

DESCRIPTION AND EVALUATION OF SERVICES AND DIRECTORIES IN EUROPE FOR LONG TERM CARE

TRAINING PACKAGE

Cristina Romero, Miriam Poole, Mencía Ruiz, Hristo Dimitrov, Rafael Martinez-Leal, Angel Broshtilov & Luis Salvador-Carulla for the eDESDE-LTC Group

Executive Agency for Health and Consumers (EAHC)

Project Ref. 2007/116



eDESDE-LTC Project Annex IV: TRAINING PACKAGE- Word Package WP6 - Deliverables D10 and D12

TRAINING PACKAGE

Cristina Romero Miriam Poole Mencía Ruiz Hristo Dimitrov Rafael Martinez-Leal Angel Broshtilov Luis Salvador-Carulla *for the eDESDE-LTC Group*

This document should be quoted as follows:

Romero C., Poole M., Ruiz M., Dimitrov, H., Martinez-Leal R., and Salvador-Carulla L., for the eDESDE-LTC Group. eDESDE-LTC Training Package [Internet]. Jerez (Spain): PSICOST and Telnet; 2011. Available from: <u>http://www.edesdeproject.eu/training.php</u>.

The contents of this publication are the sole responsibility of the DESDE-LTC Group and can in no way be taken to reflect the views of the European Union

Edition: January 2011

Edits: PSICOST Pza. San Marcos nº 6, 11403, Jerez de la Frontera (Spain)

Electronic edition and design: Telnet Consulting S.L.

ISBN: 978-84-694-4347-7





eDESDE-LTC Partners

Asociación Científica PSICOST (Spain), London School of Economics (LSE) (UK), SINTEF Technology and Society (Norway), Catalunya Caixa (Spain), Družbenomedicinski inštitut ZRC SAZU (Slovenia), Public Health Association (PHA) (Bulgaria), University of Vienna (UNIVIE) (Austria), Izobraževalno raziskovalni inštitut Ljubljana (IRIO) (Slovenia)

Collaborating Partners

Dept. of Mental Health Sciences, UCL (UK); ASL-4 Centro Studi e Ricerche (Italy), Dept Research & Development, Division of Mental Health Serv. Akershus University Hospital (Norway), ETEA University of Cordoba (Spain), GPLSI University of Alacant (Spain), University Politecnica of Barcelona (Spain), OECD – Health Division (France), Ministry of Health. National Center for Public Health Protection (Bulgaria), Catalan Department of Health, DG de Planificació i Avaluació (Spain), Psychiatry Research Unit of Cantabria (WHO collaborating Centre) Univ. Hosp."Marqués de Valdecilla" (Spain), Fundació Villablanca (Spain), Delegación Municipal de Igualdad y Salud. Ayto Jerez (Equity & Health Department. Municipality) (Spain).

Acknowledgements

The eDESDE-LTC project has been funded by the Executive Agency of Health and Consumer (EAHC) Project Ref. 2007/116



eDESDE-LTC Group (members¹, collaborating members² and main subcontractors³)

