

INSIGHTS

30–31 March 2023

Different perspectives
on conducting research
into **intra-familial
maltreatment
of children and
adolescents**

CONFERENCE PROCEEDINGS



Introduction



Caroline Semaille,
Chief Executive, Santé publique France

It has been a great honour for Santé publique France to hold this two-day working seminar on the intra-familial maltreatment of children and adolescents. The opening statements by Charlotte Caubel, Secretary of State for Children, and Agnès Firmin Le Bodo, Minister Delegate for Territorial Organisation and the Health Professions attached to the Minister of Health and Prevention, show just how important these issues are on the political agenda.

Child maltreatment is a very sensitive subject, generating strong social demands and raising multiple challenges in terms of both care and prevention.

Child maltreatment, or more specifically intra-familial maltreatment, is a determinant of physical and mental suffering among children, with major repercussions on their psychological, emotional and motor development, learning, adaptability, resilience and life pathway.

In its 2020 report on preventing violence against children, the World Health Organization (WHO) called for the systematic implementation of child maltreatment prevention programmes based on epidemiological data and robust local experimental studies on the effectiveness of prevention.

The data currently available in France measure only part of the child maltreatment problem

In France, the epidemiological data currently available are fragmentary and document only part of the problem of child maltreatment. Statistical studies and research on the subject of violence against children continue to fall short of what we need in order to understand the full extent of the phenomenon. These children are still virtually invisible in public statistics today.

The data currently available measure only part of the maltreatment – mainly physical – and is often limited to cases reported as a result of their extreme severity.

These children are still virtually invisible in public statistics today.

What about the mental abuse and neglect of children and adolescents, for example? Or maltreatment that falls under the radar of the police, judiciary and healthcare system because not reported?

Several data sources could also be cross-referenced to supplement and monitor the changes in knowledge of child maltreatment. We therefore need to start by making them more visible and by building them in a complementary way (e.g. a multi-source project) in order to improve our approach to measuring the burden of maltreatment in France. To properly understand the extent of it, we also need to have reliable data on the nature, frequency, repercussions, management and impacts of maltreatment.

The aim is to build a knowledge base in order to better understand the extent of the phenomenon and to produce indicators on the determinants linked to the onset of situations of neglect and abuse. This will help guide public action, particularly in terms of prevention strategies, in order to move towards primary prevention actions in perinatal and mental health.

Santé publique France is already conducting a large amount of work on the subject through the production of indicators, prevention actions in perinatal care, and support for research.

The aim is therefore to build a knowledge base in order to better understand the extent of the phenomenon and to produce indicators on the determinants linked to the onset of situations of neglect and abuse.

Considering maltreatment as a public health issue requires working with different stakeholders

But the subject requires a systemic approach. Therefore, as a national agency, our question for these two days was: together, how can we equip our country with a surveillance system for maltreatment that will back public policy?

Indeed, considering maltreatment as a public health issue requires working with different stakeholders: those in the health, social, medical-social, justice, education and policing fields. These various stakeholders in France – many of whom were represented among the attendees of this seminar and I thank them for their presence – approach maltreatment differently according to their disciplines, institutions, interests and constraints.

This seminar for research stakeholders has enabled us to draw up an initial overview of the epidemiological knowledge available in France today, in order to identify the data that is lacking, and to develop and improve the understanding of this maltreatment, its circumstances and health repercussions through epidemiological population surveys. It has also allowed us to share the difficulties faced by research teams when implementing studies and to discuss possibilities and solutions.

The objective of the seminar was to encourage the development of epidemiological and public health research in this field, in order to identify the levers for implementing such studies. This work will provide an in-depth understanding of the burden of maltreatment and its determinants to guide public policy, in addition to the discussions initiated as part of the Assises de la Pédiatrie et de la Santé de l'Enfant (Paediatrics and Child Health Forum) launched in December 2022.

The first part of the seminar was devoted to the lessons provided by French and international studies. The second focused on different perspectives on the conduct of research, particularly in terms of good practices, cross-referencing of data sources and the question of consent. We hope that by sharing the difficulties and solutions surrounding these issues, researchers will be better equipped to tackle them.

I would like to thank each of the speakers for agreeing to share their work and thoughts over these two days.

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Opening statement by Minister Charlotte Caubel



Secretary of State to the Prime Minister,
responsible for Children

More than ever, at a time when information – sometimes true, often false – can go viral, public policy must combine genuine political commitment with rigorously-substantiated real-world knowledge.

In France, the fight against all child maltreatment is a major challenge that, more than any other among our public policies, must obey this precept.

The investigation of maltreatment – all maltreatment, in all its diverse forms and contexts – remains fragmentary in France. This was one of the observations made in the government's 2019 plan to fight violence against children: unlike other countries, France had no specific survey on violence committed during childhood.

Such surveys are crucial in order to better understand the origin of maltreatment, its long-term effects, and the profiles of the victims – both the children and the adults they become – as well as their needs. These studies are essential because in-depth knowledge of the maltreatment enables us to efficiently plan and design our intervention strategies in terms of both prevention and reparation.

Announced as part of the plan to fight violence against children, this seminar devoted to the research conducted on the intra-familial maltreatment of children and adolescents marks the embodiment of a strong political will: that of moving from the occasional denunciation of unbearable scandals to resolute action that is sustained over time and backed by a rethinking of working methods between professionals. But in order to take concerted action, reliable data are needed.

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In order to take concerted action, reliable data are needed

Over the past few years, the data collected have been as edifying as they are intolerable:

- 1 child is killed by one of its parents every 5 days, according to a study by the General Inspectorate for Social Affairs (IGAS), the General Inspectorate for Justice (IGJ) and the General Inspectorate for the Administration of National Education and Research (IGAENR) in 2018¹
- In 2020, at least 89 infanticides were committed – 49 of which were in an intra-familial setting – vs 53 in 2019
- 33,468 minors were victims of physical abuse in an intra-familial setting in 2020
- 19,598 minors were affected by exposure to intimate partner (domestic) violence in 2020, according to the National Observatory for Child Protection (ONPE)². Here, we must add the

work of Santé publique France on the subject of shaken babies: between 2015 and 2017, a total of 1,215 (probable and possible) cases were recorded, 52 per 100,000 live births³

- In 2021 in the Paris region, there were 32 cases of shaken babies, including 9 deaths, vs 17 in 2020, according to the Necker Hospital and Inserm⁴

And we cannot discuss intra-familial violence without reiterating the French Independent Commission on Incest and Child Sexual Abuse (CIIVISE) interim conclusions on incest⁵ from its reading of 5,317 questionnaires collected as part of a call for testimonies:

- 160,000 children are victims of sexual abuse each year in France
- For 8 out of 10 victims of sexual abuse during childhood and adolescence, their abuse involved incest; 7 out of 10 victims of incest experienced this abuse repeatedly
- Regarding incest, when the child did confide in a third party, the latter did nothing in 4 out of 10 cases⁶

However, these data are fragmentary and do not fully reflect the reality; their complexity calls for the construction of a global vision combining social, judicial and, of course, health insights.

The collection of these data raises real methodological questions, as the ONPE will remind us (see p. 13).

However, these data are fragmentary and do not fully reflect the reality; their complexity calls for the construction of a global vision combining social, judicial and, of course, health insights.

Devising appropriate prevention policies

This is how we will continue to encourage victims, particularly children, to speak out; this is how we will continue to improve how we listen to them; this is how we will be able to design appropriate prevention policies, particularly to support parents when overwhelmed or in difficulty; this is how we will be able to perfect our training and support plans for all professionals who work with children.

Allow me, in particular, to extend my personal thanks to the stakeholders who have been committed alongside us for quite some time: for the children concerned by child welfare measures, Dr Vabres, spearhead of the experimental care pathway Santé Protégée (see p. 20), and Dr Rousseau for his work within Pégase (see p. 24); Dr Balençon, a stakeholder in the Paediatric Units for Children in Danger (UAPED), and the Data Protection Authority (CNIL), represented here by Manon de Fallois (see p. 43), with whom we are fighting online abuse.

By deepening our knowledge of the different manifestations of intra-familial maltreatment, this seminar is also intended to be one of the cornerstones of a new plan, which I will have the opportunity to discuss in the coming weeks at the next Interministerial Committee on Children.

Beyond these methodological and scientific challenges, this seminar expresses our unwavering collective mobilisation for the cause of children.

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Opening statement by Minister Agnès Firmin Le Bodo



Minister Delegate for Territorial Organisation and the
Health Professions attached to the Minister of Health and Prevention

The maltreatment of children and adolescents takes multiple forms – physical, mental and sexual – and it often occurs behind closed doors within the privacy of the family sphere.

The data we currently have, despite being fragmentary, give an idea of the extent of this scourge. This seminar, which provides an overview of the research into intra-familial maltreatment, is essential.

It goes without saying that research must feed into public policies, particularly on a subject as complex and poorly understood as that being addressed at this seminar.

After long being taboo, victims of intra-familial maltreatment are speaking out. Quantifying, documenting, understanding better and acting better are essential. Because what is not quantified does not exist...

Research must feed into public policies, particularly on a subject as complex and poorly understood as that being addressed at this seminar.

I wanted to say a few words about our actions in this area and our perspectives. First and foremost, this is a subject on which we must work together: academia, professionals on the ground, associations, public decision-makers, local authorities.

