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REHABILITATION THROUGH EDUCATION

An evaluation of a Supported Education programme for people with psychiatric disabilities

Summary

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Since 1999, there has been an interest in the Netherlands in supporting people with psychiatric disabilities who are returning to or remaining at regular education settings. In April 1999, at ROC Zadkine, a large community college in Rotterdam, the first structural Supported Education programme started for this target group. The aim of the programme is to help people with psychiatric disabilities to choose, get and keep regular education. ROC Zadkine, a large community college in Rotterdam, introduced the first structured Supported Education programme for this target group in April 1999.

The programme is based on the Choose-Get-Keep model, as developed at the end of the eighties of the last century by the Center for Psychiatric Rehabilitation of Boston University. The model in turn is based on the Psychiatric Rehabilitation approach of the same Center. The mission of the Psychiatric Rehabilitation approach is to increase the functioning of persons with psychiatric disabilities so they can be successful and satisfied in their environment of choice with the least amount of professional intervention.

Parallel to the Supported Education programme, a study was carried out on the experiences and results of the programme. The formulated aims of the Supported Education programme formed the basis of the guidelines for the study.
These aims included the following:

1. to determine who participated in the Supported Education programme;
2. to determine how the Impulse course (a self-contained classroom) contributed to choosing and getting a regular education;
3. to determine the kinds of problems students with psychiatric disabilities experienced with regular education and how the on-site and mobile support helped them to remain at school;
4. to determine what course the individual process of the choosing, getting and keeping phases of the Supported Education programme took.

The specific aims with respect to the outcome of the programme are:

5. that people with psychiatric disabilities choose and get a regular education;
6. that students with psychiatric disabilities keep their education;
7. that the self-esteem of the participants improves;
8. that the quality of life of the participants improves;
9. that the psychiatric symptoms of the participants remain stable;
10. that the participants value the support as provided by the Supported Education programme;
11. that dropping out of the Supported Education programme does not have a negative effect on the well-being of the participants.

The study was carried out between January 2000 and July 2003. During this period, 45 people with psychiatric problems participated in the Supported Education programme. The content of the programme was a self-contained classroom (the Impulse course), intended to help people with psychiatric disabilities in a classroom setting to choose and get a regular education , and on-site and mobile support to help students with psychiatric disabilities to keep their education.

Chapter 2 describes the importance of Supported Education programmes for people with psychiatric problems. The chapter examines the relationship between psychiatry and

education, the percentage of students with psychiatric problems in educational settings and the legislation on studying with psychiatric disabilities. Also the relationship between having a diploma and getting a job is described. The meaning of education for the personal recovery process of people with psychiatric problems is examined, as well as the barriers these people experience during the choosing, getting and keeping phases of the Supported Education programme. The educational problems of people with psychiatric disabilities as a proportion of the general problems of education are broadly recognised. In the Netherlands, there is no tradition in Supported Education for people with psychiatric disabilities. Neither is there any thing in the fields of mental health care or education.

Based on a literature study **chapter 3** presents an overview of the existing models of support provided to people with psychiatric disabilities who want to return to or remain at college. A distinction can be made between three main models namely: returning to regular education, the on-site support model and the mobile support model. The first model focuses on the preparation for **returning to regular education**. This model consists of three submodels. The self-contained classroom model that provides opportunities in a group setting to develop and practice skills and develop career choices by using a set of curriculum modules. Unlike the procedure in the self-contained classroom model, in the second submodel, the group model, the curriculum sequence is determined through an assessment of the participants' needs at the beginning of each semester. The third submodel provides individualized services, including career planning and vocational assessment, information on enrolment in colleges and assistance in obtaining financial aid.

The second model, the **on-site support model**, provides emotional and educational support through a Supported Education service at the educational establishment at which the student studies. The **mobile support model** is the third model of support. The emotional and educational support in this model is provided by a Supported Education service that is linked to the educational setting in which the student studies. In most cases, the Supported Education staff is employed by a mental health organization. Within the scope of this support, the student visits one of these staff members. However, if desired, the staff member may come to the college. The working methods of the different models can be reduced to the phases of choosing, getting and keeping regular education.

