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## **A rights and equity-based “Platform and Action Cycle” to advance child health and well being by fulfilling the rights of children.**

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## Abstract

*The Think and Action Tank (TAT) on Children's Rights to Health was established in 2013 as an international network of child health advocates. The TAT's mission is, "To develop, implement, evaluate, and disseminate rights and equity-based strategies, models, and tools to advance children's health and well-being by fulfilling their rights." Toward this end, the TAT has developed a conceptual and operational framework to support a human and child rights-based approach to health; and a Platform and Action Cycle (PAC) as a strategy and tool to translate the principles of human and child rights-based approaches to health into practice. The PAC consists of three action steps—contextualizing, assessing, and improving. Through a structured process of generating rights and equity-based statements, indicators, and reports, the PAC establishes a mechanism to engage multi-disciplinary professionals and children themselves in efforts to realize the vision of the UN Convention on the Rights of the Child.*

*Keywords: child rights, health, equity, human rights, CRC*

## Executive Summary

### Introduction

Despite advances in knowledge related to: a) the impact of social and environmental determinants on health and well-being across the life course, b) the link between health and human rights, and c) the relevance of the principles and norms of human rights, health equity and social justice to the mitigation of health disparities, the principles and norms of human rights and health equity have not been well integrated into the practice of pediatrics, health systems development, and research. The importance of this integration is underscored by the accrual of decades of knowledge related to the social epidemiology of health, and new knowledge of the biology and physiology of social determinism, epigenetics, brain development, and the impact of toxic stress on health across the life course.

### Objectives

The objective of this TAT initiative was to synthesize existing knowledge and experience with child rights, health equity and social justice into a conceptual and operational framework and tool to translate the principles and norms of human and child rights, health equity, and social justice into child health practice.

## ***Methods***

The Think and Action Tank (TAT) on Children's Rights to Health was established in 2013 as an international network of child health advocates. The TAT mission is, "To develop, implement, evaluate, and disseminate rights and equity-based strategies, models, and tools to advance children's health and well-being by fulfilling their rights." As first endeavour, the TAT convened an international group of 31 child health professionals<sup>i</sup> from Europe, the UK, and North and South America, and used a virtual interactive process to develop a conceptual framework and operational tool (Platform and Action Cycle) for translating the principles and norms of child rights, social justice, and health equity into practice. The virtual process was followed by an in-person meeting to discuss and revise the draft framework and tool, which was distributed for final vetting among the participants.

## ***Results***

A conceptual framework was developed, using the principles of human and child rights and health equity to support the translation of the principles and norms of human and child rights into practice. A framework for operationalizing the principles of a child rights-based approach to health (CRBAH) was then established using the articles of the UN Convention on the Rights of the Child. An ecological model, based on the work of Bronfenbrenner (1979), integrated to life course and CRBAH, was then generated. Finally, an operational tool, the Platform and Action Cycle (PAC), was synthesized from this work as an educational, clinical, and research tool to train professionals and support efforts to translate the principles and norms of child rights into practice. The PAC is derived partially from the Plan-Do-Check-Act (PDCA) innovation cycle developed by Deming (1976). Case studies were then developed to demonstrate the use of the PAC.

## ***Conclusions***

The Platform and Action Cycle (PAC) developed through this initial TAT endeavour provides a comprehensive and evidence-based approach to translate the principles and norms of child rights and health equity into practice. The framework and tool can be used to train child serving professionals and to advance a CRBAH by individuals, organizations, institutions, systems, networks, agencies, and children themselves. The process of developing an international group (TAT) and engaging them in a virtual process to develop translational tools for a CRBAH was highly successful and generalizable to future efforts by the TAT and other child rights advocates.

## Introduction

This article presents a conceptual framework and operational model for translating the principles and norms of child rights into a child rights based approach (CRBA) to child health practice. Recent and rapid advances in knowledge related to the social and environmental determinants of health and life course sciences will increasingly require new approaches to child health to advance children's health and well-being, respond to the root causes of contemporary childhood morbidities, and mitigate health disparities. As such, a CRBAH that translates the principles and norms of human and child rights and health-equity into practice will be increasingly relevant to the health and well-being of children and the adults they will become.

The UN Convention on the Rights of the Child (CRC) provides the foundation to advance this agenda by defining the critical requirements for the health and well-being of all children (United Nations,1989). The articles in the CRC and related documents address the political, civil, social, economic, environmental, and cultural prerequisites for the progressive generation and realization of health as defined by the World Health Organisation (WHO,2014).

