



# Child Health in the European Union

Edited by Adriano Cattaneo, Laura Cogoy, Anna Macaluso, Giorgio Tamburlini

Institute for Maternal and Child Health IRCCS Burlo Garofolo  
Health Services Research, Epidemiology and International Health  
WHO Collaborating Centre for Maternal and Child Health  
Trieste, Italy

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European Commission

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## Abbreviations

Institutional designations and abbreviations for countries:

Country	Code	Country	Code
Austria	AT	Lithuania	LT
Belgium	BE	Luxembourg	LU
Bulgaria	BG	Malta	MT
Cyprus	CY	Netherlands	NL
Czech Republic	CZ	Poland	PL
Denmark	DK	Portugal	PT
Estonia	EE	Romania	RO
Finland	FI	Slovak Republic	SK
France	FR	Slovenia	SI
Germany	DE	Spain	ES
Greece	EL	Sweden	SE
Hungary	HU	United Kingdom	UK
Ireland	IE	Croatia	HR
Italy	IT	FYR of Macedonia	MKD*
Latvia	LV	Turkey	TR
Iceland	IS	Norway	NO
Liechtenstein	LI	Switzerland	CH

\* not official

Other abbreviations:

ADHD	Attention Deficit Hyperactivity Disorder
CRC	Convention on the Rights of the Child
DALY	Disability-Adjusted Life Years
DG SANCO	Directorate General for Health and Consumers
EAHC	Executive Agency for Health and Consumers
EC	European Commission
ECDC	European Centre for Disease prevention and Control
EFTA	European Free Trade Association
EU	European Union
EUROSTAT	European Statistics
HBSC	Health Behaviour in School Children
ICD	International Classification of Diseases
IUGR	Intra Uterine Growth Restriction
LBW	Low Birth Weight
MICS	Multiple Indicators Cluster Surveys
NGO	Non-Governmental Organisation
OECD	Organisation for Economic Co-operation and Development
SES	Socio-economic status
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organization

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## Executive Summary

Health is a fundamental right for children, as stated by the Convention on the Rights of the Child. Child health is also increasingly valued as a key precursor of health in the life course. The EAHC and DG SANCO of the EC have commissioned this report to provide policy-makers and public health experts with a comprehensive, albeit synthetic, overview of child health and its main determinants. The report puts together, analyses and discusses available data and information on the health of children up to 12 years of age in the 27 Member States of the EU, the 4 EFTA States, and the 3 official candidate countries (Croatia, FYR of Macedonia and Turkey).

The report starts with an overview of data on births, deaths, health and well-being (**Chapter 1**). The infant mortality rate shows a constant and remarkable decrease, from almost 28 per 1,000 live birth in 1965 to 4.3 per 1,000 in 2009. During this time, most infant deaths shifted from the post-neonatal to the neonatal period in EU15 and EFTA countries, while post-neonatal mortality still represents a significant proportion of infant deaths in EU12 and official candidate countries. Perinatal and congenital causes, affecting mostly neonates, account for the largest proportion of infant deaths in all countries. In the age group 1 to 14 years, cancer is the first cause of death in EU27 countries, followed by external causes, mainly road accidents. The improved survival of very LBW infants and of children affected by severe diseases and congenital anomalies tends to increase the proportion of children living with functional impairments. In general, many chronic diseases show an increasing trend, while communicable diseases and injuries have a tendency to decrease. In spite of recent progress in the development and implementation of EU-wide surveys, there is still a lack of comparable data on child growth, cognitive and socio-emotional development, and well-being. There is also a serious gap in the capacity to capture inequalities across population groups; this gap seems to be deepening due to an increase in social divide and migration, and to a reduction in welfare programmes.

The main determinants of child health are described in **Chapter 2**. These determinants include not only the social, psychosocial and physical environments in which children are conceived, born and raised, but also the social and health system policies that can modify these environments and thus have an impact on the underlying determinants, and consequently on child health. Socio-economic status has a bearing on parental education, maternal health, environmental exposure, infant and child nutrition, access to care, and it ultimately contributes to health outcomes. Macroeconomic and fiscal policies, as well as public policies in various sectors (health, education, environment, gender, legal status of minorities and migrants), play a role at different levels of the causal pathways of health and disease, and contribute to increase or decrease health inequalities and inequities. Changing economic and social environments, as a consequence of economic downturns, have a direct and indirect impact on child health and well-being. Exposures and practices related to social determinants, from conception to the early years of life, are crucial for child health and development, and altogether have deep implications for population health in general.

Since many of the current trends in the health of children and adults have their explanations in changes in exposures and practices occurring from conception to birth, **Chapter 3** describes the most significant conditions affecting mothers, even if they are not included in the scope of this report, and newborns. In comparison to other regions of the world, in Europe, the most prominent indicators of perinatal health (mortality, LBW) portray a favourable situation. There are, however, important inequalities among and within countries. To ensure a good start in life, and to lay the foundation for optimal child health and development, adequate maternal nutrition, exposure to tobacco smoke, alcohol and other substances, as well as universal access to appropriate quality health care in the periconceptional period, during pregnancy and at childbirth, need to be effectively addressed.

Along with perinatal conditions, congenital malformations account for an important proportion of child deaths and long-term disabilities (**Chapter 4**). Prevalence of congenital

malformations at birth is estimated at around 2% of all live births. The most reasonable estimate of the number of newborns with a congenital malformation in the EU27 countries is approximately 160,000 per year. Temporal trends vary in relation to changes in exposure to risk factors and active preventive interventions. Increasing trends are reported for gastroschisis and Down syndrome, decreasing trends for anencephaly and spina bifida. It is difficult, however, to provide reliable time trends as diagnostic accuracy improved substantially in the last years for some conditions and may be responsible for the apparent increase. Causes and risk factors include genetic anomalies, unhealthy life styles and nutrition, some chronic maternal diseases, prenatal exposures to teratogenic drugs and environmental pollutants, and maternal age. Preventive interventions include the effective control of known causes and risk factors, preconception counselling, and early recognition followed by effective treatment.

**Chapter 5** shows that a substantial proportion of children suffer from one or more neurological and developmental disorders. Cerebral palsy is the most common child disability in Western Europe, with a prevalence of about 2 cases per 1,000 live births. Reviews show discordant data about temporal trends. The overall prevalence of some neurological and developmental conditions may be increasing due to increased survival of very LBW infants and children affected by rare diseases that affect also the central or peripheral nervous system. The International Classification of Functioning, Disability and Health represents a milestone in modern thinking about assessment and treatment for children with disability, but its implementation is still partial and not homogeneous. This hampers adequate recognition and care, as well as cross-country comparisons. There are still striking differences across countries and important gaps in the capacity to provide optimal comprehensive and multidisciplinary care to children affected by neurological and developmental disorders. For example, there are countries in which children affected by severe neurological conditions are institutionalised, when in fact children with neurological impairment should be rather provided with inclusive education and specific support.

Mental health (**Chapter 6**) is strictly linked with the disorders discussed in the previous chapter. Up to 20% of children may have mental or behavioural problems that may range from minor complaints to severe disorders, with large variations in prevalence estimates across countries. It is usually thought that mental health problems are on the rise; yet no consensus has been reached on whether this is true. For example, the great increase in autism spectrum disorders is mainly due to the adoption of broader definitions. Several biological, psychological and social risk factors are associated with mental health and the development of mental disorders from early childhood to adolescence. There is increasing awareness of the importance of improving preventive action and access to mental health services for children. Over the past few years several countries have made progress on this. However, many children with mental health problems are not receiving the care they need and community-based prevention programmes are lacking.

Cancer in children (**Chapter 7**) is a rare event, far less frequent than in adults, representing less than 1% of all cancer cases. The incidence rate in the EU27 countries is on average 131 new cases per million children per year. Cancer is the first cause of death in children between 1 and 14 years of age. The most common type of cancer in children is leukaemia (30%), followed by tumours of the central nervous system (about 20%) and by lymphomas (14%). Up until the present decade, the incidence of childhood cancer has been increasing. Improved diagnostic procedures and recording accuracy may account for part of this increase. The extent to which changes in life styles and exposure to environmental carcinogens could account for the increasing trends remains undetermined. Despite intense research, there is poor understanding of the causes and mechanisms underlying the disease onset, leaving little room for primary prevention. In the last four decades, treatment has become more and more effective, so that over 70% of children who get cancer nowadays can be cured. However, late adverse effects of therapy are common in survivors. Guidelines for long-term clinical monitoring and mechanisms to deliver targeted care need to be developed.

Rare diseases (**Chapter 8**), include an extremely diverse group of inherited and acquired conditions. They differ in terms of severity and clinical expression, but many are complex, degenerative and chronically incapacitating. A disease is defined as rare when it affects no more than 5 people in 10,000. There are about 7,000 chronic, and often incapacitating, rare diseases; about 50% of them affect children. When taken together, rare diseases are a major cause of mortality, morbidity, disability and dependency, but each rare disease, taken individually, affects a small minority of people, so that the first obstacle is to give them adequate recognition and visibility. Patients with rare diseases need special centres for diagnosis, treatment, follow-up, and psychosocial support. In addition to recognition, the main challenges posed by rare diseases in Europe are the development of comprehensive care strategies and the support to research for new drugs and diagnostics. National centres of excellence for at least some rare diseases exist in 12 Member States. As it is impossible to have a centre of excellence for every rare disease in every country, enhanced cooperation, coordination and common regulations across countries is highly necessary.

A group of different conditions of public health importance is discussed in **Chapter 9**. Oral health (**Chapter 9.1**) is essential for health and quality of life. The most widely available indicator of oral health in children is the number of decayed, missing or filled permanent teeth (DMFT) in 12-year-olds. The past 25 years have seen substantial falls in the DMFT index across EU countries, but the improvements have been less marked in Central and Eastern Europe countries and in deprived socio-economic groups. Improvement may be better achieved by broadening the scope of oral health programmes to include improvements in quality of life, reduction of health inequalities, and access to good quality care, as already done in some Member States. Improvements may also be obtained by integrating oral health activities into maternal and child health programmes and in programmes for the prevention and control of non-communicable diseases.

Obesity (**Chapter 9.2**) is currently considered a worldwide epidemic and a problem of very high public health importance, since it is associated with a number of subsequent complications and is considered to be a risk for many other diseases and conditions. The prevalence of obesity in children shows a great variability among countries, being already worryingly high in some. The trend is probably moving upwards in school children, but not in infants and pre-school children. A complex web of interrelated individual, family, social, economic and environmental determinants is associated with the rise in the prevalence of obesity through changes in diet and physical activity. To modify these determinants and control obesity, multi-sectoral approaches that tackle inequalities are needed at local and national levels. Obesity starts early in life and its determinants act mainly before conception, during pregnancy and in early infancy. Strategies for prevention should concentrate on these early life stages.

**Chapter 9.3** deals with diabetes. Type 1 diabetes remains the main form of diabetes in children. The incidence rates range from about 3 to about 60 per 100,000 children 0-14 years of age, with a north-to-south gradient. The incidence rate is increasing alarmingly in all countries, with greater increases in children under 5 and in Central and Eastern European countries, probably associated with environmental factors acting very early in life. Though data on children are scarce, type 2 diabetes occurs mostly during the second decade of life, mainly as a consequence of poor dietary habits and increasing rates of obesity in the first years of life. Primary and secondary prevention should focus on adequate nutrition and physical activity early in life, and on access to improved case management and qualified care in multidisciplinary centres. Participation in EU-wide registries and projects, with targeted indicators, is deemed essential for monitoring and a better understanding of the epidemiology of diabetes.

Congenital heart diseases are the most frequent causes of cardiovascular disease among children in Europe (**Chapter 9.4**). Rheumatic carditis is still common in some Eastern European countries. Venous and arterial thromboembolism, familial hypercholesterolemia and stroke, albeit rare, are increasingly recognised as a paediatric concern. Child poverty,

inadequate dietary habits, smoking, obesity and a lack of physical activity are important risk factors regarding cardiovascular diseases later in adulthood. Prevention, as well as control of risk factors, should start early, before conception, and should continue during pregnancy, and throughout infancy and childhood.

In the last two decades, increased awareness and new diagnostic tests have revealed that coeliac disease is a common condition, with a prevalence of about 1% in the total population in Europe (**Chapter 9.5**). For this reason, and for the wide range of signs, symptoms and associated risk of auto-immune disorders, coeliac disease is an important burden for health systems and societies. Knowledge and awareness on coeliac disease has increased significantly in the last 20 years. However, underdiagnosis is still common. Prevalence rates may be affected by bias related to case definition and diagnosis. An important challenge is to improve active case findings among patients who seek medical advice, as well as evidence-based guidelines for diagnosis and treatment. The disease fulfils many criteria for a population screening, but additional research is needed to further explore the benefits and risks of such a strategy.

Asthma and allergic conditions such as eczema, rhinoconjunctivitis and food allergy, are very widespread in children, and place a high burden on patients, families and the health care system (**Chapter 9.6**). Countries in Northern Europe report the highest prevalence of asthma and allergic conditions, although over the last decade rising trends have been observed in several countries in Eastern and Southern Europe. Causes and risk factors are complex and include genetically-inherited susceptibility and environmental exposures. Strategies to reduce the burden of asthma and allergic conditions should aim at improving prevention at household and community level, as well as facilitating access to good quality case management (including essential drugs), and promote patient and family education.

The prevalence of childhood blindness (**Chapter 9.7**) in Europe is between 0.1 and 0.41 per 1,000 children between 0 and 15 years of age, with significant variations across countries, mainly due to the variable quality of data. Prevalence of low vision is unknown, but it can be estimated as several times higher. Visual impairment may be caused by a variety of causes, including retinopathy of prematurity, which is the leading cause in high-income countries, congenital anomalies, cancer, myopia, amblyopia and injury. Prevention, early detection, treatment and rehabilitation may substantially reduce the prevalence and the severity of visual impairment problems. Technological developments may also considerably improve the prospects of children with severe visual impairment, and should be made available to all children.

National surveys report that between 1 and 2 in 1,000 children suffer from severe, usually congenital, hearing loss, while many more suffer from mild to moderate, usually acquired, hearing loss (**Chapter 9.8**). Hearing loss, when severe and present at birth or acquired in the early years of life, leads to serious problems in speech and language development if not recognised and treated. Identification of hearing loss through neonatal screening, now implemented in most European countries, and hearing screening of older infants and children, can prevent or reduce most of the consequences of severe and profound hearing loss. Current rehabilitation options focus on hearing aids and cochlear implants, and on an informed choice about communication options. Advances in human genetics and technology have improved our ability to identify carriers of inherited hearing loss and to provide genetic counselling.

Though communicable diseases are very common in children and are responsible for a large proportion of the overall burden of child health care, only communicable diseases of greater public health importance have been addressed in this report (**Chapter 10.1**). Overall, the incidence of most communicable diseases in Europe is decreasing. There are a few exceptions (campylobacter, yersinia, hepatitis C), whereas for some diseases (e.g. influenza) data are insufficient and no reliable trends can be obtained. Some vaccine-preventable diseases (e.g. measles) are still endemic in some countries and population groups. The

coverage of immunisation programmes has been improving and is on average very high, but disparities still exist among countries and population groups. New vaccines (e.g. pneumococcal, rotavirus) have been recently introduced in some but not all countries, and their effectiveness is still under scrutiny. Surveillance systems to monitor vaccine-preventable diseases and immunisation coverage are in place and rapidly improving. The surveillance of adverse events following immunisation is still meagre. Antimicrobial resistance of some pathogens is increasing, possibly representing the single biggest challenge that Europe must face with regard to infectious diseases.

Due to their global importance and specific control strategies, tuberculosis and HIV/AIDS are discussed in two separate sub-chapters. Since 2003, nearly all countries, with some exceptions, experienced a decline or stabilisation at low levels in paediatric notification rates of tuberculosis (**Chapter 10.2**), suggesting a decreased or low level of transmission in the general population. In countries with low incidence and low mortality rates, the disease is increasingly aggregating in the foreign-born population, in vulnerable groups and in risk settings associated with poverty and lowered immunity. Complementing current strategies with efforts to address risk factors and social determinants is a crucial challenge.

HIV incidence in children is very low in Europe (**Chapter 10.3**), but trends in young adults are increasing. Widespread implementation of measures to prevent mother-to-child transmission has virtually eliminated this source of infection that remains relevant in specific vulnerable populations such as migrant women coming from high-prevalence countries. Plans to identify HIV-positive pregnant women and to start early treatment on mothers and their babies, if infected, are based on routine HIV testing during pregnancy, but more integrated guidelines on the performance of antenatal HIV screening are needed.

Child maltreatment (**Chapter 11**) remains a major public health and social welfare problem in Europe. Population-based surveys show that a significant proportion of children are subject to physical and/or emotional ill-treatment, sexual abuse, neglect or exploitation. In most instances, child maltreatment is a chronic condition. Over 80% of maltreatment occurs within the close family, while sexual abuse can also be perpetrated by other relatives and/or acquaintances. Child maltreatment has long lasting effects on mental health. It also increases the risk of drug and alcohol problems, of risky sexual behaviour, of obesity and criminal behaviour. In addition, it carries a high risk of intergenerational transmission. Only a small percentage of maltreated children come to the attention of child-protection agencies, indicating failure in recognising and reporting maltreatment. Although infrequent, child abandonment, exploitation and trafficking represent forms of maltreatment that pose serious threats to the survival, health and well-being of children. The serious and long-lasting consequences of child maltreatment, abandonment and trafficking warrant increased investments as well as intersectoral and international collaboration. Challenges include the development and implementation of primary prevention for families who are at risk, improved capacity for early recognition across child education, social and health services, and appropriate institutional response once maltreatment has been detected.

Fatal and non-fatal accidents and injuries are extremely relevant to child health and represent one of the leading causes of death among children 1 to 14 years of age (**Chapter 12**). Although a mortality reduction has been observed every year in the last two decades, injuries still cause 4,000 deaths and more than 10% of all the DALYs lost among children 0 and 14 years of age. The most frequent external causes of fatal injury are transport accidents (36%) and drowning and submersion (14%). Among body regions, the head is frequently involved, accounting for a third of all injuries requiring admission to hospital. Child safety level has been judged to be fair to good in the countries involved in the 2009 Child Safety Action Plans, but improvement is still needed through the adoption, implementation and enforcement of effective approaches to injury prevention. Childhood deaths from injury follow a social gradient; inequalities among and within countries are deemed to reflect differences in the environment that determine disparities in exposure to risk factors and in enforcement practices.

Children, in particular from conception to the earliest years of life, are uniquely vulnerable to environmental hazards. A substantial proportion of child mortality, morbidity and disability is attributable to environmental exposures (**Chapter 13**). Exposure to outdoor and indoor air pollution is a major cause of mortality and morbidity in European children. Chemical and physical agents such as heavy metals, dioxins, PCBs, pesticides, noise pollution, ionizing and ultraviolet radiations cause substantial hazards to children in all countries. In rural areas and marginalised population groups, unsafe water and inadequate sanitation are also an important cause of disease. There is increasing concern about the risks deriving from multiple low-level exposures to chemicals during embryo-foetal development. Thanks to the EU REACH legislation and to the development of EU-wide environmental health indicator and monitoring systems, and of children's environment and health action plans, there has been some progress in risk reduction, notably in the area of lead, PCBs and dioxins, indoor and outdoor air and water pollution. Challenges include the further development of child-focused monitoring and biomonitoring systems, as well as the setting up of intersectoral collaboration to implement child-focused risk reduction policies that take into account the marked inequities in children's exposure and vulnerability to environmental hazards across countries, age groups and socio-economic levels.

The effort to provide a comprehensive though synthetic overview of child health allowed to identify some key issues that appear to be common to all the countries included in this report, even when the substantial differences existing across countries are taken into account. These issues are:

1. The increasing burden of chronic, non-communicable diseases and conditions.
2. The gaps in knowledge and understanding of the causes of many chronic conditions.
3. The importance of exposures to risk factors during the earliest life stages.
4. The persistence, and in some cases the increase of important inequalities.
5. The role of social determinants in shaping susceptibility and exposure to risk factors.
6. The obstacles to access to quality health services and comprehensive care for some diseases and conditions.
7. The scarcity of promotion and prevention programmes specifically devoted to children.
8. The inability to adequately describe and compare child health and well-being across Europe in a standard and valid way.

It must be recognised that in no other part of the world children enjoy better health and life conditions than in Europe. It should also be acknowledged that thanks to the initiative and leadership of the EC, of governments, of WHO, and of other international and national authorities and partners, an impressive amount of commitments have been made over the last decade to protect, promote and improve child health. Nevertheless, this report suggests that to maintain, and possibly improve, this thus far unprecedented state of child health and, most importantly, to give all children equal opportunities, there are a number of challenges ahead that need to be addressed.

## Introduction

This report responds to a call from the Directorate General (DG SANCO) and the Executive Agency for Health and Consumers (EAHC) of the European Commission to bring together available data and information on child health. The aim is to present a comprehensive overview on the health status, healthcare, diseases, social conditions and their background for children up to 12 years of age in the EU and EFTA Member States, as well as official candidate countries.

Data and information are not limited to disease. The report takes into consideration political, social, economic, cultural and environmental factors that have a bearing on child health, the so-called determinants of health. In accordance with mainstream thinking, social policies and health systems are included among the social determinants of health. As a consequence, the report does not deal only with health and health care; it expands on health protection and prevention beyond the health system, taking into account the most important factors that affect child health and well-being. Finally, although focused mainly on health status, the report makes an attempt to identify knowledge gaps and challenges to be addressed.

Given the size of this report, not all aspects of child health have been understandably covered. As instructed by DG SANCO and EAHC, the scope of the report has been limited to health conditions that are considered of public health importance, either because of their high prevalence (e.g. common infections, asthma, allergies, obesity, dental caries), their severity (e.g. type 1 diabetes, cardiovascular diseases, sensory deficits), or their emerging importance and broad health implications (e.g. coeliac disease, autism spectrum disorders). Once the task of writing the report was assigned, the authors and representatives of DG SANCO and EAHC defined the list of topics and the contents of the report. This reflects only a part of the large amount of data and information available. References are provided for those readers who wish or need to look into the different topics in further detail. Also, some of the topics cut across several conditions, nutrition being a typical example. Instead of devoting a full chapter to this, the authors have chosen to deal with nutrition as a determinant of health and disease. It is acknowledged that this choice may be an obstacle to a more complete understanding of the current state of nutrition of children in Europe, yet readers will be able to elaborate on this by going through the wealth of documents and reports available.

Depending on availability of data, the report covers all 27 EU Member States, the four EFTA countries, and the three official candidate countries. Official EU designations and abbreviations are used for all countries, except for the FYR of Macedonia, for which the provisional MKD abbreviation has been used. Whenever possible, data are presented by country. In some cases, however, it was decided to group countries with similar features as follows: EU15 (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, United Kingdom), EU12 (Bulgaria, Czech Republic, Cyprus, Estonia, Latvia, Lithuania, Hungary, Malta, Poland, Romania, Slovenia, Slovak Republic), EU27 (EU15+EU12), EU candidate countries (Croatia, FYR of Macedonia, Turkey), and EFTA countries (Iceland, Liechtenstein, Norway, Switzerland).

As much as possible, the report presents the findings through an equity lens. Inequalities and inequities have been found across and within countries, irrespective of the equity stratifier used, e.g. social class, income, gender, parental education or occupation, area of residence. Unfortunately, data on inequalities are not available on all conditions and from all countries, and when available they are seldom gathered with standard definitions and methods. This is true, needless to say, for most data on health, well-being and disease, so that caution should be observed when making comparisons and drawing conclusions. Readers should be aware of some challenges regarding interpretation of results deriving from incompleteness of data, lack of standard definitions and methods, and common misconceptions when analysing the results (see box overleaf).

## **Caveats and Common Misconceptions when Interpreting Results**

- Incompleteness. When data are incomplete, they may represent only part of the reality. As missing data may refer to individuals or events with characteristics that differ from those originating in the available data, incompleteness may introduce an inevitable bias. The higher the degree of incompleteness, the higher the chances of bias. Comparing data with different degrees of completeness may be very difficult and should be done with great caution.
- Definitions and methods, lack of standards, accuracy. The way data reflect reality depends on the instrument used to gather them and also, when the instrument is a questionnaire, on the definition used to identify an event, a disease or a health condition. Regrettably, there are few health conditions whose standard definitions and methods (including thresholds) are agreed upon by everybody in a country or by different countries in Europe. Even when standard definitions and methods are used, they may not yield results with the same accuracy. Much depends on how these standards are applied (e.g. type of measurement, instruments and their calibration, type of interviewer and training). Different definitions, methods, thresholds and levels of accuracy, add to the difficulties often encountered in comparing data from different sources.
- Absolute vs. relative risk. The absolute risk for a given disease is expressed by the incidence and mortality rates associated with that disease. The relative risk refers to the incidence and mortality in a given population group relative to another population group. The relative risk may be very high, indicating that the risk factor is strongly associated with the disease, but reducing or even eliminating the exposure to the risk factor may have very little effect on the health of a given population, if that disease is rare. On the contrary, the relative risk may be low, but if disease and exposure to the risk factor are very common, even small reductions in exposure may be very significant. Policy and decision makers prefer to look at reductions of the absolute risk, because this is a more straightforward way of looking at the effect of strategies and interventions.
- Cause vs. association. The fact that a factor is associated with a disease or health condition does not mean that there is a cause and effect relationship between that factor and the disease or health condition. For most diseases and conditions in industrialised countries there is a myriad of factors associated with any given disease or condition, and unless action is directed at all or most of them, the health situation may not improve. In addition, one factor may be associated with several diseases or conditions, and thus action on it may have effects beyond the target disease or condition.
- Lack of evidence vs. negative evidence. Lack of evidence (e.g. that an intervention has an effect on a disease or condition) means that researchers have not been able yet to demonstrate a given effect, though the effect may exist. A negative evidence, instead, usually indicates that there is evidence on the lack of effectiveness of a certain intervention, and therefore, evidence that the intervention should not be recommended.

The report is primarily addressed to policy and decision makers, as well as to other experts in the area of child health at national and subnational levels. However, whenever possible, the authors of this report have tried to use non-specialised language, so that the report is accessible to a wider, lay readership.

The term 'child' is used in a neutral way and does not imply a gender preference. The call for tender defined the 0-12 age group as the focus for this report. The authors have tried to meet this requirement as much as possible. Most demographers, statisticians, epidemiologists and researchers, however, do not use the 12-year cut off and prefer the classical 5-year intervals, and for most published data, it is impossible to obtain a different breakdown.



The data used to write this report are all published or otherwise available in the public domain from official sources, such as the EU, WHO, UNICEF and other UN agencies, the World Bank, the OECD, as well as from government reports. Data are also available from reports of EU-funded research and public health projects, some of them ongoing, on specific diseases or groups of conditions. Finally, data were drawn, when needed, from research articles and systematic reviews published in medical journals and retrievable through services such as Medline, Embase, Web of science, Cinhal, PsychInfo and Popline. Only the sources used for general purposes are cited below (see box). Those used to deal specifically with a single disease or condition, are referred to within the individual chapters.

EUROSTAT is the source of reference for most data on mortality and morbidity. The data found in this large database are provided by national statistics offices. With regard to children, data are broken down into 5-year age groups: 0-4, 5-9 and 10-14, as recommended by the EU-funded CHILD (Child Indicators for Life and Development) project, which was used also as a reference for child health indicators. More indicators are available from another EU-funded project, the ECHI (European Community Health Indicators) project. The Health for All database and the mortality database, country profiles, reports and atlases made available by the Regional Office for Europe of WHO, were used to complement information on mortality and morbidity, as needed, as well as for information on hospital admissions. Other data were available, especially as far as EU12 and candidate countries are concerned, from UNICEF sources, the ChildInfo database and the reports of Multiple Indicators Cluster Surveys. For the same EU12 and candidate countries, data were collected also from Demographic and Health Surveys, often carried out at regular time intervals. The OECD uses the data provided by countries and other agencies to develop reports that deal not only with health and disease, but also with their political, social and economic determinants. Finally, more data on different aspects of child health have been posted on the websites of other EU-funded projects, such as EUGLOREH (EU Global Report on Health) and EUPHIX (EU Public Health Information and Knowledge System).

#### **Main Sources of Information:**

- CHILD [http://ec.europa.eu/health/ph\\_projects/2000/monitoring/fp\\_monitoring\\_2000\\_frep\\_08\\_en.pdf](http://ec.europa.eu/health/ph_projects/2000/monitoring/fp_monitoring_2000_frep_08_en.pdf)
- DHS <http://www.measuredhs.com/>
- ECHI [http://ec.europa.eu/health/ph\\_information/dissemination/echi/echi\\_en.htm](http://ec.europa.eu/health/ph_information/dissemination/echi/echi_en.htm)
- European Detailed Mortality Database <http://data.euro.who.int/dmdb/>
- EUGLOREH <http://euglorehcd.euologos.it/IXT/EXT-REP/INDEX.HTM>
- European Detailed Mortality Database <http://data.euro.who.int/dmdb/>
- EUPHIX [http://www.euphix.org/object\\_document/o4581n27010.html](http://www.euphix.org/object_document/o4581n27010.html)
- EUROSTAT <http://epp.eurostat.ec.europa.eu/portal/page/portal/eurostat/home/>
- OECD [http://www.oecd.org/statsportal/0,3352,en\\_2825\\_293564\\_1\\_1\\_1\\_1\\_1,00.html](http://www.oecd.org/statsportal/0,3352,en_2825_293564_1_1_1_1_1,00.html)
- UNICEF ChildInfo <http://www.childinfo.org/>
- UNICEF MICS [http://www.unicef.org/statistics/index\\_24302.html](http://www.unicef.org/statistics/index_24302.html)
- WHO/EURO Health for All [http://www.euro.who.int/InformationSources/Data/20010827\\_1](http://www.euro.who.int/InformationSources/Data/20010827_1)
- WHO/EURO Country Profiles [http://www.euro.who.int/InformationSources/Evidence/20010827\\_1](http://www.euro.who.int/InformationSources/Evidence/20010827_1)

With such a wide variety of sources, it is inevitable to find data on the same health indicator gathered in different ways. With some exceptions, researchers and statisticians in Europe, and elsewhere, use non-standard definitions and methods of data collection. As much as possible, the authors of this report have tried to use data gathered using consistent definitions and methods. Readers will be informed when this has not been the case. Difficulties with the interpretation of results, in particular when comparing countries or population groups and analyzing trends, may arise from problems that are intrinsic to the data used (see box on page 16). Readers should be cautious in drawing conclusions from

comparisons. Some key terms and indicators used in the report are explained in the glossary.

The report starts with a brief overview on demography, mortality, morbidity, health and well-being, followed by a chapter on determinants of child health. The main body of the report is formed by chapters devoted to the selected groups of diseases and conditions. With the exception of those not dealing with diseases, these chapters are organised as far as possible in the same way to facilitate reading:

1. Key messages are listed at the beginning of each chapter, followed by a very short introduction, whose aim is to provide synthetic definitions and inform the reader of the choices made by the authors.
2. Each chapter then moves on to quote the main sources of information except for those generic sources that have already been cited in this general introduction. If other references are cited in addition to the main sources, this is done with superscript progressive numbers as in scientific articles, and the list of references is given at the end of the chapter. General comments about completeness, representativeness and accuracy of the data have already been made in this introduction. If and when needed, specific comments are made for particular diseases or conditions in respective chapters.
3. The size of the problem is subsequently presented in terms of incidence, prevalence, mortality, disability or any other measure deemed appropriate for that specific disease or condition, or for those groups of diseases and conditions. Whenever possible, information on socio-economic disparities and on the burden to individuals, families, society and health systems, as well as consequences for adult life, are reported. The chapters also present, when available, trends from over the past 10 years (or more, if available and appropriate). An indication on whether the problem will be likely to increase or decrease is also shown.
4. The size of the problem is followed by information on causes and risk factors, including social and other determinants, and relative exposure. Suggestions are provided on whether all these causes, factors and determinants are, or will, be under control.
5. This is followed by a section on challenges, i.e. on which are the problems that should be tackled to move forwards in terms of effectiveness and equity for better health outcomes. Knowledge gaps and research needs are also briefly listed as necessary.
6. When deemed necessary, boxes are used to draw attention to the lessons learned on specific child health problems, to highlight specific issues and initiatives, or to present in more detail interesting examples of interventions and strategies.

## Glossary

**Life expectancy at birth.** The average number of years that a newborn can expect to live if mortality patterns remain unchanged. Values are highly affected by mortality early in life. Validity depends on how complete the registration of births and deaths is. Life expectancy calculated using incomplete mortality data tends to be higher than real.

**Life expectancy at different ages.** The average number of years that a person at a given age can expect to live if mortality patterns remain unchanged.

**Healthy life years.** Number of remaining years that a person of a certain age is supposed to live in good health or free of disability. Calculated combining data on mortality and on the self-perceived disability as assessed by health surveys. Not suitable to estimate the impact that a disease or condition (e.g. injuries) has on a population, yet a good indicator to describe the health status of a population, monitor its trends, and compare it with other populations. Not a terribly useful measure for child health, since most years lived in less than full health tends to occur later in life.

**Disability-adjusted life years.** Number of years of healthy life that are lost due to premature mortality, ill health or disability as assessed by health surveys. A measure of overall disease burden in a population. Suitable to estimate the cumulative impact that a certain disease or condition has in a population.<sup>a</sup>

**Perinatal mortality rate.** Weight-specific (1000 g +) foetal deaths and early (0-6 days) neonatal deaths per 1,000 births (live births + stillbirths). If weight-specific data are not available, any available data provided according to national criteria can be used as proxy.

**Infant mortality rate.** A measure of the yearly rate of deaths in infants less than one year old per 1,000 live births in the same year. Usually broken down into: early neonatal (0-6 days), late neonatal (7-27 days), neonatal (first 4 weeks of life), and post-neonatal (from the 5<sup>th</sup> to the 52<sup>nd</sup> week of life). Some countries are unable to ensure complete registration of all births and deaths, and tend to underestimate these rates.

**Child mortality rate.** A measure of the yearly rate of deaths in children less than five years old per 1,000 live births in the same year. It adds the mortality rate between 1 and 4 years to infant mortality rate. In EU countries the 1 to 4 years mortality rate is insignificant compared to infant mortality. For these reasons, this report groups together this rate and the rate of mortality between 5 and 9 years of age, and between 10 and 14 years if age (data disaggregated to 12 years are not available).

**ICD-10.** The international standard diagnostic classification of diseases endorsed by the 43<sup>rd</sup> World Health Assembly of May 1990 and used by WHO Member States since 1994. The classification is the latest in a series that has its origins in the 1850s. It is used to classify diseases and other health problems registered on many types of health and vital records, including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States.

**DSM IV.** The Diagnostic and Statistical Manual of Mental Disorders is published by the American Psychiatric Association. It includes all currently recognised mental health disorders. The coding system of the DSM-IV is designed to correspond with codes from the International Classification of Diseases, commonly referred to as the ICD.

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<sup>a</sup> Since there is no uniform definition of disability, different estimates of healthy or disability-adjusted life years can be calculated depending on the particular definitions used in different health surveys.

**Incidence.** The absolute number of new cases of a disease or condition during a given period. When used with a denominator, e.g. 1,000 live births or 100,000 children of a given age, it becomes an incidence rate. This is a measure of the risk of developing some new disease or condition in a given population within a specified period of time. The cumulative incidence is the number of new cases within a specified time period, divided by the size of the population initially at risk. When the denominator is the sum of the person-time of the population at risk, it is also known as the incidence density rate or person-time incidence rate.

**Prevalence.** The absolute number of cases of a disease or condition in a given population at a given time. When used with a denominator, e.g. the total number of births or 100,000 children of a given age, it becomes a prevalence rate. Used to estimate how common a disease or condition is within a population at a certain of time. It is not a measure of risk and it is therefore inappropriate when studying causes. However, it helps physicians or other health professionals understand the probability of certain diagnoses. It is commonly used by epidemiologists, health care providers and government agencies to plan health services.

**Birth weight** is the first weight of the foetus or newborn obtained after birth. For live births, birth weight should ideally be measured within the first hour of life before significant postnatal weight loss occurs. Low birth weight is defined as a weight of less than 2500 g (up to and including 2499 g), irrespective of gestational age. Newborn infants weighing less than 1500 g are labelled as infants with very low birth weight; those weighing less than 1000 g are defined as extremely low birth weight infants. Infants with birth weight over 4500 g are defined as large or macrosomic.

**Gestational age** is given by the completed number of weeks from the beginning of the last menstrual period to birth. Gestational age is considered as normal when birth occurs between 37 and 41 completed weeks. Infants born after 41 completed weeks are defined as postmature. Infants born between 32 and 36 completed weeks are defined as mildly preterm. Infants born between 28 and 31 completed weeks are defined as very preterm, those born before 28 weeks are defined as extremely preterm. The combination of birth weight and gestational age allows to categorize infants as small or large for gestational age.

## 1. Of Births, Deaths, Health and Well-being: An Overview

### Key Messages

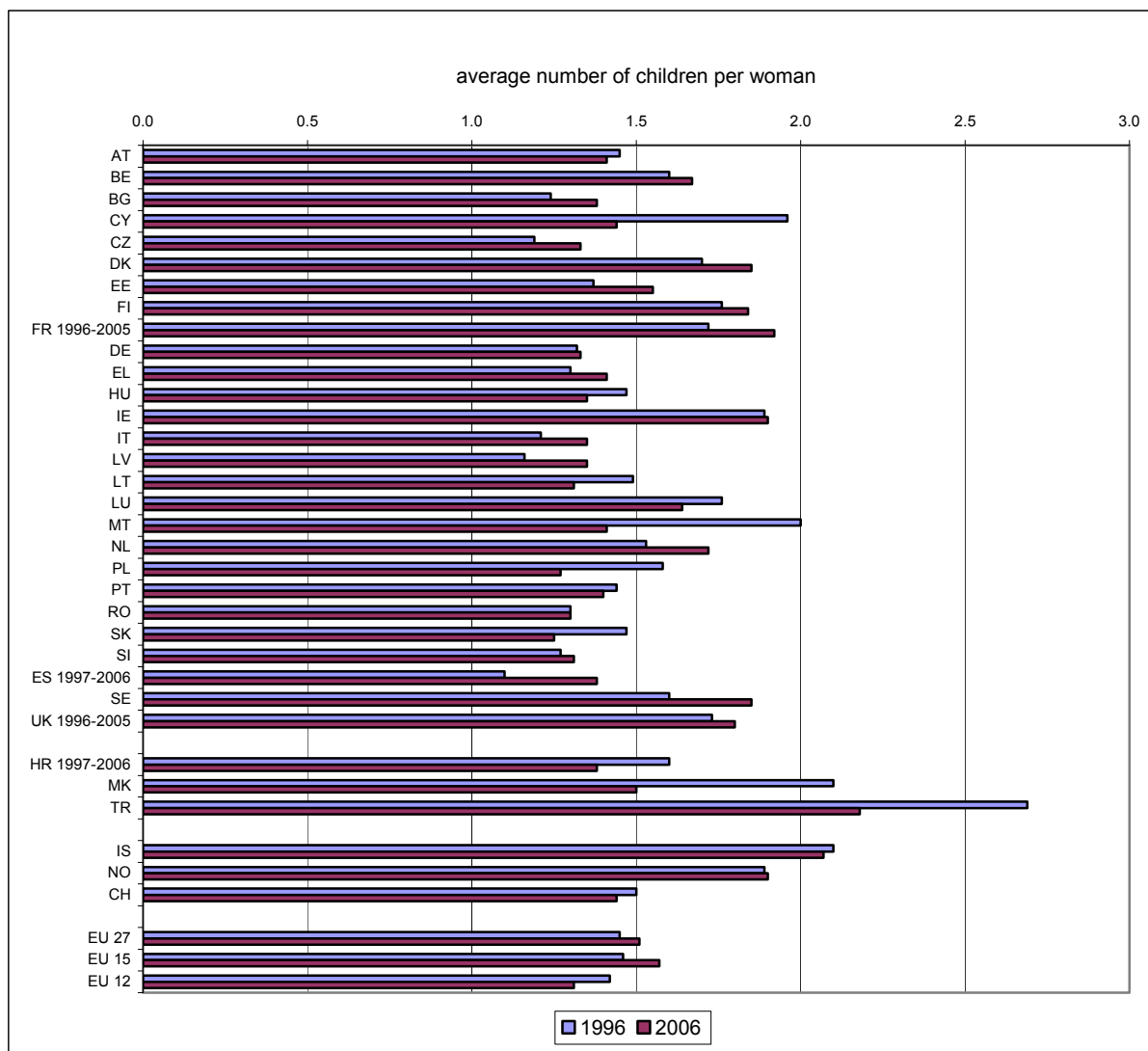
- The proportion of child population over the total population in Europe shows a decreasing trend, despite the relatively stable number of live births.
- Over the last four decades, there has been a continuous and remarkable decrease in infant mortality rates, from almost 28 per 1,000 in 1965 to 4.3 per 1,000 live births in 2009.
- The greater burden of mortality and morbidity shifted from the post-neonatal to the neonatal period and from communicable to chronic diseases and injuries, posing new challenges for the identification of causes and risk factors, for the adoption of preventive strategies and of comprehensive care.
- There are persistent and some times growing inequalities in child health outcomes, due to the increasing social divide, to migration, and to reduction in welfare programmes.
- In spite of recent progress, there are still important gaps in the ability to comprehensively and adequately describe the health status of children, and to capture inequalities and inequities within and across population groups.

A comprehensive definition of health, encompassing social and psychological well-being, is compelling when describing and analyzing child health, since what is unique to children is that they grow and develop. A comprehensive view of child health should therefore include optimal child growth and development, and should take into account all the factors that may interfere with optimal cognitive and socio-emotional development. Unfortunately, current health information systems are focusing mainly on mortality and acute morbidity. The development dimension and the ability to perform functions, undoubtedly more complex to describe and measure, are not systematically addressed. As a consequence, this chapter falls short of a comprehensive description of child health, but nonetheless attempts to provide at least a general idea about what should be observed and measured more systematically and rigorously.

### Demography

The total number of recorded live births in the EU27 countries was 5,141,876 in 1996 and 5,186,922 in 2006, passing through a lowest of 4,959,328 in 2002. The proportion of the child population out of the total population in Europe tends to decrease, despite the relatively stable, or slightly increasing, number of live births. The proportion of children under 15, which was almost 18% in 1996 (17% in EU15, 20% in EU12 countries), went down to 16% in 2006 (similar in EU15 and EU12 countries), for a total population of about 80 million children under 15. This relative reduction is explained by increasing life expectancy and by relatively stable, or slightly increasing, fertility rates, mainly due to higher fertility among migrant women, combined with a reduction in the number of women in fertile age. Figure 1.1 shows that the total fertility rate, i.e. the average number of children a woman would have in her lifetime if she were to experience over it the current age-specific fertility rates, is lower than 2 in almost all countries, when to have a stable population, slightly more than 2 is the level needed. With a total fertility rate lower than 2, the population will inevitably decrease.

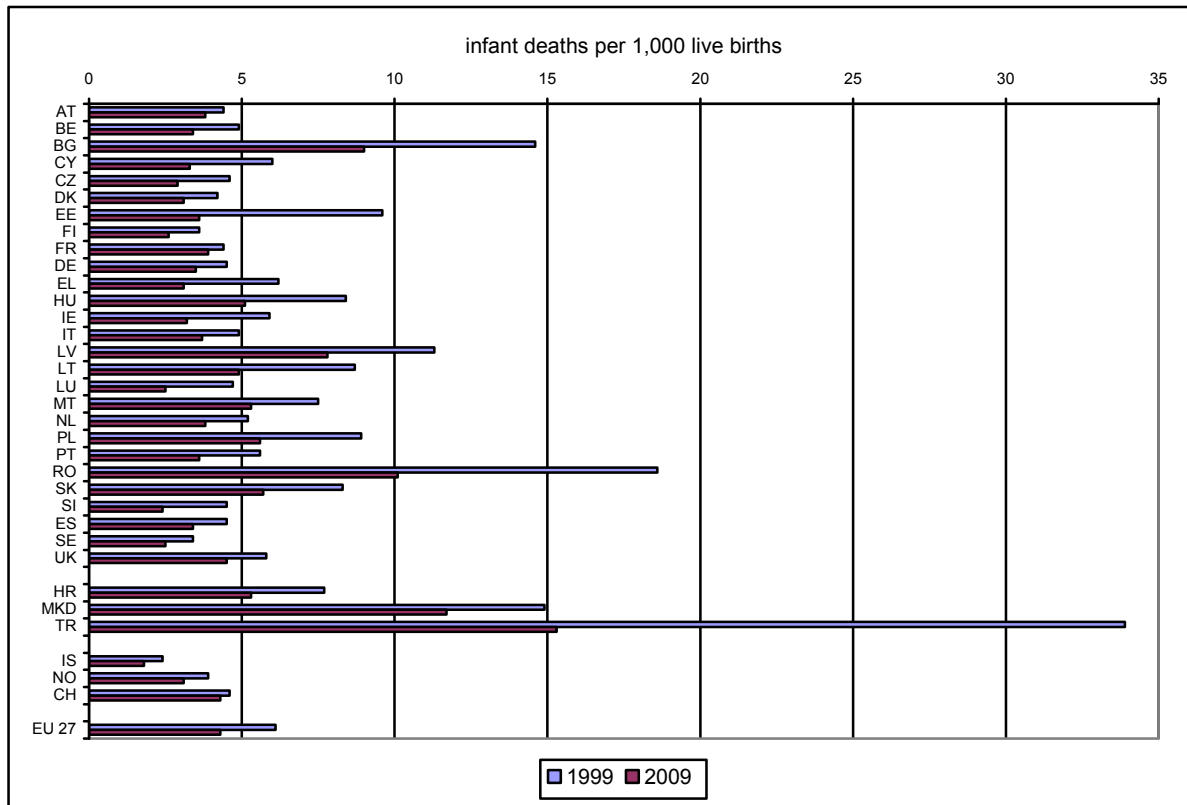
**Figure 1.1. Total fertility rate, 1996-2006 (or closest available years)**



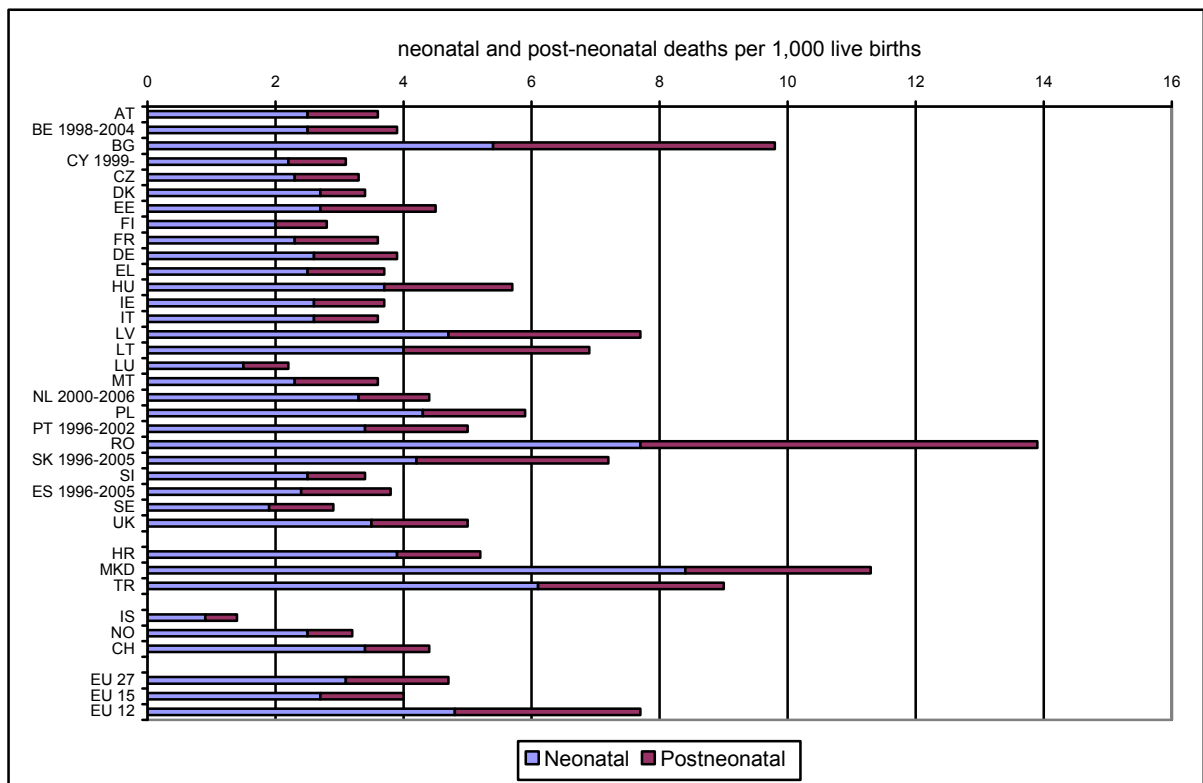
## Infant Mortality

Over the last four decades, infant mortality in EU27 countries fell dramatically, from almost 28 per 1,000 in 1965 to 4.3 per 1,000 live births in 2009. Figure 1.2 shows the decrease by country between 1999 and 2009. The reduction in infant and child mortality over the 20<sup>th</sup> century is one of the main contributing factors for the high life expectancy recorded nowadays in Europe. While most of this progress is attributable to improved nutrition, education, housing and sanitation, the relative importance of health care is increasing. This is particularly true for neonatal mortality, which currently represents over two thirds (68%) of infant mortality in all EU15 and EFTA countries, while post-neonatal mortality still represents a significant proportion of infant mortality in EU12 and candidate countries (Figure 1.3). In general, the lower the infant mortality, the higher the proportion of neonatal mortality, and the greater the importance of health care.

**Figure 1.2. Infant mortality rates per 1,000 live births, 1999 – 2009<sup>b</sup>.**



**Figure 1.3. Neonatal and post-neonatal mortality rates per 1,000 live births, 2006 (or latest available year).**



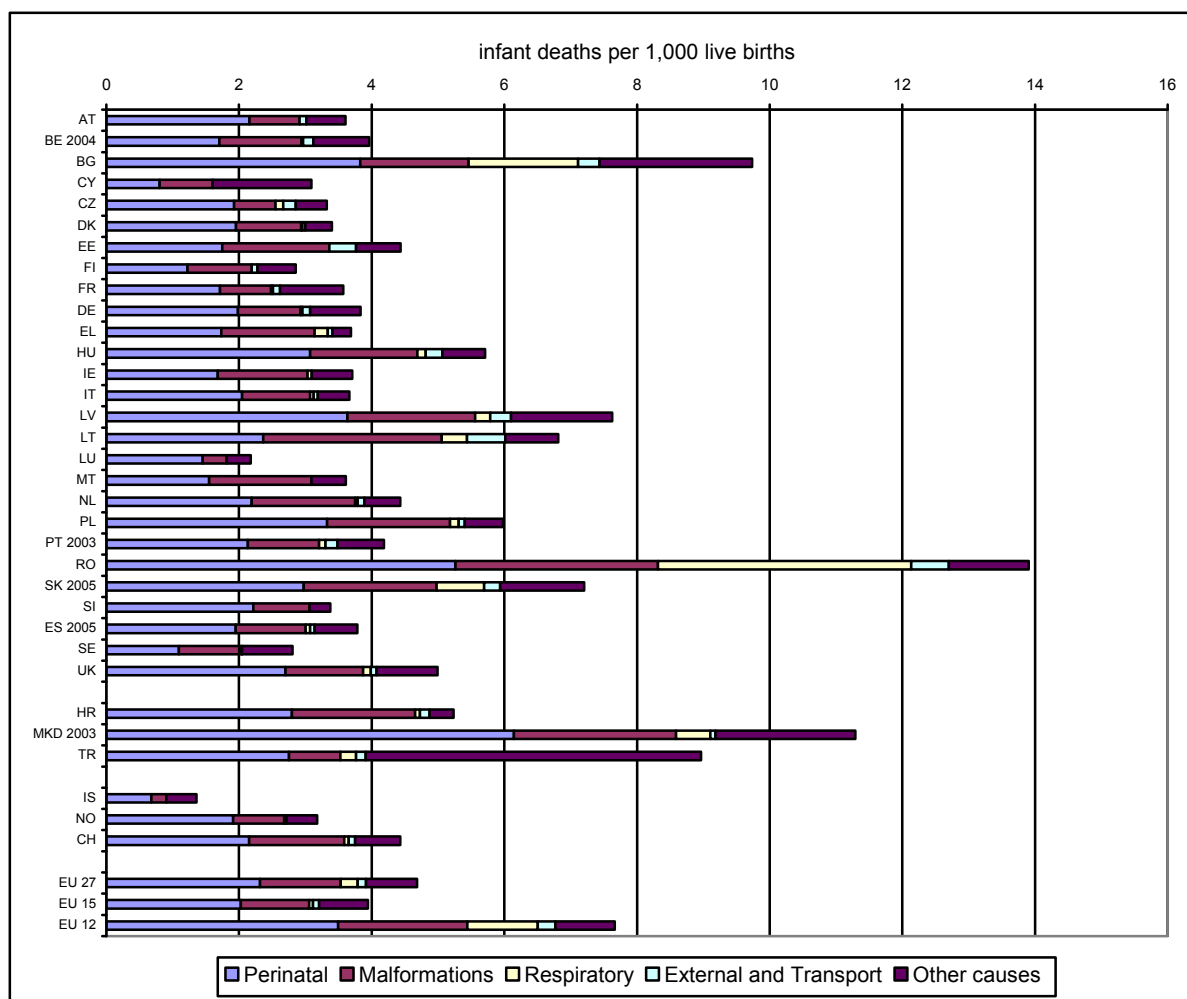
<sup>b</sup> Some countries may not yet be able to ensure complete registration of all births and deaths. When infant mortality is calculated using incomplete data, the rate is usually lower.

Since the decrease in fertility is associated with a decrease in infant and child mortality, particularly at fertility levels above 2 per woman during the fertile ages, the decrease in fertility over the past decades for EU15 and over the last decade in EU12 countries has also played a role in the improved infant and child mortality indicators. Perinatal mortality has followed the same downward pattern, the stillbirth component being usually equivalent or slightly lower than the early neonatal component. The physiologically larger number of boys born relative to girls (104:100) is offset to a small extent by higher mortality rates among boys during their first year of life. In 2006, the infant mortality rate in the EU27 was 5.1 per 1,000 live births in male infants and 4.2 per 1,000 live births in female infants.

### Causes of Infant Death

The causes of death are classified in all countries using ICD-9 or ICD-10 codes (see glossary). For the purpose of this chapter, only a few ICD-10 code groups of interest have been used to classify infant and child deaths: diseases and conditions originating in the perinatal period (P00 to P96); congenital malformations (Q00 to Q99); diseases of the respiratory system (J00 to J99); and injury and other consequences of external causes, including transport (S00 to T98). All other causes of death have been grouped. Figure 1.4 shows that in 2006 perinatal and congenital causes accounted for the largest proportion of infant deaths in all countries. Respiratory conditions, mainly pneumonia and other lower respiratory tract infections, represent an important component of infant mortality only in countries with higher infant mortality rates (Bulgaria, Romania, Slovak Republic, FYR of Macedonia).

**Figure 1.4. Infant mortality by cause, 2006 (or latest available year).**

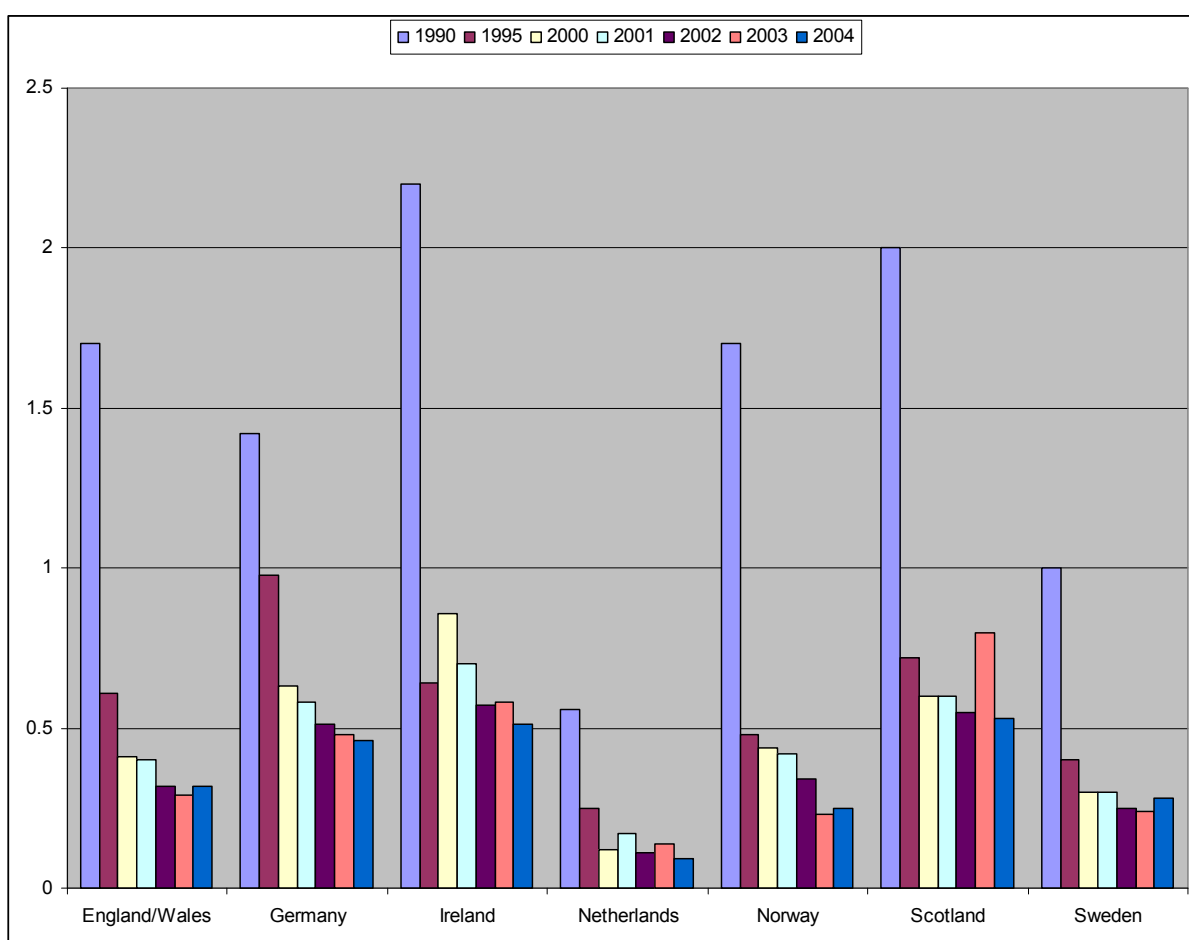




## Sudden Infant Death Syndrome (SIDS)

In the developed world, SIDS is the leading cause of death among infants between 1 month and 1 year of age. Many countries have launched campaigns aimed at reducing incidence based on known risk factors, mostly on sleep position (back to sleep) and on diverse housing arrangements (temperature, mattress, bedding, parental smoking). These campaigns have achieved substantial results and SIDS mortality has been decreasing over the past 20 years. Figure 1.5 shows the trends in SIDS mortality per 100,000 live births in some countries where SIDS campaigns started between 1987 (Netherlands) and 1992 (Sweden).<sup>1</sup> Similar declines have been observed in other countries (for example, in Italy between 1990 and 2001)<sup>2</sup> and seem to continue after 2005, for example in England and Wales,<sup>3</sup> and in Ireland.<sup>4</sup>

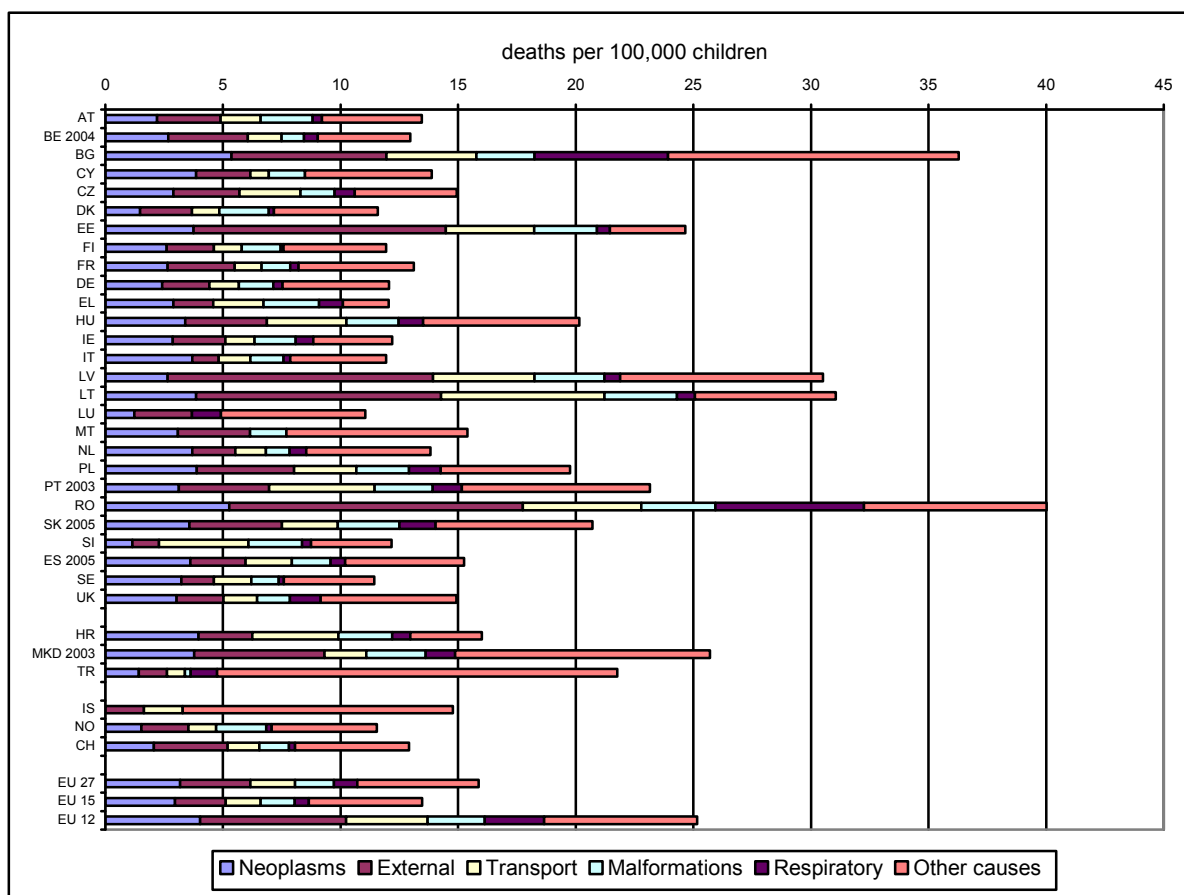
**Figure 1.5. Decreasing SIDS mortality per 100,000 live births in some countries.**



## Child Mortality

As already mentioned, the risk of death decreases progressively over the first year, and mortality rates are usually expressed per 100,000 live births after the first year. Figure 1.6 shows that in the group 1 to 14 years of age cancers are the first cause of death in EU27 countries, followed by external causes and road accidents (transport). However, cancers come second in EU12 countries, preceded by external causes. Injury and accidents, added up together, represent the overall first cause of death in this age group, with important gender differences: boys die about 25% more than girls in the age group 1 to 14 years old, mainly because of higher risk of deaths caused by injuries and accidents.

