

ANNEX VIII: SPAIN

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INTRODUCTION

Historical context of services development

In Spain care for people with Intellectual Disability (PWID) was linked to psychiatric institutions until the 1970's. The move towards a community care system started earlier for PWID than for severe mental illness. In 1985 the Spanish Psychiatric reform was approved and included in the 1986 Health Law. Although no special mention was made in this official documents to PWID, the psychiatric reform accelerated the transfer of care in PWID from the health sector to the social sector, moving to community care related to work and to community residential settings. However this process was mostly focused in PWID without behavioural problems, and a gap appeared in care for PWID and mental illness. On the other hand, the devolution of health and social services to the 17 Autonomous Communities or regions in Spain which was completed in 1991, derived into different care policies in every AC, which makes the description of the current national reality a difficult task.

From an administrative point of view, Spain is divided in 17 autonomous regions called "Autonomous Communities" (AC). The ACs have their own government and administration, full autonomy in health and social services, and varying degrees of autonomy in other issues such as crime and justice or education. In practice, Spain's administration works as a federal state although the background is different. This decentralisation process followed a different pace in every AC depending on regional policy and the model of administration transfer from the central government. Two different AC transfer models were developed in the late 1970's: a "slow" transfer process and a "quick" one for the so-called Historical Autonomous Communities which included Andalusia, the Basque Country, Catalonia and Galicia. However, this process has not been accompanied with a parallel development of national agencies or efficient inter-autonomic co-ordination systems. Internationally, services and provisions are described at national, regional and local level. We use "regional" here as a descriptor for provision at the AC level.

Following the decentralisation process, from a common health organisation mainly based on social welfare, a whole array of different health and social care systems have emerged at different periods of time. For example, Catalonia got control over both the health and social services more than 20 years ago while Andalusia assumed the health services by the same time Catalonia did, but delayed the social services transfer until the 1990s. Other 10 AC, such as Cantabria or Balearic Islands, assumed the social services by 1997 and the health services in 2001.

Before the decentralisation process started, national social services were coordinated from an agency called IMSERSO (Instituto de Migraciones y Servicios Sociales) of the Ministry of Labour which also includes Social Affairs. Health services were coordinated by the INSALUD (Instituto Nacional de Salud), a national agency of the Ministry of Health. The social services transfer was completed by 1997, and the health service transfer was completed in 2001. IMSERSO and the Ministry of Health are in the process of redefining their respective roles. Although inter-territorial councils do exist, the decentralisation process was not accompanied by a clear definition of the co-ordination mechanisms among the different ACs, or between them and the central agencies. Currently there is no national information system on service provision either for social or health services.

In terms of law and policy, major differences have emerged among ACs as well.

From 1993 on, our group has published several reports on services for MR in Spain (Salvador-Carulla et al, 1993; Salvador-Carulla et al, 1999; Costello et al, 2000). The main aspects considered in these reviews were:

- Lack of interest by the health department on MR
- Lack of co-ordination among different agencies and administration (e.g. between social services versus health services; or between central agencies and Autonomous Communities)
- Lack of reliable estimates and databases both in epidemiology and service provision and utilisation.
- Problems in accessibility of people with MR to general and mental health services
- Lack of specific services for MR (e.g. MR-MH)
- Lack of training programs
- Need of national co-ordination agencies and plans

What definitions of Intellectual Disability are typically used in your Member State?

Although there is no common definition of Intellectual Disability (ID) in Spain, this term is becoming widely accepted and it is used by the Social and Health Services and the FEAPS - National Federation of intellectual disability associations-. The Spanish Association for the Scientific Study of Intellectual disability (AEERM) has recently changed its name to the “Spanish Association of Intellectual Disability Professionals”. The word “handicap” has been replaced by “people with disabilities” in all official documents since 2005. However, the official health data systems (CMBD) and other records use “Intellectual disability” as they are linked to ICD-9 or 10 (depending on the AC). The agencies on disability depend from the Ministry of Labour and use the WHO-ICF classification.

Health Sector

Health services use the ICD-10 classification. Ministry of Health database use an adaptation of ICD-9 (CIE in Spanish) (CIE9-MC).

