



eDESDE-LTC

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

PILOT STUDY

Comparison of availability of services for Long Term Care in Madrid (Spain) and Sofia (Bulgaria)

*Luis Salvador-Carulla, Hristo Dimitrov, Miriam Poole, , Mencía Ruiz, Angel
Broshtilov, Cristina Romero, Rayna Popova ,Carlos García-Alonso and
José Alberto Salinas-Pérez, for the eDESDE-LTC Group*

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Luis Salvador-Carulla

Hristo Dimitrov

Miriam Poole

Mencía Ruiz

Angel Broshtilov

Cristina Romero

Rayna Popova

Carlos García-Alonso

José Alberto Salinas-Pérez

for the eDESDE-LTC Group

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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), 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).

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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
Anne Mette Bjerkan (Norway) ¹	Valerie Moran (France) ²
Barbara Brehmer (Austria) ¹	Carlos Mur (Spain) ²
Angel Broshtilov (Bulgaria) ¹	Carmen Omist (Spain) ²
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
Mónica Duaigües (Spain) ¹	Maria Teresa Romá-Ferri (Spain) ²
Josep Fuste (Spain) ²	Cristina Romero (Spain) ¹
Ana Fernandez (Spain) ³	Mencía Ruiz (Spain) ¹
Luis Gaité (Spain) ²	Torleiff Ruud (Norway) ²
Carlos García-Alonso (Spain) ²	Jose Alberto Salinas (Spain) ¹
Juan Carlos García Gutierrez (Spain) ¹	Luis Salvador-Carulla (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
Birgitte Kalseth (Norway) ¹	Giuseppe Tibaldi (Italy) ²
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

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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 of care availability and use.

The eDESDE-LTC Pilot Study describes the availability and comparison of services for long term care (mental health, intellectual disabilities, physical disabilities) in two macrourban areas with largely divergent care systems: Sofia (Bulgaria) and Madrid (Spain). The Pilot study is available at <http://www.edesdeproject.eu>¹.

Luis Salvador-Carulla

Coordinator of eDESDE-LTC Project

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

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

LIST OF MAIN ABBREVIATIONS

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

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1. INTRODUCTION

Until very recently, the parameters for the standardization of instruments in the evaluation of services did not include pilot and demonstration aspects. (1). However, these aspects are highly relevant with regard to the feasibility of assessment instruments in healthcare (2); especially in eHealth (3) and in impact analysis (4).

The eDESDE-LTC has been designed to facilitate the classification, coding and comparative description of long-term healthcare services. As such, it is important to select geographical areas which are highly diverse with respect to their healthcare systems (5,6); and that from these varied systems it is also important to select those areas with the greatest level of complexity and diversity of services on the basis that a tool which is adequate to describe these areas will also be suitable in less complex ones. Consequently, complex areas in macro-urban environments were previously chosen (7,8).

The aim of this study is to analyse the instrument's usability and eDESDE-LTC coding system to carry out international comparison of services (9). To this end, two macro-urban areas with distinct Socio-Healthcare Systems have been studied in very different countries (Bulgaria and Spain).

2. METHOD

2.1 WORKING GROUP

The pilot study for the evaluation of the instrument and the eDESDE-LTC standardised coding system operates within the framework of the international eDESDE-LTC "Electronic Standard Coding and Mapping of Services for Long-Term Care" project financed by the Executive Agency for Health and Consumers (EAHC) over the period 2008-2010. It is a transversal, descriptive, comparative ecological study of the long-term care services in Madrid and Sofia.

The study has been carried out by the two project partners, the PSICOST Research Association (Spain) and the Public Health Association (PHA) (Bulgaria), and with the

help of Technology and Society (SINTEF) (Norway). The study was conducted between June and December, 2010. Data collection was effected during the months of September and October, 2010.

The working group collaborated with 3 evaluators in each country, 2 experts in the instrument who have supervised the entire process (LS and CR), and the support of SINTEF.

2.2 STUDY SCOPE

Within those countries participating in the project, the healthcare systems of Spain and Bulgaria (Table 1) were chosen due to their highly distinct characteristics (10-13) which permitted testing of the instrument’s capacity to describe a wide range of services and the organisation of long-term care. At a local level, macro-urban areas corresponding to their national capitals were selected (Figure 1 and Table 2).

Table 1. Bulgaria and Spain.

	Spain	Bulgaria
Inhabitants	46,030,109	7,563,710
Area	504,030 km ²	110,993.6 km ²
Gross domestic product (Purchasing power parity)	\$29,651	\$12,052
Human Development Index (between 0-1)	0.863	0.743

Source: INE and NSI, 2010.

Figure 1. Location of studied areas: Madrid and Sofia

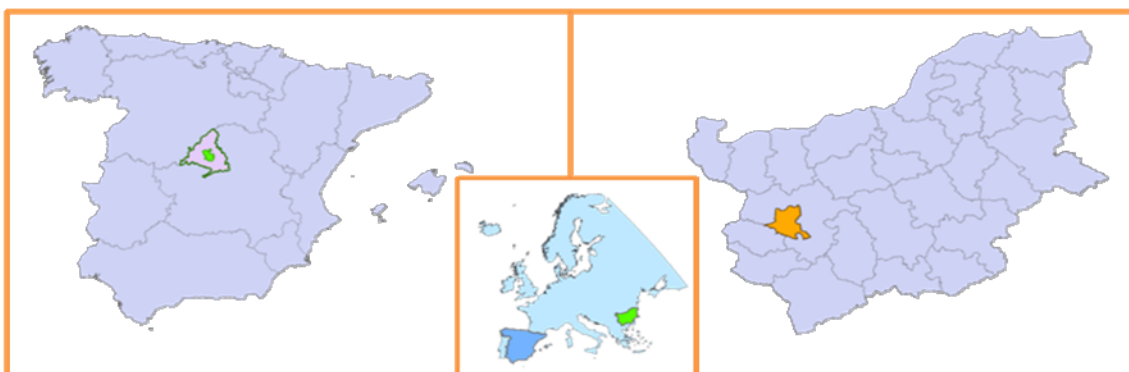


Table 2. Socio-demographic indicators for Madrid and Sofia.

	Madrid	Sofia
Inhabitants	3,255,944	1,249,798
Area	607 km ²	492 km ²
Density	4,856 inhabs/km ²	2,532 inhabs/km ²
Ageing index	136.9	113.3
Foreign immigration rate	17.4%	0.8%
Unemployment rate	12.5%	3.9%

Source: INE and NSI, 2009.

The municipality of Madrid is the capital and the most populated city in Spain. Situated in the centre of the Iberian Peninsula, it has an area of 607 km². In the year 2008 it had a population of 3,255,944 inhabitants with a density of 4,856 inhabitants/km². The ageing population index is 136.9 people over the age of 64 for every 100 people younger than 16; and the immigrant population represents 17.4% of the total. The unemployment rate is 12.5% of the active population.

The city of Sofia is the capital of Bulgaria and the city with the greatest number of inhabitants. It is located in the west of the country, with a population of 1,249,798, and covers an area of 492 km². Population density is 2,532 inhabitants/km². The ageing population index is 113.3 elderly for every 10 juveniles. Some 0.8% of the population of Sofia does not have Bulgarian nationality. The unemployment rate is 3.9% of the active population.

In summary, Madrid has a higher number of inhabitants, 2 million more, and greater population density than Sofia. Its population is also older, with a higher proportion of elderly people than children and adolescents. Although Madrid has a higher level of incomes, its unemployment rate is much higher than in Sofia.

2.3 SAMPLE

Time framework: The reference year for the study is 2010. In common with previous studies, it has used the information closest to this reference year in the databases and census.

Analysis Unit

For *categorization* of social and health services covering those people with long-term care needs, the minimal functional unit, or 'Basic Stable Inputs of Care' (BSIC) as it is defined in the eDESDE-LTC (14), was selected. The DESDE-LTC system defines a 'service' as the Basic Unit of Care comprised of an administrative unit, an organized group of structures, and professionals who provide healthcare. The Basic Unit of Care or service only refers to care functions and not to other inputs (products and devices) or to procedures (operations). The functions provided by the "micro-organization" can be described as the smallest analysis unit.

For the standardized description of the services or BSIC and its coding, the 'Main Types of Care' (MTC) indicated in the reference instrument (14) have been used. The MTCs are the main description of the activity that a service provides which is focused on a particular group of patients.

Excluded from the present analysis are those generic services which, despite being made available to this group, are not provided in a preferential way. For this, cut-off points have been used according to the percentage of the population catered for by the services indicated in the eDESDE-LTC (14) instrument. Long-term care services for the elderly have not been included in this study given the different pattern of care in this population and the possibility of carrying out a separate analysis in their case. Forensic services were described but they have not been included in the pilot comparability study.

2.4 MATERIAL

The eDESDE-LTC Instrument

The ‘Description and Evaluation of Services and Directories in Europe for Long-Term Care’ (DESDE-LTC) is an instrument for standardized description and classification of Long-Term Care (LTC) services in Europe (14). The DESDE-LTC is an adaptation of the “European Service Mapping Schedule” (ESMS-I) (15) (also including ESMS-II modifications), and the Standardized Diagram of Services for Disability in Spain (DESDE) (16) and related instruments (DESDAE and DESDE). The DESDE-LTC was developed by a European consortium and has been financed by the Executive Agency for Health and Consumers (EAHC) (Project Ref. 2007/116).

As in the case of the original instrument (European Service Mapping Schedule - ESMS), the DESDE-LTC serves as a mapping tree or system of diagrams which allows the classification of services and the degree to which they are used by those in the selected area. In this way, the tree structure of the coding system is maintained and this permits international comparisons.

2.5 PROCEDURE

Training

Two courses were undertaken to train the evaluators involved in collecting information on the instrument and the eDESDE-LTC standardized coding system. In the case of Spain, the training was done in two face-to-face sessions following revision of the online material and contact with the group coordinator to resolve any queries during the evaluation period. In the case of Bulgaria, a previous session with the study coordinator in Bulgaria was conducted and this, along with the support of the online material, covered local training. Subsequently, a review was conducted by the coordinators of each team of both coded services in each catchment area and particular cases through the data collected, followed by a further review of services with questionable coding in the case of Bulgaria.

In both cases the eDESDE-LTC (17) training package was used as online material.

Data collection

Between June and August, the evaluators in both countries contacted the relevant social and healthcare administrations to request permission to contact the services and consult their resource lists. In Madrid, this involved The Health Board (Office of Coordination of Mental Health) and the Board of Family and Social Affairs, and in Sofia the Municipal Directorate for Social Care and the National Agency for people with disabilities. The catalogues of all the institutions were examined to select the services that met study inclusion criteria.

Further contacts were made with the medical services by postal letter, telephone and fax for collection of basic information related to SECTION D: Instrument Service Inventory. In this phase new localized services were added through key contacts or service managers.

Subsequently, the working group established individual contacts with some service managers (depending on their availability) where Section D or the DESDE-LTC Inventory Sheet had been exhaustively completed for each one. In Bulgaria over 60% of data collection was done face to face. Not all services with identical profiles were contacted by the team—we relied on public registers. Collecting information from the field took approximately one month.

In Bulgaria, contacting service managers and arranging interviews from public services was not a difficult task, since we had the official permission. Managers of private LTC services, such as hospices, were much more reserved; often declining to provide basic information.

All the information was gathered by two researchers in both settings and revised by a coordination team in Bulgaria (HD & AB) and Spain (LSC, MP, CR). The Spanish coordination team also revised the coding made in Bulgaria.

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. In cases of doubt regarding the codes, telephone contact was again made with

the centre's reference individual to collect new information or to clarify information already provided.

Data gathering in Sofia took one month whilst two months were needed in Madrid. After a preliminary analysis of the data, a comparison and a full review was made at the final project meeting in Reus (November 2010). As problems were identified in the coding assignments carried out in Sofia, data from this location were re-assessed in December 2010.

