

PROJECT CEIL (CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING)

REPORT OF THE SEMINARS ON INDEPENDENT LIVING HELD IN ITALY, GREECE AND SPAIN

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INTRODUCTION

According to the CEIL project goals for the first year period, we planned to hold one Seminar on Independent Living per country involved: Italy, Greece and Spain.

To the seminar, representatives of elder and disabled people organisations were invited as well as relevant local and national government authorities and service providers to discuss the respective of Independent Living in each country with the aim of encouraging a critical and analytical discussion that would cover as many perspectives as possible.

75 people attended these national Seminars.

Each seminar included, among others, the following program points:

- presentation of the Independent Living philosophy and approach by a member of the Transnational Partnership. The presentation was to deepen an understanding of the CEIL Project goals and set the criteria under which participants were to judge the presentations of the examples of good practice. At each seminar different experts introduced the themes depending on their background and first-hand experience.
- a summary of the project documentation(s).
- experiences of several users representing different groups and opinions, government officials and service providers.
- questions and answer periods and ample room for discussions.

We expose in this document the summary of the three seminars.

On the other hand, we have also produce a sort of Guidelines for running seminar on Independent Living with the aim of helping people to organise and manage this sort of events.

Juan José Maraña
CEIL Project Co-ordinator
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C.E.I.L. PROJECT

(CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING)

ITALIAN SEMINAR REPORT



I.N.R.C.A.



European Project



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Report of the seminar of presentation of the European project

Contributing to Extend Independent Living

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1. Introduction

The European project C.E.I.L. - Contributing to Independent Living was presented on Thursday, 29th June, 2003 in the I.N.R.C.A. premises in Ancona, villa Gusso, Via Santa Margherita 5. The other partners of the project are Spain (coordinating partner) and Greece, with the “Institute for Independent Living” (IIL) and the “European Network on Independent Living” (ENIL) as advisory partners. The scientific responsible for



I.N.R.C.A. is Dr Giovanni Lamura. Among the participants in the Seminar, which had the purpose to create the conditions of a better future for disabled and elderly people through an integrated approach, there were the extraordinary commissioner of I.N.R.C.A., Dr Carlo Tassini, the President of D.P.I. Italia Ms Rita Barbuto, Ms Carla Albarello from A.U.S.E.R., the regional councillor for Social Services, Dr Marcello Secchiaroli, his colleague at a

province level Dr Giancarlo Sagramola, and several representatives of organizations of disabled people and of the elderly in the Marche Region.

After a short introduction on the basic principles of the movement for Independent Living and the objectives of the C.E.I.L. project, the present paper reports the main points emerged in the course of the seminar and gives an account of the main interventions of the participants in the seminar.

1.1. The movement for Independent Living.

The movement for Independent Living of the disabled started in the USA in the early 1960s and it is based on few but vital principles aimed at the improvement of life quality: the only real experts in disability are disabled people; all disabled people have a right to choose how to live autonomously; all disabled people who receive allowances from the Government or from an Institution, must have the right to decide how to use

them autonomously and must have the right to employ the people they like for their assistance. Disabled people must be entitled to the same rights and the same opportunities as all other citizens. Centres for Independent Living were subsequently created in Northern Europe and some years ago projects of this kind started also in Italy and especially in Northern Italy.

1.2. Objectives of the C.E.I.L. project

The C.E.I.L. project (<http://www.inrca.it/ita/ces/CEIL/index.htm>) wants to foster the philosophy of Independent Living and at the same time to set the basis for the implementation of several services in South European countries, taking inspiration from already implemented experiences. The “value added” of the project is that it proposes Independent Living as a solution to improve the quality of life not only of disabled people but also of elderly people that are not self sufficient. Thus, the Italian partnership in the C.E.I.L. project consists of one organization of disabled people (D.P.I.) and one organization of elderly people (A.U.S.E.R.) besides I.N.R.C.A. which is a scientific institution for admittance and care (I.R.C.C.S.: Istituto di Ricovero e Cura a Carattere Scientifico/ Admittance and Care Scientific Institution), operating in the field of geriatrics on behalf of the Ministry of Health.

Since there is an ever increasing number of people who become disabled in old age with reference to the total number of the disabled, it seems right to foster the development of a common line of action, which, transferring the improvements already achieved in the field of the disabled to the elderly, can cooperate to the improvement of the living conditions of both categories.

The adoption of a common strategy of intervention seems to be justified also by the need to eliminate inequity, since according to the present regional rules the use of this service is only allowed to people who have not reached 65 years of age with a clear discrimination against elderly, disabled people.

Besides, CE.I.L. aims to reduce, and possibly to eliminate, economic inefficiency due to the possible overlapping of services that are sometimes distinct for the two categories of users. The project should become an opportunity of cooperation between organizations of the disabled and of the elderly so that a more advantageous relationship between the two categories can be built up.

2. Introduction to and beginning of the Seminar

I.N.R.C.A. Extraordinary Commissioner, Dr Carlo Tassini.

After greeting the audience, Mr Tassini informed that Dr Antonio Guidi, undersecretary of state of the Ministry of Health would unfortunately not be present at the Seminar. Dr Guidi visited I.N.R.C.A. a short time ago, and suggested the idea that gave origin to a project I.N.R.C.A. will develop in 2003 with the Entrepreneurs' Association for the design and subsequent production of systems and instruments for the disabled and the fragile elderly to use in their homes, such as household appliances, remote controls, etc., that will be installed for experimentation also in I.N.R.C.A. hospital structures.

Dr Giovanni Lamura (I.N.R.C.A.)

I.N.R.C.A. representative for C.E.I.L., Dr Giovanni Lamura, summed up the aims of the C.E.I.L. project, and in particular the promotion of Independent Living through the creation of a common line of action for both the disabled and the elderly. Among the

purposes of the seminar, there is also the study and the understanding of differences and similarities between those two categories.

Ms Rita Barbuto (D.P.I.)

The President of D.P.I. Italia explained the purposes and the philosophy underlying her organization, giving the reasons for their participation in the C.E.I.L. Project.

The main principle underlying D.P.I. is that the disabled must have the control over their disability. Their slogan is: "Nothing on us without us". The majority of the Governing Body is made up by disabled people. D.P.I. decided to take part in C.E.I.L. in order to strengthen their network (at present their organization is mainly working in Southern and Central Italy) and this partnership is the first one in which they have taken part with organizations of non disabled people.

According to Ms Barbuto the disabled and the elderly are two groups that both seriously run the risk of social margination, and they have a great deal in common despite their differences.

She said it is important to stimulate institutions in their search for solutions, as with this seminar. D.P.I. is based on the 4 main principles which are the pivot of Independent Living (see par. 1.1), and they go beyond the current medical theory according to which the disabled are simply subjects to care, since the disabled are not only and not exclusively people to be cured, but the whole problem also implies the matter of human rights.

Ms Carla Albarello (A.U.S.E.R.)

The A.U.S.E.R. representative for the C.E.I.L. project greeted the audience on behalf of the President of the organization, Ms Maria Guidotti, who could not be present because she was presently engaged in Milan for the discussion of A.U.S.E.R. Social Assets.

A.U.S.E.R. strongly approves of this project since their organization fights solitude and emargination and they believe Independent Living can offer the elderly new means and instruments to more easily reach their aims. She said that the participation in this European project will make their organization initiatives even more qualified for the study of political and social strategies aimed at improving the quality of life of the disabled and of the elderly.

3. Presentation of the philosophy of Independent Life

Gianni Pellis and Elena Skall brought their contributions based on their personal life experiences according to the principles of Independent Living.

Dr Gianni Pellis(E.N.I.L. Italia and user of Independent Living services):

Dr Gianni Pellis, a paraplegic, lives in Turin where he works and lives alone. We will quote a part of his long and articulate intervention: "In 1989 my life changed. I took part in a conference in Rome where I met people who travelled around the world despite their respiratory and



motor problems, people I met again a short time ago in Tenerife on occasion of the first international congress on Independent Living. They explained to us what Independent Living means: having a perfectly normal life with the help of personal assistance. It is a philosophy. It does not mean one does not need any help, but it means exerting the same control and making the same choices as people who are not disabled normally do.

Summing up its main principles, Independent Living simply means freedom to choose despite disability. Personal assistance becomes a basic need to do things all the others normally do without any help. The personal assistant is appointed and trained directly by the disabled person.

In Italy Bill 162\98 was decisive and it marked a turning point that emphasized the right to Independent Living for the disabled and allowed them to apply for personalized projects of Independent Living. It's easier to be said than done... Each local authority interpreted the Bill as they pleased, and they implemented local projects, but only few of them enacted it in the best possible way by promoting and activating single work projects. Friuli Venezia Giulia Region can be mentioned among those that correctly applied the law, as well as Veneto, Piedmont, Lombardy and maybe in the last few months, Rome municipality as well.

In the meantime new associations of disabled people have been constituted in several regions, among which Consequor, Idea, Avirb and Avi .

