



*Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento*

# Task Force HPH Children & Adolescents (TF HPH-CA)

## Standards di promozione della salute dei minori e processo di autovalutazione

Udine, 03/12/2019

Ilaria Simonelli, PhD  
Coordinatore Task Force HPH-CA  
Direzione Integrazione Socio-sanitaria  
Servizio Governance Processi socio-sanitari  
Azienda Provinciale per i Servizi Sanitari  
Provincia Autonoma di Trento

## HPH- CA Task Force Vision

*We believe* that Human Rights must become a reference platform for political, economic, social, cultural policies in every part of the world, starting from childhood. **Children are owners of rights** and they represent those new generations that can give continuity to human progress.

*We know* that the **'Child right to health' is a fundamental right** to achieve her/his full human potential.

*We feel* that the a 'Rights Age' starts up with a 'Children's rights Age' and that a 'Children's rights Age' coincides with a **'Child right to Health Age', driven from innovative health care context.**

## Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services (TF HPH-CA)

TF HPH-CA MISSION  
(since 2004)

*"to apply HPH principles and criteria to the specific issues of health promotion for children and adolescents in & by hospitals, providing an organic conceptual and operational framework for institutions, decision-makers, healthcare organisations and their professionals, social workers".*

### The Task Force Members

Andy Mangione Standish, Lagle Suurorg, Raúl Mercer, Stella Tsitoura, Raquel Mullen, Andrew Clarke, Kjersti J. Ø. Fløtten, Ang Seng Bin, Ana Isabel Guerreiro, Dora Scheiber, Irma Manjavidze, Lucia Maria Loteran, Rosa Gloria Suárez, Sarah Spronk, Marija Radonić, Giuliana Filippazzi, Christina Dietscher, Jean R. Piard, Arian Tarbal Roquer, Francoise Galland, Nuria Serrallonga, Virginia Binns, James Robinson, Ana Lourenço, Gustavo Ramos Martín

## CARTA DI OTTAWA



Costruire una politica pubblica per la salute  
Creare ambienti favorevoli  
Dare forza all'azione della comunità  
Sviluppare le abilità personali

*Riorientare i servizi sanitari*

*La responsabilità per la promozione della salute nei servizi sanitari è condivisa tra i singoli, i gruppi della comunità, gli operatori sanitari, le istituzioni che garantiscono il servizio sanitario e i governi. Essi devono lavorare insieme per un sistema di assistenza sanitaria che contribuisca alla ricerca della salute. Il ruolo del settore sanitario deve andare sempre più nella direzione della promozione della salute, al di là della sua responsabilità di garantire servizi clinici e curativi. I servizi sanitari hanno bisogno di adottare un mandato più ampio che sia sensibile e rispettoso dei bisogni culturali. Questo mandato dovrebbe sostenere i bisogni degli individui e delle comunità per una vita più sana e stabilire connessioni tra il settore sanitario e le più ampie componenti sociali, politiche, economiche e dell'ambiente fisico.*

COME?



Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento

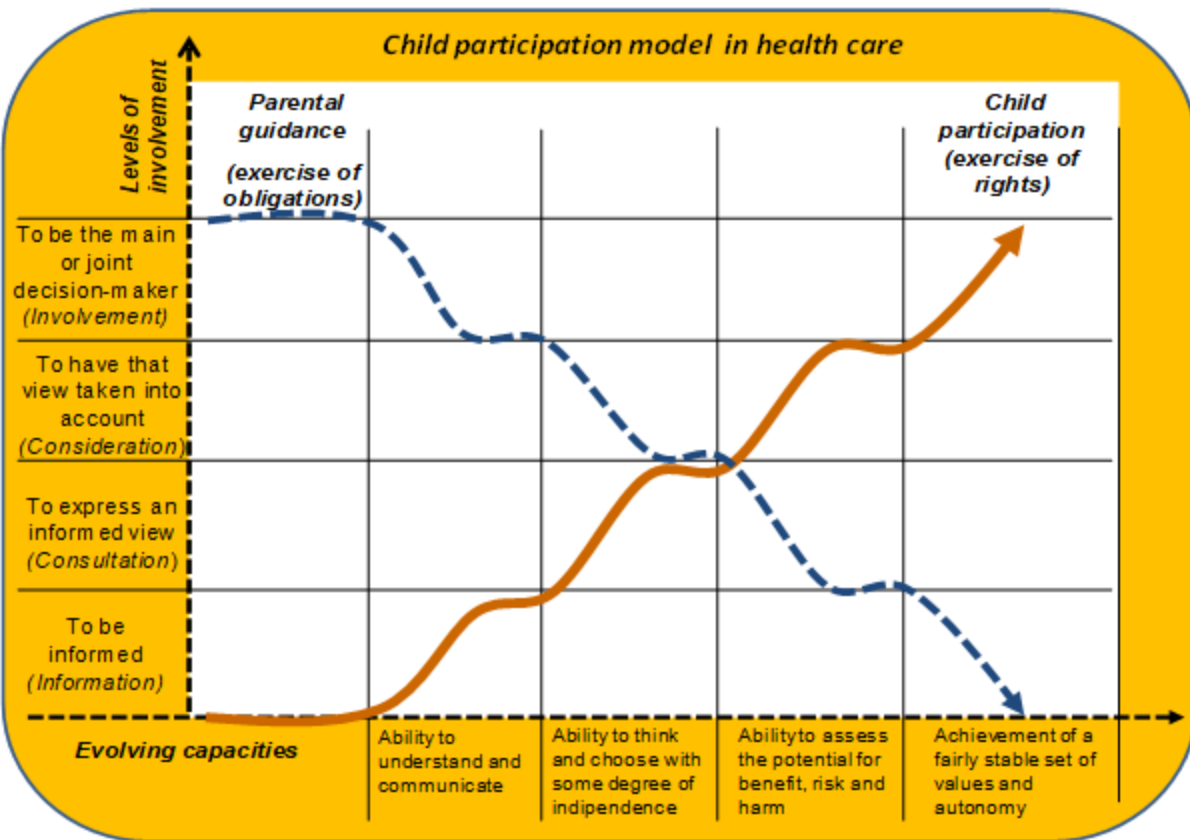
# 1. Empowerment & Partecipazione

L'empowerment può essere un processo sociale, culturale, psicologico o politico attraverso il quale gli individui e i gruppi sociali sono in grado di esprimere i propri bisogni e le proprie preoccupazioni, individuare le strategie per essere coinvolti nel processo decisionale e intraprendere azioni di carattere politico, sociale e culturale che consentano loro di soddisfare tali bisogni.

(WHO, 1998, HP Glossary)



### Child participation model in health care



**Empowerment and  
decision making**

**Guidelines of the  
Committee of Ministers of  
the CoE on child friendly  
healthcare – Sept. 2011**

EMPIRICAL STUDY

## Promoting participation in healthcare situations for children with JIA: a grounded theory study

BRITT-MARI GILLJAM, PhD Student<sup>1,2</sup>, SUSANN ARVIDSSON, PhD<sup>2</sup>,  
JENS M. NYGREN, Associate Professor<sup>2</sup> & PETRA SVEDBERG, Associate Professor<sup>2</sup>

<sup>1</sup>Region Halland, Halmstad Hospital, Sweden and <sup>2</sup>School of Social and Health Sciences, Halmstad University, Halmstad, Sweden

### Abstract

Children's right to participate in their own healthcare has increasingly become highlighted in national and international research as well as in government regulations. Nevertheless, children's participation in healthcare is unsatisfactorily applied in praxis. There is a growing body of research regarding children's participation, but research from the children's own perspective is scarce. The aim of this study was thus to explore the experiences and preferences for participation in healthcare situations among children with juvenile idiopathic arthritis (JIA) as a foundation for creating strategies to promote their participation in pediatric healthcare. Twenty children, aged 8 to 17 years, with JIA were interviewed individually and in focus groups. In order to increase the children's opportunities to express their own experiences, different interview techniques were

