

Jim Aage Nøttestad

Deinstitutionalization and mental
health changes among people
with mental retardation

Jim Aage Nøttestad

Deinstitutionalization and mental health changes among people with mental retardation

Publication from the
Norwegian University
of Science and Technology,
St Olavs University Hospital,
Department for Forensic Psychiatry,
Brøset and Department of
Neuromedicine.
Faculty of Medicine,
N-7440 Trondheim, Norway

© Jim Aage Nøttestad

ISBN 82-471-6410-8

ISSN 1503 3465

Thesis no. 244

Printed by Tapir Uttrykk

|

|

Jim Aage Nøttestad

Deinstitutionalization and mental health changes among people with mental retardation

CONTENTS

SUMMARY OF THE THESIS	s. 3.
PAPERS INCLUDED IN THE THESIS	s. 7.
ACKNOWLEDGEMENTS	s. 8.
INTRODUCTION	s. 9.
Terminology	s. 9.
History	s. 10.
The normalization principle	s. 16.
Specialized health services	s. 20.
Deinstitutionalization and evaluation studies	s. 24.
Mental health problems	s. 28.
OBJECTIVES AND OUTLINE OF THE THESIS	s. 32.
METHODOLOGICAL CONSIDERATIONS	s. 35.
Subjects	s. 35.
Designs	s. 38.
Statistical analysis	s. 39.
Assessment	s. 39.
SYNOPSIS OF THE INCLUDED PAPERS	s. 43.
Additional analysis	s. 51.
MAIN RESULTS	s. 54.
DISCUSSION	s. 55.
Mental health problems	s. 59.
Psychiatric disorders	s. 61.
Increase in specific behaviour problems.	s. 65.
Psychotropic drug use	s. 68.
CONCLUSION	s. 72.
REFERENCES	s. 74.
PAPERS 1 to 5	s. 83.

SUMMARY OF THE THESIS

The focus of this thesis is to study deinstitutionalization and its effect on: mental health problems, the use of specialized health services, and neuroleptic drug use among people with mental retardation. One among other reasons for the focus of the thesis was the authorities statement on the effects of deinstitutionalization. It was said that the ordinary health care system could give people with mental retardation the same or even better health care than they received in institutions. It was also said that institutions created psychiatric problems, and that these would diminish or even disappear with the closing of the institutions

In the thesis mental health problems are defined as behaviour disturbances and psychiatric disorders and symptoms. Psychiatric disorders were identified with the Psychopathology Instruments for Mentally Retarded Adults (PIMRA). Behaviour disturbances were identified as having occurred or not the previous year.

We studied individual and environmental factors before and after deinstitutionalization to look for factors associated with the development of mental health problems. The individual characteristics were behaviour deficits like inability to move around, use of wheelchair, difficulties with communication, and difficulties with personal hygiene, ability to dress, ability to eat, hearing and visual impairments. Medical conditions and the various aetiologies of intellectually disability, medical diseases, psychiatric disorders and use of psychotropic drugs were recorded. The environmental characteristics we studied were, the caretakers evaluation of their clients need for support in terms of behaviour disturbances and mental health problems, housing, activities, caretaker characteristics as caretaker: patient ratio, the mean number of caretakers involved in the direct care and the caretaker's education.

The first study focused on mental health problems and the use of specialized health care services before and after deinstitutionalization for the whole population, (N = 109). The results show small and insignificant changes in psychiatric health problems after deinstitutionalization. The total number of diagnoses was greater than the number of persons in the population, giving a mean of two diagnoses per person. There are high numbers of persons suffering from schizophrenic and anxiety disorders while the frequency of affective disorder was low. Somatoform problems were common. Behaviour disturbances like; attacks on others, other kinds of disruptive behaviour, like yelling, jumping and passivity increased significantly. There had been a significant decrease in the utilisation of general practitioners, psychiatrists and psychologists after deinstitutionalization. None from the study population had been admitted to psychiatric hospitals during the period.

The second study focused on older people, age above 50. Old people with mental retardation are a vulnerable group with special needs so we also here compared mental health problems and the use of specialized health care services before and after deinstitutionalization. For the elderly the psychiatric disorders remained frequent, and did not change after deinstitutionalization. Minor behavioural disturbances increased in spite of deinstitutionalization and improved living conditions. Use of specialized help from psychiatrists and psychologists was low, with a significant decrease in the use of psychologists after deinstitutionalization.

The third and fourth studies are studies on those who developed behaviour problems after deinstitutionalization, those who acquired self - injurious behaviour (SIB) and those who started to attack other people. The aim of these studies was to see if we could find any predictors which could indicate intervention points for preventive action. Those who acquired

SIB had lower developmental quotients and more often used wheelchairs and had trouble moving around without assistance. They had higher frequencies of epileptic seizures, hearing and communication impairment. In 1995, there were only minor environmental differences between the people who acquired SIB and those who did not. There were significantly more persons involved in the rotation period, and more unskilled caretakers working with the people who developed SIB than with those who did not. The individual characteristics indicating that a person may acquire SIB are behaviour deficits suggestive of a clear CNS dysfunction or damage even though the results are inconclusive. SIB development may also be facilitated by communication deficits, or by reinforcement of an incidentally occurring self-injurious behaviour if staff includes many and unskilled caretakers in the rotation period.

The individually based predictors for people who started to attack others after deinstitutionalization were presence of self-injurious behaviour, a slight increase of other behaviour problems and a low soundness score on PIMRA. The people who started to attack others after deinstitutionalization differed from people in other studies on learning deficiency and challenging behaviour. These differences indicate that the study group originally consisted of other people than those usually seen in studies on learning deficiency and challenging behaviour. The only significant environmental predictor was the caretakers' evaluation of the person's need for help due to behaviour problems and mental health. We could not identify possible intervention points for preventive action, neither individual nor environmental, so here further studies are needed.

The predominant psychotropic drugs before and after deinstitutionalization were neuroleptics. The frequency of people using neuroleptic drugs had not changed after deinstitutionalization. The population as a whole had a significant reduction in average neuroleptic dosage, but the

neuroleptic dosage reduction for those who used neuroleptics both before and after deinstitutionalization was not significant. The neuroleptic dosages for those who started or stopped using neuroleptics were very small. People with a schizophrenia diagnosis and those with an anxiety disorder received improper medical treatment both before and after deinstitutionalization. Behaviour disorders, aggression against people in 1987 and aggression against property in 1995, were the strongest predictor variables for neuroleptic dosage.

Main conclusions: Deinstitutionalization and the increased material standards seem to have had little impact on the frequency and nature of behavioural disturbances and psychiatric disorders among mentally retarded persons. The changes we observed were contrary to the stated aims of the reform. This may be due to concomitant factors, such as increased number of staff involved in each person and difficulties in obtaining specialized services.

PAPERS INCLUDED IN THE THESIS

Paper I:

Nøttestad, J. Aa., & Linaker, O. M. (1999). Psychiatric health needs and services before and after complete deinstitutionalization of people with intellectual disability. Journal of Intellectual Disability Research, 43, 523-530.

Paper II:

Nøttestad, J. Aa., Strømgren, B., & Linaker, O. M. (2000). Psychiatric and behavioural disturbances in elderly mentally retarded before and after deinstitutionalization. Nordic Journal of Psychiatry, 54, 281-286.

Paper III:

Nøttestad, J. Aa., & Linaker, O. M. (2001). Self injurious behaviour before and after deinstitutionalization. Journal of Intellectual Disability Research, 45, 121-129.

Paper IV:

Nøttestad, J. Aa., & Linaker, O. M. (2001). Predictors for attacks on people after deinstitutionalization. Journal of Intellectual Disability Research, 46, 493 – 502.

Paper V:

Nøttestad, J. Aa., & Linaker, O. M. (2003). Psychotropic drug use among people with learning deficiencies before and after deinstitutionalization. Journal of Intellectual Disability Research, 47, 464 - 471.

ACKNOWLEDGEMENTS

Many persons have been involved in the process that resulted in the thesis. First of all I want to thank my nearest family for support and endurance with me during the long-lasting work.

I wish to thank my supervisor Associate professor Olav M. Linaker, MD, PhD., to whom I am deeply indebted, without him this thesis would not have been possible. His patience and encouragement were crucial to the completion of the present work. He has generously shared his extensive knowledge and interests in the field of learning deficiency and mental health with me.

I also owe thanks to Børge Strømgren who took an interest in the work I had started and with whom the second paper was prepared.

I want to express a special gratitude to Section for Forensic Psychiatry, Brøset. St. Olav's Hospital, Norwegian University of Science and Technology where I am working, in particular to Medical Director/Chief Psychiatrist Egil Bjarnar MD who has supported my research work, not only in providing time and opportunity to do the work, but also in making it possible to travel and meet the international research community. Further, I want to thank Professor Kirsten Rasmussen at Department of Psychology, Norwegian University of Science and Technology for her scientific support, and consistent nagging about the need to make the necessary priorities, that made it possible to finish the thesis.

I am in debt to, and owe thanks to leading librarian Reidar Roksvåg a very patient man who almost sent me the papers I ordered the day before they were ordered.

I am also thankful to psychologist Elisabeth Kibuka – Musoke for her linguistic advices

I owe thanks to the Habilitation services in Sør-Trøndelag County who gave me a grant that made the collection of data possible. I will also thank the Co-ordination Council for Research and Information on Mental Retardation (Samordningsrådet, SOR) and the Norwegian Ministry of Health and Social Affairs for grants making it possible for me to periodically free myself from daily clinical work.

I also want to thank Professor K. Gunnar Gøtestam, MD, PhD, at the Department of Neuroscience, Norwegian University of Science and Technology, who introduced me to scientific work through his lessons.

The present work was conducted with support from the Section for Forensic Psychiatry, Brøset. St. Olav's Hospital, Norwegian University of Science and Technology and at the Department of Neuroscience, Norwegian University of Science and Technology.

INTRODUCTION

In January 1991, a five - year process to deinstitutionalize all care and services for people with mental retardation began in Norway. At that time all administrative responsibility for services was decentralized from county authorities to local councils. By 1996 all institutions for people with mental retardation had been closed down. The reform process had started in 1988 with new legislation, Avviklingsloven, (Lov av 10 juni 1988 nr. 48). (The Act of June 10, 1988, concerning dismantling of the institutional system). The thesis is a study of mental health problems, and the use of health services among people with mental retardation before and after the reform started in January 1991, the reform process can be considered lasting from 1988 to 1995.

Terminology

The terminology used to describe persons with developmental disabilities has been revised many times throughout history. During the reform process the Anglo – American terminology changed from the mentally retarded, or mentally disabled to a person with developmental disability or a person with mental retardation. It was considered more appropriate to speak of a person with a disease, rather than defining a person by a disease. Old habits are difficult to change, even if they are redefined as sins, and in paper II the old term “mentally retarded” and “mentally retarded people” is used.

The history of mental retardation has also been a search for destigmatising terminology. In England the terms idiot, imbecile and moron from 1913 were replaced by mental deficiency in 1959, and subsequently by sub-normality and severe sub-normality, mental handicap, mental retardation and now learning disability. The terms learning disability or learning difficulty are

synonymous in the public mind with primary educational problems such as dyslexia and, as such misleading, (Reid, 1997). The terminology in international journals varies from one journal to another. This is one of the reasons for the somewhat inconsistent terminology in the thesis. In paper II as mentioned earlier the old term "people with mental retardation is used", the term mental retardation in this paper is used in conjunction with the terminology in the International Classification of Diseases – 10 (ICD – 10), (WHO, 1993). In paper I, III, IV and V the term learning disability is used, a terminology in conjunction with the journal's policy. In the rest of the thesis the term mental retardation are used in conjunction with the terminology in the ICD – 10 (WHO, 1993).

The terms behaviour problems, behaviour disturbances, maladaptive behaviour and challenging behaviour are used as synonyms. Some (the English) journals prefer challenging behaviour. The most cited definition is; "cultural abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to serious limit use, or result in the person being denied access to, ordinary community facilities." (Emerson, Barret, Bell, Cummings, McCool, Toogod & Mansell, 1987)

History

The first organized and modern care for people with mental retardation in Norway was "The Afternoon School for Intellectually Abnormal Children" that started in 1874. The people at the school were people with mild mental retardation. The aim of the education was to teach the mentally retarded to take care of themselves and earn their own living. The first nursing home for persons with more severe mental retardation was private and established in 1898,

with 40 inhabitants. The second nursing home, opened 19 years later in 1917. The funding for the "Afternoon school" and the first nursing home were partly private and partly public until 1915. The schools for the "abnormal" were regulated by law in 1881. In 1885 three schools were opened, the fourth one about 1930. The director of the schools for the "abnormal" pointed out in 1938 that there were thousands of grown up people with mental retardation who by education and training could be more able to take care of themselves (Linaker, 1994).

The Royal Ministry of Church had until 1945 the responsibility for the schools for the "abnormal" and the hospitals for people with mental retardation. In 1945 the responsibility for the hospitals was transferred to the Directorate of Health. The needs for people with moderate, severe or profound mental retardation were from that time considered more of a medical issue and less an educational issue.

In 1949 the "payment law", was adopted (Ot.prp. nr. 57.1949). The law said that in nursing homes or institutions approved by the state, the state would pay the operating costs.

In 1952 "The national plan for care for the mentally retarded" (Landsplanen for åndsvakeomsorgen av 1952) was adopted. The concept of differentiation seems to characterise the ideas in the social policy at that time. The post war period was characterised by centralisation, public expansion, increased specialisation and professionalisation (Sandvin, 1996). The "national plan" stated that the country should be divided into 12 health regions and each individual in the regions should be given the medical and health care services they were in need of. It was said to be a need for a comprehensive system of care for people with mental retardation. This system had to be based on special institutions designed for people with mental retardation only, and had to consist of several divided units or departments,

designed for different purposes and categories of people with mental retardation. The major idea behind the development of large central institutions in the regions was the possibility of organising differentiated medical and educational treatment, adjusted to the different needs and the new medical definition of mental retardation.

The period between 1949 and 1976 can be characterised as “the phase of institutional growth”, the period between the 1970s and 80s can be called “the period of improvement,” (Tøssebro 1992a). From 1991 we got the period characterised by institutional dismantling with an accelerated deinstitutionalization which reached completion in 1995 - 6.

In 1945 there were three institutions in Norway with a total of 495 inhabitants. Two central institutions had an average of 240 inhabitants and one local institution had 15 inhabitants. In 1977 there were around 120 institutions with a total of 5627, mean was 47 inhabitants. There were 17 central institutions with an average of 221 inhabitants and 104 local institutions with a mean of 18 inhabitants.

