Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care



Building a Europe
for and with children

COUNCIL OF EUROPE
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Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care

Council of Europe

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Foreword

The health and well-being of children are priority goals shared by all Council of Europe member states. But the full enjoyment by children of the highest attainable standard of health remains a distant goal. Significant inequalities still persist in health status and health outcomes of children and their families within and between member states. Some children may be vulnerable because of poverty, abandonment, migration status or other reasons, and may therefore experience discrimination or other barriers in access to health care. These children need special protection to ensure that their rights are respected in an equal manner. More generally, many children continue to lack access to basic health care, in Europe, today.

Protection and equitable access to health care are the right of all children, without any discrimination, in order to enable their well-being and healthy development. All efforts to go further than offering standardised health services and to aim for the development of solid, long-term health policies targeting the well-being of future generations should be encouraged.

Children need a health care system that is accessible, takes into account their rights, their needs, their feelings and opinions. They wish to be listened to, to be respected and to be explained issues in a way that they can understand. So, once they come into contact with the health care system, they have the right to quality services, to be informed and to participate in decisions affecting their health and well-being.

The Council of Europe adopted these Guidelines on child-friendly health care to offer member states a clear outline of an integrated and multi-disciplinary approach to follow, to help create alignment and synergy between different kind of interventions, organisations and individuals for an efficient, child-centered health care.

These Guidelines may well be for the member states to use and disseminate among policy makers and health care professionals, but ultimately they are offered to our children.



Snežana Samardžić-Marković
Director General of Democracy

Guidelines on child-friendly health care

(Adopted by the Committee of Ministers on 21 September 2011 at the 1121st meeting of the Ministers' Deputies)

Preamble

The Committee of Ministers,

Considering that the aim of the Council of Europe is to achieve greater unity between its member states, *inter alia*, by promoting the adoption of common rules and actions;

Considering the necessity of ensuring the effective implementation of existing binding universal and European standards protecting and promoting children's rights in general, as well as those covering aspects specific to health care, including:

- the United Nations Covenant on Economic, Social and Cultural Rights (1966), and in particular its Article 12 on the right to the highest attainable standard of health;
- the United Nations Convention on the Rights of the Child (1989);
- the United Nations Convention on the Rights of Persons with Disabilities (2006);
- the Convention for the Protection of Human Rights and Fundamental Freedoms (1950, ETS No. 5);
- the European Social Charter (1961, ETS No. 35) and the Revised European Social Charter (1996, ETS No. 163);
- the European Convention on the Exercise of Children's Rights (1996, ETS No. 160);
- the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1987, ETS No. 126);
- the Council of Europe Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse (2007, CETS No. 201);
- the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997, ETS No.164), in particular its Article 6;

Recalling relevant texts adopted by the Committee of Ministers concerning children[1] and those concerning health care;[2]

Bearing in mind the Charter for Health Promotion (1986, Ottawa), and the European Charter for Children in Hospitals (1988, Leiden);

Bearing in mind that all Council of Europe member states adopted and are implementing the health for all policy framework "Health 21" for the World Health Organization (WHO) European Region in particular its target 4 – health of young people;

Taking into account the relevant recommendations of the Parliamentary Assembly of the Council of Europe and statements of the Council of Europe Commissioner for Human Rights;

Referring to the work of the Council of Europe Programme "Building a Europe for and with children", its 2009-2011 Strategy for the Rights of the Child and the future 2012-2015 Strategy for the Rights of the Child;

Recognising children as bearers of rights, including the right to the enjoyment of the highest attainable standard of health, the right to be protected, the right not to be discriminated against and the right to express their views and participate, the views of the child being given due weight in accordance with the child's age and degree of maturity;

Bearing in mind that, in all actions concerning children, the best interests of the child shall be a primary consideration;

Considering that, whenever appropriate, children's parents, other family members and carers should be closely involved in decisions relating to their health;

Considering that children, by reason of their physical and mental immaturity, need special safeguards and care, and that there are significant inequalities between and within member states of the Council of Europe in the determinants of health, access to health care and the quality of health care;

Recognising that promoting the health and well-being of children, with particular attention to the safety and quality of services, is important to society as a whole;

Conscious of a substantial change in the epidemiology of morbidity and mortality in children over the last half century throughout Europe and the cost-effectiveness of new evidence-based child-friendly health care approaches, investing in integrated

1. Guidelines on child-friendly justice, adopted on 17 November 2010;
   Recommendation CM/Rec(2010)2 on deinstitutionalisation and community living of children with disabilities;
   Recommendation CM/Rec(2009)10 on integrated national strategies for the protection of children from violence;
   Recommendation Rec(98)8 on children's participation in family and social life.
2. Recommendation Rec(2006)7 on management of patient safety and prevention of adverse events in health care;
   Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015;
   Recommendation Rec(2000)5 on the development of structures for citizen and patient participation in the decision-making process affecting health care.

services for vulnerable and disadvantaged children and families, with long-term gains in health, well-being and life chances;

Emphasising the need to create coherent policies and synergies towards a co-ordinated approach for children at all levels of government and at all levels of health-service provision in particular;

Recognising the importance of ensuring participation of civil society, in particular bodies which aim to promote the rights of the child, in the elaboration and dissemination of a child-friendly health care approach,

Adopts the following guidelines on child-friendly health care to serve as a practical tool for the governments of the member states in endorsing, adopting, implementing and monitoring the child-friendly health care approach contained therein and adapting their health care systems for children and families to the specific rights, interests and needs of children;

Invites the governments of the member states to ensure that the guidelines are widely disseminated among all authorities, service providers, groups representing the interests of children and families and other stakeholders responsible for or involved with children's rights, particularly in health care.

I. Object and purpose

1. The guidelines on child-friendly health care propose an integrated approach to the development of the full range of child health care activities.

2. This approach places children's rights, needs and resources at the centre of health care activities, taking into account their family and social environment. It promotes policies to deliver child-oriented services based on child-specific developmental needs and evolving capacities, ensuring children's participation at every level of decision making, in accordance with their age and degree of maturity.

II. Definitions

3. For the purposes of these guidelines on child-friendly health care (hereafter "the guidelines"), "child-friendly health care" refers to health care policy and practice that are centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion.

4. A "child" means any person under the age of 18.

5. A "parent" refers to the person(s) with parental responsibility according to national law. In case the parent(s) is/are absent or no longer holding parental responsibility, this can be a guardian or an appointed legal representative.

III. Principles of the child-friendly health care approach

6. The guidelines build on the existing principles enshrined in the instruments referred to in the preamble. They are further developed in the following sections and apply to all chapters of the guidelines.

A. Fundamental rights and children's specific rights

7. All children should be considered and treated as bearers of human rights as proclaimed in the existing international instruments.

8. It is also recognised that children are entitled to special care and assistance, and that children in difficult conditions need special consideration.[3]

9. The rights of children shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

B. Dignity

10. All children should be treated with care, sensitivity, fairness and respect throughout any health care intervention, with special attention for their personal situation, well-being and specific needs, and with full respect for their physical and psychological integrity.

C. Participation

11. It is an established principle that a child who is capable of forming his or her own views has the right to express those views freely in all matters affecting himself or herself, the views of the child being given due weight in accordance with the child's age and maturity.[4]

12. In the health field, this principle has two dimensions:

i. When a child, according to law, is able to consent to an intervention, the intervention may only be carried out after the child has given his or her free and informed consent. When, according to law, the child does not have the capacity to consent to an intervention, the opinion of the child shall be taken into account as an increasingly determining factor in proportion to his or her age and degree of maturity. Children should be given appropriate information beforehand.

ii. Children should also be considered as active members of society, and not as mere passive subjects of decisions taken by adults. This implies, taking into consideration their age and degree of maturity, their being informed and consulted, and given the opportunity to take part in social decision-making processes on health care issues, including the assessment, planning and improvement of health care services.

D. Equitable access to quality health care

13. All children should have equitable access to quality health care services. This includes prevention, promotion, protection and provision of services with the active involvement of children.

3. Preamble of the United Nations Convention on the Rights of the Child.
4. Article 12 of the United Nations Convention on the Rights of the Child.

14. Specific health care provision may be needed for more vulnerable children, such as children with disabilities, children in residential institutions, homeless and street children, children living in low-income families, Roma children, migrant children, refugee and asylum-seeking children, unaccompanied children and abused and neglected children.

E. Best interests of the child

15. In all actions concerning children, the best interests of the child should be a primary consideration.[5]

16. In assessing the best interests of the child, all his or her rights and interests should be taken into account. Potentially conflicting rights and interests, such as the right to protection and the right to participation, should be carefully weighed to determine the best interests of the child in the circumstances of each case.

IV. The child-friendly health care approach

A. The rights underpinning the child-friendly health care approach

17. The child-friendly health care approach constitutes an integrated conceptual and operational framework which fully respects children's rights, health needs and resources and therefore underpins all models and programmes.

18. All health care systems are currently facing comparable challenges. The epidemiology of childhood conditions is changing, current systems are not achieving all their expected outcomes and there are often unacceptable variations in the quality and outcomes of services for children and families. Rising costs of health care are a constant concern. Achieving improvements is often difficult without a shared approach to the planning and delivery of services, and for the achievement of better value with the combined resources available, it is essential that all services and stakeholders work together.

19. The importance of good co-ordination and continuity of care based on an integrated and multi-disciplinary approach, sometimes referred to as a "continuum of care", should not be underestimated. This extends across the traditional boundaries of primary, secondary and tertiary health care organisations, involving health, education, social care and justice systems whether in the public, private or voluntary sectors.

