

# DACTIVE

disability and active citizenship

## RESEARCH REPORT

*study of relational aspects as factors  
that can affect the quality of life of  
people with disabilities*

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# 1 INTRODUCTION

## **1.1 Summary of the project**

DACTIVE project aims to promote active citizenship and learning at a particular type of adults at high risk of exclusion: people with intellectual disabilities.

Project partners (institutional and private), lending their services, identified the following issues with respect to the target:

- the difficulty to realize interventions for developing key competencies and expertise (in developing the information, recommendations of the European Council, Lisbon and Barcelona Conference)
- the difficulty in identifying methods recognized in Europe that encourage concretely the development of indispensable competencies necessary for the exercise of active citizenship and for search for quality employment

To meet these needs, DActive aims to create and test tools and application models of multi-dimensional and integrated intervention in education and training, from an instrument previously used in clinical and social: I' International Classification of Functioning, Disability and Health, known as ICF (WHO recommended).

## **1.2 Output main**

Creation and testing of:

- an handbook and a model course for training educators in the implementation of measures for the development of active citizenship of persons with disabilities
- an handbook and a course model used by trained educators in interventions with persons with disabilities
- an online learning platform for the acquisition of tools, collection and comparison of research data

## **1.3 Expected impact**

- Implementation of intervention and recognized models usable in Europe
- The use of the models created in the work of education and training and for operations planning, research and comparison between different European countries

In respect to persons with intellectual disabilities and their families:

- improving the quality of life
- development of opportunities to exercise their right to active citizenship
- realization of the objectives of the European Council

***We constantly keep in mind the thoughts, perceptions and emotions caused by pain in order to become aware of our individual convictions and assumptions. This is important to arrive at a better understanding of the disabled and to find a sense in their lives.***

#### **1.4 Aims and objectives of the project DActive**

The general objectives include:

- developing alternative learning approaches to integrate marginalized and disadvantaged (particularly persons with intellectual disabilities) in society and the labor market
- the development of systems to share good practices in education of persons with disabilities
- the promotion of learning opportunities based on participation in activities within the local community

Specific objectives:

- creating and testing application models, working tools, models of training course that can develop opportunities for people with intellectual disabilities in exercising their right to active citizenship
- make the models and tools, reproducible and usable in Europe for professionals, educators, public and private bodies of training and education for families and associations and for persons with disabilities

These objectives will be realized into two experimental phases harmonically related in a interventions system:

- an action research conducted with the benchmarks of the ICF in 5 countries on samples already determined for the clear and uniform assessment of the situation departure of the target
- the drafting of guidelines for the testing of the ICF according to the criteria and guidelines of the European Council
- the first phase of experimentation
- implementing a model of courses for educators working with the target
- the second phase of experimentation
- implementing a model of course for persons with disabilities and conducted by trained operators
- the dissemination of tools and models

#### **1.5 Aims of the Research (Wp2)**

In light of the purpose of the project DActive which is to promote active citizenship of people with disabilities, the main objective of the research (WP2) is characterized by the use of tools that allow

to "take a picture" of science-based provided not only the subject of disability but also to family, social and environmental context in which it is inserted.

The innovation of the project is in the study of relational aspects as factors that can affect the quality of life of people with disabilities. Environmental factors also may affect the accessibility of resources, their availability constant or variable and their quality good / bad.

The quality of life, understood as satisfaction with their position within the context of belonging on which may affect the socio - environmental factors, is taken as a variable to assess the effectiveness of which will be built in the later stages of the project.

The relational aspects, especially as understood in the attitudes of family and operators, and emotional aspects of the relationship between CR and CG are considered as facilitators or barriers to inclusion and integration into the working world of people with disabilities, who also will compete with the relational dynamics within the working environment that will be able to manage adequately.

An important objective of phase DActive WP2 of the project is the collection of information according to which:

- produce guidelines for the construction of the Catalogue of Criteria based on which will be organized and implemented courses for educators and people with disabilities, involving in particular aspects of a socio-environmental
- produce guidelines for the selection of 10 subjects for the phase WP7

In reference to such claims is hoped the construction of tools and application models that enable European wide development of skills for the proactive search of quality working position and self-empowerment, in line with EU objectives in the field of active citizenship.

### ***1.6 Hypothesis of the Research (WP2)***

- Assessment of the relationship between CG and CR in terms of facilitation of attitudes, and relational aspects of intra-psycho dynamics in the path of promoting active citizenship
- Using the ICF classification to refine the homogeneity of the sample of CR
- Use the Quality of Life as a parameter to assess the impact of the project and as a supplementary tool in the analysis of the processes of education, training and rehabilitation

## 2 STATE OF THE ART ON DISABILITY IN EUROPE

### 2.1 State of the art in Austria

In order to be able to give an overview of the legislative framework on disability in Austria, it is necessary to provide the reader with some basic information on the legal system of Austria per se. The Republic of Austria comprises nine federal states and every single one of them has its own Land Constitution that, of course, has to be in line with the Austrian Constitution itself. Hence, in addition to all the national (federal) laws which are valid for the whole country, there are 9 different federal state laws on many fields of law. *Disability* is one of these. Nevertheless, Article 7 para. 1 of the Federal Constitution has to be mentioned as a fundamental legal guideline so to say:

**All citizens are equal before the law. Privileges due to birth, gender, status, class or religion are unacceptable. Nobody may be discriminated against because of his or her disability. The Republic (federal government, Länder and local authorities) commits itself to guaranteeing the equal treatment of disabled and non-disabled persons in all fields of everyday life (bmask 2011: 2).**

There are three important laws dealing with disability on the federal level: The Federal Disability Equality Act (BGStG), the Disability Employment Act (BEinstG) as well as the Disability Act (BBG). These three laws are also called Disability Equality Package and date back to 2005. The purpose of the aforementioned laws is to end discrimination against people with disabilities (and their relatives, partners) in every day life as well as in the employment sector on the one hand, and to support their participation in society on the other hand (e.g. by taking positive actions) (cf. bmask 2011: 2-3).

But, as has already been mentioned before, the nine Länder have the legal power to enact their own laws, too, which is the case concerning those on disability. Even the term *disability* itself is defined differently in the single Länder (cf. Steingruber 2000: 46f.).

Since discussing all the federal state laws in particular would definitely go beyond the scope of this overview, the reader will be provided with only the most important as well as most common examples of services people with disabilities can apply for in Austria in the following: Sheltered workshops, job coaching, personal assistance, clearing, housing (full time as well as part time support), training apartments, mobile support, counselling, diagnostics and increased family allowances (cf. bmask 2009: 132f.; bmask 2011: 28; Buchner 2011; Steingruber 2000: 47).

At this point it already becomes clear that the quantity of different laws and jurisdictions thereof can be quite confusing. For this reason one can find a figure on the organisational structure of the disability policy in Austria below helping to ensure comprehensibility.

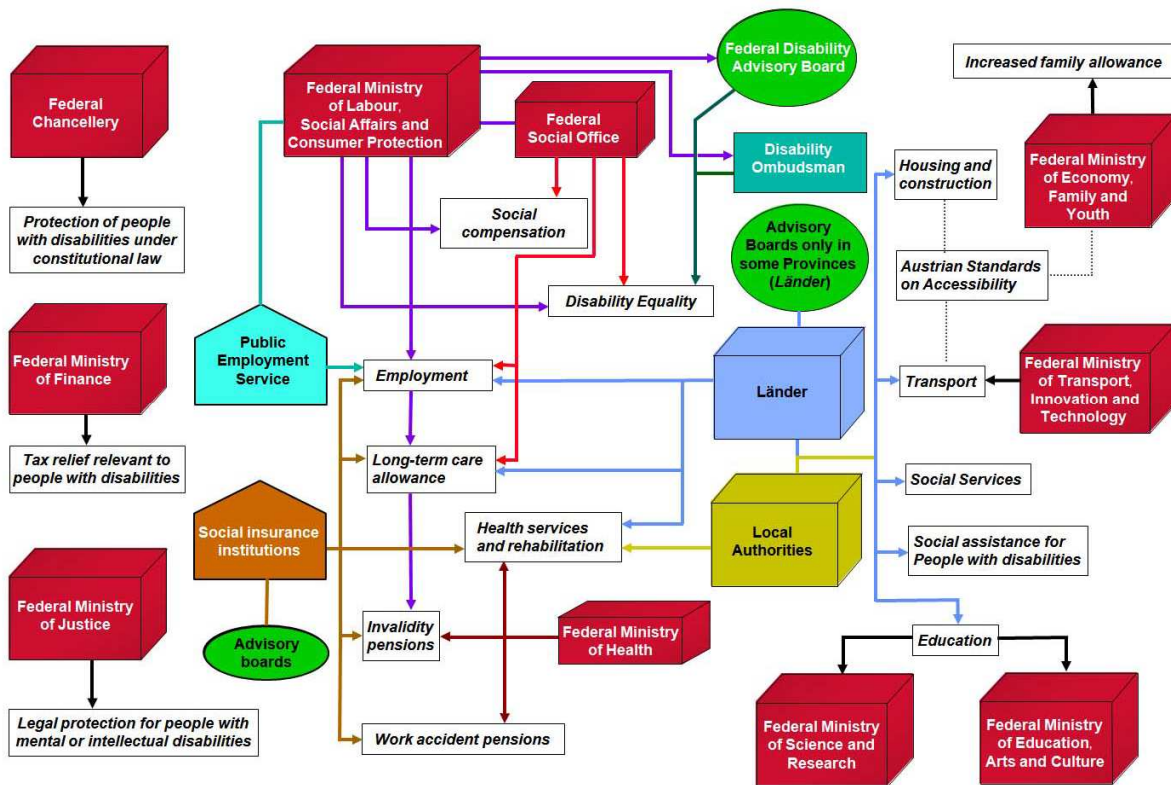


Figure 1: Organisational Structure of Disability Policy in Austria (bmask 2011: 3)

According to a survey conducted by Statistik Austria in 2007/2008 the number of Austrians who experienced a limitation of some sort during at least six months while carrying out daily work was 20,5% which equals 1,7 m. people. The aforementioned limitations were inquired with regard to the following domains: visual problems (even when using glasses, contact lenses or other visual aids), hearing problems (even when using hearing aids or having cochlear implants), problems with speaking, mobility problems, mental retardation/learning disabilities, mental health problems, problems caused by other impairments and multiple disabilities. Having a closer look at people with mental health conditions only, the number was about 205.000 people (2,5%) and 1% of the Austrian population (85.000) had a learning disability or a mild mental retardation (cf. bmask 2009: 7f.).

The Austrian system of training starts at early childhood. It is possible to apply for early intervention when having a child with disabilities. Further more there are assistance services for families and also financial support. When the child gets older he/she can enter kindergarten. There are three different types thereof: mainstream, inclusive and special kindergartens.

Compulsory education starts at the age of six. It is possible for a child with disabilities to either enter a school of general education or a special school. There are so called Special Education Centers that are supposed to provide and coordinate all measures of special needs education. Identifying special educational needs, providing information for parents and cooperating with regional schools are only some examples for the tasks Special Education Centers are concerned with.

In a school of general education the inclusion of children with disabilities can be organized in three different ways: There are inclusive classes, classes with support teachers or cooperation classes. Special needs support is legally regulated in primary, lower secondary school, and in the lower

grades of schools in general secondary education. Children who enter a special school are educated according to the curriculum of primary or lower secondary school but there are also particular curriculums for special schools. In contrast to minors who attend schools of general education it is possible for those who attend a special school to prolong attendance to 12 years (compared to 9 years of compulsory education in general). To make pupils of special schools ready for integration into the labour market there is a job preparation year during which crucial information is offered and competences with regard to the working world are trained. Career planning being a general principle in secondary education per se this is also the case in schools of general education (cf. European Agency for Development in Special Needs Education 2010).

Having entered the working world itself there are different kinds of support for people with disabilities provided by the Federal Social Office (BSA) and the Austrian Labour Market Service (AMS). In 1992 the so called *Arbeitsassistentz* was introduced. It can be described as the Austrian Version of Supported Employment (cf. König 2009: 21f.) and is aiming at advising people with disabilities as well as companies who employ them (special funding, financial aid, legal advice) (cf. AMS). In the following years the *Arbeitsassistentz* has been split up into different measures. As a consequence Clearing (link between school and the labour market; preparation of a profile containing strengths, interests and job prospects) and Job Coaching (support at the workplace itself) for example became separate programmes. Integrative Vocational training (IBA) was introduced in 2004 to close the qualification gap for people with special educational needs. It is offered in two ways: As a part qualification apprenticeship and a prolonged apprenticeship (cf. König 2009: 21f.). On the part of Austrian companies it can be said that an employer with at least twenty-five employees is obliged to employ one person with disabilities. If this is not the case the employer has to pay a compensatory tax, which does not seem daunting at all. In contrast, companies which employ people with disabilities are provided with federal funding by the Federal Social Office (cf. Adam 2006).

People who are not capable of working on the primary or secondary labour market due to their disability have the possibility of working at a sheltered workplace. Such workplaces are provided by disability organisations and social service providers (cf. bmask 2011: 42f.).

## **2.2 State of the art in France**

### ***Brief on the legislative framework on disability in their own country***

The law of the 11/02/2005

The Act of February 11, 2005 is one of the main laws on disability rights, since the 1975 Act.

The first few lines of the law recall the fundamental rights of disabled people and give a definition of disability:

"It is a disability within the meaning of this Act, any activity limitation or restriction of participation in the life suffered in its environment by a person due to a substantial, lasting or permanent one or more physical functions, sensory, mental, cognitive or psychological, a multiple disability or a disabling illness. "

The principal axes and advanced the law classified by themes:

- Welcoming disabled people
- The right to compensation



- The resources
- Education
- Employment
- Accessibility
- Citizenship and participation to social life

### ***Demographic data on the population of disabled people in their own country***

The figures most commonly used – and certainly the most significant in relation to the issue of accessibility – are those from the survey handicap, disability, dependence (HID) conducted by INSEE, between 1998 and 2001.

### **Nearly 12 million people in France**

<b>Characterization of the "seven groups of people with disabilities "</b> <b>Table drawn from the document "Disability in figures", February 2004, Centre National Technical Studies and Research (CTNERHI).</b>		
<b>Population</b>	<b>Nb (in thousands)</b>	<b>Characterization</b>
<b>Population 1</b> : isolated and minor disabilities	5 300	People who declare one or more disability (s) without restriction of activity or administrative recognition
<b>Population 2</b> : diffuse undetected disabilities	800	People who declare a limitation of activity, without disability or administrative recognition
<b>Population 3</b> : modes of recognition to different criteria	1 200	People who say recognition of a degree of disability or incapacity, without limitation or disability
<b>Population 4</b> : dependent elderly	2 300	People who reported one or more disability (s) and a restriction of their activity without official recognition
<b>Population 5</b> : "the core of disability" (?)	1 200	People who say both one or more disability (s), activity limitation and a recognition rate of incapacity or disability
<b>Population 6</b> : people with intellectual or mental disabilities	650	People who reported one or more disability (s), with a recognition rate of disability but not limited
<b>Population 7</b> : limiting disease	325	People who report a limitation with a recognition rate of disability or incapacity, disability-free

### ***Brief on the organizational system of social services targeting people with disabilities***

On local level (Conseil Général du Val-de-Marne)

On May 25, 2009, the General Council adopted unanimously the 3rd departmental plan for persons with disabilities.

Le troisième Schéma départemental en faveur des personnes handicapées binds to specific targets for improving better living of Val-de-Marne's inhabitants in situation of disability in de handicap dans all areas of their daily lives, housing transport through sport, culture and recreation. Made with all partners and in close conjunction with representatives of disabled people, this plan, covers the period 2009-2013.

## **MDPH**

Created by law for equal rights and opportunities, participation and citizenship of disabled people from 11 February 2005, the “Departmental Houses Departmental of Disabled People (MDPH) are in charge of welcoming and supporting disabled people and relatives. There is one MDPH in each department, functioning as a one-stop shop for all steps associated with various handicaps.

The disabled person is at the heart of this public service, with a real awareness of his life project and a detailed evaluation of its needs by a multidisciplinary team, to recognize its rights to compensation by the Committee on the Rights and Empowerment (CDAPH).

## **2.3 State of the art in Italy**

### **Legislative framework**

1. Law 482/1968 - contain the general rules on compulsory enrolment of disabled persons in the public administration and private enterprises. Containing the general rules on compulsory enrolment of disabled persons in the public administration and private enterprises. This law regarded the work only of physical disabled persons. With that review of legal constitutionality of 482/1999, it was definitively provided that law n. 482 should be applied also to the mentally disabled persons.
2. Law 68/1999 - concerning the right of employment for disabled people. The law protects the rights of workers with disabilities and prohibits discrimination against them in the workplace. Besides promoting access to work for disabled people, through a compulsory employment quota system, this law states that the same standards of legislative and collectively agreed treatment must apply to disabled workers as to other workers.
3. Law 18/1980 - attendance allowance for disabled civilians totally disabled. Economic support for disabled people that are totally enabled.
4. Law 13/1989 - provisions to encourage the overcoming and removal of architectural barriers in private buildings.
5. Frame – law 104/1992 - on the care, social integration and rights of disabled persons. This Law involved fundamental innovation for social policies regarding disabled people in Italy, thereby creating the premises and conditions for full affirmation of civil rights and participation in the social life of disabled people. Frame-law 104/92 fully acknowledges a disabled person despite the extent of his/her disability and takes into consideration the development of a disabled person from birth to participation in the family, at school, at work and during leisure time.
6. Law 162/1998, amending 104/1992 - concerning support measures in favour of people with severe disabilities. Providing some interventions in favor of persons in conditions of severe disabilities. In fact it shall: 1) provide some new concrete interventions and services; 2) realize some experimental projects; 3) promote the inquiries and the collection of statistical data regarding the disability; 4) gather every three years a national conference on the politics of disabilities.

## ***Demographic data***

Persons with Disabilities who have six years or more that living in the household in Italy in 2004 are 2.600.000. Persons with Disabilities who have six years or more that living in Institute of Care in Italy in 2004 are 190.000.

Level of Education: Compared to the total Italian population, persons with disabilities have a lower level of education: 17% middle school and 8% high school.

Professional Status: The 66% of people with disabilities is out of the labour market: the 43.9 per cent are retired and 21.8 percent are unable to work while only 3.5 percent is occupied and 0.9 percent seeking employment.

## ***Social and care services***

People with disabilities can be included in different types of centers whose main discrimination is the difference between residential and semi-residential.

### Residential structures:

- R.S.A. (Home Health Care): dependent on ASL, set up to give answers to the needs of disabled dependents and untreatable at home. The RSA usually are in areas already urbanized, connected by public transport to urban centres to avoid any form of isolation of the disabled or difficulty of meeting with family members or removal from the social. Social assistance is provided in the residence 24 hours a day by staff that helps disabled dependents in the household and personal care, while nurses take care of medical aid, rehabilitation therapists, family doctors, other specialists.
- Apartment Group: residential structure that holds the type of the house civilian.
- R.A. (Nursing Homes): collective structures that provide the supply of hotel-like services to the specific nature of assistance, cultural and recreational benefits, in addition to benefits which are intended for recovery or improvement of self of the person to people with disabilities, self-sufficient or partially self-sufficient. R.A. have a capacity between 10 and 60-80 beds and work permanently in 24 hours for the entire week and throughout the year.

The actions relate to the direct assistance of the person (personal hygiene, meals, routine cleaning of the rooms), the protection of the data (control and monitoring) and other aspects of welfare nature, designed to monitor changes in conditions of host, relationships with family and with the outside.

- R.A.F. (Flexible Nursing Homes): social welfare structures of "permanent hospitality" with the aim of providing accommodation, welfare benefits, and recovery for persons in psychological and physical conditions of partial or non-self-sufficiency occurring during hospitalization, unless, demands on health found not require the use of different solutions.
- Family Home: residential structure that can accommodate up to seven people with physical, mental sensory and psychiatric disability, with no family support or whose stay in the household either temporarily or permanently impossible.

### Semi-residential structure:

- **Social and Rehabilitation Day Center:** structure in social and health status during the day for citizens with disabilities.

- **Social and Educational Day Center:** semi residential structure for day care of persons with disabilities between 18 and 50, regardless of sex, with significant impairment of autonomy in elementary functions, which have completed compulsory education and for which no is a programmable way to working full time.
- **Member Employment Center:** territorial service in nature daytime and for low-intensity care for people with disabilities. Has the purpose of active interventions of training/formation at work in a protected environment, preparatory or replacement job placement in the company and support the maintenance and strengthening of operational and relational skills and personal autonomy necessary to face the world of work. The audience is made up of people with disabilities mean - seriously incapacitated or not yet ready to support a commitment to employment in a real working environment, with still higher levels of personal autonomy to those owned by our member in Social and Rehabilitation Day Center.

## ***2.4 State of the art in Romania***

Before the Revolution in 1989, in Romania only the people with a visual and hearing disabilities were given visibility and recognition (regarding forms of schooling and employment opportunities).

Following the year 1990, there appeared the first public statistics about an estimated total number of disabled people, and there also emerged the first NGOs created by people with disabilities and their parents.

Given the above situation, as a result of the civil society pressure and also as a reaction to social realities, there appeared the first normative acts (specific legislation) meant to establish the rights of people with disabilities and to frame them into the suitable disability degree.

All these factors have influenced the public opinion and if we add the spirit of tolerance, promoted by BOR (Romanian Orthodox Church), we can consider that the predominant cultural features in Romania influenced the attitude towards disabled people in a positive way.

The open, tolerant attitude is nowadays more common and more spread.

We can ascertain/observe the exclusion attitude in the business environment, meaning that employers are still not convinced of the potential of a disabled person. From a total of 311.000 people with disability (between 19 and 59 years of age) only 28.000 disabled people are employed.

