

Summary

In 1988 Dutch care providers for persons with a severe mental handicap and (very) severe problem behavior became subject for debate after the publication of a disturbing picture in the national newspapers of a young woman, called Jolanda Venema. In her interest and that of three other residents with a severe mental handicap and severe problem behavior, a very Intensive Care Project was successfully set up and implemented. The Chief Health Examiner for Public Mental Health Care proposed to conduct a scientific study on the development and implementation of this support program.

The present thesis describes this study that was carried out at Hendrik van Boeijen-Oord, an intramural facility for persons with a mental handicap. The goal of the study is to develop an effective support program for the intensive care for persons with a severe mental handicap and (very) severe problem behavior. The study focuses on two research questions: 'what constitutes the developed support program?' (research question 1) and 'does the developed support program produce the desired effect?' (research question 2). To deal with these questions, a distinction is made between a proposed, an implemented and a desired support program. The proposed support program formulates the proposed implementation scheme by the care service. The implemented support program is the actual realization of the proposed scheme. The desired support program consists of an external norm, obtained by theory and practical experience, according to which the desirability and effectiveness of the support program can be determined.

Chapter 2 describes the concepts included in the goals. The target group of the support program are persons with a severe mental handicap and (very) severe problem behavior. The person's problems are placed in a context in which the interaction between care worker and resident and the resident's optimal development are key issues. Problem behavior is seen as a social problem related to the culture and tradition of the environment to which the resident belongs. The support program under study consists of nine interconnecting components constituting the process from problem issue to solution.

Chapter 3 explains the design of the study. Program evaluation is the most appropriate type of research to examine the practical implementation of these activities. The modifications in the proposed and implemented support program ask for a developing research design, including an orientation phase, a development phase and a testing phase. The research target remains

the same. The exact course depends on unpredictable factors, resistance and other matters demanding adjustments to circumstances.

Logical, empirical and normative arguments form the basis for the description of the desired support program in chapter 4, according to which the quality of the proposed support program at the research location can be assessed. In addition, quality-enhancing measures may be suggested to move towards the desired support program. The starting point of the desired support program is that if a person wants to modify severe problem behavior, he will have to create an environment which is no longer based on restraint but on respect for the resident and where deterioration of standards are counteracted.

Chapter 5 concerns the description of the orientation phase where the implemented support program is compared with the proposed support program and the proposed support program with the desired support program. The results of the first evaluation period formed the basis of the study, which was then given direction through practical experience. Following the orientation phase of two evaluation periods concerning the implementation of the proposed support program, it emerged that the implemented program did not meet the characteristics of the proposed and desired support program.

Chapter 6 describes the development phase in which the proposed support program was formulated, introduced and evaluated. Contrary to the exploring and observing role of the researcher in the orientation phase, he now assumed a leading role. Care workers at various levels at the location were frequently consulted to develop the support program. Sticking points in the implementation led to additions to and modifications in the proposed support program. At the end of the development phase the implemented support program proved to be concurrent with the proposed support program. The result was a 'Support program for the intensive care for persons with a severe mental handicap and (very) severe problem behavior' (Wielink, 1998). Research question 1 has now been answered.

Chapter 7 deals with the testing of the support program. It is examined whether the support program has produced the desired effect on the residents, the care workers and the organization.

At the residents' level the introduction of the support program mostly resulted in improved behavior. The way in which the residents at the research location have been treated indicates a break with the caring culture from the past, in which adapted behavior was considered a necessary condition for participating in daily activities. The program seems an excellent tool for stimulating this shifting attitude.

At the level of the care worker the support program is found to have a varying effect. The care workers and staff members at the location who have

worked with the program indicate that they feel satisfied with the guidance received from the support program.

Also, at the level of the organization the support is found to have a varying effect. There has been a noticeable effect on the various plans, on the consultative structure and on the involvement of parents/family in the care and organizational culture. The plans need to be improved so that these areas can make a better contribution towards meeting the demands of the program.

The answer to research question 2 reads as follows: In general the support program has produced the desired effect. From the viewpoint of the three different levels the effect was measured as most noticeable on the residents and less apparent on the care workers and the organization. The persistence of severe problem behavior and our culture's resistance to change are delaying factors in making progress.

Chapter 8 concludes that the target of the study, "Developing an effective support for intensive care for persons with a mental handicap and (very) severe problem behavior" has been realized. The effectiveness of the support program had to be evaluated in a relatively short period of time by measuring changes in residents whose problem behavior can be characterized as persistent. The outcome is encouraging. It can be concluded that the support program can be regarded as a valuable instrument for solving the problems for which it has been designed. The support program fits in the new paradigm of the vision on the care for persons with a mental handicap.