To fight this scourge and provide the victims with redress, we need coordinated action. My ministry is fully committed to driving strong actions organised around two major projects:

- 1) Promoting the prevention, detection and reporting of maltreatment
- 2) Deploying appropriate victim care pathways across France

Reinforce continuing training for healthcare professionals

Healthcare professionals are on the frontline for detecting maltreatment. As trusted stakeholders, they are often confronted with situations of maltreatment and violence against minors in the context of their practice, against which they must act quickly and appropriately.

In this respect, we are strongly committed to the initial and continuing training of healthcare professionals.

The aim is to support them in improving their knowledge of maltreatment mechanisms, but also to strengthen their sense of legitimacy to act in the face of maltreatment: knowing how to identify it early, knowing how to guide the victims, knowing how to talk about it, and knowing how to respond to families that request support, if applicable.

Maltreatment and the screening for risk factors are part of the initial training of doctors and childcare workers. This training can be further enhanced, in particular through continuing professional development (CPD).

In addition, discussions will be initiated to incorporate specific aspects of this subject into the initial training programmes of midwives and general care nurses (registered nurses).

Facilitate reporting by healthcare professionals

Currently, only a small number of reports come from the medical and care communities. It is essential for professionals to be able to report the maltreatment observed and be supported in this process.

Following the initial work performed, the code of professional ethics for midwives will be the first to contain new provisions to clarify the reporting obligation and suspend any disciplinary proceedings. We are working in parallel with the other professional bodies in healthcare to bring about changes in this area.

Deploy appropriate care across France

France's Ministry of Health, in conjunction with all the stakeholders concerned, is working to structure specialised, graduated and coordinated care pathways for the minors concerned. This structure is based on several actions of the French plan to fight violence against children.

As such, we have developed Paediatric Units for Children in Danger (UAPED), which bring together, in the paediatric departments of hospitals, specialised healthcare resources and a child-friendly space where victims can be heard.

At the end of 2022, there were 135 UAPEDs (vs 88 in March 2022). The roll-out has continued in 2023 across all regional departments of France, with six that remain to be covered. By the end of 2025, 183 UAPEDs will be open. These units make it possible to provide care from the very first meeting; to receive the minor and interview them under conditions that are suitable and reassuring.

First and foremost, this is a subject on which we must work together: academia, professionals on the ground, associations, public decision-makers, local authorities.

Working in conjunction with the regional referral paediatric teams, the UAPEDs are also resource structures to support other healthcare professionals, particularly those working in community practice where they are more isolated.

Improve psychiatric care for child victims of maltreatment

Maltreatment suffered during childhood has negative mental health impacts in the short, medium and long term.

To promote the management of mental trauma, since 2018 we have deployed 15 Regional Psychological Trauma Centres (CRPs), which have seen an increase in their paediatrics resources following the *Assises de la santé mentale et de la psychiatrie* (Mental Health and Psychiatry Forum) of September 2021. The regional network to cover the entire French territory is continuing to expand.

The mission of these CRPs is twofold:

- Provide care for the victims
- Upskill other professionals involved in the management of psychological trauma

The necessity to be part of the reality on the ground

The conclusions of this seminar will contribute to improving the management of child victims of maltreatment. It is these occasions for reflection and discussion that bring about changes in practice.

Nevertheless, this is only useful when it is part of the reality on the ground. An example of this is Le Havre (a town I know well), where a Health-Safety-Justice-National education protocol was signed last week¹.

This protocol defines the care of children for whom one of the parents was murdered by their partner, in order to organise:

- The framework for action between the stakeholders required to act immediately after the tragedy;
- The immediate and systematic hospitalisation of the child victim in a paediatric department.

I will conclude by reiterating the work of the working group on child victims of maltreatment within the framework of the Assises de la pédiatrie et de la santé de l'enfant (Paediatrics and Child Health forum)², in which some of you are actively participating. At the end of spring 2023, this forum will give rise to the adoption of a child health roadmap, to which your seminar will undoubtedly add the voice of research.

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Session 1.1

Lessons from French
and international
studies:

**Definition and
framework**

Quantification of maltreatment: a national overview

Séverine Delaville and **Gaëlle Guibert**, National Observatory for Child Protection (ONPE)

France's National Observatory for Child Protection (Observatoire national de la protection de l'enfance, ONPE) is regularly called upon to quantify intra-familial child maltreatment. In accordance with its mission to ensure consistency of figures, in December 2022 it published a document that highlights the complexity of this work as well as the rigour required, and identifies existing national data sources.



The complementarity of two types of data sources now makes it possible to provide national quantitative information on this phenomenon. Survey data from the general population, questioning adults about the experiences of their childhood, give partial visibility to invisible and unidentified maltreatment, but do not make it possible to measure the phenomenon in real time. The utility of interviewing children and adolescents directly is complicated by the specific precautions to be taken (enhanced legal and ethical principles) and by the difficulty of accessing a population of children likely to reveal acts of maltreatment. Mobilising administrative data provides a snapshot of the maltreatment situations visible for a specific population, at a specific time, and makes it possible to monitor the changes in indicators between two periods.

Before mobilising data, the priority is to define exactly what we want to quantify. In the field of child protection, this scope is defined not only according to the forms of maltreatment (physical, mental and sexual abuse, neglect and exposure to intimate partner violence), but also according to the populations of children (general, in danger or at risk, protected). These scopes co-exist, juxtapose each other and their different contours can make comparing data more complex. Knowledge of the maltreatment is linked to what each figure is trying to describe, to what each data source shows. Quantifying intra-familial child maltreatment is complex because many situations remain invisible (unidentified and unaddressed). It is therefore essential to stress that the extent of the observed phenomenon is always underestimated.

Quantifying intra-familial child maltreatment is complex because many situations remain invisible (unidentified and unaddressed). It is therefore essential to stress that the extent of the observed phenomenon is always underestimated.

Analysing the data sources shows that maltreatment is rarely considered as a single phenomenon but rather in separate components, with some forms of maltreatment, such as neglect, studied less than others. Furthermore, the co-occurrence of several types of maltreatment makes it difficult to quantify the phenomenon in its globality.

Finally, it is essential to stress that a figure relating to maltreatment has meaning when it is linked to its context, backed up with its source, and associated with its methodology, with the population concerned and the precise definitions used. It is regrettable that figures are regularly cited in the public debate without being put into context and that they are extrapolated with a lack of care.

To conclude this introduction, while *the* figure for quantifying maltreatment is highly anticipated, it is the complementarity of the various existing data sources that will enable us to understand the phenomenon of maltreatment in all its dynamics.

Investigating abuse experienced in childhood and adolescence.

The Virage survey

Claire Scodellaro, demographer, Paris 1-Panthéon-Sorbonne University / French Institute for Demographic Studies (INED)

Alice Debauche, demographer, Strasbourg University

The Virage survey (Violences et rapports de genre; Abuse and Gender Relations) conducted in 2015 by the French Institute for Demographic Studies (INED) is the first survey in mainland France to investigate in detail abuse – mental, physical and sexual – experienced during childhood and adolescence, particularly in the family setting.

It is easier to interview adults than minors, particularly for ethical and legal reasons. The questions were therefore retrospective: 27,000 women and men, aged between 20 and 69 and living in ordinary households, responded mainly by telephone regarding the abuse they had experienced. The prevalences produced therefore evaluate the proportion of adults having experienced abuse during their childhood, and not the proportion of minors who were exposed to it.

Numerous partnerships, involving institutions and associations, were necessary to implement and fund this survey. The associations working against abuse contributed to preparing the questionnaire and to making proposals for support for the respondents who had been victims of abuse.

The questions on the abuse were structured by sphere of life (studies, work, relationship, etc.) and initially focused on the last twelve months. Familial abuse in childhood was questioned at two separate points in the questionnaire: in the social trajectory module, then in the 'family and close circle' module. These distinct contexts of questioning and different formulations led to partially discordant responses.

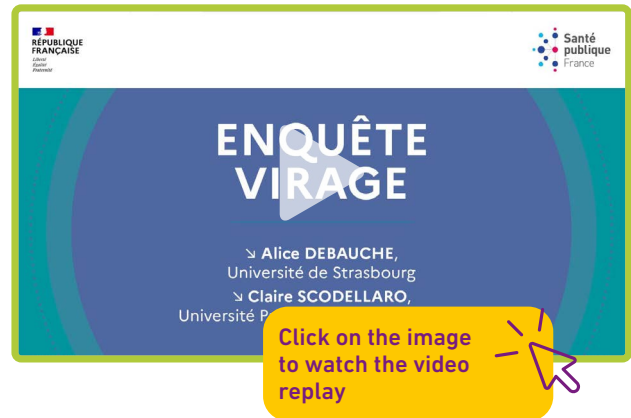
Based on a few general results concerning intra- and para-familial abuse (close circle, excluding partners) before the age of 18, we showed effects of sex and age in the reporting of abuse. Women reported domestic violence towards their mothers more than men, which could be linked to differences in the perception of abuse, the presence of children during the violence or exposure depending on the composition of the siblings. The respondents in the 50 to 69 years age group reported less childhood abuse, which could be explained by a higher threshold of tolerance for violence within the family ('right to discipline').

The Virage survey conducted in 2015 by the French Institute for Demographic Studies (INED) is the first survey in mainland France to investigate in detail abuse – mental, physical and sexual – experienced during childhood and adolescence, particularly in the family setting.

These retrospective surveys in the general population are subject to various biases:

- Selection bias: excess mortality of people having suffered abuse during childhood (general and mental health, suicide attempt, high-risk alcohol consumption), possible migration, and the non-inclusion in the survey of people living in institutions (prison, shelter, hostel, hospital, etc.) or without fixed abode, who are populations that have experienced more abuse than those living at home ('ordinary household').
- Recall bias: forgetting, approximation.
- Bias related to the identification of the abuse: different perceptions and qualifications according to age group.
- Bias related to the relationship with the investigators and the context of questionnaire completion.

