Development and usefulness of an instrument for the standard description and comparison of services for disabilities (DESDE)

Salvador-Carulla L, Poole M, Gonzalez-Caballero JL, Romero C, Salinas JA, Lagares-Franco CM. Development and usefulness of an instrument for the standard description and comparison of services for disabilities (DESDE).

Objective: Mental health research has made significant progress in international comparison and instrument development. This study reports the adaptation of the European Service Mapping Schedule (ESMS) to the assessment of services for persons with disabilities.
Method: Qualitative groups were used to develop the Description and Evaluation of Services for Disabilities in Europe (DESDE). The psychometric analysis of DESDE covered: feasibility, inter-rater reliability, descriptive validity and internal validity. A demonstration study was also carried out.
Results: Compared to the original ESMS, a new main branch and several sub-branches were added. We identified 826 services for persons with disabilities, which provided 1284 main types of care. The feasibility and reliability was good for the majority of codes. Only 6% of services were not properly classified. The Boolean factor analysis supported the internal validity of DESDE.
Conclusion: DESDE is a useful and reliable instrument for the assessment of services for persons with disabilities.

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Significant outcomes

- Technology transfer between mental health service research and research on services for disabilities is possible and useful, particularly in Europe where there is an urgent demand for international comparisons of services for the 'dependent population'.
- The Description and Evaluation of Services for Disabilities in Europe (DESDE) is an adaptation of the European Service Mapping Schedule (ESMS) to the assessment of services and main types of care (MTC) for persons with disabilities.
- The ESMS/DESDE coding based on MTC has been adopted as a classification system for disability services in several regions in Spain (macro-level).

Limitations

- The DESDE has been tested in a single country (Spain).
- Not all DESDE-defined codings were available in Spain: of 71 possible codings, 51 were observed in the three regions where the instrument was tested.
- The instrument feasibility has been assessed by a small number of stakeholders. A small number of codes showed inadequate reliability.

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Introduction

Until very recently, a geographical vacuum existed in mental health service research. Available tools allowed detailed information on the quality of individual services (1) or on the cost-effectiveness of specific interventions or treatments programs. However, little was known about how these services performed within the territory where they were run. Furthermore, the impact that geographical availability and utilization of services has both on clinical practice and assessment has been insufficiently evaluated (2). For example, relapse rate, a major outcome indicator in schizophrenia, is frequently assessed through hospitalization episodes or it is defined as 'a significant change in the clinical status of the patient related to a change in the pattern of service use' (3). In both cases, relapse is related to the use of acute hospital beds or intermediate care (i.e. day hospital places) which shows large variation across different countries and even in neighbouring areas due to local bed availability and medical practice variation, among other factors. This geographical vacuum is particularly relevant with regard to evidence-based planning and resource allocation. Standard assessment and inter-territorial comparison are key elements in service research. This approach is hampered by the intrinsic problems of service analysis in mental health (4). As a result, few studies focus on international service comparison. For example, the mental healthcare system in the Trieste area in northern Italy was generally accepted as the model for both the Italian and the Spanish mental health reforms which started in 1978 and in 1985 respectively. Nearly 30 years later, we were able to compare 12 small health areas both in Italy and Spain for the first time, showing that Trieste was not comparable with any other area in these two countries (5). Local area assessment should also produce a picture as comprehensive and accurate as possible of services available within the area. In the mental health sector, identical services may be run by different agencies in different countries or regions. Thus, it is necessary to use a system that describes both social and health services, as well as services for other disability groups. This is particularly important to understand vertical equity, financing patterns and the spectrum of services available in one area to provide care to different population groups (6, 7). During the mid-1970s, the European Office of the World Health Organisation launched a project for comparing mental healthcare systems and services across different European cities (8). Although this project failed to produce a useful assessment system, it nurtured a series of international studies in the 1990s that placed mental health at the frontline of international service research. An example of this trend was the development of the Thornicroft and Tansella Matrix for Mental Health service assessment (9), the European Psychiatric Services: Inputs Linked to Outcome Domains and Needs study on care patterns for schizophrenia in five European cities (10) and the European Psychiatric Assessment Team (EPCAT) project (11), which developed a common framework for international comparisons on service availability and utilisation. This framework incorporated an international glossary of terms, an epidemiology-based approach, and a battery of instruments for service assessment in the mental healthcare sector. EPCAT comparisons have a meso-level focus (small health areas), include operational definitions of both the target population and the catchment areas, take as unit of analysis the 'main types of care' (MTCs) instead of individual services (see below), incorporate inclusion and exclusion criteria, and provide an explicit time frame. EPCAT developed two instruments for standard service assessment at meso-level: the European Socio-Demographic Schedule (12) for assessment of indicators at small health areas, and the European Service Mapping Schedule (ESMS) (13) for mapping MTC and for providing standard service listings. A third instrument described main types of activities performed within individual services (International Classification of Mental Health Care) (14).

