From Medication to Education - People with autism in adult psychiatry

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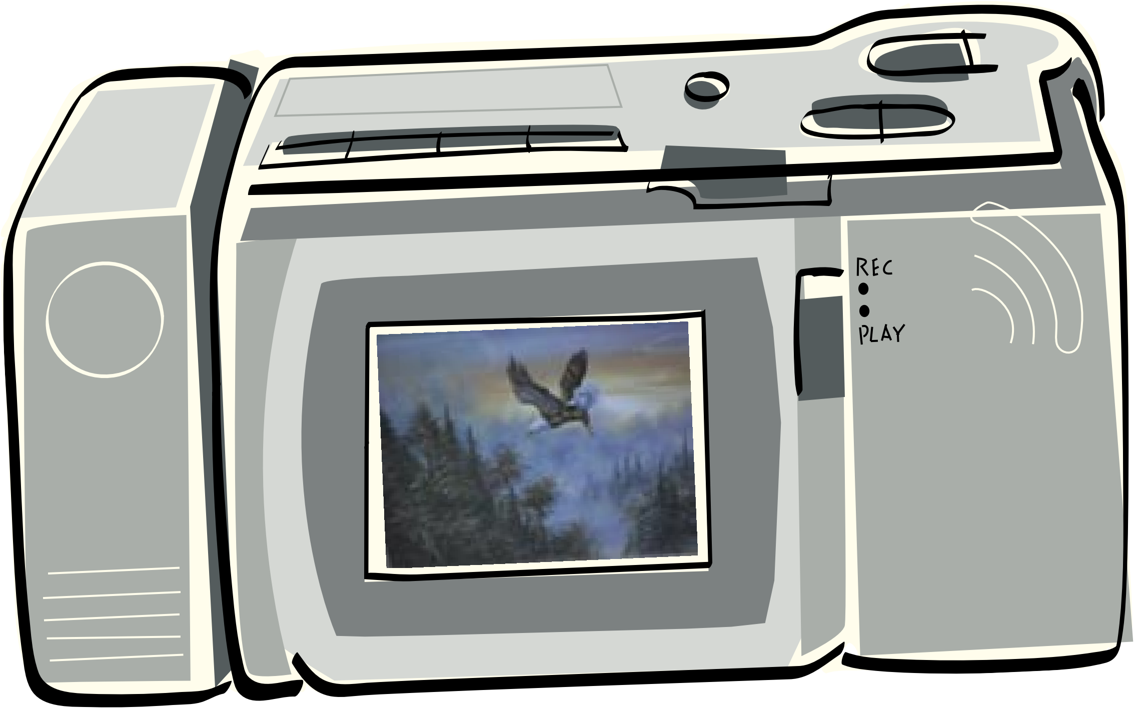
Eve Mandre

From Medication to Education

PEOPLE WITH AUTISM IN ADULT PSYCHIATRY



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From Medication to Education

people with autism in adult psychiatry

Foreword

The writing of this dissertation has been a long, educational journey involving several areas of expertise. I have gained insight into aspects of Swedish psychiatry and its operations that would have been difficult to acquire in any other way and that have expanded my previous view of what Swedish psychiatry can be. I have learnt a tremendous amount through encounters with staff and patients on “my” units. I thank you all for the opportunity of getting to know you!

I have also learnt a great deal more about Swedish geography, trade and industry through my travels to the places in which the psychiatric units are located. Several of these had only been dots on a map—now they exist as real, inner images of sparkling water, deep ravines, rivers overflowing their banks, small neighbourhoods of wooden houses and hotel rooms.

On my learning odyssey, almost four years long, my advisor, Professor Bodil Jönsson and I have had many discussions involving our different points of view—that of a natural scientist and physicist, the other of a hopeless humanist and behavioural scientists—and our views have, step by step, come closer to one another’s. First and foremost, Bodil has, through great effort, been able to convince me that my knowledge and perspective are justified at an institute of technology.

This journey, which has resulted in the completion of my dissertation, has been made possible through excellent guidance and supervision. Professor Jönsson has invested many hours of her leisure time in reading and providing feedback on what I have written. Points of view and comments have often come back to me late on a Sunday evening! Blessed Bodil!

My second advisor, Dr. Lennart Svensson, Professor in Education at Lund University, was also a quick and careful reader. He has, with his Argus eye, not only exposed the weak points in the content of the dissertation, but has pointed out language mistakes as well. Thank you, Lennart!

Dr. Åsa Lindberg-Sand has scrutinized the content of the dissertation through the eyes of health care as well as from an educational perspective. She is, like me, a practitioner who has received a doctorate in her area of professional expertise. Åsa has understood my agony when faced with scientific methods and theories and has provided me with much concrete advice. Thank you, Åsa, for all you have done!

I have Karin Rehman to thank for putting the dissertation in a readable format. Lena Leveen has taken care of all the administrative details that are part of a dissertation and Eileen Deaner has translated the Swedish version to English. Thanks for your incredible ability to work so well under pressure.

Björn Breidegard, a fellow doctoral candidate, was generous enough to set aside his own dissertation work and assist me with the programming of the new educational diagnoses. Thank you, Björn!

My grandchild, Ella, has been a master teacher in the psychological development of children. While studying the theories, I was able to try them out on Ella to see how they corresponded to reality.

As a person who has moved from the capital city, Stockholm, to Skåne, the southernmost province of Sweden, I have also had to reorient myself while working on my dissertation. I have learnt a lot about this part of the country. The contact with Region Skåne, which also funds Certec's research, has been one of many positive aspects. It has enabled me to complete my research, right down to the oral defence. Along with my thanks to the Region goes the hope that I will be able to repay my debt by sharing the knowledge that the dissertation has generated.

If Region Skåne has contributed to the completion of my doctoral studies, then it is the Vardal Foundation for Health Care Sciences and Allergy Research that has made it possible for me to begin my studies and complete the first portion up to the licentiate degree (an intermediate degree between a master's and PhD).

Due to my move south, I have no family to thank for having patiently stood by me. Instead, I would like to thank my Scanian discovery, the 12-year-old gelding, Markant, for keeping me hale and hearty, maintaining my concentration at its peak and having considerably increased my knowledge of behaviour modification as an educational method.

Summary

This dissertation deals with the field of applied psychiatry and focuses on the problems that are associated with the care and treatment of adult patients with autism spectrum disorders. The conditions that are described are valid for Swedish psychiatry and cannot be directly generalized to conditions outside of the country.

The purpose is to assist personnel in adult psychiatry in increasing their knowledge of the difficulties in contact, communication and cognition that are associated with a diagnosis of autism. By participating in an educational programme on the atypical psychological development of the patients, the knowledge can be used to establish individualized treatment based on each particular patient's problems.

Autism in adults was not perceived as a concern for adult psychiatry in Sweden until the latter part of the 1990s when Asperger Syndrome was described as a diagnostic category in the fourth edition of the DSM IV-R (Diagnostic and Statistical Manual of Mental Disorders, 1995). Attention was first drawn to the fact that these patients already existed under other diagnoses within adult psychiatry through some highly publicized cases. These cases resulted in a period of heated debate in the Swedish media among representatives of different approaches. After that, practitioners within psychiatry started in general to recognize expressions of autistic spectrum disorders and to incorporate neuropsychiatric as well as educational expertise into practice. Now—in 2002—autism spectrum disorders have been accepted, to a greater or lesser extent, as a valid diagnostic group in adult psychiatry and more and more adults have been diagnosed as being autistic. However, individual treatment methods that particularly address the communication difficulties and atypical thinking patterns of these people do not yet exist to any great extent.

When people with autism spectrum disorders are treated by psychiatry, they encounter many presumptions concerning what they should know and understand about social situations and how to communicate with people in their environment. In this dissertation, I explain theoretically how these individuals are different by applying theories of early childhood social learning to the adult patients' difficulties with contact, communication and cognition. Psychological development that lacks the social dimension can result in a person of otherwise normal intelligence having significant deficiencies in his or her communication skills and ways of understanding everyday situations.

The dissertation deals with many related fields, from the effects of atypical psychological development to the area of practical education. I involve myself in the learning process by directly working with patients in a few cases and indirectly through an educational programme for psychiatric personnel. Then I let theory, my own practical experience and reflections come into play in order to describe and analyse the process on different levels. I am the main narrator, but periodically I turn the story over to members of the psychiatric staff who have been interviewed or in some other way express themselves. It is, in other words, a narrative contextual analysis that is used as a method for placing the reader in the context in which I carry out an educational programme for psychiatric personnel. In a longer case description, I demonstrate how a change in staff perspective results in increased comprehension of the behaviour of a long-term care patient in forensic psychiatry. He has not had the ability to interact with other people in such a way that he could learn social signals and codes or acceptable means of communication. Thus, as an adult, he has been perceived as being very odd and difficult to deal with in psychiatry. His special disability requires that rehabilitation efforts be based on treatment methods that provide opportunities for social learning.

When personnel in psychiatry are going to learn to deal with patients in this new diagnostic category, it requires a reorientation in thinking and understanding in order to apply new theoretical knowledge on autism in an entrenched, practical organization. In order for the theory to result in new treatment practices, the training has to be anchored in their daily reality and be based on the problems of their own patients. One of the main sections of the dissertation deals with an educational programme for eight psychiatric units in different parts of Sweden in which the staff, by describing their patients, were provided with alternative explanations for the patients' behaviour and advice on how to deal with it. The personnel documented their learning, the effects of which have then been examined to see if they have brought about any changes in the patients.

The reorientation that has taken place among the personnel has, in most cases, resulted in significant changes for the patients. Several have been re-evaluated, resulting in new diagnoses. Some have been discharged from institutionalized psychiatric care to housing arranged by the municipality—one after 25 years in forensic psychiatric care. In another case, it has also become apparent that the housing resources the municipalities offer

KEY WORDS

Autism, autism spectrum disorders, Asperger Syndrome, design, Compulsory Psychiatric Care Act (LPT), Forensic Psychiatric Care Act (LRV), Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), learning process, neuropsychiatric diagnoses, education, psychiatry, psychiatric treatment, rehabilitation engineering, forensic psychiatry, social learning, special education, developmental psychology, adult education

according to the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) are not able to provide for persons who have great difficulties in concentration, memory and planning. An additional issue that stands out clearly in the staff training discussions as well as in interviews with the psychiatric personnel, is the difficulty in caring for patients with autism on general units in which care is based on entirely different treatment principles.

Another striking result, when observing psychiatry from the perspective of design sciences, has been that care settings in general lack expertise in the special environments needed so that the patients' cognitive difficulties, disturbances in perception and executive difficulties do not become handicapping. Nowhere has such knowledge been the basis for design of the environments in which patients live, in many cases, for years. In the light of the relative definition of a handicap, in which it is seen as an interaction between the person and his or her environment, I have observed that psychiatric environments, to a great extent, can be seen as handicapping for large groups of patients.

Content

Organization of the dissertation

chapter 1. introduction

In the introduction I describe how the view of autism has changed during the time I have been working in the area of special education and that a total consensus on the issue is still lacking.

How I became involved in psychiatry describes how I as a teacher entered into the field adult psychiatry—an area that had previously been quite foreign to me. The learning process that followed with constantly new insights and concepts of what psychiatry really was awoke an interest and curiosity that first led to a licentiate degree and then to this doctoral dissertation.

The section on *Adult psychiatry and patients with autism spectrum disorders* describes the current situation for the main subjects of this dissertation—adult individuals with autism spectrum disorders who have become psychiatric patients. These central figures and their difficulties in dealing with the *normal spectrum people* who are their treatment personnel will be variations on a theme that runs throughout the entire dissertation.

In the section *Autism in adult psychiatry internationally*, I place the treatment of patients with autism in Swedish psychiatry in a larger, international psychiatric context.

chapter 2. polyphonic psychiatry—my field of research

The educational approach and methods that I bring to the treatment context emanate from scientific disciplines other than the psychiatric and have been developed in environments other than the medical. That is why the role of education needs to be understood in the context of psychiatry to understand how education has ended up being of current interest in psychiatric treatment. For its entire existence, psychiatry has been influenced by a variety of scientific disciplines and as a result has had an ambiguous and variable identity. In order to understand today's psychiatry, it is important to look at its historical development and relate this to the clinical reality of today as well as to the reasoning behind the current Swedish legislation, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). One of the Act's distinctive features is that it unites two groups of *people with mental disabilities*: those with cognitive disabilities who need cognitive support from their surroundings, and those with mental illnesses that can be treated medically and through therapy. Legislation has previously tried to keep these two groups separate for over a hundred years.

chapter 3. some scientific-theoretical views on psychiatric theory

In this chapter, I present some scientific-theoretical standpoints on the DSM manual and its diagnostic categories. Furthermore, I critically analyse the researcher's role as expert in the area of psychiatry based on the concept of paradigm.

chapter 4. methods

In this chapter, I describe methodological considerations behind the description and analysis of the case studies and the staff training sessions. The methods chosen for material collection are described, put in a scientific-theoretical context and compared to clinical psychiatry research methods and theory of science.

chapter 5. learning through social interaction

The abilities that normal children develop and learn at an early age are taken for granted later on in life in all social interaction because they are unconsciously acquired. If treatment personnel are not aware that there are patients in psychiatry whose early childhood psychological development has paralleled the normal but with great deficiencies in the social dimension, they will be unable to understand the consequences of such a development. In most cases, this results in a considerable amount of misunderstanding.

In *Case study: Emil*, I show how theories on early ego development and social learning can be applied to a long-term institutionalized psychiatric patient and enable his caregivers and treatment providers to better understand him.

chapter 6. learning as active reorientation

This chapter starts with a section called *Professional lifelong learning*, which discusses theories of adult learning and explains the principles of the educational programme that was carried out on eight psychiatric units.

Continuing education on eight units provides a description and analysis of its implementation, carried out in the form of individualized staff training sessions. It was based on the staff's descriptions of patients and their understanding of the patients' difficulties.

chapter 7. the staff training process concerning individual patients

The chapter reports on discussions about the patients during staff training sessions and the direct effects that staff training had on the patients due to staff reorientation and change of perspective.

chapter 8. the staff training process concerning specific problem areas

This chapter describes why all the units did not deal with specific patient cases in the staff training sessions, but focused more on problem areas.

chapter 9. staff training documentation

The chapter provides a description of the personnel's learning process based on their own documentation during the training programme. Through an analysis of this documentation, along with interviews and questionnaires, I have been able to show learning effects that provided new knowledge regarding assessment and treatment of patients with autism spectrum disorders.

chapter 10. overall results

In this section, I point out the effects the continuing education programme has had on the treatment of the patients. The reorientation of the staff towards an autism perspective has resulted in the patients being better understood. The educational perspective has provided the personnel with new tools, among others, in the form of systematic observations as a basis for assessment, care and treatment plans that are more educationally oriented.

chapter 11. discussion and conclusions

Here I discuss other observations I have made about psychiatry, its settings and patients. I present suggestions for a different kind of treatment for patients who are in need of inpatient psychiatric care.

Conference articles and presentations

Pictures for Contact and Communication with a Communicatively Disabled Patient within Forensic Psychiatry. Accepted for publication as *Letter to the Editor* in the Journal of Autism, Great Britain, London.

Individualized Educational Treatment for Adult Psychiatric Patients with Autism Spectrum Disorders. Accepted for presentation at the 13th Annual International Durham Research Conference on Autism, Durham, Great Britain, 10–12 April 2002.

Special Education as an Alternative Treatment Method for Patients with Autism/Asperger Syndrome in Forensic Psychiatry. Presentation at the Second Nordic Conference of Research on Autism/Asperger Syndrome, Oulu, Finland, 21–24 Feb. 2001.

On Pedagogical Implications for People with Autism and Learning Disabilities. Keynote speaker at The First Nordic Conference on Good Pedagogical Practice in Autism Spectrum Disorders, 13–15 September 2000, Ängelholm, Sweden.

Is there still a future? Misdiagnosed persons with autism within forensic psychiatry. Poster presentation, 6th Conference Autism Europe, 19–21 May 2000, Glasgow, Scotland.

Från specialpedagogisk praktik till specialpedagogisk teknik. (From Special Educational Practice to Special Educational Technology). Special Education Biennial, 9–10 August 1999, Linköping University, Sweden.

Free Freya—Education within Psychiatric Care Services. Presentation at The First Nordic Conference of Research on Autism/Asperger Syndrome, 1–2 Feb. 1999, Växjö, Sweden.

An Ultimate Challenge for Adult Education? Presentation at NFPF (Nordiska Föreningen för Pedagogisk Forskning), 1998, Lahti, Finland.

Purpose

The main purpose of this dissertation is to increase understanding among personnel in adult psychiatry for patients with autism spectrum disorders, and in this way contribute to the patients receiving an individualized and more focused treatment based on their specific difficulties. This will be accomplished:

- by applying theories of early social learning to the difficulties adult patients have with contact, communication and cognition.

- by describing the implementation of an educational programme for psychiatric personnel with the goal of providing them with a better understanding of the existing difficulties the above-named patient group has in making contact, in communication and cognition

- by describing, analysing and evaluating the learning effects on the personnel after the staff training and seeing if they result in the patients receiving treatment that can improve their contact ability, communication and cognition based on their specific requirements.

1. Introduction

In 1969 I began my career as a teacher in a special educational facility. It was there, at a time when it was not considered proper in Sweden to test or diagnose children, that I took my first tentative steps into special education. The supervising psychologist and my colleagues interpreted learning difficulties in terms of emotional blockages and dysfunctional family systems. A child's learning difficulties would disappear and the emotional knots would be dissolved by working with relationships in the family. The same approach also existed when I started my first class for children with autism in the middle of the 1970s at a large institution (Mandre in Gerland, 1998). At that time, autism was viewed as a mental defence against unbearable internal pain or as a defect in the attachment between mother and child, and it was in that atmosphere that teaching was carried out.

One of the mental health assistants that I interviewed in the midst of my work on this dissertation reminded me of the view of autism at that time. She worked then as a caregiver in the same institution where I was a teacher and told me about a girl in her unit who was said to be autistic:

> She was unusually beautiful and she stood all evening long with her forehead pressed against the window and her gazed fixed in the distance … we were told that she stood there pining away, and that she had become autistic because her parents worked abroad …

Many of us who met in the psychiatric units during my work on this dissertation carry with us experiences and thoughts that developed from the notions about autism expressed in this description. Since then, developments have continued in different directions for quite a few years now. In one of these parallel spheres of knowledge, one can still find the yearning child who, because of an inner trauma, has cut herself off from the world. In other spheres, experts look at atypical brain functions, brain chemistry, perception distortions and other biological causes as to why a child is born with autism or develops autism-like conditions during the first years of life. Since the 1980s, educational methods have been developed based on the *functional disturbances* of autism, while the *yearning child* is still treated with psychotherapy in other spheres. Twenty-three years after taking my first step into the psychologized school world, I stepped into what, for me, was the entirely new world of adult psychiatry. It was like starting over again in the schools of the 1970s and stepping back into a world of times gone by.

How I became involved in psychiatry

I first encountered adult psychiatry in the beginning of the 1990s when, in my capacity as a special educator, I was going to instruct a 35-year-old female patient on a special unit in a hospital outside of Stockholm. She was famous in the Swedish world of psychiatry as “The Elisabeth Case” and had been considered for a long time to be a particularly incorrigible patient. When I met her, the schizophrenia diagnosis she had previously been assigned had been reassessed and she was now considered to be autistic. She had been in adult psychiatric care since she was fourteen and had been assigned a number of different diagnoses through the years. Her treatment, with various forms of therapy and medication, presents a good picture of concepts of mental illness in Swedish psychiatry during the latter half of the 20th century. Most of the therapy she had received was based on psychoanalytical theories and sought out childhood traumas as the cause of her illness. In addition to therapy, she had also tried most of the medications that had been introduced into psychiatric care during this time. She had remained an enigmatic patient until she was diagnosed as being autistic. Within that framework, her symptoms made sense and she came under the jurisdiction of what, at the time, was called the Board of Services for the Developmentally Disabled. She was then entitled to participate in Adult Special Education, a school form for adults with developmental disabilities, autism and acquired brain injuries. The schooling that Elisabeth received and that started with a few hours a week had more far-reaching consequences than I could possibly have imagined. One was that the diagnosis which had brought me to the clinic and which gave Elisabeth the right to education turned out to be something extremely controversial on the unit in which she was receiving care.

In Swedish psychiatry at the time, the concept of *autism* was still considered to be a sub-symptom of schizophrenia, while on the Board of Services for the Developmentally Disabled, it had come to be associated with a disability that had consequences for social interaction and cognition. For four years, the clinical supervisors and I were of different opinions on this issue. This became a frustrating obstacle in our co-operation. The clinic in which she resided based its approach on a fundamental view in which all references to human biological conditions were prohibited, which could not be reconciled with the fact that autism is a neuropsychiatric condition. Although they treated patients pharmaceutically, the causes of their serious psychiatric symptoms could not be found in the chemistry of the brain (Palmgren, 1995). It was a peculiar double message. The patients were frequently physically restrained, while at the same time the staff spoke of the importance of respect for the individual and of the detrimental effects the environment could have on the patient. They always anticipated finding this detrimental environment in the patient's childhood, never in the psychiatric environment in which coercion and forcible means were employed.

I was requested by the psychiatry committee in the health care district to outline an educational project for two patients who were being cared for on the small, special unit. When the rest of the clinic was closed down as the result of reorganization, the special unit remained as a two-year educational project.

This project was successful from the patients' point of view when both of them succeeded by the end of the project in being reclassified so that they were no longer under the jurisdiction of the Forensic Psychiatric Care Act (LRV) and the Compulsory Psychiatric Care Act (LPT) respectively, to the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). The patients moved out and the special unit was closed down and levelled to the ground.

LRV: Forensic Psychiatric Care Act

LPT: Compulsory Psychiatric Care Act

LSS: Act Concerning Support and Service for Persons with Certain Functional Impairments

The lasting impression I have of inpatient psychiatric care during these years of upheaval was that it tried to change course and become more humane, but still had a long way to go to achieve treatment based on the needs of the patients. The overall goals spoke of respectful and individualized treatment—reality still had medication as the first treatment priority. Medication was prescribed in surprisingly large quantities, both in dosage and type. Routines and schedules controlled treatment more than the patients' needs, and the environments seldom took into account the patients' perceptual disturbances, limitations in the ability to plan and other aspects of their mental disorders.

After this project was completed, the demands grew for my services as a lecturer and educational consultant in adult psychiatry. With that, my interest in what psychiatric care really was or could be also increased. My impressions had only been derived from the organization of the small, special unit and the adjoining ones. After a television report on Elisabeth in the autumn of 1997, many relatives of psychiatric patients contacted me—those who had sons and daughters that they thought were like Elisabeth but who had other diagnoses than autism. The relatives wanted advice on where they could receive assessments and educational treatment, but I had no one else to refer them to than The National Board of Health and Welfare. From the relatives I gained yet another perspective of psychiatry that revealed how old methods and physical restrictions were still used and how powerless both patients and relatives felt. Some of them had struggled for many years against invisible adversaries. They experienced that no one really took responsibility for current or previous mistakes that had been made. This situation is the subject of a sociology of law dissertation from the Sociology Department at Lund University (Pfannenstill, 2002). From these relatives I received copies of records, correspondence with psychiatric units and other material that showed me—still a novice in the area—the worst sides of psychiatry.

With curiosity and a newly aroused interest, however, I started to follow the psychiatric debates in medical journals and other specialist press. What grew out of this was an image of competing ideologies on the origins of psychiatric conditions, diagnoses and treatment. By reading the history of psychiatry, additional pieces of the puzzle fell into place. In my attempt to learn more about today's psychiatry and its view of treatment and diagnosis, I have, in addition to my review of the literature, carried out interviews. I have interviewed psychiatrists, nurses, psychologists, occupational therapists and mental health assistants who work on the units that participated in the staff training. They describe how they view their current jobs and the developments they have seen during their years in the profession. They also describe how new problem areas are continually making inroads and how changing demands on knowledge and changes in organizational methods make Swedish psychiatry a dynamic area in which to work. After meeting a variety of individuals in many psychiatric units, I have been able to gain a picture of psychiatry as an enormously diverse area. There are many different care and professional cultures that are mixed together and staff members struggle industriously to improve an organization in a system where they still count in terms of beds and where occupying patients with meaningful activities has been replaced to a great extent with diversions and entertainment.

In the following chapters I will describe the situation for patients with autism spectrum disorders in adult psychiatry from my experiences of psychiatric practices in Sweden.

Adult psychiatry and patients with autism spectrum disorders

During the second half of the 1990s, new knowledge and new ways of looking at old phenomena resulted in 180 new diagnoses being added to the revised DSM (Diagnostic and Statistical Manual, 1995) from the third to the fourth edition. Among these is

Asperger Syndrome. This form of autism was previously unknown and so could not be diagnosed in adult psychiatry. In child psychiatry, it has been known to a certain extent since the 1980s when Lorna Wing (in Frith, 1995) first called attention to it and translated Hans Asperger's descriptions of a group of children who had *autistic psychopathy*. In the DSM, Asperger Syndrome is listed as a diagnostic category of its own under the main category of Pervasive Developmental Disorders. The consequence of such a pervasive disturbance in development is that all the functions that depend on social learning are affected. According to the criteria for Asperger Syndrome, however, language development is normal, that is to say, the child is able to pronounce single words by the age of two and to communicate in phrases by the age of three. Furthermore, the criteria include the absence of delays in cognitive development, which, in my opinion, would result in considerably fewer people being given the diagnosis than actually are. There is no 100% consensus in the academic world as to if Asperger Syndrome should be considered an autism spectrum disorder or if it should belong in a diagnostic category of its own (Schopler & Mesibov, 1992; Dickerson Mayes et al., 2001). In several sections of the dissertation, I will describe in detail the difficulties involved in the acquisition of language and cognition that are based on deficiencies in social learning.

In adult psychiatry, those patients who according to DSM-IV fit the autism or Asperger criteria have previously received other diagnoses. This means that they need to be re-evaluated in order to receive appropriate treatment. As will be described in the educational chapters, it is not easy to make a total shift in the way of observing and interpreting patient behaviour through the use of a manual. The symptoms do not appear as clearly in adults as they do in children and many adults have learnt strategies for hiding their difficulties. As already mentioned, the symptoms can be fairly complex—disturbances in perception, executive functioning and cognitive problems can be so dominating that the autistic symptoms may not be initially detected. In many places, these patients are seen as oddities within psychiatry, as people who more appropriately should be placed in the municipalities LSS facilities or some place else, that is to say, with someone who has knowledge in the area that psychiatry claims it lacks. It became particularly apparent in the inventory of problems that I catalogued for Region Skåne (the southernmost county in Sweden) for an internal report entitled *Treatment and Assessment of Childhood Neuropsychiatric Diagnoses in Region Skåne's Psychiatric Services* (July 2001, unpublished report due to confidentiality). This report demonstrated, among other things, that the clinics often cite their lack of expertise in the area as the reason why they should not keep and treat patients with autism spectrum disorders in their psychiatric facilities. The decision to refer the patients somewhere else that the clinic staff believe is better equipped to take care of them can result in long delays before treatment can be initiated and before a care plan is drawn up for the patient.

Traditionally, adult psychiatry has concentrated on treating individuals who have mental illnesses, that is, people who once had the social abilities that enable contact and communication to function normally but who have experienced a temporary or permanent change in this area due to illness. The personnel are unaccustomed to individuals who do not have normal frames of reference for communication and who have deficiencies in elementary, everyday social skills. Since their intelligence in other areas is considered to be normal, they often remain puzzling patients who are unable to receive adequate treatment. They fall outside of the framework of understanding that psychiatry has built up around the patient groups they traditionally treat. Nor are the available treatment methods adapted for people who have lifelong disabilities.

An impairment often means a reduction of certain functions, requiring an adaptation of the individual's environment so that the impairment does not turn into a difficult handicap. A blind or visually impaired person who does not learn how to use a cane and other aids would be quite helpless. A deaf individual is communicatively handicapped if he or she is not given assistance in understanding and being understood by people in his or her surroundings. Deafness and blindness are medical problems, to a certain degree, in which specialized knowledge is required, but when the doctor, optician and technicians are finished, the patients are referred to vision and hearing centres for the educational assistance they need to learn to deal with their disabilities and aids.

