



DESDE-LTC: EVALUATION AND CLASSIFICATION OF SERVICES FOR LONG TERM CARE IN EUROPE

Luis Salvador-Carulla, Hristo Dimitrov, Germain Weber, David McDaid, Britt Venner, Lilijana Sprah, Cristina Romero, Mencía Ruiz, Giuseppe Tibaldi and Sonia Johnson for DESDE-LTC group (Eds.)



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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.

The eDESDE-LTC Dissemination and Communication report comprises the full dissemination and communication plan and implementation of the project carried out by the London School of Economics supported by PSICOST. The Dissemination and Communication report is available at¹ <http://www.edesdeproject.eu>

Luis Salvador-Carulla

Coordinator of eDESDE-LTC Project

¹If you want to provide us 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
EASPD	European Association of Service Providers for Persons with Disabilities
ELSA	English Longitudinal Study of Ageing
EPCAT	European care Psychiatric Assessment Team
ESMS	European Service Mapping Schedule
EQM	Evaluation Quality Management
IHTSDO	International Health Terminology SDO ()
IRIO	Izobraževalno Raziskovalni Inštitut
LSE	London School of Economics
LTC	Long-Term Care
MHEEN	Mental Health Economic European Network
MTC	Main Types of Care
OECD	Organisation for Economic Co-operation and Development
QAP	Quality Assessment Plan
SEP	Sociedad Española de Psiquiatría
SHA	Public Health Association
UNIVIE	University of Vienna
WHO	World Health Association

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1.

**INTRODUCTION
AND DEVELOPMENT
OF THE eDESDE-LTC
SYSTEM**

1.1. 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 (Ljubljana 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 (Rezvy 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 (Gibert et al., 2010), 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.

1.2. 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).

1.3. 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:

1. A review of the **framework of coding and classification services for LTC in Europe**. This review included a review of previous instruments (ESMS-I, ESMS-II, DESDE) focused on evaluation of services for mental health, disability, and the elderly.
2. Plans for **Evaluation** (UNIVIE) and **Dissemination** (LSE) of the eDESDE-LTC project were made and revised during the initial phase of the project.

3. 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 at adapting 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).
4. The development of the eDESDE-LTC instrument and its related coding and classification system was coordinated by the project's working group (Salvador-Carulla et al, 2011i). An iterative process was followed using **nominal groups** in the 6 participating countries (Ruiz et al, 2011). A total of 41 European researchers and stakeholders in LTC health and social services participated in this process.

The Nominal group technique (NGT) 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.

Three sessions were organised in every country 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.
- **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 was developed in 6 languages: English, Spanish, German, Norwegian, Slovenian and Bulgarian.

5. A **pilot study** of the system usability 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 was 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.

6. Development of the **last version** of DESDE-LTC Classification and coding system and Instrument (annex I and II). The versions of the instrument and the coding system were reviewed and discussed. An ontology analysis of the classification system was also performed.
7. DESDE-LTC **training programme** was devised considering a blended methodology (face-to-face and online learning). The content of eTraining Package was developed by PSICOST. It includes a reference manual and other tools to stimulate participation such as videos and a case book (annex III).
8. An eDESDE-LTC website was specifically designed and developed for project dissemination and promotion. (<http://www.edesdeproject.eu>).

9. 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 (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 Cádiz (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.

10. An impact analysis was also carried out and incorporated to the evaluation report. (E. Zeilinger 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). The first three phases of the impact analysis process were carried out by the PSICOST group: 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).

1.4. 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:

1.4.1. INTRODUCTORY SECTION

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.

1.4.2. 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:

Criterion "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:

Criterion "B": The service has its own administrative unit and/or secretary's office and fulfils two additional descriptors (see below) IF NOT:

Criterion "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 08, 06.

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.

1.4.3. MAPPING TREE

The mapping tree of the questionnaires and its related hierarchical structure is available at the Figure 1, 4 and 5. These figures indicate the evolution of the system towards a more comprehensive, ontologically sound hierarchical map. Figures 2 and 3 show characteristics on bed use and staff specifically design for ESMS II. The evolution of the original instrument ESMS I to ESMS II implied a reduction of codes to main categories in order to facilitate assessment and a special focus on utilization but branches coding structure was again reestablished for DESDE.

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”, Accessibility 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 1)

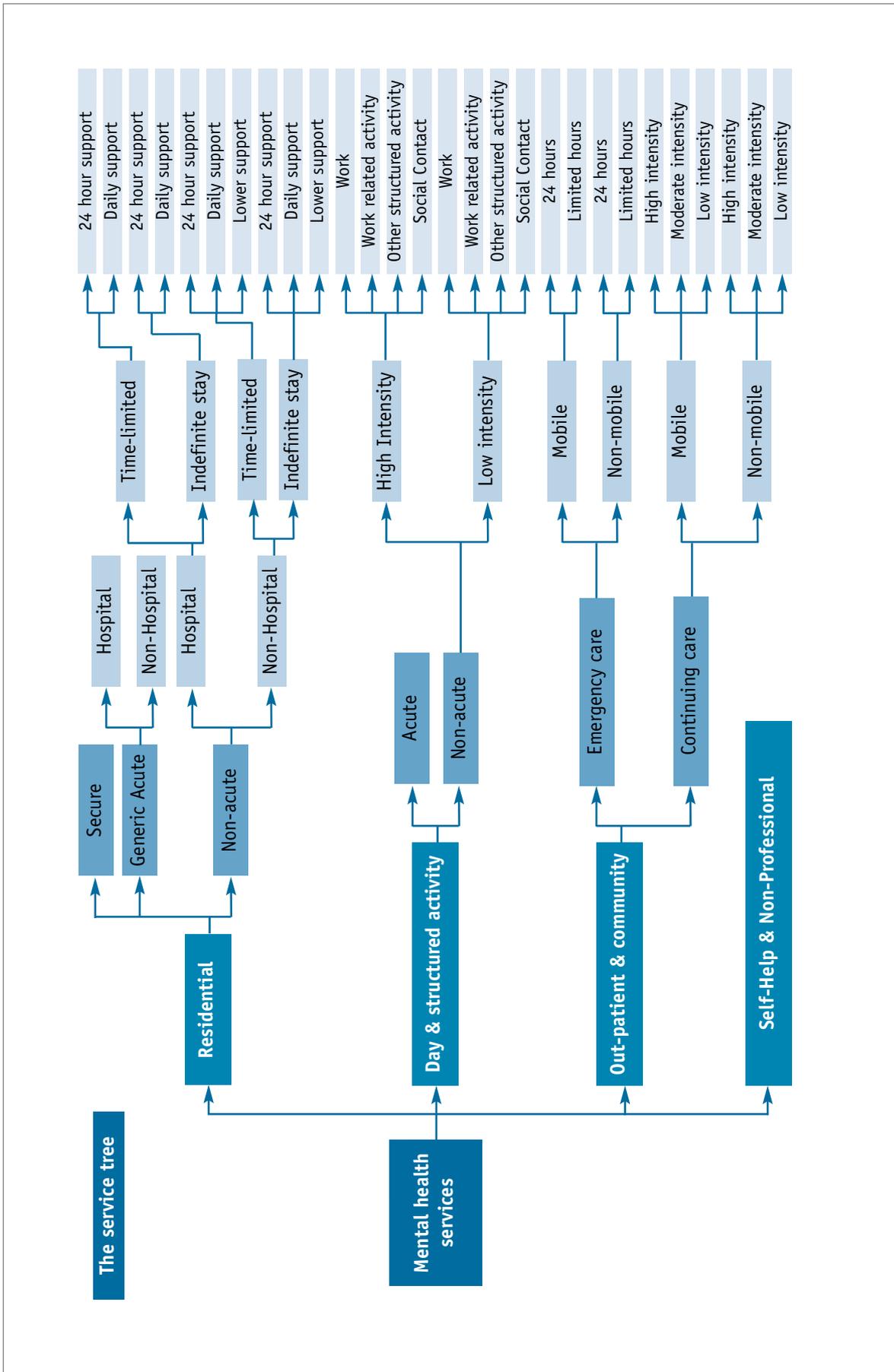


Figure 2. ESMS 2. Use of Services; One day census of hospital bed use

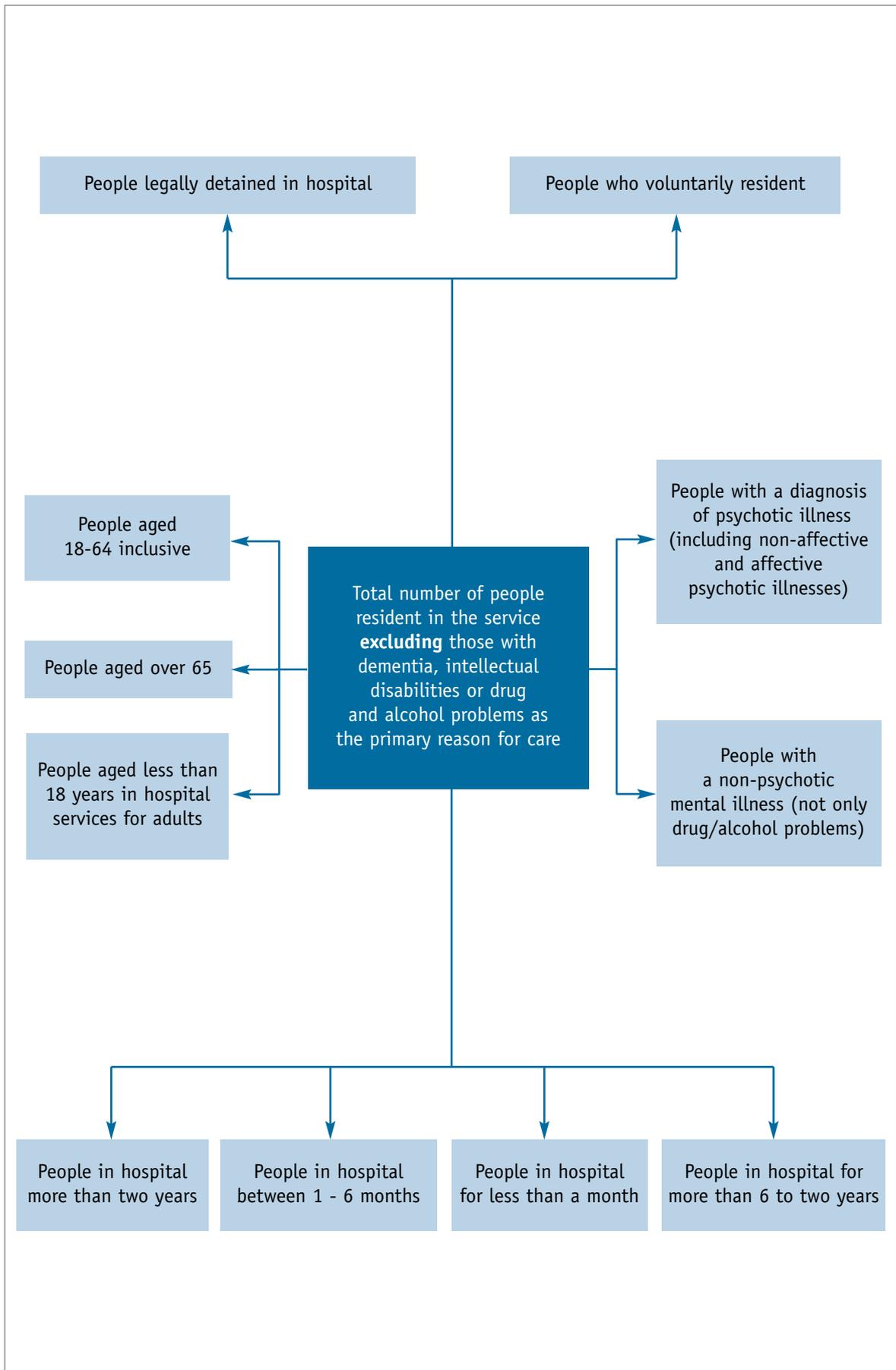


Figure 3. ESMS 2: Mapping summary: staffing

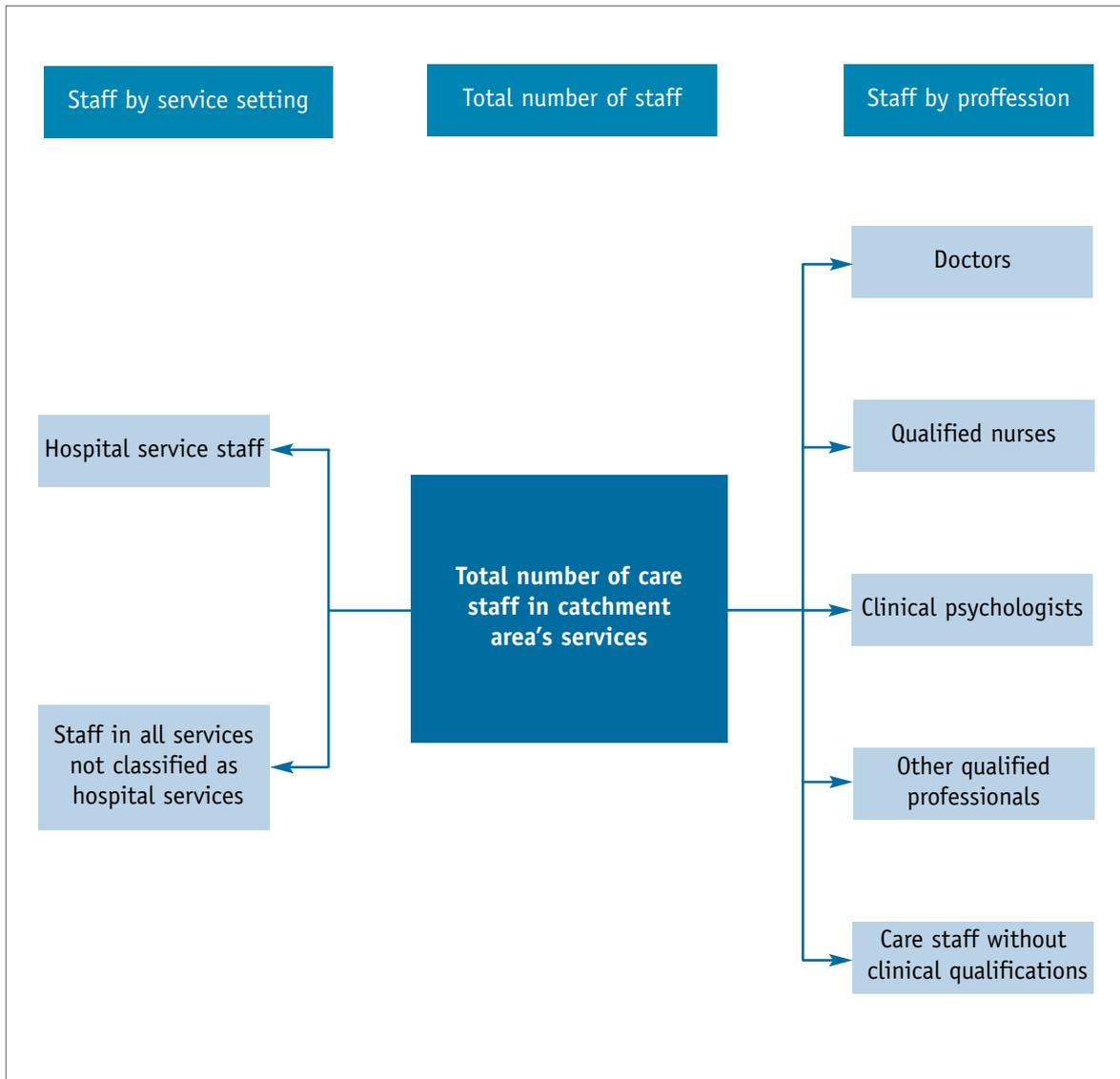


Figure 4. Hierarchical structure of the ESMS version for persons with disabilities (DESDE)

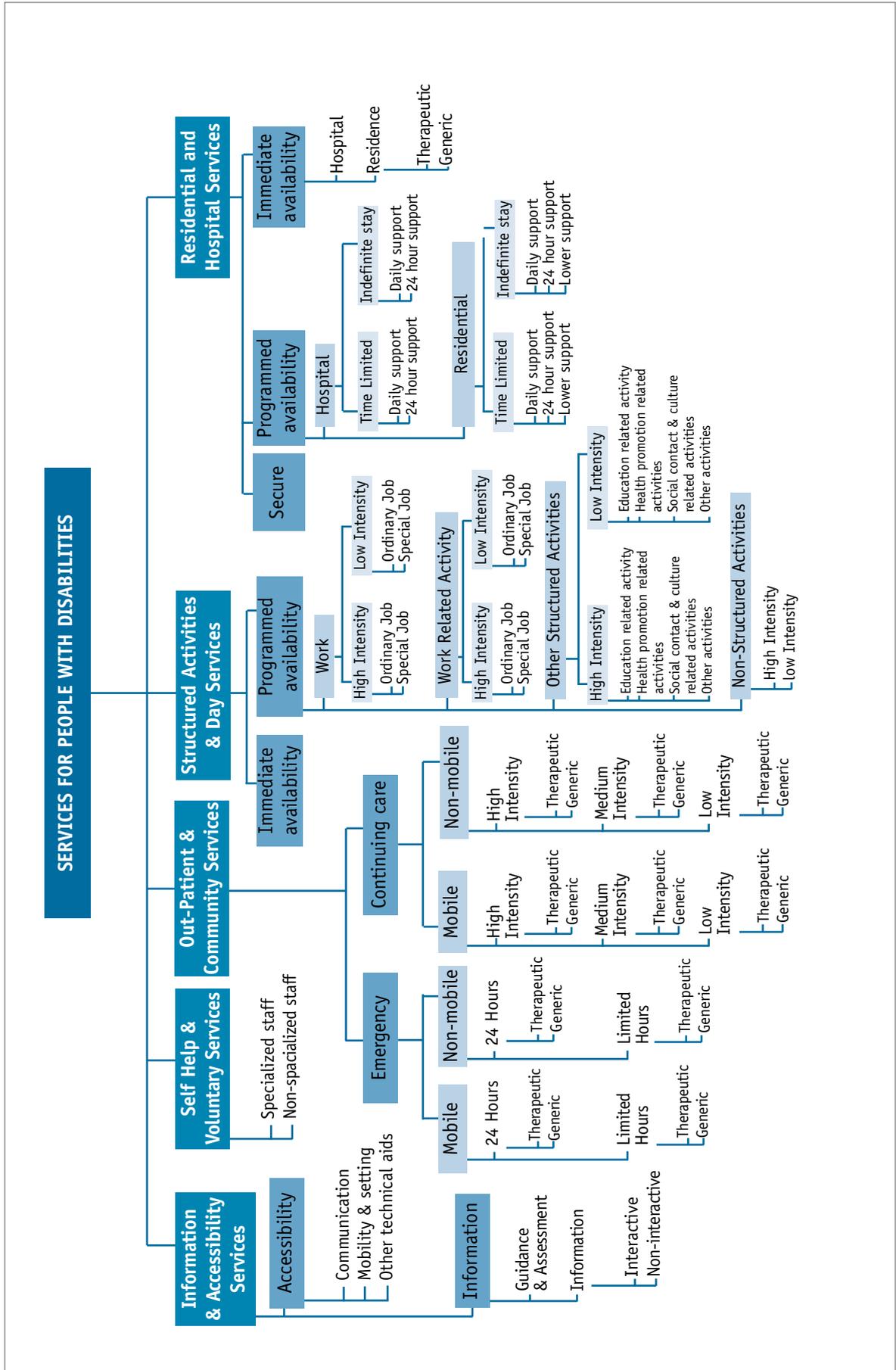
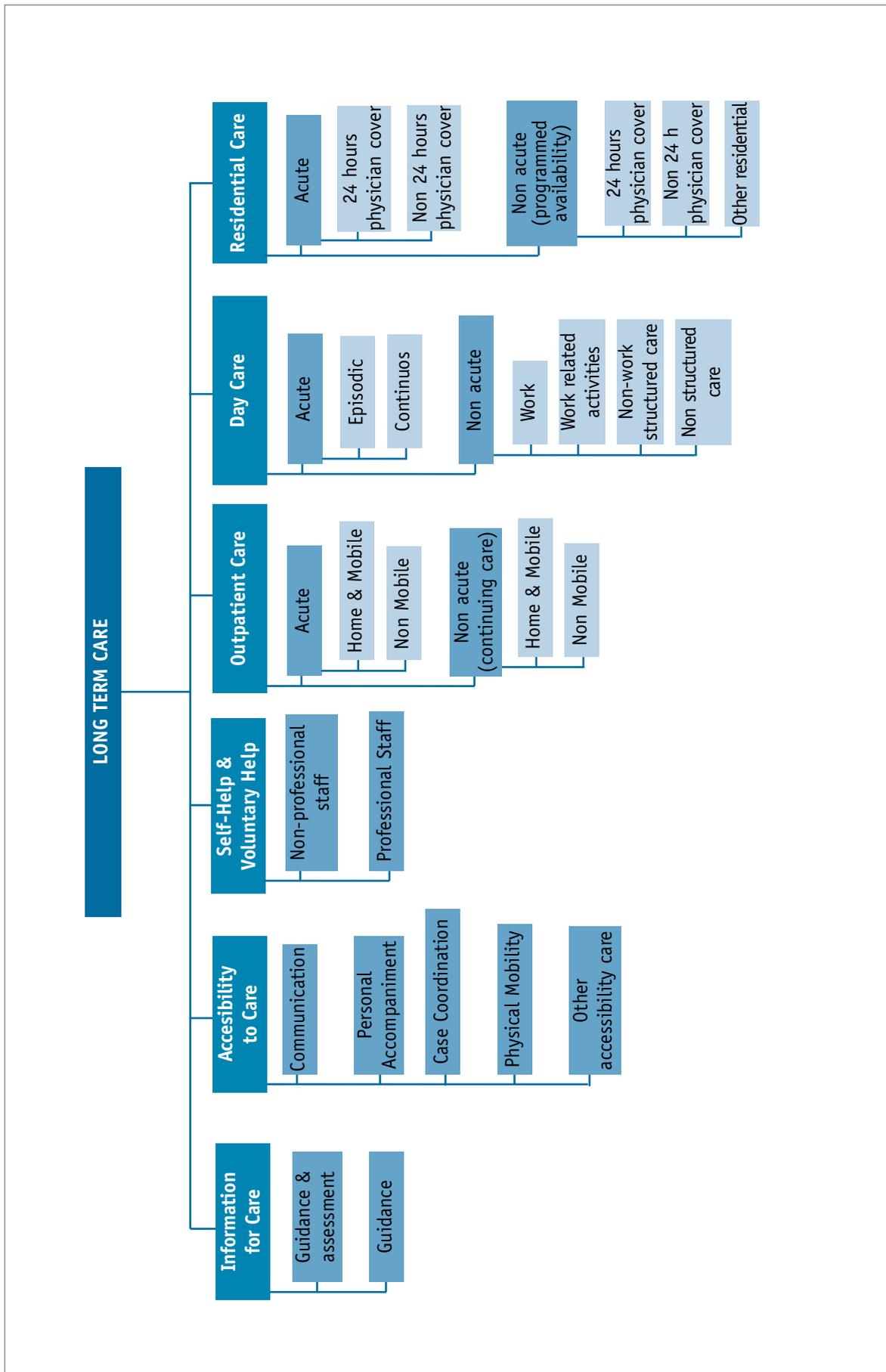


Figure 5. Hierarchical structure of the version for Long Term Care (eDESDE-LTC)



1.4.4. 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)	<input type="checkbox"/>
Adults with Intellectual disability	<input type="checkbox"/>
Adults with Mental disorder (ICD-10)	<input type="checkbox"/>
Elderly/older people with physical or intellectual disabilities (registered) or older people with mental disorders	<input type="checkbox"/>
Other diagnostic category (specify using the ICD-10 code whenever possible)	<input type="checkbox"/>

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 Disabilities, “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.**

1.4.5. 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

01	02	03	04	05	06	07	08	09	010
----	----	----	----	----	----	----	----	----	-----

B. DESDE - 71 codes

'I' Information and Accessibility

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

'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

01	011	012	02	021	022	03	031	032	04	041	042	05	051	052
06	061	062	07	071	072	08	081	082	09	091	092	010	0101	0102

All main codes of branch 'O' (01, 02 ...010) have been divided into Health related care (011, 021...0101) and Other care (012, 022...0102).

'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	I2.21	I2.211	I2.212	I2.22
----	------	------	------	------	------	----	------	--------	--------	------	------------------	-------------------	-------------------	------------------

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.

'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

01	01.1	01.2	02	02.1	02.2	03	03.1	03.2	04	04.1	04.2
05	05.1	05.1.1	05.1.2	05.1.3	05.2	05.2.1	05.2.2	05.2.3	06	06.1	06.2
07	07.1	07.2	08	08.1	08.2	09	09.1	09.2	010	010.1	010.2

New codes are added regarding frequency of care in **05.1** Non acute, health related outpatient care and in **05.2** Other care.

05.1.1-05.2.1, 3 to 6 days per week.

05.1.2-05.2.2, 7 days per week.

05.1.3-05.2.3, 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 from 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

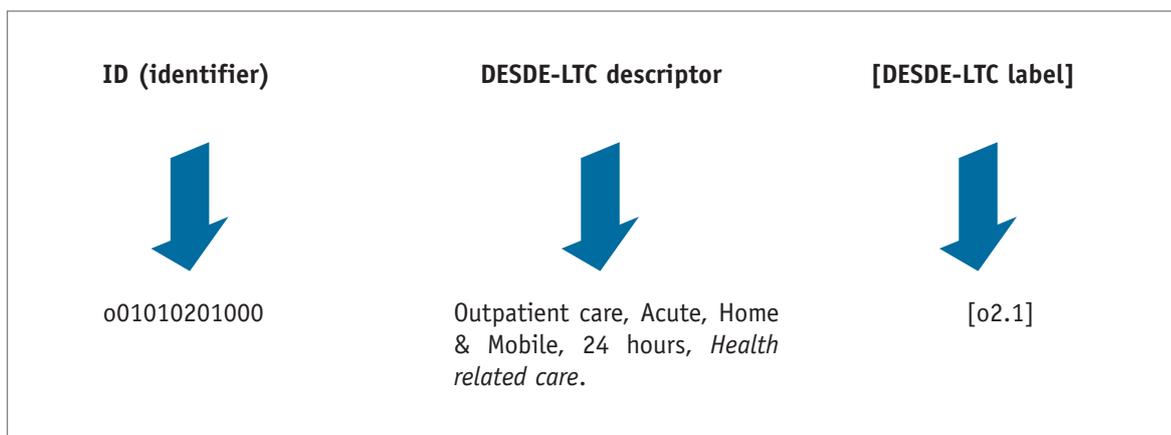
- Name of the evaluator

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 that are important to document.

1.4.6. 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 system. The 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 4).

Figure 6. Structure of the classification and coding system



1.5. 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) Accessibility: 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).



2.

USABILITY OF
THE EDESDE-LTC
INSTRUMENT:
Feasibility,
Consistency,
Reliability and
Validity

2.1. INTRODUCTION

Evaluation and assessment are essential components of healthcare, and they require assessment instruments with known metric properties. However, the foundation of health metrics has been developed in a scattered way and the related knowledge is still fragmented, with uneven development in different areas. The evaluation of intangible phenomena (pain, anxiety, disability, quality of life, quality of care), raised a whole array of complex questions with regard to feasibility, consistency, validity and cultural transferability, among others. In any case, a considerable effort towards harmonisation has been produced, particularly in item analysis and standardisation of instruments and quality measures such as validity, reliability, feasibility, usability, and comparability, as well as links between care provision and outcomes (Ishak et al, 2002; Furr & Bacharach, 2008; Salvador-Carulla & Gonzalez-Caballero, 2010).

However the assessment of the psychometric properties of instruments designed for health service research and planning has received less attention than those instrument aimed at assessing patient's status, functioning, satisfaction or preferences. This can be partly attributed to the variability of domains and related instruments in this area (Lloyd-Evans et al, 2007; IHFAN, 2008). Some information is available on care utilisation instruments such as the Client Service Receipt Inventory (CSRI) (Chisholm et al, 2000), or the Resident Assessment Instrument-Mental Health (RAI-MH) (inter-rater reliability and convergent validity) (Hirdes et al, 2002). Previous studies on the psychometric properties of instruments for assessment of availability and use of services for territorial comparisons include the European Service Mapping Schedule (ESMS) for the assessment of mental health services (Salvador-Carulla et al, 2000) and its adaptation for assessment of services for persons with disabilities in Spain (Salvador-Carulla et al, 2006).

The previous literature on the quality parameters of instruments for health service availability is scarce. Therefore a review of the relevant aspects is here provided.

FEASIBILITY

Feasibility has become a relevant issue in health assessment particularly in health care (Salvador-Carulla & Gonzalez-Caballero, 2010). There is no consensus on how feasibility should be defined and measured. Slade and co-workers have suggested a definition in the context of routine outcome assessment (Slade et al, 1999). Andrews et al. (1994) identified three dimensions of feasibility: applicability, acceptability, and practicality.

The applicability of a measure was defined as the degree to which a measure addresses dimensions of importance to the consumer, is useful for services providers in formulating and conducting decisions, and allows for the aggregation of data in a meaningful way to meet the purposes of service management. This aspect, defined as "relevance" by Slade and colleagues (1999), may be framed as follows: Is the description meaningful to recipients? (e.g., to health authorities, managers, staff, patients/families). The acceptability of a measure describes the ease with which a consumer or clinician can use a particular measure (i.e., user-friendliness). Practicality relates to implementation, training requirements, and complexity of scoring, reporting and interpreting the data. Efficiency may be regarded as the fourth dimension of feasibility. It could be defined as the relationship existing between its practicality and the costs incurred by its utilization.

CONSISTENCY (STRUCTURAL VALIDITY OR INTERNAL RELIABILITY)

Consistency comprises the psychometric solidity of a scale, its internal structure, the level to which its different items are interrelated and the possibility of adding them up to obtain overall scores. It has been defined as that property which defines the level of agreement or conformity of a set of measurements among themselves. Some authors include consistency within the category of reliability and it is also related to its structural validity.

However, the internal reliability or consistency should be clearly differentiated from the external reliability of an assessment instrument.

Homogeneity, indicates the degree of agreement among the items on a scale, which determines if they can accumulate and generate an overall score. It can be obtained by studying the correlation of the items with the total (using split-half reliability, Kuder Richardson formula KR-20 or Cronbach's alpha), by factor analy-

sis or by using Rasch's statistical objectivity models. Homogeneity based on factor analysis (acceptability of the global score as the sum of that obtained on each item) is confirmed if a one-dimensional structure is obtained, that is, all the items show a positive load on the first factor. In addition to exploratory factor techniques such as principal component analysis and principal factor analysis, the structure of a scale can be assessed using other techniques, such as the non-metric multidimensional scaling or the structural equation analysis (Salvador-Carulla & Gonzalez-Caballero, 2010).

Formal ontology provides a new perspective on the content structure of assessment instruments, particularly in the field of classification systems. Formal ontology is an explicit specification of a conceptualization (the objects, concepts, and other entities that are assumed to exist in some area of interest and the relationships that hold among them) (Gruber, 1993). It has been applied to computer sciences to formalize the concepts, hierarchies and the existing relationships among different concepts in order to enable semantic interoperability and data transfer. These techniques provide a sound method to describe the content architecture or hierarchy of any classification and assessment instrument, identifying internal errors and thus describing the content consistency of the instrument a stated formalism useful for humans and for computers. The stated formalism of the representation can be evaluated and can verify the structure consistency (dismiss partition errors and circularity errors) (for example, Heja et al, 2008). An ontology approach has been previously applied to the analysis of home care for the elderly in Spain (Valls et al, 2010). A formal ontology analysis is essential to facilitate the semantic interoperability of any classification and/or coding system (Roma-Ferri et al, 2005).

RELIABILITY (EXTERNAL RELIABILITY)

"Reliability" reflects the amount of error, both random and systematic, inherent in any measurement procedure. It has been defined as the proportion of variance in a measurement that is not error variance, excluding errors related to consistency (attributable to the internal structure of the instrument). In this sense, the reliability will provide information about the reproducibility of the test's results in different situations, or also, it will indicate the degree of the stability of the test's measures, in spite of changes in different external parameters (that is, not inherent in the test). There is a wide terminological variability in the terms and methods used to assess the reproducibility or the stability of assessment instruments (i.e. accuracy, precision, agreement, dependability and consistency) (Salvador-Carulla & Gonzalez-Caballero, 2010). Reliability could be framed in the context of the Classical Test Theory (CCT) or in the context of the Generalizability Theory (GT). The different approaches and their related statistical techniques have been previously reviewed (Salvador-Carulla & Gonzalez-Caballero, 2010). It should be noted that GT allows the simultaneous analysis of several coefficients of reliability (inter- and intra-observer, test-retest, inter-informant, etc) which could be generalized to fixed or to random conditions. As an example, a questionnaire of service utilization may be used by different observers to collect data from different sources (clinical records, patients, family carers). Using GT we may be able to assess the reliability of every section and the overall questionnaire in different groupings of observers and information sources, selecting the combination of facets which provide the higher reliability.

VALIDITY

Validity indicates which proportion of the information collected is relevant to the formulated question, and is defined by the degree to which an instrument measures what it is supposed to measure. Validity and reliability are closely connected. On the one hand, validity cannot be assessed unless the instrument is reliable. On the other, reliability and validity are related in the decomposition of the observed variance of scale's scores. It includes the random error, the construct variance, and the variance due to systematic errors (Judd et al, 1991). The construct variance has a direct influence on the validity and the reliability of any instrument, whereas systematic errors influence only the reliability. Optimizing both reliability and validity requires sacrificing the maximization of each (attenuation paradox).

Validity is considered present when the measurement predicts a criteria (criterion validity), or consistently fits a series of related constructs within the context of an accepted theory (construct validity), if there is no external criterion that serves as a gold standard. There are multiple forms of validity, with the further complication that some authors use the same term to define different concepts. The six main forms of validity can be distributed into two axes: one revolving around the presence or absence of a gold standard for the dimension assessed (criterion validity vs construct validity), and another focus on whether mathemati-

cal techniques are used in their calculation (descriptive validity vs statistical validity). Thus, a certain type of validity can be considered of the criterion or the construct type, depending on the dimension assessed. Concurrent validity of a scale for services assessment forms part of criterion validity, whereas the concurrent validity for a quality-of-life scale, for which there is no gold standard, should be considered as part of its construct validity. Likewise, estimation of discriminant validity or convergent validity may be merely descriptive, or may involve use of statistical procedures. The principle types of validity of an assessment instrument have been previously reviewed (Salvador-Carulla and Gonzalez-Caballero, 2010):

Simple validity (face validity). This is a type of descriptive criterion validity, which reflects what experts consider significant measures. There may be a certain amount of confusion between this concept and that of applicability and relevance (regarded as feasibility domains). It could be mentioned that the latter refers to the judgment of a wide-ranging group of users of the instrument, or of the information derived from it (e.g. healthcare managers or clinicians), whereas the assessment of face validity is limited to the expert's opinion.