In order to emphasize the positive attitude and tolerant spirit proved by the legislation and the population we will give an example:

- the provision within the Fiscal Code regarding the possibility of citizens who earn incomes to direct 2% of the tax on the incomes of the preceding year towards non-profit entities;
- the growing number of citizens who are applying the above mentioned provision.

## Legislative framework

There is a common law regarding disabilities for both children and adult persons (including families they belong to), namely the „*Law 448/2006 on the protection and promotion of rights for the persons with handicap*” (entered into force at 1<sup>st</sup> of January 2007, republished and consolidated in June 2009).

The legislation refers to four degrees of disability: severe, pronounced, medium, mild and ten disability categories: physical, visual, auditory, somatic, mental, psychic, HIV/AIDS, associated, rare diseases.

This legislation, with its norms modified in February 2010, has well defined sections and chapters, including “services” and “social labour conscription” as one may see below:

### a) Social services at national level

- Law 448/2006 – republished – presented above
- Law 47/2006 - regarding the national social assistance system

### b) Special services for disabled people at national level of the

- Law 448/2006 and Law 47/2006 (their norms corroborated), plus:
- Government Decision no. 329/20.03.2003 for approving the regulations, organisational and functioning framework of the institutions for the special protection of the persons with handicap: pilot centres, care and assistance centres, recovery and rehabilitation centres, centres for integration through occupational therapy, day centres.

The decentralisation process implied that the County Councils to take over the existing centres.

### c) Employment services for disabled people

- Law 448/2006 – the chapter „*Orientation, professional training, occupation and employment in labour*”
- Law 76/2002 – regarding the unemployment insurances system and the stimulation of the labour force employment

We would like to point out here that organising (by the Labour Force Employment County Agencies) a job exchange for persons with disabilities, once or twice per year, has become a habitude.

## Demographic data

The official statistics from 30.09.2009 emphasizes the figures rendered below regarding the ratio of institutionalised vs. non-institutionalised persons:

Indicator	TOTAL	Percent	Statistical weight within the total population	Institutionalized disabled persons	Noinstitutionalized disabled persons
Disabled persons	669.523	100%	3.11%	17.090	652.433
children	61.233	9.1%	0.2%	65	61.168
adults	608.290	90.9%	2.91%	17.025	591.265

From a total population of 21.498.616 citizens we can see that only 669.523 persons, that is 3.11%, have the recognition of their disability, which is much lower than the European average of 8.10%.

The **61.233** children represent **9.1%** of the total disabled population (and 0.2 % of the total population) and the majority of them live in families, which mean they are non-institutionalized. The early diagnosis within the medical care process obviously differs from one situation/case to another.

The state ensures a minimal package of free medical tests for pregnant women. These tests cannot detect the risks of giving birth to a child who is likely to suffer from the Down syndrome, micro encephalopathy or any other malformations.

For advice on all the above mentioned disorders, those who wish to receive some guidance, go to their personal doctors or to private clinics and they pay for these services.

**We appreciate that the existence of a national program meant to prevent the births of children with disabilities should be compulsory, taking into account that the number of children with autism and Down syndrome has increased during the last years.**

91% of the total of the persons with handicap are adults and only 2.5% of these are institutionalised (in different institutions and specialised centres), the rest of them, meaning 591.265 persons are at home.

We emphasize that, if for the children with disabilities there are provided social services, for the adults with handicap these are insufficient (the adults do not have alternatives).

## ***2.5 State of Art in Spain***

In 2006 in Spain, the attention (care) for dependent persons was regulated by a national law, which is referred to any person in need of support from formal and informal caregivers or services.

Among the groups which this regulation is referred to, there are people with intellectual disabilities, in case they express a dependency from another person or the need of support in the daily living activities.

To achieve this objective, an evaluation of the situation of dependent people It is required, for the assignment of a financial support in order to pay for formal or informal caregiver, or personal assistant, or a catalog service regulated by the law itself.

### ***Aspects of the law***

**Law 39/2006 of December 14, regulates the basic conditions for the promotion of personal autonomy and care for people in situations of dependency by creating a System for Autonomy and Care Unit (SAAD),** with collaboration and participation of all Public Administrations.

It aims at guaranteeing the basic conditions and forecast levels of protection which this Act is referred to. The Act establishes a minimum level of protection, defined and financially guaranteed by the Spanish Government.

Also, as a **second level of protection**, the law provides a system of cooperation and funding from the General Administration of State and the Autonomous **Communities through agreements for**

**the development and the implementation of other benefits and services** that are covered by the Act.

Finally, the Autonomous Communities may develop, if they deem it appropriate, a third level of protection to citizens. The aim is, therefore, to develop, based on a competence framework, an innovative model, integrated, based on intergovernmental cooperation and on the respect for skills.

People in a dependent situation shall be entitled, regardless of where they reside, to access, on equal terms, those benefits and services provided in this Act; they enjoy all human rights and fundamental freedoms, with full respect for their dignity and privacy, they will have access to complete and continuous information connected to their situation; they will have the right to be advised if the procedures that apply to them can be used in terms of a teaching or research project, in respect of confidentiality data; they are granted the right to participate in the formulation and implementation of policies affecting their welfare and to decide (when they have sufficient capacity to act) on the protection of themselves and their property, to decide on joining a residential center, the right to exercise their jurisdiction and property rights, equal opportunities, no discrimination and universal accessibility.

**Article 13** defines the objectives pursued by the law: The care of dependent people and the promotion of personal autonomy must geared at achieving a better quality of life and personal autonomy within a framework of effective equality of opportunities, in accordance with the following objectives:

- Facilitate independent living in their normal environment, as long as desired and possible.
- Provide decent treatment in all areas of their personal life, family and community, facilitating their active involvement in community life.

And for this, **Article 14** provides what are the services that people in situations of dependency and disability may receive.

In **Article 26**, dependence is classified according to different degrees, depending on the frequency of the need for assistance in daily activities and the need to be supported more or less permanently.

**Level I:** moderate dependence; **level II:** severe dependence; **level III:** heavy dependence.

### ***Financing***

Funding will be determined by the number of dependent people and services provided under this Act; in any case, the General Administration of the State will guarantee funding to the Autonomous Communities for the development of minimum level of protection for dependent persons contained in this Act

The system will serve in an equitable manner to all citizens in a situation of dependency. The beneficiaries contribute financially to the funding of services gradually depending on their economic capacity, taking into account the type of service provided and its cost.

## 1. Demographic data on the population of disabled people in Spain

Number of persons with disabilities: more than **4.11 million** people, of which **3.85 million** live in family homes and **0.27 million** in residential and long-stay hospitals, which represents **9% of the Spanish population**.

Source: Survey of Disability, Personal Autonomy and Dependency Situations (AGE), conducted by the National Statistical Institute in 2008.

## 2. The organizational system of social services targeting people with disabilities

Catalog of social services to promote personal autonomy and dependency care include: services for the prevention of situations of dependency and the promotion of personal autonomy, remote assistance, home help, day and night centres and residential care.

The service network of the System for Autonomy and Care for Dependency shall consist of the public schools of the Autonomous Communities, local entities, State reference centers for the promotion of personal autonomy and for the attention and care of dependency situations, as well as accredited private schools.

The communities themselves will establish the legislative framework and conditions of operation for private schools, giving priority to nonprofit organizations, while schools and independent private services must be accredited. It is also important to promote the participation of voluntary organizations and the Third Sector.

The day and night centers are carefully highlighted, providing a focus to integrate people in a situation of dependence, with the aim of supporting their families. These centres meet the needs of: counseling, prevention, rehabilitation, counseling to promote autonomy, empowerment and personal care and attention.

**Residential care services** offer, from a biopsychosocial approach continued personal and health services. The provision of these services may be either permanent or temporary, they are provided by the Government in its own regulated centers.



### 3 DISTRIBUTION OF THE SAMPLE IN EUROPE

The sample of CR of Europe is compatible with the standards of research. The sample consisted of 100 people with disabilities of mild type - medium capacity with basic reading and writing and an  $QI \leq 50-55$  and  $\geq 70$ . The 44% of participants are women, 56% are male (Fig. 1). The average age of participants is 29 years. The analysis ICF is compatible with standard selected:

- low ICF participation
- high ICF environment
- high attitudes of operators
- high attitudes of family

From analysis of Quality of Life has shown that all the CR show a high level of wellness in every area: psychological, physical, environmental and interpersonal relationships.

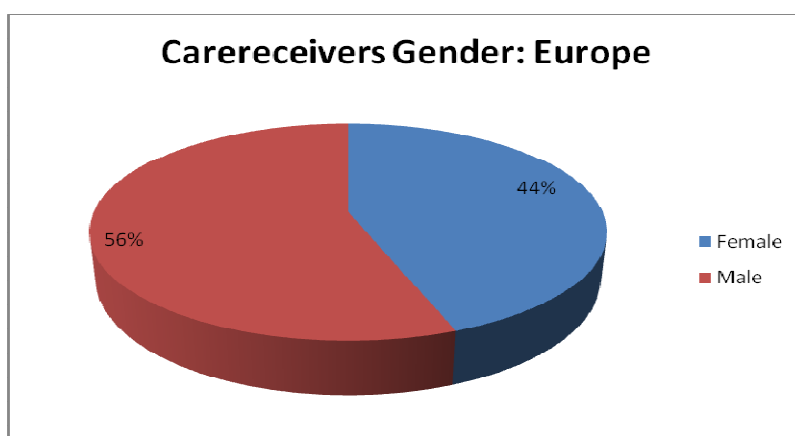


Fig 1, Distribution of CR by gender

The European sample of CR is composed in Austria with an average age of 28 years, 30 years in Italy, 28.9 in France, 27.7 in Romania and 30.2 in Spain (Fig. 2).

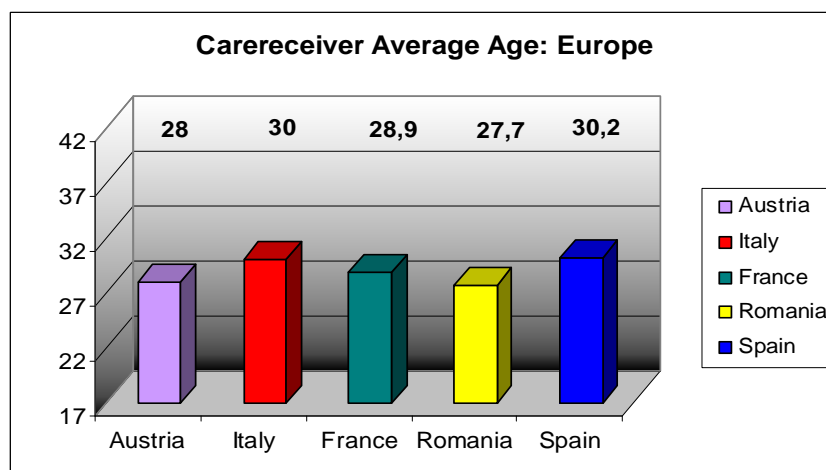


Fig 2, Distribution of CR by age in Europe

The sample of CG is composed of 100 people: 81% of them are females and 19% male (Fig. 3), with an average of age of 45 years. 58% of CG has the role of professional operator, while 42% has a role of familiar (member of family) (Fig. 4). The duration of caregiving has on average a minimum of 2 years and a maximum of 30. This depends mainly for the role of the CG, in fact, family members take care of the CR from birth.

From the analysis of the CBI, the CG had a lower burden of care to a score of 35, compatible with the standard selected, with the exception of 11 cases in which the score is above 35, with an increased risk of burnout for the CG.

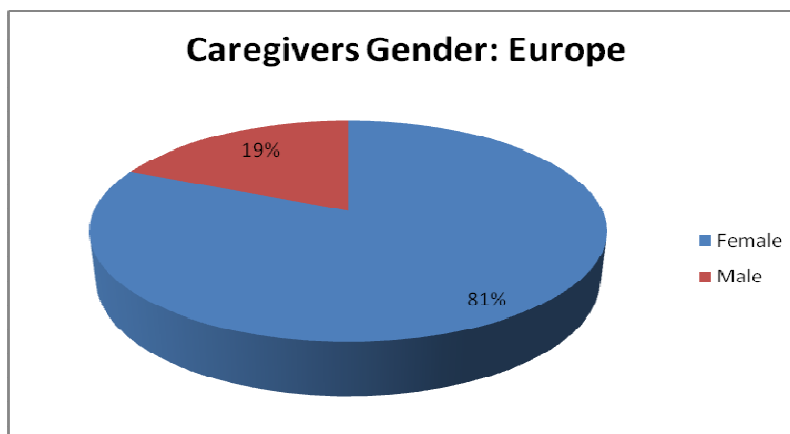


Fig 3, Distribution of CG by gender

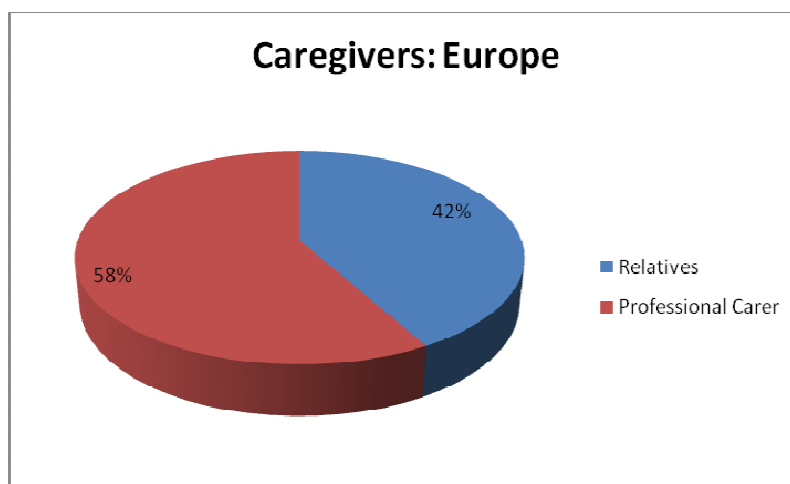


Fig 4, Distribution of CG by role

The European sample of CG is composed in Austria with an average age of 30.4 years, 59.6 in Italy, 38.4 in France, 46.3 in Romania and 52.3 in Spain (Fig. 5).

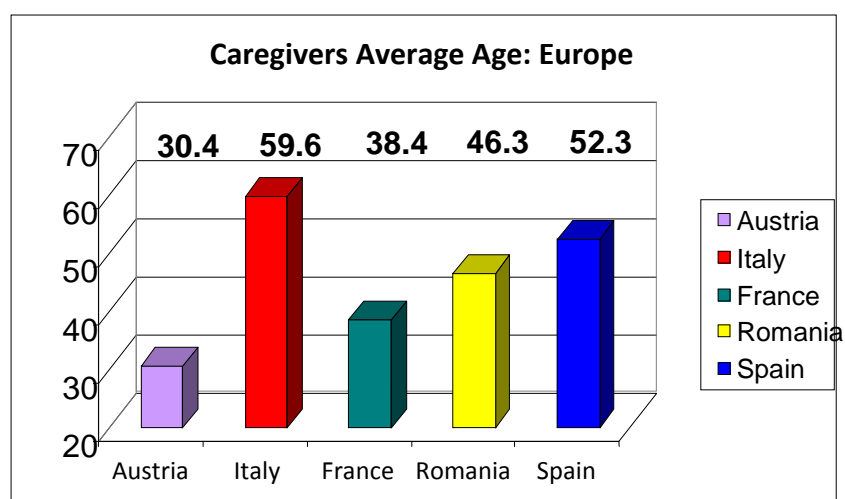


Fig 5, Distribution of CG by age in Europe

The total sample is divided by country as follows:

COUNTRY	CARERECEIVER	CAREGIVER
Austria	20	20
France	19	19
Italy	21	21
Romania	20	20
Spain	20	20

Tab.1 Sample n =100

### 3.1.Distribution of the sample in Austria

In Austria, the sample of the CR consists of 20 persons with disabilities, that 50% are male and 50% are female (Fig. 6).

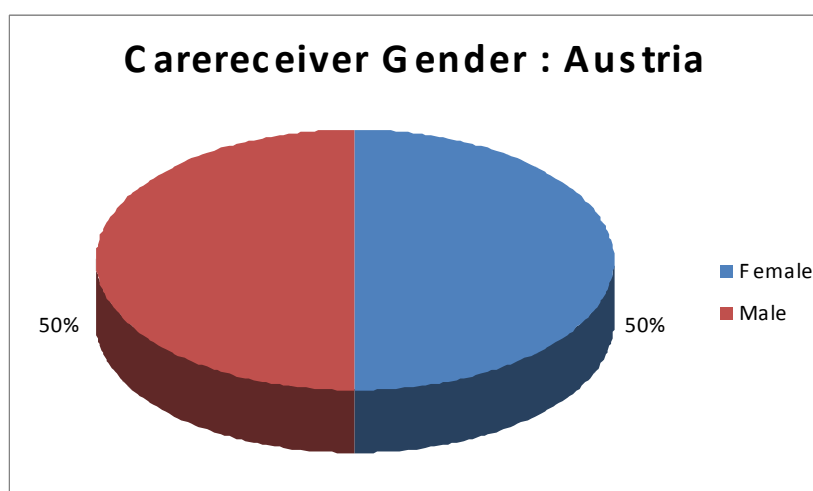


Fig 6, Distribution of CR by gender in Austria

In Austria, the sample of the CR consists of 20 persons with disabilities, 26% are between 31 and 35 years, 25% between 20 and 25 years, 16% between 36 and 40 years, 11% have less than 20 years, 11% between 26 and 30 years and 11% are over 40 years (Fig. 7). The average of age is 28.9 years.

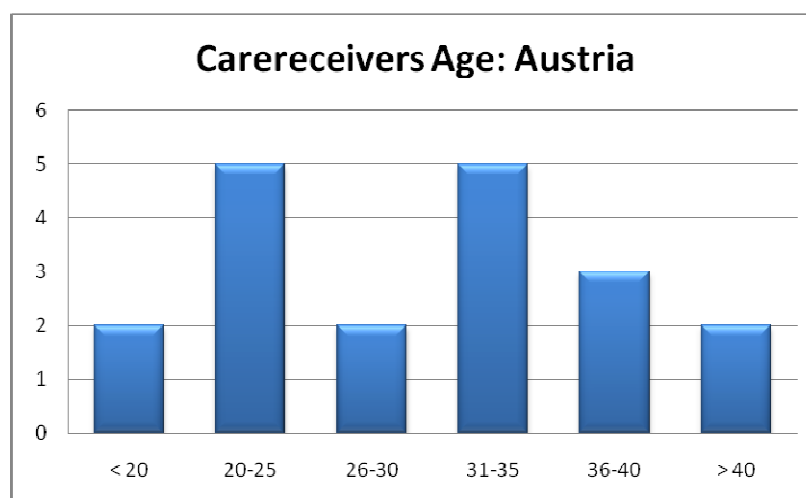


Fig 7, Distribution of CR by age in Austria

In Austria, the sample of the CG consists of 20 persons, 75% female and 25% male (Fig. 8).

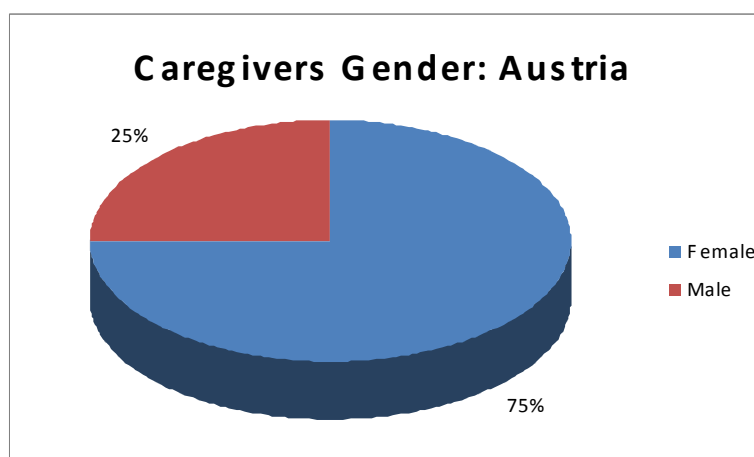


Fig 8, Distribution of CG by gender in Austria

In Austria the CG sample of 20 accounting for 66% of people aged between 21 and 30 years, 17% between 51 and 60 years, 11% between 41 and 50 years and 6 % between 31 and 40 years. The average of age was 30.4 years (Fig. 9).

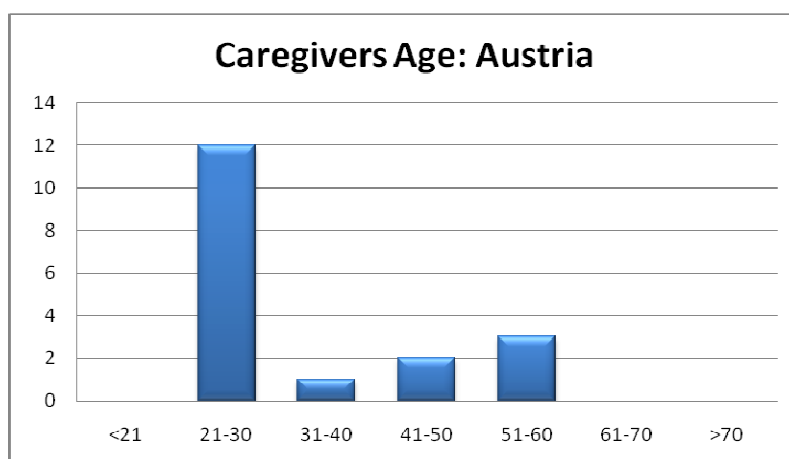


Fig 9, Distribution of CG by age in Austria

In Austria the sample of 20 CG consists of only professional carer (Fig. 10).

