PEOPLE IN SITUATIONS OF DEPENDENCY **RECOMMENDATIONS** TO LOWER THEIR VULNERABILITY

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PEOPLE IN SITUATIONS OF DEPENDENCY. RECOMMENDATIONS TO LOWER THEIR VULNERABILITY[i]

This document is the product of a group and cooperative project carried out in October 2006 by a multisectoral and multidisciplinary Expert Panel on issues relating to people in situations of dependency, which was coordinated by Professor Gómez-Jarabo.

The Panel's methodology consisted of two, in-person meetings along with email communications, through which each participant's opinions and thoughts – regarding a basic text that was prepared by the coordinator – were shared and debated.

The text below was prepared with the consensus of the members of the panel. It provides data, information, questions, answers and recommendations – which help to put the problems faced by people in situations of dependency into a framework – as well as expectations and perspectives that the new legislative initiative for the promotion of personal autonomy, and assistance to people in situations of dependency and their families raises; in addition, it includes some fundamental recommendations to ensure that this law becomes more effective in terms of providing improved conditions for the affected people and their families.

INTRODUCTION

The concept of social vulnerability has two explanatory components. On the one hand, the insecurity and helplessness that the communities, groups, families and individuals experience in their daily lives as a result of the impact caused by some kind of traumatic natural, economic or social event; and on the other hand, the management of resources and the strategies employed to confront their effects by the communities, groups, families and people.

Longhurst (1994) makes a magnificent review of the literature on vulnerabilities tied to natural disasters. Additionally, the World Food Program (1996) analyzed – from a perspective of vulnerability – the risks of regions and communities in the event of famine; vulnerability, in fact, is usually confused with poverty.

In reality, the poverty approach classifies certain attributes of groups, people and families descriptively, without taking into consideration the causal processes that produce them; while vulnerability, to the contrary, refers to the nature of the economic and social structures and institutions; that is, to the programs, systems and services offered by the social structure and to the impact that these factors have on communities, groups, families and individuals in the different dimensions and categories of their social lives.

Social vulnerability is the result of the impact provoked by these multiple causes and it expresses society's weakest groups, families and citizens' inability to confront, neutralize and benefit from them.

People are exposed to different types of vulnerability over the course of their lives. Besides the factors that we are going to highlight, we must take into consideration the increase in competition, which has lowered people's tendencies toward acts of solidarity and social responsibility; in addition, there are also the "emerging social problems" that so often worry citizens, such as corruption, drug-addition, juvenile delinquency and violence, which are taking on an important role due to the alarm they cause.

We consider the following conditions basic:

- Their membership or belonging to defined a population (ethnicity or nationality).
- Their health conditions (the disabled and chronically ill) and age.
- Their environment, isolated and scattered communities, areas at greater risk of experiencing a natural disaster or urban neighborhoods in which social and economic integration of the residents is difficult.

Vulnerability is a multidimensional phenomenon and it has become a permanent social characteristic, which evolves the same way a microorganism mutates, by adapting itself to the different environmental conditions regardless of how radical they may be. Setting aside the differences and following along with this metaphor, we associate vulnerability with natural disasters, pandemics and health epidemics, endemics, violent catastrophes, ignorance and illiteracy, inclusion into economic development, poverty, employment, unemployment, economic disasters, production models, institutions and the values that characterize development itself in any part of the world. And the same thing always happens, low-income groups, families and citizens – and even the middle class when they are exposed to heightened levels of insecurity and defenselessness – are the most vulnerable.

The complexity of social vulnerability is characterized and worsened by interdependence, globalization and uncertainty.

In conclusion, there are tons of reasons that can come up as risks for social vulnerability, which would allow us always to keep using the metaphor with the adaptation of social vulnerability to a new, emergent condition. In our case, the different conditions of inequality become intertwined and reinforce themselves in old age, trapping people into a relationship of multiple disadvantages from which it is very difficult to escape in today's world, thereby inevitably linking the aged's (or elderly's) social vulnerability to dependency.

CONCEPTS OF PERSONAL AUTONOMY AND DEPENDENCY

Assistance for people in situations of dependency emerges as a social demand. In reality, this event does not occur fortuitously, but rather it is a condition that stems from the huge biological success achieved by human-beings during the past century, which speaks, above all, of society's progress through its health care systems and services. The most transcendental result or generic conclusion is the 25-year increase in our life expectancy, with some disability affecting our daily life activities.

PEOPLE WITH SOME DISABILITY AFFECTING THEIR DAILY ACTIVITIES, BY MAXIMUM DEGREE OF SEVERITY AND AGE GROUP. SPAIN, 1999

	6 to 64 years	65 to 79 years	80 + years	Total Over 6 Years
Moderate Disability	287,610	279,230	126,977	693,817
Severe Disability	258,241	307,792	165,672	731,705
Complete Disability	261,547	257,455	296,489	815,491
Not available	13,127	17,942	13,257	44,326
TOTAL	820,525	862,420	602,395	2,285,340

Source: National Institute of Statistics. Survey on Disabilities, Deficiencies and State of Health 1999, Detailed findings, Madrid, 2002.

In the face of this spectacularly important fact, comes – as can only be expected – the rise in defects, difficulties and disabilities, which provide some disproportionate and, in some cases, exponentially growing figures. This means that we are facing a major social change with two completely contrasting conditions of assessment: 1) the rise in life expectancies as a fantastic acquisition (**"a success"**); and 2) a disproportionate increase in the representation of the population of people with difficult, restrictive or disabled conditions, that is, a **population of people in situations of dependency**, as an undesirable acquisition (**"a failure"**).

Therefore, without reticence, we feel the response to the aforementioned dichotomy should aim to prevent the social failure of this great biological success, by joining efforts and, particularly, through the immediate and committed proposal of public authorities. In regards to the latter, we assess positively the role that the current government is playing in terms of combining the basic conditions of one of the most important steps forward in the social policy of the new millennium:

- White Book;
- System of Assistance to People in Situations of Dependency; and
- Bill for the Promotion of Personal Autonomy and Assistance to People in Situations of Dependency and their Families.

The associated movement and non-profit institutions have been the first to gather together the social changes and channel their demands, and in this regard we congratulate the Red Cross Foundation for encouraging this Panel, as well as the

various associations and institutions, which have participated in it with their experts, for their sensitivity and ability.

The government should intensify its efforts to establish an alliance with the new civic organizations, to confront the large number of social problems related to the field of personal autonomy and assistance to people in situations of dependency, which also cause social instability and unrest.

Concepts

The concept of dependency is clear: physical and/or mental deficiency along with an impossibility to carry out daily life activities (DLA); thus, requiring the help of another person. It has been generally accepted almost everywhere since resolution R(98)9 of the Council of Europe that defines dependency as "such a state in which people, whom – for reasons connected to the lack or loss of physical, mental or intellectual autonomy – require assistance and/or extensive help in order to carry out common everyday actions."

In the case of the Law, the text reads: "Dependency: the permanent state of being in which people – for reasons derived from age, illness or disability and linked to the absence or loss of physical, mental, intellectual or sensory autonomy – require assistance from another person or other people or extensive help to carry out basic everyday activities."

In this definition, they have not managed to have the concept of **"intellectual autonomy"** stand on its own and carry its own weight or be separated sufficiently from interpreting it as a mere antonym of dependency. Autonomy refers in its other sense, to an individual's volitive ability to decide freely on matters that concern his/her own life – in this case, on the management of his/her situation of dependency – which should be present and protected by all legislation that is based on the respect for people's individual liberties, as is found clearly and detailed in law 41/2002, "Basic Regulating Law on Patient Autonomy and the Rights and Obligations regarding Clinical Information and Documentation."

The Law of Personal Autonomy and Protection of Dependency includes a definition of "autonomy" in article 2 that states: "The ability to control, confront and make – on one's own – decisions regarding how to live in accordance with norms and one's own personal preferences." This would necessarily lead us to have to consider that people with dependencies have "volitive autonomy" and, therefore, that it should be respected and/or encouraged. Another problem would be to consider that indeed the loss of this volitive capacity ("intellectual autonomy") can also occur simultaneously with many situations of dependency, and may in fact be its very cause.