Content validity. Defines the degree to which the set of items on a test adequately represents the domain assessed, i.e., the level of representativeness of the items of the set of components under assessment. In reality, this concept does not differ much from that of consistency, so that they may be considered synonymous. According to Thompson (1989), this type of validity is also descriptive, and cannot be analyzed using statistical techniques. Formal ontology has provided a new perspective to the analysis of content validity, particularly in the field of classification systems (Romá-Ferri & Palomar, 2008).

Commensurability is other concept closely linked to content validity. Commensurability is related to the "apples and oranges" problem, where substantively disparate items have been grouped together. Classical measures of quality of life may face content validity problems related to this factor (Steel et al, 2008)

Discriminant validity. This refers to the degree to which an instrument measures those features belonging to one domain and not to others, as well as the degree to which the features of different domains are not included within the domain examined by the instrument (inclusion and exclusion discriminant validity). Discriminant validity may be assessed either descriptively or with statistical procedures.

Convergent validity. This refers to the assessment of a certain feature of a domain with two different methods (e.g. assessment of depression using an assessment scale and a biological test). This term has also been used to denote the use of two assessment instruments, each covering a different dimension, in order to find a third (e.g. use of clinical and functioning scales to study the validity of a quality-of-life scale).

Concurrent validity. This provides a measure of the association between the scores for different items and the overall scores for other reference scales with an equivalent purpose and content. It is generally limited to the study of inter-score correlation.

Predictive validity. Predictive observation validity refers to the probability that a scale gives a correct judgement of the observed phenomenon. The use of Bayes's analysis makes it possible to determine the predictive validity of a test, its utility and its comparability, based on an analysis of the distribution of 'cases' and 'non-cases' in a given population, as well as its relationship with the results obtained on the test under study (positive or negative). In this case predictive validity is not applicable..

This study is aimed at describing the usability of the eDESDE-LTC system (instrument and coding system) thorough the analysis of quality the following domains: feasibility, consistency, reliability and validity.

2.2. METHODS

Once the final eDESDE-LTC versions of the instrument and the coding system were available, the usability of the eDESDE-LTC system was analyzed according to four quality parameters: Feasibility, Consistency, Reliability and Validity (Salvador-Carulla & Gonzalez-Caballero, 2010). As the instrument uses the coding system, consistency, validity and reliability provide information on both parts of the eDESDE-LTC system whilst feasibility mainly refers to the instrument.

The feasibility analysis was carried out by the University of Vienna. The full description of the feasibility is available at the eDESDE-LTC Evaluation and Quality Assessment report (Zeilinger et al, 2011). A summary of the feasibility of the instrument is provided here.

The consistency and validity analyses were carried out by the PSICOST research association with the University of Cadiz (Spain). The Sant Joan de Deu Foundation (Spain) contributed to the reliability analysis, and the University of Alacant (Spain) to the qualitative consistency analysis.

2.2.1. SAMPLE

The analysis was made on the PSICOST database of mental health services. This database includes full information on services from different regions in Spain. It is not limited to health services and it includes also services from other sectors related to mental health care such as social, education, work and crime and justice services. A series of services for other LTC groups were purportedly selected for the reliability and validity exercises in order to cover a range of MTC as broad as possible. This set was selected from the PSICOST database on services for disabilities. The case vignettes based on actual services and provided by other 5 European countries were also included.

2.2.2. FEASIBILITY ANALYSIS

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). This feasibility evaluation tool included four domains: Applicability, Acceptability, Practicality and Relevance. The latter is closely related to face validity (Salvador-Carulla and Gonzalez-Caballero, 2010). It is not only seen as the construct fulfilling the criteria of feasibility best, but is also considered by survey participants as the most important construct for the assessment of the feasibility of DESDE- LTC.

For creating this 23-items questionnaire a 5-point likert scale was used (1=best/highest /5= worst/lowest judgment). The participants had also the possibility to give further comments to each question, or giving the answer "the question is unclear to me" or "no answer". This questionnaire was available on-line². It was completed by members of the partner groups and nominal group participants as well as by health service researchers with previous experience in the use of ESMS/DESDE.

An analysis of the consistency and usability of the feasibility evaluation questionnaire was carried out in the preliminary sample (21 respondents). It showed good internal consistency (Cronbach's alpha over 0,7 in all domains) (Cronbach et al., 1972). Only three questions out of 23 raised some problems of understanding. The questionnaire covered main aspects of feasibility according to all the experts' opinion (high content validity) (Seyrlehner, 2010).

2.2.3. CONSISTENCY

The qualitative analysis of the hierarchy of the eDESDE-LTC coding system was made by an ontology expert (MR-F) based on previous experience in the ontology analysis of other health classification systems (Roma-Feri and Palomar, 2008). The full explanation of the procedure is described elsewhere (Roma-Ferri, 2009). The relationships of the different terms on the hierarchy was appraised according to their attributes was analyzed here are many ways in which terms can relate to each other in a hierarchy, depending on the attributes of the concept of interest: 1) structural assemble: 'part-of' (part-whole), similarity: 'is-a' (kind-of, or causal (to explain) how a chain of events could unfold. These types of links allow one term to inherit properties from other terms higher up in the hierarchy. What is inherited depends entirely on the type of link.

² Available at the eDESDE-LTC website (<http://www.edesdeproject.eu>) and at University of Viena: <http://www.unet.univie.ac.at/~a0305075/umfragen/index.php?sid=21575&newtest=Y&lang=en>

- In a 'part-of' hierarchy, terms inherit their location from parent terms higher in the hierarchical tree.
- In a 'is-a' (kind-of) hierarchy many different properties of parent terms are inherited by their children terms.

A proxy quantitative analysis of the overall consistency of the instrument was obtained by assessing the association of codes, stability and independence across the three levels at the Boolean factorial analysis (see below).

2.2.4. RELIABILITY ANALYSIS

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 Spanish eDESDE database and the case vignettes provided by other European partners. This list included services for mental health, intellectual disabilities, physical disabilities and elderly population. All services were coded according to DESDE-LTC branches (I, A, S, O, D, R; that is Information, Accessibility, Self-support, Outpatient, Day, and Residential care) 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 analyses took into account both the Classical Test Theory and the Generalizability theory (G theory) (Salvador-Carulla and Gonzalez-Caballero, 2010). The focus of classical test theory (CTT) is on determining error of the measurement but it only allows to estimate one type of error at a time. Essentially it throws all sources of error into one error term. This may be suitable in the context of highly controlled laboratory conditions, but in field research, it is unrealistic to expect that the conditions of measurement will remain constant. The Cohen's Kappa coefficient has been used to provide a measure of the degree to which two judges, A (Alpha) and B (Beta), concur in their respective sortings of n items into k mutually exclusive categories.

Generalizability theory (G Theory) acknowledges and allows for variability in assessment conditions that may affect measurements. The advantage of G theory lies in the fact that it is possible to estimate what proportion of the total variance in the results is due to the individual factors that often vary in assessment, such as setting, time, items, and raters. Another important difference between CTT and G theory is that the latter approach takes into account how the consistency of outcomes may change if a measure is used to make absolute versus relative decisions. In G a universe, its facets, and the conditions for admissible observations are defined through careful construct explication, the traditional domain of validity theory. Given a particular universe of admissible observations, a person's universe score (μ_p) can be defined as the average score based on all admissible observations (X_p) of the universe of interest. The purpose of a measurement is to accurately estimate this universe score ($\hat{\mu}_p$) based on a sample of observations.

2.2.5. VALIDITY ANALYSIS

It should be mentioned that the feasibility analysis includes several items that may be regarded also as descriptive/criterion validity domains. To avoid redundancy this domains related to content and to face validity have been analyzed within the feasibility analysis (Zeilinger et al 2011). At the feasibility questionnaire items related to face validity are Section B, Applicability, Question B1: 'In your opinion, is the data obtained when applying the instrument useful?' and Section E: 'Relevance'. Another item is related to content validity: Section B, Applicability, Question B3: 'From your point of view, does the instrument cover important dimensions?'

The quantitative validity analysis of the eDESDE-LTC instrument was made on a database comprising 1339 services. This included services from different regions in Spain (mostly on mental health care) as well as the case vignettes based on real settings by other European countries. This sample covered services for mental health, intellectual disabilities, physical disabilities and elderly population.

Boolean factor analysis was used to evaluate the content validity (the degree to which the set of items on a test adequately represents the domain assessed, i.e., the level of representativeness of the items of the set of components under assessment) and the concurrent validity (the degree to which results from one test agree with results from other, different tests) of DESDE-LTC instrument.

This analysis differs from that of classical factor analysis on binary valued data even though the goal and model (symbolically) appear similar. The goal is to express p variables ($\mathbf{X} = X_1, X_2, \dots, X_p$) by m factors ($\mathbf{F} = f_1, f_2, \dots, f_m$), where m is considerably smaller than p . *The model can be written as*

$$\mathbf{X} = \mathbf{F} \otimes \mathbf{A}$$

where \mathbf{A} is the matrix of factor loadings. and \otimes is the boolean multiplication. For n observations (cases), the data, factor scores, and factor loadings matrices may be pictured as

$$\mathbf{X}_{n \times p} = \mathbf{F}_{n \times m} \otimes \mathbf{A}_{m \times p}$$

where $\mathbf{X} = (x_{ij})$ has the value zero or one.

In Boolean factor analysis, the arithmetic used in the matrix multiplication is Boolean, so the scores and loadings are binary. For example, in Boolean algebra, the result of multiplying the two vectors below is one, whereas in classical factor analysis, the result is two.

$$(1 \ 1 \ 0 \ 1) \otimes \begin{pmatrix} 1 \\ 1 \\ 0 \\ 0 \end{pmatrix} = 1 \otimes 1 + 1 \otimes 1 + 0 \otimes 0 + 1 \otimes 0 = 1$$

In classical factor analysis the score for each case (for a particular factor) is a linear combination of all the variables: the variables with large loadings all contribute to the score. In Boolean factor analysis, a case has a score of one if it has a positive response for any of the variables dominant in the factor (those not having zero loadings) and zero otherwise. Also, in classical factor analysis it is desirable to have each variable associated with one factor (a variable should not have sizeable loadings for several factors). In Boolean factor analysis, a variable may have a loading of one for several factors.

In Boolean factor analysis, the success of the technique is measured by comparing the observed binary responses with those estimated by \otimes multiplying the loadings and the scores. The method count both the negative and positive discrepancies. The positive discrepancy is the number of times the observed score is one when the analysis estimates it to be zero, and the negative discrepancy is the number of times the observed score is zero when the estimated value is one. A useful measure of agreement between the original data x_{ij} and the estimated values \hat{x}_{ij} is the total number of discrepancies

$$\mathbf{d} = \sum_{i=1}^n \sum_{j=1}^p |x_{ij} - \hat{x}_{ij}|$$

2.3. RESULTS

2.3.1. FEASIBILITY ANALYSIS

Fifty-four experts on different aspects of service assessment participated in the feasibility evaluation. The feasibility of eDESDE-LTC has been thoroughly described by the University of Vienna group (Zeilinger et al, 2011). Participating Countries were: Spain (n:15), Slovenia (n: 10), Austria (n:8), Bulgaria (n: 8), Norway (n:6), United Kingdom (n:3), Chile (n:2), Germany (n:1) and Italy (n: 1). DESDE-LTC fulfilled the criteria of feasibility in all four factors, with arithmetic means lower than 2.5 (best to good ratings).

Applicability obtained an arithmetic mean of 2.1. According to experts data obtained using eDESDE-LTC are very useful for further processing (e.g. health care, providing LTC). As a result of the complexity of the systems in LTC expert knowledge considered an important precondition for use. It is difficult to obtain the required information for applying the instrument.

Acceptability mean rating was 2.3. It was considered user-friendly, although its handling is not comprehensible from the beginning due to many specific terms and use of new terms that are not easy to understand without special knowledge, and more practical examples are needed.

Practicality obtained the worst mean (2.4). Coding and analyses of data is quite complex and high expert knowledge is required for applying the instrument. However DESDE-LTC was rated very useful in relation to the time and effort. Relevance –related to face validity- obtained the best mean rating (1.7). According to experts, almost all aims of the project (semantic interoperability, mapping, classification) are achievable using this instrument.

2.3.2. CONSISTENCY

ONTOLOGY ANALYSIS

The work done is a model based on the observation and research. Its objective is to get an instrument to evaluate and differentiate services and features. The work contains the meaningful domain terms. It facilitates a narrative description of its meaning (glossary). All the work done is reusable to formalize an ontology based on the specification (Scope and Purpose) and the conceptualization activity.

The ontological analysis allowed for the development of a decimal systematic notation to facilitate a hierarchical scheme of services for long term care. The final system reaches this objective in four different ways (Annex I):

- The classification scheme of LTC services contains 89 decimal numeric codes (DESDE-LTC Classification). The decimal codification contributes to specify the meaning of the represented objects, determining dependency relations of specific concepts from general concepts. This structure will be reused to formalize the accepted and shared knowledge declared in eDESDE-LTC in an ontology to be used in computer-based information systems.
- A label listing which uses the specific coding of the eDESDE-LTC instrument (DESDE-LTC Code). It combines name and number of DESDE-LTC instrument branches to provide a standard description of LTC services. Every label corresponds to a decimal numeric code. This bi-univocal correspondence facilitates the precise meaning of the labels according to their position in the classification.
- A standard descriptor for every DESDE-LTC code (DESDE-LTC Coding List) that summarizes main characteristics of LTC services. It allows a quick search of branches definitions.
- A standard glossary of terms. It compiles an alphabetical list of definitions of key concepts that appear on DESDE-LTC Instrument.

STRUCTURAL CONSISTENCY (STRUCTURAL VALIDITY)

Boolean factorial analysis were run at three levels (levels 0, 1 and 3) (see table 7). The majority of codes were explained by a single factor. This indicates that codes are well defined and make a consistent structure within the instrument. This analysis confirmed that main branches and secondary of eDESDE-LTC are made by codes or items that measure independent characteristics of the services being assessed.

2.3.3. RELIABILITY

Table 1 shows results for the agreement between observers on the main type of care of the service attending to the presence or absence of main branches (A, D, I, O, R, S). The reliability coefficient for the main branch is $K = 0.9674$, where 1 is the highest value, with a confidence interval of $CI = (0.9362 ; 0.9987)$. For the main branch (main type of care of the service) Alpha and Beta rates had 14 coincident appearances in "A" (Accessibility), 51 in "D" (Day care), 2 in "I" (Information), 39 in "O" (Outpatient), 59 in "R" (Residential) and 1 in "S" (Self-help/volunteer).

Table 1. Inter-observer reliability: Agreement on Main branches coding by Alpha and Beta raters

		Beta						Total
		A	D	I	O	R	S	
Alpha	A	14	0	0	0	0	0	14
	D	0	51	0	0	0	0	51
	I	0	0	2	0	0	0	2
	O	2	0	0	39	0	0	41
	R	0	0	0	0	59	0	59
	S	0	2	0	0	0	1	3
Total		16	53	2	39	59	1	170

Table 2 shows main results according to Generalizability theory and table 3 estimates reliability starting from a different condition, in this case modifying the number of evaluators.

A reliability coefficient or index of dependability of 0.96 has been found where 1 is the highest value of the coefficient. Given the hypothetical case of information gathered by one rater, the level of reliability would also be high (0.9322). The value of the coefficient rises as the number of judges increases.

Table 2. DESDE-LTC reliability (G Theory)

Source of variance	Differentiation variance	Source of variance	Relative error variance	% relative	Absolute error variance	% absolute
	E		0.00127	1.7
S	2.02210		
	ES	0.07226	100.0	0.07226	98.3
Sum of variances	2.02210		0.07226	100%	0.07353	100%
Standard deviation	1.42201		Relative SE	0.26881	Absolute SE	0.27116
Coef_G relative	0.97					
Coef_G absolute	0.96					

When assessing presence or absence of I, A, S, O, D, R branches as main type of care of services, reliability coefficients are really strong, all over 0.9 for Kappa and Generalizability, except for Self-Help and Volunteer care 'S' where coefficients (Kappa 0.49) (Generalizability 0.66)

Table 3. Reliability modifying number of raters

	G-study		Option 1		Option 2		Option 3	
	Lev.	Univ.	Lev.	Univ.	Lev.	Univ.	Lev.	Univ.
E	2	INF	1	INF	3	INF	4	INF
S	170	INF	170	INF	170	INF	170	INF
Observac.	340		170		510		680	
Coef_G rel.	0.96550		0.93330		0.97673		0.98245	
Coef_G abs.	0.96491		0.93220		0.97633		0.98214	

A) RELIABILITY OF DESDE-LTC CODES

Table 4 shows the results for the reliability study in main branches, primary branches and final branches. Inter-rater reliability of final branches was calculated for 36 codings of MTCs.

Analysis for main branches (I, A, S, O, D, R) was based on the Generalizability Theory because sub-branches are not exclusive, that is, in one service different sub-branches can appear together (e.g. A1 (accessibility to communication) and A2 (accessibility to physical mobility) in an association) and Kappa needs incompatible elements to analyze.

For each main branch the primary subdivision or sub-branch (A1, A2, D0, D9 etc.) was taken into account and coded with '0' or '1' when absent or present. The sub-branch will be present when it is present in any of its subdivisions (I2.1.1, R9.1 etc.). The reliability in this analysis is nearly perfect for all the branches even though it is smaller than the one assessed for presence or absence of main branch due to the number of new elements incorporated in the study (sub-branches).

Agreement was strong (Kappa 0.61-0.8) for ‘accessibility to care- communication and physical mobility’ (A1, A2), ‘outpatient acute non-mobile health related care’ (O3.1), ‘self-help an volunteer care with non professional staff for accessibility to care’ (S1.2), ‘low intensity social and culture structured care’ (D8.3) and ‘residential with daily support’ (R12). The agreement was nearly perfect for the rest of the DESDE-LTC codes except for 5 codes with low levels of concordance.

There was no agreement for ‘non interactive information’ (I2.2), ‘self-help an volunteer care with non professional staff for outpatient care’ (S1.3) and ‘self-help an volunteer care with professional staff for accessibility to care’ (S2.2), as only one of the judges considered it; no agreement either for ‘outpatient home and mobile (non acute) care, related to health, 3 to 6 days a week’ (O5.1.1) and ‘outpatient home and mobile (non acute) care, not related to health, 3 to 6 days a week’ (O5.2.1) as for the same services raters considered different codes.

Table 4. DESDE-LTC inter-rater reliability: “main types of care” (MTC) in main and final branches (Kappa) (G Theory) (n= 435)

DESDE-LTC CODES (MTC)	n (Alfa+ Beta)	Kappa (k) *	G Theory *
Information for Care (I)	15	-	-Coef_G absolute: 0.95
I1	2		
I1.1	2	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
I1.2	-	-	-
I1.3	-	-	-
I1.4	-	-	-
I1.5	-	-	-
I2	11	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
I2.1	6	K: 0.79 (0.40-1.00)	Coef_G absolute: 0.89
I2.1.1	-	-	-
I2.1.2	2	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
I2.2	1	-	-
Accessibility to Care (A)	17	-	Coef_G absolute: 0.97
A1	2	K: 0.66 (0.04-1.00)	Coef_G absolute: 0.80
A2	2	K: 0.66 (0.04-1.00)	Coef_G absolute: 0.80
A3	-	-	-
A4	12	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
A5	1	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
Self-help and Volunteer care (S)	9	K: 0.49 (-0.10-1.00)	Coef_G absolute: 0.66
S1	6		
S1.1	-	-	-
S1.2	5	K: 0.79 (0.40-1.00)	Coef_G absolute: 0.89
S1.3	1	-	-
S1.4	-	-	-
S1.5	-	-	-
S2	3		
S2.1	2	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
S2.2	1	-	-
S2.3	-	-	-
S2.4	-	-	-
S2.5	-	-	-
Outpatient Care (O)	120		Coef_G absolute: 0.95
O1	-	-	-
O1.1	-	-	-
O1.2	-	-	-
O2	2		
O2.1	2	-	-
O2.2	-	-	-
O3	19		
O3.1	18	K: 0.64 (0.38-1.00)	Coef_G absolute: 0.79
O3.2	-	-	-
O4	-	-	-
O4.1	-	-	-
O4.2	-	-	-
O5	26		
O5.1	10	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
O5.1.1	6	-	-
O5.1.2	-	-	-
O5.1.3	-	-	-
O5.2	1	-	-



05.2.1	7	-	-
05.2.2	-	-	-
05.2.3	2	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
06	6	-	-
06.1	4	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
06.2	2	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
07	-	-	-
07.1	-	-	-
07.2	-	-	-
08	22	-	-
08.1	22	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
08.2	-	-	-
09	35	-	-
09.1	35	K: 0.96 (0.90-1.00)	Coef_G absolute: 0.98
09.2	-	-	-
010	10	-	-
010.1	10	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
010.2	-	-	-
Day Care (D)	129	-	Coef_G absolute: 0.97
D0	-	-	-
D0.1	-	-	-
D0.2	-	-	-
D1	27	-	-
D1.1	-	-	-
D1.2	27	K: 0.95 (0.88-1.00)	Coef_G absolute: 0.98
D2	8	-	-
D2.1	-	-	-
D2.2	8	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
D3	16	-	-
D3.1	-	-	-
D3.2	16	K: 0.93 (0.79-1.00)	Coef_G absolute: 0.96
D4	74	-	-
D4.1	42	K: 0.97 (0.92-1.00)	Coef_G absolute: 0.99
D4.2	4	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
D4.3	28	K: 0.92 (0.81-1.00)	Coef_G absolute: 0.98
D4.4	-	-	-
D5	-	-	-
D6	-	-	-
D6.1	-	-	-
D6.2	-	-	-
D7	-	-	-
D7.1	-	-	-
D7.2	-	-	-
D8	4	-	-
D8.1	-	-	-
D8.2	-	-	-
D8.3	4	K: 0.79 (0.40-1.00)	Coef_G absolute: 0.89
D8.4	-	-	-
Residential Care (R)	126	-	Coef_G absolute: 0.99
R0	-	-	-
R1	-	-	-
R2	20	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
R3	-	-	-
R3.0	-	-	-
R3.1	-	-	-
R3.1.1	-	-	-
R3.1.2	-	-	-
R4	21	K: 0.84 (0.67-1.00)	Coef_G absolute: 0.92
R5	15	K: 0.93 (0.79-1.00)	Coef_G absolute: 0.96
R6	14	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
R7	-	-	-
R8	4	-	-
R8.1	-	-	-
R8.2	4	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
R9	6	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
R9.1	-	-	-
R9.2	-	-	-
R10	-	-	-
R10.1	-	-	-
R10.2	-	-	-
R11	27	K: 0.95 (0.88-1.00)	Coef_G absolute: 0.98
R12	5	K: 0.79 (0.40-1.00)	Coef_G absolute: 0.89
R13	14	K: 1.00 (1.00-1.00)	Coef_G absolute: 1.00
R14	-	-	-

*Kappa: (poor) < 0, (low) 0–20; (fair) 0.21–0.4; (moderate) 0.41–0.6; (strong) 0.61–0.8; and (nearly perfect) 0.81–1.

2.3.4. VALIDITY

A) DESCRIPTIVE ANALYSIS OF THE BRANCHES OF THE INSTRUMENT

DESDE-LTC was used to evaluate and classify 1339 services representative of different European countries and regions of Spain. Information on the diagnostic group covered by the service was also given. (Table 5)

Table 5. Type of service and setting

	Spain	Other	Total
Mental disorder	1269	6	1275
Physical disability	4	2	6
Intell. Disability.- Develop.Dis..	18	5	23
Elderly	9	1	10
Non specific	15	6	21
Other	4	0	4
TOTAL	1319	20	1339

Regarding the information gathered in Spain table 6 shows the distribution of the 1319 services studied by regions and diagnostic groups.

According to the branches structure of the instrument, 4 levels of analysis were established:

Table 6. Distribution of services in Spain

REGION	PROVINCE	DIAGNOSTIC GROUP						TOTAL
		PHY.DIS	INT.DIS-DEV.DIS	ELDERLY	NON SPE	OTHER	MENTAL D	
Andalucía	Almería						21	21
	Cádiz						41	41
	Córdoba						21	21
	Granada						32	32
	Huelva						17	17
	Jaén						23	23
	Málaga						44	44
	Sevilla						52	52
	Total						251	251
Cantabria	Santander			1			20	21
	Total			1			20	21
Castilla-La Mancha	Albacete						23	23
	Ciudad Real						24	24
	Cuenca						11	11
	Guadalajara						11	11
	Toledo						27	27
	Total						96	96
Cataluña	Barcelona		3				367	370
	Girona		1				40	41
	Lleida		0				35	35
	Tarragona		2				37	39
	Total		6				479	485

REGION	PROVINCE	DIAGNOSTIC GROUP						TOTAL
		PHY.DIS	INT.DIS-DEV.DIS	ELDERLY	NON SPE	OTHER	MENTAL D	
Islas Baleares	Islas Baleares		12	1			37	50
	Total		12	1			37	50
Madrid	Madrid	4		3	15	4	313	339
	Total	4		3	15	4	313	339
Murcia	Murcia			2			43	45
	Total			2			43	45
Navarra	Navarra			2			30	32
	Total			2			30	32
Total		4	18	9	15	4	1269	1319

Level 0: composed by the main 6 branches 'I', 'A', 'S', 'O', 'D' and 'R'.

Level 1: primary branches into which the main branches are divided. Number of codes for this level is 42.

Level 2: intermediate level where some of the level 1 branches reach their final division and where others still subdivide in a new branch.

Level 3: final subdivision of branches were a total of 89 codes explain each branch to its final characteristics. (Table 7).

Table 7. Primary branches division

Level 0	Branch I	Branch A	Branch S	Branch O	Branch D	Branch R	Total
Level 1	2	5	2	10	9	14	42
Level 3	8	5	10	24	22	20	89

To evaluate presence (1) or absence (0) of the main branch all the subdivisions have been analyzed, therefore, the main branch (A, I, S etc.) will be present (1) as long as one of the secondary branches is present (A1, I2.1.1 etc.). The starting point was level 3 where final characteristics of the codes are represented, then level 2, 1 and 0. 45 of the 89 codes considered in level 3 do not appear in any of the 1339 services evaluated.

To analyze the overall validity it is intended to examine the underlying dimensions of the instrument, that is, studying to what extent the codes of the instrument evaluate independent characteristics (of a service) or on the other hand are redundant and therefore disposable.

Level 0: it shows a matrix of 8034 values, 6439 '0' and 1595 '1'. It was not possible to explain the 6 branches with a number of factors smaller than 6.

Level 1: it shows a matrix of 41509 values, 39872 '0' and 1637 '1'. A 17 factor model adjusts 95% of the positive discrepancies, but this model does not explain 11 codes (I1, A5, O6, O10, D2, R5, R6, R8, R9, R10 and R12) being the 'R' branch the worst adjusted of all. Using a 23 factor model still 6 codes with prevalence lower than 5 are not explained, the percentage of positive discrepancies is 0,9%. Finally a 29 factor model explains the totality of the codes and shows 0% of positive discrepancy. Association between O3 and R2 remains constant for all the models; a new connection appears between I1 and A5.

Level 3: it shows a matrix of 56238 values, 54595 '0' and 1643 '1'. To explain more than 95% of positives it is needed a 24 factor model. 12 codes remain unexplained. Again the worst adjusted is branch 'R'. A 29 factor model explains all codes with a prevalence higher than 5 except for D4.2. Table 8 summarizes the associations found in level 3 with a 29 factor model.

Table 8. Codes associations in a 29 factor model

SUMMARY				
FACTOR 1	I11	I12	I22	A5
FACTOR 2	D41			
FACTOR 3	I212			
FACTOR 4	A1			
FACTOR 5	A2			
FACTOR 6	A4			
FACTOR 7	I11	S12	D83	
FACTOR 8	O91			
FACTOR 9	O521	S13		
FACTOR 10	S21			
FACTOR 11	S22			
FACTOR 12	O81			
FACTOR 13	O511			
FACTOR 14	O523			
FACTOR 15	R13			
FACTOR 16	D12			
FACTOR 17	R11			
FACTOR 18	O31	R2		
FACTOR 19	R4			
FACTOR 20	O101			
FACTOR 21	I211			
FACTOR 22	D43			
FACTOR 23	D11			
FACTOR 24	D32			
FACTOR 25	D22			
FACTOR 26	R6			
FACTOR 27	O61			
FACTOR 28	R102			
FACTOR 29	R5			

In factor 1, (table 8) codes I1.1, I1.2, I2.2 and A5 are associated; this is mainly explained by the low prevalence of these codes in the data base, 1 time for I1.2, I2.2 and A5 and 3 for I1.1, which probably describes a very particular type of care of one service. In factor 7, codes I1.1, S1.2 and D8.3 appear together which can be explained basically in the same way than before, nonetheless, low intensity social and culture structured care (D8.3) is commonly but not necessarily associated to volunteer care (non-professional staff-accessibility to care S1.2). Factor 9 shows codes O5.2.1 and S1.3 connected which again is explained by low prevalence (1 appearance). Finally in factor 18, codes O3.1 and R2 appear together 114 times (100% of appearances) which indicates a very strong connection; facilities with hospital acute care (R2) usually offer outpatient acute care (O3.1) too and this is the case for the services collected in the data base but for example in Catalonia this type of care is described independently in some general hospitals.

2.4. CONCLUSION

eDESDE-LTC showed a high feasibility in its four domains: applicability, acceptability, practicality and relevance. It is important to note that previous expertise on the ESMS/DESDE system had a notorious influence on the assessment of feasibility. Every feasibility-dimension was better rated from participants with ESMS/DESDE experience, particularly acceptability and practicality. There were no major differences across countries in the rating of the practicality while significant differences were identified in the assessment of the acceptability, practicality and relevance of three DESDE-LTC system.

From an ontology point of view, the classification scheme of eDESDE allows for the capture and representation of knowledge, accepted and shared by consensus by all the participants of this transnational project, which initially has been formalized in natural language (specification of conceptualization). The ontology analysis executed has allowed for the development of a decimal notation of LTC services based on 'Main Types of Care' (MTCs). Each code (decimal notation) is accompanied with a identification labels and l description at the eDESDE-LTC instrument (Annex I). The labels included in the classification scheme facilitates the standardised description and classification of services for Long-Term Care (LTC) in Europe (terms assigned to concepts). eDESDE classification scheme also gives a specific meaning to each label as it determines dependency relations of specific concepts from general concepts (bi-univocal correspondence). Description accompanying every label facilitates the characterization of concepts (Intrinsic properties). These properties are the main information sources for the formal description of an ontology (explicit specification of a conceptualization) through a computing language of knowledge representation, this will facilitate the semantic interoperability in different computer-based information systems.

Structural consistency is adequate according to the factor Boolean analysis. The eDESDE-LTC codes are well defined and make a consistent structure within the instrument. This analysis confirmed that main branches and secondary of eDESDE-LTC are made by codes or items that measure independent characteristics of the services being assessed.

The external reliability obtained a high inter-observer agreement. DESDE-LTC showed high inter-rater reliability for main branches. Reliability was also high for final branches which correspond to MTCs. The branches with lower inter-observer agreement where some Information and self-support codes and special forms of outpatient mobile care. These results are better than those of the parent instruments (ESMS/DESDE) (Salvador-Carulla et al, 2000, Salvador-Carulla et al, 2006), mainly due to the improvement of the training system which has added an online training toolkit, and to a better formalisation of the service assessment instrument and its coding system. Descriptive validity and the structural analysis of the system were appropriate.



3.

**QUALITY
ASSESSMENT
AND EVALUATION
PACKAGE**

3.1. QUALITY ASSESSMENT PLAN

The Quality Assessment Plan introduced shortly to the topics of quality and quality assessment, measurement strategies of the main goals of the eDESDE-LTC outcomes and concluded with a time plan which was incorporated into the general time frame of the project. Quality can be defined as “result of care”, meaning a process characterized by feedback-loops improving a product or a work. In general, the term “quality” refers to the degree of excellence or lack and measuring quality means assessing user’s expectations with respect to an object, product or work. Thus, quality has no specific meaning unless related to a specific function and/or object, product, work or service. Quality is a perceptual, conditional and somewhat subjective attribute.

In eDESDE-LTC, quality was addressed mostly with respect to conformance to requirements (e.g. applicability, acceptability and practicality). However, requirements may not fully represent user expectations. Thus it is suggested to include the aspect of “fitness for use”, with fitness being defined by the user.

When speaking about quality in the context of eDESDE-LTC the consortium is aware of the two-dimensional model of quality: the “must-be quality” and the “attractive quality.” With the “must-be quality” being close to the “fitness for use” and the “attractive quality” representing what the user would like to have, but has not yet thought about. This latter aspect goes in line with Drucker’s definition, stating “quality in a product or service is not what the supplier puts in. It is what the user or customer gets out.”

Looking on how quality is viewed by scientific and professional societies, one can conclude that quality is a subjective term and the technical use of the term provides two meanings:

- The characteristics of a product, work or service referring on its ability to satisfy explicit (stated) or implicit (implied) needs;
- A product, work or service free of deficiencies.

In general, during quality assessment an object, product, work or service is evaluated according to its defined aims. Besides assessing an object, product, work or service itself, an analysis of existing analogue objects, products, works and services can be included and discussed comparatively to the object, product, work or service of interest. Also, product quality (the eDESDE-LTC instrument) needs to be distinguished from process quality (focus on management and coordination of the project). Process and quality indicators were defined.

3.2. PROCESS EVALUATION (Process and Quality)

This section summarizes the quality assessment of the eDESDE-LTC action. eDESDE-LTC is aimed at developing an operational system for coding, mapping and comparing services for Long Term Care (LTC) across the European Union. The main aim of the project was to contribute to the improvement of access to relevant sources of information on LTC services and to develop a classification system with a common semantic. This project was developed to facilitate the understanding of care systems and structures between EU member countries and abolish barriers to information for various users (EU GD Health and Consumer Protection, OECD, WHO, national LTC services within their European networking as well as the individual user). Overall the outcomes of the action should contribute to the right of “having access to high-quality healthcare when and where it is needed” by EU citizens.

PROCESS INDICATORS

Five process indicators were registered. Four were related to the project’s objectives whilst the fifth was a formative indicator.

- a. **Indicator of objective “1”**: Availability of a paper version of the DESDE-LTC European Classification & Coding System.
- b. **Indicator of objective “2”**: Availability of a paper version of the DESDE-LTC Instrument. A paper version of the instrument will be developed. It incorporates four sections: 1) General instructions and glossary, 2) Classification and Coding system, 3) Utilisation, and 4) General characteristics (service listing). The system which incorporates basic descriptors and indicators will be translated and available in 6 European languages: English, Spanish, German, Norwegian, Slovenian, and Bulgarian.
- c. **Indicator of objective “3”**: Availability of the webpage eDESDE-LTC: A webpage will be developed which will incorporate the electronic version of the DESDE-LTC instrument.
- d. **Indicator of objective “4”**: Availability of the eDESDE-LTC Training Package on semantic interoperability via a standard coding system of services for LTC. The professional training package will be an on-line document available at the eDESDE-LTC project webpage. It will include a general guide to the use of the instrument, FAQ questions and answers, vignettes, reference material and contact address.
- e. **Formative evaluation**: Indicators will include Availability of three reports: two interim project reports plus a Usability report. Interim reports include:
 - 1) Review of eDESDE-LTC at year 1 meeting (year 1 project report), at the Mo15.
 - 2) Review of eDESDE-LTC after the Pilot testing and at the final usability report.