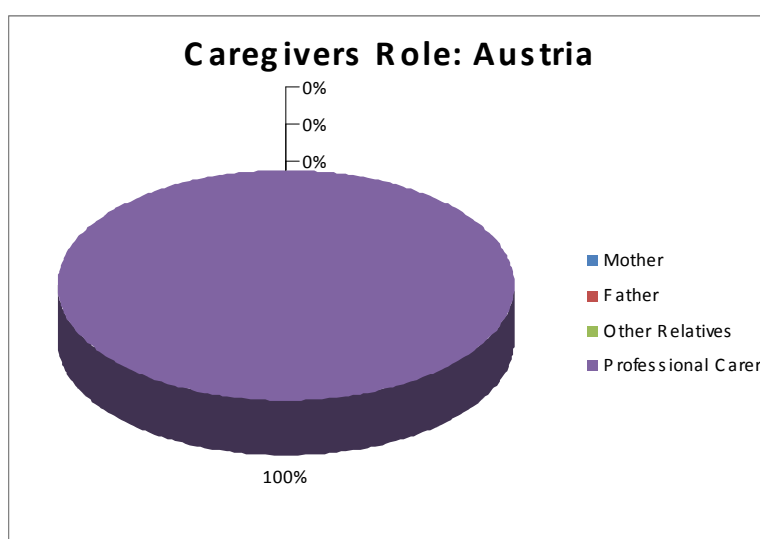


Fig 10, Distribution of CG by role in Austria

In Austria the sample of 20 to 44% CG has a duration of assistance less than 1 year, 31% from 1 to 5 years, 25% from 6 to 10 years, with an average of 2.1 years (Fig. 11).

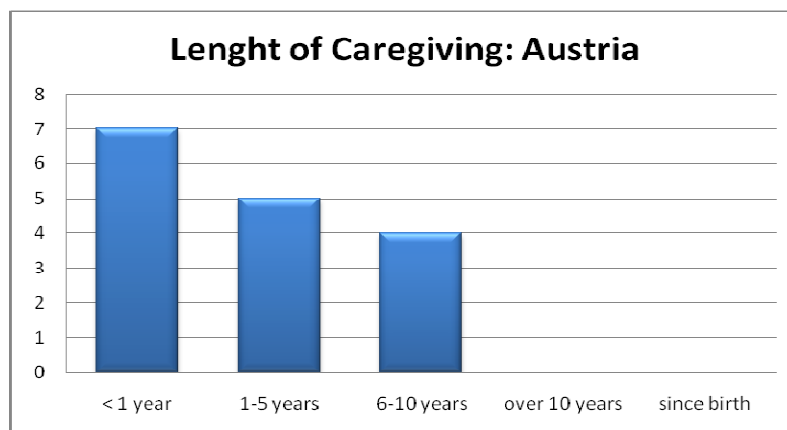


Fig 11, Distribution of CG by length of caregiving in Austria

### 3.2 Distribution of the sample in France

In France, the sample of the CR is composed of 19 persons with disabilities of which 58% are male and 42% are females (Fig. 12).

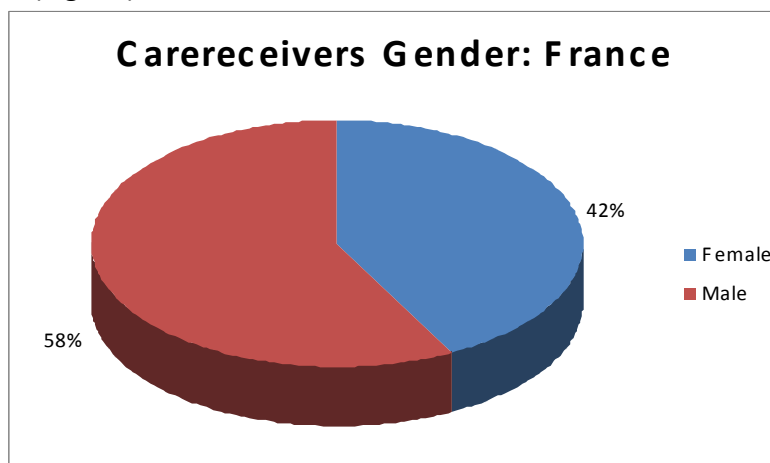


Fig 12, Distribution of CR by gender in France

In France, the sample of the CR is composed of 19 persons with disabilities of which 32% are aged between 20 and 25 years, 36% are aged between 26 and 30 years, 21 % are aged between 31 and 35 years, 11% are between 36 and 40 years (Fig. 13). The average of age was 28.9 years old.

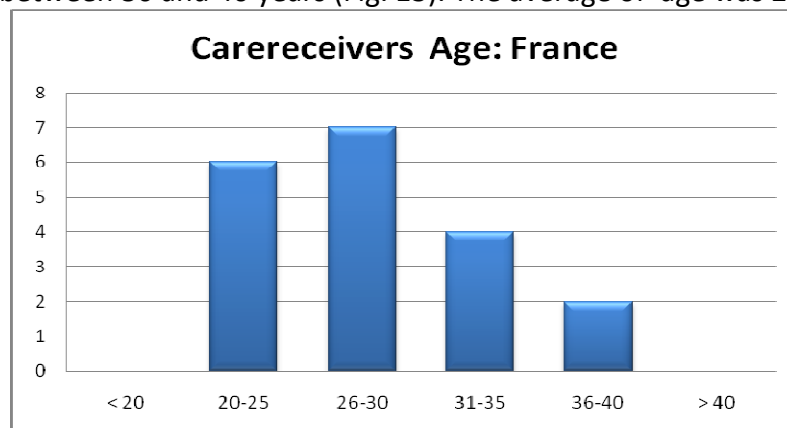


Fig 13, Distribution of CR by age in France

In France the sample of 20 CG consist of 13% by male and 87% by female (Fig. 14).

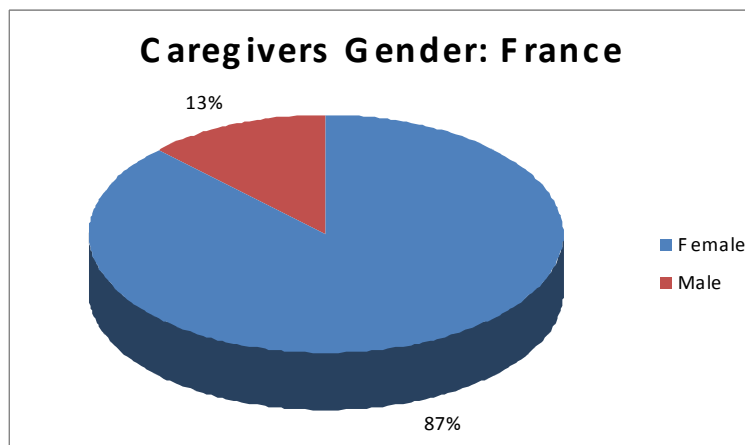


Fig 14, Distribution of CG by gender in France

In France, the CG have between 21 and 60 years, of which 19% are aged between 21 and 30 years, 49% between 31 and 40 years, 19% between 41 and 50 and 13% between 51 and 60 (Fig. 15). The average of the age is 38.4 years old.

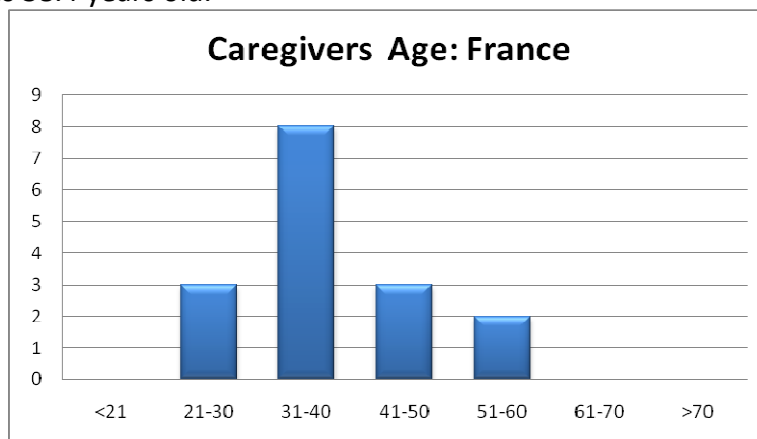


Fig 15, Distribution of CG by age in France

In France the sample of CG consists of only professional carer (Fig. 16).

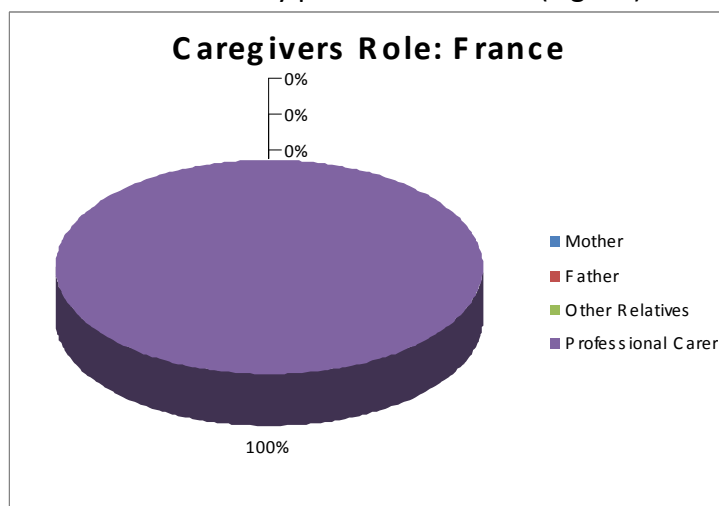


Fig 16, Distribution of CG by role in France

In France, the sample of 19 to 19% CG has a duration of assistance less than 1 year, 31% between 1 and 5 years, 25% between 6 and 10 years, 25% over 10 years (Fig. 17).

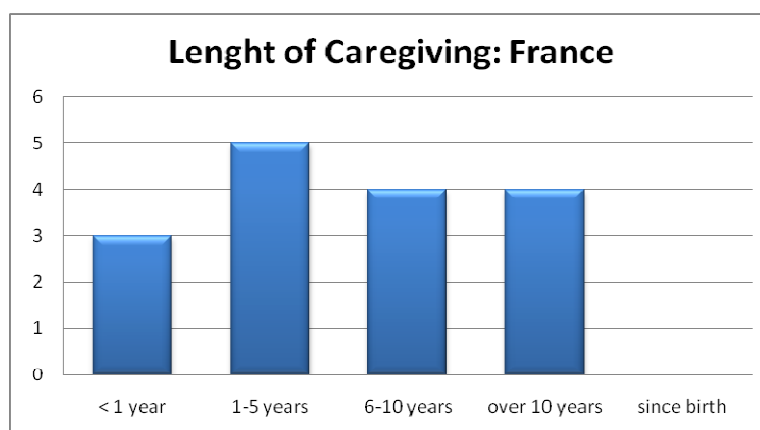


Fig 17, Distribution of CG by length of caregiving in France

### 3.3 Distribution of the sample in Italy

In Italy the sample of CR consists of 20 persons with disabilities of which 52% female and 48% male (Fig. 18).

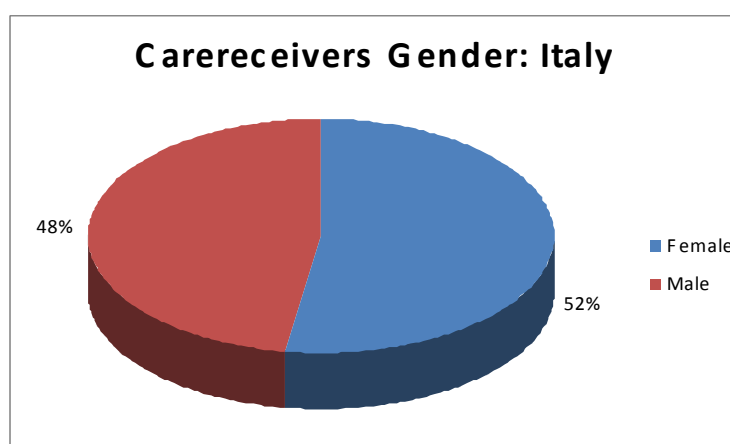


Fig 18, Distribution of CR by gender in Italy

In Italy the sample of CR consists of 20 persons with disabilities, of which 33% have between 26 and 30 years, 29% between 31 and 35 years, 19% between 36 and 40 years, 10% are over 40 years, 9% between 21 and 25 years, while no one under 20 years, with an average of 30 years. This indicates that the average age of the sample meet the criterion of selection indicated initially (age not exceeding 40 years) (Fig. 19).

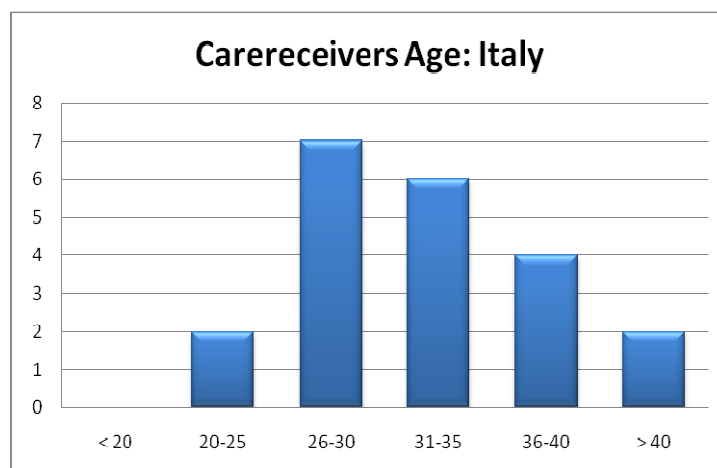


Fig 19, Distribution of CR by age in Italy

In Italy the CG sample consists of 20 relatives of the selected CR: 81% are male and 19% are female (Fig. 20).

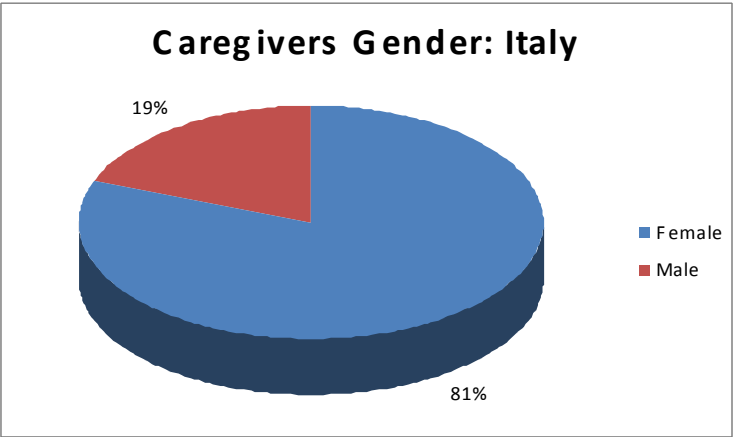


Fig 20, Distribution of CG by gender in Italy

In Italy the CG sample consists of 20 relatives of the selected CR: 47% have between 61-70 years, 37% between 51 and 60 years, 16% between 41 and 50 years, with an average of 59.6 years (Fig. 21).

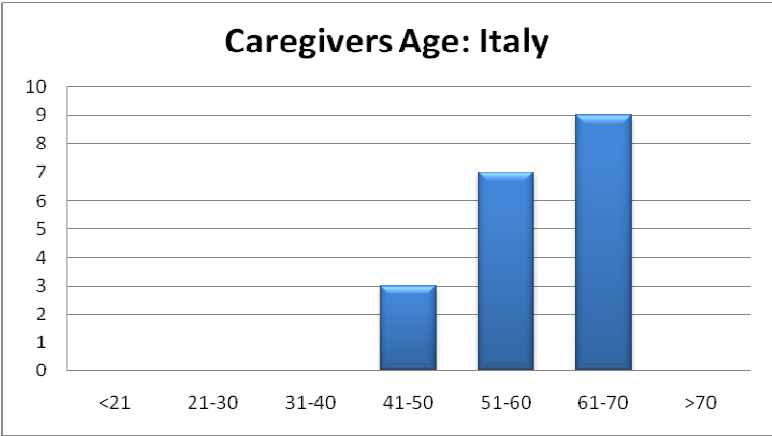


Fig 21, Distribution of CG by age in Italy

In Italy the CG sample of 20 accounting for 76% of mothers, fathers 19%, 5% by other relatives and no professional carer (Fig. 22).

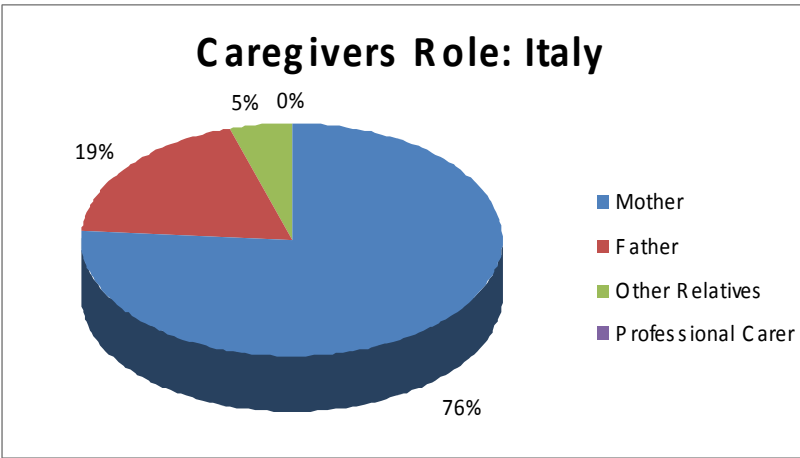


Fig 22, Distribution of CG by role in Italy



In Italy the sample of 20 CG shows a length of caregiving from birth for 95% and between 6-10 years for 5%, with an average of 30.2 years (Fig. 23).

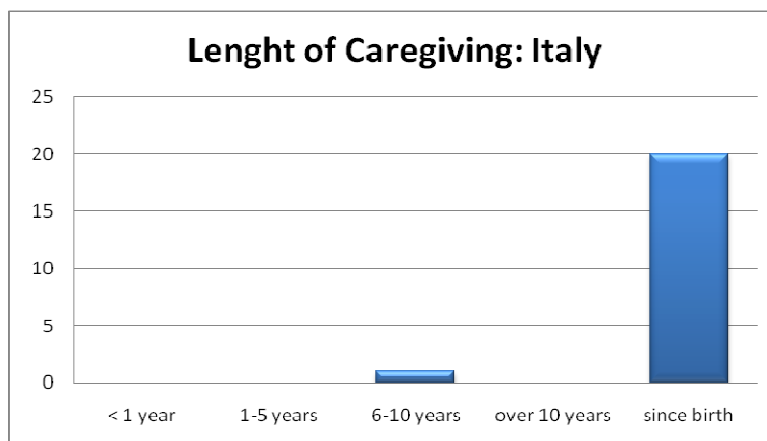


Fig 23, Distribution of CG by length of caregiving in Italy

### 3.4 Distribution of the sample in Romania

In Romania the sample consists of 20 CR, 65% male and 35% female (Fig. 24).

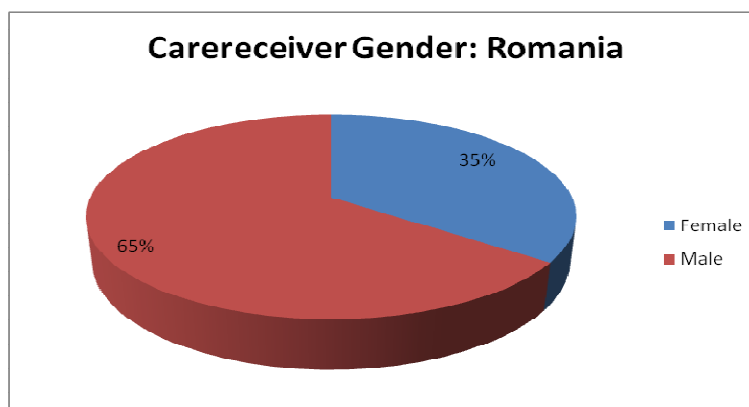


Fig 24, Distribution of CR by gender in Romania

In Romania the sample of CR consists of 20 persons with disabilities, of which 25% have less than 20 years, 25% between 20 and 25 years, 15% between 26 and 30 years, 10% between 31 and 35, 20% between 36 and 40 years, while 5% are over 40 years (Fig. 25). The average of the age was 27.75 years old.

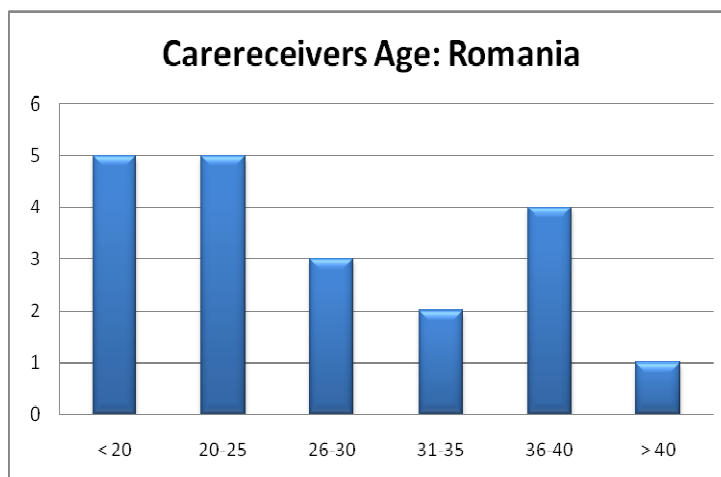


Fig 25, Distribution of CR by age in Romania

In Romania the sample of 20 CG consists of 90% by female and 10% by male (Fig. 26).

