK	✓	✗	Increasing in England

Another element of user involvement is ‘voice’. This can include service user or more general public involvement in evaluation and planning for services. It could be provided through political accountability: for example Swedish county councils are local government bodies, with elected representatives. Voice can also be provided through representation. For example, in the UK there are various types of representative bodies which have by statute to be consulted on developments and changes in health services. German sickness funds are governed by elective boards that are made of employer and employee representatives. Freeman, though, concludes pessimistically:

- Opportunities for the more direct engagement of users in health policy decisions making are limited. Where they do exist, they seem as much an effect of change as an essential part of its process. Across countries, the payers and providers of health care remain better organised and better represented than its users (2000: 116).

Parents have been in general the choosers of their children’s health services, even though children are the actual consumers. Children have thus tended to exercise neither ‘exit’ nor ‘voice’ (e.g. see Alderson 1993). However, this has been changing in certain countries. For example, Save the Children Italy (Gruppo 2003), praises the Charter of the Rights of Children in Hospital, which has been adopted by the four main Italian paediatric hospitals. Children in Denmark can make a doctor’s appointment themselves, without their parents’ knowledge, and doctors must respect children’s confidentiality (Ruxton 1996: 261; Denmark 1993: para 43).

Involvement in treatment decisions is another form of consumer choice and involvement. The Italian Charter includes the principle that children have a right to be informed and to express their opinions. Gruppo notes that the law requires children’s opinions to be heard but that their consent is not required for medical treatment. The Italian Government (1998) explains that Italian regulations require the patient’s consent to treatment but it does not specify who must give consent for minors:

- Prevailing opinion is that for small children consent must be given by the natural protector (parents or by other near relatives) while in the case of pre-adolescents

> or adolescents, proper informed consent to treatment must be given by the interested party him- or herself (para 93b).

In Ireland, children aged 16-18 years can consent or refuse medical treatment; under age 16, legal guardians have this right (Ireland 2004). Law differs across the UK in relation to child consent. In England and Northern Ireland, there is present confusion on a ‘competent’ child’s right to refuse treatment but legal decisions have determined that a ‘competent’ child can consent to treatment. Danish legislation in 1998 set the objective of involving “children and young people as much as possible in the decision process concerning their conditions, adapted to their general maturity and situation in general” (Denmark 1998: para 77). Involvement is frequently dependent, in law and formal guidelines, on children’s ‘maturity’ or ‘competence’. This can exclude certain disabled children, who are perceived as not being mature or not being competent.

Conclusion

In all seven countries, the health care system establishes officially a child’s access to health care. In national health services, this is more clearly a right for each child; in social insurance systems, frequently the right is derived through the child’s parents. All countries have specialist services for disabled children. Children and disabled people are frequently exempt from payments and receive services free at the point of use: a requirement of both the UNCRC and the European Social Charter.

Achieving the “highest attainable standard of health and to facilities”, as required by Article 24(1) of the UNCRC, is less clearly recognised. Geographical inequities, caused by decentralisation, are of considerable concern. There is no doubt, however, that in the seven countries a considerable proportion of public expenditure and of GDP is spent on health services.

The European study on assistive technology finds that not all professionals are suitably informed and trained in regard to such provision. Countries without national centres fail to ensure that disabled people and their families receive accurate and useful information. Countries' systems are typically fragmented, both in terms of disabled people's access to technology and in terms of suppliers.

Participation in both individual and collective decision-making varies in its official backing and its actual practice. Certain systems have an element of choice in service provision.

Certain health care systems include direct political accountability and/or representation opportunities. Such choices are more likely to be open to, or to be taken up by, adults than children (although children can, for example, make their own doctor's appointment in Denmark). Participative opportunities are developing for children in local evaluations and surveys. Countries are increasingly recognising children's right to have their views considered in individual health decisions, but vary in when and whether children are judged able to consent or refuse treatment. Service user involvement, as required by both the UNCRC and the Standard Rules, is not guaranteed.