20. The aim of the child-friendly health care approach is to integrate the relevant rights of children with respect to health and health care into a practical framework that drives cultural change and consequent improvement in all services which contribute to the health and well-being of children. This approach should be applicable at the level of policy/planning development, at the service-delivery level and at the level of individual children and families. The approach is universal, but one which each member state can adapt to its own situation.

5. Article 3 of the United Nations Convention on the Rights of the Child.

21. "Child-friendly health care" includes the notion of "family-friendly", facilitating bonding between newborn babies and their mother/parents, facilitating contacts between the child and his or her family and preventing the separation of the child from his or her family unless it is in the best interest of the child.

22. Five principles, enshrined in the conventions outlined in the preamble, are particularly relevant to the child-friendly health care approach:

a. Participation

23. Participation means that children have the right to be informed, consulted and heard, to give their opinions independently from their parents and to have their opinions taken into account. It implies the recognition of children as active stakeholders and describes the process by which they take part in decision making. The level of child participation depends both on his or her age, evolving capacities, maturity and on the importance of the decision to be taken.

24. Parents and families should encourage children to participate in family, community and society decision making – encouraging increasing independence and reducing their support as the child's capacity for autonomy and independence develops.

b. Promotion

25. Health promotion is "the process of enabling people to increase control over their health and its determinants and thereby improve their health".[6] Promotion therefore includes all actions that allow children to become more involved in their own health and increase their exposure to positive determinants of health (defined as factors which will improve health or well-being). Health promotion covers not only activities in families and communities, directed at health determinants or lifestyles, but also factors in health care services and settings which will improve outcomes.

c. Protection

26. Health protection includes all actions that either limit or avoid children's exposure to any hazard which can be defined as a factor that has the potential to cause harm. Hazards can occur in families, communities and health services. Medical interventions can cause harm and patient safety perspectives highlight the fact that children are particularly vulnerable to medication errors and hospital-acquired infections.

d. Prevention

27. Prevention is an active process the aim of which is to avoid future health, social or emotional problems in order to enable the fullest realisation of human potential. This includes action to reduce adverse health determinants, to prevent the development of a disease or condition, to avoid complications of a disease or condition, to prevent the impact of a disease or condition on the lifestyle or aspirations of an individual and to prevent harm caused by a service or intervention.

6. Health Promotion Glossary, WHO, 1998.

e. Provision

28. Provision refers to any service which contributes to the health and well-being of children and families, and therefore includes more than just traditional health services. "Pathway-based provision" is a concept that describes all the component parts that need to be in place and working well together to achieve an excellent patients' experience which brings about optimal outcomes for children and families in their journey safely through services.

B. A description of the child-friendly health care approach

29. The goal of the child-friendly health care approach is to ensure that the right things happen, to the right children, at the right time, in the right place and using the right staff, who are supported in the right way, to achieve the right outcomes, all at the right cost. Overall, the aim is to improve the quality of health care primarily defined by effectiveness, efficiency and equity simultaneously with attention to patient safety and satisfaction/experience. To this end, the purpose of the services should be combined with the relevant child-friendly principles in a practical approach that is applicable to individual children and families, those providing services and which informs higher levels of service planning and policy development.

30. The child-friendly health care approach assumes that at the heart of all services are the needs of children and their families. Services are then designed to enable the child and his or her family to receive a whole range of interventions, including promotion, prevention and treatment and the help and support they require, in a way that suits them and their circumstances. The individual experience of a service is called a "journey", groups of similar journeys are called a "pathway", with each individual component part being delivered by a team, with all the teams working collaboratively within a "network" that strives for continuous quality improvement.

31. For many long-term conditions, there is an initial pathway which spans the development of the condition, its identification, initial assessment and management. This is followed by a cyclical pathway where the condition is reviewed on a regular basis with a focus on the best management of the condition and prevention of complications or other morbidities. There is then a transition pathway which may represent the transition to adult services, transition back to normal if the condition has been cured, or, in the worst case, into palliative care services if there is further deterioration likely to result in death.

32. There are generally four components for each pathway: prevention, identification, assessment and interventions. Each of these components needs to be evidence-based, delivered by competent practitioners working in teams, provided in the right place and at the right time in order to ensure the right outcomes at the right price.

33. The child-friendly health care approach recognises that interventions should focus not only on managing the child's health condition, but also on their physical or social environment, thus avoiding the medicalisation of social problems. It includes addressing environmental issues (air and water quality, sanitation), socio-economic problems (poverty, social exclusion, poor housing and nutrition), access to education, or parental issues (parenting skills, parents' mental health, domestic violence or substance abuse).

34. It is important to stress the need to support children in cases where parents suffer from severe physical or psychiatric conditions, drug abuse or when parents suddenly die.

35. At each stage of the pathway, children, according to their age and maturity, and their families should be fully informed and involved. Children should be encouraged to exercise their right to participate in the decisions being made about their health or condition. Such involvement is particularly important in the cases of long-term conditions so that children are fully prepared to play an active role in managing their condition.

36. The pathway, whether initial, cyclical or transitional, should have a clear, proactive focus on prevention, either through the promotion of well-being, the protection from possible harm or early detection of potential problems.

C. Application and advantages of the child-friendly health care approach

37. The most important benefit of the adoption of the child-friendly health care approach is to bring about harmony and synergy between all the interested parties – government departments, organisations or professional groups, including children and families themselves – to create an integrated system allowing them to work together on the planning of future services for children and to consolidate and improve existing services. Three examples, corresponding to three different perspectives, will be used to demonstrate the application and advantages of the child-friendly health care approach: those of children and families, service providers and policy makers/planners.

38. This child-friendly approach will bring the following advantages to children and families:

i. a comprehensive range of services which both promote and protect their health, coupled with timely, accessible and affordable services when problems occur;

ii. when using services, all component parts required to achieve a good outcome should be in place and work well together;

iii. they are able to participate in decisions concerning them and are encouraged to provide feedback on their experience of services.

39. Service providers focus on ensuring that evidence-based interventions are delivered by competent practitioners, in the right place and at the right time. Good co-ordination and coherence between different interventions and institutions should be underlined as key points of a successful strategy. The advantages should be:

i. improved safety, experience and outcomes;

ii. a workforce committed to multidisciplinary collaboration, innovation, learning and improvement;

iii. reduced costs if the potential for prevention is realised.

40. Concerning policy makers[7]/planners: the child-friendly health care approach can be used as a policy/planning tool to align objectives and values between:

i. government departments, professional bodies and other agencies responsible for policy development;

ii. organisations responsible for the commissioning and planning of services by different agencies;

iii. by organisations and agencies responsible for the regulation and improvement of services.

V. Implementing the child-friendly health care approach

41. The priorities for implementation vary considerably between and within different member states. Three options are available, allowing for the development of an "integrated learning system", which is the practical tool for implementation of the child-friendly health care approach, based on the five guiding principles.

Participation

42. Meaningful participation requires children and families to be fully informed about the issues they are considering in order to improve the quality of their decision making. This requires relevant information to be presented in ways appropriate to the level of development and capacity of the child. Participation should be exercised at three levels:

i. individual decision making, whether this be lifestyle choices or involvement in medical decision making. Implementation will require accessible information, clinical staff able to communicate with children and measures for mediation when differences occur;

ii. children should be given the opportunity to provide feedback on their experience after they have used services. Implementation will require the development of assessment of both patient-reported outcome and patient-reported experience and different methods of involving them in the process (individually and with peers);

iii. with increasing maturity and capacity, children should be involved in the policy/planning process for the services they use. Implementation will require appropriate training/learning opportunities to enable them to participate in this process, for example understanding priority setting.

Promotion

43. Effective health promotion requires synergy between evidence-based interventions at a number of levels simultaneously. It is relevant to all children, particularly the most vulnerable, and those using health services:

i. *All children*. All children should participate in health-promotion programmes and policies, such as child-friendly cities, child-friendly schools, and child-friendly child care;

7. The term "policy" is used in the sense of "courses of action, regulatory measures, laws, and funding priorities concerning a given topic instituted by a government, its departments or representatives".

ii. *Vulnerable children*. The determinants of health are not equally distributed among children in society, whether they be social, emotional or financial. Where there is poor parental health**,** especially mental health, learning difficulties or substance abuse, children will require additional targeted support to enable them to reach their maximum potential. Implementation will require a variety of evidence-based interventions being accessible;

iii. *Children using health services*. Where children have repeated or long-term contact with health services, for example with complex illness, head injury rehabilitation or severe mental health problems, it is imperative that they maintain contact with their families and their friends and that their education or future health is not impaired through a prolonged stay in hospital.

44. In order to implement the approach it may be necessary to consider the financial impact for parents whose children have long-term conditions, to offer children the possibility to have schooling in hospital and to encourage systems for maintaining contact with friends and family.

Protection

45. All children require protection from potential health hazards, but some children are more vulnerable than others either because they have a long-term condition that impairs their abilities, or because they live in sub-optimal circumstances. Children who use health services should be protected from either deliberate or unintended harm while using services:

i. *All children.* All children require protection from physical, social, emotional or financial harm. Implementation will require interventions to improve the physical environment (for example, the quality of housing, air quality, reducing the risk of injuries and preventing violence), to improve the social environment by improving parents' parenting capacity, to prevent bullying or racism and to support families on low incomes;

ii. *Vulnerable children*. Children with long-term conditions, whether illness or disability, require special protection from the recognised hazards that might affect them;

iii. *Children using health services*. All interventions and systems have the potential to cause harm and/or adverse effects. Children are often at greater risk than adults due to their immaturity and less developed language and communication skills. Implementation will require the development of a coherent and comprehensive patient-safety policy framework, including a child-friendly reporting system for adverse events in order to learn from such incidents. Professionals working with and for children should, where necessary, be subject to regular vetting, according to national law, to ensure their suitability to work with children.

