

# **The Linked System of Institutions: A Model for Securing the Institutional Elementary Care of People with Mental Disabilities and Psychosocial Dysfunctions**

by Jakob Egli

Ladies and Gentlemen,

To introduce my subject, allow me to present you with a current example:

## **Introductory Current Example**

*Mr. S is about fifty years old and lives in a care home near the psychiatric clinic. He is mentally handicapped to an undetermined degree and shows psychological disorders. Marked by a strong vital component and the very powerful authority of his conscience noticeable in his verbal statements, he has a limited capacity for self-control. In conflict situations not always recognizable or apparent in his outer behaviour, he tends to develop blockages and demonstrate an aggressive attitude. In excessive demands situations, he occasionally deliberately hits the faces of the people caring for him. This has been going on for years. Several times, mainly female nursing staff members have been hit hard and even injured. Therefore, he has been committed to the psychiatric clinic several times already. In the latest instance, a female nurse suffered a double nasal*

*bone fracture and dropped out of service for quite a long time. The current committal to a clinic led to the administering of a higher drug dosage, complemented by his being made to wear a stomach belt equipped with cuffs for both his wrists in order to reduce his hitting potential and via a rigid, behaviourally oriented regime with 24-hour isolation periods in case of aggressive misbehaviour. In the home, a large part of the nursing team actually threatened to resign if Mr. S. were allowed to return again. The clinic considers Mr. S to be misplaced and pleads for his being taken back as his case represents an agological problem. However, the home refuses to take him back immediately, not seeing itself in a position to do so until a new team can take care of him (in a few months, at the earliest).*

The above example illustrates the complex problems with which we are dealing.

Now, let me give you some more precise definitions of the subject-matter.

### **Defining the Subject more Exactly**

As the example presented in the introduction makes clear, this contribution refers to people with disabilities who always run the risk of getting into problematic situations, where they can find themselves at the mercy of certain regulations and institutions. Clinics and homes sometimes mutually push certain handicapped or disabled people over to each other in quite an unpleasant manner: there results a game of being "pushed

around", where the losers (i.e., the individuals with mental disabilities) are established from the onset, and where the psychiatric clinic subsequently becomes forced to admit them. Formulated more precisely: Where the problems could be tackled most easily - i.e., in the homes - one tends to dispense oneself from solving the task. And where the problems inevitably present themselves - i.e., in the psychiatric clinics - a certain diagnostic and therapeutic knowledge is available, but is also bound up with problematic life conditions for mentally handicapped people.

The problems manifesting themselves in such a way can only be fully recognized when considering various dimensions and planes. On the basis of a longstanding experience, we have tried to analyse and order the problems such that neither the overall view nor our capacity to act gets lost.

Those cases that, time and again, lead to considerable arguments and difficulties are to be viewed always in their uniqueness and quite often they correspond to no existing scheme of classification or clinical picture. Psychiatric and pedagogical aspects can often not be clearly separated.

With time, it became clearer and clearer that, in many cases, the current anomalies evidently result from unsolved structural, institutional and interdisciplinary statements of the problem.

## **The Problem - Human Beings Relegated to the Background**

The starting position for the "Center for Living Space" was the still bad situation in the eighties of people with mental disabilities and deviances, who were accommodated in psychiatric clinics. Quite frequently, they were

separated out on more or less cheap excuses from the privately supported homes either for reasons of excessive demands or due to the wish for relief or a quiet course of operations and then assigned to psychiatric institutions obliged to admit them: this is the group of people "whom no one wants to have." Psychiatry then resorted to medicinal sedation, isolation, fixation, rigid structures, not rarely even to brain operations and until only a few years ago also to castrations in order to come to grips with the overwhelming situation.

