Buigen of barsten?
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Summary

This study describes the history of the care of the mentally handicapped in the Netherlands between 1945 and 2000. The central theme is the development of a separate care system for this group of citizens. At present the care of the handicapped has grown into an externally isolated and internally differentiated care system. The system is described as the body of people, means and efforts that meets the needs, specific for people with a mental handicap and their surrounding environments. In 2000, in this system about 90,000 workers supply care to approximately 120,000 people, defined as mentally handicapped. The care system includes a large number of specialized institutions, with an annual overall budget of approximately 6.7 billion Dutch guilders. As a result of this system many mentally handicapped lead “a life in apartheid”. This means that they only associate with their own kind and live, work and recreate in separate facilities, that seem to be apart from society. To find the causes of the development of this “apartheid system” is the leitmotiv in this story. The question was: “How and influenced by what factors (for instance social developments, events, individuals) did a separate system of care of the mentally handicapped develop in the Netherlands after 1945?

Chapter 1 “Introduction” deals with the three aims of the study. Firstly, giving a survey of the post-war developments in the care of people with a mental handicap. This development cannot be properly described without incorporating general social trends (like the rise of the welfare state, individualisation, denominationalism) in the study. Secondly, to give due to the dedication and commitment of all those who helped realize specialized services. Despite all comments made in this study on the “apartheid” services, they have greatly contributed to a better life for the mentally handicapped. Thirdly, to use theoretical concepts from social sciences in order to offer a more than impressionistic description of the developments. Summarized, the aim of this study is to give a historic survey of the post-war care of the handicapped in the Netherlands, based on interviews with those concerned and literature study, systematized using relevant theoretical concepts. The emphasis is on housing, and because of that services in the areas of education and work are only dealt with indirectly. Developments in psychiatry, from which the care of the mentally handicapped partly stems, are taken into account in this description and comparisons are made with developments in other Western countries. Each chapter ends with a short summary.

Chapter 2 “Theoretical points of view” states with what theoretical framework the post-war history of the care of the handicapped is approached. The starting-point is a system approach, in which the care of the handicapped is seen as a separate subsystem within Dutch health care.
This subsystem had and has as its social function to supply care of people who, based on criteria like intelligence and social adaptability, are defined as mentally handicapped. The way in which the mentally handicapped are seen and the way in which they are defined and classified is strongly influenced by the view of mankind. The ever changing names (mentally defective, idiot, feeblemindedness, mentally handicapped) is a form of labelling that stems from the “strangeness” of this people who do not meet the usual social standards. The mentally handicapped were one of the players who determined the action of the care system for the handicapped. Based on views of mankind, standards and interests, all players followed a strategy. They made their moves, and, anticipating or not, took into account the rules. The concept “hindrance capacity” is used to indicate that the more complex a system becomes (more players and rules), the more the capacity of those concerned to realize their own goals decreases.

In this study, the subsystem care of the mentally handicapped is dealt with from several interpretation levels (micro, meso, macro and meta). Based on that, various explaining factors for the developments are given. Within the system and in the games, played in those systems, several long-term processes are active, i.e. civilization, disciplining, medicalization, labelling, professionalization and protoprofessionalization. These concepts act as “spotlights” for the classification and interpretation of the many data and gave an understanding in the way in which society dealt with citizens, seen as “abnormal”.

The third chapter “Previous history “ first gives a global survey of the fate of the mentally handicapped over the ages. Over the ages general social developments, like the prevailing view of the human kind, economic situation and ideologies, determine the life of idiots and other simple minded persons. They were part of the large group of maladjusted individuals who found themselves at the outskirts of society. Starting from the 17th century, with the development of the new capitalist production methods and the Calvinistic work ethics, these maladjusted individuals were set apart in houses of correction, where attempts were made to discipline them into useful and productive citizens. The Age of Reason, with its ideal of the rational, autonomous human kind resulted in initiatives to educate “idiots” and to civilize them into civilized citizens.

At the end of the 19th century, with its social background of capitalism, its civilization offensive of the liberal citizens and confessional movements of the protestants and Catholics, the first specialized services for mentally handicapped were established. Around 1900 a separate group of citizens was defined as “feebleminded”, which was a condition for this specialization. A category of people, that were later subdivided into idiots, imbeciles and morons, were referred to as “feebleminded”. Because the authorities in accordance with the principles of the leading political parties, abstained from interfering, there was ample room for private initiators to establish the first institutions for feeble minded people.
Initially they were meant as educational institutions, but due to disappointments over the results and the emerging social Darwinism they developed into storages for socially maladjusted individuals. After 1900, the “eugenistic alarm” and the economical crisis enhanced the fear for the feebleminded, who were seen as the cause of social problems like poverty, prostitution and alcoholism. Together with the institutions the other pillars of the system or the handicapped were established before 1940, i.e. Special Primary Schools and their follow-up care (from which the Sociaal Pedagogische Diensten, SPDs1 would stem).

