



Research Inventory of Child Health:

A Report on Roadmaps for the Future of Child Health Research in Europe

A European Commission Framework 7 Project 2010 – 2013

(www.childhealthresearch.eu)

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Executive Summary

The RICHE project is a response to a call to clearly identify gaps in European child health research, and to provide justified guidance on priorities for investments in research over the next decade.

The RICHE Roadmap is based upon a sound, scientific evidence base. The project prepared an inventory of child health research and of measurements and indicators of child health in Europe. This was collated using a web platform – a resource that has developed into a useful tool for research knowledge and communication between researchers and agencies in Europe. This can be found at www.childhealthresearch.eu. In addition to this exercise, a formal study of the gaps in child health research was undertaken by carrying out surveys and interviews of researchers and research users across Europe. These results formed the basis for the RICHE Roadmap.

The Roadmap is based on a life-course perspective. It covers the important phases of a child's development, including the pre-birth phase, maternal health and pre-conception issues through to adolescent health and the different exposures to protective and risk factors, and to health services that a young person encounters throughout childhood and adolescence as they move towards adulthood. The RICHE project focused on the upstream determinants of health to identify where more work needs to be done to prevent avoidable physical and mental ill-health, disability and death in the population of European children aged 0-18 years. The concept of upstream determinants of health shows how the many influences and outcomes of children's health are interrelated; a pattern that is reflected in the RICHE Roadmap.

The work necessarily involves a series of value judgements, because there are no objective and unconditionally valid answers to the question "*Is there enough research on this topic?*", nor to the question "*Is this a topic of significance?*". Nevertheless, the RICHE Roadmap uses an inclusive and transparent process to explain the recommendations that it makes and the subject that it chooses by making values and reasons for judgements as explicit as possible.

The report is organised into broad subject areas, that reflect the key 'gaps' in knowledge about children and young people, or about particular aspects of their lifestyle and health. These key areas are described below, together with the key findings within each area.

Life Course and Lifestyle

This section focuses on children as they age, and recognises the importance of continuing to research how factors before conception, during gestation and in the very early years of life can affect present and future health. The challenges that children face as they grow up are also highlighted – these can be created because of policy decisions that fail to take account of children and young people's lives or because of the pervasive influences of individual circumstances that act as protective or risk factors for children's actions. These influences must be balanced against a young person's right, and developmental need, to experiment as they grow and become

independent adults. The concept of resilience in childhood is also highlighted, and how research needs to focus on this important and powerful means of improving children's lives. Finally, a principle that extends throughout the life course is that of mental health and well-being. This is probably one of the most important, if not the most important, aspect of children's lives. Fostering well-being in children from the moment they are born, and throughout childhood will provide numerous individual and societal benefits. It is one that justly deserves a greater research focus.

Socioeconomic and Cultural Factors

The socio-economic and cultural environment in which a child is born and grows up has a potent effect on a child's health and well-being. Inequity and inequalities in health between and within nations depending on socio-economic circumstances is known to affect health outcomes. Those in the poorest areas have worse health and shorter lives than those in the wealthiest areas. In-depth research into the effect of inequalities and how policy decisions can minimise these effects is needed as a particular focus in this area. Other groups are at risk of marginalisation from health services and from opportunities that can maximise their health. These have been identified as having particular research needs, for example migrant children where further policy and research work is needed to identify how best to support their integration into their new societies and communities, while retaining their individual identity; children in the state care system are known to have poor health and social outcomes, so improving their health, and access to and accessibility of health services by focused research is important for the future health of these children; and children from minority population groups, in particular those who travel across nations, such as the Roma need to have focused attention, to ensure that their health outcomes begin to match those of the general European child population.

Social and Community Networks

The main influences on children and young people are their immediate family and community networks. This extends from the influence of the family as a warm and nurturing environment in which to grow up – and conversely a place of the most profound danger and threat if such a family environment is toxic; to the wider influence of school, and finally the broader community. Becoming engaged and involved in community life is beneficial for the entire population, not just for the children and young people directly involved. It is an aspect of children and young people's experience that is important for well-being and social inclusion.

Environment

The environment covers several different concepts, and the RICHE Roadmap describes the physical, virtual and also the perceived environment – all of which interlink in children's lives, and have a profound effect on their health and development. In terms of the physical environment there is a need to investigate further how environmental pollutants affect children's development in utero and

throughout childhood. There is a need to look further at how prevention strategies designed for children living in areas of high pollution actually work, if they work at all, as there are still many unknowns in this area. In terms of the virtual environment there is a need for research and for health policy to catch up with the fast-moving developments of digital and new media communication. There are many unknowns about a phenomenon that is becoming an ever more salient, and possibly powerful, element in most European children's lives. Child-focused research is needed on the new ways of communicating and forming peer groups which dominate children's lives. It is essential to be able to keep children safe when they are using digital media by increasing their awareness of, and resilience to, cyber-bullying and other types of digital attack. Understanding the technology and the psychology of using such means of communication enables health promoting and health enhancing messages to become more accessible to children and young people.

An interesting avenue of investigation is the potential for such new means of communication to access population groups that have been traditionally hard to reach – such as traveller communities or migrant communities. Safety is an important part of an environmental discussion. The concept of safety involves not only physical changes to the environment that reduce the likelihood of injury, but also safety from direct and social violence. Improved data on exposures to injury, improved data about morbidity to injury in children will allow research to identify the major risk factors and develop means to counteract these threats to health.

Complex Health Issues

The majority of children in Europe are healthy, and ill-health is not a characteristic of this population as it is in, for example, an ageing population. However, there are certain health issues that affect children, and as such can blight an entire lifetime. This Roadmap does not focus on clinical issues, treatment plans and medication, but rather takes a population perspective. There are certain disorders that have a population-wide effect and are prevalent enough in the child population to warrant particular attention from a public health viewpoint.

Mental illness is an issue where children are often treated in an inconsistent way across the continent, and there are even inconsistencies in whether children can access services at all. Mental disorders can become difficult to treat and have far-reaching consequences on such diverse outcomes such as socialisation, education and future prospects for an individual child. They cause stress on the individual, the family and community, all of which are in themselves risk factors for poor health outcomes. Research needs to establish the prevalence of common mental disorders in the child population, and also to strengthen the evidence base so that common definitions of diagnosis and treatment can be agreed upon.

Sexual health is an important issue for young people not only in physical health terms, but also from a social health standpoint. Teenage pregnancy, for example, is still a problem for many young people, and has far-reaching consequences for the health of the young parents, the communities

they live in and for the resulting children. We still need to know more about how to prevent teenage pregnancy in Europe and to explain why there are such different rates across the continent. Contraceptive services need further research, particularly in the controversial subject of providing contraception to vulnerable young people who are under the legal age of consent to intercourse. Sexually transmitted infections are becoming more common and research needs to be able to identify effective ways of providing messages about how to prevent infection to young people. Treatment of infection needs to be more accessible to young people, and research needs to evaluate how to achieve this, and how services can retain the dignity of the young people who use them.

Overweight and obesity is a continuing problem in Europe, and one which will have immense consequences for population health for many years to come. There are diverse rates of obesity among children and young people across the European Union, and we do not know enough about how to effectively prevent or treat this epidemic.

Neurological and developmental disorders are in one sense loosely related to mental disorders. There is a lack of standardisation in Europe about the classification and intervention of neurodevelopmental disorders, which needs to be addressed so that care of children can be improved across the European Union. Interventions need to be evaluated in respect of pain management; and disability needs to be regarded in terms of the abilities of a particular child, rather than the disabilities of the child. Greater use of the World Health Organisation's ICF-CY system^a might be a productive means of allowing all European children to live to their personal potential rather than have to change to fit into an uncompromising environment.

Health Services

The main research needs of the health services focuses on the prevention of poor health. Issues of access have been covered earlier. This is either through empowering children by giving them the tools and knowledge about good health, through health promotion activities; or through prevention interventions and other services, such as vaccinations and health checks. Comparing health services across Europe and evaluating the means of conveying health promotion messages are important directions for health research to investigate. Indicators need developing which reflect the effect of preventive actions, particularly among younger children. Health promotion activity has the potential to reduce the social difficulties that affect health, such as social exclusion, yet little is known or evaluated about the effects on diverse social groups – this must be remedied so that real health improvements can benefit Europe's children.

Vulnerable populations, such as those in deprived communities, need to have health prevention services particularly targeted. However, there is a lack of systematic evaluation of such interventions, which compromises the development of new interventions and their implementation.

^a www.who.int/mediacentre/news/releases/2007/pr59/en

Data about interventions needs to be made explicit in terms of the child population so that those who do not access services and those who need particular attention can be identified. Research needs to help health services of all types to become developmentally appropriate, for example teenagers have very different needs compared to young children or babies but both are important to gain and sustain good health.

Public Health Infrastructure

Health surveillance is essential so that health needs can be identified and addressed effectively for the benefit of the child population. Yet, many existing sources of data are neither analysed, nor made available in a child-centric way. Children need to be made more visible in the data so that they can have more effective health promotion and health care on a population level. This is very important for specific disorders that become apparent in childhood, such as autism for example; or that profoundly affect the child population, such as injury morbidity; a topic that desperately needs more systematic research attention and surveillance.

Closely related to surveillance is the need for establishing proper measures and indicators of children's health and children's lives. Developing a European dataset of indicators and using these as sources of information to learn about the trends in health for European children is vital for effective targeting health action and budgeting of services. We cannot act properly without identifying and measuring the problem thoroughly first.

Electronic health records are an emerging technology that has great potential, and one that needs to be developed and investigated further to encourage their use across the European Union. Children's health and well-being can suffer due to breakdowns in communication between the many agencies involved in their upbringings, such as health, social and education services among many others. A safe and thorough system of electronic health communication would help to avoid such scenarios.

Improving Research Capacity

Given that child health research is important, and that children's lives matter, it is necessary to ensure that there are enough resources, both to do research, and to make use of the research findings. To sustain research activity, specialist training for junior child health researchers is needed, as are sufficient resources to maintain a critical mass of researchers and provide attractive career paths for them. In addition to this, the children and young people as subjects of research need to continue to be safeguarded by a consistently ethical framework, and information collected about children needs to be accurate, comprehensive and used intelligently so that interventions and services can be correctly directed. Much of child research also looks to the future, to the future of children and to the futures of the young people as they become adults. Recognising this need to look to the future necessitates taking a multi-disciplinary viewpoint which takes account of the many influences on children's life and health.

Conclusion

Our core value is to put children first in our work. We take the rights of the child seriously, and we are conscious that many children do not have the opportunity to exercise the right to health and healthcare that European children they ought to have.

The topics in this Roadmap are pragmatic in that they are researchable (within the grasp of presently available research methods and resources) and that are likely to have a significant effect on the lives of European children. This will go a considerable distance in improving the health and well-being of European children who may not have benefited from Europe's good fortune up until this point. At the very least, the RICHE Roadmap aims to begin a serious conversation across Europe about the need for research to focus on children and how this will ultimately benefit all members of the European population.

There is a need for children to become substantially more visible in European society. At present many children's lives are invisible to health surveillance and to research. Sometimes they are submerged with their families, as in the case of Roma or for children of illegal and undocumented immigrant families. Even in well-documented societies, children's circumstances are invisible as data are collected from the perspective of economically active adults, or households. Therefore, an overarching recommendation in this road map is the establishment of a European Child Health Observatory with a simple remit to make European Children, and their lives, health and attainment of rights more visible. We also recommend continuing and extending the discussion to the edge of existing child health boundaries, to address topics such as the effects on children's health of urban design and architecture, fiscal policy (which can affect many health issues), welfare, or health effects of immigration policy.

The RICHE Roadmap hopes to point the way in which children can be fully recognised and respected as forming a valuable population and whose health and well-being contributes to the health of our present and future European society.

1. Introduction, justification and overview

“It is easier to build strong children than to repair broken men” (Frederick Douglas).

The RICHE project is a response to a call to clearly identify gaps in European child health research, and to provide justified guidance on priorities for investments in research over the next decade^a. Our aim is to improve infant, child and youth health for over 100 million individuals in Europe.¹

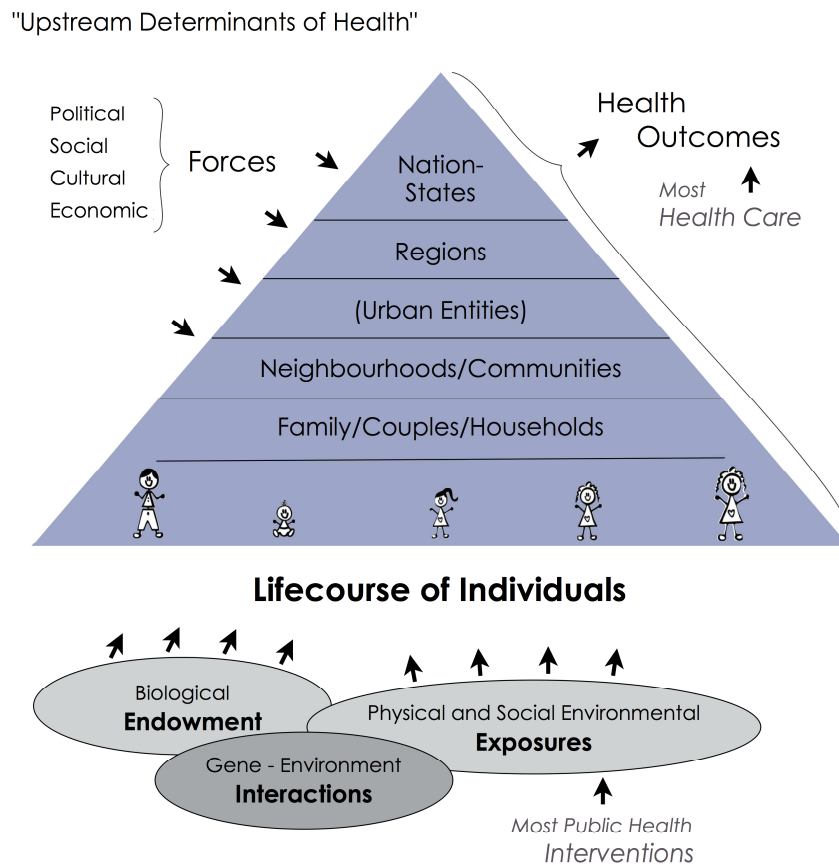
The United Nation’s Convention on the Rights of the Child,² which has been signed by all European nations, has given us guiding principles for promoting and protecting child health and welfare, as well as ensuring children’s appropriate participation in their care during childhood and adolescence.

| | |
|--|--|
| Nosotros somos culpables de muchos errores y muchas faltas, pero nuestro peor crimen es el abandono de los niños negándoles la fuente de la vida. | We are all guilty, Of many errors, and many crimes, But our worst crime is The abandonment of the children Neglecting the spring of life. |
| Muchas de las cosas que nosotros necesitamos pueden esperar, los niños no pueden, ahora es el momento, sus huesos están en formación, su sangre también lo está y sus sentidos se están desarrollando, a él nosotros no podemos contestarle mañana, su nombre es hoy | Many of the things That we need Can wait, but the kids can't Now is their instant Their bones are being shaped Their blood is being made And their senses are being developed To them we cannot say tomorrow Their name is today |
| | Gabriela Mistral |

Major advances in children’s public health, for example work on reducing health inequalities, providing health care to marginalised or forgotten groups such as Roma, and preventing child obesity, have been made using a bioecological and social determinants model of health, described in Figure 1:

a HEALTH-2009-3.3-5: European child health research platform. Address the diversity and fragmentation in child health research in Europe in an inclusive multidisciplinary way, identifying existing research programmes in Member States, recent advances and identification of gaps to explore road maps for the future of child health research in Europe.

Figure 1 The Upstream Determinants of Health



Source: Frank & Di Ruggiero³

Drawing from this upstream perspective, the RICHE recommendations are directed at population or child group level rather than at individuals. Intentionally, we have not focused on basic laboratory research or blue sky research (knowledge for its own sake). The responsibility for these types of research lies elsewhere.

Development and health

The World Health Organization (WHO) famously defines health as *"a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity"*.⁴ Health is not a single idea, but includes a capacity for self-determination, adaptation, and engagement with life. The Ottawa Charter for Health Promotion⁵ describes health as *"a resource for living, not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities"*; Huber et al⁶ see health as: *"the ability to adapt and self manage, in the face of social, physical, and emotional challenges"*. The foundations of health throughout adult life are laid in childhood.⁷ This is the time when diet, physical activity patterns, and many other health-related behaviours are established, and much of the individual risk of later chronic disease is set, even

before birth. The WHO European Strategy for Child and Adolescent Health and Development⁸ aims to ensure that children in Europe have the greatest opportunities to maximise their health. Childhood is the base for achieving the European goal of '*Active and Healthy Ageing*', and much of what is started in childhood cannot easily be undone later.

One of the difficulties in talking about the influences on children's health is the intricacy of most of the relationships involved. There are many influences on children's health – either for good or for ill. Some continue to be felt across the whole of childhood, whereas others are only of major significance at very specific times.

We focus in our roadmap on interventions and research aimed at supporting children's health. These are presented within a life-course perspective, looking at changes over time in the children, in their environments, and their influences. We examine a number of distinct contexts in which modern children live their lives.

We acknowledge, of course, that there are many other important external influences in children's lives, such as the economy and the education system.⁹ There are also many outcomes for which 'health' is too limited a perspective, such as outcomes in education, in sport, and in social life, which have a profound effect on health. Nevertheless, we believe that health gives, for all this, a useful, broad, perspective on a major part of the lives of children and adolescents in modern Europe.

The health of European children – a Europe that is changing

European children are regarded as enjoying reasonably good health. The last 50 years has seen a major reduction in mortality rates for all age groups in Europe. However, there has been an increase in morbidity from non-communicable diseases, which now make up the greatest burden of disease in Europe and worldwide. Mental health disorders, and other chronic longstanding illnesses, all create major challenges to human health and health services. A recent review of the health of younger children (from birth to age 12 years) in Europe,¹⁰ describes a substantial burden of preventable illness, and poor health status, with predictable consequences for ill health in adult life, for example obesity, type 2 diabetes, poor mental health, cardiovascular disease, stroke, and premature death.¹¹ There is less systematic information about European adolescents, particularly older ones, but recent reports from the Health Behaviour of School-aged Children (HBSC) study¹² show the diverse ways in which our societies support, or fail to support, young people navigating adolescence.

There are still large numbers of children in Europe with unacceptably poor health, particularly those living in socially disadvantaged circumstances, and in those countries in which social inequalities are relatively high. While Europe now has an agreed set of values related to health and health care,¹³ and a strategy,¹⁴ this needs to be implemented with a particular focus on some very marginalised groups, for example Roma children, recent migrants, and illegal immigrants.

Economic Impact of Child Health Research

Economic analyses show that investment in childhood is worthwhile.^{15; 16} Preventing disease is known to be a good investment, but promoting children's health is even better.¹⁷ It is now well supported by evidence that '*Healthy ageing begins before conception*',⁷ and so societies which wish to tackle successfully the challenges of ageing will need to start with their children.

All European societies spend significant amounts of funding on children's health (and even more on avoidable adult ill-health determined in part at least in childhood). In times of economic strain it is important that this expenditure is justified, and that services are delivered as effectively and efficiently as possible. This means our children should receive purposeful evidence-based services, and researchers must generate, analyse, and disseminate the evidence to justify, or change, them.

European added value

It is usually easier, and cheaper, to do a given piece of work within a single state. Why add the burdens of communication across languages and cultures, the difficulties and expense of travel, and the significant coordination cost which arise whenever this type of work is done?

Pan-European work can bring these benefits:

- Different countries arrange child and family health and support services in very different ways, providing an opportunity to do powerful comparative research into outcomes, effectiveness, and efficiency.
- Different cultures expose children, before and after birth, to a wide range of different influences, environmental, familial, dietary, educational, cultural, all of which can most effectively be studied in comparative studies. For example the EU has a tradition of sharing research infrastructure, such as birth cohort studies and EU wide surveys, which can enable inter-country comparisons and large scale primary research.
- Research into implementation of existing knowledge is more likely to identify barriers, and generalizable lessons on how to overcome them, if undertaken in many countries.
- Notwithstanding the coordination costs, it can be more efficient and powerful to design research in a way which it can be replicated, or the results validated nationally, rather than every country seeking to design and initiate similar studies of the same issue.
- Working with researchers from other countries is a powerful means for developing national capacity, and providing training opportunities for national researchers.

Aims of the RICHE Roadmap

In the spirit of the upstream definitions of health (see Page 11), and by studying the common needs of all children, and the more specific needs of potentially vulnerable groups such as disabled children, migrant children or children in poverty – we have produced a set of justified options for

child health research in Europe over the next decade. The major focus of this roadmap is the prevention of avoidable ill health, disability and death in our child population. This concept of upstream health determinants shows the interrelatedness of many influences and outcomes on children's health. This is reflected in the RICHE Roadmap; where issues are continually intertwined, and in some cases artificially separated for purposes of clarity in research recommendations. In addition, we try to optimise children's health by means of better child health services and delivery. Specifically, RICHE aims to:

- Provide evidence-based guidelines for prioritising future research on child health, research resources, research types and research methods;
- Inspire future funding allocations and research calls, as well as national and international applications for grants, which prioritise the gaps identified by the RICHE project;
- Enable a better fit between research priorities and health care practitioners' and stakeholders' needs for information. Stakeholders in this context can mean policymakers, research advocates, health care system advocates and health insurance advocates amongst others;
- Support the translation of research into policy for different stakeholders, to make better use of research in enabling evidence-based planning, monitoring and evaluation of health policy actions.

Research priorities should take into account future health scenarios. In view of this we have included in the Roadmap the need for developing multidisciplinary approaches and establishing European capacity to identify future trends in the main determinants of child health.

Within the RICHE Roadmap, the term 'children and young people' is used throughout to describe those aged under 18. Where there is a specific need to describe children and young people of different ages, for example, infants or adolescents, the appropriate terms have been used.