These biases carry essential stakes for this type of survey and argue in favour of detailed and contextualised investigations on abuse, in order to promote the process of remembering and identifying/qualifying situations of abuse among the respondents.



International epidemiological studies

Andreas Jud, Chair of Epidemiology and Trends in Child Protection,
Ulm University, Germany

Measuring intra-familial maltreatment during childhood poses many methodological challenges to epidemiologists working on the subject.

Difficulties measuring intra-familial maltreatment

One of the main difficulties is the heterogeneity of the definitions and conceptual approaches (focused on the power differential or the act, for example) on which the epidemiological surveys are based. This heterogeneity, whether between countries or within a given country, results in significant differences in prevalence¹. We also note that there is little data on neglect, a form of maltreatment that is difficult to define and measure with epidemiological tools.

In the surveys, the broad diversity in the measurement instruments used, the methodologies, the sampling and the populations surveyed also affects prevalence levels, making comparisons within and between countries complex.

In 2015, a WHO report found that administrative data on the incidence of maltreatment were rarely standardised at national level and therefore it would not be possible to cross-reference data between the health, social and justice sectors². Yet cross-referencing these data or setting up multi-sectoral studies would make it possible to: quantify the different forms of maltreatment (physical, mental, sexual) and their co-occurrences; better understand and identify their social determinants and risk factors; and characterise the care and outcomes of these children.

Cross-referencing these data or setting up multi-sectoral studies would make it possible to: quantify the different forms of maltreatment (physical, mental, sexual) and their co-occurrences; better understand and identify their social determinants and risk factors; and characterise the care and outcomes of these children.

Moving towards shared definitions requires interprofessional consensus and an interdisciplinary approach. The European Euro-CAN³ network, which now comprises 35 countries, was created to encourage and promote the development of a rigorous, consistent and comparable methodology for the collection of surveillance data on child maltreatment and related deaths.

Current knowledge of the epidemiology of intra-familial child maltreatment

Today, thanks in particular to the results of retrospective surveys on the childhood experiences of adults, we have solid evidence on the high prevalence of this maltreatment. For example, in Germany in 2016, a total of 13.9% of adults reported having been a victim of sexual abuse in childhood (regardless of the reported subjective severity) and more than 10% of people reported moderate to extreme emotional neglect.⁴ However, these studies are unable to monitor the levels of maltreatment suffered by current generations. It is therefore essential to develop epidemiological studies on maltreatment with samples of children and adolescents.

In addition, despite the current methodological and conceptual differences, the state of knowledge agrees on different points:

- The frequent co-occurrence of various forms of child maltreatment.
- The identification of vulnerable groups: children housed (temporarily or not) without parents in institutions, children whose parents are unable to fulfil their protective duties (substance abuse), children surrounded by unrelated adults, children who are victims of sexual abuse, children whose self-protection and communication skills are limited compared to their peers.
- Girls are always more often victims of sexual abuse.

- Abuse is present at all ages, even during pregnancy.
- Physical abuse and neglect are more common in families living in extreme poverty (results of meta-analyses).
- The existence of a strong transmission of maltreatment between generations⁵.

However, many themes still need to be explored such as the subjective severity of the different forms of maltreatment, their chronicity and the context in which they occur.



To conclude on a hopeful note: epidemiological surveys have been in place for a long time in some countries and show a decrease in prevalence. This is the case in the United States, where the prevalence of physical and sexual abuse has fallen sharply since the 1990s.⁶ It therefore appears that the various actions carried out over the past few decades have produced positive results, particularly with regard to the prevalence of this abuse. However, neglect remains at a high level.

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Session 1.2

Lessons from French
and international
studies:

Care pathways

Santé Protégée: coordinated care pathways for protected children and adolescents

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In terms of health, protected minors – i.e. those subject to an administrative or judicial child welfare measure, whether in the home or in care – constitute a particularly vulnerable population with specific needs. Despite several studies showing serious shortcomings in the consideration of their overall health needs¹, it appears that only one third of them undergo a health assessment upon entering the child protection system. Carrying out an initial health assessment and subsequent repeat assessments is nevertheless a mandatory element of a child's personal plan and annual reports².

Santé Protégée is an experiment under the provisions of article 51 of the Social Security Funding Law (LFSS) 2018 to guarantee a coordinated care pathway for protected children and adolescents³. The aim is to improve the overall health of protected minors⁴ by facilitating their access to healthcare, its coordination and monitoring. It is supported by a network of hospital and community healthcare professionals.

Within this scheme, a set fee of €430 per child per year is paid by the French Social Security. This sum helps towards the cost of reviewing the prevention and health assessment performed upon entry into the child protection system and any subsequent annual assessments, via a volunteer general practitioner or paediatrician. It also helps to finance access to mental healthcare from psychologists, psychomotor therapists and occupational therapists working in private practice, coordination of the care pathway and training of professionals.

Santé Protégée is currently established in four regional departments: Loire-Atlantique, Pyrénées-Atlantiques, Haute-Vienne and Seine-Saint-Denis. It also includes minors monitored by the Directorate for Youth Protection and Juvenile Justice (DPJJ) in Loire-Atlantique. It relies on coordination structures in collaboration with the Departmental Councils and Regional Health Agencies, whose main purposes are to:

- Develop a network extending across France by identifying and mobilising volunteer healthcare professionals, self-employed or employed, in the public or private sector, in collaboration with Mother and Child Protection services (PMI), paediatric hospital departments including Paediatric Units for Children in Danger (UAPEDs) and the medical-social sector;
- Connect child protection professionals with healthcare professionals;
- Provide an online medical coordination tool, with examination forms standardised by age group, that is interoperable with the shared medical record and meets identified needs for the social and medical-social sectors;

Guaranteeing health equity for protected minors is the challenge facing the programme's roll-out.

- Expand the care offer, coordinate care and ensure access to early care for any pathology (including in mental health), disability or secondary disability, or complex situations, such as minors in prostitution;
- Train professionals to improve their skills regarding the needs of minors living under child welfare measures;
- Coordinate and ensure the sustainability of this network.

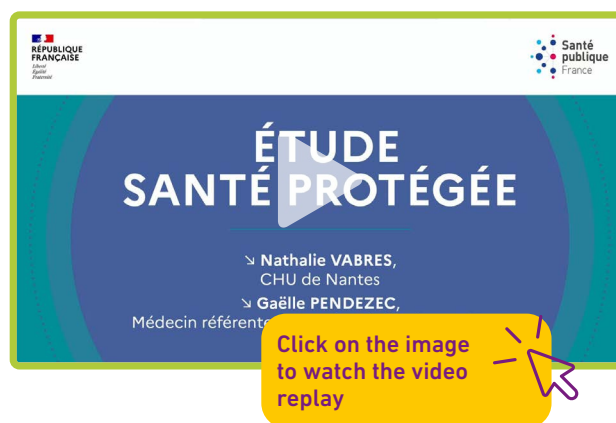
The coordination structure also guarantees the traceability of minors' medical data regardless of changes in the educational pathway or the end of this pathway.

Although the identification and mobilisation of community healthcare professionals worked very well, difficulties were encountered in funding coordination time in line with the increase in the number of minors included. Another technical difficulty is the range of different IT systems across the administrative structures, making it difficult to homogenise the data collected and extract them.

Santé Protégée aims to provide systematic access to early physical and mental health care for all children and adolescents subject to welfare measures, in accordance with French law. Several regional departments, aware of the challenges facing the health of this vulnerable population, wish to join the scheme.

Guaranteeing health equity for protected minors is the challenge facing the programme's roll-out.

Presentation prepared in collaboration with: Aline Ordureau (Santé Protégée Project Manager, Nantes University Hospital).



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Regulatory difficulties of confidential surveys on pre-diagnosis care pathway optimality

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Child physical abuse (CPA) is estimated to affect 4 to 16% of minors in developed countries¹. CPA is associated with bodily, cognitive, sensory, emotional and social consequences in the short, medium and long term²⁻⁴. The times to diagnosis reported in the literature are very long, exposing patients to repeat occurrences of violence on a worsening scale^{2,4-8}. With the aim of improving current practices by identifying recurring difficulties, we wanted to study the frequency, determinants and consequences of suboptimal care pathways prior to CPA diagnosis through two confidential studies – first retrospective then prospective⁹. We have shown that one third of children suffering from severe CPA treated at Nantes University Hospital had a pre-diagnosis care pathway deemed suboptimal by two experts¹⁰. This single-centre, retrospective, 'confidential' study on medical records obtained ethical and regulatory approvals without difficulty or delay. The parents were informed of the tacit non-opposition to the use of the data collected in the context of routine care by means of notices displayed in the hospital as well as in the welcome booklet of the department concerned.

