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printed March 2012

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ISBN 978-88-89477-59-5

www.marettieditore.com + info@marettieditore.com

# us, Italy

with

tavoloITALIA

by Anton Roca

curator Simonetta Lux

Community of Sant'Egidio

MLAC - Museo Laboratorio di Arte Contemporanea

Sapienza University of Rome



### us, Italy

with

tavoloITALIA

by Anton Roca

Roma, Palazzo del Quirinale Sala delle Bandiere 3<sup>rd</sup> December 2011- 31<sup>st</sup> January 2012

Trento, Palazzo Calepini 8th March - 30th April 2012

Exhibition and catalogue has been realized thanks to



+avoloITALIA by Anton Roca has been realized with the collaboration of

Technical sponsor

Technical advice Studio Angelo Grassi Eng. Alessandro Rossi

The Exhibition was organized by Community of Sant'Egidio MLAC- Museo Laboratorio di Arte Contemporanea Sapienza University of Rome







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in collaboration with Art studios of the

Community of Sant'Egidio

Mental Permanent Factory BY Anton Roca

conception and set up of the sculpture

*†avolo*ITALIA Anton Roca

Exhibition concept and project

Federico Lardera larderArch studio

Realized by

TAGI 2000 srl

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### One Italy for All

The exhibition *Us*, *Italy*, demonstrates, once more, the creativity of people with disabilities and their will to play an active part in our Country's life. One is struck by how much satisfaction and happiness they draw from the possibility of expressing themselves, taking possession of the tools of communication, and mastering words. As one of the authors of the texts in this book writes: "The school taught me words, Italian and foreign. We need words in order to communicate with others. We need words to express feelings. We even need them to think. And they are beautiful". This exhibition also offers a testimony to how important the work carried out by those who devote themselves to the growth of unexpressed capacities is, bringing them to maturity with professionalism, sensibility and commitment.

Hence, the exhibition has a twofold value: it offers us the chance to appreciate both the authors' creativity and the social commitment of those who have worked with them, allowing for activities of which this display is an exemplary compendium. I am particularly pleased that the theme chosen for the exhibition is the 150<sup>th</sup> anniversary of Italian Unification, and that it has been designed in view of honouring this special occasion, so rich in significance and value. At the same time, the exhibition represents an indicator of our Country's advance in the inclusion of people with disabilities. The author of a beautiful poem, a disabled girl of Somali origins who was born in Italy, reminds us of this when she writes: "I am happy to have been born in Italy", because Italy is different from other countries where they "heal your legs but believe you are lame in your heart", and she adds: "I remain enchanted because in Italy you need to make great efforts, but you can love and be loved". It is only fair to recognise that significant progress has been made towards the inclusion of disabled people, even though there certainly is still much to be done. But our main task today is to prevent a disruptive economic crisis forcing us to take steps backwards.

This is a field of public intervention - and I have affirmed this several times - in which such a risk should be averted as it would have too serious and painful consequences otherwise. Our Constitution asks this of us not only in article 38, which specifically deals with the rights of disabled people, but also in article 2, when it "requires the fulfilment of imperative duties of political, economic and social solidarity".

It is important that on the occasion of the 150<sup>th</sup> anniversary of the foundation of the Italian State this exhibition **shows** an Italy that belongs to everybody, as we want it to be. What we see appearing here is an Italy that is able to stir up admiration, and we hope that this Italy, which the previously quoted author describes when she writes: "I love a united Italy because different men and women become one single people", will continue to appear. Since, as others have said "Divided we do not make any sense".

I have also greatly appreciated the 150 pictures sketching out our history and our present society, as well as Anton Roca's reference - with his work 'tavololTALIA" - to our Country's unity and to social cohesion as a founding principle.

To all artists and authors, whose activity has made this exhibition unique, my warmest wishes for a continued success in the path to integration, which has been so happily undertaken. To those who have conceived such a brilliant exhibition, who have curated the exhibition, who have accompanied and supported the activities displayed here, I extend my deepest appreciation.

To the Community of Sant'Egidio I renew, also on behalf of our fellow citizens, the most heartfelt thanks for their devoted commitment to defending and promoting the interests of minority groups. I will take this opportunity to express to all people with disabilities and to those who find themselves in serious difficulties, my closeness and my commitment to supporting their cause, to the extent that my institutional role will allow. I would like to conclude by quoting again one of the authors of the texts on display at the exhibition: "Our forefathers and us, we write the course of history". All of us, without exception.

Giorgio Napolitano
President of the Italian Republic



## *Inhabiting* Italy

Inhabiting Italy by Simonetta Lux

### Inhabiting Italy

by Simonetta Lux

The "wordless people"\*, the last and forgotten members of Italian society, to whom the word and dignity have been given back by the Community of Sant'Egidio - one of the organizations active in Italy on the front line of the fight against marginality and exclusion - have been invited by the President of the Italian Republic to take part in the celebrations for 150 years of Italian Unity. Through paintings and words, they have conveyed their historical and critical vision of a particularly significant episode, event or prominent personality identified by them and which took place or was active during the course of the 150 years since Italy has been established. Within the experimental art laboratory of the Community of Sant'Egidio created in Rome where, thanks to systematic work, disabled people are rescued everyday from the indifference of the world and from cultural unawareness, 150 small paintings or assemblages have been created by 150 disabled artists, and texts, memories and writings have been drawn up for which each artist has freely taken up responsibility.

A renowned international artist, Anton Roca, has been invited to create a piece of work together with some of these artists, giving them a sense of responsibility, and including and involving them in his creative project of sculpture installation.

This work is called favolol TALIA and is composed of as many tables as the number of the Italian regions, whose shapes have been inhabited, whose inhabitants tell their individual Italian life experiences, and in whose passages everyone has left a gift, a mark of memory, a wish or aspiration.

We can speak of the conceptual or visual *condensations* of lives and experiences - each often very different from every other but all characterized by at least one passage, of variable length, involving overcoming, to various degrees, the bottleneck of exclusion and racism. What happens when an artist, in our case the Catalan artist Anton Roca, creates a piece of work about - and together with - "marginalized" people? He, who was invited by me, who belongs to the so called art system, and invited by the Community of Sant'Egidio, which created the Art laboratories for the so-called disabled people, who they take care of in so many respects in Rome and throughout Italy? What happens to the marginalized and banished people in this creative and cooperative encounter?

They lose their stratification, their exclusion, becoming persons, they create and challenge their limits and establish signs, re-establishing a forbidden contact with the world. The "forgetfulness" is obliterated, a story is accomplished, an idea, a critical thought, an image is condensed.

What happens to the artist?

He or she changes, losing his or her prejudices, creating another piece of work of his or her own, one that is specific to this new relation with the world of the 'other', the excluded.

What are we doing?

The entrance of affirmed artists (i.e. legitimized by the art system) into the laboratories of Sant'Egidio is the most recent

act of a long process undertaken by the Community members who have been working on a voluntary basis ever since the foundation of the Community.

The disabled people belong to the huge group of people who are considered the last in our organized, standardized society, ruled in accordance to the *defensive* prejudices that are, alas, a permanent patrimony for most of us.

Exclusion, segregation, alienation, expulsion, being hidden is the treatment that disabled people receive from us. In this way, society sublimates a fundamental ignorance and indifference towards the other, towards those who are different from the 'norm'.

As I was saying, this is the last act, perhaps the most overwhelming, of a process that within the Community of Sant'Egidio starts from scratch with establishing a person-to-person relationship with disabled people and then goes on to rescue them from segregation or confinement in special institutes and from exclusion from work, society, sometimes even from family; this process proceeds with the creation of laws for their inclusion in common classes (as opposed to special classes) at school, and continues by urging individual communication processes (the word, writing) that whilst being physically hindered, is made possible via modern information technology; with the creation of an introduction to employment; with the production of places - laboratories for drawing and for art experimentation - of periodical, systematic encounters, in which people study, thematize, discuss, observe, analyze the world and create.

A total breaking of the prejudice of stupidity, the discovery of unexpressed intelligence, the unveiling of new, perceptive and critical points of view, in short, of special people with whom we can happily enjoy life and its disasters.

Having an artist come into the field has been an intuition on the part of the laboratories curators (who are not artists). But the truth is that the artist and the so called 'disabled' people find themselves at a point which gives them a similar *vantage point* from which to start plotting their own significance as regards the world, and reality.

The artist is actually "the other". It is he that, consciously or unconsciously, the day in which he becomes an "artist", retires from the world, separates him or herself, recognizes him or herself as "other". The artist is "neverthless condemned" to transform the world into privileged matter for his artistic creation. From that moment on, every action of that artist-person will represent an assertion of their identity in a critical comparison with the world, with reality. A world with which many artists establish a relational process, which is why I call them "hyper-contemporary".

The artist's process is mysterious. His or her decision, self-inscription, unfathomable. And nonetheless, clear. The choice is essentially ethical. Anton Roca, for instance, is one of these artists, with his long history of "approaching" that he has called "common-place", a history of relation and inclusion of figures and people that are in a state of suffering or come out of a state of exclusion, or rather people that are already in a process of social inclusion. Roca's work TAVOLÆUROPA came into existence in this way too.

The marginalized or disabled person, on the other hand, in his or her state of exclusion, segregated, refused or banished, hidden or institutionalized (i.e. confined in an institution), has been artfully made *Other*.

Uninterrupted, the oblivion of a person and his/her history, broken the physical-neurological natural limits to communication, the disabled person remains - for a perverted social decision, *different* from the socially and culturally inscribed standard norm. The disabled person, too, is just an *Other*, with a world in front of them. But he or she is now ready for

action, ready to affirm him or herself as a person, to act in the world.

Encountering the artist and working together with him, working in these art laboratories, can sometimes be explosive: together the artist and participants get ready for their creative action upon the world; from themselves to the world.

Moreover, the return of the word and the study of contemporary history gives them the opportunity to send messages, words and judgments upon the Italian history of the last 150 years. A judgment that comes from their point of view, here and now, in the present.

The excluded, the emigrant that is pursued by strict laws, the so-called *fear laws*, after having been actually chased in his or her long escape path from uninhabitable countries; the prisoner to whom a hypothesis of rehabilitation and reintegration - as provided for in our Constitution - has been denied; the person formerly deported to a Nazi concentration camp who has not been able or has refused to talk about the humiliation of violence suffered and is obsessed by his own memory and the painful indifference of his fellow-citizens; the homeless (6000 today in Rome); the invisible - children born in Italy but not recognized as Italians; abandoned elderly people, terrorized and depressed in their unwanted loneliness; the Roma people, driven out from one camp to the other, subject to atavistic and historical prejudices that they disprove through evermore evident cultural change: all of them, invited by Anton Roca or invited along by the Community's friends, tell us something. And the tale of each of them concentrates on one single gesture, in a gift of signs that Roca asked them for. Asked as gesture/gift of an unheard-of desire, or a gesture/gift relative to a horrible memory and a hidden part of their self: a sign, ultimately of "inhabiting", of a "way of inhabiting" the physical and psychological territory of Italy.

Does alterity concern art?

Does this exclusion or self-exclusion, this condition of marginality, in short, this condition of alterity, concern art? Why?

As a historian, and not only an art historian, I have seen that alterity has concerned Art all along, especially within Italian culture from the unification onwards. The hidden, separated, refused, despised, confined, enslaved world of Italy has drawn artists since the 1880s, and this has determined some changes in life and some language choices, scientific discoveries in the fields of medicine and pedagogy, finally the breaking off of institutional cages which have made Italy an avant-guarde country. Which would remain such if today's Italy were not dominated - let us hope only temporarily - by people holding the opposing cultural values of contempt, racism, fear. The artist, as such - but also as a person captured by original humanitarian ideals - and art as an 'act' determined by the creative gesture of the transformation of an unacceptable world, have historically been the propulsive mainstays of important changes in mentality and customs.

In times when - like today - people have lost hope that life could change - we weave this red thread again, the thread of Art, of certain artists, which changes life. Though, mind you, there is something about art which goes beyond 'art', as it is portrayed in critical literature and in art historiography, where the complex integrity of the meaning and role of art appears to have faded.

Instead, it is something that sees painters (Nino Costa, Giacomo Balla, Duilio Cambellotti, i XXV della Campagna Romana - literally, 'the Twenty-Five of the Roman Countryside', a group of artists dedicated to portraying the real life conditions of the countryside in the early part of the 20<sup>th</sup> Century) together with poets (Giovanni Cena), physicians (Angelo Celli), actors and writers (Sibilla Aleramo), pedagogists (Alessandro Marcucci), philosophers (Maria Montessori) and, why not,

even Members of Parliament (Angelo Celli), psychiatrists (Franco Basaglia), artist-priests (Don Milani), all meeting and moving forwards this approach: an extraordinary movement among fields of knowledge, an interdisciplinary and humanistic movement.

I wonder how the persistence of an incredible number of constrictive structures and of a school which is not integrally "inclusive" is still possible here, in Italy, where we can trace that long, uninterrupted red thread of actions, educational methodologies, initiatives aimed at freeing faculties and intelligence, which runs through the history of the united Italy, to be broken only under the dictatorship to which we were submitted during the Fascist period.

From Nino Costa (1826-1903), with his association *In Arte Libertas*, to Maria Montessori (1870-1952) who died two years before the creation of the Barbiana School of Don Milani, to the association - which came into existence out of one section of the Unione Femminile Romana (Union of Roman Women) established in Trastevere - of Alessandro Marcucci (1876-1968), to the poetess Sibilla Aleramo, Giovanni Cena, the artist Giacomo Balla, Anna and Angelo Celli, the physicians who discovered a treatment and prevention for malaria and organized a plan of educational-sanitary assistance for the peasant population of the Roman countryside and the Pontine Marshes.

Such an association, committed to promoting literacy among the peasants of the Roman countryside through the development of a teaching system and the construction of rural schools, was joined by the artist Duilio Cambellotti in the early 1910s when, in that context, he decorated several school buildings and illustrated spelling and reading books.

With them, he organized the Exhibition of the Agro-Romano (the 'Roman Countryside') at the Esposizione Universale di Roma (Universal Exposition of Rome) held in 1911. Right there, on the occasion of the big Exhibition at Prati di Castello, held for the 50<sup>th</sup> Anniversary of Italian unity, Italian Sovereigns marvelled at the activities which took place in 'hutschools' recreated in a special pavilion. Italy might have seemed like Africa, with its round huts covered by straw roofs, over there, in the Pontine Marshes, where several families of peasant families cohabited.

"The school was supposed to give these ignorant and outcast people, deprived of land and even of a registry office, a human and civilized citizenship. This was something different altogether than teaching them how to do sums! The school, with all its developments, became not only a tool for material assistance but also an instrument for the assertion of social rights, for denouncing in front of the civilized world a surviving feudality, all the more unfair as it was exerted as a form of trade (commerce), artfully legitimized by some article of law".

Physician Angelo Celli also realized that it was vital to shake up the conscience of the illiterate population, otherwise prone to a fatalistic acceptance of malaria.

We owe to him, in particular, the promotion of the national body *Le Scuole per i Contadini dell'Agro Romano e le Paludi Pontine* (The Schools for the Peasants of the Roman Countryside and the Pontine Marshes). Celli's fight against malaria was taken as a model by other countries from which he received numerous acknowledgments (such as the *Honoris Causa* Degree at the University of Athens and Aberdeen and at the Royal Institute of Public Health of London, the Mary Kingley gold medal from the Institute of Tropical Medicine in Liverpool).

Maria Montessori's (1870-1952) books were set on fire by the Nazis, first in Berlin and then in Wien during the Nazi occupation of Austria. Why did they cause so much fear? In 1907 in the Roman neighbourhood of San Lorenzo she founded the first *Casa dei Bambini* (Children's House) and from the outset this upset prejudices, due to her social and scientific

commitment to children with disabilities, or who were considered disabled merely because they were from humble backgrounds.

Her scientific pedagogical method, drawn up in the volume written and published in Città di Castello (Perugia) during her first Specialization Course (1909), was translated and welcomed all over the world with great enthusiasm: For the first time a new and positive image of children was put forward, the most appropriate method aimed at allowing spontaneous development was set out and the child's great predisposition to cultural learning - the possible results of which had never before been imagined or verified - was demonstrated.