Data analysis

With the aim of analyzing the results and comparing the levels of care in the study areas, the Basic Stable Inputs of Care (BSIC) were organized into 15 groups to facilitate their analysis and interpretation (Table 3). These groups categorized BSIC codes with similar general characteristics situated in the first levels of the three branches with greater service diversity (residential care, daycare and outpatient care), and the total codes of the remaining branches (self-help, accessibility and information).

Residential care was divided into acute hospitalisation (ACUTE H), non-acute hospitalisation (NON-ACUTE H), residential care with 24-hour care from a doctor (RESID 24 h) and residential care without 24-hour care from medical staff (RESID OTHER).

Daycare was organised into day acute care (DAY ACUTE), daycare with activities related to work (DAY WORK), daycare with activities related to health (DAY HEALTH) and daycare with other types of activities (DAY OTHER).

Outpatient care was classified into outpatient emergency mobile care (EMERGENCY MOBILE), outpatient care for non-mobile emergency care (EMERGENCY NON-MOB), outpatient care for non-acute mobile care (AMB NON-ACUTE MOB) and outpatient care for non-mobile, non-acute care (AMB).

Finally, self-help (SELF-HELP), accessibility care (ACCESS) and information care (INFO).

Table 3. Groups of Basic Stable Inputs of Care.

Residential Care		
ACUTE H	Acute Hospital Care	R1,R2,R3.0
ACUTE NH	AcuteResidentialCare	R0,R3.1
NON-ACUTE H	Non-Acute Hospital Care	R4,R6
RESID 24 h	24 hoursResidentialCare	R5,R7
RESID OTHER	Non-24 hoursResidentialCare	R8,R9,R10,R11,R12,R13,R14
Day Care		
DAY ACUTE	Acute Day Care	D0,D1
DAY WORK	WorkRelated Day Care	D2,D3,D6,D7
DAY HEALTH	HealthRelated Day Care	D41,D81
DAY OTHER	OtherActivities Day Care	D42,D43,D44,D82,D83,D84,D5,D9
OutpatientCare		
EMERGENCY MOBILE	AcuteOutpatientCare / Mobile	O1,O2
EMERGENCY NON-MOBILE	Acute Outpatient Care - Non-Mobile	O3,O4
AMB NON-ACUTE MOB	Non-Acute Outpatient Care / Mobile	O5,O6,O7
AMB	Non-Acute Outpatient Care / Non-Mobile	O8,O9,O10
Self-HelpCare		
SELF-HELP	Self-Help And Volunteer Care	S
AccessibilityCare		
ACCESS	AccessibilityToCare	A
Information		
INFO	InformationForCare	I

Analysis was carried out on the BSIC totals and four large diagnostic care groups were differentiated (Table 4). This allowed the BSIC specifically related to Mental Health to be studied (MH), along with Intellectual Disability and Developmental Disorders (ID-DD), and Physical Disability (PD) in which were included sensory and chronic illnesses. Also considered were those BSICs which did not fall into any specific diagnostic group (Non-specific).

Table 4. Diagnostics groups of Basic Stable Inputs of Care.

DIAGNOSTIC GROUP	
MH	Mental Health
ID-DD	Intellectual Disability and Development Disorders
PD	Physical Disabilities
Non-specific	Non-specific Disabilities

Comparison of Basic Stable Inputs Care (BSIC) was performed through calculation of the rates per 100,000 inhabitants for each of the different BSIC groups and selected diagnostic groups. When analysis of the most recent population data available from the Spanish National Statistics Institute (INE) (18) and the National Statistical Institute of Bulgaria (NSI) (19) was carried out, data was from the year 2009. The indicators have been represented in bar graphs and in radar charts with a logarithmic scale to facilitate analysis and comparison.

3. RESULTS

3.1 ORGANISATION OF SOCIO-HEALTH CARE SERVICES IN MADRID AND SOFIA

Services for long-term healthcare needs in Madrid are found to be divided into sectors according to the administration on which they depend; healthcare by Health District and social care by Social Services District. Both sectors can overlap as the base is formed by the Madrid municipal districts.

The case of Sofia is very different; there is no socio-health zoning of the city. These differences led to selection of a municipal scale for comparison, discarding smaller catchment as it was original intention. The scale chosen does not correspond to any of the Nomenclature of Territorial Units for Statistics (NUTS) Eurostat levels (20) which makes gathering of comparable socio-demographic information more difficult.

3.2 AVAILABILITY OF SERVICES

A total of 514 social and health services were identified as addressed to people with long-term healthcare needs. The distribution by study area is 45 services in Sofia and 469 in Madrid.

Basic Stable Inputs Care in Madrid

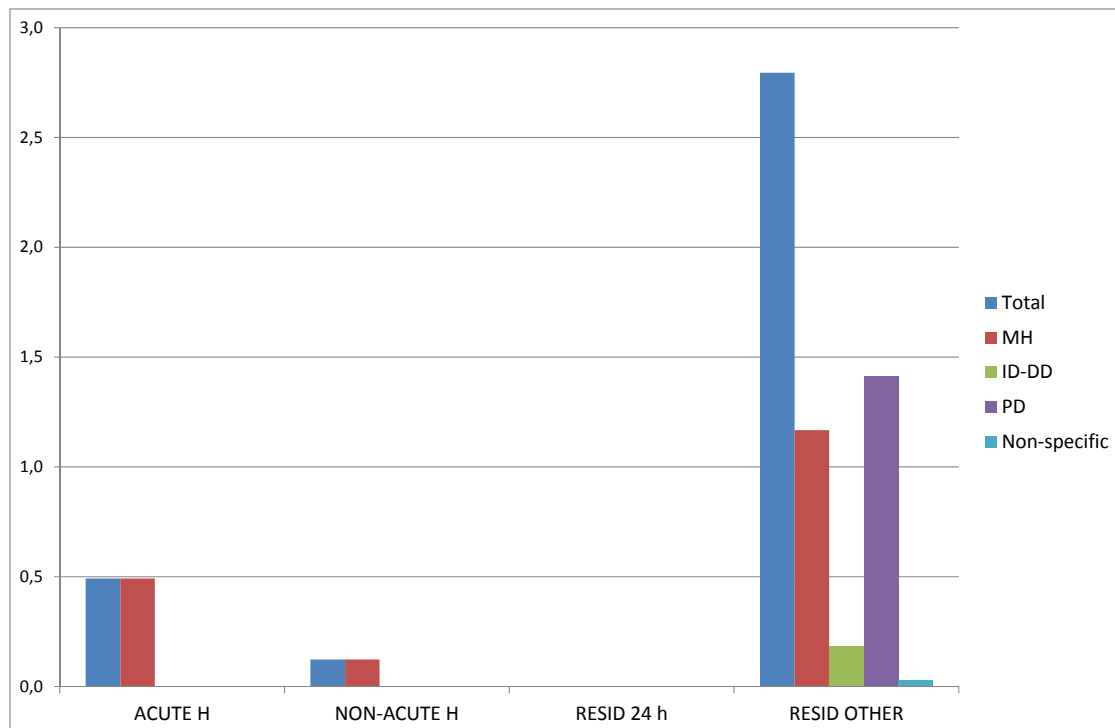
Residential care

Research identified 111 BSIC in the residential branch in the municipality of Madrid (Spain), which represents 3.4 BSIC for every 100,000 inhabitants (Table 5). The group with the highest presence were those with medical care of less than 24 hours with 2.8 BSIC per 100,000 inhabitants (91 BSIC), followed by acute hospitalization care with 16 BSIC (0.5 per 100,000), and finally by non-acute hospitalization care with 4 BSIC (0.1 per 100,000). The residential branch, which deals with people with intellectual disability or developmental disorders, physical disability or any diagnostic group only correspond to residential type without 24-hour medical support. On the other hand, those individuals with mental illness receive hospital care in the two forms of typology. No service was found which provides residential care with 24-hour availability of a health professional.

Table 5. Basic Stable Inputs of Residential Care by diagnostic groups in Madrid.
Number and rate per 100,000 inhabitants.

DIAGNOST.	ACUTE H	NON- ACUTE H	RESID 24 h	RESID OTHER	TOTAL
Total	0.5	0.1	0	2.8	3.4
	16	4		91	111
MH	0.5	0.1	0	1.2	1.8
	16	4		38	58
ID-DD	0	0	0	1.2	1.2
				40	40
PD	0	0	0	0.3	0.3
				10	10
Non- specific	0	0	0	0.1	0.1
				3	3

Figure 2. Basic Stable Inputs of Residential Care by diagnostic groups in Madrid.
Number and rate per 100,000 inhabitants.



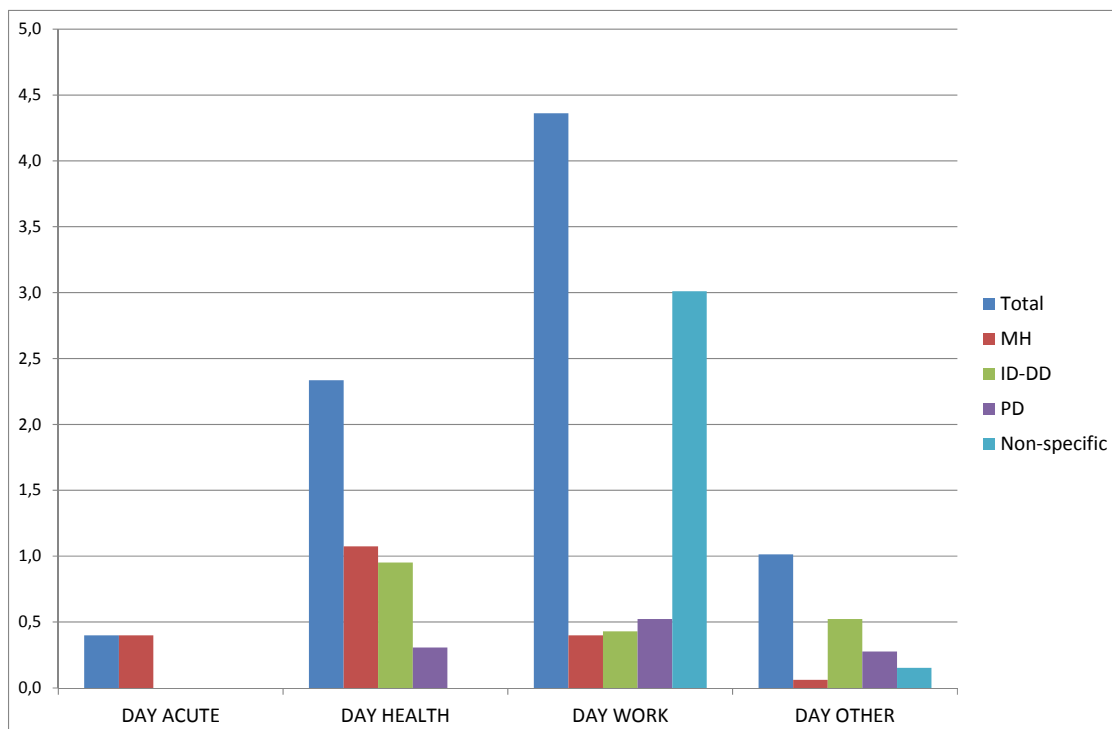
Day care

In Madrid BSIC were found corresponding to all the large diagnostic daycare groups (Table 6). In total there are 262 BSIC (8 per 100,000 inhabitants). Daycare related to work is the most numerous with 142 BSIC (4.4 per 100,000 inhabitants), followed by that related to health with 76 BSIC (2.3 per 100,000 inhabitants), other types of daycare with 31 BSIC (1 per 100,000 inhabitants) and acute care with 13 (0.4 per 100,000 inhabitants). Day care for acute patients is only available to people with mental illness. The greatest number of BSIC is addressed to the non-specific population and to mental illness. Health-related day care mainly deals with mental illness. Work-related activities are found in services that do not deal with a specific diagnosis. Other daycare activities such as those related to education or social and cultural education are principally dealt with under intellectual disability and developmental disorders.