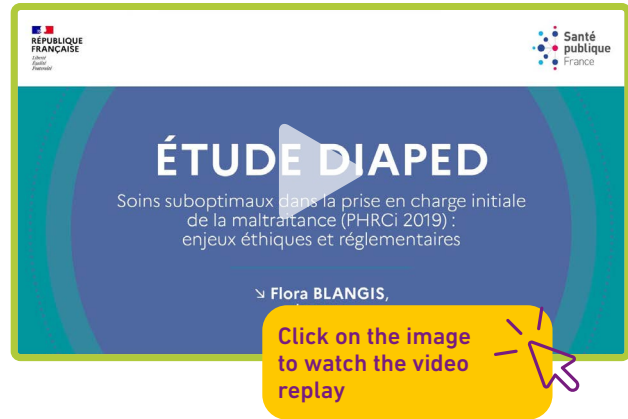
However, this study did not make it possible to analyse the determinants and consequences of the suboptimal care pathways. To investigate these areas, we obtained funding from the interregional Hospital Clinical Research Programme (PHRC) for a prospective study including the 17 hospitals under the jurisdiction of the Rennes Court of Appeal¹¹. This multicentre study raised ethical and regulatory questions surrounding the request to waive the obligation to inform individuals, and in relation to the notion of studying links between the quality of medical data, information/reports of concern, and judicial or administrative files.

As the patients are minors, the law states that the information can be given to and consent can be obtained from those legally responsible for them. However, since these people are often incriminated in these situations, the significant risk of opposition was likely to compromise the feasibility of the study and the reliability of the results. The request for exemption from the obligation to inform individuals meant that this study, classed outside of the Jardé law for research involving humans, was unable to be conducted according to the reference methodology MR-004 (see p. 41).

Once a favourable opinion was obtained from the Ethics and Scientific Committee for Health Research, Studies and Evaluations (CESREES), and after more than one year of discussions, the ethical and regulatory questions raised by this study were the subject of a deliberation by the French Data Protection Authority (CNIL), which granted the exemption¹².

Victims of CPA are the category of the French population in which there is the highest number of regulatory obstacles to conducting research aimed at improving knowledge and care. These obstacles must be removed.

A request was made for information to be provided on the Nantes University Hospital website and through notices displayed in the hospital. However, the anonymous study of the link between clinical data (diagnostic assessment, report or information of concern) and court decisions was not allowed. In conclusion, victims of CPA are the category of the French population in which there is the highest number of regulatory obstacles to conducting research aimed at improving knowledge and care. These obstacles must be removed.



Talk prepared in collaboration with: Christèle Gras-Le Guen (paediatrician, INSERM / Nantes University Hospital), Nathalie Vabres (paediatrician, Nantes University Hospital), Martine Balençon (paediatrician forensic pathologist, Rennes University Hospital / Hôtel Dieu Hospital / National Council for Child Protection), Anne Drouard (clinical study coordinator, INSERM / Nantes University Hospital), Martin Chalumeau (paediatrician, INSERM / Necker-Enfants Malades Hospital), Elise Launay (paediatrician, INSERM / Nantes University Hospital).

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French cohort studies on child protection. Why so rare?

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In the last two decades, there have been fewer than ten cohort studies in child protection, whether in France or elsewhere in the world. Yet such studies are essential because they make it possible to measure the individual and societal impact of maltreatment – in health, societal and economic terms – and to assess the potential benefits of organisational innovations aimed at preventing maltreatment or providing care for the victims over the long term.

By the end of the 19th century, the concepts of abuse and neglect, including their harmful effects on health and the beneficial effects of keeping victims safe, had already been described by clinicians. Since the middle of the 20th century, child psychiatrists and psychologists have been the only producers of the rare cohort studies on the effects of child maltreatment carried out in France¹⁻⁷.

These studies have shown that the frequency of neglect is significant, that it is associated with ongoing co-occurrences of abuse combining physical, sexual and psychological violence with

multiple and disastrous long-term physical and psychological consequences. These studies have also made it possible to observe and measure physical and psychological progress in children from the first few months of receiving appropriate care. Thus, in the Saint-Ex study (129 children monitored over 29 years) launched in 2008 by the team: one third of the children monitored are not presenting any problems at the start of adult life, which demonstrates that child welfare measures can be effective. Another third are showing signs of psychological suffering of varying intensity but without desocialisation. The last third is made up of people with mental and social disabilities. With such a heavy toll, astronomical human, social and economic costs⁸, it is one of the scourges of childhood where there is still the greatest room for improvement. Since 2019, Saint-Ex has been supplemented by the Pegase programme (1,200 children monitored for at least five years) and the Esper control cohort (800 children expected), which starts in 2023^{9,10}. These studies are based on solid links within the field, including the involvement of some 20 regional departments.

It is regrettable to note that in an area where major progress looks to be possible, these cohorts are virtually non-existent in France. One of the main reasons is the extreme difficulty in funding them due to a lack of strong institutional support and budgets earmarked for the subject of maltreatment.

It is regrettable to note that in an area where major progress looks to be possible, these cohorts are virtually non-existent in France. One of the main reasons is the extreme difficulty in funding them due to a lack of strong institutional support and budgets earmarked for the subject of maltreatment. For these studies, which go on for years, the funding parties often will not see their progress or results, which is an obstacle to convincing them to invest in setting up a cohort.

This scarcity not only deprives children of better responses, but it also deprives the scientific community and others of detailed knowledge about maltreatment and the futures of its victims; it deprives professionals of reference points and decision-makers of guidance for the implementation of public policies.



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Session 1.3

Lessons from French
and international
studies:

Hospital data

Algorithm for identifying physical abuse in young children from PMSI data

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In collaboration with the National Observatory for Child Protection (ONPE), we focused on identifying the physical abuse of children from hospital data. This form of maltreatment can more easily than others be defined on the basis of objective criteria, due to the injuries and its consequences.

We have developed an algorithm based on the codes of the International Classification of Diseases (ICD-10), which enables the identification of cases of physical abuse in children under 5 years of age in hospital databases. This algorithm has made it possible to identify, quantify and characterise traumatic injuries recorded as intentional and traumatic injuries suspected of being due to physical abuse^{1,2}.

With the support of Santé publique France, we set up a pilot study to validate the algorithm at Dijon University Hospital. By comparing the hospital stays identified by the algorithm with the data transcribed in the medical record (gold standard), we calculated the positive predictive value (PPV), to determine whether a stay identified by the algorithm corresponded to a stay linked to abuse in the medical record. The younger the children, the better the PPV: in children aged 1 month to 1 year, it reaches 95% for those with intentional traumatic injuries and 78% for those with suspicious traumatic injuries³. We used this algorithm during the COVID-19 health crisis and observed an increase in the percentage of children physically abused during the first lockdown⁴. These findings were sent to the Secretariat of State for Children from the end of summer 2020.

This algorithm has made it possible to identify, quantify and characterise traumatic injuries recorded as intentional and traumatic injuries suspected of being due to physical abuse.

In collaboration with Santé publique France, we also built an algorithm to identify head injuries caused by shaking (shaken baby syndrome) in infants under 1 year of age^{5,6}.

This research all revealed several limitations with regard to the use of hospital data, particularly in terms of exhaustiveness:

- Only certain forms of maltreatment (mainly physical abuse) are entered;
- Hospitalised children only represent the most serious cases;
- The fear of stigmatising the child and the pricing of the stays can lead to maltreatment being under-coded.

In order to continue and deepen this work, due to these limitations, we are currently working with various stakeholders in child protection, whether at local level (President of the Departmental Council, Public Prosecutor for Dijon) or at national level (Ministry of Justice, Ministry of the Interior, ONPE, Directorate of Research, Studies, Evaluation and Statistics). The aim of these collaborations is to have more comprehensive information, not just on child physical abuse, but also on the other types of maltreatment (sexual, mental) by linking, if possible, the databases of the judicial, home affairs, health and social care systems in order to better identify all children and to study their care pathways. With an awareness of both the regulatory and logistical complexity of such cross-referencing of data sources, we could nevertheless consider the construction of a barometer of maltreatment that would allow us to gather information from all sources and study the follow-up of abused children, regardless of the type of maltreatment.



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Identifying sexual abuse of minors from PMSI data

Pascal Mélihan-Cheinin, political sciences, Gustave Eiffel University

This study focuses on the use of data from the Information Systems Medicalisation Programme (PMSI), a previously untapped source of administrative data in France for this topic, except for the identification of physical abuse in infants¹.

Initially, three groups of lesions and medical causes were selected from the International Classification of Diseases (ICD-10) nomenclature: maltreatment, negative life events in childhood and problems related to primary support group.



The quality of the network collaboration and the interactions between the different players, the presence of active and highly connected resource centres (Forensic Medical Unit, National School for the Judiciary, Departmental Observatory for Child Protection) and the existence of collective training all influence care.

The mapping of these data relative to the number of inhabitants, cross-referenced with police data, made it possible to identify regions more affected by these codes: southern Brittany, Gironde, Ardennes and Reunion Island.

An additional investigation conducted in 2022 in Gironde and Brittany, involving around 20 experts from the fields concerned (police, gendarmerie, justice, child protection, paediatrics, medical information), concluded that the deviations observed were mainly due to heterogeneity in the way hospital departments coded maltreatment. The quality of the network collaboration and the interactions between the different players, the presence of active and highly connected resource centres (Forensic Medical Unit, National School for the Judiciary, Departmental Observatory for Child Protection) and the existence of collective training all influence care. This is also reflected in the PMSI coding. Gironde, a region where there is strong cooperation between the players, is where the highest number of recorded hospital stays for sexually-abused minors is observed, as well as the highest number of complaints for intra-familial abuse of minors to the national gendarmerie.