Social Sector

The AAMR-1992 criteria were translated into Spanish and are widely known. These criteria were adopted by the FEAPS but neither this organization nor any Spanish administration, either at national or at regional level, has effectively put it into practice. A number of Spanish organisations contributed widely to the new International Classification of Functioning, Disability and Health (ICF, WHO, 2001) (CIF in Spanish). The IMSERSO (Spanish National Institute for Migration and Social Services which depends from the Ministry of Labour) has sponsored both the International studies and the Spanish version of ICF. It has been adopted as the basis for definition and classification of disabilities in Spain. According to that policy, we may deduce that the IMSERSO considers Intellectual Disability as a disability included at code b117 of ICF. The AAMR-2002 definition of Intellectual Disability coincides with this approach. It states that ID is a disability and quotes the ICF as a main conceptual source for related issues such as activity and participation, or context of ID.

Education

Aspects related to disabilities (including ID) have been included in the general law of education (LOGSE) which will be reviewed in 2002. The first draft of Law of Quality of the Education approved 10/5/02 by the Cabinet includes a series of dispositions relative to the schooling of the students with special educative necessities. The law dedicates four articles to students who require throughout special support during their school years due to “physical, psychic, sensorial disability or to serious upheavals of the personality or behaviour”. Special education will be “based on the students’ characteristics, integrating them in ordinary groups, in special in ordinary centres or centres of special education, after a “psychopedagogic” evaluation to assess diagnosis and assessment of special education needs.

LEGAL RIGHTS FOR PEOPLE WITH ID

The general characteristics of the Spanish administration were described above (introduction). International documents and declarations are regarded as framework statements in Spain (i.e. Rights for people with handicaps, UNO, 1971 and 1975; Article 13 Amsterdam Treaty). In this context, the Madrid Declaration 2002 is considered a key document for future development of policies in this area in Spain. Unfortunately, the Madrid declaration is mostly concerned with physical disabilities and not a single mention of the specific problems of people with intellectual disability is made in this document.

In the Spanish administration, social services share the main responsibility for policies regarding people with handicaps at national, regional (AC) and local level. Among the specific social policies defined at national level, disability stands 3rd after policies for the retired and the unemployed. ACs can and do promote new provision of services and benefits for people with disabilities. Another important characteristic of the Spanish system is the major role of NGOs in care and policy making and planning in this area.

Specific policies relating to people with disabilities produced by central, regional or local governments

We may differentiate three aspects: legal framework, plans and institutions related to disabilities.

Legal framework for specific policies

The LISMI provides the main policy framework for intellectual disability in Spain. A new review of the 1982 law is currently under way which will be specially focused on anti-discrimination policies. The publication of the LISMI coincided with the review of the Spanish welfare state and the redefinition of general civil rights such as health (1986), education (1990), employment (1980), and social security (1990-1994). The degree LISMI has actually influenced this areas is uneven both at national and regional level. Disability rights and benefits have been regarded in legislation related to education, social security and social services. A partial influence can be traced in employment laws. On the other hand, little has been done in disability benefits in the health sector, particularly in the case of intellectual disability. The main objectives of the LISMI were normalisation and community care:

To promote personal and functional autonomy in people with handicaps, and to improve development and training of people with handicaps

To promote changes in physical, social and occupational context in order to improve social participation and equal opportunities for people with handicaps

To promote support for improving quality of life and provision of basic needs of people with handicaps.

After 20 years, LISMI has shown a limited success with uneven results across different sectors and across different ACs.

Policy plans relating to people with disability

National plans

- a.1. Plan Nacional de Acción para Personas con Discapacidad 1997-2002 // Plan Nacional de Acción para la Inclusión Social del Reino de España (2001-2003).

The “I & II National Action Plan for People with Disability 1997-2002, 2003-2007” and the “National Action Plan for Social Inclusion 2001-2003” (PINS) are two key documents for developing policies on this topic in Spain.

The PNPD were developed to provide a common framework for policies developed in different ACs. They have been widely taken into account for regional plans in several ACs, such as Madrid (Plan de Discapacidad de la Comunidad de Madrid) or Castilla-León. In the recent years, inter-territorial equity and co-operation have become key objectives, due to the special characteristics of the Spanish system. This plan were based on 5 general principles:

- Respect of rights and freedom of people with handicaps
- Development of personal autonomy and social participation of people with handicaps
- Emphasis in user’s perspectives and satisfaction
- Fight against discrimination
- Normalisation policies

The 4 main objectives of the National Plans were:

- Promote Non-governmental social initiatives with the aim of promoting social participation
- Co-operation between administration and provision organisations
- Equity in care and basic needs
- Improvement of quality and efficacy of services

The LISMI and its related National Plan has promoted in 6 main areas (Planes Sectoriales), each one with specific objectives or programmes (23 Programmes):

- Health: Health promotion and deficiency prevention
- Health care and Comprehensive Rehabilitation
- Education: Special education and school integration
- Employment and social security
- Community Integration and Social Services
- Accessibility and technical aids.