José Almenara (Spain)¹ Rafael Martinez-Leal (Spain)¹ Federico Alonso (Spain)¹ Tihana Matosevic (UK)¹ Jordi Balot (Spain)¹ David McDaid (UK)¹ Murielle Bendeck (Spain)³ Cristina Molina (Spain)² Valerie Moran (France)² Anne Mette Bjerkan (Norway)¹ Carlos Mur (Spain)² Barbara Brehmer (Austria)¹ Carmen Omist (Spain)² Angel Broshtilov (Bulgaria)¹ Maria Dolores Crespo (Spain)² Miriam Poole (Spain)³ Mojca Z. Dernovsek (Slovenia)¹ Manuel Palomar (Spain)² Hristo Dimitrov (Bulgaria)¹ Rayna Popova (Bulgaria)¹ Nikolina Djurova (Bulgaria)¹ Eugeni Rojas (Spain)¹ Maria Teresa Romá-Ferri (Spain)² Mónica Duaigües (Spain)¹ Josep Fuste (Spain)² Cristina Romero (Spain)¹ Ana Fernandez (Spain)³ Mencía Ruiz (Spain)¹ Torleiff Ruud (Norway)² Luis Gaite (Spain)² Carlos García-Alonso (Spain)² Jose Alberto Salinas (Spain)¹ Luis Salvador-Carulla (Spain)¹ Juan Carlos García Gutierrez (Spain)¹ José García-Ibañez (Spain)² Antoni Serrano (Spain)³ Juan Luis Gonzalez-Caballero (Spain)¹ Daniela Seyrlehner (Austria)¹ Karina Gibert (Spain)² Josep Solans (Spain)¹ Sonia Johnson (UK)² Lilijana Sprah (Slovenia)¹ Giuseppe Tibaldi (Italy)² Birgitte Kalseth (Norway)¹ Martin Knapp (UK)¹ Jose Luis Vazquez-Barquero (Spain)² Carolina Lagares (Spain)¹ Britt Venner (Norway)¹ Paula Llull (Spain)¹ Germain Weber (Austria)¹ Teresa Marfull (Spain)³ Elisabeth Zeilinger (Austria)¹

CONTENTS

FOF	REWORD	.VI
LIS	T OF MAIN ABBREVIATIONS	VII
LIST	T OF TABLES AND FIGURES	VII
1.	INTRODUCTION	1
2.	eDESDE-LTC TRAINING PACKAGE	2
3.	TRAINING PACKAGE AT THE eDESDE-LTC WEBPAGE	4
4.	FREQUENTLY ASKED QUESTIONS (FAQ)	5
5.	USE OF THE eDESDE-LTC TRAINING PACKAGE	5
6.	TRAINING COURSE	6
7.	EVALUATION OF THE TRAINING COURSE	8
8.	CONCLUSIONS	10
9.	ANNEXES	11
	NEX I: TRAINING LIST OF REFERENCES	11
	NEX II: eDESDE-LTC CASE VIGNETTES	12
	NEX III: FREQUENTLY ASKED QUESTIONS (FAQ)	27

FOREWORD

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

The eDESDE-LTC Training Package comprises the training documents designed by PSICOST and the training procedure followed and tested by PSICOST (Spain) and SHA (Bulgaria). The training package is available at <u>http://www.edesdeproject.eu</u>¹.

Luis Salvador-Carulla Coordinator of eDESDE-LTC Project

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

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

LIST OF MAIN ABBREVIATIONS

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

LIST OF TABLES AND FIGURES

TABLES

Table 1. Milestones in the development of the training package	1
Table 2. Structure of the eDESDE-LTC training package (beta version)	5

FIGURES

Figure 1. eDESDE-LTC webpage	
------------------------------	--



1. INTRODUCTION

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.

Basic training on the use of DESDE-LTC is required before the instrument can be used.

PSICOST has coordinated the elaboration and production of a training programme (eDESDE-LTC Training Package) to facilitate learning and practical use of the instrument.

This report provides a summary of the development and contents of the training package within the eDESDE-LTC project. It follows the Milestones described in the Annex I of the project proposal (Table 1).

Date	Milestone
<u>Mo12</u>	Training Package development (phase I)
<u>Mo 21</u>	Training course (on line) (D10)
<u>Mo22</u>	Training Package (beta version) (phase I). (D12)
<u>Mo30</u>	Final review of training package
<u>Mo 31</u>	Training package report at the final technical report (D19 Annex IV)
<u>Mo31</u>	Training package incorporated to the webpage (D20)

Table 1. Milestones in the development of the training package



2. eDESDE-LTC TRAINING PACKAGE

The design of the DESDE-LTC training programme followed a blended methodology (face-to-face and online learning).

