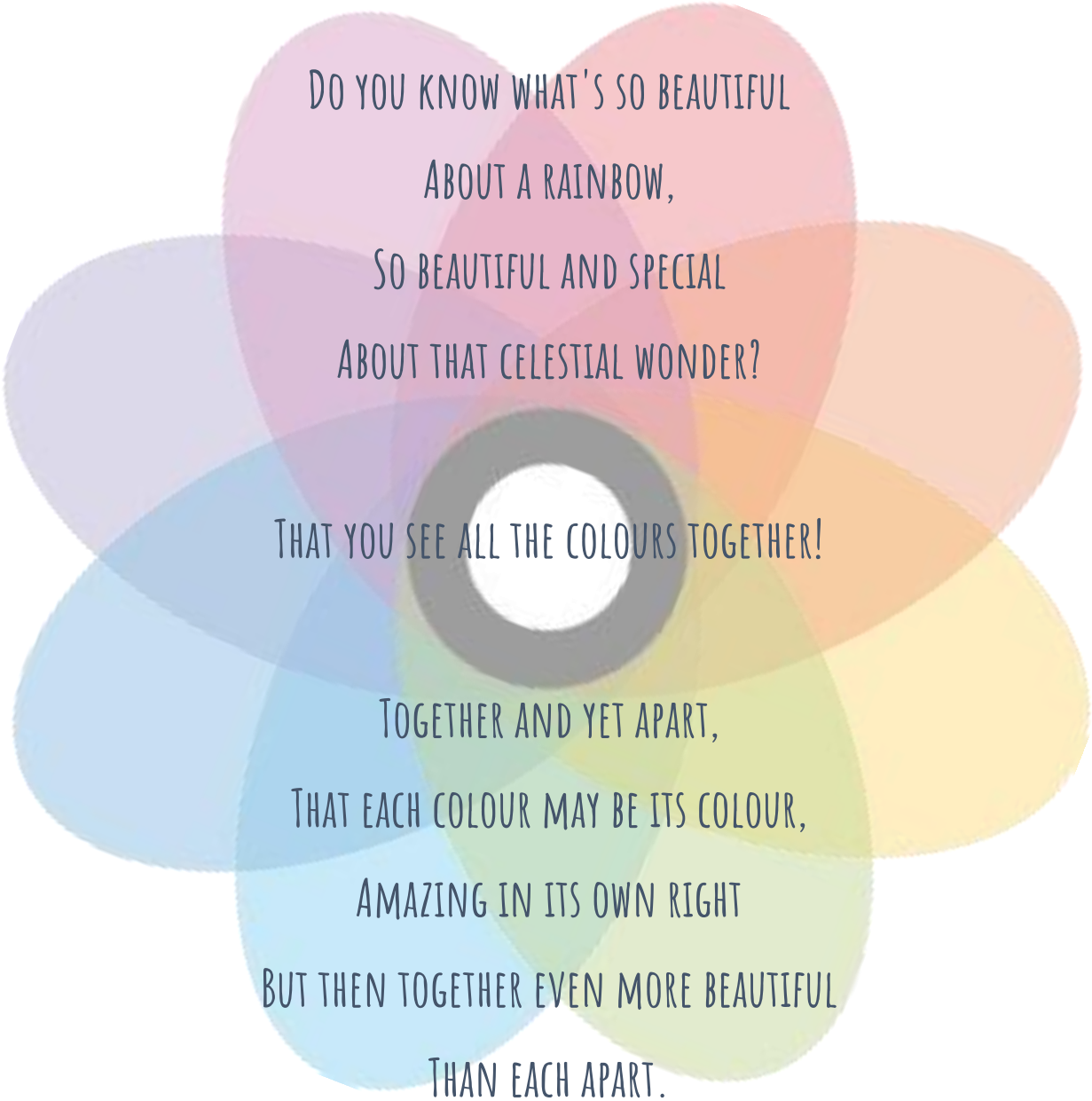
Plan Care for the Children and Young Persons

March 2024

Belgian Academy of Paediatrics



Do you know what's so beautiful
About a rainbow,
So beautiful and special
About that celestial wonder?

That you see all the colours together!

Together and yet apart,
That each colour may be its colour,
Amazing in its own right
But then together even more beautiful
Than each apart.

Based on Geert De Kockere

About this Plan

Professionals from various child-related sectors support the core principle to safeguard the children's rights and maximize efforts to ensure children receive opportunities to reach their full potential.

Recognizing children's complete exclusion from policy-making, the Belgian Academy of Paediatrics (BAOP) -in collaboration with other professionals, paediatric patients and patient representatives- took the initiative to develop this 'Care for the Child'-plan. It offers a comprehensive framework to realize the aforementioned principle, leaving no child behind.

We start with the 10 recommendations for policy makers, endorsed by a large number of health professionals within child health care.

Belgian working group of Pediatric Rheumatology

Belgian Paediatric Nephrology Society

Pediatric Cardiology

10 Recommendations

1. Base all decisions on children's rights, including within healthcare (EACH charter). Review the Patient Rights Act!
2. Give children, young people, and parents (foster parents, guardians, caregivers, etc.) a structural voice in determining healthcare policies (children's council, etc.).
3. Invest significantly more in all forms of prevention and prioritize prevention on the political agenda.
4. Establish an annual Child Report for Belgium, containing all relevant data on children's health, growth, development and disease (determine this data and all relevant health determinants for children in collaboration with an expert group).
5. Provide short-term incentives for intersectoral collaboration and connection.
6. Ensure a guarantee of quality care for the child through adequate (interprofessional) training on healthy, vulnerable, and sick children, as well as through mandatory child-specific competencies and lifelong learning. Consult children and experts for this. Make these competencies transparent and clearly visible to children, parents and health-care professionals.
7. Acknowledge that (chronically) ill children, children who have a difficult start (such as prematurity) and/or grow up in poverty, are extra vulnerable. Focus on vulnerable children!
8. Value the professionals involved in child healthcare, no longer considering them as an inconvenient appendix to adult care.
9. Establish as soon as possible a structural, Inter-federal expert group and give them a mandate for:
    - Drafting a new care program for paediatrics.
    - Developing a proposal for more preventive and integrated care involving ONE-K&G-Kaleido doctors, CLB and PSE doctors, general practitioners, paediatricians, child- and youth psychiatrists, paediatric nurses, paramedics, etc.
10. Appoint a National Minister for/of the child with coordinating and overarching powers.

10 Recommandations

1. Basez toutes les décisions sur les droits de l'enfant, y compris dans le domaine de la santé (EACH CHARTER). Révisez la Loi sur les droits des patients !

2. Accordez aux enfants, aux jeunes et aux parents (parents adoptifs, tuteurs, éducateurs, etc.) une voix structurelle dans la détermination des politiques de santé (conseil des enfants, etc.).

3. Investissez beaucoup plus dans toutes les formes de prévention et donnez la priorité à la prévention à l'ordre du jour politique.

4. Elaborez dans un Rapport annuel sur l'enfance pour la Belgique avec toutes les données pertinentes sur la santé, la croissance, le développement et la maladie des enfants (déterminez ces données et tous les déterminants de santé pertinents pour les enfants en collaboration avec un groupe d'experts).

5. Offrez des incitations à court terme pour la collaboration et la connexion intersectorielles.

6. Assurez une garantie de soins de qualité pour l'enfant grâce à une formation adéquate (interprofessionnelle) sur les enfants en bonne santé, vulnérables et malades, ainsi que grâce à des compétences spécifiques obligatoires pour les enfants et à l'apprentissage tout au long de la vie. Consultez les enfants et les experts sur les compétences spécifiques requises. Rendez ces compétences transparentes et clairement visibles pour les enfants, les parents et les professionnels de la santé.

7. Reconnaissez que les enfants (chroniquement) malades, les enfants qui ont un départ difficile (comme la prématurité) et/ou qui grandissent dans la pauvreté sont particulièrement vulnérables. Mettez l'accent sur les enfants vulnérables!

8. Valorisez les professionnels impliqués dans les soins aux enfants, ne les considérez plus comme une annexe ennuyeuse des soins aux adultes.

9. Constituez dès que possible un groupe d'experts structurel et interfédéral et donnez-leur mandat pour :
    - Élaborer un nouveau programme de soins pédiatriques
    - Élaborer une proposition de soins plus préventifs et intégrés avec les médecins ONE-K&G-Kaleido, les médecins des CLB et des PSE, les médecins généralistes, psychiatres Infanto-Juvéniles, les pédiatres, l'infirmier spécialisé en pédiatrie et néonatologie, paramédical(e), ...

10. Nommez un Ministre National de l'enfant avec des pouvoirs de coordination et de supervision.

10 Aanbevelingen

1. Neem in alle beslissingen steeds de Kinderrechten als basis, ook binnen de gezondheidszorg (EACH charter). Herbekijk de Wet Patiënten-rechten!

2. Geef kinderen, jongeren en ouders (pleegouders, voogd, opvoeder, ...) een structurele stem binnen het bepalen van het gezondheidszorgbeleid (kinderraad, ...).

3. Investeer veel meer in alle vormen van preventie en zet preventie hoger op de politieke agenda.

4. Investeer in een jaarlijks Kind-rapport voor België met alle relevante data rond gezondheid, groei, ontwikkeling en ziekte van kinderen (bepaal die data en alle relevante gezondheidsdeterminanten voor kinderen samen met een expert groep).

5. Voorzie op korte termijn incentives voor intersectorale samenwerking en verbinding.

6. Zorg voor een garantie op kwalitatieve zorg voor het kind via een toereikende (interprofessionele) opleiding rond gezonde, kwetsbare en zieke kinderen alsook via verplichte kind-specifieke competenties en levenslang leren. Consulteer hiervoor kinderen en experten. Maak deze competenties transparant en duidelijk zichtbaar voor kinderen, ouders en gezondheidswerkers.

7. Erken dat (chronische) zieke kinderen, kinderen die een moeilijke start kennen (zoals prematuriteit) en/of in kansarmoede opgroeien, extra kwetsbaar zijn. Zet in op kwetsbare kinderen!

8. Waardeer de professionals betrokken bij de zorg voor kinderen, beschouw hen niet meer als een vervelende appendix van volwassen zorg.

9. Stel zo snel mogelijk een structurele, interfederale experten groep samen en geef hen een mandaat voor:
    - Het opstellen van een nieuw zorgprogramma pediatrie
    - Het uitwerken van een voorstel tot meer preventieve en integrale zorg met ONE-K&G-Kaleido artsen, CLB-en PSE artsen, huisartsen, kinder-en jeugdpsychiaters, kinderartsen, kinderverpleegkundigen, paramedici, ...

10. Benoem een Nationale Minister van/voor het kind met coördinerende en overkoepelende bevoegdheden

About this Plan

Part 1 of this Plan “Care for the Children and Young Persons” clarifies the joint core principles, used as the foundation of the child (health) care and appeals to the shared responsibility of general practitioners, youth health doctors, child psychiatrists, paediatricians, midwifes, paediatric nurses, teachers, youth workers, … together with the family context and close community in reaching every child's full potential. Hereby using the children’s and young person’s core strengths while acknowledging possible vulnerabilities. These basic fundaments are marked with on the right side of the page.

Every sector working with children and young persons faces cross-sectoral as well as sector-specific problems. However, this Plan “Care for the Children and Young Persons” focusses on child health care specifically and these parts are marked as .

Part 2 and 3 describe the current situation in child health care while Part 4 and 5 provide a proposal on how to build collaboratively on a better integrated care for all children.

Part 6 is written for policymakers. We advocate for children and young people, as patients, and their close caregivers to get a structural voice. The government should realize and recognise that today children’s and young persons’ health care is still an appendix to adult care and they should react now!

The last section of the plan highlights paediatric care specifically. It contains a proposal of a Paediatric Care Program written from the perspective of different paediatric patient-populations, each of them with their specific needs and again based on the core principles such as children's rights, equity, and equality.

This plan does not intend to imperialistically speak as paediatricians for all sectors and experts involved in Child Health Care but aims at reaching out too everyone involved in it. The Plan “Care for the Children and Young Persons” is a work in progress and should not be seen as the end.

It is a starting point, a kick-off for a child- and young persons-specific healthcare roadmap. A germinating seed of an integral flower.

Several relevant experts were consulted on a (preliminary) version of this Plan Care for the Children and Young Persons. Their comments were discussed during joint meetings and implemented as much as possible in the final version. However, not all experts necessarily agree with the full content.

This Plan "Care for the Children and Young Persons" was unanimously approved by the Executive Board of the Belgian Academy of Paediatrics:

Prof. dr. Ann De Guchtenaere	President	Secretary General of the European Academy of Paediatrics
Prof. dr. Stéphane Moniotte	Vice- president	Head of Paediatric Department, Université Catholique de Louvain (UCL)
Prof. dr. Pierre Philippet	Treasurer	President of the Groupement Belge des Pédiatres Francophones (GBPF)
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Prof. dr. Stijn Verhulst	Board Member	Head of Paediatric Department, Universiteit Antwerpen (UA)

This Plan "Care for the Children and Young Persons" has been developed by the Belgian Academy of Paediatrics in collaboration with and input from important key partners.

We want to thank all partners for the constructive and positive input from a common vision and bounding factor: the health, resilience and strength of every child and young person in Belgium.

Special thanks to Prof. dr. Ann De Guchtenaere, Natacha Meignen and Jeroen Verlinden for coordinating and connecting all pieces of the puzzle in creating this plan and bring all different visions, expertise and stakeholders in one kind or another together.

Many thanks to all (healthcare)professionals working every day 24/7 with children, young persons and their family giving them the best care, support, education, … possible.

Heartfelt gratitude and sincere appreciation to the children, young persons and parents for their testimonials and especially their everyday courage!

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Table of contents

Introduction

Positioning

Glossary

Child Integrity and the Right to Childhood

Each child is a unique individual and a citizen with their own right, their Childhood should be characterized by health, constructive experiences, and enjoyment. Childhood is sometimes seen as a preparatory phase for adulthood or as an apprenticeship aimed at maximizing economic or social contribution to society later on. We reject this concept of childhood as a temporary period to the more important adulthood. Each unique child is a person, a citizen, and an individual in his or her own right, and of equal value to that of any other individual. Children however may not be able to express themselves or represent their own interests, especially at the time when they are vulnerable to the actions or inactions of others, or to the effects of adverse social or physical environments.

The United Nations Declaration and Convention on the Rights of the Child (UNCRC) are important internationally endorsed statements, the values and content of which have been sources of encouragement for this project.

> *Every child has the right to grow up to be the best version of itself. As a society, we must take responsibility for creating an environment where all children have the opportunity to reach their full potential.*

National policies for children's health were too often focused on individual short- term issues, fostering needless competition for scarce resources and further fragmenting services. There was inadequate attention for underlying problems, making meaningful policy changes impossible. A system-wide transformation will be required to secure the health of all children and young persons in Belgium.
A transformation based on:

- the European Child Guarantee (2021)[1];
- the Council of Europe guidelines on child-friendly health care (2011)[2];
- the 10 recommendations arising from this Plan.

> *Let's demonstrate that health systems are working for both the people who use the services, and the professionals who deliver them.*

[1] https://www.europarl.europa.eu/legislative-train/theme-an-economy-that-works-for-people/ile-european-child-guarantee
[2] https://rm.coe.int/168046ccef

0.1 Positioning

For more than 15 years, vision texts and future plans for child and adolescent care have been published in Belgium by (paediatric) doctors[3], hospital umbrella organisations[4], but also by some strong patient/parent organizations[5].
Each group emphasized the changing circumstances and much-needed adjustments and incentives from their own unique perspective, unfortunately lacking a global vison on child care.

During the CoVID-19 crisis period, the Paediatric CoVID-19 Task Force reinforced teamwork, shared knowledge, resources, and best practices, collectively fortifying the health care ecosystem for children. Encouraging an environment of mutual respect, understanding, and open communication fostered a collaborative spirit that was indispensable in tackling both routine health care needs and unforeseen challenges.

Health within all life domains of children and young persons was the focus. An interprofessional and intersectoral way of thinking was used in order to organize and collaborate with the child and young people as the common core.

The child and its context form the heart of a flower, with each leaf (or petal) around this core. Only when the heart and all leaves are in place, the flower can shine in its full and unique splendour.

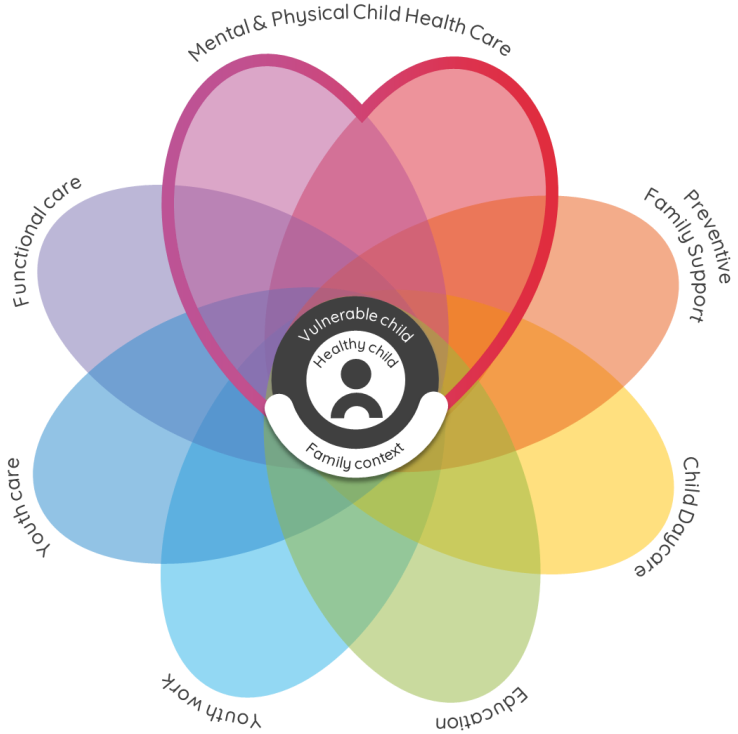


Figure 1: Interprofessional and cross-sectoral "child flower"

3 https://vvkindergeneeskunde.be/userfiles/files/Publicaties/VVK_Standpunten/160516%20definitieve%20visietekst_pediatrie_combi.pdf ; file:///C:/Users/Dokter/Downloads/TijdGeneesk-DetoekomstvandeziekenhuispediatrieinBelgie.pdf ; https://www.vwvj.be/sites/default/files/2023-09/Subsidiarie%20taakverdeling%20artsen%20en%20verpleegkundigen%20in%20CLB_20230914.pdf)

4 Zorgnet Vlaanderen: 2016 Kwaliteitsvolle zorg voor het kind in het ziekenhuis, nu en in de toekomst; ook morgen nog zeker van pediatrische zorgen

5 https://www.muco.be/nl/wat-doen-we/belangenverdediging/nieuwe-geneesmiddelen/ https://www.radiorg.be/nl/de-terugbetalingsprocedures-voor-geneesmiddelen-wordt-vernieuwd-goed-nieuws-of-niet/

This Plan Care for the Children and Young Persons always starts and ends in the core: the child and its context (Chapter 1.1 Core Principles) but focuses primarily on the petal of Mental and Physical Child Health Care. Both petals of mental and physical health are addressed as one. A strong sign from the field to eliminate this artificial division!

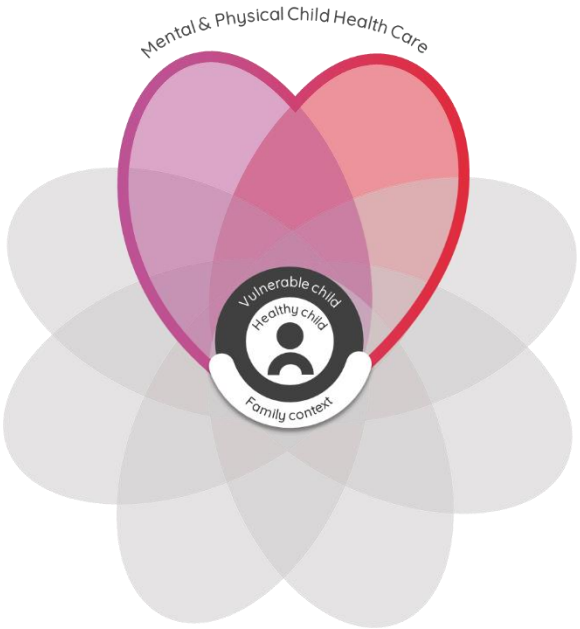


Figure 2: Mental and Physical Child Health Care petal

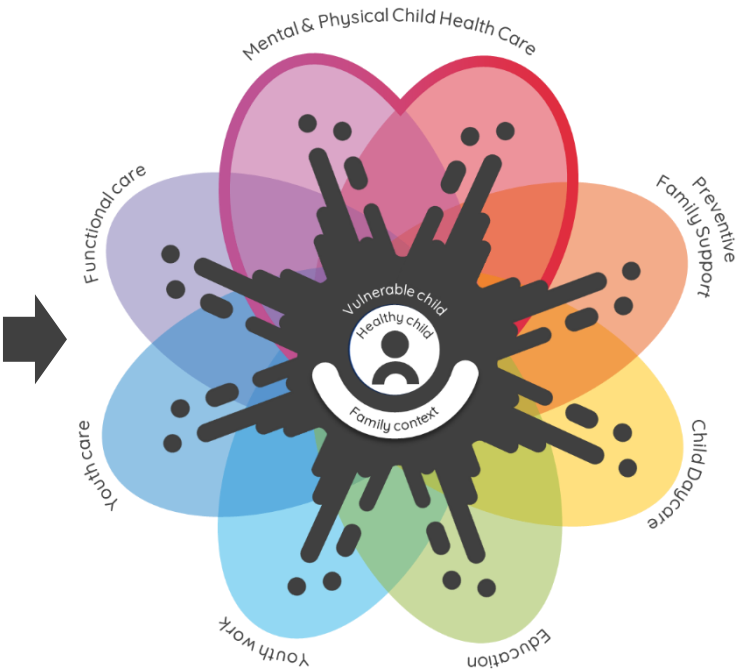
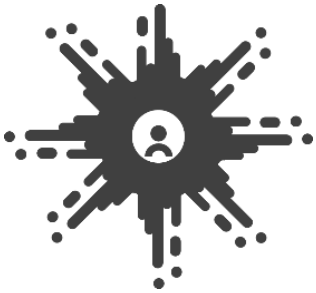


Figure 3: Interprofessional and intersectoral impact



Problems and vulnerabilities within one sector and/or specific life domains automatically impact the other sectors, ultimately influencing a child's integral health. Therefore, Medical Childcare can and should never be isolated from all other sectors and life domains surrounding children and their family-context.
These relationships work as communicating vessels and are clearly substantiated within the chapter of 1.3 The Vulnerable Child.

Therefor this Plan Care for the Children and Young Persons will promote the necessary interprofessional and intersectoral connections and competences.

Medical Childcare is a broad discipline with a range of subspecialties requiring broad as well as highly specialized paediatric competences.
From the petal of Mental and Physical Child Health Care, based on the United Nations Convention on the Rights of the Child (UNCRC), and the Sustainable Development Goals (SDGs) and starting from the diversity among of the population of children and young persons, we chose 3 major objectives within the subpopulations below.

1 From early childhood through adolescence, mobilizing societal efforts regarding the commercial, environmental, digital, and social factors affecting the
    - Healthy child and adolescent
2 Acknowledging and addressing the needs of the most susceptible
    - Vulnerable child and adolescent
3 Stimulating health systems to improve and achieve equality as well as equity in the access to high-quality care provided to the:
    - Acute severely ill neonate
    - Acute severely ill child and adolescent
    - Acute mild to moderately ill child and adolescent
    - Child and adolescent with a single long term condition
    - Child and adolescent with complex and integrated care needs

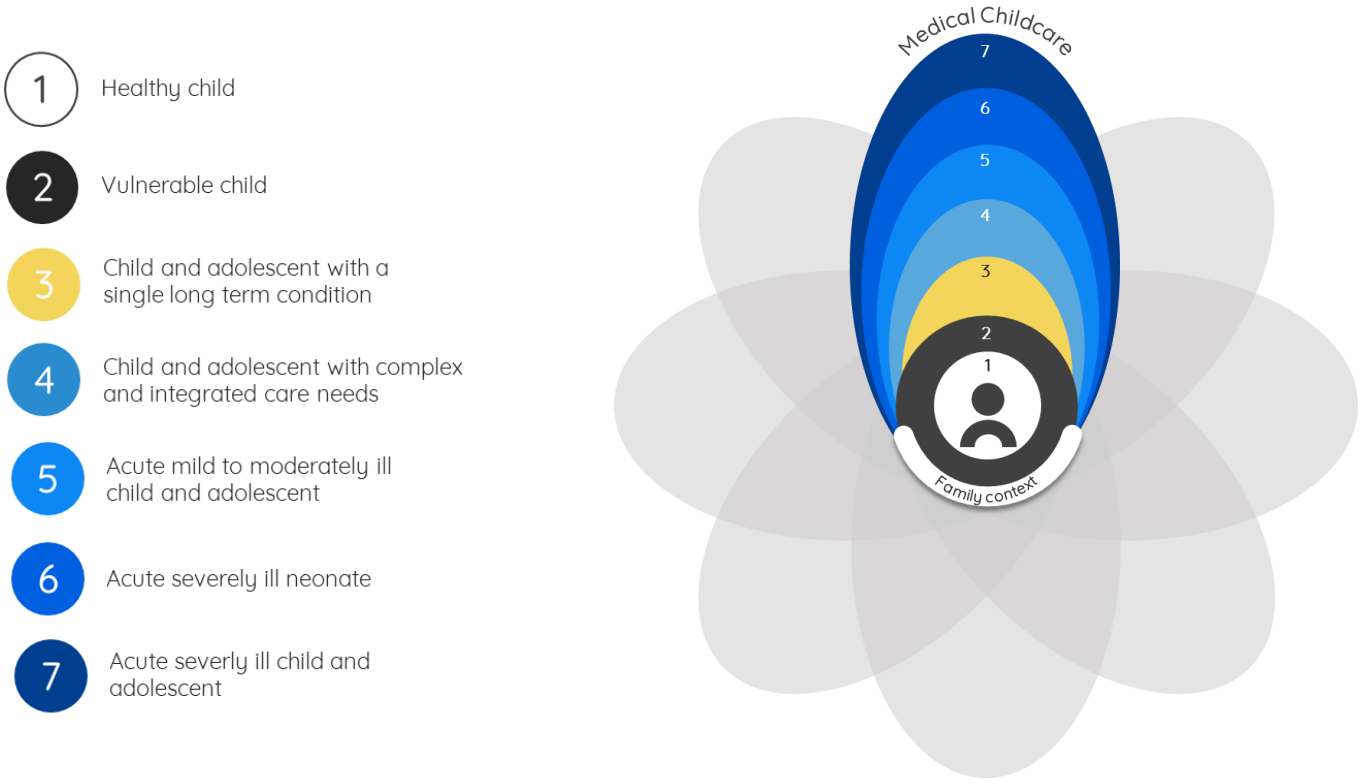


Figure 4: Subpopulations Medical Childcare

Objectives 1 and 2 imperatively need intersectoral integrative care (chapter 4-5-6), while objective 3 is elaborated in Chapter 7 using Kick-off templates. They can be used in all further discussions within an expert group discussion a final renewed Paediatric Care program with a broader panel of stakeholders.

Healthy Child

All children from ages 0 to 18y old

Vulnerable Child

Children and adolescents at risk of not reaching their full potential.

Vulnerability in this context indicates the potential to experience harm from emotional or physical causes. These can be categorized into two primary areas: Child-specific or Context-related

Acute severely ill neonate

Neonates (<28 days) with severe acute illness requiring necessitating stabilisation and/or intensive monitoring in case of in an case of (imminent) risk of failure of vital functions failing

Acute severely ill child and adolescent

Children and adolescents with a severe acute illness requiring necessitating stabilisation and/or intensive monitoring in case of an (imminent) risk of failure of vital functions failing

Acute mild to moderately ill child and adolescent

Children and adolescents with a specific condition/complaint (and reason for consultation) that is time-limited and requires no or time-restricted follow-up

Child and adolescent with a single long term condition

Children and adolescents living with a condition that is not time-limited and requires (multidisciplinary) follow-up at regular intervals

Inadequate follow-up may leads to long-term complications

Child and adolescent with complex and integrated care needs

Children and adolescents living with a persistent, not-time-limited condition undergo a pluri-disciplinal diagnostic and/or therapeutic process. This necessitates the development and implementation of a multi-professional, interdisciplinary, and integrated rehabilitation/care plan, along with regular follow-up intervals

Adequate monitoring is pivotal to achieving optimal preservation of functional performance, maximizing the quality of life, promoting age-appropriate self-management, enhancing short-and long-term health outcomes, and reducing both morbidity and overall usage of healthcare resources

Tabel 1: Subpopulations Medical Childcare

The position of the subpopulation in the leave (or petal) of the flower is not necessarily directly related to a position only in primary, secondary or tertiary healthcare.

The more the subpopulation is located towards the centre of the flower, the more influences of other sectors and context around the child and adolescent.

The more the subpopulation is located towards the centre of the flower, the bigger the need is for interprofessional and integral approach, collaboration and competencies to reach the best integral health outcomes.

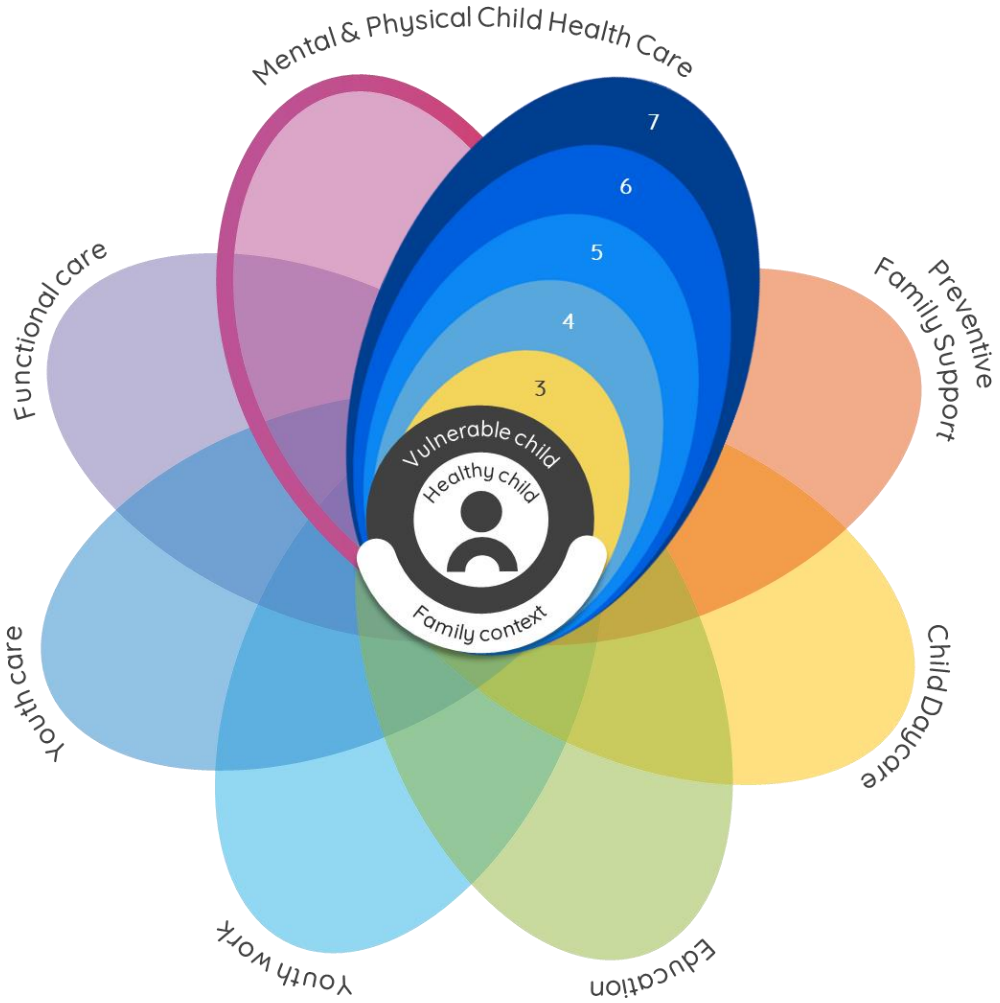


Figure 5: Integral and interprofessional position subpopulations Medical Childcare

The selection of these subgroups is additionally guided by the UNCRC[6] and World Health Organisation (WHO) Sustainable Development Goals (SDGs). With the biggest link to SDG3: *Ensure healthy lives and promote well-being for all at all ages*.

Figure 7: SDG3: Ensure healthy lives and promote well-being for all at all ages.

SDG3 identifies children as a vulnerable group requiring specific awareness and attention:

"You can raise awareness in your community about the importance of good health, healthy lifestyles as well as people's right to quality health care services, especially for the most vulnerable such as women and children." (WHO – SDG3)

> *Ensuring the health of children today is the cornerstone for building resilient and thriving societies tomorrow.*

[6] The Convention on the Rights of the Child: The children's version | UNICEF

0.2 Glossary

Having a common language is crucial for correctly comprehending and interpreting this Plan “Care for the Children and Young Persons”.

HE

In this text, the third person singular is used, employing the pronouns 'he/she/they'. This is intended to adopt an inclusive and gender-neutral language approach, ensuring that the content is accessible to every reader, regardless of gender. The aim is to maintain a balanced and respectful approach toward all individuals engaging with this text.

CHILD

In terms of the Convention on the Rights of the Child (UNCRC), a child means “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”

FAMILY

Family is the context in which a child lives and grows up.

MEDICAL CHILDCARE

Medical Childcare represents the provision of care initiated by a medical issue and/or diagnosis. It distinguishes itself from Youth care or Education. Paediatric care is still often overshadowed and considered as an appendix of adult care, lacking a distinct identity like Youth care, Education, or Child Day care. Furthermore, the term ‘Paediatric’ is difficult and unfamiliar to many professionals or to the broader society. For this reason, we have chosen to use this alternative, more comprehensive, definition of Medical Child Care which is being used throughout this Plan Care for the Children and Young Persons.

HEALTHY CHILD

The UNCRC defines the target group "children" from ages 0 till 18y old, a definition that Belgium adopted. his Convention on the Rights of the Child was adopted and ratified by Belgium in 1989.

All children (even with rare diseases, severely ill, etc.) have a healthy core that needs to protected.

VULNERABLE CHILD

Vulnerability indicates the risk of potential harm arising from emotional or physical causes and is often located in a child's immediate environment. These vulnerabilities may be categorized into two areas:

Child-specific, example:

1. A *child* has a *social communication disorder* which is undiagnosed and strategies for management are not implemented, resulting in poor educational attainment and emotional harm.

Context-related: example: (note that children are not responsible for the context they are born in)

2. A *child may have a medical diagnosis, but care givers are unable to meet the child's needs*, resulting in harm. This aspect must be considered in each encounter, acknowledging the biopsychosocial impact of a care-givers' own needs and abilities on their capacity to engage with management plans and child health outcomes.
3. A child is born into a household where members of the household have needs such as alcoholism, causing toxic stress. It is acknowledged that *childhood exposure to 'Adverse Childhood Experiences' (ACEs*) results in an increased risk of poor childhood development and has a lasting impact on the life course. These effects are dose-responsive and cumulative, yet not linear, as resilience factors serve as protective elements. Nurturing families embedded in strong neighbourhoods and communities can mitigate the effects of ACEs.
4. *Deliberate harm* can occur in a child's life, underscoring the necessity for effective, responsive child protection services, including those for looked-after children, to be present.

ACUTE SEVERILY ILL NEONATE

A newborn or infant (<28 days) experiencing a severe acute illness necessitating immediate attention, close monitoring, and specialized care. The disruptive nature of the illness is such that it interrupts a large part of the life participation of close significant individuals.

ACUTE SEVERILY ILL CHILD AND ADOLESCENT

A child or young person (>28 days – 18y old) undergoing a severe acute illness necessitating immediate attention, close monitoring, and specialized care. The disruptive nature of the illness is such that it interrupts a large part of the child's life participation and/or that of close significant individuals. The disease is characterized by:

- requiring stabilisation in case of (imminent) failure of vital functions awaiting transfer to a PICU or NICU
- requiring intensive monitoring and medical as well as nursing care but not meeting the PICU criteria as described below
- requiring PEWS (patient early warning score) assessment through monitoring, nursing and medical care every 30/60 minutes for a determined period of time
- requiring intensive and/or specialised multidisciplinary care as well as children with chronic illness requiring intensive and/or special multidisciplinary care, including at least two organs support

ACUTE MILD TO MODERATELY ILL CHILD AND ADOLESCENT

A child or young person (>28 days – 18y old) experiencing a mild to moderately severe acute illness, requiring time-limited attention and monitoring and required no or time-restricted follow-up. Although the illness's impact is notable, it does not entirely disrupt the child's life participation or that of close significant individuals. The disease is characterized by:

- birth till 18y old (based on the definition of Child by the Convention of the Rights of the Child)
- the specific condition/complaint (and reason for consultation) is time-limited and requires no or time-restricted follow-up
- the condition/complaint can initiate a long-term condition (either a single long term condition or a condition needing Complex Integrated Care)
- all children in this module, are an integral part of a Healthy Child and if applicable the Module Vulnerable child

CHILD WITH A SINGLE LONG-TERM CONDITION

A child or young person (>28 days – 18y old) living with a single long-term condition, necessitating ongoing care and management. The nature of this condition may vary, but it requires sustained attention and specialized care. There is a potential risk for dormant or occasional emerging disruptions in the child's life participation or that of close significant others throughout the child's life course.

CHILD WITH COMPLEX AND INTEGRATRED CARE NEEDS

A child or young person (>28 days – 18y old) with complex and integrated care needs that implies an individual facing a combination of health challenges, requiring comprehensive and coordinated attention across various medical, social, and psychological aspects. This encompasses the integration of diverse health care disciplines and community services to address the multifaceted nature of the child's conditions, ensuring a holistic approach to care. The disruptive impact of these needs may extend to the child's life participation or that of close significant individuals.

ABBREVIATIONS

ACE	Adverse Childhood Experience
BAOP	Belgian Academy of Paediatrics
BIHR	Belgian Integrated Health Record
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDC	Centre for Disease Control
CLB	Centrum voor Leerling Begeleiding
CPPP	Children of (a) Parent(s) with Psychological Problems
CRIA	Child Rights Impact Assessment
CRIE	Child Rights Impact Evaluation
DALY	Disease Adjusted Life Year
E	Paediatric hospital ward
EACH	European Association for Children in Hospital
ECD	Early Childhood Development
ECE	Early Childhood Education
ECG	European Child Care
ECI	Early Childhood Interventions
ECMO	Extra Corporal Membrane Oxygenation
EEG	Electro Encephalogram
ELC	Early Learning Centre
ENOC	European Network of Ombudspersons for Children
EPA	Entrusted Professional Activities
EPALS	European Paediatric Advanced Life Support
EPSDT	Early Periodic Screening, Diagnostic and Treatment provisions
ERN	European Reference Network
GAMA	Global Action for Measurement of Adolescent health
GDP	Gross Domestic Product
GP	General Practitioner
HAT	Helping Adolescents Thrive
HBSC	Health Behaviour in School-aged Children
IMA	InterMutualistic Agency
iSUPPORT	International collaborative rights-based standards to SUpport Paediatric Patients during clinical prOcedures by Reducing harm and establishing Trust
K&G	Kind & Gezin
KCE	Belgian Health Care Knowledge Centre
MCC	Medical Child Care
MCD	Mid Childhood Development
MOC	Multidisciplinary Oncologic Consult
MOCHA	Models of Child Health Appraised
NFC	Nurturing Care Framework
NICU	Neonatal Intensive Care Unit
OECD	Organisation for Economic Co-operation and Development
ONE	Office de la Naissance et de l'Enfance
PACE	Positive And Complementary Experiences
PACIC	Patients Assessment Chronic Illness Care
PICU	Paediatric Intensive Care Unit
PRE(M)	Patient Reported Evaluation (Measures)
PRO(M)	Patient Reported Outcome (Measures)
PROSA	Procedural Sedation and Analgesia

PSE	les services de Promotion de la Santé à l'Ecole
QALY	Quality Adjusted Life Year
RCPCH	Royal College of Paediatric and Child Health
SD	Standard Deviation
SDG	Sustainable Development Goals
SRH	Sexual and Reproductive Health
UNCRC	United Nations Convention on the Rights of the Child
UNCRC	United Nations Convention of the Child
UNESCO	United Nations Educational, Scientific and Cultural Organization
VAT	Valued Added Tax
WHO	World Health Organisation
YLD	Years of healthy Life lost due to Disability

01

Rationale

Core principles

Core strength of the child and the young person

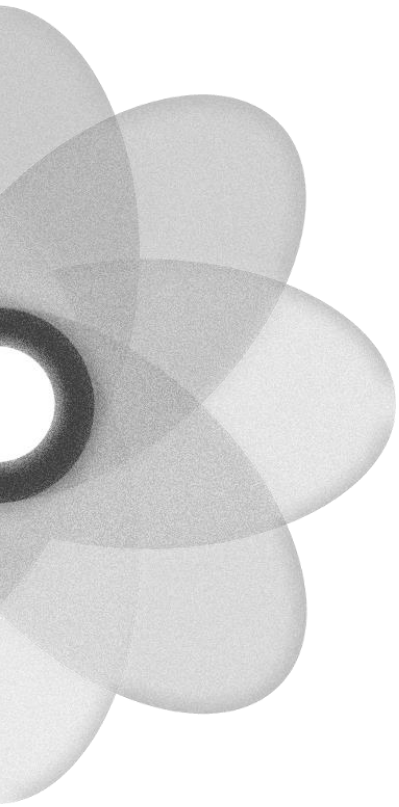
Vulnerability of the child and the young person

Core principles

No discrimination

All children have all these rights, no matter who they are, where they live, what language they speak, what their religion is, what they think, what they look like, if they are a boy or girl, if they have a disability, if they are rich or poor, and no matter who their parents or families are or what their parents or families believe or do. No child should be treated unfairly for any reason.

Article 2 United Nations Convention on the Rights of the Child



Best interests of the child

When adults make decisions, they should think about how their decisions will affect children. All adults should do what is best for children. Governments should make sure children are protected and looked after by their parents, or by other people when this is needed. Governments should make sure that people and places responsible for looking after children are doing a good job.

Article 3 United Nations Convention on the Rights of the Child

Health and healthcare

Every child has the right to the best possible health and to healthcare. The state should ensure children have healthcare services, nutritious food, clean water, a clean environment and healthcare information. Richer countries should support poorer countries in this.

Article 24 United Nations Convention on the Rights of the Child

1.1 Core Principles

"It's easier to build strong children, than to fix broken men"

Frederik Douglas – 1855

All children are entitled to survival, protection, development and participation.

The United Nations Convention of the Rights of the Child (UNCRC), ratified by our country will celebrate its 35th birthday in 2024. The UNCRC is comprehensive (one and indivisible) and protects not only the right of children to preventive, promotive and curative health care. It protects the right of every child to grow to his full potential.

The UNCRC is legally binding. As a result, it goes beyond the voluntary Sustainable Development Goals (SGD) frame work of the World Health Organization (WHO).

Our country is renowned internationally for its robust and high-quality health care system, employing highly trained and specialized health care professionals who deliver state-of-the-art and innovative care; and yet, despite this reputation, our health care system is characterized by fragmentation, a deficiency in integrated coordination, and an emphasis on performance rather than a commitment to quality and outcome-based principles. Consequently, patients in Belgium are at risk to experience unmet needs in health care and health care-related domains of quality of life.

Within the current legislature of Federal Health Minister Frank Vandenbroucke, several initiatives in medical child care have been launched, such as an obesity track for children, an investment in Mental Health Care for children and young persons, AYA care for oncology patients, etc.

These are all important and welcome initiatives.

However, this exclusive focus on specific diseases creates inequalities, exclusion and discrimination in access to high-quality health care among various conditions. A scenario in which children with a different condition are marginalized, lacking access to the same multidisciplinary and quality care pathway as other children. In this way it violates Article 2 of the UNCRC.

Moreover, this approach creates an unintended "competition" battle between subspecialties, as disorders, while having specific effects and care needs, are fundamentally influenced by broader disease-transcending factors, regardless of the disease type[7].

[7] Hatzmann, J. (2009). Consequences of Care – parents of children with a chronic disease, Universiteit Amsterdam. Hatzmann J.; Niels Peek; Hugo Heymans ; Heleen Maurice-Stam; Martha Grootenhuis. (2014). Consequences of caring for a child with a chronic disease: Employment and leisure time of parents. J Child Health Care;18(4):346-57. Hatzmann J, Heymans HS, Ferrer-i-Carbonell A, van Praag BM, Grootenhuis MA. (2008). Hidden consequences of success in pediatrics: parental health-related quality of life--results from the Care Project. Pediatrics;122(5)

Dozens to hundreds of conditions affect children, many of which differ substantially from adults. New pathologies emerge, while others become rarer or require less professional care. Consequently, the quality of a care pathway should not depend primarily on the specific condition or the influence of one lobby group associated with a particular pathology. The connecting child-specific factors, quality requirements and generic qualitative and integrative outcomes thereby evaporate or are constantly reinvented.

A metaphor emerged, presenting care pathways as if they were scattered clothes on the floor of a teenager's room, losing awareness of its contents.

Among other things, this Plan Care for the Children and Young Persons advocates the prompt and urgent launch of a generic care pathway for children. As a solid quality and integral outcome-oriented coat rack on which specific care trajectories (or modules) can be hung neatly as pieces of clothing and allowing each piece to shine but in connection with all the other pieces of clothing.

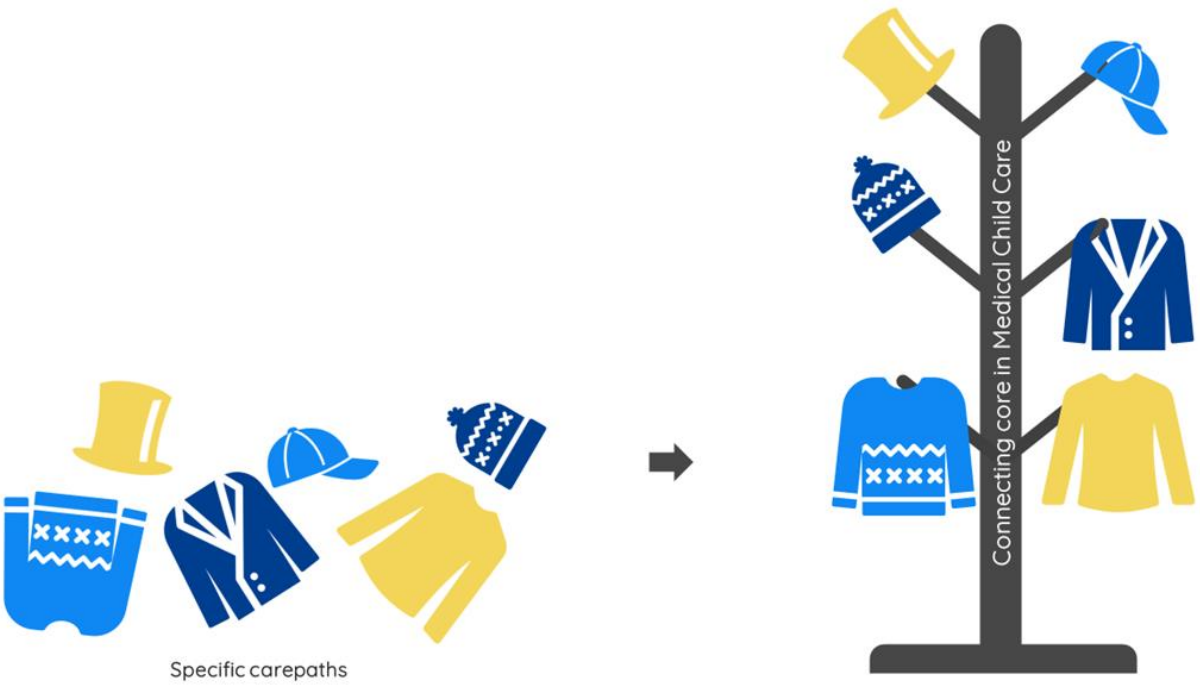


Figure 6: Metaphor of quality generic coat rack for Medical Childcare

Hatzmann J, Maurice-Stam H, Heymans HS, Grootenhuis MA. (2009). A predictive model of Health Related Quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system. Health Qual Life Outcomes, 28;7:72.

This Plan Care for the Children and Young Persons is therefore based in every detail on the 'fairness' principle for every child, transcends a disease-oriented approach and is based on two well-known and crucial core principles: Equality and Equity.

This is particularly to avoid the pitfall of discrimination based on type of pathology and truly meet the equity principle:

> Every child, regardless of type of care, type of condition and location of care!

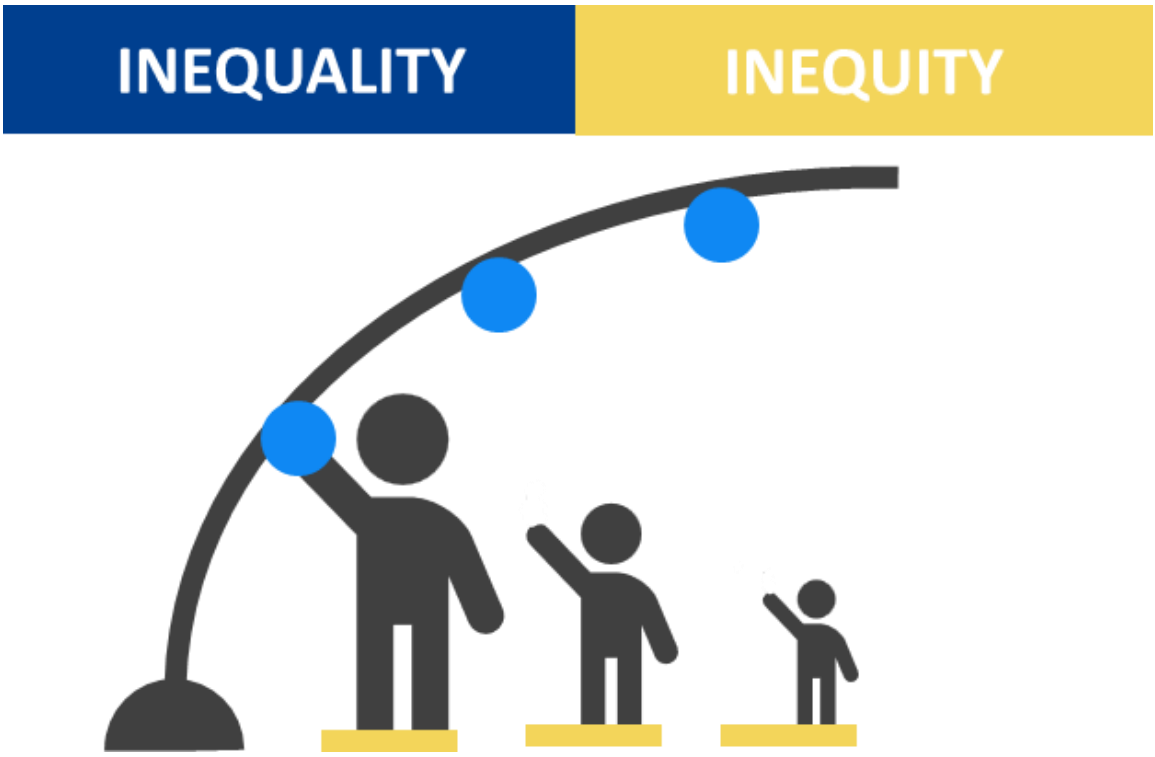


Figure 7: Pitfall of discrimination based on for example pathology

Equality ensures fair and equal-quality, accessible health care for children, regardless of type of illness, type of care, and location of care. Both the UNCRC and the European Association for Children in Hospital (EACH) charter form the core and foundation from which any policy in the care for children initiates and should not deviate.