Furthermore, this additional investigation led us to refocus the study on the sexual abuse of minors, as the code 'Problems related to sexual abuse of child' appears sufficiently homogeneous to limit coding bias. For example, over the 2014–2022 period, consultations for sexual abuse more than doubled. Girls aged 6 to 17 are the most affected, a finding consistent with the data from the Virage survey². Nearly half of the care provided in Medicine, Surgery and Obstetrics (MCO) establishments involves psychiatry. Patients aged 25 to 85 who have been the victim of someone close to them are the age group that accounts for by far the most consultations, confirming the extent of the sequelae of these attacks. This exploratory research has shown that the PMSI is a source of possible data for estimating sexual abuse and its impact on health. This work also highlights the rich insight gathered using successive interviews with stakeholders from different sectors.

In the future, we need to continue investigations in the other regions identified. An estimate of the costs associated with consultations relating to the sexual abuse of minors should also be made.

All in all, these initial health impact data contribute to advocating for the development of a vigorous prevention strategy.

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Discussion

What do we need to **drive research** and implement **a system to monitor and track** this maltreatment?

On the first day of the seminar, teams from a wide range of backgrounds shared their experiences from their current and past work. These exchanges highlighted the difficulties encountered and avenues for developing the epidemiology of maltreatment. The text below is a summary of the main discussions that took place between the speakers and people present during the first day of the seminar. The discussions were led by Linda Lasbeur and Maud Gorza from Santé publique France, and Anne Oui from the National Observatory for Child Protection (ONPE).

Building shared and operational definitions

The forms of maltreatment are multiple and complex to describe and codify. Definitions and measurement tools, suitable for the implementation of studies and shared by the research teams, are necessary and have yet to be built.

The various studies on the definitions of forms of maltreatment and how to formulate them in surveys are not at the same stage. Physical abuse, which is relatively easier to qualify, is already the subject of epidemiological research. Questions remain – for example, should shaken baby syndrome be isolated from other forms of physical abuse? The research on sexual abuse has shown that the lexicon used to interview people, based on the description of facts, has an impact on the quality of the indicators collected. Attention is also paid to the importance of properly naming this abuse so as not to convey problematic representations (we refer in French to sexual violence against children and not sexual abuse).

Questions about definitions are being raised more urgently for certain forms of maltreatment, which have been the subject of recent research:

Neglect

Neglect is a form of maltreatment which is much more complex to observe and qualify than the others. It is identified remotely by the effects on the child's development and its definition is the subject of debate. The Center for Disease Control and Prevention (US CDC) includes exposure to intimate partner (domestic) violence¹ in its

definition of neglect, while it is also considered a form of maltreatment in its own right. France's ONPE held a research seminar with specialists from different backgrounds² in order to increase their understanding of this form of maltreatment and establish an overview of the situation at national and international level.

Ordinary educational violence

Ordinary educational violence was recently prohibited in France (law no. 2019-721 of 10 July 2019 on the prohibition of ordinary educational violence). The definition of this violence for research purposes still needs to be determined. This is so important as it is still difficult to define and its impact on the development of children is poorly documented in France.

Work on the repercussions of such violence on the development and physical and mental health of children also needs to be expanded. The fact that the child has reached full development makes this work complex and requires appropriate definitions and concepts. The concept of complex psychological trauma has been mentioned by some.

The following points should also be noted:

- Depending on the elements studied, the factors of repetition and duration must be taken into account and question the definition of the thresholds to be used, which may differ depending on the objectives of the data collection (for studies, for care, etc.)
- The need to integrate a socio-historical approach and more generally the relevance of working in a multidisciplinary manner

Several participants mentioned the need to develop modules of standardised, short questions in the studies, making it possible to obtain information on adverse life events in childhood (...) the systematic inclusion of these questions would make the issue more visible.

These exchanges show that there is a need to build definitions and shared operational measurement tools for the implementation of studies with a comparable basis. Some of these tools can also be used by teams in the field (such as the ASQ-3 scale used in the Pegase project; see p. 24). This work must include coordination with stakeholders in the field, who use definitions and enter data that meet objectives different to those of research. With a view to setting up an epidemiological surveillance system, it is essential to clarify and understand the differences that may exist depending on the definitions and tools used.

Research and studies

Maltreatment suffered in childhood: a health determinant to include in surveys?

Several surveys, whether past, current or future, include questions relating to negative life events in childhood, including the different forms of maltreatment. The following were mentioned: the National Survey on Abuse and Gender Relations (Virage)³, the Mental Health of Prison Leavers survey (SPCS)⁴, the Medical-Psychological Study of Adolescents Placed in Closed Educational Centres⁵, the INSEE survey on homelessness planned for 2025, and the Evane survey on the experiences and parenting practices of parents of children aged 0 to 2 by Santé publique France planned for 2024.

Several participants mentioned the need to develop modules of standardised, short questions in the studies, making it possible to obtain information on adverse life events in childhood.

The experience derived from victimisation surveys, such as Virage, highlights the importance of recording the ages, even approximate, at which these events occurred in order to untangle the chronology of events and question the direction of causality. For example, regarding the link between suicide attempts and sexual abuse, Virage shows that in the majority of cases suicide attempts occur shortly after the initial sexual abuse⁶.

In addition, the systematic inclusion of these questions would make the problem more visible.

Data sources to explore or improve

Hospital data on deaths caused by trauma in children under 15 years of age are currently used to monitor deaths by accidental trauma. Could this data source be used to explore intentional deaths (suicide and infanticide)? Intentionality is difficult to define, so we must consider cases where intent is not determined.

The Ministerial Statistical Department for Internal Security (SSMSI) has a database ("Victimes") built from data contained in legal proceedings recorded by the police and gendarmerie. With regard to conjugal homicides, the data is verified 18 months after the event, enabling the results of any subsequent investigations to be incorporated. Currently, this procedure does not exist for infanticide.

An estimate of the number of infanticides in the intra-familial context is published by the ONPE on the basis of these data, but these should therefore be interpreted with caution⁷.

At the request of the French National Council for Child Protection, discussions had taken place on the creation of a registry of deaths of minors based on the model of the National Confidential Enquiry on Maternal Mortality (ENCMM)⁸. But such a project has not been implemented.

The National Observatory on Sudden Unexpected Death in Infancy (<https://www.omin.fr/en/>) could also be an interesting source of data.

Other data sources could be explored for monitoring purposes: data from forensic institutes, or data from Paediatric Units for Children in Danger (UAPEDs).

Developing the participatory dimension in research

Examples of participatory research were also mentioned. These involve parents whose child is subject to child welfare measures or adults who were subject to such measures when they were children. But what about the children currently affected and their place in research? This question applies more generally to work carried out on the subject of maltreatment.

Committees for young people subject to welfare measures, which are being set up in local councils, could be a space for collaboration. The ONPE has published a report on the ways different local authorities invite protected children to participate⁹.

Finally, the existence of international studies that incorporate forms of participation was mentioned. However, suitable research tools integrating this dimension remain very rare.

Training, awareness and professionalisation

Training for professionals in contact with children was mentioned by several participants. This need concerns people working on the ground in particular, especially the practices of those who carry out screening and reporting. Some French regions have already implemented specific

training for all professional bodies involved (child welfare services (ASE), mother and child protection services (PMI), public prosecutor's office, children's judges, school doctors, medical council, etc.). Appropriate training would help to establish a common language and facilitate network collaboration.

These occupations involve data collection and coding. The ongoing work on data coding within the Information Systems Medicalisation Programme (PMSI), for example, illustrates the importance of coding quality (see the presentation by Pascal Mélihan-Cheinin on p. 29).

In the health field, the necessity to professionalise the sector of child protection was raised. This would imply all players applying the same scientific rigour as for suspected meningitis or cancer in order to progress on the identification and management of cases, as well as on study protocols.

Tools exist but are little known, such as the national reference framework for the overall situational assessment of children in danger or at risk of danger published by the French National Health Authority (HAS) in 2021¹⁰.

The regional dimension of care

Understanding the organisation of screening and care systems at departmental level is an imperative. This includes data collection for study purposes.

When the data are accessible, the precise organisational context of local child protection services (regional policy, resource allocation) must also be taken into account. However, research teams in public health have little knowledge of how complex and varied this organisation can be. Disparities at regional level have repercussions on the data collected, which must be taken into account in research.

Funding research

The maltreatment of children is not a topic included in calls for research proposals. Currently, only the ONPE has the vocation of financially supporting research in this field. Several studies presented at this seminar have received financial support,

but the amount allocated in this area pales in comparison to the need for epidemiological studies on child maltreatment.

As a result, much of the work carried out involves complex financial arrangements with multiple funding parties, whose requirements and expectations may differ. At present, these multiple funding sources may entail multiple deliverables, each of which must be specific to the scope of the funding party. This may constitute an obstacle and a potential waste of time for the research teams.

In perspective: the development of prevention

The development of public health research would help to improve knowledge and increase the visibility of the problem, ultimately contributing to and supporting strategies for the effective prevention of intra-familial child maltreatment. These strategies are the subject of research and recommendations at the international level^{11,12}, which could be used as a shared framework.

