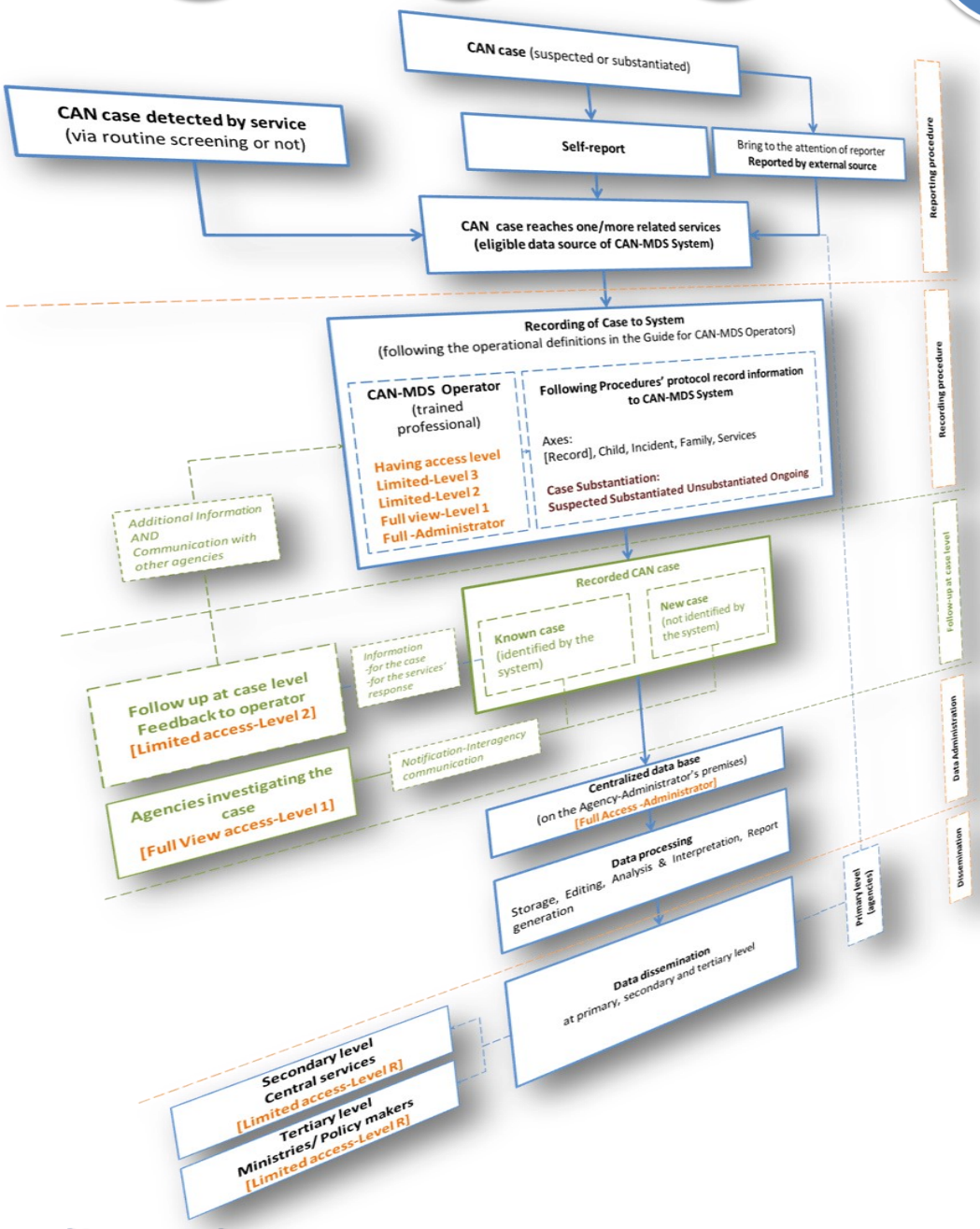


JUST/2012/DAP/AG/3250

Coordinated Response to Child Abuse and Neglect via Minimum Data Set

With financial support from the EU DAPHNE Programme

Contents

COORDINATED RESPONSE TO CHILD ABUSE AND NEGLECT VIA MINIMUM DATA SET
the project at a glance

Invitation

Dear Professional,

If you work with children it is possible that suspected incidents of child maltreatment will come to your attention.

According to your professional specialty, the service and the sector where you are working, you should undertake specific action: you may be subjected to mandatory reporting, you may be involved in the investigation and/or management of child abuse and neglect cases or even in supporting children who suffer violence.

If any of the above applies to you, the CAN-MDS Epidemiological Surveillance System could be of interest. If you would like more information, please do not hesitate to contact us .

You will find us at:

Institute of Child Health
Dept of Mental Health & Social Welfare
7 Fokidos Str.
115 27 Athens Greece

Email: info@can-via-mds.eu
URL: www.can-via-mds.eu
www.ich-mhsw.gr

the project at a glance

Coordinated

- promoting uniform data collection from all sectors involved in administration of CAN cases
  - using a common user-friendly registry tool
- creating a communication channel among involved sectors
  - involving all eligible professionals working in the above sectors
  - following pre-defined criteria & with different levels of access according to their responsibilities
  - building their capacity through
    - short training & necessary material (Guide for Operator & Protocol)

Response

- at a population level (public health surveillance)
  - allowing comparisons within and between countries
  - targeting policy makers and related stakeholders
    - providing them with continuously updated information as a basis for
      - evaluation of existing practices & policies and guiding prevention & intervention planning
- at a case-level (follow-up of individual cases)
  - facilitating case-investigation & further administration
    - following specific criteria concerning level of access of Operators

to CAN

- using broad CAN operational definitions
  - describing "case definitions" in detail
  - ensuring a common understanding among (non homogeneous) involved parties
- targeting to collect all cases identified by services
  - regardless of substantiation

via MDS

- using a standard set of variables (endorsed by all stakeholders)
  - fulfilling pre-defined criteria concerning ethics, quality, completeness, accessibility, feasibility
  - providing comprehensive, comparable and reliable data
    - targeting a standard framework of measurable indicators that are sound, practical and usable
    - providing eligible Operators with necessary information for investigation & follow up at case-level

Institute of Child Health
Department of Mental Health & Social Welfare
Centre for the Study & Prevention of Child Abuse & Neglect

Kind & Gezin
kind is koning

ONED
Observatoire National de l'Enfance en Danger

Istituto degli Innocenti

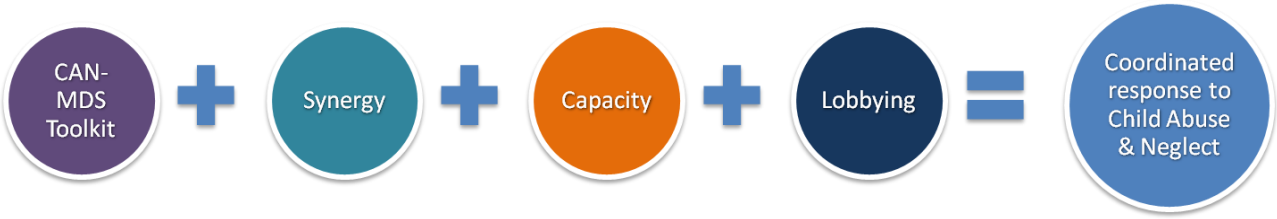
Universitatea BABEŞ-BOLYAI

SOUTH WEST UNIVERSITY "NEOFIT RILSKI"

Lucerne University of Applied Sciences and Arts
HOCHSCHULE LUZERN

1. statement of the problem

Daphne III Project "Coordinated Response to Child Abuse & Neglect (CAN) via Minimum Data Set (MDS) "



Necessity, Aim & Means

Public health importance of CAN

In 1999 the World Health Organization (WHO) recognized child abuse as a major public health problem (WHO 1999). In 2010 the US Centers for Disease Control and Prevention (CDC) identified child maltreatment as a 'critical' and 'significant' public health problem that warrants a comprehensive prevention strategy (CDC 2010). In 2008, child maltreatment was recognized as a social problem that lends itself to a public health framework of study and subsequent prevention activities (O'Donnell *et al*. 2008) while in 2010 it was noted that "child abuse and neglect prevention efforts have already moved significantly into public health terrain" (Zimmerman and Mercy 2010).