Evidenced-based education and competency are crucial. Generic paediatric Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) are essential tools to facilitate engagement in appropriate paediatric outcome-based care, focusing on shared care goals for every child with medical needs.

Equality provides a robust structural "coat rack" of quality child health/paediatric care grounded in common core principles.

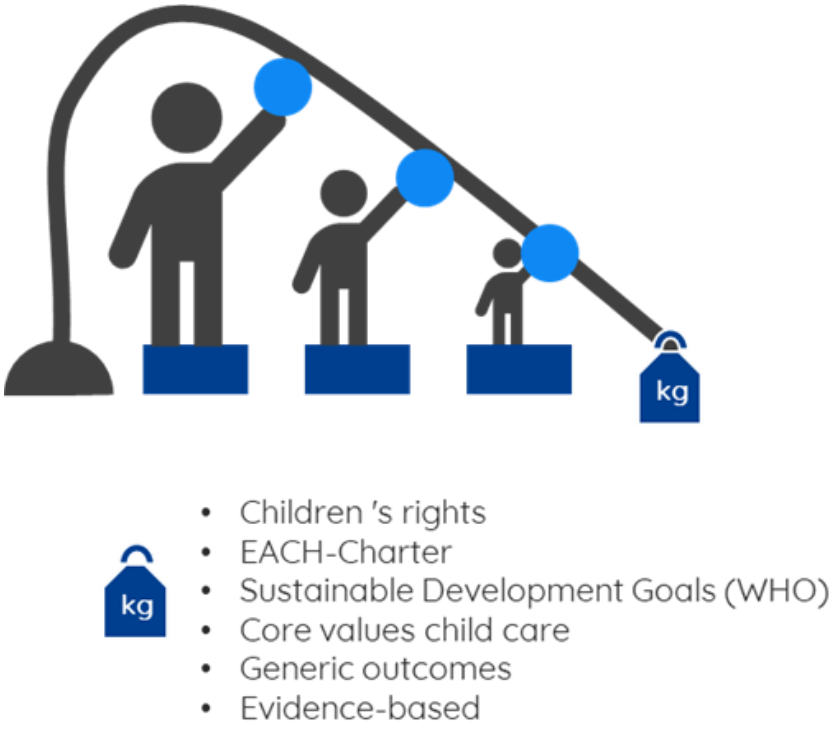


Figure 8: Equality in de Medical Childcare

Equity is about assessing the individual care needs of a particular child and family, enabling them to achieve the goals of Equality in a way tailored to their unique situation. It emphasizes tailored care with a focus on the context, recognizing that each child grows up within a unique "eco-system". Consequently, a treatment plan should prove effective for one child and not for another, even when faced with identical medical conditions and treatments. A one-size-fits-all approach cannot be universally applied to every family; instead, it requires a context-based approach and adaptation. In this sense, Equity represents "context-based practice", serving as a tool for health care professionals to deviate from standards and evidence-based practices to tailor treatment for each unique young person.

Equity are the specific garments hung on the “coat rack” of Equality. While the core remains the same for every child, the approaches and adaptations are tailored to each unique child, pathology, family and situation (context-based approach).

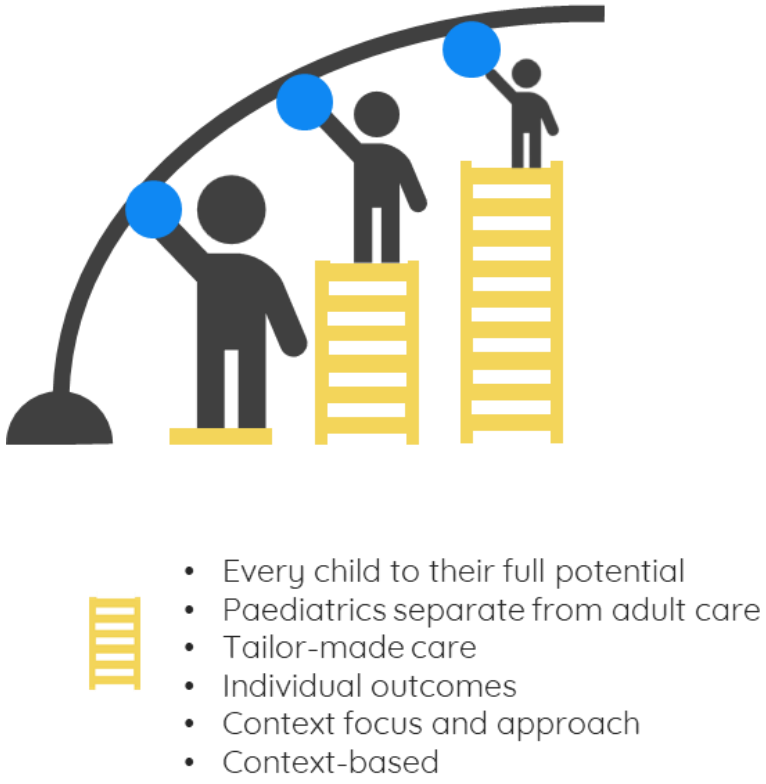


Figure 9: Equity in de Medical Childcare

The principles of Equality and Equity are pivotal for ensuring quality, sustainable and ‘fair’ health care, and both principles balance each other. It is this balance that ensures the right health outcomes and a tailored care pathway [8].

[8] Cifs Health. Equality vs Equity in Healthcare: Both Are Important. Copenhagen Institute for Future Studies.

Children's rights as the fundament of child-, family- and development-centred qualitive healthcare from policy making to daily organisation and care.

The European Association for Children in Hospital (EACH)[9] is an international umbrella organisation for the welfare of children in hospitals and other healthcare services. Belgium is not represented in this organisation.

In 1988, EACH wrote a Charter (EACH Charter) of 10 points on the rights of sick children and their families before, during and after a stay in hospital and in other healthcare services. The 10 rights in the Charter apply to all sick children, regardless of their illness, age, disability, origin, social and cultural background, reason, form or place of treatment, or whether they are in-patients or out-patients.

The 10 principles of the EACH Charter are connected to the UNCRC.

Children's rights as the fundament of child-, family- and development centred qualitive healthcare from policy making to daily organisation and care.

As Belgium is not represented in EACH, the EACH Charter is not known by patient organisations, policy makers and politicians resulting in a smaller voice of children and their family in healthcare and the absence of one structured child-centred voice.

Trained intramural paediatric healthcare workers like paediatricians and paediatric nurses are well known with the EACH-Charter.

Nevertheless, the knowledge and implementation of this Charter and the important rights of children in healthcare is still limited to the 'gates' of hospitals and paediatric chronic care centres. There is little knowledge and even less implementation in first-line and community care with an impact on complete organisation of healthcare for children. Caring for children and guarantee qualitive and safe paediatric healthcare cannot be done without placing the children's rights in the centre.

Therefore, the EACH-charter was added in chapter 7. However broadening of the EACH Charter, making it future proof and inclusive for all future challenges on the health of children might be necessary.

[9] EACH, the European Association for Children in Hospital (each-for-sick-children.org)

Core strength of the child and the young person

1.2 Core strength of the child and the young person

A child is more than "not a small adult"

'A child is not a small adult' – a phrase encountered everywhere. Yet, its significance is not universally understood. Often, this phrase gets bogged down in a form of vacuous advertising without being substantively and qualitatively integrated into the fabric of policy work and decisions.

A child's body undergoes constant growth, and children at various ages differ substantially in terms of anatomy and physiology, setting them apart from adults. Beyond these physical differences, children experience crucial motor, social, emotional, sexual, and cognitive development changes. This developmental journey in inseparable interaction with others and society plays a pivotal role in shaping the future adult.

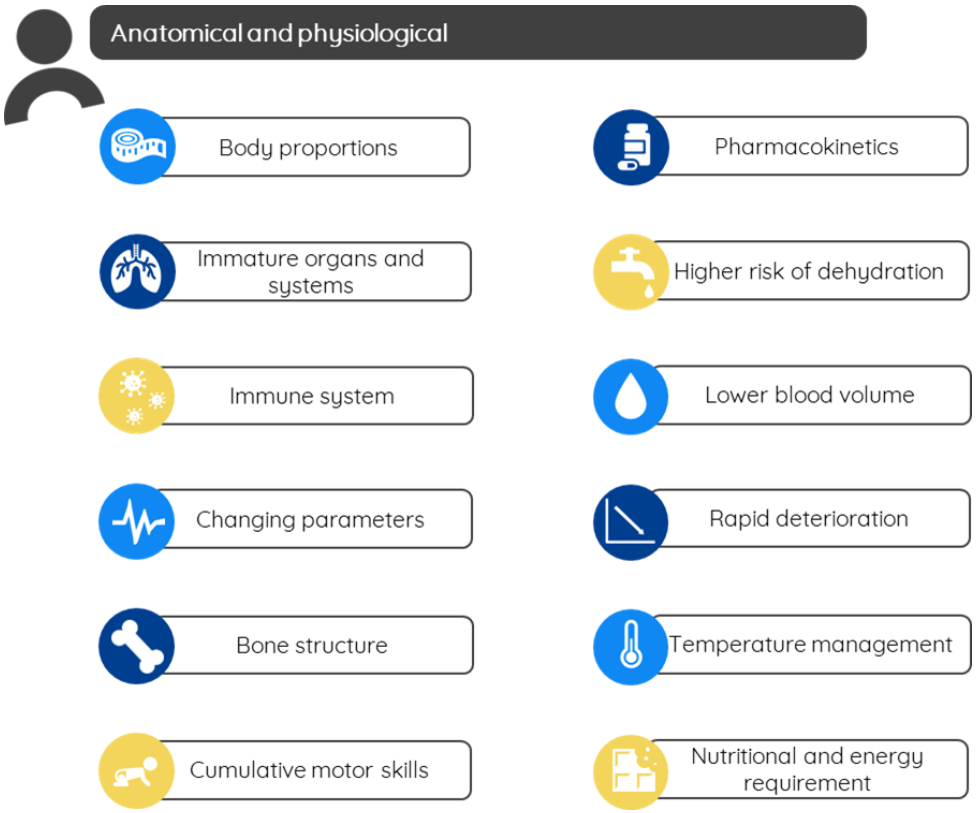


Figure 10: Anatomical and physiological differences in children compared to adults

Although many discussions on "a child is not a small adult" conclude at this physical level, it's essential to recognize that a child's uniqueness extends beyond this definition. Development and growing up is much more than physical growth[10] and involve several intertwined domains that contribute to the holistic understanding of a child's journey.

[10] WHO 2022. Framework on Early Childhood Development

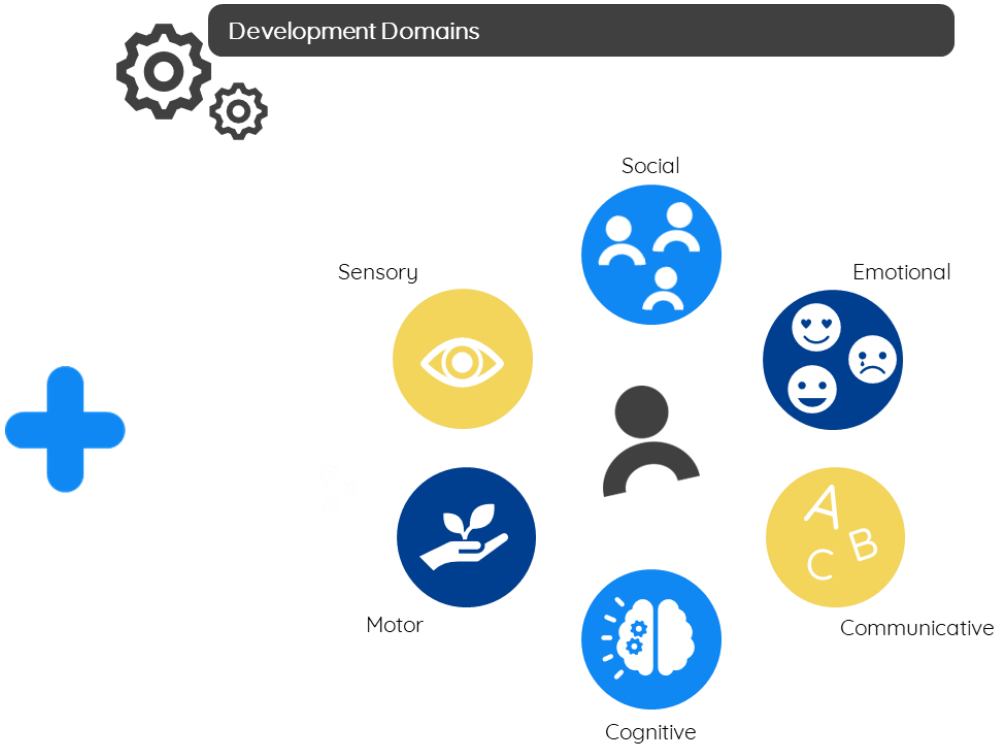


Figure 11: Development domains in children

Every child is born with a unique potential and the will to develop into the best version of itself through core abilities[11].
This developmental journey is one that children should undertake within optimal physical and mental condition, where they are afforded the opportunity to maximize and freely develop their core abilities in alignment with their unique potential. These core skills span across physical, mental, emotional, and 'spiritual' dimensions.

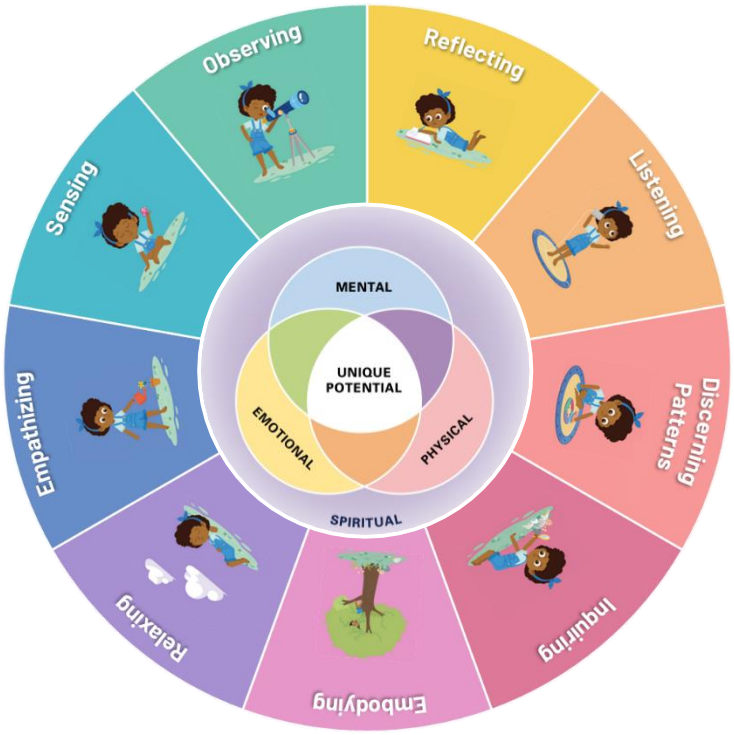


Figure 12: What shapes us? – UNICEF Innocenti

[11] UNICEF Innocenti (2021) - What Makes Me? Core Capacities for Living and Learning

Regardless of their health status, all children experience three key outcomes in their growth and development journey[12]: physical health, mental health, and the development of core skills.

However, a child does not grow up within a safe, impenetrable glass bell jar shielded from external influences. This trajectory of their development and the attainment of these key outcomes are shaped by factors within three layers (also referred to as 'worlds') of influence, as outlined in the World of Influence framework:

- The world of the child (the child itself): child-related factors
- The world around the child (immediate social environment and family in which it grows up, providing developmental opportunities and positive encouragement): context-specific factors
- The larger world: macro-level (policy and politics)

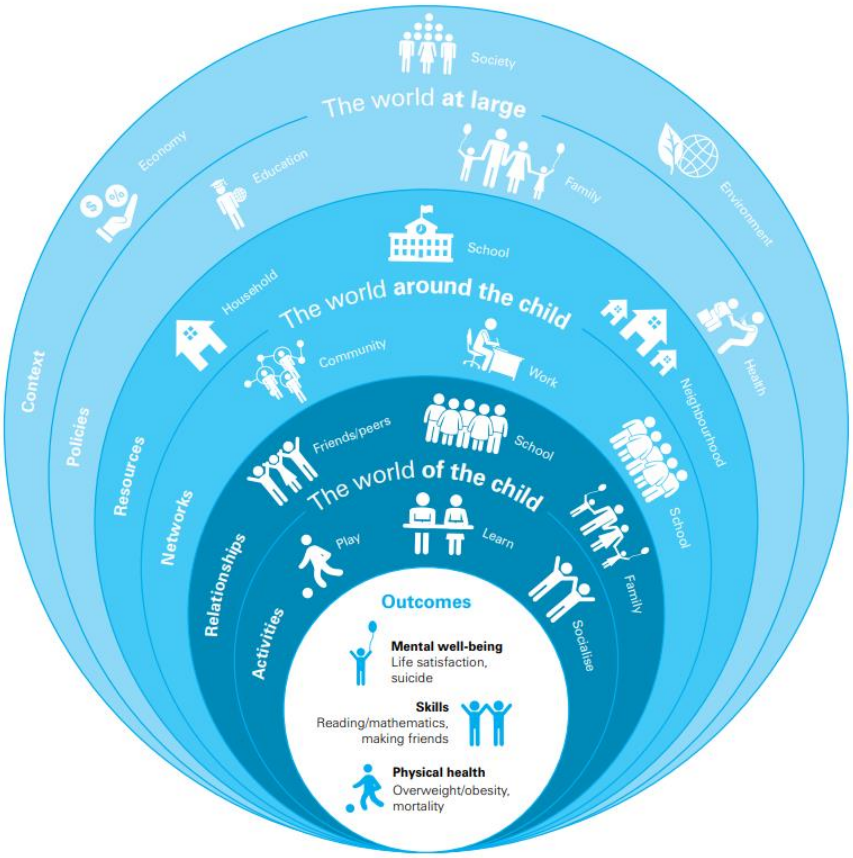


Figure 13: What Shapes Me 'World of Influences' – UNICEF Innocenti

Any disturbance within any area or layer (world) of influence can have a profound impact on the trajectory and outcome of comprehensive development, with a high likelihood that the child will have long-term consequences and even throughout their life. An impact that not only affects the child, but also the entire family, social environment, economic context and the society around it.[13] Even into the next generations.

[12] UNICEF Innocenti (2019) – What Shapes Me 'World of Influences'

[13] Hatzmann, J. (2009). Consequences of Care – parents of children with a chronic disease, Universiteit Amsterdam.

Definition of Health

We can define health as the ability to adapt and take control in the face of life's physical, emotional and social challenges (Machteld Huber, Maastricht University, 2014).

This definition goes beyond the 1948 World Health Organisation (WHO) definition of health 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. Although WHO defined the concept of health very broadly even then in a pioneering way, no one is likely to be healthy based on the absolute and static nature of the definition. Huber's dynamic definition is based on resilience, participation, context and self-direction. This ensures that children or persons with disabilities can also be healthy.

That's also why some definitions don't speak about 'health' but more about 'happiness' or other related terms. These definitions place the state of 'happiness' above the state of physical health. *"You can be free of medical disease but not happy. And you can be happy despite having a medical disease."*

Specific for children the WHO defines child health as: *a state of physical, mental, intellectual, social and emotional well-being and not merely the absence of disease or infirmity. Healthy children live in families, environments, and communities that provide them with the opportunity to reach their fullest developmental potential.*

Despite the different definitions and the importance of giving core principles as resilience, participation, shared decision making, context and self-direction a central place in the definition of health, children cannot achieve optimal health alone.
Even more, babies and young children till the age of 8 years old and/or children with cognitive developmental disorders are particularly reliant on adults for their health. On the one hand, this group of children is fully dependent on its caretakers not being able to independently participate, decide or advocate for themselves. On the other hand, it is scientifically proven that only from the age of 8 years old does a child with a 'normal' development have the ability to really understand the relation between the information given, the situation they are in and the impact on their situation[14].

Therefore child healthcare professionals, as part of the context and community of the child, feel very responsible as advocates for their (vulnerable) patients.

Children and young people unable to participate in health-care decisions might need a specific definition of "health".

[14] Tang, Y., Brummelman, E., Novin, S., Assink, M., & Thomaes, S. (2023). Children's domain-specific self-evaluations and global self-worth: A preregistered cross-cultural meta-analysis. International Journal of Behavioral Development, 47(6), 521-539.

Assessment of child health in terms of strengths

The scope of child health, including its determinants and related services, are clearly extensive and fundamentally distinct from the determinants of adult health. The development of indicators or assessment tools to measure child health proves particularly challenging due to the presence of the 4 D's: Developmental change, Dependency, Differential epidemiology, and Demographic patterns.

Furthermore, significant differences exist between infancy and adolescence in terms of age-specific developmental needs and health, including determinants of health, type of health service, and data sources.

Inherent in determining child health determinants is the concept of risk, a complex area where the inter-reaction of factors at the micro-, meso- and macro-level creates unique patterns of health determination; a similar mix of interactions occurs at the population level. Elements such as environmental exposures, societal contexts, household setting, and behavioural lifestyles are among the principal factors influencing the risk landscape for child health. Raising healthy children through health promotion and disease prevention requires an equally significant emphasis on both population-based and individual approaches.

Life course investment frameworks highlight the "dynamic complementarities":

- *Human capability:* capabilities learnt early in life provide the foundation for increasing the productivity of investments later in life, in other words, investments at different stages of life are synergistic.

- *Self-productivity* refers to the idea that capabilities are self-reinforcing for example better health promotes learning[15].

Investing in screening and prevention is of therefore of paramount importance, especially for children and young persons, to safeguard, protect and promote health, growth and development of this population. It is a joint and interdisciplinary task involving health care workers, society, and policy-makers. Without effective coordination and communication, significant opportunities are missed.

[15] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)32540-1/fulltext?ltclid=

Investing in children requires a clear long-term vision. Our society and prosperity are rather quickly judged by the quick economic gains in the short term. However, investing in children requires looking at the long-term benefits in many more areas of life than just the domain in which investments are made. The sooner we invest in children, the bigger the social-economic benefits on a long term[16].

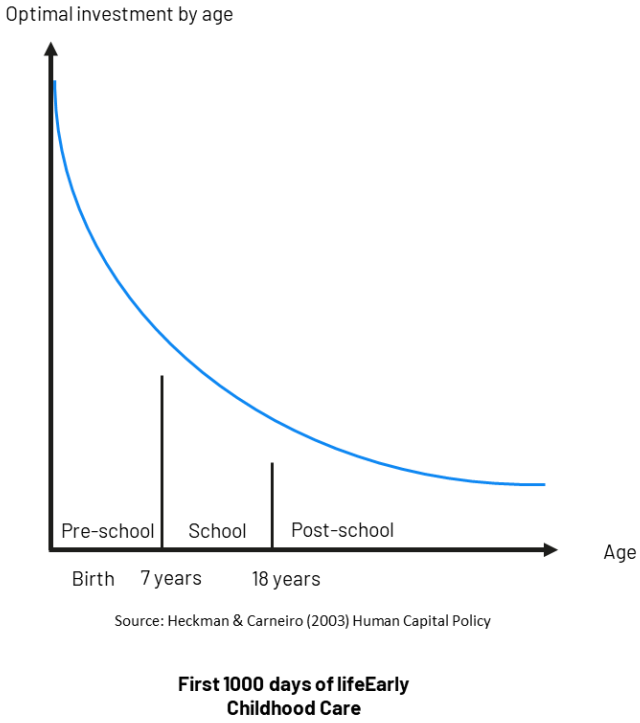


Figure 14: Investing in children and social-economic benefits on a long term

Within a narrow economic view point, the demographic of 'children' is not considered part of the actively working population that immediately contributes to the economic value to society. In this context, children and young persons as well as the investments in their developmental trajectory is viewed as an immediate cost rather than a long-term investment with substantial returns for society. As these children and young persons transition into the adult age group over time, their overall health also transitions accordingly, along with the person's ability to contribute to and participate in society.

[16] Heckman & Carneiro, 2003

Vulnerability of the child and the young person

1.3 Vulnerability of the child and the young person

Many children and young persons are fortunate to lead a healthy life within families that prioritize maximising their well-being and addressing any apparent signs of health or developmental problems.

The most vulnerable, however, are those not having this advantage. A societal priority lies in recognising and implementing the needs of these vulnerable children and young persons, as they are at risk of not reaching their full potential.

Vulnerability indicates the risk of potential harm arising from emotional or physical causes and is often located in a child's immediate environment. These vulnerabilities may be categorized into two areas:

Child-specific, example:

1. A *child* has a *social communication disorder* which is undiagnosed and strategies for management are not implemented, resulting in poor educational attainment and emotional harm.

Context-related, example: (note that children are not responsible for the context they are born in)

2. A *child may have a medical diagnosis, but caregivers are unable to meet the child's needs*, resulting in harm. This aspect must be considered during each contact, acknowledging the biopsychosocial impact of a caregivers' own needs and abilities on their capacity to engage with management plans and child health outcomes.
3. A child is born into a household where members of the household are prone to poverty, alcoholism or drug abuse, all causing toxic stress. It is acknowledged that *childhood exposure to 'Adverse Childhood Experiences' (ACEs)* results in an increased risk of poor childhood development and has a lasting impact on the life course. These effects are dose-responsive and cumulative, yet not linear, as resilience factors serve as protective elements. Nurturing families embedded in strong neighbourhoods and communities can mitigate the effects of ACEs.
4. *Deliberate harm* can occur in a child's life, underscoring the necessity for effective, responsive child protection services, including those for looked-after children, to be present.

Each child and young person is a part of a network that includes parents, siblings, school, sports, and more. Research indicates that they are most satisfied when they can lead a life as normal as possible. According to UNICEF, children and young persons consistently express three key outcomes they value: physical health, mental health, and the opportunity to discover and develop their core skills. Unfortunately, the physical and mental health, as well as the social foundation of individuals, too often depends on the place of birth, upbringing, residence, education, and job.
The socioeconomic status of individuals can contribute to them leading less healthy lives or participating less, resulting in physical and/or mental health issues. This phenomenon represents a vicious circle of health inequality.

Addressing these risk factors require specific qualitative and quantitative preconditions within Child Care, and must be coordinated within an integrated interprofessional and intersectoral approach and collaboration.

Only this way can the negative circle be broken and there can be investment in real prevention and better integral development and health outcomes in children and their family.

To do this with a proper structural and evidence base, appropriate data gathering based on the correct paediatric determinants of health is crucial.

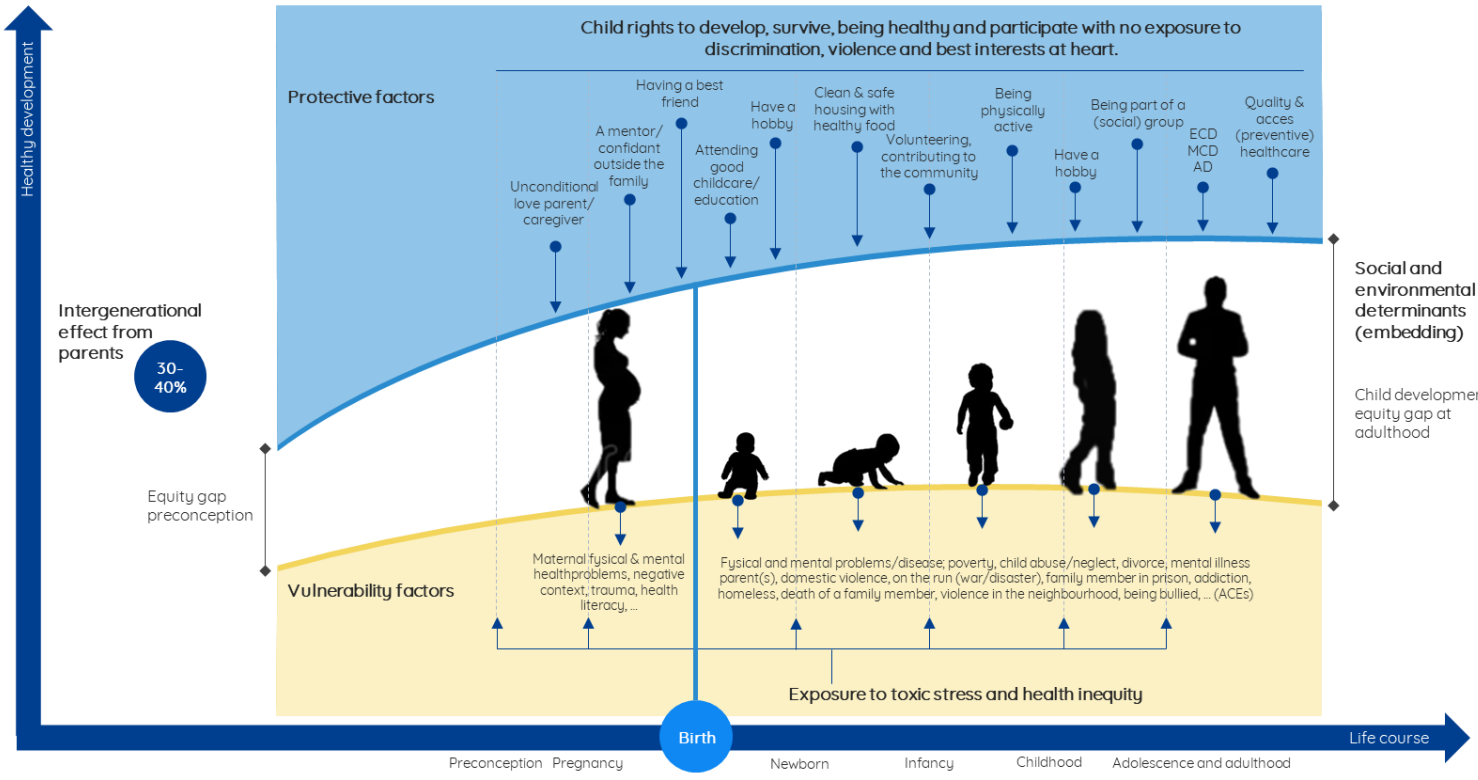


Figure 15: Adapted from: Sustainable Development Goals measuring protective and risk factors for child wellbeing across life course

(Source: The Lancet Commissions A future for the world's children? A WHO-UNICEF-Lancet Commission Executive summary)

Children and young persons' unique growth and developmental journey are constantly influenced by a myriad of factors within their distinct context and world in which they grow up. These influences are primarily shaped by adults, operating at nano-, micro-, meso-, and macro-levels, shaping the society surrounding of the children. In this regard, a child or young person is not inherently vulnerable but becomes more or less vulnerable due to the influence of the adult around them and society organisation, both formally and informally. These influences create stress and may lead to toxic stress, defined as *a severe, prolonged, or repetitive adversity with a lack of necessary nurturance or support of a caregiver to prevent an abnormal stress response*[17]. Toxic stress can impact outcomes across every developmental domain and even persist into adulthood.

Figure 16: Toxic stress and long-term health impact

Generally, toxic stress has both short-term and long-term impacts on several aspects, as indicated by the data in Belgium and worldwide[18].

17

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4928741/#:~:text=Childhood%20toxic%20stress%20is%20severe,abnormal%20stress%20response%20%5B5%5D.

[18] Nadja Rod; et al. (2021). Childhood adversity: a profound determinant of health. The Lancet Public Health; Volume 6, issue 11, E780.

All following aspects are referred to as Adverse Childhood Experiences (ACEs)[19] [20] [21].

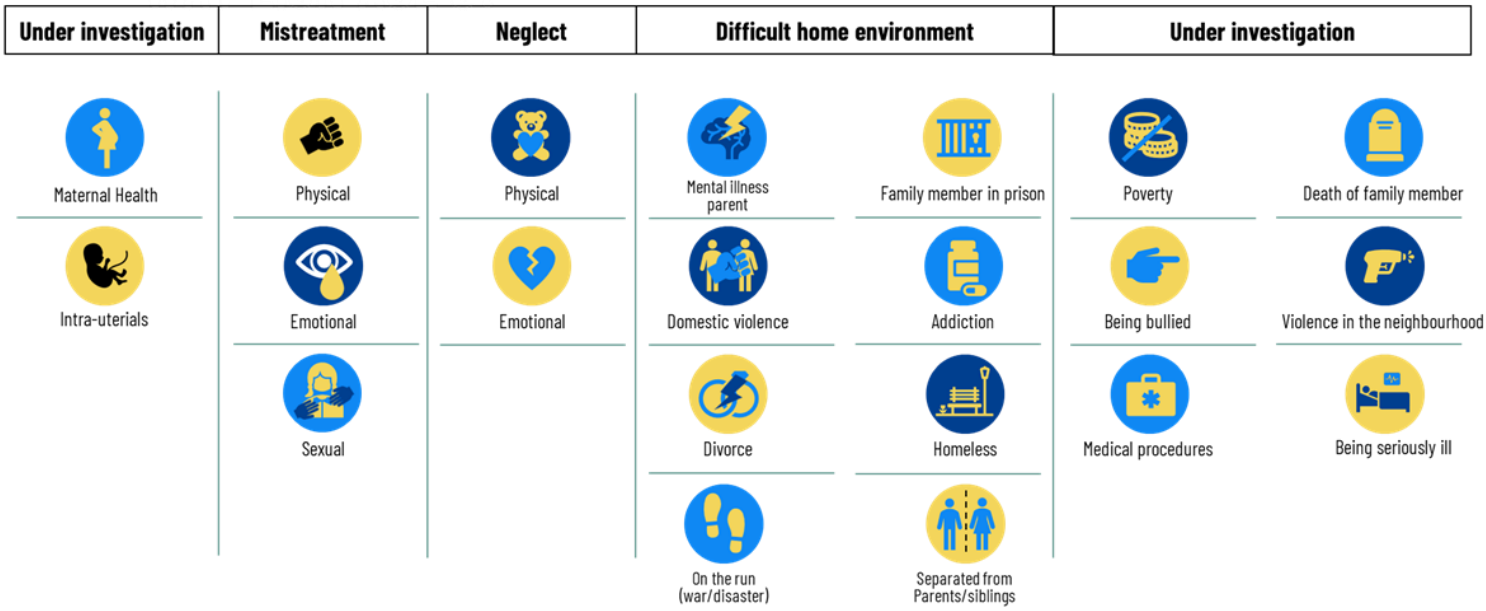


Figure 17: Sources of toxic stress and ACEs

List of possible Adverse childhood-experiences[22]		
Bereavement	Impaired caregiver	Poor academic performance
Bullying	Kidnapping	Poverty
Community violence	Living in unsafe environments	Racism over time
Domestic violence	Multiple deaths & traumatic loss	School violence
Emotional abuse	Natural disasters	Serious injury/accident
Food scarcity	Neglect	Sexual abuse
Forced displacement	Peer rejection	Sexual assault/rape
Foster care system experiences	Physical abuse	Terrorism
Illness/medical trauma	Physical assault	Traumatic loss
Interpersonal violence	Political violence	War

Table 2: List of possible Adverse childhood-experiences

[19] Nadja Rod; et al. (2021). Childhood adversity: a profound determinant of health. The Lancet Public Health; Volume 6, issue 11, E780.

[20] V J Felitti; R F Anda; D Nordenberg; D F Williamson; A M Spitz; V Edwards; M P Koss; J S Marks. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med; 14(4):245-58.

[21] Nadine Burke Harris (2018). Ingrijpende jeugdervaringen en gezondheidsproblemen - Het helen van langetermijneffecten van adverse childhood experiences (ACE's). Uitgeverij Mens.

[22] Anda et al. (2006); Anda et al. (2010); Briere et al. (1995); Bruskas (2008); Bucci et al. (2016); Burke, Hellman, Scott, Weems, and Carrion (2011); Cook et al. (2005);Felitti et al. (1998); Felitti (2009); Felitti and Anda (2010);Dube et al. (2001); Grogan and Murphy (2011);Hughes et al. (2017); Johnson et al. (2013);O'Donnell, Creamer, and Pattison (2004); Perry (2002);Schneider and Phares (2005); Simmel (2010).
Goddard et al J Pediatr Health Care. (2021) 35, 145–155

The extent to which ACEs and toxic stress impacting a growing child or young person depends on their developmental stage. Similar external influencing factors (ACEs) may yield different outcomes in terms of the child's development, growth, health, or illness. Furthermore, ACEs have a cumulative effect, amplifying negative outcomes and impact when more ACEs are present.

The analysis showed a graded-dose relationship, with adults who experienced the highest levels of childhood traumas for example being 5 times more likely to become an alcoholic, 9 times more likely to abuse illegal drugs, 3 times more likely to have clinical depression, 17 times more likely to attempt suicide, 2 times more likely to develop heart disease, and 2 times more likely to be obese.

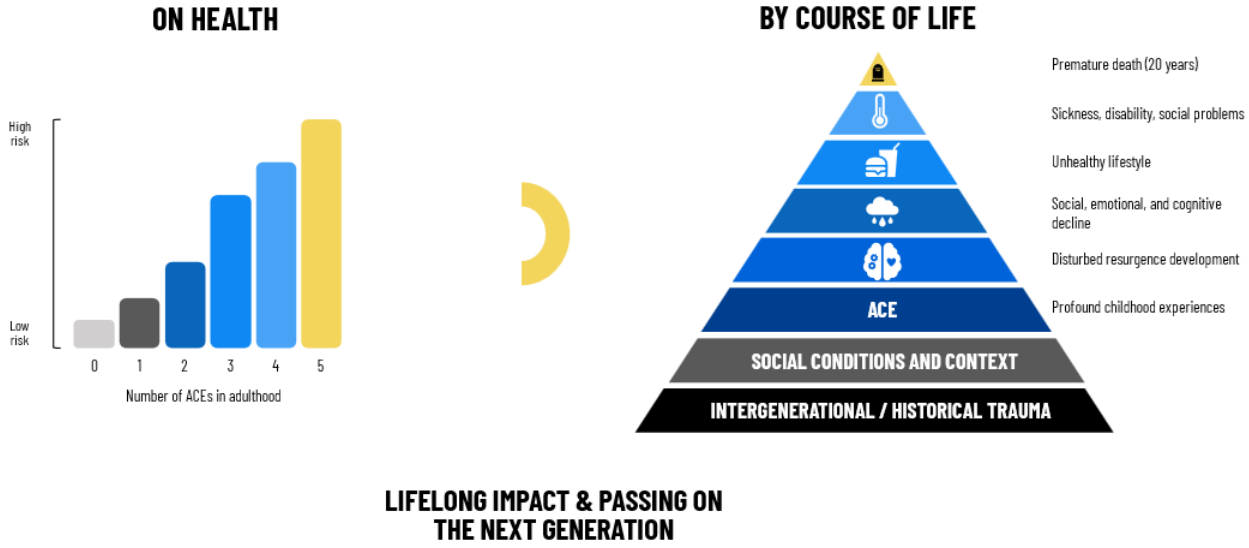


Figure 18: Impact of toxic stress and ACEs on health and life course (Augeo Foundation)

Impact of ACE's and toxic stress

In general, ACEs can have an impact on different domains[23] (Augeo Foundation):

- Physical health and chronic conditions
- Parenting and growing up safely
- Alcohol, drug use and smoking
- School functioning
- Mental health and psychological problems
- Socio-economic
- Premature mortality

[23] All pictures/graphics Based on Augeo Foundation

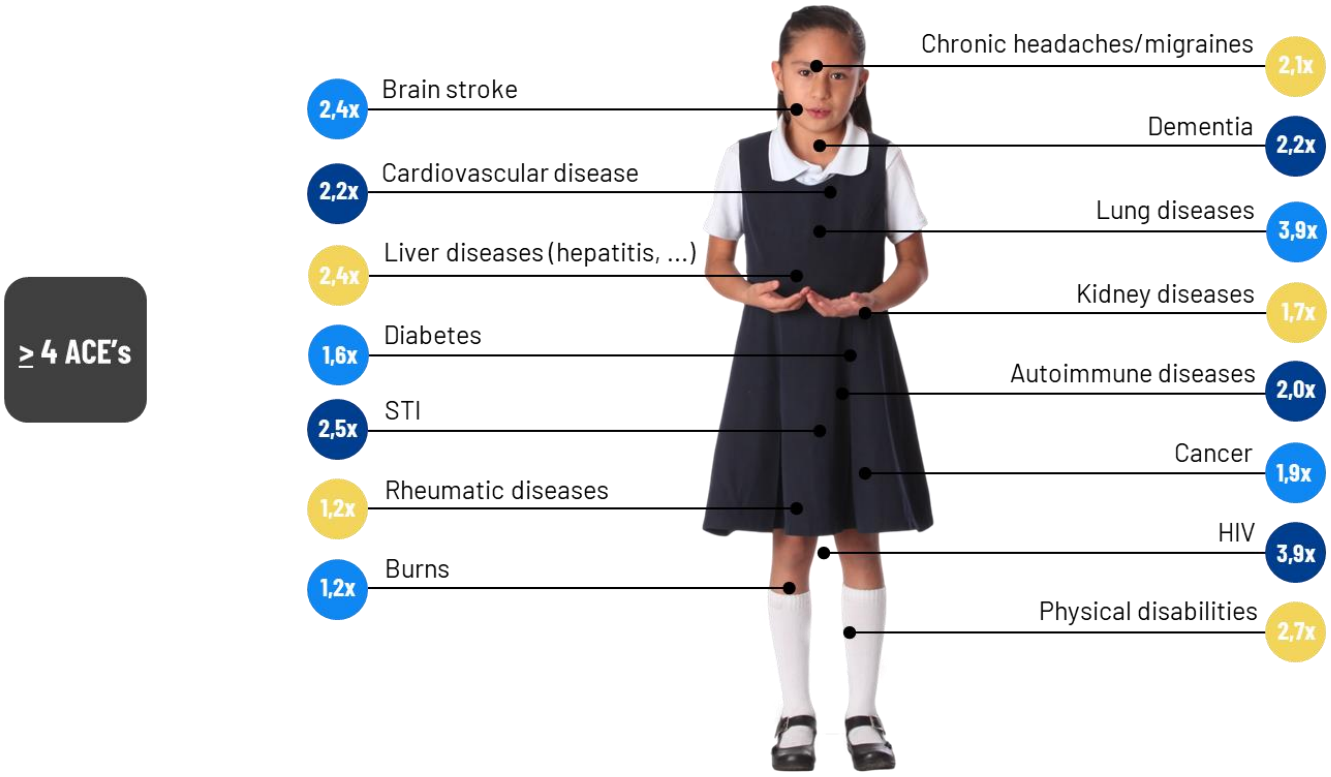
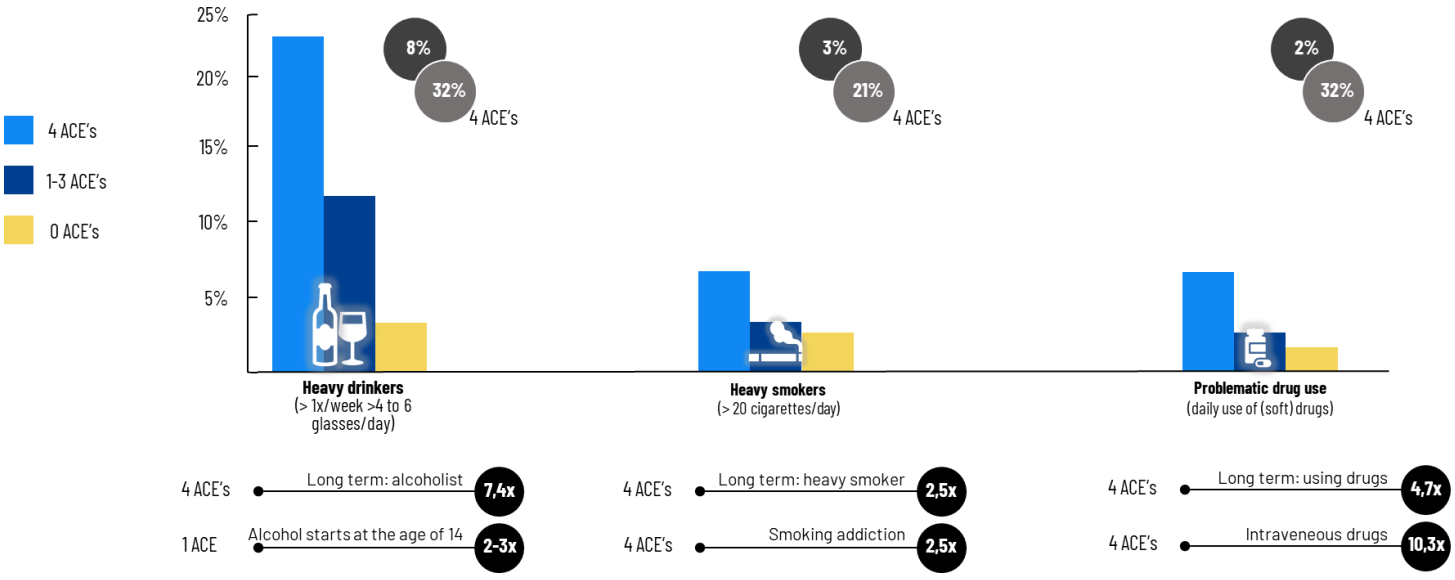


Figure 19: Impact of toxic stress and ACEs on physical health and chronic conditions (Augeo Foundation)

Figure 20: Impact of toxic stress and ACEs on parenting and growing up safely (Augeo Foundation)



20-40%

… substance use as a form of coping

… substance use as a 'solution' to an underlying problem

… 'Standard' methods aimed at behavioural change and lifestyle improvement often do not work

Temporarily escaping painful memories, stress, or anxiety

Figure 21: Impact of toxic stress and ACEs on alcohol, drug use and smoking (Augeo Foundation)

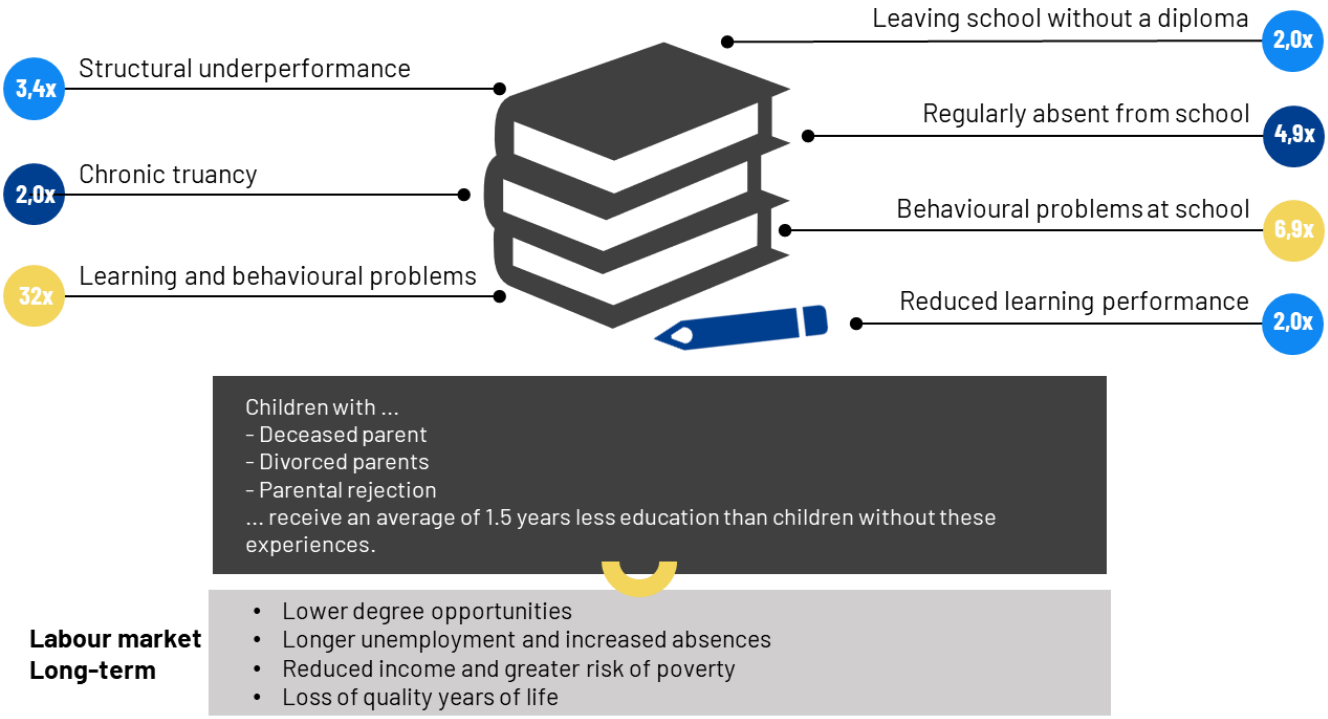


Figure 22: Impact of toxic stress and ACEs on school functioning

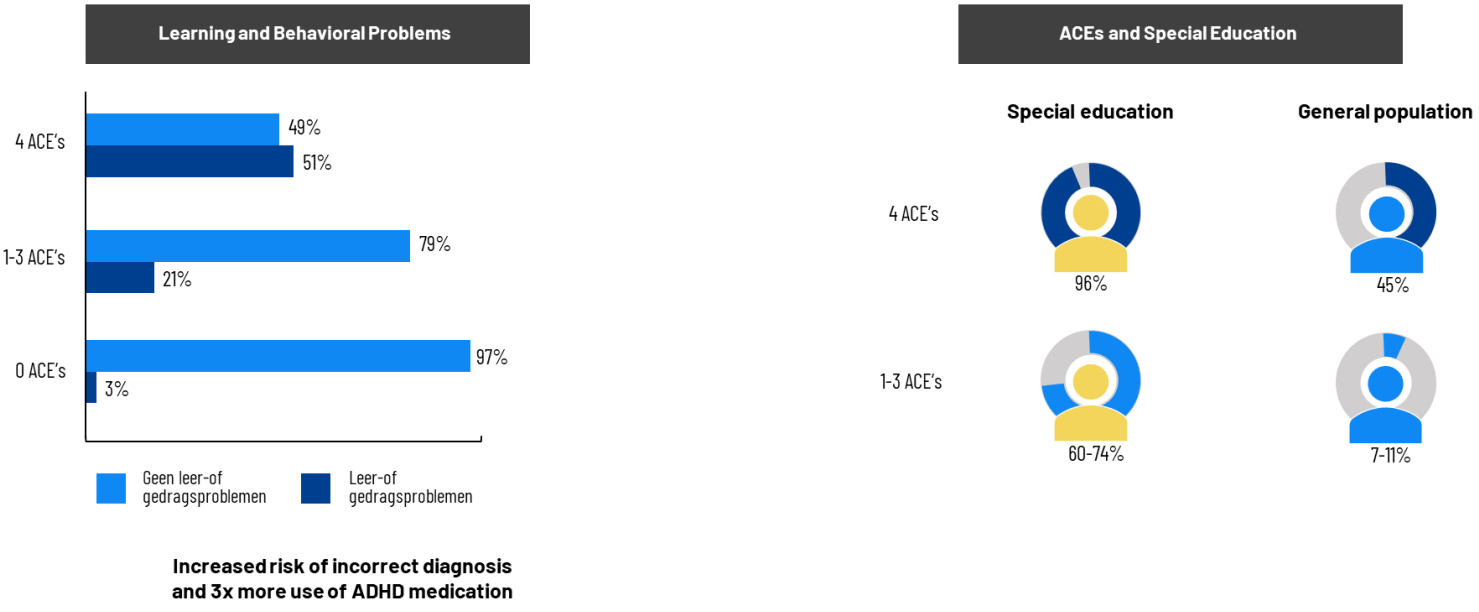
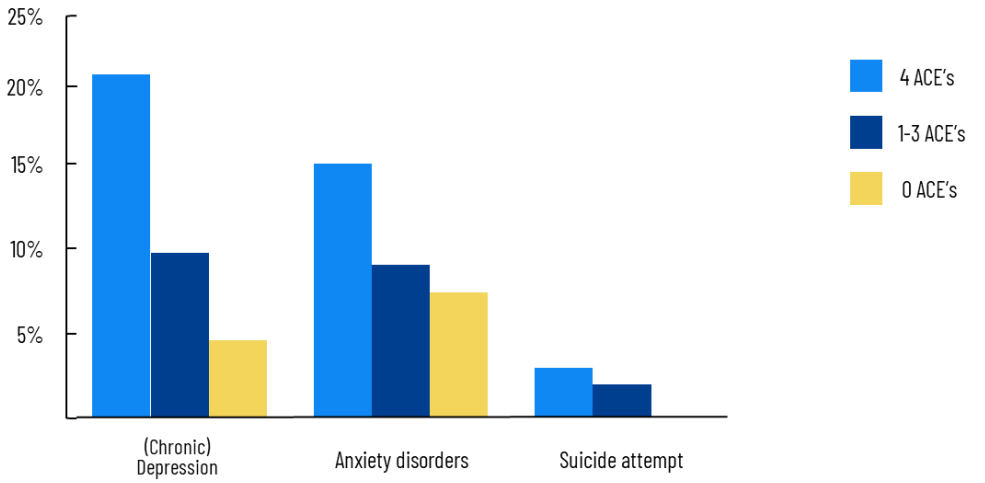


Figure 23: Relation of toxic stress and ACEs on learning problems and special education (Augeo Foundation)



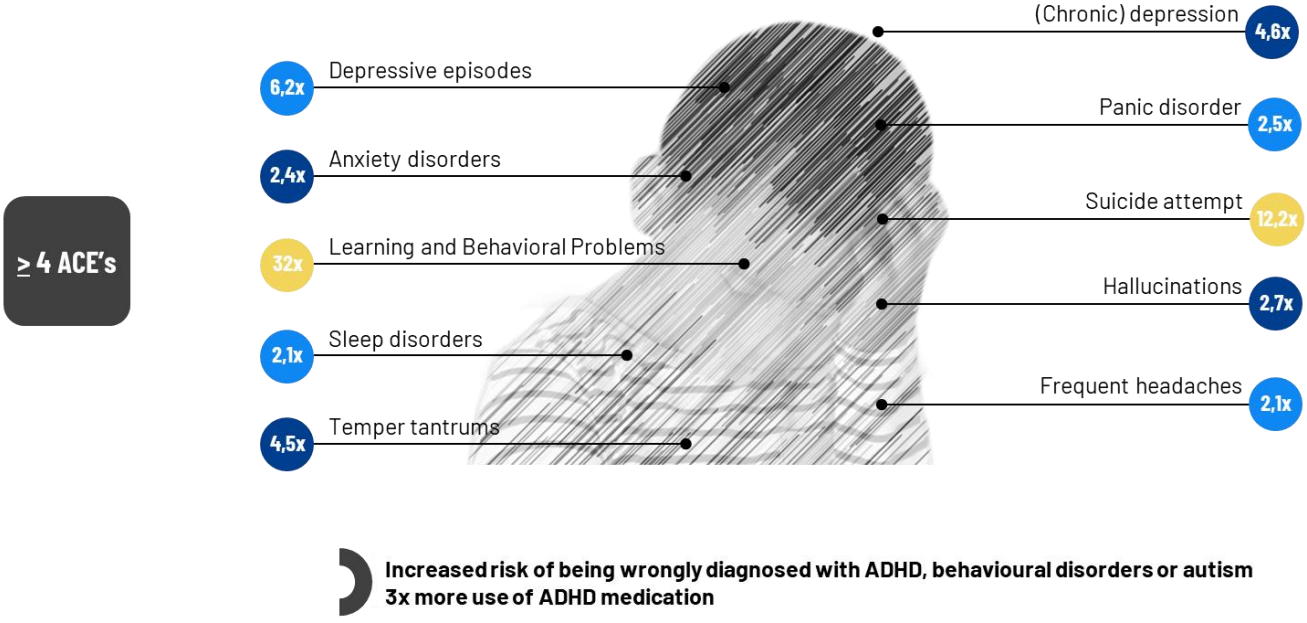


Figure 24: Impact of toxic stress and ACEs on mental health and psychological problems (Augeo Foundation)

Psycho-social problems that are often related to mental problems:

Financial problems	**2.4x**
Victim of sexual assault	**8.2x**
Perpetrator of domestic/partner violence	**5.5x**
First sexual intercourse < 14 years	**6.6x**
Unwanted pregnancy	**2.4x**
Imprisonment	**4.0x**

Contribution of ACEs in relation to total number:

School/work dropout rate > 1 year	**20%**
Depression	**41%**
Suicide attempt	**65%**
Anxiety disorders	**56%**
Treatment/medication mental illness	**43%**
Domestic violence	**52%**
Life dissatisfaction (USA)	**67%**

Figure 25: Relation of toxic stress and ACEs on mental health and psychological problems (Augeo Foundation)

All these short- and medium-to-long-term consequences reinforce the risk factors and further perpetuate the negative vicious circle and health inequalities[24].