Table 6. Basic Stable Inputs of Day Care by diagnostic groups Madrid.
Number and rate per 100,000 inhabitants.

DIAGNOST.	DAY ACUTE	DAY HEALTH	DAY WORK	DAY OTHER	TOTAL
Total	0.4	2.3	4.4	1.0	8.0
	13	76	142	31	262
MH	0.4	1.1	0.4	0.1	1.9
	13	35	13	2	63
ID-DD	0	0.6	1.3	0.6	2.4
		18	42	18	78
PD	0	0.6	0.4	0.2	1.3
		21	12	8	41
Non-specific	0	0.1	2.3	0.1	2.5
		2	75	3	80

Figure 3. Basic Stable Inputs of Day Care by diagnostic groups Madrid.
Number and rate per 100,000 inhabitants.



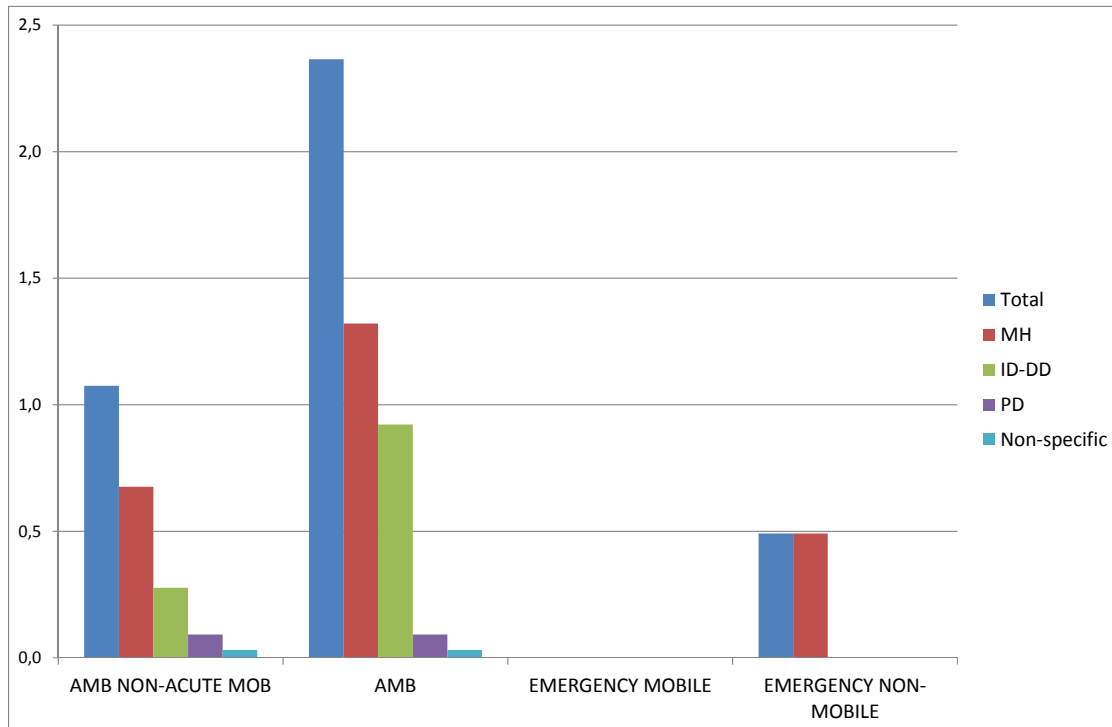
Outpatient care

There is a total of 128 outpatient care BSIC (3.9 per 100,000 inhabitants) (Table 7). The majority of codes correspond to non-acute and non-mobile care with 77 BSIC (2.4 per 100,000 inhabitants). Next is non-acute mobile outpatient care with 35 (1.1 per 100,000 inhabitants) and that of acute or emergency non-mobile with 16 (0.5 per 100,000 inhabitants). No service was found which provides care in mobile emergencies. The majority of outpatient services deal with people with mental illness followed, at some distance, by those that treat physical disability.

Table 7. Basic Stable Inputs of Outpatient Care by diagnostic groups Madrid.
Number and rate per 100,000 inhabitants.

DIAGNOST.	AMB NON- ACUTE MOB	AMB	EMERGENCY MOBILE	EMERGENCY NON-MOBILE	TOTAL
Total	1.1 35	2.4 77	0	0.5 16	3.9 128
MH	0.7 22	1.3 43	0	0.5 16	2.5 81
ID-DD	0.03 1	0.1 3	0	0	0.1 4
PD	0.3 10	0.5 16	0	0	0.8 26
Non- specific	0.1 2	0.5 15	0	0	0.5 17

Figure 4. Basic Stable Inputs of Outpatient Care by diagnostic groups Madrid.
Number and rate per 100,000 inhabitants.



Self-help, accessibility and information

Self-help care has been described on 20 occasions (0.6 BSIC per 100,000 inhabitants) and deals fundamentally with people with intellectual and physical disability (Table 8). The accessibility BSIC total 17 (0.6 BSIC per 100,000 inhabitants) mainly focused on non-specific population groups, although physical disability stands out. Finally, information BSIC is addressed principally to those with physical disabilities, mental illness or the non-specific population.

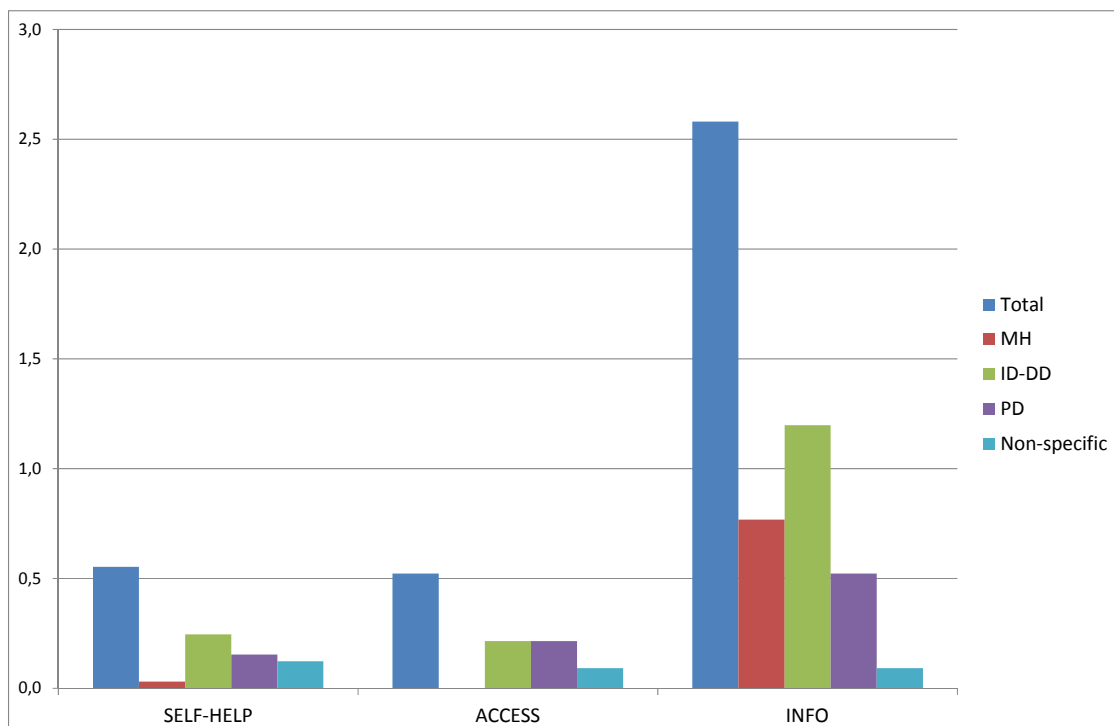
Table 8. Basic Stable Inputs of Self-Help, Accessibility and Information Care by diagnostic groups Madrid.

Number and rate per 100,000 inhabitants.

DIAGNOST.	SELF-HELP	ACCESS	INFO
Total	0.6 20	0.5 17	2.6 84
MH	0.03 1	0	0.8 25
ID-DD	0.2 8	0.1 3	0.2 7
PD	0.3 10	0.2 7	0.8 27
Non-specific	0.03 1	0.2 7	0.8 25

Figure 5. Basic Stable Inputs of Self-Help, Accessibility and Information Care by diagnostic groups Madrid.

Number and rate per 100,000 inhabitants.



Availability of Basic Stable Inputs Care in Sofia

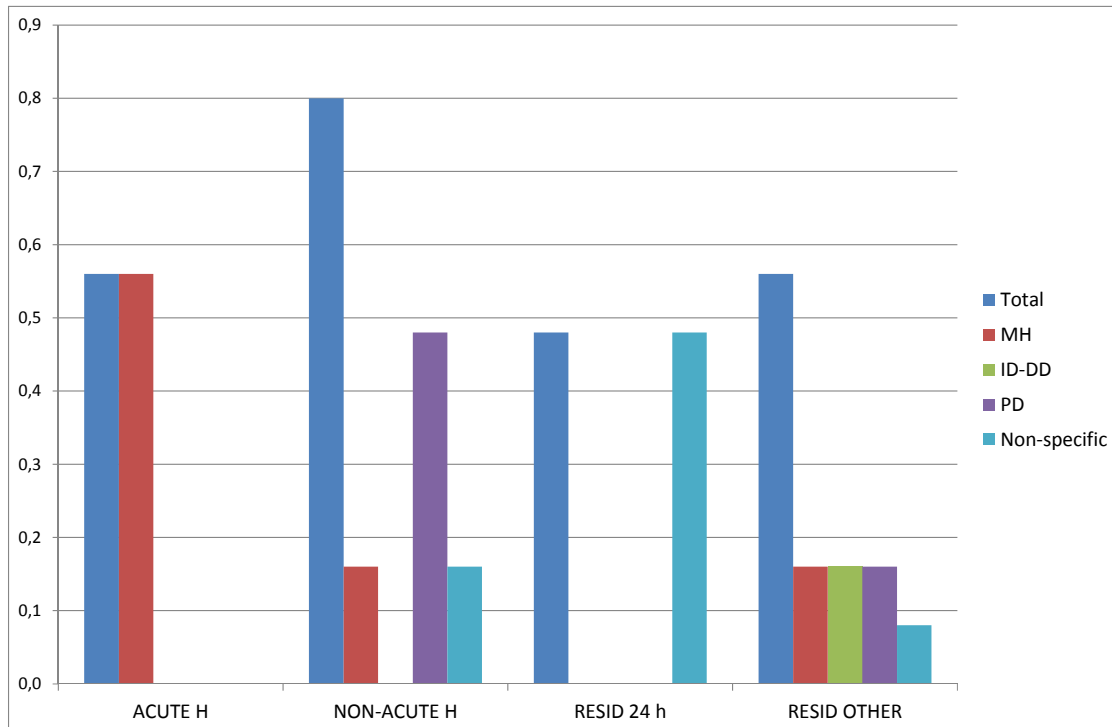
Residential Care

A total of 30 BSIC (2.4 per 100,000 inhabitants) (Table 9) dedicated to residential care have been identified in Sofia. The distribution by large groups is similar, with a rate of around 0.7 BSIC per 100,000 inhabitants in each group, although the greatest number of BSIC corresponds to the hospitalisation of non-acute cases. Distribution by care groups shows that the majority of BSIC, a total of 11, relate to mental disorders, followed by those which relate to non-specific population and physical disability. Hospitalisation BSIC with respect to acute cases only deal with mental health. There are 7 in total with a rate of 0.6 BSIC per 100,000 inhabitants. Residential homes with 24-hour medical care are not dedicated to specific diagnostic groups. The 6 non-acute hospital BSIC are mainly dedicated to physical disability; in this particular case chronic illnesses (0.5 per 100,000 inhabitants) stand out.

Table 9. Basic Stable Inputs of Residential Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.