Public health importance of CAN data collection

In 1999 WHO recommended that the international community prioritize "the development of worldwide data collection on child abuse and neglect, the estimation of the impact on public health and also the associated economic cost." After a decade the CDC noted that "the lack of reliable information as to the number of children affected by child abuse and neglect has been identified as a serious limitation in lodging an effective public health response" (Leeb *et al*. 2008).

Aim of the project 'Coordinated Response to CAN via MDS'

To create the scientific basis, necessary tools and synergies for supporting the establishment of CAN National Surveillance Systems (where such mechanisms are not available) or improving of CAN National Surveillance Systems (where they exist)

Project's Structure

WS.1 **Preparatory phase:** Literature review on methodologies for building an MDS and Country reports on available CAN surveillance mechanisms

WS.2 **Transfer the MDS practice to CAN field:** Definition of the MDS content, Creation of the CAN-MDS Toolkit and Development of evaluation components

WS.3 **Creating Synergies:** Building national CAN-MDS Core Groups of Operators

WS.4 **Capacity Building:** Training of Trainers & of National Core Groups of CAN-MDS Operators

WS.5 **Coordinated response to CAN via MDS:** Producing a Policy & Procedures Manual for establishing National CAN-MDS Surveillance Systems & Project Products Dissemination

Means towards the aim

Developing a proposal for a Surveillance System for CAN on the basis of an MDS

Subject of Surveillance

Child Abuse & Neglect through recording services' responses to individual cases

Necessity of CAN Surveillance

The fact that **'the true extent of child maltreatment is unknown'** is commonly recognized in international literature. On the basis of a variety of estimations for the extent of the phenomenon "between half to four fifths of all victims of maltreatment are not known to child protection services"; the "tip-of-the-iceberg analogy easily comes to mind when one thinks of the scope of child maltreatment" (Sedlak and Broadhurst 1996; Trocmé *et al*. 2005).

The necessity for CAN National Surveillance Systems is advocated by the need to understand the incidence of CAN based on data deriving from services' response to CAN cases; to monitor demand for services administrating cases; to set priorities for prevention; to identify the needs of professionals involved; to understand CAN consequences; and to determine the costs associated with CAN.

2. purpose & objectives

Thacker and Berkelman (1988) defined public health surveillance as "the ongoing systematic collection, analysis, and interpretation of outcome-specific data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease or injury" and that is not 'an end unto itself, but rather a tool" (p.185). It was argued, however, that this definition contains two very different activities: "case surveillance focuses on individuals, to identify those with certain diseases and take action. Statistical surveillance, on the other hand, focuses on populations, to identify differentials and trends that can inform public health policymaking, including the allocation of resources" (Choi 2012; Stoto 2003).

In the context of a **public health approach** it is suggested that surveillance data should be able to be utilized as a tool for the identification and tracking of the health threat at the population level and as a means of determining risk and protective factors among subgroups. This information can then be used to develop targeted prevention and intervention programmes (Putnam-Hornstein *et al.* 2011). However, as Finkelhor and Wells (2003) concluded in their study exploring the limitations of 13 different data sets and systems in the US, in order to improve the statistics on juvenile victimization, in addition to thinking about specific shortcomings related to existing data systems it may be valuable to think about improvements to these systems "as well as possible creation of new data systems or hybrids of existing systems" (p.98). They suggested that changes to the systems under study, such as the improvement of the data on children's trajectories within the child protection systems and adoption systems to find out how investigations influence ultimate outcomes could benefit, for example, practitioners in child protective services. In a commentary on national child maltreatment surveillance systems, among the examples of progress presented, AlEissa *et al.* (2009) noted that in the US the NCANDS data are used for a wide range of purposes, including "the development and monitoring of outcome measures related to child safety (recurrence of maltreatment, maltreatment in foster care) as part of the Child and Family Service Reviews conducted by the federal government".

Apart from the *public health surveillance of CAN*, an additional purpose is included for the suggested CAN-MDS Surveillance System -*the utilization of information at a case-level*.

Thus, the purpose can be defined at two levels:

- *To provide comprehensive, reliable & comparable case-based information for (alleged) child victims of CAN who have used social, health, educational, judicial & public order services at national and international level. (**Information for action** linked to public health initiatives.)*
- *To serve as a ready-to-use tool in investigation and follow-up of child victims of CAN or those at risk of being (re-) victimized, by respecting the national legislation and applying all the rules necessary for ensuring ethical data collection and administration (**Case-level information** linked to follow-up of individual cases.)*

The twofold character of the suggested CAN-MDS Surveillance System takes into account the difficulties relating to the nature of CAN (continuous and repeated, involving multiple sectors and professional groups without well-established common language and channels of communication), and the critical aspects required for the effective operation of a public health surveillance system (related to its acceptance and stakeholders' agreement to collect data elements). By serving as a practical tool (following strict criteria) for the dedicated involved parties (HM Government 2013) it is expected to strengthen their commitment to the system and therefore to result in better information for action. The twofold character is also expected to improve the results of a cost-benefit assessment of such a system.

Adapting the process "from discovery to delivery" as described by Sleet *et al.* (2003),the suggested CAN-MDS Surveillance System is as follows.

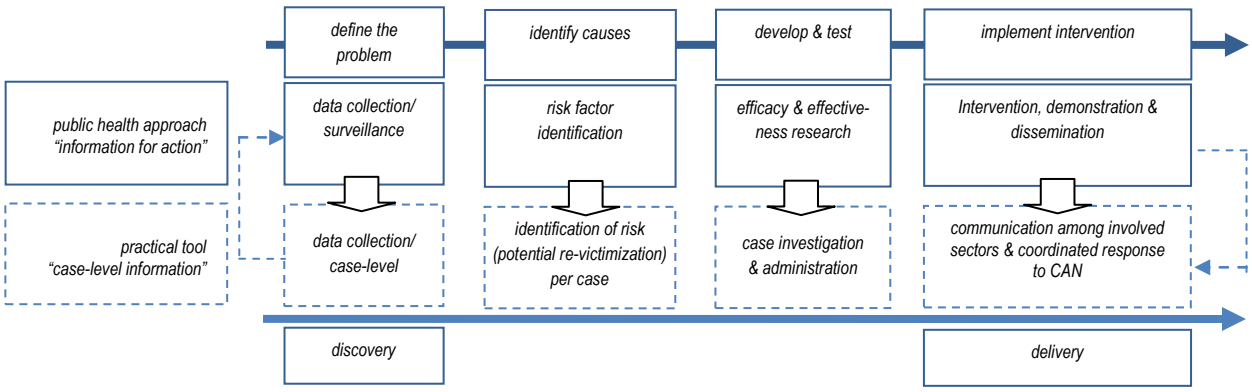


Figure 1. CAN-MDS Surveillance System: use of CAN surveillance data to support case-level administration and strengthen commitment to CAN surveillance data collection.

possible uses of data collected through a CAN-MDS Surveillance System

Data collected via a potential CAN-MDS Surveillance System can be used:

- to periodically measure the incidence of CAN and its specific forms based on data deriving from services' responses to CAN cases
  - in general
  - per sector and service
  - per specific forms of abuse and neglect, and child, caregiver and family characteristics
- to monitor trends in child maltreatment
  - at national level and local levels
  - per specific forms of abuse and neglect, and child, caregiver and family characteristics
- to provide clues for the identification of
  - new or emerging trends in child maltreatment
  - populations at high risk
- to be used as a baseline for the evaluation of
  - services' needs (needs assessment related to CAN cases administration) for prioritizing the allocation of resources for CAN primary, secondary and tertiary prevention
  - effectiveness of CAN prevention practices and interventions (and to identify good practices)
  - effectiveness of CAN prevention policies (for planning future policies & legislation)

&

Moreover, data that will be collected via a potential CAN-MDS Surveillance System can be used:

- to outline the administrative practices applied for CAN cases
  - to detect changes in administrative practices of CAN cases and the effects of these changes
- to operate as a communication channel among sectors involved in administration of CAN cases[1]
  - to facilitate follow-up at case-level
- to operate as a ready-to-use tool during new or suspected cases investigation by certified authorities
- to provide feedback to services at a case-level for already known cases

3. case definitions

One major challenge in researching CAN is overcoming variations in the definitions of maltreatment used by researchers, professionals and officials from different professional backgrounds, working in different jurisdictions within and between countries. Fallon and colleagues (2010) noted that a significant difficulty arises when comparing CAN reports because statistics are rarely presented in enough detail,. This lack of detail hinders the consideration of data collection issues and their potential impact on measurement. As a result, CAN statistics may vary considerably in the forms of maltreatment being reported, potentially leading to an underestimation of specific forms of CAN. This occurs even amongst child populations brought to the attention of services (which are the population targeted by the CAN-MDS) because of the failure to collect information on multiple forms of abuse. They also noted that "at what point a child is identified as maltreated is fundamental to understanding the limitations of data estimating the epidemiology of child maltreatment. Taking into account the difficulty of defining this point in a commonly accepted way in the context of any CAN conceptual definition, means it is obvious why conceptual definitions cannot be applied for surveillance reasons. On the other hand, how a child maltreatment event is measured is a crucial issue when comparing international rates of maltreatment (and also for comparisons within countries). Thus, comparisons across jurisdictions require the very least, that the data be disaggregated.

According to WHO and the University of Technology Sydney (2008), the "**use of standard definitions** will ensure consistency by permitting jurisdictions to develop their own, more detailed and country-specific data sets, building on the core minimum data, which will also enable regional comparison, benchmarking and standardization". In some very early studies, researchers resolved the problem of the absence of explicit definitions and the difficulty of operationalising concepts of maltreatment "by simply using the label assigned to the act by responsible agencies" (hospitals, child protection agencies, police, and courts). Even at a later phase (in the 1980s) this approach was also adopted concerning the use of empirical data based on child protection services' records, as this was thought to provide useful descriptive information with minimal data collection efforts. This was despite the fact that the absence of precise, objective criteria complicated comparability among measures of maltreatment in subpopulations defined by locality. During the 1990s, efforts were made to develop precise operational definitions of acts of maltreatment as opposed to relying on professionals' opinions. Even though this was a step in the right direction, it was argued that comparability between studies was compromised due to wide variations in the definitions adopted and their impact on the estimation of the different types of CAN (National Research Council 1993; Zuravin 1991; Wyatt and Peters 1986).

[1] In the UK HM Government's *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (2013), there is a detailed guidance on information sharing between professionals when there are concerns about children's safety and welfare. It states that "*effective sharing of information between professionals and local agencies is essential for effective identification, assessment and service provision; … sharing information can be essential to put in place effective child protection services. Fears about sharing information cannot be allowed to stand in the way of the need to promote the welfare and protect the safety of children. To ensure effective safeguarding arrangements: all organisations should have arrangements in place which set out clearly the processes and the principles for sharing information between each other…*".

child maltreatment conceptual definitions

World Health Organization and International Society for Prevention of Child Abuse and Neglect (2006)

The *World report on violence and health* (2002) noted that the International Society for the Prevention of Child Abuse and Neglect had compared definitions of abuse from 58 countries and found some commonality in what was considered abusive (Bross *et al*. 2000; Krug *et al.* 2002). The chapter "Child abuse and neglect by parents and other caregivers" included the definition drafted in 1999, by the WHO Consultation on Child Abuse Prevention: *"child maltreatment is defined as all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power"* and distinguished four types of child maltreatment: physical abuse, sexual abuse, psychological abuse and neglect (WHO 1999) .

Drawing on the definition above, in *Preventing Child Maltreatment: a guide to taking action and generating evidence* WHO and ISPCAN (2006) developed the following conceptual definitions for the types of child maltreatment :

Physical abuse*: Physical abuse of a child is defined as the intentional use of physical force against a child that results in - or has a high likelihood of resulting in – harm for the child's health, survival, development or dignity. This includes hitting, beating, kicking, shaking, biting, strangling, scalding, burning, poisoning and suffocating. Much physical violence against children in the home is inflicted with the object of punishing.*

Sexual abuse*: The involvement of a child in sexual activity that he or she does not fully comprehend, is unable to give informed consent to, or for which the child is not developmentally prepared, or else that violates the laws or social taboos of society. Children can be sexually abused by both adults and other children who are – by virtue of their age or stage of development – in a position of responsibility, trust or power over the victim.*

Psychological abuse*: Emotional and psychological abuse involves both isolated incidents, as well as a pattern of failure over time on the part of a parent or a caregiver to provide a developmentally appropriate and supportive environment. Abuse of this type includes: the restriction of movement; pattern of belittling, blaming, threatening, frightening, discriminating against or ridiculing; and other nonphysical forms of rejection or hostile treatment.*

Neglect*: Neglect includes both isolated incidents, as well as a pattern of failure over time on the part of a parent or other family member to provide for the development and well-being of the child – where the parent is in a position to do so – in one or more of the following areas: health, education, emotional development, nutrition, shelter and safe living conditions." The parents of neglected children are not necessarily poor. They may equally be financially well-off.*

Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2008)

The CDC, recognizing the communication difficulties due to different definitions used across disciplines in regard to their efforts to identify, assess, track, treat and prevent child abuse and neglect effectively, developed the following conceptual definition of child maltreatment and its associated terms. Moreover, specific data elements were introduced as recommendations for voluntary use by individuals and organizations in the public health community. It is designed to aid state and local health department staff in the collection of public health surveillance data on child maltreatment with the intention of promoting and improving consistency of child maltreatment surveillance for public health practices (Leeb *et al*. 2008).

Child Maltreatment: Any act or series of acts of commission or omission by a parent or other caregiver that results in harm, potential for harm, or threat of harm to a child.

Acts of Commission (Child Abuse)*: Words or overt actions that cause harm, potential harm, or threat of harm to a child. Acts of commission are deliberate and intentional; however, harm to a child may or may not be the intended consequence. Intentionality only applies to the caregivers' acts-not the consequences of those acts. For example, a caregiver may intend to hit a child as punishment (i.e., hitting the child is not accidental or unintentional) but not intend to cause the child to have a concussion. The following types of maltreatment involve acts of commission:* ***Physical abuse, Sexual abuse, Psychological abuse***

Acts of Omission (Child Neglect)*: The failure to provide for a child's basic physical, emotional, or educational needs or to protect a child from harm or potential harm. Like acts of commission, harm to a child may or may not be the intended consequence. The following types of maltreatment involve acts of omission:*