**Figure 1.6. Mortality rates per 100,000 children 1 to 14 years of age, 2006 (or latest available year).**



## Morbidity

When mortality rates are low, it becomes increasingly important to pay attention to morbidity indicators, particularly for conditions with long-term impact on health and well-being such as chronic diseases and disabilities. Unfortunately, definitions for these conditions and, most importantly, recording systems, vary across countries. Consequently, the information is of variable quality and often unsuitable for comparisons, although ad hoc studies conducted at country level provide useful information to assess temporal trends.

There are, however, several exceptions. The European Surveillance of Congenital Anomalies programme (EUROCAT) monitors congenital anomalies; the PERISTAT project has assessed perinatal outcomes; the Automated Cancer Control Information System (ACCIS) is providing accurate information about childhood cancers; multicentre studies such as the International Studies of Asthma and Allergies in Childhood (ISAAC) have provided useful information about prevalence across countries and hints about temporal trends of asthma and allergies; and Europe-wide registers on several diseases have been established.

Understanding trends is extremely important to orient public policies. While readers are referred to specific chapters for more in-depth analysis, an overview of temporal trends of the main disease groups is provided in Table 1.1. Some patterns emerge. While the incidence of injuries and of the main communicable diseases, and particularly of vaccine preventable diseases, has been constantly decreasing, the incidence of childhood cancer has shown a steady and rather uniform increase across countries over the last decades, at an average rate of about 1.5% per year. Rising incidence, or prevalence, has also been shown for perinatal conditions, such as prematurity and LBW, for asthma, type 1 diabetes and other immune mediated diseases, although with a wide variation across countries. An increase has

also been detected for developmental disabilities and mental health disorders. The improved survival of very premature babies have partially contributed to the increase of the former, while for conditions such as autism spectrum disorders and other mental disorders the increase is mainly due to extension of the diagnostic criteria and/or improved diagnosis. Congenital malformations appear, overall, to be stable around an overall incidence of 2 per 100 births, but show variable patterns depending on the type of malformation. Overweight and obesity have been on the rise for decades, although recently a plateau seems to have been reached.

**Table 1.1. Overview of Temporal Trends of Main Diseases and Disabilities in Children**

Disease group	Incidence (I) or Prevalence (P)	Temporal trend	Comments
Perinatal conditions (LBW, prematurity)	4-11% (<2500 g) (I)	↑	Real increase in most countries
Communicable diseases	Not applicable	↓	Real decrease in all countries
Congenital malformations	2 per 100 births (I)	↓↑	Decreasing or increasing depending on type of malformation
Overweight	33%	↑	Real increase over the last two decades
Neurological and developmental disorders	4-5% (P)	↑	Increase partially due to extended and improved diagnostic criteria
Mental health	12-16% (P)	↑	Increase partially due to extended and improved diagnostic criteria
Childhood cancer	14 per 100,000 (0-14 years) (I)	↑	Real increase in all countries
Injuries	Not applicable	↓	Real decrease in all countries

Comprehensive indicators of child health and functioning are not available. Disability Adjusted Life Years (DALY) and Healthy Life Years (HLY) have been introduced to provide a summary description of health status but country-specific estimates for children are not available. Recently, a summary score of perceived health has been introduced by the Kidscreen project. Information is available on a number of countries, showing that a percentage of school-age children (8 to 11 years), ranging from 5.7% in Poland to 1.8% in Spain, appear to be of ill-health.<sup>5</sup>

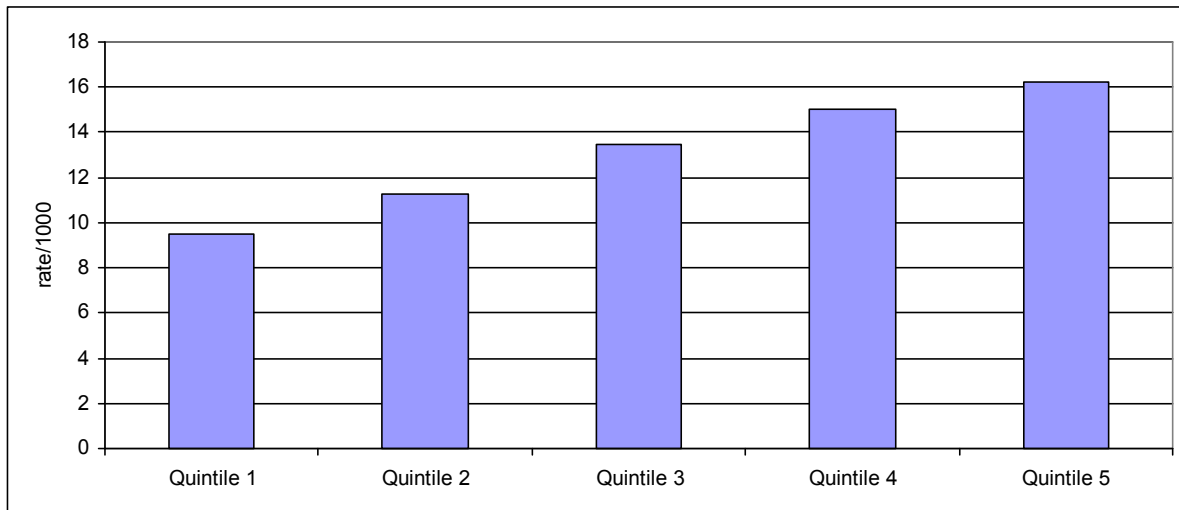
### **Inequalities and Inequities**

A cause of great concern is the persistence or increase in inequalities in health outcomes. Comparative data on health inequalities in adults have been collected across Europe,<sup>6</sup> but no Europe-wide data are available in children. This section, therefore, relies on national data and *ad hoc* study findings from individual countries.

Social inequalities in infant and child mortality have been consistently reported from the Netherlands, the United Kingdom and the Nordic countries.<sup>7</sup> Similar inequalities have been reported in Belgium, Hungary, Italy and Turkey. A study from the United Kingdom reported that, against a background of a general reduction in injury deaths among children 0-15 years in the 1980s and 1990s, rates among children whose parents were long-term unemployed did not decrease significantly. These children were over 20 times more likely to die as pedestrians and cyclists, and over 30 times more likely to die in fires compared with the children of very privileged families.<sup>8</sup> Poor children are much more likely to die from all types of injury than their wealthier counterparts.<sup>9</sup> Social gradients in pregnancy outcomes have

been noted in many European countries up to the early 2000s and more recent data from Finland, Germany, Italy, Netherlands, Spain, United Kingdom and the Nordic countries confirm these gradients.<sup>9</sup> The social gradient in very preterm birth (22-32 weeks of gestational age) reported in a study based in the Trent region of England is shown in Figure 1.7.<sup>10</sup>

**Figure 1.7. Very preterm birth by deprivation quintile (quintile 1 = least deprived; quintile 5 = most deprived).**



Studies from Germany, Sweden and the United Kingdom report higher rates of asthma among children from lower-income households. A population study from Sweden reported a 49% higher risk of cerebral palsy among children of low-income households compared to their peers from high-income homes.<sup>11</sup> Using a broad definition of disability (longstanding illness that limits the child's normal daily activities), a study from the United Kingdom has shown that these children are more likely to live in households with lower incomes than children not experiencing any limitation due to illness.<sup>12</sup> Data on social patterning of mental health problems are scarce in children younger than 12 years. However, survey data from the United Kingdom demonstrate a marked social gradient by household income in all forms of mental health problems in young children apart from conditions such as autism.<sup>9</sup> Low SES of the family in 15 European countries (including 13 EU countries), as assessed with the Family Affluence Scale, is associated with lower well-being of school children as measured by the Kidscreen-10 index at age 11, 13 and 15.

Even though migration can be traced back to several generations, children from minority groups (especially those from the Indian sub-continent in Northern European countries and Roma children in the new Member States) have much higher incidence of a variety of diseases. In the United Kingdom, the risk of admission to paediatric intensive care units (138 vs. 98 per 100,000) and mortality rates among those admitted (7.1% vs. 4.9%) were shown to be higher in children from minorities, even after controlling for SES.<sup>13</sup>

### Emerging Threats and Future Scenarios

Overall, the prospects for child health over the next decades are contradictory. On one hand, there is a continuous decrease in child mortality in all countries, accompanied by decreasing trends in communicable diseases and injuries. On the other hand, as a consequence of improved survival rates for very LBW infants and for children affected by severe diseases and congenital anomalies, as well as of emerging issues such as obesity and immune mediated disorders, there may be an overall net increase in the proportion of children suffering from some kind of functional impairment and/or needing comprehensive care. The widening inequalities across population groups and the rise in neurological and mental health disorders are also matters of great concern.

These trends pose a series of challenges to society as a whole and to health systems in Europe. These challenges will be better understood in the light of social determinants of child health and the way they influence child health outcomes, particularly in the earliest years of life.

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## 2. Determinants of Child Health

### Key Messages

- The social, psychosocial and physical environments in which children are conceived, born and raised are major determinants of their health. Socio-economic status has a bearing on parental education, maternal health, environmental exposure, infant and child nutrition, access to care, and ultimately it contributes to health outcomes.
- Macroeconomic and fiscal policies, as well as public policies in various sectors, including health, education, environment and legal status of minorities and migrants, play a role at different levels of the causal pathways of health and disease, starting from the early life stages. These policies may also contribute to the increase or decrease of health inequities.
- Exposures and practices related to social determinants, from conception to the early years of life, are relevant not only for early child health and development, but have deep implications for population health altogether.
- Changing economic and social environments, as a consequence of economic downturns, have a direct and indirect impact on child health and well-being.

Human health is the product of a series of complex causal pathways, where the ultimate causes, also known as proximal causes of health, disease and disability (e.g. infection or injury), are also the consequence of a combination of individual (such as genetic susceptibility),<sup>c</sup> and socially determined factors (e.g. education, housing, sanitation, nutrition, social protection, relationships, access to care, life styles). This is even more so in the case of children: the social, psychosocial and physical environments in which children are conceived, born and raised, are major determinants of their health. As the WHO Commission on Social Determinants of Health report *Closing the Gap in a Generation* states, 'The conditions in which people live and die are shaped by political, social and economic forces. Social and economic policies have a determining impact on whether a child can grow and develop to its full potential and live a flourishing life, or whether its life will be blighted'.<sup>1</sup>

Social and environmental factors are particularly critical in the early life stages, i.e. from conception to early childhood. Three decades of research have provided plenty of evidence to support the concept that many diseases have causes that start as soon as, or shortly after, conception, during pregnancy and in early life. Exposure to inadequate nutrition, chemical and physical pollutants, social and psychosocial adverse conditions, infectious or other harmful agents or processes, may interfere with early organ and system development, disrupt metabolic pathways, modify disease susceptibility and ultimately have profound effects, not only on outcome at birth, but also on health and development in infancy and childhood, as well as over the entire life course.<sup>2,3</sup> Thus, what happens to mothers and children is relevant for early child health and development, and it also has deep implications for population health altogether. Many of the current increasing or decreasing trends of diseases affecting children as well as adults (e.g. cardiovascular, respiratory and immune mediated disorders) have their explanations in changes in exposures and practices occurring from conception to the very early years of life.

This chapter first describes the underlying socio-economic determinants of child health and how these factors have evolved over time in Europe. It then shows how public policies, including health system policies, can modify the social environment and have an impact on the underlying determinants as well as on child health. Finally, it provides an overview of risk

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<sup>c</sup> Genetics is not all inherited; rather it interacts with the environment and as a consequence is also to some extent socially determined. For example, the way genes determine how biological systems work may be modified, in some very small but important components, by environmental exposure. This is called 'epigenetics' and there is growing evidence that it may play a role in the causality of disease.

factors to which children may be exposed over their different developmental stages, to emphasise the importance of early investments to protect and promote child health.

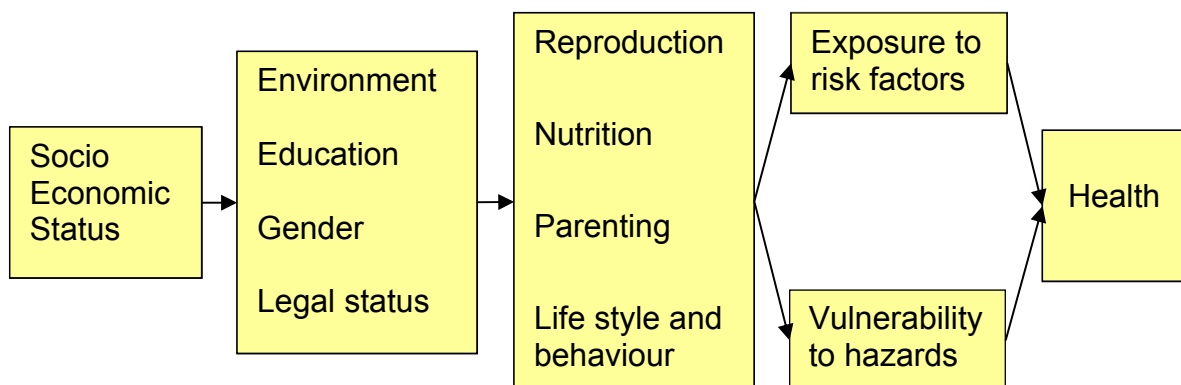
## 2.1 Social and Economic Determinants

The ways social and economic determinants influence child health are complex and not linear. First, among the various determinants, there are many interactions, synergies and interferences. Second, the causal pathways are specific to health outcomes and populations, that is to say that they vary depending not only on the outcome considered, whether for example LBW or injury, but also on the population characteristics, whether for example children living in poverty or second generation migrant children. As a consequence, if each health outcome is to be adequately addressed, an in-depth analysis of its underlying causes and contributing factors is required.

Nevertheless, it is undoubtedly constructive to have a general overview of how social determinants may work. A first important aspect to note is that there is a hierarchy among determinants, with SES usually playing a major role in shaping the built environment and, influencing the parental educational level, as well as the role of women in society and the legal status of migrants. Conversely, each of these factors may play an independent role and contribute to influence intermediate factors such as nutrition, child education, access to health care and social services, and its most proximal determinants, such as specific diseases or conditions.

Health status is the product of a combination of social, biological and psychosocial factors with a bearing on the exposure to risk factors (e.g. inadequate housing and sanitation increase the likelihood of being infected) and on the susceptibility to disease (e.g. impaired nutrition increases the likelihood of suffering from severe disease once infected). Figure 2.1 illustrates this hierarchy and will be used throughout this chapter to describe the role of the main social determinants and of public policies.

**Figure 2.1. Social and economic determinants of child health and their causal cascade.**



### Poverty and Employment

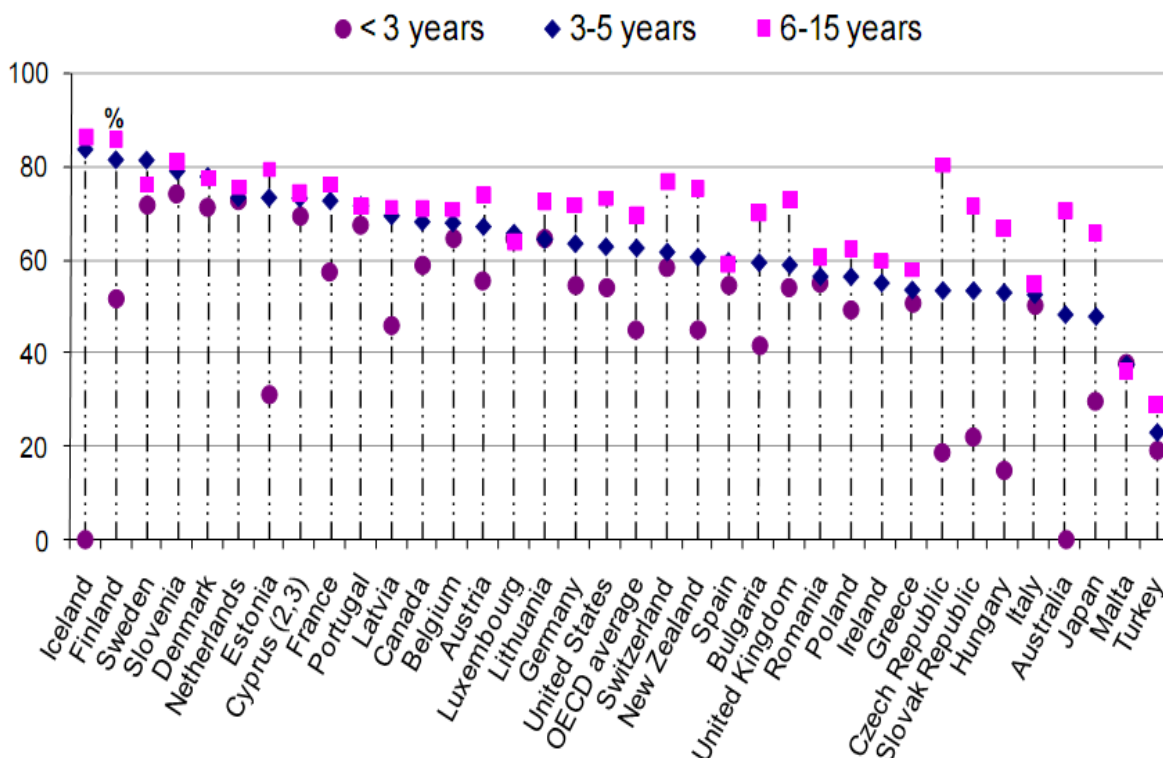
Poverty and low SES are the most important determinants of health in all countries, including high income countries.<sup>4</sup> Poverty has a particularly profound impact on child health and well-being, due to the child's high vulnerability to its consequences.<sup>5</sup>

Child poverty rates are defined as the proportion of children living in households with an income lower than 60% of the average national income. They are, therefore, a function of income distribution within each country. The fact that they vary widely across Europe is mainly due to some countries being able to achieve relatively low child poverty rates by income redistribution, through tax exemption, child benefits and subsidised services.<sup>6</sup>

Nevertheless, in most EU Member States, poverty among children is, in general, 3% higher on average than among the population as a whole. Only in Denmark, Finland and Germany is the rate of child poverty lower than for the population as a whole.<sup>7</sup> In most EU27 countries, children living in lone parent households and in large families are at an increased risk of living in poverty. Children from migrant families, or from families belonging to minorities, are more likely to be in poverty within European countries, with Roma children in the new Member States and in candidate countries being particularly vulnerable to poverty.<sup>8</sup>

Parental employment, particularly among mothers, is key to protect children from poverty. Living in a household in which no adult is employed has been shown to be closely associated with child poverty, accounting for approximately a quarter of all children at risk of poverty in general, and for more than 40% in Belgium, Czech Republic, Ireland and the United Kingdom.<sup>9</sup> Maternal employment, which has an even greater impact on child health, increases in all European countries once the youngest child reaches 3 years of age.<sup>10</sup> In 2007, only in Cyprus, Denmark, Slovenia and Sweden, mothers of children younger than 3 years old, were more than 70% employed. In most European countries, with the exception of Greece, Ireland, Italy, Malta, Romania, Spain and Turkey, however, over 70% of mothers were employed once the youngest child was older than 5 years (Figure 2.2). These data do not take into account changes since the global financial crisis. Data from around 2000 show rates of children living in unemployed households, varying between less than 2% in Portugal and Switzerland, to more than 10% in Hungary.<sup>5</sup>

Figure 2.2. Maternal employment rates by age of youngest child, 2007 (Source: OECD, 2010).



## Environment

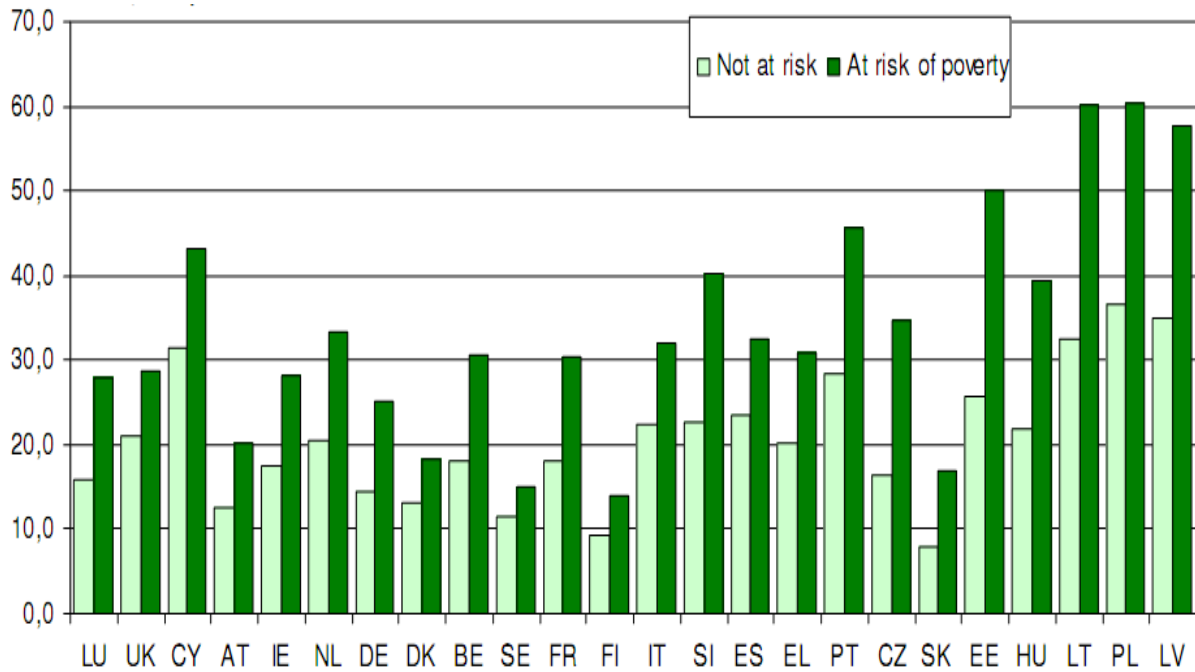
### Physical Environment

Poor housing conditions and homelessness are associated with poorer health in childhood. In all European countries, those on low-income are more likely to experience poor quality housing (Figure 2.3).<sup>11</sup> However, in some countries, even among those not living on low-income, rates of housing problems are high. A recent study reported that 14% of children in the United Kingdom live in overcrowded homes or houses unfit for human habitation.<sup>12</sup> Data



on homelessness affecting children in Europe are not readily available, yet in countries that have undergone unstable political transitions, the number of children living on the streets has increased dramatically.<sup>13</sup> The above mentioned UK study estimated that 1% of children aged between 0 and 16 years of age are classed as homeless and live in temporary accommodation.<sup>12</sup>

**Figure 2.3. Proportion of people with income above and below 60% of the national median income reporting one or more housing problem\* (Source: European Commission, 2010).**



\* no bath, shower or toilet; leaking roof; lack of natural light in dwelling

Access to clean water and sanitation is also strongly associated with poverty levels, and in most EU12 countries as well as in Turkey it is also associated with rural living. Lack of clean water and adequate sanitation increases the likelihood of a variety of infectious diseases, particularly gastrointestinal, and also of some chronic conditions, such as malnutrition, and conditions caused by exposure to water polluted by toxicants, such as nitrites.<sup>14</sup> Finally, living in poor neighbourhoods puts children at greater risk of a variety of other environmental hazards, including accidents and injuries, toxic chemicals, noise pollution and waste sites.<sup>15</sup>

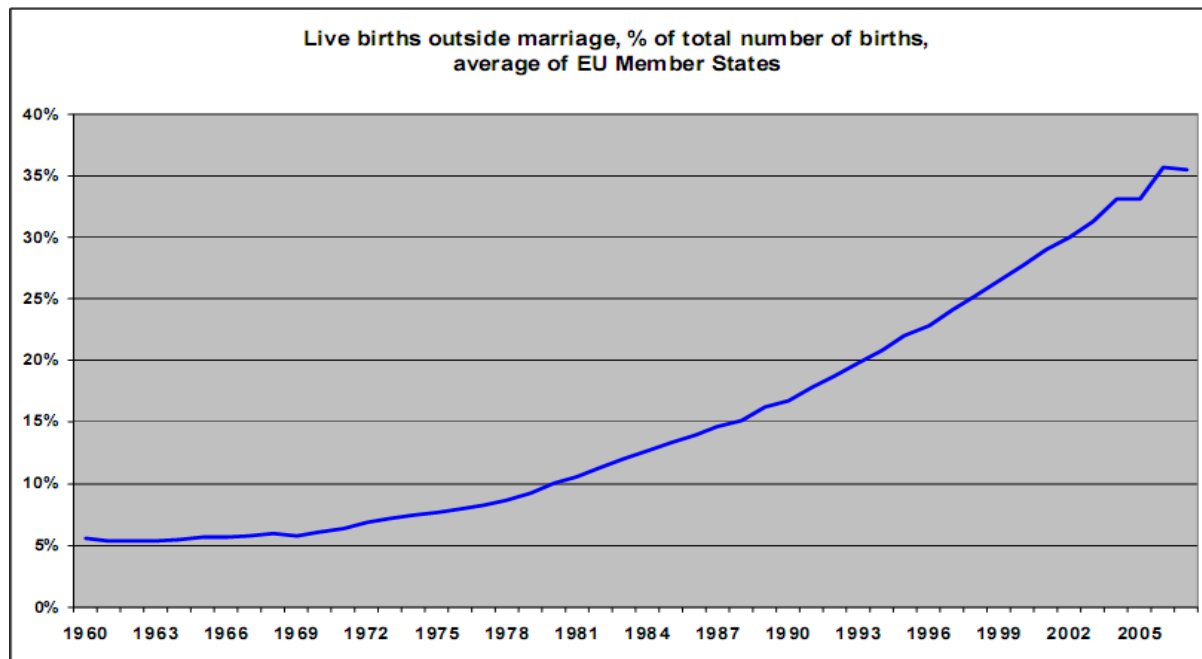
### *Family Environment*

Over the last 40 years, there has been a marked trend to birth outside marriage across European countries (Figure 2.4). In 1975, only 8% of births took place outside formal marriage, while by 2005 the rate had risen to 35%.<sup>16</sup> The general trend across EU Member States reveals considerable differences: Cyprus and Greece had rates of mere 4.4% and 5.1%, respectively, compared with Sweden (55.4%) and Estonia (58.5%). Extra-marital births are made up mainly of co-habiting couples, although over the last 40 years, single parenthood has also contributed to the trend. In 2008, about 8% of children in the EU27 countries were living in single parent households, with a range from 16% in Estonia and the United Kingdom, to 4% in Cyprus, Greece and Spain.<sup>11</sup>

Divorce rates have increased in many European countries, contributing to the increase in children living in single parent households. Among 11, 13 and 15 year-olds in European countries, between 9% to 16% live in lone parent households and between 1% to 14% live with step-parents.<sup>17</sup> Living in single parent households is not a risk *per se* yet it does increase the likelihood of living in poverty. Adopted children, particularly if adoption occurs after infancy and early childhood, and if their origin is from other continents outside Europe,

have been shown to have an increased risk of mental health disorders and substance abuse, following the results of a Swedish study.<sup>18</sup>

**Figure 2.4. Trends in extra-marital birth rates (Source: European Commission, 2008).**



## Education

Parental education, and particularly education of women of childbearing age, is widely recognised as a key determinant of child health and well-being. The association between maternal education level and child mortality is well known. It acts through improved family planning, and consequently birth spacing, less teenage pregnancies, improved care during pregnancy and better pregnancy outcome, improved care seeking and use of services.<sup>19</sup> In Europe, there has been a trend towards completion of upper secondary education, such that, in most countries, people between 25 and 34 years of age are much more likely to have completed upper secondary education than those 55 to 64 years of age.<sup>20</sup> The increase has been particularly marked in some countries: in Greece and Ireland rates have increased by 40% between the two age groups. Completion rates among 25-34 year-olds, however, vary widely across countries: in Czech Republic, Slovak Republic and Slovenia, over 90% have completed upper secondary education, compared to less than 50% in Portugal and Turkey. Compared to their male counterparts, European women aged 18 to 24 years are more likely to leave school with a higher level of secondary education. In 2007, women were less likely than men not to be in further education or training (13.2% vs. 17.2%).<sup>21</sup> Child health is also associated with early childhood education (day care and pre-school), which is in turn associated with improved school performance, reduced behavioural problems and social achievements later on in life.<sup>1</sup>

## Gender

Gender hierarchies permeate all aspects of life, governing how people live. Gender inequity, defined as systematic differences in the distribution of benefits, power, resources and responsibilities between women and men, shapes the health status for women, men, and children.<sup>22</sup> The overall status of women, their education, their role in society and within their family, is also directly linked to child health and well-being. Where women have a higher social status and a more central role in decision-making, available resources, at public and household levels, go to a greater extent to investments in child nutrition, welfare and education, and ultimately contribute to improve child health outcomes.<sup>23</sup>

Maternal education, as well as women's status, along with social and religious norms, are factors that affect reproductive styles and consequently reproductive outcomes. Improvements in all these factors is the main explanation of a sharp decline in teenage pregnancies since 2001.<sup>24</sup> In 2008, most countries showed less than 5% of all pregnancies in girls younger than 20 years of age. The exceptions were: Poland 5.1%, Hungary 6.2%, Estonia 6.5%, Malta 6.6%, FYR of Macedonia 6.7%, Lithuania 6.9%, Slovak Republic 7.1%, United Kingdom 7.1% (in 2004), Latvia 8.1%, Romania 12.5% and Bulgaria 13%. At the other end of the spectrum, many countries had, in 2008, percentages of pregnancies in women over 35 years of age above 15%, with a maximum of 28% in Italy (2004) and Switzerland.<sup>25</sup>

## **Legal Status**

### *Migration and Migrant Children*

Migration movements in Europe have increased in size and complexity. About 7.6% of the total EU population is foreign-born, and, according to national legislations, it is estimated that between 2.6 and 6.4 million migrants are considered illegal. There has also been a marked increase in migration within the EU, particularly from the new Member States to the richer countries.

The definition of migrant includes short-term and long-term migrants, transit populations and settled communities, people with and without legal residence papers, and first, second and third generation migrants. Migrant children is a broad category that can include different classifications of people coming from different countries, such as recently settled migrant children with/without regular permits of residence, unaccompanied children, paperless children, or asylum seekers. This lack of a common definition seriously jeopardises comparisons within and between countries. There is little reliable EU-wide data on migrant children, especially on those who may be in an undocumented situation. According to EUROSTAT, in 2007 migrant children aged between 0 and 14 years, who had a citizenship other than EU27, EFTA or candidate countries, reached 133,538. The EU countries with the largest reported number of migrant children were: Spain (48,897), Italy (28,520) and Sweden (10,176), while Bulgaria, FYR of Macedonia and Estonia had the smallest numbers. In 2009, the country with the lowest reported number of migrant children was the Slovak Republic (3,394), while Italy reported the highest number (862,455).

Migrant children face particular challenges and are vulnerable to a range of harming factors including social exclusion, poverty and limited education opportunities. Their condition is of course highly dependent on the overall condition and legal status of migrants in general, their rights, their access to health care and welfare, including housing and schooling, and on the conditions of migrant women in particular. A literature review of 65 studies comparing pregnancy outcomes in migrant *vis-à-vis* native-born women in Europe from 1966 to 2004, found that migrant women faced a 43% higher risk of bearing a LBW child, a 24% higher risk of a preterm delivery, a 50% higher risk of perinatal mortality, and a 61% greater risk of congenital malformations.<sup>26</sup> Many of the studies included in the review, controlled for biological factors and/or SES, suggested that other factors particular to the migration experience were salient.

Depending on host country's legislation and prevailing attitudes towards migrant people, migrant children may be subjected to discrimination based on nationality, origin, gender, and religion. Those whose parents hold an illegal status are exposed to a combination of risks, including those deriving from poverty, stress and lack of access to services. Unaccompanied migrant children are at particularly high risk of exposure to violence, abuse and trafficking.

## Roma Children

Roma people constitute Europe's largest minority. Their number was estimated between 6.3 and 8.5 million people 10 years ago.<sup>27</sup> Considering that the proportion of children under 15 years of age was around 40%, and that fertility among the Roma has remained high, the number of Roma children in the countries included in this report may vary between 3 and almost 4 millions.

Roma children are paradigmatic of most vulnerable categories, since their condition includes many dimensions of poverty (e.g. poor housing, low education, impaired nutrition), the implications of belonging to a minority (e.g. discrimination, exploitation), and those of an irregular legal status (in some cases, as most Roma children are European citizens). Roma children show much higher infant and child mortality rates, higher rates of LBW, preterm birth and IUGR, and higher incidence of recessive genetic syndromes. Communicable diseases, injuries and exposures to environmental hazards are much more common than in the general population.<sup>28-30</sup> Although there are important differences among groups depending on their overall living conditions, belonging to a Roma group is a proxy measure for a range of critically important health determinants, including attitudes, beliefs, values, social support, languages spoken, religion, diet, family traditions, and social exclusion.<sup>31</sup>

## Maternal Health

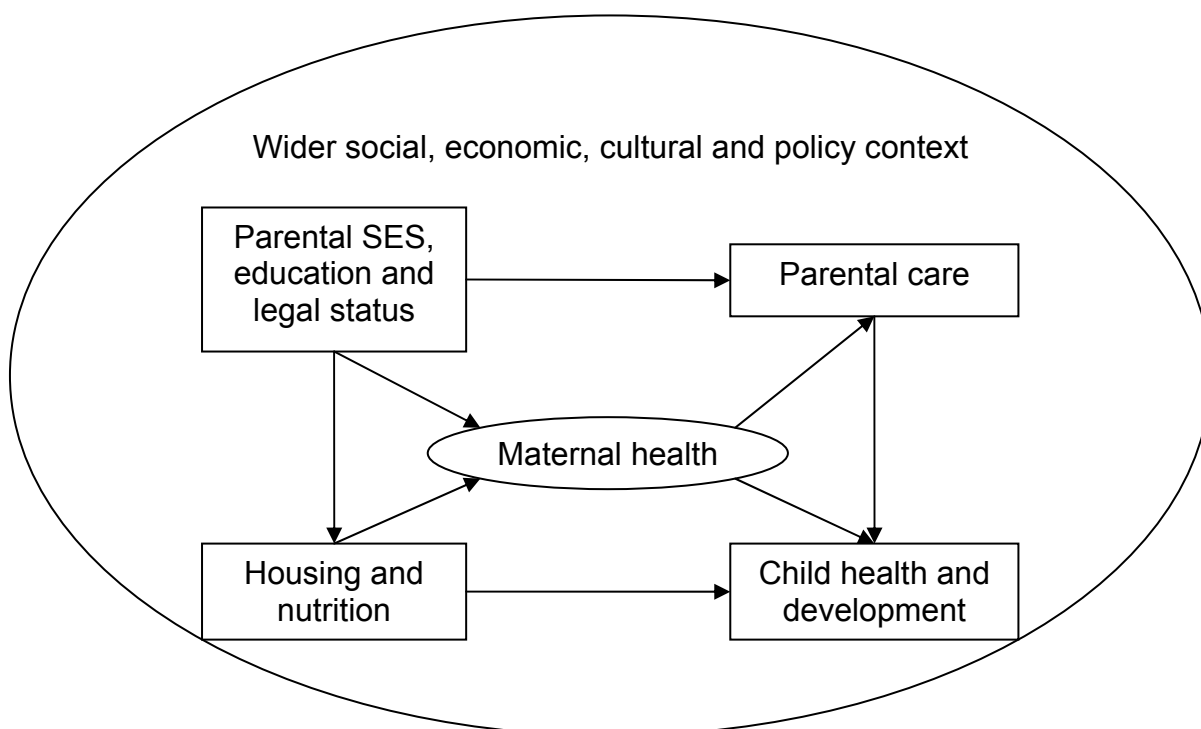
In most countries, maternal mortality was less than 10 per 100,000 live births in 2008. The highest values were recorded in Latvia (12.5), Romania (13.5), Slovenia (15.1 in 2007), Hungary (17.2), Luxembourg (18.3 in 2007), Turkey (19.4) and Malta (23.8). Maternal mortality tends to be underestimated due to misclassification and wrong definitions. In all countries that have embarked in *ad hoc* studies, maternal mortality ratios have doubled or tripled the official estimates. In all countries, maternal mortality is very closely associated with low SES, but inequalities are higher in Southern and Eastern European countries.

Maternal health is an obvious crucial determinant of embryo-foetal development and health, and has profound implications on health later in life. Over the last decades, the impact of maternal health even prior to conception on pregnancy outcomes, and also on health over the entire life span, has been altogether better understood. Exposure to environmental toxicants including alcohol, tobacco and drugs, prior to conception and during pregnancy, has been shown to affect early organ development and, consequently, it has been proven to increase the risk of congenital anomalies, LBW and other health problems.<sup>32</sup>

There are two emerging issues regarding the relation between maternal and child health. One is that women who were previously unable to get pregnant or to bear children are now able to do it thanks to advances in health care and medically-assisted conception. The other is the fact that maternal age along with the prevalence of overweight and obesity, are increasing. Both these factors contribute to a higher risk of complications during pregnancy and a higher risk of adverse pregnancy outcomes.

In addition to the above mentioned biological factors, all influenced by social factors, the health and social conditions of women have an impact on child health through two main mechanisms: a) child nutrition, and b) parental attitudes and styles, which for both parents are also shaped quite early during pregnancy and reflect in part the early experiences of the new parents with their own parents. Child nutrition and parenting are strongly influenced by the wider social context (Figure 2.5).

**Figure 2.5. Parenting and nutrition, being in turn influenced by the wider social context, are the most proximal determinants of child health and development.**



### **Parenting Attitudes and Styles**

Parenting is a complex activity that includes many specific behaviours that work individually and together to influence child outcomes. Attachment to the primary caregiver over the first years of life is a well-known determinant of the child's self-esteem and way of relating with the outside world. Although specific parenting behaviours may influence child development, looking at any specific behaviour in isolation may be misleading, since specific parenting practices are less important in predicting child well-being than the broad parenting style.<sup>33</sup> Type of family functioning, i.e. whether the family is cohesive, enmeshed or disengaged, influences children's adjustment during the early school years.<sup>34</sup> Maternal and, to a lesser extent, paternal depression are also known to influence parental attachment in the first years of life. Fathers' involvement has been shown to have an influence on children's developmental outcomes as well.<sup>35</sup> Social attitudes to children and parenting styles vary across European countries, depending on cultural and religious backgrounds. Over the last decades, these attitudes have undergone profound modifications. Early interactions and parenting styles remain fundamental in the early shaping of the child character and play a particularly important role in the child's cognitive and socio-emotional development.

### **Life style and Behaviour**

Life style and behaviour depend on personal choice only in part. They are strongly associated with the economic and social environment, and are influenced by social norms and, increasingly, also by the media. This section focuses on life styles and behaviours of major public health importance.

#### *Nutrition*

Nutrition starts in the mother's womb. IUGR is the earliest indicator of foetal undernutrition. IUGR may be caused by maternal undernutrition as well as by a variety of pregnancy complications, chronic diseases and foetal anomalies. IUGR and prematurity reflect in LBW, which is in turn, is strongly associated with infant morbidity and mortality. Prevalence and risk factors for LBW will be discussed in Chapter 3.

Exclusive and prolonged breastfeeding has an important protective effect against a series of diseases and conditions (Table 2.1). It may also enhance cognitive and intellectual development.<sup>36,37</sup>

**Table 2.1. Protective effects of exclusive and prolonged breastfeeding.**

<b>Health outcome</b>	<b>Average risk reduction</b>
Acute otitis media	50%
Gastrointestinal infections	64%
Lower respiratory tract infections	72%
Atopic dermatitis	42%
Asthma	27%
Overweight and obesity	22%
Type 2 diabetes	38%
Acute childhood leukaemia	19%
Sudden infant death syndrome	36%

For this reason, the WHO, as well as most national policies and most professional associations in Europe recommend, as a public health measure, exclusive breastfeeding up to 6 months, and the continuation of breastfeeding, with adequate and safe complementary foods, up to 1 or 2 years of age and beyond. Yet in all countries reporting data the rates of exclusive breastfeeding at six months fall short of these recommendations (Table 2.2).<sup>38</sup>

**Table 2.2. Latest available national data on breastfeeding at different ages.<sup>d</sup>**

<b>Country</b>	<b>Year</b>	<b>Any length of breastfeeding (%)</b>		<b>Exclusive breastfeeding at 6 months (%)</b>
		<b>At 3 months</b>	<b>At 6 months</b>	
AT	2005	55		10
BG	1996			42
CZ	2004	60	36	23
DK	2001			30
EE	2004	67	48	31
FI	2000	74	51	
HU	2002	93	48	37
IS	2001/04		67	14
IT	1999	64	38	5
LV	2002	66	37	24
LT	2004	50	31	26
NL	2003	51	27	18
NO	1998	88	80	7
PL	1997			29
PT	1999	63	34	
RO	1997	63	39	17
SK	2007			41
SI	2000			17
ES	2001/07	66	45	25
SE	2003	86	71	33
UK	2005		25	1

Complementary feeding covers the period between 6 months and 2 years of life, approximately, and coincides with a particularly vulnerable developmental phase. Inadequate complementary feeding, in quantitative and qualitative terms, may lead to malnutrition. It may

<sup>d</sup> Given the different definitions and methods used in each country to gather data on breastfeeding, caution should be observed when interpreting these rates.

also lead to underweight, stunting and wasting in low-income populations, and to overweight and obesity in high-income ones. Very little is known about the adequacy of complementary feeding and about feeding in pre-school and school children. In general, most local studies show that the diet in these age groups is too rich in fats, sugar (often from sweet beverages) and salt, and too low in fresh fruit and vegetables. Surveys on pre-adolescents show that these bad habits tend to be carried over. For example, daily fruit consumption is low and tends to decline with age; it varies between countries and within countries. It is lower among 11 and 13 year-old from low-income families. Similar findings are reported for the excessive consumption of soft drinks.<sup>39</sup>

### *Alcohol, Tobacco and Illicit Drugs*

Alcohol is responsible for 11% of deaths in men and 1.8% in women in Europe.<sup>40</sup> Although, in terms of population attributable harm, it impacts men disproportionately, alcohol abuse is increasing among young women in EU countries,<sup>41</sup> causing ill-health and, potentially, foetal abnormalities in case of pregnancy. Harm to women and children may also come indirectly through men's alcohol consumption, which can negatively impact the entire household through increased poverty, abandonment, and intimate partner violence.<sup>42</sup> Moreover, alcohol use may widen the gaps among socio-economic groups. Finally, alcohol consumption among men and women prior to heterosexual intercourse has been associated with decreased likelihood of using contraception or prophylaxis to avoid sexually transmitted infections.<sup>43</sup>

About 40% of men and 18% of women smoke in Europe.<sup>44</sup> In most of Western Europe, the prevalence of smoking is decreasing, or has at least stabilised. However, this is less so in Eastern Europe, with a slight rise in prevalence among women in some countries. Smoking tracks the socio-economic gradient within countries, particularly in Western Europe, with young single mothers being particularly affected.<sup>45</sup> Tobacco advertising explicitly targets women, strategically playing on norms of femininity to encourage more women to smoke.<sup>46</sup> The number of pregnant women who smoke may be high, with a study in France showing for example that 28% of them smoke.<sup>47</sup> Smoking can cause ill-health among women who smoke, and can lead to foetal complications, including LBW and decreased lung function.<sup>48,49</sup> Smoking behaviour can be established during adolescence; between 10% (FYR of Macedonia) and 50% (Estonia) of 15 years-olds report their first smoking at age 13 or younger. In most countries, boys are at a higher risk than girls.<sup>39</sup>

Generally, illicit drug use is also more common among men than women.<sup>50</sup> However, women do use drugs, and those who do, are less likely to seek health care services because of poverty, concern about having contact with the state, or other factors. Existing services to reduce drug-related harm may not be gender-sensitive nor have adequate links to sexual and reproductive health services. This limits access to antenatal care, including prevention of mother-to-child transmission of HIV.

### *Physical Activity*

Inactive children, when compared with active ones, weigh more, have higher blood pressure and lower levels of heart-protective high-density lipoproteins (HDL cholesterol). Even though heart attack and stroke are rare in children, evidence shows that the process leading to those conditions begins in childhood.<sup>51</sup>

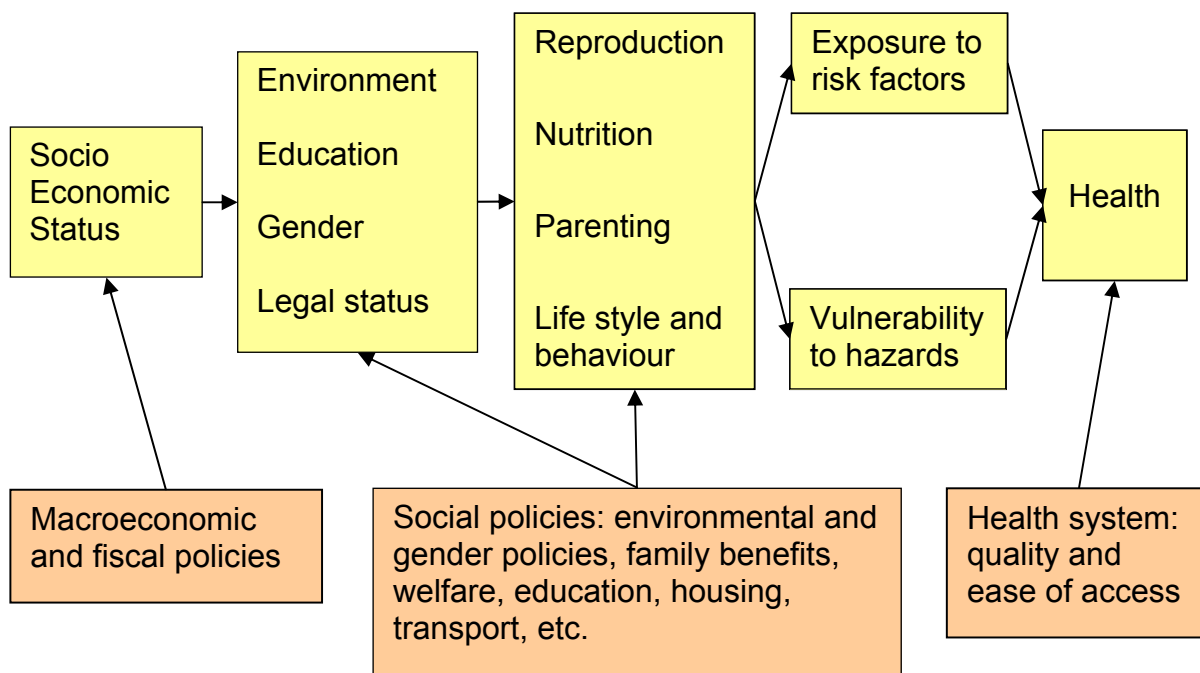
Physical activity has also been associated with psychological benefits in young people since it improves their control over symptoms of anxiety and depression. Similarly, participation in physical activity can assist in the social development of young people by building self-confidence and providing opportunities for self-expression, social interaction and integration. It has also been suggested that physically active young people adopt other healthy behaviours more readily (e.g. avoidance of tobacco, alcohol and drug use). They also demonstrate higher academic performance at school.<sup>52</sup>

## 2.2 Social Policies and Health Systems as Determinants of Health

The WHO Commission on Social Determinants of Health report *Closing the Gap in a Generation* states: ‘Social and economic policies have a determining impact on whether a child can grow and develop to its full potential and live a flourishing life, or whether its life will be blighted’.<sup>1</sup> This section will discuss health systems and related social policies insofar as they have a bearing on access to health care, on its quality, and ultimately on child health. Discussing health systems and social policies as determinants of health does not necessarily mean recommending specific policies. This is not the role of this report, but of governments.

The impact of social determinants over child health can be profoundly modified by economic policies (including the implementation of macroeconomic and fiscal policies for the redistribution of income and alleviation of poverty), by social and, in particular, welfare policies, by education policies (including pre-school services and parenting support), by environmental policies, by legislation regarding migrants and legal status, and finally by health system policies. By ensuring equitable and universal access, health services can reduce the risk differential; on the contrary, not having access to quality care can increase inequity (Figure 2.6). All this is even more important in times of economic crises which put children’s health at an increased risk, and which may at the same time have a negative impact on social policies and health systems (see box next page).

**Figure 2.6. Policies to address social and economic determinants of child health.**





## **Economic Crises and Child Health**

Children, particularly those living in low-income and migrant households, become more vulnerable as a consequence of the economic downturns associated with economic crises.<sup>53</sup> Economic downturns affect key economic and social factors by reducing household incomes due to unemployment, by reducing migrants' remittances, particularly for EU12 countries, and by lowering the capacity of the state to adequately finance social policies, including health and education. It may be useful to distinguish the direct impact of these crises on women and children, and the indirect impact produced by their consequences on social spending.

### *Direct Impact*

Many families experience a decline in living standards, particularly families with many children and with disabled members, single parent families (especially single-mother ones) and migrant families. Common coping strategies in crisis-affected households include reducing expenditure on food and shifting consumption patterns to eat more cheaply, and hence, less nutritious food,<sup>54</sup> and reducing expenditure on education and extra-curricular activities for school children. Thus, if family income is reduced for prolonged periods, children's nutrition may suffer. A combination of pre-existing deprivation (e.g. overcrowded housing and less cohesive social environments), and the additional stress of economic insecurity and delaying seeking health care, may lead to worsening physical and mental health among children and adults. Empirical data on the likely impact of economic crises on child health and well-being are limited, yet there is good evidence, based on the economic crisis in Finland in the early 1990s, that the well-being of children and adolescents was compromised as a result of the pressure of economic problems on parents.<sup>53</sup> The increase in mental health problems among children and young people in Europe, over the 20-year period starting in the early 1980s, has been linked to changes in the labour market for young people.<sup>55</sup> Thus, economic crises will impact on several economic and social/psychosocial dimensions of household poverty and intrafamilial stress, which will then interact to produce a variety of adverse outcomes that may have long lasting consequences and lead to the reversal of previous gains.

### *Indirect Impact*

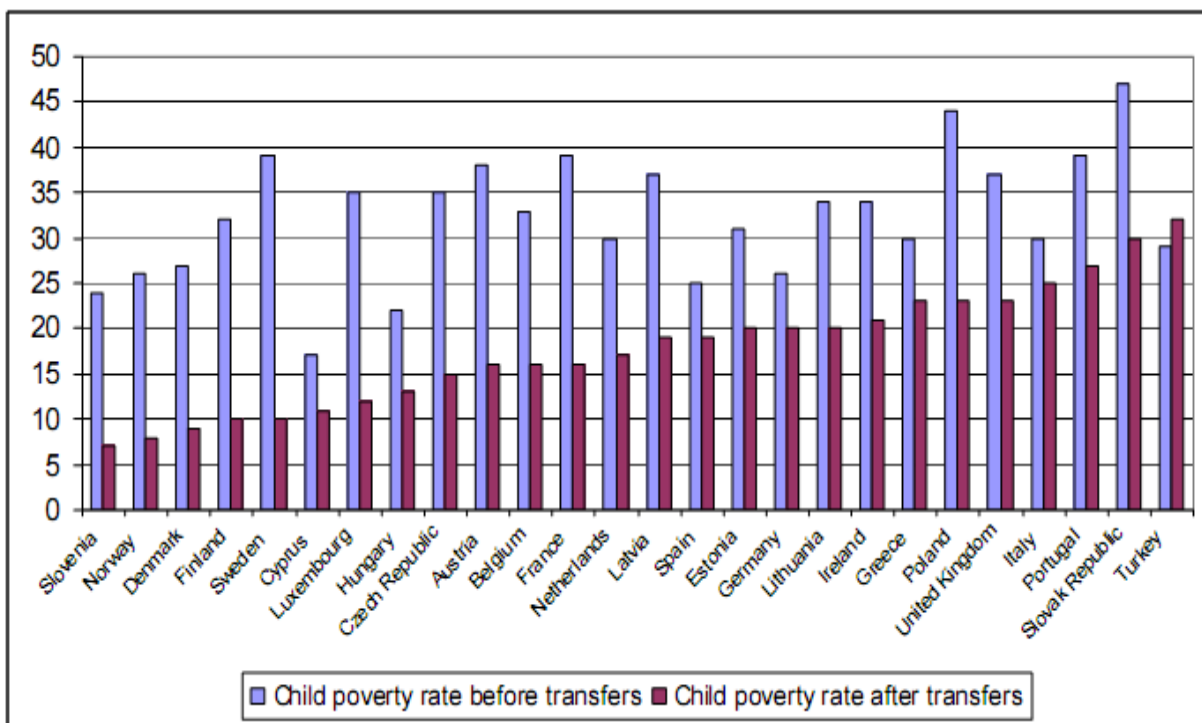
To prevent major breakdowns and to ensure stability, most countries engage in marked reductions of public spending during an economic crisis. Almost everywhere, health and welfare systems represent privileged targets of government cuts in spending. Most national economies, operate cuts in spending and consider more or less substantial trimming of the health expenditure. Services for children, particularly important for those who are already in a poor or low-income home, are significantly reduced in many European countries.<sup>53</sup> All these effects combine to reduce the chances for the most vulnerable (old and new poor, marginalised and minority groups, households depending on remittances if working members become unemployed) to access quality health care, unless specific counteracting measures are taken to improve targeting of programmes.

## **Government Financial Support and Benefits for Families, Mothers and Children**

Most European countries provide significant financial support to families with children in order to combat child poverty and to assist parents with childcare responsibilities so as to balance jobs and family life.<sup>56</sup> However, there is wide variation in the percentages of child needs covered by social support. Among EU15 countries, Austria, Belgium, Ireland, Luxembourg and the United Kingdom cover over 40% of child needs, compared to less than 20% in Italy, Portugal and Spain. Among EU15 countries, child benefit is universal and non-means tested with the exception of Italy, Portugal and Spain. Universal benefits are more likely to be taken up compared to those that are means-tested. Despite evidence that social spending in early childhood is likely to be most effective in optimising child development, very few EU countries (Finland, Hungary, Slovak Republic) spend a higher percentage of their

financial support on families with children in the early years.<sup>17</sup> Spending on the middle and late years of childhood prevails in most countries. Figure 2.7 shows how child poverty rates can be substantially reduced by public interventions.<sup>57</sup>

**Figure 2.7. Relative child poverty rates\* before and after transfers (Source: Spencer, 2010).**

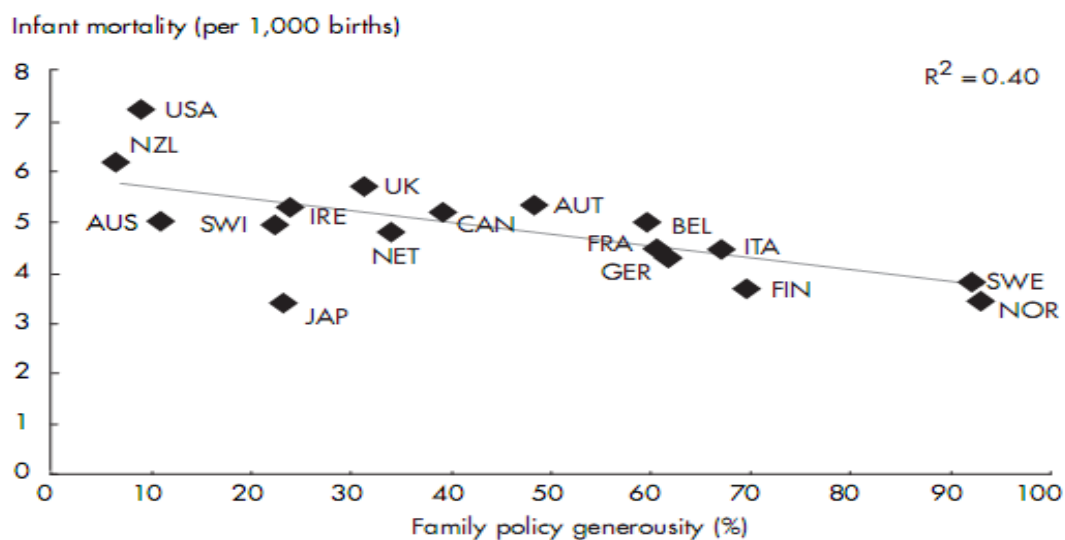


\* Living in households with an income of less than 60% of the average national income. Since child poverty rates are relative to national income, the figures cannot be compared across countries; however, what can be compared is the magnitude of change in child poverty rates after transfers.

The experience of Nordic countries (Denmark, Finland, Iceland, Norway, Sweden) in terms of social policies gives an interesting and useful example of the general impact of social policy on poverty, inequalities and health outcomes. The welfare states of the Nordic countries put an emphasis on universal social policies (social spending, coverage of social insurance) and have internationally low poverty rates, an outcome that seems to be influenced by a redistributive welfare state system. Universal social policies have positive health consequences. Among many European countries, family policies legislation, particularly dual earner family support, well-developed in these countries, seems to be more important for cross national infant mortality differences than Gross Domestic Product.

Maternity leave and maternity benefits play an important role in ensuring optimal pregnancy outcomes, and are offered to pregnant mothers in all European countries. Hungary has the most generous provision in terms of time allowed (24 weeks) and percentage of salary (100%). Parental leave after the birth of an infant is offered in all countries, but there is wide variation between countries in duration, financial support and flexibility.<sup>58</sup> Sweden has the most generous scheme in terms of financial support, flexibility and duration (up to 480 days for each child up to the age of 8 years). In addition to Sweden, Denmark, Finland, Hungary and Slovenia offer a high or moderate earnings replacement rate. Other EU countries provide a more modest allowance, or an unpaid leave. Figure 2.8 shows how higher family policy generosity correlates with lower infant mortality.<sup>59</sup>

Figure 2.8. Family policy generosity and infant mortality (Source: Ferrarini, 2010).



### Policies for Migrant Children and their Families

In principle, migrant children are entitled to emergency care services across the EU, regardless of their legal status, but many differences exist in the level of access to health care, and these are based on migrant status. Full access to health care systems is generally granted to those migrant children who possess a legal residence permit that gives them the possibility of being included in the health insurance scheme and, therefore, grants them the same rights and obligations as the host country's children. Partial access to health care services is guaranteed to refugees and asylum seekers, each country applying specific regulations. Limited access, generally in life threatening situations, is guaranteed to the remaining categories, i.e. undocumented and illegal migrant children.

This picture, consisting of different degrees of accessibility for migrant children, is in contrast with the UN Convention on the Rights of the Child (CRC), ratified by all countries considered in this report. According to the CRC, the right to health should be granted to all children without any discrimination based on nationality or legal status. In their periodic reports to the UN Committee on CRC, the majority of the state parties make reference to the category of migrant children (article 24), although in different ways. Only a few state parties explicitly mention special measures to guarantee access to health and health services for migrant children. These measures refer to: prophylactic health examination and vaccinations, annual medical check-ups, child psychiatric services, family planning assistance, and inclusion of an intercultural collaborator in order to enhance the quality of services provided to migrants. Other general mentions to the challenges of a multicultural society are made in some reports, but the actions undertaken are usually generated in response to very specific cultural habits of the migrant groups, for example the non-medical circumcision of boys or female genital mutilation. In general, it can be said that a gap exists between the ratification of the CRC and the practical integration of its contents into legislation and policies at national levels.

As far as education is concerned, access for migrant children is variable across countries. Migrant children without residence permits are denied access to education in the Czech Republic and Sweden, while other countries (Lithuania, Romania, Spain) allow access to all children.

## **Provisions and Care for Children with Special Needs**

Benefits for children with disabilities vary across Europe and include various combination of financial coverage of extra cost for health care, special education, allowances, and non-financial benefits for home care, education and transport. In general, most countries still show gaps when it comes to adopting and implementing comprehensive policies for children with special needs. These should include economic support to poor families, multidisciplinary health care, inclusive education, home support and easy access to jobs. The Nordic countries represent the model that comes closest to full support and inclusion.

Quality and continuity of care for children with complex diseases is still suboptimal and often the access to quality care is hampered by socio-economic conditions of the family. In many countries, policies and programmes to prevent child maltreatment are still insufficient and child protection services are not yet able to respond to increased recognition of child maltreatment through adequate institutional responses. Institutionalisation of children with severe disabilities or who have been abandoned is still a major problem in some EU12 countries, in spite of some recent progress.

## **Gender Policies**

Gender-based health and social services for women are rarely available. These include services against domestic violence, which may not be available, or may be delivered in a way that increases stigma.<sup>60</sup> At the same time, sexual and reproductive health services for men may be too limited, leaving them without adequate health information, and also leaving women responsible for pregnancy and prevention of sexually transmitted disease.<sup>61</sup> To promote male use of services and shared responsibility of pregnancy, increasing male participation in sexual and reproductive health decision-making is recommended, as is promoting the use of male contraceptive, and improved gender-responsive services.<sup>61,62</sup>

## **Maternal Health Policies**

In most European countries, maternal health policies are adequate, yet in many countries there are pockets of underserved communities, essentially for minority population groups. For example, in some countries, Roma women still show very low or substandard antenatal care, and skilled institutional delivery may not be available for all. Moreover, there is still a tendency to give priority to the physical aspects of pregnancy and ignore the postpartum needs of women, such as post-natal depression, and the preparation to childbirth and parenting. This is important even in countries where maternal mortality and morbidity has substantially decreased, though still subject to improvement.

As far as maternal nutrition is concerned, the large body of evidence on the adverse effects of excess or under weight of women before and during pregnancy, as well as the lack of important micronutrients in the maternal diet, has been taken into account to recommend periconceptional supplements, to monitor weight and nutritional status of women during pregnancy, and to advise mothers on healthy eating.

## **Policies to Support Parenting**

Over the last decade, several countries have launched programmes to support parenting as a strategy to promote children's health and well-being. Support to parenting includes financial and psychosocial support for those who need it the most, the provision of services such as day care centres and other pre-school services, as well as programmes to prepare couples to parenthood and to support them in their parental function after birth. These programmes are based on home visits carried out by health professionals, but also on parental groups and peer-to-peer groups. Practices such as reading aloud to children have been recommended and are supported as a mean to enhance cognitive stimulation and optimal attachment. Long exposure to television has been discouraged as have certain inappropriate

practices, such as corporal punishment. Eighteen European countries have outlawed smacking of children by any adult, including parents, and others have altogether banned corporal punishment in schools.<sup>63</sup> European countries also vary in the extent to which children, and particularly breastfed children, are welcomed in public places reflecting different attitudes to children and to their parents.