My personal experience demonstrates that leading Independent Living is possible, deciding one's rules, getting up when one decides to, going wherever one wants to go is possible. All that is possible by means of careful programming, and am happy I am here today to say it."

Dr Elena Skall (mother of one of the users of Independent Living):

Dr Elena Skall is Marco Pazzi's mother. Marco Pazzi is prelingually deaf, aphasic, and he has been affected since his birth by dystonic tetraplegia. He is availing himself of Independent Living services partly funded by the Region at Negrar, a village near Verona. For a detailed report of this intervention see Attached C.

4. Discussion

A first discussion took place after these two last reports. The advantages due to a good service of Independent Living were perceived by all presents without any exception, therefore attention was drawn to the age limits established by regional authorities for access to these services. The interventions are quoted below:

Dr Andrea Principi (I.N.R.C.A.)

National rules do not set any fixed limits for the access to Independent Living services or to other available services, therefore such services should presumably be available also to those people who become disabled in old age. However, all regional rules fix the limit to 65 years of age. In the Marche Region, for instance, even if no Independent Living service has been implemented, there exists a service of Indirect Domiciliary Assistance to very seriously disabled people that is available only to people who are younger than 65. Why do regions set this age limit? Is it fair?

Dr Gianni Pellis (Independent Living services user)

I would like to go on leading my life like this also when I am older than 65, I agree on the elimination of age barriers which at the moment apply also to Piedmont, my region. I do agree on this sort of problems. Among other things, as it was pointed out during the Tenerife Congress, Independent Living supports all kinds of disability: motor, sensorial and psychic. Lately, in Piedmont we succeeded in having a project for a blind boy financed.

Ms Rita Barbuto (D.P.I.)

It is deeply unfair to divide disabilities into standard categories, up to now there was no possibility of facing this problem since we disabled people ourselves were engaged in dealing with other problems.

Dr Elena Skall (Independent Living users)

At a political level only a link between Independent Living and certain specific kinds of disabilities is being emphasized. This is not fair. Psychic disabled people, for instance, have their own particular needs. Besides, up to now there have been few projects and many difficulties.

Dr Andrea Principi (I.N.R.C.A.)

Thus the barrier of 65 years of age is a real problem which should be solved...

Dr Gianni Pellis (Independent Living user)

And only very few people are studying this problem.

Dr Patrizia Ceccarani (Lega del Filo d'Oro\ The League of the Golden Thread)

When they reach 50 years of age, people affected by hypoacusia usually lose also their sight. There should be some sort of family education to this kind of situations as well: the spouse, the children or the brothers and sisters of a deaf-blind are often not ready to face the new situation and they need help and assistance

Mr Roberto Zazzetti (Associazione paraplegici Marche\Marche Paraplegic Association)

In the Marche region the present culture of the family represents a real problem. It is necessary to change the mind and opinions of the disabled people's families and also of the disabled themselves, making them all understand that disabled people can lead independent lives, while now they are limited by their families because of a general hyper protective attitude. Making families and even the disabled themselves understand what Independent Living is, is not an easy matter. I have got many young friends who are limited by their families, especially in rural areas. We find it difficult to make these young people understand they can lead an independent life.



Dr Gianni Pellis (Independent Living user)

One year and a half ago I took part in a convention on Independent Living at Jesi, I don't know how much the situation has improved since then, it is a problem of political goodwill.

Ms Rita Barbuto (D.P.I.)

There is no political goodwill.

Dr Giovanni Lamura (I.N.R.C.A.)

Owing to different life expectations linked with age, disabled young people and elders, have different temporal perspectives for the search of solutions, the problem is also a problem of distribution of resources. But our reflection should be deeper and should take concepts such as independence, autonomy, self-sufficiency and dependence into consideration. What is the meaning of independence in old age? Perhaps the elderly have got much to learn from the positions achieved by the disabled, and vice versa.

Dr Elena Skall (Users of Independent Living services)

There are two possible approaches in the search for solutions concerning non self-sufficiency: one from the point of view of institutions, and one centred on the individual. We must start from this latter approach, without taking differences of age into consideration. Living according to one's own desires and being happy is what really matters.

Mr Adelio Franceschetti (S.P.I.-C.G.I.L. Marche)

It is a problem of personal dignity. Dignity of a whole life and not just of a period of one's life. We should emphasize the concept of independence which is something more than just self-sufficiency. On the other hand there is also a problem of structures. In practice, it is very difficult to discuss about the autonomy of elderly, disabled people. Besides, in my opinion, the age limit is completely absurd. It is unconceivable that a person is allowed to enjoy Independent Living services up to 65 years of age, and then as soon as he is 65 and one day, he/she loses them for lack of requisites. It is a cultural problem even more than an economic and assistance problem. Obsolete solutions, such as companionship allowance for elderly people, should be updated or eliminated.

Mr Fabio Ragaini (Gruppo Solidarietà\Solidarity Group)

It is important to point out that in the Marche Region there is no Independent Living centre, Indirect Assistance is something different. There is the problem of users who do not trust their own abilities, and if they trust themselves, they are not allowed to act freely because of resistance on the part of their families. Besides, Independent Living is a philosophy which is extremely different from our current services, just think of transport services in the Marche region.

Today's problem is that we must start experimenting with Independent Living; there is already a project that has been presented to the Region (Fabio Ragaini and Roberto Frullini took part in the study of this project, e.n.), the first thing, the priority, is the financing of the service, later on we will discuss about its perspective users.

Ms Emilia Napolitano (D.P.I.)

The main point is individualized treatment, since this is the “meeting point” of the disabled and the elderly. Each project must be taken into consideration a part from the kind of disability, the aim is that of improving the quality of life of people in general.

Dr Marcello Secchiaroli (Marche Region, Social Services Councillor)

I would like to explain certain points. The choice of the limit of 65 years of age for the access to our indirect assistance service has not been fixed in order to discriminate according to age, but, rather, because the Region economic resources are limited, therefore the Region Bill 18\96 was meant to safeguard handicap specificity, also with a view to what is happening at a national level with the block of allowances decided by the 192\98 Bil , not to disperse those resources by extending them to the elderly as well. The Bari Conference was the worst conference on disability that has ever been organized, full of demagogical positions, it certainly represented a step backward if compared with the past. Independent Living is, in my opinion, a move forward in a world that is going backward. It is a good thing, it is important to get ahead with experiments, even if they are small. At present, in the Marche there is this form of indirect assistance, with allowances given to families that disabled people use as they like. But Bill 162 has no longer been financed, therefore all experimentation that had been started runs the risk of being interrupted. At the moment we are going on thanks to funds supplied by municipalities or by the Region.

Ms Rita Barbuto (D.P.I.)

Experiments are important, we must use them as weapons to force a way. It is true, the government has stopped financing, but it is also true hat the funds available are spent badly. For instance, why is so much money being allotted to Calabria institutions? Wouldn't it be better to finance individualized projects thus allowing more people to leave institutions and old people homes? Is it a political problem? Or a quest for consensus and votes? We must think of the problem of personalized treatments and of age limits since, luckily, nowadays the disabled can grow old, differently from what happened in the past. What shall I do in 20 years' time? Besides, an agreement among different regions is absolutely necessary. What is the situation in Italy like? If I am enjoying an Independent Living project in Calabria and I must move to Marche because of my job, will I have to give up my project?

Mr Roberto Frullini (Handicap Regional Council)

Our culture is the fruit of a charity like approach, joined to a hyper protective attitude towards healthy children, let alone the disabled ones... Our present culture is stifling. A strong cultural action is therefore necessary. As for Independent Living, operators' attitude is often against its philosophy and they prefer to rely on traditional services as far as the management of resources is concerned. Independent Living creates “confusion”, since it would change the status quo and it would penalize service deliverers. But if we look at Independent Living from its users point of view, it is like going to the tailor and get clothes made to measure. At present, the available services allow to choose among several clothes but none suits us perfectly; with Independent Living users would have clothes made to measure, better than all the others, that would fit like a glove. And it would cost less. Independent Living does not mean spending more, it means spending better.

Dr Gianni Pellis (Independent Living user)

Art.1 ter of the 162\98 Bill states that it is the task of the Regions to plan services to the person. Many regions have allotted the funds at their disposal to daily centres, cultural and free time activities, domiciliary assistance, but funds should actually be destined to projects of Independent Living, which, furthermore, cost less than a half if compared with the costs of direct delivery of services. There are funds available but...

Dr Elena Skall (Independent Living Users)

Regions prefer to gratify families, so politicians get more votes. If they make happy one single disabled person then they run the risk that he cannot go and vote...

Ms Rita Barbuto (D.P.I.)

And thus they finance Calabria institutions because thousands of people work there.

Dr Gianni Pellis (Independent Living user)

No, I don't think it works like that. By improving the quality of life of a disabled person you also improve the quality of life of his/her whole family.

