

**THE PHILOSOPHY OF INDEPENDENT LIVING  
PROJECTS WHICH HAVE BEEN IMPLEMENTED IN ITALY**

**CASE 1**

**1) PROJECT NAME:** S.A.V.I. (Servizio Aiuto Vita Indipendente - Independent Living Aid Service)

**2) OBJECTIVES:** S.A.V.I. aims at improving the quality of life of heavily disabled people and of their families granting people with permanent disabilities and severe limitations to personal autonomy which cannot be overcome by means of technical devices, the right to manage their own lives thanks to the implementation of aid programmes directly managed on the basis of personalized projects for people who apply for them, according to art.39 of the law 104/92 modified by the law of 21<sup>st</sup> May 1998, n. 162. According to law 382/2000, art.14, all resources must be employed to build up individualized living projects.

The instrument to reach these ends is the experimental institution of Independent Living Aid Service (S.A.V.I.). S.A.V.I. has the task of implementing development programmes of the residual communicative and social potentiality of severely disabled people whose limitations of personal autonomy in one or more essential functions cannot be overcome by means of technical aids.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** the project was started in 2000 for one year but was followed by yearly funding promoted by Italian Regional Authorities and it is still in force. Experimental activity was carried on during 2001, 2002, and 2003, confirming the objectives already individuated in the first experimental phase and with the aim of consolidating the results and of widening the number of “consumers” within the limits of available resources.

**4) IMPLEMENTATION AREA:** municipalities of Collegno and Grugnasco (Turin).

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** CISAP (Consorzio Intercomunale dei Servizi alla Persona – Intermunicipal Body of Personal Services, Collegno and Grugnasco Municipalities) ENIL ITALIA- ONLUS (European Network on Independent Living).

**6) NUMBER OF CONSUMERS:** 3 people in 2000, 4 people in 2001, 7 people in 2002.

**7) TOTAL COST OF THE PROJECT:** the project is funded by the Region with at least 20% CISAP contribution. As a matter of fact, CISAP participation has been 33.4% up to now.

<b>Regional funds</b>	<b>Financed Year</b>	<b>Year of actual allocation</b>	<b>Expenses</b>	<b>Consumers</b>
80,000,000 (41,316 euros)	1999	2000	/	/
90,000,000 (46,481 euros)	2000	2000	80,000,000 (41,316 euros)	3
90,000,000 (46,481 euros)	2001	2002	135,000,000 (69,722 euros)	4
90,000,000 (46,481 euros)	2002	2003	175,533,900 (90,656 euros)	7

Up to 31/12/2002 Regional funds amounted to L. 260,000,000 (134,279 euros) and the Consorzio spent L.390,533,900 (201,694 euros). In 2003 the Region contributed L.90,000,000 for year 2000, actually paid in January 2003 while the Consorzio will spend L. 213,000 (110,005 euros) for the present 7 consumers.

The number of people involved and the amount of help given to any single consumer (in proportion to his/her personal income) depends on the ratio between the person's needs and the available funds.

**8) GENERAL DESCRIPTION OF THE PROJECT:** the main principles on which the project is based can be summarized as follows:

- 1- Independent Living can be implemented by means of aid services managed in an indirect form, or through direct control of funds designed to the payment of personal assistants chosen by the disabled person or by the people in charge of those who are not able to choose.

- 2- Services of personal assistance are assigned “to people with permanent disabilities and severe limitation of personal autonomy”.
- 3- The implementation of the aid programmes must focus on the needs of disabled people. The definition of personalised aid plans (for those people who apply for them) and the concept of self determination become thus central, their only actual limit being the amount of available resources.
- 4- The aid services financed by the project must be checked both from the point of view of actual distribution, and from the point of view of effectiveness.
- 5- Personal assistants are directly recruited by the disabled person or by the people in charge of those who are not able to choose personally. The Consorzio helps in finding suitable personnel (by giving the names of personal assistants or of credited service agencies to those who ask for them) and it also organizes training courses if necessary.

The Director of the Personal Service Department of the Consorzio is responsible for the S.A.V.I. coordination and there will also be appointed a group for interdisciplinary action.

**Consumer Services:** the service is available to grown-ups with permanent disabilities and with severe limitations to personal autonomy that cannot be overcome by means of technical, informatic aids or of prosthesis or any other forms of help aimed at allowing these people an independent life.

**Access Modalities:** in order to avail oneself of the services, any interested person can apply to the Consorzio by sending a plain, unstamped letter of application.

**Personnel:** the disabled consumer recruits his\her personal assistants autonomously and must employ him\her by means of a regular work contract in compliance with the regulations in force.

**Supply Criteria, Statement of Account, Evaluation:** at the beginning of every month, the disabled person (the “consumer”) will receive a monthly allowance equal to one twelfth of the whole amount for the above mentioned services. Every six months the consumer must present a statement of account of the expenses met.

**9) MAIN PROBLEMS:** finding personal assistants is not always easy. S.A.V.I. philosophy implies, as stated by the Association ENIL Italia (the main partner in the project), that the consumer should train his\her assistants. However, assistants can also be employed that have already been trained thanks to a series of courses regularly held by managing or training organisations.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** the S.A.V.I. project advocates a reconsideration of the professional approach of social services starting from the consideration that equity consists essentially in the recognition of differences and that aid policies must be based on such recognition.

S.A.V.I. points out that the offer of aid opportunities does not mean replacing the disabled and their families completely considering them unable of any autonomous organization simply because they have problems. The negotiation of projects with people directly involved, best represents this process while acknowledging a primary role to the disabled person and to his\her dignity.

The opportunity to recruit their assistants personally and to train them represents a strong instance of decision making and grants the disabled the possibility of enjoying a trusting and lasting relationship, something which is often difficult to be found in institutional services because of the continuous turn-over of the personnel. Besides, S.A.V.I. allows to overcome the drawbacks of “official times” which are often delayed by bureaucratic problems and hinder therefore any sort of immediate intervention in favour of people in need of help. As for the costs involved in the supply of services, it is evident that the funding must be certain and continuous. If expenses appear to be high (in particular with reference to each single person), it must be remembered that the implementation of the traditional daily home help service for two hours a day, five days a week, often amounts up to 10,000,000 lire a year. And if we take into consideration the costs of residential care settings which are however not easily available for the physically handicapped, costs are even higher, ranging between three and 4,000,000 lire a month. As for the effectiveness of this intervention, it is based on consumers’ self-evaluation: all consumers stated and declared that their quality of life improved and that – despite the limits of their disability – the programme allowed them a decent, satisfactory social and family life. As one of the interviewed said “Now I can see the

opportunity of performing actions and gestures that I felt I had been deprived of” (comment quoted by Elena Galetto, social service responsible, CISAP, Collegno-Grugnasco, Turin).

See also Handicap grave, autonomia e Vita Indipendente / Gruppo Solidarietà. (Severe handicap, autonomy and Independent Living / Solidarity Group) – Moie di Maiolati (An): Gruppo Solidarietà, 2002. – 88 p. – Scritti di vari (Writings by several Authors). – Euro 7.00 (as quoted in the Bibliography section).

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** the project has proved to be very successful and there are prospects of extension on a regional basis thanks to the recent legislative measures of the Piedmont Region concerning projects for Independent Living (deliberation of the Giunta Regionale of 5<sup>th</sup> August 2002, n.32\6868). At the moment, however, according to a note of 24<sup>th</sup> December 2002 from the Region, all projects must come to a standstill since “ the great number of projects presented , many of which do not correspond to the aims of the programme and the amount of the financial request which is definitely higher than the available, resources, make it necessary to individuate further priority criteria for the allotment of the funds to the bodies or institutions that have presented individual projects

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Dott. Gianni Pellis (011-7180972), Secretariat ENIL Italia Onlus, [gpellis@to.alespazio.it](mailto:gpellis@to.alespazio.it), Dott. Mauro Perino (011-4037121), General Manager Cisap, [perino@cisap.to.it](mailto:perino@cisap.to.it).

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<http://www.comune.jesi.an.it/grusol/informazioni/servizioaiutovita.htm>,

<http://www.provincia.torino.it/cid/leggi/savi.htm>,

<http://www.cisap.to.it/pubblicazioni/2001/public%2012.doc>,

<http://www.edscuola.it/archivio/handicap/savi.html>,

**Handicap grave, autonomia e vita indipendente / Gruppo Solidarietà. – Moie di Maiolati (An): Gruppo Solidarietà, 2002. – 88 p. – Scritti di vari. – Euro 7.00.** (Severe handicap, autonomy and Independent Living / Solidarity Group, Writing by several Authors). The book reports some of the contributions of the seminar “Severe handicap, local planning of services: supply and demand” organized by the Gruppo Solidarietà in November 2001. Interventions dealt, in particular, with the topic of the services offered to people with severe physical handicaps in the form of experiences of services for Independent Living.