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2. Methodology

Core aims of RICHE Project

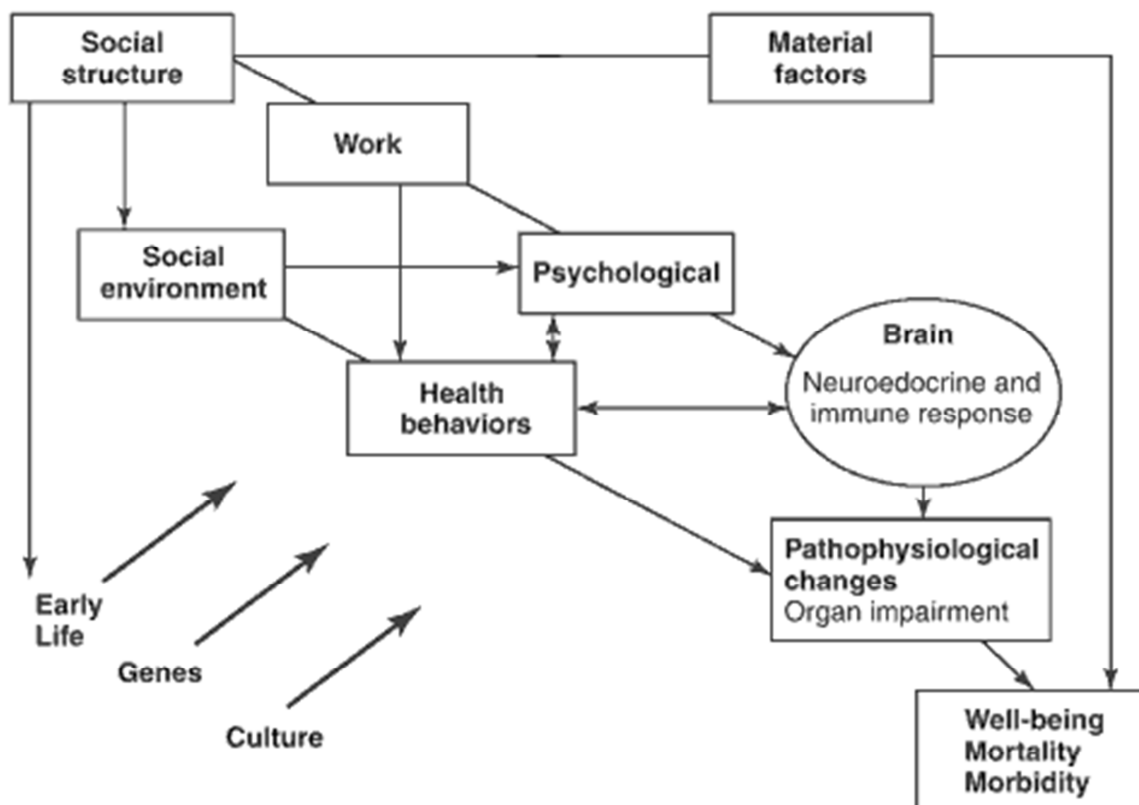
Our core objective is to produce a roadmap for future investment in child health research in Europe. This was prepared using a systematic process, which has led to a set of justifiable recommendations. These will support the future development and implementation of child health research strategies, and the use of evidence for child health action. These in turn will support innovative research, improve social policy for children, and so improve the quality of life of European children.

Processes applied by the RICHE Project

Work leading up to the roadmap

The RICHE roadmap is the end of a three year program of work designed using the concepts of a life-course approach to child health and a biopsychosocial model of child development (See Figure 1).

Figure 1: The biopsychosocial model - one formulation (Source: Brunner & Marmot, 2006⁵)



Inventory (WP1)

The first phase of the work was the Inventory (Workpackage 1). This WP aimed to gather material on currently funded child health research projects, reports of older significant projects, and child health research funders. The intent was to cover European funded projects, and those funded by major research funders across Europe. A systematic search was done through the CORDIS system, and similar databases for other funders. In addition, grey literature was collected, as systematically as possible, by asking partners to identify significant national reports, and a systematic search for significant international reports. All of this material is available on our website, which is at <http://childhealthresearch.eu/>, and can be added to, by any interested researchers, as needed.

A key part of this work was the development of a taxonomy for classifying this research. The process started with a review of existing taxonomies. After a careful evaluation it was decided that none of the existing taxonomies met the RICHE project requirements, and the decision was made to develop our own multi-axial taxonomy. This is used to classify, and search for, grey literature, research projects, research funders, and child health indicators through our platform. The taxonomy is updated every six months, to reflect identified deficiencies, and new terms and topics. It is currently available in ten languages.

The key outcome of WP1 is a detailed view of what work is being done, in child health research across Europe, and ready access to the grey literature, where much of the output from previous work is to be found. Of course, many outputs for child health research are in the journal literature, but there are already several excellent search services for this material. Much key knowledge, for example the majority of work on implementation, can only be found by looking for research in progress, official policy documents and reviews, and research commissioned by NGOs and others. This has largely been hidden from the wider community, but we have now sought to identify it, and make it more accessible through the inventory.

Child health indicators and measurement (WP2)

The second part of our project proceeded in parallel with WP1. There were several strands to this work, but the key objectives were to thoroughly review the state of the art in child health measurement, the creation of valid indicators that can be used to follow trends in child health both at European level, and at national and regional level, and the extent to which these have been implemented in Europe. There are a series of reports, based on extensive literature reviews, on international, national and sub-national measures of child health, a case study on the use of electronic health records to create indicators of child health and comprehensive reports on the new areas of child health measurement of obesity, well-being and disability. A particularly important by-product of this work package is an indexed list of validated child health indicators with key information, all of which have been classified using the taxonomy, and are available, for the first time, through the website.

WP2 provides detailed information on both the possibilities, and the reality, of child health measurement across Europe. It gives a clear view of the (limited) extent to which children's lives are being documented and made visible across Europe.

Gaps in child health research (WP3)

Both WP1 and WP2 provided important inputs for this work package. WP1 gave a reliable overview of existing activity, and WP2 showed how and where the outcomes of childhood were being measured. However merely documenting what is being done, does not, on its own answer the question of what is not being done, that ought to be done. To address this conceptually difficult question, a range of methods were used, building on the work of WP1 and WP2.

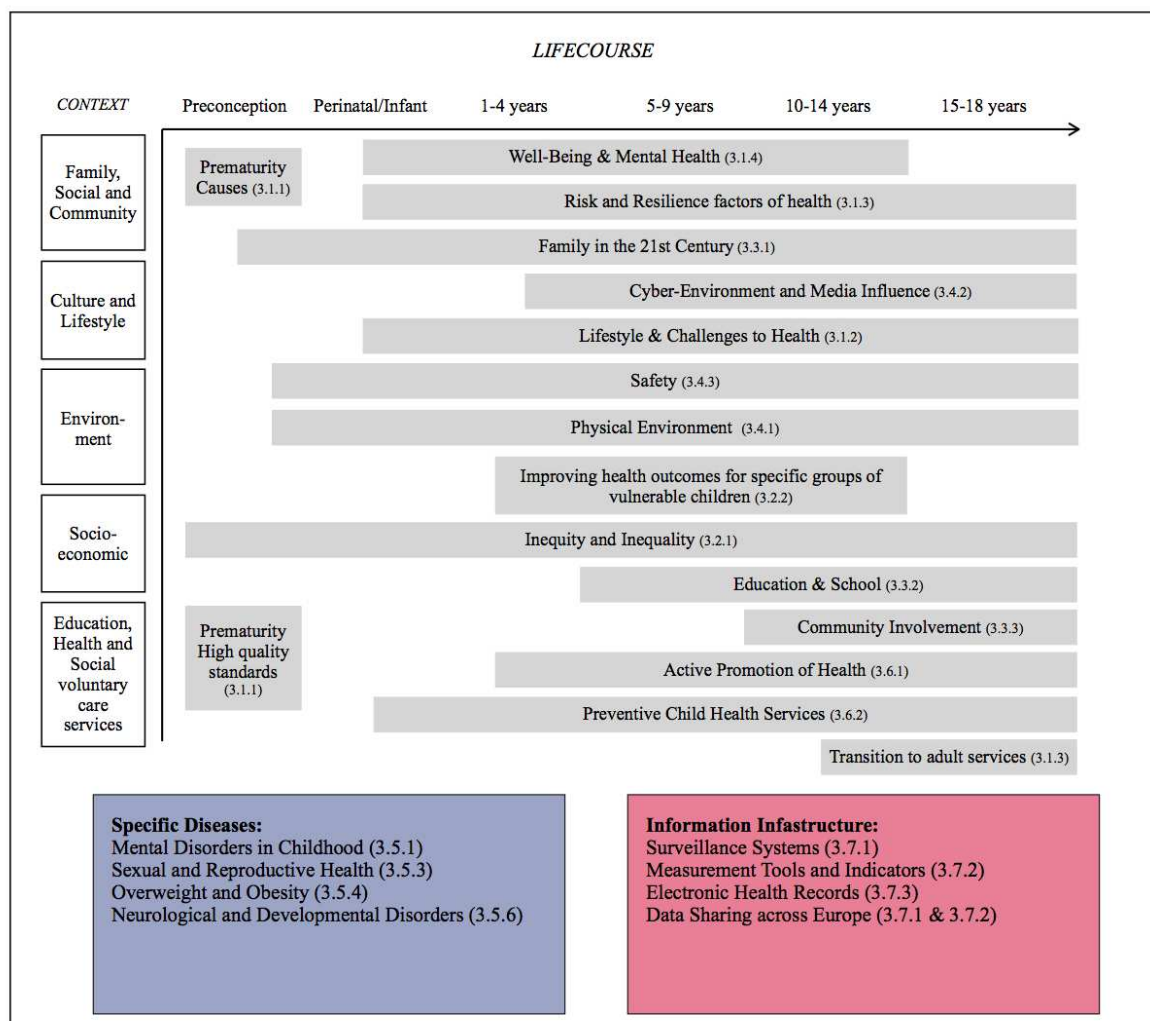
A series of discussion meetings were held with experts in several partner countries, and a questionnaire was circulated through the partners to relevant experts in their own countries to explore their current research plans, and their opinions about gaps. In a few countries, face-to-face meetings were also held with lead researchers. A content analysis of existing child health research plans and programs based on responses was done, and used to identify 26 themes identified as main gaps and priorities for further review. A second e-survey based on Delphi methodology was then done with experts across Europe, building on the results of the first round of consultations, to prioritize identified gaps. The report on Gaps in research was further reviewed at a meeting of national experts, and finally at a project meeting, attended by outside experts.

WP3 provides a detailed analysis, based on an analysis of the value judgements of a large group of experts from different professions, different backgrounds, and different countries, of perceived major gaps in child health research across Europe.

ROADMAP Development Process

The Roadmap is based on a life-course perspective. It covers the important phases of a child's development, including the pre-birth phase, maternal health and pre-conception issues. A theoretical basis for this approach comes from the Biopsychosocial model on health determinants as proposed by Engel. It shows the ways in which biology, psychology and social settings combine over a lifetime to generate health or disease. The focus is on the interactions between causes, and the ways in which different factors influence outcomes over the whole course of development from in-utero to old age. This is, in essence, the approach of modern public health. Figure 2 shows the different contexts dealt with in the Roadmap spread across the different phases, beginning with preconception and ending with age 18.

Figure 2: The interactions of the Roadmap topics in a life-course perspective

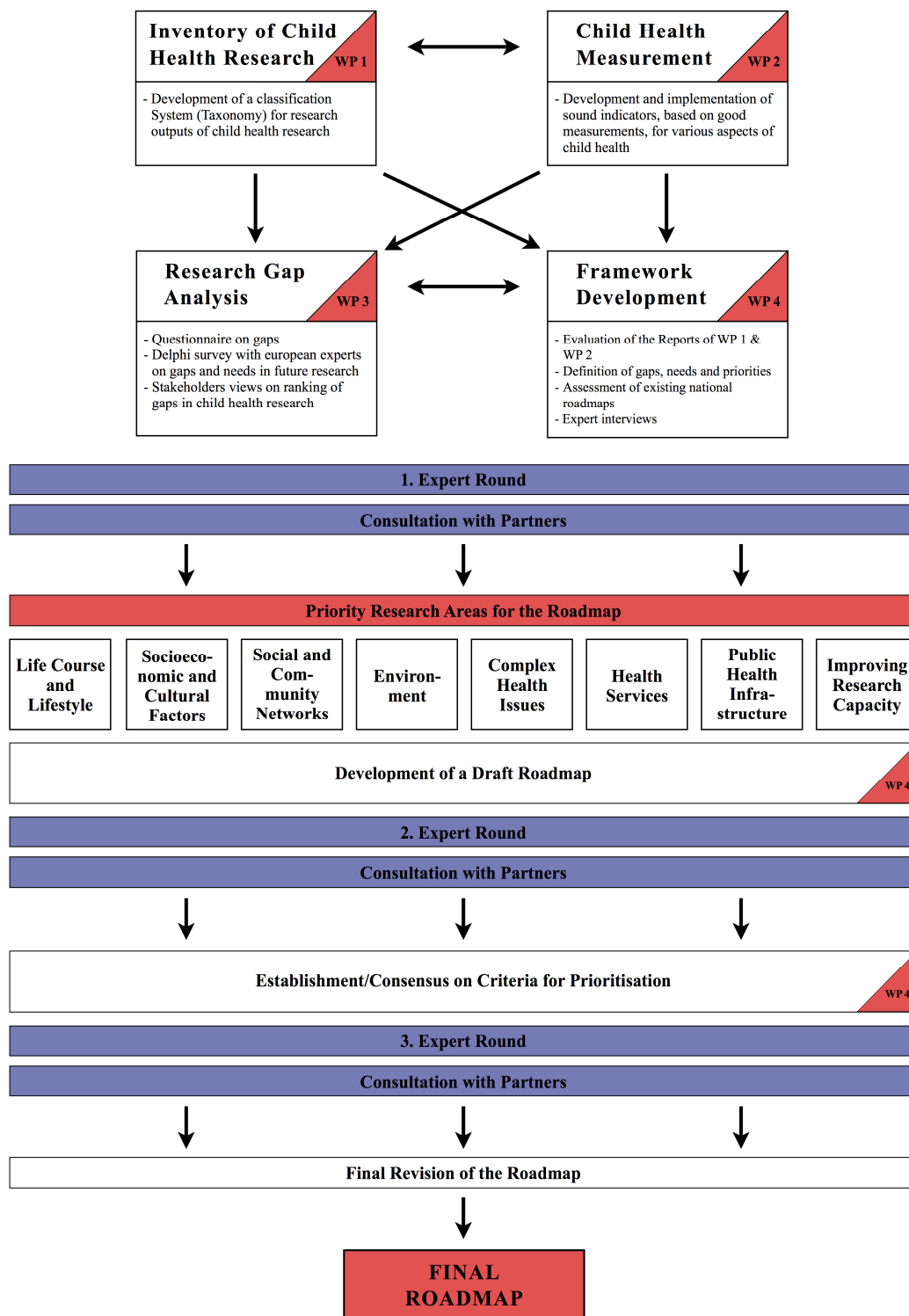


The Roadmap development process involved a number of experts from different fields, both internal and external to the RICHE project. The Roadmap developed from the work of the previous work packages, in particular Work Package 3 (Gaps). The reports of Work Package 1 (Taxonomy) and Work Package 2 (Indicators) provided the general direction for the Roadmap, whereas the WP3 report delivered the gaps in research that were essential for the formulation of the priorities and recommendations. The compilation of evidence underpinning the Roadmap topics was done by means of a literature search of scientific and grey literature. A consultative approach was then used to obtain as much feedback as possible and to ensure consensus between the partners on the joint final product. Consultations took place on a regular basis via teleconferences, email-feedback, and a series of structured meetings (WP4 Meeting in Hamburg September 2012, RICHE General Assembly Meeting in Milan February 2012, RICHE General Assembly Meeting in Lisbon November 2012) and expert panel feedback (prior to and at General Assembly meetings). The workshops held at the Hamburg Work Package 4 (Roadmap) meeting and the Final RICHE General Assembly meeting in Lisbon served to reach group consensus and to condense the range of topics and priorities and to

reduce the overall length of the Roadmap. The focus of the Hamburg meeting was on defining our criteria for setting priorities. The main aim of the Lisbon Meeting was to finalize the priorities and content of the Roadmap.

Each of these steps /phases encompassed a set of additional activities which are shown in Figure 3.

Figure 3: The Roadmap Development Process



Determining Priorities

The values we used to set priorities were built in part upon the CHILD study^{1,2}. Each topic recommended for investment meets one or more of the following criteria:

1. Significant impact^a on society
2. Significant impact on families
3. Significant impact on individuals
4. Representative of Significant Population Groups
5. Support more efficient or effective service delivery
6. Feasible

We started by selecting from the work on identification of knowledge gaps. Where there is a significant gap in the literature considering a topic of relevance, we investigated the work that has been done: either there is no research done; or the research done is not relevant to the European situation; or the research is of poor quality and cannot be used to make policy or practice decisions. There is rarely no research, but that which exists may not be relevant. Topics and questions that were chosen were deemed to have a potential for European added value, as discussed in the Introduction, Justification and Overview (see Page 10).

Having identified priority research questions, we did not then try to further rank them, partly because this would be even more difficult than identifying the broad areas; but also because different agencies are likely to come with different perspectives and remits. All topics and recommendations incorporated into the roadmap have been identified as priorities to meet knowledge gaps.

Instead, we prioritized the research topics in the roadmap by specifying the degree of “knowledge gap” and the level of “implementation gap”. This prioritization was based on the results of the WP3 Delphi in which 63 respondents were asked to assess a) the a need for further research and b) whether or not a topic is a priority for further European funding. The responses were categorized according to the level of agreement (high, moderate, mild, low). We then used these WP3 Gaps Delphi results to assess the “knowledge gap” level for each chapter (research topic) in the Roadmap. We did this by counting the number of mentions for each chapter in the Roadmap i.e. the number of mentions in the “High Agreement Group”, the “Moderate Agreement Group” and the “Mild” and

a 'Impact' is used here, as an alternative to 'burden'. There is much work on the burden of disease, whether attributed to particular causes,³ or to particular disease entities,³ which we have used in setting priorities. However, many child health interventions are not about removing hazards, or preventing harm, but are intended to improve the experiences of children as they grow and develop, such as parenting support programs. We feel impact is a more useful concept than burden.

“Low Agreement Group” (these two were combined). The group scores were then weighted (the “high agreement group” was multiplied by a factor of 3, the “moderate agreement group” by a factor of 2, and the “mild/low agreement group” by a factor of 1. The resulting scores were then added up to give a total score. The total score was then divided into: 0-10=+ (low knowledge gap), 11-20=++ (medium knowledge gap), 21 and higher=+++ high knowledge gap.

The “implementation gap” was derived by means of the evidence base, consultation with experts in each topic and discussed in the RICHE meetings that were held throughout the development of the Roadmap. Each topic has the potential to impact highly and positively on the health of children and young people in Europe, and as a direct result of this, benefit the health of the European population as a whole, both immediately and in the future. The degrees of the “knowledge gap” and “implementation gap” specified, helps us to identify where the major efforts in each topic need to be directed. These weightings appear at the head of each topic section.

Funding agencies have different priorities or areas of special interest, and the larger funding sources such as the European Commission set their research calls into wider thematic programmes. The following list describes a range of research gaps and recommendations to meet the need for missing knowledge about Europe’s children, their development, and thus the future health and related prosperity of European society. Each is worthy of accomplishment in its own right, and each organisation will apply their own priorities and make their choices.⁴

Addressing any of these topics is likely to improve the health of European children. Our recommendations are based on evidence, judgement, experience, and an explicit set of values. It is now open to others to take this work, debate it, and make use of it.

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3. Priority Research Areas

3.1. Life Course and Lifestyle

3.1.1 Periconceptual, Prenatal and Perinatal Determinants of Health and Disease

| | |
|------------------|------------------------|
| Knowledge gap ++ | Implementation gap +++ |
|------------------|------------------------|

Background

The influence of maternal health on the health of the unborn and new-born child is complex and profound. In turn, maternal health is influenced by a number of intertwined factors which it is difficult for research to unpick. The mother and infant experience a complex symbiotic relationship, in which health action and outcome are repeatedly intertwined. Three particular issues are identified: the effect of early determinants (preconceptual or periconceptual) of later disease; prematurity, and intervention programmes to prevent prematurity and/or low birth weight.

Key issues

Prenatal experience is now known to affect child health.¹ Although prenatal health is now recognised as an important influence, its results are strongly mediated through health action and later life growth. In other words, it is the interaction between growth early in life and the patterns of growth in later life which determines health outcomes. Early life growth in itself is not deterministic, so targeted intervention programmes of prevention can to be developed and used successfully.

Perinatal health has substantially improved in Europe in the last decades. For example infant mortality has decreased in the EU by 70 per cent in thirty years,² a very positive occurrence. It is not well established that prenatal and perinatal factors, not only affect the health of children and young people, but also are important determinants of adult health and disease, including cardiovascular disease and mental health both in adults, and the elderly.

Recommendation

Objective: To identify early (periconceptual and perinatal) determinants of cardiovascular, metabolic, neurological and mental disorders, occurring in childhood and along the life course, and their early makers.

Methods: Systematic review of existing evidence; Longitudinal studies to identify early markers, assessment of their predictive value and link with exposure variables.

Expected Impact: Improved health of new-born and children, and resulting improvements of health in the child population for future generations and reduction of risk for chronic disease along the life course.

There are increasing prematurity rates in some European countries, and more infants are surviving very early births. However, for reasons yet unknown, some adjacent countries, such as Finland and Denmark, have totally divergent trends. It will require novel data and further international comparative studies, to identify the factors behind these unwanted trends. One explanation may be differences in care practices related to assisted reproduction, care and interventions during pregnancy and birth, but this has not yet been explored on a European level. The impacts of clinical health care provision on national measures of morbidity after premature birth, and births as a result of assisted reproduction, are potentially a considerable economic concern. There is a lack of information to support proper resource allocation.

Research attempts to identify ways of optimising the developmental outcomes for very premature babies – from parental attachment and how it is affected by premature birth, and consequently how this affects a child's development³ to the effects of an early birth on child development⁴⁻⁶ are priorities.

Recommendation

Objective: To analyse and explain the different trends in prematurity across Europe. Identify entry points for preventive strategies.

Methods: Epidemiological studies; large register-based data enriched with sufficient data on medical practices and parental background factors from different European countries. Review of intervention studies to reduce prematurity and low birth weight.

Expected Impact: Improved knowledge of causal factors of prematurity. Development of hypotheses to be assessed in intervention studies.

The first prenatal visit, which takes place usually between the 7th and 10th week of gestation, is too late to implement many interventions. As the development of the child starts with conception, interventions are particularly important before pregnancy and should therefore be strongly

encouraged. Preconception health has been defined as “*the missing link in the maternal new-born child-health continuum of care*”⁷. Starting preventive action before as well as during pregnancy will impact on the child well into the future. An important source of potential data for the impact of perinatal good health on future health are cohort studies, of which the Norwegian Mother and Child Cohort Study (1999 to present) is the largest pregnancy and birth cohort to date. In this study the children are continuously followed up, and the eldest are now entering school age.

Recommendation

Objective: To assess the cost effectiveness of large preventive intervention programmes on known determinants of low birth weight and prematurity, including the known adverse health behaviours, such as smoking, alcohol consumption and use of illicit drugs.

Methods: Large-scale population based intervention studies, which compare different approaches and/or intensities of intervention

Expected Impact: Effective delivery of preconceptual and prenatal interventions will result in better pregnancy outcomes with long term effects on child and reproductive health.

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3.1.2 Lifestyles and risk factors

| | |
|-------------------------|-------------------------------|
| Knowledge gap ++ | Implementation gap +++ |
|-------------------------|-------------------------------|

Background

How children and young people act and how external influences impact on lifestyle and on health behaviour is important to understand. The 2009/2010 Health Behaviour in School-aged Children (HBSC) survey noted that incidences of poor health behaviour increased with the age of the children, and also increased with the level of family deprivation.¹ Children grow increasingly autonomous as they age, but some choices about health are individual from comparatively young ages. Research has yet to identify what influences are particularly powerful in informing and determining behaviour, although it is known that the major influences start in the family, and move into the wider peer group as the child grows older. It is not all clear how increasing digital literacy, and the use of new media, such as online social networking, will effect health choices and mediate family and peer group influence (see Chapter 3.4.2).