However, despite advances in knowledge related to the links between health and human rights (Mann,1997) and the relevance of the principles of rights, justice, and equity to the mitigation of health disparities (AAP,2010); as well as the findings of the WHO Commission on Social Determinants of Health, (WHO,2008) the principles and norms of human rights and health equity have not permeated medical education, nor have they been well integrated into the practice of pediatrics and child health (Cotter et al.,2009). The importance of this integration is underscored by the accrual of decades of knowledge related to the social epidemiology of health (Marmot, Brunner, 2005), and new discoveries in the biology and physiology of social determinism of health (Galea,Link,2013), epigenetics, brain development, and the impact of toxic stress on health across the life course (Shalev et al.,2012; Shonkoff,Garner,2012).

The rationale for the need for strategies and tools to translate these principles into child health practice is further highlighted by the existing gaps between the aspirational principles, standards, and norms of children's rights declarations and the global reality of children's health and well-being. Many factors contribute to these gaps, including a dearth of effective evidence-based strategies and tools required to translate these principles, standards, and norms into practice; and the inadequate education and preparation of professionals to do so. This is despite the requirement of all states that have ratified the UN Convention on the Rights of the Child to "*respect, protect and*

*fulfil each of the rights enshrined in the convention,” and “...to make the principles and provisions of the Convention widely known....to adults and children alike” (CRC, Article 42).* In order to fulfil these mandates, it is not sufficient to simply ratify the CRC and incorporate it into domestic legislation. The accomplishment of children's rights as set forth by the CRC obliges States to take action to ensure that children realize their rights.

It is also not sufficient for states to prioritize and/or focus on individual rights. The Office of the High Commissioner for Human Rights explains that “*rather than a catalogue of children's rights, the Convention in fact constitutes a comprehensive listing of the obligations that States are prepared to recognize towards the child. (Furthermore), the whole thrust of the Convention is to emphasize the inter-connected and mutually reinforcing nature of all rights*” (OHCHR, 2001). Thus, children's rights cannot be divided, nor can they be fulfilled separately - they are indivisible and interdependent (Hodgkin, Newell, 2007). As such, States must carefully assess the existence and status of all rights respecting environments that impact children, and move to ensure that professionals are trained and prepared to establish the structures and mechanisms required to pursue the best interest of all children. Also, vertical integration of policies and resource allocation across the spectrum from international bodies to the local level must be systematically applied to ensure the rights of children are realized. Local communities, even those with limited knowledge of the principles of child rights, must be supported in their efforts to improve the survival and development of children.

## **Development of the Think and Action Tank**

In response to this status quo, the Think and Action Tank (TAT) on children's rights to health was established in 2013 as an inclusive international network of health professionals, policy makers, and others committed to the health and well being of children and youth. The TAT vision is, “To achieve optimal child health by translating the principles and norms of child rights, health equity, and social justice into child health practice in all of children's life settings.” Its mission is: “To develop, implement, evaluate, and disseminate rights, justice, and equity-based strategies, models, and tools to advance children's health and well being by fulfilling their rights.” The TAT's first endeavour, as presented in this manuscript, has been to convene an international group of child-serving professionals to develop a conceptual framework and an operational rights and equity-based tool to advance child health and well-being.

## Methods

The Think and Action Tank (TAT) on Children's Rights to Health convened an international group of 31 child health professionals from Europe, the UK, and North and South America, and used a virtual interactive process to: a) develop a conceptual framework for translating the principles and norms of child rights and health equity into practice, and b) establish an operational rights-based tool, the *Platform and Action Cycle* (PAC), to train health professionals and support the translation of the principles of child rights and health equity into practice.

