Department of Mental Health - Trieste.	
SHOULDERING THE BURDEN (PROVIDING TREATMENT) PERSONS WITH SCHIZOPHRENIC DISTURBANCES IN COMMUNITY: THE DEINSTITUTIONALISED MODEL.	FOR THE
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Shouldering the burden (providing treatment) for persons with schizophrenic disturbances in the community: the deinstitutionalized model.

#### Italy's psychiatric reform law.

The laws reforming psychiatric assistance in Italy have brought about profound and far-reaching changes. Despite the many, and often superficial and disinformed, controversies and debates which accompanied the growth of the new system of community-based services and the progressive abandonment of the psychiatric hospital over the last twenty years, persons affected with mental disturbances have experienced, and are still experiencing now, an historic change which must be acknowledged. Full constitutional rights have finally been recognized, and resources are currently being employed to guarantee full rights of citizenship as well.

New therapeutic and rehabilitation prospects are possible today based on multiple forms of social integration, as are positive outlooks for recovery.

The clouds of pessimism which during this century have always obscured psychiatry's hopes for healing and recovery seem finally to be clearing.

Persons afflicted with mental disturbances, and especially those affected by schizophrenic disturbances, until now have been objects devastated by psychiatry. But today they have access to therapeutic, rehabilitative and emancipatory programs which treat them as subjects in full possession of their rights, and permit them to continue living in the concrete reality of their daily lives and within their family and social environments.

Community residences, or living groups, are now widespread, representing a rich and diversified alternative to internment, deprivation and institutional abandonment, and providing a real response to the need for real relationships.

Cooperatives, which began with the processes and changes brought about by the closing of the psychiatric hospitals, are today an important tool for liberation. The possibility of working and of assuming a social role other than that of being "mentally ill", has radically transformed the field and vistas of re/(h)abilitation. Today, "social enterprises" develop processes and promote aims and expectations which were unthinkable and unknown to persons affected with schizophrenic disturbances. Thousands of young, often highly motivated operators (teachers, instructors, non-professional escorts) are active in this area, bringing with them points of view, exchanges and relationships not usually found in the cold, sterile and geometric environments of psychiatry.

Mental health associations, made up of users/patients, family members and ordinary people, have been formed. These associations, with their active presence in the mental health network and within the city, represent the clearest sign of the reform.

And yet psychiatry still has difficulty recognizing these "new subjects" who no longer ask for restraint and control, but want a cure, healing, the possibility of recovery.

The reform act and the critical approach to total institutions have made it possible for our country to utilize, both in theoretical and operational terms, the latest know-how and discoveries concerning mental disturbance and schizophrenia.

Mental disturbances can no longer be represented, either historically, relationally or environmentally, as an existential rupture, as a static and unchangeable condition.

They are always defineable, visible and recognizeable with respect to the individual, and are as in apparent contradiction with an individual life as they are always traceable back to it.

This is what the "Italian Law" means to us.

The complex processes of transformation have been slowed down and made more difficult by resistance to change within the university and within psychiatry itself. Administrative backwardness and an intense regionalization have often resulted in discordant operational set-ups and in reduced and uneven investments.

With a few praiseworthy exceptions, the Italian university has ignored and continues to ignore the entire problem. Research goals and training programs continue to be subordinated to imported cultures oriented towards the clinical/medical model which is, in any case, far removed from the community-based approach and the provisions of national and regional laws.

We have witnessed and continue to witness, have tolerated and continue to tolerate administrative delays, opposition and confusion, and idiotic technical choices which have caused and will continue to cause harm.

Though the number of psychiatrists in the public sector has increased in the last fifteen years from 700 (in the psychiatric hospitals) to about 7000 engaged in the community services, psychiatry has still changed very little.

And yet the process goes forward. Twenty years after the law which initiated the process of change by prohibiting new admissions to Psychiatric Hospitals, the Health Ministry has decreed their definitive closure and has imposed economic penalities on those regions which either delay implementation or are in non-compliance.

The ministerial decree accelerates the process of closing down hospitals and gives more evident support to the growth of the community Mental Health Departments. By the end of the year, the approximately 15,000 guests (in the 70's there were 120,000 inmates) still present in the 57 Italian psychiatric hospitals (they numbered 90 in the 70's) will be resettled in residences and family groups, and shall return, after an entire lifetime, to their towns and communities.

To the superficial observer, the Italian situation, with its regional and community "deregulation", might appear confused. And yet it guarantees that a person affected with a mental disturbance is treated as a "citizen" in all respects: that he always be considered as a person, a subject, an individual, and not as someone who is "mentally ill".

These last statements find their confirmation in well-known historical experiences which have taken place both inside and outside of psychiatric hospitals, in countries both rich and poor, in the hearts of great cities, on their outskirts and in rural areas. And everywhere these changes have been the result of long critical processes, of changes in psychiatry and in its professional organizations, and of the involvement of patients and the presence of social movements.

A cycle is ending in Italy. It is our hope that in the new Europe of "citizens" (and in the rest of the world, as well) the century of the insane asylum has closed for good, a century which has certainly not been to the everlasting honour of either psychiatry or psychiatrists.

#### The organization of services in Trieste.

An Italian model, as such, does not exist.

However, the "Italian way" of reform has succeeded in closing psychiatric hospitals "as an elementary act of justice already contained for some time in the bill of human rights".

The progressive closing of psychiatric hospitals is orientating and conditioning the development of community services.

Our report concerning the Italian situation refers to the work carried out in Trieste.

The present network of services in Trieste was, with few variations, already operational in 1978, before the new law for psychiatric assistance in Italy was passed.

This network is a result of the total reconversion of the resources of the psychiatric hospital during the course of ten years of working within it, which led to its effective and formal closing in 1980 (see appendix).

From 1981 onwards, the new network of Mental Health Services (D.M.H.) took on a definate form and continued to reinforce itself. The Department of Mental Health replaced the administrative structure of the Psychiatric Hospital. The direction of the Psychiatric Hospital, and subsequently of the D.M.H., was assumed by Franco Rotelli, who launched a major effort for the start-up and development of the social cooperation connected to programs for the emancipation of persons effected with mental disturbances.

Currently, after 20 years of working within the community, the network of services is well defined and identifiable.

There are four operational community units active in the city, whose territories correspond to the general health districts and the community operational units for the City's basic social services.

Each area has a Mental Health Center which is open 24 hours a day, 7 days a week. In addition, there are two centers open 12 hours daily and a Women's Mental Health Center whose activities and programs are designed to deal with the special problems women face with respect to mental disturbance and the institutions. Another operational unit manages and coordinates all the programs and resources regarding residences and rehabilitation and a final operational unit provides emergency psychiatric care (Psychiatric Diagnosis and Treatment Station, SPDC) at the General Hospital in close cooperation with the community services.

At San Giovanni (the park of the ex-psychiatric hospital) there are 70 guests in 12 living groups. Another 60 persons live in residences within the city, with varying degrees of support. <sup>1</sup>

completely restored; others who have found a place in the park are the International School for the Perfecting Navigation, a Day Center for

<sup>&</sup>lt;sup>1</sup> Of the 40 buildings which made up the Psychiatric Hospital only a few are being used by the D.M.H. as residences for the S. Giovanni M.H.C., the SERT (Service for drug dependence), as workshops, literacy classes, offices and workshops for the coops; the other structures have been acquired and reutilized by private and public agencies for public schools, universities, workshops. The Department of Earth Science occupies six pavilions which have been

Specific locations for recreational, training, educational and creative activities have been established. There is an intense series of programs for job training and job placement in the abovesaid cooperatives, as well as in various companies and businesses throughout the city.

The make-up of the community services and mental health centers, of the cooperatives and the Women's Mental Health Center, and the active participation of users and family members, all create an extremely articulated scenario which better than any other indicator restores the meaning and repays the effort, risks and contradictions of the project (the utopia) in which operators and services are engaged for the creation of new mental health institutions.

The community work which has grown up in Trieste in the last 20 years, the proximity to conflicts, the early recognition (and shouldering the burden) of the suffering of individuals, has prevented (prevents) this suffering from "assembling" the psychiatric diagnosis before it is seen and recognized, thereby requiring interventions upon "the illness" which are hospital-based.

This, in our view, is the most important result to be obtained from the organization of the services. The "virtuous circle" which begins at the moment of contact (of recognition) between user and service is the "product" which these services must try to promote. The negative spiral connected with mental illness (and with schizophrenia) must be interrupted. Today, community services succeed in maintaining an interdiction "zone" with respect to illness, prejudice, stigma, social deterioration, disability and the impairment of rights. We expect still further results from this work.