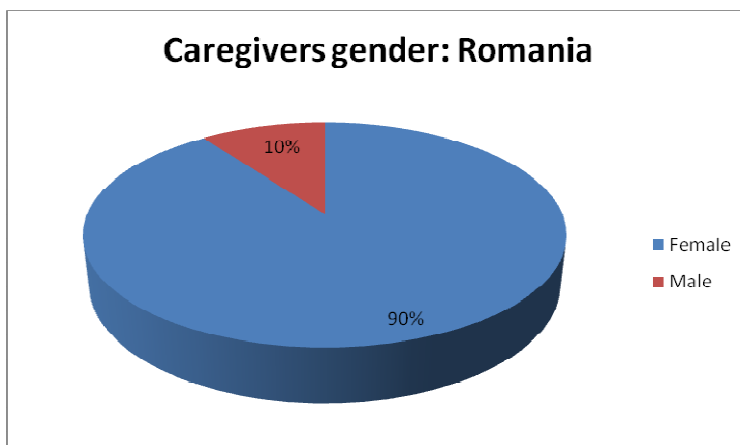


Fig 26, Distribution of CG by gender in Romania

In Romania the sample of CG consists of 20 persons of which 6% have an age between 21 and 30 years, 34% between 31 and 40 years, 24% between 41 and 50 years, 12% between 51 and 60 years, 18% between 61 and 70, 6% are over 70 years and there aren't CG with less than 20 years (Fig. 27). The average of the age was 46.35 years old.

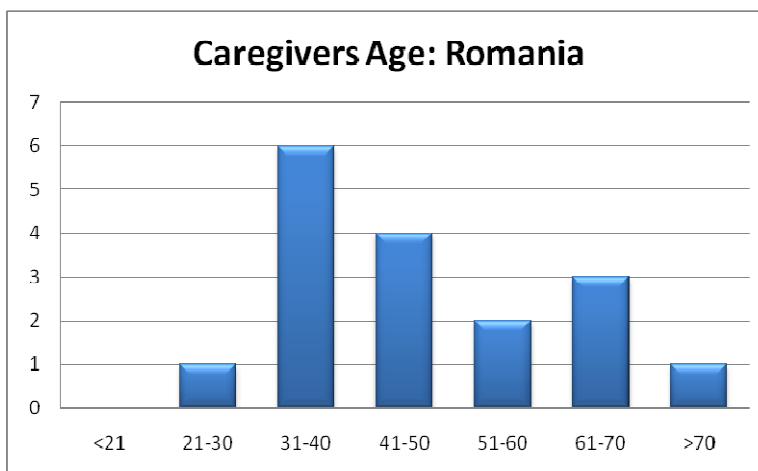


Fig 27, Distribution of CG by age in Romania

In Romania the CG sample accounting for 45% of mothers, 10% fathers, 5% by other relatives and 40% by professional carer (Fig. 28).

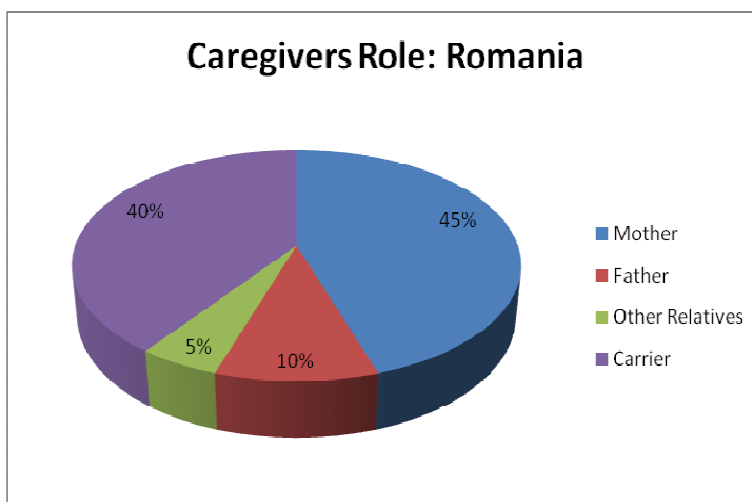


Fig 28, Distribution of CG by role in Romania

In Romania the sample of CG shows a length of caregiving from birth for 55%, 30% over 10 years, 10% between 6 and 10 years, 5% between 1 and 5 years and there aren't persons with less than 1 years (Fig. 29).

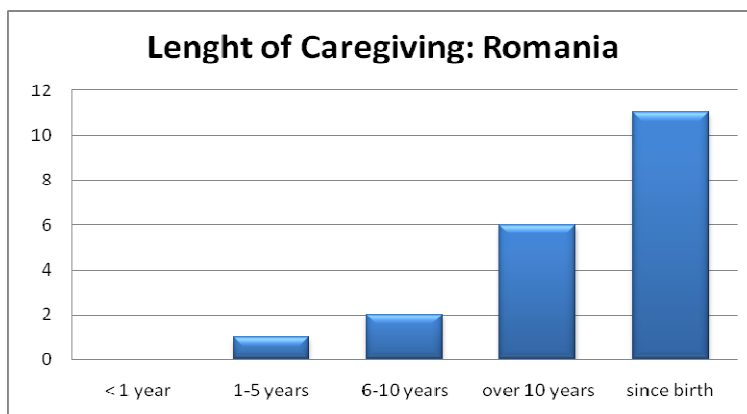


Fig 29, Distribution of CG by lenght of caregiving in Romania

### 3.5 Distribution of the sample in Spain

In Spain the sample of the CR consists of 20 persons with disabilities of which 59% are male and 41% are female (Fig. 30).

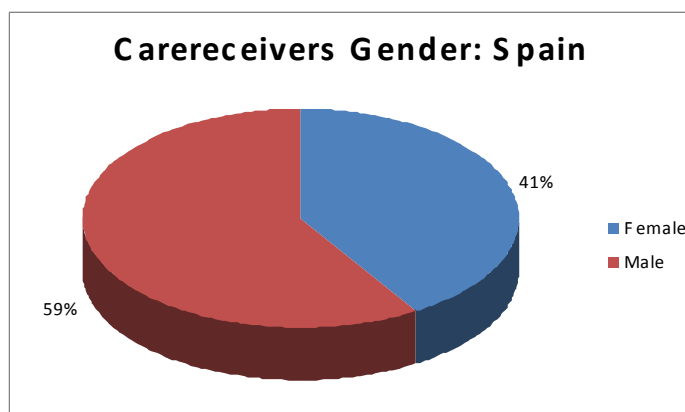


Fig 30, Distribution of CR by gender in Spain

In Spain the sample of 17 CR, 30% have between 31 and 35 years, 30% between 20 and 25 years, 15% between 26 and 30 years, 20% between 36 and 40 year, 5% more than 40 years, with an average of 30.2 years (Fig. 31).

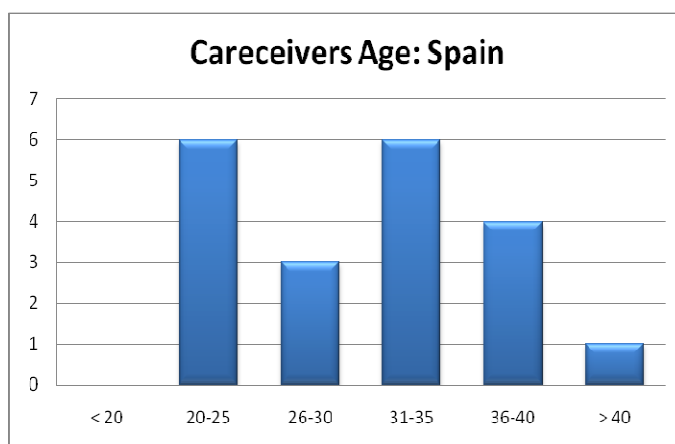


Fig 31, Distribution of CR by Age in Spain

In Spain the sample of the CG consists of 20 persons of which 75% female and 25% male (Fig. 32).

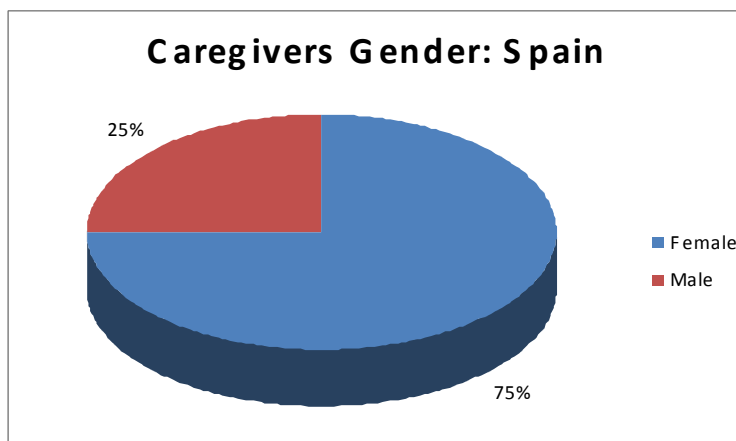


Fig 32, Distribution of CG by gender in Spain

In Spain the sample of the 20 CG, 20% have between 31 and 40, 15% between 41 and 50, 35% between 51 and 60, 30% between 61 and 70, while no one younger than 30 years and greater than 70 (Fig. 33). The average of the age is 52.35 years old.

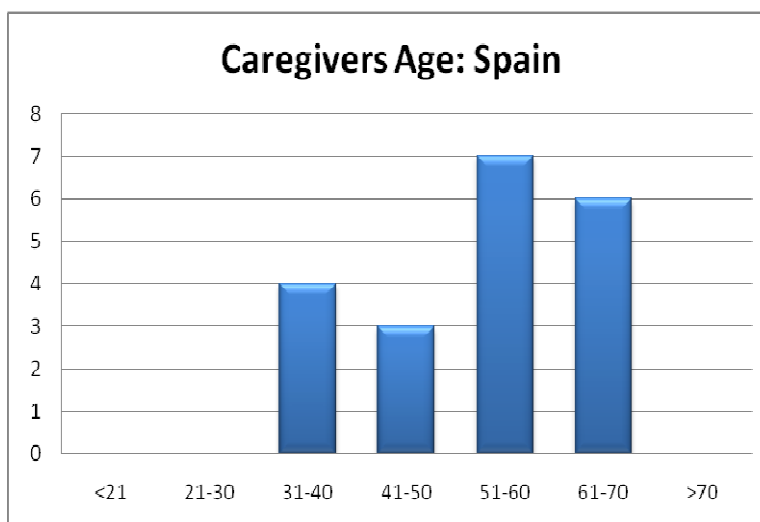


Fig 33, Distribution of CG by age in Spain

In Spain the role of CG accounting for 65% of mother, 15% of father and 20% of professionals (Fig. 34).

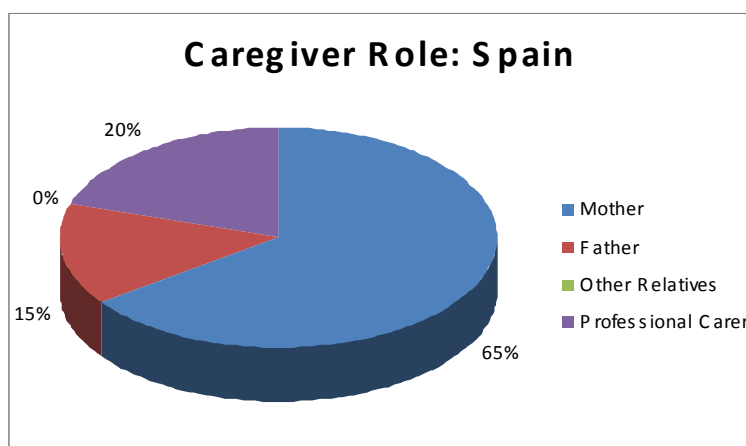


Fig 34, Distribution of CG by role in Spain

In Spain the sample of 20 CG shows a length of caregiving for 75% from birth, over 10 years for 15%, from 1 to 5 years for 10% and none between 6 and 10 years and less than 1 year (Fig. 35).

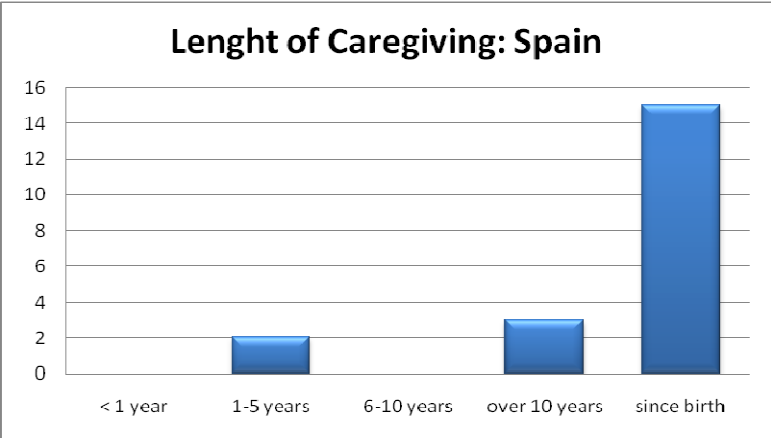


Fig 35, Distribution of CG by length of caregiving in Spain

## 4 RESEARCH METHODOLOGY

The survey was conducted through a particular type of structured interviews, built from ICF, for assessing the quality of life, by a group of experts selected from the partners (psychological, doctors, psychiatrists, professional technicians), based on a multidimensional and integrated approach.

**ICF** is a common classification about Disability and environmental barriers/facilitators. The **ICF** is a classification tool, planning and evaluation, during the research was to describe and analyze the state of health of people in relation to their areas of life, paying particular attention to the family reference and socio-environmental, including services available. **WHO's** Family Tools focus on a Standardized Assessment of Disabilities and Quality of Life.

**Caregiver Burden Inventory** assess the **burden** of caregivers as the most important "environmental" factor influencing the lives of people with disabilities.

Structured **Caregivers Role Relation Interview (Ca.R.R.I.)** point out how the relationship between caregivers and care-receivers and their deep emotional aspects play a relevant role in improving or worsening the Quality of life of people with disabilities.

Research data were obtained using a sample of 20 persons with disabilities and 20 caregivers (family and / or educators) of which we also collected socio-personal data. We have selected 20 (for each country) people with disabilities whose features should let us to identify (WP7) a group of 10 that will participate in the phase of training:

- mild mental retardation (WAIS-R QI from 50-55 to 70)
- under 40 years old
- able to learn (more details in ICF Checklist Range)
- able to participate

ICF and Who-QOL were administered by psychologists to 20 selected persons with disabilities, in the presence of an educator / operator of reference. The obtained data include the following:

- the condition of disability of the person
- restrictions on the activities and restrictions on participation
- environmental factors that constitute barriers/facilities to performance
- quality of life of the person: psychological area, natural area, social relationships, environment

The CBI and the Ca.R.R.I. were administered to 20 selected caregivers. Obtained data are the following:

- a number of stress factors related to the burden of care distinguished: objective burden, psychological, physical, social, emotional
- various aspects of the relationship between the caregiver (CG) and care-receiver (CR): CR needs and dispersion of dependency, emotional factors, change (at the personal, familial,

relational and social, professional), vision of the relationship in the future (on a realistic and idealistic)

The tools used are summarized in Table. 2

TOOLS	FROM	TO	TIME
<b>ICF Checklist</b> <b>WHODAS II</b> (36 Items)	Case Manager	Proxy	60 min (40+20)
<b>WHOQoL</b> (24 items)	Case Manager	Proxy or Care Receiver (Self-administered)	15 min
<b>CBI (Caregiver Burden Inventory)</b> (24 Items)	Relative or Proxy	Relative or Proxy	15 min
<b>Ca.R.R.I (Caregiver Role Relation Interview)</b>	Psychologist	Relative or Proxy	30 min

Tab. 2 – Tools used in WP2

#### 4.1 ICF Checklist

ICF CheckList is a selection of the complete ICF focusing on activity limitations, participation restriction and environmental factors.

ICF is a multipurpose classification designed to serve various disciplines and different sectors. Its specific aims can be summarized as follows:

- to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants
- to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities
- to permit comparison of data across countries, health care disciplines, services and time
- to provide a systematic coding scheme for health information systems

These aims are interrelated, since the need for and uses of ICF require the construction of a meaningful and practical system that can be used by various consumers for health policy, quality assurance and outcome evaluation in different cultures.

Since its publication as a trial version in 1980, ICIDH has been used for various purposes, for example:

- as a statistical tool – in the collection and recording of data (e.g. in population studies and surveys or in management information systems)
- as a research tool – to measure outcomes, quality of life or environmental factors
- as a clinical tool – in needs assessment, matching treatments with specific conditions, vocational assessment, rehabilitation and outcome evaluation

- as a social policy tool – in social security planning, compensation systems and policy design and implementation
- as an educational tool – in curriculum design and to raise awareness and undertake social action

Since ICF is inherently a health and health-related classification it is also used by sectors such as insurance, social security, labour, education, economics, social policy and general legislation development, and environmental modification. It has been accepted as one of the United Nations social classifications and is referred to in and incorporates *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*.

Thus ICF provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation.

ICF is useful for a broad spectrum of different applications, for example social security, evaluation in managed health care, and population surveys at local, national and international levels. It offers a conceptual framework for information that is applicable to personal health care, including prevention, health promotion, and the improvement of participation by removing or mitigating societal hindrances and encouraging the provision of social supports and facilitators. It is also useful for the study of health care systems, in terms of both evaluation and policy formulation.

ICF requires 40 minutes for administration.

#### **4.2 World Health Organization Disability Assessment Schedule II (WHODAS II; WHO, 2000)**

The WHODAS II has been developed to assess the activity limitations and participation restrictions experienced by an individual irrespective of medical diagnosis.

Respondents are asked to state the level of difficulty experienced taking into consideration how they usually do the activity, including the use of any assistive devices and/or the help of a person. The domains included in the instrument are:

- understanding and communicating
- getting around
- self care
- getting along with people
- life activities
- participation in society

This version (36 item) provides the most complete assessment of functioning.

Scores for six domains of functioning, as well as an overall functioning score, can be calculated.

For each item that is positively endorsed, a follow-up question asks about the number of days (in the past 30 days) the respondent has experienced this difficulty.

The day codes version assesses number of days using a five-point ordinal scale, while the days version simply asks the respondent to report the actual number of days the difficulty was present.



WHODAS II requires 20 minutes to administering.

#### **4.3 World Health Organization Quality of Life (WhoQoL; WHO, 2004)**

There are two administrations: start-end project. WhoQoL is an instrument that allow assessment of effectiveness of intervent, analyzing outcomes.

This instrument assesses the perception that individuals have of their position within the context in which they live and of values systems, dealt with their objectives, expectations, standard and interests.

This instrument provides a multidimensional profile about the environments and the aspects of the quality of life. This instrument can be applied in many contexts: medical, research, control and political.

Moreover this instrument assesses the efficacy of treatments, as well as the variations of quality of life among different cultures, in order to compare subgroups in the same culture, and to measure changes on time due to the adjustments of circumstances of life.

It is made up of 24 items subdivided in 4 domains:

- physical Environments
- psychological Environments
- social Relationships
- environment

It derives from a previous version made up of 100 items that permits a detailed valuation of the individual's characteristics relating to the quality of life.

This instrument should be self-administered if the respondent has sufficient abilities of comprehension; otherwise, it should be administered by an interviewer or the interviewer should help the subject to compile the questionnaire.

The instrument requires 15 minutes for administration.

#### **4.4 Caregiver Burden Inventory (CBI; Novak M. & Guest C., 1989)**

The CBI is an instrument that allows assessing stress level due to caregiving, taking into account multidimensional aspects.

It is a self-report instrument, compiled by the principal caregiver that is a relative or an operator who most supports the burden due to caregiving.

The caregiver is required to answer marking the box that is closer to his/her condition or personal impression.

The CBI is an instrument characterized for the quickness of its compilation and its simple comprehension.

The CBI consists of 24 questions, subdivided into 5 sections, that measures the impact of caregiving on the caregiver's:

- flexibility with time
- physical health
- social relationships

- emotional well-being
- life in general

The CBI allows obtaining a profile of caregiver's burden into the different domains, comparing various subjects and immediately observing CBI's burden variation in time.

Caregivers with the same total score can show different burden's models.

These various profiles indicate different social needs and psychological and represent different objectives of different intervention methods, planned for relieve the weak point specified in the test.

CBI requires 15 minutes for administration.

#### **4.5 Ca.R.R.I. (Caregiver Role Relation Interview; Group of psychologists of CSE "Il Totem", 2010)**

The interview has been developed by psychologists that work in the CSE "Totem", managed by Co&So and leaded by City of Florence.

The aim is to deeply understand the relationship between the caregiver (CG) and the carereceiver (CR), on an epistemological constructivist reference.

The caregiver, through qualitative techniques as semantic differential, constructivist techniques as dependence grid and questions with open answer, is stimulated to reflect on the caregivers's emotions toward the carereceiver (and vice versa), possible explanations, caregiver's needs and carereceiver's needs, future relationship with the carereceiver from an idealistic and realistic viewpoint.

This aspects are subdivide in 5 sections:

- 1) **CR's needs and support:** the carereceiver's typology and needs' amount, people which give support and intensity's support perceived by the CG about the carereceiver's needs' satisfaction.
- 2) **CR' s emotions:** the caregiver's perception concerning the way the carereceiver feels towards him, that means the capacity to understand the effects of his behaviour and on his relationship with the carereceiver.
- 3) **CG' s emotions:** the way the caregiver is feeling about the carereceiver.
- 4) **Change:** the type of change (positive or negative) the caregiver is feeling from the carereceiver, on a personal, familiar, relational, social and professional level.
- 5) **Relationship in the future:** the way the caregiver imagines the relationship with carereceiver in future.

The caregiver has the possibility to express, comment and specify different elements missed on the interview through opened questions.

The obtained information let the caregiver increase the comprehension and consciousness of various aspects of the relationship with the carereceiver and identify directions about possible and expected interventions that should improve the relationship between caregiver and carereceiver and the satisfaction of their needs in order to have positive consequences on their quality of life.