By visiting all clinics of Switzerland between 1988 and 1990, I personally was able to get an idea of the oppressive conditions prevailing both for the mentally handicapped individuals and for the nursing and medical staff of the clinics. Therapeutic goals could hardly be observed; however, there were someagogical attempts to activate and occupy the patients. Understandably, the highest priority was to remain in control at all costs within the restrictive and stressful structures. Even though hundreds of former long-term patients with mental disabilities have been separated out from the clinic structures within the last ten years, in the case of new admissions in regions devoid of a network of suitable institutions, the same mechanisms are still in existence - as shown by the example described at the beginning.

### **The Origin and Formation of the "Center for Living Space"**

In 1987, the parents of a young man with autistic traits and an undefined mental disability who had recently been committed to psychiatry, together with Professor Andreas Bächtold of the "Institut für

Sonderpädagogik" [Institute for Special Pedagogics] at the University of Zurich called into being a "Working Group for Improving the Life Situations of Mentally Handicapped People in Psychiatric Institutions". Besides the initiators, therapeutic teachers, psychiatrists, representatives of welfare organisations for the handicapped and nursing staff committed themselves to this working group.

Already in 1988, I was able to begin my work on a part-time basis - a task with considerable demands - of improving the life situations of mentally handicapped people in all the psychiatric clinics of Switzerland. Over the years, the timely limited projects could be converted into a permanent "Center for Living Space" with more personnel at hand. In the beginning, the main emphasis was upon making use of the existing possibilities for improving the life situations within the clinics, but with time, removing people from the context of the clinics and avoiding new permanent stays assumed a greater and greater importance. While the care homes located mainly on clinic areas were advocated for a long time as a necessary, and the only realizable, possibility of development, one finally endeavoured with the model of the "Linked System of Institutions for Securing the Institutional Elementary Care of Individuals with Mental Disabilities and Psychosocial Anomalies" to find the solution of the structural problem. This model was first realized in the Zürcher Oberland. Today's Team of the Center aims at introducing this model in as many Swiss regions as possible and, in particular cases, it provides a counselling support now as before.

Now, various aspects are going to be touched upon, although only allusively, which contributed to develop the

model of the "Linked System of Institutions for Securing the Institutional Elementary Care of People with Mental Disabilities and Psychosocial Anomalies".

## **Analytical Aspects**

In order to maintain our capacity to act within these always very complex situations, we had clearly to define various contexts and also became obliged to assume certain sociopolitical positions. Owing to the action- and effect-oriented form of our approach, we have not always been able to deepen partial aspects as this would have been desirable. We have always endeavoured to find a suitable way within the given situations and events arising both for the handicapped people, the staff members, the institutions and the political authorities. Apart from the expert knowledge available, our actions were also guided by a clear taking of positions in favour of the weak and thus in favour of a caring and just society.

### *Mental Disability*

The position of people with mental disabilities within a modern society is a particular one. There is a challenging area of tension between the rationalizing tendencies typical of our society and the people with mental disabilities, who represent the very counterpoint to them. In this context, I would suggest viewing Mental Disabilities not only as an incapacity to earn one's living for reasons of intellectual limitation, as the Swiss Disability Insurance Law does, but also as an incapacity to establish oneself within the social body in spite of receiving a sufficient disability allowance in the

form of a pension. Positively formulated, people with mental disabilities are dependent upon concrete living spaces (sociotopes) offered to them. Viewed in this legal/economical/sociological context, the political issue gains in importance - i.e., regarding who is responsible for providing the living space or sociotopes for adult people with mental disabilities and difficult behaviour. In Switzerland, this question of responsibility has still not been solved in a satisfactory way: only the psychiatric clinics are left with the obligation to admit such people. It is true that a large part of the mentally handicapped are able to find a convenient solution in the free offer of home places available; however, the group of people referred to here has practically no chance to find places in the free market. Be that as it may, it is uncontested that the psychiatric clinics obliged to admit people with mental disabilities and psychosocial abnormalities are not a suitable place of residence for them.