In 1924 (the year of the foundation of the Surrealist movement of André Breton, based on the project of re-unifying the divided personality of modern man) Montessori founded the Opera Nazionale Montessori (National Montessori Opera): in 1934 she was forced to relinquish her activities because the Fascists wanted her to conform to their dictates. She subsequently escaped to Holland and then to India from which she returned in 1947, after the War.

For over forty years Maria Montessori was active, not only in spreading her method but also in researching in view of liberating childhood ("the true social question of our time") and defending the child, which had been so far neglected by the adult.

After the work, today known as *The Discovery of the Child*, other works were published: *Pedagogical Anthropology*, *Auto-Education in Elementary School*, *The Child in the Family*, *Psychometric and Psychogeometry*, all of them translated abroad, where meanwhile the Montessori method was spreading more and more widely.

Not only did she discover and bring out the "new character" of the child and its irreplaceable role in preserving and perfecting humanity ("the child is the father of the man"). From her incessant exploration on *How to Educate the Human Potential* further final ideas originated. Such as the idea of an education for peace and the idea of a cosmic education.

Don Lorenzo Milani (1923 - 1967), or "Gentleman God and Painter", as he once defined himself when he was 20, studied to become an artist at the Accademia di Brera in Milan (during the Allied bombings). In 1943 he took his vows and devoted himself to the reception of the other and in 1954 took over, effectively, from the work of the great Maria Montessori (who died two years earlier) when, after having been first destined to the Parish of San Donato he was sent, as punishment, to Barbiana, becoming Prior of the Church of S. Andrea, in the small Parish on Mount Giovi, in the Vicchio del Mugello territory.

Milani, who had already put a distance between academic culture and his own interpretation of contemporary architecture (the collective experience of the group of young people around Michelucci, creator of the model building for the Italian rationalism of the '30s: the Railway Station in Florence) and of the non-formalistic strength of painting and art (he wrote the shocking *University and Sheep*), became radicalized upon meeting with the peasant culture and the illiteracy of the mountain dwellers. He then saw the necessity of giving a more central role to school, seen as a process for "giving the word back" to those who were subject to - and yet remained excluded from - the rising consumer society, in the misery of their inability to communicate. Is it not curious that, in one of the following interviews one of our Artist friends speak of himself (and, in general of their widespread condition) as one of "the wordless people"?

From the observation that "the poverty of the poor is not measured by bread, housing or warmth but by their education and their social function", Milani's method and his famous book - Letter to a Teacher - derived over a one-year activity

at the school of Barbiana.

"For him, a priest, the school was a means to be used to fill the cultural gap that prevented him from being understood by his people when he preached the Gospel; it was the instrument to give the word to the poor, in order to help them become freer and more equal, to better defend themselves and to master the use of the vote and the strike. With that tenacity that he was able to show when he was convinced he had sensed the truth, he went to seek all the young workers and peasants of his people, one by one.

He entered their houses, sat at their table in order to convince them to attend his school because the interest of workmen, of the poor people did not lay in wasting their time chasing a ball or playing cards, as their employers wanted - but in educating themselves and in trying to invert the order of the social ladder.

'You - he used to say - are not able to read the first page of a newspaper, the one that counts, but throw yourselves desperately into the sports section. Your masters want you to be like this, as those who are able to read and write the first page of a newspaper are today and will always be the rulers of the world'. He possessed an extraordinary oratory delivery and a capacity to understand people. He was able to touch the most sensitive chord and make it vibrate in each person. In his school he gathered young workers and peasants of every political leaning, a presence that he maintained and extended, showing that he meant to serve the truth above all things: 'I promise before God that I run this school solely to give you an education and that I will always tell you the truth about everything, be it in favour of my business or against it, even if it is dishonourable, as the truth has no side, there is no monopoly for truth as for cigarettes', he said to his young people on one of the first days at the school of San Donato in Calenzano; a school where commitment to trade-union activity, and hence a social commitment as such, was considered a precise duty a Christian worker could not back out of. Through the school and its young students he got to know the true problems of the people. Families welcomed him as one of their own and he was ready to give them his help on any matter" (cf.www.donlorenzomilani.it/don\_milani/).

He accomplished a great cultural, didactic and pedagogic revolution which rejected indifference and negative passivity, and strongly motivated the student. The centrality he attached to education and to promoting the development of writing ability, are still hugely relevant, considering the return to illiteracy which is so widespread today, especially in the more economically developed North of Italy where the uncritical culture of the "Society of the Spectacle" dominates. "The desire to express our thought and understand other people's thought is love. And the attempt to express truths that can only be intuited, help us to find ourselves and the others. So to be a teacher, a priest, a Christian, an artist, to be a lover and to love are, in practice, the same thing".

Don Milani died in 1967; the following year, The Institution Denied - a book that for many among us is a cult - written by the founder of Psichiatria democratica (Democratic Psychiatry), Franco Basaglia - was published. Basaglia managed to get Law 180, entailing the abolition of psychiatric hospitals, passed, but above all he, like don Milani who had stripped himself of his professional superiority to become a man among men, suspended all therapeutic prejudices in order to be able to "free" the sick person and "catch up with him" on a level of liberty.

"A mentally ill person enters a mental hospital as a 'person', only to become a 'thing". A sick person is, above all, a "person" and he has to be considered and treated as such (...). We are here to forget to be psychiatrists and to remember that we are people": this is what he wrote in 1961, when he became the director of the Mental Hospital of Gorizia with its 650 patients. His work, carried out in a renewed relational system based on listening and individually stimulating pa-

tients who were by then considered people, led Basaglia in 1971, when he was appointed director of the Mental Hospital San Giovanni of Trieste - which then counted 1200 patients - to reaffirm that Psychiatry "which had not understood the symptoms of mental illness, must cease to play a role in the process of exclusion of the mentally ill person". "A process of exclusion - he said - clearly desired by a political system "which is convinced that it can cancel its own contradictions by averting them from itself, refusing their dialectics, in order to be able to ideologically recognize itself as a society without contradictions".

Much is known of the extraordinary Basaglia's work. Re-reading today the "tale", in The Institution Denied, of the long collective process of unhinging prejudice and rethinking the relation between the medical and custody personnel and those men that until then had been permanently "sealed" inside mental institutions, is of great disruptive relevance to the present, if we only think where we are now in Italy with our prison system.

Here, in conclusion of this summary aimed at running through the red thread that connects the "Bel Paese" to the "Bel Paese Bello", I would like to recall another peculiar recurrence, among all the revolutionary experiences mentioned earlier, that is, the recourse to art practice or a devotion to art in view of accomplishing two aims: to liberate and to give critical awareness to excluded people.

As a matter of fact, Basaglia himself established some painting and theatre laboratories in Trieste, transforming them into economically self-sufficient cooperatives before deciding, with his team, together with the "mentally ill people", to go outside, in the world, in short to open the doors of mental hospitals in a sensational way, by parading through the streets of Trieste with a "scenic machine" - a horse made of wood and paper-pulp- followed by physicians, nurses, patients and artists.

This is something that makes me think of the big parade through the streets of Moscow in 1918 - on the occasion of the celebrations for the revolution - of large abstract constructivist and Suprematist sculptures placed on wagons, which shows the link between art, the political project and social freedom. We know that such an integrated project was defeated by the unawareness of popular culture, and by the lack of "sharing", in other words of the cultural elitism of the times, and because of the "separation among fields" of action (politics, art, science, economy, etc.) of the modern man. Sharing, interdisciplinary processuality and equality would have come to maturity through blood later on, in the 20<sup>th</sup> Century.

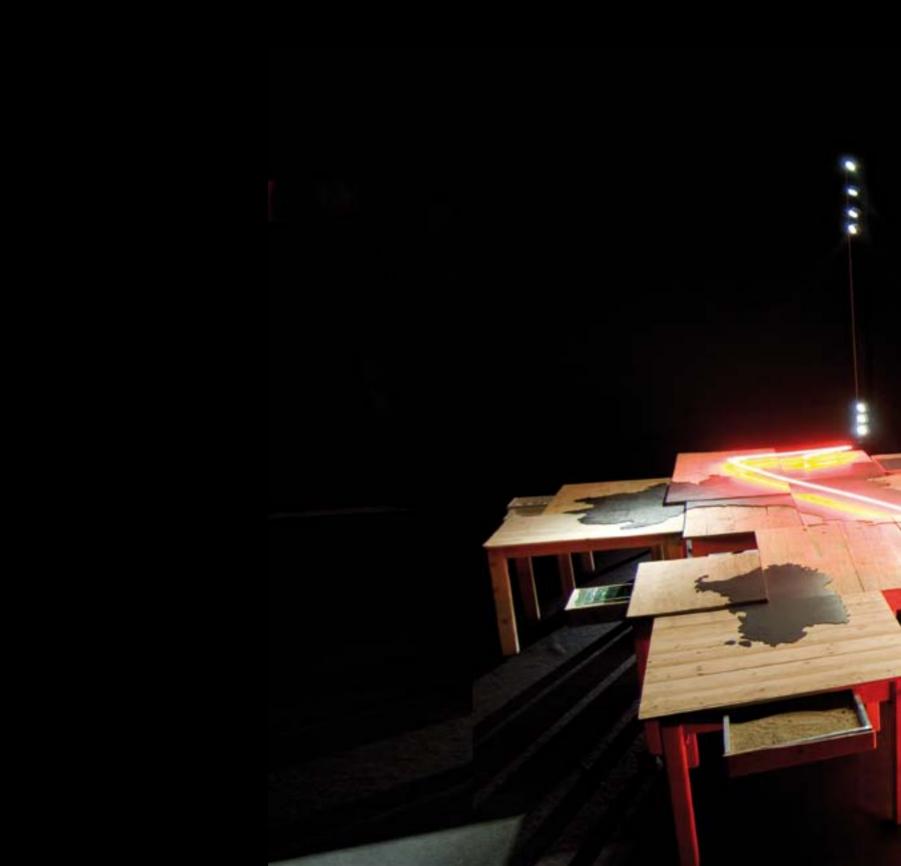
On the other hand, it seems to me that the presence of art, artists, poets in all the initiatives through which our red thread runs - a thread that undoubtedly touches today the history of Sant'Egidio Art Laboratories of the Community of Sant'Egidio and its disabled people - moves side by side with the attitude of art history which today asserts itself not as an "object" but rather as a trace and as a phenomenon of "relation" with the other, where the creative act is a "mise-en-scène" of traces, waste, refuse, fragments of the present concomitance of the fragmentation of the subject and language. It is the endless work which, within the more advanced contexts of technology and the digital network, is produced in a continuous process of delivery and reelaboration of the other. In this sense, I speak of a sort of Great Work of Relational Art, when I speak of the Friends' ongoing work and - emerging within its operative flow - of Works individually realized and accomplished.

<sup>\*</sup> In this way Micaela Vinci identifies herself in a computer-typed communication, defining the perception of her communicative handicap, shared by many of the people we are talking about. Michaela suffers from profound deafness and is mute, but her thinking and communicating capacities are activated through a computer and the Augmentative Communication method.

# +avoloITALIA

tavoloITALIA by Anton Roca

> luogoComune by Simonetta Lux





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#### tavoloITALIA by Anton Roca

I conceived favoloITALIA as a response to an invitation from Simonetta Lux and to the desire expressed by the Community of Sant'Egidio that I would take part in a creative course, with the involvement of the many marginalised social groups with which the community works, to produce a work of art in the context of the celebrations of the 150th anniversary of the Unification of Italy. I wanted, above all, to be introduced to the reality of the Community of Sant Egidio, to get to know their daily actions and the locations in which these take place. I undertook this voyage, in the direction of Rome, under the guidance of such a stimulating perspective and, at the same time, not without a certain fear. With the welcoming help of some of the people who collaborate with the Community - extraordinary figures that personify for me the Epic, in this contemporary mythless age - , I was introduced to the environment in which voluntary action takes place. Hand in hand with each of them - Cristina Cannelli, Paola Armandola, Luca Calligara, Augusto D'Angelo and many others besides - I passed through the stages of this itinerary under the sheer and amiable skin with which I identify Rome, as if it was a trip of initiation.

I came to know in this way the Scuola della Pace di Tor Bella Monaca (the School of Peace of Tor Bella Monaca) and, in the same Roman district, il Laboratorio Museo Sperimentale d'Arte (the Experimental Museum-Laboratory of Art). Both places where hope and trust are put into the practice of education and creative didactics at the same time. In Trastevere I visited the scuola Louis Massignon (the Louis

Massignon School), in which a knowledge of the Italian language is imparted in a democratic way. Subsequently, in the eyes of those who live in the Roma camp of Via di Salone, I have found the exasperation of those forced into a permanent condition of waiting without having guilt, but who, despite everything, still preserve hope. Something that causes even more suffering to my eyes.

I participated in the distribution of the *cena del martedi* (Tuesday dinners) on the edge of Stazione Tiburtina (Tiburtina Railway Station), in which the true distribution concerns the friendship disbursed by willing hands to the poor men and women without a roof, and to foreigners.

During the progress of my trip, my state of mind was attracted and intimidated by that underlying world that slowly revealed itself. A feeling entirely similar to that expressed by the young girl, represented by my fellow countryman, Dalí, in his pictures, as she lifts the veil of water from the shore...

A few months later I returned to Rome with the awareness of having seen a different city, without veils in front of my eyes. I was also different, and bore the clarity of an artistic action to be completed, after the interiorization that I had experienced on that earlier trip.

For my part, there was the need to create a work of art as a result of the constitution of an artistic platform, open to active participation, which would act as a territory for reception, to position the work so it can develop within a perspective of continuity and in the same logic of the *luogoComune* projects upon which I started work at the end of the '90s. A need that was also my only certainty.

The developing project had to remain - to be truly "genuine" and to have the possibility of reaching a 'landing point' - within the most uncertain of circumstances. The premise was to create a group of homogeneous works, constituted by a significant number of people united by diverse reasons related to their many different individual physical and mental conditions and drawn from across the margins of society. Or rather, the group has gone forward by shaping itself with the direct participation of disabled people (through group such as *Gli Amici*; 'The Friends') children, elderly, youths, Roma gypsies, foreigners and prisoners. With the group of 20 formed, we started a new phase in the process of the work,  $+\alpha +\alpha +\alpha$ 

To give the group 'the word' and lend them an ear, were the first things for me to accomplish.

During personal meetings, realised in the form of interviews (video-recorded with the collaboration of Paolo Mancinelli), I was entrusted with their existential stories. I received, gathered and wrote, in a diary dedicated to each person in the group, the urges and desires that motivate them. This active participation has been the initial nourishment from which we departed on the development of the project. Creating the conditions for mutual trust was decisive for the exercise of comprehending the conditions of diversity, of abnormality, permanent or temporary that would turn out be, ultimately, like my own condition. I have compared myself to each of these 20 people, trying to understand and to transmit that the condition of not fitting into a "norm" according to social and cultural prejudices, is within the arts a normal element of the work. Their being diverse and their assumed abnormality was equivalent to mine.

After all, if we switch the point of observation to the side of each of the people that have been compared to me, throughout the different months in which we worked together, I too would be different and not confirm to the norm. In this sense I have become one of them.

