eDESDE-LTC

DESCRIPTION AND EVALUATION OF SERVICES AND

DIRECTORIES IN EUROPE FOR LONG TERM CARE

Introduction and Development of the System

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CONTENTS

FOREWORD

The 'Description and Evaluation of Services and Directories in Europe for Long Term Care' (DESDE-LTC) is an instrument for the standardised description and classification of services for Long-Term Care (LTC) in Europe. DESDE-LTC has been designed to allow national and international comparisons of care availability and use.

The eDESDE-LTC Final Technical Report provides a description of the development, results and outcomes of the project. This document includes the introduction and the development of the eDESDE-LTC System (instrument and coding system). It is available at http://www.edesdeproject.eu[1].

Luis Salvador-Carulla

Coordinator of eDESDE-LTC Project

[1] If you want to provide a feedback on the usability of the eDESDE-LTC system, please click on the link below to complete the online questionnaire (it takes less than 10 minutes):

http://www.unet.univie.ac.at/~a0305075/umfragen/index.php?sid=21575&newtest=Y&lang=en

LIST OF MAIN ABBREVIATIONS

BSIC	Basic Stable Inputs of Care
DESDE	Description and Evaluation of Services and DIrectories
EAHC	Executive Agency of Health and Consumers
IRIO	Izobraževalno Raziskovalni Inštitut
LSE	London School of Economics
LTC	Long-Term Care
MTC	Main Types of Care
OECD	Organisation for Economic Co-operation and Development
SHA	Public Health Association
UNIVIE	University of Vienna
WHO	World Health Association

LIST OF TABLES AND FIGURES

FIGURES

Development

1. INTRODUCTION

Health services are very difficult to compare across different territories particularly when they are aimed for long term care of complex health conditions. In the past service comparison studies failed to provide useful information for health planning in areas as diverse as mental health (Salvador-Carulla et al, 2006), ageing (Johri et al, 2003), or services for functional dependency in Europe (EUROSTAT, 2003). This could be attributed to several factors, such as the influence of historical and contextual factors in the development of local services, differences in organisation, increase complexity of integrative care arrangement and mainly to the fact that services with the same name perform different activities and vice-versa. This terminological variability appears across all levels of complexity of the care settings, from day centers and day hospitals to rehabilitation units. We even lack a common definition of 'hospital' and 'service'.

On the other hand, WHO urges for international service comparison for assessing health care reforms (Lujbliana Chart) and the European Commission is urged to provide comparable descriptions of care to facilitate patient mobility. Although 'Having access to high-quality healthcare when and where it is needed' is a fundamental right of every European citizen (Charter of Fundamental Rights of the European Union, 2000), the fact is that mobility and access to health services across Europe is hampered by an inadequate framework and knowledge of available resources. The development of a common coding and assessment system is also relevant for harmonisation and equity or impartial allocation of care (resources, programmes and treatments) to different groups and individuals. Furthermore the growing linkage of European databases is accompanied by a parallel demand of 'semantic interoperability' or the development of a common language that can be used across different information systems and databases.

A common coding system and standard method of assessment is needed to overcome these terminology problems and to enable comparison of local data to generate informed evidence.

The WHO Advisory Committee on Health Research recognised that all evidence is

context sensitive –and therefore indirect to some extent- and both global and local evidence should be combined to develop usable recommendations. Local evidence (from the specific setting or territory in which decisions and actions will be taken, is needed for most other judgements about what to do, including: the presence of modifying factors in specific settings, need (prevalence, baseline risk or status), values, costs and the availability of resources (Oxman et al, 2006). The relevance of local (meso-level) and global/national/regional information (macrolevel) has been reviewed in the context of the SUPPORT programme for improving decision making about health policies and programmes (Lewin et al, 2009).

In 1994 the European Psychiatric Care Assessment Team (EPCAT) initiated the development of a common terminology and a standard assessment of mental health services aimed at overcoming these terminology problems and to facilitate territorial comparisons to generate informed evidence for health planning and resource allocation. EPCAT developed a battery of instruments for psychiatric service comparison within the European Union. This battery included a brief indicator set of small mental health areas (European Socio-Demographic Schedule – ESDS) (Beecham et al, 2000), a standard assessment of care activities within mental health services (International Classification of Mental Health care – ICMHC) (de Jong, 2000) and an instrument for coding, assessing provision and utilisation of mental health services (European Service Mapping Schedule – ESMS). This was accompanied with the consensus on a standard method for service assessment and comparison in small health areas (Johnson S & Kuhlmann, 2000). In the following years this system was used to provide territorial comparisons of mental health care in countries such as Italy (Munizza et al, 2000), Spain (Salvador-Carulla et al, 2000), Poland (Trypka et al, 2002), or Germany (Böcker et al, 2001). The system also proved its usability for international service research including comparisons of the mental health systems in Spain, Italy and Chile (Salvador-Carulla et al, 2005; Salvador-Carulla et al, 2008), or Norway and Rusia (Rezvyy et al, 2007), as well as a series of international studies mainly in Europe (EPSILON etc).(Becker et al, 2002).

Mental health care could be regarded as a prototypical example of complex care (xx), and the demand for a standard coding and assessment system draw the development of extended versions in Spain for the assessment of services for disabilities (Salvador-

Carulla et al, 2006), and services for ageing population (Salvador-Carulla, 2003).
These previous projects and instruments drew to the development of a version for Long-Term Care (DESDE-LTC), in a project funded by the European Agency of Health and Consumer (EAHC). This project has been aimed at four main objectives: 1) To develop a standard classification system to code services for LTC in Europe; 2) To develop a related instrument (DESDE-LTC), which incorporates basic descriptors and indicators in 6 European languages; 3) To improve linkages between national and regional websites, and EU health portals and the development of the eDESDE-LTC webpage, and 4) To improve EU listing and access to relevant sources of healthcare information via development of a training package on semantic interoperability in eHEALTH (coding and listing of services for LTC).

Semantic interoperability can be defined as “The ability for information shared by systems to be understood at the level of formally defined domain concepts so that the information is computer processable by the receiving systems” (Roma-Ferri et al, 2005), or the achievement of a common language in the field of service research.

2. DEVELOPMENT OF DESDE-LTC INSTRUMENT AND CLASSIFICATION AND CODING SYSTEM

The eDESDE-LTC project is aimed at the following objectives:

1. To develop a standard classification system to code services for LTC in Europe based on previous work (ESMS, DESDE)

2. To develop a related instrument (DESDE-LTC) that incorporates basic descriptors and indicators in 6 European languages.

3. To improve linkages between national and regional websites, and EU health portals and the development of the eDESDE-LTC webpage

4. To improve EU listing and access to relevant sources of healthcare information via development of a training package on semantic interoperability in eHealth (coding and

listing of services for LTC).