### *Living Spaces as Concrete Sociotopes or Abstract Spheres*

I here use the term "sociotope" to point to the fact of how far the demands of modern men, on the one hand, and those of the mentally disabled, on the other hand, differ with respect to what they expect regarding suitable living spaces. Many people nowadays move in living spaces which, being separated from place, presence and time, are held together by cognitive concepts, agenda books and electronic means of communication. In contrast to this, those who are mentally impaired are very much bound to a particular place, the people present there and the rest of their material surroundings. The term "sociotope" is meant to indicate an overlapping social and material space. At the same time, a sociotope means an experienceable community and a concrete apartment.

By way of comparison, small children have similar demands or requirements in terms of living spaces as people with mental disabilities. Until children are in a position to move freely in abstract living spaces or spheres, they are dependent upon the institution of the family, which serves as a sociotope to them. While adult individuals know how to cope with life independently, people with mental disabilities are in need of institutionally offered sociotopes. When we here refer to the demands made by small children upon their spheres of life, the perception and recognition of mentally handicapped individuals is, of course, in no way being questioned.

### *Accommodation and Treatment*

There are two tasks in accompanying people with mental disabilities and mental illnesses which are sometimes mixed up in an unwholesome way. The provision of an institutionally safeguarded living space or sociotope is a task to be solved for people with mental handicaps independently of their mental state of health or behaviour. Owing to their limitations, mentally disabled people are inevitably in need of sociotopes, in which they are able to lead a good life in function of their particular abilities and limitations. The provision of such sociotopes designed for satisfying the needs of their inhabitants is simultaneously an obligation and a justification for the welfare institutions providing for the handicapped. The more dependent and the more in need of help a person with a mental impairment is, the more indisputable is his claim for an institutionally safeguarded lodging and for being integrated into a functioning group viewed in a sociopsychological context. In my opinion, it is this very task

that homes have to fulfil for all people with mental disabilities. Otherwise, who would fulfill this task or undertake this responsibility?

The treatment of mental illnesses - of course, also in the case of people with mental disabilities - is the task of psychiatry. Even when a categorizing diagnosis is difficult or perhaps impossible, the necessity of psychiatric help in a lot of cases cannot be doubted. However, this makes sense only when the respective person is integrated into a life field which is neither permanently "under-demanding" nor causing illnesses nor even stress. Very similar modes of behaviour may be - depending upon the particular individual situation - the expression of a justified rebellion against poor living conditions, an indication of mental difficulties or forms of an adequate way of leading one's life (in cases of mentally handicapped people).

The question of the adequate use of psychiatry is a particularly significant one. As people with mental disabilities are only rarely able to play the role of the hospital patient in need of treatment, a committal to a clinic can easily lead to additional strain. Foreign people, unknown rooms, an obscure, unfamiliar order of events will nearly inevitably lead to further behavioural peculiarities. As shown by the example of Mr. S, a fatal escalation may thus be triggered in the interplay between punitive measures and the so-called misbehaviour. Therefore, the strategy to be adopted seems to be to take the psychiatric knowledge and abilities to the mentally ill or handicapped person rather than sending that person to a psychiatric clinic. This strategy presupposes that, on the one hand, the welfare institutions for the handicapped are ready and feel responsible both to both go on caring for people who show difficult forms of behaviour

and endeavour to call on psychiatric help for them in time. On the other hand, this cooperation can bear fruit only when the psychiatrists are ready to treat the patients within the homes and to give expert advice to the teams, i.e., to become active within the institutions. While this task may be accomplished for a lot of people with mental impairments and illnesses by a self-employed psychiatrist, a direct cooperation between the local clinic and the home is preferable with more demanding cases.

According to the functional specialization just outlined, people with mental disabilities who have been hospitalized for justifiable therapeutic reasons or due to a crisis intervention, would have the right to return to their institutionally safeguarded living space not only after a successfully completed treatment but also after full utilization of the psychiatric possibilities with the patient's problems persisting. The endeavour of adjustment or adaptation will then have to be made primarily by the institution.