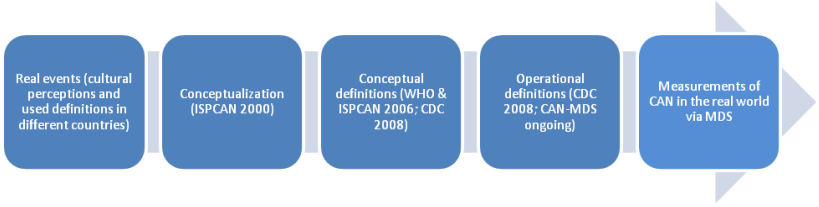
Failure to provide: *Physical neglect, Emotional neglect, Medical/dental neglect, Educational neglect;* ***Failure to supervise:*** *Inadequate supervision, Exposure to violent environments*

The first systematic effort to define child maltreatment conceptually was based on the reality of multiple different countries, understanding the worldwide problem of child abuse and neglect by taking into account the "essential nature" and the "essential attributes" of specific cases of CAN under different cultural environments. Through this process and with further elaboration, conceptual definitions of child abuse and neglect were drafted (WHO & ISPCAN 2006; CDC 2008) with the aim of providing "labels" (physical abuse, sexual abuse, psychological abuse and neglect) along with working definitions assigned to each of these labels. This was intended to serve as a specific working definition and to help in the development of actual measures. The CDC (2008) suggested subsequently a broad range of specific elements for inclusion in a data set to be able to measure child maltreatment. This was in an effort to operationalise the conceptual definitions by trying to spell out precisely how the concept would be measured via specific variables (*exhaustive* and *mutually exclusive, measuring actually only one* attribute of the case).

In addition to WHO and ISPCANs (2006) and CDCs (2008) suggested definitions, in the context of CAN-MDS case definition will be also based on **United Nations' Committee on the Rights of the Child's General comment No. 13 (2011), "The right of the child to freedom from all forms of violence" [CRC/C/GC/13 (2011) §19-33]**[1], **UNCRC Article 19**[2] and the **World Report on VAC (2006)**.[3]

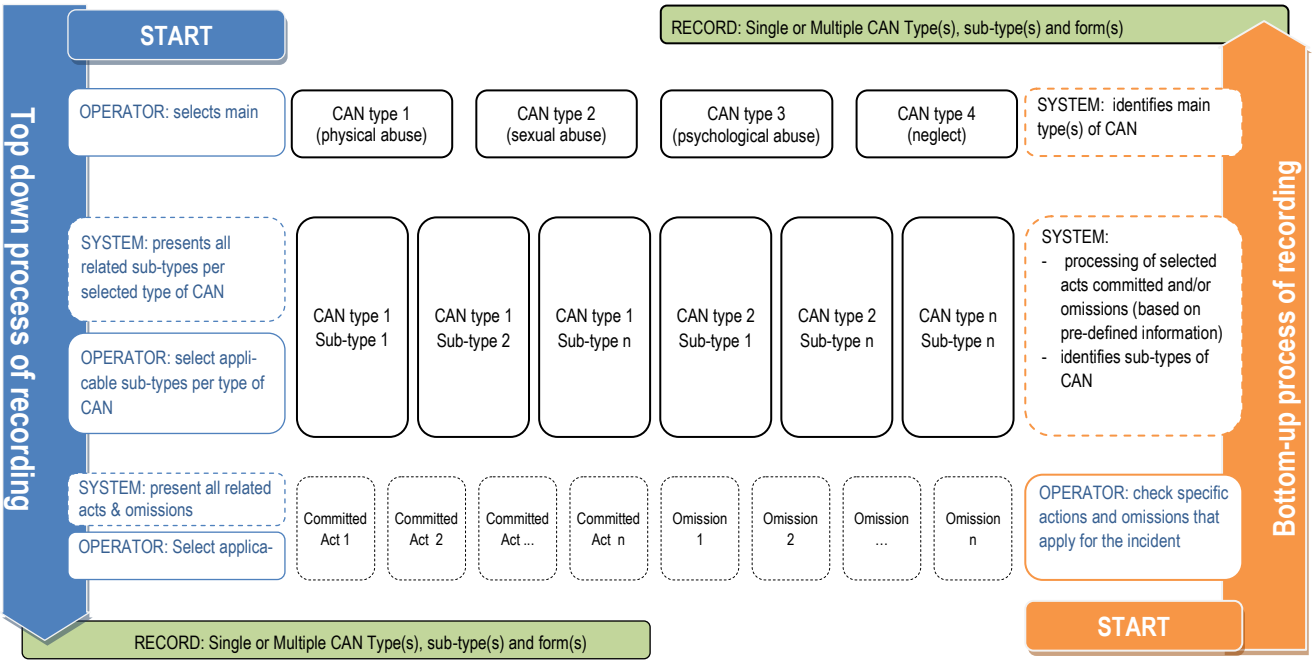
[1] *Available at: http://www2.ohchr.org/english/bodies/crc/docs/CRC.C.GC.13_en.pdf*
[2] *Available at: http://www.unicef.org.uk/Documents/Publication-pdfs/betterlifeleaflet2012_press.pdf*
[3] *Available at: http://www.unicef.org/violencestudy/reports.html*

The case definition in the context of the CAN-MDS using one of the methods, such as labels and descriptive data (mentioned above) is not considered to be effective, given that CAN-MDS intends to include a wide range of fields as data sources and to involve a variety of professionals as operators. On the other hand, the acceptance and subsequently the use of common, clear, reliable, valid and useful definitions is a prerequisite for conducting appropriate measurements: otherwise, "the vagueness and ambiguities that surround the definition of this particular social problem touch every aspect of the field-reporting system, treatment program, research and policy planning" will hinder any effort for measurement in the context of a CAN-MDS Surveillance System.



In order to ensure to the greatest possible extent a common understanding by any potential operator and subsequently, the recording and collection of reliable and comparable information, it is suggested that a bottom-up process is adopted for operationalising CAN case definitions for the needs of the CAN-MDS. It is as follows: instead of using a broad classification of the main types and subtypes of CAN, pre-coded exhaustive [check]lists of clearly defined specific commissions and omissions are developed which can be identified via observation, interview, available information or other means, AND indicate (automatically based on an algorithm) specific subtypes and consequently main types of CAN, allowing at the same time the recording of multiple forms of maltreatment (see Fig. 2).

Figure 2. CAN-MDS Case definitions: Operationalising CAN conceptual definitions towards quantifying CAN data



The CAN-MDS incorporates the main types of CAN, sub-types under each main type and form(s) under each sub-type (maltreatment acts committed and omissions). The Operator, depending on his/her familiarization with CAN definitions, can follow a different route:

- *Operators who are not familiarized with CAN definitions: a bottom up process (from commonly understood acts and omissions to broader concepts of CAN)*
- *Operators who are familiarized with CAN-Definitions: a top-down process (from main conceptually defined CAN types to specific acts and omissions)*

Note: Specific information on CAN operationalisation is provided in Guide for Operators, Part III, "Form(s) of Maltreatment"

In terms of quality of measurements, by operationalising case definitions through a bottom-up process we expect to ensure reliability (the same professional will conclude with the same type of CAN by identifying the same acts committed and/or omissions and reliability among system operators (by minimizing the need to make subjective decisions about the presence of a specific type of CAN). This aim is also expected to contribute to the training of the operators as well as developing the Guide where detailed definition of acts committed and/or omissions will be available); validity of measures (by asking operators to record acts committed and/or omissions instead of type of CAN, it is expected that the collected data will reflect the type of CAN instead of operators' understandings).