The Action Plan has shown limit results in several areas and lack of concern in others such as, co-ordination and national databases, or health services for intellectual disability.

The PINS is focused in areas such as benefits, rights, goods, services (housing, health, education and social services).

Few weeks ago, the Council of Ministers approved the new law of “Promotion of Personal Autonomy and Attention to Persons in Dependence Situation”. This Dependence law will start to be implemented during the next year (2007) and will cover attention to people with disabilities in situation of dependence including intellectual disabilities and mental health problems among others. In despite of the advances that the LISMI, The National Action Plans and the Dependence Law have brought there is not a widely national accepted work frame of reference to the social and health attention of people with ID.

a.2. Plan Nacional de Acción para el Empleo del Reino de España 2001

The National Plan Employment policies for people with handicaps are more advanced than in other sectors, in spite of the fact that legal requirements of disability employment are not put into force in Spain, and that the active population with handicaps is comparatively low. A series of programmes are aimed at promoting disability employment in Spain.

a.3. Regional Plans

Regional plans for people with handicaps have been developed in many ACs (i.e. Castilla y Leon, Castilla y La Mancha, Galicia, Guipuzkoa, La Rioja, Madrid). However, these plans do not address the specific problems of people with intellectual disability. Plans addressed to specific groups have been developed in some ACs (Child and adolescents in Catalonia).

Institutions relating to people with disabilities

The IMSERSO has played a leading role in policy and planning for disabilities in Spain. Since the transfer of social services to the ACs was completed in 2001, IMSERSO has redefined its objectives to the following aims:

- Inter-territorial equity,
- Inter-institutional co-ordination and supra-regional planning,
- international and inter-regional co-operation, and
- promotion of research.

It has pushed forward research initiatives related to quality assessment, information systems and standard methods for service mapping in Spain. It has also promoted a common research program with the Institute Carlos III and the Ministry of Health starting in 2002. The “Observatorio Nacional de la Discapacidad” (National Disability Observatory) and its satellite office “Servicio de Información sobre la Discapacidad” (SID: <http://sid.usal.es>), is a dissemination and information centre promoted by the IMSERSO and the University of Salamanca, which is playing an important role in the area.

The Ministry of Health does not have a defined policy on handicaps. Apart from the governmental institutions and the regional offices in every AC, a series of mixed national and regional institutions play an important role in policy making and planning for people with disabilities. NGOs, academics and other social sectors play an extensive role in these mixed institutions.

Among the national institutions, it is important to mention a counselling institution called “Real Patronato de la Discapacidad” (Royal Patronate for People with Disabilities); the “Consejo Estatal de Personas con Discapacidad” (National Council of People with Disabilities) and the Comité Español de Representantes de Minusválidos (CERMI) (Spanish Committee of Handicap representatives).

Regional institutions are growing rapidly. Information offices have been developed in several ACs (i.e. Castilla La Mancha, Barcelona, Valencia).

General policies produced for other reasons, which nevertheless have an impact on services for people with intellectual disabilities

As said, social services are the main source of policies concerning intellectual disability. However, social services are discretionary and not right-based, and this governmental area does not have a legal coverage similar to education, health or social security. It is important to note that health services disregard intellectual disability and do not include specific coverage in most ACs.

Policies and guidance produced by other organisations (for example, professional organisations) which, though not carrying the authority of government policy, are still influential in services for people with intellectual disabilities

ONCE (National Association of the Blind) is a widespread NGO with a significant economical and political power mainly due to the monopoly of a national lottery game. Although mainly devoted to the promotion of integration for the blind, it has a foundation that provides funding and provision of services for other handicaps including intellectual disability (Fundacion ONCE). FUNDOSA GRUPO is a corporation of 112 firms originated in 1989 which have developed 147 job centres all over Spain and provides job for 8.000 people with disabilities. However, the control over the national lottery and its blind-related policies and lobbying creates inequities in funding for disabilities in Spain.

FEAPS is the National Federation of Associations of Intellectual disability. It has an important database on intellectual disability, as well as rehabilitation, prison and family programmes. FEAPS incorporates 686 NGOs devoted to intellectual disability, providing job for 33,267 individuals

with intellectual disability (and borderline intellectual functioning) and leisure activities for 232,236 associates (0.58% of the general population). The policy of FEAPS has been summarized in a document called “Pacto de Toledo (Toledo Pact). FEAPS defines five main objectives: 1) Family life, 2) Education inclusion, 3) Work, 4) Individual management, 5) Service/programme accreditation and assessment.

