ANED country report on the implementation of policies supporting independent living for disabled people

Country: Spain

Author(s): Miguel Ángel Verdugo, Cristina Jenaro Río, Maribel Campo Blanco

The information contained in this report was compiled by the Academic Network of European Disability experts (ANED) in May 2009.

PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

Major positive policy changes in Spain have occurred in recent years. These provide choices for disabled people to live independently in their own homes and in the community and have resulted from the passing the Act 39/2006, of 14th December, on Promotion of Personal Autonomy and Care for Dependent Persons (LEPA) and the Act 51/2003. However, there are not any structured policies promoting independent living that follow the UN Convention on the Rights of Persons with Disabilities (2006). Only some groups of people with disabilities (still few in number) are playing a role in promoting independent living. In addition, there are important differences among Autonomous Communities in applying new Acts and in developing new regulations to facilitate independent living.

Although there are new laws and policies supporting people with disabilities, the emphasis has not been placed on community approaches to stimulate independent living. Consequently, segregated residential options continue to be the main option, and public administration organisations spend most resources on these.

Personal assistance services and assistive equipment and adaptations are supported and regulated by law. Nevertheless, availability of support (types, resources, people) differs between the Autonomous Communities (there are 17 in Spain). Because they have specific regulations, important differences can be found among Spanish territories.

Eligibility criteria derived from the LEPA are based on a medical approach (i.e. level of dependence). The scale used is focused on physical disabilities and aims to measure functional capabilities , instead of the assistance required for daily living. Services with a more inclusive approach, such as personal assistant services, are insufficient in terms of the financial support available as well as in terms of the legal regulation of these professionals by the various Autonomous Communities.

Support for personal assistance is financially constrained and it is only available for those disabled people classified as having major dependency. Financial support for non-professional carers also varies with the level of dependency, and level I (i.e. limited or intermittent support needs for personal autonomy) is not eligible.

Support for assistive equipment and adaptations is regulated at the level of the Autonomous Communities and there are significant differences between them. There are also financial limits for the different technical aids so disabled people must co-fund these..

To date, less than one per cent of disabled people classified as having major dependency are receiving personal assistance. Due to lack of data, it is not possible to compare differences between the Autonomous Communities in the allocation of different kinds of technical aids.

There is a lack of research and evaluation studies in the area of independent living. The existing literature focuses on specific experiences or good practice on self-advocacy, self-determination, and independent living of intellectually disabled people. Several studies were carried out by the Administration (white book) before launching the LEPA, but they consist mainly of literature reviews. CERMI, the Spanish Committee of Disabled Representatives, is playing a role in this, by calling for and initiating some studies. But independent research and evaluation should be seriously developed by the State and Autonomous Communities in order to analyze the emergence of independent living approaches and the impact of recent legislation on people's quality of life.

PART 2: LEGAL AND POLICY CONTEXT

In Spain there is a traditional guardianship orientation, which runs counter to Article 12 of the UN Convention, concerning equal recognition before the law and support to exercise legal capacity. There is also a lack of state regulation concerning support for decision making. Supports for self-determination mainly come from organizations of disabled people. In Spain, a procedure of legal incapacitation begins with a written request by the family of the mentally disabled person to a judge (Court of 1st Instance), which states that he/she is incapable and needs the designation of a guardian. The assistance of a lawyer and a solicitor is required for starting this procedure. That letter must be forwarded to the disabled individual who, may answer the letter in 20 days . After 20 days without a reply -which is the norm-, a barrister is appointed to represent the person who is allegedly incapable. The trial period, where it must be proven that the disabled person is incapable, begins at this point. This is done in various ways, such as: a) hearing the relatives and / or other close family members who are involved, examining documentary evidence, medical reports, psychological assessments, etc. b) forensic examination usually performed by medical specialists in neurology or psychiatry or by the coroner's court; c) consideration of the person presumed incapable by the court itself.

The sentence of legal incapacitation can be either total, where people deemed incapable cannot manage their property or themselves; or in part, where there is an inability to perform certain acts without the assistance another person. The sentence also determines who will be the guardian : a) parents, if an adult still lives with them, b) another appointed person.

The main policies for providing choices for disabled people to live independently in their own homes in the community relate to the provision of social services, under several recent Acts. Some major changes have occurred in recent years. One key milestone was the Act 51/2003, December the 2nd, on equal opportunities, non discrimination and universal accessibility for disabled people. This Act *acknowledges people with disabilities as having the potential for independence, choice, and control in their lives*. More specifically, in article 2a independent living is defined as: "the situation where the disabled individual exercises the power of deciding on his/her own existence and actively participates in community living, according to the right for free personality development". Article 9.1 lists positive action measures such as: additional supports (e.g. technical and financial aids, personal assistance, specialized services and supports, additional communication services) regulations, criteria and other positive practices.

Concerning strategies for supporting people living in the community rather than in institutions, the National Housing Plan of 2005-2008 (International Disability Rights Monitor-Regional Report, 2007, p.459-462), as well as the National Housing Plan 2009-2012 includes financial support for all citizens with low economic resources to purchase or rent a house, as well as to eliminate barriers. The amount of financial support depends on income level, which is adjusted in the case of persons with disability. Housing support for people with disabilities includes: economic support for living in a house; buying, renting or making a home accessible; legal support, enforcing housing or building accessibility ; and social services. Publicly promoted housing must reserve at least three percent of all houses for people with disabilities, and these homes must be accessible. However, as there are no mechanisms to ensure that the 3% quota is met, its effectiveness is reduced (International Disability Rights Monitor-Regional Report, 2007, p.459-462).