The content of eTraining Package was developed by PSICOST. Four members of PSICOST research team (M. Poole, C. Romero, L. Salvador-Carulla and R. Martinez-Leal) have actively participated in the development of the different components of this package. The first outline of the DESDE-LTC training package included a reference manual and other tools such as videos, case-vignettes and examples, and frequently asked questions. It was presented to the DESDE-LTC consortium at the project meeting held in Barcelona (Spain) in March 2009 (Phase I). It was agreed that the training package would be available on-line and therefore it was developed in coordination with the development of the eDESDE-LTC webpage.

Two initial training sessions were held in November and December 2009 to test the preliminary training package using an on-line Tele-Training Platform made by ETEA (collaborating partner). This platform uses Adobe connect for videoconference an elearning systems and has been successfully applied to e-learning by this organisation. However and due to problems in its usability at the preliminary sessions, it was decided to use the eDESDE-LTC website as the training platform for this training phase as well and not only for the final phase.

The beta version of DESDE-LTC training package (**Deliverable 12**) was completed in March 2010. It provided a reference guide with theoretical and practical indications for trainees to learn strategies for coding LTC services. This version was used for training two research groups in Spain and in Bulgaria and a final version was prepared after the completion of a pilot study in both countries in January 2011. The beta version of the training package was revised by the other partners of WP6- SINTEF (Norway), LSE (UK), UNIVIE (Austria), IRIO (Slovenia) PHA (Bulgaria) and SRC SASA (ZRC SAZU) (Slovenia) at the meeting scheduled in Reus in November 2010. A final version of this work package was produced in January 2011(**Deliverable 20**). The training package included the following material:

a Index



List of main sections of DESDE-LTC Training Package.

b DESDE-LTC Training Material

b.1. Key papers. Key and support references useful for the training (see Annex

I)

b.2. DESDE-LTC General Guide

b.3. DESDE-LTC Toolkit

- c.1. DESDE-LTC Instrument
- c.2. DESDE-LTC Classification and Coding System
- **b.4.** Case-vignettes (see Annex II)
- b.5. Frequently Asked Questions (see Annex III)

c eDESDE-LTC Video-tutorials

c.1. Origin and development of DESDE-LTC instrument (Video-tutorial)

This video provides an introduction about the origin, previous studies and development of DESDE-LTC until the current version.

c.2. DESDE-LTC Training Guidelines (Video-tutorial)

This set has a video-tutorial that provides a detailed explanation of the structure, functioning and application of DESDE-LTC instrument. It also includes a summary of the training package.

c.3. DESDE-LTC Guided cases (Video-tutorials)

This is a collection of three video-tutorials that illustrates the steps that must be followed for appropriately classify and code the proposed cases

d DESDE-LTC Case book

The case vignettes have been compiled as a separated eBook for facilitating training. Case vignettes contain descriptions of actual services for different target groups with LTC needs in 6 European countries. It also includes other examples of units of analysis at meso and micro-level that do not fulfil the criteria for "Basic Stable Input of Care" or "services" in the eDESDE-LTC Classification and coding system.



e DESDE-LTC Training Evaluation Questionnaire

An evaluation questionnaire for assessing the usability of the training package was made by the University of Viena. It is available at the website.

3. TRAINING PACKAGE AT THE eDESDE-LTC WEBPAGE

The material was incorporated to the eDESDE webpage² (Figure 1) (**Deliverable 12**). Table 2 shows the structure and type of formats available for every subsection of the training package in the website. The Training Package section explains the origins of the instrument and provides guidelines and case studies to facilitate training on how to use the instrument. All subsections are available in PDF documents that can be downloaded from the eDESDE-LTC web-page Four of them are available as video tutorials³ in English 1) Origin and development of the instrument, 2) Training eDESDE-LTC Guidelines, 3) three guided Cases. The presentation slides can also be downloaded in PDF format.



Figure 1. eDESDE-LTC webpage

http://www.edesdeproject.eu/training.php

² http://www.edesdeproject.eu/training.php

³ Video tutorials are based on the beta version of the instrument.