### **Child Nutrition Policies**

A Blueprint for Action developed by the participants of a EU-funded project outlines the actions to be included in and implemented by any national or regional plan, and addresses in particular socially disadvantaged groups and children in difficult circumstances.<sup>64</sup> Specifically, it recommends: a) the full implementation of the International Code of Marketing of Breast Milk Substitutes and subsequent relevant World Health Assembly resolutions, including mechanisms for enforcement and prosecution of violations and a monitoring system independent of commercial interests; b) a maternity protection legislation that enables all working mothers to exclusively breastfeed their infants for six months and to continue thereafter non-exclusively; and c) the support to establish standards for best practice in all maternity and child care institutions/services, the so-called Baby Friendly Initiatives. In Europe, these are far from being fully implemented, though the number of 'baby friendly' hospitals and the percentage of births in them seem to be increasing.<sup>38</sup>

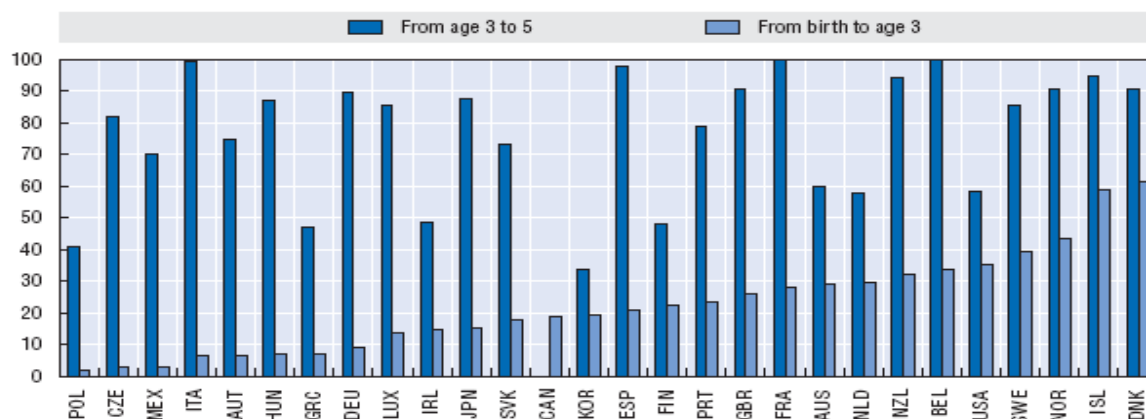
Complementary feeding is also increasingly considered as a public health priority, along with maternal nutrition and breastfeeding. A EU-funded project recommends that the promotion, protection and support to breastfeeding up to 2 years and beyond be complemented by adequate and safe complementary feeding from around the age of 6 months.<sup>65</sup> It also calls on authorities to favour availability and access to safe and healthy food for infants, young children and their families, and to give parents objective and evidenced-based information, independent of commercial interests, on appropriate complementary foods and on how and when to introduce them to their children.

During the second, and especially the third, year of life, the needs of children change and strategies referring to children in pre- and primary schools, as well as adolescents, focus on providing information regarding the importance of a varied and balanced diet along with daily play and physical activity. They also centre on the need to create school, family and social environments that encourage healthy eating habits and physical activity, and to restrict food marketed directed at children.

### **Child Care/Early Childhood Education**

In all European countries, some form of child care/early childhood education is provided, however, as Figure 2.9 shows, enrolment rates vary widely.<sup>20</sup> For children who have just been born and up to the age of 3, enrolment exceeds 50% only in Denmark and Iceland. In Austria, Czech Republic, Greece, Italy and Poland, rates are under 10%. For children between 3 and 5 years old, enrolment rates are generally higher in all countries, but vary between 100% in Belgium, France and Italy, and less than 50% in Finland, Greece, Ireland and Poland. In most countries, child care/early childhood education is publicly provided, although in some countries such as the Czech Republic, Ireland and Poland, there is very little publicly funded provision for children aged between 0 and 3 years. The exceptions to the latter are the Netherlands and the United Kingdom, where private sector provision dominates.<sup>66</sup>

**Figure 2.9. Enrolment rates in formal and informal childcare/early childhood education in 2005 (Source: OECD Family database).**



Note: The data includes formal and informal care.

Source: OECD Family database.

### Policies related to Alcohol, Tobacco and Illicit Drugs

Although health professionals, as well as professionals in the education sector, have an important role in shaping individual and family behaviours, given that some of the most effective policy measures are fiscal, regulatory or legislative, government and society bear some responsibility in reducing child exposure to substances.

With regard to tobacco, the WHO Framework Convention on Tobacco Control has been ratified by several EU countries.<sup>67</sup> Many countries have already banned smoking in public places. However, insofar as private indoor environments are concerned, there should be a focus on awareness-raising campaigns channelled by the media and by health and education professionals. Regarding alcohol, effective policy and legislative interventions may include: taxing alcohol sales, imposing laws on drink-driving with enforcement measures, restricting retail outlets, and controlling advertising.<sup>68</sup> Over the last decade, most European countries have already adopted this kind of measures.

### Policies Promoting Physical Activity

In 2005, the EC set up a Platform on Diet, Physical Activity and Health to provide a common forum for agents (governmental, non-governmental, private) interested in taking action to contain or reverse current negative trends in physical activity, associated among other factors with the obesity epidemic.<sup>69</sup> Based on the available Platform reports, few partners seem committed to promote of physical activity. The majority of commitments relate to foods and diet. Most guidelines published in the last 10 years, including those of the EU,<sup>70</sup> recommend a minimum of 60 minutes of daily moderately intense physical activity for children and young people. This can be achieved by planning age-appropriate physical activity at schools, recreational free-time physical activity, and transport-related physical activity. Education and health professionals, in collaboration with parents and others in the community, play an important role in implementing these plans. An additional aim is to include the reduction of sedentary activities, such as the time spent watching television or playing videogames.

Another initiative launched in response to the emerging challenges of obesity, is the WHO European Ministerial Conference on Counteracting Obesity, held in 2006, with its European Charter on Counteracting Obesity focusing on healthy nutrition and physical activity.<sup>71</sup> Also the Transport, Health and Environment Pan-European Programme, launched in 2002, provides support to mobility plans based on the promotion of safe cycling and walking for children.<sup>72</sup> Some of these recommended policies have been adopted by EU countries and included in their national policies as well as in their local initiatives.<sup>73</sup>

## **Environmental Health Policies**

The EU Registration, Evaluation, Authorisation and restriction of Chemicals regulation (REACH),<sup>74</sup> introduced in June 2007, makes industry responsible for assessing and managing the risks posed by chemicals and for providing appropriate safety information to their users. Biomonitoring through harmonised methods and sampling is envisaged, also for children.<sup>75</sup> The Children Environment and Health Action Plan for Europe (CEHAPE) has had an impact at national and subnational levels across the region.<sup>76</sup> It has also stimulated coordinated action on children's health, cutting across departmental and sectoral boundaries and involving different levels of government in countries. CEHAPE has positively influenced interventions to reduce environmental risks for children's health (90%), development of the information and monitoring systems (95%), public information and awareness (95%), national policy-making (80%), and intersectoral collaboration (90%).<sup>77</sup> Improvements in intersectoral collaboration have mainly occurred between health and environment sectors, followed by transport and education. CEHAPE has had a strong influence on countries in Europe to develop national plans. The framework conventions on Tobacco Smoke and Persistent Organic Pollutants (POP) have also been endorsed by the EU and are gradually being applied at country level.

## **Health System Policies and Access to Care**

A health system includes the pyramid of health facilities and associated resources that deliver personal health services, and also non-personal health actions, for example anti-smoking, diet and physical activity programmes. All the countries included in this report are committed to ensure universal access to all essential services, and particularly to maternal and child health services. This is achieved either through a prepaid tax based national health service (e.g. Italy, Spain, United Kingdom), or through health insurance systems (e.g. France, Germany).

Although based on the principle of universal access, health systems may fail to guarantee full universal access for a variety of reasons, which include poor supply of services in disadvantaged areas or for disadvantaged communities, discrimination, direct or indirect payments, and demand factors such as cultural and religious norms hampering the access to health services. There is also concern that some people may incur catastrophic levels of out-of-pocket health spending. This risk increases as the government spending on health decreases, and is often restricted to the poorest fifth (quintile) of the population. Households impoverished due to spending on health, may cope by limiting food expense, with a negative impact on child health and education. Bulgaria, Cyprus, Greece and Latvia are examples of countries with high levels of out-of-pocket spending on health.

In a General Comment on the Right to Health, the European Economic and Social Council identifies four components of access to health services: (1) non-discrimination, (2) physical accessibility, (3) economic accessibility, including ensuring that poorer households are not disproportionately burdened with health-related expenses, and (4) access to information, including the right to seek, receive and impart information.<sup>78</sup> The provision of universal access to quality preventive and curative services, including appropriate drugs for children (see box overleaf), is, together with policies addressing social determinants and cross sectoral policies, an essential factor in the further improvement of child health outcomes in Europe.

The specificity of child health is that it requires specific interventions and investments in the very early stages of life, starting from conception. To emphasise the importance of this, the following section illustrates how the early exposure to risk factors can affect health outcomes from the earliest developmental stages.

## Drug Use in Children

Drug therapy is widely used in the treatment of diseases in childhood. Studies on drugs are therefore important.<sup>79</sup> Many drugs prescribed to children are originally developed for adults and they are often prescribed on an unlicensed or off-label basis by extrapolating data for adults, without conducting any paediatric study.<sup>80</sup> Only 35% of commercially available drugs in Europe are authorised to be used on children.<sup>81</sup> Unlicensed or off-label drug use affects 16-97% of children, depending on the country, the setting (community or hospital) and the disease.<sup>80</sup> The use of off-label drugs exposes children to an increased risk of adverse drug reactions.<sup>82</sup>

In the last few years, many initiatives have been introduced at international level to guarantee safe and effective treatments for children. In 2007, the EU adopted a Regulation on Medicinal Products for Paediatric Use. For the purpose of this report, a questionnaire was sent to 30 countries so as to acquire information on drug reimbursement policies and on the availability of drugs licensed to be used in children. Twelve (40%) countries joined the survey. In five countries (Czech Republic, Estonia, Germany, Latvia, Sweden) specific reimbursement policies exist for drug prescribed to children. Only three countries were able to provide information concerning the number of drugs licensed for children: Estonia (151 drugs), Hungary (778) and Italy (131). Drugs licensed to be used in children represented 13 to 19% of the drugs included in the national drug formularies.

Overall, nearly 60% of children receive at least one drug prescription and on average each child receives three drug prescriptions per year.<sup>83</sup> The percentage of children receiving drugs is higher in children younger than 6 years (70-80% of these children are exposed to drugs). Antibiotics are the most frequently prescribed drugs, accounting for 20-33% of the prescriptions dispensed to children, followed by respiratory drugs (10-25% of total prescriptions) and analgesics (10-16%). Quantitative and qualitative differences between countries are found for some drug classes. The percentage of children receiving at least one antibiotic drug prescription is 14% in the United Kingdom, 18% in the Netherlands and 57% in Italy.<sup>84</sup> The prevalence of drugs used for asthma treatment ranges between 5% in the Netherlands and 26% in Italy. Regarding antidepressants, the highest prevalence is in Iceland (2.3%), and the lowest in Denmark (0.2%). A similar profile is observed for stimulants, with a prevalence ranging from 0.1% in France to 2.8% in Iceland.

The geographical differences in drug prescriptions depend on several factors: the epidemiology of diseases; existing health care systems; drug regulations; national pharmaceutical market structures; physician attitudes (i.e. diagnostic uncertainty, especially for the youngest age groups, or differences in diagnostic labelling, time, or market pressure); and socio-cultural and economic determinants related to patients and parents (i.e. patient's general condition or socio-economic status).

To improve the rational use of drugs in children, there is a need for further research on the efficacy and safety of medicines within the paediatric population, as well as multicountry prospective studies to monitor drug prescriptions to children, in particular for drugs for which safety concern exists (e.g. psychotropic drugs). Regulatory interventions at national and international level to harmonize drug licensing systems are also vital. Finally, educational interventions for health professionals and parents should be implemented.



## 2.3 Exposures and Risk Factors over the Earliest Life Stages

The recent decade of research has provided further evidence for the idea that many diseases and conditions that arise in childhood, but also much later along the life course, may have causes that start as soon or shortly after conception and quite often in the earliest years of life. Exposure to inadequate nutrition, to chemical and physical pollutants, to social and psychosocial adverse conditions, to infectious or other harmful agents or processes may interfere with early organ and system development, disrupt metabolic pathways, modify disease susceptibility and have profound effects not only on outcome at birth, but on health status during infancy and childhood and over the entire life course. Developmental plasticity is affected, at least in part, by epigenetic changes that are established in early life and modulate gene expression during development and maturity in mammals. The available data are now beginning to provide a molecular basis for epidemiological and experimental evidence that shows that the early period of life is critical in determining ensuing susceptibility to chronic non-communicable diseases, such as obesity, type 2 diabetes and cardiovascular dysfunction.<sup>85</sup> New insights are provided and will be provided in the future by ongoing longitudinal cohort studies (see box).

### The Importance of Birth Cohort Studies

Over the last two decades an increasing number of longitudinal cohort studies, starting from pregnancy or birth, have been launched in various parts of the world. There are also many more in the progress of being set off. Europe has given an outstanding contribution through the establishment of national birth cohort studies (BCS) – the Helsinki BCS, the Danish BCS, and so forth – and through collaborative BCS, such as the European Longitudinal Study of Pregnancy and Childhood.<sup>86</sup> BCS have already provided important contributions to our understanding of how social and environmental factors, parental practices and attitudes, and medical and social interventions, shape biological mechanisms and behavioural patterns and influence health outcomes. One of the key messages arising from these is that the potential of BCS for scientific output can be maximised by collaboration between studies, a prerequisite being that cohorts be well documented, and that data on the existing cohorts be collected in a comparable way and be easily accessible. Collaborative networks centres and websites ([www.birthcohort.net](http://www.birthcohort.net)) have been established to serve this purpose.

Thus, what happens to mothers and children since conception is relevant, not only for early child health and development, but also for the general implications on the population's health. Many of the current increasing (e.g. obesity, cardiovascular, respiratory or immune mediated disorders) or decreasing (e.g. most infectious diseases) trends of diseases affecting children as well as adults, have their explanation in changes in exposures and practices occurring in the early years of life. Table 2.3 offers an overview of how the main exposures to factors mentioned in this chapter, are associated to specific health risks, and how, in turn, these are distributed along the early life stages.

**Table 2.3. Overview of exposures and risk factors and their impact on health over the first 12 years of life**

<b>Main exposures</b>	<b>Main health risks</b>	<b>Embryo-foetal life</b>	<b>Birth to 2 years</b>	<b>Preschool (3-6 years)</b>	<b>School (7-12 years)</b>
Poor maternal health	Poor pregnancy outcomes, LBW	++++	+++	++	++
Inadequate nutrition during pregnancy and the early years	Over and underweight, anaemia, infections, immune disorders	++	++++	++	++
Inadequate parenting	Psychosocial problems and behavioural disorders		++++	++	++
Discrimination and social neglect	Psychosocial problems	++	+++	++	++
Environmental toxicants	Congenital anomalies, lung diseases, neurotoxicity, endocrine disorders, cancer	+++	+++	++	+
Unsafe home and outside environment	Injuries	+	++	+++	+++
Insufficient physical activity	Obesity, cardiovascular and metabolic risk in adult life	+	+	++	+++
Alcohol and tobacco	Congenital anomalies, LBW, respiratory disorders	++++	++	+	+(++)

### **Implications of New Knowledge on Health Consequences of Early Exposures**

Exposure to risk factors can be modified by public policies and interventions as well as, in most cases, by individual actions. Within public policies, health systems have a unique, although not exclusive role, in preventing exposure and ensuring effective and equitable care. As stated above, the likelihood of being exposed to risk factors depends primarily on the conditions in which children are conceived, and in which they grow and live and on a wide range of material, psychosocial, environmental and behavioural underlying factors.

Addressing these risk factors and their underlying social determinants across the range of domains implicated, requires an integrated response. In most cases, it will also require an approach from the government in full collaboration with civil society, local communities, the private sector and international institutions and agencies.

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### 3. Perinatal Conditions

#### Key Messages

- Many of the current increasing or decreasing trends of diseases affecting children as well as adults have their explanations in changes of exposures and practices occurring from conception to very early life, including the perinatal period.
- The most important indicators of perinatal health (perinatal mortality, LBW) portray a favourable situation in Europe compared to other regions of the world. There are, however, important inequalities among and within countries.
- Better nutrition and reduced exposure to smoke, alcohol and other substances before conception and during pregnancy, as well as social benefits associated with long maternity leave, are the key preventive strategies, especially for women of low socioeconomic status.
- Universal access to appropriate quality care in pregnancy, at childbirth, and for LBW and preterm infants, should be ensured in all countries.

Many of the current increasing or decreasing trends of diseases affecting children as well as adults can be explained through changes in exposures and practices occurring from conception to early life, including the perinatal period. This chapter describes the most important conditions that affect mothers and infants in this period, with a bearing later in life.

#### Main Sources of Information

Most data and information used to write this charter were derived from the general sources already mentioned in the Introduction (EUROSTAT, the WHO and OECD databases, UNICEF Child Info and State of the World's Children annual reports). An important source of information to which the reader is referred to for details and in depth analysis is the report of the EURO PERISTAT project and its related scientific publications (<http://www.europeristat.com/>). This report deals also with the problem regarding the completeness and accuracy of data gathered in EU, EFTA and candidate countries.

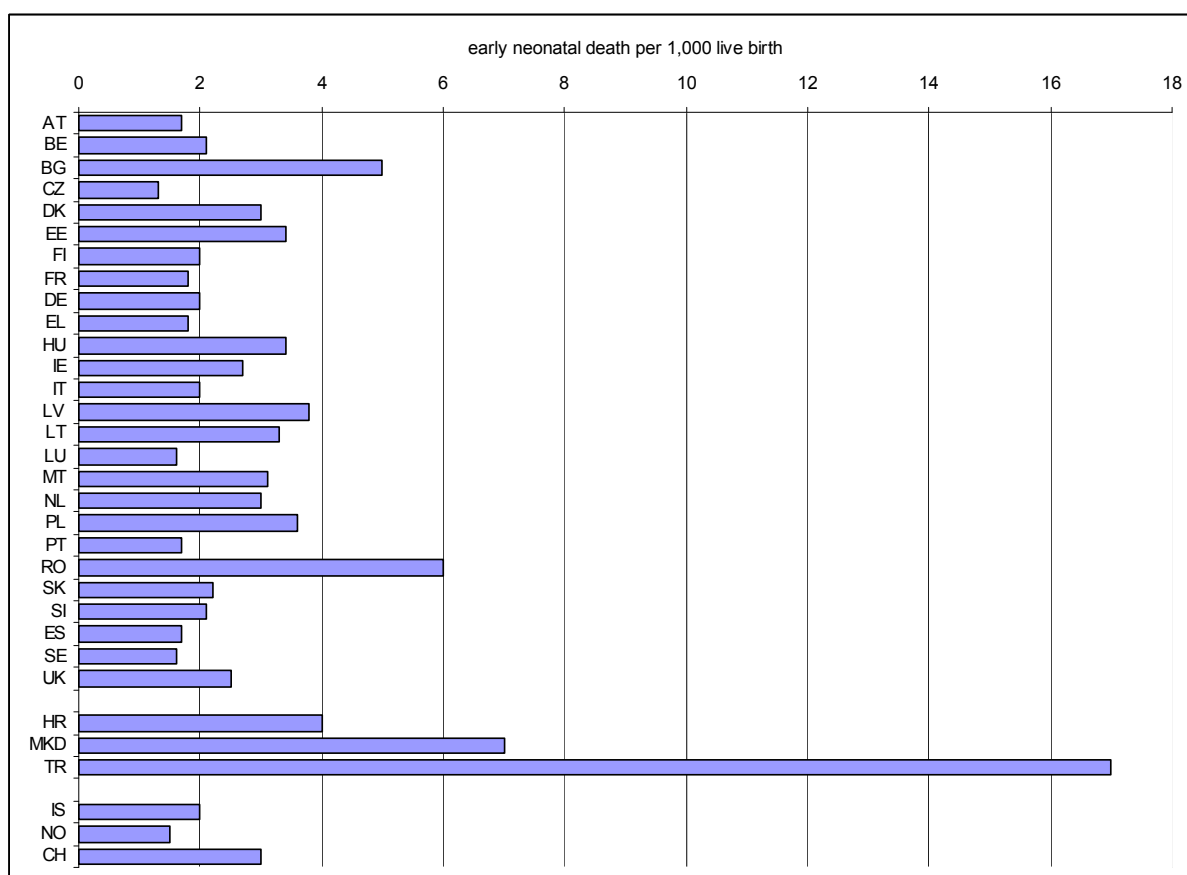
#### Size of the Problem

Perinatal mortality, i.e. the sum of foetal deaths and of early neonatal deaths (i.e. deaths in the first week of life) per 1,000 births (live and stillbirths) has been decreasing for decades in Europe. A foetal death is defined as one occurring when the foetus has completed 22 weeks of gestation. However, not all countries use the same cut off in their statistics; some countries use the old 28-week cut off. Data on stillbirths therefore cannot be compared unless they are standardised by week of gestation. The foetal death component of perinatal mortality can be further broken down into deaths before and during labour. Using the data reported by countries, irrespective of the gestational age cut off, the lowest foetal mortality rates, around 3 per 1,000 births, are reported by Germany, Luxembourg, Slovak Republic, Spain and Sweden; the highest foetal mortality rates are reported by the Netherlands (7 per 1,000), Romania (8 per 1,000), France (9 per 1,000) and Bulgaria (10 per 1,000).<sup>1</sup> Even higher rates are reported by the FYR of Macedonia (10.5) and Turkey (14.4),<sup>2</sup> and for the latter, there are reports of even higher rates (18 per 1,000 live births, with much higher rates in some provinces).<sup>3</sup> The high value in France is due mainly to late terminations of pregnancy, allowed by the legislation. The relatively high rate of foetal and perinatal mortality in the Netherlands, which in effect showed a decline between 2000 and 2006, may also be explained by the high proportion of late terminations of pregnancy; other factors that may play a role are the restrictive policies to resuscitate and to perform intensive treatment on very preterm infants, the late start of a prenatal screening programme for congenital anomalies, a high prevalence of women of non-western origin, and a large share of very preterm infants with a high proportion of congenital anomalies.<sup>4</sup> Substandard care and home birth do not seem to be associated with higher perinatal mortality. The rates of foetal death are lower, about half, if calculated only for births of fetuses 28 weeks of gestational age or

more. When foetal death rates from 28 weeks of gestational age are used, those of France and Netherlands are similar to those recorded in countries with the same degree of development.

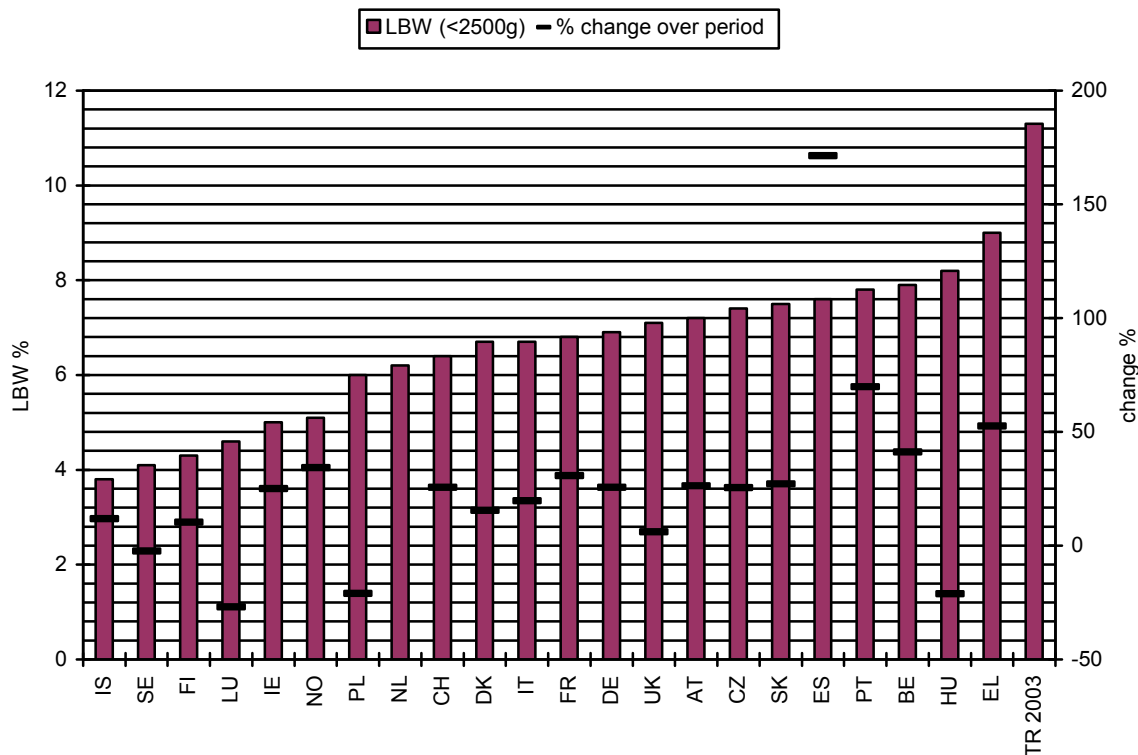
Figure 3.1 shows the rates of early neonatal mortality.<sup>1,3,5</sup> Turkey has clearly and by far the highest rate, followed by FYR Macedonia, Romania and Bulgaria. All the other countries have values of around 1-3 per 1,000 births, the lowest rate being the one recorded by the Czech Republic: 1.3 per 1,000 births.

**Figure 3.1. Early neonatal mortality by country, estimates for 2004 or latest available year.**



LBW, less than 2500 g at birth, and in particular very LBW, less than 1500 g at birth, as well as high birth weight, 4500 g or more, are closely associated with negative perinatal and longer term outcomes. LBW infants represent slightly less than 7% of all births in high income countries; very LBW infants account for about 1% of all births.<sup>1,6</sup> In Europe, the rate of LBW ranges between 4% and 11% and, in most countries, has been increasing – slightly but progressively – between 1980 and 2007, with the exception of Sweden, Luxembourg, Poland and Hungary, the highest increases being recorded in Spain (over 170%) and Portugal (almost 70%) (Figure 3.2). The highest values were recorded in Turkey, Greece and Hungary, while the Nordic countries present the lowest rates. The rates of preterm birth have increased in parallel with those of LBW. Multiple births have a higher probability of LBW. The improved survival of very LBW and preterm infants have partially contributed to the increased incidence of developmental disabilities.

Figure 3.2. Rates of LBW and changes between 1980 and 2007 (Source: OECD, 2009).



Infants may be born with LBW because they are born preterm, because of IUGR, or due to a combination of these two. IUGR is a risk factor *per se* for poor perinatal outcome and later consequences, such as overweight and obesity associated with rapid catch up growth.<sup>7</sup> Ideally, in order to understand the relative importance of preterm birth and IUGR, the birth weight distribution, or the rates of LBW and very LBW, should be presented by gestational age. Foetal deaths should be presented in the same way. In practice this is rarely done. The overall rate of preterm birth varies between 4% and 11% in Europe, with the lowest rates reported by the Nordic and Baltic countries plus France, while the highest rates are recorded in Austria and Germany.<sup>1</sup> Infants born at less than 32 weeks of gestational age represent about 1% of all births. Part of the variation may be due to the different methods used to ascertain gestational age at birth (ultrasound, registration of the last menstrual period, clinical judgement based on predefined criteria, or a combination of these). Multiple births are much more likely to be preterm. As for all other health indicators, there is a social gradient also for LBW and preterm birth, as discussed in Chapter 2.

The mode of delivery is strictly associated with maternal and perinatal health outcomes. This report will only remind the reader of the rapidly increasing rates of caesarean section in most countries in the past two decades. In the 1980s, the rates of caesarean section used to range between 10% and 15%. They are still in that range in the Czech Republic, Estonia, Finland, Lithuania, Netherlands, Slovenia, Sweden and Norway. Yet, in other countries, they have soared well above 20%, with peaks over 35% in Portugal and Italy, where in some areas rates may be as high as 60%. To understand the determinants and consequences of such an excess of caesarean sections, and to obtain further details, readers are referred to other reports.<sup>1,8</sup>



## Causes and Risk Factors

Exposure to tobacco, alcohol and drugs prior to conception and during pregnancy has been proved to affect early organ development and, consequently, it is known that it may also increase the risk of abortion, congenital anomalies, IUGR, LBW, preterm birth and other health problems, with long term and even lifelong consequences, such as obesity.<sup>9</sup> In the past two decades, the proportion of women smoking during pregnancy has decreased in all countries, yet smoking continues to account for a substantial proportion of perinatal problems.<sup>10</sup> Among countries with data, Denmark, Estonia, Finland, Germany, Latvia, Netherlands, Spain, Slovenia, the United Kingdom and Norway have shown rates of over 10% of smoking in pregnancy. France is the only country reporting a rate over 20%.<sup>1</sup> Many women give up alcohol when pregnant, yet some continue to drink, ranging from 25% in Spain to 35%-50% in the Netherlands and the United Kingdom.<sup>11</sup> Heavy drinking is confined to a smaller but significant proportion of women. Women with low social class and poor levels of education are more likely to continue to drink in pregnancy.

Nutrition starts in the mother's womb. IUGR is the earliest indicator of foetal undernutrition, which may be caused by mother's undernutrition as well as by a variety of pregnancy complications, chronic diseases and foetal anomalies. IUGR and prematurity reflect in LBW, which is strongly associated with infant morbidity and mortality. Risk factors for LBW and preterm birth include short or long birth intervals, teenage pregnancy, previous history of LBW, smoking, consumption of alcohol and drugs, poor nutrition before and during pregnancy, stress, violence, abuse and trauma, low parental SES, and in-vitro fertilisation.<sup>12</sup>

The increasing use of assisted reproductive techniques for the management of infertility, of which in-vitro fertilisation is only one, has an important bearing on perinatal health, in addition to its association with LBW. Infants conceived with these techniques have also a higher risk of preterm delivery, congenital anomalies and perinatal death, as well as multiple pregnancy. Births after in vitro fertilisation account for about 2% of all births in Europe; those including other forms of assisted reproductive technique show a higher percentage, up to a maximum of about 5% in France.<sup>1</sup>

Compared with singletons, infants born from multiple pregnancies show a higher risk of stillbirth, neonatal and infant death, associated with the higher probability of LBW and preterm birth. Multiple birth rates vary from under 12 per 1,000 women with live or stillbirths in Latvia, Lithuania and Poland, to more than 20 per 1,000 in Cyprus, Denmark and the Netherlands.<sup>1</sup> Risk factors for an increased rate of multiple births include advanced maternal age and the use of in vitro fertilisation methods.

Young (under 20 years old) and advanced (35 years old and over) maternal age are associated with increasing rates of preterm birth and IUGR, and therefore with higher perinatal mortality and other early and late complications. Young and old pregnant women are also more likely to have multiple births and to deliver by caesarean section. The risk factors for young and advanced maternal age include low SES and education, and poor access to contraceptive and antenatal care services. The percentage of pregnancies in adolescence has already been discussed in Chapter 2. The percentage of older mothers ranges from 7.5% in the Slovak Republic to 24.3% in Ireland; percentages over 20% are also found in Germany, Italy and the Netherlands.<sup>1</sup>

Parental education, and particularly education for women of childbearing age, is widely recognised as a key determinant for child health and well-being, and has already been discussed in Chapter 2. It acts through improved family planning and consequently through birth spacing and less teenage pregnancies, but also through improved care during pregnancy and better pregnancy outcome, improved care seeking and better use of services.<sup>13</sup> Migrant women are known to have poorer pregnancy outcomes due to lower education and SES, and consequent poor access to good quality preventive and curative care, associated with language barriers as well. Even within migrant women there are

disparities related partly to their country of origin, and partly to their particular situation, including occupation, in the host country. Migrant women, or women born in a different country to their country of residence, account for 7%-31% of all births in countries reporting these data, with the highest values in Austria (26%), Cyprus (31%) and England and Wales (21%).<sup>1</sup>

## Challenges

As stated in this chapter and in the reports of the PERISTAT project, there is still a lack of standard definitions and methods as far as data and indicators for perinatal health are concerned, especially regarding foetal deaths and the ascertainment of gestational age. This remains a challenge for information systems.

The most important challenges, however, as far as foetal and early neonatal health are concerned, relate to the improvement of woman and maternal health and health care before conception and during pregnancy and delivery. This is done primarily through the protection of women and mothers in the labour force, as already discussed in Chapter 2, and through health systems, which have a unique, although not exclusive, role in preventing exposure to toxic, infectious and nutritional threats, and ensuring effective and equitable care.

In most countries, more than 90% of pregnant women use antenatal care services. The coverage is lower in some Eastern European countries (Estonia 86%, Lithuania 74%, Slovak Republic 80%) and surprisingly in England (66%) and Scotland (78%).<sup>1</sup> Very little is known about the quality of antenatal care. Because maternal smoking is the most important preventable factor associated with adverse pregnancy outcomes,<sup>14</sup> and smoking cessation is considered one of the most effective interventions for improving maternal and child health, the proportion of women that quit smoking during pregnancy may be used as an indicator of the quality of antenatal preventive healthcare services.<sup>15</sup> Other interventions shown to be effective in reducing the risk of LBW and preterm birth that could be included as quality indicators of perinatal health care services are:

- Measures to reduce teenage pregnancy;
- Counselling and support to achieve a balanced diet, that includes iron and other micronutrients;
- Avoidance of excess weight gain, depending on pre-pregnancy BMI, through adequate intake of calories and physical activities;
- Measures to reduce the use of alcohol and drugs;
- Treatment of maternal conditions such as infections and diabetes;
- Reduction of multiple births after assisted reproductive techniques.<sup>12</sup>

Childbirth care is available virtually to all women in Europe, though quality may vary among and within countries. Most of this care is provided in hospitals, the Netherlands being the only country where a substantial proportion of births and hence childcare take place in the home (around 30%) or in community birth centres (around 10%), usually assisted by a midwife. These figures are decreasing, especially in the past two years, after the highly-debated publication of studies questioning the safety of home births.<sup>16</sup> Hospitals delivering less than 500 infants per year are believed to provide low quality care. In some countries the rate of deliveries in these hospitals is lower than 3% (e.g. Denmark, Ireland, Portugal, Sweden), while in others it is higher than 15% (Estonia, Germany, Latvia, Lithuania) with a highest of 68% in Cyprus among countries providing data.<sup>1</sup> The challenge is to ensure high quality care through a network of hospitals and birthing places in which timely referral ensures that all mothers and newborns are optimally managed at the adequate level of care.

The care offered to preterm and LBW infants is particularly important. Babies born before 32 weeks of gestational age account for only 1-2% of all births, but access to good intensive care for them is associated with increased survival and reduced rates of long-term problems and complications. Transport in the womb and birth in a maternity with a large neonatal intensive care unit (NICU) is the prerequisite for good care. The percentage of very preterm

infants who are born at the highest level of care varies from 33% in Latvia to 94% in Denmark.<sup>1</sup> However, the definition of a level 3 NICU varies among countries and it is difficult to interpret this indicator. The challenge here is to standardise and clearly designate the highest level of care where there might be a concentration of the majority of births of very preterm infants. It is also important to fully involve parents in decision-making and general care,<sup>17</sup> to individualise developmental care for these infants,<sup>18</sup> to prevent and control infections and treat complications, and to maintain adequate nutrition and stable temperature. All this can be facilitated by the implementation of Kangaroo Mother Care.<sup>19</sup>

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## 4. Congenital Malformations

### Key Messages

- Congenital malformations account for an important proportion of child deaths and long-term disabilities. Prevalence at birth is estimated at around 2% of all live births; the estimate rises up to 3% when elective terminations of pregnancy, carried out when malformations are identified prenatally, are included.
- The most common malformations of public health importance are: congenital heart defects, hypospadias, Down syndrome, cleft lip with or without cleft palate, anencephaly and spina bifida, hydrocephalus, limb deficiencies, oesophageal atresia/stenosis, anorectal atresia/stenosis, diaphragmatic hernia, omphalocele and gastroschisis.
- Causes and risk factors include genetic anomalies, unhealthy lifestyles and nutrition, some chronic maternal diseases, prenatal exposures to drugs causing malformations and environmental pollutants. Maternal age is also a factor.
- Temporal trends vary in relation to changes in exposure to risk factors and active preventive policies. Increasing trends are reported for gastroschisis and Down syndrome, decreasing trends for anencephaly and spina bifida.
- Preventive interventions include the effective control of known causes and risk factors, preconception counselling, and early recognition followed by effective treatment.

Congenital malformations are structural defects present in a baby since birth. They are part of the larger group of birth defects that includes also those without a clear structural anomaly, e.g. deafness, intellectual disability, metabolic and haematological disorders. In a malformation, the development of a structure is arrested, delayed, or misdirected early in embryonic life, and the effect is permanent. The impact of congenital malformations on health is extensive. It varies from lethal conditions, to more or less severe conditions requiring medical or surgical interventions, to mild cosmetic anomalies. A full list of congenital malformation can be found in chapter Q of the ICD-10 (see glossary). This report deals only with major congenital malformations of public health importance, those with a significant impact on mortality, morbidity or disability. Note that some congenital malformations are rare diseases, since many have an incidence of less than 5 per 10,000 people.

### Main Sources of Information

The best sources of information in Europe are the 41 ongoing Birth Defects Surveillance Programmes, operating in 21 countries, some of them since the early 1970s. National data are available only for eight countries: Czech Republic, Finland, Hungary, Malta, Norway, Slovak Republic, Sweden and the United Kingdom. In 13 countries (Austria, Belgium, Denmark, France, Germany, Ireland, Italy, Netherlands, Poland, Portugal, Spain, Croatia, Switzerland) only a partial coverage of the population exists, ranging from 3% in Germany to 69% in Poland. No systematic registration exists in the remaining countries.<sup>1,2</sup> In Turkey, and probably in other countries, data are available from specific surveys. Despite many efforts to standardise registration procedures (e.g. inclusion/exclusion criteria, diagnosis, reporting, coding), the level of accuracy is variable and comparisons are not easy.<sup>3</sup> For a realistic picture, recorded data should be analysed critically to obtain reasonable estimates, taking into account the global epidemiological literature.

## Size of the Problem

### *Prevalence*

For many years, the rate of congenital malformations has been expressed as birth prevalence. This is a function of incidence, i.e. the rate of products of conception affected by a malformation, and survival, i.e. the proportion of affected products of conception that survive to birth (stillbirth or live birth).<sup>4</sup> The diagnosis was made at birth, after birth, or during the first years of life. With the spreading of prenatal diagnosis and of elective termination of pregnancy of severely malformed fetuses, a different measure was needed. This is the so-called total prevalence, which includes also fetuses electively terminated during pregnancy for the presence of a congenital malformation. Where this is not permitted, birth prevalence remains the only meaningful measure; where it is permitted, the old birth prevalence cannot be compared with the new total prevalence. This applies in particular to some congenital malformations such as Down syndrome and other chromosomal anomalies. Also, birth prevalence in a country where elective termination of pregnancy is permitted cannot be compared with total prevalence in a country where it is not, especially for congenital malformations in which spontaneous foetal loss is frequent. Finally, total and birth prevalence should always include cases diagnosed after birth and within the first years of life (usually up to 1-7 years).

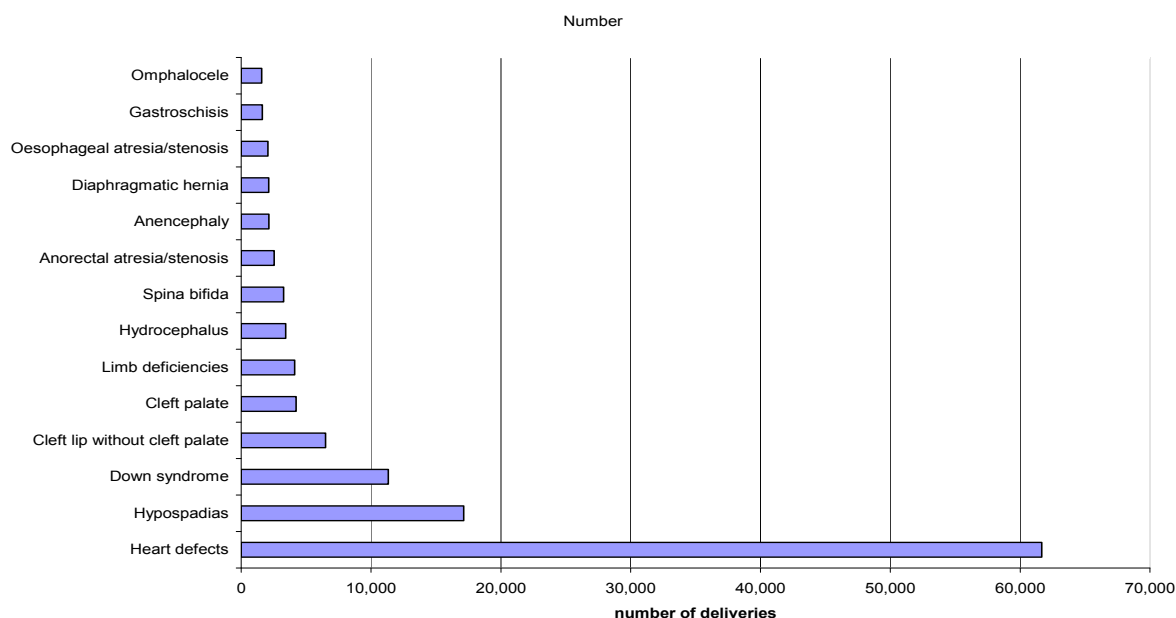
The most reasonable estimate for the number of cases with a congenital malformation delivered in the European countries included in this report is in the order of 200,000 per year. In the EU27 countries it is approximately 160,000 per year (Table 4.1). This estimate assumes a total prevalence of 3%, as suggested by a critical analysis of the recorded total prevalence in the 41 Birth Defects Surveillance Programmes in 21 countries, and based on the widely accepted hypothesis that the overall frequency is similar in every country worldwide, small variations being limited to selected malformations. The total number of births in 2008 (2007 for Belgium and Italy), as reported by EUROSTAT, has been used for these calculations.

**Table 4.1. Estimated number of deliveries with a congenital malformation in 2008**

Country	Estimated Number	Country	Estimated Number
AT	2,333	PL	12,435
BE	3,723	PT	3,138
BG	2,331	RO	6,657
CY	276	SK	1,721
CZ	3,587	SI	655
DK	1,951	ES	15,572
EE	481	SE	3,279
FI	1,786	UK	23,831
FR	23,881	HR	1,313
DE	20,475	MKD	688
EL	3,549	TR	37,870
HU	2,974	IS	145
IE	2,252	LI	11
IT	16,918	NO	1,815
LV	718	CH	2,301
LT	1,052	EU27	161,406
LU	168	EFTA countries	4,271
MT	124	Candidate countries	39,871
NL	5,539	Total	205,548

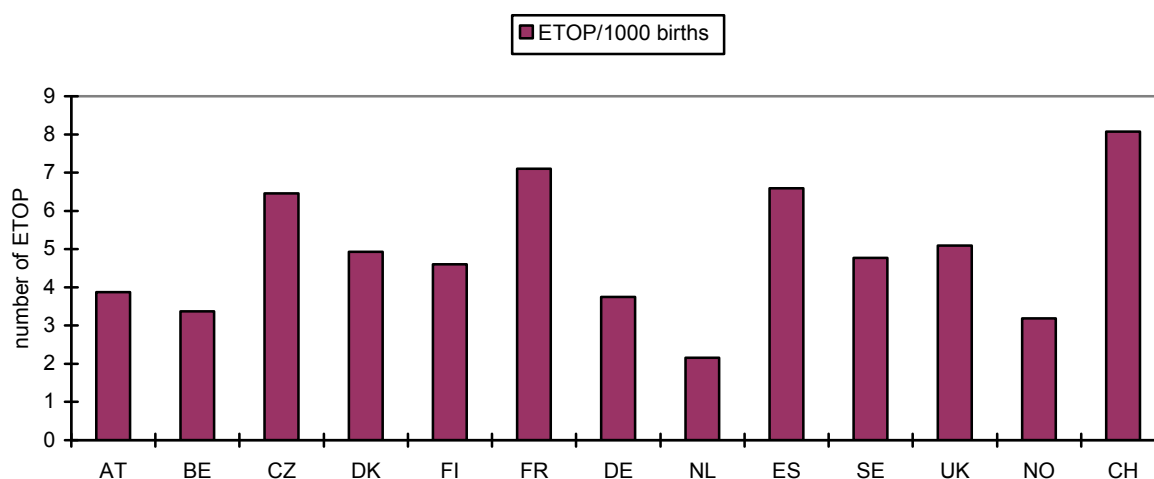
Overall, the cases with one or more of the following 14 malformations amount to approximately 50% of all malformations: congenital heart defects, hypospadias, Down syndrome, cleft lip with or without cleft palate, anencephaly and spina bifida, hydrocephalus, limb deficiencies, oesophageal atresia/stenosis, anorectal atresia/stenosis, diaphragmatic hernia, omphalocele and gastroschisis. An estimate of the annual number of deliveries associated with these 14 malformations is shown in Figure 4.1.

**Figure 4.1. Estimated annual number of deliveries associated with 14 selected malformations in the countries of this report.**



Due to the increased number of prenatal diagnoses of malformation, elective termination of pregnancy after a diagnosis of severe congenital malformation is increasing in countries where termination is legally allowed, namely, all countries except for Ireland and Malta. Figure 4.2 shows the ratio of elective termination of pregnancy to 1,000 births for any type of congenital malformation between 2003 and 2007, and the estimated number of elective terminations of pregnancy per year in selected countries with reliable, standardised records.<sup>1</sup> The estimated number of elective terminations was calculated multiplying the total number of births (most recent year available, EUROSTAT data) by the country-specific elective termination of pregnancy to births ratio. Some of these ratios may be lower than in reality.

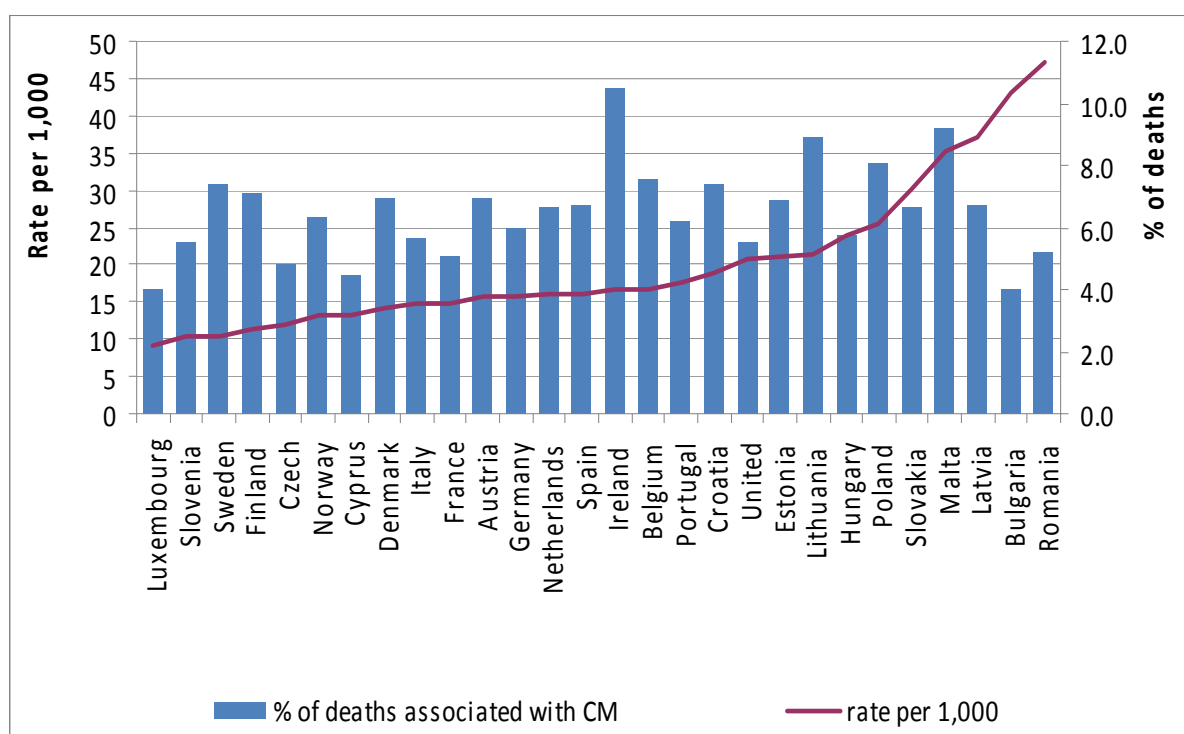
**Figure 4.2. Elective termination of pregnancy (ETOP) to 1,000 births ratio for all congenital malformations and estimated number of ETOP per year between 2003 and 2007 in selected countries (Source: EUROCAT).**



## Mortality

Data on infant mortality associated with congenital malformations are available for 28 countries (EU27 plus Norway). However, in a variable proportion of infant deaths the presence of a congenital malformation is not always registered, especially as far as internal malformations, such as heart defects, are concerned. Overall, the median rate of total infant mortality in these 28 countries lies around 3.93 per 1,000 live births and the median proportion of deaths associated with malformations is 27.8%. Figure 4.3 shows the values by country.<sup>5</sup> Heart defects are the most common malformations associated with death, followed by chromosomal and central nervous system anomalies. Heart defects contribute to approximately 35-45% of all deaths associated with congenital malformations, with wide variation across countries. It is lower in more, rather than in less developed countries.

**Figure 4.3. Infant mortality rate per 1,000 live births (red line and left values) and proportion of infant deaths due to congenital malformations (blue bars and right values).**

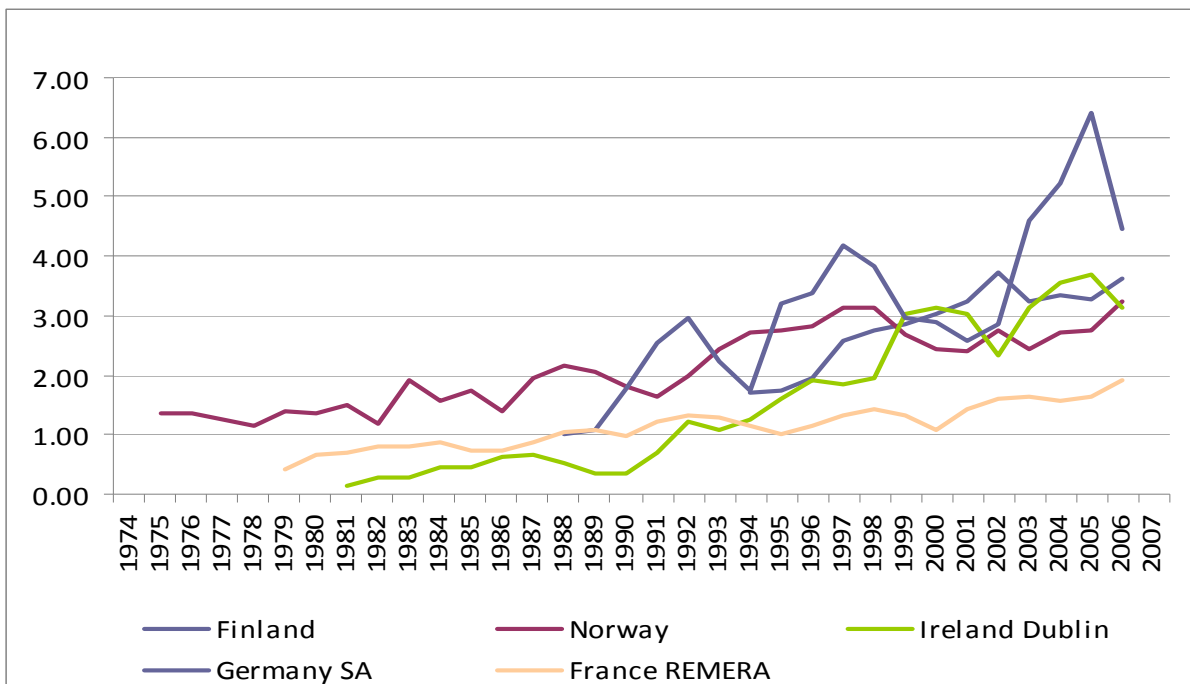


There is only one recent study from Europe dealing with long-term mortality of children born with a congenital malformation.<sup>6</sup> The study was conducted in Northern England and reports the estimated mortality up to 15 years of age for the following conditions: diaphragmatic hernia (42.9%), spina bifida (31.3%), hydrocephaly (30.2%), Down syndrome (16.6%), omphalocele (12.8%), heart defects (9.7%), oesophageal atresia (6.7%), gastroschisis (6.3%), cleft palate (3.7%), limb deficiencies (2.6%), cleft lip and palate (2.3%) and cleft lip (0.7%). The study, however, is based on a cohort of children born between the years 1985 and 2003, and may show that mortality rates are higher than those of cohorts of children born in more recent years. For example, in the Northern England study, the survival of one-year-old infants with Down syndrome was 88.4% (85.7%-90.6%). Infants with Down syndrome born between 1994 and 2004 in the Czech Republic,<sup>7</sup> Sweden,<sup>8</sup> Netherlands,<sup>9</sup> and the United Kingdom Northern Health Region,<sup>10</sup> are reported to have a survival at one year of age of around 95% (94.0%-97.7%).

## Trends

It is difficult to provide reliable time trends because better diagnostic accuracy implies more cases identified and spurious increases in prevalence, e.g. for congenital heart and renal defects. The introduction of prenatal diagnosis and elective termination of pregnancy does not allow valid comparisons since ascertainment is not performed with the same accuracy across countries in subsequent years. Most congenital malformations, those not influenced by better diagnosis and elective termination of pregnancy in recent years, show a stable frequency in the last 10 to 30 years. A real and unexplained increasing trend has been recorded for gastroschisis in some countries (Figure 4.4); similar trends have been observed also outside Europe.<sup>11</sup> Italy and Spain seem to be an exception, an increasing trend is either minimal or absent.<sup>2,11</sup>

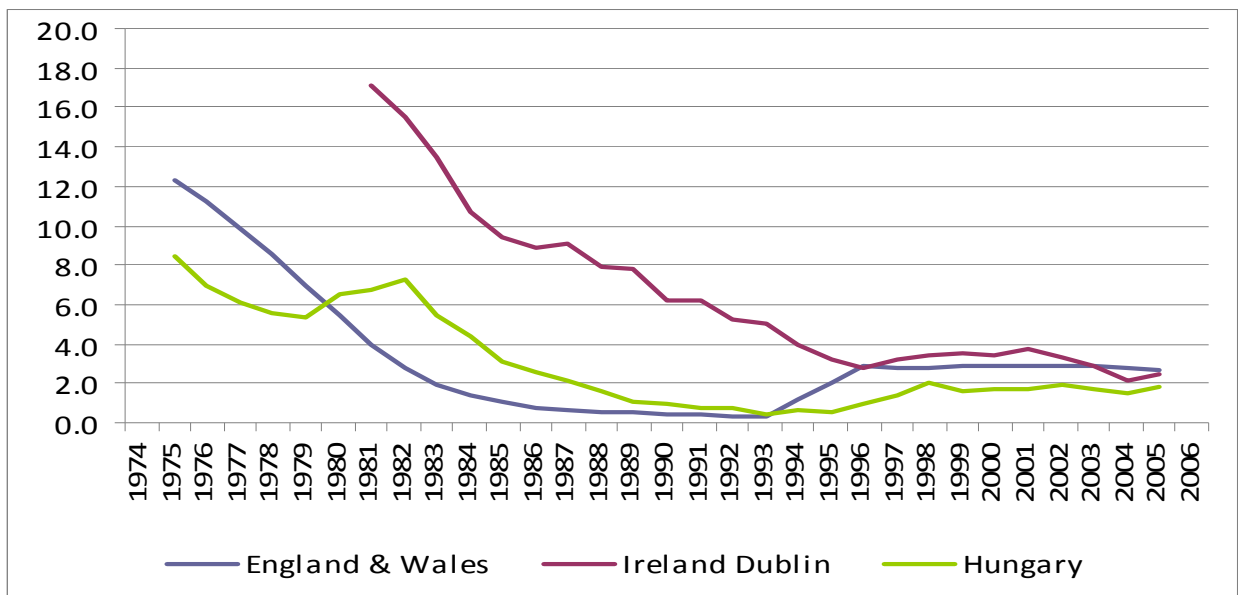
**Figure 4.4. Time trend (3-year moving average) of gastroschisis per 1,000 births in five selected countries with Birth Defects Surveillance Programmes.**



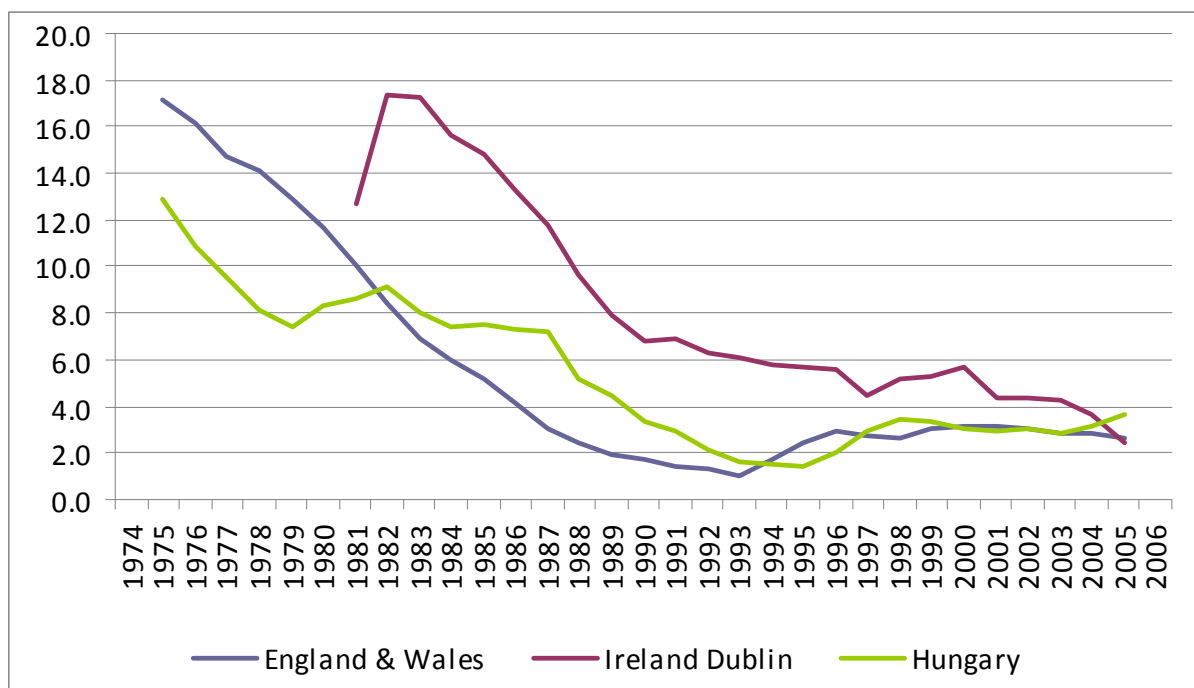
It is hard to evaluate the expected decreasing time trend of neural tube defects (anencephaly, spina bifida) associated with a better folate intake through improved nutrition, fortified foods and folic acid supplements. Some studies have shown that the recommendation to increase the use of folic acid supplements in the 1990s has not produced a significant decrease of anencephaly and spina bifida in Europe.<sup>12,13</sup> However, a decreasing trend is seen in countries with a high prevalence in the 1970s and 1980s (Figures 4.5 and 4.6). Regarding anencephaly, the decrease followed by an increase observed in the late 1980s in Hungary and England and Wales may be due to the elective termination of pregnancy effect.



**Figure 4.5. Time trend (3-year moving average) of anencephaly per 1,000 births in three countries with Birth Defects Surveillance Programmes.**

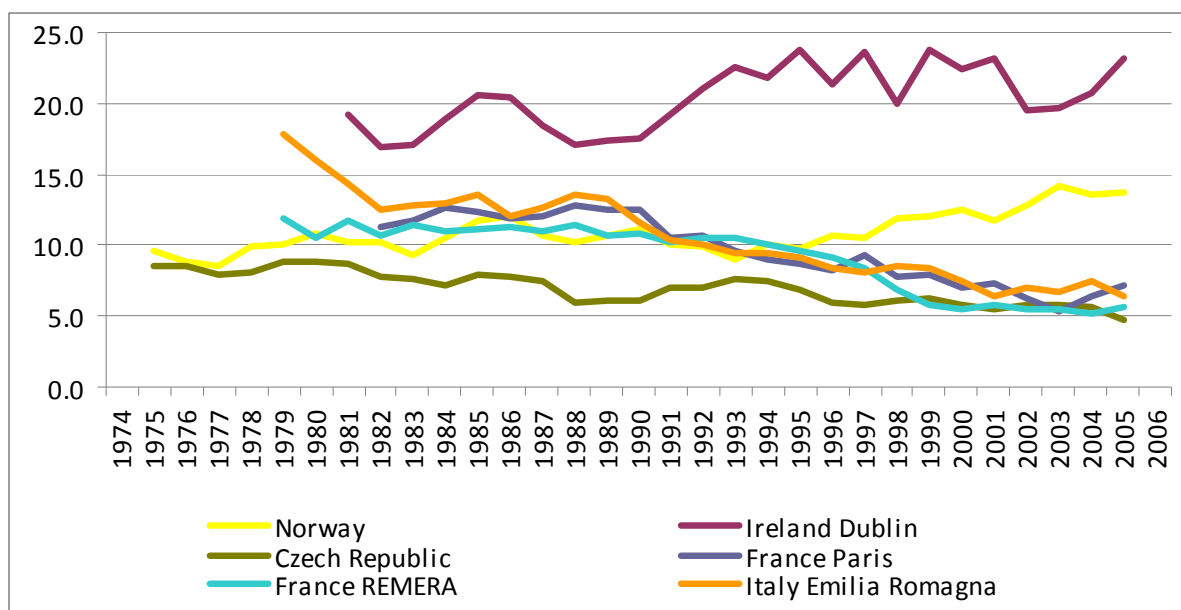


**Figure 4.6. Time trend (3-year moving average) of spina bifida per 1,000 births in three countries with Birth Defects Surveillance Programmes.**



A real increasing trend of the total prevalence of Down syndrome has been recorded in many countries and is associated with the increased proportion of deliveries after 30-35 years of age.<sup>14,15</sup> However, this has been counterbalanced by elective termination of pregnancy after prenatal diagnosis. The final result on birth prevalence is shown in Figure 4.7. In Dublin, Ireland, the prevalence is higher than in the other four sites, and the time trend is increasing, because elective termination of pregnancy is not allowed, while maternal age is increasing. In Norway, the prevalence is higher than in the other four countries because prenatal diagnosis and/or elective termination of pregnancy are performed less often.