Prevention

46. Proactive planning is central to preventing future problems. Unlike promotion or protection, prevention is targeted towards problems which could arise for which there are effective interventions:

i. primary prevention includes mainly population-based interventions such as vaccination programmes, the prevention of dental caries through fluoridation of water supplies, or the prevention of neural tube defects through folate supplementation in cereals;

ii. secondary prevention may be population-based, such as the early detection of deafness through neonatal hearing screening programmes, or targeted towards specific groups of children to prevent, for example, the secondary complications of diabetes, or hip dislocation in children with cerebral palsy;

iii. tertiary prevention requires interventions to prevent secondary disabilities or deficiencies arising from established medical conditions.

47. Implementation of the approach is on two levels. Member states should decide which promotion and prevention programmes should be implemented on the basis of the entire population and which should be targeted at a selected population of children. At an individual level, health professionals, children and their families should proactively plan the management of a child's condition, recognising the likely complications or associated disabilities and thereby reduce their impact on the child's quality of life and everyday living.

Provision

48. Provision is based on pathways: there are four components common to the three stages (initial, cyclical and transitional) of a pathway for a long-term condition, the component parts of each being prevention, identification, assessment and interventions. Each component part should be:

i. evidence-based;

ii. delivered by competent practitioners;

iii. delivered in the right way, in the right place, at the right time.

49. Implementation of the approach will require applying evidence-based and user-friendly guidelines for health professionals and families and make this evidence easily available to create an alignment of clinical expectations between patients and carers. Maintaining the competence of individuals working with children and families requires initial "child-friendly health care" training, support for staff implementing innovative measures in order to create child-friendly health care, and rewards for doing so. Likewise, assisting children to become "knowledgeable patients" is essential to achieve good outcomes.

50. Health care should be readily accessible to the population. Where possible, care should be delivered close to the child's home or in a familiar environment, for example in pre-school or school, where the child feels comfortable and where care can be delivered in partnership with his or her parents or carers. Where care needs to be delivered in hospital, the environment should be adapted to meet the needs of the child.

51. Child-friendly health care as an "integrated learning system": the child-friendly health care approach integrates the purpose and principles of the system into a practical approach based on pathways, which continually drives quality and improvement

of services. Three component parts are essential in creating this virtuous cycle of continuous quality improvement and learning:

i. clarity of purpose and principles;

ii. a pathway-based framework for delivery;

iii. a system which encourages innovation, learning and improvement.

52. Implementation requires the adoption, and where necessary adaptation, of this approach by all the agencies, organisations and professional groups contributing to services for children and families. It is particularly important to achieve alignment and synergy between:

i. policy makers from different sectors;

ii. commissioners, providers and regulators of services;

iii. health, education and social-care organisations.

53. It is essential to integrate a culture of learning and improvement into service delivery. Each agency should have a similar approach to the choice of evidence-based interventions, priority setting, maintaining staff competence, working in teams and continuous quality improvement.

54. Feeling safe, secure and comfortable should be part of the child's therapeutic process. This requires staff to be "child-friendly" and both culturally and clinically competent. Health care should be provided in a "child-friendly" environment, and separately from adults where appropriate. Fear, discomfort and pain should be recognised, assessed and managed using age-appropriate interventions.

VI. Promoting the child-friendly health care approach

55. The promotion of a child-friendly health care approach would require all member states to recognise the importance of children's rights at all times, in all settings. Three levels of promotion would be required:

i. promotion of children's rights;

ii. promotion of the principles, applicable to children's health services;

iii. promotion of the child-friendly health care approach, which integrates the principles into a practical model for service planning, delivery and improvement.

56. Success will depend on an alignment of motivation, thinking and action at three different levels: policy making, service planning and individual care.

57. Member states should endorse the child-friendly health care approach at an appropriate level and facilitate the incorporation and, where appropriate, the adaptation of the child-friendly health care approach into policies, service planning and practice, coupled with the development of relevant measures to monitor implementation.

58. Member states should include the principles proclaimed by the United Nations Convention on the Rights of the Child, the European Social Charter and the Revised European Social Charter, the European Convention on the Exercise of Children's Rights and the European Charter for Children in Hospitals, in all their policies, plans, and programmes.

59. Member states should organise activities or educational initiatives to promote children's rights. Human and children's rights should be integrated into the school curriculum, including links with health and emphasising the needs of vulnerable children, such as children without parental protection, those with long-term conditions and poor or marginalised groups of people in society.

60. Member states should endorse, disseminate and adapt the child-friendly health care approach to the planning and delivery of services, in order to drive improved effectiveness, efficiency, safety and equity within health care services.

61. Member states should promote the effective participation of children in improving their health, in taking part in decision making related to their care, in planning health care activities and evaluating the results, according to their age and maturity.

62. Member states should support programmes and policies aimed at raising the awareness of children and their parents of their rights to active participation in decision making and the promotion and protection of their health, by creating legal structures and policies that support the promotion of children's rights in health care, if these do not already exist.

63. In line with the "Health in All Policies" approach, governmental organisations and other relevant stakeholders contributing to the health and well-being of children should work together and strive to continually improve the quality of their services, especially safety, outcomes and experience/satisfaction of the users.

64. Member states should pay particular attention to the investment in services for children and families in order to secure sufficient resources to create a healthy future generation.

65. Member states should involve relevant institutions and stakeholders to measure and monitor the implementation of the child-friendly health care approach in their health care policies and practice.

66. Member states should exchange practice and promote international co-operation in the field of child-friendly health care.

Explanatory memorandum to the Guidelines on child-friendly health care

General comments

Why a new instrument?

1. For the Council of Europe, promoting and protecting children's right is a priority and was addressed by the Action Plan of the Third Summit of Heads of State and Government in Warsaw in 2005.

2. While a number of conventions and legal instruments exist at the international and European level, there are considerable variations in practice across Europe, and governments and professionals working with children request guidance to ensure the effective implementation of children's rights within health care systems.

Background

3. The following guidelines (hereafter "the guidelines") are a response to the European Health Committee's (CDSP) request to prepare guidelines on child-friendly health care, proposing a practical approach to assist member states to improve their health care systems. The intention is to improve safety, experience and outcomes for children using children's rights as the driving force for change.

Working method

4. With that transversal perspective in mind, the Council of Europe adopted an integrated approach bringing together multi-professional representatives from across Europe.

5. The Council of Europe started this work in 2009 with a conference in Madrid, thanks to the invitation of the Spanish authorities, to consider the challenges and obstacles faced by children in accessing and benefiting from health care systems. The findings of the conference paved the way for the formation of the Committee of Experts on child-friendly health care (SP-CFH) which was established to prepare these guidelines between 2009-2011.

Drafting process

6. This committee of experts was composed of 15 independent specialists selected by the CDSP – on the basis of their personal expertise in children's rights, while respecting a specialisation balance as well as a geographical and a gender balance. The committee was composed as follows: Chair – Mr Simon Lenton (UK), Vice-Chair – Mr Sverre O. Lie (Norway), Ms Veronika Wolschlager (Austria), Mr Erwin Van Kerschaver (Belgium), Ms Lada Sarajlic (Bosnia and Herzegovina), Ms Marjaana Pelkonen (Finland), Ms Brigitte Lefeuvre (France), Mr Erik Harms (Germany), Mr Fabrizio Simonelli (Italy), Mr Joseph R. Saliba (Malta), Ms Ana Isabel F. Guerreiro (Portugal), Mr Evgeny Makushkin (Russian Federation), Ms Vlasta Močnik (Slovenia), Mr José A. Diaz Huertas (Spain) and Mr Andrii Kurkevych (Ukraine).

7. A wide range of observers, including representatives of leading international inter-governmental and non-governmental organisations, also contributed to its work (European Youth Forum, European Patient Forum, European Paediatric Association, European Public Health Alliance, Schools for Health in Europe, European Network of Ombudspeople for Children, Royal College of Nursing, UNICEF and World Health Organisation).

8. The draft guidelines and their explanatory memorandum were examined and approved by the European Health Committee (CDSP) during its meeting held on 28-29 June 2011, before their transmission to the Committee of Ministers for adoption.

Consultation of children and young people

9. In accordance with the terms of reference, the Council of Europe commissioned Mr Ursula Kilkelly, an Irish children's rights expert to undertake a direct consultation of children and young people on health care in 2011. Around 2,250 children from 22 countries throughout Europe responded and their views were taken into account in the development of the guidelines. (http://www.surveymonkey.com/s/FRZYNDF). An extract of the final report is set out in Appendix I.

Introduction

Building a Europe for and with Children

10. The Programme "Building a Europe for and with Children"[8] was implemented in 2005 after the Third Summit of Heads of State and Government of the Council of Europe[9] and comprises two strands:

- the promotion of children's rights and
- the protection of children from violence.

11. The 2009-2011 Strategy[10] considered that vulnerable children should be a priority issue, particularly focusing on children:

- without parents;
- with disabilities;
- in or at risk of poverty and social exclusion.

8. http://www.coe.int/children
9. Third Summit of Heads of State and Government of the Council of Europe Warsaw 2005
10. https://www.coe.int/en/web/children/children-s-strategy

12. The Programme contains several projects including child-friendly social services, children's participation,[11] child-friendly justice[12] and child-friendly health care.