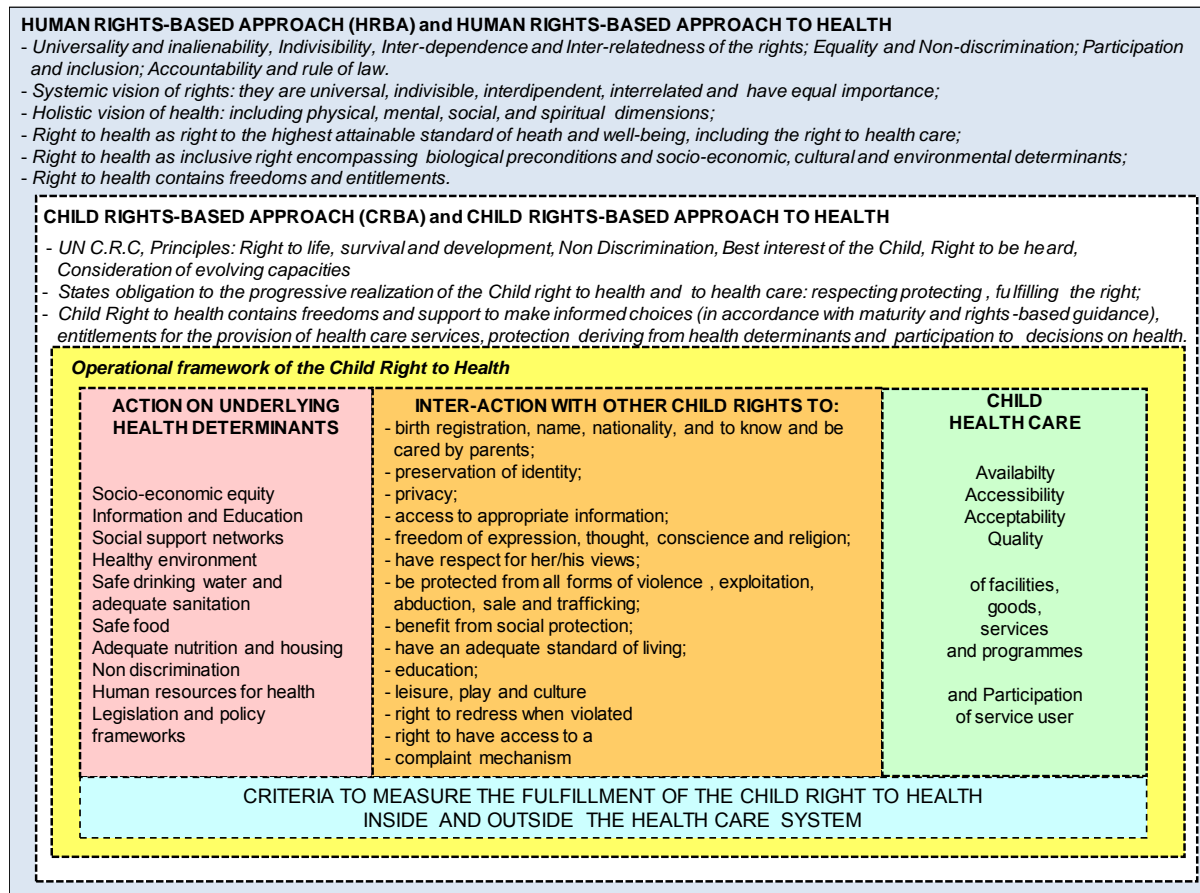
Prior to establishing the actual models, the working group was asked to identify the foundational elements required to establish the conceptual framework and translate its principles into an operational tool (PAC). Finally, examples of how the operational tool could be used were generated.

## Results

### *1. Conceptual and Operational Frameworks*

The conceptual and operational frameworks for the translation of the principles and norms of human and child rights into practice are presented in Figure 1. A *human rights based approach to health (HRBAH)* reflects a set of rights that relate to both children and adults. However, the evolving capacities of children, and their unique rights related to participation, protection, and provision necessitate additional rights that reflect these unique needs. This is delineated as a *child rights based approach to health (CRBAH)*. The operational framework engages: a) the necessity to address the complexities of the social and environmental determinants of health, b) the relation of the child's right to health with the inventory of other rights delineated in the CRC, and c) specifics related to the actual provision of health care services.

**Figure 1: Conceptual and operational frameworks for translating the principles and norms of child rights and health equity into practice**



In order to ensure the rights of children to optimal survival and development are fulfilled, child health services must be *available, accessible, acceptable* and of high *quality*. It is important to provide further insights into these dimensions, as it is not sufficient to only enact legislation required to advance the rights of children to health, additional measures must take place in order to ensure that this right can be fulfilled for all children, and that challenges related to health equity and social justice are addressed.

**Availability.** Availability encompasses:

- Guaranteeing universal financial availability.
- Ensuring the equitable distribution of services throughout rural and urban communities.
- Establishing functioning primary, secondary, and tertiary healthcare facilities within physical and geographical reach of marginalized populations of children. This includes provision of



support for transportation and/or accommodations, including mobile and/or telemedicine services.