Subsection	Video tutorial	PDF file	PDF presentation
Index			\checkmark
DESDE-LTC Training material			
Key papers		✓	
DESDE-LTC General Guide		✓	
DESDE-LTC instrument			
DESDE-LTC Classification and		✓	
Coding System		v	
Origin and development of the	1		\checkmark
instrument	v		
DESDE-LTC Training Guidelines	\checkmark		\checkmark
Training Tutorials: Guided case 1	\checkmark		\checkmark
Training Tutorials: Guided case 2	\checkmark		\checkmark
Training Tutorials: Guided case 3		✓	
DESDE-LTC Casebook		✓	√
Introduction			\checkmark
Exercises		✓	
FAQ			web
DESDE-LTC Evaluation Questionnaire		\checkmark	

Table 2. Structure of the eDESDE-LTC training package (beta version)

4. FREQUENTLY ASKED QUESTIONS (FAQ)

A series of key questions were identified at the nominal sessions, training courses and pilot testing of eDESDE-LTC. A list of 11 FAQ have been incorporated into de webpage.

5. USE OF THE eDESDE-LTC TRAINING PACKAGE

The training material (PDF documents and video tutorials), is available in English and it can be downloaded from the DESDE-LTC webpage. It is intended to support trainees in their training process. Trainees include health service researchers, providers, planners and any stakeholder in the LTC field interested in standardised assessment and comparison of services. Although face-to-face training is required and it can be requested from the eDESDE-LTC consortium, the training package is open access

To get a first on-line training it is recommended to follow the next steps:



1°. The trainee should watch the video 'Origin and development of the instrument' and review the suggested key papers. This task is useful to understand the framework, the objectives of the instrument and its structure.

2°. The trainee should carefully read the DESDE-LTC instrument and classification and coding system documents and video tutorials.

3°. The trainee should follow step by step three guided video tutorials of the classification and coding of selected services.

4°. Case vignettes also provide 21 different cases selected from different European countries useful for practice with the classification system. A list with services correct codes is provided at the end of the document for trainees to check their answers.

5°. Finally, the trainee should fill in an evaluation questionnaire of the on-line preliminary course.

Trainers from PSICOST research team are available to answer questions and doubts.

6. TRAINING COURSE

The applicability and quality of the training package has been tested through courses in the two countries which participated in the Pilot study (**D10**). First a meeting of trainers (LSC, MP, CR, and HD) was organised during the 2nd Project Meeting (Barcelona, 6-8 March, 2011). In this meeting general aspects of the use of the instrument were discussed and the use of training material in Spain and in Bulgaria was reviewed. Once the training material was available, an on-line training session was held in May 6th, 2009.

In Spain the course was organised in collaboration with the Catalan Department of Health (collaborating partner of DESDE-LTC). It consisted on two face-to-face meetings at the Catalan Department of Health in Barcelona and on-line completion of the course by 7 trainees with different backgrounds in health service research and management (psychology, medicine, geography, health service research). These 7 experts had different levels of experience in the use of related instruments (ESMS/DESDE). Two of them participated in the pilot study carried out in Madrid in September-October, 2010 and in the reliability exercise of the new instrument. Other two trainees participated in the service coding for the reliability and validity study.

The trainees in the face to face and online training course on DESDE-LTC in Spain are



listed below.

- Jose Alberto Salinas. Geographer. (ETEA, Cordoba)
- Alicia Rodriguez Psychologist (PSICOST, Jerez)
- Mencia Ruiz. Psychologist (PSICOST, Jerez)
- Susana Ochoa. Psychologist (Sant Joan de Deu, Sant Boi, Barcelona)
- Ana Fernandez. Psychologist (Sant Joan de Deu, Sant Boi, Barcelona)
- Teresa Marfull. Health manager. (Barcelona)
- Antoni Serrano. Psychiatrists and health researcher. (Sant Joan de Deu, Sant Boi, Barcelona)

The first meeting took place on 24th May 2010. It was aimed at reviewing the training material and to explain the procedure. The second meeting was held after the completion of the online course on June 23rd 2010. In this second meeting the instrument and the training package were used. The changes in the instrument and the coding system suggested by trainees were also taken into account for preparing the beta version of the training material.