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Overview

The epidemiology of maltreatment: complexity at multiple levels

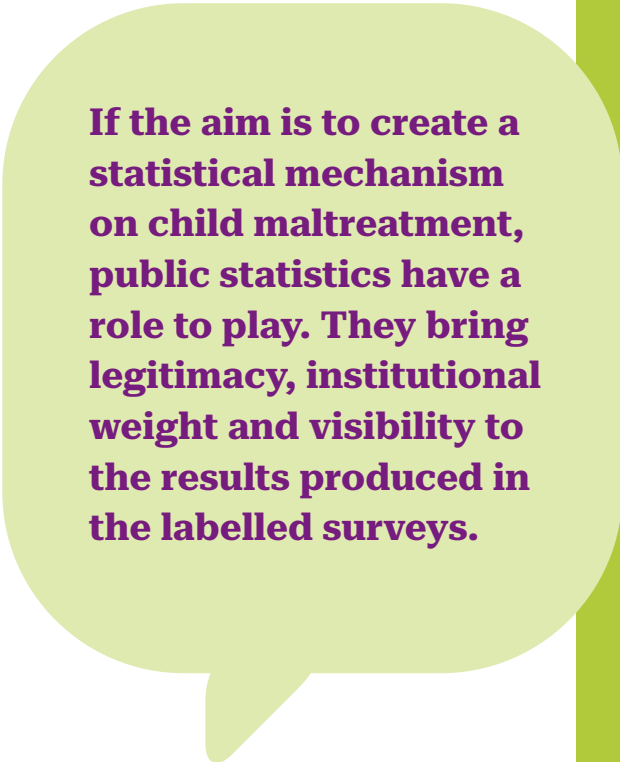
Aliocha Accardo, statistician, expert to the Public Statistics Label Committee, INSEE

I will bring to the debate a statistician's viewpoint, more particularly that of an expert to the Label Committee of the National Institute of Statistics and Economic Studies (INSEE). In this context, my role is to examine the operations and surveys submitted by public statistics and question their relevance using an institutionalised process and statistical engineering criteria.

Firstly, for the Label Committee, the aim is to verify and analyse the scope of the study. The next step is to check the quality of the sampling, ideally with random selection of participants in order to avoid bias. It should be noted that, in the event of bias, it is imperative to correct the survey mechanism with auxiliary information. Secondly, it is important to ensure that the questions can be understood by those answering them. For example, in the Virage survey, we saw that the French word "sérvices" (abuse, mistreatment) was understood differently depending on the question module. Then comes legal compliance, which is the last major area of investigation by the Label Committee.

If the aim is to create a statistical mechanism on child maltreatment, public statistics have a role to play. They bring legitimacy, institutional weight and visibility to the results produced in the labelled surveys. They can give researchers the opportunity to interact with stakeholders from different institutions, such as the Ministerial Statistical Department for Internal Security (SSMSI), the Ministry of Justice Statistics Department or the Directorate of Research, Studies, Evaluation and Statistics (DREES). Furthermore, receiving a label from the committee implies that the results drawn from the collected data are freely disseminated, so it is not necessary to provide specific reports for each of the sometimes numerous institutions that participated in funding study.

To provide an overview, I would like to revisit the main questions raised during the day, from the viewpoint of my experience as a statistician.



If the aim is to create a statistical mechanism on child maltreatment, public statistics have a role to play. They bring legitimacy, institutional weight and visibility to the results produced in the labelled surveys.

Obstacles related to defining concepts

As Séverine Delaville and Gaëlle Guibert from the National Observatory for Child Protection (ONPE) and Andreas Jud have pointed out, the problems encountered in setting up epidemiological studies on maltreatment primarily concern the design, with difficulties of standardisation and comparability.

- We need to build consistent definitions that can be positioned in relation to each other. While this is difficult, it is not impossible, provided that experts in all fields, particularly for emerging research, accept to make do with approximations. To take known examples, gross domestic product, inflation or the rate of poverty are imperfect, yet useful, indicators.
- Participatory research, as mentioned, could help with finding the best possible definitions.

Obstacles related to funding research

A second problem, which is also classic, concerns resources. For Virage and DIAPED, for example, this involved securing around €3 million. On this subject, I will reiterate the comments made by Daniel Rousseau and Karine Chevreul, who highlighted the fact that investing in statistical data makes it possible to better combat maltreatment. When these benefits are taken into account and related to the estimated cost of maltreatment, the amounts requested for conducting studies represent quite justifiable investments. Unfortunately, we have seen that researchers still struggle to find the necessary funds.

- The political willingness shown during the introduction to this day is a response to this need expressed during the discussions.

Obstacles related to disparate IT systems

Other problems, particularly related to technology, arise when we need to mobilise existing data. For example, Nathalie Vabres, for the Santé Protégée study, described problems such as incompatible IT systems between two hospitals or two local councils, or difficulties related to the fact that, even between different institutions with the same information system, data are not recorded in the same way.

- Ensuring consistency between the various information systems is certainly a key issue.

Obstacles related to ethical and legal questions

Finally, one problem that is really specific to the subject of maltreatment concerns the ethical and legal spheres. Flora Blangis explained to us that for the DIAPED study the legal obstacles were considerable from the outset. There are also difficulties related to the obligations of the Data Protection Authority (CNIL), in particular, which guarantees digital rights within the existing legislative framework.

- The discussions show that for this type of work to be deployed, a change in the current legal framework is required.

Session 2

Ethical and regulatory questions:

**Consent, data
cross-referencing
and best practices**

Feasibility and relevance of multidisciplinary law and health research

Sylvie Grunvald, lawyer, Nantes University

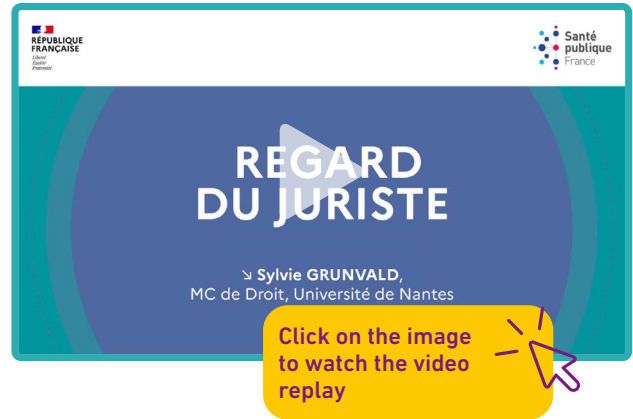
Intra-familial maltreatment is a form of abuse that is particularly difficult to explore. On the one hand it is difficult to ascertain the facts and decipher them according to the civil and criminal definitions of child-endangering behaviour; on the other it is difficult to access victims within the private sphere, where the family still often put up barriers against legal interference. However, evaluating intra-familial maltreatment carries high stakes: both at individual level for the minor, who must be recognised as a subject of rights, and collectively in terms of public health, with maltreatment having been identified as 'a serious chronic disease' in the words of Anne Turz, and its harmful consequences concretely set out.

This health dimension of intra-familial child maltreatment is therefore an essential lever for raising crucial awareness about these reprehensible behaviours. Raising awareness also involves developing the quantitative data necessary to objectively illustrate maltreatment across the entire minor population, which would form the basis for putting public policies on the agenda (as happened with the National Survey on Violence against Women in France [ENVEFF]). These quantitative data must be as exhaustive as possible and include all minors so as to avoid blind spots concerning additionally vulnerable children who are subject to welfare measures or disabled. As well as a large quantitative survey, multidisciplinary research involving medicine, law and the human and social sciences is essential for constructing empirical studies that will help explain the interactions between health, child welfare and justice services.

It seems particularly important to work on the pathway of maltreatment cases, from when they are first observed by healthcare personnel to when they reach the courts. The analysis of medical certificates, maltreatment reports and information of concern; the legal and sociological study of judicial cases; the ethnography of hearings relating to these maltreatment cases: these are all materials that would be useful to collect as they provide different perspectives to understand the mechanisms at work when dealing with intra-familial maltreatment. Since these materials contain sensitive data, the ethical and regulatory framework is decisive for respecting the fundamental rights of the protagonists to whom the research relates. However, this type of research also leads us to question the reflexivity of ethics as understood by Sarah Carvallo, and to place ethics within the purpose of the study – in this case the construction of child welfare mechanisms.

Evaluating intra-familial maltreatment carries high stakes: both at individual level for the minor, who must be recognised as a subject of rights, and collectively in terms of public health...

Therefore, in order to build relevant research frameworks aimed at preventing intra-familial maltreatment and providing better care for the victims, it would be useful to identify requests from health and justice institutions and local councils, to establish interinstitutional research protocols that promote access to the field and to materials, and to maintain the best interests of the child and the principle of non-discrimination for the inclusion of all children in these studies.



The view of the Inserm research ethics committee

Christine Dosquet, Chair of the Inserm Ethics Evaluation Committee (CEEI/IRB)

It is essential to put the landscape of health research on intra-familial maltreatment into perspective with the regulatory context in order to understand the ethical issues of this research involving minors in an abusive family environment, whether or not they are subject to welfare measures. Such studies are therefore particularly sensitive and in the French context fall within differing regulatory frameworks depending on type – retrospective on data or prospective – and according to whether or not they are categorised under the Public Health Code (CSP) as research involving human subjects (*recherches impliquant la personne humaine*, RIPH)^{1,2}. There are three categories of RIPH: RIPH 1 (interventional), RIPH 2 (interventional with minimal risks and constraints) and RIPH 3 (non-interventional).

The qualification of health research is based on the study objective and the method used to collect the data, be it during the medical, medical-social and legal care of these minors, via surveys using questionnaires and/or interviews, or through cohort studies.

Searches carried out on large healthcare, legal or medical-social databases (which may be cross-referenced) fall within the RIPH exceptions (referred to as non-RIPH or RNIPH), and therefore do not require an ethics committee opinion. They are governed by the French Data Protection Act (DPA) as amended by the General Data Protection Regulation (GDPR). Their implementation requires the favourable opinion of the Ethics and Scientific Committee for Health Research, Studies and Evaluations (CESREES) and the authorisation of the French Data Protection Authority (CNIL).