QUALITY INDICATORS

The eDESDE-LTC grant agreement referred to four quality indicators to be applied for quality assessment:

- a. Feasibility
- b. Impact Analysis (see WP2 – Dissemination McDaid et al, 2011)
- c. EQM Analysis = Quality assessment plan (QAP) and accomplishment of indicators
- d. Geographic availability (see “Evaluation of the translation”)

3.2.1. DATA COLLECTION

Within the eDESDE-LTC action eight partners of six EU countries (Bulgaria, United Kingdom, Austria, Norway, Slovenia and Spain) were participating. The University of Vienna, the only Austrian Partner, was responsible for the Work Package Evaluation. During the first year of the project the team members developed a Quality Assessment Plan including all points of evaluation, which was discussed and approved by the project coordination. This final report on the evaluation of the project follows the structure of the Quality Assessment Plan and includes results and further points of discussion.

The leader of WP3 (UNIVIE) planned and prepared the evaluation (Quality Assessment Plan). A series of evaluation tools were designed according to UNIVIE guidelines by one subcontracted company (Lebenshilfe Austria). The leader of WP3 included all evaluation dates into the general project timetable and reminded partner and project management via email or Skype on upcoming evaluation tasks and deadlines. The Quality Assessment Plan was adapted taking into account the amendment of the project (June,2010).

Initially UNIVIE suggested evaluating the other Work Packages and the main eDESDE-LTC outcomes (eDESDE-LTC standard Classification and Coding System, the Web-Page and the Training). Finally the working plan was adapted to the actual project-processing and the project’s amendment. Therefore a new Quality Assessment Plan was created (Table 9).

Table 9. Evaluation plan of the eDESDE-LTC project workpackages

Work package	Coordinator	Evaluation	Tool	Conducted by	Comments
WP 1. Project coordination	PSICOST	UNIVIE	EMC	Partners	Evaluation at partner meetings
WP 2. Dissemination of results	LSE	PSICOST & LSE	Impact Analysis	D. McDaid & L Salvador-Carulla	Impact Analysis
WP 4. Development of the coding system and instrument (DESDE-LTC)	PSICOST	UNIVIE	Evaluation of translation. Feasibility: F-Q	Partners, Partners, focus-group members and external experts	Reported by partners Filled out by partners, nominal group participants and international experts
WP 5. Website	FCC	UNIVIE	WS-C-Q Meta-tags	Partners Partners	Implications: 1.) Use results of partner-evaluation for a modification of website.
WP 6. Training package	PSICOST	UNIVIE	Trainer Trainees	Trainer Trainees	Filled out by trainees and trainees
WP 7. Pilot and usability	SINTEF	PSICOST	---	Partners PSICOST & SHA	Technical report
External Evaluation		Univ. Alacant	Ontology Analysis	Collab Partner: T. Roma-Ferri	Qualitative analysis of the formal ontology

EVALUATION QUESTIONNAIRES

A series of evaluation questionnaires have been developed for this Workpackage. The battery of evaluation questionnaires has been included at Annex 1. Specific comments on the development of these questionnaires are made at the evaluation of the different project workpackages.

UNIVIE prepared an evaluation tool for project partners to evaluate the project meetings and contacts. The construction of the questionnaires was made by an external expert, paid by the subcontracting organisation “Lebenshilfe Austria. They included an evaluation questionnaire of the Project Management and the coordination of the project, including the organization of the partnership, the communication strategy, the effectiveness of the partnerships communication and the appropriateness of the communication tools; evaluation of the translations of eDESDE-LTC; evaluation of the webpage was made by an external expert following the guidelines stated in the Quality Assessment Plan. Twelve eDESDE team members, at least one partner from each participating answered the questions. Three team members of Austria, Slovenia and Spain did participate in the evaluation. The English partner did respond to this evaluation tool.

The training package was assessed using two different instruments addressing two different target groups were designed by UNIVIE: trainers and trainees. Three trainers from Spain and one from Bulgaria with experience in the use of eDESDE-LTC participated in the development and implementation of the training course and in the monitoring of use of the instrument by trainees throughout the demonstration phase. Nine trainees from Spain and Bulgaria with different backgrounds in health service research and management and also different experience in the use of previous instruments (ESMS/DESDE) attended this training. The four trainers who participated in the coordination and training (three from Spain and one from Bulgaria), evaluated their conducted training on the correct use of eDESDE-LTC. The trainers answered to 9 questions concerning the training. A total of nine trainees, seven from Spain and two from Bulgaria, were asked to evaluate the DESDE-LTC training they participated. For this purpose, each trainee completed a questionnaire covering 10 questions, as described below.

3.2.2. ANALYSIS OF PROCESS EVALUATION DATA

WORKPACKAGE 1: PROJECT'S MANAGEMENT AND ORGANISATION

The detailed description of the quality assessment of the meetings, teleconferences (group and individual), management coordination meetings and project meetings is available at the full quality report (Zeilinger et al, eDESDE-LTC: Quality Assessment and Evaluation Package [Internet]. Jerez (Spain). PSICOST and Telnet; 2011)

a) Conceptual evaluation

1) When questioned if the members recognise defined goals in the DESDE project, all eight participants responded positively, however differences could be found in the goals identified. Below is a list of the goals noted by the team-members in relation to the project (in brackets the number of instances the respective goal was mentioned):

- Ageing.
- Assessment.
- Classification (5)
- Creating a coding system (4)
- Decision making.
- Disability.
- IT.
- Instrument (3)
- Long-Term-Care.
- Mental health.
- Ontology.
- Webpage (2)

2) When questioned if they recognise a defined concept of concerted project steps/activities of the DESDE project, six of the eight participants responded positively, while two agreed partly. Below the list of the keywords noted by participants in relation to the concept (in brackets the number of instances the respective goal was mentioned):

- Adapting training (4)

- Adapting instrument.
- Basic.
- Coding system.
- Description of services.
- Evaluating instrument.
- Feasibility study.
- MTC.
- Policy relevance.
- Ontology.

b) Structural evaluation

Participants were questioned on the structure to realise activities within the DESDE project. For this report the arithmetic mean was calculated for each assessment of the different categories, whereas a value of 2 denotes the best, and 0 the worst assessment.

The most relevant structures, with arithmetic means between 1,63-2,0 as identified by participants were:

- Identified coordination of the activities (1,88)
- Defined responsibilities (1,75)
- Structured e-mail contacts (1,63)
- Defined resources (1,63)
- Defined project language (1,88)
- Defined behavioural recommendations (2)
- Defined documentation (1,86)

The monitoring structure, with an arithmetic mean of 1,25 was considered less relevant for realizing the DESDE project activities. Furthermore, one participant mentioned dissemination coordination and informatics coordination as important points for realizing the activities within the DESDE project.

c) Result evaluation

At this point of the evaluation, participants were asked if they recognise clear products of the project. Six of eight participants were able to recognize clear products of the project, while two responded that they can partly recognise them. In a second step, participants had to assess (in percentages) to which extent they see finalised products. For each product the arithmetic mean was calculated:

- The instrument itself (80%)
- Translation in all partner languages (67%)
- Workshops for participants (50%)
- Website (60%)

According to these results the participants see the instrument itself as the most finalised product of the project, whereas the workshops for the participants and also the website are considered the least finalised.

When asked about further aspects which are still open, participants mentioned the following:

- Additional feasibility evaluation.
- Dissemination (2)
- Coding.
- Training package.
- Translations.
- Workshops (especially in the UK)

d) Sustainability evaluation

Participants were asked to assess the sustainability of the instrument, the translation, the workshops, and the homepage. For this report the arithmetic mean was calculated for each of these four assessments, where as a value of 3 denotes the best, 1,5 an average, and 0 the worst assessment:

- Instrument (2,63)
- Website (1,88)
- Translation (1,63)
- Workshops (1,57)

According to these values one can identify that participants view the instrument itself as fulfilling the aspect of sustainability best, whereas the sustainability of the website, the translation, and the workshops is considered positive, but lesser than for the instrument itself.

Participants mentioned the following factors positively influencing the sustainability:

- Clear structure of the instrument.
- Good content of the project.

Participants mentioned the following factors negatively influencing the sustainability:

- Instrument is complicated and requires extensive training.
- Sustainability requires training of trainers not just training alone.
- Training needs to be as clear as possible and needs to be computerised with easy use.
- Workshops and homepage needed to be more developed.

a) Assessment contributions by partners

- Presentations were of high quality, offering the central information.
- Consistent and congruent structure of dissemination programme.
- Substantial and careful scientifically interpretations of the projects achievements in a highly understandable way.
- First results of the study with the pilot in Sophia and Madrid allowed opening an interesting debate of types of services policy in every country.

- b) Assessment of contributions by external experts
 - Contributions were of a significant added value to the programme.
 - Excellent amendment to the projects achievements.
 - Outlook of adjacent activities within OECD programmes.
 - The contribution of external experts made possible the main objective of dissemination of the meeting.
- c) Assessment of the dissemination meeting overall
 - Meeting was very useful.
 - Interesting debates with and feedback from external experts, who were very supportive with respect to future e-Desde-LTC activities.
 - Meeting fulfilled expectation.
 - It motivated for pilot application of the instrument in selected European regions.

WORKPACKAGE 2: EVALUATION OF DISSEMINATION

The WP2 leader (D. McDaid) was asked to provide a structure for partners to report their dissemination activities, including a section for qualitative report where every partner could describe if the main target groups were reached by the dissemination activity. Forms were sent by partners via eMail to WP 2 leader for the final Work Package report. The full report on dissemination is available from the the eDESDE-LTC group.

WORKPACKAGE 4: EVALUATION OF DEVELOPMENT OF THE CODING SYSTEM AND THE INSTRUMENT

The evaluation of the eDESDE-LTC instrument and coding system included 1) an assessment of the translation in every language, 2) A feasibility study (see Quality Indicators) and 3) An ontology analysis (external evaluation).

The evaluation of country translations in 6 EU languages (English, Spanish, Bulgarian, Norwegian, German and Slovenian) (three versions) is available at the full evaluation report (Zeilinger et al, 2011) and at the project's webpage.

At the 2nd project meeting in Barcelona, it was decided to run by an ontology analysis by an external evaluator, professor Romá-Ferri (Universitat d'Alacant, Spain). Her recommendations have been incorporated into the classification system and this report will be published in a separate paper.

WORKPACKAGE 5: EVALUATION OF WEBSITE

Except for one person, none of the raters had problems to find the Website (91,7%). Eleven persons (91,7%) could find the desired information fast and easily. All managed to use the menu navigation fast and easily and found the content intelligible. Ten persons (83, 3%) had the impression that the content was clearly arranged, 2 participants answered "partly". Nine persons (75 %) did not use the search function – two stated that (at the time of the evaluation) there was still no search function available and asked for inclusion of this function. Eleven persons had the impression that the Website's content was correct (91, 7%). Two persons (16, 7%) could not recognize responsible institutions on the Website, one partly could (8, 3%). Four persons (33, 3%) did not look for the legal notice and two could not find it (16,7%). Four persons (33, 3%) were unsure whether the information by external authors is presented adequately. Five persons (41, 7%) could not find the date of the last update – five could (41, 7%). Eleven persons (91, 7%) had the impression that the Website is a useful tool for the eDESDE-LTC project and would recommend it to other projects partners and even to persons, who are currently not involved in the project. One person had the impression that the content is too complex for non-project partners.

Partners decided that a second evaluation of the website will not be necessary. To fulfill the important criteria of retrieval , every partner should provide the website manager with suggestions for meta-tags. There is a list of the most important terms by which the webpage should be found using search-engines. These results are described in the quality report (Zeilinger et al, 2011).

The Website is seen as a very important tool for dissemination, with intelligible content. The proposed terms by which the webpage should be found using search-engines, were transferred to the website-manager to improve the website. The sustainability of the website should be ensured, even after projects end. The full report on the development of the webpage is available elsewhere (Bendeck et al, 2011)

WORKPACKAGE 6: EVALUATION OF THE EDESDE-LTC TRAINING PROCEDURE AND PACKAGE

The evaluation of trainers and trainees is fully described at the quality report (Zeilinger et al, 2011). In summary trainers found the adequacy of the length of training too long. Just one trainer answered positively, while the remaining three agreed partly. They mentioned that another half day and an additional support via e-mail or skype would be necessary. When questioned if it was necessary to provide further support or assistance to the trainees after the training, three of the trainers responded with yes, while one agreed partly. Two types of support were mentioned by the trainers: face-to-face discussions, and online and conference contact via e-mail or Skype. Trainees comments are registered at the full Quality assessment report (Zeilinger et al, 2011) and additional aspects are revised at the pilot study report (Salvador-Carulla et al, 2011).

WORKPACKAGE 7: EVALUATION OF THE PILOT STUDY OF EDESDE-LTC

The qualitative report on the pilot study (description of course, content, materials, etc.) was planned in the Quality Assessment, but this evaluation was not conducted as the final report of the Pilot study was completed at the end of the study due to the need to revise the codes in Sofia after the final project meeting in Reus (Spain), in November 2010.

3.2.3. QUALITY INDICATORS OF THE eDESDE-LTC PROJECT

The quality indicators of the project are described at the full quality assessment report (Zeilinger et al, 2011). The final version of the DESDE-LTC instrument, compared to the beta version, is much easier understandable and applicable. Most of the major goals have been achieved, notably obtaining an instrument which i) enables international and interregional comparisons in standardized manner, and ii) enables mapping of all long-term-care services, allowing for detecting gaps or oversupply of services. However, the evaluation of the quality of services could not yet be achieved through DESDE-LTC, and would require modifications to the instrument. One possibility would be to add quality indicators to DESDE or to develop an own instrument for quality evaluation.

As a result of the complexity of long-term-care systems, the access to information needed for the correct use of DESDE as well as the coding are seen as very complex and difficult. Concerning access to information needed for DESDE, not all services can provide reliable data, as several services do not yet have statistics at that level. Furthermore, information about the services should be clearer arranged. In many other cases, especially facilities from the private sector are not very cooperative when it comes to providing data, since many of them are funded based on their capacity and not in respect to actual occupancy. All these points would need to be addressed so the use of the coding becomes more understandable.

Another point which has been mentioned is the application of the DESDE-LTC. The application of the instrument requires a well trained person, which should be also very well acquainted with overall organization and characteristics of LTC services in the particular region, to assure that obtained data are reliable and accurate. It would be useful to improve the methodology to further improve the user-friendliness.

Finally, some countries are still at the beginning of developing the concept of long term care, and even in questions relating to legislation or insurances there may be an absence of consensus between different actors engaged in the field of LTC. Furthermore, some definitions of LTC and terminology applied in the final DESDE-LTC instrument do not fit well in the systems of LTC as seen by some of the stakeholders. Thus, the future version of DESDE-LTC could be updated with more practical examples, norms and definitions of LTC accepted in all countries at that time, in order to make the instrument more understandable to stakeholders from both the social and medical sector.

Apart from these points, which should be still considered in the future, DESDE is seen as an instrument of great practical value for the process of planning of services for people with disabilities, both mental health and physical disorders, in need of long term care. The map, realised with DESDE, can provide instant visualization of the existent and the lacking service resources in a certain administrative or geographical region. Thus, people unspecialised in the fields of public health, or public social work, but with decision making power (such as state and municipal officials) can quickly familiarize themselves with the situation. Furthermore DESDE could be used as an excellent training exercise and training tool. For example, trainees in psychiatry, in psychosocial rehabilitation, social work, etc. could learn how to orientate themselves in the system of services in the areas of their activities.

3.2.4. EQM ANALYSIS

The EQM analysis was made taking into account previous information on Feasibility and Impact. This analysis was related to the accomplishment of the project objectives in relation to the defined key outcomes. All the objectives have been completed. (Table 10)

SUGGESTION FOR IMPROVEMENT

The suggestions for improvement are explained at the end of every workpackage assessment report (Zeilinger et al, 2011). In relation to the Website it was considered important to expand the number of publications, include search function, include examples of coding and case vignettes, include a self-training for users and inform them on their achievement, a legal notice, and an easy-to-read description of the project and its aims.

As regards to the training package it was suggested on the one hand that computerised algorithms should be developed to make the completion simpler, and on the other hand that the supervision of an experienced eDESDE trainer would be helpful.

DESDE-LTC is seen as a classification-instrument with high innovative potential, which enables: a) an international standardized description, b) a mapping of all long-term-care services, which allows for detecting gaps or oversupply of services, c) improving the international communication and semantic interoperability by using the service-codes, d) the exchange of information very well. The evaluation of the quality of services could not yet be achieved through DESDE-LTC, and would require modifications to the instrument (for example: adding quality indicators).

As a result of the complexity of long-term-care systems:

- The access to information needed for the correct use of DESDE is difficult.
- The coding is very complex and difficult.
- Expert knowledge is a pre-condition for applying the instrument.
- A development of a computerised version using standard algorithms.
- A better link with other instruments in health service research (eg quality assessment instruments).

Table 10. Summary of the Evaluation – EQM of the eDESDE-LTC Project

Indicators	Description	Outcome	Comments	References (*)
Process				
a. Objective 1	Availability of paper versions of DESDE-LTC European Classification & Coding System	Completed	It uses a decimal classification system	Romero, C., Salvador-Carulla, L., Poole, M., Roma-Ferri M. for the eDESDE-LTC Group. eDESDE-LTC: Classification and Coding System [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: http://www.edesdeproject.eu
b. Objective 2	Availability of a paper version of the DESDE-LTC Instrument.	Completed	It incorporates four sections and it is available in 6 European languages: English, Spanish, German, Norwegian, Slovenian, and Bulgarian. The evaluation of the translation was also performed in every country	Salvador-Carulla, L., Romero, C., Poole, M., for the eDESDE-LTC Group. eDESDE-LTC: Classification and Coding System [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: http://www.edesdeproject.eu
c. Objective 3	Availability of the webpage eDESDE-LTC	Completed	It includes the electronic version of the DESDE-LTC instrument	http://www.edesdeproject.eu
d. Objective 4	Availability of the training package	Completed	It includes a general guide to the use of the instrument, FAQ questions and answers, vignettes, reference material and contact address.	Romero et al. eDESDE-LTC Training Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. http://www.edesdeproject.eu/training.php
e. Formative evaluation	Availability of three reports	Completed	It includes 1) Review of eDESDE-LTC at year 1 meeting (year 1 project report), 2) Review of eDESDE-LTC after the Pilot testing and at the 3) final project report.	1) was delivered at month 15 to EAHC
Quality				
a. Feasibility	Applicability, Acceptability & Practicality	Completed	It has incorporated a forth domain of feasibility: Relevance. A five-point likert scale was used: 1 best to 5 lowest rating	Salvador-Carulla et al. for the eDESDE-LTC Group. eDESDE-LTC: Dissemination and communication [Internet]. Jerez (Spain): PSICOST and Telnet; 2011
b. Impact analysis	Screening, scoping and appraisal	Completed	Review of available instruments. Uses likert scale	
c. EQM analysis	Quality Assessment Plan	Completed		Zeilinger et al: Quality Assessment and Evaluation Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011
d. Geographical availability	Instrument availability	Completed	The instrument is available in 6 countries (see objective 2)	http://www.edesdeproject.eu
(*) Zeilinger et al: Quality Assessment and Evaluation Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011.				

3.3. EFFECT EVALUATION (IMPACT ANALYSIS)

3.3.1. DATA COLLECTION FOR PROCESS EVALUATION

Effect evaluation / 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.

- **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: A listing of key stakeholders in every country will be performed. Identification of impacts on the care system at every level of eDESDE-LTC (Listing)
- **Appraisal:** of the classification, instrument, webpage and training package using the mapping developed at the Scoping phase (Best to lowest / 5-point likert). A descriptive analysis is provided on three main areas: 1) Care policy (awareness, practice, services and governance) at the four levels (Europe, National, Regional and Local) 2) Information systems at the four levels (Europe, National, Regional and Local), and 3) Key stakeholders.

3.3.2. ANALYSIS OF EFFECT EVALUATION

SCREENING

The availability of instruments for the international assessment of territorial availability and use of services for Long Term Care was carried out by PSICOST in cooperation with LSE. Available instruments comprising international studies were mainly designed for assessing activities, utilisation and quality of individual services, but did not allowed international comparisons of small or large health areas and mostly relied on the names of services at local level to classify them without providing alternatives for improving semantic interoperability. Examples are care utilisation instruments such as the Client Service Receipt Inventory (CSRI) (Chisholm et al, 2000), or the Resident Assessment Instrument-Mental Health (RAI-MH) (inter-rater reliability and convergent validity) (Hirdes et al, 2002).

Apart from the original instruments previously developed for the assessment of mental health services (European Service Mapping Schedule – ESMS) (Johnson and Kuhlman, 2000; Salvador-Carulla et al, 2000) and its adaptation for the assessment of services for persons with disabilities (DESDE) (Salvador-Carulla et al, 2006), no instrument was identified with the objectives and characteristics of eDESDE-LTC. This was also checked with key experts working on the new classification of functions of care and health services at the OECD (V Moran and G Monaco) and at WHO (P Hernandez); and it has been acknowledged at the Pre-Edited Version of the System of Health Accounts Version 2.0 (OECD, WHO and EUROSTAT, 2011).

SCOPING

The identification of key stakeholders was made at PSICOST. A series of files were compiled. These files have not been included in the report due to data protection. More information is available from PSICOST. The list included:

- **List of ESMS/DESDE Experts:** This excel file incorporated all researchers who have used ESMS/DESDE or who contacted any of the original EPCAT members for further information, or published in related areas until 2009. This excel file listed 483 experts from 61 countries (all European countries and all world regions).
- **List of Participants at the Bridging Conference,** Barcelona, 2009. This excel included 82 participants at the International Bridging conference who attended any of the events related to the project. The bridging conference was funded by EAHC and it was co-organised by LSC, PSICOST and Catalunya Caixa and all members of the eDESDE-LTC consortium participated in it. The eDESDE-LTC was first presented at this conference.

- **List of experts and stakeholders contacted for eDESDE-LTC.** This dataset gathered all experts and stakeholders which were contacted during the duration of the project either face-to-face or by email in relation to the eDESDE-LTC. This list included 163 experts and stakeholders from the main European and international health organisations, 23 Countries from Europe (Austria, Belgium, Czech Republic, France, Finland, Germany, Hungary, Italy, Netherlands, Norway, Poland, Rumania, Slovenia, Spain, Sweden, Switzerland, UK) and elsewhere (Canada, Chile, Israel, USA).
- **Other organisation listings not directly related to DESDE-LTC**
 - International: ENMESH. This list comprises 583 researchers and planners in mental health epidemiology and policy from most European countries.
 - National (Spain)
 - SESPAS. This umbrella organisation includes major research and professional organisations in epidemiology, public health, health economics and management. SESPAS does not facilitate the database but distributes information to their associated partners via Support Serveis.
 - Spanish listing of Chronic care. This listing includes attendants to the Congress of Chronic Care which is directly related to LTC.

APPRAISAL

The appraisal of the goals of a health policy related project is difficult to assess during the duration of the time-span of the project. First, the actual appraisal should be assessed after the completion of the project. Second it is not clear to what extent the achievements made are related to the project itself, to previous work or to collateral factors. The activities and the contacts made by the consortium are listed in the Dissemination report (McDaid et al, 2011). Indicators of impact have not been developed to assess instruments in the public health area. Awareness has been assessed by level of direct contacts and participation in eDESDE-LTC related activities of policy makers and planners. Table 11 provides an appraisal of the impact analysis by the coordination partner PSICOST.

Table 11. Appraisal of the impact analysis of eDESDE-LTC (*)

IMPACT ANALYSIS INDICATORS	International	National	Regional	Local
Policy				
Awareness	1	1	1	3
Practical	2	1	1	3
Services & Governance	4	4	4	4
Information Systems				
Awareness	3	2	2	4
Practical	5	2	2	5
Services & Governance	5	5	5	5
Stakeholders				
Awareness	1	1	1	3
Practical	2	2	2	4
Services & Governance	4	3	3	5

(*) Likert scale 1: high to 5: Absent

a.- Care policy (awareness, practice, services and governance)

- **Europe (International):** The level of awareness indicated by direct contacts and participation in eDESDE-LTC activities by policy makers and planners has been mainly described at the dissemination report (McDaid et al, 2011). Decision makers and planners from the key international organisations have been contacted and have participated in eDESDE-LTC related international conference as well in eDESDE-LTC meetings. These officers at WHO-Geneva (B. Ustun, N. Kostancek, P Hernandez), WHO-Europe (C Wahlbeck), OECD (V Moran, F Colombo), European Observatory (D. McDaid). The participation of several members of the consortium (members and collaborating members) in key international institutions has played a major role in rising awareness on the eDESDE-LTC system at international care policy level. A major practical output of this awareness strategy has been the incorporation of the eDESDE reference to the pre-edited version of the new System of Health Accounts (v2.0) edited by OECD, WHO and EUROSTAT (OECD et al, 2011; p77). The interest shown by key umbrella organisations such as EASPD or MHE in the system is also a key practical output of this project.

The incorporation of eDESDE-LTC instrument in the 7th framework project REFINEMENT (2011-2013) may have large implications for the sustainability of the system. Its improvement, for its dissemination and eventually for its use in services as well as for governance.

The eDESDE-LTC has also been used to describe and code mental health service provision and utilisation in Chile, following prior use of ESMS (Salvador-Carulla et al, 2008).

- **National:** Although contacts with national social and health planners have been made by all partners, main activities were recorded in Spain, Bulgaria and Slovenia (see dissemination: McDaid et al, 2011). Whilst the awareness raised in Bulgaria and Slovenia did not developed into practical implementation, the results in Spain have been outstanding, particularly in the mental health and the disability sectors. The previous instrument (DESDE) was used for coding the services at the Spanish Listing of Disability Services made by the General Directorate of persons with Disabilities at the Spanish Ministry of Health, Social policy and Equity. In 2010 eDESDE-LTC was adopted as the reference system for mapping and coding mental health services by the National Strategy on Mental Health (Spanish Ministry of Health, Social policy and Equity) and it has been used for coding MH services in 8 Autonomous Communities or regions in Spain (to be completed in 2011).
- **Regional:** Again main awareness and practical impact has been reached in Spain and in the mental health sector. The eDESDE-LTC instrument and its coding system has been used to describe the Mental Health system in the three regional agencies which participated as collaborating partners in the eDESDE-LTC project: Cantabria (Vazquez-Barquero et al, 2010), Catalonia and Madrid (to be released next June 2011). Navarra has requested further information for implementation of this system in 2011.
- **Local:** There has been an increase of awareness at local level in the municipality of Madrid which participated in the pilot study. A similar impact is expected in Sofia when the final results of the pilot study are published. Two other Spanish municipalities have participated in this project; one as collaborating partner (Jerez, Spain) and other one hosted a project meeting (Reus, Spain). However the impact in this two territories have been scarce.

b.- Information systems: contacts with international information systems have been listed at the dissemination report. No impact was expected due to the need of long periods of time to introduce any reform in these systems. However DESDE is already implemented at the national registry of services for disabilities in Spain, and eDESDE has been considered in the Spanish registry of mental health services.

c.- Key stakeholders: contacts and awareness of stakeholders have been reported at the dissemination report. It is expected that the awareness of experts and stakeholders will raise after publication of the eDESDE-LTC reports, scheduled presentations at congresses during 2011 and scientific and public policy publications.

3.4. LIMITATIONS

The main problem encountered was the adjustment of the project due to the delay in the full incorporation of two partners to the project activities and the delay in the approval of the project amendment. On the other hand, Workpackage 7 could not be assessed due to the coincidence of its completion with the end of the project so it was not included in the final evaluation assessment.

The process and quality indicators have been summarised in evaluation of translation, website, and the instrument itself were conducted and also the training was evaluated, both for trainers and trainees. The most promising task of UNIVIE was the feasibility assessment of the DESDE-LTC coding tool. The most important product of this project, the eDESDE-LTC instrument was evaluated as very useful and promising, even if further modification needs to be done. Further products, like the website and the training material were rated as very important for the project, the dissemination and the application of the instrument itself. Impact and EQM analysis produced good results. The project and its partnership fulfilled the promised tasks of the project in a high quality standard.

Other relevant issue is the applicability of eDESDE-LTC to specific population target groups where the broad perspective provided by DESDE-LTC may hamper the assessment procedure. A case raised by some members of the experts group was the applicability of DESDE-LTC to mental health, particularly as this instrument was developed from the European Service Mapping Schedule (ESMS) to sort out this problem it was agreed that adapted versions of this instrument would be developed for specific target groups, in the case of mental health this version will be called ESMS-R (European Service Mapping Schedule Research version) to adjust it to the historical development of this classification system in the mental health sector.



4.

**DISSEMINATION
AND
COMMUNICATION**

4.1. eDESDE- LTC DISSEMINATION AND COMMUNICATION STRATEGY

The dissemination strategy identified a number of communication channels used to disseminate materials related to the e-DESDE-LTC study. Overall, the dissemination activities were highly dynamic including a range of outputs and different communication techniques intended to reach the many different stakeholders. Target audiences included professionals in the area of long-term care, academics, policy makers, and service users. The dissemination strategy involved a combination of activities undertaken at the project-level, together with activities carried out at individual country-level.

In developing the dissemination strategy main objectives were defined following the dissemination experiences and activities within other European projects, including the Mental Health Economic European Network (MHEEN) and the Content materials to Raise Employability and Reinforce Skills of carers (CARERS). Our key guiding principles for dissemination and knowledge transfer are outlined in Box 1. To ensure longer-term sustainability, the eDESDE-LTC dissemination strategy had built on a previous successful experience of the group with the European Service Mapping Schedule (ESMS), which has previously been adapted for application to the assessment of services for people with disabilities in Spain (DESDE).

Box 1. Key objectives for dissemination and knowledge transfer

- Raising awareness and interest in different stakeholders
- Building links with stakeholders, other projects/activities
- Providing opportunities for stakeholders to communicate with the e-DESDE team
- Communicating results in accessible way
- Increasing likelihood of long term sustainability of ideas in project
- Having some academic impact

Effective dissemination is not a simple linear process whereby the findings are presented to policy makers and other stakeholders, who then in turn change policy and practice. Instead knowledge transfer is a much more complex and messy process involving many iterative communications between the research and policy and practice communities. The evidence has shown that to be effective any dissemination strategy must be multi-faceted, focusing not only on the publication of academic outputs but also producing outputs such as printed products, web based products, seminars and opportunities to interact with policy makers on a face-to-face basis.



5.

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6. ANNEXES

6.1. eDESDE-LTC: CLASSIFICATION AND CODING SYSTEM

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Project Ref. 2007/116

DESDE-LTC 'Classification and Coding System' is an adaptation of the coding system of the ESMS (European Service Mapping Schedule) (Johnson et al, 2000) (it also incorporates modifications included in ESMS-II), and the coding system of the 'Description and Evaluation of Services for Disabilities in Europe' (DESDE) (Salvador-Carulla et al, 2006) and related instruments (DESDAE and DESDE).

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LIST OF MAIN ACRONYMS

BSIC	Basic Stable Inputs of Care
GP	General Practitioner
DESDE	Description and Evaluation of Services and Directories in Europe
EPCAT	European Psychiatric Care Assessment Team
ESMS	European Service Mapping Schedule
HMO	Health Maintenance Organisation
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICHA	International Classification of Health Accounts
ICHI	International Classification of Health Interventions
ISCO	International Standard Classification of Occupations (ISCO-08) Code
LTC	Long Term Care
MTC	Main Types of Care
WHO	World Health Organization

1. INTRODUCTION

The ‘Description and Evaluation of Services and Directories in Europe for Long Term Care’ (DESDE-LTC) is a system focused on:

- Providing a standard description of the main characteristics that identify the services and care provided. Each description is identified with a brief descriptor based on DESDE-LTC instrument.
- The descriptors are organized into a classification scheme of hierarchy types. The hierarchy is determined by the common and specific characteristics of each component of the scheme (services).
- Each descriptor is associated with an alphanumeric code or identifier (**DESDE-LTC Classification**). The identifier provides accurate identification of the descriptor and facilitates grouping the information for a later statistical processing of data.
- The system is reusable to formalize an ontology. It has the explicit and accepted knowledge of the services for long-term care (descriptors, description and hierarchy).

The classification scheme corresponds with a DESDE-LTC coding that provides an internal code also associated to the descriptors (DESDE-LTC Coding List). This information is complemented with a Glossary of Terms that compiles an alphabetical list of definitions of key concepts that appear on DESDE-LTC Instrument.