According to the Forum on Independent Living, a group of people with functional diversity fighting discrimination, there are no structured policies promoting independent living, as proposed by the UN Convention , but rather fragmented polices that lack a comprehensive approach.

However, the main legal framework rests on the Act 39/2006, of 14th December, on Promotion of Personal Autonomy and Care for Dependent Persons (LEPA). This Act could be considered a significant new proposal for future policies to support people living in the community rather than in institutions. It regulates the basic conditions that should guarantee equality in the promotion of personal autonomy and care for dependent persons, by creating a System for Autonomy and Care for Dependency (SAAD). It requires the collaboration of all of the Public Administrations and the guarantee by the General State Administration of a minimum common content of rights for all citizens in any part of Spanish State territory (LEPA, p.43). Its article 19 regulates Personal Assistance, which aims to promote the autonomy of severely dependent persons. Personal assistants, are people hired for a number of hours to provide the beneficiary with access to education and employment, as well as a more autonomy in daily living. Following agreement by the Territorial Council of the System for Autonomy and Care for Dependency, the Royal Decree 504/2007 established eligibility criteria. This Royal Decree determines a scale to be used, which incorporates the International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Organization.

According to article 2 (LEPA, 2006), Personal assistance consists of a service provided by a personal assistant who performs the dependent person's everyday tasks, with the aim of encouraging his/her independent living and promoting and reinforcing his/her personal autonomy (LEPA, p.45).

In addition, the LEPA establishes financial benefits linked to services (art.17), for care in the family setting, support for non-professional carers (art.18), and for personal assistance (art.19)., Following consultation with the Territorial Council of the System for Autonomy and Care for Dependency, the Government determines the minimum level of protection that is guaranteed to each of the beneficiaries of the System, according to his/her degree and level of dependency. For example, for 2009, according to the Royal Decree 74/2009, minimal amounts per month for 2009 are: 1) Degree III level 2 =263,93 €; Degree III level 1=179,47 €; Degree II level 2=102,00 €; Degree II level 1=70 €. , The Royal Decree 73/2009 establishes maximum financial benefits linked to service consisting of: 831.47 € for Degree III level 2; 623.60 € for Degree III level 1; 460.80 € for Degree II level 2, and 400 € for Degree II level 1. Maximum amounts for care in the family setting and support for non-professional carers consist of (social security taxes excluded): 519.13 € for Degree III level 2; 415.73 € for Degree III level 1; 336.24 € for Degree II level 2, and 300 € for Degree II level 1. Maximum amounts for personal assistance are 831.47 € for Degree III level 2 and 623.60 € for Degree III level 1.

According to Ripollés, Rodríguez-Picavea and Romanach (2007, p.24), the cost of a personal assistant working 40 hours/week is 1,000€ (750 € in salary, plus 250€ in Social Security) and individuals with major disabilities require an average of two personal assistants. On the other hand, according to 2009 data, the minimum pension for major disability ranges from 1,044.29€ to 819.83€. These figures reflect the insufficient financial amounts provided for professional assistance.

In spite of the above mentioned legal and policy framework, new ideas about independent living have come from disabled people's organizations as well as from academia . For example, at an academic level, RETEVI is a network on Independent living composed of experts from various universities from Madrid, Spain, as well as representatives of the associative movement, and the Forum on Independent Living. It was created in 2006 by ASPAYM-Madrid (Association of Quadriplegic and Severe Physically Disabled People) and aims to:

1) stimulate self-determination and independence among individuals with functional diversity,
2) identify and develop comparative analyses of existing Spanish projects,
3) combine a "gender perspective" with "philosophy on independent living",
4) develop cross-disciplinary groups to promote the culture on independent living.

Associated organizations are: The Office on Independent Living (Community of Madrid), The Office on Independent Living (Barcelona), The Association of Experts for the Study on Disabilities "UnoMás", ASESDIS –Spanish Association on Sociology of Disability-, Sociocultural Asociation "El Tinglao", VIGALICIA –Association on Independent Living from Galicia-, AIES –Association of Studies and Social Initiatives-, Forum on Independent Living, GIAT-D –Group o Research, Analysis, and Work on Disabilities-, and several university departments and research groups from Madrid. They also work at an international level with the European Network on Independent Living, ULOBA –Norwegian Cooperative on Personal Assistance-.

A key independent living lobby group is the Forum on Independent Living, which was created by disabled people in 2001. According to this organization (March, 2009), the Act on Promotion of Personal Autonomy and Care for Dependent Persons (LEPA) contradicts Article 19 of the UN Convention on the Rights of Persons with Disabilities (with has been enacted in Spain since May, the 3rd, 2008), because the Act is based a medical approach, whereas the Convention assumes a social approach.

Finally, progress towards independent living has come from intellectually disabled people's organizations. FEAPS, the Spanish Confederation of Organizations working for people with , intellectual disabilities promotes quality of life and quality of services . It supports self-advocacy groups and has several publications on self-advocacy, self-determination, and independent living directed to an intellectually disabled audience.

PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

The provision of support to disabled people in Spain still relies on segregated residential institutions, above all for citizens with severe cognitive or intellectual disabilities, cerebral palsy, and autism. Even though in recent years the size of residential institutions has been reduced, they are still prevalent. Mansell et. al (2007) report a total of 181.636 residential care places in Spain: a rate of .42% with regard to the total national population. Of these, they estimate that 156.004 were in residences with over 30 places (a population rate of .36%. To further illustrate the fact that a majority of disabled people are living in institutions compared to those living in the community it is important to bear in mind that residential/supported housing options in Spain for individuals with disabilities consist of three types of public or private arrangements (Disability Rights Monitor-Regional Report, 2007, p.462; Libro Blanco, 2004, p.264):

1) Residential Centers for persons with disability in a dependency situation (regulated in 1994, e.g. CAMF, CAMP, CRMF, CO, and State Centers). The goal is the residential provision for persons who need continuous help in their daily life. 71.75% of places are occupied by persons with intellectual disabilities. There are 580 centers with a total capacity of 19.895 residents (Libro Blanco, 2004, p.331).

2) Residential Centers for persons with disability who are not in a dependency situation. These aim is to provide accommodation and food for persons with any type of disability that, for various reasons have difficulty living in their previous surroundings. Persons with intellectual disability occupy 81.59% of these places, followed by persons with mental health conditionsl and physical disability. There are 254 centers with a total capacity of 7.478 residents (Libro Blanco, 2004, p.335).

3) Alternative Lodging Systems. These include residential units in buildings or housing estates in the community that target persons with any type of disability who have enough autonomy and whose support is permanent or intermittent according to their needs. Persons with intellectual disabilities occupy 51.2% of these places, followed by persons with mental health issues (44.32%). There are 508, with a total capacity of 3.603 residents (Libro Blanco, 2004, p.265).

This data provides evidence that alternative lodging systems (e.g. supported living) arestill a minor option for this population. More specifically, in 2004 (Libro Blanco, 2004, pp.338-339) there were 54 public and 223 private (subsidized or unsubsidized) residential units for people with intellectual disabilities. There were no publicly provided Alternative Lodging Systems for people with physical disabilities and 11 from private initiatives. There were 140 public residential units and 68 private for people with mental health issues.

The opinions of disabled people (especially if they have severe cognitive or intellectual disabilities or cognitive and physical disabilities) are not taken into account when decisions are made about their entering or remaining in institutions. . This decision rests with families, legal tutors and public administrators. Although people with dependence legally enjoy the same rights, freedoms and civil and political constitutional duties as other citizens, they may be deprived of them in cases of legal incapacitation, through a court order. Even without being ruled incapable, in practice, the vulnerability of their situation makes it difficult for people to exercise their rights (Libro Blanco, 2004). Lack of community alternatives, together with a lack of client-focus approaches help explain this situation.

For people with severe physical disabilities, some initiatives reflect a more client-focused approach. Thus, in 2006 the first two Offices in Independent Living (OVI) (Centers for Independent Living, CILs) were created, one in Madrid and the other in Barcelona. Both offices embrace the philosophy of the global movement on independent living.

They offer self-managed personal assistance services, financed by their respective public administrations, and develop what is called "support among peers". The OVI from Madrid serves 62 clients with major diversity (disability), and the OVI Barcelona serves 9 persons with major diversity. These are examples of good practices concerning people with severe physical disabilities, even though there are a limited number of beneficiaries of these more inclusive approaches.

Regarding public spending on institutional support compared to support for people living independently in the community, some differences in overall expenditure and the average cost per person can be noted. Yearly expenditure of residential centers for persons with disability in a dependency situation is 349.236.064 €, and 17,553.96€ per person. The yearly cost of residential centers for persons with disability who are not in a dependency situation is 90,446.653 €, equating to 12,095.03€ per person. Yearly expenditure of alternative lodging systems is 28,210.468 €, and 7,829.72€ per person.

Major investments are still being made in developing residential institutions rather than moving away from them, especially by the public administration at a national level, with the development of State Reference Centers. There are currently four centers, and another nine centers are at different stages of development (eg. CRE for people with Parkinson, CRE for the Promotion of Independent Living, CRE for brain injured individuals, etc.). Even though not all of them are residential in nature (e.g. CEAPAT), others such as the CEADAC (for brain injured people), the CRE for people with major dependency, or the CRE for people with Alzheimer and other dementias, combined residential services plus research and comprehensive resources for disabled people and their families. For example, the CRE for people with Alzheimer includes, among other services, direct care services. These services were created with the aim of ensuring that people with Alzheimer's disease and other dementias are provided with the best possible care, so improving their quality of life and that of their family caregivers. They are based on:

a) Promotion of Personal Autonomy: this service promotes the personal autonomy of people with Alzheimer's or other dementias, who are at risk of dependence. It includes a multidisciplinary assessment and the preparation of an individual program of care, functional rehabilitation and / or neuropsychological treatment. Training in activities of daily living and psychosocial and community reintegration is provided, as well as specialized services such as assistance with aids and accessibility, and leisure programs for the promotion of independent living.

b) Day and Night Residential Care Center: Accommodation comprises a Residence, Center for day and all night temporary accommodation, personal care and health care.

c) Involvement of Family Caregivers and the NGO sector: Intervention services with families and carers and the NGO sector includes: respite stays and short family stays, information, advice and support to families, training programs, training of families and carers in cooperation with the NGO sector ..

PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

For those disabled people who want help to live in their own homes there are personal assistance services, and support for assistive equipment and adaptations, both of which stem from the LEPA (2006). As we will explain in the next section, there is also support available to informal carers, by means of their inclusion into the Social Security System, as for any other Spanish worker. There are also many day centers, but they offer daily care rather than support for independence.

Support is also available to family members (parents or informal carers) who provide practical help to disabled people in their own homes, and a number of measures derived from the LEPA have improved the support that existed previously. Thus, in 2007 the Government determined by means of Royal Decree 615/2007, the inclusion of non-professional carers in the Social Security systems , as well as the requirements and procedures for affiliation, registration and contribution. The intention is to overcome the isolation faced by many and to accord a higher degree of autonomy for carers, by means of a public system of care for dependent persons and acknowledgement of the work done by carers and family members (LEPA, p. 8). Up to April 21th, 2009, there were 62.267 non-professional carers included in the System. Of this total, 94.64% (n=58.928) were female and 5.36% (n=3.339) male. Concerning ages, 45.05% (n=28.051) were under 50; 16.95% (n=10.555) aged 51-55; 16.80% (n=10.463) aged 56-60, and 21.20% (n=13.198) aged older than 60. To date, (data from April, 2009), 169.987 are obtaining financial help for care in the family setting and support for non-professional carers.

In addition dependent elderly people can benefit from various community-based services or residential services.

Public administration personnel (social workers, social assistants), decide how much support is provided to each person or family, according to the dependency level of individuals and the economic status of disabled people and their families.

Title II from the LEPA, on quality and efficacy of the system for autonomy and care of dependency, states (article 34. 3) that the Territorial Council shall agree criteria of quality and safety for centers and services, quality indicators for assessment, continuous improvement, comparative analysis of the centers and services in the System, and best practices guides. Article 35 stipulates that essential quality standards shall be established for each of the services, that residential centers for dependent persons should implement a quality management system and involve users in a form determined by the Administration responsible. Further regulations have been approved in order to guarantee the quality of the System for Autonomy and Care for Dependency (SAAD) (see Order ESD/1984/2008), as well as the quality of centers and services from the SAAD (see Resolution, December the 2nd, 2008) . This last regulation stipulates the requirement for documenting the existence of outcomes assessment based on improvements on quality of life.At the time of writing this report data is not yet available about the efficacy of the system.

4.1: PERSONAL ASSISTANCE SERVICES

support for personal assistance services for independent living that are controlled and directed by disabled people themselves

Dependent people who have been classified as having a *Degree III*, Major Dependency (levels 1 and 2), are eligible for personal assistance services and they or if necessary, their families or legal representatives select the person to provide this type of support, by means of an interview. Yet, it is important to note that there are different regulations depending on the Autonomous Communities, as we will explain later. Personal assistants do not need to have a specific training/vocational qualification. However, the forum on Independent Living has developed a profile of necessary skills, attitudes, and additional characteristics (Rodríguez & Romanach, 2006).

The application procedure for this type of support (as well as for assistive equipment support) is as follows. The Act 39/2006, of 14th December (LEPA), article 19 regulates on Personal Assistance, and aims to promote the autonomy of severely dependent persons. Its objective is to contribute to the hiring of a personal assistant, for a number of hours, in order to provide the beneficiary with access to education and employment, as well as a more autonomous life in daily living. Consequently, this kind of support is available to people in their own homes, at work, in education and training.

Following agreement by the Territorial Council of the System for Autonomy and Care for Dependency, the specific conditions for qualifying for this benefit have been established by means of the Royal Decree 504/2007. This Royal Decree determinesa scale to be utilized, which makes reference to International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Organization. This Royal Decree, as well as the LEPA distinguishes three levels of dependency: a) Degree I, Moderate dependency; b) Degree II, Severe Dependency; Degree III, Major Dependency (LEPA, pp.67-68). Each of the degrees of dependency is classified into two additional levels (1 or 2), depending on the person's autonomy and the intensity of care that is required.

The General State Budgets Act of each financial year determines the amount of funding and the method of payment to the Autonomous Communities for this and other services (article 9 of the LEPA). For example, the Royal Decree 73/2009 establishes maximum financial benefits for personal assistance of 831.47 € for Degree III level 2 and 623.60 € for Degree III level 1. The remaining levels are not eligible.

Financial benefits are integrated in the Registry of Public Social Benefits The entities managing these benefits are obliged to provide the data for all benefits that are granted.

According to national data, from April, 2009, since January 2007, 628.614 (81.74%) of 893.712 applicants have been considered eligible for various benefits. Of those eligible, 262.607 (41.78%) are still under consideration. The remaining 366.007 (58.22%) people have been considered eligible for different benefits, and 0.12% (N=454) for personal assistance.

The small percentage of personal assistance is noteworthy and even more interesting is that of 454 beneficiaries for personal assistance, 350 (77.09%) were people from the Basque country, 31 (6.83%) from Castilla-Leon, 25 from Andalucía (5.51%), and 15 (3.30%) from Catalonia. Theis data can be explained if we bear in mind that only the Basque Country (Alava and Vizcaya) (2008 and 2007, respectively), and Catalonia (2008) have developed specific legislation on personal assistance. Other Autonomous Communities, such as Andalucía (2007) or Aragón (2007), include these benefits in a general Act.