Key issues

The child and adolescents of the European Union follow very diverse lifestyles across the member states, with for example, very different levels of key lifestyle factors such as physical activity, food intake, and the use of tobacco, alcohol and illicit drugs, as indicated by repeated surveys of school children on the European level (for example, the European School Survey Project on Alcohol and other Drugs ESPAD, Health Behaviour of School-Aged Children HBSC). The 2009/2010 HBSC study found that health patterns and behaviours varied across countries, highlighting the influence of social, cultural and economic contexts on children and young people's health behaviours.¹ Policies to address these lifestyle choices and the associated health impacts vary greatly between societies. Interventions and health promotion messages offered to children and young people may not be very effective, and there is an urgent need for the development of effective health promotion for young people, particularly younger children.

Recommendation

Objective: To determine how policy in the different countries of the European Union contributes to, or reduces, unhealthy lifestyles in children and adolescents.

Methods: Comparative European studies on health policy and policies for health including sectors beyond the health sector (including nutrition, education, media, labour market, etc.).

Expected Impact: Improved knowledge about effective policies that can reduce risks to health for children and adolescents. Improved cross-European collaboration and support to promote effective policies for health.

The impact of lifestyle and challenges to health are very closely related to the concept of resilience (see Chapter 3.1.3). Resilience is the capacity to recover from setbacks. A big contributor to resilience is the young person's or the family's sense of empowerment, of control over their situation, and can ameliorate the negative influence of hazards or risk factors. This makes it impossible to predict the degree health or social outcome of individual young people, from their individual circumstances. It is nonetheless important for research to be able to identify broadly the most salient risk and protective factors, and to identify how resilience to certain negative life circumstances can be fostered and strengthened. Important individual protective factors include having a positive temperament, a sense of self-efficacy, high intelligence and good education. Those children and young people who are resilient seem to display a range of problem-solving skills and a belief that they can overcome the circumstances they find themselves in.² There is a lack of evidence-based intervention to promote these factors to individuals, families and communities to improve resilience. Resilience is thought to develop from ordinary human care – parenting, thinking skills, motivation, cultural rituals, family traditions and other basic aspects of human nature.³ However, the best way to develop these as part of an intervention is not yet clarified although some work has been undertaken.⁴

Recommendation

Objective: To identify the lifestyle factors that act as protective factors, in children and young people who are at risk of adverse experiences or environments.

Methods: Longitudinal studies.

Expected Impact: Dissemination of knowledge and awareness among both governments and population about what can maximise the protective factors in the life of children and adolescents.

Although children and young people are often aware of what constitutes healthy behaviour, both from their families, the education system, and the media, including the influence of social media and digital communication (see Chapter 3.4.2), this awareness is not always translated into action.⁵⁻⁷ Parental influence still has a profound effect on healthy behaviour, even for older adolescents – this can be seen in studies that show that young smokers tend to come from families where parents smoke,^{8;9} or that overweight children are likely to have parents who are also overweight¹⁰ (see Chapter 3.5.3). The increasing influence of the peer group is also important for children as they become adolescents, and the forms of peer influence may be, changing as use of digital media and social networking becomes almost universal in Europe (see Chapter 3.4.2).

Less involvement in risk behaviours positively influences adolescents' health, together with feelings of well-being. It also influences positively adolescents' feelings about school. Adolescents seem to choose to be less involved in risk behaviours when they have friends that are not involved in risk behaviours. Although peers' influence is only indirectly related to risky behaviours, it is nevertheless

very important for adolescents' health and well-being, as suggested in many studies. Health promotion interventions targeted at adolescents should take into account the important and positive role that peers may have in the adoption of a healthy lifestyle.^{11; 12}

Recommendation

Objective: To determine the motivation (such as from parents, peers, and social media) for adolescents' lifestyle choices that have an affect on health.

Methods: Surveys; longitudinal studies; research conducted by young people via social media.

Expected Impact: Evidence to develop interventions that successfully enable adolescents to make health choices and improve their health and well-being.

The relationship with parents is known to be a protective variable towards the involvement in risk behaviours and the increase of adolescents' health and well-being; it is also a factor that may mediate the relationship between adolescents and their peers.^{13; 14} Parental action may influence the child's activities, but not necessarily be health promoting as the parents also do not translate their health knowledge into action. Influences from the media, such as advertising and fashion also have a powerful impact on children's decision making about their health. The combination of this relationship with that of parents and the wider environment is complex and as yet, not completely understood.¹⁵ Providing tools to enable children to make healthy choices from a young age, while still balancing the developmental needs of bounded experimentation and risk-taking, will help in creating a generation that is likely to remain healthy throughout much of life and foster future healthy generations.

Recommendation

Objective: To investigate the trends in lifestyle factors in children and young people of all ages, in relation to national and regional policies.

Methods: Survey research of all ages where possible to explore the European diversity in lifestyle. Analysis of policies across the European Union. Comparative analysis of survey results and policy in national and regional settings.

Expected Impact: Translation of knowledge across the European Union as to the policies that have a successful effect on adopting healthy lifestyles in children and young people, thus improving the health of future generations.

Adolescence is a time of risk-taking, which is an essential part of growing up. Yet there is a need for young people to experience risk while avoiding the temptations that lead to a long-term addiction, health problems and other social consequences. These threats to health include obesity, alcohol, tobacco, injury and violence among other risks, and the risk of chronic or fatal illnesses. Of these, injury and violence are the most immediate adverse health outcomes, while school failure is perhaps

the most immediate adverse social outcome. Understanding behaviour related to risk in childhood and adolescence and lifestyle behaviour allows pertinent interventions to be developed and evaluated. The 2009/2010 HBSC survey concludes that health and healthy behaviours decline during adolescence.¹ There are multiple risk factors to young people’s health, and health behaviour is also subject to multiple influences. For example, an individual who is overweight may be more likely to partake in alcohol or tobacco consumption as well as adopt other health risk behaviours.¹⁶ Although individual risk factors have an influence, it is a combination of many different types of risks that leads to the highest likelihood of a poor outcome – yet it is also difficult to predict precisely how the risk factors influence each other and cause a cumulative risk to the young person’s development, health and well-being.³

There are still many unknowns relating to behaviour and what influences lifestyle choices with regard to these risk factors. McEachan et al.¹⁷ attempted to understand common characteristics of behaviour and determinants of behaviour. They found that young people characterised behaviours as easy immediate payoffs versus effortful long term pay-offs; private unproblematic versus public problematic; and important routines versus unimportant one-offs. Risk behaviours were seen as easy-immediate pay-offs and ‘public problematic’. This understanding of a young person’s point of view is an important starting point in devising effective interventions. Injury is a leading cause of death and disability in young people¹⁸ (see Chapter 3.4.3), but evidence exists to prevent many of the injuries suffered by young people while they test the boundaries of their lives, particularly those due to adult behaviour or lack of designed-in safety. However some injury risks such as the risk of permanent hearing damage due to loud music at concerts) are more difficult to control without cultural change.¹⁹

| Recommendation |
|--|
| <p>Objective: To identify developmentally appropriate preventive and curative health care for children and young people at a common European level.</p> <p>Methods: Comparative studies of different models of child and adolescent health care and youth friendly services.</p> <p>Expected Impact: More effective intervention and health promotion for children and adolescents.</p> |

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3.1.3 Transition to Adulthood: Risk and Resilience

| | |
|------------------------|------------------------------|
| Knowledge gap + | Implementation gap ++ |
|------------------------|------------------------------|

Background

The transition from childhood to adulthood has a profound effect on late development and health; yet there is little known on how, and whether, to intervene to make these key times of transition smoother, and more health promoting for young people. The discipline of life-course research builds upon the notion of the cumulative effects of experiences and physical changes; and research into these transitions is primarily undertaken using longitudinal studies. The experience of physical and mental development and the social transitions from infancy to childhood to adolescence to adult life, all combine to become risk or protective factors for health. They can promote, or hinder, good physical, mental and emotional health and a stable sense of identity for the young person. The key transitions in this section of the life course give new opportunities and new risks with increased autonomy, new social exposures, and some physiological changes. Supporting resilience to these risks is an important aspect of preventive health.

Key issues

From the earliest ages, exposure to risks and the development of resilience takes place. Pre-schools, schools, peer groups and families all play a vital part in enabling a young person to develop greater well-being (see Chapter 3.1.4), emotional health, physical health and resilience to different experiences and life events. There is a particular interest in finding effective interventions to enable smooth and productive transition through the stages of childhood and into adulthood.

There is a need for greater information and research about the effects of experiences at pre-school and younger school ages (see Chapters 3.1.4; 3.7.1; 3.7.2). Some teenagers can be especially vulnerable to the changes and challenges of adolescence;^{1;2} this is particularly true for adolescents with chronic diseases or emotional or behavioural problems.¹ As a consequence, besides the normal risks, experiences and turning points of growing up, these individuals experience also disability-related risks and experiences that may increase the likelihood of negative outcomes. These negative outcomes include being the victim of bullying (see Chapter 3.3.2), or being rejected by classmates.¹ They also are more likely to perceive their school performance to be lower than average, feel more pressed to do homework, and to feel more frequently unhappy, lonely and sad.^{3;4}

Many studies also show that external assets such as a supportive family, school, peers, and community; and internal assets in the form of emotional and social competencies are important protective factors for well-being (see Chapter 3.1.4). These factors can moderate the impact of negative life events on well-being, and the aspects of resilience.⁵

Research is needed to understand the intergenerational effects of parental health-risk behaviours on adolescent health-risk behaviours. In other words: which factors contribute towards stopping adolescents from adopting risk behaviours: parents' protection, health education conducted by professionals or youth education carried out by youth, such as trainer programs that aim to prevent smoking, drug consumption, or prevent sexual diseases.

Wolf-Branigin et al.⁶ suggest the need for early interventions to improve vulnerable young people's attitude towards adult life and their current quality of life. Interventions should aim to build resilience from a perspective of strength. There is a rather unsubtle publication bias. Much of the emphasis in the published scientific literature identifies negative outcomes, and the beneficial effects of surmounting obstacles is not emphasised enough. This can prepare young people who may face severe difficulties in adulthood by increasing their ability to become self-sufficient. Additionally, programmes that empower disabled adolescents to gain skills to manage daily life, including employment, are needed.⁷⁻⁹

Recommendation

Objective: To identify effective interventions that reduce risk factors and increase protective factors for a successful transition to adulthood in young people with chronic illness, disability, mental health problems, or with other physical or social risk factors.

Methods: Linking survey data (for example from cross-sectional approaches such as HBSC or KIDSCREEN) to exposure variables (such as the social and psychosocial family environment, personal character and social support).

Expected Impact: More successful transition through childhood for people with chronic illness, disability or other physical or social factors.

The transition from school to work; the transition from parental home to independent life; and the transition from social interaction with peers to intimate relationships are important aspects of social development that occur in late childhood and early adulthood¹⁰. It is thought that structural factors such as national wealth, income equality and access to education are strong determinants for successful navigations of these transitions from childhood to adulthood. Within this context, supportive families, schools and good social relationships all seem to influence how a young person navigates the physical and mental changes, and the concomitant changes in social roles and expectations that occur during the teenage years.¹¹

Knowledge about the emotional and mental effects of these transitions is not extensive. We do not know how experiences as young children influence future adolescent health and development. Some evidence exists from the emerging literature on life-course research, but it needs to be continued, made more systematic, and expanded.¹² Evidence for effective supports to help young people navigate the changes in their bodies and lives also needs to be developed. The importance of

protective determinants of health, and positive experiences, is becoming clear in facilitating young people's healthy transition. However translating the findings into policy changes which reduce marginalisation of certain sections of the population, and thus create stability and nurturing in young people's home environments is not taking place. The effect of transition and physical, mental and social development on specific populations of children and young people needs exploration.

Recommendation

Objective: To evaluate awareness and availability of existing interventions which promote healthy development and well-being in young people among health professionals in the non-research sector and in the general population.

Methods: National or international surveys; Systematic review of literature.

Expected Impact: This will contribute towards increasing the availability of interventions that make life better for adolescents and provide extensive evidence to develop underlying interventions.

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3.1.4 Well-being and Mental Health

| | |
|--------------------------|-----------------------------|
| Knowledge gap +++ | Implementation gap + |
|--------------------------|-----------------------------|

Background

Well-being is a critically important health outcome. It is closely associated with mental health, which is “*the foundation for well-being and effective functioning for an individual and for a community*”.¹ Research evidence shows that a substantial proportion of mental health problems in adults originate early in life and that the circumstances of childhood and adolescence have long-lasting effects² (see Chapter 3.5.1). Health, of course, does not depend solely on the delivery of health care during illness, but should also take the influence of different settings into consideration³ and socio-economic or inequalities and disadvantage.⁴ The mental health of adolescents may be affected by difficulties in maintaining social relationships with peers, through the absence of a sense of belonging, rejection by peers, exposure to violence in the family (see Chapter 3.4.3) or a break in social relations.⁵ Therefore protecting mental health and well-being in children and in young people is a high priority issue for health promotion and disease prevention. Monitoring of both positive mental health and mental ill-health is essential for human development,^{6; 7} however current mental health research in children and young people lacks well-established indicators.

The overall level of mental well-being in Europe is high,⁸ and thus it is all the more important not to limit the research focus to observing patterns of mental health problems. Observing scientifically the *positive* mental health situation in children and young people is a valid and important act of prevention. Determining how it can be measured adequately in this population group to enable identification (screening) of those with good mental health vs. those who are at risk for poor mental health is an important task for the research community.

Key issues

Perhaps mainly due to better ascertainment, an increasing burden of mental health problems can be observed across all age groups (see Chapter 3.5.1). Assessing the mental health of children and young people is a promising strategy to detect negative developments, particularly in times of profound societal changes.⁹ Early detection of problem areas is crucial, and therefore, it is essential that monitoring systems are established based on sound indicators (see Chapter 3.7.2). The issue of well-being in children and young people is closely related to resilience (see Chapter 3.1.3), and

support from family (see Chapter 3.3.1); this includes support for parenting skills and the key idea of ‘good enough’ parenting, both major factors in children’s healthy mental upbringing. Schools, preschools, and other educational settings (see Chapter 3.3.2), and effective social participation (see Chapter 3.3.3) are also important arenas in a child’s life where well-being can be developed. A current EU Project is developing a Roadmap on mental health research in Europe (ROAMER) (www.roamer-mh.org/). Among its main goals are to describe the state-of-art in mental health and well-being research in Europe, and to analyse the gaps and achievements to establish priorities in research, including an analysis of the infrastructure and capacity requirements.

Well-being during adolescence can depend on successful integration into and acceptance by peer groups. In addition, throughout adolescence family relations play an important role, as teenagers need parental support. Negative relationships with parents and peers can lead to feelings of poor well-being, and unsatisfactory interpersonal relations may lead to loneliness and unhappiness.¹⁰

Recommendation

Objective: To assess the factors that contribute to positive mental health in children and young people in Europe.

Methods: Large and representative epidemiological studies on mental health in children and young people, especially cohort studies.

Expected Impact: Greater emphasis in the population of the importance of mental health and well-being in children and young people. Evidence to inform interventions leading to improved mental health in children and young people in Europe.

Development during adolescence involves risks and opportunities, which may affect mental health problems. Furthermore, if physical development seems out of pace with contemporaries, this may pose an additional challenge. The transition from childhood to adolescence is characterised by major biological, psychological, and social challenges and opportunities (see Chapter 3.1.3).¹¹

Indicators are important tools in measuring and monitoring health status in populations. Despite the importance of well-being, the development of positive mental health indicators for children and young people is still in its infancy.¹² At the present, indicator development is primarily “needs driven”, focusing on “illness” rather than “wellness”, and in consequence, aimed at physical rather than mental health.⁶ Furthermore, it is too focused on distress, and mental health problems, such as delinquency, suicide, depression,¹² rather than positive mental health. Surveys on positive mental health in children and young people in Europe are not as common as those focusing on mental health problems. This is in part a consequence of the misconceptualization of mental health being the absence of mental disorders.¹³ Well-known surveys include the KIDSCREEN-Survey¹⁴ and the international WHO Health Behaviour in School-aged Children (HBSC) Survey.¹⁵ The latter however

does not have a primary focus on mental health. Large and representative epidemiological studies in this area are rare,¹³ and existing surveys are often too focused on specific subgroups or risk factors.

There is a need to place more focus on younger children and the development and implementation of age-specific measurement tools that are moreover culturally-appropriate. Generally, younger children are underrepresented in reports. In order to develop child well-being indicators, Casas (2011) pleads for researches that internationally collect children's own views on their well-being. In order to develop child well-being indicators, Casas¹⁶ pleads for researches that internationally collect children's own views on their well-being. The application of existing instruments on younger children would require them to undergo further validation. Generally, very young and young children are underrepresented in international data sources, and "a portrait of positive well-being among young children is not available, and in many cases, measures are lacking that are appropriate for their age".¹⁷ This implies that many indicators are adolescent-focused and hence may point attention to matters relevant for adolescents which may be quite different from those that are essential for children.¹⁸

| Recommendation |
|---|
| <p>Objective: To develop indicators of well-being (for all age groups, especially younger children).</p> <p>Methods: Development of cross-culturally valid measurement tools, especially for younger children (below the age of 8 years).</p> <p>Expected Impact: Effective indicators will facilitate international comparisons that will provide valuable information about well-being in Europe's children, leading to better identification of areas needing support to improve children's well-being. In addition, measuring well-being internationally will lead to greater acknowledgement of the importance of well-being in young people.</p> |

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3.2 Socioeconomic and Cultural Factors

3.2.1 Inequity and Inequality

| | |
|-----------------|------------------------|
| Knowledge gap + | Implementation gap +++ |
|-----------------|------------------------|

Background

Poverty has been described as one of the greatest threats to health, because of the range of risks to which it exposes children and young people.^{1;2} In all countries, poverty and low socioeconomic status are important determinants of health, either directly or indirectly.³ The risk of having unmet basic needs, such as healthy housing, safe drinking water, sanitation, nutrition, education and health care is greatly increased by poverty. Closely related to this are exposures resulting from environmental pollution (see Chapter 3.4.1), adverse societal health-related behaviour, deprivation of parental care and discrimination, which are additional risks to which children and young people living in poverty are likely to be exposed.⁴ Poverty and social exclusion also increase the risk of divorce and separation (see Chapter 3.3.1), disability, illness, injuries (see Chapter 3.4.3) addiction (see Chapter 3.1.2) and social isolation – and vice versa.

Thus, poverty has a particularly profound impact on child health and well-being due to the child's high vulnerability to its consequences. Children and young people are more likely than the rest of the population to live in poverty, and some children, such as those living in single parent households or in households with no working adult, are at increased risk.²

Roma and traveller children make one of the most vulnerable groups since they cumulate several dimensions of poverty in addition to being victims of discrimination in various life circumstances. Infant and child mortality rates as well as incidence of several diseases are higher among both of these groups than in the general population.^{3;5}

While overall health is better than ever there are marked inequalities in health in most European countries.⁶ Despite little comparability in the ways in which countries measure inequalities and inequities in health it is recognised that these inequalities form a gradient, in which health becomes worse the lower down the socioeconomic scale a child is placed. There is a large body of evidence that associates increased health risks with disadvantaged social circumstances.⁷ Evidence of social inequalities in infant and child mortality is reported from many countries (Netherlands, United Kingdom, the Nordic countries, Belgium, Hungary from example) and tends to be consistent^{3;8}. In terms of morbidity, according to a survey from the United Kingdom, household income is an apparent social gradient in all forms of mental health problems in young children, except for autism.⁹ Similarly, studies from Germany, Sweden and the United Kingdom show that the incidence of asthma is reported to be higher among children and young people from lower-income

households.³ In cases where there are improvements in national rates of mortality or morbidity, such as in the incidence of under 5 mortality, there may still be “*large and persistent inequalities*”.¹⁰ The 2009/2010 HBSC study also found that there were inequalities in health outcomes, such as obesity and overweight (see Chapter 3.5.3) or smoking rates (see Chapter 3.1.2), between the richer and poorer nations of Europe.¹¹

Key issues

An unequal society can impact upon children and young people in a number of ways, but essentially, it is the health outcome gap caused by unequal societies that is of most concern here. This health outcome gap has been identified by research, but effective policies to reduce the gap or to provide evidence-based interventions to aid those children and young people at the mercy of inequity and inequality are still needed. Policies exist that aim to level up the gradient of inequity, but these are in need of robust evaluation. It seems that it is access to services, and differential quality of services, that is at the heart of much of the inequity. Setting standards in the EU for access and quality is an on-going activity, but there is a severe lack of evidence about effective interventions.

Recommendation

Objective: To identify the most effective policies and health interventions to reduce the health outcomes gap in the most vulnerable children and young people.

Methods: Research to focus on mechanisms of social inequalities and health and describing trajectories of poverty in relation to health outcomes.

Expected Impact: Reduction in the outcome gradient of health in European societies, and an improvement in health and well-being for the poorest and most disadvantaged children and young people in the European Union.

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3.2.2 Groups Identified as Having Research Needs

Certain population groups of children and young people were identified by the RICHE project as being in particular need of research attention. These groups either face challenges which are under-researched, or have considerably poorer health outlooks than the majority of the European population.

3.2.2.1 Health of Migrant Children and Children in Migrant Families

| | |
|------------------------|------------------------------|
| Knowledge gap + | Implementation gap ++ |
|------------------------|------------------------------|

Background

Free movement of people within the EU is one of the pillars of the European Union, a policy that has created a European zone where people can move more or less freely from one country to another. The result of this has been a net migration of people from the less affluent to the more affluent countries. In addition, the open borders within the EU, and the joint outer border of this zone, has created a need also for a harmonisation of policies for immigration people from outside of the EU territory. This is particularly relevant for asylum policies for the 30,000-40,000 asylum seekers who arrive in Europe annually, one third of whom are under the age of 18. The growing influx of unaccompanied minors is a particularly significant issue for child health and welfare. A number of European Union policies bear on migration, but reception policies have so far remained a national policy issue, often hotly debated within countries. This reception policy usually includes some kind of health examination, sometimes voluntary, sometimes compulsory. This examination varies greatly with respect to mental health issues for children and young people. Migration and its effects on health are truly European issues, with significant diversity within a shared European core.

The generalizability of research into specific migrant populations is limited by the importance of national context. However, European studies that compare similar migrant populations in different national contexts have a unique potential to study the impact of a national policy. There is also a shared interest in the health situation of recently arrived migrant populations and how their health needs can be met.

Key issues

Risks to health and well-being associated with migration are particularly significant for recently settled refugee populations and undocumented migrants, although there are many issues for legal migrants as well. These risks include mental health problems (see Chapter 3.5.1),¹ limited access to services for all aspects of health care (see Chapters 3.6.1, 3.6.2),²⁻⁴ and the effects of poverty (see Chapter 3.2.1) that might lead to problems with drug abuse or other threats to health (see Chapter 3.1.2).^{5,6} Reducing these threats to health for recently arrived migrants and for established migrant communities who remain at a disadvantage in terms of children's health is a pressing need for European society.

Recommendation

Objective: To identify the most effective reception programmes for refugees / asylum seekers and integration policies across countries for migrant groups with respect to child health outcomes.

Methods: Comparative multidisciplinary policy studies and association between a variety of main child health outcomes (disability, mental health, chronic disease prevalence, perceived well-being) and exposure to diverse policy environments in refugee / asylum seeking children.

Expected Impact: Improved awareness about health impact of integration and reception policies; higher chance of implementation of effective policies and a resulting reduction of the existing gap in health outcomes leading to better health of migrant children and children in migrant families.