For its part, personal autonomy reflects the aim of the law; that is, the law seeks to ensure that certain social groups can be integrated into a society that could end up excluding them because of their physical, sensorial or intellectual deficiencies. In terms of disability, the law promotes that all people have the same rights; it affirms that they

may carry out, in equal conditions, all acts just like the rest of the people, while having access to certain services and/or technical assistance.

The concept of Personal Autonomy is a term that has more positive connotations, it focuses on an individual's abilities, whereas the term "Dependency" is a concept that takes away individuality and autonomy from disabled people.

We find that the most widespread definition of dependency refers to "a loss of physical, mental or intellectual autonomy…," which then leaves the concept of autonomy mixed and diffused with that of independence as an antonym of dependence. We find it more useful to adopt a notion of dependency that is void of any medical, economic, self-management or other kind of situation that could condition it.

Therefore, we propose that a person be considered in a situation of dependency, in regards to having rights to the provisions established in the Law of Personal Autonomy and Assistance to People in Situations of Dependency, when he/she cannot carry out without help some of the basic everyday activities related to one's own personal care, movement within one's home or basic mental functions: washing oneself; maintaining personal hygiene related to bodily functions, dressing and undressing; eating and drinking; changing the positions of one's body; standing up and lying down; moving around in one's home; recognizing people and objects; being oriented and understanding and giving instructions and/or simple tasks.

These concepts are more or less reflected in the law's title; however, since the title could then be a reason for confusion in regards to its own objective, while it not be changed, we believe that the law is more a Protection of Dependency and Promotion of Autonomous Life and we would like to stress the importance of respecting the decision-making capacity regarding the management of the provisions or services that a person in a situation of dependency may require – albeit personally or through a legal representative – which without a doubt could be the best insurance against social vulnerability and the increase in the quality of life of both the affected people and those that care for them.

In any case, we find that there should be no kind of discrimination whatsoever in regards to age among the overall group, and that – both in terms of its conceptualization as well as its protection – situations of dependency should be of a universal nature and comparative grievances should be avoided in relation to age or to the particular factors of or reasons behind the deficiencies and care of the groups involved.

The White Book also goes into more detail about the criteria to determine the degree of protection according to the lower or higher intensity of help needed to carry out daily life activities. It proposes the establishment of three degrees of dependency for the sake of classification from lowest to highest intensity.

Moderate Dependency: when a person needs help to carry out several daily life activities at least once a day.

Severe Dependency: When a person needs help to carry out several daily life activities two or three times a day, but does not require the permanent presence of a caregiver.

Great Dependency: When a person needs help to carry out several daily life activities several times a day and – due to his/her complete loss of mental or physical autonomy, requires the indispensable and continuous presence of another person.

The White Book estimates the number of people with severe or total dependency to carry out some daily life activities to be around 960,000.

PEOPLE WITH SEVERE OR COMPLETE DEPENDENCY FOR SOME DAILY LIFE ACTIVITY (*) BY SEX AND LARGE AGE GROUPS (Data refers to persons aged 6 and over). SPAIN, 1999

	6 to 64 years	65 to 79 years	80 years and over	Total: 6 years and over
Males	134,641	108,496	77,155	320,292
Females	129,441	204,444	205,713	539,598
TOTAL	264,083	312,939	282,868	859,890

(*) The activities considered are: changing positions of one's body; standing up and lying down; moving around inside one's home; washing oneself; controlling one's needs; dressing, undressing and dressing; eating and drinking; recognizing people and objects; understanding and following instructions and/or simple tasks.

Source: National Institute of Statistics. Survey on Disabilities, Deficiencies and State of Health, 1999, Detailed findings, Madrid, 2002.

Along with these people, who would be those that are protected by the Law, people that need help to leave their homes or to carry out household tasks must also be taken into consideration as well as those that have some kind of moderate disability affecting their self-care, mobility, ability to feed themselves and basic mental capacity, i.e. those who do not reach the higher degrees of dependency that characterize the aforementioned group.

These people have been divided up into two groups, with the following characteristics.

Group A: People with moderate disabilities for some basic, daily life activities, who do not need daily help.

Group B: People with a disability for some key, daily life activities (mobility outside of the home and household tasks), who do not have any other disability affecting any basic activity.

PEOPLE WHO NEED HELP TO CARRY OUT HOUSEHOLD TASKS AND/OR HAVE A MODERATE DISABILITY IN AREAS OF SELF-CARE, MOBILITY, FEEDING THEMSELVES AND BASIC MENTAL CAPACITY (*) BY SEX AND LARGE AGE GROUPS (Data refers to people aged 6 and over). SPAIN, 1999

	6 to 64 years	65 to 79 years	80 years and over	Total 6 years and over
Males	247,930	169,599	86,962	504,491
Females	309,495	379,882	232,565	921,941
TOTAL	557,425	549,480	319,527	1,426,432

(*) This includes people with moderate disabilities for any basic, daily life activity and people with a disability of any degree for any key, daily life activity, as long as they do not have a severe or complete disability for any basic, daily life activity.

Source: National Institute of Statistics. Survey on Disabilities, Deficiencies and State of Health 1999, Detailed findings, Madrid, 2002.

The help that these people need, although it is normally of a lesser degree and frequency, becomes indispensable for them to be able to live a dignified life. Even if they do not receive the general services from the National System of Dependency because they do not exceed the established threshold needed to have a right to them, these people could benefit from other public assistance social services, particularly those from the autonomous and municipal levels.

Therefore, in order to prevent situations of vulnerability, we must differentiate clearly between actions that are taken to encourage independence of other people and those designed to promote decision-making autonomy.

Services for situations of dependency are aimed at people who cannot take care of themselves, who could receive technical assistance, home aid, tele-assistance, day care facilities, placement in a nursing home, etc. The care for these people falls on their families, especially on women. Eighty-three percent (83%) of family caregivers are women and only 65% of the families that care for people in situations of dependency receive support from social services.

In our country today, the administration's services aimed at dependency come from the health care system and from social services, in a rather divergent manner. The acceptance – or rather the reciprocity of the importance of the "social" in today's view of health – by those in charge of health care, will see to it that in the coming years we continue to find a progressive and inevitable coordination between social matters and health care issues.

MODELS FOR THE SOCIAL PROTECTION OF DEPENDENCY

Models for the Social Protection of Dependency correspond to the various models of the Welfare State, which address:

Universal protection for all citizens and financing through taxation. This is the model of the Scandinavian countries and the Netherlands.

Protection through a social security system, through benefits that come from taxation. This is the German model of the central European countries, currently in force in Germany, Austria and Luxembourg.

Welfare protection, aimed fundamentally towards citizens that lack resources. This is the model that is most common in southern European countries.

It has been proven that the general, dominant trend in member states of the European Union (EU) is oriented towards universally-natured models of protection of dependency. This means that access to services does not depend on the resources of a person in a situation of dependency, but rather on one's assessed socio-medical needs.

The German model sets the initial threshold according to the amount of help needed by the people in situations of dependency, while taking into consideration the understanding that a situation of dependency is when a person needs at least 90 minutes a day of care, half of which is for personal care, and it establishes – from that point – three degrees of dependency.

The French model, for its part, establishes the initial threshold according to the type of help required, taking into account that a dependency occurs when one needs help to bathe and dress him/herself, to carry out personal activities and to feed him/herself, as well as when one needs help to get out of bed or off a chair, even though he/she may be able to move around on his/her own around the house. Unlike the German system, the personalized French autonomy subsidy only covers people over the age of 60.

Regardless of the model that is ultimately adopted by the Public Powers in Spain, its identification will not be opposed as long as it addresses the following basic principles:

- ***Universality of the benefits*;**
- ***Public nature of the benefits***: regardless of the types of financing and of those who take on the specific management of each service provided; and
- ***Equality in accessing this right****:* the Law of Personal Autonomy and Assistance to People in Situations of Dependency would be a basic, governmental regulation and, therefore, stipulate minimum guarantees.