2. DESDE-LTC CLASSIFICATION

DESDE-LTC Classification provides three elements of information from every code:

ID (identifier) – **DESDE-LTC descriptor** – [DESDE-LTC label]

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
I	1	INFORMATION AND ASSESSMENT OF NEEDS FOR CARE	
I010000000	2	Information And Assessment: Guidance and assessment	I1
I010100000	3	Information And Assessment: Guidance and assessment, Health related	I1.1
I010200000	3	Information And Assessment: Guidance and assessment, Education & training related	I1.2
I010300000	3	Information And Assessment: Guidance and assessment, Social and culture related	I1.3
I010400000	3	Information And Assessment: Guidance and assessment, Work related	I1.4
I010500000	3	Information And Assessment: Guidance and assessment,, Other (non work) related	I1.5
I020000000	2	Information And Assessment: Information	I2
I020100000	3	Information And Assessment: Information, Interactive	I2.1
I0201010000	4	Information And Assessment: Information, Face to face	I2.1.1
I0201020000	4	Information And Assessment: Information, Other Interactive	I2.1.2
I020200000	3	Information And Assessment: Information, Non interactive	I2.2

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
A	1	ACCESSIBILITY TO CARE	
A010000000	2	Accessibility to Care: Communication	A1
A020000000	2	Accessibility to Care: Physical mobility	A2
A030000000	2	Accessibility to Care: Personal accompaniment	A3
A040000000	2	Accessibility to Care: Case coordination	A4
A050000000	2	Accessibility to Care: Other accessibility care	A5

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
S	1	SELF-HELP AND VOLUNTEER CARE	
S010000000	2	Self-help and volunteer care: Non professional staff	S1
S010100000	3	Self-help and volunteer care: Non professional staff information on care	S1.1
S010200000	3	Self-help and volunteer care: Non professional staff accessibility to care	S1.2
S010300000	3	Self-help and volunteer care: Non professional staff outpatient care	S1.3
S010400000	3	Self-help and volunteer care: Non professional staff day care	S1.4
S010500000	3	Self-help and volunteer care: Non professional staff residential care	S1.5
S020000000	2	Self-help and volunteer care: Professional staff	S2
S020100000	3	Self-help and volunteer care: Professional staff information on care	S2.1
S020200000	3	Self-help and volunteer care: Professional staff accessibility to care	S2.2
S020300000	3	Self-help and volunteer care: Professional staff outpatient care	S2.3
S020400000	3	Self-help and volunteer care: Professional staff day care	S2.4
S020500000	3	Self-help and volunteer care: Professional staff residential care	S2.5

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
0	1	OUTPATIENT CARE	
0010000000	2	Outpatient care: acute	
0010100000	3	Outpatient care: acute, Home & mobile	
00101010000	4	Outpatient care: acute, Home & mobile, 24 hours	01
00101010100	5	Outpatient care: acute, Home & mobile, 24 hours, Health related care	01.1
00101010200	5	Outpatient care: acute, Home & mobile, 24 hours, Other care	01.2
00101020000	4	Outpatient care: acute, Home & Mobile, Limited-hours	02
00101020100	5	Outpatient care: Acute, Home & Mobile, Limited Hours, Health related care	02.1
00101020200	5	Outpatient care: Acute, Home & Mobile, Limited Hours, Other care	02.2
0020000000	2	Outpatient care: non acute	
0020100000	3	Outpatient care: non acute, Home & mobile	
00201010000	4	Outpatient care: non acute, Home & mobile, High intensity	05
00201010100	5	Outpatient care: non acute, Home & mobile, High intensity, Health related care	05.1

00201010101	6	Outpatient care: non acute, Home & mobile, High intensity, Health related care, 3 to 6 days a week care	05.1.1
00201010102	6	Outpatient care: non acute, Home & mobile, High intensity, Health related care, 7 days a week a minimum of 3 hours/day care	05.1.2
00201010103	6	Outpatient care: non acute, Home & mobile, High intensity, Health related care, 7 days a week including overnight care	05.1.3
00201010200	5	Outpatient care: non acute, Home & mobile, High intensity, Other care	05.2
00201010201	6	Outpatient care: non acute, Home & mobile, High intensity, Other care, 3 to 6 days a week care	05.2.1
00201010202	6	Outpatient care: non acute, Home & mobile, High intensity, Other care, 7 days a week a minimum of 3 hours/day care	05.2.2
00201010203	6	Outpatient care: non acute, Home & mobile, High intensity, Other care, 7 days a week including overnight care	05.2.3
0020102000	4	Outpatient care: non acute, Home & mobile, Med.inten.	06
00201020100	5	Outpatient care: non acute, Home & mobile, Medium intensity, Health related care	06.1
00201020200	5	Outpatient care: non acute, Home & mobile, Medium intensity, Other care	06.2
00201030000	4	Outpatient care: no acute, Home & mobile, Low intens.	07
00201030100	5	Outpatient care: Non acute, Home & mobile, Low intensity, Health related care	07.1
00201030200	5	Outpatient care: Non acute, Home & mobile, Low intensity, Other care	07.2
00202000000	3	Outpatient care: Non acute, Non- mobile	
00202010000	4	Outpatient care: Non acute, N-mobile, High intensity	08
00202010100	5	Outpatient care: Non acute, Non- mobile, High intensity, Health related care	08.1
00202010200	5	Outpatient care: Non acute, Non- mobile, High intensity, Other care	08.2
00202020000	4	Outpatient care: Non acute, N-mobile, Medium intensity	09
00202020100	5	Outpatient care: Non acute, Non- mobile, Medium intensity, Health related care	09.1
00202020200	5	Outpatient care: Non acute, Non- mobile, Medium intensity, Other care	09.2
00202030000	4	Outpatient care: Non acute, No- mobile, Low intensity	010
00202030100	5	Outpatient care: Non acute, Non- mobile, Low intensity, Health related care	010.1
00202030200	5	Outpatient care: Non acute, Non- mobile, Low intensity, Other care	010.2

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
D	1	DAY CARE	
D0100000000	2	Day Care: Acute	
D0101000000	3	Day Care: Acute, Episodic acute	D0
D0101010000	4	Day Care: Acute, Episodic acute, High intensity	D0.1
D0101020000	2	Day Care: Acute, Episodic acute, Other intensity	D0.2
D0102000000	1	Day Care: Acute, Continuous care	D1
D0102010000	4	Day Care: Acute, Continuous care, High intensity	D1.1
D0102020000	4	Day Care: Acute, Continuous care, Other intensity	D1.2
D0200000000	2	Day Care: Non Acute.	
D0201000000	3	Day Care: Non Acute, Work related	

D0201010000	4	Day Care: Non Acute, Work related, High intensity	D2
D0201010100	5	Day Care: Non Acute, Work related, High intensity, Ordinary employment	D2.1
D0201010200	5	Day Care: Non Acute, Work related, High intensity, Other work	D2.2
D0201020000	4	Day Care: Non Acute, Work related, Low intensity	D6
D0201020100	5	Day Care: Non Acute, Work related, Low intensity, Ordinary employment	D6.1
D0201020200	5	Day Care: Non Acute, Work related, Low intensity, Other work	D6.2
D0202000000	3	Day Care: Non Acute, Work related	
D0202010000	4	Day Care: Non Acute, Work related, High intensity	D3
D0202010100	5	Day Care: Non Acute, Work related, High intensity, Time limited	D3.1
D0202010200	5	Day Care: Non Acute, Work related, High intensity, Time indefinite	D3.2
D0202020000	4	Day Care: Non Acute, Work related care, Low intensity.	D7
D0202020100	5	Day Care: Non Acute, Work related care, Low intensity, Time limited	D7.1
D0202020200	5	Day Care: Non Acute, Work related care, Low intensity, Time indefinite	D7.2
D0203000000	2	Day Care: Non Acute, Non-work structured	
D0203010000	4	Day Care: Non Acute, Non-work structured. High intensit.	D4
D0203010100	5	Day Care: Non Acute, Non-work structured, High intensity, Health related .	D4.1
D0203010200	5	Day Care: Non Acute, Non-work structured, High intensity, Education related	D4.2
D0203010300	5	Day Care: Non Acute, Non-work structured, High intensity, Social and culture related.	D4.3
D0203010400	5	Day Care: Non Acute, Non-work structured, High intensity, Other structured	D4.4
D0203020000	4	Day Care: Non Acute, Non-work structured, Low intensity.	D8
D0203020100	5	Day Care: Non Acute, Non-work structured, Low intensity, Health related	D8.1
D0203020200	5	Day Care: Non Acute, Non-work structured, Low intensity, Education related	D8.2
D0203020300	5	Day Care: Non Acute, Non-work structured, Low intensity, Social and culture related	D8.3
D0203020400	5	Day Care: Non Acute, Non-work structured, Low intensity, Other structured day care	D8.4
D0204000000	3	Day Care: Non Acute, Non structured day care	
D0204010000	4	Day Care: Non Acute, Non structured day care, High intensity	D5
D0204020000	4	Day Care: Non Acute, Non structured day care, Low intensity	D9

Decimal Identifier	Level	DESDE-LTC DESCRIPTOR	Label
R	1	RESIDENTIAL CARE	
R0100000000	2	Residencial Care: Acute	
R0101000000	3	Residencial Care: Acute, 24 hours physician cover	
R0101010000	4	Residencial Care: Acute, 24 hours physician cover, Non-hospital	R0
R0101020000	4	Residencial Care: Acute, 24 hours physician cover, Hospital	
R0101020100	5	Residencial Care: Acute, 24 hours physician cover, Hospital, High intensity	R1
R0101020200	5	Residencial Care: Acute, 24 hours physician cover, Hospital, Medium intensity	R2
R0102000000	3	Residencial Care: Acute, Non-24hours physician cover	R3
R0102010000	4	Residencial Care: Acute, Non-24hours physician cover, Hospital.	R3.0
R0102020000	4	Residencial Care: Acute, Non-24hours physician cover, Non-hospital.	R3.1
R0102020100	5	Residencial Care: Acute, Non-24hours physician cover, Non-hospital, Health related care.	R3.1.1
R0102020200	5	Residencial Care: Acute, Non-24hours physician cover, Non-hospital, Other care	R3.1.2

R020000000	2	Residencial Care: Non Acute	
R020100000	3	Residencial Care: Non Acute, 24 hours physician cover.	
R020101000	4	Residencial Care: Non Acute, 24 hours physician cover, Hospital.	
R020101010	5	Residencial Care: Non Acute, 24 hours physician cover, Hospital, Time-limited	R4
R020101020	5	Residencial Care: Non Acute, 24 hours physician cover, Hospital, Indefinite stay	R6
R020102000	4	Residencial Care: Non Acute, 24 hours physician cover, Non Hospital	
R020102010	5	Residencial Care: Non Acute, 24 hours physician cover, Non Hospital, Time limited	R5
R020202000	5	Residencial Care: Non Acute, 24 hours physician cover, Non Hospital, Indefinite stay	R7
R020200000	4	Residencial Care: Non Acute, Non-24hours physician cover.	
R020201000	4	Residencial Care: Non Acute, Non-24hours physician cover, Time limited	
R020201010	5	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, 24-hours support	R8
R0202010101	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, 24-hours support, Less than 4 weeks	R8.1
R0202010102	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, 24-hours support. Over 4 weeks	R8.2
R0202010200	5	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Daily support	R9
R0202010201	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Daily support, Less than 4 weeks	R9.1
R0202010202	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Daily support, Over 4 weeks	R9.2
R0202010300	5	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Lower support	R10
R0202010301	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Lower support, Less than 4 weeks	R10.1
R0202010302	6	Residencial Care: Non Acute, Non-24hours physician cover, Time limited, Lower support, Over 4 weeks	R10.2
R0202020000	4	Residencial Care: Non Acute, Non-24hours physician cover, Indefinite stay	
R0202020100	5	Residencial Care: Non Acute, Non-24hours physician cover, Indefinite stay, 24-hours support	R11
R0202020200	5	Residencial Care: Non Acute, Non-24hours physician cover, Indefinite stay, Daily support	R12
R0202020300	5	Residencial Care: Non Acute, Non-24hours physician cover, Indefinite stay, Lower support	R13
R0202020400	2	Residencial Care: Other non-acute	R14

3. DESDE-LTC CODING LIST

DESDE-LTC Coding List provides a list of descriptors associated to DESDE-LTC codes or labels. Every label corresponds with a decimal identifier in the classification system. It allows a quick search by DESDE-LTC codes.

INFORMATION SERVICES FOR CARE CODING BRANCH

Facilities whose main aim is to provide information and assessment to users with long term care needs. This care does not entail a subsequent monitoring/follow-up of the user.

I1: Guidance and Assessment. Facilities that offer professional assessment and guidance.

I1.1: Guidance and Assessment, Health related.

I1.2: Guidance and Assessment, Educational related.

I1.3: Guidance and Assessment, Social and culture related.

I1.4: Guidance and Assessment, Other (non work) related.

I1.5: Guidance and Assessment, Work related.

I2: Information. Facilities intended exclusively to provide information to users with long term care needs.

I2.1: Information, Interactive. Information facilities where information exchange requires an interaction between the user (person with long term care need) and the professional.

I2.1.1: Information, Interactive, Face to face. Information facilities intended to inform users with long term care needs in a face to face interaction.

I2.1.2: Information, Interactive, Other interactive. Information facilities intended to inform users with long term care needs through information technologies.

I2.2: Information, Non interactive. Information facilities aimed at informing users with long term care needs where there is no interaction with the user and/or where information is not updated on a monthly base.

A. ACCESSIBILITY TO CARE CODING BRANCH (A)

Facilities which main aim (Main Type of Care- MTC) is to provide accessibility aids for users with long term care needs.

A1: Communication. Facilities which main aim is to facilitate the access to information.

A2: Physical Mobility. Facilities which main aim is to facilitate the physical mobility of users with long term care needs.

A3: Personal accompaniment. Facilities which main aim is to facilitate the paid personal accompaniment by non-care professionals of users with long term care needs.

A4: Case coordination. Facilities which main aim is to facilitate the care coordination and the related accessibility to different types of services, professionals and tests by users with long term care needs.

A5: Other accessibility care. Intended to facilitate the access to care which do not include any type of direct care provision.

SELF-HELP AND VOLUNTARY CARE CODING BRANCH (S)

The aim of these facilities is to provide users with long term care needs with support, self-help or contact,

with un-paid staff that offers accessibility, information, day, outpatient and residential care (as described in other branches).

S1: Non-professional staff. Self-help and voluntary facilities where professionals providing assessment, interventions or support to users with long term care needs are below 60% of the total personnel. The 100% of the staff is unpaid.

S1.1: Non-professional staff, Information on Care. Self-help and voluntary facilities where professionals providing information on care to users with long term care needs are below 60% of the total personnel. The 100% of the staff is unpaid.

S1.2: Non-professional staff, Accessibility to Care. As in S1.1 except that these facilities provide accessibility to care.

S1.3: Non-professional staff, Outpatient Care. As in S1.1 except that these facilities (i) involve contact between the staff and users with long term care needs and its associated clinical and social difficulties and (ii) is not provided as a part of delivery of residential or day and structured activity services, as defined above.

S1.4: Non-professional staff, Day Care. As in S1.1 except that these facilities (i) are normally available to several users at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to persons with Long-Term care needs: structured activity, social contact and/or support; (iii) have regular opening hours during which it is normally available; and (iv) expect patients to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on patients coming for appointments with staff and then leaving immediately after their appointments).

S1.5: Non-professional staff, Residential Care. As in S1.1 except that these facilities provide beds overnight for users for a purpose related to the clinical and social management of their long term care needs - users are not intended to sleep there solely because they have no home or are unable to reach home.

S2: Professional staff. Self-help and voluntary facilities designed for users with long term care needs that regularly at least 60% of staff are trained or specifically qualified for providing assessment, intervention and support to users with long term care needs. The 100% of the staff is un-paid.

S2.1: Professional staff, Information on Care. As in S1.1 except that at least 60% of staff is trained or specifically qualified.

S2.2: Professional staff, Accessibility to Care. As in S1.2 except that at least 60% of staff is trained or specifically qualified.

S2.3: Professional staff, Outpatient Care. As in S1.3 except that at least 60% of staff is trained or specifically qualified.

S2.4: Professional staff, Day Care. As in S1.4 except that at least 60% of staff is trained or specifically qualified.

S2.5: Professional staff, Residential Care. As in S1.5 except that at least 60% of staff is trained or specifically qualified.

OUTPATIENT CARE CODING BRANCH

These are facilities which (i) involve contact between staff and users for some purpose related to management of their condition and its associated clinical and social difficulties and (ii) are not provided as a part of delivery of residential or day services, as defined above.

O1: Acute, Home & Mobile, 24-h: Emergency facilities (i) provide assessment and initial treatment in response to a crisis, deterioration in physical or mental state, behaviour or social functioning which is related to the condition; and (ii) can usually provide a same day response during working hours. In Home &

mobile services, contact with patients occurs in a range of settings including patients' homes, as judged most appropriate by professionals and patients. For a service to be classified as 'home & mobile', at least 50% of contacts should take place away from the premises at which the service is based. If mobile care is provided at least for 20% of contacts a secondary mobile code should be added to the MTC Non-mobile code. In other cases of mobile outpatient care an additional qualifier "d" could be provided to describe its mobile activity. For some services, the main site of provision may vary from day to day (e.g. services in rural areas which move from village to village) – this does not mean they should be classified as 'home & mobile' unless staff go and do work at locations away from that day's main site. 24-hours are services which are available 24 hours a day, 7 days per week.

01.1: Acute, Home & Mobile, 24-h, Health related care. As in 0.1 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified health care professionals (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

01.2: Acute, Home & Mobile, 24-h, Other care. As in 01 except that these facilities do not meet the criteria for health related care services.

02: Acute, Home & Mobile, Limited hours: As in 01 except that these services are not always available (opening hours less than 24 hours, 7 days per week).

02.1: Acute, Home & Mobile, Limited hours, Health related care. As in 01.1 except that these services are not always available (opening hours less than 24 hours, 7 days per week).

02.2: Acute, Home & Mobile, Limited hours, Other care. As in 01.2 except that these services are not always available (opening hours less than 24 hours, 7 days per week).

03: Acute, Non-mobile, 24-h: As in 0.1 except that these services do not meet the criteria for 'Home & mobile'.

03.1: Acute, Non-mobile, 24-h, Health related care. As in 01.1 except that these services do not meet the criteria for 'Home & mobile'.

03.2: Acute, Non-mobile, 24-h, Other care. As in 01.2 except that these services do not meet the criteria for 'Home & mobile'.

04: Acute, Non-mobile, Limited-hours: As in 02 except that these services do not meet the criteria for 'Home & mobile'.

04.1: Acute, Non-mobile, Limited-hours, Health related care. As in 02.1 except that these services do not meet the criteria for 'Home & mobile'.

04.2: Acute, Non-mobile, Limited-hours, Other care. As in 02.2 except that these services do not meet the criteria for 'Home & mobile'.

05: Non acute, Home & Mobile, High intensity. These facilities provide service users with continuing care including regular contact with a health professional, which may be long term if required. For a service to be classified as 'home & mobile', at least 50% of contacts should take place away from the premises at which the service is based. If mobile care is provided at least for 20% of contacts a secondary mobile code should be added to the MTC Non-mobile code. For some services, the main site of provision may vary from day to day (e.g. services in rural areas which move from village to village) – this does not mean they should be classified as 'home & mobile' unless staff go and do work at locations away from that day's main site. These are facilities which have the capacity to make face to face contact with users at least three times per week when clinically indicated.

05.1: Non acute, Home & Mobile, High intensity, Health related care. As in 05 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is a qualified health care professional (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine, Psychology).

05.1.1: Non acute, Home & Mobile, High intensity, Health related care, 3/6 days/week. As in 05.1

except that these facilities offer their users a specific clinical care with a frequency lower than 7 days/week 3 hours/day.

05.1.2: Non acute, Home & Mobile, High intensity, Health related care, 7 days/week. As in 05.1 except that these facilities offer their users a specific clinical care with a frequency at least 7 days/week 3 hours/day.

05.1.3: Non acute, Home & Mobile, High intensity, Health related care, 7d/w including overnight. As in 05.1 except that these facilities offer their users a specific clinical care with a frequency of 7 days/week including overnight.

05.2: Non acute, Home & Mobile, High intensity, Other care. As in 05.1 except that these facilities do not meet the criteria for health related care services.

05.2.1: Non acute, Home & Mobile, High intensity, Other care, 3/6 days/week. As in 05.1.1 except that these facilities do not meet the criteria for health related care services.

05.2.2: Non acute, Home & Mobile, High intensity, Other care, 7 days/week. As in 05.1.2 except that these facilities do not meet the criteria for health related care services.

05.2.3: Non acute, Home & Mobile, High intensity, Other care, 7d/w including overnight. As in 05.1.3 except that these facilities do not meet the criteria for health related care services.

06: Non acute, Home & Mobile, Medium intensity. As in 05 except that these services do not have the capacity to supply three times weekly contact to patients, but which can provide contacts at least once a fortnight when indicated.

06.1: Non acute, Home & Mobile, Medium intensity, Health related care. As in 06 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

06.2: Non acute, Home & Mobile, Medium intensity, Other care. As in 06 except that these facilities do not meet the criteria for health related care services.

07: Non acute, Home & Mobile, Low intensity. As in 05 except that these services do not have the capacity to see patients as often as once a fortnight.

07.1: Non acute, Home & Mobile, Low intensity, Health related care. As in 07 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

07.2: Non acute, Home & Mobile, Low intensity, Other care. As in 07 except that these facilities do not meet the criteria for health related care services.

08: Non acute, Non-mobile, High intensity. As in 05 except that these services do not meet the criteria for 'Home & mobile'.

08.1: Non acute, Non-mobile, High intensity, Health related care. As in 08 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

08.2: Non acute, Non-mobile, High intensity, Other care. As in 08 except that these facilities do not meet the criteria for health related care services.

09: Non acute, Non-mobile, Medium intensity. As in 06 except that these services do not meet the criteria for 'Home & mobile'.

09.1: Non acute, Non-mobile, Medium intensity, Health related care. As in 09 except that main goal of

these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

09.2: Non acute, Non-mobile, Medium intensity, Other care. As in 09 except that these facilities do not meet the criteria for health related care services.

010: Non acute, Non-mobile, Low intensity. As in 07 except that these services do not meet the criteria for 'Home & mobile'.

010.1: Non acute, Non-mobile, Low intensity, Health related care. As in 010 except that main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

010.2: Non acute, Non-mobile, Low intensity, Other care. As in 010 except that these facilities do not meet the criteria for health related care services.

DAY CARE CODING BRANCH (D):

These are facilities that (i) are normally available to several users at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long-term care needs: e.g. providing a structured activity, or social contact and/or support; (iii) have regular opening hours during which they are normally available: and (iv) expect service users to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on individuals coming for appointments with staff and then leaving immediately after their appointments). The care delivery is usually planned in advance.

D0.1: Acute, Episodic, High intensity. Facilities that usually provide high intensity acute day care to patients with a deterioration of their health state on a single or a limited number of episodes of care during a defined period of time. The care episode last less than 24 hours and the user is admitted and discharged during the same day. The care episode includes complex and coordinated care activities such as diagnosis and assessment, interventions, and other type of health care which require highly trained professional staff and which is not limited to a single face-to-face contact such as in planned outpatient care.

D0.2: Acute, Episodic, Other intensity. Facilities that usually provide episodic acute care but which do not fulfil high intensity criteria.

D1.1: Acute, Continuous, High intensity. Acute facilities where (i) users are regularly admitted because of a crisis or a deterioration in physical or mental state, behaviour or social functioning related to their health condition; (ii) alleviating this crisis/deterioration is the main purpose of the facility; (iii) Care is provided on a continuous base –non episodic, at least 5 days a week- during a limited period of time. These day facilities are organised to provide an alternative to hospitalisation or to accelerate discharge from inpatient units before the crisis is ended or the user is stable. Admission to the facility is usually available within 72 hours. At least 20% of the users in the last twelve months are admitted within 72 hours.

D1.2: Acute, Continuous, Other intensity. As in D1.1 except that admission to the facility is usually available within less than 4 weeks for user discharged from an acute unit (R2 or R3). At least 80% of the users in the last twelve months are admitted.

D2: Non acute, Work, High intensity. Day care facilities that do not meet criteria for acute care for crisis. Work facilities provide users with the opportunity to work for pay. These are usually sheltered work services or opportunities on the open labour market. High intensity facilities are available for patients to attend for at least the equivalent of four half days per week. Not all the patients need attend as frequently as this for the service to be classified as 'high intensity', but it should at least be possible for them to do so.

D2.1: Non acute, Work, High intensity, Ordinary employment. As in D2 except that these are facilities where users with registered disabilities are paid at least the official minimum wage and the organisation follows standard work regulations in the open market. Where there is no minimum wage, DESDE-LTC suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month.

D2.2: Non acute, Work, High intensity, Other work. As in D2 except that these are facilities where the organisation follows specific work regulations for users with registered disabilities. Employees are paid at least 50% of the usual local minimum wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month. The work may be in a sheltered setting or in a setting where some workers are not users with Long-Term Care needs.

D3: Non acute, Work related care, High intensity. As in D2 except that these are services where users carry out an activity which closely resembles work for which payment would be expected in the open market, but where users are not paid or are paid less than 50% of the usual local expected wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month.

D3.1: Non acute, Work related care, High intensity, Time limited. As in D3 except that these are facilities where users perform a work related activity that has a time limit.

D3.2: Non acute, Work related care, High intensity, Time indefinite. As in D3 except that these are facilities where users carry out a work related activity that does not have a fixed time limit.

D4: Non acute, Non-work structured care, High intensity. As in D2 except that these services provide structured activities different from work and work-related care. Such activities may include skills training, creative activities such as art or music and group work. These activities should be available during at least 25% of the service's opening hours.

D4.1: Non acute, Non-work structured care, High intensity, Health related care. As in D.4 except that these facilities meet the criteria for programmed availability day care whose main function is to provide clinical long term care (physical, psychological and/or social). At least 20% of the staff is qualified health professionals.

D4.2: Non acute, Non-work structured care, High intensity, Education related care. As in D.4 except that these facilities offer training registered and approved as part of the official national or regional education and training system, with an official curriculum.

D4.3: Non acute, Non-work structured care, High intensity, Social and cultural related care. As in D.4 except that these facilities offer structured activities related to social and culture participation.

D4.4: Non acute, Non-work structured care, High intensity, Other non-work structured care. As in D.4 except that these facilities do not meet criteria for "health promotion, education or social and culture participation activities" which offer some kind of structured activity.

D5: Non acute, Non-structured care, High intensity. As in D.2 except that, although these services fulfil the criteria for non-acute day services, but where work or other structured activities are not available, or available only during less than 25% of opening hours, so that the main functions of the service are the provision of social contact, practical help and/or support.

D6: Non acute, Work, Low intensity. As in D2 except that in these facilities patients usually attend for less than the equivalent of four half days per week.

D6.1: Non acute, Work, Low intensity, Ordinary employment. As in D2.1 except that in these facilities users usually attend for less than the equivalent of four half days per week.

D6.2: Non acute, Work, Low intensity, Other work. As in D2.2 except that in these facilities users usually attend for less than the equivalent of four half days per week.

D7: Non acute, Work-related care, Low intensity. As in D3 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D7.1: Non acute, Work-related care, Low intensity, Time limited. As in D3.1 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D7.2: Non acute, Work-related care, Low intensity, Time indefinite. As in D3.2 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D8: Non acute, Non-work structured care, Low intensity. As in D4 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D8.1: Non acute, Non-work structured care, Low intensity, Health related care. As in D4.1 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D8.2: Non acute, Non-work structured care, Low intensity, Education related care. As in D4.2 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D8.3: Non acute, Non-work structured care, Low intensity, Social and cultural related care. As in D4.3 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D8.4: Non acute, Non-work structured care, Low intensity, Other structured day care. As in D4.4 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

D9: Non acute, Non-work structured care, Low intensity. As in D5 except that these are facilities where patients usually attend for less than the equivalent of four half days per week.

RESIDENTIAL CARE CODING BRANCH (R)

Facilities that provide beds overnight for patients for a purpose related to the clinical and social management of their long term care needs - patients are not intended to sleep there solely because they have no home or are unable to reach home.

R0: Acute, 24 hours physician cover, non-hospital. On acute facilities (i) users are admitted because of a crisis, a deterioration of their physical or mental state, behaviour or social functioning which is related to their health condition,; (ii) admissions usually available within 24 hours; (iii) users usually retain their own accommodation during the admission. "24 hours physician cover" are facilities where there is 24 hour cover by a registered physician (including medical residents). Non-hospital facilities attend users outside the location of a registered hospital.

R1: Acute, 24 hours physician cover, hospital, high intensity. As in R0 except that services are located in a registered hospital. Hospitals are meso-organisations with a legal recognition in most countries. Exceptions are units that have fewer than 20 beds and/or no 24 hour physician resident cover (these should be classified as non-hospital facilities even if they have the legal status of hospitals). In those countries where there is no legal basis for deciding what are hospital services and what are not and where doubt exists, services should be classified as hospital services if they have 24 hour resident physician cover. A stakeholder group and/or local or regional health officers should be consulted where there is doubt about which services should be viewed as hospital services or not. In these facilities, users are admitted due to a deterioration of their physical or mental status severe enough to require continuous surveillance during 24-hours a day, and/or to require special isolation measures.

R2: Acute, 24 hours physician cover, hospital, medium intensity. As in R1 except that provide regular care (medium intensity) of surveillance and/or security for in-patient admission.

R3: Acute, non-24 hours physician cover. Acute residential facilities that do not meet criteria for 24hours physician cover.

R3.0: Acute, non-24 hours physician cover, hospital. Acute residential facilities that do not meet criteria for 24 hours physician cover and are located in a registered hospital.

R3.1: Acute, non-24 hours physician cover, non hospital. Acute residential facilities that do not meet criteria for 24 hours physician cover and are located outside a registered hospital.

R3.1.1: Acute, non-24 hour physician cover, non hospital, health related care. As in R3.1 except that the main goal of these facilities is the specific clinical care, during the period described by the code, and where some of the staff is qualified on health care (Psychology, Medicine, Physiotherapy, Nursing) or has the equivalent training.

R3.1.2: Acute, non-24 hours physician cover, non hospital, other care. As in R3.1.1 except that these facilities do not meet criteria for health related care.

R4: Non-acute, 24 hours physician cover, hospital, time limited. Residential facilities that do not satisfy the criteria for acute care. These services are covered 24 hours for a physician and are located in a registered hospital. In these facilities a fixed maximum period of residence is routinely specified (temporary stay). A facility should be classified as time-limited if a maximum length of stay is fixed for at least 80% of those entering the facility.

R5: Non-acute, 24 hours physician cover, non hospital, time-limited. As in R4 except that these facilities are usually located outside a registered hospital.

R6: Non-acute, 24 hours physician cover, hospital, indefinite stay. As in R4 except that these facilities do not fulfil the criteria for 'time-limited' services.

R7: Non-acute, 24 hours physician cover, non hospital, Indefinite stay. As in R5 except that these facilities do not fulfil the criteria for 'time-limited' services.

R8: Non-acute, non-24 hours physician cover, time-limited, 24-h support. Non acute services that do not meet criteria for 24 hours physician cover. These facilities provide residential care during non working hours but there is a procedure that guarantees that the patient receives 24 hours care. A fixed maximum period of residence is routinely specified (temporary stay). A facility should be classified as time-limited if a maximum length of stay is fixed for at least 80% of those entering the facility.

R8.1: Non-acute, Non-24 hours physician cover, time-limited, 24-h support, less than 4 weeks. As in R.8 except that these services specify a maximum period of residence of less than 4 weeks.

R8.2: Non-acute, Non-24 hours physician cover, time-limited, 24-h support, over 4 weeks. As in R.8 except that these facilities the maximum period of residence is over 4 weeks.

R9: Non-acute, Non-24 hours physician cover, time-limited, daily support. As in R5 except that in these facilities members of staff are regularly on site at least five days a week for some part of the day, with responsibilities related to the monitoring and clinical and social care of the user.

R9.1: Non-acute, Non-24 hours physician cover, time-limited, daily support, less than 4 weeks. As in R9 except that these facilities specify a maximum period of residence of less than 4 weeks.

R9.2: Non-acute, Non-24 hours physician cover, time-limited, daily support, over 4 weeks. As in R9 except that in these facilities the maximum period of residence is over 4 weeks.

R10: Non-acute, Non-24 hours physician cover, time-limited, lower support. As in R8 except that these are facilities where there is a direct link between residing in the facility and some support from staff, but where staff are regularly present fewer than five days per week.

R10.1: Non-acute, Non-24 hours physician cover, time-limited, lower support, less than 4 weeks. As in R10 except that these facilities specify a maximum period of residence of less than 4 weeks.

R10.2: Non-acute, Non-24 hours physician cover, time-limited, lower support, over 4 weeks. As in R10 except that in these facilities the maximum period of residence is over 4 weeks.

R11: Non-acute, Non-24 hours physician cover, indefinite stay, 24-h support. As in R8 except that these facilities do not fulfil the criteria for 'time-limited' services.

R12: Non-acute, Non-24 hour physician cover, indefinite stay, daily support. As in R9 except that these facilities do not fulfil the criteria for 'time-limited' services.

R13: Non-acute, Non-24 hours physician cover, indefinite stay, lower support. As in R10 except that these facilities do not fulfil the criteria for 'time-limited' services.

R14: Other non-acute. Residential services not classified otherwise.

4. GLOSSARY OF TERMS

Acute: Facilities where (i) users are regularly admitted because of a crisis: deterioration in physical or mental state, behaviour or social functioning which is related to his or her condition; (ii) alleviating this deterioration is a purpose of the programme; (iii) admission to the programme is usually available within 72 hours.

Additional qualifiers: optional codes which provide additional information on the service characteristics.

Basic Stable Inputs of Care (BSIC): a minimal set of inputs organised for care delivery.

Branch: A level in the coding tree of the DESDE-LTC system. It includes a primary level with 5 Main or Large Branches, each of them divided in sub-branches based on main care descriptors at secondary and at tertiary level.

Case management: Services which main aim is defined as coordination of care but which include several forms of clinical care as part of the coordination of care process. These services may include intensive case management, assertive outreach, assertive community treatment, disease management, or even personalised care.

Case-Mix: Case mix is by definition a system that classifies people into groups that are homogeneous in their use of resources. The application of case mix is broad; it provides the basis, not only for reimbursement, but also for comparing facilities or programs, practice patterns, as an adjunct to quality of care and efficiency measurement, a staff planning tool, etc.

Catchment area: In the DESDE system it refers, mainly, to smallest catchment areas within every field. Social areas may be broader than health areas, and areas for specialised care (Mental Health) may be smaller than areas for LTC but larger than Primary Care areas. Areas between 50 and 250.000 inhabitants were outlined in the original instrument intended for use in mental health. Comparison areas in DESDE-LTC may be extended to 50-500.000 inhabitants depending on the location used in the country or region of reference and the territorial divisions of the geographical region being evaluated.

Clinical units: (or care units). Units of analysis that fulfil some of the criteria but do not fulfil overall criteria for being coded as a service (i.e a unit of eating disorders within an acute psychiatric ward in a General Hospital).

Closed care: Secluded services with high level of security which is provided under locked doors. Usually these units are for crime & justice patients or persons with mental illness with high risk for themselves or others.

Continuing care services: These services provide patients with regular contact with a mental health professional, which may be long term if required.

Counting Trees: These provide a standardized method of measuring levels of main types of care use by the population of a catchment area.

Crisis: deterioration in physical or mental state, behaviour or social functioning which is related to his or her condition.

Day care main branch: These are facilities that (i) are normally available to several users at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long term care, structured activity, social contact and/or support; (iii) have regular opening hours during which they are normally available; and (iv) expect users to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on patients coming for appointments with staff and then leaving immediately after their appointments).

Domiciliary care: Services provided at the users home and nowhere else.

eCare: It includes all medical healthcare services, social services and technologies relying on modern information and communication technologies (ICTs) (e.g. telecare/telemedicine, teleconsultation, teleradiology, telemonitoring).

eHealth: eCare in the health sector.

Emergency facilities: Acute facilities that (i) provide assessment and initial treatment in response to a crisis, deterioration in physical or mental state, behaviour or social functioning which is related to the condition; and (ii) can usually provide a same day response during working hours.

Facility: Physical location of the care provision (setting).

Function (of care): (Health care functions - ICHA). The health care functions of ICHA-HC refer to the health purpose of activities and determine the boundaries of health care consumption in the strict sense. The transactions related to the consumption of health care goods and services on the one hand and the transactions related to capital formation, education and training, as well as research and development for future health care provision on the other hand serve different purposes.

Generic services: Services designed for the general population or large groups, (i.e. elderly people, immigrant population etc.) which are important for many users with long term care needs although they have not been specifically planned for this population.

Health (in service research): As a generic term it refers to a care sector which includes all the care organisations providing assistance and information for the promotion, prevention and treatment of health-related conditions. The limits of health care sector with other sectors (justice, social, education) are imprecise. In the DESDE-LTC it refers to all organisations funded and managed throughout the official health system in any single country, region or area.

Health related care: Facilities which main goal is the specific clinical care, during the period described by the code, and where a part of the staff is qualified on health care (Psychology, Medicine, Physiotherapy, Nursing) or has the equivalent training.