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3.2.2.2 Children in the Care System

| | |
|------------------------|------------------------------|
| Knowledge gap + | Implementation gap ++ |
|------------------------|------------------------------|

Background

At the start of the Millennium, in many European countries around 3 to 4% of children and young people aged under 18 years, had spent some time under the care of child welfare services.¹ In a 2009 EUROCHILD survey² reported that around 1% of children and young people are taken into public care across the European Union, approximately 1 million children. EUROCHILD found that the percentage varies across countries with the largest percentages reported by Latvia (around 2.2%) and the smallest by Sweden (0.7%). Aside from the death of one or both parents, poverty is a significant risk factor for children and young people being transferred to state care, along with other social factors, such as single parenthood and unemployment.³

The form of welfare services for children and young people differs greatly across Europe. All EU countries uphold the recommendation that residential care should be the last resort for any child, and should be considered only after all other family based and alternative foster care options fail. The Working Group on Children at Risk and in Care⁴ identified three distinct categories of child placement in residential care: countries with high rates of child residential care coupled with large institutions (Central and Eastern Europe), where it is thought that between 5-20 per 1000 children are in residential care; countries with low rate of residential care and large institutions (South Eastern Europe) where around 1-3 per 1000 children are in residential care; and countries where the process of de-institutionalisation, prevention and alternative care has already taken place, albeit in varying degree (the more affluent European countries). A key factor leading to a high number of children in care is the abandonment of children under the age of three by their primary care-givers. As Browne et al⁵ state, more children in Central and Eastern Europe (for example Romania and Hungary) and the Baltic countries (for example Latvia) are placed in institutional care due to early age abandonment, while Western countries such Denmark, Norway and the United Kingdom report child abandonment as being a rare event. Slovakia had the highest number of children abandoned under the age of three (4.9 per 1,000 live births), followed by the Czech Republic (4.1 per 1,000 live births), Latvia (3.9 per 1,000 live births) and Poland (3.7 per 1,000 live births).⁶ However, these figures may not show the true picture, as the majority of countries were found not to keep national records of the number of children aged 0-3 years abandoned at maternity units.

Other countries, such as Italy and Malta continue to struggle with reducing the proportion of children and young people in residential care, compared to family foster care,^{7;8} despite the fact they have well established support systems for families in poverty. New child protection legislation in countries accessing the European Union saw the proportion of family foster care increase, for example in Romania by 35%, where 195 institutions, housing more than 150 children and young

people each were closed.^{2; 9} In spite of the changes, institutionalisation and child abandonment remains an unresolved problem in several countries such as Romania, Greece, and Portugal where there are severe economic difficulties.^{7; 10; 11}

Key issues

Statistical research has found that in the midst of the current economic crises in several European countries, the number of children and young people in need of foster care is increasing in spite of the reforms in child welfare.^{2; 10; 12} A particular concern is the issue of children abandoned at a young age, under the age of three years.^{2; 6} These children are at risk of difficulties in their emotional and behavioural development¹³ (see Chapters 3.1.3, 4.1.4). Another important issue is the proportion of children and young people with disabilities (see Chapter 3.5.4) and those belonging to ethnic minorities (especially Roma) who are taken in different forms of care² (see Chapter 3.2.2.1, 3.2.2.3). Children and young people in care often have much poorer physical and mental health than their contemporaries, a situation which needs to be addressed in the European Union. As the Council of Europe¹⁴ stated in its recommendations for children in care, priority should be given to the physical and mental health of the child and his or her full, harmonious development as the essential conditions for the success of the care plan.

Recommendation

Objective: To collect data on the demographics, and the specific, needs of children at risk of abandonment by parents, and of children and young people taken into care. The data should cover the needs of health and mental health services to parents and children before family disruption.

Methods: Systematic demographic data collection across Europe

Expected Impact: Better data will help service development that will improve the health, mental health and early child development services for families and children at risk of disruption.

As start above children and young people in state care are at greater risk of suffering poorer physical and mental health than their contemporaries who are not in care. They may have experienced family violence, physical abuse, sexual exploitation, parental addiction and/or long-term neglect in their birth home (see Chapter 3.3.1.1).^{15; 16} Reports from many countries also give evidence that these same children and young people are at particular risk of being maltreated in the foster homes and institutions where they are placed by child protection services.¹⁷ Studies from the United States indicate that 60% of foster children have a medical condition, and 20% have at least three medical conditions.¹⁶ The situation in Europe is not well investigated, but reports from Spain suggest that children's experiences here are similar.^{15; 18} Children entering foster and residential care often lack immunisations and other preventive child health measures, due to parental neglect or an unstable housing situation (see Chapter 3.7).^{15; 16} Dental health is often poor and early contact with dentist unsatisfactory.^{15; 16}

Recommendation

Objective: To collect data on health, including mental health of children and young people in all forms of foster care (both family and residential foster care). To combine data about children and young people in care in Europe from multiple countries to enable more comprehensive information about the health status of children in care in Europe.

Methods: Combine data from various sources including clinical data, educational data, etc.

Expected Impact: Greater knowledge about the health status of children in care will highlight this population's health vulnerabilities and stimulate the development of specific interventions to improve children and young people's health in this cohort.

Studies in the United Kingdom, United States and Spain demonstrate that around half of foster children have some form of psychiatric disorder.¹⁹⁻²¹ Behavioural disorders are the most common mental health problems, but affective disorders, anxiety and attention deficit hyperactivity disorder (ADHD) are also common.^{19; 21} Suicide and suicide attempts have been found to be three to four times more common in young Swedish adults with an upbringing/ in foster care^{22; 23} than in young adults brought up in a their own family. The aetiology of this high morbidity is to be found in a complex web of risk factors related to the care itself and exposures to risk factors before entering care(see Chapter 3.5.1).^{15; 16}

Recommendation

Objective: To identify the best practices and policies for the most vulnerable children and young people in the child care system using a health perspective. Mental health and well-being would be the main health concerns in such a study, but reproductive health, substance abuse and sexually transmitted disorders also need to be addressed.

Methods: Comparative research of the forms and quality of care within Europe.

Expected Impact: Identification of best practices will lead to better planning and targeting of services. This will lead to the improvement in the health of children taken in care and better outcomes for such children.

Many studies have demonstrated that foster children tend to be low achievers in school, and are at high risk of entering adulthood with a low level of education.²⁴⁻²⁶ Recent Swedish studies have shown the close connection of school failure to health problems in young adulthood in former foster children, and the preventive potential of addressing these learning problems effectively²⁷ (see Chapter 3.3.2).

Recommendation

Objective: To evaluate the content of care to show the circumstances under which optimal educational outcomes can be achieved for children and young people.

Methods: Longitudinal studies, intervention studies.

Expected Impact: Improved future prospects and future health for this cohort of children and young people.

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3.2.2.3 Children from Minority Population Groups

| | |
|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Europe's largest minority is the Roma population, which continue to be subject to widespread discrimination in many parts of Europe, with child health outcomes often much worse than those in the majority population.¹ The Roma children are minority children in every society in Europe, but taken together they make up a large population of several million children (according to current estimates, around 5 million children – a population similar in size to that of Nordic children. Roma children are typical of most vulnerable categories, since their condition includes many dimensions of poverty (for example poor housing, low education, or impaired nutrition). Travellers in Ireland face similar challenges.²

Children from other ethnic minorities, including recent immigrants also face difficulties. For example, in England and Wales, the risk of admission to paediatric intensive care units and mortality rates among children admitted to hospital are far higher in children from minorities (1.4 vs.1.0 per 1,000 and 7.1% vs. 4.9%, respectively) even after controlling for socio-economic status.³

Key issues

Roma children represent a category of children with multiple risks, since their situation includes many dimensions of poverty (for example poor housing, low education, impaired nutrition), the implications of belonging to a minority (such as discrimination or exploitation), and, in some cases, those of an irregular legal status. As a consequence, Roma children show much higher infant and child mortality rates, poorer perinatal health (higher rates of preterm birth, low-birth weight , and intra-uterine growth restriction) and increased risk for communicable diseases and injuries.^{1; 4; 5}

Recommendation

Objective: To improve the knowledge and understanding of health issues and their determinants in Roma children and other minority groups.

Methods: A Europe-wide survey on the health and development of Roma children and other minorities, through an adequate sample of different groups and countries so to be able to capture differences in both health and development outcomes and the factors influencing them.

Expected Impact: Improved health and development among children from minority population groups. Increased awareness and involvement of Roma people about their children's health and development.

There are important differences among minority groups, however, depending on their overall living conditions and country of residence, which need to be better known and investigated as well as the

most effective policies and interventions to improve their health, overcoming the many difficulties inherent in the work with minority groups.⁶ Depending on the legislation in the country of residence, and prevailing social attitudes, minority children may be subjected to discrimination based on their nationality, their gender, health status or religion. Failure to enact policies that support disadvantaged children and young people and their families particularly in the earliest years has long lasting consequences; missed opportunities to interrupt the accumulation of disadvantage through the life course and arrest its trans-generational transmission.

Recommendation

Objective: To identify policies and specific health interventions to reduce the health outcomes gap in children from minority population groups and to propose implementation strategies for these.

Methods: A systematic review and assessment of country policies and intervention addressing the health of children from Roma and other minority groups, and identifying the most effective policy mix and interventions models. Review should be complements by participatory research to be conducted with minority groups.

Expected Impact: Improved health and development among children from minority population groups. Improved harmonisation of policies towards minority groups across Europe.

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3.3 Social and Community Networks

3.3.1 The Family in the 21st Century

| | |
|------------------|------------------------|
| Knowledge gap ++ | Implementation gap +++ |
|------------------|------------------------|

Background

The family is recognised as the primary unit within which children grow up, develop and learn how to function in the world. The family is where a child is imbued with a set of habits, behavioural influences, cultural attitudes and lifestyle that can persist throughout life. A child's self-esteem grows as he or she is loved and cared for and feels they are part of an important social unit.¹ Conversely, the family can also be the site of risk factors for poor health and well-being – for example where there is domestic violence (see Chapter 3.3.1.1), anti-social messages or poor health behaviour; and also in the form of living in a fragile family – one which is defined by poverty (see Chapter 3.2.1), a stressed parent or caregiver, or enduring disability or illness where the child has to take on a carer's role (see Chapter 3.1.4). The influence of parents on their children is subtle and changing, particularly during adolescence when young people strive for independence. However, children and adolescents are still strongly influenced by the culture of the family and advice from their parents.

There is a great deal that research does not know about the family. This includes how to provide effective interventions to provide better experiences for children and young people within the context of the family. This can be for a number of reasons, not least because the family is a private space and there is considerable stigma in 'interfering' with family life. Key needs for research into the modern, changing family are the effect of new family structures on children, widespread evaluation and implementation of parenting programmes for all ages, and families that are lost to services for a number of reasons, for example poverty or struggles with addiction.

Key issues

Family composition varies considerably among member states. Parental separation and subsequent single parenting and step families have become increasingly common in northern Europe, whereas marriages are more stable in some countries in southern Europe, such as Greece and Italy.² There is tension in that social and public policy does not adequately reflect the vast changes that have taken place in family structure in the past few years. Single-parent families, separated families, joined families, 'sandwich' families (where the parents care for elderly relatives as well as young children), same sex parents, children adopted from overseas are but a few of the increasingly common family structures that exist.¹ A new solution to the increasing rates of divorce in Nordic countries has been alternating homes, where children change homes between parents a weekly basis. The

consequences of these new forms of family life and parenting have not been investigated consistently or at all in some cases – for example, we know the potential effects upon children after a divorce but not about the effects of growing up in a same sex family.

Recommendation

Objective: To explore the diversity of family structures to elucidate the consequences of different family types or forms on children’s well-being

Methods: International and national surveys.

Expected Impact: Focused interventions to help children cope with change and foster resilience. Improved family relationships bringing benefit to children’s physical and mental health.

As a fundamental aspect of the family and its influence on a child’s life and development, parenting has profound effects on children’s health and wellbeing.^{3; 4} The importance of parenting and a nurturing family life on a child’s development is demonstrated by the currently running EU project “Healthy Children in Healthy Families” (www.healthy-children.eu). The type of parenting style adopted by parents has been shown to have an effect on the outcome for the child – it is what helps a child to develop coping skills that increase resilience to life’s problems (see Chapter 3.1.3), or can place children at risk of a number of poor outcomes (see Chapters 3.1.2, 3.1.4, 3.3.1.1).³ Four very broad styles of parenting have been described by researchers – the authoritative parenting style – where the parents are in authority over the children, yet do not restrict the child’s autonomy unduly; the authoritarian parenting style – where strict parenting does not allow for much communication with children and is often combined with strong punishment methods; the permissive-indulgent parenting style is one of high levels of warmth and nurturance, but very little control over the child’s behaviour and little monitoring of their activities; and finally the permissive-neglectful parenting style, which is characterised by low control over the children and low responsiveness, this is sometimes known as ‘uninvolved parenting’.⁴ The general consensus in the literature is that the authoritative parenting style tends to be the most successful in generating positive outcomes for the children, although of course, parenting is an art that needs to respond individually to each child and each family circumstance.

The concept of ‘good enough parenting’ is well known in research, and is based upon a number of assumptions, the main one being that parents do not have to be perfect (in fact they should not be perfect) in order to successfully bring up their children.³ There is a multitude of factors that combine to increase confidence in an individual’s parenting skills – in general these combine elements of the parents themselves, such as genetic and environmental origins, personality and psychological makeup; the characteristics and situation of the child, and the wider environment – for example a stressful environment of poverty (see Chapter 3.2.1) or violence (see Chapters 3.4.1, 3.4.3, 3.4.3.1) increases the challenge of successful parenting.³ In cases where parents do not find it easy to parent

children, or who do not have good role models to base parenting behaviour upon, parenting programmes can be of benefit.

There is considerable evidence to suggest that parenting programmes, both before a child is born³ and while a child is growing up can have beneficial effects on a number of outcomes. These include family functioning and healthy family relationships,^{5;6} improved behaviour in the children,⁷ improved coping for families of children with chronic disease or conditions,⁸ and greater confidence of parents in their own abilities.^{5;6} These positive outcomes generally lead to improved wellbeing of the family and the individuals within the family. There are a number of parenting programmes in existence – for example the Incredible Years, Stepping Stones Triple P and Strengthening Families Strengthening Communities programmes⁹ and the Mellow Parenting programme.¹⁰ Some of which have been evaluated in terms of outcome for children and families.¹¹ However, there is a need for greater implementation of these programmes across the European Union.

Recommendation

Objective: To evaluate parenting programmes across the European Union in order to implement successful interventions throughout Europe.

Methods: Evaluation of existing parenting programmes in a variety of circumstances, such as in deprived communities, families with children with chronic disease and in fragile families. Review of results of evaluations.

Expected Impact: An increased use of parenting programme interventions will support parents and help to improve the environments of children across Europe. This will lead to better health and social outcomes for the children of Europe.

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3.3.1.1 Child Maltreatment

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|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Child maltreatment is a major public health and social-welfare problem in Europe. Exposure to multiple types and repeated episodes of maltreatment is associated with increased risks of physical injuries and psychological consequences (see Chapter 3.5.1). Child maltreatment substantially contributes to child mortality and morbidity and has long lasting effects on mental health, drug and alcohol misuse, risky sexual behaviour, obesity, and criminal behaviour, which persist into adulthood. Psychological maltreatment and neglect are both difficult to identify and research and treat and at least as damaging as physical or sexual abuse in the long term but have received little scientific and public attention.¹ Another closely related issue is the connection of gender with safety from violence, and in particular violence towards girls with disability (See Chapter 3.5.4).²

Maltreatment can have serious consequences for a child's mental health (see Chapters 3.1.4, 3.5.1), causing a range of adverse outcomes, such as poor emotional well-being, self-harm, suicide ideation, delinquent behaviour and more^{3;4}. What is more, the mental consequences of maltreatment increase with the number of different abuse types that children and young people have experienced and appear to be cumulative over time, increasing with age.⁴

Maltreatment occurs in other environments, such as in schools, and institutional or religious settings, and may take the form of abuse and child trafficking;⁵ but it is within the family that the

majority of maltreatment takes place.⁶ Research has identified some of the factors that contribute to the risk of child maltreatment⁷ but there remains a considerable gap in our knowledge of the extent to which children suffer maltreatment in the family environment and the development of effective interventions to prevent this, and to help children who are maltreated. Key issues in this area of research need are: a lack of knowledge about the extent of the problem, and a lack of proven interventions to help families and protect children.

Key issues

A systematic review in the United Kingdom estimated that only around one in 30 children who were physically abused by parents were known to child protection services.⁸ Measurement of all forms of abuse largely relies on retrospective self-report studies of episodes that are recalled years later by adolescents or adults; and very few studies have examined the prevalence of psychological abuse. Self-reports and parent reports are probably closer to the true, unobserved rate of maltreatment than are official reports to agencies; there are ten-fold higher rates reported by victims or parents than by child protection agencies.⁹

Barriers to effective measurement of maltreatment include the ethical concerns raised by an obligation to respect a child or parent's confidentiality, while having an obligation to report abuse to child protection services.⁴ In addition, research with children about parental maltreatment has to face issues about parental consent. It is unethical not to tell parents and children the real aim of the research, and it is unethical not to inform them of the safety issues, and the obligation on researchers to report abuse. As parents can make choices of their own participation in research on parenting issues, but can also decide dependent children's participation, sampling in prevalence studies will always be biased, by automatically excluding those who are aware of abusive parenting. There is a real need to balance the rights of children not to be traumatised by researchers and kept safe within the family environment; and their rights to talk to researchers or others about their experiences.¹⁰ If we take children's rights to participation in research seriously, then we have to question parents' role as gatekeepers.

There are very few international comparative studies that identify higher rates or lower rates of maltreatment within the European Union, and the relationship if any, to national policies and national cultural contexts.¹¹ National survey data from the UK and Romania show that physical discipline of children has declined significantly in the last decade. Nevertheless, abusive physical discipline and neglect is reported by both children and parents despite positive parenting.^{4;12} The International Dating Violence Study,¹³ which contains data from 32 countries, confirmed that the greater the approval or acceptance of violence in a society, the greater the percentage of parents who hit children to correct misbehaviour. One of the first steps in improving information is to find a European common ground in terms of definitions, and then to transform these definitions into

survey questions. Once these questions are piloted in diverse European contexts, a European-wide survey can be carried out.

Recommendation

Objective: To improve data about the incidence and prevalence of child maltreatment in Europe. In addition to explore the differences in rates of child maltreatment across Europe and their relation to national policies.

Methods: A European survey of school children, young adults and parents, possibly with the addition of a European surveillance system of child maltreatment with data collection from alternative data sources to administrative data.

Expected Impact: Greater likelihood of developing effective prevention strategies. Surveillance and improved data would by itself serve as an instrument for change.

The family is inextricably linked to the context in which it exists. Cultural, economic, community and societal factors influence how the family functions and to a great extent its structure (see Chapter 3.3.1. The community is in one respect the sum of the families that live within it. The relationship between wider social support and social capital and the family is one that is of interest to researchers.¹⁴⁻¹⁶ It has been found that injury prevention, for example, is most effective when changes are made by parents and in the household (see Chapter 3.4.3). However, many of these changes are difficult, or impossible, to achieve without broader environmental change.¹⁷

A particular challenge in comparative studies of child maltreatment is that what should be considered abusive and/or neglectful parenting may vary between different sociocultural contexts. The Balkan Epidemiologic study collected and examined child maltreatment and parenting practice in eight Balkan countries. The study found that despite the European focus on child protection and the prevention of abuse, and a ban on physical punishment in most European countries; children commonly experienced poor and violent parenting practices. Around a third of children reported neglect; approximately three quarters reported psychological abuse and around two-thirds experienced physical discipline in the family.¹⁸ This situation is one that must change. Seeking to establish a national and international understanding of what consists of maltreatment or abuse of children and what is 'good enough' parenting as opposed to poor parenting is an important step in improving the family environment in order to protect children. At present, however, we do not know enough about what interventions, including parenting interventions will be effective in helping families and children who we know are at risk or are experiencing maltreatment.

Recommendation

Objective: To identify how to best implement the evidence we have about how to help families and children at risk of maltreatment. To establish what kinds of interventions to prevent child maltreatment are successful in European contexts specifically, for example, in cases of abuse, domestic violence and so on.

Methods: Evaluation of existing parenting programmes Development and evaluation of interventions to prevent domestic violence, increase resilience to stress and cope with specific issues such as addiction. Evaluation of existing interventions in terms of reducing risk of maltreatment of children.

Expected Impact: A safer and more secure family environment for children and adults; which in turn increases well-being, and family and community cohesion.

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3.3.2 Education and School

| | |
|-------------------------|-------------------------------|
| Knowledge gap ++ | Implementation gap +++ |
|-------------------------|-------------------------------|

Background

School is an important environment because it is where children and young people spend much of their time, and it is a place which has profound influences on behaviour and culture. Beyond academic learning, school is where the majority of young people in Europe learn to socialise (both face to face and digitally), to form friendships, and develop social capital (See Chapters 3.1.4, 3.3.3, 3.4.2). Learning from successful interventions that take place in schools and adopting them on a European scale is an important step to maximise the health of children in school, and contributing to education about healthy lifestyles and choices. As the World Health Organization Europe¹ states, modern education seeks to equip children and young people not only with academic achievements, but also the tools to cope with stress and other factors that can lead to health problems.

In addition there is a need for health researchers to be able to access the rich data about children that is held by schools and the education system. A devastating problem regarding schooling is school failure and drop out, first because it decreases the level of schooling in the next generation, secondly because it is overall related to various health compromising behaviours, third because it is

a source of low perception of self-worth and well-being.² Also bullying is a predominantly school-based problem that has profound implications for the children involved in the present and in the future; in addition, there is little known about the present and future health effects of truancy and school refusal (see Chapters 3.4.3, 3.4.2).

Key issues

Schools are the venue of many interventions for children, and many believe that promoting school achievement and creating a positive school environment is vital to break the unhealthy cycle of *“Poverty – social exclusion – school failure – health compromising behaviours – school dropout – under or unemployment – social exclusion – poverty”* that many young people find themselves in, particularly individuals from disadvantaged backgrounds (see Chapter 3.2.1) or migrant families (see Chapters 3.2.2.1 and 3.2.2.3).¹ There is a large volume of research and research evidence and evaluation of interventions in schools for a large variety of topics: these include anti-obesity schemes, healthy living programmes, dietary advice, physical activity programmes, peer education, and many more. Indeed, Currie et al.³ found that health services for adolescents are more effective when school health services, health promoting schools and youth friendly health services are linked. Nevertheless, implementation of these preventive schemes in a systematic and comprehensive way is not taking place across Europe. There is a need for research to identify and address the barriers to using interventions successfully in schools.

Recommendation

Objective: To establish how to implement existing evidence and interventions that are currently used in the school and education environment.

Methods: Surveys of children and young people. Evaluation of interventions in the school environment by young people. Coordination of results and roll out of implementations.

Expected Impact: This will provide tools for personal improvement of health and the fulfilment of the school’s role as an educator and facilitator of healthy behaviour and health outcomes. The resulting improvement of the present and future health, well-being and resilience of all children, including those from disadvantaged groups will benefit European society as a whole.

In terms of risk factors, bullying in schools is recognised as an important risk factor for present and future poor health and social outcomes. There is still relatively little research into why bullying develops and the social context of bullying, although one study identified the need for prevention among schoolchildren in the early years.⁴ Research has identified social support as being important in ameliorating the adverse consequences of bullying on educational achievement and mental health of the bullying victim, however family and social support alone was not effective without support from the school.⁵ Cyberbullying is a phenomenon closely related to traditional forms of bullying, increasingly used to intimidate young people, and is of considerable concern⁶ (see Chapter 3.4.2).