Child-Friendly Health Care

13. The U.N. Convention on the Rights of the Child[13] includes the right to both health and health care. Specifically article 24 states:

"States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services." This is reflected in the preamble to the European Social Charter (revised 1996)[14] which reiterates this principle: *"Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable",* and Article 11 uses the wording *"The right to protection of health."*

14. Promoting the health and well-being of children and young people is important to society, both because the antecedents of adult ill-health are often established in childhood (life course epidemiology)[15,16] and because healthy, engaged and contributing adults are more able to look after their children and an increasingly elderly population.

15. An important element is equitable access to the high-quality health services highlighted in the Convention on Human Rights and Biomedicine (Oviedo Convention).[17]

16. While health services can range from neonatal intensive care to specialist care such as heart-lung transplantation and from immunisation and screening programmes (e.g. blood spot screening) to other interventions[18] such as anti-bullying and emotional literacy strategies, the contribution of other stakeholders to the health and well-being of children cannot be overstated. Health promoting schools, social care organisations supporting vulnerable families and investigating child maltreatment concerns, the voluntary sector supporting families who have a child with a long-term condition or disability, the criminal justice system for crime and social disorder and access to housing in safe communities, all play important parts.

17. Although the rights of children are well established, they are often not translated into practice within health care and children's services so there should be a significant improvement in the process of policy making, planning and delivery. The

11. https://www.coe.int/en/web/children/participation
12. https://www.coe.int/en/web/children/child-friendly-justice
13. http://www.unicef.org/crc/
14. http://conventions.coe.int/treaty/en/treaties/html/163.htm
15. EPIDEMIOLOGY. Epidemiology is the study of the distribution and determinants and health-states or events in specified populations and the application of this knowledge to improve health.
16. LIFE COURSE EPIDEMIOLOGY. Refers to the study of the effects of earlier exposures (particularly in foetal life, infancy, and childhood) on later health outcomes.
17. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine 1997. http://conventions.coe.int/Treaty/en/Treaties/html/164.htm
18. INTERVENTION. A generic term for "therapeutic activity", altering the natural course of events; covers treatment, management, therapy, surgery and rehabilitation

"Child-friendly health care approach"[19] is a rights-based approach which focuses on improving the health and health outcomes[20] of children and families.

18. Services should be designed around children and their families and must have the capacity to work together and evolve through learning based on quality improvement and innovation so that all children receive the right care, at the right time, delivered in the right place by the right people, who are supported in the right way. The intention is that the values of the 1989 United Nations Convention on the Rights of the Child drive added value[21] within services for children.

19. This approach is universally applicable from a policy-making level through to an individual family. It integrates strategies to improve health and well-being with strategies to improve services. Active participation of children, young people and their families is critical to their decisions as well to their involvement in service planning and improvement locally and nationally.

20. The approach is based around the "journeys" (the experience of visits to health providers) that children and families take through health services aiming for a safe service that provides a good experience and better outcomes than the traditional service organisation. Teams of professionals provide the component parts of the pathway and together they collaborate within a network[22] of services striving for improvement in safety, experience and outcomes.

I. Object and purpose of the child-friendly health care approach

21.1 Highlights the key principles based on the United Nations Convention and promotes their integration across a full range of services for children and families.

21.2 Health service delivery takes into account the child's age, physiological and emotional development, level of maturity and understanding, respecting the unique circumstances of each child in the context of their family, lifestyles[23] and health determinants[24] within their communities.

21.3 Endorses an integrated child-rights based approach to the development of all services for children and families.

21.4 Confirms that rights are central to the provision of health services.

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19. CHILD-FRIENDLY HEALTH CARE APPROACH integrates the principles of participation, promotion, protection and prevention into a practical framework of provision based on pathways to guide the planning, delivery and improvement of children's services.
20. OUTCOME is a measure of the effects, beneficial or adverse, as the consequence of a pathway of care. A sustainable outcome is an impact.
21. VALUE. A predetermined judgement of the worth of a service used to evaluate overall organisational performance.
22. NETWORK. A number of teams or organisations that come together and work collaboratively to achieve continuous quality improvement.
23. LIFESTYLE is a way of living based on identifiable patterns of behaviour which are determined by the interplay between an individual's personal characteristics, social interactions, socioeconomic and environmental living conditions.
24. DETERMINANTS. The range of personal, social, economic and environmental factors which contribute to the health status of individuals or populations.

21.5 Proposes an approach based on pathways[25] that:

- designs services around children and their families;
- creates alignment and synergy between:
  - family lifestyles, services and public health interventions,
  - between primary, secondary and tertiary care,
  - health, education and social care services,
  - public, private and voluntary sectors;
- introduces a culture of continuous learning to drive quality improvement which includes a system for the measurement and comparative performance.

II. Definitions

22. Definitions of notions other than "child" and "parent" are given in footnotes.

III. Principles of the child-friendly health care approach

This chapter reviews the child rights-based approach, highlights those particularly applicable to children and extracts principles that are particularly relevant to the delivery of services for children and families.

The Child Rights-Based Approach

23. Since the publication of the United Nations Convention on the Rights of the Child many organisations have adopted and adapted the articles for specific use. Examples include United Nations Fund for Children (UNICEF) and the International Save the Children Alliance,[26] Save the Children, European Association for Children in Hospital (EACH),[27] Child-Friendly Healthcare Initiative (CFHI),[28] Baby Friendly Hospital Initiative (UNICEF).[29]

24. The UN Convention on the Rights of the Child imposes obligations on States: "*States Parties shall undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised" (*art.4). This holistic nature of Rights means that all the rights have the same importance and so are indivisible, interdependent and interrelated. Therefore all rights should be respected and be valid in all life circumstances, at all times and apply to all services. Potentially conflicting rights and interests such as the right to protection and the right to participation should be carefully weighed to determine the best interests of the child in the circumstances of each case.

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25. PATHWAY (care pathway, pathway of care) is a description of all the steps that should be in place, from prevention through to interventions, in order to achieve good outcomes. The three stages are an initial, cyclical review and transition pathways. The component parts are prevention, recognition/identification, assessment and interventions.
26. http://www.savethechildren.net/alliance/index.html
27. http://www.each-for-sick-children.org/each-charter
28. http://www.cfhiuk.org/
29. http://www.unicef.org/programme/breastfeeding/baby.htm

25. The European Union Treaty of Lisbon[30] introduces the protection of children's rights among the EU's objectives for internal and external policies, supporting the idea that EU laws and policies should take into account child's perspective and contribute to promoting children's rights and interests so that children and young people should

- have parents who love, protect and care for them;
- enjoy the best possible health;
- be heard, treated with respect and have their views taken into account;
- be able to access to play, leisure, sporting and cultural activities;
- have a comprehensive range of education and learning opportunities;
- be free from abuse, victimisation and exploitation;
- have their race and cultural identity recognised;
- live in safe homes and in safe communities which support their physical and emotional wellbeing;
- not be disadvantaged by poverty.

A. Fundamental rights and children's specific rights

26. Based on the United Nations Convention on the Rights of the Child, the child rights-based approach to health:

- understands the right to health as the 'right to the highest attainable standard of health', including the right to health care;
- recognises the enjoyment of the highest attainable standard of health as one of the fundamental rights of every human being without distinction of race, sex, religion, language, political belief, national or social origin, birth, economic or social condition, health status, sexual orientation, civil, social or other status;
- follows the four general principles of the Convention of Child Rights: life, survival and development (art.6), non-discrimination (art.2), best interest of the child (art.3) and respect for the views of the child (art.12);
- recognises the holistic nature of rights, meaning that rights have the same importance; they do not follow a hierarchical logic, but they are indivisible, interdependent and interrelated;
- facilitates the integration of children's rights in the design, implementation, monitoring, and evaluation of health-related policies and programmes.

B. Dignity

27. Respecting dignity is a basic human rights requirement, underlying many existing legal instruments.[31] Every child is a unique and valuable human being and as such his or her individual dignity, special needs, interests and privacy should be respected and protected.

30. http://europa.eu/lisbon_treaty/full_text/index_en.htm
31. See for example Preamble of the International Covenant on Civil and Political Rights, as well a Preamble and Article 40 para. 1 of the UN Convention of the Rights of the Child.

28. Children shall be treated with care, sensitivity, fairness and respect throughout any procedure or case, with special attention for their personal situation, well-being and specific needs, and with full respect for their physical and psychological integrity. This treatment shall be given to children, in whichever way they have come into contact with the health care system and regardless of their legal status and capacity.

29. In particular, children shall be protected by all means against any inhuman, harmful or degrading treatment or punishment in proceedings involving or affecting them.

C. Participation

30. When a child is not able to consent, the intervention may be carried out only with the consent of parents, those who have custody or his or her legal representative or any person or body provided for by law. However, as far as possible, with a view to the preservation of the autonomy of persons with regard to interventions affecting their health, the opinion of children should be regarded as an increasingly determining factor in proportion to their age and capacity for discernment. This means that in certain situations which take account of the nature and seriousness of the intervention as well as the child's age and ability to understand, the child's opinion should increasingly carry more weight in the final decision. This could imply that the consent of a child should be necessary in certain cases.

D. Equitable access to quality health care

31. The Oviedo convention states the following:

> *Art. 3 "Equitable access to health care"*
>
> *Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.*

32. The aim is to ensure equitable access to health care in accordance with the person's medical needs. "Health care" means the services offering diagnostic, preventive, therapeutic and rehabilitative interventions, designed to maintain or improve a person's state of health or alleviate a person's suffering. This care must be of a fitting standard in the light of scientific progress and be subject to a continuous quality assessment.

33. Access to health care must be equitable. In this context, "equitable" means first and foremost the absence of unjustified discrimination. Although not synonymous with absolute equality, equitable access implies effectively obtaining a satisfactory degree of care.