#### For the definition of a model of deinstitutionalization.

The deconstruction of the psychiatric hospital and of psychiatric institutions and the creation of a network of community services constitute the substance of the experience in Trieste and help indicate the stages of transition necessary in order to construct the

Adolescents in difficulty run by the City, a School for Management (MIB), a technical institute taught in Slovene (from 1979), the Direction of the Health Department Prevention Division. The pavilions which remain unoccupied will be used as additional structures for the university. Moderate automobile traffic passes through the park of the ex-hospital which is gradually being integrated into the S. Giovanni residential district.

networks and circuits for "shouldering the burden" of persons with severe mental disturbances and especially persons affected with a schizophrenic disturbance.

The process of change begun in 1971 can be summarized, with considerable simplification, around three major themes:

- The closing of the psychiatric hospital as a practical criticism of psychiatric culture and the clinic, and which recognized in the end of the great utopia of the mental hospital the failure of psychiatry.
- The construction of a network of services which would be alternative in real terms, as the practical search for innovative cultures and procedures which would in any case have to be different.
- Placing the "patient and not the illness" at the center of the effort to create therapeutic, rehabilitative and emancipatory processes as the construction in the *praxis* of the user's active participation (as one of the actors for change) in the services.

In the light of our experience, it is evident that today there is a lack of reflection and research on the questions of change and deinstitutionalization in psychiatry. For too long now, in Italy and worldwide, the closing of psychiatric hospitals has not been accompanied by changes in the theories and practices of psychiatry. This has produced questionable or, worse, negative results in some places.

From 1971 onwards, Trieste became a great laboratory. The preceding text indicates just how profound the process of change was. The first four years seemed to burn with the tension of change and looking back now it seems as if everything occured in those years. There was no room for compromises or delays. Basaglia's builders were faced with a double task: with the one hand dealing formidable blows to the hospital walls, with the other creating the structures of a possible community.

The gates of the great park of the Psychiatric Hospital were opened. A patient wrote this graffitti on a wall: "San Giovanni is an open hospital: both coming and going". The opening up of the hospital was discussed in the weekly meetings. The doors of the wards were opened. Everyone was in movement, coming out, talking with one another.

If before freedom was unthinkable, now it seemed equally unthinkable that it could ever end, that it would ever stop its course.

But, as they say, freedom is never enough. In fact, closing the psychiatric hospital is not enough and one law is perhaps not sufficient to regulate madness.

It is the question of freedom which is at issue. It is not the freedom of the psychiatric hospital and not only the freedom to be insane, to howl one's delirium at the moon, and to pay for it with marginalization, abandonment and the loss of one's rights. It is certainly not the freedom of being alone, bizarre, against everyone and in the end at everyone's mercy, both forgotten by the world and a slave to it; and to administrative inertia, and the stupidity of so many therapeutic practices, and the violence of the institutions. Freedom is invoked by us in order to construct life experiences, individual existences, processes of emancipation.

We cannot help but recall experiences which were both historic and manifest in their meaning: the joy of freedom in the first therapeutic communities created in the psychiatric hospitals which were being opened up, the voices and excitement of the meetings, the freedom of inmates who experimented with amazement the possibility of expressing ideas and feelings, of having paying jobs and being members of a coop, of obtaining their own house and with it the possibility of an individual, intimate life. And how forget the procession of "poor devils", the population of the psychiatric hospitals which finally set off, awkward and fatigued, uncertain, viewed with distrust and hostility and yet filled with hope as it began its journey towards an equality which at that time could barely be imagined.

Clearly, it is precisely this transition (the passage to freedom) which, through the inevitable conflicts and contradictions, opens the way for the creation of new "mental health institutions" and the redefinition of the question of responsibility in psychiatry. No longer the responsibility exercised and constructed by the doctor in the psychiatric hospital as the guarantee for systems which are coercive, punitive and objectifying, but the responsibility of taking care of others. Freedom and responsibility as risk, education, as the limits of the search for an alternative to the codes for social control, for the safeguarding of personal stories, relationships, exchanges, conflicts.

And here it becomes necessary to refer to the limits, the points of resistance of psychiatric institutions; to the conflicts around power, the rigidity of roles, the vertical nature of heirarchies. It was precisely the criticism of the vertical nature of heirarchies and unproductiveness of institutional power which helped liberate resources, discover subjects, reduce distances and initiate balanced relationships. The centuries-old

distance between the various roles (nurse, patient, psychiatrist) was reduced, and systems of communication, as rich and unique as they are conflictual, were activated.

In this sense, the theory and practice of group work became possible and work with the individual (or "shouldering the burden" as it came to be called) took on meaning.

Thus, freedom and the criticism of power as the premises for guaranteeing the intrigueing, fascinating presence of subjects, of men and women. And, in thinking on it now, it is this presence which is the most important transition in all the transformations which have taken place over the years. We refer to the affective dimension, to subjective feelings; yes, feelings, all that is humanly concrete and real within the fascinating presence of individuals.

The criticism of institutional power, the transgression of the distance between professionals in traditional psychiatry, and between these and the patient, call into question the times and places in which to act, the repetition and reproduction of relations, and define the scope of the service's shouldering of responsibility. The question of time and place must be completely reconsidered in this context: no longer the times and places of the clinic but the times and places of the relationships which are formed and transformed in the context of the modifications of the relationship between the patient's demand and the Mental Health Service taken as a group.

Clearly, such places are no longer limited to specifically psychiatric locations, but any location can become a place for therapeutic action and can add specific elements or dimensions to the therapeutic relationship.

The redefinition and enrichment of place, of locations for therapeutic action, require the psychiatric operator to develop completely new abilities in order to deal with these diverse locations which do not belong to him and which are beyond his control.

In reality, a *place* for "shouldering the burden" does not exist as such. It can only exist as a place to be created and imagined out of the stuff of daily relationships, until it becomes a sort of antechamber while the cognitive relationship between the service and the operational group on the one hand, and the patient and his family members and neighbors on the other, takes shape.

The same thing can be said about the *time* of therapeutic action. If being in the community also means trying to act in *real time*, for example, by reacting to a crisis immediately, "live and direct" as it were, the dimension of "time" becomes a variable which tends to produce further changes.

In this regard, a capacity for "elastic" definitions and limitations of time develops within the therapeutic relationship. In community-based practice it is possible to imagine (utilize) a "time without end", a time for the therapeutic relationship which does not end and produces no chronicity.

The psychiatric hospital and psychoanalysis determined (and determine still) *infinite times*. But what is meant here is that when the dimension of time is removed from the inertia of institutions, the group and the service will develop the ability to "last" over time by transforming the relationship, the organizational set-up and the use of resources with respect to the patient.

The problem of human and material *resources*, like the problems of time and place, occupies a central position in the process of transformation. A service's lack of resources should be linked to the rigidity of relationships defined by power and, consequently, to the lack of projects and the impossibility for the individuals involved to invest or risk anything. The persistance of clinical and psychological models whose only objective is sickness and the sick body results in the exercise of power and the perpetuation of the emptiness of the material and relational poverty which surrounds individuals.

Instead, taking responsibility for the person, and not the illness, confers value on the different and (for psychiatry) "unusual" resources which can be found as readily in minor trades as in the operators' subjectivity when it is put into play; in well tended and personalized spaces as well as in the activation of the extended family; in personal abilities as well as in the involvement of the social network.

These transitions have elicited and conferred value on diversity (by revealing the process of alienation connected with mental illness). They have made the recognition of individuals and their personal histories possible, as opposed to the histories of their illnesses and the institutions which contain them. They have brought about the recognition of patients' needs and not the institution's need for reproduction, and the emphasis on the abilities, feelings and affections of individual subjects and not the disabilities and limits connected to the illness. Through these transitions, community practice has been able to build a relationship with patients and the general public based on reciprocity, and to negotiate the therapeutic relationship on equal terms and to reduce heirachies and institutional distance.

The chart which follows attempts to show the need for considering all operational and organizational models when projecting a community practice.