When it involves people with communication problems and cognitive disabilities that are less visible, no corresponding structure exists. If the medication does not effect a cure, a vacuum arises. People who do not change as a result of traditional psychiatric treatment methods and do not fit into existing routines are then considered difficult to handle and disruptive. That disabled people require environmental adaptations and education in order to live with their disabilities is a thought that has not yet had much impact on psychiatry.

In the Psychiatry Reform Act that went into effect in 1995, attention was called to the many patients who are not cured of their mental illnesses. Previously, these patients were labelled *chronically ill*, but according to the Psychiatry Reform Act, they are now referred to as *mentally disabled*. By reason of that, the disability concept is now also being applied to mental conditions. The patients for whom this is intended, though, are still psychiatry's own, i.e., patients with chronic schizophrenia or other chronic psychoses. This emerges more clearly when one reads the objectives describing how these patients are to be treated in municipal psychiatric care and in the Case Management System. What is also clear when patients who have *completed medical treatment* are transferred from psychiatry to municipal group homes is that psychiatry again is trying to separate the curables from the incurables, another confirmation that it is medical treatment that is offered in psychiatry and nothing else. In the same manner, psychiatry has previously in its history tried to profile itself as a medical discipline by separating the *incurable* patients from the others. This situation will be described in greater detail in chapter 2 on the history of modern psychiatry.

Marianne Spanner focused a great amount of attention on the autism diagnosis in connection with the investigative Swedish television programme, *Striptease*, in August 1997. She revealed that one of Swedish psychiatry's most puzzling patients had been diagnosed as autistic and was being treated with educational methods. This exposé resulted in quite a number of psychiatric patients' diagnoses coming under question, many times by relatives first and later on, by doctors. During the latter half of the 1990s, debate in the media raged as to the causes of autism in the daily newspapers as well as in professional journals. Competing theories were presented. There is still a clear dividing line between the psychodynamic and neuropsychiatric approaches, but the latter is winning more ground based on documented research (Gillberg, 1992; Frith, 1995).

Now—in 2002—autism spectrum disorders are accepted as neuropsychiatric conditions, first appearing in childhood and seen as valid adult diagnoses by an increasing number of professionals. Educational and informational efforts are currently underway throughout the country. In some areas, special neuropsychiatric teams have been established in order to assess and diagnose this group of patients. When it comes to treatment methods, education is an important part, but so far there are very few clinics that have gone as far as employing teachers.

Autism in adult psychiatry internationally

When I use the word "psychiatry" in this dissertation, I am referring to Swedish psychiatry. This demarcation has been necessary since the ways people with autism are treated by adult psychiatric institutions in Sweden is so strongly influenced by adult psychiatry in general and its history and roots in the community and Swedish society.

I would like to have provided international background material for comparison, but attempts to gather such information have produced meagre results. A probable reason as to why there are no reports that describe the treatment of people with autism in clinical psychiatry can be that practitioners seldom use their practical experience as a basis for research.

The unit I found that best corresponded to specialized psychiatric care for people with autism/Asperger is the Hayes Unit in Bristol, Great Britain. It can accommodate twelve residents with autism who are considered high risk because of their challenging behaviour. Most of them have been detained under the Mental Health Act of 1983, Sections 3, 37 and 37/41 (corresponding to the Swedish LPT and LRV). Treatment is carried out on a unit with enhanced security and is based entirely on knowledge of autism and expertise in dealing with severe destructiveness, aggression, ritualism and other behaviours that require specially trained personnel. (http://www.http://www.nas.org.uk/units/)

In Great Britain there is also accreditation of housing units for people with autism, something that I did not find anyplace else. The accreditation guarantees that an organization meets certain requirements concerning level of knowledge and expertise in meeting the needs of autistic adults. (www.nas.org.uk/nas/accred.html)

Digby Tantam (in Frith, 1995) is a psychiatrist who carried out a study for the Medical Research Council in Great Britain. He interviewed 60 patients who were characterized by other psychiatrists as being odd and socially isolated. Of these, he determined that 46 met the criteria for autism or Asperger Syndrome. He describes how autism is expressed in adult life, co-morbidity problems (i.e., problems with other symptoms that are not part of the autism spectrum) and where the boundary lies between autism and other diagnoses in which social isolation is a salient characteristic.

The Autism Research Centre (ARC) in Great Britain is located at the University of Cambridge (www.psychiatry.cam.ac.uk/arc/). ARC has a research project underway which aims to establish a special clinic for adults with Asperger Syndrome.

I have also searched for published articles in scientific journals that deal with psychiatric treatment. An examination of about 2,000 articles from the years 2000-2002 produced the following results:

Acta Psychiatrica Scandinavica: Gillberg, C, Billstedt, E, *Autism and Asperger syndrome: coexistence with other clinical disorders*, 2000 Nov., 102 (5) 321–30

Acta Psychiatrica Scandinavica: Nylander, L, Gillberg, C, *Screening for autism spectrum disorders in adult psychiatric outpatients: a preliminary report*, 2001 June, 103(6) 428–34

Lauritsen, M, Ewald, H, *The genetics of autism*, 2001 June, 103(6) 409–10

Advances in Psychiatric Treatment: 0

American Journal of Psychiatry: Duggal, HS, Dutta, S, Sinha, VK, *Outcome of Asperger's syndrome*, 2002 Feb., 159(2) 325–6

American Journal of Psychiatry: Frazier, JA, Doyle, R, Chiu, S, Coyle, JT, *Treating a child with Asperger's disorder and comorbid bipolar disorder,* 2002 Jan., 159(1) 13–21

Annual Revenue of Neuroscience: 0

Annual Clinical Neuroscience: 0

Annual Clinical Psychiatry: 0

Attachment in Human Development: 0

Australian and New Zeeland Journal of Psychiatry: 0

Brain Cognition: 0

British Journal of Educational Psychology: 0

British Journal of Psychiatry: Declan, GM Murphy, *Asperger Syndrome*, 2001, 179:375

Berney, TP, *Autism—an evolving concept*, 2000, 176:20–25

Forensic Science Int.: 0

Fortschritt Neurol. Psychiatr: Althaus, G, Kamolz, S, Franzek, E, Pfulman, B, *Autistic hebephrenia: concepts and findings*, 2001 Oct., 69 (10) 482–7

Psychiatry: 0

Psychiatry Clinical Neuroscience: Hayashi, *Seasonal changes in sleep and behavioural problems in a pubescent case with autism*, (2001 June 55[3]) 223-4

Psychiatric Praxis: 0

Psychopathology: 0

In other words, this search shows that autism spectrum disorders are not given priority in psychiatry—it is particularly apparent that treatment methods for adult psychiatric patients with autism are not a subject for psychiatric research. In those cases in which research is actually carried out and published, it deals mostly with etiology, diagnosis and other areas that do not involve treatment. In those cases in which treatment is described, it has to do with children.

In order to find out about treatment, one has to look outside of psychiatry, both nationally and internationally. It is habilitation or what is referred to in English-speaking countries as *services* that are involved in the development of adapted housing, adapted jobs and activities, and that provide information about autism spectrum disorders. Above all, there are large quantities of scientific reports and research about children with autism.

This situation has been described by Hugh Morgan (1996) who investigated how adults with autism were treated in a number of countries in Europe, the United States and Asia. He observed that in all countries, the resources for children are made available long before one even starts to consider adults. The situation that most influences development of services is always the enthusiasm and insistent efforts of relatives and professionals; not the result of actions taken by the authorities.

2. Polyphonic psychiatry—my field of research

The branch of psychiatry dealing with assessment and treatment of the new neuropsychiatric diagnostic groups has, for a number of years, been dominated by competing claims to knowledge. As a consequence, these mental illnesses and disabilities have been assigned highly disparate etiologies. Different scientific disciplines have contributed to shaping the body of psychiatric knowledge so that it is made up of a choir of voices. Explanations of the conditions of people who are mentally ill have been described, at times, in a manner verging on the literary and viewed as a symbolization of inner conflicts (Benedetti, 1992; Palmgren, 1995); at other times, as a normal reaction to social evils (Foucault, 1965). Heredity has also played its role in the explanations. On occasion, social heredity (Jonsson & Kälvesten, 1969; Jonsson, 1978) has been singled out and at other times genetics (Gillberg, 1992; Frith, 1994; Kristiansen, 2000). Brain injuries, deviations in the nervous system or in the chemistry of the brain are areas of current interest, while others have retreated into silence. Each and every one of the many voices that are mixed together within psychiatry have had their heyday and remnants remain in the everyday thoughts of many people as well as in the ingrained practices and notions of professionals. Each layer of thoughts and conceptions has then been added to with new layers of truths; what remains is the entire polyphony, with voices that alternately make themselves heard over the others. Different psychiatric units and professional cultures also integrate these voices in diverse ways in thought and action.

One of these voices is particularly important for understanding the conceptual division of patients in psychiatric care into those belonging to *us* or to *social services.* It stems from an epoch in the history of psychiatry that started with the 1858 Care Statute for the Mentally Ill. This had to do with psychiatry's desire to create an identity for itself as a medical specialty (Sjöström, 1992). In 1860, the first two Swedish professors in psychiatry were appointed and the care of the mentally ill began to be seen as a scientific discipline of its own within medicine. The idea of treatment was written into law, clinical research was initiated and textbooks were written

(Qvarsell, 1991). In large hospitals, experts would develop scientific treatment methods and cure the insane. The hospitals had been a repository for people with curable illnesses as well as those with all sorts of congenital and chronic conditions that could not be cured. This latter group was now to be removed in order for psychiatry to concentrate on those who were considered to be medically curable. The rest were left to the insane asylums and the poorhouse (Sjöström, 1992).

The groups that were to be removed from the hospitals according to the 1851 report:

- Fools and idiots, that is to say, those who were born feeble-minded as a result of defects in their innate constitution. This group can improve to a limited degree through suitable fostering and strict discipline, but are not the object of medical treatment and are not the responsibility of the hospital institutions.
- Those afflicted with falling sickness (epilepsy), a class of their own, who after having the illness a good while, often several years, fall into a state of mental deficiency, which cannot in any case be the object of treatment. Before the onset of the mental deficiency, persons with this illness are the responsibility of the institutions designated for care of the physically ill. After onset, they are considered completely irremediable and are assigned to the same category as idiots, and only under the conditions described for this last group should be a concern for hospital care.
- Those with mental deficiencies due to old age (amentia senilis) are also in the same situation as idiots and should with even greater reason and without exception be referred to municipal charity or care within the family.
- The lame (paralytic). Such people can be found in all hospitals and though they, in connection with and as the result of their original physical illness, just as with those who are afflicted with the falling sickness, generally suffer from a more or less learnt mental deficiency, are however, in no way harmful to themselves or others nor the object of any treatment, and consequently are also in no way the responsibility of the hospitals, for which they constitute a particularly heavy burden (ibid.).

Fools, idiots, the falling sick and lame

In the preceding description of how *fools, idiots, the falling sick* and *lame* were excluded from the hospital's cliental, you find the origins of the conceptual and actual division of individuals that for over a century has permeated all Swedish psychiatric care and legislation. Some of the mentally handicapped are perceived as being sick; consequently endeavours are made to find a medical cure within the context of the mental hospitals. Those who have congenital deviations or cognitive limitations have no business in the medical arena, but are to receive suitable fostering and strict discipline. Even though this group was to be removed from the mental hospitals, they were still kept there for a considerable time while waiting for the authorities to establish new institutions to care for them. Former medical advisor, Karl Grunewald (1997), describes what it was like at the beginning of the 1900s:

> Where to place the difficult, uneducable, mentally ill patients had been a problem for the government and parliament since the turn of the century. The question was continually postponed since it was considered more important to build mental hospitals. Many of the mentally deficient were diagnosed as schizophrenic and were admitted to the mental hospitals, but there they were thought to be too disruptive and "irremediable". More pressure was put on the state to take care of the deranged, mentally deficient children and asocial adults. There were some private homes and schools for children before the turn of the century. In 1875, training of female teachers for the care of the mentally deficient began. For adults, there were a few workhouses. However, the people who were entirely too difficult did not fit into these settings. Adults who were both *deranged* and *mentally deficient* were particularly difficult to place. The mental hospitals demanded that special hospitals be set up for the mentally deficient. "The resources that were intended for the mentally ill were wasted on the large number of uneducable, mentally deficient," as it was worded. This resulted in the state opening Salberga Hospital in Sala and Källshagen Hospital in Vänersborg for asocial men, and Västra Marks Hospital in Örebro for asocial women in 1930-31. All three were former military bases. Vipeholm Hospital in Lund was opened in 1935 for the mentally deficient who were difficult to handle as well as "persons suffering from epileptic mental illness."

Over time and to an increasing extent, people who ended up in care institutions for the mentally deficient were included in educational programmes and these efforts demonstrated that all of them had the potential to develop and learn. The notion *uneducable* also disappeared from the vocabulary and the 1967 Care of the Mentally Disabled Act extended access to education to all children. Some received special education services, but no longer were any denied because of aptitude.

Again we see the dividing line between the two groups in which one is labelled mentally ill and the other handicapped. Medicine was to determine the fate of the former, while education was to take care of the latter. Legislation eventually brought them together in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) in which those who had been *disciplined* and *fostered* were granted more far-reaching rights than those who were treated medically.

Those excluded from hospitals—how did they fare?

Those patients who were excluded from the hospitals as incurable *fools* and *idiots* had their own institutions that were called *asylums for the mentally deficient*. They continued, however, to be objects of medical diagnostics and many of them also received medical treatment. The diagnoses *idiot*, *imbecile* and *moron* were still being used well into current times in the differential diagnoses of the *mentally deficient* group. Since it was thought that these people could not be cured using psychiatric treatment methods, a few private residential homes for pupils and later asylums for the mentally deficient initiated pedagogic treatment for the *educable mentally deficient*. In 1870, the School for Mentally Deficient Children was founded in Stockholm, which later came to be the first training college for special education teachers. The mentally deficient pupils who attended school generally had a better standard of living than the ones labelled *uneducable*. Well into the 1960s, the people in this latter group were still considered to be creatures that felt nothing and experienced nothing. The following description is from a 1953 picture newsletter from Vipeholm (Grunewald, 1997).

> Two thirds of the interns at Vipeholm are men. Here are two of them. They cannot read, write or even talk. They do not know their names, how old they are, nor where they are. They are idiots. They are uneducable and consequently do not need anything to occupy their time. They lack the ability to think and feel, that is to say, they do not suffer—according to the experts.

A little more than a decade thereafter—1967—the Care of the Mentally Disabled Act was passed and with it, the *uneducable* concept disappeared and the right to ten years of compulsory education, even for the severely mentally retarded and multiply disabled pupils was established. Adults who had gone without activities to occupy their time were now to receive them in *training homes*. These were later developed into *day centres* or *daily activity centres* with educational ambitions and a developmental perspective. For the adults lacking previous schooling, study circles were established and eventually an adult special education school programme. A rather rapid change in attitude towards people with developmental disabilities came about. But the process of change that followed was not all that easy. There was a collision between the medical viewpoint that had dominated and the innovative viewpoint that was introduced by an entirely new professional category of psychologists and educators. Some examples of this can be found in *Röster från Vipeholm* (*Voices from Vipeholm)* (Carlén-Nilsson, Holmér, 1998). Ingrid Liljeroth, psychologist at Vipeholm between 1964 and 1976, describes the transition period as follows:

> Schooling introduced something new to the hospital world. The administration welcomed it, but it soon became apparent that it was based on assumptions other than the hospital's. It came from another system in society and so presented a challenge. It was not possible to check up on things in the same manner as other activities. The new ideas took shape and were expressed differently and confrontations were unavoidable.

Karin Axeheim and Margot Edin, who were responsible for the school when the new Special Education Act went into effect, summarize their experiences (ibid.):

> What stands out now when we, the first administrators in the new special education school at Vipeholm, summarize our impressions is: It was quite a significant experience that benefited us long after our time at Vipeholm. We have:
>
> – knowledge and awareness that the commitment and belief in everyone's potential for development is valid.
> – awareness that a negative view of people's potential and worth prevents development.
> – greater awareness of how difficult or in some cases impossible it is to combine the natural scientific and humanistic approaches and that our approach steers planning of both the physical and psychological environments. A hospital setting is not acceptable as a model for permanent housing nor should it be permanent housing for anyone.
> – awareness that a person's worth and dignity can easily be lost in an institutional environment. We ask ourselves: is it possible for the institutional way of thinking to return? Let it never again happen!

Sture Rayner, MD, describes the same period and the same phenomenon (ibid.):

> We requested and were able to employ behavioural scientists. When the organization was completed, there were social workers, a psychology department and a training school.
>
> We had hoped that through co-operation and understanding between representatives of the different branches in the organization we could achieve development that benefited the habilitation of the developmentally disabled while at the same time giving them as good a life as possible.
>
> It soon became obvious that the seeds of conflict were already sewn into the organization. Without having chosen it, we were in the midst of a classic clash between the doctors and the behavioural scientists.

> The main ideologist was the head of the psychology department, Ingrid Liljeroth. In step with the times, the behavioural scientists considered the medical professionals' view of people with developmental disabilities to be fundamentally wrong. The doctors were thought to have an empirical, objective, scientifically based, insensitive and treatment-aversive approach to the developmentally disabled. The term "patient" was disparaging and revealing.
>
> The psychologists had an entirely different outlook. They were hermeneutic, sensitive, understanding, affectionate and therapeutic in the true meaning.

It was not, however, only the psychologists and educators who distanced themselves from the medical view of those who were mentally retarded. Karl Grunewald, member of the medical council, did not see the relationship to psychiatry and its focus on illness as something entirely uncomplicated in the developmental process (Grunewald, 1976):

> An important step in the normalization of care services for the mentally retarded is that we separate it in all respects from psychiatric care, even when it concerns training of the staff. The one-sided use of adult psychiatrists as well as medical doctors in our care services has delayed this development.

The mentally retarded, who until recently were seen as uneducable, now were starting to be perceived as people in development, but on their own terms and in interaction with their surroundings. The importance of the environment for an optimal development was strongly emphasized:

> The principle of normalization presupposes, of course, a dynamic fundamental view of the handicapped person's opportunities to develop, which is realistic since we now understand, among other things, what the different environmental factors mean. The view of a handicap as something static has to be altered! Never forget that a *mental retardation is a function that requires a relation*—a relation to one's surroundings (ibid.).

There was a desire to quickly normalize life for the developmentally disabled people who lived in the large institutions. During the process, it was felt, however, that these units were too large to accomplish the far-reaching changes that were needed. Since all people with developmental disabilities had been granted the right to go to school, others started to see them as *people in development* too. Mental retardation was not a static condition; the developmentally disabled were people first of all and they had feelings and a will of their own. Much effort concentrated on finding alternative means of communication for those who had not learnt to talk. People started to speak in terms of civil rights even for these people. These rights included being able to live in smaller housing units, having access to a life with adapted work and recreational activities. Social services were for everybody—including those who had a developmental disability.

> The mentally handicapped are probably the group of people who throughout their entire life cycle have the biggest gap between needs and demands, even if we now, after the right kind of fostering and training, have enabled more and more of them to express their demands. We have to include this as a new element in setting goals in our education of the mentally retarded, the whole idea of increasing the individual's ability to make demands so that they, if possible, match his needs. Otherwise, the person in question can never on his own make use of the opportunities that society will continue to offer in the social, physical and mental areas (Grunewald, 1976).

Here, Grunewald uses of the concept *mentally handicapped*, something that in this context is used to describe mentally retarded individuals, but later also came to include a large group of those who lived as long-term patients in the mental hospitals. Life in the institutions had, to a large extent, been based on a suppression of the will of the mentally disabled people confined there. They were required to adapt to the routines of the institution. Now, they were to become *real people* and learn to express their own needs. Small group homes were built in which each person had his or her own room. Over time, the demands for better standards increased so that each person could have his or her own apartment within the group home. Respect for the individual, along with integration and normalization became the starting point for descriptions of goals as well as further legislation. In the revised version of the Care of the Mentally Disabled Act of 1986, attention was also given for the first time to a large group of service recipients who had been instititionalized for a long time and had been problematic. They were people with autism. It was now understood that this group was in need of a different kind of treatment and a different type of instruction than the larger number of developmentally disabled people. They came under the Care of the Mentally Disabled Act with the designation *childhood psychosis*. Since autism was considered at the time to be a psychosis, a good number of other persons with *genuine* psychoses were also included under the Care of the Mentally Disabled Act, in which they met the criteria that the psychosis had appeared before the age of 16.

It was not until 1994 that the two groups, separated from one another as described by to the 1851 report, were reunited in the LSS. This time it is the mentally ill who are included under one law for people with disabilities, but are not truly on an equal footing with those who for more than a century were the object of *fostering* and *strict discipline*. At about the same time, it also became apparent that the group that had gone under the designation *childhood psychosis* in social services was also to be found in psychiatry. In the new legislation, they were included in the new designation *autism* and *autism-like conditions*. Within psychiatry, these diagnoses had previously been adopted by child psychiatry in some parts of the country. That they could be found in adults was a new discovery in the later half of the 1990s. With that, child neuropsychiatric knowledge also became a concern for adult psychiatry, as well as the educational methods that previously had been applied in care services for the developmentally disabled.

From mental hospital to new psychiatry

Bengt Sjöström worked at St. Maria's Hospital in Helsingborg for 25 years. When he describes his experiences in a dissertation on the history of psychiatry, it is one of the familiar voices from psychiatry's polyphony that we hear (Sjöström, 1992). Even though Sjöström is depicting how care was 40 years ago, it is not difficult to recognize parts of his description in the care that is given today:

> When I studied the history of Swedish psychiatry, I was surprised to see how stable the care setting, service organization and care problems were over time. The pictures and accounts that I found in different sources on care for the insane at the turn of the 20th century, for example, largely correspond, in my opinion, to what I was a part of in the middle and end of the 1960s.

Sjöström shows how treatment consists of adaptation to institutional life. He does this by describing the situation of a patient who was admitted to St. Maria's Hospital in 1906 and died there 52 years later. In the medical records, one gathers that the expressions *calm*, *tranquil*, *amenable* are positive which is also the case when the patient is industrious and hard working. As punishment, patient privileges are withheld, they are transferred to wards that are worse, their freedom of movement is restricted by putting them on locked wards, locking them in their rooms, physically restricting them with belts, forced medication, etc.

This type of fostering that Sjöström describes presupposes that the patients understand normal social signals and that they know what, in the eyes of their assistants, is normal behaviour and have the ability to adapt accordingly. Among those who obstructed and did not follow the rules, there most likely were people with autism spectrum disorders who were unable to interpret the staff's expectations of correct behaviour.

Sjöström concludes that the treatment the patients receive during their many years of residency could be called *moral fostering*. This moral fostering is not based on curability criteria but aims, instead, to get the patients to adapt to the institution.

The *moral treatment* that was used in England, France and Germany during the first half of the 19th century, which was a source of inspiration for Swedish psychiatric treatment, was based, however, on a more optimistic view of the possibilities of a cure and also made use of *humane treatment* as well as a *beautiful setting* in treatment.

Sjöström also observes that admittance to the hospital is based on the results of a medical diagnosis, while in the medical records, the patient is described in terms of dutiful or neglectful. The patient is exposed to punishments and rewards in order to mould him into a sedate and compliant individual. In the medical records they then record observations that confirm the insanity diagnosis. Different treatments for somatic ailments are also described.

Sjöström concludes:

> If the diagnostics and validation of care are based on a medical-biological model, the actual treatment carried out on units follows an almost *moralistic* model. A paradoxical *moralistic* model that I think clearly distinguishes itself from *moral treatment*.

In the psychiatry that Sjöström describes as stagnant, however, a lot was about to happen in the decades that followed. The biological view of mental illness had a new resurgence in the 1950s. Effective medications that acted on the chemistry of the brain proved that there was some kind of organic error that could be corrected in the brain. Genetic studies demonstrated that many mental illnesses included a genetic factor. They started doing research on twins and adopted children to get at heredity and environmental factors. The biological basis of schizophrenia and manic-depressive illnesses became all more apparent.

This knowledge paved the way for pharmaceutical research. Neurology developed and was able to show with its more refined examination methods entirely new connections between brain chemistry, brain anatomy and mental illnesses. Usage of the new, effective medications, though, had its flipside; psychiatrists relied on the medical effects to such an extent that they neglected personal patient contact. It became entirely too easy to check on the effects of the medication and forget the person who was being treated. All this added fuel to the fire of the anti-psychiatry movement, which maintained that mental illness did not exist. It was simply a healthy reaction to an unhealthy political and economic climate. The problem was to be found in society and not in people. Examples of this view of mental illness can be found in Michel Foucault’s “Madness and Civilization” (1965), and Thomas Szaszs’s “The Myth of Mental Illness” (1961). This anti-psychiatry movement, which wanted to abolish mental hospitals during the 1960s, also resulted in studies of the institutions, which were carried out using the research methods of sociology and entirely new concepts and terminology that redefined the processes behind what was happening at the mental hospitals. The patients were not only objects for care, but also for *hospitalization* and *institutionalization*, processes that infantilized them. These processes could now be described as additional layers of the original illness and provided new explanations as to why so few patients could be discharged as cured or improved. Being committed to an institution meant, in reality, that contact with the outside world was lost and an imposed idleness increasingly pacified the individual who entered into a resigned and submissive patient role (Sundin, 1970).

At the same time as researchers were studying the individual as part of the total setting of the institution, the setting itself became an object of examination. Power relationships and organizational structures also became important elements in the debate and resulted in a politicalization of psychiatric care. Strong forces in psychiatry wanted to redirect care towards changes in society—it was society that needed to change and not the patients. They were, in reality, victims of different rejection mechanisms in society; it was meaningless to cure the patients and then send them out into the same harsh society again.

During the 1960s and 70s, there was also a wave of different types of experiments that swept over the patients. One of the nurses that I interviewed started working as an untrained assistant, employed on an hourly basis during this period. She relates what it was like behind the hospital walls:

> I was completely untrained when I started working in psychiatry and was paid by the hour, a little here and there where they needed staff … the patients that I worked with when I was part of the substitute pool were the long-term, chronically ill, as they were called at that time, most of whom were schizophrenics or had other forms of psychoses and after a few years I ended up caring for substance abusers—still quite untrained. And there I ended up running the groups. Someone simply came up to me one morning and said, "Today you take the group," and when I asked, "What shall I do with them?" I was told, "Well, you just talk with them." When I asked who was going to work with me, I found out that I would be doing it entirely on my own. "But I don't know anything about group therapy!"—"Well, just improvise!" is what I was told and I came to a group with some older, severely alcoholic men—well at that time I thought they were old—and then there were some guys in their twenties who today would be given a double diagnosis—they hallucinated and were psychotic. And I just didn't know what I would talk about with them, so I did what I knew—I took them out to play football instead. It was at the time when environmental therapy was in vogue and I'm certain that there was someone in the system who knew what we were supposed to talk about and what the goals were, but much of what was done and talked about was pure rubbish …

> And at the same time I also ended up on a ward where I came one morning and a well-known criminal in town opened the door for me with his own key. I thought, “My God, is he employed here?” But it turned out that they were role playing that day and the patients had been given the keys and were playing the role of staff members and the staff were the patients and would be able to feel what it was like not to have the keys … it was completely ludicrous …

Alongside all of these experiments there was, of course, a more traditional psychiatry from which the new psychiatry tried to distance itself. One of these renewal projects started at Nacka outside of Stockholm. Rose-Marie Eliasson evaluated the project (1979). She describes how from the beginning there were strong political ambitions to make the patients politically aware of society’s role in their illness. Then the staff and patients would join forces in a common struggle for a better society. Eliasson goes on to describe how the confrontation with medical reality altered the ambition of conducting an ideological struggle. The project quite quickly turned into a type of psychiatric care that admittedly had a different structure and that carried out a new treatment approach, but that completely phased out the political ambitions.