The problems faced by psychiatric service research are common to other areas such as long term care for chronic medical conditions or for the disabled/dependent population. It is important to assess the transferability of these developments in mental health service research to other long-term care areas.

Aims of the study

To report the adaptation of the ESMS to assess services for persons with disabilities.

Material and methods

The adaptation of ESMS to evaluate services for persons with disabilities followed a three stage process: i) changes in ESMS were suggested by qualitative groups and a new questionnaire was developed and agreed with main stakeholders in the disability field in Spain; ii) a demonstration study was carried out in three regions of Spain with high variability of service provision and care

models for persons with disabilities; iii) the psychometric properties of the instrument were analysed (feasibility, reliability and internal validity).

Material

European Service Mapping Schedule

European Service Mapping Schedule (13) is an instrument intended for: i) compiling an inventory of mental health services serving the adult mentally ill population of a catchment area; ii) describing and comparing the structure and range of mental health services between catchment areas; and iii) measuring and comparing between catchment areas the levels of provision of major types of mental health service. It has four modules: i) introduction; ii) service mapping: coding of MTC at small area level; iii) service counting: utilization of MTCs; iv) service characteristics listing. Three major contributions of ESMS are the use of an international terminology, its mapping structure, and its focus on MTCs instead of services. The ESMS tree divides care in main branches according to whether the patient sleeps in the setting, receives day care or has a face-to-face point contact. Care is then subdivided in secondary and tertiary branches according to the number of descriptors such as intensity, time of stay and mobility. These atheoretical descriptors are called MTC. Many individual services are coded with a single MTC, but services may be also composed of two or more MTCs. These combinations of services had previously impeded service comparisons across territories, but they can be overcome by comparing MTCs for each service. The psychometric properties of ESMS have been described previously (15, 16).

Development of a questionnaire for the assessment of services for persons with disabilities: Description and Evaluation of Services for Disabilities in Europe

A Delphi panel with seven experts in different disability areas made a working draft of the questionnaire. This working draft was sent to a national focus group made of 12 key stakeholders in the disability sector. Officers from all regions in Spain, and managers or experts at main Non-Governmental Organizations (NGOs) were invited to participate in this process. The final focus group included officers from the National Spanish Agency for Disabilities and Ageing (IMSERSO), officers from three regional agencies on disability and social services (Andalucia, Castilla la Mancha and Madrid), representatives from main user organizations in intellectual disability (FEAPS), physical disability (COCEMFE), sensory disability (CNSE), and a key NGO in vocational and community programs (AMICA).

The questionnaire was piloted in 24 selected services for persons with disabilities in six Autonomous Communities in Spain: Andalucia, Cantabria, Catalonia, Madrid, Navarre and Castilla la Mancha. Additionally, services for two populations with chronic diseases and long-term care needs (acquired immunodeficiency syndrome and renal insufficiency) were also assessed. Its feasibility was explored by experts using the questionnaire in these regions and by the focus group participants, according to Andrews's dimensions: applicability, acceptability and practicality (17). The 'applicability' of a measure is defined as the degree to which a measure addresses dimensions of importance to the consumer, is useful for service providers in formulating and conducting decisions, and allows for the aggregation of data in a meaningful way to meet the purposes of service management. The acceptability of a measure describes the ease with which a consumer or clinician may use a particular measure (i.e. user-friendliness). It refers to the simplicity of the administration and use of the interview insofar as the length of time or burden in completion. Practicality relates to cost of implementation, training requirements and complexity of scoring, reporting and interpreting the data (18). Feasibility was measured using a four-point Likert verbal analogue scale. The Description and Evaluation of Services for Disabilities in Europe (DESDE) questionnaire was published in Spanish and distributed to all the social services agencies in the Autonomous Communities and related NGOs in Spain (19).