In 1969 with the hospital law (Ot.prp. nr. 36 (1967-68)) the counties were given the responsibility to plan, organise and run the health institutions. The county based “Helsevernet for Psykisk Utviklingshemmede,” (The county based Health Care for the Mentally Retarded) (HVPU) was established. The care for people with mental retardation was from that time a public responsibility for the counties, even if the institutions were mostly owned by humanitarian organisations.

In “the period of improvement,” in the 1970s and 1980s the building of new institutions nearly stopped and the quality of the services improved. One of the reasons behind the

improvements was the recurring scandals connected to health care and living conditions in the institutions. The scandals led to official concerns, and in 1975 a committee led by the psychiatrist Ole P. Lossius suggested among other proposals, that the size of the institutions should be reduced and that people with mental retardation should live and receive the necessary care in small group dwellings. In 1970 the central institutions had an average of 224 inhabitants; the other and smaller institutions had an average of 25 inhabitants. By 1989 the corresponding figures were 142 and 13. Between 1973 and 1988 the State's funding for the care of people with learning disabilities increased with 73% compared to the "gross national product." In this period the quality of living and care significantly improved. From 1971 to 1989 the number of inmates in the wards fell from an average of 22, 9 to 6, 5 persons. The average shared area rose from 3.34 m² to 18.76 m². The percentage with private bedrooms rose from 12% to 96%, and the number of inhabitants per bedroom fell from an average of 2,6 to 1,0, (Tøssebro, 1992a).

From 1970 to 1986 the average number of persons in each central institution was reduced from 224 to 157. Hallsetheimen central institution where the population for the studies in this thesis came from had more than 400 inhabitants in 1963 (Kosberg, 1967). In 1987 this was reduced to 221 people (Linaker, 1994) and when deinstitutionalization started in January 1991, 120 persons stayed in the institution. The reduction was reached primarily by two means; institutionalisation of children was avoided, and the well functioning people with mild and moderate mental retardation moved to newly - built group homes, integrated in the local community.

The improvement of the institutions did not hinder recurring scandals connected to health care and living conditions in the institutions. The scandals lead once more to official concerns, and

in 1985 a new committee led by the psychiatrist Ole P. Lossius who also led the committee in 1975, suggested that the specialized services and the institutions for the mentally retarded should be closed down, and the responsibility transferred to the local councils. In 1988 the radical new legislation mandated dismantling. The closure of the health care system for people with mental retardation (HVPU) should start the first of January 1991, and the local councils should take over the responsibility for the care and the health care services in the decentralized and normalized services. The final date for the closure of all institutions was set for January 1996. The significance of the reform and the deinstitutionalization is, first of all, that it combines a total restructuring of the service system, with decentralization of responsibility, and it is total, and covers all institutions in the whole country.

The objectives of the reform were stated to be:

- a, - To improve and normalize living conditions for people with mental retardation.
- b, - As far as possible, to give persons with mental retardation a possibility to live and reside independently and enjoy an active and meaningful existence among other fellow human beings.
- c, - To promote a movement away from institutional care for persons with mental retardation and reinforce the development of another kind of service. (Lov av 10. Juni, 1988 nr. 48.).

The reactions to the report from Ole P. Lossius on health care and living conditions in HVPU varied from applaud to fierce opposition. The report said that health care and living conditions in HVPU were miserable. One of the reasons for this gloomy description may have been

caused by the selection of counties and institutions the committee studied. These counties and institutions had an especially low standard (Sandvin, 1996). The report's conclusions give in some respects the impression of being an argumentation for a conclusion, which had been drawn beforehand (Sandvin, 1996).

The main reasons for deinstitutionalization in Norway were adherence by the Government and Parliament to the principle of normalization, the living conditions suffered by people with mental retardation and the notion that institutions could not give this group better health care than conventional systems. But the impetus for deinstitutionalization came from a variety of other sources like theoretical work on institutional life, indictments of institutions and economy (Zigler & Hodapp, 1986).

Some of the forerunners for the deinstitutionalization and normalization ideology were people like Ervin Goffman (1961), Michel Foucault (1965) and Thomaz Szasz (1961) and their critique of the institutions and the concept of psychosis. What these three theoreticians had in common was the belief that institutional life was dehumanising, and that they all had little empirical support for their theorizing (Jones & Fowles, 1984). Barton an English psychiatrist wrote a book in 1959 entitled "Institutional Neurosis". He stated that a stay in a mental hospital could itself give the patient a new disease that he called Institutional neurosis, a condition that could be diagnosed and treated. The clinical features of the disease are apathy, loss of interest in the outside world, submissiveness, and resignation and lack of initiative. Some people outside the institution and not all people inside developed the disease. Barton meant that one could find some clusters of factors in the mental hospital environment, which caused the development of "institutional neurosis". These were: Loss of contact with the outside world, enforced idleness, bossiness of medical and nursing staff, loss of personal

friends, personal possessions and personal events, drugs, ward atmosphere, loss of prospects. Barton worked in a large mental hospital near London where most of the long - stay patients had a diagnosis of Schizophrenia. The symptoms of burned – out schizophrenia are the same as those of an “institutional neurosis”. Barnes was possibly describing the end result of a disease process, and not a new disease. Today we know much more about the interaction between a disease with self – isolating tendencies and an environment that positively promotes self – isolation than was known at the time when Barton wrote his book. Barton’s book is not translated into the Norwegian language, but some parts of it, like the symptom list that indicates an “institutional neurosis” have been translated into Swedish (Vail, 1972). The persons stating that the “institutions created mental health problems and that these would diminish or even disappear with the closing of the institutions.” (NOU 1985, p. 34) may have been influenced by Barton’s ideas from 1959.

Many authors mention economy as an essential reason for the deinstitutionalization movement (Jones and Fowles, 1992; Zigler & Hodapp, 1986) The fiscal crisis in Europe in the mid 1970`s, contributed in an essential way to the reform and deinstitutionalization. The crisis was seen in terms of the size the public sector had reached in many countries and was interpreted as an overload of public welfare expenditure on the market economy. This led to an extensive debate on the relationship between welfare policy and economic development (Sandvin, 1996). Political liberalism grew stronger towards the end of the 1970`s and it criticised the heavy pressure of costs, caused by the welfare state.

The normalization principle

The principle of normalization is said to be one of the main reasons for deinstitutionalization in Norway. Normalizing is not an unambiguous concept (Sandvin, 1992) and it may be called “a family of ideas” (Emerson, 1992). Normalizing as an idea had its roots in the creation of the welfare state in Sweden at the end of the Second World War as an expression of an ideological principle of inclusiveness in society. It was for the first time mentioned as a principle in an official policy paper in 1946. In Sweden the Committee for the Partially Able – Bodied was given the task of identifying suitable forms of support for people with handicaps. Among other statements it was said “Psychological “normalization” of living conditions, education, employment support, etc. for partially able – bodied people, is usually a great advance” (Erickson, 1996). In Norway the term was first used in an official policy paper in 1966/67, Stortingsmelding nr. 88 – 1966/67 (Report to the Parliament nr. 88 – The disabled in the society). Normalizing is here used as a superior principle for care - giving. The concept cover both the goal (the end), the means for undertaking, and the process or the reforming of society that should lead to the goal – the normalizing process (Johnsen, 1982)

In 1959 Bank Mikkelsen, head of the Danish Mental Retardation Services, defined normalization as: "letting the mentally retarded obtain an existence as close to the normal as possible." Bank Mikkelsen made significant contributions to the 1959 Danish law governing services to people with a mental retardation (Wolfensberger, 1972). In 1969 the principle of normalization was systematically stated and elaborated by Nirje. He was then executive director of the Swedish Association for retarded children. Nirje stated the principle as: "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to norms and patterns of the mainstream of society". (Wolfensberger, 1972).

Wolfensberger elaborated on Bank - Mikkelsen and Nirjes work and refined the definition of the normalization principle: "Utilizing of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible." (Wolfensberger, 1972). Wolfensberger pointed to the fact that in his definition the normalization principle is culture-specific because culture varies in their norms. Normalization does not mean that the services in different countries should resemble each other's. Wolfensberger said the living conditions were means in a process for helping the disabled to the most important quality of life: social valorised roles. The living conditions for disabled people are symptoms of the society's devaluation of them. As such normalizing is a social problem and eventually limitation of the normalization process shows the values which are linked to society's, understanding of the disabled. Wolfensberger developed a system according to a standard and a cultural norm, the "Program Analysis of Service System" (PASS) (Wolfensberger, 1972); PASS had often been used in evaluation of the living conditions and health care services for disabled people. The normalizing principle and the institutional critique grew popular. Wolfensbergers understanding of the normalizing principle soon merged with the growing body of literature on normalizing. As such giving impetus to an ideological and professional movement with profound impact on social politics in especially Scandinavia and the western world. Wolfensbergers reformulation of the principle of normalization around a social deviancy perspective gave the highly individual focused North American society a proper theoretical framework for the normalizing principle.

In Norway Wolfenbergers claim that "limitation in the normalization process shows the values which are linked to the societies' understanding of the disabled", were often used in the discussion around deinstitutionalization. Professionals who meant that people with mental

retardation were in need of a specialized health care service were said to exemplify how society, and these persons, devaluated people with mental retardation.

Political liberalism grew stronger towards the end of the 1970's and it criticised the heavy pressure of costs, caused by the welfare state. The core values were the idea of privatisation and that help and care should be given by the civil societies. The increasing bureaucracy in the public sector was heavily criticized and it was said that growth in the welfare sector was more about more jobs in the sector than an increase in the welfare for its users. It was said that the welfare society had taken away peoples sense of responsibility for their own health and development. Right wing people felt the welfare state caused more problems than it solved. Terms like "welfare problems" and "welfare diseases" were used to describe the general development seen in most western countries: families breaking up, juvenile crime, addiction and loneliness.

On the left wing criticism began to be directed towards the close concentration on economic growth, material prosperity and "planned economy" which were the foundation of the welfare policies. At the same time it was clear that the welfare state could not solve all the social and health needs of society. Over a relatively short period of time the left changed ideology from "planned economy and the welfare state thinking" to romantic Rousseauian thinking: "back to nature". The welfare society was criticized for having created a colder society where people no longer felt responsible for each other; important social arenas like family, social networks and local communities were said to be "crumbling" (Løchen, 1990). The old rural community system was said to have been a society where there had been nearness, network, community and informal care, and one wanted to recreate some of the local social qualities that were said to have disappeared as a result of the expansion of the welfare state. Social security provided

by these communities has been well documented, and its quality was the main impetus for creating institutions (Linaker, 1994).

The deinstitutionalization movement in Norway had three ideological roots. First the ideological critic of the welfare state from the right, that, among other things, was said to be the cause for families breaking up, juvenile crime, addiction and loneliness, and the loss of individual responsibility for own health and development. The second was the left's dream of a better society and their "romantic Rousseauian back to the nature thinking" with the small community as the place where one could find the solutions to "all" the problems the welfare state could not handle. Third was the normalization ideology.

Specialized health services

In the early stages of the reform, The Ministry of Health and Social Affairs stated that the existing specialized services outside the institutional system (i.e. psychiatric, psychological and medical services) should suffice also for mentally retarded persons after deinstitutionalization since "Institutions created mental health problems and that these would diminish or even disappear with the closing of the institutions." (NOU 1985, p. 34).

The specialized health care workers in and outside the institutions stated that mentally retarded people were in need of specialized services that neither the local communities nor the counties specialized health care services could serve at that time. (Jensen & Mørch, 1990; Linaker & Nitter, 1989; Ruset & Stokke, 1989). Other studies had shown that people with mental retardation had an underconsumption of health services (Beange, McElduff, & Baker, 1995). A destructive struggle developed between the reform ideologists in The Ministry of

Health and Social Affairs and one of the parents' lay organisations (Norsk Forbund for Psykisk Utviklingshemmede, NFPU) on the one hand and health care workers from in and outside the institutional systems on the other hand (Skiftun, 1993). The Ministry of Health and Social Affairs stated, among other things, that specialists in psychiatry and psychology and caretakers with work experience from institutions should not be preferred in the new residential services because they were suffering from an institutional disease and they would take the "institutional culture" with them into the new services. It was said that their knowledge was not suited and not appropriate in the new deinstitutionalized care system. It has been suggested that the consequence of this struggle is a specialized health care service that does not function well (Romøren, 1995).

In autumn 1989, Health division in Ministry of Health and Social Affairs ended the struggle with an administrative directive (Rundskriv I – 45:89) stating that people with mental retardation were in need of specialized health services after deinstitutionalization. The new services were called the habilitation services, one part for children and one part for adults. The organisation of, and the professions in, the services were up to the counties to determine. The professional positions in the habilitation services were not often based on analysis of the users needs. The result, especially for the adults, was a service that differed much from county to county (Johansen, 1995).

The habilitation services should among other things serve;

- People with great and / or complex medical diseases, including people with frequent epileptic seizures
- People with great, periodical and complex treatment needs
- People with behaviour which is difficult to control

- People with both mental retardation and psychosis
- People with large communication deficiencies, including people with autism

(Rundskriv I – 61/89)

The services were meant to be a part of the specialized health services for all disabled people and not a service exclusively for people with mental retardation. The Habilitation services should be ambulatory, and the main tasks were; assessment, diagnosis, treatment, (re) habilitation and counselling of the users of the services and the local care systems.

One major problem in Norway, as in Britain (McBrien 1994), has been to recruit specialists such as psychiatrists and psychologists to these services. In 1995 The Norwegian Board of Health published a study of the habilitation services. Of 732 positions 7% were medical doctors and 16 % psychologists and 17 % were nurse assistants, the proportion of positions to vacancies was not reported. College - educated personnel with additional special qualifications mostly provide the services.

The needs for specialized health services for people with large behaviour problems and psychiatric diseases and the quality of the services given after deinstitutionalization has been discussed since deinstitutionalization started. In 1992, the service people with large behavioural problems and psychiatric diseases received from the habilitation services, was evaluated by 181 local communities in 18 counties (Helsedirektoratet, 1993). The evaluation was made on a five point Lickert scale where the mid - point was taken to mean satisfactory. The local communities in 9 of the 18 counties said that the ambulatory and outpatient services were satisfactory or better. The local communities in only two counties were satisfied with their access to beds in hospitals for assessment and treatment. In each county the psychiatric

hospitals and outpatient treatment services were asked their opinion about their own services for people with large behaviour problems and psychiatric diseases. Only two counties rated the services as satisfactory. The habilitation services in each county were asked to evaluate collaboration with the mental and medical health services in the county. Ten, out of the sixteen habilitation services, which answered, said that the collaboration with the mental health services was not satisfying. The corresponding figure for the medical health services was seven.