One of the psychologists who participated in my training sessions was involved in the Nacka Project and relates in an interview the different ideological currents and treatment methods he experienced during 30 years in psychiatry:

> The biggest changes did not appear until deinstitutionalization in the 1980s, but in 1974 the Nacka Project started and that was when I began working in outpatient care. One of the ideas of the Nacka Project was to find a decent alternative to residential care and there was also a more psychological-psychodynamic focus in the work, which meant that we offered the patients many more counselling opportunities and that all the staff would actually work much more as therapists. This would take place on an outpatient basis, closer to where the patients lived, instead of them having to travel long distances to the residential facilities. In the Nacka area, three different clinics were established. Three psychoanalysts were appointed as heads of these units and in that way you could say that the psychoanalytical/psychodynamic approach started with the Nacka Project. I was involved in it from 1983 on, and the Project had already been running for a little over 10 years. Johan Cullberg was the director, and he thought that the needs of the long-term psychotic patients were not being met in the framework that existed at the time. As a result, he started an outpatient clinic for psychotic patients and it was the first unit that was established and also the first that was not headed by a medical doctor. I was appointed director. Cullberg realized the importance of getting someone with other expertise and what we ended up working a lot with was what one could call social psychiatry. We started working in the community, with the patients in their own settings and contexts and with social services. What dynamic psychiatry had represented was a more restricted world. Patients went to their clinics and their therapy, but did not have to reveal this to anyone … we started opening up this closed world and

letting in others such as social workers, relatives, relative organizations, etc. Nacka was also one of the first locations in which a support group for relatives was established.

There are many twists and turns in all of this, but the psychodynamic therapies for psychotic patients started with people like Barbro Sandin. And when we began our unit for psychotic patients, we said that we would offer 10-12 patients comprehensive psychosis psychotherapy with competent personnel. But that never turned out to be the case; we were never able to gather the 10-12 patients and I feel that the psychodynamic psychiatry or psychology that survived did so quite strongly in a kind of homespun way. It doesn't really correspond to the psychodynamic approach; one really doesn't work according to that … it's true that the concept system is used but sometimes it ends up turning out quite strange … they were a sort of barefoot therapists and when we started up our unit, we thought in terms of psychotic people all being alike, but what we discovered was that they are people just like everyone else. Some of them, we thought, would benefit from psychotherapy while others, as I experienced it even them, had different kinds of disturbances that made it impossible to work therapeutically. Nor did we have any knowledge of how we could otherwise treat them. I thought at the time that they must have some kind of brain injury or damage or something else that was not the result of conflicts in the family or anything like that, and yet they were still severely disturbed. The greatest benefit from this psychosis unit was that we became aware that people with psychoses had different needs and that a uniform *psychosis psychotherapy* did not exist. The problem with the psychodynamic approach is that it is so seductive and that it is applied across the boards instead of examining the patients and determining which ones can benefit from it and which framework you should have for it to work at all …

And then the results of studies demonstrated that psychotherapy for psychoses produced meagre results with perhaps a 14-15% recovery rate after extremely extensive therapies. That's when the whole movement lost steam and what was left was only medication. I see medication as a way of setting the stage for other treatments, but if you do not work with all the problems that the patients has, they will still be there and the patients will lose the ability to cope with everyday activities again and again if they do not receive help with it … this is a an extensively uncharted area, in my opinion. Then the educational programme, ESL (An Independent Life), appeared on the scene, but it has not had much of an impact. It is much more psycho-educationally constructed and is good in that way, but it is also quite an inflexible approach and rather conventional. It requires quite a lot more activity on the part of the therapist, while the other therapies were more about sitting and talking with one another. This type of talking had high status during this period.

What happened next and which no one really saw the consequences of at the time was that we started to wonder what we could do with people who were unable to make use of words to formulate their ideas. We also discovered that one person could describe a situation in therapy and then when we made a home visit, it didn't fit at all. And they were unable to apply what they had learnt in therapy to everyday life. No one knew how to deal with that. When I arrived in 1995, that is to say over 10 years later, they had started working according to another model in which you made many more home visits. You work more psycho-socially and try to initiate

> activities along with the patient. But what we didn't consider in this model is, "How do we treat people with neuropsychiatric handicaps?" I still think there is a deficiency in this area; we may know something about it now, but we need to learn a lot more.

Hans, the psychologist quoted above, participated in the large revolutionary and reorganizational process that led to a new, deinstitutionalized psychiatry. A large number of the patients were now to live out in the community, in municipal group housing and smaller nursing homes under more open conditions. This psychiatric reform, with the goal of moving patients into the community, perhaps placed too much confidence in the community that was to accept these different and unusual people. None of the treatment methods were moved out of the institutions into the new housing arrangements in which the patients were to live as having *completed medical treatment*. It was taken for granted that they would live on the same terms as other members of society. No one would need to be treated in his or her own home and if they needed treatment, they would receive it like everyone else did, in the health care system at a community clinic or an outpatient clinic.

Today, as a case manager for outpatient clients, Hans helps and supports these former patients who have completed medical treatment. However, from his lengthy experience he has a great many reflections about the means and the methods that psychiatry has at its disposal:

> What I see as the biggest problem in psychiatry is that as soon as a new approach emerges, it becomes the one that is going to save us. The proponents are Jesus types who have come with a message of redemption. The psychodynamic therapy was going to save us but it turned out not to be the case and then it was cognitive therapy that was going to save us and then networking and now it is the psycho-educational method and you wonder, "Shall I use this one as it is without considering who it might be appropriate for?" and then feel like you failed again when you realize that it doesn't work for everyone and you wait for the next saviour to come along. In order to work with this new approach, you have to have care units that work with it methodically, in a genuine manner. And the concept of schizophrenia is falling apart, which I think is really great. I don't think *schizophrenia* says so much more about a person than *Stockholmer*. We are starting to differentiate within the area of schizophrenia; everyone doesn't need the same type of treatment. The symptoms you find in schizophrenia are certain to have a great number of different causes and require different treatments and we may have to define a group of people who can benefit from this type of special educational approach and make sure that there are knowledgeable staff members who are supported in working according to these special methods. If we continue to indiscriminately place these patients on general units, there's a big risk that it will end up like it did for ESL … that you try it for a while, but then it ends up being part of the general routine. That's what I'm worried about—that a good approach for some patients will just disappear …

Today's psychiatry— voices of clinical practitioners

Even though many patients have been discharged from inpatient psychiatric care, there are still a significant number who are unable to manage with only outpatient contacts. A number of patients still have to live and be cared for in residential facilities for different reasons. It may be due to the person's inability to manage independent living, but it can also be because the person is unpredictable or dangerous to society.

From my interviews with psychiatric personnel I have selected voices that I think represent current psychiatric care as it is put into practice on the inpatient units that I have become acquainted with. What do the personnel themselves think about what they do? What does psychiatric care and treatment mean for them?

Anne, senior psychiatrist at a forensic psychiatry unit with extensive experience:

> In my opinion, psychiatry works best for those who have a true mental illness, which is, of course, psychiatry's main function. It's there to treat those who have schizophrenia, those who have illnesses that interfere with their ability to control their moods—such as bipolar affective disorders and paranoic psychotic conditions, and then there is what you could call an unspecified group with psychotic conditions in which you can't exactly determine the cause, what's also referred to as NOS (Not Otherwise Specified). Some of them can also have developed a psychotic condition secondary to long-term substance abuse. Psychiatry's primary role is to meet the needs of these people, that is to say, the ones who have a mental illness. And the entire approach to treatment is based on the patient being admitted to the hospital, being treated there for a limited period and being expected to attain a better level—even if he is not cured—and then being discharged; it's then expected that the patient will be able to manage on his own out in the community. On the other hand, people who have life-long disabilities do not fit at all well into this system. An entirely differently care process is required and another kind of treatment.

Hans-Christian, senior psychiatrist at a clinic for patients with severely challenging behaviours, has extensive experience in psychiatry:

> There are many problems to deal with on our units. It's not easy to set up good treatment environments for the patients who have committed serious crimes. At the moment, I'm experiencing the ideological antagonisms that are now more inclined to say, "Lock them up for the rest of their lives!" rather than "Give them more appropriate care!" I have kind care assistants on the unit who are quite good at setting the table and seeing to the everyday activities, but I would like to have special educators, more occupational therapists and rehabilitation staff instead of so much hospital personnel … so many nurses are not really needed on a unit like this.

> At times, I'm at a loss as to what to do when we have a truly difficult patient to treat. A patient who we have discussed is extremely compulsive—he could benefit from behaviour modification, but there is only one such therapist in our city. Medication helps a little, but he is really suffering from his compulsion. It's been difficult to come up with a diagnosis since there are many that partially fit his symptoms. It's also been difficult to determine how dangerous he is because I continually catch him lying about things that I didn't think he could make up … but it's also exciting to take on challenges that appear to be entirely impossible … you have to try to look at it from different perspectives all the time.

Annica, nurse on a unit for patients with severely challenging behaviours. She has worked for five years on the same unit:

> The idea is that the patient, in the long run, will return to the community and we have to make sure that he develops to the extent that he can live as ordinary a life as possible. The hospital environment itself and its appearance actually work against training patients to become accustomed to living in a normal setting. The psychiatric patient's environment should really look like any other ordinary home setting, but that is not the case now, since this is the environment we have. This sterile setting and the hospital walls can counteract their purpose by increasing feelings of estrangement and frustration in the patients. We count in terms of beds here on the psychiatric units as well.

Lena, mental health assistant, has been on a unit for patients with severely challenging behaviours for eleven years:

> We try to facilitate the patients' everyday activities. It is often the case that the illness makes them forget the ordinary, everyday things that need to be done and I think that it is part of my job to get them back into a regular pattern in such areas as personal hygiene, getting dressed … showing them how different devices work, something which they may have forgotten … how to use a coffeemaker and washing machine … sometimes an ordinary coffeemaker seems to be a completely foreign object to them
>
> Talking to the patients is important and you have to be yourself, because we are all different and this lets the patients meet different people with different characteristics. I am, for example, the mother of small children and that means that I become a kind of mother here too … I transfer the role I have at home here, you could say.

Buster, a recently graduated mental health assistant and licensed practical nurse, works on a unit for patients with severely challenging behaviours:

> Well, I see mental health care as a way of coming in contact with the patient, first by lying quite low and then learning his habits and other things that make it possible to work with him. The patients who we have here are most often what we call long-term and this is due, in part, to the many LRV patients we have; it's very difficult to discharge them to other kinds of housing. It's as if some of them had stopped developing somewhere in their teens. They like teenage music, fast cars, fast boats, cool gear and it's as if they haven't come any further.

> It’s as though they are floating in the sky in some way; you really don’t know either what is true or what isn’t of what they say. The adult world is a big problem for many of them. They want to assert themselves, are impulsive and have difficulties with control … substance abuse is a big problem for many. The county administrative court demands, of course, that they be drug free to be discharged, but as soon as they are on parole, they can’t handle it …

Agneta, senior psychiatrist:

> The methods that we have are medical ones and then there are the psychological ones—of different distinctions. All treatment involves, of course, a change and the question is how can I bring about the change. If we take the methods that *exist*, there are electricity and surgery, but they are not the methods we use. For me, psychology is really on a par with education. If I learn anything new, it is psychology. I really think that in that way the unit should be a learning environment. I think that in some way you have to change the content of the work done on the unit. Environmental therapy deals with a person learning something from daily life on the unit and through daily repetition you *relearn*. When a patient does something negative, you have to examine it immediately and learn from it. But this means having both the time and the competence. Having the skill, that’s what I would call it, to transform something into a learning opportunity …

Ester, a mental health assistant who became a nurse. She has worked on the same inpatient, residential unit for patients with severely challenging behaviours for 20 years

> I think it’s a matter of respect—to *really* respect a person. And it’s a matter of caring about the patient and not just letting him be—as was the case with Emil. I had to start from the beginning with him when he came from the large mental hospital. He had lived in a bare room because he had “chosen” not to have anything. He said the same thing when he came here … that he didn’t need anything; but then I thought, “My God, no one can live like that!” So we put in a little furniture for him—a bed, a nightstand and a chair. We also put a plant in the window. Then, when he got used to it, I knocked on the door and went in with some pictures. I didn’t ask *if* he wanted them, but *where* I should hang them. “Yes, that’s fine!” he said and turned away from me as he usually did when I spoke to him. And then he showed me where he wanted me to hang them. And that’s the way it happened … one thing after another was moved into his room and now it looks quite normal.

Anne-Marie, a nurse with over 30 years of experience in psychiatry. She now works on a unit for patients with severely challenging behaviours:

> I can’t claim that we have any special treatment method, but we try to follow the rules we have in a very pleasant way. We have more structure than other units and a far as I can see, none of the patients we have here seem to suffer from that. I would imagine that some of the patients who come to regular outpatient units might be offended by our methods, but they aren’t the ones that come here, so it’s never

> a problem. And forensic psychiatric care doesn't really differ from other care in any other way than that you have to talk about the crime that the patient is in for. But all this about staying within certain limits that results in you behaving in an honourable manner … why these are attitudes that should concern everyone and not just the ones who are sentenced for a crime.

Lotta, mental health assistant:

> We work with educational plans, as you know, and this involves the patients being able to tell us what their problems are, but often I am the one who has to tell them that, "You are unbearable to those in your surroundings … " This concerns, of course, the person that we have spoken about in the staff training sessions. I sometimes have to let the patient know that it is hard for other people to put up with her … that she has to take her medication in combination with the therapy that she has now started with the psychologist in order for others to manage being around her. It is somewhere at this level that you have to work and I don't think that you should be alone in dealing with these kinds of patients; they will totally wear you out …

On some of the units, I also realize quite quickly that there are divergent care ideologies within the different care teams and I ask one of the nurses how they deal with it:

> It's impossible to deal with it … the teams have different styles and I don't think there have been any changes in the years I've been here … we do try to solve it by taking it up at staff meetings, but I still don't think it works anyway. I think that the care team supervisors are too different … and then it is firmly rooted in the older and younger generations. It's a matter of different outlooks … the really old mental hospital mentality is gone. No, it's due to something else … but we still have the type of communication that we can say what we think and we can discuss it, but it's impossible to change some people … there are just so many people on a unit like ours. I don't think that it's bad for the patients since they have their contact persons, of course … the patients who I have seen that are negatively effected by it are primarily those who have autism. But so far, I don't think it has been a direct catastrophe for anyone … it has resulted in an uproar on a few occasions, though, especially with a man who is no longer here with us …

The description given by the clinical practitioners in today's psychiatric treatment is basically the same as the one Sjöström provided, only the framework has changed in modern psychiatry. The core of the non-medical treatment is the staff members furnishing structure, talking with the patients and fostering in them such things that will be required of them in the normal life that is going on someplace out there in the community. It is also assumed that everyone actually knows what is normal when it concerns socializing with others, dressing, furnishing, dealing with everyday activities and being a member of society with rights and duties. In addition, patients in forensic psychiatry are supposed to reflect on their crimes and understand that they are not allowed to commit them again in order to be discharged. The treatment methods are based on the staff members teaching the patients to behave as one is expected to outside of the psychiatric unit. There is no unified approach and great differences can exist between the teams in their views of the patients and of the care they are providing. A few of the senior psychiatrists would also like to have fewer hospital personnel and more teachers, since it is a matter of utilizing everyday encounters, actions and mistakes to establish insight and learning. In reality, it is in the interaction between people that treatment takes place in everyday therapy and training. If treatment consists of this type of general fostering in how to live a normal life, how do you then differentiate this fostering based on the different diagnoses of the patients? What help is the psychiatric diagnosis in knowing what you should do with different patients?

Ester, nurse:

> Well, I really don't know how diagnoses could help; people with the same diagnosis are so different from one another and you aren't able to come up with a treatment based on a diagnosis anyway. And when I consider our patient, Emil—the way that he is described is based on a schizophrenia diagnosis and it seems as though they really made an effort to find symptoms that met the diagnosis criteria in order to make the person fit the diagnosis. Personally, I don't take much notice of the diagnoses. It is important to describe the person and that is what I try to do when I write the care plan.

Annica, nurse:

> I think that the personalities of the patients come through so very much, but the diagnosis is a tool to use in structuring the patient's difficulties and for seeing what you can help him with … and I often see the benefit of a diagnosis for the sake of the patient. It helps in understanding why he functions as he does, which often helps him gain greater insight. But—it can be just the opposite with others, something that stigmatizes and singles them out. I think that you have to be extremely clear when you explain to the patients, which is something we can do from the care plan that we have established. I mean, the patient is here because he has certain problems and we can then look at them together from the perspective of, "I think you have a problem with this … " and ask the patient if he has experienced the same thing. It is a matter of taking the patient seriously and the ones who are not at all aware you have to have patience with and try to show them, in concrete situations, what they need help with.

Agneta, senior psychiatrist:

> Our knowledge changes all the time. We diagnose and place people in compartments and that is a chimera, an abstract concept and it is constructed in *one* manner and it doesn't apply, as we know in reality. In 20 to 25 years' time they will be saying about many of the diagnostic criteria that we have today, "How could they have been so wrong?" And both biology and psychology act together and today we can't really say in what way and how.

Hans-Christian, senior psychiatrist:

> I see DSM and ICD as pretty worthless in the clinical setting. The problem with co-morbidity is too big and you still have to have a functional diagnosis in order to know how to treat. Etiological diagnoses would, of course, be ideal, but we are a long ways from achieving that.

Hans, psychologist:

> I don't see that diagnosing with the new diagnoses themselves as being much help either. In psychiatry you are supposed to diagnose in order to arrive at a treatment, but you mustn't believe that the diagnosis and treatment are necessarily connected. First you assign the patient a diagnosis and then you treat the symptoms and there is quite a bit of leeway in how you provide the treatment. And now we suddenly are getting a lot of patients with the diagnoses DAMP, autism or something else, but we know nothing about how to treat them.

Stellan, psychologist:

> The diagnostic categories say nothing about treatment; for that you have to look at the symptoms that are present and the disabilities they result in. In addition, you have to see how the different symptoms have arisen in relation to one another. That is the way we arrive at a treatment—the diagnosis on its own says nothing—but the entire health care system is built upon the diagnostic system and that results in us also using it; but treatment is based on the specific sub-problems that need to be dealt with.
>
> Of course, the diagnoses should, in general, be arrived at as soon as possible after admittance because the treatment is to be based on a diagnosis. But—in reality, almost all diagnostics take place ex juvantibus, that is to say, you observe a symptom such as hallucinations or something else that indicates a psychotic condition and then you put the patient on medication and determine after a while "Did things improve?" If they did, it was what you thought and if they didn't, then it was something else. Quite a lot of diagnostics are carried out in this manner and because of that, I see no need of assigning a fixed diagnosis in order to come up with a reasonable treatment arrangement; if anything, the opposite—you can easily be locked into the wrong line of thinking. Instead, I like to look at the problem area and ask, "What can we do about this?" and "What is the reason for this?" There are very few patients who entirely fit into an entire diagnostic category, no matter what it is. One question, for example, might be, "Is this a substance abuse psychosis or a psychosis triggered by substance abuse?" or is there something else behind it all, because people with ADHD can be found every now and then among substance abusers. One of our senior psychiatrists has experience with this and can see that ADHD is often hidden behind the other symptoms.

Anne, chief senior psychiatrist:

> I think it is impossible to continue with the current DSM system and it is also a question that has come up in international contexts. There

> they see the future as dealing more with different spectra or different characteristics that a person has and that can appear in certain combinations. The present, very conventional approach to diagnostic categories will probably disappear. I believe that a whole new way of thinking is on the way. In the area of forensic psychiatry, we have just started to work parallel with the ordinary diagnostic system by describing which of the deviating characteristics are of significance in criminal behaviour. In that respect, I am in the process of developing a model of forensic psychiatry in which you can observe three distinct groups: those who have psychopathic features that result in a given type of criminal behaviour, those who have autistic features that result in another sort of criminal behaviour, and a third very important group that has posttraumatic features.

If the current psychiatric diagnoses do not provide any signposts indicating how treatment should be carried out, then it becomes quite obvious that treatment relies on the ability that each treatment provider has to establish contact, see others as fellow human beings or objects, enter into the world of others or live in his or her own, taking for granted that it is also valid for the patient. The life situations and experiences of the treatment personnel are also reflected in their treatment of the patients. One of the mental health assistants goes as far as to say that her role as the mother of small children also makes her a mother in relationship to the patients. The individual treatment provider is, in turn, part of a team, which also has its social rules and culture that in turn set the limits for the individual's ability to act on his or her own in the treatment context. The contact person system, which existed on all the units I visited, means that a patient has two contacts who have the major responsibility for the patient's care. How these two mental health workers themselves see and value phenomena in every day life is, of course, mirrored in their dealings with the patients. The individual treatment provider and the care team are then part of an organization that offers greater or lesser opportunities for the individual or the team to develop on the job, take part in continuing education or be allowed to lead a routine existence and to stagnate.

What opportunities exist for the staff to prepare the patients for life outside of the psychiatric unit? What do they do all day long?

Stellan, psychologist:

> Frankly, I don't know why they have done away with work activities, but a lot of it certainly had to do with the zealous budget cuts and reorganizations that were imposed on psychiatry. It was primarily in the 1980s and beginning of the 1990s that it all happened—it was ideological too, of course … that they were going to break up the big hospitals and transfer large groups of patients to non-institutionalized care and different kinds of housing out in the community—for good and for bad. As a result, the patients on

> therapy units in the hospitals disappeared and there was no organization out in the community that was building up anything similar. They started by sending the patients out and then realized that something was missing. That's how it happened and I have to admit that my profession along with the psychiatrists, that is to say those of us who were responsible for treatment, were also among the culprits. We have no doubt looked down upon work activities: "OK, it's good that the patients are distracted and kept busy to a certain extent, but the *real* treatment that had any effect was medication or psychotherapy." In the beginning it was also a case of either/or, so that the psychiatrists asserted that it should be medicine and the psychologists asserted that it should be psychotherapy, but now that battle has disappeared to a large extent. But, yes, we have had a superior attitude towards these more tangible treatment methods.

Bjarne, mental health assistant:

> Actually, there were things that were better in the old mental health care system! The patients were occupied and those who could manage to work felt that they were needed. I am quite convinced that the work activities were removed because there was a need for jobs out on the market and the hospitals were accused of taking advantage of the patients. Personally, I think that by doing that, they took from the patients their sense of human dignity!
>
> Now there are not many of the job activities that they had before, but since we moved into this new unit we have started them up again. We have, for example, gardening and we have quite a few patients who attend occupational therapy. Annica and I take care of what I consider to be the best medicine, that is to say, exercise and we have football, floor ball and volleyball. On Tuesdays we have a breakfast group and after that we go on an outing—it can be bowling, floor ball, table tennis or something else. But it is, of course, only those who have permission to leave the grounds—we have quite a few forensic psychiatric patients and there is one patient who it has been difficult to recruit personnel for and in that case, I have to say that Annica and I work a lot voluntarily. We sometimes come in on our days off to keep things going.

Helle, occupational therapist who has worked in psychiatry since 1987, is on a unit for patients with severely challenging behaviours:

> On this unit they are open to new ideas … it's true that you can still find different factions with different approaches here, but not anyone with the "no-patient-in-the-kitchen" point of view. There is a security mind-set that at times doesn't really mesh with efforts to create a homely atmosphere. But, there's no doubt that such an atmosphere would be best for these patients too *if* we were able in some way to make the unit secure. After all, some patients have been committed and we have an obligation to protect the community. Many of our patients have been institutionalized so long that they are unable to function in a normal environment anymore. They have lost so much of the common, the ordinary …
>
> Before anyone is allowed to participate in occupational therapy, a risk determination is made. I have, for example, open drawers with knives and we freely make use of tools and nothing has happened so far … those who we think might abuse the liberties occupational therapy offers are simply not allowed to come.

> We are also out in the cottage once a week. It is a house in the country where there are lots of things to do. There are things that need to be repaired and renovated; there is gardening to tend to and wood to chop … we prepare food and do all the other things that you do around the house. Each individual can take part in the kinds of activities he or she likes. Some prefer working outside, while others would rather stay inside. Some think it's nice to just get out of town and sit a while by themselves or take a stroll. In the winter, we sit by the fire and talk. Just being in a different environment has an effect on the patients. The personnel who come along usually say that many of the patients are entirely different when they are at the cottage. The division between patient and staff disappears; we are there more on the same terms and everyone helps out with what has to be done. There we also trust the patients in an entirely different way than on the ward. In the beginning, we had, for example, no knives in the drawers, but now we use both knives and axes …

The work opportunities that were once offered at the large mental hospitals have been done away with at the smaller facilities of today. The activities now available to the patients include outings, walks to the corner store, visits to the pizzeria and such. In some locations, the lack of reasonable patient activities is perceived as being directly counter productive to the treatment approach; great efforts have been made to try and find more permanent occupational activities with well thought-out content. The unit described above for patients with severely challenging behaviours has its cottage to visit regularly. Some of the units offer *classes* consisting of study circles or adult education courses in which instruction is adapted to the needs of the patients. Some of them work outside on the grounds, some with the care of animals on a smaller scale. In most locations, patients have access to exercise classes. Even though there are many activities in which to participate, it is very seldom that a patient has something to do everyday and should that be the case, it is often only a few hours a day.

3. Some scientific-theoretical views on psychiatric theory

Psychiatric practice is not the only area that has experienced significant changes. During the latter half of the 20th century, the views of the causes of mental illness as well as diagnosis and treatment have altered considerably. Since the 1950s, great efforts have been made to try and find a common diagnostic ground, which has resulted in the establishment of the DSM system. The first manual, DSM-I, contained about 60 categories of mental disturbances and had strong theoretical ties to the psychoanalytical approach to mental illness that prevailed in the USA (Shorter, 1997).

The continuing history of the DSM manuals has been influenced by the theoretical shift from psychoanalysis to a more biological-neurological focused psychiatry. The new auxiliary disciplines that have contributed to psychiatric knowledge have also left their mark on the development of the diagnostic system. The neuropsychiatric diagnoses were first described in the third edition of the DSM manual, which already had 230 illness categories. In the fourth edition from 1994, both autism and Asperger Syndrome were included in the 410 diagnostic categories. In an attempt to satisfy several divergent views in the categorization of mental disturbances, the editors have tried to present the manual’s categorizations as *atheoretical* and *based on available knowledge*. By describing some of the currently significant scientific-theoretical ideas, I will attempt to illustrate what is questionable in calling any knowledge *atheoretical* and that the ideological conflicts that exist in psychiatry cannot simply be swept away by saying that one is making use of *available knowledge*. Psychiatry is characterized by a strong theoretical rivalry rather than consensus (Pfannenstill, 2002). This rivalry is so intense at times that it results in claims that psychiatry is in the middle of a paradigmatic shift. Thomas Kuhn (1992) makes use of this concept to describe the development of science and is of the opinion that the previously accepted theoretical constructions of normal science crumble from within when new facts refute the theories on which they are based. If one strictly applies Thomas Kuhn’s proposition, it means that each paradigm has its own models. Comparison between different paradigms of the results is first possible when you attempt to translate between the different frameworks and understand another paradigm's view of the world and of knowledge. The entire process of how we construct knowledge and create a worldview constitutes a paradigm and is the basis of *any scientific* discipline. Any science exists as long as the majority of its adherents are in agreement about the degree of truth in its theories, methods and assumptions. A paradigm is its own yardstick. When the science on which a paradigm is based becomes flawed by too many *anomalies*, i.e., empirical data that do not fit the paradigm's view and that no longer can be accommodated in the paradigm's patterns of observations and theories, a paradigmatic shift occurs. Such an event is always a more or less sudden conversion from one view to another. It is not a matter of rational considerations that gradually convince the adherents of a given discipline that other theories are more truthful than those of their own established science, but is instead a crumbling of the truths of their own paradigm that the followers are forced to reluctantly accept (Rolf, 1995).

An editorial in a major Swedish medical journal (Läkartidningen, vol. 85, 1988:5) by Bengt Sjöström asserts that psychiatry, in this respect, is in a situation where different paradigms were challenging one another. The article is entitled *Motsättningarna inom psykiatrin—a mognadsprocess (Conflicts within Psychiatry—A Process of Maturation)*:

> Psychiatry as a behavioural science is currently in the same boat as the other behavioural sciences, i.e., at a stage that Thomas Kuhn in his scientifically historical classic from 1962, "The Structure of Scientific Revolutions", calls the multi-paradigmatic stage ... in which several different theoretical views contend for hegemony ...
>
> Various schools lay claim to the truth in this debate. Diverse questions, methods of gathering facts, problems and solutions set the stage for a battle. In this battle, a variety of associations, specialized journals, conferences and training programmes are established. In the midst of developing one's own theory, the rivals' assumptions become objects of criticism. In the modern communication society, the opposing paradigms are able to develop an extensive body of knowledge in their respective schools (as opposed to medicine's early years—the pre-paradigmatic stage—when each medical theoretician had his own interpretation and when the contact between centres was limited).
>
> During the one-paradigmatic stage—which psychiatry has not yet achieved—it is *theory* that governs activity. In the intensive piecing together of scientific evidence, the researchers work in an environment of consensus. Established science reigns, i.e., theory governs perception (only the puzzle pieces that fit are visible) and the theory/paradigm also determines the organization of the research community, its structure, rules and methods. "Tidying up and piecing together" are the main activities up until the time when the anomalies (or puzzle pieces that do not fit) are too many—the phase of crisis and revolutionary is at hand.