24 Hour physician cover: Facilities within hospitals or within other residential meso-organisations where there is 24 hour cover by a registered physician (including medical residents).

Health Maintenance Organisation (HMO): A type of managed care organization that provides a form of health care coverage that is fulfilled through hospitals, doctors, and other providers with which the HMO has a contract.

Hospital: Hospitals are meso-organisations with a legal recognition in most countries. This legal recognition can be used as the basis for identifying hospital services (registered hospitals). Exceptions are units that have fewer than 20 beds and/or no 24 hour physician resident cover (these should be classified as non-hospital facilities even if they have the legal status of hospitals). In those countries where there is no legal basis for deciding what are hospital services and what are not and where doubt exists, services should be classified as hospital services if they have 24 hour resident physician cover. A stakeholder group and/or local or regional health officers should be consulted where there is doubt about which services should be viewed as hospital services or not.

Institutional Care: Residential services characterised by indefinite stay for a defined population group, which usually have over 100 beds and which is described as "Institutional care".

Integrative care: A generic term which describes a model of care which incorporates all the relevant sectors involved in care for persons with a health condition and not only the health sector (ie social, crime and justice, education). It is related to Holistic care model. In the DESDE-system it refers mainly to the social and health care model.

Intensity: This is secondary descriptor of MTC in Day care and Outpatient care in the DESDE system. It refers to the actual 'capacity' of a service to provide a main type of care as shown by the pattern of maximum use by its clients in routine practice. It excludes theoretical capacity or the any exceptional use of the facility.

Intensity (High for Continuing Care): These are facilities that have the capacity to make face to face contact with users at least three times per week when clinically indicated.

Intensity (Medium for Continuing Care): These facilities do not have the capacity to supply three times weekly contact to users, but which can provide contacts at least once a fortnight when indicated.

Intensity (Low for Continuing Care): These services do not have the capacity to see users as often as once a fortnight.

Intensity (High for Day Care): High intensity day facilities are available for users to attend for at least the equivalent of four half days per week. Not all the users need attend as frequently as this for the service to be classified as 'high intensity', but it should at least be possible for them to do so.

Intensity (Low for Day Care): Day facilities where users usually attend for less than the equivalent of four half days per week.

Intervention Programmes: A set of activities programmed within a limited period of time (normally less than 1 year, and no longer than 3 years) without a stable structure in time. In some occasions services develop from programmes which are reedited through the years.

Justice care: Services which main aim is to provide crime & justice patients (security or prison hospitals, surveillance wards for patients under crime & justice custody, physical disability and psychiatric units in prisons and regional security units).

Liaison care: services where specific consultation on a subgroup of patients is provided to other area (e.g. outpatient consultation on Intellectual Disabilities to a general medical service or consultation on mental disorders to the general medical services of a hospital).

Levels of care: Classification services system according to a number of descriptors: Status of user, Type general of care, Intensity of care, Subtype of care and Additional Qualifiers.

Long-Term Care (LTC): Long-Term Care (LTC) is a blanket term that "brings together a range of services for persons who are dependent on help with basic activities of daily living (ADLs) over an extended period of time" (OECD, 2005). This range includes 'medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short- or long-term and may be provided in a person's home, in the community, or in residential facilities' (US Dept of Health). At present Member States use a variety of definitions of LTC that do not always concur (EC, 2008).

Macro-organisation (within the care system): This refers to the care system of a country or a region. It may also refers to a Large Maintenance Health Organisation which provides care in several setting across a country).

Main Types of Care (MTC): Unit of analysis in service research which describes the main characteristic of the care provided in every single service or 'micro-organisation' within a catchment area (meso-organization). MTCs are the building blocks of the classification provided by the DESDE-LTC system. This system describes 89 MTCs using a tree approach with branches and sub-branches according to a series of descriptors based on activity, location, time-frame, intensity, and type of staff required. Main branches include information on care, accessibility to care, self-help and voluntary care, outpatient care, day care and residential care. Services are arranged or organised either as a single MTC or in cluster combination of MTCs. These clusters emulate "bar codes", identifying service characteristics according to MTCs. Thus, the same service might

include one main type of care coded in Branch D as a Day service and other classified as residential in Branch R. MTC availability and use can be compared across areas regardless of how services are named. MTC cluster patterns could be also compared across areas. The same term (i.e. 'Information') may be coded as the MTC in a service, while it may be code simple activity in another service.

Matrix of Care: A framework developed for assessing long term care care which divide care components and indicators in 9 boxes related to two 2 domains: Process (input, process and output) and Level (macro, meso and microlevel) (Tansella & Thornicroft, 1998).

Maximum frequency of attendance/contact (maximum performance): Maximum number of times that a service user can be assisted by the service if they require need in ordinary care conditions.

Meso-level: Care provider or care organization in small areas (municipality, small health district, community mental health centre which provides care in a sector).

Meso-organisation (within the care system): A care organisation which includes several services within the same location (i.e. a general hospital).

Micro-organisation (within the care system): The minimum administrative unit which can be identified a small care area. See 'service'.

Mobile. (Home-Mobile): In home & mobile facilities contact with users occurs in a range of settings including users' homes, as judged most appropriate by professionals and users. For a service to be classified as 'home & mobile', at least 50% of contacts should take place away from the premises at which the service is based. If mobile care is provided at least for 20% of contacts a secondary mobile code should be added to the MTC Non-mobile code. In other cases of mobile outpatient care an additional qualifier "d" could be provided to describe its mobile activity. For some services, the main site of provision may vary from day to day (e.g. services in rural areas which move from village to village) – this does not mean they should be classified as 'home & mobile' unless staff go and do work at locations away from that day's main site.

Modality of Care is a main type of intervention (or activity) that can possibly be applied to achieve one of the restricted number of tasks that together comprise the whole range of Long-Term Care. (De Jong, 2000).

Outpatient Care Main Branch: these are facilities that (i) involve contact between staff and users for some purpose related to management of their condition and its associated clinical and social difficulties and (ii) are not provided as a part of delivery of residential or day and structured activity services, as defined above.

Packages of Care: A cluster or set of integrated care interventions designed for the same group of users.

Pathway (of care): The itinerary followed by a single user or a group of users within the care system. It could be assessed from the individual perspective of the user, or it could describe the standard trajectory of care of a group of users (case-mix).

Policy Programme: The policy implementation of a care plan at different care levels (macro, meso or micro).

Primary health care: Is essential, ambulatory and community health care, outside hospital and specialised care setting. It is the first point of contact a person encounters with the health care system. It includes mainly general medical care, paediatrics and some integrated care strategies for users with chronic health conditions. The Alma Ata Conference defined 'Primary Health Care' as essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally, accessible to individuals and families in the community by means of acceptable to them, through their full participation and at a cost that community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part of both the country's health system, of which it is the central function and the main focus and of the overall social and economic development of the community (Alma-Ata Declaration, 1978).

Process (of care): The intended sequence of procedures for the treatment of a patient.

Products (Health): Durable and non-durable medical goods intended for use in the diagnosis, cure, mitigation, or treatment of disease.

Programme: In service research this term has two main different meanings: i) policy programme; ii) intervention programme (see programme).

Reference main type care in an area: The main and/or official referral service for an MTC provided at the catchment area.

Rehabilitation: In general this term is loosely related to Long-Term Care. This term is culturally and philosophically laden and it may be used in different contexts with different meanings. This is an example of terms the DESDE coding system excludes in its atheoretical approach.

Residential care: facilities that provide beds overnight for users for a purpose related to the clinical and social management of their conditions / illnesses- users are not intended to sleep solely because they have no home or are unable to reach home.

Secondary care (Health): Care provided by health professional specialists (physicians, psychologists, nurses) outside primary care and hospital premises. In many countries these specialists generally do not have first contact with patients. Secondary care is usually delivered in outpatient clinics. In the public sector patients are usually referred to secondary care by their primary care provider (usually their GP). Secondary care does not generally include in the current definition outpatient care provided in hospital settings.

Semantic interoperability is the ability of two or more computer systems to exchange information and have the meaning of that information automatically interpreted by the receiving system accurately enough to produce useful results, as defined by the end users of both systems.

Service: A 'service' is a micro-level functional system of care organisation, defined as the smallest unit with own administrative structure available within the catchment area (micro-organization). The range of services to be considered includes those facilities that have as specific aim any aspect of the management of long term care and of the clinical and social difficulties related to it.

Service Inventory (Catalogue, service listing): It allows a detailed description of individual services for LTC, obtaining the main characteristics of every service (service listing, service directory or service catalogue).

Setting: Physical location of the care provision (facility).

Small Care Area: A catchment area or territorial sector with a common set of services for its population. It provides the meso-level of comparison in service research.

Social Care: Care provision for a particular health condition non directly related to health, crime & justice or education.

Specialised care: Services for a specific subgroup within the target population attended at the catchment area (e.g. services for Elderly persons with Alzheimer's disease within the "E" group, or services for Eating Disorders within the "MD" group).

Status of user: Level related to the clinical status of the users who are attended in the care setting (i.e. whether there is a crisis situation or not).

Support (daily): Members of staff regularly on site at least five days a week for some part of the day, with responsibilities related to the monitoring and clinical and social care of the patient.

Support (lower): Facilities where the patient resides for some purpose related to the management of his/her condition and where there is a direct link between residing in the facility and some support from staff, but where staff is regularly present fewer than five days per week.

Support (24 h): Staff is present within the facility 24 hours a day, with responsibilities relating to the monitoring and clinical and social care of the patient (i.e. domestic or security staff is not included).

Target population: The defined population for which services are designed, or the population for which services are provided. In the case of DESDE-LTC the target population are adult and elderly frail population (18+) with i) Severe Physical disabilities (registered in official national, regional or local registers for this population group, or an equivalent system where registers are not available); ii) Intellectual disabilities (ICD-10); iii) Mental Disorders (ICD-10), iv) Elderly with severe disability (registered in official national, regional or local registers for this population group, or an equivalent system where registers are not available).

Tertiary care (health): Care provided in hospital premises (both inpatient and outpatient). In some special cases tertiary care may also refer to health care centers that includes highly trained specialists and advanced technology for a specific patient group.

Units of analysis (in Service Research): The standard unit of data analysis defined in the design of a service research study. Many different units of analysis may be identified in service research whilst population studies use a single unit of analysis (patients, persons). In order to make like-with-like comparisons, these comparisons must be made across a single 'unit of analysis' group. In the evaluation of Services there are different units of analysis such as territories (Countries, Regions, Districts, Small Health Areas); Macro-organisations (i.e. a Large Health Maintenance Organisation), Meso-organisations (i.e. a Hospital), Micro-organisations (i.e. a service or "Basic Care Input System") or smaller units within a service: Main Types of Care, Care Modalities, Care or clinical Units, Care packages, Activities, Micro-Activities or Philosophy of care.

User profile: The main target groups for whom a service is intended and/or delivered.

Work (services): The users are paid at least the official minimum wage and the organisation follows standard work regulations in the open market. Users may have not obtained this work through fully open competition - their jobs may in some way specifically reserved for users with Long term care needs depending on national/regional or local regulations.

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6. ANNEXES

6.2. eDESDE-LTC: INSTRUMENT

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Project Ref. 2007/116

DESDE-LTC is an adaptation of the 'European Service Mapping Schedule' (ESMS-I) (Johnson et al, 2000) (it also incorporates modifications included in ESMS-II), and the 'Description and Evaluation of Services for Disabilities in Europe' (DESDE) (Salvador-Carulla et al, 2006) and related instruments (DESDAE and DESDE). These instruments have been developed by the EPCAT Group (European Psychiatric Care Assessment Team) coordinated by Centro Studi e Ricerche in Psichiatria,_i (Torino, Italy) and the PSICOST Association in Spain.

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INTRODUCTION

a. GENERAL PRINCIPLES

What is LONG TERM CARE (LTC)?

Long-Term Care (LTC) is a blanket term that "brings together a range of services for persons who are dependent on help with basic activities of daily living (ADLs) over an extended period of time" (OECD, 2005). This range includes 'medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short or long-term and may be provided in a person's home, in the community, or in residential facilities' (US Dept of Health). At present Member States of the European Union use a variety of definitions of LTC that do not always concur (EC, 2008).

What is DESDE-LTC?

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.

It follows the approach to service evaluation developed by the EPCAT Group (European Psychiatric Care Assessment Team) and PSICOST Scientific Association since 1997, starting with the development of ESMS (European Service Mapping Schedule) for the evaluation of services in mental health (Johnson et al, 2000), and related adaptations to the evaluation of services for older people in Spain (DESDAE) (Salvador-Carulla et al, 2005) and services for disabilities (Salvador-Carulla et al, 2006). This is called here the "ESMS/DESDE" model/approach to service research

This instrument is intended to compile service information on input and process at the meso-level (health/social catchment areas) and micro-level (individual services) as defined at a modified version of the Thornicroft & Tansella Matrix that was developed for the assessment of mental health care services (Tansella & Thornicroft, 1998).

DESDE-LTC allows the following tasks to be carried out in an standardised way:

- Compiling a standard directory of long term care services in a particular catchment area. This includes the provision of social services and health services by the public and voluntary sectors. Private sector is optional as it depends on the purpose of the analysis.
- Recording changes through time in services available within a specific catchment area.
- Delineating and comparing the structure and choice of LTC services in different catchment areas.
- Measuring and comparing the levels of provision/availability and utilisation of the Main Types Care (MTC) between different catchment areas using an international coding system.

What is the target population of DESDE-LTC?

The ESMS/DESDE model classifies services according to the specific target population served by the service system which is assessed. This specific version of DESDE-LTC is focused on services for the following groups: Adult (18+) and frail older people (65+) with i) severe physical disabilities (registered in official national,

regional or local registers for this population group, or an equivalent system where registers are not available); ii) intellectual disabilities (ID); iii) mental disorders (ICD-10), iv) elderly/older people with severe disability (registered in official national, regional or local registers for this population group, or an equivalent system where registers are not available). A full description of these LTC groups is provided at Section “B”.

What is the structure of DESDE-LTC?

DESDE-LTC uses a ‘Tree System’ to describe the availability and utilisation of services (Long Term Care Mapping Tree). Its overall structure is illustrated on page 11. It has four major sections:

- A. Introductory Questions:** These relate to the catchment area and target population that complete the questionnaire.
- B. Care Type Mapping (Main Type of Care - MTC Coding):** These provide a standardised method for classifying and coding basic care/service categories for the population of a particular catchment area, based on the main activities provided by every service.

The description of MTC it is complemented by a glossary of terms with specific examples of the codes established by the instrument .
- C. Care Use Mapping (MTC Counting):** This provides a standardised method of measuring levels of the main types of care use by the population of a catchment area
- D. Service Inventory:** This provides a detailed description of individual services for LTC, obtaining two types of lists: a categorised services list according to the codes established in section B and secondly a list with the characteristics of every service following a traditional approach (service listing, directory or catalogue).

DESDE-LTC has been designed to allow **national and international comparisons**. Therefore, the most important types of care within each catchment area must be assigned to one of a number of specific **codes** designed by capital letters: “I”: Information, “A”: Accessibility, “S”: Self-help, “D”: Day Care, “O”: Out-Patient care and “R”: Residential care. DESDE-LTC is intended to provide a description of the social care and health services within a catchment area. The instrument allows for the separate analysis of social and health care services in any geographical area if requested and agreed within all the study areas.

This schedule can be used in two ways: i) a simple description cataloguing services and the main types of care available in the target area (a maximum of two digits in coding used); ii) a complex or quantitative assessment to compare types of care and services across several catchment areas or in the same target area over a defined period of time. Basic training on the use of DESDE-LTC is required before the instrument can be used.

b. GENERAL GUIDELINES

Services to be included: The ‘default group of services’ to which the mapping tree can be applied is the group of social/health care services used in the provision of long term care in a given catchment area.

Services could be included in the analysis when, as a general rule, at least 20% of service users are people with long term care needs. Facilities provided by health services, social services, voluntary sector and private sector providers should all be included unless otherwise specified in the study.

It is important to note that there are different units of analysis used in this research and that like-with-like comparisons must be made across a single ‘unit of analysis’ group. Different units of analysis include Macro-organisations (e.g. a Large Maintenance Health Organisation), Meso-organisations (e.g. a Hospital), Micro-

organisations (e.g. a service) or smaller units within a service: Main Types of Care, Care Modalities, Care Units, Care Intervention programmes, Care packages, Interventions, Activities, Micro-Activities or Philosophy of care.

DESDE-LTC is focused on the evaluation of **Services (Section D)** and **Main Types of Care (Sections B and C)**. Every single service is described using one or more codes based on the main care structure/activity offered (Main Type of Care), e.g. the same service might include a day main type of care (coded in Branch D) and a residential MTC (coded in branch R).

Services located within the catchment area, as well as services located out of the catchment area but that are used by at least five inhabitants per annum, per 100,000 inhabitants (for residential and day facilities) will be included. Services located within the catchment area that do not provide services to local residents must be included and classified using the "0" code in section C (Utilisation).

Specific long term care services in a catchment area that do not meet the inclusion criteria of DESDE-LTC could be listed in an appendix.

Operational definition of services or Basic Stable Inputs of Care (BSIC)

A "service" or a Basic Stable Inputs of Care (BSIC), is here defined as a minimal set of inputs organised for care delivery. It is usually composed of an administrative unit with an organised set of structures and professionals that provide care within a catchment area. BSICs are the minimal micro-level functional systems of care organisation. Within the production model (input-process-output), BSIC refers only to functions of care and not to other inputs (products and devices) or to procedures (interventions). The functions provided by the service "micro-organisation" can be described by smaller unit of analysis called 'Main Types of Care' described below.

INCLUSION CRITERIA (BSIC)

In order to code a care setting as a BSIC the subsequent criteria should be followed:

Criterion "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:

Criterion "B": The service has its own administrative unit and/or secretary's office and fulfils two additional descriptors (see below) IF NOT:

Criterion "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

However, 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.

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.

Specific long term care services in a catchment area that do not meet the inclusion criteria of DESDE-LTC could be listed in an appendix.

Operational definition of Main Types of Care (MTC)

The typology of care provided by the service “micro-organisation” or “Basic Stable Inputs of Care” (BSIC) is here described by smaller unit of analysis called “Main Type of Care” (MTC).

MTC is the main DESCRIPTOR of the ‘generic care function’ provided by the service. These generic care functions describe a basic activity carried out in the BSIC (e.g. the user sleeps in the setting), which has been selected for allowing service comparisons across different territories in an iterative process by a series of European expert groups within the consecutive ESMS/DESDE projects .

This descriptor is usually but not always included in the definition and the aims of the service. Here the coding is based on the actual activity and performance of the service, and not on its theoretical purpose or its name. These descriptors do not overlap. They cannot be double counted.

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.

In order to code the MTC for a single BSIC the subsequent criteria should be followed:

INCLUSION CRITERIA (MTC)

- C. **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.
- D. **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, 03.

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, 03), 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 08, 06.

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.

Service activities may be used to define other units of analysis in service research mainly to describe care provided within a single service or across different services:

- **Modality of Care** is a main type of intervention (or activity) that can possibly be applied to achieve one of the restricted number of tasks that together comprise the whole range of care provided by a service (De Jong, 2000). It describes 10 types of activities that identify different patterns of care delivery within a similar set of services.
- **Packages of Care.** A cluster or set of integrated care interventions designed for the same group of users. Packages of care may be delivered by a single service or by a group of integrated services
- **Intervention Programmes:** a set of activities programmed within a limited period of time (normally less than 1 year, and no longer than 3 years) without a stable structure in time. In some occasions services develop from programmes which are reedited through the years.
- **Other components of the production of care:** care products, ‘goods’, 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.

TARGET POPULATION

The ‘default population’ to which the DESDE-LTC is intended to be applied is the population of the catchment area with long term care needs. In the current version of DESDE-LTC it includes older people with mental or physical disabilities, younger adults with mental disorders, intellectual disability or severe physical disability (page 4).

Of course not all these groups may be included depending on the focus of the study. This will be described in Section A.

Taking into account the possibility of different target groups to which the instrument may be applied. Here the “target group” is equivalent to “people with long term care needs”.

SELECTING PARTS OF THE DESDE

Completion of the whole instrument would provide a comprehensive mapping of the structure and level of service provision in a catchment area. However, it will not always be possible or necessary to use the full instrument schedule, and respondents may use those sections of the Tree and parts of DESDE-LTC which best meet their needs.

For example, the instrument can be used to map residential care used alone if this is the only aspect of the service provision which is of interest, or complete Section B (availability) without Section C (utilisation) if detailed information is unavailable. For the purpose of comparative studies it is important that the same portions of the Schedule be used in each catchment area.

DEFINING CATCHMENT AREAS

DESDE-LTC has been designed for comparison across geographical areas. Boundaries of health, social care and local administrative areas should be taken into account. A preliminary exercise to map catchment areas may be needed when this information is not readily available. DESDE refers, mainly, to smallest catchment areas within every field at a “H4” level (see territorialisation levels definition below). Small social areas may be broader than small health areas, and areas for specialised care (i.e. Mental Health) may be smaller than areas for LTC but larger than Primary Care areas. Areas between 50,000 and 250,000 inhabitants were outlined in the original instrument used for mental health services (ESMS). Comparison areas in DESDE-LTC may be extended to 50,000-500,000 inhabitants depending on the location used in the country or region of reference and the territorial divisions of the geographical region being evaluated.

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: Pan-national level.

For example, European Union or WHO health regions.

H1: National level.

For example, the national health system in Spain.

H2: Regional level.

For example, Lander in Austria or Germany, County in Sweden, Autonomous Community in Spain, Department in France etc.

H3: Maximum administrative territorial specific health care area.

For example, broad mental health area covered by a general hospital for acute care.

H4: Basic administrative territorial area of specialized mental health.

For example, catchment area covered by a community mental health centre.

H5: Minimum local health administrative areas.

For example, municipalities, local health authority areas, area covered by a primary care centre.

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:

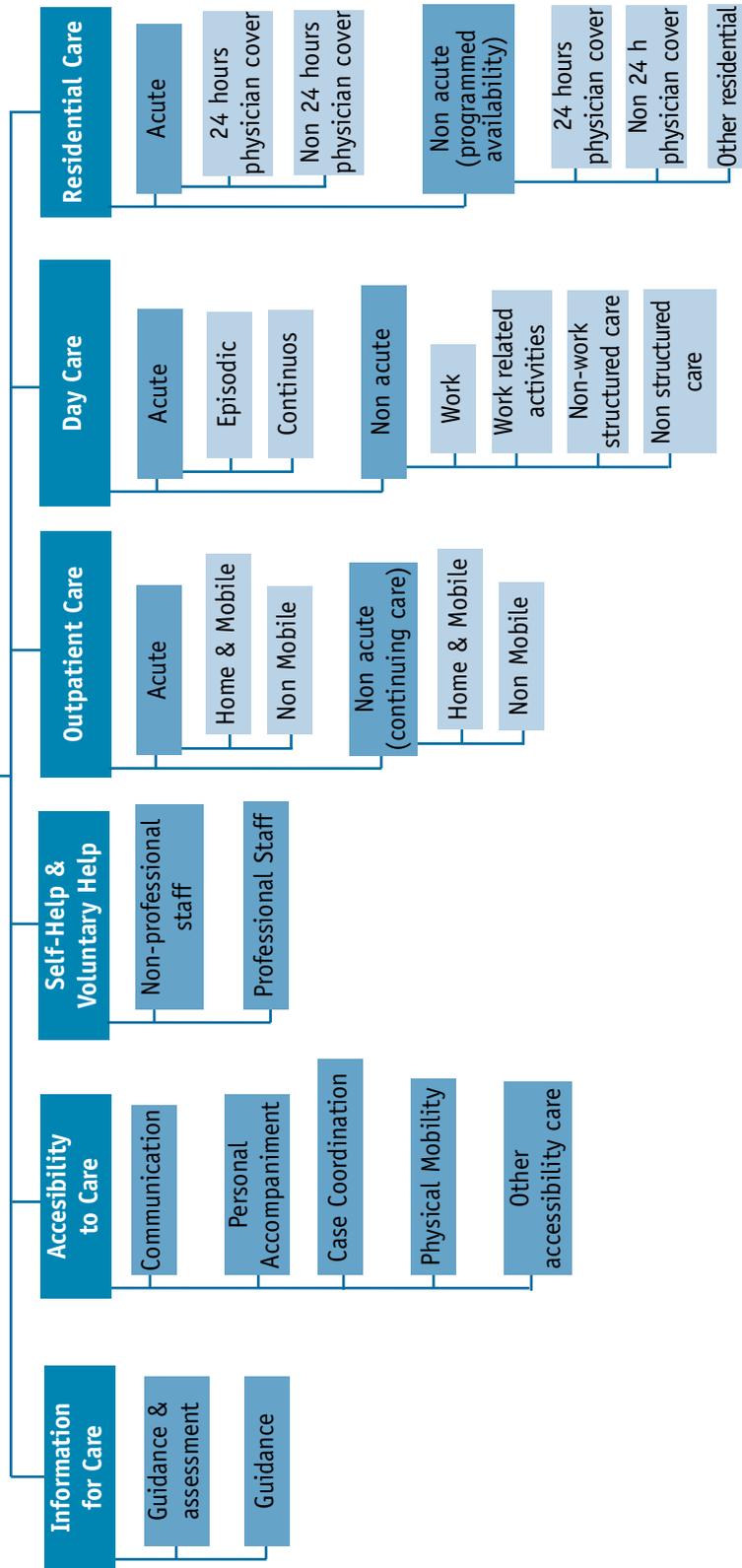
1. Direct data collected in a prospective way:

- 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.

All areas must have the same reference periods and record it in Section A.

LONG TERM CARE MAPPING TREE



SECTION A

CATCHMENT AREA MAPPING

INTRODUCTORY QUESTIONS

(TECHNICAL DATA OF THE STUDY)

1. Who has completed the schedule?

Name:

Profession:

e-mail:

Completion date:

2. What is the reference date/time interval for completing the schedule?:

Reference month (i.e. from November 1st to Nov. 30th) or prospective census

From .././.... To .././....

Prospective census in one day: in .././....

Prospective census in one week: .././.... to .././....

Prospective census in one month: .././.... to .././....

3. What sources of information have been used to complete the schedule?

4. Name and location of the catchment area

5. In which city, town or region (indicate as appropriate) and in which country is the catchment area?

6. What is the total size of its population?

7. How is the catchment area defined? (i.e. local government boundaries, health service sector, etc.) Please explain whether the area follows census boundaries or not.

8. The default population to which the DESDE-LTC should normally be applied is the catchment area population of users with long term care needs over 18 years defined in page 4 (persons with severe physical disability, intellectual disability, severe mental disorders and elderly/older people with disabilities).

Age interval of the target group for inclusion in service counts (years)	From	To
Adults with Severe Physical disability (registered)	<input type="checkbox"/>	<input type="checkbox"/>
Adults with Intellectual disability	<input type="checkbox"/>	<input type="checkbox"/>
Adults with Mental disorder (ICD-10)	<input type="checkbox"/>	<input type="checkbox"/>
Elderly/older people with physical or intellectual disabilities (registered) or older people with mental disorders	<input type="checkbox"/>	<input type="checkbox"/>
Other diagnostic category (specify using the ICD-10 code whenever possible)	<input type="checkbox"/>	<input type="checkbox"/>

SECTION B

CARE TYPE MAPPING (MTC CODING)

a. PRINCIPLES FOR CODING LONG TERM CARE

- The aim of Section B is to produce a comprehensive categorisation of the facilities providing services for a defined target group in the local population, classified according to function, availability and setting.
- DESDE-LTC provides a list of services (BSICs) identified in each catchment area and the code assigned to them. This gives a quick vision of the availability of services and type of services. You can find this in the 'Templates' of DESDE-LTC Toolkit.
- DESDE-LTC has a glossary giving definitions of all terms used in the long term care mapping trees in the Guidelines for Coding LTC. Examples of services within each category and guidelines on categories that should be mutually exclusive are also given.
- There are six mapping branches for 1) information care 2) accessibility to care; 3) self-help and volunteer care; 4) outpatient care 5) day care, and 6) residential care. However, self-help and informal care are not included in the Service Counting Trees as it is assumed that activity volumes are not often documented precisely.
- The location in the tree of each BSIC is identified by a combination of a letter and a number: (i) a capital "I", "A", "S", "O", "D" or "R" indicates whether the service is part of the information, accessibility, self help, out-patient, day and/or residential trees; (ii) within these trees, each final branch is given a number.

OPTIONAL CODES

The DESDE-LTC coding can be complemented by optional codes which provide additional information on the service characteristics.

CODES FOR THE TARGET POPULATION

These codes describe the main target group assisted in the service using capital letters before the core DESDE-LTC code:

AGE GROUPS

- **C** – Child & Adolescents (e.g. Day non-acute structured care for children C-D4)
- **A** - Adult
- **E** – Elderly/Older people

DIAGNOSTIC GROUPS

Two capital letters after age code but before DESDE-LTC code describe the supra-ordinal group of users:

- **SP** for Severe Physical disabilities
- **ID** for Intellectual Disabilities

- **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).

For example: C[ID] – D1.1 for describing Day Acute Services for Child and adolescent with Intellectual Disabilities.

Services intended for ICD sections or for specific diseases can be coded using the corresponding ICD-10 code before the core DESDE-LTC coding.

CODES FOR DESCRIBING ADDITIONAL CHARACTERISTICS

These optional codes have been incorporated to facilitate a quick appraisal of those characteristics of MTC and their related BSIC which may be relevant to local policy or for a specific research. These codes are related to the general description of the service provided at Section "D", and therefore they are not part of the hierarchical tree structure of the DESDE-LTC system. These optional codes are small letters which can be added at the end of the numeral coding to provide an additional description about the location where the service is provided, special characteristics relevant for specific research, or the means by which the service is provided when this is a important descriptor (for example eHealth/telecare). Therefore they do not use cut-off points.

"a" Acute care (complementary)

This code describes acute care which is provided within a non-acute, non-residential setting (branches "O" and "D") but which does not fit criteria for a separate MTC. As an example, this may be relevant to differentiate ambulatory facilities with the capacity to provide acute care as an ordinary activity from those ambulatory centres that do not provide acute care in a specific study of these services.

"c" Closed care

This code describes secluded BSICs with high level of security which is provided under locked doors. Usually these units are for crime & justice users or persons with mental illness with high risk for themselves or others.

"d" Domiciliary care

This code describes BSICs provided at the home of the user and nowhere else. If a service (BSIC) provides mobile home care as part of a broader or more general activity it should not be coded as "d".

"e" eCare

It includes all medical healthcare services, social services and technologies relying on modern information and communication technologies (ICTs) (e.g. telecare/telemedicine, teleconsultation, teleradiology, telemonitoring).

Specialist devices for healthcare professionals (robotics and advanced systems for diagnosis and surgery; simulation and modelling devices; healthcare grids, tools for training) are NOT included in this coding.

When an outpatient BSIC is provided using teleconsultation, the 'e' can be added at the end of the DESDE-LTC code to differentiate this service from face-to face services. (e.g. 081.e)

"h" Care provided in a hospital setting

This additional code describes non-residential care provided in a meso-organisation registered as a "hospital" but which is not related to acute residential care (e.g. an outpatient unit or a day hospital placed in a hospital setting as to differentiate these BSICs from similar units placed in the community)

This code excludes "Long-Term Institutional Care settings which are coded as "I".

“i” Institutional care

This code describes residential BSICs characterised by indefinite stay for a defined population group, which usually have over 100 beds and which is described as “Institutional care”. This code is relevant for better describing residential care in the main target population groups: “C”, “E”, “ID” and “MD”.

This additional code may provide relevant information with regard to the balance of care in specific areas such as mental health, intellectual disabilities or age, where large long-term residential care characterised an “institutional” care model (for example acute, time-limited and indefinite stay: R2.i, R4.i, R6.i).

“j” Justice care

BSICs which main aim is to provide crime & justice users (security or prison hospitals, surveillance wards for patients under crime & justice custody, physical disability and psychiatric units in prisons and regional security units). These units may be coded in an independent tree due to the special characteristics of the target population.

“l” Liaison care

Liaison” BSICs where specific consultation on a subgroup of users is provided to other area (e.g. outpatient consultation on Intellectual Disabilities to a general medical service or consultation on mental disorders to the general medical services of a hospital).

“m” Case management

Case management are BSICs which main aim is defined as coordination of care but which include several forms of clinical care as part of the coordination of care process. These services may include intensive case management, assertive outreach, assertive community treatment, disease management, or even personalised care. A special attention should be paid to whether these facilities fulfil criteria for BSIC or MTCs and are not care units or care programmes within a service.

“r” Reference main type care in an area

This letter describes the main and/or official referral service for an MTC provided at the catchment area. This optional coding is particularly relevant in mental health to differentiate the reference mental health centre from other outpatient units in the same catchment area, or the referral acute hospital service from other acute units which could also be used by the same target group within the catchment area.

“s” Specialised care

BSICs for a specific subgroup within the target population attended at the catchment area (e.g. services for Elderly persons with Alzheimer’s disease within the “E” group, or services for Eating Disorders within the “MD” group).

When needed, other optional codes could be added depending on the specific objectives of the research.

- Some BSICs may well meet the criteria for MTCs in more than one branch of the tree. This will occur especially in areas with highly integrated community services in which, for example, the same team may provide emergency, continuing care and day services - more details are given in the glossary.
- Section B is aimed at describing routine maximum service performance during a defined period of time. It should not be used to provide a description of a service’s theoretical capacity, or high intensity provision which is clearly unusual within the setting and does not represent typical provision in a reference year. DESDE-LTC coding is based on the highest activity within a given period of the service which fits into the range of minimum performance requirements defined in the instrument and agreed for every code (e. g. D1: 20%)

b. GUIDELINES FOR CODING LONG TERM CARE

BSICs are classified according to a number of descriptors (types and qualifiers), such as status of user, care typology, intensity, time of stay, and mobility. These descriptors provide a classification based on the “Main Types of Care,” including information on care, accessibility to care, self-help and volunteer care, outpatient care, day care and residential care. BSICs are arranged or organised either as a single MTC or in cluster combination of MTCs.

There are some examples of types of care that can be classified in each code. This list of examples does not pretend to be exhaustive. Some instructions are also given for situations where branches are mutually exclusive (i.e. pairs of branches where a particular service never must be classified as part of both at the same time).

The coding system follows the original order used in the European Service Mapping Schedule (ESMS) (Johnson et al, 2000) designed to be used for mental health services and its adaptation for disability services (DESDE) (Salvador-Carulla et al, 2006), although the arrangement has been modified to make it suitable for the classification of LTC according to descriptor levels (page 7). Due to this rule the codes do not follow an ordinal arrangement in Branch “D” (Day Care).

The coding system should be filled after completing “Section D” taking into account the information provided there.

I. INFORMATION FOR CARE CODING BRANCH

I INFORMATION AND ASSESSMENT OF NEEDS

Facilities whose main aim is to provide users from the defined target group with information and/or an assessment of their needs. This service does not entail subsequent monitoring/follow-up or direct care provision.