The interview is structured, and it should be self-administered, administered by a psychologist or guided for psychologists.

Ca.R.R.I. requires 30-40 minutes for administration.

#### 4.6 Data Analysis

For the tools used in the research phase were calculated descriptive statistics to analyze the average trend of the variables considered and the variability, both within a country is making comparisons between the various countries involved. Correlations were also calculated with the Pearson r coefficient, to analyze possible relationships between the variables included.

Has been set up an excel file for data analysis including:

- The paper of "users"; in which they are given the initials of the country (IT, FR, SP, AUS, ROM), the identifier (ID) subjects (1 to 20), the ICF data (average of values corresponding to technology, environment, relationship and support, attitudes, policies, delay, knowledge, tasks and communication, autonomy, interpersonal relationships), data of the areas of quality life (the percentage was calculated by the annex to the manual on cd, in reference to the areas physical, psychological, social relationships, environment). For each instrument were calculated the mean and standard deviation: the total, for each area, for each country and for Europe, in order to assess the trend and the variability within each country and to make comparisons between different countries
- The paper of " Caregivers" in which they are given the initials of the country (IT, FR, SP, AUS, ROM), the identifier (ID) subjects (1 to 20), data areas of the CBI / employee, developmental, physical, social, emotional) and Ca.R.R.I. (dispersion relation, change, future). For each instrument were calculated the mean and standard deviation: total, for each area for each country and for Europe, in order to assess the trend and the variability within each country and to make comparisons between different countries. In particular, the index of dispersion of dependency (included in column Ca.R.R.I. dispersion) is obtained by performing the following calculations:
  - 1) Index of dispersion of reference on support for the needs of the CR (Id rifScr) =  $\Sigma$  for all the support received from the CR / total number of figures that are supportive. The result is the potential value of support spread over all the figures. The better the performance, the greater the dispersion
  - 2) Index of dispersion for support from the CR (Id Scr) =  $\Sigma$  for all the support received from the CR / number of figures who have scored less than Id rifScr. The result indicates the actual distribution of support for the CR .
  - 3) Index of dispersion of reference on support received from the CG (Id rifScg) =  $\Sigma$  for all the support received from the CG / total number of figures that are supportive.
  - 4) Index of dispersion for support from the CG (Id SCG) =  $\Sigma$  for all the support received from the CG / number of figures who have scored less than Id rifScg.
  - 5) Both values (Id and Id Scg Scr) are plotted on a scale from -3 to +3 indicating a poor dispersion of the support (negative values and 0) and high (positive values),
  - 6)  $X = [(Id * 7) / 105] - 3$  (7 refers to the number of values in the range from -3 to +3 in a 7-point scale; 105 refers to the maximum score of support received, if all the

figures with the highest rating; -3 Subtraction is performed to return the value on the 7-point scale).

7) Is finally calculated the average between the values of Id and Id Scg Scr.

Contents of the report (included in column Ca.R.R.I. Relationship) is obtained by performing the following calculations:

- 1) standard deviation in Table 2 (CG perception of the feelings that CR has towards CG)
- 2) standard deviation in Table 3 (expression of CG feelings towards the CR)
- 3) Average differences between the values of Tables 2 and 3
- 4) Standard deviation of the differences between the values of Tables 2 and 3
- 5) standard deviation in Table 2 converted to bring the value to a 7-point scale (-3 to +3): =

$$\Delta t1 \Delta s1 * 7 / 2$$

The denominator 2 indicates the maximum value that can reach the standard deviation (ranging from 0 to 2)

Standard deviation of Table 3 converted to bring the value to a 7-point scale (-3 to +3):

$$\Delta t2 \Delta s2 * = 7 / 2$$

- 6) The average of the differences between the values of tables 2 and 3 changed to return the value on a 7-point scale (-3 to +3):

$$Mt = Ms * 7 / 8$$

The denominator 8 indicates the maximum value that can reach the average (ranging from -4 to +4)

- 7) The standard deviation of the mean of the differences between the values of Tables 2 and 3 changed to return the value on a 7-point scale (-3 to +3):

$$\Delta mts \Delta sm * = 7 / 4$$

The denominator indicates the maximum value that can reach the standard deviation of the mean (ranging from 0 to +4)

- 8) The index of the equation:

$$IR = [(\Delta t1 \Delta t2 + + + Mt \Delta mts / 28) * 7] - 3$$

28 indicates the maximum value that can get the IR

The result varies on a scale from 0 to 7, therefore, is subtracted -3 to return values on a 7-point scale from -3 to +3.

- The paper "Users Caregivers" in which are given the initials of the country (IT, FR, SP, AUS, ROM), the identifier (ID) subjects (1 to 20), in column "ICF ambient" the average of values of technologies areas, environment, relationships and support, attitudes, and policies of the paper "Users", in column "ICF attitudes and family" sets the value corresponding to E410 of the ICF-checklist in column "ICF attitudes of operators" in column "ICF participation" and the average of values of ICF areas of delay, knowledge and communication tasks, autonomy, interpersonal relations of the paper "Users", in column "Qdv" the average of the values of the areas of quality of life, physical, psychological, social relations, environmental of the paper "Users", in the column of "Burden", the sum of the values of the areas of the dependent CBI, developmental, physical, social, emotional of paper "Caregivers", in the column "Ca.R.R.I" the average of the values of the areas of Ca.R.R.I dispersion, relation, change, the future of the paper "Caregivers". It shows the

order of needs of CR perceived by the CG (health, nutrition, mobility, security, emotional, sexual, economic, legal, relationships, hygiene, spiritual and other) in a table on a scale of 1 to 12 (1 = most important, 12 = least important)

- For each instrument were averaged for each country. There have been reports the value of the inverted average for each need for each country (by subtracting the average value of 12) so that as the number corresponds to the increasing order of importance of needs; was also calculated the standard deviation for any need, for the country and in Europe
- The paper “ Charts” which are reported in graphs showing trends for each area investigated with each instrument and in total and compared between countries
- The paper "Descriptive Statistics" that shows the values of descriptive statistics (mean, standard error, median, mode, standard deviation, sample variance, kurtosis, asymmetry, range, minimum and maximum, sum, count, level of confidence) for each instrument, both in total and for individual areas
- The paper "Correlation" which shows the values of the correlation (r Pearson) between the instruments used, both in total and for individual areas in order to detect associations under the assumptions of the research
- The paper "Covariance" which shows the values of covariance (average of products of deviations of each data pair). The covariance is used to determine the relationship that exists between two sets of data
- The paper "Data Italy" which shows the data copied from the paper "Users", "Caregiver", "User Caregiver" for each instrument, in order to calculate the values of the correlation, covariance, variance in one factor, anova
- The paper "One factor Analysis of variance" which shows the values in a factor analysis of variance between Italy and Spain with regard to the quality of life
- The paper "Anova" which shows the ANOVA values as regards the quality of life in Italy and Spain

## 5 RESEARCH RESULTS

### 5.1 Results ICF – International Classification of functioning, Disability and Health

On the mental functioning of the CR survey conducted by the ICF the results that emerge range from 0.2 (Spain) to 1.4 (France) on a scale from 0 (no impairment) to 4 (severe impairment) (Fig. 36). This indicates that the sample has minor problems (between 0% and 24% of handicap) level of consciousness and intellectual functioning, meeting the criteria for the selection of the sample.

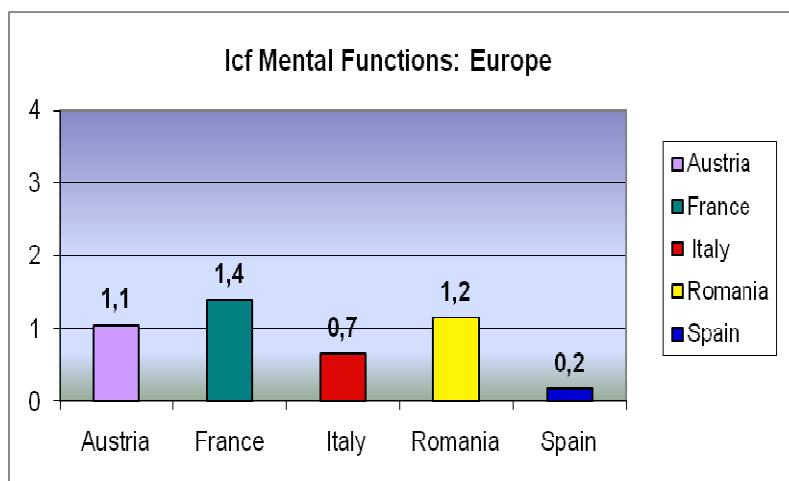


Fig 36, Results ICF - Mental retardation in the countries involved in the project

From survey on knowledge, tasks and communication of CR conducted with the ICF results that emerge range from 0.6 (Austria) to 1.7 (Italy) on a scale from 0 (no impairment) to 4 (severe impairment) (Fig. 37). This indicates minor problems (from 0% to 24%) of the sample of CR with regard to the ability to focus attention, read, write, calculate, problem solving, perform tasks, communicate verbally and in writing.

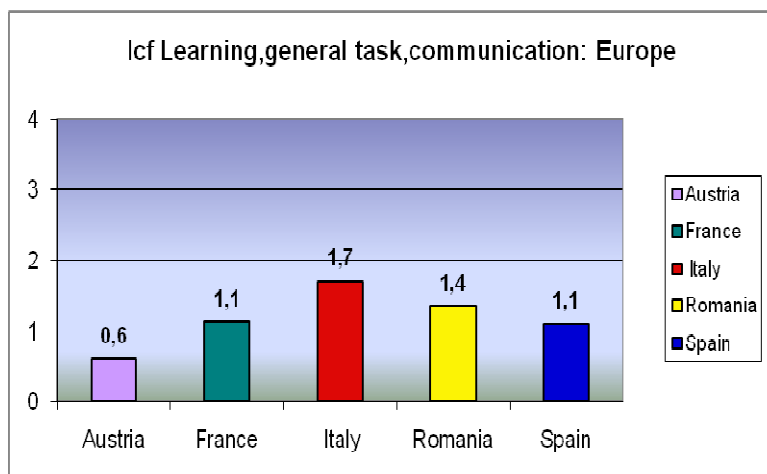


Fig 37, Results ICF- learning ,general task, communication in the countries involved in the project

From the survey conducted on the autonomy of the CR results that emerge range from 0.2 (Spain) to 1.2 (Romania) (Fig. 38) indicating mild problems (from 0% to 24%) with regard to mobility (use of the hand, walk, use public transport), self-care (bathing, dressing, care of the individual body parts, eating, drinking, taking care of your health), domestic life (purchase of goods and services, prepare dinner, do the housework).

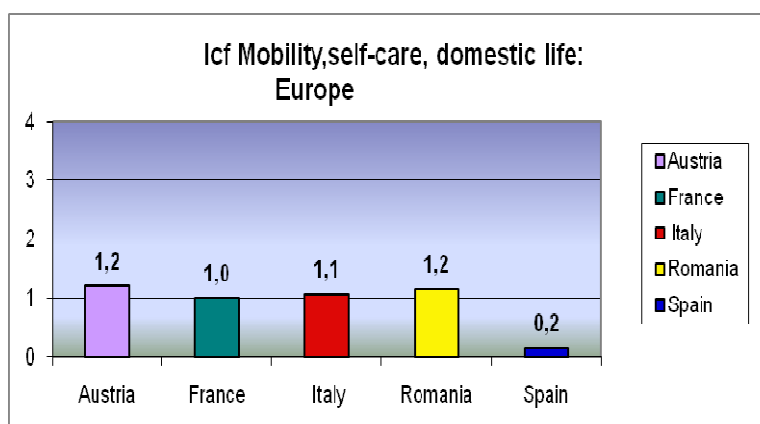


Fig 38, Results ICF- Self-government in the countries involved in the project

From the survey conducted on interpersonal relationships of CR with the ICF, results that emerge range from 0.6 (Italy) to 1.8 (Austria), indicating mild problems (from 0% to 24%) with respect to interpersonal interactions (Fig. 39). This could be a significant finding with regard to the selection of subjects with good social skills for the training course which will be held later in the project DActive.

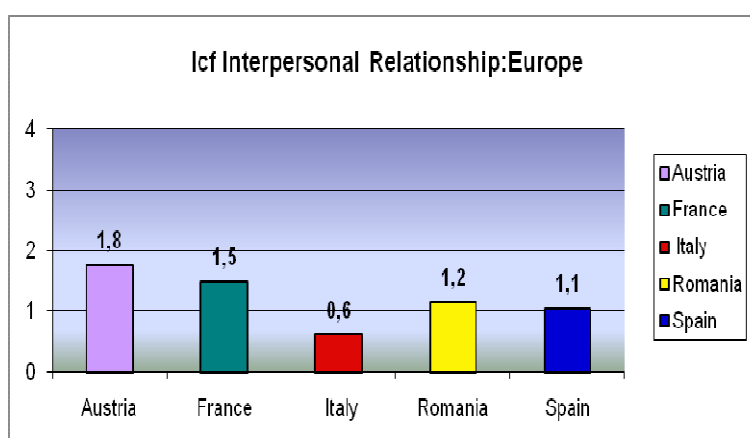


Fig 39, Results ICF - International relationship in the countries involved in the project

From the survey conducted by ICF on products and technologies in the environment in which a person lives, the results that emerge range from 0.3 (Spain) to 2.2 (Italy); data of Romania have not been received (Fig.40). The data indicate a facilitation in the use of products and substances for personal consumption (food, drugs), for personal use in daily life, mobility and transport in outdoor and indoor, for communication.

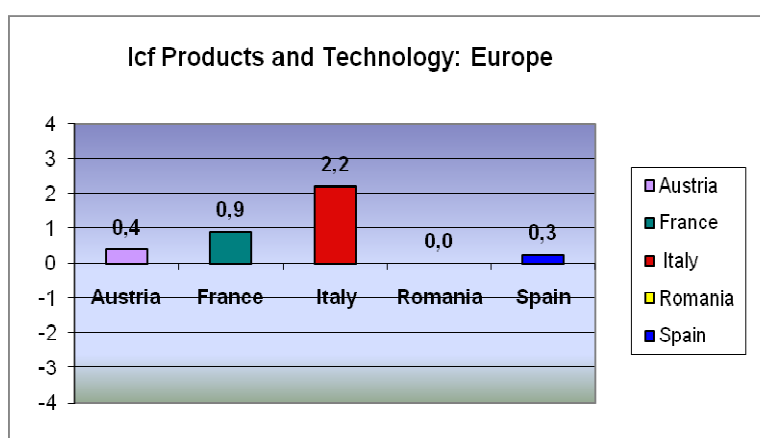


Fig 40, Results ICF - Products and technology in the countries involved in the project

From the survey conducted by ICF on the natural values, emerge range from 0.2 (Spain) to 0.4 (France), indicating a good physical environment in which a person lives (Fig. 41).

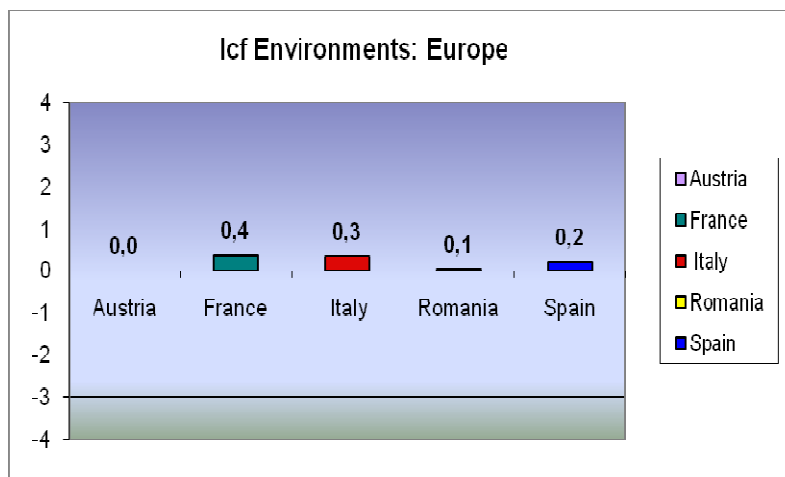


Fig 41, Results ICF - Natural environment and changes made by man in the countries involved in the project

From the survey conducted on the relationships and social support of the ICF CR with the results that emerge range from 0.6 (Italy) to 2.1 (Spain), indicating a good amount of physical and emotional support from family, family, friends, acquaintances, operators (Fig. 42). These results are useful for the selection of individuals with disabilities for the training course which will be built in the later stages of the project DActive, including the involvement of family members and professionals.

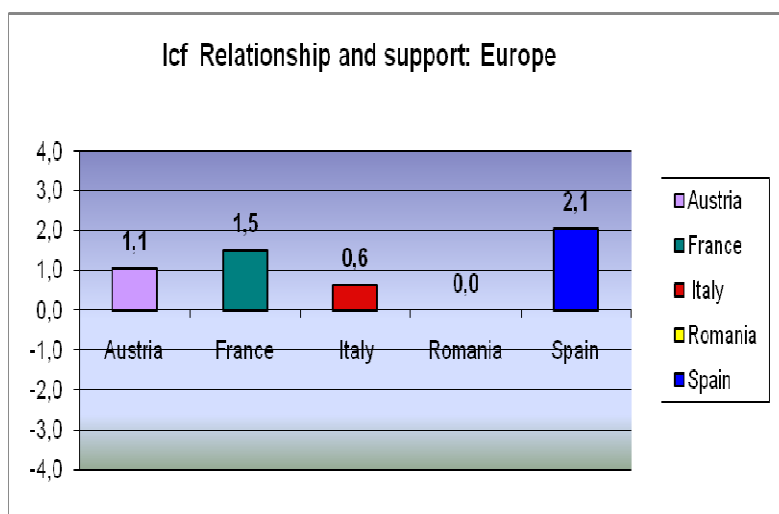


Fig 42, Results ICF - Relationship and support in the countries involved in the project

## 5.2 Results WHOQOL – World Health Organization Quality of Life

From the survey on **quality of life**, the results that emerge (Fig. 43) are positive and have a range between 60% (France) and 65% (Spain). Therefore indicate a positive perception and a good satisfaction of CR for its position in his context and a certain homogeneity in Europe. These data will be compared with those that will be collected with the same questionnaire after the implementation of the training course for the people with disabilities in order to detect any change in the various areas for individuals of the same country, and in the various countries involved in the project.



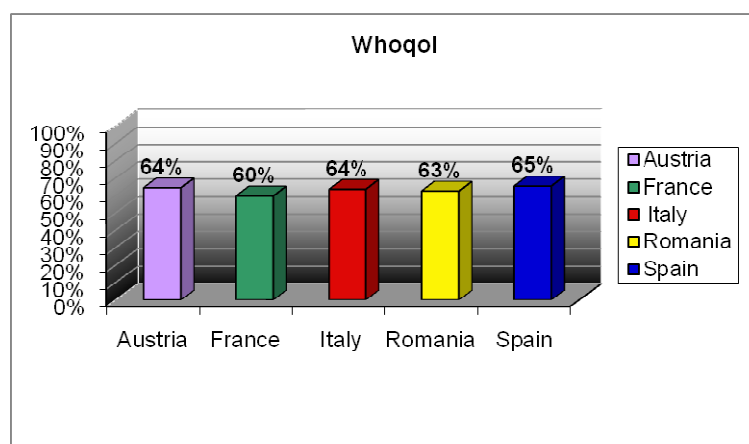


Fig 43, Results Whoqol in the countries involved in the project

From the investigation on the areas of quality of life in Europe, emerge range from 60% (social relations) to 71% (environment) (Fig. 44). The data indicate a positive perception and satisfaction for more environmental factors such as physical protection and safety, home environment, economic resources, quality and availability of social and health opportunities for the acquisition of new information or skills, participation and opportunities for recreation, physical environment of the establishments, transportation.

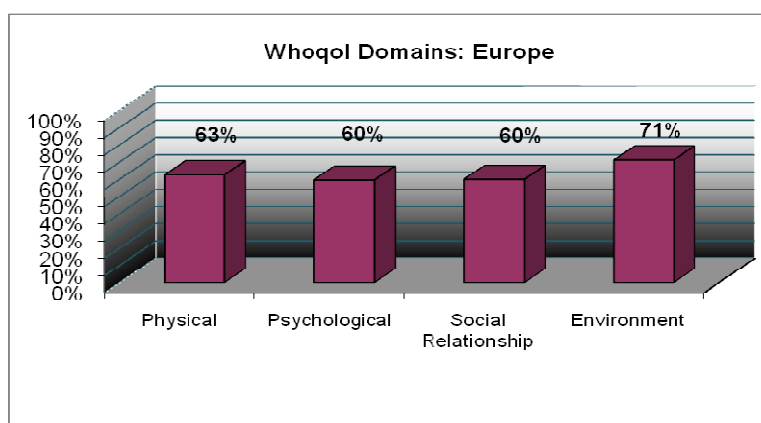


Fig 44, Results Whoqol for area in the countries involved in the project

From analysis of individual areas of Whoqol, particularly with regard to the physical environment (Fig. 45), emerging values ranging from 57% (Austria) to 68% (Spain). This could indicate a positive perception on the part of CR and satisfied with their physical health (noise, inconvenience, energy, sleep, mobility, activities, treatments, ability to work).