This leads to an increase in the demand for care, healthcare costs, the need for care providers and the use of health care due to mistrust, avoidable complications, etc, with all the personal, social and socio-economic consequences that entails.

A recent study from New Zealand shows that 20% of the population is responsible for 80% of health- and social care spending due to among other things like traumatic childhood experiences and poor deployment of care paths and prevention in childhood[25].

In Belgium, 30,2% of the population has at least 1 ACE, and of these, 6,8% have > 2 ACEs[26].

ACEs can be found everywhere. In every neighbourhood, every school, municipality, work environment, etc.

ACEs don't only 'belong' to specific populations. 70% from the people with 1 or more ACEs is high educated and white.

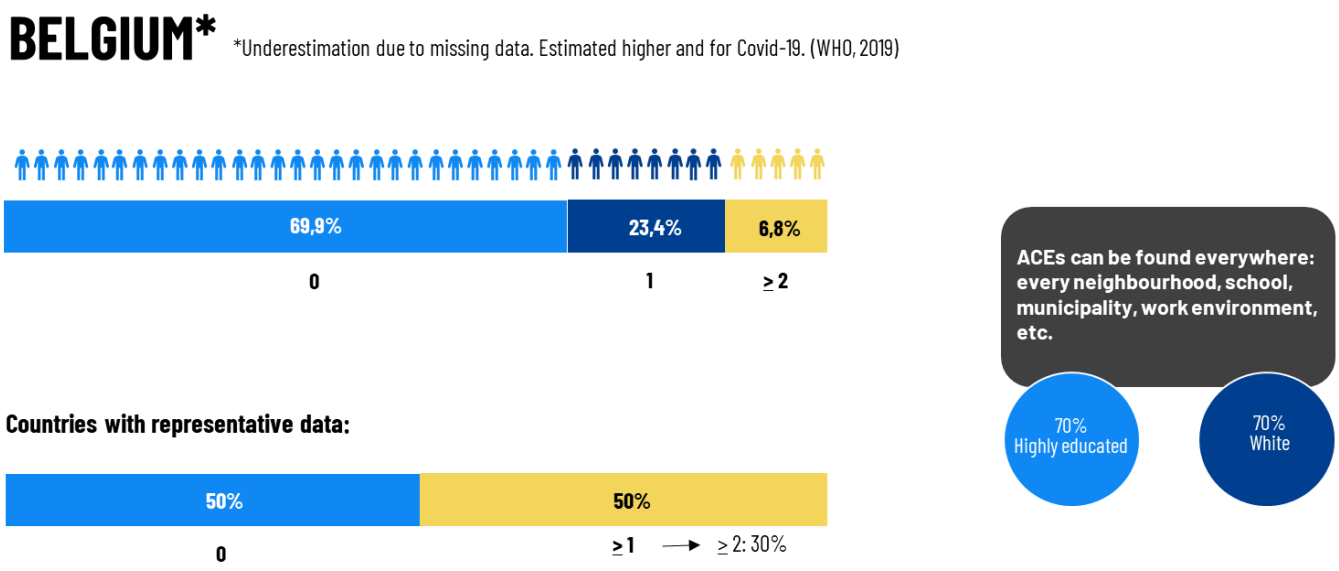


Figure 26: Prevalence of ACEs in adults in Belgium (2019)

[24] Karen Hughes, Kat Ford, Mark A Bellis, Freya Glendinning, Emma Harrison, Jonathon Passmore. Health and financial costs of adverse
childhood experiences in 28 European countries: a systematic review and meta-analysis. (2021). Lancet Public Health - WHO; 6: e848–57

[25] Leah S. Richmond-Rakerd; Stephanie D'Souza; Signe Hald Andersen; Sean Hogan; Renate M. Houts; Richie Poulton; Sandhya Ramrakha; Avshalom Caspi; Barry J. Milne; Terrie E. Moffitt. (2019). Clustering of health, crime and social-welfare inequality in 4 million citizens from two nations. Nature Human Behaviour.

[26] Karen Hughes, Kat Ford, Mark A Bellis, Freya Glendinning, Emma Harrison, Jonathon Passmore. *Health and financial costs of adverse childhood experiences in 28 European countries: a systematic review and meta-analysis.* (2021). Lancet Public Health - WHO; 6: e848–57

ACEs cost Belgian society around 7,5 billion euros annually (3.1% of GDP) and a loss of 162,600 years of life (DALYs).

Figure 27: Cost in euro and DALYs of ACEs in adults in Belgium (2019)

Medical healthcare in children can contribute to the ACEs story

Medical healthcare in children can also contribute to the ACEs story, and this on a primary and secondary level caused by stress and fear due to the encounter with healthcare, bad organisation, absence of competences, … that can lead to toxic stress.

Primary level:

Chronic illness, frequent hospitalizations, frequent contact with healthcare, undergoing medical-technical/nursing procedures, restraint during procedures, … lead to stress, fear, pain and anxiety.
For example, we know that[27] [28] [29] [30] [31]:

- almost 80% of children with a chronic illness develop a fear of admission and medical intervention. This fear is almost always the result of a previous traumatic experience in healthcare. Medical anxiety undermines confidence, increases pain and stress, and has a negative effect on healing;
- 10% of these children develops Post Traumatic Stress Syndrome (PTSS) due to stress and fear becoming toxic;
- fear of needles in 1 on 3 adults is caused by traumatic experiences with needles in healthcare during childhood;
- little to no knowledge on guidance and PROSA policy causes more traumatic experiences in medical-nursing procedures with a proven impact on socio-emotional development, the development of anxiety disorders (such as fear of needles) and an increase in healthcare costs as a result;
- little or no knowledge and use of child-specific processes and instruments leads to a decrease in trust in the patient's care. This results in more conflicts in care, poorer therapy adherence, less self-reliance and more dependence on professional help[32];
- etc.

Secondary level:

Stress and fear of illness, hospitalization, medical treatment, consultations, … can trigger (supressed) trauma caused in the past or current context in which the child grows up.
Every child carries an invisible 'backpack' filled with one or more (traumatic) experiences unknown by medical healthcare workers.

Protective or risk factors of pain, anxiety, fear and stress in healthcare becoming toxic or not, lie within the degree of investment in and implementation of specific child- and family-based competencies of the healthcare worker(s), specific quality measures, protocols, organization and collaboration.

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[27] Dwang bij medische behandeling van jonge kinderen. Letsel en Schade.; Leroy PL, Ten Hoopen RM. 2014(1):11-3

[28] Psychological interventions for needle- related procedural pain and distress in children and adolescents. Birnie KA, Noel M, Chambers CT, Uman LS, Parker JA. Cochrane Database Syst Rev. 2018;10:CD005179.

[29] Caregivers blinded by the care: A qualitative study of physical restraint in pediatric care. Lombart B, De Stefano C, Dupont D, Nadji L, Galinski M. Nurs Ethics. 2020;27(1):230-46.

[30] Managing emotions in medical encounters with children. Krauss BA, Leroy PL, Krauss BS. In: Schwartz R, Hall JA, Osterberg LG, editors. Emotion in the clinical encounter: McGraw Hill/Stanford University; 2021. p. 209-38.

[31] Early Neonatal Pain—A Review of Clinical and Experimental Implications on Painful Conditions Later in Life. MD Williams and BDX Lascelles. Front. Pediatr 2020

[32] Chronically ill children's participation and health outcomes in shared decision-making: a scoping review; R. O. Wijngaarde & I. Hein & J. Daams & J. B. Van Goudoever & D. T. Ubbink; European Journal of Pediatrics; 24 March 2021.

Protective And Compensatory Experiences (PACEs)

Additional protective or risk factors lie within the degree of resilience and Protective And Compensatory Experiences (PACEs) within the child and the context in which they grow up.

Children and young persons with complex care needs often encounter vulnerabilities that extend beyond illness and medical trauma. Their well-being is tied to factors like resilience, or the ability to cope with adversity, and the presence of Protective And Compensatory Experiences (PACEs). Resilience allows them to adapt to challenges, while PACEs encompass specific supportive elements that can mitigate negative impacts. Moreover, the context in which these children grow up, plays a pivotal role in shaping their experiences. A comprehensive approach involves recognizing and addressing resilience and PACEs as well as contextual influences factors, ensuring effective support for these children and young persons.

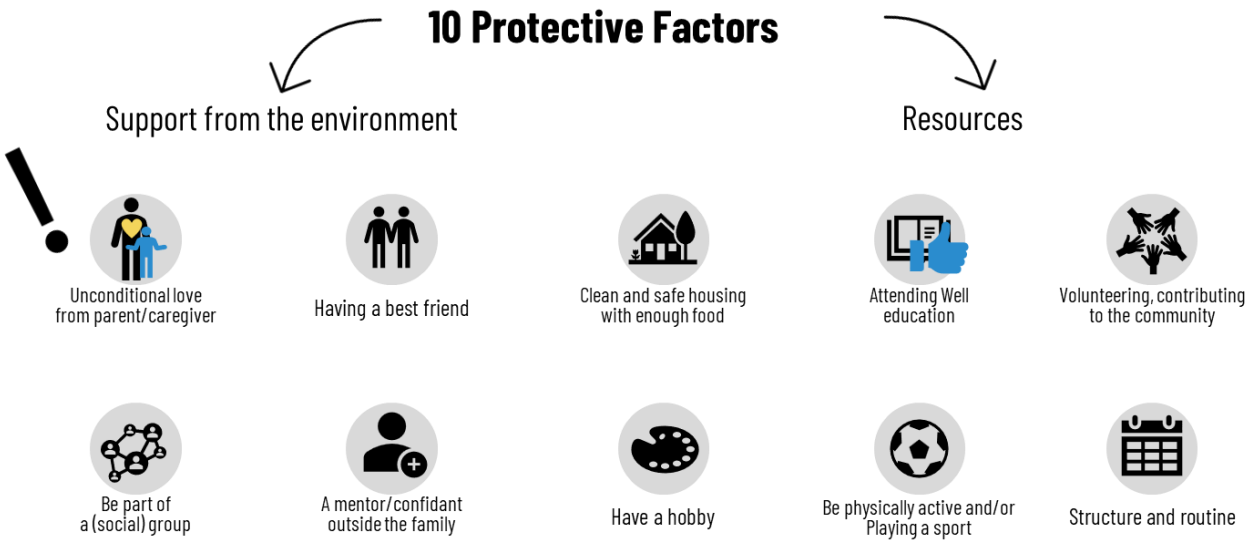
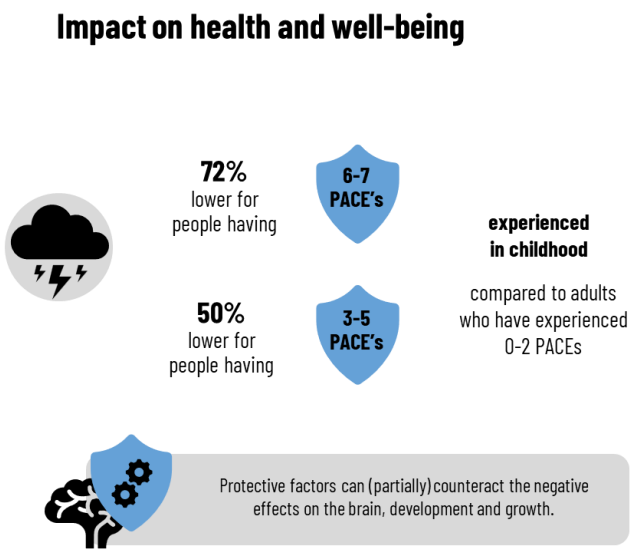


Figure 28: Protective And Compensatory Experiences (PACEs) (Augeo Foundation)



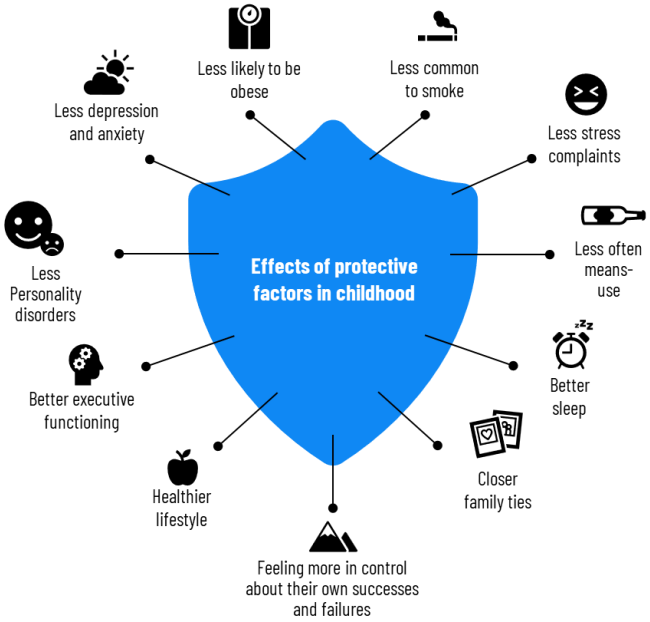


Figure 29: Impact of PACE's (Augeo Foundation)

Vulnerability of the (chronically) ill child and family

Not only the integral context around children can make them medically ill.
Conversely, children with medical care needs experience additional influencing factors that result directly from their illness and associated care-path.

Children with (chronic/complex) medical care needs have additional influencing risk and vulnerability factors that have an impact on the integral developmental and health outcomes of these children and their families:

- the presence of a serious (chronic) illness causes uncertainty, fear, sudden changes in expectations for both the future of the child and the entire family. Both child and parents go through a grieving process and long term stress;
- anxiety and stress due to frequent hospitalizations due to e.g. the uncertainty of what is to come, the practical organization of 'home' and family life, the previous experiences, etc.[33];
- anxiety and stress due to (painful) medical-nursing actions, examinations and the physical restraint in which the child is held against its own will by healthcare professionals while performing a procedure[34] [35] [36];
- a Dutch study shows that the waiting time for an examination without the right framework is experienced by children just as stressful as a painful procedure[37];
- increased risk of abuse and neglect. Stress, anxiety and having to take on a caregiving role as a parent combined with the impact on all aspects within a family makes the child more vulnerable to abuse or neglect[38] [39];
- reduced capacity and resilience of parents due to the effect of the disease, the care path and uncertainty about the future. An impact that is situated in the areas of work, financial, social, leisure[40] [41];
- increased healthcare costs in combination with 1 or both parents who are less or no longer able to work makes the family more financially vulnerable. Financial hardship and poverty cause anxiety, stress and uncertainty and are a major risk factor for health inequalities[42];
- increased risk of depression, burnout and divorce within the family due to stress, insecurities, tensions, falling away, different views between parents, etc;

[33] Managing emotions in medical encounters with children. Krauss BA, Leroy PL, Krauss BS. In: Schwartz R, Hall JA, Osterberg LG, editors. Emotion in the clinical encounter: McGraw Hill/Stanford University; 2021. p. 209-38.
[34] Dwang bij medische behandeling van jonge kinderen. Letsel en Schade.; Leroy PL, Ten Hoopen RM. 2014(1):11-3
[35] Psychological interventions for needle- related procedural pain and distress in children and adolescents. Birnie KA, Noel M, Chambers CT, Uman LS, Parker JA. Cochrane Database Syst Rev. 2018;10:CD005179.
[36] Caregivers blinded by the care: A qualitative study of physical restraint in pediatric care. Lombart B, De Stefano C, Dupont D, Nadji L, Galinski M. Nurs Ethics. 2020;27(1):230-46.
[37] Kind en Ziekenhuis, Wachttijden voor kinderen verbeteren - September 2022, Nederland
[38] Birgitta Svensson, Carl-Gustaf Bornehag, Staffan Janson. Chronic conditions in children increase the risk for physical abuse - but vary with socio-economic circumstances. Acta Paediatrica, 2011;
[39] Kumari, Nisha; Dubey, Anubhuti (May 2019); Do chronic illnesses increase children's risk of being maltreated? IAHRW International Journal of Social Sciences Review; Haryana Vol. 7, Iss. 5-I, 1074-1077.
[40] Hatzman, J. 2008-2009-2014
[41] Onafhankelijk Ziekenfonds – ZOOM studie - Kinderen met een speciale zorgnood Meer kans op (langdurige) ziekte bij ouders, 2022
[42] Chronically ill children's participation and health outcomes in shared decision-making: a scoping review; R. O. Wijngaarde & I. Hein & J. Daams & J. B. Van Goudoever & D. T. Ubbink; European Journal of Pediatrics; 24 March 2021.

- longer and frequent hospitalizations, illness increases school absences. Increased absences lead to lower graduation opportunities, loss of income and even long-term decrease in quality of life with a reinforcement of socio-economic vulnerability and health inequalities[43] [44] [45];
- longer and frequent hospital admissions and illness result in less contact with peers in one's own immediate environment. As a result, the child builds up fewer social contacts with a greater risk of a smaller social safety net/buffer later in life and a higher social vulnerability[46];
- the death of the seriously ill child and the impact on the family and siblings;
- etc.

Figure 30: Impact of toxic stress and ACEs on mental health and psychological problems

[43] UNICEF Innocenti. (2022). Research and Evidence on Children with Disabilities

[44] Research shows that every extra school year gives an average of 7% more pay per month (Mincerian wage comparison, which in scientific literature is used to calculate the return on investment of a year's training). In this respect, a year of higher education yields more than a year of secondary education. Moreover, every year of extra training also gives more job opportunities. Both are related to each other.

[45] Loss of half a year of school/training is related to 5% lower income (for the rest of life), 1.5% lower GDP, half a year lower life expectancy, lower mental well-being, higher unqualified outflow, more reorientation and retention, less transfer to higher education.

[46] Social inclusion of students with special educational needs assessed by the Inclusion of Other in the Self scale; Jana Vyrastekova; April 2021

Well, I must endure the presence of a few caterpillars if I wish to become acquainted with the butterflies.

The Little Prince

Antoine de Saint-Exupéry (1943)

02

Current Situation

General trends in (child) health care

National observations

2.1 General trends in (child) health care

2.1 General trends in (child) health care

Society is rapidly changing, impacting (child) healthcare. To ensure future-proof healthcare for children, it's crucial to understand and proactively address evolving trends and changes. Figure 37 depicts the different trends in society, healthcare in general and specifically for children.

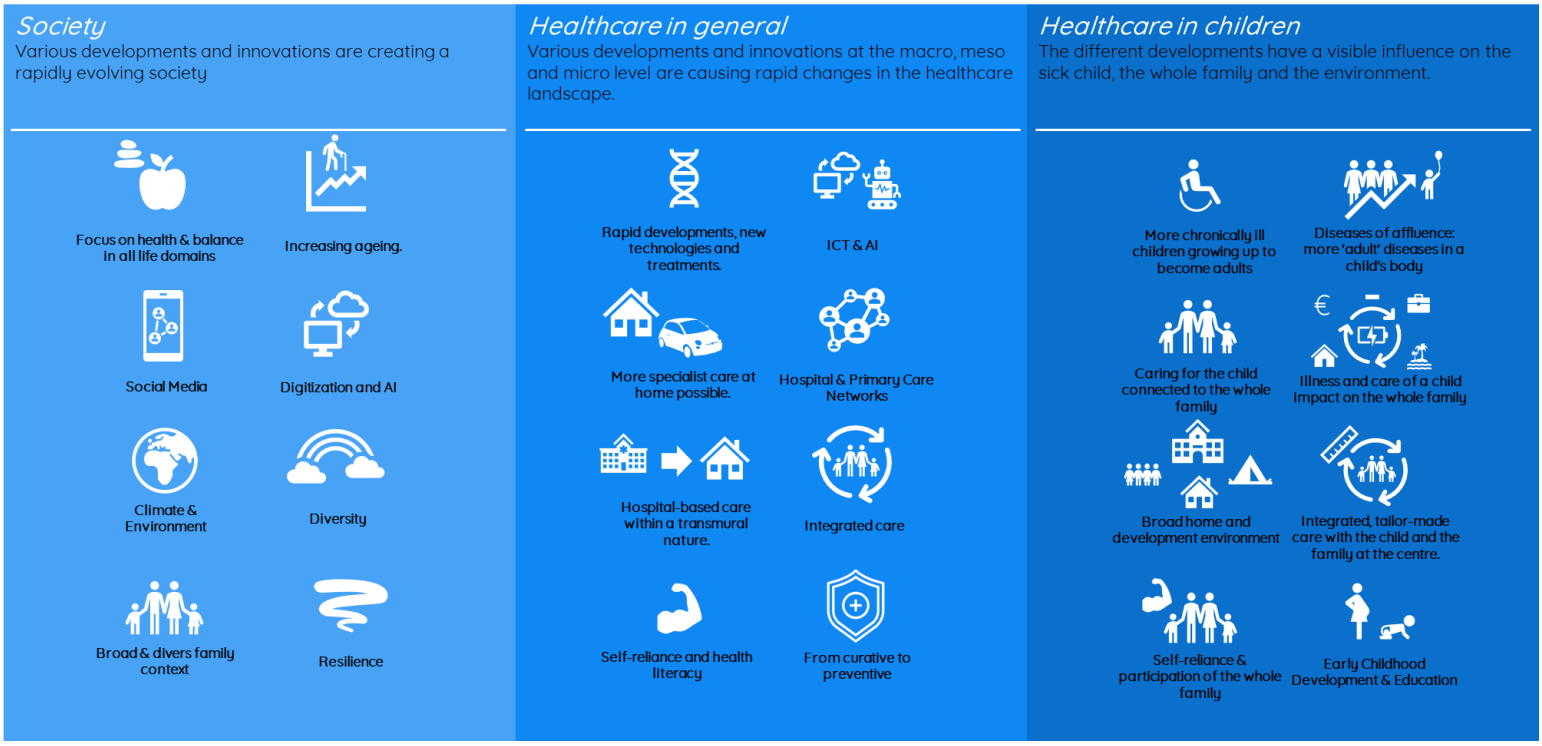


Figure 31: What is changing?

In the past few decades the health needs of children have changed beyond recognition. Large hospital wards that were once filled with children with infectious diseases requiring long-term hospitalisations have been replaced by smaller units (as well as functional non-financed paediatric day-clinics) and new care settings were created, such as for example highly specialized neonatal units caring for babies who, even a decade ago, would not have survived; tertiary care centres with in general and in all subspecialty programs, an evolution towards severe pathology/severity of illness and high/complex care burden in medical/nursing/paramedical fields (see DRG/MVG data of Belgian hospitals), incorporating multi/interdisciplinary highly specialized paediatric medicine, including novel, precision- and ATMP (Advanced Therapy Medicinal Products) -based paediatric medicine. Additionally, often a hybrid approach (surgery and medical) is adopted, within the further development of a shared-care model with regional hospitals; high technology paediatric intensive care units, paediatric oncology units, paediatric dialysis teams, specialist genetic teams who are exploiting an explosion of knowledge as well as ethical dilemmas; mental health teams, supporting children struggling to cope in what can sometimes be an uncertain and confusing world.

Despite the enormous magnitude of these changes, the delivery of care and the organizational structures within which services exist have not yet evolved sufficiently to meet the shifting burden of childhood disease.

The spectrum of care needs among children has become notably more complex. Advances in medical science have prolonged the lives of children with severe and complex conditions, necessitating comprehensive and multidisciplinary approaches. Healthcare systems should now focus not only on disease management but also on holistic care, emphasizing psychological, social, and educational support to ensure a better long-term quality of life for these children and their families.

Furthermore, the scientific attention given to rare diseases in childcare has significantly evolved. Greater awareness, improved diagnostic tools, and enhanced collaboration among healthcare professionals have led to earlier identification and intervention for children affected by rare conditions. Efforts to create networks connecting specialists and sharing knowledge globally have accelerated research and treatment breakthroughs, offering hope and support to families navigating these complex medical challenges.

The realm of childcare has seen remarkable progress in the advancements in technical procedures: Innovations in medical technology and procedures have expanded treatment possibilities, allowing for more sophisticated interventions and personalized therapies. Minimally invasive surgeries, precision medicine, and novel therapies are changing paediatric care, offering more effective and less invasive options for various conditions.

Unfortunately, with these trends as well as numerous changes underway, medical professionals specializing in paediatric care are becoming fewer and overburdened, and thus minimally engaged in certain initiatives, relegating children's healthcare to an appendix of adult-focused reforms.

Medical child care is a unique domain of medicine, a spectrum ranging from general paediatrics to (not-recognized) paediatric subspecialties and subdomains, both requiring specific knowledge and competences. With insufficient attention to these competences and with political decisions forcing a shift to one side of the paediatric spectrum (for example by reducing the paediatric subquota, decreased amount of youth health professionals, ...), an immense gap is created in paediatric care.

Moreover, viewing and approaching care for children solely from a medical perspective is socially poor care. Quality and outcome-oriented Medical Child Care cannot be achieved without a structural integrative focus on all the life and developmental domains of a child and the context in which he or she grows up.

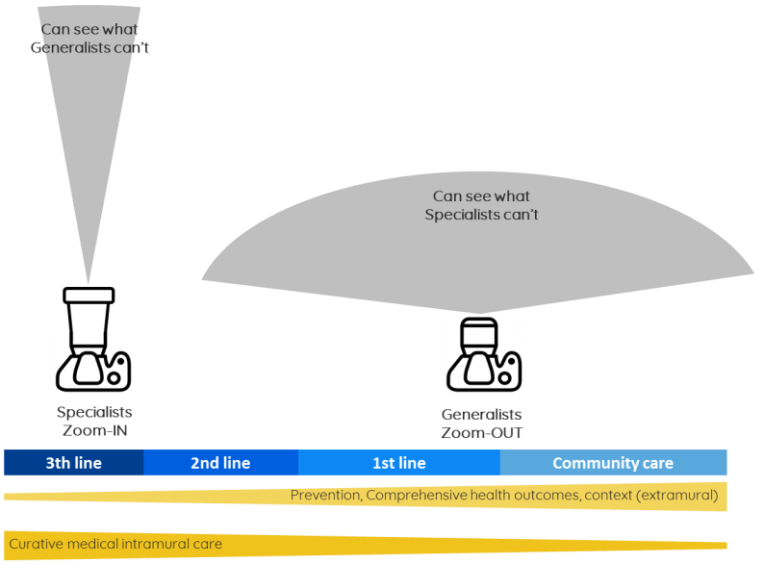


Figure 32: What Generalists and Specialists can and can't see (Milani Creative L.L.C. 2023)

2.2 National observations

2.2 National observations

> *Children are too often statistically invisible*
>
> *(OESO report 2019)*

The current lack of data for children in national surveys means that policy interventions and funding efforts are being based on the experiences of adults rather than children. Therefore important opportunities to improve the lives of children and young people will be missed.

It all starts with the perspective of Visibility, Vulnerability and Voice of children and young people and realizing the importance of including them in official statistics!

2.2.1 Health status on a population level

In Belgium, on January 1st 2023, the legal Belgian population was 11,697,557 inhabitants with 2.446.111 children and young people aged 0-18 with a slightly increasing prognosis towards 2040. (Belstat). This means that children and young persons aged 0-18 years represent 20.9% of the Belgian population.

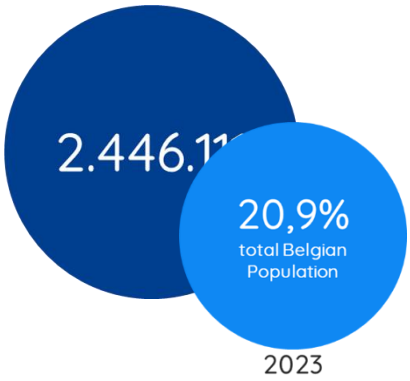


Figure 33: Belstat current population

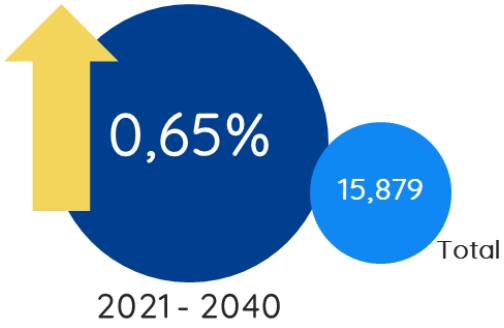


Figure 34 Prognosis population of children and adolescents 2021 – 2040 in Belgium

2023	Province	Age-group	Female	Male	Total
Vlaams Gewest	Provincie Antwerpen	< 18 y	188.388	197.074	385.462
	Provincie Vlaams-Brabant	< 18 y	119.035	124.592	243.627
	Provincie West-Vlaanderen	< 18 y	106.960	112.422	219.382
	Provincie Oost-Vlaanderen	< 18 y	147.484	154.709	302.193
	Provincie Limburg	< 18 y	80.030	83.861	163.891
Vlaams Gewest		< 18 y	641.897	672.658	1.314.555
Brussels Capital Region	Arrondissement Brussel-Hoofdstad	< 18 y	134.480	140.258	274.738
Région Wallone	Provincie Waals-Brabant	< 18 y	40.822	42.564	83.386
	Provincie Henegouwen	< 18 y	135.059	141.460	276.519
	Provincie Luik	< 18 y	110.739	115.249	225.988
	Provincie Luxemburg	< 18 y	30.266	31.635	61.901
	Provincie Namen	< 18 y	48.366	50.880	99.246
Région Wallone		< 18 y	365.252	381.788	747.040
Belgium		< 18 y	1.141.629	1.194.704	2.336.333

Table 3: Population Children by province (Belstat)

<u>In Belgium:</u>

There is no structural agreement on 'the age of children and young persons':

- Paediatric hospital wards: 0 - <16y
- Child- and adolescent psychiatry: 0 - <24y
- Chronic Care: 0 – <21y (depending on the convention cystic fibrosis unlimited; nephrology 18y; ...)

Definition of Health

We can define health as the ability to adapt and take control in the face of life's physical, emotional and social challenges (Machteld Huber, Maastricht University, 2014).

This definition goes beyond the 1948 World Health Organisation (WHO) definition of health 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. Although WHO defined the concept of health very broadly even then in a pioneering way, no one is likely to be healthy based on the absolute and static nature of the definition. Huber's dynamic definition is based on resilience, participation, context and self-direction. This ensures that children or persons with disabilities can also be healthy.

That's also why some definitions don't speak about 'health' but more about 'happiness' or other related terms. These definitions place the state of 'happiness' above the state of physical health. *"You can be free of medical disease but not happy. And you can be happy despite having a medical disease."*

Specific for children the WHO defines child health as: *a state of physical, mental, intellectual, social and emotional well-being and not merely the absence of disease or infirmity. Healthy children live in families, environments, and communities that provide them with the opportunity to reach their fullest developmental potential.*

In Belgium:

- Health, according to this definition, is not measured in children and young persons
- The first definition of health (Huber) is impossible to use for babies and small children, and needs adjustment for all 0-8y old
- Only a very rudimentary survey of Eurostat on health is vailable, 74% of children <16y in Belgium rate their health as very good (European mean 69%), 22% as good while 6% rate it as fair, bad or very bad[47]. This was a parental survey.

[47] https://ec.europa.eu/eurostat/databrowser/view/ilc_hch12$defaultview/default/bar?lang=en

Data on children

- Data on children and young persons in Belgium are fragmented and different reports of the WHO and OESO on Belgium states 'no or no good data on children'[48].

- Existing data and the structure in which they are available supports more our political structure than important health outcomes, indicators and evaluation.

- The Belgian political structure between Federal and Community levels as well as the lack of political collaboration are not helping.

- Data are sometimes not repetitive and lost in individual/regional organisations.

- Absence of children's, parents' and all child health care professionals' voices in the selection of relevant indicators and data is a missed opportunity

- Mortality and Morbidity
  In 2021, some key statistics include an infant mortality rate of 2.9 per 1000 live births in Belgium[49], compared to 1.7 in Japan and 1.8 in Scandinavian countries. The fluctuation in infant mortality rates signifies that there would be an additional 125 surviving infants if Belgium had the infant mortality rate of Scandinavia.

- Perinatal Care
  Informative reports are exemplative, they are inter-regionally streamlined and data/ new indicators are discussed in an interprofessional scientific committee (midwifes, gynaecologist, paediatrician, neonatologists). Data-management receives governmental funding.
    - Perinatal data Wallonia:
      https://www.cepip.be/img/pdf/rapport_CEPIP_Wal_2022-fr.pdf
    - Perinatal data Brussels:
      https://www.cepip.be/img/pdf/rapport_CEPIP_Bxl_2022-fr.pdf
    - Perinatal data Flanders:
      https://zeg.paddlecms.net/sites/default/files/2023-11/SPE-Perinatale%20gezondheid%20in%20Vlaanderen%202022_FINAL.pdf

- Perinatal Care and Prevention: a regional authority
  Combined reports on Belgian public health of children and young persons are non-existing. There is a lack in description of broad health determinants in children. So what do we measure?

  ONE and K&G:
  Both organisations produce reports:
  https://www.one.be/fileadmin/user_upload/siteone/PRESENTATION/Rapports_d_activite/2022-rapport-activites-chiffres.pdf
  or provide data on their website:
  https://www.opgroeien.be/kennis/cijfers-en-onderzoek

[48] OECD Child Well-being Dashboard (2023)
[49] https://data.oecd.org/healthstat/infant-mortality-rates.htm

CLB and PSE:
https://www.one.be/professionnel/sante-a-lecole/
For CLB all data have been accurately gathered by health care professionals but no reports have been produced for the last 7 years.
PSE report is published. HBSC reports on health behaviour in school-aged children: studies exist but are still scarce[50].

Sciensano:
Vaccination-coverage is estimated by sample analysis, while all data are meticulously registered by healthcare professionals[51].
https://www.sciensano.be/sites/default/files/vaccine_coverage_2020-21_fr_final.pdf
https://www.sciensano.be/sites/default/files/vaccine_coverage_2020-21_nl_final.pdf
Description of determinants of health for children are completely lacking (although an extensive report on adult data is available).

The totality of child health, its determinants and related services, is extremely large and very different from adult determinants of health.
Development of indicators is important but particularly challenging because of the 4 D's: developmental change, dependency, differential epidemiology and demographic patterns.
Moreover, there are significant differences between infancy and adolescence in terms of health and its determinants, types of service, and data sources.

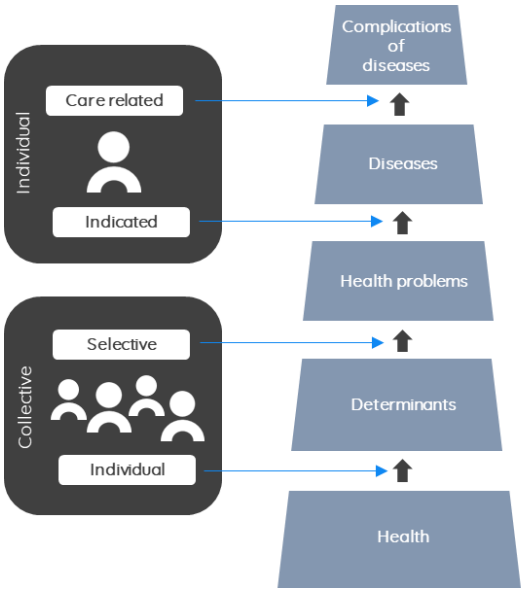


Figure 35: Prevention by target group

[50] https://hbsc.org/network/countries/belgium-flemish/ & https://hbsc.org/network/countries/belgium-french/
[51] https://www.sciensano.be/sites/default/files/vaccine_coverage_2020-21_fr_final.pdf
https://www.sciensano.be/sites/default/files/vaccine_coverage_2020-21_nl_final.pdf

- Data on ill children
    - Data on health status should involve data on ill children as well

In Belgium:

- There is a scarcity of accessible data specifically focused on children's healthcare quality, with no existing annual report dedicated to this aspect. The Quality of Healthcare Index by Sciensano only includes one query related to children. Similarly, in OECD indicators, only one indicator is available concerning children's health.
- No data are available for children's health care decisions/discussions amongst divorced parents
- An illustrative example is the governmental website with transparent data on health and disease in Belgium: https://www.healthybelgium.be/en/, this platform that encompasses data on women, men, and the elderly but lacks information focussed on the child and young persons population.
    - Even within the "mother and newborn" category, there exists only one specific item related to newborns.
    - Sparce data on children need to be searched in 'miscellaneous' (varia).

    - Data on the different paediatric subpopulations:
        - Acute severely ill neonate
          Some data are available
            - Perinatal data Wallonia:
              https://www.cepip.be/img/pdf/rapport_CEPIP_Wal_2022-fr.pdf
            - Perinatal data Brussels:
              https://www.cepip.be/img/pdf/rapport_CEPIP_Bxl_2022-fr.pdf
            - Perinatal data Flanders:
              https://zeg.paddlecms.net/sites/default/files/2023-11/SPE-Perinatale%20gezondheid%20in%20Vlaanderen%202022_FINAL.pdf

        - Acute severely ill children
            - The only data transparently available are voluntary data-gathering:
                - Microsoft Word - PICU register R 2docx.docx (belgie.be) PICU registry Belgium
                - Based on PICANet-2021-Annual-Report_v1.1-22Apr2022.pdf a PICU registry UK (governmental funded in order to make data-driven decisions)

        - Chronically ill children
          Available data (e.g. on children in diabetic conventions, children with renal problems, etc.) are not transparently released for unknown reasons.

In Belgium:

- We excel in Missing data
- There are large data gaps in key indicators
- Data on PREM (patient reported evaluation measures) and PROM (patient reported outcome measures) for child health care are unavailable.

- Data on vulnerable children

  This data are addressed in chapter “social injustice and vulnerable children”.

- Early childhood development (ECD): a MISSED window of opportunity

  ECD covers the period from pregnancy to entry into primary school, with a main focus on the development of the child to the age of 3 years. Early childhood is a critical period for the child to receive the nutrition and care that enable optimal development, and it is the time when preventative and health promoting interventions are most effective. Investing in early childhood development (ECD) is one of the best investments a country can make. Without this, the implications on children who have been left behind can cause mental and physical consequences in adulthood.

In Belgium:

- No central medical file is available for key healthcare professionals
- GMD/DMG receive governmental funding but Data in the GMD/DMG of a child are not child-proof nor focused on ECD
- Effective promotion of ECD and multisectoral coordination and integration is absent
- For the Belgian child population, according to UNICEF no data are available to evaluate Early Childhood Development on a population base https://nurturing-care.org/resources/country-profiles/

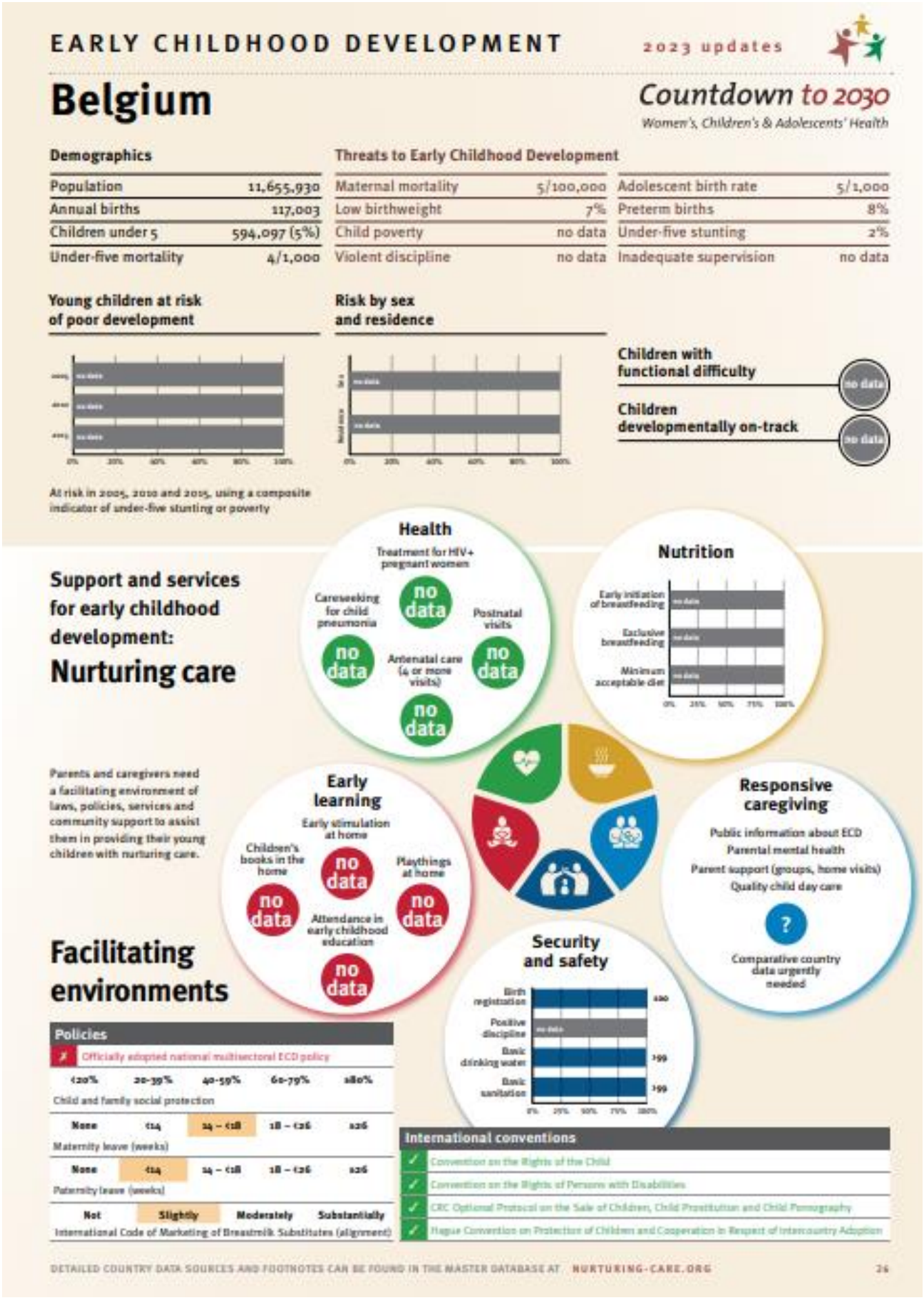


Figure 36: OECD Child Well-being Dashboard – Early Childhood Development Belgium (2023)

- Adolescent care: a MISSED window of opportunity

  The young persons period (defined as children aged 10–18 years in this Lancet Commission) is another window of opportunity, given its critical developmental timing in terms of identity, agency, and vulnerability. Young persons are a special and unique target group. They have specific needs[52] when focusing on their health and development, needs that are different than those of younger children.

  In adolescence, patterns can be laid for a lifetime of poor nutrition, reduced exercise, alcohol and tobacco use, mental ill health, and interpersonal violence. Worldwide 10–20% of children and young persons experience mental disorders.

	Males		Females	
Age	**Cause**	**YLD rate (per 100 000)**	**Cause**	**YLD rate (per 100 000)**
HICs				
10–14 years	Childhood behavioural disorders	590	Anxiety disorders	575
	Asthma	359	Depressive disorders	467
	Anxiety disorders	351	Migraine	360
	Back and neck pain	228	Childhood behavioural disorders	330
	Depressive disorders	217	Back and neck pain	312
15–19 years	Depressive disorders	561	Depressive disorders	1118
	Drug use disorders	491	Anxiety disorders	752
	Anxiety disorders	444	Migraine	605
	Childhood behavioural disorders	405	Back and neck pain	559
	Back and neck pain	382	Gynaecological diseases	426

YLDs: years of healthy life lost due to disability
Source: WHO 2019 *(172)*.

Table 4: Main causes of adolescent morbidity, by sex and age, globally and by modified WHO region, 2019 (WHO 2019)

In Belgium:

- Health, education, and legal systems have not kept pace with shifting young persons needs and demographic changes.
- Indicators, their definitions and assessment methods across indicator frameworks are inconsistent, poorly harmonized and incompletely aligned to needs.

- There are no or no good (old) data available in Belgium about the health of young persons (WHO) at least not available for benchmarking with other European countries cfr. Global Accelerated Action for Adolescent health https://www.who.int/publications/i/item/9789240081765

[52] https://www.who.int/publications/i/item/9789240081765%

BELGIUM: https://data.unicef.org/resources/adolescent-health-dashboards-country-profiles/

Transition to work		
Household chores	Average weekly hours spent on unpaid household chores by those aged 10–17 years	No data
Economic activities	Average weekly hours spent on economic activities by those aged 10–17 years	No data
Child labour by type	Percentage of those aged 10–17 years exceeding the thresholds for child labour, by activity	No data
Protection		
Intimate partner violence	Percentage of ever-married girls aged 15–19 years who experienced physical and/or sexual violence committed by a husband or partner in the past 12 months	No Data
Violent discipline	Percentage of those aged 10–14 years who experienced violent discipline in the previous month	No Data
Education and learning		
Out of school rate	Percentage out of school at the lower secondary level	No data
Youth literacy rate	Percentage aged 15–24 years who can read and write	No Data
Education level completion rate	Percentage of cohort who completed each education level (primary, lower secondary, upper secondary)	No Data
Health and nutrition		
Substance use	Percentage of those aged 13–15 years who used any tobacco	No Data
	Percentage of those aged 15–19 years who used any alcohol in the past month	M: 79% F: 53%

Table 5: Examples of missing data on UNICEF Country profiles

https://data.unicef.org/resources/adolescent-health-dashboards-country-profiles/

- Children with integrated and complex care needs care; a MISSED window of opportunity
    - These children are at high risk for 'vulnerability' and adverse childhood experiences
    - Interventions in the newborn period and good newborn care can also prevent long-term disability. We can do far more to support the 10% of children with developmental delays and disabilities, who require special care and attention; most of whom do not receive the care they need. Providing such care will allow these children to participate fully and equally, a huge gain for society.
    - A rise in rare diseases: the rarity of any singular rare disease does not reflect the substantial number of children affected by the approximately 8,000 rare diseases. Although seemingly counterintuitive, rare diseases are cumulatively common, with 3.5–5.9% of the population affected, and 70% of them exclusively start in childhood
    - WHO describes the rapid rise in childhood obesity as "one of the most serious public health challenges of the 21st century

In Belgium:

- An estimation of 3.7% (19.379) of Belgian children aged 0-19 live with one or more chronic diseases[53]
- Data on rare diseases in Belgium unknown
- Only a few diseases are covered for multidisciplinary care an care-coordination (through conventions/lump sum financing) appendix 8, leaving the other children with complex care needs behind (inequity)
- No central medical file available for these children (and thus difficult care-coordination)
- Increasing data on child-obesity in Belgium[54]

[53] Independent Health Insurance Fund, 2018

[54] https://www.gezondbelgie.be/nl/gezondheidstoestand/determinanten-van-gezondheid/gewichtstoestand

2.2.2 Value of care with deployed resources

Preventive Care

- Investing 1 euro in preventive medicine has a return on investment of 4 euro's[55]

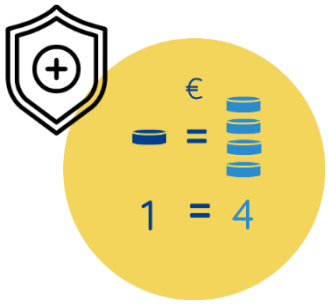


Figure 37: Return on investment of 1 euro in prevention

- Investing in screening and prevention is hugely important, specifically for children and young persons. To guard, protect and promote health, growth and development of all children and young persons, is an joint and interdisciplinary task of health care workers, society and policy-makers. Without good coordination and communication, huge opportunities are missed!
- Evidence from longitudinal studies reports that the benefits of healthy childhood development extend to older ages: birth weight, infant growth, and peak physical and cognitive capacities in childhood are associated with or predictive of older adults' physical and cognitive capacities, muscle strength, bone mass, lens opacity, hearing capacity, skin thickness, and life expectancy[56].
- A meta-analysis of 16 independent studies concluded that a 1 Standard Deviation (SD) advantage in cognitive test score assessed within the first two decades of life is associated with a 24% lower risk of death over a follow-up period of 17–69 years[57].