It is important to note that there are some other differences between regions.

For example, in the Basque Country or Aragón the conditions for qualifying for this benefit include: being able to identify required services, exercise control over them, and being able to give instructions to the personal assistant on how to perform these services. However, in Catalonia or Andalucía the law includes the possibility of legal tutors or guardians giving instructions or supervising if the individual is not able to do so by him/herself.

The General State Administration meets all costs derived from the terms of article 9 (i.e. the minimum level of protection that is guaranteed to each of the beneficiaries of the System). In the context of inter-administrative cooperation (article 10), the Conventions between the General State Administration and each of the administrations of the Autonomous Communities determine the obligations undertaken by each of the parties for funding the services and benefits in the System. The Autonomous Communities may define additional levels of protection to those set by the General State Administration,:funding from their own budgets, for which they may set rules of access and entitlement that they deem to be appropriate. Thus,there may be differences between regions concerning additional levels of protection, given that the cost of living also differs among regions.

Eligibility requirements are:
1) Legal residence in the state territory for five years, of which two must be immediately prior the date of application. The applicant must also be actually living in the territory. Even if these criteria (see Article 5.1 c) of the Act on Promotion of Personal Autonomy and Care for Persons in situations of dependency) are not met, the applicany may still have access to welfare benefits 2) Registration as resident in the specific Autonomous Community at the time of application. People who are not Spanish nationals are governed by the provisions of Law 4 / 2000 of January 11 on the rights and freedoms of Foreigners in Spain and their social integration, as well as by treaties and international conventions established with the country of origin. Children who lack Spanish nationality are treated under the Juvenile Law, which is in force at both in the state and regional levels, as well as international treaties.

Beneficiaries of dependency benefits contribute financially, according to the type and cost of the service and their ability to pay. The beneficiary's economic circumstances are taken into account in determining the amount of financial benefits. No citizen is left out of the System for failing to have economic resources. (LEPA, art.33).

Concerning dependent persons older than 65, each Autonomous Community has its own regulations, services, and financial benefits. This fact helps to explain the significant differences between Spanish territories. According to a national survey included in the 2006 Report on Older People in Spain (see 2006 report in English, p. 249), Spanish people prefer family or informal solutions rather than those of a more institutional or formal nature. Home care comes in first place, and is valued even more by older people than by those who are younger. Older people can benefit from the following (2006 Report, p. 355-363):

1) Home care services, which include public home help services (SAD), a public teleassistance services, and other home care services;
2) Public and private day care services, which include clubs for older people and day centers for dependent older people.
3) Public and private residential care services, which include residential services, temporary stays in residential centers, and alternative accommodation arrangements (i.e. sheltered housing, foster care or residential apartments).

In January 2006, there were 102.971 dependent users of home help service (SAD), 45.740 users of teleassistance, 68.889 users of residential centers, 864 users of alternative systems (sheltered housing plus foster care), and 54.400 dependent users of other services.

These other services include: public and private domiciliary meals and laundry services; financial assistance for home adaptations; financial assistance for family carers; other family support and dependency programs and financial assistance for technical aids for personal autonomy.

Data on public expenditure on social services for older people (2006 Report, p. 364) show significant differences among Autonomous Communities. Prices of social services also vary greatly from one Autonomous Community to another . For example, in 2006 the home help service (SAD), ranged from 96.88 €/month/user in Andalucía to 335.83 €/month/user in the Basque Country (Libro Blanco, 2004, p.371). Also in 2006, the coverage rate [(users/population>65)x100] of public home help service was 4.09. In autonomous communities as Galicia each user received 25.14 monthly hours of care, whereas in Aragón, each user received 10 hours. The Spanish average in 2006 was 16.24 hours/month, which equals to four hours per week, approximately.

4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

The LEPA (article 22) includes a personal alert system as a specific service for the promotion of personal autonomy and for attention and care, The application procedure follows the same process as described above.

In addition, for dependent persons older than 65, each Autonomous Community has its own regulations, services, and financial benefits.

Data from April, 2009 show that 53.363 individuals are receiving financial benefits for personal alert systems. Data on public expenditure on social services for older people (2006 Report, p. 364) again show significant differences among Autonomous Communities. In January 2006, there were 102.971 dependent users of home help service (SAD), and 45.740 dependent users of teleassistance.

Financial limits for equipment and adaptations are determined by each Autonomous Community. , Each Autonomous Community publishes yearly information on technical aids or adaptations in the home, giving the requirements and maximum amounts payable per type of product. For example, in the Autonomous Community of Madrid, in 2009, the maximum amount for acquisition of a vehicle was 2,400€ and 1,000 € for its adaptation. For removal of barriers in vehicles, the maximum amount was 2,400 €. For home adaptations, the maximum payable was 4,000€. For acquisition of hearing aids: 840 €/each, prescription glasses: 300 €, and technical aids: 3,500 €. Some requirements for eligibility are: having a certified disability, being under 65, and having income within certain limits. There are some differences across Autonomous Communities**.**

While the maximum level of support differs from one Autonomous Community to another, the General Administration stipulates a common minimum level of support. Concerning dependent people older than 65, a total of 54.400 individuals are users of other services (public and private domiciliary meals and laundry services; financial assistance for home adaptations, financial assistance for family carers, other family support and dependency programs, and financial assistance for technical aids for personal autonomy.). Once the user receives the equipment, he/she becomes the owner of it, so he/she can take it from one place to another and use it at his/her convenience.

PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

Members of the different organizations representing disabled people and their families take part in various Commissions at the Spanish Congress of Deputies, which deal with disability and dependency issues, in order to provide information, suggestions, and critical points of view.

In addition, CERMI (Spanish National Council of Disabled Representatives) is the main political platform composed of the main national disability organizations, some sectorial organizations, and regional branches. CERMI has been negotiating various framework agreements with Ministries, as well as with other stakeholders , to promote and defend the rights of persons with disabilities.

A key lobby group for policy change to promote independent living is the Forum on Independent Living, which was created in 2001. According to this organization (March, 2009), the Act on Promotion of Personal Autonomy and Care for Dependent Persons (LEPA) is in contradiction to Article 19 of the UN Convention on the Rights of Persons with Disabilities (which has been enacted in Spain since May, the 3rd, 2008). This is on the basis that the former act assumes a medical approach, whereas the Convention assumes a social approach. Just 10% of the LEPA deals with promoting personal autonomy; the remaining 90% regulates dependent situations. A second critical view relates to a lack of independence of the cross-ministry National Board on Disability, which was created following the passing the LIONDAU, and which is part of the Ministry of Work and Social Affairs. The Forum on Independent Living proposes the creation of an independent body (in line with article 33.2 of the UN Convention) based in an independent academic institution which takes a social approach. They propose that the body should be accountable to parliament and involve wide civil society participation, including the Forum on Independent living. Another example of some shortcomings of LEPA which have been emphasized by the Forum is that:in 2008, for the first time, a personal assistant was approved for an eight year-old boy with intellectual disabilities (autism) from Andalucía.. This development underscores another issue in Spain: the varying degrees of development and associated benefits from the LEPA depending on the Autonomous Community. Thus, in Andalucía, in order to receive personal assistance, the individual or his/her legal representative should be able to determine the required services, as well as to exercise control and give instructions to the personal assistant. In other Autonomous Communities, as explained earlier, legal representatives are not accepted.

Other shortcomings from the LEPA that have been emphasized by the Forum on Independent Living are:

1) the lack of job regulation across autonomous communities for personal assistancts,
2) the inadequate amount of recognized hours of personal assistance according to individual needs,
3) appropriate financial benefits,
4) the need to extend personal assistance across the entire social life of individuals,
5) equal implementation of the LOPE across Autonomous Communities.

Another key organization is Fundación ONCE for the Cooperation and Social Integration of Persons with Disability, which was created in 1988 by Spain's National Organization for the Blind (ONCE). Its main objectives are the creation and implementation of labor integration programs and ensuring global accessibility of environments, products, and services. Fundación ONCE works for the social inclusion of all persons with disability in Spain (International Disability Rights Monitor-Regional Report, 2007, p. 471).

Other effors toward independent living come from intellectually disabled people's organizations. FEAPS, the Spanish Confederation of Organizations working for people with mental retardation, promotes quality of life and quality of services for people with intellectual disabilities.

It promotes self-advocacy groups and has several publications on self-advocacy, self-determination, and independent living directed to an intellectually disabled audience. Some examples are 'A Guide on Health for People with Intellectual Disabilities' (Muñoz, Rivière, Belinchón & Tamarit, 2008), 'Code of Ethics from FEAPS-easy read version' (FEAPS, 2007), 'Do it differently! – training on social skills' (FEAPS, 2005), 'Guide for Self-Advocates' (FEAPS, 2003), 'Put it in practice! – for self-advocacy against discrimination' (FEAPS, n.d.), of the bulletin 'Europe for Us!', which represents European Self-Advocacy groups(e.g. FEAPS, 2006). FEAPS has developed a Portal for self-advocates. The Catalog of Services from FEAPS includes, among others, support for independent living, residential settings and housing for people with intermittent or limited needs of support, as well as for people with extensive or pervasive needs of support. Lastly, FEAPS has developed a quality net and periodically selects best practices (FEAPS, 2007) and publishes information about these.

At an academic level, RETEVI is a network on Independent living developed by experts from different universities from Madrid, Spain, as well as by representatives of the associative movement, and the Forum on Independent Living. It was created in 2006 by ASPAYM-Madrid (association of quadriplegic and severely physically disabled people) and aims to:

1) stimulate self-determination and independence among individuals with functional diversity,
2) identify and develop comparative analyses of existing Spanish projects,
3) combine a "gender perspective" with "philosophy on independent living",
4) develop cross disciplinary groups to promote the culture on independent living.

Associated organizations are: The Office on Independent Living (Community of Madrid), The Office on Independent Living (Barcelona), The Association of Experts for the Study on Disabilities "UnoMás", ASESDIS –Spanish Association on Sociology of Disability-, Sociocultural Asociation "El Tinglao", VIGALICIA –Association on Independent Living from Galicia-, AIES –Association of Studies and Social Initiatives-, Forum on Independent Living, GIAT-D –Group o Research, Analysis, and Work on Disabilities-, and several university departments and research groups from Madrid. They also work at an international level with the European Net on Independent Living and ULOBA – Norway Cooperative on Personal Assistance.