Sjöström also calls attention to the fact that objective knowledge which is often called for within psychiatry does not exist and cannot exist:

> But still, a competitive struggle is being carried on between biological-medical psychiatry and psychotherapeutic psychiatry. Lenninger calls for an objective assessment of the Säter Project in the Swedish medical journal (Läkartidningen 26–27/87). But the problem is that it is just as impossible to maintain a sustainable, dualistic division between subject and object as it is between body and soul, matter and mind, language and reality. It is a deeply rooted misunderstanding that we can be entirely objective in providing researcher-independent descriptions of reality.
>
> The researcher chooses perspectives in which the research situation also includes the researcher and his way of relating to the world. There is no given, objective reality that is independent of the subject.

The Norwegian professor of psychiatry, Ulrik Fr. Malt, also calls attention to the importance of carrying out scientific-theoretical reasoning at the level of psychiatric theory formation. He describes in Acta Psychiatrica Scandinavica (Malt, 1986) how the knowledge serving as the basis for the DSM-III manual is constructed. He demonstrates the infeasibility of the alleged lack of theoretical formation concerning the etiology of mental conditions in the preface. The assumption that the classifications are based on *available knowledge* and *available data* is, according to Malt, implausible. Neither does he believe that there is any generally accepted *body of knowledge* upon which there is consensus. He points out that the search for knowledge is based on some kind of a hypothesis:

> By definition hypotheses (and concepts, which are based on hypotheses) include some phenomena and exclude other phenomena as being irrelevant to the hypothesis in question. Hypotheses and concepts that are used to construct a classification system are based on conscious thoughts. Thus a classification system will be based on the known. Important phenomena and facts currently not acknowledged will not occur in the system. Accordingly, any classification system will also represent a potential hurdle to new knowledge. It is like a spotlight moving across a dark landscape. We can only see what the light focuses on.

As an example of dimensions of knowledge that have been missed in the current scientific framework, Malt takes up the diagnostic category referred to as *narcissistic disturbance*. Man's hubris has been the subject of myths and legends since antiquity. The myth of Narcissus as well as the legend of Faust provides us with metaphysical knowledge of hubris, which cannot simply be reduced to a mental disturbance. According to Malt, it is a matter of an attitude towards life lacking any sense of humility when confronted with existential issues and the fact that mankind is part of something greater than just the human.

Malt also points out culture as a co-acting agent in our perception and does not exempt economic and political factors from psychiatric knowledge and theory construction. Psychiatric diagnoses are not just *pure* observations but are also cultural creations. Since the end of the Second World War, American culture has dominated the world and consequently American psychiatry with its classifications has also been able to take precedence over the approaches of other cultures. In the wake of economic and political shifts in spheres of influence, interest also becomes focused on the predominant country's societal structure, culture and views on a great number of issues.

In his article, Malt aims to call attention to the ideo-historical implications that exist in all research and in all theory construction. His wants to promote reflection over the aspect of science that believes itself to be objective and impartial. Behind every scientific concept, behind every observation there is already a focus that is influenced by previous knowledge and a hypothesis. Malt points out that the etiology of a psychiatric condition is always a theoretical concept and that empirical observations or hypothetical deductive methods cannot be relied on as verification of the assumed etiology.

> Empirical research can only test hypotheses in the sense that its results may be used to state that the hypothesis cannot be rejected (validation). But a result, which does not permit the rejection of the hypothesis, does not necessarily imply that the hypothesis is true. Besides the hypothesis tested was only chosen as one that was currently considered reliable or interesting. From this point of view the DSM-III system is of course theoretical. It is built on hypotheses which are presupposed could not be rejected and yet are considered to be valid.
>
> A more correct statement regarding the DSM-III system would thus be to state that its aim is to construct a system, which is based on hypotheses (concepts; theory) validated by empirical research only.

Malt further explains in his article that a psychiatric classification system is definitely needed, but that one has to pay attention to its limitations. Above all, one has to always realize that behind every type of diagnostics there is a philosophical position and assumption.

The statement of purpose of the DSM system is that the manual will: 1) be a classification system that facilitates communication between clinics and researchers, 2) be an aid in planning care, and 3) enable comparisons in the assessment of different treatment alternatives.

Malt is of the opinion that it might be possible to achieve the first point because almost all current psychiatric research is based on empirical grounds and so provides the psychiatric professionals with a common language. On the other hand, he does not think that research on empirical grounds can be any assistance in planning care or comparing different treatment models. If one considers all negative mental conditions as *illnesses*, such a view can be relevant, but when one also views poor mental health as including states of mind involving the substance and meaning of life, such a view does not have the same relevance.

> Thus, even when we acknowledge the existence of rational aspects of the DSM-III system too, its usefulness in treating and understanding psychiatric disorders is limited by the heavy emphasis on empirical verification.
>
> This is not an argument against the DSM-III—or against classification in psychiatry. On the contrary, the DSM-III describes one important dimension of mental disorders and mental states, the clinical features, in a very proper way. However we have underlined in this essay the limitation of considering one approach to mental states only as *the* scientific method. We need research (culture of inquiry) that applies different models of comprehension.

Malt, like Popper (Wulff, Pedersen & Rosenberg, 1992), also brings up the social aspects of scholarly work, where science is associated with status, power and money.

> These social aspects will of course also influence the attitude towards and the content of a classification system. Sometimes a discussion about what is known—and thus to be included in a classification system—is in fact a struggle for professional power more than an inquiry of the basis of knowledge. This is demonstrated in a paper reporting on the fight for the fate of the neurotic concept in DSM-III.

Research also has its own culture and centres of power and deals with much more than idealistic scientists whose only aspiration is to find the truth about the phenomenon they are studying. Knowledge is variable and has different perspectives.

When we say that psychiatric care and treatment is based on scientific grounds, the statement first has meaning when we define the assumptions behind it and the research perspective. The Swedish National Board of Health and Welfare has compiled information on Swedish psychiatric research (Psykiatriuppföljningen 1997:22) in which it is evident that the research results that have a far-reaching effect in clinical practice are those that deal with dramatic improvements through medication. Therapeutic methods that require extensive training are not accepted to as great an extent. This is perhaps not so surprising, if you consider that a large number of the professional development programmes in which doctors participate are arranged and sponsored by pharmaceutical companies. It is not economically feasible for advocates of psychological and educational therapies to promote and spread their message.

Different scientific methods also offer different kinds of expertise and knowledge. In the next section, I will present the qualitative methods with which I was equipped when I step into the world of psychiatry. It is with theses methods that I try to understand the aspect of reality that deals with the personnel’s relationships to patients with autism spectrum disorders.

4. Methods

This dissertation is based on knowledge from the fields of education, psychology, design, rehabilitation technology and psychiatry: in other words, it is cross disciplinary. This gives rise to unique methodological possibilities as well as difficulties. To add clarity to my account, I have separated *the theoretical methods* from *the practical*.

Theoretical methods

The work on this dissertation consists of implementation, analysis and results. But it has also involved an extensive amount of pre and post reading and contemplation in the fields of study just mentioned.

The most significant methodological contributions from *education* and *psychology* have been theories on early social learning. I apply these to the difficulties adult patients have in contact, communication and cognition in order to achieve a better understanding of the impact such learning deficiencies can have. The reason why this has become the educational-psychological foundation of my work is based on my own experience from teaching in a disability context. That experience tells me that learning, to a great extent, depends on the nature of the relationship that is established between the teacher and the pupil. In cases concerning pupils with autism, the relation is even more fundamental because these pupils have extensive deficiencies in social skills and need to receive help in social learning. It does not arise spontaneously as with other pupils. This means that the relation one establishes with learners with autism is different from other teacher-pupil relationships and has to be based on factors other than *mutual social understanding* or *social reward*s.

This view of learning is in contrast to the educational methods recommending that education and training for people with autism should be *independent of person*. These approaches are based on a behaviourist view of the person and see the learning of functions as primary, while the individual's interaction with his or her surroundings is considered secondary. In addition to the behaviourally based educational approaches (Lovaas & Smith, 1988), the development of other educational programmes to instruct children with an early autism diagnosis can also be found. Within practical educational approaches for pupils with autism there are a number of aids such as comic strip conversations, social stories (Carol Gray: www.thegraycenter.org/social.htm), schedules and structures for understanding and planning (TEACCH division: www.teacch.com/). There are additional programmes based on different educational methods such as Montessori or anthroposophical remedial training. Christina Lögdahl has developed an educational model for counselling young people and adults (1996). For adults who have been diagnosed in mid-life and who are patients in adult psychiatry, however, the idea of using education as a treatment method is quite new.

I have also found theoretical support from *design* and *technology* (Jönsson & Anderberg, 1999). I began to gain respect for technological methods when Bodil Jönsson and other researchers at Certec were the first ones to understand the absurdity of the care the patient Elisabeth was receiving on a special unit in a hospital outside of Stockholm. It was *Certec* who then took the initiative to describe Elisabeth and thoroughly document this description from a more concrete, and also for her, more intelligible perspective than the multitude of descriptions up until that time. Why did such an initiative come from an institute of technology? Well, their aim was to provide Elisabeth with technology that would make life easier for her, and it was obvious that *before* making any changes one had to carry out a concrete documentation. This approach, which I now also consider to be obvious, does not exist in psychiatry. Nor did the representatives of the psychiatric profession react to how the artefacts that were to be found in that environment revealed their view of Elisabeth and the other patient. Certec saw the artefacts as implementations of the assumptions that these individuals needed to be cut off from other people and that they did not need anything more than an empty environment. For Elisabeth's part, this was in the form of a high fence, locked doors and therapy through a narrow opening in the door. In this setting, there was no awareness or knowledge that disabilities could consist of disturbances in perception that produced abnormal and extreme behaviours. Nor was there an understanding for the great need of a structured yet inspiring atmosphere. These ideas from rehabilitation technology and design also influenced my powers of observation when I stepped onto the eight psychiatric settings that were to make up the settings in which I was to conduct my training sessions of psychiatric personnel. I entered a world of psychiatry where although many of the patients were referred to as *mentally disabled*, the physical surroundings were still those of old psychiatry, in the former mental asylums, and where the lack of a progressive and inspirational atmosphere was almost as striking as before.

The methods that characterize rehabilitation technology's approach always start and end with the *individual*, that is to say, with the person who is going to use the technical solution. In the psychiatric context, this would be the *patient*. The technical solutions and educational concepts also include the environment or setting that the person lives in and which helps shape his image of himself as a psychiatric patient and the images others have of the world he lives in and his worth. Jönsson and Anderberg (1999) explain in their report on methodology:

> … problems and possibilities should be defined in their complete human and environmental context. In order for a relevant analysis to take place, one must then both break down the problem into lower levels (e.g., technically manageable levels) *and* constantly return to the original context when assessing the relevance and success of the results. And perhaps most importantly: a scientist in the field of rehabilitation engineering and design must form an image of the *prospective* reality on the basis of the *present* in that part of reality which is to be changed (including all its dependent variables).

Behind these prospective realities that are part of all development, the researcher who sets processes in motion must also be able to create internal images of a reality that as yet does not exists but which is possible. In this situation, the scientist's creativity is put to the test and it is here that his or her personal appraisal of human needs has to be spelled out.

When it comes to the habilitation services for people with physical disabilities, technical aids are a given in today's world. People with communication difficulties are offered alternative means of communication. Those who find it difficult to orient themselves in time and space are offered technical time aids and settings are created for them that are self-instructing—by being organized and designed so that it is clear what is to be done where and when. There is enough knowledge of mental disorders and their consequences for the people affected on which to base the creation of entirely different care environments than the existing ones. Cognitive assistance is a notion from the world of technology. Its effects on the care of people with cognitive limitations have been elucidated in Arne Svensk's licentiate thesis, (*Design for Cognitive Assistance*, 2001). There is no doubt that cognitive assistance needs to be transplanted into the world of psychiatry.

Very little of this kind of thinking from design and technology has penetrated the world of psychiatry, though. Actually, one of the principal reasons that this dissertation is presented at an institute of technology is that I want to establish a link between the fields of technology, education and psychiatry that in the future can be utilized to achieve technical solutions for people who have mental disabilities. In other areas of medicine, impressive technical developments have taken place, while the idea of technical aids in the field of psychiatry has barely been considered.

At the same time, I would also like to emphasize that my acclimation process to the world of technology has been surprisingly free of conflicts. Step by step, I have begun to understand that it is a matter of *implementation*, also on the abstract level. My chief interest is in the practical activities that result in development and improvement. My questions issue forth from practice and it is in practice that I want the final results to be used in order to improve life for a group of psychiatric patients. This is identical with the way technology and design formulate their problems and purposes.

In psychiatry I have, above all, found a theoretic and methodological challenge. Education, sociology and literature were the original fields of knowledge in which I learnt research methodology and where I learnt about the nature of science. In recent years, rehabilitation technology has also contributed its perspective. The research methods that were valid in education in the early 1970s when I took my first research classes are similar to those that dominate the field of medicine today—empirical studies based on statistical methods. It was with these methods that researchers thought they would find unadulterated knowledge, devoid of the human subject's values and feelings. In this approach, scientists/researchers are to divorce themselves from their own subjectivity and emerge directly into the role of objective observer of the world around them. This faith in objective knowledge still exits to a large extent in psychiatric research that, almost without exception, equates the scientific with a research design based on the experiment.

This type of research requires questions that can be dealt with in this manner. It requires hypotheses that can be validated or invalidated. Epidemiological studies are also carried out in this way; you go out into the world and find out how many there are who have whatever it is that you are studying.

It is against this background of empirical and quantitative methods that psychiatry also tries at times to place completely *atheoretical knowledge* that is said to be based on the knowledge available at the moment, which does not take a position for or against theory (Malt, 1986).

If anything, my own position on issues of methodology is based on a belief in the complexity of the world, particularly in the study of humans. Added to that are my doubts that researchers can be objective observers in the human sciences. We are schooled in a certain way of thinking from childhood and then in a compulsory educational system. That of itself steers our perception and tells us which observations are important and which are not. Clinical practice has its own control mechanisms in a professional culture that continues to shape its conception of the world and to create its own professional identity. The research world has, in turn, its codes that determine what constitutes valid research design.

From my own background as a practitioner, I have put into practice and reflected over education's view of training, teaching and learning. Practitioners create knowledge in and through their actions (Schön, 1999). The research methods to be considered when trying to establish order in complex activities in a practical organization are of a qualitative nature, based on the idea of the researcher as a co-actor in the research process. I have not tried to stand outside of the research area as an observing educational practitioner from a rehabilitation engineering environment; on the contrary, when I have stepped into the world of psychiatry to carry out research on some of its activities, I have started by gaining a concept of what this world is like from the inside—from the mental health care practitioners' perspective. Not until then have I gone on to start to examine it from my perspective.

Practical methods

The research methods that are usually available in medical and psychiatric research and for which there are seldom any alternatives are the quantitative ones. The customary design is that you select an experimental group in which you want to introduce some kind of change in a defined variable and study the differences between the experimental group and a control group on just that variable. The groups should be of the right size and matched with one another on important characteristics so that the individuals in question are as similar to one another as possible. With this type of research design you can detect certain changes on a group level, but it is of little use when you are studying the effects of change on the individual level and want to understand them in context. Above all, the fields of *learning* and *teaching* are not the kinds of simple experimental areas in which you offer instruction to one group and not to the other and then quantify the differences through test results or percentages. The processes of change that occur in the development of human knowledge and understanding do not just involve the transfer of a certain number of facts, but involve an altering interplay in which there are many variables that change during the process. A major difficulty in such cases is the formulation of hypotheses that can be tested against reality. The practical methods that I was searching for would be applicable to the following research issues:

1. What are the background reasons as to why patients with autism spectrum disorders are so difficult to understand and treat in adult psychiatry?
2. Can you better understand these patients' deficiencies in contact, communication and cognition based on theories of social learning?
3. How can you create a more individualized and focused treatment of these patients on the basis of a better understanding of their difficulties?

There were many methodological considerations behind my decision to proceed, in part with my own case study, in part by carrying out and describing an educational programme for psychiatric personnel with the aim of providing them with a better basis for their treatment of autistic patients' deficiencies in their abilities to make contact, to communicate and think.

The eight units, whose personalized staff training programmes are the topic of this dissertation, all have something in common: they had all contacted me at some time with a request to give them a lecture on autism and educational methods, or had consulted me on a few individual patients. From the start, there were more units interested in continuing education than I could accommodate due to time limitations.

Motivation played an important role in the selection process of the eight units. The staff needed to be motivated to participate in the programme and to actively contribute to putting the new knowledge into practice.

Geographical distribution was important. I wanted the clinics to be spread over different parts of the country and in larger and smaller communities. I expected that there would be differences between metropolitan and provincial psychiatry. The three areas that were represented were Södra Götaland (southern Sweden), Västra Götaland (west central Sweden) and Östra Svealand (east central Sweden). The northern part of the country was ruled out due to distance and travel costs. It was preferable that the units were within outpatient care, institutionalized care and forensic psychiatry.

Case studies

In order to gain new knowledge about individuals and the processes of change they go through, case studies and qualitative methods are more appropriate approaches than hypothesis testing and experiments. Case studies are included in qualitative research methods without actually being a method of their own (Merriam, 1988). All methods for gathering scientific information, from test to interview, can be used in a case study even if certain methods are more customary than others. There are different criteria on which to base your choice of cases. One of Bent Flyvbjerg's (1991) categories is what he calls *paradigmatic cases*: ones that are so exceptional that you could say, "If it works like this in this case, it can work like this in all." The single, extended case study that I present in this report is one of these. It deals with a patient who against all odds is now on his way out of institutionalized psychiatric care. The method I used to initiate this process was taken from rehabilitation technology: using a digital camera to take personal digital pictures that become a language, which makes the world more understandable (Jönsson & Danielsson, 2001).

Case studies deal with *interpretation in context* (Cronbach in Merriam, ibid.). What one wants to illustrate by using cases are complex situations in which it is not possible to isolate individual variables. The variables are dependent on a given context or are part of a situation involving interaction between different factors.

The special focus that case studies can have, results in this method being particularly suited for practical problem—questions, situations or difficulties that arise in everyday situations.

Case studies can be used for different purposes and are a part of a variety of research designs depending on how the case is to be used. Merriam (ibid.) discusses a list compiled by Olson, which presents various aspects or characteristics of case studies. They are:

1. *Heuristisc*, that is, they improve the reader's understanding of a phenomenon. They can explain why or how a problem arose and provide background to a given situation.
2. *Descriptive*, and so can demonstrate the complex interaction between factors in a situation. They attempt to describe in order to understand how the parts work together to build a whole.
3. *Inductive*, that is to say, concepts and hypotheses arise out of the information that one acquires during the research processes. If anything, it is new knowledge and the discovery of new connections that are interesting rather than the verification of hypotheses specified in advance.

It is these aspects of case studies that I consider legitimatize their use in this dissertation. They make it easier to understand both the parts and the whole of the problem I want to investigate; it also makes it possible to follow the process of change that I have initiated. These case studies deal not only with the patients who need to be understood by their care providers: the care providers and their process of understanding is an equally important subject to study. The patients and care providers are both part of a context made up of the clinic in which they jointly reside and in which the care providers are to treat the patients.

The contexts that need to be understood are:

1. The patients' situation: How do they understand the circumstance they find themselves in when they are the subjects of psychiatric care? What possibilities and obstacles exist for the patient with autism in understanding the treatment personnel's communication and actions?
2. Psychiatric personnel's situation: What constitutes the psychiatric care that they are going to give the patients? What do they think about the care or treatment that they provide? What resources do they have at their disposal? How prepared are they to treat patients with an autism diagnosis?
3. What can be done in the form of training so that the care providers will better understand the patients and consequently, that the patients will receive treatment on their own terms, which is particularly focused on their specific problems?

No one on the staff is an empty, unwritten page the moment that I come in contact with them. They are a number of individuals with different educational backgrounds. They all have a certain amount of experience in psychiatric care and have certain notions about what care and treatment are. They have different personalities, interests, temperaments and all this influences, of course, the way they practise their profession. They take part in the workplace camaraderie and are part of a professional culture that is shaped *on* and *by* their particular place of employment. The unit teams, in turn, are part of a bigger organization, which defines the resources and sets limitations to freedom of action. In order to understand the entire situation, I make use of interviews as a method for obtaining staff members' descriptions of themselves in their professional setting.

Methods of data collection

My entire teaching career (30 years) can be seen as a period of research preparation for this dissertation. During my time as a PhD candidate (3½ years, 2½ after my licentiate degree.), I have concentrated on education within psychiatry. This report is based on close to 40 hours of taped interviews with 33 people on eight units. In addition to these and the extended case study already mentioned, an additional six people are included whom I have worked with on my own and described.

observations and participation

The principle method for collection of the material found in this dissertation is my own participation in the settings in which the staff and patients see one another and interact on a daily basis—the psychiatric unit. In most cases, I have gone to the units to meet the staff and the training sessions have taken place in the therapy or conference rooms outside of the units so that we would not be disturbed. In all cases, though, I have been on the units part of the time on almost every occasion that I have had training sessions. I have gone through the forensic psychiatric unit's *security procedures* where the door behind must always be locked before the one in front can be opened. On the forensic psychiatric assessment units, I had to show identification and be accompanied by a guard, thus experiencing the rigorous security regulations that govern these units. I have seen the small exercise yards to which the patients were escorted; I also know from experience how it feels to work in such an environment. In that way I have gained quite a good understanding of the setting. In half of the cases, I have met the patient/s we discussed during the training sessions on one or more occasions. The personnel have, in turn, explained to the individual patient what I was doing and asked him—all of the patients were men—if he had anything against meeting me. None of the patients have been negative to this. In some cases, the contacts with the patients have been more extensive and in two cases they have gone on for several years and still continue. In these cases, I have intervened more actively in the persons' lives and met them regularly on the ward or outside of it. One of the two is the subject of the longer case study and his guardian—who is a nurse who has had long-term contact with the patient—has approved the final manuscript.

a semi-structured interview methodology

In order to gather the necessary background material for my understanding of psychiatric working methods and conditions that exist today, I have interviewed a number of people who worked on the units in question. In the selection process I have made every effort to choose people from different professional categories in the proportion that they were employed on the units. This means that mental health assistants and nurses made up the largest number of people interviewed. There are fewer occupational therapists, psychologist and psychiatrists. For purely practical reasons, most of the people interviewed were chosen because they happened to be working the days that I had already planned to interview some of the clinic's key employees. Altogether I interviewed 33 people: 4 psychiatrist, 3 psychologists, 3 occupational therapists, 1 social worker, 9 nurses and 13 assistants.

I chose to use a semi-structured interview method (Kvale, 1997), which does not just proceed from specific, pre-formulated questions but rather consists of a plan including the areas of interest to be covered (see Appendix 1). What I wanted to gain from the interviews was the staff members' own subjective descriptions of their psychiatric setting.

Since the interviews took place with people who I had met regularly for almost a year, they were more like discussions than formal interview situations. They started as planned, but there were often digressions because the people being interviewed had interesting experiences to relate that provided me with entirely new knowledge and new perspectives of the work they carried out. The length of the interviews, which were to be between 40 and 60 minutes, could take up to 80 minutes or more when the person being interviewed had material to relate that I considered extremely interesting for the dissertation.

In analysing the individuals' statements, I first sorted out the information that dealt with the development of current psychiatry as it was described and experienced by the people being interviewed. After that, I categorized the statements based on the different levels that influence treatment:

1. The individual and his/her attitude in treatment
2. The unit's approach to work and the work culture
3. Possibilities and limitations in the organization

interpretation of statements

It was often indirectly, through the personnel, that I was able to gain knowledge of the patients and their situations. I tried to relate staff descriptions of the patients to my knowledge about autism spectrum disorders. In such guidance situations the statements you get from the staff are only *true* in the sense that they reflect the staff members' subjective understandings and interpretations of the patients' behaviours. A study by Gerd Ahlström presented at the *Eighth Research Conference on Everyday Life, Quality of Life and Habilitation* (Örebro, Sweden, 13-14 March 2002), clearly demonstrated that relatives and personal assistants of people with disabilities have entirely different conceptions of the disabled person's difficulties and experiences than the person herself. It is highly likely that the differences between patients and personnel in psychiatry are even greater. Nor have I taken the personnel's statements at face value. Instead, I have assumed that the closest I could get to the truth about a patient was by attempting to interpret the narratives. I was assisted in this by my own practical experience, particularly as described in my licentiate thesis (Mandre, 1999). I also found support in the theories I have attempted to formulate about early social learning. In addition, there were all the established theories on autism to be found in the literature (Frith, 1995; Hobson, 1995; Happé, 1994; Trevarthen, 1996 and more).

documentation from the learning process

In the staff training sessions, I am the actor who initiates the learning process with the staff and guides it in a certain direction based on the narratives I have received from the personnel. After each session, the staff members write about what they have learnt. To facilitate their understanding of what I am trying to get at, I have asked them to respond to such statements as, “This was new for me in today’s session”, “I didn’t know this … ” or “In today’s session there was nothing new for me.”

In this way, I collect information from the participating staff members. I then categorize this information on its own merits, not according to any predetermined categories. The staff documentation guides the process and my interpretation develops through my efforts to find the categories that translate the new knowledge into practically applicable skills in patient work.

I subsequently supplement this documentation with *questionnaires* to gain additional information about the personnel’s previous and continued interest in autism spectrum disorders and other childhood neuropsychiatric conditions (see Appendix 2).

narrative contextual analysis

As described above, the material used in this dissertation has been collected through direct contact with personnel and patients who participated in my staff training sessions. The staff’s written documentation reflects the different ways they interpret what we have dealt with during the sessions; the interviews I have carried out reveal aspects of how the individuals experience their professional reality. I then analyse and assemble these many impressions to produce an overall picture of the unit, the clinic and finally, the generalized concept of “Psychiatry in relationship to patients with autism spectrum disorders”. I have applied a *contextual analysis* method in the interpretation and analysis of the material, because the contexts I am trying to understand are so complex.

Contextual analysis starts with a specific and limited entity in which one looks for relationships and their significance in relation to one another and to the whole. The available data is interpreted not only through categorization but is extended to include the relationships between the different categories as well (Svensson, 1985). In an attempt to understand the background of present-day treatment methods, I study the history of psychiatry. I examine the situation of mentally disabled people through history in order to understand the current situation for patients who have autism. I enter into the psychiatric settings myself and start to train the staff so as to provide them with a new perspective on this patient group. It is in this environment that my understanding of the system gradually increases. Through the insights gained on location, I can then ask additional questions in interviews and questionnaires based on observations I have made of certain correlations.

In a qualitative analysis you have little use of linear thinking involving simple, fixed statements of cause and effect based on isolated variables. If anything, a linear way of thinking which disregards the context can hinder understanding of a phenomenon. If I had tried to isolate variables in my staff training, I could have formulated a number of hypotheses concerning who was going to learn what and in what manner, but I would not have gained the overall picture that I was after. In the study of human relationships, you have to take into account that people mutually influence one another in ways that can be paradoxical and unpredictable. There can be crucial factors affecting the results that you have not even considered. In a qualitative analysis, you are constantly alternating between the whole and its components, between concrete events in realty and the abstractions of them. In this matter, different perspectives give different results. (Patton in Merriam, 1988; Ejvegård, 1996).

In the presentation of this material, I have chosen a narrative style, closer to that of fiction. Steiner Kvale (1997) sees the analysis of an interview as a continuation of the story that was told by the persons interviewed—a narration. This narrative analysis develops a primordial story and its theme and many such stories together are combined into an entirety that in this case is *Psychiatry's relationship to patients with autism spectrum disorders*. Kvale (ibid.) emphasizes that psychological research (just as well as educational and rehabilitation-technological research, [author's comment]) under ideal conditions creates scientific knowledge that is both sustainable and of value to the potential users. According to Kvale (ibid.) there is a conflict between the demands of research and those of the public as to how results should be presented. Users who are practitioners will be able to identify themselves through a captivating story while the research world requires a more formal presentation of methods and results. It is between these different demands for reporting that I have tried to manoeuvre the story of my encounter with psychiatry in an educational context.