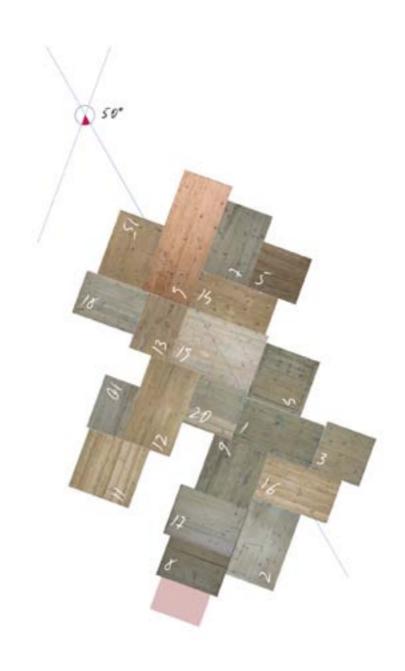
Anew, 'I am the other' ('io sono l'altro'). (1)

At this point of the process, the initial artistic platform has become an artistic and human territory: precisely, the *territory* of 'favololatia'. Having reached an awareness of the constitution of this *new territory*, we proceeded, via an exchange and an interpersonal dialogue based on the previously recorded videos, to the definition of the content to be appended to the *territory*, which will take the form of a personal 'gift'. Such a gift has been the fruit of a shared trial in which a synthesis of concepts has emerged during meetings. The nature of these concepts concerns the personal reflections on the idea of one's self in relation to the concept of an affiliation to Italy directly derived from each person's





Anton Roca, Study for favolo ITALIA - Project n.1, 2011, calculating angle of 50° of the Italian peninsula from the meridian of Greenwich, digital drawing, cm 130x84



tavoloITALIA 2011



particular experience of life.

Identifying these concepts, we have effected a sort of formal and objective translation of it: a form, gesture or thing, that each of the people has subsequently given to the territory. In this way 'difference', the single personal condition meets within the territory, to become a constitutive part of the final work. The constitutive final act of the process,  $\forall avololar ALIA$ , completed over ten months, has been the inclusion of all forms of social exclusion via the presence of the twenty people who, together, have lived temporarily the territory ' $\forall avololar ALIA$ '.

Each person has chosen a proper location inside this human and artistic territory. Twenty people have interacted simultaneously to recreate an interweaving of relations and interpersonal rapports from within a choral gesture of universal values. The finished gesture is Italy, but is also the world, because, beyond simple representation, it becomes existence. It is at the same time both presence and testimony.

To strengthen this sense of universality, expressed through the complex and articulated whole that is the work  $\neq a \vee o - \ell o$  ITALIA, I have suggested a direct connection with the canon of art so that the presence of each of the twenty people returns to a concrete work of artistic inheritance, both Italian and European, within the territory. This decision responds to a circular conception of artistic time, from which derives the insubstantiality of concepts such as past and future and within which all the works produced by humankind are contemporary because they are all equally equidistant from art's centre.

The photographs, taken by Antonello Idini, have halted that temporary gesture within circular time. Both the elements, the gift and the 'living' within the territory, confirm the wish and the desire to reach the constitution of a work of participatory art, in which the authorial responsibility overcomes the border of the artist-author, reaching a form of coresponsibility or widened and shared responsibility. The deep critical reflection completed by Joseph Beuys upon 'social sculpture', in which it is still the artist Beuys who is the final person responsible for the artistic gesture, comes to my aid here. I hope the benefit of trying, even unsuccessfully, to bring Beuysian reflection towards a dimension in which I can consider myself and the twenty people that have participated in a direct way as co-authors of the work  $\frac{1}{2}$  and  $\frac{1}{2}$  of oITALIA will be granted to me.

#### Some considerations on the form of favoloITALIA

At the formal level the territory favolo|ITALIA| is composed of 20 wooden tables that have been recovered from domestic environments and from public meeting places (such as restaurants). Each table is different from every other table in respect of their size and the wood they are made from, yet are the same as the others in the sense that they are all tables. They are also united by the fact that they are *old* tables, characterized by having really lived.

It is like this also for the people involved in the project: each person is different, yet the same as the others in the sense that *they are all people*. All are bearers of a lived personal experience.

20 tables / 20 people: The number of Italian Regions.

The tables are presented formally grouped together in a unique assemblage, joined together with purpose-made fixings. This gathering of tables, this reunion, this human and artistic territory is subject to a unique global movement, in unison, thanks to the spheres placed under each of the 80 legs that make up the whole, allowing the assemblage to be moved. In this way the sense of unity is preserved, treating of an assemblage given to concrete possibilities, informed by a diligent study, which approaches the tables with no empty spaces remaining between them.

The result is a reUnion, intentionally diverse, that doesn't coincide with the actual Italian territorial organization - regions, provinces and communes. and which underlines the lack of a sense of cohesion at the social and convivial level within this territory. A territory that excludes all that doesn't adhere to the "norm", that is to say, the 'different' in the widest sense of the term. On the assemblage of the tables an outline has been laid out in Corten Steel that reproduces the perimeter of the Italian peninsula, including the largest and smallest islands. Such an outline presents sectioned -

in correspondence to the perimeters of the single tables on which it is placed - a division of the unitary sense of the symbol which the outline brings back.

The arbitrariness of the cuts inflicted on the sense of Italian unity are symbolic, yet are actually performed upon the Corten Steel outline - a choice that I consider as a paradoxical recourse - aim to testify to that feeling, widely felt, that the unity of Italy has not reached its conclusion yet.

The reunion proposed in +avoloITALIA aspires to differentiate itself from the tensions that exist today in this country: for additional to foreign or Italian affiliations there is, within Italy, still the distinction between 'southern' or 'northern'. In the specific case of the people that have participated in this project, the element of tension is the parameter with which society establishes 'normality' and creates categories and enclosures to define and to confine abnormality. I consider these tensions to be damaging to the goals of a correct interpretation of the common good and towards the collective lifestyle. Because they underline difference, rather than elements of equality. The formal result of this work proposes a renewed Union while, at the conceptual level, it expresses the attempt to point out a possible valid street for the correct interpretation and understanding - intimate and personal this time - of the historical and cultural facts that belong to us as a collective, dealing with the unity of Italy which considers the inclusion of diversity in daily life. This last factor contributes, like the former, in acquiring the sense of a unified country.

The work favolo ITALIA will be completed with a video projection, comprising 20 photographs that the co-authors of the project have taken, on which will appear, in the form of a text, the synthesis of their 'gift'.

Furthermore, two identical 'neons' will be





installed, situated in a double symmetrical situation in comparison to the surface of the territory favololTALIA, a graphic-emotional translation of two voyages. Above the tables, the voyage to the Nazi extermination camps: the dramatic facts related to the Holocaust, recognized today by history. Underneath, among the wooden table legs, the uncertain voyage of migration facilitated by Italian law today.

These trips are for me like open wounds, from which the red sign illuminates. The neon positioned under the surface of the tables, refers to the internal trip and the existential play of all of the people who have participated in the realization of the work favoloITALIA. I finally intend the process favoloITALIA as a personal contribution to support the process of the emancipation of the individual which is related - with the specific peculiarities of each person - to all the present forms of social exclusion in the project and is comparable to the historical emancipation from which the unity of Italy has sprung.

Anton Roca November 2011

1. Io sono l'altro/ I am the Other. The quote makes reference to a course of research completed in the last ten years of the last decade that is the expression of a synthesis of language: "The artistic I", acquires an impersonal merit, so far as is possible, which goes beyond the sphere of the personal to meet the collective: from the egocentric comes the egotopic". In light of which I have affirmed, referring to the twenty people with which we have travelled to the territory tavololTALIA: "... I have become one of them. Anew, I am the Other".

The entire project *Io sono l'altro* is presented in *luogoComune*, catalogue for the exhibition held at *La Galleria Comunale*, Cesena. 2002.

See also: *Io sono l'altro* in Das Erd Projekt. Danilo Montanari Editore / Imaginaria, Ravenna, 1998.

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tavoloITALIA

anton roca 2011

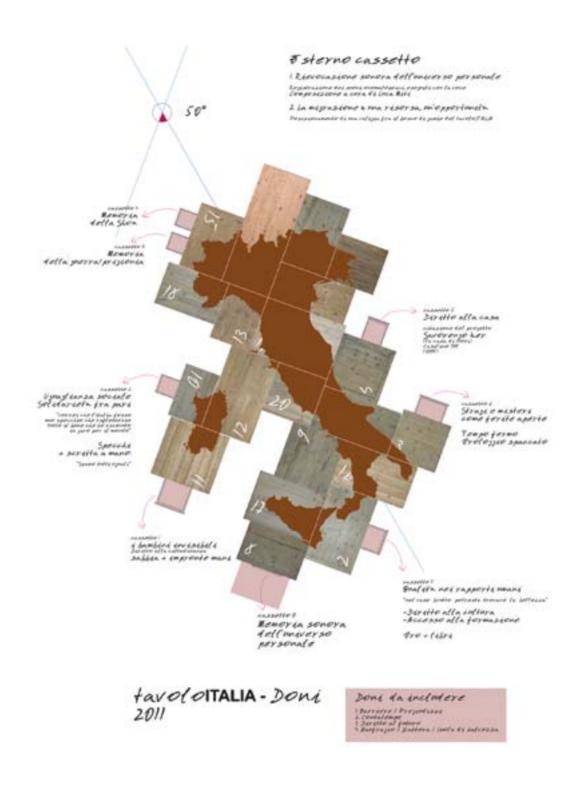
anaderno di lavoro



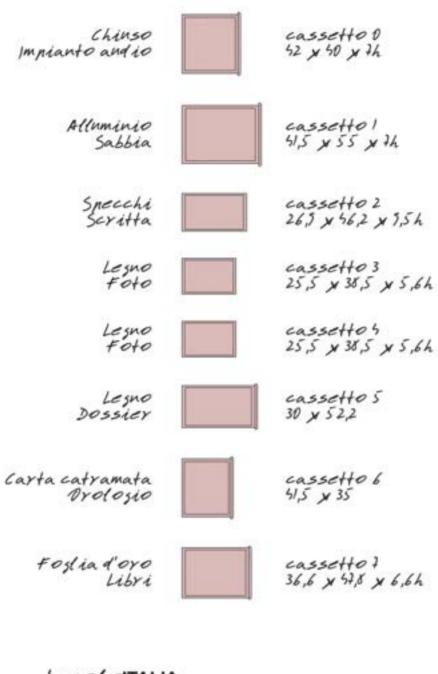
Anton Roca, from the Work notebook favolo ITALIA, cover page and photo-study of tables and flat surfaces, 2011



Anton Roca, Study for favolo ITALIA - Project n.2, 2011, The flat surfaces of 20 tables, digital drawing, cm 130x84

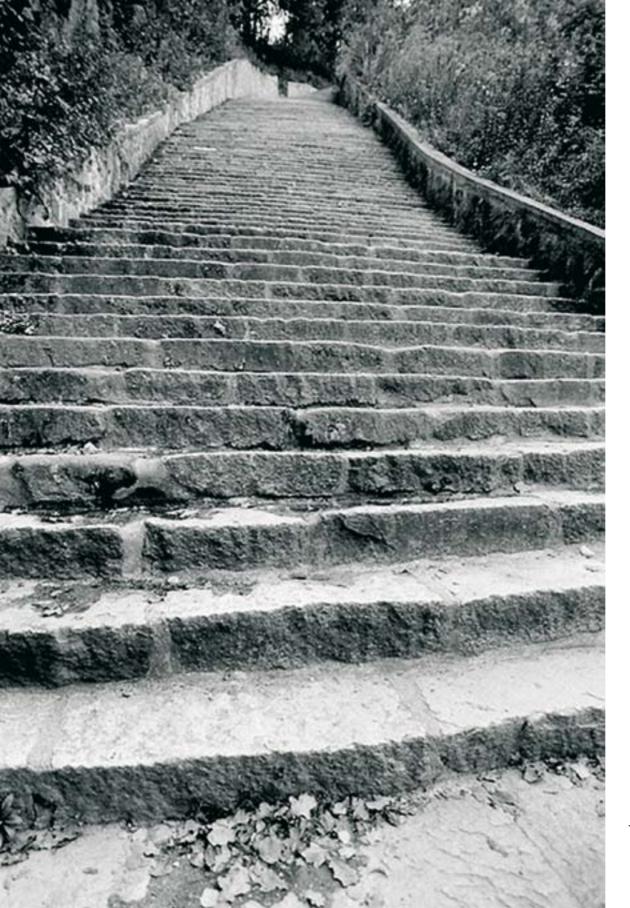


Anton Roca, Study for favolo ITALIA - Gifts, Project n.8, 2011, digital drawing, cm.130x84



tavoloITALIA 2011



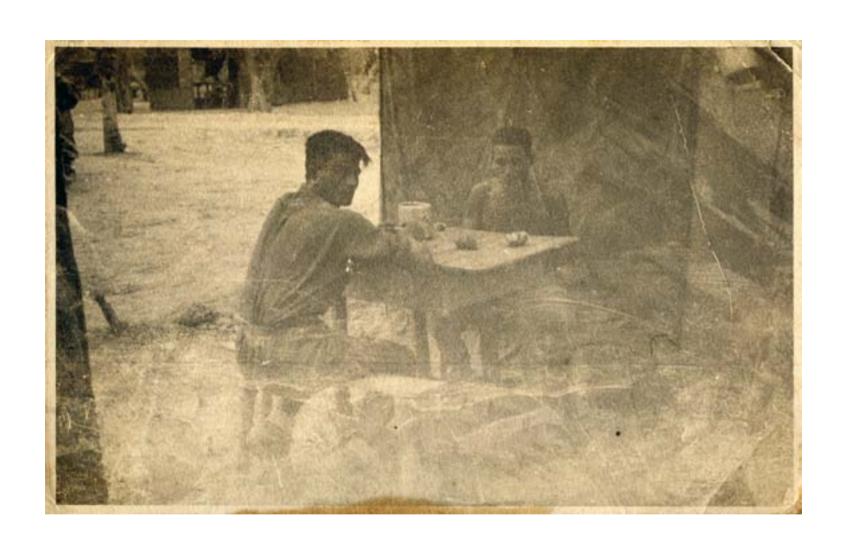


Gifts of Mario Limentani, The Stairway of Death at Ebensee.





Gift of Francesca Orlando. Books: (*The Leopard*, by Giuseppe Tomasi di Lampedusa, *The Betrothed* by Alessandro Manzoni and *Poems* by Alda Merini), because there's no future without culture.





Gift of Alessia, with the invisible children, Richard, Camilla and Valerio: a gesture, a mark on the sand, which soon disappears, just like the invisible children born in Italy, who aren't given citizenship.



Gift of Boban Trajkovic, Dragana and their daughters Esmeralda and Claudia. Wish for a home. Picture from the gypsy Camp Casilino 900, in Rome, while Romani community realizes the experimental housing project of Savorengo Ker (The house of all). During a stormy night, the house burned down.

The dossier Savorengo Ker, from which this photo has been taken, was incorporated as part of the project favol oITALIA, thanks to the gift of Stalker, Rom Community former Casilino 900 Rome, and the Department of Urban Studies, University of Rome 3.



Mario Limentani, interview with Anton Roca, Photo: Cristina Barducci









foto cassetto con fascicolo savorengo Ker

#### luogoComune

#### by Simonetta Lux

The artist Anton Roca has realized the sculptural installation " $+\alpha v$  of oITALIA", invited by the Community of Sant' Egidio to measure himself and his art against the ideas of exclusion and separation, realizing a creative work that includes figures neglected by contemporary society, and not only in Italy: figures and people who the Community embrace, cure, free from the impact of the persistent cultural prejudices that persist still today.

The challenge involves the artist himself following an interior path to which he has been inclined, conceptually and artistically, for at least 20 years: making evident an idea of art that is not concerned with the creation of an object abandoned to future fruition, but is a shared process, an art that jointly holds - first with one's self, and then with the 'other' - its relationship with reality,

The artist has trodden, from the start, a true and profound inner analysis, in order to reach a future public by necessity unknown, minding the gup between Ideal and Real, which is the kernel of artistic creation, the existing gulf between Ideal and Real.

"This happens", writes the artist, "in subjecting one's 'I', whose value is the simple one associated with whatever material of artistic work, to a series of experiences that are transformed into a life made available to the others". The materializations of this creative process come about, therefore, from the continuous inner transformation of the artist, in correspondence with the experiences which are undergone, using a mechanism comparable to the artistic medium. Therefore, the artistic "I" acquires a value, that is, so far as is possible, impersonal, neutral, and which goes beyond the sphere of the personal in order to meet the collective: from egocentric it becomes egotopic".