Estimated prevalence figure for id

There are several official statistics and studies on the prevalence of ID in Spain. The main sources of information are the National Survey on Disabilities, Deficits and Health States, the National Database on People with Disability, as well as other sources of information such as the FEAPS (National Federation of NGOs on ID) database. According to the National Disability Survey 139.859 persons above 6 years old had ID in 1999. This estimate represents 0.37% of the Spanish population above 6 years old. The National Database of people with a legal status of handicap in Spain includes 144.331 cases with intellectual disability (0.36% of the Spanish population). These two numbers are very similar, however, the FEAPS keeps a database of associates to 686 NGOs related to intellectual disability. It provides any type of care to 232.236 associates (0.58% of the general population). The Catalanian department of health has estimated a rate of 0.56% in 2006.

National Survey on Disabilities, Deficits and Health States (Encuesta Nacional sobre Discapacidades, Déficit y Estados de Salud; INE e IMSERSO, 1999):

This sociological study based on home interviews at national level, explored the rate of disabilities grouped by age, condition and type of impaired function. Criteria were drawn from ICDDH-1980, and data can be compared with a previous survey made in 1986. The sampling procedure excluded people living in residencies, institutions or secluded settings such as prisons. People with mild intellectual disability and borderline intellectual functioning were grouped in a common category in this surveillance seriously hampering its overall validity and its ability to draw useful information out from the aggregated data. According to the 1999 survey, 9% of the Spanish population had some sort of handicap in 1999. The main causes were birth related conditions, traffic accidents and chronic diseases. According to the Disability Survey, 134.468 persons had profound to mild intellectual disability or borderline intellectual functioning in 1999. 139.859 persons above 6 years old profound to mild intellectual disability or borderline intellectual functioning in 1999. This estimate represents 0.37% of the Spanish population above 6 years old.

This survey shows a higher proportion of moderate intellectual disability than mild/borderline intellectual functioning, which is highly improbable. Furthermore, people with borderline intellectual functioning have been aggregated with mild intellectual disability. Following a conservative approach, this fact would imply that 50% of these cases should not be classified as intellectual disability and that the rate of mild intellectual disability would be around 20.400 people, which again seems highly unreliable.

National Database on People with Disability (Base de datos Estatal de Personas con Discapacidad):

This is a general register of all people with a legal status of handicap in Spain (last update: June 1999). This register includes 144.331 cases with intellectual disability (0.36% of the Spanish population). This rate stands for 11.5% of all handicap registers in Spain (14.1% intellectual disability males; 9.2% intellectual disability females). The age distribution is as follows:

0-14 yrs	44.8%
15-34 yrs	27.0%
35-64 yrs	5.7%
Over 64 yrs	0%

Intellectual disability is the main cause of disability in children. 63% of intellectual disability are of unknown origin while the cause is known in 37% of cases. Down Syndrome is the most frequent diagnosed cause (12% of cases, 54% male); followed by brain infectious diseases (ie meningitis and encephalitis) (10% of cases, 53% males). The National Database does not record cases with mild impairment (below 33% in the official classification table), or those who have not applied to legal handicap qualification. The lack of cases above 65 years of age reflects the problem of this data system. In spite of all, the national database provides a good estimate of the lower range of intellectual disability in Spain.

Regional registers of people with disabilities:

The ACs keep their own records of people who have qualified for disabilities. For example, in Catalonia 13.8% of all registered disabilities have intellectual disability (34.006 individuals with intellectual disability) (IEC, 2002). The registered prevalence of intellectual disability is 0.54% in Catalonia, well above national statistics.

Other databases

FEAPS, the National Federation of intellectual disability associations keeps a database of associates to 686 NGOs related to intellectual disability. It provides any type of care to 232.236 associates (0.58% of the general population). This estimate is above the rate provided by other sources and closer to rates published in international literature.

Epidemiological studies

La Safor County Study on MR (Comarca de La Safor, Comunidad Valenciana) (Tomás, 1991).

This study analysed the prevalence of intellectual disability and borderline intellectual functioning in a health area of the Comunidad Autonoma Valenciana. The sample was representative of the school child and adolescent population (0-14 years) in this area. Rate of intellectual disability was 13.97 per 1000 while borderline intellectual functioning was 14.10 per 1000. If we adopt a conservative approach and assume a constant prevalence rate of intellectual disability for the population below 45 years old (0.14 per 1000), half of it for the population between 45-60 years old (0.7 per 1000), and 0.2 above 61; the rate of intellectual disability would be around 0.55% (225.000 individuals, which is still below the rates published in international literature).