It is possible that the protecting action's viability demands the co-participation of the user; in principle, it would be desirable to have the financing be reflected in the General Budgets of the State or that it become a new part of the budgets in the Social Security system, although we do not believe that any citizen would refuse such co-participation if the conditions were established in a general manner and there was no territorial, autonomous or social discrimination.

Assessment of the Dependency

Assessing dependency requires the application of various scales in accordance with the situation of the person in a situation of dependency, which should be approved by the government and classified as a basic regulation, as per the Law of Personal Autonomy and Assistance to People with Dependency, and – therefore – applicable throughout the entire state, through which it will be possible to distinguish – with objective criteria – if a person is in a situation of dependency and, if so, to what degree.

Administrative organs of the autonomous communities, health centers and municipal social services centers should be trained in carrying out assessments of dependency.

The national system of dependency, in its first stage, should focus primarily on the population that faces the most problems of dependency. The assessment should address and serve:

As an instrument to determine the right to economic compensation, in accordance to the intensity of the aid required, to demarcate homogenous groups with the aim of coming to a specific type of assistance and/or pinpointing the users of a service according to the same characteristics.

As an instrument of a complete assessment to establish a program of care, periodically evaluating the results of the assistance, as well as the planning of resources and control of the quality of the services rendered.

As a guarantee of the participation of the person in a situation of dependency in terms of choosing the resources that he/she needs, for his/her specific needs.

ANALYSIS OF DEPENDENCY

DEMOGRAPHICS AND DEPENDENCY

According to the definition, which has been widely accepted, dependency is the result of the combination of three factors:

- Firstly, the existence of a physical and/or mental limitation that diminishes certain capacities of a person;
- Secondly, the incapacity of a person to carry out by him/herself daily life activities; and
- Thirdly, the need for assistance or care from a third party.

There is no doubt that the vehicles that drive us to dependency are age, disability or both age and disability.

Available empirical evidence shows that there is a narrow relationship between dependency and aging, as the percentage of people with limitations in their functional capacities increases with age. This increase does not occur at a constant rate, as there is an age – around 80 years – at which it accelerates notably. It is therefore of no surprise that dependency is seen as a problem that is closely linked to the aging population. In reality, dependency spreads across the population's entire range of ages and is not confined to the older generations even though they are the ones who are most strongly affected by it. Dependency can appear at any point in one's life.

Also, dependency may not appear – and in fact in many cases it does not appear – until a person reaches a very advanced age. There are social and environmental variables (as well as genetic factors), which condition the appearance and the development of the triggers of dependency, which differ among individuals. This means that it is possible to prevent dependency by encouraging healthy living habits, improving the efficacy of the health care systems and ensuring early treatment of chronic illnesses.

Congenital malformations, accidents (occupational, traffic, domestic), new disabling illnesses, and the aging process itself, are factors that contribute to making dependency a full-scale social problem.

While it is true that this is not a new problem, the accelerated aging process of our population is giving a new dimension to the phenomenon of dependency, both quantitatively and qualitatively, as it coincides with profound changes in the social structures of both the family and the care-giving population.

There is a clear interrelationship between health and situations of dependency. Specifically, there is evidence of the efficacy of health care interventions in middle-aged people in order to prevent the appearance of dependency at more advanced ages; moreover, it has been shown that improving the population's daily habits contributes significantly towards improving one's life expectancy without dependency.

On the other hand, in the cases in which there is already dependency, care of one's health is essential in order for the person to properly adapt to his/her new situation and therefore improve his/her quality of life.

INFORMAL SUPPORT SYSTEMS

The family is the ultimate structure of protection for people with serious disabilities and pronounced dependencies; within the family, the women are those who take responsibility for the care of the person in a situation of dependency, to a much greater

extent than the men, even though the latter are progressively taking part in such personal care.

Despite the leading role of the family in long-term personal care of aged people, a widely shared idea has emerged that such responsibility should not fall exclusively upon women and the family in general; that is, the role of the person who provides such care must be dignified, publicly recognizing their dedication and defining the support given as the very expression of solidarity.

Therefore, the responsibility of attending to situations of dependency should be shared in all aspects with the Public Administrations, social agents and civil society, and, above all, it should avoid the bias of the caregiver's gender. This involves recognizing the crisis of the informal caregiver because of the very reasons and demands of the most modern and evolved social conditions that are found in a change of values, not only in the acknowledgement of the family structure but also in the taking on by women of new occupational responsibilities.

In this process of real change alongside the restructuring of the Welfare State, a field of uncertainty is opened in terms of the protectorate role of the family and it redefines the role of the social institutions and of the social agenda itself, towards some new forms and methods of professionalizing personal assistance, which in this case refers to people in situations of dependency.

These complementary functional and technical means in terms of the development of programs and activities for prolonged personal care signify an important step forward in regards to the effectiveness of policies for the protection of dependency. However, we find they will not reach their full development if they are not placed within a coherent framework of a universal public insurance plan that protects the various situations of dependency across the range of age groups.

Therefore, we are faced with a contingency that affects the aged as a consequence of the aging of the population and that is also present in younger ages due to new illnesses and, above all, to the dramatic effects of automobile accidents. Their scope and impact are modifying social needs and the structure of social demands. It requires a new universal and coherent framework of protection that integrates the network of existing resources and includes not only coverage of the needs of the person in a situation of dependency, but those of the caregiver too.

There is quite a widespread belief that there is selfless dedication and superior care of people in situations of dependency in Mediterranean families, and even though informal care in our country is much greater than that which is given in other countries in our community, we cannot deny the fact that changes are taking place in our values and occupational conditions.

The role of the informal caregiver, which corresponds to a moral, dominant code, according to which such aid is a "duty" that, moreover, should be carried out by women, is beginning to break down.

In Spain, the need for aid in basic, daily life activities is between 7 – 10%t of the aged between the ages of 75 – 79 and between 14 – 22% in the age group of those over 80 years old.

Support for the family of a person in a situation of dependency should not be a mere recognition of their efforts, but rather the establishment of public services and provisions, and in the worst case scenario, it should include an additional component to the different informal resources. Such a complementary nature of resources involves various levels:

The existence of economic compensation and services that protect the needs that arise from dependency;

A sufficient network of community services: day centers, home care support services, short-stays, services to give the families' a break or ease their responsibilities; and

Legal protection of the person in a situation of dependency to protect his/her rights in the case that he/she loses his/her autonomy, as well as protection of his/her professional career and of the insurance of the female or male worker or caregiver.

PROTECTION

Protection in the European Union

Social protection of senior citizens in the European Union, is less uniform than what would be expected. Income programs and social services for seniors include a broad spectrum of protection systems that can change the relative circumstances of the aged population in situations of dependency in each country. In this context, the relevant aspects include not only consolidated systems of protection, like pensions, health care and traditional services, but also additional programs for income, housing allowances and fiscal spending.

Only scattered and fragmented information is available on this last protection and the budgets that comprise it. Moreover, the information that has to do with the needs of senior citizens is also scarce. There is no standardized system of information that makes it possible to research the needs of seniors in situations of dependency.

What is known is that the current situation tends to focus more on the diversification, innovation and experimentation with new forms of assistance rather than on the provision of public resources and quantitative development of the available systems. This trend tends to be observed in all of the countries but mainly in those where there are systems of universal coverage.

The trend towards diversification is an indicator of advanced development of the systems of Welfare States, even though the opposite trend (public spending cuts) is illustrative of the general trend towards less state involvement. When this is related to senior citizen services and the need for long-term care, common practice goes against demographic trends and the spending power of the older generations, whose welfare needs are the highest. Therefore, in a large number of countries there is quantitative growth, well-financed systems (Germany, more health care slots (France) and better housing and assistance for seniors (the Netherlands). A growing appeal for social assistance to cover these needs has been evident in several countries.