Mr Roberto Zazzetti (Associazione Paraplegici Marche)

We must destroy the present charity mentality. Everybody is constantly asking for money

Ms Rita Barbuto (D.P.I.)

More projects are needed...

Dr Giancarlo Sagramola (Ancona Province, Social Services Councillor)

Well, there is emerging a rather pessimistic view of politics, and I feel I must contradict it. I worked in the sector of social services for many years, I worked as a volunteer, I started my political career when I was quite old, and I have never thought that political decisions in this field are linked to consensus, so, now, when I must make decisions I don't bother about consensus because if one works well one gets consensus, therefore one must try to work well. Independent Living is a primary right to freedom, I am willing to cooperate on it, let's see what the Region will do about it. Everybody has a right to fair living conditions, no matter their birthplace. It is true, "regionalized" health care will be a problem since there is little communication among municipal institutions. There is little dialogue, but the present initiative deserves great interest. I think there will be problems with the unification of the two sectors of the disabled and the elderly and the elimination of the age limit of 65 years of age for access to services. I need further reflection about this point.

Ms Stefania Angeli (A.N.I.E.P.)

We disabled people must become a resource for politicians and for society. I became independent only when I understood it. But as a professional person, as a specialist in tax law, I have always been independent since there are constant relationships with other people, with society. Independent living is our "value added", a "cherry" on the cake, and one must not forget that a cherry in the wrong place makes the cake look ugly. There is often lack of information, we must look for more diffused information, which is what Ancona is doing with this seminar.

5. Presentation of some examples of projects of Independent Living implemented in Italy

At this point, after some short reports on the three projects that were selected out of the ten originally taken into consideration, (see attached B, 10 projects implemented in Italy with reference to the philosophy of Independent Living) the management of Independent Living Centres in different local environments was studied and discussed, (See Attached B for further details on the actual implementation of the projects.)

5.1. Dr Gianni Pellis: SAVI – Servizio Aiuto Vita Idipendente \ Independent Living Aid Service (Case 1)

The service (of which Dr Pellis is a user) is delivered in the municipalities of Collegno and Grugliasco (To) through CISAP and it has been in action since 1999. Every 6 months users must produce a report on how they made use of the form of service they received. At present there are 7 users but soon 2 more will join them. The need of continuity of the allowances was emphasized, since this point always causes anxiety in the users who must wait for the project to be approved year by year. SAVI has received great consensus in Italy both for its fully satisfactory structure and for its organization. As a matter of fact the project was presented at the Bari Conference and it will be adopted also by other municipalities that consider it a good example. Availability of resources does not seem to be a problem, since up to now public authorities have proved to be fairly sensitive about the problem.

5.2. Ms Irene Patscheider - Dr Elena Skall: Projects of Independent Living (Case 8)

This example should have been illustrated by Ms Skall, but the report was also prepared by Ms Irene Patscheider, who works at ULSS 22 Veneto that delivers the service, and who was unofficially present at the seminar. The service started thanks to the constant stimulus of the disabled, and not, as one might imagine, from the institutions; rather, the disabled themselves were decisive for its implementation. At first some projects were financed for 3 or 4 hours of personal assistance a week, then better structured projects were implemented. At first it was difficult to make people understand what having a personal assistant meant, then the number of users increased and the bureaucratic management of the activity became more difficult, such as for instance, the work contract with the personal assistant, the final statement of account, etc. In the end, last September, ULSS 22 decided to appoint an operator to assist users in such tasks (the operator is Ms Patscheider). ULSS 22 made this decision and now that people know about Ms Patscheider and her job, something important happened which is worthwhile mentioning in this context since it corresponds to one of the main aims of the C.E.I.L. project: many children of non self sufficient or partially self sufficient elderly people contacted her to have advice on personal assistance and on the problems linked with work contracts. This clearly means that also in the sector of elderly people a movement is starting from the base towards Independent Living. What is more, Elena Skall added that if at the beginning the users themselves insisted on the implementation of Independent Living centres, now it is the social workers who promote it, thanks to the synergy of funds between the Region and some Municipalities (5 municipalities). The head of the handicap area of ULSS22 has also put forward new proposals for the service

to be managed directly by means of USL funds in order to guarantee more continuity in time.

Dr Andrea Principi: Programmes of help to the person and assistance to families (Case 4)

This regional service has been in operation in Friuli Venezia Giulia since 1999. It has been considered among the best in Italy for its very good organizational structure, devised by the Region together with an organization of disabled people called I.D.E.A. presided over by Roby Margutti, that gives support and advice to people who want to apply for the service by means of a special guide devised for this purpose. The quality of the service is measured according to two parameters: on the one hand the improvement in the users' quality of life, on the other hand the decrease in the access to other kinds of services available to the disabled. As for the number of users involved, it is the largest in Italy. The latest data report 202 users in the region. Also in this case, as in the others already reported, the access age limit is 65 years of age. However, it is interesting to note that from a study on the service conducted by a regional Conference of Consensus constituted on purpose in order to analyse the service after some years from its implementation, there has emerged the need of the implementation of an integrated strategy of intervention in order to face the consequences of diseases and ageing processes since - the members of the Conference of Consensus say - there is a clear feeling that there exists just one wide front of intervention. This consideration, which is vital for the aims of C.E.I.L. project, is one of a series of proposals of the Conference for the improvement of the service. This study, into which the Friuli Venezia Giulia Region has invested some resources, is the "value added" of this project compared with others already implemented in Italy.

6. Discussion

The description of the 3 projects made the audience more conscious of the efficacy of the service and predictably led the short final discussion to the topic of costs. How much does a project of Independent Living cost? And how much does the institutionalization of a disabled person or of an old person cost? These are the questions posed by Adelio Franceschetti of S.P.I.-C.G.I.L. Beyond any ethical or moral consideration, evidence of the efficacy of the service from an economic point of view is also important. If Independent Living is less expensive, it would be obvious to adopt it instead of, say, institutionalization. But according to Mr Fabio Ragaini of the Gruppo Solidarietà the problem is more complicated. In fact, who pays for Independent Living services? And who pays for institutionalisation? If the same body were in charge of both, things would be much easier, but if there are two different institutions involved, then the conflict of interests could be solved only thanks to a "really exceptional" spirit of cooperation. The discussion ended with the interventions by Rita Barbuto of D.P.I. and Gianni Pellis of E.N.I.L. Italia, who said they were sure there are financial resources for Independent Living, provided the available funds are rationally invested. Gianni Pellis also gave evidence that an hour of personal assistance for Independent Living is less expensive than an hour's pay of a public assistant, and he ended his intervention by advocating that self-managed personal assistance is adopted as the main form of assistance for the future.

This opinion is agreed upon by the organizers of the Seminar. On the whole, the Seminar can be considered successful and encouraging from several points of view: for the contents of discussions, for the positive attitude towards the problems involved in the topics of discussion, for the sufficient acceptance of the extension of the philosophy of Independent Living to old age, and for the clear will to contribute to the compilation of a perspective pilot-project on the part of all the organizations that took part in the Seminar and on the part of public institutions (see Attached D that contains all information collected by means of the questionnaire of seminar evaluation). They all believe in Independent Living, but it is necessary to find the best way to pass from theory to practice.

7. Synthesis and Conclusions

As a whole, the philosophy of Independent Living, was positively interpreted by the participants in the Seminar. I.N.R.C.A. organizers, taking advantage of the positive feelings aroused by the interventions by Gianni Pellis and Elena Skall, focussed attention on the problem of age limit for access to service at present in force in Italy. C.E.I.L. wants to implement a service of Independent Living both for disabled people and non self sufficient elders. Dr Andrea Principi focussed the discussion according these lines of perspective. The reaction was positive, and the subsequent interventions by Gianni Pellis (user of Vita Indipendente), Rita Barbuto (D.P.I.), Elena Skall (users of Vita Indipendente), Patrizia Ceccarani (Lega del Filo D'Oro) all agreed on the need to eliminate the age limit, whatever the cause of disability (old age included). Up to this point all interventions were made by representative of disabled people.

Starting from the need of an integrated service both for disabled people and the elderly, with the central point of the need to eliminate the age limit of 65 for access to service, the discussion was then focussed on the disabled, with an interesting contribution by Roberto Zazzetti of the Associazione Paraplegici delle Marche (Marche Paraplegic Association) and of Gianni Pellis who pointed out a certain political sluggishness in the Marche region in the last few years about Independent Living, and by Rita Barbuto (D.P.I.) who commented on politics in general supporting Gianni Pellis's view.