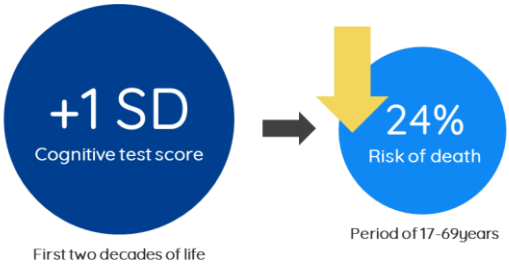


Figure 38: Advantage of 1 SD difference on cognitive test score on a long term

[55] Vlaamse LOGO en Preventieplatform HiAP

[56] Dodds R, Denison HJ, Ntani G, et al. Birth weight and muscle strength: a systematic review and meta-analysis. J Nutr Health Aging 2012; 16: 609–15. 9
Hanson MA, Cooper C, Aihie Sayer A, Eendebak RJ, Clough GF, Beard JR. Developmental aspects of a life course approach to healthy ageing. J Physiol 2016; 594: 2147–60. 10
Sayer AA, Cooper C, Evans JR, et al. Are rates of ageing determined in utero? Age Ageing 1998; 27: 579–83.

[57] Calvin CM, Deary IJ, Fenton C, et al. Intelligence in youth and all-cause-mortality: systematic review with meta-analysis. Int J Epidemiol 2011; 40: 626–44. https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(19)32540-1.pdf

In Belgium:

Only spent 0.23% relative to GDP on preventive care in 2020, well below the European average (0.37%) and half the budget of the Netherlands (0.51%) (Eurostat data). This is just 2% of the entire Belgian healthcare budget.

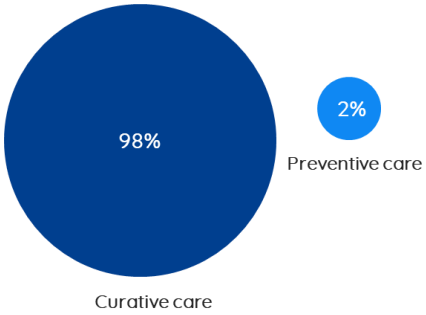


Figure 39: % expenditure in Belgian Healthcare on Curative and Preventive Care

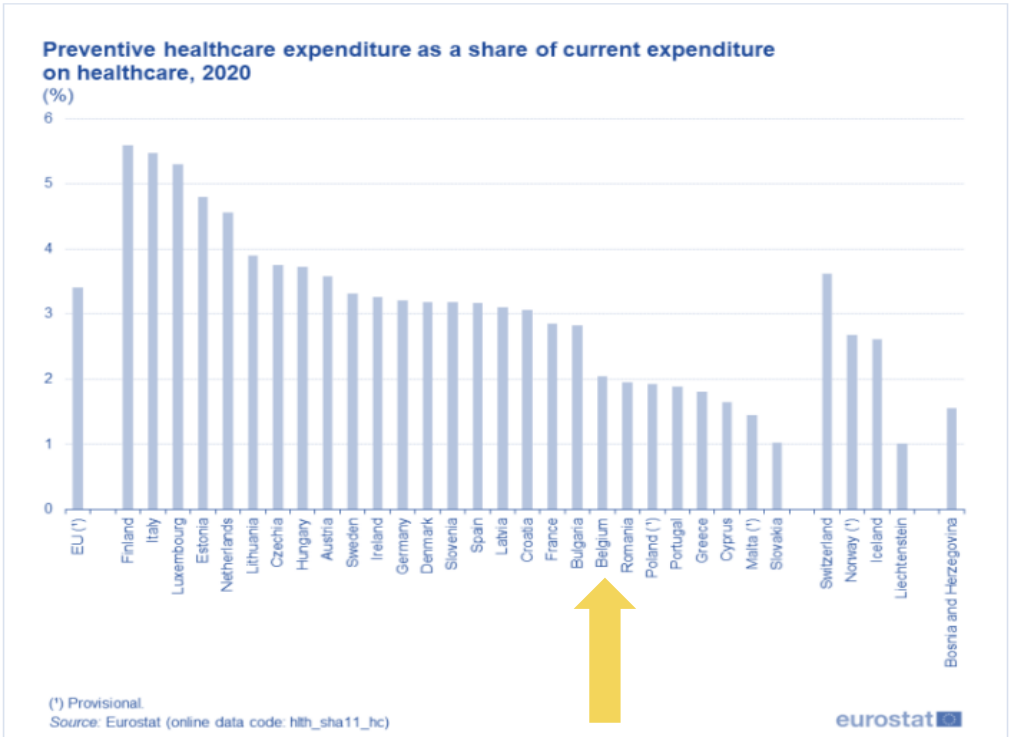


Table 6: Preventive Healthcare expenditure as a share of current expenditure on healthcare (2020) - Eurostat

Curative care

Paediatric consultations:

- a mean of 2.132.826 outpatient paediatric consultations yearly (0-19y) and mean yearly expenses of 68.580.789 €. Data on recurrence of consultation the same year show that 58,3% consult with its paediatrician ≥ 2 times a year.
- Paediatricians see 6.2% of the population. This has been fairly stable since 2012, with the exception of a slight decrease in 2020 (5.3%). Since paediatricians are supposed to see only a portion of the population, their percentage of consultations can be considered relatively high[58].

Paediatric hospitalisations:

- There were 168,373 classic hospital admissions in 2018[59] (7.7% of the Belgian children)
- 88.8%: under the age of 15 in a paediatric ward (total: 149.515);
- 5.6%: over 15 years of age in a paediatric ward (total: 9429);
- 5.6%: under the age of 15 in another hospital department (non-paediatric ward) (total: 9429);
- More than 30% of these admissions are attributable to children under the age of one. The proportion of traditional accommodation decreases as the age of the children increases. While for a one-year-old child the share of hospital stays is still 76.4%, this share drops to 49.6% for 14-year-olds.
- The age profile of children who were admitted with an overnight stay differs greatly from the age profile in the day hospital.
- The proportion of surgical admissions is 13.1%.
- Nearly one-third of stays include gastroenteritis, nausea and vomiting; upper respiratory tract infections; lower respiratory tract infections (bronchiolitis and RSV pneumonia).
- In the group of children under the age of one, they account for 79.1% of traditional hospital admissions.
- The average length of stay: 3.6 days with a median of 2 days. There is limited variability in the length of stay between hospitals, although admissions to university hospitals and to hospitals with fewer than 200 beds take longer on average. Long-term admissions, i.e. admissions of seven days or more, are often related to respiratory disorders and are concentrated in larger paediatric departments (see Figure 2).
- Long-term admissions are more common in children with multiple admissions in the same year than in children with a single admission
- There is no data on admissions due to social problems
- 161,410 outpatient stays in 2018[60].
    - 89.6% in one of the 99 hospital locations with an approved paediatric department.
    - 10.4% in 61 hospital sites without a paediatric department.
    - 93.4%: older than one year.
    - 40%: surgical procedure.

[58] IMA, 2022

[59] Minimum Hospital Data (MZG) 2018

[60] Minimum Hospital Data (MZG) 2018

Medication use:

- 50% of the children <3 years receive at least 1x/year antibiotics
- 57,533 IV-therapies were given (RIZIV, 2018)
- 17% of the young persons takes psycho-active medicines (Rilatine, ...) (Drugline, 2022)
- In child oncology: here is almost none positive evolution in mortality rate and new innovative medicines for children in comparison with adult oncology (KickCancer, 2024)
- There is no data available on medication use in schools and child day-care given by teachers or care-givers (type of medication, incidents, frequency, ...)

Mortality rate:

- Belgium has a mortality rate in children of 2,9/1000 life births. In comparison: 1,8/1000 in Scandinavian countries.
- Suicide is still the most important cause of death in young persons.
- 1200 EU deaths every year in children due to air population (EEA, 2023)

Mental problems[61]:

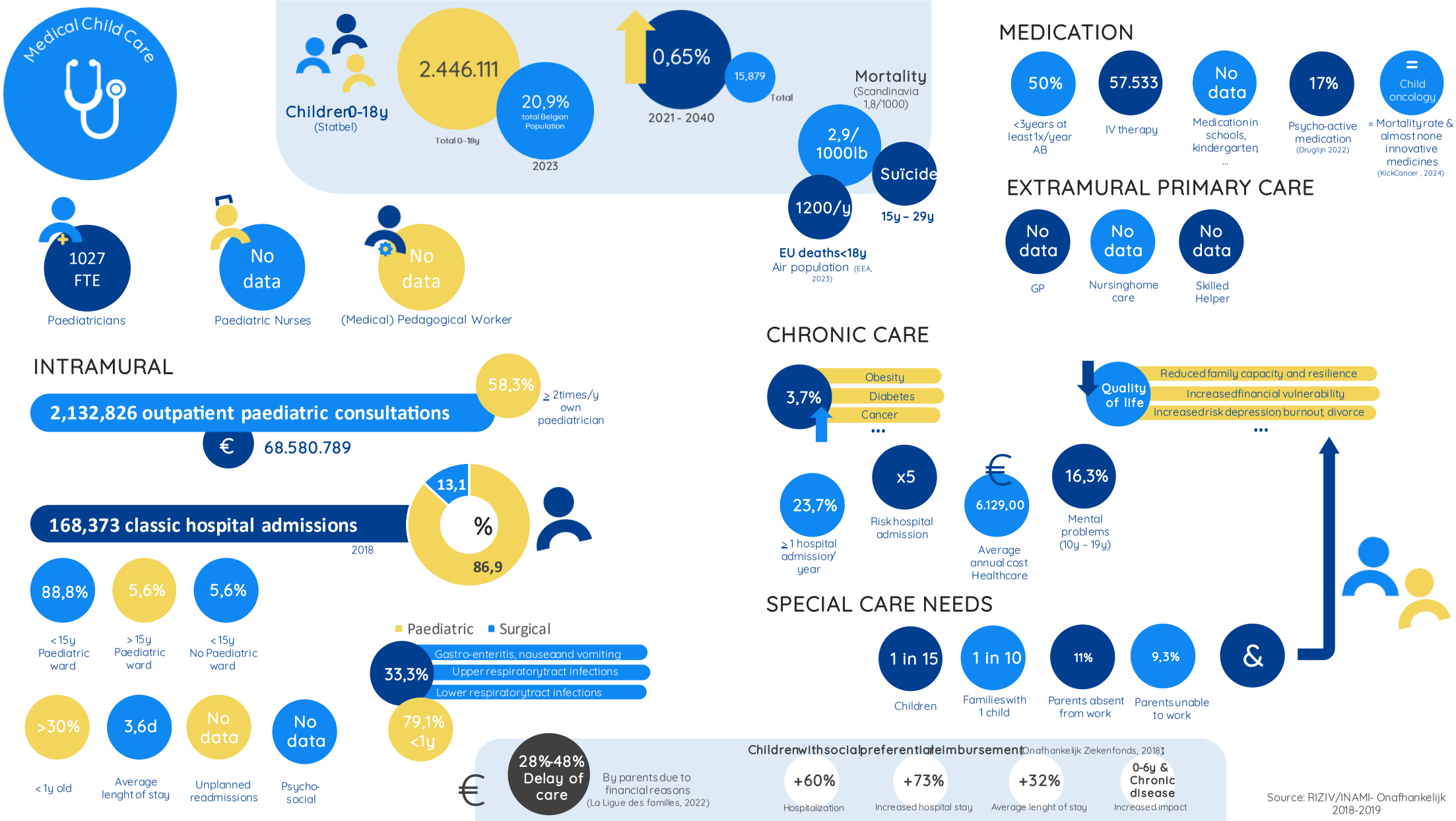
- 16,3% of the children between 10y and 19y have mental problems
- On an annual basis, about one in five young people suffers from a mental disorder.
- The average and median age at which a mental disorder becomes apparent in Belgium is 21 and 17 years, respectively. This means that half of the disorders are already effectively present before the age of 17 to 21 years.
- A quarter of all mental disorders in the Belgian population develop before the age of 14.

In Belgium:

- 20% of the population is responsible for 80% of the expenditures in social and healthcare sectors (RIZIV, 2019)
- No data are available on the distribution of consultation for acute mild to moderately ill children or consultations for children with single long term conditions or complex care needs
- No data are available on the total amount of consultations in emergency departments and consultations of children 0-19y with their general practitioner
- There are no data available on 'unplanned readmissions', despite the fact that this is included as a quality indicator in the Quality Indicators General Hospitals[62]

[61] Bruffaerts, Ronny. 2021. De mythes voorbij. Het Public Health perspectief in de geestelijke gezondheidszorg. Zorgnet-Icuro.

[62] Flemish Institute for Quality of Care



Source: RIZIV/INAMI- Onafhankelijk 2018-2019

Integral Care

ACEs cost the Belgian society around 7,5 billion euros annually (3.1% of GDP) and a loss of 162,600 years of life (DALY's)[63].

In Belgium:

There is no structural inter-federal plan aiming to reduce Adverse Childhood Experiences

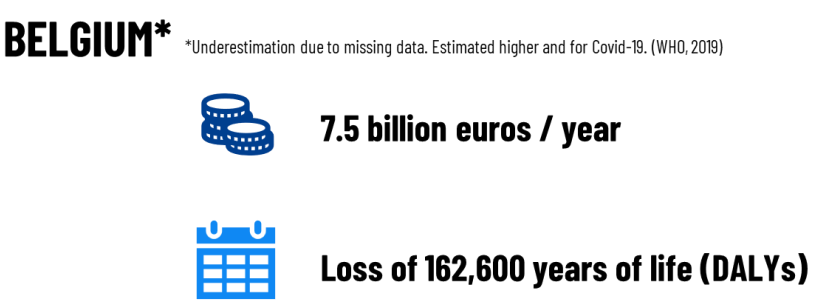


Figure 40: Cost in euro and DALYs of ACEs in adults in Belgium (2019)

> *Many economists, including Nobel prize winners Joseph Stiglitz and Paul Krugman, have described the harm done by neoliberal austerity policies. Clear evidence shows that austerity cuts welfare benefits, increases inequality, and harms the poorest families the most. The proponents of austerity say it is necessary to cut national debt. Yet these policies often actually increase the national debt burden—in the UK the national debt increased by £860 billion from 75% to 85% of GDP between 2010 and 2018. So, in arguing for investment for children, advocates should contest the arguments put forward for austerity policies being necessary for national debt reduction.*
>
> *The Lancet Commissions Vol 395 February 22, 2020*

[63] Karen Hughes, Kat Ford, Mark A Bellis, Freya Glendinning, Emma Harrison, Jonathon Passmore. Health and financial costs of adverse childhood experiences in 28 European countries: a systematic review and meta-analysis. (2021). Lancet Public Health - WHO; 6: e848–57

2.2.3. Social injustice and exclusion of (vulnerable) children

"The right to the highest attainable standard of health"(adults)

≠

"The right to grow up into your full potential" (children)

The Health gap widens

In Europe and in Belgium as well[64]

Exclusion of children

- Although Belgium has signed the UNCRC in 1989
- Although all children's hospitalisation should be avoided
- Although children have the right to be treated by skilled professionals
- Although children have the right to be involved in shared-decisions making
- Although children can be patients and have complex integral care needs as well

In Belgium:

- Children can be patients, but the Law on patients' rights does not include any specific children's rights. No child nor parent was asked for input.
- For children only hospital stay is reimbursed, no day-care clinic for medical purposes exists
- (FL)1st line zones are supported to form multidisciplinary teams with physiotherapists, nurses, psychologists,, dieticians, without any need for child-specific competences
- The Federal Advisory Council for the Elderly (FAVO) provides seniors with a voice at the federal level. Children, young people and their parents do not have this voice.
- For children in contrast to adults with complex care needs, no incentives for multidisciplinary consult is available

[64] https://knowledge4policy.ec.europa.eu/foresight/widening-health-related-inequalities_en

Data on vulnerability of Children in Belgium

As reported by UNICEF[65]:

- The different systems of the three federal regions do not align and are not fully comparable.
- The impression exists that data are collected, but are either not made publicly available or are difficult to find or access.
  https://www.unicef.org/eca/sites/unicef.org.eca/files/2022-03/Belgium.pdf

Adverse Childhood experience and their cumulative effect determine the vulnerability of a child. Secondary, ACE's lead to more preventable disease and care needs with a growing pressure on the availability of health care for non-preventable disease and care.

- *No data are available on the cumulative effect of ACEs in Belgium*

High quality data availability on Adverse childhood-experiences					
Bereavement		Impaired caregiver		Poor academic performance	
Bullying		Kidnaping		Poverty	
Community violence		Living in unsafe environments		Racism over time	
Domestic violence		Multiple deaths & traumatic loss		School violence	
Emotional abuse		Natural disasters		Serious injury/accident	
Food scarcity		Neglect		Sexual abuse	
Forced displacement		Peer rejection		Sexual assault/rape	
Foster care system experiences		Physical abuse		Terrorism	
Illness/medical trauma		Physical assault		Traumatic loss	
Interpersonal violence		Political violence		War	

No data on children | Limited data on children | Data on Regional level | Data on Federal level

Table 7: Data availability on Adverse Childhood-experiences

- *Bereavement (death/loss of a caring person)*
  - No data are available on the total amount of children that suffer parental loss

- *Bullying*
  - 19.7% of Flemish children are bullied during their youth (1/5). This represents an increase of approximately 3.2% compared to the 2018 figures https://www.allesoverpesten.be/cijfers
  - 17.6% of Walloon/Brussels children are bullied during their youth https://www.ulb.be/medias/fichier/hbsc2022-victimes-harcelement-2_1700122932952-pdf

[65] Unicef - DataCare project, 2021

- *Community violence*
  - No accurate data on children affected by community violence are available
  - No data on:
    - Holistic interventions in the family environment: positive parenting
    - School-based violence prevention programmes
    - Community-based programmes

- *Domestic violence*
  - Only data are available on population +15y old and date from 2018 Sciensano https://www.sciensano.be/sites/default/files/vi_report_2018_nl.pdf
  - Some data are available in police-reports 2022 but no specific focus on children
    https://www.politie.be/statistieken/sites/statspol/files/statistics_files_upload/Criminalit%C3%A9%20-%20Criminaliteit/2023_T01/crimi_nl/01_Rapporten/01_Federaal/rapport_2023_trim1_nat_belgie_nl.pdf

- *Emotional abuse*
  - No data are available in Belgium

- *Sexual abuse*
  - 12% of the young people already made deepnudes of other persons (University of Antwerp, 2024)
  - Of all sexual abuse, 13,5% are children below the age of 12 (Sensoa-Sexpert study)

- *Poverty*
  - Belgium: 18,6% of Belgian citizens had a risk of poverty (2024). In 2022 12,3% of the Belgian families lived in poverty (Statbel).
  - Flanders: 25% increased cost per child in 5 years' time for an average family (Opgroeien, 2024)

- *Illness/medical trauma Chronic diseases*
  - In general: limited available data
  - 3.7% (19,379) of Belgian children aged 0-19 live with one or more chronic diseases[66];
  - Expected increase in the coming years
  - Chance of hospitalization: almost 5 times higher than their peers without chronic disease (4.8% - 23.7%)[67];
  - 23.7% are hospitalized at least once during the year
  - A chronically ill person (all ages) spends an average of 6129 euros annually on health care. Of which respectively 3665 euros for one chronic condition and up to 33648 euros for five chronic conditions. For a healthy person, this amounts to 860 euros per year. This only concerns the expenditure for medical expenses. This does not include the loss of, for example, quality of life and/or other non-medical costs. There is no specific data for children on this cost.

[66] Independent Health Insurance Fund, 2018
[67] Independent Health Insurance Fund, 2018

- There is no data available on the impact of a child's chronic illness on quality of life in Belgium. In general (inter)national studies states:
    - Reduced capacity and resilience of parents due to the effect of the disease, the care path and uncertainty about the future. An impact that is situated in the areas of work, financial situation, social, leisure.
    - Increased healthcare costs in combination with 1 or both parents who are less or no longer able to work make the family more financially vulnerable. Financial hardship and poverty cause anxiety, stress and uncertainty and are a major risk factor for health inequalities.
    - Increased risk of depression, burnout and divorce within the family due to stress, insecurities, tensions, falling away, different views between parents, etc[68].

- *Children with special care needs:*
    - No or very little data available on children with special (care) needs and the impact on the lives of their parents[69].
    - 1 in 16 children in Belgium and 1 in 10 families have at least one child with special care needs[70]
    - 8.6% of parents without children with special care needs are absent from work due to illness, compared with 11% of parents with a child with special care needs and even 12.9% if they have two children with special needs.[71]
    - 6.1% of parents without children with special care needs are disabled (unable to work for more than a year), compared with 9.3% of parents with a child with special care needs and even 13.5% if there are two.[72]
    - The same increased impact on the different areas of life within a family as indicated for 'chronic diseases'[73].
    - 6% of all students attend school in Special Education[74].

[68] Hatzmann, J. 2008-2009-2014)
[69] Independent Health Insurance Fund, 2022
[70] Independent Health Insurance Fund, 2022
[71] Independent Health Insurance Fund, 2022
[72] Independent Health Insurance Fund, 2022
[73] Hatzmann, J. 2008-2009-2014
[74] 'Cross-country reports' – European Agency: https://www.european-agency.org/

- *Physical abuse*
    - A KCE rapport 269 of 2016 scientifically researched how to improve the detection of child abuse in Belgium[75];
    - Flanders: the Flemish Trust Centres for Child Abuse received in 2021 7,535 reports about a total of 10,070 children and young people.
    - Wallonia: SOS Enfants since 2017 yearly increase of +2.4% child abuse (total mean 2020-2022 6672 and 2017-2019 6518.

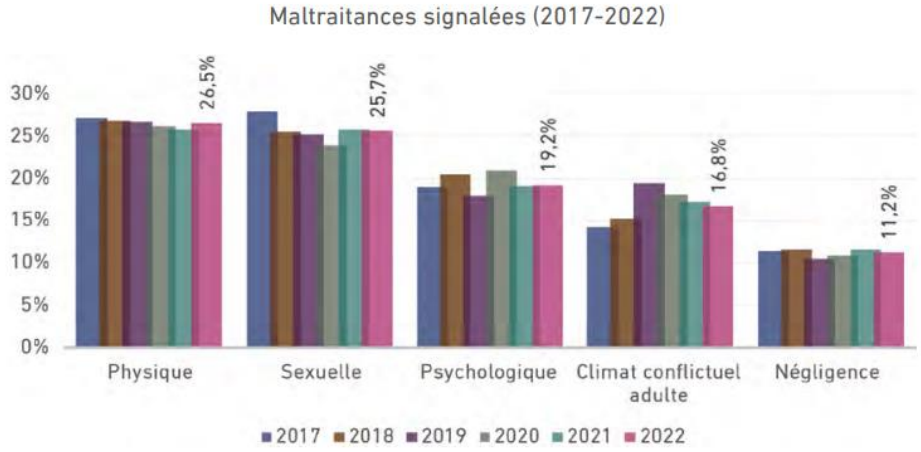


Table 8: Reported child abuse – SOS Enfants (2017-2022)

Although 33% of traumatized children are redirected to medical care, no data are available on the knowledge level, competences for trauma-sensitive care of child health care professionals
These competences are not controlled, (digitally) listed or consultable.

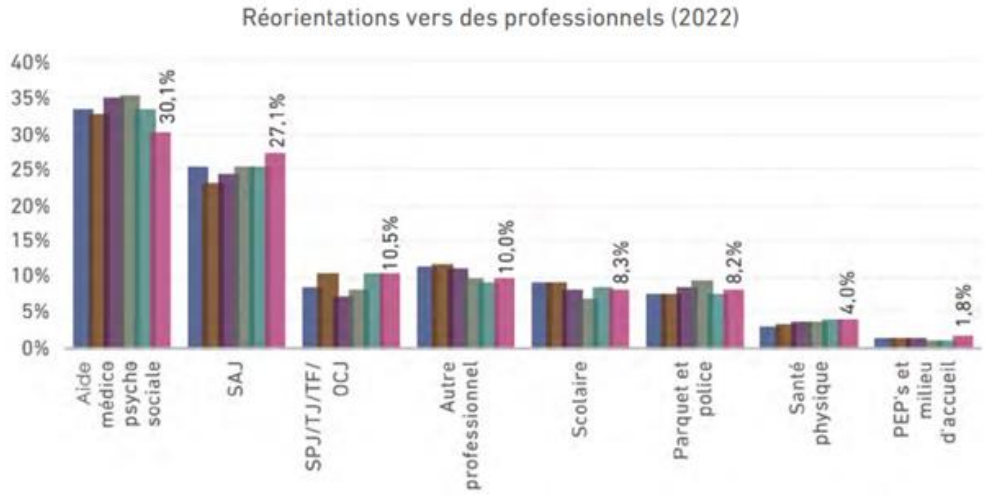


Table 9: Réorientations vers des professionnels – SOS Enfants (2022)

[75] https://kce.fgov.be/en/publications/all-reports/how-to-improve-the-detection-of-child-abuse-in-belgium

Data on social injustice

- Vulnerability can be due to determinants of health.
- Whether a child is healthy or not is determined to a large extend by socio-economic circumstances of his family, environment, genetics, income, education level, social bonds, whereas access and use of health care services often have less impact.
- WHO Determinants of health 2017 https://www.who.int/news-room/questions-and-answers/item/determinants-of-health
- Centre for Disease Control (CDC) FAQ What are social determinants of health https://www.cdc.gov/nchhstp/socialdeterminants/faq.html
- A societal priority lies in recognising and acting on the needs of the most vulnerable children and young persons.
- But there are no good prevalence data for Belgium

Inability to...	Household below the poverty line	Household not below the poverty line
eat fruit and vegetables at least once a day	3,5%	1,0%
have outdoor leisure equipment such as a bicycle, roller skates, a skateboard, etc.	15,9%	1,9%
celebrate events such as birthdays and religious ceremonies (communion, bar mitzvah, etc.)	10,1%	2,1%
have a suitable place to study or do their homework (large and quiet enough	17,0%	2,5%
have new clothes (and not second-hand)	32,4%	4,8%
eat one meal with meat, chicken, fish or a vegetarian equivalent at least once a day	7,8%	2,0%
have indoor toys suitable for their age	11,0%	1,0%
have friends over to play or to eat from time to time	13,4%	2,2%
go once a year on a one week holiday	57,0%	10,6%
have two pairs of shoes, including a pair of all-weather shoes	13,6%	1,9%
have age-appropriate books, excluding school books	9,6%	1,7%
participate regularly in leisure activities away from home, such as sports clubs, music, youth movements, etc.	25,0%	2,3%
participate in activities organised by their school for a fee, such as school trips, excursions, etc.	5,0%	1,5%

Table 10: Belgian data on poverty (StatBel)

An increasing number of children and young people require support in school, youth care, mental health care, or child psychiatry.

Reports and complaints received by the Children's Rights Commissioner indicate that structural problems often underlie difficulties for children and young people. A group of children remains deprived of the support and assistance they need, despite their contact with facilities and organizations set up or recognized by the government for them.

In Belgium:

- Data from the Children's Rights Commissioners:

  Flanders:
  https://kinderrechten.be/advies/jaarverslag-kinderrechtencommissariaat-2022-2023-kinderen-tonen-de-weg

  Wallonia:
  http://www.dgde.cfwb.be/index.php?eID=tx_nawsecuredl&u=0&g=0&hash=08b29f83f94d176a53d5c6e82c403e4bbf532f9e&file=fileadmin/sites/dgde/upload/dgde_super_editor/dgde_editor/documents/Rapports/RA_2022-2023/RAPPORT-D-ACTIVITE_2022_2023_DGDE_BASSE-QUALITE.pdf

In 2012, economist and Nobel laureate Heckman asserted that the best investment for vulnerable children is to invest in the quality of the first five years of life. The quality of a child's development in the earliest years significantly influences the health, economic, and social outcomes of individuals and society as a whole[76]

Since then, there is also neuroscientific evidence linking Adverse Childhood Experiences (significant childhood experiences[77]*) and nurturing care (WHO, 2018) on one hand, and the development and functioning of the brain throughout the life course, as well as the lifestyle and health of adults on the other hand.*

[76] https://heckmanequation.org/resource/the-heckman-curve/
[77] https://www.cdc.gov/violenceprevention/aces/prevention.html

Benchmarking

On the last OESO report, Belgium did not score well and again excelled in missing data.

https://www.oecd.org/els/family/child-well-being/data/dashboard/

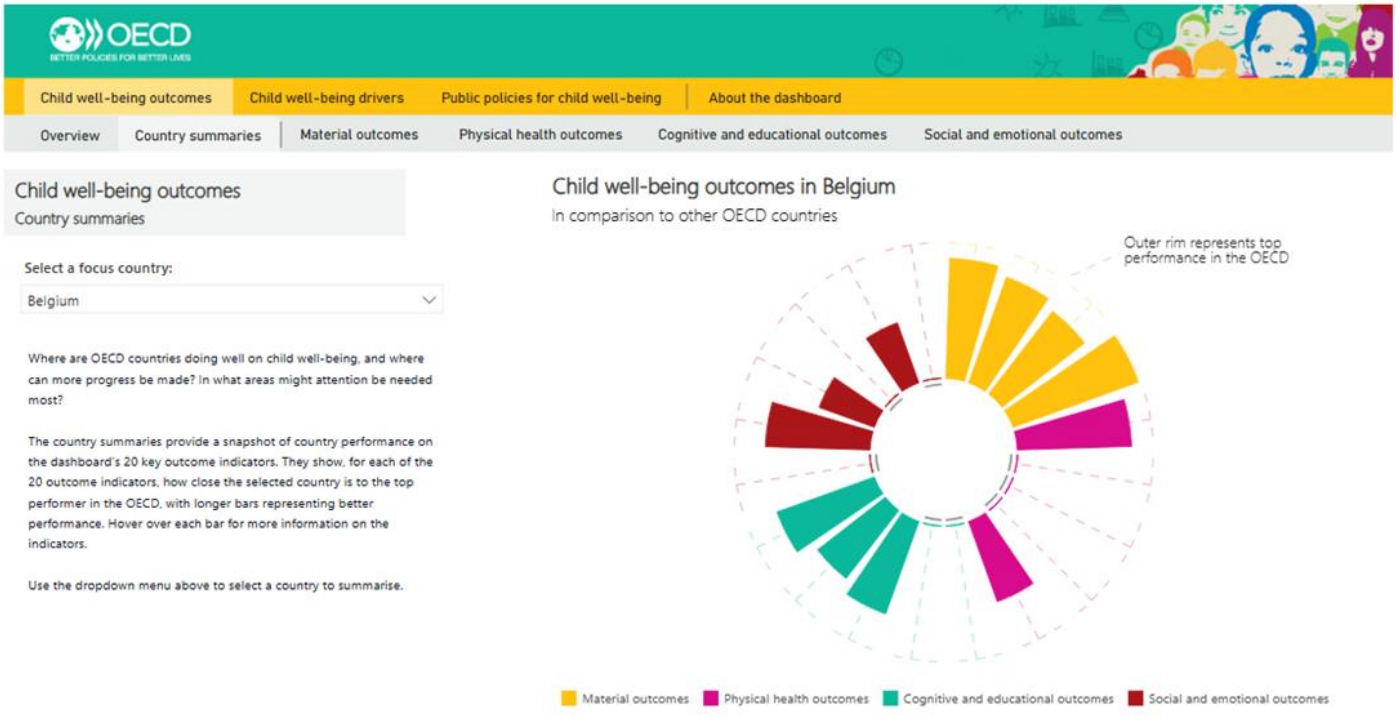


Figure 41: OECD Child well-being outcomes

To ensure our children grow and flourish, we require timely and accurate population data on health, nutrition, educational access and performance, housing, and environmental security, among other entitlements. Harnessing the power of citizen accountability mechanisms will be essential to fill the data gaps. We also propose the development of user-friendly country dashboards to assess the effects on children's wellbeing and sustainable development. Given the urgency for action, regular reports on the SDGs to the UN General Assembly must be the anchor of strong advocacy on action for children everywhere.

The Lancet

Figure 42: Cost of ACEs in Belgium

Data:
- Fragmented regional
- Not alligned
- Not always comparable
- Different datasets
- Small projects
- ...

Children 0-18y (Statbel)

2.446.111 Total 0-18y

20,9% total Belgian Population 2023

0,65% 15,879 Total 2021 - 2040

2,9/1000 Mortality (Scandinavia: 1,8/1000)

Poverty

+28% Increased cost per child in 5y period (Opgroeien)

18,6% risk Poverty Risk 2023 (Statbel) (2022: 12,3% in poverty)

Physical Abuse

Physical Neglect

Emotional Abuse

Emotional Neglect

Sexual Abuse

*Data very difficult to generalize

1/10 EU: 10 to 15% Flanders >10 000

No data on neglect

13,5% <12y Of all sexual abuse (Sensoa-Sexpert study)

7038 Reports in Wallonia (SOS Enfants 2021)

7535 Reports in Flanders (VK, 2021)

12% young persons Made ≥1 deepnude (UA, 2024)

Mentalproblem(s) (Bruffaerts, Ronny. 2021)

25% starts before age 14

1/5 young persons

1/3 adults **Mentalproblem(s)** (GezondLeven)

378.000 CPPP (Flanders)

Mental illness parent

7% adults **Burn-out** (GezondLeven)

No data children Only data >15y

Domestic violence

Mother-Child ward

No data children

Family member in prison

16% **Psycho-active medication** (Druglijn 2022)

14,5%; 19% problematic Secundary school (Druglijn)

5% XTC; 2% problematic

Addiction

11% Daily 15y-24y (Sciensano 2018)

Death of family member

No data children

No data children

Acces healthy food

19,7% Flanders

Being bullied

17,6% Wallonia

Violence in the neighbourhood

No data children

No data children

Physical activity

1/3 marriages 61,8% have children

1,9/1000 EU average: 1,7/1000

Divorce

27% (4320) children

Homeless

On the run (war/disaster)

2394 **Non-accompanied minors** (2022-DVZ & CGVS)

Separated from Parents/siblings

No data children

BELGIUM*

*Underestimation due to missing data. Estimated higher and for Covid-19. (WHO, 2019)

7.5 billion euros / year

Loss of 162,600 years of life (DALYs)

2.2.4. Current status of the professionals

In Child Health Care, many medical and non-medical actors are involved.

In Belgium:

- These actors are certainly not all represented/involved in policy-making
- All of these actors observe quality reduction to address work force shortages
- Before 2018, advices were asked (but often been neglected)
- No advices were asked since 2018 to the College and no structural communication organ was installed.

https://overlegorganen.gezondheid.belgie.be/nl/advies-en-overlegorgaan/colleges-van-geneesheren/college-van-geneesheren-voor-het-zorgprogramma-voor

Public Health Sector

- The situation for public child-care workers has worsened since 2020 and the coronavirus pandemic
- Quality standards have been downsized for care of school aged-children: For doctors working in a CLB (Centrum voor Leerlingenbegeleiding), no additional training expectations are imposed. Also, the remuneration of CLB doctors is no longer contingent on obtaining the master's degree after the master's degree in Youth Health Care, as it was previously. This decision was made in mid-November 2020.
- For nurses working in Public Health Sectors there is no structural educational curriculum in collaboration with and/or integrated in the existing curricula of e.g. Postgraduate Paediatric and Neonatal nursing. Most training programs are in-service with an unclear curriculum.

In Belgium:

Health-care professionals working in this sector report unanimously suffering from chronic underfunding, heterogeneity of organisation and human resource shortages (doctors, who are in desperately short of supply, but nurses too).

Paediatrics

- According to RIZIV/INAMI data, Belgium has 1027 FTE paediatricians (FR 537, NL 491)
- Continuously ignoring an entire professional group (paediatrics) results in policy distrust and policy disapproval. It fosters individualism, policy counteractions, decrease in paediatric workforce and finally destruction of qualitative paediatric care:
    - One example of this complete paediatric neglect by the government is the persistent 25-year refusal to acknowledge paediatric subspecialties, despite receiving several favourable recommendations from the High Council.
    - The non-recognition of the Neonatal and Paediatric Surgery.
    - Another example is the long lasting demand of the Recognition of PICU and the Level-3 title of Paediatric Intensivists.
- The Belgian government keeps supporting a notable discrepancy between paediatric health care professionals, paediatricians, and their counterparts in adult care. This inequality resulting in long-term inequity is a serious threat to the wellbeing of the paediatric workforce.
  These differences encompass various facets, ranging from resource allocation and training opportunities to societal recognition and financial remuneration.
    - Research funding, medical equipment tailored for children, and specialized facilities fall short in comparison to their adult counterparts. This inequality in resource allocation impacts the quality and accessibility of paediatric care, hindering advancements and innovation in paediatric medicine.
    - Training Opportunities: Another facet of this disparity lies in training opportunities. Paediatricians now face again fewer training positions compared to those in adult medicine. This disparity will affect the breadth and depth of expertise among paediatric specialists and will contribute to a shortage of general as well as highly specialized paediatric practitioners.
- Despite their heavy workload, night duties and permanence as well as 24/24h close to hospital availability, paediatricians on average receive comparatively lower remuneration than their counterparts in adult medicine. This disparity in compensation already affects career choices.
- The government provides data to the WHO stating too high hospitalisation rates in Belgium, without any discussion with paediatricians on this subject[78]

[78] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9850873/

Paediatric Nurses (in hospital setting ,neonatology, PICU, first line and transmural care)

- There are no data available on:
    - how many nurses in Belgium have a specialized title in Paediatrics and Neonatology;
    - the degree of education and life-long learning on paediatrics and child healthcare of nurses giving care to children;
    - how many children are getting care in the first line of care, the kind of care, the place of care and the duration of a care moment.
- In nursing: general legal competence takes precedence over child specific competence, with legal competence being defined very vaguely.
- Permanent absence of linking paediatric training, knowledge and competences as a requirement in the care of children. The new quality law does not define what competence specifically means (open to interpretation).
- Any licensed nurse without a specific education, knowledge and experience on children is allowed to provide care to children without any child specific education and experience (exposure).
- The new 'learning ladder' and 'function ladder' in nursing means that, since the expansion of their legally permitted nursing activities, more 'lower' educated profiles in healthcare can provide care to children without any paediatric training.
- The Intramural Care Program in Paediatrics and Neonatology requires at least 75% of nurses in possession of a specialized title including requirements for its preservation through exposure and continuing education. These requirements and quality assurance do not exist in primary and community care.
- As a result, the same child has access to specifically trained healthcare professionals in an inpatient setting, but not at all in an outpatient setting.
- Results of the Pilot projects of Paediatric Transmural care are awaited on how to guarantee these paediatric competences in the first line of care, the quality of these competences and how it will define paediatric competences in the first line. Intramural Paediatric competences 'on a distant intramural guidance' of non-paediatric competent nurses in the first line cannot be the answer for safe and qualitive care for children.
- All too often, the required knowledge and skills within the curriculum of the Postgraduate Paediatrics & Neonatology in the care of children are limited to the curative intramural aspect.
- Abolition of recognition and abolition of funding for further education in Bachelor after Bachelor Paediatrics and Neonatology Nursing in Flanders in 2016 resulted in the fact that the quality of the training is no longer guaranteed and the cost is noticeably higher in the newly Postgraduate paediatric programs.
- 'Embedding' the Paediatrics & Neonatology specialisation in Flanders as a small module within a generic Bachelor's degree programme in Nursing means that there is insufficient time and attention for building up in-depth knowledge and insight.
- Decrease in the number of bachelor nurses in Flanders who obtain the postgraduate degree in paediatrics-neonatology, as a result of which other professional profiles have to be employed in paediatrics. As a result, knowledge, know-how and therefore the quality of care are undeniably decreasing.

- The pitfall is that departments no longer meet the statutory requirement of 75% specialized paediatric nurses as described in the Paediatrics & Neonatology Care Programme.
- Paediatric nurse with a specialized title and function complement loses a financial reward when he/she moves from the hospital to the outpatient or paediatric rehabilitation setting.
- Without this specialized title, there are no longer any requirements for continuing education and competence within the care of children.
- The RN4Cast study and the clear finding that investing in highly educated nurses pays off: "The second economic analysis, the extrapolation from results of a major national study of nearly 800 hospitals, suggests that moving all United States general hospitals to a skill mix of highly educated and some- what more expensive personnel to the 75% percentile nationally would not only save lives, but could actually reduce expenses for the health care system as a whole by lowering complications and shortening length of stay. This latter analysis suggests that the policy approaches increasing skill mix rather than the numbers of personnel would be more effective in improving quality in American hospitals."
- In regard to the shift of integral care and care paths, it is unclear what the curriculum and competences are from the in-service training programs of nurses working with children in the community like K&G, CLB, ONE and PSE. Integral care paths requires a complementary match between the curriculum and competences of all these nurses and an objective external quality and outcome check.

Comparison Paediatric curriculum within Nursing education			
	Specialization Paediatrics & Neonatology (Postgraduate)*	Child Module within Nurse responsible for generic care (Bachelor)*	Basic Nurse (HBO5) – 3 year*
Hours Theory	450	75 to 90	Unclear
Hours Practical	450	Variable	Unclear
Studypoints	60	± 3	Unclear
	*Associated with legislations Specialized title Paediatrics & Neonatology	*Unclear legislation on the integration of children	*Unclear legislation on the integration of children
Al these educations with or without focus on children makes the caregiver legally competent to care for children and to perform technical medical and nursing techniques and actions in paediatric healthcare.			

Table 11: Comparison Paediatric curriculum within Nursing education

Required life-long learning en competence in children for nurses			
	Specialized title Paediatrics & Neonatology*	Nurse responsible for generic care (Bachelor)*	Basic Nurse (HBO5) – 3 year*
Life-long learning	450	Not specified	Not specified
Paediatric exposure / experience	Working in Paediatric care	Not specified	Not specified
	*Associated with legislations Specialized title Paedicatrics & Neonatology	*Unclear legislation on the integration of children	*Unclear legislation on the integration of children
Life-long learning in Paediatric care doesn't change the legal competence of a caregiver to care for children and to perform technical medical and nursing techniques and actions in paediatric healthcare.			

Table 12: Required life-long learning en competence in children

Child and youth psychiatrist

The Memorandum of the Committee on the New Mental Health Policy for Children and Adolescents (COMGGKJ) of May 2019 provided concrete recommendations.We reiterate here, by way of illustration, three recommendations from this memorandum.

- The importance of the first 1,000 days, the need for a specific offer for children aged0 to 5 years, focusing on attachment-promoting interventions;
- The need for a strengthened outpatient offer, where lege artis can also be worked with children, adolescents and their families in an intensive way for longer periods of time;
- Expansion of (semi-)residential capacity with a more balanced territorial distribution and with the possibility of intensive psychological care.

There are investments in integrated care - including psychological/ortho pedagogical care - in the first line, but the needs described above point out to specialised mental health care in the second and third lines.
A strengthening of the second-line mental health care as a priority action point for the youth, which includes substantially increasing the capacity of the children's teams at the Centres for Mental Health, also in terms of the capacity of the mobile home-based care teams, and bringing in/repaying clinical psychologist and remedial educationalist in the second line.
This multidisciplinary working can also reduce the pressure on the child and adolescent psychiatrist.

(Medical) pedagogical care provider.

According to the current Paediatrics and Neonatology Care Programme (2006) a pedagogical counsellor is mandatory
Not all hospitals fulfil this function as described in the Care Programme with no objective data on this subject.
Moreover, the minimum budgetary requirement and FTE are insufficient to meet the need for guidance of the child and the parents as well as to support the caregivers.

Skilled help (Bekwame helper / L'aidant qualifié)

- There is no data available on:
    - the number of Skilled helpers and their profiles;
    - the number and kind of care they give;
    - how many children are getting care;
    - the paediatric protocols being used;
    - etc.
- There are no quality measures and legislations on:
    - the degree of paediatric competence and experience of the educating healthcare professional;
    - medication safety;
    - trauma-informed care (PROSA);
    - follow up of (near) incidents;
    - medication safety and prescription

In general there is no intention on obliged quality guidelines, data gathering, follow-up of incidents and a structural intersectoral approach.

In Belgium:

In general no competences on children are required to give care to children. Every generic training program, even if only focused on adults, makes a healthcare professional legally competent to give care to (sick) children.
There is a total lack of data on which healthcare professionals give care to children.

2.2.5 Current (perceived) Quality of Care

- Most reports concern education (42%), youth care (19%), and divorces (13%). Reports about issues faced by refugee children rank fourth (6.6%)

In Belgium:

Children's rights in healthcare are a blind spot[79].

- There is a scarcity of accessible data specifically focused on children's healthcare quality, with no existing annual report dedicated to this aspect.

In Belgium:

The Quality of Healthcare Index by Sciensano only includes one query related to children. Similarly, in OECD indicators, only one indicator is available concerning children's health. All surveys/questionnaires are +15y.

- Quality of care is based on
  - Adequate dedicated workforce with child-specific competences
  - Well-chosen policy incentives

In Belgium:

- Subquota for paediatricians are established
- Declining number of qualified paediatric nurses
- No paediatric quality criteria/level of competences in the first line of care versus high quality criteria in inpatient settings (Care Program, Quality labels like NIAZ, JCI, ...)
- No centralized possibility to appoint
- No structural and objective external patient or parents participation: PREM or PROM measurements of children, young persons and parents.

[79] https://kinderrechten.be/advies/jaarverslag-kinderrechtencommissariaat-2022-2023-kinderen-tonen-de-weg

”

In general there are no or no good data available on the health and vulnerability-factors of children in Belgium.

The available data are not structural and mostly divided and lost in individual organisations or not on a Federal but on the level of the Community.

There is a lack in description of broad health determinants in children.
So what do we measure?

How can we build a data driven quality investment in the health of all children in Belgium when reliable data are lacking or insufficient?

03

Unheard Voices

Unheard Voices

"As a teenager, I spent more time in the hospital than at school," says Karsten Vanden Wyngaert (32) from Drongen. At the age of 11, he was diagnosed with the rare, chronic kidney disease IgA Vasculitis. "I had to redo my 3rd year of secondary school. Something that, with better coordination between the medical providers and the school could have been avoided. I was also completely denied sports at the time. As an avid tennis player and skier, this was particularly difficult for me. Especially because a large part of my social network disappeared as a result. The contacts at the tennis club were one of the few bright spots that time. If doctors and coaches had talked to each other, they probably would have found a way to get me to exercise responsibly. That would have made such a big difference!"

"We are now almost 20 years later and fortunately steps forward have been taken for some target groups, mainly under the impetus of lobby associations, such as 'Kom Op Tegen Kanker' for example. However, we are not there yet. A structural solution is needed at policy level and resources in order to achieve coordination in practice. The coordination between different players in healthcare must be better for all children and young people with a chronic condition, not just for certain types of patients who happen to have a strong lobby network behind them. Only if different parties in child care work together better can we give children and young people with a chronic condition the same opportunities as healthy children. Opportunities to which they are also entitled."

KARSTEN VANDEN WYNGAERT (32) - DRONGEN

Why don't they make medicines for ALL diseases?

Child, age 10y

I have experienced the care as heavy. Before the heart operation, it was a child who ate with great difficulty, was easily ill and had many check-ups. The care during the treatment of the leukaemia and cerebral infarct was very heavy, there was no time for anything else.

Only the care for the sick child and also the care for the other healthy child. As a parent, the rest of your life stands still.

Anonymous parent

I wish my brother was dead so my parents could again pay more attention to me.

Brother of a chronic sick child, age 6y

I was the linchpin, my parents helped a lot when I had to be at work, but with another small child at home it was necessary to be there for him as well and not just in the hospital or only taking care of our sick daughter.

Also mentally I couldn't handle the extra stress of work, it was a necessity to ventilate (as much as possible) and to be away from the problems.

Anonymous parent

All these quotes of children, young people and parents are anonymous due to the complexity and vulnerability of their situation and context.

"Our 5-month-old son was abused and was in very critical condition. Fortunately, he quickly received the medical care he needed. In the meantime, the judicial investigation was started and, pending a verdict, he was understandably placed under the supervision of UZ Gent. After more than a month, he was healthy enough to continue his rehabilitation at home, with the necessary outpatient care. Because there was no decision in the case yet, the juvenile court decided that he had to remain under the supervision of UZ Gent and was therefore not allowed to go home. As a result, he would have to stay in the hospital for an extra 5 months. And that's despite the fact that, from a medical point of view, it wasn't really necessary. All the while, he would take the place of another child who does need medical care. Incomprehensible!"

"We are, unfortunately, one of the painful examples, which shows that the best interests of the child are not always acted upon. Not only in the interest of our child, but also not in the interest of other, sick children. The slowness with which the decisions are made, the inhumane way in which they are communicated, the fact that we had to tell our story over and over again because there is no talking among ourselves, ... It makes the whole situation all the more difficult. No matter how well the doctors and nursing staff do their job, if there are no structural solutions for these kinds of situations, not only will the quality of care deteriorate, but also the development of our children. As a nurse, I know how important the first year of a child's life is. If you're not sick, a hospital isn't an environment where you're supposed to grow up as a child. Point. Our son can't speak for himself yet, so I do it for him. In the hope that our story will change something for all children and young people who end up in a similar situation."

ANONYMOUS FAMILY - YPRES

I was teacher and my wife was self-employed. Our son was only 1 year old when he got cancer and we soon realized that he was/would be in the hospital very often, almost continuously. I had given up my job when I was diagnosed and temporarily only received an exemption of 10.22 euros per day.

Afterwards I became self-employed out of guilt because I felt like I had taken advantage of society.

The emotional processing is extremely heavy...

Anonymous parent

Maybe the hardest thing was to see my friends grow-up, having fun, go out, having their first girlfriend. I was sick and most of the time in the hospital and at home. I lost a lot of friends and I feel that had never had a youth.

Teen, age 17y

As a mother, I had to stop working, because the care became too heavy, as well as all the stress around it.. which caused me to collapse myself.

Anonymous parent

You are constantly under stress. In addition, there was an older child who did not get the attention she needed.

Anonymous parent

All these quotes of children, young people and parents are anonymous due to the complexity and vulnerability of their situation and context.

"From birth, my daughter Marie-Lynn (9) has suffered from a rare metabolic disorder called 'primary hyperoxaluria type 1'. In her first three years of life, her life hung by a thread several times. We travelled with her from one hospital to another, from one specialist practice to another. Time and again, it turned out that there was no communication between the various care providers, no medical file that could be shared, no history. This is particularly worrying, because without the right medical background, the risk of incorrect diagnoses and treatments is all the greater. Anyone who, as a parent, fails to pass on crucial information themselves, risks being sent from pillar to post: double blood draws, double scans, incorrect medication, etc. We experienced it too. That is not only expensive and harmful, you also lose valuable time."