3. METHOD

The DESDE-LTC Team has been made by several major institutes in service research, provision and funding in Europe: PSICOST Research Association and the Foundation of Catalunya Caixa (Spain), the University of Vienna (Austria), the Public Health Association (Bulgaria), the Scientific Research Centre of the Slovenian Academy of Sciences and Arts and the IRIO Institute (Slovenia), SINTEF (Norway), and the London School of Economics and Political Science (UK). Collaborating partners included major experts in the development of the European Service Mapping System (S. Johnson, G Tibaldi and T Ruud), international organisations (OECD), health agencies at national level (Ministry of health Bulgaria), regional level (Regions of Cantabria, Catalunya and Madrid in Spain) and municipality level (Jerez in Spain). Other collaborating partners were main academic organisations in formal ontology (University of Alicante, Politecnical University of Catalonia) and support decision systems for health decision making (ETEA, Spain).

The methodology carried out in DESDE-LTC project followed a series of related steps:

- A review of the **framework of coding and classification services for LTC in Europe.** This review included previous studies (ESMS, DESDE) focused on evaluation of Mental Health, Disability, Ageing services.

- Using this information a first **draft of the instrument and the classification and coding system** was made. This beta version included modifications from DESDE instrument (developed for disability services) aimed to adapt the system to people with long term care needs. The development of this draft has followed the methodology used for developing the previous classification system for disability services in Spain (DESDE, Salvador-Carulla et al, 2006).

- Beta version of DESDE-LTC Instrument and Coding System was discussed in **Nominal groups** in every country.

The Nominal group technique (NGT) has been the methodology used for the development of the evaluation system. This technique is a decision-making and planning tool which allows a group to achieve consensus and prioritise issues and it can be seen as a more structured variation of the focus group, as it retains the consensus-building benefits of the group dynamic while harnessing a range of individual views.

In DESDE-LTC project, main stakeholders in the disability field including health and social care professionals, providers, representatives from user organisations and decision makers in the 6 partner countries (Austria, Bulgaria, Norway, Slovenia, Spain, United Kingdom) worked in Nominal groups providing further comments and review of the instrument and the coding system. Groups were formed of 4-6 participants plus a rapporteur contributing with their reports to obtain a first version of the instrument. Points of disagreement were solved by the working group. In the case that there were no agreement, a simple majority vote were cast.

Three sessions were organised in every country (see Nominal Group Reports in Annex V.1) with following objectives:

First session of nominal groups: to get acquainted with the problems of service research and comparability of services across different geographical areas, to know the EPCAT Approach to service research and to know the DESDE-LTC instrument and coding system in order to prepare comments and amendments which was discussed at Session 2.

This session was developed in the first half of 2009 except for England team

The results of this first session were commented in the second project meeting in Barcelona on March, 5-7th 2009 (see Minutes in Annex VIII.B).

- Second session of nominal groups: to get acquainted with the eDESDE-LTC instrument, to check the aim, structure and use of the instrument and to check the cut-off points provided at the instrument.
- Third session of nominal groups: last review of definitive version of DESDE-LTC instrument and confirm that suggestions of every nominal group have been included in an adequate way.

A conceptual and transcultural adaptation of this preliminary version of DESDE instrument and coding system has been developed in 6 languages: English, Spanish, German, Norwegian, Slovenian and Bulgarian. The first translation was revised by a local expert in service research and critical terms were discussed in a project meeting with DESDE group. Every country version should be checked and approved by every national nominal group.

- A **pilot study** (D14) of the usability of the system was made in two European main cities with highly different income level and health care systems: Sofia in Bulgaria and Madrid in Spain (Salvador-Carulla et al, 2011). This is a transversal, descriptive and ecological study to pilot the classification and coding system and the instrument.

The study has been carried out by the two project partners, the PSICOST Research Association (Spain) and the Public Health Association (PHA) (Bulgaria), and with the help of Technology and Society (SINTEF) (Norway). Two courses were undertaken to train the evaluators involved in collecting information on the instrument and the eDESDE-LTC standardized coding system.

From the information collected, services were coded according to Main Types of Care (MTC) in 'services' or Basic Stable Inputs Care (BSIC) identified in the two metropolitan areas.

- Development of the **last version** of DESDE-LTC Classification and coding system and Instrument.

The versions of the instrument and the coding system were reviewed and discussed at the final project meeting. An ontology analysis of the classification system was also performed. The nominal group participants worked in a third session of nominal groups to confirm the adequacy of last modifications on the definitive version of DESDE-LTC Classification and coding system and Instrument (see related Project Annexes).

An update of the translations of the beta version to 6 partner languages was made to obtain the definitive translated versions.

- DESDE-LTC **training programme** was devised considering a blended methodology (face-to-face and online learning). The content of eTraining Package (see Annex IV) was developed by PSICOST includes a reference manual and other tools to stimulate participation in classes as videos and documents with vignettes and examples. The material was uploaded to DESDE-LTC webpage in PDF documents and video tutorials (see Annex III).

- An eDESDE-LTC website was specifically designed and developed for project dissemination and promotion.The webpage has been incorporated into a general website on knowledge transfer by PSICOST: www.bridgingknowledge.net and can be found at http://www.bridgingknowledge.net/Flyer_eDESDE-LTC.pdf. Final web The website was developed in English and included the following sections: Home, About eDESDE-LTC, Participants, DESDE-LTC Toolkit, DESDE-LTC Training Package, FAQ, News and events and Links.

- Finally the feasibility, consistency, reliability and the validity of the instrument were tested (Salvador-Carulla L, et al, 2011).

  Once the final version of the instrument eDESDE-LTC was available, its usability was analyzed according to three main quality parameters: Feasibility, Reliability and Validity. The **feasibility** sub-study was carried out by the University of Vienna and its full report is available at the evaluation and quality assessment report (Zeilinger et al, 2011). The reliability and validity sub-study was carried out by the PSICOST research association with Sant Joan de Deu Foundation and the University of Cadiz (Spain). An ad-hoc instrument was designed by the University of Vienna group to assess the feasibility of eDESDE-LTC (Seyrlehner, 2010). The feasibility questionnaire followed the approach developed by Andrews (1994) and Slade et. al (1999).

  To carry out the **reliability** analysis, 170 services covering main types of care in Europe were selected by one member of the group (MP) from the international eDESDE databases. All services were coded according to DESDE-LTC branches by two judges Alpha and Beta, where Alfa represents an experienced person on the use of the instrument and Beta a non experienced person. The reliability analysis

took into account both the Classical Test Theory and the Generalizability theory (G theory) (Salvador-Carulla and Gonzalez-Caballero, 2010).

Feasibility analysis includes several items that may be regarded as descriptive **validity** domains. To avoid redundancy face validity and content validity were assessed as part of the feasibility analysis. The quantitative validity analysis of the eDESDE-LTC instrument was made on a database comprising 1339 services from different regions of Spain and other European countries. Boolean factor analysis was used to evaluate the content validity.

- An impact analysis was also carried out and incorporated to the evaluation report. (E. Zeilinguer et al, 2011).