The possibility was also discussed for the supply of economic contributions to become an integral part of a support project to the individual and his/her family. The title and the names of the authors of this publication are: “Handicap grave. Il Progetto SAVI e l’affidamento intrafamiliare” (“Severe handicap. The S.A.V.I. project and intra-family custody”) (E. Galetto); “Esperienze di affidamento intrafamiliare di disabili intellettivi adulti” (“Experiences of intra-family custody of mentally disabled adults”) (M. Perino); “L’assistenza personale autogestita ed il Progetto SAVI” (“Self-managed personal assistance and the S.A.V.I. Project”) (G. Pellis); “Comune di Roma: il SAISH (Servizio per l’Autonomia e l’Integrazione Sociale della persona Handicappata) nel sistema di accreditamento” (Rome municipality: SAISH – Service for the Autonomy and Social Integration of Handicapped People – in the system of fund allocation) (F. Giancaterina). The book can be directly requested to Gruppo Solidarietà, via Salvo D’Acquisto, 7 – 60030 Moie di Maiolati (An). Tel. e Fax 0731-703327 – E-mail [grusol@tin.it](mailto:grusol@tin.it).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

## CASE 2

**1) PROJECT NAME:** Autonomous Living.

**2) OBJECTIVES:** the experimental project of assistance and social integration of disabled, severely handicapped people contemplates the implementation of two main actions: 1) an integrated service for independent and autonomous life 2) a network of services for the city of Lamezia and for the Lamezia district.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** it is an experimental project and it will be implemented for one year. The project was started on 1<sup>st</sup> January , the first two months of the year being devoted to the preparation of the project (individuation and selection of the personnel, arrangement of flatlets, individuation of service networks in the area for daily life, etc.) The project was actually activated on 1<sup>st</sup> March 2002, it is still going on.

**4) IMPLEMENTATION AREA:** Lamezia Terme District, Province of Catanzaro-Calabria.

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** the project was promoted by the Welfare Ministry and by Calabria Region. It is operated by a non-profit Association called Associazione Comunità Progetto Sud. It is funded by the Welfare Ministry according to Law 162/98.

**6) NUMBER OF CONSUMERS:** six consumers take part in the first macro-action. In the second macro-action there have been involved 50 disabled people and about 70 people who are social workers in the municipalities of the Lamezia Terme area and of Lamezia Terme ASL, administrators and associations of disabled people or in favour of disabled people, with the task of building up an integrated service network. 42 more people were involved in the Alogon Camp , an activity which is part of the project. The people involved were: 25 disabled people, 10 personal assistants, 7 volunteers. Fifty more personal assistants took part in the seminar on personal services, a hundred people in the Meeting on Work, while about two hundred people took part in a cineforum.

**7) TOTAL COST OF THE PROJECT:** the costs amount to about 340,000,000 lire (175,595 euros). The project is wholly funded by the Welfare Ministry.

**8) GENERAL DESCRIPTION OF THE PROJECT: FIRST MACRO-ACTION - “Integrated Services Network for Independent and Autonomous Living”.** The project “Independent Living” was carefully planned in its structural and architectonic modalities with a view to “liveable housing”. Flatlets in blocks of flats and in the old town area were suitably converted with a view to the elimination of architectonic barriers and of other obstacles in order to promote relations with the town and its inhabitants. The disabled people live in the small flats and manage and furnish them in full autonomy, there are common areas where social contacts and relations between them and the people who live in the area can take place more easily, and they get the necessary services which are also available to some disabled people who live in property houses by themselves.

**Consumers** - The consumers of the “integrated services for independent and autonomous living” are severely handicapped people with motor disability with. Each person exploits the service with different modalities according to his\her needs for shorter or longer periods.

**General Objectives** - The general objectives are: a) activating structures, made up of small flats, where disabled people can experiment autonomous living (with the help of the assistance services they need) and new social relations, b) building up the autonomy of disabled people thanks to personalized projects.

**Specific Objectives** - More specific objectives are the supplying of services to help people, personal services (personal assistance, laundry and house cleaning, cooking, etc.) making interpersonal relations possible and easier, arousing interests, improving individual skills and abilities, etc.

**Interventions** - Guided cohabitation. The project intends to form a sort of community in some small flats in one of the Association ‘s buildings situated in the town of Lamezia. The flats offer services for the Independent Living of the disabled or guided cohabitation of reasonably

autonomous people with the help of project staff. Some of the flats can give accommodation up to 3 people.

Activities-Selection and training of personal assistants (30 hours). Singling out of the consumers, etc.

**“Services for Independent Living”** – Setting up of a “Centre for Independent Living “ to allow Independent Living to the disabled who live with their families or by themselves in order to promote autonomous, independent or interdependent living on the part of disabled or severely disabled people. The Centre for Independent Living will offer advice and services concerning different aspects of living , from personal autonomy to autonomous living, to working, etc. At the moment the Centre is being set up and organized.

Activities- Giving advice for the setting up and the realization of the project of Independent Living for the disabled of the Lamezia area; help and support to the disabled in the implementation of their projects of Independent Living.

**Other Activities - “Self -help groups”. Lower level coordination team.** The lower level coordination team and the implementation of this action consist of a service coordinator, a representative of the disabled, a member of the administrative staff, an assistant-tutor.

**SECOND MACRO-ACTION - The “network” in the town.** This project is part of a range of services and activities offered in the area and it consists of a network system for a more functional implementation of social services, health services, job opportunity services, transport services. The network is managed through a coordination body made up of representatives of the services, institutions, organizations, and of organizations of the disabled who take part in the network activities.

**Consumers** - The consumers are the disabled. Organisations of the disabled and/or their families, social services, institutions , the local community.

**General Objectives** - The general objectives are: 1) to build up a “main network” that is a group of people who are able to manage an integrated centre together, with a view to empowering the skills and resources of the disabled (to organise and implement a method that allows the participation of different subjects in an area, in particular disabled people and their organizations, non profit institutions, local authorities, etc.). 2) to foster forms of direct management and self-help measures of the disabled who will improve their skills to face problems and difficulties and to involve local authorities and the whole community of citizens in the building up of professional services and a feeling of solidarity for citizens and inhabitants. (to increase self-determination of the disabled through empowerment processes.). 3) to promote cultural processes and interdependence among people living in the same area (for instance by means of so called time-banks) and exchanges between the disabled and the non disabled in order to develop interdependence processes between them.

**Second level coordination team** - This macro-action is coordinated by a person responsible for cultural and innovative activities, a representative of the disabled, the representative of an organization of the disabled, the representative of an organization of parents of the disabled.

**9) MAIN PROBLEMS:** the main problems concerning the project refer to the low number of hours of personal assistance that amounted to just 5 hours a day.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** the project is still in progress and no final evaluation has therefore been possible yet.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** the project is going on, and it is hoped to continue also after the project expiry term on 1<sup>st</sup> March 2003.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Associazione Comunità Progetto Sud – Onlus, Dott.ssa Marina Galati, psychologist. Tel. (0968) 200022 e - mail [galatima@c-progettosud.it](mailto:galatima@c-progettosud.it). **BIBLIOGRAPHY REFERENCES** -<http://www.c-progettosud.it/Welcome.html>, <http://www.dpi.it/seminario/seminario.htm>.

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

### CASE 3

- 1) **PROJECT NAME:** “Model for the Creation of a Centre for Independent Living”
- 2) **OBJECTIVES:** the project mainly aimed at the divulgation of the philosophy of Independent Living in Italy through two different phases; the objective was therefore mainly “promotional”. The project also created work relationships between disabled people and personal assistants.
- 3) **SET UP DATE AND LENGTH OF THE PROJECT:** the project lasted two years, 1998 and 1999.
- 4) **IMPLEMENTATION AREA:** the Tuscany Region.
- 5) **INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Associazione Vita Indipendente (AVI, Independent Living Association) Onlus (<http://www.avitoscana.org/index.htm>).
- 6) **NUMBER OF CONSUMERS:** about 20 personal assistants taking part in the first phase of the project, a certain number (not stated) of disabled people who took part in the second phase.
- 7) **TOTAL COST OF THE PROJECT:** the project was presented in 1997 and cost 190,000,000 lire (98,127 euros). 70% of the project was financed by the E.U., 15% by the Tuscany Region and 15% by private sponsors (the most generous one being the Cassa di Risparmio of Florence – the Saving Bank of Florence).
- 8) **GENERAL DESCRIPTION OF THE PROJECT:** the project consisted of two main activities: a) a training course for personal assistants b) a seminar for disabled people.
- 9) **MAIN PROBLEMS:** the main problems were mainly of logistic nature since it was not easy to find suitable premises for the seminar and the course.
- 10) **OFFICIAL FINAL evaluation (evaluators must be mentioned):** according to Luca Pampaloni of AVI, this project was very useful to make the philosophy of Independent Living known in Italy. A list of the personal assistants who took part in the course can be found on the site [www.avitoscana.org.it](http://www.avitoscana.org.it).
- 11) **PRESENT SITUATION AND FUTURE PROSPECTS:** the project has come to an end. In some cases there started a long standing work relationship between the disabled and their personal assistants.
- 12) **SOURCES OF INFORMATION: MAIN REFERENCES** - Associazione Vita Indipendente (AVI) Onlus, Luca Pampaloni, [luca.pampaloni@tiscalinet.it](mailto:luca.pampaloni@tiscalinet.it), Tel. 055-8878275. Associazione Vita Indipendente (AVI) Onlus, Dott. Raffaello Belli, [Raffaello.Belli@libero.it](mailto:Raffaello.Belli@libero.it), Tel. 055-4399610.  
**BIBLIOGRAPHY REFERENCES** - The project has been dealt with in several publications:
  - 1) **Vademecum per una domanda per la richiesta di assistenza personale per la vita indipendente** - Guide for applications to allowances for personal assistance in projects of Independent Living (by Raffaello Belli), [http://www.avitoscana.org/vademecum\\_di\\_assistenti\\_personali.html](http://www.avitoscana.org/vademecum_di_assistenti_personali.html). Guide for personal assistants. There are also references to the regional legislation concerning this topic: Tuscany Region Law n. 72 of 1997.
  - 2) **Libertà inviolabili e persone con disabilità** - Inviolable Liberties and disabled people - (by Raffaello Belli). Marzo 2000, Franco Angeli Editore, L. 28.000 (14,46 euro). <http://www.francoangeli.it>.
  - 3) **Assistenti personali per una vita indipendente** – Personal Assistants for Independent Living (by Raffaello Belli). Aprile 2000, Franco Angeli Editore, L. 30.000 (15,49 euro). <http://www.francoangeli.it>. Info: <http://www.avitoscana.org/pubblicazioni.htm>.
  - 4) Final report of the project for the E.U. (not available at the moment).A one-day workshop for jurists was also organized within the project. The title of the workshop was “Inviolable liberties and disabled people” in order to study the juridical aspects of the topic of freedom for disabled people. The workshop was held on 28<sup>th</sup> September 1990 in the Aula Magna of the Faculty of Political Sciences “Vittorio Alfieri” of Florence University, Via Via Laura, 48), <http://www.avitoscana.org/GiornataDisabili.htm>.
- 13) **AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** no.

