European Union Community Health Monitoring Programme

Child Health Indicators of Life and Development

(CHILD)

Report to the European Commission

Executive summary

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Editors: **Michael Rigby** [a] and **Lennart Köhler** [b]

[a] CHILD Project Manager
Senior Lecturer in Health Planning and Management,
Keele University, United Kingdom

[b] CHILD Project Chair
Former Dean and Professor of Child Health, Nordic School of Public Health, Sweden

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Centre for Health Planning and Management

Darwin Building,
Keele University,
Keele,
Staffordshire,
ST5 5BG,
United Kingdom

European Commission
Directorate-General for Health and Consumer Protection

Bâtiment EUROFORUM,
10 rue R. Stumper
L-2557
Luxembourg

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1. Introduction

The Child Health Indicators of Life and Development (CHILD) Project is a third-wave project in the European Union Community Health Monitoring Programme. It is the first project to cover a particular population group, namely children. It has provided an important opportunity whose significance is seen to unfold as other partner projects within the Health Monitoring Programme (HMP) have concluded their initial work, and realised that the health and information needs of children are different.

We follow precedent and use the term "child health" when looking at the needs of persons up to adulthood, and thus this encompasses the alternative of "child and adolescent health". Indeed, infants, young children, older children, and adolescents are very distinct sub-groups, with different dependencies and health determinants, requiring different services, and needing different measures of health. Throughout, therefore, our reference to "child health" should be read as fully inclusive unless specified otherwise, and we give equal weight and recognition to each of thee four sub-groups.

There are some 70 million children aged under 18 years in the Member States of the European Union, and almost another million more in the three European Economic Area countries. It is a serious responsibility to seek to have a beneficial impact on their health and development, primarily by identifying current weak areas and deficiencies, yet that is the task we have addressed. Even a marginal improvement will have tremendous positive yield in term of human benefit.

We recognise that our recommendations will require investment by Member States, and by health providers and others, in developing new data gathering mechanisms and surveys. We have picked our proposed new indicators carefully, to seek to have maximum impact in areas from policy development to service delivery, from environment to societal support, whilst minimising the need for extra data collection resources. We believe this is an important opportunity, within the framework of the Health Monitoring Programme, to benefit Europe's children. We hope that policy makers agree that this is too important an opportunity, and responsibility, to merely read and put to one side.

2. The CHILD Project

2.1. Context and Terms of Reference

Being a third wave project of the Health Monitoring Programme (HMP), the CHILD Project came into existence in a developing context. Previous or contemporaneous projects including framework projects, of which the most relevant was the European Community Health Indicator (EHCI) project, which set a broad framework for a complete set of indicators. Other projects fall broadly into two categories – those looking at health topics or disease groups ranging from

nutrition to cardiovascular disease and cancer; and those looking at data sources and methodologies such as Health Surveys and Primary Care Sentinel Practices.

Most significant for the CHILD project was the simultaneous establishment of a project on maternal and perinatal health entitled PERISTAT. This project was set up to cover the period spanning from pregnancy through delivery to the end of the first week of life. Thus the formal terms of reference of the CHILD project were for the total period from the first week of life to age fifteen years (as being the end of the last quinquennial age band solely within childhood). We return to the issues of the age group later.

The Child project was established to run from the period 1st October 2000 to 30th September 2002. However, formal exchange of contracts did not occur until January 2001, giving an effective period of twenty months. As the first full meeting of the Project Team could not be fixed on a mutually convenient date until April 2001, in effect the project has been undertaken over eighteen months.

The project has been satisfactorily extensive in coverage. All fifteen EU member states had representation, as did two - Iceland and Norway - of the three European Economic Area States. These were the only two categories of country eligible to take part in this phase.

2.2. Membership and Process

The membership of the full Project Team is given in Appendix 1. There was an overall high level of commitment and activity, giving a satisfying quality and richness to the results. Some countries' membership changed once the project had established its approach, when the active detail of the work became appreciated and more topic-specific alternate members were nominated.

The full Project Team met as planned on eight occasions and took responsibility for planning and undertaking the work. Individual members volunteered to undertake particular tasks, in line with the division of topics devised, and reported back to the main project. This has resulted in a high degree of corporate ownership of process and results throughout. A number of countries' delegates provided additional resource from their own local organisations, which significantly enriched the project.