34. Financial barriers may not constitute an obstacle to access to health care, including medication.

E. Best interests of the child

35. The child's best interests should be a primary consideration in all cases involving children. The assessment thereof needs to be done accurately. These guidelines promote the development of multidisciplinary methods for assessing the best interests of the child acknowledging that this is a complex exercise. This assessment becomes even more difficult when these interests need to be balanced with the interests of other involved parties, such as other children, parents etc. Such balancing should be done professionally; on a case-by-case basis.

36. The best interests of the child have always to be considered in combination with other children's rights, e.g. the right to be heard, the right to be protected from violence, the right not to be separated from parents, etc.[32] A comprehensive approach shall be the rule.

IV. The child-friendly health care approach

The child-friendly health care approach combines children's rights and systems thinking described here to create a practical approach for the planning, delivery and improvement of services for children and families.

A. The rights on which the child-friendly health care approach is based

Five principles, enshrined in the Conventions outlined in the preamble, are particularly relevant to the child-friendly health care approach. They are:

a. Participation

37. Meaningful participation is central to human rights and democracy. Children are often denied this right due to the cultural belief that they are "immature" and therefore "unable" and due to the additional burden of time or other obstacles preventing true communication. There is good research demonstrating that participation improves the quality of decision-making and compliance with treatment or other interventions. Increasingly there is recognition that users of services are "co-partners" in achieving better outcomes and should become competent in the management of their conditions. This is equally true for children and young people where, with age and maturity, they take increasing responsibility for their lifestyles.

38. Ascertainment of user views is an integral part of the process of service evaluation and improvement. Patient reported experience measures and patient reported outcomes measures are underdeveloped fields in relationship to children and families. It is essential that the views of children and their families are included as they have a critical insight into how services are delivered and unique perspective on how they might be improved.

32. For practical suggestions see UNHCR Guidelines on Determining the best interests of the child, 2008 (http://www.unhcr.org/refworld/docid/48480c342.html).

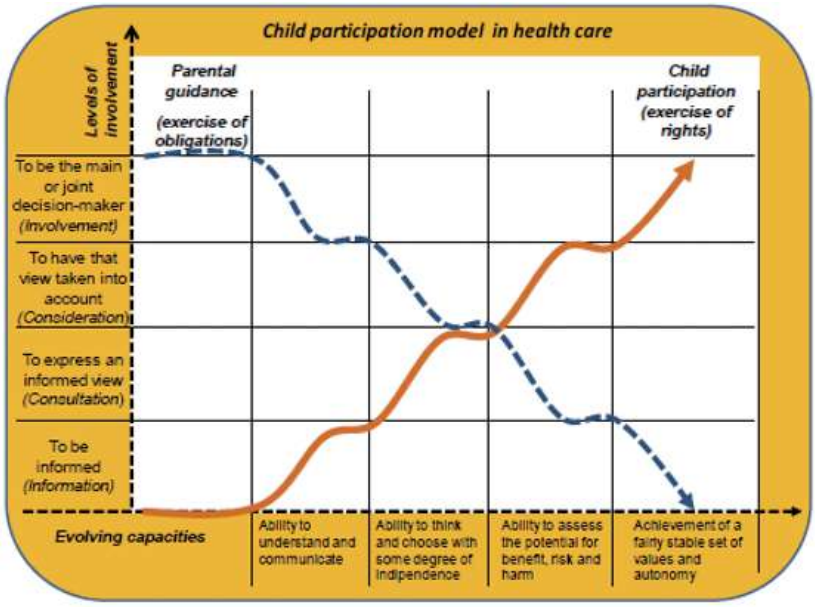


Fig. 1 – Degrees of children's participation

b. Promotion

39. The promotion of health and resilience is essential to the achievement of better health, well-being and quality of life. The alignment of healthy lifestyles, healthy determinants of health with the contribution health services make to promoting health is essential. True synergy between lifestyles, determinants and services requires that policy makers and major stakeholders create alignment between different policies or departments; that private sector promotes healthy choices and that health services promote and implement the activities based on the best available evidence. This is particularly true with regard to health and nutrition where individuals often need assistance to make healthy choices. That food processing industries diminish the content of sugar, salt and fat in the food; health services promote healthy hospital food, healthy eating throughout childhood and work with partners such as schools to ensure children and young people are fully informed about the dietary decisions they take.

c. Protection

40. Health protection is essential to avoid harm caused by exposure to hazards. Hazards appear in many forms including environmental, social, economic, thermal or chemical. Children require protection from all forms of abuse and maltreatment, including a negative emotional environment.

41. One specific area of protection relating to health care is the patient safety agenda which intends to prevent harm from medical adverse events and medical errors occurring through contact with health services. Children are particularly vulnerable as they are physiologically immature and are often unable to communicate their concerns; therefore, patient safety reporting systems designed for adult patient safety may require adaption for children.

d. Prevention

42. Preventing development of diseases or their progression and the resulting disability is central to the provision of all services. Prevention should be combined with promotion and protection measures in order to detect treatable conditions early enough to improve long-term outcomes. Traditionally medicine has studied pathogenesis (the study of disease development) rather than salutogenesis (the study of health creation). Both are important and need to be integrated into a consistent approach tackling lifestyles, improving determinants of health and within health care. Prevention activities are performed at different levels:

- *primary level:* aims to avoid the development of a disease/condition, for example through vaccination, and to prevent a problem before it occurs;
- *secondary level:* attempts to diagnose and treat an existing disease in its early stages before it results in significant morbidity, for example post-natal metabolic screening;
- *tertiary level:* aims to reduce the negative impact of established disease by restoring function and reducing disease-related complications, for example disability;
- *quaternary level:* aims to mitigate or avoid the consequences of unintended harm caused through contact with a health system.

e. Provision

43. High-quality health care improves health, reduces inequalities and creates sustainable system within the resources available. To achieve these three ideals health care needs to be well organised to ensure all the necessary parts are in place and working well together for an individual and their family. This requires a high level of cooperation and collaboration between those planning, providing and where appropriate regulating services. Creation of competent teams working collaboratively within integrated structures has been shown to improve safety, patient satisfaction and outcomes. Public services contributing to the health and well-being of children should be seen as a whole system, designed around families and ensuring they receive effective interventions in a timely and cost-effective way, which drives learning, competence and continuous quality improvement.

B. A description of the child-friendly health care approach

Creation of health and development of diseases

44. The creation of health and well-being is a complex process that happens over many years and has been conceptualised in many different models throughout the lifetime of human beings. The terms quality of life, happiness, success could be substituted for health and well-being. The model adopted in this document is based on the concepts behind life course epidemiology which propose that exposures to positive determinants of health promote quality and duration of life, whereas exposures to negative determinants of health reduce both quality and duration of life. Salutogenesis is therefore the process of creating health and well-being, pathogenesis is process of development of disease or medical condition.

45. Following a salutogenic perspective, the child-friendly health care should – in delivering services - also stimulate and strengthen the child capabilities to face the challenges for health and development and – in planning and implementing services – activate and co-ordinate actions with other external salutary resources for health and development, from other social sectors such as education, social networks, environmental agencies.

46. Children should be provided with a more extensive meaning of health care and health. Health care and health in general, constitute resources for the full realisation of the human potential and children should be recognised not only as protagonists in their own health management, but also as salutogenic agents for their families, peers and communities.

47.

Salutogenesis	**Determinants**	**Pathogenesis**
Security	Housing	Hypothermia
Growth	Food	Obesity or starvation
Nurture	Parenting	Abuse
Hydration	Water	Dehydration
Immunity	Infection	Disease

48. Understanding how ill health, diseases and medical conditions are caused and treated has always been a major challenge for all scientific communities, particularly over the last century as scientific methods have improved. In the same time there has been less emphasis on understanding how good health is created. Likewise there has been relatively little effort to understand how services are best structured to create optimal value for money. The result is that many children in Europe still live in suboptimal conditions for the creation of good health and well-being, with few evidence based interventions available to improve their life chances; so that when concerns are raised services often fail to respond in an effective way (for example obesity, teenage pregnancy).

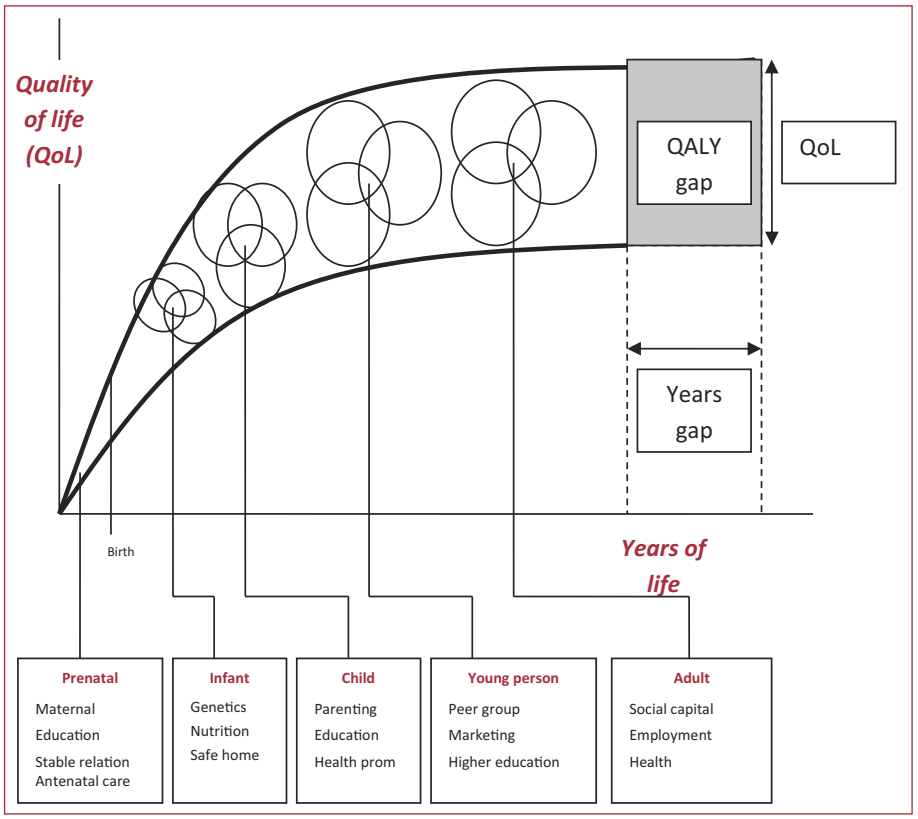


Fig. 2 – Determinants of health and well-being and their impact on quality and length of life at different stages in childhood

Systems thinking

49. A *health system* is defined by WHO[33] as "all organisations, people and actions whose primary intent is to promote, restore or maintain health." Its purpose is to "improve health and health equity[34] in ways that are responsive, financially fair and make the best use of available resources". It continues to state that "systems thinking has huge and untapped potential, first in deciphering the complexity of an entire health system, and then in applying this understanding to design and evaluate interventions that improve health and health equity. It can open powerful pathways to identifying and resolving health system challenges."