True to the egotopic artistic character it is fitting to cite "Parola di Luogo" (Word of Place) (1992) "in which," Roca asserts, "I have given a name to 'other' places responding to a need to reacquire them, retaking the sense that they had previously had in themselves".

An inner modification that goes *before*, and at the same time is chosen *from* the modality of expressive language. The relationship with the *other* is open.

Once commissioned with the work for the 150 years of Italian Unity, Anton Roca was moved immediately to empower the people with which he was confronted: individual subjects, persons, generally underestimated in terms of how many people exactly are neglected or forgotten in contemporary society.

It was not so much a matter of thematizing, or of attributing a content to a work to be realized, so much as understanding how to carry in the form of art and within the artwork a process of liberation from indifference. The artist has chosen to share, through signs and deliberate gestures, inserted like "languages" into his sculptural installation "for of oITALIA", various methods for the material and gestural compression of a mutual story - his own and of that other people and figures involved of memory and reflection, life experience, referring to various periods of a united Italy and, therefore, to Italy as it is today.



Anton Roca, *Parola di luogo*, 1992, photography, tar paper and neon on wood, cm 248x224

"\fav ol o\TALIA" is a new form of the luogoComune project, the latest development in the work of Anton Roca. What is "luogoComune"?

I cannot put it better than in the words of Anton Roca himself:

"By luogoComune I mean those places and/or spaces that, for factors inherent to their nature, are easily recognisable to all. Spaces and/or places in which all diversities merge, without being forced, but as the expression of one natural normality of 'ancestral' character' and, in this sense, common to all.

*luogoComune* is also a method of aesthetic and ethical action, put into action during the course of collective work. Characterized by the interaction between participants and the ability to take advantage of the instruments of reflection, comparison, sharing and encountering. This initial phase is valid from the start to the end of the project.

The idea driving luogoComune, is to activate a creative collective course through which it would be feasible to make comparison with a given territory: that of belonging, of election,... and to the human and social fabric that it inhabits. Finally, to make emerge elements of cohesion under the aegis of an aesthetic, as well as an ethical, action.

The founding characteristic of this course is that which picks out one luogoComune from all of the realities that will share



Anton Roca, tavolaEuropa, 2002, lambda print on photographic paper on forex, cm.400x100, permanent exhibition in the hall of Palazzo Albornoz, seat of the Municipality of Cesena (Cesena)

in the collective creative course and, in so doing, to activate one strategy that brings forth an action in line with logic of the *luogoComune*. In order to carry out the entire planning procedure and to reach its common fixed objects, the necessity to construct a stable working group and to activate an coherent operative modality was agreed.

I started this course of work at the beginning of the third millenium, in Cesena, in light of two important facts: one, the change that happened inside the social components of the territory of Cesena, due to the influx of migrants and, two, a personal reflection in which I felt the strong requirement to go beyond the solipsism of the creative fact. To surpass the decadent aesthetic and the inefficacy of many individual exercises that are limited in their benefits to the artist.

The first stage of luogoComune focused on the changes happening at a social level in the local territory of Cesena - but with one eye focused upon the Italian territory and the developing new European social fabric - and involved many migrant associations present in the city and some of the local services, activated by the Councillor for Social Politics in the

same administrative area. Jointly we focused on newly arrived immigrants.

Among the migrant associations were: Yakkar, Mammafrica, ADI (Associazione Donne Internazionale - The International Association of Women), Edo, l'Oeil de retour and Altra Medina Altra città (Another Medina, Another City). Among the services: Spazio Donna (Space for Woman), Centro Stranieri (Centre for Foreigners) and the Consulta dell'Immigrazione (Immigration Consultnacy). As well as the collaboration of the Cooperativa Mappamondo (Cooperative World Map) that managed the services activated by the Council in Ravenna.

The whole planning procedure spanning two years (2000 - 2002) was presented in a conclusive exhibition, enriched by a nourishing programme of collateral events, realized by the Galleria Comunale di Palazzo del Ridotto (The Municipal Gallery of the Palace of Ridotto) between 30<sup>th</sup> November 2002 and 6<sup>th</sup> January 2003.

The main element utilised in this first project, was the table. As can be seen here, in the photographic image "ta-volÆuropa", which is today displayed permanently in the entry porch of Palazzo Albornoz, home of the Municipality of Cesena. Other stages for this course of reflection have been proposed in Reus and Berlin. With the purpose of strengthening the European character of reflection proposed through the project *luogoComune*".\*\*



Anton Roca, favoloITALIA, work in progress, 2011, wood and corten steel, about sqm.30

Roca tells of the successive developments in the form of luogoComune:

"Other phases of this course of reflection have been proposed in Reus and Berlin, to reinforce the European character of this reflection proposed in the course of luogoComune.

Reus, Catalonia, November 2001

Two modalities:

- through the involvement of one class at the Istituto di Scuola Superiore IES Baix Camp. Via an internet link with Berlin, the students have published directly, on the site of the Netdays initiative organized by the Centro Culturale Ufafabrik, their opinions in relation to the modification of the social fabric of the Catalan city.
- The exhibition of tavolÆuropa, in January 2002, in the same scholastic institute.

Berlin.

- In the UfaFabrik International Centre of Culture in Berlin, the project has been hosted, under the initiative Netdays, on the occasion of the world convention centres for the arts, Res Artis, September 2005.

luogoComune # 2 has given continuity to the first stage opening itself up to the participation of other artists that were formed into a permanent group and who have taken part in the project between the months of October 2006 and March 2007.

The focal point of interest for this stage of the luogoComune projects is multiculturalism as a reality, rather than a chimera: we live a territory, both Italian and European, which IS multicultural.

From our origins, as the historians teach us.

<sup>\*\*</sup>Anton Roca, in *luogoComune*, Cesena, 2002.

In "\favolololTALIA" the form/course - because we must refer like this to the process of realizing the work, up to the final result that is material and conceptual, visible and invisible both at once - was precisely an opera (in Italian opera means 'artwork', as well as Operatic performance, i.e. the process of making was an artwork), which started from the identification of the luogoComune in question, that is: the unity of Italy, as seen today. But it was also a question: is Italy united, today?



Anton Roca, favoloITALIA, during the trial placement of corten steel gauges

Anton Roca entered into this *luogoComune* fascinated by *a* group of people that feel part of Italy *but who live at its margins*. Following meetings and stories exchanged between them, Roca felt the voice of beauty, the aesthetic, the making of art, from the people at the margins of Italy who could now make felt the way in which they live in this luogoComune, Italy; and the way in which *they would want to live* in it.

The result would have to be a collective work.

The result was above all a unitary work, empowering, certainly; an expression of unexpressed desires, or of aspirations for a change in Italian culture, and the expression also of lived experiences and memories hidden in the depths of the soul.

They have served to bring the artist close - right the beginning of the work - along with the guidance of the Community, among the Roman locations of separation, of exclusion, of enclosure, abandonment and forgetfulness.

Disabled people, migrants, Roma gypsies, ex-inmates, the elderly, the homeless, ex-concentration camp inmates: whoever was there to speak, narrating life and the difficulty of living within the Italian territory, in diverse moments and situations. This phase of work has been very important, in order to reach the two phases in which the people involved properly enter into the work - the sculpture farololar

The work itself made up of twenty old tables - the number of regions there are in Italy - and of a large geographically precise outline in Corten Steel superimposed over the tables: it represents Italy geographically but also the idea of a material and conceptual Italy.

There were two phases in two moments which were conceptually and geographically different.

In the first moment or phase, the people working with the artist chose to condense their stories, or desires, into a gesture and a *gift*. These people gave traces, fragments, objects, linked to the symbolic synthesis of their message on Italy. And they put such gifts in parts (table drawers) of the sculpture that they chose together with the artist.

In the second moment, they enter into the same work, living it, living, that is, the Italian territory, preparing him or herself with a gesture, each drawn from the great history of European art.

In this way a 'tableau vivant', entitled "abitare favoloITALIA" ('to live favoloITALIA') has been captured by the artist in a large photograph, exhibited in full scale in front of the sculpture like a great installation.

Over the sculpture "favoloITALIA", and in the darkness under it, Anton Roca has prepared two neon "signs", one mapping a line from Rome toward Dachau, the other from the far southeast, toward Italy. They represent deportation, migration.

With "favoloITALIA" and with the installation "abitare favoloITALIA", Roca and his friends send us more layers than messages and more layers than sense: we find ourselves in front of a united Italy, but made of many disjointed and disassociated pieces.

We find ourselves in front of an Italy made of incredible stories, more or less painful, more or less resolved, all however, taking place within the beloved Italian territory, united within it.

We find ourselves in front of a unity of the present and the past: the artist has plotted the threads of a great ancient and modern artistic culture, Italian and European, which one can relive completely, fully considering these represented



Anton Roca, study for favoloITALIA - Inhabiting a territory 2011, project n.11, 2011, digital drawing, cm. 130x84



# tavoloITALIA Abstare il territorio 2011

gestures to be 'now', in the present.

Agostino Di Pasquale appears, in the centre on the foreground as the figure of youth from Edouard Manet's "Breakfast in the Studio" (1867). On his left, Alessia De Montis is represented as Paul Gauguin's "Siesta" (1892-1894). To her right, on the foreground, is Ivan as the figure of Protest in "Aidez l'Espagne" (1937) created to support the Republican combatants of the Spanish Civil War by Juan Mirò. Again on the right, Stefania Zimmaro and Bose Bamawo, hug with affection and respect, as in the fresco by Giotto in the Chapel degli Scrovegni in Padua, "The meeting of Joachim and Hannah at the Golden Door" (1303-1305). Boban Trajkovic are Dragana Novakov are depicted in the "Déjeuner sur l'herbe" (1862-1863) of Edouard Manet, and their daughters Esmeralda and Claudia as, respectively, the "Women of Thaiti (on the beach)" by Paul Gauguin (1892-1894) and as the little "Paul en Arlequin" (1924) by Pablo Picasso. Edda Zordan is presented as "Madame Clementine Stora in Algerian Dress" by Pierre Auguste Renoir (1870) and on her back leaning in the opposite direction, Juan Espinoza Badajos, as "Luncheon of the Boating Party" (1881). Francesca Orlando and Ahammed Mohamed Taizuddin are bent over an open book, as the group of philosophers in the "School of Athens" by Raphael. Mario Limentani is the noble figure from the grand painting of Pellizza da Volpedo "The Fourth Estate" (1898-1901).

Aurelio Bagaglini, as the thoughtful boy sat on the shore of the river in "Bathers at Asnières" (1884) by Georges Seurat and Giuseppe Pisu semi-extended as in "A Sunday Afternoon on the Island of La Grande Jatte" (1884-86).

Sergio Calvello and, to his left, Nana Estateshvili, are respectively in the pose of the "Flagellation of Christ" and the "Madonna del parto" by Piero della Francesca (1415-1492). To their right, Aniello Bosco portrays himself as the infirm figure from the fresco by Masaccio "St Peter healing the sick with his shadow", painted between 1425 and 1427 in the Brancacci Chapel in Florence. To their left, Hirseyo Tuccimei poses as "The Scream /Skrink" (1893) by Edvard Munch.

Lastly the artist himself, as Diego Velázquez in "Las Meninas" (1656) is reflected in a mirror, at the foot of  $+\alpha v$  of oITA-LIA, thus inserting himself amongst the new diverse friends.

To "inhabit ∤avolo|TALIA", together.







#### Anton Roca, portraits

Anton Roca, portraits Biographies

## Agostino Di Pasquale





### Ahammed Mohamed Taizuddin





#### Alessia De Montis





#### Aniello Bosco





# Aurelio Bagaglini





# Boban Trajkovic





### Dragana Novakov





# Claudia Trajkovic





# Esmeralda Trajkovic





#### Bose Eghosa Bamawo





# Edda Zordan





#### Francesca Orlando





### Giuseppe Pisu





### Hirseyo Tuccimei



Anton Roca, Portrait of Hirseyo Tuccimei, 2011

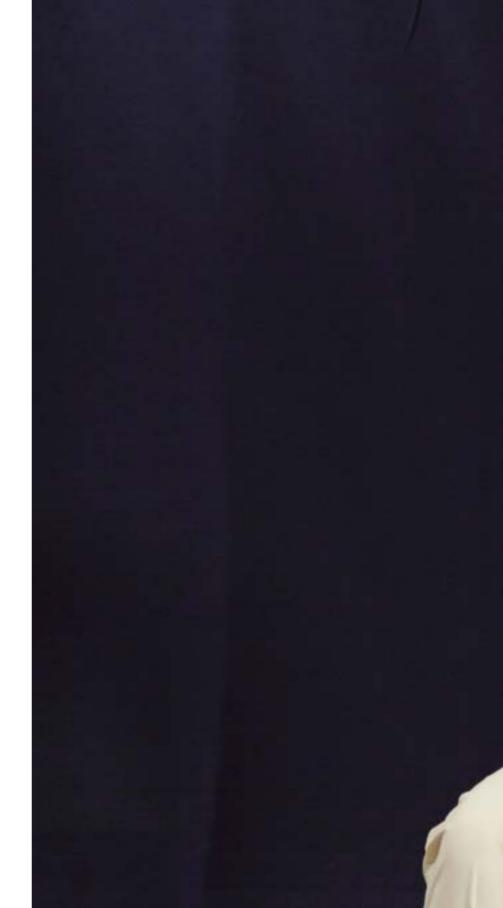


#### Ivan Marciano





# Juan Espinoza Badajos





#### Mario Limentani





#### Nana Estateshvili





### Sergio Calvello





### Stefania Zimmaro





Biographies of those who took part in the work of Anton Roca, a few excerpts from interviews and talks. A Portrait of each one has been realized by the artist and reproduced in this catalogue.

The full interviews and talks will be published in a special booklet.

## Agostino Di Pasquale

"I was born on September 22, 1910. I just turned 101 years. I went to a lot of trouble for freedom; I suffered very much." That's the way his interview with Anton Roca begins. From Andria, his hometown, Agostino moved with his family to Rome, where he studied and cultivated his passion for cycling, joining the Italian Cycling Federation. In 1939, before going to war, he got married. His wife had just given birth to their son, when Agostino was enrolled and sent first to Albania and later to Greece with Company 104 Marconisti (Wireless Operators).

"From Kalamata, after September 8 1943, they took us on board with the promise to return to Italy. The ship was bound for Germany. In October, we arrived at the prison camp in Meppen, where I worked for 22 months in a former caterpillar and a farm-vehicle factory, converted into a war material factory.

Our sustenance was two slices of bread every three days. After the American liberation, on November 11 1945, I started off on foot, and after a two day march, I reached Innsbruck, from where I went to Bolzano by freight train. On entering Italy I was fumigated, and in Bolzano I got a ride to Rome by truck. Once in town, I got on number 11 bus and went back home to my wife and my son.

Agostino is proud to have refused more than once to collaborate with the Nazis during his captivity and that's why he has recently been awarded the Gold Medal of Honor, and received the title of Knight of the Order of Merit of the Italian Republic. After the war, he settled in Rome, and began working as a driver and then as a taxi driver. He

was living with his wife and two children in a house at the heart of the Garbatella. When he was left a widower, owing to the sudden death of his wife, he welcomed home his daughter Anna and his grandchildren. He experienced a moment of great distress when his eldest son died in 2009. In this moment of difficulty, Agostino met the Sant'Egidio Community, and made good friends with many people, living many moments of meeting and prayer. Today, his blue eyes are shining again with joy and serenity. When you ask him for his secret to get to the age of 100, Agostino answers with his recipe for health: a well balanced diet, exercise, wisdom and culture, which should never be neglected, and finally, the most important "to be loving and friendly to everybody."

## **Ahammed Mohamed Taizuddin**

Ahammed was born 34 years ago in a large family at Brahmanbaria (Bangladesh), where he studied "Chemistry for the tanning industry" for four years. He worked for two years in a tannery and in 2004 made up his mind to emigrate to Switzerland to continue his studies.