Vetvik and Hem (1994) found in a study of 34 local councils, which had been hosts for institutions for people with mental retardation, that the local councils were not satisfied with the counties specialized health care services. Satisfaction was scored on a scale ranging from very good, good, and tolerably / reasonably good to modest. The results show that 63 % of the local councils were well or reasonably satisfied with the medical health services they received from the counties, the corresponding figures for the psychiatric health services and the habilitation services were 16 % and 45 %.

Lichtwarc (1995) studied the local council appraisal of the quality of services received from the habilitation services in 181 local councils from six counties. The appraisal was done on a Lickert scale from one to seven, one indicated very bad and seven very good. The results were calculated in percent. The psychiatric service got a score of 54 %; the corresponding figures on the psychological and medical service were 60 % and 64 %.

In 1999 another study was carried out (Statens helsetilsyn, 2000) (The National Board of Health, 2000). The report shows great deficiencies in the services offered by both the local councils and the county. Helsetilsynet (The National Board of Health) says that the

specialized services must be organised in a way that gives people with mental retardation access to qualified diagnostic assessment and treatment from specialists in psychiatry, neurology and clinical psychology.

Deinstitutionalization and evaluation studies

The reform and deinstitutionalization initiated a lot of research on different topics such as: Quality of life and living conditions before and after deinstitutionalization (Tøssebro, 1992a; 1995 and 1996a). The degree of satisfaction with the reform in families where a member had mental retardation (Lund, 1992; Syse, 1996; Tøssebro, 1992b, 1996a). Adaptive behaviour before and after deinstitutionalization (Western 1995; Jensen, 1996), Civil rights and quality of life, (Syse, 1995). Health, the use and need for health and social services (Linaker & Nøttestad, 1998; Skjellum, 1997). The specialized health services (Helsedirektoratet, 1993; Johansen, 1995; Lichtwarc, 1995; Statens Helsetilsyn, 1995; Statens Helsetilsyn, 2000; Linaker & Nøttestad, 1998; Nøttestad & Linaker, 1998; Vetvik & Hem, 1994).

The results differ from one study to another. Western (1995) found that adaptive behaviour increased, but the increase was not significant when $p = .05$. Jensen (1996) found a decrease in adaptive behaviour and no essential change in behaviour problems.

The largest study on the living conditions for people with mental retardation before and after deinstitutionalization were a study by Tøssebro (1995 and 1996a). In this study the main themes are housing and, equipment in the dwellings, social relations, work and daytime activities, leisure time and activities and degree of self-determination. Health and access to health care services, one of the main components of the concept "Quality of life" (Tøssebro,

1988) is not mentioned or studied. The reason for expelling health and access to health care services stems from his preliminary research. The results showed that the caretakers did not know if the people with mental retardation had had any thorough medical health assessment and their answers on questions on health were at random (Tøssebro, 1988). Tøssebro's study from three counties, Nord – Trøndelag, Sør – Trøndelag and Møre og Romsdal shows that 69% of the caretakers, who knew the people they cared for well, were of the opinion that the reform had given people with mental retardation an opportunity for a better life. Nearly one fifth (17%) said that it was likely the reform had given them an opportunity for a better life, six percent said it were better before the reform. The caretakers rated the life areas as: Housing, day care activities, private financial status, social contact, leisure activities, and the right to self-determination. At all 73% and respectively 24%, 27%, 11%, 14% and 33% rated these life areas as much better after then before deinstitutionalizing. On the same areas 7%, 51%, 42%, 62%, 54% and 26% were rated by the caretakers as “no differences” or even to be worsened after deinstitutionalizing (Tøssebro, 1995). The relatives were sceptical to the reform and nearly two thirds of them thought the reform would have a negative impact on the life's of people with mental retardation (Tøssebro 1992b). After the reform the relatives, 67% parents, 27% siblings, were asked if the reform had changed living conditions for people with mental retardation, 73 percent said the living condition were better, 12% said it was unchanged and 15% said the living conditions had worsened (Tøssebro, 1996a). In Finnmark County relatives were asked about their view on the situation after the reform compared with before (Syse, 1996) and 48% said the conditions were better, 26% meant it was as before and 26% meant the conditions had worsened.

Syse (1995) studied the nearest relatives and the service provider's assessment of civil rights, welfare and quality of life for people with mental retardation before and after

deinstitutionalization. The nearest relatives were mostly the parents, but also others, mainly siblings. The service providers' answers were answers given in cooperation with the caretakers and representative persons from the local councils professional leadership in the councils where the people with mental retardation lived, N = 105 of a total of 177 people with mental retardation that received services from the county services (HVPU) in Finnmark County. Two thirds (69%) of the nearest relatives rated the housing standard after deinstitutionalization as "Good". The same figures for the home - based services, employment / daytime activity, cultural and leisure activities and services from county or national authorities were 38%, 36%, 17% and 23%. Syse said his results, by and mean, correspond to the results from a study in Nordland County of 241 families (Lund, 1992). In this study 44% felt that the reform had led to a better supply of services, 38% felt that nothing had changed and 8% felt that the provision of services had become poorer. A composite score of the welfare dimensions was used to compare the description of the local council services with a retrospective description of services in the county institutional system. Only 42% of the near relatives thought there had been an improvement in welfare; 31% rated deterioration, that is, an insignificant improvement. Service providers were somewhat more upbeat, reporting significant improvement: 56% had rated "improved," and only 12% had rated deterioration in welfare. The answers on legal rights showed a similar pattern: 28% of the relatives reported an improvement, 21% reported deterioration. The same figures for the service providers were 47% and 6%.

The data from the near relatives and the service providers, for each resident, showed no significant correlation, no consistent pattern of agreement was found. These results raise some essential methodological questions about the validity of the instruments used and their results, not only in this study but also in most of the rating studies used to evaluate the reform.

Only one of the studies on the specialized health care systems studied the use of these services among people with mental retardation. The rest of the studies were on the local communities and the counties satisfaction with these services. In a study by Skjellum (1997) of the health needs, the use of health and social services and relatives assessment of these services among people with mental retardation above the age of two years in Akershus county, N = 684, the respondent rate is 53%. The results show that between 20 to 30 percent said they were a bit troubled by nervousness, anxiety, and jumpiness, depression and sadness. Ten to eleven percent said that their nervousness, anxiety, jumpiness, depression and sadness were chronic. The results partly indicate a large need for help from psychiatrists or psychologists. The results show that only two percent of the population had visited a psychologist the previous month. The relatives were exceptionally well satisfied with the dental services, but the dissatisfaction with the psychiatric health care, the habilitation services and the home based services was large. The percentages among the relatives who were more dissatisfied than satisfied with the psychiatric health care, the habilitation services and the home based services were respectively 49 %, 44% and 57%.

The cited studies may be used in the evaluation of parts of the deinstitutionalization process, but as an evaluation of the reform as a whole they are inconclusive. Tøssebro (1996b) says the results from the evaluation studies have shown that housing conditions have improved substantially, and that people are living more private and possibly more isolated lives. Apart from this the changes have been minor.

Health is a main component of the quality of life and the use of general practitioners and of specialised psychiatric health professionals has not been studied before or after

deinstitutionalization. We do not know the reason for this omission, may be one of the reasons is caused by methodological problems.

Mental health problems

People with mental retardation have more mental health problems than the rest of the population (Linaker, 1990). A high prevalence of mental health problems has been established both in institutionalized populations and among those living in private homes or community residential facilities. The prevalence of people with psychiatric disorders and behaviour disturbances varies from under 10 to 80 percent (Borthwick-Duffy 1994a; Reiss, 1994). Also in studies on unselected populations the results varies. Lund (1985) in a study of a random sample of 302 adults with mental retardation found using modified Diagnostic Statistical Manual III (DSM III) criteria (American Psychiatric Association, 1980) 28 % to have a mental disorder, 5 % a psychosis of uncertain types, 1,7 % an affective disorder and 1,3 % schizophrenia. Gøstason (1985) used the DSM III criteria. Mental illness was diagnosed in 55% of people with severe and 17% in people with mild mental retardation. The risk for psychiatric disease is three times higher for people with mental retardation than in the ordinary population (Borthwick-Duffy, 1994a).

Stortingsmelding nr 25 (1996-97) states that among people with mild mental retardation psychiatric diseases appears to be found one and a half time as often as for the rest of the population, and two to three times as often among people with mental retardation of moderate and severe degree. This means that about 50 percent of people with mental retardation have some kind of mental health problem.

There are several reasons for the cited variations in results. Most studies focused on selected populations, such as patients referred to clinics. The study populations also vary in respect of age, degree of mental retardation, living conditions and institutional living. The diagnostic criteria for mental disorders have also differed from one study to another. There is no consensus regarding diagnostic criteria for psychiatric disorders in people with mental retardation. The DSM criteria are useful and mostly valid for mild and moderate mentally retarded people, however there is disagreement concerning the applicability of psychiatric diagnosis for the more severely mentally retarded people with IQ less than 50 (Dosen, 1993; Reid, 1983). Some say that psychiatric diagnosis can be based on behavioural and biological markers, whereas others believe that it is often impossible to make certain psychiatric diagnosis. Bouras, Brooks and Drummon (1994) studied 356 referrals to a community psychiatry service. Most of the sample was made up of people with mild mental retardation (57, 6%), 27.4 percent had a moderate mental retardation and 15 had a severe mental retardation. A psychiatric diagnosis was possible in 42, 8 percent of the people they evaluated. In the remaining cases, behavioural problems were evident, but it was not possible to determine a specific psychiatric diagnosis.

Psychometric scales and interviews that could differentiate between various forms of psychopathology or behaviour disorders in persons with mental retardation have been developed to assist the diagnostic process. The Abberant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985) is aimed at assessment of the effects of pharmacological and behavioural treatment. The scale was developed with samples of people with moderate and profound mental retardation. The purpose of Diagnostic Assessment for the Severely Handicapped Scale (DASH) (Matson, Gardner, Coe, & Sovner, 1991) was to provide a structured survey of the psychiatric problems among people with severe or profound mental

retardation. The psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Senatore, Matson, & Kazdin, 1985) is one of the scales most often used. It covers all the levels of mental retardation. Reiss Screen for Maladaptive Behavior was the first standardized measure of psychopathology in persons with mental retardation. It covers people that have a mild through profound mental retardation. The Psychiatric Assessment for Adults with a developmental Disability (PAS-ADD) is a semi structured clinical interview for use with respondents who have intellectual disability and for key informants. The ICD 10 version of PAS-ADD is derived from the Schedules for Clinical Assessment Neuropsychiatry (SCAN) (World Health Organisation, 1994). It uses the SCAN's glossary unmodified to provide the clinical definitions for coding (Costello, Moss, Proser, & Hatton, 1997).

The prevalence rate for behaviour problems varies as the prevalence rates for psychiatric diseases. Winchel and Stanley (1991) found in a review study a range of prevalence estimates from 3, 5 to 40% for self-injury in facilities that care for people with mental retardation. The reasons for the variability in reported prevalence rates are the same as for psychiatric diseases.

Borthwick-Duffy (1994b) made a study of an administratively defined population of more than 91164 people served by the California Department of Developmental services. The inter rater reliabilities of the behaviour problem scores in the study are said to be acceptable, ranging from .60 to .72. The overall prevalence rates for the sample showed that 2,1 % were aggressive, 2,2 % were self-injurious, both severity and frequency were accounted for and 7.1% had serious problems related to property damage. The study showed: "Prevalence rates of all destructive behaviours.... (a) are higher for males and people who are nonverbal; (b) increase as severity of retardation increases. (although mild retardation was underreported in the data); increase with age; (d) in general, are higher in residential placements that are more

restrictive; (e) are higher among persons with a dual diagnosis than in those with only mental retardation; and (f) are dramatically higher among persons whose psychiatric disorder is rated as having a severe impact on daily functioning" (p. 20).

OBJECTIVES AND OUTLINE OF THE THESIS

The main reasons for deinstitutionalization in Norway were adherence by government and parliament to the principle of normalisation, the living conditions suffered by mentally retarded, and the notion that institutions could not give mentally retarded better health care than ordinary health care systems. It was said "institutions created mental health problems and that these would diminish or even disappear with the closing of the institutions" (NOU, 1985:34). Our null hypotheses were: The ordinary health care system could give the mentally retarded the same or even better health care than the institutions, that institutions for mentally retarded people create mental health problems and that these would diminish or even disappear with the closing of the institutions. Mental health problems were defined as behaviour disturbances and psychiatric disorders and symptoms. The main questions addressed in the thesis are listed below under the title of the paper to which the hypothesis was put to test.

Paper I: Psychiatric health needs and services before and after complete deinstitutionalization of people with intellectual disability.

The aim of this study was two – fold:

Firstly to compare the frequency of psychiatric disorders and behavioural disturbances before and after deinstitutionalization. We wanted to test one of our null hypotheses: Institutions for mentally retarded people create mental health problems and these would diminish or even disappear with the closing of the institutions.

Secondly we compared psychiatric health services provided before and after deinstitutionalization to test the other null hypothesis: The ordinary health care system could give the mentally retarded the same or even better health care than the institutions.

Paper II: Psychiatric and behavioural disturbances in elderly mentally retarded before and after deinstitutionalization.

The aim of this study was also two – fold:

Firstly we wanted to test the null hypotheses: Institutions for mentally retarded people create mental health problems among elderly people with mental retardation, and that these would diminish or even disappear with the closing of the institutions.

We also wanted to compare utilization of general and psychiatric health services among elderly before and after deinstitutionalization to test the second null hypothesis: The general health services will supply equal or better service than institutions had done before deinstitutionalization.

Paper III: Self injurious behaviour before and after deinstitutionalization

In this paper the focus was on persons without self - injurious behaviour (SIB) who developed SIB after deinstitutionalization. We studied frequencies, individual and environmental characteristics before and after deinstitutionalization to look for factors associated with SIB development which were assumed to be possible intervention points for preventive action.

We wanted to study if the frequencies of the behaviours changed, and if persons developed such behaviours after deinstitutionalization. We also wanted to establish if development of such occurrences could be explained by changes in health care or other structural or individual factors. This relates to both hypotheses.

Paper IV: Predictors for attacks on people after deinstitutionalization.

The focus of this study was persons who did not attack people before, but started attacking people after deinstitutionalization. We studied frequencies, individual and environmental characteristics before and after deinstitutionalization in search of predictors for the development of attack on other people, since such predictive factors could be possible intervention points for preventive action.

We wanted to study if the frequencies of the behaviours changed, and if persons developed such behaviours after deinstitutionalization. We also wanted to establish if development of such occurrences could be explained by changes in health care or other structural or individual factors. This relates to both hypotheses.

Paper V: Psychotropic drug use among people with learning deficiencies before and after deinstitutionalization.