## CASE 4

1) **PROJECT NAME:** Programs of help to people and of support to their families.

2) **OBJECTIVES:** personalised projects for Independent Living and personalised projects for support of their families by means of the same intervention.

**Personalized projects for Independent Living:** they are targeted at severely disabled people “who can gain control over their lives”. The ability of self-determination is a very difficult aspect: it must be assessed by a multidisciplinary team because it implies the evaluation either explicit or implicit of the maintenance of the necessary critical and cognitive abilities of the disabled person. The disabled person is an integral part of the team in the choice of the objectives, methods and forms of intervention; the model of action is a model of sharing. The increase in autonomy and independence, also measured in terms of a decrease in the other forms of social and sanitary assistance, makes up the aim of the project and at the same time the final evaluation parameter of the effectiveness of the intervention. The objective of the programme is the individuation of possible needs linked to the implementation of one’s own personal life project, needs that cannot be satisfied by means of the services and the intervention offered in the area but can be satisfied thanks to a budget and/or specific supplemental interventions to be made available to the disabled person and his/her family.

**Personalized projects for the support of the families of disabled people:** the main objective is to keep the disabled person in his/her own family environment and its affective support. As for the family members engaged in the assistance, the objective is to bring out their willingness to offer assistance and at the same time to help them in their toil, to foster their ability to look after the disabled person and to help them to have a better social life.

3) **SET UP DATE AND LENGTH OF THE PROJECT:** they are individual programmes on a yearly basis. The programmes have been in action since 1999.

4) **IMPLEMENTATION AREA:** the Friuli Venezia Giulia Region.

5) **INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** the Friuli Venezia Giulia Autonomous Region (government funds of Law 162/98). For the support to disabled people: non-profit Association I.D.E.A.

6) **NUMBER OF CONSUMERS:** in 1999: 109 consumers, in 2000: 202 consumers, in 2001: 202 consumers, in 2002: 202 consumers.

7) **TOTAL COST OF THE PROJECT:** in 1999: 318,000 euros; in 2000: 620,000 euros; in 2001: 620,000 euros; in 2002: 620,000 euros. In 2003 the funds will probably be increased. On the basis of the expenses for individual projects it must be pointed out that the average cost of each individual project is about 3150 euros (6 million lire) a year. The costs of projects range from a minimum of 60 euros (L. 118,000 corresponding to the cost of a few hours of weekly assistance) to a maximum of 21,170 euros (L. 41,000,000 corresponding to the cost of 24 hours’ assistance a day). The funds are allotted to the Municipalities by the Region according to the number of approved projects. Besides each Municipality usually integrates the amount at its disposal with its own funds.

8) **GENERAL DESCRIPTION OF THE PROJECT:** special application forms to be filled in are published by the region for the request of funding of individual projects of Independent Living or of support to the consumers’ families. The forms are distributed by the social services of all Municipalities in Friuli Venezia Giulia (see Bibliography for the text of the form). These actions are only intended for severely handicapped people (see art. 3,3 of Law 104/92 as certified according to art.4 of the same Law). **People whose disabilities derive from pathologies strictly linked to old age are excluded.**

Those who are interested in the project fill in the form with the help, if they like, of the staff of the non-profit Association I.D.E.A. that has published a guide for the filling in of the application.

The applicant states his personal needs in the form and on this basis individual programmes are envisaged with different periods of assistance. The programmes are the task of a multidisciplinary team with the cooperation of a social worker from the local Municipality Social Services. Every single personalized programme is decided according to the criteria and the priorities stated in the



project after careful study on the part of the services together with the disabled person and/or his/her family in order to grant Independent Living to people with permanent disability and heavy limitations of personal autonomy.

The evaluation criteria of the programme to be approved must take the following elements into consideration:

- a- severity of handicap considered as social disadvantage due to inadequate approach to problems owing to disability
- b- likelihood to get results through the implementation of a programme of personalized help
- c- likelihood of the programme to end at a certain, stated date, or to continue after two years.

Every person who is interested in a personalized programme can apply to the Municipality where he/she lives. Later on all applications will be sent to the multidisciplinary team which, in order to arrange the programmes in accordance with the above mentioned criteria, will contact the applicants.

The team will also check the results. In order to have one same approach and homogeneous, clear procedures all over its area, the Region also holds a general meeting where methods and instruments to be used all over the Region are defined and stated.

**9) MAIN PROBLEMS AND 10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** final evaluation and main problems are dealt with together because the final evaluation of the project also points out the main problems. The “documento di consenso” (a sort of document of general agreement, see bibliography) of the Region points out that the composition of the Multidisciplinary Teams for handicap does not seem to be homogeneous all over the Region. As for the costs of projects, it must be pointed out that in many cases the Region contribution only funded a part of the project and there was no integration; in other cases projects only offered sanitary interventions.

Besides, it must be noticed that advertising has increased the number of applicants thus creating expectations which cannot be adequately fulfilled because of scanty funding. It was also difficult to form lists of merit because of the lack of homogeneous instruments all over the Region area and it was also quite difficult to find adequate staff for the projects of personal assistance and Independent Living.

On the other hand, the Associations of the disabled, while requiring an adequate increase in the funding of the projects, also point out that the disabled and/or their families are not always involved in the planning of the project and they very seldom find a person in charge of the project with whom to discuss any changes in the actions in progress.

Multidisciplinary teams are the pivot of the planning of personalized programmes with the cooperation of the disabled and/or their families. From the analysis of the personalized programmes, it is evident that when all subjects are really involved, and all resources (social and sanitary, economic and human) are activated, the projects reach very satisfactory levels of integration while the disabled leave their role of passive consumers to become active subjects in the management of their lives.

The developments of the social and sanitary policy in Friuli Venezia Giulia are important and must be pointed out. In particular, as far as Law 162/98 is concerned, service assistants and disabled people have been able to take great advantage of the opportunity to implement personalized and articulated projects. There is however some criticism that does not put up the opportunity or the importance of Law 162/98 for dispute or the importance of new operative models and of the results of the intervention, but rather wants to put the purposes of the Law into wider practice, to increase resources, and to increase the number of consumers of personalized programmes for Independent Living and personal autonomy. The multidisciplinary teams involved give a yearly evaluation of the programmes.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** after a three years' stoppage due to the lack of funds, at present there seems to be hope for an increase in the funding and, consequently, in the number of consumers.

The above mentioned “Documento di Consenso” has also established the following measures:



- a- **a strategy of intervention to face the consequences of illness and of the process of growing old , since it is clear that we are facing very similar and linked phenomena.** The frame of rules and laws that regulate this sector is characterized by sectoriality and overlapping of different measures. The terms used to define needs and fields of intervention are often sources of ambiguity, in the sense that such terms as: handicap and its various uses, self-sufficiency, autonomy and dependence, rehabilitation, disability, and so on tend to assume – depending on the speaker – different meanings that may make sense for a specific sector of the services , for a certain group of specialists or in the context of a certain medical or legal procedure, but make it difficult cooperation for a common task. “Disability” is the unifying key term that can best define a sector of reference , a sort of “umbrella term “. The OMS proposed to refer to limitations in the activities of social and daily life which, a part from their causes and origins and of their specific aspects and forms, require a common strategy, with specific details and solutions at an operative level.
- b- **Individual projects for interventions concerning disability.** Planning of interventions that can only be specific, individualised and designed on purpose for a specific consumer and his\her environment.
- c- **Promoting independence as an indicator of the service quality.** Services must not be “mechanical distributors” of interventions and allowances. The logic of any intervention must focus on the person and his\her needs and must activate all resources (technical, managerial and political) to recompose the picture of all available resources rather than force citizens to strive and collect all information that is necessary to obtain basic rights and a decent quality of life. Besides, it is necessary to plan all interventions over three years, getting clear of yearly balances, in order to assure personal projects greater continuity.
- d- **Better understanding of the territory in terms of needs and resources.** In general the hypothesis of implementing programmes that consist in a mere contribution of money and that leave “complete autonomy to the disabled and\or their families in the management of the resources” arouses some perplexity.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Regione Autonoma Friuli Venezia Giulia: Dott. ssa Marina Guglielmi, tel. 040-3775582, e-mail: [marina.guglielmi@regione.fvg.it](mailto:marina.guglielmi@regione.fvg.it) . Associazione I.D.E.A. Onlus: Roby Margutti, tel. 0431-31273, e-mail: [robymargutti@tiscalinet.it](mailto:robymargutti@tiscalinet.it). **BIBLIOGRAPHY REFERENCES** - “Documento di Consenso” elaborated during the preliminary work for the conference of approval and for the World Meeting on Disabilities (Trieste, 16<sup>th</sup>-20<sup>th</sup> April, 2002), Autonomous Region Friuli Venezia Giulia, Assessorato della Sanità e della Sicurezza Sociale (available on file) designed by resolution of the Giunta Provinciale n. 4271 of 11<sup>th</sup> December 2001.