Here he attended a course in Industrial Management, but was forced to abandon his studies after a term, because they were too expensive. He arrived in Rome on January 8, 2005, and, like many others, had to wait for five years for his Residence Permit. "In Italy it's very difficult to achieve recognition of academic qualifications obtained in your home country," Mohamed said during the interview with Anton Roca; "even access to training stages is not at all easy, but the quality of work depends on the training of workers: the higher the level of its workforce, the better the future of Italy."

He met the Community of Sant'Egidio as soon as he arrived in Italy, while working at a gas station at night, and immediately he began to attend the free school of Italian language. "By remaining ignorant I can be of little use to Italy and it is not good even for myself."

After several years of work at the fruit and vegetable market, from March 2011 he began working as an operator in the program "Long Live the Elderly" in the Community of Sant'Egidio, an active monitoring service for the prevention of loneliness and mortality of the elderly.

## Alessia De Montis

Alessia is a 31 years woman with Down syndrome. She lives with her parents, her sisters and two most beloved nephews. During the interview with Roca, Alessia said poetic words to those children, who in Africa are not recorded in the Civil registry and those who, though born in Italy, have no citizenship.

Invisible children, you can't see them, but they are there. They are seeking hands.

Hands you have to shake and accompany.

Hands that play, because far from war.

Hands that write, because they can go to school.

Invisible children, you can see them, but they are not there. They aren't children, because they have no mother or father. They are not citizens, and yet were born in Italy.

Alessia attended high school and got a degree in hotel management. Since then, she has been looking for a job, often taking apprenticeships, which have not materialized in actual jobs. She has a friendly and very outgoing personality, she loves to paint, especially using words, written on the canvas with great patience and precision. The work she is most proud of, is titled "Ascolto" (Listening). The word is repeated continuously without any interruption to invade all the space of the picture.

## **Aniello Bosco**

Aniello was born on July 3, 1984 in Rome. Since his earliest days of life, he was diagnosed with congenitalarthrogryposis multiplex, a syndrome that forces him to live in a wheelchair. During one of his first hospitalizations at the

Bambin Gesù, he met some young people of the Sant'Egidio Community and for quite a few months he lived in a family house for children of the Community. Later, he went back to live with his parents, went to school, up to junior high level, in the quarter of Tor Bella Monaca, on the far eastern outskirts of Rome.

Since the late 90's he started attending the Laboratories of Art in the Community of Sant'Egidio, which has become for him a place of friendship, but also of learning. On the occasion of the celebration of 150 years of the Unification of Italy, he studied the history of our country and, as he said in the interview with Anton Roca, was touched by "the hidden truths. Italy is injured - he said - the manslaughters (of Bologna, and the murders of judges Falcone and Borsellino ...) are like open wounds." He currently lives in a Family House of the Community of Sant'Egidio in the Monteverde quarter, along with other disabled persons.

## Aurelio Bagaglini

Aurelio was born March 16, 1968 in Rome. He has a family history of hardship: the early failure of his parents, a disabled brother, the loss of public housing. Aurelio's first meeting with Sant'Egidio dates back to 1983, when he was a junior high school student and attended afternoon school run by the Community in the quarter of Torre Maura. Since 1985 he began to take part in the activities of "Gli Amici", The Friends. He currently lives in a Family house of the Community in Capodarco and works as a commis de cuisine at Friends' Trattoria; he's very proud of his autonomy.

In the art laboratory of the Community, he realizes his works of art with recycled materials, that he is always searching for and collecting. Commenting on one of his paintings in 2003, he said: "Disabled people sometimes cannot say in words what they think. Me too. But I can draw. The most beautiful things I have ever said, were with my paintings. "Aurelio's painting reproduced the image of the great Matisse, already elderly, who was sculpting, seated perhaps

in a wheelchair at his home. "That old man is disabled - Aurelio imagined - he cannot speak, but creates wonderful things." Even in the interview with Anton Roca, Aurelio focused on the lack of words for the disabled and has jokingly reproduced the sounds that surround his life, the sounds of the street and of his working environment.

Boban Trajkovic Dragana Novakova Esmeralda Trajkovic Claudia Trajkovic

"My name is Boban, I come from Serbia, but I was born in Rome. I belong to the Rudara culture, a minority among Romani people. I married Dragana, and we have two daughters, Claudia and Esmeralda.

I studied in Italy, until the age of sixteen, attending the first People's School of the Community of Sant'Egidio, today called the School of Peace. Later, I went to secondary school and for two years to a Vocational Institute. I had to fight for citizenship, which I obtained only at the age of 24, five years after my request. You attend school, you feel integrated, and then, at eighteen, you are denied the right of citizenship... It's a bit hard! Today I work as a cultural mediator in the Rebibbia Prison and I'm involved in the project "Right to School", managed by the Community, which supports school inclusion of Roma children. I have always lived (and I'm still living) in a gypsy campsite, but I have never gotten into trouble, as my parents have always supported me since I was a child. It's not we who choose to live in the camps, we are forced to. When they decide to get rid of a gypsy campsite in a given area, they send you away and you have to move to another camp. They don't give you the alternative of a house... I applied for public housing fifteen years ago, but I have not yet reached the 10 points needed to obtain it. The City of Rome doesn't consider the evacuation from the nomad camp as an eviction ...

Residence in a gypsy camp is an obstacle to getting a regular job, it creates distrust in possible employers. If you are jobless, how can you think of renting a house or of raising a mortgage to buy one? Today we can no longer live in camps. We must make the step to get a home. Living in a gypsy camp precludes any possibility for the future. My dream would be to live in a house, for the future of my two daughters. I'd like to see them growing up in a house ..."

## Bose Eghosa Bamawo

Bose was born in Lagos (Nigeria) in 1963. A clothing merchant for infants, in 1990 she decided to emigrate to Italy to support her two children and ensure them a right to a future. Equipped with a tourist visa, Bosa arrived in Rome by plane. Here she worked for many years as a maid and caregiver for elderly people to pay back the money borrowed for the trip.

The quite difficult approach to Italian society shines through her words: "We chose Italy, but Italy did not choose us," said Bose in the interview with Anton Roca. Working with elderly people, she explains, has changed her life: "I assist the elderly, I take care of them as if they were my own relatives. The elderly are our heritage, as they are the keepers of history. In my country, the elderly stay at home with their children. Here, instead, they are often alone." Bose met the Community of Sant'Egidio in 1996 and learned Italian at the Louis Massignon school. In 2002 she obtained a degree as intercultural mediator and now she is working as a mediator in the New Rebibbia Jail Complex. For many years, she has volunteered for the reception of immigrants at the Peace People center of the Community of Sant'Egidio in Rome. At the end of her interview with Anton Roca, she said: "I arrived with hope, but what you become later, depends on what welcomes you: a hand or a fist. The Community of Sant'Egidio has given me the opportunity to improve my condition and to help other people."

## Edda Zordan

Edda was born in Rome April 18, 1936, and never left her beloved hometown. Until the outbreak of World War II, Edda lived near the Ostiense station, via del Porto Fluviale 45. Because of the bombing in 1943 that devastated some neighborhoods of the capital, she moved into a basement with her family and some acquaintances of hers of Jewish origin: she shared with them a makeshift house, as well as risks and fear during the Nazi occupation. Only at the end of the war Edda was able to return to her home.

"I have always worked - she said in the interview with Anton Roca - from a very early age. I worked as a maid in four houses. I have always liked houses!

I have never had the superfluous, but I have never missed the necessary. I have always been happy with my condition and what I had in life. "

From a cleaning woman, Edda became a barmaid in her brothers' bar in Piazza Gioacchino Belli and then in Via della Lungaretta, in the Trastevere quarter, where she moved after her marriage. "Working at the bar was tiring - Edda says - but I did it with pleasure." Many "trasteverini" (people from Trastevere) still remember her behind the counter, always polite and friendly, just as she is now, that she has retired. She kept living in Trastevere until 2007, when she and her old mother were evicted from their apartment. Edda was desperate, she didn't not know how to cope with that situation. On that occasion, she met the Community of Sant'Egidio and a deep friendship was born, a friendship that will support her in times of need. The operators of the Long Live the Elderly Movement, helped her to find a lawyer. When she could no longer postpone the eviction, she was invited with Vincenzina, another elderly woman in difficulty, to live in an apartment in a "sheltered" house of the Community of Sant'Egidio, at Via Fonteiana. "It is a building they call the Little Castle - Edda says - and I feel ... like a Castellana".

## Francesca Orlando

"I was born in Rome, November 25, 1985. I attended the High School (Liceo scientifico) and I am getting a degree in Spanish Translation at the University La Sapienza. I live in Spinaceto, a suburb south of Rome. I met the Community of Sant'Egidio through the School of Peace, that in my neighborhood welcomes Italian and Roma children in order to educate them to peace and coexistence.

I opened my eyes! I discovered a different reality from my neighborhood. What we know so far about the Roma people is mostly the result of prejudice. I discovered that the reality of my neighborhood could change even through my being different. Today I work together with other university students in the School of Peace of Torpignattara. I belong to a generation that is sometimes considered to be pessimistic, disengaged and unwilling to emerge. I feel touched because I think that we young people, migrants and second generation Italians, here in Italy and in Europe, can build our future starting from the realization of a true coexistence. A change in mentality is required. So I think it is increasingly important and mandatory to invest in culture. In a society where sometimes the value of education and knowledge is in danger of getting lost, we need once again to focus on a culture that comes from the study, the interest for the world and for the others, from the knowledge of history, that allows us to have a deeper understanding of our time and offers us the tools to build our future and the future of the world."

## Giuseppe Pisu

Giuseppe was born in Sardinia, near Cagliari, March 19, 1943. At 18, "bewitched by the Moira Orfei Circus", as he himself says in the interview with Anton Roca, he left Sardinia and began to travel the world with the circus caravan. His work took him to live in countries as diverse as Eastern Europe (in Tito's Yugoslavia, but also in Hungary, Bulgaria, Romania, Poland), the Maghreb (Morocco and Tu-

nisia), but also Turkey and Jerusalem. His long pilgrimage ended in Iran where, in 1979, the circus was placed under sequestration by the Khomeini regime. Giuseppe was arrested and imprisoned for five months in Tehran. After serving his sentence he made up his mind to go back to Italy and, after a daring journey he landed in Rome. Here, he found himself alone, no job, no money and eventually ended up living on the streets. The experience of the times in which he was traveling with the circus has marked him, he thinks he has received much in his travels, so much to say, during the work in progress of the project +avolol-TALIA: "Italy? It is only a mirror of what I got around the world." His meeting with the Community of Sant'Egidio dates back to 1983, Termini Station, during the distribution of sandwiches the Community organized weekly. Giuseppe is highly bound to his new friends, he is faithful to his appointments with them. He wants to help: he starts handing out dinners, serving at the table of the Community at Via Dandolo. When the Community opened a house in Via della Cisterna to offer shelter to some homeless people, he was among the first ones to be accepted. In the new house his sympathy and friendship helped to create a welcoming environment for other guests. From several years Giuseppe has resumed contact with his family of origin, going from time to time to Sardinia. But he always comes back to Rome, to the house in Via della Cisterna, where he found a new family.

## Hirseyo Tuccimei

Hirseyo was born in Rome 26 years ago in a family of Somali immigrants. She spent the early years of her life hospitalized in various hospitals and institutions because of her disability, later diagnosed as a spastic tetra paresis with cerebral leukomalacia, that has totally impaired her verbal expression and autonomy. She was adopted at the age of three. The meeting with the Community of Sant'Egidio and her adoptive family has been crucial, as she claims.

By the age of 12, she began to communicate through the Augmentative Communication strategy. This has enabled her to study: today she is about to graduate in Humanities (Land Science and International Cooperation) with a dissertation on Somali women's life stories. In her writings, some of which are in this catalog, often she starts from the condition of the migrants to offer deep reflections on our country's life. Even during her interview with Anton Roca, she referred to the desperate journey that many people have to make to come to Italy:

I thought

of the desperate poor people dying on our closed borders closed cities

fences and walls everywhere closed hearts, paralyzed by fear.

Her look is not indulgent, but opens the vision to a different future for our country: I say Anton plays with everything. He has to present Italy as the endless embrace of a mother who accepts all.

## Ivan Marciano

Ivan is 35 years old and has an intellectual disability. He has been doing many internships for job placement, waiting for a real job, but so far Ivan has been unable to realize this dream. To Anton Roca he said "I'm doing an internship at the Forlanini Hospital as a laborer in the warehouse." To while away the hours, he takes long walks, on foot or by bus, along the streets of his neighborhood, the Magliana, in Rome. For this, he said in the interview:

"To Italy I would ask for more services:

More trains

More undergrounds

More work"

He calls everybody by name and remembers all the special features of all. For him the central moment of the year is the Christmas lunch with the poor organized by the Community in the Basilica of Santa Maria in Trastevere. Throughout the year Ivan does the countdown to know how many days are left. "Today, that we are opening the exhibition, "us, Italy", 22 days more to Christmas lunch!"

Ivan communicates in an explosive way his happiness to be with his friends and to have met Sant'Egidio. You can tell this even from his portrait in this catalog, where you can look at him while saying: "Great!" as he often does.

Juan is 44 years old. Peruvian, married with a daughter of 14. Majoring in mathematics, he held several jobs in his hometown, Lima, until the decision to emigrate to Italy in 2000, wanting to offer his family a better life. "It was at school, in 1982, that I discovered the existence of Italy, its artistic heritage, the Roman law ...". His first job was as a caretaker of an elderly lady, who was afraid of being alone: "She, alone, but with a daughter. Me, alone, without my family."

After some time, he lost his job, and became a homeless person. It took him eight years before finding another home. In the meantime, he worked for 9 years as an assistant cook in some famous hotels of Rome. In the interview with Anton Roca he said: "I learned Italian culinary traditions - and I acquainted them with my Peruvian recipes. You know, it is a sharing, a meeting. At first I thought you were... Now that I know you, you look different." He met the Community of Sant'Egidio in 2000, and graduated in 2002 as an intercultural mediator. In 2008, his wife and daughter joined him in Rome. He volunteers for the reception of immigrants in the Peace People center. "Being together fills your loneliness, now we are a family".

## Mario Limentani

Mario was born in Venice in 1923 in a family of Jewish origin. In '37 he moved to Rome, a year before the promulgation of racial laws, and underwent its immediate consequences,

including expulsion from public schools. When Italy went to war, he was not drafted, as he was a Jew. During the German occupation, on October 16, 1943, he was living inside the Roman ghetto, Via della Reginella, 10. He saved himself and his family from Nazi looting, escaping through a tunnel that led from the kitchen to the basement. They were able to hide, all but his sister, who was pregnant. Later, Mario and his family found occasional shelters and obtained false documents. But that didn't guarantee salvation. At the end of October he was arrested by two fascists, because he had no documents on him and was identified as a Jew. He was brought to the prison of Regina Coeli where he remained until his deportation: "The train left Rome on January 4, 1944, and three days later, on January 7, it arrived at Dachau where I stayed for four or five days. Sealed, along with others, in a narrow space with a water tank in the middle.

On 11 January 1944, we were transferred by trucks to Mauthausen. At the roll-call, they screened the Jews from other prisoners. I was forced to work in a quarry, from the day after my arrival at Mauthausen. In this mine there was the so-called Stairway of death, with its 186 steps, we had to climb, carrying on our shoulders 25 Kg boulders.

In Melk, I worked in a factory of military vehicles. Along the walking path to get there, people were throwing stones at us. In the camp of Ebensee they were about to throw me into a mass grave, when they left me on the ground, because the camp had just been liberated by allied forces. It was May 5, 1945. A boy of 16 years took me back to the barrack and took care of me. I was 20 and weighed 27 kg and 200 gr. I couldn't speak. I was reborn one night when I woke up suddenly and regained consciousness of myself. 'Mom, I'm alive!' I yelled.

On 27 June 1945, I went back to Piazza Giudia ... 'The Venetian is back!' cried someone."

Since then, Mario has never left Rome. Every year, on October 16, he takes part in the memorial day organized by the

Jewish Community and by the Community of Sant'Egidio. He is one of the few Roman survivors of the death camps: he is a passionate witness to the horrors of the Holocaust, especially with young people, because they must not lose the memory of the enormous suffering inflicted on millions of people because of racial hatred.