There are a number of interventions to prevent and stop bullying, e.g. establishing an ombudsman for bullying in one county of Norway, which, if successful may become a national scheme;⁷ the Zero program,⁸ the Finnish KiVa antibullying program,⁹ and the Olweus Bullying Prevention Program.¹⁰ However, there is no systematic or comprehensive implementation of such interventions across Europe. The HBSC surveys have clearly demonstrated that the rates of bullying in school children differ greatly between the participating countries, but the reasons behind these variations are not well studied.

Recommendation

Objective: To explore the diversity in Europe of bullying rates and national policies to address the issue.

Methods: Comparative research between member states to identify successful interventions in European contexts, and how they can be implemented. Specific situations need to be addressed, particularly bullying

Expected Impact: A reduction in bullying, improvement in well-being, community cohesion, and educational and social outcomes will benefit all children in Europe.

The right to education applies to all groups of children, including disabled children. Policies concerning inclusive education worldwide use different definitions of “disability”. In some countries disability is viewed as a medical-based term, while in others it is a social-based one, or a combination of both. Data collection on the difficulties experienced by children and adolescents with special needs and with disability in school requires a multidisciplinary approach because different sources of information, including medical, psycho-social and education, need to be collated in a single profile of functioning.¹¹ At present this is compromised by the lack of an accepted, universal definition of disability. Although there is evidence on the educational developmental effects of inclusive education, there is comparatively little evidence about the effects on the physical and mental health of disabled children in mainstream school. This is perhaps because of a lack of training of child welfare workers in disability, specifically in identifying children with disabilities. Use of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) could assist as a guide to organize data management in a multidisciplinary team.

Recommendation

Objective: To establish how to implement evidence and interventions that we already have in the school and education environment. Research needs to be undertaken into school and educational systems, and how they respond to children's special educational needs.

Methods: Close collaboration between the education sector and the health sector.

Expected Impact: Improvement in educational attainment and participation for children and young people with specific issues – such as learning difficulties, physical impairments, chronic illness and disability.

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3.3.3 Community Involvement

| | |
|------------------------|------------------------------|
| Knowledge gap + | Implementation gap ++ |
|------------------------|------------------------------|

Background

Young people are a critical and beneficial resource of any society, and should not be regarded as a burden.¹ However, in Europe's ageing and increasingly gerontocratic society, it is becoming harder for children and young people, particularly adolescents, to combat negative stereotyping by the media for example. The older generation hold the power, and outnumber the young in many communities. It is particularly difficult for young people living in deprived communities, and young people from vulnerable population groups (see Chapter 3.2.2.3) where there are few if any facilities for young people to mix socially. Community participation is closely linked to social capital and well-being, and also involves online social networking – which can be seen as part of the solution, as well as a potential danger (see Chapter 3.4.2).

Children and adolescents who are environmentally active, volunteer in community or political organisations, and who commit smaller pro social acts such as helping someone carry their groceries, actively improve their homes, communities, schools, and the society they live in² (see Chapter 3.1.4). Such positive citizenship promotes healthy psychological, social, and intellectual growth for the young person by increasing an adolescent's sense of control and self-efficacy; and also provides needed services to a community (see Chapter 3.1.4). These aspects increase protective factors against poor individual and community health.³ Matos and Sampaio⁴ aimed to foster inter-generational dialogue and collaboration between ages in community issues with the aim of promoting social cohesion and well-being, but there is still much to be done. However, we know very little about how to promote community involvement, and what interventions are successful in including children and young people as active members of society.

Key issues

There is a lack of understanding as to why some young people participate in civic life while others do not; when they are more likely to participate and in which arenas.⁵ The mechanisms that influence the decision to participate in community life have yet to be studied. Work with other vulnerable groups has echoes for youth participation, for example, Verdonschot et al.⁶ found that good social and family support, positive attitudes towards this population and a variety of facilities encouraged participation by individuals with intellectual disability; conversely a lack of transport and not feeling accepted by the rest of the community were deterrents. The role of family, peers, and school needs to be investigated for better understanding of what stimulates or prevents young people in particular from participating in their local community. Nevertheless, there is a knowledge gap about how to increase community involvement and participation for children and young people, in particular those from poor and vulnerable populations.

Recommendation

Objective: To improve knowledge about the mechanisms that may influence greater participation of children and adolescents to community and social life.

Methods: Specific target groups may be addressed, such as those living in low socio-economic areas, young people with specific chronic conditions such as disabilities, migrant populations and other special groups.

Expected Impact: Empowerment of marginalised children and young people as a valuable part of society; greater cohesion and appreciation of issues pertinent to all age groups in society. A possible reduction in marginalisation of certain populations and in social exclusion.

Some work has been carried out to establish ways in which youth participation can be achieved in policy making, using young people's terms of reference and the ability to develop responses to issues that most concern them which found that there is a gap between young people's 'lived realities' and older generations' understanding of their needs.⁷ However, limited methods of consultation and a lack of people with a designated responsibility for ensuring young people's participation remains a serious obstacle to genuine community involvement for Europe's young population.⁸ It is not known how family, social and economic status (such as poverty, living with a disability, or living in a violent or crime-prone area) influence the decision for community participation and engagement. This means that the creation of targeted policies to encourage specific social groups is unlikely to be evidence-based. It is as yet unclear what happens during policy making on youth issues; and whether local, regional or national policies are the most effective in increasing access to information on services for young people.

Recommendation

Objective: To enhance the participation of young people in community activities, and to support young people to build positive social networks, using traditional and digital social networking methods.

Methods: Research on the existence and supporting factors for community, volunteering and activism among young people; Intervention studies to increase these activities.

Expected Impact: This knowledge is likely to promote the importance of participation among youth and increased value of their contribution among other members of society.

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3.4 Environment

3.4.1 Physical Environment

| | |
|------------------|------------------------|
| Knowledge gap ++ | Implementation gap +++ |
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Background

Children are entitled to grow and live in healthy environments. The physical environment has a profound effect on their future, not only in a physical and developmental sense, but also in terms of being supported by a healthy community (see Chapter 3.3.3, 3.4.3.1). Environmental health is an important cross-sectoral issue, especially because of its comprehensive nature, its impact on quality of life, its diversity and far reaching consequences, in particular for vulnerable and at-risk groups.¹ In order to protect the health of future generations, specific information is needed about exposures to unhealthy environments, high risk communities, and successful interventions to protect children and young people.

Key issues

Increasing urbanisation, the introduction of new technologies, industrialisation in developing countries, ecosystem degradation, and the consequences of climate change are changing the environment in which children live. Children, especially during early years of life, are highly vulnerable and may be more exposed than adults to many environmental factors for a number of reasons.² Their organs are still growing and developing, and environmental factors and toxicants thus exert an influence on the organ for a longer period of time. Due to their low height and amount of time spent outdoors children also have more ground and water contact. They have less selection and control over their environment than adults, and during adolescence they may adopt behaviours that put them at greater risk. Early exposure to toxins such as tobacco smoke is held accountable for much of child mortality and disability.³⁻⁵ What is still unknown is a comprehensive picture of the levels and types of exposure to environmental pollutants to which children in Europe are exposed.

| Recommendation |
|--|
| <p>Objective: To assess the degree of exposure of children living in the different areas to environmental pollutants from pregnancy through childhood to the end of adolescence.</p> <p>Methods: Prospective, longitudinal birth cohort studies (with the possibility of combined analysis of data from different cohorts) with exposure assessment via biomarkers, where feasible.</p> <p>Expected Impact: Increased knowledge about the exposure to and the effect of environmental pollutants during pregnancy and throughout childhood, reduction in exposure of children to harmful pollutants and an improved health outcome.</p> |

Despite the abundance of information and the knowledge about the association between adverse socioeconomic circumstances and poor health, it is still not possible to assess the magnitude of environmental health inequalities in children in Europe due to important knowledge and research gaps in this area.⁶ Specifically, there is a need for research on social inequalities in exposure and susceptibility to hazardous environments, as well as “*research on social inequalities in environmental salutogenic resources and a community-based participatory research strategy*”.⁶ Given the fact that inequalities play a role in environmental health as well makes it important to investigate the link between living conditions, such as poor housing conditions and homelessness, and poorer health. The living conditions depend largely on the economic situation of the families. Poverty is also closely associated with problems in access to clean water and sanitation facilities, which are a factor for the spread of infectious diseases. Moreover, unsafe living conditions pose a risk for other environmental hazards, such as accidents and injuries, toxic chemicals, noise pollution and waste sites.⁶

Recommendation

Objective: To evaluate prevention strategies and actions in the home that aim to protect children’s health and neurodevelopment particularly for children from socio-economically deprived communities who are disproportionately exposed to pollutants.

Methods: Identification and evaluation of prevention strategies used in deprived and marginalised communities.

Expected Impact: Reduction in exposure to pollutants to populations that are at present disproportionately at risk. Improvement in child population health.

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3.4.2 Cyber environment and media influence

| | |
|-----------------|------------------------|
| Knowledge gap + | Implementation gap +++ |
|-----------------|------------------------|

Background

Children and young people born from 1990 onwards are sometimes referred to as “digital natives”. They have grown up in the information society, in a media-rich, networked world of wide possibilities. This digital lifestyle is more than having the latest gadget (device); it is a means of engagement with others on a local or global scale, self-directed learning, creativity and empowerment. It is in effect a fundamental change of communication and social engagement and capital for young people. Several reviews and studies have indicated that the effects of early and prolonged use of web connections may have adverse effects, particularly on the most vulnerable¹ as a consequence of psychological cruelty and bullying. Ways of learning may also be profoundly changed with some cognitive functions being enhanced but others being lost.² The phenomenon of internet addiction is rapidly spreading is causing great concern. The emerging research need is an investigation of how this rapid change in form of lifestyle, habits, behaviour and communication impacts upon children’s health. This necessitates an investigation into such diverse subjects as the potential increase in sedentary behaviour caused by increased ‘screen time’ (see Chapter 3.5.3) to how the habits of the digital world affect social and psychological development.

Key issues

Modern children and young people start playing games online and sending text messages via mobile telephones at a very early age. Many young people in Europe have smartphones with internet access almost all around the clock and a majority of them use social media. Social media is an overarching term referring to interaction and exchange in virtual communities, and it includes networking sites and services such as Facebook, Twitter, messaging such as Skype, blogs and other websites, and other mobile communication. There are many opportunities for, and also great need of, research to understand, and utilise the power of these new social media, and at the same time minimize the risks and side effects of the novel digital environment. The effect of this profound change in communication and socialisation on social and psychological development is as yet unknown. The digital environment transcends national boundaries within the continent, and as a result European research is needed to study the effects of the digital environment in more than one culture and context, to identify how different cultures and contexts use and adapt to digital communication.

Recommendation

Objective: To conduct European-wide, and European child-focused research into the effects of the digital environment on cognitive development, psychological development, personality development and social development.

Methods: Longitudinal, comparative studies

Expected Impact: This would shed light on the effects of new forms of communication, identify opportunities for its use and achieve a more balanced and healthy relationship between children and adolescents and digital technologies.

Social media is increasingly used in health campaigns³ and also as a means of researching ‘hard-to-reach’ groups. Much of the extant research has been done in the United States, and concentrates on adult usage of social media. There is an emerging body of work into the power of social media sites to promote health messages, and provide social and psychological support for young people. Some specialised uses of these communication tools include support groups for young people with chronic illness, including cancer, congenital heart disease and mental disorders (see Chapter 3.5.1).⁴ Social networks have also been used to support public health campaigns, such as organ donation, parenting advice and lifestyle factors.⁵⁻⁸ A European, child-focused approach on this issue is not yet available. It may also be important to identify means of guaranteeing equality of access to these tools, for children. This is increasingly possible because of the almost universal and equal access to consistent digital information. Health education tools for children and adolescents using digital media need to be developed, and the effectiveness of interventions implementing digital media needs to be comprehensively evaluated. A focus should be placed on the effects of using social media in reaching specific “hard-to-reach” populations in particular.

Recommendation

Objective: To conduct European focused research into the uses of social media and their ability to communicate with traditionally ‘hard-to-reach’ populations.

Methods: International surveys from different countries in Europe.

Expected Impact: Increased access to health information and other tools for improving health for deprived, marginalised and otherwise hard to reach communities in all countries in Europe. Better child health for all children, including those at risk of poor health outcomes because of the environment or community in which they live.

A negative side of the cyber environment is cyber-bullying and the loss of contact with the real non-digital non-virtual environment. Cyber-bullying can take the form of an individual attack on an individual – even a young child – which is all pervasive and constant; the adoption of another’s

online persona to ridicule and libel a person (for example in the case of identity theft); or persuading an individual into bad habits and poor health behaviours, such as the ‘thinspiration’ websites where advice is given about how to hide eating disorders such as anorexia and bulimia from parents and other authority figures.

Cyber-bullying is an increasing problem and websites exist that help to empower young people in learning how to deal with cyber-bullying and/or how it can be prevented⁹ – but of course, the internet in itself is also a source of such bullying. Currently, there are few evaluated interventions that can be used to prevent cyber-bullying from occurring or to cope with its effects (see Chapters 3.3.2,4.5).

The Internet is a decentralised network assuring a robust system on the one side, but also with relatively limited accountability, and enforcement of regulations on the other. DG Connect and other organisations run programmes about safely using the internet; issues such as control of information and how to retain privacy and security of identity when online is something that all children and young people need to know. It is important that children and adolescents have the appropriate skills and knowledge, so that the benefits of this information tool outweigh the potential risks.

Recommendation

Objective: To conduct comprehensive evaluation of interventions designed to prevent and cease cyber bullying, including steps that can be taken by individuals to handle cyber-bullying.

Methods: Case study, cohort studies, evaluations.

Expected Impact: This would lead to a greater protection of children from cyber bullying; and a more positive and productive use of digital media to enhance personal and community health.

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3.4.3 Safety

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|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Safety is a right included in the United Nations Convention on the Rights of the Child,¹ and has a significant effect on the development, health, and well-being of children. Yet, safety means different things to different cultures – and this is an important area for specifically European research to address. Safety is a broad topic that covers both unintentional injury (“accidental” injuries such as transport related injuries, drowning, burns, etc.) and intentional injury (injuries where there is intent to do harm such as child maltreatment, suicide and interpersonal violence, including bullying). Injury prevention is a high public health priority because injuries are common, can have severe consequences, including major effects on health, well-being, disability and life-expectancy, and have a very high cost. Injury is a leading cause of death in 1 to 14-year-old children in the European Union² and the number one cause of death, disability and burden for children aged 5 to 19 years in Europe.³ In addition, non-fatal injuries are heavy burden for individuals and families, and can carry medical, psychological and social consequences, all of which impose a significant health, social and economic burden on societies.⁴

Children and young people need to explore and test their environments as an essential part of their development; however, society has both a responsibility, and the capability, to prevent unnecessary harm and injury, particularly where it may lead to death or disability. Safety is particularly important for children living in disadvantaged communities (see Chapter 3.2.1). Globalisation has brought about changes in social and material environments, with health inequalities rising especially in vulnerable groups (see Chapter 3.2.2). Inequalities in child mortality have increased, challenging ideas of social justice, and showing our failure to deliver equal opportunities to safe environments for all children.³ A safe environment is also important to support children and families in spending time outdoors, and engaging in outdoor physical activity. Whether perceived or actual, an unsafe environment will inhibit or limit the development of positive health behaviours in childhood, and lead to adopting more sedentary, in-door activities with negative consequences for health in adulthood.⁵

Key aspects of safety for children are unintentional injury prevention; intentional injury; and the effects of the built environment on safety and physical and social activity. Research needs for unintentional injury and the built environment are addressed directly under this section while those for intentional injury, including the prevention of domestic and neighbourhood violence and the amelioration of its effects on children and young people are covered in Chapters 4.3.1 and 4.3.1.1.

Key issues

Despite the public health importance of child injury, current European research on child injury and its prevention is limited. *“Reductions in child injury mortality have been achieved in some developed countries as a result of the application of evidence-based programmes based on rigorous research and priority-setting. Unfortunately, such research is not widespread even in all high-income countries and is particularly limited in low-income and middle-income countries, resulting in a significant gap in knowledge”*.⁶ Further although the evidence is sufficient to start taking action in a number of areas,³ recent assessments indicate that many countries in Europe have not adopted and implemented evidence-based policies and programmes that should lead to reductions in unintentional child injury.⁷⁻⁹ In addition, there are knowledge gaps where effective preventive measures have yet to be established or research is needed to understand how best to integrate injury prevention into child health programmes and other settings.

Child injury has not received investment commensurate with the magnitude of the issue and this is in part due to a lack of data to create the political case for more investment. A comprehensive assessment of the burden of child injury would provide the evidence for the need for more investment in prevention and supporting infrastructure. Yet, knowledge about the extent to which this is happening is still incomplete in Europe. One key research gap is the lack of methods/tools to accurately gauge injury related disability specific to children.

Recommendation

Objective: To conduct a study on the burden of child injury in Europe. This needs to include measures of morbidity and disability resulting from injury in addition to mortality and key to this is the measurement of disability in children rather than the application of adult measures. Both unintentional and intentional injuries should be studied.

Methods: Cohort studies. Exploration of data linkage between databases, that cover all severities of injury and the social and economic background of the person and environment where the injury occurs. Economic analyses.

Expected Impact: Accurate calculation of the burden of child injury would assist in building a stronger political case for adequate investment to address the issue, enable better targeting of interventions, development of more effective interventions and investments in safe infrastructure, including data systems that allow monitoring of the impact of prevention programmes and policies.

Recommendation

Objective: To identify cost-effective strategies where none exist, and to evaluate the impact and cost-effectiveness of policies and programmes already in place. There is also a need for knowledge translation research to better understand factors that increase likelihood of successful uptake and implementation of evidence-based strategies and integration into child health programmes and other settings at the local, regional or national level in Member States.

Methods: Systematic reviews and descriptive research, including case studies, case series and qualitative methods, specifically addressing adoption and implementation factors that impact policy and programme effectiveness.

Expected Impact: Increased understanding of how to successfully transfer and implement evidence-based strategies in new settings, increased effectiveness of policies and programmes in reducing injuries and better use of scarce resources.

Risks for injury and challenges to safety change as children grow from infant to adolescent. The family home is a key environment for children and young people, and is viewed, usually correctly, as a place of safety (see Chapter 3.3.1). However, particularly for young children, because of the amount of time spent in the home, it is the place where most injuries occur.¹⁰ As children grow, they spend more time in other environments and the settings where injuries occur also expand to include school, road, and neighbourhood, for example. While there are some data to identify the types and causes of injuries, key knowledge gaps to understanding the large disparities in rates between and within countries in Europe include a lack of data on exposure to both hazards and prevention efforts across countries and high-risk populations within countries, including gender differences. These gaps in data are particularly important given the inequalities in injury mortality and morbidity that exist between and within countries.

Recommendation

Objective: To develop methods to collect exposure data related to unintentional injury (hazards and protective factors) and etiologic studies to better understand population differences between and within countries are required to both develop more effective interventions and to better target their delivery.

Methods: Cross-sectional surveys for individual level factors; standardised assessment tools allowing roll-up from local to regional to national level for neighbourhood/community factors. Exploration of data linkage and geographic information systems to examine relationship between injury, social and economic measures and the natural and built environments where injuries occur.

Expected Impact: Increased understanding of inequalities and inequities related to child injury,

more effective interventions, more effective targeting and enhanced ability to monitor impact of programmes and policies.

The safety of the built environment is a research area that is in need of investigation. The built environment (the human-made surroundings that provide the setting for human activity) affects health in different ways and needs to be regarded in European as well as national, regional, local and cultural terms. Safety in the built environment is to some extent related to culture-related differences in practice, for example in some countries or communities it is common to walk to school unaccompanied, but in others it is frowned upon. As such, it relates to risks of both unintentional and intentional injury, and both actual safety and perceived safety are important concepts to be explored and understood (see Chapter 3.3.1.1). The built environment is an arena of safety that is relevant to many disciplines in addition to health. There is an urgent need to connect with all relevant professions and agencies to work together to improve children's safety in the built environment – these include town planners, architects, engineers, police, transport coordinators, local councils and so on. Children's ability to access safe playgrounds, walk or bicycle to school, friends and activities have profound effects on safety, physical health, mental health, community cohesion and many other health promoting factors. Research needs to identify what aspects of the built environment directly affect child health and safety, and what tools are needed for measuring this.

Recommendation

Objective: To understand the different effects of the built environment on perceived safety, injury, physical activity and social development through better data collection and analyses.

Methods: More detailed data collection; multidisciplinary studies with planners, architects, developers, and local government.

Expected Impact: Improved neighbourhood design and home design that reduces the likelihood of injury and enhances children's overall health. Better ability to evaluate the effectiveness of injury prevention measures, and how to ensure the best uptake of such measures. Ultimately resulting in better, safer, more health promoting, built environments for children and young adults and increases in perceived safety that lead to community cohesion and benefit community health more broadly.

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3.4.3.1. Crime, antisocial behavior and violence

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|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

An important concern of safety is perceived fear of crime and of being a victim of crime. For children, growing up in an environment where violence and crime are common, or is a widely-held fear, can have profound effects on mental and physical health. Living in a violent, or crime-ridden environment increases the likelihood of a young person committing a crime him- or herself, thus perpetuating the cycle. These neighbourhoods are also often characterised by poverty, deprivation and inequalities in health (see Chapters 3.1.3, 3.2.1, 3.3.3).

Key issues

To a certain degree, a child's environment can influence a child's behaviour, whether it is participation in criminal acts or in working to maintain or improve the community in which they live (see Chapter 3.3.3). There is a psychological and physical effect on the child of an environment where crime and violence are often experienced (see Chapter 3.1.4). Children rightly seek adventure, including exploring boundaries in ways which entail crossing them, and inevitably this may include characteristics of criminal behaviour. Such isolated episodes are not the start of an emerging criminal career, but for a small group of children it may be an indication of a criminal career.

Crime can have a direct effect on health in illegal drug use, under-age drinking and smoking (see Chapter 3.1.2). These behaviours are also linked to poverty, a deprived community, lack of social capital and other factors that are also linked to areas of high crime. Another aspect of crime and health is anti-social behaviour and interpersonal violence. Anti-social behaviour in terms of older children or adults dominating a neighbourhood and causing social concern and fear has an adverse effect on (younger) children who are frightened to go about normal childhood activities such as outside play, or to ride a bicycle without it being stolen or damaged, as well as adverse mental health effects on adults who become deeply stressed. Bullying, whether in the street or at school, is a more personalised form of violence with a direct negative effect on health and well-being (see Chapters 3.3.2, 3.4.2).

Recommendation

Objective: To investigate the root causes of violence and anti-social behaviour and how living in such an environment affects children and young people. Further evidence is needed to identify and implement effective interventions that can break the cycle of violence.

Methods: Surveys, detailed anthropological studies, community intervention studies.

Expected Impact: Better understanding of, and more ready access to, community interventions aimed at reducing crime and violence, and providing young people with alternative outlets.