5. Learning through social interaction

It takes a special understanding on the part of the staff for adults admitted to psychiatric units for assessment or treatment who are suspected of having autism spectrum disorders. The personnel need to try and put themselves in the distinctively different psychological development that these adults went through as children. In the assessment and treatment process, they have to take into consideration the different way that these people have of relating to the clinic's personnel and not assume that they understand what assessment and treatment are all about.

The significance of social learning

The childhood development of adults with an *autism spectrum* diagnosis is characterized by considerably less social interaction than that of normally developing children. Thus, an understanding of the normal infant's capabilities for social interaction is crucial for understanding the psychological development that occurs when conditions are other than normal. These capabilities are so significant that we speak today of *the social infant*. Many mothers of children with autism can describe how they experienced at a very early stage that there was *something* about the child that they were unable to put their finger on. That *something* has since lived on as a silent suspicion that over time has increasingly confirmed the mothers' forebodings, but that outsiders have had difficulties observing. The same mothers can also recount conversations they had with the pediatric clinic personnel and pediatricians who dismissed their diffuse misgivings that something was wrong with the child. They have pointed out the child's normal development concerning such milestones as sitting, crawling, standing and speaking single words or communicative phrases at the right time. "The right time" may have been a bit delayed, but there were also explanations for that such as, "children are so different" or "you shouldn't compare children with one another." It is also possible to find comforting support in the statistical variation that exists concerning children's maturity and development of skills—there is a fairly wide variation in the maturation of different skills in small children.

In this chapter, I will attempt an explanation of the diffuse uneasiness that many mothers whose children later are diagnosed as being autistic feel about their children's development early on. The words of comfort that doctors and pediatric clinic staff offer these mothers are understandable when you examine how the knowledge on which these theories of child development was established.

different research worlds—different knowledge

Theories on infant and child development have come into being as the result of research traditions that have often lived parallel existences and in which the theories have dealt with different aspects of child development. Developmental psychologists have examined the maturity milestones of the nervous systems and have often made use of physiological experiments to map out the infant's reactions to different stimulation of the senses. The significance of physiological maturity in the development of a variety of abilities has been studied and described in relation to age. The forerunners in this area are international, among them Arnold Gesell and Charlotte Bühler (Gästrin, 1967).

Simultaneously, reconstructions of the child's emotional life from the adult patients' psychotherapy were developed out of the psychoanalytic theories of Freud. In this case, it was the study of the pathological that formed the basis for theories of normal development. The child therapists who followed in Freud's footsteps used similar reconstructions in their therapies.

Daniel Stern (1985) describes it as follows:

> In contrast to the infant as observed by developmental psychology a different "infant" has been reconstructed by psychoanalytic theories in the course of clinical practice (primarily with adults). This infant is the joint creation of two people, the adult who grew up to become a psychiatric patient and the therapist, who has a theory about infant experience. This recreated infant is made up of memories, present re-enactments in the transference, and theoretically guided interpretations. I call this creation the *clinical infant*, to be distinguished from the *observed infant*, whose behaviour is examined at the very time of occurrence.

Stern continues the comparison:

> Up to that point, the observed infant concerned mostly non-social encounters: physical landmarks like sitting and grasping, the emergence of capacities for perceiving and thinking about objects. The clinical infant, on the other hand, has always concerned the social world as subjectively experienced. As long as these two infants involved different issues, they could go their own ways. Their coexistence was non-problematic and their collaborative potential was small.

The psychoanalytic theories were further developed through psychodynamic object relational theories that continued along the lines of Freud, but that took as their point of departure *object relationships* as the basis of the child's mental development. By this they meant primarily how relationships to important people in the child's surroundings were internalized and became the child's own internal mental structures. According to these theories, the basis of abnormal development in the child could be found in the occurrence of a *fixation* on one of the earlier phases or that the child did not go through such a phase in a satisfactory manner. The child was seen in all of these theories as being passive from the start and surrounded by a stimulus barrier. The child lived in an objectless state, that is to say, in a state where it had no interaction with its surroundings. From that first relationless, diffusely experienced state, the child gradually starts to be differentiated as an individual, but this development occurs by means of a symbiotic attachment to the mother (Mangs & Martell, 1976). Mahler, for example, saw the newborn baby as being enclosed in an autistic shell. It was through the activity of the mother that the child could attach to her and progress to the symbiotic phase (ibid.). If the bonding took place incorrectly, the child could be left behind in the autistic phase, which was considered as being a causal explanation of *autism* until quite recently among psychodynamic/analytic oriented psychologists and psychiatrists. They felt that is was the mother who had been incapable of properly bonding with the child.

Along side these theories, the cognitive development of children was also being studied. Among the researchers who have had the greatest influence on educational development in this respect in Sweden is Jean Piaget (Tryphon & Vonèche, 1996). Piaget's contributions deal with the significance of concept formation in the development of higher thought processes, particularly logical and mathematical thinking. Especially important were his observations that a given degree of physiological maturity was necessary for a child to be able to form concepts at a given mental level. Through this approach, Piaget's influence on educational methods in pre- and elementary school has resulted in a greater awareness that a child needs to reach a certain level of mental maturity before he or she can learn to read or start learning certain school subjects. The shortcomings in Piaget's research were that the children he studied appeared to live in a social vacuum and did not seem to be engaged in interaction with other individuals or the culture that they were a part of.

Piaget's theories, just as most of the other theories on child development prevalent during a good part of the 20th century, have ignored the child as a social individual. Those who at that time had another approach and were carrying out research based on entirely different hypotheses were to be found in the young Soviet Union. Their research results, however, were not made known in the West until long after they had been published and not until the world of Western research was prepared to accept such an approach. These researchers were Lev Vygotsky and Alexander Luria who were productive primarily in the 1920s and 30s. They demonstrated in a considerable number of experiments how perception was steered by social and cultural concepts (Luria, 1976). Vygotsky has also shown how mental processes develop through learning (Bråten, 1998) and how interwoven the development of cognition is with the cultural concepts surrounding the child. Adults who lived in isolated villages and had not received any schooling did not develop their thought processes any further than they needed for what was situation-bound and concrete in their everyday lives and work. When the villagers moved to the agricultural collectives and had to co-operate with others, their thought processes also developed from being egocentric to being able to see things from different perspectives. Vygotsky and Luria also found that self-reflection and understanding of psychological qualities were, to a high degree, associated with the social conditions under which the individuals lived.

Vygotsky has influenced many subsequent researchers to study the significance of social interaction in child development. Jerome Bruner, an American researcher has also been influenced by Vygotsky's approach. When Bruner speaks of interaction he is not just concerned with the learning that occurs through human and cultural mediation, but also of interaction in the wider sense—as interplay between the individual's biological equipment and the influence from his surroundings (Bruner & Bornstein, 1989). Bruner criticizes research that approaches human development as something that only exits inside the skin of the individual. If anything, he takes a social anthropological approach and points out how much of the socialization of children has to do with the child's introduction into the culture's symbolic concepts. The child's view of how the world is constructed is not only concerned with having the experience of something that he or she remembers later on and learns to connect with previous knowledge as in Piaget's model. According to Piaget, the child *assimilates* something new and then finds a place for it among previous conceptions by *accommodating* the new knowledge so that it changes something of the old way of thinking and in that way builds a new concept. What Bruner finds lacking in this approach is that there are no *pure* perceptions and experiences. Perceptions are guided from a very early age to conform to the culture's concepts of how the world is constructed (ibid.)

Bruner also points out that the choice of research methods determines to a large extent what you see and the results you achieve. Interaction is not easily measured in *before* and *after* studies in which you examine how the influence of one variable produces a certain effect. There are many variables in social interplay. In studies of child-parent interaction it is not just the parents who effect change in their child, but the child who influences the parents' behaviour as well. Bruner calls for research methods in which the researcher much more unconditionally tries to come up with knowledge that is not just based on the simple and direct cause-effect relationships that you are able to gain from the analyses of variables (ibid.).

the social infant

The new approaches that Bruner and his colleagues called for were consequently developed in the new research methods of the 1970s and 80s. Research questions were formulated in a different manner than before and scientists started to use new technology such as video filming. This made it possible for them to observe behaviours that had previously been inaccessible in early infant research.

Daniel Stern (1985) is one of these new researchers who try to unite the knowledge gained from several different theories. He is psychoanalytically schooled and his main perspective is also based on the ego development of the child. To this, he has added the perspective of developmental psychology. In this way, he has broadened the scope of his research and sees child development as a process in which all aspects are connected and dependent upon one another. Physical growth and motor development offer the child new opportunities for physical activity and new experiences that result in an inner sense of core self as acting and experiencing on increasingly more mature levels. As the ability to relate changes, relationships gain new qualities and thus contribute to changes in the sense of self. In this development there is a subjective *self* that experiences the qualitative changes of social interaction and coherence in existence. Stern does not see these changing senses of self and the development of subjective experiences as phases that are replaced by new and more mature ones, but as an ongoing reorganization process that continues throughout a person's life and that contains all the more immature stages within itself.

By making use of video technology, Stern and his colleagues have studied infants in natural interactive situations and could see that they, by no means, live in some kind of diffuse and relationless existence. This was in contrast to what many had previously concluded based on experimental situations in laboratory environments and through conclusions drawn from adult therapeutic, after-the-fact reconstructions. The questions that are now being asked in more recent research on infant abilities are receiving more active answers from the child himself as investigators make use of the abilities a child has to provide the answers on his own. Infants that are just a few months old, for example, can respond with a fixed gaze, with eye movements and by sucking at different intensities.

Stern (ibid.) demonstrates in this manner that infants have a number of innate abilities with which they start to orientate themselves in the world quite soon after birth. Infants less than a month old can imitate someone who opens her mouth or sticks out her tongue and can respond with sound and hand movements. This also means that the infant has an innate ability to translate information from one sensory channel to another, that is, to take in visual or auditory impressions and transform them to motor actions. In natural interaction, it is not only the child who imitates the mother, but also the mother who just as often imitates the child in a unconscious tactic that mothers often have for mirroring their infants. The infant, by responding, causes the mother to respond in return in such a way as if the child already in gesture and sound had intentions for what he was doing and as if he had willing and conscious motives. The mother starts to speak *to* the child and *about* the child as if the child already had consciousness and will.

In experimental situations where mothers react in ways that in normal interaction are entirely irrelevant or when they suddenly stop their involvement in the communication chain, two-month-old infants react by immediately displaying clear signs of frustration—they make faces, avoid eye contact and show that they need to be comforted (Trevarthen in Olson, 1980).

What an infant is *able* to do during the first months of life is direct his eyes, focus his gaze, listen for sound, and use his mouth and hands. Hands are ready to be stretched out; feet are ready to make walking motions. The face has a repertory of expressions for different emotions such as happiness, surprise, alarm and fear. The infant also has distinct emotional patterns of expression to show agitation or interest, to withdraw from an activity, etc. The infant is primarily motivated to interact with other people. This is not a skill that has to be learnt or conveyed by anyone else. During these exercises in his first months of life, the child is establishing a range of social abilities, including: taking the initiative in interaction with others, adapting to the rhythm of another human being, having certain expectations of what another person is going to do, and adjusting to turn taking when interacting with others. Even though the infant has immature perceptions and limited possibilities to act, he or she is mentally equipped at a fairly high level. The child finds it meaningful to communicate with others and has an inner drive to increase his repertoire of communicative actions. Based on these first pre-conversational exercises with other people, a kind of proto-conversation develops. Trevarthen relates (in Olson, 1980) Bateson's account of such a proto-conversation between mother and infant in a study from 1971 in which the mother and infant took turns speaking. At that time it was considered a strange result, since most studies still considered an infant less than three months of age to be only a creature of reflexes, reacting to stimuli in a purely physiological manner.

The infant's activities during the first months of life consist of establishing relationships with close family members and in becoming more skilful in communicating with them. Play during this period is something that takes place face-to-face with another person and is made up of small talk, smiling and games with the child's hands, feet and body. After about four months, the child changes perspectives and starts to take a greater interest in the world of objects. Eye-hand co-ordination is now such that the child can reach for objects and he starts, for shorter or longer periods, to pull away from direct face-to-face interaction in order to concentrate on his own activities that involve learning about the world outside of the one-to-one relationship.

Nonverbal communication, such as eye contact, facial expressions and gestures, takes up a large portion of the child's waking hours during the first six months. In the interplay with the mother, face-to-face, it is eye contact, turn taking, initiating of interaction and expectations of the other's response that steers the child towards a social existence with other people. Children with autism display deficiencies in all areas that the normal infant practises intensively during these first months of life. Lack of training and practice in interacting with other people produces the autism criteria:

- Significantly limited nonverbal communication skills such as eye contact, facial expressions and gestures.
- Lack of interest in sharing fun and interests with others or in participating in play and co-operative activities with others.
- Deficiencies in social or emotional reciprocity.
- Reduced communication abilities.

When video technology has been used to examine the social interaction of autistic children, researchers have, for natural reasons, not been able to film in the same manner as in other studies where long sequences of the child-mother interaction have been recorded. It is uncommon that autism is diagnosed during the first year of life, which is why researchers have had to settle on examining home movies after the fact. The information thus gleaned is limited since they only have access to material the family, for whatever reasons, decided to film. Interactive sequences can be few and less elucidatory for the purposes of studying an activity after the fact.

In a collaborative effort between Cornell Medical Center, New York University; the Scientific Institute Stella Maris, Division of Child Neuropsychiatry, University of Pisa; and IUPG in Geneva (Stern et al., 2001), home videos were examined. The first two years of development of fifteen children who were later diagnosed as being autistic were studied and compared with fifteen normally developing children. The videos were mixed so that it was impossible to determine which were of children with autism and which were not. They were then judged according to the *Grid for the Assessment of Normal Behaviour in Infants and Toddlers*. This screening instrument was constructed specifically for the study and was based on previous findings indicating that infants display social competence at an early age. The study focused on three developmental areas: *social competence*, *intersubjectivity* and *symbolic activity*. The child's behaviour was analysed by examining the family videos when the child was 0–6, 6–12, 12–18 and 18–24 months old. The differences between the two groups that could be detected during the first six months of life were that the children with autism displayed to a lesser degree that they understood the pointing function and showed to a lesser degree expectation of something that someone else was about to do. During the next six-month period, the greatest difference was in the lack of declarative pointing, that is to say, the autistic child did not point in order to draw the attention of others to something he or she thought was interesting. At eighteen months, the differences dealt with deficiencies in joint attention, lack of communicative gestures and meaningful vocalizations. What the authors found to be most noticeable in the lowest age groups was that there were no significant differences between the groups who later developed normally and those who developed autism in *social competence*, that is, eye contact, smiling, babbling and expressions of pleasure in being with their mothers and other close family members.

Stern et al. draw the following conclusions from their material: That which appears to be disturbed in children with autism is not primarily the ability to make eye contact or to smile socially at their caregivers but instead it is the ability to interact with someone else. This basic social contact does not develop into dialogue and the difference between the two groups of children increases significantly when symbolic functions start to gain greater importance. The difference between the groups also increases as the normally developing children become increasingly more proficient in all areas while those with autism develop more slowly in all respects concerning social interaction. The authors feel it is necessary to study development in depth during the first year of life, since autistic children in the first months display periods that are free from autistic symptoms. In that respect, the authors see hope for much earlier intervention than is currently possible and in trying to get the child's development going on the right track.

In another study (Adamson et al., 2001), young boys diagnosed as being autistic before three years of age were compared with typically developing boys around 20 months of age. The investigators chose to examine the differences between both groups in mother-child interaction. The mothers were all assigned the same communication activities to which they were to invite their sons to participate. What they wanted to compare was: 1) the degree to which the children could share verbal comments with their mothers when they looked at pictures or searched for hidden objects, for example, 2) turn taking in social interaction, and 3) whether the children could request something they were unable to reach themselves.

The activities were filmed and the analysis showed that the typically developing toddlers were best at participating with interest in their mothers' attention-regulating comments about pictures and objects. Mothers of children with autism best caught their sons' attention with things that did not require any spoken comment. One surprising result was that there were quite a few children in both groups who declined communication attempts, 33 and 31% respectively, of which the first-mentioned was for children with autism. There was, however, a higher percentage of children in the autistic group who were unaware of the mothers' attempts, 14 % as opposed 3% of the typical one. There were also more children in the autistic group who actively rejected their mothers' attempts at interaction, 12% as opposed to 6%. Only one child with autism totally rejected or ignored all of the mother's attempts to make contact. The authors wanted not only to demonstrate that there are degrees of difference between children with autism and children without concerning social interaction with their mothers, but to also show that such interaction does not run smoothly of its own accord even in normal children. It apparently requires a lot from the mothers to find the right ways to achieve shared attention during social interactions with their children, which the mothers of children who have autism also demonstrated by putting more effort and time into initiating communication. The study also shows that an extra sensitivity is required on the part of the mothers to initiate and maintain the child's attention on what they are doing at the moment.

These studies along with the current plethora of theories on the causes and symptoms of autism (Gillberg & Peeters, 1995; Frith, 1994, 1995; Wing in Frith, 1995; Hobson, 1995: Happé, 1994; Trevarthen et al., 1996; Kristiansen, 2000; Cotterill, 1994, etc.) demonstrate that the autistic child's communication and learning, even at a very early age, differ from the normal child's. The autistic child's lack of intersubjectivity in concept learning, as well as deficiencies in symbolic function, result in a development devoid of *the other person*. As was shown in the last section on Vygotsky's model, what is required is learning that begins with the social dimension. Language and symbols are shared in social and cultural groupings and can never be individual. Those who have their own individual interpretation of symbols end up outside of the social community.

It is through social interaction that the child learns the meaning of words and other symbols, while it is the child's own internal reconstruction that transforms them into knowledge. Words have many definitions that vary according to the context in which they are used. They can be pronounced with the stress on different syllables, be emotionally charged in different ways and have different purposes; all of these variations alter the content and meaning of language. Just learning words and their relative positioning through grammatical and syntactical rules without having reconstructed what they mean is not sufficient to establish the basis for communication with other people. The autistic child's difficulties in using symbols in interaction with others results in the autism criteria:

> Noticeable difficulties, in spite of adequate speech, in being able to initiate and maintain a conversation with others: monologues instead of conversations.

The increasing number of children and adults with the autism diagnosis are far from a homogeneous group. This also means that communication cannot be simply classified as either being normal or abnormal. In between you will find an endless number of nuances and you need to keep in mind that communication always involves at least two people. As Adamson, McArthur and others have demonstrated, communication abilities are not only a question of an adult starting a chain of communication and a child responding to the adult's attempt. Adult conversational partners also differ in their abilities to elicit responses and interest from the child. They may not have the patience to keep up the effort of trying to reach a child who has difficulties understanding or who is not interested in what the adult has to say at the moment. It requires more patience and imagination of the person attempting to initiate communication with a person—child or adult—who from the start has problems understanding social interaction.

the subjective sense of self

From the constructions about the infant that are described in the theories of the *observed* infant and the *clinical* infant, Daniel Stern (1985) goes a step further in the understanding of the inner world of the infant. He attempts to construct the child's subjective sense of *self* and in that way tries to understand the infant's own inner mental sense of itself. Stern is of the opinion that studies of the infant's capacities do not reveal anything about the way in which the infant experiences his or her inner world. Constructing the infant's intrapsychic and subjective experience of *self* is also a construct just like the other constructed infants, but Stern sees that as being justified because every new aspect that one can add to previous knowledge of infant development contributes something that the others lack. What the intrapsychic perspective contributes is an understanding of how external, observable events take form internally when, "mamma did this," "mamma said that," are transformed into the subjective experiences of, "I experienced that mamma did this; that mamma said that." It is in these experiences that the infant's own life narrative starts to be told—first through nonverbal experiences and then through an inner monologue that continues throughout life.

According to Stern (ibid.), four self-experiences are needed to form an organized sense of a core self, and in that way gain a feeling of being one and the same person independent of external events.

He calls the first *self-agency,* which is when the child starts to understand that his own actions influence the world and that he can influence things through deliberate actions. The infant gradually begins to experience that his actions have consequences.

The second self-experience is called *self-coherence,* that is, the feeling of being a coherent person with both the external physical limitations of one's own body and the internal feeling of being a subject.

To the inner self-experiences is added the feeling that it is *I* who feels and experiences and that these feelings and experiences are connected to my other experiences and action—*self-affectivity*.

Based on a feeling of continuity in the flow of events around the self, a sense of *self-history* grows, which means that the self starts to gain experiences, see patterns and construct a self-image in which the self starts telling his or her life history. In this early phase of life, experiences are nonverbal. Gradually, as language appears on the scene, experiences are transformed into linguistic and conscious experiences. Stern maintains that the sense of self is not primarily a cognitive construction but an integration of experiences and this first *core-self* becomes the foundation for the entire development of the sense of self over time.

Stern also tries to place psychiatric conditions in his theory of subjective sense of self in order to see which of the four self-experiences are deficient or absent. S*elf-agency* is absent in catatonia where action has completely ceased, and in some forms of paranoia where the patient feels deprived of freedom of action by something or someone. The absence of *self-coherence* can be manifest in certain psychotic states in which the patient experiences personality fragmentation. Absence of *self-affectivity* can be seen in the schizophrenic's emotional extremes.

Autism can also be added to Stern's list, where deficiencies in the area of *self-affectivity* are the greatest. In the case description of Emil, I will show that he has no clear sense of *self-agency*. A number of patients I have met also feel they are victims of the actions of others, and that the only way they can act on their own is to *strike out* or be obstinate. To obstruct and be difficult can become a life style for a person who is unable to come up with other strategies. It can also develop into a paranoid attitude towards life in which the evil world out there "forces" the person to strike first or avenge real or imaginative injustices. The person feels he has no alternative. Because the person has difficulties in seeing the bigger picture and in managing situations of choice, this can result in his actions being characterized by chance solutions with no basis in an overall plan. Rather, they are a way of dealing with the immediate, troublesome situation. Insufficient impulse control and a low stress threshold can also result in a person acting rashly and fragmented in chance situations rather than reasonably. Even one's own life story, which is a continuous, on-going inner monologue, is more fragmented and less coherent in people with autism. This is because the inner monologue does not update the perception of self-in-the-world to the same extent, and that social interaction is of less importance for the establishment of self-image. I have, on a few occasions, asked people with autism to write their life stories. They often consist of factual information about the place of birth, parents and siblings, schooling, further studies and the like. When I have asked them if they could fill in with more descriptions of events, places and people, I have often encountered indifference and comments that such additions are of no interest.

As will be seen in the case description of Emil, the life story of a person who finds it difficult to evoke thoughts and associations can be very fragmented. Not until Emil is able to see a picture that provides associations can he relate something. Likewise, he can answer if people ask him about details in his life.

the learning child

When the child has learnt to gain better control over his body and by means of an ever increasing repertoire of movements can acquire knowledge about the physical world, he again starts to direct his attention to his closest family members through interaction that he can now initiate on his own and master at a higher level. When the child is 8–9 months old, he starts to be more observant of familiar and unfamiliar people. He starts to take in others perspectives of new phenomena by asking nonverbal questions of those closest to him. When the child encounters something that he has not experienced before, he first looks at his mother's face to see how she reacts before he knows what attitude he should have (Trevarthen in Olsen, 1980). In the following account I will present examples of a young child's development and compare them with that of adult psychiatric patients' to illustrate the intuitive and spontaneous learning that occurs in typically developing children.

From the world of the young child (E. Mandre):

> Ella, 8 months old, is visiting a farm for a week in the summer and her maternal grandmother is carrying her when some clucking chickens run up to them. Ella immediately looks at her grandmother's face to see her reaction. When grandmother laughs and smiles, Ella accepts that the chickens are not dangerous. She learns a lot about chickens that week. Each morning they have to be fed from a special pan. Sometimes they fly and sometimes they walk on the ground. Sometimes they cluck and sometimes they crow. They can fly up and sit on the fence or in a tree. And grandmother is happy and not afraid of the chickens. All that the chickens do and the reactions they elicit influence Ella. However, the word *chicken* does not yet have an effect on her. And above all, this word has no meaning when someone says it outside of the context in which the chickens exist.

From the world of psychiatry (E. Mandre):

> I often talk with Erik, 40 years old, and try to describe for him what it means <u>not</u> to understand the perspectives of others. He knows that other people understand something that he doesn't. Then I describe for him how infants take in the perspectives of others about different phenomena. I draw a triangle with an adult, a child and an object. I try to give Erik an idea of how you can understand what others are thinking and feeling by explaining how the child, who see something new, first looks at the adult and then decides her own attitude and feeling for what is new through that of the adult's. Erik starts to realize that it is possible to understand other people's inner state based on their exterior actions and he becomes more and more observant of other people. Something in Erik slowly starts to change.

The interaction the child now has with the mother and other close family members enables their perspectives to become a part of the child's own comprehension of the world. The child becomes a mobile and active agent in the world, testing how other people and objects function. She does this by manipulating objects, by imitating and through others showing her how to do something. Early in life, the young child is also able to draw her own conclusions and make some generalizations.

From the world of the young child (E. Mandre):

> Ella, 1 year old, has emptied her small box of blocks on to the floor and tries to stack them. When she has put the blocks in different combinations for a while, grandmother turns the box upside down and places a couple of blocks under the short end. The box now has a slanting surface and grandmother shows how the blocks that are placed on the surface slide down and fall on the floor. Ella watches at first with great amazement. Then she tests it out herself and the blocks slide down, one after the other. Suddenly Ella stands up and tries to sit on the box and slide down herself. She has now understood that the blocks slide according to the same principle that makes it possible for her to go down the slide when she visits the park.

Such learning did not take place because Ella suddenly was mature enough to generalize, as Piaget would explain it. Rather, in this instance we can make use of Vygotsky's theory of *the closest developmental zone* (Bråten, 1998). This is the area that lies between the child's own actual problem-solving abilities and that which the child can manage when he gets some help. On her own, Ella would not have come upon the idea of constructing a slanting surface, but when it was constructed and the principle demonstrated, her ability to generalize was such that she could make a comparison between the new phenomenon and the very familiar slide in the park. This educational theory is based on the principle that learning fosters the maturation of thought processes through the assistance provided by the good teacher. The teacher aids the child in progressing in her mental development by providing the right help along the way, which enables the child to come up with a solution on her own.

From the world of psychiatry (E. Mandre):

> Interaction with Emil, 50 years old, which began after his first encounter with my digital camera, deals to a large extent with creating such developmental zones. Emil's mental world was empty and monotonous all the years he lived isolated on a ward in the big hospital. By giving him pictures that provide associations and thoughts, you can ask questions and present problems that he can solve himself. From the one example of learning how to send birthday cards, Emil was able to generalize to sending Easter and Christmas cards as well. He would never have come up with the idea on his own and without the example, however.

Vygotsky (Bråten, 1998; Luria, 1976; Vygotsky, 1981) views social interaction as a prerequisite for the development of higher mental processes to take place. He views the lower processes as being innate. They are based on a concrete and situationally bound reality, and actions are immediate and not mediated by language.

The higher processes include such things as culturally borne cognitive tools like the use of language, writing, creative activities, art, mathematics, etc. He sees the higher and lower mental processes as being qualitatively separated: the higher processes do not develop from the corresponding lower ones, but are instead an entirely new form of thought. Vygotsky actually views all higher process learning as being mediated by social interaction and cultural symbols. This means that every function in the child's development is learnt twice. First the child learns on the social level through interaction with others. This social knowledge and way of thinking are then transferred to the child's inner world and the social thinking becomes the child's own internally. This does not mean that one can just transfer a given amount of knowledge to the infant which is internalized and directly becomes the child's own, but rather that the internalization process in and of itself produces thinking on a higher level as it is transformed into the child's own, individual knowledge. Thus, the general knowledge that makes up the external world needs to be internally reconstructed.

When the infant has internalized the forms of the language, Vygotsky sees the most important step in the development of thought to be when concrete, practical activities and problem solving converge in speech; inner speech starts to control perception and actions. A child who can use speech to organize his actions no longer is living in the present but can compare the actions of the present with those of the past. The symbols of language give thinking the liberty to select parts, making it possible to plan by using symbols instead of acting directly on the immediate, concrete reality. Language also offers the opportunity to plan and prepare solutions. In this way, actions are not as impulsive as they were before.