The use of psychotropic medication among people with intellectual disability is widespread, and they are one of the most medicated groups in society. A substantial number of individuals with intellectual disability receive psychotropic medications that may be inappropriate for their diagnosis. The aim of this paper was to study psychotropic drug use before and after

deinstitutionalization and factors contributing to this kind of treatment before and after deinstitutionalization. The study is an indirect test of the null hypotheses: Institutions for mentally retarded people create mental health problems, and that these would diminish or even disappear with the closing of the institutions. The appropriateness of the prescriptions would also relate to the quality of the health services before and after deinstitutionalization.

METHODOLOGICAL CONSIDERATIONS

Subjects.

The base population in the thesis consists of all the 128 residents of the Hallsetheimen central institution for people with intellectual disability who lived in Sør-Trøndelag County after deinstitutionalization. In all 109 out of the 128 persons were followed up eight years after the first examination. They were aged between 15 and 67 years in 1987, when they were first examined. The population came from 14 local communities. The male: female ratio was nearly 2:1 (70 men and 39 women). In 1995, the mean age of the subjects was 46 years, with a range of 24 – 75 years. Four per cent were classified as mildly mentally retarded, 21 % as moderately, 55 % as severely and 13% as profoundly mentally retarded. Seven percent could not be classified because of multiple handicaps, but had a functional level comparable to those with severe or profound intellectual disability.

At the second examination in 1995, 18 dropouts were caused by dead and one was living in another county. The study population consisted of the remaining, 109 persons.

The 18 who had deceased were older ($M = 46$ years) than the 109 that participated in the study ($M = 38$ years), $t(126) = -2.39$, $p = .02$. There were no gender differences between the dropouts and the study population.

Among the deceased 11 % were classified as mildly, 11 % as moderately, 33 % as severely and 44 % as profoundly mentally retarded. The frequency of people with a profound mental retardation is significantly higher among the deceased $\chi^2(7.863, DF = 3, p = .05)$.

The frequencies of people with behaviour deficits were higher among the deceased than in the study population on behaviour deficits as: Personal hygiene (Mann - Whitney U, $z = -2.52$, $p = .01$), ability to dress ($z = -2.89$, $p = .004$), ability to move ($z = -2.91$, $p = .004$), ability to communicate ($z = -2.03$, $p = .04$), ability to orient / travel ($z = -2.53$, $p = .01$), and loss of sight ($z = -2.17$, $p = .03$). We could not find differences between the two groups on behaviour deficits as: ability to feed oneself, use of wheelchair, and loss of hearing.

The frequencies of persons with behaviour problems as attacks on people are fewer among the deceased than the people in the study population $\chi^2(8.54, DF = 1, p = .003)$.

We could not find any differences between the deceased and the study population on the PIMRA diagnosis except for anxiety. The frequency of people with a PIMRA anxiety diagnosis are higher among the study population than the drop outs $\chi^2(5.39, DF = 1, p = .02)$.

To conclude: The deceased were older, had more severe retardation, higher frequencies of behaviour deficits and less behaviour problems than the study population. The deceased were excluded from the original examination in 1987 to secure that the scorings at the two time-

points were based on the same persons, and to eliminate the possible differences, which the deceased might introduce by being included at the first examination.

As former inhabitants of a central institution the population under study is believed to be heavily selected compared with the general population of mentally retarded individuals. It comprised about 5% of the expected number of all persons with mental retardation in the area based on an assumption of 1 % of the population being affected. The group is thus not representative for mentally retarded persons in general (Linaker, 1994).

The subjects in the first study consisted of all the 109 persons. In 1995, the mean age of the subjects was 46 years, with a range of 24 – 75 years.

The subjects in the second study consisted of 23 persons. The subjects were all persons among the 109 in the age range 58 to 75 years in 1995.

The subjects in the third study consisted of a selection of the 68 persons without self-injurious behaviour before deinstitutionalization. Our study group consisted of 15 persons who showed no self-injurious behaviour before deinstitutionalization, but who started with self-injurious behaviour after deinstitutionalization. The comparison group was the 53 persons who showed no self-injurious behaviour before or after deinstitutionalization.

The subjects in the fourth study consisted of a selection of the 64 persons who did not attack others before deinstitutionalization. Our study group consisted of 22 persons who had never attacked people before deinstitutionalization but started doing so afterwards. The comparison

group was the 42 persons who never had attacked others neither before nor after deinstitutionalization.

The last study included all 109 persons.

Design.

To be able to throw light upon the questions within the restrictions of the data available, we chose to use several different designs. The study designs are quasi-experimental. We could not exert the control required in a true experiment: We could neither manipulate the independent variable, - the reform, nor assign subjects randomly to different groups.

Study I, II and V are prospective follow up studies. The studies III and IV are based on prospective follow up data, but with comparison groups defined retrospectively by different outcomes.

The covariates studied in all papers were individual, such as mental health, behaviour disturbances and use of neuroleptics. Behaviour deficits, such as use of wheelchairs, degree of assistance during ambulation, personal hygiene, ability to eat and dress, hearing and vision deficits, communication skills as well as developmental quotient and epileptic seizures were also included.

Environmental covariates were caretaker education, caretaker: patient ratio, housing and leisure activities and the caretakers' evaluation of the need for help due to behaviour disturbances and mental health problems.

Statistical analysis

Bivariate statistics with tests of significance have been used in paper I – IV. Multivariate analysis could have extracted more information about our multiple measures and possible interrelations. But since the data collected in our study are mainly ordinal and categorical and cannot reliably be used in multivariate analysis we have mostly chosen to omit such analyses. The exception is the use of multivariate analyses in paper V which made it possible for us to compare the determinants for psychotropic drug use before and after deinstitutionalization and the relative importance of behaviour disorders and psychiatric symptoms for neuroleptic dosage. The predictor variables were the scores on the eight PIMRA subscales, and the presence of behaviour disturbances last year, which are ordinal scales. Even if the data is not quite normally or equally distributed, we feel that the use of multivariate analyses in this paper are justified by the need to examine whether the earlier findings, that the medication seemed mainly motivated by disruptive behaviours, still held true after deinstitutionalization.

In all relevant statistical tests we have used the two tailed p – value to allow for both positive and negative group differences.

Assessment

Clinical diagnosis and Mental retardation

The ICD-10 (World Health Organization 1993) constitutes the official diagnostic system in Norway, and was used in the classification of the degree of mental retardation. The aetiology

of mental retardation and the prevalence of medical diseases were extracted from the participant's medical records and were categorised according to the ICD-10 main chapters.

The assessment of degree of mental retardation was based on behavioural data and not on IQ score. The reason for this is that only a small fraction of the population had been IQ tested, and many of them were assessed as "not testable".

Behaviour deficits

Behaviour deficits, as degree of assistance during ambulation, personal hygiene, ability to eat and dress, hearing and sight deficits and communication skills were scored on a scale from one to five. One indicated normal or not in need of help, and five indicated full dependence on the help of others.

Medical conditions

Information about medical health and the aetiology of mental retardation were extracted from the participants' medical records and categorized according to the main chapters of the ICD – 10 (WHO, 1993).

Drugs.

Information on drugs was taken from the people's medical records. Drugs were categorised according to the Anatomical Chemical Classification (ATC) (World Health Organisation 1991), and the dosages were transformed to percentage of the defined daily dosage (DDD %) for comparisons within main classes of drugs.

Mental health problems

Mental health problems were defined as behavioural disturbances, psychiatric disorders and symptoms. Psychiatric disorders and symptoms were identified with the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson et. al.1984). The PIMRA consist of 56 items in eight subscales: Schizophrenia, affective disorder, psychosexual disorder, adjustment disorder, anxiety disorder, somatoform disorder, personality disorder and a soundness score. Only schizophrenia, affective disorder, anxiety disorder, adjustment disorder, and no axis I diagnosis were considered mutually exclusive. Somatoform, psychosexual, and personality disorder were considered compatible with the existing axis I diagnosis, except for schizophrenia.

Among the scales designed to detect psychiatric disorders, the PIMRA was chosen because it was the only scale that had been extensively studied. It was developed in both a self reported version and an informant version. The informant version of the scale has shown high to moderate internal consistency for the subscales, high to moderate test – retest reliability, and high to moderate inter rater reliability (Aman et. al. 1986; Watson et. al. 1988; Iverson, & Fox, 1989; Sturmey & Ley, 1990; Linaker, 1991). The concurrent validity in mentally retarded populations is difficult to assess, as no standards exist to compare it to. Comparison with the Hamilton Rating Scale for depression (Hamilton, 1960) has shown a moderate correlation of $r = .49$ (Helsel & Mattson, 1988). Linaker & Helle (1994) showed, in a validity study, comparing the schizophrenia scale in PIMRA with the DSM III diagnosis of schizophrenia in a psychiatric population, that the specificity and sensitivity of the scale was satisfactory for practical use.

Several studies have correlated the total scores on the informant – rated version of the PIMRA and the total score on the Reiss Screen for Maladaptive Behaviour. The studies show

correlations varying from .61 to .87 (Reiss, 1994). The findings provide some evidence for the concurrent validity of the PIMRA.

The translation of the PIMRA was not performed according to internationally accepted rules for cross-cultural translation procedures (Flaherty et al., 1988), and after translated it has not been back translated to US English. Difficulties in translation of diagnostic tools and personality scales have been rightfully emphasised by some authors (Simonsen & Mortensen, 1990). Two main issues are of concern: One relates to linguistic aspects, that is, does a good translation exist. The other relates to psychometric properties, that is, does the instrument have the intended characteristics in the target. Research on the Norwegian version of PIMRA has yielded very similar results as international studies for PIMRA's psychometric properties (Linaker, 1994). A Swedish version exists and the two versions show similar meaning of the item wording in the two translations.

Two independent raters scored 19 of the 109 subjects in 1995. On the PIMRA, the mean single-item inter-rater reliability corresponded to $\Phi = 0.64$. The 1-year frequencies of behaviour problems had high inter-rater reliability with Φ varying between 0.80 and 1.0.

The occurrence of specific behaviour problems were identified by the caretakers. They were asked if the behaviours had occurred during the previous year or not. These questions were asked both in 1987 and 1995 and were used to study behaviour changes after deinstitutionalization. In 1995 we also asked more specific questions about challenging behaviour. The frequencies of this behaviours were scored on a scale from one to five, one indicated never and five always. The correlations between the two different measures of

behaviour disturbances aggression against people, aggression against/attacks at objects, and self-injurious behaviour were $r = .86$, $r = .86$, and $r = .98$ respectively.

SYNOPSIS OF THE INCLUDED PAPERS

Paper I: Psychiatric health needs and services before and after complete deinstitutionalization of people with intellectual disability.

The aim of this study were twofold, first to see if the ordinary health care system could give people with mental retardation the same or even better health care than they received in institutions, and second, to see if the statement that psychiatric problems were created by the institutions and that these problems would diminish or even disappear after deinstitutionalizing could be verified. The study is a prospective cohort study without control group, using a pre – post comparison of frequencies and scores on several variables to discover changes.

There was a small and insignificant increase in psychiatric health problems between 1987 and 1995. In 1987 there were high numbers of persons suffering from schizophrenia (28%), anxiety (60%), personality disorders (80%), somatoform problems (12%) and none had affective disorder. The corresponding figures in 1995 were 34%, 57%, 89%, 13% and 2%. The results show a population with a heavy load of psychiatric disorders, only 11% in 1987 and 6% in 1995 had no axis I disorder.

The total number of diagnoses was greater than the number of persons in the population, giving a mean of two diagnoses per person.

The one-year frequency of challenging behaviours such as attack on others, passivity and other kinds of disruptive behaviour, like yelling and jumping showed a significant increase after deinstitutionalization. Although the frequencies were higher, there was no significant change after deinstitutionalization in the number of persons who attacked material objects or showed self-injurious behaviour. Among the 28 persons without behaviour disturbances before deinstitutionalization, 25 acquired behaviour disturbances after deinstitutionalization a total of 24 persons with behaviour disturbances before deinstitutionalization had ceased this activity after deinstitutionalization. Only three persons were without behaviour disturbances both before and after deinstitutionalization.

The living conditions for the present population had been considerably improved after the reform. Before the reform all, except four persons, shared kitchen, living room, bath and toilets with others. After the reform, in 1995, half the population had apartments with their own living room, bedroom, kitchen and bath. The rest shared one or more rooms with other mentally retarded persons and four percent of the population shared bedroom with another person.

The mean organised leisure time, in-and outside their homes increased significantly after deinstitutionalization. All subjects received services from community agencies, and most of them received comprehensive help. There was a small and insignificant decrease in the mean caretaker: patient ratio between 1987 and 1995. The level of professional qualification for caretakers was low, both before and after the reform. In 1987, 12% of had been trained as general nurses or special nurses for people with mental retardation, 37% had a one year training as a nurse assistant and 53% were unskilled. In 1995 these figures were 13%, 48%

and 39% respectively. There were no significant changes in the caretakers' education from 1987 to 1995.

The proportion of the population, which had consulted general practitioners, psychiatrists or psychologists during the year previous to data collections showed a significant decrease from 1987 to 1995. None from the study population had been admitted to psychiatric hospitals during the period.

Forty-five percent had utilised the habilitation service since the reform started in January 1991 until the last examination in April 1995. This service was established during the reform period, and provides specialized services to several groups of disabled people, but mainly mentally retarded persons. The services were mainly provided by college-educated persons with additional special qualifications.

Paper II: Psychiatric and behavioural disturbances in elderly mentally retarded before and after deinstitutionalization

The aim of this study is the same as in the first study. Older people, age above 50, with mental retardation are a vulnerable group with special needs and we wanted to see if the ordinary health care system could give them the same or even better health care than they received in institutions, and to see if the statement that psychiatric problems were created by the institutions and that these problems would diminish or even disappear after deinstitutionalizing could be verified. The study is a prospective cohort study without control group, using a pre – post comparison of frequencies and scores on several variables to discover changes.

All but one had at least one psychiatric diagnosis. The total number of diagnoses in the population under study was 44, giving a mean of 1.9 diagnoses per person in 1995. There were high numbers of persons with anxiety (70 %) and personality disorders (87 %). Schizophrenic disorders (22%) were common, while somatoform (9%) and psychosexual disorders (4%) were less frequent. None suffered from affective disorder (major depression). There were no significant changes in frequencies of psychiatric disorders between 1987 and 1995.

The prominence of a psychiatric disorder such as schizophrenia in the population would be expected to reflect the consumption of psychotropic drugs but in fact, only two out of five persons suffering from schizophrenia received treatment with neuroleptics. The high frequency of anxiety disorders was not reflected in the consumption of anxiolytics or antidepressants, two persons used anxiolytics/sedativa before deinstitutionalization and none after deinstitutionalization. One person used hypnotics both before and after deinstitutionalization. There had been no significant changes in drug consumption after deinstitutionalization, mean dosage of neuroleptics before deinstitutionalization was 26% of defined daily dosage (DDD), and the figure after deinstitutionalization was 33 % of DDD.