Domestic violence seriously affects psychological and social development, a consideration for research is the development and implementation of effective interventions to detect, prevent and help families with domestic violence (see Chapter 3.3.1.1).¹ There is still much to learn about the effect of domestic violence on the children and young people in the home, particularly in terms of which families are more likely to experience domestic violence, and the role of inequality and inequity in changing the likelihood of children and young people experiencing domestic violence (see Chapter 3.2.1).

Recommendation

Objective: Investigation of the effects of domestic violence on children and young people in the home, and the effect of social and economic on the prevalence of domestic violence.

Methods: A European survey of school children, young adults and parents on the subject of domestic violence. This could possibly draw upon any European surveillance system of child maltreatment.

Expected Impact: Greater knowledge of the extent and effects of domestic violence in Europe would help in the identification of appropriate intervention for decreasing domestic violence.

While no estimates exist for the European Union, interpersonal violence is the third leading cause of death and a leading cause of disability among people aged 10–29 years in the 53 countries of the WHO European Region.² Physical violence affects mostly males, who comprise four of five homicide deaths. As noted previously, victims of violence are prone to a variety of behavioural and mental problems including high-risk health behaviours, such as smoking, alcohol and drug misuse (see Chapter 3.1.3) and importantly, to being victims and perpetrators of violence in the future.² It is possible, through community and societal action, to prevent much violence among young people. Multi-disciplinary interventions, involving many disciplines and agencies are known to work, particularly if the interventions adopt a public health stance, rather than a criminal justice approach to the issue. Reducing the risk factors for violence and strengthening the preventive factors among

young people early in life (see Chapter 3.1.3) are far more effective than attempting to reduce violent behaviour once it is present in a community.

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3.5 Specific Complex Health Issues

3.5.1 Mental Disorders in Childhood

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| Knowledge gap + | Implementation gap +++ |
|-----------------|------------------------|

Background

Mental illness takes a grave personal, social and economic toll on the young. Mental disorders have an alarmingly high prevalence among children and young people in Europe. It is estimated that the overall prevalence of mental disorders in childhood and adolescence lies between 10% and 20% worldwide.¹⁻³ However, it can be substantially higher in underprivileged and poorly integrated population subgroups, such as migrants. Mental disorders can be transient or long-term, and in children and young people 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 and young people can lead to school failure, family discord and violence, and later on to substance abuse and even suicide.

The co-occurrence of risk factors and protective factors restricts the identification of the specific elements responsible for the onset and continuity of mental health problems. Risk factors for mental disorders work together with direct causes to create a unique path towards mental distress in some children and young people.⁴ Early emotional and behavioural problems significantly alter a child's mental health trajectory, leading some individuals do embark on a "pathogenic path"⁵ from an early age. Such early mental health problems may prevent young children from developing healthy relationships with peers and adults, and impede the development of fundamental cognitive, linguistic and regulatory abilities.⁶ This not only becomes a source of risk factors for the development of mental disorders, but also a risk for other poor health, educational, economic, and social outcomes.

Key issues

There is no consensus on whether or not mental health disorders have increased over the past decades, as studies using comparable measures and reporting methods have been sparse.⁷ There are also cultural differences in that there are large discrepancies in the perception of whether mental disorders are transient or not, and whether and how they require treatment in different countries and communities. What is known is that risk factors for mental health problems tend to cluster together⁸ and that the effect of these risks in early childhood has not been thoroughly studied.⁴

Recommendation

Objective: To promote population-based prevalence studies on mental health disorders in children and young people across Europe, by type of disorder and age group of children, including identifying standardised methods for assessing defined mental disorders in Europe.

Methods: Methods and definitions are to be identified and validated.

Expected Impact: Important knowledge of the cultural, socio-economic and ethnic differences in Europe and how these might influence mental disorders and their progress or severity can lead to effective prevention of mental and behavioural disorders, whilst taking into account cultural and socio-economic differences between countries or vulnerable population groups.

In addition to comparative studies in European countries, there is a need for research into the risk factors for mental disorders and the means by which they interact and lead to disorders developing in children and young people. There are a number of genetic and non-genetic factors that interact differently in different age groups to produce behavioural phenotypes. This includes the child's environment prenatally (see Chapter 3.1.1) and during childhood: it is known that experiences shape brain development and subsequent behaviour. The social environment and other factors (for example experiencing abuse, stress or neglect (see Chapters 3.3.1.1, 3.4.3) during childhood have an effect on the brain or neural circuitry. A cumulative effect of disparate risk factors may lead to adjustment problems and behavioural disorders, such as drug abuse (see Chapter 3.1.2), risky sexual behaviour (see Chapter 3.5.2) or mental disorders such as depression. Knowledge about these factors can lead to more effective interventions designed to prevent mental disorders resulting from risk factors and particular circumstances (see Chapter 3.1.2, 3.1.3).

Recommendation

Objective: To identify the risk factors for mental disorders, including genetic, environmental, social and behavioural risk factors, and how they react to each other, and how they affect mental health from a cumulative and life-course perspective.

Methods: Cohort studies, case-control studies, clinical trials, community observational studies.

Expected Impact: Knowledge about the complex interaction of risk factors can lead to better preventive measures and fewer mental disorders in childhood.

Recommendation

Objective: To identify intervention strategies for prevention of mental disorders in children and young people. These interventions need to be adopted in the cultural and social environment of children and young people in Europe and provided to parents, families, teachers, schools, care providers, hospitals and other community services.

Methods: Cross sectional cohort and longitudinal studies, intervention trials of existing strategies.

Expected Impact: The development of suitable intervention tools for different age groups and population groups in Europe.

Access to treatment for mental disorders in children and young people differs across the European Union. Some young people are not treated due to a misconception that mental health problems in childhood are transient⁹ while others wait for extended periods – more than one year – before obtaining professional treatment.¹⁰ Work to intervene early and prevent mental ill health from developing among vulnerable children and young people needs to be more extensively carried out and researched.¹¹ There is a lack of consistent research and action in the European Union on access to treatment for mental disorders in children and young people. In addition, when treatment is received, it is in itself a matter of contention. Drug treatments are not subject to consistent and evidence-based guidelines in Europe. Clinical trials are normally carried out in adults, and children are an under-researched group in terms of medication for mental disorders. Pharmacosurveillance in children exists but needs further research. There is still considerable debate as to the effectiveness of many drugs, and the long-term side effects because of the lack of comparable outcome evidence.

Recommendation

Objective: To conduct population-based studies on accessing methods of treatment (medical and non-medical) of mental health disorders used in children and young people across Europe, by type of disorder and age group, including the most significant results and comparing different methods.

Methods: Comparative cohort studies across the European Union.

Expected Impact: Knowledge about the different methods of treatment, and criteria for accessing mental health services across Europe will lead to greater communication and identification of the most effective and efficient means of treating mental disorders in children and young people, and hopefully a greater number of successful outcomes of treatment.

Recommendation

Objective: To undertake research that provides a sound evidence base for access to services and strategies for treatment and medication use in mental disorders in children and young people.

Results need to provide strategies/policies for different methods of treatment (medical and non-medical) used for mental disorders in children and young people in Europe (for example ADHD, or depression). These need to be used consistently across the European Union.

Methods: Comparative studies and randomised control trails across the European Union, evaluation of services provided and of outcomes.

Expected Impact: Greater consistency and access to services for children and young people with mental disorders, greater coverage of treatment, and more successful outcomes of treatment for children and young people in the European Union.

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3.5.2 Sexual and Reproductive Health

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| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Teenagers have to have the relevant knowledge, skills, and motivation to achieve the positive outcomes and avoid the possible negative consequences (e.g. abusive relationships, unwanted pregnancy, and sexually transmitted diseases) of sexual behaviour, in order to have good sexual and reproductive health. Within Europe there are economic, social, religious, cultural and political differences, all of which influence national teenage sexual and reproductive health policies and practices. For example, a recent EU report highlighted the substantial variation in the timing of sexual initiation and in contraceptive use in EU countries.¹ On a European Union level there is no common policy on sexual and reproductive health. Comparative data on teenage sexual activity and patterns of contraception use among teenagers are scarce.

Key issues

During the last two decades, adolescent pregnancy rates have fallen significantly in Europe.² Though data are scarce where adolescent pregnancy is concerned, it is reasonable to assume that teenage pregnancy is frequently unintended, at least in most developed countries. Analysis of current trends shows that even in countries with good sexual education and health services, such as the Nordic countries, have substantial variation in their teenage birth and abortion rates. Teenage pregnancies are preventable, yet teenage birth is still a medical problem for many young women, and it is also a significant social problem, which may have negative consequences for the later life of the mother and her child.^{2; 3} The teenage abortion rate varies by country, even more than the teenage birth rate, and there are very few studies on the effects of teenage pregnancies ending in termination. In the development and monitoring of strategies to decrease teenage pregnancy rates, research should focus on the reasons behind the currently observed variations, their significance, and how best to reduce them. The large observed differences in between countries, within countries and between population groups in various sexual and reproductive health indicators should be explored. This work should include a variety of both qualitative and quantitative approaches that are usually undertaken by a multi-professional or multidisciplinary team.

Recommendation

Objective: To establish the reasons why there is such diversity in rates of teenage pregnancy in Europe.

Methods: Comparative research between member states and regions.

Expected Impact: Reduced teenage pregnancy rates due to effective and targeted prevention interventions. Improved pregnancy rates by identifying and disseminating information about optimal reproduction timing.

Sexually transmitted Infections (STIs) are of great concern for young people's sexual health. The most frequently occurring sexually transmitted infections – Chlamydia, gonorrhoea, and syphilis - have increased in several European countries in the last decade though they are difficult to estimate, especially among adolescents.² On the other hand, the number of people with HIV is decreasing in most countries (from 2001 to 2009) in all ages, including young people. In order to prevent teenage pregnancy and STIs, there is evidence that sex education programmes that promote personal and social skills, as well as access to contraceptive services, with staff who have received training for working with adolescents, and taking into account social disadvantages are crucial.⁴ Preventing STIs in particular depends upon enhancing personal and social skills, as well as guaranteeing condom accessibility.^{4;5} The use of modern media, including online social networking and digital communication is likely to be essential in developing effective and accessible sexual health promotion messages to young people (see Chapters 3.1.2, 3.1.4, 3.4.2). Accurate information about adolescents' sexual motivations, practices, and their readiness to use condoms for STIs prevention should guide the development of interventions that more effectively promote healthy sexual behaviours.⁶ Such information is essential to help understand changes in STIs patterns as well as to monitor the progress of public health activities.

Recommendation

Objective: To establish effective health promotion tools through the use of modern social media for sexual health, prevention of sexually transmitted infections and teenage pregnancy rates.

Methods: Comparison of health education strategies in their social settings that are designed to promote sexual health, this includes Sexually transmitted infection (STI) rates and teenage pregnancy rates. European cross-country comparisons should help identify successful approaches that may be adapted to culturally similar countries. Ethnographic studies of teenage sexuality.

Expected Impact: Improved sexual health, reduced rates of sexually transmitted infections, and reduced teenage pregnancy rates.

The SAFE project is a collaborative project between the International Planned Parenthood Federation, Lund University and the World Health Organization. According to the SAFE project,

young people's sexual identities are influenced by their social, economic, ethnic and cultural environment. Therefore, it is essential to consider that diversity when developing sexual health related policies. Some groups are particularly vulnerable, for example are out-of-school youth, street children, children with disabilities and special needs, orphans and young people living in residential institutions, ethnic minorities, young people living with HIV/AIDS, migrants, young people who have been sexually abused, girls who have been victims of female genital mutilation and young people who are lesbian, gay, bisexual or transgender. In order to develop effective policies and programmes to reach these groups, services must account their specific settings, backgrounds and experiences, therefore services must be flexible and sensitive to religious and cultural beliefs, though encouraging human rights and gender equality. It is commonly accepted that as yet, policies and services do not successfully meet these groups' specific needs; and this needs urgently addressing.⁷

Recommendation

Objective: To investigate the cultural variation in access to services across the European Union and develop interventions to improve communication between provider and adolescent service users.

Methods: Surveys, cohort studies, qualitative research, youth advocacy.

Expected Impact: More pertinent sexual health services that take account of the diverse social and cultural influences on sexual identity in young people.

The SAFE project's goal is to develop ways to reach young people (according to WHO those who are between 10 and 24 years old) with sexual and reproductive health and rights (SRHR) information and services as well as to support and progress policy development. These rights are embodied in several agreements and conventions, including the Convention on the Rights of the Child. According to the SAFE's Project guidelines, comparative data on SRHR is scarce in Europe. Moreover, sexually transmitted infections and unwanted pregnancies are still an issue in several countries. Therefore, it is crucial to address SRHR through sexuality education and services that must be age appropriate, affordable, accessible and integrated into other youth related services in order to develop healthy young people.⁷

Other reports provide more detailed information. Overall, reports show large differences between European countries in rates of contraceptive use among adolescents (and adult women) mainly due to issues related to accessibility and affordability of sexual and reproductive health services, especially where those that are under legal age are concerned.^{3; 8}

Recommendation

Objective: To investigate access to contraceptive and sexual health services for under-age young people.

Methods: Surveys, analysis of existing services data.

Expected Impact: More comprehensive care of the sexual health of young people, lowering of teenage pregnancy rates and lower rates of sexually transmitted infections in future populations.

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3.5.3 Overweight and Obesity

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|------------------------|------------------------------|
| Knowledge gap + | Implementation gap ++ |
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Background

A recent review found that in the Western world, there seems to be a levelling off of the obesity epidemic in children and young people.¹ However, the prevalence of overweight and obesity has reached in most countries very alarming levels, in view of the pervasive adverse effects on health, both immediately and along the life course. Moreover, the levelling off less evident for those children and young people in lower socio-economic groups, and in particular in ethnic minority groups.² As a result, research into the causes, preventions and treatment of obesity needs to remain a priority. A levelling off is not a reduction, and previous stability has been followed by increases in prevalence of obesity.¹

A significant challenge in tackling overweight and obesity is to collect and 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. Epidemiological data from the 2010 *Health Behaviour School Age-Children* survey (which surveys school children aged between 11 and 15 years of age) showed that, among HBSC countries, an average of 14.3% of young people are overweight. In Europe, Greece had the greatest number of overweight people with 20.8%, and the Netherlands had the lowest with 8.3%.³ Overweight is more common in boys than girls in almost all countries surveyed. There is little information about overweight and obesity in younger age groups.

Key issues

Developing interventions to prevent and treat obesity in children and young people is a major challenge. In fact, many adolescents fail to meet recommended levels of physical activity, and exceed recommended dietary intake, and sedentary behaviours, confirming that adverse health behaviours do not occur in isolation. A systematic review has recently shown that, despite a significant effect on intermediate outcomes (lower intake of saturated fatty acids, reduced 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.⁴

Recommendation

Objective: To understand the personal and environmental factors affecting overweight and the cause of the diversity in childhood obesity rates and trends in Europe.

Methods: Cross-sectional and longitudinal studies linking exposure and outcomes and assessment of policies adopted to counteract the phenomenon across Europe and of their.

Expected Impact: Culturally adapted and integrated multi-component intervention strategies are worked out and evaluated for large scale implementation.

The existing scientific evidence into what works best in the management of adolescent overweight shows that combined behavioural lifestyle interventions can produce a significant and clinically meaningful reduction in overweight.^{5;6} Combining positive changes to physical activity levels, healthy eating and reducing sedentary behaviour is the best way to achieve behaviour change in children and young people.⁷ Psychosocial factors such as motivation, self-regulation and body satisfaction; the ability to adopt healthier lifestyles; and improving well-being is widely recognised by research as key variables of the adoption and maintenance of health behaviours. Family and peer relationships and satisfaction with school represent a context that can support and facilitate change of habits.⁷ 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 increasing physical activity.^{8;9}

Recommendation

Objective: To evaluate the multi-faceted effective measures of reducing dietary, physical activity and other risks (school meals, advertising and so on.)

Methods: Comparative research across the European Union, involving all ages of children and young people.

Expected Impact: Optimally balanced dietary behaviour, increased physical activity and reduction of sedentary lifestyle of European children.

Overweight and obesity is considered to be among the other chronic diseases such as coronary heart disease, hypertension, type 2 diabetes mellitus, asthma, eating disorders, various cancers and HIV/AIDS; which remain the most common causes of morbidity and mortality in European countries.¹⁰ These diseases are still highly prevalent despite increasing knowledge, awareness and education about their risk factors.¹¹ Most of these diseases have their origin in childhood and adolescence,¹² but the complex relationship between the environment, family surroundings, genetic predisposition and growth in children and young people have not yet been thoroughly studied and are not fully understood.¹³ Childhood and adolescence are crucial periods in life which imply multiple physiological and psychological changes that affect children lifestyle and their habits (see Chapter

3.1.2).¹⁴ The reduction of general non-communicable disease risk factors in childhood and adolescence may reduce morbidity and mortality in adulthood – these risk factors include poor dietary habits and physical activity.¹⁵ To identify children and young people at risk and find solutions to diminish their occurrence, known risk factors have to be measured, new biological markers have to be identified and new indices should be developed combining biological and lifestyle/environmental data.

A comprehensive assessment of phenotypes, personality traits and their changes during ageing from early childhood to adulthood allows us to understand how the environment exerts its influence on people who are genetically vulnerable or predisposed to develop risk factors of chronic diseases such as overweight/obesity, overeating and eating disorders, their relationship to metabolic syndrome, and to explain how genes and environment interact to influence this vulnerability. In recent genome wide association studies (GWAS),¹⁶ which are mainly conducted on adult cohorts, new loci have been identified that play clear roles in determination of physiological parameters leading to the development of risk factors, and expressed in central nervous system (CNS) showing the plausible role of CNS in predisposition to metabolic syndrome and obesity through general behaviour and cognitive factors. More specifically for example, neuropsychological processes that potentially influence risk behaviour, among them eating habits in children and young people, may have impulsive tendencies, lack of inhibitory control and cognitive flexibility.

Recommendation

Objective: To examine the genetic association with obesity using quantitative markers of metabolic traits, gene-lifestyle interaction and neuropsychological behavioural determinants in the development of risk factors.

Methods: Multi-centre prospective cohort studies with well-established biobanks involving all ages of children and young people and their transition to adolescence and adulthood.

Expected Impact: The identification of pathophysiological mechanisms and environmental determinants in the development of risk factors, which will help to develop effective interventions as well as optimal clinical management with already existing clusters of risk factors.

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3.5.4 Neurodevelopmental Disorders

| | |
|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Neurological and developmental disorders are a group of conditions that includes learning disabilities, epilepsy, brain injury, cerebral palsy, autism spectrum disorders, and specific learning difficulties such as dyslexia, dyscalculia, dysgraphia, auditory processing and visual processing disorders. Recent advances in neurobiology and neuroscience show that majority of mental health disorders also have some neurobiological basis (see Chapter 3.5.1). This distinction between neurodevelopmental and mental health disorders is still adopted by ICD 10, but comorbidity between the two groups is common.

Key issues

According to the World Health Organization Europe,¹ misdiagnosis and/or mismanagement of infant and child neurodevelopmental disorders is widespread in many European countries. The main causes for this situation seem to be: low compliance with international classification systems, lack of evidence-based clinical guidelines, non-adherence to evidence based clinical guidelines, out of date training for health professionals, and inadequate health and welfare system regulation. A lack of adequate data makes comparisons between countries difficult. Where data are available, they often come from non-representative samples and studies. Establishing common definitions and standardised assessment procedures are important starting points for valid comparisons and analysis of trends over time.

Recommendation

Objective: To evaluate and compare across EU the practices of classification, assessment and intervention for childhood neurodevelopmental disorders.

Methods: Studies of disease prevalence; Development and evaluation of standardised assessment procedures; health system studies of disease ascertainment and management.

Expected Impact: Raised standard of classification, assessment and intervention for childhood neurodevelopmental disorders, so that clinical care of children improves and inter-country comparisons and trends over time can be made.

Pain is a common symptom in some neurodevelopmental disorders such as cerebral palsy and there is evidence² that such pain is neither adequately assessed nor adequately managed in children. Both psychological and physical approaches to management of chronic and recurrent pain may be helpful. There is a need for improvement in clinical practice, and measurement of the impact of pain

reduction, not only for its intrinsic value but also as a means to reduce disability and improve quality of life in the longer term.

Recommendation

Objective: To evaluate strategies for pain management in children and young people with neurodevelopmental disorders such as cerebral palsy.

Methods: A comparative trial (for ethical reasons, there could not be a trial with a non-intervention arm). Crucial to identify appropriate validated outcome measures.

Expected Impact: Raised awareness of the prevalence and under-management of pain. Evidence based strategies for pain management.

The World Health Organization International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) is a milestone in thinking about assessment and care planning for children and young people with disability. ICF-CY conceptualises disability as resulting from the interaction between the person and their environment, and this is especially important for children and young people with neurodevelopmental disorders which are relatively unchanging and in which therapy, even if helpful, rarely eliminates impairment.³ The use of the ICF-CY remains partial and heterogeneous.¹ A priority is to extend the use of ICF so as to have a common definition of functioning and disability as well as to acknowledge an important role of environmental factors on children's functioning.

Recommendation

Objective: To understand the barriers to introduction of the concepts of ICF-CY across Europe; at the levels of legislation, health service planning and clinical care.

Methods: Surveys or in-depth case studies.

Expected Impact: Recommendations on how to increase the use of ICF-CY across Europe.

Adoption of the ICF-CY should shift attitudes from trying to "fix" or "normalise" a child's body to consideration of environmental adjustment. The aim is to promote participation in life situations and subjective well-being (quality of life).

Recommendation

Objective: To determine how the home, community and school environment can be optimally adjusted for children and young people with neurodevelopmental disorders to increase participation and raise quality of life.

Methods: Intervention trials and comparative policy analysis, addressing different domains of life such as leisure or home life.

Expected Impact: Achievement of improved well-being and functioning of these children and young people.

Nevertheless, there are many therapies and treatments that are directed to trying to “normalise” the child’s body. In some circumstances, such as use of Intrathecal-thecal Baclofen or deep brain stimulation, the effect can be dramatic. However in general the evidence base for many therapies is very weak; and even where small studies claim benefit, the changes are usually small and the follow up period only a few months. There are a very large number of therapies, often popularised in different countries; and even within countries, the therapy is rarely standardised and there are as many approaches as there are therapists.⁴

Recommendation

Objective: To establish what therapeutic interventions have sustained benefit (for instance at five years post intervention) for children and young people with neurological and developmental disorders.

Methods: Systematic reviews of any evidence of sustained benefit; or observational studies of large European cohorts.

Expected Impact: The resulting information needs to be used to design a trial using a therapeutic intervention for which there is evidence of benefit (if there is one).