**Children's right to participate in their own healthcare has increasingly become highlighted in national and international research as well as in government regulations. Nevertheless, children's participation in healthcare is unsatisfactorily applied in praxis. There is a growing body of research regarding children's participation, but research from the children's own perspective is scarce.**

### RESEARCH ARTICLE

## Patient participation, a prerequisite for care: A grounded theory study of healthcare professionals' perceptions of what participation means in a paediatric care context

Ing-Marie Carlsson | Jens M. Nygren | Petra Svedberg

School of Health and Welfare, Department of Health and Nursing, Halmstad University

### Abstract

- 1. Children are a group of patients who are excluded from patient participation, with little attention paid to their views** (Runeson, Elander, Hermeren, & Kristensson-Hallstrom, 2000; Runeson, Hallstrom, Elander, & Hermeren, 2002) and with a marginal role in discussions about their care (Cahill & Papageorgiou, 2007; Coyne, 2006; Moore & Kirk, 2010; Savage & Callery, 2007).
- 2. Children are not included when information is given concerning decisions about their care and in terms of their possibilities for being involved in decisions that need to be made about their care** (Coyne, Amory, Kiernan, & Gibson, 2014; Coyne & Gallagher, 2011; Hallstrom & Elander, 2004; Runeson, Martenson, & Enskar, 2007; Runeson et al., 2002; Feenstra et al., 2014; Koller, 2016; Moore & Kirk, 2010; Wyatt et al., 2015).





1. If the pediatric team has not learned how to handle difficult situations and to build relationships of trust and empowerment for the child, the result will be that pediatricians will talk about difficult children as if they were objects instead of with them as members of a team.

(Lilly Damm, MD, Ulrike Leiss, PhD, Ulrike Habeler, MD, and Jochen Ehrich, MD, DCMT, Improving Care through Better Communication: Understanding the Benefits, EPA)

2. Research is way too limited (...and limiting): 'Most of the studies have ignored the implications of a child's presence in medical encounters. Although all studies claim to examine the interaction in the doctor-parent-child triad, most research methodologies used are based on dyads'.

(Tates, K., Meeuwesen, L. Doctor–parent–child communication: a (re)view of the literature. Soc. Sci. Med. 2001;52:839–851.)

1. Effective doctor–child communication is a necessary prerequisite for safe medical care

(Lilly Damm, MD, Ulrike Leiss, PhD, Ulrike Habeler, MD, and Jochen Ehrich, MD, DCMT, Improving Care through Better Communication: Understanding the Benefits, EPA)

3. '...'children's participation' appears to have a protective and preventive effect for health-related problems. Therefore, it is argued, that 'enablement', a key-element of both the Ottawa Charter on Health Promotion and the International Convention on the Rights of the Child, should be at the core of every child-health promotion programme'.

(de Winter, M., Baerveldt, C., Kooistra, J. Enabling children: participation as a new perspective on child-health promotion. Child Care Hlth. Dev. 1999;25:15–25)

**Physicians can improve the likelihood that children will answer their questions by:**

**(a) asking them social questions early in the visit**

**(b) phrasing their questions as yes-no questions**

**(c) directing their gaze at the children during each question.**

(Physician-child interaction: When children answer physicians' questions in routine medical encounters, Stivers, Tanya, Patient Education and Counseling , Volume 87 , Issue 1 , 3 – 9)

**As chronically ill adolescents need to prepare themselves for transition to adult care, healthcare providers should encourage them to take the lead in communication by initiating independent visits and changing the parents' roles.**

(Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: The added value of mixed methods research, van Staa, AnneLoes, Patient Education and Counseling , Volume 82 , Issue 3 , 455 – 464)

**Instead....**

**'There are still no established definitions, standardized diagnostic methods and effective interventions to treat and prevent this problem (ndr. non adherence to transplant related therapies). We propose the recommendations to approach the problems of adolescent transplant non-adherence from the transplant clinician's viewpoint. With early identification and appropriate interventions, significant improvement in adolescent graft survival is possible'.**

Rianthavorn, P. and Ettenger, R. B. (2005), Medication non-adherence in the adolescent renal transplant recipient: A clinician's viewpoint. Pediatric Transplantation, 9: 398-407. doi:10.1111/j.1399-3046.2005.00358