Non profit Association I.D.E.A.: <http://www.ideaonlus.it/index.htm>: application form for the request of a personalized programme of Independent Living or for support to the family: <http://www.ideaonlus.it/domanda.htm>.

Non profit Association I.D.E.A.: A guide for filling in the application form <http://www.ideaonlus.it/domanda.htm>.

“The right to Independent Living for disabled people.”, a collection of the papers of the convention held in Grado in 2000 by the Non profit Association I.D.E.A. (available on file). Regional College of the associations of disabled people of Friuli Venezia Giulia on the project of Independent Living [http://www.sanita.fvg.it/cittadino/6/consulta/txt\\_quaderni6.htm](http://www.sanita.fvg.it/cittadino/6/consulta/txt_quaderni6.htm).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

## CASE 5

**1) PROJECT NAME:** Casa-più: an experience of Independent Living (designed for people affected by the Down's syndrome).

**2) OBJECTIVES:** trying to live everyday life without parents: going shopping for the house (linen, kitchenware, lamps, other household equipment, etc.) cooking, cleaning the house, welcoming guests, growing and empowering the consciousness that, despite disabilities, people can grow up and live their lives outside their families, helping people affected by the Down's syndrome to grow up stressing the importance of relationship in a "peer-group".

**3) SET UP DATE AND LENGTH OF THE PROJECT:** the project started in 1995 and is still going on. It works all year long apart from a break in the months of July and August.

**4) IMPLEMENTATION AREA:** Rome

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Associazione Italiana Persone Down (Italian association of people affected by Down's syndrome), AIPD Sezione di Roma (Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. and Fax 06/37351749; Rome Municipality.

**6) NUMBER OF CONSUMERS:** at the moment about 40 people affected by the Down's syndrome aged between 18 and 50 are taking part in the project. 21 of them are adults and this is their first experience of autonomy while the others have already had similar experiences.

**7) TOTAL COST OF THE PROJECT:** in 2002 the cost of the project amounted to about 15,000 euros, all expenses (rent, operators, water and electricity supply, etc.) included. AIPD is funded by Rome Local Council but the remainder must be paid by the Association and by the consumers' families that contribute with their subscription fee and a monthly quota of 50 euros to ATL.

**8) GENERAL DESCRIPTION OF THE PROJECT: WHAT CASA PIÙ IS** – Casa Più is the house where people affected by the Down's syndrome spend some weekends during the year in small groups of 3 or 4 people and have the opportunity to manage their stay autonomously.

**WHEN AND WHY CASA PIÙ STARTED** – Casa Più was implemented in Rome in 1995 to allow young people affected by the Down's syndrome to leave their families in order to gradually learn to interact with their peer-group and to acquire the minimum necessary abilities to live far from their homes.

It was also implemented to host grown ups who were not allowed to live any socialization experience and autonomy outside the family because of the different socio-cultural approach of the past. The project takes into account the fact that the context in which a Down teen-ager grows nowadays offers greater opportunities of interaction, socialization and learning than ten years ago. Casa Più can play a basic role for people affected by the Down's syndrome as a bridge between family life and independent life not necessarily linked to a sudden loss of the family. Disabled people grow up and responding to their growth means giving them real opportunities of enjoying their life and of having their needs satisfied: we are trying to avoid that the disabled person, once grown up, may remain alone, we want to offer him more opportunities of growth and friendship. The project, beside giving the possibility of learning new strategies to live in a more autonomous way, means for some people finding a place rich in affective stimuli, in friendship and love where to live well and satisfactorily.

**TIME AND PLACES OF THE WEEKENDS** – Casa Più is a flat situated in Rome where four participants with an operator who is in charge of the flat and two volunteers meet on Friday afternoon to decide what they will do at the weekend. The meeting is above all an opportunity to explain what Casa Più is and to offer a place where the participants start organizing the weekend according to the group; the operator mediated wishes and proposals so that everybody can take part in the planning. Later on the group will live together from Saturday morning to Sunday night and spend the weekend together in complete autonomy, involving all in the activities though respecting everybody's character and personality. The number of the consumers depends on the wish to guarantee these prerequisites.

**SPENDING THE WEEKEND** – During the weekend the Down's people are requested to do all activities that normally take place in a house: cleaning the rooms, making beds, doing the shopping for Saturday and Sunday, cooking and so on. And above all they are requested to organise their free time activities that are often decided by the family. All weekends are different since every group gives a different meaning to free time, choosing among numerous activities young people love : from the pub to the disco, to supper in a restaurant, to a party in the house, to an afternoon in the country, etc. Free time is spent merrily with great enjoyment and the participants are the only actors and main characters of the choices they make: a person's growth often depends on how things are made rather than in things themselves. During the weekend there are several periods and while some of them are intended to teach new abilities, for instance learning how to switch the cooker on or going to the baker's by oneself, others are only meant to allow the consumer to do exactly what he\she wants to do. Thus it may happen that the person decides to do what he\she usually does in his\her free time: the project implies that the disabled must not necessarily be always pushed to improve their abilities, but they have the same right as the others to have a time to do things just for the pleasure of it, because they like them, because they are simply enjoyable.

**WHY CASAPIU' IS IN THE CITY** – This has been a choice to allow the consumers to live this experience in a sort of continuum with their everyday life: they can live it as part of their life on a Saturday and a Sunday without having to leave school or work, joining the others at lunchtime, for instance. Since Casa Più is their house, it is open to their friends and they, when invited of the participants, can join the consumers to spend an evening together. Casa Più is a place where consumers can go by themselves and it represents continuity with everyday life, which allows them to learn how to move in their area easily and how to use services and shopping facilities.

**WHAT TO DO TO TAKE PART IN THE PROJECT** – In order to take part in CasaPiù , the first thing is a meeting among the person affected by the Down's syndrome, the members of his\her family, and the operator who is responsible for the project. During this meeting there will be an interview in order to fill a sort of "starting document" where all the interesting and pertaining data and information will be collected (consumer's interests, personal data, schooling, personal and social autonomy, particular problems, etc.). Then the consumer will be given a personal card where he\she will write his\her data and the fees to be paid for each weekend. The bookings for each weekend are effected on request of the family or of the consumers themselves and they are accepted according to an evaluation criterion of the operators which keeps several factors into account, such as age, character, particular physical or psychic problems and previous experiences with CasaPiù. After every weekend a document is written to check the functionality of the group and the degree of participation of every single consumer. These data are also used for the organization of the following weekends.

Every year two meetings are held with all families and individual interviews are organized on request of the families or of the operators during the whole period of activity of CasaPiù.

**PROFESSIONALS WHO TAKE PART IN THE ACTIVITIES** – They are: 1 social worker who has the task of coordinating all activities, organizes the groups, keeps contacts with families, consumers and operators; 6 operators trained by the Association who are in turn responsible for the weekend. Beside the professionals, many volunteers are involved in the projects and they support the operators' activity by terms during each weekend.

**9) MAIN PROBLEMS:** no problem.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** after 7 years the spreading of the project to new families and the positive comments of our consumers, **confirm to the operators involved**, the importance of this initiative and therefore the need to accept grown-up people affected by the Down's syndrome in a project which considers them the main actors of their lives and people who grow up, mature and get old, people who must get their independence from their families, people who want love and affection beside the love and affection of their families of origin.

A basic assumption of the project is that there are different levels of independence but that at each of them everybody has a right to be what they are, to live one's life according to one's times and

specificities and, above all, that nobody has a right to replace to another person, that those who need help can learn how to ask for it when they really need it, and they can learn, above all, as every weekend clearly shows, that there are a thousand different ways to do the same thing, to understand a situation, to live a day, etc. The responsible for the project think that the young and the grown-up affected by the Down's syndrome can live a pleasant, enjoyable life, and above all a real life within the community and they acknowledge everybody their own identity: this is the reason why each weekend is a discovery of different interactions and possible situations.