### For the definition of a "deinstitutionalization model"

THEORETICAL/CULTURAL/ ORGANIZATIONAL MODELS	OPERATIONAL RESIDUES / ELEMENTS (SCENARIOS) USEABLE FOR THE CONSTRUCTION OF NEW MENTAL HEALTH INSTITUTIONS	
ASYLUM (PSYCH. HOSP.)	<ul><li>Tutelage. Protection. Guarantees.</li><li>Response to needs.</li><li>Active 24 hours a day.</li></ul>	
SECTOR	<ul> <li>Identification, definition of territory, of the reference area.</li> <li>Identification of the population's needs.</li> <li>Inventory, knowledge and reorganization of community resources.</li> </ul>	
THERAPEUTIC COMMUNITY	<ul> <li>Reciprocal knowledge. Extension of the relationship.</li> <li>Attention to therapeutic climate and to communication.</li> <li>Encourage participation in management of treatment.</li> <li>Reinforcing users, social network, self-help practices, diffused therapeutic community.</li> </ul>	
PSYCHO-THERAPEUTIC	<ul> <li>Personal history, events, meanings.</li> <li>Knowledge / approach / listening to the individual, the family, the network of relationships.</li> <li>Conferring value on the individual, the family, the network of relationships.</li> </ul>	
DEHOSPITALIZATION	<ul> <li>Reconversion of expenses.</li> <li>Resources used for client's needs.</li> <li>Service closer to the public.</li> </ul>	
ANTI-PSYCHIATRY	<ul> <li>Human rights.</li> <li>Rights of citizenship.</li> <li>Processes of emancipation / work.</li> <li>Safeguarding and valueing of diversity.</li> </ul>	

#### For the making of a dialectical use of the diagnosis.

The aspect of this century's psychiatric knowledge which we would like to underline is its pessimism, its anticipation of failure (chronicity/ uncureability).

Emil Kraepelin's contribution was fundamental to modern psychiatry (and the clinic). An extremely keen observer and clinician, he helped found modern psychiatric nosography. He identified the dementia praecox which Bleuler would later call "schizophrenia". However, he developed his convictions and theories on mental illness based upon the observation of inmates and despite his formidable scientific rigor did not avoid the error of describing illnesses whose manifestations were already formed by the institutional context and the career prognosis which psychiatric hospitals allotted to inmates as their destiny.

In defining "dementia praecox", he considered its unfavorable outcome as the primary characteristic of the disturbance.

Thus, schizophrenia, and by extension, mental illness, took on (with authoritative scientific validation) the attribute of incurability.

Eugene Bleuler, an essential point of reference in modern psychiatric literature, was the first to use the terms ambivalence, dualism and schizophrenia.

He discussed Kraepelin's "diagnostic pessimism" and introduced a somewhat brighter view of schizophrenia's course and outcome.

The positive results obtained in the Burgholzli in Zurich can perhaps be attributed to a therapeutic approach which was broader, enlightened, non-coercive, that is, based on more optimistic expectations and not inevitably tragic in the prognosis.

But despite Bleuler's having amply demonstrated the possibility of positive outcomes for severe mental disturbances, Kraeplin's original pessimism has been more widely accepted and has contaminated psychiatric action and contributed to solidifying its institutions throughout this century.

It is worthwhile to recall this aspect of the founding of psychiatry because, as regards the diagnosis of schizophrenia, not only is its therapeutic and institutional treatment conditioned by the different ways in which its nature and evolution are conceived, but the experience of the illness, the manner in which that person's individual existence is accepted, refused or punished are also directly linked to them.

It is evident that the different theoretical conceptions can either exclude or facilitate the recourse to human experiences which, as in the case with schizophrenia, are disturbing, enigmatic, often tragic in their condition of being confining, limiting.

It is likewise evident that "reducing" the psychotic experience or mental illness to the pharmacological model or to simple brain damage (without, however, underestimating these factors), to neural micro-structures, single enzymes, neuro-transmitters or genes, takes away meaning and significance from the experience, from the personal history and feelings of the individual who suffers from a mental disturbance.

The deprivation and negation of meaning has produced and continues to produce catastrophic consequences.

Once an individual has been defined as mentally ill, a series of automatic, progressive and rigidly applied measures label him as helpless and lacking in self-determination, deprive him of his rights and make him legally an "other", and in many countries still confine him to special structures for custody and treatment. The medical model continues to base its actions on a concept of mental disability founded on the geometric certainties of naturalistic investigation and on the taxonomic criteria of a heirarchic catalogueing and ordering of human behaviour.

Through this process of (progressive) deprivation, individuals who suffer from mental disturbance end up losing their subjectivity, individuality and personal history. They become objects, encumbrances to be pigeonholed or placed in their appropriate containers.

As a logical consequence, someone who suffers from mental disturbance becomes "mentally ill", for himself and for others. He is thus made to conform to, and included in, an inexistent category - mentally ill, schizophrenic - which views the "sick portion" as dominant (or as the common denominator), thereby over-determining all the rest. And it is in these processes that the stereotypes which fix the figure and role of the mentally ill (the insane) in the collective imagination find and take their substance.

The massive phenomenon of labelling which continues to endure in our society is fed and sustained by this circular process of reverberation between social institutions, the legal system, health institutions, the collective imagination, clichès and the mass media.

With a disturbing reciprocity, stigma, prejudice and psychiatric diagnosis feed and reinforce one another.

The words *dangerous*, *incureable*, *incomprehensible*, *unproductive* and *irresponsible* indicate the most common prejudices. They hinder optimum access to treatment for the person affected with a mental disturbance.

Prejudices impede the acceptance of mental suffering and an access to treatment which is conscious, aware.

The recognition that there is something wrong, that one is "out of their mind" or has a mental disturbance, means accepting the fact of being mentally ill. And being mentally ill means acknowledging oneself to be at the bottom of the social ladder.

Psychiatric diagnosis legitimizes itself scientifically as the research and extrapolation of the signs of illness in the ill person's behaviour. But in reality, it ultimately expresses or attaches a total value to the entire social and personal existence of the individual.

Psychiatric intervention which is based on the medical model, by moving backwards through the individual's personal history ultimately conditions the very analysis of the historical development of the suffering and illness. Real, lived experience is subjected to a process of *a posteriori* recodification. The behaviour involved in a personal history is progressively objectified and channeled into the canons prescribed by the diagnosis being imposed.

In the end, the psychiatric paradigm manifests itself as being falsely inductive. In reality, it seeks a correspondence between the subject's behaviour and a series of prefabricated schemes (illnesses, syndromes).

The personal history, in clinical terms, the "anamnesis", is nothing other than a search for the signs of the illness.

The facts of a given life appear as nothing more than factors prompting or unleashing this or that effect, as simple situations of stimulus which accelerate the pathological "process" which, in any case, is considered as being present.

Once the pathological is given a priori, a search begins for the "refuse" of normal behaviour, for manifest signs of the pathology itself.

When this priority of the pathological is taken to extremes, it invalidates the individual's practical acts and choices, his real life, because between that life and the illness there is a logical and analytical leap.

In fact, in psychiatric diagnosis, facts and gestures are approached according to meanings which are external to them.

Due to the totalizing meaning of the diagnosis, the situation will necessarily be exposed to incapacity, incomprehensibility, incureability and dangerousness if, as occurs, the illness is superimposed upon the choices and free will of the person.

As with schizophrenia, this approach, which still forms the basis of psychiatric action and knowledge, has likewise contaminated many organizational choices and, most certainly, psychiatric research during this century.

Starting with the diagnosis, a sort of "therapeutic pessimism" has shaped the actions and expectations of psychiatrists and psychiatry.

#### Finding useful cognitive models for community operations.

The opposition between different cognitive models (biological-psychological; psychological-social) has shown its limits, even though the efforts on behalf of this or that "school of thought" are still intense and, we might add, certainly harmful. Rigid extremes continue to exist due to reasons which have less to do with a scientific dialectic than with the interests of the pharmaceutical industry or schools of psychotherapy.

The more attentive areas of psychiatry and a growing literature support the study of causal models which are non-linear, polymorphous, complex and much more articulated than in the past. In this approach, different factors interact to maintain a condition of mental health, or to determine the individual conditions of vulnerability which may indicate the possible onset of a mental disturbance.

Biological, psychological, ecological and cultural factors all contribute, by interacting with and complementing one another, to maintaining mental health or determining particular and individual conditions of vulnerability.

In this framework, the conditions of psychic well-being (or illness) can better be described as a condition of "extremely fragile and unstable equilibrium" which, as such, allows for a nearly infinite range of behaviour in response to the most varied situations, ie. the capacity to establish adequate (or different) relationships and of knowing how to respond with pertinent behaviour to the environmental, chronological and institutional changes which occur in one's life. The vital cycles of individuals and the evolution of the family constitute a succession of progressive

changes (and, sometimes, of unexpected leaps) which test an individual's ability to adapt or demonstrate in a dramatic fashion their vulnerability.

With the name of Diathesis-Stress Theory we define a model according to which the mental disturbance (schizophrenia) manifests itself in subjects with a specific vulnerability, in part hereditary and in part acquired as a result of stressful events (Life Events Stressors). The course of the condition is typically episodic, and an evolution towards chronicity or serious social disability occurs only in a limited number of cases due to the persistance of risk factors, of which the social-environmental ones are certainly the most important. From this point of view, the different causes which are invoked for the onset or development of illness and, in particular, of schizophrenia, can be considered as factors which increase the predisposition towards the illness and which in particular circumstances can cause its appearance or increase the risk of a relapse.