The one-year frequency of various behaviour disturbances in the population before deinstitutionalization and after shows a significant increase in the proportion of people with passivity, and "other disruptive behaviour", like yelling and jumping. There was a significant decrease in persons with no behaviour problem. Although there were higher frequencies after deinstitutionalization in the number of persons who attacked other people, attacked objects, or displayed self-injurious behaviour, the changes were not significant

The number of persons who had consulted general practitioners, psychiatrists and psychologists during the previous year was 22, 0 and 1 respectively in 1995. The corresponding figures for 1987 were 23, 0 and 7. The change in the utilization of general practitioner services was not significant. None had seen a psychiatrist, neither before nor after, deinstitutionalization. There was a significant decrease in the use of psychologists. While few used specialized psychiatric health services, 22 % had utilized the habilitation services between January 1991 and April 1995.

Paper III: Self-injurious behaviour before and after deinstitutionalization

The results in Paper one showed that deinstitutionalization did not prevent the development of behaviour problems. Thirty-eight percent of the population showed self-injurious behaviour before, and 46 percent showed self-injurious behaviour after deinstitutionalization. The objectives of this study were to see if there were any risk factors for SIB which could be possible intervention points for preventive action. The study is a retrospective cohort study with a control group. In the study we compare individual scores on several variables to discover significant covariance's or group differences. The persons who developed SIB after deinstitutionalization (N=15) were the study group (Group A). Those who did not (N=53) comprised the control group (Group B). The population was examined before and after deinstitutionalization. As far as possible the same methods were used at both occasions.

The persons who developed SIB had lower developmental quotient, used wheelchairs more often and needed more assistance during ambulation in 1987. They had more epileptic seizures, and more impaired communication and personal hygiene. The study did not show

any differences in individual characteristics between the two groups in 1987 or in 1995 on variables like mental health, behaviour disturbances, use of neuroleptics, the ability to dress and the ability to eat. Our second observation in 1995 shows only minor environmental differences between the people in Group A and Group B. There were significantly more persons involved in the direct care, and more unskilled caretakers working with the people in Group A than Group B. There were no differences in other environmental factors such as living alone in an apartment or in the number of times they had been moved after deinstitutionalization. Neither was the caretakers' need for help due to behaviour disturbances and mental health problems significantly different. There were no differences in the caretaker: patient ratio, in the number of caretakers with a three or one year education, nor in the time spent in structured activities.

Paper IV: Predictors for attacks on people after deinstitutionalization.

The results in Paper one showed that deinstitutionalization did not prevent the development of behaviour problems. Forty-five percent of the population attacked people before, and 62 percent attacked others after deinstitutionalization. The aim of this study is the same as in study three. We wanted to see if there were any risk predictors that could be possible intervention points for preventive action. The study is a retrospective cohort study with a control group. The persons who started attacking others after deinstitutionalization (N=22) were the study group. Those who did not (N=42) comprised the control group. The population was examined before and after deinstitutionalization. As far as possible the same methods were used at both occasions.

The people who started to attack others after deinstitutionalization showed significantly more self-injurious behaviour in 1987 than those who did not start to attack others. The sum of behaviour disturbances shown last year, self-injurious behaviour, attacks on property and other disruptive behaviour were significantly higher among those who started attacking others. The soundness scores on PIMRA in 1987 for the people who started with attacks were lower than for those who did not start attacking. The group contained significantly fewer people without behaviour problems the last year in 1987. We found no differences on other individual characteristics like, aetiologies of intellectual disability, medical diseases, signs that indicated organic predisposing factors like epileptic seizures last years or degree of intellectual disability and behaviour deficits. The caretakers' evaluation of the clients need for help due to behaviour disturbances and mental health problems in 1987, were significantly higher for those who started attacking others. The people in the study group differed in age, gender and degree of intellectual impairment from the people in most other studies on learning deficiency and challenging behaviour. These differences indicate that the study group originally consisted of people who differed from those usually seen in studies on learning deficiency and challenging behaviour. The individual predictors for starting to attack others after deinstitutionalization were self-injurious behaviour, a slight load of other behaviour problems and a low soundness score on PIMRA. The environmental predictor was the caretakers' evaluation of the people's need for help caused by behaviour problems and mental health. We could not identify obvious intervention points for preventive action, so further studies are needed.

Paper V: Psychotropic drug use among people with learning deficiencies before and after deinstitutionalization

It is unclear whether antipsychotic medication helps people with learning disability regardless of the presence of a psychiatric disorder or not, we wanted to study psychotropic drug use before and after deinstitutionalization and factors contributing to this kind of treatment. One hypothesis was that psychotropic medication, neither before nor after deinstitutionalization, was given as treatment for a psychiatric symptom or diagnosis. The study is a prospective cohort studies without control group, using a pre – post comparison of frequencies and scores of several variables to discover changes.

The changes in the frequencies of psychotropic drug use and in the average DDD% of psychotropic drugs from 1987 to 1995 are small and not significant. The predominantly given psychotropic drugs continue to be neuroleptics. The frequency of neuroleptic drug usage has not changed significantly after deinstitutionalization; five people had started using neuroleptics and ten had stopped after deinstitutionalization. The population as a whole has had a significant reduction in average DDD%, but the DDD% reduction for those who used neuroleptics both before and after deinstitutionalization was not significant. The drug doses (DDD %) for people who started or stopped using neuroleptics were very small. Less than 50 percent of people with a diagnosis of schizophrenia used neuroleptics. There were no changes in the proportion of people with schizophrenia or anxiety diagnoses who used neuroleptics from 1987 to 1995. The anxiety disorders were treated psycho pharmacologically in a manner that must be considered inadequate. In all 37% and 25% were treated with neuroleptics before and after deinstitutionalization. None neither with nor without an anxiety diagnosis received treatment with selective serotonin reuptake inhibitors. The distribution of drug use across diagnostic main groups indicates an indiscriminate prescription practice. Four stepwise multiple regression analyses were conducted to predict the neuroleptic total dosages (% DDD) in 1987 and in 1995. The predictor variables in two of the analyses were scores on the eight

PIMRA subscales taken separately for both 1987 and 1995. The other two analyses used the presence of behaviour disturbances during the previous year separately for 1987 and 1995 as predictor variables for DDD%. The analyses indicated that behaviour disturbances, aggression against people in 1987 and aggression against property in 1995, are the strongest predictor variables for neuroleptic dosage. If one considers the PIMRA diagnosis of adjustment disorder as a description of behaviour disturbances, the main predictor variable for neuroleptic dosage was behaviour disturbances both before and after deinstitutionalization.

Additional analysis

The people living at the institution moved from the institution at different times. Both the time spent in the local community and the time spent in the institution could possibly affect their mental health. The population was divided in two groups those 69 persons leaving early, before 1994, and those 40 persons who left late after 1994. Table 1 - 4 show the differences in mental health problems among those who had been living in their local community and those still living in houses, apartments and refurbished wards on grounds of the institution.

Table 1

The numbers with different PIMRA diagnosis in 1987, among the people who left early (N = 69) and those that would be leaving the institution late after deinstitutionalization (N = 40).

	Leaving early N = 69	Leaving late N = 40	P-value
Schizophrenia	23	7	NS
Affective disorder	1	1	*
Anxiety disorder	57	36	NS
Adjustment disorder	41	25	NS
Somatoform disorder	11	2	*
Psychosexual disorder	11	4	NS
Personality disorder	57	30	NS

* The figures are too small for significance testing.

Table 2.

The numbers with different PIMRA diagnosis in 1995, among the people who left early (N = 69) and those leaving the institution late after deinstitutionalization (N = 40).

	Leaving early N = 69	Leaving late N = 40	P-value
Schizophrenia	26	7	NS
Affective disorder	2	1	*
Anxiety disorder	62	39	NS
Adjustment disorder	40	28	NS
Somatoform disorder	11	3	NS
Psychosexual disorder	4	4	*
Personality disorder	62	35	NS

* The figures are too small for significance testing.

Table 3.

The number of persons with behaviour disturbances in 1987, among the people that left early (N = 69) and those that would be leaving the institution late, after deinstitutionalization (N = 40).

	Leaving early N = 69	Leaving late N = 40	P-value
Attacks people	29	16	NS
Attacks objects	27	15	NS
Self – injury	24	17	NS
Other disruptive behaviour	33	16	NS
Passivity	16	8	NS
No behaviour disturbances	18	10	NS

Table 4.

The numbers of persons with behaviour disturbances in 1995, who left early (N = 69) and those that would be leaving the institution late after deinstitutionalization (N = 40).

	Leaving early N = 69	Leaving late N = 40	P-value
Attacks people	39	23	NS
Attacks objects	33	20	NS
Self – injury	32	18	NS
Other disruptive behaviour	46	31	NS
Passivity	28	16	NS
No behaviour disturbances	16	11	NS

Table 1 to 4 show that there were no significant differences in mental health before or after deinstitutionalization among those who left the institution early to live in their local community, and those who left late, and had been relocated to houses, apartments and refurbished wards on the grounds of the institution. Since the persons leaving the institution early did not differ from those leaving late, neither at the starting point of the

deinstitutionalizing process nor at the end point in 1995, the time passed since deinstitutionalization does not seem to affect the degree of behaviour problems and mental health.

MAIN RESULTS

The studies showed that mental health problems defined as behavioural problems and psychiatric disorders measured by PIMRA were not reduced by, but increased after deinstitutionalization.

The ordinary health care system could not give people with mental retardation the same or better health care than they received in institutions.

Deinstitutionalization did not prevent the development of behaviour disturbances such as self-injurious behaviour and attacks on other people.

People who developed SIB had significantly more persons involved in direct care and more unskilled caretakers in their service after deinstitutionalization than people who did not show SIB after deinstitutionalization. These factors may represent risk factors for developing SIB.

We could not identify obvious intervention points for preventive action among the people starting to attack others. Further studies are needed.

The changes in the frequencies of psychotropic drug use from 1987 to 1995 are small and not significant. The average DDD% of psychotropic drugs was marginally reduced. The predominantly given psychotropic drug continues to be neuroleptics.

Less than 50 percent of people with a schizophrenia diagnosis used neuroleptics. There were no changes in the proportion of people with diagnosis of schizophrenia or anxiety that used neuroleptics from 1987 to 1995.

The anxiety disorders were treated psychopharmacologically in a manner that must be considered inadequate. None in the population with or without, an anxiety diagnosis received treatment with the selective serotonin reuptake inhibitors.

The distribution of drug use across diagnostic main groups indicates an indiscriminate prescription practice. The analyses indicated that behaviour disturbances, both in 1987 and 1995 were the strongest predictor variables for neuroleptic dosage.

DISCUSSION

As former inhabitants of a central institution the population under study is believed to be heavily selected and it comprised about 5% of the expected number of all persons with mental retardation in the area based on an assumption of 1 % of the population being affected. In 1987 (Statistisk sentralbyrå, 1989) 0.6 ‰ of the Norwegian population stayed in central institutions in Norway. Our study population amounted to 0.5 ‰ of the population in South Trøndelag county. The young and old ones, below 16 and above 65, were excluded from our study population. This indicates that the proportion of the people staying at the central

institution in South - Trøndelag county were nearly the same as in the rest of the country. The group is not however representative for mentally retarded persons in general (Linaker, 1994). The two main reasons for this were: the intake procedures, and the changing patterns of residential placement before deinstitutionalization. Maladaptive behaviours have been identified as important in the determination of residential placement, the persons with challenging behaviour had an increased likelihood of being placed in larger, and more restrictive institutions than those without challenging behaviour (Borthwick-Duffy, 1994b). The characteristics of people living in institutions had changed the twenty years prior to the reform. The residents of the institutions evolved into a residual group of adult persons with severe and profound retardation who were likely to have an identified organic diagnosis and concomitant behaviour problems. The prevalence rate of challenging behaviour in the institution increased over time as persons with less severe problems were placed in less restrictive environments in small institutions and in the local community. This development can be seen in many countries (Eyman, Borthwick, & Tarjan, 1984; Farmer, Holroyd, Rhode, 1990).

Table 5. Prevalence of behaviour deficits in studies on mental retardation before deinstitutionalization.

	Epilepsy	Sight deficits	Hearing deficits	Movement deficits
Tøssebro (1992a)	-	36 %	9 %	37 %
Tøssebro (2003)	-	35 %	9 %	28 %
Stokke & Ruset (1989)	27 %	26 %	11 %	-
Wester (1982)	20 %	-	-	-
Syse (1995)	23 %	22 %	8 %	-
Norsk Institutt for Sykehusforskning (1978)	26 %	29 %	7 %	29 %
Nøttestad & Linaker (2003)	20 %	22 %	9 %	23 %

Table 5 shows the prevalence of medical deficiencies in this study and some other studies done before deinstitutionalization. In Tøssebro (1992a) the population under study were the people living in institutions for mentally retarded in the middle of Norway,- Møre and Romsdal and Sør – Trøndelag counties in 1989, with age between 18 and 67 years in 1989, N = 591 (Tøssebro, 1992a). Tøsssebro's 2003 study is an unpublished part of his study on people staying at Hellandheimen, the central institution in Møre and Romsdal county, N = 117. Stokke & Ruset (1989) is a study on deficiencies among all the people staying at Hellandheimen, the central institution in Møre and Romsdal county in 1986, N = 164. Wester (1982) is a study of all institutionalized people with mental retardation in Norway. Syse (1995) is a study of 177 institutionalized people with mental retardation from Finnmark county. One third (35 %) of the population lived in central institutions. NIS (1978) is a study of the people living at Hallsetheimen the central institution in Sør – Trøndelag in 1977, N = 339. Nøttestad & Linaker (2003) are unpublished data from Hallsetheimen in 1995.

Table 5 indicates that the prevalence of medical deficiencies in our study population appears to be fairly comparable to findings in other studies.

As cited above Jan Tøsssebro's 1992a study also contains the results from Hellandheimen Central institution in Møre and Romsdal County, and Tøsssebro's 2003 study is an unpublished part of his study, on people staying at Hellandheimen, the central institution in Møre and Romsdal county, N = 117 (Tøssebro, 2003). The study also contains results on behaviour deficits. It is difficult to compare the two populations on behaviour deficits because the questioning and the categorization of the deficits differ. A comparison could maybe be done between the extreme degrees of deficiencies, such as complete need for help. The frequencies of persons at Hellandheimen with behaviour deficiencies categorized as complete

need for help on behaviours as ability to dress, to feed oneself, to orient/travel without companion and in communication, were 19 %, 5 %, 26 and 23 %. The corresponding figures for the people living at Hallsetheimen were 24 %, 8 %, 18 % and 18 %. The male: female ratio in the two studies was nearly 2:1. At Hellandheimen 62 % were men, the figures for Hallsetheimen were 64 %.

