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

Volume 2

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

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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 It is a unique collation, although the review does not cover all EU countries and will inevitably become out of date.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

DENMARK

Denmark is a constitutional monarchy, with a Parliament responsible for legislation and a central administration with 17 Ministries, each headed by an elected member of the Government. Denmark is divided into 14 counties, containing 277 municipalities. The municipalities of Copenhagen and Frederiksberg make up their own administrative units. Both counties and municipalities have their own elected council and council mayor (municipalities) or council chairman (counties).

In most service areas, central government sets the law, general rules and framework. Responsibilities are then divided between the counties and municipalities. For example, municipalities have the primary responsibility for state schools up to lower secondary while counties have responsibilities for upper secondary schools. Counties also have responsibilities towards children who require more special educational support than municipalities can provide. Municipalities have responsibilities for preventive health for children and young people while county councils are responsible for primary and secondary health care, hospitals and specialist institutions. The rationale for this decentralisation is explained, in relation to special education:

- Thus, the Danish system balances local flexibility for most children, with economies of scale at regional level for those children who require more assistance. Further, municipalities can call upon specialists from county social centre, regional or national institutions or special national consultants. (European Agency for Development of Special Needs Education (EADSNE) Denmark 2003).

An exception to this decentralisation is the social security system, which is more centralised and, while municipalities have administrative responsibilities, they have far less policy control.

Wendt’s comparative work (1999) between Denmark, Germany and the UK concludes that the Danish health care system has the ideal structure for children. He applauds its local organisation, which can set targets for an area's local population, and the close relationship that children can have with their general practitioner (GP). He also notes the co-operation between GPs and other services. Indeed, four year health plans are required from municipal and county councils, in order to improve coordination an efficiency of administrative levels (MISSOC 2002a: 5).

Not all commentators approve of such decentralisation. The National Council for Children (NCC) points out inequities across areas:

- This difference is predominant when it comes to day-care facilities. But the quality of schools also varies significantly. The same applies to the standards of local health schemes and the quality of social work for children with special needs (NCC 2000: para 17).

Further concerns are expressed particularly for disabled children:

- The continued decentralisation of responsibility for and efforts towards disabled children is a cause for concern, as the quality and the options of the services provided for the children are at risk (NCC 2000: para 137).

The NCC attributes some of these difficulties to the social and financial basis of municipalities and counties (2000: para 17). Even with these criticisms, Denmark ranks highly in terms of its public expenditure on welfare services (see Table 5.4 in Chapter 5) and its low levels of child poverty (see below). According to welfare regime typologies (see Chapter 1), it is a "socio-democratic welfare state with abundant social care services". Denmark has forged a distinctive path, in at least two ways, in comparison to other socio-democratic welfare states such as Sweden.
First, it introduced an 'activation policy' in the 1990s – described by Torfing (1999) as 'workfare with welfare'. This policy has emphasised improving the skills and work experience of unemployed people, on training and education rather than benefit and minimum wage reductions, and on broad workfare programmes rather than solely targeting those unemployed (Torfing 1999: 5). Other countries have subsequently taken on these ideas. This impacts on children, in that families which receive social assistance are part of this social activation policy (see below).

Second, Denmark is regarded as a forerunner in inclusion for disabled people and in valuing both children and disabled people. It has a consultative approach, with disabled people, with parents and increasingly with children. But political decision-making has resisted an overtly civil rights approach, refusing either to pass civil rights legislation for disabled people or to incorporate the UNCRC fully into domestic law (see below). Instead, the Danish government has promoted equality of opportunities, set up programmes to encourage it and supported the ‘sector responsibility principle’: “that responsibility for the equalisation of opportunities for disabled people in a specific area in society is placed with the authority responsible in general for the area in question” (Danish Disability Council (DSI) 2002: 10).

Equality/ anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No	No
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law ?	No	Parliamentary Resolution on the equalisation of opportunities for disabled people and non-disabled people (1993). This is not legally binding.
What type of domestic law is it? (criminal, constitution, civil rights, social welfare (Degener (2003))	Social welfare	Social welfare
Is there an enforcement mechanism?	National Council for Children <ins>does not</ins> handle individual complaints. The Folketing Ombudsman <ins>does</ins> handle individual complaints and may initiative investigations.	Danish Disability Council <ins>does not</ins> handle individual complaints The Folketing Ombudsman <ins>does</ins> handle individual complaints and may initiative investigations.
Are there (other) standing national bodies to provide policy advice?	Young People's Committee	• Government: Inter-Ministerial Committee on Disability • Council of Organisations of People with Disabilities

Denmark has ratified the anti-discrimination articles within the European Convention on Human Rights (ECHR, Article 14) and has agreed to Article 13 of the EU Amsterdam Treaty. Denmark has not, however, yet signed (and thus not ratified) the new Protocol 12, which would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority.

The UNCRC is applicable in court and administrative authority decisions (CRIN 2004). Denmark does not have general anti-discrimination rights in its Constitution, although Section 70 does protect civil and political rights on the basis of ‘creed or descent’.

Anti-discrimination by age and by disability

Denmark has ratified the UN Convention on the Rights of the Child (UNCRC). Ratification of a human rights instrument – such as the UNCRC – does not bring it automatically into Danish domestic law (Children’s Rights Information Network 2004). Legislative changes have been made subsequently but there is no overarching domestic legislation incorporating the UNCRC. An inter-ministerial committee examined the incorporation of several human rights instruments into Danish law, and reported in 2001. The conclusion was that Danish law was found to be “in harmony” (Denmark 2003a: 9) with the UNCRC and that the UNCRC does have relevance to Danish law because it can be invoked and applied by Danish courts and authorities.

The Danish Parliament established the National Council for Children in 1994 and then made it permanent in 1998. The Council is independent of government and promotes children’s rights, provides advice and assesses the current situation for children. It neither deals with individual complaints nor undertakes formal investigations. The Danish Government has promised to assess whether there is a need to change children’s individual access to lodge complaints (Denmark 2003a: 15).

Until very recently, neither Danish authorities nor most organisations of disabled people supported civil rights legislation in regard to disability: Such laws were, in a

Danish context, considered to be an expression of undesirable individualisation and legalisation and thus risked undermining the principle of solidarity which characterises Danish disability policy. It was also feared that such legislation would, if anything, contribute to separating disabled citizens as a group from the rest of the society and thus rather prevent than promote equal opportunities and equal participation. (DSI 2002: 8). Instead, the Danish parliament set out a resolution concerning the equalisation of opportunities for disabled people and non-disabled people. The resolution states that all national and municipal authorities and private enterprises should follow the principle of equal rights and equality of opportunities for disabled people and:

- …show regard for and create possibilities for expedient solutions in consideration of disabled citizens' needs in connection with the preparation of resolutions in which such consideration is at all relevant. (quoted in DSI 2002: 9)

The resolution is not legally binding but sets out a decision in principle.

The Danish Disability Council, with its affiliate the Equal Opportunities Centre for Disabled Persons, is tasked to implement the 'sector responsibility' approach. The Council is an advisory body to the Government and Parliament, established under the Ministry of Social Affairs. It includes representatives from organisations of disabled people and from government departments. Central authorities must consult the Council in matters of disability policy (Council of Europe (CE) 2003) but again the Council does not have formal rights to take forward individual complaints nor formal investigations. It can take initiatives and propose changes and all central authorities "are expected to take the Council's advice" (DSI 2002: 12). The Equal Opportunities Centre for Disabled Persons is tasked with drawing the attention of authorities to areas and situations where there are not equal opportunities for disabled people and non-disabled people (DSI 2002: 12). An action plan on disability was issued on February 5th 2003 (Denmark 2004).

Individual complaints and formal investigations, in regards to public authorities, can be undertaken by the Folketing [Parliamentary] Ombudsman.

Advocacy and Information

There are a variety of mechanisms for children and young people's involvement in policy decision-making. The National Council for Children is required to establish permanent contact with one or several groups of children (Denmark 1993: para 28). The Ministry of Social Affairs has recently piloted a youth forum, to include the views of children and young people in relevant initiatives (Denmark 2003a: 29). The Ministry of Education has used the nationwide pupils' organisations to consult on bills and proposals (Denmark 1998: para 83). The Danish Parliament itself holds a Youth Parliament, which involves school pupils asking questions to Ministers (Denmark 2003a: 29-30). The Government's Children's Committee, however, was disbanded (Denmark 2003a: 13-14).

Disabled people would seem to have stronger structures for representation. The Danish Disability Council is an advisory body to Government and Parliament for disability policy. It has representatives from organisations of disabled people and from government. An Inter-Ministerial Committee on Disability has been established (Denmark 2000: 4). The Council of Organisations of People with Disabilities has existed since 1934 and has had substantial influence on legislation since (Bengtsson 2000: 364).

Municipalities must give advice on services and subsidies that families may obtain for their disabled children (Council of Europe (CE) 2003: 102). The Equal Opportunities Centre for Disabled People can provide information to individuals as well as professionals and organisations (CE 2003: 107).

Education[1]

	All children	**Disabled children**
Key education legislation	Folkeskole Act 1993	Folkeskole Act 1993
Does a child have the right to education?	Yes	Yes
How is education organised?	Devolved and decentralised Overall aims of education set out in Folkeskole Act. Ministry of Education sets targets and publishes curriculum guidelines for guidance Municipalities responsible for pre-school institutions, primary and lower secondary schools	As for all children. In addition: Municipalities responsible for special education and other special educational assistance for children and young people under the age of 18. Counties responsible for special educational support for children whose development requires special and extensive consideration and assistance
How is education monitored?	Danish Evaluation Institute, an independent institution under the Ministry of Education, undertakes systematic and mandatory evaluations of teaching and learning. Municipalities supervise state schools Ministry of Education supervises independent schools	As for all children
Is there compulsory education?	Yes	Yes
What are the ages for compulsory education?	7-16 (the requirement is for 9 years of compulsory education)	7-16. Children with special needs can have up to 11 years
Is there a national curriculum?	Yes, in the sense of centrally set aims, knowledge and proficiency requirements and obligatory topics No, in the sense of curriculum guidelines but municipalities set curricula	As for all children.
Is compulsory schooling free at the point of use?	Yes, except if parents send children to an independent school (80-85% of costs met)	Yes – as for all children
Are incidental costs of	Yes, free books	Yes – as for all children as

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[1] This section relates to primary and lower secondary schooling, which extends from the ages of seven to.

schooling free at the point of use?	No, no meals provided	well as personal assistance, educational aids
Does the state provide free school transport?	Yes, depending on distances and age	Yes
Can parents exercise school choice?	Yes	Yes
To what extent are parents involved in school decisions about their individual child?	The Folkeskole Act requires parents to be informed regularly about their child's progress Parents are represented on school boards	As for all parents
To what extent are children involved in school decisions about them?	The Folkseskole Act sets out requirements for participation in school boards, school decisions including lessons, and individual decisions about progression. Pupils are entitled to form pupil councils at higher levels of schooling.	As for all children

In regards to special educational needs

Is there an official policy for school inclusion?	Yes
What type of education system is there (one-track, multi-track, two-track)?[2]	Multi-track
What percentage of children are in special schools and (full-time or nearly full-time) special classes?[3]	1.5%
What percentage of children have 'special educational needs'?[4]	11.9%
Are there special schools?	Yes
How is eligibility for special support determined?	
• **Categorical/ noncategorical**	Non-categorical
• **Who can initiate?**	Parents, classroom teacher, head of school, school health service
• **Assessment**	Yes
Do children have right to support for special educational needs?	Yes
Is there compulsory teacher training on special educational needs?	No

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[2] Information from EADSNE 2003

[3] 2001, Information from Table 4.1 EADSNE 2003

[4] 2001, Information from Table 4.1 EADSNE 2003

Principles and Structure

The Folkeskole Act of 1993 sets out the aims and general principles of teaching. Certain levels of knowledge and proficiency are set for individual subjects and certain topics are made obligatory. Otherwise, the Ministry of Education issues guidelines for the teaching of all subjects but the municipalities set the curricula locally.

Denmark places primary responsibility for school education at local level. Decision-making is now primarily between the schools and local authorities. The municipalities are responsible for pre-school institutions and primary and lower secondary schooling. The counties are responsible for the higher levels of schooling (upper secondary – Gymnaiser), as well as regular health care and medical attendance. The municipalities are responsible for special education and special educational assistance for children and young people under the age of 18, except if for children "whose development calls for special and extensive consideration and assistance" (Egelund 2000: 89). Thus, the Danish system balances local flexibility for most children, with economics of scale at regional level for those children who require more assistance. Further, municipalities can call upon specialists from county social centre, regional or national institutions or special national consultants (EADSNE Denmark 2003).

Since 1980, Danish education legislation has applied to all children and this is underlined by the Constitution (see below). The education system is required by law "to help promote each individual pupil's personal and social development according to his or her abilities" (EADSNE Denmark 2001) and has the following aims:

- The 'Folkeskole' shall - in cooperation with the parents - further the pupils' acquisition of knowledge, skills, working methods and ways of expressing themselves and thus contribute to the all-round personal development of the individual pupil.
- The 'Folkeskole' shall endeavour to create such opportunities for experience, industry and absorption that the pupils develop awareness, imagination and an

urge to learn, so that they acquire confidence in their own possibilities and a background for forming independent judgements and for taking personal action.

- The 'Folkeskole' shall familiarise the pupils with Danish culture and contribute to their understanding of other cultures and of man's interaction with nature. The school shall prepare the pupils for active participation, joint responsibility, rights and duties in a society based on freedom and democracy. The teaching of the school and its daily life must therefore build on intellectual freedom, equality and democracy (Section 1, quoted in Eurydice Denmark 2001: 4.6).

Disabled children are thus both obliged and entitled to education. This education need not be in Folkeskole, though, and could be undertaken in an independent school or at home. Compulsory school age is from seven to 16 years, although children with special educational needs can have 11 years of compulsory schooling in addition to pre-school class (EADSNE Denmark 2001). The starting age is somewhat misleading, as parents in Denmark have the right to request childcare services from municipalities and there is a very high level of provision in early years.

Free schooling is guaranteed by the Constitution: “All children of school age shall be entitled to free instruction in the elementary schools” (Section 76). Books are free and school transport is provided until upper-secondary level (Egelund 2000). Further, Denmark has introduced a policy of parental choice. This extends to independent schools. The state covers 80 to 85% of the costs of independent schools (EADNE Denmark 2003). Denmark spends a considerably greater proportion of public expenditure on education than the European Union average (8.0% compared to 5.3%) and it is the highest proportion of all seven countries in this review (see Table 5.4 in Chapter 5).

As stated above, a curricular framework is set out centrally but locally detailed. Municipalities approve curricula proposed by individual schools. No curriculum guidelines are set for special education. Central guidelines state that pupils, particularly those in special classes, can use textbooks normally used for children at lower ages.

The Danish Evaluation Institute was established in 1999, to undertake systematic evaluations of teaching and learning at all levels of education, and across all types of education. Head teachers are responsible for their schools' quality and for ensuring the aims, central knowledge and proficiency areas set by central government are met. Municipalities have a role in supervising state schools, while independent schools are responsible to the Ministry of Education. According to the Eurydice report, administrative monitoring and reporting was abolished in the 1960s and, instead, Denmark has a system of national advisers to the Ministry of Education. (Eurydice Denmark 2001)

Danish education law requires the participation of children, both in school and classroom decisions (e.g. pupil councils, participation on school boards, planning and arrangements of lessons) and in relation to individual decisions about progression etc. However, the National Council for Children (NCC) advocates improvements and greater clarity: It notes that little information is presently available on the extent to which disabled children can influence their own lives (2000: para 136). Pupils at higher levels of schooling are entitled to form pupil councils (but are not entitled to at lower levels) (Eurydice Denmark 2001).

Parental participation in school decision-making is a core principle in the Danish system. They are represented on the school board, for example. Each school board lays down the principles for school activities, approves the school budget and teaching materials, and draws up school rules. It sets the proposal for the school's curricula, which is then submitted to the municipality (Eurydice Denmark 2001).

Schooling for Disabled Children

Denmark takes a firm stance on its inclusion policy, as reported to the UN Committee on the Rights of the Child:

- In Denmark the main principle is that children with a physical or mental handicap should live as close to a normal life as possible. To the extent that this is possible disabled children are therefore integrated in the ordinary day-care institutions and schools run by the municipal authorities. (Denmark 1993: para 209)

The inclusion policy though is not absolute. Special institutions are provided for certain children and young people at county level (Denmark 1993: para 210). Some children are reported as easier to include than others:

- Some functional problems have been easier to tackle in the ordinary school than others. In general, handicaps such as communication failure: deafness, autism, severe mental handicaps - have presented the greatest difficulties. As far as deaf children are concerned, it has not been possible to set up integrated solutions that are acceptable to all parents; hence, a lot of them prefer to have their children attend schools for deaf. The same applies to a great extent to autistic and psychotic children. As regards mentally handicapped, including multi-handicapped, children, certain experiments have been made, the result of which is that some parents are for, others against, integration of their children in the ordinary school. (Eurydice Denmark 2001: para 4.12)

According to 1998/99 statistics, 0.7% of children were in special schools. Denmark also provides schooling in special classes in mainstream schooling (1%). Concerns have been raised about the rise in children attending special schools and classes, although overall numbers remain small (Egelund 2000). The number of children who receive supplementary support remains steady at approximately 13% of pupils. In 1994, approximately 1% of the compulsory school-age in the Folkeskole received ‘extensive’ special educational assistance. This proportion increased steadily until 1999 (1.4%) and fell slightly in 2000 to 1.3%. (Ministry of Education, Denmark 2002)

The Folkeskole Act legislates for special education: “Special education and other special educational assistance shall be given to children whose development requires special consideration or support” (Section 3, reported in EADSNE Denmark 2001: 10.2) A range of services may be provided, such as:

- Special education in the classroom – a teacher from the special municipal centre supports one or more pupils with difficulties, or offers teachers consultancy
- Small group education – groups consisting of three to four pupils. Children are taught in a combination of classroom lessons and lessons at the special centre.

- Intensive intervention – offered for a limited period, usually for three to four months. Groups consist of 10 to 15 pupils.
- Individual education – pupils have their own teacher
- Motor-training – groups consisting of three to four pupils are given one or two lessons/ week for two months (Egelund 2000)

Denmark has a system of personal assistance (see below) which can provide individual support for children in the classroom. A particular concern expressed by the National Council for Children (2000) is the need to improve physical access for Danish primary and lower secondary schools.

Denmark firmly works to a non-categorical system and provides no definition of special educational needs:

- As it is the Danish philosophy that all children can receive instruction, hence are entitled to instruction, all special educational measures are conducted in or in connection with the mainstream education. It therefore goes without saying that it is not possible to divide the pupils of the school into one group with and one group without special needs. (EADSNE Denmark 2001: para 10.10).

Parents, classroom or head teachers, or the school health service can all make a recommendation that a pupil be assessed. The municipal Pedagogical-Psychological Advice Office undertakes such assessments, to determine whether the pupil needs special education or assistance. Pupils and parents must be consulted (EADSNE Denmark 2001) The Office produces a report, which parents must be informed about, and a recommendation made. The head teacher determines whether to start with special education or other special assistance. The Office and head teacher must have strong arguments if they wish to overrule parents who do not want special education for their child. Pupils referred to special education are monitored by the Office. Parents are entitled to receive an alternative proposal to a special school, for instruction in the mainstream classroom or special class. (EADSNE Denmark 2001)

If a parent wishes to complain against the decision of the head teacher, they can do so to the municipality. The municipality has the final decision. Parents can complain about municipal or county decisions on special educational assistance to a complaints' board that deals with extensive special educational assistance. (EADSNE Denmark 2001)

Initial training for teachers does not include mandatory training on special needs. The 1998 Act on teacher training does require teacher training colleges to offer courses called 'children with different needs' (Egelund 2000). Should a disabled child attend a Folkeskole, teachers there must receive continuous training (CE 2003).

Social security

Proportion of children aged 0-15 in relative poverty[5]	3%
Proportion of children aged 0-15 in absolute poverty[6]	5.1%
Key social security legislation[7]	▪ Act on General Family Allowance (Lov om børnefamilieydelse) 1986 ▪ Social Services Benefits Act 1998 (Lov om social services) ▪ Act of Child Allowance and Advance Payment of Child Maintenance (Consolidation Act No. 1017 of 17 November 2002, Lov om børnetilskud og forskudvis udbtealing af børnebidrag)
Value of child benefit package, as % of average earnings[8]	7.7%
Ranking (leaders, second rank, third rank, laggards)[9]	Second rank
What % of GDP is spent on family cash benefits and family services?[10]	3.8%
Tax benefits for families with children	No
Income related child benefits	No
Non-income related child benefits	Yes • Family allowance (Børnfamilieydelse) - not means-tested; varies by age; up to age of 18; not taxed; annually up-rated and indexed. • Child allowances - paid for particular groups of parents and children (but not disability)
Social assistance for families with children	Yes. Act on active social policy (Lov om aktiv social politik 1 July 1998) - conditional on experiencing a social event (e.g. divorce or unemployment); social event resulted in individual not being able to provide for him or herself; no other coverage; claimant over age 18; additional amount for children; taxed.

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[5] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

* Information from Bradshaw and Finch (2002), as of July 1 2001.

[6] Children who are living in households with incomes below the US official poverty line converted into national currencies 1997 data, from Figure 2 UNICEF 2000.

[7] Information from Denmark (1998) and Denmark (2003)

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] Information from Bradshaw and Finch (2002), as of July 1 2001.

[10] See Table 5.1 Chapter 5.

Parental leave	Yes. 1 year per child, not flexible, up to the age of 9. 60% of maximum unemployment benefit; job guaranteed
Statutory leave for care of sick children	Yes. Paid (60% of wages) and payable for 52 weeks within any 18 month period; available for parents of seriously ill child aged under 14.
Type of benefits for disabled children	
• **supplement or extend child benefit**	No
• **benefits for caring costs**	Yes. Income replacement benefit for domiciliary care of a disabled child (with severe or permanent physical or mental impairment or chronic or long term illness); up to age 18.
• **benefits based on child being disabled**	Yes. Supplementary costs allowance - costs over a certain amount compensated for disabled person (with severe or permanent physical or mental impairment), with monthly amount discounted; not means-tested or taxed. Personal assistance scheme – see below.

No more than one in 20 children in Denmark lives in poverty, whether this is judged by relative poverty (3%) or by absolute poverty (5.1%). This places them high on the child poverty league tables internationally, with some of the lowest rates of child poverty (UNICEF 2000). Public expenditure (as a percentage of GDP) is high on family cash and services benefits – 3.8% compared to a European average of 2.2% (see Chapter 5).

The central government has responsibility for social security legislation and planning. Municipalities are responsible for most of the administration (Torpe 2002). Municipalities do have discretion for one-off expenditure payments but this discretion has been steadily reduced with increasing central directives (Hölsch and Kraus 2004). Diagram Denmark shows the administrative system. The system is, for the most part, not contribution-based but rather based on citizenship and paid for out of taxation.

Bradshaw and Finch (2002) only place Denmark in the second rank of countries, however, for its generosity of child benefit package. By their calculations, the child benefit package is 7.7% of average earnings. Denmark does not follow the general trend, identified by Bradshaw and Finch, of supporting families through the tax system. Instead, Table 5.5 in Chapter 5 shows that key component of the child benefit package is non-income related child benefit (i.e. family allowance). This is a universal benefit, varied by children's age. Additional child allowances are available for numbers of children or family type: for example, for pensioners with children and for parents who are in education. No child allowance is specifically directed towards disabled children.

For the 'social assistance' family case, a substantial proportion of the child benefit package is from social assistance – although it is taxed. It is part of Denmark's social activation policy, which obliges acceptance of 'activating provision' for unemployed people as a condition for continued financial support (Torpe 2002). Thus, to be eligible, the adult must have experienced a 'social event', that results in the adult not being able to provide for him or herself. People are not eligible for cash benefit because they are low paid or students (Ploug 2002).

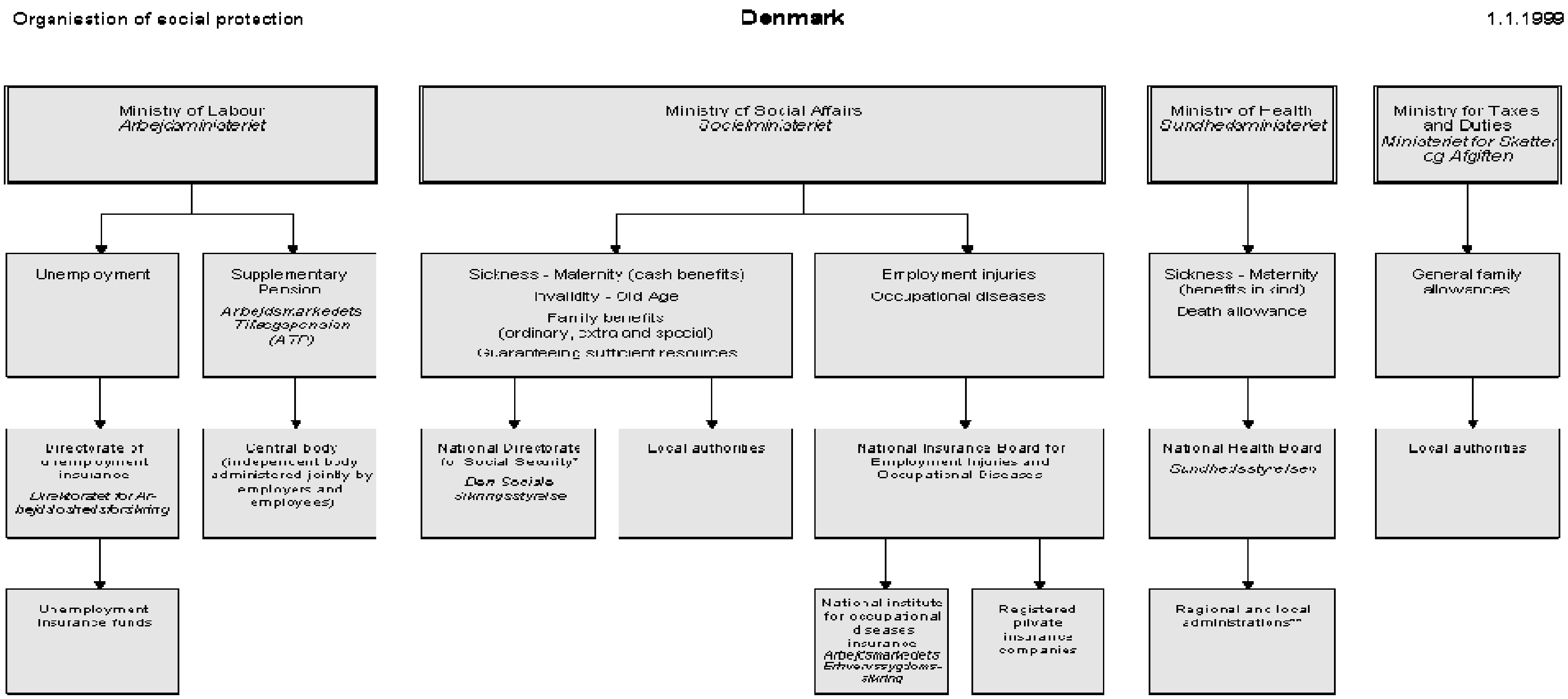
As well as maternity and paternity leave when children are born, Denmark also has statutory parental leave arrangements. This is dependent on the child not being in childcare. A parent can take one year per child, until the child is aged nine. The leave is not flexible (i.e. it must be taken in one block). It is paid -- 60% of the maximum unemployment benefit -- and the parent's job is guaranteed. Denmark compensates parents of seriously ill children who have to give up work or go part-time in connection with the child's illness (Denmark 1998: para 164). All public sector and most private sector workers have workplace policies that allow parents to remain at home with full pay for the first day of a child's illness (ClearingHouse 2004).

Denmark does not support disabled children and their families through supplementing or extending family allowance. However, it does provide benefits to cover loss of earnings, for carers, and for the costs of disability. The eligibility criteria are that: (a) the child is taken care of at home; and (b) the child has a "significant and permanent physical or mental impairment or a serious chronic or long-lasting disorder" (Denmark 2003a: 57). Entitlement is not determined by a medical diagnosis but the overall situation of the disabled person and family and the possibilities and obstacles encountered by the disable person (MISSOC 2003: 22). More carers receive extra expenses than they do replacement of earnings: in 2001, 31,911 parents received extra expense allowances.

From 1st January 2003, various improvements have been introduced such as contributions to pension and qualification and payment for holiday allowances, for those receiving loss of earning allowance (Denmark 2003a: 58).

While not recorded by MISSOC, disabled children and young people can receive personal assistance. The municipal authority will subsidise or pay the cost of engaging personal assistants, should the disabled person meet the eligibility requirements of requiring intensive support. (CE 2003: 101) Particular rules apply for 16 to 18 year olds (Denmark 2004).

Diagram Denmark: Administrative Arrangements for Social Security in Denmark



* Institution which deals with pensions of persons living abroad, works in conjunction with municipalities in this field.
** A public-company (*Hovedstadens Sygehusfællesskab*) manages the hospitals in Copenhagen and Frederiksberg.

Source: MISSOC (undated) Comparative Tables
http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

Support and Care services

	All Children	**Disabled Children**
Key childcare legislation	▪ Social Service Act (Lov om social service) ▪ Act on Due Process an Administration in the Social Field (Lov om retssikkerhed og administration på det social område) ▪ Folkeskole Act 1993	As for all children
Does a child (or carer) have the right to childcare?	245/271 municipalities have a childcare guarantee (Denmark 2003a: 69)	Yes
Is there formal out-of-school care provided by the State or with State support?	Yes, state provided or supported	Yes, state provided or supported
How is childcare organised?	Municipalities responsible for: provision of childcare, by themselves or by others; inspection; financing	As for all children. In addition, county authorities provide special care services.
Are there eligibility criteria for childcare?	Age of child	Age of child and child has “impaired physical or mental capabilities”. Municipalities can recommend a child to county authority special care services, if the child has “significant and permanent physical or mental impairment” and there needs cannot be met within municipal services.
Is childcare free at the point of use?	No, but it is subsidised	As for all children. Fully or partially free places can be awarded for social, educational or therapeutic reasons.
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there policy commitment to living in a family environment?	Yes	Yes

Key support legislation	▪ Social Service Act (Lov om social service 755 9 September 2002) ▪ Act on Due Process in Administration in the Social Field (Lov om retssikkerhed og administration på det social område 807 26 September 2002)	As for disabled children and ▪ Act of Active Social Policy (Lov om aktiv socialpolitik 1 July 1998)
Does the disabled person have the right to support services?	Yes	Yes
How are support services organised?	Municipal and county authorities. unicipalities have responsibility but can refer to county authorities for specialist assistance.	As for disabled children
What are the eligibility criteria?	No legal definition of disability. For financial assistance, see above. For support services, guidance states “considerable and durable reduced physical or psychic functional ability”, reference to the UN Standard Rules and that disability is a dynamic concept.	As for disabled children
How are such criteria assessed?	Municipality assesses. Can make recommendation to county authority	As for disabled children
What involvement do parents/ carers have in decisions for support services?	Rights in legislation to be involved in decisions	No rights in legislation to be involved in decisions
What involvement do disabled people have in decisions for support services?	Rights in legislation to be involved in decisions	Rights in legislation to be involved in decisions
Is support provided in cash or in kind?	Cash and in-kind	Cash and in-kind
Does supply meet demand?	No	No

What support is available for carers?	Support for caring, financial and in-kind
What support is available for siblings of disabled children?	Ad-hoc
Are short-term breaks available?	Yes, both foster and institutional placements are available.
Does the State regulate non-family placements (i.e. residential or foster)?	Yes.

Childcare and out-of-school care

Denmark has a strong commitment to providing state-funded childcare. It has a developed framework that covers children aged 0-18 years:

- Crèches: For children between the ages of six months and three years – mainly available in towns.
- Local authority childminding: Mainly for children between the ages of six months and three years. Children are looked after in the childminder's private home. The childminders are selected, engaged and paid by the local authority, which also determines which children should be looked after in the individual home.
- Kindergartens: For 3-6 year-old children; found both in urban and rural areas.
- After-school centres: For 6-10 year-old children.

For the same age group, school-based day-care facilities have been established at many schools, under education legislation.

- Age-integrated institutions: In most cases, facilities catering for children aged six months to about six years.
- Pool schemes: Established privately, typically by groups of parents who make an agreement with the local authority on receiving subsidies.
- Youth clubs: A facility for older children and adolescents for the purpose of creating activities and a social life that encourages independence and the ability to be part of a community

For the older age groups, clubs aim to provide general leisure activities. Children and young people have the right to influence the services and clubs must:

- …cooperate with the children and young people to create activities and forms of being together that promote the multi-faceted development and independence of the individual and his or her ability to take part in a binding relationship. (Denmark 1998: para 153).

Municipalities have the primary responsibility for childcare, in providing (or arranging to provide), financing and inspection. There is no absolute right for most children and their parents for childcare, but nine out of 10 municipalities provide a ‘childcare guarantee’. Municipalities must, however, provide day care services to children with impaired physical or mental capabilities. If children have needs that cannot be met within regular day care or club services, municipalities can make a recommendation to the county authority and the country authority decides on admission. Numbers of children registered in special day care services have been slowly increasing over recent years. For the 10 to 13 age group, 130 children were registered in special services in 1999 and this has grown to 163 in 2002 (Denmark 2003a: 57).

Childcare is substantially subsidized by municipalities but approximately 30% of operational costs are paid by parents (Denmark 1998: para 130). Reduced fees are available for multiple children, recipients of social assistance, etc. Special day care or club services are free of charge, when children are admitted exclusively or mainly due to need for treatment (Denmark 2003a: 57).

Support at home

Social legislation, which covers all disabled people and all children, requires municipal authorities to make help available if the child needs personal care or help and practical support for tasks in the home, which go beyond what parents can handle. Help may be offered in the home or relief outside the home. Extra costs of disability are covered under this legislation and the parent can be compensated for loss of earnings, should the parent care for the disabled child at home or stay with the child in hospital (CE 2003: 102-103).

A range of possible support services can be provided, such as:

- Personal care and/ or home care services for those with severe disabilities
- Respite and relief for persons caring for spouses or close relations at home
- Motor rehabilitation
- Care and support for people unable to travel alone
- Support and contact persons
- Consumer goods and apparatus
- Vehicles. transport assistance using personal vehicles
- Adaptation of housing and help with moving home
- Specially adapted housing for disabled or elderly people (MISSOC 2003: 23)

The personal assistance scheme is directed towards a person needing care, supervision and attendance. The attendance scheme provides help to make activities possible out with the disabled person's home. (CE 2003: 101) An attendance scheme gives disabled people the right to 15 hours a month for an attendant. The disabled person has flexibility on how this time is used. Young people aged 16-17, however, do not have the right to this scheme; municipal authorities may provide it but are not obliged to do so (CE 2003: 103).

Municipalities are, in the first instance, responsible for providing these services. Again, the National Children's Council criticises the inequity caused by this decentralised approach (2000: 8) and supply does not meet demand (Denmark 2003b).

No set definition of disability is provided within the legislation. The Danish Government stresses the social model approach to disability: The assessment of incapacity is undertaken by the municipalities, for granting and financing aids and support services. If offered, such services are generally free at the point of use although certain family expenditures may not be covered (Denmark 2003b).

The Social Services Act explicitly lays out children's and parents' right to be involved in decision making about services (Denmark 2003a), although families may not feel this in practice (Denmark 2003b).

Separate assessment and services do not seem to be available for carers nor for siblings of disabled children. The three exceptions are:

- compensation for loss of earnings, for carers
- reimbursement for the additional costs of training to deal with a child's disability
- short-term breaks for the disabled child

Care and support away from the family home

Danish policy sets out a commitment for the child to live in his or her family home, and be integrated into the immediate environment. However, special facilities are available for those children whose special needs require them. (CE 2003) Special homes are available with two or more disabled people or specialised boarding schools. Foster homes are more typically used for short-term breaks rather than long-term placements. No payment is required from families, once need has been assessed.

Health services and assistive technology

Type of health care system	National health service
What % of GDP is spent on health care?[11]	8.8%
What % of expenditure on health is public expenditure?[12]	83.1%
What are the average out-of-pocket payments (per capita, US$)?[13]	396

	All children	Disabled children
Key health legislation	Administrative reform in 1970s	
Are all children covered by the system?	Yes	Yes
How is health care organised?	Decentralised. • Central state sets goals for national health policy, regulates, promotes co-operation, provides guidelines and deals with patient complaints • County councils are responsible for primary and secondary care, regulating general practitioners, hospitals etc. • Municipalities are responsible for home nursing, dental care and preventative health care for children and young people	As for all children. In addition: • County councils own and run specialist institutions for disabled people • Agreements are made between counties and with Copenhagen Hospital Co-Operation for sharing of highly specialist departments.
How is health care monitored?	By providers. Four-year plans are submitted to the National Health Board	As for all children
Is health care free at the point of use?	Mostly, although there are direct and co-payments	Usually exempt from any payments
What choice do parents and children have?	Depends on type of membership of health reimbursement scheme. Most members (Group 1) choose a general	As for all children

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[11] 2002, Information from OECD in Figures (2003).
[12] 2002, Information from OECD in Figures (2003).
[13] 2002, Information from OECD in Figures (2003).

	practitioner, who then is a gatekeeper to specialist services. Fees can be paid to access other GPs or specialist services. Choice of hospitals possible	
To what extent are parents involved in their child's health care decisions?	A policy statement regarding co-operation has been made	A policy statement regarding co-operation has been made
To what extent are children involved in health care decisions about themselves?	Required by legislation	Required be legislation
How are specialist services accessed?	Generally, through the GP	Generally, through the GP

Key legislation for assistive technology	• Social Service Act (Lov om social service 755 9 September 2002) • Act on Due Process an Administration in the Social Field (Lov om retssikkerhed og administration på det social område 807 26 September 2002)
How is assistive technology organised?	Through municipal and county councils
How is it funded?	• All but consumables are free of charge through municipal and county councils • User must pay for 50% of consumables

Principles and organisation

Denmark has a national health service. Its basic principles are:

- free and equal access to health care services;
- public health services are jointly financed by taxes
- self-determination
- freedom of choice (MISSOC 2002a: 1)

It is a decentralised system, with most of the responsibility lying with county councils. Their responsibilities include:

- Funding primary and secondary care
- Regulating general practitioners
- Owning and running prenatal care centers
- Owning and running hospitals
- Owning and running special institutions for disabled people
- Providing district psychiatry services
- Preventing ill health and promoting health (European Observatory on Health Care Systems (EOHCS) 2002: 2)

The municipalities are then responsible for nursing homes, health visitors, home nurses, home help, municipal dentists, school health services, and preventing ill health and promoting health (EOHCS 2002: 2-3). The home health visiting, one of the responsibilities of the municipality, provide routine check-ups until the child is aged six. When the child then goes to school, the school health service undertakes annual sight and hearing tests and other oversight. (ClearingHouse 2004; European Committee on Social Rights (ECSR) 2003). Municipalities are therefore important for health services to children, young people and their families. Central government is responsible for setting the goals of national health policy, preparing health legislation, regulations, supply of health care professionals, promoting co-operation, providing guidelines, providing information, promoting quality and tackling patient complaints (EOHCS 2002: 2).

Hospital providers are mostly public organisations, although there are small private institutions that may have an agreement with one or several counties (MISSOC 2002a: 4). Only 1% of hospital beds are provided by such private institutions (EOHCS 2002: 2).

Most primary care is provided by general practitioners (GPs), who are paid on a combined capitation and fee-for-service basis (EOHCS 2002: 2).

Municipal and county councils are required to have four year health plans, to improve the coordination and efficiency of the different administrative levels (MISSOC 2002a: 5). The plans much be submitted to the National Board of Health (EOHCS 2002:3), which is linked to the Ministry of the Interior and Health.

Rehabilitation services are available through the National Health Service. Counties and their equivalent in Copenhagen are required to make agreements for using highly specialised national and regional departments (MISSOC 2002a: 4-5). Pedagogical Psychological Counselling Centres, established throughout municipalities, have speech, language and hearing therapists amongst their professional teams (Egelund 2000: 94).

Despite this encouragement of co-operation, decentralisation has been criticised for creating inequality both for general services and for specialist services for disabled children:

- A serious consequence of decentralization is unequal access to health care in different counties. Danish politicians appear to have considered local self governance (and its potential to achieve innovation) to be more important than geographical equity. This has led to differences in waiting times, in availability of medical technology and in rates of specific diagnostic and curative activities … (Vallgårda et al 2001: 25)

The NCC makes a similar criticism in regard to local health provision for children with special needs (2000: 8).

Funding and costs

The National Health Service is predominantly funded through local and national taxes. The budget is annually negotiated between the levels of government. The central government uses this negotiation as a means of influencing the health care system, e.g. by establishing targets (EOHCS 2002: 3).

A health reimbursement scheme is divided into Groups 1 and 2. The Groups differ in the extent of choice and payment. Group 1 members choose a GP, who they can then consult without a fee. The GP can recommend Group 1 members to free specialist treatment. If the Group 1 member is not recommended, the member can pay for the specialist treatment. Equally, a Group 1 member can also pay to consult another GP. Group 2 members can use any GP and any specialist without a referral. They are only entitled to be reimbursed up to the amount fixed by the reimbursement scheme. Only 2% of the population choose to be in Group 2. (Denmark 1993; MISSOC 2002a: 3)

Funding for health services can be through direct or co-payments. For example, certain treatments can be subject to co-payments, such as physiotherapy, as can medicines (MISSOC 2002a: 3). Out-of-pocket payments cover 16.2% of total expenditure on health, while 1.4% is covered by voluntary health insurance some people choose to obtain (EOHCS 2002: 5). For children, there are exemptions for payments: e.g. they receive free dental care until the age of 18 (Clearing House 2004). The Social Assistance Act ensures that all children are covered if their parents cannot pay (Denmark 1993: 216). Disabled children are further exempted from certain costs, if deemed necessary by a physician, such as physiotherapy (CE 2003).

Assistive Technology

A range of legislation, from the Danish Constitution to social services legislation, sets the structure and fundamental principles for individual social needs. Assistive technology is divided into four categories:

a very personal devices e.g. prostheses
b personal devices e.g. hearing aids
c technical devices e.g. wheelchairs
d consumables, which can be used to compensate for a disability (Deloitte and Touche 2003: 22).

Categories differ on ownership, choice and payment. Categories (a) to (c) are available free to the user and are owned by the municipality or the county council. Typically, the user can only choose their supplier for particularly personal devices. The user has to pay for 50% of the cost of category (d) consumables, has freedom to choose and owns the devices. The Social Services Act divides responsibility between municipalities and the county council. They can specify a supplier; following the Standard Rules, user representatives are involved in drafting requirement specifications.

A request can be initiated by anyone. A GP and/ or occupational therapist generally carry out the assessment. There is a national information and resource centre (the Danish Centre for Technical Aids for Rehabilitation and Education). There are also 14 regional centres. A database on assistive devices can be accessed, which includes purchasing information. Deloitte and Touch (2003) report that “users are involved whenever necessary in this process” (83), although municipalities and county councils have the final say for categories (a) to (c). Repair and maintenance is free to the user.

Choice, consent and user involvement

Group 1 members can choose their GP and can change after a minimum of six months. The GP is the ‘gatekeeper’ to specialist services. Group 2 members have further choice, as outlined above. Patients can choose hospitals for treatment, if considered necessary for medical reasons (Denmark 1993: para 198). Concern about waiting lists has led to guarantees. If a public hospital was not able to provide treatment, for certain conditions, within a maximum waiting time, then hospitals must pay for treatment in other hospitals – including hospitals abroad or private hospitals (MISSOC 2002a: 7).

Children are not insured separately under the health care reimbursement scheme but are ensured under their parent(s)’ health insurance. A child can make an appointment with the GP, without the parents’ knowledge being required. The GP is bound to maintain confidentiality with the child (Denmark 1993: para 48). Legislation requires children and young people to be involved “as much as possible in the decision process concerning their conditions, adapted to their general maturity and situation in general (Denmark 1998: para 77). Children over the age of 15 have legal capacity to consent to treatment; children under this age are to be informed and involved in treatment discussions, if the children are sufficiently mature (Denmark 1998: para 78, 80). A policy statement has been made about health professionals co-operating with parents over decisions (Denmark 2004).

Physical Environment

Housing stock[14]	51% owner-occupation; 45% rented sector; 4% other
Key housing legislation?	Rent legislation includes the Rent Act and the Act on Temporary Regulation of Housing Conditions applying to private rental housing, as well as the Act on the Rent of Social Dwellings. For disabled people: Social Services Act 1998
How is housing policy organised?	• Central government sets policy and provides funding • Municipalities administer and deliver policy, and provide funding • County councils provide accommodation for disabled people requiring extensive assistance and support
Housing benefits for families with children	Yes
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[15]	0.7%
Accessibility regulation to buildings etc.	Building Regulations 1995
Has accessibility to public places improved over the past 10 years?[16]	Yes, according to public opinion. 9.2% think it has improved very much while 48.1% think it has improved somewhat
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[17]**:**	
• **How accessible is public transport?**	3.56 (fairly to very difficult) for physically disabled people 3.01 (fairly to very difficult) for intellectually disabled people
• **How accessible are cultural events?**	2.99 (not very to fairly difficult) for physically disabled people 2.92 (not very to fairly difficult) for intellectually disabled people
• **How accessible are sports events?**	3.09 (fairly to very difficult) for physically disabled people 2.87 (not very to fairly difficult) for intellectually disabled people
• **How accessible are restaurants, hotels etc.?**	3.27 (fairly to very difficult) for physically disabled people 3.14 (fairly to very difficult) for intellectually disabled people

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[14] 2002, Information from Table 3.4, International Centre for Research and Information on the Public and Cooperative Economy (2003)

[15] See Table 5.4 in Chapter 5.

[16] See Chapter 2.

[17] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	No framework legislation for transport Social Services Act 2002	As for disabled children
Are there enforcement mechanisms?	Limited	Limited
Are fare concessions available for public transport?	Fare concessions on trains Fare concessions on buses vary	As for disabled children
Can an accompanying person go free, or for a reduced price, on public transport?	Yes on trains Varies on buses	As for disabled children
Is special transport available as an alternative to public transport?	Yes	Yes
Is there a parking badge scheme?	Yes	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Denmark has the second lowest rate of owner occupied dwellings in the European Union and a correspondingly substantial rental market (Ball 2004: 36). As with most countries, Denmark has multiple elements to its housing assistance for low income earners. It provides supply-side subsidies – for example, the government provides capital subsidies for new social housing building and improvements (Ball 2004: 37) – and demand-side subsidies – such as housing benefit. The housing benefit (boligsikring) is granted to families with and without children, who live in rented accommodation. Along with the family income and the rent, the benefit also takes into account the number of children. (Bradshaw and Finch 2002: appendix, page 14) The housing benefit is administered by municipalities. Overall, Denmark's public expenditure on housing as a percentage of GDP is higher than the European Union average - 0.7% compared to 0.4%. (Table 5.4, Chapter 5).

Municipalities generally have responsibility for the administration and delivery of housing policy. The central government sets the policy and the central government and municipalities share subsidy costs. (Kalisch et al. 1998: Table 9.2) Denmark has local income taxes, which go to municipalities and county councils. The taxes are only paid by owner-occupiers and not directly by renters.

Municipalities have particular responsibilities for disabled people. They have a preferential right to rented accommodation that is suitable for those with restricted mobility. The Social Services Act 1998 provides families with assistance for the increased housing costs due to a child's handicap, either by housing adaptations or moving to another dwelling. County councils can provide accommodation for disabled people who need very extensive support and assistance (CE 2003; Denmark 1993; MISSOC 2003: 23).

Accessibility to buildings and public spaces

Denmark has national building regulations, with performance requirements for accessibility. Local municipalities are required to check that these are met in buildings in their local area. Dispensations from the regulations can be requested.

The system was changed, so that municipalities were required to send a detailed written explanation for any dispensations to central government (Toegankelijkheidsbureau (Toe) and Living Research and Development 2001: 17).

General accessibility standards have been issued by the Danish Standards Association. These cover accessibility to and within buildings and facilities. They cover a full range of buildings: public buildings; industrial and commercial buildings; house buildings; buildings for private use; house building for older and disabled people requiring care; and summer houses. (Toe 2001: 17)

There are questions about whether the legal requirements are always met (Denmark 2003).

Respondents to the Eurobarometer survey think that access is not very to fairly difficult for both disabled and intellectually disabled people, in regard to certain activities. Just over half of respondents feel that access to public places has improved over the last ten years either very much or somewhat.

Transport

There is no overarching legislation that requires transport accessibility for disabled people, although there is political commitment to this (CE 2003). Specific requirements exist, such as:

- One departure per day must be adapted to take two passengers using wheelchairs, for passenger transport by road over 100 km. (amendment to 1990 legislation)
- A taxi is exempt from vehicle registration tax if it is equipped to take at least one passenger using a wheelchair.

There are codes of practice and mandatory requirements are set on certain contracts. (Council of Deputies (CD) 2000a: 21-22). Various concessionary fares are available for disabled people. For example, disabled people can obtain a special identity card if they are blind, visually impaired, use a wheelchair or use walking aids. The Ministry of Social Affairs then provides concessionary fares for travel by train and allows people to bring along one companion either free or at a reduced charge. The Ministry also funds certain concessions on bus transport for blind passengers and for travel companions, but there is no national policy and criteria for reductions vary (CD 2000c: 4)

Special transport is provided. County and municipal authorities are required by the Social Service Act 2002 to provide individual transport schemes for those people with restricted mobility who are not able to use public transport (CE 2003: 92; MISSOC 2003). There can be a charge for this transport (Denmark 2003). Further, the health care reimbursement scheme pays for the costs of transportation between the home and place of medical treatment, in special cases (CE 2003).