Dr Giovanni Lamura from I.N.R.C.A. focussed again the audience attention on independence in old age, and once again discussion reverted to the topic with the interventions by Elena Skall and Adelio Franceschetti of S.P.I.-C.G.I.L. Marche who is the representative of old people, a group that is still extraneous to Independent Living. Mr Franceschetti's attitude towards the problem is best synthesized by his own words: "It is a problem of personal dignity. Dignity of a whole life and not just of a period of one's life. We should put the concept of independence in evidence, independence is something more than just self-sufficiency. The age limit is completely absurd. It is unconceivable that a person is allowed to enjoy Independent Living services up to 65 years of age, and then, as soon as he is 65 and one day ears old, he/she loses them for lack of requisites. It is a cultural problem even more than an economic and assistance problem". Thus, there is room for discussion that also involves old people's organizations. In agreement with Mr Franceschetti's words and after a short intervention by Fabio Ragaini of Gruppo Solidarietà (Solidarity Group) who stressed, on the other hand, "that the priority is the financing of the service, later on we will discuss about its perspective users", there was an intervention by Emilia Napolitano (D.P.I. Italia), who pointed out how the meeting point of the two different fronts could be the use of personal assistants.

Next there was the first intervention by a politician, Dr Marcello Secchiaroli, the regional Councillor of Social Services who commented on the lack of government funds for the handicap sector which, in his opinion, is the main reason for the choice of the age limit of 65 years of age for access to the service of the Marche region. It is not –the Councillor explained - Independent Living service, but Indirect Assistance through a money allowance that disabled users and their families manage as they prefer. This means a sort of refusal for the front of elderly people, but also goodwill towards the implementation of an experimental service, even a small one, at least temporarily devoted only to young disabled people, with the official explanation of the scanty funds available.

This explanation was contested by Gianni Pellis and Rita Barbuto who declared that, in their opinion, the problem is not the lack of funds but rather their irrational use. Between these two interventions, there was the intervention of Roberto Frullini of the Consulta Regionale Handicap (Regional Handicap Council) who agreed with them: “With Independent Living, users would have clothes made to measure, that would fit like gloves. And it would cost less .Independent Living does not mean spending more, it rather means spending better”. Therefore if we spent better, there could be funds also for elderly people in Independent Living projects. The more so since - as Franceschetti said: “obsolete solutions, such as companionship allowances for elderly people should be updated or eliminated”.

Then discussion shifted towards criticism of politics in general since politicians seem more interested in the quest for consensus rather than in the search for actions aimed at improving the quality of life of both the disabled and the old people.

Dr Giancarlo Sagramola, the Regional Councillor to social services replied, and he also gave his willingness to work with the region on the project of independent Living, even though he expresses some doubts about its extension to old people as well “I need further reflection on this point”.

The first phase of the discussion was concluded by Stefania Angeli who expressed her satisfaction about the contents of the seminar.

Some distinctive aspects can be detected in the attitudes and the interventions of the three types of organizations represented in the seminar.

Disabled people organizations: They were the most active during the seminar, and they accounted for the largest number of interventions. These organizations are the most active to push for the implementation of Independent Living services ,which they consider the best possible solution to any problem of disability. As for the extension of the services of Independent Living to old people as well, they seemed well disposed, maybe also because they think of their own future, and the handicap sector did not show any will to monopolize the available funds thus excluding old people (which was one of the possible risks).

Old people organizations: They were not very active during the seminar, maybe because they were present at the seminar in a smaller number if compared with the disabled. There were however positive interventions concerning the extension of the

philosophy of Independent Living to the sector of old people and the willingness to take part in the works of a pilot project.

Public Authorities: The principles of Independent Living were favourably accepted by Public Authorities who stressed the importance of projects based on personal assistance. The Public Authorities present at the seminar showed a rather defensive attitude as if they had to face a series of requests on the part of many different categories and not always easy to be fulfilled. The request for the implementation of an Independent Living centre in the Marche region was quite explicit and such need was also acknowledged by the Public Authorities themselves. Despite a general willingness assured for the participation in the pilot project, it appeared clear that there exists some resistance to the idea of eliminating the age limit of 65 for access to services, and consequently to the access to the services of Independent Living to old people as well. In this sense, the existence of more clearly binding rules at a nationwide level would be extremely important, since it would not leave much room for local interpretations on this and on several other points (as it is happening now for the services to which funds should be allotted). A careful work of “prevention” should also be carried out in order to discourage possible future normative interventions of temporary and partial nature, such as measures aiming exclusively at the safeguard of the disabled older than 65 who were already enjoying the service before reaching 65 years of age, an “escamotage” which is to be considered among the possible risks.

ATTACHEMENTS

A) Participants' list.

B) Materials distributed to participants: Seminar programme; What Independent Living is; European project: Contributing to Extend Independent Living; 10 projects that have been already implemented in Italy with reference to the philosophy of independent living.

C) Report by Elena Skall: “Our” Independent Living.

D) Evaluation questionnaire of the C.E.I.L. seminar and resulting data.

E) Tenerife declaration.

PARTICIPANT'S LIST

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ATTACHMENT D: EVALUATION QUESTIONNAIRE OF THE C.E.I.L. SEMINAR AND DATA OBTAINED

EVALUATION QUESTIONNAIRE OF THE C.E.I.L. SEMINAR

FILLED BY (NAME OF ORGANIZATION): TOTAL QUESTIONNAIRES: 13

- 1) Associazione Paraplegici Marche \ Marche Paraplegic Association
- 2) Gruppo Solidarietà \ Solidarity Group
- 3) ANIEP \ Disabled organization
- 4) Lega del Filo d'Oro \ League of the Golden Thread
- 5) Consulta Regionale Handicap \ Regional Council of Handicap
- 6) ANFFAS \ Disabled organization
- 7) Provincia di Ancona \ Ancona Province
- 8) Regione Marche-Assessorato Servizi Sociali \ Marche Region- Social Services Councillorship
- 9) Regione Marche- Settore Anziani \ Marche Region- Elders Sector
- 10) Regione Marche- Settore Anziani \ Marche Region- Elders Sector
- 11) FNP-CISL MARCHE \ Elderly organization
- 12) FNP-CISL MARCHE \ Elderly organization
- 13) S.P.I.-C.G.I.L. \ Elderly organization

To which extent the seminar fulfilled your expectations?	None	Very little	Moderately: 6 2, 4, 5, 7, 11, 13	A great deal: 6 1, 3, 6, 8, 9, 10	No answer: 1 12
How important is/could be the issue of independent living in your daily life?	None	Very little	Moderately	A great deal: 9 1, 3, 4, 5, 6, 7, 8, 10, 13	No answer: 4 2, 9, 11, 12
How do you rate the importance of the common work between elder and disabled people?	None	Very little: 1 2	Moderately: 5 1, 5, 6, 8, 12	A great deal: 7 3, 4, 7, 9, 10, 11, 13	No answer
How effective were presentations?	None	Very little	Moderately: 8 4, 5, 6, 7, 8, 10, 11, 13	A great deal: 5 1, 2, 3, 9, 12	No answer
How helpful did you find the meeting material?	None	Very little	Moderately: 4 1, 11, 12, 13	A great deal: 8 2, 3, 4, 5, 6, 8, 9, 10	No answer: 1 7
How do you rate the meeting facilities?	None	Very little: 1 7	Moderately: 7 2, 3, 4, 5, 11, 12, 13	A great deal: 5 1, 6, 8, 9, 10	No answer
What is your future commitment with the independent living system?	None	Very little	Moderately: 5 2, 7, 8, 9, 10	A great deal: 5 1, 3, 5, 6, 13	No answer: 3 4, 11, 12
Did the contents in this seminar create	None	Very little	Moderately: 8	A great deal: 5	No answer

opportunities for broadening and deepening your future commitment?			2, 3, 4, 5, 8, 9, 12, 13	1, 6, 7, 10, 11	
Did seminar develop ways of future cooperation?	None	Very little: 2 11, 13	Moderately: 7 2, 3, 5, 6, 7, 8, 10	A great deal: 1 1	No answer: 3 4, 9, 12
Do you think it necessary to implement an Independent Living Centre in the Marche Region?	None	Very little	Moderately: 1 7	A great deal: 12 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13	No answer
Would your organization be interested in taking part in the elaboration of a pilot project to that aim?	None	Very little	Moderately: 2 2, 8	A great deal: 10 1, 3, 5, 6, 7, 9, 10, 11, 12, 13	No answer: 1 4

PLEASE PROVIDE ANY ADDITIONAL COMMENTS:

1) The Associazione Paraplegici Marche\ The Paraplegic Association of the Marche Region, was created on 6th June, 2002. According to its Statute, its primary aim is the implementation of Independent Living, as proposed by Ms Carmen Mattei of Capodarco Community. We are willing to give our cooperation for the implementation of a project of Independent Living, and in particular for the implementation of a residential centre where Independent Living is possible.

4) a good percentage of grown up people becomes deaf-blind in old age owing to degeneration or decline of their sight and hearing. All the precautions and measures that are necessary where deaf-blind people live, are applicable also to old people with sensory problems.

9) I think the way for common projects concerning handicap, disability and old people is still unknown, and I think this common work could be very useful to find organizational and structural solutions for the places where those people live.

QUESTIONNAIRE RESULTS

In accordance with the conclusions of the discussions during the Seminar, also the information derived from the questionnaire points out a general favourable attitude towards Independent Living .