Retrospective research on healthcare data – such as the DIAPED study³ (see the presentation by Flora Blangis on p. 22) – is also non-RIPH, and so does not require an ethics committee opinion. It may also require a favourable CESREES opinion and CNIL authorisation, in particular to be exempted, in complicated family settings, from informing holders of parental authority by replacing this, for example, with collective information in the form of posters. Indeed, in this type of situation, the data processing cannot be brought into compliance with

It is essential to put the landscape of health research on intra-familial maltreatment into perspective with the regulatory context in order to understand the ethical issues of this research involving minors in an abusive family environment, whether or not they are subject to welfare measures.

CNIL reference methodology MR004 dedicated to non-RIPH health research.

Prospective surveys by questionnaires and/or interviews must be considered individually with regard to the CSP according to the objective of the research. Indeed, questionnaires and interviews are considered to be 'procedures' in the RIPH 2 and 3 decrees. If the research is categorised as RIPH, it falls under the opinion of an ethics committee and the DPA. If not, it is legally covered by the DPA but not by the opinion of an ethics committee. However, for the organisation of this research, the issues of recruiting participants and providing information to minors (plus the consideration of their consent according to their age) as well as to the holders of parental authority all raise many regulatory and ethical questions.



Researchers should be supported by an institutional committee on research ethics, which plays a key role in non-RIPH research. The committee must rigorously guide regulatory procedures, identify ethical questions and answer the research team's questions. In all cases, the management of personal data and its compliance with the GDPR and DPA must be certified. The protection of personal data, and therefore of privacy, is a fundamental right and an integral part of a favourable ethical opinion.

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Implementing health research in compliance with data protection principles

Manon de Fallois, Deputy Head of the Health Department, French Data Protection Authority (CNIL)

Research on maltreatment is intrinsically sensitive since it concerns minors and requires collecting particular categories of data; data that relate to health but additionally, in certain cases, sexuality, criminal convictions or offences, etc. Such research involving human subjects must therefore be implemented in accordance with data protection principles¹ and, where applicable, in accordance with certain provisions of the Criminal Code and Public Health Code².

In France, scientific health studies that require the processing of health data must, unless it comes under the exceptions provided for by law³, be the subject of a formal arrangement with the French Data Protection Authority (CNIL). Thus, most of these studies are conducted within the context of a declaration of compliance to a standard data processing methodology as described in a reference framework published by the CNIL, which is referred to as a 'reference methodology'. Research that does not comply with these reference frameworks due to specific sensitivity (e.g. processing of data on criminal offences) must be authorised by the CNIL. On this occasion, researchers receive legal and technical support from the CNIL alongside the data protection officer of the organisation to which they report.

Since 2018, the CNIL has authorised four research studies⁴ on the detection of child maltreatment cases. The discussions around these study authorisations focused on two main points: the procedures for informing subjects and the specific nature of the data collected for processing.



Procedures for informing subjects

In principle, the French Data Protection Act envisages that data subjects (and their legal representatives in the case of minors) should be informed individually in accordance with articles 13 and 14 of the General Data Protection Regulation (GDPR).

When the research involves collecting data directly from minors, both holders of parental authority must be informed individually.

However, there are two potential exceptions:

- If it is impossible to inform one of the holders of parental authority or if the times for consulting him or her are too long, and only for certain research categories⁵, it is acceptable to inform only one of them. It is recommended that an information sheet for the absent party should be created, as they may exercise their rights at a later date.

- When the minor is 15 years of age or older, he or she can exercise their rights alone and object to the holders of parental authority being informed of the research under certain conditions⁶.

Where data are not collected directly from data subjects, it has been possible to invoke two exceptions for research on child maltreatment. This particularly applies if informing individuals:

- requires 'disproportionate efforts' by the data controller, for example, due to the age of the data or the number of people to inform, or;
- is likely to make the study objectives impossible to achieve or seriously compromise them, such as by weakening or breaking the relationship of trust with healthcare workers and/or by compromising the safety of the child by informing them of the transmission of information of concern or of the existence of a judicial report.

In these scenarios, the GDPR envisages that appropriate measures must be taken to protect the rights and freedoms of the data subjects, particularly through the systematic implementation of collective information via communication channels appropriate to the study context (at least on the data controller's website).

The specific nature of processed data

Some of these studies also involved collecting special categories of data relating, for example, to criminal convictions, offences or associated security measures, or even the reconciliation

of these files. This data processing can only be carried out by certain bodies such as the public authorities and legal entities managing a public service, acting within the framework of their legal powers, such as hospitals⁷.

In this scenario, certain guarantees must be implemented:

- The demonstration, through a Data Protection Impact Assessment (DPIA), that it was strictly necessary to collect these data
- Where applicable, verification that the data collected from the courts was processed in accordance with the provisions specifically applicable to them and that they did not preclude this transmission
- In all cases, the implementation of technical and organisational measures to ensure a level of security appropriate to the risks generated by the processing⁸ (limitation of the number of people able to access the study data, management of authorisations, use of a secure environment compliant with the state of the art when collecting and analysing the data and, for data collected from courts, pseudonymisation of the data 'at source' by people authorised to access these data as part of their duties, etc.).

This doctrine draws on the benevolent and constructive exchanges that the CNIL can have with researchers. It will develop as the CNIL continues to provide support⁹ for teams working on the intra-familial maltreatment of children and adolescents, with the aim of encouraging a rise in such research.

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Notes

1. These principles are set out in Regulation (EU) 2016/679 of 27 April 2016 known as the General Data Protection Regulation (GDPR), in French law no. 78-17 of 6 January 1978 as amended (Informatique et libertés [Data Protection Act]) and its implementing decree (decree no. 2019-536 of 29 May 2019 as amended).
2. Article R. 1121-1 of the French Public Health Code (Code de santé publique).
3. For example, internal studies as well as certain studies carried out using data from the National Health Data System (SNDS) by organisations that have permanent access to these data.
4. See, for example, deliberation no. 2021-033 of 18 March 2021 and deliberation no. 2023-003 of 12 January 2023.
5. Interventional research without risks or minimal constraints; non-interventional research with no risks or constraints in which all procedures are carried out and products used in a usual manner; research not involving human subjects as well as studies and assessments in the field of health.
6. If participation in research reveals information regarding a prevention action, screening, diagnosis, treatment, or an intervention for which the minor has expressly opposed consultation by these holders or if the family ties are broken and the minor is personally entitled to reimbursement of the procedures in kind by national health and maternity insurance and to supplementary cover.
7. This concerns article 10 of the GDPR and article 46.1° of the French law of 6 January 1978 as amended.
8. On this point, see the guide relating to the security of personal data published by the CNIL.
9. The CNIL has published a fact sheet on what it looks for when examining applications for health research authorisation.

Exchanges on **the regulatory framework** and **ethical questions**

The second part of the seminar focused on regulatory aspects related to the implementation of research and to the collection and use of data, as well as the ethical questions that may be raised by epidemiological surveys on child maltreatment. The text below is a summary of the principal exchanges on these different points, between the speakers and the people present.

The discussions were led by Martine Balençon, paediatrician and forensic pathologist at Rennes University Hospital within the unit for children in danger since 1998, and Isabelle Frechon, social demographer and researcher at the National Centre for Scientific Research (CNRS).

Multidisciplinary research

Several institutions and disciplines were represented during these two days, highlighting the interdisciplinary nature of this field. During the seminar, the questions focused mainly on health research, which is governed by regulations that everyone must adopt.

But the boundaries between subjects and disciplines are porous. This is particularly the case when working on maltreatment, where several fields intersect: legal, social, educational and health. This multidisciplinary approach must be encouraged, in order to take stock of the maltreatment suffered by minors in France.

Part of the debate focused on the difficulty of qualifying the different types of research that mobilise a variety of data sources, some of which are not health related. Yet it is this qualification that dictates the regulatory framework and procedures to follow.

Health research requiring the reuse of multiple data sources

In practice, studies on child maltreatment may use data from different sources: medical records, data collected by Mother and Child Protection services (PMI), data from services that collect information of concern, judicial data, etc. When they do not comply with an existing reference methodology of the French Data Protection Authority (CNIL), authorisation from the latter is required, following an opinion from the Ethics and Scientific Committee

for Research, Studies and Assessments in the Field of Health (CESREES). Beforehand, the databases concerned must comply with the law (regarding the constitution and purpose of the database, the duration of data retention, etc.) and their data must be pseudonymised (processing that protects the data from being connected to a natural person without additional information).

Cross-referencing data from different institutions raises difficulties in accessing and matching data. For example, the implementation of research based on data from an ongoing judicial case comes up against an issue of secrecy concerning the inquiry and investigation, as such procedures can go on for years. The data from archived cases can then only be used on condition that the nominative data of those incriminated and the victims have been concealed by the courts and that only the data necessary for the study are made available to the researchers.

Matching survey data with those of the French National Health Data System (SNDS)

In 2021, the CNIL published a guide to help researchers match health data from surveys with those of the SNDS, using the social security number (SSN)¹. However, it seems that those involved find it difficult to take ownership of the typical SSN circuits proposed in the guide. In order to support the adoption of the standard circuits, the CNIL will publish additional documents drawn up in consultation with several research teams by the end of 2023.

The matching of clinical data or data from a previous study with those of the SNDS using the SSN requires prior authorisation from the CNIL. In this case, the protocol must scientifically justify the necessity for this matching and the data circuit. Matching may also be decided upon once the study is already in progress. In this case, an additional request may be submitted.