There are difficulties and surprises, but they also bring strong emotions, laughters, self-confidence, increasing self-esteem and the real effort of operators and parents who share the project and work so that everybody may also a "possible freedom" to make life "an interesting thing". Since the beginning of the project we have had the confirmation that consumers that they want to do "by themselves", they want to be able to face situations where they can make their own choices, express their preferences, their tastes, their opinions, make their suggestions. When consumers do not want to leave the house and go out or do not want to live this type of experiences, this very often means that they were kept secluded in a world which did not contemplate these opportunities. After a short period of confusion, due to a completely new situation, most of the consumers react positively and ask to reiterate the experience. For instance, taking part in CasaPiù has meant for some thirty-year-old consumers to sleep in a different house without their family for the first time and be glad to have breakfast with "friends" the next morning.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** the project is very successful and it will be continued along the same line also in the future.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Michela Colapinto, Associazione Italiana Persone Down, AIPD Sezione di Roma (Italian association of people affected by Down's syndrome, Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749, [aipd.sezionediroma@tiscalinet.it](mailto:aipd.sezionediroma@tiscalinet.it). **BIBLIOGRAPHY REFERENCES** - Michela Colapinto, Associazione Italiana Persone Down, AIPD Sezione di Roma (Italian association of people affected by Down's syndrome), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749, [aipd.sezionediroma@tiscalinet.it](mailto:aipd.sezionediroma@tiscalinet.it).

**AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** no.

## CASE 6

**1) PROJECT NAME:** Agenzia del Tempo Libero (A.T.L.) - Free Time Agency (designed for people affected by the Down's syndrome)

**2) OBJECTIVES:** to foster positive behaviour such as : socialization (promoting friendship and relationships with people of the same age, going to public places); integration (being with others and doing different activities together); interdependence (being in a reciprocity relationship).

To foster autonomy and self-determination so that young people are the main actors of their lives as they can freely choose and decide how to manage and spend their free time.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** the project started in 1992 and it is still going on. It is in operation from October to June. There are weekly meetings.

**4) IMPLEMENTATION AREA:** Rome.

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Associazione Italiana Persone Down (AIPD) Sezione di Roma (Italian association of people affected by Down's syndrome, Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749.

Rome Municipality (with which A.T.L. has stipulated an agreement).

**6) NUMBER OF CONSUMERS:** there are about 90 consumers. Their number varies according to the number of yearly subscriptions. Consumers are then divided into sub-groups.

**7) TOTAL COST OF THE PROJECT:** in 2002 the cost of the project amounted to about 120,000 euros.

**8) GENERAL DESCRIPTION OF THE PROJECT:** A.T.L. is a time and a space where young people, aged between 20 and 30, can meet and live their teenagers' or adults' lives with people of their age where they can spend one day , once a week, doing what people of their age do, such as going to the cinema, to cultural meetings, to concerts, etc.

The task of A.T.L. is to make consumers maintain the abilities and skills acquired thanks to the Course of education to personal autonomy and can put themselves to the test experimenting new strategies to reach new objectives of autonomy. In the planning of activities they are initially given a wide choice of proposals concerning the activities, so that they know what people do in their spare time and what is available in town; then they will be able to choose what to do autonomously.

During the meetings they are accompanied by operators (professional educators), helped by volunteers and conscientious objectors, who make up together the whole operative team of the project. The work of this team is checked by a social worker who acts as a coordinator and a supervisor. The social worker also acts as an observer and helps the members of the team to establish a positive and friendly relation with the young people and also with their families. Thus the group is the only reference for consumers and their families, while the coordinator is rather an outside advisor of their relational dynamics. The characteristic of this project is its reference to a social model of disability different from the traditional one which was based on assistance and considered the disabled person an ill person, different from others and therefore to be cured.

The social model of disability, on the contrary, is centered on the disabled people who advocate their right to citizenship, with the same opportunities as all other individuals. This model is based on basic values which belong to all mankind, regardless of sex, age, race, culture, social class, religion and disability. These values are :

**The wealth of diversity.** All human beings have some physical characteristics (colour of their eyes, of their hair, height, weight, etc.), emotional characteristics, a personality structure etc. which are different from anybody else's: thanks to the whole of them each individual is absolutely unique. Same applies to the disabled people who are different from others not because they are disabled but simply because they are human. From this point of view, disability is no longer a diagnostic label we are afraid of, but rather a diversity to know and to take into account as a contribution which can make society more open and more free from prejudice.

**Interdependence.** In any kind of society all people, both disabled and not disabled, live with other people, with their own abilities and limits. This interdependence and reciprocity which characterises

the relationship among people and between people and the surrounding world, makes up that social wealth that every person receives from society, just as it happens in nature where all vegetable and animal species live with all their diversity in an ecosystem that lives and reproduces with its specific equilibrium.

**Self-determination.** Each person, whether disabled or not, has a right to self-determination, within the limits of his\her capacities; this means that everybody has a right to decide for themselves, to express their own potentialities, to choose for their life.

At A.T.L. people meet and plan the activities they want to do autonomously, for instance, watching a film, going to an exhibition, visiting a monument, etc. From a wide range of choices they pick the things they would like to do in that month, negotiating a decision that can be acceptable for all. During these meetings consumers are also asked to speak about their experiences and their feelings during their A.T.L. experience with the help of operators and volunteers. One afternoon a week is devoted to these activities. Once a month an evening out is organised, such as going to the cinema, going out for a pizza, etc. At the end of the year weekends in other cities are organised.

**Human resources.** 6 operators (professional educators), 1 conscientious objector or volunteer, and one social worker who acts as a coordinator. For each sub-group of 5 people there are 1 professional educator and one volunteer.

**Material resources.** One room with chairs and a desk, 4 packets of white drawing paper with 500 sheets, 4 boxes of paints (2 boxes of felt tip pens and 2 boxes of crayons), 2 boxes of pencils, a notepad for each consumer, street maps and maps of the routes of public means of transport, magazines about shows and other free time activities.

**9) MAIN PROBLEMS:** the main problem is the huge number of consumers, the low and inadequate number of operators, the lack of an adequate number of green areas and places where activities can be held.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** a part from the above mentioned criticism, confirm to the operators involved, the project is satisfactory.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** at the moment the project is in progress and it is meant to continue along the same lines. The same project has also been activated in other Italian cities and in a neuropsychomotor rehabilitation centre in Naples: GIFFAS Gruppo Italsider Famiglie Fanciulli Subnormali (Italsider Group of Families with Subnormal Children). In this last case the project is funded by the centre itself.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Lorenzo Boccadamo, Emanuela Di Palma, Associazione Italiana Persone Down (AIPD) Sezione di Roma (Italian association of people affected by Down's syndrome, Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749, [aipd.sezionediroma@tiscalinet.it](mailto:aipd.sezionediroma@tiscalinet.it).

**BIBLIOGRAPHY REFERENCES** - Anna Contardi, Libertà possibile – Educazione all'autonomia dei ragazzi con ritardo mentale (Freedom is possible – Education to autonomy of subnormal children), ed. La Nuova Italia Scientifica, [www.aipd.it](http://www.aipd.it).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** no.

## CASE 7

**1) PROJECT NAME:** Course of education to autonomy (for people affected by the Down's syndrome).

**2) OBJECTIVES:** the objective of this course is to foster the acquisition of competences concerning autonomy outside home. Facing the problem of autonomy means, both as operators and as parents, not only to encourage the acquisition or the development of these abilities, but also to acknowledge and foster the change from the status of child to the status of adolescent and of adult. This means we must create an atmosphere and a relationship of trust and respect towards the young person affected by the Down's syndrome where he/she can find greater motivation to learn, thus growing as a person.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** the project was started in Rome in 1989 and it is still in progress. It is possible to enrol every year between 1<sup>st</sup> July and 10<sup>th</sup> September: activities start in October and finish in June. During the summer holiday, weeks are organised for those who wish to take part in them, provided they followed the centre activities. An attendance of three years has been established, since such a period has been considered adequate to allow everybody to acquire competence and self-assurance, within the limits of personal resources.

**4) IMPLEMENTATION AREA:** Rome.

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Associazione Italiana Persone Down (AIPD) Sezione di Roma (Italian association of people affected by Down's syndrome, Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749. Rome Municipality.

**6) NUMBER OF CONSUMERS:** every year the course is attended by about 35 young people affected by the Down's syndrome, aged between 15 and 20.

**7) TOTAL COST OF THE PROJECT:** in 2002 the cost of the project amounted to about 68,000 euros.

**8) GENERAL DESCRIPTION OF THE PROJECT: COURSE STRUCTURE** - The course of education to autonomy is organised in a series of afternoon meetings of about 3 hours each. Every young consumer meets a group consisting of 8 to 10 young people affected by the Down's syndrome and 3 or 4 operators one afternoon a week. After spending some time together, the group is divided into subgroups of two or three young people, an operator and a volunteer (in the last few years also trainees of the University Diploma for Social Workers or from the School for Educators have joined the meetings). The organisation into groups and subgroups is fundamental to reach the educational aims. Autonomy, in fact, means being able to face problems and difficulties without any help, but also learning to cooperate, to ask for help, to wait for one's turn. Activities are centered around 5 main areas which are considered as basics for education to autonomy outside one's home: - **communication:** learning how to ask, learning how to give personal data, learning how to use public telephones, etc. - **sense of direction:** learning how to read and follow street directions, recognising reference marks, bus and underground stations, etc. - **street behaviour:** crossing, traffic lights etc. - **use of money:** learning to understand the value of money, coins and banknotes, counting money, price/value relationship, change, etc. - **use of services:** shops, supermarkets, everyday shopping, cinemas, coffee bars, bowling alleys, etc, the difference between shops and services or facilities, post offices, public means of transport etc.

