

D-ACTIVE PROJECT

WP2 Research

DACTIVE – Disability and Active Citizenship

**project n°:510773-LLP-1-2010-1-IT-
GRUNDTVIG-GMP**

Social-demographic characteristics of the sample in Europe

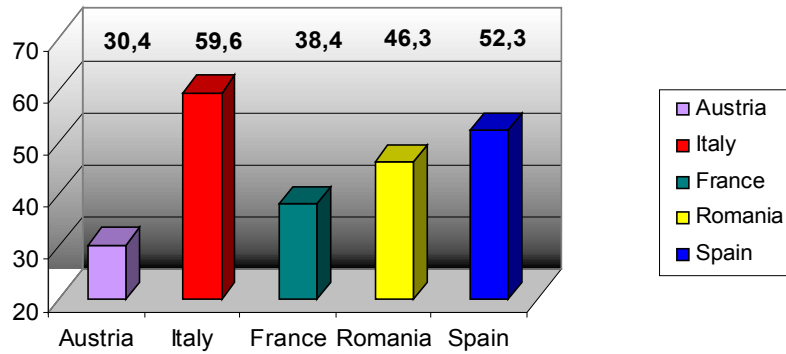
- 100 people with disabilities: Male (56%) and Female (44%)
- Age of Carereceiver: 29 years old (average)
- 100 people employed in Caregiver Role: Male (19%) and Female (81%)
- Age of Caregiver: 45 years old (average)
- Distribution of CG by role: Relatives (42%) and Professional Carer (58%)

Division of sample by country:

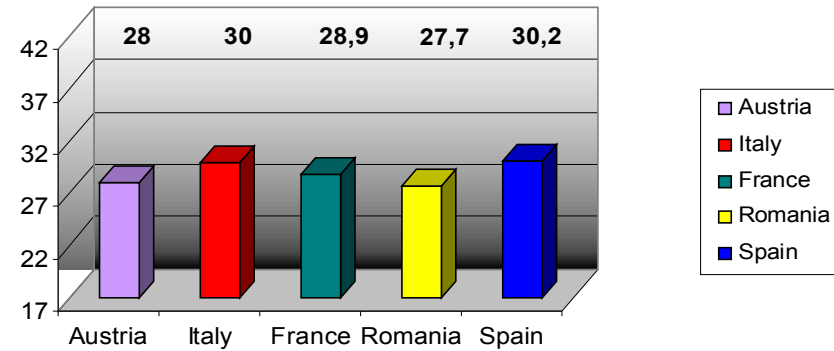
COUNTRY	CARERECEIVER	CAREGIVER
Austria	20	20
Francia	19	19
Italia	21	21
Romania	20	20
Spagna	20	20

City of Florence

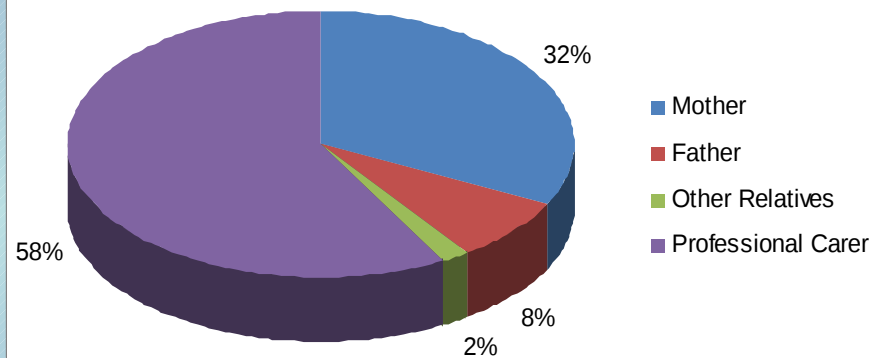
Caregivers Average Age: Europe



Carereceiver Average Age: Europe



Caregivers Role: Europe



SAMPLE IN AUSTRIA

CARERECEIVER:

- Gender: Male = 50% - Female = 50%
- Average of Age: 28.9 years old

CAREGIVER:

- Gender: Male = 25% - Female = 75%
- Average of Age: 30.4 years old
- Role: 100% Professional Carer

Length of Caregiving: 44% less 1 year,
31% between 1-5 years,
25% between 6-10 years

SAMPLE IN FRANCE

CARERECEIVER:

- Gender: Male = 58% - Female = 42%
- Average of Age: 28.9 years old

CAREGIVER:

- Gender: Male = 13% - Female = 87%
- Average of Age: 38.4 years old
- Role: 100% Professional Carer

Lenght of Caregiving: 19% less 1 year,
31% between 1-5 years,
25% between 6-10 years,
25% over 10 years

SAMPLE IN ITALY

CARERECEIVER:

- Gender: Male = 48% - Female = 52%
- Average of Age: 30 years old

CAREGIVER:

- Gender: Male = 19% - Female = 81%
- Average of Age: 59.6 years old
- Role: 100% Relatives

Lenght of Caregiving: 95% since birth,
5% between 6-10 years

SAMPLE IN ROMANIA

CARERECEIVER:

- Gender: Male = 65% - Female = 35%
- Average of Age: 27.75 years old

CAREGIVER:

- Gender: Male = 10% - Female = 90%
- Average of Age: 46.35 years old
- Role: 60% Relatives,
40% Professional Carer,

Lenght of Caregiving: 55% since birth,
5% between 1-5 years,
10% between 6-10 years,
30% over 10 years

SAMPLE IN SPAIN

CARERECEIVER:

- Gender: Male = 59% - Female = 41%
- Average of Age: 30.2 years old

CAREGIVER:

- Gender: Male = 25% - Female = 75%
- Average of Age: 52.35 years old
- Role: 80% Relatives,
20% Professional Carer

Lenght of Caregiving: 75% since birth,
10% between 1-5 years,
15% over 10 years

Analysis of the research :

- Analysis of variance (univariate) between groups with post hoc Bonferroni both in Europe and in several countries (male / female, mothers / fathers, and operator / family).
- Correlations between scales

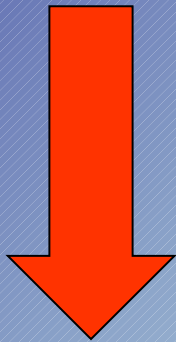
RESULTS OF RESEARCH

SOME TENDENCE

Ca.R.R.I.

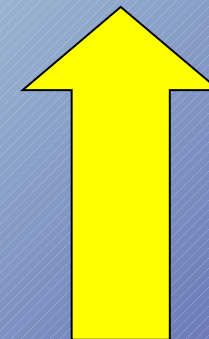
Relation Factors as:

- Support in satisfaction of CR's needs
- View of future
- How Disability Changes CG's life



Quality
Of
Life

CARERECEIVERS



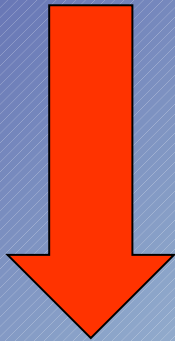
CAREGIVERS

SOME TENDENCE

Ca.R.R.I.

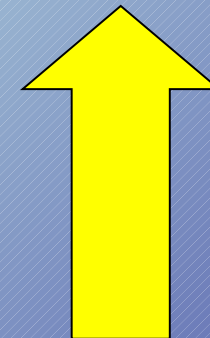
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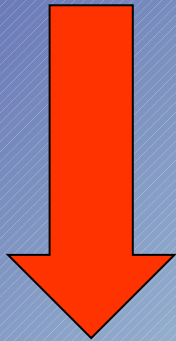
CBI
Burden in
giving care