Impact analysis has followed the recommendations made for this type of analysis in Europe (EUROSTAT, 2003; European Union High level group on Health Services and Medical Care, 2004), based in a previous approach developed to assess health interventions (Parry and Stevens, 2001). Due to the time frame of the study the first three phases of the impact analysis process have been carried out by the PSICOST group in cooperation with M Poole: *Screening*: Review of available instruments and literature on the topic with a focus on European Union; *Scoping*: Identification of scope at European, National, Regional and Local level at every participating country; *Appraisal*: of the classification, instrument, webpage and training package using the mapping developed at the Scoping phase (Best to lowest / 5-point likert).

4. RESULTS

The evolution from ESMS to DESDE-LTC implies not only an adaptation to other target population as Long Term Care. The application in several studies in Spain and other countries in Europe allowed updating the instrument. Several of these changes already appeared in DESDE instrument for evaluating services for people with disability.
We can find changes in every sections of DESDE-LTC Instrument:

Development

4.1. INTRODUCTION

There is an introductory section with a brief explanation of the main structure of the instrument; DESDE-LTC has included here some information on long term care and the target population.

4.2. GENERAL PRINCIPLES

-ESMS: a) Services to be included, b) Definition of mental health services, c) Target population, d) Selecting parts of ESMS II

-DESDE: a) Services to be included, b) Definition of services for people with disabilities , c) Target population, d) Selecting parts of DESDE, e) Defining catchment areas, f) Period of reference for the comparison.

-DESDE-LTC: a) Services to be included: 20% of service users are people with long term care (LTC) needs, b) Operational definitions of Basic Stable Input of Care (BSIC) and Main Types of Care (MTC) with inclusion/exclusion criteria are included, c) Target population, d) Selecting parts of DESDE-LTC, c) Defining catchment areas: Geographical levels H0-H5, d) Period of reference for the comparison.

These are concepts that have been changed:

- **Operational definition of Service or Basic Stable Inputs of Care (BSIC):**

  Inclusion criteria (BSIC)
  In order to code a care setting as a BSIC the subsequent criteria should be followed:
  Criterium "A": The service is registered as an independent legal organisation (with its own company tax code or an official register). This register is separate and not as a part of a meso-organisation (for example a service of rehabilitation within a general hospital) IF NOT:
  Criterium "B": The service has its own administrative unit and/or secretary's office and fulfils two additional descriptors (see below) IF NOT:
  Criterium "C": The service fulfils **4** additional descriptors:
  C1. To have its own professional staff.
  C2. All activities are used by the same users.
  C3. To have its own premises and not as part of other facility (e.g. a hospital)
  C4. Separate financing and specific accountancy
  C5. Separated documentation when in a meso-organization

  Exclusion criteria (BSIC)
  Exclusion criteria are important to differentiate BSIC from other components of the production of care and other organisations in the care system.
  1.- Other components of the production of care:
  - *Care products, tools or devices* are other input components of the production model. Health care products such as injections, radiology or surgical material are not coded by DESDE-LTC.
  - *Care interventions* are part of the care process and they are not coded by DESDE-

LTC. Care interventions are listed at the International Classification of Health Interventions (ICHI)

2.- Other organisations in the care system:

- *Settings at other levels of organisation.* Organisation systems exist at meso-level (grouping of services or structures that compile different services within a larger organisation such as General Hospitals) or at macro-level (i.e. large national or international Health Maintenance Organisations) are excluded from this classification.
- *Generic services* for the general population or large groups within it, (i.e. older people, migrants etc) which are important for many users with long term care needs but have not been specifically planned for this population, should not be included, with the exception of those services where more than the 50% of service users are people with long term care needs. Services delivering primary health care, which may include some kind of care for service users with LTC but do not provide any specialist care for LTC should also be excluded unless it is otherwise specified in the study.

- **Operational definition of Main Types of Care (MTC)**

. Inclusion criteria (MTC)

A. PRINCIPAL MTC: The definition and description provided at DESDE-LTC for a given code fits with the main purpose/aim/objective of a BSIC AND with the routine activity of it In case of disagreement between the defined aim and the actual current main activity of the BSIC, the main activity will be used for selecting the MTC code. Cut-off points are provided when necessary to allow coding based on the main activity/performance of the BSIC.

B. ADDITIONAL MTC s: Additional MTCs should be used to describe the range of main activities when the main characteristics of the BSIC cannot be registered by a single DESDE-LTC code. In this case the BSIC should be described using MORE THAN ONE main descriptor. For instance the acute unit of a hospital may also provide 24-emergency care non mobile, which is a completely different descriptor than R2 (principal main descriptor) and it is for a different set of users. Then this BSIC has two main descriptors or "MTC": R2, O3.

The subsequent criteria should be followed when registering additional codes:

a. The additional main activity is critical to differentiate the BSIC from other related BSICs both from the perspective of users and managers. Following the previous example (R2, O3), an acute residential unit in a general hospital with outpatient emergency care would clearly differ from a similar unit without emergency care. Registering a secondary MTC instead of an additional qualifier should clarify that the unit fits the criteria for MTC
b. The service fulfils criteria A or B for BSIC but there are multiple user groups. Then the main user group could be used to select the principal MTC and the others to select additional MTCs.
c. Clinical units have been identified within the service which fulfil the three first criteria of section "C" provided for the operational definition of a BSIC
    c1. To have its own professional staff
    c2. All activities are used by the same users who are clearly a different group from the target group assisted at the BSIC
    c3. To have its own premises and not as part of other facility
d. A significant part of the activity of the service is related to another DESDE-LTC code apart from the principal code. For example more than 20% of the activity of a non-acute non-mobile care outpatient service is home/mobile care. This BSIC may be coded as O8, O6.

Exclusion criteria (MTC)

Exclusion criteria are important to differentiate MTCs from other units of analysis in service research

1.- Care units (e.g. clinical units). Input care units that fulfil some of the criteria but do not

fulfil overall criteria for being coded as a BSIC and therefore should be considered as part of a service (e.g. a unit of eating disorders within an acute psychiatric ward in a General Hospital). MTCs are not care units. However a care unit may identify an additional MTC when it fulfils criterium 'c3' above.

2.- Service Activities: MTCs are not simple activities of the service. MTCs descriptors are based on the main activities or functions that are critical to compare services across different territories. Services (BSICs) should fit one code and it is unusual that a service may get more than three codes. When two clearly different functions of a service provide care for the same group of users, only one of them should be coded as an MTC whilst the other should be regarded as an activity and not as an MTC. Check carefully the inclusion criteria mentioned above before coding a service activity as a MTC. Activities within a BSIC should be coded using other instruments for describing individual services.

- **Definition of Levels of care**

Every care function is described in simple language and has a specific alphanumeric code (for example: provides night accommodation for acute users in a setting with 24-medical care: R2). These codes are defined by a series of qualifiers hierarchically arranged in 5 levels:
-First Level –Status of user. This level relates to the clinical status of the users who are attended in the care setting (i.e. whether there is a crisis situation or not): acute or non-acute care.
-Second Level –General type of care. This level describes the main general typology of care (home & mobile/non-mobile, physician or non-physician cover).
-Third Level – Subtype of care. This level refers to the intensity of care that the service can offer except for residential acute care where the third level describes whether care is provided in a registered hospital or not.
-Fourth Level – Specific qualifiers. This level provides a more specific description of the type of care at the setting.
-Fifth Level – Additional qualifier. This level incorporates additional qualifiers when needed to differentiate across similar care settings.