The activities proposed are connected with the above mentioned areas and take the main interests of young people, particular events, the need of going shopping etc as starting points.

Streets, shops, "real life" are the environment where most of the learning takes place in accordance with the principle of learning through direct practice. The meetings take place in the Association premises, and there they finish, but activities very seldom take place there for all afternoon. The general atmosphere of the course is relaxing and gratifying and the young people feel they are "young adult" and that they are the most important presence. To this purpose a "Youth Club" has been set up whose members are the young people taking part in the course who are given a personal



membership card. This atmosphere helps young consumers in their identification as adolescents and stimulates communication and friendship within the group.

**MAIN ASPECTS OF METHODOLOGY** - Some principles the course and its implementation strategies are based on.

**Relationships based on “the truth”.** Great importance is attributed to motivation as a stimulus for learning since motivation can be a powerful engine of a method of teaching that starts and operates in the real world. This means, for example, that money is counted **in order to** go and have a snack at the fast-food restaurant, the telephone is used **in order to** contact a friend, information is asked **in order to** reach the place where we want to spend the afternoon together, etc. This is in evident contrast with a learning process based on mere repetition as it sometimes happens at school or in general with the idea of those who believe that a mentally disabled person learns more easily in a mechanic and repetitive way. Young consumers are also extremely sensitive to the choice of real motivations rather than fictitious ones. None of them willingly goes to buy milk if there is already some in the fridge or if they know that in any case their mother will go if they do not. (A whole series of episodes of this kind has been related by the families). At the same time this relationship mode reinforces in consumers the firm belief that they are young adults and their families trust them. The more real the situation is, the more involved, the more important, the more motivated the young consumers will feel.

**Active involvement of the young people in the choice and the management of activities.** This point aims at motivating the young people to act correctly and responsibly, making them more and more central in the various activities. In their lives it often happens that also when an active role is proposed, it is always presented as a form of help (please, help me to cook, please help me to do the shopping, etc.) just as it happens with young children, just to make them move around but without a strong trust in their capacities. They feel and realise it and are therefore little ready to help (Why should I do it, if you are here and my help is not necessary?). This reaction is sometimes attributed to incapacity or lack of willingness. The choice of the course has always been of paying attention so that their role in the various activities is always as central as possible.

**Consideration of their being “grown up” and explicit acceptance of this role as a reinforcement of their acquisition of further autonomy.** This aim is obtained through the approach to young consumers, to the language used, to the kinds of activities proposed to spend the afternoon, activities that are adequate to adolescents (cinemas, discos, bowling, fast food restaurants, etc.). Making them important has triggered situations where both their abilities emerged and family often binding conditioning, such as the attribution of specific feminine or masculine roles in housework activities.

Trusting young consumers is of primary importance, since it stimulates them to greater initiative and courage in doing things. The consideration of their being grown up also implies sticking to reality, not indulging in impossible dreams, but helping them to face real facts. This aspect is particularly taken into consideration when talking with young consumers about their wishes and plans for the future, for instance trying to understand which are the skills and abilities that are necessary to do a certain job

**Personalised strategies:** Specific strategies are designed for each single boy or girl according to their resources. For instance, if a boy can read, he is encouraged to do it by reading the names of products in the shop windows, and if he cannot, he is encouraged to recognise the image of the product or of the written text on the box.

**THE STAFF** - The implementation of the Course of education to autonomy is conducted by a staff made up of a coordinator, educators and volunteers. Educators are normally chosen among people with a University degree of psycho-pedagogic kind (graduated or students attending the Faculty of Social Services or of Psychology or Pedagogy or a School for Educators) or with a long experience as volunteers as educators\animators and not older than 30-35 years of age. They are also requested to get a specific training about the project methodology. Volunteers must not be older than 30 years of age as well. Their task is sharing the experience of young consumers under the guide of an

educator and following his\her directions. Formative and evaluation meetings are also organised for volunteers during the year.

The coordinator is a professional person who works in the sector of social services, usually a social worker, a paedagogist or a psychologist. He\she does coordination and supervision work, helps the operators in the planning of activities and in the interpretation of successes and failures during regular meetings. Furthermore, the coordinator organises meetings with parents where educators must always be present.

**9) MAIN PROBLEMS:** there are no big problems.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** in the organisers' opinion, the Course is very successful and the results are extremely satisfactory. Attendance to the course during a year can teach consumers, as far as communication is concerned, to call friends by name, as for sense of direction, it can teach to recognise their house door and go up the stairs by themselves, as for the use of money, the course can enable young consumers to enter a shop by themselves with a shopping note and then pay, etc.

AIDP believes all this is very important not only for the acquisition of new abilities, but also as a conquest of dignity and for the acquisition of personal identity.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** at the moment the project is in progress and it will be continued. Similar experiences have already started and some are just starting in other Italian cities where AIDP seats are located (at the moment there are other courses at Oristano, Pisa, Viterbo, Bari, Avellino, Campobasso, Teramo, Catania, Matera, Belluno) while other courses are held by similar associations that took inspiration from this model (Milan, Naples, Venice) as well as in private educational and rehabilitation centres.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Anna Contardi, Associazione Italiana Persone Down (AIPD) Sezione di Roma (Italian association of people affected by Down's syndrome, Rome centre), Viale delle Milizie, 106 - 00192 Roma. Tel. 06/3700235 - 06/37351717 - Tel. e Fax 06/37351749. Francesca Pompili, (AIPD), tel. 06-3700235. [aipd.sezionediroma@tiscalinet.it](mailto:aipd.sezionediroma@tiscalinet.it). **BIBLIOGRAPHY REFERENCES** - Anna Contardi, Libertà possibile – Educazione all'autonomia dei ragazzi con ritardo mentale (Freedom is possible – Education to autonomy of subnormal children), ed. La Nuova Italia Scientifica, [www.aipd.it](http://www.aipd.it).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

## CASE 8

**1) PROJECT NAME:** Projects of Independent Living.

**2) OBJECTIVES:** to assure the right of Independent Living to permanently disabled people with severe limitations of personal autonomy in one or more essential functions of life which cannot be overcome by means of technical aids. To foster and promote the disabled person's autonomy, to implement programmes of help taking into account all available resources (personal and family resources, implemented services, economic help) in the socio-cultural environment of the disabled. To implement help programmes for the families, both natural and non natural families, of severely handicapped people stating the budget for their implementation.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** yearly, renewable programmes, that have been in progress since 2000.

**4) IMPLEMENTATION AREA:** Western Verona area (area of action of ULSS 22, including 37 municipalities with a population of about 250,000 inhabitants).

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Azienda ULSS n. 22 Veneto, Bussolengo di Verona. Tel. 045-6769111/6769300/6338111.

**6) NUMBER OF CONSUMERS:** 8 individual project were financed in the year 2000. 23 individual projects were financed in 2001.

**7) TOTAL COST OF THE PROJECT:** on the basis of the Region financial plan of the year 2000 ULSS financed project of Independent Living for a total amount of 114,900,000 lire. On the basis of the Region financial plan for the year 2001 for projects of Independent Living, ULSS financed projects of Independent Living for a total amount of 113,022.93 euros. As for the year 2002, Region funds, which were communicated a short time ago, amount to 115,000 euros, but they are very likely to be integrated by the Region itself or by the Conference of Mayors. An individual specimen of application form is available in Italian.

**8) GENERAL DESCRIPTION OF THE PROJECT:** in the Veneto region government funds as defined by Law 162\1998 are allocated among the ULSS Districts which check the implementation of projects from an administrative point of view. Municipalities also give their contribution through a Conference of Mayors and with integrations to the funds allotted to them by Law 162\1998.

The management and the organisation of individual projects is the task of those who apply for the funds.

**TYPES OF INTERVENTION** - The main sectors of intervention are: forms of domiciliary service thanks to the implementation of suitable services as per art. 3 of Law 104\1992 up to 24 hours a day; repayment of documented expenses for assistance within programmes previously agreed upon, implementation of programmes of personalised help by means of personalised projects for those who apply for them, implemented in compliance with rules set by the Region.

**CUSTOMERS** - **The people who can avail themselves of programmes are: citizens aged between 18 and 65 years, who reside in the Municipalities in the ULSS 22 area who hold a certificate of severe disability according to art. 3 of Law 104\1992. Older people are not included in the area of interest of Social Services for handicap since the disability of people older than 65 is considered to be mainly due to old age.** "Severe disability" is defined as follows: It is to be considered as handicapped any person who has a physical, psychic or sensory disablement, that is stable or progressive, which causes difficulties in learning, in relations, or at work, and such as to cause a process of social disadvantage or non integration. Handicapped people have a right to all services in their favour according to the nature and severity of their disability, according to their residual general capacities and according to the effectiveness of rehabilitation therapies.

In case the disability, whether single or multiple, has reduced personal autonomy, correlated with age, so that continuous, permanent, and total assistance becomes necessary both at a personal and social level, disability is defined as severe. Situations which are defined as "severe" have priority in the programmes and in the interventions of public services.