Parking badges can be available for private cars. Subsidies can be granted to purchase or adapt a car, if special and public transport does not meet transport needs (CE 2003: 93). County authorities finance the costs, often on the recommendation of municipalities (MISSOC 2003: 20).

Leisure and Recreation

As described above, the Social Services Act requires all municipalities to provide club schemes and other leisure time services for young people up to the age of 17. The Danish Government (1998) describes how the clubs function, emphasising children’s involvement in services:

- The purpose of the clubs is to provide an opportunity for general leisure-time activities, in particular for older children and young people not availing themselves of other leisure-time services. The clubs have to cooperate with the children and young people to create activities and forms of being together that promote the multifaceted development and independence of the individual and his or her ability to take part in a binding relationship

Typically, parents pay 20% of the operational costs and half the costs of materials used and meals. No fixed payment is set for young people who are involved in leisure-time arrangements at schools. Free places or reduced fees may be provided. (Denmark 1993: para 240) Provisions under the Social Assistance Act may provide for the special costs associated with leisure time activities, for disabled children (Denmark 1993: para 213). Overall, though, the National Council for Children (2000: 32) writes that after-school facilities are too limited for disabled children.

A further range of activities is cited in the Danish Reports (1998, 2003) to the UN Committee on the Rights of the Child, such as sports, libraries and museums. A national child culture programme ran from 2000-2002 (Denmark 2003: 73). There are various initiatives to extend and ensure access for disabled children. While there are a large number of sports organisations, the National Council for Children (2000: 13) criticises that they are very dominated by adults and insufficiently include children in decision-making.

A national Action Plan for Disabled People's Access to Culture was published in 1999 (CE 2003: 98).

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FRANCE

France retains a highly centralised system of government and administration. Central government sets the national social policy and legislation and generally has control of funding. There are then three types of local government: the 24 Regions; the 96 Metropolitan Départements and 5 Overseas Départements; and over 36,000 communes. Each of these types has elected councils and people can be elected onto more than one level. Both Regions and Départements, though, also have an administrative arm with personnel appointed by central government to administer and implement policy.

- The power of the centre remains strong, although decentralisation was introduced through legislation in 1982. Both administrative and political power was to be decentralised to the lower levels of government. (Ruxton 1996: 44) The different levels of government are responsible for different elements of provision. For example, Regions are responsible for the higher level of secondary schooling – Lycées – while Départements are responsible for matters such as school transport, specialist education and social care, and communes have responsibility for the building, maintenance and administrative control of primary schools.

The UN Committee on the Rights of the Child, in 1994, expressed concerns about the impact of decentralisation on children:

- The Committee is concerned about the need to take sufficient safeguards against the possible negative social impact of decentralization, for instance, in order to avoid the risk of aggravated disparities between the regions, in regard to the standard of living, and to minimize the possible adverse effects on the enjoyment of economic and social rights by children, especially those belonging to the most vulnerable groups (13).

Of particular concern was inequity between regions. In 2004, the Committee particularly criticised the lack of co-ordination:

- The Committee notes the multitude of actors involved in the implementation of the Convention but is concerned, as noted also by the State party, at the lack of coordination between them. In particular, the Committee is concerned that the increased responsibility of the Departments, coupled with inadequate coordination, may result in duplication and in significant disparities in implementation of the Convention. (para 8)

Beyond the state, there are other significant actors in France's social policy. It has a social insurance system, with implications for social care as well as health, which involve employers and employees as well as the state. Private health provision and private health insurance are growing within the health system (see below). This fits within the 'conservative corporatist state' model of Esping-Andersen (1990, see Chapter 1). France's 'social economy' of voluntary organisations, organised community groups, private schools etc. is also substantial. The social economy is active within social care, social services and community development, under license by the General Councils of each Départements (Ruxton 1996: 45).

Despite these and other activities, the UN Committee does not feel that the rights of disabled children are adequately met:

- … the Committee is concerned that these [programmes] remain insufficient and that too many children are not included in these efforts and remain without appropriate care with the main burden upon the families alone. Furthermore the Committee is concerned that efforts aimed at detecting disability may not be adequate (2004: para 40).

France has long had a strong family policy – represented in its extensive support for young families. One expression of this is the extensive range of childcare provision and the more recent pilots of 'wrap around care' for children out of school. Sometimes this is expressed by emphasising the family as the focus of support (e.g. assisting parents to leave employment to take on caring responsibilities) rather than state provision. The UN Committee seems to be expressing concerns about such reliance on the family.

Equality/ Anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has protocol been ratified?	No	No
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law on … ?	Yes	Yes
What type of domestic law is it? (criminal, constitution, civil rights, social welfare (Degener (2003))	Constitution	Constitution Criminal
Is there an enforcement mechanism?	Défenseur des Enfants does handle individual complaints Défenseur des Enfants can suggest modifications to policy	Courts
Are there (other) standing national bodies to provide policy advice?	Yes • National Consultative Commission on Rights • Institution of Childhood and the Family	Yes • Inter-ministerial delegation for people with disabilities • National Consultative Council of Persons with Disabilities

France is subject to the anti-discrimination articles within the European Convention on Human Rights (ECHR, Article 14) and has agreed to Article 13 of the EU Amsterdam Treaty. France has not yet signed (and thus not ratified) the new Protocol 12, which would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority. France states its promotion of equality in its Constitution:

France is an indivisible, secular, democratic, and social Republic. It ensures the equality of all citizens before the law, without distinction as to origin, race, or religion. It respects all beliefs (Article 2(1)).

Rather than addressing age or disability, the French government's reports to the UN Committee on the Rights of the Child have discussed this constitutional right only through consideration of minority groups (1992, 1997).

Anti-discrimination by age

France has ratified the UN Convention on the Rights of the Child (UNCRC). France's first and second reports to the UN Committee on the Rights of the Child list numerous acts, in particular areas of children's legislation, that help to implement these rights in policies and services. In France, when international human rights instruments are ratified and published they become self-executing and may be invoked in national courts; in other words, they do not need domestic law to become French domestic law (Article 55 of France's Constitution). However, the UN Committee on the Rights of the Child reported that it was unclear on the status of the UN Convention in French law, following certain court decisions (1994: para 12).

In 2000, legislation established an Ombudsman for Children (Défenseur des enfants). The Office of the Défenseur des enfants is an independent agency with statutory powers. It has four functions: it reviews individual cases in relation to children, which have otherwise not been satisfactorily resolved and intervenes in situations where it appears children's rights have not been respected; it identifies any problems in the implementation of children's rights; it has a promotional role for children's rights; and it is responsible for ensuring that children's views are heard in matters that affect them directly. (European Network of Ombudsmen for Children 2004)

In addition, the National Advisory Commission on Human Rights has commented on questions relating to children's rights. The Commission is answerable to the Prime Minister.

Anti-discrimination by disability

France is unusual amongst countries in Europe – and internationally – in having anti-discrimination provisions for disability contained within **criminal** law. Under the Law 90 602, 12th July 1990, 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.

An independent authority is to be established in 2004, to prevent and combat all forms of discrimination (UN Committee on the Rights of the Child 2004: para 18)

Coverage

Inferior treatment consists of:

- refusing to supply an object or a service
- hindering the normal exercise of any economic activity
- refusing to recruit, penalise or dismiss a person
- making the supply of an object or a service conditional on one of the situations listed in Art 225-1 or
- making an offer of employment conditional on one of those situations (MISSOC 2003: 55)

Because the law is 'symmetrical' (i.e. it applies equally to people who are disabled and who are not disabled), the law has explicit exceptions to allow for preferential treatment in social, medical and financial support (Malaga 2003: 26).

There is no definition of disability and France has therefore relied upon the International Classifications of Disability from the World Health Organisation (MISSOC 2003: 48).

Enforcement and sanctions

Enforcement is through the courts. This is dependent on individuals taking cases (or people acting on an individual's behalf). Unlawful discrimination is punishable by a fine of up to €30,000 or imprisonment for up to two years. Higher penalties can be given should the discrimination be committed by someone with powers vested by a public authority and if the discrimination denying a legal right or hindered the "normal exercise of an economic activity" (Gooding and Casserley 2003: 3-4).

France has a national action plan in relation to disability. Its key measures are:

- integrating children with disabilities into general pre-school and childcare facilities and nursery schools, as the norm
- improving the level and quality of integration within schools, following on from the 1999 'Handiscol' plan
- keeping all those with disabilities in employment and increasing the number of such people working in the civil service
- constructing more purpose-built accommodation
- overhauling public transport to enable disabled people to travel independently
- promoting equality of access to leisure facilities, tourism, sport and culture
- improving specialised institutions' services, strengthening the rights of clients within these structures, and preventing mistreatment from occurring in them
- giving greater acknowledgement to the contributionof disabled people to society
- increasing the independence of people with disabilities
- modernising the state's assessment and orientation service
- updating the 1975 law that laid down guidelines for dealing with disability (a bill updating actions in the field of social and health services, one of the domains covered by the 1975 law, was debated by parliament in early 2001)
- incorporating the European dimension into the planned measures. (European Industrial Relations Observatory 2001)

Such a plan may address Hurst's criticism, which she made in 1995, that France lacked comprehensive measures to ensure non-discrimination although not her criticism about mechanisms to enforce this range of measures (530).

Advocacy and Information

France introduced a form of commissioner for children, the Défenseur des enfants (D Defender of Children), through legislation in 2000. This Défenseur has various powers to: handle individual complaints; to suggest modifications to legislation and regulations; to make annual reports; and to disseminate information (France 1997: para 13-14). France has a developed system of children and young people's councils, at local, departmental and national levels (France 1997: para 74-76). Various experiments are reported in assisting young people to access legal information about rights (France 1993: para 95).

The National Advisory Commission on Human Rights issues opinions on the implementation of human rights in France. The Commission is answerable to the Prime Minister (France 1997: para 15).

The National Consultative Council of Persons with Disabilities (Conseil national consultatif des personnes handicapées) is consulted in relation to national policy. The Council includes organisations of disabled people and their families. (European Committee on Social Rights (ECSR) 2003) Every year, the Council makes a report to the ministry. There are similar councils at départements level. (Handicap Government France (HGF) 2003a translation). The government provides funding for representative organisations of disabled people and for various research centres. There is an informal grouping of associations of disabled people and of parents of disabled children (HGF 2003c translation).

In 1998, the Government made a commitment to help develop parental support network. An administrative circulaire (3) and charter of 9 March 1999 took forward this commitment. The networks are to allow for parental exchange and professional support, as well as being recourse for family mediation. Initial results suggest that the networks are successful in meeting their aims (Embassy of France 2001: 2).

Education[1]

	All children	**Disabled children**
Key education legislation	Framework law no 89-486 of 10 July 1989	As for all children. In addition: Framework Law no 75-534 of 30 June 1975
Does a child have the right to education?	Yes	Yes
How is education organised?	Centralised system Ministry for Education responsible for: the curriculum; recruitment, allocation, training; management and payment of staff; establishing the operating rules of schools. At the regional level, the Recteur must ensure the implementation of statutory and regulatory provisions. Départements responsible for school transport. The Inspecteur d'Académie responsible for the organisation of primary education and has the power to inspect schools. Communes responsible for the building, maintenance and administrative control of primary schools. School councils must produce a school plan. School head teachers admit pupils and organise teaching.	As for all children. In addition: Département commission for special education (CDES). Powers may be delegated to local commissions. For primary school children, these are pre-elementary and elementary local commissions (CCPE). Ministry for Social Services is responsible for various institutions that provide special education.
How is education monitored?	Central General Inspectorate of the National Education and Research Department. Inspecteurs d'Académie also have power to	As for all children, when in mainstream schools

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[1] This section relates to primary schooling, which extends from the ages of 6 to 11 years.

	inspect schools.	
Is there compulsory education?	Yes	Yes
What are the ages for compulsory education?	6-16 A pupil who has not reached the required level of education at 16 is entitled to continue in school	As for all children
Is there a national curriculum?	Yes	Yes
Is compulsory schooling free at the point of use?	Yes	Yes
Are incidental costs of schooling free at the point of use?	Municipalities often pay for cost of books and other teaching materials, in primary schools. School meals are paid for by parents, with subsidies available for those with low incomes. Financial support can be provided through the family allowance fund and school transport grants.	As for all children. In addition: If a child is eligible, a parent could receive a special education allowance and accompanying allowances
Does the state provide free school transport?	Unknown	Yes
Can parents exercise school choice?	Limited choice. Parents are allocated a school but may apply to the mayor of their commune or another commune for an alternative school.	Limited choice. As for all children. In addition, the CDES may decide what school a child should attend.
To what extent are parents involved in school decisions about their individual child?	Unknown	Unknown
To what extent are children involved in school decisions about them?	Unknown	Involvement in their individual educational plan

In regards to special educational needs

Is there an official policy for school inclusion?	Yes. The 1975 law states that education is preferably in mainstream classes; the 1889 law emphasises school integration
What type of education system is there (one-track, multi-track, two-track)?[2]	Multi-track
What percentage of children are in special schools and (full-time or nearly full-time) special classes?[3]	2.6%
What percentage of children have 'special educational needs'?[4]	3.1%
Are there special schools?	Yes
How is eligibility for special support determined?	
▪ **Categorical/ noncategorical**	Categorical
▪ **Who can initiate**	Child or young person, parents or teachers
▪ **Assessment**	Yes
Do children have the right to support for special educational needs?	Yes
Is there compulsory teacher training on special educational needs?	Yes

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[2] Information from EADSNE 2003.

[3] 2000/2001, Information from Table 4.1 EADSNE 2003.

[4] 2000/2001, Information from Table 4.1 EADSNE 2003.

Principles and structure

The French Constitution sets out the State's duty to organise free secular public education at all levels. While the educational system has been decentralised somewhat since 1982, it remains considerably centralised. Central government still determines teaching content and is responsible for staff recruitment, allocation, training and management. State-appointed personnel have responsibilities at various levels in the tiers of regional and local authorities. Head teachers themselves have the responsibility to organise teaching and to admit pupils. All schools must have school councils, composed of school teachers, parent representatives and commune representatives. School councils must be consulted on operating conditions in schools and the councils draw up school plans. (Eurydice France 2002)

French education legislation applies to all children, in that the Framework law no 89-486 of 10 July 1989 guarantees everyone the right to education. Separate legislation also covers disabled children, in regards to their education. The Framework law no 75-534 of 30 June 1975, titled the "Act on counselling for disabled persons", recognises disabled children's right to education and training and requires certain support and assessment services.

Children from the ages of six to 16 must attend school, although this starting age is somewhat misleading as France has considerable state support for pre-school provision (see below). In addition, pupils who have not reached the required level of education are entitled to continue past the compulsory school leaving age (European Agency for Development of Special Needs Education (EADSNE) 2004).

France has a national curriculum, divided by school levels, that is set by central government. A revised primary school curricula has been implemented gradually since 1996 (Eurydice France 2004: para 5.3.1.6.2). Exceptions are made for disabled children.

State schooling is free of charge up to the age of 18. Parents can choose to send their children to private schools, for which they must pay; over one in 10 of primary school pupils attended private schools, in 1999/2000 (Eurydice France 2002: para 2.16.1).

Communes frequently cover the cost of books and other teaching materials for state primary schools (Dialogue with Citizens France 1999). Parents can receive a special education allowance, which is intended to offset the additional expenses associated with educating a disabled child in the family. The amount depends on the adjudicated seriousness of the disability (France 1993: para 332). Support for school transport is also available (Dialogue with Citizens France 1999). Students with a disability assessed at equal to or over 50% (by the CDES) have a right to individually adapted transport to and from school (HCF 2004 translation). France spends a greater percentage of its GDP on education, than the European Union average: 5.8% compared to 5.3% (see Table 5.4, Chapter 5).

All teachers receive a small amount of initial training on disability. Specialised teachers must have specialist certification. (EADSNE 2004) Schooling is monitored through the General Inspectorate of the National Education and Research Department, with the assistance of administrative departments at lower levels (Eurydice France 2002: para 9.1). Primary schools carry out self-evaluation annually (Eurydice France 2002: para 9.2.1).

Schooling for Disabled Children

A presumption for school integration, or mainstreaming, is set out by policy:

- The 1975 law states that education should “preferably” take place in mainstream classes for all children “capable of being admitted in spite of their handicap” (Eurydice France 2002: para 10.2)
- The 1989 law promotes the principle of educational integration.
- Circular no 99-187 of 19 November 1999 repeats the right of every child to education. It states, as a general rule, the duty of every educational structure to admit a young disabled person at the request of his or her family (EADSNE 2004).

As can be seen by the qualifying statements, France does not promote full inclusion for all disabled children. Rather, it has a complex structure of institutions, to create a ‘multi-track’ approach under EADSNE (2003) definitions: i.e. a multiplicity of approaches to inclusion is maintained, with a variety of services between mainstream and special educational needs systems.

The French educational system distinguishes between individual and collective integration, which can be in ordinary or special segregated settings and full or part-time. Individual integration involves a child being integrated within a mainstream class. Collective integration involves small classes of disabled children being attached to a mainstream school. More collective integration is taking place in primary schools than in secondary schools (ECSR 2003). Individual integration was not that common, for disabled children, in 1999. France reported to the OECD that 12.5% of students with defined disabilities, and receiving additional resources, were in mainstream classrooms. A higher proportion of these students were collectively integrated, 17.2%. (OECD 2003b). In 1999, then, 70.3% of students were in segregated educational settings.
There are four sectors of French educational system:

- The school adaptation and integration sector
- The medical educational sector
- The socio-educational sector
- The health sector

The first sector is composed of the individual and collective integration referred to above. The sector provides specialised help networks, to support students in mainstream settings. It also organises educational integration classes. These are organised around disabilities and are attached to mainstream primary schools. Further structures are available at secondary level.

A range of services is available to support school integration. For example, specialised teachers work across schools. There are networks of special help for students with difficulties, composed of specialised teachers and school psychologists. These networks provide support to children with learning difficulties.

School auxiliaries assist in both collective and individual integration. (HGF 2004 translation)

The medical educational sector is under the authority of the Ministry for Social Services, although the education remains under the control of the Ministry of National Education. This sector is intended to provide for those children for whom attendance at an ordinary educational institution is considered “impossible or undesirable”. This is determined by the CDES, who can propose an institution in this sector as appropriate. (EADSNE France 2003). There is a range of different institutions, dependent on disability categories. For example, there are institutions for children and young people with intellectual disabilities, with behaviour problems, with multi handicaps, with motor disabilities, and for those with auditory or visual impairments.

The socio-education sector works with children coming through the child welfare system: e.g. for children who have committed offences or who are without family support. The Ministry for Social Services or the Ministry of Justice are responsible for these institutions. Other provision is available in the health sector. Eligibility to be admitted and to leave this sector is determined by a medical evaluation (EADSNE 2004).

This complex structure, with different responsibilities at central level, is seen as a barrier to educational integration:

- The dual character of the supervisory administrations and methods of financing introduces greater complexity into the relations between institutions or staff with different statuses
- The processes of regional decentralisation and administrative de-concentration have changed decision-making but the special needs sector has not adapted sufficiently
- Budget constraints
- Different professional cultures may harm dialogue between teaching, educational, rehabilitation or care personnel (EADSNE France 2003).

Difficulties in accessing educational institutions are identified by French adults, responding to the Eurobarometer survey (see Chapter 2). French respondents overall support all disabled children being educated in mainstream schools but with one-quarter who somewhat disagreed (20.6%) or strongly disagreed (5.0%).

Very recently, France has sought to increase educational inclusion through a ‘HandiScol plan’ put forward in April 1999. The French government, though, recognises that this plan has not been fully successful:

- Despite the 'Handiscol' plan, the access to schools enjoyed by children with disabilities varies widely from one département to another. Increasing numbers of parents of children with disabilities have been taking the state to court over this issue during recent months (EIRO 2001).

France announced a further plan in 2001 and school head teachers would be required to justify refusing a place to a disabled child. (EIRO 2001) Nonetheless, France was criticised by the European Commission of Social Rights (2003) for its low numbers of disabled children integrated in mainstream education. The UN Committee also stated its concerns “that thousands of children with disabilities are deprived of their right to education” (2003: para 48).

No one eligibility category applies across all education sectors. The EADSNE report notes that the definitions are “all very specific, linked to certain connotations, and marked by a historical situation”. The legal definition of a disabled person is set out in the 1975 Law. For children, a Commission of Special Education (Commissions départementales d'éducation spéciale (CDES)), or its associated institutions, determines whether a child needs assistance measures. The Commission decides on the child’s degree of disability, compared to a scale of disabilities (EADSNE France 2004). MISSOC (2003: 48) reports that there have been “some progress” away from a medical approach recently although Armstrong and colleagues (2000) are more dismissive on how far this moves away from focusing on the individual child’s difficulties. The Commission’s assessment is critical not only for education but also for other supports, both in kind and financial.

Disabled pupils, their parents or their teachers can ask for an assessment by the Commission. A multidisciplinary team does the assessments. An individual education plan must by drawn up for those children deemed disabled, with the involvement of the child’s family, the teachers and other relevant people (ECSR 2003).

Social Security

Proportion of children aged 0-15 in relative poverty[5]	24%
Proportion of children aged 0-15 in absolute poverty[6]	10.7%
Key social security legislation	Social Security Code (Code de la sacurita sociale), Book V. Article L. 511-1 and following Family and Social Welfare Code
Value of child benefit package, as % of average earnings[7]	10.9%
Ranking (leaders, second rank, third rank, laggards)[8]	Second rank
What % of GDP is spent on family cash benefits and family services?[9]	2.8%
Tax benefits for families with children	Yes. Working tax credit - varies by number of children and family type but not age of children.
Income related child benefits	Yes. Benefits for - households with ≥ 3 children, households with children < 3 years, allocation de rentrée scolaire (ARS, back to school allowance) for children 6-18 and others
Non-income related child benefits	Yes. Allocations familiales - varies by age of children, number of children but not characteristics of children; up to age 16 or 20 if child in education, training or unemployed; government decides on up-rating and not indexed; not taxed. Also allocation de soutien familial for single parents.
Social assistance for families with children	Yes. Revenue minimum d'insertion (RMI) - means-tested; addition for children. not for lone parents with child < 3 (allocation de parent isole instead) nor adults under 25 without dependents.
Parental leave	Yes. 3 years per parent per child; flexible; up to the age of 3; payment depend on if working and number of children; job guaranteed

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[5] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

* Information from Bradshaw and Finch (2002), as of July 1 2001.

[6] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[7] Information from Bradshaw and Finch (2002), as of July 1 2001.

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] See Table 5.1 Chapter 5.

Statutory leave for care of sick children	Yes. Short sickness leave - 3 days per year per child, 5 days if child is <1 year or if 3 dependent children; not flexible; up to age 16; unpaid[10]; job guaranteed Allocation de presence parentale (APP, parental presence leave) - 4 months, can be renewed twice/ year (MISSOC 2002b); flexible; up to age 20; payment depend on family type and hours; job guaranteed.
Type of benefits for disabled children	
• **supplement or extend child benefit**	Tax reduction for a dependent child with a disability card[11].
• **benefits for caring costs**	Yes, APP and complement d'allocation spéciale based on AES
• **benefits based on child being disabled**	Yes. Allocation d'éducation spéciale (AES, allocation special education) – not means-tested; parents caring for a child with a permanent incapacity, requiring one parent to suspend work or the need of a third person; 3 levels of flat-rate payments; for child with permanent incapacity of 80% or at least 50% and attending CDES recommended special education scheme; up to age 20

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[10] Note that other sources say that this leave is paid – information from Bradshaw and Finch 2002 here.

[11] Information from France (2003), para 285.

The French Government recognises that some families with children are impoverished (France 1993, France 2002). Nearly one in four children lived in relative poverty and over one in ten children were in absolute poverty, according to 1997 data. The French Government describes how its policy has evolved to address such poverty:

- The economic and social problems of the 1980s led to the establishment of a statutory minimum income (Act of 1 December 1988), the law passed on 31 May 1990 on the right of disadvantaged people to housing, and the Act of 31 December 1989 on unmanageable private debt. These measures have not managed to halt the rise in economic precariousness and social exclusion … Hence the adoption by the Government of a global programme to prevent and combat exclusion based on the Framework Act of 29 July 1998. The objectives of the Act are to permit the genuine exercise of fundamental rights and forestall exclusion by dealing with problems as early as possible (France 2002: para 319).

Despite this description, the UN Committee on the Rights of the Child remained concerned

- by the inadequate measures taken to address the situation of the most vulnerable groups in society and either economic and social rights, in particular related to housing of poor families, such as families of immigrants" (2004: para 10). France's spending on family cash benefits and a family experience is above the European average: 2.8% of GDP compared to 2.2% (see Table 5.4, Chapter 5).

Diagram France shows the complex administrative arrangements for France's social security system (but does not show all arrangements as they relate to children – e.g. CDES is not listed). France has a tradition of occupationally-based welfare and hence the dominance of the social insurance principle (Kleinman 2002). The introduction of the minimum income guarantee (RMI), described above, now provides a citizenship-based aspect of the social security system. It has not, however, helped with the complexity of the system: "An evaluation of the law of 29 July 1998 shows a system that remains too complex and administered by a many authorities whose powers sometimes overlap" (Heikkillä and Kuivalainen 2002: 37).

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Diagram France: Administrative Arrangements for Social Security in France

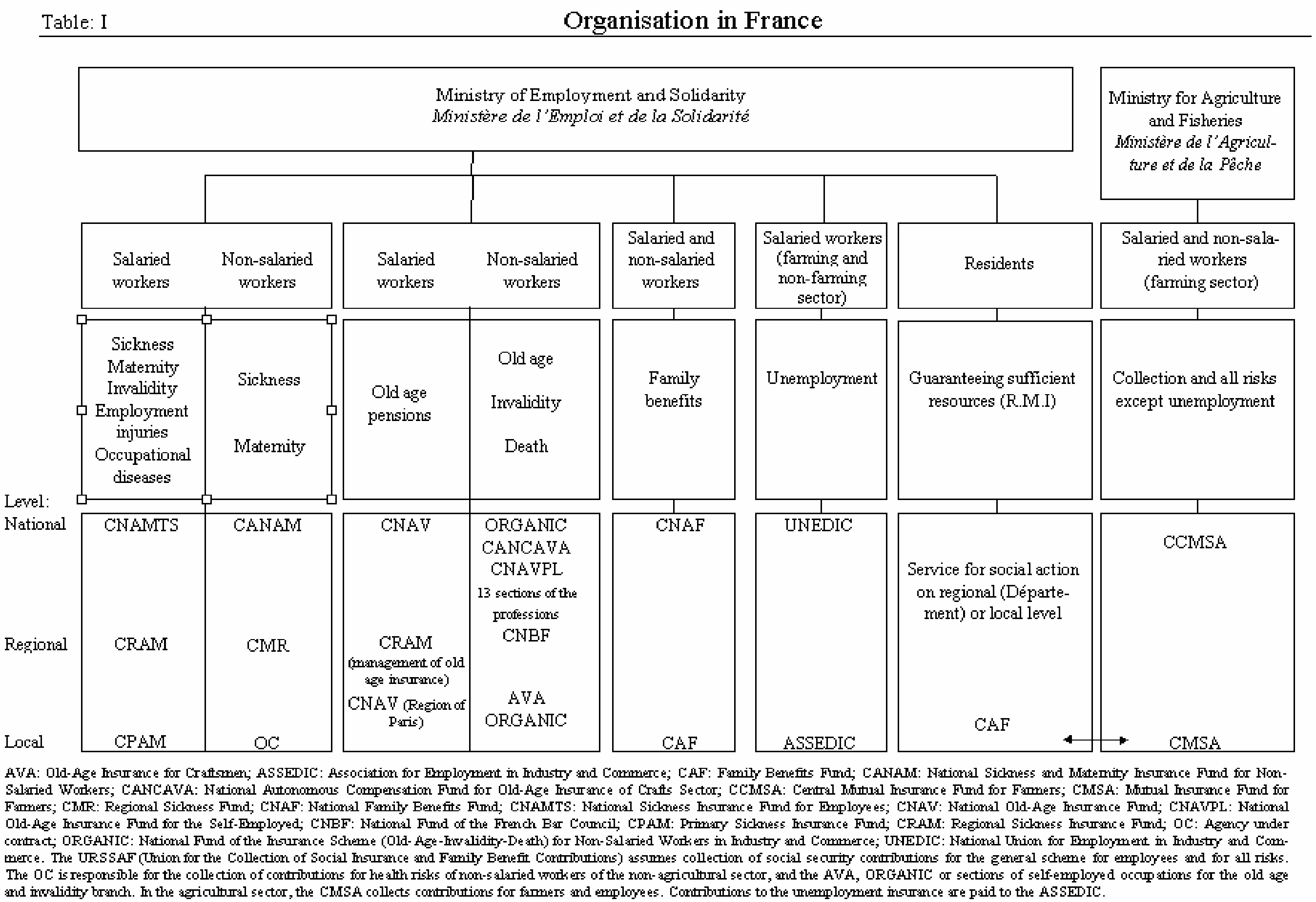

Table: I

Organisation in France

Level								
	Ministry of Employment and Solidarity *Ministère de l'Emploi et de la Solidarité*							Ministry for Agriculture and Fisheries *Ministère de l'Agriculture et de la Pêche*
	Salaried workers	Non-salaried workers	Salaried workers	Non-salaried workers	Salaried and non-salaried workers	Salaried workers (farming and non-farming sector)	Residents	Salaried and non-salaried workers (farming sector)
	Sickness Maternity Invalidity Employment injuries Occupational diseases	Sickness Maternity	Old age pensions	Old age Invalidity Death	Family benefits	Unemployment	Guaranteeing sufficient resources (R.M.I)	Collection and all risks except unemployment
National	CNAMTS	CANAM	CNAV	ORGANIC CANCAVA CNAVPL 13 sections of the professions CNBF	CNAF	UNEDIC		CCMSA
Regional	CRAM	CMR	CRAM (management of old age insurance) CNAV (Region of Paris)				Service for social action on regional (Département) or local level	
Local	CPAM	OC		AVA ORGANIC	CAF	ASSEDIC	CAF	CMSA

AVA: Old-Age Insurance for Craftsmen; ASSEDIC: Association for Employment in Industry and Commerce; CAF: Family Benefits Fund; CANAM: National Sickness and Maternity Insurance Fund for Non-Salaried Workers; CANCAVA: National Autonomous Compensation Fund for Old-Age Insurance of Crafts Sector; CCMSA: Central Mutual Insurance Fund for Farmers; CMSA: Mutual Insurance Fund for Farmers; CMR: Regional Sickness Fund; CNAF: National Family Benefits Fund; CNAMTS: National Sickness Insurance Fund for Employees; CNAV: National Old-Age Insurance Fund; CNAVPL: National Old-Age Insurance Fund for the Self-Employed; CNBF: National Fund of the French Bar Council; CPAM: Primary Sickness Insurance Fund; CRAM: Regional Sickness Insurance Fund; OC: Agency under contract; ORGANIC: National Fund of the Insurance Scheme (Old-Age-Invalidity-Death) for Non-Salaried Workers in Industry and Commerce; UNEDIC: National Union for Employment in Industry and Commerce. The URSSAF (Union for the Collection of Social Insurance and Family Benefit Contributions) assumes collection of social security contributions for the general scheme for employees and for all risks. The OC is responsible for the collection of contributions for health risks of non-salaried workers of the non-agricultural sector, and the AVA, ORGANIC or sections of self-employed occupations for the old age and invalidity branch. In the agricultural sector, the CMSA collects contributions for farmers and employees. Contributions to the unemployment insurance are paid to the ASSEDIC.

Source: MISSOC (undated) Comparative Tables http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

Financial support for all children

France has a tradition of a strong family policy, which has taken a dominant role in the social security system (Sainsbury 1994; Kleinman 2002). Bradshaw and Finch (2002) place it within their second rank of countries, but at the top of this grouping. France's child benefit package is 10.9% of average earnings. This generosity comes from a range of sources, as demonstrated in Table 5.2 of Chapter 5. France uses the tax system, through a working tax credit, and has both income-related and non-income related child benefits. There have been a growing number of means-tested benefits for families. (France 2003: para 264). France has a number of special allowances, such as the back-to-school allowance for low-income families, an adoption allowance and a single parent allowance. One of these special allowances is one for disabled children, described below.

The child benefit package for the social assistance family case, in Bradshaw and Finch (2002), is not particularly generous. The average family case has an improved income of £144, compared to a childless couple but the social assistance case only has an improved income of £102 due to the child benefit package. Thus the child benefit system may be redistributive from households without children to households with children, but less so between families with average incomes and those eligible for social assistance.

A strong strand of French family policy is support for parents in reconciling work and caring for their children (France 2003: para 301), particularly for young children. This is evident in their parental leave arrangements. These are generous, with up to three years per parent per child, but leave is only available until the child is aged three. This can be extended for one year if a child is disabled (ClearingHouse France 2003). Parents have only three days per year statutory leave for care of a sick child (five days per year in the child is under one or the parent has three children). This is, however, available until a child is aged 16 and is paid. France also has flexible working arrangements.

Financial support for disabled children

France takes all three routes to supporting disabled children financially:

- It provides support through the tax system (tax reduction);

- It supports caring costs by income replacement through the Allocation de presence parentale (APP); and
- It provides benefits to pay for the extra costs of disability through the Allocation d'éducation spéciale (AES.

Both APP and AES are dependent on external assessments: to be granted APP, the carer must obtain a medical certificate for the child (Comitedenterprise 2003 translation); to be granted AES, the carer must send a medical certificate for the child to the CDES. The level of AES is entwined with CDES' decision in relation to special schooling. AES can be granted at a lower level of incapacity, should the child be recommended by CDES for a special education scheme. APP is flexible in whether the parents work part-time or full-time but is not available indefinitely. In contrast, the AES is available until the child is aged 20 years.

Support and Care services

	All Children	**Disabled Children**
Key childcare legislation	Framework Law 1989	Framework Law 1989
Does a child (or carer) have the right to childcare?	Yes, in nursery schools for children aged 3-5 years	As for all children
Is there formal out-of-school care provided by the State or with State support?	Yes • Pre-School provision for children aged 3 months-2 years • Nursery schools (écoles maternelles) for children aged 2 to 5 years • Out of school care provided in centre de loisir sans hebergement	Nursery schools are available to all
How is childcare organised?	• Pre School – administered under the Ministry of Health • Nursery schools - administered under the Ministry of Education	As for all children
Are there eligibility criteria for childcare?	Age	Age
Is childcare free at the point of use?	• No, pre-school and out of school • Yes, nursery school	As for all children
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes and no	Yes and no
Key support legislation	Framework Law no 75-534 of 30 June 1975	Unknown
Does the disabled person have the right to support services?	Yes	Unknown
How are support services organised?	Caisse nationale des allocations familiales	Caisse nationale des allocations familiales

	(CAF) Département commission for special education (CDES).	(CAF) Départements
What are the eligibility criteria?	See school education	Unknown
How are such criteria assessed?	See school education	Unknown
What involvement do parents/ carers have in decisions about support services?	See school education	Unknown
What involvement do disabled people have in decisions about support services?	See school education	Unknown
Is support provided in cash or in kind?	Cash (see social security)	Unknown
Does supply meet demand?	Unknown	Unknown

What support is available for carers?	Cash and leave
What support is available for siblings of disabled children?	No basis in statute
Are short-term breaks available?	Unknown
Does the State regulate non-family placements (i.e. residential or foster)?	Yes

Childcare and out-of-school care

France has a long history of child care support. Legislation in 1989 laid down organisational and operational guidelines for nursery schools (Eurydice France 2002).

For children aged three months to two years, a range of crèche types and child care services are available. These services are primarily for working mothers, have income-related fees and are administered under the Ministry of Health.

The Écoles Maternelles are publicly funded and administered under the Ministry of Education. They are free for the standard school day, with additional 'wrap-around' services available at other times. These wrap-around services are paid for by parents, with income-related fees. The Écoles Maternelles are available for 2-5 year olds, although there are usually not enough places for all 2 year olds (Clearinghouse 2003).

Bradshaw and Finch (2002) report that formal out-of-school care is most commonly provided by Centres de Loisir sans Hebergement. These have fees but they can be reduced and childcare is highly subsidised.

Support at home

The French Government describes the purpose of French legislation as "to ensure that disabled children are brought up and cared for in the best possible conditions and without undue expenditure by their families" (2002: para 328). This does not explicitly state a commitment to promoting community inclusion, wherever possible. The Government then goes on to state that children can be looked after in different types of specialised institutions. However, it does stipulate that disabled people should be in 'ordinary' living environments (para 329).

The main source of family and child services in France is through the semi-public body the Caisse d'Allocations Familiales (CAF). Social care delivery, along with social assistance, is delivered through the Départements level with local centres, communaux d'action sociale. Family centres, centres sociaux, complement the local centres and other forms of provision. These family centres employ family social workers, animateurs (involved in community development) and some advisers. They can provide family benefits and activities such as holidays, after-school care and casework (Madge and Attridge 1996). Minimum levels of provision are set nationally. There has been a considerable growth in not-for-profit organisations, who may be contracted to provide services. Social workers, according to Madge and Attridge (1996), rarely specialise in child care and spend much of their time providing financial aid.

Caisse nationale des allocations familiales (CAF) interacts with the CDES to determine the amount of support.

Care away from home

As stated above, France has a range of specialised institutions for disabled children:

- Homes offering medical care and educational or vocational training
- Institutes for muscular or sensory training and re-education
- State education facilities including special regional educational establishments at secondary school level (France 2002: para 328)

Decisions about placement are made through CDES (see above). Certain involvement of children (over the ages of 12) and their parents is required, if the children are living in social and medio-social institutions (France 1993: para 81).

Health services and assistive technology

Type of health care system	Social insurance
What % of GDP is spent on health care?[12]	9.7%
What % of expenditure on health is public expenditure?[13]	76%
What are the average out-of-pocket payments (per capita, US$)?[14]	268

	All children	**Disabled children**
Key health legislation	• 1927 Medical Charter establishes principles of la medicine libérale • 1945 reform of national health insurance • 1970 Hospital Act • Juppé Plan in 1996 • 2000 Universal Health Coverage Law (Loi de la Couverture Medicale universalle)	As for all children. In addition: Decree of 9 March 1956 as amended
Are all children covered by the system?	Yes	Yes
How is health care organised?	Centralised. • Central government sets policy, budget and regulations • Regional and department levels co-ordinate regionally planning of medical equipment and local services delivery • CNAMTS responsible for general	• medical-social examination and care centres (CAMSP) – children from birth to aged 6 • medical educational sector (CMPP) -- diagnosis and treatment for those with learning or psychomotor disability

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[12] 2002, Information from OECD in Figures (2003).
[13] 2002, Information from OECD in Figures (2003).
[14] 2002, Information from OECD in Figures (2003).

	development of sickness insurance - Regional funds co-ordinate capital development - Local funds register members, collect contributions and reimburse claims	
How is health care monitored?	Unknown	Unknown
Is health care free at the point of use?	No	No
What choice do parents and children have?	Choice of doctor Direct access to specialist	As for all children
To what extent are parents involved in their child's health care decisions?	Unknown	Unknown
To what extent are children involved in health care decisions about themselves?	Unknown	Unknown
How are specialist services accessed?	Directly by patient	As for all children. In addition, access through assessment to specialist centres.

Key legislation for assistive technology	Framework Law no 75-534 of 30 June 1975
How is assistive technology organised?	Unknown
How is it funded?	Unknown

Principles and organisation

France has a “complex, universal but limited compulsory insurance system” (Freeman 2000: 52). It has mixed public and private funding and provision (Imai et al. 2000: 9).

The system is fairly centralised. As part of the Juppé Plan, a constitutional amendment was made to give Parliament legislative authority over health spending. It became part of the annual law on the financing of social security. Key decisions thus lie with the Parliament and are implemented by the Government. (Imai et al. 2000: 33) Further, the central government has regulatory control over coverage. At a Regional and Départements levels are Bureaux of Health and Social Affairs, which co-ordinate regional planning of medical equipment and local service delivery.

Despite this centralisation, inequities remain across geographical areas. Imai and colleagues (2000: 12) report that numbers of hospital beds, medical staff, heavy equipment and budget funds differs across regions. Waits for treatment can be excessive in certain areas, both in hospitals and for ambulatory care (OECD Observer 2003: 3).

The general development of sickness insurance is the responsibility of the Caisse nationale d’assurance maladie des travailleurs salaries (CNAMTS), which is a fund that covers 80 per cent of the population. Regional funds then co-ordinate capital development while local funds register members, collect contributions and reimburse claims (Freeman 2000: 52).

Public hospitals provide a significant majority of beds[15], while the rest are provided by non-profit and for-profit private hospitals. In public hospitals, doctors are salaried civil servants. In ambulatory care, doctors are self-employed and can be either generalist or specialist (Freeman 2000: 52).

Free services are available for mothers and children under the age of six, and in school. These are preventative services, offering free medical checks (France 1993; ECSR 2003).

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[15] Freeman (2000) reports that two-thirds of beds are provided by public hospitals; Imai et al. (2000) states three-quarters.

Specialist care for disabled children is available through the medical-social examination and care centres (CAMSP) and medical educational sector (CMPP). CAMSP provide examinations and treatment for disabled children from birth to age six. CMPP provide diagnosis and treatment for those with learning or psychomotor disability (UNAPEI 2003 translation; EADSNE France 2003).

Funding and costs

The health insurance system has two tiers: a basic mandatory public tier and a supplementary insurance provided by private insurers and mutuelles (Imai et al. 2000: 9-10). Following the principles of social insurance schemes, contributions to the first tier are dependent on income and not on risk. Because of concerns that some people were still excluded, universal health coverage was introduced in 2000 legislation. If people have at least three months continuous residence in France and are entitled to minimum income or to medical aid, because of a lack of financial resources, they become part of the general health insurance scheme (ECSR 2003; OECD Observer 2003). Around eight per cent of the population are covered by these provisions (MISSOC 2002b: 4-5).

Although a social insurance system, in fact three-quarters of funding is provided through public sources. What is unusual is the extent of private insurance, which is 13 per cent of the total health spending and thus higher than in most OECD countries. Private insurance reimburses a significant amount of out-of-pocket payments, so that the share of health spending paid directly by patients is lower than in most OECD countries – 10 per cent of total health spending. (OECD 2003a: 3) The direct and co-payments of patients have grown since the 1990s (ECSR 2003) but that has been mediated by the supplementary insurance. Eight out of ten of the population are now covered by the insurance. Since this reimburses patients' payments, the government's attempt to moderate consumption by these payments is largely ineffective (Imai et al. 2000: 10).

Children are insured via their parents. Children are included up to the age of 16 but later if they are in education or are disabled (France 1993: para 362; MISSOC 2002a: 2-3).

Assistive technology

Article 53 of the Framework Law no 75-534 of 30 June 1975 states that “procedures and modalities for the allocation of orthoses, prostheses and appliances to people with disabilities will be progressively simplified” (quoted from Deloitte and Touche 2003: 26). The Act delegates responsibility to two organisations in every Départment. For adults, this is COTOREP and for children this is CDES. Children are covered by CDES until age of 20. A more recent law, the Law on Social Modernisation of 17 January 2002 (Loi 2002-73 dite de modernisation sociale), sets out a disabled person’s right to compensation: “… for the consequences of his or her disability ... and has the right to sufficient resources to cover the essential needs of daily living” (Article 53, quoted in Deloitte and Touche 2003; 26-27).

Social security contributions to technical aid costs are limited. Certain products are covered – such as wheelchairs, beds and lifts – although often only partial reimbursement is made. Other products are neither regulated nor are there legal obligations for reimbursement. (Deloitte and Touche 2003: 27). Individuals then must approach their insurance funds, where their situations are considered on a case-by-case basis, or apply to other organisations for financial aid (Deloitte and Touche 2003: 85-86). For those covered by social security contributions, a doctor must make a prescription (Deloitte and Touche 2003: 84).

The recently instituted Sites for Autonomous Living (Sites à la vie autonome), to be available in every Département, will facilitate access to assistive technology and provide a single entry point to identification of aids and financial support (Deloitte and Touche 2003: 28-29). A variety of other information sources is potentially available, such as the Centre d’Information et de Counseil sur les Aides Techniques.

Choice, consent and user involvement

Choice is one of the hallmarks of the French system. Patients can choose their own doctor. There is no need for a referral to a specialist: patients can consult with one directly. (Freeman 2000: 52)

Imai and colleagues (2000: 2 and 4) summarise the benefits of the French system. Health statistics show a healthy population, in comparison to other industrialised countries. Patients appreciate the reimbursement of health spending, they have considerable choice amongst care providers, and they do not generally have to wait long for treatment. Satisfaction levels are thus high.

Physical Environment

Housing stock[16]	54% owner-occupied; 20% private rented; 18% social rented; 7% other (largely work related)
Key housing legislation	Act of 31 May 1990 Law No. 2001-1247 of 21 December 2002
How is housing policy organised?	Central government organises housing allowances
Housing benefits for families with children	Yes
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[17]	0.9%
Accessibility regulation to buildings etc.	• Framework Law no 75-534 of 30 June 1975 • Law No. 91-663 of 13 July 1991 • Numerous decrees – e.g. Decree No. 95-260 of 8 March 1995, Decree no 99-756 and no 99-757 (31 August 1999)
Has accessibility to public places improved over the past 10 years?[18]	Yes, in public opinion. 7.8% think it has improved very much while 43.2% think it has improved somewhat
On a scale of (1) ‘not at all difficult’, (2) ‘not very difficult’, (3) ‘fairly difficult’, and (4) ‘very difficult’[19]**:**	
• **How accessible is public transport?**	3.56 (fairly to very difficult) for physically disabled people 3.34 (fairly to very difficult) for intellectually disabled people
• **How accessible are cultural events?**	3.22 (fairly to very difficult) for physically disabled people 3.43 (fairly to very difficult) for intellectually disabled people
• **How accessible are sports events?**	3.24 (fairly to very difficult) for physically disabled people 3.38 (fairly to very difficult) for intellectually disabled people
• **How accessible are restaurants, hotels etc.?**	3.23 (fairly to very difficult) for physically disabled people 3.32 (fairly to very difficult) for intellectually disabled people

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[16] Information from Ball 2004: 52.

[17] See Chapter 5.

[18] See Chapter 2.

[19] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	• Framework Law no 75-534 of 30 June 1975 • Internal Transport Orientation Act (30 January 1982) • Act no 91-663 (13 July 1991) and Decree no 94-84 (26 January 1994)	As for disabled children
Are there enforcement mechanisms?	Yes	Yes
Are fare concessions available for public transport?	Yes, although varies by mode of transport and/or area	Yes, although varies by mode of transport and/or area
Can an accompanying person go free, or for a reduced price, on public transport?	Yes, although varies by mode of transport and/or area	Yes, although varies by mode of transport and/or area
Is special transport available as an alternative to public transport?	For school transport	Unknown
Is there a parking badge scheme?	Yes	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Over half of France's housing stock is owner-occupied. Most private rented households are located in the inner city areas of large cities. Inner city areas generally are the most common location for rented housing. The French government has invested recently in regenerating social housing. One of the aims is to increase the social mix in renewal projects and to introduce stronger incentives to build social housing (Ball 2004: 52-55).

Ball (2004) reports a long history of state involvement in housing, both in rented and owner-occupied sectors. This has included subsidies, tax breaks, land use policies and financial market controls. There are several types of housing allowances:

- APL, which can be used to cover mortgage costs partly
- AFL, for households with children or young couples with no children
- ALS, the social housing allowance for those who are not entitled to the other allowances (Ball 2004: 55; France 1993: para 338-340)

Around one-quarter of households receive housing allowances (Ball 2004: 55). Overall, France spends more than the European Union average, as a percentage of GDP, on housing (0.9% compared to 0.4%). It has the second highest spending of any of the seven countries in this review (see Table 5.4 in Chapter 5).

There are local taxes, based on the relative value of the property. The number of children is taken into account in calculating the tax. Those receiving social assistance are exempted from the local tax (Bradshaw and Finch 2002: appendix, page 20).

Under legislation, disabled people have priority in social housing allocation (COLIAC 2004 translation). A range of grants is available for adapting homes for disabled people. These can differ by region: for example, there is a particular adaptations grant for people living in the North (Hacavie 2004 translation).

Accessibility to buildings and public spaces

The Framework Law no 75-534 of 30 June 1975 sets out the principle of accessible buildings “the architectural layout of residential buildings and facilities open to the general public … shall be designed as to be accessible to handicapped persons” (Section 49, quoted in ECSR 2003). The French government has published legislation, and associated specifications and government circulars, to make public spaces accessible for disabled people (Toegankelijkheidsbureau (Toe) and Living Research and Development 2001: 18). They thus provide national regulation with both performance requirements and dimensional specifications for accessibility.

Public authorities have the responsibility to ensure that the public buildings they finance conform to the legislation. Requests for building work must consider disability access and are sent to the Commission of Security and Accessibility (CCDSA). Special dispensation can be granted. (Handicap Government France 2003b) Receipt of a building permit and the opening of the building is dependent on the rules being respected. (ECSR 2003) However, these rules and regulations only apply to new buildings and the reconstruction of existing buildings. (Malaga 2003: 56).

Despite this legislation and regulations, respondents to the Eurobarometer survey (see Chapter 2) report considerable inaccessibility to specific events and activities, for both intellectually and physically disabled people. The results are consistently higher than the European average scores. About half of respondents think that access to public spaces has very much or somewhat improved over the past decade.