Demonstration study and psychometric properties

Sample. In Spain, there is a national assessment system for eligibility for access to disability benefits and social services. In 2004 and 2005, all services for persons with disabilities (child and adolescent and adult population) in three regions of Spain were identified and coded. The regions were Castilla la Mancha in central Spain (1 718 242 inhabitants), Navarre in the north (535 211 inhabitants) and Cadiz in the south (1 116 491 inhabitants). Services for severe mental illness were also included in this group. An operational definition of service for persons with disabilities was used. Small areas were defined in the three regions using EPCAT criteria for meso-level comparison. These

areas were mapped and compared with available registers including national census, the mapping of health services, social services, mental health services, road map and other maps relevant for area comparison. In all, 20 meso-level areas have been defined in the three regions.

Procedure and data analysis. The assessment of all services was carried out by a multidisciplinary team from the PSICOST Research Association, including service researchers and geographers. All the services identified in every region by the group were contacted by the regional agency of social services and invited to participate in the study. A questionnaire was filled by the reference person at every service and a PSICOST researcher contacted him or her to check the items and code the MTC. Services with unclear codings were visited on-site and doubts were discussed by the PSICOST team before a definite code was provided. When the regional mapping of disability services had been completed and checked by regional agencies, it was presented to all regional stakeholders and organizations to identify errors and to introduce final comments. A subsample of services was selected for the inter-rater reliability study. The inter-rater reliability was assessed in 311 MTCs, coded by two raters previously trained in the use of the ESMS and the EPCAT model. Rater 'A' identified 515 MTCs and rater 'B' identified 498 MTCs (or DESDE codes) in the 311 services. A randomized category-stratified sample of 50 services was used to test the Kappa agreement coefficient (15) for every observed category (MTC) at final branches. Kappa values were transformed into ordinal measures following Kramer and Feinstein criteria (20) (Kappa: poor <0, low 0–02; fair 0.21–0.4; moderate 0.41–0.6; strong 0.61–0.8; and nearly perfect 0.81–1). For the inter-rater agreement in non-mutually exclusive categories (main branches which could be subdivided in other branches), we have used the second coefficient proposed by Kupper and Hafner (21), which considers the categories selected and not selected by either rater.

The consistency or internal validity of the DESDE-MTC coding at module B was analysed by Boolean factor analysis (BFA) for dichotomous variables. As in classic factorial analysis, BFA obtains, with dichotomous variables, a group of dichotomous factors to explain the underlying structure within the population. BFA adjusts the items observed to estimated ones by multiplying the factor loadings and the factor scores by the Boolean product (22). Both positive and negative discrepancies are counted. Positive discrepancies

are counted when the observed rating is 1, while the analysis estimate is 0. Negative discrepancies are the number of times the observed rating is 0, while the estimate value is 1. The BFA carried out in this study used all services and 51 dichotomous variables; all MTCs were rated at least once. Further data on DESDE can be found at http://www.proyectodesde.com.