The project also benefited from an Expert Review Group of four members, which met four times (one more than originally planned) to review the material from an informed outside view point, to ensure overall balance, strength and credibility and to give feedback on the presentation of findings as they emerged. The schedule of meetings was also designed to give good opportunity for interface and exchange with local approaches and expertise across Europe – the locations of meetings are given in Appendix 2.

3. The CHILD Project Approach and Values

3.1. The CHILD Project Philosophy

The CHILD Project was commissioned within the Health Monitoring Programme, which is an important and ambitious programme within the European Commission's Public Health

Strategy. The opportunity and responsibility of promoting the interests of children within this programme are important.

At the same time, though, from its first meeting the CHILD project members looked not just to producing a recommended set of indicators, but to seeking to stimulate understanding of and commitment to their positive use by child health professionals and the child health community in each member state across Europe. Therefore the health professional readership was viewed as strategically important throughout the work. Project members felt that there would be comparatively little value in producing a report unless it led to pressure for adoption of the indicators at national level within a child health context: bottom-up pressure is needed to match the hoped for top-down policy.

The project therefore resolved from the outset to work to the philosophy that:

> **"The CHILD work should be in the centre of Child Health, not in the periphery of health monitoring."**

Whilst this approach has sprung naturally from the professional commitment of members to children and child health, we were also encouraged by other important congruent influences. Most important of these was the United Nations Declaration on the Rights of the Child, endorsed by virtually all countries in the international community, not least by its unequivocal commitment to the rights of health, safety, and equity regardless of circumstance and background. This commitment was supported by other initiatives, such as the experience of Children's Ombudsman post-holders acting as advocates to review policies and services to ensure they adequately addressed the needs of children.

Consequently, the project has sought to be **child-focused and child-centric** in all its work. This has determined the approach, the analyses and indicators recommended, and the presentation of material.

3.2. Priorities within Child Health Indicators

Child health is a large topic, but existing precedent has led to the development of a number of well known indicators including infant mortality. Other topics such as child abuse, and unhealthy behaviour such as tobacco use, substance abuse, or excessive alcohol consumption, attract popular attention. It would have been comparatively easy to concentrate on such populist and "obvious" topics, though some of these are in fact difficult to measure meaningfully at the population level. However, it was felt that a traditional approach would not have the appropriate impact upon child health itself. Instead, the project resolved to take an approach which was potentially more difficult, yet should have much greater impact in terms of health gain, namely to address the determinants of child health. In essence, the philosophy of the project has been that:

Health Status Measures alone are not sufficient to describe the whole range of phenomena of health and development, not least as many address negative aspects such as mortality and morbidity, which measure damage already suffered by a generation of children. Positive aspects of health and well-being are also important to measure, and we have sought to achieve a balance.

Health Process Measures have their own value, but where addressing therapeutic services many in essence focus on minimising damage to children whose health is already compromised. Measurement of positive process is also important, if challenging.