**Instead...**

**'Analyses of 105 videos show that in most consultations, both GP and parent displayed non-supportive behavior. Despite the GPs' initial efforts to involve the child in the interaction, 90% of the consultations ended up in a non-participatory way. During this last segment of diagnosis and treatment information, the child's voice was hardly heard, as reflected in the minimal involvement displayed and the absence of turning to the parent for support'.**

(Doctor-parent-child relationships: a 'pas de trois' Bates, Kiek et al., Patient Education and Counseling , Volume 48 , Issue 1 , 5 – 14)





The child's perspective as a guiding principle: Young children as co-designers in the design of an interactive application meant to facilitate participation in healthcare situations

Anna Stålberg<sup>a,\*</sup>, Anette Sandberg<sup>b</sup>, Maja Söderbäck<sup>a</sup>, Thomas Larsson<sup>c</sup>

<sup>a</sup>School of Health, Care and Social Welfare, Mälardalen University, Sweden

<sup>b</sup>School of Education, Culture and Communication, Mälardalen University, Sweden

<sup>c</sup>School of Innovation, Design and Engineering, Mälardalen University, Sweden



#### ARTICLE INFO

##### Article history:

Received 27 September 2015

Revised 11 February 2016

Accepted 27 March 2016

Available online 5 May 2016

##### Keywords:

Participatory design  
Children  
Child's perspective  
Application  
Participation  
Healthcare situation

#### ABSTRACT

During the last decade, interactive technology has entered mainstream society. Its many users also include children, even the youngest ones, who use the technology in different situations for both fun and learning. When designing technology for children, it is crucial to involve children in the process in order to arrive at an age-appropriate end product. In this study we describe the specific iterative process by which an interactive application was developed. This application is intended to facilitate young children's, three-to-five years old, participation in healthcare situations. We also describe the specific contributions of the children, who tested the prototypes in a preschool, a primary health care clinic and an outpatient unit at a hospital, during the development process. The iterative phases enabled the children to be involved at different stages of the process and to evaluate modifications and improvements made after each prior iteration. The children contributed their own perspectives (the child's perspective) on the usability, content and graphic design of the application, substantially improving the software and resulting in an age-appropriate product.

© 2016 Elsevier Inc. All rights reserved.

The application, “Inter-Active Communication Tool for Activities” [IACTA], is intended to facilitate young children's, three to five years, participation in healthcare situations. The application will be run on a touchscreen tablet. When entering the examination or treatment room, the application is used jointly by the child and the professional.

COME?



Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento

## 2. Valutazione (Auto)

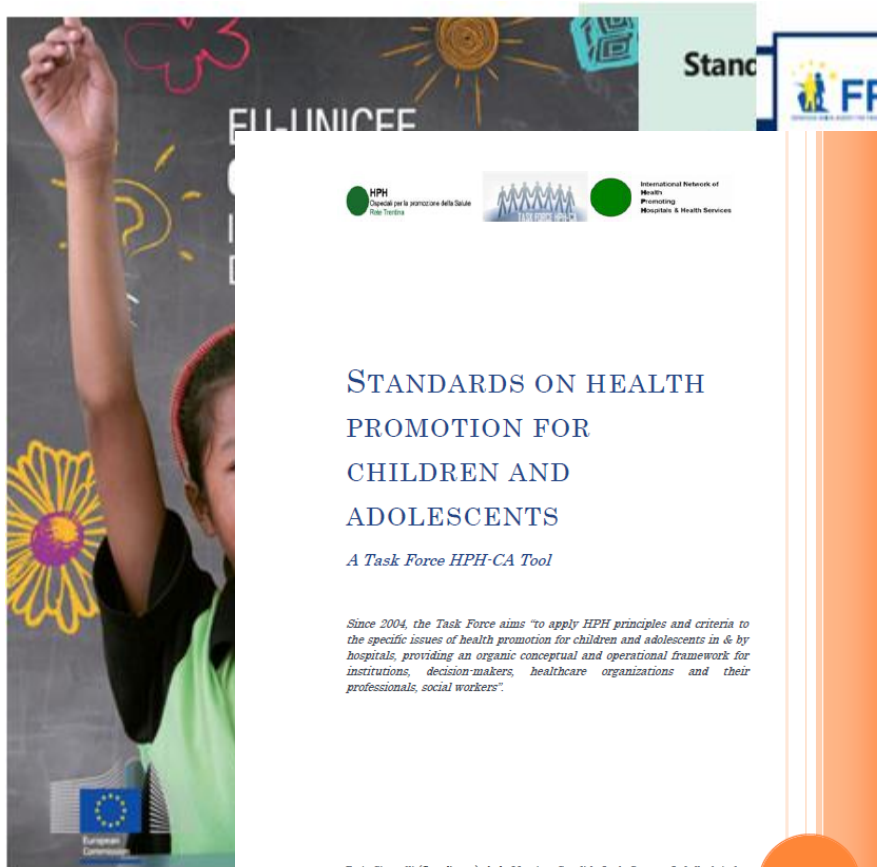
### Measuring the World

Indicators, Human Rights, and Global Governance

by Sally Engle Merry

Indicators are rapidly multiplying as tools for assessing and promoting a variety of social justice and reform strategies around the world. There are indicators of rule of law, indicators of violence against women, and indicators of economic development, among many others. Indicators are widely used at the national level and are increasingly important in global governance. There are increasing demands for "evidence-based" funding for nongovernmental organizations and for the results of civil society organizations to be quantifiable and of complex phenomena began in st recently migrated to the regulation to indicators in the field of global g implications for relations of power civil society. The deployment of sta expertise. The growing reliance on corporate form of thinking and gov

Indicators can effectively highlight deficits, areas of inequality, spheres of human rights violations, and other problem areas. Reform movements depend on producing statistical measures of the wrongs they hope to redress, such as human rights violations, refugee populations, disease rates, and the incidence of poverty and inequality. They are a valuable reform tool in their ability to show areas of state failure.



# STANDARDS ON HEALTH PROMOTION FOR CHILDREN AND ADOLESCENTS

*A Task Force HPH-CA Tool*

*Since 2004, the Task Force aims "to apply HPH principles and criteria to the specific issues of health promotion for children and adolescents in & by hospitals, providing an organic conceptual and operational framework for institutions, decision-makers, healthcare organizations and their professionals, social workers".*

Ilaria Simonelli (Co-ordinator), Andy Mangione Standish, Lagle Suurorg, Isabelle Aujoulat, Raul Mercer, Stella Tsitoura, Raquel Mullen, Andrew Clarke, Kjersti J. O. Fletten, Ang Seng Bin, Ana Isabel Fernandes Guerreiro, Dora Scheiber, Irma Manjavidze, Lucia Maria Loteran, Rosa Gloria Suarez, Sarah Spromk, Marija Radonić, Giuliana Filippazzi, Christina Dietscher, Adrian Tschal Roquer, Nuria Serrallonga, James Robinson, Ana Lourenço, Paul Rainer, Giulio Fornara, Domenico Tangelo, Anabela Fonseca

11/3018

HPH  
Ospedal per la promozione della Salute  
Riva Trentina



International Network of  
Health  
Promoting  
Hospitals & Health Services

# STANDARDS PER LA PROMOZIONE DELLA SALUTE DI BAMBINI E ADOLESCENTI

*Task Force HPH-CA*

*Dal 2004, l'obiettivo della Task Force è quello di "applicare i principi e i criteri di HPH alle questioni specifiche della promozione della salute di bambini e adolescenti negli ospedali e nei servizi sanitari, fornendo un quadro concettuale e operativo per le istituzioni, i decisori politici, le organizzazioni sanitarie e i loro professionisti".*