- **Definition of Territorialization levels**

Different geographical areas are coded in relation to the sector that describe. For example, health areas are designed by capital letter "H", social areas by "S" and educational areas by "E". Here just the "H" area have been described:
H0: International administrative territorial unit
For example, European Union
H1: Country administrative territorial unit
For example, Spain
H2: Next level before Country administrative territorial unit
For example, autonomous community, lander, federal state
H3: Maximum administrative territorial mental health unit
For example, mental health area (with a reference general hospital)
H4: Basic administrative territorial unit of specialized mental health
For example, catchment area of a community mental health centre
H5: Basic administrative territorial unit of general health
For example, territorial division for primary care centres

- **Period of reference for the comparison**

The reference period for filling section B (coding) is one month. When information is available average month utilisation in a natural year could be used. However when information is not available or it is not reliable, it is necessary to collect data within a single specific month. February should be excluded. Months with major holiday periods should also be excluded. Typically May, October and November may be the most appropriate months for cross country comparison.
The collection of service utilisation data for Section C should be made in the same reference period. When this information is not available the collection of the use of services might follow

one of the following patterns:

1. Direct data collected in a prospective way:
   - in one week for outpatient and day services
   - in one day for information, accessibility, emergency and residential services

2. Indirect data collected from the average monthly rate obtained from the annual data base.

4.3. MAPPING TREE

The mapping tree of the three questionnaires and its related hierarchical structure is available at the Figure 1, Figure 2 and Figure 3. These figures indicate the evolution of the system towards a more comprehensive, ontologically sound hierarchical map.

ESMS: Residential services “R”, Day care and structured services “D”, community and outpatient services “O” and self-help and volunteer services “S”
DESDE: Information and accessibility services “I”, Residential services “R”, Day care services “D”, Community and outpatient services “O” and self-help and volunteer services “S”.
DESDE-LTC: Information and assessment services “I”, Accessiblity services “A”, self-help and volunteer services “S”, Outpatient services “O”, Day care services “D” and Residential services “R”.

Figure 1. Hierarchical structure of the European Service Mapping Schedule (ESMS) (Johnson et al 2000)

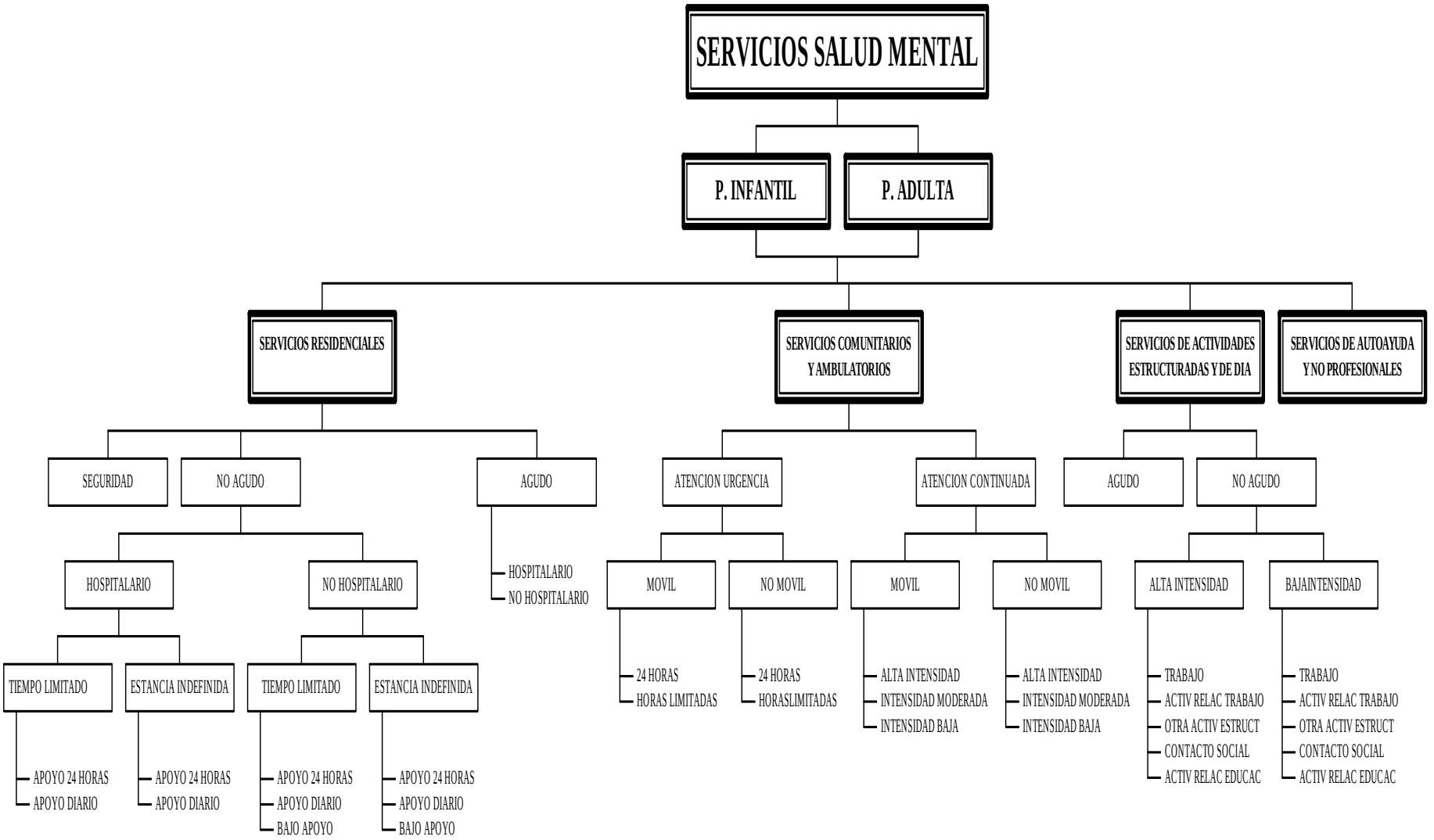


Figure 2. Hierarchical structure of the ESMS version for persons with disabilities (DESDE) (Salvador-Carulla et al, 2006)