4. sources of data

Identification of potential sources of data for a CAN-MDS Surveillance System

A **4-step methodology** was developed to define the eligibility criteria for CAN-MDS Core & Expanded Groups of Operators:

DEFINING ELIGIBILITY CRITERIA FOR CAN-MDS DATA SOURCES, CORE & EXPANDED GROUPS OF OPERATORS	
Step A	Identification of relevant fields to be involved in a future CAN-MDS system as data sources
Step B	Identification of eligible professionals to be invited as potential operators of a CAN-MDS system per working field
Step C	Identification of responsibilities of each eligible professionals' group and suggested involvement (core group, expanded group, both groups)
Step D	Decision for level of access of eligible professionals to be included in the expanded groups of operators in a future CAN-MDS according to their responsibilities for the administration of CAN cases

Respondents

- Van Puyenbroeck, B. Child and Family Agency, **BELGIUM**
- Stancheva-Popkostandinova, V. South-West University "Neofit Rilski" (SWU), **BULGARIA**
- Seraphin, G. and Bolter, F. National Observatory of Children in Danger (ONED), **FRANCE**
- Goldbeck, L. and Witt, A. University Ulm, Dept of Child and Adolescent Psychiatry/Psychotherapy, **GERMANY**
- Stavrianaki, M., Ntinapogias, A. and Nikolaidis, G. ICH, Dept of Mental Health and Social Welfare, **GREECE**
- Mamini, S. and Bianchi, D. Istituto degli Innocenti, **ITALY**
- Roth, M., Antal, I. and Tonk, G. Babes-Bolyai University, Dept. of Social Work (BBU), **ROMANIA**
- Jud, A. Lucerne University of Applied Sciences & Arts, School of Social Work, **SWITZERLAND**
- Castellanos Delgado, J. L. and Solis de Ovando, R. Ministerio de Sanidad, Servicios Sociales e Igualdad, **SPAIN**

The suggested sources of data and the operators for a potential CAN-MDS System are presented in the respective report (D3.1 Eligibility criteria for CAN-MDS Operators' Core Groups and Expanded Groups). By taking into account the information provided by the respondents in the Step A, the classification of data sources resulted is presented in Figure 4.1.

Figure 4.1: Core (a), expanded (b) & under consideration (c) data sources for a potential CAN-MDS Surveillance System

Comments on the Results

The criterion for the assignment of a specific level of access within each individual eligible group of professionals was based on the responsibilities of the professionals undertaking their daily work activities. Moreover, the classification of professional groups was based on the positive answers provided by respondents concerning the applicability of the specific activity for the specific professionals (number of countries). Taking into account that one the aims of the project is to formulate a wide base of data-sources and at the same time to provide potential operators with a useful tool for following up child maltreatment at a case level via different levels of access, the above criterion for assigning level of access was not considered to be strict enough.

The information collected from the project's partner countries together with information from further countries (the Associate partner and the voluntary contribution by Spain) can be re-analyzed in the future by using additional criteria (for example, using weighting for the "responsibilities" under consideration or to modify the *thresholds* in the number of countries where a service is in place). Given that assigning different levels of access, even to specific professionals who are subject to professional codes of ethics and/or relevant legislation, is closely related to legislation relating to the administration of sensitive personal data, the feasibility of the eligibility criteria will be checked at a next step.

In conclusion, the eligible group of professionals and the eligible sectors presented in this report are a basis for future development rather than a final classification.

INFORMATION FROM ADDITIONAL COUNTRIES ON SECTORS INVOLVED IN CHILD MALTREATMENT ADMINISTRATION AND THE RESPONSIBILITIES OF PROFESSIONAL GROUPS WILL LEAD TO A MORE CLEAR DEFINITION OF DATA SOURCES & OPERATORS FOR A CAN-MDS SYSTEM. YOUR CONTRIBUTION IS WELCOMED!

Through the 4-step process an effort was made to identify, in a *systematic way,* the professionals who are eligible to be invited as *operators* of a potential CAN-MDS Surveillance System and, as a prerequisite, to identify the relevant fields/ sectors involved in the administration of CAN cases in the participating countries (see Table 4.1).

Table 4.1: Core and Expanded Groups (where professions/ services are applicable, according to country specifics)

Full View Access (Level 1)	Limited Access (Level 2)	Limited Access (Level 3)
♦ **Public Prosecutors working in Judicial Services** ♦ **Social Workers working in the Child Protection System**	♦ Social Workers working in Social Welfare Services ♦ Social Workers working in Accredited NGOs/ Community Organizations ♦ Mental Health Professionals (psychologists, psychiatrists) working in Mental Health services ♦ Child Psychiatrists working in Health Care Services ♦ Child Psychiatrists working in Mental Health Services ♦ Psychologists working in Child Protection/Social Welfare Services ♦ Psychologists working in Health Care Services ♦ Psychologists working in Mental Health Services ♦ Paediatricians working in Health Care Services ♦ Medical Doctors (different specialties, e.g. orthopaedists, radiologists) working in Health Care Services ♦ Police Officers working in Law Enforcement-related Services ♦ Mental Health Professionals *(psychologists, psychiatrists)* working in Law Enforcement related services ♦ Licensed Counsellors working in CPS/Social Welfare Services ♦ Licensed Counsellors working in Mental Health Services ♦ Judges working in Judicial Services ♦ Gynaecologists working in Health Care Services ♦ Nurses working in CPS/Social Welfare Services ♦ Midwives working in CPS/Social Welfare Services ♦ Data administrators working in existing related registries ♦ Legitimate researchers working on human subject protection	♦ Social Workers working in Health Care Services ♦ Mental Health Professionals *(psychologists, psychiatrists, licensed counsellors)* working in Accredited NGOs/Community Organizations ♦ Social Workers working in Education Services ♦ Social Workers working in Mental Health Services ♦ Care Providers in Institutions working in the Child Protection System/ Social Welfare Services ♦ Psychologists working in Educational Services ♦ Licensed Counsellors working in Education ♦ Probation Officers working in Judicial Services ♦ Other Justice-related professions working in Judicial Services ♦ Nurses working in Accredited NGOs/ Community Organizations ♦ Teachers/educators (pre-school, kindergarten, primary & secondary education, special education, school principals) working in Educational services ♦ Other personnel working in antitrafficking, directorate for disability, Child Ombudsman, etc.) working in Independent Authorities

What a CAN-MDS Operator can contribute to CAN-MDS

- *to record new CAN incidents for new cases (children) identified or following a report*
- *to add data for new incidents under already known cases*
- *to update data for already recorded incidents for known cases (follow-up)*

What CAN-MDS can provide to a CAN-MDS Operator

- *a user-friendly tool for reporting CAN incidents (especially when the professional is mandated to report)*
- *a user-friendly tool for keeping basic information for all new incidents of CAN brought to his/her attention*
- *a tool for checking demographic and other data for already known children (via auto-produced reports)*
- *a communication channel with other professionals working in the same or different sectors on the same case*
- *basic information on previous incidents for already known cases (children) (according to his/her level of access)*
- *a ready-to-use tool for*
  - *informing other agencies on his/her agency's response (e.g. what services have already been provided)*
  - *notifying other agencies of new cases (for example, via referrals)*