Results

The national consensus group held six focus group meetings over a 1-year period. The modified version kept the original ESMS tree structure, coding system and the essence of every topic being assessed. However, a series of structural and terminology problems appeared in the DESDE working draft developed, mainly related to the acceptability of some terms in the disability sector and the difficulty in classifying several types of care in the working draft of the instrument. The wording of the questionnaire was adapted to make it acceptable to the users' organizations. The final DESDE instrument with a glossary of terms and the explanation of every code can be found at http://www.proyectodesde.com. In comparison with ESMS, a new main branch on 'information and accessibility' (I) has been added, and the 'self-help and voluntary' main branch (S) has been expanded to other sub-branches. At first, six new codes were defined at the 'I' branch and eight at the 'S' branch. Branch 'D' (day care) was expanded to better describe a whole arrangement of service provision in different disability care areas. As an example, 'other day and structured care' (D4) was divided in four sub-branches to describe activities related to education, health, social and cultural participation, and other activities (D4.1–D4.4). Sub-branches were also added to the 'out-patient and ambulatory' main branch (O), in order to differentiate health-related care and generic care. Additional branches were also added to branch 'R' (residential care), in order to differentiate non-hospital residential care limited to less than 1 month and other types of time-limited residential care. The order of codes was also modified and residential services were rated at the end so as to improve their acceptability in the disability field. The last DESDE code is R1 (secure services), which is the first one in ESMS. DESDE module 'D' (service characteristics listing) underwent extensive modification in order to provide a comprehensive description of services available in different small areas. The pilot testing allowed a series of new modifications, and then the feasibility was explored. Twelve stakeholders and experts on

service research including officers from several Autonomous Communities provided information on the applicability, acceptability and practicality of DESDE. The 'applicability' and 'acceptability' were judged 'high' by 11 and 10 raters respectively. An unexpected outcome was the applicability of the DESDE coding and glossary as a classification system for disability services both at regional (Navarre, Madrid and Castilla la Mancha) and national level (IMSERSO). The 'practicality' was judged 'moderate' to 'low' by the experts in module 'C' due to training requirements and complexity of scoring. The cost of assessment was estimated in the Cadiz area by officers at the local social service agency in comparison with another service listing of services for the elderly (Diputacion de Cadiz). Time for full completion at small area level was 15–20 days for module 'B', 120–140 days for module 'C' and 40–65 days for module 'D'.

In the 20 small health areas explored in three regions of Spain, we identified 826 services for persons with disabilities (Table 1). These services provide 1284 MTC (mean: 1.55 ± 0.9 MTC per each service, range: 1–7) (Table 2).

Of 71 possible DESDE codings, 51 were observed at least once in the three regions screened. The rate of MTC for persons with disabilities in the three regions is shown in Table 3. The homogeneity test between regions (macro-level) was nearly significant: $\chi^2 = 10.86$ ($P = 0.09$). The homogeneity test between areas (meso-level), joining 'physical and other disabilities and sensory disabilities', was: Cadiz: $\chi^2 = 17.96$ ($P = 0.05$); Castilla la Mancha: $\chi^2 = 10.48$ ($P = 0.57$), and Navarre: $\chi^2 = 17.28$ ($P = 0.139$).

Reliability

The overall reliability of DESDE was high (Kupper, C12: 0.99; 95% CI: 0.9–1). All main branches provided Kupper coefficients above 0.9 (Table 4). Inter-rater reliability of final branches was calculated for 34 codings of 51 MTCs identified in the three Spanish regions or ACs. Reliability was poor in 'day and structured continuous care, high intensity, related to social activities and cultural participation' (D4.3 code). Although the observations in D4.4 'other structured continuous

Table 1. Demonstration study

Regions (macro-level), areas: meso-level	Services for persons with disabilities				
	Intellectual disabilities	Physical and other disabilities	Sensory disabilities	Mental disorders	Total
Cadiz (Andalucia)					
Bahía de Cádiz	27	30	4	25	86
Campiña de Jerez	10	13	2	17	42
Campo de Gibraltar	10	17	2	7	36
Costa Noroeste	6	4	0	4	14
La Janda	7	1	0	2	10
Sierra de Cádiz	7	4	0	1	12
Subtotal 1	67	69	8	56	200
Castilla la Mancha					
Albacete	36	38	8	27	109
Ciudad Real	24	45	5	21	95
Cuenca	21	22	2	16	61
Guadalajara	21	18	0	16	55
Puertollano	13	14	1	5	33
Talavera de la Reina	21	27	2	11	61
Toledo	37	38	3	19	97
Subtotal 2	173	202	21	115	511
Navarre					
Estella	5	1	0	2	8
IIA	2	0	0	0	2
Navarra Noroeste IA	2	0	0	0	2
Navarra Noroeste IB	3	2	0	2	7
Pamplona y Comarca	19	24	5	31	79
Tafalla	2	0	0	2	4
Tudela	5	4	1	3	13
Subtotal 3	38	31	6	40	115
Total	278	302	35	211	826

Services for persons with disabilities (intellectual disabilities, physical and other, sensory and disabilities related to severe mental illness) in 20 small areas in three regions in Spain (meso-level).