Chapter 4 examines the effects of studies on the Supported Education programmes in Canada and, especially, the United States. The selection criteria for participation used by the Supported Education programmes are discussed, as well as the socio-demographic and clinical characteristics of the participants. Each study focuses on a part of the Supported Education process. Some studies focus on the preparation phase of the process (self-contained classroom) or on the on-site and/or mobile support in a regular educational setting. Studies examining the whole process of choosing, getting and keeping regular education are not found. Although not large in number, all (qualitative) studies reviewed show the following consistent results:

1. people with psychiatric disabilities are able to choose, get and keep regular education;
2. participants of Supported Education programmes show that they are able to keep a job and education;
3. the self-confidence and the self-esteem of participants in a Supported Education programme increase;
4. students benefit from the provided support and they value the support in the application phase; they also value the support at the educational settings and the support in getting and keeping financial aid.

The focus of **chapter 5** is the development of the Supported Education programme in Boston to the *Begeleid Leren-programma* in Rotterdam. The conceptual framework underlying the Boston Supported Education programme is described, as well as the process

of making it operational in the 'Choose-Get-Keep'-model. The organisation and content of the Supported Education programme in Rotterdam, adapted to the Dutch context, are examined. The phases of choosing and getting were made operational in a self-contained classroom, called Impulse, and the keeping phase was made operational in on-site and mobile support. The self-contained classroom as well as the on-site support took place at ROC Zadkine. The ROC Zadkine, being the research location, is described separately.

Chapter 6 deals with the methodology of the study and includes an overview of the research instruments. The overall research question is based on the overall aim of the Supported Education programme: '**To what extend is the Supported Education programme successful in helping people with psychiatric disabilities to choose, get and keep a regular education of choice, so they can function successfully and be satisfied in their role of student?'.** The aim of the programme evaluation is to collect data which make it possible to make a systematic judgment about the attainment of the aim. The study consists of three substudies:

- substudy 1 researches the choosing and getting phases of the Supported Education programme: the Impulse course;
- substudy 2 concerns a study of the results and experiences of students with psychiatric disabilities in the keeping phase of the programme, and of the contribution in content of the on-site and mobile support service to this phase;
- substudy 3 is a case study of the individual process of choosing, getting and keeping a regular education.

Substudy I focuses on aims 1, 2, 6, 8, 9, 10 and 11 of the Supported Education programme. To get an answer on the research questions the percentage of participants who completed the Impulse course has been assessed, as well as how many participants has chosen an education and how many participants has received an education. To measure the effects of the Supported Education programme on the self esteem, the quality of life and the psychiatric symptoms, the Rosenberg self esteem scale, the Quality of Life scale (the short Dutch version of Kroon) and the SCL-10 has been used. Also the participants and the Supported Education workers have been interviewed about their experiences of the programme. Participants who dropped out of the programme have been interviewed about the reasons behind this as well as the consequences of this on their daily functioning six months after they dropped out.

Substudy II focuses on aims 3, 7, 8, 9, 10 and 11 of the programme and consists of a quantitative and a qualitative part. The qualitative part is descriptive in nature and reports the experiences of fifteen participants with psychiatric disabilities who went to college after the Impulse course. The participants have been interviewed at the end of their first year at college and the same scales on self esteem, the quality of life and the psychiatric symptoms has been used (the quantitative part of the substudy) in an attempt to answer the research question.

In substudy III the central focus is on the whole individual process of choosing, getting and keeping a regular education. Aim 4 of the Supported Education programme forms the basis of the guidelines for a multiple case study. Over a period of three and a half years, five participants of the course were studied in the choose-get-keep process. The main research question is: 'how is the course of the choose-get-keep process for the individual participant?' The subquestion that goes with the main question is: 'Which beneficial elements and barriers do the individual participants experience during the process?. During this period, data was collected at baseline and at five follow-up points. In this substudy the perspective of the participants is the central focus.

The aim of **chapter 7** is to gain a clear insight in the characteristics of the participants of the Supported Education programme. Supported Education is a relatively new concept in

the Netherlands. Not much is therefore known about who participates in this kind of rehabilitation programme. This chapter thus deals with the characteristics of the participants of the Impulse courses in detail. This description is followed by a comparison with the characteristics of participants of other relevant (mental health) programmes.