DIAGNOST.	ACUTE H	NON- ACUTE H	RESID 24 h	RESID OTHER	TOTAL
Total	0.6 7	0.8 10	0.5 6	0.6 7	2.4 30
MH	0.6 7	0.2 2	0	0.2 2	0.9 11
ID-DD	0	0	0	0.2 2	0.2 2
PD	0	0.5 6	0	0.2 2	0.6 8
Non- specific	0	0.2 2	0.5 6	0.1 1	0.7 9

Figure 6. Basic Stable Inputs of Residential Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.



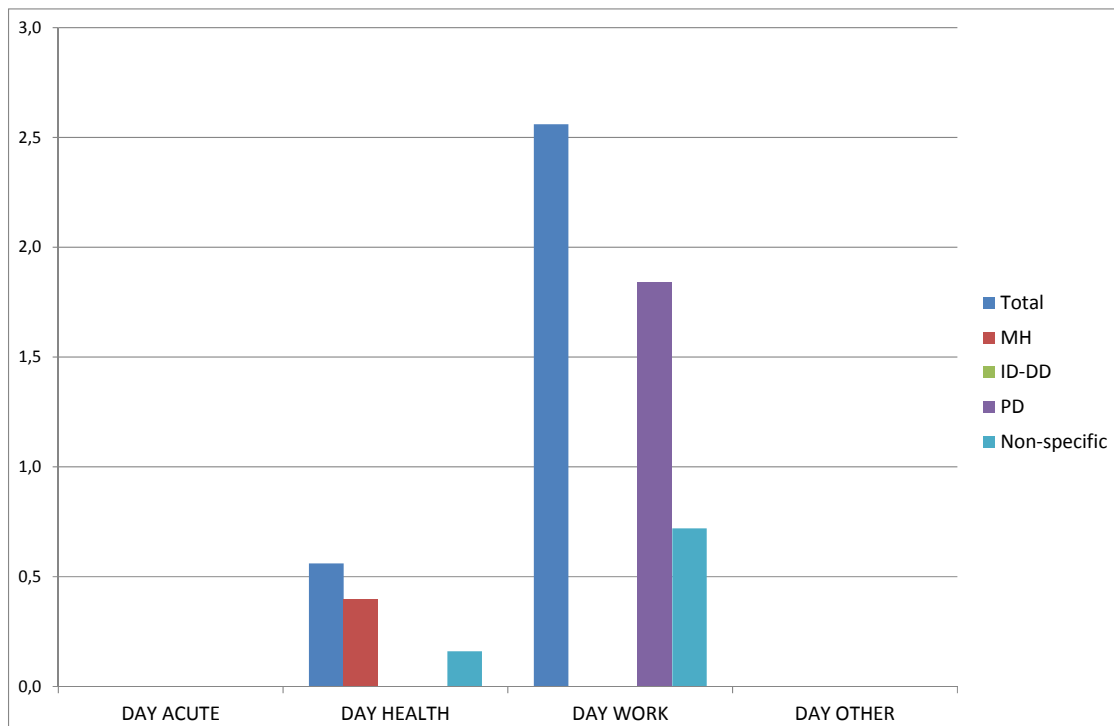
Day Care

A total of 39 day care BSIC (3.1 per 100,000 inhabitants) (Table 10) have been identified in Sofia. Only health or work-related day care BSIC have been found. The great majority of these are work-related BSIC, with 32 codes described (2.6 per 100,000 inhabitants). Work-related day care, with 23 BSIC, is mainly aimed at people with physical disabilities (1.8 per 100,000 inhabitants), while those related to health mainly deal with people with mental illness and also non-specific diagnostic groups. There is no day care BSIC solely addressed to those with intellectual disability or developmental disorders.

Table 10. Basic Stable Inputs of Day Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.

DIAGNOST.	DAY ACUTE	DAY HEALTH	DAY WORK	DAY OTHER	TOTAL
Total	0	0.6	2.6	0	3.1
MH	0	7	32	0	39
ID-DD	0	0.4	0	0	0.4
PD	0	5	0	0	5
Non-specific	0	0	1.8	0	1.8
Non-specific	0	0.2	0.7	0	0.9
Non-specific	0	2	9	0	11

Figure 7. Basic Stable Inputs of Day Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.



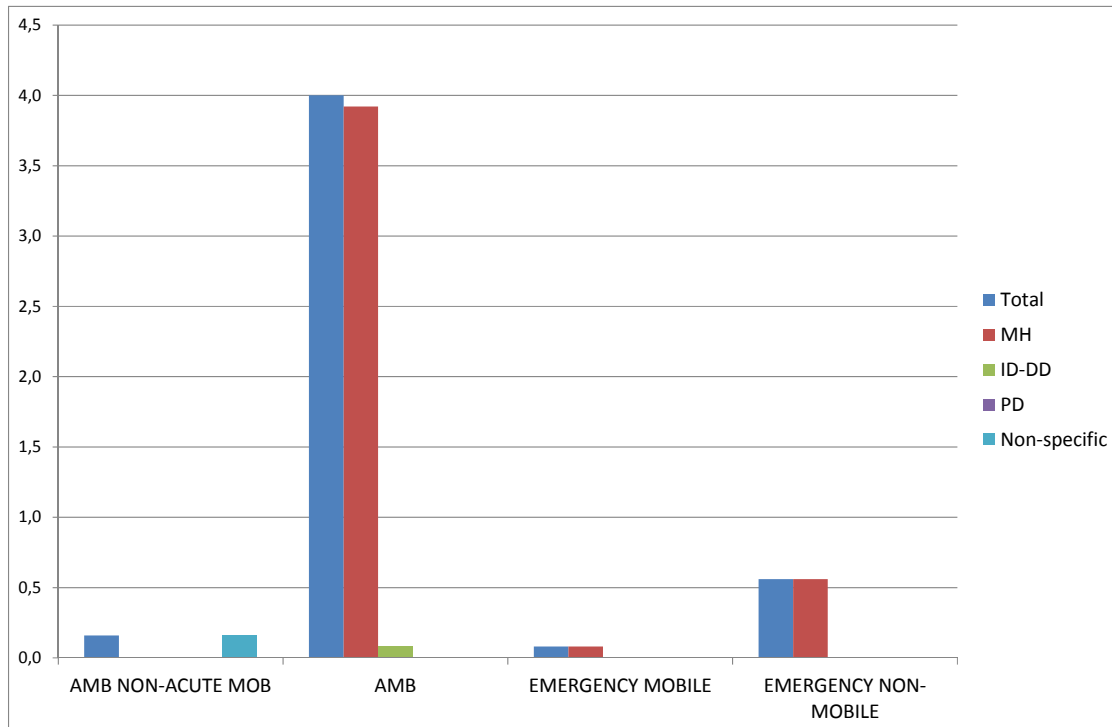
Outpatient Care

Outpatient care has been described with 60 BSIC (4.8 per 100,000 inhabitants) (Table 11). A total of 50 BSIC correspond to non-mobile, non-acute outpatient care (4 per 100,000 inhabitants), while the remaining types have a very low incidence. It was also found that almost all of the BSIC, a total of 57 (4.6 per 100,000 inhabitants), relating to this branch are directed at people with mental disorders. There is no outpatient care dealing specifically with physical disability.

Table 11. Basic Stable Inputs of Outpatient Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.

DIAGNOST.	AMB NON- ACUTE MOB	AMB	EMERGENCY MOBILE	EMERGENCY NON-MOBILE	TOTAL
Total	0.2 2	4.0 50	0.1 1	0.6 7	4.8 60
MH	0	3.9 49	0.1 1	0.6 7	4.6 57
ID-DD	0	0.1 1	0	0	0.1 1
PD	0	0	0	0	0
Non- specific	0.2 2	0	0	0	0.2 2

Figure 8. Basic Stable Inputs of Outpatient Care by diagnostic groups Sofia.
Number and rate per 100,000 inhabitants.



Self-help, Accessibility and Information

No self-help BSIC services have been identified in Sofia. (**Table 12**). There are only 3 accessibility BSIC (0.2 per 100,000 inhabitants) addressed to people with physical disabilities. Finally, the 36 information BSIC do not deal with specific diagnostic groups (2.9 per 100,000 inhabitants). None of these BSIC has been described as dealing with mental illness or intellectual disability.

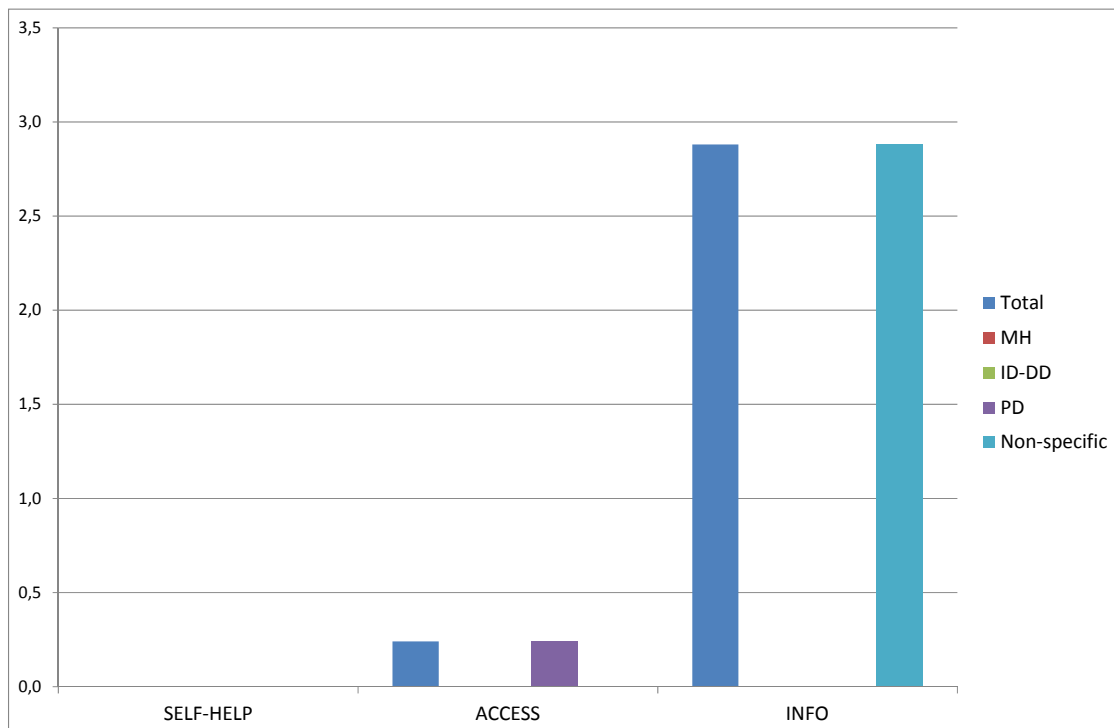
Table 12. Basic Stable Inputs of Self-Help, Accessibility and Information Care by diagnostic groups Sofia.

Number and rate per 100,000 inhabitants.

DIAGNOST.	SELF-HELP	ACCESS	INFO
Total	0	0.2 3	2.9 36
MH	0	0	0
ID-DD	0	0	0
PD	0	0.2 3	0
Non-specific	0	0	2.9 36

Figure 9. Basic Stable Inputs of Self-Help, Accessibility and Information Care by diagnostic groups Sofia.

Number and rate per 100,000 inhabitants.