Transport

France has overarching legislation that requires public transport to be accessible:

- Framework Law no 75-534 of 30 June 1975 requires regulations to progressively to adapt, plan and manage all public transport services to make them accessible
- The Internal Transport Orientation Act (30 January 1982) allows for special measures to be taken for people with mobility handicaps. There is a right to transport and the right to information on services offered

- Act no 91-663 (13 July 1991) and Decree no 94-84 (26 January 1994) require existing and new transport terminuses (e.g. stations and stops) to be accessible

There are also specific regulatory texts for such areas as buses, taxis, and roads and guidelines for underground railways and buses and tramways (Committee of Deputies (CD) 2000a: 29). There are two means of enforcement. One, a licence to operate may be withheld if accessibility rules are not complied with. Two, a criminal case can be taken for non-compliance with the 1975 Framework law (see above) (CD 2000a: 29).

SNCF (inter city trains) offers a range of concessions for disabled people. For example, concessionary fares may be provided for those with 50 to 100 per cent degree of invalidity. Disabled people may have an invalidity card that indicates the requirement of an accompanying person: if so, that person can travel free of charge. People using wheelchairs are upgraded to first class. Air France offers accompanying persons to travel free with disabled children. Concessions on urban transport are determined by the local authorities (CD 2000c: 5).

Parking badges are available for private cars. Under the AES benefit, families can receive assistance for the extra costs of transport, including buying and/ or adapting a family car (LegiFrance 2004).

Leisure and recreation

There is no overarching legislation that recognises children's right to culture. The French Government's report (1997) to the UN Committee on the Rights of the Child lists a range of funding streams and activities, including sports and out-of-school opportunities in disadvantaged areas. The report describes the system of supervised group holidays for young people, available in France. A priority is to develop this provision to be more inclusive of disabled young people (1997: para 370). To encourage participation, many local authorities have reduced fees for recreational activities, which are set according to age (France 1993: para 343).

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GERMANY

The Federal Republic of Germany is a federal state, with 16 Länder (including three city states). Eleven of the Länder are in the former West Germany, with the other four are within the former East Germany. Länder are subdivided into 29 administrative regions (Regierungsbezirke), 439 districts (Kreiise) comprising 116 municipalities with the status of a district (kreisfreie Städte) and 323 rural districts (Landkreise), and 13,416 municipalities (Gemienden). The unification between East and West Germany in 1990 has placed financial strain on Germany as a whole, which is one cause of the rise in child poverty since that time (see below).

The Basic Law is the German Constitution. It sets out various individual rights (e.g. anti-discrimination, Article 3) and establishes various standards (e.g. living conditions should be of equal standard throughout the Länder, Article 72). But unless they are stated within the Basic Law, responsibilities lie with Länder rather than the federal government. Thus social welfare is the responsibility of the Federal government, whereas education is the responsibility of each Länder. Further, detailed policy responsibility and administration is often further devolved. This results in considerable diversity of legislation and provision throughout Germany – with the benefits of decentralisation and devolution of power but also the disadvantages of inequality and disparities in services. One means to address the problems of decentralisation and devolution is the Standing Conferences of Ministers, who can make recommendations with political backing. These have set national standards in education, for example.

Germany is an exemplar of the social insurance principle, where social security and health provision is paid for through contributions by employers, employees and the state. Social assistance is a residual and relatively ungenerous safety net provided by the state. The complexity of the social insurance system has led to increased federal regulation through the Social Code. This complexity is shown in Table G.1, of benefits under the Social Code (Book IX):

Table G.1: Rehabilitation agencies responsible for participation benefits, for disabled people

Type of benefit	Accident insurance	Social compen-sation	Health insurance	Statutory pension insurance	Youth services	Supplem-entary welfare
Medical rehabilitation	X	X	X	X	X	X
Social participation	X	X			X	X

Source: MISSOC 2003: 26

To address the potential gaps and overlaps in the responsibilities of various rehabilitation agencies, legislation now requires the agencies to group together so that there is a smooth transition from one agency to another (MISSOC 2003: 26). Germany actively encourages a ‘mixed economy’ of providers, including private and voluntary agencies. This is particularly true for disabled children:

- Non-governmental organisations predominate in the provision of social welfare services for disabled, disadvantaged and vulnerable populations. They have a unique legal status based on the subsidiarity principle, under (91) which the state has a duty to intervene in instances of individual social welfare but only after all the alternatives have been exhausted (Theyn and Johns 2003: 90-91).

In the reporting period, the conditions setting the framework for families of children with disabilities have become significantly worse. There is practically no chance to ensure that children with special needs attain the greatest amount of independence, self-determination, parity of treatment and integration possible while still enjoying a certain amount of care and supervision, since the specific legislative basis for this is lacking, as is the requisite planning and structures (2002: 21).

Equality/ anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No	No
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law on … ?	Article 3 of the Basic Law (German Constitution)	• Article 3 of the Basic Law (German Constitution) • Act on Equal Opportunities for Disabled Persons (Gleichstellungsgesetz für behinderte Menschen (BGG)) 2002 • Social Code (Sozialgesetzbuch (SGB)) Book IX
What type of domestic law is it? (criminal, constitution, civil rights, social welfare (Degener (2003))	Constitution	• Constitution • Civil Rights • Social welfare
Is there an enforcement mechanism?	Court	• Federal Government's Commissioner for Disabled People (Behinndertenbeauftragter der Bundesregierung) • Court
Are there (other) standing national bodies to provide policy advice?	Yes • Parliamentary Children's Commission • Federal Youth Panel • Working party for youth welfare	Yes Council for Participation of Disabled People

Germany is subject to Article 14, the anti-discrimination article, within the European Convention on Human Rights (ECHR) and has agreed to Article 13 of the EU Amsterdam Treaty. Like most countries, Germany has signed but not ratified the new Protocol 12 of the ECHR. This Protocol would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority.

Article 3 of the Basic Law (the German Constitution) sets out that “All humans are equal before the law” and prohibits discrimination:

- No one may be disadvantaged or favoured because of his sex, parentage, race, language, homeland and origin, his faith, or his religious or political opinions. No one may be disadvantaged because of his handicap (Article 3(3), Germany (2002) translation).

An amendment in 1994 added the specific mention of handicap to Article 3(3). Disabled children are covered by this, as well as disabled adults.

Age is not specified in the anti-discrimination clause. The German Government explains that children are covered by the general Basic Law principle that prohibits improper inequality of treatment (2001: para 122). There is an ongoing debate about the adoption of children’s rights into the Basic Law (2001: para 62-63). The UN Committee on the Rights of the Child has asked the German Government to reconsider incorporating the UN Convention on the Rights of the Child (UNCRC) into the Constitution (2004: para 9-10).

Anti-discrimination by age

Germany has ratified the UN Convention on the Rights of the Child (UNCRC) and has now reported twice to the Committee. The German Government reports a range of activities, at federal and Länder level, which incorporate the UNCRC into domestic law and practice. Ratification of the UNCRC made it part of German law, but it is only taken into account in the interpretation of domestic German law and ordinary statutes (Children’s Rights Information Network 2004). The UN Committee on the Rights of the Child criticises the German Government for the lack of knowledge about the UNCRC amongst the population in general:

- The Committee notes the various activities undertaken by the State party to disseminate the provisions and principles of the Convention but remains particularly concerned that, according to recent studies, most children and adults, notably those belonging to vulnerable groups, are not aware of the rights contained in the Convention (2004: para 19).

Most Länder and local communities are reported to have a child welfare officer or children's commissioner (Germany 2001: para 19, 46). The German Government in 2001 did not accept the need for a Children's Commissioner at the federal level:

- Germany's federal structure and the fact that the individual Länder are responsible for child and youth welfare alone reveal a federal child welfare officer to be an inadequate solution. The majority of decisions in the area of childhood policy are made at local level. A contact at federal level would arouse false expectations among children and those with an interest in policies affecting children; as such a federal officer would repeatedly have to refer inquiries to the lower-level government authorities, explaining that the matter did not fall within his or her remit (Germany 2001: para 41)

The UN Committee on the Rights of the Child, however, does not agree: The Committee is concerned that there is no central independent mechanism for a comprehensive monitoring of the Convention which is empowered to receive and address individual complaints of children at the Länder and federal levels (2004: para 15).

Anti-discrimination by disability

Germany has taken three approaches to anti-discrimination by disability: constitutional, civil rights and social welfare. As described above, Article 3(3) of the Basic Law prohibits disadvantageous treatment of disabled people. The Act on Equal Opportunities for Disabled Persons 2002 is civil rights legislation that includes general provisions on:

- the ban on discrimination for public authorities
- taking account of the special needs of disabled women/gender mainstreaming
- the definition of disability and barrier-free environments

- target agreements to establish barrier-free environments
- the obligation of the Federal Government to construct barrier-free buildings
- sign language and the disability-suited design of notices in administrative procedures
- barrier-free information technology
- the right of associations to take legal action (Federal Ministry of Health and Social Security (HSS) 2003: 2)

There is a further Act – the Act to Combat Unemployment among Severely Disabled Persons 2000 – that addresses discrimination in employment. The social welfare approach is taken through Book IX of the Social Code (SGB IX). This promotes the self-determination of disabled people (or those likely to become disabled) and their equal participation in society (CE 2003: 146-147).

Coverage

The Basic Law extends not only to public authorities but also applies to the private sector (Malaga 2003: 24). Article 3(3) is asymmetrical, in that it would not be discriminatory under this Article to treat disabled people *more* favourably than non-disabled people but it would be to treat disabled people *less* favourably. There are limits, though. Even if a differentiated measure is disadvantageous for persons with disabilities, it is prohibited only if there is no valid reason for the differentiation. Preferential treatment of a person with a disability is acceptable only if its purpose is to compensate for an existing disadvantage (Malaga 2003: 34).

Both the 2002 Act and the Social Code cover the public sector only and have the same definition of disability:

- 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)

A further judgement is made on a metric of disability. Someone must be judged to be at least 20 and a maximum of 100, in terms of the effect the disability has on participation in social life. For the Social Code, people are severely disabled if they have a degree of disability of at least 50%. People with a degree of disability of less than 50% but of at least 30% have an equal status as severely disabled people, if without equalisation they would be unable to obtain suitable work or leave employment as a result of their disability. (Boeltzig with Clasen 2002: 9). The Federal Ministry of HSS stresses that the six months does not apply to early interventions for children who are already disabled or in danger of becoming disabled (2003: 3). The Social Code has wide coverage, in that it covers not only people presently disabled but also those who risk becoming so.

Gooding and Casserley (2003) write that the 2002 Act's main purpose – and perhaps main strength -- is to establish accessibility targets and standards, which are set with the involvement of disability associations. Article 7 does prohibit discrimination, which occurs when:

- …a disadvantage existing where disabled and non-disabled persons are treated differently without cogent reason and thereby disabled persons are directly or indirectly impaired from participating in an equal manner in everyday life

Thus, both indirect and direct discrimination are covered by this Article – and both children and adults are covered by these provisions.

Enforcement and sanctions

Federal and state legislation, as well as individual administrative acts, must comply with the Basic Law. If they do not, individuals can make an appeal to the Federal Constitutional Court to have the legislation revised or checked or to appeal the authorities' decision on grounds that constitutional rights have been violated. Children have the right to appeal, as well as adults. It may be that parents exercise their children's rights, depending on the children's age and ability (CE 2003: 152). However, Degener and Quinn (2002) conclude that Article 3(3) has been made "a toothless tiger" (32) by the Federal Constitutional Court, because it determined that separate but equal provision was not disadvantageous discrimination. Gooding and Casserley (2003) are more positive, in light of a recent Court decision (see also CE 2000: 20). This rules that it would be against the Constitution to restrict service provision to both disabled and non-disabled people, when this has particularly detrimental effects on disabled people and there are no compensatory measures taken.

Individuals can also take cases to court under the 2002 Act and the Social Code. Individuals can be supported by associations, who can assert the individual person's rights in court. Further, associations that are recognised by the Federal Ministry can go to court directly to assert the equal rights of disabled people, without having an individual case. (CE 2003: 152) The accessibility target agreements under the 2002 Act can contain a contractual penalty agreement for delay or failure (Gooding and Casserley 2003: 35).There is a Federal Government Commissioner for Disabled People.

Advocacy and Information

Within the Parliament, there is a Children's Commission. It conducts hearings and discussions (Germany 2001: para 17). The Commission is seeking to expand its powers in Parliament (Germany 2001: para 176). There are child welfare officers or children's commissioners in most Länder and in many local communities (see above). There is a range of government bodies for children's policy:

- The Federal Youth Panel ('Bundesjugendkuratorium'), which advises the Federal Government on fundamental matters of child and youth welfare
- The commissions responsible for drawing up the child and youth reports
- The Working Party for Youth Welfare ('Arbeitsgemeinschaft für Jugendhilfe'), a discussion forum for the Federal Government, Länder governments, voluntary welfare organizations, youth associations and specialist organizations
- The Federal German Youth Ring ('Bundesjugendring'), in which a large number of child and youth associations are organized (Germany 2001: para 23)

In relation to disability, there is the Council of Participation of Disabled People that links to the Federal Ministry of HSS. The remit of the Council is set out in statute and provides advice, involvement in funding decisions and consideration of proposals for research and evaluation (CE 2003: 147).

Participation is promoted by a range of procedural and legal requirements. For example, regular reports must be made to the Supreme Länder authority, about the situation of disabled people in the Länder and about the effectiveness of participation benefits. Section 8, Book 8 of the Social Code (SGB VIII) states that children are to be involved in all decisions affecting them in the area of public youth welfare, according to children's level of development. Despite this Section, the UN Committee is concerned about its implementation:

- The Committee notes the progress achieved in the implementation of article 12 of the Convention with various legal provisions recognizing the right of the child to express his/her views, but remains concerned that the general principle as laid down in that article is not fully applied and duly integrated in practice into the implementation of the policies and programmes throughout the State party (2004: para 28).

Further, the NC believes the views of disabled children are particularly ignored (2002: 21). Book 9 of the Social Code (SGB IX) makes a similar provision for disabled people, requiring "the justified wishes of those concerned must be complied with and the individual personal circumstances respected" (CE 2003: 148).

Germany has a rich network of non-governmental organisations, for children, disabled children and their parents, and disabled people. These organisations can provide information, advocacy and support, along with statutory organisations. Rehabilitation agencies' local joint offices are intended to provide advice on entitlements and services (CE 2003; Federal Ministry of HSS 2003: 32) and there is an internet information service for families with disabled children (Germany 2001: 508b). Despite these activities, research with parents of disabled children[1] suggests unmet needs:

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[1] 400 families were accessed through physicians from hospital-based speciality clinics, at a large children's hospital in Northern Germany. These families had a child aged 0-18 years, who was living at home, had a chronic health condition, and had an inability to perform one or more daily living tasks due to impairment. Parents were sent postal questionnaires, with a 68% response rate.

Table G.2: Parents' unmet needs for information, counselling and support (%)

Education about illness	**Yes**	**Yes, partly**	**No, but not needed**	**No, but needed**
Has your child's condition, disability or developmental delay been sufficiently explained to you?	63.2	24.0	6.6	6.2
Does anyone counsel you about special appliances?	84.8	8.7	5.3	1.1
Social counselling				
Does anyone give you general advice about educational or behavioural problems?	30.2	15.1	32.2	22.5
Can you talk to someone who understands the special problems of raising a child with an illness or disability?	34.1	25.1	25.1	15.7
Did you receive information on parents groups or self-help organizations?	31.4	17.8	32.9	17.8
Did you receive information on social services (e.g. disability card, home nursing benefits)?	39.9	16.6	30.5	13.9
Did you receive information about family support programs (e.g. family helper, respite services)?	23.1	11.9	45.8	19.2

Source: Thyen et al. (2003), Table 1 – selection of questions

Of particular note is the 22.5 per cent of parents who report needing advice about educational or behavioural problems. Nearly one in five parents needed but had not received information on family support programmes or parents groups or self-help organisations.

Education[2]

	All children	**Disabled children**
Key education legislation	• Basic Law • Länder constitutions and legislation • Agreements and resolutions of Standing Conference of the Ministers of Education and Cultural Affairs (e.g. the Hamburger Abkommen agreement 1964, 1971)	As for all children. In addition: • Social Code (Sozialgesetzbuch (SGB)) Book IX • Social Assistance Act (Bundessozialhilfegesetz (BSHG)) • Expert opinion in order (rules) to the Special Education System from the Standing Conference
Does a child have the right to education?	Yes	Yes
How is education organised?	Federal system – devolved and decentralised. National agreements of the Standing Conference Länder are the government level to set educational policy and administration details (e.g. school structure, curricula). Local authorities responsible for construction and maintenance of schools. School head teachers have particular responsibilities; teachers' independence in teaching protected.	As for all children except special schools
How is education monitored?	National evaluation standards.	As for all children
Is there compulsory education?	Yes	Yes
What are the ages for compulsory education?	6-15 full-time (extended in some Länder), 16-18 part-time	Can be extended by Länder
Is there a national curriculum?	Curricula fundamentally decided by Länder Lower secondary principles	As for all children, with exceptions

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[2] This section relates to primary and lower secondary schooling, which extends from the ages of 6 to 16 years.

	set by Standing Conference	
Is compulsory schooling free at the point of use?	Yes except if private schools	Yes except if private schools
Are incidental costs of schooling free at the point of use?	Yes books and materials No school meals	As for all children. Additional funding can be provided through Social Code/ Social Assistance Act
Does the state provide free school transport?	Yes only if local school	Yes
Can parents exercise school choice?	Yes	Yes
To what extent are parents involved in school decisions about their individual child?	Yes	Yes
To what extent are children involved in school decisions about them?	Yes	Yes

In regards to special educational needs …

Is there an official policy for school inclusion?	Yes
What type of education system is there (one-track, multi-track, two-track)?[3]	Moving from a two-track to a multi-track approach
What percentage of children is in special schools or special classes?[4]	4.6%
What percentage of children have ‘special educational needs’?[5]	5.3%
Are there special schools?	Yes
How is eligibility for special support determined?	
▪ **Categorical/ noncategorical**	
▪ **Who can initiate**	Parent or school
▪ **Assessment**	Yes
Do children have the right to support for special educational needs?	Yes
Is there compulsory teacher training on special educational needs	Yes

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[3] Information from EADSNE 2003.

[4] 2000/2001, Information from Table 4.1 EADSNE 2003.

[5] 2000/2001, Information from Table 4.1 EADSNE 2003.

Principles and Structure

The Basic Law establishes a few principles for education, such as the freedom of faith and creed (Article 4), equality before the law (Article 3), and the rights of parents (Article 6(2)). It establishes that the school system is under the supervision of the state (Article 7(1). Administration of the school system, though, is predominantly that of the Länder. Detailed regulations are thus set out on school education within Länder constitutions and legislation. To co-ordinate education and training throughout Germany, the Standing Conference of the Ministers of Education and Cultural Affairs was established in 1948. It produces agreements and resolutions, which are backed by political commitment and subsequently enacted by the Länder. (Eurydice Germany 2002) The Standing Conference has, for example, set out the principles for lower secondary schools:

- Furthering the overall intellectual, emotional and physical development of pupils, teaching them to be independent, make decisions and bear their share of personal, social and political responsibility
- Providing instruction based on the latest state of academic knowledge that takes the pupils' age-related conceptual faculties into account in its organisation and in the demands made on them
- Gradually increasing the degree of specialisation in line with each pupil's abilities and inclinations
- Maintaining an open system of free interchange that affords opportunities to switch to a different course of education after an orientation stage (Eurydice Germany 2002: para 5.3.1.6)

The Federal Government has authority over the pay and pensions of teachers, as they are civil servants (Eurydice Germany 2002: para 2.2). Each Länd has its own ministry, commonly the Ministry of Education and Cultural Affairs. These Ministries are responsible for schools, as well as other matters (Eurydice Germany 2002: para 2.5.2.1). They organise the school structure, determine the content of courses and teaching objectives, and supervise teachers' work in public-sector schools. Local authorities (Kommunen, i.e. district and municipalities that are not part of a district) are responsible for the construction and maintenance of public service areas, such as nursery schools (Kindergärten) and school buildings (Eurydice Germany 2002: para 1.2.8, para 2.11.1). Primary schools usually are answerable to the local authorities' schools offices (Eurydice Germany 2002: para 2.5.4.2). Schools' headteachers have particular responsibilities (Eurydice Germany 2002: para 2.5.5.2) while teachers' independence in the classroom is protected (Eurydice Germany 2002: para 2.8.1, 2.13.2). Devolved funding to schools is being developed (Eurydice Germany 2002: para 2.14.2). This decentralisation is of some concern to the UN Committee on the Rights of the Child (2004: para 52), as it leads to geographical disparities.

The primary school level (Grundschule) provides comprehensive schooling for grades 1-4 (and up to grade 6 in Berlin and Brandenburg). After this level, lower secondary schools (generally up to the age of 15) are highly differentiated by educational paths. The common divisions are between: Hauptschule (basic general education); Realschule (more extensive general education); Gymnasium (intensified general education) and Geasmatscule (comprehensive schools). There are also several other types, specific to different Länder. Upper secondary schools are then further differentiated by educational and/ or vocational paths. (Eurydice Germany 2002: para 2.4.3) Indeed, Länder (and thus local authorities) have a responsibility to maintain "a sufficiently varied range of schools in all regions" (Eurydice Germany 2002: para 2.11.1).

Compulsory education is from the ages of six to 15 (16 in some Länder) full-time, and then a further three years part- or full-time. All children, disabled or not, are subject to compulsory schooling. Compulsory schooling can be extended for children with certain types of disability (Federal Ministry of HSS 2003: 18).

Compulsory schooling is free (except if children attend private schools). Teaching aids are provided either free of charge or subsidised. Parents are generally expected to pay for expendable materials but not in all Länder. Generally, children who live a certain distance from school are provided with school transport or have public transport costs reimbursed. Children with special educational needs are typically provided with help with transport (Eurydice Germany 2002: para 2.15.2). Generally, neither school meals nor meal subsidies are provided. (Bradshaw and Finch 2002: appendix, 25). In terms of public expenditure on education (as a percentage of GDP), Germany spends less than the European average (4.5% compared to 5.3%) (see Table in Chapter 5).

Each Länd sets its own primary school curriculum, which is binding on teachers (Eurydice Germany 2002: para 2.5.4.2, 4.7). In turn, teacher councils (see below) determine further details, such as choosing textbooks from a set list (Eurydice Germany 2002: para 2.8.1). The Standing Conference established a framework schedule for the first years of lower secondary schooling (Eurydice Germany 2002: para 5.3.17) but otherwise responsibility follows the pattern of the primary school curricula. Special schools are expected to work to the set curricula, except for special schools for children with learning difficulties or with mental handicaps. These schools have their own curricula from the relevant Länd (Eurydice Germany 2002: para 10.9, EADSNE Germany: 15). There has been pressure for further exceptions to be made for other disabled children (EADSNE Germany: 15).

There is a mixture of private and public schools. Generally, public sector schools are jointly maintained by the Land and a local authority. Teaching staff costs are typically covered by the Land and other staff and material costs are paid for by the local authority (Eurydice Germany 2002: para 2.5.4.2). The Basic Law sets out the right to establish private schools (Article 7(4)). While common in the pre-school sector (see below), private are rarely permitted at primary school level (2.4% of schools in 2001); however, one reason for permission is for schools for children with special educational needs. At lower secondary level, there are two types of private school – alternative schools (Ersatzschulen) and complementary schools (Ergänzungsschulen). Such private schools are under state supervision. They must not be inferior to public-sector schools in their educational aims, facilities and teaching staff training. They may charge fees but they must ensure not encourage segregation by parents' means: they thus typically charge moderate fees or grant relief for poorer families (Eurydice Germany 2002: para 2.6, para 4.3). Länder provide financial support to private schools (Eurydice Germany 2002: para 2.15.2).

Under the Basic Law, parents have the right to care and bring up their child (Article 6(2)) while the state is responsible for the schooling of children (Article 7(1)). Beyond school councils (see below) and other collective means of parental involvement, parents have a say in school choice at secondary level. If a parent disagrees with the feeder school's recommendation, the school authority will decide.

Public-sector schools have teacher councils, school councils and pupil councils. Teacher councils are composed of teachers (and sometimes parents and pupils), who decide on instruction and education in each school. School councils involve teachers, parents and pupils. They typically are involved in the organisation of school life and teaching, pupils' protection, and organisation of events outwith school. Länder education legislation recognise the right of pupils to participate and have a representative body. Each school provides a spokesperson for the town or district pupil councils, who in turn put forward representatives to the Länder pupil councils. Further, Länder legislation requires general pupil assemblies for discussion (Eurydice Germany 2002: para 2.8).

Over recent years, there has been considerable attention to inspection and evaluation across Länder. Thus, the Standing Conference has sought to establish nationally binding educational standards (Eurydice Germany 2002: para 2.5.2). Responsibilities for monitoring and evaluation follow the administrative responsibilities (see above). An independent scientific institution monitors the national standards (Eurydice Germany 2002: para 9.2).

Initial teacher training contains training on special education. There is also a specialism of special education teaching (Eurydice Germany 2002: para 8.1.1.6).

Schooling for Disabled Children

At the age of six, some children's development is considered insufficient to attend school. These children can then attend Schulkindergärten or Vorklassen. These alternatives are available to all children in such a position, including disabled children. They are either assigned to the pre-school or the primary sector, according to each Land (Eurydice Germany 2002: para 2.4.1).

The Standing Conference set out ten different types of special schools (Sonderschulen):

1. Schools for children who are blind
2. Schools for children who are deaf
3. Schools for children who are visually impaired
4. Schools for children who are hearing impaired
5. Schools for children who are mentally handicapped
6. Schools for children who are physically disabled
7. Schools for children who are sick
8. Schools for children with learning difficulties
9. Schools for children with speech defects
10. Schools for children with behavioural problems (wording changed 1-7, Eurydice Germany 2002: para 10.3)

There are also schools outwith this classification (EADSNE Germany 13). The private sector is a key provider of special schools (Eurydice Germany 2002: para 10.15). Notably, a greater proportion of children of foreign origin attend special schools than their German counterparts (6.2% of foreign children, in comparison to 3.8% of German children) (Germany 2001: para 525).

EADSNE (2003) describes Germany as moving from a two-track to a multi-track approach. Education works to the principle "as much special assistance as necessary, as much shared learning with non-disabled persons as possible" (Federal Ministry of HSS 2003: 17). Over time, there has been a shift from focusing on the need for education at a special school, to the concept of special educational needs (Sonderpädagogischer Förderbedarf (SF)):

- Special needs education relating to development is to presume for children and adults who are disabled or who have limited possibilities for education, development and learning. Therapy and social aids from additional external school services could be necessarily included (EADSNE Germany 11)

All Länder have agreed this joint definition (EADSNE Germany: 11). Those with SF are then categorised into impairment-based categories, that match the 10 types of special schools (EADSNE Germany: 11).

Greater cooperation has been encouraged between special and mainstream schools, to enable individual children to move between them (Eurydice Germany 2002: para 10.3). Special schools are legally obliged to examine, at the end of every school year, whether a pupil's attendance at the school is still required in future. They should cooperate with other schools to work towards the participation of their pupils in classes with non-disabled children, as far as possible, or to seek other forms of co-operation. (Federal Ministry of HSS 2003: 17) This is one of the five types of SF assistance listed by the German Government, which are:

1. Preventive measures
2. Joint teaching with non-disabled pupils (integrative teaching)
3. Special schools
4. Co-operation between special and mainstream schools
5. Special educational support centres (2001: para 522)

The EADSNE overview also tells of special education within special units (13). Despite these measures, the UN Committee expresses concern about the "lack of adequate services for the education of children with learning difficulties" (2004: para 52).

The push towards inclusion has only been partial. The German [Federal Constitutional] Court reasoned that educational segregation of disabled children is not discriminatory because it is separate but equal. (Degener and Quinn 2002: 32) However, this applies in a specific case and generally segregation of disabled children in special schools would be a violation of Article 3(3) of the Basic Law (CE 2000: 33). The NC reports children and young people's views: "Instead of separating children with disabilities, more schools should be built in a way suitable for people with disabilities, making the shared 'experience' of life together made possible" (2002: 6).

Parents can initially choose at the start of compulsory schooling whether to enrol their child in the primary or special school. If the child “cannot be sufficiently helped in lessons at a mainstream school without special educational assistance” (Eurydice Germany 2002: para 10.5), the child is recognised as having SF. Assessment can also be initiated later on in a child’s schooling, either by the parent or the school (EADSNE GERMANY 8) The decision is made in consultation with the parents and, if possible, with their agreement. If parents do not agree, they can go to arbitration or the courts. (Eurydice Germany 2002: para 10.5) However, this is described as limited:

- In German Länder the parents only have a limited right to choose the place of education for their child - in integrated or in segregated settings (depending on the budget). A free choice is forced by parents [sic] associations and teachers [sic] unions (EADSNE Germany)

School authorities make this decision in co-operation with other agencies, such as school psychological services, public health and youth welfare offices (Eurydice Germany 2002: para 10.5). According to the 1994 Standing Conference recommendation, eight key elements should be considered for identification and diagnosis: motor, perception, cognition, motivation, communication, interaction, emotion and creativity (EADSNE Germany 9). As far as the schools do not provide the disability-specific assistance that is required by a disabled child to attend school, the social assistance funds intervene irrespective of the level of income and assets of the parents (section 40(1), no. 4, section 43(2) of the Federal Social Assistance Act) (Federal Ministry of HSS 2003: 18, see also Germany 2001: para 510) and assistance through the Law of Children and Adults Welfare (EADSNE Germany 6).

Social Security

Proportion of children aged 0-15 in relative poverty[6]	24%
Proportion of children aged 0-15 in absolute poverty[7]	12.5%
Key social security legislation	• Income Tax Act • Federal Child Benefit Act • Parental Leave Reform Act • Social Code (Sozialgesetzbuch (SGB)) Books VIII and IX, Federal Social Assistance Act
Value of child benefit package, as % of average earnings[8]	8.3%
Ranking (leaders, second rank, third rank, laggards)[9]	Second rank
What % of GDP is spent on family cash benefits and family services?[10]	1.9%
Tax benefits for families with children	Yes • Children's tax allowance (Kinderfeibetrag) – not varied by number and age of children but by family type • Lone parent allowance (Haushaltsfrebetrag) • Children's tax credit (Kindergeld) – varies by number of children but not age nor family type.
Income related child benefits[11]	Yes Kindergeld - varies by number of children but not age or characteristics of children; not taxed.
Non-income related child benefits[12]	No
Social assistance for families with children	Yes Social assistance (Sozialhilfe) – means tested; addition for children.
Parental leave	Yes 3 years per parent per child; flexible; up to the age of 8; child care benefits during first 2 years, income related; job guaranteed.
Statutory leave for care of sick children	Yes 10 days per year per parent per child up to maximum payment; not flexible; up to age 12; 70% gross earnings and 90% net maximum; job

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[6] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

* Information from Bradshaw and Finch (2002), as of July 1 2001.

[7] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] Information from Bradshaw and Finch (2002), as of July 1 2001.

[10] See Chapter 5.

[11] Information from Bradshaw and Finch (2002), as of July 1 2001.

[12] Information from Bradshaw and Finch (2002), as of July 1 2001.

	guaranteed. Lone parents up to 20 days up to maximum payment.
Type of benefits for disabled children	
• **supplement or extend child benefit**	Yes no age limit if child disabled
• **benefits for caring costs**	Yes
• **benefits based on child being disabled**	Yes eligibility a) Statutory long term care insurance: payments for home care; in kind benefits for basic care and housework; 3 levels of payment b) Social assistance: if not eligible for care insurance; cash benefits for home care; benefits up to the amount of need for basic care and housework. 3 levels of payment Aids and appliances.

The German Government identifies child poverty as one of its key tasks in its report to the UN Committee (2001: para 596). Nearly one in four children in Germany is in relatively poverty and over one in ten children are considered in absolute poverty, according to 1997 data. The NC comments starkly:

- Having children in Germany is inseparable from an increased risk of poverty or downward social mobility. Even families capable of combining employment and childcare are not always able to master a life above the poverty line (2002: 23)

The UN Committee on the Rights of the Child agreed with this assessment, stating:

- It welcomes the first national report on poverty (2001) and notes the increase in child allowances over the past years as well as the income tax reform which provides for measures to help families with children, but remains concerned at the prevalence of poverty, mainly affecting large families, single-parent families, families of foreign origin and disproportionally [sic] families from the eastern part of the State party (2004: para 50).

Of the seven countries in this review, Germany was the third-lowest spender on family benefits (cash or in kind): 1.9% of GDP (see Chapter 5), which compares to a European Union average of 2.2%.

Germany’s social security system relies considerably on the social insurance principle, with contributions from employers, employees and the state. Referencing Mangen (1991), Kleinmann notes a sharp division between benefit types: “While the core, insurance-based social benefits are relatively generous, social assistance is both harshly means-tested and carries considerable stigma” (2002: 37). Kleinmann further notes that this distinction has become increasingly important since the fall in employment during the 1980s, so that a growing minority of adults (and, through them, their children) do not have the contribution records to be eligible for the more generous social insurance system.

Central government has policy responsibility for social assistance and the Länder are responsible for implementation. The Länder can set benefit rates within a band fixed by federal law. They can delegate administration down to district and municipal authorities, who have some discretionary powers (Hölsch and Kraus 2004: 147, and Diagram Germany). Municipal and rural districts act as local social assistance authorities. Some benefits are administered through regional social assistance offices such as regional welfare organisations, regional social services offices and agricultural associations (Federal Ministry of HSS b: 4).

Financial support for all children

The child benefit package is considered moderately generous by Bradshaw and Finch (2002), placing Germany in the second rank of countries. The package represents 8.3% of average earnings in Germany. Germany follows the general trend, identified by Bradshaw and Finch, of increasing use of the tax system to support families with children. It has a number of tax allowances and tax credits; it also has income-related benefits but has no non-income related child benefit.

The income-related benefit (Kindergeld) combines with the means-tested social assistance (Sozialhilfe) to be the sole contributions to the child benefit package, for the social assistance family case in Bradshaw and Finch's calculations. Notably, the social assistance family gains considerably less from the child benefit package (£105) than the average family case (£189). Clearly, the child benefit package does redistribute money from childless couples towards families but is not as redistributive between average families towards families on social assistance. The payment is not consistent across Germany and in West Germany there are additions for children and these amounts differ by age. Social assistance is dependent on availability for work, with exceptions for lone parents and for couples with young children (Bradshaw and Finch 2002 Appendix: 25).

Both statutory parental leave and leave for sick children are for younger children (aged 8 and 12 respectively). It is paid, with payment income-related, and the parent's job is guaranteed. Despite these provisions, the NC reports the views of children and young people: "Working parents need to be granted special benefits to allow them to take care of their ill child personally without the fear of losing their job" (2002: 6).

Diagram Germany: Administrative Arrangements for Social Security in Germany

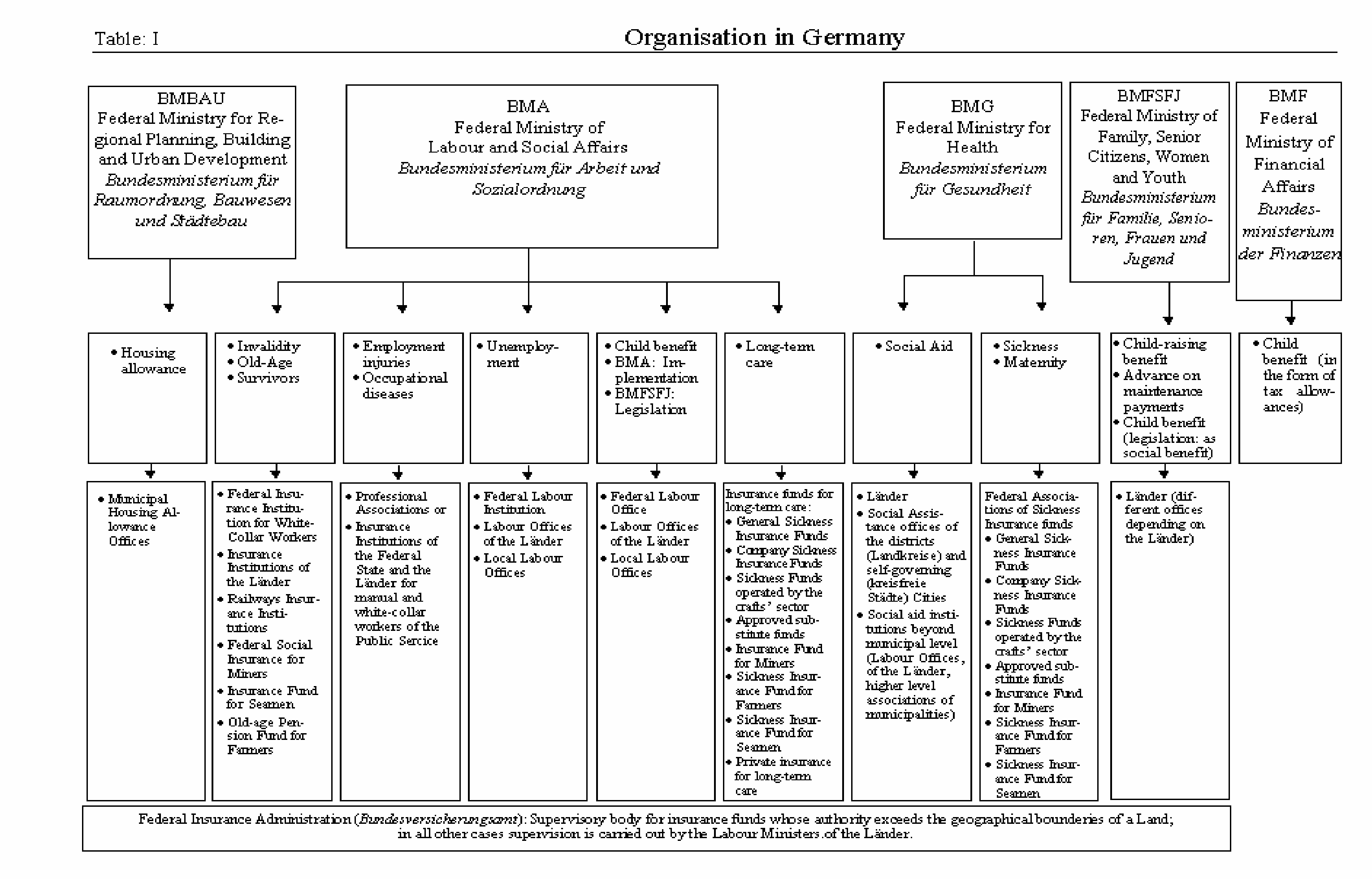

Table: I

Organisation in Germany

BMBAU Federal Ministry for Regional Planning, Building and Urban Development *Bundesministerium für Raumordnung, Bauwesen und Städtebau*	BMA Federal Ministry of Labour and Social Affairs *Bundesministerium für Arbeit und Sozialordnung*					BMG Federal Ministry for Health *Bundesministerium für Gesundheit*		BMFSFJ Federal Ministry of Family, Senior Citizens, Women and Youth *Bundesministerium für Familie, Senioren, Frauen und Jugend*	BMF Federal Ministry of Financial Affairs *Bundesministerium der Finanzen*
• Housing allowance	• Invalidity • Old-Age • Survivors	• Employment injuries • Occupational diseases	• Unemployment	• Child benefit • BMA: Implementation • BMFSFJ: Legislation	• Long-term care	• Social Aid	• Sickness • Maternity	• Child-raising benefit • Advance on maintenance payments • Child benefit (legislation: as social benefit)	• Child benefit (in the form of tax allowances)
• Municipal Housing Allowance Offices	• Federal Insurance Institution for White-Collar Workers • Insurance Institutions of the Länder • Railways Insurance Institutions • Federal Social Insurance for Miners • Insurance Fund for Seamen • Old-age Pension Fund for Farmers	• Professional Associations or • Insurance Institutions of the Federal State and the Länder for manual and white-collar workers of the Public Sercice	• Federal Labour Institution • Labour Offices of the Länder • Local Labour Offices	• Federal Labour Office • Labour Offices of the Länder • Local Labour Offices	Insurance funds for long-term care: • General Sickness Insurance Funds • Company Sickness Insurance Funds • Sickness Funds operated by the crafts' sector • Approved substitute funds • Insurance Fund for Miners • Sickness Insurance Fund for Farmers • Sickness Insurance Fund for Seamen • Private insurance for long-term care	• Länder • Social Assistance offices of the districts (Landkreise) and self-governing (kreisfreie Städte) Cities • Social aid institutions beyond municipal level (Labour Offices, of the Länder, higher level associations of municipalities)	Federal Associations of Sickness Insurance funds • General Sickness Insurance Funds • Company Sickness Insurance Funds • Sickness Funds operated by the crafts' sector • Approved substitute funds • Insurance Fund for Miners • Sickness Insurance Fund for Farmers • Sickness Insurance Fund for Seamen	• Länder (different offices depending on the Länder)	

Federal Insurance Administration (*Bundesversicherungsamt*): Supervisory body for insurance funds whose authority exceeds the geographical bounderies of a Land; in all other cases supervision is carried out by the Labour Ministers of the Länder.

Source: MISSOC (undated) Comparative Tables http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

Financial support for disabled children

Germany takes all three approaches to financially supporting disabled children and their families:

- Child benefit is extended indefinitely if a child is disabled, so that no age limit applies as long as certain conditions are met (Federal Ministry of HSS a: 2)
- Benefits are provided towards the costs of caring.
- Benefits are provided towards the costs of disability

Two kinds of help are available to families with a disabled child, dependent on whether one of the adults is available for the more generous social insurance. If so, statutory long term care insurance provides payments for home care and in kind benefits for basic care and housework. If the adult is not eligible for the care insurance, more limited assistance is available through social assistance, which is generally means-tested. The disability definition to determine eligibility is that of the Social Assistance Act (see below).

Research with parents of disabled children (Thyen et al. 2003) shows that financial strain increases with the disabled child's age. Families with employed mothers report the highest financial strain but those mothers who quit their jobs report the highest financial impact.

Support and Care services

	All Children	**Disabled Children**
Key childcare legislation	Social Code (Sozialgesetzbuch (SGB)) Book VIII	As for all children. In addition: Social Code (Sozialgesetzbuch (SGB)) Book IX
Does a child (or carer) have the right to childcare?	Limited guarantee from the ages of 3-6 years	If eligible for community participation benefits under SGB IX
Is there formal out-of-school care provided by the State or with State support?	Yes	Yes
How is childcare organised?	• Federal and Länder legislation • Delivery implemented at local level • Encouragement of mixed economy Providers independent (60%) and public (40%) agencies	As for all children, although higher levels of independent agencies involved
Are there eligibility criteria for childcare?	No	Yes to be eligible for community participation benefits
Is childcare free at the point of use?	No	No
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes	Yes
Key support legislation	• Social Code (Sozialgesetzbuch (SGB)) Book IX • Social Code (Sozialgesetzbuch (SGB)) Book XI • Social Assistance Act	• Social Code (Sozialgesetzbuch (SGB)) Book IX • Social Assistance Act (Bundessozialhilfegesetz (BSHG))

	(Bundessozialhilfegesetz (BSHG))	
Does the disabled person have the right to support services?	Yes	Yes
How are support services organised?	As for social security – depending if through social assistance or social insurance	As for social security – depending if through social assistance or social insurance
What are the eligibility criteria?	Disability definitions	Disability definitions
How are such criteria assessed?	Social services or fund. Typically involves a medical assessment.	Social services or fund. Typically involves a medical assessment.
What involvement do parents/ carers have in decisions about support services?	Required by law to be involved in decisions. May receive benefits in cash rather than in kind.	Unkown
What involvement do disabled people have in decisions about support services?	Required by law to be involved in decisions.	Required by law to be involved in decisions. May receive benefits in cash rather than in kind.
Is support provided in cash or in kind?	Both	Both
Does supply meet demand?	Unknown	Unknown

What support is available for carers?	Support is available
What support is available for siblings of disabled children?	Support can be available but it is ad-hoc
Are short-term breaks available?	Yes
Does the State regulate non-family placements (i.e. residential or foster)?	Yes

Childcare and out-of-school care

Day care for children is regulated under Book 8 of the Social Code (SGB VIII) at federal level. The Länder have their own implementation legislation, with services delivered at local level. Germany has a limited child care system, which is at least partially due to public attitudes: “A strong streak in public opinion considers it wrong for infants and toddlers to be reared outside the home – unless their families are ‘inadequate’ (ClearingHouse Germany 2004).

There is no guaranteed childcare for children below the age of three but every child between the ages of three and six years is entitled to a kindergarten place for four hours per day (Bradshaw and Finch 2002, Appendix: 24). While an improvement, the NC notes that this does not cover families’ need for relief and support (2002: 18) Certain Länder have more extensive guarantees (Eltern im Netz 2004 translation). In most Länder, the responsibility lies with the social ministries(Eurydice Germany 2002: para 2.5.4.1).

There are four types of out-of-home childcare available, differentiated by age group:

- Nurseries (Krippen): up to the age of three years
- Kindergärten: three years until start of school (six years)
- After-school-care (Horte): school children
- Combination facilities (Kombi-Einrichtungen): for children of different ages (Kinderbetreuung Destatis 2004 translation: 9)

A minority (40%) of facilities are run by public agencies, such as local and municipal authorities. Otherwise, facilities are run by independent organisations, with church, church-related and voluntary organisations the most common. Only 0.6% of facilities are run by companies for their employees.

With the guarantee for kindergarten, 90% of children have a place (Clearinghouse Germany 2004). Two-thirds of women organise day care themselves due to lack of public provision (Eltern im Netz 2004 translation). In West Germany, after-school care does not meet demand: only 5% of school children have a place

(Kinderbetreuung Destatis 2004 translation: 5). In East Germany, 41% have an after-school place (Kinderbetreuung Destatis 2004 translation: 6) and this is reported to meet demand (Eltern im Netz 2004). Primary schools are increasingly providing fixed opening hours with supervised provision (Eurydice Germany 2002: para 4.12).

Day care costs are typically divided between government, the providers and the parents. For non-profit childcare provision, 90% of the total costs are subsidised by local and federal governments (Bradshaw and Finch 2002 Appendix: 24). The level of parental contribution varies widely (Germany 2001: para 626). Section 90 of SGB VIII allows for child care fees to be waived or paid for by public youth welfare agencies, for families with too large a financial burden (Kinderbetreuung Destatis 2004 translation: 48).

Section 19, paragraph 3 of SGB IX promotes integrated rather than segregated services for disabled children. Community participation benefits under the Social Code include pre-school provision (see below). Just over one in five day care facilities take both disabled and non-disabled children, while 0.6% are facilities only for disabled children Kinderbetreuung Destatis 2004 translation: 13). The NC, however, perceives a “pressing need” for more integrated provision (2002: 21) and criticises:

- Although children with disabilities can receive all-day care in kindergartens and schools, this is only the case where facilities have been specifically provided for children with special needs. The parents themselves then have to shoulder the funding for any treatment and care needed. If the services of an ambulant child nurse are needed, the parents have to pay for this from their public assistance benefits for the payment of nursing care. (NC 2002: 21)

Support at home

The Social Code promotes the inclusion of disabled people in their communities (paragraph 10 of Book 1 of the Social Code (SGB I), Boeltzig with Clasen 2002: 6). Book 9 of the Social Code (SGB IX) outlines community participation benefits:

- Provision of aids or resources that cannot be counted as medical or vocational rehabilitation

- Special education provision for children who have not yet started school
- Help with the acquisition of practical knowledge and skills that disabled people need to enable them to participate in community life to the extent achievable by them
- Help to encourage disabled people to communicate with the world around them
- Assistance with the acquisition, equipment and maintenance of accommodation meeting the particular needs of disabled people
- Assistance with independent living in sheltered accommodation
- Assistance with participation in community and cultural life. (MISSOC 2003: 32)

Integrational assistance is provided through other legislation, the Social Assistance Act (Bundessozialhilfegesetz (BSHG)). Under this Act, there are three types of disability definitions that determine eligibility: considerably physically disabled; considerably mentally disabled; and considerably psychologically disabled. These three types are in turn defined by people's impairments reducing their abilities to participate in society. There are two types of social assistance: assistance with the cost of daily living and assistance in special life situations. There are four kinds of assistance for disabled people, who require assistance in special life situations: provisions for participation (rehabilitation), integrational assistance, assistance to blind people, and assistance with care. Of particular note for this project are provisions for: pedagogical assistance such as day or residential care for disabled children; assistance with social integration, such as purchase of books, newspapers and TV, attendance of public venues, telephone etc; personal assistance ('permanent accompaniment'). Social assistance is generally means-tested but not for those eligible for integrational assistance (Boeltzig with Clasen 2002: 29-33). Boeltzig with Clasen (2002) note both overlap and differences between legislative provisions:

- The terms 'integrational assistance' and rehabilitation (or 'provisions for participation') seem to be used interchangeably within the area of social assistance. However, although provisions do overlap across both types of support, not all provisions/ types of assistance provided within integrational assistance are also listed in Book IX

An applicant needs to provide proof of disability. People can be assisted to complete forms by social workers, counselling or advice services for disabled people. Additional medical information may be sought from the claimant's medical practitioner or a contracted medical practitioner may be used. Medical assessments combine information on a person's deficits and incapacities, as well as a diagnosis. An administrator assessor at social services makes the final decision for integration assistance (Boeltzig with Clasen 2002: 35-36).