These models succeed in ordering the different factors which influence the development and course of schizophrenia and assume a specific importance over time, at different stages in the individual's development and during the course of the illness.

It is evident that we are not dealing with a sum or accumulation of causes, but of life-phases and experiences and neuro-psychological conditions which interact.

The operational choices stemming from these hypotheses help widen and integrate the range of therapeutic offers, in an hypothesis of the concrete integration of different ways and means.

In fact, it should be underlined that the rehabilitative therapeutic intervention ought to be based on the integration between a pharmacological approach and an intensive psycho-social intervention, or better, upon maintaining a field of tension (dialectic) created by the clinical intervention ("hard") and courses of action and tools which are extra-clinical (soft) in a play of timeliness/actuality and integration, and which mark, qualify and validate the completeness of the intervention.

For example, the effectiveness of treatment with neuroleptics in preventing relapses has been documented in numerous studies and there is general agreement in recognizing their great value in resolving crises and relapses. More questionable is the impact of these drugs on the long term course of the illness and even moreso

on the possible evolution towards chronicity and social disability. The fact that these drugs impact unfavorably on the patient's motivational system and that this complicates his social reintegration should be considered. In any case, the evidence currently available seems to suggest that neuroleptics alone are not sufficient to prevent relapses or, in particular, an evolution towards disability, and that their effectiveness is directly linked to the extent to which they are integrated with a system of individualized and differentiated responses/services.

An additional aspect regarding the treatment stemming fom the stress-vulnerability theory and, more generally, from the model of deinstitutionalization, is the need to set up long term therapeutic-rehabilitation programs which are adequately coordinated and whose continuity is guaranteed by a limited number of operators who are aware of the problems and in which the patient is involved to some degree in the management.

In this instance, it is easy to see how it has been possible to identify courses of action and invest in resources which have produced significant changes in the course of mental disturbance, schizophrenia in particular. In fact, today it is possible to consider as "protective factors" tools and opportunities which until a few years ago were seen as palliatives, and thus ultimately useless, or even ideologically-motivated.

In the meantime, these hypotheses, only outlined here, offer the possibility of escaping the "cognitive flatness" which occurs around mental disturbance and render the course and outcome of the disturbances themselves much less predefined. In other words, if it is true that particular events and conditions can induce mental disturbance, it is equally true that different events and different conditions can promote mental well-being.

People's lives and experiences are always different and unique, provided that the institutional forms and the flattening typical of psychiatric and psycho-therapeutic knowledge and practices do not intervene to render them all alike.

With these premises it is clear that community work must (and can) be undertaken only after a critical examination of psychiatry itself.

The procedures, the clinical practices and institutions that today perform the "recognition" of mental disturbance must be subjected to a dismantling of the knowledge and know-how (deinstitutionalization) upon which they are based. To

continue to sustain the objectifying *regard* of psychiatry in this day and age is no longer justifiable.

The choice of promoting the growth and strengthening of subjects (and of their rights) and of constructing strategies of "recognition" able to safeguard and guarantee both the multiple courses of action and the identity of individuals - processes and strategies for normalcy capable of influencing and altering social relationships, workplaces, the family - all this seems to be both clearly evident and widely shared by now.

In practical terms, and though fully aware of the risk of over-simplification, today it is possible to agree to the following affirmations:

- "Healthy" psychological dynamics can be found, though quantitatively altered, in persons affected by schizophrenic disturbance (mental disturbance).
- Mental disturbance can no longer be considered as incomprehensible. Comprehension is possible through the subjectifying and individualization of that particular person, and his unique life.
- A person's history can no longer be overlooked or ignored. Conferring value onto a history gives meaning to even the most extreme experiences. The search for meaning in even the most "incomprehensible" events creates the value of a life story.
- Relationships and communications which have been compromised between persons and within their environment are a factor in the production of disorganized, incongruous, inadequate or risky behaviours which can no longer be ignored. Social and environmental factors not only work together in producing the disturbance but also condition its course and outcome.
- The person who suffers from a schizophrenic disturbance *always* preserves his own human dimension. Mental illness can no longer be considered as having the attribute of total alienation.
- Persons affected with mental disturbance can be treated and cured. In any case, it is possible to reduce the effects of the disturbing behaviours and favor the maintaining of relationships.
- Hospitalization as social isolation and marginalization is always harmful. Institutionalization, isolation and marginalization must be defined as "risk factors". They create the disability. Disability is never connected *per se* to mental illness.

- Community-based therapeutic and rehabilitative work must recognize the mandate for social control. Social control and the therapeutic vocation which form the basis of institutional psychiatry must at present be repositioned in order to define a field of tension which contains the dual elements of "control-treatment", no longer as irreconciliable opposites but as the very context of community work, and as different orders of discourse which must find the possibility of coexistence in a space which is dynamic, new and based on dialectic.
- The family members of persons affected by schizophrenic disturbance experience an emotional and relational condition which presents an "excessive" subjective and objective BURDEN.

At present, the contamination of normalcy represents the most important way for breaking out of the spiral of mental disturbance / labelling / marginalization, given that prejudice, stigma, disability and social abandonment all pass through the opinions, values and expectations which individuals and the collective build up around the question of mental disturbance.

In this country, the legal reform of psychiatric assistance and the consequent closing of the psychiatric hospitals represent the first measure (worldwide) which has proven itself capable of creating effective processes for realizing this contamination.

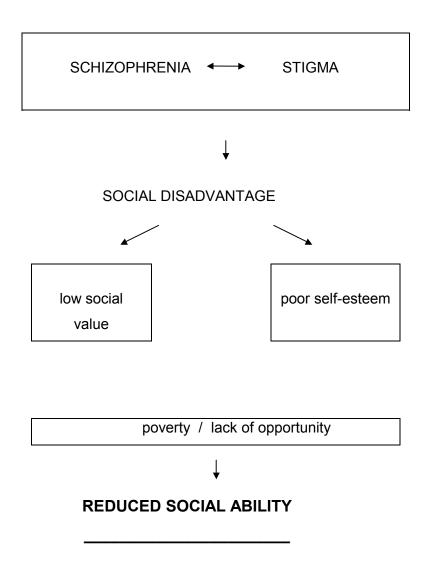
This prospect substantiates the thought and work of Franco Basaglia.

# ENABLEMENT - REHABILITATION EMANCIPATION

- REAL ACCESS TO THE RIGHTS OF CITIZENSHIP
- PROGRESSIVE EXERCISE OF RIGHTS
- THE ABILITY TO PRACTICE THEM
- CHANGING LEGISLATION
- LIBERATION / USE OF RESOURCES
   REAL POSSIBILITY FOR TRAINING AND INFORMATION

# SOME INDICATORS FOR THE PROCESS OF DEINSTITUTIONALIZATION

- Definition of the area of reference
- Assumption of responsibility
- Shouldering the burden with the patient
- Criticism of the medical model as praxis
- Placing the crisis in context/personal history
- Conferring value on new subjects
   (natural operators, family members, volunteers)
- The group as a tool for work
- Attention to places, to the therapeutic climate and organizations
- Promotion of social enterprises (coops)



the practice of involving the users seeks to impact on the connection between mental disturbance and stigma, between distress and low social value

Department of Mental Health / Trieste
The family burden and mental disturbance

#### IN THE REALITY OF DAILY LIFE

- USE OF GOODS AND SERVICES NORMALLY NOT USED
- SUPPORT (BUT NOT ACRITICAL) OF A REBELLIOUS ACT (apparently incongruous)
- APPRECIATION FOR A USEFUL ACTIVITY PERFORMED
- IDENTIFICATION OF CAPACITIES AND ABILITIES
- ACQUISITION OF NEW THOUGH MINOR ABILITIES
- IMPROVEMENT OF THE QUALITY OF HOUSING (find and keep a house in order)
- SENSE OF BELONGING TO SOMETHING
- POSSESSION OF THINGS AND RESOURCES.
   MANAGEMENT OF MONEY AND OWN ECONOMIC RESOURCES.
- PARTICIPATION IN GROUPS / COLLECTIVES / ASSOCIATIONS (seek and maintain friendships)
- PARTICIPATION IN COLLECTIVE ACTIONS TO SATISFY COMMON NEEDS
- QUALITY OF PLACES AND PRODUCTS RELATED TO TRAINING AND WORK ACTIVITIES (there is no purpose in producing useless objects / filling up the time)
- REALIZATION OF ONE'S DESIRES AND BELIEFS
- SUPPORT SO AN INDIVIDUAL FEELS RESPECTED / HIS DIVERSITY IS RESPECTABLE

RECOGNITION OF SEXUAL IDENTITY AND FEELINGS

Department of Mental Health / Trieste Family burden and mental disturbance

#### THE GUIDING PRINCIPLES OF THE DMH IN TRIESTE

<u>The therapeutic-rehabilitative</u> intervention has shifted progressively from the Hospital to the community. The Hospital has ceased to operate, the community has been enriched by Mental Health Centers open 24 hours a day, 7 days a week.