Table 2. Description and Evaluation of Services for Disabilities in Europe (DESDE) demonstration study

Main branches	DESDE final branches (MTCs)																Total
Residential	R2	R4	R6	R81	R82	R91	R92	R102	R11	R12	R13						
n	16	3	2	27	22	4	2	6	107	33	9						231
Day care	D1	D21	D22	D31	D32	D41	D42	D43	D44	D5	D72	D81	D82	D83	D84	D9	
n	2	6	112	36	122	12	96	88	3	1	1	3	12	32	3	4	533
Out-patient	O12	O31	O41	O51	O52	O61	O62	O71	O72	O81	O91	O101					
n	1	9	23	11	24	6	3	1	14	25	86	28					231
Information and accessibility	I11	I12	I13	I21	I2211	I2212											
n	30	19	5	76	25	4											159
Self-help	S11	S12	S13	S21	S22	S23											
n	35	63	1	6	21	4											130
Total																	1284

Main types of care (MTC) assessed by final DESDE codings available in three regions in Spain (Cadiz, Castilla la Mancha and Navarre). Main branches: R (residential care), D (day and structured activity), O (out-patient and community care), I (information and accessibility), S (self-help and voluntary care).

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Table 3. Description and Evaluation of Services for Disabilities in Europe demonstration study

Branches by region	Intellectual disability	Severe mental illness	Other disabilities	Total
All MTCs				
1	7.64	5.84	10.05	23.53
2	13.20	11.52	19.25	43.97
3	10.95	10.77	12.66	34.37
Information and accessibility (I)				
1	0.17	0	2.66	2.83
2	0.27	0.97	4.60	5.84
3	0	0.86	2.22	3.08
Self-support (S)				
1	0.69	0.26	1.29	2.23
2	0.49	0.70	3.79	4.98
3	0.68	0.00	1.54	2.22
Work-related (D2, D3, D6, D7)				
1	2.23	1.03	2.58	5.84
2	3.84	0.97	3.84	8.65
3	5.13	0.68	2.57	8.38
Other day care (other D)				
1	1.98	1.20	1.55	4.72
2	3.19	1.62	3.73	8.55
3	2.39	1.54	3.25	7.18
Out-patient and ambulatory (O)				
1	0.77	1.63	1.72	4.12
2	0.32	4.76	2.81	7.90
3	0.51	4.62	1.20	6.33
Hospital care (R2, R4–7)				
1	0.00	0.43	0.00	0.43
2	0.00	0.32	0.05	0.38
3	0.00	1.54	0.00	1.54
Non-hospital care (R3, R8–13)				
1	1.80	1.29	0.26	3.35
2	5.08	2.16	0.43	7.68
3	2.22	1.54	1.88	5.64

Rate of main types of care (MTC) per 100 000 inhabitants in three regions of Spain: i) Cadiz; ii) Castilla la Mancha; iii) Navarre. Main branches: R (residential care), D (day and structured activity), O (out-patient and community care), I (information and accessibility), S (self-help and voluntary care).

care, high intensity' were small in number (n:3), no agreement was reached in this code. Agreement was low in the 'information' sub-branch (code I2), and fair in branches I2.2 (self-support provided by specialized voluntary staff) and D8. A moderate agreement was obtained in branches I2.1 (information), S2.2, D3, D4, D8, O3.1 (non-mobile emergency care), O6 (mobile out-patient continuing care). The agreement was 'strong' or 'nearly perfect' for all other DESDE codes (MTCs).