The outcome shows that the participants in general are younger than the psychiatric population in the Rotterdam region and participants in other rehabilitation and mental health programmes. The explanation could be that the need for education the related perspective on work is more present in younger people. This is similar to the younger age of the participants in Supported Education programmes in the United States. This is probably related to the age where most of the participants are single. The level of education of the participants is higher than that of the participants in other rehabilitation and mental health programmes. This is probably related to the content (low education jobs and day activities) other (vocational)rehabilitation and day activities programmes provides and who are less attractive to young, intelligent people. About as many men as women participated in the Impulse courses. There is much diversity among the psychiatric diagnoses of the participants (schizophrenia, mood disorders, personality disorders and other diagnoses). In comparison with to other populations who have been studied, the personality disorder appears more.

Chapter 8 deals with substudy I and describes the results of and the experiences with the Impulse courses 1, 2, and 3. On all areas concerned (self-esteem, psychiatric symptoms, participation and graduation percentage, choosing and getting regular education and goal formulation), the Impulse course shows a consistently positive outcome. Given the limitations of the research design, it is not possible to attribute the outcome to the Impulse course. The negative side effects (the image of being difficult to teach, a negative self-image and lower expectations for the future) of dropping out of the Impulse course on the well-being of the participants are not found in this study. For the most part, the Impulse course is highly valued by participants and teachers alike.

There is not much known about the experiences people with psychiatric disabilities have with regular education. Therefore, **chapter 9** describes the experiences of the participants of the Supported Education programme who started regular education directly after the Impulse course. To that end fifteen participants were interviewed. The nature of this chapter is mainly inventorial and descriptive.

Education ranges from important to very important to all interviewees. They mention different reasons, but most participants (75%) see getting a job as the most important reason to start an education. A paid job means independency and being fully functional in the community. Education also means more knowledge and a chance for general development. Through education participants can see what they are capable of. They also have the opportunity to participate in discussions with others. Education also gives them the opportunity to be active, to have contact with other people and to prevent them for isolation.

Almost all participants say that they are functioning better since they started their education. They feel more secure, have more self-confidence and enjoy life in general more. They feel more at ease in their contact with others, and are easier in their conversations. They also notice this in their contact with relevant significant others. They report improvements in their relationships with their partners and family due to an ability to communicate and debate more and fight less.

Although, for several participants, the illness is still a problem in that they haven't left their sick role behind them, most participants value the role of student as more important. The role of student means that you are an ordinary, normal person without a label. The role of student is a role with a high value in the community. It means that you belong to the community and that you are equal to others.

Besides the positive experiences the interviewees also mention some bottlenecks: The study costs a lot of energy, especially the needed attention and concentration. The

participants are often very tired after a day at school. The field work is problemmatic for some of the participants, especially the change from the role of student to the role of employee and colleague; Education in itself already provides often stress, but especially the combination of the study with the responsibility with housekeeping and children; dropping out of school was related to the choice of education for two of the participants; self disclosure is an issue for most participants. They are afraid of being victims of stigmatization disclose their psychiatric background and if they choose not to tell they do not feel free. Another problem is related to requesting assistance. Some of the participants do not recognize the need for assistance and participants who do recognize the need do not request the needed assistance because they have the opinion that they have to solve the problems themselves. This does not always happen. Also some of the participants do not accept the offered and needed assistance.

Much of the observed bottlenecks also exist in fellow students without any psychiatric disabilities. Probably because of the lack of self confidence and of the feeling of insecurity, the bottlenecks seem more stressful to the participants of the Supported Education programme, which possibly explains the (great) need for emotional support. The combination of difficulties in different domains (study, illness, daily life) makes studying difficult.

Chapter 10 presents the outcome data of the fifteen participants of whom chapter 9 describes the experiences with regular education. The focus is on the research question: 'Are people with psychiatric disabilities able to keep their regular education?' To answer this question, the participants who started regular education directly after the Impulse course were interviewed at the end of the first year of their regular education.

The support provided by the Supported Education programme provided in this phase is examined separately. To gain clear insight into the contribution in content of the on-site and mobile support, the participants were interviewed about their experiences with the provided support. The five staff members of the Supported Education programme were interviewed about the support they provided to the participants during the phase of keeping their education.