<u>Individuals</u>, <u>their personal histories and contexts</u>, their dis/abilities have been placed at the center of the therapeutic-rehabilitative task. No longer and never again the sickness only: "deal with the person, not the sickness".

<u>Programs and resources</u> move in a community dimension organizing the participation of subjects, groups and resources within the community itself.

**Transformation and therapeutic action** is possible stimulating and seeking out the active participation of subjects (operators, users, the general public). The affective dimension, relationships and exchanges take on particular value in this framework.

The therapeutic rehabilitative work always makes reference to an intervention group, a set of operators who project and make contact with both the patient and his social and family environment.

The patient's rights have been and are still sustained not only by legal and administrative provisions and by resources which must be actively sought out and formalized, but also by daily actions and interventions which make access possible.

The lives of individuals and their social reproduction is always central. Social policies, access to the use of resources different from those proper to psychiatry (housing, job, canteen, subsidies, training) are the common denominators of every therapeutic/rehabilitative program and of any emancipatory course of action.

The individual affected by mental disturbance and his needs must be returned to the context of social citizenship. The constant articulation with the political administration and its requirements is unavoidable.

(in cartoon bubble) "nothing human is strange to us"

## From the mental health department regulations Approved with measure n° 2885 of 28.12.95

#### Art. 16 - USER RIGHTS

- **1** All persons affected with mental distress or a mental disturbance which use the services and structures of the M.H.D. shall be guaranteed access to the rights guaranteed by the constitution, in all circumstances and at any time.
- **2 -** With regard to the guarantees as per paragraph n. 1, access to the following rights shall be promoted and guaranteed:
- The right to freedom of expression, in any place or situation.
- The right to the respect of one's moral, religious and political convictions.
- The right to the respect of one's sexual choices.
- The right to communicate with anyone, at any time.
- The right to have one's abilities recognized, sought out and reinforced, instead of simply having one's difficulties and disabilities emphasized.
- The right of being informed concerning any treatment, and of being involved in decisions which may involve one's health or life.
- The right of not being subjected to acts harmful to one's physical integrity or dignity, in particular to any form of physical containment.
- The right of having one's elementary needs met and of being supported in the search for responses to needs for emancipation.
- The right of choosing the èquipe for treatment, and within it, of individual professional figures.
- The right of association.
- The right to decide that any act of treatment/manipulation of the body be performed by operators of the same sex.
- **3** The services shall give every possible attention to the real respect of differences of gender, race, religion, ethinic origin, age, language, organizing, where possible, adequate responses and structures for the concrete exercise of such attention.

Second part.

### INTEGRATED CARE OF PEOPLE WITH PSYCHOSIS IN THE COMMUNITY: THE APPROACH IN TRIESTE

#### 1. Introduction

1.1 The how and why of an integrated treatment of psychosis, in the short and long term.

The hypothesis of an integrated treatment in the short and long term is certainly suited to the multiplicity of factors inherent to the psychotic condition, both as regards the etiological factors as well as the course the condition takes:

- integrated, because it is fundamental to operate through a contextuality, not a fragmentation, of treatments; this, in turn, requires a therapeutic continuity (managed by a single community team or unit);
- in the short term, because the impact must be sufficient to meet the complexity,
   and
- in the long term, it must be sustained during the course of the condition, in the long "trekking" through the illness, if for no other reason than the persistence of vulnerability to illness.

We believe that the interpretative models of schizophrenia in psychiatry can be codified on the heuristic-operational level as follows:

- 1) Based on the principle of "singularization": "key" or hermeneutic models (psychodynamic-psychotherapeutic, anthro-phenomenological, etc.);
- Based on the principle of "serialization" or the extrapolation of invariances (models from the natural sciences); a simple reductive etiological or mono-factor model (biological-medical) or complex or integrated multi-factor (generally

- corresponding to "behaviourial" therapeutic-rehabilitative packages: harm reduction of the illness through the learning of behaviours);
- 3) Based on the principle of complexity-meaning : an interactive projectual or interactive comprehension model (between observer and observed), flexible.

The presentation will demonstrate that in our case (3) this multiplicity of factors stems from the broad observation of subjects and the providing of total care for their needs ("shouldering the burden") within the community which deinstitutionalization has allowed. From the moment it posed the problem of the social reproduction-reintegration of patients, our model became strategic. The opening up of the interpretative model of schizophrenia thus occurred within deinstitutionalization and as an indirect result of it. The providing of global and integrated care had, and has, the aim of helping the person to live by "thinning down the illness".

Deinstitutionalization has modified the course and outcome of these conditions. It became prevention from the moment it intervened upon "jatrogenic" risk factors (institutional), but cannot consider itself resolved in an intervention on such factors. It is obviously also therapy and rehabilitation, but not solely. In fact, it proposes a radical change, both epistemological and practical.

If we examine the current practices in Trieste, we note that the prescription rate is low. In fact, these practices should be considered more as a range of options, possibilities and choices for the user. It is precisely around the needs of each individual patient that this system maintains its coherence: by following the principles of non-selection and dealing with each case from within its user catchment area without hospitalization, as a rule avoiding any form of hospitalization other than that provided by the Mental Health Center with their "neighborhood" beds. The continuity of treatment, and the accessibility and use of integrated social/health strategies and resources form the obvious complements to this approach. The point is that an approach and course of treatment which may seem "casual" is instead highly personalized for each given case, thereby providing an alternative to structured approaches which involve the risk of standardization and "prefabricated" responses.

What is conceived of here is an integrated system of structures and programs with the aim of producing, as its final objective, an individualized treatment project. More general questions regarding public health are also taken into account, for example:

- What sort of work must be carried on within (upon) the community in order to transform the prevailing culture with respect to these problems?
- Beyond the normalization of symptoms, the handling of stress and the improvement of abilities, where will the external resources, that energy "for wellbeing", come from, in order to transform lives which are in a state of suffering?
- And therefore, what is there beyond and outside of a "good treatment", provided that it can be considered as such?

#### 2. The principles and their implementation.

#### 2.1 Constructing the subject.

These strategies can be seen as attempts to (re)construct the subjectivity of patients threatened and distorted by the experience of illness.

In this sense, it is necessary to conceive of an **open set of possibilities**. The entire system of mental health can be seen as a range of practicable options, of possibilities for experience: which is why the **medium of acting** (which can be described by using action theory), that is, of "doing with" the patient, is of fundamental importance. The operators accompany the patient through the vital, real-life areas of his world, helping him to resolve practical problems such as housing and income. This communicates attention and a willingness to help and give support, thereby helping to creating a relationship of trust.

It is likewise necessary to create special **contexts for experience** to function as levels of mediation with reality and experimentation with oneself (and not simply as "protection" or, worse, as a seperation from reality). Above all, the service must become a place to frequent and an ensemble of relations of support: in the spontaneous groups which gather there and the networks invented and originating

within the service itself - self-help networks, for example, or informal networks with laymen, volunteers, ordinary people.

It is thus possible to **break out of social isolation** through some very simple and immediate forms of socialization which the Mental Health Center affords (for example, the use of the canteen which provides the possibility of meeting people and making exchanges).

#### 2.2 The central importance of the user (negotiation).

In this model, the user is central. His needs, points of view and proposals, as well as his desires, expectations and interests represent the initial materials for constructing, in a "positive" way, the therapeutic project. In fact, from the moment the psychiatric demand becomes radical and regards the individual existence and the possibility of maintaining, changing or reconstructing one's identity, it is no longer possible to exclude the "patient's world" (taken in its entirety).

The use of **self-help** principles have taught us that it is necessary to value the user as an expert and to utilize the abilities, energy, and personal resources he possesses for the (re)construction of his subjectivity. It is thus necessary to **learn from the patient**, to listen to his opinions and also the way in which he perceives the treatment which he is receiving, including receiving critical stimuli regarding the power relationship with the technician. A personal project of normality can be reconstructed based on his expectations (the so-called "normalization" approach) and "positive" work can be done in order to realize some of his expressed lifegoals. It is therefore necessary to develop a "**nosology of the positive**", which means conferring value, offering adequate affective support, enhancing abilities and health-promoting values and emphasizing the "quality" of the user, thereby reversing the typical psychiatric vision which is based on the pathological, the negative.