**Figure 4.7. Time trend (3-year moving average) of Down syndrome prevalence per 1,000 births among live births in five selected countries with Birth Defects Surveillance Programmes.**



### Causes and Risk Factors

A number of causes and risk factors associated with congenital malformations has been established or estimated. Some of them are not modifiable (e.g. genetic anomalies in parents), others cannot be easily modified by public health and health care interventions (e.g. maternal age at delivery or consanguinity); complex intersectoral interventions are needed. Table 4.2 lists some of the established causes and risk factors that are modifiable with public health and health care interventions: rare and unconfirmed causes and risk factors are not listed. As many congenital malformations have several causes, the final result of preventive intervention is often a reduction of their prevalence, not their elimination. This is an important point for the distribution of correct information to the public and to patients.

**Table 4.2. Well-established, not uncommon and modifiable causes and risk factors for congenital malformations**

Infections	cytomegalovirus, rubella, syphilis, toxoplasmosis, varicella
Medications	ACE-inhibitors, androgenic hormones, anti-epileptics, high doses of vitamin A, lithium, medications to treat cancer, paroxetine, retinoic acid, thalidomide
Maternal diseases at conception or in early pregnancy	diabetes, high fever, phenylketonuria
Life style habits	cocaine use, folate inadequacy for reproduction, obesity and overweight, poor nutrition, smoking

Many congenital malformations are due to similar causes and risk factors acting before conception and influencing the prevalence of other adverse reproductive outcomes as, for example, preterm and small-for-gestational-age births, and developmental disabilities. This means that the control of a risk factor may bring about multiple positive outcomes. The classical example is smoking, a risk factor for many adverse reproductive outcomes.

## Challenges

Prevention of congenital malformation is based on:<sup>16</sup>

- Pre-conception genetic counselling, to avoid pregnancies in couples with a high risk of a genetically determined malformation.<sup>17</sup>
- Interventions to reduce the number of new cases through effective control of known causes and risk factors (primary prevention). This would include a reduction of the number of elective terminations of pregnancy.
- Early recognition of a disease in its pre-symptomatic period, followed by effective treatment, to avoid clinical manifestation of the disease (secondary prevention).

The following actions will help reduce the risk of some specific malformations and/or other birth defects, or adverse reproductive outcomes:

1. A healthy life style (e.g. good nutrition and physical activity, restriction of alcohol and smoking, safe sex) to prevent neural tube defects (anencephaly, spina bifida), cleft lip and/or palate, and possibly other malformations. A healthy life style will also help prevent preterm and small-for-gestational-age births and developmental disabilities.<sup>18,19</sup>
2. Frequent checks for chronic diseases, and in particular maternal diabetes, followed by adequate treatment, to prevent heart defects and other malformations. Women treated with antiepileptics should reassess the need for treatment at least every two years and use the most appropriate therapeutic regimen when they become pregnant.<sup>20</sup>
3. Plan pregnancies and immunise against rubella and varicella as early as possible when entering the fertile age in order to prevent congenital rubella and varicella syndromes.<sup>21</sup>
4. During pregnancy, avoid those medications established as teratogens (e.g. thalidomide, retinoic acid, valproic acid).<sup>22</sup> They can cause many adverse reproductive outcomes, such as miscarriages, preterm births and developmental disabilities.
5. Intake correct amounts of folic acid. With adequate nutrition, a daily dose of 0.4 mg of folic acid, at any age when fertile and especially when a pregnancy is not correctly or efficiently avoided, will reduce the risk of neural tube defects (anencephaly and spina bifida) by 50%. It may also prevent other malformations (e.g. heart defects). Higher doses (4-5 mg/day) are recommended for women at higher risk of having a child with congenital malformations.<sup>23,24</sup>
6. Check immune status against toxoplasmosis and cytomegalovirus at any age when fertile, and especially when a pregnancy is not efficiently avoided, followed by careful avoidance, if needed, of dangerous contacts with food or people carrying these infections, so as to help prevent hydrocephalus, deafness and ocular anomalies.
7. Immunise against influenza when pregnancy is planned so as to prevent high fever during the first weeks of pregnancy and therefore reduce the risk of having a child affected by anencephaly, spina bifida and other malformations.
8. Avoid contact with pesticides and organic solvents when a pregnancy is planned, in order to prevent limb deficiencies, oral clefts and defects of the central nervous system.<sup>25</sup>

The most urgent challenge for governments and health systems is to promote these actions and clinical interventions within maternal and child health services in all countries and in all population groups, using an equity approach. The first prenatal visit, which takes place usually between the 7<sup>th</sup> and 10<sup>th</sup> week of gestation, is too late to implement many of the above interventions. As the development of the child starts with conception, these actions are particularly important before pregnancy. Pre-conceptual and inter-conceptual care should therefore be strongly encouraged.<sup>26</sup>

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## 5. Neurological and Developmental Disorders

### Key Messages

- Neurological and developmental disorders are a very heterogeneous group of conditions including common problems, such as headache and learning disabilities, and serious disabilities, such as cerebral palsy. All together, a large proportion of children suffer from one or more of these conditions.
- The overall prevalence of some of these conditions may be increasing due to higher chances of survival of very LBW infants and of children suffering from rare diseases affecting also the nervous system.
- The WHO International Classification of Functioning, Disability and Health (ICF) represents a milestone in modern thinking about assessment and treatment for children with disability, but its implementation is still not homogeneous.
- There are important differences and difficulties in adopting uniform international classifications and definitions and this hinders adequate recognition and care.
- Although there are countries that have developed some of the most advanced models of care for children with complex disabilities, there are still striking differences across countries and important gaps in the capacity to provide optimal, comprehensive and multidisciplinary care to children affected by neurological and developmental disorders.

Neurological and developmental disorders are a very heterogeneous group of conditions including common problems, such as headaches and learning disabilities, as well as serious disabilities, such as cerebral palsy. This chapter deals only with conditions of public health importance in terms of prevalence and/or severity. They are listed and defined in Table 5.1.

**Table 5.1. Definitions of some neurological and developmental disorders**

CONDITION	DEFINITION
Cerebral palsy	A group of permanent disorders of the development of movement and posture (often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, and by secondary musculoskeletal problems), causing activity limitations.
Mental retardation	Disability characterised by significant limitations in intellectual functioning and adaptive behaviour, as expressed in conceptual, social, and practical adaptive skills, evident before the age of 18 years.
Movement disorders: hyperkinetic (common) and hypokinetic (uncommon) movements	Hyperkinetic movement disorders (sometimes referred to as dyskinesias) are abnormal, repetitive, involuntary movements including tics, chorea, dystonia and stereotypies.
Epilepsy	Heterogeneous group of neurological conditions and syndromes characterised by recurrent and unprovoked seizures. Infantile spasms, Lennox-Gastaut syndrome and absence seizures are unique to children.
Learning disabilities (learning disorders, learning difficulties)	These include reading, writing and math disorders, and non-verbal learning disabilities. The most common types are dyslexia, dyscalculia (or math disability) dysgraphia (a deficiency in the ability to write), dyspaxia, auditory processing disorder and visual processing disorder.
Headaches (among the most common disorders of the nervous system)	The most common primary headache disorders are migraine, tension-type headache, cluster headache, and the so-called chronic daily headache syndrome. Headache can also occur as a symptom of a large number of other conditions.

The differentiation between neurological and developmental conditions and mental health disorders (see Chapter 6) is somewhat arbitrary, being based on the fact that the former have a clearer biological basis than the latter, which on the contrary have a strong environmental and social component. However, this distinction, which is still adopted by international classifications, is not totally in agreement with the most recent advances in neurobiology and neuroscience, which show that most mental health disorders have some recognizable neurobiological basis. Furthermore, comorbidity between the two groups of conditions is common.

### **Main Sources of Information**

For cerebral palsy the main source of information is the Surveillance of Cerebral Palsy in the Europe database, which includes 24 registers in 13 countries. For learning disabilities the main source are OECD documents. Headaches are dealt with by the Eurolight project (<http://www.eurolight-online.eu/>). Biomedical and social science databases have been searched to look for data on movement disorders, mental retardation and epilepsy.

As far as completeness and quality of data are concerned, there are several difficulties:

1. For certain conditions, no common definition is available, and there are differences in classification and assessment, particularly for learning disabilities.
2. Country data are often drawn from studies carried out on non-representative samples of the population.
3. Some types of disorders might be difficult to diagnose, such as learning disabilities and movements disorders, and as a result prevalence is higher in countries where diagnostic capacity is more advanced.

### **Size of the Problem**

**Cerebral palsy** is the most common disability of children in Western Europe, with a prevalence of about 2 cases per 1,000 live births.<sup>1</sup> The incidence is higher in boys than in girls. The Surveillance of Cerebral Palsy in Europe project reports a M:F ratio of 1.33:1.<sup>2</sup> In 2006, a Dutch study based on review of studies from 1965 to 2004 reported that in the last 40 years the prevalence of cerebral palsy had risen to well above 2 per 1,000 live births.<sup>3</sup> Another extensive review showed that the prevalence of cerebral palsy in the past 40 years was stable, that a modest increase in prevalence probably occurred in the last decades of the 20<sup>th</sup> century due to the increased survival rate of very LBW infants, and that this recent increase may have levelled itself off.<sup>4</sup>

For **mental retardation** the data present several uncertainties. The prevalence in children between 0 and 14 years old is generally estimated at 1%, although in groups defined only by their Intelligence Quotient it ranges from 2% to 3%. Mental retardation is more common in boys than in girls with a 1.4:1 ratio.<sup>5</sup> Individual countries report rates from 0.3% to 2.5% in school-aged children depending on the criteria used to determine eligibility for special educational services, the labels assigned (i.e. developmental delay, learning disability, autism, and/or mental retardation), and the environmental and economic conditions within the country.<sup>6</sup>

**Movement disorders** include a wide variety of disorders. For Tourette syndrome differences in study methods yield a range in prevalence estimates between 1 and 3 cases per 1,000 children.<sup>7</sup> In general, higher rates have been found in younger age groups, substantiating the idea that many cases are partially or completely resolved by adulthood. Tourette syndrome is more common in boys than in girls.<sup>8</sup> Chronic tic disorders are more common than Tourette syndrome, occurring in 2% to 5% of school-aged children.<sup>9</sup> Sydenham's chorea patients represented 5.6 per 1,000 hospitalised children in a retrospective French study regarding children seen between 1987 and 1997, with an average age of 10.5 years.<sup>10</sup>

The true prevalence of **dystonias** in children and the relative frequency of primary versus secondary forms are unknown.<sup>11</sup>

**Stereotypies**, such as self-harming behaviour and head-banging, are believed to occur 3 times more frequently in boys than in girls. Self-biting may be more prevalent in girls than in boys.<sup>12</sup>

Moderately or severely distressing **restless legs syndrome** symptoms are reported to occur two or more times per week in 0.5% of children. There are no significant gender differences.<sup>13</sup>

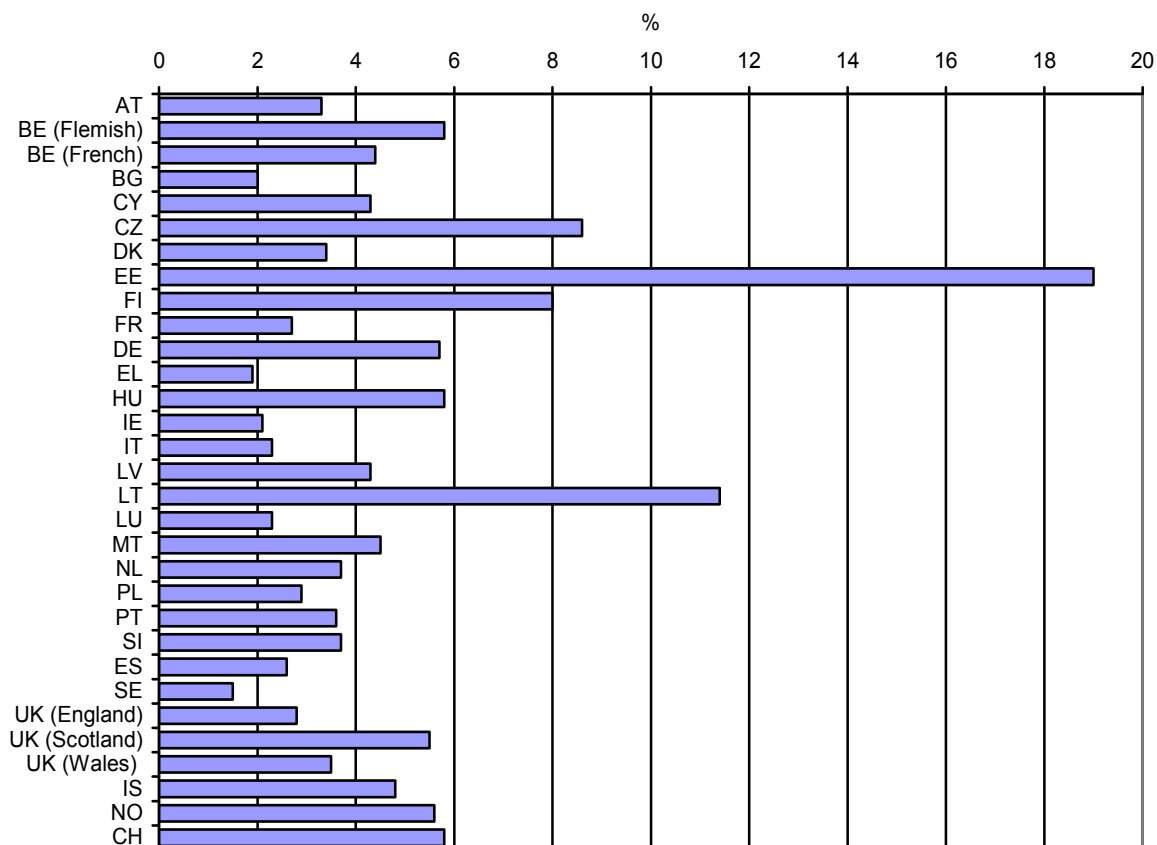
The prevalence of **developmental coordination disorders** is around 5% of the school population, with a ratio of boys to girls of 3:1.<sup>14</sup>

**Epilepsy**: the estimated number of children and adolescents in Europe with active epilepsy is that of 0.9 million (prevalence 4.5–5.0 per 1,000) based on the prevalence of epilepsy in different studies and when accounting for incomplete case identification. The estimated number of new cases per year among European children and adolescents is 130,000 (incidence rate 70 per 100,000). The proportion of new and established cases with epilepsy in individual countries may differ substantially from the total European distribution.<sup>15</sup>

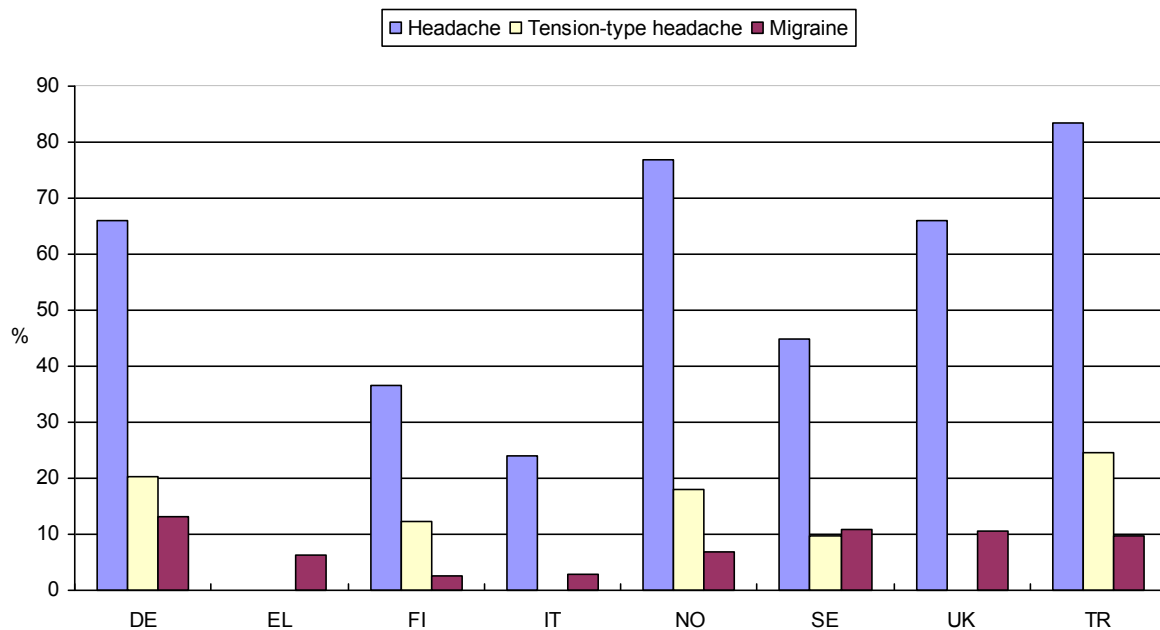
**Learning disabilities**: it is estimated that 5% to 10% of school-aged children struggle with reading, writing, or mathematics. The majority of these children have difficulties with language skills, reading, and spelling, dyslexia being the most common of all learning disabilities (80%). According to different studies, the prevalence of dyslexia ranges between 5% and 17.5% and is strongly dependent on the characteristics of the mother tongue, being more frequent in Anglo-Saxon languages than in Romance ones. A smaller number of children with this condition struggle with problem solving, arrhythmic and visual-spatial problems, and with motor and tactile-perceptual problems. The prevalence of dyscalculia is estimated at around 5%.<sup>16</sup> Figure 5.1 shows the estimated percentage of children who need special education by country. The wide differences across countries may be due to differences in criteria and definitions rather than in prevalence.

**Headaches** are common in childhood and the prevalence increases further during teenage years. Epidemiological studies have shown that 15-20% of school-aged children complain of headache and 3-5% of these of actual migraine headaches.<sup>17</sup> Studies have reported annual prevalence rates in children between 3% and 11% for migraine, and between 10% and 24% for tension-type headache. The prevalence of self-reported headache is higher.<sup>18</sup> Migraine is seen in 5% of children aged 7-10 years and in 17% of adolescents. There is an equal prevalence in girls and boys prior to puberty. After puberty, however, the prevalence is 2-3 times higher in girls.<sup>17</sup> The prevalence of headache, tension-type headache and migraine in school children of given countries is shown in Figure 5.2.<sup>19</sup> The data, however, are not accurate enough to provide a cross-country comparison; classification, data collection and age grouping are somewhat heterogeneous. The need for standardised and uniformed practices of data collection in this area is fundamental for a reliable and complete analysis of differences and trends.

**Figure 5.1. Percentage of children who need special education over all compulsory school aged children; data provided by countries. Source: European agency for development in special needs education. Academic year of reference 2006/7 or 2007/8.**



**Figure 5.2. Prevalence of headache, tension-type headache and migraine in school children in some countries in different years and age groups\* (Source: Stovner, 2010).**



\* FI: headache/migraine (1994, 8-9 y), tension-type headache (2002, 12 y); DE: headache (2004, 10-18 y), tension-type headache (2007, 12-15 y), migraine (2009, 9-14 y); EL: (1999, 4-15 y); IT: (1995, 11-14 y); SE: (2004, 7-15 y); UK: (1994, 5-15 y); NO: (2004, 13-19 y); TR: headache/migraine (2007, 9-17 y), tension-type headache (2005, 8-16 y).



**Cerebral palsy** affects gross motor function to a varying extent. A child's resulting overall development, specifically in mobility and different aspects of development and learning, is compromised by relative deprivation of experience. Children with cerebral palsy are considerably more likely to have functional difficulties unrelated to movement but related to their central nervous system. These include sensory, epileptic, learning, behavioural, and related developmental impairments.<sup>20</sup> These impairments may begin early in life as difficulties in feeding, irritability, and disordered sleep. These problems, when present, affect day-to-day life and can cause considerable distress to children, parents, and carers. These problems are not inevitable or intractable, but it is essential to identify them and interfere before they become entrenched.

Insofar as behavioural and psychiatric problems such as autism, hyperactivity, and self-injurious behaviours are concerned, children with **mental retardation** are at higher risk than those who are part of the general population

All **movement disorders** have the potential to produce social stigma and distress depending on the environment in which they occur. Although the range of physical consequences varies greatly, serious medical complications are rare. For example, some stereotypies may not directly cause observable physical damage to a child. Instead, they may result in impairment in social functioning. The resulting stigma can bring about considerable distress, humiliation, social rejection, academic problems, feelings of shame and guilt, discomfort in social activities, and depression or anxiety.<sup>12</sup>

In most cases, **epilepsy** can be treated effectively. It is important to follow the process of patient identification, diagnostic evaluation, choice of treatment, treatment and re-evaluation as needed. The most common treatment is medication. Nevertheless, the impact of epilepsy on a child, his family and, indirectly, on the community can be significant. Raising awareness in the family and in the community is important, as epilepsy is often still associated with stigma. When seizures are controlled, a social burden of epilepsy could still exist due to:

- Physical hazards due to the unpredictability of the seizures.
- Social exclusion because of the negative attitudes of others towards children with this condition.
- Stigma, as children with epilepsy may be banned from school and are more likely to become victims of bullying.<sup>21, 22</sup>

Many children with epilepsy do not have special educational needs, and may never experience seizures at school. About two thirds of them may underachieve academically, and a minority will experience seizures during school time. The educational needs of young people with epilepsy can be met by working together with education professionals, so that they can feel safe at school.

The failure to succeed academically in children who have **learning disabilities** depends more on the quality of age-appropriate teaching and learning experiences, than on the cognitive deficits or socio-cultural factors. Dyslexia shows high comorbidity with other developmental problems, including impairments in language, motor skills, and behavioural control.<sup>23</sup> Reading disability is also a contributor to juvenile delinquency and leads to higher rates of recidivism.<sup>24</sup> The presence of dyscalculia should prompt physicians to look for medical and psychiatric syndromes, given that mathematic disorders are present at higher than average rates in conditions such as epilepsy and Fragile X syndrome.<sup>25</sup> At the early stages of schooling, academic or learning difficulties can show through low marks, delay in completing assignments, attention deficits, delay in learning new skills, and difficulties in general understanding of tasks given or reading.<sup>16</sup> Children with this condition may also be shy and withdrawn, and may have behavioural problems at school. Differential diagnosis should include ADHD, sensory impairments, developmental coordination disorder, and mental retardation or borderline intellectual disability. It is important to recognise that learning disabilities are not cured, and various deficits persist throughout life. When compared to

those with typical reading ability, adolescents with poor reading skills have higher rates of overall impairment, poor role functioning, poor behaviour when relating to others, swinging moods, self-harm and disturbed thinking.<sup>26</sup> The continuation of reading difficulties into adulthood does not necessarily lead to poor educational achievement, yet it may increase the risk of psychiatric disorders.<sup>27</sup> Adolescents with learning disabilities have increased rates (up to 40%) of dropping out of school; they also show low self-esteem, and lack of social skills.<sup>28</sup>

**Headaches** have a negative effect on quality of life. Some studies report a significant decrease in the number of school attendance days due to headache, and a significant impact on the performance and success in school as a consequence.<sup>17</sup> Childhood headaches are especially complicated for three reasons: a) the parents' fear, communicated to the child, that a serious medical pathology may underlie the pain; b) the lack of evidence-based pharmacological treatment, and c) the belief that these headaches are largely psychological.<sup>29</sup>

### **Causes and Risk Factors**

Several studies report that risk factors associated with **cerebral palsy** are grouped into prenatal, perinatal, and postnatal. Prenatal risk factors include prematurity, LBW, maternal epilepsy, hyperthyroidism, infections, bleeding in the third trimester, incompetent cervix, severe toxæmia, eclampsia, drug abuse, trauma, multiple pregnancies, and placental insufficiency. Out of these, prematurity and LBW are the two most important risk factors in developed countries with high standards of obstetric care. Perinatal risk factors are prolonged and difficult labour, premature rupture of membranes, presentation anomalies, vaginal bleeding at the time of admission to labour, bradycardia (slow heart rate) and hypoxia. Postnatal risk factors, up to 2 years after birth, are encephalitis, meningitis, hypoxia, seizures, coagulopathies (clotting or bleeding disorders), neonatal hyperbilirubinemia (jaundice in newborns), and head trauma.

A wide variety of medical and environmental conditions can cause **mental retardation**. Some are genetic (e.g. chromosome abnormalities), others occur during pregnancy (e.g. severe maternal malnutrition), during birth (e.g. asphyxia), or after birth (e.g. brain infections such as meningitis and encephalitis). More specifically, the three major known causes of mental retardation are Down syndrome, foetal alcohol syndrome and Fragile X syndrome. For some of the affected people the cause remains unknown. Poverty, associated with malnutrition, exposure to environmental health hazards and inadequate health care, and cultural deprivation increase the risk of mental retardation in children.

There are many causes of childhood **movement disorders**. Cerebrovascular accidents, collagen vascular diseases, drug intoxication, hyperthyroidism, Wilson's disease, Huntington disease, and infectious agents are all well-known causes of chorea. In addition, various medications can induce movement disorders. The increased use of stimulants, antipsychotic agents, and antidepressant drugs in children by primary care physicians, psychiatrists, and neurologists has inevitably led to an higher number of paediatric patients manifesting the side effects of these drugs, including movement disorders.<sup>30</sup>

Factors increasing the risk of **epilepsy** in children include: congenital malformations of the central nervous system, moderate or severe head trauma, central nervous system infections, certain inherited metabolic conditions, febrile seizures, genetic factors and ADHD. However, these account for only 25% to 45% of cases, and thus the cause of most cases remains unclear.<sup>31</sup> Although epilepsy is defined as a condition characterised by recurrent, unprovoked seizures, it has long been recognised that even if most seizures appear to occur spontaneously, they may be provoked, or their occurrence may be altered, by a variety of endogenous and environmental phenomena (such as emotional stress, sleep deprivation and loud noise).

The precise causes of **learning disabilities** very often remain unknown. The known causes (often indirect) include genetic and nutritional factors, infections, toxic exposures, trauma, perinatal factors and multifactorial conditions.

For **headaches**, when there are no organic causes, there may be many other factors involved. In chronic daily headaches, stress may be a primary factor in the genesis of headache or in perpetuating it. Family and school relationships, relationships with friends, bullying, substance abuse, and participation in extracurricular activities are areas that would need to be checked.<sup>32</sup> In children and adolescents, migraine headaches may be precipitated by psychological factors. They may also be exacerbated by psychological or environmental stressors, and may adversely impact the quality of life of the child and the family.<sup>29</sup> Psycho-social stressors at home or at school, and disruptions in the daily schedule such as missing meals, having inadequate or excessive sleep, are well-known triggers of headaches. Parents and children with migraines may notice behavioural and emotional changes that occur in relation to migraine attacks.<sup>29</sup>

## Challenges

A first challenge is to extend the use of the WHO International Classification of Functioning, Disability and Health (ICF).<sup>33</sup> ICF represents a milestone in modern thinking about assessment and treatment for children with disability, but its implementation is still partial and not homogeneous. Moreover, in order to make comparisons among countries and draw a meaningful analysis of trends, common definitions are needed for certain conditions, in particular for learning disabilities.

Another challenge is to reduce the gaps among countries in their capacity to provide optimal comprehensive and multidisciplinary care to children affected by neurological and developmental disorders. For example, there are countries in which children affected by severe neurological conditions are institutionalised.<sup>34</sup> Children with neurological impairments should be offered inclusive education in public schools, receive specific support, as opposed to being sent to special educational institutions.

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## 6. Mental Health

### Key Messages

- It is estimated that up to 20% of children in Europe may have a mental or behavioural problem that may range from a minor complaint to a severe disorder, with large variations in prevalence estimates across countries.
- There is no consensus regarding whether or not mental health disorders have increased over the past decades. It is therefore not clear whether mental health disorders are showing changes over time. The great increase in autism spectrum disorders is mainly due to the adoption of broader definitions.
- Several biological, psychological and social risk factors are associated with mental health and the development of mental disorders from early childhood to adolescence. Many mental health disorders in adults have their origin in childhood.
- There is increasing awareness of the importance of improving preventive action and access to mental health services for children. Over the past few years several countries have made progress on this. However, many children with mental health problems are not receiving the care they need and community-based prevention programmes are lacking.
- Population-based prevalence studies on mental health disorders in children across Europe, using standard methods and definitions, are needed.

Mental health is the state in which an individual is able to achieve and maintain optimal psychological functioning and well-being. Child and adolescent mental health is based on the development of a sense of identity and self-worth, and it is nurtured by sound family and peer relationships.

A mental health disorder is diagnosed under an accepted system of classification<sup>e</sup> through the identification of a pattern of signs and symptoms that ultimately cause an impairment of psychological and social functioning, and which meets criteria for disorder. A proportion of children and adolescents suffer from overt mental health disorders. However, another proportion of children suffer from mental health and behavioural problems that do not fit into specific categories but lead, nonetheless, to sub-optimal well being.

Mental health, as opposed to mental illness, implies the ability to learn and to be productive. Mental health could be defined as the capacity to take advantage of growth stages and cultural resources to maximise development. Some projects, e.g. Kidscreen, have made an attempt to measure positive mental health; however this has not been applied on a wider scale yet.

This chapter will focus on the main mental health disorders and associated impairment in childhood. In addition, it will deal with behavioural patterns that increase the risk of mental health problems (for instance, bullying and the use of videogames).

### Main Sources of Information

Comparable data on mental disorders are not currently available in Europe due to the lack of a standard system of data collection. Some countries are greatly improving their national data collection, and have been able to define and describe the mental health situation of their child population. Although there is evidence to show that prevalence and incidence of mental disorders are different between countries, the available information from individual countries is useful to understand associations between mental disorders and risk factors.

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<sup>e</sup> For certain disorders some authors use one of the version of DSM system while others use different classification e.g. versions of the ICD system, or clinical tools such as SCAN, SCID, CIDI, PSE-GHQ, SCL-90. The use of different systems has a bearing on estimates of prevalence.

The Kidscreen project (<http://www.kidscreen.org/cms/thekidscreenproject>) has gathered data in 13 countries (Austria, Czech Republic, France, Germany, Greece, Hungary, Ireland, Poland, Spain, Sweden, Switzerland, Netherlands, United Kingdom) in an attempt to provide an overall picture of positive mental health by assessing the well-being and subjective health in a sample of children and adolescents 8 to 18 years of age. Some data on prevalence of mental health problems are available from the 16 countries (Austria, Belgium, Bulgaria, Estonia, Finland, Germany, Greece, Hungary, Latvia, Lithuania, Norway, Poland, Romania, Slovenia, Spain, United Kingdom) that participate in the Child and Adolescent Mental Health in enlarged EU (CAMHEE) project ([http://www.camhee.eu/about\\_project/](http://www.camhee.eu/about_project/)), which mainly provides an overview of the situation of child mental health infrastructures, policies and programmes.

### Size of the Problem

Mental disorders in children include anxiety disorders, depression, conduct and eating disorders, attention deficit hyperactivity disorder (ADHD), psychotic disorders (such as schizophrenia) and autism spectrum disorders. These can disrupt daily life at home, at school or in the community. Without adequate support, mental health problems in children can lead to school failure, family discord and violence, and later on to substance abuse and even suicide.

Mental health disorders have an alarming prevalence among children and adolescents in Europe. It is estimated that the overall prevalence of mental disorders in childhood and adolescence lies between 10% and 20% worldwide.<sup>1-3</sup> However, it can be higher in underprivileged and poorly integrated population subgroups, such as migrants. There is no consensus regarding whether or not mental health disorders have increased over the past decades. It is therefore not clear whether mental health disorders are showing changes over time.<sup>4</sup>

In general, girls tend to suffer more than boys from internalizing disorders (e.g. depression, anxiety, obsessive-compulsive disorders, somatic disorders). They also have a tendency to deal with problems internally rather than act them out in the environment through externalising disorders (e.g. conduct disorders), as boys more frequently do. Besides a clear gender pattern, mental disorders have some typical age ranges of presentation (Table 6.1).<sup>1</sup>

**Table 6.1. Typical age ranges (years) for presentation of selected disorders (Source: adapted from WHO, 2005)**

Disorder	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
ASD	x	x	x	x	x	x										
Conduct disorders			x	x	x	x	x	x	x	x	x	x	x	x	x	x
Anxiety disorders						x	x	x	x	x	x	x	x	x	x	x
Psychotic disorders														x	x	x
Substance abuse											x	x	x	x	x	x

It has been found that one in five children diagnosed with a disorder actually suffered from more than one, the most common combinations being conduct and emotional disorders, and conduct and attention deficit disorders. The majority of children (72%) with multiple disorders were boys, reflecting the high proportion of children with conduct disorders in this group. Children suffering from more than one disorder were at a greater risk of encountering

additional difficulties; for instance, 63% of those with multiple disorders showed impaired intellectual development, compared to 49% of those with a single disorder. Children with multiple disorders accounted for approximately one third of those using mental health services.<sup>1</sup>

**Anxiety** is a common psychological disorder in childhood and adolescence, perhaps the most common, even according to the most conservative studies. In the United Kingdom, one child in an average primary school class of 30 children has an anxiety disorder.<sup>5</sup> Anxiety disorders include generalised anxiety disorder, panic disorder, phobias, obsessive-compulsive disorder, post-traumatic stress disorder and separation anxiety. The most common of these in children under 12 years of age appears to be Separation Anxiety Disorder.<sup>6</sup> Some evidence suggests that this is not always a transitory disorder.<sup>7</sup> The reported prevalence of any anxiety disorder in children under 12 years of age varies between studies. One of the most quoted estimates ranges between 4% and 5%.<sup>6</sup> Prevalence increases if adolescents are included.<sup>2</sup> There are anyway problems in interpreting the results of studies. The first concern is that the DSM-III-R classification (see glossary) used in many studies may have been over-inclusive since it did not require a child to be experiencing distress or impairment as a result of his/her symptoms. On the other hand, there are children that experience substantial levels of impairment yet do not meet criteria for a formal diagnosis.

There are few data on **depression** and depressive disorders in children in Europe. The reported prevalence ranges between 1% and 6%, if adolescents are included, with a higher prevalence in girls.<sup>2</sup> Symptoms of depression change with age and range from sleep disturbances and changes in appetite to irritability, aggression and excessive crying. Children tend to deny symptoms of depression; this partly explains the difficulties in estimating true prevalence. Depression in children is often associated with co-morbid conduct disorders.<sup>8</sup> Major forms of depression may lead to suicide; however, this is very rare in children under 12 years of age and there are no estimates of its incidence in Europe. In Germany, suicidal behaviour and suicide ideation was reported by about 3% of children 11 to 17 years of age, with higher rates in girls than in boys; however, only half of the parents of these children reported the behaviour.<sup>9</sup>

**Conduct disorders** are probably the most common reason for referral of young children to mental health services and are more prevalent among boys.<sup>10</sup> The term is generally used to describe a pattern of repeated and persistent misconduct. The primary behaviours that fall into this category are aggression, non-compliance, defiance, and aversive interpersonal behaviour. The DSM-IV categorises children with the less severe form of disruptive behaviour disorders as having Oppositional Defiant Disorder, the symptoms of which include: a pattern of negativistic, defiant, noncompliant, and argumentative behaviour, which can last for at least 6 months and can cause significant impairment in social or academic functioning.<sup>2</sup> As for other mental disorders, there is a wide variation across countries and data are not comparable. In the UK, the prevalence is 6.5% for boys and 2.7% for girls in children between 5 and 10 years of age.<sup>10</sup> Epidemiological studies suggest that approximately half of those who meet diagnostic mental health criteria for conduct disorder, also meet criteria for at least one other disorder: the most frequent combination is with ADHD.

**ADHD** is a chronic disorder with lifelong impact on personal and social functioning as well as on academic performance. It also has a significant impact on the health system since it requires long-term treatment. It is defined as a developmentally inappropriate level of inattention and/or hyperactivity-impulsivity that is present before the age of seven. A literature review reports highly-variable rates of ADHD world wide; prevalence rates in Europe are slightly lower than those in North America (about 4% vs. 7%).<sup>11</sup> Differences in methods are significantly associated with differences in prevalence across countries. In Europe prevalence rates vary between 1.7% in Norway and 10.7% in Poland, with intermediate values in the United Kingdom (2.5%), Germany (4.6%) and Romania (4.9%).<sup>2</sup> ADHD tends to affect boys more than girls, as reported by the KiGGS study.<sup>12</sup> There are

disparities across the EU regarding awareness, diagnosis, treatment and management of ADHD. These differences are reflected in the lack of, or outdated professional knowledge, in the limited access to medication, and in scarce resources and social support.<sup>13</sup>

**Autism spectrum disorder** is a group of lifelong neuro-developmental disorders; criteria for diagnosis are defined in the DSM-IV-TR and ICD-10 international classifications. Data on prevalence are scarce and do not allow to draw conclusions on trends. Recent surveys reveal much higher rates than surveys conducted 30 years ago; this is the result of the current broader concept of autism used. Nowadays, improved health and social services have led to better diagnosis and identification of autism, sometimes even in children with average intelligent quotient. There is no information on the average prevalence of autism in Europe. Existing information suggests that age-specific prevalence rates for “classical autism” could vary between 3.3 and 16.0 per 10,000 children less than 12 years of age. These rates could increase to between 30 and 63 per 10,000 if all forms of autism spectrum disorders are considered.<sup>14</sup>

**Psychotic disorders** such as schizophrenia, schizoaffective disorders and affective and atypical psychoses are rare in children, since schizophrenia appears typically after puberty and peaks in early adulthood.<sup>2</sup> Onset of schizophrenia in childhood generally occurs after the age of five. Its prevalence is about 1 per 10,000 in children and 1-2 per 1,000 in adolescents. A meta-analysis shows that individuals with youth-onset of the first episode of schizophrenia demonstrate large deficits in almost all cognitive measures.<sup>15</sup>

**Eating disorders** become usually important in terms of prevalence only after the onset of puberty. In Germany, however, the KiGGS study found that at 12 years of age 25% of girls and 18% of boys already reported an eating disorder.<sup>16</sup>

**Bullying** is an attempt to create or enforce an imbalance of power between individuals or groups through emotional, verbal or physical aggression. Childhood bullying has long-term effects and is strongly associated with antisocial behaviour. Boys are more likely to report bullying and having been bullied than girls.<sup>17,18</sup> Bullying is more common at 11 than at 13 years of age, and bullying children may report other health risk behaviours, such as smoking or excess drinking.<sup>17</sup> Most of the so-called “bullies” are also victims of bullying, and most bullying occurs in playgrounds, although some may occur in the classroom.<sup>18</sup> Bullied children have lower self-esteem, are more likely to be depressed, and are more often users of mental health services.<sup>19</sup> The rates for being a victim of bullying decline between the ages of 11 and 15.<sup>17</sup> Differences between countries in the definition and methods for assessing bullying in primary school children preclude direct comparisons of prevalence rates. There are considerable cross-national variations in the frequency with which young people, in particular 11 year-olds, report having been a victim of bullying at school at least 2 or 3 times in the previous couple of months; it varies between 4% in Sweden and 33% in Turkey.<sup>17</sup>

An emerging threat to the mental health of children and adolescents in Europe is **computer game addiction**. Computer games may have developmental benefits or positive effects for educational or therapeutic purposes. Several studies, however, show that excessive playing of computer games is associated with behaviours that mimic the ones of other addictions.<sup>20</sup> Moreover, computer game addiction may be associated with other mental disorders (e.g. depression, anxiety, ADHD) and with impaired communication patterns (e.g. withdrawal from the rest of the family and from school life).<sup>21-23</sup> Another risk posed by this condition is the exposure to age-inappropriate content when using information technology. Contents that may pose a risk include commercial, violent, hateful, pornographic, racist or biased content. The number of adolescents reporting spending several hours a day using a computer, specifically on weekends and in countries that more recently were integrated into the EU, increased dramatically between 2002 and 2006.<sup>17</sup> Some studies in EU countries, mostly in Germany and in the United Kingdom, reported percentages of overuse or behavioural addiction to computer games and the internet of between 2% and 9% among adolescents.<sup>21-24</sup> These percentages are even higher for portable video games systems.<sup>20</sup>



## Causes and Risk Factors

Mental disorders are typical examples of conditions with many causes and risk factors. Genetically inherited susceptibility plays a role as well as early relationship and attachment patterns. Perinatal problems, such as severe prematurity, mother's exposure to infectious agents, alcohol, tobacco, toxic chemicals and drugs while pregnant may also play a role. Severe chronic diseases may lead to mental disorders. Parental care, particularly in the early years, contributes to the shaping of the child's overall mental well-being and may therefore have a bearing on mental health. The main risks, as well as protective factors, regarding the mental health of children and adolescents are listed in Table 6.2.<sup>1</sup>

**Table 6.2. Selected risk and protective factors for mental health of children and adolescents (Source: WHO, 2005)**

<b>DOMAIN</b>	<b>RISK FACTORS</b>	<b>PROTECTIVE FACTORS</b>
<b>Biological</b>	Exposure to toxins (e.g. tobacco and alcohol) in pregnancy Genetic tendency to psychiatric disorder Head trauma Hypoxia at birth and other birth complications HIV infection Malnutrition Other illnesses	Age-appropriate physical development Good physical health Good intellectual functioning
<b>Psychological</b>	Learning disorders Maladaptive personality traits Sexual, physical and emotional abuse and neglect Difficult temperament	Ability to learn from experiences Good self-esteem High level of problem-solving ability Social skills
<b>Social</b>	Inconsistent care-giving Family conflict Poor family discipline Poor family management Death of a family member	Family attachment Opportunities for positive involvement in family Rewards for involvement in family
a) Family		
b) School	Academic failure Failure of schools to provide an appropriate environment to support attendance and learning Inadequate/inappropriate provision of education	Opportunities for involvement in school life Positive reinforcement from academic achievement Identity with a school or need for educational attainment
c) Community	Lack of community efficacy Community disorganisation Discrimination and marginalisation Exposure to violence Lack of a sense of place Transitions	Connectedness to community Opportunities for constructive use of leisure Positive cultural experiences Positive role models Rewards for community involvement Connection with community organizations including religious organizations

Risk factors tend to cluster together and interact. The vulnerability to risk factors varies with age and gender, and depends on the duration of risk impact and on the sequential or simultaneous occurrence of the factors.<sup>9</sup> Many risk factors are in their turn influenced by social determinants. Also, it is not surprising to find that socio-economic inequalities

emerge in mental health disorders among adolescents in Europe, whenever such an analysis is carried out.<sup>25</sup>

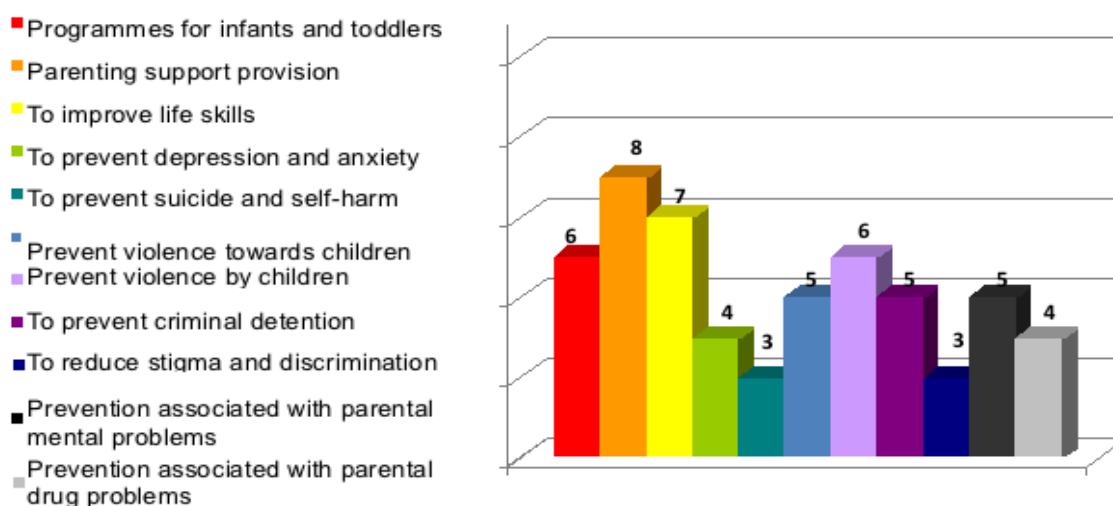
Some children and adolescents live in difficult circumstances and are therefore vulnerable to mental health problems. Among these, migrant children are particularly at risk. Being member of a minority, particularly if combined with low SES, is a risk factor for mental disorders and the adoption of risky behaviours in adolescents. Early-school leavers, young people leaving school before the legal school leaving age and/or with limited or no formal qualifications, are at higher risk as well.<sup>2</sup> Children with learning disabilities are more likely to suffer from mental health problems: 40% suffer from some form of mental health disorder, and the prevalence is even higher among those suffering from severe learning disabilities.<sup>1,2</sup>

The use of alcohol and drugs can exacerbate and trigger mental health problems. For example, alcohol can be attractive to those suffering from depression since its consumption increases confidence and may produce a feeling of well-being, drowning out problems in the short-term. Alcohol, however, is also a depressive substance, and it can worsen the symptoms of depression, and thus increase the risk of suicidal thoughts and behaviour.<sup>1,2</sup>

## Challenges

The first challenge is to promote population-based prevalence studies on mental health disorders in children across Europe, using standard methods and definitions. Another important challenge is represented by the gap existing between needs and services, and by the lack of preventive programmes. Although there is much variation across Europe in the institutions and organisations involved in implementing action for children and adolescents with mental health problem, it is estimated that only a small proportion of these children and adolescents receive help from existing services.<sup>2,26</sup> Nearly all countries in Europe have made significant progress over the past few years, and many are global leaders in the promotion of mental health, the prevention of mental disorders, and service reform. Community-based psychiatric inpatient units and units in district general hospitals provide mental health services for children and adolescents in 14 of the EU15 countries and 5 of the EU12 countries. Almost all countries report that specialist mental health services for children and adolescents are available in mental health outpatient facilities. Day treatment facilities for children and adolescents are available in all the EU15 countries. Although a number of reviews and meta-analyses have shown that prevention and promotion approaches can be effective in reducing mental health problems, prevention programmes are active only in few countries (Figure 6.1).<sup>26,27</sup>

**Figure 6.7. Number of countries with budgeted and implemented policies and large-scale programmes for child and adolescent mental health (Source: Carral, 2009)**



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## 7. Cancer

### Key Messages

- Representing less than 1% of all cases, cancer in children is a rare event, far less frequent than in adults. However it is the first cause of death in children 1 to 14 years of age.
- The incidence of childhood cancer increased in most countries up until the 1990s. Improved diagnostic procedures and recording accuracy may account for some of the increase. The extent to which changed life styles and exposure to environmental carcinogens could account for secular trends remains undetermined.
- Despite intense research, we have a poor understanding of the causes and mechanisms underlying disease onset, leaving little room for primary prevention.
- Treatment has become more and more effective in the last four decades, so that nowadays over 70% of children who get cancer can be cured.
- However, late adverse effects of therapy are common in survivors. Guidelines for long-term clinical monitoring and mechanisms to deliver targeted care need to be developed.

The term cancer, or neoplastic tumour, indicates the excessive proliferation of cells in a tissue; it contains its own characteristics and has the ability to grow independently of its surrounding environment. Neoplastic tumours are said to be benign if they grow only locally, and they are said to be malignant if they have the ability to extend to other tissues and organs and affect their function. The diagnosis of most cancers is confirmed by pathologists who examine a sample of tissue through the microscope. Compared with other diseases, therefore, cancer diagnosis is generally accurate and highly reproducible, which facilitates systematic monitoring at the population level. Nevertheless, reliable statistics that allow meaningful comparisons across countries require *ad hoc* rules and procedures performed by staff devoted to the task, services which are not available in any European country.

This chapter first describes the size of the cancer problem □ probability of developing cancer in childhood, curability, and probability of dying from the disease □ and how it has evolved over time. This is followed by a review on what is known about the causes of paediatric cancer and by a discussion of long-term impact on cured children who live on into adult life.

### Main Sources of Information

Incidence and patients' survival are recorded by population-based cancer registers that are unevenly distributed in Europe. Most incidence data presented in this chapter are drawn from two databases produced and maintained by the International Agency for Research on Cancer (IARC), a specialised agency of WHO in collaboration with the International Association of Cancer Registries (IACR). They are the Cancer Incidence in Five Continents (<http://ci5.iarc.fr/CI5i-ix/ci5i-ix.htm>)<sup>1</sup>, and the Automated Childhood Cancer Information System (ACCIS) (<http://www-dep.iarc.fr/accis.htm>)<sup>2</sup> projects. Long-term data on time trends (30 years) are available only for few countries (Denmark, Finland, Sweden, Iceland, Norway). Short-term time trend data (10-20 years) are available for the Czech Republic, Estonia, France, Germany, Italy, Latvia, Netherlands, Poland, Slovak Republic, Slovenia, United Kingdom, Iceland and Switzerland. Data on short-term time trends (15 years) are not available for Cyprus, Greece, Hungary, Luxembourg, Portugal, Romania, FYR of Macedonia or Turkey. However, even where registers have been in operation long enough to assess trends, many cover too small a region to allow meaningful interpretations or analyses by tumour subtype.

Survival probability figures were abstracted from publications of the EURO CARE<sup>3,4</sup> and ACCIS<sup>2,5</sup> projects, both partly funded by the EC. Figures on cancer mortality in children, at least in recent years, are available from the WHO mortality database online elaborations by IARC (<http://www-dep.iarc.fr/WHOdb/WHOdb.htm>), for all countries included in this report,

except Cyprus and Turkey.<sup>6</sup> Limited accuracy of the coded/registered cause of death permit an analysis only of major cancer subtypes. Long-term trends of mortality rates are the average of countries for which data exist since the 1950s. Direct measures or estimates of the prevalence of children living with the disease (being treated) are not published in a standardised and comparable format for European countries. The number of survivors living in Europe were estimated based on prevalence rates recorded in the Nordic countries.<sup>7</sup>

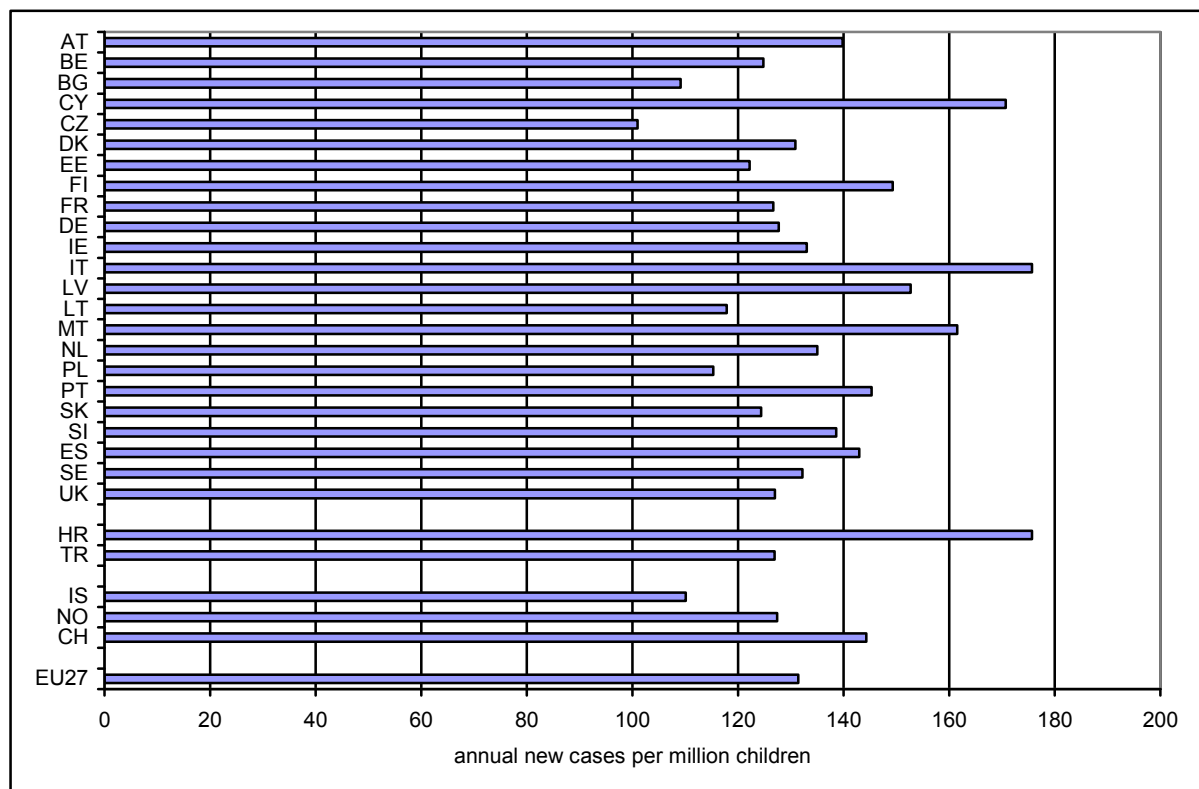
## Size of the Problem

### *Incidence*

Cancer in children younger than 15 years of age is a rare event, far less common than in adults. It represents less than 1% of all cases of cancer in all ages. Yet it is the first cause of death in children 1 to 14 years of age. Despite impressive improvements in the effectiveness of treatment, at the turn of the century, cancer led to the demise of around 40% of affected children (European average). Every year, 10,200 children aged 0-14 years are newly diagnosed with cancer in EU27 countries; 13,200 in EU33.

Annual incidence rates per million children (Figure 7.1) vary between 101 (Czech Republic) and 176 (Croatia); the EU27 average is 131. The rates (or disease risk) are generally greater in South and South-Eastern Europe, with few exceptions. Overall, the risk of cancer is slightly greater in boys than in girls, though the male to female ratio varies by cancer type. Very few cancer subtypes are more common in girls than in boys.

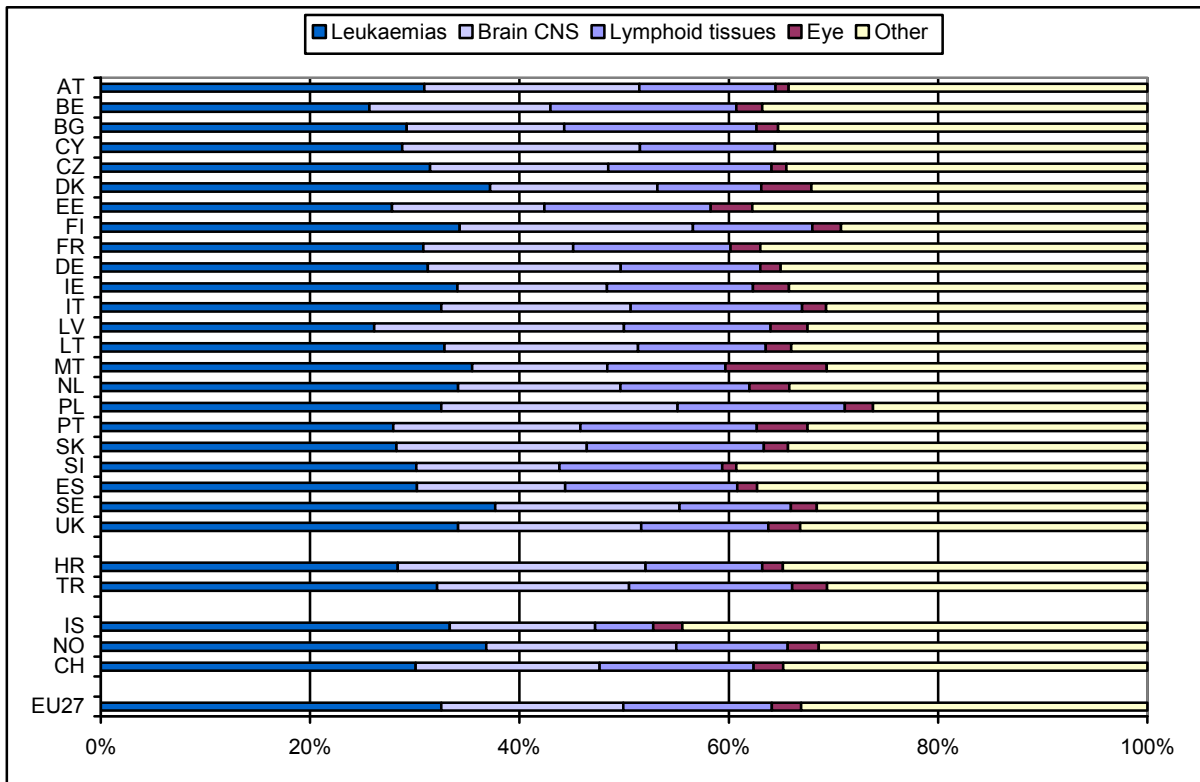
**Figure 7.1. Crude annual incidence rates of childhood cancer per million children by country.**



The most common (30% of all) type of tumour in children is leukaemia (a cancer of white cells in the blood). This is followed by brain tumours and tumours in the central nervous system (about 20%), and by lymphomas (tumours that normally arise in lymph nodes but which may show itself as malignant white cells infiltrating the skin or other organs, 14%) (Figure 7.2). The remaining 40% of cases are an heterogeneous group of even rarer cancers

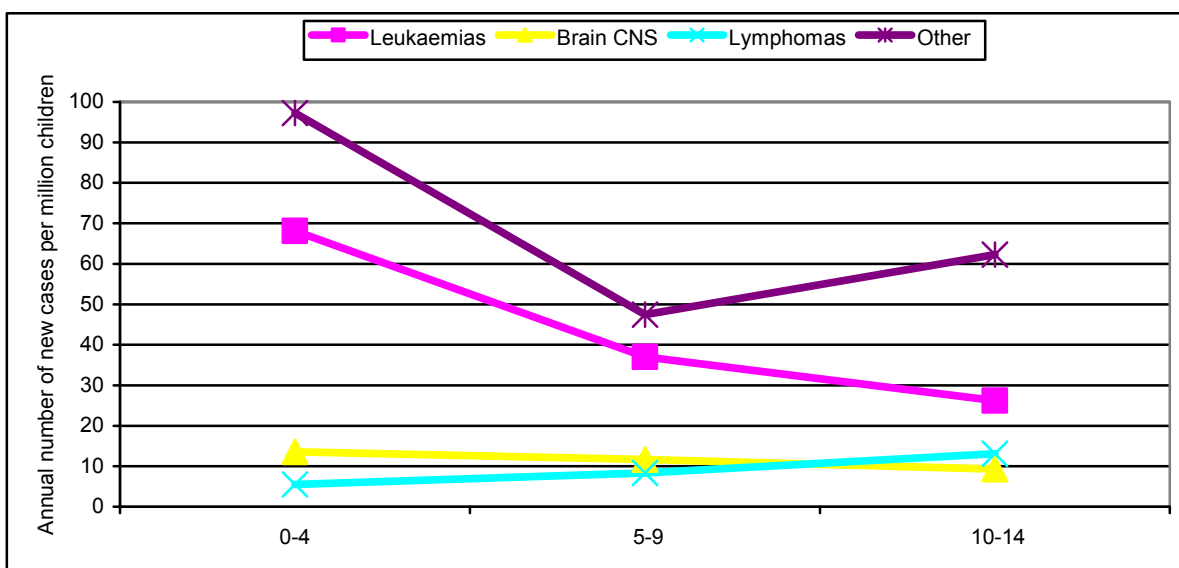
including sarcomas (arising in connective tissue, bones and muscles), peripheral nerve tumours, germ cell tumours and carcinomas, collectively referred to as solid tumours.

**Figure 7.2. Relative frequency of childhood cancer subtypes by country.**



Incidence by age has characteristic distributions that vary by type of cancer: acute lymphoblastic leukaemia (the most common type of leukaemia in children) peaks at around 4 years of age and declines thereafter. Lymphomas grow steadily with age and peak in adolescents and young adults. Tumours of the central and sympathetic nervous system are high in infants and then decrease with age. A similar pattern occurs for retinoblastoma, a cancer of the eye. Other solid cancers, e.g. those arising in bones and kidney, are low in young children but the risk increases with age (Figure 7.3).<sup>1</sup>

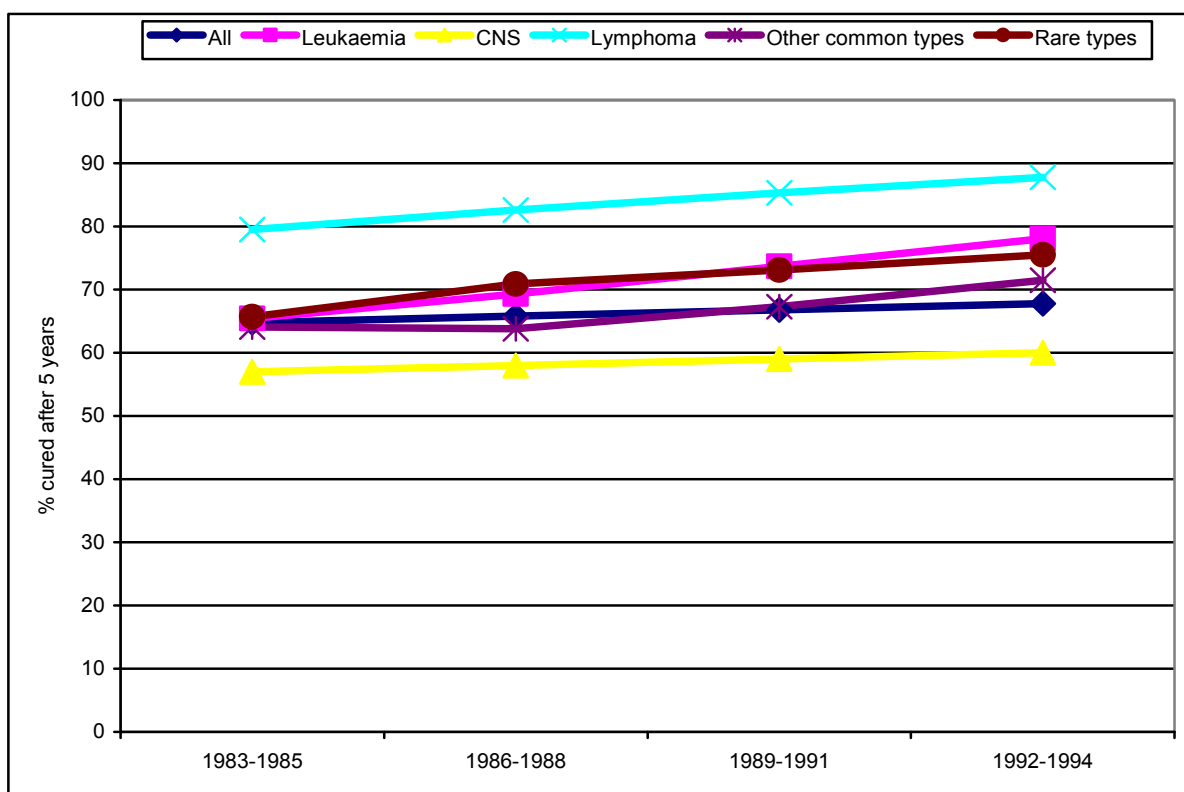
**Figure 7.3. Age-specific incidence rates by type of tumour.**



## Survival and Mortality

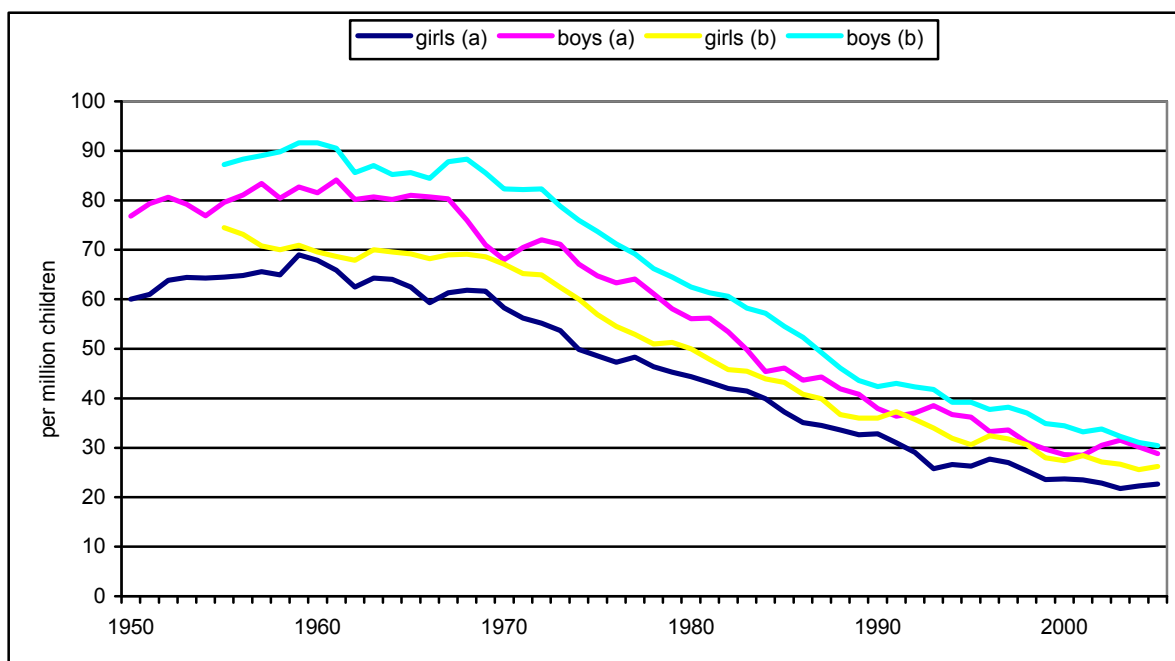
Nowadays cancer mortality in children is largely determined by access to optimal treatment. As already mentioned, the prognosis for some cancers, if diagnosed at an early stage and treated according to modern protocols, is extremely good. Overall, 58% of all newly diagnosed cases are alive and clear of disease 10 years after diagnosis. The proportion is greater for lymphoid leukaemia (64%) and for certain tumours that occur only among children (retinoblastoma and Wilm's tumours). These figures are the averages for Europe, they thus reflect heterogeneity across countries, and are the experience of cases treated between 10 and 20 years ago. In recent years, treatments continued to improve so that 80% of children who develop acute leukaemia today may expect to be cured five years from diagnosis, provided they receive the best possible treatment. Similarly, expected survival is now greater than 58% for retinoblastoma (cancer of the eye) and sarcomas occurring in bones, kidney and muscles (Figure 7.4). The survival of cases diagnosed today is generally higher than 70%. Such favourable trends in prognosis have been observed throughout Europe; however, population-based data show that survival of children with cancer is lower in Eastern Europe compared to Western Europe.<sup>2</sup> This probably reflects insufficient coverage of specialised treatment centres and limited access to optimal treatment.