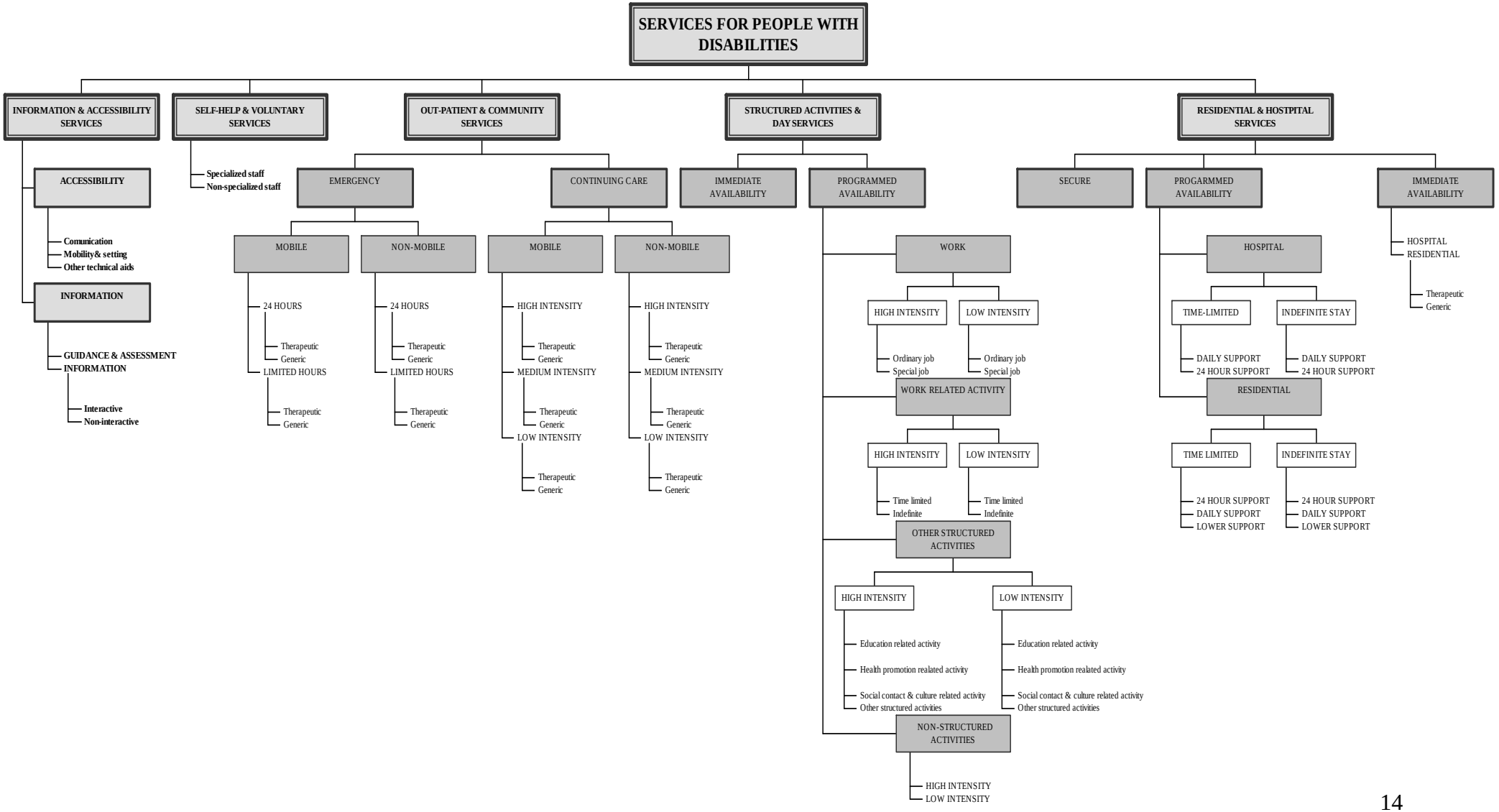
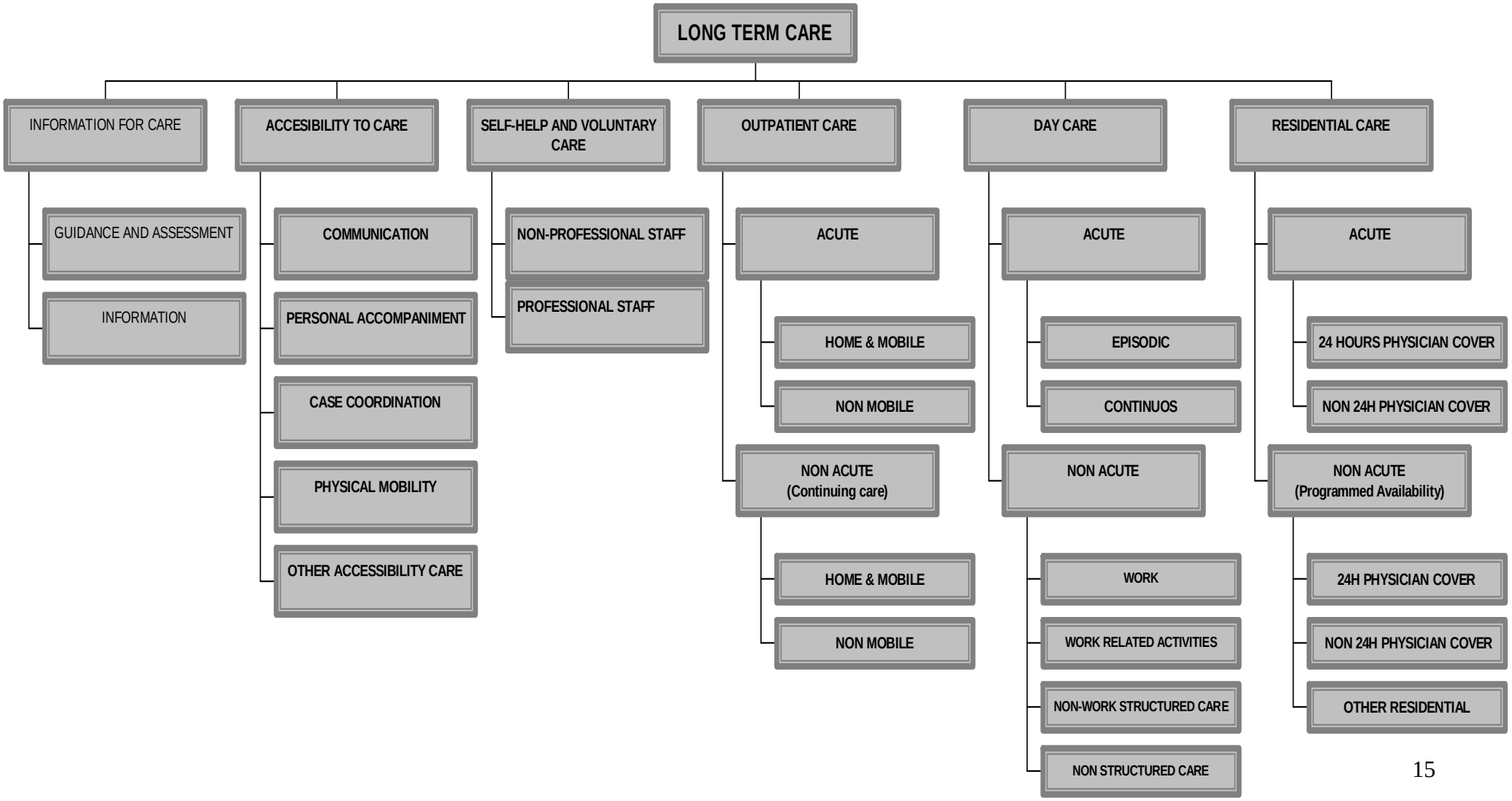


Figure 3. Hierarchical structure of the version for Long Term Care (eDESDE-LTC)



Development

4.4. SECTIONS OF THE INSTRUMENT

The original four sections of the instrument have been preserved in the following versions. However major changes have been introduced in the content of the four sections at eDESDE-LTC.