Studies in Mental Health centres

The Catalan Health service records all care contacts with the mental health system. In year 2000, 1726 people with intellectual disability contacted the mental health system (1.3% of all care contacts). The rate was similar in children and adolescent care (368 out from 26777 cases, 1.4%) and adult care (1358 out from 108.240 cases, 1.3%) (Servei Català de la Salut, 2002)

Studies in occupational centres and institutions

A series of studies have analysed the prevalence and typology of psychiatric and behavioural disorders in occupational centres (Salvador-Carulla, 1996; Salvador-Carulla, 1998; García González-Gordon et al, 1996). Over 30% of people with intellectual disability have a formal ICD-10 or DSM-IV psychiatric diagnosis. Over 10% of people placed in these centres have borderline intellectual functioning.

Studies in prisons

According to the available data (Llobet et al, 1995; IMSERSO/Real Patronato, 1999), approximately 0.5-1% of the prison inmates in Spain have a intellectual disability or are borderline cases. As this rate is based on unstructured reports, it may underestimate the actual rate. In November 2001 there were 48,162 convicts in the Spanish prisons (INE, 2002). It can be estimated that over 500 may have intellectual disability, although the actual rate may be at least twice that. Mostly are men, re-offenders, less than 10% have a co morbid psychiatric disorder other than drug addiction, and 14% show violent behaviour in jail. 70% were newly identified cases during the studies performed by the task-force. However, these data are highly biased since they are based on reports from the institutions. There is a lack of epidemiological studies using adequate screening and interview methods as well as standardised screening instruments for CI and psychiatric assessment.

ELEGIBILITY

Eligibility for services

The qualification of handicap entitles the person a number of special civil rights in order to compensate the social disadvantages produced by the handicap. The most relevant are fiscal benefits and pensions. From a legal perspective, two different types of provisions and benefits exist in Spain: right-based provisions and discretionary provisions and benefits. Education, health and social security are right-based while social services are discretionary. Thus, the demand of social security pensions, subsidies and benefits, or special support services in education are guaranteed while other individual support and social aids such as social funds for ngos, are not mandatory.

Eligibility for pensions and other social benefits

The eligibility for social benefits depends on the percentage of handicap severity (maximum level of severity: 100%). These benefits have been specified by a national norm (disposición) (BOE 26 January 2000):

Mild handicap (0-32%): Mild handicaps do not qualify for official recognition as “handicapped” and thus for pensions or special social benefits.

Moderate handicap (33-64%): The official qualification of “handicapped” is given when the EVO assigns a severity level above 33%. A pension is provided and a series of social benefits are afforded in order to compensate restrictions in functioning.

Severe handicap (Above 65%): A severity level over 64% merits full compensatory pension, and full handicap benefits.

The pensions and fiscal benefits for the handicapped are defined in a series of laws on Social Security (Legislación sobre Invalidez de la Seguridad Social); Welfare pensions (Pensiones no contributivas), Support pensions (Pensiones asistenciales) and the LISMI.

Eligibility for health services

Health services are guaranteed through the General Law of Health (Ley General de Sanidad). MR, as Spanish citizens, are entitled access to free general medical care. This law also entitles access to rehabilitation care to any handicapped person. However, law enforcements and empowerments have not been sufficiently developed and care gaps do appear in mental health, early care and other relevant areas. The law does not include prevention of handicaps, a topic included in the Law for the Handicapped (LISMI). To make matters worse, many services for MR have been transferred from the health sector to the social sector. As said, health care is right-based while social care is discretionary. The extent to which health services provide care and allow access to those with MR differs in each AC. During the last 20 years major regional differences have risen and inequities certainly do exist.

Eligibility for social services

Apart from being discretionary and not right-based, social service provision is not guaranteed by a general law as health or education are. The autonomous communities have full responsibility on this area and have issued regional laws regulating social services. All of them mention the handicapped and describe discretionary rights to special social services by this population group. However, most acs have not put forward decrees and norms to provide empowerment and regulate these rights. Local administration also has responsibilities on this topic. Major regional differences do not attain eligibility but provision and access to services.

Eligibility for education services

As said, special support services for people with handicaps are right-based. Aspects related to disabilities (including MR) have been included in the general law of education (LOGSE), which will be reviewed in 2002. Special education and centres of special education are mentioned in the Royal Decree 696/95. Norms have been also developed in the ACs. However the degree of provision of staff and support services is far beyond the real need.

In order to become eligible for these programmes a report from the psychopedagogical assessment team is required.