The training course in Bulgaria was conducted by one trainer (HD) in June 2010. The course was provided to the researchers who collected the data for the Pilot study in Sofia (Bulgaria) by the two project national members (HD, AB). The on-line training material was used to complement the face-to-face training.

Both, trainers and trainees got direct experience in using the instrument both in the pilot study and in the validity and reliability study. At the last project meeting in Reus (Tarragona) the assessment made in Bulgaria was revised by the Spanish coordination team and some further checking was requested.

An interesting observation at the Pilot was the problems of the interaction of researchers with service managers that had never took part in a scientific endeavor aiming a classification of services and/or measurement of service usability and quality of services. The attitudes of the managers towards the interview and the questionnaire itself was interesting to observe; these attitudes varying from benevolent attention to the topic (with most of the respondents), to an apprehensive concern (with some of them). In any case a recommendation to assess this issue in the procedure of completion of eDESDE-LTC was made.



To measure the psychological impact of eDESDE procedure and the instrument on service personnel was not a pre-set objective of the current project. Nevertheless, we think, these effects should be taken into consideration in further application of eDESDE in transnational comparative studies of services. First it will be a practical issue in the training process where trainers from an "experienced" country teach evaluators from and "inexperienced" country how to contact services and get information from managers. Next, trans-cultural issues in data collection should be brought into a research that studies not only service inputs (such as availability of services in a certain geographical areas), but service processes as well. An interesting aftermath of the project would be to present service managers from Sofia and Madrid with the results of the comparative study and ask them their opinion and propositions of change. This could also involve decision-making figures from the two municipalities and be realized in focus-group format or in a trans-national project.

In the case of Sofia a major problem was to fill in those parts of the questionnaire, requesting information of the exact weekly and daily activities of the services (for example how many hours per day are dedicated to cognitive behavioral therapy, to musical therapy etc.). The reason is that in Bulgaria specific therapeutic programs are not well structured in time and space. In residential services, the research team was often given answers such as "We have a social worker and an art therapist, but she does not engage the clients on a strict time schedule, everything depends on the needs of the day". In contrast, programs in community ambulatory services were much better scheduled, so that respondents could provide a much more structured information on the weekly schedule of activities.

7. EVALUATION OF THE TRAINING COURSE

In order to evaluate the training course two different instruments addressing different target groups were designed by the University of Viena: an evaluation questionnaire for trainees and an evaluation questionnaire for trainers asking about the adequacy of this type of training, the materials, the applicability and quality of the training. The completion of these evaluation questionnaires was scheduled for December 2010 after the trainees had got enough experience in the use of eDESDE-LTC and could



effectively assess the usability of the training package. More details are provided in the Quality Assessment Report.

Apart from the two questionnaires, open remarks were gathered from trainers and trainees who participated in the pilot and reliability studies in both countries. A common remark both in Spain and in Bulgaria, was the need to incorporate an additional training module on the eDESDE procedure including 1) preparation of the study and contact with national and/or regional agencies, 2) contact with local agencies and services, 3) data gathering and interviews by researchers with service managers; 4) presentation and use of the information. Both groups highlighted the need of the face-to-face training in spite of the availability of the on-line training material.

Spanish trainees also suggested for a future stage to develop a more user-friendly fully computerised version of the instrument using structured algorithms for the coding of service so as to allow direct on-line completion by service managers.

Participants in Bulgaria highlighted the fact that interviewees, although subject to numerous check-ups and control procedures, had never took part in a scientific endeavor aiming a classification of services and/or measurement of service usability and quality of services. Therefore the attitudes of the managers towards the interview and the questionnaire itself was interesting to observe; these attitudes varying from benevolent attention to the topic (with most of the respondents), to an apprehensive concern (with some of them).