## Nana Estateshvili

In the golden vase you can get the running water. In the ugly vase, you can find the hidden gold. (Georgian aphorism) Nana was born in 1971 in Tbilisi, Georgia. She studied industrial technology in her hometown, she got a degree in Fashion Studies and worked as a secretary in a chemical laboratory for 4 years. In 2003, shortly before the Rose Revolution, she made up her mind to emigrate to improve her future. She spent the first 4 years in Italy as illegal and learned Italian idiom working as a babysitter. Later, wanting to get an official certificate, she looked for an Italian school in Rome, so by chance she met the Comunità di Sant'Egidio. In 2008 she qualified as an intercultural mediator, and has since worked in an integrated cooperative as a home caretaker for elderly in the historical center of Rome. In this interview, released during the preparation of the installation/sculpture favoloITALIA, she said: "The elderly are vulnerable, because they don't seem happy with what they had in their life. It is important to start with a smile! It all depends on the availability and attitude that you show at first meeting. Some people believe in an idea, but they feel otherwise and the way they behave ends up betraying them. Sometimes, in a golden vase you can get the water running ... However, I have a positive outlook: I have learned to defend myself ." She volunteers in the Peace People in Rome.

## Sergio Calvello

Sergio was born at Somma Lombarda on July 23, 1942, but lived and grew up with his family in Livorno. He worked abroad for an Italian oil refinery company and his work led him to travel for many years. When he finally settled down in Italy, he went back to Livorno, but due to a series of negative circumstances, at the end of the nineties, he had to leave his job and his family. So, at the age of 57, he went to Rome and tried to get by doing small jobs (bike rental) and living in makeshift shelters. In his conversation with Anton Roca, during the project favoloITALIA, Sergio said: "When you're on the street, the real problem is where to sleep. Sleeping in the open is always a crucial problem and not only when there is the so-called cold emergency. I was an homeless, but I tried not to live like a bum. An aggression during the night changed my life, making me come to my senses and re-emerge. I met the Community of Sant'Egidio, which for me was like a raft in the shipwreck." During a "cold emergency "Sergio was welcomed for a night in the shelter facilities of the Community. "I worked for 35 years - he went on - among the whistles of four sirens: the start of work, lunch break, resuming work in the afternoon and the end of the day." He would like to apply for retirement, to obtain the INPS pension, but he has no fixed abode. They proposed him to take up residence at the canteen of the Community, via Dandolo. After a while, he also got a retirement pension. Today, thanks to the benefits received, he can pay a small room for himself and has found his peace of mind. To while away the hours, he volunteers for the Community, and from time to time, he devotes himself to his great passion: fishing.

## Stefania Zimmari

Stefania was born in Rome in 1948, and grew up in public housing on the outskirts of Rome.

The meeting with the Comunità di Sant'Egidio was in the late eighties at the canteen of the Community, Via Dandolo. Stefania began to attend the mess with her husband and son, little Andrea. The family had serious economic difficulties. After some time. Stefania parted from her husband and Andrea began having serious health problems, so she was forced to foster him with a family home to ensure him all treatments. In the interview with Anton Roca she said: "Immediately, I found myself on the street, because I trusted the wrong people and their false promises. After losing everything, home, work, affections, it's hard to regain trust in the others. You see everything black. When I met the Comunità di Sant'Egidio, I realized that we are all equal, we all need help. As the foreigners who come to the canteen. They arrive in Italy by boat, and they are many. Even we Italians are many and we too need to be helped: we are just like them, there is no difference."

## Thanks to:

Simonetta Lux, for all that she has given to me Cristina Cannelli, for her presence Antonella Antezza, for her accurate support

Special thanks to

Maria and Marco

Alessandra, Eddy and the entire staff of The Friends' Trattoria

The Community of Sant'Egidio, for the responsibility they assumed in supporting this project My wife, Cristina Barducci, for her unconditional support

Luca Miti, for his critical and disinterested collaboration

Finally, each of the 20 people who have allowed me to be part of their lives, at least for this short stretch.

Anton Roca

# From Prejudice to Creative Judgment

From Prejudice to Creative Judgment
The Courage of Initiative
by Alessandro Zuccari



## From Prejudice to Creative Judgment

## The Courage of Initiative

by Alessandro Zuccari

This is not only an exhibition of disabled artists or the result of "art-therapy", it is something different. As a matter of fact, it stands as an essential step in a long liberating and creative process in which "disabled people" or the "others" (the so-called normally endowed) are no longer typified as such. Rather, thanks to an equal and dialogical relationship, they become the protagonists of that complex totality of action and thought Simonetta Lux defined as "a sort of Great Relational Artwork", which has now come into an open exchange with the art circuit and with recognized artists such as Anton Roca\*.

All of this started from the initiative of the Community of Sant'Egidio which, since the beginning of its activity, has been taking care of disabled and marginalized people, unveiling their hidden troubles, their stories of exclusion and humiliation, but also their unexpressed thought, their hidden expectations and energies, their desire to express themselves, their *joie de vivre*.

Soon we realized that first of all we needed to get close to them, instead of rejecting them, to break the wall of prejudice that weighed on them and recognize them as persons rather than subjects defined by their physical or mental deficit. We started by changing our way of thinking and assuming a radically different cultural attitude: treating them as our peers, discovering them as intelligent, capable of deep thoughts and feelings, defending their dignity and denied rights, fighting a widespread mentality of contempt. An old cultural habit, an old world, had to be changed profoundly. It was not only a question of giving protection and assistance, even though these were indeed necessary, but of taking a shared initiative with and for them, an initiative undaunted by the inertia of the political and institutional world accustomed to ignoring and marginalizing them.

But how could all this be carried out? We reread the Gospel precept "You shall not call you brother *raka*" as if discovering it anew. The word *raka* and the sentence comprising it come from the Gospel of Matthew (5:22) and it is significant that the original Greek text has maintained this typical Semitic expression: *rakà* in Syriac, *reqa* in Aramaic. *Raka* is an insult that cannot be literally translated and it means "stupid, mentally deficient, brainless, useless". Such an insult was used to scorn people with mental deficits and physical or behavioural disabilities, and it is not irrelevant that the Gospel of Matthew, immediately afterwards, also censures the use of the word "fool".

<sup>\*</sup> On the experience of the Laboratories of Art with the Community of Sant'Egidio and on their itinerary, see the essay written by Simonetta Lux in this catalogue.

But there is more. Jesus of Nazareth accomplished a paradoxical and revolutionary operation: not only did he prohibit such insults but he judged them so serious as to consider them comparable to homicide. Actually, after saying "whoever murders will be in danger of the judgment" (Mt 5:21), he declared that whoever called his brother *raka* would be in danger of the council: something unprecedented, since nobody was ever brought to trial for using such a common epithet.

Jesus' position needs to be viewed within the mentality of the time: whether Jewish or Hellenistic, it considered children and disabled persons as having no value and being less than human. It is not by chance that in this context the term *adelphòs*, 'brother', is introduced, which designated also a fellow countryman or member of the community in the language of the time. Therefore, "You shall not call your brother *raka*" appears, for the first time in history, as a dedicated defence of the physical and mentally disabled person that breaks the atavistic conception which made them the object of a culture of contempt, with its set of well known consequences.

It is unnecessary to re-examine the idea that the ancient world, and not only the ancient world, assumed regarding disability (which has been well reconstructed by Massimo Fioranelli, and from a different perspective by Andrea Canevaro and Alain Goussot). It is sufficient to recall the archaic Roman laws of the Twelve Tables, that prescribed: "Cito necatus insignis ad deformitatem puer esto" (visibly deformed newly born babies must be killed immediately). A practice reproposed five centuries later, in 41 A.D., by Lucius Annaeus Seneca in his De ira: "We suffocate the monstrous foetuses, we drown even our children, if they have come to the light disabled or anomalous: it is not anger, however, but common sense to separate useless beings from healthy ones". Nec ira sed ratio, the celebrated philosopher confidently affirmed, interpreting the spirit of the time, juxtaposing "healthy beings" and "useless ones": useless for work, for military service, for political life, for marriage and procreation.

If it is true that a form of protection for the weak was anticipated in the code of Hammurabi or in ancient Israel, only with the Gospels were disabled people recognized as *persons*, and, moreover, as persons that were to be considered, sustained and beloved as *brothers*. This brotherly relationship is realized not only with the prohibition on homicide, rather, it is founded upon what one thinks of the *other*, on what one wishes for him, including full dignity and the enjoyment of every right.

It is a radical change of mindset that turns consolidated social values upside-down: it is known that the Gospels give priority to the *last* over the *first*, to the *sick* over those that are considered *healthy*, and oppose the official culture of which Seneca is an exponent. This official culture separates "useless beings from healthy ones" and feeds a culture of contempt for the other, the *different*, its most tragic apex being the Holocaust and the Nazi extermination camps. More recently this same official culture has produced other conflicts with an ethnic or racial background, such as in Rwanda and the Balkans.

However, we must remember that there was "an Auschwitz before Auschwitz" - to use an expression taken from Henry Friedlander - in the sense that the majority of the extermination methods used in the Nazi concentration camps were 'tested' with the "euthanasia" of disabled and mentally impaired people, in which around 250.000 people were killed. It is not irrelevant that in 1941 Hitler closed this 'sector' of the extermination programme following a revolt by the Church led by courageous Bishop Von Galen, whose sermons were defined by the office of Nazi Propaganda as "the strongest frontal attack mounted against Nazism throughout its existence".

I have cited for its paradigmatic value and efficacy this exemplary - though limited - revolt, rooted in that evangelical humanism which uncompromisingly opposes the system of exclusion and repression, forbids contempt and breaks the atavistic fear of diversity, overturning the canons of beauty and health, and ultimately disrupting the concept of intelligence and normalcy.

Historical consciousness regarding these prejudices and their persistence up to the present day is the foundation of the actions of the Community of Sant'Egidio, even with regard to disabled people.

Why did we create the 'Art studios' for them? And among these the Art Studio Museum of Tor Bella Monaca, in one of the most deprived districts of Rome's periphery?

Why was the experience of the studios widened to include collaboration with artists of renown?

It all began in the early '70s, with Sant'Egidio's work in the outskirts of Rome and in the old neighbourhood of Trastevere, where it happened to meet people with physical and mental disabilities, who were not only victims of prejudice, but were often hidden for fear and shame by their own families, marked by a heavy social judgment and by a total lack of support and assistance. The only institutional response was - and partly still is today - their segregation in institutes and psychiatric hospitals. They were young and less young people, for the most part considered cumbersome and embarrassing presences, sometimes condemned through unfounded diagnosis, excluded from employment and discriminated against at school (the abolition of segregated classes came with Law 517 of 1977 that makes Italy the only European country providing, at least legally, full scholastic integration).

Among the many available I will provide just a few examples, one characterized by what we could define as a diagnosis without appeal, the other by a typical and unjustified imprisonment in a mental hospital.

Maurizio Valentini (1966) was marked by the stigma of an absurd and unfounded diagnosis that blocked him from access to employment. Who would have ever employed a young man who was certified an invalid in these terms: "due to the nature and degree of his invalidity he is a danger to his own health and safety and to those of his co-workers, as well as to the safety of the workplace"? After a long battle, this certification - furthermore never verified, nor legally confirmed - was cancelled. Today Maurizio works in The Friends' Trattoria, where he is a great and affable sommelier, and he is also an extraordinary photographer, as documented in the video made by Italian-Brazilian artist César Meneghetti.

Anna Maria Colapietro (1954), was interned for long periods in a psychiatric hospital. Incredibly she was there from the age of 3 to 20. She told us: "I don't remember why, but they brought me to the mental hospital, Santa Maria della Pietà. Not only once. They would take me there, then release me, then bring me back again. They said I was mad... tied me up and put me in a dark room; I screamed and they beat me". Today, Anna Maria, who only learned to read and write when she was 50, lives in a family home at Tor Bella Monaca in Rome, and paints vibrant chromatic works of art using "an expressionist code of flux, whose linguistic choices relate to her internal flow of conscience and thought".

But at the beginning, what could we do? How could high school and university students face up to often complex situations and react to these systems generating mechanisms of exclusion and suffering?

Immediately we asked ourselves: why is everyone so scared?

Actually, in approaching disabled people, we discovered in them unexpressed thoughts and an inner life that was generally ignored, as well as stories of uneasiness and fear, of abuse and defeat.

Ours was a naive but 'real' approach, that created a feeling of trust and parity. On the other hand, the novelty of our initiative consisted in privileging in the disabled person, the sick, even in the *monstrum*, the person who suffers, not the "useless" and repugnant being, but the person. With different eyes we looked upon the disabled person, the excluded. We approached them without any fear of contagion, participating in the pain of the *other*. The handicap, in fact, is not the product of destiny or of guilt, and nobody can be reduced to a manifest deficit: we always need to distinguish the *person* from the *symptom* and re-establish the unity of *body* and *soul*.

In this way one can break the stigma and the cycle of marginalisation, restoring trust and discarding the idea of the *dan-*gerousness of the patient, or of the physical and mentally disabled person.

In humanistic thought, as with the Gospels, the ontological equality of all humans is evidenced; the interesting choice made in this instance, however, was to accomplish a liberating action, breaking the perpetuating systems of minority and starting a course of emancipation. The person is thus rehabilitated and recovers his or her faculties.

Ultimately, it is a creative and paradoxical action: against every pre-comprehension, the barrier of inevitability breaks, and with it prejudice itself. The faculty to communicate is re-established: this entails igniting hidden energies, unexpectedly gifted to all people, even those who are considered the most "severe".

Miralem Pavani (1989), a mentally disabled young man of Roma origin put up for adoption, has severe difficulties with verbal communication. Today he writes on a computer using the Augmentative Communication method. In this way, in one of his first sessions, he wrote to us:

I want words

words to break silence

we take off and fly with prodigious thought that is not reproduced in words

a very strange idea, many think we are boring.

You reason little when your brain is full of sad stories.

Neurological handicap, for example, imprisons thought, it impedes gestures, words and thoughts from coinciding with the will. From here follows the judgment of stupidity. It is denied that people with disabilities are intelligent and have the ability to elaborate complex thought. Yet, paradoxically, those who have weaknesses in communication can find new forms to express their creative thought.

This was the course followed also by Daniela Parisini (1964). At the age of 10, due to family problems, she was confined in an institution for the elderly, where she lived for thirty years:

I lived for many years in an institution... What sense was there in this?... Away. I was a typical child, a child with dreams of going away, of being free, I don't know, I had this dream. In the institution unfortunately, I, ... it was a beautiful institution, but it was an institution all the same. I lived within those four walls and I didn't have any friends, I didn't have anything, no values, nothing. When I met the friends of the Community they began to teach me many beautiful things. The thing that struck me was this: to see the Community with disabled people, this struck me the most. I said: "My God - it struck me like lightning - why would the Community care for a person like me?". When I grew up I told everyone: "I want to go away, when I am 40 years old I want to leave this place, because I'm fed up with it".

And so it came about. When she turned 40 Daniela's dream came true: she left the institution and now lives in a beautiful apartment in the Roman district of Monte Verde that the Community of Sant'Egidio arranged to welcome Daniela and other people with disabilities coming from institutes or without a family. This was the turning point in a process of liberation that led to Daniela's participation in the Art studios, and made a painter of her in the original creative vein of a "dreamlike and surreal" streak, expressed through an abstract language.

The practice of breaking prejudices is actually a slow process, which finds in the formation and valuing of individuals the premise for an action of creative liberty where disabled people not only disclose to us their identity and depth, but also a way of critically observing the world.

On the methods and results of this experience Simonetta Lux, Cristina Cannelli and Massimiliano Mori speak equally in an articulate and diverse way.