5. system's attributes

operational characteristics of potential National CAN-MDS Surveillance Systems

Legal authority for the data collection	The coordinating role of a national CAN-MDS System could be undertaken by an Authority activated in the field of children's rights that satisfies criteria concerning: 1. legal status; must be an officially recognized governmental institution, statistical office, research organization or independent authority; 2. to be legally authorized to maintain and administrate sensitive personal data; 3. to demonstrate sufficient human and financial resources as well as physical infrastructure (this, however, does not imply that excessive resources are required; if an existing authority becomes an CAN-MDS Administrator and allocates part of the available resources for the system's coordination, the operational costs would be significantly lower than in the case of establishing a new service); 4. last but not least, to be able to commit in advance to the system's objectives and operation, ethical rules on data collection, maintaining and administration of personal sensitive data in compliance with the currently applied legislation, and the timely dissemination of the information.
Data sources of data for the system	The CAN-MDS Surveillance System aims to collect reliable data on child abuse and neglect cases covering the largest possible part of the target population (children up to 18 years old). For this reason, the system is directed towards an expanded base of potential sources of information,* which would systematically provide the system with complete data to fully describe a limited number of data elements accessible by all sources (minimum data set). *More information on eligibility criteria for identification of Sectors and Professions groups –data sources are available in the report "Development of eligibility criteria for the creation of national CAN-MDS Operators' Core & Expanded Groups" and "Eligible members of national CAN-MDS Operators' Core & Expanded Groups".* **sectors with different jurisdictions (health, mental health, welfare, education, justice, law enforcement), services with different responsibilities (belonging to one of the eligible sectors) and professions groups with different specialties (who are involved at any stage of child abuse and neglect cases' administration)*
Type of data to be collected	The CAN-MDS registry is a password protected e-tool that was developed on the basis of the minimum data set. It consists of 18 data elements, which are classified under five areas: *child*, *incident*, *family*, *services* and *record*. Each operator-data source is requested to collect CAN incident-based data that will be entered into the CAN-MDS registry, as well as data that will be communicated to the Administrative Authority (and will never be entered in the registry). The data to be entered in the registry can be primary (raw data regarding the incident, as the date of the record) or secondary (data deriving from calculations based on the raw data, such as the age of the child at the time of registration as calculated on the basis of date of birth or pre-existing international classification systems such as the international classification of professions ILO-ISCO-8). The data to be available only to the Administrative Authority, are mainly supplementary data for the identification of child's identity and exclusively serve the administration of child abuse and neglect at a case-level and are not related to public health surveillance objectives. In this category sensitive personal data or other identifiers such as contact details are included.
Targeted population groups	All minors (0-18 year olds) who are victims of child maltreatment or at risk of being victimized (main beneficiaries). Caregivers of minors who are victims of child maltreatment, or at risk of being victimized & Professionals (indirect beneficiaries)
Policies in place to ensure data privacy, confidentiality, security	In order to ensure protection of sensitive personal data in the context of the CAN-MDS Surveillance system, the following provisions were adopted: a. use of the *pseudoanonymisation* technique (following the rationale of ISO/TS 25237:2008(en)-***Pseudoanymisation***): no personal identifier is recorded in the e-registry; instead, a *pseudonym* is used. The supplementary data linking the pseudonym with the subject of information (i.e. the child, a caregiver) is available ONLY to the Administrative Authority of the system (IOM, 2009); b. **eligibility criterion for operators**: only professionals subjected to a code of ethics or practice or equivalent code can participate in the CAN-MDS as operators; c. **password protected access**: each eligible operator is provided with a unique username and password that contains information on the operator's identity (secondary data related to the agency where s/he works, the geographic area where the agency is located, the professional's specialty and his/her ID within the agency); and d. **graduated 4-level access**: operators are designated with different levels of access to the available information according to their responsibilities in the process of child abuse and neglect cases' administration.
Data analysis, interpretation & reporting	"*CAN-MDS data analysis, interpretation and reporting*" refers to periodical analyses of aggregated data extracted by the CAN-MDS, reporting and dissemination at multiple levels. Data collected via a CAN-MDS Surveillance System can be used to periodically measure the incidence of CAN and its specific forms based on data deriving from services' responses to CAN cases in general, per sector and per specific form of abuse and neglect. Moreover, CAN-MDS data can be used to monitor trends in child maltreatment at national and local levels and to provide clues for the identification of new or emerging child abuse and neglect trends and for populations at high risk. Last but not least, these data can be used as a baseline for evaluation of services' needs (needs assessment related to CAN cases administration), of effectiveness of preventive interventions and identification of good practices and of effectiveness of applied policies, planning of future policies and legislation as well as prioritizing the allocation of resources for CAN prevention. Periodic CAN-MDS reports are released on a regular basis (e.g. every 3 months) and addressed to a. Agencies participating in the CAN-MDS (primary level); b. Central Services of involved sectors (secondary level) and c. Ministries/policy decision making centres relevant to involved sectors (tertiary level)

Components of a CAN-MDS Surveillance System & attributes to deal with major public health surveillance limitations

Basic components of public health surveillance systems are data collection, analysis, interpretation and dissemination (Amal 2009; Thacker 2000). In order to be functional a surveillance system should: have clear objectives; use minimal relevant data collection for appropriate action; address a defined target population; have specified sources of data; and incorporate a well-identified information flow with feedback and information-dissemination mechanisms in place (CDC 2012).

COLLECTION—Limitations	*CAN-MDS response*
distrust of the system and its necessity	providing all related stakeholders with sufficient justification about the necessity for ongoing and systematic data collection for CAN cases based on a surveillance system
under-recording due to under-reporting Under-reporting of cases and lack of timeliness in recording due to reporting procedure	widen the spectrum of data sources and consequently the "pool of reporters" (providing them with graded access level)[1] by facilitating the reporting process: by allowing all eligible professionals working in different sectors to become operators of the system instead of guiding them to report to other professionals (working in services such as CPS/Social or Judicial services)
under-reporting due to lack of legislation for mandatory reporting	including professionals-operators who are not mandated to report
under-recording of reported cases due to passive recording (Konowitz *et al*. 1984)	adopting an integrated surveillance (combining passive and active systems – according to country specifics) by using a single methodology and tool to gather information on the basis of case definitions
recording is time consuming due to unwieldy form or procedure	use of an online application on the basis of a minimum data set with pre-coded variables (no text will be required) and simplified recording process
lack of incentive for recording; lack of feedback leading to the perception that there is no action on the record	Provision of timely, informative feedback, relevant to case administration (according to the level of access); long term, providing operators on a regular basis with information on public health interest (such as CAN trends, risk factors etc.).
on the part of professionals-operators: they are unaware of their responsibility to record or assume that someone else would record	- dedicated pre-defined professionals per agency (individual usernames) - specific professionals will be dedicated by their agencies to enter CAN incidents records in the CAN-MDS system (they will be provided with personal usernames and passwords)
professionals are unaware of which cases must be recorded	dedicated professionals to become operators of CAN-MDS system will be provided with detailed case definitions
professionals are unaware of how to make the record	dedicated professionals to become operators of CAN-MDS system will be provided with a short training and the necessary material (Guide and Protocol of procedures).
professionals have a negative attitude toward the recording process	simplification of the recording procedure via a user-friendly user-sensitive on line application
professionals concern that recording may result in a breach of confidentiality or may compromise the professional -(alleged) victim relationship	- ensuring data encryption/anonymisation, graded access levels, following national legislation on administration of personal sensitive data - providing all involved stakeholders with sufficient argumentation on ethical aspects related to confidentiality and sensitive personal data

ANALYSIS—Limitations	*CAN-MDS response*
based on services' responses (not the general population)	widen the spectrum of data sources & range of eligible system's *feeders*[2, 3]
lack of representativeness (mostly serious incidents and from specific sources, e.g. social services or legal system)	widen the spectrum of data sources widen the case definitions (CAN incidents regardless substantiation)
disagreement with the need to record specific cases because the case is not that serious or recording mainly severe cases leading to an inflated estimate of severity	detailed case definitions that will not allow for subjective judgments concerning seriousness and eligibility of cases

INTERPRETATION—Limitations	*CAN-MDS response*
different data collection tools	*use of an MDS (agreed upon by national and international experts) allowing comparisons at a national and international level*
"Case definitions" related difficulties different definitions	use of practical operational definitions of MDS variables, simple, understandable and accepted by all eligible professionals-operators on whom the system will rely for recording cases, regardless of the sectors where they are working
inconsistency of case definitions	use of case definitions resulting from a bottom-up process for definition, in order to eliminate misunderstandings and subjective judgments on the types and the severity of incidents
different data collection procedures	-availability of short training module, trained national core-groups, guide for professionals & short operations' protocol

1. *"...Unfortunately, the data systems discussed here are not for the most part managed in any coordinated way. The people involved with these data systems do not come from the same field or federal agency. One method of setting priorities and generally improving the data systems is to bring together users and managers of different data sets as well as people from different fields such as criminologists, social workers, public health professionals and others in part to learn from other systems. A way to proceed may be to work with the interagency task force on "Integrating Federal Statistics on Children" and other organizations to develop more conferences, focus groups, task forces and other opportunities for people in different systems to come together and apply lessons from each other's work"* [Source: Finkelhor and Wells, 2003].
2. *"...Data systems could expand the coverage of the systems to include more jurisdictions or other segments of the population"* [Source: Finkelhor & Wells, 2003].
3. *"...National Incidence Study of Child Abuse and Neglect collects data from child protective service agencies, as well as from "non-CPS sentinels" in law enforcement, medical services, education, and other services (mental health, day care, voluntary social services), who come into contact with maltreated children"* [Source: Sedlak & Broadhurst, 1996].
4. *"...The data systems need to be modified to provide continuity and interrelationships among systems, either by using uniform definitions, or integrating data systems to facilitate the tracking of children across systems"* [Source: Finkelhor and Wells, 2003].