CAREGIVERS



CAREGIVERS

SOME TENDENCE

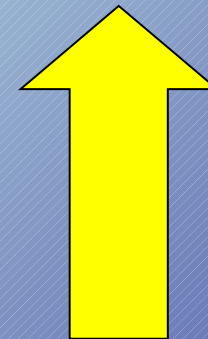


Quality
Of
Life

CARERECEIVERS

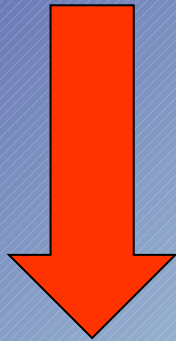


CBI
Burden in
giving care



CAREGIVERS

SOME TENDENCE

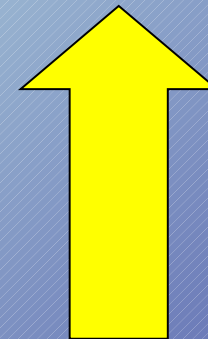


Quality
Of
Life

CARERECEIVERS



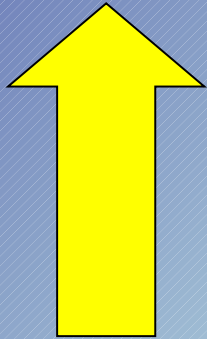
ICF
Limitation of
Partecipation
(Disability)



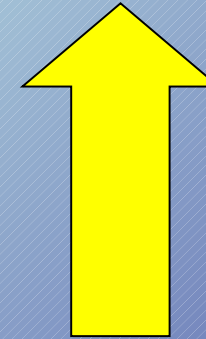
CARERECEIVERS

SOME TENDENCE

ICF
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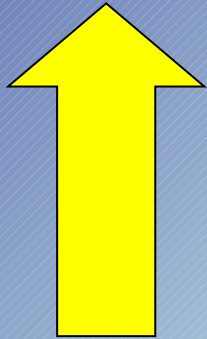
CBI
Burden in
giving care



CARERECEIVERS

CAREGIVERS

ICF
Environmental
(facilitators)



CARERECEIVERS

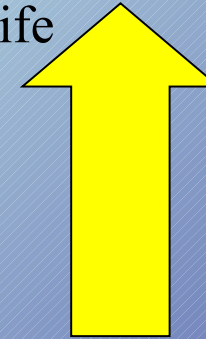
SOME TENDENCE



Ca.R.R.I.

Relation Factors as:

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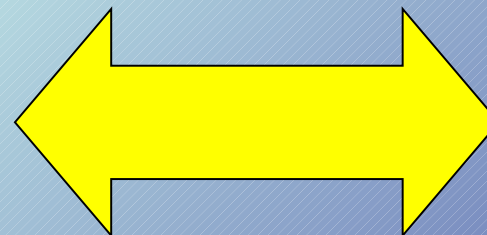