To conclude, the secular thinkers (philosophers, pedagogists, physicians, psychiatrists, writers, poets and artists) that acted and theorized on the theme of difference and alterity, have retrodden that evangelical humanism that I have highlighted here. It may not always be recognised as such, but it constantly returns and is inseparably united to the practice of art and free expression, as stressed by Lux. Even this aspect of the course is slow and difficult. But after the disenchantment of the project of world transformation conceived by 20<sup>th</sup> Century avant-gardes, once again many artists appear involved in a process of change: they no longer create only objects, they activate creative courses that involve themselves and the others as subjects. No longer only declarations of intent, but the activation of procedures of subjective and cultural change that produce this dialogical and effective meeting with artists working on the same wavelength.

The laws Glossary of pathologies

## The laws

## Inclusive Education Laws and Right to Education

In the Italian legal system the process of recognizing disabled students' right to education started in the 1960s. Disabled students had right to enroll and attend the different school levels, but at the time they had still to do so in special schools and special classes. In the sixties, the laws 1073/1962 and 942/1966 provided appropriations for such special facilities. The law n. 1859 of 31.12.62, set up a single middle school and provided for refresher classes and differential classes for "pupils who are scholastically non-adapted" (Art. 12) and Law no. 444 of 18.03.68 set up special sections for children between three and five years with "intelligence or behavioural disorders or with physical or sensory disabilities".

In the seventies, this process was essentially reversed. The law of 30.03.71, no. 118 on "Conversion of Legislative Decree No. 5, 30 January 1971, into Law and New Regulations Concerning Maimed and Disabled Persons", at Art. 28 reads: "The compulsory education must be in ordinary classes in public schools, except in cases where individuals are suffering from serious mental deficiency or physical impairments of such severity as to prevent or make it very difficult to learn or the normal insertion within these classes. Will be facilitated, also, the insertion of the disabled and maimed civilians at high schools and universities." And again in Article 29: "Only when it is found impossible to attend public school for the handicapped, obligation will be set up for children admitted in hospital and rehabilitation centres, classes such as detached sections of normal public school". However, the integration will be effectively implemented only in 1977 with Law No. 517/77, articles 2 and 7, prescribing regulations on the evaluation of students and on the abolition of re-sitting exams as well as other regulations modifying the school system. Law 517 abolished the special classes (art . 7, last paragraph) and provided for the primary school (art. 2) and secondary school (Art. 7) forms of integration and support of pupils with disabilities - to be achieved through numerical limitations of the classes in which they are placed and above all by the teachers with particular specialized qualifications (support teachers).

To get clearer rules regarding support to inclusive school we must wait until the law 270/1982: Article 12 defined the administrative role of the support teacher in compulsory education. Another significant milestone for the integration, in particular for the inclusion in high school, was marked by the Constitutional Court Sentence no. 215 dated 1987 that states that education must be guaranteed for all, and not only for those defined as "capable and worthy"; others *must* be rehabilitated through integration and insertion into normal classes; pupils with disabilities "can" attend high school.

## University

Law 104/92 art. 12 sets out handicapped person's right to education in all schools including the right to attend university. The law indicates in this respect, Art. 13, three program lines:

- a) provision to universities of special technical equipment and educational aids and any other kind of required technical support (in some cases through agreements with specialized centres);
- b) the planning from the University of interventions adjusted to the needs of the person, for the development of a tailored educational plan;
- c) assignment of tasks to professional interpreters to be allocated to universities to facilitate attendance and learning of deaf students.

The Law 104/92¹ has been supplemented by Law 17/99, which provided for the appointment by the dean of a teacher delegate with coordinating, monitoring and support for all activities of the university and the provision of specific tutorial support (set up by the University within one's budget and resources). This service may also, if deemed necessary, propose to take exams in a way equivalent to the way ordinary exams are taken, upon request of the specialized tutor.

With the D.P.C.M. 9/4/01 "Uniformity of treatment on the right to higher education" were then dictated the terms for access to certain facilitated services. It specifically provided for total exemption from the registration fee and tuition fees for students with disabilities up to or ex-

<sup>1</sup> See p. 293

ceeding 66% and partial exemptions for lower disability. It was also established that Universities, Regions and Autonomous Provinces should be provided with access to information to provide broad guidance. From this rule are born, within many universities, a series of information points that students with disabilities can contact. The decree also stipulates that any intervention is made to ensure that disabled people should not be subject to influences by individual tutors or lending institutions, and that mentoring can also be entrusted to "advisors at par", meaning people with disabilities who already faced and solved similar problems. Besides the tutor, there must be an assistant guide who has the task to welcome the disabled at the entrance of the University, to lead him to the classroom and, in case, to accompany him to the bathroom and at at the end of the lesson to accompany him out of the university at the transportation service. The assistant guide is not considered during the lessons.

#### Other European Countries

Unique to Europe, Italy's National Law 118 (1971) and National Law 517 (1977) established Inclusive Education as national policy and provided that persons with disabilities "regardless of their type and degree of disability" attend mainstream school from child day care to the highest possible education, from kindergarten to university. In other European countries, the tendency to integrate, at least as regards the less severe disabilities, is gradually gaining ground. However, the models of integration are very varied and often coexist in the same country different solutions, even on an experimental basis.

To schematize, school education is taught in four different forms:

- a) completely separate special education
- b) special education but occasionally connected with mainstream schools
- c) special classes in ordinary schools
- d) inclusion of disabled students in mainstream schools

#### Germany

Given the right of every disabled person to education and training, guaranteed by the IX volume of Sozialgesetzbuch about the rights of the disabled person, every single Lander legislates in a different way and therefore the education system for disabled people is not unique. There is still the prevailing trend to a rigid separation. All Bundesländer provision for special kindergartens and several types of special schools: they are the so-called Förderschulen or Sonderschulen (special schools), divided between special schools for mentally disabled children, children with behavioural disorder and with learning difficulties.

In almost all federal states, students that attended a special school for disabled, are not allowed entrance to high secondary school (and therefore to college), but only to vocational training; in some regions, however, special schools for behavioural children and for children with learning difficulties are slowly disappearing.

#### France

France follows a mixed system: in addition to special schools there are special classes in ordinary schools and individual placements in regular classes. The French law, at least in principle, provides the student, whenever possible, with ordinary school access. However, this is realized with many limitations and caution. Compulsory education, for instance, can be fulfilled also in special schools.

In primary school, along with some individual placements in mainstream classes, most often the disabled are included in CLIS (School Integration Class), (ten disabled children and special teachers), and they share a number of activities with the other students. At the secondary level, when the demands of individual schooling become excessively taxing, disabled students can join the integrated learning units (UPI), but don't have any chance to be enrolled in ordinary classes. This framework covers 66% of French people with disabilities at school age. The remaining 44% fulfils the requirement of special education in the schools placed in specialized institutions.

#### **United Kingdom**

In the United Kingdom, as in many European countries, there is no law providing for the integration of disabled people in mainstream classes. There are "Recommendations" that recommend the inclusion. The English school system gives great autonomy to local authorities that have full discretion to organize the necessary supports for integration. In recent years there has been a particular consideration on issues related to school, diversity, disability. The term used in England for the identification of disability - "special educational needs" - introduced techni-

cal education Act of 1981 - focuses on diversity not only as a disability but as "an expression of special needs." This has opened the doors to the affirmation of the concept of inclusive education, involving not only disabled, but all the students and directs the education policy towards a greater individualization. Pupils with special educational needs are 3% of the school population. Of these, 59% attend normal schools, 39% special schools and 3% private schools.

#### COMPULSORY JOB PLACEMENT AND VOCATIONAL TRAINING

The job placement of persons with disabilities became compulsory, and was regulated for the first time thanks to the Law 482,April 2, 1968. Italian legislation evolved when Law 68 passed on March 12, 1999. This act went further the vision of the previous law, promoting job placement and integration of persons with disabilities in the labour world through support services. Article. 3 of Law 68/99 provides for public and private employers compulsory hiring of disabled people and the need for mandatory quotas<sup>2</sup> as follows:

- a) seven percent of employees, if they have more than 50 employees;
- b) two workers, if they have 36 to 50 employees;
- c) a worker, if they have 15 to 35 employees.

Three observations can explain the surpassing of the old law:

- Social change, i.e. the changed conditions of our labour market which tends to reward the resources that already have a level of preparation/specialization.
- The new trend of assistance that led to Law 328, 8 November 2000, that went further the Act 68/99, where we notice a lack of clarity and of parameters of disability and handicap
- A new idea of the disabled person, no longer crushed by the percentage of disability, but valued for his abilities, which in reality are
  not so residual and can be highly productive if properly organized.

To promote the inclusion and integration of disabled people in the job world, law provides for a range of support services and targeted placements. It consists of a set of tools to assess the work ability of disabled persons, in order to include them in the appropriate place, through the analysis of jobs, the identification of forms of support and the solution of problems that may arise in workplaces. A series of contributory benefits for enterprises and government agencies who take certain percentage of disabled people, are also planned.

Disadvantaged unemployed people who aspire to a job suitable to their own work skills can enrol in the mandatory placement at the Centre for Employment with territorial jurisdiction, in a single pass-list.

In order to facilitate the placement of disabled people, the departments may reach with the employers agreements relating to the determination of a program to achieve the placement targets set by law. Through special agreements the departments may allow private employers some relief from taxes.

<sup>2</sup> The categories to which the art. Refers are the following:

<sup>-</sup> Invalid civilians> 45%

<sup>-</sup> Invalids of labour> 33%

<sup>-</sup> Persons who are blind

<sup>-</sup> war invalid civilians

<sup>-</sup> Widows, orphans, refugees

Recent data provided by the Ministry of Labour indicate that the employment rate of people with disabilities is equal to 19.3%, while for people without disabilities is around 55.8% <sup>3</sup>. The levels are highest in the north and decrease in the middle and then in the south.

Eight year after Act 328, compulsory hiring of disabled people is still a reality in large part to realize. The quest for a targeted placement has just begun.

## Vocational training

Vocational training is becoming of increasingly strategic importance in the world of work. It meets the training needs expressed by companies, as well as the needs of young people to acquire skills and the need of workers to stay abreast of the ever-changing market.

The European Social Fund, through special agreements with Regional and local authorities, co-finances mainstream vocational training courses in public and private centres. The courses are organized at all levels: post-compulsory education, post-diploma and college degree, post-graduation courses (and master). These mainstream courses, mostly free, enable people to get skills and qualifications required by the labour market. Moreover, vocational training can be a decisive resource for improving their professional position.

As regards the disabled, often vocational training is - unfortunately - an end in itself. Years of job placements, internships, courses do not lead to a working outlet. In the eighties, training has played a critical role for entry into the world of work, but in later years this was the case in much smaller form. Today, apprenticeships and internships get mainly the function to "approximate" the world of work and improve the training of participants, but in many cases do not lead to a job.

#### LAW 180/MAY 13 1978

Law 180, May 13 1978 is the Italian Mental Health Act of 1978, the legal framework that regulates the health examinations and compulsory treatments of psychiatric patients. It is more commonly known as Basaglia Law by the name of the psychiatrist Franco Basaglia, principal proponent of this large reform of the psychiatric system in Italy. It contained directives for the closing down of all psychiatric hospitals and led to their gradual replacement with a whole range of community-based services. Indeed, it was only after 1994 that implementation of the psychiatric reform law was accomplished and marked the very end of the state psychiatric hospital system in Italy.

Thanks to Law 180 psychiatric assistance was to be shifted away from mental hospitals to Community Mental Health Centres, newly organized in a sectorised or departmental manner to assure integrations and connections with services and community resources. The psychiatric patient is no longer considered as a dangerous person. Law 180 has shifted from defence of society towards better meeting of patients' wants through community care. New hospitalizations to the "old style" mental hospitals stopped instantly. The patient also has the right to retain his civil rights. With the implementation of Law 180 are born the Community Mental Health Centres, and with them we affirm the need of creating new structures and new types of community services, including home care, which have among their goals the guarantee of a good quality of life of the patient taken in charge. The law also sets new targets of preventive and rehabilitative kind.

## LAW 104/ FEBRUARY 5 1992

Law n. 104 of February 5, 1992, is the Italian frame Law for "assistance, social integration and the rights of persons with disabilities". Article 3 of Act 104/1992 provides the following definition of the disabled person: "A handicapped person is one who has a physical, psychological or sensory handicap, which can be either stabilized or progressive, and the cause of learning, relational or work integration difficulties, and so determining a process of social disadvantage or alienation". It also specifies what is the severity of disability: "Whatever the impairment, be it single or multiple, it reduces personal independence, in relation to age, in a manner that makes the individual require permanent assistance, which is constant or extensive in the individual's sphere or in that of reference, the situation assumes connotations of severity. The

other sources:

<sup>3 (</sup>ISTAT, 2002)

<sup>&</sup>quot;Detection of workers who use the rules on compulsory hiring" (Ministry of Labour, 1996-2000) for the section on mandatory job placement

<sup>&</sup>quot;Quarterly Labour Force Survey" (ISTAT, 2002) for the section on job placement

<sup>&</sup>quot;Survey of Social Cooperatives (ISTAT)" (ISTAT, 2001) for the section on social cooperatives that deal with job placement of persons with disabilities

<sup>&</sup>quot;Monitoring of Employment Services" (ISFOL, 2003, 2004), Survey on the Operation of the Fair Employment Centres (ISFOL, 2005) for information relating to services and users of the targeted placement.

situations identified as severe are determined as priority in public service programs and operations."

Important items are article n. 4 which establishes the criteria for assessment of a handicap and n. 8 which is about inclusion and social integration. This article establishes that people with disabilities who are not self-sufficient or partially self-sufficient can take advantage of home care service based on an individualized plan of care, coordinated by the family doctor. To submit the application, one should contact the family doctor or the Home care point of the Sanitary District. Beneficiaries are:

- persons or families partially or totally incapacitated, who are unable, even temporarily, to handle their needs;
- people, including minors, with little or no autonomy because of disability, or mental health problems;
- people living in situations of social exclusion;
- elderly people over sixty-five.

One of the major goals of this service is to enable not self-sufficient or partially self-sufficient people to continue living in their living environment through the provision of social welfare and/or health benefits. Among the social welfare services are:

- help with personal care;
- help for the housekeeping;
- · help in dealing with paperwork;
- help in doing the shopping and preparing meals;
- laundry;
- mobility and transport for personal or medical needs;
- interpreting service for deaf people.

The Service is set by central, regional and local authorities, and by ASL (Local Health Unit) in most cases in agreement with private organizations. Not all Italian municipalities provide home care services and remain significant differences between the north and south.

Act 104/92 art. 14 refers to the right for disabled persons to education and training, working integration, architectural barriers, access to information and communication, collective and individual mobility and transport. The competencies are among Regions, provinces and Local Health Authorities, upon request of the concerned party.

#### FRAME LAW 328/ NOVEMBER 2000

Law 328/2000 is a frame Law for the Realization of the Integrated System of Social Service Interventions which has radically changed the Italian social welfare system.

One of the main innovations introduced by this bill refers to the division of competencies among the different administrative levels. This division has been significantly altered by the ongoing process of increasing privatization of the Italian welfare State, based on the principle of subsidiarity.

The Act gives in fact a significant role to local actors - like municipalities, counties, third sector and therefore it shifts:

- 1. from interventions for "categories" to universal interventions focused to the individual as part of a family nucleus
- 2. from interventions mainly of financial support to a set of vouchers and social services and interventions provided in the form of an integrated network.
- 3- from a fragmented and dispersed series of measures at local level, to a National Plan at the level of the whole national territory
- 4. from public interventions to interventions implemented by many sub-national authorities, such as regions, provinces, municipalities
- 5. from government measures to interventions that involve many social situations (private organizations along with volunteer network)

Recipients entitled to social and health care services are identified as follows:

- live in poverty or with low income
- suffer from a strong reduction of personal physical and mental skills
- have difficulties in social inclusion and active labour market
- are involved in criminal allegations, and need legal help
- minors, especially if in a condition of a needy family.

The law also provides for the reclassification of the forms of financial support for people with disabilities with new terminology and new goals.