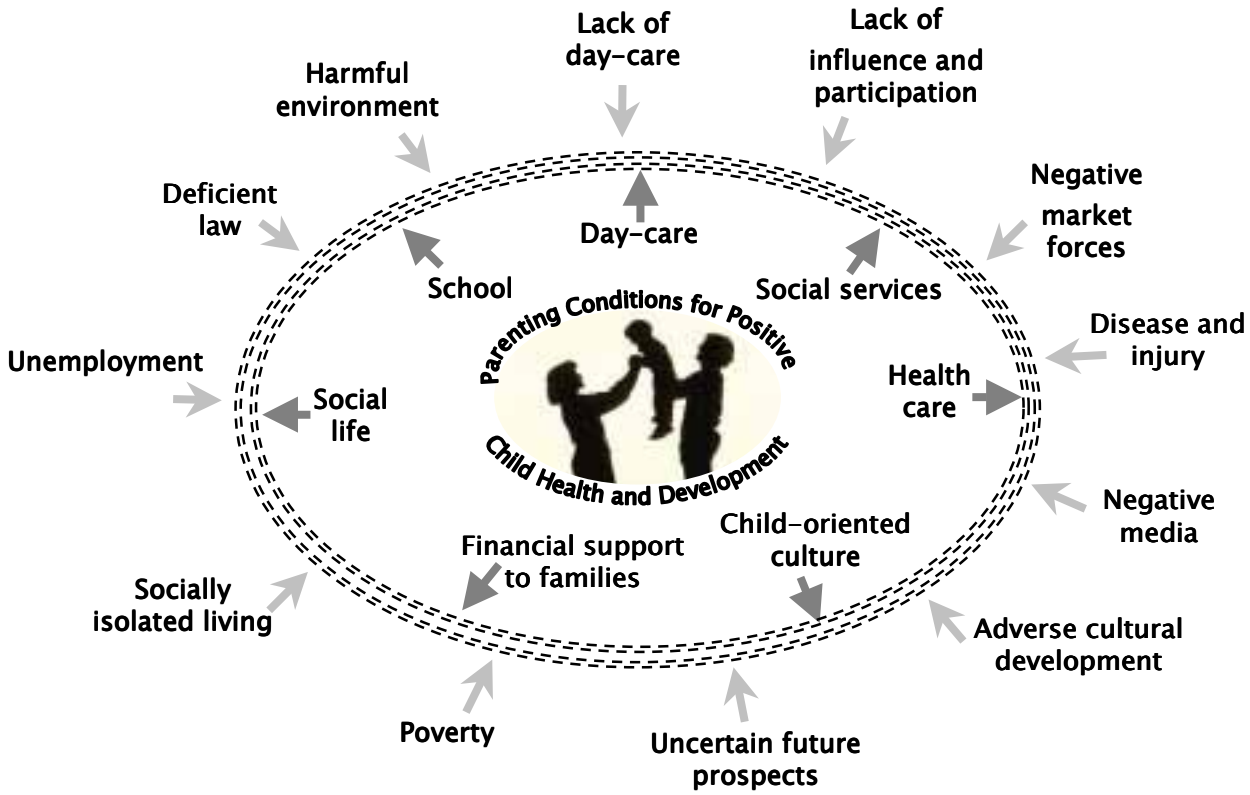
Measures of Determinants are most valuable, as they give a chance of reducing or protecting against risk and thus damage to health.

This view held by the project has helped shape the approach to the final selection of indicators.

3.3. An Overview of Child Health Determinants

Children are born and grow up in a complex environment – physiological, familial, domestic, social, and physical. All these elements can have positive, or negative, influences on health. Health services, and social welfare services, are among those charged with protecting health, and addressing specific population and individual problems.

The overall determinants of the child health and development context can be viewed as shown in Figure 1. This is the domain which the CHILD Project sought to address, with a particular focus on responsibilities within the health sector, but with a strong inter-sectoral viewpoint as to other policy and service responsibilities too.



Adapted by Gunnlaugsson G and Rigby M from Skolhälsovården 1998. Underlag för egen kontroll och tillsyn. Stockholm: Socialstyrelsen, 1998.

Figure 1: Determinants of the Child Health and Development Context

3.4 Risk and Child Health

Inherent in this understanding of child health determinants is the concept of risk. This itself is a complex area, with an inter-reaction of general and individual-specific risks creating personal patterns of health determination; a similar mix of inter-actions occurs at the population level. Environmental exposures, societal contexts, household setting, and behavioural lifestyles are just some of the principle elements of risk affecting child health. Whilst it was outside the scope of the project to calculate risk itself, the approach we have taken to indicators has included the importance of taking a barometric reading approach to key risk aspects.

3.5. The Burdens of Child Ill-health

The project philosophy was also underscored by recognition of the multiplier effect of the burden of ill health in children, when compared with that upon adults. It can have not only a much longer life-time effect given the greater lifespan ahead for a child, but will also have an extended impact upon parents, families, and society. In essence, ill health in children, particularly when it is medium to long term or produces impairment and disabling effects, has the following potential generation of burden:-

- Burden of discomfort and pain on the child
- Burden of anxiety, distress, and possibly loss of earnings for the parent(s) looking after the sick child
- Burden on society funding the health services, and on occasion special education and social services support
- Burden in more severe cases on the social welfare system, potentially for a lifetime.
- Burden caused by medium or long term illness causing loss of normal play and socialisation, thus impeding normal development with potential life long effects
- Burden caused by lost education which may jeopardise career and thus income potential for a lifetime
- Burden on future generations, as the child with an extended ill health burden becomes a parent with restrictions on their parenting skills, and becomes an older family member dependent on their successor generation.