There will always be new needs and new systems of care, but the large majority of the needs of dependency can be simplified to normal Social Security needs: the need for sufficient income and the need for health care and other Social Services that to a great extent are caused by medical reasons.

In many EU countries, there is a growing debate in regards to the financing of the long-term care of the aged in situations of dependency. There is also an important debate on how to pay for informal care. The model of care that we decide to promote is also one of the decisions that must be defined. Taking into consideration the social protection of dependency, in our opinion, the choice should reflect the German or the French model.

Protection in Spain

Until now, informal care by the family is the main source of support to the aged person in a situation of dependency, along with the guarantee of his/her pensions, free health care and pharmaceutical services and some type of social services (like home care). It appears that the creation of additional insurance or dependency insurance could change the Social Security system.

Private solutions are not very feasible, since there is no market in demand with an important economic consolidation. The cost of long-term care insurance is still not identified as a universal risk, but rather as an exception (like an occupational accident, a disability). Until now, dependency insurance has not been included in the priorities of Social Security reform, which is focused on the feasibility of the public pensions system and the promotion of supplemental private insurances.

In the debate that is taking place on the estimates of the population of people in situations of dependency, an indicator that can be used is the sum of those that say: "I can do it with help" and "I can't do it at all" in the three big categories of dependency.

***Personal care*:** walking without a cane, eating, cutting a piece of bread, cutting one's nails, showering, bathing, washing one's face and upper body, getting out of bed and lying down, combing one's hair and shaving, being alone all night long, and dressing and undressing.

Household Tasks: changing the sheets, sewing a button, washing the dishes, making the bed, washing a stain off the floor, making breakfast and lunch for oneself.

Personal Matters: managing one's own money, walking for one hour straight, taking a bus, metro or taxi, buying food and clothes, taking medicines and using the telephone.

It has been proven that the need for help is less, the more frequently an activity is carried out: activities that are repeated on a daily basis (eating, dressing, washing) require a lot less support from third parties than those that are done at greater intervals (showering, doing the laundry) or simply those that are done without any set interval (walking for an hour straight or cutting one's toenails).

Except for the need of help by third parties to carry out some of their daily life activities, many characteristics differentiate the population of people in situations of dependency and, therefore, the manner of providing this aid may differ from one person to another, particularly when we consider a disability as a sign of imminent dependency; however, home care is demanded by two thirds of people in situations of dependency and it also calls for assistance from social volunteer services and tele-assistance and tele-alarm programs for people in situations of dependency.

One of the things that is most mentioned by the affected people is the fear of losing one's memory, loneliness and concerns about the situation of dependency itself, like pain and illness.

DEPENDENCY IN FIGURES

In Spain, people in situations of dependency (the aged and severely disabled who cannot take care of themselves), according to the White Book on Dependency, total 1,125,000 in number, of whom more than 80% are over the age of 65.

The National Survey on Health of 1993 limited the questions on dependency about carrying out of daily life activities to people aged 65 and over. Serious dependency affects 640,000 people; in this group, the prevailing need has to do with household tasks, as 85% of them need this type of help, the majority of whom are male. Lastly, 146,000 aged people need help to carry out almost all daily activities; this group is made up 60% by women, who overwhelmingly are over 80 years old.

PEOPLE WITH A DISABILITY FOR DAILY LIFE ACTIVITIES WHO RESIDE IN FAMILY HOMES (ESTIMATE FROM THE EDDES 1999) DISTRIBUTION ACCORDING TO THE DEGREE OF CARE NEEDED.

DEGREE	Males	Females	Total	Percentages
People in Situations of Dependency (*)				
3 (Great Dependency)	40,607	80,502	121,109	14.1%

2 (Severe Dependency)	101,941	160,545	262,485	30.5%
1 (Moderate Dependency)	177,745	298,551	476,296	55.4%
Total	320,292	539,598	859,890	100.0%
People who need help to carry out household tasks and/or have some form of moderate disability for any basic DLA. (**)				
A (Moderate disability for any basic DLA)	247,503	432,063	679,565	47.6%
B (Disability for DLA)	256,988	489,878	746,867	52.4%
Total	504,491	921,941	1,426,432	100.0%
Total of People with a Disability for daily life activities				
Total	824,783	1,461,539	2,286,322	

(*) Including people with severe or total disability for any of the following activities: changing the position of one's body; getting up and lying down; moving around one's home; bathing; controlling one's needs; dressing, undressing and getting oneself ready; eating and drinking; recognizing people and objects and being oriented; understanding and carrying out instructions and/or simple tasks.

(**) Including people that do not fall into degrees 1, 2 or 3 of dependency, who have a moderate disability for any basic daily life activities related with the previous note (*) and those who have a disability for any of the following activities: wandering about without any means of transportation; taking care of the shopping and the control of supplies and services; taking care of meals; taking care of washing and ironing clothes; taking care of cleaning and maintaining the house; taking care of the well-being of the rest of the family members.

Source: National Institute of Statistics. Survey on Disabilities, Deficiencies and State of Health 1999, Detailed findings, Madrid, 2002.

The deterioration of health with age, along with other social correlates of the aging process, like widow/widowerhood or loneliness, heighten this population's need for help. The evolution of this group's dependency comes both from the general aging of the population and the aging of the senior citizens. In 2005, the 80 years old and over group already made up a fourth of all the elderly population. Among the people in situations of dependency their presence exceeds 40%.

PEOPLE WITH A DISABILITY FOR DAILY LIFE ACTIVITIES (SPAIN 99). DISTRIBUTION ACCORDING TO THE DEGREE OF NEED FOR CARE				
DEGREE	At family homes	At residences - estimate	Total	Percentages
People in situations of dependency				
3 (Great dependency)	121,109	20,300	141,409	14.7%
2 (Severe dependency)	262,485	41,600	304,085	31.7%
1 (Moderate dependency)	476,296	38,100	514,396	53.6%
Total	859,890	100,000	959,890	100.0%
People who need help to carry out everyday household tasks and/or a moderate disability for any basic DLA.				
A (Moderate disability for	679,565	45,000	724,565	47.5%

any basic DLA)				
B (Disability for DLA)	746,867	55,000	801,867	52.5%
Total	1,426,432	100,000	1,526,432	100.0%
Total of People with a disability for DLAs.				
Total	2,286,322	200,000	2,486,332	

Source: IMSERSO

Up until now assistance towards these people is given, above all, within the family environment and this responsibility falls mainly upon the women, which traditionally makes it impossible for them to hold a professional occupation. Moreover, such situations of dependency seriously tax the economy and lives of the people who provide the care, who show physical, psychological and emotional problems to a much wider extent than the rest of the population, which is known as "Caregiver's Syndrome."

Currently, from the administrations, assistance is given to people in situations of dependency from both the health care system and social services with insufficient coverage and major differences among the autonomous communities and rural and urban areas. This places Spain well behind the levels of coverage provided in other European countries.

The SAAD will be established with the aim of encouraging personal autonomy and guaranteeing assistance to and protection for people in situations of dependency, with the collaboration and participation of all of the public administrations.

The assessment of the degrees of dependency will be done through the application of the scale agreed to in the Territorial Council and approved as per the regulations.

***Degree I: Moderate Dependency*.** In order to carry out several basic, daily life activities the person needs help once a day.

***Degree II: Severe Dependency*.** In order to carry out several basic, daily life activities the person needs help from someone two to three times a day, but does not require the permanent presence of a caregiver.

***Degree III: Great Dependency*.** In order to carry out various basic, daily life activities the person needs help several times a day, requiring the continuous presence of another person due to his/her complete loss of mental or physical autonomy.

PROJECTION OF THE NUMBER OF PEOPLE IN SITUATIONS OF DEPENDENCY FOR DAILY LIFE ACTIVITIES ACCORDING TO DEGREES OF NEED FOR CARE (Spain, 2005 – 2020).

