9. Discussion.

9.1 Introduction.

In this study the development, implementation and evaluation is described of a bottom up rehabilitation programme for schizophrenic patients. The first aim of the study was to determine whether the programme positively affects cognitive functioning, problem oriented coping, social skills, general functioning, and psychotic symptoms of patients. In addition it is investigated whether this programme prevents long term hospitalization of patients. To determine the effect of the programme, the results are compared to drop-outs (patients who participate for less than 75% in the programme) and control subjects (patients who participate in traditional long stay ward programmes).

The second aim was to determine the additional value of cognitive skills training. Therefore, in one condition, such a training is added to the standard programme. Besides training cognitive functions, training tactics are used in every subdivision of the programme which take into account the presence of cognitive disturbances. Consequently, an essential question is whether remediation of cognitive disturbances is necessary, or whether consideration of these disturbances in the programme is sufficient to obtain improvement on the different levels of functioning.

The final aim concerns the prediction of success during the first and second stage of the programme and during the total programme.

The programme has a duration of eight months and is divided into two stages of four months each. The first stage of the programme is directed at learning to accept and deal with vulnerability for psychotic decompensation, and at the development of basic skills. In one condition the cognitive skills training as developed and evaluated by Van der Gaag (1992) is added to the programme. This training aims to remediate cognitive disturbances and to establish executive control. The second stage focuses on learning to deal with external sources of stress, optimalizing self-care and social skills, seeking appropriate accommodation and developing daily activities.

Overall, during the programme, patients have participated in nineteen programme subdivisions. Twenty-four (31%) of the 78 patients admitted to the rehabilitation ward, could not participate for 75% or more in this rather intensive programme. These patients are considered to be drop-outs of the study. At the first assessment, in general, the drop-outs could not be differentiated from non drop-outs. Only if patients have a very high disorganization score and very poor general behaviour at the first assessment, it seems reasonable to assume that they are unable to participate in a rehabilitation programme as applied in the present study.

After eight months of training, significant improvement is found on proceduralization, competence of social skills, asking W-questions as a reaction to social prompts, general behaviour, the psychomotor poverty syndrome, and reality distortion. However, the improvement cannot be attributed to participating in the rehabilitation programme for 75% or more, since most improvements are also found in the drop-out and control conditions. Also, the outcome is not dependent upon the additional training of cognitive skills, since patients who have participated in the standard condition of the programme show as much improvement as patients who have participated in the cognitive
skills training condition.

Improvement on a particular variable can only be predicted by the first assessment scores on that particular variable. Although information processing (CPT-d') is stable, this vulnerability marker of schizophrenia does not predict improvement of functioning or successful rehabilitation in terms of resettlement in the community.

Although the improvements in the rehabilitation condition do not differ significantly from the improvements in the drop-out and control conditions, significantly more patients who have participated in the rehabilitation programme (drop-outs and non drop-outs), are referred to housing facilities outside the clinic and to 'working situations' outside the clinic. However, if patients suffer from profound cognitive disorganization and have very poor general behaviour at the first assessment, they have a lesser chance to be discharged after participating in the rehabilitation programme.

Given these results it can be concluded that it is not the programme and improved functioning perse that enables patients with schizophrenia to live outside the hospital. It appears that the professional intention and attitude to prevent hospitalization and the reinforcement of residual abilities is the key issue that leads to success. Thus the present study demonstrates that:

(1) In many cases, chronic schizophrenia does not need to implicate long term hospitalization.

Consequently, the rehabilitation programme may be understood as a 'massive exposure treatment' to the residual mental and behavioural abilities of patients. This exposure only is useful, if professionals really help them to find suitable accommodations and working situations outside the clinic. However,

(2) Being discharged from the hospital and finding a working situation outside the hospital can be hindered if patients suffer from severe cognitive disorganization and have very poor general behaviour.

In general, until six and twelve months after the programme, the functioning of the patients participating in the rehabilitation programme improves. However, comparing the final assessment scores to the first assessment scores, problem-oriented coping, social inattentiveness, mannerisms and delusional thinking do not improve. Thus,

(3) Specific interventions are needed to improve problem-oriented coping and to reduce severe symptoms of disorganization and reality distortion.

In this chapter, the question is discussed which interventions should be applied, along with other questions that remain.
9.2 How to improve rehabilitation in schizophrenia?