### *Difficulties of Communication between Psychiatry and Home due to Structural Shortcomings*

Even in the prephase of such extraordinary situations, certain lines of reasoning by home staff and psychiatric personnel can regularly be observed. Psychiatry will point with a certain embitterment to the difficult spacial, operational and social conditions prevailing in the respective wards. Often, a comparison is made with the homes, where small groups, a greater number of staff members and nicer lodgings are the rule and where the corresponding expert knowledge is likely to be readily available. The fact that the clinic has to come to grips with people demonstrating

irregular forms of behaviour, justifies, from the point of view of psychiatry, the use of high dosages of medication, isolation or other types of restraint. The knowledge about its own obligation to solve the task is justifiably linked with the homes' possibilities to give notice to their handicapped inmates or to have them committed to the clinic by medical order or intervention. The temptation to "camouflage" certain problems in the case of attempts at placements outside the clinic, i.e., to withhold certain pieces of information about handicapped people in order not to be immediately rejected, is considerable and also perhaps understandable.

The homes, however, will rather see themselves committed to a target group and will tend to weigh the inmates' and staff members' need for a quiet order of events higher than the claims of the people perceived as "disturbers". The more difficult the conditions in the sociopedagogical field become, the higher the social pedagogues will estimate psychiatry's potential. What cannot be achieved by sociopedagogical means, would have to be brought about by medication and psychiatric therapies. "That's a psychiatric case!" will then be said. Only with great reluctance will the homes accept to solve certain sociopedagogical problems also by separating out the patients. Their tendency to instrumentally dramatize behavioural disorders and to let processes escalate - perhaps unconsciously but still in a purposeful manner, in order to achieve an expulsion or committal to a clinic - is unlikely to be perceived.

Starting from the assumption that the qualified personnel involved on both sides intend to do their best, the suspicion arises that such situations

can hardly be solved by direct discussions, because in the background questionable or doubtful structures seem to have an aggravating effect.

### *Target Groups and the Residue*

The activities of the welfare institutions for the handicapped in Switzerland have been increasingly oriented to narrower target groups during the phase of specialization and professionalization. This process of homogenization has undoubtedly led to achievements such as an increased technical and professional development. However, for people with mental disabilities, who, in addition, are often multiply handicapped, the above development is less welcome. They represent no target group taken care of by a professional body, but they are among those "whom no one wants to have." Among themselves, moreover, they are not able to form a functioning group in a sociopsychological sense. These people represent an exacting demand for each group and institution and are economically a bad risk. Considered as a group, constellations emerge which are highly problematic from social, professional and economical viewpoints. An accumulation of such problems ought to be avoided at all costs. If this statement is to be proven first, I refer to the former conditions on oligophrenic wards of the psychiatric clinics, which, partly, can still be met today. It must be the declared aim to care for these people in as many heterogenous groups as possible. In this way, the tasks arising will tend to remain within a framework that makes solutions still possible. The target group orientation of the welfare institutions for the handicapped should be complemented by measures for safeguarding the elementary care of people with mental disabilities and psychosocial abnormalities living outside the clinics.

### *Integration and Separating-Out*

Integration and separating-out are processes that obey the same laws but run in different directions. These processes have at least one social and one topological component. For this reason, I like to use the above-presented word coinage: "sociotope". Both regarding the group formation and the staying on in the living space, the question of power seems to play a central role. In social integration and separating-out processes, the group as well as the individual dispose of a certain adaptation potential. This potential refers in both cases - in accordance with Piaget's terminology - to their capacities for assimilation and accommodation. If one gives free rein to nature, the weak can be saved only in certain determined cases. The group - and the team of attendants - must therefore know by order of a superior authority that in the event of an "either-or" situation, the weaker party, i.e. the handicapped person, has the right to stay whereas the stronger party, i.e., the personnel, has to leave. The mere declaration of this by the respective institution usually results in the problems being taken seriously, especially in an endeavour to avoid further escalating tensions with the personnel and the fellow-inmates. In groups of handicapped people, other courses of action can also be observed, with other resources becoming activated if - in case of intolerability - the withdrawal of the stronger, more competent and more adapted people is under discussion. Of course, this position should not be abused, but it clearly counterbalances the naturally employed and prevalent utilitarian practices. Time and again, of course, the borders of what can or should be tolerated, will be transgressed. In these cases, it may be indicated to create a new sociotope for the individual with marked psychosocial difficulties. If the