**Accessibility.** Accessibility to health services requires health literacy among children and their caregivers. Lack of knowledge of how health systems work and individuals' rights within these systems; as well as basic knowledge of how the body functions, disease conditions, and wellness; can be barriers to accessibility of health care. Barriers to accessibility can be overcome through rights and health education programs, patients' education initiatives, interventions for adolescents in transition to adulthood.

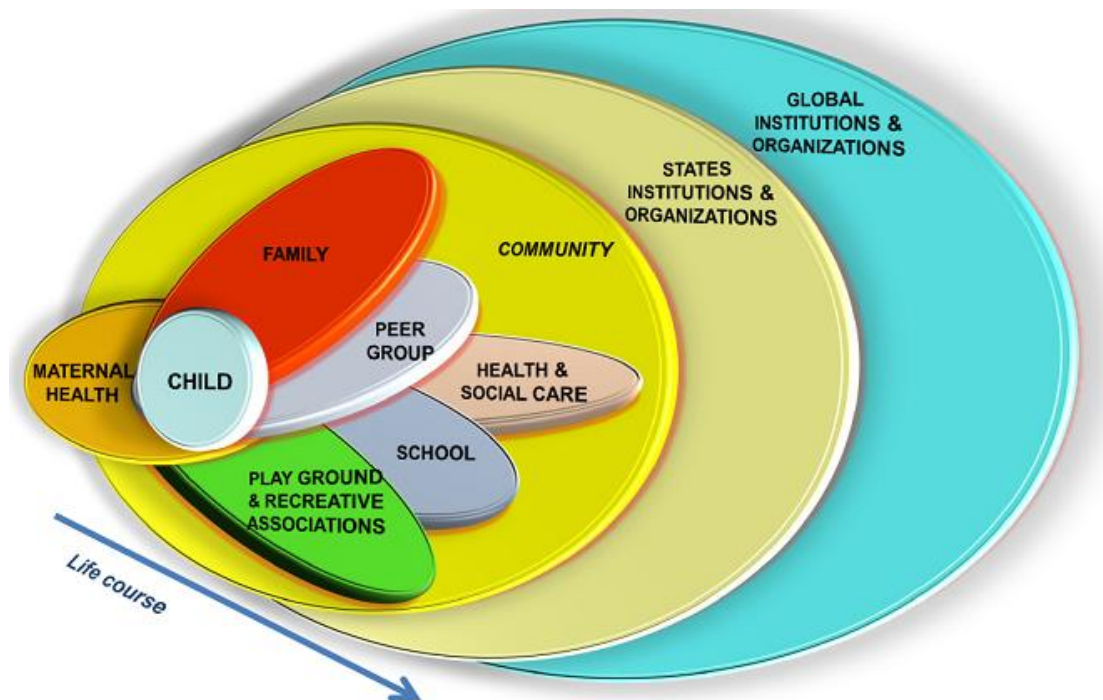
**Acceptability.** Services need to be provided in ways that are *acceptable* to children and youth. This requires that health services pay attention to factors that impact children's rights to health, including: a) attitudes and behaviors of staff, b) elimination of discrimination, c) protection of privacy and dignity, d) ensuring information needs of all children and their families are respected, and e) respectful for cultures..

**Quality.** The child's right to access quality services entails providing healthcare for children that is: a) founded on evidence based-medicine and clinical protocols; b) delivered by health professionals trained in providing care for children; c) delivered in child friendly and rights respecting facilities; and d) in line with children's needs and expectations. This last criterion considers children's rights to participate, as well as patient safety.

## ***2. Child life settings***

As previously mentioned, a holistic ecological approach to a child's right to health, in particular considering the importance of social and environmental determinants of health, requires addressing these rights in all life's settings. Figure 2 reflects the complex environments in which children grow and develop.