9.2.1 Bottom-up or top-down rehabilitation?

In the present study, the recognition of 'vulnerability', operationalized in terms of cognitive disturbances, serves as a central and general starting point. According to the vulnerability model cognitive disturbances are impeding factors for the learning of skills. Following this central conception, a bottom-up strategy has been employed in the rehabilitation programme. Training started at the level of cognitive functioning and basic skills before 'survival skills' (or independent living skills) were trained. In a reversed order this strategy may be called 'top-down' rehabilitation; an independent living situation and daily activities outside the clinic are provided for the patient and in case of particular skills deficits, these skills are trained, starting at the level of established incompetence. Considering the conclusions as formulated in the previous section, the question is whether the results in the present study are obtained 'as a result of', or 'despite' the use of the bottom-up approach.

If cognitive disturbances have a pervasive effect on general functioning, then the results of the present study should be related to it. However, with regard to information processing as measured with the CPT-d (which is the most recognized vulnerability marker) it appears that this variable does not predict the (absence of) functional improvement. In addition, patients who participated in the cognitive skills training condition did not profit more from the programme and patients who participated in the control condition did not improve less on functional measures. Based on this finding, it may be concluded that the training of cognitive skills is not necessary to improve general functioning of patients with schizophrenia and to prevent long term hospitalization. However, if a 'massive exposure to residual abilities in a reinforcing environment' is the key issue, then the same may be concluded for every other subdivision of the programme. In other words, each training may contribute to the reinforcement of mental and behavioural residual abilities. Possibly, only the general intention to prevent long term hospitalization, combined with the search for independent living facilities and working situations outside the clinic, is sufficient to obtain the same results.

What about the use of the tactics, as described in chapter three? First, it may be concluded that taking into account the presence of cognitive disturbances doesn't do any harm to patients. However, in some cases (if cognitive disturbances are absent) it may unnecessary slow down the tempo of training and therefore, the tempo of rehabilitation. Second, a clearly operationalized training methodology 'forces' professionals to use the same strategy and enables them to discuss their attitudes in an atmosphere of openness, which is not typified by different opinions about 'the right way to deal with difficult situations'. Again, this is a rather a-specific advantage, which also counts for other generally accepted training methodologies.

As described in section 7.5.2., since the onset of the present study, several other studies show that cognitive training does not positively affect disturbed automatic aspects of information processing (Olbrich & Mussgay, 1990; Van der Gaag, 1992; Benedict et al., 1994). Controlled cognitive operations requiring mental effort (as in the present study performance on the Tower of Hanoi) do benefit from training. However, it is not the
training of cognitive skills, but the general 'exposure' to residual mental abilities that seems to account for this result.

Thus, on the one hand, together with the results of Hodel (1993), who shows that cognitive and social skills training can be applied in arbitrary order, it seems justified to conclude that strongly emphasizing the impeding effect of cognitive disturbances in the process of rehabilitation is not necessary. On the other hand, patients with profound cognitive disorganization (which is related to cognitive disturbances) dropped out of the study or (if they did not drop out) were less able to obtain a living and working situation outside the clinic after the programme. Also, profound social inattentiveness (and mannerisms) has not improved.

With regard to top-down rehabilitation, there are two interesting recent studies. Leff et al. (1994) studied a group of 114 long-stay patients (81% had a diagnosis of schizophrenia) who were discharged to community placements because the hospitals they stayed in had to close down. Thus, these patients were 'resettled' without prior rehabilitation training. All patients were matched with patients who were likely to remain in hospital for a further year. One year after discharge, in general, the leavers benefited from their placement in the community. Although there were no changes in their clinical state or social behaviour compared with their matches, they were living under much less restrictive conditions, and their social networks were enriched by having more friends. While they were in the hospital, 76% of patients wished to leave, after one year, 80% wished to remain in the community (86% after five years). The score on delusions and hallucinations remained steady throughout the follow-up.

Wykes (1994) also investigated long stay patients (n=49) who moved from the hospital to community-based services. Until six years after discharge, the overall change in the group was negligible. However, individual variation can be accounted for by two factors; time since transfer to the community and information processing problems. Regarding the first factor, patients who had stayed at least three years in a less dependent setting did improve on behavioural functioning, whereas those who had spent less time in the community did not improve. Patients with profound cognitive disturbances (reaction time data) demonstrated poorer functioning after they had moved to less dependent care, compared to patients without cognitive disturbances. Wykes concludes that 'cognitive impairment seems to affect the ability to take advantage of further social stimulation'.