CAREGIVERS

**promote autonomy involves a change in
both the CR and CG**

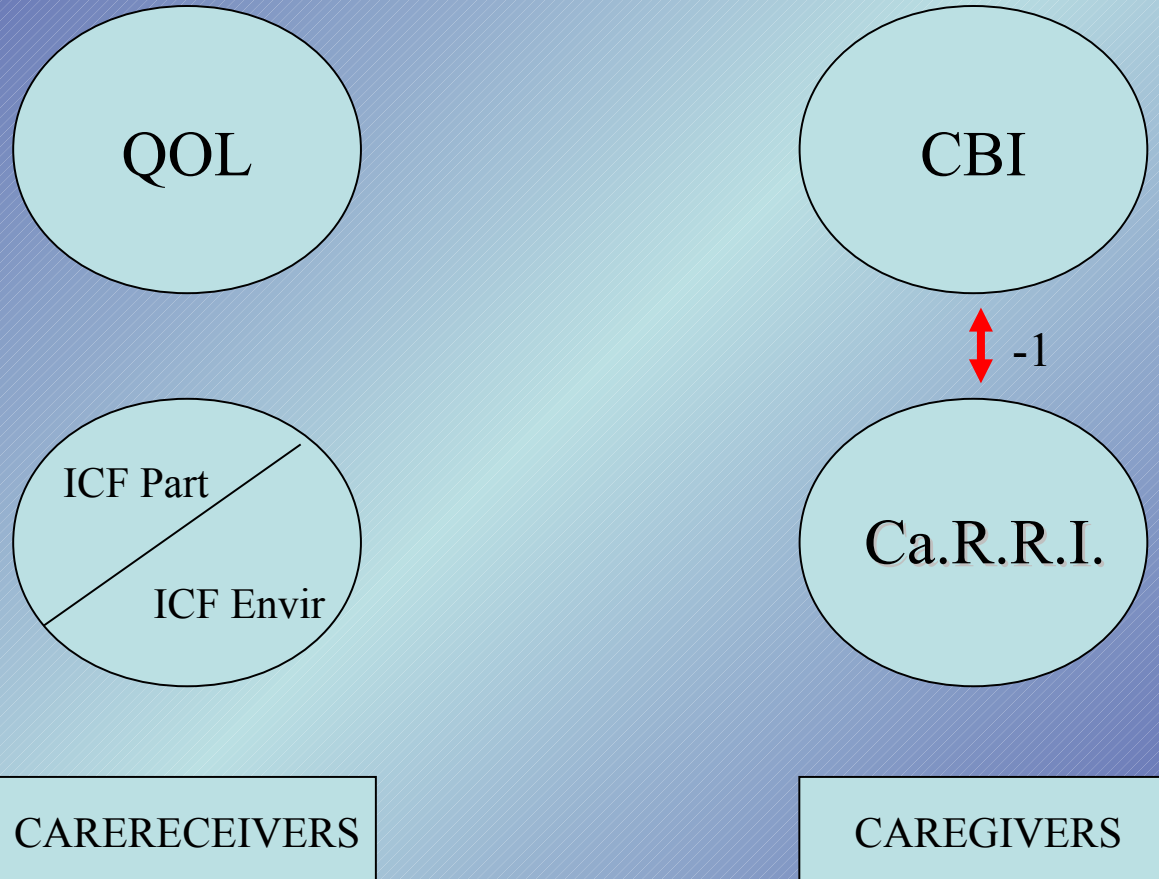


CARERECEIVERS

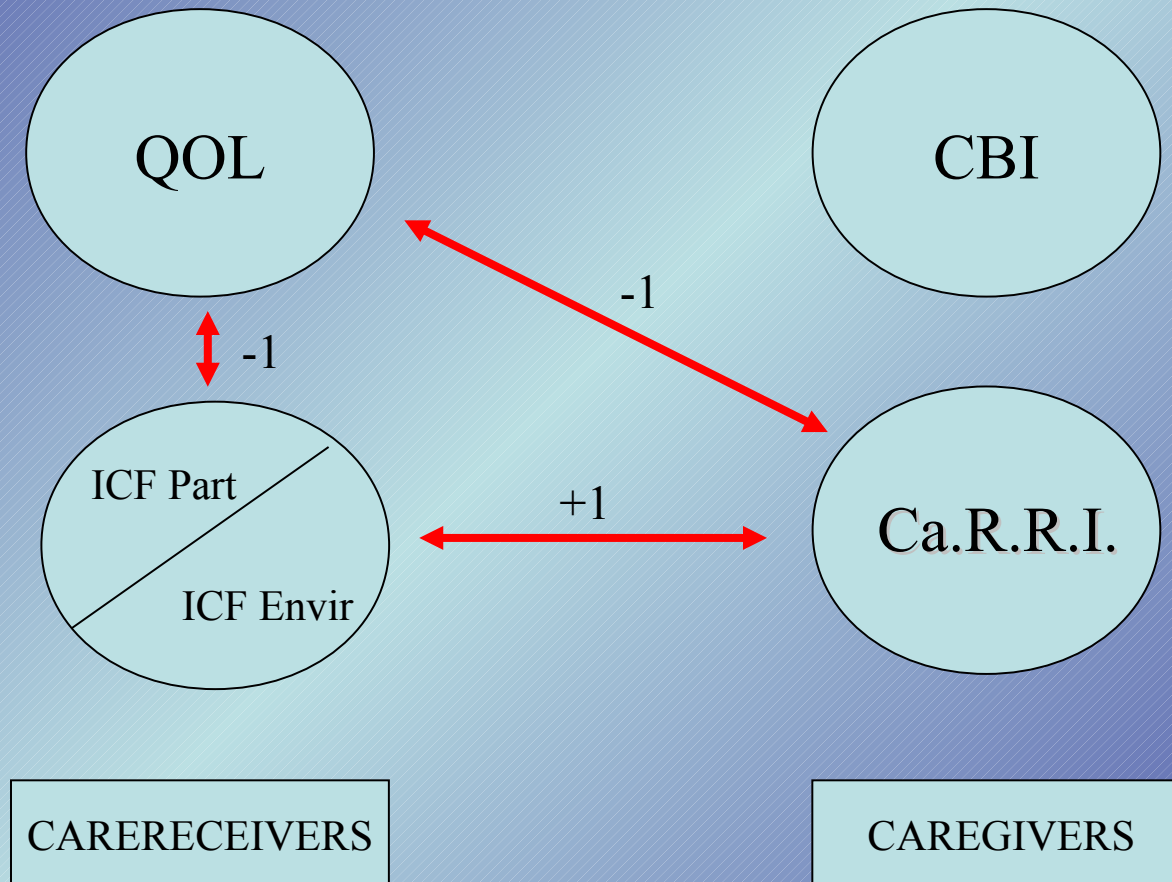


CAREGIVERS