In practice, families can receive support and relief services. They have a degree of control, with service users being able to choose whether they want their benefits in kind or in cash (CE 2003: 148). Family support and relief services aim to be flexible and helpful to families' individual needs and provide: help with care in or out of the home; advice; assistance regarding child-care, school, accommodation; support and training for parents; individual care for severely disabled people; transport services; and general advice and assistance (Familienhandbuch). Büchner (1997 translation) notes that the costs are only covered for a limited amount of hours for such services. Individualised, comprehensive care can be available for severely disabled people (ISB). Parents apply to providers for an ISB but there are always a limited number of placements. Some other means of gaining personal assistance are available. (Büchner 1997 translation)

A mix of public and independent agencies, health and social welfare agencies, provide the benefits or assistance (Eltern im Netz 2004 translation). The system is explained by the Federal Ministry of HSS:

- There is not one single independent social benefit fund which holds responsibility for participation-oriented benefits as a whole or even individual benefit categories. Because of their comprehensive range of responsibilities, the funds responsible for public youth welfare and social assistance step in as subsidiary funds in case of all benefits aimed at participation where the required benefits cannot be obtained from funds responsible in the first place because the respective eligibility requirements are not met in individual cases (2003: 6)

The Social Code now requires rehabilitation funds to cooperate and co-ordinate (Book IX).

Short-term breaks are available for families, under Book XI of the Social Code or the BSHG. These can provide care for the disabled person when the main carer is temporarily unavailable or needs a break in caring. It can be available in part-time residential facilities and can involve holidays for the disabled child (Büchner 1997; Familienratgeber translation) .

As noted above, support for parents in their own right is built into the family support and relieving services (e.g. counselling, short-term breaks, training). There are support groups for siblings of disabled children but these are not available throughout Germany.

Care and support away from the family home

Both foster and residential care are planned for and regulated by the Länder A certain amount of the cost is paid for by families if their child is in residential care (Familienraatgeber translation). A range of residential homes are available for children with severe multiple disabilities:

- short-term care homes
- five day boarding special schools
- fully residential homes for severely disabled children and young people
- treatments at health resorts and holiday residences (Eltern im Netz translation)

Health services and assistive technology

Type of health care system	Social insurance
What % of GDP is spent on health care?[13]	10.9%
What % of expenditure on health is public expenditure?[14]	78.5%
What are the average out-of-pocket payments (per capita, US$)?[115]	292

	All children	**Disabled children**
Key health legislation	• Social Code (Sozialgesetzbuch (SGB)) Book V - general health care • Social Assistance Act (Bundessozialhilfegesetz (BSHG))	As for all children. In addition: • Social Code (Sozialgesetzbuch (SGB)) Book IX • Provisions within BSHG for special life situations
Are all children covered by the system?	Yes	Yes
How is health care organised?	Decentralised and corporatist model • Federal government sets policy and makes regulations • Länder can make concurrent legislation and have certain public health and hospital responsibilities • Sickness funds • Mix of providers, private and public	As for all children
How is health care monitored?	• Federal Ministry of HSS supervises federal associations of physicians and sickness funds and joint committees	As for all children

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[13] 2002, Information from OECD in Figures (2003).
[14] 2002, Information from OECD in Figures (2003).
[15] 2002, Information from OECD in Figures (2003).

	• Federal Insurance Office supervises sickness funds	
Is health care free at the point of use?	Yes for children	Yes for children
What choice do parents and children have?	Choice in general practitioner and specialist care	Choice in general practitioner and specialist care
To what extent are parents involved in their child's health care decisions?	Required by law to be involved in decisions	Required by law to be involved in decisions
To what extent are children involved in health care decisions about themselves?	Required by law to be involved in decisions	Required by law to be involved in decisions
How are specialist services accessed?	Service user can go directly to specialist	Service user can go directly to specialist

Key legislation for assistive technology	Social Code (Sozialgesetzbuch (SGB)) Book IX
How is assistive technology organised?	For funded technology, prescription from doctor required. Prescription is sent to the provider, who proposes an aid.
How is it funded?	Primarily through application to sickness insurance fund

Principles and organisation

Germany has a social insurance system which is highly regulated but financed by independent institutions and delivered by a mix of private and public providers. Over 88% of the population are members of the statutory health insurance scheme (Gesetzliche Krankenversicherung). This in turn is made up of over 450 independent sickness funds. High earners can make their own private insurance arrangements. Two per cent of the population such as police and soldiers are covered by free government health care (Busse with Riesberg 2000: 39; Freeman 2000: 55).

The Basic Law (Article 72) requires living conditions to be of equal standard through the Länder but health is not specifically mentioned. The Federal Ministry for HSS and the Parliament are the key actors at the national level. At this level, regulations address issues of equity, comprehensiveness and the rules for providing and financing social services. Länder are responsible for maintaining hospital infrastructure, through planning and funding hospital investments, public health services (including health education and school health services), and for undergraduate education of health professionals (Busse with Riesberg 2000: 31-33). The rights and responsibilities of sickness funds are defined in the Social Code.

The German health care system is thus highly decentralised. Partly this is through devolved responsibilities to the Länder (Busse with Riesberg 2000: 37) but also the system delegates state power to interest groups with a privileged relationship to the state (see Freeman 2000: 63). Examples are the sickness funds and provider physicians' associations. Co-ordination can be problematic within this system.

Another feature of the system is its privatisation. The public sector provides half of hospital beds (Freeman 2000: 55). Others are provided for by for-profit and non-profit organisations. The office-based ambulatory and dental care sectors, and the distribution of pharmaceuticals through private pharmacies, are provided entirely through private providers (Busse with Riesberg 2000: 36).

Book 9 of the Social Code addresses benefits for disabled people and Section 26 outlines specific medical rehabilitation benefits:

- Treatment by doctors, dentists and other healthcare professionals
- early identification of disabled children and children who may become disabled in the future, and early improvement of their opportunities
- medicines and dressings
- treatment, including physiotherapy, speech therapy and occupational therapy
- psychotherapy in the form of medical and psychotherapeutic treatment
- aids and appliances
- exercise and work therapy (MISSOC 2003: 28)

For disabled children there are regional out-patient interdisciplinary early intervention centres and social-paediatric centres catering for large areas. The first type provides all psychological, paediatric and social assistance for parents and children and can be combined with mobile early intervention teams that make home visits. The social-paediatric centres provide a wide range of diagnostic and medical therapy services.

Table G.3 shows, medical care needs are fairly well met except with respect to communication and co-ordination between health and other sectors.

Table G.3: Unmet needs in families with children with disabilities

	Yes	Yes partly	No but not needed	No but needed
Medical care				
Does your child have a doctor who regularly takes care of his or her health needs?	86.2	10.1	1.5	2.2
Does anyone watch your child's growth and development?	86.0	9.3	3.5	1.2
Care coordination and communication				
Does your child's doctor make arrangements if your child needs to see a specialist?	73.5	17.8	6.5	2.3
Does child's doctor communicate with kindergarten, school or therapists?	32.0	20.6	39.3	8.1

Source: Thyen et al. (2003), Table 1 – selection of questions

As stated above, most of the population is covered by the statutory health insurance scheme. Contributions to social insurance are based on income and not on risk.

Children are covered by their parents' insurance arrangements. Additional payments can be required for a range of medications, hospital treatments etc. (Maarse and Paulus 2003: 125). These payments are not adjusted for income, although there are provisions for groups who might otherwise be overburdened (MISSOC 2002: 3). Health reform in 2003/04 by the federal government leaves children mainly exempted from payments (Federal Ministry of HSS 2004). Children receive free medical health check-ups and dental care (Germany 2001: para 533-536).

Assistive Technology

As listed above, aids and appliances are covered by Book 9 of the Social Code (SGB IX), for those that meet the eligibility criteria of disability. Further, Section 55 specifies 'community participation benefits', which lists the provision of aids or resources that cannot be counted as medical or vocational rehabilitation (MISSOC 2003: 32). Such provision is underlined by a Federal Constitutional Court decision: "…the state should provide sufficient technical aids for persons with disabilities to enable them to take part in life with dignity" (Malaga 2003: 69; CE 2000: 50).

Social Code Book V specifies what the delivery system should cover. All people insured by a sickness fund have the right to receive the technical aids they need to alleviate their disability. Principles are that the delivery system: must be sufficient, pertinent and economically sound (Deloitte and Touche 2003). To obtain an aid, a prescription is required from a doctor. The prescription is sent to the provider who makes a proposal for the aid. Choice can be limited by the sickness funds, which can have contracts with providers (Deloitte and Touche 2003). Sickness funds will meet the costs of the aid if it is on their list, up to a certain amount. If a more expensive product is picked, then the individual may have to finance the additional costs.

Choice, consent and user involvement

There is considerable patient choice. Patients can choose and change their doctor. Patients have direct access to doctors working in local practices, who can be either generalists or specialists (Freeman 2000: 54). Book IX of the Social Code sets out the rights of disabled people to express their wishes and state choices. In decisions and implementation, "justified" wishes must be complied with (CE 2003: 148).

Physical Environment

Housing stock[16]	41% owner-occupied; 48% private rented
Key housing legislation	• Housing legislation such as Homes Act, Second Housing Act, Housing Allowance Act, the Act to Reform the Law of Tenancy • Social Code (Sozialgesetzbuch (SGB)) Book IX
How is housing policy organised?	• Social housing: Federal government sets policy and provides some funding; Länder set policy details and provide funding; local and district authorities administer and deliver • Housing allowance: Länder consent to national legislation; funding shared by Federal government and Länder; administered and delivered by local housing allowance offices or social assistance offices (for those on social assistance)
Housing benefits for families with children	Yes
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[17]	0.2%
Accessibility regulation to buildings etc.	Equal Opportunity for Disabled Persons Act 2002 (Gleichstellungsgesetz für behinderte Menschen (BGG)) DIN standards for dwellings
Has accessibility to public places improved over the past 10 years?[18]	Yes, in public opinion. 10.5% think it has improved very much while 53.6% think it has improved somewhat
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[19]**:**	
How accessible is public transport?	3.23 (fairly to very difficult) for physically disabled people 3.24 (fairly to very difficult) for intellectually disabled people
How accessible are cultural events?	2.74 (not very to fairly difficult) for physically disabled people 3.02 (fairly to very difficult) for intellectually disabled people

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[16] Information from Ball 2004: 60, 63.

[17] See Chapter 5.

[18] See Chapter 2.

[19] See Chapter 2.

How accessible are sports events?	2.78 (not very to fairly difficult) for physically disabled people 2.96 (not very to fairly difficult) for intellectually disabled people
How accessible are restaurants, hotels etc.?	2.96 (not very to fairly difficult) for physically disabled people 3.14 (fairly to very difficult) for intellectually disabled people

	Disabled children	**Disabled adults**
Key transport legislation	Equal Opportunity for Disabled Persons Act 2002 (Gleichstellungsgesetz für behinderte Menschen (BGG)) Social Code (Sozialgesetzbuch (SGB)) Book IX	As for disabled children
Are there enforcement mechanisms?	Yes	Yes
Are fare concessions available for public transport?	Yes, varies by mode of transport and type/ severity of disability	Yes, varies by mode of transport and type/ severity of disability
Can an accompanying person go free, or for a reduced price, on public transport?	Yes, varies by mode of transport and type/ severity of disability	Yes, varies by mode of transport and type/ severity of disability
Is special transport available as an alternative to public transport?	Yes	Yes
Is there a parking badge scheme?	Yes	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Germany has the lowest level of home ownership in Europe: 43% in the former West Germany and 31% in the East. Recent policy has sought to increase home ownership[20], although its impact is reported as limited to date. The private rented sector is 48% of the housing stock, which is the highest proportion in Europe except for Switzerland. Social housing is different than elsewhere in Europe, in not having a specific set of non-profit housing providers in special relationships with government. Instead, social housing subsidies are used by private landlords (Ball 2004: 60-64).

The Federal government sets social housing policy and provides some funding support to Länder. Länder decide on the policy details, while social housing is administered and delivered by local and district authorities. Housing allowance is slightly differently organised: funding is equally shared between the Federal government and Länder, and local housing allowance offices or social assistance offices administer and deliver it (Kalisch et al. 1998: Table 9.2).

Germany provides housing benefit for rental accommodation, which is means-tested and varies by household numbers and family type. Households receiving social assistance are given a lump-sum housing benefit. There is a tax, set locally by the local authority, which is based on the value of the property. (Bradshaw and Finch 2002: appendix, page 24). Overall, Germany spends a low percentage of GDP on housing support: 0.2% compared to an European average of 0.4% (see Chapter 5).

Disabled people are eligible for assistance with the costs to purchase, maintain, adapt and decorate accommodation, under Book 9 of the Social Code (SGB IX). (Boeltzig and Clasen 2002: 11) There are state subsidies to build private buildings and dwellings that meet German accessibility standards and are for people with low incomes (Malaga 2003: 57, 75).

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[20] For example, families who have built or purchased their own homes can claim supplementary child benefit, in addition to normal child benefit and the basic tax relief on homebuilding, for up to eight years. (Federal Ministry of HSS a: 3)

Accessibility to buildings and public spaces

Germany has both national legislation and regulations but they do not comprehensively cover all buildings and public spaces.

The Act on Equal Opportunities for Disabled Persons 2002 creates a statutory duty to create a barrier-free environment in relation to federal public buildings and facilities (Section 4) (Malaga 2003: 55). Further, Germany has standards for accessible housing for disabled people (Toegankelijkheidsbureau (Toe) and Living Research and Development 2001: 55). New private buildings or dwellings are subsidised, if they meet standards and are reserved for people on a low income (Malaga 2003: 57). Certain Länder have legislation that provides the legal right to free access to public buildings for any disabled person but only new and reconstructed building are covered (Malaga 2003: 55). Similarly, the 2002 Act only covers new buildings and the reconstruction of existing buildings (CE 2000: 41).

Over two-thirds of adult respondents to the Eurobarometer survey (see Chapter 2) think that access to public places had improved, in West Germany, over the past decade. Access to certain public places and activities was still seen as fairly difficult. Unlike certain other countries, this access tended to be seen as more difficult for intellectually disabled people than for physically disabled people. Attitudinal barriers, for example, may be more difficult than physical barriers.

Transport

Disabled people have the right to accessible transport “in the usual way, without particular difficulties and without help from others”, under Sections 4 and 8 of the Equal Opportunity for Disabled Persons Act 2002 (CE 2003: 150). Public transport providers must design their new vehicles and transport facilities so that disabled people can use them independently (CE 2003: 152). Municipal authorities can only receive federal funding for transport investments if consideration is given to the interests of disabled people, old people and other people with restricted mobility (Germany 2001: para 213). Enforcement of the 2002 Act is described above.

If a person were severely disabled (or has equal status – see above) and had limited mobility, the person could purchase an annual travel pass and otherwise local public transport is free (Book 9 of the Social Code; Federal Ministry of HSS 2003: 31). This covers city trains, buses, trams, underground and national railway services within 50 km of the person's residence (Familienratgeber translation). Otherwise, travel costs to and from education and health care can be reimbursed (Boeltzig and Clasen 2002: 32). Accompanying persons can go free of charge, should the 'severely disabled' person have an identification card that says an accompanying person is required (Parents on the internet, translation; Federal Ministry of HSS 2003: 31). Other concessions are available for certain modes of transport and for certain categories of disability (Council of Deputies (CD) 2000c: 6).

Specialist transport is increasingly being offered to those disabled people who cannot use public transport. This transport is provided by local authorities (Kommunen), assistance organisations and welfare associations. Regulations are issued by towns and districts and thus they differ, along with cost (Federal Ministry of Health and Social Security 2003: 31).

Parking badges are available for private cars. Funding may be available for buying or adapting a car (Familienratgeber translation; CE 2000: 38; Federal Ministry of Health and Social Security 2003: 31).

Leisure and Recreation

There is no overarching legislation that recognises children's right to culture. The German Government (2001) reports a range of national funding available to cultural, sports and other activities and a rich sector of voluntary organisations involved in provision. Planning requirements and standards require play areas and, the Government reports, increasingly children are being involved in the planning of play areas (2001: para 769).

The Government recognises that there are barriers to participation, particularly on grounds of costs. In many areas, there are reduced fees and entry charges (2001: para 782).

For disabled people, Section 58 of the Social Code Book IX requires assistance to be given for participation in community and cultural life. This include benefits: to promote meeting and spending time with non-disabled people; to enable disabled people to visit events or facilities serving sociability, amusement or culture; and to provide equipment to enable disabled people to inform themselves about events of the day or cultural events. A range of potential leisure activities is listed by voluntary organisations which include segregated activities such as sports clubs for disabled people and inclusive activities such as Scouts. The costs of being involved in sports can be covered by statutory health insurance or social assistance, for example (Elltern im Netz). Rehabilitative sport is covered under the Social Code, with particular provision for disabled girls and women (Federal Ministry of HSS 2003: 16).

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IRELAND

Ireland has experienced considerable social and economic change over the past decade, as well as political and legislative change. Ireland has had a 'tiger economy' (although with some indications that it may be slowing down (Eurydice Ireland 2002: para 1.6), which has allowed for more state expenditure. Ireland has had more inward migration from elsewhere in the world than in its recent past (Eurydice Ireland 2002: para 1.7.6), increasing nearly three-fold from 1996 to 2001. It has a much younger population than the other seven countries in this project, with one-third of the population below the age of 20 (Eurydice Ireland 2002: para 1.7.5).

Political upheaval in part has been caused by political scandals, as well as cultural changes that have tested the predominance of the Catholic Church in Irish society. The Irish Constitution continues to situate itself firmly within a Christian ethos, in its preamble, and goes on to assert: "The State recognizes the Family as the natural primary and fundamental unit group of Society" (Article 41). The influence of these two elements can be seen clearly within the history of state provision for children. For example, there is little tradition of public childcare in the early years and only now has increasing such provision become a political priority. The Catholic Church continues to be a major provider of social, education and health services. Children frequently have their rights through their parents and the 2000 National Children's Strategy seeks to balance this with the traditional rights to family.

There has been – and continues to be – rapid and substantial policy change in relation to equal opportunities and children's services. For example, enhanced rights to inclusive education and a system of assessment and support have been introduced for children with special educational needs. Disability rights legislation, such as the Equal Status Act 2000, has recently been enacted. The National Children's Strategy is spearheading change across children's services. A slightly earlier National Anti-Poverty Strategy sought to address the poverty and inequality in Ireland, including that amongst children.

Ireland is a fairly centralised state. It does have local elected authorities in a range of different councils (county 29, borough 5, city councils 5 and town councils 75). These have such responsibilities as culture and leisure, local planning and maintenance of essential services like housing and roads (Eurydice Ireland 2002: para 1.2.2). There are seven regional Health Boards plus the Eastern Regional Health Authority (which has three area Health Boards). They are statutory bodies responsible for the delivery of health and personal social services in geographical areas. Health Boards are not directly politically accountable. Rather, they are composed of elected local representatives, ministerial nominees and representations of health professions employed by the Board. The Board's Chief Executive Officer has responsible for day-to-day administration and is answerable to the Board (Department of Health and Children (DHC) 2003: 33). There are plans, though, to centralise responsibilities through a Health Services Executive with regional offices (see below). Schooling, by contrast, has a long tradition in voluntary and Catholic Church provision. Thus, there are central responsibilities and localised responsibilities but no powerful middle tier of elected councils, in school services.

Despite this centralisation, there are concerns about variation in service provision across administrative areas. For example, health support has been criticised for its limits and variability. The UN Committee for the Rights of the Child commented in 1998:

- The Committee is concerned about the lack of a national policy to ensure the rights of children with disabilities and the lack of adequate programmes and services addressing the mental health of children and their families (para 20)

For a large part, this could be explained by the discretionary duties presently on Health Boards to provide such support. The recent education act is an example of tightening up the precise responsibilities of government for provision, in order to ensure all children's rights to services are upheld.

Equality/ anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No but signed	No but signed
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law on..	No for children	No
What type of domestic law is it? (criminal, constitution, civil rights, social welfare (Degener (2003))	N/A	Constitution Civil rights Social welfare
Is there an enforcement mechanism?	Ombudsman for Children • The Ombudsman can handle individual complaints • The Ombudsman can research issues but does not have formal powers of investigation beyond individual complaints • The Ombudsman has an advisory role to government Human Rights Commission • The HRC can assist individuals in legal proceedings • The HRC can conduct enquiries • The HRC has an advisory role to government	Equality Authority (EA) • The EA can support individual cases • The EA can carry out formal investigations • The EA can advise government Human Rights Commission (as for children) The Office of the Ombudsman can hear individual complaints about public services and can undertake investigations. The Ombudsman will have a particular role in complaints for accessibility, under Part 3 of the Disability Bill 2004.
Are there (other) standing national bodies to provide policy advice?	Yes • National Children's Advisory Council • National Children's Parliament	Yes • Council for the Status of People with Disabilities • Forum of People with Disabilities

Ireland's Constitution sets out a general guarantee of equality before the law:

- All citizens shall, as human persons, be held as equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to difference of capacity, physical and moral, and of social function (Article 40.1)

The Constitution applies equally to children and adults. However, the Irish Equal Status Act 2000 explicitly excludes children under the age of 18 from the 'age grounds' for discrimination protection (Section 3(3)). This Act specifies prohibited forms of discrimination and enforcement mechanisms.

Ireland is subject to the anti-discrimination articles within the European Convention on Human Rights (ECHR, Article 14) and has agreed to Article 13 of the EU Amsterdam Treaty. Ireland has signed (but not yet ratified) the new Protocol 12, which would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority.

Anti-discrimination by age

Ireland has ratified the UN Convention on the Rights of the Child (UNCRC) but it is not fully implemented into domestic law. Indeed, the Children's Rights Alliance (2004) advocates that children's rights are incorporated into Ireland's Constitution.

The Convention is, however, central to its National Children's Strategy, which was published in 2000. It is a ten year plan with the following vision

- An Ireland where children are respected as young citizens with a valued contribution to make and a voice of their own; where all children are cherished and supported by family and the wider society; where they enjoy a fulfilling childhood and realise their potential

It has three stated goals:

- 1 Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity.
- 2 Children's lives will be better understood; their lives will benefit from evaluation, research and information on their needs, rights and the effectiveness of services.

- 3 Children will receive quality supports and services to promote all aspects of their development.

The National Children's Office, which is a Government agency, has lead responsibility for goals (1) and (2) and certain issues identified by the Government's Cabinet Committee on Children under goal (3). The Committee otherwise has lead responsibility for goal (3). Individual Government Departments are responsible for implementation and the National Children's Office is responsible for monitoring progress and supporting co-ordination. The first progress report has been published on the implementation of this strategy (NCO 2003).

The National Children's Strategy is based on extensive consultation with stakeholders including children, a firm implementation and monitoring strategy and an ambitious agenda (Pinkerton 2004). The Strategy called for an Ombudsman for Children. The legislation was finally passed in 2002 and an Ombudsman appointed in 2003. The Ombudsman has a broad range of functions, which includes investigations following an individual complaint by or on behalf of a child. The Ombudsman cannot formally investigate, however, without such a complaint. The Human Rights Commission (HRC) has stronger statutory powers than the Ombudsman, for example, in relation to enquiries. The HRC was established recently and may provide another avenue for children to protect their rights under the ECHR and the UNCRC.

Anti-discrimination by disability

While the Equal Status Act 2000 excludes children from the age grounds, disabled children are covered under the disability ground. This is a civil rights approach. After considerable controversy over earlier versions, a new Disability Bill has been published. It takes a social welfare approach, in defining rights to assessment and services, and a civil rights approach in detailing accessibility requirements.

Coverage

The Equal Status Act covers three areas:

- Buying, selling or renting a wide variety of goods

- A wide range of services, including public services like welfare, health and services provided by the Department of Education and Science
- Buying, selling or renting houses, apartments etc. (Equality Authority 2003: 3)

It is notable that transport and education are included from the start in this legislation. Disability is one of the nine grounds on which discrimination is prohibited. Disability is defined as:

- the total or partial loss of a person's bodily or mental functions, including the loss of a part of the person's body or
- the presence in the body of organisms causing, or likely to cause, chronic disease or illness or
- the malfunction, malformation or disfigurement of a part of a person's body or
- a condition or malfunction which results in a person learning differently from a person without the condition or malfunctions, or
- a condition, illness or disease which affects a person's thought processes, perception of reality, emotions or judgement or which results in disturbed behaviour

The definition thus relies on a medical approach of impairment.

The Act prohibits three forms of discrimination. These are laid out by the Equality Authority (2003: 3) as:

- *Direct discrimination* occurs if a person is treated less favourably than another person is treated, has been treated or would be treated specifically on the basis of membership of any of the nine grounds or where it is imputed
- *Indirect discrimination* occurs when a person has to comply with a condition – whether that be a requirement, a practice or otherwise – but they cannot do so. If the condition can be met by significantly more people who belong to a group than those who do not belong to it, and if the group is defined by any of the nine grounds, then it is discrimination unless the condition can be justified as being reasonable

- *Discrimination by association* occurs when a person is associated with somebody from any of the nine grounds and is treated less favourably because of that association

This is a broad approach, including future, past and imputed disabilities and discrimination directly, indirectly and by association. Harassment is prohibited on the nine grounds. A refusal or failure to make reasonable accommodations by a service provider would be discriminatory, but there is no obligation for special treatment, facilities or adjustments if they give rise to more than a “nominal cost”. Gooding and Casserley (2003) see this has a “serious restriction” on the duty (26). This legislation is symmetrical: i.e. it applies to anyone discriminated on disability grounds either because they have or do not have a disability. Provisions in the Act allow for positive measures in relation to disability.

The Act can be trumped by other legislation or a court order. If anything is required, for example, by the Education Act, this would supersede the Equal Status Act 2000 requirements (Equality Authority 2003).

The Disability Bill 2004 covers assessments and services provided through health (which includes personal social services) (Part 2). Should a special educational need be identified in such assessments, the Bill requires a link to education (Sections 7, 10). Ministers will need to draw up Sectoral Plans, which will be laid before the Dáil (Irish Parliament). Public bodies must make their public buildings and services accessible, including information. A statutory requirement will be introduced 31 December 2005, to require the ‘mainstreaming’ of public services: i.e., public bodies must integrate “where practicable and appropriate” their services for disabled people (Section 24(1)). Assistance can be requested to access services (Section 24(2)).

The Disability Bill does not have the same definition of disability as the Equal Status Act. Section 2 of the Bill defines disability as:

- … a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the

> State by reason of an enduring physical, sensory, mental health or intellectual impairment

This definition retains a medical approach, although with less detail. Further, it seems to concentrate on the ‘public’ life of individuals (i.e. employment and participation in social and cultural life), which may limit the inclusion of disabled children who will not be in employment and may require support, say, in their personal activities rather than social or cultural ones.

Enforcement and Sanctions

The Equality Authority was established as an independent organisation in 1999. It provides advice, information and legal support in relation to the Equal Status Act. A claim can be taken by an individual to the Equality Tribunal (with a few exceptions). The tribunal, unlike the court, is inquisitorial and not adversarial (Equality Tribunal 2004).

The HRC is another possible route to enforcement, for rights established under the Constitution or through international agreements. The Commission can undertake four types of case work: it can assist individuals in legal proceedings; it can offer its expertise to the court; it can take legal proceedings to vindicate human rights; and it can conduct enquiries. These powers are subject to various conditions (HRC 2004).

The Disability Bill introduces complaints and appeal procedures. Health boards will need a complaints procedure. The proposals have some strength: should a formal complaint be lodged and a recommendation made, this must be followed unless the Chief Executive Officer (CEO) of the health board believes that services cannot be provided because of eligibility, practicality or available resources (Section 14(11)). Appeals can be made to an independent appeals officer (Section 15-19). In regards to access to public buildings, services, information and heritage sites, complaints can be made to inquiry officers appointed by public (Sections 36-37). Individuals who are not satisfied with the outcome of the complaint, under Part 3 of the Bill, may appeal to the Ombudsman (Section 38).

Advocacy and Information

In the 1990s, Government structures were changed to reflect a co-ordinated approach to children's rights and needs. A National Children's Office was established to lead and oversee implementation of the National Children's Strategy. A National Children's Advisory Council brings together representatives of statutory and voluntary agencies, the research community, parents and children. Its remit is: to advise the Minister on all aspects of children's lives and the better co-ordination and delivery of children's services; to contribute to the monitoring and evaluation of the Strategy's implementation; and to advise on consultative mechanisms with children (NCO 2004). Following the Strategy, a National Children's Parliament (Dáil na nóg) has been created, with representatives from local areas' youth councils. The Parliament meets once a year, and submits and publishes a report to the Cabinet Committee on Children. The Ombudsman for Children was established by legislation in 2002.

Similarly, Government structures were also changed in relation to disability in the 1990s. The Commission on the Status of People with Disabilities was created in 1993 and issued several influential policy documents. Over half of the Commission was composed of disabled people, their advocates and parents (Ireland 1996: para 318). Subsequently, a standing Council for the Status of People with Disabilities was created with individuals elected from disability-specific constituencies (O'Gorman and Lohan 2000: 38-39). There are active organisations of disabled people, such as the Forum of People with Disabilities and the lobbying group People with Disabilities in Ireland.

Both the Equality Authority and the HRC have statutory powers to protect and promote rights in relation to disability. The National Disability Authority is an independent statutory agency, established by legislation in 1999. It has five main functions. First, it assists in the coordination and development of disability policy. Second, it undertakes research and develops statistical information. Third, it advises the Minister on standards and prepares codes of practices and, fourth, it monitors these. Lastly, it has a promotional role. Every three years, it produces a strategic plan to the Minister for Justice, Equality and Law Reform.

Education[1]

	All children	**Disabled children**
Key education legislation	- Article 42.3.2 of Irish Constitution and the 'The Rules for Primary' - Education Act 1998 - Education (Welfare) Act 2000	As for all children. In addition: - Equal Status Act 2000 - Education for Persons with Special Educational Needs Bill 2004
Does a child have the right to education?	Yes	Yes
How is education organised?	- Policy set by House of Oireachtas (Irish Parliament) and Department for Education and Science - The National Council for Curriculum and Assessment provides curriculum guidelines - School Boards of Management are responsible for the day-to-day government of schools	As for all children. In addition: - The Department for Health and Children is required to make resources available for schools. - The National Council for Special Education disseminates information and plans and co-ordinates the provision of special education and integration with schools and health.
How is education monitored?	Inspectors of the Department of Education and Science	As for all children
Is there compulsory education?	Yes	Yes
What are the ages for compulsory education?	6-16	6-18
Is there a national curriculum?	Yes	Yes, adapted for disabled children
Is compulsory schooling free at the point of use?	Yes, for state schools and independent schools if in the state system	As for all children
Are incidental costs of schooling free at the point of use?	Yes, grants available for text books and uniforms; school meals are provided for some children, based on need	As for all children, as well as grants for special equipment, specialised seating and other furniture
Does the state provide free school transport?	Yes, in rural areas. In urban areas, children entitled to reduced fares for public	As for all children, as well as free transport to special schools; grant if special

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[1] This section relates to primary schooling, which extends from the ages of four to twelve.

	transport.	transport not feasible.
Can parents exercise school choice?	Yes	Yes
To what extent are parents involved in school decisions about their individual child?	Promotion of parental participation.	Parents have statutory rights, should their child be identified as having an 'educational disability'
To what extent are children involved in school decisions about them?	Education Act 1998 recommends school councils	Education Act 1998 recommends school councils

In regards to special educational needs …

Is there an official policy for school inclusion?	Yes, in legislation
What type of education system is there (one-track, multi-track, two-track)?[2]	Multi-track
What percentage of children is in special schools or nearly full-time special classes?[3]	1.2%
What percentage of children has 'special educational needs'?[4]	4.2%
Are there special schools?[5]	Yes, 125 special schools
How is eligibility for special support determined?	
▪ **Categorical/ noncategorical**	Yes
▪ **Who can initiate**	No
▪ **Assessment**	Yes
Do children have the right to support for special educational needs?	Yes
Is there compulsory teacher training on special educational needs?	Yes

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[2] Information from EADSNE 2003.

[3] 1999/2000, Information from Table 4.1 EADSNE 2003

[4] 1999/2000, Information from Table 4.1 EADSNE 2003

[5] 2001/02, Information from Government of Ireland 2003a

Principles and Structure

According to the Irish Constitution, families are seen as the primary educators of their children:

- The State acknowledges that the primary and natural educator of the child is the Family and guarantees to respect the inalienable right and duty of parents to provide, according to their means, for the religious and moral, intellectual, physical and social education of their children (Article 42.1)

The state, in support of this or if parents are not able to fulfil their duties, must ensure that “children receive a certain minimum education, moral, intellectual and social” (Article 42.3.2). Primary education must be provided free by the state (Article 42.4). The Education Act 1998 restates this constitutional requirement, as its first of its 13 objectives for the Act: “to give practical effect to the constitutional rights of children, including children who have a disability or who have other special educational needs, as they relate to education” (Section 6(a)).

The Education Act also revised the structure of the Irish educational system. A significant number of powers and functions are retained centrally: the Department of Education and Science (DES) is responsible for setting the regulations to recognise schools, manage, resource and staff schools, for prescribing the curricula and negotiating teachers’ salary scales (DES 2003). Most schools are privately owned and managed, although funded by the state (DES 2003c). Religion retains a significant role in Irish schooling. Almost all primary schools remain in the ownership and control of religious bodies, whether they are religious orders or parish bodies. Multi-denominational schools have more recently been founded by parents, with 25 operating in 2000/01 (Eurydice Ireland 2002: para 1.3, para 2.5.3.2).

Until the 1998 Act, the education of children “with severe or profound mental handicaps” attended services provided by health. Now, education for all children is provided through educational services. The Act requires that a “level and quality of education” should be provided which is appropriate to the “needs and abilities” of all

State residents, subject to practicality and resources (Section 6(b)). The general aims of primary education are similarly inclusive:

- To enable the child to live a full life as a child and to realise his or her potential as a unique individual
- To enable the child to develop as a social being though living and co-operating with others and so contribute to the good of society
- To prepare the child for a continuum of learning (DES 2003: 9)

Disabled children are thus entitled to state schooling and their parents must ensure that they do receive education. This education need not be in a state school, or those registered with the state, but could be at home or in an independent school. The Constitution strongly protects parents' rights in regards to their child's schooling. Compulsory school age begins at age six and Comhairle reports that it is being extended until the age of 16. Disabled children have the right to attend special schools up to the age of 18 (Comhairle 2003: 101; Eurydice Ireland 2002: para 10.6).

The National Council for Curriculum and Assessment was established by the 1998 Act. It advises the Minister on the curriculum and assessment procedures. There is a national curriculum. Modifications are made for children with mild and moderate learning difficulties, which have particular curriculum guidelines (European Agency for the Development of Special Needs Education (EADSNE) Ireland 2002).

Schooling is free of charge for all schools financially maintained by the State, as well as the majority of independent secondary schools provided by the voluntary sector (Ireland 1996: para 475). Grants are available for certain ancillary costs, such as school transport, text books and uniforms (Dialogue with Citizens 1998). Free transport is provided for children attending special schools or special classes in mainstream schools, or a grant should such transport not be feasible. Escorts and safety harnesses are also available for school transport (Oasis 2004a). The provision of school transport, however, is criticised as inadequate by the Children's Rights Alliance (1997). In terms of public expenditure on education (as a percentage of

GDP), Ireland spends less than the European average (4.4% compared to 5.3%) (see Table 5.4 in Chapter 5).

Ireland's Constitution outlines both the right and duties for parents to decide on their children's education. Parents associations are encouraged at school level, and together create the National Parents' Council. Parents have the right to representation on schools' Boards of Management and each Regional Education Board (Ireland 1996: para 179; Eurydice Ireland 2002: para 2.5.4.2). The National Council for Special Education will be able to designate the school for any child determined to have special educational needs. This decision must have regard to the wishes of the child's parents (Section 10(2) of the Education for Persons with Special Educational Needs Act) – but these wishes are not determinative. The intentions of the Government are clear, for parents of disabled children:

- A key element in the education of any child is the close involvement of his or her parents. One of the objectives of this Bill is to ensure that parents have a central role in all important decisions concerning the education of their children (Government of Ireland 2003b: 1))

The corollary of this involvement is the right to appeal, so that parents can raise any concerns about deficiencies in their child's education (Ireland 2003b: 1).

School boards must inform students of school activities and facilitate the involvement of students in the operation of the school (Section 27). School councils are encouraged in post-primary schools (Section 27 (3)). Children with 'educational disabilities' should be involved in their education plans, under the Education for Persons with Special Educational Needs Act 2004.

Monitoring is undertaken by the Inspectorate of the DES. Primary schools are inspected approximately every 6 years (Eurydice Ireland 2002: para 2.13.2).

Schooling for disabled children

A stated presumption for inclusive education is made in the Education for Persons with Special Educational Needs Act 2004:

- A child with special educational needs shall be educated in an inclusive environment with children who do not have such needs unless the nature or degree of those needs of the child is such that to do so would be inconsistent with – (a) the best interests of the child as determined in accordance with any assessment carried out under this Act, or (b) the effective provision of education for children with whom the child is to be educated

The Equal Status Act 2000 protects the rights of disabled people to access schools and prohibits discrimination but does have exceptions, once again. These are if it would "… make impossible, or have a seriously detrimental effect on, the provision of an educational establishment of its services to other students" (Section 7(4)(b)).

In the Eurobarometer survey (see Chapter 2), a 8 out of 10 respondents from Ireland either strongly or somewhat agree that all disabled children should be taught in mainstream schools. However, this question does not necessarily distinguish between special classes within mainstream schools, of which there are considerable numbers (see below). Shevlin and colleagues' opinion, writing in 2002, is that "no infrastructure exists to support inclusion and furthermore that the systematic barriers to inclusion have not been challenged" (160). Without this infrastructure, they found that the disabled young people they interviewed "had to continually inform others of their needs and ask for help" (167).

Schools must produce a school plan that states the school's objectives in regards to equality of access to and participation in the school and proposed measures to ensure such equality (Section 21 of the Education Act 1998). All teachers have training in regards to children with special needs and this is supplemented by specialist training for those employed in special education services (Ireland 1996: para 323).

A continuum of provision has been preserved in Ireland, which could be described as the multi-track approach; a multiplicity of approaches to inclusion is maintained, with a variety of services between the two systems (EADSNE 2003). There are three main models of provision:

- enrolment in a mainstream classroom with additional support from a resource teacher or special needs assistant
- placement in a special class in a mainstream school
- enrolment in a special school catering for the student's particular disability. (Eurydice Ireland 2002: para 10.3.1)

In 2001/02, there were 125 special schools with about 1.6% of the school population attending national schools (Ireland 2003a). A further 2.1% of pupils, who were identified as having special needs, were in ordinary national schools; this however does not distinguish between those in special classes and those in mainstream classrooms (Ireland 2003a). 421 such special classes were reported in 1999/2000 (Eurydice Ireland 2002: para 10.3).

Under the 1998 Act, the state must ensure the provision of support services. A range of services can be provided – special resource teachers for ordinary classes in mainstream schools, special needs assistants or remedial teacher services (Oasis 2004a). Additional funding may be available to schools, such as payment for visiting teachers or grants for special equipment (EADSNE Ireland 2003).

Provision for students' needs is not solely dependent on eligibility definitions and formal assessments. The 2004 Act will require school principals to take "such measures as are practicable" to meet the needs of students who do not seem to be benefiting from the general educational programme (Section 3(2)). But, should these measures not be sufficient, the principal can arrange for a student assessment.

Disability is a key gate keeping definition within Irish educational law. Currently, the Education Act 1998 and the Equal Status Act 2000 use the same definition of disability (see above). This commonality had the advantage of consistency for schools: under both the provision of services and the prohibition of discrimination, they were to consider the same population of students. This is, however, going to change with the 2004 Act. A revised definition of special educational needs (SEN) is made in the Act:

- .., in relation to a person, a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition (Section 1(1))

This new definition loses the advantage of consistency between legislation and provides the potential that children with educational disabilities are not synonymous with children with disabilities under the Equal Status Act 2000.

The Bill's definitions are reliant on definitions of impairment. As McDonnell (2000) describes, these "… reflect a clinical/ pathological model of disability … Accordingly, activities such as identification, assessment and categorisation are considered to be of central importance" (16). Under the 2004 Act, the principal has a duty to arrange for an assessment (or to ask the National Council for Special Education to do so) if the requirements stated above are met.

If SEN are established by the assessment, the principal must create an education plan for the student. Parents should be consulted, as should the special needs organiser for that school. Similarly, if the Council initiates an assessment, it must provide information on the child's disability and an evaluation and statement of services needed. The Council would then direct the relevant special needs organiser to convene a team, in order to prepare a plan. This would include the child, the parents, a psychologist and others. Appeals can be made on a range of grounds and would be made to a Special Education Appeals Board.

Being considered to have SEN is thus a key eligibility criterion for the individualised assessment, education plan, services and rights to appeal. The Bill enumerates specific procedures, types of professionals that should be involved, and the contents of plans. This might be described as 'rights by bureaucracy', with parents in these circumstances having rights (that other parents do not have) to involvement and appeals. The assessment is concentrated on education, with mutual reference between health boards and the Council for identification and service provision. This concentration is criticised by Enable Ireland (2003), who argue for a holistic assessment.

Social Security

Proportion of children aged 0-15 in relative poverty[6]	28%
Proportion of children aged 0-15 in absolute poverty[7]	21.4%
Key social security legislation	▪ Social Welfare (Consolidation) Act 1993, as amended ▪ Health Act 1970 ▪ Carer's Leave Act 2001
Value of child benefit package, as % of average earnings[8]	6.9%
Ranking (leaders, second rank, third rank, laggards)[9]	Third rank
What % of GDP is spent on family cash benefits and family services?[10]	1.6%
Tax benefits for families with children	Only for one parent family additional tax allowance.
Income related child benefits	Yes • Family income supplement for full-time workers on low pay - varies by number of children but not their age nor characteristics; not taxed. • One parent family payment • Child dependent allowance for families in receipt of welfare - varies by number of children but not their age nor characteristics; not taxed.
Non-income related child benefits	Yes, Child benefit - varies by number of children but not age or characteristics of child; up to age 16 or 19 if in full-time education; not updated regularly nor indexed; not taxed.
Social assistance for families with children	Yes • Supplementary welfare allowance - means-tested; addition for children • One parent family payment - received until child is 18 or 22 if in full time education • Unemployment benefit and unemployment

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[6] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

[7] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] Information from Bradshaw and Finch (2002), as of July 1 2001.

[10] See Chapter 5.

	assistance
Parental leave	Yes • Parental - 14 weeks per parent per child; flexible; up to the age of 5; unpaid; job guaranteed • Homemaker scheme - carer gives up work to take care of child; not flexible; up to the age of 12; unpaid but insurance (PSRI) credits; job not guaranteed
Statutory leave for care of sick children	Yes, 3 days per year per parent per child; flexible; up to age 5; paid; job guaranteed
Type of benefits for disabled children	
• **supplement or extend child benefit**	Yes, extend age limit to 19 if disabled child (also if child in full-time education or training)
• **benefits for caring costs**	Yes • Carer's Benefit - meet insurance contributions; carer must be aged 16-65; addition for child under 18 years; taxed; up to 65 weeks • Carer's Allowance - not eligible for Carer's Benefit; means-tested, carer must be aged 18-65; addition for child under 18 years; taxed • Respite care grant - annual grant • Incapacitated Child Tax Credit
• **benefits based on child being disabled**	Yes, Domiciliary Care Allowance (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; not taxed.

Ireland has a high level of child poverty, with over one in four children living in relative poverty and over one in five living in absolute poverty, according to 1997 data. The level of child poverty is commented upon by the UN Committee on the Rights of the Child in 1998:

- While acknowledging the existence of a National Anti-Poverty Strategy, the Committee is particularly concerned about the incidence of child poverty and homeless children in the State party and encourages it to strengthen measures and programmes for the protection of the rights of the most vulnerable children. (para 21)

This situation is likely to have improved since 1997, due to the efforts of the Irish Government to improve family income and the child benefit package since that time (Bradshaw and Finch 2002; Clearinghouse 2004). The National Children's Strategy states that: "Child poverty must remain a major concern and it will continue to be a key priority of Government" (2000: 64).

Diagram Ireland displays the administrative arrangements for the social security system. It is centrally organised, with local offices. National regulations are set by central government while Health Boards have limited discretion. Payments are set nationally by Parliament (Hölsch and Kraus 2004: 147).

Financial support for all children

Bradshaw and Finch (2002) place Ireland in its third rank of countries, in relation to its child benefit package. The package provides only 6.9% of average earnings. Ireland has a dense package of benefits for families, as shown in Table 5.2 in Chapter 5. The Table also shows that the child benefit package serves to redistribute and target funds on families in more need. The 'social assistance' family case receives £143 more than a childless couple, due to the child benefit package, in comparison to the 'average' family case who receives £114 more. Ireland follows the general trend identified by Bradshaw and Finch, towards increasing the use of the tax system to support families.

The non-income related child benefits contribute considerably to the child benefit package for both the average and social assistance family cases. The universal child benefit is paid until the child is 16 years or 19 if the child is disabled or in full-time education or training. There is a range of income-related child benefits, as listed above, and social assistance. The social assistance contribution is significant to the 'social assistance' family's child benefit package (see Table 5.2 in Chapter 5). Supplementary welfare allowance is a means-tested payment for adults with a weekly income below a set rate for family size. Special payments can be given for urgent or exceptional needs. Registration for work is normally a requirement for the claimant. There are other supplements and associated allowances, such as the back to school clothing and footwear allowance scheme. Applications go through the Community Welfare Officer to the Health Board. (Oasis 2004f) Other social assistance is available for unemployment and for one-parent families.

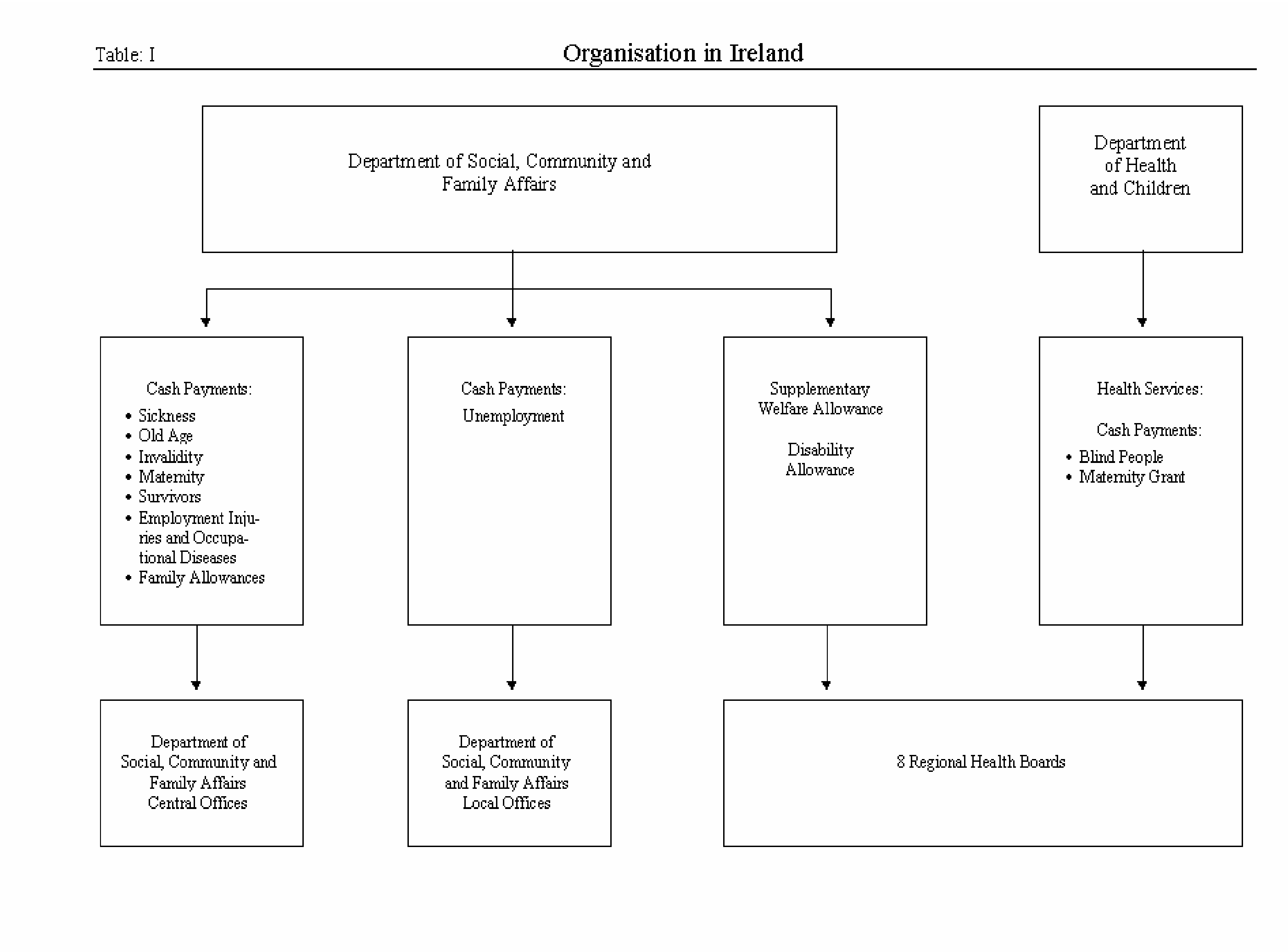
Ireland has recently introduced statutory parental leave and leave for sick children. Parental leave is unpaid and only available until the child is aged five. The parent's job, though, is guaranteed. A further scheme allows for a parent to give up work to take care of a child up to the age of 12; the advantage of this scheme is that it makes insurance contributions during this time. Similarly, leave for sick children is statutory and the parent's job is guaranteed but it has limited days and only applies until a child is aged five. A statutory right to Carer's Leave is described below.