In summary, the question whether the results in the present study are obtained 'as a result of', or 'despite' the use of the bottom-up approach, can be answered in three ways.

Firstly, in most cases a bottom up strategy does not seem to be necessary to resettle chronic patients. Patients who have been discharged from the hospital without rehabilitation training, are also able to survive in the community.

Secondly, without training, the level of functioning does not improve after discharge. Training skills prior to discharge does not seem to be an optimal strategy since compared to a traditional long stay ward programme the rehabilitation programme does not unambiguously have additional value to the improvement of functioning. An interesting question is whether a positive effect on general functioning will be found if training as applied in the present study is given to patients after they move to the community.

Thirdly, in case of profound cognitive disorganization the strategy employed is not 'good enough'. Profound cognitive disturbances do not respond to a general bottom-up
strategy, they prohibit participating in a rehabilitation programme as applied in the present study, they hinder resettlement, and seem to be related to poor long term follow-up outcome after discharge without specific rehabilitation training.

Thus, top down rehabilitation (moving patients to independent accommodation and working situations outside the clinic, before applying specific skills training) seems to be an interesting domain for further research. In case of profound cognitive disorganization, the most important question is not 'where patients should be treated or guided' but 'how this should be done'.

Together, these conclusions strongly plead for further development and implementation of 'community based care' for schizophrenic patients. After supplying a meaningful environment to patients, a 'top down' rehabilitation programme should be formulated based upon the individual skills deficits of patients. In case of profound cognitive disturbances this programme 'goes down to the bottom' since it should include the training or compensation of basic skills, related to the adequate processing of information.

9.2.2 The reduction of profound reality distortion.

According to Anderson's model for skills acquisition (1983), information processing is related to the process in which a gradual transition takes place from controlled declarative knowledge to a production system with automatized procedural knowledge. Cognitive disturbances may hinder this process. In clinical practice these are related to cognitive disorganization which, among others, includes poverty of content of speech, social inattentiveness, incongruent emotions and diminished understanding of speech. Together, these symptoms may be typified as 'formal cognitive disturbances'. Regardless the content of the skill that has to be performed, the production system will not be executed in the right way.

Besides formal cognitive disturbances, also the content of cognition can be disturbed. Reality distortion (delusions and hallucinations) may be regarded as 'cognitive disturbances of content'. For example, the patient may interpret a particular situation in a delusional way. Although the form of this interpretation may be very clear (the patient always uses this interpretation in difficult situations), the content will be comprehended as 'abnormal' and consequently, lead to aversive social reactions. Thus, with regard to form, psychotic production systems may be well-established in the information processing of patients. This explains why reality distortion is not related to cognitive disturbances (Buchanan & Carpenter, 1994).

In many cases, aversive environmental reactions will reinforce 'psychotic systems' (Van den Bosch, 1993). For example, a patient who tells his neighbours that he is 'Jesus and has to save the world' will probably be ignored by them. This being ignored will reinforce the conviction since Jesus was also misunderstood.

In the present study, after eight months of training 'ideas of persecution' show improvement. However, compared to the first assessment, at the one year follow-up this item of reality distortion does not improve. Apparently, after the programme, these delusional thoughts have re-emerged, possibly due to aversive environmental reactions. Besides anti-psychotic medication, during the programme, specific attention to cognitive disturbances of content was given only during social skills training. Apparently,
this is not enough to reduce paranoid delusions permanently. As a consequence, a practical implication of the present study is that during the process of rehabilitation, especially when patients have left the hospital, more emphasis should be put upon the reduction of cognitive disturbances of content or the establishment of 'thought control', especially with regard to delusional interpretations of reality.

Lately, the application of cognitive behavioural therapy is one of the highlights in schizophrenia research (e.g. Alford & Correia, 1994; Kingdon & Turkington, 1994). Besides in the process of symptom monitoring and (pre-) psychotic symptom management (Birchwood, 1992; Birchwood & Tarrier, 1992) it is proposed here that cognitive behavioural therapy should also focus on symptoms lower in the diagnostic hierarchy like anxiety and depression and on emotions related to the process of accepting the mental illness and its consequences. It is a well known fact that anxiety, depression and emotions related to grief can be successfully treated with rational emotive therapy (Dryden & Hill, 1992). Illustrative for the need to apply this therapy is the finding of Penn et al. (1994). They found that social anxiety is related to negative symptoms in schizophrenia. According to the authors, instead of training social skills, cognitive restructuring of irrational thoughts leading to anxiety is in that case indicated.