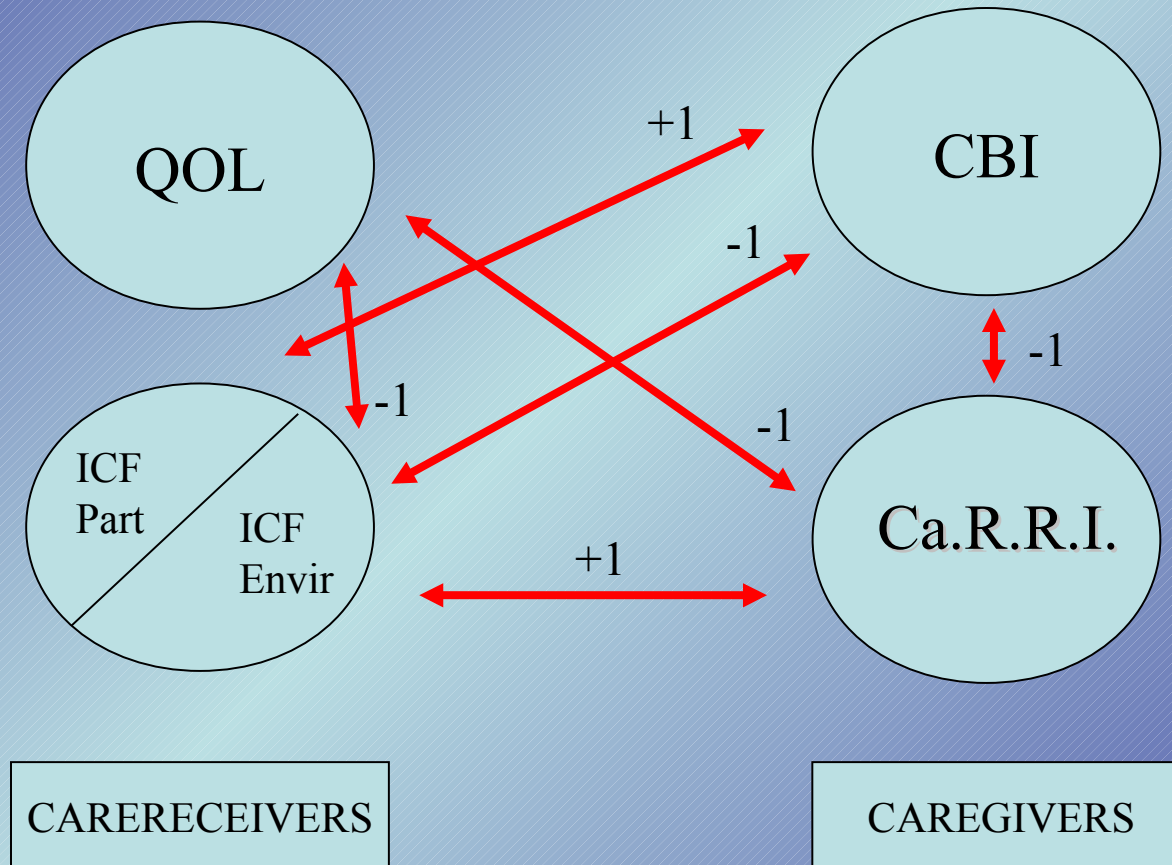
AUSTRIA



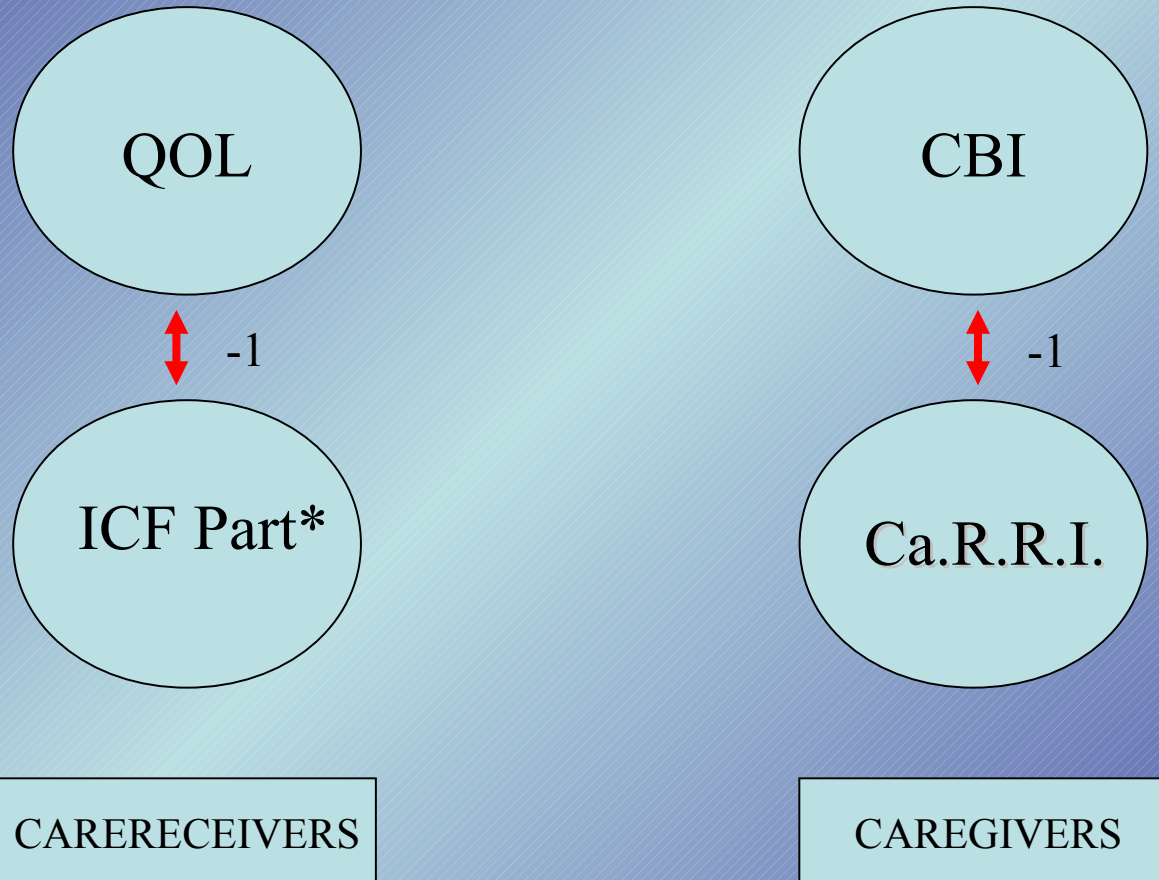