The percentage of participants who dropped out of the Supported Education programmes has been compared with the percentage drop outs in secondary education. In secondary education the yearly drop out percentage is 37%. The highest percentage of drop outs is in the first year of secondary education. The percentage of drop outs among the participants of the Supported Education programme is 15% (3 out of 20) in their first year of secondary education. This is a positive result in comparison with this national percentage

The outcomes on the self esteem scale, the quality of life scale and the symptom scale are also positive. The hypotheses that the self-esteem and the quality of life would improve and the amount of symptoms would stay the same has been affirmed. The variation analysis for repeated measures (start Impulse course, end Impulse course and end of first of education) shows a significant improvement of the scores of the self-esteem scale of Rosenberg and the Quality of Life scale (total score). The symptoms measured by the SCL-10 showed no significant change in time. This outcome is also according to the formulated hypothesis.

The study has some limitations. First, only a small number of participants have been interviewed. Secondly, since the participants have only been followed during the first year of their education; it is difficult to predict how many drop outs there will be in the later years of college. Thirdly, it is difficult to determine the relationship between the positive results and the contribution of the on-site or mobile support the Supported Education programme provided to the participants. There was no control group of subjects.

The eleven participants who got support for the Supported Education programme expressed their satisfaction about the support which they received. Some participants complained about the telephonic inaccessibility of the Supported Education workers. Only a

few persons expressed a need for more or more intensive support. The four participant who didn't received support from the programme received enough from relevant others. They are also satisfied about the support they received.

The Supported Education programme emphasizes provision of emotional support. Besides this kind of support the support focuses on the conversation skills with professors and fellow students as well as skills used to request help for accommodations and how to activate resources. The lack of social and emotional skills are the most important personal barriers to the participants. Intellectual and physical skills have hardly been mentioned. Because of this, it seems to be important to develop lesson plans for the following skills:

- Requesting assistance and requesting accommodations;
- Activating resources;
- Interpersonal skills.

The Supported Education workers believe that a personal and good educational choice is the most important factor for success. The psychiatric illness in itself is not a real barrier, although a relapse could be.

Together, the actual outcome (dropout percentage), the outcome of the questionnaires and the outcome of the interviews with the participants and the staff (about success, satisfaction and meaning) show a consistently positive image of the capacity of people with psychiatric disabilities to remain at college and provide a clear picture of the contribution of the Supported Education programme to it.

Chapter 11 concerns substudy 3, with a focus on the whole individual process of choosing, getting and keeping a regular education. In this substudy, five participants of the first Impulse course were followed for three and a half years. During this period, data was collected at baseline and at five follow-up points. The case study (N=5) shows how the Choose-Get-Keep-process works out for an individual participant. In the chapter, the selection of the cases and the course of the interviews are described. The chapter also contains a description and an analysis of the process of the five individual cases and a comparison between the five cases.

The comparison of the data of the case study's leads to some careful conclusions with regards to the process of choosing, getting and keeping regular education:

1. Support is important in all phases of the Supported Education process.
2. The chance to fail at school seems more related to the amount of daily responsibilities (housekeeping, care for children) and less to the psychiatric diagnosis.
3. Fear of stigmatizing differences per person. Young people seem to be more afraid of it.
4. Going to school has great meaning for the participants. It gives them the chance to exchange the role of patient role with that of student.
5. The role of student becomes difficult when the mental problems become dominant.
6. A pro-active attitude of relevant others can be necessary when the person do no recognize the need for support and/or do not request for assistance when necessary.

Chapter 12 presents a summary of the findings and some conclusions and recommendations. Based on the aims of the Supported Education programme the outcome of the three substudies is discussed. It can be inferred that especially young adults with psychiatric disabilities participated in the programme. Of the 45 participants who started the Impulse course thirty completed the course. Of these thirty participants 26 set a concrete educational goal and twenty of them actually started regular education. At the end of the first year of the regular education, three of the twenty participants dropped out. The results in the areas of self-esteem, quality of life and symptoms are in keeping with the original aims of the programme. The experiences of the participants and the Supported Education staff were mainly positive. Suggestions have been made to come to an integrative Supported Education

programme. In such a programme educational and mental health care organizations together provide preparation activities for returning to regular education and also on-site and mobile support for their own clients/students as well as for clients/students of other educational and mental health care organizations in the region. The chapter ends by giving recommendations for improving the Supported Education programme and for further activities and research in the field of Supported Education.

This is the English summary of the dissertation:

REHABILITATIE DOOR EDUCATIE. Onderzoek naar een Begeleid Leren-programma voor mensen met psychiatrische problematiek. Amsterdam, SWP, 2005.