Eligibility for vocational services

Employment has generated a significant amount of norms and laws in Spain. Some of them are specific for people with handicap (ie LISMI), while others are general laws or norms which include specific aspects related to the handicapped. They include social security invalidity legislation, support pensions law (pensiones asistenciales), law on pensions not related to paid work (pensiones no contributivas), as well as fiscal benefits related to disability.

Several employment rights are obtainable, such as discounts and social security bonuses when hiring persons with a handicap qualification. Others are possible but they are not put into practice for a variety of reasons (i.e. the legal requirement of hiring 2% of handicapped employees in companies with more than 50 workers). Other services are discretionary and depend upon budget availability. For example, funds for developing support employment.

As a matter of fact, most supported employment places in Spain are for people with MR (Informe sobre Empleo con Apoyo, IMSERSO, 1999a)

SERVICE PROVISION

Care provision by health and social services

We lack a comprehensive mapping of services for intellectual disability in Spain, or reliable information on how many places are provided or how many people do they serve. Unfortunately, the transfer of health and social services has been accompanied by lower information availability at national level. This trend has been described in all previous papers (Salvador-Carulla & Martinez-Maroto, 1993; Salvador-Carulla et al, 1999; Holt et al, 2000).

Health services

The role of general health services, primary care and mental health care, on intellectual disability is fairly limited and most responsibilities have been shifted to the social services. The low utilisation rate of mental health services in Catalonia (1.4% of all people using mental health services or 0.02% of the general population) (ICS, 2001) reflects a clear under utilisation of mental health care services by this population group. It should be noted that this trend is changing nationwide due to several reasons such as the appearance of new demands (care for the elderly, or care for borderline intellectual functioning), lobbying of family associations, difficulties on integrating people with intellectual disability and psychiatric and/or behavioural problems in residential facilities and vocational programmes intended for non-psychiatric intellectual disability.

In a previous review (Salvador-Carulla et al, 1999), we highlighted the need of a health and social co-ordinated system for residential and community care. Liaison services in the community and

diagnostic and evaluation residential units play a key role in the care network. Residential care may provide 3-5 beds per 100,000 population. The care system should include diagnosis and evaluation units, acute & sub acute units, long-stay units, respite and sheltered homes. Special attention should be paid to the functions of the diagnosis and evaluation units, which may coordinate care plans, hospital admissions and follow-up. A case-management system should be implemented and these units should be linked to specialised liaison services working in the community with primary care and general psychiatric services.

Liaison mental health services for intellectual disability have been actually developed in Catalonia (2 planned), Galicia (1) and Castilla-Leon (2 developed by INTRAS Foundation).

Specific hospitalisation units for intellectual disability patients with psychiatric problems are being developed in several ACs such as Andalusia and Catalonia. Catalonia is the only AC which has developed a global care plan on Mental Health for people with intellectual disability implicating both social and health services. Madrid, Galicia, Castilla la Mancha, and other AC are also developing mental health services for people with ID. This effort has been put forward during the last five years and it is too early to assess the results.

Social Services

The social services provide residential care for cases without severe needs in occupational centres and for high dependency cases through residential facilities called CAMP (Centros de Atención a Minusvalía Psíquica). CAMP provide comprehensive care for intellectual disability 16 or older who may need it because of family, social or financial problems. They are not specifically designed to help patients with dual diagnosis. Currently, there are 74 CAMP facilities in Spain. The total number of beds and characteristics of the facilities and of the people being cared for are being assessed by our group since there is no national database gathering this information. The average number of beds was 50-60 in CAMP and 30-40 in occupational centres in 1993 (Salvador-Carulla & Martínez-Maroto, 1993).

During the last 5 years a number of residential centres for people with dual diagnosis have been set up in several ACs (Catalonia, Andalusia, Madrid...).

Intermediate care including work, leisure and social activities are more developed for intellectual disability than for mental illnesses. However, intermediate services provided by the social system are rarely able to cope with the specific difficulties of people with intellectual disability and psychiatric problems as it happens with residential services.

Vocational support facilities are classified in four groups:

Occupational centres: Provide occupational therapy, and social and individual adjustment. These services are aimed at people who are unable to work in competitive placements or in special vocational centres. People at occupational centres do not receive a normal salary. Occupational centres may provide residential care.

Special vocational centres (Centros Especiales de Empleo): These centres are aimed at providing competitive employment and at producing competitive goods. Normal salary and social security benefits are provided to employees who should be disabled.

Support employment. Workers receive individualised support both at training stage and after starting normal employment.

Ordinary employment. Workers receive a normal salary and work in ordinary firms.