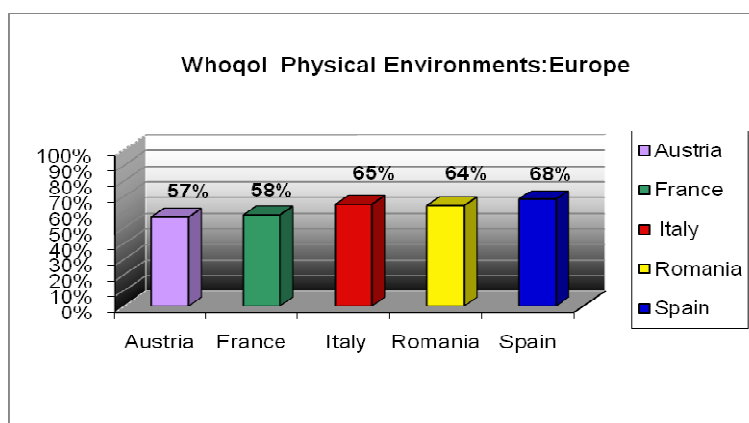
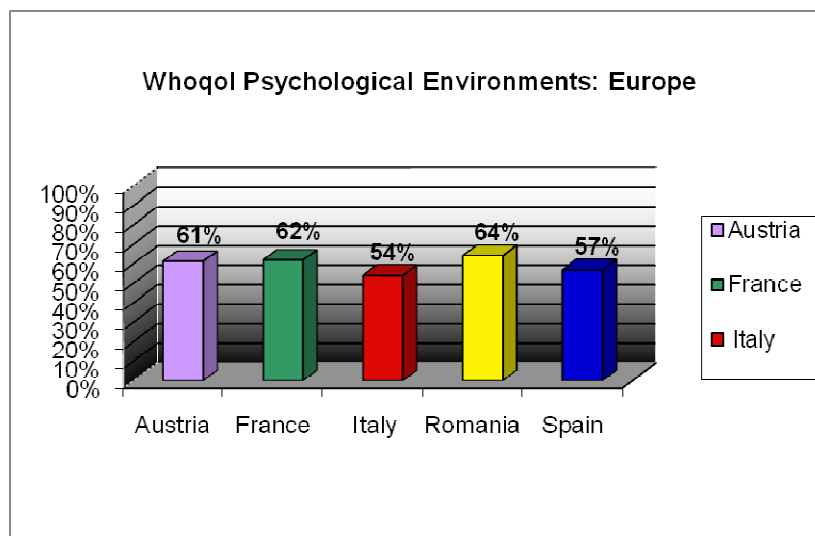


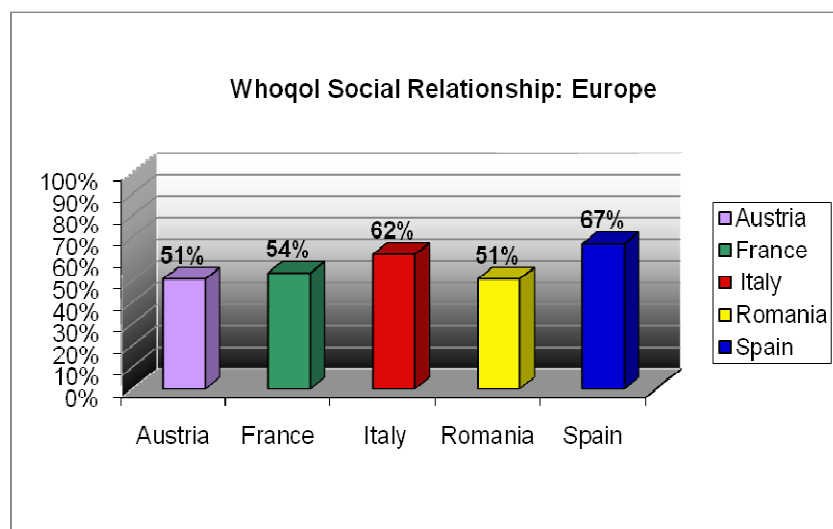
Fig 45, Results Whoqol for physical area in the countries involved in the project

From the specific psychological investigation (Fig. 46) emerge values ranging from 54% (Italy) 64% (Romania), indicating a positive perception by the CR of their feelings, reasoning ability, memory and concentration, imagine body and appearance, personal beliefs and good self - esteem.



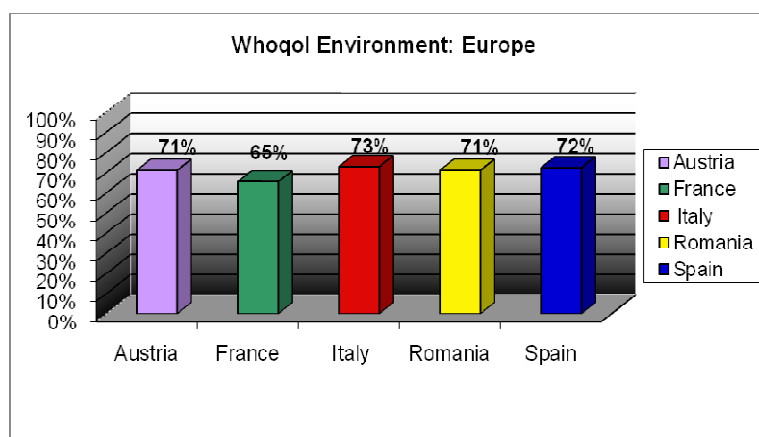
*Fig 46, Results Whoqol for psychological area in the countries involved in the project*

From specific investigation on social relationships (Fig. 47) emerge results ranging from 51% (Austria and Romania) to 67% (Spain). This could indicate a positive perception and satisfaction of a good CR for their interpersonal relationships and social support received.



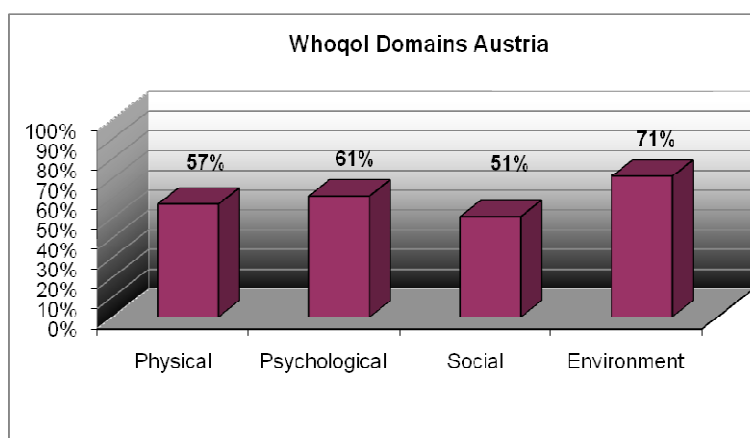
*Fig 47, Results Whoqol for social relationship area in the countries involved in the project*

From specific investigation of environment of origin (Fig. 48) emerge values ranging from 65% (France) 73% (Italy), indicating a positive attitude and a good satisfaction of environment of CR in terms of safety and security, home environment, financial resources, health and social care, opportunities to acquire new information or skills, participation and opportunities for recreation, fitness, transportation. The area of the environment gets the higher score than other areas of quality of life in all countries involved in the project.



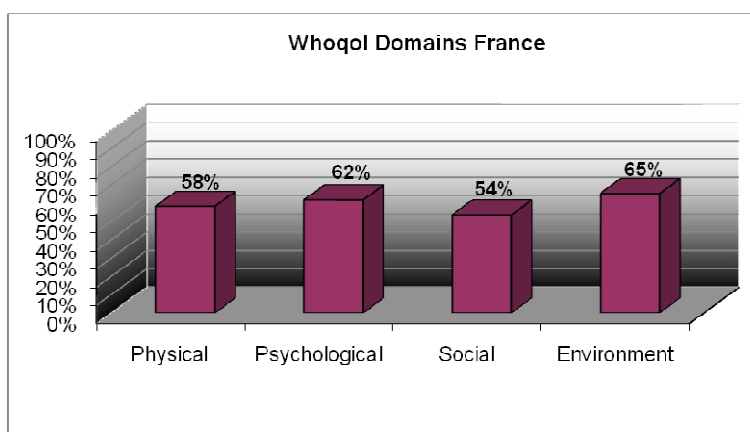
*Fig 48, Results Whoqol for environment area in the countries involved in the project*

From the investigation the Austrian sample in Whoqol (Fig. 49) emerge values between 51% (qol social) and 71% (qol environment), indicating a small but positive perception and satisfaction on the part of CR reports more social and the environment in which they live.



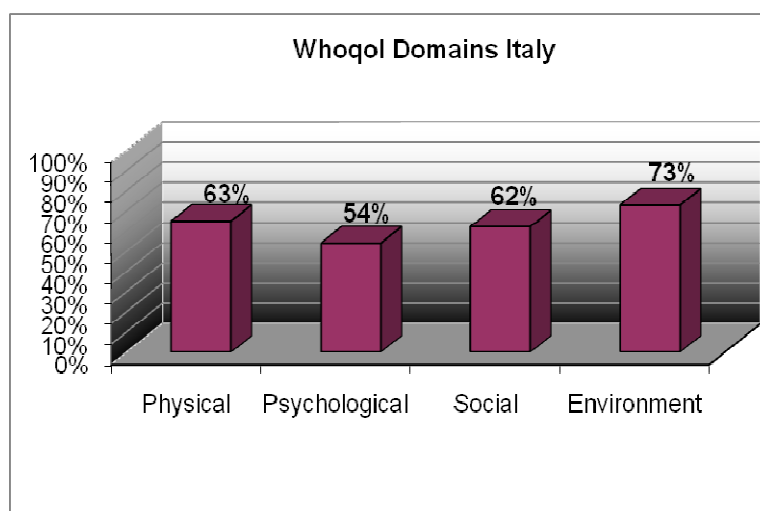
*Fig 49, Results Whoqol for areas in Austria*

The French sample in Whoqol (Fig. 50) have revealed values between 54% (qol social) and 65% (qol environment), indicating a perception of lower and lower satisfaction on the part of CR for their social relations and more for the environment in which they live.



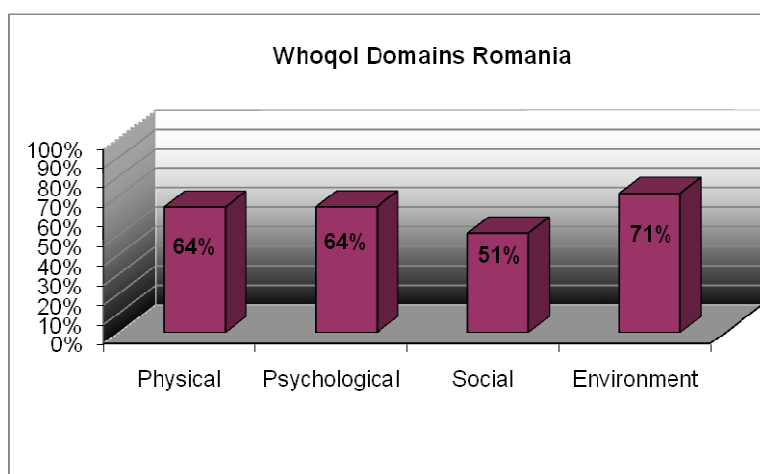
*Fig 50, Results Whoqol for areas in France*

Whoqol investigation of the Italian sample (Fig. 51) have revealed values between 54% (psychological qol) and 73% (qol environmental), indicating a positive attitude and high satisfaction on the part of CR for your environment of life, while the lower is the satisfaction with their quality of life, psychological.



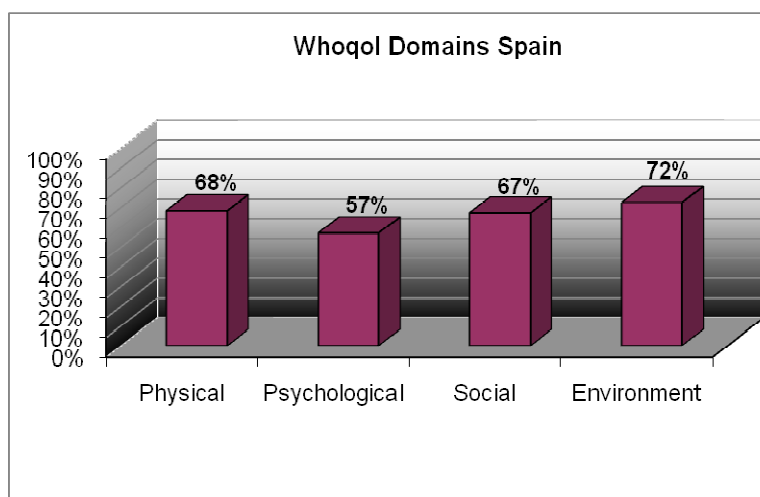
*Fig 51, Results Whoqol for areas in Italy*

Whoqol investigation of the Romanian sample (Fig. 52) have revealed values between 51% (qol social) and 71% (qol environment), indicating less satisfaction and perception on the part of Cr for their social relationships and more the environment in which they live.



*Fig 52, Results Whoqol for areas in Romania*

The Spanish sample in Whoqol (Fig. 53) are revealed values between 57% (psychological qol) and 72% (qol environment), indicating less satisfaction and perception on the part of CR for their psychological condition and more for the environment in which they live.



*Fig 53, Results Whoqol for areas in Spain*

### 5.3 Results CBI – Caregiver Burden Inventory

From the survey conducted on the burden of care the mean scores ranging from 14 (Austria) to 26 (Spain) (Fig. 54) and do not indicate a risk of burnout. The data were not available in France. Content level of stress perceived by the CG in the care of CR, could be an indicator for the selection of 10 adults with disabilities for the course will be conducted in subsequent phases of the project and the possible involvement of the CG.

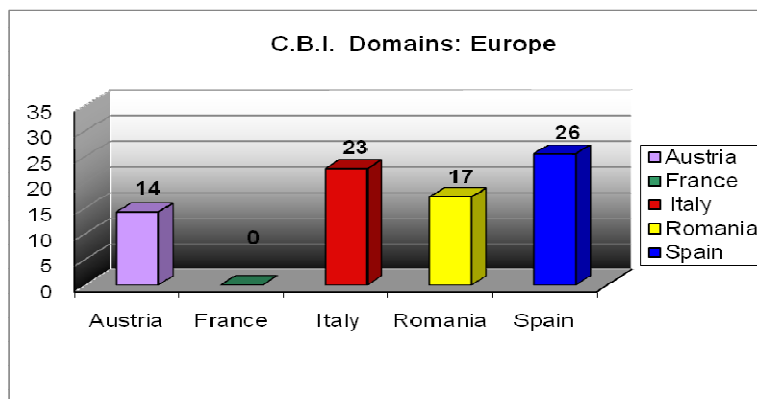


Fig 54, Results CBI in the countries involved in the project

From the survey on areas of the burden of care (Fig. 55), the values range from 1.8 (emotional burden) to 7.8 (dependent burden), indicating a higher level of stress due to the decrease of the time the CG has available for himself on assistance to the CR, there is a lower level of stress in relation to the emotional aspects of the relationship between CG and CR.

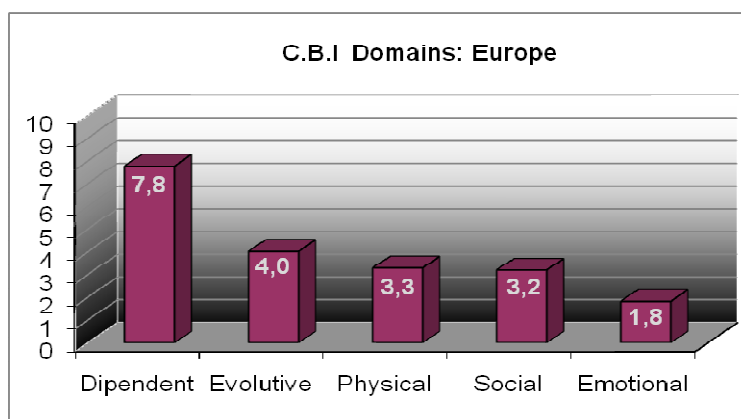


Fig 55, Results CBI for area in the countries involved in the project

From the burden of care in the areas of CBI in Austria (Fig. 56), values ranging from 1.83 (emotional burden) to 5.72 (burden dependent).

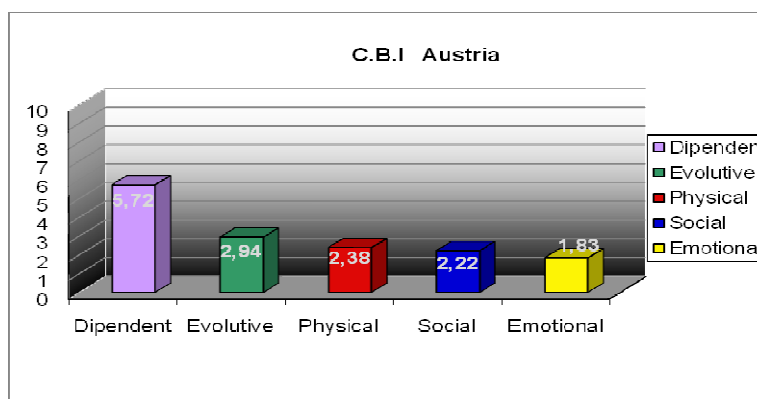


Fig 56, Results CBI in Austria

From the burden of care in areas of CBI in Italy (Fig. 57), values ranging from 1.95 (emotional burden) to 7.4 (dependent burden).

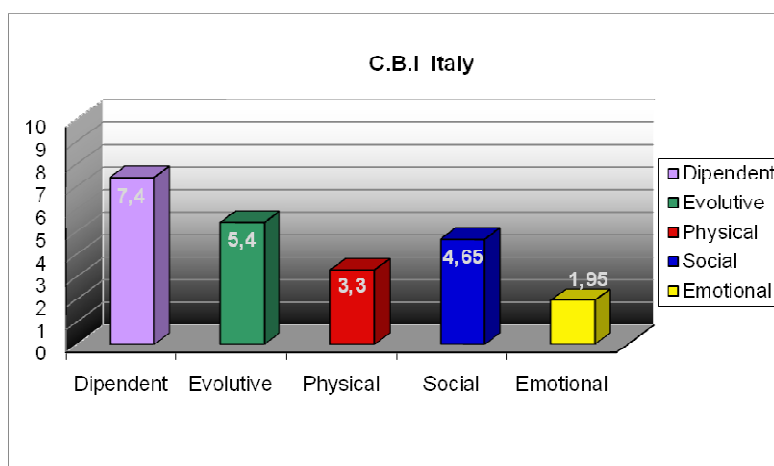


Fig 57, Results CBI in Italy

From the burden of care in the areas of CBI in Romania (Fig. 58), values ranging from 0.75 (emotional burden) to 8.9 (dependent burden).

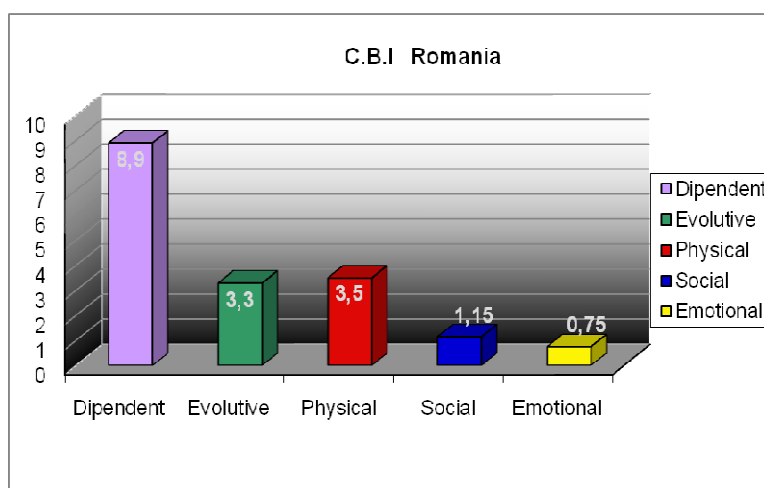


Fig 58, Results CBI in Romania

From the burden of care in the areas of CBI in Spain (Fig. 59), values ranging from 2.58 (emotional burden) to 9.17 (burden dependent).

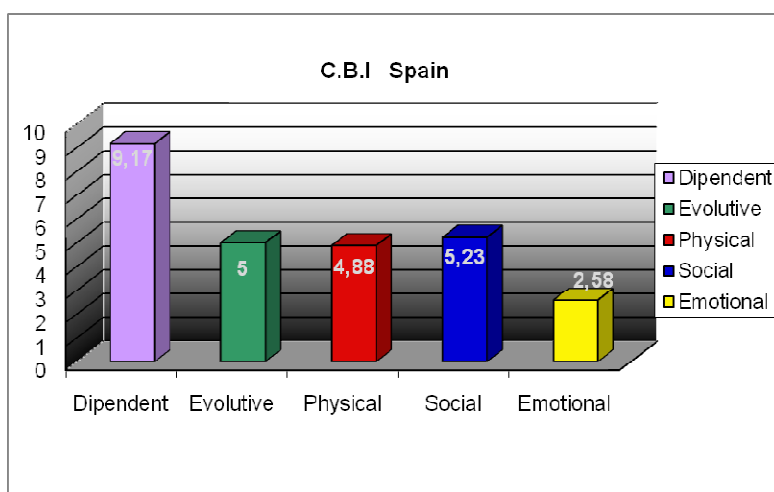


Fig 59, Results CBI in Spain

#### 5.4 Results Ca.R.R.I. – Caregiver Role Relation Interview

From the survey in Europe on the relationship between Caregiver and Carereceiver the results range between -0.4 in Italy and 0.1 in France (Fig. 60).