From a theoretical point of view there can be noticed a positive approach to the idea that it would be right to extend Independent Living to old people as well.

There are however practical obstacles to this extension such as the simultaneous management of two fields of action (the disabled and the old people) that are at present managed and administered by different public bodies. The unification of these two sectors would be attainable only if a really strong will to reach this aim existed.

However, despite obstacles and difficulties, the respondents showed sufficiently strong motivation to guarantee a satisfactory possibility of negotiation for the near future.

In conclusion, Italy seems to offer feasible conditions to reach the objectives of the C.E.I.L . project in its second year of activity: namely the realization of a partnership proposal for a pilot project.

A short analysis of the data obtained from the questionnaires distributed to all participants at the end of the Seminar is given below. Questions are analysed each by each.

1 Positive answers to this question are one of the elements to be considered as evidence of the success of the Seminar.

2 This was resulted the most difficult questions by the respondents. It was meant to evaluate the participants attitude towards the problems discussed. A part from a few exceptions, the question mostly interested the representatives of the organizations of the disabled as prospective users of Independent Living. Also some of the Public Authorities felt they had a particular duty to fulfil.

3 Only one of the respondents did not seem to believe in common work between the disabled and the old people. On the whole, results were quite encouraging for possible developments of C.E.I.L.

4 On the whole, the reports seem to have had a satisfactory impact on the participants.

5 Also in this case positive answers were given.

6 This question was meant to valuate whether the premises were satisfactorily equipped for the needs of the disabled that took part in the Seminar. Since only one of the respondents answered "very little", it can be inferred that reactions were in general positive.

7 Almost all respondents showed the intention to work in future for the theme proposed, "moderately" or "a great deal". The groups of the non disabled answered they would work "moderately", and the group of disabled answered "a great deal". Also SPI-CGIL Marche answered they would work "a great deal". The Lega del filo d'Oro did not answer the question but they added the following note: "The Lega considers it an important target and we are devoting resources to it."

8 All participants acknowledged the Seminar was very useful since it increased and deepened their engagement towards Independent Living.

9 There was no extraordinary feedback concerning the forms of future cooperation. Though the majority of the respondents answered “moderately”, there was one single answer “a great deal”, while 2 representatives of organizations of the old people answered : “ very little” and 3 did not answer at all. It is the group of the disabled who showed greater hope in cooperation.

10 The answer was unanimous. All respondents seemed to consider the implementation of the service very important.

11 This question required a more concrete commitment since it required a possible involvement in the objectives of the second phase of the C.E.I.L. project. Almost all the organizations that took part in the Seminar declared they would be “a great deal” willing to cooperate, with the only exceptions of Gruppo Solidarietà and the Marche Region (presumably because there is a proposal in this sense already presented to the Region and Gruppo Solidarietà took part in its planning.)

12 Comments (supplied by 3 different organizations, namely the Associazione Paraplegici Marche, the Lega del Filo d’Oro and the Elderly Sector of Marche Region), emphasized the opportunity to implement services of Independent Living both for the elderly and for the disabled.

C.E.I.L. PROJECT

(CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING)

GREEK SEMINAR REPORT

SEMINAR FOR THE INDEPENDENT LIVING



THESSALONIKI 27 JUNE 2003

**Living Room of the
Center for the Support of the
Old People of Municipality of Thessaloniki
Karakasi 1, Thessaloniki**

The seminar is organized by the Non-Profit Company Disability NOW in the framework of CEIL Project (Contributing to the Equality from Independent Living) which is implemented with the financial contribution of the European Commission. The seminar aims to present the Independent Living Philosophy to the Greek people with disabilities and the elder people as well and to emphasize the II's contribution against Discrimination. Representatives are invited from: Greek Government, Local Government, Organizations of disabled people, Organizations of older people, University Professors, Students, People with disabilities, Older people

SEMINAR PROGRAM

Friday 27.06.2003

11.00-11.30 Welcome Speeches by:

- Efi Koutsouraki (Disability NOW)
- Thomas Vakaloudis (Center for the Support of the Old People of Municipality of Thessaloniki)

11.30-12.15 Presentation of the Independent Living Philosophy

- People with disabilities and Independent Living- The current situation in Greece
(Nikos Voulgaropoulos, Disability NOW)

12.15-13.00 Presentation of the CEIL project

- Partners, Aims, Main Activities, Examples of Good Practice
(Afroditi Baka, Disability NOW)

- 13.00-13.15 Coffee Break
- 13.15-13.40 The Independent Living on Old People
- The current cooperation between organizations of old people and organizations of disabled people. The cooperation within CEIL's project- The immediate need for further cooperation (Irina Tsoukala, Center for the Support of the Old People of Municipality of Thessaloniki)
- 13.40-14.00 Independent Living and Accessibility
- The Accessibility's importance for the implementation of the Independent Living approach in Greece (Gerasimos Polis, Paraplegic, Consultant in the Greek Developmental Department)
- 14.00-15.00 Lunch Break
- 15.00-15.25 The Local Government's role
- The Local Government's obligation for actively contribution in the creation of the requested configurations for an independent and respectable living for people with disabilities and old people (Ioannis Vafiadis, Municipal Society for Vocational Training and Research of Municipality of Thessaloniki)
- 15.25-16.30 Questions and Discussion between the speakers and the audience
- 16.30-16.45 CEIL's impact on the improvement of Greece situation
- The importance of CEIL's implementation for Greek people with disabilities and old people-The chances for improvement through the CEIL project (Nikos Voulgaropoulos, Disability NOW)

The Greek Seminar for the CEIL project took place on 27th June 2003 in the Living Room of the Centre for Old People of Municipality of Thessaloniki.

The seminar started at 11.00 p.m. and lasted for 6 hours. At the seminar attendants were especially activists from organizations of people with disabilities, personal care assistants, psychologists, lawyers, specialists on Independent Living products and social workers. The total attendants' number was 19 persons especially from Central Macedonia.

Presentations

Presentation of Independent Living

The seminar opened with the presentation of the Independent Living philosophy by Nikos Voulgaropoulos, representative of Disability NOW. Nikos Voulgaropoulos is a quadriplegic himself and has a first-hand experience on Independent Living approach as an advocate of Independent Living philosophy since his paralysis.

Nikos Voulgaropoulos made an interesting presentation focused on the basic principles of the Independent Living philosophy and its methods. After making an historical retrospect from the first movement in Berkley since nowadays he presented the methods that this philosophy uses in order to assist people with disabilities to organize themselves into cross-disability self-help organizations and gain their independency through peer support training and personal assistance services. "The Independent Living approach recognizes the right of the citizens with disabilities to gain the control of their lives by testing choices and taking their own decisions and their risks as well. Independent Living states that people with disabilities are the most experts to appoint their needs and able to find solutions to their problems. For years, the common practices demanded big personal efforts for the person's adjustment to the social environment. The Independent Living prototype is designed to adjust the environment to the person's needs contrarily to the old model which was trying to change the person in order to fit it to the environment".

Finally he made a complete description of the situation in Greece underlining the lack of legislation, the ignorance of the Independent Living approach and the prompt need for direct payments' policy and professional personal assistants' services.

Presentation of the CEIL project

The CEIL project was presented at the seminar by Afroditi Baka, psychologist with a great experience in spinal cord injuries and volunteer in Disability NOW since 1993. After presenting the partners in the project and marking the importance of the financial contribution of the European Commission in the project's implementation, Afroditi Baka explained the basic goals of the project and the process that the partners have followed since now in order to fulfil these goals.

During her speech, Afroditi Baka emphasised at the significance of the cooperation between the organizations of older people and the organizations of people with disabilities for the promotion of Independent Living to disabled and older people as well.

After describing the project in general, Afroditi Baka presented the process followed by the partners for the selection of the examples of good practice in each country and explained the need for the documentation of the examples. Concerning the Greek examples, she firstly punctuated the difficulties that Greek Local Team faced at selecting these examples because of the special situation

in Greece and pointed as a good but not so functional example the groups of peer support that the Association for the Multiple Sclerosis ran from 1994 to 1999. More specifically, she said that the Association for the Multiple Sclerosis ran for five years projects of peer support for people with multiple sclerosis but for financial reasons these projects finally stopped working even though the interest was still very high. Afroditi Baka explained to the audience that it was too hard for the Greek partners to find projects or policies that promoted Independent Living in Greece and that the Greek Local Team decided to present the example of the AMS on account of the lack of other better or more effective examples. At the end of her presentation she also made a brief reference to the Italian examples that had been already distributed to the audience and talked about the Institute for the Independent Living in Suede as a great prototype for the promotion of Independent Living in Greece.