**Figure 2: Main child life settings and range of the platform for translating principles of rights and equity into practice across the life course**



### 3. The Platform and Action Cycle

The TAT's proposed *Platform and Action Cycle* (PAC) is meant to operationalize the child's right to health in all the child's life settings. The foundational elements of the PAC are:

- *Child*. A holder of the rights required to achieve the highest attainable standard of health and well-being, including the right to full participation in all aspects of life, taking into consideration her/his evolving capacities emerging across the life course from birth until age 18 (Lansdown, 2005).
- *Health*. A process leading to physical, mental, social, and spiritual well-being influenced by a wide spectrum of determinants (genetic, biological, social, economic, cultural, environmental); and a resource for the full realization of the human potential. In its complexity, health is defined in the multiple dimensions of well being, development, safety, equity, freedom and peace. As delineated in the UN Convention on the Rights of the Child, Article 24 recognizes the "right of the child to the enjoyment of the highest

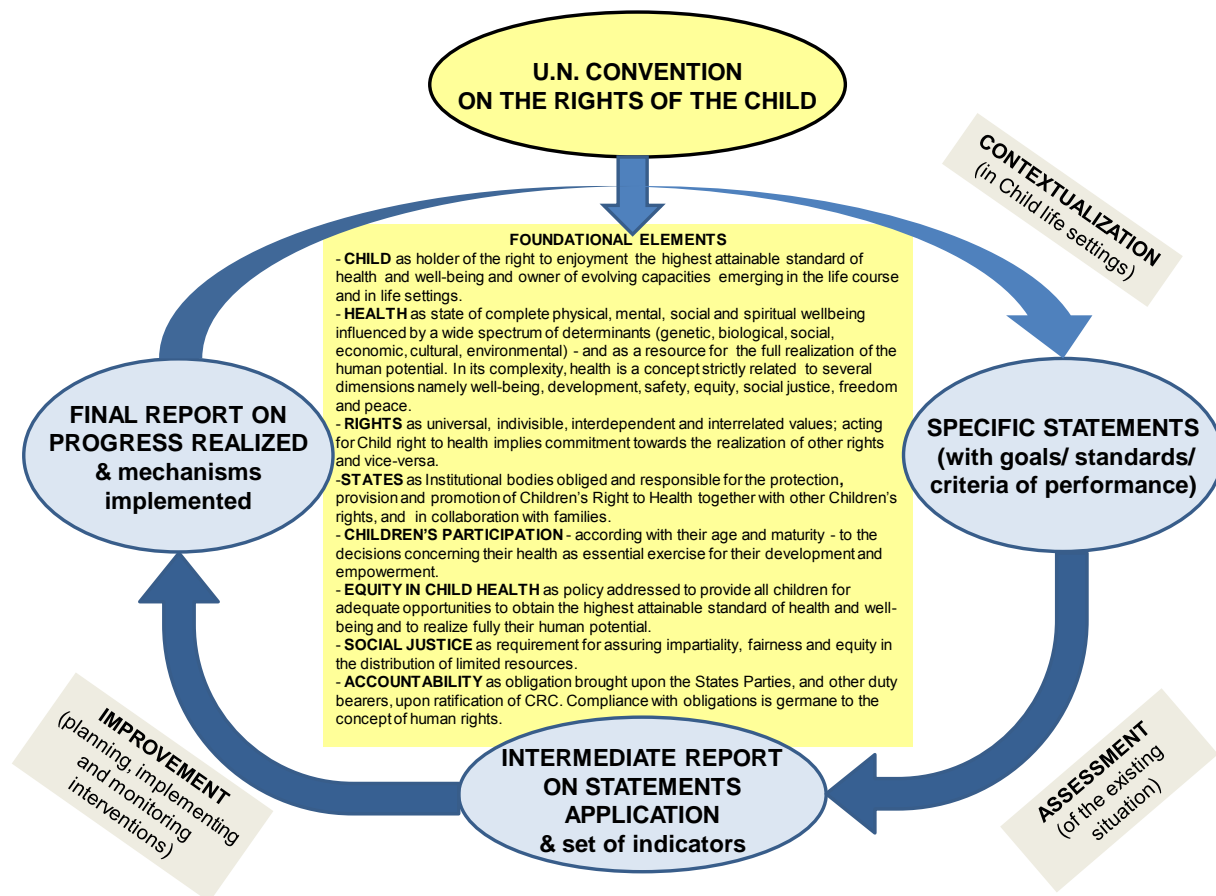
attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". Recently General Comment 15 based on Article 24 of CRC, reinforces the need to act proactively in order to operationalize the principle of the Convention (UNCRC,2013).