People in situations of dependency	*2005*	*2010*	*2015*	*2020*
Degree 3	194,508	223,457	252,345	277,884
Degree 2	370,603	420,336	472,461	521,065
Degree 1	560,080	602,636	648,442	697,277
Total	1,125,190	1,246,429	1,373,248	1,496,226

White Book as per the population projections by the INE

Two levels will be established within each degree of dependency, in accordance with a person's autonomy and the intensity of the care needed.

Recognition of dependency will be done upon official request by citizens, who will be able to be assessed by the corresponding organs of each autonomous community as of 2007.

In conclusion, with this law, people in situations of dependency will be able to access direct aid or social services that will be paid based on their income.

RECOMMENDATIONS TO LOWER THE VULNERABILITY OF PEOPLE IN SITUATIONS OF DEPENDENCY

PREVENTION

We understand that not only should situations of dependency be considered, but so should the risks of such situations. This would lead to the examination of primary, secondary and tertiary prevention of illnesses and traumatisms, deficiencies and functional dependency. Moreover, we would like to most especially stress the importance of the participation of the interested-parties and informal actors in these preventive conducts and tasks.

Therefore, we briefly present some data on the effects of preventive interventions in regards to the issue of dependency. Many of the projects and initiatives within the bounds of the concept of healthy aging, constitute adequate strategies to prevent or slow down situations of dependency, working on physical as well as cognitive, emotional and social aspects.

a. Healthy Habits

Older people that have healthy habits show four times less dependency than those who smoke, drink in excess, do not exercise or are obese. Moreover, in people with healthy habits, if dependency does finally appear, it is postponed by 7.7 years.

Regular physical exercise lowers mortality by 30% and is a factor of protection against cognitive deterioration.

b. Cognitive Functioning

A higher frequency of cognitive activity in daily life is associated with more or less a decrease in 19% of the annual rate of cognitive deterioration and is considered an undeniable factor of protection against dementia. The effects of cognitive exercises are of an equal importance to that of the expected decline in healthy people (without dementia), which is estimated to be between 7 and 14 years. Memory exercises cause 0.75 standard deviations both in memory tests and in subjective perception.

Cognitive stimulation is a widely used tool in terms of the devices used to assist dependent people.

c. Emotional Functioning

Positive affection lowers the probability of morbility and mortality (in such instances as cerebral-vascular accidents, coronary problems, etc.). The activation of positive emotions is associated with positive changes in the cardiovascular, endocrine and immune systems. On the other hand, positive self-stereotypes, as compared to negative ones, increase health and longevity by 7.5 years. All in all, positive attitudes towards life are protections against fragility in the aged.

Just as strengthening the self-esteem of aged people is important, so too is battling against age discrimination; that is, the "ageism", which is so present in today's societies that associate aging to deterioration, inactivity, pensioners and economic problems.

d. Social Participation and Involvement

Social ties are not only essential for the well-being of aged people, but have a predominant role in their health and longevity. People with broad social support networks are at 50% less risk of mortality than those with fewer support networks. Socially-involved aged people have a lesser probability of becoming disabled or dependent. The most active people show less prevalence of disability.

Social support and the maintenance of social networks is one of the most secure guarantees in terms of fighting against dependency. All of the projects and strategies that are focused on building social links and on getting the affected people to participate in their communities should be prioritized when it comes to the issue of dependency. Another segment of people to which we should pay attention when we deal with issues

like isolation and loneliness is that of the caregivers, whose social networks shrink as a result of the role that they carry out. Services that give caregivers a break and provide substitutions, self-help devices; training in the area of care, psychological support, etc. and the promotion of a social network are all absolutely essential.[ii]

NEED FOR TRAINING AND PROFESSIONAL RECOGNITION

The Law for the Promotion of Personal Autonomy and Assistance to People in Situations of Dependency (Law of Personal Autonomy and Assistance to People in Situations of Dependency), whose plan was approved by the government on April 21st of this year (2006), constitutes a new point of inflexion for social policies and is already known as the fourth pillar of the Welfare State.

From our perspective, the fact that it has been defined and structured as a right of all citizens who cannot take care of themselves regardless of the reason, is of enormous importance.

As a result, it is of an individual nature, is public and has unrestricted access; and all of the administrations (state, autonomous and municipal) participate in its application and, in essence, it is constitutional.

The road through the Cortes (Spain's bicameral legislature) appears to mark its coming into force for 2007, which makes it necessary to begin facilitating it's the Law's feasibility. As such, the creation of a National System for Dependency is obviously key, which would develop at the territorial level a network (for public use) that integrates – in a coordinated manner – public and private centers and services.

We would like to express that our clear determination for change means facilitating the application of the White Book and providing a response, implementing the technical application structures so that there are no problems in the implementation of this Law.

Within this great responsibility, there is a mandated need for training at three levels to guarantee the ability and quality of the participating human resources in regards to the fulfillment and application of this Law. In our opinion, the training and quality pair, is a clear indicator for the improved quality of life of people in situations of dependency.

- Training of highly qualified, specialized professionals;
- Training of professionals in the attention, assistance and care of citizens in situations of dependency; and
- Training and capacity-building of personnel for services and personal assistance.

As is the case in almost all social aspects and characteristics, changes are elements of daily life and it is through our adaptation to and confrontation of these changes that the

instruments and structures emerge that should be incorporated in order to respond to the new social demands.

Normally, social structures progress much slower than everyday social change, but the ultimate outcome is that the social structures cannot help but to accept the experience of their initiatives and regulate them so that they are recognized within the systems and services that we provide ourselves.

a. Training of highly qualified, specialized professionals

We find that a specialization course for highly qualified professionals – based on an application of homogeneous and uniform criteria as tools of assessment for the condition of a person in a situation of dependency in each in every citizen who has the right to solicit it – is a guarantee for the feasibility of the Law of Personal Autonomy and Assistance to People in Situations of Dependency and a security for the next administration for the resources made available to people in situations of dependency. That is, a course that will guarantee fairness, transparency and – above all – the use of a methodology that does not depend expressly on the subjective conclusions made by the evaluator.

This is the starting point and an essential condition in the application of this Law of Personal Autonomy and Assistance to People in Situations of Dependency, given that it deals with making a determination, from a technical profile, about the conditions and the intensity in which a citizen's Dependency falls within the law. We are talking about the professional Evaluator of dependency, who we must understand as both an Assessment and Training instrument, at the same time, and to whom we should indeed refer the possible beneficiaries.

The starting point for the initiation of a training process for trainers and the specialization of those who make the assessments is being able to rely upon a professionalized, critical group so that the established timeframes for the application of this law can be met.

b. Training of professionals in the attention, assistance and care of citizens in situations of dependency.

At this second level, we believe that a homogenous profile in the training of professionals who provide attention, assistance and care for dependency is now an inexorable condition. This profile must take into consideration the experiences of all of the movements that – because of their novelty or collateral effects, or simply because they are "sufferers" of the problem – have been being developed as the conditions of dependency among the citizens of our society have grown.

That is, this means simply offering the person in a situation of dependency a professional who has a homogenous and uniform profile, and that the person who coordinates the actions taken by different professionals who apply different instruments

and techniques, should be a common reference point for the dependent person and his/her family.

The objectives should be aimed at: equipping with some theoretical and practical knowledge all people who are involved in some way with conditions of dependency and who constitute a social group that has not received this attention. In essence, this implies that we consider modifying the new profile of the worker dedicated to dependency – who is therefore a professional in that area – in order to facilitate the professional intervention in the specific and, mostly, territorial application of the dependency system.

c. Training and capacity-building of personnel for services and personal assistance.

This level takes into consideration perfectly the evolution of the family structure and it most definitely unites in solidarity with the condition of the person close to the dependent person, who is indirectly affected; or the informal caregiver who is generally a direct family member and, in the majority of cases, a woman.

We find it necessary to ensure that the feelings of both the caregiver and the person in a situation of dependency are brought to light. Socially speaking, it is safe to say that the responsibility of caring for a person in a situation of dependency is generally taken by the family and this is precisely even more likely the deeper or more intense the dependency; this situation, which we take as something natural, is not in itself a stable or settled situation; rather it is unstable and tense.