In essence, the responsibility of child health services is an exponential one – not just to maintain and protect the health of the child for the immediate benefit of health in childhood, but with recognition that failure in this respect can have life-long health, lifestyle, social and economic impacts. Whilst Disability Adjusted Life Years (DALYs) have been postulated as a means of calculating ongoing burden of illness or accident, they are not adequate alone in the child health context.

3.6. Child Integrity and the Right to Childhood

At the same time, the project has adopted the position that the child is an individual and a citizen in their own right, and that childhood should be healthy, constructive, and enjoyable. There are some approaches which appear to see childhood merely as a training period for

adulthood or as an apprenticeship for a maximised economic or social contribution to society later. The CHILD Project rejects this concept of childhood as a lesser period to be passed through on the way to more important adulthood.

The child is a person, a citizen, and an individual in his or her own right, of equal value to any other individual. The difference is that children may not be able to express themselves or represent their own interests at the time when they are vulnerable to the actions or inactions of others, or to the effects of adverse social or physical environment. The United Nations Declaration and Convention on the Rights of the Child are important internationally endorsed statements, the values and content of which have been sources of encouragement for the project.

Thus the concept of Child Health indicators has an enhanced value and importance as representing the needs of a sector of the population not able to express their own interests and concerns.

3.7. A Focus on the Most Vulnerable

We recognise fully that most children are fortunate enough to lead a healthy life, and to live in families where there is natural concern to maximise health and to address any apparent signs of health or developmental problems. It is the children who do not have the advantage of this caring environment who are most vulnerable.

Therefore, we have sought to develop an innovative set of indicators, which give greatest focus to those children most at risk of compromised health, care, and development by virtue of their grouping in society or the illnesses from which they are at risk.

3.8. … and on the Protection of the Interests of All

At the same time, new challenges to health, or changes to health determinants, can occur and not be noticed other than at the individual level, and thus the overall patterns of change of determinants may pass undetected and unaddressed. The CHILD project has therefore also been aware of the importance of a broad framework of ongoing surveillance, to monitor changes over time or affecting the overall population structure, in the interests of ensuring the health of the whole child population.

3.9 The Child Health Domain

The totality of child health, its determinants and related services, is clearly extremely large. Moreover, there are significant differences between infancy and adolescence in terms of health and its determinants, types of service, and data sources. It was recognised also to be important to achieve a balance between description of broad health determinants, and measurement of some of the preventable childhood diseases and less common but generally serious illnesses in childhood. It was also important to ensure representation across the entire child age-range from infancy to adolescence.

In order to seek a balanced overall coverage, at its first meeting the project membership considerd a paper identifying the principal topics within population-level child health and the approaches to be taken. As a result, the project identified the following topic areas, for each of which a lead investigator was identified from among the project members:

Demography
Socio-economic Status and Inequity
Social Cohesion/Capital
Migrants
Marginalised Children
Family Cohesion
Mental Health
Quality of Life
Well-being
Lifestyles
Health Promoting Policies
Nutrition and Physical Growth,
Development (including Intellectual and Social)
Mortality, Morbidity, Injuries
Environment
Access and Utilisation of Services

Each of these topics formed a focus for study, to identify key issues and their measurement. Subsequently, the ideas emerging from these groups were merged into a single integrated set of proposed indicators. This in turn was matched to the framework of the European Community Health Indicators (ECHI) umbrella project, which is intended to act as the vehicle for integrating the recommendations form all the individual Health Monitoring projects.

3.10 Health Impact

In identifying measures of child health and its determinants, the project recognised the importance of ensuring a sound spread across all aspects of child health, from upstream environmental and other determinants, to the actions and behaviour of the child in the family and immediate social group setting. All these impact health, and health services seek to provide positive education and prevention, and therapeutic care when needed. Policies – health policies and other social policies – are over-arching determinants. Thus health is subject to many pressures, intentional and incidental. Though indicators require numeric data for their creation, many aspects are more amenable to qualitative measurement.

Given the importance of the qualitative areas, but the necessity for quantitative measures, not least in the important area of policy impact, we have sought quantification of coverage and effect of focussed policy outcome measures. We recognise the need to develop further measures of qualitative areas, not least in behavioural and attitudinal areas which are important in child health, and for this reason we identify that further work is necessary before our task can be fully completed.