**Figure 7.4. Increase in survival probability over time by cancer type.**

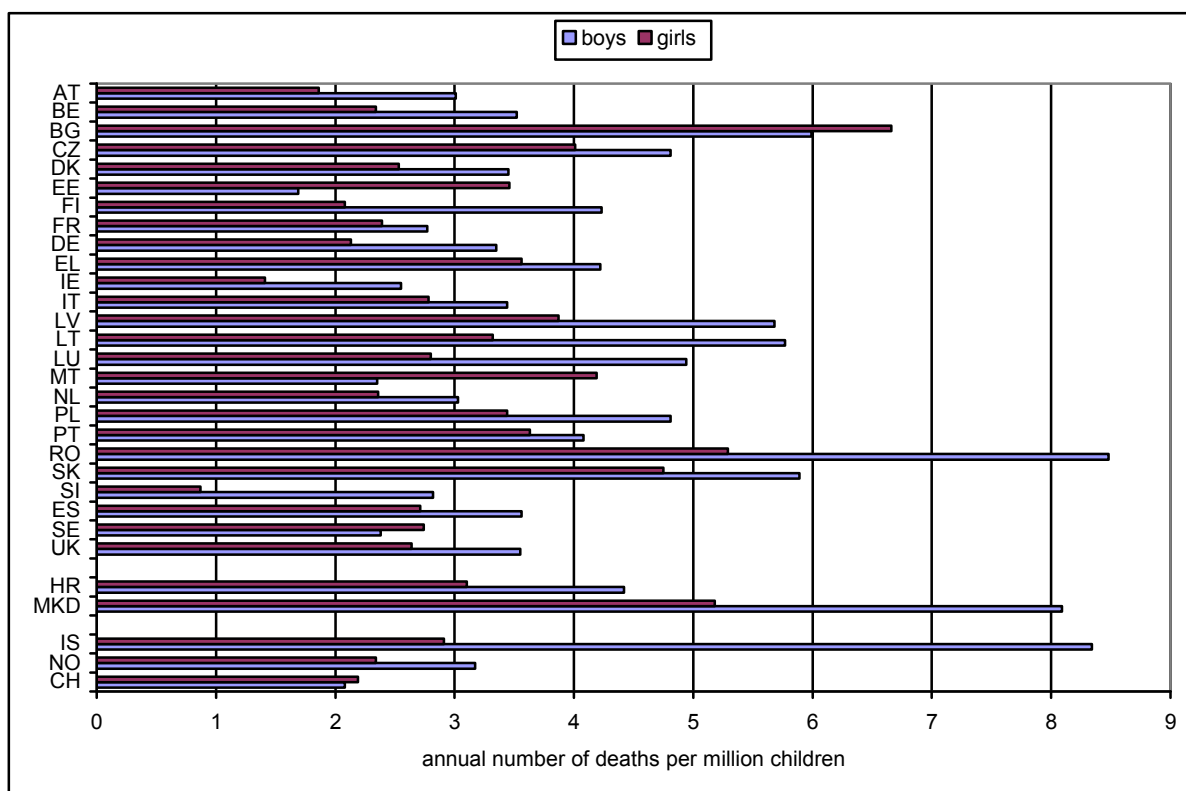


The success of treatment for childhood cancer has had a profound impact on time trends of mortality from the disease. The risk of dying from cancer in children began to decline steadily in the early 1960s, and until recent years the trend persisted throughout Europe in boys and girls (Figure 7.5). Nonetheless, there is evidence of disparities across countries, which are not explained by differences in the incidence of the disease (Figure 7.6).

**Figure 7.5. Mortality rates from childhood cancer over time; averages of countries with long-term monitoring: (a) 4 countries, (b) 17 countries**



**Figure 7.6. Mortality rates from childhood cancer in 1999 by gender and country.**



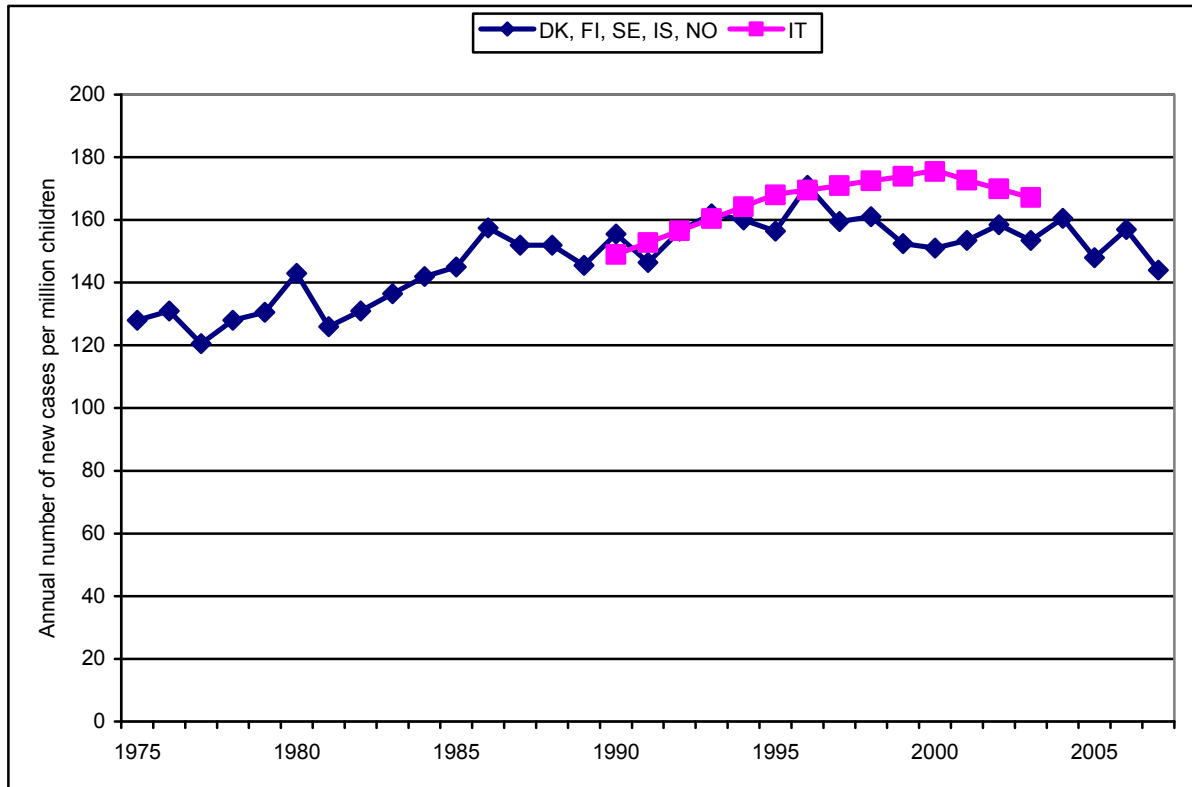
### Trends

Up until the beginning of the 1990s, many European countries, as well as North America and Australia, reported an increase of childhood cancer incidence. In Europe, on average, incidence rates increased by 1.1% per year.<sup>2</sup> The extent to which improved diagnostic procedures and recording accuracy contributed to such increase has generated much controversy about the magnitude of the actual change in risk of the disease. Nonetheless,



there is general consensus that the gradual increase is real and not spurious due to improved ascertainment, at least for the most common cancer types. The increase occurred in every age group and is detectable in all European regions. The increase was driven mainly by tumours of the CNS and peripheral nerves, followed by leukaemia, lymphoma and sarcoma. Systematic analyses of European data for the last 10 years have not been carried out, but analyses for individual countries,<sup>8</sup> or groups of countries,<sup>9</sup> suggest that trends have levelled off or have even begun to decline (Figure 7.7).

**Figure 7.7. Time trends of childhood cancer incidence rates in Italy and the Nordic countries.**



### Clustering

Episodes of clusters – groups of cases that represent a significant ‘sudden’ excess compared to background incidence –, mostly involving leukaemia, are numerous and have been reported for decades, becoming a characteristic feature of the epidemiology of childhood cancer. Given the rarity of the disease, occasional excesses are to be expected simply by chance fluctuation. Much of the difficulty in interpreting clusters, therefore, lies on establishing whether the excess is compatible with chance variation or whether it is more likely to be real, pointing therefore to a shared cause.

One of the first episodes that received much public attention and generated intensive *ad hoc* investigations is known as the Sellafield excess of childhood leukaemia,<sup>10</sup> after the name of a nuclear site in the northwest of England. The possibility that there had been an excess of leukaemia in the community living in the proximity to the nuclear plants was raised by the media in the 1980s. Several epidemiological studies have been undertaken since, to assess in the first place whether, compared to other counties, the incidence was indeed greater than expected, and therefore to ascertain the role of the nuclear plants. The body of information gathered could not link the occurrence of childhood cancer in the area with environmental or occupational exposures, in children or parents, directly originating from the nuclear plants or from other sources. The episode remained unexplained.

The Sellafield case is a paradigm for many other clusters: none has ever been explained.<sup>11</sup> Chance has probably played a role in several of these cases. Yet, the history of cluster episodes is long, and it dates back to the 19<sup>th</sup> century, when childhood leukaemia was considered an infectious disease.<sup>12,13</sup> It is probable that unidentified specific agents, including viruses, are involved in the onset of the disease. The hypothesis that the Sellafield and other clusters could be linked to viral epidemics due to population mixing remains plausible but virtually unexplored.<sup>14</sup> The recent impressive developments of high throughput technologies applied to molecular biology may offer new opportunities to stimulate research on this topic.

## Causes and Risk Factors

Much analytical research has been conducted in Western countries since the 1960s to identify the causes of cancer in children. Causal hypotheses have addressed a variety of environmental, physical and chemical exposures, known infectious agents and genetic susceptibility in parents and children.<sup>15-17</sup> Possible sources of chemical, physical or biological carcinogens have been suggested by descriptive studies including episodes of specific clustering. Many of the investigated agents, however, co-exist in the environment, making it difficult to distinguish specific exposures, particularly when relying on proxy information derived from interview data.

For example, an excess of brain tumours<sup>18</sup> and leukaemia<sup>19</sup> in children born to farmers have been reported in several (but not all) countries. These observations suggested a possible influence of products used in large amounts in agricultural practices (pesticides and herbicides), particularly those that have mutagenic properties and have been associated with cancer in adults. However, rural populations, where farming is the prevailing economic activity, may be exposed to rare viral infections that cause leukaemia in animals and might generate cancer in children with an immature immune system. Another hypothesis proposes the existence of a specific rare leukaemia virus that would cause excesses in the form of a cluster when introduced in an isolated population group where it was previously known to be absent. To explore and distinguish between these different hypotheses, one would need to be able to assess specific exposures through reliable and accurate measures based, for example, on biological markers or direct environmental assays. Most historical studies, instead, could only rely on retrospective interviews administered to parents of affected (cases) and unaffected (controls) children.

Exposures that have been investigated as possible causes of leukaemia, brain tumours and other cancers in children belong to several major groups. Ionizing radiation is the only well-established physical agent that proven to cause leukaemia as well as solid tumours in children and adults. The excess risk is documented for exposures of moderate and high intensity that occur in unusual circumstances, such as in the case of the Japanese population who survived the atomic bomb, or in workers at the Chernobyl base and in the resident community at the time of the accident. Intentional exposures are delivered only for therapeutic scope, mainly cancer. Modern non-invasive diagnostic procedures, unlike X-rays, entail very low doses and are increasingly replaced by new procedures that avoid ionising radiation (e.g. ultrasound, magnetic resonance). Finally, it should be mentioned that 10%-20% of paediatric leukaemia is attributable to ubiquitous natural background radiation.

Analytical studies, mainly using a case-control design, have investigated a wide spectrum of parental (preconception or during pregnancy) and children exposures: low-frequency electromagnetic fields, pesticides, hydrocarbons including benzene, insulation material including asbestos, N-nitroso compounds and certain metal dusts and fumes; common infections, vaccinations, allergies and proxies for the likelihood of unidentified infections; maternal exposures during pregnancy including life style factors (e.g. diet and tobacco smoking); maternal reproductive history, illnesses and related medicine use. Some inherited genetic factors are associated with an increase of cancers. Genetic susceptibility has been established for children affected by Down syndrome, Li-Fraumeni syndrome, familial adenomatous polyposis, neurofibromatosis, ataxia telangiectasia, Fanconi anaemia, all rare

inherited conditions which, however, explain a very small proportion of paediatric cases. At present, none of the possible causes investigated has been firmly associated with the disease and can explain the two main features of the occurrence of childhood cancer: the increased incidence up until the turn of the century, and episodes of clustering.

The inability to detect discernable excess risks associated with exposures that do cause cancer in adults, might still be due to limitations in the study design. New research is moving towards large prospective studies, through international collaborations, that will overcome most of the limits of research conducted so far.<sup>20</sup>

## Challenges

Despite intense research, there is still poor understanding of the causes and mechanisms underlying the onset of childhood cancer, leaving little room for primary prevention. The first challenge is therefore to set up research with a higher chance of identifying causes and mechanisms. This can only be done through large prospective cohort studies using accurate ways to determine exposure, such as biological markers and direct environmental assays. For rare diseases such as childhood cancer, however, these studies will be very expensive.

Faced with a lack of evidence regarding causes of childhood cancer, the precautionary principle should anyway be applied to avoid or reduce exposure of children to known physical and chemical carcinogens in adults. This would generate benefits regarding other diseases (see Chapter 13) and somewhat prevent the risk of developing cancer as adults. It is well known, for example, that sunburns suffered in childhood substantially increase the risk of skin melanoma, an aggressive type of cancer, in adulthood.<sup>21</sup> Similarly, for a fixed cumulative amount of tobacco smoked (depending on duration of the habit and number of daily cigarettes smoked), the risk of developing lung cancer is greater the earliest the habit began and it is highest for smokers who started before the age of 14.<sup>22</sup> Furthermore, the carcinogenic potential of ionizing radiation in causing leukaemia and solid tumours in adults is greater for those exposed as children.<sup>23,24</sup>

In recent years, immunisation against Human Papillomavirus (HPV) has been debated among the measures applicable to children so as to prevent cancer in adults. Since the 1980s, certain types of HPV were identified as the cause of virtually all cervix cancers and a proportion of cancers in the vagina, penis, rectum, head and neck in men and women. Vaccines against the so-called high-risk HPV types are now available with proven efficacy in preventing persistent infection that may lead to cancer.<sup>25</sup> The virus is transmitted through sexual contact; immunisation strategies, therefore, aim at targeting children before they become sexually active, i.e. between 11 and 12 years of age. Besides financial considerations, much of the debate stems from concerns over vaccines' safety and the impact on teenage sexual behaviour. The continuation of the monitoring of immunised cohorts will provide direct measures on the long-term efficacy and safety of vaccines, which, for the time being, appear to be favourable. The implications on personal behaviours are more complex and policies imposing mandatory vaccination have been poorly received by the public. Yet, immunisation interventions are cost-effective only if they reach high coverage. To include the HPV vaccine as part of routine immunisation programmes of younger children would overcome much of the parents' concerns but there are no data on the efficacy and safety of HPV vaccines if administered together with other vaccines and in younger children. At present, such strategy can only be the object of research. The ECDC provides guidance on several aspects of HPV immunisation strategies to help policy-makers, but it does not recommend a specific policy. Pilot projects currently running in several European countries will hopefully provide the much needed information on the best policy.

The second challenge is treatment and cure. Treatment has become more and more effective in the last four decades, so that nowadays over 70% of children who get cancer can be cured and will live on into adult life. In Europe, however, there is evidence of disparities in the performance of health systems in managing childhood cancer. In some countries, gaps in

expertise and specialised services lead to limited access to curative and least disabling treatments. While all European countries guarantee the right to optimal health care to their citizens, organisational and budgetary restrictions may limit treatment, in particular for rare diseases such as some paediatric cancers. Unnecessary suffering can be reduced with relatively small investments so that all cases of childhood cancer are managed in specialised and highly qualified services.

The third challenge is the management of late adverse effects of therapies received for paediatric tumour in the growing population of childhood cancer survivors. This is also a new area of clinical research. The aim is to determine an optimal balance between clinical monitoring for a variety of complications, in order to treat them since their early symptoms, and the risk of burdening survivors with chronic fears about threats to their health. Most health systems have not yet developed well-defined models or guidelines to monitor and manage late effects once these children have grown into adulthood. This is a priority in most European countries.<sup>26</sup>

The fourth and final challenge is to ensure care and long-term quality of life for survivors of childhood cancer. In the EU27 countries there are around 17,000 teenagers and young adults (aged between 15 and 24), who had cancer when they were children. By the year 2020, it is estimated that 1 in 600 people under 50 years of age will be a childhood cancer survivor. With continuing improvements in survival and with population aging, the prevalence of survivors increases steadily. Yet, the success of treatments responsible for long-term survival is not consequence-free, as people who have been given the all-clear are at an increased risk of a number of late adverse effects. Some disabilities are soon evident; for example, a proportion of children who undergo cranial irradiation or surgery for brain tumours experience neurological disorders, including cognitive deficits that compromise their quality of life permanently. Life-threatening late effects of treatment in survivors include the onset of new cancers (particularly in the thyroid, if irradiated), cardiac and pulmonary diseases. Other health conditions that affect the survivors' quality of life include reduced fertility in women and hearing and sight loss.<sup>27</sup> Survivors can instead be reassured that there is no evidence of an increased risk of congenital malformations in their offspring. Fears about the health of their own children should not prevent them from starting a family if they so wish.<sup>28-30</sup>

Not all late effects are known as cohorts of survivors are only beginning to be middle-aged. There is concern as to the magnitude of their risk of developing chronic illnesses that may well become common in the general population with aging. Long-term monitoring of these cohorts will provide information relevant to the management and prevention of late adverse effects. It will also inform clinical research providing leads for the development of less harmful treatments. In fact, nowadays much of clinical research in paediatric oncology is committed to testing reduced or compartmentalised treatment and to replace old molecules with new, less harmful ones, with the aim of reducing adverse effects of therapy, yet maintaining efficacy. Technological developments will also help to protect unaffected organs and tissues from irradiation that is intended only to the tumour, thus reducing the risk of late secondary cancers.

The prospect of potential threats to their health does not necessarily undermine survivors' psychological well-being or prevent them from engaging into social life and the pursuit of personal goals. For example, those who have not suffered from neurological damage (who are in effect the majority), are less likely to develop serious psychiatric disorders or risky behaviours compared to their unaffected peers.<sup>31</sup> Moreover, many survivors develop positive expectations towards their future even when they perceive a deterioration in their health.<sup>32</sup> Carers, including family and treating staff, have a substantial role in promoting such positive outcomes by implementing coping strategies.

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## 8. Rare Diseases and Conditions

### Key messages

- A disease is defined as rare when it affects no more than 5 people in 10,000. There are about 7,000 chronic and often incapacitating rare diseases; around 50% of them affect children.
- Patients with rare diseases need special centres for diagnosis, treatment, follow-up and psychosocial support.
- The main challenges posed by rare diseases in Europe are related to their recognition and visibility, to the development of common health care strategies, to the enhancement of cooperation, coordination and common regulations, and to the financial support of research for new drugs.

The current definition of a rare disease, adopted by the Community Action Programme on Rare Diseases (1999-2003), is that it should affect no more than 5 people in 10,000. Rare diseases widely differ in terms of severity and clinical expression. Many of them are complex, degenerative and chronically incapacitating. They often affect several organs and systems, leading to physical, cognitive and psychological impairment. Some relatively common conditions can hide behind rare diseases, e.g. autism (in Rett syndrome, Usher syndrome type II, Sotos cerebral gigantism, Fragile X syndrome) and epilepsy (in Shokeir syndrome, Feigenbaum Bergeron Richardson syndrome). This chapter deals with some of the common features and issues related to rare diseases since many of them are covered in other chapters (congenital anomalies, Chapter 4, neurological conditions, Chapter 5; and cancer, Chapter 7).

### Main Sources of Information

The non-governmental patient-driven alliance EURORDIS is an essential source of information ([www.eurordis.org/](http://www.eurordis.org/)). The ORPHANET database is a free multilingual source of data on rare diseases and orphan drugs; it contains information on more than 5,000 diseases ([www.orpha.net/consor/cgi-bin/index.php](http://www.orpha.net/consor/cgi-bin/index.php)). EUROCAT ([www.eurocat-network.eu](http://www.eurocat-network.eu)) and ENERCA ([www.enerca.org](http://www.enerca.org)) are databases on congenital malformations and anaemia, respectively, and therefore they also deal with rare diseases. These registries and databases are key instruments to stimulate knowledge and develop research on rare diseases. Unfortunately, their distribution varies greatly in the countries covered by this report. Some registries are compiled at European level but others are only operating at national or local levels. The ICD-10 (see glossary), used in most countries to classify disease and death, is not 100% appropriate for rare diseases.

### Size of the Problem

The number of people affected by rare diseases is estimated to vary between 29 and 36 million in the EU27 countries, with on average around 246,000 people affected per disease. This corresponds to about 6% of the overall population. Less than 100 rare diseases have a prevalence rate close to the threshold of 5 per 10,000; most of the remaining rare diseases affect one in 100,000 people, or less.

The age in which the first symptoms appear varies considerably. About half of the rare diseases are diagnosed at birth or during childhood (e.g. spinal muscular atrophy, *osteogenesis imperfecta* or brittle bone disease, Duchenne muscular dystrophy), whereas the remaining half becomes visible during adulthood (e.g. Huntington disease, amyotrophic lateral sclerosis). Despite clinical diversities, patients and families usually refer to and complain about the same difficulties: scarcity of expertise and knowledge, which often come hand in hand with delayed diagnosis and difficult access to care. Whilst many rare diseases cause symptoms in childhood, these may not translate into a specific diagnosis for years.

Moreover when a diagnosis is arrived at, there is lack of information about the disease and its possible therapies, as well as lack of qualified professionals for health and social care.

Beyond problems directly related to the disease, affected people suffer from social exclusion and discrimination, and are usually unable to find a job to get social benefits, so that inequalities and inequities in access to care increase. As a consequence, rare diseases become a heavy psychosocial burden for patients and families, and the lack of treatment, of hope for recovery, and of practical support for everyday life, often affect quality of life and self-esteem. People affected by rare diseases often have a life expectancy significantly lower than the average in the population.

### **Causes and Risk Factors**

Most rare diseases are genetically inherited, or are due to mutations or to chromosomal abnormalities. Other ones are cancers, autoimmune disorders, environmental and infectious diseases, and thus share with these causes and risk factors. For these reasons, there are few rare diseases for which primary prevention is possible. These interventions have already been discussed in the respective chapters, such as the prevention of neural tube defects by supplementation with folic acid (in Chapter 4). Secondary prevention through early diagnosis is possible in other cases and will prevent subsequent disabilities, e.g. the neonatal screening for phenylketonuria set up in the 1960s that has allowed to prevent mental impairment in affected children when diagnosis and treatment are established before 21 days of life. The same applies to the recently adopted Neonatal Enlarged Metabolic Screening that could help lower morbidity and mortality in the case of some diseases. However, consensus has not been reached yet on this enlarged screening, especially as far as cost and psychological implications are concerned.<sup>1,2</sup>

### **Challenges**

Taken together, rare diseases, are a major cause of mortality, morbidity, disability and dependency, and have important consequences on individuals, families and societies, and also in particular on health care systems.<sup>3,4</sup> Given the number of people affected, they should be considered a serious public health problem and a priority for health care and research. On the other hand, because when taken individually each rare disease affects a small minority of individuals, the first challenge is to give them adequate recognition and visibility.

The second challenge is to overcome the lack of common EU strategies for health care and research. National centres of excellence for at least some rare diseases exist in 12 Member States. As it is impossible to have a centre of excellence for every rare disease in every country, it is clear that expertise, rather than patients, should travel, although patients should also be able to travel to the centres when needed. Some countries have so far tried to focus on specific areas such as data collection, research, orphan drugs or support to patient's organisations,<sup>5</sup> and several initiatives are ongoing. In other cases no clear target seems to exist. Much more has to be done by Member States to establish common EU strategies. This is particularly true for the so-called orphan drugs, that is, drugs that are needed by such a small number of patients, that they are unattractive for industrial research and development. The development of these drugs has already improved the health and quality of life of patients affected by rare diseases, e.g. in the case of the substitutive enzymatic therapy for children with lysosomal diseases.<sup>6</sup> The problem is that the price for research and development makes it impossible for these drugs to meet the conventional criteria for cost-effectiveness. Also, the annual cost for enzyme replacement therapy in rare diseases, such as Gaucher and Hurler Scheie diseases, is in the order of 150,000 to 300,000 euros per year, respectively; a cost that families cannot afford and which represents a burden also for health systems. Only an alliance of all sectors in society, including the private sector, can address this problem effectively.



Finally, national approaches to rare diseases are in many cases ineffective and generally inefficient. EU-wide action is needed. Countries need to pool scarce resources together to standardise and improve classification and records; they also need to share knowledge, plans and regulations. Initial measures in this sense have already been taken,<sup>7,8</sup> and have led to the setting up of ORPHANET, EURORDIS (the European Organisation for Rare Diseases, a community of patient organisations and individuals active in the field), EUROPLAN (the European Project for Rare Diseases National Plans Development), the Orphan Medicinal Product Regulation (to define orphan drugs and stimulate research), and a Committee of Experts that should build links between centres of excellence and support researchers and health care professionals in different countries. Since 1999, 39 international projects costing a total of around 14 million euros have been funded to support research on rare diseases. It is clear that with new therapies and new knowledge, patients will be able to live longer and will have new special needs. Cost, however, will also increase. Only a coordinated EU action will allow the balancing of health outcomes with the respective social and economic costs.

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## 9. Other Conditions of Public Health Importance

### 9.1 Oral Health

#### Key Messages

- The most widely available indicator of oral health status in children is the number of decayed, missing or filled permanent teeth (DMFT) in 12 year-old children. In 2004, the European weighted mean of DMFT was 2.57.
- The past 25 years have seen substantial falls in the DMFT index across EU countries, but the improvements have been less marked in many Central and Eastern European countries and in deprived socio-economic groups.
- A DMFT index under 3 is considered a goal to be achieved in all communities within countries. Promotion of oral health and prevention of oral diseases are better provided through Primary Health Care.

Good oral health is essential to general health and quality of life. Yet oral disease is still a major public health problem in some high income countries and oral health promotion is a widely neglected area in public health.<sup>1,2</sup> Oral health means more than healthy teeth; the health of the gums, oral soft tissues, chewing muscles, palate, tongue, lips and salivary glands are also important. Tooth decay and gum disease are among the most widespread conditions in human populations. This chapter will focus on caries as main indicator of oral health in children.

#### Main Sources of Information

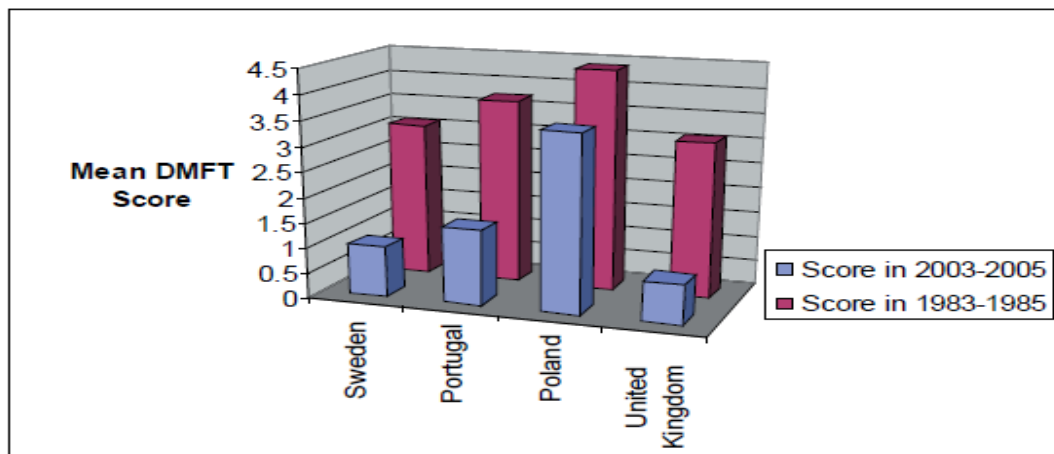
The most widely available indicators of oral health in children are the DMFT and the SiC (Significant Caries) index. DMFT describes the amount of dental caries in an individual by the number of decayed, missing or filled permanent teeth at 12 years of age. A DMFT index lower than 3 should be considered the goal for all communities, in all countries. The SiC is calculated by selecting the third of the population with the highest caries scores. The mean DMFT of this subgroup is the SiC index. It brings attention to those individuals with the highest prevalence of caries in a given population. The WHO Oral Health Programme (<http://www.whocollab.od.mah.se/expl/globalcar1.html>) is the main source of data on DMFT and SiC. Some data are available also in the Health-for-All WHO database and from the OECD. Few countries in Europe have established a national data collection system; only the United Kingdom has secular data on the prevalence of caries in young adults.

#### Size of the Problem

The global weighted mean DMFT value is 1.61 (this comprises 188 countries); in 2004, the European weighted mean DMFT was 2.57. The past 25 years have seen substantial falls in the DMFT index across EU countries, but data are missing for many countries. Improvements have been less marked in some Central and Eastern European countries (Bulgaria, Croatia, Hungary, Latvia, Lithuania, Poland), and there has been no improvement in deprived socio-economic groups (Figure 9.1.1).

Oral health is characterised by social inequalities in disease and patient management.<sup>3-6</sup> In European countries with reliable data, one third of children have around 80% of DMFT teeth, one fourth have around 65%, and 10% have around 40%. This means that conventional population-based preventive methods fail to reduce inequalities, as shown by high rates of tooth decay in high-risk groups. In 2003, the total expenditure on all aspects of care and treatment provided by dentists in EU15 countries has been estimated at about 45 billion euros. At least 66% of this money is probably spent to treat dental caries and its consequences, as well as periodontal diseases.<sup>7</sup>

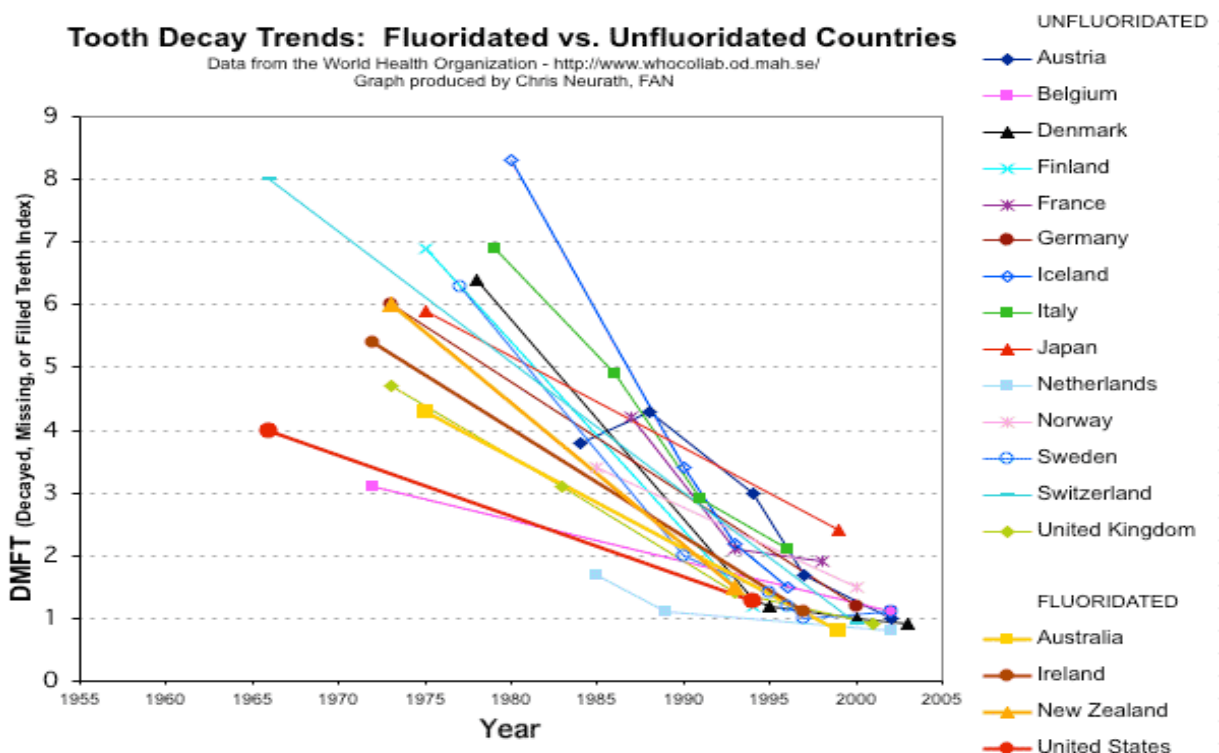
**Figure 9.1.1. Changes in national mean DMFT scores in Sweden, Portugal, Poland and the United Kingdom between the 1980s and the first decade of 2000 (Source: Eaton, 2007).**



### Causes and Risk Factors

Oral health is highly related to life style factors, such as high sugar diet and oral hygiene, while also reflecting whether or not protective measures, such as exposure to fluoride, are present. Dental plaque is the primary causal factor for caries and periodontal diseases. For prevention of caries at population level, it has become clear that regular exposure of the tooth surfaces to fluorides is key and that the major anticaries benefit of tooth brushing is given by the application of fluoride toothpaste.<sup>8,9</sup> Water fluoridation policies do not seem, at least so far, to have had an impact on tooth decay trends, which are in fact similar in countries with and those without fluoridation policies (Figure 9.1.2). Social class, frequency of eating/drinking, brushing frequency with fluoridated toothpaste, tobacco use and general health are other determinants of oral health.

**Figure 9.1.2. Tooth decay trends in fluoridated and unfluoridated countries (Source: Eaton, 2007).**



## Challenges

The past 25 years have seen substantial falls in the DMFT index across EU countries, but the improvements have been less marked in many Central and Eastern European countries and in deprived socio-economic groups. An important challenge is to reduce inequalities between countries and socio-economics groups. This may be better achieved by broadening the spectrum of oral health programmes in order to include improvements in quality of life, reduce health inequalities, and facilitate access to good quality care. This has already been done by some Member States.<sup>10</sup> This may also be achieved by integrating them into maternal and child health programmes and programmes for the prevention and control of non-communicable diseases.<sup>11</sup>

The changes in caries levels have been attributed to the use of salt, toothpaste, and fluorides in water. However, fluoridated water and salt are available in only a few European countries and many more children in Europe access fluoride through toothpaste. A systematic Cochrane review has provided firm evidence for the practice of regular, twice-a-day tooth brushing with fluoridated toothpaste to prevent dental caries.<sup>9</sup> There is little association between the number of DMFT among children and the number of dentists per inhabitant. Public health measures and free-of-charge access to oral health care are more effective.

At present, there is no permanent national surveillance system for oral health in Europe. An important challenge is to integrate the oral health sector with the national and European health information system, as proposed by the EGOHID (European Global Oral Health Indicators Development) project.<sup>12</sup>

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## 9.2 Overweight and Obesity

### Key Messages

- The prevalence of obesity in children shows a great variability among EU countries, being already worryingly high in some of them; the trend is probably upwards in school children, but not in infants and pre-school children.
- A complex web of interrelated individual, family, social, economic and environmental determinants is associated with the rise in the prevalence of obesity through changes in diet and physical activity.
- Multi-sectoral approaches that tackle inequalities are needed at local and national level to change these determinants and control obesity.
- Obesity starts early in life and its determinants act mainly before conception, during pregnancy and in early infancy; strategies for prevention should concentrate on these stages of the life course.

Obesity is currently considered a worldwide epidemic and a problem of very high public health importance. The increasing prevalence of obesity in children raises concern in all EU countries because of the implications for future health and the fear that health and social services will progressively become unable to cope with the burden. Obesity is not a disease in itself, but it is associated with a higher risk of many other diseases and conditions, some of which start to occur in childhood. The consequences of obesity may affect not only health and life expectancy, but also mental well-being, overall quality of life, school performance, as well as income and productivity.

### Main Sources of Information

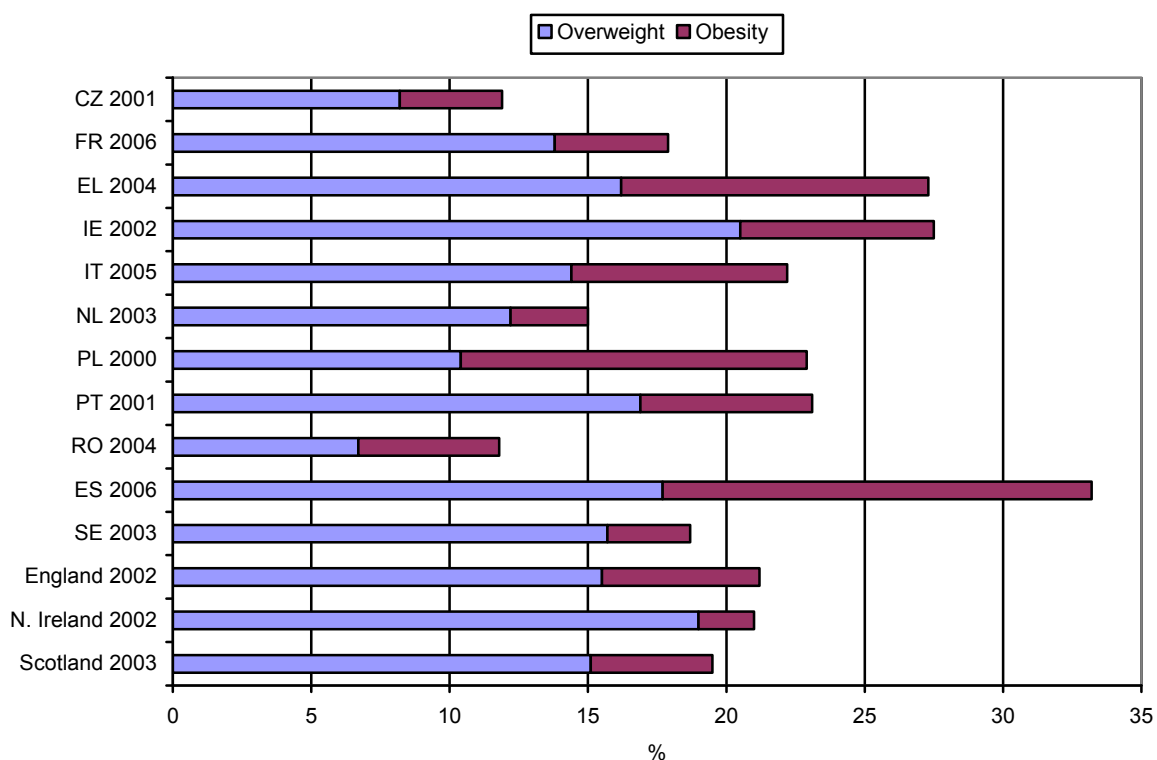
Most experts agree that the Body Mass Index (BMI), obtained from weight and height, should be used to calculate and compare rates of overweight and obesity in children. Weight and height data can be gathered routinely, e.g. in child health clinics, or through sample surveys. The latter is the preferred method when there is a need for rates that represent or approximate real values in a population. Weight and height data can be self-reported by individuals, or by parents in case of small children, or can be actually measured. Measured data are preferred to self-reported data because they are more accurate, if measurement methods are standardised. The BMI obtained in this way has then to be categorised, usually into four groups: underweight, normal weight, overweight, and obese children. The problem is that criteria for assigning children to these groups may vary. The most commonly used is the reference established in 2000 by the International Obesity Task Force (IOTF), with its cut-off points.<sup>1</sup> The IOTF reference, however, starts from the age of two. More recently, the WHO has published new global growth standards for children under five years of age.<sup>2</sup> These standards cover all infants and children from birth, but tend to yield overweight and obesity rates that differ from those yielded by the IOTF reference and cut-off points when applied to the same set of data. In addition, the WHO standards do not cover children older than five years; to obviate, WHO has merged its data for under-fives with data for older ages taken from the 1977 US National Centre for Health Statistics (NCHS) growth reference.<sup>3</sup> Once again, however, rates of overweight and obesity estimated with the two methods, IOTF and WHO, will differ. For this report, only surveys and reviews that are representative of national populations and that used comparable methods of getting BMI data were used. When confronted with results that differ because of different criteria used to categorise BMI data, it was decided to present all results.

## Size of the Problem

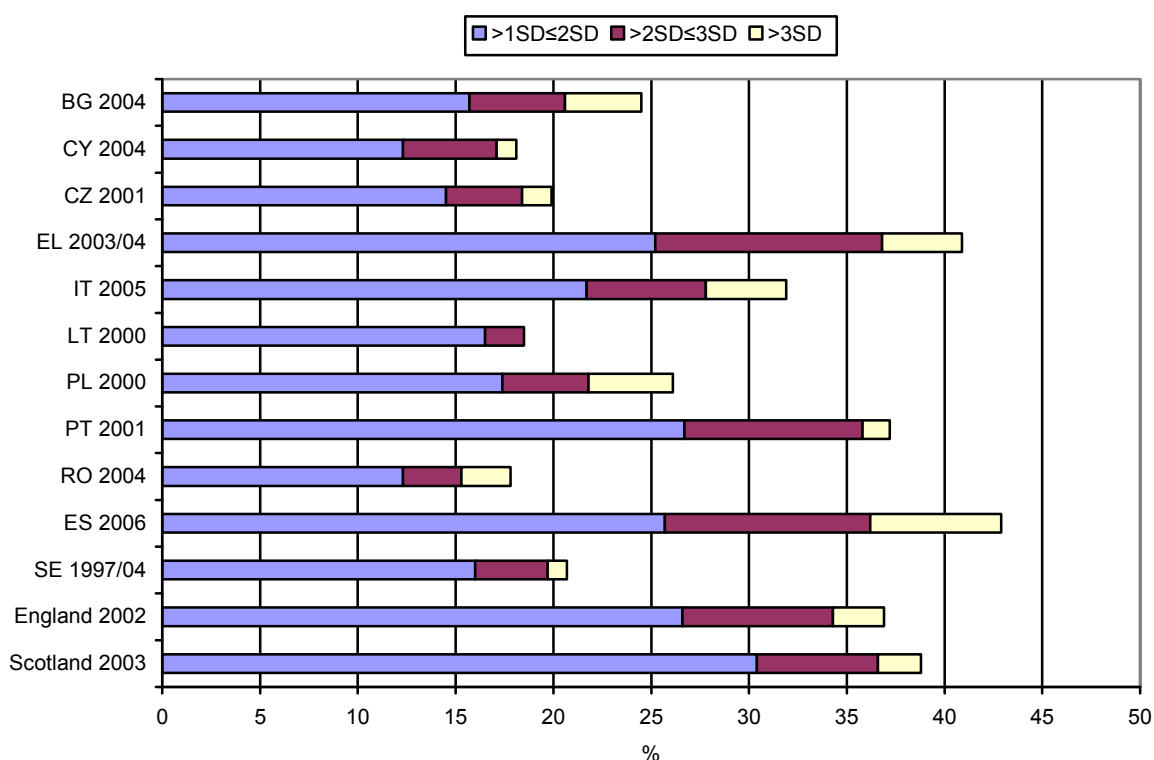
### Pre-school Children

Nationally-representative data on overweight and obesity in infants and pre-school children are available from 18 EU countries.<sup>4</sup> Using the IOTF reference and cut-offs, the prevalence of overweight plus obesity at four years ranges from 11.8% in Romania (2004) to 33.2% in Spain (2006), a three-fold difference (Figure 9.2.1). Countries in the Mediterranean region and the British Isles report higher rates than those in Central, Northern and Eastern Europe. Rates are generally higher in females than in males. Using the WHO standard, with cut-offs at 1, 2 and 3 standard deviations (SD) for risk of overweight, overweight and obesity, respectively, the rates are lower and the gender differences disappear. The difference between the highest (Spain 2006: 17.2%) and the lowest (Lithuania 2000: 2.0%) reported rates of BMI-for-age above 2 SD at four years is more than eight-fold (Figure 9.2.2). Data on trends over time are available only for four countries using the IOTF reference and cut-offs (Czech Republic, France, Netherlands and England) and for three using the WHO standard (Czech Republic, Netherlands and Romania). They refer to children who are 24 to 59 months old, except for England (24 to 71 months) and France (36 to 59 months). With the possible exception of England, there is no obvious trend towards increasing prevalence in the past 20-30 years in these countries.

**Figure 9.2.1. Prevalence rates (%) of overweight and obesity (IOTF reference and cut-offs) at 4 years of age by country.**



**Figure 9.2.2. Prevalence rates (%) of BMI-for-age higher than 1, 2 and/or 3 SD (WHO reference and cut-offs) at 4 years of age by country.**

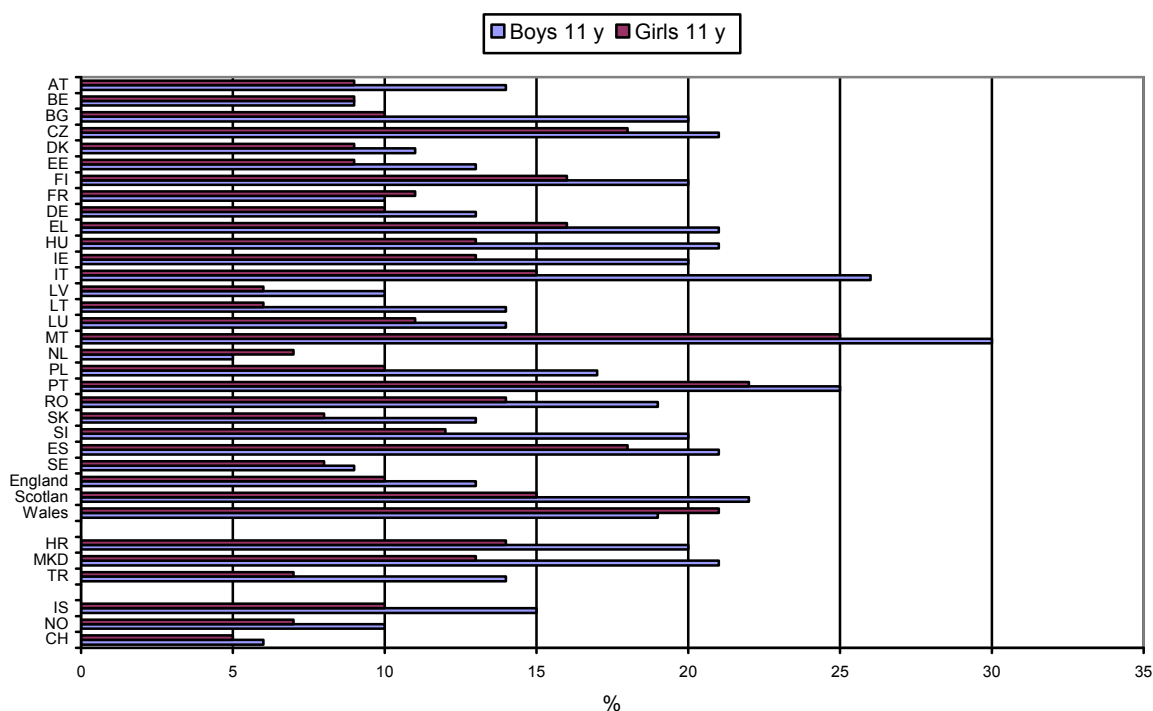


### *School Children*

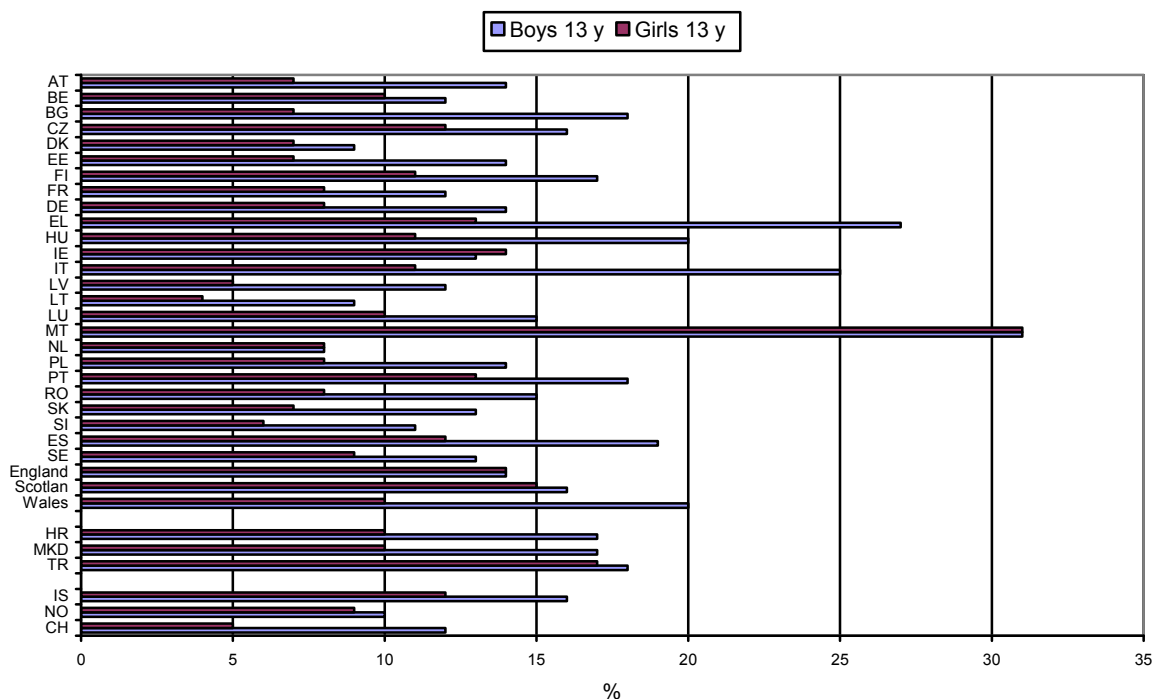
Data on the prevalence of overweight and obesity in school children are available and show increasing trends.<sup>5</sup> They are however difficult to use for comparisons across countries because they were gathered with different definitions and methods, and analysed using different references and cut-offs. WHO/EURO has coordinated from 2007 an inter-country survey in 12 countries and one region: Bulgaria, Cyprus, Czech Republic, Ireland, Italy, Latvia, Lithuania, Malta, Norway, Portugal, Slovenia, Sweden, and the Flemish region of Belgium. In 2010, four more countries joined the group for the second round of surveys: Greece, Hungary, FYR of Macedonia and Spain. The surveys were conducted on representative samples of school children aged 6-9 years using standard methods. Preliminary results of the first round indicate that on average 24% of the children aged 6-9 years old are overweight or obese, based on the WHO/NCHS growth standards.

Standard Health Behaviour in School Children (HBSC) surveys have been carried out for years in children aged 11, 13 and 15 years. They provide self-reported data on overweight and obesity; these are likely to be below the real values.<sup>6</sup> Figures 9.2.3 and 9.2.4 show the data available from the latest 2005/06 HBSC surveys in children 11 and 13 years old, respectively, by gender. The United Kingdom participated with three countries. There is little evidence of significant age differences in overweight or obesity among either boys or girls, but there is a tendency for 15-year-old girls to have lower levels of overweight or obesity than those aged 11. In approximately half of countries, compared to girls, boys are significantly more likely to be overweight or obese when they are 11 years old; and in the majority of countries, when they are 13 and 15. Family wealth is significantly associated with overweight or obesity in around half of countries. In most of these cases for boys, and in all of them for girls, those from lower income families are more likely to be overweight or obese. This pattern is strongest in Western Europe.

**Figure 9.2.3. Prevalence of overweight plus obesity (IOTF reference and cut-offs) reported by 11-year old boys and girls in Europe, by country.**



**Figure 9.2.4. Prevalence of overweight plus obesity (IOTF reference and cut-offs) reported by 13-year old boys and girls in Europe, by country.**



The percentage of children of 11 and 13 years of age meeting the recommendations on physical activity (60 minutes or more of activity on 5 or more days a week) is higher in boys (30% and 25% at 11 and 13 years of age, respectively) than in girls (22% and 15%, respectively), and is higher at 11 than at 13 years of age. At 11 years of age, the highest percentage was recorded in boys in Ireland and in the Slovak Republic (51%), the lowest in



girls in Switzerland (11%). At 13 years of age, the highest value was recorded once again in boys in the Slovak Republic (51%), and the lowest in girls in France (5%). Differences in levels of daily physical activity are high across countries, but are not patterned by geography. In almost all countries boys and younger children are more active. A significant association between low family income and lower prevalence of daily physical activity was found in under half of the countries across all geographic regions for girls and boys. Levels of reported physical activity are fortunately higher in 2005/06 than those recorded in the previous HBSC survey in 2001/02.

The 2005/06 HBSC survey also shows that:

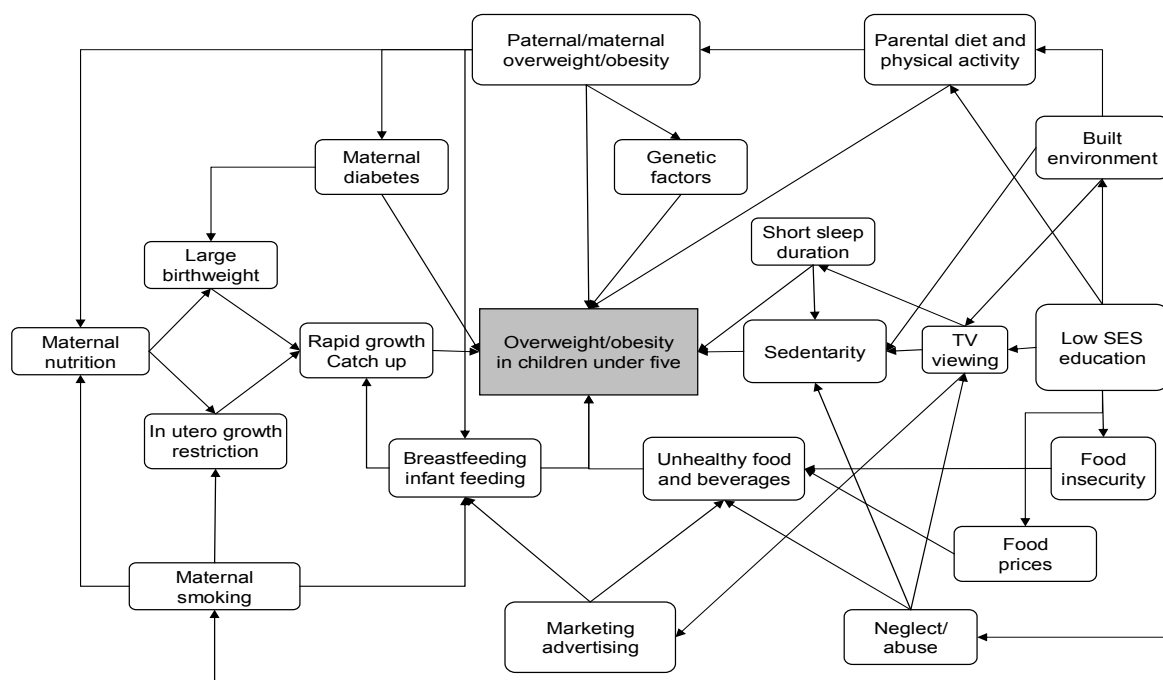
- Only about two thirds of adolescents eat breakfast every day before school and that this percentage decreases with age and is generally higher in boys than in girls;
- Only about a third eat fruit every day or more than once a day. The percentage decreases with age and is higher in girls;
- About a fifth take sugar-sweetened drinks every day or more than once a day. The percentage increases with age and is higher among boys.

Needless to say, adolescents watch television. The percentage spending two or more hours per day every weekday in front of a screen, including computer and other electronic media, is on average around 60-70%, with the highest values in Bulgaria (more than 80% in boys and girls) and the lowest in Switzerland (around 30% at 11 and 40% at 13 years of age). A further round of HBSC surveys has been carried out in 2009/10 but the results were not yet available at the time of writing this report.

## **Causes and Risk Factors**

Figure 9.2.5 shows the complex web of individual, familiar and social determinants associated with overweight and obesity in preschool children.<sup>7</sup> Obesity in children is predicted by parental obesity, including maternal birth weight, gestational diabetes and prenatal exposure to smoking. It is also associated with LBW: infants whose growth has been restrained in the womb tend to gain weight, or catch up, more rapidly during the early postnatal period, which leads to increased central fat deposition and greater insulin resistance. But obesity is also associated with large birth weight and early growth. Most studies show that rapid weight gain in infancy is consistently associated with increased risk. The exclusivity and duration of breastfeeding seem to be inversely associated with childhood and later obesity, though the adjustment for possible confounders tends to reduce the effect. Among other family factors, short sleep duration in infancy and early childhood was found to be associated with overweight at later ages. Recent studies have also related obesity in adulthood to early life experience of abuse and/or neglect. Finally, several studies found a higher risk of fatness associated with lower SES in childhood as determined by parental occupation or education or family income, or a combination of these factors. Food insecurity or insufficiency may affect the cause of pre-school obesity, even in high-income countries. As far as the physical and social environments are concerned, sedentariness, including high levels of television watching, is among the variables associated with overweight and obesity, while increasing levels of physical activity lower the risk. Social models of consumption may affect eating and drinking behaviours, and sedentariness. A positive association was found between greater intakes of sugar-sweetened beverages and weight gain and obesity in children. The association between television watching and childhood obesity is solid and confirmed by many studies, including a non-systematic review and an intervention study. However, the direction of causation and specific contribution of food advertising remains equivocal; a perennial problem in interpreting many of these studies is their cross-sectional design which raises the issue of reverse causality: while it is of course possible that the sedentary nature of television watching may induce weight gain, it is equally likely that obesity in its own right may be related to television viewing because other more strenuous childhood pastimes, such as sports or active play, are uncomfortable and therefore prohibitive for the overweight child.

**Figure 9.2.5. The complex web of individual, familiar and social determinants associated with overweight and obesity in preschool children (Source: Monasta, 2010).**



## Challenges

The first challenge has already been discussed at the beginning of this chapter: to gather and to analyse data on BMI in a standard way so that rates of overweight and obesity can be compared among and within countries, and also over time. This is essential to monitor the progress of the epidemic and the effect of its control strategies.

The second challenge is to develop effective interventions. A systematic review has recently shown that, despite some significant effect on intermediate outcomes (lower intake of saturated fatty acids, television watching), no effect on BMI and other growth measures could be attributed to a number of single or combined interventions for the prevention of overweight and obesity in pre-school children.<sup>8</sup> Action research is therefore needed to study the effect of complex multi-faceted interventions on micro (family) and macro (social) determinants on diet, by reducing the consumption of energy-dense foods high in fat and sugars, and physical activity. This action research would include:

- Control of smoking, diet, physical activity, disease and infection in pregnancy to reduce low and high birth weight;
- Protection, promotion and support of breastfeeding to increase its initiation, exclusivity and duration;
- Protection, promotion and support of appropriate and safe complementary feeding based on healthy family diets, that will lead to improved nutrition and set the basis for a healthy diet at older ages;
- Promotion of adequate and age-appropriate physical activity, including the reduction of television watching and other sedentary activities, starting very early in life and with parental participation, that will lead children to live a more active and less sedentary life;
- Action on social determinants (income, education, occupation, built environment), including the control of marketing of breast milk substitutes and unhealthy foods and beverages, and incentives and/or taxes that will stimulate the purchase and consumption of healthier foods.

All this requires firm commitment and intersectoral coordination.