living spaces and structures are sufficiently adapted to a certain person's need, there are good chances for a positive change of behaviour.

However, such space may also become attractive for other handicapped people, because in them a good social status may be achievable.

Moreover, in small groups the staff members may be more loving and caring; also, smaller groups are more manageable and easier to guide.

Living together in such a sociotope with a person demonstrating difficult behaviour should not only be a demanding task but should also have positive aspects. Hinting at the high costs of such solutions is also justifiable. However, a society in which all members may put forward their claims for sufficient space cannot be had at a bargain price. But if one then takes into consideration how expensive and mordant alternative non-solutions can be in the long run, such an investment will be justified - even economically.

### *Strategic Direction in Solving the Problem*

When discussing the problem of how to deal with mentally handicapped people with extreme or acutely disruptive patterns of behaviour, we are always led back to the fundamental question of whether our aim is the greatest happiness for the greatest number - where losses are consciously taken into account - or whether exactly the most difficult and weakest fellow-beings are particularly in need of our help and love. From there, the obligation arises to provide suitable living space for those people. Only when convenient living conditions have been created, will it make sense to therapeutically tackle conspicuous forms of behaviour. Many of these forms of behaviour, considered to be troublesome and diseased, are in reality awkward forms of rebellion against inadequate living conditions,

which, in their effect, may be counterproductive, but essentially sane. If reasonable solutions can be found for such extreme challenges, situations that are easier to deal with, may - viewed from this background - also be positively influenced. At this stage, I would also like to point out the great number of people with mental disabilities who are well-liked in both homes and clinics, but whose overadaptation and resigned withdrawal unto themselves clearly demonstrate the characteristics of a mental disease.

How do these patient sufferers receive adequate attention?

### *The Role of the Caretakers, Counselling and Further Education*

The particular people and situations under discussion also require particular ways of behaviour demonstrated by the staff. Starting from the needs, the abilities and the vulnerability of those people designated as "mentally handicapped", one has to look for new paths beyond the usual, standardized ways of treatment. Quite often, a particular institutional form must become evolved anew. For this, staff members are required who not only dispose of methodico-professional skills, but who are also willing to develop strategies in cooperation with counsellors and to act creatively within their given context. In the post-diploma training, apart from dealing with methodico-technical subjects, the role of handicapped people in our society, terms of disabilities, the position and tasks of the institutions and one's own attitudes have to be discussed again and again. In linked regional systems, common further-education trainings for psychiatry and home personnel will be particularly fruitful.

## **The Different Planes and Why the Solution of the Structural Problem is Considered to be of Primary Importance**

In each individual case, many different questions and problems will focus themselves. Starting from the actual, material situation - with the questions of food, the entourage, control and responsibility - onion-like layers of conditions, which can be experienced either as helpful or as detrimental, will become visible. The particular kind and furnishing of the rooms, the staff members' number and professional qualities as well as their attitudes, operational structures or institutional concepts, are all among the factors to be considered.