Independent Living and Old People

Irini Tsoukala, Social Worker in the Centre for the Support of the Old People of Municipality of Thessaloniki, started her presentation by describing the present cooperation between the organizations of old people and the organizations of disabled people in Greece. First of all, Irini Tsoukala, with her great experience on older people, indicated that these people consider they are completely different from disabled people and they usually refuse strongly that any kind of their incapability may be presumed as disability. “It is very hard for older people to admit themselves as disabled people and this is the main reason for the slight cooperation between their organizations and the organizations of disabled people”. Beyond this current perception Irini Tsoukala underlined that it’s necessary for the organizations of older people and the organizations of disabled people to find ways to reverse this climate and that the promotion of Independent Living is a great opportunity to carry it out. But, above all, old people with some kind of disability and old people who will probably acquire a disability in the future have to comprehend that they won’t lose their dignity if they are defined as disabled people.

Independent Living and Accessibility

The government’s view for the promotion of the Independent Living was arranged to be presented by Gerasimos Polis who is paraplegic and consultant in the Greek Developmental Department. Unfortunately Gerasimos Polis didn’t manage to come to the seminar for health reasons so his presentation was made by Despoina Fotiadou, who as an advocate nurse herself and as an consultant in the Lavda Center for the Independent Living has also a first-hand experience on the needs but also on the policies that have been implemented the previous years in order to cover these needs. After making a brief report on the problems she has faced as a personal care assistant she started presenting the speech that Gerasimos Polis has prepared.



“Accessibility is a basic precondition for the Independent Living”. That’s what he was emphasizing in his speech. The most important need for disabled people and for older people in Greece is the accessibility of public buildings, of transports, of stores etc. All these people just don’t want to meet obstacles during their transportation and to be forced to live isolated on account of these obstacles. Independency also means freedom: freedom to make your own choices, freedom to select your

destination, freedom to live respectfully. These are really very simple things in the daily life for the physical able people but not for the disabled and powerless people". In his speech Gerasimos Polis was also underlining that his Department is already pondering over the big issue of the accessible transports and the accessible public buildings and is going to adopt policies "for all" which means that everyone with or without disability, young or old, will benefit from these policies.

The Local Government's role

The Local Government was represented at the seminar by Ioannis Vafiadis who is the director in the Municipal Society for Vocational Training and Research of Municipality of Thessaloniki. Ioannis Vafiadis made a brief presentation of the previous projects that have been implemented by the Municipality of Thessaloniki for the improvement of the living conditions of disabled and older people and particularized to the initiative of the Municipality to put ramps in the center of the city five years ago. What Ioannis Vafiadis emphasized most is the fact that the Municipality has the willing and the obligation as well to create all the requested configurations for an accessible and friendly city, but, unfortunately it doesn't have the financial sources to accomplish it.

DISCUSSION

The above presentations followed open discussion between the audience and the speakers. Taking into account the questions posed, the attendants obviously weren't enough aware of the Independent Living approach and many of them asked to learn more about it and to have relevant information in the future. They paid attention especially to how our country could implement direct payments policy and what would that possibility requires. The conclusion was that it's indeed very difficult to have such a policy in Greece as the Greek governments have shown since now that they are not willing to invest the required money for its implementation.

The first reasonable question after that was if there is a way for people with disabilities or older people to have their personal care assistants without direct payments. The basic problem for this possibility, as said, is the financial difficulties that all these people face for their survival as especially the people with disabilities are obliged to spend too much money to equipment and often their insurance don't cover a large part of this expenditure. On the other hand, in Greece we don't have many specialist assistants, so everyone agreed that it's difficult even for someone who can afford the above expenses to have the support he actually needs.

Some attendants proposed as a good alternative the new technology systems (new kind of wheelchairs, etc.) which could offer some kind of support and don't demand special know-how. But, as indicated by the people with disabilities who took part in the discussion, this kind of support would never be enough as since now technology can't cover basic needs as the catheterisations, the cleanness etc.

It was also said that, the professional employment could help to some extent to gain the financial sources but this is an another problem in Greece as the demand especially for people with disabilities is too low while there is still the problem of transportation, the low educational level and the fear of working in inaccessible environments.

Finally, some attendants with disabilities proposed the idea of the self-organization but as they admitted after the intervention of some other attendants it is something very difficult too because it also demands money that they wouldn't be able to find with the present conditions.

CEIL's impact on the improvement of Greece situation

The interesting discussion between the attendants and the speakers lasted for about 45 minutes. Then Nikos Voulgaropoulos took the floor again in order to underline the possibilities that the CEIL project creates for the improvement of the situation in Greece and the directions that the Greek people with disabilities have to follow in order to succeed it.

First of all, Nikos Voulgaropoulos emphasized again that: "The Independent Living can only be implemented in Greece with big obstacles because unfortunately in our country there is not direct payments' policy while the accessible means of transport as well as the accessible public buildings are tragically few. The people with disabilities can't afford to hire staff for their personal needs and that's why they depend on foreign employees who live in Greece, as they don't have to pay for them the taxes they are obliged to pay for Greek assistants.



As it seems the Greek State will delay enough to create a direct payments' policy and for that reason it's important to start creating the whole system from the beginning. We have to take into account that on the score of the fact that people with disabilities constitute the poorest minority in Greece and are generally untrained it is necessary to find means for the occupation of cheap assistants. We believe that the CEIL project is going to help us find an appropriate and easily operable Independent Living model that will be able to function without direct payments and regardless the state

support through the partners' examples of good practices. Also, this project is going to help us to inform widely the Greek people with disabilities about the Independent Living and its goals and to present the situation in other countries so they can understand better the benefits and the change that this model will bring into their lives".

But, the most important as Nikos Voulgaropoulos indicated is the activation of the people with disabilities so as to pretend their lives and their participation to the society: "if someone is disabled and lives under the family's protection or vest the administration of his personal needs to third people or is not allowed to manage his own needs and his own future he can't live independently. One of the basic principles of Independent Living is that all the parts which constitute its structure (users and employees) have to be the masters of themselves. They can't be dependent on anything and anyone.

Unfortunately in Greece the users are not activated. They can't assume responsibility for their mistakes, so they prefer to rely on a kind of life that they haven't chosen without taking risk for anything. So, it is absolutely necessary to create a system for the re-training of people with disabilities and inabilities that will firstly train them as employers, as they will be the employers of their assistants, and then will introduce them to the Independent Living model".

QUESTIONNAIRES FOR EVALUATION

Disability NOW, after distributing to the attendants the questionnaire for the evaluation of the Seminar and the Project, in general, gathered 16 filled questionnaires.

The questionnaires' analysis show that the audience found the seminar's issue very interesting. Especially for the issue of Independent Living their estimation is that it's very important as in relevant question the 13 of the 16 chose the answer "a great deal" while the rest 3 answers were "moderately".

Regarding to the extent to which the seminar fulfilled the attendants' expectations the estimation was also positive with 12 of "a great deal" answers and 4 of "moderately". Analogical was the audience's opinion on the presentations' effectiveness as well as their estimation for the meeting material. More specifically the above questions gathered 13 of "a great deal" answers and 3 of "moderately" answers. The importance of the common work between elder and disabled people proved to be of high importance for the attendants too, as all of them answered absolutely positively to the relevant question.

Concerning the meeting facilities the questionnaires show that the attendants were very satisfied so they all answered positively to the relevant question ("a great deal") whilst the 14 of them answered that they will absolutely commit with the independent living system in the future as the seminar created serious opportunities for future activities. The rest 2 attendants answered to the relevant questions that they are going to commit moderately with the independent living in the future after the seminar's contribution. The results regarding the ways for future cooperation after the seminar were exactly the same as above.

Greek Seminar for the Independent Living

List of Participants

FULLNAME	PROFESIÓN	CITY
Thomah Aidoni	Psychologist	Thessaloniki
Dimitris Basoglou	University Professor- Psychologist	Thessaloniki
Aria Atsalaki	Personal care assistant	Thessaloniki
Anastasia Bantioudi	Personal care assistant	Edessa
Irini Hetrive	Personal care assistant	Thessaloniki
Giorgos Oikonomidis	Personal care assistant	Kalamaria
Stavros Nasioudis	Independent Living products specialist	Thessaloniki
Vasilis Katsioridis	Independent Living products specialist	Kalamaria
Katerina Stafilidou	Disability Marketing	Nea Krini
Kostas Kosmatos	Lawyer	Thessaloniki
Stella Papadimitriou	Project Manager	Thessaloniki
Giannis Avramakis	Social Worker	Nea Raideustos
Christos Tassios	Computers' specialist	Thessaloniki
Vaggelio Kabilaki	Paraplegic doctor	Thessaloniki
Eleni Hontolidou	University Professor	Thessaloniki
Dora Dimitrakopoulou	Psychologist	Thessaloniki
Christina Papadimitriou	Social Worker	Thessaloniki
Giorgos Avgoustidis	Paraplegic	Thessaloniki
Mixalis Kontominas	Quadriplegic	Katerini

EVALUATION QUESTIONNAIRE OF THE CEIL GREEK SEMINAR

To which extent the seminar fulfilled your expectations?	None	Very little	4	12
How important is/could be the issue of independent living in your daily life?	None	Very little	3	13
How do you rate the importance of the common work between elder and disabled people?	None	Very little	Moderately	16
How effective were presentations?	None	Very little	3	13
How helpful did you find the meeting material?	None	Very little	3	13
How do you rate the meeting facilities?	None	Very little	Moderately	16
What is your future commitment with the independent living system?	None	Very little	2	14
Did the contents in this seminar create opportunities for broadening and deepening your future commitment?	None	Very little	2	14
Did seminar develop ways of future cooperation?	None	Very little	2	14

C.E.I.L. PROJECT

(CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING)

SPANISH SEMINAR REPORT

CEIL PROJECT (CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING)

MADRID SEMINAR REPORT

The current situation of the persons with disability and elder people in Europe is similar in many aspects, especially in relation to its origins and the generating mechanisms of prejudices and forms of discrimination and also in terms of practical implications in policies and community based services.