#### 2.3 Institutional problems.

If one operates knowingly within the service and attempts to optimize its therapeutic resources, one must take into account the problems which it, as an institution, may present in the development and application of therapeutic programs.

Institutional inertia is one of the major risks. Often the service has difficulty aiding the formulation and realization of a therapeutic project because it resists mobilizing its internal resources. Accordingly, it will be that much more difficult for it to recognize and set into motion those resources which it encounters in the patient's environment. All this occurs due to the generally-noted tendency towards homeostatic stabilization (towards self-reproduction) found in institutional systems, which are based on more or less rigid rules or routine practices which have been consolidated over time.

The service organization must strive towards the "opening up of settings", that is, the creation of therapeutic settings which are "rough", mobile and multiple, an aspect which is already implicit in the principles of providing total care for the user. Furthermore, from the moment that everything tends to be socialized, from information among the staff to discussions on interventions, to the individual and collective involvement of patients in the therapeutic programs, all acts and gestures tend to take place on what we call the institutional scene. In fact, the service can be seen as a collective environment, a space for social interaction (not only strictly therapeutic, ie. what establishes itself as the "service relationship" between staff and patients) where the patient's condition ceases to be purely private and begins to generate the "socialization and secularization of madness". Equipe management means valueing the individual contribution, but it also means emphasizing the interchangeability of operators and the "inter-vision" of the group made up of autonomous but inter-dependent professionals. Dual and exclusive therapeutic relationships must be avoided (the model for the therapeutic contract in a private care system), in order to socialize the crisis and the management of the illness. To achieve this, the maximum diffusion of information must be practiced within the service.

The equipe (Oury) allows the patient to **multiply the transfert** onto different subjects, and the equipe's work consists precisely in trying to recompose this fragmentation into a unified whole.

"Passing through the service" is possible when the service has become familiar to the patient, and he is able to establish certain points of reference and feels that he is listened to and treated as a "person". Before the equipe can establish a relationship which is flexible and suited to the patients needs, it must overcome the limits of its professional role (which is "used but at the same time denied" - Basaglia) and thus of the institutional relationship which it establishes with the user.

The **affective dimension**, when it appears, can be taken as an indicator that a transformation has taken place. If affective movements or human episodes occur between a user and a staff member, or within the staff itself, it means that it has been possible to go beyond the limits of the reciprocal roles and of the institutional relationship.

#### 2.4 The terapeutic use of resources.

The situation of the patient manifests itself progressively to the attention of the service in all of its complexity, as an ensemble of subjectivity, social relations and the material conditions of life.

The first contacts and instances of verification focus on the real life of the patient and how he meets his **basic needs**: where does he live and sleep, what does he eat, what are his income and expenses, who does he see and who is around him, where does he work. These discussions encourage the placing of these elements of real life in a **historical perspective**, make the patient and his family more aware, clarify the contradictions and conflicts at work.

The mental health centre has provided itself with an ever increasing quantity of **resources**, such that it can attempt to respond to a diversity of situations and needs. By resources we mean what is at the disposal of the service in terms of material aid, tools, services, locations and occasions for meeting and socializing.

The richness of the service is the result of choices made as a direct consequence of the work of deinstitutionalization, oriented, in our case, toward developing moments of social security and legal protection and support for patients in the community.

Besides activating other services and institutions, resources or services are directly provided by the C.S.M. The principal of these concerns the living situation (restoration, maintenance and cleaning, the search for other housing solutions),

money, income (cash subsidies, use of the safe in centre, daily money management on a temporary basis, action taken in defense and protection of property), food and catering (lunches at the centre, groceries for the house), personal hygiene (laundry, personal cleanliness, hairdresser, linens), work possibilities (assignment to a co-operative society, chores at the centre, work grants), free time (workshop in theatre, painting, music, graphics, sewing, ceramics, gymnastic and boating, day trips, holidays, parties, cinema, shows). In our view, the peculiar therapeutic quality of and intervention conceived in this manner is evident, though it is often interpreted reductively as "charity and sympathy". The work that develops around the crisis as "response to need", continually offers workers (nurses, attendants, social workers, doctors) a real level of possible relation; permits the immediate translation of technical terms into concrete problems; inhibits the tendency in psychiatry to expel from the intervention as dross, anything that has to do with the material condition of life; encourages concrete exchange between the diverse subjects in action: promotes

We do not pretend to effect a reading or gloss of the needs which underlie the psychiatric demand, but, rather, to furnish responses, in the awareness that these have a circumscribed value in time relative to the appearance of the need as a contingent fact, and which permit the patient to reinforce himself and make a further progress towards the reacquisition of social identity.

#### 3. The project

"standing by" the patient.

#### 3.1 The individual project and collective programs.

The construction of the individual project has as its starting point a partial use of the range of programs which the service has at its active disposal in any given moment.

This relationship can be viewed in terms of software (project) and hardware (activated collective programs useable by single individuals). The project is created through a process of negotiation with the user, which singles out the problematic areas together with him, also with the contribution of the èquipe as a whole (for example, during meetings). Abstract programs which do not work due to the fact that it is the user himself who must take control of his own project

based on his own motivation, must definately be avoided. Likewise, if the offer exceeds the demand, that is, if the service is too "giving" because it does not activate the personal resources of the user, who therefore adheres passively, and adjusts to the offer itself, a similar problem exists.

#### 3.2 Implementation of the project through the use of programs.

The typical therapeutic-rehabilitative process can be outlined in the following diagram, which we will now explain.

These strategies can be implemented according to the theoretical fork outlined above (Anthony and Libermann, 1986) as (i) subject intervention, and thus on capacities, and the network into which the user is integrated and (ii) environmental intervention, including the possibility of supplementary resources (iii). (see table n.2)

(i) In our opinion, it is extremely important to use the community mental health services (24-hour center, day hospital) in subject intervention, such that they become actual places where and by which an individual's life-time and relation time can be temporarily but considerably modified.

In this case, social support is offered by instruments (offer of resources) and/or relations (to go/be with the user) and service facilities are interpreted as areas of social exchange (Mezzina et al. 1982). This implies, among other things, conceiving the community mental health center as a place in which different subjects meet and interweave relations (and we could go on to describe at great length all the moments of social re-learning and support).

<u>Outside institutional facilities</u>, the promotion of self-help groups, self-organization and aggregation activities for young patients (Mezzina et al. 1992), arts and expression workshops, vocational training in integrated cooperatives (Gallio, 1991; De Leonardis et al. 1994), education and cultural programs (a special school project involving psychiatric patients and youth at risk has already been started), pre-training and "social – cultural rehabilitation" programmes represent other forms of intervention to empower and develop subjects.

(ii) As regards environmental interventions, we emphasize those aimed at the family burden and which go beyond mere family "counselling", in particular the psycho-educational and self-help groups involving the relatives of long term patients (Dell'Acqua et al. 1992).

For users, we offer experiential opportunities outside the family, such as cohabitation (especially for young users), which are followed and supported by the service or which involve volunteers or attendants in flats which are not "residential facilities" of an institutional nature, but "temporary" life-places. We also organize activities for socializing and spare-time and encourage patients to attend day programs in order to limit the "face to face" contacts between users and relatives and to de-referentiate family attitudes, thereby encouraging forms of progressive emancipation.

(iii) This approach can be supported by supplementary resources when users are unable to access autonomously, whether due to severe disability or mechanisms of social exclusion, or because of personal resistance and difficulty in adhering to programs which imply a therapeutic change in their lives.

Examples of possible "support integrating services" are the designation of a "keyworker", or professional who undertakes a special relationship of continuity with a single user; utilizing attendants and volunteers as "therapeutic assistants" to make home visits and permit the user to go out (Arieti, 1981); or the possibility of long-term integration in a protected group-flat.

Synergies (which can be described) exist between the various programs; as well as the possibility of leaving and reentering. We are thus dealing with a system that has a high degree of freedom of choice within the therapeutic-rehabilitative offer.

There is a notable accessibility to the demand: it is, as we have said, a "low threshold" service.

#### 4. Treatments

We can now begin to describe additional stages of the program in terms of its individual parts, which can be defined as "interventions" or "treatments".

#### 4.1 Intervention in an acute crisis.

Short-term hospitalization in acute units can expose the individual to a risk of cutting the ties with his existential context. Once experienced, it could become an easy way out both for the patient and his environment, thereby "inducing" relapses. It tends to enclose the suffering experience in a "mentally ill role", which often crystallizes it and facilitates chronicity (Asioli, 1984; Scott, 1967).

The intervention procedures at the initial crisis (acute onset) need a high mobility of the service in establishing the contact and an ability to cope with crisis difficulties in patient's own environment (home crisis management as a first option).