The fourth chapter “The foundations” investigates why more and more mentally handicapped individuals ended up living in separate facilities. The extensive distress in the families with a mentally handicapped child in the post-war era was a very important factor. Social developments like denominalization, the room the authorities left private initiatives, the economic growth and the appeal of the institutions themselves contributed to the fast increase in the number of institutions. In those institutions a process of professionalization took place through the attitude of various experts. The seventies brought criticism on the massiveness, the lack of privacy and the isolation of the institutions. The critical staff of Dennendal formed a radical exponent of this criticism of the traditional institution. From the seventies on the institutions introduced more humane elements (smaller communities, more parent participation), but characteristics of the “totalitarian institution” (lack of freedom of choice, living in a subculture) partly remained present.

Compared to other Western countries, the Netherlands took a different road in the care of the handicapped, often lagging behind developments elsewhere and with its own features that resulted from the character of the Dutch society. Typical for the Netherlands was the continual growth in the number of institutionalized mentally handicapped, while institutions in other countries (Norway, United States) were cut back. From the sixties a differentiation took place in the supply of services due to the rise of new services, like the “surrogate-family” units and day-care centres. These services were the semimural sector, as distinguished from the intramural sector with its institutions, and the extramural sector (ambulatory care) of the SPDs. All these sectors developed their own culture, working methods, training and umbrella organizations and own categorical legislation. This internal differentiation caused a “jungle” of services that were not tuned to one another. Attempts for co-operation, through a national body for care of the mentally handicapped or regional consultative bodies for care of the mentally handicapped, met with difficulty because the institutions put their own interests first. It took until the mid seventies to realize of one umbrella organisation for all services in the care of the handicapped, the Dutch Society for Care of the Handicapped.

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1 An SPD is an independent organization, specializing in services and support to people with learning difficulties or special needs, their parents and carers
Chapter 5 “The experts: scientists and professionals” states that after 1945 more and more specialized experts have addressed the care of people with a mental handicap. These experts were responsible for the definition of people as “mentally handicapped” and stimulated the development of specialized research, treatment and guidance and support methods. By the label “mentally handicapped” they provided a group of citizens with a ticket to services of the care system for the handicapped. At the same time, this label interfered with their social participation.

The scientific infrastructure for the care of the handicapped was built up along various channels, i.e. institutions, universities and several specialized organizations. The institutions initially concentrated on etiological research. Next they paid much attention to the development of guidance and support methods and sometimes established special chairs. The academic research was scattered over various disciplines, often of unidisciplinary nature and aimed at the individual. The scientific research was continually at risk to justify the existing situation of apartheid. A number of organizations, in particular the Bisschop Bekkers Institute, tried to combine the fragmentarian knowledge and to bring more coherence in the research policies.

There has never been developed a sound definition of a “human with a mental handicap”. It is primarily a social construction, the contents of which varied, based on the changing social and professional ideas on intelligence and social adjustability. Over the past decades, several scientific models have been developed, i.e. the medical model, the development model, the living and relation model and the guidance and support model. The succession of these models was determined by changing views of the mentally handicapped and general social developments in, for instance, democratization and participation.

The various types of experts (physicians, behavioural scientists, living coaches) professionalized to different degrees, with the physicians the most outspoken, while, for a long time, the status of the other groups remained lower. Professional groups put up struggles over competence, the outcome being determined by the degree of professionalization and the arrival of new views on care. Thus, in the seventies the behavioural scientists won over the physicians, because their views better matched the development model. The theory that states that a group derives its power in an organization from its capacity to offer successful solutions for the key problems, offered a good approach to interpret this change from one type of expert to another professional.

Chapter 6 “Parents” describes the role parents of mentally handicapped children have played over the past decades. For a long time, the mentally handicapped themselves have not been taken seriously. The age-long negative image contributed to the fact that they were seen as abnormal people: they deviated from the ideal image of mankind and were not seen as productive citizens of society.
The establishment of separate services, however positive for the instant improvement of the quality of their existence, promoted a “life in apartheid”. In that way they were labelled and developed a negative self-image, were further stigmatized and remained far from participation in society.

To parents, to get a handicapped child was a far-reaching event that evoked feelings of hurt of self esteem and disappointment over expectations of life. The individual reactions of parents were determined by the attitude of their environment, level of education, social-economical status and individual character traits. Parents and their pressure groups had an ambivalent attitude towards the system for the handicapped. On the one hand, they promoted the establishment of specialized service, but on the other they often had a troublesome relation with professionals who frequently confronted them with jargon and an arrogant pose. Typical for the Dutch care of handicapped was the large role of identity and denomination in the development of the system for the handicapped. For instance, for a long time parents urgently requested the establishment of institutions based on a denomination.