50. *Systems thinking* is therefore the process of understanding how the components interact and influence one another within a system. In nature, examples of systems thinking include ecosystems in which various elements such as air, water, movement, plants and animals work together to either survive or perish. In organisations evidence, people, information, structures and processes work together to achieve their stated purpose, thereby creating a system.

33. http://www.who.int/alliance-hpsr/resources/9789241563895/en/index.html
34. EQUITY. A measure of fairness or justice.

51. Three important interrelated concepts of systems thinking, as it applies to services, are that:

- an output is always a changed input, so from an individual perspective health is restored through interventions within a pathway; from the community[35] perspective the needs of a population are met through provision within a network of services;
- the perspectives of all the stakeholders are included in any evaluation;
- it must be able to deliver, learn and evolve simultaneously.

52. Every system has its "principles" for how it operates and makes decisions. These principles bind individuals, teams and organisations into how they work together.

53. Services for children and families should have a very clear purpose - to improve health, reduce inequalities and to be sustainable within the resources available. Secondly, the pathway should be driven by sound principles - participation, promotion, and protection. Thirdly, the services should be based on the best possible evidence – i.e. what should be done, by whom, where and when.

54. The complexity of children's services is due to the necessity to simultaneously consider both the family and their lifestyles and the determinants within the community when assessing and responding to children's needs[36]. For example concerns about behaviour may be related to the child, but can also be secondary to parenting styles, or indeed issues within the community such as bullying. Concerns or conditions of the child must therefore be seen in the context of lifestyles and determinants, which in turn can help or hinder health service interventions for the problems identified.

55. Sometimes health can be improved by a single contact with a service provider but for more complex problems a series of contacts with services are required to achieve the intended outcome. When planning services based on pathways four components always need to be considered. These are prevention, identification, assessment and interventions. These individual components may be delivered within the health service, or by other services that contribute to the pathway.

56. **Glue ear (serous otitis media) – an example of a short-term condition**

Glue ear can be prevented through the promotion of breastfeeding and protection of the child from passive smoking, recognised through awareness of the signs of hearing impairment, assessed both from an audiological, a language perspectives, with interventions ranging from hearing aids, grommets, parental awareness and language programs.

35. COMMUNITY. A specific group of people, often living in a defined geographical area, who share a common culture, values, lifestyles and determinants of health.
36. NEED. A measure of "ability to benefit" from a service or intervention. NEEDS ASSESSMENT. A systematic procedure for determining the nature and extent of health needs in a population.

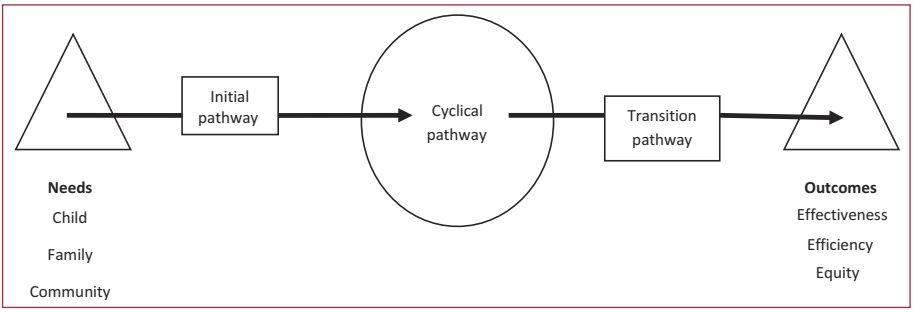


Fig. 3 – Four component pathway of care

57. This simple model of a four component pathway can be expanded into more complex systems depending on requirements, for example by expanding the model into cyclical review pathways and transition pathways (Fig 4), and then including alignment with the lifestyles and determinants (Fig 5).

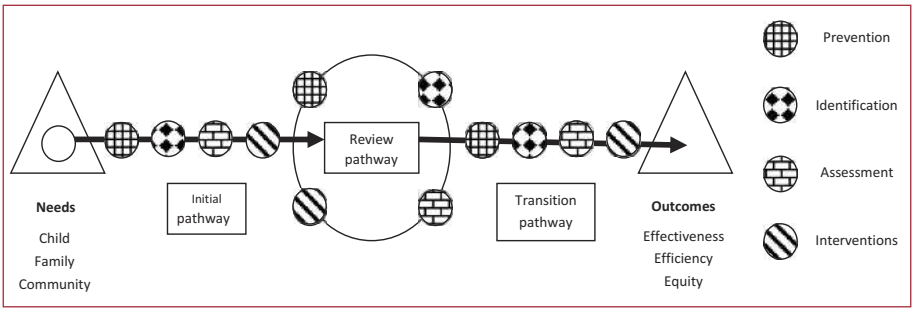


Fig. 4 – Diagram illustrating the combination of an initial, review and transition pathways to meet needs and achieve outcomes

58. **Diabetes –an example of a long-term condition**

The *initial pathway* includes the prevention of obesity, identification of diabetes at an early stage, assessment of the family and interventions based on insulin and family education about diabetes. Once diabetes is established, the review and transitional pathways are applicable.

The cyclical review pathway consists of regular reviews which intend to prevent complications through good diabetic control, recognise the early signs of complications, assess them fully and then access appropriate interventions**.**

The transition pathway to adult services includes the prevention of handover errors through good communication, identification of the necessary local services, assessment of the young person's ability to live with diabetes, with appropriate interventions and ongoing support.

59. Individual lifestyles, determinants of health and health services are interdependent on each other and the added value of systems thinking is to create alignment and synergy between these various elements to create a system that is effective, efficient and equitable at all times.

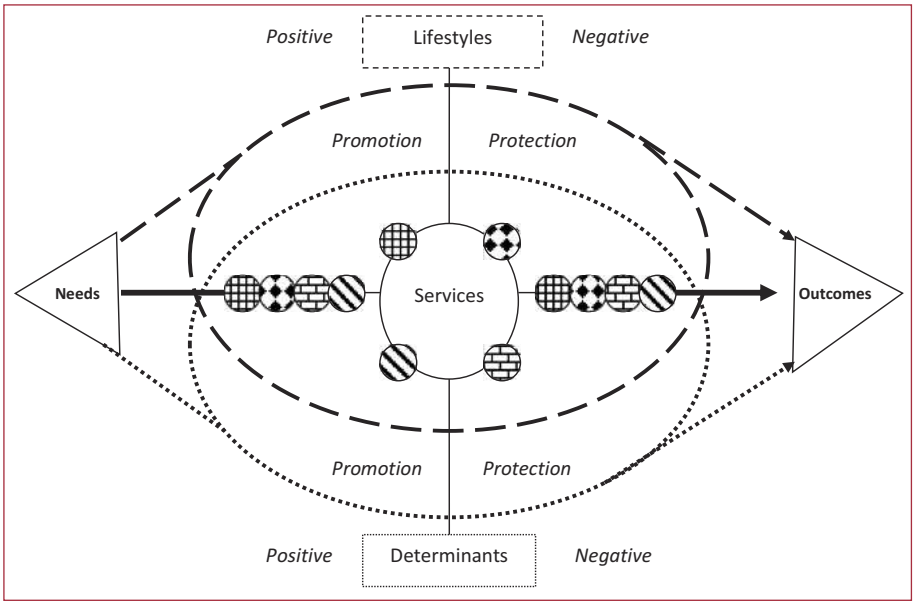


Fig. 5 – Diagram of the overlap and interaction between the lifestyles, services and determinants

C. Application and advantages of the child-friendly health care approach

60. *Users.* Service users are primarily concerned about access, timeliness, good outcomes, and their experience. By ensuring all parts are in place and working well together the child-friendly health care approach ensures these expectations are delivered. The approach recognises that health is not distributed equitably, therefore there is an emphasis on improving access for vulnerable groups and reducing variations in health outcomes what leads to reduction of health inequities and improves social solidarity.

61. *Professionals.* Professionals are primarily concerned that their competence is put to best use and is maintained through professional development and so ensure effectiveness. The child-friendly health care approach puts evidence and competence of practitioners high on the agenda and links measurement, feedback and learning into a virtuous cycle of continuous quality improvement which should reduce unnecessary variations and provide opportunities for ongoing learning. Innovation and improvement should be an integral part of service delivery and should enable financial flows to follow the evidence-based service delivery within a pathway.