Financial support for disabled children

Ireland has taken all three routes to additional financial support for disabled children.

- The child benefit is extended by age, for disabled children, up to the age of 19. There are also tax credits (the Incapacitated Child Tax Credit) for parents with a child who is permanently incapacitated
- Ireland has specific caring benefits/ allowances, along with a statutory right for care leave. Carers of children are eligible for these
- The Domiciliary Care Allowance (DCA) is a child-only benefit, to meet the costs of additional care and attention

Diagram Ireland: Administrative Arrangements for Social Security in Ireland



Source: MISSOC (undated) Comparative Tables http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

The Carer’s Benefit (CB) is for insured people, who meet certain employment and insurance criteria and who leave work to care full-time. The maximum time period is 65 weeks The carer must be aged 16 to 65. Medical certification is required in the application (unless the disabled child is already certified through the DCA) and the disabled person must require full-time care and attention and not normally be living in an institution (Oasis 2004c).

Carer’s Allowance (CA) is for those who lack the insurance contributions to be eligible for Carer’s Benefit and has no maximum time period. The minimum age for the carer is higher than for CB: 18 years rather than 16 years. The Allowance is means-tested. It is a passport benefit to other benefits, such as free telephone rental allowance and a free travel pass. The disabled child under age 16 must be receiving DCA and meet the following criteria:

- He or she is so incapacitated as to require continuous supervision in order to avoid danger to him or herself or continual supervision and frequent assistance throughout the day in connection with normal bodily functions, and
- He or she is so incapacitated as to be likely to require full-time care and attention for a period of at least 12 month. (Oasis 2004d).

Eligibility for the Carer’s Benefit is not a prerequisite for Carer’s Leave. This leave protects employment rights for a minimum of 13 weeks and a maximum of 65 weeks and can be taken all at once or at different imes. The leave is unpaid but social insurance records are credited. Eligibility is determined by the Department of Social and Family Affairs, based on medical information. This information is from the doctor of the person being cared for. The criteria are that the person requires:

- Continuous supervision and frequent assistance throughout the day in connection with his or her normal personal needs; or
- Continuous supervision in order to avoid danger to him or herself (Oasis 2004b).:

The DCA is a monthly, means-tested payment to the carer of a disabled child. The means test, though, only applies to the means of the child and not to the means of the carer.

Support and Care services

	All Children	**Disabled Children**
Key childcare legislation	No statutory provision Regulation by Child Care Act 1991 Child Care (Pre-school Services) Regulations, 1996	As for all children
Does a child (or carer) have the right to childcare?	No	No
Is there formal out-of-school care provided by the State or with State support?	No	For some disabled children
How is childcare organised?	Parents make their own arrangements. Regulated by health boards	Health boards and/ or voluntary organisations
Are there eligibility criteria for childcare?	Yes	Yes, 'severe and profound disability'
Is childcare free at the point of use?	No	Yes
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes	Yes
Key support legislation	▪ Child Care Act 1991 ▪ Health Act 1970 ▪ Disability Bill 2004 See also social security	Disability Bill 2004 See also social security
Does the disabled person have the right to support services?	No, Health Boards are empowered but not required to provide assistance.	No
How are support services organised?	8 Health Boards, who may arrange provision through voluntary organisations	Same as for disabled children
What are the eligibility criteria?	Assessed need	Assessed need
How are such criteria	By the organisation	By the organisation

assessed?		
What involvement do parents/ carers have in decisions about support services?	As per organisation	As per organisation
What involvement do disabled people have in decisions about support services?	As per organisation	As per organisation
Is support provided in cash or in kind?	See social security for cash support In kind support discretionary	See social security for cash support In kind support discretionary
Does supply meet demand?	Variations across Health Boards	Variations across Health Boards

What support is available for carers?	Financial support in statute; no basis for in kind support in statute
What support is available for siblings of disabled children?	No basis in statute
Are short-term breaks available?	Yes, although demand exceeds supply
Does the State regulate non-family placements (i.e. residential or foster)?	Yes

Childcare and out-of-school care

Childcare and out-of-school care are largely left to parents to arrange and pay for. There is no statutory provision for all children. Childcare provision is regulated by legislation and Health Boards are responsible for its enforcement. The National Development Plan 2000-2006 identifies childcare as an investment priority (ClearingHouse Ireland 2004). A Centre for Early Childhood Development and Education was established in 2002, funded through the DES (National Council for Curriculum and Assessment (NCCA) 2004: section 1.2). Special programmes are available: for example 'Early Start' to tackle educational disadvantage and pre-school provision for travellers (ClearingHouse Ireland 2004; Oasis 2004g).

Children with special needs may receive childcare. If a child has a visual and/or hearing impairment, they can receive a visiting teacher service from the age of two. This is provided through the DES (Oasis 2004g). Health Boards and/ or voluntary organisations provide childcare for children with 'severe or profound disabilities'. Such care is provided at Child Education and Development Centres. (Oasis 2004g)

Support at home

The Irish Government wrote in its report to the UN Committee on the Rights of the Child that: "Overall policy is to assist children with a disability to live with their families" (1996: para 306). Disabled children and their families have rights to cash support, through the benefit system (see above). They do not have strong rights in legislation, however, to in-kind support. Until the Disability Bill is passed, Health Boards[11] are empowered, but not required, to provide services. This is described by the national information service, Comhairle, as: "In general, medical card holders are entitled to community care services free of charge. Others may also be entitled but it is not always possible to actually get the services."(Oasis 2004h). Services that may be made available are:

- Public health nurses, Home helps, Personal assistance, Psychological services, Speech and language therapy, Occupational therapy services, Social work services, Physiotherapy, Day care, Respite care (Oasis 2004i)

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[11] See next section for proposed changes to Health Boards.

Funding for such organisations is generally provided through the Health Boards although certain national organisations are funded directly by the Department of Health. (Ireland 1996: para 306, Oasis 2004f)

Non-governmental organisations have criticised the extent of discretion in service provision:

- … it was felt that the standard of care might vary too much from one Health Board area to another and that while acknowledging that treatment has to meet local needs, there should be agreement on key principles within the context of a national plan relating to the care and protection of children (Ireland 1996: para 641)

The Children's Rights Alliance (1997) adds that supports are frequently centre-based and located in urban areas. Thus children living in rural areas may have problems with accessing services. Further, there are long waiting lists for assessments. Even when assessed, services are not always available for the needs identified. In order to make health services more 'people centred', the Government will be introducing a statutory complaints and appeals process (DHC 2004b).

The Disability Bill should improve disabled children's – and their families' – rights to services. Disabled people (see above for definition) will have certain rights to assessments and services if they have a

- …substantial restriction … which is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility and gives rise to a need for services to be provided to the person continually (Section 6(2))

They will have the right to an independent assessment. The participation of the disabled person should be encouraged: the assessment officer should ensure that those assessing the disabled person communicates in a way "which facilitates appropriate participation by him or her in the assessment and promotes dialogue about the nature of the assessment" and ensures that the disabled person receives adequate information, unless this would be prejudicial to the person or inappropriate due to age or disability (Section 8). These rights, however, do not require the disabled person's own assessment of their needs and desired services formally to be part of the assessment.

As detailed in the social security section above, cash benefits are available for carers of disabled children and adults and there are forms of carers' leave etc. There is no statutory in-kind support for carers in their own right, nor for siblings of disabled children. Support groups for siblings may be offered but they have no basis in statute (Ireland 2003c).

Care and support away from home

- As detailed above, families can receive a respite grant. The Children's Rights Alliance (1997) notes that respite care services have expanded significantly but that demand is not yet met

Short-term placements are not always appropriate for children: "For example, it is unacceptable that the only respite available to a 16-year-old with cerebral palsy is a ward in a home for elderly men with disabilities" (Children's Rights Alliance 1997: 38).

Both foster and residential care are regulated by legislation, under the Child Care Act 1991 and associated statutes. Health Boards are required to ensure such provision, although it may be provided by other organisations, and to inspect such provision. The Irish Government writes:

- Children with a disability who are accommodated in residential care are encouraged, as far as possible, to integrate into the social life of the community. They are also helped to achieve their full potential in regard to social and educational skills. (1996: para 307)

Health services and assistive technology

Type of health care system	National health service
What % of GDP is spent on health care?[12]	7.3%
What % of expenditure on health is public expenditure?[13]	75.2%
What are the average out-of-pocket payments (per capita, US$)?[14]	311

	All children	**Disabled children**
Key health legislation	▪ Health Act 1970 ▪ Health (Amendment) No.3 Act 1996 ▪ Health (Amendment) Act 2004 ▪ Disability Bill 2004	As for all children
Are all children covered by the system?	Yes	Yes
How is health care organised?	Centralised 7 regional Health Boards and the Eastern Regional Health Authority (which has 3 area Health Boards) are the main providers of health care Substantial reforms are planned: to replace the Health Boards and Eastern Regional Health Authority with the national executive agency (Health Services Executive); and to rationalise agencies	As for all children. In addition: • Health Boards have appointed Disability Services Managers to co-ordinate delivery of services to disabilities • Health Boards give grant aid to voluntary organisations to provide services Under the reforms, the relationship of specialist services with primary care networks and teams will be revised
How is health care monitored?	Department of Health and Children at present. It is proposed that the new Health Services Executive will take on this role.	As for all children
Is health care free at the	Yes, for children	Yes, for children and

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[12] 2002, Information from OECD in Figures (2003)
[13] 2002, Information from OECD in Figures (2003)
[14] 2002, Information from OECD in Figures (2003)

point of use?		disabled people
What choice do parents and children have?	Limited	Limited
To what extent are parents involved in their child's health care decisions?	For children under age 16, guardians must be consulted	For children under age 16, guardians must be consulted
To what extent are children involved in health care decisions about themselves?	Children aged 16-18 can consent/ refuse treatment.	Children aged 16-18 can consent/ refuse treatment.
How are specialist services accessed?	Through referral from general practitioner	Through referral from general practitioner

Key legislation for assistive technology	??
How is assistive technology organised?	Available through Health Boards or DES
How is it funded?	• Typically free of charge through Health Boards • DES discretion about requiring payment for primary school students; free of charge for secondary school students

Principles and organisation

Ireland has a national health service: it has a high degree of state intervention and it is primarily tax-financed. It differs from the ‘ideal type’ as described in Chapter 7, however, in its long-standing mix of public and private institutions. The Catholic Church, for example, provides half of the hospital beds in Ireland that are provided by the non-state sector (McLaughlin 2001: 238).

It is a centralised system. The major structures of the system were established by the Health Act 1970. The Government, through the Minister for Health and Children and the Department of Health and Children, are the head of the system. The Department is responsible for strategic planning, in consultation with other relevant organisations. Health Boards (see above for description) are the main providers of care. Beyond the Health Board, other providers are voluntary organisations and hospitals and other private organisations.

A number of reports have identified problems with this system. Summarised from the 2001 health strategy *Quality and Fairness*, these are:

- overly complex decision-making structures
- lack of clarity about appropriate level of decision-making
- imbalance between national and local concerns and priorities
- patchy strategic planning and resistance to evidence-based approaches …
- competition between health boards and inconsistencies in service standards and development across boards
- unclear regional identity at board level and county loyalties (DHC 2003: 37)

The Irish Government itself, in its 1996 report to the UNCRC, noted that “the standard of care might vary too much from one Health Board from another” (para 641). The health strategy also found a lack of co-ordination across services (DHC 2001). The health care system is being reorganised to further centralise and streamline the organisation. This will involve:

- A consolidated health care structure – a single national Health Services Executive (HSE) to replace the existing Health Boards and Easter Regional Health Authority. The HSE will be a statutory body with a governing board
- Delivery of services will be organised through four Regional Health Offices and a National Hospital Office for existing health board and voluntary hospitals (DHC 2003)

The Primary Care Network will involve a range of professionals working collaboratively with a number of primary care teams. This network includes such professionals as dentists, psychologists and speech and language therapists. Primary care teams will include professionals such as nurses, health care assistants, occupational therapists, physiotherapists, social workers etc. These teams are to deliver "comprehensive, flexible, multi-disciplinary primary care services" (DHC 2004a: 49).

The relationships and links between specialised services, and the Primary Care Teams and Networks, need to be worked out (DHC 2004a: 50). Regional planning structures already exist for people with physical, sensory and intellectual disabilities and autism; regional committees have representatives from health boards, voluntary service providers, disabled people and their families (DHC 2004b). Health Boards presently provide a range of services for disabled people, including assessment, rehabilitation, income maintenance, community care and residential care (Oasis 2004f). Gaps in these are described above. For child health prevention and early identification, preschool and school health services are provided. These provide examinations and are free of charge.

Funding and costs

The health care system does ensure that "everyone is entitled to public in-patient and out-patient services regardless of their income" (Comhairle 2003: 71). This, however, does not mean that the National Health Service is free and, according to McLaughlin (2001), this was never the intention.

There are two categories of eligibility for the public health services. Category 1 eligibility is for someone who is “unable without undue hardship to arrange services for oneself and one’s dependents” (MISSOC: 2) and for those aged 70 or over. “Hardship” is now determined by income thresholds. About one-third of the population meet these eligibility requirements (European Committee on Social Rights 2003). Those in category 1 are issued with a medical card by their Health Board and are given full access to public health services free of charge. Concerns are expressed in the recent national strategy, *Quality and Fairness*, about whether the thresholds are too high and do not recognise the financial barriers to accessing necessary care (DHC 2001); the strategy recommended that eligibility be reviewed and that investing in children’s health should be a priority.

As dependents of their parents, children’s eligibility is typically determined by their parents’ category. Disabled children, however, typically receive their own medical card and thus services etc. are free of charge (Ireland 1996: para 312, 334). For example, the Long-Term Illness Scheme provides drugs and medicines free of charge to children with a number of specified illnesses (Ireland 1996: para 316). Pre-school and school examination services, and dental care, are free of charge for children.

Assistive Technology

Ireland is not covered by the recent Deloitte and Touche (2003) European study on assistive technology.

Funding for assistive technology may be available from two routes: health and education. Submissions can be made to Health Boards, based on assessed need, and decisions are made by the Board. The Board can decide to purchase and commission the agreed equipment. (Ireland 2003c) This is generally free of charge, although category 2 members may be asked to make some payment. The DES appears to have discretion in funding the technology needs of primary level students but should pay for secondary level students. The school must apply to the DSE for the funds. (Comhairle 2003: 103-4).

Choice, consent and user involvement

The national strategy (DHC 2001) raises concerns about the involvement of service users, at both an individual and collective level. At an individual level, the results of consultation are reported: “Attitudes of providers to service users were seen, in some cases, as showing a lack of courtesy, sensitivity, flexibility or respect“. At a collective level, there is a need for better mechanisms. The health system reforms have raised further concerns that patient, client and community input will be diminished in the new system. The regional and local offices will need to “enhance existing community participation and support a sense of ownership for local communities” (DHC 2004A: 127).

Choice in services is reported as limited (Ireland 2003c), as there is typically not a local choice of service. Those with medical cards must choose a general practitioner from a local list. Category 2 members can choose their own doctor as they pay fees directly to the general practitioner (MISSOC 2002: 6). There will be new requirements to facilitate the participation of disabled people in Health Board assessments for services, under the Disability Bill 2004 (see above).

Children over the age of 16 can give their own medical consent or refusal for treatment (Non-Fatal Offences against the Person Act 1997). The situation for children under the age of 16 is less clear. A recent Supreme Court decision ruled that “only in exceptional circumstances would the court intervene to make an over that was contrary to the decision of parents regarding procedures for their children” (Oasis 2004b). Parental consent is thus a general requirement.

Physical Environment

Housing stock[15]	78% owner-occupied; 9% social rented; 9% private rented
Key housing legislation?	Housing Planning and Developments Act 2000-2002
How is housing policy organised?	Central government sets policy and funding; local authorities administer and deliver social housing
Housing benefits for families with children	No, benefits for low-income households
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[16]	1.4%
Accessibility regulation to buildings etc.	• Building Control Act 1990 and subsequent regulations • Disability Bill 2004
Has accessibility to public places improved over the past 10 years?[17]	Yes, in public opinion. 16.1% think it has improved very much while 53.1% think it has improved somewhat
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[18]**:**	
• **How accessible is public transport?**	3.60 (fairly to very difficult) for physically disabled people 3.03 (fairly to very difficult) for intellectually disabled people
• **How accessible are cultural events?**	3.04 (fairly to very difficult) for physically disabled people 2.97 (not very to fairly difficult) for intellectually disabled people
• **How accessible are sports events?**	3.14 (fairly to very difficult) for physically disabled people 2.90 (not very to fairly difficult) for intellectually disabled people
• **How accessible are restaurants, hotels etc.?**	3.18 (fairly to very difficult) for physically disabled people 2.88 (not very to fairly difficult) for intellectually disabled people

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[15] Information from Ball 2004: 78.

[16] See Chapter 5.

[17] See Chapter 2.

[18] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	Disability Bill 2004	Disability Bill 2004
Are there enforcement mechanisms?	Office of the Ombudsman	Office of the Ombudsman
Are fare concessions available for public transport?	No	Yes
Can an accompanying person go free, or for a reduced price, on public transport?	No	Yes
Is special transport available as an alternative to public transport?	No, except for school transport	In some areas
Is there a parking badge scheme?	Yes, aged 5 and over	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Ireland has the third highest rate of owner-occupied dwellings in the EU (Ball 2004: Figure 2.5). Social housing includes local authority housing (8%) and various forms of voluntary and co-operative housing (1%) (Ball 2004: 79). The Government has put extra money into building social housing (Ball 2004: 78).

Housing policy is centralised, in relation to both social housing and private sector assistance. Central government is responsible for the funding and the policy while local authorities deliver policies on social housing. There are both demand- and supply-side subsidies. For example, there are grants to voluntary organisations to help them provide social housing. There are various forms of housing assistance, including:

- Supplementary welfare allowance scheme for those with low income, for mortgage or rent assistance
- Mortgage interest tax relief
- Income tax relief on rent paid (Kalisch et al. 1998, table 9.1)

There are forms of shared ownership with local authorities and, under certain criteria, local authority tenants have been able to buy their houses at discounted prices. A range of allowances assist with the costs of electricity, telephone etc. (Comhairle 2003: 54-55). With these public expenditures, Ireland is just above the European Union average as a percentage of GDP: 0.5% compared to 0.4% (see Table 5.4 in Chapter 5).

Grants are available to fund housing adaptations for disabled people. Adaptations could include an extra room or other structural changes, or the provision of ramps etc. For a rented social housing, the full cost of the adaptation is covered, up to a maximum amount, or 90% for private housing, again up to a maximum amount. More limited funding is available for a new house. Eligibility is determined by assessed need, with the local authority determining if the proposed work is necessary. Comhairle (2003) notes that the grant scheme is currently under review: “This scheme has received considerable criticism due to delays in processing applications and the shortage of money available for the scheme" (Comhairle 2003: 88).

Accessibility to buildings and public spaces

National legislation – the Building Control Act – and subsequent regulations address accessibility. Part M of the Building Regulations, most recently revised in June 2000, address access for disabled people. They require all dwellings where constructed began on or after 1 January 2001 to be visitable by disabled people. There are stringent requirements for access to non-residential buildings and places of employment and leisure. Building control officers monitor and enforce the regulations (Malaga 2003: 55-56).

Further accessibility requirements are being enacted, through the Disability Bill 2004. Under Part 3, public buildings will need to be accessible. Certain public buildings can be excluded by the Minister if they are only being used temporarily, will not be used as public buildings after three years, or their use by disabled people is too infrequent to justify refurbishment on cost grounds (Section 23). Heritage sites must be accessible, unless this would have an adverse impact on the conservation of the site (Section 27). A new Centre for Excellence in Universal Design will promote best practice in design of building and projects (Section 50).

Transport

The Communities of Deputies (2000) report states that Ireland has national regulatory texts (see Table 8.4 in Chapter 8). However, the report refers to Building Regulations and thus applies to terminal facilities etc. and not the transport itself. Proposed disability discrimination legislation – the Disability Bill 2004 – will address public transport more fully. There are further regulatory texts and guidelines for taxis (with a new Taxi Regulation Act 2004). There are free travel schemes but these appear only to apply once a young person is aged 16 or over. Children generally have reduced fares (Ireland 2003c, 2004). Those receiving Carer's Allowance – which can be parents of disabled children – are eligible for the Free Travel Scheme.

There is a parking badge scheme for private cars, although this does not extend down to disabled children under the age of five (Comhairle 2003: 81). There is a motorised transport grant but it does not seem to be available for disabled children (Comhairle 2003: 81). Families may be eligible for tax relief for the purchase and use of specially adapted vehicles (Comhairle 2003: 82). The Public Transport Accessibility Committee has both non-governmental organisations and transport providers' representatives. Its remit is to advise the Minister for Transport on accessibility aspects of investment projects and on other issues (Department of Transport 2004: 9).

The Outline Sectoral Plan (2004) sets out a summary of targets shows progress, promises and certain remaining gaps:

Table 1: Summary of Targets

Service	**Date by which services will be accessible**
Urban bus services	
• Dublin	Currently 45% of buses and 50 routes are fully accessible. All new buses acquired by Bus Átha Cliah will be fully accessible.
• Cork, Galway, Limerick and Waterford	In general, all services are fully accessible, except for a small number of non-low floor buses used in the peak hour in Cork. All new buses acquired by Bus Éireann will be fully accessible
Inter-City coach services	Wheelchair accessible coaches for scheduled Inter-City services are not yet available. As soon as they become available, Bus Éireann will begin the process of replacing the current inaccessible fleet with accessible coaches.
Bus stations	All stations are scheduled to be made fully accessible by 2006.
Rail	
Suburban rail services	All are now fully accessible
Inter-City rail services	An accessible service at a basic level will be available on all trains by 2006. With new rolling stock coming on stream, almost half of the rolling stock will be fully accessible by 2007. The remainder of the rolling stock will be brought up to fully accessible standards as the fleet is replaced and expanded over time.
Railway stations	An accessibility refurbishment programme to make all 134 railway stations accessible has commenced
Luas	Luas is a fully accessible light rail service

Source: Table 1.10, Department of Transport 2004

Leisure and Recreation

There is no overarching legislation that recognises children's right to culture, play and recreation. However, the National Children's Strategy (2000) prioritises improving opportunities for children in play, leisure, sport and culture. The Strategy recognises that little is know about children's participation but that that children exercise less as they get older and that indoor leisure pursuits are taking up more of their social time. The Children's Rights Alliance (1997) reports that 47% of local authorities do not provide playgrounds and the Alliance criticises the lack of more formalised support in education. The Strategy states:

- The need for more opportunities for community based play, leisure and cultural activities was high on the list of the issues raised by children during the consultation process. The absence of such opportunities may be a contributory factor in their current play and recreational preferences (33)

The National Children's Office has published a play policy for children under the age of 12 and plans for a recreation policy for older children. Various funds have been put towards sports, recreation and arts activities. The 2002-2006 Art Plan prioritises encouragement of children's activities, as one of its four strategies (NCO 2003).

Within the play policy itself (NCO 2004: 13), there is a specific objective to maximise the available public play opportunities for disabled children. Action is proposed at both local and national levels, such as a local audit of play opportunities.

If leisure services are provided as public services, they would be covered by the forthcoming Disability Bill. This would require the integration or mainstreaming of services.

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ITALY

Italy has a highly devolved and decentralised structure. Central government tends to set the legislative structure and sets national plans in such areas as health. The 20 regions, however, have considerably more control in policy detail and provision; they can make law, within the general principles of central legislation. There are further subdivisions into provinces (over 90) and then communes (over 8000). In some areas, devolution goes even further: for example, schools have powers of certain functions, defining the curricula and the organisation of school times and classes.

Commentators frequently note three problems in relation to this structure. First, there is considerable disparity in wealth between the generally rich Northern regions and the poorer Southern regions. The financial decentralisation of the structure means that poorer regions can raise fewer resources, and thus the lack of services only leads to further inequality. There are national funds, such as for health, which redistribute funds to address such inequality. Taroni and colleagues (2003), however, are worried that this dependency will lead to poorer regions having less say than the richer regions. Second, political decisions as well as financial differences can lead to wide variations on services available in different areas. This is noted in many areas of children's services: the availability of children's centres locally; special needs support in schools; social assistance; choice in social support; and health (see below). Third, these differences occur despite legal rights established in legislation. There is far-reaching national legislation, particularly in the area of disabled people's social welfare rights (the Framework Law 104 of 1992), but many of the provisions are not implemented on the ground. The Italian Government acknowledges this:

- Framework Law No.104/92, together with subsequent State and regional legislation, has not been fully implemented in every social context and geographic area. A number of factors - among which, the fact that sector laws continue to exist in the legislation, the lack of adequate practical laws, the scarce responsibilities of competent bodies in observing these laws, the intermittent coordination among different institutions and the insufficient involvement of local bodies and the local community - still prevent children with disabilities from fully enjoying their civil rights and make it difficult for them to integrate into all social spheres (family, school, community) (1998: para 393)

- Children are particularly disadvantaged by income inequality, with over one in four children identified as living in poverty (whether absolute or relative). Public expenditure is accused of having been ineffective in addressing this (see below). Italy has traditionally relied on families, rather than state provision, for welfare
- Italy's limited and fragmented welfare state is the result of the strong Catholic tradition coupled with a weak national government, on the one hand, and strong regional governments coupled with an industrialized and affluent north on the other (ClearingHouse Italy 2002: 1)

Voluntary activity is considerable in Italy, traditionally dominated by church-based organisations but secular activity has been growing. Ruxton (1996) notes the fragmented and localised nature of many voluntary organisations, which again may ensure some children are supported in some areas but not throughout all of Italy.

The Italian Government's reports to the UN Committee on the Rights of the Child are open about these difficulties. The reports list the new structures, funds and legislation that they have put in place in order to address them, which are included below.

Equality/ anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No but signed	No but signed
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law on … ?	Yes	Yes
What type of domestic law is it? (criminal, constitution, civil rights, social welfare (Degener (2003))	Constitution	Constitution Social Welfare
Is there an enforcement mechanism?	Office for Public Defender of Childhood in 4 regions; national Defender 'Garante dell'infanzia e dell'adolescenza'	Courts
Are there (other) standing national bodies to provide policy advice?	Yes • National Documentation and Analysis Centre for Children and Adolescents • Parliamentary Commission on Children • National Observatory on Children and Adolescents	Yes • National Committee for Disability Policies • Consultation with organisations of disabled people and their families

Italy is subject to the anti-discrimination articles within the European Convention on Human Rights (ECHR, Article 14) and has agreed to Article 13 of the EU Amsterdam Treaty. Italy has signed but not ratified the new Protocol 12. This Protocol would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority, under the ECHR.

As quoted in Chapter 3, Article 3 of the Italian Constitution states that “all citizens have equal social status and are equal before the law, without distinction as to sex, race, language, religion, political opinions, and personal or social conditions”. Age and disability could be contained within the general phrase ‘personal or social conditions’. Its application to age is described by the Italian Government as:

- The principle of non-discrimination is not provided for in our legal system with specific reference to minors but, by constituting a general principle of law at constitutional level (article 3, paragraph 2, of the Constitution), it does not permit derogation and, therefore, also fully protects citizens who have not reached the age of majority (Italy 1998: para 95).

Anti-discrimination by age

Italy has ratified the UN Convention on the Rights of the Child. Ratification, however, does not automatically incorporate the UNCRC into Italian domestic law (Children’s Rights Information Network 2004). The Italian Government’s reports to the UN Committee on the Rights of the Child (1995, 1998) describe a range of domestic legislation passed in order to incorporate the UNCRC.

The UN Committee complemented the Italian Government on several bodies established to promote and/ or monitor children’s rights:

- National Documentation and Analysis Centre for Children and Adolescents
- Parliamentary Commission on Children, which reports annually to the Chambers, proposes legislation and approves a national plan of action for children
- National Observatory on Children, as part of the Council of Ministers, Department of Social Affairs. This is composed of experts, representatives from

other ministries, representatives from local authorities, private and voluntary organisation representatives and groups involved in promoting children's rights.

- The National Research Centre for Children and Adolescents, which monitors particular legislation (Law 295/97 – see below), trains staff, provides technical support for implementation, and reports annually to the Parliament on the current state of implementation (Italy 1998: para 21)

Save the Children Italy (Gruppo), however, notes that the National Observatory on Children has failed to connect with the regions: "Only in a few regions have these Councils been established, while elsewhere they exist in name only or indeed have yet to be established" (2003: 8). This criticism was picked up on by the UN Committee (2003: para 10). Further, the UN Committee felt there remained insufficient data on areas covered by the Convention and that it was still "obtained on the basis of a family-centred approach rather than an approach in which the child is considered as an autonomous human being (para 16). The UN Committee recommended more coherence in data collection by various institutions, at both national and regional levels (para 16-17).

Law 142 of 1990 (Article 8) provides for the nomination of an ombudsman. Regional Law 41 of 1992, in Lazio, nominated such a figure 'difensore civico'. Law 285 of 1997 provided for the nomination of a 'Garante dell'infanzia e dell'adolescenza'. Regional law 38 of 2002 nominated this figure in Lazio; there are Offices of Public Defender of Childhood in four regions of Italy (Maroni 2003; UN Committee 2003: para 14). This office can do little to oblige relevant bodies to take action but rather can seek to convince them (Italy 2005).

In summary, Italy has introduced numerous organisations to promote and/ or monitor children's rights. However, there appear to be significant difficulties in co-ordination between national and regional levels, notable gaps, and cultural preferences for a family-based approach that risks submerging children's rights.

Anti-discrimination by disability

Italy has two approaches to anti-discrimination by disability: constitutional and social welfare. The relevant article of the Constitution is stated above. The UN Standard Rules on the Equalization of Opportunities inspired Law 104 of 5 February 1992, the "Framework Law for the Assistance, Social Integration and Rights of Persons with Disabilities". The law begins with aims to:

- guarantee complete respect for the human dignity and the right to freedom and independence of disabled people and promote the full integration of the disabled within the family, in school, at work and in the community
- prevent and remove disabling conditions which hinder a person's development, the achievement by disabled people of the greatest possible degree of independence and participation in the life of the community and the exercise of civil, political and property right
- pursue the aim of ensuring the functional and social rehabilitation of people affected by physical, mental or sensory impairments, provide the services required to prevent, treat and remedy disabilities, and ensure the legal and financial protection of disabled people
- develop actions intended to overcome the social exclusion and isolation of disabled people (Article 1, translation from Discapnet)

Coverage

The coverage of the 1992 Law is wide, including civil, political and social rights. A listing of its article titles is given in Figure 1.1. The Law contains numerous provisions specifically for disabled children and their families (as well as being included under the general provision). There is no definition of disability within the Constitution. A definition of a disabled person is given in the 1992 Law:

- 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 places the person in a situation of social disadvantage or exclusion (Article 3(1), translation from Discapnet).

Figure 1.1: Listing of Article titles in the Law 104 of 5th February 1992

Article No	**Title**	**Article No**	
1	Purposes	21	Priority in choosing the place of work
2	General principles	22	Health checks for employment in public and private organizations
3	Persons entitled	23	Removal of obstacles which hinder sports, tourism and recreational activities
4	Ascertaining the disability	24	Removing or overcoming architectural barriers
5	General principles relating to the rights of disabled people	25	Access to information and communication
6	Prevention and early diagnosis	26	Mobility and public transport
7	Treatment and rehabilitation	27	Individual forms of transport
8	Social integration	28	Facilities for vehicles driven by the disabled
9	Personal care services	29	Exercising the right to vote
10	Measures for the benefit of people with severe disabilities	30	Participation
11	Stays abroad for treatment	31	Reserved accommodation
12	The right to education and training	32	Tax concessions
13	Access to school	33	Concessions
14	Methods by which integration will be achieved	34	Protheses and technical aids
15	Working groups on integration in schools	35	Admittance of disabled minors to hospitals/ institutions
16	Performance assessments and examinations	36	Increase in penal sanctions
17	Vocational training	37	Penal proceedings involving a disabled person
18	Integration into the world of work	38	Agreements
19	People entitled to compulsory enrolment	39	Duties of the regions
20	Open competition and professional qualification examinations	40	Duties of municipalities
		41	Duty of the minister for social affairs and creation of the national committee for disability policies

Source: translation from Discapnet

The legislation further distinguishes those whose situation is ‘severe’: “Accounting for age, if the impairment, whether single or multiple, has reduced a person’s independence to such an extent as to require permanent, continuous and total care in the personal or the social sphere” (Article 3(3), translation from Discapnet). All disabled people have the right to receive services in relation to their impairments (Article 3(2)) but those whose situation is ‘severe’ have priority (Article 3(3)).

Enforcement and sanctions

The Law lays out the responsibilities for municipalities, regions and national government. Article 41 establishes the National Committee for Disability Policies (Comitato nationale per la politiche dell’handicap), which consists of regional and municipal representatives, experts, representatives from trade unions and Ministers. The Minister for Social Affairs, who chairs this Committee, must submit an annual report on the state of implementation of disability policies and on the way forward. Problems have been noted with the systematic implementation of the law, across Italy (see above). There are no sanctions for failure to apply the law: for example, the ombusdman can seek to convince the local government to apply the law but the ombudsman cannot oblige the local government to do so (Italy 2005).

Advocacy and Information

As described above, Italy has a range of bodies to gather information and inform policy. In addition, it has a Parliamentary Commission on Children (described above) following passage of Law 151 in 1997. There is an active non-governmental sector of organisations promoting children’s rights (Italy 1998: para 23l). Children’s councils are developing in municipalities (Italy 1998: para 120). Equally, the Italian government cites a growing number of organisations related to disability (Italy 1998: para 383-384).

Parental involvement in policy making has been given legal status in the Law 328 of 2000. Working groups form policy on support services, alongside representatives of various disability organisations. (Italy 2005). There is a free telephone helpline for children, Telefone Azzurro, for children who have been maltreated or abused.

Education

	All children	**Disabled children**
Key education legislation	▪ Article 34 of the Italian Constitution ▪ Single text no. 297 of 1994 ▪ Law 59 of 1997: reform administration and decentralise ▪ Law 9 of 1999 and Law no. 53 of 2003: extend compulsory education	As for all children as well as: ▪ Framework Law No. 104 of 1992 ▪ Directive no. 53 of 2002
Does a child have the right to education?	Yes	Yes
How is education organised?	Highly devolved and decentralised ▪ Central state responsible for: criteria and parameters for organisation of school system; its evaluation; resources from state budget; allocation of staff to schools. ▪ Regions responsible for: programming of school network; school calendar; ▪ Provinces (for upper secondary schools) and municipalities (for schools at lower levels): number of schools; school collegiate councils ▪ Schools: administrative and management functions; definition of curricula;	As for all children Provinces responsible for the organisational support of disabled pupils. Centro Servizi Amministravati provide support teachers or special teachers.
How is education monitored?	▪ Planning at class or school level involves regular self-evaluation. ▪ Head masters monitor quality and performance of teaching ▪ Inspector staff ▪ National Institute for the Evaluation of the Educational System	As for all children
Is there compulsory education?	Yes	Yes

What are ages for compulsory education?	6-18 or 5-17	6-18 or 5-17
Is there a national curriculum?	Yes	Yes, as for all children, with specific guidelines for children with mild to moderate learning difficulties
Is compulsory schooling free?	Yes	Yes
Are incidental costs of schooling free at the point of use?	At primary school level free books and education materials are provided. At higher levels, they are not free. Meals are provided, with charges varying by income.	As for all children
Does the state provide free school transport?	At the discretion of the local municipality	As for all children
Can parents exercise school choice?	Parents can choose their school; schools can set admissions criteria if over-subscribed. Parents can choose private education. Some funding may be available for 'equal' schools, which are private but meet state requirements.	As for all children
To what extent are parents involved in school decisions about their individual child?	Parents have a right and a duty to ensure their children are educated.	As for all children. Three meetings are held per year with parents, school and health workers and municipal representatives.
To what extent are children involved in school decisions about them?	Upper secondary school students can have their own councils and assemblies and participate in decision-making in classes and beyond Participation is promoted in legislation but there are regional variations.	As for all children.

In regards to special educational needs

Is there an official policy for school inclusion?	Yes
What type of education system is there (one-track, multi-two-track)?[1]	Virtually one-track
What percentage of children are in special schools and special classes?[2]	1.2%
What percentage of children have 'special educational needs'?[3]	4.2%
Are there special schools?[4]	Yes, 0.03% of all schools
How is eligibility for special support determined?	
▪ **Categorical/ noncategorical**	Categorial
▪ **Who can initiate**	Parents, teachers, health department workers
▪ **Assessment**	Yes
Do children have the right to support for special educational needs?	Yes. Support teachers are provided
Is there compulsory teacher training on special educational needs?	No but changes are underway Law 53 of 2003

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[1] Information from EADSNE 2003.

[2] 2001, Information from Table 4.1 EADSNE 2003

[3] 2001, Information from Table 4.1 EADSNE 2003

[4] 1999/2000, Information from ECSR 2003.

Principles and structure

The Italian Constitution requires compulsory primary education for at least eight years and this is free at the point of use (Article 34(2)). Law No. 53 of 2003 has extended the ages of compulsory schooling: from 6 to 18 or 5 to 17 years, or twelve years of schooling.

Italy has a highly decentralised system of schooling and, indeed, more decentralisation is being proposed (Eurydice Italy 2003). There are several administrative units involved: the state, in setting a general framework; the regions, provinces and communes; and schools themselves. Law No. 59 of 1997 gave considerable independence to schools, giving them increased autonomy over financial, administrative, and organisational matters (Gruppo 2003: 59).

Such decentralisation is also evident in the curriculum. The Ministerial Decree of 1979 defines the goals and contents of each subject, in terms of general content and methodology. School teaching staff then can adapt the curriculum in both methods and contents. This curriculum is further adapted for classes and individual pupils. Handicapped student, for example, are entitled to individual education plans, which set out an educational programme and goals adapted for each student.

Article 34(1) of the Italian Constitution states that "Schools are open to everyone". Disabled children are thus both obliged and entitled to school education. Further, disabled children have the right to attend nursery school, if their parents wish, as well. The Italian Government writes, in its submission to the UN Committee on the Rights of the Child, that "The presence of children with difficulties or handicaps is actually considered a generally enriching factor" (1995: para 159).

As stated above, the Constitution establishes that free tuition should be provided at primary schools. Textbooks are provided by the municipality. Transport and canteen services may also be provided, with family contributions, except for those on low incomes (Dialogue with Citizens 1998). After primary school, families must pay for education materials (Italy 2005). In terms of public expenditure on education (as a percentage of GDP), Italy spends less than the European average (4.5% compared to 5.3%) (see Table 5.4 in Chapter 5).

As with its management, school monitoring is also highly decentralised. The quality and performance of teachers is monitored by the head master of each school. In special cases, the school administration can call in 'technical inspectors'. Accounts are monitored by auditors (Eurydice Italy 2003: para 2.13).

Pupil participation is particularly promoted at secondary school level, where students can elect representatives to the secondary school council. (Italy 1998). In researching the impact of 1998 legislation that further promotes participation, Gruppo (2003) report that the knowledge level of children's participation in schools was very low – and even lower results were found for actually implementing such participation.

Parental rights are emphasised by Article 30 of the Italian Constitution: "Parents have the duty and right to support, instruct, and educate their children, including those born out of wedlock" (1). Parent representatives are involved in school governance and teaching plans (Eurydice Italy 2003: para 2.5.1.4). It may be that parents are consulted but they may not have much impact or involvement in decisions (Italy 2005).

Schooling for Disabled Children

Italy is well known for its one-track approach in school provision: i.e., policies and practices include almost all pupils within mainstream education. The right of disabled children to integrated schooling is buttressed by Article 34 of the Italian Constitution, described above, and firmly laid out in the Law No. 104 of 1992: "The disabled shall be guaranteed the right to receive education and training in kindergartens, in the ordinary classes of all types and levels, and in universities" (Article 12(2), translated from Dispanet). This education is to "develop the potentials of all disabled people in learning, communication, relationships and social interaction" (Article 12(3), translated from Dispanet).

The Italian Government asserts that school inclusion has now been accepted in Italy (1998: para 486) and this would be largely supported by the Eurobarometer survey of adult attitudes (2001). The survey found that nearly nine out of 10 respondents either strongly or somewhat agreed with all disabled children being taught in normal schools and were thus above the European average score (see Chapter 2). The problem, according to the Italian government, is that services are not universally available through the country: "In some places, especially small towns and villages, the involvement of the local administrations is still insufficient to guarantee that all disabled pupils can exercise their right to study" (1998: para 486). This is particular true in Southern regions of Italy (Italy 1998; Gruppo 2003).

Gruppo (2003) identifies two specific barriers that still hinder integration: architectural or other physical barriers and staffing. Law No. 118 of 1971 requires schools and nurseries to be accessible, from when they are built or to be modified as is possible (Article 27). This is emphasised again in Article 24 of the Law No. 104 of 1992. Despite this, two out of five school buildings still had architectural barriers (Italy 1998: para 487). Staffing is problematic, in several ways. First, the study also found that 50% of teachers said they felt "completely unprepared" for teaching disabled pupils because they had not received specialist training (Gruppo 2003: 63). Second, expenditure had been cut for support staff and, third, training of support teachers was not sufficient. The 2003 legislation has improved training somewhat (Italy 2005). In fact, a very small minority of children are not educated in ordinary schools, and this is allowed for in the 1992 legislation:

- Compulsory elementary education must take place in normal classes in the ordinary State schools, except where the child is affected by mental or physical disabilities which are so serious as to prevent, or make very difficult, his/her to learning and becoming part of the aforesaid normal classes(9/b) (Article 28)

There remain a few special institutes for children who are blind or deaf (European Agency for the Development of Special Needs Education (EADSNE) 2003). In 1999/2000, 0.03% of all schools were special schools and had 2883 children (ECS 2003). This equates to less than 1% of the school population (EADSNE 2003: 10).

The Law No. 517 on 1977 on compulsory education underlines the requirement of schools to use specialist teachers to help ensure the integration of disabled pupils. This support is a central component to the Italian system (EADSNE 2003). These teachers work within schools and take part in classes along with the class teacher. The support teachers may, at times, extract children for support lessons. Classroom sizes are restricted, by law, when there are disabled students; exceptions are allowed if there are no other solutions or if the pupil has a minor handicap (Deloitte and Touche 2003: 36; Eurydice Italy 200: para 10.6). Other support must be provided for handicapped pupils, under Law No. 517 of 1977:

- Furthermore, the necessary specialist training, social and psycho-pedagogical services and particular forms of support must be provided by the various government and local authority organizations in relation to their respective responsibilities, within the limits of their budgetary resources and on the basis of the programme set out by the consiglio scolastico distrettuale (district educational council) (Article 2, translation from Discapnet)

Specialist teachers must have specialist training: 2 years at University, for all special educational teachers, as of 2003. Other teachers do not have mandatory training as part of their initial training.

The definitions of disability are described above. Determination of disability first requires a certificate of ‘handicapped’ status, from a specialist or psychologist. Then, a functional diagnosis must be provided by a multidisciplinary unit of the local health authority, which details the “functional limits and capabilities of the person” (Eurydice Italy 2003: para 10.5) and then a “dynamic-functional profile”. These units include a social worker and an expert on the particular kind of disability. Once the pupil is identified as handicapped and has a functional diagnosis, Article 12(5) of the 1992 legislation requires an individual plan to be constructed. This is prepared by the health and education staff, and the disabled child’s parents. It covers not only educational activities but also rehabilitation and social opportunities (EADSNE 2003; Eurydice Italy 2003). Parental involvement is mandatory, under Law No. 328 of 2000, but disabled children under the age of 18 do not have statutory rights to participate (Italy 2005).

Social Security

Proportion of children aged 0-15 in relative poverty[5]	24%
Proportion of children aged 0-15 in absolute poverty[6]	36.1%
Key social security legislation	▪ Law No. 104 of 1992. ▪ Law No. 285 of 1997 (National fund for children and adolescents) ▪ Decree No. 446 of 1997 ▪ Decree No. 237 of 1998 ▪ Decree No. 306 of 1999 ▪ Law No. 328 of 2000 (establish National Fund)
Value of child benefit package, as % of average earnings[7]	2.0%
Ranking (leaders, second rank, third rank, laggards)[8]	Third Rank
What % of GDP is spent on family cash benefits and family services?[9]	1.0%
Tax benefits for families with children	Yes • Credits for children, vary by employment, number of children, family type. • Tax credits for children < 3 years
Income related child benefits	Yes • Household cheque (support for household members and not just children), varies by household size and characteristics; paid monthly; contributory; not taxed. • Benefit for households with ≥ 3 children
Non-income related child benefits	No
Social assistance for families with children	Yes • Minimo Vitale – means-tested; differs between municipalities; addition for children • Reddito Minimo di Inserimento – means tested; national; addition for children
Parental leave	Yes, 10 months per child; not flexible; up to the age of 8 years; 30% of household wage when

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[5] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

[6] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[7] Information from Bradshaw and Finch (2002), as of July 1 2001.

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] See Chapter 5.

	child 0-2 years; unpaid when child 3-8 years; job guaranteed. There is no age limit for disabled children.
Statutory leave for care of sick children	Yes, any time for child under 3; 5 days per year per child 3-8 years; not flexible; unpaid; job guaranteed
Type of benefits for disabled children	
• **supplement or extend child benefit**	Yes, no age limit if disabled child. Increase level of family income eligible household cheque
• **benefits for caring costs**	No
• **benefits based on child being disabled**	Yes, disability allowances and annual tax benefit

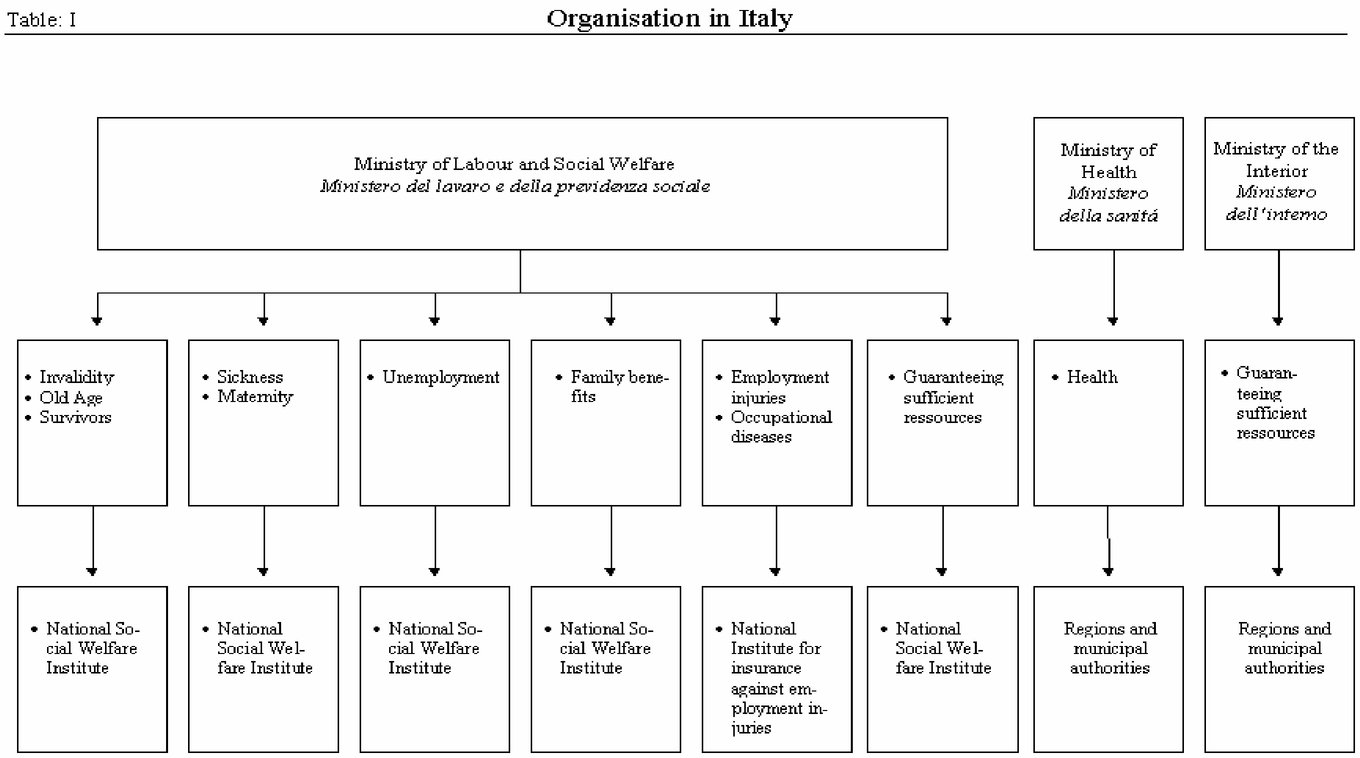
Italy has a high level of child poverty: nearly one in four children, by an absolute poverty standard, and over one-third, by a relative poverty standard (see Chapter 5). Public expenditure (as a percentage of GDP) on family cash and benefits is low, compared to the European average: 1.0% compared to 2.2% (see Chapter 5).