As individual cases can never be seen only as examples or items of a structure manifesting itself, of a particular disability or of a clinical picture, there must always be a readiness to recognize the uniqueness of each case. Focussing too one-pointedly upon the needs of any one individual may disrupt the overall order of events, rules, habits, etc. It is necessary to deal with this in a flexible way. Exceptions will have to be made and the temptation to immediately generate new rules will have to be resisted. As shown by experience, this can be very demanding. However, in the individual cases analysed by us, it became apparent that, in the background, there are structures which seemed to stand in a direct causal relationship to the difficulties. Structural shortcomings tend to cause a great number of individual problems. The most serious structural problems turned out to be:

- Missing clarification of responsibilities/no claim existing by mentally handicapped people for a living place outside the clinic

- Accumulation of problem cases within institutions, which placements were not made due to therapeutical reflections but rather on the basis of social disposal impulses
- Dissimulation instead of cooperation between homes and psychiatric units
- Unclear borderlines between economic priorities and public service

On the basis of these insights, the model of the Linked System of Institutions was developed. It was clear to us from the very beginning that, even after recognition and clarification of the structural problems, there would always be cases which would take us near or beyond the limits of what can adequately be dealt with. However, we are no longer ready to reconcile ourselves with the avoidable causes of structural problems.

## **The Idea and Effectuation of the Linked System of Institutions**

Psychiatric clinics are centres of competence and places of treatment: however, for people with mental disabilities they are not suitable living places. Mentally handicapped people must have the right to claim a living space, which is located outside the clinic.

The homes which are privately supported are free to select their category of patients. With a qualitatively good offer, they endeavour to

assert themselves on the market for home places. However, people with mental disabilities and difficult behavioural problems represent economically bad risks. Assuming responsibility for them presupposes an external or self-imposed commitment. Since these homes render a service to the public, the state authorities are reluctant to annoy them (via imposing regulations upon them), so the only viable solution becomes one of self-commitment through an insight into greater correlations and because of moral-ethical considerations.

The cooperation between psychiatry and social pedagogics should be based upon the understanding that homes are obliged to provide suitable living spaces and that psychiatry has to give ambulatory treatment, counselling and in-patient treatment to people with mental illnesses. If these treatment possibilities have been fully exhausted, the clinic may then discharge mentally handicapped people and send them home even when serious behavioural problems continue to exist.

## **Practical Implementation**

We from the "Center for Living Space" conceived the idea of "The Linked System of Institutions for Securing the Institutional Elementary Care of People with Mental Disabilities and Psychosocial Dysfunctions" in a very broad form. It was particularly at meetings of the Center that the subject was presented and discussed and where we endeavoured to find possibilities to put the idea into practice. It became apparent in these meetings that only very few people doubted the existence of the problem.

There was also a widespread agreement concerning the necessity for finding a solution. However, when the question arose as to **who** might realize the solution, many of the participants felt that they themselves could not do that.

For the first concrete attempt at realization, we chose the *Zürcher Oberland*. Apart from a relatively high home density, the great number of personal contacts was also a help, together with the fact that, in some instances, the Center had already committed itself.

At the initiative of the *Center for Living Space*, some directors of privately supported welfare institutions for the handicapped in the *Zürcher Oberland* decided to commonly look for a solution.

The area to be chosen for the Linked System of Institutions was determined by the existing psychiatric region, since - in the case of committals to a clinic - the legal residence is decisive. The region of the *Zürcher Oberland* counts about 195,000 inhabitants living in 31 communities, of which the smallest has 350 inhabitants and the largest, 25,000. The eight homes for people with mental disabilities in the region offer 550 places totally. The smallest institution has 5 places to offer; the largest has 220.

From the very beginning, all the people concerned agreed that only a clear allocation of communities and institutions would make sense. The work in advance can be resumed in three steps:

1. This first temporary assignment of the communities to the existing institutions enabled the directions and supporting bodies to get an idea of the task to be solved. Fears that several such "special cases" would have to be dealt with played a great role in this process.

The results of the first attempt at assigning the communities to the institutions were uncertain as it was not clear for a long time which institutions would finally be ready to join the Linked System. The greater the number of the homes involved, the smaller became the number of the communities assigned.

In the institutions people also tried to grasp the consequences of the fact that they would no longer define their target-groups in a market-oriented manner, but that due to being a member of the Linked System, they would have to contribute their share for Securing the Institutional Elementary Care of People with Mental Disabilities and Psychosocial Dysfunctions.