- *Rights.* Universal, indivisible, interdependent, and interrelated values standards, and norms without a hierarchical ranking ((Hodgkin, Newell,2007) that, in accordance with the principles proclaimed in the Charter of the United Nations (1945) and expressed in the United Nations Convention on the Rights of the Child, recognize the inherent dignity of children and their inalienable claim to the fundamental guarantees to the rights that accrue to all human beings, including rights to optimal survival and development, civil and political rights; economic, social, and cultural rights. The Committee on the Rights of the Child identifies a core group of four rights as guiding principles of the CRC, namely Article 2 (*Non-discrimination*), Article 3 (*Best interest of the Child*), Article 6 (*Life, Survival and Development*), and Article 12 (*Respect for the views of the child*).
- *States.* Sovereign political bodies obliged and responsible for the participation, protection and provision of children's right to health, together with other children's rights. The role of States and their institutions is to provide the capacity for families to fulfil the rights of their children and to act directly when families are unable to do so. "In a human rights-based approach, relationship between individuals and groups with valid claims (rights-holders) and State and non-State actors with obligations (duty-bearers). A Human Rights-Based Approach identifies rights-holders (and their entitlements) and corresponding duty-bearers (and their obligations) and works towards strengthening the capacities of rights-holders to make their claims, and of duty-bearers to meet their obligations" (UNFPA,2014).
- *Children's participation.* A Human Rights-Based Approach "*is not only about achieving human rights goals and outcomes, but also about achieving them through a participatory, inclusive, non-discriminatory, transparent and responsive process*" (OHCHR, 2014). According to their age and maturity, decisions concerning their health require their full empowerment and participation, with consideration of their evolving capacities. The realization of children's rights must consider the context of their ongoing development, evolving competence, and emerging autonomy.

- *Equity in child health.* Policies that establish the conditions required to ensure all children have the opportunity to fulfil their right to the highest attainable standard of health and well-being, and to realize their full human potential.
- *Social justice.* The requirement for assuring impartiality, fairness, and equity in the distribution of resources.
- *Accountability.* Obligations brought upon State parties and other duty bearers to fulfil the rights of children, as explicated in and following ratification of the UN Convention on the Rights of the Child. Compliance with these obligations is germane to the concept of human rights.

The Action Cycle of the PAC involves three action steps - *Contextualizing*, *Assessing*, and *Improving*. Figure 3 provides an overview of the Platform and Action Cycle. Children must be involved in every stage of the PAC process. They should be consulted and their opinions must serve as catalysts for change.

**Figure 3: The rights- and equity-based Platform and Action Cycle**



## Step 1. Contextualization

In order to remain relevant across the life course of a child, from birth through adolescence, rights must be contextualized in relation to the developmental stages of childhood, and then applied to all children in the multiple settings in which they live. These rights can be formulated as objectives that are: a) *consistent*, with the principles of the CRC; b) *coherent*, with the guidelines and resources of the agencies tasked with implementing these rights; and c) *clear, measurable and accountable*, using performance standards and tools that are generally available in the community in which children live.

Key-questions in this step include:

- “Who would undertake the contextualization?”
- “Does the contextualized statements meaningfully represent the application of the selected right?”
- “Is the statement clear and understandable; and are the objectives measurable?”

In order to answer these questions, policy makers and practitioners must consider the context of the program to be developed (school, city, family, health facility) and its general aim. The CRC should be used as a framework for development of the program in two ways.

1. *Align the program aims to the principles of the CRC by:* a) taking into account children's views about the program and involving them in decision-making processes; b) putting the child's best interest at the centre of the program; c) taking into account children's overall well being and development; and d) ensuring that all groups of children benefit from the program.
2. *Identify other rights that are relevant to the development of the program.* As aforementioned, children's rights are indivisible and interrelated. Any program addressing children's well being and development should take into account various rights that are closely related to the right and program area in development.

At its conclusion, this step will deliver a list of statements related to specific child life settings framed in the context of goals, objectives, standards, and performance criteria required to define the status of the realization of a child's right to health. For example, the child's right, “to be protected from any form of harm including violence, neglect, and all types of abuse” (CRC, article 19) could be contextualized in hospital settings where children are experiencing inadequate pain management during their stay in health services with the following statement: “All children receive

individualized, culturally, and age appropriate prevention and management of pain and palliative care.”

## Step 2. Assessment

The second step of the PAC is meant to assess the status of the realization of children's rights in a particular setting, and identify gaps and potential improvements required to progressively realize these rights by applying the criteria defined in the first step of the PAC. For this purpose root cause analysis and other available tools can define the underlying social and environmental factors responsible for the generation of rights-respecting settings in which the child lives and develops. The assessment step must routinely and actively involve children and their families.