**PERSONAL HELP PROGRAMMES** - These programmes aim at improving the opportunities of integration of severely handicapped people into normal life and consist of personal and global programmes where the disabled and their families participate in the decision making process as much as possible. These programmes are the result of careful evaluation on the part of the services responsible for the handicap area and of the municipal services that make up the so called Unità Valutativa Distrettuale (District Evaluation Body). All interventions are centred on the disabled person. Requests of funding for residential accommodation also for short periods or day assistance in structures of diurnal assistance such as CEOD or voluntary Associations are excluded. The intervention modalities are the following:

- a- **self-determination and self management of the service of Independent Living.** In these programmes the disabled themselves propose and manage personalised plans of assistance in order to get mobility, independence and better social integration .
- b- **self-management of the home help service.** These are programmes of assistance in favour of people affected by particularly severe pathologies who must stay in bed or at home and whose family must bear a heavy organising and economic burden.
- c- **Strengthening of already existing services (S.I.I.-S.A.D.).**

**ACCESS PROCEDURE** - applications of the disabled or of their families, (depending on the kind of project) are handed by 31<sup>st</sup> December of every year to the Social Worker of the Municipality where the disabled reside .The project must define the aims, give a description of the interventions and state their unitary and total costs. The Social Worker will deal with the disabled and their families and will negotiate a reshaping of the project with them in case the funding should be lower than the request, he\she will define the objectives of the programme, and the audit criteria, and he\she will monitor the implementation of the programme and the final certificate.

**THE COMMISSION FOR TECHNICAL EVALUATION** - The Commission evaluates the congruity of the application approved by the Unità Valutativa Distrettuali, draw up the list of merit, and define the amount of each contribution or repayment, keeping in mind the number of applications received and the budgets limits assigned to every District.

**ACCESS CRITERIA** - To be resident in one of the Municipalities in the District area of ULSS 22, to be between 18 and 65 years old, to hold a certificate of severe handicap according to art. 3 of Law 104\1992; requests must be congruous with the aims of Law 162\1998 and its objectives.

**PRIORITY CRITERIA** - The general criteria of evaluation for the compilation of the list of merit of the projects and their funding are: the severity of the disability, the global income of the disabled person. However, considering the nature of these intervention a distinction is made between the funding of projects for Independent Living and the funding of projects of help to the person and to the family. **Projects of Independent Living:** possibility to reach specific and innovative results that improve the person's autonomy, autonomous management of the assistance, fruition of a general network of the services available. **Projects of support of the family:** composition of the family, giving priority to disabled people with one single person in the family, lack of suitable services in the general network of services available, with particular reference to the pathology and the need of the service.

**RESOURCES AND LIMITS OF THE FUNDING** - Within the global funds allotted to ULSS, considering that District budgets as calculated on the number of residents, it has been decided to allocate at least 70% of the yearly regional funds to Projects of Independent Living and the remaining 30% to other kinds of intervention.

The funding of each project must not exceed 80% of its global cost, the remaining 20% to be borne by the disabled person and\or his\her family. **There is an established maximum of admissible expenditure that should not normally exceed 18,600 euros (that is 36,000,000 lire).** In no case the contribution allotted will correspond to the cost of the project.

**9) MAIN PROBLEMS:** there were two main problems, both linked to financial factors:

a) the funding allocated was lower than in the previous year while expenses were higher so that applicants had to ask for the economic support of their families thus creating heavy economic inconveniences;

b) a part from insufficient funding, the system of distribution of funds in the form of repayments, causes very serious problems of liquidity. According to consumers, it is absolutely necessary that funds should be given before the expenses are met, possibly at the beginning of every month.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** evaluations were expressed by the district teams and in yearly reports of individual reports of consumers. One of these reports concerning year 2002 is at present available. It is a report by Marco Pazzi, Elena Skall's son, who is affected by dystonic tetraplegy caused by a neonatal or congenital cerebral lesion. Marco's intelligence was not impaired, he is prelingually deaf, aphasic, and he uses a personal, gestural and easily understandable code of communication as an alternative to spoken or written language. His disability degree is 100%. Marco cannot perform any of the basic everyday tasks autonomously. His report is positive, his experience of Independent Living has proved valid and effective.

**11) PRESENT SITUATION AND FUTURE PROSPECTS:** the operators involved intend to go on trying to widen the number of our consumers. These plans, however, are strictly linked to an increase in the available funds. The operators hope more resources will be available in the future.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Person in charge at ULSS 22: Dr. Marco Piccoli, responsible for the Handicap Department. Tel. 045/6769349, fax. 045/6769344. E-mail: [mpiccoli@ulss22.ven.it](mailto:mpiccoli@ulss22.ven.it). For the consumers: Dott.ssa Elena Skall, Tel. 045/6000118, E-mail: [eska47@libero.it](mailto:eska47@libero.it). **BIBLIOGRAPHY REFERENCES** - Azienda ULSS n. 22 Veneto, Area Handicap, **Regolamento per il finanziamento degli interventi previsti da L. 162/1998** – Rules for the funding of interventions as per Law 162/1998 (available on file).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

## CASE 9

**1) PROJECT NAME:** “Independent Living” for the activation of projects of personal, self managed assistance.

**2) OBJECTIVES:** the purpose is that of granting the right to Independent Living to people permanently disabled and with severe limitation of personal autonomy in the performance of one or more essential functions of living which cannot be overcome through the help of technical aids. This is done by means of the implementation of programmes of personal assistance “directly managed” thanks to personalised programmes for the people who apply for them (in compliance with art.39, point 2 of national Law 104\92, modified by Law 162\98). The implementation of personalised projects of self managed assistance aims at the full integration of disabled people as per Law 104. As a matter of fact, the opportunity to manage one’s own personal assistance, acts positively on the quality of life and allows to overcome several of the obstacles the disabled have to face in their everyday life: from lack of integration at school owing to the difficulty of following the course of studies, to the scanty social relations due to the objective difficulty of reaching meeting places autonomously, to the difficulty of finding a spouse, from the help to families to the progressive reduction of their burden of assistance. In a word we should first solve the problems of primary assistance if we want to meet the challenge of the problem of social integration. The objective is the protection of the rights of citizens thanks to the implementation of service policies at a local level with the following purposes: to promote new opportunities for the improvement of the quality of life, to favour living at home rather than in institutions, to create a real instrument of social integration, to relieve families from the assistance burden they are forced to bear, to improve schooling, to offer the same opportunities as those offered to non disabled people, to develop each individual’s potentialities, to eliminate the social circumstances that cause disadvantage, to prevent ousting and institutionalisation that do not solve problems, but rather make health and the quality of life of disabled people even worse.

**3) SET UP DATE AND LENGTH OF THE PROJECT:** personal projects activated in 1999. They are yearly and renewable. This initiative is still in progress. The starting point was the European project “ Independent Living: a good practice” organised by Venice UILDM and its Swedish partner STIL with the comparticipation of Venice municipality. The project was started at the end of 1997 and it consisted of a course on Independent Living for 30 disabled people. The course was followed by the experimentation of a personalised project based on the autonomous management of a certain number of hours of assistance. When the project ended, at the end of 1998, thanks to Law 162\98 it was possible to implement some personal projects in 1999 for the people who had applied for them. Later on, thanks to the close cooperation between AUSSL and Venice municipality the present project was started. The project is still going on as described below.

**4) IMPLEMENTATION AREA:** Municipalities of Venetian AUSSL n. 12 (Venice, Cavallino, Marcon and Quarto d’Altino).

**5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Aulss 12 Venice – Dott. Maurizio Fontanella.

Venice Municipality – Dott.ssa Francesca Corsi; U.I.L.D.M. (Unione Italiana Lotta Distrofia Muscolare – Italian Association against muscular dystrophy) Venezia – dott.ssa Elisabetta Gasparini; A.I.A.S. (Associazione Italiana Assistenza Spastici – Italia Association for the assistance of people affected by spastic paralysis) Venezia – Giampaolo Lavezzo; A.V.I.R.B. (Associazione Vita Indipendente Roberto Bressanello – Roberto Bressanello Association for Independent Living) – Angela Zanghierato.

**6) NUMBER OF CONSUMERS:** 1999: 3 consumers; 2000: 25 consumers; 2000: 13 consumers (added in a second phase); 2001: 63 consumers; 2002: 64 consumers; 2003: 83 applications under scrutiny.

**7) TOTAL COST OF THE PROJECT:** 1999: 11,230 euros, 2000: 125,500 euros, 2000: 25,820 euros (integration), 2001: 588,000 euros, 2002: 514,000 euros, 2003: amount to be determined.

Regional funding (Law 162\98) covers at the moment 25% of the total cost and some more funds will be contributed by Venice Municipality.

**8) GENERAL DESCRIPTION OF THE PROJECT:** the project was authorized by a Commission composed of representatives of the Municipalities, of Venice AUSSL and of associations of disabled people in the area. The Commission defined a set of rules, access modalities and the modalities for the final audit. Personalized projects are examined by the Operative Body for personal projects of Independent Living. The Commission is formed by the Head of the Handicap Department of Venice AUSSL 12, by the person in charge of the organisation office of the Department for the disabled of the municipalities in the AUSSL area , by the person responsible for the project of Venice municipality, and by a representative of associations with a proxy of the disabled person who applied for the project.