Validity

Face/descriptive validity was tested in one region (Cadiz, with 200 services). Face validity was judged 'high' by 11 of 12 experts. The description of MTCs provided by DESDE was accurate, logic, coherent and provided meaningful results. Content validity was high except for 38 MTC (6%), which were not adequately described by the DESDE codings according to the final judgment. Twelve MTC

Table 4. Description and Evaluation of Services for Disabilities in Europe inter-rater reliability: 'main types of care' (MTC) in main and primary branches (Kupper) and in final branches (Kappa) ($n = 311$)

ESMS codes (MTC)	n	Agreement Kupper (C_{12}) (95% CI), Kappa (κ) (95% CI)*
Information and accessibility		C_{12}: 0.98 (0.96–1.00)
I1	18	κ: 0.83 (0.67–0.99)
I1.1	12	κ: 0.89 (0.74–1.00)
I1.2	11	κ: 0.75 (0.52–0.98)
I1.3	5	κ: 0.67 (0.38–0.96)
I2	35	κ: 0.06 (−0.18 to 0.30)
I2.1	28	κ: 0.55 (0.31–0.78)
I2.2	9	κ: 0.24 (−0.01 to 0.50)
I2211	8	κ: 0.43 (0.14–0.71)
I2212	1	–
Self-support and voluntary		C_{12}: 0.99 (0.99–1)
S1	25	κ: 0.72 (0.53–0.91)
S1.1	8	κ: 0.76 (0.51–1.00)
S1.2	17	κ: 0.62 (0.39–0.85)
S2	22	κ: 0.72 (0.52–0.91)
S2.1	6	κ: 0.81 (0.56–1.00)
S2.2	12	κ: 0.54 (0.29–0.80)
S2.3	4	–
Day and structured		C_{12}: 0.98 (0.97–1)
D2	28	κ: 0.92 (0.81–1.00)
D2.1	6	κ: 0.90 (0.70–1.00)
D2.2	22	κ: 0.96 (0.88–1.00)
D3	43	κ: 0.56 (0.21–0.90)
D3.1	15	κ: 0.85 (0.69–1.00)
D3.2	34	κ: 0.86 (0.71–1.00)
D4	65	κ: 0.51 (0.33–0.69)
D4.1	8	κ: 0.85 (0.65–1.00)
D4.2	37	κ: 0.64 (0.40–0.88)
D4.3	24	κ: −0.05 (−0.24 to 0.14)
D4.4	3	–
D7	1	–
D7.2	1	–
D8	25	κ: 0.40 (0.15–0.65)
D8.1	2	–
D8.2	11	κ: 0.75 (0.52–0.98)
D8.3	13	κ: 0.67 (0.43–0.91)
D8.4	3	–
Out-patient and ambulatory		C_{12}: 0.99 (0.99–1)
O3	8	κ: 0.50 (0.14–0.86)
O3.1	8	κ: 0.50 (0.14–0.86)
O4	6	κ: 1.00 (1.00–1.00)
O4.1	6	κ: 1.00 (1.00–1.00)
O5	19	κ: 0.78 (0.60–0.96)
O5.1	10	κ: 0.71 (0.44–0.97)
O5.2	13	κ: 0.89 (0.74–1.00)
O6	8	κ: 0.55 (0.24–0.87)
O6.1	5	κ: 0.62 (0.29–0.96)
O6.2	3	–
O7	6	κ: 0.90 (0.70–1.00)
O7.2	6	κ: 0.90 (0.70–1.00)
O8	10	κ: 0.72 (0.49–0.95)
O8.1	10	κ: 0.72 (0.49–0.95)
O9	34	κ: 0.49 (0.23–0.75)
O9.1	34	κ: 0.49 (0.23–0.75)
O10	13	κ: 0.89 (0.74–1.00)
O10.1	13	κ: 0.89 (0.74–1.00)
Residential		C_{12}: 0.99 (0.99–1)
R2	14	κ: 1.00 (1.00–1.00)
R8	19	κ: 0.87 (0.73–1.00)
R8.1	14	κ: 0.59 (0.33–0.85)
R8.2	11	κ: 1.00 ± (1.00–1.00)
R9	6	κ: 0.64 (0.27–1.00)