Previously mentioned organizations such as the Forum on Independent Living, RETEVI, FEAPS, Fundación ONCE, among other organizations representing people with disabilities and their families, are also involved at different levels (as support providers, lobbyists for policy changes, advocates, etc.).

New ideas about independent living come from disabled people's organizations and there are some groups lobbing for policy change to promote independent living. People with physical disabilities from the Independent Living forum are promoting the development of Offices for Independent Living throughout Spain**.** These Offices are called (Centers for Independent Living, CILs) In 2006 the first two Offices for Independent Living (OVI) were created, one in Madrid and the other in Barcelona. Both offices embrace the philosophy of the global movement on independent living. They offer self-managed services of personal assistance, financed by their respective public administrations, and develop what is called "support among peers". The OVI from Madrid serves 62 clients with major diversity (disability), and the OVI Barcelona serves 9 persons with major diversity. More specifically, the Madrid OVI personnel is composed of a technical team (coordinator, two social workers, and two staff members), 62 people with physical functional diversity, and 120 personal assistants. Since July 2006, Madrid ASPAYM has managed, the first pilot project on "Promotion of Independent Living and Social Participation" (2006-2008), fully funded by the Ministry of Social Affairs and Family of Madrid, through the Directorate General of Social Services. To give continuity to this first project, it will manage a new program of support to independent living (2009-2011), again funded by the same organisations.

The project and the program will fall under Rule 19. "Right to live independently and being included you in the community," of the Convention on Human Rights of Persons with Disabilities (functional diversity) (UN, December 2006).

Therefore, the goal is to promote self-determination and independence of people with functional physical diversity in their regular environment and inclusion in the community. A permanent staff of 120 personal assistants (PAs) who work for these 62 participants, help them perform various tasks such as getting up, lying down, supporting their studies and / or work, sports, leisure, travel, vacations, volunteering.

The new program is focused on 61 people with physical functional diversity who have been considered eligible. Therefore, for the first time in Spain, people with functional diversity have an opportunity to take charge of their lives, and experience active lives. From now on, these people can bring wealth and human values, and fully participate in all areas of the community on equal terms and, therefore, exercise their right to full citizenship.

In the previous project, over 98% of the budget went towards direct job creation. The Office for Independent Living (OVI) of Spain, in Madrid, offers not only "personal assistance services, but also, advice and training in Independent Living and personal assistance.

Both offices are examples of good practices concerning people with severe physical disabilities.

PART 6: REFERENCES

Act 39/2006, of 14th December, on Promotion of Personal Autonomy and Care for Dependent Persons (LEPA). Madrid: IMSERSO, MInisterio de Trabajo y Asuntos socials.

Decreto Foral 11/2008, del Consejo de Diputados de 12 de febrero, que aprueba la normativa reguladora de la prestación económica de asistencia personal prevista en la Ley 39/2006, de 14 de diciembre, de promoción de la autonomía personal y atención a las personas en situación de dependencia en el Territorio Histórico de Alava (BOTHA 23 , Viernes, 22 de febrero de 2008, pp. 2190-2198).

Decreto Foral 99/2007, de 19 de junio, de la Diputación Foral de Bizkaia, por el que se regula la prestación económica de asistencia personal (BOB núm. 125. Martes, 26 de junio de 2007, pp. 18239-18247).

Encuesta sobre Discapacidades, Deficiencias y Estado de Salud 1999. Avance de Resultados. Datos Básicos. (2000). Madrid: Instituto Nacional de Estadística.

FEAPS (2001). Calidad FEAPS. Red de calidad. Madrid: Autor.

FEAPS (2003). Guía para autogestores. Hacer que tu historia se escuche: Madrid: Autor.

FEAPS (2004). Cartera de servicios socialesdel movimiento FEAPS. Resumen ejecutivo Madrid: FEAPS.

FEAPS (2005). Hazlo de otra forma!. Madrid: Autor.

FEAPS (2006). Europa para nosotros! El Boletín del Movimiento Europeo de Autogestores. Madrid: Autor.

FEAPS (2007). Buenas prácticas FEAPS. ¿qué son y cómo se valoran? Madrid: Autor.

FEAPS (2007). FEAPS Código ético. Versión en lectura fácil. Madrid: Autor.

FEAPS, Spanish Confederation of Organizations working for people with mental retardation.

FEAPS. Ponlo en práctica. Madrid: FEAPS.

FEAPS. Portal autogestores. Madrid: FEAPS.

Foro de Vida Independiente. Nada sobre nosotros sin nosotros. Madrid. the

IMSERSO (2004). Atención a las personas en situación de dependencia en España. Libro Blanco. Madrid: Autor.

IMSERSO (2006). 2006 Report. Older People in Spain. Madrid: Ministerio de Trabajo y Asuntos Sociales, Secretaría de Estado de Servicios Sociales, Familias y Discapacidad, IMSERSO.

IMSERSO (2007) Autonomía Personal y Dependencia. Normativa Comunidades Autónomas (Web page). Madrid: Autor.

IMSERSO (2009) Información estadística del Sistema para la Autonomía y Atención a la Dependencia. Situación a 1 de Abril de 2009. Madrid: Instituto de Mayores y Servicios Sociales

(IMSERSO)/ Subdirección General de Planificación, Ordenación y Evaluación.