I1 Guidance and Assessment

Professional assessment and guidance are offered to the user in this service.

I.e. Centre for assessment and guidance where professional intervention includes evaluation and design of an individual plan for the user.

I1.1. HEALTH RELATED

I1.2. EDUCATION & TRAINING RELATED

I1.3. SOCIAL AND CULTURE RELATED

I1.4. WORK RELATED

I1.5. OTHER (NON WORK) RELATED

I2 Information

Intended exclusively to provide information to users with long term care needs.

This includes information on accessibility. Assessment facilities are not included here.

I2.1. INTERACTIVE

Information facilities where information exchange requires non face-to-face interaction between the service user (individual with long term care need) and the professional.

I2.1.1. FACE TO FACE

Intended to inform users with long term care needs through face to face interaction.

I2.1.2. OTHER INTERACTIVE

Intended to inform users with long term care needs through information technologies (IT) or telephone. To be coded here the service should meet all of the following criteria:

- It has specific staff for long term care.
- It provide useful information specifically aimed at long term care
- for websites, information is updated at least monthly.

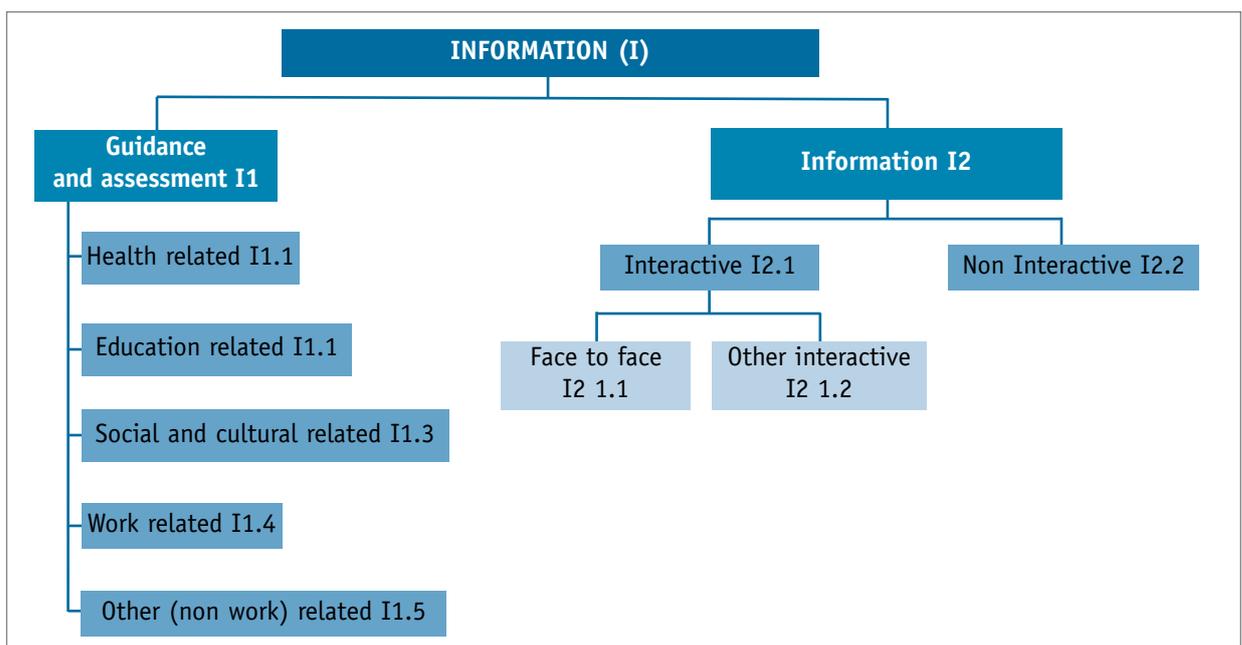
In order to fill this code the person that manages the website and the updating should be identified. Interactive information facilities via internet and telephone are included here.

I2.2. NON INTERACTIVE

Services aimed at informing users with long term care needs where there is no interaction with the user and/or where information is not updated on a monthly base

Non interactive informative websites are included here. If the service is web based in order to fill this code the person that manages the website and the updating should be identified.

INFORMATION SERVICES FOR CARE CODING BRANCH



A. ACCESSIBILITY TO CARE CODING BRANCH

A ACCESSIBILITY TO CARE

Facilities which main aim is to facilitate accessibility to care for users with long term care needs. These services do not entail direct care provision.

A1 COMMUNICATION

Facilities which main aim is to facilitate the access to information by the user. Sign language and healthcare related translation services are included in this section

A2 PHYSICAL MOBILITY

Facilities which main aim is to facilitate the physical mobility of users with long term care needs.

This includes services which main aim is to improve the physical mobility of the person with long term care needs, (e.g. transportation services). It does not include mobility devices (e.g. wheelchair)

A3 PERSONAL ACCOMPANIMENT

Facilities which main aim is to facilitate the paid personal accompaniment by non-care professionals of users with long term care needs. Personal accompaniment does not include any type of direct care provision (unpaid or voluntary accompaniment is classified in branch "S")

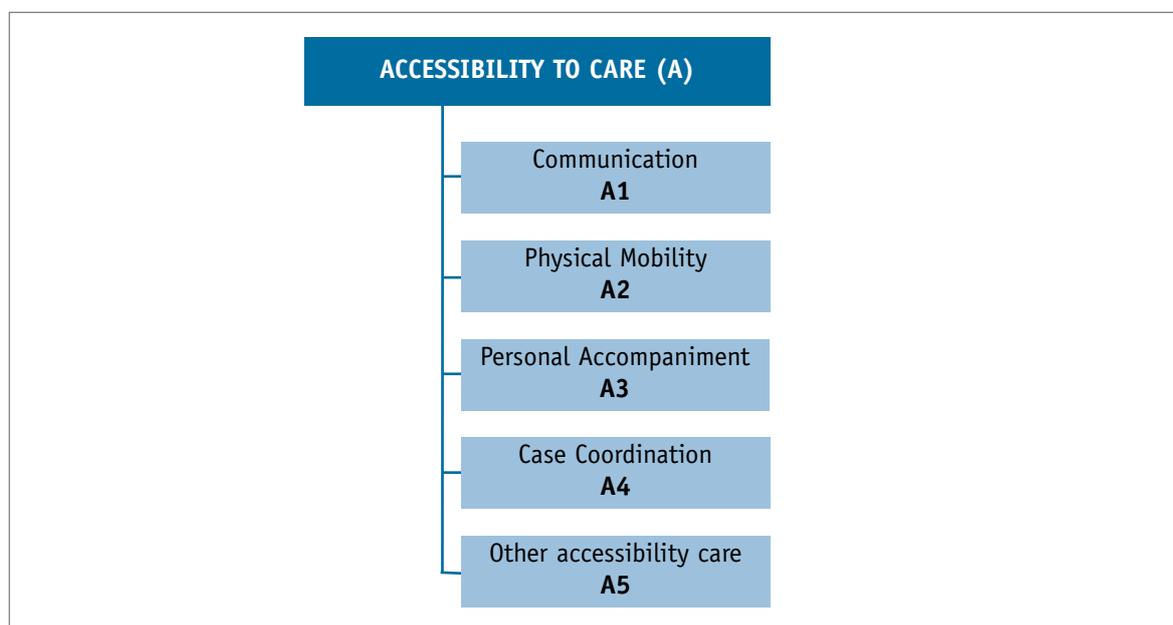
A4 CASE COORDINATION

Facilities which main aim is to facilitate the care coordination and the related accessibility to different types of services, professionals and tests by users with long term care needs. Care coordination does not include any type of direct care provision (e.g. it includes case management but not intensive case management with assertive community care in the mental health area)

A5 OTHER ACCESSIBILITY CARE

Other accessibility facilities which main aim is to facilitate the access to care which do not include any type of direct care provision.

ACCESSIBILITY TO CARE CODING BRANCH



S. SELF-HELP AND VOLUNTEER CARE CODING BRANCH

S SELF-HELP AND VOLUNTEER CARE

The aim of these facilities is to provide users with long term care needs with support, self-help or contact, with un-paid staff that offers accessibility, information, outpatient, day and residential care (as described in other branches).

S1 NON PROFESSIONAL (NP) STAFF

Facilities aimed at users with long term care needs, where graduate professionals providing assessment, interventions or support to users with long term care needs are below 60% of total full time equivalent personnel. 100% of staff is unpaid, although administrative and management personnel can be paid.

Self-help groups conducted by users, informal care associations of mutual help and services entirely provided by volunteers are included in this section

- S1.1. S-NP- INFORMATION ON CARE
- S1.2. S-NP- ACCESSIBILITY TO CARE
- S1.3. S-NP OUTPATIENT CARE
- S1.4. S-NP DAY CARE
- S1.5. S-NP RESIDENTIAL CARE

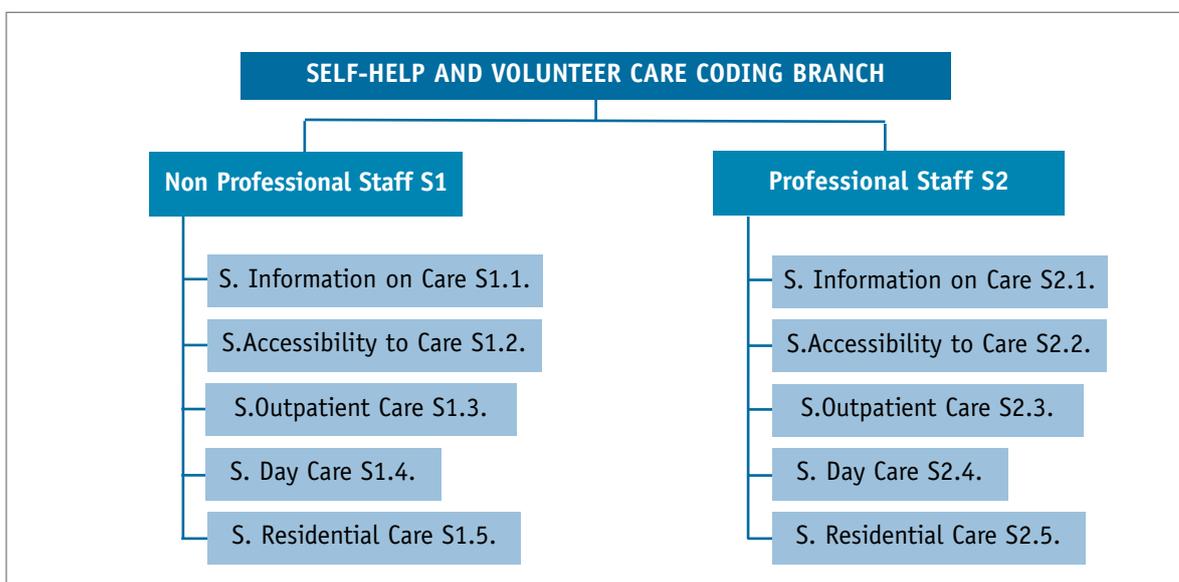
S2 PROFESSIONAL (P) STAFF

Facilities designed for users with long term care needs that regularly at least 60% of staff are graduate professionals trained or specifically qualified for providing assessment, intervention and support to users with long term care needs. 100% of staff are un-paid, although administrative and management personnel can be paid.

Services run by un-paid professional and specialised volunteers on a regular or stable basis.

- S2.1 S-P INFORMATION ON CARE
- S2.2 S-P ACCESSIBILITY TO CARE
- S2.3 S-P OUTPATIENT CARE
- S2.4 S-P DAY CARE
- S2.5 S-P RESIDENTIAL CARE

SELF-HELP AND VOLUNTEER CARE CODING BRANCH



0. OUTPATIENT CARE CODING BRANCH

0 OUTPATIENT CARE

These are facilities which (i) involve contact between staff and users for some purpose related to management of their condition and its associated clinical and social difficulties and (ii) are not provided as a part of delivery of residential or day and structured activity services, as defined below.

ACUTE CARE (01-04)

These emergency facilities (i) provide assessment and initial treatment in response to a crisis, deterioration in physical or mental state, behaviour or social functioning which is related to the condition; and (ii) can usually provide a same day response during working hours. At least 20% of the users in the last twelve months do meet the criteria for acute outpatient care for crisis.

HOME & MOBILE (HOME-MOBILE) (01-02)

In home & mobile facilities contact with users occurs in a range of settings including users' homes, as judged most appropriate by professionals and users. For a service to be classified as 'home & mobile', at least 50% of contacts should take place away from the premises at which the service is based. If mobile care is provided at least for 20% of contacts a secondary mobile code should be added to the MTC Non-mobile code. In other cases of mobile outpatient care an additional qualifier "d" could be provided to describe its mobile activity. For some services, the main site of provision may vary from day to day (e.g. services in rural areas which move from village to village) – this does not mean they should be classified as 'home & mobile' unless staff go and do work at locations away from that day's main site.

Facilities should not be classified as "home & mobile" and "non mobile" at the same time – If the 50% of the visits take place out of the main location this will be classified only as home & mobile, although both home & mobile and non-mobile utilisation will be counted at section C. Services which are not specifically aimed at mobile care and which do provide mobile care as part of their usual care activity could be differentiated from non-mobile services by adding an additional qualifier "d" (e.g. 08.1d).

01 24 hours

24-hours are acute services which are available 24 hours a day, 7 days per week.

01.1 Health related care

BSICs whose main goal is the specific clinical care, during the period described by the code, and where some of the staff is qualified health care professionals (Medicine, Nursing, Physiotherapy, Rehabilitation Medicine and Psychology).

01.2 Other care

Facilities that do not meet the criteria for health related care services.

02 Limited-Hours

These facilities are not always available (opening hours less than 24 hours, 7 days per week).

Examples for branches 01 and 02 – crisis teams and home & mobile teams which provide crisis treatment in older people's homes. Outpatient facilities can also offer emergency care (besides continuing care) so they will be classified in both branches.

Facilities should not be classified as "24 hours" and limited-hours" at the same time. – If there is a period of time during the week when the service is closed and does not allow visits, this service must be classified as limited hours".

02.1 Health related care (as in 01.1)

02.2 Other care (as in 01.2)

This code may include BSICs whose main care function is to provide support for daily activities (cleaning, grooming, cooking etc) provided at home just in crisis situations during a limited time during the week (i.e. due to illness of main carer). This is a marginal code.

Non-mobile (03-04)

Services which do not meet the criteria for 'home & mobile'

03 24 hours (as in 01)

03.1 Health related care (as in 01.1)

Emergency Units in General Hospitals which can provide specific care to users with LTC needs. These services should provide specific care for a defined specific population group. For example care for mental health users is provided by health professionals with specialised training in mental health.

03.2 Other care (as in 01.2)

04 Limited-hours (as in 02)

Facilities should not be classified as "24 hours" and "limited hours" at the same time - if there is a period of time during the week when the service is closed and do not allow visits this must be classified as limited hours".

04.1 Health related care (as in 01.1)

Emergency facilities in outpatient and primary care centres, or in Mental Health centres which can provide specific care to users with LTC needs under a crisis situation in limited-hours.

04.2 Other care (as in 01.2)

Non-acute care (05-010)

These facilities provide service users with continuing care including regular contact with a health professional, which may be long term if required. Continuing care services may also provide acute/emergency care on a regular basis. Only when acute care is over 20% of the ordinary activity of the service both acute and non-acute branches should be registered.

Home & mobile (05-07) (see home & mobile for acute care)

05 High intensity

These are facilities which have the capacity to make face to face contact with users at least three times per week when clinically indicated.

05.1 Health related care (as in 01.1)

05.1.1 3 to 6 days a week care

Facilities which main goal is the specific clinical care for users with a frequency lower than 7 days/week 3 hours/day.

05.1.2 7 days a week a minimum of 3 hours/day care

Facilities which main goal is the specific clinical care for users with a frequency at least 7 days/week 3 hours/day.

05.1.3. 7 days a week including overnight care

Facilities which main goal is the specific clinical care for users with a frequency of 7 days/week including overnight care.

05.2 Other care

Facilities that do not meet the criteria for health related care services.

05.2.1 3 to 6 days a week care

Facilities that provide non-clinical care for users with a frequency lower than 7 days/week 3 hours/day.

05.2.2 7 days a week a minimum of 3 hours/day care

Facilities that provide clinical care for users with a frequency of 7 days/week 3 hours/day.

05.2.3. 7 days a week including overnight care

Facilities that provide non-clinical care for users with a frequency of 7 days/week including overnight care.

06 Medium intensity

These facilities do not have the capacity to supply three times weekly contact to users, but which can provide contacts at least once a fortnight when indicated.

06.1 Health related care (as in 05.1)

06.2 Other care (as in 05.2)

07 Low intensity

These facilities do not have the capacity to see service users as often as once a fortnight.

Examples for branches 05 to 07 –Community nurse teams and support teams are a good example for these branches.

‘High intensity’, ‘medium intensity’ and ‘low intensity’ are mutually exclusive – if a facility is able to offer contact 3 days a week it will be classified as “high intensity” even if some of the users have a lower contact frequency than that. If a service is able to offer contact once fortnightly but not 3 days a week is considered “medium intensity” even if the contact is lower. Only services unable to offer contact at least once fortnightly will be classified as “low intensity”.

07.1 Health related care (as in 05.1)

07.2 Other care (as in 05.2)

Non- mobile (08-010)

08 High intensity (as in 05)

08.1 Health related care (as in 05.1)

08.2 Other care (as in 05.2)

09 Medium intensity (as in 06)

09.1 Health related care (as in 05.1)

09.2 Other care (as in 05.2)

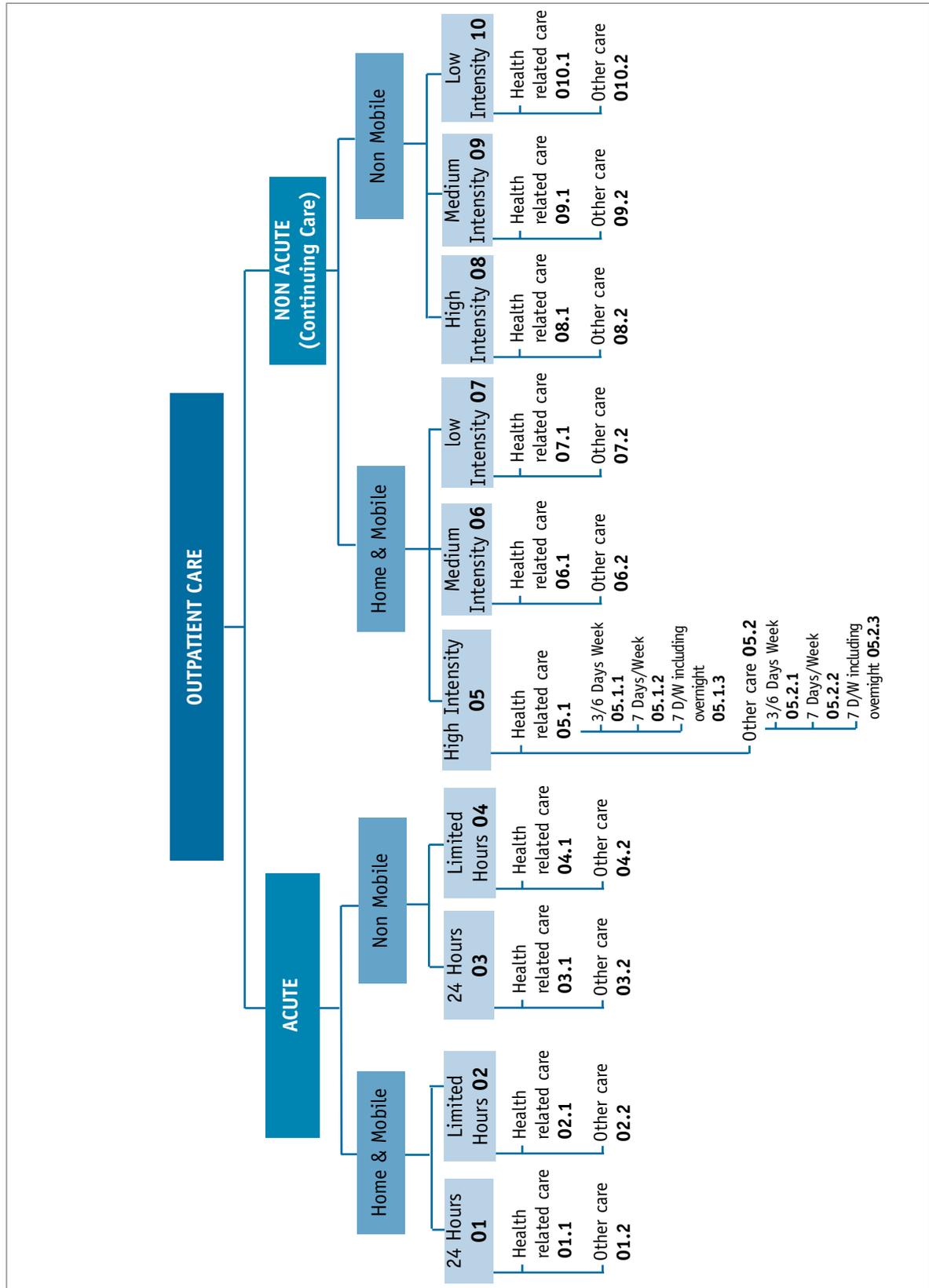
010 Low intensity (as in 07)

Examples of branches 08 to 010 – Outpatient clinics and community mental health centres where less than 20% of the contacts with users take part outside the setting are examples to be classified in this section.

010.1 Health related care (as in 05.1)

010.2 Other care (as in 05.2)

OUTPATIENT CARE CODING BRANCH



D. DAY CARE CODING BRANCH

Codes do not follow an ordinal ranking arrangement in this branch.

D DAY CARE

These are facilities which (i) are normally available to several users at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long-term care needs: e.g. providing a structured activity, or social contact and/or support; (iii) have regular opening hours during which they are normally available: and (iv) expect service users to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on individuals coming for appointments with staff and then leaving immediately after their appointments). The care delivery is usually planned in advance.

ACUTE CARE

Facilities where (i) users are regularly admitted because of a crisis or a deterioration in physical or mental state, behaviour or social functioning related to their health condition; (ii) alleviating this crisis/deterioration is the main purpose of the facility. At least 20% of the users in the last twelve months do meet the criteria for acute care for crisis.

DO EPISODIC ACUTE CARE

Facilities which usually provide day care to users with a deterioration of their health state on a single or a limited number of episodes of care during a defined period of time.

DO.1 High intensity

Facilities which usually provide high intensity day care to users with a deterioration of their health state on a single or a limited number of episodes of care during a defined period of time. The care episode last less than 24 hours and the user is admitted and discharged during the same day. The care episode includes complex and coordinated care activities such as diagnosis and assessment, interventions, and other type of health care which require highly trained professional staff and which is not limited to a single face-to-face contact such as in planned outpatient care. The complexity of the intervention is such as to assimilate it to a crisis care situation.

Examples of Acute episodic care are Day chemotherapy units in oncology or outpatient electroconvulsive therapy units in mental health.

DO.2 Other intensity

Facilities which usually provide episodic acute care but which do not fulfil high intensity criteria.

D1 CONTINUOUS ACUTE CARE

Facilities where (i) users are regularly admitted because of a crisis or a deterioration in physical or mental state, behaviour or social functioning related to their health condition; (ii) alleviating this crisis/deterioration is the main purpose of the facility; (iii) Care is provided on a continuous base –non episodic, at least 5 days a week- during a limited period of time. These day facilities are organised to provide an alternative to hospitalisation or to accelerate discharge from inpatient units before the crisis is ended or the user is stable.

Day hospitals are usually included in this section.

Admission to the facility is usually available within less than 4 weeks from the crisis onset for user discharged from an acute residential unit (R2 or R3). At least 80% of the users in the last twelve months are admitted within less than four weeks of the crisis onset (in any other case classify the facility as D4.2.).

D1.1 High intensity

Admission to the facility is usually available within 72 hours. At least 20% of the users in the last twelve months are admitted within 72 hours.

Day hospitals included in this section are focused on care for users with a crisis or significant aggravation of their health status which is associated to a risk for themselves, their family or others needing immediate care. These services are an alternative to hospital admission. The user would have needed hospitalisation in a catchment area without this facility.

D1.2 Other intensity

All day continuous acute care facilities that do not meet the criteria for acute care for crisis.

Day hospitals included in this section are also focused on care for users with a significant aggravation of their health status which is associated to a risk for themselves, their family or others needing immediate care. These services are NOT designed as an alternative to hospital admission but as a complementary system to hospitalisation that allows early discharge before the crisis is over. The user would have needed a longer hospital stay in a catchment area without this facility. Intensive case management services may be coded here.

NON ACUTE (D2-D9)

All day care facilities that do not meet the criteria for acute care for crisis.

WORK (D2, D6)

Work facilities which provide users with the opportunity to work for pay. These are usually sheltered work services or opportunities on the open labour market.

D2 High intensity work care

High intensity facilities are available for service users who attend for at least the equivalent of four half days per week. Not all service users need attend as frequently as this for the service to be classified as 'high intensity', but it should at least be possible for them to do so.

D2.1 Ordinary employment

Users with registered disabilities are paid at least the official minimum wage and the organisation follows standard work regulations in the open market. Where there is no minimum wage, DESDE-LTC suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month. However employees with registered disabilities may have not obtained this work through fully open competition - their jobs may in some way specifically reserved for users with disabilities depending on national/regional or local regulations.

D2.2 Other work

The organisation follows specific work regulations for users with registered disabilities. Employees are paid at least 50% of the usual local minimum wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month. The work may be in a sheltered setting or in a setting where some workers are not users with Long-Term Care needs.

D6 Low intensity work care

Facilities where users usually attend for less than the equivalent of four half days per week.

D6.1 Ordinary employment (as in D2.1)

D6.2 Other work (as in D2.2)

WORK RELATED CARE (D3, D7)

These are facilities where users carry out an activity which closely resembles work for which payment would be expected in the open market, but where users are not paid or are paid less than 50% of the usual local expected wage for this form of work. Where there is no minimum wage, we suggest calculating an expected level based on starting salaries for similar jobs advertised in the local press over the past month.

D3 High intensity work-related care (as in D2)

D3.1 Time limited.

These are facilities where users perform a work related activity that has a time limit.

It includes centres giving courses for Occupational Training for a fixed time period e.g. 2 years.

D3.2 Time indefinite

Facilities where users carry out a work related activity that does not have a fixed time limit.

It includes other occupational centres and workshops that have the aim of social and labour integration.

When a centre offers training or continuing occupational care to the same group of people for long periods of time (i.e. more than 2 years) the facility is not coded as “time-limited” even when it has different programmes with a time limit (i.e. individuals use the centre for a period of time longer than the duration of a course).

D7 Low intensity work-related care (as in D6)

D7.1 Time limited (as in D3.1)

D7.2 Time indefinite (as in D3.2)

NON-WORK STRUCTURED DAY CARE (D4, D8)

These facilities provide structured activities different from work and work-related care. Such activities may include skills training, creative activities such as art or music and group work. These activities should be available during at least 25% of the service’s opening hours.

D4 High intensity structured day care (as in D2)

D4.1 Health related

Facilities that meet the criteria for programmed availability day care whose main function is to provide clinical long term care (physical, psychological and/or social). At least 20% of staff are qualified health professionals.

Facilities for physical rehabilitation and social or psychological rehabilitation are included in this section. Facilities aimed at improving social aspects of long-term care by health professionals are included here (i.e. social skills workshops).

D4.2 Education related

Facilities that offer training registered and approved as part of the official national or regional education and training system, with an official curriculum.

This includes centres for Special Education and Occupational Training.

D4.3 Social and culture related

Settings that offer structured activities related to social and culture participation.

This includes centres that offer non-official complementary education and training, as well as support to education. Sports activities, social clubs which enable social contacts in a structured way and workshops whose main goal does not include social and labour integration are also included.

D4.4 Other structured day care

Settings that do not meet criteria for “health promotion, education or social and culture participation activities” which offer some kind of structured activity.

It includes services aimed at prevention.

D8 Low intensity structured day care (as in D6)

D8.1 Health related (as in D4.1)

D8.2 Education related (as in D4.2)

D8.3 Social and culture related (as in D4.3)

D8.4 Other structured day care (as in D4.4)

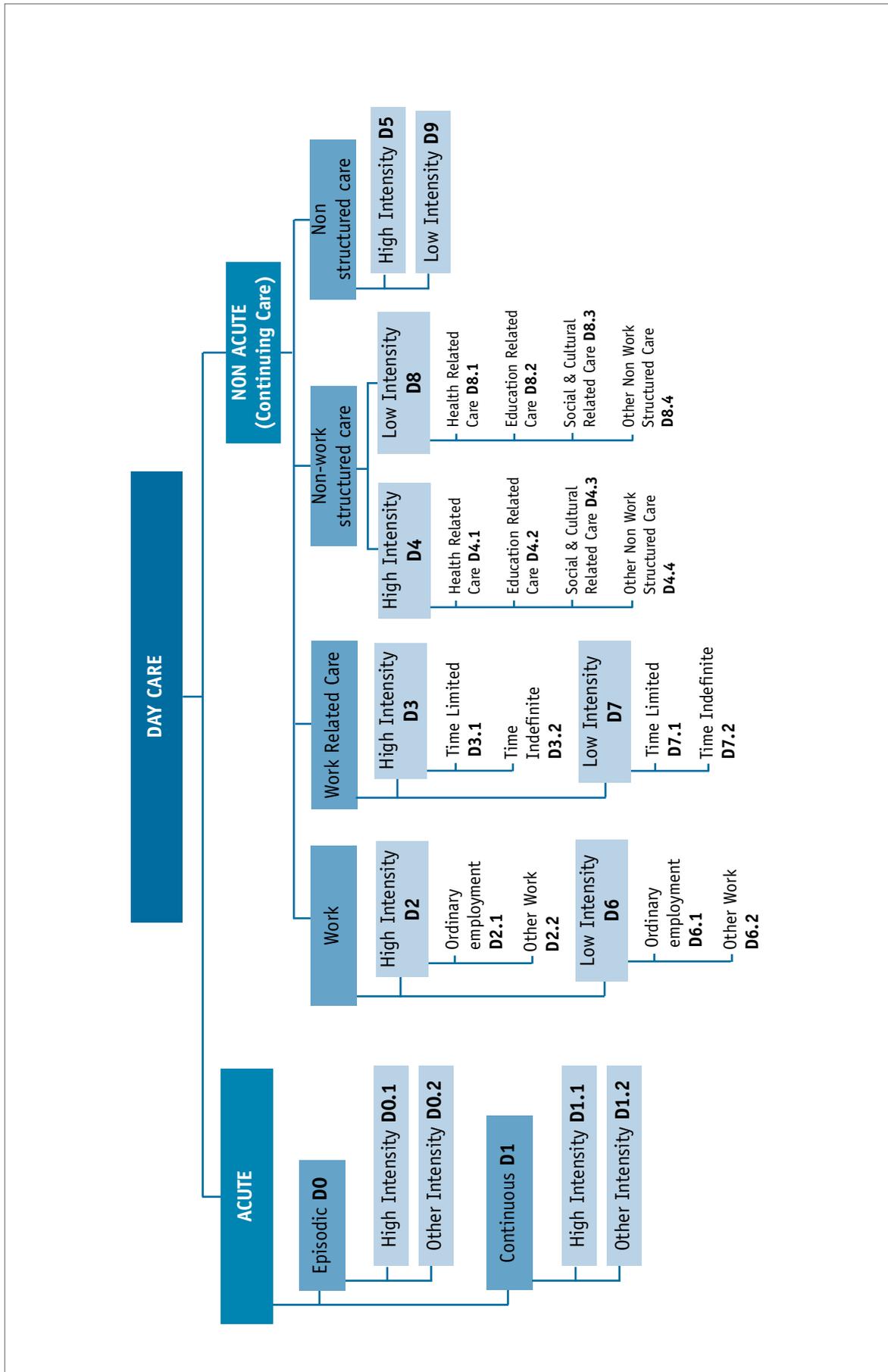
NON STRUCTURED DAY CARE (D5, D9)

Facilities which fulfil criteria for non-acute day services, but where work or other structured activities are not available, or available only during less than 25% of opening hours, so that the main functions of the service are the provision of social contact, practical advice and/or support.

Social clubs with paid staff that meet the criteria for “non structured care” are included in this section.

D5 High intensity non-structured day care (as in D2)

D9 Low intensity non-structured day care (as in D6)



R. RESIDENTIAL CARE CODING BRANCH

R RESIDENTIAL CARE

Facilities which provide beds overnight for users for a purpose related to the clinical and social management of their health condition - users do not make use of such services simply because they are homeless or unable to reach home.

Usually residential settings are classified as belonging to only one code, although occasionally it might be needed to classify a facility in more than one code i.e. a residence that includes beds for crisis admissions and beds for programmed admissions for an indefinite time period.

ACUTE

Facilities where (i) users are admitted because of a crisis, a deterioration of their physical or mental state, behaviour or social functioning which is related to their health condition;; (ii) admissions usually available within 24 hours; (iii) users usually retain their own accommodation during the admission. At least 20% of the users in the last twelve months do meet the criteria for residential acute care for crisis.

24 HOUR PHYSICIAN COVER

Facilities within hospitals or within other residential meso-organisations where there is 24 hour cover by a registered physician (including medical residents). Services where cover is provided by medical pregraduate students are excluded.

HOSPITAL

Hospitals are meso-organisations with a legal recognition in most countries. This legal recognition of registered hospitals can be used as the basis for identifying hospital BSIC. In those countries where there is no legal basis for deciding what are hospital services and in those cases where doubt exists, services should be classified as hospital BSIC if they have more than 20 beds and 24 hour resident physician cover. A stakeholder group and/or local or regional health officers should be consulted where there is doubt about which services should be viewed as hospital services or not.

RO Non-hospital

Acute care facilities with 24-hours physician cover outside the location of a registered hospital (e.g nursing homes with 24 hour medical care which have less than 20 beds and which are not registered as hospitals).

Example branch RO are acute services for specific conditions with 24-hour physician cover but which are not registered as hospitals at national, regional or local level. (i.e. some residential services with low provision for persons with mental illness, geriatrics or brain Injury)

This is a residual code which should be registered only after a careful assessment.

HOSPITAL

R1 High intensity

Beds to which users are admitted due to a deterioration of their physical or mental status severe enough to require continuous surveillance during 24-hours a day, and/or to require special isolation measures.

Example branch R1 –These services include intensive care facilities for LTC. In mental health “continuous surveillance” also includes secure services where users are admitted because they are considered by clinicians to be too dangerous to themselves or others to be managed adequately in non-secure facilities, or because of a specific legal judgement which states that for reasons of safety they must

go to this particular facility rather than to the local generic facilities. Beds to which compulsory admissions can be made should not automatically be categorised as secure beds- it is possible for a patient to be compulsorily admitted to a generic acute facility. Facilities with beds specifically intended to provide a greater level of surveillance and/or security than those to which users from the catchment area are routinely admitted should be classified as high intensity.