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Table 4. Continued

ESMS codes (MTC)	n	Agreement Kupper (C_{12}) (95% CI), Kappa (κ) (95% CI)*
R9.1	4	–
R9.2	2	–
R10	6	κ: 1.00 (1.00–1.00)
R10.2	6	κ: 1.00 (1.00–1.00)
R11	29	κ: 0.96 (0.88–1.00)
R12	13	κ: 0.95 (0.85–1.00)
R13	6	κ: 1.00 (1.00–1.00)

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

Table 5. Description and Evaluation of Services for Disabilities in Europe (DESDE) internal validity: Boolean factor analysis of 1284 main types of care (DESDE codings) in 826 services for persons with disabilities identified in three regions in Spain

Factors	Codes
1	O91
2	R81
3	R82
4	R12
5	R92
6	R102
7	R11
8	R13
9	D42
10	I11
11	D22
12	D32
13	D43
14	D44/I2212
15	I21
16	S12
17	D32/D81
18	D82
19	D83
20	I2211
21	D9/I11
22	O101
23	R2/O31
24	O41
25	D31
26	O52
27	S11
28	O81
29	S22
–	–

insufficiently described by DESDE were in the 'self-help and voluntary' branch (S) (particularly 10 types run by unpaid/voluntary professional staff), 12 were in the 'information and accessibility' branch (I), nine in the 'residential' branch (R) and five in the 'day and structured care' branch (D).

We used BFA to test consistency or internal validity. Weights were set up for positive discrepancies. The positive adjusted values were 1241 of 1284 positive observed values, meaning that 43 MTCs (3.34%) could not be adjusted by the model.

The 'positive discrepancy' provides an error measure of the use of this factor model to explain positive values. The model provides an optimal adjustment of negative values (negative observed values: 40 842, negative adjusted values: 40 813, percentage of discrepancies: 29–0.07%). A 29-factor model explained 36 DESDE codings (MTCs) out of 51 codes rated at least once in the three regions. Five codes (D2.1, D4.1 O5.1, O7.2 and I1.2) were also explained by this model, although they have no weight in any of the 29 factors. The MTCs (DESDE codes) assigned to each factor are shown in Table 4. Factors 14, 17, 21 and 23 included more than one code (see 7 Table 5).

Discussion

To our knowledge, DESDE is the first instrument designed for international comparison of services for disabilities and long-term care. The psychometric properties of the DESDE (feasibility, reliability and validity) are good. This instrument is an adaptation of an assessment tool previously designed for mental health service research (ESMS).

Nevertheless, a measure of caution should be taken when evaluating these results. First, the instrument has so far been developed and tested in a single country (Spain). However, the coding system is based on ESMS, which is now broadly used for international service comparisons in the mental health care sector. Furthermore, the modified version has been developed by a multidisciplinary panel made up of stakeholders working in the majority of disability sectors. At present, studies are being carried out in Eastern Europe and Latin America using DESDE. Secondly, a number of DESDE codes could not be identified in services for persons with disabilities in Spain. In addition, inter-rater reliability of other codes could not be explored due to a small number of observations. However, we were able to test more codes than those screened in previous ESMS studies both in Italy and Spain (15, 16). Thirdly, the number of stakeholders and service researchers who participated in the feasibility and face and descriptive validity analyses was small (n:12). As we were developing a new instrument, it was not possible to increase the number of participants as raters needed to know both the instrument and the disability care system. A similar problem occurred with ESMS when it was first published in 2000. ESMS usability is now being re-analysed in a larger sample, 6 years after the instrument was first published. Fourthly, we did not carry out an

analysis of module 'C' (utilization of MTCs) in the demonstration study. The counting system used in the module 'C' was not modified from the original ESMS.