A mental handicap was seen more and more as a “learning disability” or “disease”, a process known as medicalization. The mentally handicapped and their parents were increasingly guided and supported by professionals. In the fifties, from the family ideology point of view, a mentally handicapped child was a disturbing factor that had to be removed to enable a well-balanced development of the family. In order to support the families, the specialized social work of the SPDs grew. They started to function as the gatekeepers of the apartheid care system for the handicapped and made parents responsive to thinking in the terms of the care of the handicapped. The SPDs were an example of a specialized professional groups who advanced its interests through training and umbrella organizations, etc. The history of the Early Recognition teams (meant to identify a mental handicap at an early stage and to come to an adequate support) showed that the interests of handicapped children and their parents sometimes lagged behind the interests of conflicting professionals, departmental interests and political opportunity.

Chapter 7 “Authorities” discusses the role of the authorities, the referee that largely determined the rules of the game. To what extent they actually determined the game varied in the past decades, swerving between regulation and withdrawal. The economic situation determined the government policy concerning the care of the mentally handicapped to a great extent. In the framework of the post-war reconstruction of the Netherlands, government gave priority to industry and housing. There was no room for the systematic construction of services for the mentally handicapped, who were seen as non-productive.
In the sixties more means became available for the extension of the number of specialized services, thanks to the economic growth. As a consequence of the economic crisis in the seventies and eighties, the authorities once more tried to set limits to the rising costs. From the ideal of the makable society legislation was issued to direct the developments methodically. When that failed and the political priority in the eighties became to decrease the budget deficit, the government policy was reduced to inertia. In the nineties there was a turning point in the direction of the sector. The memorandum “Outside the pale” (1995) of the Ministry of Health was an important crystallization point in the turn to socialization of the care, through more personal forms of financing schemes and the separation between housing and care.

The mentally handicapped were not a in the centre of interest in politics. After all, they do not represent a large part of the electorate and do not yield much publicity, except in case of incidents. The political priority has always been on reducing the waiting lists and not or hardly on large changes in the system. For a long time there had been a fierce interdepartmental competition between the Ministry of Culture, Recreation and Social Work and the Ministry of Health, that had different interests and views on care. Only from the realization of one directorate for the policy for the handicapped (1988) better conditions developed for a more integrated governmental policy. Further explained aspects of the government policy include the realization of the General Law on Special Medical Expenses (which initially would lead to a sharp increase in the intramural sector), the influence of the corporaristic paragovernmental bodies (that were an “iron ring” in the decision-making circuit) and the role of the inspectorate (which gradually declined).

Chapter 8 “Analyses, discussion, preview and conclusions” concludes by means of the used model of analyses that the care of the mentally handicapped developed into a separate subsystem in the Dutch care system. The origin, development and rigidity and the (start of a) disintegration of this subsystem is the subject of this study. The system developed because a group of citizens were defined as “mentally handicapped” based on criteria of intelligence and social adjustability, for whom separate services were established. In the history of this care system processes of civilization, disciplining, medicalization, protoprofessionalization and labelling had a major impact and were important interpretation factors.

As the system emancipated externally and differentiated internally, the game became more complex by the increase in the number of players and rules of the game. Speaking in terms of systems, the hindrance capacity of those concerned increased. Not until the nineties there was room for fundamental adaptations of the system, due to coinciding economical prosperity and withdrawal of the authorities.
An important fact is, that in the Western world, the Netherlands is a developing “country”, because of the large number of mentally handicapped living in institutions. The continuing dominance of institutions can be explained from a tradition of relatively good-quality care, the unwillingness to reduce precious infrastructure, the interests of the institutions and the lack of an energetic government policy in a society in which consensus is the leading principle.

Looking ahead, a continuation of the trends of individualization, a withdrawing government that provides frameworks and economical growth can be expected. It seems that the position of those with a mental handicap will be stronger and that, together with the increase in the number of parent initiatives, will greatly change the relations between the mentally handicapped, parents and professionals. Speaking in black-and-white terms, there will be a struggle between “normal life” and continuing medicalization of the life of a group of citizens.

The main conclusions of this study are as follows. Firstly, there are no “mentally handicapped”, but individuals with, as a consequence of varying causes, a handicap or disability. The label “mentally handicapped” led to stigmatization, discrimination and a negative self-image. Secondly, the development of the system for the handicapped is the result of a dynamic interaction between developments, events and persons on meta, macro, meso and micro level. The system and game theories offered a sound theoretical handle to study the interaction between social developments and the role of various players. Thirdly, despite a pursuit of independence, the system for the handicapped has always been part of the environment. Indeed, changes in the system often originated from that environment, as for instance the emancipation of the citizen and the client, which was translated into the introduction of the personal budget. In the fourth place, the level of care of the mentally handicapped was largely determined by the economic situation. Special services for the mentally handicapped are a luxury society can afford if a certain measure of economical growth and prosperity has been reached. In the fifth place, at the end of the eighties the system of the handicapped care got stranded in its own complexity and did no longer harmonize with the emancipation of those with a mental handicap. To survive, the system will tend to bend with social developments but it will not abolish itself. In view of the decision-making culture in the Netherlands, a radical dismantlement of the apartheid system is not to be expected, rather a gradual disintegration.