Cognitive behavioural therapy should also play a more significant role in the process of psycho-education. For example, Birchwood and Shepherd (1992) found 'fear of going crazy' to be an important pre-psychotic symptom. The rational normalization of schizophrenic symptoms, anxiety and sleep-disturbances in schizophrenic patients is suggested by Kingdon and Turkington (1994). Also, the restructuring of irrational thinking of relatives with regard to schizophrenia and the patient's behaviour, seems to enhance the effect of psycho-education for relatives (Lam, 1991).

In summary, cognitive behavioural therapy, aimed at reducing reality distortion and guiding the process of psycho-education, is believed to be a challenging and promising field for further research.

9.2.3 The establishment of problem-oriented coping.

Apart from executive control (the smooth processing of information) and thought control (diminished reality distortion), patients also need to know how to cope with problems. As stated in chapter 1, the subjective evaluation of the meaning of a stressor supposedly has more causal significance to the behaviour which follows, than the objective stressor itself (Reich et al., 1988). 'Coping' is defined as constantly changing cognitive and behavioural efforts to control internal or external stressors that threaten to exceed one's threshold (Lazarus & Folkman, 1984). In order to achieve the goals of rehabilitation it is necessary to develop control over stressful situations. Therefore, a central feature of the programme has been the establishment of problem-oriented coping. Patients were taught to deal with their illness, its consequences and the general stressors of daily life. All subdivisions focus on the initiation of appropriate behavioural strategies when faced with a problem.

In the present study, the application of problem-oriented coping as reported by the patient, does not improve. Comparing the final score (17.0) to the norm score of a 'healthy' Dutch male (Schreurs et al., 1988) it appears that patients score low on the average range.
So, in general, this result is not alarming. However, considering the fact that patients have a higher degree of vulnerability to stress than normal it seems desirable for them to have a higher level of (self-reported) problem-oriented coping than average. Apparently, the application of a general rehabilitation programme, does not supply patients with this extra expedient. Although self-reported application of problem-oriented coping is not the same as the actual application of problem-oriented coping behaviour, it is assumed here, that the training of problem-oriented coping should be more related to specific problems of patients. Thus, the training should not be focused on general skills, which were probably already present in the behavioural repertoire of most of the patients. Training problem oriented coping related to individual and specific problems of patients, may contribute to the subjective experience that problem control is possible, and consequently to increasing self reported application of problem oriented coping strategies.

9.2.4 The role of society.

Rehabilitation not only is a process of patients, relatives and health care professionals. Rehabilitation also is a social matter; patients will be unable to obtain a gratifying social position if 'society' does not create the opportunities for them to seize. For example, if a patient lives outside the hospital and finishes a training to perform the role of part-time employee effectively, the employer should not valuate this former patient with regard to his 'psychiatric history' but in respect of his present abilities and skills. It is generally an open secret that the employer will prefer an applicant without such history. In that case, the patient will not be able to show he is capable to carry out the role behaviour and will not achieve the related social position. Consequently, the chances of becoming involved with 'non-patients' are minimized. The 'patient-role' may easily be reinforced by this. In this sense, it is assumed here that society also should contribute to the successful rehabilitation of patients. It should prevent patients from being faced with the same problems as the 'handicapped people' described by Goffman (1959); They must prove to be far better than normal to obtain equal to normal chances. Therefore, a rehabilitation programme as evaluated in the present study, even if it is applied 'top-down', is not enough to establish 'real' resettlement. Educating society about schizophrenia aimed at the reduction of prejudices such as 'the fear of madness' is necessary to reduce social stress inflicted upon patients as soon as they leave the hospital.

In the present study 'social stress', a component of the 'vulnerability-stress-coping' model, has been included as far as the subdivision of psycho-education for families and relatives of patients is concerned. It is not argued here that psycho-education for society should be managed by the staff members of psychiatric institutions. However, if governments want to gradually close or reduce the capacity of mental hospitals they should also help to prepare society to 'welcome' those who leave the hospitals. According to Anthony (1993) 'recovery' from mental illness is 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles'. It is stated here that it is also a deeply social, human process of changing negative attitudes, values, feelings and behaviours with regard to 'the abnormal'.
9.2.5 Methodological considerations for further research.

Based upon the present study, besides practical reasons to implement 'top down' rehabilitation, a statistical reason strengthens this implication as it is shown that clinical, groupwise rehabilitation of schizophrenia does not always take into account statistical procedures and rules.