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CHAPTER EIGHT: PHYSICAL ENVIRONMENT

This chapter considers Housing, Accessibility to buildings and public places, Adaptations, Transport and Leisure

International and European requirements

There is no specific right to housing and shelter within the United Nations Convention on the Rights of the Child (UNCRC). Such a specific right can be found under generic international documents, such as the Universal Declaration of Human Rights (Article 25) and the International Covenant on Economic, Social and Cultural Rights (Article 11). In the UNCRC, housing and shelter would presumably be part of the child's right to an adequate standard of living (Article 27). The World Summit for Children (2002) recognises the important role of adequate housing:

- Adequate housing fosters family integration, contributes to social equity and strengthens the feeling of belonging, security and human solidarity, which are essential for the well-being of children. Accordingly, we will attach a high priority to overcoming the housing shortage and other infrastructure needs, particularly for children in marginalized peri-urban and remote rural areas (para 27).

There is no specific mention of transport within the UNCRC. Article 15 does set out a child's right to freedom of association but with no requirement on States to promote this right. Freedom of movement is protected in the European Union, which has a connection with transport. The UNCRC specifies a child's right to leisure, recreation and cultural activities. Article 31 sets out a child's right: “to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts”. Further, States shall promote this right and encourage the provision of “appropriate and equal opportunities for cultural, artistic, recreational and leisure activity” (Article 31(2)). This is emphasised in the specific article for disabled children, Article 23. The importance of facilitating the disabled child's “active participation in the community” is recognised. Assistance should be provided, free of charge whenever possible, for recreation opportunities.

The UN Standard Rules on the Equalization of Opportunities for People with Disabilities (the Standard Rules) do not deal directly with housing and transport but these rights could be implied, for example, by other Rules on the right of disabled people to live with their families. Within these Rules is mention of places being accessible to disabled people and that organisations of disabled people should be involved. Rule 5 is on accessibility and here there are requirements for access to the physical environment:

- States should remove obstacles to participation in the physical environment. This requires standards and guidelines and to consider (not require) legislation to ensure accessibility in such areas as housing, buildings and public transport services.
- Those involved in the design and construction of the physical environment should have sufficient information on disability and accessibility.
- Accessibility requirements should be built into the designing stage
- Organisations of disabled people should be consulted on standards and guidelines and locally for public construction projects.

By contrast, three rules address culture, recreation and sports, and religion respectively:

- States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis (Rule 10)
- States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports (Rule 11)
- States will encourage measures for equal participation by persons with disabilities in the religious life of their communities (Rule 12)

At a European level the right to housing is explicitly recognised. Article 31 of the European Social Charter contains the right to housing. Parties must take measures:

- to promote access to housing of an adequate standard
- to prevent and reduce homelessness
- to make the price of housing accessible to those without adequate resources

Housing is also listed within other services under Article 15 (the right of disabled people to independence, social integration and participation in the life of the community) and Article 30 (the right to protection against poverty and social exclusion). Housing is not specifically listed in rights for children and families (e.g. Articles 16 and 17) but transport, communication and mobility are listed in Article 15.

The proposed European Constitution has even less coverage. Neither transport nor leisure is mentioned. The right to housing assistance is, however recognised:

- In order to combat social exclusion and poverty, the Union recognises and respects the right to social and housing assistance so as to ensure a decent existence for all those who lack sufficient resources, in accordance with the rules laid down by Union law and national laws and practices (Article II-34).

Compared to other issues – for example, education, health and social security – rights to housing, leisure and transport are not as consistently recognised in international documents (see Table 8.1 below). In European documents, there is commitment to the right to housing but limited attention to transport and leisure.

Table 8.1: Summary of specific mention of rights to housing, transport and leisure

	Housing	**Transport**	**Leisure**
UNCRC	Partially. 'Adequate standard of living'	✗	✓
Standard Rules	✗	✗	✓
European Social Charter	✓	Partially.	✗
Proposed European Constitution	✓	✗	✗

The European Union has undertaken a range of work in regard to accessibility. This is most evident for disabled people, in relation to transport and design standards, where there are recommendations and directives for accessibility[1]. There is,

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[1] For example, the Bus and Coach Directive (3.10.01), the High Speeds Train Directive (14.7.03), Council Directive 98/18/EC (19.3.98) on safety rules and standards for passenger ships, Council Directive 99/35/EC (29.4.99) on a system of mandatory surveys for the safe operation of regular roll on-roll off ferry and high speed passenger craft services. There is an European standard for the safe and independent access and use of lifts as well as an EU Directive (95/16/EC)

however, no clear, comprehensive non-discrimination directive for transport[2]. The focus of the existing patchwork of directives is on design and construction and does not sufficiently include accessible information and appropriate access. Air travel is under a voluntary code only (Matthews and Lawson 2003: 14).