"I'm a pharmacist, so I have quite a bit of medical background. I speak both Dutch and French, have my own car and am financially well-off. It is because we were able to move around easily, because I was able to explain the medical background to the doctors and because I was able to make myself understood in French that Marie-Lynn is still alive. It is incomprehensible that in a country like Belgium, the chances of survival of a child still depend on the caregiver. After all, a child cannot tell his or her own story. Anyone who happens to grow up in a foreign-speaking family or a family with less educated parents is just out of luck?"

"This is not a blame to the doctors. With the information they have, they try to do what they can. There is a need for structural decisions and action: every patient, and especially children who cannot make their voice heard, have the right to a complete, medical file about themselves. A record that is easy for doctors to interpret and that they can share with the healthcare providers they trust. That doesn't exist today. To build that, different parties must be willing and allowed to share data. This not only requires IT development, but also requires a new way of working from many hospitals, doctors and medical players. That takes time and money. In addition to data, there is also a need for structural consultation between various healthcare providers. That also takes time, and therefore also money. If we want integrated care, we may have to abandon the remuneration principle of paying a doctor per consultation and reimbursing a hospital per scan performed. There, too, decisive policy and impactful actions are required."

KARLIEN HOLLANDER - EKEREN

Home doesn't feel like home anymore, other children spend a lot of time staying with grandparents, 1 of parents often in hospital with sick child. Sleeping a lot separately (sometimes month at a time), no time and space for privacy or just talking. Constantly being ready to re-admission in the hospital, no relaxation, no vacation, no night out or time to celebrate, for example, 10 years of being married.

Anonymous parent

I don't understand why my older brother can't stay and sleep with me in the hospital. At home, I share a room with him for many years and we are so close. Now I almost haven't seen him for weeks. I miss him and I'm afraid.

Boy, age 6y

You have less time to meet up with friends. Friends are worried, but their lives go on. It seems as you cannot follow society any more, that you are alone and lose all your friendships.

Anonymous parent

Due to my sickness it's hard for me to concentrate. In the past I was the top student of my class. Now I feel I am nobody. What will the future bring? Will I find work? Will I earn money?

Teen, age 15y

We are sent from pillar to post.

Anonymous parent

All these quotes of children, young people and parents are anonymous due to the complexity and vulnerability of their situation and context.

Our societies created these challenges

- meaning it is within our power to reverse them.

04

Transition to integrated care

Transition to integrated care

The Quintuple aim intends to optimize health care and transition to integrated care, as described in the KCE report 359 (KCE, 2022)[80], by simultaneously considering the experiences of patients, the health of the population, the cost of care, the well-being of health care professionals, and the overall experience of providing care.

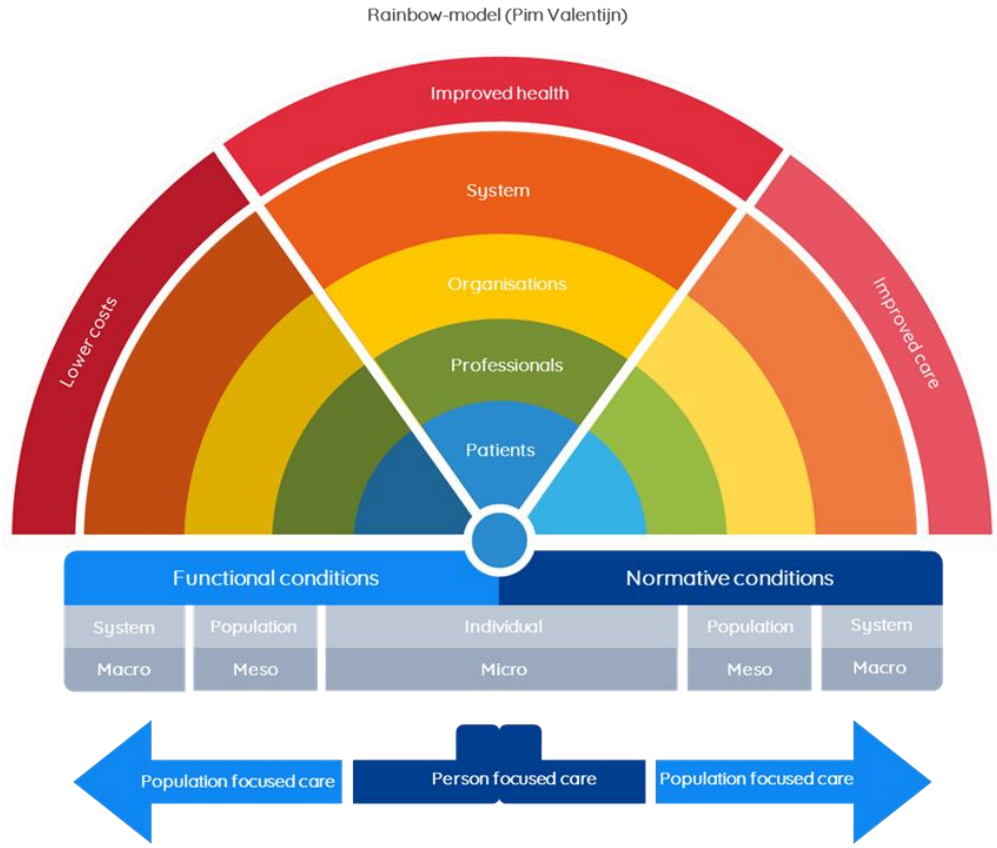
Figure 43: Quintuple aim model

As during the CoVID-19 period, let's sustain the collaborative synergy and highlight the importance of co-creation in policy design in order to recognize the key roles of children, parents, paediatric patients and health care professionals, and to ensure that transformation initiatives capture their voices and needs.

Considering Children's rights, their concerns and needs for short-and long-term health, this plan aims to provide frameworks and strongly urges policymakers to engage in ongoing structural dialoques (no pseudo-communication) with all stakeholders, but in particular with children, young persons and their parents.

[80] https://kce.fgov.be/en/towards-integrated-care-in-belgium-stakeholders-view-on-maturity-and-avenues-for-further-development

Based on this quintuple aim and guided by the Rainbow model of Valentijn[81] a regional-adapted, goal-oriented and integrated care is possible for all children.



Rainbow-model for Integrated Care (Pim Valentijn-Essenburgh)

Domain	Level	Description	Examples
System	Macro	Influence of law and legislations on cooperation between healthcare providers	Intersectoral policy healthcare and wellbeing Outcome based financing Population management
Organisations	Meso	Cooperation between different departments and organisations	Network care Shared Electronic Patient File Accountable care
Professionals	Meso	Cooperation between different professionals	Multidisciplinary consult Guidelines and protocols for multimorbidity Interdisciplinary curricula
Patients	Micro	Coordination of care on patient level	Shared decision making Personal health record eHealth applications

Figure 44: Rainbow-model for Integrated care (Pim Valentijn – Essenburgh)

[81] Dr. Pim Valentijn, 2021

Every child deserves a champion – an adult who will never give up on them, who understands the power of connection, and insists that they become the best that they can possibly be.

Rita F. Pierson

05

Aims

Improve health status on population level

More value of care with deployed resources

Social justice and inclusion

Added value and wellbeing for the professional

Perceived quality of care

Aims

5.1 Improve health status on population level

What gets measured, gets done!

- The overall aim for every child and young person is to reach their full potential
- We must recognize children and young people as a unique sector of the population
- We must realize that health before the age of 8y old is (in contrast to young persons and adults) fully context-dependent
- Together with family and close community, (paediatric) health care workers are part of this context and therefore are accountable.

RECOMMENDATION 4

We need quality data and specific health determinants in order to start data driven quality investment for the health of all children in Belgium

- Data in the sector of Health Care, Education, Youth Care, Public Health and Preventive care are not sufficiently connected. Relevant health outcomes can only be achieved by connecting all these influential domains.
- Measuring Health (according to the definition of Huber) in childhood and adolescence should not only be based on governmental data of disease. An expert panel together with patients and parents should develop and validate Patient Reported Evaluation (PRE) tools as for example the tool of My Positive Health[82] (from the age of 8y old).

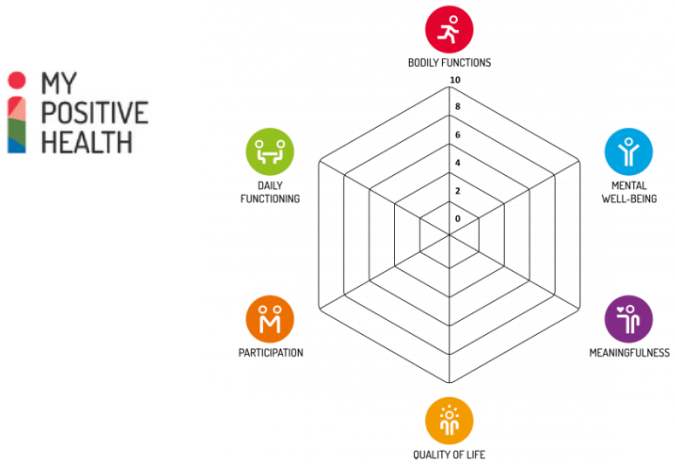


Figure 45: My Positive Health adult tool (Mijnpostievegezondheid.nl)

[82] https://mijnpositievegezondheid.nl

- The validated Patient Reported Evaluation (PRE) tools should be combined with international validated General Paediatric PROMs based on PREM comparable child health determinants.
- Assure data for European benchmarking:
    - Special attention to different developmental stages (neonate – baby-toddler-school age-adolescent-young adult)
    - Special attention to parameters that encourage strengths in children
    - Special attention to parameters that cause vulnerability
    - Special attentions to different subpopulations ill children
- Involve professionals and experts in the field to advice on relevant data
- Start of an excellent dataset on maternal and child health can be found on: Example UK for data on public health and all indicators Child and Maternal Health - Data - OHID (phe.org.uk)
- A yearly open report on children's and young persons' health
    - Make a report as for example 'Child health in Europe' on 'Child Health in Belgium', https://www.researchgate.net/publication/232815234_Child_Health_in_the_European_Union
    - Due to the wide diversity in curative child care, data would be ordered according to the proposed subpopulations (public health data on healthy and vulnerable of children as well as:
        - acute mild to moderately ill children and young persons;
        - acute severely ill neonate;
        - acute severely ill children and young persons;
        - child and young person with a single long term condition;
        - child and young person with complex and integrated care needs.

      With each group having its own developments, health-care gaps, pitfalls and opportunities for improved care.
- Data on ill children needs to be closely monitored and reviewed to induce timely and relevant action.
- Quick wins are adapting the website of:
    - Healthy Belgium (https://www.healthybelgium.be/en/) featuring a dedicated tile for all data available of those under 19 years old;
    - recalculate relevant IMA data (Inter Mutualistic Agency) per 100.000 child population (instead of per 100.000 insured);
    - Make the Belgian Health Status Project child-proof https://www.sciensano.be/en/biblio/health-status-report-2021-state-health-belgium

- An open and transparent report on the workforce for these different (paediatric) subpopulations:
    - regarding the number of children per general practitioner, paediatrician, CLB/PSE doctors and nurses, K&G /ONE doctors; the ratio of responsible, accountable doctors per regional child population;
    - assuring adequate competences for this workforce (targeting on specific child- and young persons care competences)
    - engaging this workforce in life-long learning with a focus on child-specific public health training.

Prevention should be higher on the agenda

- Prevention should be higher on the agenda and based on a the power of a healthy mix of contacts (every contact (with a health care professional) counts for health promotion and prevention). Key-players are ONE, K&G, CLB, PSE, general practitioners and paediatricians, as well as paediatric nurses, midwifes and other qualified paramedics in child-healthcare. Accept from logistical conditions, a good definition of each role, accountability and responsibility in a specific care-pathway is key in goal- but especially patient-oriented collaboration.
- Early Childhood and Adolescence are the time-limited windows of opportunity

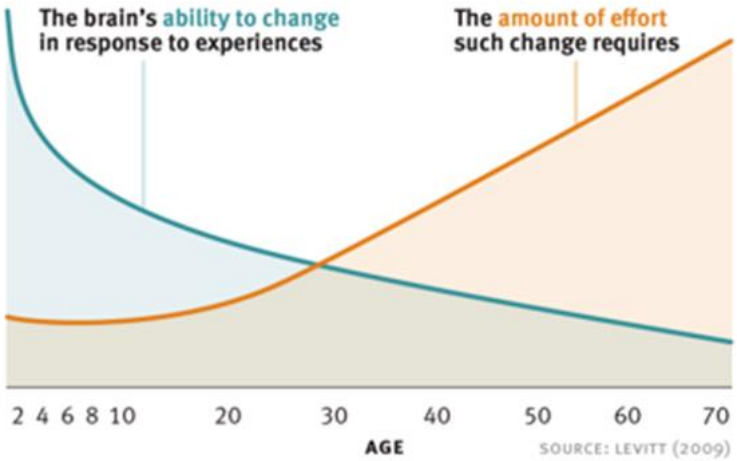


Figure 46: Relation brain's ability to change and the amounts of effort (Levitt, 2009)

P-5

- Promotion of ECD Early childhood development (ECD): first window of opportunity.

  The Nurturing Care Framework for Early Child Development (ECD) is a global initiative by WHO, UNICEF, the World Bank and other key partners providing an overarching strategic framework to promote ECD of young children.
  The European Framework on Early Childhood Development in the WHO European Region adapts the Nurturing Care Framework for the European region providing information to countries on measures to enable young children to reach their full potential equally. The European Framework covers the period from pregnancy to entry into primary school, focusing on the development of the child to the age of 3 years due to the critical period for action that this represents. The overall goal of the framework is for every child in the region to reach their full potential by:
  - living in a caring environment, nurtured by parents and caregivers;
  - being visible to policymakers;
  - having access to health care and services that support and monitor development and address developmental difficulties.

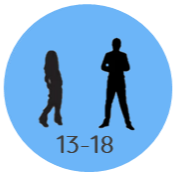
The health, education and social sectors are crucial in supporting parents and caregivers to provide responsive and nurturing care and in providing policies and services that support optimal ECD.

Frequently the health sector has the principal role in supporting ECD from pregnancy to three years, with a transition to early learning and childcare (ELC) from the age of three onwards. Effective promotion of ECD requires Multisectoral coordination and integration.

- Concerning preventive care for preschool children:
  Services should be organised and articulated in such a way as to ensure that every child is followed-up and receives preventive care (health promotion, disease prevention, ..) at regular intervals.

- Make every school a health promoting school (based on UNESCO-WHO):
  - It is essential to ensure the sustainability of prevention and health promotion among children, adolescents and young people in schools and student environments.
  - Prevention is an essential part of the healthcare system. The school is the best place to reach all school-age children according to WHO. School Health Promotion is universal, free of charge and available throughout the country. For some children, it is the only regular contact with a doctor and nurse.
  - Support this sector with:
    - extra funding to address human resource shortages;
    - centralized organisation;
    - incentives for qualitative public child health care;
    - refinance: ensure per-pupil subsidies that enable all legal missions to be carried out, without depending on the various organizing powers, in a more homogenous way between services and for greater equality between children;
    - strengthen social additional subsidies (taking greater account of schools' socio-economic Indices in the funding of services), so resources are available where they are most needs to reinforce the fight against social inequalities in health and strengthen health equity;
    - develop a regular collaboration between Education and School Health representatives and other stakeholders in support of health-promoting school environments;
    - provide free healthy meals in schools; these could contribute to reduce costs of curative care for obesity and its complications;
    - organize systematic tooth brushing in schools (with equipment supply);
    - improve reimbursement of spectacles (lenses and frames) for children;
    - improve multidisciplinary care for abused or neglected children;

- improve school-age children health data analysis to better plan preventive activities[83];
- improve communication between healthcare professionals and post-referral feedbacks.



- Adolescent key indicators of health:
  - Involve this age group fully in health care decisions
  - Invest in adolescence: it presents an ideal time for conversations about nutrition, exercise, mental health, relationships, drug use—such as smoking, vaping, and alcohol consumption—domestic and gang violence, positive sexuality, and active and engaged political citizenship. GAMA (Global Action for Measurement of Adolescent health) provides a package of evidence-based interventions and adolescents key indicators of health 9789240081765-eng.pdf it provides a huge opportunity to improve wellbeing throughout a person's lifespan[84].
  - Harmonize data and align them to needs

[83] • WHO Guideline on school health services: https://www.who.int/publications/i/item/9789240029392
• WHO Making every school a health promoting school – global standards and indicators:
• https://www.who.int/publications/i/item/9789240025059

[84] The Global Action for Measurement of Adolescent health (GAMA) Initiative-Rethinking Adolescent Metrics (sciencedirectassets.com)

RECOMMENDATION 5

RECOMMENDATION 6

Provide incentives for integrated child healthcare

- provide all stakeholders with incentives for interprofessional consulting and discussion building a strong Collaborative Adaptive Health Network Strategy
- Invest in structured child-care pathways instead of separate projects[85], based on subpopulations characteristics and need for complementary competences.

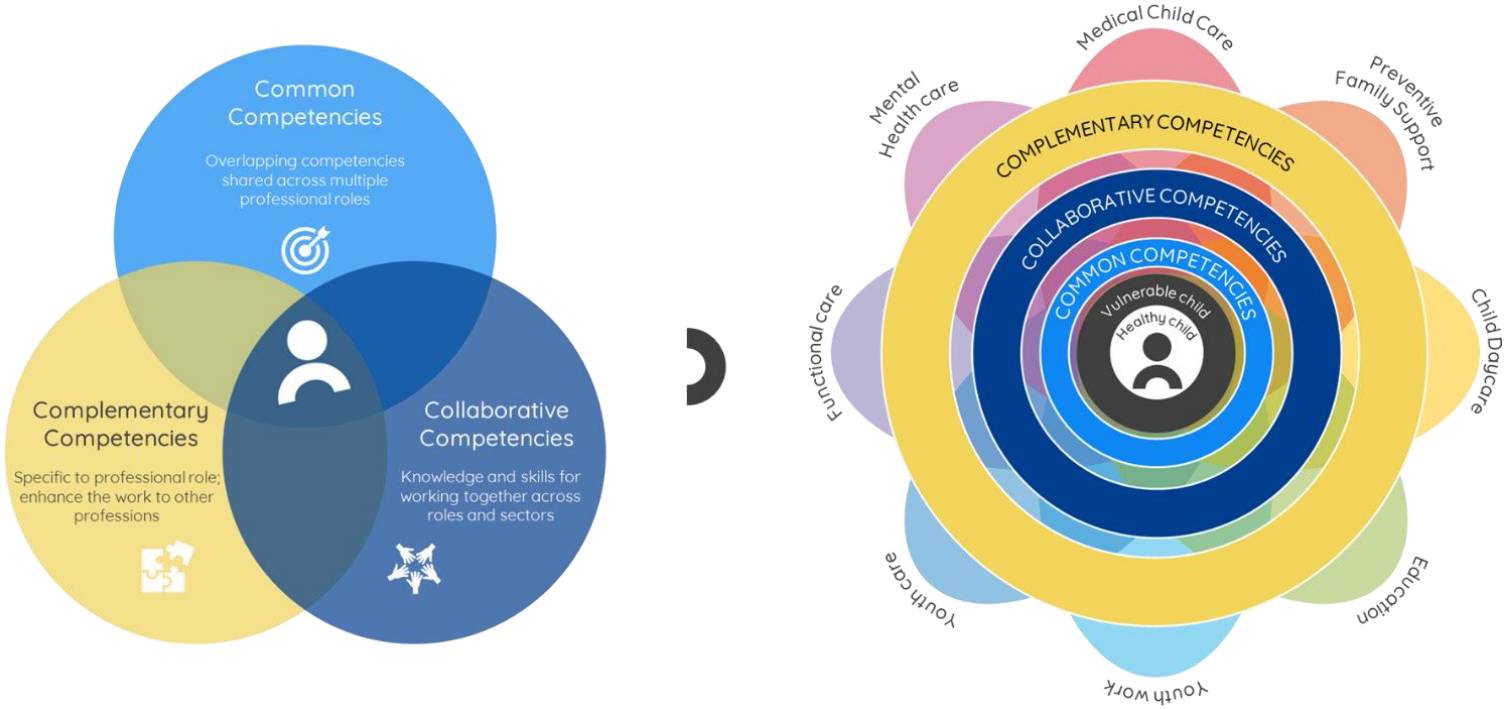
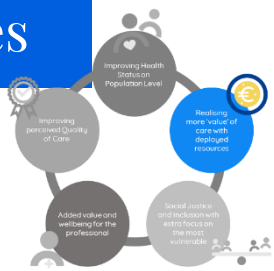


Figure 47: Interprofessional competences

(Interprofessional Education Collaborative Experts Panel, 2011)

[85] WHO indicators Global Strategy for Women's, Children's and adolescents' Health 2016-2030

5.2 More value of care with deployed resources



Allocating resources for children should be regarded as an investment rather than an expenditure

RECOMMENDATION 1

Assure the child guarantee in all policy decisions

- Why invest in children?
  - Children are entitled to benefit from investment.
  - Investing in children's rights is an investment in all of society, now and in the future.
  - Without investment to ensure that all children have an adequate standard of living, children cannot enjoy their other rights.
- Where to invest?
  - All children should be included in public expenditure, especially children who are living in vulnerable conditions.
  - Investment needs to reflect and meet the requirements of children in the communities and localities in which they live.
  - Investing in families enables investment in children.
- How to make good decisions about investment?
  - Governments should provide information about how they are spending money for children, including in ways that are accessible to children.
  - For example https://www.childrightsconnect.org/wp-content/uploads/2016/09/GC_IIC_ChildFriendlyVersion_English.pdf
  - Governments should plan well and not waste or misuse public resources.
  - Decisions about public expenditure should be made wisely to protect the rights of children now and in the future.
- Why and how to involve children?
  - Children want to be included in decision-making about government expenditure, and they consider that their insight will help governments to make better decisions about investment.
  - Children need support from respectful adults who will help them to understand public spending processes and to express their views.
  - Governments should work hard to ensure that children's views are taken into account in decision-making processes.

- Centralize responsibilities according to necessary competences.
- Promote structural and interprofessional collaboration using the same tools for measuring the physical and mental health of the child.

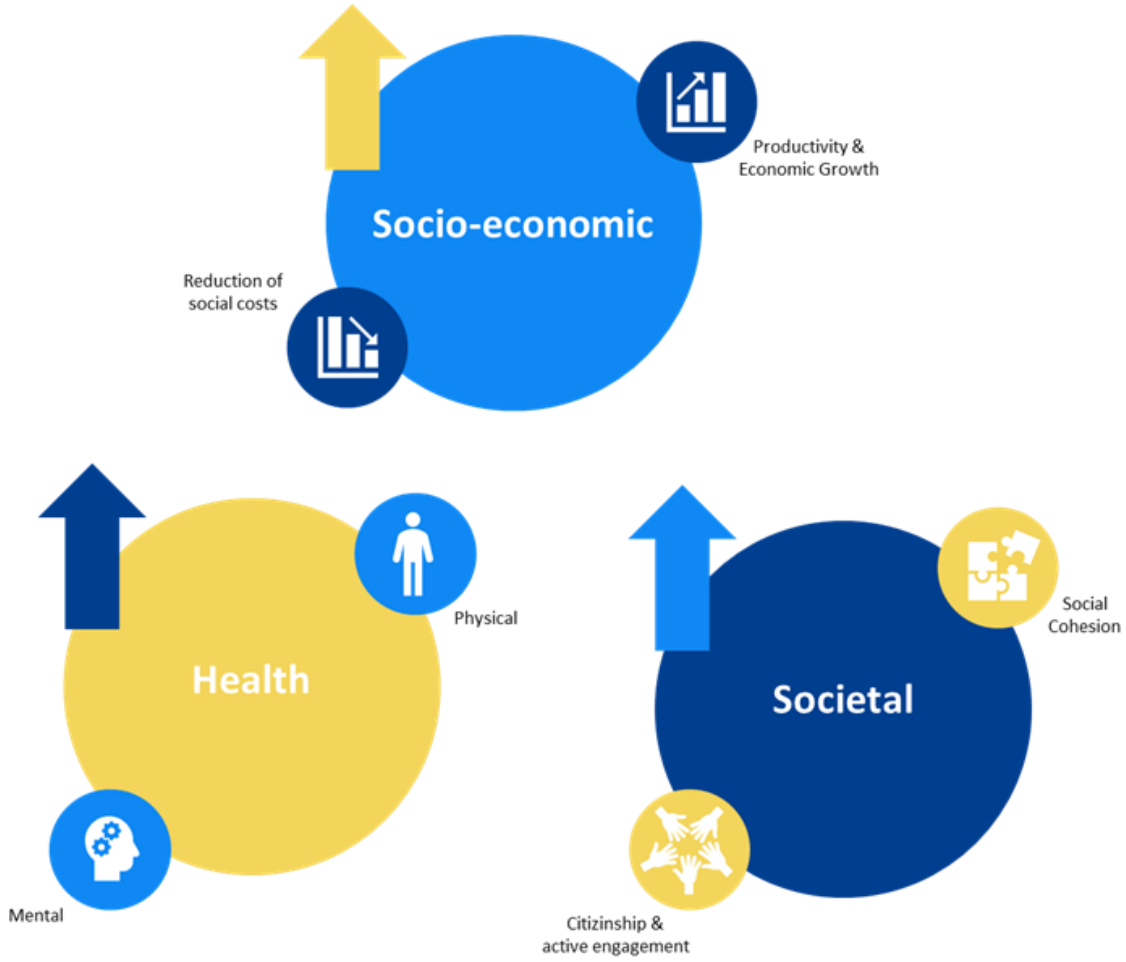


Figure 48: Benefits of investing in children

An ounce of prevention is better than a pound of cure.
(Benjamin Franklin)

- This figure is provided for Low and middle income countries. The same exercise should be done for High Income Countries[86].

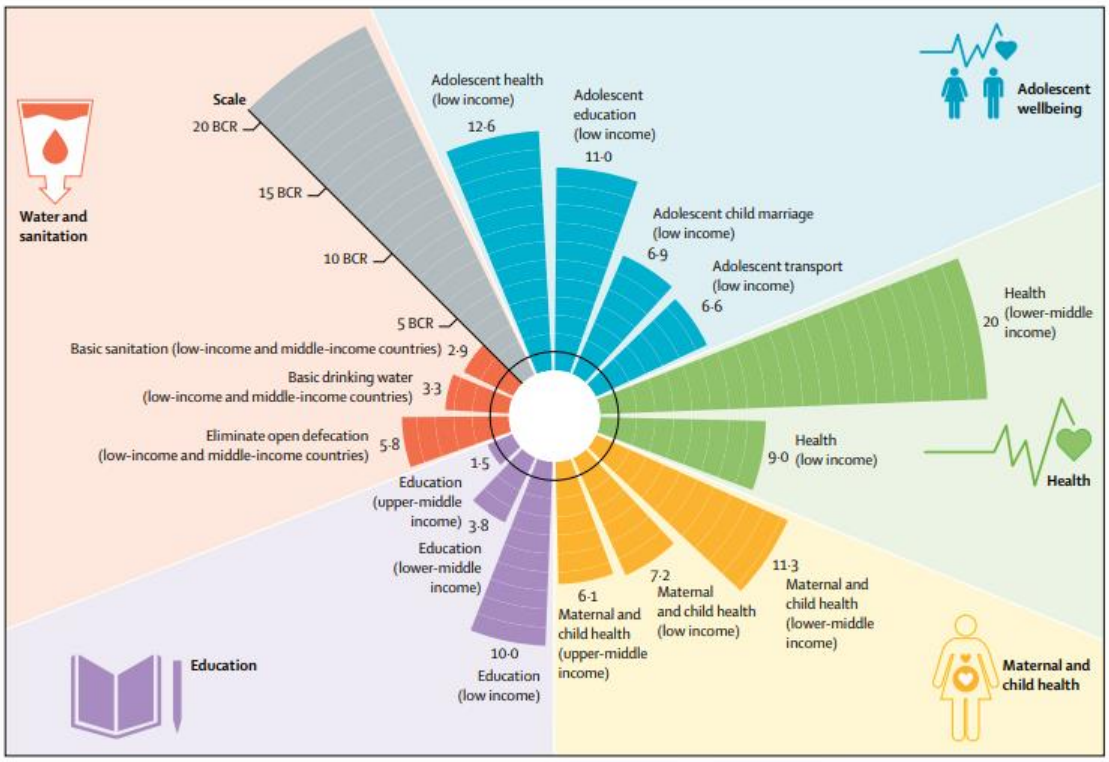


Figure 49: Benefit-cost ratios: return on every US dollar invested

- Provide improved transparency of child-focused spending.
- Focus on the preventable increases of care-demands
- Focus on reaching full potential of every child, also the most vulnerable and chronically ill with often complex care need!

[86] https://www.thelancet.com/action/showPdf?pii=S2352-4642%2821%2900190-5

5.3 Social justice and inclusion

Every child has the right to grow into its full potential, each child at every age, born with a (rare) disease or with complex care needs, with difficult context determinants, every child has a core of strengths that needs to be promoted and protected

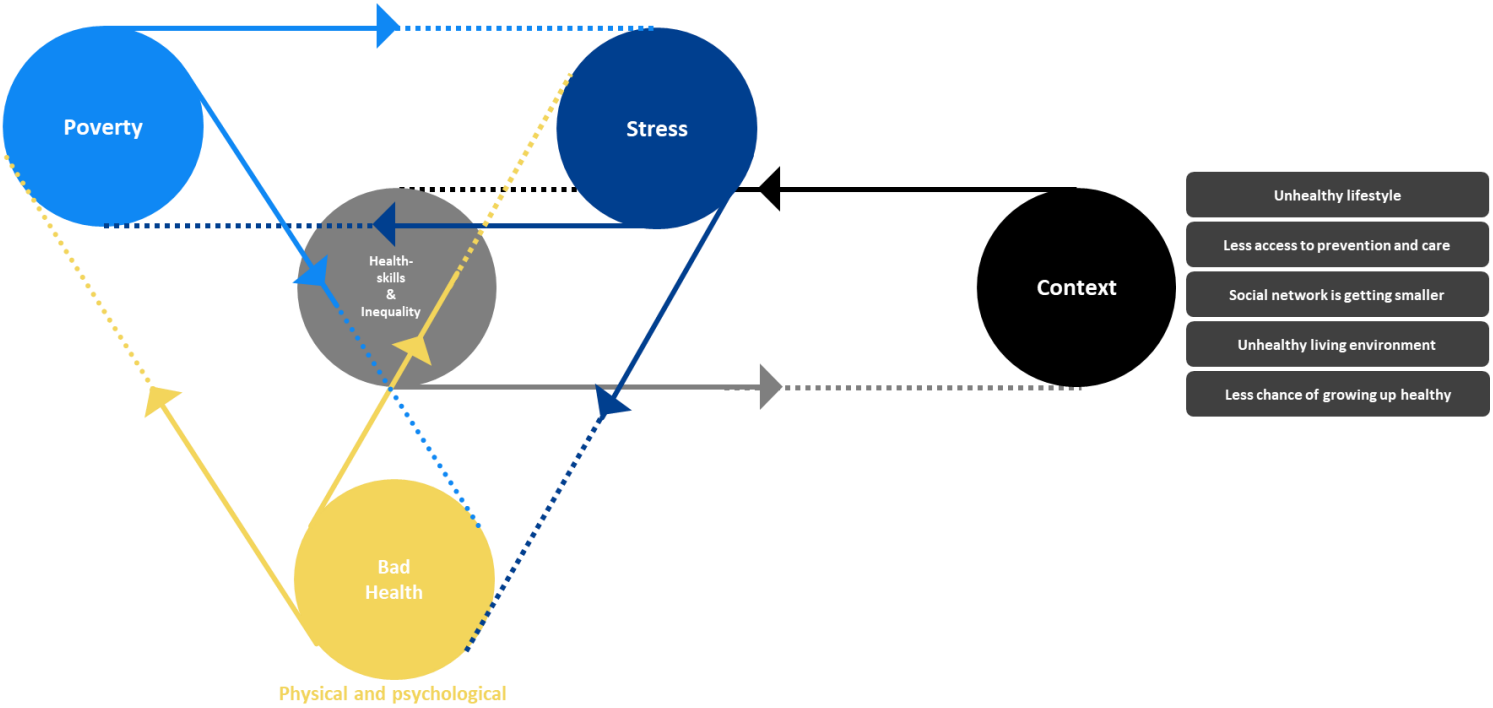


Figure 50: Poverty as a negative catalysator of health inequity

- Policy measures and programs for children are crucial for the growth and flourishing of children, building towards a healthy generation[87]
- Inherent in determining child health determinants is the concept of risk. This itself is a complex area, with an inter-reaction of general and individual-specific risks creating personal patterns of health determination. A similar mix of inter-actions occurs at the population level. Environmental exposures, societal contexts, household setting, and behavioural lifestyles are just some of the principle elements of risk affecting child health. In raising healthy children through health-promotion and disease prevention, both a population-based and an individual approach is equally important:
    - Insufficient country experience and capacity for planning policies across sectors is common, and stronger mechanisms are needed to help sectors coordinate.
    - Take deliberate action to coordinate and share responsibility for children across sectors.
    - Health matrix: "every contact counts"; the power of a healthy mix of contacts.
    - An interprofessional education and shared competences is urgently necessary to provide specific measures for those with intersecting and multiple vulnerabilities.
- Realize the promises in EU Child Guarantee national action plan
  One of the important goals is ensuring effective and free access to quality healthcare for all.
- Essential is to take a life course-based approach, from preconception to adolescence, which makes an intergenerational link seeing that the health and wellbeing of children is linked to that of their parents and other individuals making up their society, as well as their own future children and grandchildren. Children's specific factors of vulnerability, and protective factors across their life course should be addressed as early as possible
- Chronically ill children and children with complex care needs are vulnerable. General policy measures and programs for chronically ill children should be installed to address the inequalities between different pathologies : initiate a Convention (lump sum financing) of the Child with complex care needs: current pathology-based conventions increase exclusion and inequity among very vulnerable ill children.
- Invest in trauma-sensitive care in all sectors in contact with vulnerable children in order to create positive childhood experiences:
    - Realize the impact of trauma.
    - Recognize the signs and symptoms of trauma.
    - Respond to trauma by coordination of all involved sectors (healthcare, welfare, education, community, ...).
    - Resist to re-traumatisation.

[87] Black MM, Walker SP, Fernald LCH, et al. Early childhood development coming of age: science through the life course. Lancet. 2017;389(10064):77–90.

Realize refers to understanding the widespread impact of trauma	
	Understand how ACEs impact development and long-term effects into adulthood
	ACEs have neurological, physiological, biological, psychological, and social effects
	Shift perception from "what is wrong with you?" to "what happened to you?"
Recognize the signs and symptoms of trauma in patients and families	
Open-ended questions	"Has your living situation changed in any way?"
	"Has anything stressful, sad, or scary happened to you or your child?"
Diagnosis	Include comorbidities such as depression, anxiety, and substance abuse
Red-flag presentations	Be aware of red-flag presentations of trauma such as suicidality, self-injurious behavior, or presenting in psychosis
Assess for	Disordered eating
	Sleep disorders
	Elimination concerns
	Developmental delays
Respond to trauma by coordination with the health care system, community referrals, and education system to best support the child and family	
Screening	ACE-Q
	Pediatric ACEs screening and related life-events screener
	Children's stress disorders checklist (The National Child Traumatic Stress Network, 2020)
Anticipatory guidance	Resiliency promotion
	Consistent, developmentally appropriate parenting
	Nonphysical discipline
	ACEs education, to include possible symptom presentation
	Sleep hygiene recommendations
	Healthy eating recommendations based on symptoms
	Healthy toileting and elimination support based on symptoms
Treatment referrals	Community connections
	After-school programs and activities
	Spiritual and religious community connections
	Parent support groups
	Mentoring programs (e.g., Big Brothers)
	IEP referral
	SBHC
	Behavioral health therapy (see Table 2)
	CPS if indicated
Resist re-traumatization refers to rethinking the clinical approach to patient care, including support for those providing the care	
Become a trauma-informed organization	Review policies, protocols, and procedures for care with a trauma-based lens
	Consider input from clients and providers (employees) who provide care
	Approach all patients with a *universal precautions* mindset
	Provide training for all staff, regardless of position, on ACEs and trauma-informed care

Note. *ACEs, Adverse Childhood Experiences; ACE-Q, Adverse Childhood Experience-Questionnaire; IEP, Individualized Education Program; SBHC, school-based health centers; CPS, Child Protective Services. Four R's = realize, recognize, respond, resist re-traumatization.*

Table 13: Trauma-sensitive care competences (Source: Trauma-Informed Care Implementation Resource Centre - Centre for Health Care Strategies, 2021)

5.4 Added value and wellbeing for the professional

The wellbeing of healthcare professionals is the cornerstone of a resilient and compassionate health care system

RECOMMENDATION 6

RECOMMENDATION 8

General recommendations

- Initiate transparent consultation rounds on which model of child health care Belgium is aiming for, with the right balance between expertise and accessibility:
    - Mixed model of child-health care (current).
    - GP-led system.
    - Paediatric-led system.
    - Other: Regional differences/ Mobilisation of expertise/ Age-dependent.
- This is key to be able to calculate a reasonable workforce and to decide on subquota and necessary training competences and exposure.
- Realize that professional representation of child health professionals is minimal in the current policy-structures (and is dominated by adult medicine representatives).
- Transparent and mixed interprofessional policymakers-expert group interaction with (open) reports (fe. federal government college).
- Ensure that the same stringent quality standards (Competences – equipment – quality criteria and -assessment), as provided in paediatric hospital care, are maintained when scaling towards more transmural care.

Paediatricians

- Bridge the gap between adult and paediatric resource allocation, training opportunities, renumeration, research funding, innovative initiatives
- Ensure renumeration is proportional to the doctor's quality of life, i.e. for paediatricians' heavy workload, night duties and permanence as well as 24/24h close to hospital availability, high responsibility, mostly unplanned care
- Ensure availability of medication and medical equipment tailored for children
- Increase the paediatric quota to avoid shortage of general as well as highly specialized paediatric practitioners
- Increase the paediatric quota to avoid a paediatric hospital exodus due to heavy on-call service with a significant impact on the quality of life
- Finally recognize the paediatric subspecialties after 25 years and 2 positive advices of the High Council

Nurses

- Mandate the specific paediatric competences in all nurses working with children. Regardless of the kind of care, the kind of disease, the place of care (3rd, 2nd, 1st line of care) and the Federal or Regional level. Without exception.
- Recognise the specific paediatric competences in all nurses working with children (specialised title). Regardless of the kind of care, the kind of disease, the place of care (3rd, 2nd, 1st line of care) and the Federal or Regional level. Without exception.
- Create for all these nurses better incentives on all levels to obtain and hold the correct paediatric competences.
- Recognize nursing paediatric subspecialities.
- Make the portfolio of the nurse transparent for the child, family and other health care professionals.
- Invest in structural child-specific life-long learning on an integral and interprofessional level.
- Make work of a transparent accreditation system on life-long learning in nurses.
- Create incentives for interprofessional collaboration in transmural and integral health care and the care path around the child.
- Involve paediatric nurses and their professional organisations in policy making and advise. Advises that also involve the paediatric patients can only be provided by organisations representing paediatric nurses.

Midwifes, Public Health, Child and youth psychiatrist, paramedics, …

The input of these import child health-care partners should be assessed and taken into account as well.

5.5 Perceived Quality of Care

It is impossible for them to invest in us
if they do not ask us what to invest in!
We know; they should ask!
(a child)

Incorporating the voices of children and parents in healthcare policy decisions is not just a matter of inclusivity; it's fundamental to achieve equality and equity. By actively listening to and involving children and parents in policy decisions, we pave the way for a more responsive and compassionate healthcare system.

- Involve children, patients and parents in a structural manner and encourage active participation.

- Children's Perspective: Ask their perspectives, they are invaluable in understanding the impact of healthcare policies on their well-being, treatment experiences, and access to care. By engaging children in discussions tailored to their understanding, policymakers can gain invaluable insights into crafting more effective, child-centric healthcare policies.

- Implement Rights-based standards for children having health care tests, treatments, examinations or intervention already created by iSupport and a panel of international experts in 2023[88].

- Change the current reporting on health care quality which is concentrated on what's most easily measured and mostly on diseases of adults.

- Transparency on competences of child health professionals for patients and parents.

[88] https://www.isupportchildrensrights.com/

- Access to health related information (age-specific) is crucial to uplift health literacy from early age on.

- An easy accessible centralized reporting point for incidents regarding healthcare-issues related to children.

- The standards for improving Quality of care for children and young persons in health care facilities as already clearly described in 2018 by the WHO[89] .

- Ensure that the Council of Europe guidelines on child-friendly health care (Adopted by the Committee of Ministers on 21 September 2011 at the 1121st meeting of the Ministers' Deputies) 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[90].

- Consider what needs to be measured from the perspectives of young people, policymakers, healthcare practitioners, and programmers, and taking into account the disease burden, opportunity for intervention, drivers of health inequality, and different contexts of various regions. Building on this, the second task will map existing indicators and available data of sufficient quality and coverage against the defined priorities. This process will help define indicators that are aligned with the priority areas but also identify data gaps

- Give all these Quality criteria and Assessments a legal base and implement them in obliged quality measures objectively and externally controlled by the health inspection.

- Evolve to a (for the patient (child and family)) transparent quality label for Child Health care.

- Due to the wide diversity in curative child care, subdivide the population of children and young persons with physical and/or mental health-care problems in:
  - Acute mild to moderately ill child
  - Acute severely ill neonate
  - Acute severely ill child
  - Child with a single long term condition
  - Child with complex and integrated care needs

  with each group having its own developments, health-care gaps, pitfalls and opportunities for improvement.

[89] https://iris.who.int/bitstream/handle/10665/272346/9789241565554-eng.pdf?sequence=1.

[90] Council of Europe guidelines on child-friendly health care (2011): https://rm.coe.int/168046ccef

The well-being of our children and young persons is a shared responsibility

06

The Ultimate Child Guarantee

The Ultimate Child Guarantee

'There is no such thing as a child-neutral policy. Whether intended or not, every policy positively or negatively affects the lives of children[91].'

As previously discussed, all sectors have a role to play in promoting children's health and wellbeing, and the evidence is clear on the need for multisectoral action for children.

However, ministries responsible for different aspects of child wellbeing rarely coordinate well.

Several factors perpetuate this problem. One is national financing arrangements, which are siloed by ministries, a problem compounded by poor impetus for multisectoral coordination in national cabinets.

Interministerial politics, competition for annual budgets, and interpersonal rivalries are further obstacles. Building a structural policy on the integral health of children, young persons and their families needs the cooperation of at least 29 ministers and secretaries of state in Belgium.

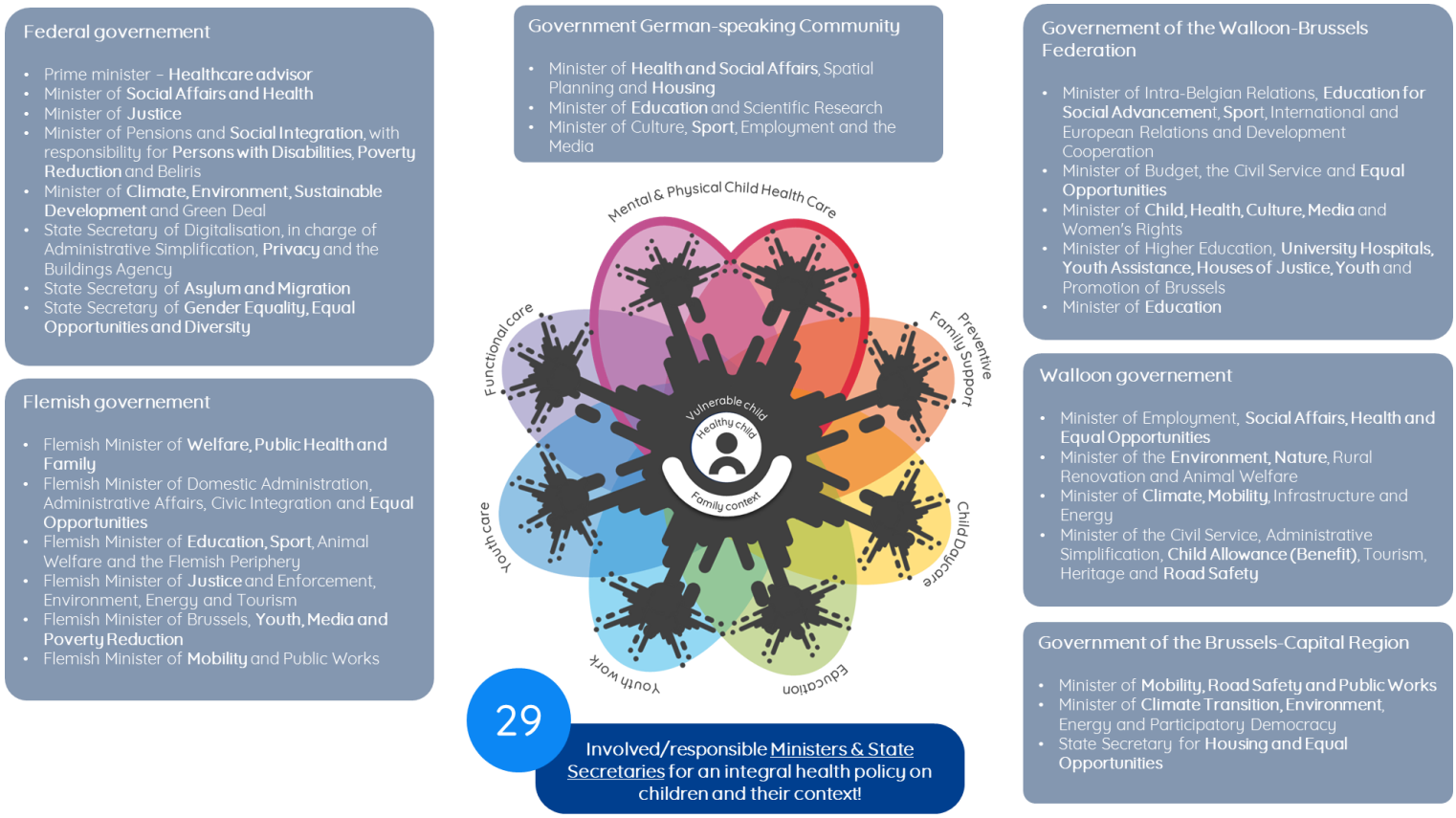


Figure 51: Overview ministers and State secretaries

[91] https://enoc.eu/wp-content/uploads/2020/11/ENOC-2020-Position-Statement-on-CRIA-FV-1.pdf

In comparison, during the CoVID-19 crisis and now on the topic of coordinating the problems on drugs, a National Commissioner was installed to[92]:

- advise the involved ministers on the preparation of a national plan of action;
- coordinate the implementation of the national plan of action;
- put forward policy proposals to strengthen the operational approach;
- make policy recommendations;
- facilitate, promote and optimise cooperation between governments, services and all stakeholders;
- report to all governments, policymakers and stakeholders.

The overall aim of our Plan "Care for the Children and Young Persons" should be the continuous improvement of integral outcomes for children, young people and their family.

As a European example: Scotland installed a national Child Health Commissioner (CHC)[93]. This function is based on their "The Children and Young People (Scotland) Act 2014". It places a requirement on Local Authorities and Health Boards through Children's Services Plans to identify local needs, priorities, and actions, and to develop solutions that address the needs of the children, young people and families they support. This aligns with Scotland's approach to promoting and improving the health and wellbeing of every child through Getting It Right For Every Child (GIRFEC).

All of the above reflects the values in Scotland's National Performance Framework, which aims to ensure all of Scotland's children and young people grow up loved, safe and respected so that they realise their full potential.

The CHC has a senior, professional leadership role in informing and influencing, and to ensure that health priorities are identified, understood and addressed in health service planning and integrated service planning partnerships with NHS Boards, local authorities and key agencies.

The Function of the Scottish Child Health Commissioner (CHC):

- The CHC will advocate both locally and nationally that the rights and interests of children and young people, as detailed in the UN Rights of the Child are recognised, promoted and acted on in the development and implementation of policies, strategies and services.
- The CHC will have a lead role in identifying the health needs of the infant, child and young person population. This will require an understanding of the role of strategic planning, public health, the specialist and non-specialist workforce and the operational resources required to meet this need.
- The CHC will have a lead role in the development and performance monitoring of local and regional child health strategy and improvement plans, ensuring equity of access to services in order to reduce health and social inequalities.

[92] Oprichting van een nationaal drugscommissariaat | News.belgium
[93] https://www.publications.scot.nhs.uk/files/dl-2019-13.pdf

- Advocate for infants, children, young people and their families / carers across Health and Social Care systems and Community Planning Partnerships (CPPs) in relation to children's and adult service provision.
- Advise on and support the application of the Getting it Right for Every Child approach for all infants, children, young people and their families / carers across Health, Social Care systems and Community Planning Partnerships (CPPs) in relation to children's and adult service provision.
- The CHC will make a significant contribution to improving child health outcomes via their specific and unique role as a professional expert advisor to the NHS Board on all aspects of child health, health services and related policy and legislation.
- The CHC will advise on and promote the implementation and scrutiny of the health component parts of the Children and Young People (Scotland) (2014) Act and where required, integrated health and social care models as per the Public Bodies Act (Scotland) 2014.
- The CHC will provide, evidence based/rights informed child centred advice to NHS Boards on relevant policy The CHC will be part of a communication pathway to receive and impart relevant health information/intelligence regarding infants, children and young people across local, regional and national networks. Whist there is variation across all NHS Boards in relation to the role and function, job designation and description, it is vital that the CHC is fully supported within their local Health Board and wider systems and has access to appropriate resources to effectively undertake their role and responsibilities; including participation in the National Child Health Commissioners Group (NCHCG) to inform and recommend on national policy.

A number of priorities for the CHC have been identified including:

- Improving outcomes for infants, children and young people with experiences that may compromise their chances across the life course
- Improving outcomes for Care Experienced Children and Young People.
- Driving improvement in transition, including to adult services, for children with disability, complex needs, mental health needs and/or long term medical conditions
- Horizon scanning: the CHCs will identify emerging risks or other issues, utilising local, regional and national contacts to plan, intervene and mitigate where possible
- Involvement in performance reviews of children and young people's services, including recommendations to address unwarranted variation.
- Contribution to key challenges such as child poverty, mental health and wellbeing and the development of trauma informed culture and practice across systems and services for infants, children and young people and their families.

Even when policies are coherent, they are rarely backed up by funded implementation plans. So we need someone with a long-term vision and a plan.

Therefore, the ultimate child guarantee is a 'Minister' of Children in Belgium based on the examples of our National Commissioner on CoVID-19 and drugs and certainly based on the Scottish example of the Child Health Commissioner.

A person politically installed but who:

- is neutral and does not belong to a political party and/or organisation politically connected;
- has huge experiences and competences in the care for children and young people;
- always starts from a child and family centred point of view (UNCRC);
- has the talent and ability to use a helicopter view on all sectors involving children and young people;
- has the competences of positive leadership by connecting, listening, working from a constructive and pro-active vision, … between all stakeholders and children, young people and their families;

The SDGs provide an opportunity and key strategies are available to support improved multisectoral governance and execute the political push to move forward on a child-centred SDG agenda. Specifically, executive pressure must bring the sectors together!

- A person who gives clear roles and responsibilities to each sector, with clear accountabilities and indicators;
- A person who ensures financing from a coordinating source to be used as incentive and facilitator;
- A person who urges cross-cutting ministries (such as ministries of finance, social welfare,…) to validate, coordinate, and share data.
- A person who prioritizes general child health objectives that are applicable and implementable across various policy domains (Belgian, Flemish, provincial, communal)
- A person who ameliorates fragmented national governance with a powerful new framing around children's rights and the Sustainable Development Goals
- A person with pro-child political commitment at executive level to coordinate and harness coalitions across sectors to overcome ecological and commercial pressures to ensure children receive their rights and entitlements now and a liveable planet in the years to come.