The results from the studies at Hellandheimen (Tøssebro, 2003; Stokke & Ruset, 1989) indicate that the two populations appear to be fairly similar to the one studied at Hallsetheimen.

Tøssebro (1992a) states that the area in the middle of – Norway, Møre and Romsdal and Sør – Trøndelag counties is relatively representative for Norway. It has the same topography, the same residential areas, the same economic life, trade and industry structure and the same local council structure as the rest of Norway. In the study area 1, 4 % of the population stayed in HVPU-institutions, the same as the mean for the country as a whole. The development in the county-based health-care system for the mentally retarded, HVPU, in these two counties had been like the rest of the country. He says that the middle of Norway looks like “a little Norway”. The prevalence of medical deficiencies in our study population appears to be fairly comparable to findings in other studies. A comparison between the extreme degrees of deficiencies categorized as complete need for help and gender between the people staying at Hellandheimen and Hallsetheimen indicates that the two populations appears to be fairly alike.

The cited results indicate that our population could be representative for those who stayed in central institutions.

Mental health problems

The thesis shows that mental health problems were increased not decreased after deinstitutionalization. Access to qualified help, such as psychiatrists and psychologists had been significantly reduced. The frequencies of psychiatric disorders did not change after deinstitutionalization and behaviour disturbances increased.

Our study on mental health is a prospective cohort study without a control group, which leaves the results open to several interpretations. Eight years elapsed between the two data sets and innumerable things may have happened in the lives of these people. However we are not aware of any major events, unrelated to the reform, which were common to the subjects during these eight years. With a control group we could have studied effects of specific life events such as somatic illness, loss of relatives or significant others. The period between the first and to second assessment, eight years, as well as the large number of different observers makes systematic biases over the two observations in the caretakers' judgements improbable.

Several studies show that about two thirds of those with behaviour problems are below the age of 45 years (Queereshi, 1993). After the age of 40 there is a decrease in aggression and challenging behaviour. The present average age of 46 years should thus indicate an expected decrease in behaviour problems, not an increase. Age therefore seems an unlikely explanation.

Three of the papers reports quasi-experimental studies. Very strong inferences can be drawn from quasi-experimental studies (Kazdin, 2003), but the threats to validity are larger in these studies than in experimental studies.

“The institutional culture,” may be such a threat to internal validity. It was said that the “institutional culture” could dismantle the reform in such a way that mental health problems would not diminish or disappear after the reform.

Another threat to internal validity could be the time each had been living in the local community. A short stay might not be long enough to cause the disappearance of their mental health problems.

In 1995 40 persons still lived on the former institutions area. The caretakers had been working in the institution for a long time, and presumable were influenced by the “institutional culture” (K. Nicolaisen personal communication). Many but not all of the people moving back to their local communities had been followed by one or two persons from the institution. The mental health problems among those still living in houses, apartments and refurbished wards on grounds of the institution, in the “institutional culture” and the people living in their local community did not however differ in mental health problems from those who moved out earlier.

Nearly all the people leaving the institution left in 1991 and 1992. Only 4 -5 left in 1993 (K. Nicolaisen, personal communication), and none in 1994. We do not know the exact time when each person left the institution, but we know who remained in the institution after 1993. This means that all the people who left the institution before 1993 had been living in the community at least three years, and many for four years. The exception is four to five people that had been living in the community for at least one year.

Our comparison showed no differences in mental health problems among those who had been living in their local community for at least three years and those still living in houses, apartments and refurbished wards on grounds of the institution in 1995.

Psychiatric disorders

The only measure of psychiatric disorders was PIMRA. No clinical psychiatric assessment had been carried out so the results must be taken with some caution. Singh, Sood, Soneklar, & Ellis (1991), say it is important in clinical assessment practise to collect information on adaptive behaviour and intellectual functioning, to do screening on general measures of psychopathology such as PIMRA, rating scales and checklists for specific disorders, but also to make direct observations and experimental analysis of behaviour and laboratory analysis. Assessment in clinical work is a guide for clinical decisions and interventions. This study is a screening study of psychopathology before and after deinstitutionalization and not in need of the same accuracy as in individual clinical practice. That is one of the reasons for using only PIMRA as a screening instrument. A clinical psychiatric assessment by a trained psychiatrist or psychologist and a PIMRA diagnosis would have improved the validity of the results.

When people with mental retardation and mental health problems are assessed, there is a tendency to underestimate the importance of the psychiatric disorders. This phenomenon is referred to as diagnostic overshadowing and refers to instances in which the presence of mental retardation decreases the diagnostic significance of an accompanying mental health problem (Reiss & Szyszko, 1983).

Mental retardation in itself affects the behaviour and the verbal self reports we use in diagnostic decision – making. Sovner (1986) says the interaction between mental retardation and mental illness is the result of four factors. Intellectual distortion refers to concrete thinking and impaired communicating skills which hamper the ability to observe and describe one's own behaviour and feelings. Psychosocial masking describes the phenomena that people with mental retardation often have impoverished social skills and life experience. This could devoid the self - reports of the richness of conceptions and details that is associated with the symptoms of major psychiatric disorders, and symptoms could be missed. Cognitive disintegration refers to the tendency of people with mental retardation to become disorganized under emotional stress with a deterioration in intellectual functioning and a clinically significant behavioural regression, a psychotic-like state that may be misdiagnosed as schizophrenia. The last factor, baseline exaggeration describes the fact that people with mental retardation often show cognitive deficits such as distractibility and a variety of behaviour problems. During a period of emotional stress, these deficits and behaviour problems often increase in severity. The signs and symptoms of illness may be new non - adaptive behaviours or an increase in the severity of existing deficits and behaviour problems. Both the onset of new behavioural problems and the increase in cognitive deficits and old behavioural problems are diagnostically relevant information, not only the onset of new behavioural problems.

Our results show a population with a heavy load of psychiatric disorders, only 11% in 1985 and 6% in 1995 had no axis I disorder, the corresponding figures for schizophrenia were 28 and 34 percent. Studies on prevalence of people with psychiatric disorders vary from under 10 up to 80 percent (Borthwick-Duffy, 1994a), and studies on prevalence of psychosis vary from 5.5 to 37.3 percent (Skiftun, 1993). The population under study is highly selected and had

stayed many years in institutions. In the years before deinstitutionalization the well functioning people with mild and moderate mental retardation moved out of the institution to newly built group homes, integrated in the local community. Even if our study group is highly selected, the results correspond with other studies on this topic.

The frequencies of psychiatric disorders assessed by PIMRA did not change after deinstitutionalization. The assessment of psychiatric diseases was made both before and after deinstitutionalization with the same scale (PIMRA) administered with identical procedures, so the figures compared are believed to be compatible. The mental health problems which deinstitutionalization were meant to change (NOU: 34, 1985) were not defined further. Neither the clustering of mental health problems assessed by PIMRA, or the psychopathology score, show changes after deinstitutionalizing. We have found no study on deinstitutionalization and psychiatric disorders that could confirm or disconfirm the results on psychiatric disorders in our study.

By asking which behaviours had occurred during the previous year behaviour disturbances both before and after deinstitutionalization were identified. The present measures are coarse but the changes are considerable and the tendency is the same across the range of behaviour disturbances. The causes for the increase in behaviour problems may be found in the deinstitutionalizing process itself. Half of the population had moved more than twice and thus changed carers and suffered disruption in their physical and psychological environment. The loss of a well-known institutional milieu may have caused anxiety that could have contributed to the increase in behavioural problems. The reduced contact with psychiatrists and psychologists indicates a reduction in the treatment of psychiatric disorders and behaviour disturbances and may partly explain the increase in these problems. Studies evaluating the

effects of deinstitutionalization on behaviour disturbances among people with intellectual disability are inconclusive, and cannot confirm or disconfirm the results of this thesis. Some studies show an increase, some show a decrease and some show no change in such behaviours after deinstitutionalization (Emerson and Hatton, 1996; Larson & Lakin 1989). Kim, Larson & Lakin (2001) found three studies published since 1990 that reported significant improvements in behaviour problems after moving into the community. Nine studies reported no significant differences in behaviour problems for those who moved compared to those who remained in institutions.

Our results, an increase in mental health problems and a decrease in access to qualified help, such as psychiatrists and psychologists, are in concordance with the results in a study on somatic health and use of medical health services, in the same population, after deinstitutionalization (Linaker & Nøttestad, 1998). The study showed a worsening in physical handicaps. The carers' knowledge of their clients' physical health was inadequate in more than half the cases. Medical treatment needed improving in 36% of the cases, while it was clearly deficient in 9%. There had been a significant reduction in the use of general medical services, as well as in specialized neurology services.

O'Brien, Thesing, & Tuck (2001) retrospectively studied changes in "quality of life" nine years after deinstitutionalizing in New Zealand (N=35). One dimension in the "quality of life" was health. The questions used were not reported but they found a significant improvement in the staff's ratings on the health dimension after deinstitutionalization. The methodological weakness of the report is such that the results cannot be used either to confirm or disconfirm our results on health.

The study on mental health problems in elderly people with mental retardation generally shows the same changes as cited above. The proportion of psychiatric disorders in elderly people assessed with PIMRA did not change after deinstitutionalization. The proportion of elderly with behaviour problems increased and the proportion of elderly people without behaviour problems decreased. None had seen a psychiatrist before or, after deinstitutionalization, but there were a significant decrease in the use of psychologists.

The naive understanding of normalization and its effects on mental health problems that dominated the ideological arena in Norway before deinstitutionalization (NOU: 34, 1985) is not supported in this study. The ideologically based declaration that the ordinary health system could give people with mental retardation the same or even better health care than they received in institutions (NOU: 34, 1985) is not confirmed.

About such naive understanding of normalizing and the glorification of the ordinary health system's possibilities, Wing (1989) says "The idea of normalization, if accepted uncritically, can hide or even deny the fact that mental handicaps of varying degrees of severity exist in reality, even given the best environment and care possible" (p.3.)

Increase in specific behaviour problems.

We found an increase in behaviour problems after deinstitutionalization, some of the population acquired self-injurious behaviour (SIB), and some started to attack others after deinstitutionalization. Our measures of SIB and "attacks" were coarse, and defined as occurring during the previous year. Neither severity nor frequency was coded for these behaviour problems in 1987. Recording frequencies and severity could have given a more

detailed picture and revealed more nuances. In 1995 the frequencies of SIB and “attacks” were scored and the correlation the two different measures were satisfactory.

Of the total population of 109 persons, 15 persons acquired SIB and 22 persons started attacking others after deinstitutionalization, six ended the self – injurious behaviour and six ended their attacks on other people. Our results are tentative because of the relatively small numbers in our study group.

The persons who developed SIB, in study three, had lower developmental quotient, they used wheelchairs more often and needed more assistance during ambulation before deinstitutionalization. They also had more epileptic seizures, and more impaired communication and personal hygiene. There were no differences between the two groups on variables like mental health, behaviour disturbances and use of neuroleptics. Nor were the caretakers’ evaluations of the need for help, due to behaviour disturbances and mental health problems significantly different. After deinstitutionalization there were only minor environmental differences between those who acquired SIB and those who did not. Among those who acquired SIB we found more persons involved in their direct care, and more unskilled caretakers.

It seems that some organic predisposing factors may increase the likelihood of SIB. This may later continue for other reasons. Continuation of the behaviour can be established by dysfunctional reinforcement from the caretakers. This is more likely with many, and unskilled workers involved in direct care that often lack the competence necessary to avoid reinforcing unwanted behaviour (Lovaas & Smith, 1994; Schroeder & Tessel, 1994).

Study four shows that individual predictors for starting to attack others after deinstitutionalization were self-injurious behaviour, a slight load of other behaviour problems like attacks on property and other disruptive behaviours and a low soundness score on PIMRA. The environmental predictor was the caretakers' evaluation of the people's need for help due to behaviour problems and mental illness. We found no obvious intervention points for preventive action, neither individual nor environmental, so further studies are needed.

Those who acquired SIB are different from those who started to attack others. Those who acquired SIB are in some respects more like people with behaviour problems on variables such as, communication deficits, degree of mental retardation, hearing status and immobility. But they differed on variables as "clustering of aggression, self-injurious behaviour, destructiveness and other maladaptive behaviour" (Bihm & Poindexter, 1991; Borthwick-Duffy, 1994b; Collacott, Cooper, Branford, & McGrother, 1998; Moss, Emerson, Kiernan, Turner, Hatton, & Alborz, 2000; Sigafos, Elkins, Kerr, & Attwood, 1994).

Unlike those who developed SIB, those who started to attack others did not show signs which indicated organic predisposing factors for their behaviour, neither could we find any environmental factors related to this behaviour after deinstitutionalization. It looks as if people with a slight load of behaviour problems are at risk for worsening after deinstitutionalization.

Those who started to attack others had a little higher load of behaviour problems before deinstitutionalization than those who did not. We could not find any signs that indicated a disturbance in the central nervous system. After deinstitutionalization they showed a "clustering of behaviour problems" like those identified in the cited studies. The results

indicate that those who started to attack others after deinstitutionalization differ from those with mental retardation and behaviour problems most often described in epidemiological studies. The late onset of aggressive behaviour sustains this hypothesis.

Unknown individual characteristics, aspects like the deinstitutionalization process, individual experiences, or combinations of these may cause the development of the heavy load of aggressive behaviour after deinstitutionalization.

Studies on behaviour problems and deinstitutionalizing are not conclusive, some show an increase and some show a decrease after deinstitutionalization, one reason may be the study populations' access to specialized health care people like psychiatrists and psychologists. Further studies on mental health, deinstitutionalization and among other variables the use of specialised health care services are needed.

Our study groups were those with an increase in behaviour problems, those who acquired self-injurious behaviour, and those who started to attack others after deinstitutionalization. Another interesting study population could have been those who stopped being self injurious and those who stopped to attack others, but the groups were too small, namely six persons in each group.

Psychotropic drug use

There were no major changes in the use of neuroleptics after deinstitutionalization either in frequency or in dosages, and there was little evidence of discriminate use in relation to diagnosis. People with schizophrenia or anxiety disorders did not receive proper drug

treatment before, or after deinstitutionalization. The main predictor variable for neuroleptic dosage both before and after deinstitutionalization was behaviour problems. The results are in concordance with results from other studies on mental retardation, mental health and the use of neuroleptics (Singh, Ellis, & Wechsler, 1997).