Section A:

ESMS: Introductory questions

DESDE: Introductory questions: it includes a table with diagnostic groups referred to disability

DESDE-LTC: Introductory questions: it includes a table with diagnostic groups referred to long term care problems as follows:

Diagnostic groups to be included in the application of the instrument (tick those you will include in your counts)	
Adults with Severe Physical disability (registered)	☐
Adults with Intellectual disability	☐
Adults with Mental disorder (ICD-10)	☐
Elderly/older people with physical or intellectual disabilities (registered) or older people with mental disorders	☐
Other diagnostic category (specify using the ICD-10 code whenever possible)	☐

Section B:

-ESMS: Care Type Mapping: Principles- The location in the tree of each service is identified by a combination of three letters and a number, "A" or "I" for adults or children, "R", "D", "O", "S" indicates the type of care, a number accompanying the final branch within the tree "R2", "D4", etc. and a final letter, numbers and final letters give extra information of the service.

-DESDE: Care Type Mapping: Principles- The location in the tree of each service is identified by a combination of a letter and a number, "I", "S", "D", "O", "R" indicates the type of care and a number for the final branch within the tree. "R2".

-DESDE-LTC: Care Type Mapping- Principles- The location in the tree of each service

is identified by a combination of a letter and a number, "I", "A", "S", "O", "D", "R" indicates the type of care and a number for the final branch within the tree "R2". It includes optional codes depending on the age "**C"** child, "**A"** adult, "**E"** elderly, diagnostic group "**SP"** for Severe Physical disabilities, "**ID"** for Intellectual Disabilitie,s "**MD"** for Mental Disorders (ICD-10,) "**ED"** for Elderly/older people with Disabilities, "**MG"** could be used for medical users without non further specification (generic). And codes for describing additional characteristics: "**a**" acute, "**c**" closed care, "**d**" domiciliary care, "**e**" eCare, "**h**" hospital setting, "**i**" institutional care, "**j**" justice care, "**l**" liaison care, "**m**" case management, "**r**" reference main type care in an area, "**s**" specialised care. Guidelines for coding long term care.

CHANGES IN THE CODING SYSTEM

A. ESMS*- 33 final codes*

'R' Residential Services

R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	R11	R12	R13

'D' Day Care and Structured activities services

D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11

'O' Outpatient and community services

O1	O2	O3	O4	O5	O6	O7	O8	O9	O10

Self-Help and Volunteer care

B. DESDE*- 71 codes*

'I' Information and Accessibility

I1	I11	I12	I13	I2	I21	I22	I221	I2211	I2212	I222

A new branch on information and accessibility is added where I1 represents Accessibility to care (I11 communication, I12 physical mobility, I13 other technical aids) and I2 represents Information for care (I21 guidance and assessment, I22 information: interactive I221 (I2212 face to face, I2212 other interactive) or non interactive I222).

Development

'S' Self-Help and Volunteer care

S1	S11	S12	S13	S14	S2	S21	S22	S23	S24

Even though the branch self-help and volunteer care was present for ESMS specific codes have been added. S1 non professional staff and S2 professional staff: Information and accessibility to care (S11, S21), Day care (S12, S22), Outpatient and community care (S13, S23) and Residential care (S14, S24).

'D' Day Care and Structured activities services

D1	D2	D21	D22	D3	D31	D32	D4	D41	D42	D43	D44		
D5	D6	D61	D62	D7	D71	D72	D8	D81	D82	D83	D84	D9	~~D10~~	~~D11~~

D2 Day structured activity related to work is divided into D21 Ordinary employment and D22 Other work (employees are paid at least 50% of the use local minimum wage for this work).

D3 Work related care is divided into D31 Time limited (activity for a limited period of time) and D32 Time indefinite.

D4 High intensity non-work structured day care is divided into D41 health related care, D42 Education related care D43 Social and culture related care and D44 Other structured day care

D6 Low intensity work care is divided into D61 Ordinary employment and D62 Other work

D7 Low intensity work-related care is divided into D71 Time limited and D72 Time indefinite

D8 Low intensity non-work structured day care is divided into D81 health related care D82 Education related care D83 Social and culture related care and D84 Other structured related care

D10 and D11 (high and low education related care) are deleted and incorporated in D4 and D8.

'O' Outpatient and community services

O1	O11	O12	O2	O21	O22	O3	O31	O32	O4	O41	O42	O5	O51	O52
O6	O61	O62	O7	O71	O72	O8	O81	O82	O9	O91	O92	O10	O101	O102

All main codes of branch ‘O’ (O1, O2 ...O10) have been divided into Health related care (O11, O21...O101) and Other care (O12, O22...O102).

‘R’ Residential Services

R1	R2	R3	R31	R32	R4	R5	R6	R7	R8	R81	R82	R9	R91	R92
R10	R101	R102	R11	R12	R13									

R3 Acute residential (non-hospital) care is divided into R31 Health related and R32 Other care

R8 Residential 24 hour care is divided into R81 Less than 4 weeks and R82 Over 4 weeks

R9 Residential care daily support is divided into R91 Less than 4 weeks and R92 Over 4 weeks

R10 Residential care lower support is divided into R101 Less than 4 weeks and R102 Over 4 weeks.

C. DESDE-LTC*- 89 final codes*

Like in the previous instruments codes are represented by a letter and a number but bullets are added between numbers.

‘I’ Information

I1	I1.1	I1.2	I1.3	I1.4	I1.5	I2	I2.1	I2.1.1	I2.1.2	I2.2	~~I221~~	~~I2311~~	~~I2312~~	~~I222~~

Information and accessibility is split into two different branches being ‘I’ the branch devoted to information to care, where I1 is Guidance and assessment: I1.1 is Health related, I1.2 Education related, I1.3 Social and culture related, I1.4 Work related and I1.5 Other and I2 is information: I2.1 Interactive (face to face I2.1.1 and other interactive I2.1.2) and non interactive I2.2.

Only I2 corresponds with I2 (Information) in DESDE for disability, the rest of the codes, although similar have a different meaning.

Development

'A' Accessibility to care

A1	A2	A3	A4	A5

A1 Communication

A2 Physical mobility

A3 personal accompaniment

A4 Case coordination

A5 Other

'S' Self-Help and Volunteer care

S1	S1.1	S1.2	S1.3	S1.4	S1.5	S2	S2.1	S2.2	S2.3	S2.4	S2.5

S1 and S2 still correspond to non-professional and professional staff but subdivisions are different from those in DESDE except for S1.3/S2.3 Outpatient care.

S1.1-S2.1 Information

S1.2-S2.2 Accessibility

S1.4-S2.4 Day

S1.5-S2.5 Residential

O' Outpatient and community services

O1	O1.1	O1.2	O2	O2.1	O2.2	O3	O3.1	O3.2	O4	O4.1	O4.2
O5	O5.1	O5.1.1	O5.1.2	O5.1.3	O5.2	O5.2.1	O5.2.2	O5.2.3	O6	O6.1	O6.2
O7	O7.1	O7.2	O8	O8.1	O8.2	O9	O9.1	O9.2	O10	O10.1	O10.2

New codes are added regarding frequency of care in O5.1 Non acute, health related outpatient care and in O5.2 Other care.