Sgritta (2001) comments on three constants within child poverty in Italy. First, the gap has continued to widen between the more developed regions in Northern Italy and the less developed regions ones of Southern Italy. Second, larger families (i.e. those with three or more children) are the most likely ones to experience poverty. Third, Italian social expenditure has advantaged older people but taken away resources from other groups. Further, what has been spent has been ineffective for children:

- In Italy, public policies have also been largely ineffective in reducing poverty and inequality by means of social and economic relief aimed at families children … these measures leave families with children worse off, because income tax exceeds overall social and economic benefits (8)

Diagramme Italy describes social security administration in Italy. Italy is described as the "epitome of categorical, decentralized and targeted social policies" (ClearingHouse Italy 2002: 3). Central government is responsible for cash and tax benefits. Social assistance has been the responsibility of local government. Sgritta (2001), however, sees the Law No. 328 of 2000 as a potential milestone in reforming social assistance and services. It establishes a National Fund for social policy measures, management models for social services and introduces basic levels of performance and service delivery to create minimum equality throughout the country. It establishes a system of social assistance, partially correcting the present imbalance between social assistance and social insurance, and sets up compulsory local networks for social assistance (ClearingHouse Italy 2002). The Social Assistance policy will be established by a National Social Plan, drawn up by central government and regions every three years. Regions will then develop collaborative regional plans while all municipalities must have their own local social plan (including both social assistance and health care initiatives). Voluntary and not-for-profit organisations are given an important role in service provision.

Diagram Italy: Administrative Arrangements for Social Security in Italy



Source: MISSOC (undated) Comparative Tables http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

Financial support for all children

Bradshaw and Finch (2002) place Italy in the third rank of countries, for the extent of its child benefit package. It is only 2.0% of average earnings. Table 5.2 in Chapter 5 shows that the 'average' family case does receive additional income (£102) to a childless couple, thanks to the child benefit package. But the 'social assistance' family case is actually disadvantaged by the child benefit package, at minus £159. A means-tested guaranteed minimum income has been recently introduced, for those with no earnings and no other sources of income. Regional authorities are responsible for administering this (ClearingHouse Italy 2002). Italy has no universal child benefit but instead has income-related benefits for households (the 'household cheque'), which is not specifically for children but for households. The household cheque requires social insurance contributions – thus eligibility is strongly tied to past employment. Italy also has tax credits for children.

Parental leave policy was enacted in 2000, entitling parents to take up to 10 months leave at any time until the child is eight years old. Extensions are available should the father also take leave. The leave is paid but only at 30% of earnings. Leave to take careof sick children is available for a seriously ill or disabled child under age three, with no time limit but unpaid after 10 months, and for children aged three to eight with a maximum of five working days per year. Thus the leave policy does not address leave for parents of children over age eight, except for disabled children. The Minister of Labour and Social Affairs, writing to the UN Committee on the Rights of the Child in 2003, states that "Particular attention has been given to supporting families with severely handicapped dependents through special measures in the workplace" (4), although no further details are given. In their 1995 report, the Italian Government stated that working mothers or fathers of children with severe disabilities could take three days leave per month (para 133). There is no age limit for a disabled child, in regards to parental leave (Italy 2005).

Financial support for disabled children

Italy's support for disabled children comes through supplementing and extending its family allowances. First, the age limit of 18 years for including children in the ‘household cheque’, or family allowance, is removed for disabled children. Second, the level of family income is also increased, for eligibility for the household cheque. No other benefits, for the costs of caring or of disability, are detailed in MISSOC.

Correspondence with the Italian partner (Italy 2005) provided further information. Law No. 104 of 1992 provides for a monthly cheque ‘assegno di frequenza’, whose eligibility can be reassessed and removed. For those with very serious disabilities, a monthly cheque is also available (assegno di accompagnamento), whose eligibility will not be reassessed and thus the cheque will not be removed. The Commission can decide to give this for a specified number of years after which it is reassessed. At a regional level, financial assistance can be provided in the home should a person have a severe disability; the regions, who provide this assistance with the local municipalities, vary on the extent of this assistance. A tax benefit for disabled children was introduced in the 2002 Budget. There are a range of tax deductions in such areas as reduced VAT on the purchase of special equipment and on medicines and personnel required. These deductions depend on the individual case an dincome. Eligibility is decided by a commission from the health department.

The 1993 Italian government report to the UNCRC mentions certain specific financial assistance (para 133-135):

- Deducting health and assistance costs required in cases of disability from the total taxed income (Law No. 104/ 92)
- Payment of monthly allowance for minor disabled civilians who are required to attend specialised therapeutic treatment and rehabilitation centres (Act No. 289 of 11 October 1990)
- Financial assistance for disabled children who attend educational establishments and vocational training centres for their reintegration into society (Act no. 508 of 21 November 1988)

Support is provided through social services, as described below.

Support and Care services

	All Children	**Disabled Children**
Key childcare legislation	1971 Legislation??	Framework Law No. 104 of 1992
Does a child (or carer) have the right to childcare?	Yes, for children aged 3 months-3 years No, for children aged 3-6 years	Yes, entry into child care centres 0-3 years Guarantee integration into nursery school
Is there formal out-of-school care provided by the State or with State support?	• Catholic oratori (places of sociability) • Some municipalities have set up 'ludoteca' centres for play and homework supervision	As for all children
How is childcare organised?	▪ Childcare Centres (Asilo nido) (aged 3 months-3 years) – Regions and municipalities ▪ Pre-school (Scuola Materna) (aged 3-6 years) – Ministry of Education	As for all children and, in addition, there are certain health or social rehabilitation centres
Are there eligibility criteria for childcare?	Yes, all eligible but priority places	Yes, defined as disabled under the 1992 Act for statutory rights
Is childcare free at the point of use?	No, childcare centres – income-related fees Yes, pre-school	As for all children
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes	Yes
Key support legislation	▪ Law No. 104 of 1992 ▪ Law No. 328 of 2000	As for disabled children
Does the disabled person have the right to support services?	Yes	Yes
How are support services organised?	▪ National government provided funding and sets minimum levels of social care (although these levels are often not met) ▪ Regions planning and policy	As for disabled children

	tasks ▪ Municipalities managerial functions	
What are the eligibility criteria?	Disability	Disability
How are such criteria assessed?	Combined assessment by local health department and municipality social service	As for disabled children
What involvement do parents/ carers have in decisions about support services?	Parents are part of the 'gruppo lavoro handicapti', as required by legislation. This group meets three times annual to monitor, review and plan. Law No. 162 of 1988 requires that parents are involved in decisions about support services, for children who have 'serious disabilities'	Law No. 162 of 1988 requires that parents are involved in decisions about support services, for their children who have 'serious disabilities'
What involvement do disabled people have in decisions about support services?	None	Disabled adults are part of the 'gruppo lavoro handicapti', as required by legislation. This group meets three times annual to monitor, review and plan.
Is support provided in cash or in kind?	In cash and in kind	In cash and in kind
Does supply meet demand?	No	No

What support is available for carers?	Financial and in kind support
What support is available for siblings of disabled children?	Financial and in kind support
Are short-term breaks available?	Yes
Does the State regulate non-family placements (i.e. residential or foster)?	Yes

Childcare and out-of-school care

For very young children, childcare is available through the Childcare Centres (Asilo Nido). These are publicly funded and largely publicly operated. They charge income related fees. In 1971, legislation gave all mothers the right to use such programmes. At the same time, there are priority places for children whose mothers are working, poor or lone parents and for disabled children (guaranteed by Framework Law No. 104 of 1992). Responsibility for this provision lies with the regions and municipalities, although there are proposals to transfer it to the Ministry of Education (ClearingHouse Italy 2002). Only 9% of children, in 2001, were using public childcare (Bradshaw and Finch 2002).

In contrast, 71% of children aged three to five years use pre-school (Scuola Maaterna) (Bradshaw and Finch 2002). This is financed by national government, through the Ministry of Education, and is free for the core school day. Disabled children have the right to be integrated into such provision (Article 12, of the Framework Act 103 of 1992, as translated).

Bradshaw and Finch (2002) report that out of school childcare is most commonly provided through catholic oratori (places of sociability). There are no or very low fees, which in themselves may be reduced for those with low income etc.. Law No. 285 of 1997 established a National Fund, to encourage rights for children.

Support at home

Community inclusion is promoted for disabled children both through children's and disability legislation. Law No. 184 of 1983 establishes children's right to be brought up in their families, except as a last resort (Italy 1998: para 191). Law No. 104 of 1992, as described above, promotes the "full integration of the disabled within the family, in school, and in the community" (Article 1 (1)(a), translation Discapnet). The arrangements for service provision were reformed in 2000. Central government provides finance, through a National Social Fund, and defines the minimum level of social care. Regions have planning and policy tasks, such as further specifying the minimum requirements, criteria for accrediting, approving and supervising service providers, and defining quality requirements. Municipalities have managerial functions and are central to the actual delivery of social services. Every three years, the central government, with local authorities, defines the national social plan. This plan sets out the main objectives and activities (Donatini et al. 2001: 106).

If the eligibility criteria of Law No. 104 of 1992 are met, disabled people are entitled to a range of services, such as: home help, personal care services, and extra-curricular activities. The definition and assessment of disability are described above. Personal assistance may be available for those with “severe impairments”, under Law No. 162 of 1988; if eligible, this assistance is provided free. Parental involvement in the GLH is mandatory but children’s involvement is not, as described above in the education section. Financial support is available for carers, as detailed above in social security. In kind support is available to all household members, under Law No. 328 of 2000, and thus could apply to carers or siblings (Italy 2005).

Care and support away from the family home

The Italian Government has sought to decrease the institutionalisation of disabled children and reports considerable success:

- In Italy, the practice of institutionalizing children with disabilities, although still in existence, is becoming less common and in fact is nearly obsolete. In its place, integrated structures that provide alternatives to the family of origin are being set up. In 1992, the total number of children under 18 years of age with disabilities assisted by health and social services programmes within institutions was 3,901. The exact number of children with disabilities in institutions is currently unknown, but with the progressive implementation of the provisions of Law 104/92, it is likely that their numbers are decreasing dramatically (1998: para 398).

However, for those children who are in care, there have been difficulties shifting from residential to foster placements. The Italian Government reports that many regions and municipalities have not shifted their procedures and services (1998: para 263). Short-term breaks can be available through foster placements. Municipalities, working with the health departments, are responsible for residential and foster placements (Italy 2005).

Health services and assistive technology

Type of health care system	National health service
What % of GDP is spent on health care?[10]	8.5%
What % of expenditure on health is public expenditure?[11]	75.6%
What are the average out-of-pocket payments (per capita, US$)?[12]	439

	All children	Disabled children
Key health legislation	▪ Italian Constitution ▪ Law No. 833 of 1978 ▪ Legislative Decree No 502 of 1992 ▪ Legislative Decree No 517 of 1993 ▪ Legislative Decree No 229 of 1999	As for all children. In addition: Framework Law No. 104 of 1992
Are all children covered by the system?	Yes	Defined as disabled under the 1992 Act
How is health care organised?	Decentralised • Central government sets general objectives and fundamental principles • Regions responsible for legislative and administrative functions, planning health care, and organising activities. • Providers are Local Health Enterprises (ASL), public and private accredited hospitals, and voluntary organisations	As for all children
How is health care monitored?	▪ Regions responsible for monitoring quality, appropriateness and efficiency of services ▪ 3 year plans set at national and regional	As for all children

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[10] 2002, Information from OECD in Figures (2003).
[11] 2002, Information from OECD in Figures (2003).
[12] 2002, Information from OECD in Figures (2003).

	levels	
Is health care free at the point of use?	Health care is free, although certain services are not. Children are exempt from a range of costs, but not all.	Yes
What choice do parents and children have?	Choice of GP; once secondary services authorised, choice of provider	As for all children, although can be limited in practice
To what extent are parents involved in their child's health care decisions?	Parents have the right to be involved and to provide consent.	??
To what extent are children involved in health care decisions about themselves?	Health legislation requires it although not always found in practice	As for all children. In addition, disabled children can be considered less 'competent' by certain professionals, and thus their involvement is limited.
How are specialist services accessed?	Through GP	Through GP

Key legislation for assistive technology	▪ Law No. 502 of 1992 ▪ Law No. 833 of 1978 ▪ Framework Law No. 104 of 1992 ▪ Law No. 104 ▪ Ministerial Decree 332 of 1999 ▪ Law No. 328 of 2000
How is assistive technology organised?	Potential users must apply through General Practitioner, for specialist assessment
How is it funded?	For children who are "permanently disabled" under the age of 18, devices are free of charge when a. they are assessed to need the devices and b. they devices are included on the National Register. Tax deductions on partial payment on special equipment; reduction of VAT (IVA in Italy) for the purchase of special equipment.

Principles and organisation

Article 32 (1) of the Italian Constitution addresses health: “The republic protects individual health as a basic right and in the public interest; it provides free medical care to the poor” (translation ICL). Law No. 833 of 1978 established the National Health Service (Servizio Sanitaario Nazionale (SSN)), which sought to:

- … guarantee everyone equal access to uniform levels of health care, irrespective of income or geographical location, to develop disease prevention schemes, to reduce inequality in the geographical distribution of health care, to control health expenditure growth and to guarantee public democratic control (exerted by political parties) over the management of the whole system (Donatini et al. 2001: 14)

Financing came from general taxation and statutory health contributions (Donatini et al. 2001: 14). Due to conflicts between tiers of government and the politicisation of health care, the SSN was reorganised in the 1990s. This involved a significant decentralisation. Central government is responsible for setting the general framework and principles for the SSN. The 20 Regions are responsible for legislative and administrative functions, ensuring the provision of services, and monitoring services. There is a network of Local Health Enterprises (ASLs), to provide services, alongside public and private accredited hospitals and voluntary organisations. Reforms in 1999 sought to encourage partnership, promoting integration between primary care physician and district services (e.g. social and home care) (Donatini et al. 2001: 60).

Thus, the decentralisation includes a ‘purchaser’ (Region) and ‘provider’ (ASLs and others) split. ASLs are independent organisations, which cover a certain geographical area. The areas contain population sizes ranging from 50,000 to 200,000; some are much bigger such as in Viterbo (250,000) even bigger in the sectors of Rome. (MISSOC 2002a: 3). The ASLs are responsible for assessing needs and providing comprehensive care to that population (Donatini et al 2001: 25).

The decentralisation has raised substantially concerns about geographical inequity, again particularly between the richer northern and poorer southern regions.

Concerns were raised by the European Commission Directorate (2003: 44) that decentralising legislation to the Regions could lead to varying levels of health care services. Specialist services are not guaranteed throughout Italy for disabled children:

- Some Regions have long had structures capable of meeting the specific rehabilitative needs of children with disabilities. Others, instead, have such inadequate facilities that they cannot assure continuity of treatment, forcing individuals in need to seek treatment in centres in other Regions (Italy 1998: para 397).

This is despite Law No. 104 of 1992, which should guarantee disabled children specific forms of medical assistance (Italy 1998: para 394). Indeed, there are numerous sections within this law that establish disabled people's right to health care, rehabilitation and assistive technology (see Figure I.2).

A National Health Plan is drawn up by central government, every three years, and approved by Parliament. The Plan specific priority activities, the levels of health care expected, and allocation of funding. Regional plans must follow the National Health Plan and regions are accountable to central government for meeting health care targets (Donatini et al. 2003: 30). The National Health Plan 2002-04 has several elements directly relevant to disabled children: the reduction of waiting lists; the development of domicilliary hospitalisation and integration of social-health care for disabled people (MISSOC 2002a: 3).

Funding and costs

Along with political and administrative decentralisation, there was fiscal decentralisation. The SSN is current financed through regional taxes, general taxation collected centrally, and users' co-payments (Donatini et al. 2003: 35). Regions who are unable to raise sufficient funds receive additional funding through the equalisation fund, the National Solidarity Fund. Taroni (2003: 140) fears that this Fund will undermine poorer regions' autonomy, who will likely continue to be dependent on this fund for transfers from the richer northern regions.

People must register with the local ASL office. The ASL then issues a ‘health card’, which entitles the holder to access national health services. (MISSOC 2002a: 1). ASLs are funded under a global budget, with a weighted capitation mechanism. Hospital providers are paid fees for services.

Basic health care is provided either free (diagnostic and specialised health care services, primary care provided by general practitioners and paediatricians, care services during hospitalisation) or by a co-payment (ESC 2003) – the ‘ticket’ (Freeman 2000: 37). Co-payments are reduced for families who have children under the age of six (Italy 1998: para 69) and generally for low income (MISSOC 2002a: 7). Taroni (2003: 141) accuses the system of a “creeping privatisation” as services that were previously considered essential and covered by the national health service are “delisted” and thus subject to payment. In 1999, 30% of the population were covered by private insurance (Donatini et al. 2001). Private insurance allows patients to receive services from providers not accredited by the SSN. Doing this can be attractive, as waiting lists for services can be lengthy, co-payments high and people can be dissatisfied with service quality at secondary and tertiary levels (Donatini et al. 2001: 63). Kalisch et al. (1998: para 336) criticised the shift of health care costs to families, which is disadvantaging families with children compared to other households.

Disabled children, if they have ‘severe’ disabilities, are exempt from all payments. They should receive treatment free of charge, including prostheses, pharmaceutical supplies, specialist examinations and medical treatments abroad (Gruppo 2003: 53). Other disabled children may have tax deductions on medicines (Italy 2005). Rehabilitation programmes are available but are given nationally-set limitations on the extent of rehabilitation given. These limits are criticised by Gruppo (2003: 53) as acceptable for adults but insufficient for children.

Assistive Technology

The Italian legal framework for assistive technology has been described as “very fragmented” (Deloitte and Touche 2003: 32). As with the SSN generally, there is both national and regional legislation. Further, there is specific legislation for certain disabled people (e.g. for those who are blind or for people in certain situation, such as work). Again, there is a concern that the power of regions to make administrative legislation leads to inequalities across regions.

Law No. 104 of 1992, though, does specifically recognises assistive devices to assist people with physical and sensory disabilities, as part of addressing social exclusion. The 2003 study also reports that the Government has introduced draft legislation to discourage the virtual barriers that disabled people face in accessing information technology (35).

A national centre (Servizio Informazioni e Valuatzione Ausili) provides information and counselling on technical aids. It has information points in nine of the Italian regions, but not in all 20 (Deloitte and Touche 2003: ECSR 2003: 89). Local occupational therapy and rehabilitation centres can also provide information (ECSR 2003: 89). Access to state-funded technology goes through the general practitioner, where the doctor authorises a specialist visit. The assessment is carried out by a medical specialist. Various requirements of the initial assessment are set out by Law No. 104 of 1992. The views of the user are taken into account by the assessment but the specialist has the final decision. Children with a “permanent disability” under the age of 18 are eligible for assistive devices listed in the National Register. All these devices are available to users free of charge. If the user were to choose a different type or model of device than that included on the Register, the ASL could decide to supply the alternative device and pay for the equivalent amount to the Register device. If it cost more, the user (and/ or family) would generally have to pay the extra cost. Certain devices are not included on the Register – such as touchtone phones – and must be paid for directly by the user, with a certain proportion funded publicly.

There are minimum times for user requests for replacement, unless it does not function properly. ASLs are required to ensure that the device works and it is safe (ECSR 2003: 93).

Further information is provided by the Italian partner (Italy 2005): there are tax deductions for partial payment for special equipment, as well as reduced value-added tax (IVA in Italy) from 20% to 4%.

Choice, consent and user involvement.

Primary care is provided by general practitioners. They act as gatekeepers to secondary services. (Donatini et al 2001: 59) Patients and their families have several layers of choice. First, they can choose or change their general practitioner (as long as the practitioner has not reached a maximum number). Second, once the practitioner has authorised specialist services, they can choose their provider amongst those accredited. This could be a provider within their local ASL or outwith (Donatini et al. 2001: 59, 63, and 66). However, Gruppo (2003) criticise that families do not enjoy a “real right” of choice between different health services, for two reasons. First, there is the unequal distribution of services geographically, as described above. Second, certain professionals in the public sector are said to distrust the work of private welfare institutions.

Italian health legislation incorporates the child’s right to have his or her views heard. The Charter of the Rights of Children in Hospitals underlines that children should be informed of their own health status and any necessary treatment. The Charter has been accepted by various Regions and by the four main Italian paediatric hospitals – but does not have national legislative backing (Gruppo 2003: 17; Italy 1998: para 424).

The law, though, is vague on children’s right to consent or refuse treatment. Article 32(2) of the Italian Constitution states that “Nobody may be forcefully submitted to medical treatment except as regulated by law. That law may in no case violate the limits imposed by the respect for the human being”. While this would apply to children as well as adults, there is no further specification. The Italian Government reports that, in practice, parents or near relatives give consent for small children while adolescents are given more power to consent or not. Gruppo (2003), however, is concerned that this power is not equally extended to disabled children.

Figure I.2: Relevant health provisions within Law No. 104 of 5th February 1992

Article 5.- General principles relating to the rights of disabled people

1. The aims of removing the causes of invalidity, promoting independence and achieving social integration shall be pursued by means of the following:

- developing scientific, genetic, biomedical, psychopedagogical, social and technological research by various means, including the implementation of specific programmes in agreement with public and private organizations, particularly universities, the national research council [Consiglio nazionale delle ricerche (CNR)]
- ensuring prevention, diagnosis, prenatal and early treatment of impairments and systematic research into their causes
- guaranteeing that timely action is taken by therapeutic and rehabilitative services to ensure that the level of recovery permitted by current scientific knowledge and available technology is achieved, that disabled people remain within their family and social environment, and that they are integrated into and participate in the life of the community
- ensuring that the families of disabled people receive information on health care and welfare programmes to help them understand the situation, including the integration of the disabled person in society
- ensuring that families, communities and disabled persons have a say in the choice and implementation of health and social measures
- ensuring primary and secondary prevention at all stages of development of children and minors in order to prevent or detect the occurrence of impairments at the outset and to reduce and overcome the damage caused by impairments which have already developed
- implementing the geographical decentralization of services and measures for prevention and for the support and recovery of disabled people, ensuring co-ordination and integration with other local services on the basis of the programme agreements [accordi di programma] referred to in article 27 of Law no. 142 of 8th June 1990

- ensuring that disabled people and their families receive adequate psychological and psychopedagogical support, personal or family care services, technical instruments and aids
- promoting by various means, including the participation of organizations and associations, permanent information and popular participation campaigns for the prevention and treatment of disabilities and the rehabilitation and social integration of those affected
- guaranteeing the right to choose the services considered most suitable, even if they are provided outside the local area

Article 6.- Prevention and early diagnosis

1. Measures for the prevention and the prenatal and early diagnosis of impairments shall be implemented within the framework of the health programming referred to in articles 53 and 55 of Law no. 833 of 23rd December 1978

2. In conformity with the responsibilities attributed to them by Law no. 142 of 8th June 1990, and Law no. 833 of 23rd December 1978 and subsequent modifications, the regions shall, within six months of this Law coming into effect, issue directives regarding:

- health information and education for the public on the causes and consequences of disability, on prevention before conception and during pregnancy, delivery, the post-natal period and the various stages of development, and on the services which carry out these tasks
- respecting the natural rhythms and requirements of both mother and baby during labour and birth
- identifying and eradicating, in both living and working environments, any risk factors causing congenital malformations or disabling illnesses
- services for genetic counselling and and early diagnosis to prevent genetic diseases that can cause physical, mental or sensory disabilities
- periodic checks during pregnancy in order to identify and treat any complications and prevent their consequences
- intensive care during high risk pregnancies and births

- during the post-natal period, any checks which may serve to ensure the early diagnosis of malformations and compulsory checks to identify and ensure the timely treatment of congenital hypothyroidism, phenylketonuria and cystic fibrosis. The forms taken by these checks and the way in which they are administered shall be regulated by guidelines and co-ordination documents issued under the terms of article 5, paragraph 1, of Law no. 833 of 23rd December 1978
- on-going prevention activities to protect children from birth through, among other things, co-ordination with the staff of nurseries, primary and secondary schools, to ascertain the absence or the onset of illnesses and disabling conditions, and by checks carried out on children eight days, thirty days, six months and nine months after birth and then every two years from the first birthday onwards. A personal health record book shall be introduced for this purpose, the features of which shall be as described in article 27 of Law no. 833 of 23rd December 1978, setting out the results of the aforementioned checks and any other health information useful in establishing the child's state of health
- information, education, participation and control activities aimed at eliminating environmental hazards and preventing accidents in all living and working environments, with particular regard to accidents in the home

3. The State shall promote immunisation measures aimed at preventing all forms of disability, in particular vaccination against rubella.

Article 7.- Treatment and rehabilitation

1. The treatment and rehabilitation of disabled people shall be effected by means of programmes that provide for integrated health and social care, make the most of the disabled person's abilities and deal with the disablement situation in a holistic way, involving the family and the community. To this end, the National Health Service shall ensure, through its own and through affiliated centres:

- action for the early treatment and rehabilitation of disabled people, in addition to specific rehabilitative and outpatient services provided at home or in the community rehabilitation and educational day-care or residential establishments referred to in article 8, paragraph 1, letter l)

- the supply and repair of equipment, facilities, prostheses and technical aids required to treat impairments

2. The regional authorities shall be responsible for providing full and accurate information on the services and aids available in Italy and abroad.

Article 8.- Social integration

1. The social integration of disabled people shall be ensured by means of:

- a) social, psychological and pedagogical counselling, health care in the home, home helps and financial assistance under the terms of current legislation, in support of disabled people and of the families with whom they live

Article 11 - Stays abroad for treatment

Article 34.- Prostheses and technical aids

1: By means of a decree to be issued by the Minister for Health, after consulting the Consiglio sanitario nazionale [national health council], within six months of the date on which this Law comes into effect, electronic equipment and other technical aids which allow people with physical and sensory disabilities to compensate for their impairments will be added to the reviewed and redrafted classified tariff list of prostheses referred to in paragraph 3, article 26, Law 833 of 23rd December 1978.

Physical Environment

Housing stock[13]	83% owner-occupied; 16% rented; 1% other
Key housing legislation?	▪ Framework Law No. 104 of 1992 ▪ Decree 238 of 18 June 1998
How is housing policy organised?	▪ Social housing: Central government sets policy: Regions administer and deliver ▪ Rent assistance etc.: Regions set policy, administer and deliver
Housing benefits for families with children	Depends on region. Based on income rather than children
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[14]	0.0%
Accessibility regulation to buildings etc.	• Framework Law No. 104 of 1992 • Law No. 13 of 1989 • Law No. 188 of 1971 • Decree 503 of 1996
Has accessibility to public places improved over the past 10 years?[15]	No, in public opinion. 44.9% think access has not improved very much and 10.4% think it had not improved at all
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[16]**:**	3.38 (fairly to very difficult) for physically disabled people 3.31 (fairly to very difficult) for intellectually disabled people
▪ **How accessible are cultural events?**	2.96 (not very to fairly difficult) for physically disabled people 3.28 (fairly to very difficult) for intellectually disabled people
▪ **How accessible are sports events?**	3.04 (fairly to very difficult) for physically disabled people 3.23 (fairly to very difficult) for intellectually disabled people
▪ **How accessible are restaurants, hotels etc.?**	2.91 (not very to fairly difficult) for physically disabled people 3.16 (fairly to very difficult) for intellectually disabled people

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[13] Information from Ball 2004: 84.
[14] See Chapter 5.
[15] See Chapter 2.
[16] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	• Framework Law No. 104 of 1992 • Law No. 160 of 1996	As for disabled children
Are there enforcement mechanisms?	Yes, but ineffective	Yes, but ineffective
Are fare concessions available for public transport?	Yes, for certain categories of disabled people and certain modes of transport	Yes, for certain categories of disabled people and certain modes of transport
Can an accompanying person go free, or for a reduced price, on public transport?	Yes, for certain categories of disabled people and certain modes of transport	Yes, for certain categories of disabled people and certain modes of transport
Is special transport available as an alternative to public transport?	Yes, but subject to budget constraints	Yes, but subject to budget constraints
Is there a parking badge scheme?	Yes	Yes
Is there financial support for private transport?	Yes, but subject to budget constraints	Yes, but subject to budget constraints

Housing

The proportion of owner-occupied dwellings in Italy is the fourth highest in the European Union (Ball 2004: Figure 2.5), at 83%. There is a moderate rented sector, at 16%, but with little social housing (Ball 2004: 84).

Some regions of the country have rent assistance and/or reductions in local taxes but this depends on regional decisions (Bradshaw and Finch 2002: appendix, 36; Kalisch et al. 1998, table 9.2). There is social housing, whose policy is decided at central government level and delivered through regions (Kalisch et al. 1998, table 9.2). Legislation in 1998 facilitates renting or acquiring homes for young people and one-parent families (Italy 1998: para 182). The concentration of policy has been on promoting ownership and renovations (Ball 2004: 84). For example, there is mortgage interest relief and tax relief on renovation works (Ball 2004: 88). Italy is recorded as having no public expenditure (as a percentage of GDP) on housing, compared to an European average of 0.4% (see Table 5.4 in Chapter 5).

Disabled people and their families are given priority within state housing allocation (Italy 2003). Further, there is tax relief and financial assistance for home adaptations (Italy 1998: para 400).

Accessibility to buildings and public spaces

The Framework Law No. 104 of 1992 requires “actions aimed at ensuring access to public and private buildings and at removing or overcoming physical or architectural barriers which hinder movement in public places and places which are open to the public (Article 8(1d), Discapnet). Article 24 makes further requirements, such as:

- All construction for public and private buildings that will be open to the public must meet accessibility standards
- Requests for planning permission must contain drawings and a declaration with compliance on accessibility standards
- Issue of the building permit or authorization is subject to verification
- Failure of building work to comply with the standards can result in a fine and suspension of registration

- Funds will be used to remove barriers from public residential complexes already built (Discapnet)

Despite these requirements, respondents to the Eurobarometer survey (see Chapter 2) think that access to most events etc. is fairly to very difficult for disabled people and, for most categories, more difficult than the European average response. Progress over the past decade seems to have been limited. Over half of respondents think that access to public places has not improved very much or has not improved at all.

The Italian Government's report to the UN Committee on the Rights of the Child (1998) cites the commitment for child-friendly committees. Children's needs and spaces are to be considered within urban planning. There is an office in the Ministry of Environment to monitor local measures.

Transport

Italy has national legislation that requires accessible public transport. Framework Law No. 104 of 1992 requires regions to regulate how municipalities: "… take action to allow disabled people to move freely around their locality, using suitably adapted public transport or alternative services, under the same conditions as other citizens" (Article 26 (1), Discapnet). Thus, nearly all regional administrations have passed legislation on accessible transport. Act No. 160 (24 October 1996) further requires transport and infrastructure to be accessible to disabled people.

Despite this legislation, enforcement is considered unsatisfactory:

- Notwithstanding the existence of specific and effective laws, their enforcement is quite unsatisfactory due to a lack of penalties laid down by the laws themselves. Whoever needs to enforce them is not given the possibility to do so. For example, local governments may be requested to invest on accessibility to transport modes for disabled people but they are not given the possibility to collect the necessary funds. (CD 2000a: 38)

Enforcement can be through refusing funding: the Government or any public body cannot grant funds to public works or public buses that do not comply with accessibility rules (CD 2000a: 38). A range of work has been undertaken in various spheres of public transport, such as Italian Rail, to increase accessibility (Council of Europe (CE) 2000).

Concessionary fares differ by mode of transport and disability. For example, Italian Rail does not provide special fares for disabled people but does provide free tickets for those requiring an accompanying person. Public transport fares are decided by local governments but most provide reduced fares for those with assessed 67% disability. Alitalia gives a 30% discount to disabled passengers (CD 2000c: 7).

Municipalities are responsible for providing special transport for those unable to use mainstream public transport. Free taxis may be provided – but these are only for transport to and from work and health treatment. (CD 2000a: 7). Further, the 1992 legislation allows for any provision to be subject to budgetary limits (Article 26(2), Discapnet translation).

Parking badges are available for private cars. The 1992 legislation provides for financial assistance with the purchase or adaptation of private cars (Article 27, Discapnet). Assistance, however, is not available uniformly throughout Italy (Italy 2003).

Leisure and Recreation

Law No. 285 of 28 August 1997 established a National Fund for children's services. The Fund had four aims and one of these was to create recreational and educational services for spare time activities. The National Fund was administered by the Council of Ministers and divided amongst Regions and cities (Italy 1998: para 21f). The Italian Government hopes that this Fund will yield results:

- Of course it cannot be said that the network of such [educational activities] is everywhere equally widespread but the commitment of all the local authorities – which was given a boost by Law No. 285 of 1997 – gives reason to hope that the lacunae will soon be filled (1998: para 496)

Gruppo (2003: 65), though, notes that one problem with the fund is its annual financing, that prevents integration of initiatives into children's services. The Italian report goes on to note existing provision: there are childen's play centres; public spaces for games; recreation centres and educational centres for young people; initiatives for summer school holiday activities; network of municipal library. There are young people's cultural and ecological groups, that involve

- Approximately 15% of boys and 19% of girls aged 14
- Approximately 15% of boys and 20% of girls between 15-17 years (Italy 1998: para 505). The report notes that more needs to be done "to develop genuine cultural interests in the generation who face the future" (Italy 1998: para 503)

The Italian Government recognises the rights of disabled children to leisure and recreation – and that these rights are not yet met. Within its report on Article 23, the report states:

- Children with disabilities do not have special requirements in this respect, but often, precisely because of the permanent situations of disadvantage with which they live, they have more need than others do for this kind of space.

This growth of social awareness has not given rise, in all areas of the country, to the necessary arrangements for related services and extracurricular measures. Often the right of children with disabilities is still conditional and, in some cases, denied. The barriers that exist in public and private buildings, in social and tourist structures, in urban areas and in public transport are for many children with physical or motor difficulties the concrete indicators of their daily discomfort. When local authorities create recreation and social services and areas for children, they do not always take into consideration the needs of children with mental disabilities and they do not arrange adequate forms of support to facilitate their participation (1998: para 404-405.

Legislation for disability, the Framework Law No. 104 of 1992, does set out a range of provisions to ensure adaptation, training and access of recreational, sports and cultural facilities for disabled people. For example, Article 23 requires the removal of obstacles that hinder sport, tourism and recreational activities.

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SWEDEN

Sweden is divided into 21 county councils (Landsting) and 290 municipalities (Kommuner). The municipality of Gotland is an exception, as it does not have a county council. Decentralisation is a key principle for Sweden. The Swedish Government typically establishes the legal framework, with central administrative authorities and agencies responsible for implementation. County councils and municipalities have responsibilities for provision, and considerable control over policy details. County administrative boards frequently have a supervisory role, working closely with the relevant central administration agency. The aim of decentralisation is clearly stated, for children's services:

- It is a fundamental principle of Swedish society that decisions affecting children must be made by persons as near as possible to the child. That is why, subject to the national objectives, the planning of activities for children and young persons in Sweden is a municipal [and sometimes county] responsibility (Sweden 1998: 16)

However, decentralised decision making means that different decisions can be made about provision. The resulting inequalities are recognised by Swedish non-governmental organisations, the Swedish Government and the UN Committee on the Rights of the Child:

- While noting the positive aspects of decentralization in the provision of services by the municipalities, the Committee is concerned that it has caused inconsistencies in policies and disparities in the provision or accessibility of services to children and their families (1999: para 7)

Sometimes the allocation of responsibilities between county councils and municipalities is not absolutely clear – e.g. for assistive technology – and people can find it difficult to access the necessary services. Along with recognising the right of service users to have their views heard (whether it be children in schools or disabled people in assessments for social services), there has been a recent emphasis on consumer choice. This is evident in parents' right to choose schools, including schools in the independent sector, with state funding following the parent's choice. Patient choice has equally been increased in the health sector. However, these have been contentious policies in Sweden.

Sweden has generous state provision and is described as a social-democratic regime (see Chapter 1), with an emphasis on universal provision. Child poverty is low, in comparison to other European Union countries, and child benefit packages generous (see Chapter 5). The generosity of public expenditure was severely curtailed by the economic crisis in the 1990s. Families with children were particularly badly affected by these cuts. Another major change for Sweden has been the considerable increase in immigration. It has changed from a largely homogenous society, to one in four children now having at least one parent born outside Sweden (Sweden 2004a).

Sweden has embraced international instruments on human rights, including the UN Convention on the Rights of the Child (UNCRC) and the UN Standard Rules on the Equalization of Opportunities (Standard Rules). Nonetheless, the Swedish Government (2004a) itself recognises that the rights of children with learning difficulties are not adequately met. The quotes below show perceived deficits in provision, in habilitation services, social support and education:

- A study by the National Association for Disabled Children and Young People shows that many parents are dissatisfied, for example, with habilitation activities, above all as regards their availability, their continuity and the time which staff are able to devote to child and family (Sweden 2000: 12)
- Social support for children with disabilities is regarded, according to the Disability Ombudsman, as a negotiable benefit hinging on economic considerations. The Disability Ombudsman has seen tendencies for applications for support to be refused, regardless of the child's need, on the grounds that resources are lacking. Children with disabilities are badly affected by such attitudes, dependent as they are on support for their opportunities for development (Sweden 2000: 12)

Equality/ anti-discrimination, Information and Advocacy

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13: Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14: Has the ECHR been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No	No
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law on … ?	Yes. Government Bill on a strategy for Implementing the UNCRC	Yes. Government Bill on a national action plan for disability policy
What type of domestic law is it? (criminal, constitution, civil rights, social welfare?	Social welfare	Social welfare Constitution – under consideration
Is there an enforcement mechanism?[1]	Office for Children's Ombudsman <u>does not</u> handle individual complaints but can carry out investigations. Reports on strategy to Swedish Parliament Inspection and monitoring by National Boards	Office of Disability Ombudsman <u>does</u> handle individual complaints and can carry out investigations. Reports on national action plan to Swedish Parliament Inspection and monitoring by National Boards
Are there (other) standing national bodies to provide policy advice?	Yes ▪ Parliamentary Children's Committee ▪ Child & Youth Advisory Committee	Yes Government Disability Advisory Panel

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[1] Sweden has a range of other ombudsman with statutory powers. See Sweden 2000 for more information.

Anti-discrimination by age

In relation to children's rights, Sweden has ratified the UNCRC. The Swedish Parliament passed a Government Bill on its implementation in 1999, setting out a national strategy (Ministry of Health and Welfare, Sweden 2002). Child impact assessments must be made for all government decisions affecting children. In-service training on the UNCRC is provided to all government employees (Sweden 2004a: 13). Central agencies – the National Boards – can inspect and monitor authorities, and have been instructed by the Government to take on particular tasks in regards to the strategy. These create a strong package of training, assigned responsibility and monitoring, to implement the UNCRC.

Unlike the Disability Ombudsman, the Children's Ombudsman (BO) does not deal with individual complaints. The Children's Ombudsman can request administrative authorities, municipalities and country councils to report on measures taken in their own operations to implement the UNCRC and these agencies may be required to attend discussions (BO 2003).

The Children's Ombudsman has a particular role in enabling children's views to be heard in public debates. The Ombudsman herself gathers children's views by a variety of questionnaires and studies, by letter, telephone and the internet. She has links with school classes throughout the country and has a 14-member child and youth council. There is also a special telephone information line where children can obtain advice (Swedish Institute 2000: 3; Sweden 2004a: 14).

Anti-discrimination by disability

To implement the Standard Rules, the Swedish Parliament passed the Government Bill *From Patient to Citizen: a national action plan for disability policy* in May 2000. The Swedish National Action Plan (2000), for example, states three national objectives for disability policy:

- A social community based on diversity

- A society designed to allow people with disabilities of all ages full participation in the life of the community
- Equal opportunities in life for girls and boys, women and men with disabilities (4)

The National Action Plan fits into the ‘social welfare’ category of Degener’s (2003) typology (see Chapter 3). The Plan focuses on the duties of the providers rather than the rights of the individuals. It thus has the positive elements of establishing national standards and requiring proactive change. While Degener (2003) venerates civil rights approaches for being more specific and radical than other approaches, the National Action Plan does have the potential to be specific on goals and monitoring and has arguably sought to incorporate the ‘social model’ of disability. The Plan deliberately seeks a holistic approach, as described by the Swedish Government in its report to the UN Committee on the Rights of the Child: “It is the Government’s view that disability aspects must be taken into account in all policy fields and in planning at central, regional and local levels” (1998: para 465).

Sweden takes a civil rights approach in its employment legislation: the Prohibition of Discrimination against Persons with Disabilities in Employment Act SFS 1999-132. However, this approach is not taken to other areas, which disabled children themselves would directly access or experience, like school education.

While the employment legislation above has a definition of disability, the National Action Plan does not. Sweden has a tradition of a non-categorical approach, which is seen as avoiding discrimination through labelling, while recognising barriers created by society. Within individual services, though, some categories can be found (such as in social insurance – see below).

The National Action Plan has established goals and monitoring procedures and the Swedish Parliament expects regular reports on progress. The Office of the Disability Ombudsman, set up under separate legislation, has the ability to investigate individual complaints as well as to investigate particular issues (HO 2003). According to the National Action Plan (2000), Sweden may also incorporate a constitutional approach in time. The Commission on the Constitution has been asked to consider ways of clearly expressing “the principle that disabled people and other vulnerable groups should participate in society on equal terms” (18) within the Instrument of Government.

Advocacy and Information

Both Ombudsmen have a major role in disseminating information. In addition, there is a Parliament Children’s Committee and Advisory Committee within the Cabinet Office on Child and Youth Affairs (Sweden 1998: para 13-14, 106). There is a state foundation that addresses children’s issues, with an emphasis on social issues (Allmänna Barhuset) (Sweden 1998: para 16). The BO seeks to involve children actively in its work (BO 2003a), with consultation arrangements and children’s and youth councils. At a local level, a survey found nearly half of municipalities reporting the active involvement of children and young people. Eighty-one municipalities had special youth councils and seven had youth parliaments. (Sweden 1998: para 20) Nationally, children’s and parents’ opinions are gathered through the National School and Home Union and the Swedish Union of School Students (Sweden 1998: para 643).

In relation to disability, there are legal provisions requiring the representation of disabled people in policy-making (Ministry of Social Affairs, Sweden 1996). There is a Governmental Disability Advisory Panel and there are joint consultation procedures for policy makers and organisations of disabled people at national, county council and municipality levels (European Committee of Social Rights (ECSR) 2003).

There is an active sector of children’s organisations and organisations of disabled people (ECSR 2003). For example, there is an umbrella group particularly for disabled children and young people – the Swedish National Association for disabled children and young people (RBU). There is the Swedish Disability Federation, which brings together 46 disability organisations (HSO 2004).

Education

	All children	**Disabled children**
Key education legislation	Education Act 1985 and ordinances	Education Act 1985 and ordinances
Does child have the right to education?	Yes	Yes
How is education organised?	Devolved and decentralised. ▪ General management and goals: ▪ Swedish Parliament (Riksdag) and the Government ▪ National Agency for Education ▪ National Agency for School Development ▪ Operational implementation primarily through the 290 municipalities Except: Saami schools, which are supervised by the National Agency for Education	As for all children except ▪ The National Agency for Special Schools for the Deaf and Hard of Hearing (established 2000): 6 units for pupils as well as a central administration ▪ The Swedish Institute for Special Needs Education (established 2001): provides support to municipalities and schools (including independent schools) Technical aid is provided by the 21 county councils
How is education monitored?	▪ National Agency for Education ▪ Municipalities should on a regular basis follow up and evaluate schools' plans. Municipalities provide an annual written report on activities at a municipal and school level. ▪ Schools must monitor and evaluate their activities annually	As for all children
Is there compulsory education?	Yes	Yes
What are the ages for compulsory education?	7-16	7-16 except an option of an additional year in special schools
Is there a national curriculum?	Yes, although flexibility locally	Yes, although flexibility locally and adapted syllabuses
Is compulsory schooling free ?	Yes	Yes
Are incidental costs of schooling free at the point of use?	Yes, books, writing materials, school meals, health care	Yes, as for all children as well as personal assistance, educational aids

Does the state provide free school transport?	Yes, except municipality is not obligated to pay if parent chooses school not proposed by municipality	Yes, except municipality is not obligated to pay if parent chooses school not proposed by municipality
Can parents exercise school choice?	Yes, including for approved independent schools	Yes, including for approved independent schools. However, choice can be restricted for organisational or financial difficulties.
To what extent are parents involved in school decisions about their individual child?	Schools must work with parents on school content and activities as well as informing parents regularly on their children's progress	As for all children
To what extent are children involved in school decisions about them?	Education Act states that all pupils in school shall be able to influence the design and content of their education, in light of the pupils' age and maturity	As for all children

In regards to special educational needs …

Is there an official policy for school inclusion?	Yes
What type of education system is there (one-track, multi- two-track)?[2]	Primarily one-track
What percentage of children is in special schools or special classes?[3]	1.3%
What percentage of children has 'special educational needs'?[4]	2.0%
Are there special schools?	Yes ▪ Special schools for Deaf and Hard of Hearing ▪ Special programmes for those with learning disabilities (särskola) – although these programmes are closely linked or integrated into mainstream school activities
How is eligibility for special support determined?	
▪ **Categorical/ noncategorical**	Non-categorical
▪ **Who can initiate**	Head teacher
▪ **Assessment**	Yes
Do children have the right to support for special educational needs?	Yes
Is there compulsory teacher training on special educational needs?	Yes, at initial teacher training

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[2] Information from EADSNE 2003.

[3] 2001, Information from Table 4.1 EADSNE 2003.

[4] 2001, Information from Table 4.1 EADSNE 2003

Principles and Structure

Sweden has a highly devolved and decentralised structure for state education. The Swedish Parliament (the Riksdag) and the Government are responsible for the general management and goals for schools, while operational responsibilities are devolved to municipalities. (Sweden 1998: para 536) Schools have considerable control: for example, they determine the precise curriculum offered. There are exceptions to such devolution. Saami schools, for the indigenous Saami population, and special schools for pupils who are Deaf and Hard of Hearing remain under national management.

The guiding principle of Swedish education is “a school for all” (European Agency for Development in Special Needs Education (EADSNE) Sweden 2004), which is evidenced in the Swedish Education Act (SPS 1985, Chapter 1 para 2):

- All children and young people shall, regardless of gender, geographical residence and social or economic situation, have equal access to education in the public school system for children and young people. (Persson 2004: 3)

Disabled children and young people are both obliged and entitled to such education. Compulsory school age is from age seven to 16, although special school pupils can have an additional year (Sweden 1998: para 565). Children have the right to start school at age six if their parents want this and the municipality has capacity (Dialogue with Citizens Sweden 1998). Pre-school classes for six year olds are available, free of charge for 525 hours per year (Sweden 2004a: 93). Further, children who frequently miss school due to illness are entitled to be taught at the hospital or in their home (National Agency for Education (SNAE), Sweden 2003).

In terms of public expenditure on education (as a percentage of GDP), Sweden spends more than the European average (7.8% compared to 5.3%) (Table in Chapter 5). Compulsory schooling is free at the point of use for children, and a range of incidental costs are also funded by the State – e.g. transport, school meals, health care, educational aids. Should a parent, though, choose to send their child to a school not proposed by the municipality, the municipality is not obliged to pay for school transport. Parental choice of school is encouraged, with money following the pupil. This has encouraged a growth in independent schools (Lundahl 2002: 691-692). Rädda Barnen reports that disabled children are more restricted in school choice than other children; local authorities can cite organisational or financial difficulties as a reason for a child to attend a particular school (2004: 19).

The Education Act states that all pupils in school shall be able to influence the design and content of their education, in light of the pupils' age and maturity. Children and young people report on implementation of this right: Although they were generally confident of their ability to exercise influence, they pointed out that some teachers were better at listening than others. They also maintained that the older they became the less influence they had – contrary to what one might normally expect (Sweden 2004a: 7).

Schooling for Disabled Children

Sweden's 'a school for all' policy supports inclusion:

- There has been an important philosophical shift in terms of education and inclusion, whereas earlier debates focused upon prerequisites for mainstream now the focus has shifted to the need for justification for segregated options (EADSNE Sweden 2003)

Twenty-one per cent of Swedish compulsory school pupils are said to be in need of special education (Persson 2000), although Persson (2004) reports that only 17% of all children receive special support. A small – but growing – proportion of children attend special schools. There has been a rise of just over 50% in the proportion of children registered for special programmes, while the number of children in comprehensive schools has only increased by 17% since the 1990s (BO 2002: 10). While the percentage rise in special schools may be large, it represents a small number of children: a little more than one per cent (Persson 2004). A range of special support is possible, such as:

- In-classroom support for students, including classroom assistants, personal assistants for children, adapted teaching materials and expert advice for the classroom teacher

- Support for the classroom teacher, through a consultant special teacher and/or the local resource centre
- Removal of the student for limited periods to work with a special teacher or in a group with those with similar needs (EADSNE Sweden 2004)

Physical barriers remain in many schools (RB 2004: 43). The local municipality has the responsibility to ensure that each school has sufficient resources for disabled pupils (Ingmanson 2003). The National Agency of Special Needs Education offers pedagogical support for local authorities (EADSNE Sweden 2004). The headmaster of the school decides about support for the individual pupil. Rädda Barnen is critical that there is no definition of 'support', so that there are regional differences and financial priorities can negatively impact on support provided (2004: 42).

Pupils who "cannot attend compulsory or upper secondary schools because of their learning disability" (Eurydice Sweden 2002: 56) have the right to special education for those with learning disabilities, the Särskola, as do autistic children and those with "significant or permanent functional impairments as a result of brain damage" (Eurydice Sweden 2002: 56). These programmes are said now to be linked closely to, or integrated, into mainstream school activities (EADSNE Sweden 2004).

The Board of the Specialskola, for those who are Deaf and Hard of Hearing, decide whether a child should be given a place. Applications can be made by the child's parents, guardian or home municipality. Should a place be refused, a child's parents or guardians can appeal (Eurydice Sweden 2002). Following this, parents can contact the National Agency for Education. The National Agency has no sanctions against an authority but the authority is obliged to address any criticism of the Agency.

Swedish teacher training requires all teachers to have knowledge and experience of special needs education. However, the Eurydice report on Sweden (2002) notes that in the past this was delivered in varying degrees and, in some institutions, not at all. A specific teaching degree is also available following an advanced training programme in special needs.