Figure 52: Minister of the child

To reach the Ultimate goal of a Minister of the Child different short term quick wins should already start based on:

- the European Child Guarantee (2021);
- the Council of Europe guidelines on child-friendly health care (2011);
- the 10 recommendations arising from this Plan.

10 Recommendations

Base all decisions on children's rights, including within healthcare (EACH charter). Review the Patient Rights Act!

Give children, young people, and parents (foster parents, guardians, caregivers, etc.) a structural voice in determining healthcare policies (children's council, etc.).

Invest significantly more in all forms of prevention and prioritize prevention on the political agenda.

Establish an annual Child Report for Belgium, containing all relevant data on children's health, growth, development and disease (determine this data and all relevant health determinants for children in collaboration with an expert group).

Provide short-term incentives for intersectoral collaboration and connection.

Ensure a guarantee of quality care for the child through adequate (interprofessional) training on healthy, vulnerable, and sick children, as well as through mandatory child-specific competencies and lifelong learning. Consult children and experts for this. Make these competencies transparent and clearly visible to children, parents and health-care professionals.

Acknowledge that (chronically) ill children, children who have a difficult start (such as prematurity) and/or grow up in poverty, are extra vulnerable. Focus on vulnerable children!

Value the professionals involved in child healthcare, no longer considering them as an inconvenient appendix to adult care.

Establish as soon as possible a structural, Inter-federal expert group and give them a mandate for:

- Drafting a new care program for paediatrics.
- Developing a proposal for more preventive and integrated care involving ONE-K&G-Kaleido doctors, CLB and PSE doctors, general practitioners, paediatricians, child- and youth psychiatrists, paediatric nurses, paramedics, etc.

Appoint a National Minister for/of the child with coordinating and overarching powers.

”

The question is not
whether we can afford
to invest in every child;
it is whether
we can afford not to!

Marian Wright Edelman

07

Road to a new Paediatric Health Care

Kick of templates

EACH-CHARTER

JOY-Platform

Symbolically, almost 10 years after the proposal and rejection of the New Paediatric Care Program in 2014, the Belgian Academy of Paediatrics wishes to prioritize a constructive discussion with the government, starting with a proposal for a new paediatric care program based on the various subpopulations of children.

Former Paediatric Care programs failed since perspectives of professionals or healthcare institutions often end in financial and domain-discussions instead of the provision of qualitative care.

Centralizing the paediatric patient in all its aspect, with core principles as equity, equality and children's rights for all paediatric patients (summarized in the EACH-charter) has led to this paediatric health care program which is open for discussion with all relevant stakeholders.

The subpopulations of Healthy Child and Vulnerable Child require children and parents, as well as a very broad expert panel with expertise on all petals of the flower.

Therefore Kick-off template 1 and 2 are not available at this moment since by recommendation 9 we urge the government to establish a structural, interfederal expert group and empower them to work on a proposal for more integrated care involving general practitioners, CLB and PSE doctors, ONE-K&G doctors, paediatricians, child-an youth psychiatrists, paediatric nurses, midwifes, teachers, youth-workers, … .

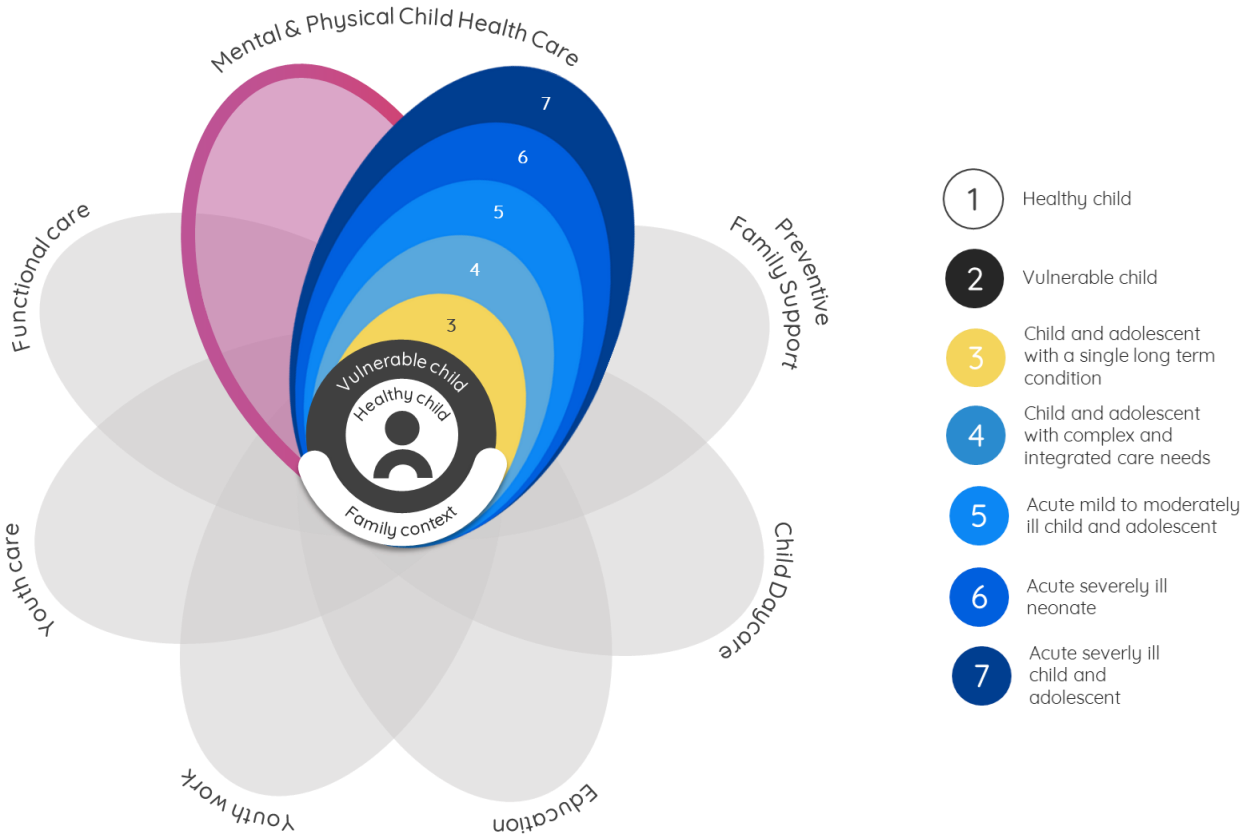


Figure 53: Subpopulations in Medical Childcare

Figure 54: Items per subpopulation

Kick off templates

7.1 Kick off templates

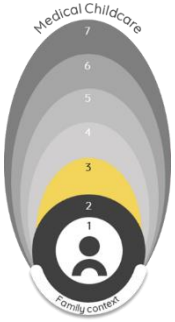
Anyone can make something simple complicated. Making something complicated simple, that's creativity.

The full version of these Kick-off templates are available upon request through info@baop.be .

This is part of our Strategy to challenge the government in recognizing expertise and engaging in establishing an inter-federal working group of experts on the Paediatric Care Program, as described in Recommendation 9.

Norms and legal criteria fall outside the scope of this document.

In all Kick-off templates an increased inclusion of mental health problems in children is mandatory and expertise of child-and youth psychiatrist is needed in the proposed working-group.



3 Child and adolescent with a single long-term condition

Cumulative to 1 2 5 6 7

Non-exhaustive summary. Full detailed kick-off document available at the BAOP on demand.

- birth till 18y old
- condition is not time-limited and requires (multidisciplinary) follow-up
- adequate follow-up/monitoring leads to improved health outcomes
- Inadequate follow-up leads to long-term complications (expressed in DALYs)
- prevalence of the condition(s) can be common or rare (<1/2000).

- Medical health care professionals al competences for Healthy and Vulnerable child and resumed in Appendix 1, 2, 3, 4.
- Interprofessional education on mental health in children and adolescents
- Training in trauma-sensitive paediatric care and PROSA
- Clear competency profile for nurses and other healthcare professionals
- Competences for appropriate care TEAM (inpatient and outpatient)
- Entrusted Professional Activities and continuous learning

- General paediatricians
- Adolescents and young adults
- Parents (family context)
- Child- and adolescent psychiatrist
- Subspecialized paediatricians
- Other medical specialists
- Dietician
- Paediatric nurses
- Specialized Paediatric Surgeon
- Other: Psychologist, physiotherapist, speech therapist, occupational therapist, pharmacists, ...

- More time compared to caring for adults.
- Appropriate medical, social, ethical and rights based competencies to provide adequate care to support children's and adolescents' survival and development.
- Adhere to evidence-based guidelines
- Continuous professional training
- Pre-and postgraduate education for all healthcare workers is strengthened

General (in-and outpatient, transmural care)

- Staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.
- Specific professional paediatric training, skills and sensitivity to meet the special needs of children and their parents.
- Children are examined, treated and cared for by staff with specific paediatric education, qualifications and experience.
- Appropriate training and continuing education.
- Vulnerable children: child protection training and be competent to recognise the signs of child abuse or neglect, and be able to intervene in close cooperation and collaboration
- The intramural presence of Medical Educational Care Providers obligatory.

General
- EACH charter for all sick children
- Informed participation in all decisions involving their health care.
- Protection from unnecessary medical treatment and investigation.
- Informed appropriate to age and understanding.
- Mitigation physical and emotional stress.
- National clinical guidelines to prevent unwarranted clinical variation and need to be provided by funding scientific paediatric health care societies / need to be followed
- Embedded in Electronic patient record.
- International, uniform classification system
- IT support 24/7
- Module Vulnerable Child can be started immediately
- Acces to appropriate and confidential health advice and counselling.
- Sufficient and timely access to laboratory support.
- Rapid availability of results
- Laboratories utilize machines suitable for small volumes.
- Emphasis is placed on minimizing radiation exposure.
- Network agreements.

Outpatient
- Coordination and is responsibility for the 'Healthy Child' module (transparent Care Plan)
- Obligatory Registry
- Appropriate age-dependent healthy child visit (prevention)
- Vulnerable Child (check during every consultation visit!): Module Vulnerable Child
- Tele- Medicine
- 1733 special paediatric number for triage

Inpatient
- Special clinics or times allocated for seeing children with chronic conditions that do not overlap with those for children with acute problems.
- Policy on Paediatric Surgical care, children with developmental difficulties and young persons

Quality criteria
- In general, focus on outcomes in five domains:
  - Management of the 'condition' and improved health outcomes
  - Patient safety
  - Activity and patient flow
  - Patient and parent/carer experience
  - Staff experience
- Specific pathology transcending and disease based indicators for monitoring the quality of routine clinical paediatric care Government funded paediatric working-group in INAMI/RIZIV cell of Appropriate Care
- Communication with parents and the child

Quality assessment
- Specific quality assessment tools in primary, secundary and tertiary care
- Harmonisation of key indicators embedded within existing assessment tools
- Paediatric PREM/NREM/PhREM
- General and Specific Paediatric PROM based on international literature
- Specific attention to surgery
- PROSA policy

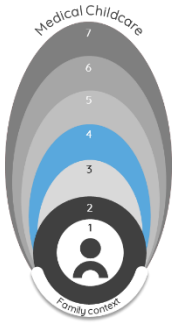
Quality Measures
- Specific Paediatric quality measures in primary, secundary and tertiary care
- Policy on Unnecessary procedures, treatment, other harmful practices and admissions
- Policy on medication prescription, use and errors
- Specific attention on notifications of (near) incidents that affects general and specific paediatric outcomes

General (in-and outpatient)
- Implementing EACH charter

Out-patient
- Creation, promotion of trustable self-triage websites
- Specific child triage telephone number (cfr 1733)
- Minimum paediatric materials

In-patient
- Day-Clinic and temporary hospitalisation ward fully adapted to the needs of moderately sick children with specific premises
- Accessible to wheelchair users.
- A parent or accompanying person must be able to stay in the room with their child and involved in the care.
- The size, number and nature of the facility, equipment and materials are appropriate to specific needs of all children.
- Minimum paediatric materials

Hospitalisation
- Cumulative with outpatient care and a day care unit.
- Nursing ward fully adapted to the needs of sick children and including specific premises
- Children are grouped as much as possible according to their age.
- The play and educational room is in use 24/7h and specific equipped.
- Accessible to wheelchair users.
- Special attention to Adolescents.



4 Child and adolescent with integrated and complex care needs

Cumulative to 1 2 3 6 7

Non-exhaustive summary. Full detailed kick-off document available at the BAOP on demand.

- From birth till 18y old
- The condition (usually > 1) not time-limited and requires follow-up at regular intervals
- Definition based on literature review by Brenner et all. Frontiers Dec 2021
- Inadequate follow-up leads to long-term complications (expressed in DALYs)
- Prevalence of the condition(s) can be common or rare (<1/2000)
- Complexity is also often determined by the psychosocial context, language and culture barriers, etc.

General
- Integrated EACH charter
- The Module Vulnerable Child is always applicable
- Network agreements are in place when Module Acute Severely Ill Child needs to be activated
- A written tailor-made integrated care pathway and Advanced Care Planning
- Conventions based on individual complexity, goals and needs

Outpatient
- Module Child with a single long term condition
- Contacts with children with complex care needs are time-consuming and should be honoured according to time-investment
- Complex but schedulable care should be planned/coordinated as efficient as possible for patients/parents Telemedicine (with GP's), digital triage tool
- Integration Vulnerable Child Module

Inpatient
- Minors between 15 and 18 years must be given the choice
- All necessary treatment options at one single site.
- Registry/Data Collection is necessary
- Paediatric palliative care
- Paediatric Surgical care
- Rare diseases
- Children with developmental difficulties
- Young persons

- MD: Healthy and Vulnerable child; Appendix 1, 2, 3 and 6
- Interprofessional education: mental health in children and young persons
- Essential topics according to the International Classification of Functioning, Disability and Health
- Competency of Rare and Undiagnosed Diseases
- Competences autonomous decision-making
- Training in trauma-sensitive paediatric care and PROSA
- Nurses and other healthcare professionals: clear competency profile
- All (paediatric) health-care workers: a shift to EPA's and continuous learning
- Competences for appropriate care TEAM (inpatient and outpatient)

- Parents
- Child- and adolescent psychiatrist
- Children and young persons
- Paediatricians, paediatric nurses, midwifes
- General practitioners, emergency medicine professionals
- Rehabilitation physician
- Specialized Paediatric Surgeon
- Medical educational/pedagogic care provider
- ...

Quality criteria
- Different models of care from the traditional episodic reactive health service of the past
- Quality criteria should be determined by a team of experts (both parameters pathology-specific and pathology-transcending, as well as PREMs and PROMs).
- These data should be registered in a pathology-specific as well as a pathology-transcendent registry
- Quality criteria for a specialized Complex and/or Multidisciplinary Paediatric Care Department need to be listed by a team of experts
- Special indicator set are needed for children with complex care needs

Quality assessment
- Specific quality assessment tools in primary, secundary and tertiary care
- Paediatric PREM/NREM/PhREM
- General and Specific Paediatric PROM based on international literature
- Key indicators: pathology-transcending; pathology-specific; rare diseases, young persons
- PROSA policy
- Outpatient and inpatient policy and assessments

Quality Measures
- Specific Paediatric quality measures in primary, secundary and tertiary care
- Policy on Unnecessary procedures, treatment, other harmful practices and admissions
- Policy on medication prescription, use and errors
- Specific attention on notifications of (near) incidents that affects general and specific paediatric outcomes

- Time based care organisation and financing
- Physical, emotional and developmental Child & Family centered care
- All healthcare lines: specific paediatric education, qualifications and experience, competent to recognise the signs of child vulnerability, abuse or neglect
- Non-exhaustive list of possible paediatric subspecialties High level ability and sensitivity: appropriate training and continuing education.
- Human resources for the specialized Complex and/or Multidisciplinary Paediatric Care Department
- Intramural presence of Medical Educational/Pedagogical Care Providers: elimination of stress and anxiety & prevention of trauma during medical procedures and hospital admission (counselling, preparing, supervising, distraction)

General
- Play, recreation and education even in case of a communicable disease
- Total child friendly infrastructure
- a multidisciplinary paediatric outpatient department
- a department for complex and/or multidisciplinary paediatric care
- a multidisciplinary paediatric day hospitalization department
- General and pathology-specific equipment
- The coordinating physician will decide according to the condition, context and circumstances for:
  - Inpatient care with all requirements for admission of a mild to moderately ill child
  - Inpatient care with all requirements for admission of an acute severely ill child
  - Inpatient care with all requirements for complex and integrated care needs
- This latter centre has:
  - a recognized Paediatric Intensive Care Unit
  - a recognised specialist paediatric haemato-oncology care programme
  - a centre for human genetics
  - a recognised paediatric cardiac pathology care programme
  - a recognised medical service transplant centre.
  - for the diagnosis and treatment of children with 'renal insufficiency'

5 Acutely mild to moderately unwell child

Non-exhaustive summary. Full detailed kick-off document available at the BAOP on demand.

Cumulative to

1 2 6

- From birth till 18y old
- Time-limited & no or time-restricted follow-up
- Can initiate a long-term condition (Module Single long term condition or Complex Care Needs)
- Could result in/follow upon an acute severe condition(Module Acute severely ill child)
- Integral part of Healthy Child and Vulnerable child

- MD: Appendix 1, 2 and 3
- Interprofessional education: mental health in children and young persons
- Competences autonomous decision-making
- Training in trauma-sensitive paediatric care and PROSA
- Nurses and other healthcare professionals: clear competency profile
- All (paediatric) health-care workers: a shift to EPA's and continuous learning
- Additional in- and outpatient skills

- Parents
- Child- and adolescent psychiatrist
- Children and young persons
- Paediatricians, paediatric nurses, midwifes
- General practitioners, emergency medicine professionals
- Medical educational/pedagogic care provider
- ...

- Time based care organisation and financing
- Physical, emotional and developmental Child & Family centred care
- All healthcare lines: specific paediatric education, qualifications and experience, competent to recognise the signs of child abuse or neglect
- Cooperation with, and supervision of, staff who are specially trained and qualified to care for children.
- High level ability and sensitivity: appropriate training and continuing education.
- Trained and competent to recognise and collaborate when signs of child abuse or neglect Competences WHO and Unicef).
- Intramural presence of Medical Educational/Pedagogical Care Providers: elimination of stress and anxiety & prevention of trauma during medical procedures and hospital admission (counselling, preparing, supervising, distraction)

General
- Integrated EACH charter
- ICD-10CM or the international SNOMED-CT classification system, HAT guidelines
- Appropriate managerial leadership with a special focus on children and young persons

Outpatient
- Age-dependent healthy child visit (prevention)
- Regional agreements on who takes care of the 'Healthy Child' module
- Telemedicine (with GP's), digital triage tool
- Integration Vulnerable Child Module
- Automated and financed data-based registry
- Network agreements on Module 'Acute severely ill child'
- National clinical guidelines prevent unwarranted clinical variation and need to be provided/ followed (WHO? funding scientific societies?)
- Communicating vessels Emergency – Private Paediatric consultation – GP: local initiatives are mapped and data are registered
- Parent education initiatives locally (by GP and Paediatricians)

Outpatient
- EACH charter
- Between 15 and 18y: given the choice

Quality criteria
- In general, focus on outcomes in five domains:
  - Management of the 'condition' and improved health outcomes
  - Patient safety
  - Activity and patient flow
  - Patient and parent/carer experience
  - Staff experience
- Specific disease based indicators for monitoring the quality of routine clinical paediatric care Government funded paediatric working-group in INAMI/RIZIV cell of Appropriate Care
- Outpatient: Non-exhaustive list of indicators for monitoring the quality of routine clinical paediatric care
- Inpatient: At least 75% percent of the paediatric nursing staff is trained pre-service as paediatric nurse

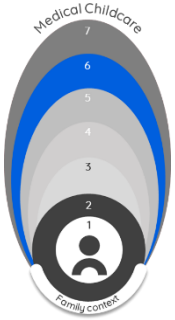
Quality assessment
- Specific quality assessment tools in primary, secundary and tertiary care
- Paediatric PREM/NREM/PhREM
- General and Specific Paediatric PROM based on international literature
- Specific attention to surgery
- PROSA policy
- Outpatient and inpatient policy and assessments

Quality Measures
- Specific Paediatric quality measures in primary, secundary and tertiary care
- Policy on Unnecessary procedures, treatment, other harmful practices and admissions
- Policy on medication prescription, use and errors
- Specific attention on notifications of (near) incidents that affects general and specific paediatric outcomes

General
- Play, recreation and education even in case of a communicable disease
- Total child friendly infrastructure
- Disinfectable and washable by established procedure.

Out-patient
- trustable self-triage websites for children and young persons
- Specific child triage telephone number
- Presence of minimal paediatric materials (medical, educational, stress-fear relieve)

In-patient
- Day-Clinic and temporary hospitalisation ward
- Hospitalisation
- Special attention to adolescents



6 Acute severely ill neonate

Non-exhaustive summary. Full detailed Kick-off document available at the BAOP on demand.

Cumulative to

1 2 3 4 5

Infants less than 28 days. The approach of infants and children aged 28 days to 18 years see: 'the acute severely ill child and adolescent'.

- 1st hour Care
- N*
- Neonatal Intensive Care (NICU)

- Based on European Requirements for Training in Neonatology.
- shift to using EPA (Entrusted Professional Activities)
- See Appendix 7

- Parents
- General practitioners
- Paediatricians
- Neonatologists
- Gynaecologists-obstetricians
- Midwives
- Paediatric nurses
- Psychologists
- Neurodevelopmental specialists
- Physiotherapists
- Surgeons (general, cardiac, neuro- and other)
- ...

Belgium needs new ideas and solutions to address the disparities in the care of preterm and ill babies.

- EACH-Charter all sick children
- Belgium needs new ideas and solutions to address the disparities in the care of preterm and ill babies.
- The European Standards of Care for Newborn Health project presents such a solution
- Architecture standards: reference: Report of the Ninth Consensus Conference on Newborn ICU Design, Clearwater Beach, Florida (March 5, 2019)
- Organisational standards, infrastructure, equipment and human resources, as well quality criteria and quality assessment should be built upon proposed standards combined with the recommendations provided by the KCE Report : Infant- and family-centred developmental care for preterm newborns in neonatal care.
- ...

7 Acute severely ill child and adolescent

Non-exhaustive summary. Full detailed Kick-off document available at the BAOP on demand.

Cumulative to 1 2 3 4 5

Infants and children aged 28 days to 18 years.
The approach of infants less than 28 days see: 'the acute severely ill neonate'.

- 1st hour Care and Emergency department
- Intermediate Care
- Paediatric Intensive Care (PICU)

- Entrusted Professional Activities
- Life-long learning
- 1st hour Care and Emergency department
- Intermediate Care
- Paediatric Intensive Care (PICU)

- Parents
- Child- and adolescent psychiatrist
- Children and young persons
- Paediatricians, paediatric nurses
- General practitioners, emergency medicine professionals
- Medical educational/pedagogic care provider
- Paediatric subspecialist
- Paediatric surgeons
- ...

- Caring for children demands more time compared to caring for adults.
- Every physician: trained in ACEs and trauma-sensitive care.
- 1st hour Care
- Intermediate paediatric care department
- Paediatric Intensive Care Unit
- Coordinating physician: trained in ACEs and trauma-sensitive care.
- Specific medical leadership of a 'paediatric intensive care'
- Specific medical team
- Specific nursing leadership of a 'paediatric intensive care'
- Specific Nursing team
- Involved paramedical professionals

- EACH-Charter all sick children
- Only in-patient (intrahospital) care / 1st hour paediatric care can be done on MUG intervention and Emergency admission (meeting the standards)
- Network agreements and clear cooperation between centres offering emergency paediatric care (1st hour care), Intermediate Care (P*) and PICU
- Arrangements according to patient- transport
- Organisation of regular, affordable nationally or internationally certified training and refresher courses for all paediatric staff .
- At all levels: uniform PROSA and all principles of trauma sensitive care.
- Paediatrics network that offers at least the care circuits : severe trauma; acute renal failure; acute liver failure; cardiorespiratory failure; intracranial hypertension.
- Telephone advisory function for paediatric emergencies;
- 1st hour care
  - 112 emergency call centre with specialized training for operators (HC112/100) and call-takers (CIC101) focusing on child-related emergencies.
  - All medical doctors and nurses employed in the emergency ward possess the aforementioned competencies
  - Protocol for transfusions in children.
  - 24/7 paediatric ultrasound with a immediate protocol available
- Intermediate acute care unit
  - Staffing ratio: 1 nurse per 3 IAC patients.
  - Central monitoring for beds.
  - 24/7 staffing for these beds.
- PICU:
  - Similar services as the Intermediate Care Unit
  - Offers diagnostic and treatment options for children with kidney failure.
  - Ensures urgent medical intra-hospital transport for critically ill children
  - A paediatric intensive care physician is available within 20 minutes to join the transport team.
  - Guidelines for urgent medical transport of critically ill children
  - All data recorded in a register maintained by the hospital
  - Paediatric Intensive Care services collaborate on an electronic system to track admission capacity in real-time.
  - Surgery-specific

Quality criteria & assessment

- Appropriate Qis for PICU
- Specific disease based indicators for monitoring the quality of 1st hour care, high dependency unit and PICU
- Specific criteria for transports
- Specific criteria for death of a child
- Specific surgery criteria

- Specific quality assessment tools in tertiary care of 1st hour care, high dependency unit and PICU
- Specific Paediatric PROM based on international literature
- Specific attention to surgery
- PROSA policy

- Specific Paediatric quality measures in tertiary care of 1st hour care, high dependency unit and PICU
- PICU data collection
- Specific attention on notifications of (near) incidents that affects specific paediatric outcomes

1st hour Care

- Specifics on emergency department
- Separate paediatric units equipped with paediatric resuscitation carts.
- Child-friendly environment/design
- Specifics on Equipment

Intermediate acute care

- At least 2 individual rooms/positions should be available in a paediatric hospitalization unit and/or emergency department (NOT in adult Intensive Care!)
- provisional hospitalization for critically ill patients whenever necessary.
- Parent or caregiver to stay near the child and sleep nearby, off the ward
- Each position: intensive monitoring and medical care materials
- A program for systematic technical supervision
- Specifics on Equipment

PICU

- At least 9 individual rooms/positions within a completely separate unit, with the capacity to an additional 3 beds
- At least 2 rooms positive/negative pressure systems
- Parent or caregiver to stay near the child and sleep nearby, off the ward
- Each position must be equipped with all necessary intensive monitoring and medical care materials, including the capability for artificial ventilation.
- A program for systematic technical supervision of all equipment
- Minimal PICU equipment for every room for admitting patients

EACH-CHARTER & JOY-Platform

7.2 EACH-CHARTER

What does the world look like if we put the best interests of the child first? In every decision that affects children? Where we make an effort to hear the opinion of children themselves? Without distinction of status or origin?

Children's rights are the fundament of child-, family- and development centred qualitive healthcare from policy making to daily organisation and care.

The European Association for Children in Hospital[94] (EACH) is an international umbrella organisation for the welfare of children in hospital and other healthcare services. Belgium is not represented in this organisation.

In 1988, EACH wrote a Charter (EACH-Charter) of 10 points on the rights of sick children and their families before, during and after a stay in hospital and in other healthcare services. The 10 rights in the Charter apply to all sick children, regardless of their illness, age, disability, origin, social and cultural background, reason, form or place of treatment, or whether they are in-patients or out-patients.

The 10 principles of the EACH-Charter and its annotations are connected to the UNCRC. They do not replace the UNCRC but are an addition due to the extra vulnerability of children and their family when being 'sick' and having need of health care. The 10 principles don't have any legal bounding but should be seen as an intention and the fundaments of child- and family centred care in health care.

We believe that children's rights are the fundament of child-, family- and development centred qualitive healthcare from policy making to daily organisation and care.

As Belgium is not represented in EACH, the EACH-Charter is not known in many patient organisations, policy makers and politicians meaning a smaller voice of children and their family in healthcare and the absence of one structured child centred voice.

Trained intramural paediatric healthcare workers like paediatricians and paediatric nurses are well known with the EACH-Charter. Implemented in their daily work and competences.

[94] https://each-for-sick-children.org/

Nevertheless, the knowledge and implementation of this Charter and the important rights of children in healthcare is limited to the ‘gates’ of hospitals and paediatric chronic care centres. There is no knowledge and implementation in first line and community care with an impact on how healthcare for children is organised. Caring for children and guarantee qualitive an safe paediatric healthcare cannot be done without placing the children’s rights in the centre.

Meaningful and broad implementation of children's rights in prevention, support and health care for children requires actions by all stakeholders on micro, meso and macro level. Government, administrators, managers, professionals and researchers.

However broadening of the EACH-Charter and its annotations for Belgium, making it future proof and inclusive for all future challenges on the health of children might be necessary.

7.3 JOY-Platform

A positive balance with a focus on the rights, health, well-being and development of all children and young people in Belgium.

What?

The JOY platform was launched in 2020 as an initiative of the Belgian Paediatric CoVID-19 Task Force with the support of the National Commission on the Rights of the Child, a consultation platform between more than 90 governmental and non-governmental actors on children's rights in Belgium, and Le Délégué Général aux Droits de l'Enfant with the support of the King Baudouin Foundation and Unicef Belgium.

During the CoVID-19 period, the Belgian Paediatric CoVID-19 Task Force represented experts from the medical paediatric domain, from paediatricians, child and adolescent psychiatrists to paediatric nurses, under the umbrella of their respective professional organisations.

Currently, the JOY platform belongs to the Belgian Academy of Paediatrics and partners.

Logo

JOY is the English word for 'joy and happiness'. It's easy, recognizable, hip, short, powerful and it brings 'joie de vivre'. In addition, it is language, gender, and age-neutral. The JOY logo symbolizes all developmental domains of children and young people in a cheerful and positive way. The rainbow colours emphasise the diversity and involvement of ALL children and young people in Belgium.
By using this logo and providing a JOY logo for individual organizations and sectors, we want to make JOY widely visible in society as a constant reminder to put children and young people first at all times.

Goal

Because children and young people are our future!

With JOY, we want to offer a positive counterbalance by focusing on the importance and benefits for children and young people of an adequate development, in all its aspects, of this target group in their growth towards the healthiest and happier adulthood possible.

This requires not only that children and young people are given a face and a voice in policy, but also that fear and uncertainty in society and within the professional framework are reduced and, if possible, eliminated.

Professional cooperation and the joining of forces of all agencies that care and work with children is a crucial condition for this.

The aim is to set up a long-term connecting platform and raise awareness to put and keep the rights and well-being of children at the heart of every decision at every level in a sustainable way. The JOY-Platform is a reaching out and connection from the Medical Childcare to all other sectors and professionals around children.

Subgoals

Advise
As a group of experts from the medical field concerning children and young people, we are best placed to translate rapidly changing, up-to-date scientific insights about children and health into objective and understandable information.
This is necessary for policymakers in their elaboration of decisions and scenarios, so that the well-being and development of children and young people always remains central.

Inform
Scientific knowledge provides more insight into the 'why' behind certain decisions and measures that are sometimes different in children and young persons than in adults. Understanding this 'why' is an important first step in removing fear and insecurities.

Balance
With scientific information and tools, you are in a stronger position and you can better maintain the balance between your private and professional life.

Connect

Standing up for all children and young people in Belgium means transcending one's own walls and entering into real cooperation in which these children and young people are central at all times. Based on this overarching goal, JOY wants to connect all existing and valuable initiatives concerning children and young people in the different regions and domains. In this way, the loopholes can be closed as much as possible and every child and young person in Belgium really counts.

Empowerment

Correct information provides tools and points of support to be able to respond to questions and concerns. The right information gives you more power in controlling emotions and insecurities; and distinguishing erroneous information.

www.joy-platform.be

There can be no keener revelation of a society's soul then the way in which it treats it's children.

Nelson Mandela

08

Appendixes

Appendixes

Grades of Competence:

1. Knowledge

1.1 knows basic concept
1.2 knows general
1.3 knows specifically and broadly

2. Clinical Skills

2.1. Has observed – the trainee acts as an 'Assistant'. From complete novice through to being a competent assistant.

At end of level 1 the trainee:

2.2. Has adequate knowledge of the steps through direct observation.

2.3. Demonstrates that he/she can handle the apparatus relevant to the procedure appropriately and safely.

2.4. Can perform some parts of the procedure with reasonable fluency

2.5. Can do with assistance - a trainee is able to carry out the procedure 'Directly Supervised'. From being able to carry out parts of the procedure under direct supervision, through to being able to complete the whole procedure under lesser degrees of direct supervision (e.g. trainer immediately available).

At the end of level 2 the trainee

2.6. Knows all the steps - and the reasons that lie behind the methodology.

2.7. Can carry out a straightforward procedure fluently from start to finish

2.8. Knows and demonstrates when to call for assistance/advice from the supervisor (knows personal limitations).

2.9. Can do the whole procedure but may need assistance – a trainee is able to do the procedure 'indirectly supervised'. From being able to carry out the whole procedure under direct supervision (trainer immediately available) through to being able to carry out the whole procedure without direct supervision i.e. trainer available but not in direct contact with the trainee.

At the end of level 3 the trainee

2.10. Can adapt to well-known variations in the procedure encountered, without direct input from the trainer.

2.11. Recognizes and makes a correct assessment of common problems that are encountered.

2.12. Is able to deal with most of the common problems.

2.13. Knows and demonstrates when he/she needs help.

2.14. Requires advice rather than help that requires the trainer to intervene

2.15. Competent to do without assistance, including complications. The trainee can deal with the majority of procedures, problems and complications, but may need occasional help or advice.

2.16. Can be trusted to carry out the procedure, independently, without assistance or need for advice. This concept would constitute one Entrusted Professional Activity (EPA). An EPA is 'a critical part of professional work that can be identified as a unit to be entrusted to a trainee once sufficient competence has been reached'. This would indicate whether one could trust the individual to perform the job and not whether he is just competent to do it.

At the end of level 4 the trainee:

2.17. Can deal with straightforward and difficult cases to a satisfactory level and without the requirement for external input to the level at which one would expect a consultant to function.

2.18. Is capable of instructing and supervising trainees.

3. Technical Skills

3.1. Has observed.

3.2. Can do with assistance.

3.3. Can do whole but may need assistance.

3.4. Competent to do without assistance, including complications, but may need advice or help.

3.5. Can be trusted to carry out the procedure, independently, without assistance or need for advice (EPA). EPAs have been explained previously.

Appendix 1

Competences for screening and monitoring the healthy child

GENERAL COMPETENCES

Communication and interpersonal skills :

Good communication is a core clinical skill, utilizing effective listening and nonverbal cues:
Establish a positive therapeutic relationship with children/adolescents and their families in an age appropriate manner. This relates to involving and empowering the patient/parents in the care, and delivering patient- and family-centred care.
Respect patient confidentiality, privacy, autonomy and ability to consent.
Communicate relevant understandable information and provide support in a crisis situation.
Elicit and draw together relevant information and perspectives of children, families, colleagues and other professionals/caregivers; taking into account factors such as age, gender, disability, ethno-cultural background, social support and emotional influences, and appropriately respecting the child and family's different value systems.
Develop a common understanding on issues, problems and plans with patients, families, and other professionals to develop a shared plan of care.
Convey effective oral and written information about a medical encounter, both to families and to other professionals.

Ethics and professionalism

Display:
Compassion, integrity, and respect for others
Sensitivity and responsiveness to a diverse patient population, including diversity in gender, age, culture, race, religion, and disability
Responsiveness to situations where the wellbeing of the child is endangered/compromised
Accountability to patients, society and the profession
Compliance with all legal and moral obligations for reporting disease and potential or real abuse/neglect
Recognition of special Issues pertaining to children participating in research

Understand the roles and responsibilities:

- In the safeguarding of babies, children and adolescents
- To support and enable parents and carers to be effective in caring for their children
- To know where and when to ask for help and support
- To follow the principle that all decisions are to be made in the best interest of the child

Use the generic competencies (knowledge, skills, behaviour) that relate to clinical practice:

- History taking, clinical examination, effective skills in paediatric assessment
- Clear record-keeping and report-writing
- Effective responses to challenge, complexity and stress in paediatrics.

To maintain Good Medical Practice:

Ensure to be up-to-date, conform with highest standards of practice, and promote evidence-based medicine where possible. Active participation in the scientific meetings organized by the main Belgian/European societies of Public Child and Adolescent Health as well as Paediatrics is therefore strongly encouraged.
Knowledge of the science-base for paediatrics.
An understanding of growth, development, health and well-being in paediatrics.
An understanding of health promotion and public health issues in paediatrics.
An understanding of an evidence-based approach to paediatric practice.
A reflective approach to improvement of equality and diversity in paediatric practice.
Knowledge of the law regarding paediatric practice.
To promote teaching, training, assessing and appraising

To achieve good relationships with patients and their parents:
Effectively communicate with children, young people and their families.
Understand and apply effective communication and interpersonal skills with children of all ages.
Manifest empathy and sensitivity and skills in engaging the trust, consent and involvement from children and their families.
Understanding of listening skills and basic skills in giving information and advice to young people and their families.
Respect the religious beliefs and behaviours of foreign children and families.

To be able to work with colleagues as a multidisciplinary team with:
Effective communication and interpersonal skills with colleagues.
Professional respect for the contribution of colleagues in a range of roles in paediatric practice.
Effective time management skills.
Effective handover, referral and discharge procedures in paediatrics.
An understanding of the effects of local, national and international policies on their work and on the health of children.

Probity:
Respect the high standards of care and professional behaviour within paediatrics and the medical profession as a whole:
Ethical personal and professional practice in providing safe clinical care.
Reliability and responsibility in ensuring their accessibility to colleagues and patients and their families.
An understanding of the importance of self-awareness and a responsible approach to personal health, stress and well-being.

Leadership, management skills and a commitment to lifelong learning
Effectively delegate and follow-up on tasks, be able to manage stressful situations and know when to ask for help.
Deliver the highest quality of care.
Manage tasks including prioritizing, and assigning
Maintain comprehensive, timely, and legible medical and hospital records and legal documents.
Make a lifelong commitment to learning by accepting responsibility for developing, implementing and monitoring a personal continuing education strategy.
Be able to search for evidence and review medical literature with a EBM approach.
Use a range of sources of research publications and electronic literature databases.

Patient safety and quality improvement
Participate in activities that contribute to effectiveness/quality of the healthcare system and patient safety.
Commit to quality assurance through systemic quality process evaluation and improvement.
Maintain their own health and that of the team they work with.

GENERAL KNOWLEDGE AND SKILLS
NORMAL DEVELOPMENT:

- Knowledge:

Normal gross and fine motor, cognitive, social and emotional, receptive and expressive language development of infants and young children
Pre-, peri- and postnatal risk factors and causes of delayed or abnormal development
Current neonatal and childhood screening tests used in respective national child health visits

- Skills:

Taking a history of developmental milestones reached
Developmental assessment of a child 5 years and under.
Basic assessment of speech, hearing and vision

NORMAL GROWTH

- Knowledge base:

Normal physical growth from birth to the completion of puberty
Genetic, hormonal, nutritional, environmental, psychological, and social factors affecting normal growth
Common disorders of height and weight, as well as indications for further evaluation
Effects of foetal growth restriction on long-term health
Meaning, use and limitations of bone age
Causes of poor weight gain in infants and young children
Normal and abnormal variations in head shape
Specific conditions:
Common causes of short or tall stature
Common genetic conditions affecting growth

- Skills:

Weighing and measuring an infant and child accurately
Assessment of normal growth at all stages of development using appropriate growth charts, correcting for prematurity when appropriate
Assessment of nutritional status by using anthropometric measurements and calculation of body mass index (BMI)
Referral of a child with short or tall stature

NUTRITION:

- Knowledge:

Recommended nutritional requirements at different ages
Effect of disease states on nutritional requirements
Practical aspects and benefits of breastfeeding
Practical aspects of infant formulae
Health implications of restricted diets, fat diets, diets determined by custom or socioeconomic situation
Indications for, physiological basis of and complications of parenteral and enteral nutrition

- Skills:

Nutritional assessment
Breastfeeding evaluation
Interpretation of biochemical and other laboratory indices of nutritional status

SLEEP:

- Knowledge:

The basics of sleep
- Sleep across development (e.g., sleep needs and sleep concerns in special populations)
- Normal sleep physiology (e.g., sleep stages and cycles, sleep–wake regulation, circadian rhythms, homeostatic
processes)
- Cultural influences on sleep
Causes of sleep problems
- Behavioural causes of sleep problems (e.g., parent and child behaviours)
- Environmental causes of sleep problems (e.g., light, activity, noise, temperature, bedding)
- Cognitive/emotional causes of sleep problems (parent and child cognitive/emotional factors)
- Physiological causes of sleep problems, effects of diet and medication on sleep
Outcomes of inadequate sleep
- Functional outcomes of sleep problems on behaviour, cognition, and affect (e.g., school, social, daytime sleepiness)
- Functional outcomes of sleep problems on physical health (e.g., illness, injury, obesity)
- Outcomes on parents (e.g., effects on parenting, parent sleep, daytime functioning)

- Skills:

- Differential diagnosis of behavioural insomnia from other related disorders and nonbehavioral insomnia problems of sleep in paediatrics (e.g., OSA, RLS, night terrors)
- Knowing when to refer to a sleep specialist
- Measurement of sleep problems using sleep diaries

- Measurement of sleep problems using screening tools
- Measurement of sleep problems using questionnaires
- Clinical interview techniques (e.g., interviewing and evaluating a child and parent, observing parent–child interactions, cultural competency and respect for diversity during interview)

Behavioural interventions
- Sleep hygiene, sleep-promoting routines and behaviours
- Sleep scheduling and age-appropriate periods of wakefulness
- General principles of behaviour change (e.g., reinforcement, shaping, rewards)
- Extinction/graduated extinction/extinction with parental presence, and alternative strategies
- Sleep restriction and bedtime fading
- Approaching behavioural interventions with cultural competence and respect for diversity
- Understanding cognitions and emotions, and how they relate to behavioural interventions

Supporting parents throughout a behavioural insomnia intervention
- Helping parents set goals and expectations, assessing confidence and support
- What parents should expect during treatment process, common pitfalls of sleep training
- Helping parents evaluate treatment progress

ENVIRONMENT:
- Identify how climate change and environmental exposures (e.g., pesticides) affect children's health (short and long term).
- Recognize and assess structural and systemic harms (e.g., built environment, climate change, risks associated with exposure) on children's health.

ACCIDENT PREVENTION:
-Ability to describe and explain injury and/or violence as a major social and health problem.
-Ability to build and manage an injury and/or violence prevention program.
-Ability to disseminate information related to injury and/or violence prevention
-Demonstrate the knowledge, skills and best practices necessary to address specific injury and/or violence topics (e.g. motor vehicle occupant injury, intimate partner violence, fire and burns, suicide, drowning, child injury, etc.)

PHARMACOLOGY:
- Knowledge base:

Placental transfer and breast milk excretion of drugs
Complementary and alternative medicines: availability / prevalence / efficacy
- Specific conditions:

Principles of sedation and analgesia for procedures (child-centred care)
Pharmaceutical and non-pharmaceutical prevention and management of (procedural) pain

RESEARCH:
- Knowledge base:

Biostatistics
Types of variables
Data distribution patterns
Common statistical tests
Understand measurement of association
Diagnostic tests (sensitivity and specificity, positive and negative predictive value)
Principles of systematic reviews and meta- analysis (interpretation and application)
Principles of epidemiology and types of epidemiologic studies
Bias and confounding variables
Causality (causal versus association)
Incidence and prevalence
Decision analysis
Cost- benefit, cost- effectiveness and outcomes
Sensitivity analysis

Measurement principle (reliability and validity; accuracy and precision)

- Skills:

Knowledge about the various settings of clinical studies and the role of Ethics Committees
Compliance and regulatory (GCP, GDPR, law, etc)
Assessment of study design
Assessment of generalization of results
Critical reading of literature
Application of information to patient care
Appropriate evaluation and critique of medical literature
Research ethics

SUBSTANCE ABUSE/TOXICOLOGY/POISONING
Epidemiology of substance abuse: current data & trends / developmental patterns / risk factors (genetic & social)
Common substances abused / age profiles
Common childhood poisonings / exposures
Epidemiology of poisoning: local / global / age demographics
Prevention measures

ADOLESCENT MEDICINE:

- Knowledge:

Legal and ethical principles dealing with adolescents
Normal bio-psycho-social development of puberty in boys and girls
Level of cognitive reasoning in early, middle and late adolescents
Influence of family and peers in modelling adolescent behaviour
Epidemiology of the pattern of social and sexual behaviour at various ages
Gender and sex identity
Safer sex practices, sexually transmitted infections, contraception and post-coital contraception

- Skills:

Effective communication, developing a professional relationship with adolescents
Discussion with a young person the concept of confidentiality and assent/consent depending on the degree of his/her maturity and in accordance with the local legal guidance
Assessment of growth and development including sexual maturity rating (Tanner stages)
Assessment and diagnosis of substance misuse, violence and risk-taking behaviour
Assessment of suspected psychiatric symptoms using validated screening questionnaires
Assessment and diagnosis of eating disorders
Assessment and delivery of anticipatory guidance of healthy lifestyle including eating habits, physical exercise and media

COMMUNITY MEDICINE:
Knowledge:
Local, national, and international structures of community based healthcare
National vaccination program

PATHOLOGY-SPECIFIC KNOWLEDGE AND SKILLS

CARDIAC DISEASES:

- Knowledge – general:

Anatomy, physiology and pathophysiology of normal heart; cardiac malformations and diseases
Referral thresholds for a specialist cardiology opinion

- Knowledge – specific:

Common murmurs

- Skills:

Assessment of the cardiovascular system, including pulses
Assessment of heart sounds and murmurs
Measurement of blood pressure from birth to adolescence

DERMATOLOGY:

- Knowledge base:

Anatomy and histology of the skin, hair and nails
Characteristics of common dermatological problems

- Knowledge – specific:

Common pigmentary or vascular congenital lesions e.g. nevi, haemangiomas
Molluscum contagiosum, warts
Hair disorders (e.g. hypertrichosis and hair loss)
Pigmented lesions (hyper- and hypopigmentation)
Contact dermatitis
Seborrheic and atopic dermatitis
Urticaria

- Skills:

Recognize and manage dermatological emergencies
Plan and manage appropriate treatment

DISEASES OF THE ORBITA AND EYES:

- Knowledge base:

Normal vision development

- Specific conditions:

Management of squint

- Skills:

Screen for possible visual acuity problems by use of standard visual acuity charts
Check strabismus by strabismus charts

ENDOCRINE DISORDERS AND DIABETES:

- Knowledge base:

Normal growth patterns, including constitutional delay and growth disorders

- Specific conditions:

Ambiguous genitalia
Maldescended testis
Short and tall stature

- Skills:

Ability to assess pubertal status (Tanner staging)

GASTROINTESTINAL AND HEPATIC DISEASES:

- Knowledge base:

Anatomy, physiology and pathophysiology of the gastrointestinal tract, liver, biliary tract and pancreas
Normal nutritional needs and common causes of malnutrition

- Skills:

Assessment of GI system and liver
Assessment of nutritional status, including dietary history

GENETICS AND DYSMORPHOLOGY:

- Knowledge base:

Principles and molecular basis of Mendelian- and non-Mendelian inheritance
Embryological basis of malformation and environmental factors in foetal development
Principles of dysmorphology and syndrome identification
Basis of genetic and molecular techniques
Ethical and social implications of genetic testing
Indications and limitations of prenatal diagnosis
Rationale of newborn screening

- Skills:

Construction and interpretation of a family pedigree
Recognition of common genetic, chromosomal and dysmorphic syndromes
Ability to access genetic databases
Understanding the meaning of genetic results
First steps in management/communication of abnormal newborn screening results
Ability to address specific health issues is newborns and children with trisomy

HAEMATOLOGICAL AND ONCOLOGY DISORDERS:
Physiology and pathophysiology of bone marrow derived cells
Physiology and pathophysiology of the coagulation system

NEONATOLOGY:

- Knowledge base:

Foetal physiology and the physiology of extra-uterine adaptation
Antenatal and perinatal effects on neonatal outcomes, including infants of diabetic mothers
Epidemiology: Outcomes for survival and factors influencing outcome
Neonatal nutrition and feeding, including maturation of oral skills and support of breastfeeding
Prevention and treatment of neonatal hypoglycaemia
Newborn screening
Congenital and neonatal infections
Congenital malformations, major and minor including surgical/cardiac malformations
Respiratory conditions, RDS, BPD, respiratory prevention after discharge including RSV prophylaxis, and familial vaccination
Neonatal neurology
Drug withdrawal
Prescribing for newborns and breastfeeding mothers

- Skills:

Gestational assessment
Examination of the newborn at birth and 6 weeks examination
Management of healthy newborn
Communication with parents/family
Basics in infant- and family-centred care/NIDCAP (newborn individualized developmental care and assessment program)

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:

- Knowledge base:

Physiology and pathophysiology of host defence mechanisms
Common infectious agents: epidemiology / pathogenicity / characteristics
Common infant and childhood infections: viral / bacterial / fungal / parasitic
Principles of infection control
Principles of immunisation and national policy
Patterns of antimicrobial resistance / safe prescribing

- Specific conditions:

Communicable disease control/prevention/immunisation
Travel medicine / infections / immunisation

- Skills:

Hygiene
Adequate prescribing
Being able to address parental vaccine hesitancy

METABOLIC MEDICINE:

- Knowledge:

Principles of metabolic disorders: mitochondrial beta-oxidation, lipids, carbohydrates and aminoacids; storage diseases
Genetic base of common metabolic disorders
Screening tests for metabolic disease

- Specific Conditions:

Acute metabolic presentation in the newborn and infant

- Skills:

Adequate sampling of biomaterials
Newborn screening for metabolic diseases
Consider underlying metabolic disease in unclear clinical presentation

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:

- Knowledge:

Stages of cognitive and emotional development from infancy to adolescence
Biological function of the attachment system, attachment behaviour and style
Risk factors affecting the role of parent-child attachment and relationship
Common predisposing and protective factors related to mental health
Long-term effects of trauma and neglect in the first years of life
Regulatory disorders of infancy and early childhood
Common emotional and behavioural problems in preschool and school-age children
Factors influencing learning and school performance
Definition and clinical presentation of intellectual disabilities, attention deficit/hyperactivity disorder or autism spectrum disorders
Indications for specific genetic and metabolic tests and imaging tools in children with intellectual disabilities
Diagnostic criteria of somatoform disorders (SFD) and chronic fatigue syndrome (CFS)
Basic investigations in cases of possible SFD and CFS
Clinical features and presentation of emotional disturbances (e.g., anxiety, depression)
Clinical features of acute psychosis
Be familiar and collaborate with colleagues and caregivers from the preventive youth health and wellbeing sector as well as the mental health sector

- Skills:

Evaluation and diagnostic formulation of common emotional and behavioural problems in preschool and school-age children
Management strategies and counselling for common emotional and behavioural problems including referral as appropriate
Parent/child communication in case of possible SFD
Initial assessment of a child with intellectual difficulties, hyperkinetic disorder or autism spectrum disorder
Using rating scales and questionnaires for assessment of mental health problems
Apply the principles of trauma-sensitive care

NEPHRO-UROLOGY DISORDERS:

- Knowledge base:

Development of the kidney, urinary tract and external genitalia.