In this whole process, no attempt was made at establishing new definite categories for the handicapped people concerned. It is enough to consider them as those mentally handicapped people of the Zürcher Oberland who, due to their particular forms of behaviour, become separated out from their rooted living fields and finally end up - or threaten to end up - in psychiatric institutions.

Committals to psychiatric clinics may further be made by medical order. However, a stay in a clinic should not last longer than the time when the clinic considers a further hospitalization to be unnecessary. The homes are confronted with the task of avoiding - if at all possible - hospitalizations by an early resorting to psychiatric help.

2. The results of the discussions held within the institutions were transferred into the Linked System by the home directors. A sufficiently great number of supporting bodies was willing to put the project into practice. A further issue arising was whether and to what extent the Canton should bear the costs incurrent. To judge this question, one has to bear in mind that, in Switzerland, the financing of home stays is principally guaranteed by the Swiss Disability Insurance. As the respective contributions are identical with the additional expenditure caused by the small number of handicapped people in question, this does not lead to financing problems; i.e., the cantons pay relatively small sums. In principle, the solution to the problem had been found by now, but it was still unclear which homes would participate in the project.

3. On 9 September 1996, eight institutions joined the Linked System of Institutions. A vote of the governmental body in charge had decisively contributed to this step. In case of a shortage of money for social matters, it was decided that the Canton would give priority to the institutions belonging to the Linked System. As all institutions wanted to profit from this offer and possibility, they were all ready now to join the Linked System. Thus, the maximum decentralization aimed at could be achieved, with the task of each participating institution being held relatively small.

## **The Agreement**

The agreement that was concluded on 9 September 1996 comprises 12 points:

### 1. Determination of the Institutions in Charge

All communities of the Zürcher Oberland (Psychiatric Region) are assigned to respective institutions. The principle right of the respective handicapped people to make their choice remains inviolable. The Linked System of Institutions offers a place to those people "whom no one wants to have." The respective institutions must accept only those handicapped people living in the area assigned to them.

### 2. Flexibility of the Institutions

If necessary, the possibilities offered by the institutions must be adapted to the special requirements of a handicapped person.

### 3. No Separating-out of Patients

The institutions in question do not make use of their principal right to give notice in the case of handicapped people living in the Zürcher Oberland. Of course, changing the institution remains possible on condition of mutual agreement.

### 4. Mutual Help

The institutions belonging to the Linked System for the Zürcher Oberland oblige themselves to mutually help each other.

### 5. Ambulatory Psychiatric Support

All institutions endeavour to call, as early as possible, on required ambulatory help by psychiatric clinics, particularly that of the Psychiatric Clinic Schlössli in Oetwil.

### 6. Obligation of Taking a Patient Back after a Stay in a Clinic

If stationary psychiatric treatment is required (acute mental disease or crisis intervention), the institution obliges itself to take the respective person back as soon as psychiatry considers a dismissal appropriate.

#### 7. Coordinative Conference

Any problems arising are regularly discussed in coordinative conferences.

#### 8. Cooperation of Canton, Institutions of the Linked System and the Local Psychiatric Clinic of Oetwil

The respective administrative cantonal authorities (Welfare and Health Direction) are also invited to take part in the coordinative conferences.

#### 9. Offer of the Center for Living Space for People with Mental Disabilities

The co-initiating Center cooperates in the initial phase offering its support.

#### 10. Trial Phase and Evaluation

The trial phase extends to the years 1997 and 1998. The experiences made are evaluated by the Center. In mid-1998, it will be decided whether to continue the Linked System of Institutions.

#### 11. Payment of the Services Rendered by the Canton

Institutions for the handicapped joining the regional Linked System are financially given priority according to the Director of the Zurich Welfare and Health Department in charge.

#### 12. Information Policy

Here, all bodies to be informed, such as communities, schools and counselling offices should be listed.