6. recording tools & procedures

Data Framework - selecting indicators to be measured

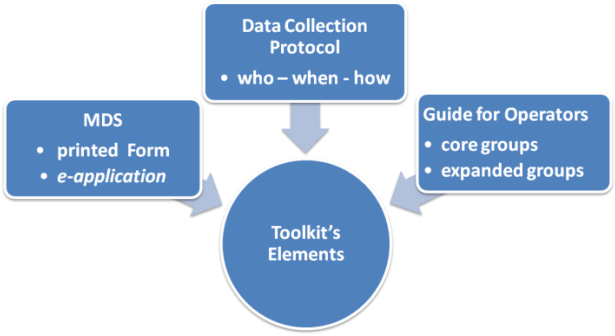
Targeted indicators by the CAN-MDS are expected to be policy relevant, able to provide guidance for critical decisions on child abuse and neglect prevention and administration, simple (mainly incidence rates), sensitive and continuous (able to indicate trends in the phenomenon over time)

The data framework for indicators to be measured through a CAN-MD system can be summarized in the Figure below.:

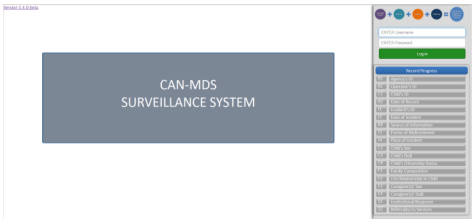
Exposure to child abuse and neglect	**Child abuse and Neglect incident** per type/form of abuse/neglect, per child (alleged) victim age/ per time period/ per geographic area (Axes: **RECORD** and **INCIDENT**)
Exploration of risk determinants for child abuse and neglect	**Characteristics** of children (alleged) victims/ children's families/ primary caregiver(s) when the incident took place (Axes: **RECORD** and **CHILD** and **FAMILY**)
Services' response to child abuse and neglect	**Services' & Professionals' Response** (immediate and log-term) in recoding/ reporting/ investigating/ assessing/ administrating of child abuse and neglect at a case-level (Axes: **Record** and **SERVICES** and **INCIDENT**)

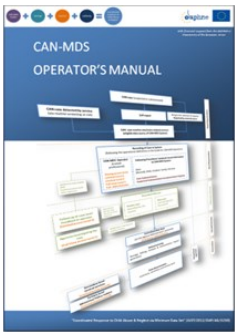
CAN-MDS toolkit at a glance

Structure of the CAN-MDS Toolkit



The CAN-MDS Toolkit consists of three main elements: a. the first version of the Minimum Data Set currently comprising of 18 data elements that were produced via a multiple-round quality and feasibility evaluation process, where international stakeholders participated; an e-version and a printed version of the CAN-MDS is available for use [mainly for training purposes]; b. the data collection protocol that was drafted on the basis of the CAN-MDS, suggesting a *step-by-step* procedure for using the CAN-MDS; this protocol could be used by any professional who has already been trained to become an operator; and c. the Guide for Operators where all necessary background information is included for the professionals who fulfill the eligibility criteria and the prerequisites to use the system. Apart from information concerning the necessity for child maltreatment surveillance in the country, a special section on ethics, privacy and confidentiality issues related to CAN data collection is also included in the Guide. The main body of the document is dedicated to the detailed presentation of the variables included in the CAN- MDS along with technical specifications and definitions of data elements.





During the development of CAN-MDS Toolkit, international standards and classifications were used –where feasible- such as ISO standards for developing agencies IDs (indicating country and regions) and the ILO-ISCO-08 (for developing Operators' IDs). In other cases the rationale of international standards was followed (such as the *pseudoanonymisation* methodology for ensuring sensitive personal data protection, recording of dates and of secondary data such as contact details). For the design and description of the CAN-MDS in general the rationale of metadata registries was followed, as is described in ISO/IEC 1179. As already mentioned, operationalisation of case definitions were made on the basis of UNCRC, Art. 19 and the UN CRC/GC/C/13 (2011)], while the permissible values were matched –where feasible- with international classification systems such as ICD-9, ICD-10 as well as the DSM-5 (2013). For data elements that no relevant classifications were identified, codification was made on coding developed and agreed upon in the context of the CAN-MDS (as, for example, for the eligible agencies and sectors to participate in the CAN-MDS as data sources and for provision of different levels of access to operators). The methodologies followed in such cases are clearly defined in order for any interested party to be able to use them for adapting the CAN-MDS in other settings or for the updating the information.

Table 6.1 CORE CAN-MDS DATA ELEMENTS (DE) & AXES

Data Elements related to INCIDENT	
DE_I1:	Incident ID
DE_I2:	Date of Incident
DE_I3:	Form(s) of maltreatment
DE_I4:	Location of Incident
Data Elements related to CHILD	
DE_C1:	Child's ID
DE_C2:	Child's Sex
DE_C3:	Child's Date of Birth
DE_C4:	Child's Citizenship Status
Data Elements related to FAMILY	
DE_F1:	Family Composition
DE_F2:	Primary Caregiver(s) relationship to child
DE_F3:	Primary Caregiver(s) Sex
DE_F4:	Primary Caregiver(s) Date of Birth
Data Elements related to SERVICES	
DE_S1:	Institutional response
DE_S2:	Referral(s) to Services
Data Elements related to RECORD	
DE_R1:	Agency's ID
DE_R2:	Operator's ID
DE_R3:	Date of Record
DE_R4:	Source of Information

CAN-MDS toolkit at a glance

The CAN-MDS aims *inter alia* to promote:

- *standard description of data*
- *common understanding, harmonization and standardization of data within and across organizations activated in the same or different sectors*

The data comprise the CAN-MDS registry are deriving from 18 data elements classified under 5 broader *axes* (data element concepts): "RECORD", "INCIDENT", "CHILD", "FAMILY" and "SERVICES".

Common understanding of the meaning of the data among all stakeholders is a prerequisite for proper use and interpretation of data. Targeting to achieve this common understanding, a number of characteristics of the data are defined following the recommendations of international standards, which are known as "metadata", that is, "data that describes data". The CAN-MDS system aims to keep information about data elements related to incidents of child maltreatment and associated concepts on the basis of pre-defined set of permissible values for each individual data element.