It would seem that access to their home and community environment, particularly for disabled children, is less of a policy priority than other issues. The material across the seven countries is fragmented and not comprehensive. Yet, as the introduction suggests, housing, transport and leisure can have a considerable impact on the lived experiences of disabled children and their families.

Housing

While a literature on housing and disability exists, Oldman and Beresford (2000) argue that it largely ignores disabled children and their families and it has little to say about associated health issues or the role of domestic space in disabled children's lives. The literature, they write, tends to concentrate on issues to do with physical disability and on the individual disabled member rather than the whole family. Yet disabled children are more likely to spend time at home than non-disabled children. Oldman and Beresford (1998, 2000) undertook research in England to address these gaps by identifying difficulties for disabled children and their families.

Some of their findings are likely to be applicable beyond the UK. For example, they found that poor housing adversely affected families' physical and mental health. Bathrooms are reported to be the most difficult room in the house. Children with physical impairments can be stranded in one area of the home and have to rely on an adult to move them around: "When I'm at school I go round in my wheelchair, and when I'm at home I just sit in my chair" (Oldman and Beresford 1998: 3).

Parents' and children's concerns are not always the same. Parents are more concerned about risk in, say, the kitchen while children tend to be more concerned with being able to use or even be in the kitchen. Children generally want to be more

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[2] Should there be a comprehensive directive on disability, however, transport would likely be covered (see European Disability Forum, http://www.edf-feph.org/ (3.9.04)).

independent in terms of their self care and particularly want more privacy. Self-care aids that are installed seem to be more for parents to use than ‘independence aids’ for the children. Parents express concern that children have limited space to play, exercise or to have therapy and that siblings can suffer from lack of space such as having to share a room with a disabled sibling who has difficulty sleeping.

Central government is frequently but not always highly involved in housing policy and funding (see Table 8.2). The exceptions are Germany and Italy (for rent assistance), where the Länder and regions respectively have more of a contribution in both funding and setting policy details. Administration and delivery is frequently undertaken at a local level. France is not included in Table 8.2 There is substantial state involvement in housing, in both the rented and owner-occupied sectors, through subsidies, tax breaks, land use policies and financial market controls (Ball 2004: 52). Central government administers a separate housing benefit scheme (Kalisch et al. 1998: Table 9.1 in Appendix).

Kalisch and colleagues (1998) note certain common features of housing assistance arrangements across OECD countries:

- Most countries have multiple elements to their housing assistance for low income earners. This is evident in Table 8.2.
- The mix of assistance typically covers households who rent or own their homes.
- Many forms of housing benefits are means-tested and may be targeted on certain categories of households (e.g. on low-income families with children, disabled people). There is a trend towards greater targeting by income.
- There are constraints on the maximum subsidy for to low-income households.
- Public or social housing is usually offered to tenants at a subsidised rent.

The primary approach to housing policy in France and Germany is to increase home ownership. This carries certain risks for low income earners as they may find it difficult to make an initial deposit, can be vulnerable if their property’s value declined and may find it difficult to move in order to take up employment. Home ownership, though, does have the potential to provide households with a substantial investment.

Table 8.2: Governmental responsibility for housing policy

Country	**Programme**	**Government level that sets policy**	**Funding responsibility**	**Government level that sets policy details**	**Admin and delivery**
Denmark	Housing subsidies	Central government	Central government and municipalities responsible for sharing subsidy costs according to established rules. Municipalities cover administration costs	Central government	Municipalities
	Public housing	Central government	Central government	--	--
Germany	Social housing	Central government	Some central government support to Länder	Länder	Local and district authorities
	Housing allowance	Länder consent to national legislation	Shared equally by central government and Länder	Central government and Länder	Local housing allowance offices generally, social assistance offices for social assistance and war victims beneficiaries
Ireland	Social housing	Central government	Central government	Central government	Local authorities
	Private sector assistance	Central government	Central government	Central government	Central government
	Except sale of local authority housing to tenants	--	--	Central government	Local authorities
	Shared ownership	--	--	Central government	Local authorities
Italy	Social housing	Central government	--	--	Regions
	Tax allowances for first home buyers	Central government	Central government	Central government	--