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3.6 Health Services

3.6.1 Health Promotion Activity in Children and Young People

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| Knowledge gap ++ | Implementation gap +++ |
|------------------|------------------------|

Background

It is recognised that providing youth-friendly health services is vital to engage with children and young people, and to achieve positive health outcomes.¹ Non-communicable diseases are the dominant contributors to the global burden of disease, both in developed and less-developed countries and are becoming increasingly prevalent among younger age groups.^{2;3} Many of these are potentially amenable to health promotion approaches. Some of the greatest challenges to children's health in Europe including obesity and malnutrition, emotional health and well-being, injury prevention, the promotion of cognitive speech and language skills, adolescent lifestyle issues such as substance misuse and sexual health behaviours (see Chapters 3.5.3, 3.1.4, 3.4.3, 3.3.2, 3.1.2, 3.5.2).^{4;}
⁵ Evaluation of active interventions to promote good emotional and physical health in children and young people needs further focus; in terms of their efficacy and accessibility to a wide range of children. Those living in socially disadvantaged circumstances are particularly vulnerable and we need to better understand how these target groups can be reached most effectively (see Chapter 3.2.1).⁶

Most European countries have preventive programmes for both preschool and school-aged children, which include basic services as well as a focus on health promotion and the prevention of disease involving both parents and young people themselves. Health settings such as health centres and hospitals and community settings such as early years' centres and nurseries can all provide opportunities for health promotion.^{7;8} School has an important role to play as an arena of active promotion of health and the role of school health services needs to be recognised as an important venue where interventions can be implemented and evaluated.⁹ A recent literature review carried out in the UK has highlighted the value of standardising health reviews at key transition points during the school period including reception, transition from primary to secondary school and around 15 to 16 years old.¹⁰ According to the European Health Committee,¹¹ promoting Child-Friendly health programs is important as it involves children in health promoting behaviours and helps to prevent the antecedents of adult ill-health that are often established in childhood.

Key issues

Preschool screening and immunisation were reviewed by the RICHE project as part of the investigation into measurements and indicators (see www.childhealthresearch.eu). This work highlights the need for more systematic comparative approaches so that quality can be compared

across countries. In order for health promotion activities to be effective they must be accessible in terms of language and how they are conveyed to parents and children and young people of different ages and backgrounds.

Recommendation

Objective: To compare the performance of preventive child health systems across Europe.

Methods: Development of an inventory of preventive child health systems (pre and school aged) and agree a core set of quality indicators particularly focusing on process and output.

Expected Impact: Improved delivery of child screening and immunisation services in Europe, thus improving the health of children and young people through the reduction of disease, and resulting reduction of risk of disease to all ages in Europe.

There is an increasing use of social media and internet usage by both parents and children (see Chapter 3.4.2).^{12; 13} It is unknown to what degree health promotion activities could be effectively delivered using such media and in particular how effective they might be reaching the most socially vulnerable groups.

Recommendation

Objective: To evaluate the methods of communicating health promotion messages, particularly in terms of children's age, and new digital media.

Methods: Intervention trials of different methods of health promotion delivery in relation to key health outcomes.

Expected Impact: Improvement in health behaviours in both parents and young people. A reduction in health inequalities related to health behaviours.

In addition, active health promotion needs to be able to reduce social exclusion or other types of marginalisation, in order to improve health or allow individuals to take control of their lifestyles in a way that is health promoting (see Chapter 3.2.1). Leisure-time activities provide enriching opportunities for children to interact with peers¹⁴ (which is an important component of social capital (see Chapter 3.1.4). Indeed, hobbies and leisure activities such as music, sports, drama, arts and dance and active youth organisations are important parts of living and learning (see Chapters 3.3.3, 3.1.2); emphasising the importance of leisure to adolescents – they are also vital to physical and mental good health. Using leisure time and leisure activities as part of an intervention may create alternatives for young people to help them respond to issues such as social exclusion, feeling unhappy and poor interpersonal relationships in a positive way. Such an intervention may also enhance their search for well-being, personal competence and social participation.^{15; 16} This warrants further research into its application and the effectiveness of any interventions developed across Europe.

Recommendation

Objective: To evaluate interventions that help children and young people to respond to issues of social exclusion through leisure, sport and music, as well as active youth organisations. The long-term effects of their implementation on children and young people's health and well-being needs to be explored.

Methods: Longitudinal studies with oversampling of those socially excluded, such as minority groups, socially-deprived groups, etc.

Expected Impact: Improved well-being and quality of life, greater social inclusion and long term economic and social benefits.

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3.6.2 Preventive Child Health Services

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| Knowledge gap ++ | Implementation gap ++ |
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Background

To prevent or detect diseases, disabilities and health problems in childhood early is generally accepted as a highly rewarding investment, both in humanitarian and economic terms.^{1,2} Across Europe these services are provided in many different ways. They are designed, organised and executed very differently, and the reach different target groups. Also the contents vary, from a general offer of high quality medical, social and educational programmes, accessible and used by practically all families, to selected medical interventions for those who can show clear need.

Key issues

Child Health Services are a valuable contribution to the general health policy in any country. In most of them, the Child Health Services are directed towards the whole child population, and include various forms, such as medical examinations, screening programmes, vaccinations as well as counselling on medical, dental, mental and social issues. Health education and parental support are important parts, a number of non-medical professionals are usually involved, and ideally, the Child Health Services function as nearby centres for advice, education and support for all families in matters of child health and well-being.

In some places, Child Health Services can also provide targeted services for parents and children in particular need, in other places these children and young people can be referred along well established channels. Throughout Europe a range of services are provided, such as parenting support in some countries (see Chapter 3.3.1), specialised help for pregnant teenagers, specialised help for those parents facing challenges such as drug or alcohol addiction (see Chapter 3.1.2), and

help for young people and young parents with mental health issues (see Chapter 3.5.1). Other dimensions of services to young people include targeting ethnic minority groups (see Chapters 3.2.2.1, 3.2.2.3), those on low family incomes and children and young people with cognitive or behavioural problems (see Chapter 3.5.4). However, these services are not available in every country and there are barriers to access and type of services across Europe.

Recommendation

Objective: To determine the most effective preventive health services for particular vulnerable populations, for example deprived communities or ethnic minorities.

Methods: Studies to identify good practice in preventive strategies (considering the health system and political level). Methods to feed the results back to health bodies and policy makers, to support policy change and implementation.

Expected Impact: Minimizing the gaps in preventive child health services in Europe.

The quality of Child Health Care Services (CHCS) is influenced by a complex range of socio-environmental factors such as parental mental health, geographic, financial, cultural, organisational factors as well as training and education. The OECD Health Care Quality Indicators project³ stresses the importance of health promotion, prevention and primary care, but a lack of child focus is evident. There is a potential for improving the overall quality of child health care services in Europe by comparative analyses of the diverse health care systems in place. A European project that makes an inventory of the available national data from child health care (preventive) services including the indicators in use would be the first step in a process towards such a comparative analysis. A second step could be the development and evaluation of new quality indicators of preventive child health services, preferred to process indicators.

Research has seldom been a strong component of most Child Health Services. Efforts to critically examine the value of various health surveillance programmes, or educational and health promoting actions have not been systematically carried out, neither when it comes to quality nor economy. Research in prevention, protection and health promotion, the basic components of Child Health Services, is more complicated than straightforward clinical or other experimental research, for several reasons:

1. Health is a much broader, more positive and more complicated issue than disease.
2. There is a long delay between actions and results, which makes studies more expensive and also more difficult to interpret due to confounding factors.
3. The effect of actions may be minimal for the individual, but substantial for a population, which means that large groups must be involved.

4. Traditional clinical evaluation methods are not sufficient as there are too many psychological, social, epidemiological and non-traditionally clinical aspects that serve as confounding factors.
5. Ethical aspects must be considered particularly carefully, when parents are not actively looking for immediate help for symptoms or diseases, but are encouraged to take risks for a possible better health in the future.

Recommendation

Objective: To establish the effectiveness and efficacy, as well as availability of national/regional data from preventive child health services and access measures.

Methods: Inventory of child preventive services and access measures. Development and evaluation of new, mainly process indicators. Based on that focus on European comparative research.

Expected Impact: Availability of comparative data supports the knowledge where improvements of child health services are needed.

Recommendation

Objective: To identify the population groups with restricted access to essential health care services.

Methods: This requires detailed analysis of provision, access and use of health services by background (sex/gender, socioeconomic status, type of family, ethnic background, non-indigenous language, etc.).

Expected Impact: Increased equity of access to services.

Co-operation and communication between education and health services is important, as is linkage to overall health policy. Using standardised systems across Europe will help in improving access, and identifying difficulties in access in particular populations. An important aspect of access to services is the provision of suitable environments for children and young people. This “developmentally-appropriate” approach to services spans information, treatment, competencies of service providers and the physical environment of the service centre. Children deserve hospitals that are child friendly, and provide a suitable environment for children and young people; these hospitals must also, however, provide appropriate environments for adolescents and young adults.⁴

Recommendation

Objective: To develop indicators of developmentally appropriate health care (for young children, older children and adolescents) at a European level.

Methods: Detailed analysis of suitable health service environments for children and young people regarding gaps in access. Search strategies to link the education level and service level.

Expected Impact: Standardised systems will minimize difficulties in access in particular population.

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3.7. Public Health Infrastructure

3.7.1 Surveillance Systems

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|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

Health Information is essential to good governance, and the health information systems and surveillance systems have a central function in any health system. Decision-makers need a systematic way of increasing their capacity to access and synthesise the information that is part of contemporary Public Health. Reliable and timely information is necessary at facility, local, sub-national and national levels in order to respond to rapidly-evolving health needs, to design and monitor policies and health care reforms, to evaluate the impact of services, and to define budget priorities. The goal of the health information system is to allow all professional and lay users within and outside the health sector to use, interpret and share information in order to transform it into knowledge.^{1; 2}

In contemporary Europe where many people move to work or to live in different areas or nations, it is important to link national surveillance records on a European scale in order to deliver care properly. Linking records in this way and throughout life is possible, as most countries already have good recording and linkage systems. However, electronic health records would need to be made available in all countries which is not yet the case, and this has not been done for all age groups (see Chapter 3.7.3). Key challenges in Europe, for the health surveillance of children and young people, are to find ways in which surveillance data can be used in an appropriate and child centred way; the lack of a European health survey for minors; limited surveillance for major neurodevelopment disorders such as autism (see Chapter 3.5.4); and proper surveillance of injury to children of all ages in Europe (see Chapter 3.4.3).

Key issues

There are many potentially rich data available in Europe, although at present they are seldom analysed in a child-centric way. Many population-based data sources, such as national censuses, household surveys, and specific health topic surveys, such as those on household expenditure, and labour markets, have large amounts information about children's health and living environments, as members of surveyed households. However, these data are locked up and inaccessible as analyses are usually undertaken on a household basis and not on a child-centric basis, so it is not possible to analyse how many children in a particular age group are exposed to specific circumstances. Research into how to unlock this expensively collected data through new analytic approaches, in order to use it to contribute to child health improvement is important, and likely to have a high cost-benefit yield.

Recommendation

Objective: To devise templates for child-centric analyses of census and household data, so as to make currently inaccessible data available; similar approach with health activity data, such as hospital discharges. Make these available to national and other statistical offices so as to make cost-effective progress.

Methods: Conduct studies identifying common data items across national data sets, for different types of data, and agreed common analysis definitions. Discussion with European bodies. Seek European repositories such as Eurostat and WHO to enable creation of comparative databases compiled from national data.

Expected Impact: Availability of powerful comparative data sets at low cost, given that the raw data are already captured.

All European countries have a health information system, which consists, typically of registers, statistical data collection and routinely collected surveys. However, there is limited information on children and young people within countries and on a European level. There is, in general, good coverage of perinatal and infant health, including vaccinations and breastfeeding (see Chapter 3.1.1); and information on the use of health care services, such as hospital discharges and medication; but these data are seldom reported separately for children and young people. There is a similar picture for many disease-specific information systems (for example infectious diseases, cancer and diabetes), for which data for minors are usually reported in five-year age groups or for all below 15 years. There is no European health survey for children and young people today. The European Health Interview Survey (EHIS) specifically excludes children below 15 years. There are separate school health surveys, of which the WHO Health Behaviour of School-Aged Children (HBSC) is the most well-known (see Chapters 3.3.2, 3.7.2), but this survey only collects data on 11, 13 and 15 year old children. Funding issues limit the widespread use of these data in research in many countries. There is little information on children aged between 1-10 years and children and young people who are outside the school system. Adult health surveys that collect data from young people aged over 15 are seldom able to capture the particular health needs and health experiences of adolescents between the ages of 15 and 18 years.

Recommendation

Objective: To establish a European Health Survey for children, which can capture health information from children from preschool age and young school children (aged 1-10 years) as well as older children (aged 11-14) and teenagers (aged 15-18 years).

Methods: For the younger age group (aged 1-10) new data collection methods, such as examinations, and improved utilisation of existing data (e.g. gathered at child welfare clinics and school health services or in electronic patient journals) are needed to fill in the missing information.

Expected Impact: Greater knowledge and resulting better health surveillance of children of all ages, and knowledge about the differences and effects of health experiences and development at different ages.

Screening for autism spectrum disorder (ASD) and other neurodevelopmental disorders often does not satisfy the stringent criteria for population screening (see Chapter 3.5.4);³ in particular screening tests for these relatively rare disorders can be very difficult to establish. Children with pervasive development disorders (PDD) generally have other learning problems, such as language delay or behaviour problems (see Chapter 3.5.4). In such a case a parent-professional partnership is needed for the best outcome for the child. In order to conduct a thorough assessment, a multidisciplinary approach is required. In addition, there are difficulties in differentiating between diagnoses of ASD and related PDDs, yet screening and immediate medical treatment can prevent disability, and may improve the outcome for the child.⁴

Studies demonstrate that if there is a lack of parental or professional recognition of a developmental delay before the age of two, diagnosis is unlikely to take place before the age of three, and in many cases by the age of five.⁵ Tests and rating scales for autism exist which measure the severity of autistic symptoms; but these most of these tests and scales are used only in clinical settings.^{6;7}

The Checklist for Autism in Toddlers (CHAT) is designed to prospectively identify autism at 18 months of age, the value of its benefits could be increased if it is used more widely.^{8;9}

Recommendation

Objective: To identify the countries that put in place interventions for autism spectrum disorder (ASD) before the age of two. To evaluate screening approaches and assessment tools for ASD. To evaluate the effectiveness of early intervention for autism and compare experiences of the countries.

Methods: Literature search; Development of a multidisciplinary approach for children under the age of two considering a parent-professional partnership; evaluation studies.

Expected Impact: Early diagnosis in childhood autism combined with early intervention may improve outcome; mainly functional skills, communication problems and management of behaviour, and thus improve the quality of life of autistic children.

One particularly important aspect of health surveillance that needs greater investment is that of measuring the prevalence and burden of injury in children in Europe. Injury is the leading cause of death for children aged 1-14 in the EU,¹⁰ and the leading cause of death, disability and burden for children aged 5-19 years in Europe¹¹ (see Chapter 3.4.3). However, surveillance of injury is not comprehensive. There is a need for improved data systems (in order to have complete injury data for example), and higher quality data. A set of standardised methods for collecting exposure data to injury is vital for completion of this research. Many injuries are only measured in terms of mortality, and this misses recording the extremely high levels of morbidity to injury (and the corresponding disability, stress, cost and toll on family and community life) that occurs to children every year. In addition, injuries such as road traffic injury, drowning, burns, poisoning, intentional injury such as child abuse, suicide and so on are often recorded separately rather than together. A combined recording would give a higher profile to the burden of injury that is carried by the young people of Europe.

Recommendation

Objective: To develop a European-wide surveillance system for injury that measures morbidity as well as mortality, by location, age group of child, and type of injury (road traffic, drowning, burns, poisoning, intentional injury, suicide) and all injury.

Methods: Architecture to improve and harmonize data systems and the quality (validity) and comprehensiveness of data.

Expected Impact: The creation of a valid European surveillance system for injuries can be used in comparative research to improve preventive measures.

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3.7.2 Measurements and Indicators

| | |
|------------------------|-------------------------------|
| Knowledge gap + | Implementation gap +++ |
|------------------------|-------------------------------|

Background

There are few child health indicators currently routinely collected in most EU countries. Those few are quite unsophisticated, and limited to measures such as infant mortality rates, under 5 mortality rates, low birth weight and prevalence of certain diseases. Measuring child health poses some specific methodological challenges compared to the measurement of health in adults. Children are growing human beings, and the age and maturity of the children and young people defines the available means of data collection as well as the meaning of the measurements. For instance, traditional questionnaires cannot be used to measure well-being before the age of literacy. There are also issues of ethics and consent to participate in surveys. Definitions are also different for children – for instance, the meaning of BMI in terms of obesity varies greatly with increasing height and age.

Key issues

Routinely collected data is one of the most common data sources for creating and populating child health indicators. However, current routine health statistics produced by the EU with relevance for children and young people are minimal, apart from perinatal health. The European Union has funded several comprehensive projects to develop proposals for indicators of child health, but these are either specific to certain ages or have not been adopted systematically on a European-wide scale. Important indicator projects were the Child Health Indicators of Life and Development (CHILD) project¹ and EURO-PERISTAT (www.euoperistat.com). Proposals for indicators also came out of subject-specific projects, especially the Children's Environment and Health Action Plan for Europe (CEHAPE) (www.hpa.org.uk/cehape); Child Safety Action Plans – Child Safety Alliance (www.childsafetyeurope.org); and determinants of overweight and obesity.² The lack of consistent application of these indicators across countries and regions means that public health monitoring for child and adolescent health is missing in Europe. As a result, there are considerable gaps in European statistics for reliable comparative research on child public health. Even when these data are available for children and young people, a sizeable proportion of the variation between countries can be expected to be caused by artefacts and biases, such as misclassification, referral and socio-economic bias rather than by differences in the parameters the indicators were meant to capture.³ To identify these alternative causes of variation between countries and over time an expert group that evaluates such administrative data, based, for example, on hospital care, education and employment records, health surveys, medication data, and cause of death statistics needs to be established. The success of this approach has been demonstrated by EURO-PERISTAT⁴ adult injury groups⁵ and cause of death statistics.⁶

Recommendation

Objective: To collect and evaluate a European dataset of indicators based on routinely collected data after infancy.

Methods: The formation of a European expert group of register researchers and health information experts to collect and evaluate the data.

Expected Impact: The creation of a valid European dataset of relevant child health indicators that can be used in comparative research.

Although the European Commission has sponsored the very important development of a harmonised Health Interview Survey and Health Examination Survey for adults, there is no equivalent for children and young people despite their importance in terms of population health now and into the future. International surveys into children include the Health Behaviour in School-Aged Children (HBSC) study (www.hbsc.org) and the European School Survey Project on Alcohol and Other Drugs (ESPAD) (www.espad.org). The KIDSCREEN project produced a data collection tool for children aged 8-18 (www.kidscreen.org). The European Network of National Observatories on Childhood (ChildONEurope) (www.childoneurope.org) focuses primarily on well-being measurement rather than health specifically.⁷ However, there is still work to be done to collect data about certain age groups, in particular those children aged 1-10 years.

Recommendation

Objective: To create a Health Interview/Health Examination series for children and young people, by age-group.

Methods: Linking child public health experts, health data experts, health behaviour experts and statisticians to ascertain current effective initiatives where they exist, and to devise both data sets and data collection tools, and to validate these in use.

Expected Impact: Much better knowledge of the health of the child population of Europe and nationally, so as to enable protective and facilitatory methods and public policies, such as a much more targeted Health in All Policies approach concerning children and young people's health.

As part of the drive to create European Health Indicators the European Commission established the European Community Health Indicators Project (ECHI), which later developed into the European Community Health Indicators Monitoring (ECHIM) project, to develop and implement a short-list of health monitoring indicators. Child Health was seriously under-represented in the resultant short list and long list indicator sets, and moreover most of the child health indicators selected were already collected by other agencies, rather than filling any of the many gaps. The ECHIM project concluded in June 2012. More work is needed to provide a comprehensive and comparable set of indicators of child health at a European level.

Recommendation

Objective: To improve the availability and comparability of child health indicators at European level.

Methods: The establishment of common data collection methods and improvements in indicator methodology are required for better information and knowledge.

Expected Impact: Valid common indicator sets as well as data quality at a European level.

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3.7.3 Electronic Health Records

| | |
|-----------------|------------------------|
| Knowledge gap + | Implementation gap +++ |
|-----------------|------------------------|

Background

An Electronic Health Record (EHR) is a systematic collection of digitally recorded health information about individuals who seek health care services, collected within a healthcare setting for use within healthcare. It is a record in digital format that is theoretically capable of being shared across different health care settings; it may include a range of data, such as clinical observations, treatments, medications, laboratory tests, diagnostic images, details of allergies, and immunisation status. Its aim is to achieve continuity of care at all times.

While a more recent vision is of a lifelong EHR from cradle to grave,¹ Europe has a long history of pioneering child health electronic records.²⁻⁴ Both child and lifelong versions of the EHR require it to be created at birth, or ideally, during pregnancy, and continued throughout childhood.

As most children and young people in Europe are born in good health, and later enjoy preventive services delivered in well-baby clinics, privately- or publically-run, an Electronic Health Record for children and young people (EHRc) is in most cases created to serve for the general surveillance of their health and development rather than curative care. An EHRc is primarily a tool for clinical work, enabling easy access for health care services for comprehensive information about a particular child. It is also a tool for instant communication between health care providers about patients.

Unfortunately, despite early proven benefits,^{5,6} and a recent study continuing to show the same benefits,⁷ an EHRc has never so far had the support to achieve widespread use across Europe – to the detriment of our care of and knowledge about the child population. It was initially probably a concept ahead of its time, being victim of the pull to integrated primary care records, and hospital records, while today modern technology would make easy data networking or broking solutions within a closed trusted environment. EHRc systems also provide a powerful tool for epidemiological, outcomes, and service evaluation purposes, but were ahead of recognition of the value of big databases holding anonymous data.

In terms of effective health care, sharing information in this way is essential, indeed one could say that not to share information can lead to a violation of children's rights in that they may, as a result, be unable to access the help and care they need.⁸ Such aggregation may also show the complete picture for children and young people presented to different clinical settings, enabling much more appropriate support to be provided. In terms of implementation of EHRcs, key issues are to pool experiences and identify current record keeping practices in Europe, and from this to develop and implement electronic health record systems to yield the benefits which continue to be demonstrated. There are also certain hurdles to be overcome, such as the legal concerns as to who owns the health records (individuals or the National Health Information System), and what penalties there are for misuse of data; how the records are paid for and managed; increasing the confidence of agencies such as health or social care to share information (which includes encouraging the software companies to develop and release appropriate tools).

Key issues

Collection of health data, either electronically or in paper format, however, is not only for the individual or the health professional. Good health data collected in an orderly manner can contribute to deeper knowledge on the health status of the population, as well as care seeking patterns. Thus, it is in the interest of the society that such information is collected in a way that supports retrieval and subsequent analysis of relevant data regarding population groups. In Europe there are many different systems for collecting data, and in many countries the data are not stored

electronically and not coordinated. There may be no systems of access to past data so that health professionals cannot cross reference experience. In addition to clinical care, good health registry data can be useful for research on clinical problems or preventive health issues. If systemically collected and of sufficient quality, access to such data gives opportunity for analysis of the health of whole populations that is both cost-effective and effective in filtering out information that adds to existing knowledge, and useful for informing health policy.

In terms of children's rights, particularly the rights of disabled children and young people to have comprehensive health care and live to their full potential, this is an important issue. There is an ongoing debate about data and data ownership in Europe and in the rest of the world,⁹ which has relevance to the creation of and research into EHRs, with the additional overlay of the rights and competencies of children and young people.

Recommendation

Objective: To establish a European project to collect and share experiences gained in the process of developing and introducing an Electronic Health Record for children and young people in Member States/EEA. Such a project would be independent from, but collaborate with, major software companies in this area.

Methods: Identification and comparison of current methods of policy formulation, system provision and funding, and data collection in nations in Europe, followed by assessing the experiences of Electronic Health Records for children and young people.

Expected Impact: Better availability of individual clinical data and of population epidemiological data; better preventive health and thus reduction of long-term adverse outcomes.