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## 9.3 Diabetes

### Key Messages

- Type 1 diabetes remains the main form of diabetes in childhood, with a wide variation in its estimated incidence rate ranging from about 3 to about 60 per 100,000 children 0-14 years of age, with a north to south gradient.
- The incidence rate is increasing alarmingly in all countries, with greater increases in children under 5 and in Central and Eastern European countries. This is probably associated with environmental factors acting very early in life.
- Though data on children are scarce, type 2 diabetes occurs mostly during the second decade of life (mean age at diagnosis: 13.5 years), mainly as a consequence of poor dietary habits and increasing rates of obesity in the first years of life.
- Primary and secondary prevention should focus on adequate nutrition and physical activity early in life, as well as on access to improved case management and qualified care in multidisciplinary centres.
- Participation in Europe-wide registers and project, with targeted indicators, is essential for monitoring and better understanding of the epidemiology of diabetes.

Diabetes mellitus is a group of diseases characterised by high levels of glucose in the blood resulting from defects in insulin production, insulin action, or both. Diabetes can be associated with serious complications and premature death, but can be controlled, so that risk of complications can be greatly reduced. Type 1 diabetes is an autoimmune disease in which the immune system destroys the insulin-producing beta cells of the pancreas that help regulate blood glucose levels. It mostly has an acute onset, and most often occurs in children and adolescents. Type 1 diabetes remains by far the main form of diabetes in childhood. Other forms of diabetes now include monogenic diseases: the various forms of permanent and transient neonatal diabetes and the maturity onset diabetes of the young (MODY). Type 2 diabetes is due to insulin resistance and is one of the main consequences of the obesity epidemic, since overweight and obese children are at increased risk of developing it during childhood, adolescence and later in life.

### Main Sources of Information

The main sources of information are EURODIAB and DIAMOND, the type 1 childhood diabetes registers at European and global level, respectively. At present, the EURODIAB registers include 47,000 children diagnosed between 1989 and 2006 and cover 40 centres. The EUCID (European Core Indicators of Diabetes) project is another important source of data. Population-based studies have examined the epidemiology of type 2 diabetes in children. Their reports have been used here as sources of information.

### Size of the Problem

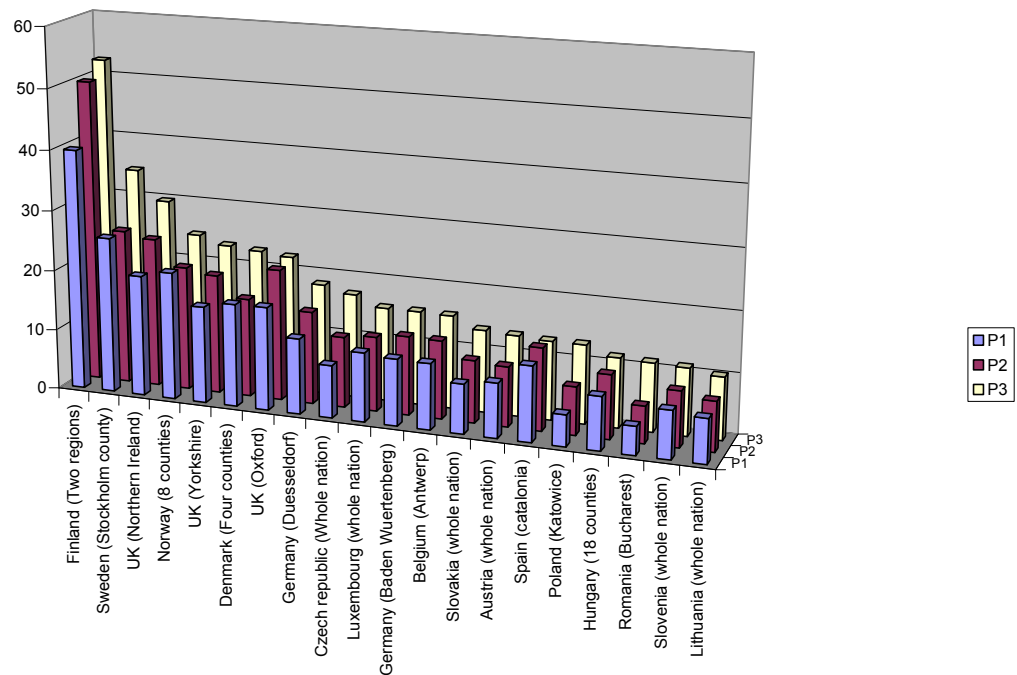
The incidence rates of newly diagnosed cases of type 1 diabetes per 100,000 children per year vary widely in different populations at global and European levels. In most populations, boys and girls are equally affected and the incidence increases with age, with a peak at puberty.<sup>1</sup> In Europe, a north to south gradient has been described, with Sardinia (Italy) being an exception. In the period 1989-1994, the standardised average annual incidence rate ranged from 3.2 cases per 100,000 per year in FYR of Macedonia to 40.2 cases per 100,000 per year in two regions of Finland. Other countries or regions with high incidence were Sardinia (36.6), Sweden (28.8), Norway (21.1), and Northern Ireland (19.6).<sup>2</sup>

Data from all but two out of 20 population-based registers in 17 countries, covering a 15-year period from 1989 to 2003, show significant annual increases in incidence, ranging from 0.6% to 9.3% (Figure 9.3.1).<sup>3</sup> The overall annual increase was 3.9% and the increases within the age groups of 0-4, 5-9 and 10-14 years were 5.4%, 4.3% and 2.9%, respectively. Data from

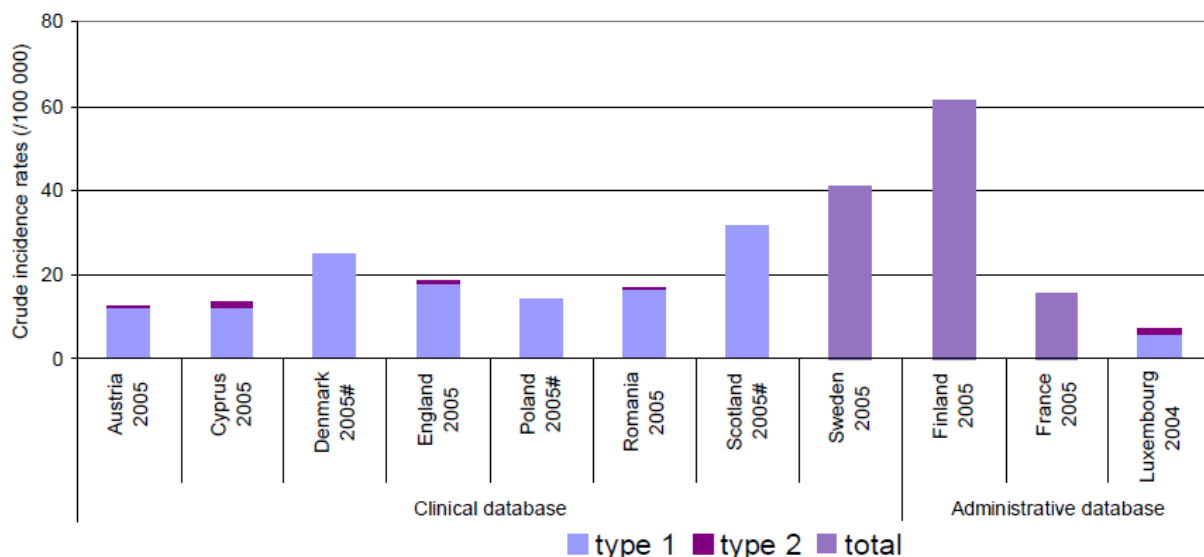
20 countries covering the 2004 to 2006 period show that Finland had the highest incidence (more than 60 per 100,000), followed by Sweden, Scotland and Denmark, all with incidence rates above 20 per 100,000 (Figure 9.3.2).<sup>4</sup> The same report shows that only five countries were able to provide data for type 2 diabetes in children.

The number of new cases in Europe in 2005 was estimated at around 15,000, 24% in the 0–4 age group, 35% in the 5–9, and 41% in the 10–14 years. Estimates of type 1 diabetes in European children for 2010 range from 3.2 in Turkey and 3.9 in FYR of Macedonia to 57.4 in Finland. Other three countries have incidence rates above 20 per 100,000: Norway 27.9, United Kingdom 24.5, and Denmark 22.2. In 2020, the predicted number of new cases is 24,400, with a doubling in children under five.<sup>3</sup>

**Figure 9.3.1. Trend in the incidence of type 1 diabetes in some European countries in three periods between 1989 and 2003 (Source: Patterson, 2009).**



**Figure 9.3.2. Age-standardised annual incidence rates of diabetes per 100,000 children of 0-14 years of age (Source: EUCID, 2008).**



Children with type 1 diabetes risk developing disabling and life-threatening complications at an early age, placing a significant human and economic burden on families and societies. Moreover, autoimmune diseases such as Coeliac disease and autoimmune thyroiditis are associated with type 1 diabetes. As compared to the type 1 diabetic adult patients, there are major physiological, medical, psychological, social and emotional differences in children. These differences arise from the stages of growth and development of the child (infants and toddlers, pre-school and school children, adolescents). Each period poses particular management problems with regard to insulin requirements, the responsibilities of the child and the parents, and monitoring the effects of insulin.

There is little information available on the epidemiology of type 2 diabetes in children.<sup>5</sup> This affects mainly obese children over 10 years of age belonging to certain population groups. Whereas type 1 diabetes is distributed throughout the population proportionate to socio-economic distribution, type 2 diabetes disproportionately affects those with fewer resources, e.g. lower income, less educated parents, with less insurance cover. Despite its milder symptoms, type 2 diabetes in children is a severe condition. Compared to their peers with type 1 diabetes, young people with type 2 diabetes have an increased risk of hypertension, dyslipidaemia, albuminuria, cardiovascular diseases and polycystic ovarian syndrome.

### **Causes and Risk Factors**

The DQ2/DQ8 genotype has been identified as a high risk for type 1 diabetes. However, the increasing incidence over a short period of time, the low concordance rate in monozygotic twins, and the lower frequency of the high risk genotype in recent years support the importance of environmental pressure.<sup>1</sup> Population based studies have suggested that some environmental risk factors, such as viruses (enteroviruses), may be associated with the initiation of autoimmunity towards the beta cells of the pancreas, while life style habits may put an overload on them. Early exposure to cow's milk protein as a consequence of no or short breastfeeding has also been highlighted as a risk factor. A large EURODIAB case control study has confirmed the importance of other risk and protective factors.<sup>3</sup> Among the former, there are perinatal factors such as maternal pre-eclampsia, neonatal respiratory disease, jaundice and high birth weight, as well as rapid weight gain in infancy and high BMI during childhood. Atopic disease and early supplements of vitamin D, which probably act as immuno-modulating agents, appear to be protective. As far as type 2 diabetes is concerned, up to 25% of obese children have impaired glucose tolerance, placing them at high risk. Overweight and obesity are therefore the most important risk factors for type 2 diabetes.

### **Challenges**

Although the mechanism through which the risk factors operating early in life lead to the development of type 1 diabetes is not yet fully understood it seems important to start taking preventive measures from the perinatal period through the early months and years of life. Actions should include control of weight gain in pregnancy, prevention and treatment of pre-eclampsia, protection, promotion and support of breastfeeding, increased physical activity, and improved nutrition at school and at home.

An important challenge is to further broaden the participation in Europe-wide registers and projects such as EURODIAB, EUCID and EUROBIROD (European Best Information through Regional Outcomes in Diabetes)<sup>6</sup> for monitoring the epidemiology of diabetes and quality of care. Case management should be optimised throughout Europe by means of:

- Access to qualified and multidisciplinary specialists, including paediatricians, nutritionists, diabetes nurses and educators.
- A solid infrastructure for easy access to specialist teams, protocols, databases, and recall systems for regular reviews.
- Universal access to medical technologies such as improved insulin administration and blood glucose monitoring devices.

- Effective parenting and children participation through full understanding of the disease, careful planning of diet and physical activity, daily monitoring and adjustments of insulin dosage.
- Group activities such as peer-to-peer groups and diabetes camps.
- Identification and implementation of specific participation in social life, e.g. training of schoolteachers and sports.

The SWEET Project aims to address these issues by supporting the development of centres of reference for paediatric and adolescent diabetes services across EU countries.<sup>7</sup>

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## 9.4 Cardiovascular Diseases and Stroke

### Key Messages

- Congenital heart diseases are the most frequent causes of cardiovascular disease among children in Europe. Rheumatic carditis is still common in some Eastern European countries. Venous and arterial thromboembolism, familial hypercholesterolemia, and stroke, albeit rare, are increasingly recognised as a paediatric concern.
- Child poverty, dietary habits, smoking, obesity and insufficient physical activity are important risk factors for cardiovascular diseases later in adulthood.
- Prevention of cardiovascular disease, as well as control of risk factors for cardiovascular disease, should start early, before conception and during pregnancy, and should continue throughout infancy and childhood.

Cardiovascular diseases in children include a wide variety of congenital and acquired conditions, the latter being a consequence of infections and autoimmune disorders. This chapter focuses on the main causes of cardiovascular diseases in children and on the risk factors for cardiovascular disease which are increasingly recognised as being the consequence of early social and environmental exposure and life styles.<sup>1</sup> It also covers thrombosis and stroke as rare but frequently overlooked paediatric issues.

### Main Sources of Information

Systematic reviews and practice guidelines are the main sources of information, in addition to the EUROCAT register and database for congenital malformations. For the majority of these diseases, and for stroke, there are few detailed country specific data.

### Size of the Problem

#### *Congenital Heart Diseases*

Congenital heart diseases are among the most frequent congenital defects (see Chapter 4). In Europe, prevalence ranges from 30 to 180 per 100,000 births, with wide variations among countries depending on practices for prenatal diagnosis and elective termination of pregnancy. The variable severity of the heart defect, the timeliness of diagnosis and the quality of available surgical and medical care determine a substantial variation in the quality of life of the affected children, which may range from premature death to severe impairment to a completely normal life.<sup>2,3</sup>

#### *Rheumatic carditis*

Rheumatic fever is an immuno-mediated disease caused by common streptococcal pharyngeal infection (known colloquially as 'strep throat'), which, if unrecognised and untreated, can eventually lead to chronic carditis. There are geographical differences in incidence; in Western Europe the incidence rate is low, less than 10 per 100,000 children per year, while in Eastern Europe the incidence is higher.<sup>4</sup>

#### *Thrombosis, Thromboembolism and Stroke*

Thrombosis is the development of a blood clot inside a blood vessel, which causes obstruction to the blood flow. If the clot breaks loose, it is carried by the blood stream (thromboembolism) and it can plug another vessel.<sup>5-7</sup> Stroke is a rapid loss of brain functions due to disturbances in the cerebral blood supply. Venous and arterial thromboembolism, albeit rare, are increasingly recognised as paediatric concerns. Population data on the prevalence of thrombosis and stroke in children in Europe are scanty. The reported incidence of stroke is 1.9-3.1 per 100,000 children per year, with children under one year of age



presenting a higher incidence.<sup>8-9</sup> Long term admission to hospital, from 20 to 80 days on average, and subsequent disabilities, are common.<sup>10</sup>

### *Cardiovascular Risk*

It is difficult to quantify the proportion of healthy children that are at risk of cardiovascular disease in adult life, since this depends also on genetic susceptibility. All overweight and particularly obese children should be considered at risk, with the addition of children affected by familial hypercholesterolemia.<sup>11</sup>

### **Causes and Risk Factors**

Factors potentially leading to congenital heart diseases include maternal infections, such as rubella, maternal use of alcohol and other drugs (e.g. hydantoin, lithium, thalidomide), maternal illness (diabetes, phenylketonuria, systemic lupus erythematosus), and genetic defects. Vaccination against rubella, reduced alcohol consumption, pharmacovigilance and appropriate use of drugs in pregnancy, together with effective treatment of maternal disease, can reduce the burden of congenital heart disease. Supplements of folic acid aimed at decreasing the incidence of neural tube defects may also reduce the incidence of congenital heart defects.

Rheumatic disease is clearly associated with unfavourable environmental conditions and low SES. The increased incidence of thromboembolism and stroke is probably due to a number of factors such as improved survival from serious underlying illnesses, greater use of invasive vascular procedures and devices, and a growing awareness, but also to raising prevalence of obesity as a predisposing risk factor.

### **Challenges**

With the exception of congenital heart diseases (see Chapter 4), insofar as cardiovascular diseases and stroke are concerned, there are few detailed country-specific data. The first challenge, therefore, is to set up a standardised data collection system that will allow comparisons and analysis of trends between countries.

The second challenge is timely prevention, including the control of risk factors. This should start very early, before conception and during pregnancy, and continue throughout infancy and childhood. Primary prevention is based on preconception counselling, improvement of housing conditions for the poorest households, adequate nutrition and physical activity from infancy and childhood, and diagnosis and treatment of streptococcal pharyngitis. Secondary prevention includes prenatal ultrasound screening for congenital defects, introduced over 20 years ago and now increasingly available in all European countries. There are large regional variations in screening practices in Europe, as well as in organisational and cultural factors, associated with wide differences in prenatal detection rates. Widespread teaching and training is required to achieve a uniform standard.<sup>12</sup> Screening for familial hypercholesterolemia is not recommended, but children with high cholesterolemic levels should be considered for medical treatment.<sup>13</sup>

As far as specialist care is concerned, the challenge is to make access to referral centres for child heart surgery available to all children through appropriate inter-country agreements when necessary, and increasing inter-country collaboration and adoption of common evidence based guidelines for emerging conditions such as stroke.<sup>14</sup> Access to appropriate drugs is still a problem: studies in Europe report that about 60% of the most commonly used cardiovascular medications are off-label for the paediatric population and therefore their use should not be permitted. Efforts are needed to stimulate good quality paediatric research to better identify children at risk, as well as effective protocols for prevention and treatment. In addition, efforts are needed to improve drug labelling for children.<sup>15</sup>

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## 9.5 Coeliac Disease

### Key Messages

- Increased awareness and new diagnostic tests have revealed in the last two decades that coeliac disease is a common condition, with a prevalence of about 1% in the total population in Europe.
- Coeliac disease is an important burden for societies and health systems due to its high prevalence, wide range of signs and symptoms, and associated risk of autoimmune disease, cancer and increased mortality.
- The disease satisfies many criteria for a population screening, but more research is needed to explore further the benefits and risks of such a strategy.

Coeliac disease (genetic gluten intolerance) is an immune mediated enteropathy triggered by the ingestion of gluten, the major protein component of wheat, and related proteins in rye and barley, in genetically susceptible individuals. The disease can present in early infancy with gastrointestinal symptoms and malabsorption (classical form), but more frequently later in life with other signs and symptoms as short stature, anaemia, abdominal pain and a variety of autoimmune disorders (atypical form). Due to increased awareness of atypical forms and new diagnostic tests, most cases are now diagnosed in childhood.

### Main Sources of Information

Systematic reviews and other scientific articles identified by a systematic literature search. Prevalence rates may be affected by bias related to case definition and case selection: differences between tests for prevalence assessment, types of antibodies, non-mandatory biopsy, and patient sampling. Moreover, ICD-9 and ICD-10 codes refer only to the malabsorption syndrome, which in European countries accounts for only about 0.1-0.5% of all admissions to hospital.

### Size of the Problem

Although with some variability, several studies and systematic reviews highlight that coeliac disease is a common disorder with a prevalence in the general population that is close to 1% (Table 9.5.1).<sup>1-3</sup> The rate of diagnosis of coeliac disease has markedly increased in recent years due to higher awareness of the disease and the introduction of simple serological tests with high specificity; however, it is unlikely that the true prevalence has really increased in the population.

**Table 9.5.1. Prevalence of coeliac disease in some European countries**

CZ	0.45%	NL	0.1%
DK	0.2-1.2%	PT	0.74%
EE	1.1%	ES	0.3-0.9%
FI	0.6-1.2%	SE	0.6-1.8%
DE	0.2-1.5%	UK	0.8-1.5%
HU	1.1%	IS	1.1%
IE	0.8%	NO	0.3-0.8%
IT	0.3-1%	CH	0.1-0.75%

There are no detailed country specific data on mortality in the general population. Cohort studies and surveys show that, when compared to the general population, symptomatic patients with coeliac disease have a 2 to 3-fold excess mortality. Causes of death show an excess risk of cancer, with non-Hodgkin's lymphoma accounting for two thirds of the cases. No excess mortality and morbidity has been reported in patients with mild or asymptomatic coeliac disease,<sup>4</sup> with the exception of reduced bone health.<sup>5</sup>

Coeliac disease is a common condition with a variety of possible presentations. Unnecessary health examinations and under-diagnosis with misdiagnosis of other conditions (e.g. allergies) are common in patients with coeliac disease, with a consequent cost for the individual, the health system and the society. The increasing use of non-validated diagnostic tests may result in over-diagnosis and growing number of prescriptions for gluten-free diets, with increased spending in public health care.<sup>6</sup>

### **Causes and Risk Factors**

Coeliac disease occurs in genetically predisposed people. The factors that lead to the development of the disease in predisposed individuals when they are exposed to gluten or gluten-like proteins are still under investigation. They include infections with intestinal viruses, the presence of other diseases (e.g. Down syndrome, type 1 diabetes, immuno-mediated disorders), and dietary factors. Among these, the timing of introduction of gluten and the diet the infant has when this occurs, have attracted the interest of researchers. Infants exposed to gluten in the first three months have 5 times the risk of developing coeliac disease compared to those exposed at 4 to 6 months. Those exposed when older than 6 months old have only a slightly increased risk. Prolonging breastfeeding until the introduction of gluten is associated with a reduced risk of developing coeliac disease in infancy and childhood.<sup>7,8</sup>

### **Challenges**

Knowledge and awareness on coeliac disease has massively increased in the last 20 years. However, under-diagnosis is still very common. Prevalence rates may be affected by bias related to case definition and case selection (differences between tests, types of antibodies, non-mandatory biopsy, and patient sampling). An important challenge is to improve active case finding through newly available rapid point-of-care tests among patients who seek medical advice,<sup>9,10</sup> as well as evidence-based guidelines for diagnosis and treatment. There is a general agreement on investigating systematically for coeliac disease patients with symptoms (e.g. growth failure, anaemia) or other conditions associated with the disease (type 1 diabetes, Hashimoto disease, Down syndrome).<sup>11,12</sup> Primary prevention at the moment is limited to the promotion of exclusive breastfeeding and its continuation when complementary foods containing gluten are introduced to the infant's diet.

Another challenge is to promote effective patients' education to a simple and affordable gluten-free diet, which should not depend only on industrial products with an average cost higher than ordinary foods. On the other hand, availability of gluten-free foods is fundamental in places as school canteens, but this is heterogeneously implemented across different regions in Europe. The mandatory disclosure of substances containing gluten on food labels is supported by the law on food labelling enforced by the EU in 2005, yet the disclosure of possible cross-contamination still remains unsupported.

Finally the disease satisfies many criteria for a population screening, but further research and collaborative studies between epidemiologists and clinicians are needed to find an agreement on screening of first and second-degree relatives of patients with asymptomatic coeliac disease. Population screening is debated and no country in the world has yet adopted it (Table 9.5.2).<sup>1</sup>

**Table 9.5.2. Arguments for and against population screening for coeliac disease.**

<b>For</b>	<b>Against</b>
<ul style="list-style-type: none"> <li>• Early clinical detection is difficult</li> <li>• Condition is common</li> <li>• Screening tests are highly sensitive and specific</li> <li>• Untreated disease could lead to increase mortality, morbidity and high costs</li> <li>• Effective treatment is available</li> </ul>	<ul style="list-style-type: none"> <li>• Implications of a false positive diagnosis</li> <li>• Lack of complete knowledge on the natural history of the disease</li> <li>• Uncertainty on the effectiveness of the therapy (diet) in preventing all disease-related complications*</li> <li>• Variable compliance with treatment (strict gluten-free diet)**</li> </ul>

\* There is limited evidence that adherence to a gluten-free diet will prevent and/or improve complications in which the pathogenic mechanisms is uncertain.<sup>13,14</sup>

\*\* Compliance in adults range from 40% to 90%, and is reported to be lower for asymptomatic cases detected through screening.<sup>15</sup>

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## 9.6 Asthma and Allergic Diseases

### Key Messages

- Asthma and allergic conditions, such as eczema, rhino conjunctivitis and food allergies are very common in children in Europe and place a high burden on patients, families and the health care system.
- Countries in Northern Europe report the highest prevalence of asthma and allergic conditions, although rising trends have been observed over the last decade in several countries in Eastern and Southern Europe.
- Causes and risk factors are complex and include genetically inherited susceptibility and environmental exposures.
- Strategies to reduce the burden of asthma and allergic conditions should aim at improving prevention at both household and community level, access to good quality case management (including essential drugs), and patient and family education.

Asthma is a chronic, inflammatory disease in which the airways become sensitive to allergens and other triggers of bronchial constriction. Its symptoms are respiratory (cough and difficult breathing) and may be either constant or intermittent. Allergic conditions such as rhinoconjunctivitis and eczema (a skin condition with onset in infants and young children), are common in children. Food allergy is an allergic response to a variety of foods, which causes symptoms that may range from uncomfortable to life threatening. Allergic diseases may coexist in the same child, although generally appearing at different life stages. Only asthma and the commonest allergic conditions in children, such as eczema, rhinoconjunctivitis and food allergy will be discussed in this chapter.

### Main Sources of Information

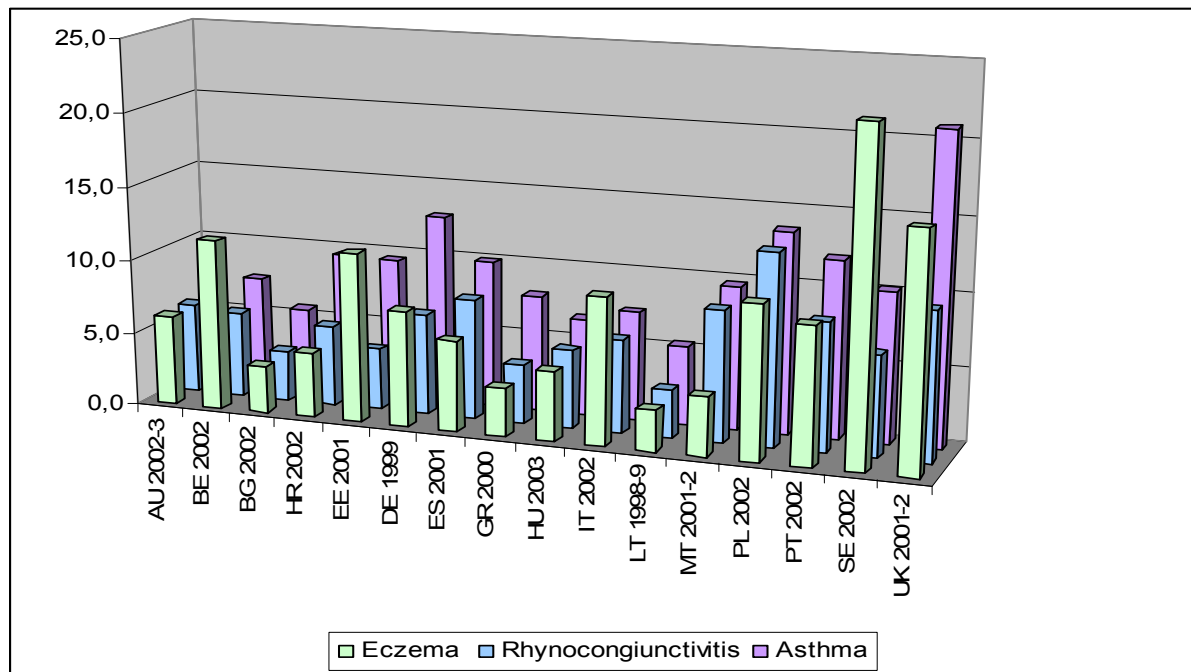
For data on prevalence and trends, the sources are the International Study of Asthma and Allergies in Childhood (ISAAC),<sup>1</sup> systematic literature reviews, some country-specific surveys, and the Global Initiative for Asthma (GINA) reports.<sup>2</sup> For hospital admission, the sources are the WHO European Hospital Morbidity Database,<sup>3</sup> and the GINA reports. For mortality, the GINA reports are the main source of data. Heterogeneity in case detection and definition may differentially affect the databases, making comparisons problematic. The ISAAC questionnaires are the most widely used methods of case detection and are therefore the main source of reliable data.

### Size of the Problem

Asthma and allergic diseases are the most common chronic illnesses among children in Europe, accounting for a substantial proportion of childhood admissions to hospital under the age of 12. The prevalence of asthma and allergic conditions in Europe varies widely. In general, a higher prevalence of eczema, rhinoconjunctivitis and asthma is reported by Northern European countries such as the United Kingdom, Ireland and Scandinavia, while the lowest rates are usually found in Eastern and Southern countries (e.g. Bulgaria, Greece, Hungary, Lithuania, Poland, Romania) (Figure 9.6.1). Countries with high prevalence of asthma and allergic diseases in children 6-7 years old also show high prevalence in the age group of 13-14 years, with few exceptions. Wide geographical variations in the prevalence of allergic conditions are reported also within countries. For example, the prevalence of wheeze in children who are 6-7 years old in 10 different centres participating in the ISAAC study in Italy and Spain ranges between 5.4% and 9.7%, and between 7.1% and 12.9%, respectively. Similar wide variations in prevalence are observed also for other allergic conditions in other countries and/or age groups. These variations within a population of a similar genetic pattern are not surprising and reinforce the hypothesis of a role for environmental determinants in the origin of allergic conditions. For this same reason, the prevalence of asthma is generally

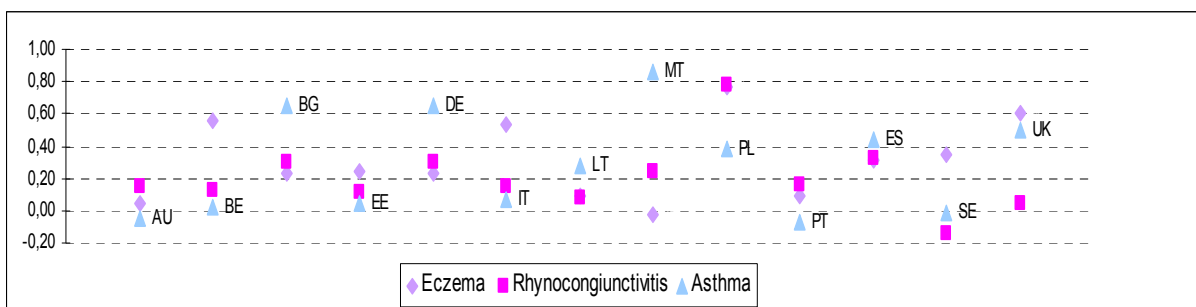
higher in urban areas compared with suburban areas, and is even lower in communities living in areas of high altitudes.<sup>2</sup>

**Figure 9.6.1. Prevalence rates of symptoms of eczema, rhinoconjunctivitis and asthma in children between 6 and 7 years of age in some countries (Source: ISAAC Phase Three studies).**



In most European countries, the prevalence of allergic conditions continues to increase (Figure 9.6.2). Important increases in the prevalence of asthma have been reported in Eastern Europe, probably due to the rapid changes in life style. With increasing urbanisation, further increases are likely to occur, with a higher burden of asthma in Eastern Europe. A stable prevalence, or even some reduction, has been observed in some regions, in particular within countries where allergic conditions had already reached high levels (Ireland, United Kingdom, Sweden).<sup>1,4-7</sup>

**Figure 9.6.2. Annual changes in prevalence rates of eczema, rhinoconjunctivitis and asthma in children between 6 and 7 years of age in some countries.**



In most countries in Europe, there has been a general declining trend of asthma mortality in the general population. This pattern has been primarily attributed to changes in management, in particular the increasing use of inhaled corticosteroids. However, there are a number of countries in Western and Eastern Europe where mortality from asthma has not fallen over the last decade to the degree observed in other countries. High case fatality rates are likely to be due to a number of factors including access to health care, and in particular to drugs, investments in patients' education, and quality of care in emergency medical services.

Allergic conditions place a high burden on the health care system and society. Asthma is one of the leading causes of outpatient visits and hospital admissions in children, representing 3%-15% of total admissions, half of which occur in children younger than 4 years of age.<sup>3,8</sup> Anti-asthmatic drugs, such as bronchodilators and steroids, are among the most prescribed drugs in children, accounting for 19% of outpatient prescriptions in Italy, 13.9% in Denmark, 9.1% in Norway and 6.2% in the Netherlands.<sup>9-10</sup> Indirect costs are also very high. In the United Kingdom and Ireland it is estimated that overall about 20 million working days are lost due to childhood asthma each year.<sup>2</sup> The prevalence of food allergy is uncertain, also because various types of food intolerance are frequently confused with food allergy, and symptoms may remain unrecognised.

## **Causes and Risk Factors**

Childhood asthma is a disease, or more likely a group of diseases, caused by a complex interaction of factors, which is not yet completely understood. There is certainly a genetic basis, such as an inherited susceptibility to allergens, or to bronchial reactivity. But this susceptibility can also be shaped by early exposure to infections and allergens, usually very early in life. Triggers include respiratory infections, most frequently in the earliest years, and exposure to allergens, most frequently later on in childhood. Some children have exercise-induced or stress-induced asthma. The environment plays also an important role in causing exacerbations of asthma in asthmatic patients and maybe in triggering the development of asthma in susceptible subjects. Also the cause of eczema is not completely known. It is commonly found in children with allergies, or who will develop allergies, and/or in children with parents or siblings who have allergies, and it is frequently linked to exposure to certain foods. The hygiene hypothesis, which interprets the inverse association in allergy risk with family size as a result of differential exposure to infections acquired in childhood, and explains it with an immuno-modulating effect of early infections, is not yet definitely confirmed.<sup>11</sup> Recently, the increased risk of developing asthma in children born from caesarean section has been explained with the reduced early exposure to bacterial contamination at birth.<sup>12</sup>

The main risk factors for developing childhood asthma are: presence of eczema or allergic rhinitis, family history of asthma and/or allergies, LBW or being overweight, exposure to cigarette smoke before and/or after birth, being male and being raised in a low-income environment, exposure to exhaust fumes or other types of pollution. Risk factors for rhinoconjunctivitis and eczema are a family history of the disease, while breastfeeding is a known protective factor. As mentioned above, asthma and allergic diseases are more common in industrialised and urbanised societies than in the rural and agricultural ones, although these differences are becoming less defined.

## **Challenges**

The first challenge is to use standard methods of case detection and definition (e.g. using the ISAAC questionnaires) in order to make analysis of trends and comparisons across and within countries more reliable.

Asthma is a common condition with a high burden on individuals, families and society. A comprehensive public health approach is needed to reduce the burden of asthma, including:

- Extensive patient and family education;
- Identification and control of environmental triggers;
- Measures to reduce tobacco smoking, improve housing and reduce exposure to indoor and outdoor air pollutants;
- Objective monitoring of severity;
- Development of a comprehensive step-wise medication programme focusing on anti-inflammatory therapy;
- Plans for home management of exacerbations and regular follow-up care.



All of the above must be done with an equity approach. Asthma affects some minority and low socio-economic groups disproportionately. Socio-economic factors also reduce access to appropriate health care and tend to be related to adverse health outcomes.

The national asthma public health programmes developed in a number of Scandinavian countries, particularly in Finland, are considered a model for their effect on morbidity and mortality. The United Kingdom National Asthma Campaign is a successful example of a national education, management, research-based programme which has contributed to reducing the burden of asthma.<sup>2</sup> The availability of anti-asthmatic drugs is limited by their cost in some Eastern European countries. Confidential inquiries have shown substandard routine care in Eastern and North-Western Europe, where under-treatment and overuse of anti-allergic drugs have been reported.<sup>2,9,13</sup>

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## 9.7 Visual Impairment

### Key Messages

- The prevalence of childhood blindness in Europe is between 0.1 and 0.41 per 1,000 children between 0 and 15 years of age, with wide variations in prevalence mainly due to variable quality of data across countries. Prevalence of low or poor vision is unknown, but it can be estimated as several times higher.
- Visual impairment may be brought about by a variety of causes, including retinopathy of prematurity, which is the leading cause in high-income countries, as well as congenital anomalies, cancer, myopia, amblyopia and injury.
- Prevention, early detection, treatment and rehabilitation may substantially reduce both the prevalence and the severity of visual impairment problems.
- Technological developments may substantially improve the prospects of children with severe visual impairment, and should be made available to all children.

Visual impairment is a condition that prevents normal vision in both eyes.<sup>f</sup> Many children have poor eyesight, which can be corrected by wearing glasses or contact lenses. However, there are a number of serious problems that cannot be corrected, such as those caused by retinopathy of prematurity, cancer of the retina (retinoblastoma) and a variety of congenital syndromes, such as Usher's syndrome. This chapter focuses on the most serious causes of visual impairment.

### Main Sources of Information

The main sources of information are articles reporting data from national registries for blind people, often showing data on low vision, and articles found via web-based databases. The State of the World Sight's report produced by WHO and the International Agency for the Prevention of Blindness (last available, 2005) is the most reliable global source of data.<sup>1</sup>

### Size of the Problem

Available data suggest that globally there may be a ten-fold difference in the prevalence of childhood blindness between the wealthiest and the poorest countries in the world, ranging from as low as 0.1 per 1,000 children aged 0-15 years within the former, to 1.1 per 1,000 within the latter.<sup>1</sup> Prevalence of childhood blindness in Europe is between 0.1 and 0.41 per 1,000 children 0-15 years of age, with wide variations across countries (Sweden 0.11 per 1,000 children 0-19 years of age, Denmark 0.41, Finland 0.15, Iceland 0.19, and Norway 0.15 per 1,000 children aged 0-15 years).<sup>2</sup> A study carried out in the United Kingdom on a large sample of visual impaired children, identified through national active surveillance schemes in ophthalmology and paediatrics, reported that the annual incidence was highest in the first year of life, 4.0 per 10,000 infants, with a cumulative incidence by 16 years of age of 5.9 per 10,000.<sup>3</sup> There are no reliable data on the prevalence of low vision among children. It is expected to be several times more frequent than blindness.

### Causes and Risk Factors

These can be classified as:

- Hereditary (e.g. genetic diseases, chromosomal abnormalities);
- Acquired during pregnancy (e.g. congenital cataract due to rubella, toxoplasmic macular retinochoroiditis);

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<sup>f</sup> Visual impairment includes blindness and low vision. Blindness is defined as visual acuity, or clearness of vision, of less than 3/60 with best possible correction (ICD10 categories 1 and 2). Low or poor vision is defined as visual acuity of less than 6/18 but equal or superior to 3/60 (ICD10 categories 3, 4 and 5).

- Acquired in the perinatal period (e.g. retinopathy of prematurity, birth injury, neonatal conjunctivitis);
- Acquired in childhood (e.g. vitamin A deficiency disorders, measles, eye infection and trauma).

Retinal disorders, optic atrophy, and injury of the higher visual pathways are the main anatomic causes of visual loss in children. In the United Kingdom, of 439 newly diagnosed children, 336 (77%) had additional non-ophthalmic disorders or impairments: cortical visual impairment, retinal disorders, and disorders of the optic nerve affected 48%, 29%, and 28% of cases, respectively.<sup>3</sup> About 10% of these children died within a year of diagnosis, 77% in the first year of life, because they had associated non-ophthalmic disorders causing death. Prenatal causal factors affected 268 children (61%), with perinatal or neonatal and childhood factors each affecting 77 children (18%). Incidence and causes varied with the presence of non-ophthalmic impairments or disorders, birth weight, and origin. At least 75% of children had disorders that were neither potentially preventable nor treatable, with current knowledge.

The most frequent causes of severe visual impairment in European countries are retinal affections (particularly retinal dystrophies), congenital cataract, optic atrophy, retinopathy of prematurity and congenital anomalies, often within multi-organ complex inherited and congenital syndromes. Due to variability in the incidence of risk factors and the implementation of preventive interventions, there is some variation of the most frequent causes across Europe (Table 9.7.1).<sup>2,3</sup>

**Table 9.7.1. Main causes of severe visual impairment in children in some European countries**

<b>Scandinavia</b>	<b>United Kingdom</b>	<b>Hungary</b>	<b>Czech Republic</b>
1. Cortical visual impairment	1. Cortical visual impairment	1. Congenital cataract	1. Retinopathy of prematurity
2. Optic atrophy	2. Retinal dystrophies	2. Congenital anomalies	2. Congenital anomalies
3. Congenital anomalies	3. Optic atrophy	3. Myopia	3. Hereditary disorders
4. Retinal dystrophies	4. Congenital cataract	4. Retinopathy of prematurity	4. Congenital cataract
5. Retinopathy of prematurity	5. Congenital ocular anomalies	5. Retinal degeneration	5. Congenital glaucoma

It is known that up to the age of 2 years, LBW infants or infants requiring special care in the neonatal period have a greater risk of visual and ocular defects compared to the rest of the population. There are a number of interlinked risk factors that are associated with retinopathy of prematurity: IUGR and prematurity, high levels of supplemental oxygen, mechanical ventilation, intraventricular haemorrhage, and maternal factors including heavy smoking, diabetes, and pre-eclampsia.

Refractive errors that affect a large proportion of the population, including children, can be easily diagnosed, measured and corrected with spectacles or other corrections to attain normal vision. However, if they are not corrected during the critical period of visual pathway development (from birth to 8-10 years of age), or if correction is inadequate, refractive errors can become a major cause of low vision and even blindness. In the 5-15 years age group, lack of correction of refractive errors is mainly due to the lack of screening and the availability and affordability of refractive corrections.

## **Challenges**

Since most European countries face an increase in the number of newborn infants of extremely LBW, and given the fact that improved perinatal services are leading to increased survival of these infants, it is crucial that prevention of retinopathy of prematurity be

strengthened by appropriate perinatal care, including appropriate use of oxygen, and close monitoring of early signs through close collaboration between neonatologists and child ophthalmologists.<sup>1</sup>

Vision screening is to be recommended from the very first weeks of life until school age in all children.<sup>4,5</sup> All premature children are at higher risk of other eye and eyesight complications. Thus, eye examinations every six months are recommended for all infants born with a gestational age of under 32 weeks or with a birth weight of less than 1500 g. About 20% of premature infants without retinopathy of prematurity will still develop vision problems, particularly myopia, which will require prescription of eye glasses, and strabismus. Primary and secondary prevention of all causes of visual impairment in children is particularly vital in pockets of underprivileged populations that are at higher risk of perinatal complications and may have limited access to vision screening and eye care.

Most children with visual impairments cope perfectly well in mainstream schools, with appropriate glasses, but some have problems that go undetected, and others have significant difficulties that require specialist help. For these children, without proper assistance, education can be a difficult process. A specific challenge for these children is having access to teaching and learning aids, including adaptive equipment, such as electronic whiteboards, wrist watches and wallets that talk, which have been developed to be used by people with visual impairments; there are also electronic devices that expand mobility. The visually impaired child should also have access to texts in Braille, tape recorders, and other learning aids; teachers and educational institutions should be informed and supportive.<sup>6,7</sup> Advances in technology have made learning opportunities for the visually impaired, more readily available. The technology will hopefully continue to improve and will become less expensive, so that every child with a visual impairment will be provided with opportunities to succeed in school.

The Right to Sight, the global initiative of the International Agency for the Prevention of Blindness and of WHO, with its international membership of NGOs, professional bodies, national associations, academic institutions and caring corporations, provides information and support to the development of national policies.<sup>8</sup>

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## 9.8 Hearing Loss

### Key Messages

- European national surveys report that between 1 and 2 in 1,000 children suffer from severe, usually congenital, hearing loss, while many more suffer from mild to moderate, usually acquired, hearing loss.
- Hearing loss, when severe and present at birth or acquired in the early years, leads to serious problems in speech and language development if not recognised and treated.
- Identification of hearing loss through neonatal screening, now implemented in most European countries, and hearing screening of older infants and children, can prevent or reduce most consequences of severe and profound hearing loss.
- Current rehabilitation options focus on hearing aids and cochlear implants (an electronic medical device that replaces the function of the damaged inner ear, also known as 'bionic ear'), and on informed choices about communication options.
- Advances in human genetics and technology have improved our ability to identify carriers of inherited hearing loss and to provide genetic counselling.

Hearing loss refers to complete and partial loss of the ability to hear.<sup>9</sup> Transitory hearing loss is quite common in children as a consequence of acute or chronic otitis. Depending on the part of the hearing system involved, hearing loss is classified as conductive, if the problem is in the middle ear, or sensorineural, when the problem is in the inner ear, or mixed, when the hearing loss involves both. This chapter focuses mainly on sensorineural hearing loss (SNHL), since it is usually severe, in most instances congenital or acquired very early in life, and consequently leads to serious problems in speech and language development if not recognised and treated.

### Main Sources of Information

Information on the epidemiology of hearing loss was collected in review articles, national registers on deaf people and national surveys. While information on generic hearing loss in children is heterogeneous, information on prevalence of profound hearing loss tends to be rather uniform across European countries.

### Size of the Problem

The proportion of children suffering from any hearing loss in Europe is unknown. Surveys carried out in European countries indicate that between 3% and 7% of all children are suffering from some kind of hearing loss, depending on the survey method, the definition used, and the age group considered. For example, data from Germany and Finland show that 7% of German and 8% of Finnish schoolchildren aged between 6 and 7 years, suffer from a loss of 20 dB or more in at least one frequency.<sup>1</sup> Data on severe or profound hearing loss, which is much less frequent but more easily identifiable, show less variability. In the United Kingdom, the Royal National Institute for Deaf People estimates that about 20,000 of British children aged 0 to 15 years suffer from moderately severe to profound hearing loss.<sup>2</sup> Of these, 8,000 are severely or profoundly deaf, corresponding to 2 per 1,000 and 0.8 per 1,000 within the population under 5 years of age, respectively, while 840 children with moderate to profound deafness are born every year (1.2 per 1,000). The prevalence of confirmed permanent childhood hearing impairment (loss of more than 40 dB) in the United Kingdom has been estimated to rise with age to 1.33 per 1,000 live births among children aged 5 years or older, and to 1.65 per 1,000 live births (even as high as 2.05 per 1,000 live

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<sup>9</sup> Severity of hearing loss is graded as mild (20–40 dB), moderate (41–55 dB), moderately severe (56–70 dB), severe (71–90 dB), or profound (90 dB). And the frequency of hearing loss is designated as low (500 Hz), middle (501–2000 Hz), or high (2000 Hz). A child's hearing acuity is classed as normal if it is within 20 dB of these thresholds.

births) among children of 9 years of age and older.<sup>3</sup> In Estonia, between 1985 and 1990, 0.17% of children were born with permanent childhood hearing impairment, according to the first study on this issue to be published in that country.<sup>4</sup>

Children with untreated hearing loss tend to experience problems with speech development, language, and communication skills, particularly if severe hearing loss occurs at birth, or before speech and language is acquired. This may lead to emotional difficulties, learning and behavioural problems in school. However, with early identification and treatment, the impact can be reduced. During the past three to four decades, as a result of improved neonatal care and the widespread implementation of immunisation programmes, the incidence of acquired SNHL in children living in more developed countries has decreased, with a relative increase in the proportion of inherited forms of SNHL.<sup>1</sup>

## Causes and Risk Factors

Hearing loss can be congenital or acquired. Most of the congenital hearing loss is sensorineural and include hereditary hearing loss and hearing loss due to other factors present either in the womb or at the time of birth. Genetic factors are now thought to cause more than 50% of all congenital hearing loss in children.<sup>1</sup> Allele variants of a gene called GJB2 account for roughly half of hereditary cases of SNHL in many European countries.<sup>5</sup> Inherited SNHL generally appears as an isolated physical finding but about 30% of cases are associated with other disorders, such as Pendred's, Ushers's or Alport's syndromes. Causes of non-genetic SNHL are women's exposure to infectious pathogens during pregnancy. Some of these (toxoplasmosis, rubella, cytomegalovirus, and herpes simplex) remain important causes not only of acquired SNHL, but also of visual loss and neurological dysfunction. In developed countries, where women are vaccinated against rubella, congenital cytomegalovirus infection is generally recognised as the most frequent cause of acquired hearing loss in neonates.<sup>6</sup> Acquired SNHL in infants and children is most commonly caused by bacterial meningitis, which accounts for about 6% of all cases of SNHL in children.<sup>7</sup> Ototoxic drugs during the neonatal period may also cause SNHL, while trauma and brain tumour are less common causes and are usually associated with unilateral hearing loss. An increasingly important risk factor for late-onset hearing loss among school-aged children is noise-induced hearing loss from toys and personal listening devices. Besides exposure to the above mentioned factors, the most common risk factors for SNHL in children are a family history of hearing loss, very LBW and severe prematurity. The most common cause of intermittent mild to moderate hearing loss in infants and young children is the conductive hearing loss caused by acute otitis media or otitis media with effusion.<sup>8</sup>

Children whose severe or profound hearing loss is not identified until one year of age may suffer from permanent impairment of speech, language, and thus learning. Moderate hearing loss may also interfere with the normal development of speech and language and produce a distinct disadvantage in development and learning.

## Challenges

Primary prevention, early detection, treatment and rehabilitation all play an important part in reducing the number of children suffering the consequences of hearing loss.

Primary prevention of congenital deafness includes rubella immunisation, appropriate use of drugs in the neonatal period, and interventions to prevent prematurity. Vaccination against *Haemophilus influenzae* type b and several serotypes of *Streptococcus pneumoniae*, currently implemented in several European countries, are mainly aimed at preventing severe diseases, such as meningitis and sepsis, yet they cause the adjunctive benefit of reducing the incidence of hearing loss secondary to bacterial meningitis and to acute and chronic otitis media. In countries where congenital cytomegalovirus has supplanted congenital rubella syndrome as the commonest cause of acquired congenital SNHL in children, the development of an effective vaccine may represent a significant advance. Efforts should also

be directed to increase awareness and control of the exposure to personal listening devices, particularly if producing sound in excess of 100 dB, among older children and adolescents.

The most important preventive intervention for the potentially severe consequences of severe hearing loss is the early detection of SNHL through universal neonatal hearing screening, which most European countries have introduced and are scaling up. Newborn infant hearing screening programmes are designed to identify all children born with moderate to profound permanent bilateral deafness occurring shortly after birth. The most valid screening system is the Automated Otoacoustic Emission.<sup>1,9</sup> As a result of these programmes, the average age of detection of children with SNHL has fallen from 12–18 months to 6 months or younger. Results suggest that these programmes facilitate normal language achievement for more children with SNHL, thus offering cost savings in the long term compared with either selective screening or no screening at all.<sup>10</sup>

Screening programmes must be associated with early treatment and rehabilitation, which includes hearing aids and cochlear implants, the latter being the foremost treatment for children with severe to profound SNHL detected at birth, and close follow-up of language development with language rehabilitation if necessary.<sup>11,12</sup> Depending on timeliness of diagnosis, severity of hearing loss and parental choice, decisions are to be made on communication options, including auditory verbal training, oral training, lip reading, and various recognised sign languages.<sup>13</sup>

The challenge is not only to extend hearing screening programmes to all children but to promote and develop family-friendly integrated services which support effective early intervention for deaf children. The challenge is also to empower parents to make informed choices for their child throughout the entire newborn hearing care pathway.<sup>9,12</sup> Focused genetic counselling and health education might lead to a decrease in the prevalence of inherited SNHL. The recent identification of simple methods used to recognise GJB2 carriers, opens the way to identification of carriers and consequent genetic counselling.<sup>14</sup>

Detection of children with mild or unilateral or previously undetected SNHL, or with acquired hearing loss is also important and is based on well-child, periodic consultation programmes carried out by paediatricians, family doctors or community nurses/health visitors in all European countries. Given current yields from universal neonatal hearing screening, it has been predicted that an additional 50% to 90% of children remain to be detected in the postnatal years.<sup>3</sup> Children suspected as suffering from learning disability, autism spectrum disorders or pervasive developmental disorder should always be tested for SNHL.

Research to evaluate the cost/benefit and effectiveness of various preventive, treatment and rehabilitation approaches, as well as Europe-wide introduction of uniform surveillance systems and biotechnological developments, represent the key priorities to reduce the burden of hearing loss in children.

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## 10. Communicable Diseases

Communicable diseases are illnesses caused by microbial agents capable of spreading among human populations, through direct or indirect transmission. They may be classified using different criteria: the causative agent (e.g. viruses, bacteria, fungi), the mode of transmission (e.g. food borne, zoonosis), the organ involved (e.g. respiratory system, liver), and whether they are vaccine preventable or not. The broadness of the topic does not allow a complete coverage in this report. Though communicable diseases are very frequent in children and are responsible for a large proportion of the overall burden of child health care, this chapter focuses only on communicable diseases of greater public health importance. Tuberculosis and HIV/AIDS are discussed in two separate sections due to their global importance and specific control strategies.

### 10.1 Communicable Diseases of Public Health Importance

#### Key Messages

- Overall, the incidence of most communicable diseases in Europe is decreasing. There are a few exceptions (campylobacter, yersinia, hepatitis C), while for some diseases (e.g. influenza) data are insufficient to be able to work out reliable trends.
- Some vaccine preventable diseases (e.g. measles) are still endemic in some countries and population groups.
- The coverage of immunisation programmes has been improving and is on average very high, but disparities still exist among countries and population groups. New vaccines (e.g. pneumococcal, rotavirus) have been recently introduced in some but not all countries and their effectiveness is still under scrutiny.
- Surveillance systems to monitor vaccine preventable diseases and immunisation coverage are in place and rapidly improving. The surveillance of adverse events following immunisation is still weak.
- Antimicrobial resistance of some pathogens is increasing, possibly representing the single biggest challenge facing Europe in the area of infectious diseases.

#### Main Sources of Information

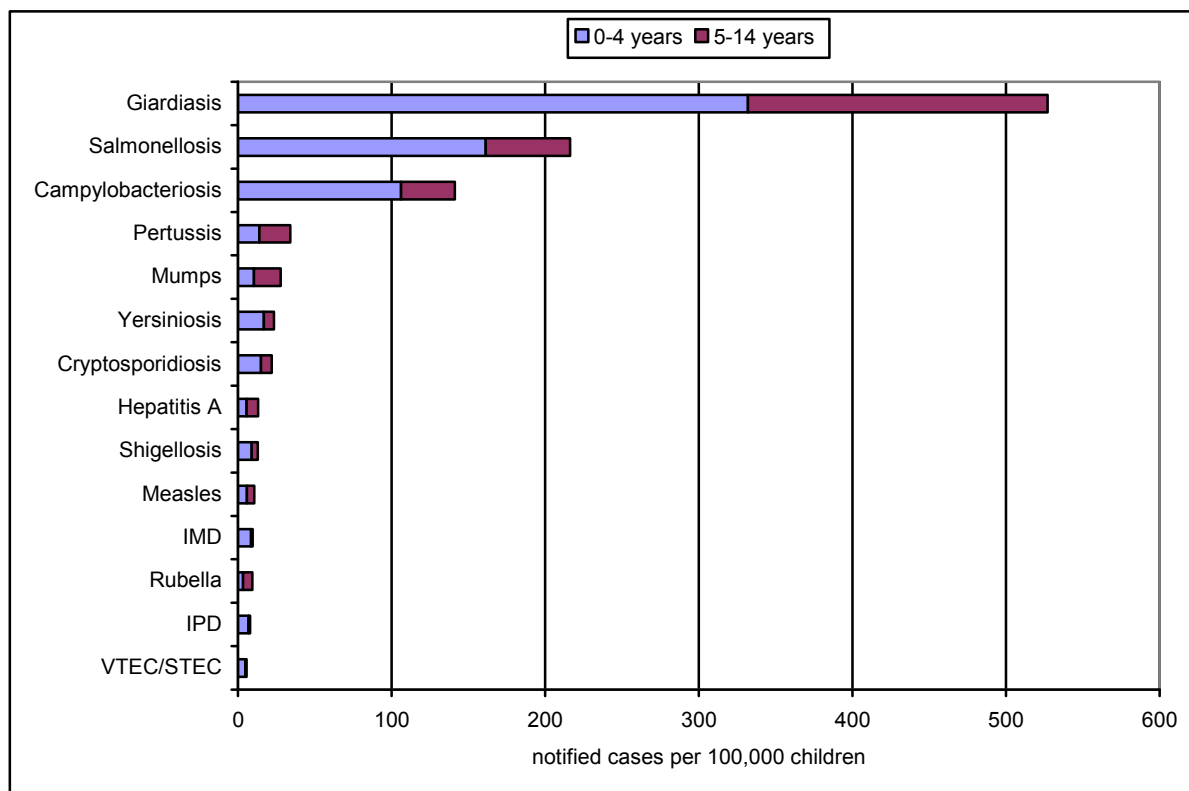
Data have been drawn from ECDC (European Centre for Disease Prevention and Control, [www.ecdc.europa.eu/en/Pages/home.aspx](http://www.ecdc.europa.eu/en/Pages/home.aspx)) annual reports on diseases for which notification is mandatory in EU and EFTA countries. Data routinely collected by surveillance systems in Member States are uploaded into the European Surveillance System (TESSy) and are subsequently made available in ECDC annual reports. Further information has been retrieved from other surveillance networks (EUVACNET, EUIBIS, DIPNET) not yet fully integrated into TESSy. Relevant data from cohort studies, cross sectional surveys and records from hospital and primary health care facilities were also used.

As far as quality and completeness of data are concerned, surveillance systems relying on physicians' notification, even if widely available, tend to underestimate the real disease incidence in a way that may vary across countries, making any comparison problematic in time. The burden of communicable diseases would be better described by incidence data drawn from large community cohort studies or by cross sectional surveys. Due to their high cost, these studies are scarce and generally insufficient at identifying trends or variations across countries. Data on hospital admissions can be useful to calculate the incidence of severe conditions (e.g. invasive pneumococcal disease). Yet, they are generally unreliable for less severe conditions for which decisions on hospital admission depend on national or local policies. Finally, the use of non-standard case definitions represents another threat to data quality.

## Size of the Problem

Figure 10.1 shows the notification rates of some communicable diseases for which notification is mandatory in EU and EFTA countries; only diseases with a notified incidence higher than 1 per 100,000 children are included, and not all the countries report on all diseases.<sup>1</sup> The ECDC reports show that over the past 10 years the notification rates of most communicable diseases is stable or decreasing. There are some exceptions (e.g. campylobacter, yersinia, hepatitis C), while for some diseases (e.g. influenza) data are still insufficient to work out reliable trends.

**Figure 10.1. Notification rates of some communicable disease reported in 2008.**



### *Acute Respiratory Infections*

Acute infections of the upper and lower respiratory tracts include a large number of different diseases such as common cold, otitis, pharyngitis, bronchitis, bronchiolitis and pneumonia. Overall, these infections represent the highest burden for health care services and families. Some of these infections are self-limiting conditions of lesser public health importance. This section will deal only with acute otitis media; pneumonia caused by *Pneumococcus* and *Haemophilus influenzae* will be dealt with under vaccine preventable diseases.

*Pneumococcus* and *Haemophilus influenzae* are the most common causes of acute otitis media. The peak incidence of this disease is between 6 and 11 months of age. By the age of three, 50-85% of children have had at least one episode. Recurrent acute otitis media (3 episodes or more) is also common, affecting 10-20% of children up to and including 12 months olds. Nearly 40% of older children eventually have 6 or more total episodes.<sup>2</sup> Spontaneous resolution is fortunately the most common outcome of acute otitis media. Trends are difficult to estimate due to changes in health care systems, access to and use of health care.

## *Acute Gastroenteritis*

Acute gastroenteritis is a common disease caused by a variety of pathogens, rotavirus being the most frequent (see below under vaccine preventable diseases). It is associated with a high use of health care services for children, second only to respiratory infections. In Europe, the incidence is stable, with no appreciable changes over the past two decades, and mortality is very low. A study conducted in Ireland in 2003 found an annual incidence of community-acquired gastroenteritis of 0.6 episodes per person per year; the incidence was higher among children and health services were contacted by 27% of those affected.<sup>3</sup> Another study from Germany found that 13.8% of children under 5 years of age had been seeking medical care for acute gastroenteritis in 2004.<sup>4</sup>

## *Vaccine-Preventable Diseases*

In the pre-vaccination era, about 30,000 children were affected each year by **poliomyelitis** in the WHO European Region. Since the introduction of vaccines, in the 1960s, the incidence dropped progressively and in 2002, the region was certified as polio-free. The last outbreak had affected the Netherlands in 1992–93, when 79 people were infected in a community that refused vaccination for religious reasons. In 2010, the European Region of WHO experienced the first import of wild poliomyelitis since 2002, the previous cases being in 2001 with three children belonging to a Roma community in Bulgaria. The wild poliovirus was imported from India and caused an outbreak of 458 laboratory-confirmed cases in Tajikistan, including 27 deaths. The outbreak propagated rapidly to neighbouring countries: the Russian Federation reported 14 cases, Turkmenistan 3, and Kazakhstan 1 case.<sup>5</sup> Should the outbreak move west, nearby European countries may need to intensify surveillance.

**Tetanus** and **diphtheria** have been under control in Europe since the introduction of vaccines in the 1960s. Between 100 and 200 tetanus cases are still reported every year in EU and EFTA countries, the majority of them in non-vaccinated adults and elderly people.<sup>1</sup> Since 1995, most diphtheria cases have occurred in the Baltic States, and have tended to be connected with the large outbreak that involved the Russian Federation in the 1990s. Currently, Latvia is still reporting a small number of cases, and sporadic imported cases are notified by other EU countries.