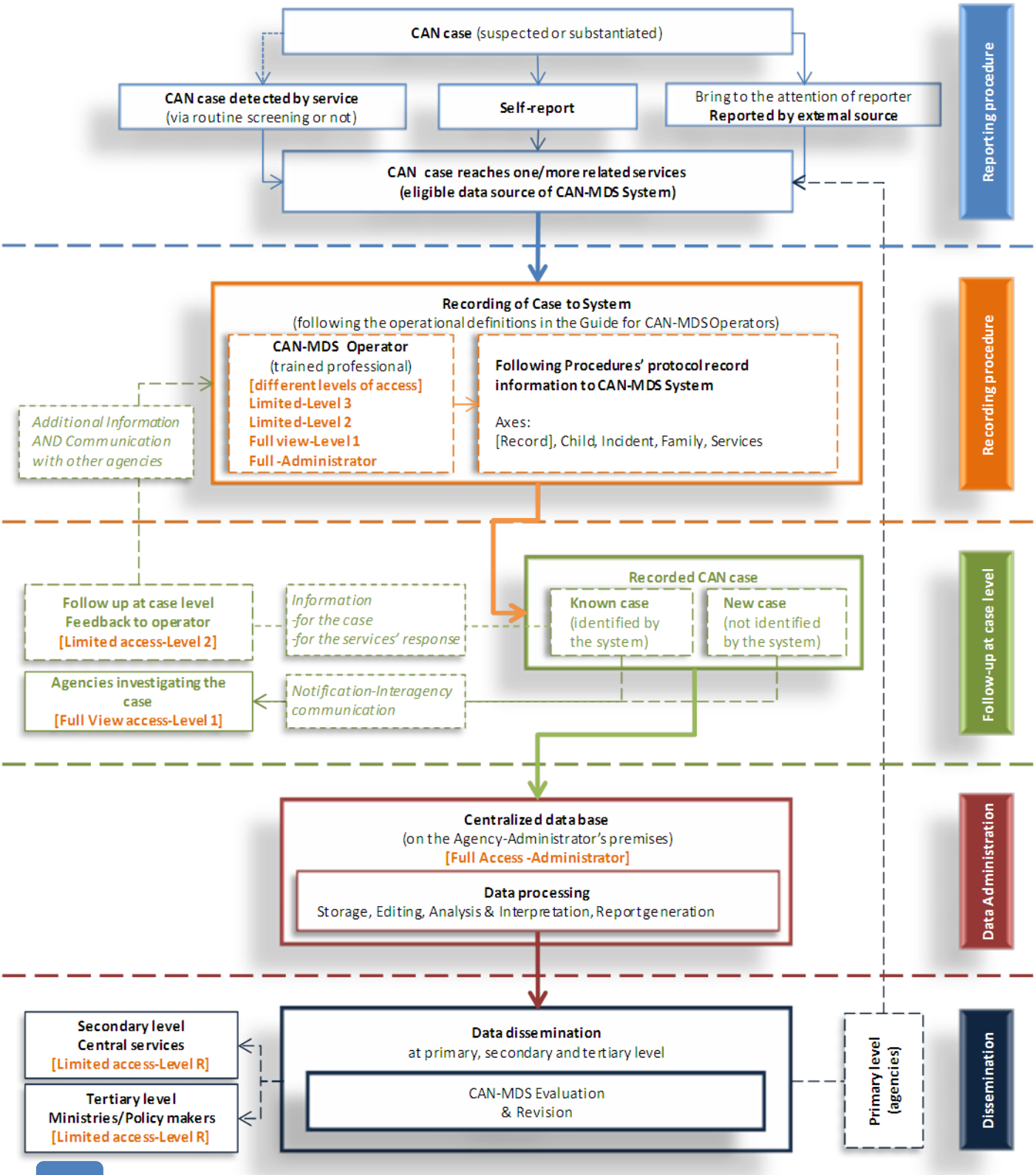
All the above are necessary to clearly describe, record, analyze, classify, and administer data to be collected via the CAN-MDS.

Attributes of DE	**short name of data element**		
CAN-MDS ID:	Identifier of the data element in the context of the CAN-MDS		
Definition:	Short definition of the data element		
Instruction for recording:	Instructions to the Operator for the recording of the specific DE (including steps and examples)		
Completion:	*potential alternatives*		by the CAN-MDS Operator
			by the System
			by the Administrator
			by other CAN-MDS Operator
Obligation:	*potential statuses*		mandatory (*always required)*
			conditional (*required under certain specified conditions)*
			"for your information" only
Multiplicity:	*potential statuses*		single (unique) selection *(one per data element)*
			multiple selection *(one or more per data element)*
Data type:	**Primary records** (case-based *raw* data):		date
			date and time
			value *(pre-coded lists of permissible values)*
			number (integer)
	Secondary data (deriving from primary record & contain selected data elements):		Identifier
			Duration
			auto-generated value
			pre-existing value (such as international classification systems concerning countries/regions, agencies, professions)
	Supplementary data:		necessary information (such as CAN-MDS Agencies' inventory)
			restricted supplementary data (such as child's and caregiver(s) personal identifiers and contact details) available only to the Administrator
Relevance:	*The DE is linked to*	*axis/axes*	
		other DE (primary and/or secondary data type)	
Values:	*List of applicable pre-coded values defined in Part III "Data Dictionary"*		

7. flowchart of a CAN-MDS public health surveillance system

Ongoing and systematic data collection on 4 axes related to child maltreatment cases from a wider basis of data sources by trained professionals-operators with different levels of access

Data analysis, interpretation and dissemination provides a **basis for public health action** (within and between countries), that will lead to the setting of priorities, planning, implementation and evaluation of prevention and administration policies and practices. Case-level information provides a **communication channel** between different sectors and professionals responding to CAN cases and a tool for case administration, including feedback for investigation of new cases and follow-up of cases.



more information

Project's Identity

Title: **Coordinated Response to Child Abuse and Neglect via Minimum Data Set**
Co-Funding: EC DAPHNE III Programme, DG Justice, [80%] and Participating Organizations [20%]
Contract: JUST/2012/DAP/AG/3250
Duration: 24 months (starting date Feb 2013)

Insitute of Child Health
Department of Mental Health & Social Welfare

Project's Consortium:

Coordination Institute of Child Health, Dept. of Mental Health & Social Welfare (ICH-MHSW)-EL
Ethical Issues: Prof P Durning
External Evaluator: Ms J Gray

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South-West University "Neofit Rilski" (SWU)-BG
University Ulm, Dept. of Child and Adolescent Psychiatry/ Psychotherapy-DE
National Observatory of Children in Danger (ONED)-FR
Istituto degli Innocenti (IDI)-IT
Babes-Bolyai University, Dept. of Social Work (BBU)-RO

Associate partner Lucerne University of Applied Sciences & Arts, School of Social Work-CH

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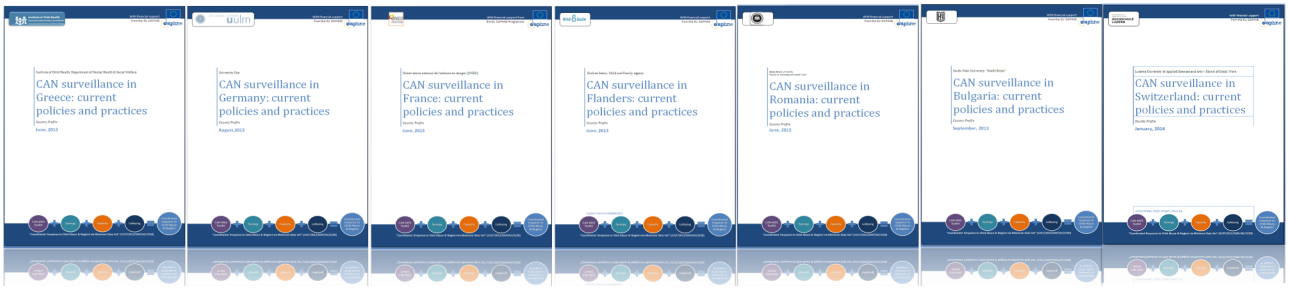

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