To measure the psychological impact of eDESDE procedure and the instrument on service personnel was not a pre-set objective of the current project. Nevertheless, we think, these effects should be taken into consideration in further application of eDESDE in transnational comparative studies of services. First it will be a practical issue in the training process where trainers from an "experienced" country teach evaluators from and "inexperienced" country how to contact services and get information from managers. Next, trans-cultural issues in data collection should be also considered in the training process.

In the case of Sofia specific problems appeared when filling several sections of the instrument. For example it was difficult to gather information on weekly and daily



activities carried out in some services (for example how many hours per day are dedicated to cognitive behavioral therapy, to musical therapy etc.). This may be attributed to the fact that specific intervention programs are not well structured in time and space in Bulgaria. In residential services, the research team was often given answers such as "We have a social worker and an art therapist, but she does not engage the clients on a strict time schedule, everything depends on the needs of the day". In contrast, programs in community ambulatory services were much better scheduled, so that respondents could provide a much more structured information on the weekly schedule of activities. These local problems should be taken into account for future training strategies.

Given the fact that the final classification of Bulgarian services, produced by the local team, had to be thoroughly revised by Spanish headquarters, it cannot be said that training of the Bulgarian researchers was satisfactory. This result however, could be easily amended with the refinement of the overall training process, such as employing face-to-face training sessions delivered by highly experienced trainers to local trainees.

It should be pointed out that satisfaction of Sofia team with the instrument and the mapping exercise was high; participants declaring that these processes helped them to orientate better in the local system. This may indicate that eDESDE-LTC approach may be useful for educational activities and could easily fit into the curricula of mental health professionals, social workers, and other relevant health and social professionals.

8. CONCLUSIONS

eDESDE-LTC could be satisfactorily used when adequate training is provided. However training requires a face-to-face intensive course conducted by experienced trainers. The eDESDE-LTC training package is a useful complementary tool but does not replace face-to-face training. Apart from the use of the instrument and the coding system it is necessary to provide complementary information on how to conduct a research in this area using the eDESDE-LTC system. This complementary information should address relevant issues such as contact with national and local public agencies, contact with local service managers, data collection and data interpretation. In the next future a computer completion of the questionnaire and the coding system using structured algorithms may facilitate the training and the use of the instrument.

9. ANNEXES

ANNEX I: TRAINING LIST OF REFERENCES

DESDE USE IN SERVICES FOR DISABILITIES / LONG TERM CARE

- Salvador-Carulla L, Poole M, Gónzalez-Caballero JL, Romero C, Salinas JA, Lagares-Franco CM for RIRAG/PSICOST Group and DESDE Consensus Panel. Development and Usefulness of a Instrument for the Standard Description and Comparison of Services for Disabilities DESDE. Acta Psychiatr Escand 2006: 114 (suppl. 432): 19-28.
- Romero C, Salinas JA, Saldivia S, Grandón P, Poole M, Salvador-Carulla L, García Gutiérrez JC. Comparative study of mental health services availability and use in Chile and Spain. International Journal of Integrated Care 2009: 9.

DESDE USE IN SERVICES FOR ELDERLY POPULATION

Salvador-Carulla L. Descripción estandarizada de los servicios de discapacidad para ancianos en España. IMSERSO [en línea] 12/07/2005 [fecha de acceso 18 de enero de 2009]: <u>http://www.imsersomayores.csic.es/documentos/documentos/imsersoestudiosidi-24.pdf</u> (SPANISH)

ESMS USE IN SERVICES FOR MENTAL HEALTH

- Johnson S, Kuhlmann R and the EPCAT Group. The European Service Mapping Schedule (ESMS): development of an instrument for the description and classification of mental health services. Acta Psychiat Scand 2000; 102 (Suppl. 405): 14-23.
- Salvador L, Romero C, Martínez A, Haro JM, Bustillo G, Ferreira A, Gaite L, Johnson S for the PSICOST Group. Assessment instruments: standardization of the European Service Mapping Schedule ESMS in Spain. Acta Psychiatrica Scandinavica, (suppl) 405 (102), 24-32, 2000.
- Salvador-Carulla, L., Tibaldi, G., Johnson, S., Scala, E., <u>Romero, C.</u>, & Munizza, C. Patterns of mental health service utilisation in Italy and Spain: an investigation using the European Service Mapping Schedule. *Social Psychiatry and Psychiatric Epidemiology*, 40(2):149-59, 2005. ISSN: 0933-7954.