The availability of acellular vaccines has considerably improved the control of **pertussis** in Europe. In 2008, 18,807 confirmed cases (out of 20,442 reported) were reported by 28 EU and EFTA countries. The overall notification rate was 5.28 per 100,000 people, unchanged over the previous two years.<sup>1</sup> The most affected group are children between 5 and 14 years of age, with a notification rate of over 14 per 100,000, followed by infants not yet fully immunised. The high rate in older children and adolescents is probably due to the waning of vaccine protection from five years after the third dose. The results of long-term surveillance show a dramatic drop of laboratory-confirmed cases as a result of vaccination with acellular pertussis vaccine, and the need for a booster dose at 5-7 years of age.<sup>6</sup>

Although the **measles** vaccine has been part of routine national childhood vaccination programmes throughout Europe for at least 20 years, the disease is still endemic in many countries.<sup>1</sup> Between 2006 and 2007 several countries reported high numbers of cases and outbreaks: 85% of 12,132 recorded cases in 32 EU, EFTA and candidate countries came from 5 countries (Italy, Germany, Romania, United Kingdom and Switzerland). In the same two years, 6 measles-related deaths were recorded in these countries: 3 in Romania, 2 in Germany, 1 in the United Kingdom.<sup>7</sup> The largest number of cases in 2006 were reported from Romania (39% of the total) and Germany (28%), and the highest incidence rates were in Greece and Romania (4.7 and 14.8 per 100,000 people, respectively). In 2007, the overall incidence fell significantly compared with the previous year. The United Kingdom and Switzerland reported the largest number of cases and the highest incidence (1.6 and 13.8 per 100,000 people, respectively). About a fifth of these cases were in people aged 20 years or older, but most cases were in unvaccinated or incompletely vaccinated children. As

expected, the number of reported cases of measles fluctuates from one year to another. Increased measles transmission continued to be recorded from 2008 to 2010, particularly in Austria, Belgium, Cyprus, France, Ireland, Italy, Poland, Spain, the United Kingdom and Switzerland,<sup>1</sup> with annual incidence rates being quite far from the elimination goal set by WHO at less than 1 case per 1,000,000 people. Other outbreaks have been described in specific groups such as Roma and Sinti communities in Italy, Roma and immigrant families in Greece, orthodox Jewish communities in Belgium and the United Kingdom, and Traveller communities in the United Kingdom and Norway. The recent outbreak in Bulgaria is paradigmatic. Since its onset in April 2009, over 23,000 measles cases and 24 deaths have been reported; 90% of these cases occurred within the Roma community, the majority (over 60%) in children younger than 15 years old, 30% of which were not fully immunised.<sup>8</sup>

A total of 19,640 cases of **mumps** (9,940 confirmed) were reported in 2008 by 27 EU and EFTA countries, with an overall notification rate of 2.79 per 100,000 people, slightly lower than the rate in the previous 2 years.<sup>1</sup> Only Iceland reported zero cases, the last outbreak in that country having been reported in 2005 and 2006. The highest notification rates were observed in Ireland, Bulgaria, Romania, Luxembourg and the United Kingdom. The most affected groups are children between 0 and 4 and 5 and 14 years of age, with notification rates ranging from 10 to 17 per 100,000. About 10% of notified cases were admitted to hospital and 1% developed complications. It is however impossible to generalise as not all countries notified hospital admissions and complications.

In 2008, 1,921 **rubella** cases were confirmed out of the 21,307 cases reported from 26 EU and EFTA countries, showing a slight decrease compared to previous years.<sup>1</sup> Children aged 0–4 years are the age group with the highest notification rate, 9.34 cases per 100,000 children. Among those cases for which information is available, the majority, over 80%, occurred in unvaccinated children and adolescents. Rubella is a mild disease in these age groups. For public health purposes, only rubella infection during pregnancy represents a problem due to severe consequences on the development of the foetus.

In the early 1990s, **hepatitis B** infection showed different patterns of endemicity in Europe, from very low (less than 0.5%) to medium (2–7%) prevalence rates of chronic carriers. After the introduction of vaccination programmes, the rates in children fell considerably. In 2008, there were 6,369 confirmed cases of hepatitis B virus infection reported by 28 EU and EFTA countries, a rate of 1.29 per 100,000 people.<sup>1</sup> Only a small minority of these cases occurred in children 0–4 and 5–14 years old, with rates lower than 0.2 per 100,000.

The different serotypes of *Haemophilus influenzae*, of which type B is the most important and for which a vaccine is available, cause several diseases ranging from non-severe acute upper respiratory infections to severe meningitis and deadly invasive septicaemias. Data on the incidence of all infections caused by *Haemophilus influenzae* are somewhat patchy. In 2008, a total of 2,122 confirmed cases of invasive disease (all serotypes) were reported by 24 EU and EFTA countries, for a notification rate of 0.46 per 100,000 people, similar to the one reported in previous years.<sup>1</sup> Young children are the most affected; children under 5 years of age have reported rates that may double those reported in the general population. In 2006, Estonia reported the highest incidence, followed by Ireland. In 2008, however, the highest incidence was reported by Sweden and Norway. These rankings have to be taken cautiously as notification policies change across countries and over time. The number of cases of invasive disease has been decreasing progressively since the introduction of vaccination. For example, in the United Kingdom, the implementation of an accelerated vaccination programme since 1992 led to a virtual elimination of cases, attributed to a strong herd immunity effect. However, since 1999, an increase has been observed that led to the introduction of a booster vaccine dose to re-establish the herd immunity and control the disease.<sup>9</sup>

There is a wide heterogeneity in the surveillance of **invasive pneumococcal disease** in the EU, particularly as far as surveillance systems, coverage and case definition are concerned.

In some countries there is no surveillance at all. Data should therefore be compared with caution. In 2008, 14,883 cases of invasive pneumococcal disease were reported by 24 EU and EFTA countries, of which 14,757 were confirmed.<sup>1</sup> The most affected age groups were people aged 64 years and over, followed by children aged under 5 years and under, with a notification rate of 6.96 cases per 100,000. The overall notification rates varied widely across countries as a consequence of the surveillance problems discussed above. The highest rates were reported by Sweden, Norway, Belgium and Finland. Compared with previous years, there were increases in Belgium, Finland and Slovenia, most likely due to improvements in the effectiveness of surveillance systems. A systematic review using data from studies published between 1980 and 2003, before the introduction of the vaccine, estimated an incidence rate of invasive pneumococcal disease of 11–93 cases per 100,000 among Western European children under the age of 2 years.<sup>10</sup> Incidence has dropped to less than 10 per 100,000 after the introduction of vaccination. There are concerns regarding the possibility that serotypes covered may be replaced by serotypes not covered by current vaccines, as already observed in the United States.<sup>11</sup>

**Rotavirus** accounts for about 40% of cases of acute gastroenteritis in Europe.<sup>12</sup> The incidence is highest in children aged 6 to 24 months. Mortality is low, but the disease is responsible for a high number of outpatient visits and hospital admissions. In 2006, a review of the literature estimated that in Europe there were more than 70,000 hospital admissions per year, with a considerable economic burden for families and health systems; about 20% of these admissions may have been due to hospital acquired infections.<sup>13</sup> In the same year, another review estimated 3.6 million episodes of disease per year in children under 5 years of age, with 231 deaths, 87,000 admissions to hospital and almost 700,000 outpatient visits.<sup>14</sup>

A recent ECDC report highlights the lack of high-quality, European-specific data on **influenza**.<sup>15</sup> This is not surprising as influenza surveillance has historically focused on the collection of viral data for vaccine strain selection, with limited concern for the epidemiology of the disease. As a result, large gaps remain in our understanding of its burden, trends and variation in severity across countries. An analysis of data drawn from surveillance networks in four EU countries (Italy, Netherlands, Spain and England) for the period 2002–2008 indicates that during a winter of average temperatures, 0.3% to 9.8% of children aged 0–14 years consulted a physician with regard to influenza, with the A(H3N2) virus playing the most significant role. With the exception of Spain, these rates were higher in children aged 0–4 years.<sup>16</sup> Approximately in the same period, among children living in the Netherlands, Spain and England, the annual hospital admission rate due to influenza varied between 5 and 21 per 100,000 children 0–4 years of age and 7 to 46 per 100,000 infants less than 1 year.<sup>17</sup>

## Causes and Risk Factors

The classic paradigm of infectious disease transmission depicts the microbial agent, the human host and the environment as each one representing a corner of a triangle. Transmission of a pathogen from one host to another depends on two processes: frequency of contacts and infectivity, i.e. the probability of infection given a contact. The first quantifies the interaction between hosts or between a host and the environment, vectors included, and is generally determined by the host behaviour (contacts with animals, personal hygiene) and properties of the environment (sanitation, housing). The second, infectivity, is a function of the virulence of the pathogen and the immune status of the host (vaccination, nutrition). Finally, the burden of communicable diseases reflects not only the level of transmission but also the severity of the disease, which may be influenced by the nutritional state and genetics of the host, as well as by the availability of effective health care services. The majority of these proximal determinants may influence each other mutually and may also be influenced, through multiple mechanisms, by broader and more distal environmental, social and economic determinants.

Investigating such complexity, requires the identification of subpopulations at higher risk of communicable diseases across Europe and the explanation of the specific chain of determinants active in these subpopulations. Since national statistics are average values, generally unable to detect intra-national variation, key information comes mainly from research projects carried out among vulnerable groups. They indicate that poor educational performance, low-employment class, or recent change in migration status are associated with increased frequency and severity of several communicable diseases all over Europe. The recent measles outbreak in Bulgaria is paradigmatic of this. A number of factors converged to precipitate this epidemic: socio-economic and health system reform, social marginalisation, crowded living conditions and poor access to preventive and curative health service among Roma communities. These socio-economic conditions constitute a fertile ground for outbreaks of measles and other communicable diseases, including the recent poliomyelitis outbreak in Tajikistan or the reported foci of tuberculosis in specific population groups.

## Challenges

Surveillance of communicable diseases in Europe is supported mainly by ECDC and by WHO/EURO. In the last decade, the EC has listed the diseases that are to be notified at EU level, has delineated rules and criteria to set up surveillance networks to monitor such diseases, and has promoted coordination between the Member States, as well as between national and international agencies. The coordinating role of ECDC is gradually emerging and surveillance systems are progressively improving.

The strategy for the control of communicable diseases among children in Europe encompasses a range of preventive and curative interventions, from food safety to the use of antibiotics. However, vaccination programmes remain the most cost-effective measure for the prevention and control of the most important communicable diseases; more than 2.5 million deaths a year are prevented globally as a result of vaccination against diphtheria, tetanus, pertussis and measles. Several communicable diseases can be effectively prevented by vaccines and several new vaccines are under development.

In 2007, the VENICE project conducted a survey to collect information on immunisation programmes in 29 countries (EU27 plus Iceland and Norway) and found that a small group of vaccines constitute the common basis for vaccination schedules in Member States: poliomyelitis, DTP (diphtheria, tetanus, pertussis), and MMR (measles, mumps, rubella).<sup>18</sup> The vaccine for *Haemophilus influenzae* type b (Hib) was offered in almost all countries with the exception of Romania and Bulgaria, where a discussion over its inclusion in the national programmes was ongoing. In most countries, universal vaccination against hepatitis B was also offered, either to the newborn, infant or teenager. However, a number of countries in Northern Europe have not yet introduced it into their routine programmes because of controversial results from cost-effectiveness studies. In those countries, strategies focusing on risk groups have been implemented instead. By 2008, universal childhood vaccination with the conjugate 7-valent pneumococcal vaccine was part of the national programme in 15 countries. Many countries are currently introducing new 13-valent vaccines. National authorities have so far delivered recommendations in favour of rotavirus vaccination in very few countries. Similarly, there is very limited experience of universal chickenpox vaccination. Finally, until recently, introduction of universal influenza vaccination among healthy children has not been considered a priority because the risk of influenza-related complications is generally low in this age group. Following the introduction of a policy on influenza immunisation in US children in 2004, the issue is currently under debate in EU, with 5 countries recommending it in 2008: Austria, Estonia, Latvia, Slovak Republic and Slovenia.

There is no standardised system in the EU for collecting data on vaccination coverage. Among the systems used there are administrative methods, surveys and computerised records systems. In addition, coverage is assessed at different ages and with different timings in different countries. It is therefore difficult to make comparisons. Based on data

collected by WHO/EURO for 2008 through the centralised information system for infectious diseases, currently the only available consolidated source of data, coverage for DPT3, Polio3, Hib3, MMR1 and MMR2 was above 90% in all countries except for Austria, Cyprus (MMR1, MMR2), Denmark (2007), France (Hib3, MMR1, MMR2), Germany (MMR2), Greece (Hib3, MMR2), Ireland (MMR1), Italy (MMR1), Malta, Poland (Hib3), United Kingdom (MMR1, MMR2) and Switzerland (MMR1, MMR2). Coverage may have increased subsequently; in 2009, Denmark, for example, reported values over 90%.

Antimicrobial resistance is a worrying and increasing problem due to the widespread use of antibiotics at community and hospital levels and to the massive use of antibiotics in animal breeding. The 2006 annual report of the European Antimicrobial Resistance Surveillance System (EARSS) describes the developments between 1999 and 2006 and demonstrates the continuous decline in the effectiveness of antibiotics across Europe.<sup>19</sup> Although this general trend applies to all countries, Scandinavian countries and the Netherlands are less affected, and resistance levels are still fairly low. Mediterranean and Eastern European countries witness the fastest deterioration. The only positive trend occurred in Slovenia and France where the proportion of methicillin-resistant *Staphylococcus aureus* has decreased over the past years due to increased attention paid to infection control in hospitals. In France, a substantial decrease in antimicrobial prescription was achieved through a significant public campaign, taking place over the last 3 years. Based on these results, the ECDC identified antimicrobial resistance as possibly the single biggest challenge facing Europe in the area of infectious diseases.

## 10.2 Tuberculosis

### Key Messages

- Since 2003, nearly all countries, with some exceptions, experienced a decline or stabilisation at low levels in paediatric notification rates of tuberculosis suggesting a decreased or low level of transmission in the general population.
- In countries with low incidence and mortality rates the disease is increasingly aggregating in the foreign born population, in vulnerable groups, and in risk settings associated with poverty and lowered immunity.
- Action plans to fight tuberculosis in the EU have to deal with problems such as multidrug resistance, co-infection with HIV, and concentration of cases in vulnerable groups.
- To achieve long term control targets, current strategies need to be complemented with efforts to address risk factors and social determinants.

Tuberculosis is an infectious bacterial disease caused by *Mycobacterium tuberculosis*, which most commonly affects the lungs. It is transmitted from person to person via droplets from the throat and lungs of people with active lung disease. It is a treatable infection, requiring usually a 6-month course of combined treatment.

### Main Sources of Information

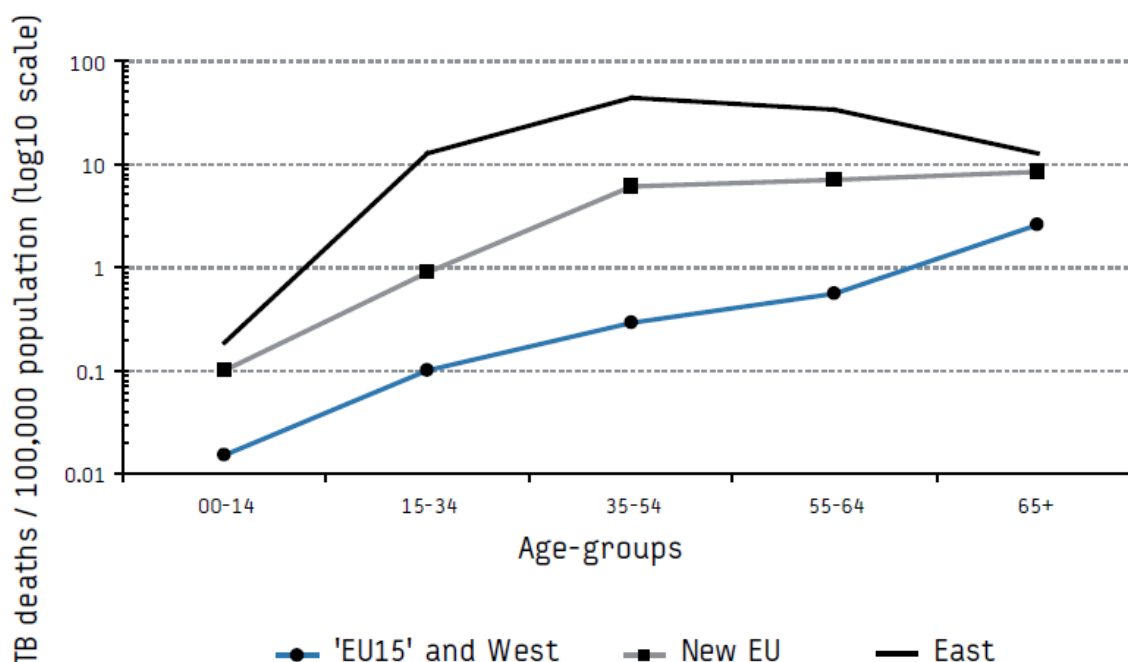
The main sources of information are the databases and reports on tuberculosis of the surveillance systems based at ECDC and at WHO/EURO. An important challenge for this surveillance is the use of standard reporting methods and definitions of paediatric cases, including multidrug-resistant tuberculosis, through integration of laboratory, clinical and epidemiological data, as the majority of children with the disease are smear sputum negative. A combination of clinical symptoms, tuberculin skin testing, chest radiography and contact history, has been used in Europe, in order to define cases of children lacking laboratory confirmation for surveillance purposes.

## Size of the Problem

In 2008, in EU and EFTA countries, excluding Switzerland, paediatric cases (of children younger than 15 years of age) represented 4.2% of the total number of reported cases of tuberculosis.<sup>1</sup> In absolute terms this corresponds to about 3,400 cases, of which about 3,100 were new cases. Approximately 80% of all cases were of national origin, the remaining 20% being foreign born. Between 1999 and 2008, nearly all countries experienced a decline or stabilisation at low levels (less than 10 cases per 100,000 children) in notification rates, suggesting a decreased or a low level of transmission in the general population. Some countries, however, show higher than average rates. Latvia and Romania report rates ranging between 15.3 and 32.2 per 100,000; Bulgaria reported an increase from 11.8 to 22.3 per 100,000 between 2000 and 2008, Lithuania from 15.8 to 19.3 per 100,000 between 2007 and 2008. Minor increases were recorded also in Cyprus, Italy, Spain, United Kingdom and Norway. In France, Italy, Netherlands, Spain and the United Kingdom a higher proportion of paediatric cases, between 5.6% and 14.4%, was recorded among cases of national origin, maybe in children born to foreign-born parents.

Children are more likely than adults to develop tuberculosis after infection and are at higher risk of developing extra-pulmonary and severe disseminated diseases. Tuberculosis in children is considered a sentinel event that may indicate rising levels of transmission in the community.<sup>20</sup> Children, however, experience a higher rate of treatment success and a lower death rate than adults (Figure 10.2.1).<sup>21</sup>

**Figure 10.2.1 Tuberculosis mortality rates by age group in different regions of Europe. (Source: Falzon et al, 2008).**



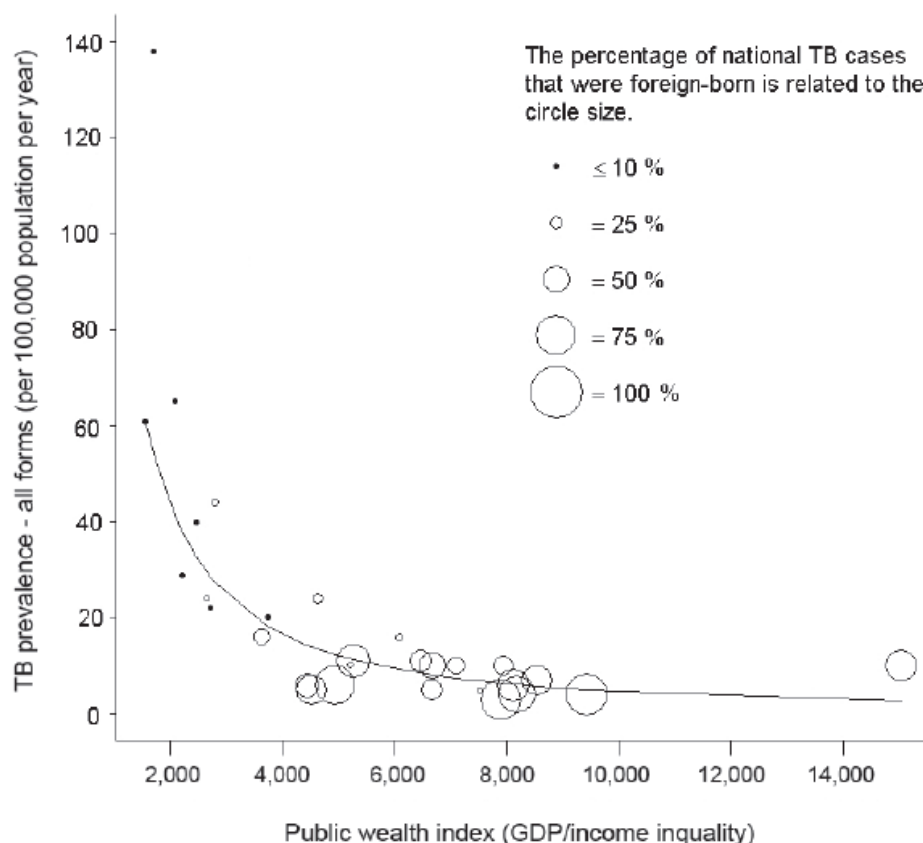
The emergence of drug resistant strains poses a serious challenge to the control of tuberculosis. Data on multidrug resistance in children in Europe are scarce; the best estimates come from adult and child combined studies. Three countries (Estonia, Latvia and Lithuania) report that around 20% of children suffer from multidrug resistant tuberculosis, as opposed to approximately 1% in Western European countries.<sup>22</sup>

The burden of tuberculosis follows a strong socio-economic gradient across countries, with the highest rates among children of low-income families. The same gradient is recorded within countries and communities, where the poorest have the highest risk. In EU27 countries, and in Norway and Iceland, there is a strong inverse relationship between public



wealth index and the rates of tuberculosis. As countries rank higher, the proportion of foreign-born cases increases (Figure 10.2.2).<sup>23</sup> Important pockets of higher prevalence have been found in children under 16 years of age in urban areas such as London and Stockholm. This might be due to a high number of children born in high-prevalence countries.<sup>20</sup>

**Figure 10.2.2. Public wealth index and tuberculosis prevalence rates in 27 EU countries plus Norway and Iceland, 2006. (Source: Semenza et al, 2010).**



### Causes and Risk Factors

Historically, the decline of tuberculosis in Europe preceded the introduction of antimicrobials and coincided with rapid improvements of the quality of life. Tuberculosis is most commonly acquired following inhalation of bacteria in droplets produced by a person with pulmonary disease. Factors lowering the immune response increase the chances of getting the disease following infection. Proximal risk factors include people living or working in high-prevalence environments, such as inmates, health workers and prisoners, particularly if these environments are overcrowded or poorly ventilated, since they have an increased exposure to infectious droplets. Additionally, proximal risk factors also include HIV infection, malnutrition, tobacco smoke, indoor air pollution, alcohol abuse and diabetes, since these decrease host defences. Rapid urbanisation can create ideal conditions for epidemics associated with high population density, crowded living and working conditions and life style changes. The higher risk of tuberculosis among people in low socio-economic groups is probably due to a greater exposure to some of these risk factors and to limited access to high quality health care. However, the causal pathway linking poverty and low SES to increased risk of tuberculosis is not fully understood.<sup>24</sup> In EU countries, the contribution of HIV to the case-load of tuberculosis in the general population differs between countries,<sup>25</sup> but socio-economic risk factors appear to be more important, especially in countries with low incidence and mortality rates.<sup>26,27</sup>

## Challenges

Tuberculosis control in the general population relies mainly on the detection of infectious patients and treatment for at least 6 months with a combination of several antibiotics so as to cut transmission, reduce suffering, avert mortality and avoid the emergence of drug resistance. Effective treatment exists, but inadequate treatment or insufficient compliance may result in failure of cure, early relapse or the development of drug resistance. The DOTS (Directly Observed Therapy, Short-course) strategy launched in the 1990s took into account the basic health care elements required to deliver antibiotic treatment effectively. After a decade of DOTS implementation, in 2006 the new Stop TB Strategy was launched to improve the tackling of multidrug resistance, the tuberculosis and HIV epidemics, and the challenges of ineffective health systems.<sup>28,29</sup> The focus of the new strategy is on diagnosis and curative treatment rather than on prevention. However, the variation in tuberculosis trends is more strongly associated with biological, social and economic factors than with the performance of the National Tuberculosis Programmes. In Eastern Europe and former Soviet Union the increase of the burden of tuberculosis in the 1990s has been explained by economic decline, social deprivation, poor living conditions and alcoholism (while in Africa, for instance, it was largely due to HIV). To achieve long term control targets, the current strategy needs to be complemented with efforts to address risk factors and social determinants.<sup>24</sup>

A framework action plan to fight tuberculosis in the EU has been developed in recent years with the aim of reducing and eliminating the disease.<sup>25</sup> Control efforts are challenged by problems such as multidrug resistance, HIV co-infection and concentration of cases in vulnerable groups. The EU plan is complementary to that of the WHO/EURO to stop tuberculosis in 18 high priority countries, six of which are either EU Members States or candidate countries (Bulgaria, Estonia, Latvia, Lithuania, Romania and Turkey).<sup>30</sup>

The BCG vaccine has been available since 1921. Though it is effective in limiting severe disease and mortality in childhood, it has no effect over the transmission of the disease. There is a wide variability and continuing evolution of BCG vaccination practices across Europe.<sup>31,32</sup> Countries with an adult prevalence above 20 per 100,000 (Bulgaria, Estonia, Hungary, Latvia, Lithuania, Poland, Portugal, Romania, Croatia, FYR of Macedonia and Turkey) recommend universal newborn vaccination. Countries with low prevalence range from non-systematic use in 6 countries (Austria, Belgium, Denmark, Germany, Luxembourg, Spain) to universal coverage at birth in 4 (Czech Republic, Finland, Ireland, Slovak Republic). Vaccination of all children at older ages is offered in 5 countries (France, Greece, Malta, United Kingdom and Norway), while vaccination only for high risk groups is implemented in Cyprus, Italy, Netherlands, Slovenia, Sweden and Switzerland. These differences are not based on evidence and countries should collaborate with ECDC to uniform practices, since the current situation has an important impact on the quality of surveillance data.

## 10.3 HIV/AIDS

### Key Messages

- HIV incidence in children is very low in Europe, but trends in young adults are increasing throughout EU countries.
- Widespread implementation of measures to prevent mother-to-child transmission has virtually eliminated this source of infection that remains relevant in specific vulnerable populations such as migrant women coming from countries of high prevalence.
- Plans to identify HIV-positive pregnant women and start early treatment of mothers and their babies, if infected, are based on routine HIV testing during pregnancy, but more integrated guidelines on the performance of antenatal HIV screening are needed.

After the epidemics due to transfusions of blood products in the 1980s and early 1990s, paediatric HIV/AIDS in Europe is nowadays almost exclusively due to vertical transmission. The main focus of this chapter is on mother-to-child transmission and on preventive strategies.

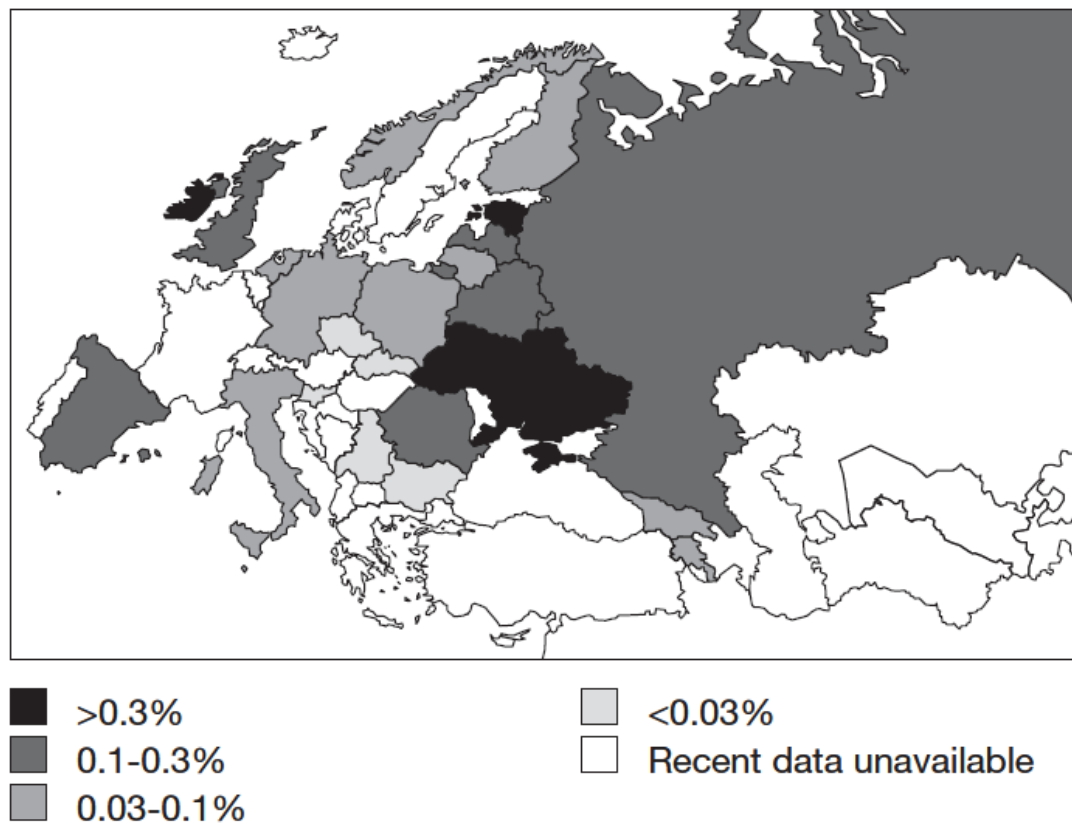
### Main Sources of Information

Data were drawn from the European Centre for the Epidemiological Monitoring of AIDS (<http://www.eurohiv.org/>) and from the most recent UNAIDS epidemic updates and reports (<http://www.unaids.org/en/>). Paediatric HIV incidence and prevalence in most European countries are not available due to lack of national registers.

### Size of the Problem

By the year 2000, 60% of Europe's paediatric HIV/AIDS cases were registered in Romania, mostly in infants living in public institutions. Policies adopted by Romania and further improvement in the control of blood products all over Europe have virtually eliminated this source of infection. Also, widespread implementation of measures to prevent mother-to-child HIV transmission, complemented by improved detection and early treatment, has virtually eliminated this source of infection in the region and contributed to the reduction of paediatric AIDS all over Europe. HIV incidence in the paediatric population of EU, EFTA and candidate countries is very low compared to other regions of the world. In 2008, only 116 HIV cases infected through mother-to-child transmission were reported, a 50% decrease compared to 2004.<sup>1</sup> However, HIV in children needs to be considered as a public health priority since trends in adults are increasing throughout the EU25 countries. In addition, the proportion of heterosexual transmission is also on the rise. In 2008, women accounted for 31% of newly diagnosed HIV cases, compared to 24% in 2001. In general, in Europe, prevalence among pregnant women is below 0.5%; there are, however, wide disparities across countries and pockets of higher prevalence are common in major urban areas (Figure 10.3.1).<sup>33</sup>

**Figure 10.3.1. Highest reported HIV prevalence at national or regional level among pregnant women or women giving birth in Europe, 2002-2004.**



### Causes and Risk Factors

HIV transmission in children living in Europe is almost exclusively mother-to-child. Without adequate prevention, the risk of transmission of HIV from infected mothers to their children is approximately 15-30% during pregnancy and labour, with an additional 10-20% of transmission risk attributed to prolonged breastfeeding. Maternal factors that increase the risk of transmission include the timing of seroconversion, a high viral load, a low CD4 count, an advanced stage of the disease, co-infection with hepatitis C virus, tuberculosis and sexually transmitted diseases, as well as the timing and mode of delivery. Prolonged rupture of membranes and vaginal delivery complicated by episiotomy, perineal laceration and intrapartum haemorrhage, are associated with an increased risk of transmission. The most important child factor is the type of feeding. Breastfeeding is associated with a risk of transmission that is roughly proportional to its duration. Avoidance of breastfeeding prevents postpartum transmission of HIV, but formula feeding requires access to clean water and health education.<sup>34</sup> In Europe, mother-to-child transmission is particularly relevant in specific vulnerable populations such as migrant women coming from countries of high prevalence.

### Challenges

Strategies for the prevention of mother-to-child transmission rely on identification of HIV-positive women followed by adequate treatments, delivery practices, as well as support for safe infant feeding.<sup>34-36</sup> HIV tests during pregnancy are needed to identify HIV-positive pregnant women adequately. Table 10.3.1 shows the different practices reported in 2004/05 by EU countries for routine testing of HIV in women.<sup>37</sup> In most countries, mandatory HIV screening is considered as undesirable and unethical. Tests are known to be acceptable for pregnant women if they are accompanied by adequate and sensible counselling focused on the risk for the newborn. HIV-testing and counselling should be available to all pregnant women as focusing on vulnerable groups alone has not been successful. However, little is

known on the effectiveness of different strategies. More integrated guidelines on the performance of antenatal HIV screening are needed.

**Table 10.3.1 Practices on antenatal HIV screening around 2004/05.**

Antenatal HIV screening	Country
Universal screening, voluntary testing, opting in	Austria, Finland, France, Germany, Ireland, Latvia, Lithuania, Poland, Portugal, Slovak Republic, Spain, Sweden, United Kingdom
Universal screening, voluntary testing, opting out	Czech Republic, Estonia, Netherlands
Selective screening, voluntary testing, opting in	Denmark, Malta
No national screening policy	Belgium, Greece, Hungary, Italy, Slovenia

The package of specific interventions to prevent HIV transmission from an infected mother to her child includes antiretroviral drug use, safer delivery practices and counselling and support regarding infant feeding. In Europe, the wide implementation of these guidelines has reduced transmission to very low levels.<sup>38</sup> Since with adequate prevention and treatment measures the risk of mother-to-child transmission can be reduced from 15-30% to less than 2%, it is of paramount importance that health systems are prepared to support HIV-positive mothers during pregnancy, delivery and post-partum with adequate care. Efforts have to focus on the identification of women in need of prevention. Children of infected mothers need accurate follow-up and monitoring, in addition to antiretroviral treatment according to guidelines.<sup>39</sup>

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## 11. Maltreatment

### Key Messages

- A significant number of children in Europe are subject to physical and/or emotional ill-treatment, sexual abuse, neglect or exploitation. In most instances child maltreatment is a chronic condition.
- Only a small percentage of maltreated children come to the attention of child-protection agencies, indicating failure in recognising and reporting maltreatment.
- Child maltreatment has long-lasting effects on mental health, it increases the risk of drug and alcohol problems, risky sexual behaviour, obesity and criminal behaviour. It furthermore carries a high risk of intergenerational transmission.
- Although infrequent, child abandonment, exploitation and trafficking represent forms of maltreatment that pose serious threats to the survival, health and well-being of children.
- The serious and long lasting consequences of child maltreatment, abandonment and trafficking, call for increased investments as well as intersectoral and international collaboration.
- Challenges include the development and implementation of primary prevention programmes for families who are at risk, improved capacity for early recognition across child education, more effective social and health services, and appropriate institutional response once maltreatment has been detected.

Child maltreatment is defined as ‘all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child’s health, survival, development or dignity in the context of a relationship of responsibility, trust or power’.<sup>1</sup> Four types of child maltreatment are commonly identified: physical abuse, sexual abuse, psychological abuse (sometimes referred to as emotional abuse), and neglect.<sup>h,2</sup> Witnessing intimate partner violence is also regarded as a form of child maltreatment. Over 80% of maltreatment occurs within the close family, while sexual abuse can also be perpetrated by other relatives and acquaintances. This chapter will also cover issues such as child abandonment and trafficking, which are closely related to abuse and maltreatment.

### Main Sources of Information

The main sources of information are systematic reviews on child maltreatment, governmental and NGO websites, the WHO Health for All database for mortality data, and country reports from ECPAT (End Child Prostitution, Child Pornography and Trafficking of Children for Sexual Purposes: <http://www.ecpat.net/EI/index.asp>). Information is often incomplete since only a few countries provide data from official registers on child protection and safety services and from the judiciary. *Ad hoc* studies include population-based studies centred on self-reports and studies on cases referred to emergency departments in hospitals. The incidence of child maltreatment varies according to the reporting procedures and definitions used.

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<sup>h</sup> Physical abuse: intentional use of physical force against a child that results in, or has the potential to result in, physical injury. Sexual abuse: any completed or attempted sexual act, sexual contact, or non-contact sexual interaction carried out by a caregiver on a child. Psychological (or emotional) abuse: intentional behaviour that conveys to a child that he/she is worthless, flawed, unloved, unwanted, endangered, or valued only to satisfy someone else’s needs. Neglect: failure to meet a child’s basic physical, emotional, medical/dental, or educational needs; failure to provide adequate nutrition, hygiene, or shelter; or failure to ensure a child’s safety.

## Size of the Problem

Child maltreatment remains a major public-health and social-welfare problem in Europe. According to population based surveys, every year 4% to 16% of children are physically abused, and one in ten is neglected or psychologically abused.<sup>3</sup> During childhood, between 5% and 10% of girls and up to 5% of boys are exposed to penetrative sexual abuse, and up to three times this number are exposed to some type of sexual abuse.<sup>4</sup> Population-based surveys indicate that the number of people who have been victim of maltreatment in their childhood far exceeds the number reported by official agencies, which include only referred cases. For example, in 2006 in England, 24 in every 10,000 children aged 0-17 years were on child protection registers following reports of actual or highly suspected abuse and/or neglect,<sup>5</sup> while a study of young English adults 18-24 years of age, who gave retrospective self-reports on their childhood, showed that 7% had suffered physical abuse, 6% physical neglect, 5% psychological/emotional neglect, 6% psychological/emotional abuse and 16% sexual abuse (11% contact sexual abuse).<sup>6</sup> Young women reported more sexual and emotional abuse than young men. In 2002, a national prevalence study of child maltreatment in Romania reported that 84% of 714 female and 581 male adolescents aged 13-14 years had experienced corporal punishment and 24% physical abuse.<sup>7</sup> Emotional abuse was reported by 21% and contact sexual abuse by 9%, while 8% claimed exploitation by family members. Neglect was far more prevalent than abuse, with physical neglect reported by 46%, emotional neglect by 44% and educational neglect by 34%. With the exception of educational neglect, no gender differences were found. The box provides examples of the available data, mainly taken from a review of *ad hoc* surveys from countries included in this report.<sup>3</sup>

### Self-Reported Maltreatment or Parent-Reported Perpetration

#### *Physical Abuse*

- United Kingdom, Finland, Italy, and Portugal: severe parental violence or worse (hitting with fist/object, kicking, biting, threatening/using a knife/weapon are classified as severe violence) from 3.7% to 16.3% (5%-35% cumulative).
- FYR of Macedonia, Latvia, Lithuania: yearly prevalence of physical abuse of 12.2%-29.7%.
- Romania: cumulative prevalence of physical abuse of 24%-29%.

#### *Psychological Abuse*

- United Kingdom and Sweden: cumulative prevalence of 4%-9% (based on categories consistent with severe emotional abuse).
- FYR of Macedonia, Latvia, Lithuania: yearly prevalence of severe or moderate psychological abuse of 12.5%-33.3%.

#### *Sexual Abuse*

- Cumulative childhood prevalence of some sexual abuse is:
  - Non-contact sexual abuse: 3.1% boys, 6.8% girls;
  - Contact sexual abuse: 3.7% boys, 13.2% girls;
  - Penetrative sexual abuse: 1.9% boys, 5.3% girls;
  - Any kind of sexual abuse: 8.7% boys, 25.3% girls.<sup>8</sup>

#### *Neglect*

- Incidence of persistent absence of care or provision: 1.4%-15.4% (likely to place a child at risk of harm, e.g. not enough food, no medical care when needed, no safe place to stay, serious lack of care).

#### *Witnessing Intimate-partner Violence*

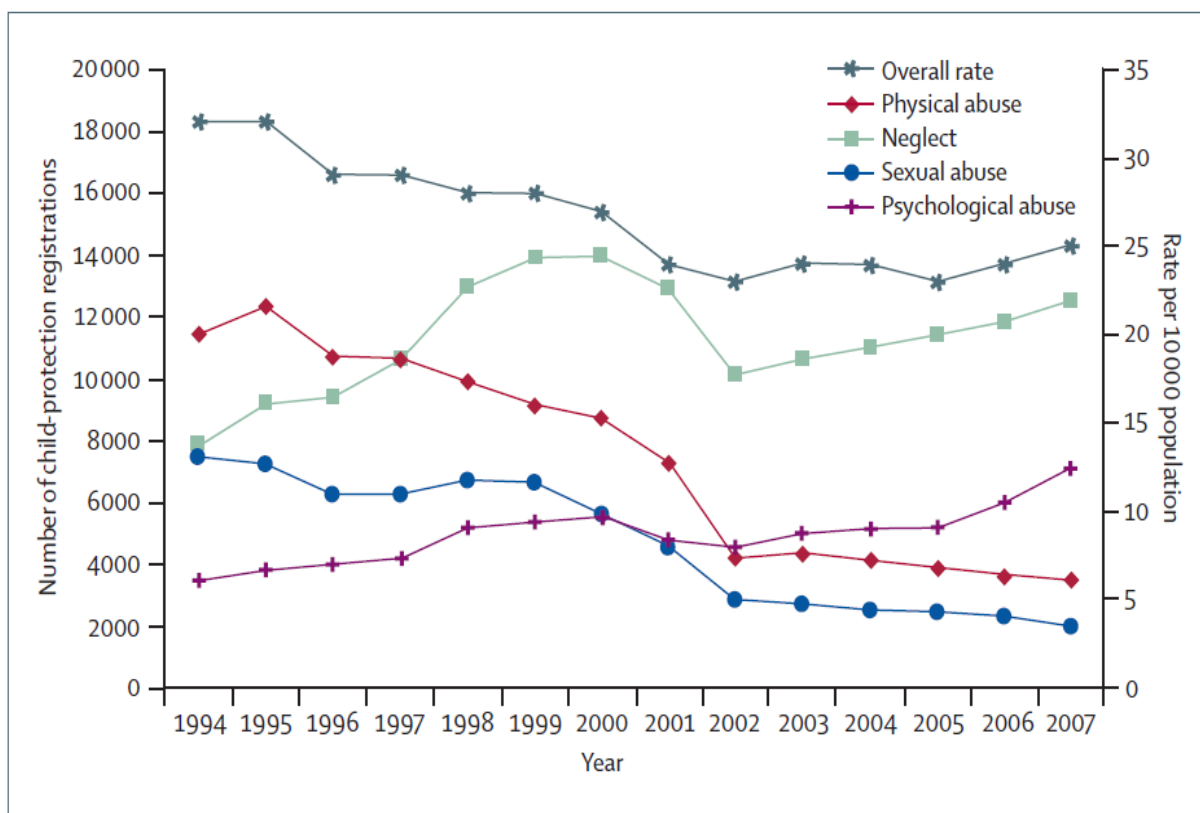
- Cross-sectional surveys of adolescents and adults: childhood prevalence of witnessing intimate-partner violence of 8%-25%.

Retrospective self-report studies consistently show that some children are exposed to more than one type of maltreatment.<sup>4,6</sup> Due to the heterogeneity of sources, it is not possible to assess temporal trends across countries. Data from the United Kingdom provide a visual



idea of the relative proportion among four types of child maltreatment and of temporal trends (Figure 11.1).<sup>9</sup>

**Figure 11.1. Number of child-protection registrations in the United Kingdom according to primary type of maltreatment and overall rate of registration per 10,000 children younger than 18 years, 2007-8 (Source: UK Department for Children, Schools and Family Referrals, 2008).**



### *Abandonment, Relinquishment and Institutionalisation*

Child abandonment and relinquishment<sup>i</sup> put the life of the child at risk as an immediate consequence, and may lead to institutionalisation and adoption or foster care following a period of residential care. Most of abandonment and relinquishment cases occur soon after birth, mostly in maternity hospitals or in their vicinity. In the 1990s, rates were particularly high in Romania and Bulgaria, reaching over 1% of all children by the mid 1990s.<sup>10</sup> The situation has improved since then, more as a result of deinstitutionalisation than of a notable decline in child abandonment. In Romania there has been a steady decline in the number of children 0-3 years of age in public institutional care, from 2,880 to 446 per 100,000 between 2001 and 2005. Data for Bulgaria also indicate a substantial decrease in children under 3 years in institutions,<sup>11</sup> particularly important for the long-lasting adverse effects of institutionalisation and for the fact that in some cases it was accompanied by institutional abuse.<sup>12</sup>

### *Trafficking*

Although the clandestine nature of child trafficking makes quantitative information very scarce, several studies, included those funded by the EU-funded STOP project, have

<sup>i</sup> Abandonment concerns the physical desertion of a child in circumstances where his/her immediate and future care cannot be guaranteed or presumed. Relinquishment refers to the act of leaving a child with, or surrendering him/her to the care of an individual or institution with the purpose and conviction that his/her immediate and future needs will thereby be ensured. Relinquishment may be carried out by an identified parent or anonymously.

documented trafficking of children for sexual exploitation. Most children are trafficked from Eastern to Western Europe.<sup>13</sup> Data from the United Kingdom Human Trafficking Centre show that between April 2009 and March 2010, 215 of the 843 potential cases of human trafficking from 33 countries were children. The real number might of course be much higher. Evidence for child trafficking was found in each case, with the majority of cases involving girls aged between 15 and 18 years.<sup>14</sup> ECPAT reports indicate a decline in child trafficking from south-eastern countries, such as Albania, between 2000 and 2006. This decline may be due to various interrelated factors, including the introduction of tougher penalties for traffickers and the promotion of prevention and protection activities by local and international NGOs. The same reports also show gaps in the provision of support for the reintegration of victims.<sup>15</sup> Working children and children from Roma communities are some of the social groups most targeted by trafficking networks. Sexual exploitation is the prevailing purpose of trafficking in Roma children, who are particularly vulnerable due to social marginalisation, non-school attendance and a lack of birth registration.<sup>16</sup>

### *Consequences on Health*

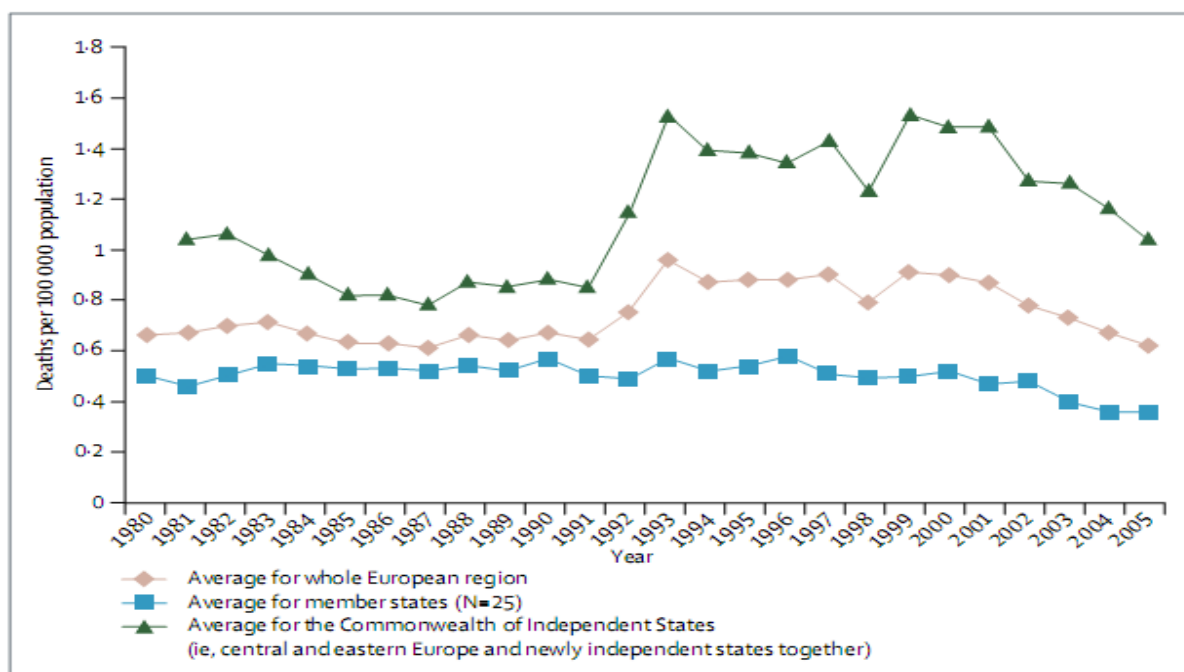
Child maltreatment can cause death, serious injury, mental health disorders and long-term consequences that may affect the child's life into adulthood. WHO Health for All estimates that deaths due to maltreatment in children younger than 15 years might be around 0.4 per 100,000 children in EU25 countries. Yet, substantial under-reporting occurs because in most countries there is insufficient routine investigation and a lack of post-mortem examination of child deaths, including cases diagnosed as SIDS. The biological parents are responsible for over 80% of cases, and step-parents are to blame for most of the remaining cases (15% of the total deaths).

Studies show that institutional rearing is associated with substantial psychiatric morbidity. Removing young children from institutions and placing them in families reduces significantly internalising mental disorders, although girls are significantly more responsive to this intervention than boys.<sup>17</sup>

Child homicide occurs most frequently during infancy. In the United Kingdom, 35% of child homicide victims younger than 16 years of age, are younger than one year. Large differences in infant homicide rates exist across Europe, with higher rates recorded in Central and Eastern Europe, and the lowest rate consistently higher than in the Western European countries. The lowest figures are reported from Scandinavia and Southern Europe.<sup>18</sup> It is worth noting that the peak incidence from 1993 to 2003 in Central and Eastern Europe coincided with the period of economic and political transition, when community services were severely disrupted and families were affected by unemployment, loss of security, and conflict.<sup>19</sup> Although the past 30 years have seen an improvement in child protection in most European countries, there has been little decrease in the rate of child homicides (Figure 11.2).

Consequences of child maltreatment continue into adulthood and substantially impair physical and mental health, invariably reducing the person's quality of life. Table 11.1 provides an overview of the most commonly reported health and social consequences of child maltreatment. It is also worth noting that a link has been shown to exist between maltreatment in childhood and the risk of later victimisation, and of becoming a perpetrator of violence or other antisocial behaviour as a teenager or adult.<sup>20</sup>

**Figure 11.2. Age-standardised rates of child death (0-14 years) due to homicide or manslaughter per 100,000 population in the WHO European Region (Source: WHO Regional Office for Europe. Health for All database).**



**Table 11.1. Long term health and social consequences of child maltreatment as documented by long term prospective studies (+ = moderate association; ++ = strong association).<sup>3</sup>**

Low educational achievement +	Attempted suicide +
Low skilled employment +	Alcohol problems +
Behavioural problems as child/adolescent ++	Prostitution/sex trading +
Post-traumatic stress disorder ++	Obesity ++
Depression +	Criminal behaviour ++

### Causes and Risk Factors

A number of studies have identified risk factors for child maltreatment, associated with child and parental characteristics, and with aspects related to the whole family and the community (Table 11.2).<sup>3,7,19,21</sup>

**Table 11.2. Risk Factors for Child Maltreatment**

Child	Premature, unwanted, disabled, young
Parent	Young age, single parent, unwanted pregnancy, exposure to violence, substance violence, inadequate prenatal care, poor parenting skills, physical or mental illness, marital problems, depression
Family	Poverty, lack of social support, size, stress, domestic violence, high residential mobility
Community/society	Lack of child protection laws, lack of birth registration, decreased value of children (minority, disabled), social inequalities, racial and religious discrimination, high levels and tolerance of violence (media, crime, war), cultural norms, absence of community services

Most of the above risk factors also apply to abandonment and trafficking. LBW, health problems or physical and/or mental disabilities in newborns are typically common causes of

abandonment. Other causes are: extreme poverty, mother working as a sex worker, and family disruption. A consistent finding across Europe is that infants are more at risk of fatal injury, physical abuse and neglect than older children, indicating that it is essential to intervene early in the child's life with health and social services to prevent maltreatment.<sup>22</sup> It should be noted that there is no reliable evidence to suggest that some minority groups are more likely to maltreat their children than others, although children from some minorities may be over-represented in residential care due to poverty and social neglect. Regarding abandonment and trafficking, young children and their families are especially vulnerable in countries undergoing social and economic transition, where health and social services may be poorly resourced.<sup>18</sup>

## Challenges

The main challenge is to increase cross-sectoral investments to prevent child maltreatment, abandonment and trafficking, and to minimise their consequences. Investments should address:

- Primary prevention, through universal services aimed at providing support to parenting, and parenting competence and skills.
- Secondary prevention, through targeted services aimed at providing social and psychological support for families and communities with risk factors, identified as being in need of further help.
- Tertiary prevention, through specialist services offered once child maltreatment has been detected, or abandonment has occurred, and aimed at preventing re-victimisation, and at preventing or reducing the consequences of institutionalisation.

There is increasing awareness in Europe of the scale of child maltreatment and of the need for prevention and child protection. However, there are still many gaps in the capacity to identify and report child maltreatment, and even greater gaps in the capacity to develop and implement preventive and intervention programmes.<sup>3,22</sup> The threshold for intervention differs from country to country, and even within countries, depending on the quality of social services and the judiciary's specific competencies. Services offered to children also depend on available resources. A key aspect of this is what children are actually offered once a serious maltreatment has been documented. When parents fail to protect or take care of their children, there is often no alternative between keeping the child in the family and extrication (and possible institutionalisation).<sup>22</sup>

Child protection systems cannot be based on legislation alone. Guidelines and legislation to prevent violence to children should develop in parallel with public awareness and cross-sectoral service provision. Where systems and sectors do not work harmoniously and according to shared principles and procedures, several problems emerge, with consequent lack of recognition, delay in interventions, inappropriate solutions (e.g. residential care), and long judiciary processes that are not in the best interest of the child. Better surveillance systems able to capture the real dimensions of this problem, and studies carried out to understand the causal pathways of maltreatment and to assess the effectiveness of alternative options to residential care are also necessary. Universal birth registration and improved international collaboration are of paramount need to fight child trafficking.

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## 12. Accidents and Injuries

### Key Messages

- Although reduction in mortality has been observed in the last two decades, every year in Europe injuries still cause 4,000 deaths, as well as more than 10% of all the DALYs lost among children 0-14 years of age.
- The most frequent external causes of fatal injury among children 0-14 years of age are transport accidents (36%) and drowning and submersion (14%). Among body parts, the head is frequently involved, accounting for a third of all injuries requiring admission to hospital.
- Child safety level has been judged to be fair to good in the countries involved in the 2009 Child Safety Action Plans, but improvement is still needed through the adoption, implementation and enforcement of effective approaches to injury prevention.
- Childhood deaths from injury follow a social gradient. Inequalities among and within countries probably reflect differences in the environment that determine disparities in exposure to risk factors and in enforcement practices.

This chapter will present information showing the relevance of fatal and non-fatal injuries to child health, and trends, as well as a description of the distribution of selected types of injuries across population groups. An overview of programmes and actions implemented at international and national level will be provided, along with examples of effective interventions. Current debates and information gaps will also be highlighted.

### Main Sources of Information

Data on mortality by cause are available in the WHO Mortality Database Table of Registered Deaths,<sup>1</sup> in the WHO/EURO European Detailed Mortality Database and in the European Mortality Database.<sup>2,3</sup> Data on incidence can be found in the EU Injury Database of the European Commission, DG SANCO, and the network of national Injury Database data providers for all cause injuries and leisure and home accidents.<sup>4</sup> EUROSTAT is the source of data for accidents in the workplace.<sup>5</sup> For hospital admissions the source is the WHO/EURO European Hospital Morbidity Database,<sup>6</sup> for burden of disease, the WHO Burden of Disease database.<sup>7</sup>

Different databases use different cut-offs for the different age groups. In the WHO Mortality Database Table of Registered Deaths, age is grouped as: <1 year, 1-4, and 5-14 years. In the WHO European Detailed Mortality Database and European Hospital Morbidity Database age is categorised as <1, 1-4, 5-9, 10-14 years. The European Mortality Database only presents data for the age group 0-14 years. In the Injury Database, age is categorised as 0-4, 5-9, 10-14 years. In EUROSTAT, accidents at work are presented only for the category 0-17 years. The WHO Burden of Disease database includes the age group 0-14 years.

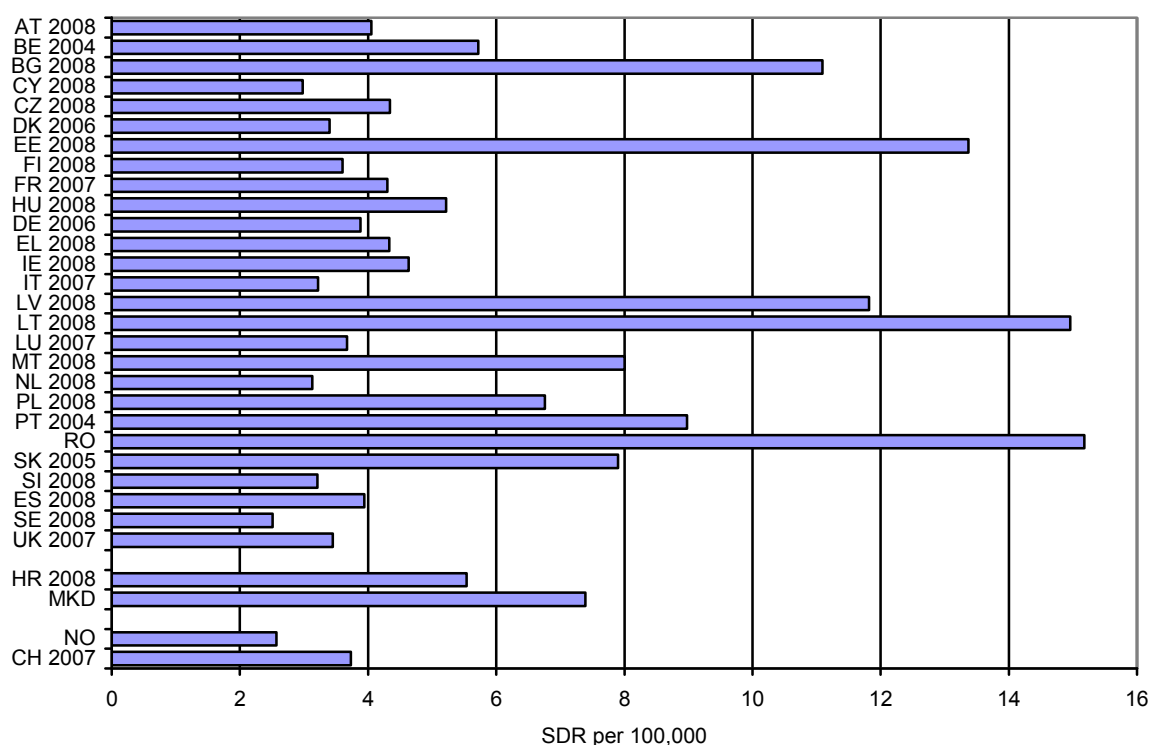
Completeness of data varies across countries. The WHO European Mortality Database and Burden of Disease database do include all countries, yet for the last 20 years data on child injury mortality have not been available for Turkey. The WHO Mortality Database Table of Registered Deaths and European Detailed Mortality Database does not include Turkey. The WHO European Hospital Morbidity Database does not include Bulgaria, Estonia, Greece, Malta, Romania, Sweden, FYR of Macedonia nor Turkey. EUROSTAT includes information on the EU27 countries, Norway and Switzerland. The most recent version of the Injury Database publicly available contains data only from 6 countries: Austria, Denmark, France, Netherlands, Portugal and Sweden.

## Size of the Problem

### Mortality

In the EU27 countries, injury is one of the leading causes of death in children 1-14 years of age, accounting for 32% of all deaths within this age group.<sup>8</sup> In EU27 plus Croatia, FYR of Macedonia and the EFTA countries, approximately 4,000 children 0-14 years of age die from an injury every year.<sup>1,2</sup> About 3,500 additional deaths are estimated to occur every year among children in Turkey.<sup>7</sup> Figure 12.1 presents the age-standardised death rates (SDR) by country. For EU27, this was around 5 per 100,000 in 2008, while in EU15 countries it was around 4, and 9.5 in EU12 countries. The highest SDR were recorded in Bulgaria, Estonia, Latvia, Lithuania and Romania. The difference between countries at the two ends of the SDR spectrum is significant: up to 6 times. In 2008, in the EU27 countries, and in the age group 0-14 years the SDR of boys (6.15 deaths/100,000) was almost double than that of girls (3.86). The crude death rate estimated for the year 2004 among children in Turkey was 16.9 deaths per 100,000 less than 15 years of age.<sup>7</sup>

**Figure 12.1. SDR from injury per 100,000 children 0-14 years of age, by country.**



Approximately 15% of injury deaths among children 0-14 years of age occur in infancy, 27% in children 1-4, 23% in children 5-9, and 35% in those 10-14 years of age.<sup>2</sup> Figure 12.2 shows the number and the distribution of injury deaths by age group and country.

### Trends

In the last 20 years, a reduction in the SDR was observed across Europe, as shown in Figure 12.3. However, in the EU15 group of countries, the rate of non-fatal occupational injuries in people younger than 18 years of age has remained stable in the decade between 1998 and 2007.<sup>5</sup>

Figure 12.2. Number and distribution of injury deaths by age group and country.