Key questions in this step of the Platform and Action Cycle are:

- “What are the best indicators to measure the fulfilment of the child's right to health in a specific setting?”
- “Who should undertake the assessment? Can it be managed internally within the child's life setting, or does it require external facilitation?”
- “What will be the most appropriate methods and tools to make this assessment?”
- “Are the monitoring indicators specific, measurable, available, relevant, and time-bound?”
- “What is the baseline status of the current situation in relation to each indicator?”
- “If present, what are the deficits and problems emerging from the assessment?”
- “What are the causes of deficits and gaps in fulfilling the child's rights?”

The assessment should include the identification of services, the performance of those services, and children's and family's views on the extent that services meet their needs and expectations. Following the example mentioned in the *Contextualization* step, the assessment of the provision of “individualized, culturally, and age appropriate prevention and management of pain and palliative care” in hospitalized children, would entail collecting data to monitor and evaluate the percentage of children that report:

- Receiving attention when experiencing pain or discomfort.
- Their pain or discomfort was improved completely or partially by actions to alleviate their pain.
- They were asked about their pain today.

- They are receiving non-pharmaceutical interventions, as well as drugs.
- Child-friendly pain assessment tools are being routinely used.
- Health workers trained in palliative care and pain management cared for them.

The indicators used in the assessment phase should reflect the availability of services (pain management and prevention services), the quality of care (health professionals with specific training; and use of non-pharmaceutical techniques), accessibility (number of children who had access to such services) and the participation of children in the assessment of pain. This example serves to demonstrate how it is possible to assess different aspects of health care services, in accordance with a child rights-based approach to health.

This step will use and/or develop indicators that align with the recommendations made by the Office of High Commissioner on Human Rights (2012) with respect to the components of programs to advance human rights. These elements include:

- *Structure*, including existing policies, financial provisions, and organizational environments in support of the right;
- *Process*, including programs, interventions, initiatives; and
- *Outcomes*, including the impact on young children's health, development, and well-being.

At its conclusion, this step will collect data comprehensive enough to deliver an intermediate report on the existing situation, and a set of indicators that can be used to measure the realization of rights in the following step.

### **Step 3. Improvement**

The third step in the PAC involves ongoing planning, and implementation of interventions and quality improvement strategies required to realize the rights reflected in the statements and objectives, and situational and gaps analyses accomplished in the first two steps. Indicators developed in Step 1 and utilized in Step 2 of the PAC should be used as the framework for improvement and reporting in Step 3.

Key-questions in this step include:

- "What are the most important gaps that we should try to address? How should we prioritize them and who should be involved in that decision?"
- "How is it possible to overcome the existing gaps?"

- “What are the best strategies required for improving the application of the statements and how can they be implemented?”
- “What support for children (according to their age and maturity), families, tutors and caregivers, professionals, etc. is required to facilitate each of the steps in the PAC?”
- “What actions shall be taken; who will do these; and by when?”

In addition to these points, it is important to consider two other aspects, namely time frames for the implementation of improvements and budget allocation. Following the above-mentioned example, this step entails developing a plan that includes:

- *Priorities* for interventions emerging from the Assessment step, i.e., professionals training in pain management and palliative care.
- *Objectives* to be reached, i.e., number of health professionals to be trained.
- *Actions* to be implemented (with related responsibilities, resources, timeline), i.e., training materials and time lines for training.
- *Results* of the Improvement step, i.e., percentage increase in trained health professionals, new child-friendly pain assessment tools routinely implemented, specific protocols adopted, reduction in the percentage of children that report pain or discomfort, etc.

At its conclusion, this step will deliver a final report on the activities carried out in all three PAC steps, and the planning of new cycles.

## Implementation

The implementation of this operational model proposed by the TAT may seem difficult when considered in its entirety. An incremental approach should facilitate its application, starting from the *Contextualization* step. This first step is important because it begins the entire process, and should engage policy makers, professionals, people caring for children, and children themselves in an interdisciplinary effort to improve child health and well-being using the rights and equity-based framework and tool.