The reasons are easy to understand and clearly expressive: it is impossible to dedicate to anything else the time that we dedicate to the situation of dependency; therefore, the quality of life is worse, the person has less incentives to carry out his/her responsibilities and this negatively affects the caregiver's efficiency.

Burn-out can lead to unsettled behavior and, to some extent, belligerence towards the personnel of the resources directed at the disability and dependency.

The professionalization, training of caregivers and investment in human and material resources are ideal ways to combat this conflict.

Besides, it is important to recognize the conflict between personal perceptions, especially regarding the time between the person in a situation of dependency and the informal caregiver.

Let's take an example of a problem: a skeletal muscle injury, with immobility or severe difficulty of movement. The person in a situation of dependency has an evident difficulty in terms of movement, which makes its absolutely necessary to have someone change his/her bodily position. Now let us imagine a room with a person in a situation of dependency laid up in bed or seated on a sofa and the caregiver is asleep or deep in

his/her own thoughts. The need arises for the dependent person's position to be changed; he/she bears the situation, waiting for the caregiver to wake up or for some kind of magical circumstance to occur that would change the situation; however, this does not happen and when the person in a situation of dependency cannot stand it any longer he/she requests the change and the caregiver who receives this information, at that moment, perceives it as an order, without taking into consideration the situation that the other person was in.

This is demonstrative of a clear conflict in perceptions that is crying out for and demanding his/her rightful professionalized attention, which in this case could be taken on by the family member him/herself with the right training, along with the corresponding economic and social recognition. It is therefore necessary to resolve the technical assistance in the facilitation and adaptation of the personal cases to the demands of the dependency.

The essential and fundamental aim is the academic and institutional recognition of the daily activity, the day-to-day activity carried out by what we have called the indirectly affected-person, immediate family member or informal caregiver of the person in a situation of dependency, with the explicit requirement of carrying out this recognition after the completion of a capacity-building course that addresses the caregiver's conduct and habits and adjusts them to the needs of a person in a situation of dependency, which is also the common denominator for the acceptance of the reinforcement and economic compensation or the benefits and provisions stipulated in the law.

The term "caregiver" is not the most appropriate, as it is not generally applied, since the majority of people with disabilities to whom this law should be applied are capable of caring for themselves, and what they really need are "personal assistants" to carry out certain activities.

NEW TECHNOLOGIES FOR INDEPENDENT LIVING

Information and Communication Technologies (ICTs) have developed rapidly in recent years. Undoubtedly, this progress has had a huge impact on people's daily lives. With the New Technologies (NTs), a person's capacity to be informed, communicate and access services has increased. In this regard, the ICTs constitute a huge opportunity in terms of supporting the independent lifestyle, accessibility and integration of people with disabilities.

According to the e-Accessibility Initiative, "the use of Information and Communication Technologies is quickly turning into an essential part of the economic, educational and social life of European citizens. There is a concern about the full accessibility to new products and services, especially for aged and disabled people. At the same time, the ICTs provide enormous potential to help these groups maintain and improve their quality of lives, integration and independence." [e-Accessibility, 2002].

In the above paragraph, proposed by the European Commission in 2002, two key ideas are established in the relationship between new technologies and the disabled:

Accessibility to the ICTs: As full-fledged citizens, people with disabilities must have access to technologies, products and services of the Information Society.

The ICTs as Support for an Independent Life: Because of their huge potential, the ICTs can be used in the design, development and supply of support services towards the independent lives of disabled persons. The following stand out because of their importance:

Automation;
Tele-assistance; and
Mobile and cordless communications

Accessibility of the ICTs

The ICTs have a growing importance in today's world, since they gain increasing influence in the different aspects of people's lives, as they are currently used in a widespread manner both in the workplace and as en element in daily life as well as for fun.

The number of services is increasingly larger, including those – provided by both public and private entities – that users access through terminals or ICT services. Moreover, it is not uncommon that some of these service that were traditionally offered in person, are now provided only via the Internet, over the telephone or through vending machines.

However, it is indeed true that a great deal of people cannot, for various reasons, access these services. The reasons may include any of the following:

Geographical limitations on availability. There are parts of the planet in which electronic services are simply not offered. For instance, mobile phone – or even landline – services suffer from considerable delays in rural areas that have low population densities, as compared to urban areas in which services are beginning to be provided with greater speed.

Gender aspects: Women have had traditionally greater difficulties in accessing the new technology services. This difference, which tends to have disappeared in today's world, still exists in those countries in which there is a culture, and especially a religion, that consider women inferior to men.

Age: The aged usually use the new technologies to a lesser extent than the younger and middle-aged population.

Socio-economic differences: Citing an example to illustrate this circumstance, half of the world's population has never made a telephone call.

Functional limitations: People that have some type of disability have various kinds of problems in regards to accessing products and services of the information society.

Of the aforementioned limiting factors, it can be said that the first three (geographic location, gender and age) have been losing their relevance little by little. In regards to the latter two (socio-economic differences and disability), they seem to involve more powerful limitations that are structural in nature, which must be confronted with more comprehensive resources.

Evidently, new technologies have provided a clear support for people with disabilities so that they can achieve greater autonomy by gaining independence despite the ongoing need for personal assistance. People with disabilities still confront, however, a great deal of problems as users of the products and services of the information system in the European Union [EC,2005]:

- Lack of harmony in services. For instance, lack of access to emergency 112 services in many member states.
- Lack of interoperability of existing solutions for ICT accessibility.
- Existence of commercial software that is not compatible with technical devices, like digital monitors that are often impossible to use with the newer versions of operating systems.
- Interference between widely used products and technical devices, as in the case of GSM mobile telephones and hearing aids.
- Absence of applicable standards throughout the Union, as proven by the existence of up to seven different kinds of text-telephones for people with hearing impairments.
- Lack of adequate services, as shown by the abundance of highly complex, official websites, which limit the access of those who have cognitive limitations.
- Absence of products and services for certain user groups, like telephone communication for users that communicate through sign language.
- Physical design that makes usage difficult, as occurs in the overwhelming majority of mobile telephone models that have increasingly smaller keyboards.
- Limitation on the supply of availability, price and quality of services that are ICT accessible.

Some of these problems can be solved by the technology itself. In this regard, for instance, some Bluetooth devices have emerged that allow mobile phone communication without interference from hearing aids.

On the other hand, the widespread use of email and SMS has allowed text-messaging communication to be done by a hearing impaired person in a text telephone, or even more interactive tools like chats and their gradual integration into mobile devices that make it possible for a fluid communication to be assimilated into a telephone conversation. Moreover, the arrival of broadband will facilitate video transmission, something that is necessary for sign language communication.

Finally, "Design for All" integration standards have emerged, like W3C, which provides design guidelines to facilitate disabled people's access to new technologies.

Nevertheless, there is still much road to be covered for the complete adaptation of technology to people (and not people to technology), in such a way so that it constitutes an element of integration instead of creating new barriers.

THE ICTS AS AN ELEMENT OF SUPPORT FOR INDEPENDENT LIVING

As mentioned earlier, the ICTs could facilitate dependent people's autonomy and integration. The spectrum of new technologies is immense; however, in this report, a general overview – classifying them by technology – is provided below about what they could provide.

Domotics

Technological development, related above all to Information and Communication Technologies (ICTs), facilitates a change in paradigm that is taking place today in the provision of social and health care services.

The services that have been traditionally provided in nursing homes and hospitals, will gradually begin to get closer to other more common environments of people's daily lives, like the health care centers or their own homes.

One example involves the technological platforms of digital homes. These platforms constitute an instrument of accessibility that makes it possible to prevent, compensate, mitigate or neutralize functional limitations, thereby contributing to greater personal autonomy and quality of life by facilitating access to domestic devices and to external assistance-oriented resources [ICTSB, 2000]. From a perspective of support for independent life, it can be said that generically, these platforms integrate four types of services: environment control, personal monitoring and management of both alarms and communication [ETSI, 2005]:

Environment control services. Environment control services allow home applications and devices to be controlled by users according to their abilities and preferences. Aged people and those with disabilities encounter numerous difficulties when they attempt to use home devices, as it is common that these items are not adapted to their physical, sensory or cognitive abilities. The use of environment control services can be considered a key element in the naturalization of one's relationship with his/her home environment.