	Rent assistance, reductions in council tax	Local (selected ones only)	--	Regions	Regions
Sweden	Housing allowance	Central government	Central government	Swedish National Social Insurance Board (responsible for supervising, monitoring and evaluating)	Local social insurance offices
UK	Housing benefit	Central government	Central government	Central government	Local authorities in England Northern Ireland Housing Executive
	Social housing	Central government	--	Local authorities, registered social landlords	Local authorities, private sector, voluntary sector

Source: Kalisch et al. 1998, Table 9.1 in Appendix

Bradshaw and Finch (2002) find particular difficulties in comparing housing benefits across countries. These can vary by many factors, from the age, condition, size of dwellings, location, to tenure etc. They also note, however, that housing benefits are an important element of benefits for families and can vary considerably across countries. Housing subsidies can be on the supply side such as financing builds – or demand side subsidies or housing benefits that go directly to the household. Bradshaw and Finch (2002) primarily gather information on the latter. Four out of seven countries in this project (Denmark, France, Sweden and the UK) are known to have supply side subsidies and six out of seven countries have housing benefits (see Table 8.3). Ireland is recorded in this Table as not having demand-supply subsidies, which is probably an artefact of the particular method used by Bradshaw and Finch. In fact, Ireland has a supplementary welfare allowance scheme for those not in full-time employment, mortgage interest relief and income tax relief on rent paid.

The majority of countries take income into account, directly or indirectly. Germany considers work status, unlike other countries. Denmark and Sweden are alone, across the seven countries, in providing a benefit specifically for families with children. Bradshaw and Finch (2002: 74) report that France had planned to change its housing benefit, to both simplify it and increase it.

Chapter 5 considers the child benefit package structure for the ‘average family’ case (a couple plus two children with one earner on average male earnings) and the ‘social assistance’ family case (a couple on social assistance plus one child). Considering Table 5.2, only Sweden’s housing benefit significantly increases the child benefit package for the social assistance family. Small positive increases can be seen in Denmark and France.

Table 8.3: Supply and demand side housing subsidies

Country	Supply side subsidy	Demand side subsidy	Varies with						Administered by	Contribution	Taxed	Uprated
			Income	Work status	No of adults	No of child	Age of child	Family type				
Denmark	✓	✓	✓	✗	✗	✓	✗	✗	Local	✗	✗	Annually in line with other benefits
France	✓	✓	✓	✗	✓	✓	✗	✓	National	✗	✗	No rule
Germany	✗	✓	✓	✓	✓	✓	✗	✓	Local	✗	✗	Not regularly
Ireland	✗	✗[3]	-	-	-	-	-	-	-	-	-	-
Italy	✗	✓[4]	✓	✗	✗	✗	✗	✗	National	✗	✗	According to the uprating of the INSP minimum pension level and of local income thresholds to access social housing
Sweden	✓	✓	✓	✗	✓	✓	✗	✓	National	✗	✗	Government decision
UK	✓	✓	✓	✗	✓	✓	✗[5]	✗	Local	✗	✗	In line with income support scales

Source: Bradshaw and Finch (2002), Table 4.1

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[3] Ireland, though, does have private sector housing assistance: e.g. supplementary welfare allowance; mortgage interest relief; income tax relief on rent (Kalisch et al. 1998, Table 9.1)

[4] The Milan subsidy has not been included.

[5] According to the UK information, benefits will vary by age of child (Bradshaw and Finch 2002: appendix, page 64) and the Department of Work and Pensions' website.

Adaptations

Adaptations, when successful, are perceived as transforming a child's life for the better (Oldman and Beresford 1998, see also Tozer with Shah 1999). However, Heywood (2001) finds that some adaptations are unused, unusable or caused increased stress. The most commonly described problems originate from poor consultation and communication, poor quality work and failure of supervision. Professionals can feel constrained by imposed policies and criteria.