Psychiatric disorders were assessed by PIMRA without the supplement of an additional clinical psychiatric assessment, so the diagnosis could be inaccurate. Some of the reason may have to do with the difficulties in determining the extent to which presenting behaviours are the result of a psychiatric disorder or behaviour disorders. If some of the disorders assessed by PIMRA prove to be isolated behaviour problems, and people with a psychiatric disorder are assessed as people with behaviour problems, some part of the mismatch between psychiatric disorders and medication can be explained. According to a validation study (Linaker & Helle, 1994) faulty assessment cannot explain why only 35% of people with schizophrenia got neuroleptics. Studies on the relationship between behaviour problems and psychiatric disorders are not conclusive. Some studies show positive correlations between challenging behaviour and psychiatric disorders (Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000), other studies do not show significant correlations between the two (Fraser, Laudar, Gray & Campbell, 1986). In a study on the relationship between PIMRA and the Checklist of Challenging Behaviour, Jenkins, Rose & Jones (1998) found that the relationship between non-aggressive behaviours and mental health showed a significant overlap. Aggression indicated significant positive relationships only for "Adjustment disorder" and "Inappropriate adjustment".

Before deinstitutionalizing, few psychiatrists and psychologists were interested in this problem, and the use of psychiatrists and psychologists has decreased after

deinstitutionalization. The low and decreasing access to specialized help may explain some of the indiscriminate use of neuroleptics.

Another reason for the indiscriminate use of neuroleptics may be due to a lack of knowledge among the caretakers. The ratio of caretakers with an education as general nurse or special nurse for people with mental retardation had not changed between 1987 and 1995. In 1995 13 % of caretakers were educated as general or special nurses for people with developmental disabilities. Studies early in the deinstitutionalizing period from two counties, on the caretakers' needs for education, indicated needs for more knowledge about: "hands - on work", "civil rights" and "language /communication training". Normalization and integration, the superior principle for the reform were not mentioned (NOU 1994: 8). The authorities decided that the normalizing principle demanded a new professionalism that could impede the development of an institutional culture in the local communities (NOU 1994: 8). An essential part of the education and training for caretakers in the local communities and also at the nurse colleges circled around normalization, and the gains normalization would bring people with mental retardation. In 1995 (Rundskriv I-41/95) 77% of the Norwegian local communities reported to the authorities that they were in need of caretakers with proficiency in behaviour problems. The same figures in 1997 were 68% (Rundskriv I-16/97). Lectures on mental retardation and mental disorders, in schools for special nurses for people with mental retardation, are relatively new topics and started around the mid 1990s. The needs in the local counties for assistance in the care for mentally retarded people with large behaviour problems and psychiatric disorders have been documented in many studies (Helsedirektoratet, 1993; Lichtwarc, 1995; Vetvik and Hem, 1994).

Seeking help and treatment for a psychiatric problem depends much upon the caretakers. They must be able to recognize the signs and symptoms of psychiatric illness and take adequate action (Nøttestad & Linaker, 1994). The signs and symptoms recognised and referred to specialized health services are for them "untreatable" behaviour problems (Day, 1985; Nøttestad & Linaker, 1998).

The lack of knowledge among general practitioners, and the lack of access to specialized health services seem to be part of the explanation for the indiscriminate medication in relation to diagnosis. Langan, Russel and Whitfield (1993) found that general practitioners generally lacked special expertise for dealing with people with mental retardation and almost all felt further training was appropriate. Similar problems have been found in USA. Harper and Wadsworth (1992) argue that health care professionals in the USA often lack the opportunity to gain experience in interacting with people whose ability to express and understand health care information is limited. People with psychiatric illness with no outstanding behaviour problems will remain unrecognised and not seen as in need of referral and psychiatric assessment (Bortwick-Duffy & Eyman, 1990).

CONCLUSIONS

Mental health problems defined as behavioural problems and psychiatric disorders measured by PIMRA were not reduced, but increased after deinstitutionalization.

The ordinary health system could not give people with mental retardation the same or better health care than they received in institutions.

People with mental retardation had substantially reduced access to qualified help such as psychologists and psychiatrists, after deinstitutionalizing.

It is not likely that elderly people with mental retardation had a decrease in psychiatric disorders. We found that there was an increase in minor behaviour disturbances such as disruptive behaviour and passivity after deinstitutionalizing

Mentally retarded people who developed SIB had a lower developmental quotient, used wheelchairs more often, and needed more assistance during ambulation. They had more epileptic seizures, more impaired communication and personal hygiene than people who did not show SIB after deinstitutionalization. They also had significantly more persons involved in direct care and more unskilled caretakers in their services after deinstitutionalization than people who did not show SIB after deinstitutionalization. These factors may represent risk factors for developing SIB.

The individuals who started to attack others after deinstitutionalization had more self injurious behaviour, a slightly higher load of other behaviour problems and a lower soundness score on PIMRA than those who did not develop person - attack behaviour. Their caretakers evaluated these people's need for help in terms of behaviour problems and mental health, as larger then the need of those who did not develop attack behaviour before deinstitutionalization.

We could not find obvious intervention points for preventive action against the development of aggressive behaviour, neither at individual nor environmental level so further studies are needed.

There had been no major changes in either the frequency or the dosage of neuroleptics after deinstitutionalization.

People with schizophrenia or an anxiety disorder did not receive adequate drug treatment, either before or after deinstitutionalization.

The main predictors for neuroleptic dosage both before and after deinstitutionalization were behaviour disturbances.

The deinstitutionalization may have had many advantages, but our results show that it has not lived up to the hopes many had that it should ameliorate the burden of mental health problems suffered by persons with mental retardation. Instead it seems to have made access to adequate help more difficult and has resulted in some increases in mental health problems.

REFERENCES

- Aman, M. G., Wattson, J. E., Singh, N. N., Turbott, S. H., & Wilsher, C. P., (1986). Psychometric and demographic characteristics of the Psychopathology Instrument for Mentally Retarded Adults. Psychopharmacology Bulletin, 22, 1072-1076.
- Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The Aberrant Behavior Checklist: A behavior rating scale for the assessment of treatment effects. American Journal of Mental Deficiency, 89, 485-491.
- American Psychiatric Association (1980). DSM-III-D: Diagnostic and Statistical Manual of Mental Disorders. 3d ed. Washington, DC: The Association.
- Barton, W. R. (1959). Institutional neurosis. Bristol: John Wright & Sons.
- Bihm, E., & Poindexter, A. R. (1991). Cross-validation of the factor structure of the Aberrant Behavior Checklist for persons with mental Retardation. American Journal of Mental Retardation, 96, 209-211.
- Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: a population study. American Journal on Mental Retardation, 99, 595 – 604.
- Borthewick – Duffy, S., A. (1994a). Epidemiology and Prevalence of Psychopathology in People with Mental Retardation. Journal of Consulting and Clinical Psychology, 62, 17 – 27.
- Borthewick – Duffy, S., A. (1994b). Prevalence of Destructive Behaviors. A Study of Aggression, Self Injury, and Property Destruction. In T. Thompson & D. B. Gray (Eds.), Destructive behaviour in developmental disabilities, pp. 3-23. London: SAGE Publications, Inc.
- Bouras, N., Brooks, D., & Drummon, K. (1994). Community psychiatric services for people with mental retardation. In N. Bouras (Ed.), Mental health in mental retardation. Recent advances and practices (pp. 293-318). New York: Cambridge Press.
- Collacott, R.A., Cooper, S-A., Branford, D. & McGrother, C. (1998). Epidemiology of self-injurious behaviour in adults with learning disabilities. British Journal of Psychiatry, 173, 428-432.
- Costello, H., Moss, S. C., Prosser, H., & Hatton, C. (1997). Reliability of the ICD 10 version of the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD). Social Psychiatry and Psychiatric Epidemiology, 32, 339-343.
- Dosen, A. (1993). Mental health and mental illness in persons with retardation: What we are talking about? In R. Fletcher & A. Dosen (Eds.), Mental health aspects of mental retardation - Progress in assessment and treatment (pp. 3-17). New York: Lexington Books.
- Emerson, E. (1992). What is normalization? In H. Brown & H. Smith (Eds.) Normalization: A reader for the Nineties, pp. 1 – 18. London: Routledge.

- Emerson, E., & Hatton, C. (1996). Deinstitutionalization in the UK and Ireland: Outcomes for service users. Journal of Intellectual and Developmental Disability, 21, 17-37.
- Emerson, E., Barret, S., Bell, C., Cummings, R., McCool, C., Toogod A. & Mansell, J. (1987). Developing services for People with Severe Learning Difficulties and Challenging Behaviours. Institute of Social and Applied Psychology: Canterbury.
- Ericsson, K. (1996). Housing for the person with intellectual handicap. In J. Mansell, & K. Ericsson, Deinstitutionalization and Community Living. Intellectual disability services in Britain, Scandinavia and the USA, pp.81 – 95. London: Chapman & Hall.
- Eyman, R. K., Borthwick, S. A., & Tarjan, G. (1984). Current trends and changes in institutions for the mentally retarded. In N. Ellis & N. Bray (Eds.), International review of research in mental retardation, (vol. 12, pp. 177-203). New York: Academic Press
- Farmer, R., Holroyd, S., & Rhode, J. (1990). Differences in disability between people with mental handicaps who were resettled in community and those who remained in hospital. British Medical Journal, 301, 646.
- Flaherty, J. A., Gavira, F. M., Pathak, D., Mitchell, T., Wintrob, R., Richman, J. A., & Birz, S. (1988). Developing instruments for cross-cultural psychiatric research. Journal of Nervous and Mental Disease, 5, 257-263.
- Foucault, M. (1965). Madness and civilisation. A history of insanity in the age of reason. New York: Random House.
- Fraser, W. I., Laudar, I., Gray, J. & Campbell, I. (1986). Psychiatric and behavior disturbances in mental handicap. Journal of Mental Deficiency Research, 30, 49-57.
- Goffman, E. (1961). Asylums: Essays on the social institutions of mental patients and other inmates. New York: Doubleday & Company Inc.
- Gøstason, R. (1985). Psychiatric illness among the mentally retarded. A Swedish population study. Acta Psychiatry Scandinavia, 71, 1 – 117.
- Hamilton, M. (1960). A rating scale for depression. Journal of Neurology, Neurosurgery, and Psychiatry, 23, 56-62.
- Helsedirektoratet, (1993). Helsedirektoratets utredningsserie 5-93. Spesialisthelsetenesta sine tilbod til funksjonshemma med utviklingsforstyrningar og atferdsavvik. (The specialized health services offer to people with a developmental disorder and behaviour problems). Oslo: Helsedirektoratet (The National Board of Health).
- Helsel, W. J., & Matson, J. L. (1988). The relationship of depression to social skills and intellectual functioning in mentally retarded adults. Journal of Mental Deficiency Research, 32, 411-418.
- Iverson, J. C., & Fox, R. A. (1989). Prevalence of psychopathology among mentally retarded adults. Research in Developmental Disabilities, 10, 77-83.

- Jenkins, R., Rose, J., & Jones, T. (1998). The Checklist of Challenging Behaviour and its relationship with the Psychopathology Inventory for Mentally Retarded Adults. Journal of Intellectual Disability Research, 42, 273-278.
- Jensen, T. (1996). An evaluation of the deinstitutionalization of persons with developmental disabilities in Norway. Doctoral Dissertation, Department of Psychology Oslo: Oslo University.
- Jensen, T., & Mørch, W. - T. (1990). HVPUs' spesielle tjenester og bruk av ordinære spesialisttjenester fra 2. linje tjenesten. En intervju-undersøkelse om dagens situasjon og brukergruppens behov i fremtiden. (The use of county based specialized health services for mentally retarded in Norway. A survey of the situation today and future needs). Tidsskrift for Norsk Psykologforening, 27, 177 – 187.
- Johnsen, F. (1982). Farvel til særomsorgen. (A farewell to the segregated care system). Oslo: Universitetsforlaget.
- Johansen, K. (1995). Etableringen av fylkeskommunale habiliteringstjenester. I T. I. Romøren (Ed.), HVPU - Reformen i forskningens lys. (The HVPU - Reform in the light of research), (pp.285-307). Oslo: Ad Notam Gyldendal.
- Jones, K., & Fowles, A. J. (1984). Ideas on institutions. Analysing the literature on long-term care and custody. London: Routledge & Kegan Paul.
- Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalization for people with intellectual disability: a review of US studies conducted between 1980 and 1999. Journal of Intellectual & Developmental Disability, 26, 35-50.
- Kazdin, A. E. (2003). Research design in clinical psychology. London: Allyn and Bacon.
- Kosberg, P. I. (1967). Klæbu offentlige pleiehjem. 50-års beretning 1917 - 1967. Festskrift til Klæbu pleiehjems 50-årsjubileum. Klæbu.
- Larson, S. A., & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. Journal of the Association for the Severely Retarded, 14, (4), 324-332.
- Lichtwarc, W. (1995). Habiliteringstjenesten i Buskerud. Kommunenes bruk og vurdering av den fylkeskommunale habiliteringstjenesten. NF - rapport nr. 18/95. Bodø: Nordlandsforskning.
- Linaker, O. M. (1991). DSM-III Diagnosis compared with factor structure of the Psychopathology Instrument for Mentally Retarded Adults, in an institutionalised , mostly severely retarded population. Research in Developmental Disabilities, 12, 143-153.
- Linaker, O. M. (1994). Mental retardation and psychiatry. Past and present. (Doctoral thesis). University of Trondheim, Trondheim: Tapir.
- Linaker, O. M., & Helle, J. (1994). Validity of the schizophrenia diagnosis of the Psychopathology Instrument for Mentally retarded Adults (PIMRA): A comparison of

schizophrenic patients with and without mental retardation. Research in Developmental Disabilities, 15, 473-486.

Linaker, O. M., & Nitter, R. (1989). Hvem er igjen i sentralinstitusjonene ? (Who is left back in the large institutions?). Tidsskrift for den Norske Lægeforening, 109, 473 – 475..

Linaker, O. M., & Nitter, R. (1990). Psychopathology in institutionalised mentally retarded adults. British Journal of Psychiatry, 156, 522-525.

Linaker, O. M., & Nøttestad, J. Aa. (1998). Helse og helsetjenester til mennesker med psykisk utviklingshemming før og etter ansvarsreformen. (Health and health services for the mentally retarded before and after deinstitutionalization). Tidsskrift for den Norske Lægeforening, 118, 357 - 361.

Lovaas, O. I., & Smith, T. (1994). Intensive and long-treatments for clients with destructive behaviors. In T. Thompson & D. B. Gray (Eds.), Destructive behavior in developmental disabilities, Diagnosis and treatment. London: Sage publications.

Lov av 10. juni 1988 nr. 48. Midlertidig lov om avvikling av institusjoner og kontrakter om privatpleie under det fylkeskommunale helsevern for psykisk utviklingshemmede (Preliminary act concerning the closing of institutions and private care contracts under the county – based health – care system for the mentally retarded). Oslo.