An example of its use: a woman with functional limitations is in her home and would like to lower the blinds. By means of voice interaction with the automated platform, she activates the order "Lower the blinds." In an instant, the motorized blinds of her home are lowered and the automated system tells the woman that the action is taking place.

Information and Communication. Information, communication and educational services play a role of growing importance in the provision of health care services. With the technical development that currently provides continuous access to broadband networks, the vision of a world in which the ICT resources that surround us improve the quality of our lives, is more realistic than ever, and promises very interesting services in the field of prevention and communication assistance.

Personal monitoring. Personal monitoring services are divided into two general areas: physiological monitoring and monitoring of daily activities. Typically, physiological monitoring requires that the client uses a sensor in order to measure one or more physiological parameters that will be stored either locally or remotely in an electronic file on the patient. Monitoring of daily activities is usually based on the use of sensors that are placed throughout the client's home environment, and the events that are detected have to do with his/her activity like, for instance, falls, unexpected departures from the home, etc.

An example of its use: an aged man has a sensor to detect falls that he comfortably carries with him in his usual clothes. Suddenly, he trips on the rug and falls down. This situation is detected by the sensor, which sends a signal to the management system that automatically tries to get in touch with the aged man in order to ensure that he is in perfect shape. If no response is received from the gentleman, the management center would send some type of assistance to his home to verify his state of health.

Management of home alarms. This refers to monitoring based on ICTs and control parameters of the environment that are related to the general well-being of those people that need care. Some examples are the home monitoring systems as a means of protecting the inhabitants from accidents (gas leaks, floods, fire, etc.) and anti-theft alarms.

An example of its use: an aged woman is in her kitchen preparing dinner for herself. At that moment, her usual television program begins and she goes to the living room, forgetting to turn off the gas. The gas sensor installed in her home, detects the leak and automatically the home platform turns off the supply of gas. At the same time, an alarm goes off both in the home and in the management center, which gets in touch with the woman to make sure that she is fine.

Tele-Assistance

Home assistance, today, is inconceivable without the support of ICTs. In an increasingly aged society, home-based tele-assistance services take on vital importance. Currently, this assistance is a public service; under the Law of Personal Autonomy it is

a right. In 2004, the number of people that benefited from this service was about 150,000 people, approximately 20 times more than ten years ago.

Tele-assistance is a service that provides assistance through the ICTs with the help of actual personnel in response to immediate emergency situations, or those involving insecurity, loneliness or isolation. Its main characteristic is that it makes immediate assistance possible when it is needed. In this regard, it is possible for users to stay in their usual surroundings in a safe environment, increasing their autonomy, independence and quality of life.

Fixed Tele-Assistance

Traditional tele-assistance systems are based on a small user device, like a necklace or a bracelet, which includes an alarm button that, when pressed, dispatches a call to the Assistance Center via the telephone line. The Assistance Center then assesses the actions that are to be followed in each case.

Mobile Tele-Assistance

The biggest problem that the fixed tele-assistance services have is that they only provide security inside the home. This inconvenience has been resolved with the growth of the Global System for Mobile (GSM) communication and the adoption of Global Positioning Subsystems (GPS). Thus, mobile tele-assistance emerged that provides a clear advantage over the traditional system: people's mobility. Mobile tele-assistance is based on a device with an integrated GPS and GSM antenna and is characterized by how simple and easy it is to use. The dynamic of this service is that by pressing the alarm button, the device dispatches a call to the Contact or Assistance Center, while simultaneously also sending the user's location coordinates, which were made available by the GPS.

In this manner, people can have complete mobility, freedom and autonomy, without diminishing their security.

Tele-Assistance with Additional Services

The trend in tele-assistance is to complement reactive services – in which location and assistance are provided – with proactive services that are more oriented towards prevention.

As such, automation and tele-assistance complement each other to produce a system that focuses on the user, which can integrate:

- Passive security for control over fires, gas leaks, floods, etc.
- Access to details and information about leisure activities, transportation, public services, etc., which encourage social participation.

- Access to details and information about healthy habits, nutrition, hygiene, prevention, etc.

Tele-Assistance integrated into Environmental Intelligence

Environmental Intelligence is a term that is gaining importance. Environmental Intelligence systems are characterized by their ubiquity, transparency and intelligence. The devices and computers of this technology fade into the background, while the individuals find themselves surrounded by intelligent and intuitive interfaces that are integrated into all kinds of daily objects. It is based on the following three fundamental technologies:

Ubiquitous computing, encouraged by the progressive miniaturization of processors and the increase in their offerings, which makes it possible for increasingly powerful machines to be integrated almost invisibly into any element of the environment.
Intelligent interfaces, with multi-mode entrances and exits, which make natural interaction with the technology possible.

Ubiquitous communication, encouraged by the huge development of mobile and cordless communications.

Mobile and Cordless Communications

There is no doubt that mobile communications have had an extraordinary influence over people's lives. A large number of activities that traditionally required the physical displacement of people has now been substituted by electronic means. Moreover, mobile communications represent a very important potential for applications in regards to helping people to overcome the barriers and mobility limitations that they face.

In this regard, the advantages that mobile and cordless communications provide are unquestionable [TICD-DD, 2005]:

For people with disabilities or in a situation of dependency, mobile communications represent a fundamental means of integration into the working, economic and social world.

The mobile telephone, with more than 100 percent penetration in Spain, constitutes a ubiquitous platform of personal services, accentuated by its increasingly broader multimedia and computing capacities.

Cordless, short-range networks (Bluetooth, Zigbee, UWB, RFID) allow a multiple-device connection that is capable of sending information, which is relevant for a large array of services.

These technologies are what make the sensory networks possible, which are essential for the automation and environmental intelligence environments that contribute so much to people's autonomy.

The Role of Companies

In principle, companies, due to their objectives, are not active agents in terms of the Law of Personal Autonomy and Assistance to People in Situations of Dependency, which falls in the realms of the relationship between the public administration and society, in general. However, and from a new paradigm that makes companies a new social agent (social corporate responsibility, SCR) that is not only oriented towards making a profit, there are aspects in which companies can have an influence on lowering people's level of dependency and increasing their degrees of autonomy.

In this sense, some lines of action are proposed that companies can develop from the private sector, which follow the same lines as the objectives of the new law.

***Policy of Social Benefits*.** Along these very lines and within company social benefits policies it is expected that along with contracting private health insurance, charged to both the company and the worker, the same will eventually apply for dependency insurance, currently a scarce practice that will be developed in the future.

Establishing flexible work methods

Schedules: Both for a person in a situation of dependency, who will be able to continue working in accordance with his/her particular physical or mental limitations (schedules…) and for the caregiver, especially family, who will be able to carry out his/her supportive role towards the person in a situation of dependency if he/she has flexible work hours, works from home (virtual jobs, shortened work week, part-time jobs…). Work-family policies have a direct bearing on this objective.

Functional: Taking into consideration certain physical or cognitive limitations, a company can adapt a person's job to the possibilities of his/her new situation without lowering productivity and in accordance with labor laws and social security norms.

Progressive retirements: While it is still not a widespread practice, it is expected to be developed in the future; that is, the legal possibility to gradually leave a job in accordance to the needs of both the company and the employee. This flexibility could eventually have an indirect bearing on the constriction of morbility because it involves the prolonging of physical and emotional activity.

***Prevention of Occupational Risks*.** This has a direct bearing on the accident rate and consequently on the generation of situations of dependency and limitations on both physical and mental autonomy.

***Creating Accessible Environments*.** The certification of work spaces as accessible environments will make people's (employees) autonomy possible, especially those with physical limitations. Accessibility ranges from physical space (certification UNE 170001-1) to technological accessibility (telephones, Internet, etc). to increase autonomy.