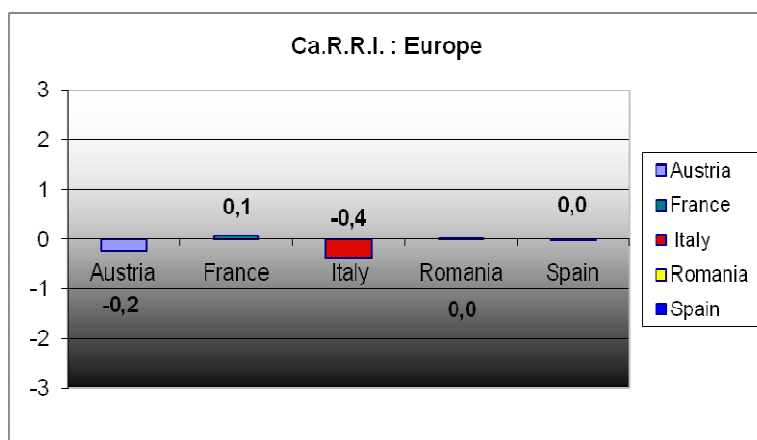


Fig 60, Results Ca.R.R.I. for areas in the countries involved in the project

From the analysis conducted with Ca.R.R.I. for investigate how the caregiver perceives that the carereceiver depends on him, the results show a score of - 1 in Spain and in Austria, 0 in Italy and Spain and 1 in France (Fig. 61).

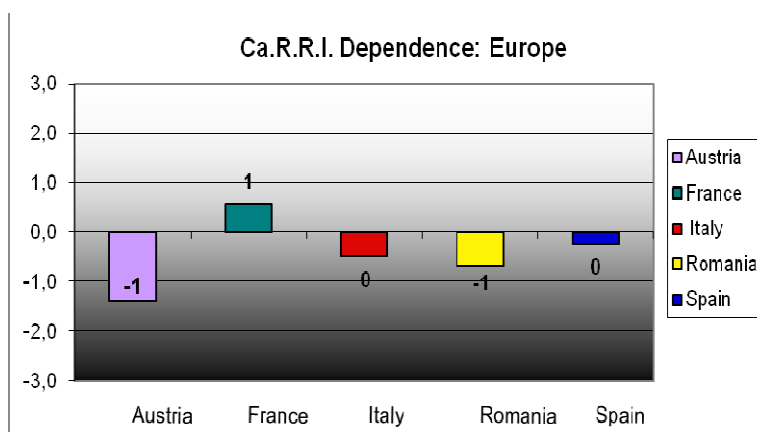


Fig 61, Results Ca.R.R.I. Dependence in the countries involved in the project

Regarding the perception of change in the relationship by the CG, the scores are 0 in France, Italy and Spain, 1 in Austria and Romania (Fig. 62).

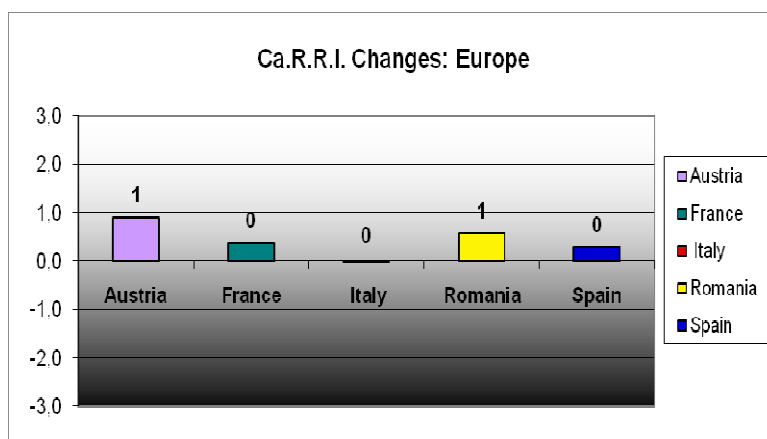


Fig 62, Results Ca.R.R.I. Changes in the countries involved in the project

From Analysis of the perception of the future by the CG has been detected in Italy a score of 0, 1 in Austria, France and Spain and 2 in Romania (Fig. 63).

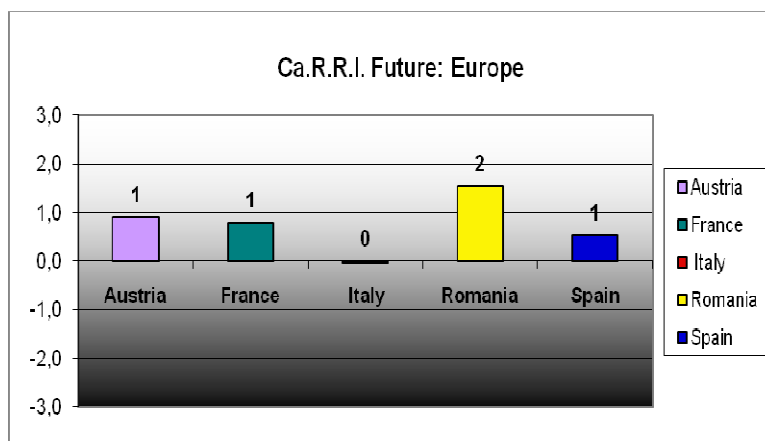


Fig 63, Results Ca.R.R.I. Future in the countries involved in the project

Regarding the relationship between CG and CR, all countries have achieved an average score of -1 (Fig. 64).

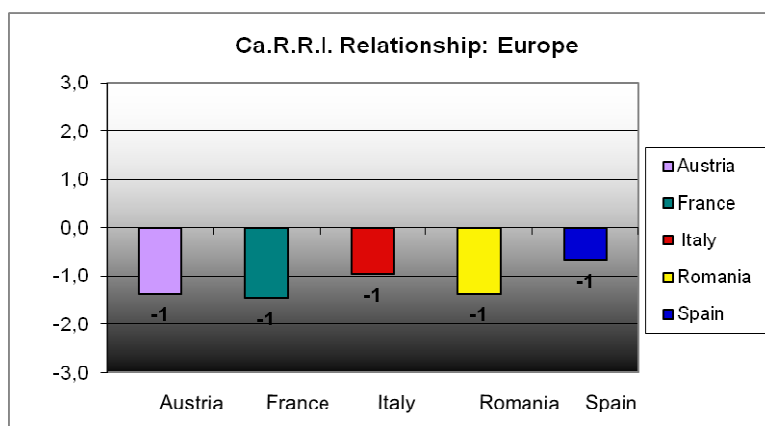


Fig 64, Results Ca.R.R.I Relationship in the countries involved in the project

It was also called on the CG (table section 1.A Ca.R.R.I.) to order the needs of the CR numerically using numerical values from 1 to 11, with 1 being the most important needs to be met and 11 the least important. It was also given the opportunity to add and order any other needs also not present in the grid (No CG has used this option). The following chart shows the orders of need on average for Europe (fig. 65).

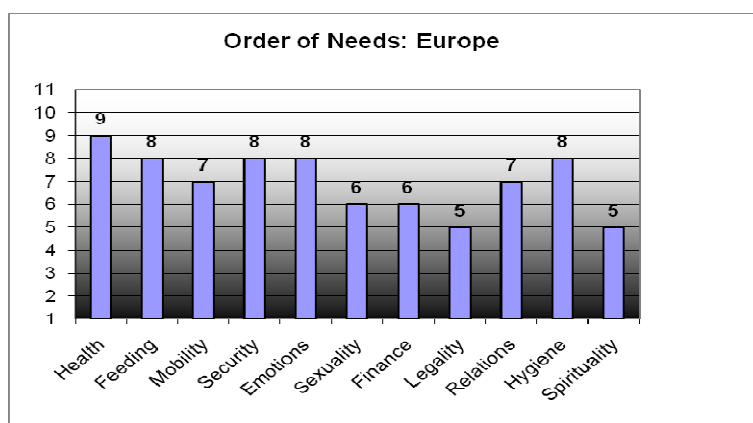


Fig 65, Average of Order of Needs: Europe



On average, it appears that the CG for the health of the CR is the most important need, followed by food, emotions, safety, hygiene and mobility. Sexuality and finances are important but not sufficiently fundamental and precede a legal and spiritual needs.

#### 5.4.1 Analysis of the frequencies of Ca.R.R.I. Relationship

In the tables below will be described frequencies analysis about emotions and feelings, like table 2 and table 3 in Ca.R.R.I. interview.

We have chose only per cent frequencies of value 2, in a scale from -2 to +2.

#### AUSTRIA

<i>Emotions</i>	<i>CR's emotions</i>	<i>CG's emotions</i>
Understood	42,9%	42,9%
Helped	42,9%	42,9%
Active	42,9%	
Encouraged		38,1%
Reassured	47,6%	61,9%
Involved		52,4%
Accepted	57,1%	57,1%
Participant	47,6%	61,9%

*Tab. 3 Frequencies of emotions (per cent) in Austria*

#### FRANCE

<i>Emotions</i>	<i>CR's emotions</i>	<i>CG's emotions</i>
Understood	42,1%	
Accepted	36,8%	
Participant	42,1%	

*Tab. 4 Frequencies of emotions (per cent) in France*

The French CG have primarily answer with the value in the middle of the scale (0). It's possible clarify this data with the hypothesis that the role of CG is covered primarily by professional carer, that, diversify by family members, show less involvement; the chose of the middle value would be depend, also, by difficult on comprehension of test.

## ITALY

<i>Emotions</i>	<i>CR's emotions</i>	<i>CG's emotions</i>
Understood		33,3%
Beloved	71,4%	52,4%
Intrigued	42,9%	38,1%
Helped	71,4%	
Active		42,9%
Reassured	61,9%	
Stimulated	42,9%	38,1%
Involved	57,1%	38,1%
Accepted	85,7%	57,1%
Gratified	42,9%	33,3%
Appreciated		42,9%
Protected	57,1%	
Participant	47,6%	
Cheerful		28,6%
Welcoming	38,1%	42,9%
Attracted	38,1%	33,3%
Pleasant	33,3%	

Tab. 5 Frequencies of emotions (per cent) in Italy

## ROMANIA

<i>Emotions</i>	<i>CR's emotions</i>	<i>CG's emotions</i>
Understood	66,7%	76,2%
Beloved	66,7%	66,7%
Helped	85,7%	47,6%
Active	57,1%	71,4%
Encouraged	76,2%	57,1%
Reassured	90,5%	90,5%
Amused		52,4%
Stimulated	61,9%	61,9%
Involved	66,7%	76,2%
Protected	81%	47,6%
Accepted	85,7%	90,5%
Energetic	57,1%	47,6%
Calmed		61,9%
Participant		71,4%
Cheerful	57,1%	
Comforted	66,7%	33,3%
Calm	42,9%	52,4%
Appreciated	90,5%	85,7%
Gratified	66,7%	57,1%
Pleasant	90,5%	81%
Welcoming	76,2%	81%
Acquitted	52,4%	66,7%
Attracted	61,9%	47,6%

Tab.6 Frequencies of emotions (per cent) in Romania

The Romanian CG have give about totally value 2 in the scale from -2 to +2.

## SPAIN

<i>Emotions</i>	<i>CR's emotions</i>	<i>CG's emotions</i>
Understood	54,8%	47,6%
Beloved	76,2%	71,4%
Intrigued	57,1%	47,6%
Helped	66,7%	66,7%
Active	61,9%	52,4%
Encouraged	52,4%	42,9%
Reassured	54,8%	57,1%
Amused	40,5%	42,9%
Inhibited	38,1%	42,9%
Involved	66,7%	61,9%
Protected	61,9%	57,1%
Accepted		38,1%
Calmed	35,7%	33,3%
Participant	57,1%	47,6%
Cheerful	42,9%	38,1%
Comforted	28,6%	28,6%
Calm	45,2%	
Exculpated	38,1%	33,3%
Appreciated	64,3%	66,7%
Gratified	54,8%	52,4%
Euphoric		23,8%
Pleasant		42,9%
Welcoming	57,1%	52,4%
Acquitted	38,1%	38,1%
Attracted	40,5%	33,3%

*Tab. 7 Frequencies of emotions (per cent) in Spain*

The Spanish CG have answer about totally value 2, in the scale from -2 to +2, in exception item “inhibited / stimulated”, where they answer -2. This data show that CG is feeling “inhibited”, a negative emotions, and the CG’s perception concerning the way the CR feels toward him is also negative emotions.

The data reported above show how interviewed tend to give a “positive” emotional profile of the feelings involved in the CR - CG relationship.

## 5.5 Correlation matrices and Data Analysis with SPSS

### 5.5.1 Correlation in Austria

	Qol	Qol Ps.	Qol Soc.	Icf part	Ca.R.R.I. D	Ca.R.R.I. F	Ca.R.R.I.
CR Age	0,46	0,49	0,49				
CG Age					0,77		
Att Op				0,60			
Lenght CG					- 0,69	- 0,56	
Burden Ev.							- 0,44
Burden Soc.							- 0,52

Tab. 8 Matrix of correlations in Austria

- 1) The QOL is positively correlated with the age of CR with a value of 0.46. With increasing age of the CR corresponds an improvement of the quality of life.
- 2) The QDV PSYCHOLOGICAL is positively correlated with the age of CR with a value of 0.49. This data takes over the point 1, specifying the relationship with psychological well-being.
- 3) The QDV Social is positively correlated with the age of CR with a value of 0.49. This data takes over the point 1 and 2, specifying the relationship with social welfare.
- 4) The scale ICF Participation is positively correlated with the attitude of the operators (ICF) with a value of 0.60. This indicates that if CR had greater disability, the operators will have attitudes facilitating for the CR, that will try to support them more.
- 5) The scale Ca.R.R.I. dependence is positively associated with age of the GC with a value of 0.77. This indicates that with the increasing age of CR corresponds the better perception of the CG of the availability of support to meet the needs of the CR.
- 6) The scale dependence Ca.R.R.I. is negatively correlated with the lenght of caregiving with a value of -0.69. This indicates that with a more lenght of caregiving, corresponds a worse perception of the availability to support of the CG to meet the needs of the CR.
- 7) The scale Ca.R.R.I. Future is negatively correlated with the duration of caregiving with a value of -0.56. This indicates that with the more lenght of caregiving, corresponds a worse perception of the future by the CG.
- 8) The Ca.R.R.I. is negatively correlated with the Evolutionary Burden with a value of -0.44. This indicates that the perception of the CG to feel cut off from the opportunities of his peers, affects the relationship between CG and CR.
- 9) The Ca.R.R.I. is negatively correlated with the Social Burden with a value of -0.52. This indicates that if the CG perceives a greater social burden, this will lead to a worse relationship between CG and CR.

In summary the role of CG in Austria is covered entirely by professionals. The lenght of caregiving affects the perception of dependency dispersion (availability of support) and future prospects with regard to the relationship with the CR. The perception of increased burden of care on social and developmental level affects the relationship between CG and CR. As for the CR, with advancing age is associated with improved quality of life, especially on psychological and social aspects.

### 5.5.2 Correlation in France

	QoL	QoL Ph.	QoL Ps.	Att. Fam.	Att. Op.	Icf Env.
<b>Ca.R.R.I.</b>					0,77	0,53
<b>Ca.R.R.I. C</b>	- 0,47	- 0,56				
<b>Ca.R.R.I. D</b>					0,81	0,59
<b>ICF Part</b>	- 0,46		- 0,47			
<b>ICF Env</b>				0,68	0,59	

Tab. 9 Matrix of correlations in France

- 1) The Ca.R.R.I. is positively correlated to the scale of the attitude of operators (ICF) with a value of 0.77. This indicates that with the better mode of relationship between CG and CR, corresponds the better attitude of workers towards the CR.
- 2) The Ca.R.R.I. is positively linked to the ICF-scale environment with a value of 0.53. The relationship between CG and CR improves with support of environment.
- 3) The scale Ca.RRI change is negatively correlated with QOL with a value of -0.47. The lower the ability of the CG to perceive positive changes due to his meeting with the CR, the better the QOL of the CR.
- 4) The scale Ca.R.R.I. Change is negatively correlated with QOL Physical with a value of -0.56. This data takes up the third point in relation to the physical well-being.
- 5) The scale Ca.R.R.I. Dependence is positively correlated with the scale of attitude of the Operators (ICF) with a value of 0.81. This indicates that if CG had a attitudes facilitating , improves the perception of disponibility of supports for try to support needs of CR.
- 6) The scale Ca.R.R.I. Dependence is positively correlated with the scale ICF Environment with a value of 0.59. The environment in which lives the CR improves perception of the CG of the support availability to meet the needs of the CR.
- 7) The scale ICF Participation is negatively correlated with QOL with a value of -0.46. This indicates that with great disability of the CR, corresponds his worse well-being.
- 8) The scale ICF Participation is negatively correlated with QOL psychology with a value of -0.47. This confirms what is said in point 7, specifying the relationship with psychological well-being of the CR.
- 9) The scale ICF Environment is positively associated with the Family Attitude Scale (ICF) with a value of 0.68. The environment in which lives the CR (as a part of the activities, relationships with others, availability of facilities), influences positively attitudes of family members.
- 10) The scale ICF Environment is positively correlated with the scale of attitude Operators (ICF) with a value of 0.59. This data incorporates the point 9, but in relation to the attitudes of operators.

In summary the role of CG in France is covered entirely by professionals. Regarding the CG, the relationship, and in particular the perception of the dispersion dependence that is support, is positively correlated with an easing mode by the operators and a supportive environment. Moreover, a negative perception towards future prospects, in particularly on change, and the change that occurred for the relationship between CG - CR are associated with a better perception of QOL, particularly in the physical well-being by the CR. This indicates that workers, in some way, adversely affected, on the relationship level, the continuing effort in trying to improve the quality of life of people. As for the CR, a great level of disability corresponds in a lesser sense of well being, particularly psychological. The environment is more favourable if the attitudes of workers and their families are more facilitative.

### 5.5.3 Correlation in Italy

	QoL	QoL Ps.	QoL Ph.	QoL Soc.	Att. Fam.	Icf Part.	Burden	Burden S.	Burden F.	Lenght CG
Ca.R.R.I. D	- 0,45									
Ca.R.R.I. Fut.					0,60					
Ca.R.R.I. R							0,43			
Ca.R.R.I. C							- 0,47	- 0,61		
Ca.R.R.I.		- 0,52	- 0,52		0,54			- 0,54	- 0,54	
Att. Fam.		- 0,66								
Att. Op.				0,55	0,55					- 0,48
Burden D.					- 0,66					
Burden Soc.						0,63				
Burden					- 0,48	0,49				

Tab. 10 Matrix of correlations in Italy

- 1) The QOL of the CR is negatively correlated with the scale of the Ca.R.R.I. Dependence with a value of -0.45. This indicates that increasing the QOL of CR there is a perception, by the CG, of a lower availability of support to meet the needs of the CR or a greater reliance on himself. This can be interpreted as if the relationship of support from the CG in any way obstruct the satisfaction of the CR. In practice, the action could help to meet our needs but this may limit somewhat the sense of total well-being by the CR (I protect you but I will limit myself).
- 2) The QOL Psychological of CR is negatively correlated with Ca.R.R.I. of CG with a value of -0.52. This data specifies the considerations in point 1, in relation to the fact that the relational aspects, reported with Ca.R.R.I., affect negatively on the QOL psychological of the CR and also vice versa.
- 3) The QDV Psychological of CR is negatively correlated with the level of family attitudes (ICF) with a value of -0.66. To reduce the psychological well-being is a mode facilitating the attitudes of family members. This could confirm the considerations on points 2 and 3 compared to the fact that a family attitude was seen as facilitating the satisfaction of needs related to disability but that at the expense of psychological satisfaction of CR.
- 4) The QDV SOCIAL of CR is positively correlated with the scale of Attitudes Operators (ICF) with a value of 0.55. This indicates that if the operators have attitudes facilitating for the CR, this affect positively the QOL Social of the CR.
- 5) The scale Attitudes operators (ICF) is positively correlated with the scale ICF Attitudes of family members with a value of 0.55. The scale Attitudes operators (ICF) is positively correlated with the scale ICF Attitudes of family members with a value of 0.55. This is an indication of family attitudes and operators attitude are consistent. The statistical analysis is not meaningful to say the same considerations for operators expressed in point 3 about the family. Can be thought that this figure may also indicate to the operators, to some extent, that the report will help focus primarily on meeting the needs of disability and, unlike the familiar, even to the social (point 4).
- 6) The Family Attitude Scale (ICF) is positively correlated with the scale of future Ca.RRI with a value of 0.60. This indicates that, if the family has facilitating attitudes, there is a positive perception of the future by the CG.
- 7) The QOL Physical of CR is negatively correlated with the Ca.R.R.I. of CG with a value of -0.52. To reduce the physical well-being of the CR (in terms of better availability to rely on others to perceive a positive meeting with the CR and to have a better vision of the future) improves the relationship between CG and CR. This can be interpreted in accordance with points 1 and 2.
- 8) The family attitude scale (ICF) is negatively correlated with the scale of dependency burden of CG with a value of -0.66. These data demonstrate that increased perception of attitudes easily, and the help of CG corresponds to a lower perceived burden of special attention for the time taken away from him.

This can be interpreted as an attitude perceived by others (operators and CR) to help enable the CG to hear a load of varying intensity with respect to time mostly to himself.