Accessibility to buildings and public spaces

A recent report gives an overview of accessibility legislation across European Union (EU) member countries at the time (Toegankelijkheidsbureau and Living Research and Development 2001). Key findings are:

- Disabled people are discriminated against through building and environmental design, inappropriate building management practices and inadequate service provision. They are not generally empowered, however, to seek restitution or compensation through the courts.
- Accessibility legislation varies widely in scope and structure. Accessibility is frequently not consistently defined across sectors.
- Authoritative access standards for the built environment are lacking.
- Accessibility is influenced by technical aids available to disabled people. Design standards need to be reviewed and updated to reflect new technical aids available.
- Where they do exist, design standards and guidelines for accessibility vary according to national, regional and local conditions.
- Knowledge of good practice is thinly spread within and between countries.
- The public and professionals have poor awareness of accessibility issues or misconceptions (e.g. that increasing access will be prohibitively expensive).
- Incentives for improving accessibility are weak.
- Enforcement of accessibility legislation is generally poor.

These findings suggest poor implementation of the Standard Rules. The report suggests a typology of regulatory instruments for building (2001: 14):

National regulations

- Building regulations with performance requirements for accessibility e.g. Denmark and Sweden
- Building regulations with performance requirements and dimensional specifications for accessibility e.g. France, Germany and Italy

Additional regulations

- Supplementary building regulations with performance criteria and dimensional specifications for access – applied only to those buildings which must be accessible e.g. Part M of UK building regulations

Obligatory standards and guidelines

- European or International accessibility standards or norms e.g. European Lift Directive
- National accessibility standards or norms e.g. Denmark, Germany, UK
- Accessibility guidelines – approved by the national regulator e.g. Greece
- Accessibility guidelines – approved by local municipality or city e.g. Barcelona
- Accessibility guidelines – voluntary requirements to obtain a quality label or in house standards, e.g. UK
- Accessibility guidelines – optional, based on best practice and/ or research e.g. European concept of access.

The four levels of the typology are of descending strength, so that national regulations provide a more comprehensive and legal requirement than do the other three types.

People think that access to public places has improved over the past decade. In the Eurobarometer attitude surveys report in Chapter 2, Sweden and the UK had the two highest average scores. Ireland and West Germany also have an above the European average score. East Germany is equivalent to the European average score. Denmark, France and Italy are all lower than the European average score. So it appears that respondents in Sweden and the UK perceive more improvements over access than the other countries, and particularly in comparison to France and Italy.

Transport

For many families with severely disabled children, transport is necessary for virtually all activities outside the home (Widdows 1997). Children may be dependent on medical equipment, which can be difficult to transport. Leisure and access to 'public space' have not always been prioritised by statutory assessments and associated policy making, yet disabled children and young people report the centrality of these issues to them (Shelley 2002). Access to transport and leisure outside the home can be limited for some disabled children and their families.

As with building accessibility, a European overview on legislation to improve transport access (Committee of Deputies (CD) 2000a) shows considerable variability across EU member countries. Some countries have a proactive policy embedded in legislation and regulations whereas others have very little. Equal opportunities or anti-discrimination legislation frequently addresses transport. The power of such legislation is enhanced by strong enforcement and penalties but these vary greatly across countries (see Chapter 3). Responsibility in some countries is regionalised, which can lead to variability. Table 8.4 gives an overview of legislation for the seven countries in this review.

Improving the accessibility of public transport is one way to increase disabled children's mobility. This can be done through accessibility in terms of design but also through finance. Fare concessions are a wide-spread practice (e.g. Denmark, France, and Germany, UK), although these can be locally determined. Some countries allow for an accompanying person to travel free, with the disabled person (e.g. Germany, Italy). Fees in Sweden are generally the same across public transport. Certain areas do allow for free travel, if the person is already entitled to use the special transport service (CD 2000b). Other ways to make transport accessible are to provide specialist transport or to make private transport easier. The latter can again be spatial, such as allowing cars which have been carrying disabled people to park in special, more convenient spaces. This is available in all seven countries (CD 2004). Another common practice is to assist families in having an adapted car, by funding purchase or adaptations. Ireland, though, seems to have the weakest system for disabled children, whereas a range of support is provided for disabled adults.