Through the acquisition of an inner language, the child gains the additional function of being able to self-monitor. Language provides self-awareness and the ability for self-reflection. This ability, however, presupposes social awareness. Ratner (1991) expresses it in the following manner:

> Human consciousness is great because it is social, and social life is great because it is conscious. To become advanced, sociality—i.e., social concern and understanding, communication and planned, extended conjoint action—requires consciousness. Conversely, consciousness requires the social stimulation of complex social relations, knowledge amassed by other individuals, symbols derived from social communication, and deliberation that is necessitated by considering the desires and responses of others. Social consciousness and conscious sociality are two sides of the same coin.

From the school world (E. Mandre):

> Jeanette is a 10-year-old girl with autism. When she begins talking, it is first in one-word sentences that she uses when she wants something. Gradually her language starts to become her internal conscious and one day I hear her talking inside one of the school's storage areas where fruit is kept. I hear her repeating the words "no, no." When I open the door, Jeanette is eating an apple, well aware that she is not allowed to until snack time later in the day. The words that have been imprinted in her by others when doing something she shouldn't, she is now saying herself, and yet they do not stop her from doing what is not allowed.

The function of inner language for many people with autism appears to be different from that of normally developing people. The ongoing inner monologue in the thoughts of most people appears to be lacking in many of those with autism. They describe how their heads are empty of thoughts and that the only thoughts that spontaneously occur in the emptiness are obsessive ones or ones that have gotten stuck and keep going around and around in a closed circuit.

From the world of psychiatry (E. Mandre):

> Emil is 50 years old and has a thought vacuum as well as a lack of associations. This situation can be helped with pictures and with other people's thoughts. Emil's thoughts are almost exclusively steered by action, not the other way around. He finds it difficult to keep up a self-reflective, inner monologue. His actions are to a large extent impulsive and the tendency in situations that he can't manage is to choose the first action alternative that comes to mind without trying to determine if it is the best. Sten, a university student diagnosed as being autistic, says when asked about his inner monologue: "When I am alone, I just have no other thoughts than the obsessive ones … that's why I am so dependent on company!" He also describes his self-image as role-playing in different situations, "My self-image is a mental construction that requires a lot of hard, mental effort."

Vygotsky presents four stages in development that the child has to go through to be able to think in concepts and abstract categories (Bråten, 1998). He calls the first stage in the child's thinking *the primitive stage*. Mental activity takes place in the form of *syncretic images*. By this, Vygotsky means that the child's perceptions consist of incidental inner images that arise in here-and-now situations. Direct perception steers experiences and memory tells whether something is familiar or not. The body has a memory of having performed a movement before and there are memories of social interaction and its rules. Images and memories are subjective and incidental and constructed for the moment. When something is no longer in view, it is no longer in thought either. The child's actions are steered by the immediate perception, which as of yet does not have any connection with the socially constructed categories. Perception leads to actions which are not controlled by any kind of conscious planning. It is action that steers thought and not the opposite. The purpose of what the child is doing is established in the moment. It is during this phase that the child's primary activity is to establish communication with the outside world and to receive confirmation for her communication attempts. Reactions from people in the surroundings to these early attempts at communication are crucial for how the child will develop her ability to act according to her own intentions and if she can initiate a dialogue with the outside world. Ella is at this stage when she encounters the chickens.

From the world of psychiatry (E. Mandre):

> Emil at 50 years of age is still in an earlier developmental phase cognitively, one in which the world is made up of situations in the here and now. He has fifty years of life experiences but they are not firmly anchored in a social context. In addition to the activities that have become habits and routines, Emil's world and life experiences consist of notions that are entirely his own. When adults like Emil explain the world as they see it in a completely idiosyncratic manner, they sound delusional. Emil looks out through the window on a warm August day and says: "It's strange that the leaves are so green on the tree outside. When I was growing up, leaves were black." This statement seems quite strange at first, but when I tell him that I don't understand what he means, he tries to explain: "I don't like it when the sun shines so I usually sit in the shade of a tree." He thinks it over a bit more and then says: "Or maybe there were other kinds of trees when I was growing up."

When the child progresses to *the naive* stage, there is a shift from the entirely subjective towards a set of answers and reactions that are learnt from the way the child's environment responds. Connections with objects in the world are no longer by chance, only arising in the here and now, but fixed relationships are starting to be established between different objects. Certain sound combinations are always articulated when the child lays her eyes on a certain phenomenon, for example.

From the world of the young child (E. Mandre):

> When grandmother comes to visit, she always takes Ella for a walk to the lake to feed the birds. When Ella was 8-9 months old, there was no connection between the bag of bread that was put in the baby carriage when she went out with grandmother and the big swans that were soon to come to take the bread from grandmother's hand. When Ella was a year old, though, the entire ceremony of grandmother coming, Ella putting on her overalls, bringing the bread bag along and grandmother saying, "Now we are going to feed the swans. . . the swans that say 'sssss'", had acquired meaning in which the entire sequence of actions reminded her of something she had done before.

Thought is based on concrete connections and actual similarities. The large white bird that flaps its wings vehemently and hisses when there is no more bread has the designation *swan*. Yet the swan is not yet a *bird*. All shaggy, four-legged creatures that walk next to people and seem to be somehow attached to them with a rope have the designation *dog*, no matter if they are little and shaggy or big and short-haired, white with black spots or entirely black. A premonition that all phenomena in the world belong in larger categories is perceptible and during the first year of life, the infant's ability to arrange phenomena according to objective principles that no longer bind them to space and time develops. The principle of categorizing is trained and tested. The child can sit at home on the couch and point at pictures in a book and recall the memory of *swan* or *dog*.

Thought starts gradually to precede action and it is also possible to plan an action that the child knows will have a certain effect. When Ella pulls out the plug from the wall when mum is listening to music, she has, at the moment of carrying out the action, an expectation that mum will react strongly. It was exactly that reaction which was the purpose of the action. Gradually, Ella's own inner language will steer her actions so that she stops pulling out cords. The greater the significance language has for Ella, the more she will be able to make generalizations that are connected to the socio-cultural environment in which she is growing up. The child first acquires established connections between objects and words. In that way, the child and adult have linguistic symbols in common that tie them to the cultural context in which they are situated. When grandmother says *swan*, the meaning of the word is the same for both of them. When mum says, "No, no, don't touch the cord!" they both know what it means. The child thinks in other structures, but the words call forth the same image for both of them.

From the school world (E. Mandre):

> Adults diagnosed as having high-functioning autism can be extremely irritating for the staff when they, just like Ella, are out to get a reaction. Magnus is 24 years old when he is a student of mine in adult education. One summer, during a three-week course at a folk high school, he tries the patience of all the teachers to the utmost. He takes the greatest pleasure in exasperating the staff in different ways and finds the changes in facial expressions that his antics cause to be most entertaining.
>
> On the last day of class, we plan to celebrate by having lunch together. Magnus has been given the assignment of going grocery shopping, but when the time comes, he refuses. Attempts to persuade him are to no avail and he runs away from the school and hides in a grove of trees. Two other people do the shopping instead. I try to play off his conscience by pointing out that there are two women who have to carry the heavy grocery bags instead of a man with his strong arms. Magnus counters my arguments with a more theoretical contribution: "I pray that the Lord grants them success and prosperity so that the bags hold the whole way and that they don't

> drop the groceries on the road!” I try to convince him to go and meet the two women and give them a hand, but he refuses and laughs, amused by my increasingly desperate attempts to get him to see that he has to help out with something that we are doing as a group project. When the women arrive, I try to get him to carry one of the bags up to the school, but instead Magnus starts to rummage around in the bags and happily exclaims: “Oh, soda! Finally! I’ve missed it during the entire course!” And then he says something about the food, still refusing to lend a hand. The more irritation we show, the more he laughs with delight.

In child language development, the forms appear long before true understanding of the words exists. It is through interaction with others that the meanings of words become apparent and become an internalized part of the child’s knowledge. The same goes for the use of grammatical structures and forms that appear before understanding of the corresponding logical mental operations. *Because, if, when, but* require an understanding of cause, time and conditional relations that the child has not yet mastered. For Vygotsky the concept *naive mental operations* has the following significance:

> I also associate the naive with the unconscious, everyday, habitual acts that fill our lives. I associate the naive with that existence which is an obvious background to what we say and do (Bråten, 1998).

Magnus, like many other adults with autism, has the superficial form of a well-developed language and makes use of a large vocabulary. He has no real knowledge of the content of the words, though, because his mental operations have not reached the level of development that corresponds to what the words are expressing. There is a large gap between the form of the language that he uses and his understanding of its contents. Interaction with others has little influence in helping him gain alternative meanings and perspectives.

On the level of the *external signal,* the child uses external operations to solve internal tasks. Memory needs support from signals in the external world such as using fingers to do arithmetic or a list of things to remember. Language has become *egocentric speech* for the child that serves to assist her in thinking. It is speech that is directed at the child herself, but is spoken out loud so that others hear. Through language, it is now possible to hold on to impressions and organize one’s surroundings through conscious thinking.

After these early stages in the child’s development, she should begin to internalize the external mental operations so that they take place there instead, in the form of a soundless internal language assisted by logical memory. Psychologically, the child can now reconstruct events from the external world internally with the aid of signs and symbols. The child is now released from the concrete and from her immediate visual field. Through language, she is able to organize her activities. Vygotsky calls the thought that is characteristic of this first stage of language *thinking in complexes*. Words, as yet, lack direct hierarchic connections such as those that exist between *hammer* and *tool*, *dog* and *animal*. The connections are still diffuse and generalizations can glide over into one another. Thought is tied to the concrete and real. The child is unable to abstract elements and use them in other contexts without them being tied to the real one.

The transition from thinking in *complexes* to thinking in *concepts* means that the child starts to reconstruct the meanings of words. With language as an aid, a transition takes place from concrete to more abstract and general thinking in which elements can be abstracted and put together in new combinations mentally. The child needs to be able to analyse context and come up with something entirely new by establishing new combinations of thought. This means that a creative process begins in play and is gradually transferred to learning at different levels. Creative play, which starts when the child picks out different features from a situation and recreates them in another, is an exercise in liberating the self from that which is situationally bound. This transition from thinking in complexes to thinking in concepts is nothing that happens only through maturation. This is where social learning has great significance. If the child who thinks in complexes is surrounded by people who think in concepts, the child will also be able to develop her thinking to the conceptual level. The highest level in conceptual thinking is the one in which a person can write fiction, create works of art or write academic papers.

Thinking in complexes can also be seen as an obstacle for in-depth learning. Lennart Svensson (1987) points out two aspects of thinking that are particularly central: the focus of thought and the organization of thought. By learning something in-depth and comprehensively, one learns the content at hand while simultaneously learning how to *learn* in that manner. Svensson also emphasizes that humans, through their ability to contemplate their activities and train their thinking, can surpass their previous limitations and break with earlier established habits; they are able to adapt their thinking and actions to what the situation demands. According to this view, an absence of self-reflection results in difficulties in learning in a more profound and holistic manner. Examples of such deficiencies in self-reflection and its consequences for cognition and learning are presented in the research of Luria.

The studies that Luria (1976) carried out in Uzbekistan in the 1930s contain many examples of the development in cognition that occurred in adults who, after growing up in remote villages, gained access to schooling and became involved in collective agricultural work. Those who continued living as isolated peasants in small villages continued to think in complexes all their lives, while those who came in contact with other ways of thinking through co-operative work and though access to a certain amount of abstract thinking in school started to think in terms of concepts.

from thinking in complexs to thinking in concepts

Vygotsky's theories on the socio-cultural origins of thought and the mediating function of language in the development of higher mental processes were used by his colleague, Luria, in his research in Uzbekistan (1976). Vygotsky was involved in planning the research but was too ill to actually participate.

During the 1930s, Uzbekistan was one of the regions in the new Soviet Union in which enormous structural transformations were taking place. For the remote village inhabitants in particular, the transformation from the traditional rural way of life to collective farms involved new ways of thinking that replaced older, traditional ones. This was an excellent opportunity for studying how lower mental processes are replaced by higher, symbolic ones through schooling and co-operation with other people on the collectives. Perception, problem solving, ability to generalize, imagination and self-image were studied, among other things. The researchers wanted to test the earlier notion of perception as a passive mediation of information through the senses as opposed to one in which perception is considered to be an active process through which incoming sensory information is interpreted according to already existing categories. This would mean that perception also involves being able to quickly interpret crucial characteristics such as form or colour nuances in order to correctly categorize. Thus, perception entails a decision-making function, which is closely connected to language. The simplest form of classification is based on the object's direct, concrete area of use. In this case, thinking is situationally bound and the concrete object is not placed in a general category; categorization is based entirely on the person's own idiosyncratic needs. Such concrete ways of organizing and classifying the world according to one's own principles have proven to be much more rigid than those based on more advanced classification principles. Similar principles of categorization have also been observed in patients with brain injuries who do not use language as a mediator of thought.

Some of Luria's examples of this type of practical, situationally bound thinking:

> Rakmat is 39 years old and is illiterate. He lives in a small village and has never been to town. He is shown drawings of a saw, a hammer, a log and a hatchet. He is to tell in what way these objects are related to one another and if there are any that do not belong with the rest:
>
> *They're all alike. I think that all of them should be here. See, if you're going to saw, you have to have a saw and if you're going to split something, you have to have a hatchet. So all of the things are needed here.*
>
> The interviewer tries to explain by using another example: *Look here—there are three adults and a child. Now clearly the child doesn't belong in this group.* For Rakmat, it is not an example that facilitates understanding of the previous task; he answers instead:
>
> *But, you see, the boy must stay with the others! All three of them are working, and if they have to keep running out to fetch things, they'll never get the job done. The boy can do the running for them. The boy will learn from the others and then they'll all be able to work together.*
>
> The interviewer tries to lead Rakmat's thoughts in a different direction by asking: Which of these things can you call by one word?
>
> *How's that? If you call them all "hammers", that won't be right either.*

I have had experiences similar to those of the caseworker and support staff of a former forensic psychiatric patient when he was to be rehabilitated after being discharged from inpatient care. The concept "rehabilitation" in his mind meant a job and a place to live. All the people involved in rehabilitation were expected to take part in arranging this. He stubbornly insisted that rehabilitation meant work and housing, in that order, and all attempts to explain the difficulties in providing them he saw as unwillingness. An endless number of people tried to clarify for the patient his own role in finding a job and the difficulties in renting an apartment with his previous history in relation to landlords to whom he had written threatening letters. With the same stubbornness, he continued to react to what he saw as the unwillingness of everyone else to assist him. The concept "rehabilitation" had only one meaning involving certain, concrete actions in his mind.

When Luria's experiment was repeated with people who lived on a collective farm and had received some education, the differences in their way of thinking were quite apparent:

> Yadgar, 18 years old, has attended the village school for two years and works on the collective. He is asked to describe which of the following objects have something in common: a glass, saucepan, a pair of spectacles and a bottle:
>
> *The glass, spectacles and bottle go together. They are made of glass. The saucepan is made of metal.*
>
> The interviewer tries to show that there are other ways to categorized them: *One person told me that it was the spectacles that didn't belong in this group*:

> No, they are made of glass and the pan is made of metal. I don't understand why he said that.
>
> Interviewer: Can you try to figure out why he said that?
> *I would tell him that I don't agree. These things are made of glass and the pan is made of metal. How can he say that they are alike?*

Yadgar's mental processes have come part of the way towards general categorization, but he still does not comprehend that you can categorize according to different principles.

From psychiatry (E. Mandre):

> When Emil gets a TV and video on his new unit, he comes in contact with a world that lies outside of his own ability to comprehend. At the large hospital, the isolated unit and the hospital park were his only sources of stimulation. Now he can watch nature programmes in which fishermen reel in large, silvery salmon. Emil does not associated the fish he observes on the TV screen with the large fish that he sees in the unit's many aquariums. Acquarium fish are blue, zebra striped with spots and big mustasches. Emil's also has his own notion of the nature programme's fish when he goes fishing with two of the unit assistants one summer day. On the way to the lake Emil says: "The fish—aren't they made of metal with motors inside?" Not before he sees a pike pulled out of the lake by a neighbour does he understand that this is not the case. For Emil, his thoughts are so peculiar that they can appear to others to be delusions; his prolonged social isolation has resulted in him being forced to create interpretations of the world entirely on his own.

Luria demonstrates how both perception and cognition are bound to the way the culture we live in interprets the world. Lacking these established concepts, Emil is forced to come up with his own way of interpreting reality. It becomes particularly evident that it is not just a matter of physiologically regulated maturational processes that generate higher levels of cognition and understanding almost automatically, but that it also involves the incorporation of socio-cultural concepts.

In other experiments, Luria demonstrates that people who think concretely find it difficult to use their imagination creatively. Luria differentiates between *reproductive* imagination and *creative* imagination. In the former, imagination is closely connected with practical experience, in the latter, it is more on a mental level in which aspects of different behaviours are combined with one another through language.

In order to examine the degree to which a person could use his imagination to formulate questions to ask the interviewers, subjects were assigned the following task: *Ask me three questions. What would you like to know?*

Burkhash, an illiterate man from a small village:

> *I don't know how you get knowledge … where would I get the questions from? For me to ask questions I have to know something. You can ask questions when you understand but my head is entirely empty. . .*

> Think, for example, about the tea that you drink—do you know how it is grown?
>
> *I don't know anything about tea. I get it from the co-operative and then I drink it.*
>
> Irgash, 30 years old, is given the same task: Ask me something. What are you interested in knowing?
>
> *I don't know what I should ask.*
>
> We are, for example, from other places, from other towns. Ask me about the other towns!
>
> *I like the place where I live best. I'm not interested in other towns.*
>
> Would you like to know what people do there?
>
> *I haven't seen what people do in other towns, so what would I ask?*
>
> You might want to know what kind of animals, people or houses are there.
>
> *But I haven't seen them, so what would I ask about?*

In the same way that the Uzbek peasants find it difficult to imagine things that they have no experience of, Emil is unable to imagine things that he has not had any direct experience of. During his many years in inpatient psychiatric care, Emil cannot imagine what the world is like outside the walls of the hospital. This is why he is unable to think of another kind of life than the one he has there. He cannot even ask questions about something until he has had direct experience of it or second-hand experience through pictures. When the staff want to re-evaluate him for a new diagnosis after his discharge from institutionalized psychiatric care, he is unable to envisage what this means and will not agree to it.

Luria came to the conclusion that the peasants simply were unable to move outside of their own frame of reference in their thinking. They were limited to their own practical experiences and could not mentally go beyond them. In their own lives they had many interests, but they had no experience of talking about things that were not a part of their world. Akhmet, 44, from a remote mountain village answers a bit more expressively:

> We are not interested in anything; we only need to harvest the grain with a sickle and chop wood with an axe. We ask the government for many horses and much land. When they come and ask us how many cows we have, we answer them because we know. When the autumn comes we harvest the crops; that much we know. But, we do not know what we should ask about.

When the same question is asked of the farmers living on the collective who have attended a couple of years of school, the answers reflect a different way of thinking. Siddakh, 19, who has attended school for two years:

> Well, how am I going to improve workers on our collective? How can we get the crops to grow better? And I'm also interested in knowing how the world came into being, where things come from, how the rich become rich and the poor become poor.

When Luria continues his research, he wants to find out if self-awareness and knowledge about psychological qualities can be found in people who are unable to think abstractly. His hypothesis throughout the entire investigation is that social and linguistic mediation is necessary for the development of higher mental processes, which is why he assumes that neither self-awareness nor self-reflection are as primary and obvious as they are depicted by the psychologists of the day.

Luria carries on a longer interview with a young woman and tries to explain for her that people have different traits and that they are different from one another in a variety of respects. Then he asks the question:

> What shortcomings do you think you have? Is there anything about yourself that you would like to change?
>
> *Everything is fine with me. I have no shortcomings myself, but if somebody else has, I'd let them know. For my own sake, my only shortcoming is that I only have one dress and two skirts; those are my shortcomings.*
>
> No, what I'm asking about is what kind of person you are now and the person you would like to be.
>
> *I'd like to be good, but now I'm bad … I have so little clothing that I can't visit another village.*
>
> What does it mean to be "good"?
>
> *To have more clothes.*
>
> Does your sister have any shortcomings?
>
> *She's still little and doesn't talk very well yet. But how would I know that? I'm here and she lives in another village. My brother has learnt a lot, so he doesn't need to change anything.*

When I speak with Valdemar, a man with Asperger Syndrome, about himself and his traits, he always says that he thinks he is nice when others are nice to him. When others are not nice, he feels that they are harassing him.

The only thing he thinks he can do to protect himself from this harassment is to attack the weak points in others and strike out so that they learn. The thought of making any changes in his own behaviour so that others would treat him differently is nothing that he contemplates, only in exceptional cases.

> Khaidar, 25, works on a collective farm and can read some: Have you changed in any way of late?
>
> *Before I worked as a farmhand. I worked for a foreman and I never dared to answer him; he did whatever he wanted to with me. Now I know that I have rights.*

What shortcomings did you have before and which ones do you have now?

Before I didn't know about freedom; now I do. Before I worked a lot for others and hardly had any bread for my family and myself, but on the collective farm things are much better. I have things that I can give to others and I got married this year.

In what way have you changed on the inside?

Inside? Before I couldn't handle anything, but now I can manage a lot as you can see.

What good points and shortcomings can a person have?

A good point is that he knows how he should act around others. A shortcoming is if he hasn't gone to school. If you go to school, you become a good person. If you have gone to school, you don't behave badly towards others.

Are there good people and bad people? What does that mean?

If I had gone to school before and learnt how to read, I wouldn't have had as many problems. I would have known my rights and myself and could have defended myself. If someone would come up to my sister and insult her, I would answer back. If he can read, he wouldn't do something like that. But if he still does it, I wouldn't act like a coward but start insulting him and that is a shortcoming in me.

What traits do you think a wise person has?

If a person has gone to school as a child and learnt to write, then we think he is a wise man. But if he hasn't learnt that, but instead only rides on his donkey and sings and doesn't know anything about where people come from—then we say that he is a fool.

Do a wise man and a fool have the same mind?

No, it's different, of course. There are people who are different, like you and me, for example. We have different minds.

In what way are they different?

You have your amusements, your studies and your work and I amuse myself in my way. That's how we have different minds.

Has your mind changed since you started working on the collective farm?

Yes, it has, of course. I work better. I go another way now. I worked for the landowner before and had a miserable life, but now things are better.

What is the mind made up of? Is memory, for example, a trait of the mind?

Yes, without memory you couldn't work, could you? Memory is what tells you what you need to do. The mind just checks up on things. If you were to leave everything up to the mind, it wouldn't be able to do anything entirely on its own.

And what other traits does a person have?

She has her nature. If it's in your nature to do something, you will know it. If it is against your nature, you can't do anything. People also have the power of imagination, intelligence, thought and temperament. All of this combined results in work. If a person can't use her power of imagination, then she doesn't have her attention on her work and she won't be able to do it.

These diverse ways of thinking and reasoning about oneself and one's traits reflect various ways of thinking at different abstraction levels.

These descriptions of the mental processes of Uzbek farmers deal with individuals who had grown up in isolated, small villages that had limited contact with the outside world. These individuals lived in a concrete and practical world, where thinking was tied to situations that were meaningful in their lives. This concrete way of thinking based on your own experiences, the inability to imagine and think through things that you have not experienced and the difficulty of thinking in terms of abstract traits, characterizes in many respects the conversations I describe with some adults who have autism. They have seldom lived isolated in the physical sense as the Uzbek peasants, but their perceptions and cognition have been limited by psychological isolation from other people's thoughts and perspectives. Ratner describes the difference between various forms of social competence in the following manner:

> Genuine sociality is a profound interpenetration of individuals such that each is a formative influence on the other. Genuine sociality is not mere coexistence of individuals but mutual constitution of individuals by each other. Lesser forms of sociality include primitive communication, modelling, and stimulating of sequential behaviours, but real sociality entails fashioning one's entire individuality (personality, consciousness, and behaviour) from interaction with others (Ratner, 1991).

Case study: Emil

In this section, I will describe an adult who has been in forensic psychiatric care for many years. Emil has a diagnosis of schizophrenia when I first meet him and his staff. There is much that will indicate that he really should have an autism diagnosis, but due to the way his disability manifests itself, he will be very difficult to re-evaluate for a possible new diagnosis. The aims of this case study are to:

- make a person with very idiosyncratic ways of thinking more understandable based on theories of the significance of social interaction for the development of self-image and mental processes.
- demonstrate how to practically go about initiating communication based on assumptions that are considerably different from the prevailing ones: When we first meet Emil, he has no desire for contact or communication with other people, indicating that he would rather be left in peace.
- demonstrate how, with alternative means of contact and *communicative transactions,* one can initiate communication that subsequently offers the person opportunities to learn

through and with other people in social interaction.

The prism through which I see and describe Emil is made up of the theories that explain the significance of early social development for later development and the effects that a deficiency in this kind of learning can have on the adult.

It is obvious that the congenital difficulties found in children with autism constitute obstacles for social learning in early childhood and result in developmental limitations even later in life. If the primary social learning that occurs in a one-to-one relationship and which normally results in a person adapting to other people's social signals is not functioning, all other stages leading to further socialization will be effected by developmental delays; certain types of development are often precluded. If at the same time other functions in the individual develop normally or even better, this will result in an uneven profile of competencies, incomprehensible for other people. This is because the ability of an individual with autism to acquire the social aspects of learning is limited or nonexistent. He is thus left to create his own mental constructions without being able to include other people's perspectives in the process. When this has been going on for many years, up through adulthood, the effect increases exponentially (based on the assumption that any given change in social insight is proportional to the existing social insight). For an adult with autism, this has a huge impact and can become the dominating component in the manifestation of the disability.

Emil is one of my personal case studies and thus not a patient that I only observed. By having direct contact with him, I have been able to observe as well as develop a pedagogical interaction with him. In that way, I have also learnt much more about him than about most of the other patients who will be described in another section by the professionals who work with them.

My first encounter with Emil was through a project that was to be carried out on a psychiatric unit for long-term care patients, most of whom had been diagnosed with schizophrenia. The senior psychiatrist who contacted me was interested in education as a treatment method. We outlined a project that we intended to seek funding for after a trial period. The project was to be evaluated according to current psychiatric scientific methods: there would be a test group of patients on one unit (called the *Wild Goose*) and a control group on the unit next door (called the *Lighthouse*) where the patients would not receive any kind of educational treatment. The results were to be measured by testing the patients *before* and *after*.

At in introductory meeting with the unit's senior psychiatrist (not the same as the one who initiated the project) we discussed the patients who would be included and the psychiatrist brought out a thick medical record describing a man, almost 50 years old, who had been an extremely difficult forensic psychiatric patient to treat for over twenty years. He had the diagnosis *schizophrenia NOS (not otherwise specified).* He was described as being extremely hard to reach, very paranoid and delusional. He strictly followed his routines and did not want to do anything new. Emil was fairly new on the unit—he was one of the last patients to leave the big mental hospital, one of the city's largest, which has since been closed down. Emil lived isolated at the mental hospital, had never participated in group activities, lived meagrely and minimally and had never asked for anything or expressed a desired for anything. Emil was also considered dangerous and that is why he had never been granted leave on his own from the hospital grounds for the twenty years he had been cared for there.

The description of Emil aroused my curiosity since it reminded me a lot of the people with whom I have been involved much of my professional life, namely, people with autism. But the psychiatrist warned me: "You'll never reach him—his is entirely too paranoid!"

I was to visit the unit twice a week from October 1998 until January 1999. During that time I was to select patients who could benefit most from an educational treatment approach. My task was to establish contact with them, observe them with their contact person on the unit and put the project idea in writing.

I had already formulated some of the ideas in advance and one of them was to use experiences from Certec, Lund University's Division of Rehabilitation Engineering Research. I had the following working hypothesis: by photographing a variety of everyday situations, you can create more internal images and associations in people who have difficulties doing so themselves about things and events that cannot be found in their immediate field of vision. Certec's experience in working with people with cognitive limitations, aphasia and brain injury have demonstrated that you can considerably improve mental abilities and communication in this manner (http://www.certec.lth.se/doc/picturesas/). The use of digital pictures on the trial psychiatric unit would consist of providing a picture schedule of daily, routine activities for those patients who needed one. This schedule would also divide the activities up into steps for those who found it difficult to remember them and their sequence. This is a way of clarifying complex situations, preparing new activities, etc. The pictures can also be of assistance in preserving personal memories of important events and in providing patients with a history. The histories of psychiatric patients during their time in care are often very sketchy in the area of memories. It is as if the time spent in the hospital is not really a part of their life histories or narratives.