O5.1.1- O5.2.1, 3 to 6 days per week

O5.1.2- O5.2.2, 7 days per week

O5.1.3- O5.2.3, 7 days per week including overnight

'D' Day Care and Structured activities services

D0	D0.1	D0.2	D1	D1.1	D1.2	D2	D2.1	D2.2	D3	D3.1	D3.2
D4	D4.1	D4.2	D4.3	D4.4	D5	D6	D6.1	D6.2	D7	D7.1	D7.2
D8	D8.1	D8.2	D8.3	D8.4	D9	~~D10~~	~~D11~~				

A new sub branch is included: D0 Episodic acute care

D0.1 High intensity

D0.2 Other intensity

D1.1 Continuous acute care is also subdivided in High intensity D1.1 and other intensity D1.2.

'R' Residential Services

R0	R1	R2	R3	R3.0	R3.1	R3.1.1	R3.1.2	~~R3.2~~	R4	R5	R6	R7
R8	R8.1	R8.2	R9	R9.1	R9.2	R10	R10.1	R10.2	R11	R12	R13	R14

DESDE-LTC instrument introduces a new specification to define service care; it is a 24 hour physician cover in the service. The categories for hospital and non-hospital remain stable but services have to be defined including this description.

24 physician cover: R0, R1, R2, R4, R5, R6, R7

Non 24 physician cover: R3.0, R3.1, R3.1.1, R3.1.2, R8, R8.1, R8.2, R9, R9.1, R9.2, R10, R10.1, R10.2, R11, R12, R13

R0 Acute 24 hour physician cover residential (non-hospital) care, is a new sub branch included in the instrument.

R3 Acute, non 24 hour physician cover. R3.0 Hospital, R3.1 Non-hospital: R3.1.1 Health related and R3.1.2 Other. R3.2 is deleted from this instrument as it is included in R3.1.2.

R5 and R7 are different form DESDE because they are 24 hour physician cover services but in a non hospital setting.

R14 is included to describe residential non-acute services not classified elsewhere.

Section C:

ESMS: Care Use Mapping: Principles; Principles for counting services. When information is limited it can be used a one month census

DESDE: Care Use Mapping: Principles; Principles for counting services. When information is limited it can be used a one month census

DESDE-LTC: Care Use Mapping: Principles; Principles for counting services. When

information is limited only some portions of the tree may be selected and used alone,

Section D: Services Inventory

ESMS collects detailed information in 14 items and DESDE-LTC extends the information to **19 items**. New and modified items are above:

- Code. This item includes DESDE-LTC code and the possibility of giving information of ICF (International Classification of Functioning, Disability and Health), ICHI (International Classification of Health Interventions) and ICHA (International Classification for Health Accounts) codes.
- Setting. Give extended data of the service.
- Local definition of the service
- Availability
- Price (fare/tariff)
- Specific activities. Specify if the service offers specific and permanent activities for users with long term care needs.
- Catchment area of service users. Specify if the service is available for users, either at local/ county/province/region /national/or other territorial levels
- Admission requirement
- Opening hours
- Specific date about information has been registered
- Name of the evaluator
-

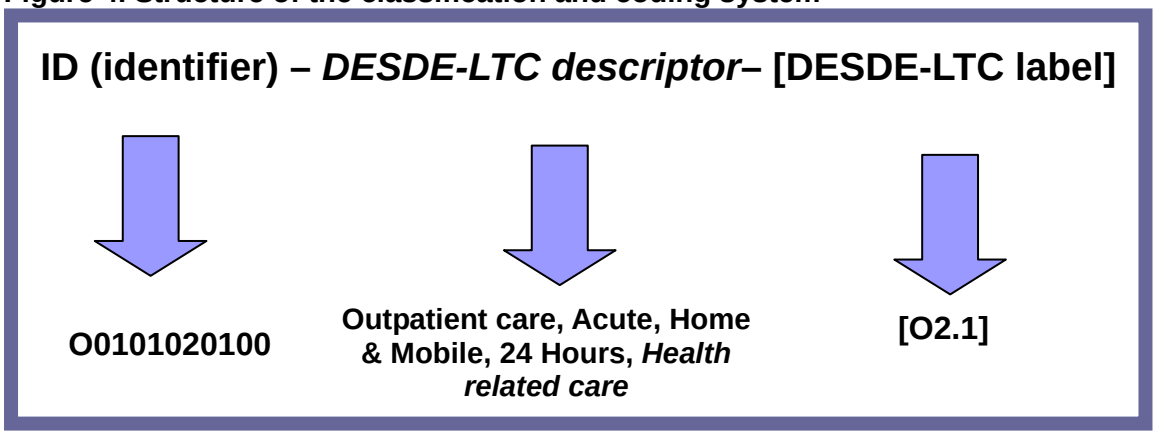
Observations. This final section provides an opportunity to document additional details or characteristics of the evaluated service that have not been captured elsewhere in the instrument and are important to document.

eDESDE_LTC CLASSIFICATION

The overall structure of the eDESDE-LTC system (instrument and coding system) has been analysed and framed based on a formal ontology approach to develop an ontology sound classification systemThe general structure of the eDESDE-LTC coding and classification has incorporated a decimal identifier, a formal descriptor and a label

used at the instrument (Figure 1). This process has been part of the usability study and it is described there (Salvador-Carulla et al, 2011) and it is available at this specific document of the project report (Romero et al, 2011).

Figure 4. Structure of the classification and coding system



5. CONCLUSIONS

The eDESDE-LTC system (instrument and coding system) is a unique tool for assessing availability and use of services for long term care both in small health areas and at macro-level. It has been developed following a bottom-up approach in a process dating from the initial assessment of mental health services in Europe in 1997. It has evolved from the original system comprising 4 main branches and 33 final codes, to a highly comprehensive hierarchical system comprising 6 main branches and 89 final codes. The original instrument has also evolved to classification system which is ontology driven. The classification system includes a decimal identifier, its formal description, and a related label at the questionnaire or eDESDE-LTC code, as well as a glossary of terms. Therefore it allows for semantic interoperability in European health and social information systems and databases.

This development may have a significant impact in equity assessment in the next future. It should be noted that the main domains of health equity are: 1) Eligibility: Equal opportunity criteria to access care services. Specific groups are not excluded; 2) Availability: The care option is available in the catchment area 3) Accesibility: The care

option is not influenced by restrictions and/or limitations in time, distance or information (e.g. user rights), 4) Utilisation: Available care alternatives are actually utilised by users; and 5) Mobility: When moving to a new placement users can access and utilise similar care alternatives to those available in the former location or basic care alternatives are available and comparable across two different territories. To adequately assess the different domains of equity a system such as eDESDE-LTC is needed as it incorporates a common terminology, a classification, a coding of LTC services in Europe, and a standard procedure for data collection and comparison (Roma-Ferri et al, 2005).

