

# A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND CHAPTER 5: EUROPEAN MODELS OF CARE FOR CHILDREN AND YOUNG PEOPLE



# 5.1 INTRODUCTION

The health care needs of Europe's children are changing as a result of variations in diseases, disabilities, and social factors that affect their lives. Infectious diseases have become easier to prevent or cure, and non-communicable diseases increasingly dominate paediatric practice. European health systems need to develop new models of care to meet children's current and evolving health needs. Although rare disorders, such as childhood cancers, cardiac anomalies, and some neonatal conditions, need highly specialised care provided in selected centres, common problems such as asthma, behavioural disorders, and mental health issues should be cared for in the community to enable children and their families to live as normally as possible.

Child survival has improved greatly in the past three decades in all EU15 countries (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, United Kingdom) as a result of improvements in public health, health care and wider societal factors. Morbidity in children is also dominated by non-communicable diseases, accounting for 79% of disability-adjusted life years lost. Striking inequities can be noted in children's life chances and health outcomes, resulting from a complex interaction of cultural, social and economic forces, including differential risk exposure and access to high quality health care. If all countries in the EU15 could reduce their child mortality to that of Sweden (the best-performing country), more than 6000 excess deaths could have been prevented in 2010. This goal is achievable.

Many aspects of child health are affected by government policies, especially policies that affect the distribution of resources, employment, housing, education, and health care. Thus, countries with high spending on social protection for families generally have lower rates of child death. The extent of child poverty and inequality in Europe is not always realised. In Sweden, less than 2% of children live in deprivation, whereas in Portugal 27% of children live in households that cannot afford to eat three meals per day. The Roma people are Europe's largest minority population, and continue to be subject to discrimination in many parts of Europe: child health outcomes, such as preterm birth, incidence of communicable diseases, and death, are often much worse in the Roma than in the majority population.

The Innocenti Report Card 11 (UNICEF) was published in 2013 and is designed to compare performance across a range of variables reflecting child wellbeing in countries in Europe. Striking variation exists.

### The main points are highlighted were:

- The Netherlands is the clear leader (closely followed by the four nordic countries Norway, Sweden, Finland and Denmark) in terms of child wellbeing
- · There is no strong relationship between per capita gross domestic product and overall child wellbeing
- · All countries demonstrate reduced infant mortality and reduced smoking compared to previous reports
- · Ireland has made progress in relation to physical exercise in young people

### **Meeting Health Needs**

Two common illnesses show variability in outcomes and thereby scope for improvement:

- Pneumonia is the most common serious bacterial infection in children presenting in primary care, and deaths
  in childhood from this disease should be avoidable in most cases. However, death rates vary substantially
  within the EU15, from 0-1.76 per 100,000.
- Mortality from asthma, a chronic disease common in childhood, varies substantially between countries, even
  after adjustment for the incidence of wheeze as a proxy indicator for prevalence of asthma. However,
  mortality is not the only consideration: research in several countries has shown that as many as two-thirds
  of hospital admissions for asthma in children could be avoided with better preventive care, including asthma
  action plans, improved asthma education, and reduction of risk factors such as parental smoking.

### **Policy Evidence**

The United Nations (UN) Convention on the Rights of the Child offers a framework for policies to support child health and wellbeing and the European Council has issued guidelines on child-friendly health care. Provision of universal access to high quality, affordable early years education is a key strategy for reduction of social inequalities. Countries should identify a few context-relevant indicators for child health services and appoint a monitoring organisation with open and transparent responsibility for collection and analysis of data. A national child health oversight committee should report to a minister of state responsible for child health, who should regularly review progress based on data and be able to implement remedying action. Real and sustained improvements in child health in Europe can happen if political will across the EU can be brought to bear on the problems facing children now and in the future.

### *In Ireland, as in other EU countries, a few key drivers for change exist including:*

- · Significant geographical variation in care available to children
- Vulnerable groups including immigrants and traveller populations
- · Higher rates of attendance out-of-hours and high admission rates in under one year olds
- Social care issues
- · Rising burden of non-communicable disease
- · The ongoing rise in prevalence of obesity
- Safeguarding / child protection issues

# 5.2 LEARNING FROM EXPERIENCE IN DELIVERY OF CARE

Although there is a broad consensus that many non-acute health services could shift from hospital-based to community-based delivery, thereby improving access and responsiveness and reducing costs, most countries have yet to do so.