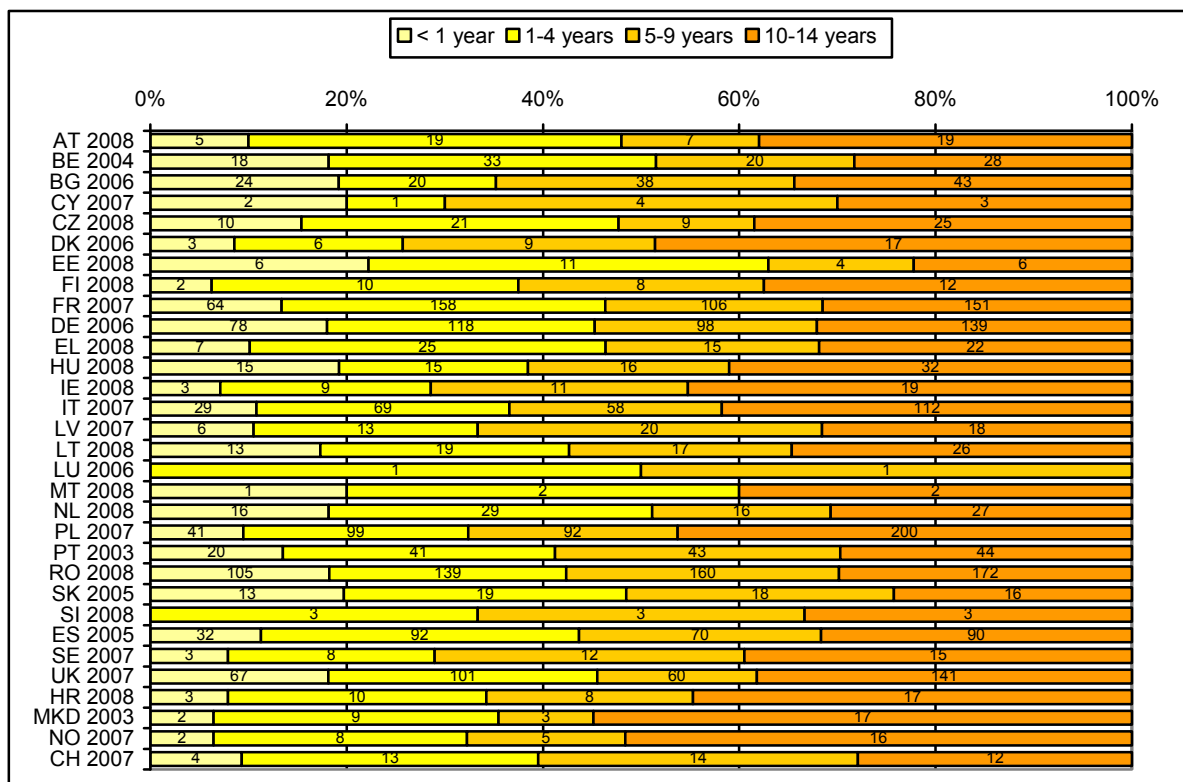
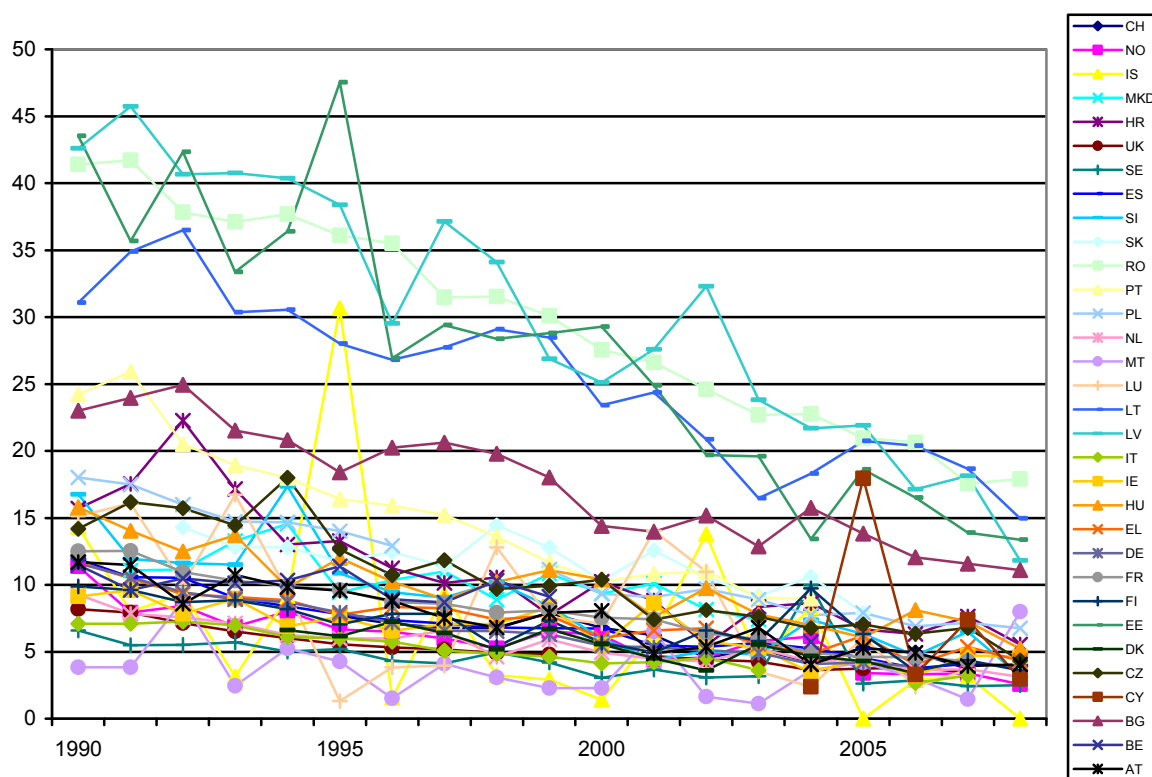


Figure 12.3. Trend of SDR from injury by country in the age group 0-14 years from 1990 to 2009.

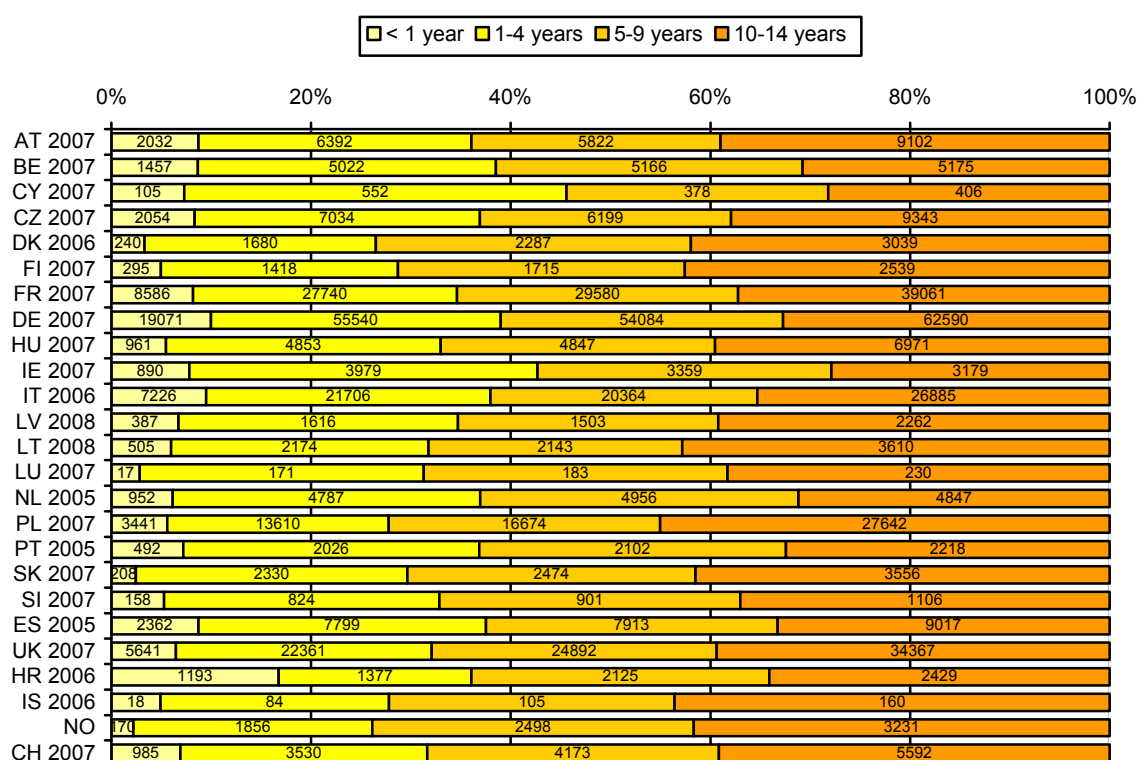




## Admission to Hospital

In addition to fatalities, non-fatal injuries and their disabling consequences have a tremendous impact on health. It is estimated that each year, 7.8 million children 0-14 years of age have to be treated for an injury in EU hospitals, meaning that 1 out of 10 children in the EU suffers each year from an injury requiring emergency medical attention.<sup>8</sup> In this age group and every year, there are over 700,000 admissions to hospital because of injuries.<sup>6</sup> Figure 12.4 shows the number and the distribution of hospital admissions by age group and country. It should be noted, comparing Figures 12.4 and 12.2, that for some countries, e.g. Portugal, there is no correspondence between the ranking according to the absolute number of deaths and the number of admissions. Approximately 8% of admissions involve infants, 27% children 1-4, 28% those 5-9, and 36% those 10-14 years of age.<sup>6</sup>

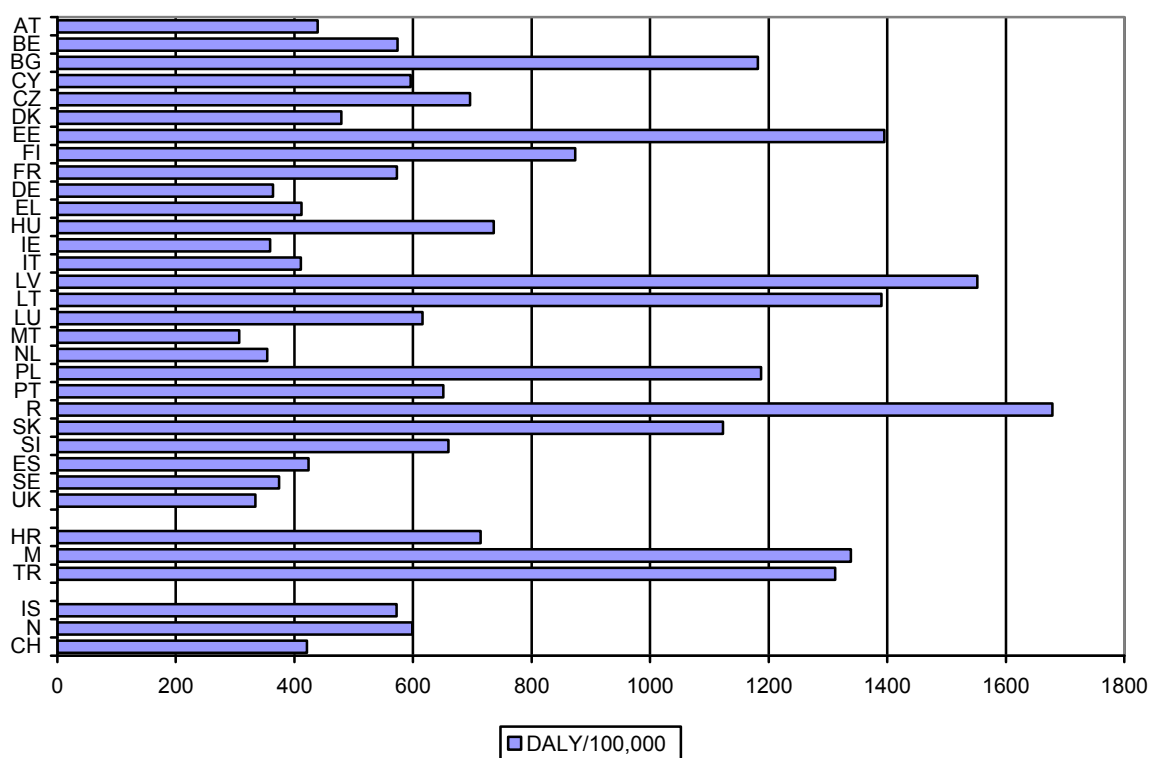
**Figure 12.4. Number and distribution of hospital admissions due to injury by age group and country.**



## Burden of Disease

In the 33 countries analysed, injuries are responsible for the annual loss of approximately 760,000 DALYs among children 0-14 years of age.<sup>7</sup> DALYs lost because of an injury represent more than 10% of all the DALYs lost annually among children. The rate of DALYs by country is shown in Figure 12.5. Generally, the distribution of the rate of DALYs by country reflects the distribution of mortality. However, that is not always the case. For example, there are countries, such as Finland and Norway, where child injury mortality is relatively low, but the rate of DALYs is high, indicating that an important source of the burden of injuries in those countries depends on the disability that comes as a result of non-fatal events.

Figure 12.5. Estimated DALYs per 100,000 children 0-14 years of age, by country, in 2004.



### Causes and Risk Factors

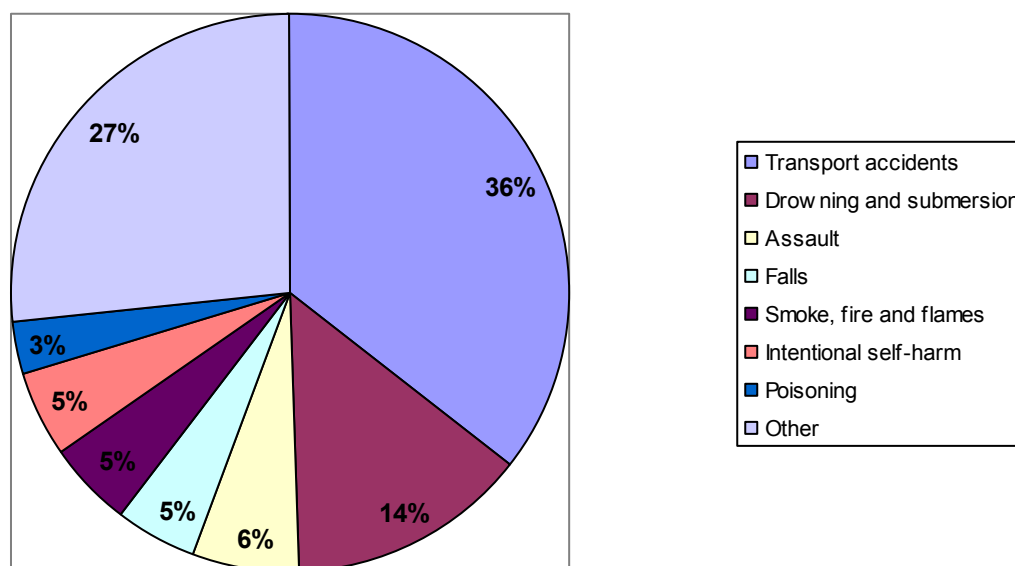
Injuries can be classified according to a number of characteristics, such as their outcome (fatal vs. non-fatal), the place of occurrence, the activity being carried out when injured, the objects/substances involved, the role of human intent (unintentional vs. intentional), or the mechanism. For ease of presentation, often the two classifications by intention and mechanism are combined so that the mechanism is shown in case of unintentional injury, whereas the persons responsible for the injury are highlighted for intentional injuries. This is known as the classification of injuries by external cause. Its distribution is important for preventative purposes. Figure 12.6 shows the distribution of fatal injuries according to external cause. For some causes, there is a great difference across age groups. In fact, the proportion of fatal injuries determined by transport accidents increases with age (from 14% in infants to more than 40% in children 5-14 years of age), whereas the proportion of fatal assaults decreases with age (from 12% in infants, to 2% in children 10-14 years of age). Fatal falls are particularly frequent among children 1-4 years of age (7%), with drowning being an important cause of death in children between 1 and 9 years of age (almost 20%). Among children 10-14 years of age drowning is a less common cause of death (10%), and even rarer among infants (3%). Suicide is almost not existing among children less than 10 years old, whereas among older children the relative frequency becomes high (14%).

Among children 0-14 years of age, approximately 91% of the DALYs are attributable to unintentional injuries and only 9% to intentional ones.<sup>7</sup> In particular, one fifth of DALYs is attributable to road traffic accidents. Another fifth is attributable to falls, meaning that the impact of falls on the health of children is mostly attributable to the disability caused by non-fatal events. On the other hand, the proportion of DALYs which can be attributed to drowning is 4%, meaning that this mechanism of injury often leads to death.

Regarding non-fatal injuries, in children under 5 years of age over 50% occur at home, with falls being the most frequent mechanisms. Traffic injuries account for about 17% of all child

injuries, with more severe consequences compared to other injuries. The main role of children in traffic injuries is as riders (63%), passengers (23%) or pedestrians (6%).<sup>8</sup>

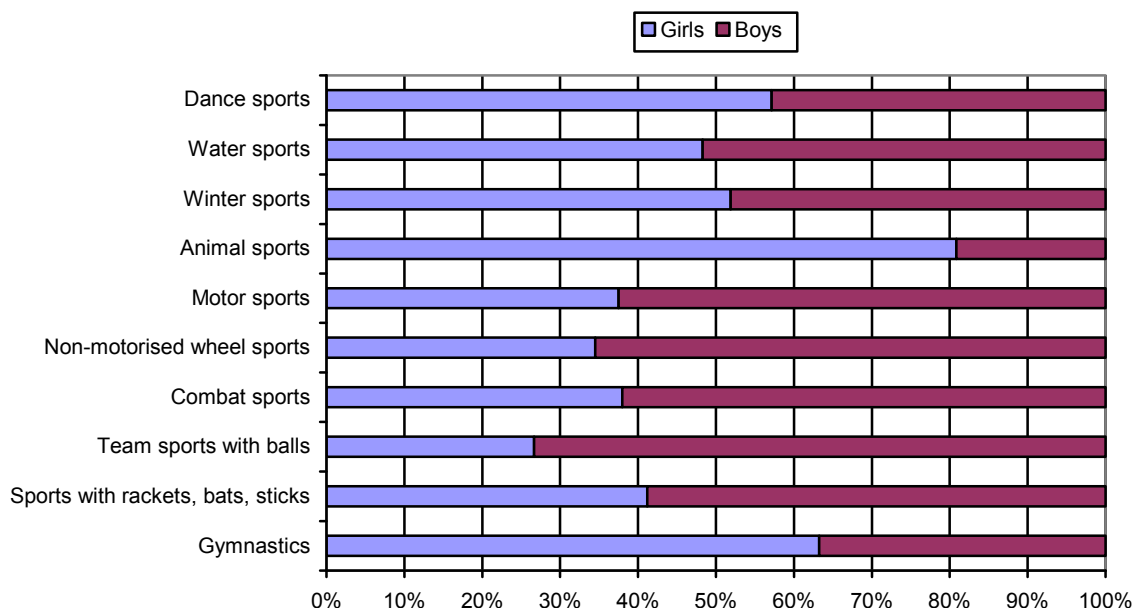
**Figure 12.6. External causes of fatal injuries in Europe among children 0-14 years of age.**



### *Sport Injuries*

Sports injuries represent an interesting issue because they occur during activities that are encouraged as part of a healthy life style.<sup>9</sup> In 2005, in the 6 countries providing input into the Injury Database, over 700,000 injuries were estimated to have occurred during sports activities among children 0-14 years of age, with a crude incidence rate ranging from 13 accidents per 1,000 in Portugal to 47 per 1,000 in France.<sup>4</sup> Approximately 80% of these accidents involved children 10-14 years of age, who had the highest incidence rate, ranging from 34 per 1,000 in Portugal, to 113 per 1,000 in France. Children 5-9 years of age had much lower rates, ranging from 4 to 30 per 1,000 in Portugal and Austria, respectively. Only about 2% of accidents involved children less than 5 years of age, whose rates were very low (from less than 1 per 1,000 in Portugal to 4 per 1,000 in Austria). The sports during which injuries were more common were team sports with balls (over 300,000 cases/year in the 6 countries) and non-motorised wheel sports (about 140,000/year), followed by winter sports (about 80,000/year), gymnastics (70,000), combat sports and animal sports (50,000 respectively). In some countries (Denmark, Portugal, Sweden), the incidence rate of sports injuries was similar between boys and girls, whereas in others (Austria, France, Netherlands) the rate was higher among boys, possibly due to differences in the sports practised by boys and girls. In those countries, more girls than boys were injured while doing gymnastics, animal and dance sports. On the other hand, more boys than girls resulted injured while doing sports with rackets, bats or sticks, team sports with balls, combat sports, non-motorised wheel sports, and motor sports. Similar number of boys and girls suffered an injury while doing athletics, winter, water and climbing sports. Figure 12.7 shows the relative frequency of injuries in boys and girls for the most common groups of sports. Almost one in 10 accidents involved the head, over one in 3 the lower extremities, and almost half affected the upper extremities. Injuries to other body regions were less common.<sup>4</sup> Approximately 7% were examined in the emergency room and sent home without treatment, 40% were sent home after treatment, 8% were referred for further treatment by general practitioners, 35% were referred for further treatment as an outpatient, 5% were admitted to hospital, and a smaller proportion died.

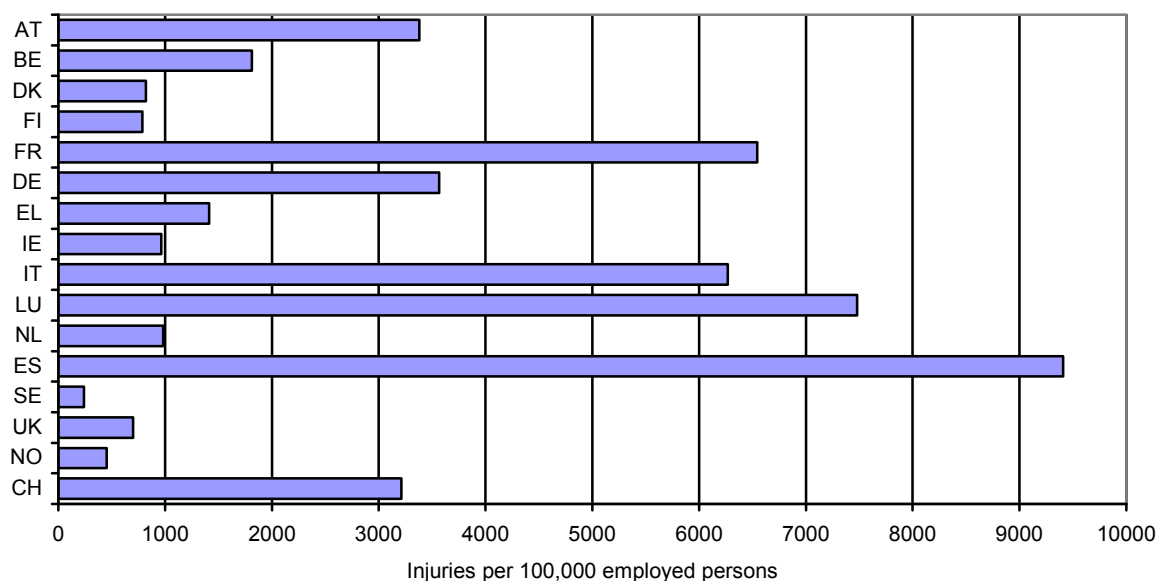
**Figure 12.7. Relative frequency of selected sport injuries in boys and girls 0-14 years of age.**



### Occupational Injuries

Injuries occurring at work are another important issue because working is an activity that most people do not choose to do, and this is especially true when children are concerned. In the EU15 countries and Norway, in 2006, there have been approximately 44,000 occupational injuries causing more than three working days to be lost, and 18 deaths, among individuals younger than 18 years of age. Figure 12.8 shows the incidence rates (injuries per 100,000 people employed) of non-fatal injuries standardised by economic activity in the EU15 countries, Norway and Switzerland.

**Figure 12.8. Incidence rate of occupational injuries causing more than three days lost, standardised by economic activity in the EU15 countries, Norway and Switzerland in people younger than 18 years of age (no data from Portugal).**



## *Injuries to Specific Body Regions*

Information on the distribution of injuries by body region is important in order to estimate their impact on health. In effect, even injuries caused by the same mechanism, e.g., motor vehicle crash, may have different impacts depending on the body regions affected. For example, a fracture to the skull or the femur is likely to have more implications in terms of disability, pain, loss of school or work days, and limitation of leisure activities, than a fracture to a finger, regardless of the external cause determining the injury. Of all children admitted to the hospital because of an injury, 20% suffered intracranial injuries and another 14% other kinds of injuries to the head, 15% had fractures to the forearm, 5% to the lower leg, and 2% to the femur.<sup>6</sup> The distribution of hospital admissions due to different types of injuries is not uniform across age groups. For example, infants accounted for 18% and 13% of admissions due to intracranial and other head injuries, respectively, whereas they represented less than 1% of those due to fractures of the forearm and lower leg. On the contrary, children 10-14 years of age account for the greatest proportion of admissions due to those types of injury (50% of admissions for forearm fracture and 64% of those for lower leg fracture). These patterns may reflect, on one hand, the types of injuries actually suffered by children of different ages, depending in turn on the activities carried out when injured, as well as on the mechanism of injury. On the other hand, they reflect a different tendency of admission to hospital of children of different ages with particular types of injuries (e.g. head injuries).

## **Challenges**

In 2004, the 4<sup>th</sup> Ministerial Conference on Environment and Health held in Budapest approved the Children's Environment and Health Action Plan for Europe (CEHAPE). The CEHAPE identifies four priority goals (see Chapter 13). The second of these goals was: 'to prevent and substantially reduce health consequences from accidents and injuries [...] by promoting safe, secure and supportive human settlements for all children'.<sup>9</sup> The CEHAPE encouraged the development and implementation of national action plans on children's health and the environment. To assess the status of these plans, a survey conducted in 2009 showed that most countries had already developed their national plans, some were still developing them (Ireland, Italy, Poland, Slovenia, FYR of Macedonia), and two (Croatia, Switzerland) had not yet started. No information was available on Romania.<sup>10</sup> Most plans were part of other programmes rather than stand-alone plans. Measures included in the plans ranged from legislation (including, for example, harmonisation with EU legislation) to health promotion, awareness-raising campaigns, monitoring of exposure, health surveillance and research.

Most CEHAPE plans addressed accidents and injuries. They were not, however, specific to injuries. Other more focussed action plans have been developed under the leadership of the European Child Safety Alliance (ECSA) through the Child Safety Action Plans (CSAP) initiative, with co-funding and partnership from the EC, the Health and Environment Alliance, UNICEF, WHO/EURO, two UK universities, and partners in each of the participating countries. The CSAP initiative aims to facilitate the development of government-endorsed child safety action plans. Participating countries work through a common process that includes standard collection of data on uptake of good practices and leadership, as well as infrastructure and capacity building actions to enhance child injury prevention efforts. The first phase involved 18 EU countries and ran from 2004-2007. As a result, in addition to national CSAPs, Child Safety Report Cards and Profiles were produced to serve as part of the assessment phase in the development of the action plans and as a baseline for future benchmarking and evaluation. The cards summarised a country's performance regarding the level of safety provided to children and adolescents through national policies. Country progress in the CSAP process until September 2007, measured in 9 steps, is shown in Figure 12.9. The 9 steps include: government engagement (step 1), national partner engagement (step 2), situational analysis (step 3), vision statement (step 4), identification of critical issues (step 5), goals and objectives (step 6), action steps (step 7), government endorsement (step 8), and communication of plan (step 9). The second phase of the project

involves 26 countries: Austria, Belgium, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Portugal, Slovenia, Spain, Sweden, Wales, Scotland and Northern Ireland in the United Kingdom, and Israel. In addition, eight countries follow the process as observers, namely: Denmark, Croatia, FYR of Macedonia, Norway, Poland, Slovak Republic, Switzerland and England.<sup>j</sup> Child safety level in those countries has been judged to be fair to good, as illustrated in Figure 12.10. Countries that overall scored the highest were Iceland, Netherlands, Sweden, Czech Republic, Austria, Slovenia, France, United Kingdom, Germany and Finland.<sup>11</sup> All countries that participated in the 2007 and 2009 assessments showed an improvement in the level of child safety performance.

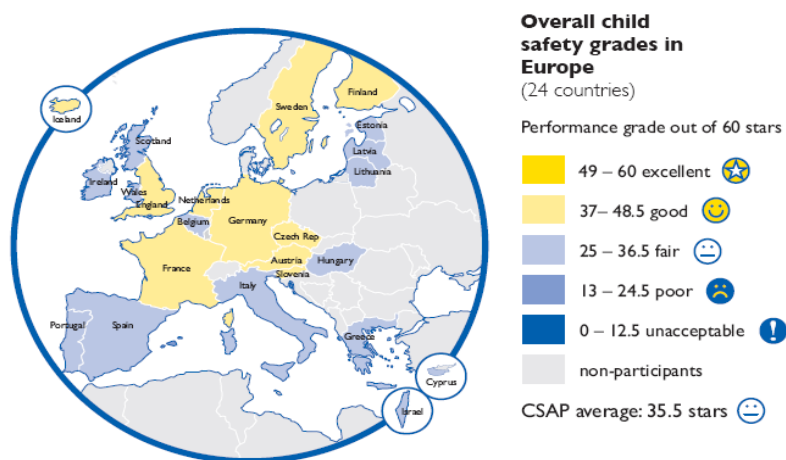
**Figure 12.9. Child Safety Action Plan process: country progress as of September 2007.**<sup>12</sup>

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9
AT	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	Step in progress
BE	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	No action
CZ	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress
DE	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	Step in progress
DK	Step in progress	Step completed	Step in progress	No action	No action	No action	No action	No action	No action
EE	Step in progress	Step in progress	Step in progress	No action	No action	No action	No action	No action	No action
EL	Step in progress	Step completed	Step in progress	Step in progress	Step in progress	Step in progress	Step in progress	Step in progress	Step in progress
ES	Step in progress	Step in progress	Step in progress	No action	No action	No action	No action	No action	No action
FR	Step in progress	Step in progress	Step in progress	No action	Step in progress	Step in progress	Step in progress	No action	No action
HU	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	No action	Step in progress	Step in progress
IT	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	Step in progress
NL	Step completed	Step completed	Step in progress	No action	No action	No action	No action	No action	No action
NO	Step in progress	Step completed	Step in progress	No action	No action	No action	No action	No action	No action
PL	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	Step in progress	Step in progress
PT	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step in progress	Step in progress	No action
SE	Step completed	Step completed	Step in progress	Step in progress	Step in progress	No action	No action	Step in progress	Step in progress
UK*	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	No action	Step in progress
UK**	Step completed	Step completed	Step completed	Step completed	Step completed	Step completed	No action	Step in progress	Step in progress

\* Northern Ireland; \*\* Scotland

Step completed      Step in progress      No action

**Figure 12.10. Overall child safety grades in Europe.**<sup>11</sup>



<sup>j</sup> Updated Child Safety Report Cards and Profiles have been published in 2009 for 24 countries and are available at <http://www.childsafetyeurope.org/csi/eurosafe2006.nsf/wwwVwContent/I4downloads-111.htm?OpenDocument>.

ECSA has also published a Child Safety Good Practice Guide to prevent ineffective strategies from continuing to be practised across Europe despite evidence that they are not making the best use of resources.<sup>13</sup> The Guide describes several approaches that offer proven or promising strategies in child injury prevention and safety promotion, but it also provides examples of good practice, such as:

- Modifications of the environment (e.g. playground equipment design and installation);
- Modifications of products (e.g. child-resistant lighters);
- Legislation, regulation and enforcement (e.g. regarding the use of child passenger restraint);
- Promoting the use of safety devices (e.g. smoke detectors);
- Supportive home visits to families of young children;
- Community-based interventions (e.g. promotional campaign bicycle helmet);
- Education and skills development (e.g. pedestrian skills training).

Deaths from injury follow a social gradient. Child injury mortality rates are higher in countries with lower income, and in children from lower socio-economic class families within these. These inequalities are a growing concern.<sup>14</sup> They may reflect differences in the environment that determine disparities in exposure to risk factors and in enforcement practices. The experience of countries that have already developed effective approaches to injury prevention, and rank now among the safest countries regarding this particular issue, should be regarded as a valuable resource and be seen as motivational force for other countries to invest in child injury prevention. In fact, a number of strategies, actions, and practices have been proven to reduce childhood injury. Despite this evidence, and as reflected by the sub-optimal child safety scores assigned in the CSAP initiative, many countries have not yet adopted and/or fully implemented and enforced those evidence-based measures. Challenges in the implementation of action plans include insufficient human and/or financial resources, insufficient capacity to implement the plans, low relative importance compared to other priorities, inadequate intersectoral collaboration, and insufficient political support.<sup>15</sup> More attention needs to be drawn to the promotion of actions for child safety. ECSA is very active on this and is constantly involved in initiatives and campaigns to raise awareness on child safety issues or that aim at influencing key decision makers.

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## 13. Environment-Related Diseases

### Key Messages

- Exposure to outdoor and indoor air pollution is a major cause of mortality and morbidity in European children.
- Chemical and physical agents such as heavy metals, dioxins, polychlorinated biphenyls (PCB), pesticides, noise, ionizing and ultraviolet radiation cause substantial hazards to children in all countries.
- Unsafe water and inadequate sanitation are also an important cause of disease in rural areas and marginalised population groups.
- There is increasing concern about the risks deriving from multiple low level exposures to chemicals during embryo-foetal development.
- There has been progress in risk reduction, notably in the area of lead, dioxins and PCBs, indoor and outdoor air and water pollution thanks to the EU REACH (registration, evaluation, authorisation and restriction of chemical substances) legislation, the development of Europe-wide environmental health indicator and monitoring systems and of children's environment and health action plans.
- Challenges include the further development of child focused monitoring and biomonitoring systems, and the establishment of intersectoral collaboration to implement child focused risk reduction policies that take into account the marked inequities in children's exposure and vulnerability to environmental toxicants across countries, age groups and socio-economic levels.

Environment-related diseases include all conditions that are entirely or partially attributable to exposure to environmental factors, including the physical and the wider psychosocial environment. Children, particularly from conception to the earliest years of life, are uniquely vulnerable to environmental hazards and a substantial proportion of child mortality and disability is attributable to early environmental exposures.<sup>1,2</sup> This chapter presents a synthetic overview of the evidence regarding the health effects of children's exposure, from conception to adolescence, to the main environmental contaminants in Europe. It follows the framework adopted by the Children's Environment and Health Action Plan for Europe (CEHAPE),<sup>3</sup> approved by the 4<sup>th</sup> Ministerial Conference on Environment and Health held in Budapest in June 2004 (see box), and focuses on priority goals I, III and IV. Goal II is covered in Chapters 2 and 9.2, for physical activity, and in Chapter 12, for accidents and injuries.

### CEHAPE Priority Goals

- I. 'To significantly reduce the morbidity and mortality arising from gastrointestinal disorders and other health effects, by ensuring that adequate measures are taken to improve access to safe and affordable water and sanitation for all children'.
- II. 'To prevent and substantially reduce health consequences from accidents and injuries and pursue a decrease in morbidity from lack of adequate physical activity, by promoting safe, secure and supportive human settlements for all children'.
- III. 'To prevent and reduce respiratory diseases due to outdoor and indoor air pollution, as well as contributing to a reduction in the frequency of asthmatic attacks, in order to ensure that children can live in an environment with clean air'.
- IV. 'To reduce the risk of disease and disability arising from exposure to hazardous chemicals (e.g. heavy metals), physical agents (e.g. excessive noise) and biological agents and to hazardous working environments during pregnancy, childhood and adolescence'.

### Main Sources of Information

The main sources of information are the Environmental Burden of Disease (EBD) estimates for children,<sup>2</sup> the exposure estimates of a 2007 report on children's health and environment in Europe,<sup>4</sup> the WHO European Health Reports of 2009,<sup>5</sup> a recent progress assessment on

health and environment in Europe,<sup>6</sup> the Environment and Health Information System (ENHIS) fact sheets,<sup>k</sup> and a number of other primary studies and reports.

Available data on mortality and DALYs attributable to environmental factors are available only from regional estimates,<sup>l</sup> they are mostly based on estimates of exposure and dose-response studies, and usually extrapolated from primary data available from single country or multi-country studies. As a consequence, the confidence intervals are large for all mortality rates and DALYs estimates. Exposure data are relatively complete for main air pollutants, including passive smoke, unsafe water and inadequate sanitation, although not for all countries considered in this report. Exposure data on chemicals and physical agents are available at country level for restricted and often selected population groups.

## **Size of the Problem**

### *Unsafe Water and Inadequate Sanitation*

The health effects of poor water and sanitation are relatively limited in Europe. It is estimated that almost 100% of the population of the countries included in this report has access to improved water supply and sanitation.<sup>4</sup> The EBD study estimated that in the EU15 countries, 60% of diarrhoea cases and 0.01% of total under 5 mortality was attributable to lack of water and sanitation facilities. But the proportion rises up to 87% of diarrhoea cases and 2% of overall mortality in rural areas in Turkey and other south eastern countries, where a significant part of the rural population, and in some cases part of the urban population living in poor neighbourhoods, has no access to public water supply and live in dwellings with no connection to sanitation facilities.<sup>7</sup>

### *Polluted Air*

Several factors contribute to determine respiratory disease in children, including infections, diet, social conditions and the availability of medical care. Air pollution, from out and indoor, is among the key determinants of preventable respiratory disease. Air pollution increases the incidence of acute and chronic diseases in infants and very young children and affects the development of their respiratory system.<sup>8</sup> Over half of the children, in Europe are regularly exposed to environmental tobacco smoke at home. In some countries, the prevalence of exposure reaches 90%.<sup>9</sup> Around 15% of people live in damp homes, which contribute to the development and exacerbation of asthma.<sup>10</sup> Exposure to products derived from the combustion of solid fuels is a considerable health problem in the eastern part of Europe.

### *Outdoor Air Pollution*

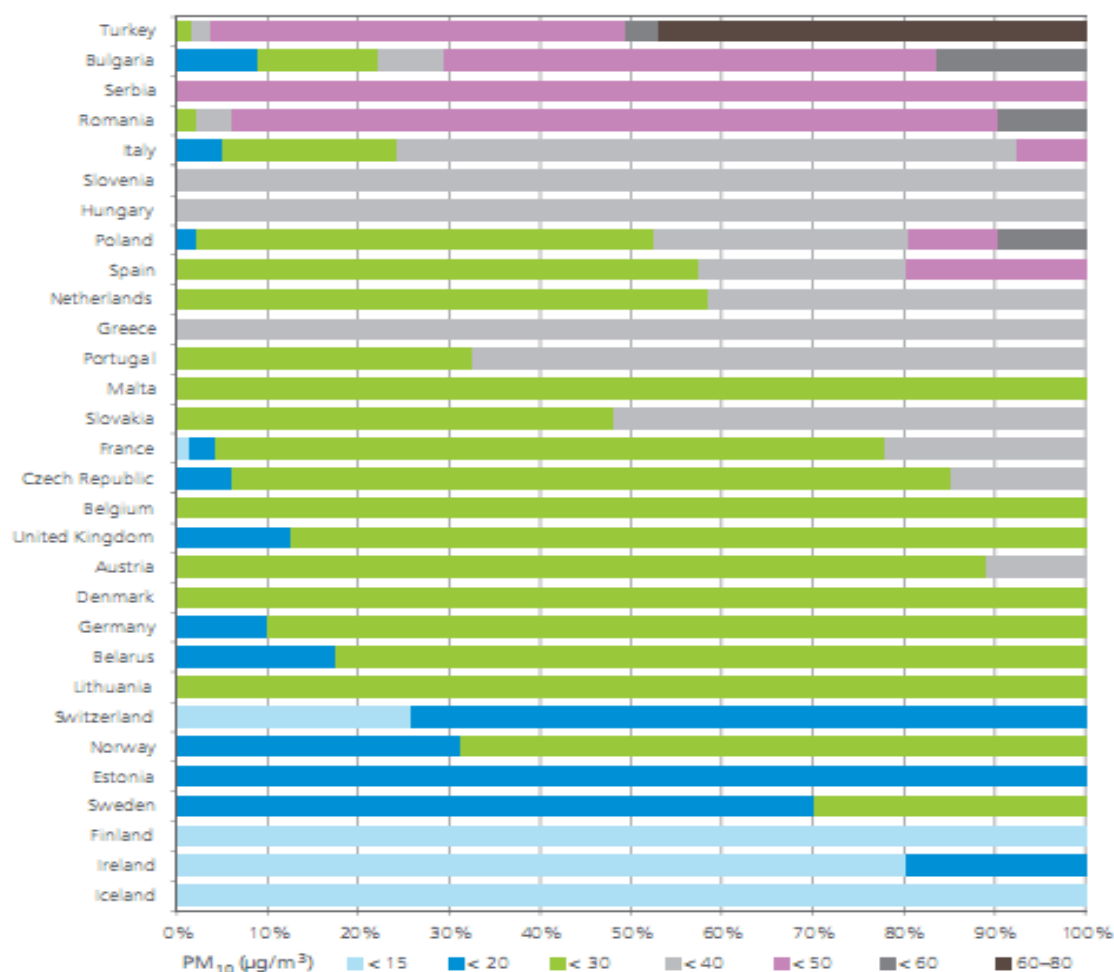
Figure 13.1 shows the population exposure to PM<sub>10</sub> (particulate matter of 10 micrometers or less), as an average annual concentration, in various European cities in 2004, or in the last available year. This is expected to approximate the exposure in children, assuming children comprise similar proportions of the cities' populations. Over the last few years, there has been some improvement in average exposure levels in urban areas of Europe.<sup>11</sup> However, the vast majority (89%) of people, including children, living in European cities where PM<sub>10</sub> is monitored, are exposed to levels exceeding the WHO air quality guideline level of 20 µg/m<sup>3</sup> and for 14% of people, the higher EU limit value of 40 µg/m<sup>3</sup> is exceeded.<sup>5</sup> This gives rise to a substantial risk to children's health.

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<sup>k</sup> The ENHIS has been developed through collaborative projects coordinated by the WHO European Centre for Environment and Health in Bonn, together with several Member States and the EC DG SANCO as part of a broader initiative on European Health Information Systems.

<sup>l</sup> Estimates are based on the WHO European Region, which includes all former USSR countries and Israel.

**Figure 13.1. Percentage of population living in cities with various PM<sub>10</sub> levels, 2007 or last available year (Source: ETC/ACC Technical Paper, 2010).**



According to the EBD study, outdoor air pollution is estimated to be responsible for a percentage between 0.1% and 5.9% of all-cause deaths among children 0–4 years of age, with the higher estimates in South Eastern European countries and Turkey.<sup>7</sup> These results are significant because they quantify the impact of outdoor air pollution on child mortality. However, they are likely to underestimate the real impact on health for a number of reasons. On one hand, PM<sub>10</sub> was used as a proxy for outdoor air pollution, yet other co-pollutants, spatially or temporally unrelated to PM<sub>10</sub> may have an impact on child health and may in turn affect the data. On the other hand, only a subset of adverse outcomes (i.e. fatal outcomes) was estimated, while upper respiratory illnesses, LBW and its long-term health effects, were not considered.

A review of several studies demonstrated the strong effect of PM on respiratory mortality in the post-neonatal period.<sup>8</sup> The risk of respiratory-related post-neonatal mortality is more than doubled for each 10 µg/m<sup>3</sup> increase in PM<sub>2.5</sub>, after adjustment for other risk factors.<sup>12</sup> While evidence suggests that air pollution is associated with the exacerbation of pre-existing asthma, an association with the onset of asthma has not been consistently shown. However, recent studies, including birth cohort studies, are addressing these limitations, and there is increasing evidence that exposure to traffic-related air pollutants such as fine PM, black smoke and nitrogen dioxide, is associated with an increased risk for the onset of asthma in young children.<sup>13</sup> Among the major contributors to urban air pollution, road transport is becoming more and more important. The exposure of children to traffic related air pollutants such as PM has a considerable impact on their health and well-being.<sup>14</sup>

## *Indoor Air Pollution*

The main sources of indoor air pollution are the use of solid fuel for heating and cooking purposes, and second hand tobacco smoke. The household combustion of coal or biomass produces smoke that contains carbon monoxide, nitrogen oxides, sulphur oxides, benzene, formaldehyde, polyaromatic compounds (such as benzopyrene and benzene), and suspended particulates. There are wide differences within Europe regarding the proportion of children living in homes where solid fuel is used. In most countries, less than 5% of the population, is exposed to solid fuel, but this proportion increases in rural areas. The proportion of children exposed to second hand tobacco smoke at home ranges between 20% and 85%, with the higher rates observed in Central and Eastern European countries (FYR of Macedonia, Croatia, Greece, Romania, Slovak Republic, Hungary) and Turkey.<sup>15</sup>

In infants and young children, exposure to second hand tobacco smoke increases the risk of SIDS, acute lower respiratory tract infections, chronic respiratory symptoms, middle ear disease, reduced pulmonary function and asthma.<sup>9</sup> Smoke-free policies have led to drastic decreases in exposure to second hand tobacco smoke (up to 90% in low-exposure settings) as well as in daily cigarette consumption and in smoking by young people.<sup>16</sup> Several diseases have been linked to the exposure to solid fuel use, including acute lower respiratory infections in young children and asthma in school-aged children.<sup>17</sup> In the EBD study, up to 5.6% of all deaths in children younger than 5 years were attributable to indoor air pollution. This burden was virtually confined to South Eastern European countries and Turkey.<sup>7</sup> A few studies provide suggestive evidence of a link between indoor air pollution and adverse pregnancy outcomes, in particular LBW.

Children, who tend to spend more time at home than adults and whose immune systems are still developing, are at increased risk of developing respiratory disorders when living in damp, mouldy housing. European survey data indicate that exposure to damp is a frequent health risk, with 18% of the EU population exposed in 2007.<sup>10</sup> Exposure varies greatly among countries, however, ranging between 5% and 37%. Damp houses are especially frequent in the new EU Member States. The prevalence of asthma, cough and wheezing among children living in homes with problems of damp or mould is 1.4–2.2 times higher than among children living in drier housing conditions.

## *Chemical and Physical Agents*

Several thousands of chemical agents are dispersed in the environment; they enter the human body mainly through food and air. The information on exposure is only available for few countries and for limited population samples. Data on exposure to chemical hazards in food are only available for the general population in 15 EU countries and there is no harmonised monitoring in children.

## *Heavy Metals*

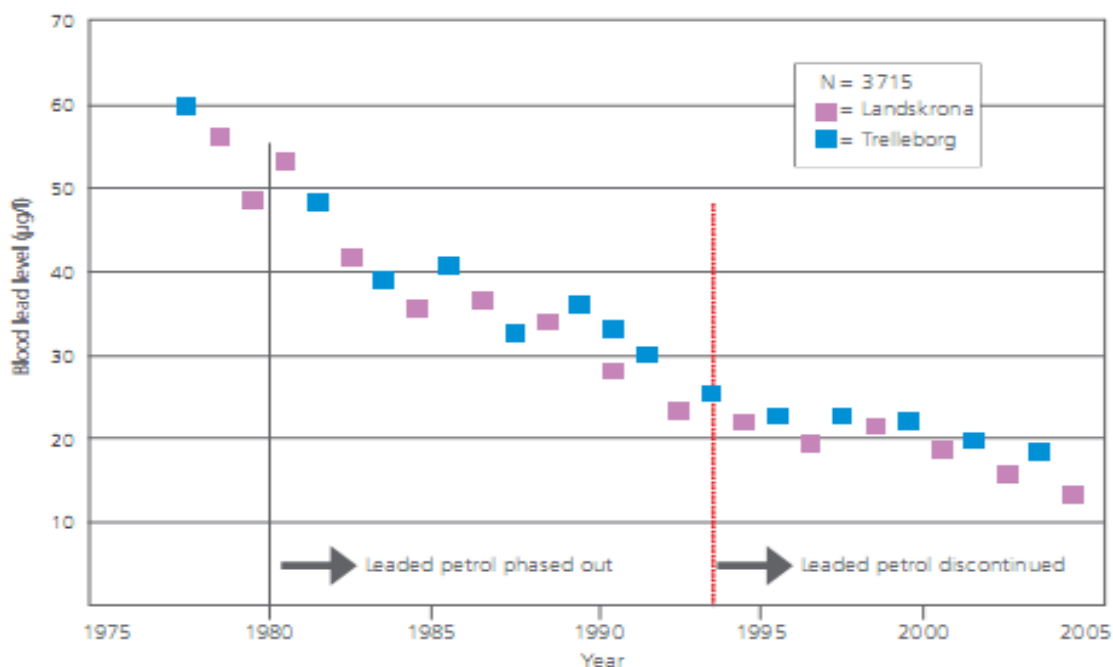
Heavy metals remain of particular concern, despite having been a priority for regulatory measures for decades. This section focuses on lead and mercury; evidence on developmental neurotoxicity is within both of these very strong.<sup>18</sup>

The organic form of mercury, methylmercury, appears to be of greatest concern when it comes to children. The main source of exposure to methylmercury in the general population is food, in particular fish. Toxicity has been demonstrated at low exposure levels, yet fish can also be an important component of a healthy diet and the risks and benefits of fish consumption must be considered.<sup>19</sup> The estimated intakes of methylmercury in Europe vary by country and region, depending on the levels of pollution and on the amount and type of fish consumed.

Lead is responsible for intellectual disability, measured as loss of intelligence quotient score. The most important toxic effect of long-term exposure is on the brain, particularly during the first two to three years of life, when early development of the central nervous system takes place. Exposure to lead during this period increases the risk of intellectual disability, ADHD and other developmental disabilities.<sup>18,20</sup> Blood lead level above 5 µg/dl has been associated with toxicity in the developing brain and nervous system of young children, leading to a lower intelligence quotient.<sup>18</sup> Lead in the environment has multiple sources, including the combustion of leaded petrol, industrial processes, paint, solder in canned foods and water pipes. Exposure to lead occurs through a number of pathways, such as air, household dust, road dirt, soil, water and food. Evaluation of the relative contribution of the different sources is complex and is likely to differ between areas and population groups.

The EBD study estimated in 0.94% the average proportion of children with a measurable loss in intelligence quotient due to exposure to lead in the EU15 countries. This proportion rises to 2.82% for the other countries included in this report. Emission trends from 24 European countries have shown that, between 1990 and 2003, the total emissions of lead dropped by 90%.<sup>21</sup> In the mid 1980s, a collaborative study between WHO and the EC found that levels of lead in children's blood were of 18.2–18.9 µg/dl in Bulgaria, Hungary and Romania, compared to 11.0 µg/dl in Italy and 7.4 µg/dl in Germany.<sup>20</sup> This difference was still evident in the 1990s, with considerably lower levels in France, Germany and Sweden. The benefits of unleaded petrol are illustrated by a series of blood lead measurements carried out in 3,700 children living in urban areas of Sweden, where a dramatic decline was observed between 1978 and 2005 (Figure 13.2).<sup>21</sup>

**Figure 13.2. Blood lead levels in Swedish children, 1978–2005 (Source. WHO/EURO, 2007).**

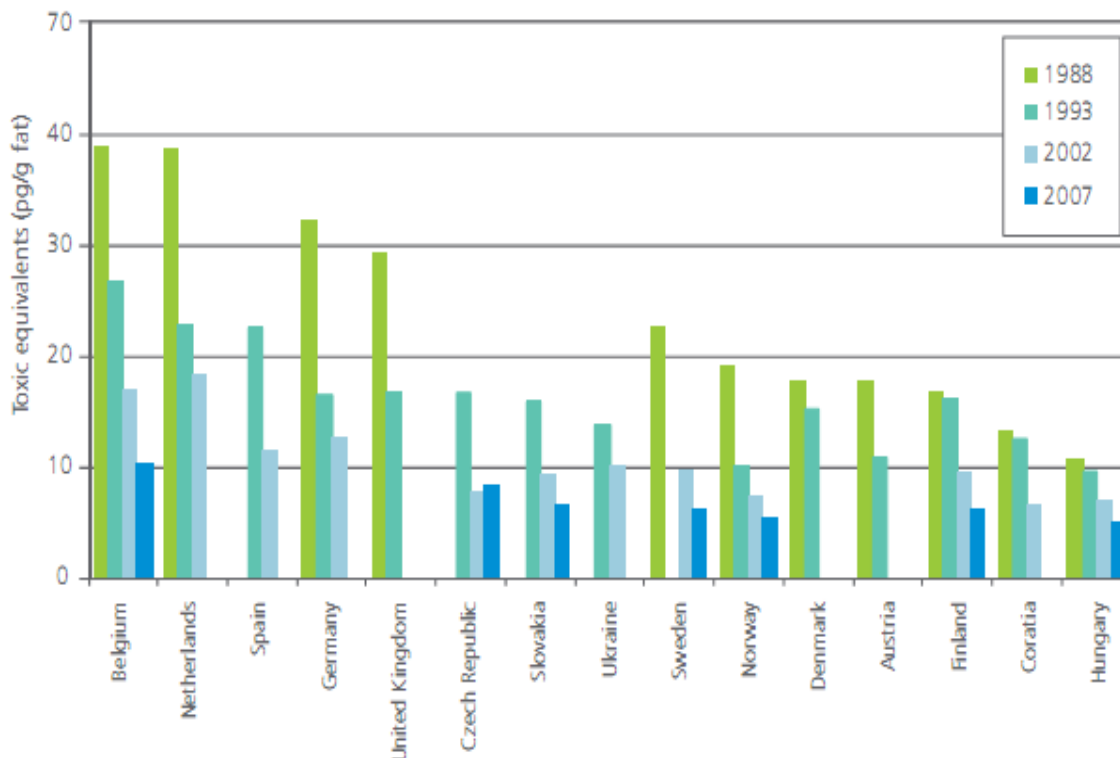


### PCBs and Dioxin-like Compounds

Dioxins and PCBs are highly persistent and highly toxic environmental pollutants, which at present are derived mainly from waste incineration and other industrial processes. From these sources, they spread into nature and pollute human food, including breast milk, so that basically all children in Europe are exposed to measurable levels. The toxicity of dioxins and PCBs is well described from animal studies and from a number of human epidemiological studies, including several large cohort studies.<sup>22</sup> Developmental exposure has been shown to affect endocrine (mainly for dioxins) and cognitive (mainly for PCBs) systems. Measurable outcomes include reduced intelligence quotient and changes in behaviour patterns. Some

measures aimed at reducing exposure to dioxins have been partly successful: since the 1980s, there has been a 70–80% decrease in intakes, suggested by intake estimates and concentrations in human breast milk (Figure 13.3).<sup>23</sup> Among the persistent organic pollutants (POP), PCBs and dioxin-like compounds have the lowest safety margins, therefore monitoring is still called for.

**Figure 13.3 Dioxin levels in human milk in selected countries, 1988-2007 (Source: WHO 2007).**



### Pesticides

Children may be exposed to pesticides in several ways, such as transplacental transfer during foetal life, intake of contaminated breast milk and other nutrients, or contact with contaminated subjects and areas in the environment, such as pets treated with insecticides, house dust, carpets and chemically, treated lawns and gardens. Pesticides may cause a variety of health effects in children, ranging from acute poisoning to chronic subtle effects on the immune and nervous systems. Exposure early in life, and particularly during periods of rapid development, such as during foetal life and infancy, may have severe effects on the child's health and development by raising the risk of congenital malformations, cancer, immunological dysfunction, endocrine disease, and neurobehavioural deficiencies. Exposure of parents may have consequences for the offspring, leading to reduced chance of male birth and an increased risk of childhood cancer.<sup>24</sup> Little is known about children's exposure to pesticides by direct biomonitoring, and information on food concentrations. Exceeding the limit values is rare in European products, but more common in fruits and vegetables imported from outside Europe. A safety factor of 100 is usually used in setting the tolerable daily intake values for pesticides. Estimates of actual pesticide intake are usually 1% or less of tolerable daily intake, but children living close to areas where pesticides are used, may be exposed to much higher doses through a variety of sources.

## *Physical Agents*

Exposure to physical agents, such as ionizing radiation, ultraviolet radiation (UVR), noise and electromagnetic fields (EMF), is widespread and is known to be hazardous to the development of organisms, from conception to adolescence. Among exposures to physical agents, the most common is exposure to UVR, but there are increasing concerns regarding noise and EMF, including those deriving from the use of mobile phones.

Children and adults are exposed to natural solar UVR, but artificial sources of UVR, such as sun beds, also contribute to exposure and health risks. UVR has a number of beneficial effects, including the endogenous production of vitamin D. However, excessive exposure to UVR causes a considerable disease burden in many populations. UVR in childhood is an important risk factor for severe diseases in adulthood, including melanoma and non-melanoma skin cancer, which in many European countries, particularly in the north, is showing an impressive increase in incidence. Evidence suggests that sunburn during childhood and adolescence is linked to melanoma in relatively young people. Other skin cancers, as well as some eye diseases and other skin problems, are associated with excess exposure to UVR.<sup>25</sup> Efforts towards environmental health protection must therefore focus on the reduction and avoidance of excess exposure. Data on the incidence of melanoma are direct measures of UVR-related disease, and time trends of melanoma in people aged under 55 years, can be interpreted as indicators of effective reduction in the exposure of children and adolescents to UVR.

The percentage of the population complaining about noise ranges between 12% in Hungary, Iceland, Ireland, and Norway, to 31% in Cyprus and Romania.<sup>5</sup> Children exposed are at risk of adverse health effects, such as sleep disturbance and learning impairment, and adolescents may suffer from severe hearing loss due to the use of portable music devices.<sup>26</sup>

Extremely low frequency EMF is increasingly present in the home and outside environment. The average residential exposure to EMF densities higher than 0.3-0.4  $\mu$ T has been associated with an increased risk for developing childhood acute lymphoblastic leukaemia and has been classified as a possible human carcinogen.<sup>27</sup> The rapid increase in mobile phone use has also generated concern about possible health risks related to radiofrequency EMF, particularly in children, due to their longer exposure over the life course. Overall, no increase in risk of glioma or meningioma was observed with the use of mobile phones; though there have been suggestions of an increased risk of glioma at the highest exposure levels.<sup>28</sup> Despite this limited evidence, the EU and the WHO recommend the use of the precautionary principle in incorporating all technological and industrial processes.

## *Environmental Inequity in Children*

The EBD study showed striking differences in the burden of environmental-related diseases across countries. Differences are particularly clear in poverty-related exposures such as lack of water and sanitation, or traditional heating and cooking systems using biomass fuel. Differences are marked within countries too. A systematic literature review conducted to evaluate the evidence on environmental inequalities among children in Europe, showed that children living in adverse social circumstances suffer from multiple and cumulative environmental exposures. A low socio-economic position is associated with an increased exposure of children to traffic-related air pollution, noise, lead, environmental tobacco smoke, inadequate housing and residential conditions.<sup>29</sup> For most of these exposures, there are no studies investigating the modification of the exposure/response function by SES, and it is therefore impossible to quantify the magnitude of environmental inequalities.

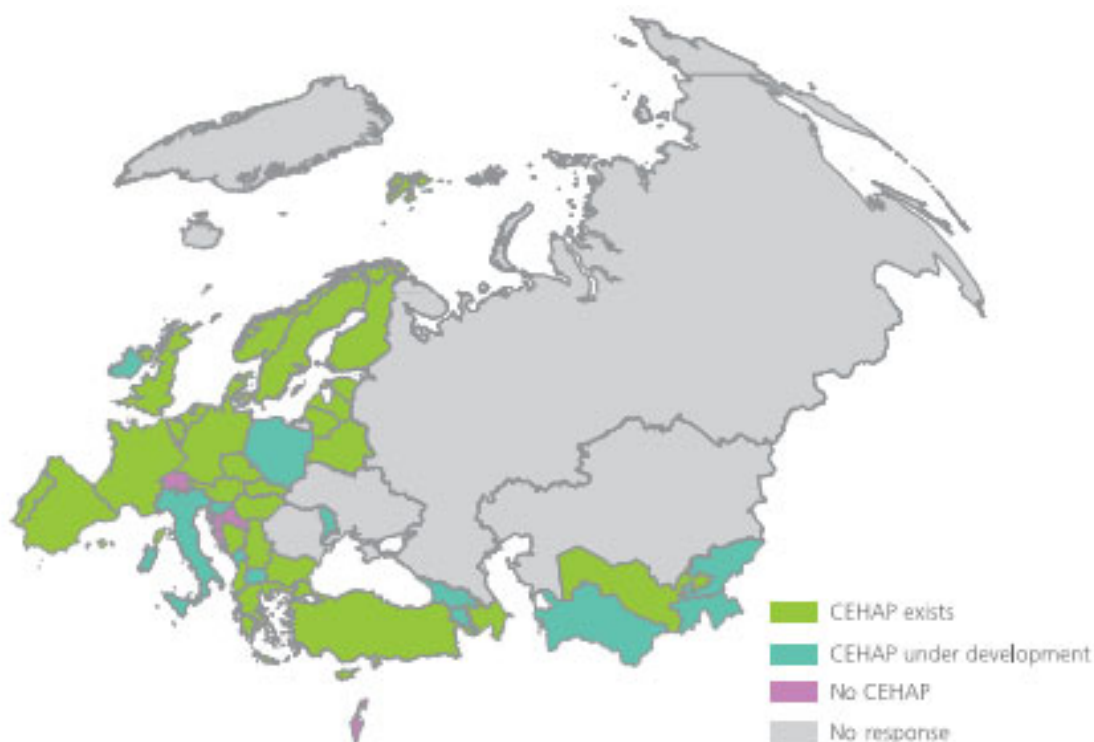
## Challenges

### *Comprehensive Plans and Initiatives*

The main challenges include the assessment of specific hazards and risks posed by children's exposure to the environment, the further development of child-focused monitoring and biomonitoring systems, and the establishment of intersectoral collaboration to implement child-focused, risk-reduction strategies that address the marked inequities across socio-economic groups in children's exposure and vulnerability to environmental toxicants.

Over the last decade, since the issue was first raised in the 3<sup>rd</sup> Ministerial Conference on Environment and Health held in London in 1999, considerable progress has been made in Europe, through the adoption of comprehensive regulations and plans, such as REACH and CEHAPE, and through the issuing of policies addressing specific environmental health issues. REACH is a EC regulation on chemicals and their safe use. It entered into force on 1<sup>st</sup> June 2007. Its aim is to improve the protection of human health and the environment through better and earlier identification of hazards of chemical substances, including the identification of those hazards which are specifically harmful to children. REACH makes the industry responsible for assessing and managing the risks posed by chemicals and for providing appropriate safety information to users. As part of CEHAPE, many Member States have already developed national children's environment and health action plans (Figure 13.4).<sup>6</sup> In addition to stimulating countries to develop national policies and plans, CEHAPE has also promoted and coordinated action on children's health that cuts across departmental and sectoral boundaries and involves different levels of government. It has positively influenced interventions to reduce environmental risks to children's health, the development of information and monitoring systems and of public information and awareness, and intersectoral collaboration between health and environmental sectors, followed by transport and education.<sup>5</sup>

**Figure 13.4. The state of the art of CEHAPE development in the European Region in 2009**  
(Source: WHO, 2010).





The challenge is now to put into practice plans at country level, and Europe-wide action so as to support this implementation. The setting up of a standard information system for environmental health focused on children is a key step. ENHIS, run in collaboration between the EC and WHO, is an example of harmonised and evidence-based information system for the support of public and environmental health policies. First released in 2007 and updated at the end of 2009, ENHIS enables users to apply scientific information to public health decision-making in countries, to monitor trends and assess the effectiveness of interventions, to make comparisons with the progress made in other countries, to measure the rate of achievement of targets set by Europe-wide action programmes, and to share knowledge and good practices.

### *Specific Actions*

Specific actions have been taken to control chemicals used in the food production chain, through adequate enforcement of the instructions for their use and the meeting of limits set by the European Food Safety Authority (EFSA) and adopted by the EU and FAO/WHO Codex Alimentarius standards. If these were strictly enforced, ample safety margins would be guaranteed also for children. For unwanted contaminants (heavy metals, POPs, microbial or plant toxins, and other natural contaminants), regulatory methods can control intake only to a limited extent. Whenever possible, control measures should be directed also at the primary source of contamination. This has been done, for example, by discontinuing the use of lead in petrol and the commercial use of PCBs and persistent pesticides, as well as by controlling dioxin emissions from waste incineration and industries.

EU Member States have also implemented strong control measures for smoking, since the adoption of Recommendation 2003/54/EC, and most countries have enforced laws in response to EU Directives 2003/33/EC and 2001/37/EC. The WHO Framework Convention on Tobacco Control has been ratified by most European countries, and many have already banned smoking in public places. For private indoor environments, the focus should now be on awareness-raising measures. More information is needed on the effects of exposure to environmental tobacco smoke at home for children's health. In addition, further information is required on what kind of campaign is most effective for parents to encourage smoke-free homes. In the long term, a non-smoking social norm can be envisioned, with a trend towards smoke-free societies.

While action continues based on REACH and CEHAPE, the main future challenges lie in ensuring adequate intersectoral collaboration, particularly between health, education, transport, industry and agriculture, and in communicating risk and promoting awareness at local level, as a complement to international and national programmes and directions.<sup>30</sup> To achieve this, it will be important to incorporate health and environmental issues in the curricula of all health professionals, and to ensure that appropriate information is circulated to families and communities. Establishing biomonitoring systems through standard methods and sampling will also be crucial so as to observe exposure and risk, and prioritise action.

Finally, action is needed along the entire causal pathway of the social divide in environmental hazards, with priority to measures aimed at preventing that socially-determined differences in environmental conditions contribute to health inequities from the earliest stages of life.<sup>31</sup>

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