***Design of Products and Services*:** The increase in people with limitations has led to the promotion of the philosophy, "Design for All" under the paradigm that what can be helpful to a disabled person will also be helpful to a person who does not have problems of autonomy. Moreover, the increase in the number of people in need of assistance will make the products and services profitable and not only respond to a social action approach.

***Technological Advances*:** In accordance with the aforementioned point, the ICTs can make big advances possible in terms of autonomy, especially in communication, personal life management systems (automation) and mobility systems.

***Promoting a Healthy Environment*:** According to studies on prevention, a healthy environment will produce a constriction on morbility with concrete actions: encouraging the practice of sports (delaying physical dependency), social networks (emotional) and mental activity (cognitive). In this regard, what stands out is the promotion of physical activity through clubs, social participation in associations and the definition of "enriched" posts.

***Social Action*:** The progressive spread of volunteer programs in companies in many cases already makes assistance and help for people in situations of dependency possible. This trend is expected to increase through cooperation with the Administration in attending to the aged, disabled, etc. and encouragement of personal autonomy.

***Preparation for Retirement*:** Companies can establish programs as part of their social action with their own employees, by preparing them for the new phase of life in aspects such as health care, lifestyle, emotional relationships, financial and economic information, etc. and associations with former employees.

PROPOSALS

1. We believe it would be useful to have the possibility of an advisory service so that, when faced with certain situations, affected people can make inquiries in order to make the most appropriate decision, at the most appropriate time. We believe it would be useful to have intervention teams for critical situations that unexpectedly arise in the attention, assistance and care of people in situations of dependency.

2. We also believe it would be very useful to give more importance to associations of disabled people and those who are in situations of dependency, as well as entities that work with dependent people, since they know the general problems of the sector and the

specific problems of the particular condition. Moreover, they should be institutions that are prepared to offer clear and concise information to the beneficiaries.

3. It is important to pay close attention to the employment and protection pair, in regards to situations of dependency. Many people are currently acting as caregivers in the black market and do not have the proper training or, as the case may be, do not have a certification of their abilities. The law opens a framework that would allow them to enter the legal job market.

4. Safeguard gender equality. We cannot continue to insist on a model to lower vulnerability that is based on the overloading/overburdening of women.

5. We believe that the unequal distribution of the population and of services throughout the national territory invalidates the very models that are aimed at providing assistance in both the urban and rural settings. Therefore, models need to be devised and developed that ensure that the rights of citizens in situations of dependency who reside in rural areas are just as effective as those for the urban centers.

6. To avoid situations of compartmentalization and/or a lack of adequate development of the various regulations in a field that is clearly multidisciplinary and inter-institutional, with the risk of increasing the vulnerability that it could bring with it, it appears we need to increase coordination among institutions and harmonize legislations both at the local and the national levels. A shared vision should be reached and protection of situations of dependency should be approached from an integrative, synergistic and standardized point of view.

7. A consensus should be reached on the criteria related to the new technologies and technical aids that focus on the user.

8. Raising social awareness of the aspects related to this Law, through educational training, will guarantee the acceptance of the principles that inspired it, by all citizens so that new generations arrive with the "lesson learned."

9. Use of the ICTs for support in situations of vulnerability, taking into account the opinion of the ultimate users in their decisions.

10. We propose the creation of some quality control mechanisms of the services offered, which would involve the participation of state, autonomous and municipal institutions in addition to the user, his/her family and the associations of professionals in the attention, assistance and care of people in situations of dependency.

CONCLUSIONS

The need for the display of a framework of rights to lower vulnerability. The need to deepen the development of models of action that firmly set out the principles of

subjective rights, universality, equity, solidarity and proximity, without having budgetary circumstances limit the scope of these rights.

The necessary regulation of the rights of disabled people who are institutionalized. Disabled people who are in institutions find themselves in an objective situation of vulnerability insofar as their human rights are concerned. Institutionalized, disabled people need to have their rights guaranteed. The institutions that receive people with disabilities most definitely have to be spaces that are permeable to human rights, to which the institutionalized person is entitled. As long as there are "closed" establishments, the protection regime for people taken into them should be of the utmost priority.

The need to prevent "territorial inequality," with the presentation of the legal framework that guarantees these principles. The need for a basic governmental law of social services, in which the basic elements of the social services laws of the Autonomous Communities are listed.

The need to consolidate the model in the Autonomous Communities before carrying it down to the local level. While it is true that lowering vulnerability occurs with local actions, the model must first be established at the autonomous level in order to have it later spread locally.

Intensifying and consolidating the coordination between the social and health sectors. People with dependencies have a need for resources of both a social and a health-related nature. Currently, each system "works on its own;" in fact, in the bill of this Law, there is hardly any reference to the health care sector. Coordination should be encouraged.

The need to deepen the consideration of the situation of dependency and personal autonomy as a cross-cutting factor of other policies. Policies aimed at lowering dependency and promoting personal autonomy should be present in policies on housing, culture, pensions, education, etc.

The assessment of personal autonomy and dependency should include a comprehensive, individualized and cross-disciplinary **Care Plan,** in which the person that requires the long-term care as well as his/her family or caregiver all participate.

Services that allow people **to stay in their homes** and their surroundings should be prioritized.

If the option chosen is the provision of services, **these services should be arranged in a flexible manner**, adapting to the needs of the recipient as well as those of his/her care-giving family and not the other way around.

If the option chosen in terms of assistance and care, is through the family, we find the following necessary:

- Preparation of a Charter of caregivers and personal assistants;
- An assessment of the degree of the caregiver or personal assistant's load of work;
- Legal regulation on behalf of caregivers and personal assistants; and
- Provision of services to caregivers and personal assistants: training, prevention of occupational risks and injuries.

GENERAL CONCLUSION

We, the professionals and experts that work with and for people with disabilities and in situations of dependency, are convinced of the need to involve the affected people in the fight for social inclusion. Therefore, assistance for personal autonomy and for the condition of dependency should be considered an unwaiverable right of citizens, while recognizing the valuable social progress that the Law for the Promotion of Personal Autonomy and Assistance to People in Situations of Dependency and their Families signifies.

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[i] Panel Coordinator: Gregorio Gómez-Jarabo, Professor of Psycho-Biology. Director of the Masters program in the Assessment of Disabilities and Occupational Handicap. Universidad Autónoma de Madrid (UAM). Assistant: Sara Olavarrieta. Psychologist. Master in the Assessment of Disabilities. Universidad Autónoma de Madrid (UAM). Experts: Francisco Rodríguez Santos and Cristina Vera, *Asociación UnoMás*: Association of Experts on the Study of Handicaps; Catalina Alcaraz Escribano, Department for the Aged – Spanish Red Cross; Demetrio Casado. Director of the Seminary on Social Intervention and Policy (SIPOSO); Elena Cruz, ONCE Foundation; Estela Conde, Expert on Disability and Technology, Universidad Politécnica de Madrid; Javier Albor, Federation of Organizations on behalf of People with Intellectual Disabilities (FEAPS National); Luis Gangoiti, Medical Director of State Assistance Center for Brain Damage (CEADAC-IMSERSO); Miguel Querejeta González, Assessment Doctor of the Assessment and Orientation Team of Disabled People from the Social Policy Department of the Autonomous Delegation of Gipuzkoa; Rocío Fernández-Ballesteros, Professor of Personality and Treatment at UAM and expert on geriatrics; Roser Romero, State Coordinating Confederation of the Physically Handicapped of Spain (COCEMFE). With the collaboration of: María Fernanda Ayán San José, Director of Assistance Programming and Coordination of la Obra Social Caja Madrid; Antonio Fuertes Zurita, Corporate University, Development and Alliances of Unión FENOSA; María Puerto Asensio, Fundación Vodafone; and Susana Gende Feely, Department of Social Intervention of the Spanish Red Cross.

[ii] There are many sources of information available regarding issues about healthy aging and support for the immediate caregiver. Please also consult the website www.sercuidador.org for further information.