Table 8.4: Overview of legislation, regulations and guidelines on transport accessibility

	National regulatory texts		**Standards, guidelines and recommendations**	**Enforcement and redress mechanisms**
	General	Specific		
Denmark		• Road transport • Specialised transport • Taxis and minibuses • Air transport		
France	Yes	• Transport terminals • Buses • Taxis • Road network	• Infrastructures • Bus networks • Rail networks • Specialised transport • Automatic vending machines • Airports • And others	Sanctions which could go as far as preventing operations in case of disrespect of regulations on accessibility of terminal installations
Germany	1 national 1 regional	• Train, metro • Train	DIN norms – accessibility rules	
Ireland	Yes	Taxis	Taxis	Construction –not specified Taxis –traffic police
Italy	National and regional	Specialised transport		
Sweden	Yes	• Public transport • Specialised transport	• Terminals • Bus stops and bus networks	Checks prior to operations
UK	National and regional	• Trains • Thoroughfares		Sanctions

Source: Table pp. 7-11 CD 2000a.

A summary of this range is recorded in Table 8.5. Note, however, that different aspects of public transport can have different rules and this is not fully captured in the columns on fare concessions and an accompanying person.

Respondents to the Eurobarometer attitudinal survey (see Chapter 2) tend to think that public transport is fairly inaccessible for physically and intellectually disabled people. Respondents for France and Italy thought transport was more inaccessible than the European average.

The Committee of Deputies also reviewed consultative arrangements with organisations of/ for disabled people (2000c). They found that some countries do have such consultative arrangements. Some were by general organisations (e.g. Denmark, Italy and Sweden) whereas others were by specialist groups focusing on transport (e.g. France, Ireland, Sweden and the UK). Germany is noted as consulting with many different organisations but not having a single consultative body. The countries are thus going some way to meeting the Standard Rules' requirement for consultation.

Table 8.5: Summary of transport support for disabled people

	Fare concessions	**Free or reduced fee accompanying person**	**Special transport**	**Parking badge**	**Other assistance with private car**
Denmark	✓ on trains; ~ varies on buses	✓on trains; ~ varies on buses	✓	✓	✓
France	✓	✓	For school	✓	✓
Germany	✓ for certain categories of disabled people and certain modes of transport	✓ for certain categories of disabled people and certain modes of transport	For school and employment	✓	✓
Ireland	✓ for disabled adults and carers Yes, for children	✓ for disabled adults	In certain areas	✓for children aged 5 or over	✓

	generally but not for disabled children specifically				
Italy	✓for certain categories of disabled people and certain modes of transport	✓for certain categories of disabled people and certain modes of transport	In certain areas	✓	In certain areas
Sweden	Usually not	Usually not	✓	✓	✓
UK	✓for certain modes of transport but not all	Sometimes	✓	✓for children aged 2 or over	✓

Leisure

As Aitchison (2003) writes, leisure is frequently conceptualised in spatial terms. Access to leisure opportunities can be very dependent on transport and the accessibility of buildings, which has been covered above. Leisure, and its associated aspects of culture and recreation, need not require travel as some things can be accessed through the person's home. Aitchison (2003) points out that leisure is also conceptualised through time, with ideas about 'free time'. This concept can be problematic for some disabled people, who rely on others for support and care and who may need assistance to access leisure. Personal assistants (see Chapter 6) can provide wider opportunities for disabled children and adults.

In their reports to the UN Committee on the Rights of the Child, the seven countries all report a variety of activities under Article 31. Denmark, though, is unique in having an organised and ongoing commitment to children's and young people's right to culture. Further, all Danish municipalities must make provision for out-of-school opportunities and care until young people are aged 18 (see Chapter 6). Without such a commitment, funding can be precarious, as has been found in Sweden:

- Municipal cultural activities, which were previously subsidised so that they would be available to all children and young people, are being dismantled in many quarters by, among other things, increased charges resulting in a reduced

> number of places. This means that not all children in society are afforded an opportunity to participate (Rädda Barnen, Sweden 1998: 14).

In the Eurobarometer survey (see Chapter 2), sports, cultural events and restaurants, hotels etc. tend to fair better for accessibility than public transport. The average responses, however, are still weighted towards access being difficult in all countries. These countries were below the European average, in accessibility:

- For physically disabled people
    - Cultural events: Denmark, France, Ireland, Italy, UK
    - Restaurants, hotels etc.: Denmark, France, Ireland, UK
    - Sports events: Denmark, France, Ireland, Italy, UK
- For intellectually disabled people
    - Cultural events: Italy, France
    - Restaurants, hotels etc.: France
    - Sports events: Italy, France

France and Italy, then, are viewed as inaccessible across a range of activities for disabled people. Denmark, Ireland and the UK are seen as particularly inaccessible for physically disabled people, across these activities.