All interventions aim at avoiding psychiatric hospitalization, the alternative being the **24-hour hospitality in the CMHC**. The hospitality/admission response in the CMHC is applied on the basis of "case by case" evaluations which take into account diverse criteria (e.g. social support network, type of therapeutic relationship, levels of individual accountability, acceptability or harmfulness of the contact with the environment, etc.), and not merely the symptomatology or factors of severity and risk.

The CMHC's 24-hour hospitality does not sever ties with his/her environment (family contacts, time away from the centre alone or accompanied, taking care of specific personal needs). If the user should break the agreement by leaving the

centre, every effort is made to re-establish contact by seeking him out and listening to his requests and claims (**re-contracting**). In any case, hospitality is only one phase in the overall response to each case, and is preceded and followed by other modalities.

There is a peculiarity to managing a crisis 24 hours a day, and that is that the crisis maintains its central importance in the operational model. In fact, there is an effort to **make full "use" of the crisis** in terms of a possible transformation. The crisis must be accepted within the service, which does not delegate it to hospital structures or "clinical" treatments, but allows itself to be invaded by its confusion and "uproar".

*Crisis is multiplying resources:* it is necessary to mobilize the user during the crisis, to preserve the context through the possibility of maintaining or even mending the ties with the family and the social network, and to unblock frozen resources of the micro-context through the therapeutic work.

Crisis is increasing informations and knowledge around the person: the knowledge of the case that the community equipe acquires during the crisis, by means of the **direct relationship and interactive observation**, permits a strong relationship to be formed with the user, even confronting the situations of defiance.

Crisis is increasing communication within the service: the circulation of knowledge mobilizes and cathalyzes the human resource (professionals and non professionals) of the service.

The crisis may open itself up to a "subjectivization" ("illumination" as "a social visibility") when it comes in contact with all the points of the service and activates the human contacts and resources around it. The individual becomes "someone" during the exchange with the service, and this allows him to break out of the anomia of the psychosis. (re-constructing the identity trough different therapeutic relations).

In the course of these operations, the <u>service's model of recognition</u> is important, meaning:

 to take into account the globality/complexity of the problems, placing at the center the multiple <u>meanings</u> which are possible (mediated between the participants in the crisis/conflict);  to visualize the range of needs (multiplicity of places for contact and of the institutional subjects involved, temporal/spatial extension of interactive observation).

Instead of following the most common strategy of crisis intervention which aims at resolving conflict within the personal context (familial or micro-social) and attempts to arrive at a rapid normalization of the individual, crisis response in our case is more inclined to connecting and placing the user in **contact with a system of relations** and the human and material resources present in a community service.

Resistance conditions in general can be overcome if we put attention on flexibility, availability, and informal style of relating. It allows to maintain an extremely low use of compulsory treatments. Whenever neede, the are managed in the same community mental health center, with the same modality and "the open door".

#### 4.2 Development of relationship models.

"Shouldering the burden" with the patient has the aim of constructing relationships which reassure the user in a psychotic crisis. Inevitably, he finds himself in a condition of grave apprehension regarding his inter-personal sphere, which he experiences as potentially destructive to his fragmented identity. He needs to verify things, and thus requires a period of time (which is subjectively variable) before gaining a sufficient degree of confidence. And it is only an approach which is globally directed towards communication at all levels and between all subjects present within the service, in short, in the management framework of a therapeutic community ("open or diffused") which allows him the possibility of carrying out such "movements".

The crisis must allow for experimenting with different relationship models in the activation of the entire service-system. A **first network of relationships** is provided by the operators whose willingness and availability is in direct relation to the closeness of their relationship (which, however, should be as "relaxed" as possible) with the patient. Out of this informal way of containing his anxiety there emerges, at minimum, a **personalized therapeutic relationship** with a limited nucleus of operators who make themselves more directly available in the various stages of the intervention, and thus "enter into play" with him.

These human points of reference should be such as to familiarize the user with others. The closer affective dimension which is thereby made possible, contributes to deconstructing the institutional relationship.

The resistance which arises out of a severe psychotic condition sometimes requires a **mirror** comportment of distance and refusal. Such behaviour is certainly defensive but is motivated by a reasoning which is coldly provocative and strongly evocative of similar responses among the operators. This mirroring should not be pushed beyond certain limits and at some point must be interrupted, otherwise it will lead to an escalation which will result in an institutional power clash, forcing the service to use heavier means (sedation).

Such a clash or direct confrontation on the part of the service while seeking to maintain the relationship rarely becomes inevitable. Yet it seems better to "lean on the illness" in a clear and direct way, using the institutional power and knowledge of the operator and the weight of the service, instead of allowing it to regress and be set adrift or even abandoned within the service itself.

#### 4.3 Psychotherapy vs. relationship models.

In the face of situations of such interpersonal difficulty as those presented by schizophrenia, it seems to us important that a service develop a capacity for seeing and for "therapeutic value" through a graduated sequence of different types and possibilities of relationships with the patient (such as the informal ones described above in "passing through the service") before arriving at the construction and the crystallization of more stable and structured relationships which we can call "organized listening" or "psycho-therapeutic" in a strict sense. This characteristic pertains to an approach with the capacity to engage in more profound and longer-lasting relationships than occurs with formalized methods. In the enlarged setting of the service, rigid procedures (even without respecting them) and different orientations (experiential, cognitive, relational and others) can be used in an eclectic way within the service if the psychotherapeutic relationship is not seen as self-sufficient and an end in itself, but as part of a global strategy to be discussed and adequately socialized by the group or èquipe.

#### 4.4 Development of network models: mobilizing social support.

It is precisely as a result of the relationships described above that the service acts as a network in and of itself, and as a sort of pole of attraction, or builder of a social network (often ex-novo) for the patient. As is well known, schizophrenia corresponds to a "crisis in the network of relationships" which drastically reduces and impoverishes the patient's social network. The difficulty of mobilizing social support is evident due to the level of conflict that exists within the family and neighborhood, at work, and in all the vital settings which are important to the patient. It is therefore necessary, by using the first impulses towards resocialization which drug, relational and milieu therapy begin to bring about, to unblock the patient and the significant persons who are "stuck" in such situations, in order to reactivate personal energy, and social and support resources which have been frozen.

The use of **daily meetings** for the patients in the 24 hour services allow them to begin to look around them, to verify their own problems through reciprocal listening and confrontation; and to establish the first bonds of solidarity. Subsequently, it will be possible to enter into a perspective of real **self-help**, and of the user's active involvement in the service, in the context of individual and collective decisions.

With these steps it is possible to develop an initial **orientation towards rehabilitation**, in which the user begins to explore his possibilities which have often been long abandoned and which he risks losing for good. An essential element in this phase is an initial (re)education and a conscious choice among the various opportunities for self-development.

The conscious involvement of **family members** must occur from the outset, by means of the various informative phases, the request for opinions, the listening to their requests, the discussions in the presence of the patient designed to renew the possibilities of relationships which have often been compromised by the disturbance. As stated earlier, their contribution is fundamental for the reconstruction of the patient's history and, above all, for the first attempts at decoding in a group, from diverse points of view, the meaning of the crisis (**participatory decodification**) and to bring the problems into focus together with the patient.

Their inclusion in the specific **family program** occurs as soon as possible and primarily allows them to break out of their isolation and to confront themselves with others (in the multi-family groups) in order to then to consciously face their family member's situation and the family crisis ("coping"). Here as well, confronting the objective and subjective burden of their family member's illness permits the freeing up of potential resources for support. Their reinforcement is often completed through the establishment of relationships of solidarity with other families and thus of possible social support and self-help networks.

#### 4.5 Rehabilitation

At this point, other programs in the area of rehabilitation become possible.

The social experience of the "ill" individual must be dealt with not only with regard to factors of stigmatization or labelling, but also through the disclosure of individual horizons for recovery (Anthony and Farkas).

- The use of creative laboratories related to individual purposes and "meanings";
- Entry into "pre-training" courses, pertaining to "socio-cultural rehabilitation";
- Job training programs, professional rehabilitation and job placement, utilizing Social Enterprises (integrated coops) and businesses outside of the mental health circuit;
- Access to residence programs: where the duality between the right to housing against social deterioration and cohabitation as rehabilitation enter into play.

(See the synopsis in the appendix)

#### 4.6 Operational residues.

The service's position as representing a "guarantee" implies a change in perspective and in the consequent mode of operations. Priority must be given to

"difficult" or resistant cases, and different programs and interventions must concentrate and apply themselves to them in a tendentially integrated form of treatment with possible synergies between them. The hypthosis is that of "clear" action upon the factors which influence the course of the illness and the social experience of the "sick" individual.