A Seminar in Spain was planned within the CEIL activities. The close co-operation among partners, CEOMA and Asoc. IES, made possible to bring together relevant participants because of their personal engagement in both NGO's of elder (CEOMA) and disabled people (COCEMFE, ONCE, ...) as well other institutions (Luis Vives Foundation). A relevant and rich contribution to the seminar came from many members of the Spanish Forum on Independent Living who attended the meeting.

This is the summary of it.

C.E.I.L. PROJECT

(*CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING*)

SEMINAR
MADRID, JULY 19, 2003.

Place:

University College “ JUAN LUIS VIVES ”,
Street Francisco Suárez n ° 7, Madrid.

Attendees:

SEMINAR MADRID "CEIL" 19-July-2003

	Name	E-mail	Notes
1	Javier Romanach	jromanac@grupoeid.com	
2	Manuel Lobato	mlobato@reterioja.com	
3	Jose M ^a Fernández de Villalta	jfvillalta@aupace.org	
4	Elena de Los Santos	jfvillalta@aupace.org	Personnal assit.
5	José Vidal	vidal@telefonica.net	
6	Marita Iglesias Padrón	marita@asoc-ies.org	
7	Juan José Maraña	jjmarana@asoc-ies.org	
8	M ^a Sol Neira	marisol@asoc-ies.org	Personnal assit.
9	Jesús Vizcaino	vizcainoje@wanadoo.es	
10	M ^a Isabel Velasco Menéndez	mabi@mas-servicios.com	
11	David Alonso Martinez	mabi@mas-servicios.com	
12	Luis Miguel Bascones	luisbase@telefonica.net	
13	Alejandro Rodriguez-Picavea	picavea@arrakis.es	
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17	Jesús Hernández	jgalan99@yahoo.com	
18	Susana Sáez (*)	susana_saez@yahoo.es	
19	Estanislao Jaime Rodríguez	EJRCG@telefonica.net	
20	Jose Luis Herrero	jlherrerosg@yahoo.es	
21	Laida San Sebastian	lss@icavibikain.com	
22	M ^a Soledad Arnau	msarnau@yahoo.com	

C.E.I.L. PROJECT

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PROGRAM

11:00 h.:

Welcome and presentation

11:30 h. to 13:30 h.:

Presentation of the Project CEIL, by Juan Jose Maraña, Co-ordinator (Asoc. IES)

D. Jesus Vizcaíno's intervention (CEOMA), of the group of elder people. "Disability and elder people: the keys of the cooperation".

Presentation of Good Practices, by Marita Iglesias (Asoc. IES).

Open colloquium:

Independent Living: a definition, only one concept?

14:00 h.:

Lunch

16:00 h. to 19:30 h.:

Open colloquium: led by Manuel Lobato and Javier Romanach

IL and the coming legislation (Law of Equality of Opportunities, European Constitution ...).
Independent Living Forum – Proposal for future

SUMMARY OF THE MEETING

After a brief biographical sketch of the aims and goals of Project CEIL made by its Coordinator, Juan José Maraña (IES) and, fundamentally with D. Jesus Vizcaíno's intervention (CEOMA) an open discussion began orientated to analyze the existing relations between the disability world and the group of elder people.

The Spanish experience.

This is a summary of Juan José Maraña's exposition which marked the begging of a very lively discussion among participants. Juan José Maraña stressed that the differences that can be established between the course of Independent Living in Europe and Spain rest, to a large extent, in the institutionalised criteria of providing the cover of social needs and the quality of life of individuals according to the State in which they take place.

Part of the differences between the course that Independent Living takes in the north of Europe and that of our country stem from the adaptation that the democratic system has had to adopt to evolve from an authoritarian system that had renounced establishing mechanisms of tax collection in an attempt to satisfy fairer criteria of wealth distribution. At the same time, the economic situation limited by the low income per capita, the high rates of unemployment, and a demographic tendency towards the continued ageing of the population paved the way for a Social Security system unable to reach levels comparable with those of the northern European states.

With the passage of time, radical transformations have taken place in our system of social cover that have achieved a greater social attention and justice, but not to the point of being able to defray the economical cost that on occasions may be necessary for the full development of disabled people. The access that these people may have, in our country, to employment, not only has a component of demand for equal opportunities with respect to the rest of the population, but also the palliation of the structural deficiencies within the system with respect to the disabled. This continuously implies a large dose of inequality: the State does not always provide accessible means of transport, yet if the disabled individual provides for them with the remuneration obtained from his or her job, it only diminishes one inequality, given that for the rest of the citizens the State does plan means of transport, and the fact that they must be adapted or made accessible for their use by all it is not considered.

On the other hand, the access to employment is only feasible for a segment of the population with disability, as there will always be a significant percentage of disabled people that will never, or very rarely, be able to gain access to the job market, and not because they lack economic self protection should they have to renounce any of their civil rights or delegate the planning of their lives. This is, among others, one of the great challenges that society and the Independent Living movement must confront.

It is these structural deficiencies which of disabled people organisations, as well as other institutions, are attempting to palliate by identifying the solutions most appropriate to their rights as components of the community, according to their order of priority and necessity. To a large extent this is one of the social contributions that the movement of Independent Living brings with it, that of displacing the disabled individual from a distorted social consideration, stripped of identity and rights, yet determined, as any other citizen, to exercise a clear control over their life and the way in which it is conducted.

After Juan José Maraña's contribution, Jesus Vizcaíno (CEOMA) underlined the manifest relations of dependence that it exists since the beginning of the individual's life. With the arrival of the oldness, the situations of dependence substitute gradually to those which can be considered as self determined, especially if disability appears in that period of life.

According to Jesus Vizcaíno, all our life is related to the dependence. When we are born we are dependent, need help to develop ourselves in the daily life and we return to this dependence to carry out some of our daily routines. For this reason, our aim should be to delay the most possible the arrival to this dependence. The oldness is the final point of the vital cycle, which is aggravated by the arrival of the disability in this moment of the person's life. To delay this situation, we need the PREVENTION. It is at this point, where, there is nothing which helps us to be aware and therefore to delaying the appearance of the disability in the elder people. In order that this situation was different, we would need preparation and means.



If we analyze a bit the current situation, 17 % of the population in Spain is older than 65 years, but in 2050 it is foreseen that 37 % of it will be older than 65 years. The aging of the population is taking place and it is accelerated, since we live more years and, as consequence, there is more probability of having a disability.

Which role do elder people play in the world of the disability?

One must think that, in Spain, 3.500.000 of persons are disabled and 60 % of them older than 65 years. Elder people who are disabled suppose an important number inside the group of the disability. Nevertheless, this fact is not known because we live in a world of cult to the youth and the perfectionism. We all have to be always young and be perfect.

To care of elder people is turning more and more complicated. The administration dedicates 7 % of GDP to the social actions whereas in some of the Northern countries it can come to 40 %. Nevertheless, 83 % of elder people is taken care by the family what is named "informal help".

Lack of institutions exists for those persons who need long care. There is the medical trend to say that the doctors are to recover and not to take care, for this reason those persons who have difficulties to leave a hospital, that is: that person who is given of discharge but he/she does not know where to go, becomes a person in risk of social exclusion. This it is a topic that affects both elder people and persons with disability.

A key point is that a change in the social structure of the family is taking place. In the future, the family will not be able to take care of the elder people and we return to the initial point: it is necessary to anticipate, to prevent, in order to delay the appearance of the disability in the elder people so that they can be independent during more time.



It is necessary that the Social Law of the Dependence, which is being elaborated in Spain, has an universal approach to include both disabled and elder people. The aim of this law should be to obtain the necessary resources in order that elder and disabled people can remain at home as much as possible. On the other hand, it is very important to create centers of long permanency for those persons who cannot remain in their families' home.

A fundamental element is to put into action the introduction of the "check of services", that is to say, that the user of external services for his/her independence can receive directly a quantity of money that he/she will manage according to his/her criterion and not as it happens nowadays that it is the social services of the town hall who have the power of decision and management.