### **Care of Chronic Disorders**

The research informing chronic care has shown that several factors are consistently associated with successful health-care delivery for adults:

- shared practice with common guidelines
- co-location of health and social services
- information sharing
- supportive financial processes
- administrative support
- common training and education opportunities
- shared values with, and effective leadership by, respected individuals

In view of the growing numbers of children with chronic disorders in Europe, development of models of care for children is a major priority. This will involve a substantial change from a hospital-centred model to a model in which primary care and secondary care providers and public health services work closely together. Focusing efforts

on prevention of non-communicable diseases and improvement of outcomes of care will necessitate a sustained commitment from bodies representing paediatricians, general practitioners (GPs), child and adolescent psychiatrists, other healthcare professionals, management and policy makers at national and European levels.

### **First Contact Care**

One of the greatest challenges facing health professionals working with children is how to distinguish potentially serious illness from minor problems. 17-57% of patients attending emergency departments have problems that are judged to be non-urgent or minor by clinicians and could have been dealt with in primary care. The challenges associated with first contact care are further exemplified by childhood cancer. Prompt diagnosis is crucial but can be difficult because cancer is rare, so the likelihood of a GP encountering a child with cancer is low. On average, GPs will encounter a child presenting with cancer once every 20 years.

### There are four important issues for children's first contact care:

- 1. Organisation of services
- 2. Professionals and training
- 3. Skill mix
- 4. Out-of-hours care

### There are three main models for first contact care:

- · Care delivered by GPs, e.g. in the UK and Ireland
- A model with primary care paediatricians, e.g. in Italy
- · A combination of both, e.g. in France

Comparisons as to which system is superior are complex. Although Sweden's model could be defined as GP-delivered, it differs substantially from that in the UK. Most GPs in Sweden receive at least three months specialist training in paediatrics and often work closely with paediatricians and children's nurses, with whom they might be co-located in health centres. By contrast, the UK has a more segregated model with GPs who might not have received any specific training in paediatrics beyond that received as an undergraduate student and who work separately from paediatricians. The potential consequences of inadequate paediatric training and supervision of child health clinicians in Europe were shown by an inquiry into child deaths which drew attention to failures in recognition and management of severe diseases.

The most recent and comprehensive data from first contact services and professionals for children comes from the European Paediatric Association's survey of 46 European countries. This study revealed a substantial diversity of service models, showing countries' different approaches to achievement of a balance between expertise and accessibility. Eleven of the EU15 countries provide five or more years of training for paediatricians. A three year so-called 'common trunk' of general training, including training for primary and secondary care, is followed by a further two years of training for specialty work or primary care, or both. GPs usually train for at least three years with a minimum six months requirement in both a hospital speciality and primary care for the general population. Although 13 European countries have extended family doctor training to four years or longer, training in child health remains highly variable between countries. Increasingly, much routine and some specialist care for children is delivered by nurses. Nurses lead many services in Sweden's child health-care centres and GPs, paediatricians, psychologists, therapists and dentists are called upon when needed. In the UK and the Netherlands, nurses provide

community-based care for children with asthma, which seems at least as effective as that delivered by a GP or paediatrician and might be less expensive. The rising prevalence of eczema has stimulated interest in nurse-led care because outcomes seem similar whether delivered by nurses of specialist doctors.

Several European countries have instituted substantial changes to how primary care services are provided outside working hours. Reforms in Denmark, the Netherlands, and the UK led to centralised systems in which large groups of GPs provide care. Rises in emergency department attendances and short admissions in children in the UK since 2000 may be related to changes in provision of out-of-hours care, and emphasise the crucial role of first-contact care. The 30% rise in child admissions between 1999 and 2010 for acute infections usually managed in primary care suggests that several factors probably contributed.