- Specific conditions:

Enuresis: nocturnal and diurnal
Management of voiding disorders
Common causes of hypertension

- Skills:

Taking history in nephro-urological disorders
Measurement of blood pressure

NEUROLOGY AND NEUROMUSCULAR DISORDERS:

- Knowledge base:

Anatomy, physiology and pathophysiology of the central and peripheral nervous system
Pathophysiology of common disorders affecting the nervous system (including neuromuscular)
Developmental problem: autism spectrum, language delay, intellectual disability
Learning problems: dyslexia, ADHD, etc…

- Skills:

Age appropriate neurological examination, head circumference measurement
Detailed developmental assessment

PRE- PERI- AND POST- SURGICAL CARE:

- Knowledge:

Basic principles of pre-operative assessment

- Specific conditions:

Hernias
Maldescended testis

RESPIRATORY DISORDERS:

- Knowledge base:

Physiology and pathophysiology of the respiratory system in children, including age dependent changes.
Important epidemiological and genetic factors for respiratory diseases, including tobacco smoke exposure, pollution and

RHEUMATIC & SYSTEM-INFLAMMATORY DISEASES:
Normal patterns of leg alignment (bow legs, knock knees, in toeing) AM H

SPORTS MEDICINE:

- Knowledge:

Understand common sports injury and treatment
Understand the importance of regular exercise to promote good general health
Understand the importance of skeletal maturity in dictating the appropriate type of training
Understand the risks of contact sports in healthy children

- Skills:

Physical examination of the musculoskeletal system.

DENTAL HEALTH
ENT (Ear Nose Throat)
Understand common dental and ENT problems and their treatment

Appendix 2

Competences for monitoring and treating the vulnerable child

⇨ Specific end-terms for ACE's need to be added

Competences for appropriate care MEDICAL	All general and specific knowledge, skills and competences defined for a Healthy child AND GENERAL COMPETENCES Communication and interpersonal skills : Develop a common understanding on vulnerability issues, problems and plans with patients, families, and other professionals to develop a shared plan of care. Ethics and professionalism Display sensitivity and responsiveness to a diverse patient population, including diversity in socio-economic status Responsiveness to situations where the wellbeing of the child is endangered/compromised Compliance with all legal and moral obligations for reporting disease and potential or real abuse/neglect Understand the roles and responsibilities: - In the safeguarding of babies, children and adolescents - To support and enable parents and carers to be effective in caring for their vulnerable children - To follow the principle that all decisions are to be made in the best interest of the vulnerable child Use the generic competencies (knowledge, skills, behaviour) that relate to clinical practice: - Understanding of safeguarding and vulnerability in paediatrics To maintain Good Medical Practice: Ensure to be up-to-date, conform with highest standards of practice, and promote evidence-based practice where possible according child welfare. SPECIFIC KNOWLEDGE AND SKILLS ABNORMAL DEVELOPMENT: • Knowledge: Pre-, peri- and postnatal risk factors and causes of delayed or abnormal development Range of deficits in common genetic syndromes (eg, fragile X, trisomy 21, foetal alcohol syndrome) Screening and basic diagnostic assessment instruments for developmental delay and intellectual disability • Skills: Initiation of appropriate investigations to make a diagnosis based upon the history and pattern of abnormal development observed Communication of findings and implications of developmental assessment to parents

	NORMAL AND ABNORMAL GROWTH: • Knowledge base: Genetic, hormonal, nutritional, environmental, psychological, and social factors affecting normal growth Effects of foetal growth restriction on long-term health • Skills: Assessment of nutritional status by using anthropometric measurements and calculation of body mass index (BMI) Advising carers on management with failure to thrive if there are eating difficulties NUTRITION: • Knowledge: Health implications of restricted diets, fat diets, diets determined by custom or socioeconomic situation • Specific conditions: Overweight and obesity Failure to thrive Nutritional deficiencies and excesses Feeding disorders Recognition and early management of anorexia nervosa PHARMACOLOGY: • Knowledge base: Placental transfer and breast milk excretion of drugs Drug selection: generic vs. labelled / cost implications / compliance issues / health insurance planning • Specific conditions: Drug withdrawal SAFEGUARDING: • Knowledge base: WHO definitions of neglect and of physical, emotional, and sexual abuse Other forms of abuse: bullying at school, cyber-bullying, institutional abuse, Munchhausen by proxy, and all adverse childhood experiences Family, social and other characteristics associated with increased risk of abuse/neglect Features in the history that raise suspicions that presenting symptoms may be due to abuse or neglect Clinical signs of non-accidental injuries Diseases that may mimic physical abuse/neglect Sequelae of shaking of a child during the first year after birth Common fracture locations and types in physically abused children Locations of fractures, bruises, burns/scalds, scars that are rarely accidental Clinical, psychological and behavioural signs suggesting emotional abuse Possible physical, psychological, behavioural and maturational problems due to neglect or abuse Clinical, psychological and behavioural signs suggesting child sexual abuse Indications for referral of a child to other specialists experienced in child abuse evaluation Indications for referral to social and/or psychological services, interprofessional care

	• Skills: Recognition and assessment of suspected acute physical, emotional, sexual abuse Differentiation of intentional neglect from deprivation associated with poverty or low education Utilization of appropriate laboratory tests and skeletal-imaging to differentiate between disease, accidental and intentional injury, including sexual abuse Complete documentation of clinical signs and procedures that are made to identify the abuse or neglect in accordance with local and/or national law Appropriate communication with the abused/neglected child and the family SUBSTANCE ABUSE/TOXICOLOGY/POISONING • Knowledge base: Epidemiology of substance abuse: current data & trends / developmental patterns / risk factors (genetic & social) Common substances abused / age profiles Common childhood poisonings / exposures Epidemiology of poisoning: local / global / age demographics Prevention measures Poison centres / operating procedures / poison information data / online Toxicology signs and symptoms Types of ingestions / poisonings Community and home chemical hazards: pesticides / industrial waste / occupational home renovation risks, lead poisoning Poisoning as possible sign of child abuse / neglect Poisoning by unknown agent COMMUNITY MEDICINE: • Knowledge: Local, national, and international structures of community based healthcare Key social determinants of child health and well-being Effects of family composition, socioeconomic factors and poverty on child health Community assets and resources toward preventing illness, injury, and related morbidity and mortality Resources that may be available from health agencies, including the voluntary sector and allied health professionals Support programs for families and children with special health care needs • Skills: Ability to work together with schools, childcare, facilities and others Management of children in need of protection and the pathways to ensure follow-up Demonstration of advocacy skills to address relevant individual, community, and population health issues MENTAL HEALTH AND BEHAVIOURAL DISORDERS: • Knowledge: Stages of cognitive and emotional development from infancy to adolescence Biological function of the attachment system, attachment behaviour and style Risk factors affecting the role of parent-child attachment and relationship Common predisposing and protective factors related to mental health Long-term effects of trauma and neglect in the first years of life Regulatory disorders of infancy and early childhood Common emotional and behavioural problems in preschool and school-age children Factors influencing learning and school performance

	Definition and clinical presentation of intellectual disabilities, attention deficit/hyperactivity disorder or autism spectrum disorders Diagnostic criteria of somatoform disorders (SFD) and chronic fatigue syndrome (CFS) Clinical features and presentation of emotional disturbances (e.g., anxiety, depression) Clinical features of acute psychosis Be familiar and collaborate with colleagues and caregivers from the preventive youth health and wellbeing sector as well as the mental health sector • Skills: Evaluation and diagnostic formulation of common emotional and behavioural problems in preschool and school-age children Management strategies and counselling for common emotional and behavioural problems including referral as appropriate Parent/child communication in case of possible somatoform disorder Initial assessment of a child with intellectual difficulties, hyperkinetic disorder or autism spectrum disorder Using rating scales and questionnaires for assessment of mental health problems Apply the principles of trauma-sensitive care RESPIRATORY DISORDERS: • Knowledge base: Important epidemiological and genetic factors for respiratory diseases, including tobacco smoke exposure, pollution and allergens. ADOLESCENT MEDICINE: • Knowledge: Influence of family and peers in modelling adolescent behaviour Epidemiology of the pattern of social and sexual behaviour at various ages Safer sex practices, sexually transmitted infections, contraception and post-coital contraception • Skills: Assessment and diagnosis of substance misuse, violence and risk-taking behaviour Assessment of suspected psychiatric symptoms using validated screening questionnaires Assessment and diagnosis of eating disorders

Appendix 3

Competences for diagnosing, monitoring and treating the Acute mild to moderately ill child

Competences as defined for Healthy child

Competences as defined for Vulnerable Child

AND in addition

MEDICAL

GENERAL COMPETENCES

Understand the roles and responsibilities:

- To understand their role in the management in permanent prevention of illness in children

Use the generic competencies (knowledge, skills, behaviour) that relate to clinical practice:

- History taking, clinical examination, effective skills in paediatric assessment and formulating an appropriate differential diagnosis in paediatrics

- Management of ill-health and clinical conditions in paediatrics, seeking additional advice and opinion as appropriate

- Recognition of behavioural, emotional and psychosocial aspects of illness in children and families.

- Order the appropriate investigations in paediatrics, and know how to interpret them.

- Safe practical skills in paediatrics (peripheral blood samplings; electrocardiogram; lumbar puncture; urethral catheterization; collection of blood from central lines;; administer intradermal, subcutaneous, intramuscular & intravenous drugs

- Clear record-keeping and report-writing

- Safe prescribing of common drugs in paediatrics: appropriate indications, dosages in babies, children and adolescents, drug interactions, how to use formulary, guidelines and recognize adverse events

- Effective responses to challenge, complexity and stress in paediatrics.

To maintain Good Medical Practice:

Knowledge of common and serious paediatric conditions and their management.

SPECIFIC KNOWLEDGE AND SKILLS

ABNORMAL DEVELOPMENT:

Knowledge:

Abnormal gross and fine motor, cognitive, social and emotional, receptive and expressive language development of infants and young children

Pre-, peri- and postnatal risk factors and causes of delayed or abnormal development

Common patterns of developmental abnormality (gross motor, speech and language, global)

Range of deficits in common genetic syndromes (eg, fragile X, trisomy 21, foetal alcohol syndrome)

Screening and basic diagnostic assessment instruments for developmental delay and intellectual disability

Indications for imaging (ultrasound, MRI), metabolic and genetic testing

Indications for physio-, educational, occupational and/or speech therapy

Indications for referral of a child to a paediatric neurologist, speech pathologist

Skills:

Taking a history of developmental milestones reached

Developmental assessment of a child 5 years and under.

Basic assessment of hearing and vision

Initiation of appropriate investigations to make a diagnosis based upon the history and pattern of abnormal development observed

Communication of findings and implications of developmental assessment to parents

ABNORMAL GROWTH

Knowledge base:

Normal physical growth from birth to the completion of puberty

Genetic, hormonal, nutritional, environmental, psychological, and social factors affecting normal growth

Common disorders of height and weight, as well as indications for further evaluation

Effects of foetal growth restriction on long-term health

Meaning, use and limitations of bone age

Causes of poor weight gain in infants and young children

Normal and abnormal variations in head shape

Specific conditions:

Common causes of short or tall stature

Common genetic conditions affecting growth

Skills:

Weighing and measuring an infant and child accurately

Assessment of normal and abnormal growth at all stages of development using appropriate growth

charts, correcting for prematurity when appropriate

Assessment of nutritional status by using anthropometric measurements and calculation of body mass index (BMI)

Investigations in a child with short or tall stature

Advising carers on management with failure to thrive if there are eating difficulties

NUTRITION:

Knowledge:

Recommended nutritional requirements at different ages

Effect of disease states on nutritional requirements

Practical aspects and benefits of breastfeeding

Practical aspects of infant formulae

Health implications of restricted diets, fat diets, diets determined by custom or socio-economic situation

Indications for, physiological basis of and complications of parenteral and enteral nutrition

Specific conditions:

Overweight and obesity

Failure to thrive

Nutritional deficiencies and excesses

Feeding disorders

Recognition and early management of anorexia nervosa

Skills:

Nutritional assessment

Breastfeeding evaluation

Interpretation of biochemical and other laboratory indices of nutritional status

ADOLESCENT MEDICINE:

Knowledge:

Legal and ethical principles dealing with adolescents

Normal bio-psycho-social development of puberty in boys and girls

Level of cognitive reasoning in early, middle and late adolescents

Influence of family and peers in modelling adolescent behaviour

Epidemiology of the pattern of social and sexual behaviour at various ages

Gender and sex identity

Safer sex practices, sexually transmitted infections, contraception and post-coital contraception

Causes of delayed puberty

Impact of chronic conditions on adolescent social, psychological and physical development

Transition from paediatric to adult care

PHARMACOLOGY:

Knowledge base:

Pharmacodynamics: absorption/systemic availability/interpretation of drug concentrations

Drug interactions & adverse drug reactions

Pathophysiology of drug action mechanisms, correction of pathophysiological states

Pharmacokinetics in children in different age groups

Placental transfer and breast milk excretion of drugs

Drug toxicity and therapeutic drug monitoring

Guidelines and protocols for antimicrobial prescribing

Drug dosage modification in disease (liver/kidney dysfunction)

Drug selection: generic vs. labelled / cost implications / compliance issues / health insurance planning

Off label use

Complementary and alternative medicines: availability / prevalence / efficacy

Specific conditions:

Management of (procedural) pain

Principles of sedation and analgesia for procedures (child-centred care)

Drug withdrawal

Skills:

Prescribing skills / rational drug therapy

Formulary use in practice

RESEARCH:

Biostatistics

Types of variables

Data distribution patterns

Common statistical tests

Understand measurement of association

Diagnostic tests (sensitivity and specificity, positive and negative predictive value)

Principles of systematic reviews and meta- analysis (interpretation and application)

Principles of epidemiology and types of epidemiologic studies

Bias and confounding variables

Causality (causal versus association)

Incidence and prevalence

Decision analysis

Cost- benefit, cost- effectiveness and outcomes

Sensitivity analysis

Measurement principle (reliability and validity; accuracy and precision)

Skills:

Knowledge about the various settings of clinical studies and the role of Ethics Committees

Compliance and regulatory (GCP, GDPR, law, etc)

Assessment of study design

Assessment of generalisation of results

Critical reading of literature

Application of information to patient care

Appropriate evaluation and critique of medical literature

Research ethics

CARDIAC DISEASES:

Knowledge – general:

Assessment and initial treatment of congenital heart diseases

Foetal circulation and changes in circulation at birth

Clinical manifestations of congenital and acquired heart diseases

Basic understanding of structural and functional echocardiography

Principles of pharmacotherapy

Referral thresholds for a specialist cardiology opinion

Knowledge – specific:

Common causes of chest pain in children

Common murmurs

Common ECG abnormalities

Endocarditis (causes, investigations, indications for prophylaxis)

Palpitations, tachycardia, arrhythmias

Causes and management of syncope

Common causes of systemic and pulmonary hypertension

Skills:

Assessment of the cardiovascular system, including pulses

Assessment of heart sounds and murmurs

Measurement of blood pressure from birth to adolescence

DERMATOLOGY:

Knowledge base:

Anatomy and histology of the skin, hair and nails

Characteristics of common dermatological problems and serious erythematous, rashes

Specific conditions:

Common pigmentary or vascular congenital lesions e.g. nevi, haemangiomas

Molluscum contagiosum, warts

Hair disorders (eg, hypertrichosis and hair loss)

Urticaria

Acne

Skills:

To recognize common exanthemas

Recognize and manage dermatological emergencies (e.g. Steven-Johnson, …)

Skin manifestations of common infectious diseases

Identify mucosal, skin infection, bacterial infected eczema, eczema herpeticum

Plan and manage appropriate treatment

DISEASES OF THE ORBITA AND EYES:

Knowledge base:

Common causes of visual impairment

Ophthalmic presentations of systemic diseases

Specific conditions:

Acute management of trauma

Conjunctivitis

Orbital infection, orbital swelling, edema

ENT DISORDERS:

Knowledge base:

Deafness and hearing loss AM

Indications for tonsillectomy, adenoïdectomy and transtympanic drains

Specific conditions:

Rhinitis (allergic rhinitis, infectious rhinitis), polyps

Epistaxis

Trauma or foreign body

Tonsillitis and complications, adenoidal hypertrophy

Pharyngitis

Laryngitis, Croup

Otitis media / otitis externa

Mastoiditis and sinusitis

Skills:

Understand the techniques for hearing evaluation at different ages

Performance of simple tests of hearing and assessing eardrums

Interpretation of soft tissue X-rays in acute upper airway obstruction

Institute the appropriate treatment for laryngitis

GASTROINTESTINAL AND HEPATIC DISEASES:

Knowledge base:

Gastrointestinal infectious diseases and infection control

Indications for diagnostic procedures – eg, sonography, radiology, endoscopy and biopsy

Specific conditions:

Acute and chronic abdominal pain

Constipation

Gastroenteritis and diarrhoea

Principles of oral rehydration and intravenous fluid therapy

GI Bleeding

Gastro-esophageal reflux

Common causes of hepatitis

Common causes of jaundice

Iron deficiency anaemia

Ingestion of a corpus alienum

Skills:

Taking history in GI and hepatic diseases

Assessment of GI system and liver

Assessment of nutritional status, including dietary history

Ability to manage paracetamol poisoning

GENETICS AND DYSMORPHOLOGY:

Knowledge base:

Principles of dysmorphology and syndrome identification

Indications and limitations of prenatal diagnosis

Skills:

Recognition of common genetic, chromosomal and dysmorphic syndromes

Ability to address specific health issues is newborns and children with trisomy

HAEMATOLOGICAL AND ONCOLOGY DISORDERS:

Knowledge base:

Physiology and pathophysiology of bone marrow derived cells

Pathophysiology of anaemia and haemolytic diseases

Physiology and pathophysiology of the coagulation system

Management of common non-malignant haematological conditions

Principles of management of cancer

Short and long term side effects of chemotherapy and radiotherapy

Indications for bone marrow transplantation

Specific conditions:

Anaemia

Sickle cell disease and thalassaemias

Acute lymphoblastic leukaemia

Lymph node enlargement, lymphadenopathy

Coagulation disorders, haemophilia

Common causes of neutropenia

Common causes of purpura

Skills:

Taking history in hematologic and oncologic disorders

Ability to assess children presenting with haematological or oncological conditions

Interpretation of blood smears results

Acute management of child with febrile neutropenia

Management of long term central lines

Care of child requiring isolation

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:

Knowledge base:

Physiology and pathophysiology of host defence mechanisms

Common infectious agents: epidemiology / pathogenicity / characteristics

Common infant and childhood infections: viral / bacterial / fungal / parasitic

Appropriate and safe prescribing of antibiotic or antiviral therapy

Principles of infection control

Principles of immunisation and national policy

Patterns of antimicrobial resistance / safe prescribing

Use of diagnostic tests, culture methods bacterial & viral

Specific conditions:

Perinatal infections

Pyrexia/fever of unknown origin

Communicable disease control/prevention/immunisation

Diarrhoea and vomiting

Pneumonia

Septic shock

Tuberculosis

HIV

Acquired and congenital immunodeficiencies

Travel medicine / infections / immunisation

Covid disease, PIMS

Skills:

Taking history in infectious diseases

Ability to assess child presenting with infectious disease

Care of child requiring isolation

Hygiene

Adequate prescribing

Considering development of resistance

Being able to address parental vaccine hesitancy

BETTER EDUCATION IN MENTAL HEALTH

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:

Knowledge:

Stages of cognitive and emotional development from infancy to adolescence

Biological function of the attachment system, attachment behaviour and style

Risk factors affecting the role of parent-child attachment and relationship

Common predisposing and protective factors related to mental health

Long-term effects of trauma and neglect in the first years of life

Regulatory disorders of infancy and early childhood

Common emotional and behavioural problems in preschool and school-age children

Factors influencing learning and school performance

Definition and clinical presentation of intellectual disabilities, attention deficit/hyperactivity disorder or autism spectrum disorders

Indications for specific genetic and metabolic tests and imaging tools in children with intellectual disabilities

Diagnostic criteria of somatic symptom disorder (SSD) and chronic fatigue syndrome (CFS)

Basic investigations in cases of possible SFD and CFS

Clinical features and presentation of emotional disturbances (e.g., anxiety, depression)

Clinical features of acute psychosis

Be familiar and collaborate with colleagues and caregivers regionally involved in preventive youth health and wellbeing sector as well as the mental health sector

Skills:

Evaluation and diagnostic formulation of common emotional and behavioural problems in preschool and school-age children

Addressing and Assessing Mental health at every patient/parent contact

Management strategies and counselling for common emotional and behavioural problems including referral as appropriate

Parent/child communication in case of mental health problem or possible somatoform disorder

Initial assessment of a child with intellectual difficulties, hyperkinetic disorder or autism spectrum disorder

Using rating scales and questionnaires for assessment of mental health problems

Apply the principles of trauma-sensitive care

NEPHRO-UROLOGY DISORDERS:

Knowledge base:

Renal physiology and pathophysiology, principles of fluid balance, electrolyte and acid base regulation

Renal imaging and function tests

Drug prescribing in renal failure

Specific conditions:

Urinary tract infection

Vesicoureteral obstruction and reflux

Enuresis: nocturnal and diurnal

Management of voiding disorders

Haematuria/proteinuria, including IgA vasculitis and nephrotic syndrome

Haemolytic uraemic syndrome

Common causes of hypertension

Acute scrotal pain and torsion

Skills:

Taking history in nephro-urological disorders

Measurement of blood pressure

Appropriate urine collection: catheterization / bladder aspiration

Interpretation of urinalysis, microscopy, dipstick

Interpretation of biochemical investigation results

Recognized renal failure

NEUROLOGY AND NEUROMUSCULAR DISORDERS:

Knowledge base:

Pathophysiology of common disorders affecting the nervous system (including neuromuscular)

Principles of antiepileptic drugs

Specific conditions:

Meningitis

Acute encephalopathy

Febrile and afebrile seizures

Headache (acute and chronic) including migraine

Hypotonia

Traumatic brain injury

Skills:

Acute management of seizures, meningitis, (sub)-coma

Detailed developmental assessment

Recognizing Intracranial hypertension and Shaken Baby Syndrome

Basic concepts of imaging and indications of the different modalities : CT, MRI and ultrasound

Lumbar puncture and interpretation of results

Ability to communicate with (disabled) children and their families

METABOLIC MEDICINE:

Knowledge:

Principles of metabolic disorders: mitochondrial beta-oxidation, lipids, carbohydrates and aminoacids; storage diseases

Metabolic crisis

Common presentations of metabolic disease (including encephalopathy, neurodevelopmental regression, weakness, visceromegaly and poor growth)

Genetic base of common metabolic disorders

Screening tests for metabolic disease

Basic dietary principles in the care of children with metabolic disease

Specific Conditions:

Acute metabolic presentation in the newborn and infant

Skills:

Adequate sampling of biomaterials

Newborn screening for metabolic diseases

Consider underlying metabolic disease in unclear clinical presentation

PRE- PERI- AND POST- SURGICAL CARE:

Knowledge:

Basic principles of pre-operative assessment

Basic principles of surgical referrals

Principles of perioperative management

Principles of post-operative management, including pain/fluid management

Know high-risk patient factors

Specific conditions:

Hernias

Acute abdomen

Acute scrotal pain

Bowel obstruction; intussusception; pyloric stenosis

Appendicitis

Abscess

Skills:

Be able to diagnose acute abdomen, peritonitis, ileus

Able to take care of surgical wounds

RESPIRATORY DISORDERS:

Knowledge base:

Physiology and pathophysiology of the respiratory system in children, including age dependent changes.

Important epidemiological and genetic factors for respiratory diseases, including tobacco smoke exposure, pollution and allergens

Specific conditions:

Acute or recurrent stridor

Asthma

Lower respiratory tract infection (including pneumonia and bronchiolitis)

Hemoptysis

Recurrent or chronic cough

Sore throat and/or mouth

Skills:

Take a respiratory history and examination.

Develop a management plan for common respiratory disorders

Prescribe and interpret common laboratory tests, skin prick tests, Mantoux/IGRA, chest x-rays and lung function.

Prescribe appropriate inhalation devices according to age and be able to educate the patient and his/her parents on how to use them.

Define indications for bronchoscopy

RHEUMATIC & SYSTEM-INFLAMMATORY DISEASES:

Knowledge base:

Aetiology and pathophysiology of rheumatic diseases, systemic inflammatory diseases

Specific conditions:

Acute / chronic arthritis

recurrent fever/auto-inflammatory syndromes (PFAPA, CAPS, FMF, TRAPS,…)

Common causes of joint swelling

Common gait disorders (limp, torsional and angular deformities of lower limbs) Am

Common causes of musculoskeletal pain, including limb pain, neck pain, back pain

Normal patterns of leg alignment (bow legs, knock knees, in toeing)

Septic arthritis and osteomyelitis

Recurrent fever/auto-inflammatory syndromes (PFAPA, CAPS, FMF, TRAPS,…)

Skills:

Taking a musculoskeletal history

Detailed examination of the joints and musculoskeletal system

PAEDIATRIC AND ADOLSCENTS SPORTS MEDICINE:

Knowledge:

Understand common sports injury and treatment

Understand the risks due to incomplete healing of previous injury

Skills:

Physical examination of the musculoskeletal system.

Recognition of examination findings that are consistent with common sports injuries in children and adolescents.

Plan the appropriate management/treatment/referral of an athlete with sports injury.

Appendix 4

Competences for diagnosing, monitoring and treating the child and adolescent with a single long term condition

Competences as defined for Healthy child

Competences as defined for Vulnerable Child

Competences as defined for Acute mild or moderately ill child

Competences as defined for Acute severely ill neonate/child (1st hour care and medium care)

AND in addition

GENERAL COMPETENCES

Understand the roles and responsibilities:

- To understand their role in the management of chronic illness in children

SPECIFIC KNOWLEDGE AND SKILLS

ADOLESCENT MEDICINE:

- Knowledge:

Causes of delayed puberty

Impact of chronic conditions on adolescent social, psychological and physical development

Transition from paediatric to adult care

- Skills:

Effective communication, developing a professional relationship with adolescents, including evaluation of compliance

Discussion with a young person the concept of confidentiality and assent/consent depending on the degree of his/her maturity and in accordance with the local legal

Planning, providing and integrating care for adolescents with a single long term condition

ALLERGIC DISEASES:

- Knowledge base:

Knowledge of basis of host defence mechanisms

Basic knowledge of immunology relevant to allergic diseases

Influence of genetic and environmental factors on allergic disease

Variations in normal immune response with age

Various phenotypes of allergic diseases

Basic diagnostic laboratory techniques involving the immune system

Pharmacologic and immunologic therapy of allergic disorders

Specific conditions:

Allergic diseases, including rhinitis, eczema and anaphylaxis

Allergy testing (including skin prick testing, RAST, serum IgE, serum tryptase)

Indications for immunoglobulin therapy

Management of cow's milk protein intolerance

- Skills:

Taking a history in allergic patients

Recognizing clinical symptoms and signs of allergy

Prescribing a diet for food allergic children

Demonstration of the use of an adrenalin pre-loaded injection

Demonstration of the performance and interpretation of the skin prick test

CARDIAC DISEASES:

End competences Level 3 paediatric cardiology

Basic knowledge

Red flags and management

Manage chronic treatments and follow-up

DERMATOLOGY:

Contact dermatitis

Seborrheic and atopic dermatitis

Urticaria

- Skills:

Skin manifestations of systemic disease (i.e. Henoch Schönlein, lupus)

Plan and manage appropriate treatment

DISEASES OF THE ORBITA AND EYES:

Basic knowledge : myopy, strabism, infections, …

Red flags and management

- Knowledge base:
- Specific conditions:

Disorders of refraction

Retinopathy of prematurity

Ophthalmic presentations of systemic diseases

ENT DISORDERS:

Basic knowledge

Red flags and management

Cleft lip, cleft palate

Mastoiditis and sinusitis

ENDOCRINE DISORDERS AND DIABETES:

- Knowledge base:

Normal and abnormal puberty development, ambiguous genitalia, precocious puberty, disorders of sexual development

Recognition and initial investigation of commonly presenting endocrine disorders, including hypothyroidism, AGS, diabetes type 1 and 2

Understanding of the endocrine manifestation of systemic diseases

Understanding the pathophysiology and signs of diabetes

- Specific conditions:

Common congenital and acquired endocrine disorders, including pituitary, thyroid, and adrenal disease

Ambiguous genitalia

Short and tall stature

Precocious puberty and pubertal delay

Thyroid disease and adrenal disease

Obesity, including complications and clinical management strategies

- Skills:

Taking history in endocrine disorders

Ability to measure growth accurately and to chart and interpret it appropriately

Ability to assess pubertal status (Tanner staging)

Ability to institute appropriate insulin regimes to treat diabetes mellitus

GASTROINTESTINAL AND HEPATIC DISEASES:

- Knowledge base:

GI symptoms of systemic disease

Indications for diagnostic procedures – eg, sonography, radiology, endoscopy and biopsy

- Specific conditions:

Acute and chronic abdominal pain

Common congenital conditions

Constipation

Common causes of dysphagia

Gastro-oesophageal reflux

Common causes of hepatitis

Common causes of jaundice

Inflammatory bowel disease

Iron deficiency anaemia

Malabsorption, including coeliac disease and cystic fibrosis

- Skills:

Taking history in GI and hepatic diseases

Assessment of GI system and liver

Assessment of nutritional status, including dietary history

Indications for, physiological basis of and complications of parenteral and enteral nutrition

GENETICS AND DYSMORPHOLOGY:

- Knowledge base:

Principles of dysmorphology and syndrome identification

Basis of genetic and molecular techniques

Ethical and social implications of genetic testing

- Skills:

Construction and interpretation of a family pedigree

Recognition of common genetic, chromosomal and dysmorphic syndromes

Genetic counselling related to common conditions

Understanding the meaning of genetic results

First steps in management/communication of abnormal newborn screening results

HAEMATOLOGICAL AND ONCOLOGY DISORDERS:

- Knowledge base:

Physiology and pathophysiology of bone marrow derived cells

Pathophysiology of anaemia and haemolytic diseases

Physiology and pathophysiology of the coagulation system

Management of common non-malignant haematological conditions

Risks and benefits of blood transfusion

Principles of management of cancer

Short and long term side effects of chemotherapy and radiotherapy

Indications for bone marrow transplantation

Principles of palliative care

- Specific conditions:

Anaemia

Sickle cell disease and thalassaemia

Acute lymphoblastic leukaemia

Lymph node enlargement, lymphadenopathy

Hodgkin and non-Hodgkin lymphoma

Medullo-, neuro-, nephro-, hepatoblastoma

Coagulation disorders, haemophilia

Common causes of neutropenia

Common causes of purpura

- Skills:

Taking history in hematologic and oncologic disorders

Ability to assess children presenting with haematological or oncological conditions

Interpretation of blood smears results

Acute management of child with febrile neutropenia

Management of long term central lines

Care of child requiring isolation

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:

- Knowledge base:

Physiology and pathophysiology of host defence mechanisms

Common infectious agents: epidemiology / pathogenicity / characteristics

Common infant and childhood infections: viral / bacterial / fungal / parasitic

Appropriate and safe prescribing of antibiotic or antiviral therapy

Principles of infection control

Principles of immunisation and national policy

Patterns of antimicrobial resistance / safe prescribing

Use of diagnostic tests, culture methods bacterial & viral

- Specific conditions:

Pyrexia/fever of unknown origin

Communicable disease control/prevention/immunisation

Diarrhoea and vomiting

Pneumonia

Septic shock

Tuberculosis

HIV

Acquired and congenital immunodeficiencies

Travel medicine / infections / immunisation

Covid disease, PIMS

- Skills:

Taking history in infectious diseases

Ability to assess child presenting with infectious disease

Care of child requiring isolation

Hygiene

Adequate prescribing

Considering development of resistance

Being able to address parental vaccine hesitancy

METABOLIC MEDICINE:

- Knowledge:

Principles of metabolic disorders: mitochondrial beta-oxidation, lipids, carbohydrates and aminoacids; storage diseases

Metabolic crisis

Common presentations of metabolic disease (including encephalopathy, neurodevelopmental regression, weakness, visceromegaly and poor growth)

Genetic base of common metabolic disorders

Screening tests for metabolic disease

Basic dietary principles in the care of children with metabolic disease

- Skills:

Adequate sampling of biomaterials

Consider underlying metabolic disease in unclear clinical presentation

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:

- Knowledge:

Stages of cognitive and emotional development from infancy to adolescence

Biological function of the attachment system, attachment behavior and style

Risk factors affecting the role of parent-child attachment and relationship

Common predisposing and protective factors related to mental health

Long-term effects of trauma and neglect in the first years of life

Regulatory disorders of infancy and early childhood

Common emotional and behavioural problems in preschool and school-age children

Factors influencing learning and school performance

Definition and clinical presentation of intellectual disabilities, attention deficit/hyperactivity disorder or autism spectrum disorders

Indications for specific genetic and metabolic tests and imaging tools in children with intellectual disabilities

Diagnostic criteria of somatoform disorders (SFD) and chronic fatigue syndrome (CFS)

Basic investigations in cases of possible SFD and CFS

Clinical features and presentation of emotional disturbances (e.g., anxiety, depression)

Clinical features of acute psychosis

Be familiar and collaborate with colleagues and caregivers from the preventive youth health and wellbeing sector as well as the mental health sector

- Skills:

Evaluation and diagnostic formulation of common emotional and behavioural problems in preschool and school-age children

Management strategies and counselling for common emotional and behavioural problems including referral as appropriate

Parent/child communication in case of possible SFD

Initial assessment of a child with intellectual difficulties, hyperkinetic disorder or autism spectrum disorder

Using rating scales and questionnaires for assessment of mental health problems

Apply the principles of trauma-sensitive care

NEPHRO-UROLOGY DISORDERS:

- Specific conditions:

Vesicoureteral obstruction and reflux

Therapy-resistant enuresis: nocturnal and diurnal

Management of therapy-resistant voiding disorders

Cortico-resistant or -dependent nephrotic syndrome

Haemolytic uraemic syndrome

Common causes of hypertension

NEUROLOGY AND NEUROMUSCULAR DISORDERS:

- Knowledge base:

Pathophysiology of common disorders affecting the nervous system (including neuromuscular)

Common causes of disability

Principles of antiepileptic drugs

Sensory deficits e.g. hearing and visual impairment

- Specific conditions:

Headache (chronic) including migraine

Hypotonia

Developmental problem: autism spectrum, language delay, intellectual disability

Learning problems: dyslexia, ADHD, etc…

- Skills:

Taking history in neurodevelopmental and neurological disorders

Age appropriate neurological examination, head circumference measurement

Detailed developmental assessment

Basic concepts of imaging and indications of the different modalities : CT, MRI and ultrasound

Ability to communicate with (disabled) children and their families

PRE- PERI- AND POST- SURGICAL CARE:

- Knowledge:

Basic principles of pre-operative assessment

Basic principles of surgical referrals

Principles of peri-operative management

Principles of post-operative management, including pain/fluid management

Know high-risk patient factors

- Skills:

Be able to diagnose abscess, acute abdomen, peritonitis, ileus

Able to take care of surgical wounds

RESPIRATORY DISORDERS:

- Knowledge base:

Physiology and pathophysiology of the respiratory system in children, including age dependent changes

Important epidemiological and genetic factors for respiratory diseases, including tobacco smoke exposure, pollution and allergens

- Specific conditions:

Acute or recurrent stridor

Asthma

Recurrent or chronic cough

Sleep disordered breathing

- Skills:

Take a respiratory history and examination.

Prescribe and interpret common laboratory tests, skin prick tests, chest x-rays and lung function.

Prescribe appropriate inhalation devices according to age and be able to educate the patient and his/her parents on how to use them.

Define indications for bronchoscopy

RHEUMATIC & SYSTEM-INFLAMMATORY DISEASES:

- Knowledge base:

Aetiology and pathophysiology of rheumatic diseases, systemic inflammatory diseases

Inflammatory and non-inflammatory connective tissue diseases

Effects of chronic rheumatic diseases on physical growth and social development

Rheumatological manifestations of systemic diseases

- Specific conditions:

Acute / chronic arthritis

Common gait disorders (limp, torsional and angular deformities of lower limbs)

Common causes of musculoskeletal pain, including limb pain, neck pain, back pain

Juvenile idiopathic arthritis (JIA)

- Skills:

Detailed examination of the joints and musculoskeletal system

SPORTS MEDICINE:

- Knowledge:

Understand common sports injury and treatment in relation to the single long term condition

Understand the importance of regular exercise to promote good general health despite the single long term condition

Understand the importance of skeletal maturity and the influences of the single long term condition in dictating the appropriate type of training

Understand the risks due to incomplete healing of previous injury

Understand the risks of contact sports in children with a single long term condition

- Skills:

Physical examination of the musculoskeletal system.

Recognition of examination findings that are consistent with common sports injuries.

Appendix 5

Competences for diagnosing, monitoring and treating the child and adolescent complex and integrated care needs

Competences as defined for Healthy child

Competences as defined for Vulnerable Child

Competences as defined for Acute mild or moderately ill child

Competences as defined for Acute severely ill neonate/child (1st hour care and medium care)

Competences as defined for a child with a single long term condition

AND

- Pathology-specific

All level 3 subspecialties have extended competences and skills (provided to the High Council in 2012 and repeatedly - last 03/2024)

- Rare diseases

Training Requirements for the Competency of Rare and Undiagnosed Diseases

- Pathology-transcending competencies

Planning, providing and integrating care

! vulnerable child!

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:

- Knowledge:

Stages of cognitive and emotional development from infancy to adolescence

Biological function of the attachment system, attachment behaviour and style

Risk factors affecting the role of parent-child attachment and relationship

Common predisposing and protective factors related to mental health

Long-term effects of trauma and neglect in the first years of life

Regulatory disorders of infancy and early childhood

Common emotional and behavioural problems in preschool and school-age children

Factors influencing learning and school performance

Definition and clinical presentation of intellectual disabilities, attention deficit/hyperactivity disorder or autism spectrum disorders

Indications for specific genetic and metabolic tests and imaging tools in children with intellectual disabilities

Diagnostic criteria of somatoform disorders (SFD) and chronic fatigue syndrome (CFS)

Basic investigations in cases of possible SFD and CFS

Clinical features and presentation of emotional disturbances (e.g., anxiety, depression)

Clinical features of acute psychosis

Be familiar and collaborate with colleagues and caregivers from the preventive youth health and wellbeing sector as well as the mental health sector

- Skills:

Evaluation and diagnostic formulation of common emotional and behavioural problems in preschool and school-age children

Management strategies and counselling for common emotional and behavioural problems including referral as appropriate

Parent/child communication in case of possible SFD

Initial assessment of a child with intellectual difficulties, hyperkinetic disorder or autism spectrum disorder

Using rating scales and questionnaires for assessment of mental health problems

Apply the principles of trauma-sensitive care

GENETICS AND DYSMORPHOLOGY:

- Knowledge base:

Principles of dysmorphology and syndrome identification

Basis of genetic and molecular techniques

Ethical and social implications of genetic testing

- Skills:

Construction and interpretation of a family pedigree

Recognition of common genetic, chromosomal and dysmorphic syndromes

Genetic counselling related to common conditions

Ability to access genetic databases

Understanding the meaning of genetic results

Ability to address specific health issues in newborns and children with dysmorphia, syndromes, complex pathology or rare diseases

NEONATOLOGY:

- Knowledge

Epidemiology: Outcomes for survival and factors influencing outcome

Prematurity and low birthweight sequelae (short- and long-term; prevention where possible)

Neonatal nutrition and feeding, including maturation of oral skills and support of breastfeeding,

Congenital malformations, major and minor including surgical/cardiac malformations

Respiratory conditions, RDS, BPD, respiratory prevention after discharge including RSV prophylaxis, familial vaccination

Neonatal neurology including hypoxic ischemic encephalopathy/ hypotonia/seizures

Drug withdrawal

- Skills

Ethical principles involved in the management of the dying baby

Prescribing for newborns and breastfeeding mothers

Basics in infant- and family-centred care/NIDCAP (newborn individualized developmental care and assessment program)

PRE- PERI- AND POST- SURGICAL CARE:

- Knowledge:

Basic principles of pre-operative assessment

Basic principles of surgical referrals

Principles of peri-operative management

Principles of post-operative management, including pain/fluid management

Know high-risk patient factors

- Skills:

Be able to diagnose specific complications related to surgery

Able to take care of surgical wounds

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:

- Knowledge base:

Physiology and pathophysiology of host defence mechanisms

Common and specific infectious agents

Appropriate and safe prescribing of antibiotic or antiviral therapy

Principles of infection control

Principles of immunisation and national policy

Patterns of antimicrobial resistance / safe prescribing

Use of diagnostic tests, culture methods bacterial & viral

- Specific conditions:

Pyrexia/fever of unknown origin

Communicable disease control/prevention/immunisation

Tuberculosis

HIV

Acquired and congenital immunodeficiencies

Travel medicine / infections / immunisation in patients with CCN and rare diseases

Covid disease, MIS-C

- Skills:

Taking history in infectious diseases

Care of child requiring isolation

Considering development of resistance

Being able to address parental vaccine hesitancy

SPORTS MEDICINE:

- Knowledge:

Understand common sports injury and treatment in relation to the complex medical condition

Understand the importance of regular exercise to promote good general health despite the complex medical condition

Understand the importance of skeletal maturity and the influences of the complex medical condition in dictating the appropriate type of training

Understand the risks due to incomplete healing of previous injury

Understand the risks of contact sports in children with complex care needs

- Skills:

Physical examination of the musculoskeletal system.

Recognition of examination findings that are consistent with common sports injuries.

- Adolescents and young adults

ADOLESCENT MEDICINE:

Knowledge:

Legal and ethical principles dealing with adolescents

Normal bio-psycho-social development of puberty in boys and girls

Level of cognitive reasoning in early, middle and late adolescents

Influence of family and peers in modelling adolescent behaviour

Epidemiology of the pattern of social and sexual behaviour at various ages

Gender and sex identity

Safer sex practices, sexually transmitted infections, contraception and post-coital contraception

Causes of delayed puberty

Impact of chronic conditions on adolescent social, psychological and physical development

Transition from paediatric to adult care

Skills:

Effective communication, developing a professional relationship with adolescents, including evaluation of compliance

Discussion with a young person the concept of confidentiality and assent/consent depending on the degree of his/her maturity and in accordance with the local legal guidance

Assessment of growth and development including sexual maturity rating (Tanner stages)

Assessment and diagnosis of substance misuse, violence and risk-taking behaviour

Assessment of suspected psychiatric symptoms using validated screening questionnaires

Assessment and diagnosis of eating disorders

Assessment and delivery of anticipatory guidance of healthy lifestyle including eating habits, physical exercise and media

Planning, providing and integrating care for adolescents

Appendix 6

Competences for diagnosing, monitoring and treating an acute severely ill child/adolescent

⇨ Level 2 N* - High Dependency Unit Child

1st hour Care AND High Dependency Care

Knowledge base:

- Pathophysiology of shock / respiratory failure / cardiopulmonary arrest
- Principles of monitoring: invasive / non-invasive, biochemistry
- Fluid & electrolyte management in the acutely ill patient
- Assessment and triage for transfer to Medium or High care
- Intra & inter-hospital transport
- Child protection issues

Specific conditions:

- Assessment/ triage of the acutely ill child
- Acute respiratory distress, hypoxia
- Shock, severe hypotension and hypertension
- Sepsis
- Acute allergy/anaphylaxis
- Acute febrile illness
- Burns
- Diarrhoea / vomiting / dehydration
- Hypoglycemia
- Seizures
- Syncope
- Coma
- Trauma: abdominal / multisystem / head / limb
- Wound and laceration evaluation and basic management
- Special needs children in emergency department

Skills:

- Resuscitation, including access
- Acute seizure intervention
- Patient stabilisation and transfer skills
- Analgesia in children

SUBSTANCE ABUSE/TOXICOLOGY/POISONING

- Knowledge base:

Common substances abused / age profiles

Common childhood poisonings / exposures

Epidemiology of poisoning: local / global / age demographics

Poison centres / operating procedures / poison information data / online

Toxicology signs and symptoms

Types of ingestions / poisonings

Community and home chemical hazards: pesticides / industrial waste / occupational home renovation risks, lead poisoning

Poisoning as possible sign of child abuse / neglect

Poisoning by unknown agent

- Specific conditions:

Paracetamol poisoning

Specific therapies elimination measures/antidotes

Toxins: button batteries / coins / iron / ethylene glycol

Plants / complementary medicines / over the counter medicines

- Skills:

Assessment / vital signs, monitoring / history taking

Acute management

Diagnosis: clinical assessment / laboratory methods, screening methods

DERMATOLOGY:

Recognize and manage dermatological emergencies (e.g. Steven-Johnson, ...)

Recognize petechiae

Plan and manage appropriate treatment

ENT DISORDERS:

Interpretation of soft tissue X-rays in acute upper airway obstruction

Institute the appropriate treatment for acute laryngitis with respiratory distress

ENDOCRINE DISORDERS AND DIABETES:

Ability to manage acute diabetic ketoacidosis, including assessment of major complications

Ability to manage acute hypoglycaemia, including an understanding of the importance of glucose

HAEMATOLOGICAL AND ONCOLOGY DISORDERS:

- Knowledge base:

Physiology and pathophysiology of bone marrow derived cells

Pathophysiology of anaemia and haemolytic diseases

Risks and benefits of blood transfusion

Principles of management of cancer

Short and long term side effects of chemotherapy and radiotherapy

Indications for bone marrow transplantation

Principles of palliative care

- Specific conditions:

Anaemia

Sickle cell disease and thalassaemia's

Acute lymphoblastic leukaemia

Lymph node enlargement, lymphadenopathy

Hodgkin and non-Hodgkin lymphoma

Medullo-, neuro-, nephro-, hepatoblastoma

Coagulation disorders, haemophilia

Common causes of neutropenia

Common causes of purpura

- Skills:

Taking history in hematologic and oncologic disorders

Ability to assess children presenting with haematological or oncological conditions

Interpretation of blood smears results

Acute management of child with febrile neutropenia

Management of long term central lines

Care of child requiring isolation

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:

- Knowledge base:

Physiology and pathophysiology of host defence mechanisms

Common infectious agents: epidemiology / pathogenicity / characteristics

Common infant and childhood infections: viral / bacterial / fungal / parasitic

Appropriate and safe prescribing of antibiotic or antiviral therapy

Principles of infection control

Patterns of antimicrobial resistance / safe prescribing

Use of diagnostic tests, culture methods bacterial & viral

- Specific conditions:

Pyrexia/fever of unknown origin

Acquired and congenital immunodeficiencies

Covid disease, PIMS

- Skills:

Taking history in infectious diseases

Ability to assess child presenting with infectious disease

Care of child requiring isolation

Hygiene

Adequate prescribing

Considering development of resistance

METABOLIC MEDICINE:

- Knowledge:

Principles of metabolic disorders: mitochondrial beta-oxidation, lipids, carbohydrates and aminoacids; storage diseases

Metabolic crisis

Common presentations of metabolic disease (including encephalopathy, neurodevelopmental regression, weakness, visceromegaly and poor growth)

- Specific Conditions:

Acute metabolic presentation in the infant

- Skills:

Adequate sampling of biomaterials

Consider underlying metabolic disease in unclear clinical presentation

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:

- Knowledge:

Risk factors affecting the role of parent-child attachment and relationship

Common predisposing and protective factors related to mental health

Long-term effects of trauma and neglect in the first years of life

Regulatory disorders of infancy and early childhood

Common emotional and behavioural problems in preschool and school-age children

Factors influencing learning and school performance

Clinical features and presentation of emotional disturbances (e.g., anxiety, depression)

Clinical features of acute psychosis

Be familiar and collaborate with colleagues and caregivers from the preventive youth health and wellbeing sector as well as the mental health sector

- Skills:

Using rating scales and questionnaires for assessment of mental health problems

Assessing Mental health and trauma after every ICU admission

Apply the principles of trauma-sensitive care

NEUROLOGY AND NEUROMUSCULAR DISORDERS:

- Knowledge base:

Pathophysiology of common disorders affecting the nervous system (including neuromuscular)

Principles of antiepileptic drugs

- Specific conditions:

Meningitis

Acute encephalopathy

Febrile and afebrile seizures

- Skills:

Acute management of seizures, meningitis, (sub)-coma

Basic concepts of imaging and indications of the different modalities : CT, MRI and ultrasound

Lumbar puncture and interpretation of results

Ability to communicate with (disabled) children and their families

PRE- PERI- AND POST- SURGICAL CARE:

- Knowledge:

Basic principles of pre-operative assessment

Principles of perioperative management

Principles of post-operative management, including pain/fluid management

Know high-risk patient factors

- Specific conditions:

Acute abdomen

Acute scrotal pain

Bowel obstruction; intussusception; pyloric stenosis

Appendicitis

Abscess

- Skills:

Be able to diagnose acute abdomen, peritonitis, ileus

Able to take care of surgical wounds

NEPHRO-UROLOGY DISORDERS:

- Knowledge base:

Renal physiology and pathophysiology, principles of fluid balance, electrolyte and acid base regulation

Drug prescribing in renal failure

- Specific conditions:

Haemolytic uraemic syndrome

Common causes of hypertension

Indications for renal dialysis and transplantation

Acute scrotal pain and torsion

- Skills:

Interpretation of urinalysis, microscopy, dipstick

Interpretation of biochemical investigation results

Recognized renal failure

RESPIRATORY DISORDERS:

- Knowledge base:

Physiology and pathophysiology of the respiratory system in children, including age dependent changes

- Specific conditions:

Acute or recurrent stridor

Acute respiratory distress

Asthma

Haemoptysis

- Skills:

Recognize and respond to respiratory distress and respiratory failure

⇨ Level 3 – Paediatric Intensive Care Unit

A candidate-specialist for a level 3 professional title in PICM must hold a level 2 professional title in

Paediatric Medicine or in Anaesthesiology.

A training program in PICM results in theoretical and clinical competences in following modules:

Theoretical modules (Non-limitative)

'Basic' level

o Anatomical aspects

o Physiological and metabolic aspects

o Respiratory physiology

o Cardiorespiratory interactions

o Pathophysiology of shock

o Acid-base equilibrum and disturbances

o Water- and electrolyte homeostasis

o Coagulation pathways

Monitoring

o Respiratory monitoring

o Hemodynamic monitoring incl cardiac output monitoring

o Neurologic monitoring

o Metabolic monitoring incl calorimetry

Therapeutics

o IV fluids

o Pharmacotherapy

o Blood transfusion

o Vasoactive medication

o Antibiotics

EPALS/APLS

Ethics

o Patient rights, rights of the child

o Organ donation procedures

o Medical responsibility

o Patient safety/incident reporting

Level ‘advanced’

Respiratory I

o Intubation/(difficult) airway management

o Principles respiratory support

NIV and HFNO

IMV modalities

o Principles VV-ECMO

Respiratory II

o Paediatric ARDS

o Diagnostics and approach acute severe asthma

o Diagnostics and approach bronchiolitis

o Diagnostics and approach upper airway obstruction

o Diagnostics and approach acute barotrauma

o Interpretation imaging

Cardiovascular I

o Diagnostics and approach arrythmia

o Diagnostics and approach shock

o Diagnostics and approach heart failure

o Diagnostics and approach pulmonary embolism

o Diagnostics and approach hypertension

Cardiovascular II

o Physiology and diagnostics congenital heart disease

o Postoperative care after congenital cardiac surgery

o Pulmonary hypertension

o Vasoactive medication

o Cardiac pacing

o Principles VA-ECMO incl E-CPR

Hemato-oncology

o coagulopathies

o Sickle cell anaemia: Diagnostics and approach complications

o Tumour lysis syndrome

o Stem Cell transplantation and complications

o Thrombosis

o Immunodeficiencies on PICU

o HLH

Gastro-intestinal

o Nutritional aspects incl parenteral nutrition

o Acute gastro-intestinal bleeding

o Acute liver failure

o Principles and postoperative care after liver transplantation

o Paediatric surgical emergencies and perioperative care

o Abdominal compartment syndrome

Metabolic

o Severe diabetic ketoacidosis

o Severe fluid and electrolyte disturbances

o Diabetes insipidus

o Severe metabolic acidosis

o Acute presentation of inborn errors of metabolism

Renal

o Acute Kidney Injury

o Principles of RRT, incl PD, CVVH and haemodialysis

o Rheumatologic emergencies and immunosuppression

Paediatric neuro-intensive care

o status epilepticus

o acute coma

o CNS-infections

o Stroke

o intracranial hypertension

o Neurotrauma and neuroprotection

o Neuromuscular failure

o Procedural analgo-sedation

o Continuous analgo-sedation

o Withdrawal and critical illness neuropathy

o Principles multidisciplinary rehabilitation

o Approach, diagnostics and procedures non-accidental head injury

o Diagnostics brain death

Infectiology

o Community-acquired infections

o Hospital-acquired infections

o Sepsis and septic shock

o Antibiotic stewardship

Intra- and inter-hospital transport

o Organisation and teamwork

o Communication protocols and telephonic advise

o Transport protocols

Ethics

o Caring for the paediatric organ donor

o End-of life care

o Psychosocial aspects of a PICU admission

o Post-PICU follow up

o chronic patients on PICU: ethical considerations

o Limitation of care

Trauma/others

o ATLS/ETC

o Orthopaedic emergencies and perioperative care

o ENT-procedures and perioperative care

o Severe burns

o Intoxications

Technical skills (Non-limitative):

-IV access

-Arterial cannulation (US guided)

-Central venous cannulation (US guided) incl percutaneous haemodialysis catheter

-Intra-osseus access

-Nasogastric and nasoduodenal tubes

-CRRT management

-ECMO (VV- and VA-) management

-Paediatric Advanced Life Support (APLS of EPALS standard)

-Neonatal Life Support (NLS standard)

-POCUS (basics)

Academic modules

a) Science

-Severity of illness scores

-Evidence based medicine

-Basis statistics

-Interpretation research

b) additional modules, facultative: quality and safety.