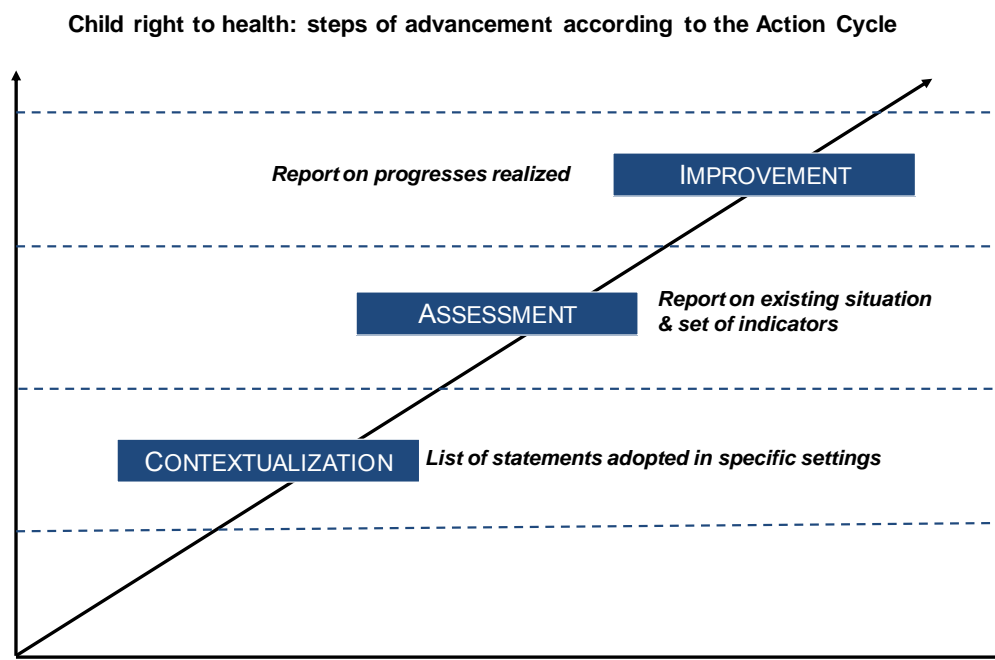
The application of the *Assessment* step should demonstrate that the right to health is not only stated but also evaluated in a specific setting. This second step needs indicators and should provide results on the realized assessment in terms of analysis, databases, reports, and evaluations. The OHCHR (2012) manuscript on rights-based indicators provides a comprehensive approach to develop such indicators.



Finally, the *Improvement* step should demonstrate - through a final report – the effective progress realized in children's rights to health. This third step should formulate action plans, programs, and monitoring tools able to function as guidance for practitioners and for all stakeholders.

Figure 4 provides an overview of this process for implementation of the PAC

**Figure 4: Platform and Action Cycle steps**



## Discussion

The UN Convention on the Rights of the Child is an instrument for advocacy and action to promote children's health, well-being, and development to their fullest potential. The framework and PAC presented in this manuscript can be used to advance the rights of children in all settings in which they live, and by all advocates for children's rights including children themselves. We invite:

- *Multi-sectoral professionals*, including but not limited to health, education, social, and justice system professionals, to implement the PAC in their workplaces, while involving children in the process.
- *Families, caregivers and community workers* to use the PAC to support their commitment and advocacy to advance the health and well-being of children.

- *Public health and social systems* to use the PAC in the generation of policies to fulfil the rights of children to optimal health and well-being; health equity; and the availability, accessibility, acceptability, and quality of their health care services.
- *Policy makers in all sectors* to include the PAC among their strategies for a) ensuring the best interest of children are considered in all relevant policies, and b) promoting child health and well-being.
- *Private health institutions and agencies* to adopt the PAC as tool for contributing to children's right to health, and for improving the quality of services.
- *NGOs and associations* defending and promoting the child's right to the highest attainable standard of health to participate and contribute in the implementation process of the PAC.
- *Universities and other educational institutions* managing courses for health professionals to add the PAC to their curricula and training modules.
- *Social networks and organizations* working on the child's right to health to disseminate the PAC and to contribute to its adaptation and implementation.
- *National and regional governments* to use the PAC to translate the child's right to health into practice.
- *International agencies and organizations* to use the PAC in their efforts to fulfil children's rights to health.
- *Media organizations* to disseminate information about children's rights, their right to health, and the results of applying a rights and equity-based approach to health, including the PAC.
- *All the above mentioned advocates* to apply the PAC with special consideration for children living in marginalized social, economic, and cultural conditions; growing and developing in unhealthy environments; and/or living in disadvantaged and/or violent settings, where the enjoyment of their rights is denied or neglected.

- *Children and adolescents* to use the PAC as a tool to reclaim their right to participation, as well as their right to be heard and considered in issues concerning their health and well-being.

## Notes

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