LONG TERM CARE

- OECD. The OECD Health Project: Long Term Care for Older People. Paris: OECD Publishing; 2005.
- Office of Disability, Aging, and Long-Term Care Policy. Glossary of Terms. United Status. Departament de Of Health & Human Services [on line] 12 November 2003 [cited 2009, January the 18th] URL available from: <u>http://aspe.hhs.gov/daltcp/diction.shtml</u>

ANNEX II: eDESDE-LTC CASE VIGNETTES

This annex 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 real 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 in the document "Instrument – Mapping Tree" and using the eDESDE-LTC coding.

NUMBER	GENERIC DESCRIPTION
V1	Workshop for occupational therapy of people with disabilities
V2	Social Home for people with impaired vision
V3	Agency for social assistance. Department for integration of people with disabilities
V4	Municipal sheltered home for people with ID
V5	Municipal day care centre for people with mental disabilities
V6	District Mental Health Centre
V7	Community Mental Health Team
V8	Day Centre
V9	Hospital
V10	Supported Living
V11	Social care institution for adults who need long term care
V12	NGO for and with people with ID and their Families
V13	NGO for supported living and/or employment for adolescents with mental illnesses
V14	NGO: Food delivery for frail persons in a city
V15	Employment for people with SMI and/or ID
V16	Supported living and/or employment for ID
V17	Supported housing in community
V18	National Association of People with Dystrophy
V19	Day Care Centre For Elderly
V20	Payable services – Social Service services
V21	Work and care centre

The coding of every vignette is provided in table 3.

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 sometimes get consultations from a psychologist, engaged on a honorary basis, normally once per month.

eDESDE-LTC CODE _____

VIGNETTE 2

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.

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.

eDESDE-LTC CODE _____

VIGNETTE 4

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.

eDESDE-LTC CODE

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.

eDESDE-LTC CODE _____

VIGNETTE 6

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).

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.

eDESDE-LTC CODE __

VIGNETTE 8

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.

eDESDE-LTC	CODE

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.

eDESDE-LTC CODE _____

VIGNETTE 10

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.

eDESDE-LTC CODE _

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 kineziotherapist and 1 Dephectologist.

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.

eDESDE-LTC CODE ____

VIGNETTE 12

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.

Vignette 13 is a nongovernmental 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.

eDESDE-LTC CODE _____

VIGNETTE 14

Vignette 14 is a nongovernmental 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.

Vignette 15 is an employment-project of a nongovernmental 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

eDESDE-LTC CODE _____

VIGNETTE 16

Vignette 16 is a nongovernmental 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.

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 counseling 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.

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 indispensible 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.

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 therapists 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.

eDESDE-LTC CODE _

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.

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.

Nº VIGNETTE	DESDE CODE
1	D3.2 O10.1
2	R11 R8.2
3	I1.1 A5
4	R11
5	D4.1
6	O9.1d O2.1
7	O8.1d O2.1
8	D3.2
9	R2 O3.1 R4
10	AR11 AR13
11	R11
12	12.1.2
13	R11
14	O5.2.1 S1.3
15	D2.2
16	AR11
17	R11 D4.1 O8.1
18	A2
19	ED4.1
20	O5.2.3
21	D3.2

Tabla 3. eDESDE-LTC: final Coding of the Case-Vignettes

For any comments regarding this coding please refer to <u>http://www.edesdeproject.eu/contact.php</u>

ANNEX III: FREQUENTLY ASKED QUESTIONS (FAQ)

1. What is LONG TERM CARE (LTC)? (See Guide)

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).