-multi- and interdisciplinary communication and collaboration – human factors

-patient safety

-Audit of care processes

-Analysis and interpretation of clinical data

-Quality improvement

-Organisation and communication

-Reporting and analysis of (near) incidents

-Patient rights

-Communication with family and patients

Appendix 7

Competences for diagnosing, monitoring and treating an acute and severely ill neonate

Level 2 N* - High Dependency Unit Neonatology

Medical staff:
1st hour Care:
Neonatal Life Support Course (every ### years)
Minimal 6 months neonatology training/daily exposure
Minimal ### neonatal night-duties
Skills and Competences: Stabilisation and resuscitation of the newborn with particular regard to maintenance of temperature, timing of cord clamping, airway management, facemask ventilation, oxygen supplementation and physiologic monitoring. Insertion of catheters (umbilical and peripheral), establishment of intravenous infusion

High Dependency CARE (N*)
Neonatal Life Support Course (every ### years)
Minimal 6 months neonatology training
Minimal ### neonatal night-duties
Knowledge, Skills and Competences:
Principles of neonatal stabilisation/ resuscitation particular regard to maintenance of temperature, timing of cord clamping, airway management, facemask ventilation, oxygen supplementation and physiologic monitoring.
Foetal physiology and the physiology of extrauterine adaptation
Antenatal and perinatal effects on neonatal outcomes
Epidemiology: Outcomes for survival and factors influencing outcome
Prematurity and low birthweight sequelae
Growth aberrance: IUGR, SGA/LGA
Neonatal nutrition and feeding
Newborn screening
Neonatal jaundice/ Exchange transfusion
Congenital and neonatal infections
Congenital malformations, major and minor including surgical/cardiac malformations
Respiratory conditions, RDS
Neonatal neurology including hypoxic ischaemic encephalopathy/hypotonia
Drug withdrawal
Ethical principles involved in the management of the dying baby
Prescribing for newborns and breastfeeding mothers
Skills
Gestational assessment
Examination of the newborn at birth and 6 weeks examination
Neonatal resuscitation
Insertion of chest drain
Stabilisation and transfer of the sick neonate
Insertion of arterial catheters (umbilical and peripheral), establishment of intravenous infusion and percutaneous insertion of long intravenous lines
Blood sampling, interpretation of common laboratory tests, umbilical arterial and
Venous catheterization
Fluid management
Use of /imaging / point of care abdominal ultrasound/cardiac evaluation/cranial ultrasound interpretation
Communication with parents/family

NEONATOLOGY:

Knowledge base:
Foetal physiology and the physiology of extra-uterine adaptation
Antenatal and perinatal effects on neonatal outcomes, including infants of diabetic mothers
Epidemiology: Outcomes for survival and factors influencing outcome
Prematurity and low birthweight sequelae (short- and long-term; prevention where possible)
Growth anomalies: IUGR, SGA/LGA
Principles of neonatal stabilisation/ resuscitation
Introduction of mechanical ventilation and principles of assisted ventilation, non-invasive ventilation
Principles of surfactant and nitric oxide administration
Neonatal nutrition and feeding, including maturation of oral skills and support of breastfeeding, NEC
Prevention and treatment of neonatal hypoglycaemia
Newborn screening
Neonatal jaundice/ Exchange transfusion
Congenital and neonatal infections
Congenital malformations, major and minor including surgical/cardiac malformations
Respiratory conditions, RDS, BPD, respiratory prevention after discharge including RSV prophylaxis, familial vaccination
Neonatal neurology including hypoxic ischemic encephalopathy/hypotonia/seizures, use and value of neonatal neuromonitoring devices (aEEG, EEG)
Drug withdrawal
Ethical principles involved in the management of the dying baby
Prescribing for newborns and breastfeeding mothers
Indications for neonatal transfer to high-care unit
Skills:
Gestational assessment
Examination of the newborn at birth and 6 weeks examination
Management of healthy newborn
Neonatal resuscitation, including airway management/intubation
Emergency thoracocentesis
Stabilization and internal transfer of the sick neonate
Blood sampling, interpretation of common laboratory tests, umbilical arterial and venous catheterization
Placement PICC line (peripherally inserted central catheter)
Arterial blood gas by PAC (peripheral arterial catheter) or capillary
Fluid management of the neonate
Use of imaging/point of care abdominal ultrasound/cardiac evaluation/cranial ultrasound interpretation/IVH
Communication with parents/family
Basics in infant- and family-cantered care/NIDCAP (newborn individualized developmental care and assessment program)

DERMATOLOGY:
Recognize and manage dermatological emergencies (e.g. Steven-Johnson, …)
Recognize petechiae
Plan and manage appropriate treatment

ENDOCRINE DISORDERS AND DIABETES:
Ability to manage acute diabetic ketoacidosis, including assessment of major complications
Ability to manage acute hypoglycaemia, including an understanding of the importance of glucose
Testing and administration of glucose in patients with impaired consciousness

GASTROINTESTINAL AND HEPATIC DISEASES:
Specific conditions:

Necrotizing Enterocolitis
Common congenital conditions
Principles of oral rehydration and intravenous fluid therapy in neonates
Common causes of hepatitis
Common causes of jaundice
Malabsorption, including coeliac disease and cystic fibrosis

HAEMATOLOGICAL AND ONCOLOGY DISORDERS:
Knowledge base:
Physiology and pathophysiology of bone marrow derived cells
Pathophysiology of anaemia and haemolytic diseases
Physiology and pathophysiology of the coagulation system
Management of common non-malignant haematological conditions
Risks and benefits of blood transfusion
Principles of palliative care
Specific conditions:
Anaemia
Sickle cell disease and thalassaemias
Coagulation disorders, haemophilia
Common causes of neutropenia
Common causes of purpura
Skills:
Taking history in hematologic and oncologic disorders
Ability to assess children presenting with haematological or oncological conditions
Interpretation of blood smears results
Acute management of child with febrile neutropenia
Management of long term central lines
Care of child requiring isolation

INFECTIOUS DISEASES AND IMMUNODEFICIENCIES:
Knowledge base:
Physiology and pathophysiology of host defence mechanisms
Common infectious agents: epidemiology / pathogenicity / characteristics
Common neonatal infections: viral / bacterial / fungal / parasitic
Appropriate and safe prescribing of antibiotic or antiviral therapy
Principles of infection control
Principles of immunisation and national policy
Patterns of antimicrobial resistance / safe prescribing
Use of diagnostic tests, culture methods bacterial & viral
Specific conditions:
Perinatal infections
Pyrexia/fever of unknown origin
Communicable disease control/prevention/immunisation
Diarrhoea and vomiting
Pneumonia
Septic shock
Tuberculosis
HIV
Acquired and congenital immunodeficiencies
Travel medicine / infections / immunisation
Covid disease, PIMS
Skills:
Taking history in infectious diseases
Ability to assess the neonate presenting with infectious disease
Care of neonates requiring isolation
Hygiene
Adequate prescribing in neonates

Considering development of resistance

METABOLIC MEDICINE:
Knowledge:
Principles of metabolic disorders: mitochondrial beta-oxidation, lipids, carbohydrates and aminoacids; storage diseases
Metabolic crisis
Common presentations of metabolic disease (including encephalopathy, neurodevelopmental regression, weakness, visceromegaly and poor growth)
Genetic base of common metabolic disorders
Screening tests for metabolic disease
Basic dietary principles in the care of children with metabolic disease
Specific Conditions:
Acute metabolic presentation in the newborn and infant
Skills:
Adequate sampling of biomaterials
Newborn screening for metabolic diseases
Consider underlying metabolic disease in unclear clinical presentation

MENTAL HEALTH AND BEHAVIOURAL DISORDERS:
Biological function of the attachment system, attachment behavior and style
Risk factors affecting the role of parent-child attachment and relationship
Common predisposing and protective factors related to mental health
Apply the principles of trauma-sensitive care

NEPHRO-UROLOGY DISORDERS:
Knowledge base:
Renal physiology and pathophysiology, principles of fluid balance, electrolyte and acid base regulation
Renal imaging and function tests
Drug prescribing in renal failure
Specific conditions:
Vesicoureteral obstruction and reflux
Indications for renal dialysis and transplantation
Skills:
Measurement of blood pressure
Appropriate urine collection: catheterization / bladder aspiration
Interpretation of urinalysis, microscopy, dipstick
Interpretation of biochemical investigation results
Recognized renal failure

NEUROLOGY AND NEUROMUSCULAR DISORDERS:
Knowledge base:
Pathophysiology of common disorders affecting the nervous system (including neuromuscular)
Principles of antiepileptic drugs
Sensory deficits e.g. hearing and visual impairment
Specific conditions:
Meningitis in the neonate
Acute encephalopathy in neonate
Cerebral palsy
Hypotonia
Skills:
Acute management of seizures, meningitis, (sub)-coma in the neonate
Basic concepts of imaging and indications of the different modalities : CT, MRI and ultrasound
Lumbar puncture and interpretation of results

PRE- PERI- AND POST- SURGICAL CARE:

Knowledge:
Basic principles of pre-operative assessment
Basic principles of surgical referrals
Principles of peri-operative management
Principles of post-operative management, including pain/fluid management
Know high-risk patient factors
Specific conditions:
Bowel obstruction; intussusception; pyloric stenosis
Abscess
Skills:
Be able to diagnose acute abdomen, peritonitis, ileus
Able to take care of surgical wounds

RESPIRATORY DISORDERS:
Knowledge base:
Physiology and pathophysiology of the respiratory system in children, including age dependent changes
Specific conditions:
Acute or recurrent stridor
Acute respiratory distress
Skills:
Recognize and respond to respiratory distress and respiratory failure

Neonatal Intensive CARE
Level 3 recognition Neonatology

Level 3 – Neonatal Intensive Care

Specific recognition criteria physician specialist in Intensive Care Neonatology
(NIC - Neonatal Intensive Care - Level 3)
Version 14 11 2023

Neonatology training can be summarized in several modules, to be completed during each candidate's pathway:
A. Compulsory modules
B. Additional modules, but "mandatory" to function in an academic environment

A. Compulsory modules

1. Theoretical modules

The candidate shows at the end of his training knowledge of the basic principles, diagnostics, treatment and prevention in the following areas and knows the corresponding recent scientific literature on the following subjects:
Pregnancy and childbirth
As indicated above, the Medical Specialist with the professional title of Neonatology is competent to discuss with the obstetrician problems identified in the prenatal period, together with the Head of Maternal Intensive Care (M.I.C.).
Diseases of the mother prior to pregnancy but affecting it, medical complications of pregnancy in the mother as well as detected fetal anomalies and problems are fully described in the 2008 KCE Report 94B, specifically
- Annex 2 (Theoretical model, not pregnancy related pathology)
- Annex 3 (Theoretical model, pregnancy related pathology)
- Annex 4 (Theoretical model, fœtal pathology)

The Medical Specialist with the professional title of Neonatology will organize and lead (supervise) with the head of the M.I.C. department any multidisciplinary consultation, this with the Obstetrician, Neonatologist, Specialist in the relevant field (e.g. Pediatric Cardiologist), Midwife, Psychologist, Social Worker, Geneticist, Ethicist.
The result of this conversation is communicated to the parents jointly by the midwife, the neonatologist (and by the other specialists involved).
During this conversation, the place of the parents in the decision-making about the proposed care will always be respected. The various stakeholders will always put the main principles of ethics at the centre of their concerns. Finally, legal requirements must be integrated and respected. Adjustment at birth- Thorough knowledge of the physiology and pathophysiology of respiratory and cardiocirculatory adaptation and thermoregulation in the newborn.
- Knowledge of the normal evolution of saturation (SpO2) in a full-term neonate and in a premature infant.
- Knowledge of metabolic and neurological adaptation.
- Knowledge of the influence of any pharmaca & substance use in the mother

Transitional care and basic and advanced cardiopulmonary resuscitation

- As a leader, performs basic and advanced cardiopulmonary stabilization and resuscitation according to the latest recommendations (European Resuscitation Council (ERC), International Committee on resuscitation (ILCOR))
- Is an "NLS provider" (Newborn Life Support) and remains so (or accreditation through an equivalent course in other continent)
- Pays particular attention to maintaining optimal temperature and optimal timing of umbilical cord clamping

- Knows the SpO2 target values during cardiopulmonary resuscitation in a full-term neonate and in a premature infant
- Has particular attention to checking the receiving chamber and all its equipment, this before each resuscitation
- Interactive "debriefing" after each resuscitation led by a neonatologist; possibly (if video is used during care) analyse video recording afterwards (after informed consent obtained from the expectant parents and secure and anonymized storage of the recording).

Breathing difficulties
- Recognizing signs of respiratory distress
- Treatment of respiratory distress syndrome (RDS) in neonates, including indication (via ultrasound of the lungs), administration of surfactant via Less Invasive Surfactant Administration (LISA), Intubate Surfactant Extubate (INSURE) and monitoring
- Interpretation of blood gases and practical application in artificial ventilation - Comprehensive knowledge of the various forms of ventilatory support (see "manual skills" and "techniques") and oxygen administration
- Application of knowledge in analgesia, sedation and use of muscle relaxants in severe respiratory pathologies
- Knowledge of the pathophysiology of pulmonary bleeding and its treatment - Thorough knowledge of bronchopulmonary dysplasia (BPD), including the indication and side effects of postnatal steroids, the long-term respiratory and overall prognosis of BPD, monitoring after discharge, including home oxygen therapy
- Recognition and treatment of pneumothorax (chest drain placement) - Knowledge of the etiopathogenesis, differential diagnosis and treatment of apnoea and bradycardia in neonates- Knowledge of the indications for extracorporeal membrane oxygenation (ECMO) and organization of its performance with possible transfer to a reference centre

Cardiac and circulatory problems

- Recognition of the signs of Persistent Arterial Duct (PDA), confirmation by ultrasound and its targeted treatment according to the intrinsic complications of PDA - Diagnosis and treatment of arterial hypotension at different gestational ages - Diagnosis and treatment of heart failure and shock with reference to functional ultrasound (autonomy)
- Examination and treatment of neonatal hypertension
- Diagnosis, ECG interpretation and treatment of common arrhythmias - Differential diagnosis between cyanotic congenital heart disease and primary pulmonary hypertension; treatment of the latter (inhaled nitric oxide (iNO), pulmonary vasodilators, etc.)
- Knowledge of the place of echocardiography in the evaluation of congenital heart defects - Diagnosis and emergency treatment of ductus-dependent heart disease
- Multidisciplinary care (paediatric cardiologist) of congenital heart defects

Neurological problems
- Performing a complete neurological examination of full-term and preterm newborn

- Basic skills for observing the behaviour of a newborn in its environment: FINE level 1 training or equivalent- Intra- and periventricular bleeding in premature infants: thorough knowledge of aetiology, different stages, short- and long-term prognosis, treatment; detailed and objective communication with parents- Knowledge of other intracranial haemorrhages in newborns, traumatic or spontaneous - White matter disease: thorough knowledge of etiopathogenesis, the different stages, short- and long-term prognosis; detailed and objective communication with parents- Knowledge of the causes and semeiology of cerebral infarction ("stroke")- Neonatal hypoxic and ischemic encephalopathy (HIE): knowledge of the indication for therapeutic hypothermia, knowledge of prognosis; initiation and monitoring during therapeutic hypothermia- Knowledge of other causes of neonatal encephalopathy- Knowledge of aetiologies and treatment of neonatal convulsions- Development and initial treatment of neuromuscular pathologies

- Knowledge and identification of the major malformations of the central and peripheral nervous system
- Thorough knowledge and application of analgesia and sedation
- Recognition and treatment of withdrawal syndrome
- Interpretation of aEEG (amplitudo integrated EEG), Video-EEG and continuous EEG (in collaboration with neuro-paediatricians)
- Interpretation of brain imaging (ultrasound and MRI)Gastroenterological problems and nutrition-

Understanding of the importance and principles of neonatal nutrition
- Thorough knowledge of enteral and parenteral nutrition
- Knowledge of the indications and complications of long-term (prolonged) parenteral nutrition
- Knowledge of the many benefits of breast milk, the indication of donor breast milk (when own breast milk is not available) and the composition and indication of substitute milk; dialogue with the mother and respect for her choice
- Diagnosis and multidisciplinary treatment (paediatric surgeon, paediatric radiologist) of necrotizing enterocolitis (NEC)
- Pre- and postoperative treatment of newborns with congenital abnormalities of the gastrointestinal tract or liver and bile disease
- Recognition of the importance of monitoring and treating postnatal growth disturbance in high-risk infants
- Differential diagnosis between trivial versus complicated gastroesophageal reflux with judicious adjustment of examinations and treatments
- Pre- and post-operative management of newborns with congenital gastrointestinal tract abnormalities or liver and bile disease
- Recognition of the importance of monitoring and treating postnatal growth disturbance in high-risk infants
- Differential diagnosis between trivial versus complicated gastroesophageal reflux with judicious adjustment of investigations and treatments
- Development and possible transmission of a newborn with hepatobiliary pathology (e.g., bile duct atresia) or significant gastrointestinal pathology (e.g., occlusion, intestinal atresia)
- Administration of vitamin therapy (Vitamin D and K)Hematologic problems
- Perinatal management (in collaboration with obstetricians) of severe haemolytic disease of the foetus and newborn (including Rhesus disease and other allo immunizations); coordination and implementation of exchange transfusion
- Knowledge of screening for certain hematologic problems (e.g., haemophilia) and knowledge of multidisciplinary perinatal care (paediatric haematologist)
- Identification and treatment of polycythaemia and hyper viscosity syndrome - Transfusion management

Infectious and immunological problems
- Understanding the neonatal development of immunity and neonatal susceptibility to infection
- Diagnosis and treatment of congenital viral and parasitic infections
- Care of the newborn at risk for perinatal HIV infection
- Diagnosis and treatment of newborns with "Early-Onset Sepsis"
- Diagnosis and treatment of newborns with "Late-Onset Sepsis," including treatment of infections related to central lines and infections caused by multidrug-resistant bacteria (MRSA, ESBL and others)
- Knowledge of hygiene measures to prevent infections
- Knowledge of the major congenital and acquired immune deficiencies
- Active and passive immunization, including prevention of RSV and the classical and adapted vaccination schedule for premature infants

Metabolic and endocrine problems
- Development and treatment of disorders of carbohydrate metabolism, including transient and persistent hypoglycaemia, hyperinsulinism and hyperglycaemia

- Identification and development of the newborn with ambiguous genitalia (multidisciplinary care with paediatric endocrinologist and paediatric neurologist-surgeon)
- Identification and treatment of congenital endocrine disorders (multidisciplinary care with paediatric endocrinologist)
- Investigation, care and emergency treatment in suspected congenital metabolic disorders (multidisciplinary care with metabolic disease specialist)

Water-electrolyte balance and renal problems
- In-depth knowledge of the physiology of the internal environment, and in particular the rapid postnatal changes in body water distribution and trans epidermal water loss, especially in premature babies
- Thorough knowledge of aetiology and treatment of hypo/hypernatremia, hypo/hyperkalaemia, hypo/hypercalcemia
- Thorough knowledge of acid-base balance
- Anticipation and treatment of acute renal failure, including the organization and possible implementation of peritoneal or blood dialysis
- Treatment of congenital renal failure
- Treatment of prenatally diagnosed urinary tract abnormalities and organization of multidisciplinary follow-up (paediatric urologists and nephrologists)

Pharmacology
- Knowledge of the absolute and relative contraindications of medications during pregnancy
- Knowledge of the influence of maternal medications on neonatal adaptation (e.g., beta-blockers)
- Knowledge of the effect of drug use during pregnancy on the foetus and neonate
- Knowledge of how medications and drugs pass through breast milk
- Knowledge of pharmacokinetics of drugs in premature and full-term infants (e.g., antibiotics)
- Knowledge of toxicity and drug interactions
- Knowledge of the absolute and relative contraindications of medications during breastfeeding

Genetic abnormalities

- Identification and treatment of chromosomal abnormalities and frequent syndromes

- Diagnosis and primary treatment of the most common malformations
- Counselling parents when an inherited disorder is suspected and obtaining informed consent for genetic sampling
- Use of literature and specialized sites in the identification of complex syndromes
- Development and treatment of a newborn with multiple congenital anomalies; multidisciplinary counselling and possible transfer to a specialized centre

Musculoskeletal and skin disorders
- Knowledge, explanation screening and organization of follow-up in newborns with congenital hip dysplasia
- Administration (multidisciplinary with geneticist, paediatric radiologist, paediatric orthopaedist) of a newborn suspected of severe skeletal dysplasia
- Diagnosis and therapeutic management of infants with "metabolic bone disease of premature babies" (rickets)
- Recognition of the need to refer a newborn with severe skin disorders to a specialized centre (multidisciplinary care with paediatric dermatologist)

Imaging
- Knowledge of the indication and interpretation of radiographs, magnetic resonance imaging (MRI) and computed tomography (CT)-
interpretation of cerebral ultrasounds
- interpretation of pulmonary ultrasounds
- interpretation of functional cardiac ultrasounds (including the arterial tract)

Other
- Treatment (multidisciplinary with specialized ophthalmologist) of a child with significant prematurity retinopathy; complete information for parents
- Organization of follow-up by an O.R.L. specialist for a child suspected of hearing loss; full information for parents

Technical modules
Manual skills.
- Oral and nasal intubation in premature and full-term newborns
- airway treatment in a newborn suspected of having a difficult airway (use of Mayo cannula, laryngeal mask)
- Placement of a peripheral venous access- Placement of a peripheral arterial catheter- Placement of arterial and venous umbilical catheter
- Placement of an intraosseous access route
- Placement of a percutaneous central venous catheter
- Lumbar puncture for diagnostic and therapeutic purposes
- Drainage of the pleural cavity (needle exsufflation and placement of a chest drain)
- Pericardial puncture
- Puncture or drainage of the peritoneal cavity
- Bladder puncture and placement of a bladder catheter

The candidate should be competent in the indication, practical realization, limits and risks as well as interpretation of the techniques listed below:
- Neonatal cardiopulmonary resuscitation.
- Mask ventilation, using a T-piece and oxygen delivery guided by oxygen saturation measurement (SpO2)
- Installation and monitoring of non-invasive ventilation (High Flow, nCPAP, Minimal Flow)
- Installation and monitoring of invasive ventilation (all techniques including NAVA and HFOV)
- Thoracic transillumination
- Intratracheal administration of surfactant (including LISA and INSURE) and monitoring
- Transcutaneous blood gas monitoring, pulse oximetry
- Monitoring of respiratory and cardiac activity using monitoring devices
- Non-invasive and invasive blood pressure measurement
- Neurological monitoring by video-EEG, aEEG and/or NIRS
- Phototherapy and exchange transfusion
- Use and replacement of blood products
- Understanding the mechanical and electrical operation of incubators, open care units, resuscitation tables, ventilators and other assisted ventilation devices (C PAP, High Flow)
- Intramural and extramural transport of newborns in distress of life, including organization of the newborn, stabilization of the newborn before transfer, anticipation of possible complications and their treatment during transfer.

In the field of medical imaging, it is
- necessary to be able to autonomously perform and interpret the technique of cerebral ultrasound
- desirable, in consultation with the internship master, to master at least one of the following POCUS techniques:
- thoracic ultrasound (diagnosis of gas or fluid effusion, pulmonary aspect compatible with the indication for surfactant administration)
- hemodynamic cardiac ultrasound (ductus arteriosus and other hemodynamic assessment + screening for critical cardiac abnormality)
- ultrasound to locate the tip of a central venous catheter

B. Additional modules
Global quality and safety management.
The candidate has a thorough knowledge in the area of:- integral approach to care processes

- multi- and interdisciplinary cooperation
- patient safety culture
- follow-up and monitoring of care processes (critical)
- analysis and interpretation of data and its didactic presentation - continuous improvement according to quality cycles with support for quality improvement (planning, implementation and monitoring)
- organization and communication of transitions in the patient care process within and outside the hospital- reporting and analysis of (near) incidents
- concrete applications of regulations regarding patient rights in the broadest sense
- communication with healthcare providers, patients and their families

Organization of follow-up
- Performing a structured neurological examination on a full-term newborn
- Performing a neurological examination in a 2-year-old child
- Organization of follow-up of newborns at risk of neurodevelopmental disorders
- Diagnosis and referral of a child with a neurodevelopmental problem discovered during follow-up, in particular the demonstration of cerebral palsy (CP) or a neurosensory disorder, an eating disorder,...
- Organization of long-term follow-up of children with bronchopulmonary dysplasia, especially those requiring home oxygen therapy
- In all these cases, recognition of the importance of full and sincere communication with parents
- Knowledge of rehabilitation centres

Organizational, teaching and psychological skills
- Management of the care team (nurses, psychologists, social workers and doctors, etc.), even in difficult situations
- Personal involvement in local, national and international studies
- Personal involvement in postgraduate and continuing education (nurses and doctors)
- Close collaboration with the Department of Obstetrics and Prenatal Medicine
- Experience in conducting interviews with parents before and after birth
- Triage of patients, organization of transfers to other departments or other healthcare facilities
- Use of consulting physicians (paediatric cardiologists, paediatric neurologists, surgeons, geneticists, paediatric respirators, ophthalmologists, imaging specialists) and consideration of their opinions in the overall examination and treatment plan
- Identification of the psychosocial situation of the child and his family and multidisciplinary organization of possible follow-up
- Priority integration of parents in the overall care of the newborn (family-centred care)
- Organization of general and neurological follow-up of the patient after discharge (organization of follow-up is up to the neonatologist)Medical ethics, health economics and epidemiology

Medical ethics

Acquire the skills necessary for medical ethics care in the management of healthy and sick people. The training objectives are:
- Knowledge of the important notions of medical ethics
- Ability to independently use tools to facilitate ethical decision making

- Independent handling of ethical issues in typical situations (e.g., providing patients with information before an intervention, research on human subjects, end-of-life decisions and support)
- Indication of measures aimed at prolonging life in extreme cases while respecting ethical principles- Indication of measures aimed at not prolonging and/or shortening life in extreme cases while respecting ethical principles and the legal framework. - Assistance to parents in difficult situations (child with multiple abnormalities or with a
very unfavourable prognosis) by integrating them in the decision-making process and respecting their choices within the limits of the legal framework. The process must be

multidisciplinary and integrate all the parties involved (doctors from different specialties, nurses, psychologists, ethicists, cult representatives, etc.).- Counseling a family whose newborn is dying and family support after his death

Health Economics
- Acquire skills that enable judicious use of diagnostic, prophylactic and therapeutic resources in helping healthy and sick people.
The training objectives are:
o Knowledge of key concepts in health economics.
- Acquire skills that enable judicious use of diagnostic, prophylactic and therapeutic agents in helping healthy and sick people.
o Optimal use of the resources provided, taking into account the legal bases.
Epidemiology
- Know the mortality and morbidity rates in the perinatal period and the factors affecting them.- Know the methods for capturing perinatal data, at the national and local level, including procedures for declaring births and deaths. - Be able to provide data collection for quality improvement purposes (NIC Audit, etc.).
- Know the biostatistical methods that enable the analysis of epidemiological data, the design of studies and the adequate interpretation of scientific information

Appendix 7

General minimal transmural competences for paediatric nurses and nurses working with children (Proposal Vlaamse Vereniging voor Kinderverpleegkundigen)

Vlaamse Vereniging voor Kinderverpleegkundigen vzw

Transmurale Kinderverpleegkundige rollen en competenties

De competenties, kennis en bekwaamheid van een zorgprofessional, die betrokken is bij de zorg van een kind en het gezin, moeten binnen eender welke zorgsetting gelijkwaardig en gewaarborgd zijn. Met 'het kind' bedoelen wij de pasgeborene, de zuigeling, het kind, de adolescent en de jongvolwassene. Van 0 tot 18 jaar zoals omschreven binnen het UNCRC (United Nations Convention of the Rights of the Child).

Wij nemen de definitie van competentie over van de American Nurses Association uit 2010. Een competentie is een te verwachten en meetbaar niveau van verpleegkundige beroepsuitoefening die kennis, kunde, capaciteiten en beoordeling/inschatting integreert; dit gebaseerd op algemeen aanvaarde wetenschappelijke kennis en verwachtingen van het verpleegkundig beroep (American Nurses Association [ANA], 2010).

Als kinderverpleegkundige beroepsorganisatie zijn wij ervan overtuigd dat kinderverpleegkundige competenties transmuraal[95] moeten zijn. Er zijn verschillende basissen van waar we zouden kunnen vertrekken. Er is het CANMEDS-model, het Competency framework for paediatric nursing education programmes van de PNAE en de 'Core Competencies' van SPN (Society of Pediatric Nurses)[96]. Omwille van de duidelijkheid, overzichtelijkheid en focus op de pediatrie, vertrekken wij vanuit het model van de Society of Pediatric Nurses. Een integrale focus wordt gelegd op alle leefdomeinen binnen het transmurale traject en de technische handelingen of een specifieke zorgsetting vormen niet de basis voor dit competentieprofiel.

[95] Transmuraal: lettelijk betekent dit 'door de muren heen'. Met transmurale zorg bedoelen wij de zorg die een kind/gezin nodig heeft en/of ontvangt en dit over de grenzen van instellingen of organisaties heen en is breder dan de opdeling tussen eerste- tweede en derdelijnszorg. Zo kan dit bijvoorbeeld ook gaan over zorg op school.
[96] https://www.pedsnurses.org/core-competencies

Om competenties te ontwikkelen is het belangrijk om deze te vertalen in meetbare doelstellingen. Door het gebruik van het Competentiemodel van de SPN, wordt het éénduidig en overzichtelijk wat van de kinderverpleegkundige mag verwacht worden en hoever zij/hij in de ontwikkeling van een competentiegebied staat. Transmurale kinderverpleegkundige competenties en beroep zijn op deze manier veel meer dan enkel het uitvoeren van een verpleegkundige handeling bij het kind.

Onderstaande basiscompetenties zijn voor ons, als beroepsorganisatie, de minimale competenties waarover elke ervaren kinderverpleegkundige moet beschikken. Deze competenties zijn van toepassing bij de zorg voor élk kind, ongeacht soort zorg, moment en/of plaats van zorg. Ze kunnen daarom in meerdere of mindere mate doorgetrokken worden naar elke professional die betrokken is in de zorg rondom het kind en het gezin.
Het is belangrijk om aan te geven dat wettelijke bevoegdheid niet gelijkstaat aan kwalitatieve bekwaamheid[97]. Permanente bekwaamheid wordt enkel bereikt door opleiding, kennis en ervaring.
Boven op deze minimale basis kinderverpleegkundige competenties kunnen er nog extra aanvullende competenties nodig zijn binnen specifieke subdomeinen in de pediatrie zoals: NICU, PICU, kinderoncologie, kinderdiabetologie, PROSA (Procedure sedatie en analgesie), kinderpalliatieve zorgen, extramurale zorg, acute zorg, chronische zorg, …

[97] Wet inzake kwaliteitsvolle praktijkvoering in de gezondheidszorg' (22 april 2019): *Art. 8. De gezondheidszorgbeoefenaar verstrekt enkel gezondheidszorg waarvoor hij over de nodige aantoonbare bekwaamheid en ervaring beschikt.*
De gezondheidszorgbeoefenaar houdt in een portfolio de nodige gegevens bij, bij voorkeur in elektronische vorm, waaruit blijkt dat hij beschikt over de nodige bekwaamheid en ervaring.

Ontwikkelingsgerichte zorg	
Ontwikkelingsgerichte zorg op maat	• Observeert kind, gezin en context. Maakt inschatting van ontwikkelingsstadium van het kind en het gezin, detecteert noden en organiseert bijsturing zo nodig op de plaats waar nodig (transmuraliteit). • Houdt bij de zorg voor een kind rekening met de rechten van het kind, de patiëntenrechten, het EACH-charter en toekomstige evoluties. • Richt zich op de autonomie van het kind en het gezin (coach-gedachte). • Kan adviezen geven aan het kind en het gezin en daarnaast motiveren en instrueren • Gebruikt positieve en verbindende taal om de doelen te bepalen en te bereiken. • Is in staat zelfmanagement en zelfregie van het kind en het gezin te ondersteunen en te bevorderen. • Garandeert te allen tijde de veiligheid van het kind en rapporteert onveilige situaties na het veiligstellen van het kind (fysiek, emotioneel en psychisch). • Is in staat adequaat invulling te geven aan gezamenlijke besluitvorming met het kind en de andere betrokkenen. • Kan gesprekstechnieken toepassen, passend bij de ontwikkelingsfase van het kind en het gezin. Kan daarbij het juiste niveau van communicatie toepassen: luisteren, vragen stellen, parafraseren, spiegelen en gevoelsreflecties geven. • Heeft kennis over, van, voor gezonde voeding bij het gezonde en zieke kind in functie van hun leeftijdsniveau en aandoening.
Toewijding	
Samenwerking	• Is in staat te werken vanuit een gelijkwaardige, collegiale, respectvolle en open houding met het kind, het gezin, het sociale netwerk, de collega's binnen het interdisciplinaire team en andere samenwerkingspartners. • Is op de hoogte van het specifieke zorgnetwerk en multidisciplinaire samenwerking rond het kind en het gezin. • Is in staat een afweging te maken tussen inschakelen van ouders, mantelzorgers, vrijwilligers vs. Professionele zorgverleners. • Is zich bewust van zijn/haar autonome professie en neemt deze plaats in binnen een interprofessioneel team. • Kan binnen het team en samenwerkingsprocessen zijn/haar bijdrage leveren en zichzelf positioneren. • Kan zijn/haar visie op samenwerken formuleren, uitdragen en hiernaar handelen. • Kan op basis van kennis, bekwaamheid en competenties benoemen waar verantwoordelijkheid ligt van de transmurale kinderverpleegkundige zorgverlening. • Weet waar de eigen professionele competenties ophouden en kan adequaat doorverwijzen met respect voor keuzevrijheid van kind en het gezin. • Is in staat bij transmurale zorgverlening samen te werken met partners binnen en buiten de gezondheidszorg (leerkrachten, kinderopvang…). Neemt hier een coördinerende rol in op. • Kan een doeltreffend en doelmatig verslag opstellen op basis van ISBAR(R) en geeft een adequate overdracht aan de samenwerkingspartners • Kan optreden als bemiddelaar als er conflicten optreden binnen de samenwerking. • Kent het verschil tussen transmurale en integrale zorg en begrijpt het belang van de inzet op beide domeinen
Professionalisering	• Heeft kennis van de basisprincipes van de anatomie, fysiologie en pathologie van het kind binnen alle leeftijds- en ontwikkelingsniveaus (medisch, psychosociaal,)

	• Heeft kennis van de basisprincipes farmacokinetiek en farmacodynamiek bij baby's, kinderen en adolescenten • Heeft kennis van de ontwikkelingspsychologie, ontwikkelingsaspecten (lichamelijk, motorisch, cognitief, emotioneel, sociaal, biologisch en psychologisch), ontwikkelingsfases, ontwikkeling van zelfmanagement en coping stijlen van het kind • Heeft kennis van pathologieën, symptoomherkenning en behandeltechnieken binnen verschillende sub domeinen in pediatrische zorg. Zowel medisch als psychosociaal. Is in staat om bijkomende correcte informatie op te zoeken hierrond • Weet informatie terug te vinden over specifieke doelgroepen en subspecialisaties • Heeft kennis van medische alarmsignalen die een dreigende acute fysische achteruitgang voorspellen en kan de gepaste maatregelen nemen • Heeft kennis van signalen die een dreigende achteruitgang in psychosociaal welzijn voorspellen en kan de gepaste maatregelen nemen. • Kan uitstekend mondeling en schriftelijk communiceren volgens structurele principes zoals ISBAR(R), zonodig over eigen organisatiegrenzen heen • Is vaardig op het gebied van informatie- en communicatietechnologie en staat open voor innovaties op dit gebied. • Kan zichzelf ontwikkelen door zelfreflectie en zelfbeoordeling van eigen resultaten. • Is in staat eigen grenzen van bevoegdheid en bekwaamheid aan te geven en te onderbouwen in iedere situatie. • Identificeert maatschappelijke ontwikkelingen en zet deze duurzaam om in acties. • Heeft kennis over de rechten van het (zieke) kind • Houdt zich aan de verpleegkundige professionele waarden en normen, organisatieregels en wet- en regelgeving. • Gaat vertrouwelijk om met informatie, beroepsgeheim, privacy en GDPR • Is proactief op de hoogte van brede ontwikkelingen binnen het pediatrische zorglandschap en vakgebied en toetst deze ontwikkelingen op bruikbaarheid binnen het eigen werkveld en zorgcontext. • Werkt in een klimaat van vertrouwen tegenover het kind en het gezin waarbij de zorgverlener voorziet in een begripvolle zorgverstrekking met respect voor individuele keuzes en waardigheid. • Kan collega's en toekomstige kinderverpleegkundigen aanspreken op (on)professioneel gedrag. • Is een zelfbewuste beroepsbeoefenaar en draagt persoonlijk en professioneel kinderverpleegkundig klinisch leiderschap uit. • Kan omgaan met spanningsvelden zoals zakelijkheid-betrokkenheid (empathie), afstand-nabijheid.
Professionele ontwikkeling	• Begeleidt studenten en leidt (nieuwe) collega's op. Is in staat te fungeren als rolmodel voor (nieuwe) collega's en aankomende kinderverpleegkundigen. • Is in staat gezamenlijke verantwoordelijkheid te dragen voor het opleiden van een verpleegkundige tot kinderverpleegkundige heeft daarin een coachende en begeleidende rol. • Zet de collega kinderverpleegkundige aan tot de ontwikkeling tot een autonome zorgprofessional. • Heeft door het regelmatig volgen van bijscholingen kennis van actuele thema's en ontwikkelingen in het eigen vakgebied en het pediatrische zorglandschap • Stuurt het eigen handelen bij op basis van de feedback van het kind, ouders en andere zorgprofessionals.

Normen/Basisprincipes	
Gelijkheid/ Diversiteit/ Inclusie	• Bouwt een professionele relatie op met het kind en het gezin. • Streeft ernaar steeds dezelfde onbevooroordeelde, kwaliteitsvolle zorg te verlenen onafhankelijk van geslacht, religieuze overtuiging, politieke overtuiging, nationaliteit, sociale klasse, huidskleur, geaardheid, … • Staat open voor de mening en overtuiging van het kind en de andere gezinsleden. Tracht te bemiddelen als deze overtuiging een kwaliteitsvolle zorgverlening aan het kind in de weg staat. Durft beslissingen te nemen en te handelen als een overtuiging de veiligheid van het kind in gevaar brengt. • Kent de relaties tussen leefstijl, context, gezondheidsongelijkheid en gezondheidsproblematiek en probeert deze te verbeteren
Holistische zorg	• Houdt rekening met persoonlijke factoren, wensen en behoeften van het kind, het gezin en hun sociale netwerk. • Ziet en benadert het kind, het gezin en de omringende structuren als één geheel en heeft respect voor de manier waarop de personen elkaar beïnvloeden, met aandacht voor de veiligheid van het kind. • Is in staat de zorgvraag te inventariseren en analyseren en op basis hiervan een zorgplan op te stellen. • Tracht de zorg zodanig te organiseren dat het past binnen de manier waarop de patiënt en het gezin naar gezondheid en zorg kijkt en hoe zij dit zelf kunnen organiseren (streven naar zelfredzaamheid) • Heeft zowel aandacht voor fysieke als psychosociale problemen bij het kind en het gezin.
Patiënt en familiegerichte zorg	• Is in staat zich in te leven in het kind, het gezin en hun unieke context. • Kan een zorgrelatie met het kind en het gezin aangaan, gebaseerd op vertrouwen en gericht op zelfregie en zelfmanagement van het kind en het gezin. • Kan vanuit alle objectieve professionele kennis en informatie de zorg afstemmen op de unieke context van het kind en het gezin en gemaakte keuzes professioneel motiveren. • Heeft visie en deskundigheid rond omgaan met vroegere trauma's bij het kind en het gezin en hoe verder trauma te vermijden. • Vermijdt te allen tijde het gebruik van dwang in niet onmiddellijk levensbedreigende situaties. • Kan vaktaal voor kind en gezin omzetten in begrijpelijke taal. • Kent het belang van Comforttalk en het belang in de vertrouwensrelatie • Heeft kennis over oudermishandeling en intra familiaal geweld. • Heeft kennis van contexten en beïnvloedingsdomeinen rond het kind en het gezin. • Houdt in het handelen rekening met de wensen, behoeften en privacy van het kind en het gezin. • Is in staat het kind en het gezin te voorzien van constructieve feedback. • Kan verschillende copingstrategieën van het kind en het gezin inschatten. Deze benutten en/of versterken of bijsturen. • Kan het kind en het gezin ondersteunen bij het nemen van beslissingen over de behandeling (shared decision making).

Waarden	
Advocacy	• Informeert en begeleidt het kind en de familie over hun rechten; meer specifiek de rechten die betrekking hebben op gezondheid en zorg • Zal binnen de context van multidisciplinair overleg de belangen van het kind bewaken en verdedigen • Is in staat adequaat om te gaan met agressie, grensoverschrijdend gedrag en onbegrepen gedrag bij kind en gezin en hun sociale netwerk. • Kan adequaat handelen bij vermoeden kindermishandeling. Kan detecteren, signaleren, risicofactoren bepalen, specifieke communicatie gebruiken en hulpverlening inschakelen. • Door gepaste gedragsbeïnvloeding en empowerment begeleidt en ondersteunt de kinderverpleegkundige het kind en het gezin naar maximale onafhankelijkheid van professionele zorg zonder dit gezin 'los te laten'.
Ethiek	• Handelt binnen de moreel-ethische context van de zorgverlening. • Kent de wet- en regelgeving die van toepassing is op de verpleegkundige beroepsuitoefening en de context waarin zij/hij werkzaam is. • Houdt binnen het uitoefenen van zijn beroep rekening met de financiële draagkracht van het gezin en de organisatie. Gaat op een duurzame wijze om met de voorziene middelen. • Is zich bewust van eigen morele en ethische waarden en kan hier professioneel naar handelen. • Kan ethische vraagstukken en zingevingsvraagstukken bespreken met collega's en het kind en het gezin. • Is zich bewust van de eigen voorbeeldfunctie. Draagt de waardigheid van het beroep hoog in het vaandel
Kwaliteit van leven	• Is zich bewust van zijn/haar eigen visie op 'kwaliteit van leven' en waakt er over deze niet zonder meer te projecteren op het kind en het gezin. • Peilt naar visie over, van, voor kwaliteit van leven bij de patiënt en het gezin; helpt mee om dit bespreekbaar te maken. • Verdedigt de visie van de patiënt en het gezin binnen een multidisciplinaire zorgverleningscontext, waakt hierbij over de belangen van de patiënt. • Treedt mee op als bemiddelaar als er binnen het gezin tegengestelde visies zijn op wat 'kwaliteit van leven' is. • Is in staat zelfmanagement en zelfregie van het kind en het gezin te ondersteunen en te bevorderen met als doel de kwaliteit van leven in al de aspecten te behouden of verbeteren. • Kan de omschakeling van cure naar care begeleiden bij een palliatieve patiënt
Zorgverlening	
Zorguitvoering	• Kan B1 en B2 handelingen autonoom uitvoeren met inachtneming van eigen bevoegdheid, bekwaamheid en focus. • Observeert, schat de zorgbehoefte in, stelt de zorgplanning op, voert uit en evalueert. • Kan bij (complexe) problemen vroegtijdig herkennen, signaleren, doelen stellen, interventies kiezen en uitvoeren. Kan het verloop monitoren, resultaten evalueren en doelen bijstellen. Dit is een continu proces. Pleegt hiervoor het nodige overleg met andere zorgprofessionals en neemt een coördinerende rol op zich. • Gaat op verantwoorde wijze om met materialen en middelen.

	• Heeft kennis van actuele richtlijnen, protocollen en professionele standaarden
Zorgcoördinatie	• Behoudt het overzicht over de zorg die al aangeboden wordt, in aanvraag is of een meerwaarde zou kunnen zijn • Aanspreekpunt voor andere zorgverleners • Coördineert informatieverzameling en –verstrekking • Begeleidt kind en gezin in de organisatie van zorg rondom hen, met het oog op autonomie • Kan het patiëntendossier adequaat aanvullen om de kwaliteit en continuïteit van de zorg te bevorderen.
Zorgplanning	• Is in staat adequaat invulling te geven aan gezamenlijke besluitvorming (shared decision making) met het kind en de andere betrokkenen. • Kan doelen voor een zorgplan opstellen, evalueren en bijstellen en geeft uitvoering aan het zorgplan • Is in staat beslissingen te nemen over beleid (prioritisering) en middelen voor individuele zorg van het kind en het gezin waarbij een afweging wordt gemaakt op basis van kosteneffectiviteit. • Start tijdig in overleg met kind, gezin en andere zorgprofessionals de transitie naar volwassenzorg op.
Gezondheidsbevordering	• Geeft gepast gezondheidsbevorderend advies • Coacht/begeleidt • Heeft kennis van epidemiologie en adviseert binnen de juiste context. • Heeft kennis van preventie en gezondheidsvoorlichting, gezondheids- en gedragsdeterminanten bij het kind, het gezin en de sociale omgeving. Kan het kind en gezin adviseren en ondersteunen in het maken van juiste keuzes en deze toe te passen. • Kan zorgvrager ondersteunen bij gedragsverandering met behulp van individuele en groepsgerichte voorlichtings-, gespreks- en begeleidingsmethoden. • Stimuleert therapie adherence bij het kind en het gezin • Heeft kennis van het belang van preventieve begeleiding en zelfstandigheid om het kind en het gezin zo onafhankelijk mogelijk te maken van professionele zorg. • Kan interventies uitvoeren inzake collectieve preventie en gezondheidsvoorlichting.
Continue verbetering	
Evidence based zorg	• Kan eigen visie evidence based en context based onderbouwen met feiten, context argumenten en voorbeelden. • Heeft kennis van de principes van evidence based en context based practice en kan het toepassen. • Heeft elementaire kennis van methoden van (wetenschappelijk) onderzoek. • Kent de principes van reflectieve praktijkvoering en kritisch redeneren vanuit pediatrische achtergrondkennis en expertise. • Houdt vakliteratuur bij. Weet informatie adequaat op te zoeken en op waarde te beoordelen. • Kan de stappen van het gebruik van wetenschappelijk onderzoek doorlopen (vraag stellen, efficiënt en doelmatig zoeken, beoordelen, toepassen en evalueren). • Kan participeren in (praktijk)onderzoek.

	• Past EBP steeds toe binnen CBP (context based practice) en kan professioneel motiveren en onderbouwen waarom er in een specifieke situatie beslist wordt af te wijken van EBP in het belang van het kind en de kwaliteit/veiligheid van zorg. • Is zich bewust van/volgt nieuwe ontwikkelingen in de pediatrische zorg • Stelt zichzelf continu in vraag, en zoekt steeds naar verbetermogelijkheden
Outcomes	• Is in staat SMART doelstellingen te formuleren in overleg met het kind en het gezin • Kan deze doelstellingen monitoren, evalueren, interpreteren en bijsturen • Handelt naar een outcome gericht op een zo groot mogelijke autonomie bij het kind en gezin • Heeft kennis van impact van zorg, kwetsbaarheid, complicaties op het ontwikkelingstraject/uitkomst en integrale gezondheid op lange termijn. • Kent en werkt mee aan een beleid rond pijn, angst, vertrouwen. Heeft kennis over de invloed van traumatische ervaringen op lange termijn en het effect op latere zorgverlening.
Kwalitatieve zorg	• Kan werken volgens richtlijnen en protocollen en deze toepassen op specifieke situaties. Kan daarnaast beargumenteerd afwijken van richtlijnen en protocollen wanneer de specifieke zorgcontext daarom vraagt of eigen professionele en morele afwegingen daartoe aanleiding geven. • Stimuleren tot meedenken met beleidsmakers en voorstellen doen voor verbeteracties en verbeterprogramma's en deze uitdragen naar betrokkenen. • Kent en handelt naar veiligheidsbeleid (landelijk en in de eigen organisatie) en wet- en regelgeving omtrent veiligheid van medewerkers en zorgvragers. • Past standaard voorzorgsmaatregelen toe ter preventie van kiemoverdracht naar het kind. • Neemt (gedrags)regels en protocollen in acht, die horen bij beroepsmatige verantwoordelijkheid. • Kan op transparante wijze werken volgens de organisatie gehanteerde kwaliteitscyclus zoals bijvoorbeeld de PDCA-cyclus.

Appendix 9

Current conventions (multidisciplinary care) (Belgium)

1. Endocrine and metabolic diseases
   - Diabetes
   - Rare inherited monogenic metabolic diseases
   - Cistic Fibrosis
2. Blood and immune system (disorders of)
   - Hemophilia
   - AIDS
3. Disorders of the genital-urinary system
   - Pediatric Nephrology (Kidney Diseases in Children and Adolescents)
4. Respiratory diseases
   - Respiratory rehabilitation
   - Respiratory support
   - Oxygen therapy at home
   - Counselling sessions for asthma patients in the pharmacy
   - Cardiorespiratory monitoring of infants
5. Heart disease
6. Disorders of the circulatory system
   - Lymphedema
7. (Neuro)locomotor diseases and disabilities
   - Locomotor and neurological disorders (general)
   - Neuromuscular diseases
   - Hersenverlamming (CP)
   - Spina bifida
   - Occupational therapy
8. Mental and neurological disorders
   - Neurological Disorders Linked to Psychiatric Disorders in Children and Adolescents
   - Refractory epilepsy
   - Advanced neurological disease
   - Early Dementia – Memory Clinics
9. Chronic fatigue syndrome
10. Transgender a gender dysphoria
11. Childhood obesity
12. Diseases in infants or young children
    - Premature infants: follow-up examinations in specialised centres
    - Cardiorespiratory monitoring of infants
    - Sudden and medically unexplained death of young children
13. Chronic Paediatric Pathologies
    - Chronic conditions (residential treatment only)
    - Morbid obesitas
    - Consequences of maltreatment in children/adolescents (residential treatment only)

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