When I begin my time on the unit, I have a digital camera with which I photograph the staff at work. I also take pictures of the large, beautiful fish in the aquarium and other prominent items on the unit. I do this so that the patients will become accustomed to seeing me and so that the pictures I place on the noticeboard each day will become a means of communication. The more social patients immediately react and interact with me and want me to take pictures of them to place on their doors. Emil is the patient that I want to establish contact with, but he slips quickly past me the first days and hides his face by covering it with his arm.

contact

Emil, who works in the kitchen, comes out of his room at exactly the same time every day, fetches the food cart at the outer door and goes into the kitchen from whence he emerges again at exactly the same time. He does not eat with the other patients in the dinning room but stands in a corner of the kitchen.

Once aware of the time Emil emerges from his room, I make sure that I am standing in a place that he has to pass on his way to the kitchen. After he has passed by me several days, Emil comes up to where I am standing with the camera in my hand and asks: “What kind of camera is that? I’ve never seen one like that before!” I tell him that it is a digital camera and suddenly Emil has many quite appropriate questions to ask about the camera.

Emil and I talk about the camera several days in a row when he is on his way to the kitchen. When he asks how you take pictures with it, I show him and tell him that he can take it with him into the kitchen on his own and try it out. Emil’s first twelve photographs are taken in the kitchen before he has washed the dishes and put things in order. There is no computer on the unit at first; instead I take the camera home with me and return with the developed pictures the next time.

The pictures are a means through which I establish contact with Emil. This does not take place face-to-face; he always shields his face with his arm and never looks me in the eye. He stays at arm’s length from me when we converse, has no body language and no facial gestures.

communication

Our communication deals only with concrete objects. We talk about Emil’s pictures, the ones that he has photographed himself, and those that I have taken and given to him. We now have something in common on which to focus our attention, something we can discuss. Emil’s questions are entirely adequate and relevant to the situation; they do not reflect a schizophrenic person’s mental confusion. As soon as we have exhausted a subject of its factual content, though, Emil ends the conversation and leaves. The "object" is what matters; the person is but a conveyer of objects. Emil also demonstrates through his comments about some of the pictures that for him, people do not have a high priority—not even when they appear in the pictures. If there happens to be a person in any of the pictures that I give him, he removes it saying: "There's a person in this one. I don't want it! "

It is through pictures that Emil makes associations with different phenomena. I ask where he lived when he was young. After he tells me, I bring pictures from Estonia and Russia that I think he will associate with Sweden in the 1950s when he was growing up in a rural environment. When Emil sees the woodpiles, midsummer bushes and the overgrown gardens, he starts to associate with the time he chopped wood and carried it in to the wood stove. They also had a pump in the yard, as do some of the pictures. After discussing the concrete content of the pictures, Emil has no more associations and is unable to continue associating freely about things that are not to be found in the pictures. With that, the conversation is over.

Our communication is not a true dialogue, although we take turns talking, asking questions and giving answers. The closest designation I can give this form of verbal interchange is a series of *communicative transactions*. We deliver replies to one another and the terms for continuation of the transactions are determined by how much information they give Emil about something he is interested in knowing. When he has drained my sentences of their concrete content, the communication is over. There is no continuation of the conversation through the establishment of any socially significant contact. The communicative act contains nothing more than the concrete content of the words. Nonverbal signals are impossible to convey; emotional messages are not part of the transactions.

cognitive structures

Emil lives almost entirely in the here and now. He has tremendous difficulties in creating associations with things, persons and events that are not within his field of vision. Concrete objects and pictures, though, provide him with associations and develop his world of ideas. He gains more and more associations from the increasing number of new pictures. During the three months that Emil and I meet, in the framework of the educational project's trial period, the number of pictures grows to a couple hundred. As the pictures provide Emil with associations, which in turn result in thoughts and words, it becomes clear that action precedes thought for him. Normally, it is the other way around in adults. During the conversations we now have every time I am on the unit, I notice how idiosyncratic his thought processes are. Emil has lived so long in a very isolated world and his thoughts have also "lived" in their isolation resulting in rather peculiar and odd notions of what the world is like. No one has tried to change any of these conceptions by infringing upon his world of thought. A social context is needed to enable a person to think thoughts that resemble those of other people.

The world comes to Emil through a steady flow of new digital pictures. He has been granted an hour's leave from the unit each day to take a walk. I ask him if he wants to take the camera along and Emil returns with it after an hour and informs me: "It says *memory full* on the camera!" That means that Emil has taken 59 pictures of his walk. Emil's photographs indicate that he has a developed visual sense and I ask him if he thinks in pictures. Emil contemplates this for a moment and then says: "No, it's like I'm not able to produce the whole picture when I try!" I interpret this to mean that he is only able to see fragments of thoughts that are not related. It can also mean that the images flicker by so quickly that he is unable to hold on to them. I try to give Emil printed texts. His reaction is: "Letters are just people's fabrications. . . I don't want anything to do with that!" Sometime I succeed in finding books with interesting pictures and almost no text. These he accepts and becomes a great consumer of picture books for a while. He is particularly interested in buildings. He really wants to learn how to build houses so that he can move out in the countryside and build a cabin or a wigwam. "It's unnatural to live in cities!" according to Emil.

Emil and I now have the type of contact that he can ask me for pictures from places he has never dared to go. When the Christmas window displays go up around the first of December, they remind him of a time when he rode in the hospital bus through the centre of town. He remembers that the windows were so pretty and he would like me to go there and photograph them for him. I take a great many pictures and happen to get one of the king's state coach, which is out for a tour. When Emil sees the picture of the coachman wearing a thick fur hat and a black cape with silver braids, he starts to laugh. For the first time during the two months we have known one another, I see movement in his face. When he has finished laughing he says: "It looks like *Revenge of the Vampire*!" and tells me that he saw the film at the cinema. When he tries to figure out when, it turns out to be almost 25 years ago.

Soon thereafter, Emil asks if he can have photographs from a department store and I ask him what he would like pictures of. "I'd really like to see what it's like in the toy department!" Emil says. It has been a full six months since Emil moved to the smaller unit from the large hospital. He still wears hospital clothes and refuses to remove them. On my way to the toy section of the department store, I pass through the men's department and photograph sweaters, shirts, trousers and underwear. At about the same time that Emil gets the pictures from me, Ester, his contact person, tells him that the ward's Christmas party is coming up soon and that patients are not allowed to come in hospital clothing. Christmas is an important celebration for which you have to dress up. When Emil has had the opportunity to prepare himself mentally by seeing the pictures, he has time to get used to the idea of new clothes before Christmas. Ester takes his measurements and buys them in time for the Christmas party.

Of the toy department pictures, Emil really likes a remote controlled car and asks for that for Christmas. Ester applies for money from a fund and purchases the car for him. She sees the advantage of having a car that Emil has to steer with both hands—then he won't be able to cover his face with his arm when driving the car. Within a couple of months, Emil has started to make eye contact and no longer hides his face.

sense of self

Of necessity, Emil's sense of self that is presented here is a construction based on theoretical reasoning, since Emil himself would not understand the reasons for me starting to ask him question about who he is or how he sees himself.

The theory I have adopted is Daniel Stern's (1985), described in a previous section of this chapter. According to Stern, there are four vital experiences that have to be developed during the first years of life for a person to acquire a complete and coherent sense of core self.

The first experience has to do with how one acts towards the world—*self-agency*. Through the early experiences the child has of her actions being her own and having certain consequences, she will gain a feeling of being one who *can*, one who *does*, one who *wants to* and one who *doesn't want to*, etc.

Looking at Emil as an adult man from the perspective of *self-agency*, I first see him as a person who exists in a *passive state* a good part of the day. The only activity he initiates is *withdrawing* from situations that he is unable to cope with. Most of these involve interacting for interaction's sake, or ones that place demands on him and that he finds stressful. The daily activity that has been chosen for him and that he carries out routinely is the work in the kitchen. It is a job that he will not give up for any other activity and that he never takes a break from. It has become a firmly rooted part of his sense of self. He appears to be driven more by automatic routines and actions than opportunities to try out and learn anything new.

Stern's second form of self-experience deals with *self-coherence*, i.e., the feeling of being a whole person with both external physical boundaries and an internal sense of a cohesive self. What characterizes Emil in this regard is that his physical boundaries are set at a given distance from other people's bodies. He does not want to touch anyone and so keeps his physical self under control. Emil is his own centre, but a centre that *cannot*, *will not* or *does not see it as meaningful* to reflect himself and his actions in other people. His actions have no continuity. His mental processes are fragmented and he is unable to associate to the extent needed to retain whole concepts. It seems as if his sense of self is being created and recreated constantly in new, *here-and-now* situations.

In addition to the internal experiences of self, according to Stern, is the feeling that it is *I* who feels and experiences and that these feelings and experiences are connected to my other experiences and actions—*self-affectivity*. Emil lacks affect in all that he does, says or experiences. This is one of his most salient characteristics—that he does not express any feelings with his face and body; his voice does not convey any nuances of emotions and experiences seldom elicit emotional reactions. His most prominent emotions are: *happiness* and *laughter* on isolated occasions, *obstinacy* when it comes to adherence to routines when someone tries to change them, *stress* and *frustration* when he is placed in situations that he is unable to work out. There is no indication that his emotional expressions exist as part of a coherent self-image. It is more likely a self-image that arises out of an action and is, thus, situationally related.

In order for a person to acquire a cohesive and connected *self-history*, the self has to be able to preserve its experiences, form associations with them and gradually start to see a pattern in life. From the beginning, these experiences are nonverbal: they are found in the body's actions, in those expectations that the infant has of different events and in the feelings the infant has for different phenomena. Eventually, these experiences are transformed into linguistic and conscious ones. Stern maintains that this early experience of self is not primarily a cognitive construction but an integration of experiences that are continuously updated through interaction with other people and through the things with which we are confronted. This self-history extends for the rest of our lives and is inside us as a constant, ongoing inner monologue.

Due to difficulties in associating and creating concepts, Emil's inner monologue is not an ongoing and connected story of his life. Because Emil has lived for such a long time in isolation and in a mental void, he has had extremely few opportunities to update his sense of self and his self-history. An updating of your own self-experiences also requires that you are reflected in other people and that this reflection, in turn, influences the self. Emil has no photos from when he was growing up; nor does he have any of his parents or from the more than twenty years he has spent in psychiatric care. I start photographing Emil on the psychiatric unit. The first picture I take of him is from behind as he clings to the object that is his security on the unit—the food cart. This picture is the first in a series of photographs, but the road to the first photograph taken from the front will be a long one.

A person with Emil's memory problems and cognitive difficulties can hardly be expected to have an inner self-history consisting of more than unconnected fragments. He has never in his self-narrative been able to insert an intelligible explanation for his stay in psychiatry, even though it has comprised his entire adult life. Emil does not know anything about his diagnosis and does not think about it. As a result, he does not understand what it would mean for him to be assessed and given a new diagnosis.

contacts with continuity and a developmental perspective—the beginning of social learning

When I entered into Emil's life, it was to carry out a pilot study for a project. Within a few months' time, Emil, who was considered difficult to reach, was my most important communication partner on the unit. After three months, the pilot study was over. The unit now has its own digital camera and computer in order to continue the work I initiated. Because there is a small group of dedicated staff who are helping Emil expand his world and because there now is a way to prepare him for it, the coming year will involve many new experiences for him. The change in the personnel's approach to Emil will be described in the interviews I have with them in a later section.

My own role in Emil's world is temporarily over. It was time to apply for funding for the bigger project and I was moving from Stockholm to Lund to begin my doctoral studies at Certec. Yet, I could not entirely abandon Emil; I decided instead to keep in touch with him on a purely private basis through letters, pictures and by visiting him once a month. We would continue our work with pictures. When I told Emil that I was moving to southern Sweden and that I would not be coming as often in the future, his reaction was: "You can't move to southern Sweden because it doesn't exist!" Emil had no concept of southern Sweden in his mental world and as far as he was concerned, I could not move to a non-existent location. After the move, I sent Emil pictures of the train, the station in Lund, the road from the station to my building and the view from my apartment over the rooftops. I wrote to

Emil: “I live on the roof, just like Karlsson” (a well-known character in a Swedish children’s book). Emil was now able to accept my move. The next time I visited him, he wondered: “Who is Karlsson?” When he found out that there was a little man with a propeller on his back who could be found in pictures and stories in books, he was curious. Since summer was coming and I knew that Emil and I had birthdays nine days apart, I suggested that he could write and send a birthday card to me. If I got a card, he would get a book about Karlsson on his birthday. Emil found the idea terrifying and stressful at first. He did not know where to buy a card, what to write on it, where to get a stamp or what mailbox to put it in. After receiving instructions from me in the form of text and pictures of mailboxes and the post office, he settled down.

On my birthday, a card arrived with the exact wording that I had written down for him. I sent him his book in return and on the card I wrote: “I will read this book to you the next time I come to Stockholm!” When I came in August, Emil informed me: “I have already read the book myself!” Emil became in that way a reader. His range of activities increased as the staff gave him new opportunities for experiences. Everything was carefully prepared for him through pictures. Emil has also started on his self-history in pictures from the recent years in psychiatry. His sense of self has changed through his contacts with the personnel on the unit. We are still in contact, even though the educational project was never implemented because the clinic was reorganization and eventually moved. Emil discovered Easter and Christmas cards on his own and calculated that he would receive Easter and Christmas presents as well. We exchange cards and presents three times a year and have done so for several years now. Emil was discharged from forensic psychiatric care a year and a half after our first meeting. He participated in the county administrative court hearing on that occasion and spoke of his desire to move. He now had concepts of what the world outside of the hospital walls had to offer him and what life was like in other places. Early in 2002, Emil moved into a municipal group home and started his new, freer life after 25 years as a psychiatric patient.

6. Learning as active reorientation

For several years, I conducted an educational project on a special psychiatric unit where I trained the staff who worked with the unit's two patients. It was then I realized the difficulties with a continuing educational effort that only *transmitted knowledge* without it being practically anchored in the personnel. It was not until I adopted the role of caregiver for a longer period and demonstrated to the staff that "If you do this, it will results in that", that they began to see that it *was* indeed possible to do things differently. The concrete examples demonstrated that they could not just assume the results from the previous knowledge they had about the patients. The perspective of the caregivers entirely determined the potential for progress they saw in their patients. It was also the case that the knowledge the caregivers previously had about their patients and the deeply ingrained routines of the unit, if anything, were hinders to new thinking and reorientation. They had become tacit knowledge, imbedded in body and soul, which could not be changed at will. For some, this meant they simply could not continue working on the unit. For those who remained and received training, my examples were a first step towards trying to do things differently. At a much later stage, theoretical instruction could be introduced to the educational programme.

In addition to individual aspects of learning, is the learning that takes place on the collective level (Rolf, 1995; Lindberg Sand, 1996) and which forms the care culture that exists in a team or on a unit. It is in this cultural environment that the co-workers learn to carry out practices that are a mixture of conscious and unconscious, tacitly operating traditions. These traditions are passed on as knowledge of their own about how things are to be done. When a new approach is introduced, the traditions of the previous care culture are uprooted; divisions and feelings of emptiness arise before a new culture is established within the collective.

Learning, in other words, is a much more complex process than the transmission of expertise and knowledge from the person who possesses it to those who do not. The concept *knowledge* *transfer*, which is often used in similar situations, is inadequate if you consider knowledge to be something an individual has actively constructed from within and which has changed something in the person's previous thought structures. This becomes particularly apparent when it concerns something as complex as the work carried out by psychiatric personnel.

Professional lifelong learning

Today's society emphasizes the development of skills and lifelong learning. Advances in most professional areas are moving at such a fast pace that what you learnt in school is not sufficient for the rest of your professional life; you have to regularly keep adding to it through continuing education. In policy statements that have been drawn up on lifelong learning in the new information society, it is often pointed out that it is not just professionally specific training that is required; that which develops the individual's creativity, communication skills, ability to co-operate and other skills that can be seen as aspects of personality development are needed as well. Ellström (1996) cites the following from a report of the Nordic Council of Ministers:

> We will not be able to manage future challenges in the Nordic countries without more education—and above all, more learning. We need both more technical expertise and knowledge of the humanities, learning in the workplace, learning in schools and in courses, learning in everyday events. But all of this will only help if learning strengthens both the individual and the community and provides us with an overall view which enables us to overcome division and the domination of experts.

Continuing education is ascribed such great importance due to the increasing complexity of working life as well as the ongoing organizational changes that delegate decision-making and increase demands on employees to be versatile and flexible (ibid.). Ellström also refers to research indicating that a working environment that encourages learning and skills development also stimulates the employees' personal development, which in turn has significance for employee health and well being. There are a number of differences in learning that takes place in educational settings and that which takes place in practical working settings. According to Ellström, very little of what formal training has to offer forms the basis for what a person actually does in practice.

Theories on competence development and learning in professional life are based on different views of the relationship between theory and practice. Ellström (ibid.) describes Andersson's ACT theory in which theoretical knowledge is seen as something stored in a general knowledge bank, while practical knowledge is stored in the form of a rule system. General knowledge is converted into practical action through the application of the rules to practical work. Over time, this results in the rules becoming automatic, professionally specific skills that in the final stage become tacit knowledge. It is at this point that a person knows the job.

This theory sees knowledge as something that is first learnt mentally on the theoretical level and then in practice by doing. Learning, then, is a transfer of knowledge from people who can to those who cannot. This view of knowledge forms the basis of many educational programmes that teach theory in the college classroom and practice in a clinic setting. The training of nurses is an example. In her dissertation, Åsa Lindberg Sand demonstrates that the reality is considerably more complex (Lindberg Sand, 1996). When she studies how nursing school students learn in their clinical practicums, she finds that knowledge is not transferred in a neutral manner but to a great extent is steered by the local professional culture and traditions. It is the working community that determines how the job is to be carried out, making it difficult for the content of formal education to have an impact on the clinical practicums, where the employees in their own context already know the job.

Birgitta Höglund (2001) in her dissertation also points out this situationally bound transfer of knowledge as the basis of how a job is carried out. She shows how a psychiatric unit for patients with severely challenging behaviours develops two different work cultures depending on the situation. The work carried on *outside* of the unit in the rehabilitation-oriented programme is aimed at the patients' adaptation to life outside of the hospital. The rehabilitation culture there emphasizes taking responsibility, flexibility, openness, etc. *Inside* the unit, on the other hand, the work culture emphasizes security demands with strict restrictions and surveillance as a central element of the job. She also observes that the rehabilitation approach that was to be integrated into the care given on the inside was impossible to implement. This was because the separate work cultures had developed different explanations for justifying their own approaches.

Ellström (ibid.) indicates the difficulties in accounting for a complex reality in theory because theories are unable to embrace all the possible variables; of necessity they need to be simplified models of the complexity of reality:

> In many situations, theoretical education has proven to be exceedingly difficult to "transfer" and "apply" as the basis for practical action in daily life and work. Inversely, experienced-based learning, that is to say, learning in practical situations, tends to result in a fairly limited, situationally based learning that is difficult to

> generalize and profit from in new or unfamiliar situations. Much indicates the need for a coupling between these forms of learning.

Ellström also discusses additional aspects of the complex relationship that exists between the individual's learning and the attitudes of the surroundings in what is called *adaptation-oriented* and *development-oriented* learning. The former involves learning based on stated goals or assignments and by means of predetermined methods. In regards to on-the-job training, it involves the acquisition of basic knowledge and rules of work routines.

Development-oriented learning, on the other hand, is based on the active involvement of the learner in formulating problems and finding methods to solve them. The goal, in this case, is not stated from the start but is instead formulated as the individual gains more insight into the issues involved. This kind of learning requires an entirely different set of abilities than those needed for learning a certain amount of factual material that is then formulated as the right answer to questions. It requires flexibility in thinking along with the abilities to analyse and interpret. To this, Ellström also adds the importance of an organization that values creativity and independence in its co-workers. He asks himself if this creativity and development-oriented learning can in any way be put into practice in today's workplace or if it is more of a vision for the future.

Another problem when dealing with professional skills development that is taken up by Ellström and others (Rolf, 1995; Polanyj, 1966) is the way procedures for dealing with frequently recurrent activities are turned into automatic routines. It is something that is built into the human structure for learning and procedural memory (Tulving & Schachter, 1994) that frees the mind from unnecessary work and also frees up resources for new learning and for carrying out more complex activities. The downside of this kind of automatization is that it shields us from new information that arises and needs to be included in alternatives for action. By trying to fit new information into old routines, we often misinterpret the information in an effort to make it suit the existing way of thinking and acting (Ellström, 1996; Lindberg Sand, 1996; Höglund, 2001; Rolf, 1995).

The tacit knowledge that exists in all routine work and that becomes automatic impedes new knowledge from making inroads and changing anything in the existing routines. The solution to this problem as Ellström sees it is:

> To the extent that one can speak of an ideal learning situation, it probably means that you reach a balance and a pendulum swing

between adaptation-oriented and development-oriented learning and in this way also between routine-based and reflective action.

From this discussion of the problems and issues involved in learning, it should be evident that learning can hardly be reduced to a transfer of knowledge or to some simple, educational gimmicks. A general programme of *competence development* in an organization is not sufficient for the individuals to automatically acquire more knowledge with which they can improve the organization and working methods. Learning is a process in which the individual has to be prepared to give up ingrained perceptions and ideas and actively work through the new information that one gains in education. Ideas and entrenched practices are changed though one's own actions and one also needs to have opportunities to try out and experiment in practice in order to learn new ways of treating patients and to experience the consequences. In a professional development programme it is also important to pay attention to the workplace culture the individual is a part of and how this limits or allows new approaches and new ideas. The entire structure of the organization as well as the tacit culture that exists are important factors that contribute to the potential for learning in the workplace. Factors that Ellström takes up and that foster learning are:

- An on-going interchange between development of the individual and of the organization. The individual needs to feel he or she is a part of the organization's development and is able to support the goals.
- Opportunities for reflecting on methods and results and continuously being able to reformulate goals and methods to adjust to changing needs.
- Opportunities for reflecting on learning acquired through experience. In several theories on adult learning, this is seen as necessary for experience to result in insight and knowledge. Reflection is defined as a critical examination of the concept of reality that an individual has and that steers his or her actions. Reflection means being able to relate the actions one carries out to the organization's goals and to the results. It is also a matter of understanding one's own values and motives for job-related actions.
- Job assignments that have a potential for learning. Those that are too easy can be experienced as monotonous, offering nothing in the way of learning. Those that are highly complex can be stress provoking, particularly when no alternative options for influencing the solution of the problem are provided.
- Employees possessing enough theoretical knowledge to

interpret and draw conclusions from the information available. This also requires that they are able to observe, interpret and evaluate the consequences of their actions.

- Looking at the group processes in a team. The team can be an arena for the exchange of experiences and a learning environment, just as it can also be a source of conflicts of interest, territorial struggles, rejection of some and favouring of others.
- Understanding that team composition has a considerable significance for the work climate. There needs to be a balance between heterogeneity and homogeneity. In teams that are too heterogeneous, with considerable differences in personalities, attitudes, knowledge and other important factors, there are risks for destructive conflicts; a team that is too homogeneous can become entirely too regimented, not allowing opinions or ideas that do not fit into the group's established expertise.
- That the attitudes and ideologies of management, to a large extent, determine the conditions for development in an organization and decide if there is room for new ideas and learning.

Continuing education on eight units

The educational programme that I carried out on eight clinical psychiatric units can be seen as continuing education in a specific problem area in psychiatry that calls for pedagogical expertise. Theoretically, I have adopted Ellström's descriptions of the learning process, which is somewhat more complex than the mere transfer of factual information. I have also been influenced by Marton, Booth and Svensson (Marton & Booth, 1997; Svensson, 1984, 1996) as well as Bråten and Vygotsky (Bråten, 1998) who see the learning process as a change in previous ways of thinking, something that is the result of an active reconstruction by the person who is learning. Another important starting point for learning is the process of reflecting on the problems of one's own organization (Schön, 1999).

The educational programme was based on each clinic's particular needs to learn more about and gain a better understanding of patients with autism spectrum disorders. This has motivated the participants to learn, since they have been able to formulate what have been their own problems concerning the patients we have discussed. This problem-oriented method has meant that new knowledge and information could be related to their daily work situation immediately and could be tested and retested. The staff groups that participated in the programme have, in most cases, consisted of mental health assistants, psychiatric nurses, occupational therapists and psychologists. Psychiatrists participated occasionally when they had the time. This way of bringing together the different professional categories in a joint educational programme also resulted in the problems being defined from different perspectives and different angles. I had decided in advance that the programme would consist of six, two-hour-long sessions. Fewer than six occasions were considered insufficient to cover what I had to convey: basic information about autism, the opportunity to test different treatment approaches in practice and to receive feedback in the form of "*What we tried worked,*" or "*What we tried didn't work.*"

A total of about 100 people participated in the sessions, including those who participated irregularly by attending only one or two sessions. Sixty people participated on a more regular basis. A group of forty came practically every time with a few, isolated exceptions. It is this last group that I consider to have received the complete educational programme. It is hoped that the others have gained a little more knowledge of autism spectrum disorders and education than they had before. Some of them have also turned in documentation, which is why I will be referring to some of them in my analysis and conclusions in order to see what they got out of the sessions they attended.

The material I collected and with which I have evaluated the learning process of the personnel and its effects on the patients consists of: 1) The staff's written documentation, 2) Interviews and 3) Questionnaires.

After each training session, the staff wrote down what they had learnt during the session. Fifteen minutes were set aside for this. To guide them in their writing, they were given the following headings:

1. This was new for me in today's session
2. I did not previously think that …
3. There was really nothing new for me in today's discussions
4. In other respects, I thought/was of the opinion …

The eight units that participated in the educational programme are located in the following areas of Sweden: Östra Svealand (east central Sweden), Södra Götaland (southern Sweden) and Västra Götaland (west central Sweden).

the wild goose is a unit for patients with severely challenging behaviours in a large metropolitan area. Most of the patients have been placed there by court order in accordance with the Compulsory Psychiatric Care Act (LPT) and the Forensic

Psychiatric Care Act (LRV). I have had more long-standing contact with this unit than with the others. I first came there in the autumn of 1998 to carry out a preliminary study for a prospective educational project for patients with chronic schizophrenia. The project never materialized, though, due to several reorganizations of the unit. One of the patients, however, became a long-term patient contact of mine (see *Case Study: Emil* in chapter 5). Because of him, I continued visiting the unit once a month for two years. The educational programme I then instituted for the staff on this unit was a continuation of the contacts I had already established with them and the patient.

the case management unit is also located in the same city and in the same turn-of-the-century mental hospital as the Wild Goose. The patients have their own apartments or group living arrangements and are treated as outpatients. Case management units can be found in a growing number of places in the country. Case managers participate in the rehabilitation of those defined as *long-term psychiatric patients*. The stated purpose of the unit that I worked with is to rehabilitate long-term patients with schizophrenia. In reality, however, not all the patients' symptoms fit the schizophrenia diagnosis when it comes to the actual rehabilitation efforts. The case managers I met in the training programme suspected that some of their patients might have autism spectrum disorders, which could be the reason why they did not respond to treatment. I had already met these case managers for patient consultations on several occasions before the staff training sessions began. I met four of the case managers on two occasions; three of them went on to participate in seven training sessions for approximately one year. After the training sessions were concluded, I also had telephone contact with them on a few occasions to answer follow-up questions about a patient.

unit 11 is a forensic psychiatric care unit. It is located in a medium-sized city with old traditions of caring for psychiatric patients in large institutions. The unit is part of the only remaining department in the large mental hospital, the rest of which has been closed-down. My first contact with the unit was at the request of the psychologist for a lecture on autism spectrum disorders. At the same time, he wanted me to see a patient in his 30s along with the patient's parents. The psychologist had wondered for a long time if the patient was autistic instead of schizophrenic. He was not like any of the schizophrenic patients they had had on the unit. One way of following up on the patient's continued assessment and treatment was through the staff training programme, which took place on six occasions over an eight-month period.

unit 12 is a forensic psychiatric care unit and is located in the same department as the previous one. The staff training sessions were the same in number and spread over the same period as for Unit 11.

unit 99 is a unit that has patients with severely challenging behaviours that are being treated under the Compulsory Psychiatric Care Act (LPT) and the Forensic Psychiatric Care Act (LRV) and is located in a hospital complex, the rest of which has been closed down. I had previous consultations with this unit's chief psychiatrist and it was also natural to offer a training programme to the rest of the staff. There were six sessions spread over close to a year. Contact with the unit has continued after conclusion of the training programme. One of the results of the programme was that I found a job placement in a company for a patient. The terms for this employment included that I consult and advise the personnel and the patient himself at his place of work.

the forensic psychiatric assessment unit is part of a department in a large mental hospital just outside of a major city. The department contains both assessment and research units. Patients are referred there when the results of a paragraph 7 evaluation determine that they need a more extensive forensic psychiatric assessment, which usually takes 3–4 weeks. The assessment services are carried out by several teams, each consisting of a psychiatrist, psychologist and a social worker. The department personnel are also important in the assessment process since they are the ones who have daily contact with the patients. The departmental units are large as are the number of employees. My contacts involved one of the assessment units and part of the team's personnel. The staff training started with a lecture for the entire department to which the team members and staff from the care units were invited. After the lecture, one of the units indicated an interest for continued staff training. The supervisor, however, felt that his unit would benefit most from a series of lectures, since training that focused on specific patients was precluded due to the short time they were on the unit.

rehab is situated in a smaller city, which also had a large mental hospital in its day. The rehab unit is all that is left in the old hospital location. Adjacent to this is a psychiatric centre and other care units such as a treatment home, child and adolescent psychiatric care units, geriatric care, etc. Rehab offers inpatient and outpatient care according to the principles of environmental therapy. On the unit there are structured group activities in different areas and patients can also take part in services offered by the municipality in the area of education, employment and housing. The staff training programme consisted of six sessions spread over close to a year.

rallaren is an outpatient unit located in a smaller city. The unit is housed in a fairly modern complex adjacent to an industrial park. A neuropsychiatric assessment team is also connected to the unit. There are approximately 800 registered patients. The staff team that participated in the training programme at Rallaren was composed of psychiatric nurses, social workers, occupational therapists and mental health assistants. On this unit, we did not discuss any patients during the entire training programme but instead focused on immediate problems that the staff wanted to discuss from an autism or educational perspective.