Feasibility was adequate except for module 'C' (service utilization). In our view, problems in practicality relate not to the instrument itself but to the construct being rated. The difficulties of international service comparison appear in areas as different as mental health (4, 6), ageing (24) and disabilities or dependency (persons in need of support of a third person). The European Commission Report on Care for Dependent Adults concluded that it was not possible to obtain comparative statistics on care services for the dependent population or to compare formal care for this population group across the different EU countries (25). This statement mirrors the final report of the 1987 WHO-Europe study (6) and may indicate that the complexity of service assessment lies not in the assessment system but in the 'service' construct itself. Although it may seem counterintuitive, different units of analysis in this field overlap. 'Services', 'clinical units', MTC, 'care programs' and 'activities' are dimensional and not categorical domains.

Description and Evaluation of Services for Disabilities in Europe showed high inter-rater reliability for main branches. Reliability was also high for final branches which correspond to MTCs. 'Information' final branches showed lower agreement coefficients. Therefore, the MTCs at the 'information' branch have been reduced to two sub-branches instead of six in the final DESDE version. The definition of these services has been reviewed. The low reliability found for codes D4.3 (and D4.4) may be due to the difficulty in differentiating structured and non-structured culture and leisure care. The definition of these codes has also been expanded in the final questionnaire. O6 (ambulatory care, continuous, mobile and medium intensity) showed a moderate coefficient of agreement. This may reflect a problem in differentiating medium and low intensity services at this specific coding or health-related and generic care at low to medium intensity mobile care. As expected, best ratings were obtained in the residential branch.

Descriptive validity was appropriate. Only 6% of services were not properly described using DESDE. The BFA provided 29 factors. As this questionnaire describes categories, it should be expected that DESDE had as many factors as categories observed. Nevertheless, the four factors with two MTCs or DESDE codings could be explained by the arrangement of MTCs within individual services in Spain. For example, factor

'23' includes acute hospital units (R2) and non-mobile, 24-h health-related emergency care (O3.1). These two MTCs can be found together in general hospitals. Factor '17' includes work-related indefinite stay high-intensity care (D3.1) and 'other structured care, low-intensity, related to education' (D8.1). This arrangement of MTCs is common in a type of vocational training centre in Spain. Factor '21' included 'non-structured day care, low intensity' (D9) and accessibility related to communication (I1.1). This pattern was found in services for persons with sensory disabilities. The aggregation found in factor '14' (day and structured care not classified elsewhere – D4.4) and a subcoding of information (I2.2) may be related to problems in the definition of the information on types of care. The number of observations in this final branch was low.

The demonstration phase showed the usability of DESDE and the EPCAT approach in service research. Two findings support the use of DESDE instead of the traditional approach to inter-territorial service comparison. First, many services with the same traditional name (i.e. 'day centre') were classified in different DESDE codes or MTCs. Second, a mean of 1.5 MTCs were coded per service identified. The BFA supports the use of the EPCAT approach based on MTC instead of traditional service comparison.

Main types of care varied not only by region but also by type of dependency. Information and accessibility (I) and self-support and voluntary MTCs predominate in non-psychological disability. A more institutional, health-related pattern was observed in mental health care. Social community care prevailed in services for intellectual disability. This findings support our previous studies, which found a low development of community services for severe mental illness in Spain in comparison with Italy (5), and a lack of specific mental health services for intellectual disabilities, particularly in residential care (26). A broad array of services for severe mental illness depends on social services. There is, however, little interest in assessing the care pattern and the proportion of mental health expenditure that depends on social services, while similar information has been extensively analysed in the healthcare sector (27). DESDE may help us to understand and compare mental health care, not only in relation to other health sectors, but also to care provided to other disabilities. The available international service classification systems (i.e. Organization for Economic Co-operation and Development's International Functional Classification of Health care) (28) provide an incomplete coding list of services

related to mental health care, and cannot be used for coding social disability services. DESDE coding has been adopted as the classification system for disability services in three Autonomous Communities in Spain (Navarre, Castilla la Mancha and Madrid).

To sum up, we have presented the DESDE, an instrument that can contribute greatly to improving international service research outside the mental health sector. Mental health care may not be an exception, but the paradigm of integrative social and health care. Advances in mental health service research, including the seminal work by Leginski et al. in 1989 (29), the EPCAT model of service research, the Thornicroft and Tansella Matrix and instruments such as ESMS, can be adapted and applied to the assessment of other long-term care services for persons with disabilities.

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