**Customers** - Prospective beneficiaries are all citizens with temporary or permanent limitations of personal autonomy that cannot be overcome by means of technical, aids, prosthesis or other devices designed to facilitate self-sufficiency and integration of the disabled residents (art.9 of Law 104\92). The service is designed for adult, severely handicapped people, aged between 18 and 65 who hold a certificate of severe handicap according to art.3, line 3 of Law 104\92 and who need and want to organise their own assistance autonomously.

**Modes of fund allocation** - Once the personal project has been accepted, 50% of the total amount is paid. Successive payments take place in three different instalments: 30%, 15% and final settlement. Payment covers a certain number of hours of assistance at a stated hourly tariff (19.82 euros). The final audit checks the total expenditure and not the number of hours, which means the applicant is free to negotiate the hourly pay with the personnel autonomously. Applicants decide how to recruit their assistants and employ them in compliance with the law. Consumers decide tasks, times and modes of assistance and pay for them. No particular professional training is required since the consumer will train his\her own assistant. Only regularly documented expenses can be admitted to funding (invoices of service agencies, or pay packet for direct employment).

**Access modalities** - In order to avail themselves of the service, applicants must send plain, unstamped applications to the Department of Social Services of the Municipality where they reside by 30<sup>th</sup> October of every year. The following documents must be enclosed: 100% disability certificate, a certificate stating the condition of handicap, the personalised project stating the times of assistance and their integration, if any, with other services, and lastly the amount of money requested. Also personal data, the hourly cost and the total amount of yearly expenditure. Projects can only last one year, from January to December. Almost all consumers have asked for a renewal of the project for the following years. Renewals have been proposed and the regular implementation of the service, if requested after a test of 24 hours, is desirable.

**9) MAIN PROBLEMS:** excessive length of technical times necessary for the approval of the projects. As for personnel, it is very difficult to find adequate assistants.

**10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned) AND 11) PRESENT SITUATION AND FUTURE PROSPECTS:** official evaluations and comments on the present situation and future prospects are supplied by Elisabetta Gasperini, of the Veneto Coordination Agency of Groups for Independent Living.

One of the first advantages is the improvement of the quality of life of consumers involved in the project not only from a social point of view but also from a sanitary one.

The opportunity of managing one's own assistance service allows choices, and gives back the inalienable right to equal opportunities. Severely disabled people must be educated to this new kind of approach to personal services. In the area of Venice the Associazione Vita Indipendente Roberto Brassanello (A.V.I.R.B.) has been formed by disabled people whose project was financed; it works as an agency for Independent Living; it promotes and organises meetings for the exchange of experiences and information and, for the support of the principles of Independent Living (in the executive committee A.V.I.R.B. there is a national representative of E.N.I.L.). A training course of "peer support" for disabled people was organised and held by disabled partners of U.I.L.D.M. and of A.V.I.R.B. who have been enjoying personal assistance for longer than 2 years. An even greater



effort must be carried out towards a change of social operators, in particular of social workers who should modify their role: from the laying out of personal projects, which created a condition of dependence of consumers, to a new role of planning and implementation of services based on free choice and managed directly by consumers. In this sense, Venice municipality has realised a training course for its operators with a view to redesign their role in the light of the new legislation and of the new cultural phenomena.

A new set of rules for the creation of the Aid service for Independent life (S.A.V.I.) is being defined by disabled people belonging to U.I.L.D.M., A.V.I.R.B. and E.N.I.L. Italia. An amendment to the regional financial law was approved at the beginning of January 2003, proposed by the Veneto Regional coordination for Independent Life (which includes several associations of the disabled whose spokesperson is Dott. ssa Elisabetta Gasparini) that establishes a regional contribution of 1,500,000 Euros for projects of self managed personal assistance. Its criteria and access modalities are being defined.

**12) SOURCES OF INFORMATION: MAIN REFERENCES** - Elisabetta Gasparini, Coordinamento Veneto dei Comitati per la Vita Indipendente (Veneto Coordination Agency of Groups for Independent Living), 30126 Venezia - via Hertz, 6 - Tel. 041-5260050, [elisabetta.gasparini@tin.it](mailto:elisabetta.gasparini@tin.it). **BIBLIOGRAPHY REFERENCES** - [www.uildm.org](http://www.uildm.org): official site of the UILDM. On its web page Independent Living informative materials can be found, among wick: *Guida alla Vita Indipendente (A guide to Independent Living)*, by Roberto Bressanello - *UILDM Direzione Nazionale (National Direction)- Padova 1997* (the text is also available in the form of a pamphlet and can be requested from UILDM – National Direction); *Progetto “Vita Indipendente”- Project “Independent Living”* – Acts of the conference held in Padua on 4<sup>th</sup> May 1996 as a part of the initiative *Civitas* (Salone Nazionale dell’Economia Sociale e Civile – National Exhibition of Social and Civil Economy); *Autonomia e Vita Indipendente (Autonomy and Independent Living* – a collection of interventions and opinions on Independent Living published in DM magazine (UILDM magazine) from 1993 to today.

[www.avirb.it](http://www.avirb.it): official site of AVIRB (Roberto Bresanello Association for Independent Living), active in Venica since 2001. It supplies informations about the rules and access modes to funds as per Law 162/98 and illustrates already implemented experiences of Independent Living.

- Comment on the project of Dr. Fontanella, responsible for Independent Living Aulss 12 Venezia (available on file).

- Deliberation of U.L.S.S. 12 Municipalities of Venice - Marcon - Quarto d’Altino, Deliberation n° 002002 of 23rd September 1999 – Reference number 99/0048223/000 – Socialò Services.

- Deliberation of the General Director. Object: Projects of year 1999 on “Independent Living”. Law 162/98 fundings – P.I.E. (available on file).

**13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** yes.

## CASE 10

- 1) PROJECT NAME:** Total Mobility.
- 2) OBJECTIVES:** this project aims at removing barriers to transport through the following activities: implementation of a transport service, a kind of “door to door” service for people with reduced mobility, the compilation of a user’s guide concerning all available regional services, the organisation of cultural events and other activities to favour the participation of disabled people in any kind of social milieu, the encouragement of actions and proposals aimed at the integration of the problems faced by the disabled into mainstream local transport policy.
- 3) SET UP DATE AND LENGTH OF THE PROJECT:** one year, from October 1998 to October 1999. The project was extended for two months and it came to an end on 31<sup>st</sup> December 1999.
- 4) IMPLEMENTATION AREA:** Syracuse municipality.
- 5) INSTITUTIONS AND ORGANIZATIONS INVOLVED IN THE PROJECT:** Cooperative “Progetto Vita” (“Life Project”), via Forlanini 3/a, 96100, Siracusa. Tel. 0931-415477; Municipality of Syracuse; Dpi Italia; Consorzio di Cooperative Sociali Consolidas di Siracusa (Association of Syracuse Social Cooperative); Syracuse Province only gave its patronage but in practise it cooperated neither from the point of view of funding nor from the point of view of services.
- 6) NUMBER OF CONSUMERS:** about 40 consumers, for about 800 monthly performances offered by ”Progetto Vita”.
- 7) TOTAL COST OF THE PROJECT:** 196,255 euros (EU funding amounted to about 103,292 euros - 200,000,000 lire -), municipal contribution to 92,963 euros (180,000,000 lire).
- 8) GENERAL DESCRIPTION OF THE PROJECT:** Cooperative “Progetto Vita” owns 4 vehicles for the transport of disabled people. According to the project the use of those vehicles was intended for the transport of the disabled through a sort of “door to door” service, when the disabled asked for it for study, for work, for rehabilitation therapies, for their free time activities. Consumers were allowed to call whenever they wanted in order to book the service which was active every day from 7 a.m. to midnight. Two disabled people were employed for secretarial work.
- 9) MAIN PROBLEMS:** the main problem was the mentality of consumers who lived in a traditionally little innovative region. The project became successful only after several months because at first the disabled did not call. The people responsible for the cooperative Progetto Vita had to try hard to persuade the disabled. But after these initial difficulties the project became very successful.
- 10) OFFICIAL FINAL EVALUATION (evaluators must be mentioned):** the project, after the above mentioned difficulties at the beginning, was very successful. At first consumers contacted the cooperative for personal needs, but in the long run, when friendship relationships became stronger, consumers often autonomously decided to go out on a trip together, or on a cultural visit or to go and eat a pizza, etc. Report by Raffaele Ciccio, spokesman for the project of the Cooperative “Progetto Vita”.
- 11) PRESENT SITUATION AND FUTURE PROSPECTS:** Total Mobility (Mobilità Totale) came to an end in June 1999, at present the project is no longer active and consumers who had started to know and appreciate the service miss it. There is an agreement between the Cooperative Progetto Vita and Syracuse Municipality for the transport of the disabled, but with a fixed and reduced timetable and only for study, work and rehabilitation. Transport for free time activities is no longer taken into consideration. The Province has promised its help for the future but on very vague terms .
- 12) SOURCES OF INFORMATION: MAIN REFERENCES -** Raffaele Ciccio, spokesman for the project of the Cooperative “Progetto Vita”, tel. 328-101038, 0931-36183, e-mail [rafciccio@infinito.it](mailto:rafciccio@infinito.it). - **BIBLIOGRAPHY REFERENCES –** Not available at the moment.
- 13) AVAILABILITY OF FURTHER INFORMATION IN ITALIAN:** no.