The following should therefore be considered:

- the problem of resistance to drugs (also taking into account cases of "false resistance" or of "partial response");
- the problem of access to the therapeutic rationale (prejudiced by all the forms of abandonment, chronicity and institutionalization), moving towards the realization of a "guaranteed therapeutic minimum" in terms of continuity and opportunity for treatment;
- the problem of institutionalization "in and of itself" (as described by Spivak in its spiral of "chronic desocialization", including through interaction with operators);
- the problem of a lack of success, of "blocked" cases, or of therapeutic failures.

The service's position of representing a guarantee expresses itself vis-a-vis all these elements through the identification of categories at risk among the users with schizophrenic disturbance and the use of intensive programs for dealing with them.

The multiplicity of factors in the determinism of the course of the illness is dealt with by developing access to opportunities for rehabilitation and social intergration; by activating social support within the illness; and by opposing the jatrogenic factors inherent to assistance models, even if they result from deinstitutionalization.

#### Then:

- Definition of High Priority Cases and intensive programs (Community Rehabilitation Unit, atypical anti-psychotic drugs, individual family programs, behavioural-cognitive therapies for resistant cases). Here, we can think of a system of networks with synergies, for which we can give some examples:

Drug ⇒ access to rehabilitation programs

 $\uparrow$ 

Inclusion in a residence program

or:

Drug ⇒ access to rehabilitation programs

 $\uparrow$ 

involvement of family members (program)

#### 5 Evaluation.

In Trieste:

- it has not been possible to evaluate the effectiveness of single interventions (i.e. psycho-educational, rehabilitative, psycho-therapeutic, etc.) because the approach is "global";
- it has not been possible to use control groups because the model of "deinstitutionalization" and the integrated approach/shouldering the burden which resulted from it was applied to the entire population of the psychiatric hospital (an ethical and political choice);
- what is self-evident, however, is that the new, completely community-based system "stands on its own" and has changed/superseded the need for internment;

it has been possible to use longitudinal follow-up studies on small test-groups.
 There has never been any interest on the part of the competent bodies of the Ministry of Health to in any way utilize or profit from this process, or to even objectively evaluate it.

Nevertheless some follow-up researches have been done and published on international magazines, as regards as co-ortes of patients suffering of psichosis, family burden, crisis intervention, satisfaction and attitudes of users and family members toward community care.

## 6. The possibility of "translating" and comparing the Trieste model with other integrated care treatments.

If compared to the Integrated Community Treatment strategies, and taking into account those treatments which seem to have a proven effectiveness for psychosis at the international level, the Trieste model can be formalized with a certain degree of simplification as follows, and in accordance with the articulation of the ICC's scheme (Falloon et al..):

#### 1) Social and vocational skills training through:

- Education (150 hour course and literacy training)
- Social-cultural pre-training, through courses managed by the department (for example, language, self-care, identity, use and knowledge of the community, etc.)
- "On-site" teaching and training for daily living ("on-site" and not in a "setting"; ie.
  within the family, at the mental health center, within the protected residence; in
  patient's self-help groups and therapeutic social clubs, and through recreational
  and social organizations).
- Inclusion in coops and supported employment with private companies.

- 2) Work by the èquipe, with key-operators, towards a model of **case management** (seeking to maximize the potential of the therapeutic group through the deinstitutionalization of roles).
- 3) Use of **cognitive-behaviourial intervention** principles (in an unstructured way:

daily programming of activities, or time structuring;

ability of coping with symptoms and crises;

cognitive restructuring tending towards the production of meaning or "sensemaking";

(plus some case of cognitive-behaviourial therapy for "formalized" psychoses).

- 4) Psycho-educational interventions for the heavily-burdened family (counseling, stress management sessions with the patient, group psycho-educational interventions for patients, self-help groups for family members, multifamily group approach, with information and small group encounters on coping)
- 5) **Home crisis intervention** + intensive community residence treatment (in the 24 hour health centers) or crisis management in the day-hospital (also in the mental health center)
- 6) **Drug management strategies** with informal psycho-education for their proper use

(multiple controls of their effectiveness and collateral effects - patient, family, service: "negotiate the best treatment" for obtaining "compliance")

#### 7. Conclusions.

It is difficult for us to imagine any way of modifying the initial conditions, and thus of carrying out therapy and rehabilitation, which does not have a high level of specificity with regard to the *contexts* for application. Instead, other current approaches offer packages which are applicable anyway, anyhow, regardless of the frame of reference, situational as well as institutional (for some rehabilitation

approaches it is even irrelevant whether they are applied in a psychiatric hospital or in the community). As if rehabilitation **WERE A DRUG**, the indications and applications of which are described in the abstract, without any regard for the specific contexts in which treatment takes place. In some - if not in all - cases, it almost seems as if we are dealing with the "resetting" of a program (re the metaphor of the "computational mind") in order to write another program over it, based on the deficit of the target-object (the patient's mind, the cognitive sphere or other) which has been previously identified and "measured". Instead, for us it is fundamental to:

- begin with the "materials which the patient brings with him and with the context";
- work on the institutional contexts and not on abstract "programs" in the same
  way as on the experiential contexts, and to consider their reciprocal interactions This leads to the pathoplastic, or to changes in the phenomenology of the illness;
- anticipate the necessity of "moving" within the model;
- avoid producing "remains", and thus try to rework or redesign approaches to failures.

This leads us to observe that, from a research perspective, not considering the "macro-frame" determined by the presence or absence of the psychiatric hospital, at least in terms of the initial selection of cases, is an error.

Community-based crisis management should be given its proper due as an "engine" for the analysis and understanding of the user's problems, where a medicalized, or worse, a psychiatric hospital management conceals and mystifies the subjective reasons ("the meaning") for illness.

## Let us now summarize the **THERAPEUTIC-REHABILITATIVE COURSE OF ACTION.**

The problems, the next (family, interpersonal, social) which always manifest themselves in the area of relationships but almost always involve the individual's material living conditions, which has become evident through the participatory decodification among multiple subjects (user, family members, service), makes possible the elaboration of a therapeutic project.

Its aim is to take the crisis, which arrived "frozen" or, as a result of micro-social and institutional mechanisms (the various passages, referrals among services, the non-response) was already assembled into an *illness*, and "get it moving again".

The therapy can be seen as the promotion of more effective coping mechanisms for the problems which have been revealed. Crisis management has already begun to "get them into focus" and confront them, but this managment is immediately replaced by a therapeutic offer (as re-construction of the Self) based upon discovering and exploring parts of oneself, upon health-promoting values and the possibilities for the expression and experimentation of social roles in the small network which the service offers. This often leads to a more conscious exploitation of unexpressed abilities, which then require participation in creative or socio-cultural (pre)training programs.

The cognitive and experiential work in organized listening situations is often aimed at "mastering" symptoms: in order to understand, objectify and bring out positive elements (this is now developed further by information courses on mental disturbance for users). The service's intervention, being both wide-ranging and of long duration, is aimed at reducing the "noxae", favoring processes of self-promotion and recovery, and unblocking support resources. With respect to conditions of dependence or excessive reference to the family, of closure and self-entrapment, it seeks to de-reference, to put into practice a "re-framing", redirecting the psychotic experience towards other significant relationships (therapeutic and other). Thus the offer of resources for one's own life seeks to (re)construct and redefine the subject's living-spaces, from his home to every other location, from income to a sense of social belonging. Most of all strives for a greater integration of the Self.

The phase or aspect which is most properly rehabilitative, and which in any case begins immediately, can be defined as pedagogy: learning and training oneself and acquiring tools (resources, know-how) vs. training in the formal or official sense. It is necessary that, as soon as possible, patients avoid (or are removed from) separate courses of rehabilitation which place them in danger of desocialization or social abandonment.

Recovery is a <u>personal process</u>, which runs parallel to rehabilitation interventions, and which requires entering into a more conscious course of action.

At issue is whether we are dealing with an offer which is merely "casual" or with a proper course of action, and whether this course of action corresponds to a cognitive map for the user, or is instead merely extrinsic, hetero-directed. Rehabilitation requires that the status of "subject" be reinforced. An effort must thus be made to fully realize the individual's rights of citizenship: by resisting or contesting barriers, reinforcing personal resources, and offering practical resources and other "outside forces".

Empowerment, which deals with the capacity/possibility of handling resources and thus, in psychological terms, of reinforcing one's self esteem, relates to the user's involvement in his therapeutic program and in the service itself (in terms of controlling and directing the treatment which he receives), as well as to the transition of aggregation to the group, and with the "pedagogy of power" (to unmask and put into play institutional roles). This aspect of training and information is one of the strategies for attaining full citizenship, by means of the group or the service itself, seen as a means for obtaining rights.