Minimum income for total disability	Pensions to integrate, as a result of impairment, lack of income	In case of severe disability it may be cumulated to allowance to encourage independent living and communication
Minimum income for partial disability	Allowances and cash benefits granted to people with different degrees of psychophysical impairment to support training programs, access to job training contracts and grants	Also to be used temporarily to start work and to be suspended at the time of the final insertion
Allowances to promote independent living and communication	Adapted to the gravity, and to enable continuous monitoring and assistance to persons with severe limitations of autonomy, with the aim of removing social exclusion, promote communication and home assistance to people with severe disability or to people who are totally dependent	Adapted to the gravity, and to enable intensive monitoring and medical assistance to persons with severe limitations of autonomy, with the aim of removing social exclusion, promote communication and home assistance for people with severe disability or totally dependent

To date, the forms of economic support provided are divided into three categories, assistance, allowances and pensions, and are measured to the income of the disabled. Only the "disability allowance" is not tied to income. For the purpose of entitlement to disability support pension, it must be taken in consideration the income from the dwelling house.

TYPE OF SECURITY	AMOUNT	LIMIT
Pension for absolute blind civilians	281.46	15,305.79
Pension for absolute blind civilians (if hospitalized)	260.27	15,305.79
Pension for partially blind civilians	260.27	15,305.79
Pension for totally invalid civilians	260.27	15,305.79
Pension for dumb/deaf	260.27	15,305.79
Monthly allowance partially invalid civilians	260.27	4,470.70
Monthly allowance for minors	260.27	4,470.70
Aaccompanying allowances absolute blind civilians	807.35	None
Accompanying allowance totally disabled civilians	487.39	None
Allowances for communication hearing impaired	243.10	None
Special allowance for the sight impaired	189.63	None

# Pathologies Glossary

#### Arthrogryposis Multiplex Congenita

Arthrogryposis, also known as Arthrogryposis Multiplex Congenita, is a rare congenital disorder that is characterized by multiple joint contractures and can include muscle weakness and fibrosis. It is a non-progressive disease. The disease derives its name from Greek, literally meaning 'curved or hooked joints'.

There are many known subgroups of AMC, with differing signs, symptoms, causes etc. In some cases, few joints may be affected and may have a nearly full range of motion. In the most common type of arthrogryposis, hands, wrists, elbows, shoulders, hips, feet and knees are affected. In the most severe types, nearly every joint is involved, including the jaw and back.

Frequently, the contractures are accompanied by muscle weakness, which further limits movement. AMC is typically symmetrical and involves all four extremities with some variation seen. AMC is relatively rare occurring in 1 out of every 3,000 live births.

#### **Autism**

Leo Kanner first used the term autism, introducing the label "early infantile autism" in a 1943 report of 11 children with striking behavioural similarities. Kanner noted the following characteristic features:

- Onset between 2 and 3 years of age
- Inability to relate to people, little eye contact and hearing impairment.
- Severe language deficits
- Abnormal responses to environmental objects and events and anxiously obsessive desire for the maintenance of sameness
- Repetitive and stereotyped pattern of behaviours

The term "infantile autism" first appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM III), third edition. Autistic disorder is currently listed as 1 of 5 pervasive developmental disorders (PDDs), characterized by delays in the development of multiple basic functions including socialization and communication.

Autism is a relatively rare pathology: experts estimate that 4-5 children out of every 10,000 will have an ASD. Males are three-four times more likely to have an ASD than females.

As for the cause of autism, there exist two schools of thought. Today, the majority of scholars believes that autism has organic causes, and that it is the result of biochemical abnormalities, neurological damages, genetic problems. But in the past, they believed that the parents of children with autistic behaviours were emotionally cold, rejecting and intellectually distant, with psychological problems.

Currently, this last theory has been dismissed. Anyway, hostile environment, sensory deprivation, reduction of stimuli may have negative effects on the development of autistic disorder, as is the case, for instance, of institutionalized children and/or intellectually disabled children. Autism is a complex disorder whose core aspects have distinct causes that often co-occur. Quite a few autistic children have hearing and visual impairments. Sometimes mentally disabled individuals exhibit autistic characteristics. There are also autistic individuals, with Asperger syndrome, the so called "high functioning autism".

#### **Hydrocephalus**

Hydrocephalus, also known as "water in the brain," is a medical condition in which there is an abnormal accumulation of Cephalo-rachidian liquid (that surrounds central nervous system) in the ventricles, or cavities, of the brain. This may cause increased intracranial pressure inside the skull and progressive enlargement of the head, motor and sensibility impairment and mental disability.

Hydrocephalus can be caused either by overproduction of cerebrospinal fluid (relative obstruction) or by blockage of the normal drainage of the fluid. Among the causes:

- congenital malformations, hindering the free passage of cerebrospinal fluid
- infections, for instances toxoplasmosis infection during pregnancy (within the first few months) or neonatal infections such as purulent meningitis.
- · intracranial haemorrhages

- head traumas
- brain tumour

Congenital hydrocephalus: in newborns and toddlers with hydrocephalus, the head circumference is enlarged rapidly and soon surpasses the 97th percentile. Since the skull bones have not yet firmly joined together, bulging, firm anterior and posterior fontanelles may be present. Symptoms of increased intracranial pressure may include headaches, vomiting, nausea, papilledema, sleepiness, epilepsy. The most common treatment for hydrocephalus is the surgical insertion of a drainage system, called a shunt. It consists of a long, flexible tube with a valve that keeps fluid from the brain flowing in the right direction and at the proper rate. People who have hydrocephalus usually need a shunt system for the rest of their lives, and regular monitoring is required. If surgical intervention is delayed, symptoms may include palsy, blindness, deafness, mental deficit.

## Hhypothyroidism

Congenital hypothyroidism (CH) is the most common disorder of the endocrine system: around one child in 3,000-4,000 is born with congenital hypothyroidism. Congenital hypothyroidism is inadequate thyroid hormone production in newborn infants. This can occur because of an anatomic defect in the gland, an inborn error of thyroid metabolism, or iodine deficiency and results from a partial or complete loss of thyroid function (hypothyroidism). Congenital hypothyroidism occurs when the thyroid gland fails to develop or function properly. In 80 to 85 percent of cases, the thyroid gland is absent, abnormally located, or severely reduced in size (hypoplastic). In the remaining cases, a normal-sized or enlarged thyroid gland is present, but production of thyroid hormones is decreased or absent. You may also have swelling of your thyroid gland. This is called a goitre. If untreated, congenital hypothyroidism can lead to intellectual disability and abnormal growth, obesity. In many countries, all newborns are tested for congenital hypothyroidism. If treatment begins in the first month after birth, infants usually develop normally. Hypothyroidism is treated with hormone replacement therapy, such as levothyroxine, which is typically required for the rest of the patient's life. Thyroid hormone treatment is not expensive and may simply be taken in tablets, given under the care of a physician and may take a few weeks to become effective.

#### Cerebral leukomalacia

PVL (periventricular leukomalacia) is a form of brain injury, characterized by the necrosis of white matter (the brain primarily consists of white matter and gray matter; gray matter has neural cell bodies, which can initiate nerve impulses, while white matter transports impulses between gray matter cells) surrounding the lateral ventricles, which fill with fluid (a condition called leukomalacia).

At the greatest risk of this disorder are:

- premature infants
- premature infants with Intracranial haemorrhage (IVH)
- infants with congenital heart and respiratory diseases

Other risk factors associated with periventricular leukomalacia include:

- Intrauterine infection, where abnormal bacteria can infect the amniotic fluid; infection around the time of delivery also increases likelihood
- Placental blood vessel conditions, known as placental vascular anastomoses
- Inflammation of foetal membranes due to a bacterial infection, known as chorioamnionitis.

Currently, there are no treatments prescribed for PVL. Preventing or delaying premature birth is considered the most important step in decreasing the risk of PVL, to minimize the risks of hypoxia (decreased oxygen flow) or ischemia (decreased blood flow) that can occur for a number of reasons.

## Oligophrenia

Oligophrenia, (Greek: oligos, little, phren, brain) is an alternative term for mental retardation. The term is widely used in assessments of civil disability, but cannot identify a diagnosis or a pathology. It points out the symptoms of a disease that results from many harmful causes, that may affect the normal development of the CNS (Central Nervous System.)

#### Cerebral palsy

Cerebral palsy is caused by damages to the motor control center of the developing brain. It can occur

- during pregnancy
- mother's diseases, such as measles or toxoplasmosis, ionizing radiations, alcoholism, circulatory or respiratory system damage.
- · during childbirth
- decreased oxygen flow to the brain, (twisting of the umbilical cord around the neck of the child, or hypoxia in the premature) or birth trauma (for example for use of forceps)
- after birth up to about age one
- meningitis, encephalitis, brain tumours, trauma, etc.

Spastic cerebral palsy is by far the most common type of overall cerebral palsy, occurring in 80% of all cases, one or two months after birth: muscles are contracted without any voluntary control. It may affect only one limb (monoparesis), both lower limbs (paraparesis), only one side of the body (hemiparesis) or all 4 limbs (quadriplegia).

Paralysis can be accompanied by other symptoms related to involvement of the extrapyramidal system (which controls the precision and subtlety of movements). In this case it may exhibit impaired motor coordination and / or involuntary movements involving mainly the upper limbs and muscles of the face and are present even at rest. Other symptoms that may be associated with cerebral palsy are cognitive disorders, language disorders and epilepsy

## Cohen syndrome

Cohen Syndrome (also known as **Pepper syndrome** or **Cervenka syndrome**, named after Michael Cohen, William Pepper and Jaroslav Cervenka, who researched the illness) is believed to be hereditary and transmitted as an autosomal recessive trait, i.e. it is an illness that involves a non-sex chromosome in the human genome. Genes come in pairs. Recessive inheritance means both genes in a pair must be defective to cause disease. People with only one defective gene in the pair are considered carriers. However, they can pass the abnormal gene to their children. So, if you are born to parents who both carry an autosomal recessive change (mutation), you have a 1 in 4 chance of getting the malfunctioning genes from both parents and developing the disease. You have a 50% (1 in 2) chances of inheriting one abnormal gene. This would make you a carrier. In other words, if four children are born to a couple who both carry the gene (but do not have signs of disease), the statistical expectation is as follows:

- One child is born with two normal genes (normal)
- Two children are born with one normal and one abnormal gene (carriers, without disease)
- One child is born with two abnormal genes (at risk for the disease)

A risk factor for autosomal recessive disorders is consanguinity. In fact, consanguineous parents are more likely to be carriers of the same genetic mutation. Cohen syndrome affects many parts of the body and is characterized by obesity, hypotonia, mental retardation, characteristic craniofacial dimorphism, abnormalities of the feet and hands. Other features include ocular anomalies, such as optic atrophy, microophtalmia, pigmentary chorioretinitis, myopia, strabismus, nystagmus, retinal coloboma. It has been suggested that there are two types of Cohen syndrome, one with neutropenia and the other without neutropenia. Until now, nearly 100 cases have been reported. Obesity progresses over time, along with the orthopaedic alterations and oral problem, though the patient life expectancy is not alterated in any significant way. Recently characterization of a novel gene COH1 (locus q22-q23) that is mutated in patients with Cohen syndrome has been reported. COH1 encodes a putative transmembrane protein which may be involved in vesicle-mediated sorting and transporting of proteins within the cell.

#### Down Syndrome

Down syndrome (also called Trisomy 21) is a genetic disorder caused by a chromosomal abnormality, i.e. the inheritance of three chromosomes 21. Causes of this chromosomal abnormality are unknown and we can only speculate about them: chemicals, ionizing radiations, viral infections, metabolic or endocrine alterations of the mother. There are risk factors that increase the odds of conceiving a child with trisomy 21. The likelihood of having a baby born with Down's syndrome increases with the mother's age, especially over the age of 40. Having a child with Down's syndrome is more likely if a woman already has a child with the syndrome.

Babies with Down syndrome have some distinct facial features which can include: almond shaped eyes, small ears and a protruding tongue. They also have a single crease across the palms of their hands and short stubby fingers. They exhibit developmental delays, such as impairment

of physical growth and of cognitive ability. Individuals with Down syndrome usually have mild to moderate intellectual disability. Anyhow they can reach a good autonomy and have work experiences.

Many individuals with Down syndrome also have congenital heart disease, gastro-intestinal problems, and other health issues, because they have got a compromised immune system. Life expectancy for individuals with Down syndrome has dramatically increased over the past few decades. A person with Down syndrome in good health will on average live to age 60-62. This is due to improvements in heart surgery, because congenital heart disease may need to undergo major corrective surgery soon after birth.

#### Pendred syndrome

Pendred syndrome is an hereditary genetic disorder. Its incidence ranges between 1/100,000 and 10/100,000 births. It maps on chromosome 7. and leads to congenital bilateral sensorineural hearing loss and goitre with occasional hypothyroidism. Pendred syndrome accounts for at least 5% of cases of congenital deafness. It usually occurs before adolescence, however, the severity of symptoms and age of onset are extremely variable from one family to another and between members of the same family. Deafness occurs early, starting at birth or during the first years of life. It is bilateral, sometimes asymmetrical, fluctuant and often progressive. Thyroid perturbations, such as thyroid goiter and/or hypothyroidism appear most commonly during adolescence, but they can be congenital or appear later.

## Williams syndrome

The syndrome was first identified in 1961 and has an estimated prevalence in the general population of 1/20,000 births. It is caused by the deletion of the gene that makes the protein elastin from chromosome 7, responsible for providing strength and elasticity to blood vessel walls. This deletion may account for many symptoms of this pathology. Individuals with Williams syndrome experience cardiac problems, commonly heart murmurs and the narrowing of major blood vessels as well as supravalvular aortic stenosis, joint limitation or laxity and hoarse voice. Inguinal (groin) and umbilical hernias are more common in Williams syndrome than in the general population. Children with Williams syndrome usually have distinctive physical characteristics. These include 'elfin' facial features, such as a broad forehead, widely-spaced eyes, small head. They suffer from moderate-to-severe mental retardation and have very sensitive hearing, so they may be startled easily by loud noises.

#### Spina bifida

Spina bifida is a developmental congenital malformation caused by the incomplete closing of the embryonic neural tube. It affects the fetus during the first 12 weeks of pregnancy. Both genetic factors and environmental factors, such as nutrition and exposure to harmful substances, probably contribute to spina bifida. Studies show that intake of the B vitamin folic acid every day before and during early pregnancy, decreases the risk of neural tube defects.

Spina bifida occulta is the mildest form of spina bifida. In occulta, the outer part of some of the vertebrae are not completely closed. The split in the vertebrae is so small that the spinal cord does not protrude

Aperta spina bifida defines the dorsal malclosure of vertebrae, associated with various degrees of spine defects. Some vertebrae overlying the spinal cord are not fully formed and remain unused and open. If the opening is large enough, this allows a portion of the spinal cord to protrude through the opening in the bones. Spina bifida with myeloschisis is the most severe form of myelomeningocele. The exposure of nervous tissue make the baby more prone to life-threatening infections. As a result, there is usually some degree of paralysis and loss of sensation below the level of the spinal cord defect. Thus, the higher the level of the defect the more severe the associated nerve dysfunction and resultant paralysis. Among physical signs of spina bifida are: bladder and bowel control problems, including incontinence, and orthopaedic abnormalities. The diagnosis is prenatal and requires the attention of urologist, neurologist and orthopaedist. Spina bifida can be surgically closed after birth, but this doesn't restore normal function.

## International Classification of Functioning, Disability and Health: ICF

The change in the condition of disability led WHO to study a new classification that took into account that disability and health are multidimensional and do not concern only groups or categories of persons.

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. It was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001. The ICF is WHO's framework for measuring health and disability at both individual and population levels.

It replaced its predecessor, the old ICIDH, (International Classification of Impairments, Disabilities and Handicap -1980). This first classification was important because it recognized that handicap places the individual at a disadvantage in relation to his peers, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, and social and cultural factors, for that individual. ICIDH provided a conceptual framework for disability which was described in three dimensions—Impairment, Disability and Handicap.

The ICF puts the notions of 'health' and 'disability' in a new light. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric - the ruler of health and disability. The objective of this new international classification is to provide tools that can be used to improve health policies, to achieve a better level of health and to ensure that health and social systems are effective. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. The ICF thus 'mainstreams' the experience of disability and recognizes it as a universal human experience.