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ANNEXES

ANNEX 1. EVOLUTION OF MAIN BRANCHES AND CODES THROUGH ESMS, DESDE AND DESDE-LTC

RESIDENTIAL

ESMS

R1 R2 R3 R4 R5 R6 R7 R8 R9 R10 R11 R12 R13

R1 R2 R3 R4 R5 R6 R7 R8 R9 R10 R11 R12 R13

R31 R81 R91 R101

R32 R82 R92 R102

DESDE

R0 R1 R2 R3 ~~R3.2~~ R4 R5 R6 R7 R8 R9 R10 R11 R12 R13 R14

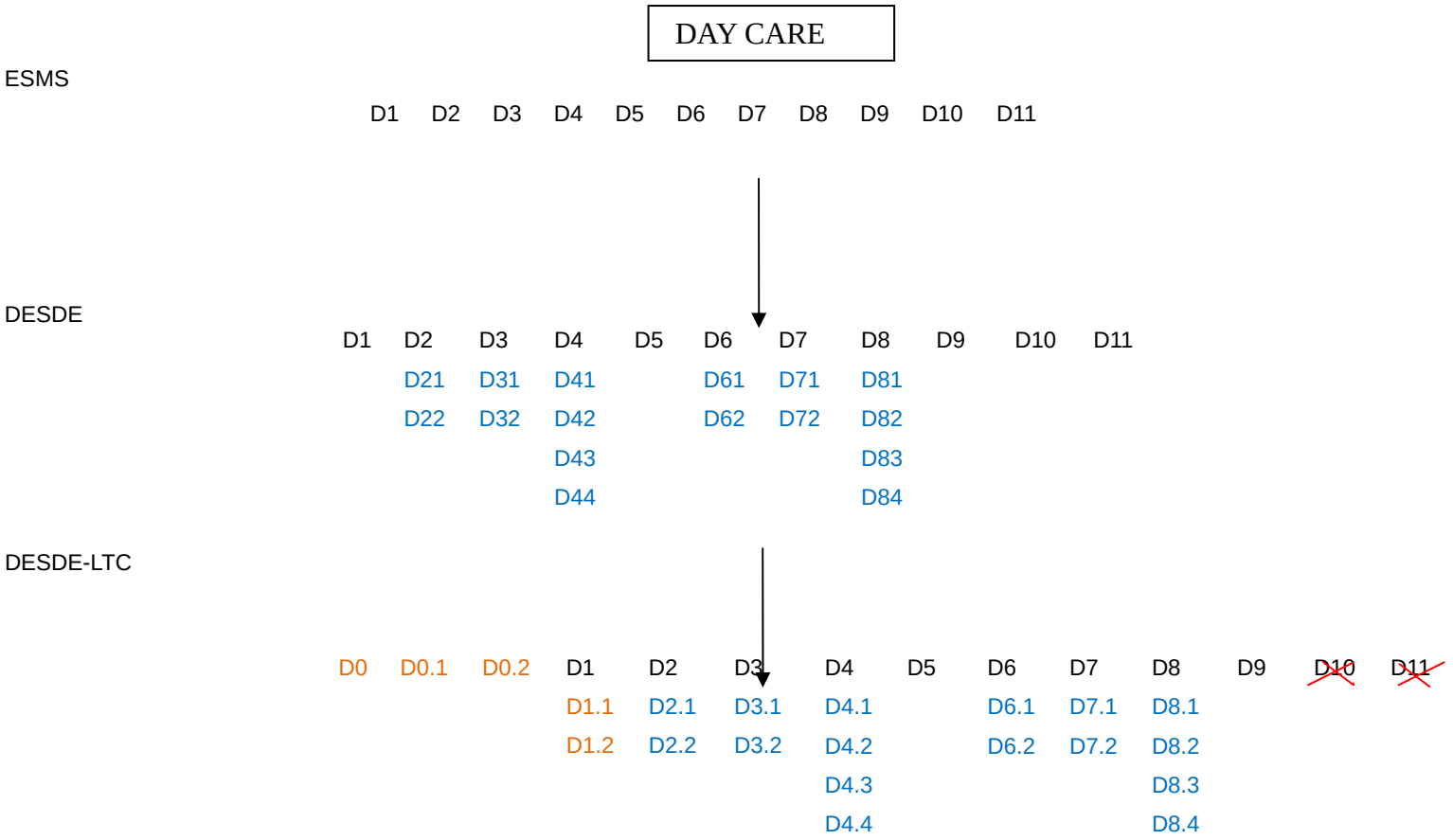
R3.0 R8.1 R9.1 R10.1

R3.1 R8.2 R9.2 R10.2

- R3.1.1 -

R3.1.2

DESDE-LTC


DAY CARE
ESMS
D1 D2 D3 D4 D5 D6 D7 D8 D9 D10 D11
DESDE
D1 D2 D3 D4 D5 D6 D7 D8 D9 D10 D11
D21 D31 D41 D61 D71 D81
D22 D32 D42 D62 D72 D82
D43 D83
D44 D84
DESDE-LTC
D0 D0.1 D0.2 D1 D2 D3 D4 D5 D6 D7 D8 D9 D10 D11
D1.1 D2.1 D3.1 D4.1 D6.1 D7.1 D8.1
D1.2 D2.2 D3.2 D4.2 D6.2 D7.2 D8.2
D4.3 D8.3
D4.4 D8.4

INFORMATION ACCESSIBILITY

ESMS

Not present

DESDE

I1 I2
I11 I21
I12 I22
I13 I221
-I2211
-I2212
I222

DESDE

I1 I2 I2.2
I1.1 I2.1 I2211
I1.2 -I2.1.1 I2212
I1.3 -I2.1.2 I222
I1.4
I1.5

SELF HELP AND VOLUNTEER CARE

ESMS — **Not present**

DESDE

S1 S2
S11 S21
S12 S22
S13 S23
S14 S24

DESDE LTC

S1 S2
S1.1 S2.1
S1.2 S2.2
S1.3 S2.3
S1.4 S2.4
S1.5 S2.5

OUTPATIENT AND COMMUNITY SERVICES

ESMS **Not present**

DESDE

O1	O2	O3	O4	O5	O6	O7	O8	O9	O10
O11	O21	O31	O41	O51	O61	O71	O81	O91	O101
O12	O22	O32	O42	O52	O62	O72	O82	O92	O102

DESDE LTC

O1	O2	O3	O4	O5	O6	O7	O8	O9	O10
O1.1	O2.1	O3.1	O4.1	O5.1	O6.1	O7.1	O8.1	O9.1	O10.1
O1.2	O2.2	O3.2	O4.2	- O5.1.1	O6.2	O7.2	O8.2	O9.2	O10.2
				- O5.1.2					
				- O5.1.3					
				O5.2					
				- O5.2.1					
				- O5.2.2					
				- O5.2.3					

ACCESSIBILITY CARE

ESMS — **no present**

DESDE — **not present**

DESDE LTC

A1 A2 A3 A4 A5