- 9) The scale ICF Participation is positively correlated with the scale of the Burden Social of CG with a value of 0.63. This indicates that the greater the restriction on participation by the CR, the greater the social burden perceived by the CG.
- 10) The scale ICF Participation is to be positively correlated with the Burden with a value of 0.49. This indicates that with high limitation of participation corresponds a high burden of CG.
- 11) The scale of the Family Attitudes (ICF) is negatively correlated with the Burden with a value of -0.48. If the CR perceives a more facilitating attitude by CG there is a correlation with a lower welfare weight by the CG itself. This report covers the considerations in paragraph 8 to the whole load received by the CG.
- 12) The scale ICF Participation is positively correlated with the Social Burden scale with a value of 0.63. This indicates that with greater disability corresponds a high perception of social burden by CG.
- 13) The ICF participation scale is positively associated with the Burden of the CG with a value of 0.49. This indicates that with greater disability corresponds a high perception of social burden by CG.
- 14) The Burden of CG is positively correlated with the scale Ca.R.R.I. R with a value of 0.43. This indicates that with high perception of burden by CG corresponds a skill of CG to discriminate his emotions, their emotions and his emotions from emotions of another persons (ability to understand self and other).
- 15) The Burden is negatively correlated with the scale Ca.R.R.I. C with a value of -0.47. This indicates that with low perception of burden by CG, corresponds a skill by CG of positive perception of changes for the meeting with CR. the lower the total load received by the CG, the greater the ability of the CG to perceive positive changes due to his meeting with the CR.
- 16) The Social Burden is negatively correlated with the scale Ca.R.R.I. C with a value of -0.61. This indicates that with high perception of burden by CG corresponds a low skill by CG to perceive positively the changes for the meeting with CR.
- 17) The Social Burden of CG is negatively correlated with the Ca.R.R.I. of CG with a value of -0.54. This indicates that with a good perception by CG for the relationship with CR (in terms of better availability to rely on others to perceive a positive meeting with the CR and to have a better vision of the future ) corresponds a low perception of social burden by CG.
- 18) The Physical Burden is negatively correlated with Ca.R.R.I. with a value of -0.54. This indicates that with better perception by CG, of relationship with CR (in terms of better availability to rely on others to perceive a positive meeting with the CR and to have a better vision of the future ) corresponds a lower perception of physical burden by CG.
- 19) The scale of Attitudes Operators (ICF) is negatively correlated with length of caregiving for a value of -0.48. This indicates that the lower length of relationship between CG and CR affect the perception of CR of facilitating attitude by the operators.

In summary the role of CG in Italy is covered only by family members, dealing with CR since birth (with the exception of one case where the length of caregiving has lasted 10 years). The relationship between CG and CR is characterized by the satisfaction of needs, primarily related to disability. This mode does not consider other aspects such as overall satisfaction, psychological and physical CR, and also allows the CG to feel less burden of care.

#### 5.5.4 Correlation in Romania

	Icf Part.	Age CR	Lenght CG	Burden D	Burden F	Burden S	Burden
QoL	- 0,57						
QoL Soc	- 0,55						
QoL Ps							
Att. Fam.	0,45						
Ca.R.R.I. D		- 0,50	- 0,45				
Ca.R.R.I. R				- 0,48			
Ca.R.R.I. F				- 0,52	- 0,62	- 0,55	- 0,71

Tab. 11 Matrix of correlations in Romania

- 1) The QOL is negatively correlated with the ICF PARTICIPATION scale with a value of -0.57. This indicates that greater is disability and lower is quality of life. In this case it seems that overall satisfaction corresponds to the degree of disability.
- 2) The Social QOL is negatively correlated with the ICF Participation scale with a value of -0.55. This confirms the point 1 and especially with respect to satisfying social life.
- 3) The scale Ca.R.R.I. Dependence is negatively correlated with the age of CR with a value of -0.50. This indicates that CR is most senior and lower the ability of CG to rely on others.
- 4) The scale Ca.R.R.I. dependence is negatively correlated with the length of caregiving with a value of -0.45. This indicates that with long duration of caregiving corresponds a perception of a low availability of support by the CG to meet the needs of the CR.
- 5) The scale Ca.R.R.I. Relationship is negatively correlated with the Burden dependence with a value of -0.48. This shows that with the perception of the burden of addiction (the load level perceived by the CG in relation to the dependence of the CR against it) corresponds the low ability of CG to discriminate against their emotions, others' emotions and their by others (ability to understand self and other).
- 6) The scale Ca.R.R.I. Future is negatively correlated with the Burden dependence with a value of -0.52. This indicates that with the perception of the load dependence (the load level perceived by the CG in relation to the dependence of the CR against it) corresponds the negative perception of the future by the CG.
- 7) The scale Ca.R.R.I. Future is negatively correlated with the Burden Physical with a value of -0.62. This indicates that more the CG perceives a greater physical burden, the more it will perceive the future (either their own, the CR and the relationship with it) in the negative.
- 8) The scale of Ca.R.R.I. future is negatively correlated with the Social Burden with a value of -0.55. This data specifies the considerations in point 7, but with regard to social care received by the CG.
- 9) The scale Ca.R.R.I. Future is negatively correlated with the Burden with a value of -0.71. This indicates that with a great burden of care perceived by the CG, the more it will perceive the future (either their own, of the CR and of the relationship with it) in the negative.

In summary the role of CG in Romania is covered mainly by family members, but in some cases the operators to take care of the CR. The CG is affected most of the burden of care of the CR, then feeling the load as substantial in terms of physical, social and addiction. Everything load on the relationship between CG and CR, which will then have more difficulty, which will be higher if the age of the CG will be high or if the length of caregiving will be long. In this group there is a correlation between disability and quality of life.



### 5.5.5 Correlation in Spain

	Att. Fam.	Att. Op.	Burden D	Burden F	Ca.R.R.I. F
QoL Ps.				- 0,48	
Icf Part.			0,64	0,60	
Icf Env.	0,61	0,61	- 0,51		
Att Op.					- 0,69

Tab. 12 Matrix of correlations in Spain

- 1) The QOL PSYCHOLOGICAL is negatively correlated with the Physical Burden with a value of -0.48. This indicates that a better psychological well-being of the CR will adversely affect the physical burden received by the CG.
- 2) The ICF PARTICIPATION scale is positively associated with the Burden Dependence scale with a value of 0.64. This indicates that with a great restriction of the participation of CR, the CG shows a suffering in the time devoted itself.
- 3) The ICF PARTICIPATION scale is positively associated with the Physical Burden scale with a value of 0.60. This indicates that with a high restriction of participation of CR corresponds a high perceptions of burden physical by CG.
- 4) The scale ICF ENVIRONMENT is positively correlated with the scale of the Family Attitudes (ICF) with a value of 0.61. This indicates that the environment in which lives the CR is associated with the attitude of family members.
- 5) The scale ICF ENVIRONMENT is positively correlated with the scale Attitudes of Operators with a value of 0.61. This data takes the point 4, but in reference to the attitude of the operators.
- 6) The scale ICF ENVIRONMENT is negatively correlated with the scale Burden Dependence with a value of -0.51. This indicates that the higher help of environment to the CR affect a lower perception, by CG, of the dependence.
- 7) The scale of Attitudes Operators (ICF) is negatively correlated with Ca.R.R.I. Future with a value of -0.69. This indicates that with a good facilitating attitudes of operators corresponds a negative vision of the future relationship between CG and CR.

In summary the role of CG in Spain is covered mainly by family members, and a minority of CR is borne by the professionals. The relationship is influenced by severity of disability in the sense that with a great restriction on participation by the CR, greater is the strain and the dependence perceived by the CG. The relationship is also influenced by a facilitating environment that helps the CG to feel a perception lower of dependence against itself. With regard to the future perception of the relationship by the CG, it is negative if attitudes of operators are shown in facilitating mode. This data can be interpreted in terms of facilitating an intervention that undermines the CG professionals (family)? The environment is more favourable if the attitudes of workers and their families are more facilitative.

## 5.6 Analysis of Variance

Were carried out comparisons between groups relatively to sex (male/female) to the extent of the burden of care (CBI) and the mode of relationship with the CG (Ca.R.R.I.) and between role groups (professional carer/family) and family role (mother/father) always relatively the burden of care (CBI) and the mode of relating with the CG (Ca.R.R.I.). Moreover were evaluated differences between groups of males/females compared to CBI and Ca.R.R.I. and between countries outside France (which has not completed the CBI). The results can be summarized as follows:

- 1) There are significant differences between the CBI test operators and family members. Family members have a higher score that are most burdened in assisting the CR
- 2) There are significant differences in the interview Ca.R.R.I. between males and females: males show features lower quality relationships (understood as a readiness to feel supported in the helping relationship, to have heard more negative as the meeting with the CR) than females
- 3) There are significant differences in the interview Ca.R.R.I. R (relation of role) between males and females: females, compared to males, show less ability to discriminate and to understand of their own and others emotions and experienced within the relationship with the CR, even both values are negative
- 4) There are significant differences between males and females in the interview Ca.R.R.I. F (future prospects of the relationship): females have a better perspective of the future than males
- 5) There are no significant differences between the burden (CBI) and sex (male/female)
- 6) There are no significant differences between the Ca.R.R.I. and the role (professional carer/family) covered by the CG
- 7) There are no significant differences between the Ca.R.R.I. R (relationship role) and role (operator/family) covered by the CG
- 8) Respect to the difference between Mothers and Fathers, the mothers show kind of relationship (Ca.R.R.I.) best than fathers, although slightly negative. This feature is highlighted more in the perception of the future (Ca.R.R.I. F). With regard to the characteristics of discrimination and articulation of experiences and emotions (Ca.R.R.I. R) the fathers (as demonstrated in the gender differences) have less negative performance than the mothers

In different countries this is specified in:

- AUSTRIA: There are significant differences between males and females in the scale of Burden Evolutionary, the males show a positive value, as the females, but lower.
- FRANCE: The absence of data on C.B.I. not possible to develop statistical analysis for this specific point.
- ITALY: There are significant differences between males and females in the Burden Emotional scale and Burden evolutionary, in which males show positive values higher than females. In Italy there are significant differences between mothers and fathers in relation to Ca.R.R.I. and Ca.R.R.I. F. in the sense that the fathers have in both the scales negative values, while the mothers show higher and positive values than fathers in the scale Future and show higher values, but always negative (ie less negative) to the total scale.

- ROMANIA: There are significant differences between males and females at Ca.R.R.I., in which males have negative values and female have positive values. In Romania there are significant differences between mothers and fathers in relation to Ca.R.R.I.: the fathers show negative values and the mothers, instead, show positive values.
- SPAIN: there are not significant differences between males and females. While there are significant differences between mothers and fathers in Ca.R.R.I. R (relationship), the fathers have a positive value while the mothers showed a negative value.

### **5.7 Critical Issues**

All countries, except Romania, have used the ICF.

All countries, except Italy, completed the WHODAS II, which is a similar tool to collect data on the condition of disability.

The forms used in Italy for the ICF are of two different types.

Should be realized, therefore, more training for the ICF. This is a qualitative analysis, in particular as regards the analysis of the relationship between CG and CR. The results can not achieve significance in dependence on the size limited of the sample, on the difference of the CG respondents (family members or professional carer) and response variables are not considered likely to make the reports identified spurious. The imbalance of the sample helps to consider the hypothesis suggested as necessary for a proper experimental design.

Data from the CBI can not be fully compared because France has not given the CBI.

## 6 CONCLUSIONS

### 6.1 Verification of assumptions about Data Analysis

The European sample shows that the CG and CR:

- 1) Regarding the perceived burden (as assessed by the administration of the CBI) in the activity of care in respect of the client (CR), there was a perception of increased difficulty in devoting time to himself than emotional, physical and social evolution burdens. Please note that in Spain, in Italy and in Romania, the CGs are mainly family members and therefore have a greater perception of suffering (burden) compared to CGs OF Austria, which are exclusively operators. France has not taken the test.. **The considerations on the burden can be assumed that the assistance's action between CG-CR seems to focus exclusively on to satisfy needs, but this could limit, somehow, the perception of overall well being by the side of CR, responding to the intention " I protect you, but I limit you". Besides this "limiting" taking care that seems to be associated with a lower burden by the side of the CG, to be more precise, operators and especially relatives, seem to "lighten" if their attitude is considered facilitating by the CR**
- 2) Regarding the characteristics of the CG-CR relationship as explored by the interview Ca.R.R.I, no significant statistically differences emerge between countries even if France shows positive values. This means that the interview shows a positive relational mode in French CG, of while the other slightly negative. Specifically, it seems that this difference is found especially regarding to the relationship based on the satisfaction of needs (Ca.R.R.I Dependence). This means that almost all groups except the French CG, have a perception of poor social support network to refer, to be more precise , users and families have a low dispersion of dependency in their way to attend own CR. In the part about the meeting with the person with disability (Ca.RRI Changes) the Austrian and Romanian CG refer to average a greater impact than Italian, French and Spanish CG, although they have a positive or neutral value to the limit. However, the differences are not statistically significant. The perception of the future (Ca.R.R.I. Future) on the relationship between CG and CR has a positive value for all countries except Italy. The value found in Romania is statistically significant compared to the value found in Italy. **The ability to discriminate their own and others emotions and experiences (Ca.R.R.I Relation) shows negative values in all countries or rather that the CG seems to have little inclination to articulate their own and others internal world (emotions and feelings),that it seems that this dimension is considered to be relatively unexplored and perhaps considered only an effect of the caring relationship instead of a crucial component which channel the educational, training and rehabilitation choices.**
- 3) As previously reported the males have a lower relational quality (the ability to feel supported in helping relationships, and having more negative expectations in the encounter with the CR) compared to females. Instead females compared to males, show less ability to discriminate and understand their own and others emotions and feelings within the relationship with the CR, both values are negative. Specifically regarding the differences in family role, fathers (as demonstrated in the gender differences) have less negative performance of the mothers in some discrimination "Me-You". **These data support the hypothesis that mothers are more involved but also have greater difficulty in the relationship with the CR.**

- 4) The correlation analysis shows that QOL is negatively correlated, ie decreases with increasing disability, only for France and Romania, while for Italy this correlation is reverse regards facilitation of environment and relationships (see point 1). In France and in Italy the QOL also decreases with increases of kinds of facilitating relationship (Ca.R.R.I.) and also for this case can be considered to be reasonable considerations in point 1. The Burden (C.B.I.), often (especially for Italy and Romania) has a negative effect on relationship (Ca.R.R.I.) and is positively influenced, get worse when increase the degree of disability.
- 5) As reported the sample of CR of Europe is compatible with the standards of research. This means the selection of people can be done keeping as much as possible of the following criteria:
  - skill of writing and reading
  - age under 40
  - low ICF participation
  - high ICF environment
  - CBI < 35
  - high attitudes of operators
  - high attitudes of family

## **6.2 Methodological guidelines for courses**

Given the characteristics of the sample and the data analysis shows that:

The Role of CG is essential for the success of the training course for operators and for users. For "Role" means the ability to understand emotionally and support the CR in their own life choices without focusing solely on the satisfaction of needs related to disability. Is necessary that the CG is supported, if this is a family members in the process of understanding the meanings that the CR is putting into play the participation in the training course. If the CG is an operator, the necessary support will be directed also to grasp the aspects of psychic life that refer to family dynamics. This translates into the need during the course of training for educators and users to reserve time for this psychological work. The form could lead to participation in psychological support groups. Regarding the CR refers to the need to offer him a support similar to what they are currently receiving in order to facilitate their participation, while it is necessary that teachers take into account the intrapsychic experiences and family dynamics that have accompanied the history of disability. We suggest, for example, to the teachers of the courses, that the contests of the training leverage to how the meeting with the disabled person goes through emotional and relational aspects consolidated over time and that the welfare and educational practices have unfortunately continued to strengthen. The promotion of autonomy, sociability, social inclusion and employment, educational interventions and rehabilitation has been relegated to the background, meaning that the construction of "disability" conveys implicitly and explicitly all the other aspects of personal, family and relationships. This research, supported by our experience shows us that in the face of an impairment that is playing a key staff, the child has to cope not only to their congenital characteristics, but also the mode in which the parents and who cares for him / her develop this feature.. The child is identified as a "disabled" before being identified as a person. Subsequently, this leads to a reduction in relationships of family in terms of possibility to open up and "trust" to others. In this step, the CG takes care totally of care-assistance limiting the social development of CR .We can imagine this process as if the sense of inadequacy experienced by his parent after his son's diagnosis will help to crystallize the relationship with him / her in a way that relegates him to a role that can not be anything but disabled. The relational and social

achievements of the disabled, paradoxically, put in great difficulty the relationship with the parents, and every attempt to growth will be prevented in spite of themselves. These efforts show how much difficulties and resistance is in meaningful relationships, then any intervention will be productive if those who accept the challenge to deal with this process.

Some aspects from the research would suggest that one of the factors limiting the development of the disabled person is precisely the construction, the definition of that person from others. As reported in the conclusions, the person is labelled "disabled" before as a person from the family. In some cases it appears that this approach will also transfer to the operator.

It seems therefore important to work within the training to educators on the construction and definition of the person with disabilities, beyond the social and diagnostic labels and how this can be translated into educational work and the prospects for development of autonomy.

A point that may be particularly important for the construction of training interventions targeting people with disabilities seems to be the following: one of the elements that seem to further limit the development of autonomy seems to be difficult to imagine (imagine itself and its context) by the person with disabilities, as a person who has acquired skills and become more autonomous.

In practice it is difficult to imagine what is the answer to the question: how to change my scenario, my world if I become autonomous (or most autonomous)? What do I face? In fact, the process of development of autonomy is accompanied by a changing relationship, of context, of relationships with family members.

It seems however that this is so hard to build, imagine, anticipate, that the CR is that the CG might result frightened, or to have engaged in projects of life is clearly not feasible for this, even if they were acquired or are These skills also high, they may not be used to increase autonomy in daily life.

This may explain (certainly not as the sole cause) that is found in the training system in certain cases: some people with disabilities participate in numerous training courses, but this is not reflected in the practice of everyday life, in a development autonomy.

**It seems therefore necessary to provide a training course that allows no time and not only the increase of knowledge, but to allow the imagination to shift the focus of new scenarios, new experiences, experimentation within new contexts.**

These considerations can be summarized in the following :

- Give psychological support of CG especially parents during the courses
- Support educators in understanding the aspects of psychic life that refer to family dynamics of CR
- Support teachers in how to meet with the disabled person beyond the ICF aspect like the promotion of autonomy, or sociability, or social inclusion and employment, or educational interventions and rehabilitation.
- have as main aim the improvement of quality of life of CR
- Work within the training to operators on the construction and definition of the person with disabilities.
- In training courses for people with disabilities, favouring the construction of practice experiences and real possible scenarios.

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## 8 GLOSSARY

**ANOVA** is a set of statistical techniques that allow you to compare two or more groups of data comparing the internal variability in these groups with the variability between groups

**BARRIER** obstacle environmental and/or physical which limits the participation of disabled person

**NEED** state of lack that drives the organism to deal with the environment

**BURDEN** physical and emotional burden perceived by caregiver and derived from its relationship with the CR

**C.B.I. (CAREGIVER BURDEN INVENTORY)** multidimensional assessment tool of the burden of care of the CG towards the CR

**Ca.R.R.I. (CAREGIVER ROLE RELATION INTERVIEW)** is an interview developed with the aim of understanding the relationship between caregiver (CG) and carereceiver (CR) according to a reference epistemological constructivist

**SAMPLE** number of surveys carried out for investigation

**CAREGIVER** a person that focuses on providing assistance, physical and emotional support to the disabled person. The Caregivers can be family, friends, neighbours, professionals

**CARERECEIVER** a person that receives assistance, physical and emotional support by the Caregiver

**ACTIVE CITIZENSHIP** connecting to the problems of knowledge and awareness of rights and duties. It is also linked to civic values such as democracy and human rights, equality, participation, cooperation, social cohesion, solidarity, tolerance of diversity and social justice

**CORRELATION** is a relationship between two random variables such that with each value of the first variable corresponds a regular value of the second

**CONSTRUCTIVISM** is a philosophical and epistemological position according to which there can pursue an objective representation of reality because the world of our experience, the world we live in, is the result of our business builder

**COVARIANCE** is a number (X, Y), which provides a measure of how two variables vary together, or of their dependence

**STANDARD DEVIATION** is an index of dispersion of the experimental measurements (a measure of variability of a population of data or a random variable). It has the same unit of measurement of the observed values and measures the dispersion of data about the mean

**DISABILITY** after one or more disabilities, disability is the personal condition who has a limited capacity for interaction with the social environment than what is considered the norm, therefore



is not independent in performing daily activities and often has a disadvantage in participating in social life

**EMPOWERMENT/SELF-EMPOWERMENT** process by which people become aware of their potential and their effectiveness, they gain control of their lives and their environment

**FACILITATOR** support physical and environmental that encourages the participation of disabled people

**ENVIRONMENTAL FACTOR** are the attitudes, physical and social environment in which people live and conduct their lives

**I.C.F. (INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH)** instrument used for the International Classification of Functioning, Disability and Health grouped into categories characterized by a bio-psycho-social model that health is a consequence of health conditions, participation in social life and ability to perform activities

**MEDIA** can be calculated only on quantitative variables. It is calculated by adding the values of all observations in the collective and then dividing it by the number of observations

**IMPAIRMENT** is the loss of structure or of function of a psycho-logical, physiological or anatomical

**QUALITY OF LIFE** individuals perceptions of their position in life in the context of culture and of value systems in which they live and their objectives, expectations and interests. This is a concept of physical health of people, psychological state, level of independence, social relationships, personal beliefs, and their relationship with the salient features of the environment

**RESTRICTIONS ON PARTICIPATION** the problems that an individual may experience in involvement in life situations

**DESCRIPTIVE STATISTICS** studies the requirements for recognition, classification and synthesis of information related to the population under study. Descriptive statistics collects information on the population, or part of it (Sample), in Distributions simple or complex (at least two characters), and the sums described by families of indexes: mean values, indices of variability, indices of shape, statistical reports, statistical reports

**DEPENDENT VARIABLE** Dependent variable: the variable is not manipulated but observable from the sample and its changes depend on the influence of independent variable

**INDIPENDENT VARIABLE** is the variable manipulated by the investigator, but it can also be measured

**VARIANCE** is the value that provides a measure of the variability of the values of the variable, or to deviate from the Media

**WHO (WORLD HEALTH ORGANIZATION)**

**WHODAS II (WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE, SECOND VERSION)** is an instrument compatible with the ICF. WHODAS II assesses every day, the functioning in six domains of activity. The results provide both a profile of functioning across domains, and an overall score of disability

**WhoQoL (WORLD HEALTH ORGANIZATION QUALITY OF LIFE)** is an instrument that measures the quality of life

**WP (WORK PACKAGE)** phases in which work is divided