Comparison of the availability of Basic Stable Inputs Care in Madrid and Sofia

Total Availability of Services for Long Term Care (Basic Stable Inputs of Care – BSIC)

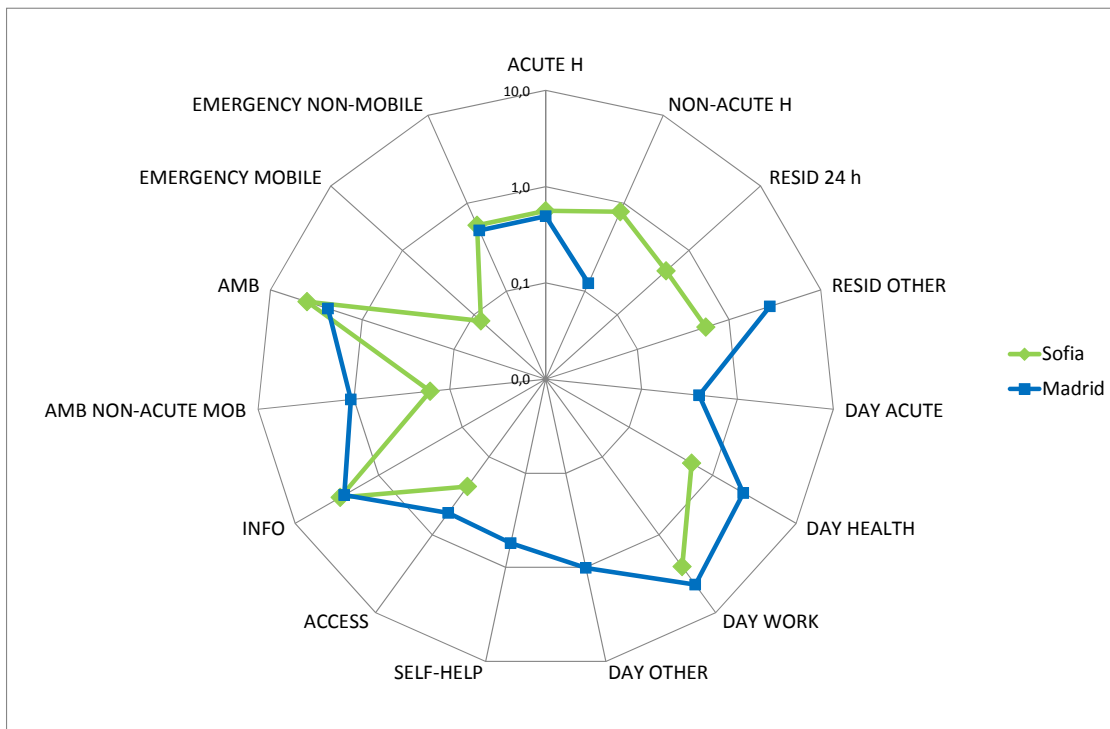
The rates of acute hospitalisation BSIC are similar in both cities (Figure 10). Sofia surpasses Madrid in non-acute hospitalisation rates, and Madrid has a higher rate than Sofia in residential care without 24-hour medical attention. Sofia, unlike Madrid, has residential care BSIC with qualified medical personnel present 24 hours a day.

Madrid has higher rates of availability of health and work-related day care than Sofia. However, Madrid has no acute day care or care dedicated to activities other than health or work.

The emergency non-mobile outpatient care rate is similar in both cities. Sofia surpasses Madrid in non-acute, non-mobile outpatient care rates, although it falls way below in mobile care of this type. Sofia, in contrast to Madrid, has mobile emergency care BSIC.

There are similar rates of information BSIC in Madrid and Sofia. The self-help BSIC are only present in Madrid. Moreover, Madrid surpasses Sofia in Accessibility Care.

Figure 10. Total Basic Stable Inputs of Care rates per 100,000 inhabitants in Madrid and Sofia.



Mental disorders

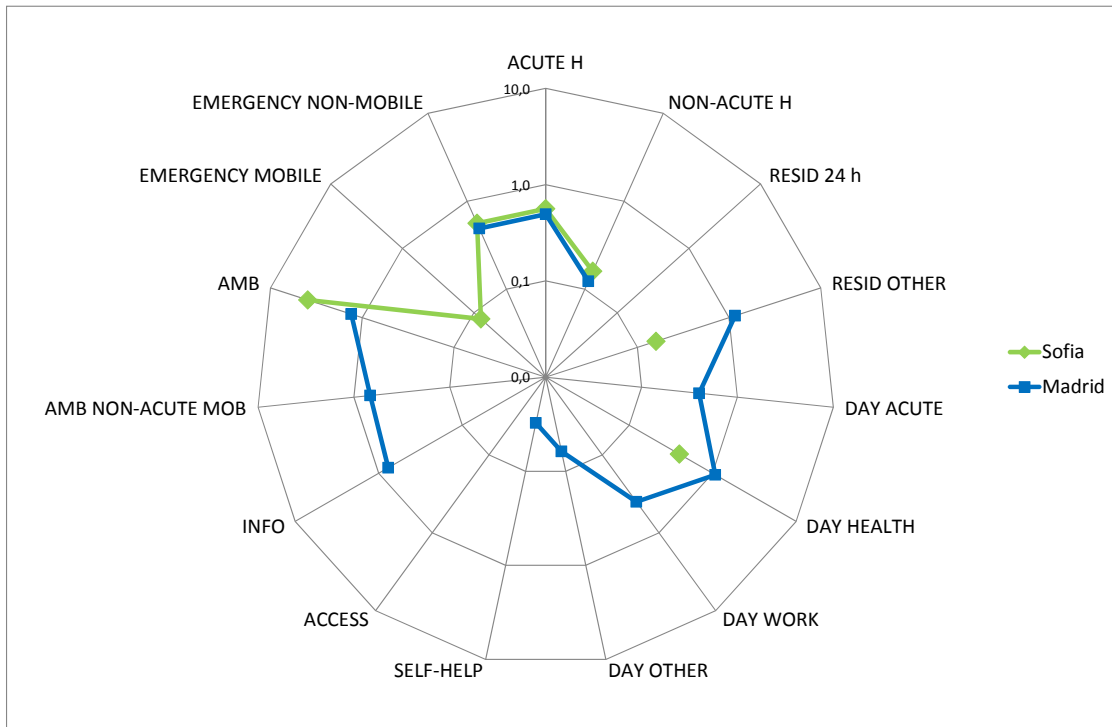
Mental health hospital care BSIC are similar in both capitals (Figure 11). There is no community residential care with 24-hour medical supervision in either of the two cities. Madrid surpasses Sofia in availability of residential BSIC without 24-hour supervision.

Sofia only has health-related day care centred on mental disorders and the rate per inhabitant is found to be lower than that of Madrid.

In Sofia, there is a higher rate per inhabitant of outpatient care in non-mobile mental health for non-acute cases. The non-mobile emergency rate is similar in both cities. With respect to mobile BSIC, differences in availability are noted. Madrid only has mobile mental health BSIC and Sofia only has emergency mobile care.

Neither of the two capitals has accessibility BSIC focused on mental disorders. In contrast to Madrid, Sofia has neither information nor self-help BSIC.

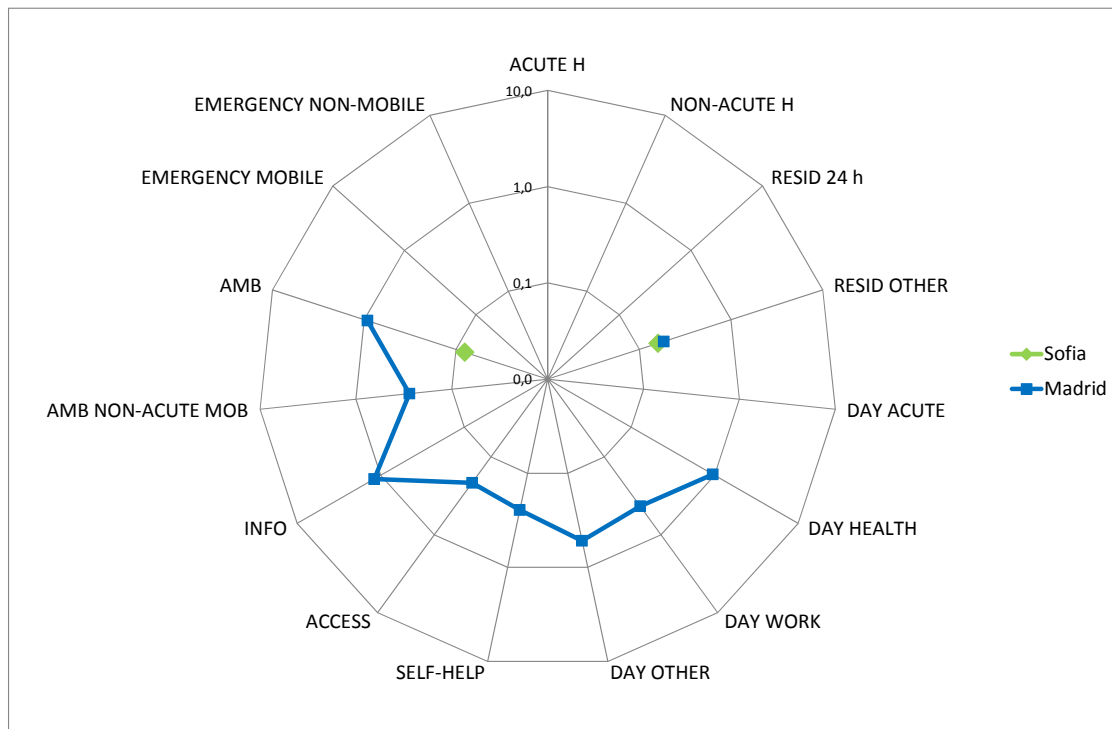
Figure 11. Mental Health Basic Stable Inputs of Care rates per 100,000 inhabitants in Madrid and Sofia.



Intellectual Disability and Developmental Disorders

Specific care for intellectual disability and other developmental disorders is very scarce in Sofia (Figure 12). Residential care BSIC do exist in this macro-urban area, though below the availability rates in Madrid, as do non-acute outpatient care BSIC, the availability of which is similar to that in Madrid. The Spanish city also has day care BSIC, except in the acute, self-Help, accessibility and information groups.

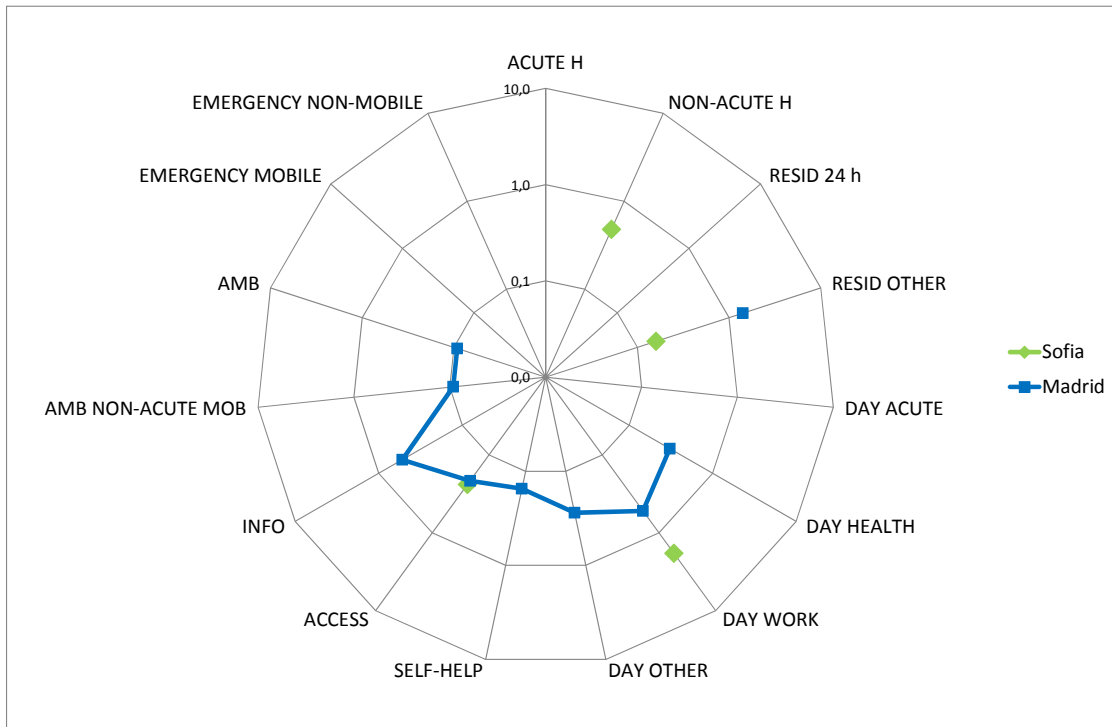
Figure 12. Intellectual Disabilities and Developmental Disorders Stable Inputs of Care rates per 100,000 inhabitants in Madrid and Sofia.