Ilaria Simonelli (Coordinatore), Andy Mangione Standish, Lagle Suurorg, Isabelle Aujoulat, Raul Mercer, Stella Tsitoura, Raquel Mullen, Andrew Clarke, Kjersti J. O. Fletten, Ang Seng Bin, Ana Isabel Fernandes Guerreiro, Dora Scheiber, Irma Manjavidze, Lucia Maria Loteran, Rosa Gloria Suarez, Sarah Spromk, Marija Radonić, Giuliana Filippazzi, Christina Dietscher, Adrian Tschal Roquer, Nuria Serrallonga, James Robinson, Ana Lourenço, Paul Rainer, Giulio Fornara, Domenico Tangelo, Theresa Bengough, Sarra Mougel

11/3018



Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento

LD  
ON  
COL

ators  
press  
ding  
dren  
people  
ge of  
cate  
cern  
them



## PARTECIPANTI

Hospital San Joan De Déu, Spain  
Budapest Pediatric General Practitioner, Hungary  
SEMMELOWEIS Hospital and Pediatric Clinic, Hungary  
Tallinn Children's Hospital, Estonia  
Regina Margherita Children's Hospital, Italy  
DRMC Medical Center, USA



HPH TF on Standards  
GB TF Reference person  
WHO CC of Vienna and Copenhagen



### PROCESSO DI DEFINIZIONE

Raccolta riferimenti internazionali  
Redazione prima bozza  
Testing prima bozza  
Definizione documento finale  
Implementazione e Diffusione

## FRAMEWORK

Gli standard e gli indicatori per la promozione della salute di bambini e adolescenti negli ospedali e nei servizi sanitari sono uno strumento che consente ai professionisti di valutare le specifiche esigenze di promozione della salute. Sono rivolti agli operatori sanitari, ai decisori politici, alle associazioni che lavorano per i bambini negli ospedali e prevede un doppio utilizzo:

1. Misurare il livello di promozione della salute dei bambini negli ospedali e nei servizi sanitari
2. Supportare i professionisti nella valutazione peer to peer sul livello di realizzazione della promozione della salute negli ospedali e nei servizi sanitari

## Risultati:

**Adozione da parte della Taiwan Society for Adolescent Medicine and Health (TSAMH) nell'ambito di un Progetto sponsorizzato dal Ministry of Health and Welfare.**

## Next step:

**Preparazione di un Corso online per professionisti sanitari (da adottare a Livello Universitario e/o Professionale)**



*Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento*

Posta in arrivo (1) - X | Posta in arrivo (148) - X | Lavori del corso per i... | Presentazione senza... | Project Officer Smar... | empowerment glos... | +

← → ↻ 🏠 🔒 https://classroom.google.com/u/1/w/Mzg5MTI2NDEzNjBa/t/all ☆ 📄 👤

App 📱 GHG | By indicator 🚦 Anziani le condizio... 📄 Dementia overview... 📄 Modulistica UVM 📄 2\_savviso\_di\_selezio... 📄 Colorful product ro... 📄 Untitled Diagram ~...

☰ Children's Health Promotion and Children's R... Stream Lavori del corso Persone Voti ⚙️ ⋮ 🌐

Online Training modules for professionals

+ Crea 📅 Google Calendar 📁 Cartella Drive del corso

Tutti gli argomenti

Standard Number 1

Standard 1 Task

Standard Number 2

Standard 2 Task

Standard Number 3

Standard 3 Task

Standard Number 4

Standard 4 Task

Standard Number 5

Standard 5 Task

Additional Module

Additional Module T...

Standard Number 1

Training Module 1. Management Policy Ultima modifica: 13 nov

Standard 1 Task

Standard 1 Data pubblicazione: 13 nov

Standard Number 2

Training Module 2. Patient Assessment Ultima modifica: 12 nov

Standard 2 Task

Standard 2 Task Data pubblicazione: 15/21

Standard Number 3

15:22 18/11/2019



**Proposta:**  
**Esercizio di Autovalutazione**  
**coordinato da Regione FVG e**  
**supportato da APSS**

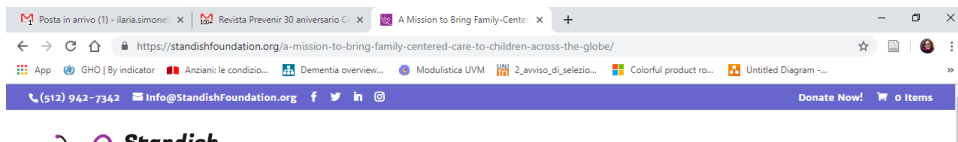
- Giornata formativa con esercizio di auto-valutazione (2020)
- Creazione di un calendario di auto-valutazione annuale o semestrale da svolgere in autonomia o con supporto della TF e con registrazione del dato
- Pubblicazione congiunta dei risultati a fine 2020 (collaborazione FVG-APSS Trentino)