Social Security

Proportion of children aged 0-15 in relative poverty[5]	10%
Proportion of children aged 0-15 in absolute poverty[6]	5.3%
Key social security legislation	• General Child Benefit Act (Lag om allmänna barnbidrag) of 1947 mended • Advance on Maintenance Payments Act (Lag om underhllsstöd) of 1996 • Housing Allowance Act (Lag om bostadsbidrag) 1993 • Social Insurance Act from 1 January 2002 • Social Services Act 1982 as amended (Socialtjänstlagen) • Act concerning Compensation for Assistance (LASS) 1993
Value of benefit package, as % of earnings[7]	10.2%
Ranking (leaders, 2nd rank, 3rd rank, laggards)[8]	Second rank
What % of GDP is spent on family cash benefits and family services?[9]	2.9%
Tax benefits for families with children	No
Income related child benefits	No
Non-income related child benefits	Yes, Barnbidrag – does not vary by number of children, age or characteristics of child; age 16 or over 16 and in full time education; government decides on up-rating and not indexed or taxed
Social assistance for families with children	Yes, Socialbidrag - adults who lack means of supporting themselves or cannot meet their needs in other ways; additional amounts for children.
Parental leave	Yes, Parental leave – 480 days (2 month for each parent of first 360 days); flexible; age limit 8 years; paid; job guaranteed
Statutory leave for care of sick children	Yes, 60 days/ child/ year; child aged to 12 years; 80% of wage; job guaranteed
Type of benefits for disabled children	
• **supplement or extend child benefit**	Yes, extend Barnbidrag for person in special school for mentally handicapped.
• **benefits for caring costs**	Yes, Care Allowance (Vårdbidrag). Temporary parents' allowance.
• **benefits based on child being disabled**	Yes, Assistance, Car and housing allowance,

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[5] Children living in households with below 60% median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

[6] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[7] Information from Bradshaw and Finch (2002), as of July 1 2001.

[8] Information from Bradshaw and Finch (2002), as of July 1 2001.

[9] See Chapter 5.

Sweden has a low rate of child ‘absolute’ poverty of: one in twenty children. The rate is substantially higher when a relative poverty measure is used, of one in ten children, in 1997. Economic problems in the 1990s and subsequent cut-backs in the welfare state disproportionately and negatively impacted on children and their families (Rädda Barnen 1998, 2004; Bernhardt undated). Bernhardt reports that there was a trend towards less generous provision and decreased coverage. The situation has improved since 1997, according to the Children’s Ombudsman (2002), but in 2000 children were still not returned to the economic level they were at in the early 1990s. The Swedish Government reports further efforts to improve the financial situation of families with children, in its report to the UN Committee (2004). Public expenditure (as a percentage of GDP) is high on family cash and services benefits – 2.9% compared to a European average of 2.2% (see Chapter 5).

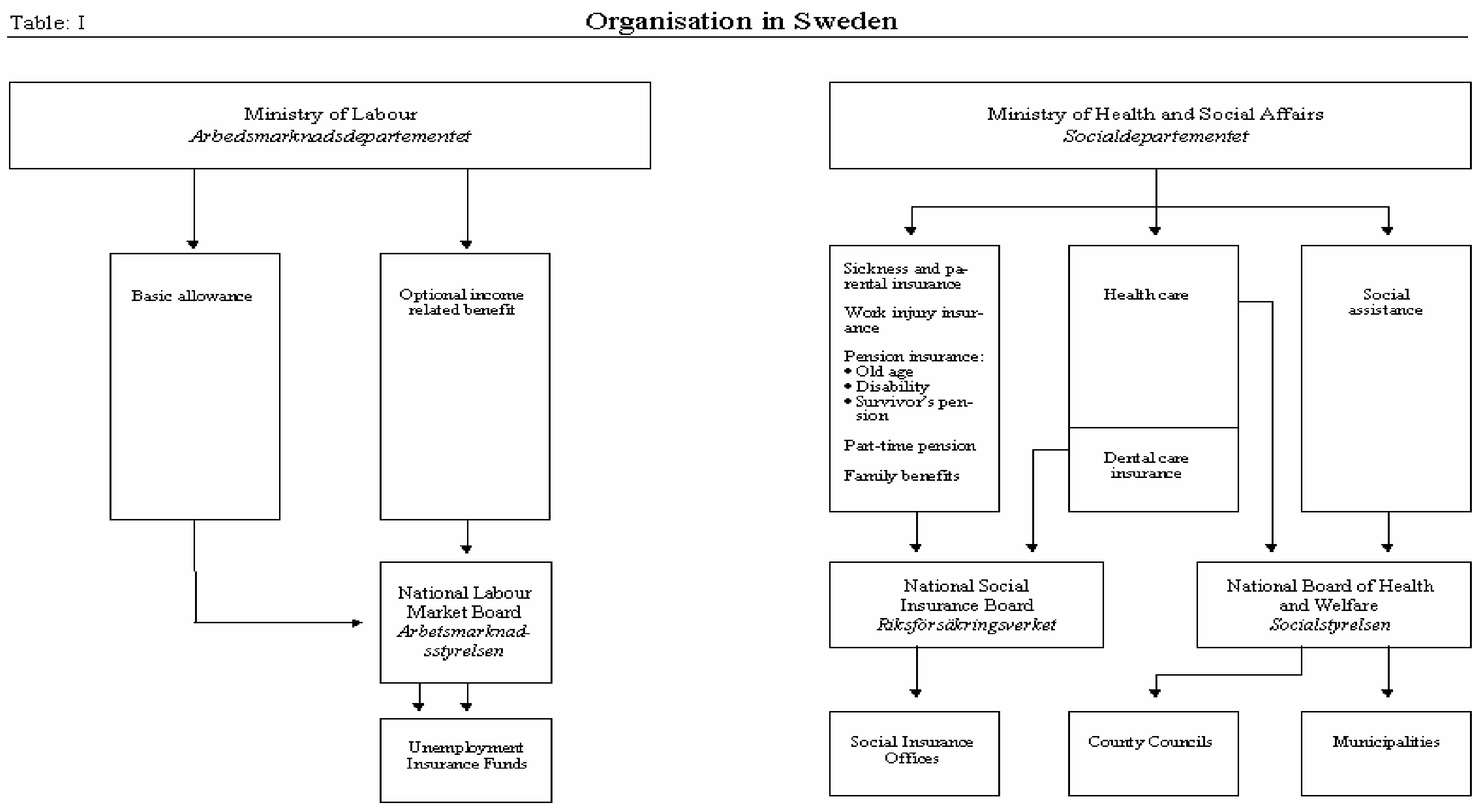
Administrative arrangements are shown in the Diagram Sweden. Legislation and guidelines are set nationally in Sweden but the administration is undertaken locally by municipalities (Bradshaw and Finch 2002; Ginsburg 2001). This decentralisation has led to inequality.

The Swedish Government, in its report to the UN Committee on the Rights of the Child, identified cut-backs in a growing number of municipalities, in regards to: help below the recommended national level for families dependent in the short term on financial support; assistance given to children in need of special support; and limiting the choice of care alternatives (1998: para 169). New legislation is attempting to create more uniformity (Sweden 1998: para 553).

Financial support for all children

Sweden’s child benefit package in 2001 was worth 10.2% of average earnings, in Bradshaw and Finch’s calculations, leading to it being placed within the second rank of countries. Sweden is unlike many other countries, in that it is not increasingly supporting families through the general tax system. Rather, a substantial proportion of its child benefit package comes through a flat rate, non-income based child benefit (Barnbidrag) and a minor contribution to school costs.

Diagram Sweden: Administrative Arrangements for Social Security in Sweden



Source: MISSOC (undated) Comparative Tables http://europa.eu.int/comm/employment_social/soc-prot/missoc98/english/f_tab.htm (14.5.04)

Sweden is well-known for its generous parental leave. Each parent has the possibility of 480 days of parental leave and, to try and encourage gender parity, there is two month quota for each parent (Sweden 2004a: 86). The age limit for the child is eight years. There is tapering wage replacement and the job is guaranteed. The temporary parental allowance provides a statutory right to parents, to care for their sick or disabled children. A parent can take up to 60 days per child per year, to take care of a child under the age of 12 in particular circumstances: i.e., when the child is ill or contagious; when the regular caretaker is ill; to visit the child welfare centre; when the child's other parent is visiting a doctor with another child. The circumstances are extended if the child is disabled, to include: taking the child to treatment' learning how to take care of the child, visiting the child's doctor or visiting the child's school. Further, the age is extended up to 16 and sometimes beyond to 21 or 23 and extra days are added. The wage replacement is 80% and the parent's job is guaranteed (Bradshaw and Finch 2002; Ingmanson 2003 translation: 84; MISSOC 2002; Sweden 1998: para 365).

Other financial support for disabled children

Sweden has extended its age limit for its child benefit (Barnbidrag) for disabled young people, if they are part of the Särskola, but no additional amounts are paid for children who are disabled. Instead, Sweden provides benefits for caring and for the costs of disability. The Care Allowance intends to compensate for the extra care, loss of income and additional costs due to a child's disability (Ingmanson 2003 translation: 38).

Assistance Allowance is available, through LASS (see below), which compensates for personal assistance. This allowance is available for disabled people, children as well as adults. For a child, consideration is given to the extent of parental assistance but the allowance can be combined with the Care Allowance. This allowance is available for people who need more than 20 hours of help per week with basic needs. (Ingmanson 2003 translation: 101-105) A car allowance is available, to contribute to the purchasing of or adapting a car, when the disabled person cannot use public transport.

Support and Care Services

	All Children	**Disabled Children**
Key childcare legislation	Education Act 1985 and ordinances	As for all children. In addition: Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) (lagen om stöd till vissa funktionshindrade) 1993
Does a child (or carer) have the right to childcare?	Yes	Yes
Is there formal out-of-school care provided by the State or with State support?	Duty to provide out-of-school care until the age of 12	As for all children. In addition, LSS provides for short-term supervision of disabled children over the age of 12
How is childcare organised?	Municipalities ensure the provision, the financing and the inspection of childcare.	As for all children
Are there eligibility criteria for childcare?	Age	Children with physical disabilities have priority to a pre-school place Assessment needed for LSS
Is childcare free at the point of use?	No, but state subsidised and maximum fees. Quota of free hours for pre-school education.	As for all children
Does supply meet demand?	No	No

	Disabled Children	**Disabled People or Adults**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes	Yes
Key support legislation	• Social Services Act 1982 as amended (Socialtjänstlagen) • Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) (lagen om stöd till vissa funktionshindrade) 1993 • Act concerning Compensation for Assistance (LASS) 1993 • Assistance Benefit Act 1993	As for disabled children

Does the disabled person have the right to support services?	Yes	Yes
How are support services organised?	• Local municipalities provide all support services under LSS except for counselling and personal support, which is a county council responsibility. • National Board of Health and Welfare performs a normative, coordinative and method-developing function in its supervision of the social services • County administrative boards bear the operational responsibility for supervision.	As for disabled children
What are the eligibility criteria?	• Social Services Act – needs tested; standard 'a reasonable level of living'; no explicit definition of disability • LSS – needs tested; standard 'good living conditions'; 'considerable and lasting physical or mental physical disorders'	As for disabled children
How are such criteria assessed?	Assessed by municipality	As for disabled children
What involvement do parents have in decisions about support services?	▪ Social Services Act – actions should be with agreement of parents	Should be involved
What involvement do disabled people have in decisions about support services?	▪ Social Services Act -- a child's attitude should be ascertained	Should be involved
Is support provided in cash or in kind?	▪ Social Service Act – cash and in-kind. Fees subsidised ▪ LSS – free of charge, with some exceptions	As for disabled children
Does supply meet demand?	Yes, although local variance	Yes, although local variance

What support is available for carers?	• Support interviews and counselling • Contact person to provide support
What support is available for siblings of disabled?	As above for parents. Limited.
Are short-term breaks available?	Yes
Does the State regulate non-family placements (residential or foster)?	Yes

Childcare and out-of-school care

Sweden has a strong commitment to providing State-funded childcare. Children aged three to five years are guaranteed a pre-school place for 3 hours per day (15 hours per week). Other parents, with children aged one to five years, also have the right to access pre-school education (e.g. parents who are studying, are unemployed or employed or are taking off time from work because a child is sick). (Sweden 2004a: 87) The childcare commitment applies to children aged one to 12. Five types of municipal childcare are available:

- Day nurseries accept children aged approximately one to six whose parents are working or studying. Some day nurseries accept children up to the age of 12 before and after school hours.
- Family day nurseries. A municipally employed child-minder looks after children aged one to 12 in her home.
- Leisure centres are open for children aged from seven to 12 who need supervision before and after school.
- Nursery school or play school provides free care for all four to six year olds, three hours a day. Children of immigrants can start at the age of four.
- Open pre-school. In many places pre-school teachers or child nurses organize activities for children and their parents or child-minders. No charge is made for visits. (Dialogue with Citizens Sweden 1998)

Disabled children are given priority (EADSNE Sweden 2003; CE 2003). Further, they have the right to take part in ‘ordinary’ pre-school and after-school centre activities, with municipality support as required. Where this is not possible, a special group may be attached (CE 2003: 343). School aged children who are hospitalised or receiving treatment should also have the right to participate in activities offered to those in leisure centres (SNAE 2003).

The numbers of older children using childcare services is low: approximately 7% of children between the ages 10-12 attend after-school and family day-care centres, while another 5% use open leisure activities (BO 2002). Younger children are more likely to use such services: as of 2001, 69% of all school children aged six to nine were enrolled in after-school and family day-care centres (SNAE 2003)

Fees are generally subsidised. In order to qualify for central government grants, municipalities must set fee ceilings based on a household's income and the number of children (Ministry of Health and Social Affairs, Sweden 2003; Sweden 2004: 88). Fees vary across the country (Dialogue with Citizens 1998). At least 525 hours of pre-school, for children aged four to five, must be free (Sweden 2004a: 88). Fees are not further reduced on the basis of a child's disability (Sweden 2004c).

Support at Home

Disability reform in the 1990s resulted in new legislation and policy. Lindqvist (2001) describes its intentions:

- to protect the most vulnerable from cutbacks in welfare and decentralisation
- to give disabled people precise social rights, to compensate for the looseness created by de-regulation and open-ended framework laws
- service users would be able to request services and they should be able to influence services
- to supplement, rather than replace, ordinary health and social services (paraphrased from page 31)

Two complementary pieces of legislation – the Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) and the Act concerning Compensation for Assistance (LASS) – came into force in January 1994. This legislation applies to both children and adults. Service eligibility is determined by three categories:

(a) Persons with intellectual handicap, autism or quasi-autistic conditions
(b) Persons with a considerable and enduring intellectual handicap following brain damage in adulthood as a result of external violence or physical illness
(c) Persons who, as a consequence of other major and persistent functional impairments, have considerable difficulties in their daily living and, accordingly, are extensively in need of support (Sweden 1998: para 469)

Families apply for services, and this can be done verbally as well as in written or other form. Medical assessments can be part of the assessment, according to Lindqvist (2001: 25-26): either to assess which of the three categories the disabled person fits or medical certification to determine difficulties under category (c). Officially, though, professional assessment of (c) should be sufficient. Ten different services are available under LSS:

- Counselling and support
- Escort services
- Assistance from a contact person
- Relief service in the home
- Short-term stays away from home
- Short-term supervision for school pupils over the age of 12 away from home, in connection with the school day and during holidays
- Accommodation in family homes or in housing with special services for children and young persons needing to live away from the parental home
- Housing with special services or other modified housing for adults
- Daily activities for persons of employable age who are not gainfully employed and not educationally active
- Personal assistance (Sweden 1998: para 471)

Personal assistance is perceived as particularly important service, in providing disabled people self-determination over their daily lives (CE 2003: 338, Ingmanson 2003 translation: 30).

The National Board for Health and Social Welfare (2003) provides statistics on use of LSS services, for children and young people aged 0-22 years. As of 1 September 2001, almost 14,800 children and young people used such services. This was an increase of 1,500 children since 1999. Lindqvist notes that social services have become stricter on their needs-test, creating more pressure on LSS for support (2001: 31).

Support can also be offered under the more general Social Services Act 1998. The Act aims to “promote people’s economic and social security, equality of living conditions and everybody’s chance to participate in social life” and has a particular responsibility to do this for disabled people (Ingmanson 2003 translation: 39). Section 21 sets out the general requirement:

- The municipal social welfare committee shall work to ensure that persons who, for physical, mental or other reasons, encounter difficulties in their everyday living are given the opportunity of taking part in the life of the community and living like others. (Sweden 1998: para 468)

Assistance is provided in cash or in kind under this Act. The National Board of Health and Social Welfare provides a list of available services under the Act:

- Specially adapted apartments with support facilities
- Group accommodation or an apartment in a special housing complex, for individuals who want and need to have staff available 24 hours a day
- Home help services or home-based assistance in the form of service, practical assistance or personal care
- A companion to assist recreational activities, outings, shopping or social contacts
- Support/part-time assistance in the home or in temporary accommodation, for functionally disabled individuals cared for by relatives
- Occupational or other activities for those who are free in the day-time
- Contact person for individuals who need social contact (2002: 23)

The Act does not have an explicit definition of disability (Lindqvist 2001: 27). Municipalities are responsible for services. Lindqvist (2000, 2001) identifies certain key differences between the Social Services Act and the LSS/ LASS legislation:

- The Social Services Act has a lower standard than the LSS/LASS legislation: a ‘reasonable level of living’ and ‘good living conditions’, respectively
- The Social Services Act only requires services to be provided if the need cannot be met in another way whereas the services can be provided under the LSS if needs are not met in another way

- There are income-related charges for services under the Social Services Act, and financial assistance is means-tested, whereas services are typically free of charge under LSS (with a few exceptions)

The Children's Ombudsman has criticised that, until now, LSS has lacked a clear child and youth perspective (BO 2002: 30). In particular, the Ombudsman asked that children be given a "clearly stated right" to express their views in applications' procedures, for support and services (2002: 30). Rights for parental and child involvement are set out within the Social Services Act (Sweden 1998: para 250, 370; Sweden 2004a: 47).

Personal support and counselling is available to parents, as listed above. The Children's Ombudsman, however, notes that insufficient support is provided to both siblings and parents; the office recommended that the list of available forms of support be extended in law. (2002: 31) LSS provides for short-term breaks: 8000 disabled young people used this service in September 2001 (National Board for Health and Social Welfare, Sweden 2003: 5). If the child does not qualify for LSS, breaks may also be funded under the Social Services Act (Sweden 2004a: 58).

Care and support away from the family home

The legislation described above supports disabled people living within their communities. However, if this is not possible or the best solution for children, foster homes and housing accommodation can incorporate special arrangements for disabled children to live away from their family home (CE 2003: 342; Ingmanson 2002 translation: 36; Sweden 1998: 473).

Social services in municipalities are responsible for ensuring that the children receive good care and they must now have a care plan. These services are subject to inspection and the placements are regulated by legislation. Parents are asked to contribute to the costs of children placed away from home (Ingmanson 2003 translation: 27). Recent amendments establish a child's right to have his or her view considered in such decisions.

Health services and assistive technology

Type of health care system	National health service
What % of GDP is spent on health care?[10]	9.2%
What % of expenditure on health is public expenditure?[11]	85.3%
What are the average out-of-pocket payments (per capita, US$)?[12]	*No information*

	All children	**Disabled children**
Key health legislation	Health and Medical Services Act 1982 (Hälso- och sjukvårdslagen) Dental Care Act 1998 Education Act 1985 and ordinances	As for all children. In addition: Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) 1993
Are all children covered by the system?	Yes	Yes
How is health care organised?	Decentralised • Central government sets general legal framework and is responsible for ensuring the system is efficient and meets national objectives. National Action Plans • County councils provide primary, secondary and tertiary care. They have authority over the hospital structure and regulate the private health care districts. • Municipalities are responsible for certain health care services, including community-based child care centres and school health care	As for all children. In addition: • County councils are responsible for (re)habilitation services • County councils are brought together into 6 medical care regions for highly specialist care
How is health care	National Board of Health	National Board of Health

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[10] 2002, Information from OECD in Figures (2003).
[11] 2002, Information from OECD in Figures (2003).
[12] 2002, Information from OECD in Figures (2003).

monitored?	and Welfare	and Welfare
Is health care free at the point of use?	Yes, for children but not adults	Yes
What choice do parents and children have?	• Choice of primary health care provider • Some choice in treatment/ hospital	As for all children
To what extent are parents involved in their child's health care decisions?	Involved	Involved
To what extent are children involved in health care decisions about themselves?	No legal right to consent to treatment. General Swedish principle of self-determination by young people with sufficient maturity.	No legal right to consent to treatment. General Swedish principle of self-determination by young people with sufficient maturity.
How are specialist services accessed?	• Outpatient services at hospitals can be directly accessed • Primary health care provider	As for all children. In addition: (re)habilitation services are accessed through primary health care providers and depend on the decision of the (re)habilitation centre

Key legislation for assistive technology	• Health and Medical Services Act 1982 (Hälso-och sjukvårdslagen) • Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) (lagen om stöd till vissa funktionshindrade) 1993 • Law on medical technical products (lag om medicintekniska produkter) 1993
How is assistive technology organised?	County councils are primarily responsible for provision, with municipalities responsible in some cases (e.g. limited mobility for older people). County councils can make agreements with municipalities, for the latter to make provision.
How is it funded?	Generally free at point of use for user, although co-payments for certain devices

Principles and organisation

The Swedish health care system can be categorised as a national health service, with its fundamental principle: "that the provision and financing of health services for the entire population is a public sector responsibility" (Swedish Institute 2003: 1). Section 2 of the Health and Medical Services Act 1982, as amended, sets out the goals of health and medical services:

- Health and medical services are aimed at assuring the entire population of good health and of care on equal terms.
- Care should be provided with respect for the equal dignity of all human beings and for the dignity of the individual. Priority for health and medical care shall be given to the person whose need of care is greatest. (Government Offices of Sweden translation)

It has a decentralised system. Centrally, the Ministry of Health and Social Affairs retains the responsibility to ensure that the health care system is efficiently run and meets the fundamental objectives set by Parliament. These include National Action Plans. The National Board of Health and Welfare is the government's advisory and supervisory agency for health and social services, with all health care personnel under its supervision.

The 21 county councils have the greatest responsibility for the health care system. They are responsible for primary care to hospital care. The county councils have authority over the hospital structure and regulate the private health care market. County councils are usually subdivided into health care districts. County councils themselves are grouped together into six medical care regions, for tertiary care. These organise highly specialised care through regional hospitals (EOHCS 2002: 2, 5). County councils are also responsible for free dental care for children and young people (Sweden 1998: para 486).

Municipalities are responsible for certain health care services. These include community-based child care centres for children under the age of six. Here, children are regularly followed by nurses and doctors (Sweden 1998: para 450; Sweden

2004b). Once the children reach school, municipalities must provide school health care. This care is intended to be preventive, with general health checks and specific vision and hearing tests. (Sweden 1998: para 454-456) These services are free of charge for children under the age of 20.

General services are obliged to meet the care needs of disabled people. County councils have responsibility to organise (re)habilitation services for disabled children, which include medical checks, examination and treatment, testing of technical aids, physiotherapy, occupational therapy and speech therapy (CE 2000: 325; Sweden 1998: 475). Advice and support is provided under the LSS Act, which is listed as including psychologists, physiotherapist, speech trainers, speech therapists and occupational therapists. It is intended to be complementary to services under the Health and Medical Services Act, although Ingmanson (2003 translation) notes that the boundary is “undefined” (5). Eligibility for the LSS Act is addressed above; it could be that some disabled children do not meet the eligibility of the LSS Act but could access treatment and therapies under the Health and Medical Services Act.

In order to contain costs and increase efficiency, internal markets were introduced in the late 1980s and 1990s. Half the country councils have introduced some form of purchaser-provider split. Competition increased through the contracting out of services by county councils and through increased patient choice (see below). Some of the disadvantages of these reforms are now evident and initiatives have sought to encourage co-operation amongst purchasers and providers and re-centralised some delegated powers (EOHCS 2002: 7). Despite this, certain problems of decentralisation are evident:

- … a co-ordinated reform strategy has been difficult to achieve, due to changes in government, increasing fragmentation of governance and provision, problems of coordination among different administrative levels, and lack of a global perspective whereby all policy goals are considered as part of an overall reform process (EOHCS 2002: 8)

Funding and costs

Financing of the health care system is also decentralised, with the largest proportion from county council taxes. Other sources are municipal and central government taxes, the national social insurance system, and private expenditure (out-of-pocket payments and private insurance). County councils decide their own fee schedules for out-of-pocket payments for outpatient care. Central government has established fee ceilings, for what people would pay within a 12-month period. Hospital care is also subject to payments. Payments are paid towards prescribed drugs, with ceilings again centrally established. Voluntary insurance is still very limited in Sweden.

Children and young people under the age of 20, however, do not pay patients' fees (MISSOC 2002a: 2). They receive free dental care. Ingmanson (2003, translation: 11) notes that age limits can vary for free care and treatments. County councils have the discretion – but not a duty – to cover transport costs for health care, treatment etc. (Ingmanson 2003 translation: 13).

Assistive Technology

The Health and Medical Services Act 1982 identifies county councils as having primary responsibility for assistive technology provision. It is frequently through Assistive Technology centres, with primary health care providers and hospital clinics also having a role. Municipalities have responsibility for certain specific needs, such as devices for older people with impaired mobility. County councils can make agreements with municipalities, for municipalities to take on responsibilities. There is a national resources centre, the Swedish Handicap Institute, which seeks to ensure access to high quality and well functioning assistive technology. It gives out information and trains professionals (Deloitte and Touche 2003: 46-47).

Most assistive devices for everyday life are provided free of charge. Devices provided through county councils can be subject to a co-payment from the patient. Again, decentralisation is criticised as leading to inequities geographically: "It can happen that an assistive device is not available in one county, while it is in another" (Deloitte and Touche 2003: 46).

Assistive technology is available through prescription and this is generally issued by county council or municipality staff (e.g. doctors, district nurses and occupational therapists). The prescription should “always be made out in close co-operation with the disabled person” (Deloitte and Touche 2003: 104), which is required legally by Section 3b of the Health and Medical Services Act 1982 as amended.

An overall evaluation of the system states that:

- Users are pretty satisfied with this delivery system and the knowledge provided. It can happen that it sometimes takes quite a long time to get the Assistive Technology or that the device a person wants is just not accessible. The disability movement complains about the differences in rules, the differences in the number of places to which people have to turn for obtaining certain types of Assistive Technology and possible fees. These can vary a lot throughout the country as a result of decentralisation. They also complain about the fact that it is not possible to appeal a decision (Deloitte and Touche 2003: 106; see also Rädda Barnen 2004: 36).

Choice, consent and user involvement

Unlike in most national health services, general practitioners have not comprehensively been gatekeepers to health care. Patients have been able to consult hospital doctors in outpatient departments directly, without referral. This resulted in 46% of outpatient visits being made at hospitals rather than primary health centres. However, certain county councils have been introducing barriers to such direct access to hospitals (Freeman 2000: 35; EOHCS 2002: 5).

Access to habilitation services is not direct for patients. A doctor must make a written application for services and this often includes a medical assessment as well as assessments from a psychologist and physiotherapist. The habilitation centre decides on what services that will be provided, in consultation with the parents. If a child has an unclear diagnosis and a mild disability, it may be difficult to access services (Sweden 2004b).

Recent changes have sought to increase patient choice. Patients can choose amongst primary health care providers (MISSOC 2002a: 1-2; Hjortsberg 2001: 46). A patient should be able to choose between several adequate alternatives, with the county council meeting the cost. If considered medically valid, this includes treatment outwith the patient’s county council provision. County councils have an obligation to inform patients about health care and treatments available outwith their provision. (Ingmanson 2003 translation: 10; Health and Medical Services Act 1982 as amended). Children themselves do not have the right to request legal or medical advice or to consent to treatment, without their parent’s consent. The Swedish Government underlines the general principle in Swedish law that children “who are old enough and have attained sufficient maturity have a right to self-determination in certain matters” (2004a: 30).

No minimum set of health care provision standards has been defined, although the Health and Medical Services Act 1982 (as amended) lays out requirements of good care: it must:

- be of good quality and cater to the patient’s need of security of care and treatment,
- be readily available
- be founded on respect for the self-determination and privacy of the patient
- promote good contacts between the patient and health and medical personnel (Section 2a, Government of Sweden translation)

The lack of minimum provision, however, leads to considerable professional discretion (EOHCS 2002: 5). Ingmanson states that personnel should take into consideration what children and their families want (2003 translation: page 3) and Section 2a of the Act does require that “Care and treatment shall as far as possible be designed and conducted in consultation with the patient” (Government of Sweden translation). The patient must be given individualised information about his or her state of health and available treatment methods.

Physical Environment

Housing stock[13]	42% single family owner-occupied; 18% owner co-operatives; 40% rented
Key housing legislation?	• Housing Allowance Act (Lag om bostadsbidrag) of 1993 • Social Services Act 2002
How is housing policy organised?	• Central government sets policy and funds housing allowance • Housing allowance is administered by offices of National Insurance Board • Municipalities have responsibility to ensure a 'reasonable standard of living'
Housing benefits for families with children	Yes
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[14]	0.6%
Accessibility regulation to buildings	Planning and Building Act 1987
Has accessibility to public places improved over the past 10 years?[15]	Yes, in public opinion. 19.2% think it has improved very much while 61.5% think it has improved somewhat
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[16]**:**	
• **How accessible is public transport?**	3.11 (fairly to very difficult) for physically disabled people 2.74 (fairly to very difficult) for intellectually disabled people
• **How accessible are cultural events?**	2.50 (not very to fairly difficult) for physically disabled people 2.60 (not very to fairly difficult) for intellectually disabled people
• **How accessible are sports events?**	2.65 (not very to fairly difficult) for physically disabled people 2.59 (not very to fairly difficult) for intellectually disabled people
• **How accessible are restaurants, hotels etc.?**	2.76 (not very to fairly difficult) for physically disabled people 2.77 (not very to fairly difficult) for intellectually disabled people

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[13] Information from Ball 2004: 107

[14] See Chapter 5.

[15] See Chapter 2.

[16] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	▪ Responsibility for Public Transport Act 1998 ▪ Special Transport Services Act 1998 ▪ National Special Transport Service Act 1998	As for disabled children
Are there enforcement mechanisms?	Yes	Yes
Are fare concessions available for public transport?	Not generally	Not generally
Can an accompanying person go free, or for a reduced price, on public transport?	Not generally	Not generally
Is special transport available as an alternative to public transport?	Yes	Yes
Is there a parking badge scheme?	Yes	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Sweden has a comparatively low share of owner-occupied dwellings, compared to other European countries. This includes owner co-operatives. Legally, co-operative associations own the apartment structures as it is not possible to own an individual apartment outright. Social housing is open to all, as Swedish policy has emphasised equal access and avoiding spatial differentiation by income or social group. Such housing is typically owned by municipal housing companies, which are independent non-profit housing organisations closely linked to municipalities. In some areas, there are considerable waiting lists for social housing (Ball 2004: 107-108).

Traditionally, Sweden has large, general supply-side subsidies for housing construction and rehabilitation. This is now changing into more targeted, income-related subsidies. (Ball 2004: 114) Sweden also has demand-side subsidies for families with children and families with pensioners. The housing benefit (Bostadsbidrag) is income-related and the amount depends on the number of people in the household and family type. This can be available to both renters and owner-occupiers (Bradshaw and Finch 2002: appendix, page 6; Sweden 1998). This allowance can make a substantial difference in the child benefit package for families on social assistance (Table 5.2 in Chapter 5). The housing allowance is centrally funded, and administered through offices of the National Social Insurance Board. Municipal taxes are income related and below a particular income threshold people do not pay income tax (Bradshaw and Finch 2002: appendix, page 61). Overall, Sweden's public expenditure on housing (as a percentage of GDP) is higher than the European average (0.6% compared to 0.4%).

Under the Social Services Act 2002, municipalities have a responsibility to ensure people have a 'reasonable standard of living' (see above). A special home adaptation grant may be available, to allow dwellings to be designed or adapted for a particular disabled person (CE 2003: 337; ECSR 2003). Extra costs can be covered, such as adding an additional room to the home (Ignmanson 2003 translation: 73).

Accessibility to buildings and public spaces

National legislation sets standards for new buildings, their surroundings and projects involving extensive structural renovation (CE 2003: 335). Over 80% of respondents to the Eurobarometer survey thought that access to public places had improved very much or somewhat over the past 10 years. For specific events and activities, Swedish respondent reported the greatest accessibility of the seven countries and considerably better than the European average.

By 2010, existing public buildings and places must remove easily dealt with obstacles. The National Board of Housing, Building and Planning is tasked with clarifying the present requirements of the Planning and Building Act regarding accessibility in the construction and alteration of public buildings and places: new legislation is proposed (Swedish Disability Federation, HSO 2003). Local organisations of disabled people should have a more central role in reviewing planning and building applications (Ministry for Health and Social Affairs, Sweden 2000: 12). All citizens have a formal right under the Planning and Building Act to take part and influence physical planning. However, the Swedish Government acknowledges that children and young people have had very little opportunity to do so (2004a: 50).

Complaints about access problems can be taken to the Office of the Disability Ombudsman, who will have wider powers. A National Accessibility Centre has been created. The Government will issue ordinances to public authorities to present action plans by December 2001 and the Government expects annual progress reports (Toe 2001).

Transport

Sweden legislation requires public transport to become more accessible. The Public Transport Authority (PTA) must, under the Responsibility for Public Transport Act 1998, improve the adaptation of the public transport system to disabled people’s needs. A yearly plan is required, that describes improvements measures. There are a range of further regulations, recommendations and guidelines, such as those for urban traffic networks (Committee of Deputies (CD) 2000a: 55). The National Action

Plan for Disability Policy proposes new regulations for the adaptation of public transport vehicles, with the aim of all vehicles being adapted by 2010 (Ministry for Health and Social Affairs, Sweden 2000: 14). There are no concessionary fares for public transport. Some PTAs, though, allow for disabled people who are entitled to access special transport services to travel free of charge on mainstream public transport. (CD 2000b: 11). A national training programme, on positive attitudes and approaches to disabled people, has been developed for public transport service staff (CD 2002).

For those disabled people who still cannot access public transport, the Special Transport Services (STS) Act 1998 requires municipalities to provide people with a 'permanent disability' with special transport. The National Special Transport Service Act 1998 requires municipalities to subsidise travel to another municipality, for disabled people who cannot use public transport at normal costs or who cannot travel without a companion. The government sets the fare. Home to work trips are excluded. The Special Transport Act 1998 allows for municipalities to transfer their responsibility for special transport services to the PTA. This is seen as creating an economic incentive for the PTA to make its public transport more accessible, in order to decrease the costs of STS (CD 2000; CE 2003).

Eligibility for STS is determined through a doctor making an application to the special transport company (Sweden 2004b). There are costs to using the special transport service and indeed these are often more than costs for public transport generally (Ingmanson 2003 translation: 46). Transport between school and home is free. Families book the transport themselves (Sweden 2004b).

- The legislation has enforcement mechanisms. If a person is refused STS or NSTS, the person can take the case to an administrative court. Public transport vehicles must pass an accessibility test. Consultative mechanisms are available through Regional Disability Committees, which include regional disability organisations

For private cars, there are parking badges for disabled people. Parents can apply for a grant, to allow them to purchase or adapt a private car in order to transport their disabled child. The grant is means-tested, to purchase a car, and there are maximum limits to the grants. There must be at least seven years between applications for the car allowance. The scheme is administered through local Social Insurance Offices (CE 2003: 336; Ignmanson 2003 translation: 11).

Leisure and Recreation

Sweden does not protect children's right to culture through legislation, unlike other Nordic countries (Rädda Barnen 1998: 13). The Planning and Building Act does require play opportunities to be available close to children's homes (Sweden 1998: para 658). There are numerous state grants for central and local youth activities. (Sweden 1998: para 321). However, these provisions have been insufficient to ensure children's activities and certain children might be excluded:

- 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 (Rädda Barnen 1998: 13)

For disabled people, the Swedish government reports that there are well-established sports clubs (CE 2003: 339). The companion service available through LSS can assist disabled people in taking part in leisure activities, travel and social visits (Ignmanson 2003 translation: 32). There is a specific national fund, the State Inheritance Fund, which supports voluntary activities for disabled people (Sweden 1998: para 323). The Care Allowance can cover costs such as leisure trips (Ignmanson 2003 translation: 73). However, the Children's Ombudsman (BO 2002) notes that disabled children's socialisation can be hampered by transport restrictions, as cited above.

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UK

In the late 1990s, the UK devolved political power from the Westminster Parliament to Northern Ireland, Scotland and Wales. In Northern Ireland, the Northern Ireland Assembly was elected in 1998 and had devolved powers over a range of areas such as education, health and social services. However, the Assembly was suspended in 2002, with Northern Ireland returning to direct rule.

Governmental structures vary considerably between Northern Ireland and England. Northern Ireland has District Councils but they cover a narrow range of functions. Because of sectarianism, potentially sensitive functions such as health and social services are not their responsibility. A range of bodies is responsible for schools. For example, there are five Education & Library Boards (ELBs), which are responsible for certain schools and for special educational needs provisions. There are four Health & Social Service Boards (HSSBs) that commission health and social services. A range of providers can be commissioned to provide the services, such as Health & Social Services Trusts (HSSTs) – an example of the purchaser-provider split that was supposed to increase competition and thus quality in services.

England, by contrast, has democratically elected local authorities who are legally responsible for social services and aspects of education. Some areas still have two tiers of local authorities: district councils, responsible for such issues as housing and local planning, and county councils, which are responsible for education, social services, transport etc. There are 238 district councils and 34 county councils. In 1998, some areas amalgamated the two tiers into one, and there are now 445 all-purpose authorities (including ones in London, metropolitan districts and unitary authorities). Health responsibilities are differently organised, as detailed below. Again, there is a purchaser-provider split in health between those who commission and those who provide services. There has been considerable structural reform in all these services, which is continuing with pilots of other forms (e.g. Children’s Trusts, which will bring together local authorities and health).

Services differ in how they are organised. Social security is particularly centralised: it is legislated for across the UK, by the Westminster Parliament; administration is a centralised responsibility, with local administrative offices. Education has become both more and less centralised, cutting out the local authorities. The National Curriculum in England is set centrally while schools have increasingly gained policy and financial powers. Health (and social services in Northern Ireland) have particularly emphasised the purchaser-provider split. Areas of provision are particularly encouraged to have a ‘mixed economy’ of provision, meaning there are providers from voluntary and independent organisations as well as the public sector. The voluntary sector is large and varied in the UK, and many organisations rely on state funding. They are increasingly contracted to provide services.

When comparing welfare regimes across Europe, the UK is classified as a ‘liberal welfare state’, with means-tested assistance, modest universal transfer or social insurance plans (see Chapter 1). The social security system for example, provides a safety net for those with low income but is frequently means-tested although not for key disability benefits. The National Health Service and the compulsory education system are largely free at the point of delivery. The UK is unusual in the European Union for the large public expenditure on social housing, although this is diminishing.

‘Joined up services’ has been a policy mantra for the UK, over recent years, and the need for this has been particularly evident for disabled children and their families. The Audit Commission (2003), however, still finds considerable problem: “Joint working was hampered by differing eligibility criteria, referral systems and cultures among agencies, and barriers between disciplines”. Child poverty is on the political agenda again, with concerns about socio-economic inequality and the particular vulnerability of children to child poverty.

More children in Northern Ireland are categorised as having severe disabilities than in England (10 in 10,000 compared to 8 in 10,000 reported in Kilkelly et al 2004: xix).

Equality/ anti-discrimination Advocacy and Information

	Anti-discrimination by age	**Anti-discrimination by disability**
Article 13 UNCRC[1]. Has the Amsterdam Treaty been agreed?	Yes	Yes
Article 14 UNCRC Has the ECHR[2] been ratified?	Yes	Yes
Protocol 12, ECHR: Has the protocol been ratified?	No	No
Article 2: Has the UNCRC been ratified?	Yes	Yes
Is there domestic law?	England – No Northern Ireland – Yes Northern Ireland Act 1998	England: Yes • Disability Discrimination Act 1995, amended by - • Disability Rights Commission Act 1999 • Special Educational Needs and Disability Act 2001 Northern Ireland Yes • Disability Discrimination Bill Northern Ireland: • Disability Discrimination Act 1995 • Equality Northern Ireland Order 2000 • Northern Ireland Act 1998 • Special Educational Needs and Disability Bill
What type of domestic law is it? (criminal, constitution, civil rights, social welfare)	Northern Ireland – civil rights	England and Northern Ireland – civil rights
Is there an enforcement mechanism?	England – Children's Commissioner (CC) proposed in the Children Bill • CC will be able to handle individual complaints, at the request of the Secretary of State • CC will be able to	England – Disability Rights Commission (DRC) • DRC does handle individual complaints • DRC can carry out investigations • DRC can be asked for advice by government and

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[1] UNCRC United Nations Convention on the Rights of the Child

[2] ECHR European Convention on Human Rights

	consider or research the operations of complaints procedures as they relate to children - CC will be able to advise the Secretary of State Northern Ireland – Northern Ireland Commissioner for Children & Young People (NICYP) - NICYP does handle individual complaints - NICYP can carry out investigations - NICYP can be asked for advice by government and other bodies and to give advice Northern Ireland Human Rights Commission (NIHRC) - NIHRC does handle individual complaints - NIHRC can carry out investigations (but cannot compel people to give evidence) - NIHRC can be asked for advice by government and other bodies	other advice Equality Commission for Northern Ireland (ECNI) for matters under the Disability Discrimination Act 1995 and for implementation of Section 75 of the Northern Ireland Act 1998 - ECNI does handle individual complaints - ECNI can carry out investigations - ECNI can be asked for advice by government and other bodies Northern Ireland Human Rights Commission (NIHRC) for matters under the Northern Ireland Act 1998
Are there other standing national bodies to provide policy advice?	Government committees and advisory groups at various times. Parliamentary committees, including the Joint Committee on Human Rights, House of Lords/ House of Commons Westminster	

The UK is subject to the anti-discrimination articles within the European Convention on Human Rights (ECHR, Article 14) and has agreed to Article 13 of the EU Amsterdam Treaty. The UK has not, however, yet signed (and thus not ratified) the new Protocol 12, which would expand anti-discrimination to all legal rights and prohibit discrimination on any grounds by a public authority.

The ECHR became part of UK domestic law, through the Human Rights Act (HRA) 1998. In Northern Ireland, the Human Rights Commission can support individuals in taking cases under the HRA; they will do so, however, only in exceptional cases. There is no equivalent Commission in England to provide such support.

Anti-discrimination by age

In relation to children’s rights, the UK has ratified the UN Convention on the Rights of the Child. Such ratification in UK law does not mean that it is incorporated in domestic legislation. Certain articles of the UNCRC have been incorporated into particular pieces of legislation: for example, the welfare principle and, to a lesser extent the right of children to express their views, is incorporated in children’s legislation throughout the UK (e.g., England - Children Act 1989; Northern Ireland - Children (NI) Order 1995). However, this is a piecemeal approach and the UN Committee on the Rights of the Child have twice noted considerable gaps in domestic legislation (1995, 2002).

This is in contrast to the ECHR which has been incorporated into domestic law through the Human Rights Act 1998. Thus Article 14 is part of domestic law in the UK. UK court decisions need to take account of case law from the European Court on Human Rights, which is increasingly making reference to the UNCRC (Kilkelly 1999). In this way, the UNCRC is coming to have some legal effect through the ‘backdoor’ in court decisions.

Northern Ireland is unique in the UK in addressing age discrimination against children. Section 75 and Schedule 9 of the Northern Ireland Act 1998 places a statutory duty on public authorities[3] to carry out their functions relating to Northern Ireland, with due regard to the need to promote equality of opportunity:

- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation
- between men and women generally
- between persons with a disability and persons without
- between persons with dependants and persons without
- and to produce an equality scheme to this effect

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. Thus, Northern Ireland may be unique but has very weak legislation in this regard.

In Northern Ireland, there are three commissions that might be involved in protecting children from discrimination. Northern Ireland's Commissioner for Children and Young People (NICYP) was recently established, with the first commissioner appointed in June 2003. The Commissioner can: review policy and legislation; advise the Government and the Parliament, and other relevant authorities if the Commissioner wishes to or is requested to do so; carry out investigations; and assist children with individual complaints of a particular type. The Commissioner is limited to issues that are devolved to Northern Ireland – and can only comment, for example, on issues such as social security that are not devolved. The NIHRC and the Equality Commission of Northern Ireland also have powers to support individual complaints, undertake investigations and provide advice. Further details are given below.

A Children's Commissioner is being proposed for England, through the Children Bill that is presently going through the Westminster Parliament. The Children's Commissioner has significantly weaker powers than the NICYP in two ways. The

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[3] Northern Ireland departments, most non-departmental public bodies, District Councils and other bodies including UK departments designated by the Secretary of State.

Commissioner will only be able to investigate individual complaints at the request of the Secretary of State and not on the Commissioner's own initiative.

Anti-discrimination by disability

While disabled people have various social welfare rights in legislation, the Disability Discrimination Act (DDA) 1995 has introduced a civil rights approach. It is also worth noting that the Human Rights Act 1998 and the Northern Ireland Act 1998 also address anti-discrimination on the basis of disability. The DDA has since been strengthened and amended by subsequent legislation, although the legislation differs between Northern Ireland and England. Disability discrimination is a 'transferred matter' under the Northern Ireland Act 1998 and thus separate legislation is now required for that jurisdiction.

Coverage

The DDA protects disabled people in regards to employment, access to good, facilities and services and the management, buying or renting of land or property. The Government can set minimum standards for assistance to disabled people, so they can use public transport easily. The original 1995 Act did not extend to education. The Special Educational Needs and Disability Act 2001 did extend the DDA to education, both private and state-funded, in England, Scotland and Wales. A parallel Special Educational Needs and Disability Bill is presently being consulted upon in Northern Ireland; thus disabled children do not yet have these protections in schools there.

The DDA as amended still has notable gaps in coverage. An example would be that, at present, if a disabled person attempts to board a train but is refused entry this does not constitute discrimination under the DDA (example given in Gooding and Casserley 2003). Certain gaps will be closed by the Disability Discrimination Bill presently being considered by the Westminster Parliament.

The DDA has a specific definition of disability – indeed most of the case law on the DDA has been about whether people are included or not within the definition.

- … 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

As discussed in Chapter 3, this definition relies on a notion of ‘impairment’ and is arguably adult-centred. It is different from the definition of disability in other legislation such as social security and from definitions of special educational needs. This may cause confusion for children, parents and professionals.

Service providers covered by the Act can not discriminate against disabled people. It is unlawful to treat disabled people less favourably than other people for a reason related to their disability. Discrimination can occur if service providers fail to take reasonable steps to ensure that disabled people are not placed at a substantial disadvantage to non-disabled people.

There are various justifications, defences and exemptions to these requirements. Protection is also extended to those who report potential discrimination in employment and education (England). There is no provision for ‘indirect’ discrimination, which would recognise the institutionalised nature of discrimination and the impact that has on disabled people as a minority group.

Enforcement and sanctions

There are no provisions for group claims under the DDA. Adults can make individual claims of discrimination. This includes parents on behalf of their children and young people at the age of 16 or above.

The Disability Rights Commission, for England, and the Equality Commission for Northern Ireland both provide an advice service. They offer a conciliation services for certain types of discrimination (not for employment). This does not preclude an individual’s right to take legal action in relation to a claim. They can also support individuals in taking cases. Both Commissions have the responsibility to promote equality and can undertake formal investigations (For further information on enforcement mechanisms, see Department of Trade and Industry 2004; Office of the First Minister and Deputy First Minister 2004).

Disabled children may be protected by the legislation – particularly when extended to education – but they must rely on their parents or other adults for enforcement.

Advocacy and Information

The Joint Committee on Human Rights in the Westminster Parliament considers matters in relation to human rights but does not deal with individual cases. In Northern Ireland and in England, various government commissions and working groups are established. For example, there is the Disabled Persons Transport Advisory Committee (Council of Europe (CE) 2003: 373). Similarly, local government can have various forums and working groups. There has been recent encouragement of school and youth councils, as well as experiments to consult children and young people nationally (e.g. children's and young people's advisory forum to the Children & Young People's Unit; the UK Youth Parliament).

The UK has an active non-governmental sector, which provides advocacy at individual and policy level and provides information to children, disabled children and their families. For example, there are umbrella children's agencies such a Child Care Northern Ireland, associations especially for disabled children like England's Council for Disabled Children, and disability organisations. There are networks of general Citizens Advice Bureau to provide information, as well as numerous organisations using both private and public funding to provide information. An Advisory Forum of young people was set up, in Northern Ireland, to advise the Government on the Children's Commissioner and, while initially welcomed, is now criticised for how young people were selected and for its limited remit (Kikelly et al. 2004: 31).

There is a statutory duty on local authorities to ensure the provision of relevant information, to parents of disabled children (Children Act 1989 and the Children (NI) Order 1995). There has been a growth in advocacy services for both parents and children. As yet, there is no statutory duty to provide such advocacy, so that provision is dependent on local availability.