Although in the present study, multivariate statistical techniques have been applied to compare the conditions, one of the most important preconditions for these techniques (independent observations) was violated. According to Stevens (1986) whenever the treatments involve interaction among subjects, such as discussion method or group counselling, the observations may influence each other. In the present study, including many group trainings, participants were encouraged to help each other, for example to find problem solving methods.

A second methodological problem was the fact that during the present study, the rehabilitation ward 'had' to move from an old psychiatric building with dormitories, to newly built comfortable houses with private bedrooms. Consequently, history (significant environmental events other than the treatment or experience of interest (Neale & Liebert; 1980), occurred between the first and second assessment for a CST-group, and between the second and third assessment for a Standard-group.

Thirdly, the issue of randomness of the sample is under discussion. Exclusion criteria determine some limits to the generalizability of the present study; patients with schizophrenia and manifest mental retardation, addiction or selfmutilating behaviour, are not included in the population just as patients who involuntary stay in the hospital. However, another issue is much more interest; The longer the present study continued, the less the inclusion criterion 'admission indicated for long stay wards' could be guaranteed. After the first groups finished the programme and some 'treatment resistant' patients seemed to be able to live outside the hospital, it appeared that some other hospital's staffmembers were impressed by the results. Also, family members, sometimes united in a society for families of schizophrenic patients (Ypsilon) started to pass the news from mouth to mouth. As a result of this, more patients were referred to the ward and entered 'indicated for this rehabilitation programme'. Although clinically and morally encouraging this obscured the randomness of the sample and consequently the application of advanced statistical procedures.

Fourthly, in the present study a practical stand was taken with regard to the effect of medication (antipsychotic medication and benzodiazapines). Patients who needed a major change in antipsychotic medication were excluded from the study and benzodiazepines and anticholinergics were only changed temporary within a small range of dosage. Thus, in the statistical analyses the results were not controlled for the effect of medication. Especially the comparison of control subjects and patients who participated in the rehabilitation programme, may be obscured by this omission.

The application of individually tailored rehabilitation programma's after discharge will do justice to the condition of 'independent observations', reduces the chance of independent environmental changes, and prohibits the formulation of 'treatment-dependent' inclusion criteria.

With regard to the inclusion criteria, it is suggested here to operationalize the three syndromes of schizophrenia before the interventions start. In view of the large within-
patient variability regarding the occurrence of the psychomotor poverty syndrome, cognitive disorganization and reality distortion, it seems wise to establish their prognostic value in every study on the effect of specific interventions.

Finally, it is stressed that the concept of control has statistical significance as well. Firstly, if independent variables (demographics and dosage of medication) significantly correlate to dependent variables, they have to be included in the MANCOVA's. Secondly, as long as the studies on the rehabilitation of schizophrenia raise more questions than they answer, there is a great need for controlled evaluation of the various interventions that focus on the same goals.

9.3 Summary and conclusion: schizophrenia and selfcontrol.

The present study demonstrates that in many cases, chronic schizophrenia does not need to implicate long term hospitalization if patients are exposed to their residual abilities and helped to find suitable accommodations and working situations outside the clinic. Thus, the results strongly plead for further development and implementation of 'community based care' for schizophrenic patients. Top down rehabilitation should be based upon the assessment of individual skills deficits and should be individually tailored.

Together with this general implication, the present study shows that more emphasis should be put upon the further development of training and prosthetics to optimize formal cognitive functioning, the further development of cognitive behavioural interventions to reduce cognitive disturbances of content (reality distortion), and the identification of specific problems, in need for training of a more elaborate style of problem-oriented coping. Thus, if patients with schizophrenia want to 'survive' outside the hospital, it seems necessary for them to develop more control with regard to the process of information processing, the content of information processing and specific individual problems. Consequently, the implications of the present study stress that it is not 'vulnerability' alone that is the central impeding factor in the rehabilitation process of patients with schizophrenia. Schizophrenia is also associated with symptoms lower in the diagnostic hierarchy, especially with irrational thinking which is associated with the inability to perform particular skills, depression, grief, hopelessness, anxiety, worrying, muscular tension and irritability (Dryden & Hill, 1992). Therefore, it is suggested here, that not 'vulnerability' but 'cognitive selfcontrol' in general should be the central theoretical and practical concept in rehabilitation. It seems, in other words, that rehabilitation should return to its source; Bleuler (1911) defined it as 'the development of selfcontrol, and the proper utilization of time'.