Lund, J. (1985). The prevalence of psychiatric morbidity in mentally retarded adults. Acta Psychiatrica Scandinavica, 75, 563 – 570.

Lund, R. B. (1992). Planlagt og iverksatt. (Planned and implemented). NF – rapport nr. 38/92 - 60 Bodø: Nordlansforskning.

Matson, J. L., Kazdin, A. E., & Senatore, V. (1984). Psychometric properties of the Psychopathology Instrument for Mentally Retarded Adults. Applied Research in Mental Retardation, 5, 881-889.

Matson, J. L., Gardner, W. I., Coe, D. A., & Sovner, R. (1991). A Scale for Evaluating Emotional Disorders in Severely and Profoundly Mentally Retarded persons. Development of the Diagnostic Assessment for the Severely handicapped (DASH) Scale. British Journal of Psychiatry, 159, 404-409.

McBrien, J. (1994). The Behavioural Services Team for people with learning disabilities. In E. Emerson, P. McGill, & J. Mansell (Eds.), Severe learning disabilities and challenging behaviours. Designing High Quality services, (pp. 179-205). London: Chapman & Hall.

Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C., & Alborz, A. (2000). Psychiatric symptoms in adults with learning disability and challenging behaviour. British Journal of Psychiatry, 177, 452-456.

Norsk Institutt for Sykehusforskning (1978). Behovsanalyser I omsorgen for psykisk utviklingshemmede (Analysis of the needs in the care for the mentally retarded). Trondheim: Norsk Institutt for Sykehusforskning.

NOU 1994: 8. Kompetanseutvikling i arbeidet for psykisk utviklingshemmede (Proficiency development in work with persons with developmental disability). Oslo : Det kongelige Sosial og helsedepartement (The Royal Ministry of Social Affairs and Health).

NOU: 34. (1985). Levekår for psykisk utviklingshemmede (Living Conditions for the Intellectually Disabled). Oslo: Universitetsforlaget.

Nøttestad, J. Aa., & Linaker, O. M. (1994). Behov for og bruk av habiliteringstjenester etter avviklingen av HVPU (The needs and use of specialized habilitation services for the mentally retarded after the Norwegian deinstitutionalization). Tidsskrift for Norsk Psykologforening, 31, 291 – 297.

Nøttestad, J. Aa., & Linaker, O. M. (1998). Kommunenes bruk av habiliteringstjenesten for voksne etter ansvarsreformen. (The municipalities use of the habilitation services after deinstitutionalization). Tidsskrift for Norsk Psykologforening, 35, 979 – 986.

O'Brien, P., Thesing, A., & Tuck, B. (2001). Perception of change, advantage and quality of life for people with intellectual disability who left a long stay institution to live in the community. Journal of Intellectual & Developmental Disability, 26, 67-82.

Ot.prp. nr. 57. (1949). Om lov om hjem som mottar åndsvake til pleie, vern og omsorg (The law on homes that receives people with mental retardation for nursing, protection and care). Oslo : Det Kongelige Sosial og Helsedepartement (The Royal Ministry of Health and Social Affairs).

Ot.prp. nr. 36 (1967-68). Om lov om Sykehus m.m. (The law about hospitals). Oslo : Det Kongelige Sosial og Helsedepartement (The Royal Ministry of Health and Social Affairs).

Quereshi, H. (1993). Prevalence of challenging behaviour. In I. Flemming & B. Stenfert Kroese (Eds.), People with learning disability and severe challenging behavior. New developments in service and therapy (pp. 11-42). Manchester: Manchester University Press.

Reid, A., H. (1997). Mental handicap or learning disability, A critique of political correctness. Brithish Journal of Psychiatry, 170, 1.

Reid, A. H. (1983). Psychiatry of mental handicap: a review. Journal of the Royal Society of Medicine, 76, 587-592.

Reiss, S. (1994). Handbook of challenging behaviour: mental health aspects of mental Retardation. Ohio: IDS Publishing Corporation.

Reiss, S., & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally retarded persons. American Journal of Mental Deficiency, 87, 396 – 402.

Romøren T., I. (1995). Reformen for psykisk utviklingshemmede. I T. I. Romøren (Ed.), HVPU - Reformen i forskningens lys (pp.15-33). Oslo: Ad Notam Gyldendal.

Rundskriv I-45/89. Behovet for spesialiserte tjenester for mennesker med psykisk utviklingshemming. Fylkeskommunenes oppgaver etter 1.1.1991 (The needs for specialized

services among people with mental retardation. The counties duties after 1.1.1991). Oslo : Det Kongelige Sosial og Helsedepartement (The Royal Ministry of Health and Social Affairs).

Rundskriv I-61/89. Planleggingen av de fylkeskommunale spesialisthelsetjenester for mennesker med psykisk utviklingshemming. (How to plan the counties specialized health services for people with mental retardation). Oslo : Det Kongelige Sosial og Helsedepartement (The Royal Ministry of Health and Social Affairs).

Rundskriv I-41/95. Status for gjennomføring av reformen for mennesker med psykisk utviklingshemming. Sammenfatning av resultatene fra kommunenes rapportering 1995. (Status report on the implementation of the reform for persons with mental disabilities. Summary of the results from the municipals reports of 1995). Oslo : Det kongelige Sosial og helsedepartement (The Royal Ministry of Health and Social Affairs).

Rundskriv 1-16/97. Status for tilbudet til mennesker med psykisk utviklingshemming. Sammenfatning av resultatene fra kommunenes rapportering 1996.m.m.(Status for the services for people with mental retardation. Summing up of the results from the local communities reports 1996). Oslo : Det kongelige Sosial og helsedepartement (The Royal Ministry of Health and Social Affairs).

Ruset, A. & Stokke,G. (1989). Kartlegging av funksjonshemmingar hos bebuarane ved Hellandheimen. (A study of disabilities among the mentally retarded in Hellandheimen central institution). Møre og Romsdal Fylkeskommune: Hellandheimen.

Sandvin, J., T. (1996). Velferdsstatens vendepunkt. En analyse av reformen for mennesker med utviklingshemming som uttrykk for brytninger i velferdsstaten. (The welfare state`s turning point. An analysis of the reform for people with mental retardation as an expression for conflicts in the understanding of the welfare state). Bodø: Nordlandsforskning.

Schroeder, S. S., & Tessel, R. (1994). Dopaminergic and serotonergic mechanisms in self-injury and aggression. In T. Thompson & D., B. Gray (Eds.), Destructive behavior in developmental disabilities, Diagnosis and treatment (pp. 198-210). London, Sage

Senatore, V., Matson, J. L., & Kazdin, A. E. (1985). An inventory to assess psychopathology of mentally retarded adults. American Journal of Mental Deficiency, 89, 459-466.

Sigafoos, J., Elkins, J., Kerr, M., & Attwood, T. (1994). A survey of aggressive behaviour among a population of persons with intellectual disability in Queensland. Journal of Intellectual Disability Research, 38, 369-381.

Singh N. N., Ellis C. R., & Wechsler, H. (1997). Psychopharmacaeepidemiology of mental retardation: 1966 to 1995. Journal of Child and Adolescent Psychopharmacology 7, 255-266.

Singh, N. N., Sood, A., Soneklar, N., & Ellis, C. R. (1991). Assessment and diagnosis of mental illness in persons with mental retardation. Behaviour Modification, 15, 419-443.

Simonsen, E., & Mortenson, E. L. (1990). Difficulties in translation of personality scales. Journal of Personality Disorders, 4, 290-296.

Skiftun, Å. (1993). Åtferdsavvik/psykiske lidningar hos psykisk utviklingshemma menneske - utfordringar i eit grenseland (Behaviour problems/psychiatric diseases among people with mental retardation challenges in the borderland). I Å. Skiftun (Ed.), Utfordrande åtferd. Om åtferd og psykiske lidningar hos dei djupast psykisk utviklingshemma (Challenging behaviour. About behaviour and psychiatric diseases among people with profound mental retardation) (pp.9-20). Oslo: Universitetsforlaget.

Skjellum, T. (1997). Psykisk utviklingshemmede og helse-og sosialtjenesten i Akershus. En survey undersøkelse blant psykisk utviklingshemmede og deres pårørende (People with mental retardation and the health and social services in Akershus county. A survey among people with mental retardation and their relatives). Heltef rapport nr.2. Akershus: Stiftelsen for helsetjenesteforskning.

Sovner, R. (1986). Limiting Factors in the Use of DSM-III Criteria with Mentally Ill/Mentally Retarded Persons. Psychopharmacology Bulletin, 22, 1055 – 1059.

Statens Helsetilsyn. (2000). Utviklingshemmede med alvorlige atferdsavvik og/eller psykiske lidelser. En kartlegging av spesialisthelsetjenestens tilbud og behov (People with mental reardation with large behaviour problems and/or psychiatric diseases. A study of the needs and the services offered). Oslo: Statens Helsetilsyn (The National Board of Health).

Statens helsetilsyn (1995). Den fylkeskommunale habiliteringstjenesten 3 år etter HVPU-reformen (The habilitation services in the counties 3 years after the HVPU-reform). Oslo: Statens Helsetilsyn (The National Board of Health).

Statistisk sentralbyrå. (1989). Central Bureau of Statistics. Statistical Yearbook of Norway. Oslo: Central Bureau of Statistics.

Stortingsmelding nr 25 (1966-97). Åpenhet og helhet. Om psykiske lidelser og tjenestetilbudene (Report to the Parliament nr.25. Openness and totality. About psychiatric diseases and the sevicees). Oslo: Det Kongelige Sosial og helsedepartement (The Royal Ministry of Social Affairs and Health).

Stortingsmelding nr. 88 – 1966/67. Om utviklingen av omsorgen for funksjonshemmede (Report to the Parliament nr.88 – On the development of care for the handicapped). Oslo : Det Kongelige Sosial og helsedepartement (The Royal Ministry of Social Affairs and Health).

Ruset, A. & Stokke,G. (1989). Kartlegging av funksjonshemmingar hos bebuarane ved Hellandheimen. (A study of disabilities among the mentally retarded in Hellandheimen central institution). Møre og Romsdal Fylkeskommune: Hellandheimen.

Sturmey, P., & Ley, T. (1990). The Psychopathology Instrument for Mentally Retarded Adults: internal consistencies and relationship to behaviour problems. British Journal of Psychiatry, 156, 428-430.

Syse, A. (1995). Velferd og rettsikkerhet for psykisk utviklingshemmede gjennom en reformprosess. "Finnmarksundersøkelsen 1993". (Welfare and civil rights for people with mental retardation throughout a reform process. "The Finnmark study 1993"). I Syse A. (Red.), Rettssikkerhet og livskvalitet for utviklingshemmede. Rettigheter, vern, og kontroll

som rettslige virkemidler. (Civil rights and quality of life for people with mental retardation. Rights, care and control) pp 319 – 405. Oslo : Ad Notam Gyldendal.

Szass, T. S. (1961). The Myth of Mental Illness: foundations of a theory of personal conduct, New York: Dell.

Tøssebro, J. (1988). Velferd for psykisk utviklingshemmede. Hvordan måle det? (Welfare for the mentally retarded. How to measure it). Trondheim: Norsk Institutt for Sykehusforskning.

Tøssebro, J. (1992a). Institusjonsliv i velferdsstaten, – levekår under HVPU (Institutional life in the welfare state, the living conditions in a county - based institutional health care system HVPU). Oslo: Ad Notam Gyldendal.

Tøssebro, J. (1992b) Hvorfor så negative? Pårørendes syn på institusjonsavvikling. (Why so negative? The relatives meanings about deinstitutionalizing). In J. Sandvin (Ed.), Mot normalt ? (Against the normally ?), pp. 91 – 124. Oslo: Kommuneforlaget.

Tøssebro, J. (1995). En utvidelse av velferdsstaten. (An expansion of the welfare state) I T. I. Romøren (Ed.), HVPU - Reformen i forskningens lys (The Norwegian deinstitutionalization for mentally retarded persons in the light of research), (pp.15-33). Oslo: Ad Notam Gyldendal.

Tøssebro, J. (1996a). En bedre hverdag? Utviklingshemmedes levekår etter HVPU reformen. (A better working day? Living conditions for the mentally retarded after the HVPU reform). Oslo: Kommuneforlaget.

Tøssebro, J. (1996b). Deinstitutionalization in Norway: continuity and change. In: Program and Abstracts of the 10th World Congress of the International Association for the Scientific Study on Intellectual Disabilities (IASSID), Helsinki 8 – 13 July 1996 (ed. IASSID), p.60. Helsinki: IASSID.

Vail, D. J. (1972). Dehumanisering och institusjonskarrieren (Dehumanization and the institutional career) I K. Grunewald (Ed.), Menniskohantering på totala vårdinstitutioner. Från dehumanisering til normalisering. (Treatment of people at total institutions, from dehumanization to normalization), (pp.37 – 82). Stocholm: Bokforlaget Natur och Kultur.

Vetvik, E. & Hem S., M. (1994). Vertskommunene mot 1996. Status 1993 for gjennomføringen av ansvarsreformen. (Municipalities with institutions. Status for the reform in 1993). Oslo: Diakonhjemmets høgskolesenter.

Watson, J. E., Aman, M. G., & Sing, N. N. (1988). The Psychopathology Instrument for Mentally Retarded Adults: Psychometric characteristics, factor structure, and relationship to subject characteristics. Research in Developmental Disabilities, 9, 277-290.

Wester, K. (1982). Epilepsi hos psykisk utviklingshemmede. (Epilepsy among the mentally retarded) Tidsskrift for den Norske Lægeforening, 102, 225 – 230.

Western, K. I. (1995). Hjelpetbehov og kostnader før og etter ansvarsreformen (The need for services and costs before and after the reform). I T. I. Romøren (Ed.) HVPU - Reformen i

forskningens lys (The Norwegian deinstitutionalization for mentally retarded persons in the light of research), (pp.61-80). Oslo: Ad Notam Gyldendal.

Winchel, R., M. & Stanley, M. (1991). Self-injurious behavior: A review of the behavior and biology of self-mutilation. American Journal of Psychiatry, 148, 306-317.

Wing, L. (1989). Hospital closure and the resettlements of residents. Aldershot: Avebury.

World health Organisation. (1994). Schedules for Clinical Assessment in Neuropsychiatry, version 2. Geneva: WHO.

World Health Organization. (1993) The ICD-10 Classification of Mental and Behavioural Disorders, Geneva: WHO.

World Health Organization (1991). ATC Index, including DDDs for plain substances. Oslo: WHO Collaborating Centre for Drug Statistics Methodology.

Wolfensberger, W. (1972). Normalization. The principle of normalization in human services. Toronto: National Institute on Mental Retardation

Zigler, E. & Hodapp, R. M. (1986). Understanding mental retardation. Cambridge: Cambridge University Press.

Papers are not included due to copyright.