Another important point arisen during the discussion:

To recognize the importance of the family, in this way, relatives should form part of the social security system, without taxes.

To reflect fiscal benefits for disabled people and their relatives due to the greater expenses that disability has.

To eliminate VAT from services and technical aids. If a person needs a sort of device or set of instruments to make life more independent, the State should not take advantage of this situation and collect money with this tax.

The collaboration between disabled and elder people should be a reality, though many differences exist:

- The origin and the treatment of the disability in a young person and in an elder one is different.
- The way of confronting the disability is very different according to the age of the person.
- The spirit of struggle is minor in elder persons that in the disabled young men and women.
- The elder people's difficulty for learning.
- The concept of independence is very different for elder and for disabled.
- Both groups have different ambitions. A young man wants to study to work, whereas in an elder person it is not the most normal thing.

During the celebration of this seminar, these questions were the basic points of the discussion. Finally, the final conclusion was that the collaboration between elder and disabled people is difficult but it is necessary to try to obtain it and to be together to fight for the wished aims.

The concept of independent living can be the same for both groups but the aims, expectations and needs are different. It is necessary to have in mind that the disability is not related to the dependence. The dependence has more to do with the social situation of the person and with what he/she wants to do in the life.

The most important thing is that the two groups want to live their lives under their control, each one is able to take their own decisions. Nobody should decide for the other. The key to obtain this is to recover the rights of disabled people for being disabled and the elder people for being elder.

Elder people stated that they want to have the means and resources to live independently in the future because they know that, in the future, according to the current characteristics of the family, children are not going to be able to take care of their elders. This is why they ask for:

- Basic pensions.
- Improvements in these pensions according to what he/she has contributed during his/her working life.
- If his/her salary is enough, to be able to invest it in order to improve their incomes when they will get older.

In this aspect, the majority of the persons with disability that were in the seminar did not agree with this alternative, because it is OK for the persons that worked during their lives and had a good job, but a young disabled person is not going to be so productive in order to quote very much, he/she is not going to have a good salary, so he/she will receive only basic pensions. Finally, there was a general agreement that the person must not be valued for what he/she has worked, since, in this case, disabled people will continue being isolated.

The right to independence should be incorporated to the human rights.

QUESTIONNAIRE OF EVALUATION

- 22 questionnaires were distributed. 11 questionnaires were answered.

Questions:

1. To which extent the seminar fulfilled your expectations?

None	Very little	Moderately 6	A great deal 5
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It is possible to say that for 54,5 % of the attendees to the seminar it fulfilled moderately what they were expecting, whereas for 45,5 % it was very productive.

2. How important is/could be the issue of independent living in your daily life?

None 0	Very little 1	Moderately 1	A great deal 8
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For 9 % it is of very little importance, other 9 % of moderate importance and 72,72 % gives much importance to this system. Whereas 9 % did not answer the question.

3. How do you rate the importance of the common work between elder and disabled people?

None	Very little	Moderately 2	A great deal 9
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18,18 % of attendees give moderated importance to the joint work between both groups whereas 81,81 % give very much importance.

4. How effective were presentations?

None	Very little	Moderately 5	A great deal 6
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45,45 answered that the interventions were moderately effective whereas 54,54 % answered they were very effective.

5. How helpful did you find the meeting material?

None 1	Very little 3	Moderately 4	A great deal 3
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For 27,27 % materials seemed to be very slightly interesting, 36,36 % said that they were moderately interesting, 27,27% very interesting and 9 % did not answer the question.

6. How do you rate the meeting facilities?

None	Very little	Moderately 3	A great deal 8
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For the 27,27 % of attendees facilities were found moderately right whereas 72,72 % valued them very much.

7. What is your future commitment with the independent living system?

None 0	Very little 1	Moderately 1	A great deal 8
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9 % has a very small commitment with the Independent Living system; 9 % moderately, 72,72 % were related to this system and 9 % did not answer to the question.

8. Did the contents in this seminar create opportunities for broadening and deepening your future committeemen?

None	Very little	Moderately 7	A great deal 4
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63,63 % believes that the seminar can have created moderately opportunities to extend commitments whereas 36,36 % think that very probably can create and extend commitments.

9. Did seminar develop ways of future cooperation?

None	Very little	Moderately 3	A great deal 8
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As for this question, 27,27 % believes in a future cooperation, whereas 72,72 % is sure that there will be a future cooperation.

It was suggested in some questionnaires to continue carrying out more meetings to go in depth the topic arisen during this Seminar.

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(*CONTRIBUTING TO EQUALITY FROM INDEPENDENT LIVING*)

GUIDELINES FOR ORGANIZING INDEPENDENT LIVING EVENTS

The notes are intended to serve as a check list for planning training sessions, seminars, workshops or conferences on Independent Living.

Planning process

One of the important principles of Independent Living is the concept of cross-disability, meaning that disabled people are not to be grouped into medical diagnoses or sorted by the nature or extent of their disability. Instead, regardless of whether we are blind, sight-impaired, deaf, hearing-impaired or mobility-impaired, consumers of mental health care, intellectually disabled or have substance sensitivities, we need to see ourselves as one group.

Diagnoses serve to separate and, sometimes, to pit us against each other. The Independent Living movement emphasizes that our common history and experience of oppression, exclusion and discrimination should help us see disability not as a medical, technical or humanitarian problem but foremost as a problem of lack of political power. Only by organizing ourselves and speaking with one voice we can effectively improve our position in society.

Cross-disability requires that IL events are open to persons with all disabilities. For this to happen we need to involve persons with different types of disabilities in planning and organizing events in order to ensure that people with different disabilities

- will be reached by your information about and invitation to the event through the appropriate media (printed, audio, Braille, etc.) and through the proper channels (general media, disability magazines, mailing lists, word of mouth, etc.)
- will be able to attend your event which requires that date, time of the day, location is accessible to people with different types of disability. Do not see access only as a question of avoiding steps and stairs at the entrance but also as an issue of the size, equipment and number of toilets, use of induction loops and sign language interpreters, avoidance of perfume and tobacco smoke, etc.

Ask those who plan to attend to inform you about their needs.

Event format

Starting late in the morning, say 9:30 a.m. or later, will enable more people with extensive disabilities to participate who often need more time for their morning routine and transportation.

Frequent breaks are not only a necessity, if you try to enable many disabled people to come. Many and long breaks give people a chance to get to know each other, exchange views and plan actions.

Do not overload the program with many or long presentations. Less is better: people will not get tired and learn more, if you have shorter and fewer program points.

Allow question and answer periods after each presentation. This gives the presenter the opportunity of further explaining and illustrating important points. For a 20 min presentation a 10 min question and answer session might be appropriate.

Schedule discussions but limit questions or comments from the floor to 1 min at a time.

Discussions involving people from the floor need a strict moderator to stay focused. The moderator should allow people to address only the point currently under discussion. The alternative that is often used is to let participants raise questions or make statements in the order they ask for the microphone. This will often prevent a deeper and more fruitful exploration, because each new speaker can change the subject by taking up a new topic whether or not it is related to the current discussion.

If you have presentations in a foreign language and need interpretation, the economical solution is consecutive or sentence-by-sentence translation as opposed to simultaneous interpretation. If you have a 30 min presentation, for example, reserve a time slot of at least 60 min for presentation plus translation. Usually, consecutive translation is more appreciated by the audience, because it leaves more time for understanding. It is also less demanding on the skills and energies of the translator.

Interpreters and translators should be prepared by the organizers for their job. Best results are achieved by giving them the written papers a few days in advance of the event and by pointing out important concepts which may not always be easily understood and translated. For example, some languages lack a non-medical term for “disability” that is compatible with the image of dignity and citizenship which the IL movement wants to propagate. Sometimes, the commonly used word for “disabled” implies that we are persons of lesser value. You want a term to be used which does not sabotage your intended message.

Event contents

While there is much theoretical literature about Independent Living, the Independent Living approach – how to put the principles into practice – can be presented in down-to-earth and easily understood language. A vivid example of good practice presented by a disabled person with first-hand experience of the subject is more effective than an abstract scholarly lecture by a non-disabled person.

Personal experiences will be better remembered. Personal is always political - if the speaker not only deplors a situation but also analyzes it and outlines actions towards solutions. This will help counteract our image as victims of thoughtless, careless or obnoxious people.

Victimization weakens us, since it makes other people responsible for our situation and, in doing so, puts them in control of the situation and reduces us to passive objects of their actions. Empowerment means to help people see themselves in the driver’s seat.

Invite disabled people as presenters. Show the participants that we are the foremost experts on our needs and their solutions. Remember, “nothing about us without us!”

Make sure to invite presenters whose work you know well. If your message is “rights not charity”, for example, you do not want presenters who make the audience cry with pity.

Media work

In order to get the most out of your efforts, you need to spend time and energy on media work before, during and after the event. Disability Awareness in Action (DAA) have an excellent kit on media work on their website at www.daa.uk.org or at www.independentliving.org/docs2/daakit1.html .