### **Effects of the Linked-System Solution**

- Each person with mental disabilities and/or difficult forms of behaviour has a right to a living place outside psychiatric clinics, which cannot be revoked and to which place she/he is always allowed to return.

- The institutions for the handicapped know exactly for which people there is no feasible solution (via the separating-out mechanism). This results in the institutions informing themselves about any possible Linked-System cases in their specific area and in taking those people directly from the school or the family. This avoids any potential damage caused at home or in their "home careers", which might later aggravate their case.

Additionally, ambulatory and counselling help by psychiatry is requested at an early point in time as escalations and hospitalizations might greatly hinder the continuation of the work.

- Relatives and legal representatives must still look for the best solution possible; however, in case of need they can rely upon an institution, which is then responsible for admittance. Corresponding contacts may be established already years ahead of school-leaving or the family's withdrawal from the handicapped individual's daily care.

- From the professional point of view, these demanding tasks can be best solved if they are tackled as individual cases in an otherwise socially functioning surrounding field, a so-called sociotope. Whether integration into an existing group is possible and tolerable, or whether a new sociotope is to be built around the person in question, must be decided in each individual case.

For the inmates of the respective institutions, the further caretaking or new addition of a person with problematical behaviour may be a severe burden. To a certain extent, one should have the humility to admit this. Owing to the fact that the institution in question is primarily responsible for helping those people most in need, a change of institution for the more adapted group members who possibly feel harassed, may be envisaged - for as a rule, these people have better chances to find suitable new living

places. In the cases of people who are no longer tolerable, their integration must be achieved by building around the person demonstrating difficult behaviour a sociotope, which may also be attractive for the other people concerned. For people not seriously handicapped, such sociotopes can become interesting as they may offer a good social position or a context for increased care by the nursing staff.

- The psychiatric clinic responsible for admittance is able to concentrate on its professional task and must no longer fear that people with mental disabilities whose social or individual difficulties have become "psychiatrized", will be foisted on them indefinitely. When psychiatry has exhausted its possibilities, the patient with mental abnormalities will return to her/his institutionally safeguarded living place, even when no improvement of the state of health could be achieved.

## **Conclusion**

The Linked System of Institutions had such a strong preventive effect that, after the first one or two years, the necessity of the Linked-System solution was already questioned. It is hoped that the forthcoming evaluation by the Center will cast light on the reasons for the unspectacular course of events. However, the following correlations have already shown themselves:

- Handicapped people from the Linked-System communities are taken on in a spontaneous way, thus no longer becoming an imposed Linked-System case.

- People with mental impairments who are hospitalized, can naturally return to their accustomed institution, thus no longer becoming an imposed Linked-System case in their turn.
- Various institutions call on counselling or psychiatric help provided by the regional clinic, and a common attempt is made to find the best solution.
- In the case of longlasting, demanding situations which could not be solved in a satisfactory way (even with external counselling), the wish was expressed in some homes to return to former practices.
- Common further training events for psychiatry and home personnel opened respectively new insights into the other's position.
- Thanks to the clearer definitions of the tasks by the Linked System, the cooperation between clinic and homes became more relaxed.

Particularly comparisons with other regions show which difficulties occur again and again without an existing Linked System of Institutions.

Mr. S., from the introductory example, lives in a region in which there exists such a Linked System, but without any clear definition of responsibilities. While meanwhile a solution for Mr. S. is about to be found, there are no concrete perspectives for other hospitalized people with mental disabilities in the same clinic.

Thank you for your Attention.

Lit: Egli J. und Haltiner R.: Der Institutionen - Verbund. Luzern 1997 SZH ISBN 3-908263-55-7

Jakob Egli

Unterdorf 10

CH - 9044 Wald

*Tel. 071 877 35 31*

*Fax 071 877 35 62*

*E-Mail [egliaj@bluewin.ch](mailto:egliaj@bluewin.ch)*