Physical Disability

Non-acute hospital care BSIC, for the care of people with physical disabilities (including chronic illnesses), have been identified in Sofia which are not present in Madrid (Figure 13). Residential BSIC are found in both cities, though their availability per inhabitant is lower in Sofia. With regard to day care, Sofia only has work-related BSIC with a far greater level of availability than in Madrid. However, Madrid has all types of non-acute day care and, unlike Sofia, Madrid provides non-acute outpatient care, information and self-help for this population group. Both cities have similar availability of accessibility BSIC for those with physically disabilities.

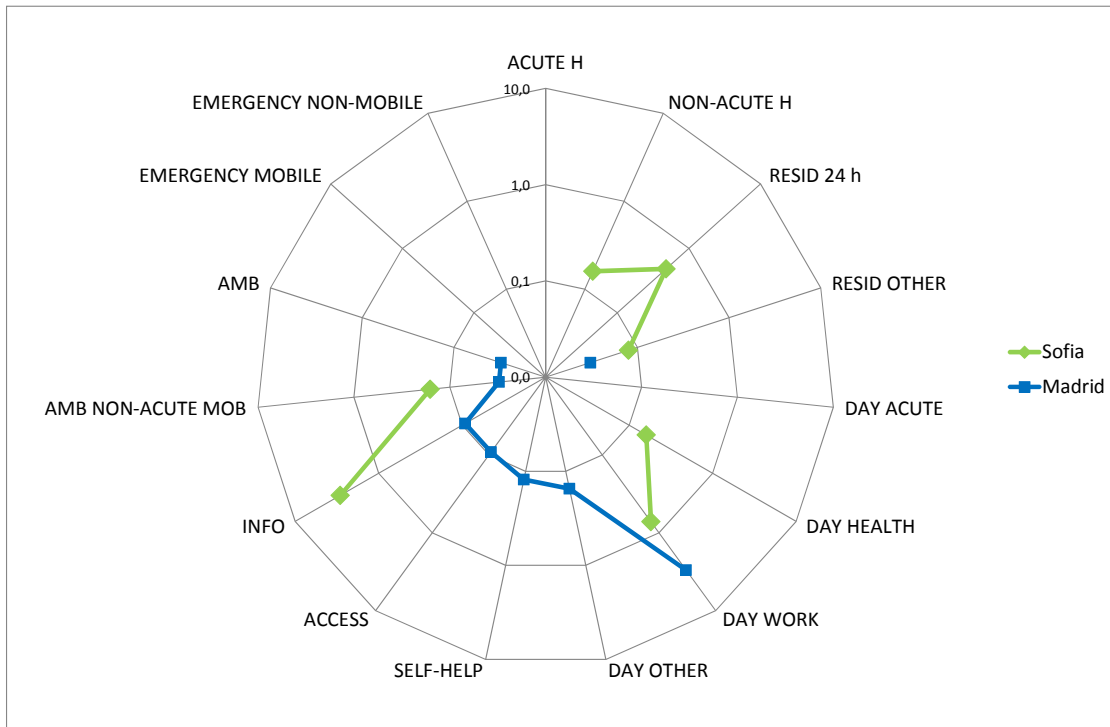
Figure 13. Physical Disabilities Stable Inputs of Care rates per 100,000 inhabitants in Madrid and Sofia.



Non-specific

Finally, the BSIC which are not addressed to a specific diagnostic group were/are compared (Figure 14). Sofia has hospitalisation BSIC of non-acute and residential patients in non-specific populations, while Madrid only provides residential care without 24-hour medical support at an availability rate similar to that of the Bulgarian capital. The rate of health-related day care is higher in Sofia, while that related to work is higher in Madrid. Furthermore, Sofia shows greater availability rates in information and mobile outpatient care for the non-acute.

Figure 14. Non-specific Stable Inputs of Care rates per 100,000 inhabitants in Madrid and Sofia.



Availability of beds and places for Long-Term Care in Sofia and Madrid

The rate per 100.000 population of beds in hospital and residential care for long term care patients (mental health, intellectual disabilities, severe physical disabilities and non-specific) was registered in Sofia and in Madrid per every identified Main Type of Care. Residential MTCs were grouped in Hospital (Acute and Non-acute) and Non-hospital residential care (with 24 hour medical coverage and other). Rates of places for Day care were also recorded. It was not possible to count all beds and places as a number of private organisations did not provided their places availability both in Sofia and in Madrid. In the case of Madrid these organisations were working under contract with the social or health sector.

The total rate of beds and places appear in Table 13 and in Figure 15. The rates per specific and non-specific target groups appear in Figure 16, Figure 17, Figure 18 and Figure 19. Figure 20 shows the distribution per three major groupings: Non-community Residential care (including hospitals and large institutions with 24 hour medical care), Community Residential care and Day care.

Table 13. Long Term Care beds and places rates per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid

Area (City)	DESDE Label	ACUTE H	NON-ACUTE H	RESID 24 h CARE	RESID OTHER	DAY ACUTE	DAY HEALTH	DAY WORK	DAY OTHER
	DESDE Code Target Group	R1,R2,R3.0	R4,R6	R5,R7	R8-R14	D0,D1	D4-D8 Health	D2,D3,D6,D7	D4-D8, D5, D9 Others
Sofia	Total	22,7	94,8	7,1*	15,8*		43,4	22,2	
	MH	22,7	9,3		1,3		10,6		
	ID-DD				8,2				
	PD		52,7		3,9*			22,2	
	Generic LTC		32,8	7,1*	2,4		32,8	0,0	
Madrid	Total	13,0	8,6		67,7*	11,9	86,0*	143,3*	26,0*
	MH	13,0	8,6		10,5*	11,9	50,1	17,8	0,0*
	ID-DD				43,3		15,7*	90,8*	14,6*
	PD				13,2*		19,8*	2,4*	3,8*
	Generic LTC				0,68		0,5	32,2*	7,5*
*Data are incomplete as several private providers did not disclose number of beds/places MH: Mental health / ID-DD: Intellectual disabilities with dual diagnosis / PD: Physical disabilities									

Figure 15. Total Long Term Care: Beds and places per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid

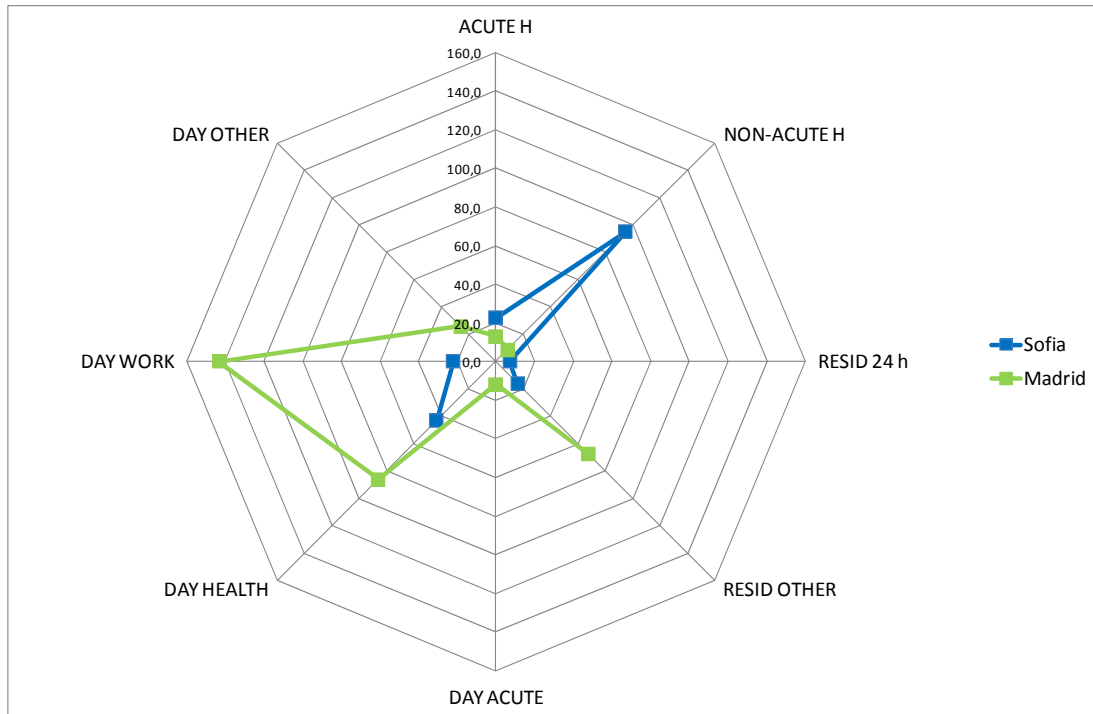


Figure 16. Mental Health: Beds and places per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid

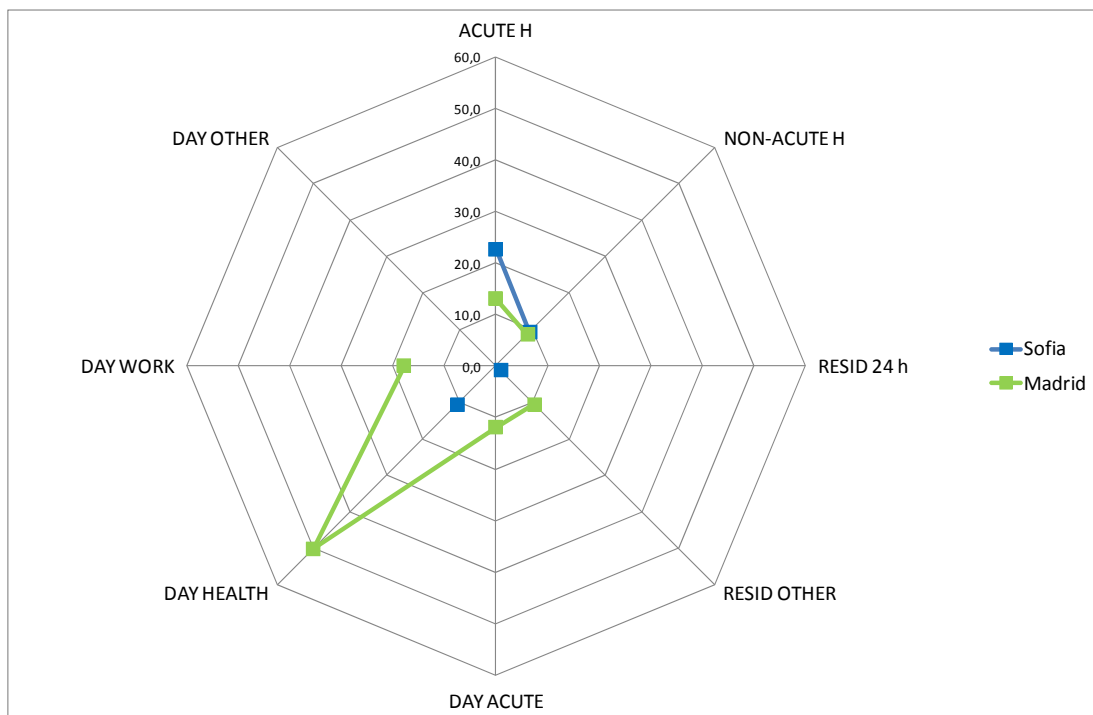


Figure 17. Intellectual Disabilities and Developmental Disorders: Beds and places per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid

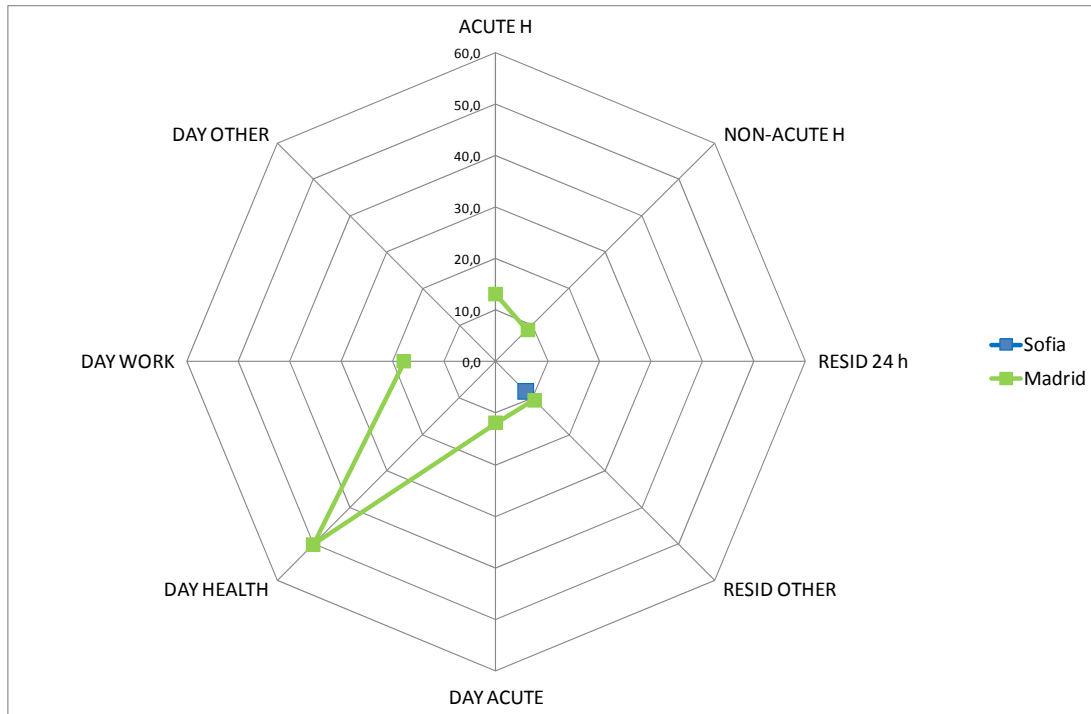


Figure 18. Physical Disabilities : Beds and places per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid.

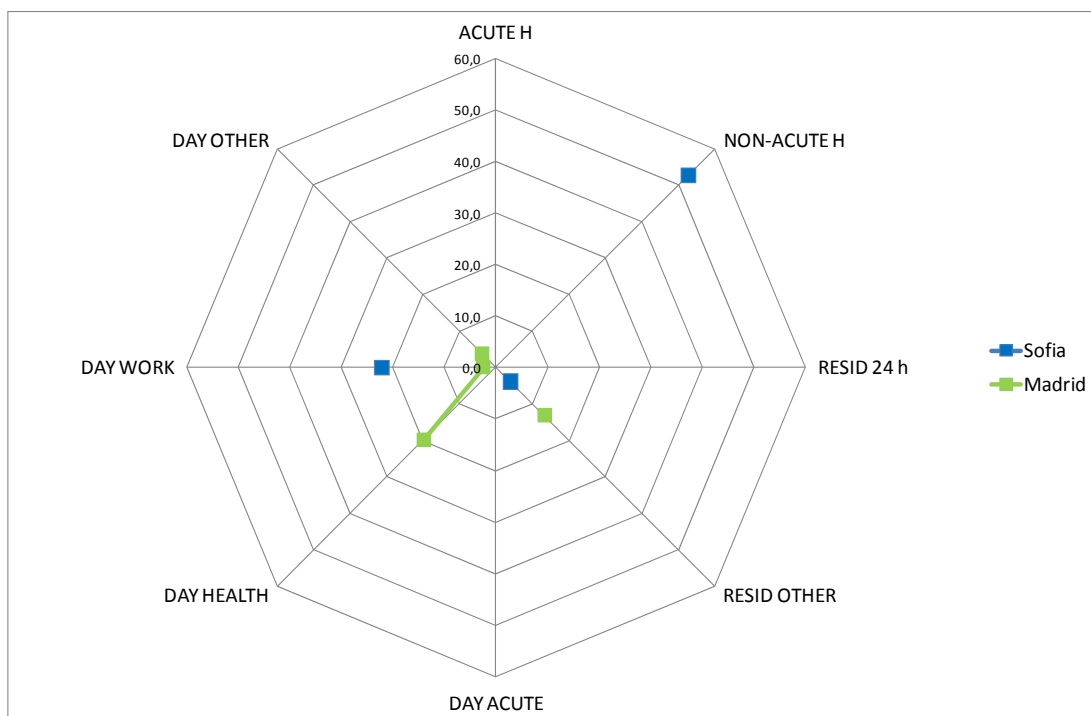


Figure 19. Non specific Long Term care: Beds and places per 100,000 inhabitants for groups of Main Types of Care in Sofia and Madrid

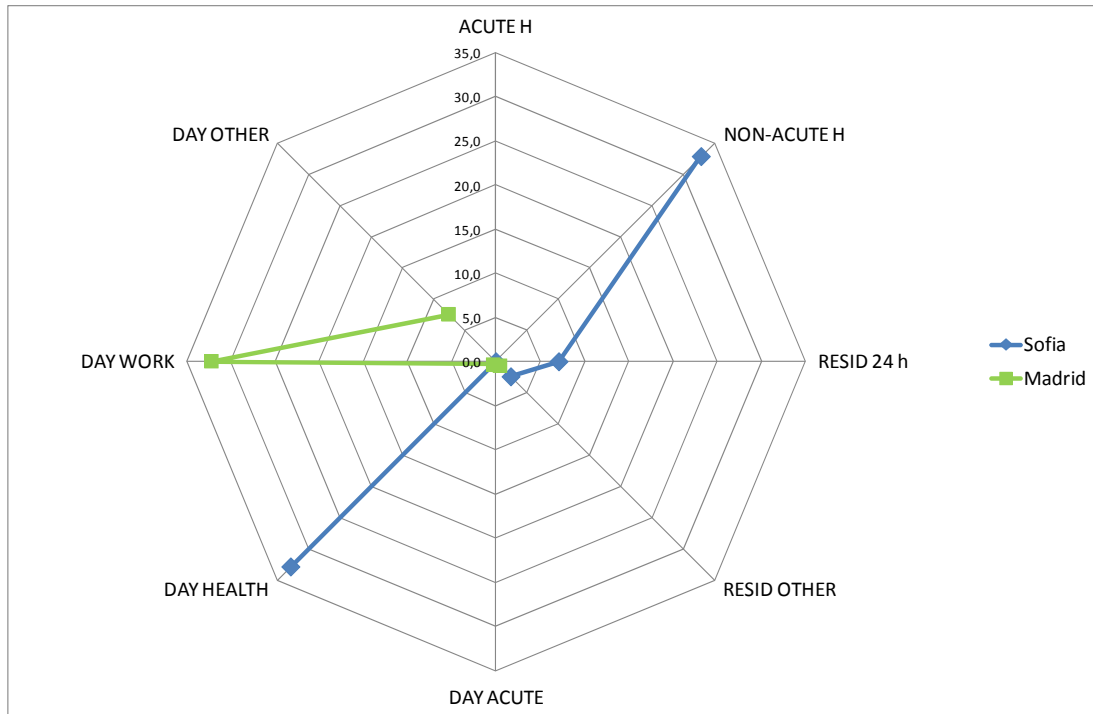
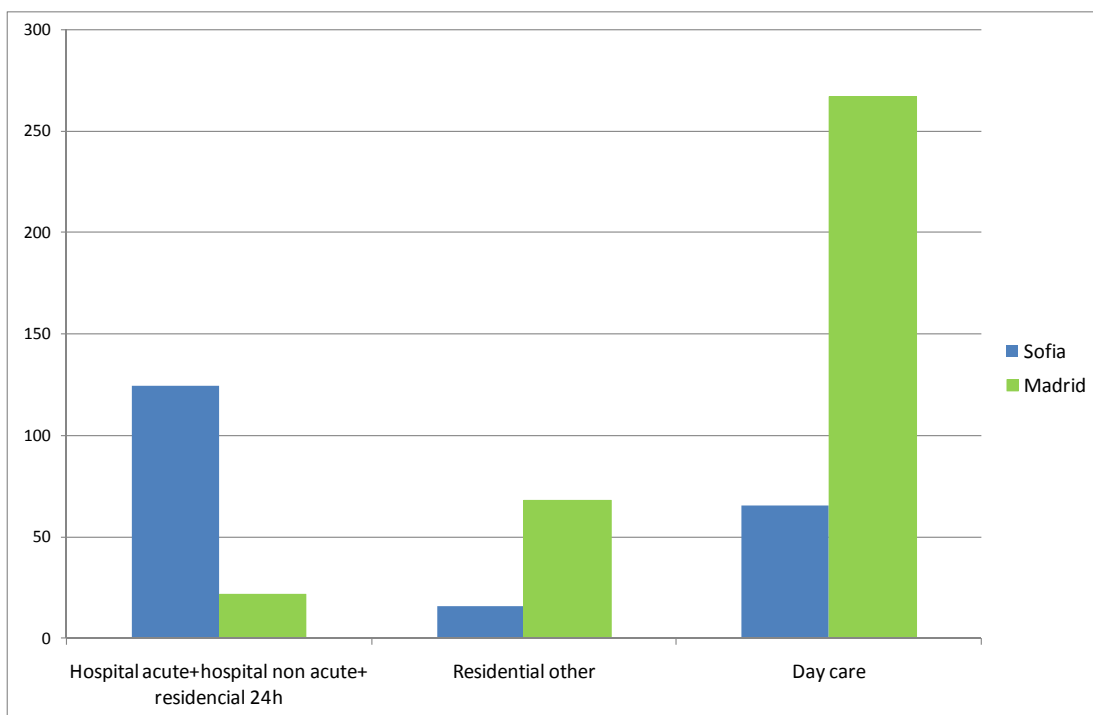


Figure 20. Distribution of beds and places in Sofia and Madrid per major groupings: Non-community Residential care (including hospitals and large institutions with medical care), Community Residential care and Day care.



4. DISCUSSION

4.1 NATIONAL CARE SYSTEMS

According to estimates from the International Monetary Fund in 2010, Spain was in 26th position and Bulgaria in 68th with respect to Gross domestic Product (GDP) at values of Purchasing Power Parity (PPP) (21), which places them in clearly distinct development groups. The cities of Madrid and Sofia represent the two most complex macro-urban environments in their respective countries. Regarding care systems, there are notable disparities in the organisation of health and social services in both countries. The World Health Report 2000 (22) placed Spain's Overall Health System Performance in 7th position out of 189 countries evaluated, while Bulgaria was in position 102. Unfortunately, this ranking has not been maintained. Some indicators such as the EuroHealth Consumer Index (23) indicate a decrease in the quality of the care system in Spain in recent years and stagnation in the reform process in Bulgaria.

The health system set-up in Spain results from the health law of 1986. There are various general descriptions of the healthcare system in Spain (24). Its main characteristic within the European systems is that it actually is a 'meta-system' composed of 17 systems corresponding to the different regions and autonomous Spanish communities which manage 97% of the national health budget. As such, Madrid is not an example of the organisational system of long-term care in Spain but rather a care system in itself. Health coverage is universal; it is financed through general taxes and taxes on some products and has a limited *subsidised/co-payment* system for pharmaceutical care in non-elderly and persons with disabilities. Healthcare is community oriented with a network of primary care centres which cover the entire country, in coordination with specialised care which has also been divided into sectors in the case of mental health. There are descriptions of specific population health care systems such as mental health services (13,25).

Social care is discretionary except for those in a situation of functional dependence. In these cases they may opt for direct payment to the user or through access to care services for this group.