FEAPS includes 686 NGOs related to intellectual disability. These organisations comprise 493 Occupational centres, 243 special employment centres and 277 leisure clubs. As a whole, 33,267 people with intellectual disability are in job placements (23,890 in occupational centres and 9,377 in special job centres). 232,236 people with intellectual disability participate in social and leisure FEAPS programmes. The exact number of people in Day centres is not available, those services

are given to persons who get support in the day-time, but stay with their family at the weekends and evenings and is situated in the domain of adapted activities for adults who cannot work on the regular labour market. Support programmes for families and home care are also available, family support services can give educational and psychological support to families and parents who take care for a family member with intellectual disability .

NGOs have also played a significant role in developing sheltered homes (maximum 10-15 residents per home). Those group homes are situated in the community, close to a residential facility, persons with disabilities can also participate in daily activities (maximum 10-15 residents per home).

Child and adolescent education services

Special services for this population include:

Early care/stimulation programmes for children with intellectual disability

Special education programmes:

Special Education Centres, special nursery and primary education are aimed at children who need special help, temporarily or permanently. This can be due to a physical or mental impairment, serious behavioural or emotional problems, or serious learning difficulties.

Integration classes, for special groups/classes in regular schools, this education makes children with impairments or having learning or educational difficulties attend lessons or activities in a school for mainstream education with assistance provided by special education.

This may be temporary or permanent and apply to some of the lessons or all of the lessons difficulties

- *Psychopedagogic teams*: Support from psychopedagogic teams in the school for children with low learning difficulties

Emerging service structures

The lack of adequate resources implies that many services structures regarded as “usual care” in other countries can be considered as emerging services in Spain. Emerging care demands which are being deployed in some local and regional areas include:

1-Child and adolescent care. It deserves special attention in the Basque and the Catalanian planning. Specific units have been developed in Guipuzkoa.

2-Geriatric care: The Guipuzkoa province (Basque Country) keeps 5% of all geriatric places for intellectual disability. Specific units have been planned in Catalonia. NGOs such as PROMI have put forward geriatric units for people with intellectual disability.

3-Dual diagnosis: Four hospital units for people with intellectual disability and psychiatric problems have been developed in Catalonia. Two NGOs working under agreement with social services have developed non-hospital dual diagnosis residential units in Andalucia.

4-Respite units: NGOs are developing respite units in most ACs (i.e. AMICA in Cantabria, FADEM in Madrid, and several NGOs in Catalonia). These units are mainly addressed to people with intellectual disability and psychiatric problems. The FEAPS respite family programme started in 1995 has 5 modalities: weekends, crisis mobile support services, emergency residential short-stay.

5-MH-intellectual disability Liaison Community care units: Catalonia has recently deployed two community care liaison units on its territory. A liaison unit is currently functioning in Castilla Leon (INTRAS foundation) and Galicia.

6-Tutorship organisations (entidades tutelares): Developed by local administrations (municipalities), or NGOs; these organisations provide tutorship when parents die and there is no other alternative available.

7- *Supported living* are being developed at local level. Services of supported living give psychosocial support or assistance in activities of the daily life for people in their own homes.

8- *Teleassistance*: Support for people through on-line TV communications are being developed in several Acs.

There are important differences in the treatment of PWID-MH across the 17 ACs. For example, in Andalusia care to PWID-MH is provided together with other MH population. There are not outpatient specialised health services for dual diagnosis within the public health system and little interest and/or attention to this population group which is not mentioned in the new “Global Plan of Mental Health for Andalusia 2003-2007”. Therefore, ID-MHP population is attended in the ESMC –Mental Health Community Teams- which are equivalent to Community Mental Health Centres in other ACs. These teams are not specialised to attend this population. During 2002 they attended 375 persons with intellectual disability in Andalusia, a 2,31% of the total number of users that they attended that year. However, several NGOs have set up day centres/units for this population group. These new services are funded by the Social Services and do not follow any specific pattern.

By contrast Catalonia established in 2002 a care framework for PWID-MH. The mental health needs of this population were analysed and a system in which the responsibilities were shared between the Social and Mental Health Services was proposed. They also set up two new specialised services: the Mental Health Specialised Service for People with Intellectual Disability (SESM-DI) and the Specialised Hospital Units for People with Intellectual Disability (UHE-DI). SESM-DI is a liaison psychiatric service providing support to mental health centers and primary care centers on ID-MH. The new mental health plan of Catalonia (2006) has planned one unit per 1.000.000 inhabs. UHE-DI are non-acute hospital units for ID-MH.