Conclusion

Existing policies on housing, transport and accessibility tend to concentrate on disabled adults and do not necessarily take into account the particularities for disabled children. Where there is policy for children, it tends to be fragmentary at international, European and national level.

Play and leisure are recognised as critical rights for children in the UNCRC but also tend to lack a strong national policy profile compared to areas such as health, social assistance or social care. An exception is Denmark, which has a longstanding commitment to children’s rights to culture and a duty on municipalities to provide out-of-school care.

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Widdows, J. (1997) A Special Need for Inclusion: children with disabilities, their families and everyday life, London: The Children's Society

CHAPTER 9 APPENDIX: GENERAL KEY DOCUMENTS AND STATISTICS SOURCES

In this appendix are key publications, websites and statistical sources that cover more than one country. Tables are then provided that list the country coverage of each of these sources.

Publications

Bradshaw and Finch (2002) A comparison of child benefit packages in 22 countries, http://www.dwp.gov.uk/asd/asd5/rrep174.asp (10.5.04) [Brad 2002]

Commission of Deputies, Group on Transport for People with Mobility Handicaps (CoD) (2000) *Legislation to Improve Access*, http://www1.oecd.org/cem/topics/handicaps/pdf/TPH0010Fe.pdf. (21.3.04) [CoD 2000]

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Table 9.1

	Brad. 2002	CE 2003	CoD 2000	D&T 2003	EADSNE 2003	Euro 2004	Kalisch+ 1998	SSA 2002	UNICEF 2000
Albania								✓	
Andorra								✓	
Australia	✓						✓		✓
Austria	✓	✓	✓		✓	✓	✓	✓	
Belarus								✓	

	Brad. 2002	**CE 2003**	**CoD 2000**	**D&T 2003**	**EADSNE 2003**	**Euro 2004**	**Kalisch+ 1998**	**SSA 2002**	**UNICEF 2000**
Belgium	✓	✓	✓		✓	✓		✓	✓
Flemish Comm					✓	✓			
French Comm					✓	✓			
Bulgaria			✓					✓	
Canada	✓		✓				✓		✓
Croatia								✓	
Cyprus								✓	
Czech Republic			✓				✓	✓	✓
Denmark	✓	✓	✓	✓	✓	✓	✓	✓	✓
Estonia			✓					✓	
Finland	✓	✓	✓		✓	✓	✓	✓	✓
France	✓		✓	✓	✓	✓	✓	✓	✓
Germany	✓	✓	✓	✓	✓	✓	✓	✓	✓
Greece	✓		✓		✓	✓	✓	✓	✓
Guernsey								✓	
Hungary		✓	✓				✓	✓	✓
Iceland					✓			✓	
Ireland	✓		✓		✓	✓	✓	✓	✓
Isle of Man								✓	
Italy	✓	✓	✓	✓	✓	✓	✓	✓	✓
Japan	✓		✓				✓		✓
Jersey								✓	
Korea							✓		
Latvia								✓	
Liechtenstein								✓	
Lithuania		✓	✓					✓	
Luxembourg	✓				✓	✓	✓	✓	✓
Malta								✓	
Mexico							✓		✓
Moldova								✓	
Monaco								✓	
The Netherlands	✓		✓	✓	✓	✓	✓	✓	✓
New Zealand	✓						✓		
Norway	✓	✓	✓		✓		✓	✓	✓
Poland		✓	✓				✓	✓	✓
Portugal	✓	✓	✓		✓	✓	✓	✓	
Romania			✓					✓	
Russia								✓	
San Marino								✓	
Serbia								✓	
Slovak Republic							✓	✓	
Slovenia		✓						✓	
Spain	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sweden	✓	✓	✓	✓	✓	✓	✓	✓	✓
Switzerland		✓	✓		✓		✓	✓	
Turkey			✓				✓		✓
Ukraine								✓	
UK	✓	✓	✓	✓	✓	✓	✓		✓
England and Wales					✓				
Northern Ireland									
Scotland									
USA	✓		✓				✓		✓