Education

	England		Northern Ireland	
	All children	**Disabled children**	**All children**	**Disabled children**
Key education legislation	• Education Act 1996 • School Standards and Framework Act 1998	As for all children. In addition, Special Educational Needs and Disability Act 2001 (which amends the Disability Discrimination Act 1995)	• The Education (NI) Order 1996 • The Education (NI) Order 1998	As for all children. In addition: • Special Education and Disability Bill • Disability discrimination legislation (see above)
Does a child have the right to education?	Yes	Yes	Yes	Yes
How is education organised?	Department of Education and Skills sets the national curriculum and decides policy Local education authorities have responsibility for certain schools School governors have responsibilities	As for all children, except that Local education authorities are responsible for special educational needs provision.	• Department of Education for Northern Ireland sets the national curriculum and decides policy • Education & Library Boards are responsible for controlled schools • Council for Catholic Maintained Schools have responsibilities for Catholic maintained schools • Voluntary schools are managed by trustees • Integrated schools are grant-maintained	As for all children, except that Education & Library Boards are responsible for special educational needs provision
How is education monitored?	OFSTED	OFSTED	Inspectors from the Department of Education	Inspectors from the Department of Education
Is education compulsory?	Yes	Yes	Yes	Yes
What are the ages for compulsory education?	5-16	5-16	4-16	4-16
Is there a national curriculum?	Yes	As for all children. Can be modified for disabled child	Yes	As for all children. It can be modified for

				disabled children.
Is compulsory schooling free at the point of use?	Yes	Yes	Yes	Yes
Are incidental costs of schooling free at the point of use?	Yes, means-tested provision of school meals and clothing allowance. No charges for books/materials	As for all children.	Yes, means-tested provision of school meals and clothing allowance No charges for books/materials	As for all children.
Is school transport free?	Yes	Yes	Yes	Yes
Can parents exercise school choice?	Yes	Yes	Yes	Yes
To what extent are parents involved in school decisions about their individual child?	Involvement of parents supported in policy documents.	As for all children. In addition: specific rights for and appeal in relation to special educational needs and disability discrimination legislation.	Involvement of parents supported in policy documents.	As for all children. In addition: specific rights for and appeal in relation to special educational needs and disability discrimination legislation.
To what extent are children involved in school decisions about them?	Increasing involvement, with some statutory rights, of children and young people in school councils.	Increasing involvement, with some statutory rights, of children and young people in school councils.	Increasing involvement, with some statutory rights, of children and young people in school councils.	Increasing involvement, with some statutory rights, of children and young people in school councils.

In regards to special educational needs

	England	Northern Ireland
Is there an official policy for school inclusion?	Yes	Yes
What type of education system is there (one-track, multi-track, two-track)?[4]	Multi-track	*No information*
What percentage of children is in special schools?	1.12% of pupils in state-funded schools[5]	1.4% of all pupils were in 'special schools'[6]
What percentage of children has 'special educational needs'?	14.0% of pupils had SEN without statements; 3.0% with statements of SEN[7]	10.6% have SEN without statements; additional 3.2% with statements[8]
Are there special schools?	Yes	Yes
How is eligibility for special support decided?		
▪ **Categorical/ non-categorical**	Categorical	Categorical
▪ **Who can initiate**	Parent or school	Parent or school
▪ **Assessment**	Yes	Yes
Do children have the right to support for SEN?	Yes	Yes
Is there compulsory teacher training on SEN?	Yes	Yes

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[4] Information from EADSNE 2003.

[5] 2002, Information from DfES 2003b.

[6] 2002, Information from National Statistics 2003.

[7] 2002, Information from DFES 2003b.

[8] 2002, Information from DENI 2003 and 2004a.

Principles and Structure

Education is a devolved responsibility and thus there is separate legislation and policy for Northern Ireland and England. One of the main differences between England and Northern Ireland is variation in local organisation of education. In England, the Local Education Authorities (LEAs) are part of the local council, which also typically has responsibility for other services such as social services but does not have responsibility for health services. In Northern Ireland, the five Education & Library Boards (ELBs) are the equivalent to LEAs (e.g. they have duties to provide education for pupils with special educational needs, up to the age of 19). ELBs are separate from Health and Social Services Boards.

Both countries have a range of school types, which have different relationships with central government and regional bodies. A general trend has been the encouragement of schools to take on increasing responsibility for school management and funding. There is an independent sector and non-maintained special schools which are part-funded by LEAs paying for special needs pupils to attend. Northern Ireland has traditionally been segregated between Catholic and Protestant provision. Different schools have different management and funding:

- **Controlled:** Controlled schools are owned and funded by the ELB although boards of governors are increasingly taking control. The ELB employs teaching and non-teaching staff but here too they are relinquishing responsibility to governors. The role of the ELB is to plan provisions for schools, employ teachers and meet recurrent costs. These are mainly Protestant schools and the church is represented on the board of governors.
- **Catholic Maintained:** These schools are owned by the Catholic Church through a system of trustees. They are managed by a board of governors. Regular costs are met by the ELB and they are responsible for employing non-teaching staff. Teachers are employed by the Council for Catholic Maintained Schools.
- **Other Maintained:** These are owned by the Protestant church through a system of trustees and they are managed by a board of governors. Regular costs are met by the ELB who also employ the non-teaching staff.

- **Voluntary Grammar:** These are owned by the school trustees and are managed by a board of governors, who employ all the staff. Regular costs are funded by the Department of Education.
- **Grant Maintained Integrated:** These are usually partially owned by trustees and managed by a board of governors who employ all staff. Regular costs are met by the Department of Education.

Central government has a determining role in education policy, so that the national curriculum is set centrally, along with funding, target setting and other aspects of education policy. As stated above, Northern Ireland and England each have a national curriculum. This is established centrally. Specialist schools, that still receive state funding, have been allowed to experiment in varying the national curriculum (DfES 2003).

The compulsory school age starts earlier in Northern Ireland, at the age of 4, rather than 5 in England. Compulsory education is free of charge, although there can be ancillary costs such as school uniforms and school meals. These are means-tested grants for such costs. School transport is available under certain circumstances and children with special educational needs have particular rights to school transport. In terms of public expenditure on education (as a percentage of GDP), the UK spends less than the European average (4.5% compared to 5.3%) (see Table in Chapter 5).

Both Northern Ireland and England have legislated for parental choice of schools. A choice of a mainstream school, for a child with SEN, will be protected by the mainstreaming presumption (see below). Assessments for children with SEN may determine that a placement at a special school is required, and this would be funded by the LEA or ELB respectively.

Initial teacher qualification requires candidates to show competency elements in SEN. In-service training on SEN is also available, as well as advanced study (European Agency for Development in Special Needs Education (EADSNE) 2003). Both educational systems are inspected nationally: in England, by the independent agency OFSTED, and by Inspectors of the Department of Education in Northern Ireland. Schools are inspected regularly and reports are publicly available.

Schooling for Disabled Children

The national curricula can be modified for children with special educational needs. Educational legislation in both Northern Ireland and UK includes disabled children. There is also separate legislation for children with 'special educational needs' (SEN) in both countries, plus equal opportunities legislation that protects disabled children from discrimination.

The promotion of school inclusion has increased over recent years. Both Northern Ireland and the England could be described as having a multi-track approach (EADSNE 2003), with a multiplicity of approaches to inclusion and variety of services between mainstream and SEN systems. The standard formulation is expressed in by the latest DfES strategy for SEN (2004):

- We have strengthened parents' rights to choose a mainstream place for their child but we recognise that some children have such severe and complex needs that they require more specialist provision than is currently available in most mainstream schools (para 2.14)

The strategy does state its intention that a 'unified system' should be created between mainstream and special schools, with the sharing of staff, pupil movement and co-location. The promotion of inclusion has increased over the past two decades. There is now a presumption for a mainstream school in the Education Act 1996, as amended by SENDA 2001. All children without statements of SEN must be educated in a mainstream school. Children with statements of SEN must be educated in a mainstream school unless this is incompatible with the wishes of his parent (no mentioned is made of the child's wishes) or "the provision of efficient education for other children" (Section 316). A similar presumption is proposed in the Special Educational Needs and Disability Bill, which is presently still at the consultation stage (2002), for Northern Ireland. Governing bodies of maintained mainstream schools in England must publish information about, and report on, the schools' policy on special educational needs (DfES 2001: para 1.26). A similar requirement is placed on school governing bodies in Northern Ireland (Article 9 of the Education (NI) Order 1996).

Statutory rights to special provision come through the legal definition of 'special educational needs'. In England, as defined in the Education Act 1996 (Section 316):

- Children have special educational needs if they have a learning difficulty which causes for special educational provision to be made for them. Children have a learning difficulty if they:
  - have a significantly greater difficulty in learning than the majority of children of the same age; or
  - have a disability which prevents or hinders them from making use of educational facilitates of a kind generally provided for children of the same age in schools within the area of the local education authority; or
  - are under compulsory school age and fall within the definition at (a) or (b) above or would do so if special educational provision was not made for them.

Special educational provision means:

- for children of two or over, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of their age in schools maintained by the LEA, other than special schools, in the area; or
- for children under two, educational provision of any kind

The definition explicitly excludes those who have a learning difficulty solely because the language or form of language of their home is different from the language in which they will be taught. The definition is circular – children have SEN because they need special education. If the educational provision met their needs, they would not have SEN.

There are no definitive statistics on the number of school–age children who would be considered disabled under the DDA and statistics on numbers of children with SEN are also questionable. Nonetheless, it is generally thought that about one in five children experience SEN at some time, while a much smaller proportion of between one and three per cent would be considered disabled. Children with acknowledged SEN are not necessarily disabled under the DDA; even children with statutory statements of SEN are not necessarily disabled under the DDA and vice versa.

The numbers of pupils in state schools has remained fairly constant at around 3.0% of the school population (DfES 2003b). In contrast, the proportion of pupils reported as having SEN without statements has declined in England -- from a high of 18.6% in 2001 to 14.0% in 2003 (DfES 2003b). This is not evident in Northern Ireland statistics (DENI 2004a).

Despite these structures and rights, the Audit Commission (2002) found considerable problems with the SEN system in England: wide variations in support; parental concerns about fighting for resources; variable attitudes to disabled pupils in mainstream schools; a lack of clarity about schools' delegated budgets and spending on children with SEN/ disability.

While there has been an increased focus on 'joining up' services and assessment procedures, the statutory assessments of SEN are educational documents. Education legislation is much more prescriptive on procedures and assessments than other types of legislation, with accompanying rights of parents to appeal.

Beyond their statutory rights of appeal, parents also have statutory rights of involvement and specific promotion of this through the Codes of Practice. This is described in the 2001 Code of Practice:

- Parents hold key information and have a critical role to play in their children's education… It is therefore essential that all professionals … actively seek to work with parents and value the contribution they make. (para 2.2)

Social Security

Proportion of children aged 0-15 in relative poverty[9]	39%
Proportion of children aged 0-15 in absolute poverty[10]	29.1%
Key social security legislation	Social Security Contributions and Benefits Act 1992 Child Support, Pensions and Social Security Act 2000
Value of child benefit package, as % of average earnings[11]	7.5%
Ranking (leaders, second rank, third rank, laggards)[12]	Second rank
What % of GDP is spent on family cash benefits and family services?[13]	2.0%
Tax benefits for families with children	Yes • Working Tax Credit: means-tested; age limit 16 or 19 if in full-time education; 1 adult working at least 16 hours per week • Child Tax Credit: means-tested; age limit 16 or 19 if in full-time education
Income related child benefits*	No
Non-income related child benefits*	Yes, child benefit: varies by number of children, does not vary by age or characteristics of child; age limit 16 or 19 if child in full time education; government decides on uprating and not indexed; not taxed.
Social assistance for families with children	Yes, income support; income-tested Job Seekers' allowance. Means-tested; adults working less than 16 hours; additional amounts for children.
Parental leave	Yes, 13 weeks per child (18 weeks for disabled children); discretionary whether flexible; age limit 5 but for disabled children up to age 18; unpaid; job guaranteed.
Statutory leave for care of sick children	Yes, right to take a reasonable amount of time off work to deal with certain unexpected or sudden emergencies and to make any necessary longer-term arrangements; unpaid; job guaranteed.
Type of benefits for disabled children	
• **supplement or extend child benefit**	Yes, supplement to child tax credit
• **benefits for caring costs**	Yes, Carer's Allowance
• **benefits based on child being disabled**	Yes, Disability Living Allowance

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[9] Children who are living in households with below 60% of median equivalised income. 1997 data, from Table 2.1 Bradshaw 2002

[10] Children who are living in households with incomes below the US official poverty line converted into national currencies. 1997 data, from Figure 2 UNICEF 2000.

[11] Information from Bradshaw and Finch (2002), as of July 1 2001.

[12] Information from Bradshaw and Finch (2002), as of July 1 2001.

[13] See Chapter 5.

The UK has been much criticised for its substantial level of child poverty (UNCIEF 2000), which rose in the 1990s to over one-third of the child population. The change of UK Government in 1997 led to revised policies in relation to child poverty and the Prime Minister Tony Blair announced an end to child poverty by 2020. There have been extensive changes in the social security system for families, to address child poverty, as well as a concentration on employment for parents. There has been a drop in child poverty over the most recent years (New Policy Institute 2004).

Diagram UK shows the administrative arrangements for the social security system, from MISSOC. This diagram, however, is not up to date: for example, the Department of Social Security is now called the Department of Work and Pensions, and the Inland Revenue is not included, although it administers the tax credits. The diagramme does demonstrate the centralised nature of social security, where national government departments have a substantial role not only in setting payment levels but also in administration.

Bradshaw and Finch (2002) place the UK in its second rank of countries, in relation to its child benefit package. By their calculations, the package is 7.5% of average earnings. The UK follows the general trend identified by Bradshaw and Finch, towards supporting families through the tax system. There have been a number of tax credits introduced over recent years, which are now being consolidated into the Working Tax Credit and the Child Tax Credit. The Working Tax Credit can help with childcare costs. However, income is required in order to benefit from a tax credit.

The UK has social assistance to support those without a sufficient external income. Income support is available to those who are not required to be available for work, such as a lone parent or carer. Usually this person has to be working less than 16 hours per week and any partner must be working less than 24 hours a week. Carers, though, may be able to claim income support regardless of the hours they work. The household income must have savings below £8000. Premiums are added to the weekly payments. Certain aspects of income, such as part-time earnings and other social security benefits, are deducted from the total income support amount. Income-based Jobseeker's Allowance are for those who cannot claim Income Support, have a low income and are looking for work (Contact a Family 2003).

Income support or income-based Jobseeker's Allowance are means-tested, targeted benefits. Bradshaw and Finch (2002) show that the child benefit package for the 'social assistance' family case is considerably above the child benefit package for the average family case (£86) and the childless couple comparator (£220)[14]. Table 5.2 in Chapter 5 shows that a substantial amount of this £220 comes from social assistance (£132). Only two other sources contribute to the package for the social assistance family case: the universal child benefit (£67) and a small contribution from help with school costs (£21).

Income support or income-based Jobseeker's Allowance are passport benefits. Those who receive these benefits then qualify for a range of other benefits and assistance:

- Housing benefit if paying rent (rent rebate in Northern Ireland)
- Council Tax benefit (rate rebate in Northern Ireland)
- Free prescriptions and dental treatment
- Free NHS eye tests and vouchers to help with costs of glasses
- Free school meals
- Help with the cost of travelling to hospitals for NHS treatment
- Free milk and vitamins for pregnant women, nursing mothers and children up to 5 years old
- Help from the Social Fund

The Social Fund has been a contentious system (Dean 2000), where people must apply to this discretionary fund for either loans or payments. Despite its overall trend towards targeting and means-testing, the UK has maintained its universal child benefit. It has been raised recently above the rate of inflation but it is not raised routinely nor is it index linked (Bradshaw and Finch 2002, Table 3.7).

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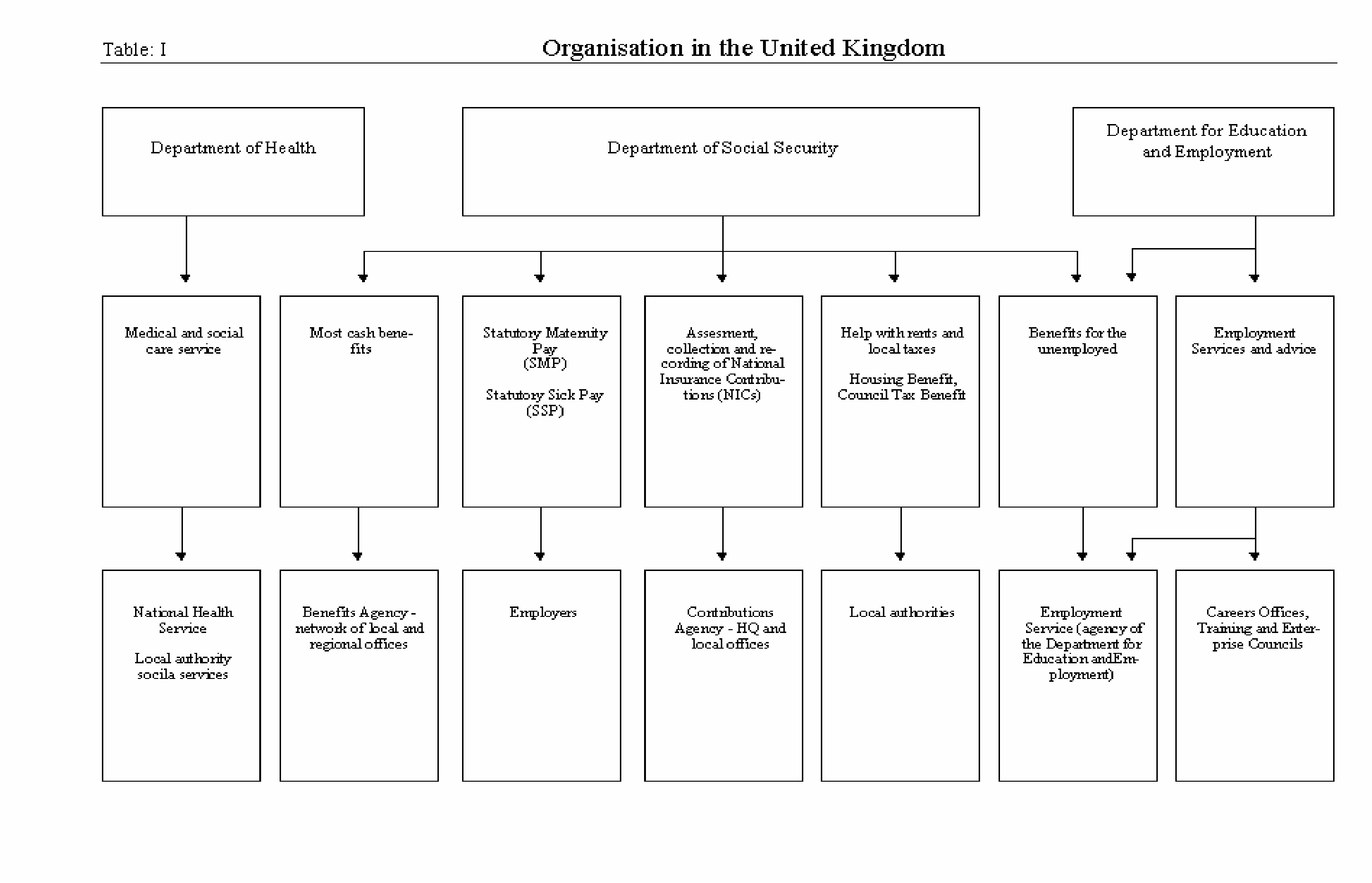
[14] These amounts are differences in income from a childless couple at this earnings level in £ purchasing power parities.

Diagram UK: Administrative Arrangements for Social Security in the UK



The UK has recently introduced statutory parental leave and leave for parents to care for sick children. It is presently unpaid but parents' jobs are guaranteed. The fact that is unpaid has been criticised (Trade Union European Information Project 2000). Parental leave is limited -- 13 weeks parental leave per child -- compared to other European countries (Bradshaw and Finch 2002, Table 7.5). Disability is considered within parental leave. Parental leave is extended 18 weeks, for a disabled child (defined by receiving Disability Living Allowance (DLA)). The leave is extended by age for disabled children: parental leave is available until the age of five except when the child is disabled, when it is extended until the age of 18 years.

The UK has taken all three routes to additional financial support for disabled children. The passport benefit is the DLA. This is one that all disabled people can apply to and is not a child-only benefit. The Disability Living Allowance has care (three levels) and mobility (two levels) components. At three months, a child can receive DLA care component. The mobility component is available when a child is over the age of five years. Recently, severely disabled children with difficulty walking, at the ages of three and four may be granted the higher mobility rate of DLA. Applications for children must show that their need for care or mobility assistance is substantially more than for other children at their age. The DLA is tax free and not means tested. If DLA is granted, the parent can qualify for extra amounts on benefits and tax credits.

The middle and highest rate of DLA care component are passports for the carer to apply for the Carer's Allowance. The carer must be caring for the child for at least 35 hours per week, earning less than £79, be over 16 years of age and not be in full-time education. A severely disabled child receives a further amount. Unlike most other countries (see Chapter 5), the UK does not extend the age limit for either the Child Tax Credit, or the universal child benefit, because a child is disabled.

Research in the UK shows that a substantial number of families with disabled children is dependent on the social assistance system. 9 out of 10 lone parents and a third of two-parent families have no income except for benefits (Beresford 1995). In-depth research with parents of severely disabled children found a shortfall of

£27.97 per week between parents' minimum household budget and the benefits received (calculated by 2001 benefits). (Dobson and Middleton 1998, Dobson et al. 2001a and b) On average, household incomes are lower amongst families with severely disabled children compared to families with non-disabled children. Parents report high levels of distress over money and are frequently unaware of benefits to which their families are entitled (Beresford et al. 1996). In contrast, disabled children in Dobson and colleagues' research (2001b) think their families do have enough money and are no better or worse off than other families. It seems that children do limit their requests to what they think their parents can afford, although the evidence is not conclusive. Kilkelly and colleagues (2004: xvii) note that children with disabilities are at extreme risk of poverty in Northern Ireland.

Research finds problems with the inflexibility of the benefits system. For example, benefits are not able to take into account a sudden crisis – such as hospitalisation – that can involve substantial transport (Roberts and Lawton 1999) and other costs for families. Benefits for children assume that younger children cost less than older children whereas, in fact, research shows that the essential minimum spending for older disabled children is lower than for younger disabled children (Dobson and Middleton 1998).

Lawton (1998) undertook research on the financial situation of families with two or more severely disabled children. She concludes that, although they may receive more in total from disability benefits than families with one disabled child, the benefit system does not take into account the cumulative effects of care. She gives an example in relation to the care component of DLA. Each child would be assessed individually. If each child fell outside the criteria, the family would receive no award despite the family's overall amount of care.

Support and Care services

	England		**Northern Ireland**	
	All Children	**Disabled Children**	**All Children**	**Disabled Children**
Key childcare legislation	Children Act 1989	Children Act 1989	Children (NI) Order 1995	Children (NI) Order 1995
Does a child (or carer) have the right to childcare?	Part-time place for 4 year olds; aiming for part time-place for 3 year olds	Yes	Part-time place for pre-school year	Yes
Is there formal out-of-school care provided by the State or with State support?	No, although increased national funding for out of school care through New Opportunities Fund etc.	No, although increased national funding for out of school care through New Opportunities Fund etc.	No, although increased national funding for out of school care through New Opportunities Fund etc.	No, although increased national funding for out of school care through New Opportunities Fund etc.
How is childcare organised?	Mix of providers	Mix of providers	Mix of providers	Mix of providers
Are there eligibility criteria for childcare?	Age	Age and disability definition	Age	Age and disability definition
Is childcare free at the point of use?	No, except for free part-time pre-school place	Fees can be charged for childcare. Free part-time pre-school place.	No, except for free part-time pre-school place	Fees can be charged for childcare. Free part-time pre-school place.
Does supply meet demand?	No	No	No	No

	England	**Northern Ireland**
Is there a policy commitment to community inclusion/ living in a family environment?	Yes	Yes
Key support legislation	Children Act 1989 Carers and Disabled Children Act 2000	Children (NI) Order 1995 Carers and Disabled Payments Act (Northern Ireland) (2002)
Does the disabled person have the right to support services?	Vague right (children in need)	Vague right (children in need)
How are support services organised?	Local authorities	• Health & Social Services Boards • Health & Social Services Trusts deliver services
What are the eligibility criteria?	Definition of disability and age	Definition of disability and age
How are such criteria assessed?	By social work services, often through multi-disciplinary assessment	By social work services, often through multi-disciplinary assessment
What involvement do parents/ carers have in decisions about support services?	Statutory right to involvement	Statutory right to involvement
What involvement do disabled people have in decisions about support services?	Not in children’s legislation, although recommended in guidance	Not in children’s legislation, although recommended in guidance
Is support provided in cash or in kind?	Direct payments, vouchers and in kind	Direct payments, vouchers and in kind
Does supply meet demand?	Yes	Yes

Child care and out-of-school care

State support for child care and out-of-school care has developed rapidly over recent years. A free part-time pre-school place is now available for all four year olds in England and there are targets to provide a part-time place for all three year olds. Compulsory school begins at the age of four in Northern Ireland, with expansion in the pre-school year for three year olds (DENI 2004: 7). Northern Ireland and England have National Childcare Strategies, announced in the late 1990s which aim to rapidly expand and improve child care services.

The childcare and pre-school education system is complex in the UK, with a 'mixed economy' of statutory, voluntary and private provision, which include:

- Day nurseries: run through social services, by employers or private companies.
- Pre-schools/ Playgroups: run by private or voluntary groups. They typically provide part-time or sessional provision.
- Nursery school or classes: run through education or private schools.
- Childminders: A self-employed person who provides day care for more than two hours per day. Provision is usually in the childminder's own home. Childminders can cater for children aged zero to eight years

Other forms of childcare include parent and toddler groups, combined nursery/ family centres, Early Excellence centres, reception classes, early years units etc. Formal childcare is registered and inspected, under national requirements. A range of other provision is also potentially available for older children, such as before- or after-school clubs and holiday clubs for three to fourteen year olds. These can be offered by public, private or voluntary groups and typically charge fees.

Beyond the provision of a free part-time education place, childcare is generally paid for by parents. The introduction of tax credits is another mechanism the Government is using to contribute to childcare funding for low income families. The New Opportunities Fund, which is funding from the national lottery, has provided funding for childcare provision. This and other pump-priming funding has expanded provision but the National Audit Office reports that only half of new providers know what they will do when start-up funding ends (2004: 7). As reported in Eurostat (2004), "Access is therefore currently limited significantly by cost and the shortage of quality childcare places available, particularly for babies" (93).

Children with Special Educational Needs (SEN) may attend special schools, provided through education, from the ages of three to five. These are free to the parent and have a reduced staff: student ratio. Opportunity Groups may also be available on a free sessional basis, for children with SEN, to facilitate their entry into mainstream schooling. The National Audit Office (2004: 6) reports that few providers are currently able to cater for disabled children and many are not trained to do so. Home-based educational schemes, or Portage, provide practical support and advice for children with SEN. Local authorities (England) and HSSBs (Northern Ireland) must provide out-of-school care and holiday care for children in need, including children with disabilities, under children's legislation (see next section). Despite this, DENI (2004: 37-38) acknowledges problems with provision for children with SEN, in ensuring consistency of diagnosis and support across all pre-school sectors.

Support at home

Child-specific legislation requires local authorities and HSSBs to provide social services for children 'in need'. Unless it is counter to children's welfare, these services should promote the upbringing of such children in their families. The definition of 'children in need' includes children with a disability, defined as meaning:

- 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 1995 Article 2(2); Children Act 1989 Section 17(11))

Beyond day care, legislation sets out a range of services that must be provided for children in need. For disabled children, such services should be designed:

- To minimise the effect on disabled children within their area of their disability
- To give children the opportunity to lead as normal lives as possible (Sch 2, Part 1, (6) Children Act 1989; Sch 2, Part 1, (7) Children (NI) Order 1995)

A local register of disabled children must be maintained. Services can be provided free at point of use but there can also be means-tested charges. Provision of services is based on assessment, which is undertaken by the local authority or board. There is no required link between assessment and service provision.

Carers have individual rights to assessment under legislation. This gives carers, including parents of a disabled child, the right to request an assessment of their needs. The local authority or board must take that assessment into account when deciding what services, if any, to provide under children's legislation to support the disabled child and the family. Siblings of disabled children are not specifically covered by the children's legislation in England or Northern Ireland but could be considered 'children in need' if they are judged otherwise to fit the category.

A recent development has been the extension of direct payments to disabled children. Local authorities or boards can provide funds, rather than in-kind services, so that parents can purchase services to meet the assessed needs of the disabled child and family. Parents can also be provided with vouchers, which they may use to buy short-term breaks, for example.

The Audit Commission (2003) reviewed provision in England and found:

- A lottery of provision, with services depending on how hard families pushed for services and where they lived. Eligibility criteria differed between agencies in the same area as well as across councils
- Too little was provided, too late. Too many families had "unacceptably long waits for interventions, equipment and adaptations" (3)
- "Families struggled through a maze of services to track down essential information" (3)
- Children from black and minority ethnic groups risked being inadequately cared for by disabled children's services (21)

In Northern Ireland, services for disabled children are still found within a disability programme of care along with adults: There can however be a lack of recognition of the particular needs of children and young people in planning and delivering services for people with a disability. This conflicts with the Children Order which is clear that children with a disability are children first and that this should find expression in the services provided for them (DHSSPS 2003a: para 9.65).

Care and support away from home

Over three-quarters of parents caring for a severely disabled child express the need for short-term breaks, in Beresford's national survey (1995). For most, this need is unmet or only partially met (see also Hunt 2002; Monteith et al. 2002). Increased investment in the Carers Special Grant is hoped to increase short term breaks for parent carers (DOH 2003: 29). Still, one-third of parents responding to the survey carried out by Beresford (1995) have chosen not to use a short term care scheme.

Morris (1998b and c) reports mixed views of young disabled people on short-term breaks. On the one hand, a young person appreciates the opportunities to go on outings and to get away from a stressful environment at home. On the other hand, some young people feel excluded by being sent away from home, sometimes without warning, and into segregated provision. Morris (1998a) finds that children's views were only ascertained, for statutory reviews of short-term break placements, in 19 out of 57 cases. Findings of Connors and Stalker (2003) are more positive with children reporting enjoyment of short-term breaks, except in hospitals. Friendships with other children, good relationships with staff and access to a range of activities are reported benefits of short term care (Beresford et al. 1996; Prewett 1999).

For those children who are not able to live with their original families, there is a system of foster and residential care. This is regulated by statute, provided through local authorities (although may be provided by private or voluntary organisations as well as state-run ones), and inspected. There have been concerns about the lack of foster families and the poor quality of provision and outcomes for children who are looked after by the state (e.g. DfES 2003c).

Health services and assistive technology

Type of health care system	National health service
What % of GDP is spent on health care?[15]	7.7%
What % of expenditure on health is public expenditure?[16]	83.4%
What are the average out-of-pocket payments (per capita, US$)?[17]	*No information*

	England	**Northern Ireland**
Key health legislation	• National Health Service (NHS) Act 1946 • NHS Act 1977 • NHS and Community Care Act 1990 • NHS Reform and Health Care Professions Act 2002	• Health and Personal Social Services (NI) Order 1972 • The Health and Personal Social Services (NI) Order 1991 • Health and Personal Social Services Act (NI) 2001
Are all children covered by the system?	Yes	Yes
How is health care organised?	• Central government sets policy framework, performance targets etc. • Strategic Health authorities are responsibly for planning and monitoring • Primary Care Trusts commission services • Range of Trusts deliver services	• Central government sets policy framework, performance targets etc. • Health & Social Services Boards (HSSB) commission services • Health & Social Services Trusts (HSST) deliver services
How is health care monitored?	• Central government oversees performance targets	• Central government oversees performance targets

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[15] 2002, Information from OECD in Figures (2003).

[16] 2002, Information from OECD in Figures (2003).

[17] 2002, Information from OECD in Figures (2003).

	and clinical governance • Patient and Public Involvement Fora will monitor effectiveness in local NHS trusts, from the patients' perspectives • Local authorities will have new powers to scrutinise and review health services (Overview and Scrutiny Committees) • Health Care Commission is responsible for audit and inspection	and clinical governance • Health and Social Services Councils, covering each HSSB area • Health and Personal Social Services Regulation and Improvement Authority will monitor the quality of services
Is health care free at the point of use?	Yes, for children	Yes, for children
What choice do parents and children have?	Limited but expanded	Limited
To what extent are parents involved in their child's health care decisions?	Parental rights to be involved	Parental rights to be involved
To what extent are children involved in health care decisions about themselves?	Children over the age of 16 can consent to treatment; those under 16 may consent to treatment if considered competent. Law is not clear on refusal of treatment.	Children over the age of 16 can consent to treatment; those under 16 may consent to treatment if considered competent. Law is not clear on refusal of treatment.
How are specialist services accessed?	Through GP	Through GP

Key legislation for assistive technology	Range of legislation
How is assistive technology organised?	England - primarily through social services departments or NHS Northern Ireland – primarily through HSST
How is it funded?	• If provided through NHS, free of charge • If provided through social services, free or part-payments

Principles and organisation

The UK has the prototype national health service (NHS). It has a high degree of state intervention; health services are publicly financed; and, for the most part, health services are delivered by public employees in facilities that are publicly owned.

The NHS is a centrally driven service, with both policy goals and performance targets set by central government. Central government fixes the global budget for health services, which is financed primarily through taxation and national insurance (Freeman 2000: 36). In England, the Healthcare Commission has responsibility for audit, inspection and regulation of the NHS. In Northern Ireland, plans and quarterly reports are required from HSSBs and from HSSTs to the DHSSPS (2004: 5).

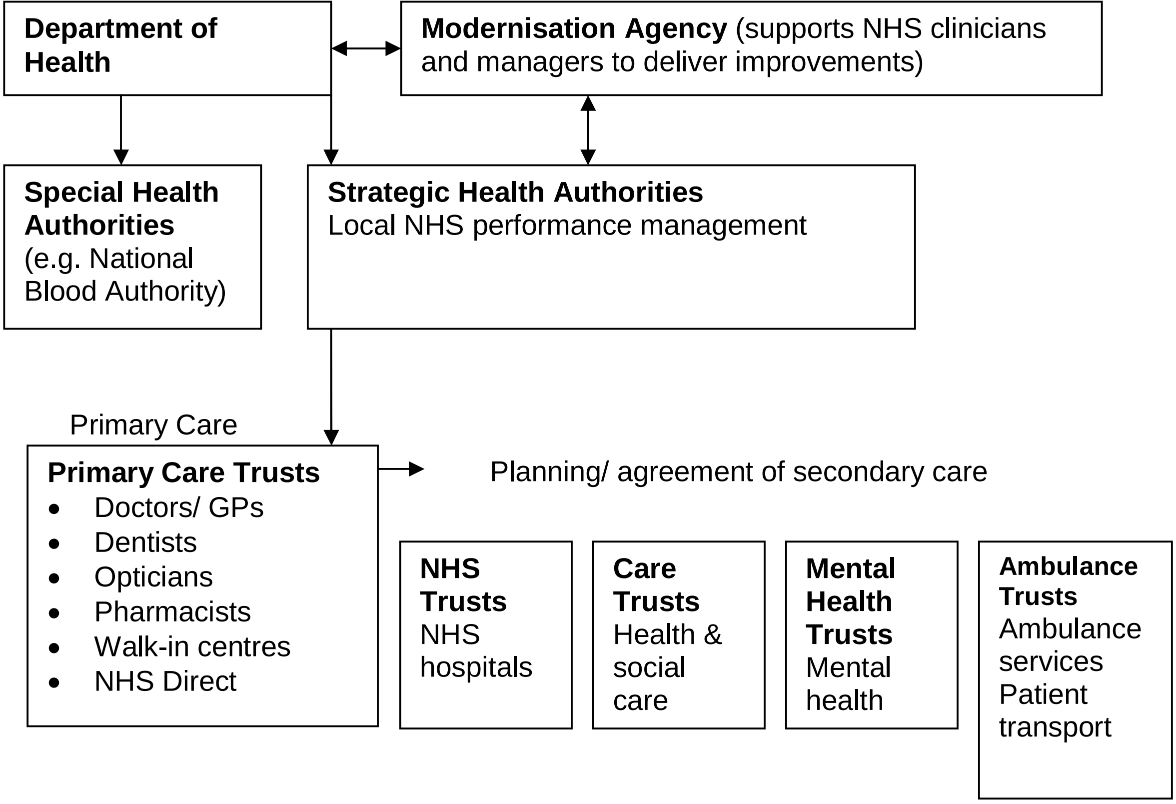
The NHS in England and, to a lesser extent, in Northern Ireland has had frequent structural reforms. The diversity of providers is increasing in England, with Foundation hospitals being created and a greater role planned for independent provision. Northern Ireland has had less radical change. Four HSSBs have retained their responsibilities for planning and purchasing services; 14 independent HSST provide health services. All these bodies are appointed and not elected, so that they do not have direct political accountability.

Privatisation has been introduced to the NHS in several ways. In the 1980s, hospitals were required to tender for certain services and contracts with external organisations resulted. Patients can also choose to pay for private health care, which can be through separate private hospitals and practitioners or indeed may be beds set aside for private patients in public hospitals. There has been controversy that ‘going private’ is a way to jump the long waiting lists for treatment (Alcock 2003).

While the NHS has promised universal coverage, in fact, provision remains unequal throughout the country (e.g. Acheson report (1998)). Inequality is recognised in Northern Ireland, across areas, as well:

- Children with complex needs, chronic illnesses and life-limiting conditions are being maintained at home through the provision of community children’s nursing services. However, the level of community children's services varies greatly across Northern Ireland. Further development in nursing services is required (DHSSPS 2004: 24)

Diagram UK: Key organisations in England NHS



Source: adapted from NHS UK (2004)

The General Practitioner (GP) model dominates primary health care in the NHS. GPs are the 'gatekeeper' to specialist services, as they provide the referrals. Recent government policy in both England and Northern Ireland have only sought to emphasise primary care more (Alcock 2003: 65; DHSSPS 2004). Partnership has been a major emphasis, with health encouraged to work more closely with local authorities (DOH 2003).

To improve quality, the government has introduced a rolling programme of national service frameworks. These have been issued for children's services (in England and Northern Ireland). A separate standard for the hospital care of children, in England, has also been published. This standard was a response to the negative findings of the Kennedy Report[18]: Improving child health is a priority in both England and Northern Ireland (DOH 2002; DHSSS 2004).

Funding and costs

The principle of the NHS is that it is free at the point of use. Certain services do require payments but children are typically exempted from them. For example, children under the age of 16 or those in full-time education under the age of 19, receive free NHS prescriptions and free NHS sight tests and vouchers towards the cost of glasses or contact lenses. Free dental treatment is available until a child is 18 or in full-time education up to the age of 19.

The role of private funding within the NHS remains small – but it is growing. Alcock (2003) reports that private health spending is 15% of health expenditure in the UK. Around one in eight of the population have private health insurance (Alcock 2003: 69).

Assistive Technology

A range of different legislation can potentially cover assistive technology for disabled children, in social work, health and other legislation. Disabled children and their families may be able to gain financial assistance through the Disability Living Allowance and its mobility component or through direct payments.

Disabled children and their parents can ask for an assessment as a ‘child in need’ or apply to health. Equipment used in the home is typically provided by social services departments/ HSST, following an assessment by an occupational therapist. There can be costs for this equipment. A referral from the GP, to the specialist, is required for aids and equipment provided through the NHS. These aids and equipment are for nursing and medical care in the home and mobility. Such equipment is provided free of charge. There is local variability on assessment of need. Vouchers are sometimes available to obtain devices outside the NHS or to part-pay for wheelchairs not

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[18] This was the inquiry into children’s heart surgery at the Bristol Royal Infirmary. For further information, see http://www.dh.gov.uk

available free on the NHS. Maintenance and repair costs are covered by the NHS, for their equipment.

There are problems with the system, in regards to co-ordination across health and social services boundaries (Deloitte and Touche 2003: 53) – as well as education. It can take a lengthy time to obtain a device, in part due to insufficient numbers of occupational therapists (Deloitte and Touche 2003: 54). Research undertaken in Northern Ireland (Monteith et al. 2002) finds that one-third of parents say their child does not have aids and equipment that their child needs.

Choice, consent and user involvement

Extending choice has become a dominant policy drive of Government (DOH 2003). For example, in England, patients are being given more choice when they receive treatment -- in the time and date for hospital appointments and elective admissions (by 2005) – and where they would receive treatment – allowing for choice of alternative providers should waiting times be excessive (DOH 2003: 11-12).

NHS bodies now have a statutory duty to consult with, and involve, patients and the public. Several bodies will seek to involve 'the public' in collective decision-making about the NHS. Nationally, the Commission for Patient and Public Involvement in Health is tasked with this responsibility. This statutory body will report to the Secretary of State for Health and to Parliament. The Commission oversees the local Patient and Public Involvement Fora (PPIFs). Every NHS Trust should have a PPIF, tasked to report on local people's concerns about services, to carry out inspections and represent local people's views on the Trust (Allsop and Baggott 2004: 33).

Both the Department of Health (2003) and the Department of Health, Social Services and Public Safety (DHSSPS 2003b) stress that children and parents should be involved in decisions about children's treatment and plan, and makes specific mention of disabled children. Children aged 16 and over can consent or refuse their own treatment, if considered legally competent.

Physical Environment

Housing stock[19]	69% owner-occupiers; 10% private rented; 7% rented registered social landlord; 14% rented local authority
Key housing legislation??	Housing Act 1998 Housing (NI) Order 1992 (new legislation is being proposed)
How is housing policy organised?	Housing benefit: central government sets policy and funds; English local authorities and Northern Ireland Housing Executive administer Social housing: central government sets policy; local authorities and registered social landlords responsible for policy details and delivery with private and voluntary sector
Housing benefits for families with children	Yes
Supply-subsidies	Yes
What % of GDP is public expenditure on housing?[20]	1.5%
Accessibility regulation to buildings etc.	Part M of the Building Regulations 1991 as amended Accessibility also covered, to some extent, through the Disability Discrimination Act 1995. Certain gaps will be filled by the Disability Discrimination Bill.
Has accessibility to public places improved over the past 10 years?[21]	Yes, in public opinion. 17.7% think it has improved very much while 59.9% thought it has improved somewhat
On a scale of (1) 'not at all difficult', (2) 'not very difficult', (3) 'fairly difficult', and (4) 'very difficult'[22]**:**	
How accessible is public transport?	3.45 (fairly to very difficult) for physically disabled people 3.15 (fairly to very difficult) for intellectually disabled people
How accessible are cultural events?	3.00 (fairly difficult) for physically disabled people 2.91 (not very to fairly difficult) for intellectually disabled people
How accessible are sports events?	3.02 (fairly to very difficult) for physically disabled people 2.82 (not very to fairly difficult) for intellectually disabled people
How accessible are restaurants, hotels etc.?	3.17 (fairly to very difficult) for physically disabled people 3.00 (fairly difficult) for intellectually disabled people

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[19] Information from Ball 2004: 78.

[20] See Chapter 5.

[21] See Chapter 2.

[22] See Chapter 2.

	Disabled children	**Disabled adults**
Key transport legislation	• Disabled Persons Act 1981 • Transport Act 1985 • Disability Discrimination Act 1995 • Transport Act 2000 • Disability Discrimination Bill	As for disabled children
Are there enforcement mechanisms?	Yes, for DDA	Yes, for DDA
Are fare concessions available for public transport?	Yes	Yes
Can an accompanying person go free, or for a reduced price, on public transport?	Yes	Yes
Is special transport available as an alternative to public transport?	Depends on local authority	Depends on local authority
Is there a parking badge scheme?	Yes, for children aged 2 or over	Yes
Is there financial support for private transport?	Yes	Yes

Housing

Most dwellings are owner-occupied in the UK. Local authority social housing has been decreasing. First, there has been a 'right-to-buy' policy where tenants who met particular criteria could but their homes for discounted prices. Second, policy has encouraged (and increasingly required) local authorities to sell off their stock to registered social landlords (RSL). These are predominantly non-profit housing associations and trusts. (Ball 2004: 125-126). UK public expenditure on housing is a considerably higher percentage of GDP, than the European Union average: 1.5% compared to 0.4% (see Chapter 5).

A Disabled Facilities Grant can help with the costs of home adaptations. They must be considered 'necessary and appropriate' for meeting the disabled person's needs and must be 'reasonable and practicable', taking into account the age and condition of the property. The grant can cover the costs of adaptations up to a set amount. Any higher costs may be covered by the local authority; the local authority also has discretion to provide financial and other assistance for improvements or repairs to the home.

Adaptations can be highly successful and, in such cases, are perceived as transforming a child's life for the better (Oldman and Beresford 1998, see also Tozer with Shah 1999). Heywood's study (2001) of adaptations in England found that small alterations (costing £500 or less) are generally perceived as a highly effective use of money. The effectiveness of major adaptations is lowest for children. Heywood finds that some adaptations are unused, unusable or caused increased stress.

Accessibility to buildings and public spaces

The UK has both national regulations and legislation, for accessibility to buildings. Part M of the UK Building Regulations 1991 requires reasonable provision for disabled people to access and use buildings. The Regulations have been extended to cover all new dwellings, so that disabled people can visit friends and relatives and so occupants can adjust more easily to any chances in their own mobility. The regulations also apply to non-domestic building extensions but do not apply to alterations, changes of use or extensions to domestic buildings. Some buildings are not covered such as schools and crown buildings. (Toegankelijkheidsbureau (Toe) and Living Research and Development 2001).

The DDA does not set definite standards for compliance. Instead, it requires service providers to make reasonable adjustments for disabled people in the way they provide their services. When a physical feature makes it impossible or unreasonably difficult for disabled people, service providers will need to consider an alternative method to provide the service. Service providers may have to make reasonable adjustments in their premises' physical features, in order to overcome physical barriers to access. There are separate provisions for employers.

Despite this legislation, disabled people still report difficulties. In the Eurobarometer survey (see Chapter 2), respondents report many activities as fairly or very difficult to access for both intellectually and physically disabled people. However, a large majority of respondents feel that access has improved over the past 10 years to public places.

Transport

The UK has several requirements for accessible public transport:

- Disabled Persons Act 1981, Section (1) requires local authorities to give regard to disabled people's needs when undertaking works on pedestrian environments. This is a relatively weak duty, as it requires consideration but no positive action
- Transport Act 1985. Section 63(8) requires local authorities to give regard to disabled people's needs when providing transport services. This is a relatively weak duty, as it requires consideration but no positive action
- DDA 1995 has various provisions, including a duty on transport providers to remove physical barriers to access or provide the service by an alternative means if reasonable; and to amend policies, procedures and practices which discriminate against disabled people. Part III of the Act provides a right of access to goods, facilities and services, which covers all public transport infrastructures

- Northern Ireland 1998. Section 75 requires disability equality in relation to public transport

The DDA's coverage of transport has been criticised as insufficient and not comprehensive (Matthews and Lawson 2003). The proposed Disability Discrimination Bill will prevent transport operators from discriminating against disabled people on the basis of their disability and provide more comprehensive coverage of transport areas.

The Railways Act 1993 requires a discount fare scheme on rail services (CD 2000c: 12) Local authorities now have the duty to provide concessionary fares on buses (Transport Act 2000) and have the power to provide further reduced fares (Section 93(7) of the Transport Act 1985). London has further requirements to provide free travel on all transport modes (Greater London Authority Act 1999). The Transport Act 1985 allows for, but does not require, local authorities to make grants for special transport services, to meet the needs of disabled people (Section 106). (Malaga 2003: 51-52) In Northern Ireland, the national Transport Programme for People with Disabilities funds specialist transport operations. The current concessionary fares scheme allows for children under the age of 16 half-fare concessions but does not otherwise incorporate disability. The Government stated its intention to extend this scheme. (Department for Regional Development 2002) Help with transport to hospital may also be available (Audit Commission 2004: 2).

Parking badges are available for private cars (for children aged two or over) (Audit Commission 2004: 1). The higher mobility component of the Disability Living Allowance can be used to buy or adapt private cars and allows for tax exemptions (for eligibility, see above). Families can lease a car from the Motability Scheme, which offers vehicles on lease-hire or hire-purchase terms. (Malaga 2003: 53) Roberts and Lawton (1999) suggest that current help through the DLA is insufficient, finding several groups of children being less well served:

- Children who have particular diagnoses, especially those linked to chronic illness
- Children who experience frequent medical crises

- Children who are dependent on medical equipment (technology dependent)
- Children who have life limiting conditions and who may die in childhood
- Very young disabled children (since this research, the DLA higher rate mobility component has been extended to disabled children aged three and four)
- Children over two who have severely impaired motor functions, sight or speech

Leisure and Recreation

There is no overarching legislation that recognises children’s right to culture, recreation and play. Disabled children have rights, under the DDA, not to be discriminated in accessing or using goods and services – and these would cover a range of cultural, recreational and play services.

Children’s agencies have criticised the lack of national child play strategies in the UK (e.g. Children in Wales et al. 2002: 24) The Government did announce a review of children’s play opportunities in 2002 – but this was to inform a proposed lottery funding programme. In Northern Ireland, 68% of children’s submissions to the NICCY school research complained of the inability to access appropriate play, leisure, sport and youth club facilities (Kilkelly et al. 2004: 159).

Cavet (1998) notes how the relative poverty of disabled people and their families, plus the extra costs associated with disability, can make leisure participation inaccessible. Families in rural areas can find it particularly difficult to access opportunities outside their homes (Murray 2002).

Recent studies express concern about the lack of access to clubs and sports activities. In a survey involving more than 2200 disabled children and young people (aged six to 16 years), just over one in 10 disabled young people is a member of a non-school sports club. This compares to just under half of non-disabled young people in a comparable survey (Finch et al. 2001). Young people with a hearing impairment are the most likely to participate in sport and to enjoy it, while those with a mobility impairment or ‘self-care related’ disability are least likely. This is attributed to the lack of suitably adapted facilities for the later groups (Finch et al. 2001).

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