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4. Improve Research Capacity for Child Health Research

Child health research, as with any form of research, is dependent on the capacity to undertake it. Such capacity can be viewed under five headings:

- People
- Skills and Competencies
- Research-enabling Environment
- Appropriate Methods and Tools
- Looking to the future

To achieve this, a policy orientation towards young people, that says that the lives of children, and adolescents, are worth study, worth intervention, worth investment, and worth care, will be necessary.

4.1 People in Child Health research

The number of people involved in child public health research is largely determined by the funding available, and the interests of policy departments, research units, and specialist NGOs. However, effective child health research requires a combination of knowledge and skills which crosses several domains, including subject awareness, generic research and statistical skills, and importantly a cross-sectoral knowledge of a number of the issues, domains, and professions involved in determining and addressing children and young people's health. Thus initial backgrounds might include physiology, psychology, sociology, social work, nursing, medicine, environmental studies, and family studies, and to these need to be added research skills; or alternatively of holders of generic core research competencies may seek to gain understanding of the child health domain. Few, if any, people start out as child public health researchers, so it very important that interested researchers can acquire the necessary skills.

4.2 Skills in Child Health Research

Undertaking child health research requires specialist knowledge, and some very specialist skills. *Knowledge* requirement are true, of course, for any domain, but a high level awareness of child health, of its determinants, and its data sources, needs to be acquired if the efficiency and quality of research and research findings are not to be compromised. Similarly other aspects, such as the special ethical issues of researching in this area, need careful study. A particular challenge is the need to integrate high level qualitative and quantitative research methods, and to interpret these to the users of child health research, who are often policy makers in governments, businesses and NGOs.

For any early career researcher seeking to specialise and be effective in this area finding that knowledge can be a challenge. A search of the listings of postgraduate courses in Europe finds none specifically focused on “child health research”, though there are many in related fields such as child psychology, family studies, child development, and the like. It would aid effective child health research in Europe, and its conduct in all counties and regions, to identify the appropriate package of knowledge required, so that one or more institutions could provide it as a designated course for a European catchment. The determination of this is itself a small research requirement.

Recommendation

Objective: To identify the package of knowledge necessary for effective undertaking of child health research, and creation of a model curriculum.

Methods: Focused research study based on research topics, literature review, interviews, and syllabus evaluation.

Expected Impact: One or more institutions being able to offer a focused Masters-level course; more effective and efficient research being undertaken.

The *skills* required depend on the precise field of research being undertaken, such as ascertaining the views of teenagers, data gathering with pre-school children, or finding child-specific material in statistical sources. No one course is likely to be appropriate, so skill acquisition will be much more of a personal journey. Sources such as the RICHE self-reporting inventory of skills should be valuable in enabling direct contact with other research workers with these skills, to enable skills acquisition, secondments, or apprenticeships through European Commission programmes such as Marie Curie and Erasmus.

Furthermore, there is no identifiable and cost-effective forum for child health researchers to meet, share knowledge, and debate current issues including tools and methods. Current public health meetings, even with a child health track, are very much focused on short papers, while summer schools accommodate only small numbers and tend to take a few topics deeply. Low cost means of interaction would promote more effective child health research.

Recommendation

Objective: To establish a working forum (virtual and physical) to enable development and sharing of child health research skills.

Methods: Assessment of unmet need, researchers’ views, and possible European opportunities.

Expected Impact: More effective research through better sharing of skills and focussing on issues and solutions.

4.3 Ensuring an Effective Child Health Research Environment

Undertaking child health research has special challenges of which one is the invisibility of children and young people in general public health and population data, and a second is ethical challenges.

Getting information about children and young people is difficult as their records are usually linked with their parents – and in some cases such as obstetric and genetic history inevitably so. Data about children and young people’s living environment are usually locked into household level data, and this is seldom analysed in a child-centred way. This is a relatively easy and cost-effective way to obtain rich data, for example exposure to domestic tobacco smoke, and the data have already been collected (see Chapter 3.7.1).^{1,2}

Furthermore, gathering individual information about children and young people faces challenges which have not been fully overcome, as does the separate but related issue of obtaining the experiences and views of children especially young children. Parents often act as proxy informants, but they may not give accurate information, particularly on issues like parenting, household behaviour, the more contested areas of development, such as sexuality and risky behaviour, or challenges to health such as smoking or diet. Parents simply may not know all the details of a child’s daily life and experience, may not represent the child's views effectively, and moreover, may not be aware of that. It is noticeable that the priority list of unmet child research topics identified by the RICHE project includes at the very top issues such as pre-school child health, child mental health and well-being, maternal health and in utero health determinants, family lifestyle issues, and better understanding of child abuse and neglect (see Chapter 3), all topics on which data gathering currently faces major challenges.

New research methods are needed to capture important, and often, concealed data. This demands a sensitive and ethical approach, which respects individual and family privacy, but also considers the needs of children and young people – the research equivalent of the clinical data disclosure rule of over-riding public health or individual health interest. This conundrum is exacerbated by the fact that effective public health research needs data from a cross-section of the whole relevant population, not just those who are the prime subject of study, so as to give comparators and thus determine significance. Lack of this specific ethical framework is hampering research in key areas.

Recommendation

Objective: To research, consult, and seek consensus on a developed ethical framework for child health research (a) where young children are involved; and (b) where parents may not be an accurate source of the data, recognising that sound ethical principles are important but that current constructs may inhibit gaining of knowledge which would enable better protection of children and young people.

Methods: Literature reviews, expert consultation, consultation in professional and public interest domains, confirmation of developed ethical frameworks and related governance.

Expected Impact: Facilitation of more effective research in challenging priority areas.

4.4. Appropriate Child Health Research Methods and Tools

The challenge of obtaining information *about* children and young people has been partially addressed above, insofar as routinely collected data for populations are concerned. However, as indicated, new tools are needed to be able to gather effectively and ethically data about *individual* children, and about their wider context, whether about children and young people in particular situations, or from a representative population sample. Without such approved methods and tools research is hampered, knowledge is not generated, and children and young people at risk may suffer.

Recommendation

Objective: To develop, through research and validation, a data-collecting set of tools to enable the accurate obtaining of health information and views about individual children and young people, according to age-group and health topic.

Methods: Examination of unmet research needs; consultation with topic experts and child advocates, assessment of ethical and accuracy issues, and validation in practice.

Expected Impact: Significantly improved data about children and young people related to specific health-threatening issues.

Equally challenging is the obtaining of information *from* children and young people – whether about living environment, diet and food intake, social and peer pressure exposure, or personal anxieties, worries or beliefs, in particular. The Health Behaviour of School-aged Children (HBSC) study series makes an important contribution but covers only three age groups (11-, 13-, 15-year-olds), and has limitations not least over frequency and flexibility – it is more a data source than a tool.

Creation of appropriate data-gathering research tools is a major need but itself needs resourced research. A major European success was the creation (through funded research) of the KIDSCREEN

tool to obtain the health views of children in the age range from 8 years upwards, and the DISABKIDS tool for children and young people with a disability. But as identified earlier, several current unmet research priorities relate to pre-school and primary school age children, who are learning from their environments and establishing their own health behaviour, and sadly in some cases developing mental anxieties, eating inappropriately, and/or suffering undetected neglect or abuse. It is seen as an important priority to build on the KIDSCREEN success by developing through research a set of equivalent tools for younger age-groups.

Recommendation

Objective: To develop, through research and validation, a set of tools to enable the accurate obtaining of health information and views from children and young people, according to age-group and health topic.

Methods: Multiple research methods linking public health researchers with child psychology, development, and behaviour experts to create new innovative tools, including use of play and drawing; validation of the tools in practice.

Expected Impact: Effective research in currently unresearched areas; as a result, creation of effective policies and interventions.

4.5. Developing future child health scenarios

The development of policy strategies as well as the identification of research priorities requires foreseeing the future at least as much as understanding the past. Knowing in what direction the main determinants of health are moving is crucial for informing effective policies, including prioritising resource investments. While research provides accurate information on current health status and factors having impact on health, projections into the future are much more difficult, due to complex multifactorial causal pathways and difficulties to standardize results.³ The development of future scenarios requires multidisciplinary expertise (health, social, economic, etc.) The 2010 Global Burden of Disease study⁴ has included attempts to estimate future trends in the GBD

Child health researchers and other experts should engage, together with experts in other disciplines, to build future scenarios of child health. This enables far-sighted policy making. Credible exercises to develop scenarios in health should take into account: temporal trends in health status indicators; new knowledge about causality; technological advances relevant to health; trends in the most important determinants of health; policy developments, not only in health, but across all sectors.^{5;6} Finally, as a consequence of the current economic difficulties in Europe, the consequences on children and the limitations in welfare policies, it is also likely that health inequalities will increase particularly in the earliest years.⁷

Within the RICHE Work Package 3 (Gaps) investigations a preliminary exercise was done to identify these trends, it showed that there is likely to be a further increase in risk factors and conditions such as premature birth, low birth weight, obesity, unhealthy health styles, and in chronic conditions such as mental health disorders, cancer and non-communicable diseases. At the same time, it is unlikely that such technological advances as genomic medicine will be sufficient to address the early onset of many lifestyle related chronic illnesses, such as obesity, hypertension, and dyslipidaemia. In the future, newly developed biological drugs may be accessible to very few if their costs continue to increase.

It is also foreseeable that ICT developments and social networks will play a greater role in influencing the lifestyles of the new digital natives. The persistent economic crisis means that the proportion of children living in poor families will continue to increase, and many of these will be children from migrant families, who have additional psychosocial risk factors.⁶ An increasing use of alcohol and drugs and other unhealthy lifestyle choices are likely as a consequence of increased uncertainty about the future. Finally, current policy developments include trends towards restrictive migration policies and restrictions in welfare policies, yet there are unmet gender and civil rights issues in many countries.

This preliminary exercise shows the wealth of strategic knowledge that could be produced by conducting this exercise with adequate resources and competences, well beyond the child health arena. The establishment of a European observatory on early years may provide an ideal environment for making this exercise sustainable as an on-going activity to inform health related policies in the future.

Recommendation

Objective: To develop innovative multidisciplinary approaches and methods to build credible future scenarios in health with particular attention to the earliest years of life. To establish European capacity to identify future trends in health by creating interdisciplinary networks of researchers in key domains such as economics, sociology, ICT and public health.

Methods: Currently used methods based on analysis of risk factors should be complemented by a social determinants approach, looking at their role in shaping future health. Systematic reviews of available information on child health trends should be complemented by analysis of grey literature and reports. Trends in the main social determinants of child health should be analysed to build a variety of possible future health scenarios, taking into account variables such as macroeconomic and social policy environments.

Expected Impact: Credible future scenarios in child health, and forecast on the impact of a variety of policy environments will be useful to inform policy at European level, within and beyond the health sector.

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5. Conclusion

Our key task on this project was to produce, and justify, a roadmap for the future of child health research in Europe. As part of this, we have prepared an inventory of child health research in Europe; compiled an inventory of child health indicators; examined the inventory, and solicited expert input to identify gaps; and finally, prepared this report of recommendations for future research in child health.

Challenges

Our work is a series of value judgements. There are no objective, and unconditionally valid, answers to the question “*Is there enough research on this topic?*”, nor to the equally reasonable question “*Is this topic of significance?*”. Our intent was to provide a reasoned justification for our recommendations, using an open, inclusive, and transparent process. We have sought to make our values and the bases for our judgements as explicit as possible. A key value judgement for each reader to make is to ask how well, overall, we have achieved this goal.

Our core value is to put children first in our work. We take the rights of the child seriously, and we are conscious that many children do not have the opportunity to exercise the right to health and healthcare that children living in a wealthy, stable democratic society ought to have. Within this frame we have tried to select research topics which are both *researchable*, that is which are within the grasp of presently available research methods and resources, and *important*, in the sense that the subject of the research is believed likely to have a significant effect, for good or ill, on the lives of European children.

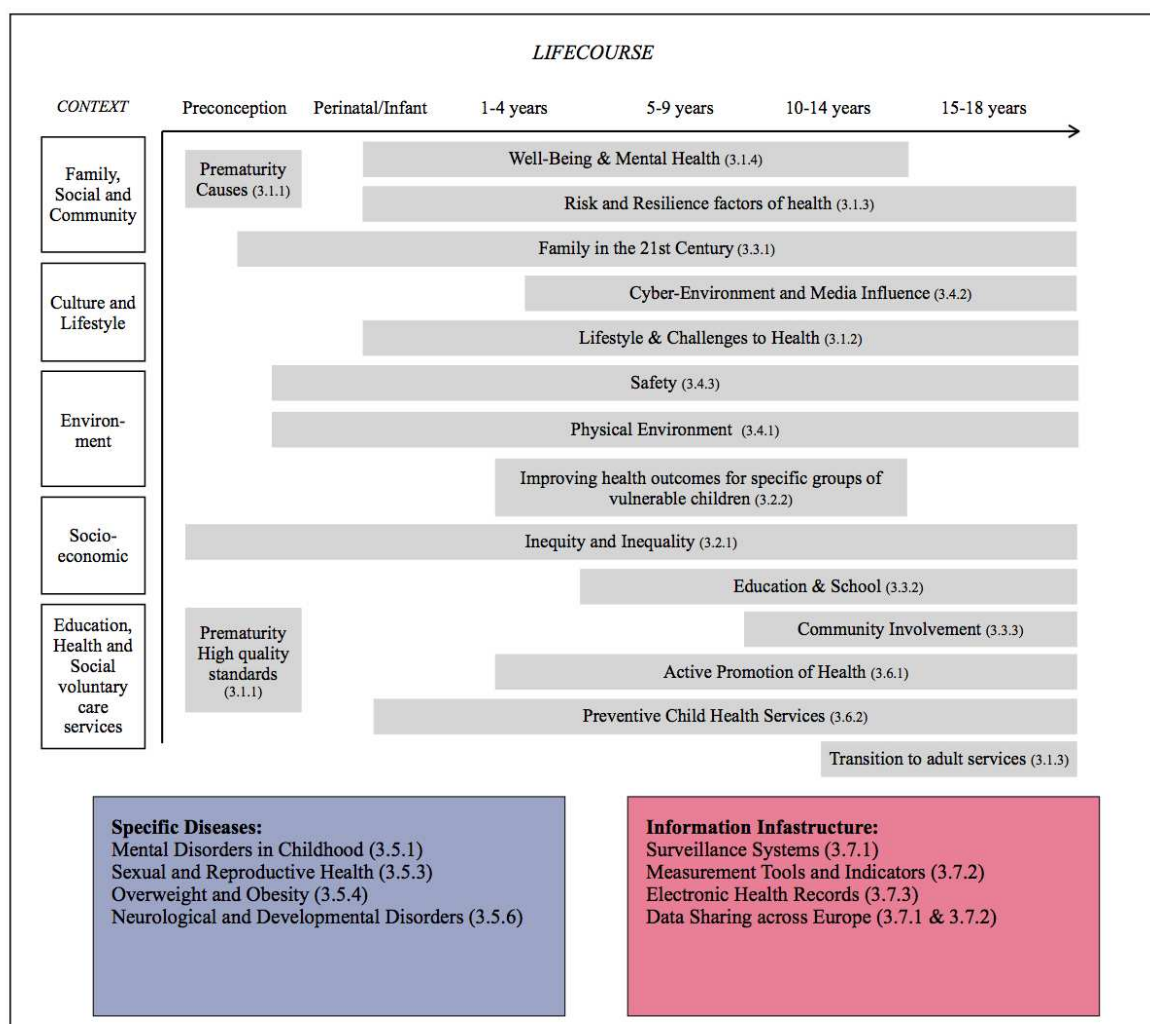
We have tried to strike a balance between looking at topics relevant to those groups of children who are most severely disadvantaged, for example children from ethnic minorities, and the children of legal and illegal immigrants; and looking at topics which affect nearly all European children to some extent. For some topics, we have been able to identify world leading experts, whose experiences and insights flowed into our recommendations. For others, we have had to rely on our own resources and capabilities. As a large multi country research group, we are well aware of the heterogeneity of our report and we accept that there are likely to be errors both of judgement and of omission in our results. However, we are in agreement that this Roadmap, produced by an inclusive and consensual approach process, represents a “best buy” and a well-founded set of recommendations for the Commission and other research funders.

Findings

Research priorities for the future

There is a large volume of research on child health across Europe, and a further large volume of work carried out in other countries, and relevant, or potentially relevant, to the health of European children. Our Gaps analysis has identified several key themes which make up the foundations for a roadmap of research activity for the future. These have been laid out earlier in this report and are succinctly illustrated in Figure 2, on page 17, which is reproduced below. We are taking these themes to national groups for their consideration and debate, and they represent a common starting point for in and between country discussion and research prioritisation.

Figure 2: The Interactions of the Roadmap Topics in a Life-course Perspective



There are two dimensions which we wish to particularly emphasise. The idea of European Added Value (EAV), and that of keeping an eye on future needs and trends in child health through monitoring, and looking at the use of evidence in child health.

European Added Value (EAV)

One essential criterion for European funding of research, is that there is added value in carrying out the work within the framework of an EU funded research programme. The principle advantage of a whole continent approach to child health is to exploit the great diversity of cultures, policies and resources within Europe, and compare interventions and specific programmes aimed at improving the health and well-being of its children and young people. We can, and must, learn from each other. Certain countries have either more experience or better resources to deal with specific child health issues, and so can serve as “beacons” for development for the whole continent.

Meaningful cross country comparisons are enhanced considerably by well validated routinely collected indicators of child health and its determinants. In this report we have suggested several ways of improving the accessibility and quality of child health surveillance in Europe, and a tool for already available indicators has been created on the RICHE website www.childhealthresearch.eu. This same website has been a useful tool in bringing together a number of experts in child health during the time of our project, signposting to articles and reports on topics and we believe having the potential to grow further as a “platform” for those researchers and policy makers as well as young people themselves wishing to search for or add relevant information in their fields of interest in a way which is highly relevant to a European context.

Child Health Research – an Implementation Deficit

We have described in some detail avenues which might be explored to increase capacity for supporting and sustaining child health research in Europe over the next decade. We have shown that, for many common situations, what is required is more research on implementation of child health supports. Without a significant base of research in this area, very large costs will arise in trying to implement inappropriate interventions, implementing remedial “cures” when prevention would have been cheaper and also less damaging, or failing to implement appropriate ones. A significant base of capacity for undertaking, and understanding, child health research is essential to deliver services, effectively, and efficiently.

Child Health Futures

More fundamentally, the benefits of improved child health will only be achieved if societies are aware of how far they fall short of what could be achieved. The economic merits of the case of investment in child health are well established, most notably in the work of Nobel laureate James Heckman.¹ As the population of Europe ages, and, without considerable immigration, declines over the next fifty years,² it will become ever more important to achieve the best possible outcomes for every child in Europe – both to optimise the health of each individual, and to maximise the social capital of healthy older citizens able to contribute to their peers’ well-being.

This will not happen unless children become substantially more visible in our societies. One of our partners pointed out that their country has far more detailed information about every calf, piglet, and lamb, than it has about every child. This is amusing, but reflects a widespread issue. Many European children's lives are invisible. Sometimes they are submerged with their families, as is the case for the Roma, for Irish Travellers, and for many children of illegal and undocumented immigrant families. Even for well documented families, records are often presented from the perspective of the economically active adults, and the data on children are not routinely available. Indeed, even in the analysis of fully stable populations, such as through censuses and household surveys, children are counted in total, but the results are never analysed from the perspective of children's domestic and social environments.

We have identified two approaches to these issues. The first is a wider use of the many existing and well validated indicators, which we have collated as part of the overall RICHE project. The second, which is described in detail earlier in this report, is the development of child focused reports from routine statistics. Modern technology makes the technical problems which arise comparatively trivial. What is lacking is the political desire.

Making Children and their Health visible

Individual recommendations appear throughout this road map set in the context of the child health aspects systematically reviewed. However, an overarching theme to emerge is the lack of any appropriate coordination of the identification and representation of the needs of Europe's children, coordination of research to focus on current and emerging priorities, or appropriate strong profiling of children's research needs and health issues.

Therefore, an overarching recommendation in this road map is the establishment of a European Child Health Observatory with a simple remit to make European Children, and their lives, health, and their attainment of rights more visible.

The European Commission has shown and invested in the value of European expert collaboration centres on health issues, such as those shown by the European Communicable Disease Surveillance Centre, the European School Survey Project on Alcohol and other Drugs (ESPAD), and the European Observatory on Health Systems and Policies – to all of which a European Child Health Observatory could link. Such an initiative could also maintain and promote the platform and database of knowledge and experts which was created for the RICHE project. Such an organisation would meet a major gap, while complementing other observatories of health, well-being, policies and statistics but which omit any focus on the vital topic of child health. It could readily be established with a small core expert function complemented by a virtual organisation of national agents and specialist European agencies, working across Europe and gathering information on our children, on the policies which affect them, and on the evidence base for those policies. The Child Safety Report Cards initiative European Child Safety Alliance³ shows the huge impact such a researched and evidence-

based approach can have, while the Innocenti report cards, prepared for OECD member states by UNICEF,⁴ provide one model of how this sort of work could be taken forward and applied systematically to benefit all the children of Europe.

Recommendation

Objective: To monitor and promote current and emergent child health issues; stimulate and coordinate child health research and knowledge implementation, and advocate for children be ensuring the visibility of child health issues in Europe.

Methods: Establish a focused European Child Health Observatory, linking to other initiatives with a specific contribution to offer, working virtually with national agents and with expert centres, and facilitating the continuation of the RICHE platform as a knowledge repository of research results, grey literature, research projects, and child health research community members.

Expected Impact: Raising the profile of child health issues in Europe and potential means of addressing these, advocating for children's health at a European level, and thus improving the health of children in Europe and thereby ultimately of the overall European population. .

Moving Forward

This roadmap proposes actions, yet at the same time our work inevitably has limitations. The first action will be to stimulate discussion of its contents, and rationale at political, policy, professional and societal levels, to raise public awareness of the issues and at the same time ensure improvement of the content through that exposure.

Possibly the main weakness is the limited scope for more radical thinking as to the scope of child health and its determinants. While we were clearly excluded clinical paediatrics, and included traditional child health determinants, such as poverty, nutrition, and environmental issues, the boundary of child health is inevitably very fuzzy. This makes it difficult to decide all the research areas to include, or indeed how and whether to engage with the scientific and policy communities which do not traditionally see that they have a role in child health. Thus we have not managed adequately to cover the effects on children's health of the built environment, nor have we included issues such as fiscal policy (which can affect many health determinants such as safety equipment and food pricing), welfare policy (though poverty is a key determinant of poor health), nor immigration policy (which can affect unsupported entrants, but also the supply of labour). In short, the Commission's approach of Health in All Policies can be extended to recognise that many policy areas can affect children's health. So our second action will be to take this work outwards in order to stimulate discussion and self-examination in these adjacent and related domains, to identify their related research gaps.

Thirdly, young people should be more engaged in identifying future research needs and gaps, and indeed in contributing ideas for new child-aware research methods. We could not take this as far as we would have liked, though that can be rectified.

Thus in essence we suggest that the necessary next steps are promotion and discussion; refinement; resourcing; and extension. But while necessary, these must not be reasons for delay. We now know enough as a result of this project to be able immediately to start taking action to improve research into child health and its determinants in Europe, and to improve the health of those who really are “all our futures”.

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