Websites

Clearing House (CH) on international developments in child, youth and family policies http:// http://www.childpolicyintl.org/
European Agency for Developments in Special Needs Education (EADSNE) http://www.european-agency.org/
European Observatory on Health Systems and Policies (EOHSP) http://www.euro.who.int/observatory
European Observatory on the Social Situation, Demographics, and the Family (EOSDF) http://europa.eu.int/comm/employment_social/eoss/research_en.html#Monitor
Eurybase http://www.eurydice.org
MISSOC http://europa.eu.int/comm/employment_social/missoc/missoc_info_en.htm

Table 9.2

	CH	EADSNE	EOHSP	EOSDF	Eurybase	MISSOC
Albania			✓			
Armenia			✓			
Australia	✓		✓			
Austria	✓	✓	✓	✓	✓	✓
Azerbaigan			✓			
Belarus			✓			
Belgium	✓	✓	✓	✓	✓	✓
Flemish Comm		✓			✓	
French Comm		✓			✓	
Bosnia and Heerzegovina			✓			
Bulgaria			✓		✓	
Canada	✓		✓			
Alberta						
New Brunswick						
Saskatchewan						
Croatia			✓			
Czech Republic		✓	✓		✓	
Denmark	✓	✓	✓	✓	✓	✓
Estonia		✓	✓		✓	
Finland	✓	✓	✓	✓	✓	✓
France	✓	✓		✓	✓	✓
Georgia			✓			
Germany	✓	✓	✓	✓	✓	✓
Greece	✓	✓	✓	✓	✓	✓
Hungary			✓		✓	
Iceland	✓	✓			✓	✓
Ireland	✓	✓		✓	✓	✓
Israel	✓		✓			
Italy	✓	✓	✓	✓	✓	✓
Japan						
Kazakgstan			✓			
Kyrgyzstan			✓			
Latvia		✓	✓		✓	
Liechtenstein					✓	✓
Lithuania		✓	✓			

	CH	EADSNE	EOHSP	EOSDF	Eurybase	MISSOC
Luxembourg	✓	✓	✓	✓	✓	✓
Malta			✓		✓	
Mexico						
The Netherlands	✓	✓		✓	✓	✓
New Zealand	✓		✓			
Norway	✓	✓	✓		✓	✓
Poland			✓		✓	
Portugal	✓	✓	✓	✓	✓	✓
Republic of Moldavia			✓			
Romania			✓		✓	
Russian Federation			✓			
Slovakia			✓		✓	
Slovenia			✓		✓	
Spain	✓	✓	✓	✓	✓	✓
Sweden	✓	✓	✓	✓	✓	✓
Switzerland	✓	✓	✓			
Tajikistan			✓			
The former Yugoslavia republic of Macedonia			✓			
Turkey			✓			
Turkmenistan			✓			
UK	✓	✓	✓	✓	✓	✓
England and Wales					✓	
Northern Ireland						
Scotland					✓	
United States	✓					
Uzbekistan			✓			

Statistics

European Opinion Research Group (EORG) for the Education and Culture Directorate General, European Commission (2001) *Attitudes of European to Disability*, Eurobarometer 54.2, http://europa.eu.int/comm/employment_social/index/7002_en.html (31.3.04)

OECD (2003) *Education Policy Analysis*, http://www.oecd.org

OECD (2000) *Special Needs Education: Statistics and Indicators*, http://www.oecd.org

Table 9.3

	EORG 2001	**OECD 2000**	**OECD 2003**
Australia		✓	
Austria	✓	✓	
Belgium	✓	✓	✓
Flemish Comm			✓
French Comm			✓
Canada		✓	✓
Alberta			✓
New Brunswick			✓
Saskatchewan			✓
Czech Republic		✓	✓
Denmark	✓	✓	
Finland		✓	✓
France	✓	✓	✓
Germany	✓ (E & W)	✓	✓
Greece	✓	✓	✓
Hungary		✓	✓
Iceland		✓	
Ireland	✓	✓	✓
Italy	✓	✓	✓
Japan		✓	✓
Korea		✓	
Luxembourg	✓	✓	✓
Mexico		✓	✓
The Netherlands	✓	✓	✓
New Zealand		✓	
Norway		✓	
Poland		✓	✓
Portugal	✓	✓	
Spain	✓	✓	✓
Sweden	✓	✓	✓
Switzerland		✓	✓
Turkey		✓	✓
UK	✓	✓	✓
England and Wales			
Northern Ireland			
Scotland			
United States		✓	✓

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