Research

The INICO “University Institute for the Integration in the Community” aims to promote researching, specialised training and counselling to potentiate and facilitate the living conditions for people with disabilities. The Institute conducts several researching projects related to people with Intellectual Disability –e.g. Quality of life indicators- and mantains and database of information for disabilities. Further information can be found in their web page <http://inico.usal.es/>

The Ageing Researching Group at the University of La Coruña has established a line of research relating the process of Ageing to the Intellectual Disability. They try to identify health needs a problems for people with ID during the ageing process. Further information can be found at: <http://gerontologia.udc.es>

The AEECRM –Spanish Association for Professionals related to Intellectual Disability- conducts different projects focused on Intellectual Disability. The POMONA and POMONA-II projects which studies the usefulness of a set of indicators of health for Intellectual Disability, the IDRESNET network participation, the DESDE development (ESMS version to describe services for persons with disabilities) are only several examples among the great body of research conducted by this association. For more information visit: <http://www.aeccrm.com/>

Health Indicators in People with ID

There is no data regarding life expentacy for people with ID although we know it has increased considerably during the last years. We also lack of health data about comparisons between population with ID and general population. We can provide data from different studies

about health data in people with ID attended in NGOs, and residential and health services. Promotion health programs have been developed for parents with children with ID but little is known about national or regional programs promoting the health of adult people with ID or setting up health screening programs.

STUDY I –Residential settings- n = 962

Working Group on mental health care for people with ID. Needs of mental health for persons with ID. Servei Català de la Salut (CatSalut); 2002

PSYCHIATRIC DIAGNOSIS (some subjects with more than one diagnosis)

Diagnosis	n	%
Psicosis in elderly	8	0.93%
Organic Psicosis	12	1.25%
Schizophrenia	84	8.72%
Afective Psicosis	18	1.87%
Paranoid states	3	0.31%
Other non-organic psicosis	25	2.6 %
Psicosis with origin in infanthood	66	6.86%
Neurotic disorders	25	2.6 %
Personality disorders	1561	6.21%
Sexual disorders	5	0.52%
Alcohol dependency	4	0.41%
Drugs abuse	26	2.70%
Psychosomatic disorders	4	0.41%
Special Symdroms	90	9.35%
Adaptative reactios	6	0.62 %
Organic non psychotic disorders	3	0.31%
Depressive disorder non specified	2	0.20%
Behaviour disorders	328	34.09%
Without diagnosis	221	22.97%

SOMATIC DIAGNOSIS

	N	%
Infectious and parasitary illnesses	136	14%
Neoplasy	41	4%
Endocrine, nutritional and metabolic illnesses. Inmunitary disorders	289	30%
Blood and hematopoietic organs illnesses	78	8%
Nervous System and sensory organs illnesses	595	62%
Circulatory system illnesses	305	32%
Respiratory system illnesses	89	9%
Digestive system illnesses	227	24%
Genitourinary system illnesses	156	16%
Skin and subcutaneous illnesses	60	6%
Locomotor system and conective tissues illnesses	218	23%
Congenital anomalies	83	9%
Problems with perinatal etiology	150	16%
Poisonings and lesions	169	18%

STUDY II NGOs Settings

Almenara Barrios J, García González-Gordon R, Novaldos Ruíz JP, Merello Martel B, Abellán Hervás MJ, García Ortega C. Evaluación Médica y Psicosocial de una Población Adulta con Discapacidad Intelectual. *Revista Española de Salud Pública*. 1999. N=129

Allergic Problems	39.5%
Quirurgical interventions	50%
High blood pressure	6%
Diabetes	3.10%
Epilepsy	22.48%
Vision problems	17.05%
Hearing Problems	2.32%

Training

ID is not included in the core curriculum of medicine or psychology. There is no postgraduate training on this topic. A number of universities have run master degrees or postgraduate courses on ID based on personal initiatives of several professors linked to the Spanish Association of Professionals in ID (AEECMR). AEECMR has carried out update training courses on ID-MH and published training material for psychiatrists and psychologists, and for other carers in cooperation with the Spanish federation of families with ID (FEAPS). At present there is only one chair on disabilities in Spain (University of Salamanca) and one clinical training program for residents in psychiatry at the SESM-DI of Gerona (Catalonia).

The AEECRM has developed a training package for assessment and diagnosis of psychiatric problems in mental retardation addressed to general psychiatrists in Spain. The FEAPS is working on a package for carers. Catalanian government has developed a similar programme in order to fit future demands in this area. Although no formal training is provided on mental retardation either in medicine or in psychology, the IMSERSO and other agencies have promoted postgraduate training in many Spanish universities. These programmes are filling a gap in the graduate education system in our Country.

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