Development of research: authorisation by the holders of parental authority vs the child's best interests

Depending on the type of research, the consents to collect differ. For interventional research involving human subjects (RIPH 1), the consent of the participant and both parents is required. For interventional research with minimal risks and constraints (RIPH 2), the agreement of one parent is possible under certain conditions. For RIPH 3 (non-interventional), the principle of individual information and non-opposition by the participant as well as by one or both parents applies.

Research that does not involve human subjects (see the presentation by Christine Dosquet on p. 41), as with research requiring the reuse of data already collected, is simply subject to the General Data Protection Regulation (GDPR), the French Data Protection Act of 6 January 1978, and the principle of information and non-opposition (i.e. the person is given the means to object to the use of their data for research purposes). This use of the principle of non-opposition to the inclusion of children assumes that both holders of parental authority are informed or, in exceptional cases, only one – or, in some cases, none (see the presentation by Manon de Fallois on p. 43).

When children are the subject of administrative or judicial welfare measures, the parents usually retain parental authority. As such, they decide whether their child will participate in the research. However, it is difficult to ask parents for permission to include their child in research on intra-familial maltreatment. The obligation to inform and/or the obligation for authorisation by holders of parental authority hinders the participation of these children and compromises research in this field.

The principle of the best interests of the child, which is fundamental in French and supranational law with the International Convention on the Rights of the Child, must be mobilised when it comes to research on child maltreatment.

For research that involves collecting data directly from minors, according to article 70 of the French Data Protection Act², exceptions for minors aged 15 and over may be applied. Indeed, minors aged 15 and over may object to their parents having access to information about them collected as part of research. In certain cases limited by law, the minor may request that their parents are not informed of their participation.

During discussions with the room, the idea was raised that this limit could be lowered to 13 years of age, in order to be consistent with the Juvenile Criminal Justice Code that came into force in 2021³. This option does not solve the problems of younger minors, who are considered not to have sufficient judgement. It should be noted that law no. 2002-303 of 4 March 2002 on the rights of patients and the quality of the care system⁴ provides for situations in which the minor can receive care without the consent of the holders of parental authority, without any notion of age being mentioned.

For research where the data are not collected from data subjects, two exceptions to individual information may be invoked: if this requires 'disproportionate efforts' on the part of the data controller or if this is likely to render impossible or seriously compromise the achievement of the study objectives (see the presentation by Manon de Fallois on p. 43).

The principle of the best interests of the child, which is fundamental in French and supranational law with the International Convention on the Rights of the Child, must be mobilised when it comes to research on child maltreatment.

Conclusion

In conclusion, child victims of intra-familial maltreatment currently face a double penalty: they are victims and they are not visible, at least not sufficiently visible, given the difficulties of conducting research on this population. However, the development of research is essential to advance knowledge on the prevalence of maltreatment and its determinants. This knowledge is essential for the development of effective prevention policies and programmes to reduce the incidence of maltreatment, and improve the detection, diagnosis and care of these children.

Establishing study protocols requires reconciling the scientific, legal, regulatory and ethical aspects. Various working groups have proposed practical guides for setting up research on maltreatment⁵⁻⁷. It was mentioned during the discussions that adapting these guides to both the context and French legislation would be very useful for teams wishing to embark on this subject.

Furthermore, experiences of the difficulties encountered and the solutions implemented, as shared by the authors of the research on the outcomes of 'protected' minors⁸, should be more systematically disseminated to the scientific community.

The current political context reflects the desire to build a comprehensive system to fight maltreatment. Examples include the États généraux de la maltraitance (Forum on Maltreatment), the referrals to the French High Council for Public Health or the thematic workshops of the National Council for Reform on Healthy Ageing and Maltreatment. The stakeholders concerned must seize this opportunity to advance their projects.

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Overview

Maltreatment of children and adolescents and 'whole life' repercussions: a blind spot for French research

Martin Chalumeau, paediatrician, Inserm / Necker-Enfants Malades Hospital

The physical, sexual and mental abuse of children and adolescents is a worldwide health and societal scourge. Although one quarter of adults report having suffered maltreatment, only a minority are identified early enough to receive care and avoid the 'whole life' health repercussions and major socio-economic impact of that maltreatment¹⁻⁵. Research on the maltreatment of children and adolescents requires choosing a neutral scientific questioning stance that is made more complex than in other fields given the emotional implications and the diagnostic evidence that is not always clear. Generally speaking, this scientific questioning can be structured into three interconnected areas: (1) study of the epidemiology of maltreatment and optimisation of prevention; (2) optimisation of detection, diagnosis and protection times; (3) study and prevention of 'whole life' repercussions. This scientific questioning must be multidisciplinary given the complexity and challenges of maltreatment, particularly when intra-familial.

Despite being necessary in order to answer many research questions, the linking of highly sensitive medical, judicial and administrative data is currently impossible to implement exhaustively. National prioritisation could be effective based on the model of a recent decision applied in the Ile-de-France region by its Regional Executive.

As with any other scientific field, research on the maltreatment of children and adolescents requires researchers, structures, funding, an environment, and an ethical approach in order to question concepts and practices. An evaluation of France's level of engagement in such research can be found by answering simple questions: how many researchers, teams, research centres and structures, and how much targeted funding? If children and adolescents are the most neglected category of the French research effort, there are many causes of this. The paucity of calculations of the direct and indirect 'whole life' cost of maltreatment in

France is a major obstacle to directing the limited resources, and the same goes for numerous calls for proposals looking for an impact in terms of 'value-creation' such as intellectual property⁶. The regulatory context for research in France, one of the most complex in Europe, is also a major obstacle to research on the maltreatment of children and adolescents. Obtaining the consent of both legal representatives, who are often incriminated in such situations, is most often impossible. The regulatory adaptations necessary for this type of research lead to considerable delays in studies being conducted⁷. Despite being necessary in order to answer many research questions, the linking of highly sensitive medical, judicial and administrative data is currently impossible to implement exhaustively. National prioritisation could be effective based on the model of a recent decision applied in the Ile-de-France region by the Regional Executive.

Before being assassinated in Treblinka with the children he was trying to protect, Dr Janusz Korczak, paediatrician, educator and father of the Declaration of the Rights of the Child, left us a message: protecting children and teenagers who are victims of maltreatment is a moral obligation⁸. For Korczak, research was essential in order to provide children with better protection: 'Statistical manuals have enabled me to deepen my knowledge as a doctor. Statistics discipline thought, making it more logical and more objective in the assessment of the facts.'

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Translating these
lessons into **public
policy**

Outlook of the seminar by Éric Delemar, Children's Defender

Deputy Defender of Rights, in charge of defending and promoting the rights of the child

I would like to thank the teams of Santé publique France for holding this seminar.

The world is preparing to celebrate the centenary of the Geneva Declaration. This is the first international text to recognise the existence of specific rights for children. Those who wrote it called for children to be protected from the ravages of armed conflict, fighting their exploitation in all its forms, combating poverty, and provision of the necessary services for good health and quality education. This context remains strangely topical.

As Children's Defender, my role is to defend and promote the best interests of children in accordance with the International Convention on the Rights of the Child. This means I remind institutions of the texts that have been ratified, voted on and therefore must be applied. And it is important to note that the best interests of the child have also been reaffirmed in French law by the Constitutional Council and the Council of State, and that this concept has been present in the Civil Code since 2004.

Through the 10,000 referrals received and investigations carried out since my arrival, it is clear that taking into account the rights and needs of children is not always a priority for the institutions concerned. I would say that children continue all too often to be considered as 'objects' of care, rather than 'subjects' to be considered.

The referrals we receive concern children who are required to wait six months or one year before obtaining a consultation at a Medical-Psychological-Educational Centre (CMPP); or adolescents who are treated in an adult psychiatry setting due to a lack of space in child psychiatry; or children who are victims of intra-familial or institutional

maltreatment who go undetected due to cooperation difficulties; or young people recognised as victims after a hearing in a Paediatric Unit for Children in Danger (UAPED) but who receive no medical follow-up once entrusted to Child Welfare Services (ASE).

We are particularly concerned about the increase in unimplemented welfare measures, children who remain unprotected despite the decision by a magistrate, children with disabilities who do not have access to a long-term care system or schooling, or to such little schooling that they are not given the status of pupil.

The lack of coordination between the different policies, the multiple overlapping programmes, packed with acronyms that professionals themselves often do not understand... these factors help to keep the most vulnerable populations away from accessing their fundamental rights.

Despite France's regional departments having never invested so much money in child protection, the professionals are not seeing the effects. The lack of coordination between the different policies, the multiple overlapping programmes, packed with acronyms that professionals themselves often do not understand... these factors help to keep the most vulnerable populations away from accessing their fundamental rights.

Children are growing up in a particularly anxiety-provoking world: climate change, health crises, war in Europe, fear of losing social position... the violence against them only continues to increase.

Therefore, for children's rights to become a political subject, they must be made public. The development of epidemiological research in the field would contribute by making this problem concrete through data, and by highlighting the protective and risk factors for this maltreatment.

We have never heard so much talk in the media about the maltreatment of children, about the imperative to protect them, about encouraging adults who were victims as children to speak out. But now it is more than time to listen so that children today no longer need to wait to become adults before they are finally heard.

It is through an ambitious, decompartmentalised policy serving the field and not technostructures, through increased resources and enhanced training, that we will protect our children today for the adults they will be tomorrow.

Organisation Committee

For the organisation of this seminar, Santé publique France set up a multidisciplinary team combining prevention and health promotion with the epidemiological surveillance of trauma. The programme was developed with the support of a Scientific Organisation Committee.

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