R2 Medium intensity

Acute care facilities with 24-hours physician cover in a registered hospital where (i) users are admitted due to a deterioration of their physical or mental state, behaviour or social functioning which is related to their health condition; (ii) admissions usually available within 24 hours; (iii) users usually retain their own accommodation during the admission. Facilities that provide regular care (medium intensity) of surveillance and/or security for in-patient admission.

Example branch R2 –Hospital units where routinely admissions from a specific catchment area are included. It also includes acute units from general hospitals, psychiatric hospitals and other specialist hospitals. A ward which is placed within a meso-organisation and which lacks direct 24-hour physician cover, should be coded here if there is 24-hour physician cover available at the meso-organisation which could provide acute treatment if necessary.

These residential facilities usually offer also outpatient emergency care (besides acute residential care) so they will be classified in both branches (R2 & 03) if emergency care for the specific target group is provided in the same hospital by staff of the service being described.

R3 Non-24hours physician cover

Facilities without 24-hour physician cover where (i) users are admitted because of a crisis, a deterioration in their physical or mental state, behaviour or social functioning which is related to the condition; (ii) admission usually available within 24 hours; (iii) users usually retain their own accommodation.

R3.0. Hospital

Acute care facilities without 24-hours physician cover in a registered hospital.

Example code R3.0: Some registered hospitals may provide low intensity acute care without 24-hour medical cover (i.e. some acute wards at specialised psychiatric hospitals, some hospitals for geriatric users, or some hospitals for brain Injury). A hospital ward which does not have 24-hour medical cover but where this provision is available at the meso-organisation where the service is placed, this service should NOT be coded here.

This is a residual code which should be registered only after a careful assessment.

R3.1. Non-hospital

Acute care facilities without 24-hours physician cover outside a registered hospital.

R3.1.1 Health related care

Residential settings aimed at providing specific clinical care, during the period described by the code, and where a part of the staff is qualified on health care (Psychology, Medicine, Physiotherapy, Nursing) or has the equivalent training, but which does not provide 24-hour physician cover.

Example branch R3.1.1 –It includes a range of non-hospital beds which may be used as alternatives to hospital admission. Facilities such as crisis houses, crisis hostels or emergency beds in community primary care or mental health centres should be placed here. “Residential facilities” with high intensity medical staff but without 24 hour medical cover are included here (i.e nursing homes)

R3.1.2 Other care

Facilities that do not meet the criteria for acute non-hospital health related care.

NON ACUTE (PROGRAMMED AVAILABILITY) (R4-R13)

Residential facilities that do not satisfy the criteria for acute care. Crisis admissions are sent to other facilities routinely.

24 HOURS PHYSICIAN COVER (R4-R7)

HOSPITAL

These are facilities officially registered as 'hospitals' at national, regional or local level.

R4 Time-limited

These are facilities where a fixed maximum period of residence is routinely specified (temporary stay). A facility should be classified as time-limited if a maximum length of stay is fixed for at least 80% of those entering the facility.

Example branch R4 – It includes units for rehabilitation or community therapeutic programmes that specify a fixed length in months or years.

R6 Indefinite stay

These facilities do not fulfil the criteria for 'time-limited' services.

Example branch R6 - It includes nursing homes for older people where users are admitted for an indefinite period of time and are assisted by the staff 24 hours/day.

NON-HOSPITAL (AS IN R3)

These are facilities with 24-hour medical cover that are NOT officially registered as 'hospitals' at national, regional or local level.

R5 Time limited (as in R.4).

R7 Indefinite stay (as in R6)

NON-24H PHYSICIAN COVER (R8-R13)

TIME LIMITED (R8-R10) (AS IN R4)

R8 24-h support. Facilities that provide residential care during non working hours but where there is a procedure that guarantees that the user receives 24 hours care.

Example branch R8 – It includes living services that provide non acute care from 3 pm until 8 am because all users are at work from 8 am to 4 am. Careers can stay for the whole day in the residential facility when it is needed (e.g. if a user get ill).

R8.1 Less than 4 weeks

Stay is usually limited to a short time usually less than one month

I.e. Respite units that admit users with severe problems

R8.2 Over 4 weeks

R9 Daily support

Members of staff are regularly on site at least five days a week for some part of the day, with responsibilities related to the monitoring and clinical and social care of the user.

R9.1 Less than 4 weeks (as in R8.1)

R9.2 Over 4 weeks (as in R8.2)

R10 Lower support

These are facilities where the service user resides for some purpose related to the management of his/her health condition and where there is a direct link between residing in the facility and some support from staff, but where staff are regularly present fewer than five days per week.

R10.1 Less than 4 weeks (as in R8.1)

R10.2 Over 4 weeks (as in R8.2)

Examples R8 to R10 – Residences, houses for groups, therapeutic communities and other specifically designed services for users with long term care needs are classified in this section as long as they specify a fixed period of stay

For example, services that offer rehabilitation programmes with a fixed period of time or those offering temporary stay.

INDEFINITE STAY (R11-R13) (AS IN R6)**R11 24-h support (as in R8)****R12 Daily support (as in R9)****R13 Lower support (as in R10)**

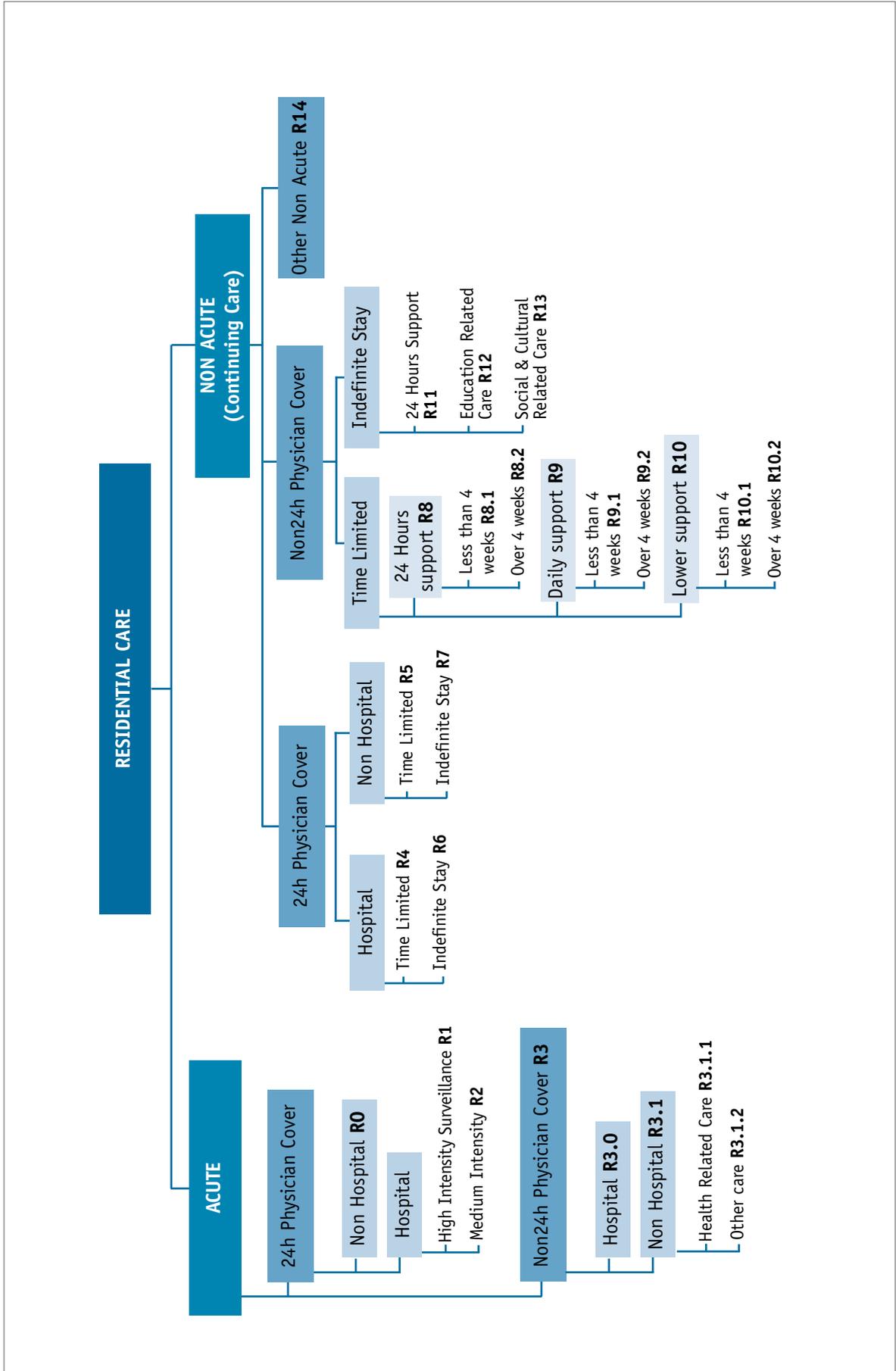
Example branches R11 to R13 – It includes residential facilities where no duration of stay is specified and offer permanent accommodation when required.

R14 Other non-acute

Residential non-acute facilities not classified elsewhere.

This code is used for residential facilities that cannot be classified elsewhere. Usually these facilities require a detailed explanation of their characteristics at section D and/or other codes from non-residential branches to understand its MTC. A possible example is a Hostel close to a care centre (usually a hospital), whose main aim is not to provide care but just accommodation for users attending a care facility. However the local officer judges that this service, which is publicly funded, is a critical component of the care system of the catchment area and therefore it should be added to the local mapping.

RESIDENTIAL CARE CODING BRANCH



SECTION C

CARE USE MAPPING

(MTC COUNTING)

a. PRINCIPLES FOR COUNTING LONG TERM CARE SERVICES

The care trees in this section allow the counting of levels of provision of the major forms of service (BSIC) within a catchment area. The following general principles should be noted:

- **Catchment area population:** The basic unit once again is the population of the reference catchment area. Counts should therefore include all use of facilities by users with long term care needs from this population. This includes all those whose permanent address is in the catchment area and those whose last non-institutional permanent address prior to admission to a residential facility was within the catchment area.
- **Target group:** In order to count service contacts, the target groups whose contacts will be counted need to be identified. The default target group for application of the schedules is users with long term care needs. However, the needs of particular studies or the structure of individual services may lead to a decision being made to vary these criteria.

In section A, the characteristics of the target group used in the study are specified.

- **To allow comparisons between areas,** service use per 100,000 local general population should be calculated for each count in each catchment area. This can be done by dividing raw totals by the total number of inhabitants of the catchment area and then multiplying by 100,000.

General population rates are preferred for counting. However, as an alternative, service use can be referred to the specific population defined as the “target group” (i.e. adults 18+) per 100,000. This should be clearly specified in the study characteristics.

- Double counting may occur when this method is used, i.e. users living in a residential facility and attending a day facility will be counted in two categories. The DESDE-LTC is not therefore a valid method of ascertaining an overall total for users of long term care services in a catchment area.
- However, whilst a user may attend several facilities and thus be counted in several different parts of the schedule, no service contact should be counted in more than one branch. The rules set out below should allow each contact between an individual and a particular facility for those with long-term care needs to be counted only once.
- The counts should be based on the target population established above. In comparative studies, it is essential that the same target group is used in each centre.
- The final branch of each main branch summarises the level of use of the different types of care in the particular branch. Boxes for each final branch should be used to indicate the count for level of use for each end-branch. Counts for adjacent branches may be added together to derive overall numbers for larger categories of use (i.e. counts for high, moderate and low intensity continuing care may be combined to give an overall continuing care count, for which a box is provided).

- Where information is limited, and it does not allow one to fill a specific or end branch, it is possible to count data just for a branch on higher level of the mapping tree (i.e. when it is not possible to differentiate contacts according to intensity in outpatient non-acute care, the counting could be made just for home & mobile [05 to 07] and non-mobile contacts [08 to 010]).

It is possible to obtain different grades of detail in the final information depending on the access and availability of the data required:

- **Grade I:** general information at the level of Main Branches - e.g. 90 users for Outpatient services but no specifications for home & mobile/ non mobile or on the level of intensity. These are classified as "0".
- **Grade II:** extended general information at the level of sub-branches -i.e. 20 places for home & mobile and medium intensity (classified as 06) and 70 non mobile and low intensity places for (classified as 010) continued outpatient care.

- **Grade III:** Extensive data gathering by external raters:

- retrospective use of databases and prospective assessment limited to one day (i.e. emergency care)
- retrospective use of databases and prospective assessment limited to one week (i.e. day care)

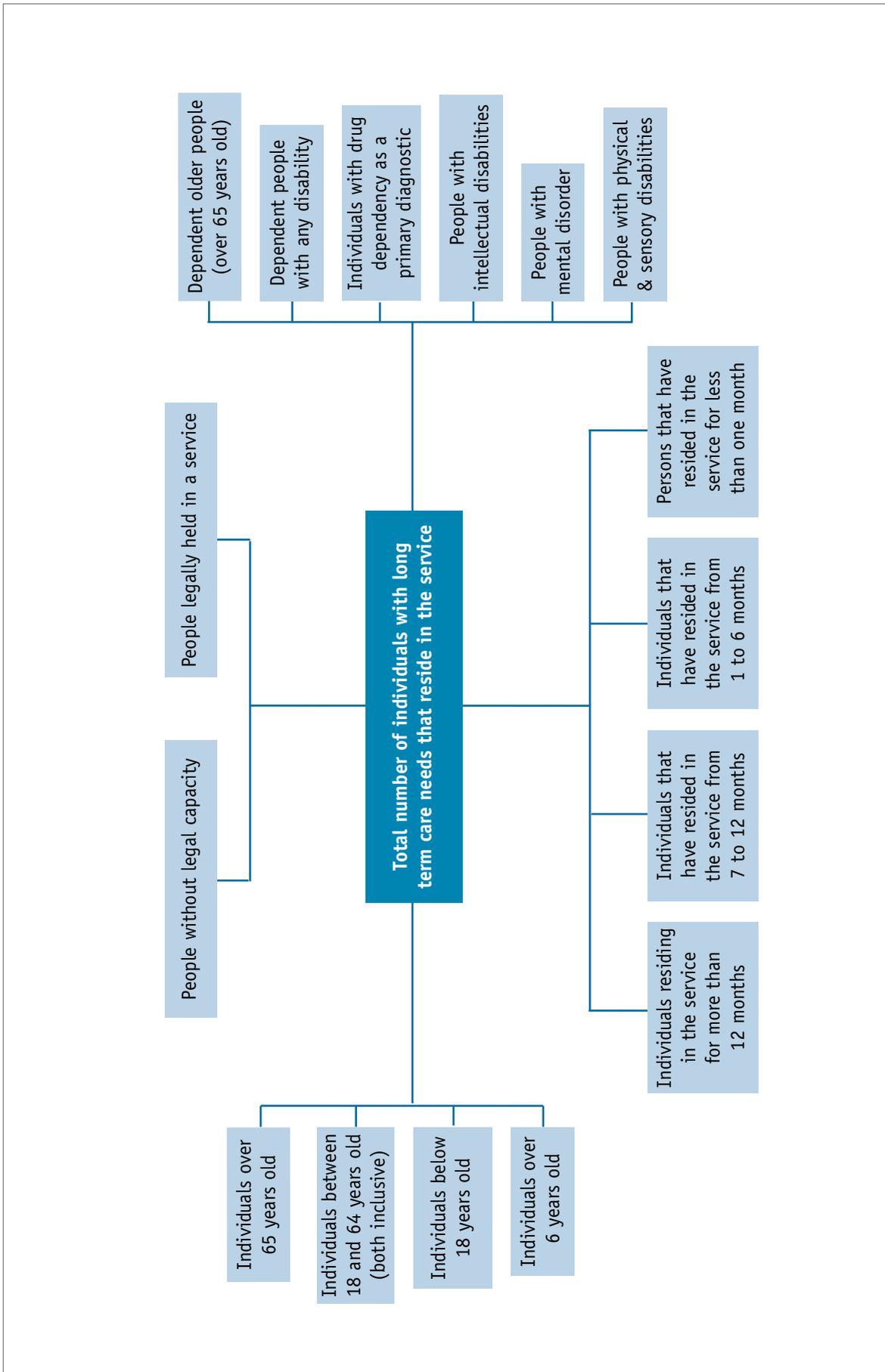
For retrospective data gathering the monthly average rate of use registered in the database for a specific month of the previous year excluding holiday periods (December, January, February, April, June, July and August) may be used.

- Prospective data collection limited to a one month period.

It is important that the level of specificity reached, as well as the period of reference for the data gathering, are the same for all the evaluated geographical areas and recorded in Section A, general information.

- Where information is limited, only certain portions of the trees may be selected and used alone i.e. when there is no information on the use of a service use, simply fill in Section B, classifying and codifying the service but do not complete the counting exercise in Section C. Again it is essential that comparative studies agree to complete the same portions of the tree making use of the same target population.
- Care Counting Branches have been designed so that where data are not already available, it should be possible to collect the information required by prospectively collecting service use data by the target population of the reference catchment area.
- Self help services are not included in the service counting schedules, as they are it is likely to be difficult to assess their volumes of activity precisely. Use calculation in Information and Accessibility branches are optional

In the case of using prospective data collection, data for use of service will be broken down as shown above in the Service Utilisation figure.



b. GUIDELINES FOR COUNTING LONG TERM CARE SERVICES

Definitions of the Main Types of Care are provided in the glossary for Section B (Map of Main Types of Care for Long Term Care).

Counting should be limited to branches "O", "D" and "R". Optional counting can also be provided for branches "I" and "A".

INFORMATION FOR CARE COUNTING BRANCH

The count should be obtained by calculating the mean number of contacts for information established with the service, made by the target group of a catchment area in the past month. In case of the unavailability of such information, other levels of quality of information will be used as explained in the chapter on Principles for Care Use Counting.

ACCESSIBILITY TO CARE COUNTING BRANCH

The count should be obtained by calculating the mean number of contacts for accessibility established with the service, made by the target group of a catchment area in the past month. In case of the unavailability of such information, other levels of quality of information will be used as explained in the chapter on Principles for Care Use Counting.

OUTPATIENT CARE COUNTING BRANCH

Acute care (crisis)- the count for use of emergency services should be obtained by calculating the total number of emergency contacts in the past month.

- **Home & Mobile acute care contacts**- Emergency contacts are those that take place outside the setting where the staff involved are routinely based.
- **Non-mobile acute care contacts**- Emergency contacts are those that take place on the site where the staff involved are routinely based on that day.

(NB: Non-mobile contacts may take place in services which have been classified on Section B as home & mobile)

- **24- hours contacts**- emergency contacts taking place in a facility open 24 hours a day seven days per week.
- **Limited hours contacts**- emergency contacts taking place in a facility which is not open 24 hours a day seven days per week.

NON-ACUTE CARE

The number of users of continuing care services in the past month should be counted. This shall include all users who have had any contact with care staff which (i) was not an emergency contact and (ii) was not an integral part of the care delivered by residential or day services.

- **Home & Mobile non-acute care services**- Service users should be counted as home & mobile service users if at least one of their contacts in the past month has taken place outside a designated facility for users with long term care needs or a setting in which care clinics are routinely held.
- **High intensity non-acute care service users**- Continuing service users who during the past month have at some stage been seen three times or more in the space of a single week should be classified as high intensity service users. For example, if a user has been seen on Monday, Wednesday and Friday during one

of the weeks in the previous month, he/she should be classified as a high intensity service user, even if there were no other contacts during the month.

- **Medium intensity non-acute care service users-** Continuing service users who have been seen at least twice during the month but less than three times in a week at any stage in the previous month.
- **Low intensity continuing care service users-** Service users who have used the service, only once or twice during the past three months and with whom further contact is definitely planned within the next three months.

(NB: As with day care, some of those in contact with services classified in the service mapping trees in the previous section as high intensity services, will be classified here as low intensity service users. If a user is seen once a month by members of a team, he/she is a low intensity service user, even if the team is in contact with other users several times per week).

DAY CARE COUNTING BRANCH

Acute day care: this refers to the immediate use of day care services by the target population within the past month due to crisis events.

- **High intensity users-** service users who have been admitted to the facility within 72 hours.
- **Low intensity users-** individuals whose pattern of admission from an acute residential unit does not meet criteria for high intensity users.

In case of the unavailability of such information, other levels of quality of information will be used as explained in the chapter 'Principles for Counting Long Term Care' (37).

Non acute day care: For all other day care services the numbers of individuals who made use of each type of service in the past month should be counted, with individuals divided into two categories:

- **High intensity users-** service users who have attended the day structured facility for at least the equivalent of four half days per week during at least three of the past four weeks.
- **Low intensity users-** individuals who have attended non-immediate availability day care during the past month, but whose pattern of attendance does not meet criteria for high intensity users.

In case of the unavailability of such information, other levels of quality of information will be used as explained in the chapter on Principles for Care Use Counting.

(NB: It is important to underline that Section B has been designed to measure maximum ordinary actual performance and not service theoretical maximum capacity. Section C is used to measure actual levels of service use by the population. Therefore, using this method of counting some users of services classified in the Long Term Care Mapping Trees as 'high intensity services' will be count here 'low intensity users').

RESIDENTIAL CARE COUNTING BRANCH

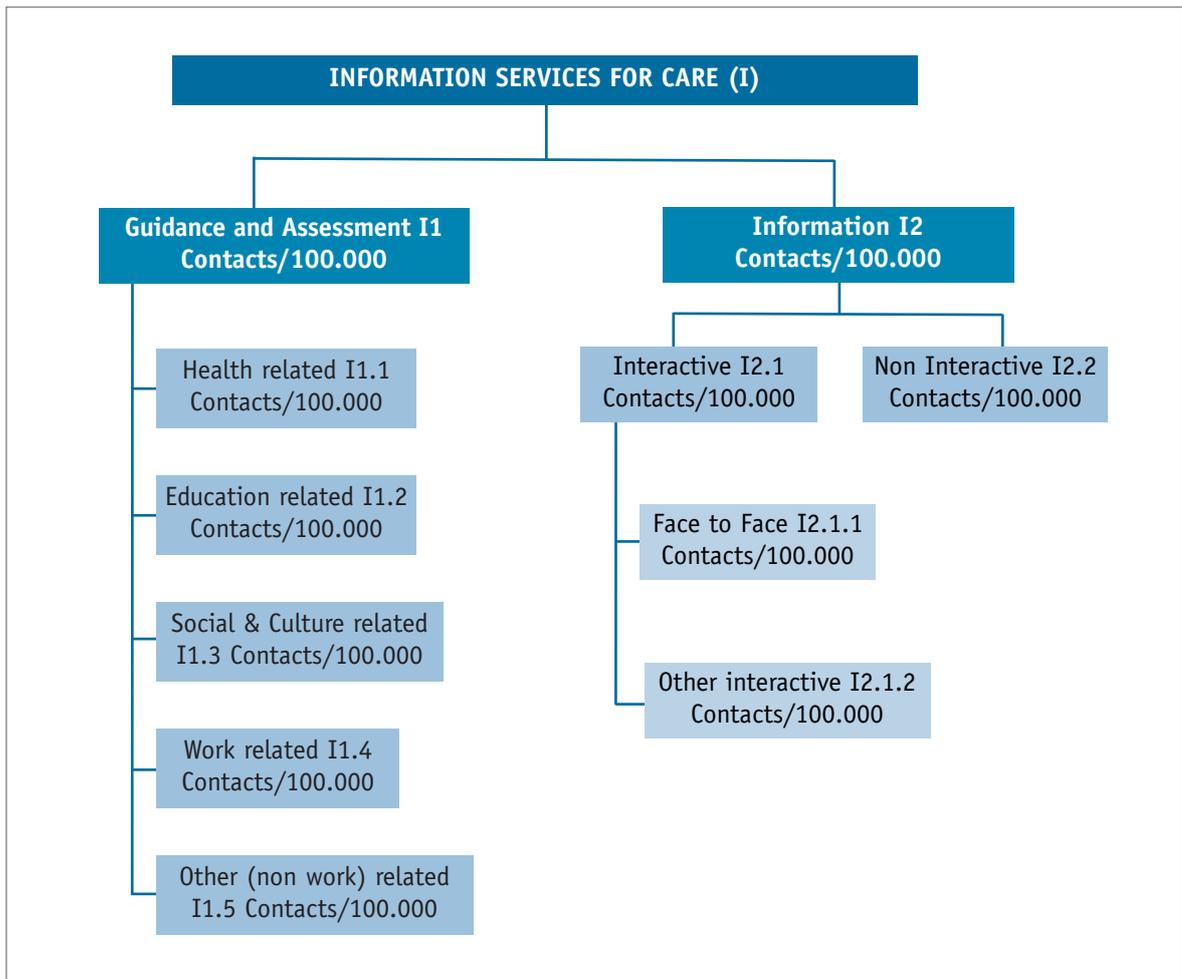
Each type of residential service is defined in the glossary for Section B (Long Term Care Mapping Trees).

The count for each residential service type is obtained by calculating the mean number of people from the catchment area staying overnight in each type of facility at any time during the previous month.

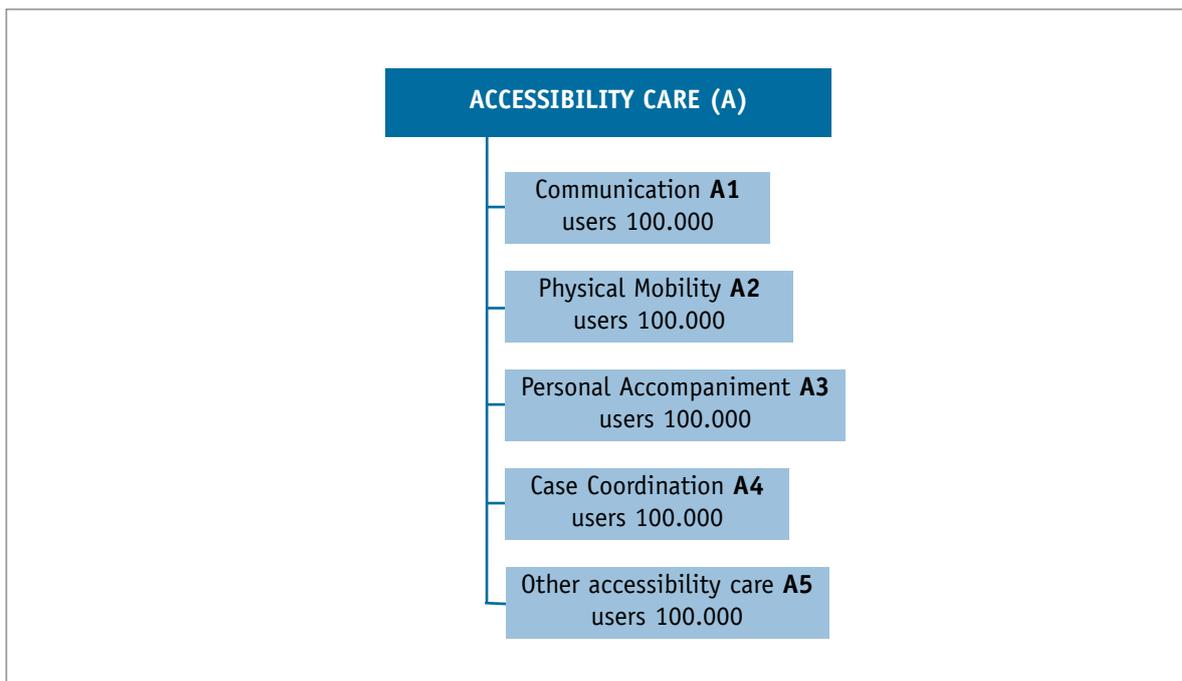
Users should not be counted as occupying two beds on the same night- if they have a long-term residential place, but have in fact been admitted to an acute bed during the census period, only the acute bed should be counted.

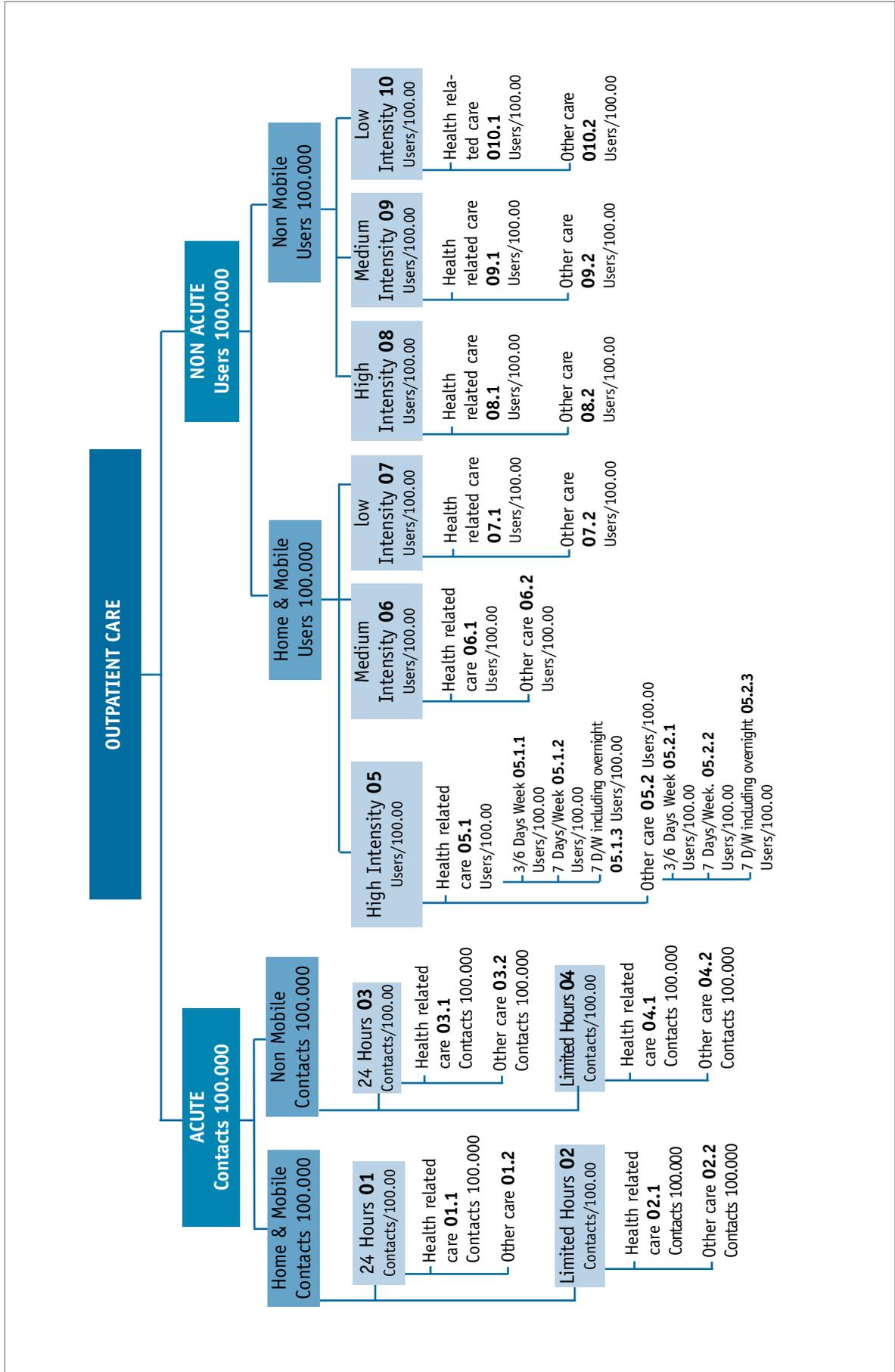
(If the number of people from the catchment area using a particular type of residential service has fluctuated over the last month, the mean number should be calculated by counting the total number of nights of bed occupancy by members of the catchment area population who slept in the facility in the month, and then dividing by the number of days in the month).