IMSERSO (2009). Convenio especial de cuidadores no profesionales de personas en situación de dependencia. Situación a 21 de abril de 2009. Madrid: IMSERSO.

International Disability Rights Monitor-Regional Report (2007). Chicago: Autor.

LEY 51/2003, de 2 de diciembre, de igualdad de oportunidades, no discriminación y accesibilidad universal de las personas con discapacidad (BOE num. 289, pp. 43187-43195) [Act 51/2003, December the 2nd, on equal opportunities, non discrimination and universal accessibility of disabled people]

Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007), *Deinstitutionalization and community living –outcome and costs: report of a European Study. Vol.2. Main Report*. Canterbury: Tizard Centre, University of Kent.

Muñoz, J., Rivière, L., Belinchón M. y Tamarit, J. (2008). Guía de Salud. Madrid: Centro de Psicología Aplicada (CPA) de la Universidad Autónoma de Madrid.

Oficina de Vida Independiente (OVI) de la Comunidad de Madrid. Madrid

Orden ASC/344/2008, de 14 de julio, por la que se regula la prestación económica de asistencia personal y se amplía el nivel de protección del Sistema Catalán de Autonomía y Atención a la Dependencia (SCAAD). (Diari Oicial de la Generalitat de Catalunya Núm. 5174 – 16.7.2008, pp. 55731-55738).

Orden de 3 de agosto de 2007, por la que se establecen la intensidad de protección de los servicios, el régimen de compatibilidad de las Prestaciones y la Gestión de las Prestaciones Económicas del Sistema de Autonomía y Atención a la Dependencia en Andalucía (BOJA núm. 161 Sevilla, 16 de agosto 2007, pp. 22-27).

Orden de 7 de noviembre de 2007, del Departamento de Servicios Sociales y Familia, por la que se regula el régimen de acceso a los servicios y prestaciones económicas del Sistema para la Autonomía y la Atención a la Dependencia en la Comunidad Autónoma de Aragón (BOA Número 132 9 de noviembre de 2007, pp. 15273-15279)

Orden ESD/1984/2008, de 4 de julio, por la que se crea la Comisión Especial para la mejora de la calidad del Sistema para la Autonomía y Atención a la Dependencia.

Real Decreto 2066/2008, de 12 de diciembre, por el que se regula el Plan Estatal de Vivienda y Rehabilitación 2009-2012. (BOE núm. 309 Miércoles 24 diciembre 2008, pp. 51909-51937)

Real Decreto 504/2007, de 20 de abril, por el que se aprueba el baremo de valoración de la situación de dependencia establecido por la Ley 39/2006, de 14 de diciembre, de promoción de la autonomía personal y atención a las personas en situación de dependencia.(BOE num.96, Sábado 21 abril 2007, pp. 17646- 21355).

Real Decreto 6/2008, de 11 de enero, sobre determinación del nivel mínimo de protección garantizado a los beneficiarios del Sistema para la Autonomía y Atención a la Dependencia en el ejercicio 2008.(BOE núm. 11 Sábado 12 enero 2008 pp. 2289-2290)

Real Decreto 614/2007, de 11 de mayo, sobre nivel mínimo de protección del Sistema para la Autonomía y Atención a la Dependencia garantizado por la Administración General del Estado

(BOE núm. 114 Sábado 12 mayo 2007 pp. 20601-20602)

Real Decreto 615/2007, de 11 de mayo, por el que se regula la Seguridad Social de los cuidadores de las personas en situación de dependencia. (Sábado 12 mayo 2007 BOE núm. 114, p. 20602 - 20605)

Real Decreto 73/2009, de 30 de enero, sobre las prestaciones económicas de la Ley 39/2006, de 14 de diciembre, de promoción de la autonomía personal y atención a las personas en situación de dependencia para el ejercicio 2009. (BOE Núm. 27 Sábado 31 de enero de 2009 Sec. I. pp. 10425-10427)

Real Decreto 74/2009, de 30 de enero, por el que se determina el nivel mínimo de protección garantizado a los beneficiarios del sistema para la autonomía y atención a la dependencia para el ejercicio 2009. (Núm. 27 Sábado 31 de enero de 2009 Sec. I. pp. 10428-10430).

Red de Trabajo en Vida Independiente (RETEVI). Madrid.

RESOLUCIÓN de 2 de diciembre de 2008, de la Secretaría de Estado de Política Social, Familias y Atención a la Dependencia y a la Discapacidad, por la que se publica el Acuerdo del Consejo Territorial del Sistema para la Autonomía y Atención a la Dependencia, sobre criterios comunes de acreditación para garantizar la calidad de los centros y servicios del Sistema para la Autonomía y Atención a la Dependencia.

Ripollés, S., Rodríguez-Picavea, A. y Romanach, J. (2007) Asistencia personal para la vida independiente y la promoción de la autonomía de las personas con diversidad funcional (discapacidad) en España. Madrid: Depto. De Filosofía y Filosofía Moral y Política (UNED)-Foro de Vida Independiente.

Rodríguez, A. & Romanach, J. (2006). Consideraciones sobre la figura del Asistente Personal en el Proyecto de Ley de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia.

Romanach, J. (2009). Comparecencia en la subcomisión de la discapacidad del Congreso de los Diputados el 17-mar-2009. Madrid.

U.G.T. (2009). Pensiones mínimas 2009. Madrid: Autor.