62. *Policy makers/planners.* Policy makers are concerned that resources are used wisely, that financial flows are optimal, services are safe and there is no unnecessary waste in the system. The child-friendly health care approach drives efficient, equitable and effective use of resources, by examining the whole system, putting patients at the centre of service design integrating learning and improvement to increase value for money, reduce likelihood of harm and avoiding waste.

V. Implementing the child-friendly health-care approach

This chapter describes three implementation levels:

1. *a policy and planning level,*
2. *a service delivery level, and*
3. *a level that applies to individual children and families.*

The priorities for implementation will vary considerably between and within different nations. Therefore implementation requires the adoption, and where necessary adaptation, of this approach by all the agencies, organisations and professional groups contributing to services for children and families.

The intention is to create a synergistic, coherent strategy that integrates the relevant principles and creates mutually reinforcing virtuous cycles of learning to generate continuous improvement.

Policy and Planning

63. In order that comprehensive children's service could come together and share the same purpose and principles to support the delivery of services, government departments, national organisations[37] and other stakeholders should be able to develop integrated policy and planning tools, leading towards locally applicable good practice models.

64. Examples include:

- promotion of early interventions (the responsibility of one department) to prevent later problems (the responsibility of another department);
- integrated commissioning and planning arrangements between parts of the health service and between other agencies and stakeholders that contribute components to pathways and networks;
- ensuring that resources can be moved across organisational boundaries to support evidence-based delivery of care.

Service Delivery

65. Organisations and institutions delivering services should work collaboratively to ensure that there is both coordination and continuity between the component parts of a pathway. Each service needs to understand their specific contribution to the care pathway and attempt to make their component parts based on best evidence, delivered by competent teams, in the right place at the right time.

37. Royal College of Paediatrics and Child Health, *Not Just a Phase – A Guide to the Participation of Children and Young People in Health Services*, 2010.

66. Examples of good practice include:

- collaboration across a network to drive learning through continuous quality improvement;
- shared workforce planning, training and development strategies;
- improved communication at both a management and practitioner level supported by appropriate communication technologies.

Individual children and families

67. Children and young people and families should be fully involved in decision-making within health care systems. This depends on their level of understanding and maturity, but they should feel competent in the relevant health issues in their lives.

68. Examples of good practice are:

- development of family health records, including relevant information about health conditions and services available;
- active participation in decision-making about children life styles and medical conditions;
- involvement with service evaluation and improvement.

VI. Promoting the child-friendly health care approach

*This section examines how major stakeholders, policy makers, services and families with children are enabled to promote children's rights, the principles applicable to children's health services and the CFHC approach***.**

Promotion of children's rights

69. All public policy relating to children and families should actively promote the rights of children in all settings and throughout all services, whether or not they relate directly to children and families. Opportunities for young people to be involved with priority setting and policy development need to be explored.

70. Children and families are often unaware of their rights, have low expectations of services and tolerate poor quality. Children and families should be active partners in shaping high-quality services. All available opportunities to promote children's rights should be exploited, including programmes within the school curriculum, public awareness programmes and co-operation with the private sector. Care has to be taken to ensure that children are not exploited, abused nor maltreated during their journey of care. Continuing professional development programmes should include how to communicate with children and respond to the children's rights agenda.

71. The promotion and protection of the rights of vulnerable or marginalised children is of particular importance. The work on child-friendly health care should be linked to child-friendly justice and child-friendly social care to create a synergy of approach for the promotion of children's rights across all the agencies who may be involved.

72. Children have the right to high-quality services that achieve their expected outcomes and all agencies and services should work together to achieve this aim. Services should be encouraged to implement and evaluate initiatives that promote children's rights.

73. Policy makers should both share and learn from the successes and failures of policy across European nations.

Promotion of the principles applicable to children's health services

74. The five key principles should be promoted within health services by all the relevant stakeholders working at a policy level. Promotion may include reviewing the evidence on the impact of incorporating children's rights into health care so this should be included in the training of all professional groups and in the criteria used by regulatory agencies to ensure quality in all services.

75. Children and families should receive information to enable them to promote and protect their own health, be active participants in decision-making and be involved in service improvement initiatives.

76. Practitioners and their representative organisations should consider how they, and their services, can promote children's rights, particularly participation, health promotion and health protection.

Promotion of the child-friendly health care approach

77. The child-friendly health care approach based on care pathways should be endorsed and adapted to national and local priorities. Services should be reviewed in the light of this approach and plans made to improve safety, children's satisfaction and outcomes.

78. Every opportunity should be taken to facilitate and create alignment and synergy between government departments, professional organisations and bodies representing the users of services in order to create "added value". Of particular importance is designing services around children, recognising the importance of their families, planning services based on pathways, integrating teams where appropriate and creating a measurement system that drives learning and quality.

79. Service planners should adopt a "whole system" approach to performance management and the improvement of services. They should encourage measurement systems that identify the "weakest point" in the system and design services that can adapt to new knowledge.

80. Practitioners should apply the child-friendly health care approach by translating the evidence into practice, improving their professional competencies and seeking opportunities to provide care in more appropriate settings or in a more timely manner. They should seek feedback on the quality of the service they provide at every opportunity and then strive to improve their services.

81. Synopsis and aide memoire – the 5-4-3-2-1 approach.

In order to help embed the key concepts of the child-friendly health care approach into practice a simple mnemonic has been derived based on 5-4-3-2-1 (Appendix II). Five principles, four component parts to pathways, three pathway stages, two driving forces and one purpose - to improve children's services.

Appendices

Appendix I – Child-friendly health care: the views and experiences of children and young people in Council of Europe member states

Final Report – excerpts
Dr Ursula KILKELLY, Ireland

Introduction

The Council of Europe guidelines on child-friendly health care are designed to provide a framework to ensure that health care systems operate in line with best practice in children's health care and fulfil commitments under the United Nations Convention on the Rights of the Child (UNCRC) and other international standards. At its meeting in December 2010, the Committee of Experts mandated to draft the guidelines agreed to consult children and young people on their opinions and experiences of health care. The survey was developed, piloted on a small scale, and made available to the Council of Europe's national partners in the health care and children's sectors. The survey was then placed online in 14 languages at the beginning of June 2011. This report presents the findings of that consultation process.

It is important that the Council of Europe has begun to involve children in its legal and policy-making work. Children and young people have a right to have their voices heard and taken into account in matters that affect them in accordance with Article 12 of the UNCRC, and in this regard the Council of Europe has broken new ground at international level. This work is not without its challenges – logistical and methodological – and it is important that the Council of Europe and other organisations continue to learn from, and improve, their work in this field.

Methodology

As noted above, the principal method used in this consultation process was a survey or questionnaire. In one instance – Ireland – the Ombudsman for Children undertook five focus group discussions with 125 children and young people aged between 9 and 12 years from a variety of rural, city and disadvantaged backgrounds. In all other cases, the surveys were completed by children and young people usually by completing hard copies of the survey which were then sent to the Council of Europe for processing. A small number of children also undertook to complete the survey online.

In total, 2,257 surveys were completed by children from the following 22 countries: Armenia, Austria, Bosnia and Herzegovina, Bulgaria, Estonia, Finland, France, Georgia, Germany, Greece, Ireland, Italy, Malta, Netherlands, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain and the United Kingdom.

At the same time, it is important to highlight that a large proportion of the surveys – almost half – were completed by children in Austria.

The survey

The survey is broken down into several sections. Some of the main results are presented below.

Who accompanied you to your visit?

The vast majority of children (84.5%) who completed the survey were accompanied to their appointments by a parent or family member. Only 3% attended with a friend, while 11.8% said that they went alone.

Waiting time at the appointment

The majority (40.8%) of respondents said that the waiting time was short, that they were seen in a few minutes; 13.6% reported that they had to wait a long time. In the Irish consultations, most of the children felt that the time they spent in waiting areas (a period of 1.5 to 2 hours was cited) in advance of being seen by a health care professional was too long.

The health care setting

According to those consulted, health care settings should be bright and colourful. Hospitals and paediatric units should:

- include places to relax;
- not be too cramped and include individual rooms;
- have rooms with windows;
- have comfortable and clean beds;
- have television with lots of channels, DVDs, computer and other games, a games room and internet access;
- enable parents/families to stay with their children;
- provide good food;
- have outside spaces if possible;
- smell better;
- provide storage space for children to put their possessions.

At the appointment

There is clear consistency in this question with the same proportions – roughly four out of five children – saying that they were given the information they wanted at their appointment with their health care professional, that they understood this information, that they were given the opportunity to ask questions and that they felt

respected. Similarly even numbers across the questions answered these questions in the negative or were not sure of their answer.

Question 14 then asked the more specific question of whether the health professional in question spoke directly to them. Here, the vast majority of children – 84.6% – said that they did, while just under one in ten – 9.4% – said they did not. The majority of children consulted by the Ombudsman for Children in Ireland expressed the view that health care professionals often speak too quickly and use words children do not understand.

Finally, in this section, the survey asked children whether they knew what was going to happen next once the appointment was over. Here, only two thirds of children (63%) said that they did while almost equal proportions said that they either did not know (17.6%) or were not sure (17.1%). Similarly, children consulted by the Ombudsman for Children in Ireland described experiences of not being sure what was happening after seeing a health care professional.