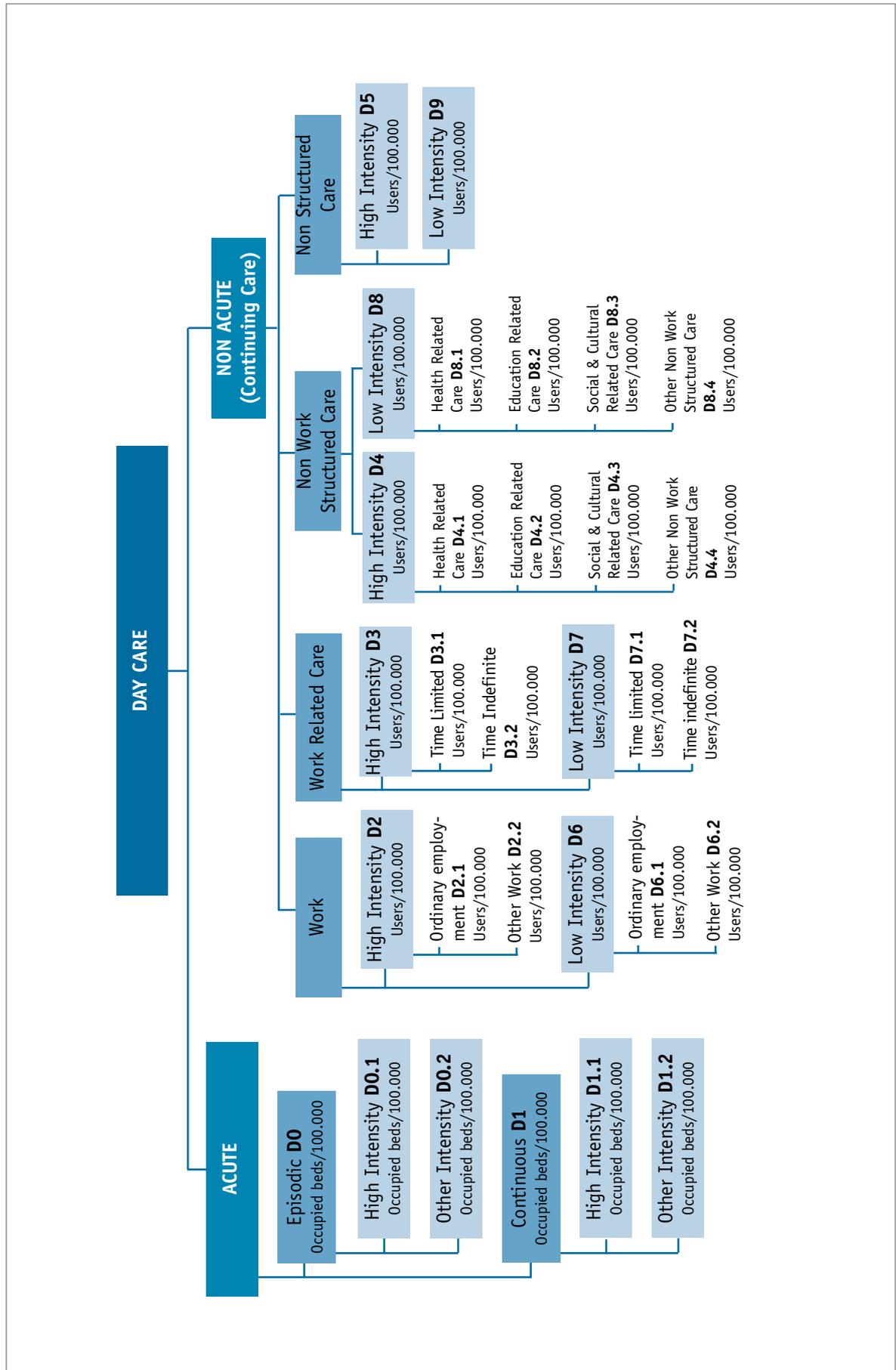
INFORMATION SERVICES FOR CARE COUNTING BRANCH

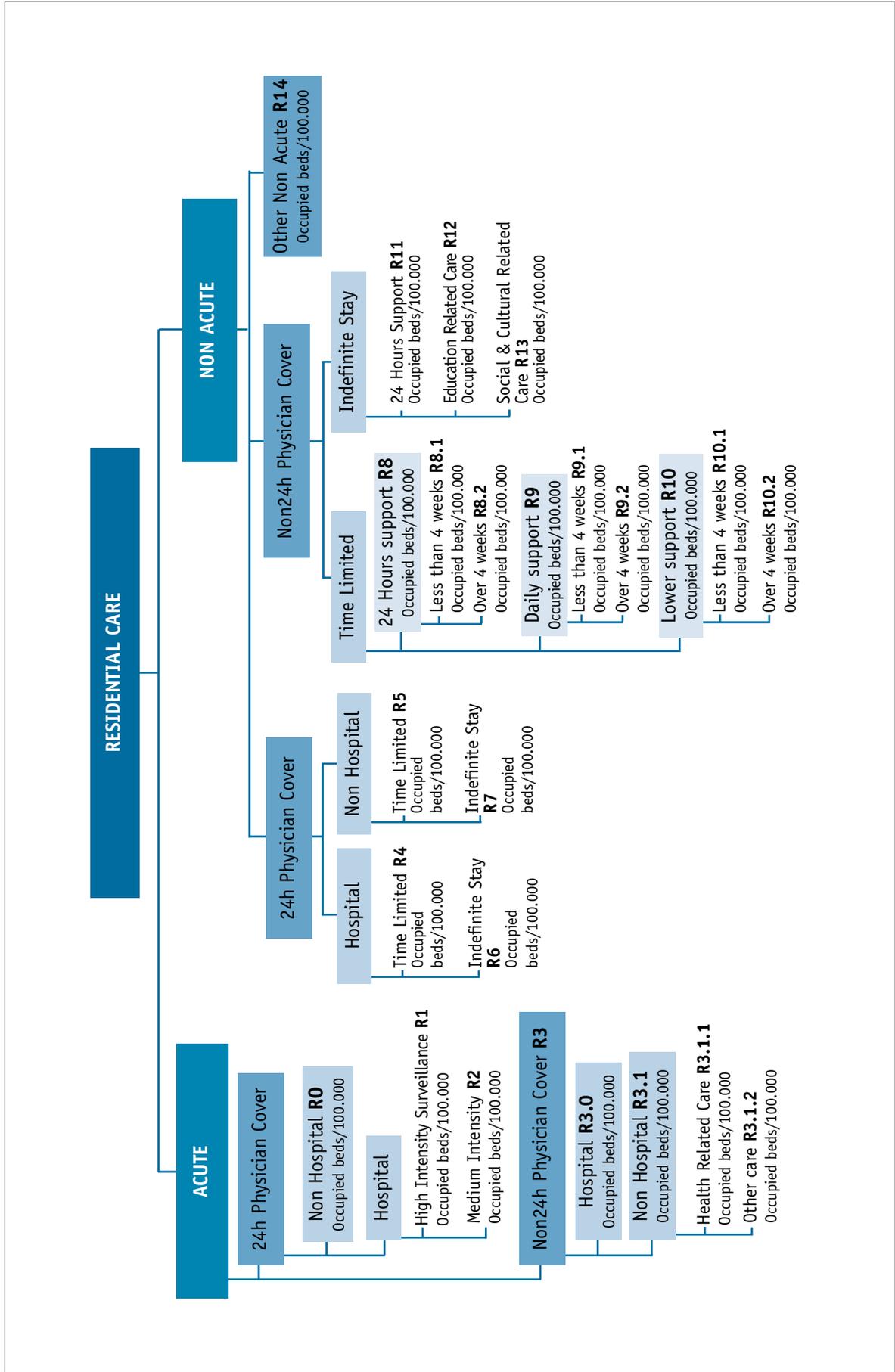


ACCESSIBILITY TO CARE COUNTING BRANCH









SECTION D

SERVICE INVENTORY (LISTING)

a. PRINCIPLES FOR SERVICE INVENTORY

This section supplements Section B by allowing for a more detailed listing of local services (BSICs) and a description of their characteristics (service listing or catalogue).

You can find Section D Form (Service Inventory) in Form 3 of DESDE-LTC Forms and Templates

The Service Inventory Form must be copied as many times as required to review all local services- the service inventory forms are therefore not numbered.

In addition in the DESDE-LTC Forms and Templates, you can find Template 1 (Mapping of Service Availability in the Area - Service Listing) where you can compile a list of all the services located in the reference area.

b. GUIDELINES FOR SERVICE INVENTORY

Below some instructions are specified for filling each item in the questionnaire:

1. NAME OF THE SERVICE

Complete name of the service (BSIC).

2. CODES

– DESDE-LTC CODE

Provide the codes for the service MTCs according to Section B guidelines.

– ICF CODE

Provide the service code according International Classification of Functioning, Disability and Health (ICF)

<http://www.who.int/classifications/icf/en/>.

– ICHA CODE

Provide the service code according the International Classification for Health Accounts (ICHA).

http://ec.europa.eu/health/ph_information/dissemination/hsis/hsis_10_en.htm.

– ICHI CODE

Give the service code according the International Classification of Health Interventions (ICHI)

<http://www.who.int/classifications/ichi/en/>

3. SETTING

Give the following service data:

- Region in federal country (if appropriate), county council, department, province (as appropriate), borough or municipality (as appropriate) and post code of the service.
- Address, Telephone, Fax, e-mail and web address of the service.

(Where applicable) Tax Registration, Charity Registration etc of the service as a legal entity.

- OFFICIAL STARTING DATE OF THE SERVICE

LOCATION. Is the service freestanding or located within a larger institution (meso-organisation) for “Long-Term Institutional Care”:

4. LOCAL DEFINITION OF THE SERVICE

For example: day centres, sheltered workshops, mental health centres, nursing homes, psychiatric hospitals, etc.

5. SECTOR

This should be classified as Social/ Health/ Education/ Justice /Other

6. PROPERTY, MANAGEMENT AND FUNDING SOURCE

- **Property:** Provide the name of the entity owner of the service.
- **Management agency:** Provide the name of the agency responsible for the employment of staff and the management of the service.
- **Main funding source:** Specify if the funding is public, private or other
- **Legal System:** Describe the legal status of the service (Registered Charity, Foundation, Cooperative, Social Firm, Public Corporation, Private Company or Others.

7. AVAILABILITY

Specify the availability of the service evaluated according to the criteria of each type of care.

- Phone Assistance Service

Give the number of terminals of the service specifying occupied and available terminals.

- Home Assistance Service.

Give the total number of users specifying number of hours users/month occupied and available

- Day Care service

Give the total number of places offered by the service specifying occupied and available places.

- Residential Care Service

Give the total number of places/beds offered by the service specifying occupied and available places.

IF RESIDENTIAL/DAY CARE IS AVAILABLE

Describe the total number of beds/places available at the service and the number of beds/places assigned to LTC, occupied and available.

- Limited time stay

Provide the number of limited-stay beds/places available at the service for LTC.

8. PRICE (FARE/TARIFF)

- Only for Phone Assistance.

Specify cost per month/user and cost per year/user.

- Only for Home Assistance

Specify public price, cost per month/user and agreed price.

- Only for Residential and Day Care Services.

Specify beds/places public price, agreed price and private price and the interval of prices per bed.

9. SPECIFIC ACTIVITIES

Specify if the service offers specific and permanent activities for users with long term care needs, provide the name of the activity, whether it is for an individual or for a group, and the number of hours and days per week that it is available. Whether this activity has a specific budget and setting (different from the service) and if it is authorised by the appropriate authority.

INTERVENTION PROGRAMMES OFFERED BY THE SERVICE

Specify if the service offers specific programmes for people with long term care needs, the timetable when they are available (hours and days per week) length and whether these programmes are authorised by the appropriate authority.

OTHER SPECIFIC ACTIVITIES

Records if there is a specific activity offered by the service for LTC service users excluding transport and meals.

10. STAFF

Provide International Standard Classification of Occupations (ISCO-08) Code
<http://www.ilo.org/public/english/bureau/stat/isco/index.htm>

Specify the actual occupation of staff, not their academic training and/or qualification.

11. CATCHMENT AREA OF SERVICE USERS

Specify if the service is available for users, either at Local/ County/Province/Region /National/or Other territorial levels (i.e mental health areas).

12. ADMISSION REQUIREMENT

Specific admission criteria for a new user (Age, Gender and Type of Long Term Care user that is attended at the service).

13. USER PROFILE

The main target groups for whom the service is intended. Specify:

- Type of Long-Term care. In the case that the person fulfils the criteria for more than one target group (i.e. being over 65 years and having a mental disorder) detail them.
- Age range
- Number of users/contacts for every type of health condition

14. OPENING HOURS

Specify the hours and days of service availability.

15. MAXIMUM FREQUENCY OF ATTENDANCE/CONTACT (maximum performance)

Specify the maximum number of times a service user can be actually assisted by the service if they require need in ordinary care conditions. This assistance can be daily (specify 1, 2 or 3 times/day), weekly (specify more or less than 3 times/week), fortnightly or monthly

16. SPECIFIC DATE ABOUT INFORMATION HAS BEEN REGISTERED

Specify the date when data has been collected.

17. LINKS WITH OTHER SERVICES

Any major joint working or exchange of staff which takes place regularly with any other long term care services should be described - e.g. visits to a hostel by members of the local community mental health team.

18. NAME OF THE EVALUATOR

19. 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 what the assessor continues to be important to document.

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6. ANNEXES

6.3. eDESDE-LTC: CASE BOOK

L. Salvador, C. Romero, M. Poole, M. Ruiz for
the eDESDE-LTC Group
Executive Agency for Health and Consumers
(EAHC)
Project Ref. 2007/116

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LIST OF MAIN ACRONYMS

BSIC	Basic Stable Inputs of Care
DESDE	Description and Evaluation of Services and Directories
EAHC	Executive Agency of Health and Consumers
EQM	Evaluation Quality Management
EPCAT	European Psychiatric Care Assessment Team
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
QAP	Quality Assessment Plan
SHA	Public Health Association
UNIVIE	University of Vienna
WHO	World Health Association

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INTRODUCTION

This document includes a series of 21 **case-vignettes** to illustrate the use of the coding system eDESDE-LTC as well as its related instrument. These are actual cases gathered in several European countries with different income level, North-South and East-West distribution, and health and social systems. The cases should be rated following the steps described at the document "Instrument – Mapping Tree" and using the eDESDE-LTC coding.

If you want to provide us 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>.

You can get full information on the eDESDE-LTC project at:
www.edesdeproject.eu/training.php/vignettes.pdf.

VIGNETTE 1

WORKSHOP FOR OCCUPATIONAL THERAPY OF PEOPLE WITH DISABILITIES

Permanent staff of Vignette 1, providing services to clients, numbers two people: the manager, who is an economist with no training in a helping profession and an occupational therapist.

Vignette 1 is a workshop that runs a foundation with an identical name. Most often it is sponsored by municipal programs targeted at the unemployed. The workshop provides services involving some forms of work activity – occupational therapy to people with disabilities living in the catchment area. Clients manufacture small objects-souvenirs from cardboard and wood. Clients have either physical or intellectual disability or a combination of these conditions. There is no formal obligation for clients to be registered as people with a disability status in local social agencies, in order to make use of the services of the area.

Depending on the availability of funds, the workshop engages 7 and 60 clients, 5 days a week. Employees of the workshop usually get paid for the objects manufactured by them, but payment is very irregular, depending on the sales of the products and very rarely amounts to the minimal salary for the country. Employees some times get consultations from a psychologist, engaged on a honorary basis, normally once per month.

eDESDE-LTC CODE

VIGNETTE 2

SOCIAL HOME FOR PEOPLE WITH IMPAIRED VISION

Vignette 2 is a social home that provides boarding, food and support with daily living to people with impaired vision. The service admits people who have only slight visual difficulty, those with serious impairment and completely blind clients. The home does not have a strictly defined catchment area, still most of its clients come from the district of the capital of the country and the adjacent small towns and villages.

People living here are either single, or widowed, or come from families with limited resources for care. Although there is no requirement for minimal age, the majority of the clients are over 60 years old. Once admitted, clients would stay indefinitely long, most of them- for a lifetime. Sometimes, families leave their family members for a few months- in the unit for respite care, when the family is going through some major change- change of place of residence, illness, etc. When a resident develops dementia, he/she usually has to leave; to be transferred to a facility, more equipped for taking care of such conditions.

Besides the manager, who is a social worker, the staff of the home includes one GP, 2 nurses and 8 caretakers who work, by threes in two shifts during daytime and night. The home does not provide any special treatments for people with visual impairments; the residents spend most of the day listening to the radio, or engaged in some type of art therapy provided by the personnel. The full capacity of the home is 27 beds; people live in rooms having 2 to 6 beds. At the moment of compiling this description, 20 beds were occupied.

eDESDE-LTC CODE

VIGNETTE 3

AGENCY FOR SOCIAL ASSISTANCE. DEPARTMENT FOR INTEGRATION OF PEOPLE WITH DISABILITIES

Besides the department for integration of people with disabilities, the agency for social assistance in our town, hosts two other: department for child protection and the department for social protection. However, more than 50 % of the clients of the agency are people in need of long term care. Officially, they are designated by the agency as “people with long term decrease in work capacity” and “people with reduced capacities for social adaptation”.

The agency provides free services to people with physical and mental disabilities. The department for integration of people with disabilities employs 5 people: 2 medical doctors with specialization in social care, 1 pedagogue, 1 theologian, 1 social worker. In the following year it is expected the personnel to grow up to 25 people.

Besides specific products, the agency provides information and assessment. This stuff provides products such as medical apparatus and technical aids for the various needs of disabled people. Services are integrated in this process, such as providing information as to all services for people in need of LTC, available on the territory of the catchment area. Furthermore, the personnel is engaged into providing clients with the so called individual integration plan- an individual care plan, comprising social, health, educational, etc, rehabilitation measures.

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VIGNETTE 4

MUNICIPAL SHELTERED HOME FOR PEOPLE WITH ID

According to the original plan of municipal authorities, Vignette 4 is a sheltered home for indefinite stay that has been stipulated for female-clients with mild and moderate mental disability, hitherto living in a social care home for the mentally disabled- a dilapidated building, in the outskirts of the town.

The home- a newly constructed 2 storey-house in the centre of the city, disposes of 4 two-beds rooms and the corresponding living rooms, study rooms and other premises needed for work and recreation.

The vision of service envisaged employment of three permanent staff members to assist inhabitants in achieving the goals of social skills learning and social inclusion. These were two social workers and a psychologist. Additionally the project foresaw employment of two therapist educators specialized in educating people with special needs, on day by day, honorary basis, when needed.

The deinstitutionalization program started with three women moving from the social care home to the sheltered house. Objectives of social rehabilitation, however proved not to be easily achievable- clients felt lonely and depressed once moved away from the social home, where they have spent all their lives.

Therefore, municipal authorities decided to concede the remaining five beds to young single mothers, living in strained economic circumstances.

After several months the three disabled women opted for returning to their former habitation. The deinstitutionalization program was abandoned and all 8 beds in the sheltered house have been occupied by single mothers. Staff remains the same the psychologist and the two social workers help clients achieve their socialization goals.

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VIGNETTE 5

MUNICIPAL DAY CARE CENTRE FOR PEOPLE WITH MENTAL DISABILITIES

Vignette 5 is a service disposed of a two storey, newly repaired building and the adjacent playgrounds, used in the village of the catchment area for sporting activities.

According to initial plans, the day care centre aimed to provide structured (more than 25% of opening hours) and unstructured day-time activities for people with severe mental illness, 8 hours a day, Monday, to Saturday. However, not enough clients with SMI enlisted as clients, therefore the management decided to offer services for people with mild mental retardation as well. Currently 10 places are allotted to clients with SMI and 10 places to clients with intellectual disabilities. 19 places are occupied at present. Usually clients attend separate programs, depending on their diagnosis clients are offered to join programs such as social skills learning, art therapy, exercise program, etc. Having an official disability status is a prerequisite to make free use of centre's services. Clients are also offered free catering.

The implementation of programs is entrusted to a manager with social work specialization, two nurses and two social workers. A psychiatrist is employed by the centre on a fee/per consultation basis, therefore clients can be provided with psychiatric consultation and medication. Initially the centre started as a foundation-run project sponsored by the ministry of labour, but two years after the elapse of the project it is sponsored by the municipal budget.

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VIGNETTE 6

DISTRICT MENTAL HEALTH CENTRE

Vignette 6 is a team which provides support, care and assessment for people with mental illness who live in the community. Sometimes they are required from hospital but this is not a usual practice. All patients under 18 years old are first evaluated in this centre although they are sent to the Area's Child Mental Health Team/Centre for treatment and follow-up.

The service has a team with 4 psychiatrists, 2 psychologists, 2 psychiatric nurses, 1 social worker and 2 nursing assistants.

If one of their clients has a sudden deterioration of mental state or functioning due to their psychiatric disorder, a professional can visit them at home, always in office hours. After assessment they can program a monitoring care or refer them to hospital when it is needed. The frequency of attention is once every 15 days.

The team has a total caseload of 1359. The core caseload is 1306 when we exclude patients who are seen mainly due to dementia, substance misuse or intellectual disability. 90 of the people on their caseload are aged over 65.

On a census week, the team made a total of 269 face-to-face contacts with their patients. 20 of these were with a user who was over 65. The majority of these contacts (250) took place either at the District Centre or at the patient's home (19 contacts).

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VIGNETTE 7

COMMUNITY MENTAL HEALTH TEAM

Vignette 7 has a team of seven support staff including their manager – five nurses (Community Psychiatric Nurses) and two social workers. They provide support, care, and assessment for people with enduring mental illness in the area of Fordham, living in the community (although they will visit people who are in hospital if required, this is not part of their day-to-day remit).

If one of their clients has a sudden deterioration of mental state or functioning due to their psychiatric disorder the CPN or social worker can visit them that day to provide care and assessment, before referring them on to more specialist crisis or hospital care if required. Non-acute care once per week makes up the main role and working pattern of the team. This involves clients attending meetings at the service premises, or staff visiting clients in community locations such as their own accommodation.

The team has a total caseload of 172. Each of the CPNs currently has between twenty-five and twenty-seven on their caseload. The Social Workers have a caseload of thirty nine in total and there were two new referrals accepted to the team on the day they provided this data. Four of the people on their caseload are aged over 65.

On the census week that they completed, the team made a total of 50 face-to-face contacts with their clients. Five of these were with a client who was over 65. The majority of these contacts (25) took place either at the service premises (a health centre) or at the client's home (25 contacts). There were three contacts recorded at hospital.

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VIGNETTE 8

DAY CENTRE

All the people that attend the Vignette 8 day centre live in the catchment area. The centre provides activities for people to attend five days a week on a variety of topics, such as gardening and cooking. The main target group of the centre are adults aged between 18 – 64 with enduring mental illness, however a couple of people aged over 65 are regularly attending.

Some of the classes they provide have recently started to focus on providing employment skills for the service users, and seven of the service users have started to volunteer in the office and reception at the centre for a few hours a week to develop these skills further. This new development has been called the 'Horizons Programme'. They are not paid to do this work or have a contract, but are being trained and assisted in employment-like roles to develop their employment skills for the future.

On the census week there were thirty attendees at the centre on Monday, twenty four on Tuesday, twenty seven on Wednesday, thirty four on Thursday and ten on Friday (when just one class operates). There were two attendees during the week who were over 65. Both attended the gardening classes only, which are held twice a week.

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VIGNETTE 9

HOSPITAL

Vignette 9 is a service that provides hospital in-patient care in the catchment area. There are five wards in the service – two acute in-patient wards for the adult population; one rehabilitation ward for longer term patients; and two older person wards (for patients over the age of 65). Each of the acute wards have twenty beds, and the same staff: qualified health professionals and a 24h physician. Admission in the service can be possible within 24 hours.

On Thursday the 8th February 2007 all the beds in one of these acute adult wards (called the Gold ward) were occupied. All the patients were under 65 and over the age of 18. Eleven of the patients were male and nine female. The majority, fourteen, had been in hospital less than a month, four had been in hospital since December 2006, one since November 2006, and one since late June 2006.

Of these twenty patients, two had been diagnosed with non-psychotic illnesses of personality disorder, five had depression, seven had been diagnosed with schizophrenia and six with other forms of psychosis, one being drug-induced. Seven of the patients were currently legally detained in the hospital.

Of the other wards at the service, the rehab ward provides ten beds for a temporary stay (less than 6 months), and the older person wards, fourteen beds each y shared staff with adults acute wards. One of these older person (OP) wards are used only for patients with dementia, and the other for patients with a functional mental illness. Both are acute wards.

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VIGNETTE 10

SUPPORTED LIVING

Vignette 10 is an agency that provides accommodation and support for people with enduring mental illness, living in the catchment area.

One manager oversees the two accommodation units they provide in that area, number six and number ten in the same street, which are actually part of the same building. Number six has space for six residents in a shared house, and there are support staff (social worker, nurses) onsite twenty-four hours a day. Number ten has been split into three self contained flats with official registration and independent budget, each having room for one resident,. Support staff visit number ten every day including weekends, but only for a couple of hours..People usually move from number six to number ten before they move into their own mainstream accommodation in the future.

Of the nine people that the service staff supports, one is aged sixty six and has lived there for over three years but they normally would only accept residents aged under sixty five and over the age eighteen, and are trying to find somewhere for this resident to move to in the future. Three other residents have lived there for over two years. Four have lived there between twelve and fourteen months, and one moved in recently, just a month ago.

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VIGNETTE 11

SOCIAL CARE INSTITUTION FOR ADULTS WHO NEED LONG TERM CARE

Vignette 11 is a 60 years old institution intended to take care for people with different types of disabilities and disorders. Its formal status is public social care institution for adults who need long term care. Residents in the institution are adults with chronic mental health problems, adults with moderate to severe learning disability, adults with several disorders – developmental disorders and behavioural problems, sensory disabled and physically disabled and adults with severe sensory disability who need special care for indefinite periods of time. The catchment area is the whole country. The number of residents in the service is now 430 in old but beautifully redecorated castle and buildings around it.

Management of Vignette 11 follows the rules of the act of social care. Its management is independent.

The service is financed from three sources:

- 53% social care sources– 6.603.293,86 evr per year
- 43% health care sources – 5.305.247,04 eur per year
- 4% other sources

There are employed different professionals in Vignette 11 to provide 24h support:

3 psychiatrists, 1 psychologists, 24 registered nurses, 5 social worker, 84 nurses, 82 nursing assistants, 3 kinezioterapist and 1 Dephctologist.

Residents have occupational therapy, sports activities (swimming pool in the basement of the castle, sauna), the possibility to engage in different therapies and spend summer and winter holidays in the organisation of the institution as well.

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VIGNETTE 12

NGO FOR AND WITH PEOPLE WITH ID AND THEIR FAMILIES

Vignette 12 is a nongovernmental, non confessionally committed association that works for and with people with intellectual disabilities and their families. The association acts as an umbrella organization for nine regional organizations that provides persons with intellectual disabilities online and print information on their specific care services in the nine provinces of the country. This organization also organizes trainings for professional staff on different topics related to care.

There are 12 people employed in this association: 1 executive director, 1 office management, 1 support of office management, 1 administration concerning rights, 1 trainee of administration concerning rights, 1 administration academy, 1 pedagogue/psychological specialist, 1 person for the library, 1 trainee, 1 marketing / PR-staff, 1 trainee and 1 voluntary person.

The funding is provided by the Social Ministry of Vienna and by donations.

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VIGNETTE 13

NGO FOR SUPPORTED LIVING AND/OR EMPLOYMENT FOR ADOLESCENTS WITH MENTAL ILLNESSES

Vignette 13 is a non governmental organisation that provides supported living and/or employment for adolescents with mental illnesses and/or people with severe or profound disabilities. It has eight living units in the country, and one exclusively for people with severe ID. They also allocate occupational therapy in three different districts.

The unit for people with severe ID provides 24h non acute support for 9 persons for an indefinite stay. The users are between 15 and 25 years old and the support is adapted to their needs.

The team for people with severe ID includes two voluntaries, one nurse and six carers with special training for psychiatric patients and/ or people with severe disability.

The funding is provided by the Social Ministry and by donations.

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VIGNETTE 14

NGO: FOOD DELIVERY FOR FRAIL PERSONS IN A CITY

Vignette 14 is a non governmental service that provides food delivery for people in the catchment area. The target group is especially elder frail people. The user can decide on the intensity (daily delivery, delivery on certain days and delivery of packages for a week excluding Sundays in a day time basis). It is possible to choose between several menus, including starter, main dish and dessert. Furthermore the service offers dietary food for people who suffer from food dependent illnesses, like diabetes mellitus. The users pay for this service themselves.

The team includes social workers, pedagogue and voluntary, nonprofessional staff.

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VIGNETTE 15

EMPLOYMENT FOR PEOPLE WITH SMI AND/OR ID

Vignette 15 is an employment-project of a non governmental organization. It provides the possibility of paid employment (50% of local normal salary) for people with a non acute mental disorder or an intellectual disability. There they can work, according to their agreement, daily or at least several times a week. The project includes a café as well as a second-hand-shop for books, records, CDs and DVDs. Hence there are a lot of different jobs to do and if necessary or required, the workers can be supported by at least two present caregivers. This support includes also psychosocial aspects and is adapted to the special needs of all employees. Furthermore the premises are equipped accordingly.

People can get care for at most 5 times/week, from 9:00 till 19:00 (only workdays). There are 18 users with a range of age of 21 to 56 years.

The work team is composed by caregivers with different education/profession: 1 psychologist, 2 social workers, 1 psychology student, 1 Executive Director, 2 voluntaries.

The funding is provided by social found, donations and the revenue of the shop.

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VIGNETTE 16

SUPPORTED LIVING AND/OR EMPLOYMENT FOR ID

Vignette 16 is a non governmental organisation that provides supported living care for 11 persons with mild intellectual disability for long periods of time. The users are between 25 and 45 years old. The team includes two voluntaries and five carers with special training for people with disabilities. Carers are available for users from 3pm until 8am. All users are at work from 8am until 4pm. If someone gets ill, carers can stay for the whole day in the flat.

The funding is provided by the Social Ministry and by donations.

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VIGNETTE 17

SUPPORTED HOUSING IN COMMUNITY

Vignette 17 is NGO with two services for mental health located in different buildings: long term supported housing in community for people with chronic and disabling mental illnesses; day centre and counselling. The formal status of the service is association and there is an act on functioning of associations of civil society associations. Management of the centre follow the rules of the act of this act.

The program is financed from different sources: from grants and from donations are financed day centres and counselling. Supported housing is financed by persons who live in the facility in case that the person is capable to pay the costs. In case that person is not able to pay the cost of living in the facility, the costs are paid by local community or by social service. The living in supported housing costs 22, 5 E per resident per day. They have residential care for this price. They can visit day care centre as well for free.

Here we will describe only the supported programme for the region. Residents live in rented flats with specific administration unit. 22 residents live in 8 flats: 5 flats have 3 rooms, 1 flat has 2 rooms and there are also 2 flats with one room. There are 4 social workers in the centre who are responsible for these residents. Social worker visits them according to the plan and supports them in their activities. In case of emergent need resident could contact social worker immediately 24 hours a day and social worker have to respond at once. Residents have different mental health problems. They suffer from schizophrenia, bipolar disorder, organic psychosis, comorbidity – substance use disorders and somatic diseases. One third is older than 65 years. There are 4 social workers taking care for residents. The waiting list is long.

Residents could use the programme of day centres and counselling as well. One third of them are involved in day centre activities.

Day centre and counselling are located together in a different house and are run by a specific administration, there is a large living room for different activities, a room with computers and room for group meetings. There is also a kitchen. The day centre has planned activities and there is at least two guided activities per day. There is a language course, meeting on healthy living, self support group, course for using computers, learning to cook and many others. Every second week there is guided trip to mountains and twice a year there are organised holidays. The trips and holidays have to be paid by participants. All other activities are free of charge. There are two social workers and several volunteers (up to five) who run the day centre. Every day there are thirty to forty participants. In the list of occasional users are 300 people with mental disorders.

Counselling service is organised in the same building but a different entrance. There are two social workers who run this activity. There is a phone counselling and personal counselling. The number of counselling per month is up to 30 for personal contact and up to 45 for phone contact. People could be in counselling every day when needed. There are up to ten people who need frequent contact – every week at least. The number of people per year is up to 265. The counselling is free of charge.

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VIGNETTE 18

NATIONAL ASSOCIATION OF PEOPLE WITH DYSTROPHY

The programme Transport of People with Dystrophy is the central special social programme of association as it enables and is also a condition for implementing and inclusion of people with dystrophy in all the other special social programmes and in a broader social environment. Because of their advancing physical disability people with dystrophy need not only ever increasing extent of physical help from other people, but their indispensable aid is also a wheeling chair and with that they need an adapted means of transport.

With transport vehicles adapted for transportation of physically disabled people on wheel chairs association performs transports of people with dystrophy and other physically disabled people daily across the country and abroad.

All transports are planned and organised with the help of transports-coordinators in the country. Because of technical and work-force limitations they are giving priority to transport to work place, educational institutions, doctor visits and other health institutions, other public institutions and littoral regeneration rehabilitation facility.

There are professional (social workers, psychologists) and non-professional (drivers, volunteers, companions) staff.

The service is available for people with dystrophy. People who need transport to go to work or to go to the medial care are first to serve. The transport is organised in advance, but there is a possibility to make urgent arrangement.

Every day there are up to 50 -100 people who need transport due to their disability.

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VIGNETTE 19

DAY CARE CENTRE FOR ELDERLY

Day care centre is a new form of daily institutionalized care. In Day centre they combine daily care and daily activities, which are intended for elderly people that live at home and wish to spend daily a few hours in company and involve in cognitive and psychical rehabilitation activities. At the same time daily care at least partly relieves relatives that take care for the elderly people.

Day centre is open from Monday to Friday, during 7 am and 17 pm. It offers: supervision, health and social care, nutrition (breakfast, lunch, drinks), diet, if preferred relaxation activities: tombola, reading hours, exercises, movies, social games, trips and walks, knitter hours...., workshops for memory training, various theme workshops (Carnival, Easter, New year...), celebration personal holidays.

Daily care is intended for elderly people who because of special needs require care and supervision; for elderly people who need certain forms of help and not whole-day care, with intention that they would remain as long as possible in their home environment; users of daily care have assured transport to Daily care and home.

The basic price for daily care depends on the needs of the individual, the price includes: care, social care, and daily nutrition and relaxation activities. All additional services are charged in accordance with validated and confirmed prices of services by the Council and include: expert guided exercises, yoga, music, dance and singing, workshops for creativity, memory training exercises, literary and debate club, cooking workshop, foreign languages courses etc.

These activities are intended to all who wish to actively spend the day, to all who wish to learn something new, to all who wish to do things that they already did in the past, but didn't have the time, chances of will to do them in the present, to elderly who wish to socialize with their peers, meet new people and customs etc.

The day centre was established by Nursing home Šiška. There are up to 50 elderly included in every day care and up to 100 are included in some activities. The care is financed by users. The prices are reasonable. There are 4 nurses, 2 social workers and 2 occupational therapist present every day. Other specified activities are delivered by part time workers and volunteers. In municipalities there is a trend to develop day care for elderly. There are waiting lists for users in some day centres, but people could go to another centre as well.

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The services of social care outside of the public service network are performed by legal and physical subjects that acquire the appropriate work-licence. It is a service, that is payable and is not a part of the public service. It is carried outside the centres for social work, institutions for home care, etc. You're legitimate for this service if you order it and assume the responsibilities for payment and covering of costs with regards to the service.

The service of Social Service is similar to social care, but it is more extensive and encompasses more home help, such as delivering of prepared meals, grocery shopping and delivery of groceries, preparing of woods for heating, purchasing of winter stores, laundry and ironing, garden maintenance, house cleaning and repairing, decorating, accompanying visits to shops, shows, friends or family, organization of other social meetings, pedicure, hair dressing and other similar services for body care, whole-day monitoring over personal telephone alarm, monitoring of medication use, protection and monitoring of state over night.

The Social service is organised as small enterprises with up to 15 employees. Almost every community has one enterprise and there are only few of rural areas without this service. In Ljubljana and other bigger cities there is more than one. The permission for work as Social service is given by local community government (municipality). The prices are regulated by municipality. The quality of care is supervised by Ministry of social care, family and employment. The staff is qualified (nurses, social workers, carers who finished three year secondary school for nursing) and not qualified (drivers, companions). The service is available 24 hours a day 7 days/week but not all users need 24 hours support otherwise this kind of help would be too expensive. The meals on wheels are one of the most frequently used services and it is available every day. Next most frequently used service is helping family member to wash and bath the person who is not able to do it alone. This service is used twice a week and it is not expensive.

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VIGNETTE 21

WORK AND CARE CENTRE

Vignette 21 is a work and care centre that was established in the beginning of 1984. In the first year already twenty-one mentally and physically affected adults found their place and self-confirmation in it. After ten years of existence the number of clients doubled, there were already forty of them. After 12 years, in the institution worked 75 clients and employees, in the new millennia already 100: 85 clients and 15 employees. Consequently there was a lack of basic conditions for working and living and the situation became intolerable. In 1999 the Ministry of Labour, Family and Social Affairs ratified the investment programme for the construction of new, modern object.

In 2004 the service began its work in the new location. On two floors, encompassing 1800 square feet of space, there is enough room for 120 people, sufficient for quality life and work. Although spacious, this building quickly became friendly home.

They are performing the tasks of supervising and caring, organising employment under special conditions for mentally and physically disabled adults. Employment under special conditions encompasses all forms of work that are enabling the disabled people to preserve their acquired knowledge and development of new skills.

The motive for work is not profit (they are not paid), but rather work as an element of quality life, work that brings more equal options, that means higher degree of humanity and respect of rights. In the manufacture they cooperate with numerous companies and developed their own attractive programme. In this way they acquire the majority of resources for covering the material costs, awards, trips and vacations, cultural and sport activities. Smaller, but also important source of income represent donations from benefactors. Their own manufacture programme consists of paper goods and hand embroidering products. The price of products is comparable, the quality very good. Besides developing of hand skills, this kind of products also enable work-creativity.

Now there are 25 qualified (social worker, nurse, psychologist, occupational therapist, pedagogue, technical staff) and nonqualified (drivers, cleaning staff, companions) staff.

The number of included people could not be increased due to the need of the community. There is limited amount of funds from local, regional and national government.

At the moment 95 clients are included in day work. Around 30 of them need every day the driver to pick them up and after work drive them home.

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