The noted variation in outcomes of childhood disorders and appropriateness of emergency contacts and admissions suggests a clear need to learn from experience. Sweden's flexible model of first contact care might offer important lessons in view of Sweden's achievement of some of the best outcomes for children in Europe. Italy, where primary care paediatricians provide most primary care for children, also has high quality outcomes and offers an opportunity for comparison to, and contrast with, Sweden. Although paediatric specialists working in primary care are more expensive to train than are GPs, and barriers still exist between primary and secondary care, these problems might be balanced by better outcomes.

## 5.3 WORKFORCE

The EU provides for free movement of health professionals on the basis of the principle of mutual recognition of qualifications. Standards for competencies of child health professionals, particularly those working in first contact care, need to be defined. Children's health professionals should find ways to overcome structural and cultural barriers to work towards a transformative model of health professional education needed for sustained progress in the improvement of child health.

# 5.4 PERFORMANCE INDICATORS

Meaningful understanding and international comparisons of the health needs of children and the ways in which health systems respond necessitate appropriate data. Few Europe-wide indicators are specifically designed for assessment of children's primary and secondary care services. In Spain, a list of primary care-preventable hospital admissions is available that includes several illnesses relevant to children such as immunisation-preventable disease and pneumonia. In Italy, frequency and choice of antibiotic use has been used as an indicator of quality of paediatric care and professional continuing education. New indicators for health outcomes in children and young people, including some specifically for aspects of primary and secondary care, should supplement existing ones. The Dutch College of General Practitioners developed 139 indicators from 61 clinical guidelines, including several for children relating to asthma, non-traumatic knee disorders, otitis media with effusion and fever. Development of indicators that measure the quality of services provided to especially vulnerable children and young people, e.g. those who are victims of maltreatment, have mental illness or disabilities, or live in the care of state social systems, will also be important.

# 5.5 RESEARCH

Research about health services for children is in its early stages, for example, only 5% of all research about cancer relates to children. 11-80% of all paediatric prescribing is estimated to be off label, partly because of the paucity of clinical trials in children. What research has been done focuses disproportionately on the most complex disorders. Between 2000 and 2009, the number of Cochrane systematic reviews relevant to children increased by 17%, but the number of reviews applicable to childhood illnesses in primary care increased by only 2%. Europe has the infrastructure in place, e.g. networks of longitudinal pregnancy and birth cohort studies, to research important issues in child health. Some countries, such as Denmark, Finland and Sweden, have benefited from linking of several data sources from primary and secondary care and social services. The EU-funded Global Research in Paediatrics (GRiP) Network of Excellence was launched in 2011 to enable the safe use of children's medicines and create international standards for paediatric research.

# 5.6 FUTURE SCENARIOS

Child health experts should develop modelling techniques to examine the future of child health, thus enabling farsighted policy making. Increases in risk factors, e.g. low birth weight, obesity, unhealthy lifestyles, and increases in chronic disorders, such as mental health disorders, cancer and non-communicable diseases, are likely to impede improvement in child health.

# 5.7KEY LEARNING POINTS

- Child health systems in Europe are not adapting sufficiently to children's evolving health needs, leading to avoidable deaths, suboptimum outcomes, and inefficient use of health services.
- If all the 15 pre-2004 countries of the European Union had child mortality closely similar to that of Sweden (the country with the best rate), more than 6000 deaths per year could be prevented.
- Chronic care models for children are needed to improve care and outcomes for non-communicable diseases, and ensure better quality of life for children and families. Several countries have made progress in development of chronic case services, and offer lessons for others.
- First contact care services and outcomes for children in Europe are highly variable. Flexible models, with teams of primary care professionals trained in child health working closely together, might offer a way to balance expertise with access.
- Child-health indicators sets with reliable and uniform systems for data collection would ease efforts to monitor needs and improve services.
- Awareness of the importance of investment in the earliest years is growing. Individual countries should strengthen investment in child health and health services research.
- Politicians and policy makers should do more to translate high-level goals for child health into implemented
  policies with accountability structures to ensure delivery. Investment in social protection policies for the
  earliest years and the most vulnerable children will improve health, reduce inequities, and accumulate
  advantages throughout the life course.

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