Important elements of health care

The next part of the survey asked respondents to rate from 1 (not at all important) to 10 very important) a range of elements or factors of health care. In particular, the following answers were supported with a very strong rating of 10 by the following percentages of children:

- having your parent/family with you – 48.6%;
- knowing the name of the doctor/nurse – 19.6% (note: 16.7% rated this "not at all important");
- having treatment explained in advance/being prepared – 44.1%;
- being able to understand what the doctor is saying – 49.1%;
- being able to ask questions – 44.6%;
- being listened to – 47.3%;
- not being afraid – 48.7%;
- not being in pain – 60.1%;
- other categories – 77.6%.

In respect of the open-ended "other categories", the following were among the most popular answers: being respected or being treated nicely, getting better quickly and not being bored/being entertained.

Accommodation

Most children had to cope on their own without having a parent stay overnight. Nearly two thirds of children (63.6%) said that they did not have a parent or other relative stay overnight with them, although 31.1% said that they had. Interestingly, perhaps, a majority of respondents said that they would not have liked to have had a parent stay overnight – suggesting they were content with current arrangements – with 50.5% answering accordingly. However, a third (33.5%) said that they would have liked this. 16% did not know. In the majority of cases (60.2%), parents/relatives

were present when children were having treatment but in almost a third of cases (30.7%) children were treated alone. The latter group were almost evenly divided on whether they would have liked to have a parent or other family member present. – 44% said yes and 37.3% said no. It is likely that this is a more important issue for younger children who would like to have their parents stay with them in hospital.

The children who participated in the survey reported being able to personalise their space and room in the hospital. This was noted as of particular importance to the children who were consulted by the Irish Ombudsman for Children.

Feedback

A majority of respondents (50.4%) said that after their appointment in the health care setting, no one asked about their experiences. However, over one third (33.7%) of respondents reported that they had received follow-up, although 15.9% did not know.

When asked what children would like to change about the health care system, they ranked the following highly in significant numbers:

- health professionals should be more friendly (54.6%);
- health professionals should talk to children more (60.3%);
- health professionals should listen to children more (67.8%);
- children should be given information about what is going to happen to them (80.9%).

Health care policy

When asked whether they would like to have a say about children's health care in their area, a large proportion (47.2%) said that they would, whereas 27.7% said "no" and an even larger proportion (29.6%) – possibly due to a lack of comprehension of 'health care policy' – said that they "did not know". When asked how they would like to participate in health care policy- making, the most popular answer was by speaking directly to a person face to face although other avenues, including school, was also popular.

Finally, children were asked to identify a number of statements as "true or false". A large number identified as "true" that children have the right to information about their health care and what is going to happen to them (86.6%); children should be asked their views by their health professionals (75%); hospitals and health centres should always be child-friendly (91.3% – the highest number here) and those who run hospitals and health centres should ask children what they think about them (54.2%).

Conclusion

The findings of the survey do not contain many surprises in that they are largely consistent with research evidence on children's experiences of health care and their views about the health care setting. They show how important is the child-friendly nature of the health care setting to children across Council of Europe member States

and highlight, in particular, how acutely aware children are of their treatment by health care professionals. Their appetite for information and respect for their rights is clear. To some extent, they are also aware of the unsatisfactory nature of delay and of cost and that the impact of these practical barriers to child-friendly health needs further study. The survey also provides a useful indication of how valuable children's perspectives are on their health care, and on the development and delivery of health care services; yet as the survey shows, children are rarely consulted or asked their views on these important matters. This is arguably the most important lesson from this research, in other words that children have a right to be heard, to be supported to participate in matters that affect them, not just to make decisions about their clinical care and medical treatment but on the broader issues affecting health care policy and the health care system.

Appendix II – Synopsis and aide mémoire – the 5-4-3-2-1 approach

Introduction

The previous chapters have described the child-friendly health care approach, provided examples of implementation and suggested proposals for promotion of the approach.

In order to help embed the key concepts of the child-friendly health care approach into practice a simple mnemonic has been derived based on 5-4-3-2-1. ***Five*** *principles,* ***four*** *component parts to pathways,* ***three*** *pathway stages,* ***two*** *driving forces and* ***one*** *purpose – to improve children's services*

Five principles

1. Participation

a. individual decision-making
b. service feedback
c. priority setting

Participation is central to the implementation of children's rights. Children who are knowledgeable, empowered, involved and respected have the greatest chance of becoming successful, healthy adults, who in turn can pass these values to their own children.

Participation in the decisions they make for themselves, whether lifestyle choices or medical decisions is an important component to improve the experience and outcomes of services. Disabled children will require additional support to achieve a similar level of participation to their less vulnerable peers.

Participation in the process of service improvement, largely through creating feedback to providers about their experience is a powerful driver for change.

2. Promotion

a. all children
b. vulnerable children
c. children using health services

Health promotion is the process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health by increasing the exposure of children and families to positive experience and determinants to improve their health and well-being. Health promotion is important to prevent conditions, ameliorate co-morbidities and improve the experience of health services.

3. Protection

a. all children
b. vulnerable children
c. children using health services

Protection is the process of decreasing the exposure of children and families to hazards that may harm their health. Health protection aims to prevent conditions occurring, the negative consequences of medical conditions, to reduce complications and prevent adverse events and medical errors whilst using health services.

4. Prevention

a. promotion/protection
b. proactive care best condition management
c. expert patient programs

Prevention in health settings relates to specific programmes based on best evidence and proactive care which considers the impact of a condition on the child and the consequences for their family and prevent future complications. The intention is to create competent patients who are fully knowledgeable about their health and health condition.

5. Provision

a. journeys, pathways, networks
b. evidence-based, competent practitioners, right place, right time
c. measurement, feedback, action and learning

Equitable provision of health care of appropriate quality whether acute, long-term or rehabilitative is an essential human right. To create a safe service, with good outcomes all the parts of the pathway need to be in place and working well together. Each component part needs to be based on best evidence, delivered by competent practitioners all working together in a network of services committed to driving improvement through learning.

Four pathway components

1. Prevention

a. primary, secondary and tertiary
b. promotion, protection and education
c. lifestyle, physical, socio-economic

Prevention is at the start of every stage of every pathway. Prevention can be achieved through promotion, protection and education, coupled with the best management of conditions. The importance of creating alignment between lifestyles and factors in the physical and social environment that contribute to good outcomes is imperative.

2. Identification

a. screening
b. surveillance
c. awareness

Early recognition of a problem which may lead to complications or co-morbidities generally reduces long-term costs. Identification can be achieved in an informal way through general education and awareness or through specifically designed programs such as screening programmes.

3. Assessment

a. child, family, community
b. condition, lifestyles, determinants
c. evidence

Good assessment is essential in order to identify appropriate interventions. Symptoms recognised in a child may relate to the child, their family or the community in which they live. Comprehensive assessment of all the relevant elements is important so that a management plan is relevant to the unique circumstances of an individual child.

4. Interventions

a. medical, surgical, psychiatric
b. education, social care, criminal justice
c. family, community, society

Interventions may be required to improve the child's condition, to alleviate the impact on the child or the consequences for the family. It is essential that various interventions come together into a holistic programme tailored to the needs of individual families, particularly those with multiple health care needs related to a long term condition.

Three pathway stages

1. **Initial**
2. **Review**
3. **Transition**

The greatest burden on health services are the long term diseases and other medical conditions. Generally the care starts with an initial pathway where the condition is recognised and diagnosed, in the next stage a process of regular review is included over a period of time and the final stage leads to the transition back to normal, on to adult services or into palliative care services. Each stage involves prevention, identification, assessment and access to a range of interventions.

Two driving forces

1. Alignment

a. policy makers , service providers, users
b. health, education, social care
c. public, private, community sectors

Alignment between the various individuals, teams, services and agencies that provide services for children and families is essential for success. Each need to share the same approach to getting evidence into practice, maintaining the competent practitioners, delivering services in the right place and at the right time and using resources wisely to create a sustainable long-term system.

2. Measures-feedback-action

a. measures that matter and motivate
b. analysis, feedback, reflection,
c. action-innovation, evaluation and learning

Due to the complexity of providing services for children and families there has been an under investment in the process of identifying where the service is, and is not, working well. The future success depends on developing measures that represent the viewpoints of the key stakeholders that create meaningful feedback and can be used to drive learning and innovation.

One goal – improvement!

1. Improvement in outcomes and impact

a. health
b. inequalities
c. sustainability

Ultimately the purpose of implementing children's rights in health care is to drive improvements in outcomes (creating better health, reduce avoidable conditions), reduce existing health inequities, while at the same time improving the safety of services and patients' satisfaction. All services must use resources wisely and be sustainable.

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The Guidelines on child-friendly health care were adopted by the Committee of Ministers in 2011. They are designed to provide a framework to ensure that health care systems operate in line with good practices in children's health care, in line with commitments under the United Nations Convention on the Rights of the Child, the European Social Charter as well as other relevant international and European standards. They thus offer Council of Europe member states a set of practical directions to assist them in improving their healthcare systems and services while implementing a child-friendly health care approach.

This publication contains the Guidelines and their Explanatory memorandum, the latter including a summary of views on the health care experiences of children and young people in 22 Council of Europe member states, which informed the preparation of these guidelines.

The resulting Guidelines are thus a reaffirmation of principles applicable to children's health services and the promotion of a child-friendly health care approach, namely participation, promotion, protection, prevention and provision, illustrated through examples and promising practices.

This publication aims to support agencies, organisations and professional groups contributing to services for children and families, in particular policy makers, health, education and social care practitioners throughout Europe.

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The Council of Europe is the continent's leading human rights organisation. It comprises 47 member states, 28 of which are members of the European Union. All Council of Europe member states have signed up to the European Convention on Human Rights, a treaty designed to protect human rights, democracy and the rule of law. The European Court of Human Rights oversees the implementation of the Convention in the member states.

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