Bulgaria's Healthcare System is currently in the middle of reform, and has been since the 1998 Health Insurance Act was passed. Basically, it consists of an institutional model based on long-term healthcare, with structural problems which have already been pointed out in previous European projects on the characteristics of the residential care system in Europe (DECLOC Project) (26) or in specific sectors such as that of mental health (MHEEN project) (27).

The Human Rights and ethical problems have been outlined by different institutions (28-31). However the legislative basis, definition of the structures and responsibilities for solving the different problems have not been completed. The main factors influencing these problems are the ineffective organisation of the Bulgarian public health care sector, the overall lack of financial resources for health care in the country (10) and the fragmentation of responsibilities across different agencies playing a significant role in this situation (11).

As mentioned previously, services in Madrid are organised geographically into small health areas. These areas, although they differ according to the administration on which the services depend, are based on the municipal districts and, as such, their integration is uncomplicated. In contrast, in Sofia there is no socio-health zoning of care services for long-term care as the geographical basis is the Province. The lack of geographical organisation of services in Sofia represents an obstacle to service management and planning.

4.2 USE OF THE EDESDE-LTC INSTRUMENT (TRAINING, PROCEDURE AND INFORMATION GATHERING)

Given the fact that the final classification of Bulgarian services, produced by the local team, had to be thoroughly revised through Spanish coordination, it cannot be said that training of the Bulgarian researchers was satisfactory. This result however, could be easily amended with refinement of the overall training process, such as using face-to-face training sessions involving trainers with long experience of DESDE, coming from the same country in which the instrument originated, and with trainees from the country of comparison.



It should be pointed out that the satisfaction of the 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 shows that eDESDE-LTC philosophy could be used in educational activities and could easily fit into the curricula of mental health professionals, social workers, and other relevant professionals in training.

Levels of collaboration with the public administration were very different in the two locations. In Madrid, the service administrators worked closely with the teams, the contact officers were sensitive to the problem and bore in mind the importance of standardised evaluation. In Sofia this contact was more complicated as the experience was new and required step by step explanation to the service administration of the process of evaluation of their network. This led to the following difficulties.

The technical difficulties found with regard to data collection resulted mainly from the long administrative delays in providing information. The data available were clearly insufficient which made it necessary to seek other sources distinct from service administration (in Madrid this involved turning to some General Hospital managers) There were also incomplete forms that needed additional information.

The greatest deficiencies and difficulties encountered in the provision of information on the part of the services were found regarding information on professionals and beds/places by centre, which are those that have undergone the greatest administrative changes. The importance of maintaining updated registers of professionals and beds was noted. In the case of Madrid, information available from the administration regarding the functioning of organised resources is scarce.

Although subject to numerous check-ups and control procedures, the interviewees had never taken part in a scientific endeavour aimed at 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 (most respondents), to apprehensive concern (some respondents).

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 believe that these effects should be taken into consideration in further application of eDESDE in transnational comparative studies of services. Firstly, it will be a practical issue in the training process where trainers from an “experienced” country teach evaluators from an “inexperienced” country how to contact services and get information from managers. Furthermore, trans-cultural issues in data collection should be brought into research that studies not only service inputs (such as availability of services in certain geographical areas), but service processes as well. An interesting consequence 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 proposals for change. This could also involve decision-making figures from the two municipalities and be carried out in focus-group format or as a trans-national project.

In the case of Sofia a major problem was to fill in those parts of the questionnaire, requesting information about 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 programmes 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, programmes in community outpatient services were much better scheduled, so that respondents could provide far more structured information on the weekly timetable of activities.

DESDE-LTC coding

In completing Sección B of the DESDE-LTC we found services which presented great coding difficulties, especially those which offered more than one basic type of care. In many cases this resulted in the need to establish new contact with the service.

The results indicate that there is a series of services classified in more than one branch, especially those services for people with disabilities in the social sphere. The majority of these are classified in *day care and information* as the principal code. This

is due to the fact that there is great diversity of types of care which *day care and information services* tend to present currently in Spain and above all in the area of disability which has added a profusion of new emerging services in this field. As a consequence of this, the system of classification which is offered by the tree with respect to *day care and information services* tends to classify the services under various codes which describe distinct basic types of care in such a way that in many cases it is not possible to obtain a complete description of a service with a single code. We found, therefore, services which offer education in social skills, through occupational training to rehabilitation activities. These activities should not be considered as mutually exclusive as these services have been classified under more than one DESDE-LTC code, describing distinct types of basic care.

It should be pointed out that some DESDE-LTC codes classify single services as basic types of care within a service. For instance, the code *care related to health promotion*, D4.1, can describe a service which brings together various physical rehabilitation and psychotherapeutic activities for all users as is the case in the Carlos Castilla del Pino Day Centre in Madrid; and can also describe basic types of care for distinct users within the same service, such as D4.1 in all the Mental Health Care Plan for Psychosocial Rehabilitation Centres which provide activities addressed to the promotion of health in a particular group of users.

The fact that some services can be classified under more than one code increases the instrument's precision as it describes all the basic types of care available in each service. One example would be the APHISA Residential and Day Care Centre which offers different types of basic care to two distinct groups of users. The DESDE-LTC classifies this care as *health promotion related activity and residential care* described under two codes: R11 and D4.1.

The standardised description of the devices that comprise the mental health network through the DESDE-LTC instrument proves to be of great utility in understanding the psychiatric care characteristics with regard to the basic types of care which the various mental health services offer. For instance, the Eating Behaviour Disorders Units (UTCA) in Madrid provide various types of care under the same name. The Ramón and Cajal Hospital UTCA offers acute hospitalisation care (R2 O3.1) which is not available at the Santa Cristina Hospital UTCA (D1.2), or in the units of the Gregorio Marañón

Hospital (O9.1) or at Móstoles (O9.1). In Madrid differences between services appear even when they share the same name. This terminologic variability is even greater when services are compared with other Spanish Autonomous Communities.

Following the DESDE-LTC model, we evaluated the services and places available to achieve a precise snapshot of care available to people with long-term care needs although it would be necessary to know the level of use of these services and carry out an evaluation of the programmes that are provided. It is very important not to mix stable services with programmes and that the difference between them is clearly defined by the instrument.

4.3. COMPARISON OF MADRID AND SOFIA

Main Types of Care

Residential Care (R)

As can be seen, there is no difference between the two cities in hospitalisation of acute cases, although there is a difference in hospitalisation of non-acute, in that there are more centres available in Sofia. In the case of Madrid, these centres have a higher number of places and are easily accessible, given that they are located in the city centre and well-connected in terms of transport. This leads us to consider what would be the appropriate relationship between centres and the number of beds available. In order to have an exact idea, comparison would have to be made with other countries and other autonomous communities.

Long-term residential care in Madrid consists of centres within the community where 24-hour support is provided by nursing or auxiliary staff. Therefore, residential care BSIC with 24-hour medical staff presence are scarcer. Community residential care is more common in Madrid, whereas there is more institutionalisation in Sofia, with greater availability of non-acute hospital care.

Day Care (D)

Madrid has made a great effort in recent years with respect to the creation of day care places (D1.2 y D4.1) in the area of mental health. This is divided into sectors throughout the community within the Department of Family and Social Affairs Mental Illness Care Plan. The same applies with work-related day care centres (D3.2). There are higher availability rates in both these types of centre than in Sofia.

According to our data, there are 32 services from the D branch in Sofia, providing work for people with disabilities. These are mainly small and middle-sized companies that provide work for all their employees, on the basis of competitive market salaries, but have a quota for people with disability status. However, none of these firms provides work specifically to people with MH problems, although unemployment in this population is the largest among disability groups.

Outpatient Care (O)

Madrid has a lower availability rate for this kind of care than Sofia. In the case of Madrid, the low level could be explained by the high accessibility to services that the community provides. This highlights the need for a study to be carried out on the use of these services, allowing better interpretation of this information.

Information, Accessibility And Self-Help Care

In these branches, in which Madrid has higher availability than Sofia, we observed that in many of the services studied, activities fundamentally related to information are carried out but they are unstructured and not conducted on a regular basis. As a result, the DESDE-LTC has not classified them as a type of independent care.

The standardised description of the *Information and Accessibility* services is very relevant with regard to people needing long-term care since, in Spain, many of the newly-created services in this domain are being developed to facilitate accessibility and therefore the inclusion of this group.

Given the voluntary and selfless nature of the care provided, these services depend on personal initiative and the availability of family members or rehabilitation professionals and social workers. These circumstances explain their lower presence in basic types of care offered in Madrid without underestimating their enormous importance.

As regards the predominant care offered by Madrid in the field of *Self Help*, care offered by people with no specific training in daily leisure and free time activities stands out (sport, workshops, recreational activities ...) aimed at improving and normalising the quality of life of people with some kind of disability. The majority of them describe the personal care provided in small local associations which deal with a small group of users and are created by family members. Many of these associations develop depending on the needs of users and, in time, come to provide more specialist care, specific programmes, or may eventually become Occupational or Day Centres, and obtain subsidies and grants from the Department of Family and Social Affairs. This basic type also describes the care provided by many of the Leisure Clubs for people with intellectual disability.

The lack of services providing any type of care coded in this main branch in Sofia identifies a major gap of long term care in Bulgaria. It highlights lack of empowerment of users and families in this country.

Services for specific Diagnostic Groups

Mental Disorders

The availability and variety of mental health services provided in Madrid is, on the whole, better than in Sofia with the exception of non-mobile, non-acute mental health outpatient care. Previous studies showed that availability of these kinds of resources alone and their use were not good indicators of basic mental health community care (6).

The lack of division into sectors represents a serious problem with respect to the organisation of care in Sofia, where over a third of patients have direct access to

specialised services (12). We should also take into consideration the fact that our comparative study listed and classified all non-mobile psychiatric services, registered in Sofia, regardless of the “severity” of mental health problems they treat; that is, whether they treat serious and/or common mental illnesses. There are no specific outpatient health services in Sofia, focused on the serious mental illness which corresponds fully to the criteria for long-term care. Therefore, doubts remain as to whether this greater availability of non-acute, non-mobile outpatient services actually takes care of the problems of those in greatest need. Further investigation is much needed to clarify this very important question of the target groups of mental health outpatient services in Sofia.

Intellectual Disability, Developmental Disorders and Physical Disability

Madrid has high availability of care resources for this population in comparison with Sofia in terms of diversity as well as the number of centres and places available.

Comparing the two systems of care from the perspective of different diagnostic groups, our study shows quite clearly that in Madrid there is a spectrum of services dedicated to the long-term care of people with ID-DD. Such differentiation is not extant in Bulgaria, where there are only two specialised residential facilities for ID-DD. In Sofia outpatient services and the scarce day care services available serve both the population with MH problems and those with intellectual disabilities.

The comparative graph showing the availability of services for ID-DD is perhaps the most striking visual result of the study. It is an illustration of the developmental stage of the Bulgarian service system where, only some five years ago, an effort was made to set apart residential services caring for the MH and the ID-DD population. The process of differentiating other branches of services, apart from those providing beds, has apparently not yet begun in the community of the Bulgarian capital.

Non specific

The availability of centres which are not addressed to a specific diagnostic group is greater in Sofia with the exception of work-related centres, which are greater in Madrid,



and where most of the centres have been developed for the care of a particular population profile.

Availability of beds and places for long term care in Sofia and Madrid

There are major differences in total availability and distributions of both beds and place in the two catchment areas. Whilst a clear pattern of institutional care is shown in Sofia, the pattern of beds and places available in Madrid are closer to a community care model.

4.4. CONCLUSIONS

The pilot study carried out shows that the eDESDE-LTC is an instrument that can be applied in very different environments and allows us to compare availability of services in areas with distinct care systems. In the future, similar comparisons will have to be made of services for the elderly and a precise protocol established for the different practical procedures for gathering information about care services from different organisational environments and geographical distribution of care services.

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