FRANCE



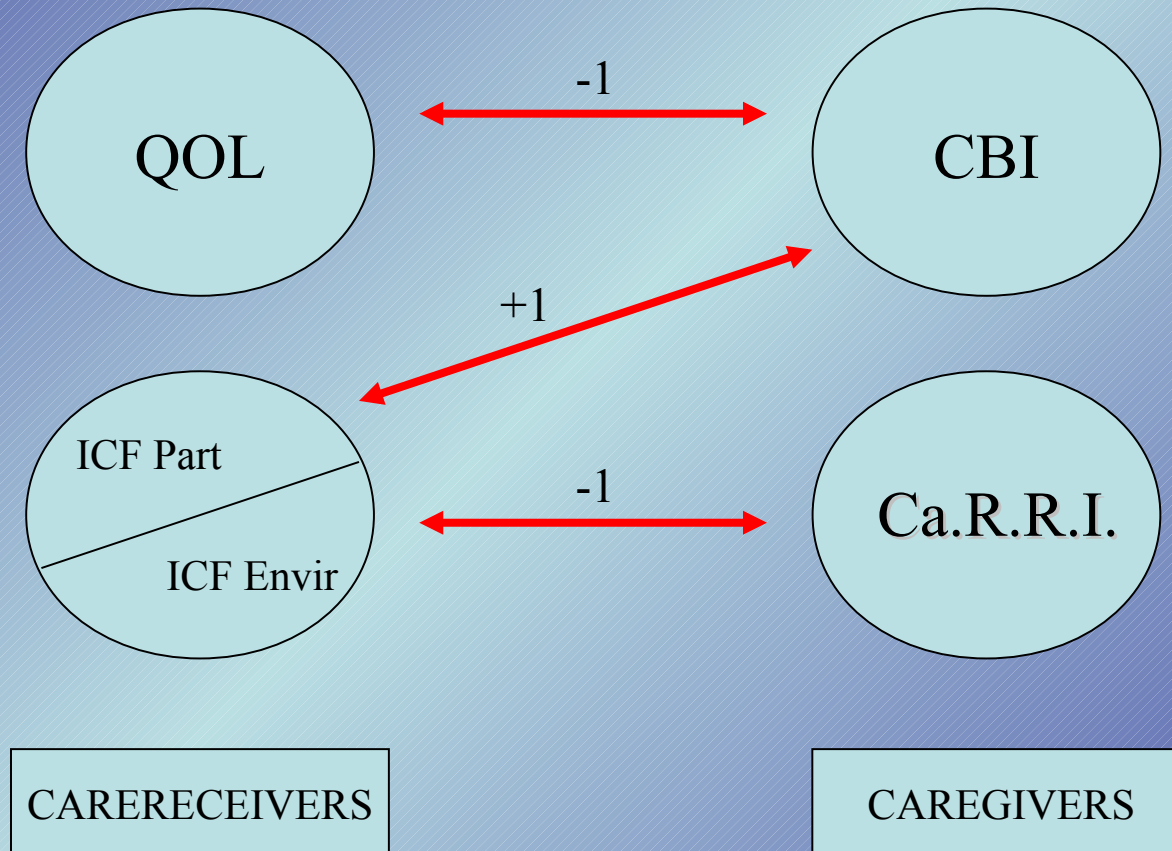
ITALY



ROMANIA



SPAIN



In summary:

- In Austria, in Italy and in Romania the correlation between CBI and Ca.R.R.I. is negative
- In France and in Italy the correlation between Ca.R.R.I. and QOL is negative
- In France and in Italy the correlation between Ca.R.R.I. and ICF Environment is positive, while in Spain is negative
- In France and in Romania the correlation between QOL and ICF Participation is negative
- In Italy and in Spain the correlation between CBI and ICF Participation is positive

City of Florence
Conclusions

- CBI: assistance CG – CR “I protect you but I will limit yourself”
- Ca.R.R.I. Relationship: the CG have a low inclination to articulate their own and others internal world (emotions and feelings) respect to CR
- CBI shows differences between Professional carer e Relatives. Relatives have higher burden.
- Difference of role and gender: mothers are more involved but have the greatest difficulties in the relationship with CR respect to fathers
- The European sample of CR is compatible with the standards of research:
 - Skill of writing and reading
 - Age under 40
 - Low ICF Participation
 - High ICF Environment
 - CBI < 35
 - High Attitudes of Operators
 - High Attitudes of Family

Critical Issues

- European sample is comparable but not balanced
- The hypothesis made so far have an exploratory nature, which can be added, in a second time, more variables
- Data from CBI can not be fully compared because data missing

Methodological Guidelines For Courses

- Give psychological support of CG especially parents, during the courses in order to facilitate the participation of the CR
- Support educators in understanding the aspects of psychic life that refer to family dynamics of CR, with particular regard to the relationship with the mother
- Support teachers in how to do in relationship with people beyond their disabilities aspects and promote a personal development and not only 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 representation of the person with disabilities
- In training courses for people with disabilities, favouring the construction of practice experiences and real possible scenarios

We would like to say a few words freely, to give perspective to the work we all did and because we think there is still so much to do in terms of research to do more adequately our work on mental retardation.

Centering our information not only on I.C.F. but also on the quality of relations among caregivers and care receivers we started a journey towards a study on mental retardation in an effort to understand how a trauma at birth, so difficult and delicate to accept, appears to the family.

This event influences the whole life of parents. In fact the ideas and expectations about the future, the fantasies of continuity of themselves are compared with the collapse of the project of the couple and the fear of the future. In this moment the representations of a disabled person and the defenses of both parents which take place, particularly in the mother, have the utmost importance for rehabilitation. In fact in most cases they represent a further state of alienation for the disabled person.

and care-receivers are on the stage and play their everyday performance.

Following this perspective the disabled person, integrated into a system of care and rehabilitation, might be deprived of his personal expression, when caregivers and parents neglect those parts of knowledge unknown to their consciousness but essential to do a good job and guarantee effective training.

It is important for example to be able to question our way of thinking and to recognize and take in consideration experiences located in non-verbal language; a dimension in which not words but the body is used to communicate with others and with ourselves. An exploration like this could bring us closer to the communicative styles daily used by the disabled persons.

Think for while of the encouragement or reinforcement given.

We do not know whether behind praise received the care-receivers feel or perceive a message of doubt and alienation?

Again parents, and especially mothers, continue to promote, and fight a social and health battle with no distinction between their own existence and the existence of the disabled. In this case they often they risk to fight against the care-receiver in the name of a mutual suffering part of which has its roots in the trauma and pain they had and have to bear.

This drama was often played even before birth and its very difficult to understand where the child's illness begins and where the neurosis of parents ends.

This scene also feeds on relations with grandparents. So the relations among care-givers, relatives, parents and care-receivers are on the stage and play their everyday performance.²⁸