2. What is DESDE-LTC? (See Guide)

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 instrument is intended to compile service information on input and process at the meso (-level (health/social 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).

3. What is the eDESDE-LTC Training Package?

The training material (PDF documents and video tutorials), is available in English and it can be down-loaded from the DESDE-LTC webpage. It is intended to support trainees in their training process.

4. Who can be a trainee for the eDESDE-LTC Training Package?

Trainees include health service researchers, providers, planners and any stakeholder in the LTC field interested in standarised assessment and comparison of services. Although face-to-face training is required and it can be requested from the eDESDE-LTC consortium, the training package is open access

5. What are the 'Main Types of Care' (MTC)?

DESDE-LTC describes services according to a number of descriptors classified at different levels of care:

-First Level – Status of user. This level relates to the clinical status of service users (i.e. whether there is a crisis situation or not).

-Second Level – Type of general of care. This level describes the general typology of care (home & mobile/non-mobile, hospital/non hospital,..).

-Third Level – Intensity of care. This level refers to the intensity of care that the service can offer.

-Fourth Level – Subtype of care. This level provides a more specific description of the type of care in a setting.

-Fifth Level – Additional Qualifiers. This level incorporates additional qualifiers that may be needed to differentiate between similar care settings.

6. What is the target population of DESDE-LTC?

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 (ICD-10); iii) mental disorders (ICD-10), iv) 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).

7. 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 9 of the instrument. 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 (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 in this section is summarised in Appendix I with a list of the principal characteristics of the services analysed. It is complemented by a glossary of terms with specific examples of the codes established by the instrument in Appendix II.

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 service 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: Information, Accessibility, Self-help, Out-Patient, Day Car and Residential. 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.

8. Does the mapping of services include services outside the catchment area?

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.

9. When utilisation data are lacking or they are incomplete how can the coding be completed?

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 "O".

-Grade II: extended general information at the level of sub-branches -i.e. 20 places for home & mobile and medium intensity (classified as O6) and 70 non mobile and low intensity places for (classified as O10) 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.

10. Are hospitals Basic Stable Inputs of Care?

Hospitals are meso-organisations. They don't fulfill the criteria of a BISC because they constitute a higher unit of analysis. A hospital is constituted for a set o BSICs in the same location.

11. Are emergency rooms Basic Stable Inputs of Care)?

These services should be rated as BSIC if they fulfil the following criteria:

-Criterium "A": The service is registered as an independent legal organisation (with its own company tax code or an official register). This register is separate and not as a part of a meso-organisation (for example a service of rehabilitation within a general hospital) IF NOT:

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

- Criterium "C": The service fulfils 4 additional descriptors:

C1. To have its own professional staff.

C2. All activities are used by the same users.

C3. To have its own premises and not as part of other facility (e.g. a hospital)

C4. Separate financing and specific accountancy

C5. Separated documentation when in a meso-organization

12. What are "mobile services" ?

Mobile services or BSIC are facilities where contact with users occurs in a range of settings outside the service premises including users' homes, as judged most

appropriate by professionals and users. In order to provide more clarity to this group it has been re-named 'Home and mobile'. For a service to be classified as 'home & mobile' at the eDESDE-LTC, at least 50% of contacts should take place away from the premises at which the service is based. There are several services which are difficult to code and where additional information is needed:

- Services that provide care to other services (i.e. a liaison unit providing care on a weekly basis to a nursing home) In this case the service will be classified as 'home & mobile' if at least 50% of contacts 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 Nonmobile code. In other cases of mobile outpatient care an additional qualifier "d" could be provided to describe its mobile activity.

- Services which provide care in a different setting every day of the week (for example rural services that provide care on a different municipality from Monday to Friday). Although in this case the main site of provision for service delivery vary from day to day 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. A fix scheduled day is assigned for service delivery which is actually 'non-mobile'.