11/30/2018

**SCHEDA DI VALUTAZIONE VELOCE**

A: risultato raggiunto pienamente B: risultato raggiunto in modo moderato C: risultato raggiunto in modo parziale D: risultato minimo o non raggiunto □

INDICATORI	VALUTAZIONE
Presenza di una politica scritta sulla promozione della salute pubblicata in documenti, newsletter, opuscoli, sito web	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Consultazioni annuali con bambini e adolescenti	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Menzione dei diritti dei bambini nella politica scritta	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Attività di promozione della salute registrate nelle cartelle cliniche	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Fornitura di strumenti adatti ai bambini per esprimere le proprie opinioni (schede, raccolta consigli,...)	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Riunioni dei dipartimenti sulla comunicazione con i pazienti	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Presenza di materiale informativo	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Incontri con bambini, famiglie e associazioni	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Presenza di spazi per scopi di promozione della salute (ospitare genitori e pari, ospitare associazioni, ospitare scuole, ...).	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Adozione di documenti ufficiali sulla sicurezza dei bambini	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Accordi con le parti interessate della comunità (ad esempio medici generici, aziende ICT, associazioni, servizi sanitari territoriali, ...)	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A
Adozione di Check lists per la valutazione delle attività di promozione della salute	<input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D <input type="radio"/> N/A



## Alcuni contributi recenti della TF



### ECHO Toolkit:

### Supporting Rights of Children in Hospital

(V1) 20.11.2019

#### Artículo MARCO DE REFERENCIA ITALIANO DESPUÉS DE LA CONVENCIÓN MIRANDO HACIA ATRÁS A MEDIDA

En Italia, es difícil definir claramente la Convención, porque el proceso que se ha desarrollado en las Autoridades para la Protección de Niños y Adolescentes es un proceso derivado de las Regiones y de los indicadores específicos, especialmente en el ámbito de la violencia para facilitar establecer un marco "antes" y un "después" de 1989.

#### Legislación

Si nos fijamos en la legislación anterior en 1989, la Constitución italiana garantiza la importancia de garantizar a los niños el derecho a la salud y el derecho del niño a tener un entorno familiar seguro. Estas situaciones difíciles, previamente enviadas a Institutos *ad hoc* para otra familia, evitando procesos institucionales.

En los años setenta, la sociedad ya estaba evolucionando a la vez que garantizar los derechos de todos los ciudadanos, incluidos los niños. La CDN desarrollara una acción. Si examinamos el cambio de mentalidad podemos ver cuán activamente trabajó el País de acuerdo con la Convención. Comenzando con el marco legislativo provisto para la protección de la explotación sexual, podemos ver claramente el esfuerzo para garantizar los derechos de los niños.

Se implementaron varias acciones significativas. En particular, las acciones internacionales:

- Ley núm. 148 de 25 de mayo de 2000, Ratificación del Convenio Europeo sobre formas de trabajo infantil;
- Ley núm. 46 de 11 de marzo de 2002, Ratificación e implementación de la Convención sobre los derechos del niño, relativos a la explotación de niños en la pornografía, así como la protección de los niños redactados en Nueva York el 6 de septiembre de 2000; Ley núm. 77 de 20 de marzo de 2003,





*Azienda Provinciale  
per i Servizi Sanitari  
Provincia Autonoma di Trento*

**GRAZIE PER L'ATTENZIONE!**

**Info & Contact: [ilaria.simonelli@apss.tn.it](mailto:ilaria.simonelli@apss.tn.it)**