7. The staff training process concerning individual patients

The patients that are described in this chapter are taken from case descriptions provided by the personnel. The anonymity of the patients has been maintained by changing their names and by not identifying them by the units they were on. Nor do their life histories include information presented in such a way that they can be singled out. What is presented are fairly general facts concerning people in the diagnostic categories *autism* and *Asperger Syndrome* who find themselves in a situation similar to these patients. Some details, moreover, have been changed and exchanged with other patients in order to make recognition impossible. This does not, however, change the actual staff training programme discussions and advice about dealing with them that is reported. In one case, the crime for which the patient has been convicted is stated because this one—arson—has proven to be over-represented in people diagnosed as having autism (SOU [Swedish Government Commission Report] 2002:3).

Emil

I have previously described Emil in chapter 5 under “Case study”. In that section I described my own contacts with Emil and my perspective. The staff training programme on Emil’s unit consisted of everything from lectures for large groups, individual discussions with older staff members on the unit, to information for summer substitutes and new employees. Two reorganizations that split up the personnel groups and patients had a considerable effect on the staff training year. The main staff training efforts on the unit were from the time before the first reorganization and when I had previously worked there preparing another educational project. Further reporting on how the staff changed in its approach to Emil can be found in chapter 10, *Overall results*.

Jan

Jan is a forty-year-old man who has received psychiatric treatment since he was a teenager after what was presumed to be a suicide attempt. His current diagnosis is that of schizophrenia. Jan has been described as being odd since childhood. He probably managed through life because his mother protected him and interpreted for him in situations that he could not cope with himself. He has difficulties with reciprocity in relationships and holds more of a monologue than a conversation with other people. He is not attuned to the rhythm and body language of others and is described by his case manager as robot-like in his manner of moving and speaking. He lived with his parents well into adulthood and still has difficulties functioning on his own, even though he has a placement in a group home for psychiatrically disabled adults where he can receive support.

Jan is also described as very compulsive and ritualistic and has, on a few occasions, called one of his previous case managers and threatened him. He has no understanding of the effect threats like these can have on the person he threatens and on his relatives. His relationship to other people is characterized by both an interest in having many superficial contacts and a suspicion bordering on paranoia.

The whole description presents the picture of a person with Asperger Syndrome, lacking social understanding other than that which he has learnt by rote. He cannot generalize to similar situations. He has difficulties comprehending how other people think and function and as a result finds it hard to know what is expected of him in different situations. He never keeps his end of agreements and it is doubtful that he understands them.

Jan's case manager, Hans, is given the assignment in a staff training session of keeping a notebook in which he clearly writes down all the agreements that he and Jan have made. Hans is to try and make himself as clear as possible, coming at it from more angles than usual when he explains to Jan what is expected. In the notebook, he can also include other things that Jan needs to remember and learn.

Since Jan is assumed to have delusions, Hans will also start documenting them under the heading *Delusions* and *Misconceptions*. Hans thinks that Jan has quite peculiar notions about certain things and has always thought of them as delusions. Through documentation, Hans will be able to define these notions and also determine if they stem from ignorance on Jan's part. In that case, Jan simply needs to be told how they correspond to reality. Some of these notions, for example, have to do with Jan being afraid of wild animals on TV nature programmes; he believes they can attack him. Hans tells Jan to write in the notebook, "Animals on TV cannot attack me". It turns out that Jan himself thinks that the written text helps him deal with these thoughts.

Hans also brings up the problem of Jan's inability to distinguish between expressions of emotion. Jan uses the word *anxiety* for an entire range of feelings including fear, anger, disappointment and the like. Hans has started to deal with Jan's descriptions of situations in which he says he experiences anxiety. Hans then tries to teach Jan the appropriate name of the emotion the situation actually calls for. Jan writes all of this down and Hans relates with great amazement that Jan *actually* does not know such basic feelings but has to learn them. Hans also relates that he now is beginning to understand that a person who lacks such fundamental knowledge is not necessarily trying to fool those in his surroundings. Previously he often thought: "This guy's pulling my leg!" when Jan has in realty been demonstrating ignorance. Hans also says that it requires an unlearning of the old way of looking at patients when dealing with people who do not fit into the old theories and the ingrained ways of thinking about patients.

Kerstin

One of the other case managers, Lotta, describes Kerstin's problems:

> She is described as having been strange since childhood. Has always been dependent on her mother, siblings or someone else. Finds it extremely difficult to structure her life and understand social rules. Is socially awkward and doesn't hesitate to blurt out unpleasant truths to whomever it may be. In spite of her difficulties, she has earned more university credits than necessary for a bachelor's degree. However, she is unable to convert the information she has to any kind of usable knowledge; instead she has worked as a cashier. She has had problems on the job, though, and is currently on sick leave. Her arm became infected in connection with a visit to the doctor and she is now fixated on the tiny scar that it left; she incessantly dwells on it when talking to others, whether they want to hear about it or not.

Lotta also makes use of a notebook in her work with Kerstin. Everything is written down that Kerstin needs to know and remember to better manage her dealings with other people. In addition, she needs to learn a considerable amount of common, everyday knowledge. Lotta has drawn up a schedule for Kerstin to have at home that helps her manage daily living activities. Kerstin is very interested in learning and likes writing down rules, but then finds it difficult to make use of them on her own. Someone has to be there to remind her and someone needs to be on hand to explain when she has failed. Kerstin is also considerably skilled in getting help from various people and involving them in her life in different ways. She calls different doctors in order to collect certificates about the scar on her arm. She is constantly filing complaints about the psychiatrists who are responsible for her care. Kerstin has very little insight into her own problems and her own way of acting and blames all her failures on others. She totally lacks the ability to reflect upon herself and cannot see the part she plays in communication with others.

All three case managers know Kerstin well since her case has been discussed frequently during their meetings. They have had different opinions as to how she should be treated. They now see, though, how Lotta's educational efforts have paid off. Even before the staff training programme, Lotta had started using an educational approach that she learnt during her time as an assistant to a pupil in special education. Many of Kerstin's characteristics are similar to those of the autistic pupils she had in special ed.

A major stumbling block in the rehabilitation effort is Kerstin's psychotic diagnosis, which she has had since she was first admitted. For a long time, Lotta has felt that Kerstin has an autism spectrum disorder. She has been in contact with adult rehabilitation to apply for housing benefits, but Kerstin needs to have the autism diagnosis in order to qualify for assistance. A new assessment is needed, but this will not be easy to carry out since Kerstin has never been willing to accept any type of psychiatric diagnosis. She has learnt to attribute all of her problems to her childhood and her parents' inability to teach her what she needed to know to manage in the world.

In an effort to relieve Lotta, a psychologist has been engaged to have regular counselling sessions with Kerstin. It soon becomes apparent that the psychologist has a psychodynamic view of Kerstin's problems that is in total opposition to how Lotta and the other case managers see her. The different views of Kerstin's problems run the risk of ending up in a dispute, which is why we decide to invite the psychologist in for a discussion. Lotta also carries out an educational diagnosis of Kerstin using the 60-point assessment survey that I developed and presented in my licentiate thesis (Mandre, 1999); results from this will be used as the basis for the discussion.

When we have examined the points on the survey that characterize Kerstin, it becomes apparent the significant difficulties she has in perception, cognition, social contact and communication. She entirely lacks the ability to reflect on her own mental processes and actions; nor is she able to understand the perspectives of others. It is also apparent from the assessment that it is easier for her to memorize facts and complete university courses than to manage customer contact in a store. The psychologist starts to see Kerstin in a different light, but still finds it difficult to accept.

Christina

Kerstin's psychologist is also participating in Christina's assessment. Christina is a young woman who recently interrupted her high school studies and was admitted for psychiatric care. She is a relatively new patient of Gunilla's, the third case manager, and there is a difference of opinion between Gunilla and Christina's psychologist on the appropriate diagnosis. They are both participating in the assessment but have entirely different opinions about Christina's abilities to make social contact. The psychologist thinks that Christina makes contact and is not withdrawn. In her opinion, Asperger Syndrome is such a severe communication disability that Christina cannot possibly have it since she speaks fluently and answers questions adequately. The psychologist might be able accept a diagnosis of DAMP (Deficits in Attention, Motor control and Perception), which she considers to be a milder disability. It becomes obvious the great extent to which previous knowledge and background theory influence the interpretation of the diagnostic criteria *absence of reciprocal contact and communication.*

During one staff training session we make two lists: one of the symptoms for Asperger Syndrome and one for DAMP. Then we go through them to see which symptoms apply to Christina. It is evident that Christina has more symptoms that are typical of Asperger Syndrome than of Damp.

The psychologist tests Christina with the WAIS and finds that she has an IQ of about 50. An IQ that low is entirely inconsistent with the fact that Christina has completed compulsory school with above average grades. With an IQ that low, she would have attended a special education training school. It is obvious that you cannot just go by IQ when evaluating, but that you need to look at discrepancies in a patient's profile and interpret them. In the case of autism, the profile usually contains discrepancies that are fairly characteristic. Hans, who is also a psychologist, concludes that Christina is considerably more autistic and does not just have a few autistic traits, while the other psychologist sees it as an autistic defence and judges Christina to have good emotional capacity. Christina works with children at a day care centre, which is a job that demands intuitive skills as well as awareness of the needs of others. These skills contradict an Asperger Syndrome diagnosis. Soon thereafter, though, the supervisor of the day care centre informs Christina that she will no longer be able to work there since she is unable to take initiative and is only able to carry out those tasks that have been explicitly given to her.

It becomes increasingly clear that the differences between the two psychologists concerning Christina are based on their different theoretical backgrounds. This, in turn, results in different interpretations. Things become critical as Christina grows more desperate over her situation. The opinion of one psychologist indicates that she is cognitively limited. At the same time, her employer has told her that there are significant problems with her job performance. She has done her best but it hasn't been good enough. At this point, the case manager suggests that I should meet Christina and draw my own conclusions.

In the two-hour-long discussion I have with Christina, I assume the Asperger's hypothesis and ask questions based on that. During the course of the conversation, a noticeable change takes place in Christina. When she meets her case manager the next morning, she is still desperate, but now she recognizes herself in the questions I ask and can confirm, with examples, that I am on the right track. When she finds out that you can have different mental processes that result in an uneven test profile, she feels a bit better. She relates that she has been quite distressed over the test results indicating that she was retarded. All the years she was in school, she was teased for being "dumb". She feels that she understands things quite will, but that she needs more time to think before she can react and take action.

She also relates that it is difficult for her to be with the children at the day care centre if she does not know exactly what she is to do. She cannot think of anything spontaneously to talk to them about, but can read stories to them, for example. All the work situations in which she has to figure out on her own what to do are difficult. When the questions are asked in such a manner that she recognizes herself, Christina is able to talk about her difficulties and it also becomes clear why school and work have been so hard for her. The new assessment will be based on the Asperger hypothesis.

Michael

Michael was born in the mid 1960s. He has been in psychiatric care for a long time—first as a child and then as an adult. As an adult, he was diagnosed as schizophrenic. Michael, his parents, psychiatrist, psychologist and both contact persons participate in a meeting before the staff training sessions begin. In that discussion, his parents immediately recognize many of the autistic characteristics I mention and think that they describe Michael as a child. Michael himself sits, quietly observing at first. During the course of the discussion, though, he moves closer to the table at which the rest of us are sitting. He becomes more and more interested in the discussion and starts to answer questions himself after a while, and to corroborate a good number of the autistic symptoms that his parents recognize. The meeting results in the psychologist and psychiatrist deciding to carry out a new assessment.

Shortly thereafter we have our first staff training session and start by going through the descriptions of Michael that are found in his medical records. According to some earlier entries, he hallucinates. On the present unit, however, they have not observed anything like that and there is nothing in the records that indicate how it was determined that Michael had hallucinations. His problems are many, which is why we start to list them in an attempt to see which behaviours can be attributed to autism, which have to do with disturbances in perception, which are related to his sleep disruptions and to try and find the origin of his tantrums and aggressiveness. I provide the staff with special forms that I have developed for observational documentation. Michael's tantrums and aggressiveness are to be documented on these forms for a month. An analysis at the end of that period reveals:

- Group activities are impossible!
- There are fewer outbursts when Michael has constant supervision; the nights are calmer then too.
- Sleep disturbances: He doesn't wake up as early in the morning now that he has a window shade.
- It is better if he is can be given more time to wake up; this is accomplished by playing calm music when it is time to get up so that the process is not so abrupt.

new treatment plan

New treatment planning is to be drawn up that will include:

- An individual treatment plan which contains structured, long-term goals with short-term objectives.
- A treatment plan with the parents in which their role in the habilitation process is described and in which objectives are concretely stated and possible to realistically fulfil.
- A treatment plan with the municipality's LSS administrator (LSS = Act Concerning Support and Service for Persons with Certain Functional Impairments).
- The adult social services unit in Michael's local municipality will participate in the process so that it will receive support in finding housing and employment for him.

It has come to light in a staff training session that Michael needs to have variation. He finds it hard to concentrate and is restless, and the staff feel that he will be more alert with something novel in his daily existence, which is otherwise quite monotonous and uneventful. Michael is to have more control over his daily activities. He moves into a new room with his own lavatory.

Activities of daily living are put on a list and he is able to choose what he wants to do and the order he wants to do them in everyday. This is coupled to a list of rewards that he can choose from every week if he has done all the things he is supposed to. The reward can be going for a drive, playing golf, visiting the hamburger restaurant and other similar activities. The list is planned for a month at a time, and once during this period he can choose to go on a longer excursion such as a fishing trip to the coast or dinner in a restaurant.

Everything works fine the first week, but then, little by little, Michael becomes disruptive and starts causing trouble. It appears that the staff's ambitions have been too high and that a month was too long to start with; the job of managing a whole month may feel like an insurmountable task. The question arises: What is Michael's concept of time?

It also becomes apparent how difficult it is for the personnel to give one patient special treatment, using entirely different methods with him than with the others. It is hard to explain to the other patients what is so unique about Michael.

Michael's continual drowsiness, alternating with periods of hyperactivity, needs to be further investigated. A special team is contacted for this purpose. Perhaps Michael needs to be treated with amphetamines to cope with these problems. But when his psychiatrist finds out that the waiting period is close to a year, he decides to apply for a license to prescribe and treat with amphetamines.

The forensic psychiatric clinic carries out a new diagnostic assessment, the results of which indicate autism with a secondary diagnosis of ADHD (Attention Deficit Hyperactivity Disorder). The psychologist then gets in touch with the local authorities in Michael's hometown. With the new diagnoses, Michael is now included in the group that falls under the first section of the LSS; as such he has the right to housing and a day activity programme. There is no reason for having Michael committed to psychiatric care when he has not been convicted of a crime and is not judged to be dangerous to himself or others. On the other hand, he requires much support and assistance in everyday living, and very likely will continue to for a long time to come. He is in need of practical help as well as instruction in the basics of how people act, in social rules and in how to socially interact. And he needs staff members who see him from an autism perspective and teach him step by step how to deal with other people, with social situations and to live as independently as is possible.

A little over a year after our first meeting about Michael, the clinic personnel confer with the LSS administrators in order to find housing for him. The local authorities do not agree with the proposal that the clinic and parents have for independent housing and personal assistants. Michael needs male staff and the authorities from the small municipality in which he resides do not think they will be able to find as many as are required. Instead, they suggest a group living arrangement, for which there is currently a waiting list; Michael's move will take place in about a year's time.

contacts with child psychiatry

The improvement in Michael's behaviour that occurred the week after he moved into a new room was only temporary. He reverts to being just as restless and drowsy as before. The novelty of getting a new room sufficed to raise his level of alertness for a while, but once accustomed to that, he is in need of new variation. One way is to cause trouble and chaos on the unit.

Michael's psychiatrist has requested all the medical records from the different psychiatric treatments Michael has had since his time in child psychiatry to build a case for possible treatment with amphetamines. Perhaps Michael would be less tired and more energized by drinking coffee or something else containing caffeine. He should also be observed on those occasions when he has tantrums and is disruptive in order to ascertain how much of his conduct is deliberate and how much he could control if he was more alert.

Furthermore, it is important to find out the time units Michael is able to comprehend. It was clear from the start that a weekly schedule was too long. Is a schedule for the whole day too long as well? Should reinforcement come after each successful step? It does not seem possible for him to manage all the steps that are needed to behave for a day. Most likely, he has no idea of what it means to *behave yourself* either. This is an all-encompassing concept that the assistants working on the unit use in a self-explanatory manner, never having explained to Michael exactly *what* it means to do so. As a result, he lacks both the opportunities and the motivation to behave himself. Moreover, there will be a drop in motivation when he finds out that he loses credit for the successful steps he has completed if he is unable to successfully complete all the steps that are required during the day.

One important concern on the unit does not become apparent until towards the end of the staff training sessions: the two teams working there treat Michael differently. The team that does not attend the training sessions deals with him in a much more restrictive manner, which more easily leads to violent behaviour on Michael's part. The psychologist suggests that I return and hold a one-day seminar for the other team, with the hope of making it easier to co-ordinate treatment when both teams have the same information.

Six month after I have concluded my training sessions on the unit, I interview the psychologist who summarizes Michael's current situation as follows:

> Actually, things are going both good and bad for Michael. We do have an LSS decision and it has been determined that he belongs to group 1. They are to find a group living arrangement for him and there already is one for people with autism, which is evidently quite good. When he is placed there, the municipality is prepared to pay, but he is certain to need extra personnel in the beginning … and when it comes to medication, we discontinued all for the treatment of psychosis … at first it was fine, but after a while he became anxious, more aggressive, agitated … and then we were granted a license to prescribe amphetamines and that was started in the beginning of December, but had no direct effect as we had expected. The dose was gradually elevated, but there was still no effect … so our suspicions concerning that treatment were not confirmed … and the chief psychiatrist has now thoroughly read all the medical records, beginning with those from child psychiatry, and has noted that Michael's delivery at birth was very difficult involving lack of oxygen, so one of the sub-components can be brain injury and that along with the autistic symptoms more than qualifies him for coming under paragraph 1 of LSS. We are giving him Cisordinol again, but his motoric restlessness remains … he walks back and forth a lot in the corridors, but, on the other hand, he is so extremely unhappy here … and he goes out for walks with a staff member everyday, but they are not long because he is too anxious for that as well, so they are just short snatches … and then there is considerably more opposition in this team than what there is on the other unit … half of the staff do not go along with the educational treatment approach … the different teams on the unit simply have entirely different views of treatment and that makes it much more difficult …

My question: *But how do you deal with this, when two different teams behave so differently?*

> We have tried to talk about it and to inform and push for that approach, but it has not really helped …

My reply: *I remember that Svante said at one staff training session that fifteen minutes after the other team started their shift, Michael was belted down …*

> Well, yes, it's been that way on a few occasions, but I have to say that tolerance has increased considerably of late, but there is still a basic difference between the teams and the best thing would be to move Michael to a smaller unit where the staff are in agreement and where he would receive treatment that is primarily based on his autism spectrum disorder.

Jasper

Jasper is a little over thirty years of age and was committed to psychiatric care by the courts under the Forensic Psychiatric Care

Act (LRV) for several counts of arson and death threats. His time at school was spent in special education and he has also participated in activities at a municipal day activity centre for adults with cognitive limitations.

At the first staff training session we discussed his compulsive behaviour. He does not seem able to control when he laughs, and does so at inappropriate moments. It seems to be more tic-like than a true laugh.

Jasper has previously been compulsively fixated on weapons and violent films. The result of living an isolated life with these interests has left Jasper with a view of the world dominated by violence. His violent fantasies are compulsive and he is unable to hide his thoughts but, instead, relates all his bizarre fantasies quite openly and naively. Jasper is also insensitive to the suffering of others and does not think much about the consequences of putting his fantasies into action. For him, it seems that real deeds are equivalent to the deeds he has seen on video.

jasper's educational diagnosis

After the second training session, I carried out an educational diagnosis (Mandre, 1999) to try to define Jasper's problems more precisely. When we then went through the evaluation with the staff to see how my perception of him corresponded to theirs, we did not diverge on any of the points. However, I discovered that my observation points did not cover all the different forms of compulsion that to a large extent characterized Jasper's life. It made me much more observant thereafter of all kinds of compulsions and tics that could occur in the people we discussed in the different training sessions.

jasper's sense of self

The staff describe Jasper as a person who "disappears into the wallpaper". He is quiet and taciturn and makes no efforts to initiate contact with anyone. The occupational therapist starts meeting Jasper in order to begin charting how he sees himself and what he thinks about his existence. She asks him to draw a self-portrait. The first one shows that his reproduction abilities are quite limited. In the first picture, the person has only a couple of fingers. On a latter occasion, he draws more fingers and more hair; there are, however, fewer than five fingers. He also writes his name when requested, but the signature is just a scribble, until the occupational therapists asks him to print it. He draws, on request, the people he thinks are closest to him. They are his contact person on the unit and a patient whose name he cannot remember. It seems as though people hardly exist for him when they are not physically present. He finds it difficult in general to make associations. He also finds it hard to remember the names of staff members, for example, when they are not present.

When Jasper is asked to draw the distance he would like to have from other people, he draws a circle around himself and says that he does not want to have anyone close him. When he is in the company of the occupational therapist, he decides where she can stand and what distance feels right for him. On the unit, his two contact persons have been able to come closer and closer, and are now able to sit on the edge of his bed and talk and also touch him without him recoiling. Jasper says himself that it is best if people approach him straight on or at a slight angle from the front so that he is prepared.

The occupational therapist continues to work with drawings in order to start talking to Jasper about a variety of feelings and how they are expressed. He draws a happy face by making the corners of the mouth turn up. Sadness and surprise prove to be more difficult and he draws something on the face that is more by chance than because of thought or understanding.

relations and feelings

When you speak with Jasper about people, he can tell you which staff members he prefers and motivates his choice by saying that they are happy and nice and that he likes happy, nice people the most. Could it be that he finds it easiest to read a happy facial expression? More neutral expressions are harder to decipher. Some on the staff think that he divides them up more according to functions than relationships. He appears to have very poor knowledge about feelings and how they are expressed.

When we discuss Jasper's various relationships to staff members, it becomes clear that they also vary in emotional quality and that relationships are not unimportant for him. They are just expressed differently and have another more needs-determined emotional basis than what is considered normal.

The contact person relates:

> Establishing contact with Jasper has taken a long time … first he had to get used to the idea that "this is my contact person … " then he had to remember that my name is Lars and that I am a nurse and gradually he started to take the initiative and come to me … but it has taken so much time … and there is also the risk that you'll wait too long for him to come to you, thinking that he will eventually approach you if you hold your ground, but he doesn't do it … and then he has his territory and is afraid that people will come too close … and now that we know a little more about autism, it is easier to be more persistent with him, knowing that he's *unable* to show certain things, not that he doesn't *want* to … and it is also difficult to establish contact with him in the normal manner … you get a "hello" out of him or some other phrase he has memorized and nothing more. You really have to make an effort to find something to talk

> about . . . and talking to him and trying to find ways of establishing contact are up his contact persons, for the most part … it's usually the case that you have your patients and those are the ones who come first.

When the psychologist starts talking to Jasper about the threat he made against a woman, assumed to be his girlfriend, it comes out that she is not a girlfriend at all, but a distant acquaintance, the thought of whom had become a compulsion. He wants to get rid of her in the sense of getting her out of his mind.

Jasper's understanding of emotional expressions is close to non-existent. One can question how many expressions of emotion he can even name. Which ones does he understand and is able to connect to corresponding situations? He laughs involuntarily when he has written his compulsive letters. Writing threatening letters seems to be a means of releasing the tension in his body. Efforts have been made of late to try and get him not to actually send the letters off, but to give them to his contact person on the unit instead. They are also trying to explain what the consequences are for him as well as for the recipients—if he were to send them. Jasper, however, has no real understanding of the effect his threatening letters have on the people who receive them. He might be able to understand that they will be angry and go to the police, but when his contact person tells him that the letters scare the recipients, he only shows surprise.

cognitive difficulties

Jasper attends adult education classes once a week and likes going to school. He realizes that he has a lot to learn. He manages elementary school mathematics and Swedish with difficulty. We also discussed the possibility of him receiving instruction in adult special education classes for students with autism and cognitive limitations, and in that way receiving even more time in school.

It is uncertain how much Jasper really understands of what we talk to him about. He often answers with a monosyllabic "yes" or "no" and finds it hard to hold up his end of the conversation. It ends up being mostly a case of questions and answers. He has asked about what is needed in order for him to be discharged and it has been explained to him, but he does not remember from one time to the next. Thus, it is decided that this information will be written down for him and divided up into steps so that he can cross off the steps, one by one, as he completes them. In this way, the concrete objectives he has to aim for are made clear and understandable for him; he also knows when he has fulfilled them.

On one occasion, I meet Jasper for about 15 minutes to discuss his situation. He is not easy to talk to; it is mostly a matter of questions and answers and he appears to have a vague perception of what is required for him to be released from forensic psychiatric care. He says that the plan is for him to get out in two years. What does he need to do to be discharged?—“Behave myself”—What does it mean to behave yourself?—“To not revert to crime”—What does it mean to not revert to crime?—“I don’t know.”

The psychologist starts to take up in his sessions with Jasper what he needs to better understand: what it means to “behave himself”, “not revert to crime” and other things that are necessary for him to be discharged from psychiatric care. Jasper also has to find strategies for dealing with his compulsive thoughts so that he does not fall back into the ritualistic pattern of drinking beer and then committing the same kind of crimes as before. He has to learn which drinks contain alcohol and, consequently, which ones he is not allowed to drink.

The contact person, Lars, about Jasper:

> What he needs the most would be to have some people around him all the time who knew about autism and who could interpret the world for him, who could tell him how things worked and what you are supposed to do … after your course I’ve understood that you have to start at a much lower level than what you had otherwise thought … otherwise, you think that Jasper is, after all, 30 years old and that he should be able to manage this and that, but you are misled by the exterior … others don’t consider the fact that people like Jasper simply don’t understand what most of us take for granted.

alternatives to obsessive thoughts and more structure

Jasper has many obsessive thoughts. One way of giving him alternatives to these is to provide him with more things to do so that there is less of a vacuum in his thinking, which he ends up filling with obsessions and rituals. The occupational therapist decides to draw up a schedule for him that will make life easier for him to comprehend.

In the spring, Jasper joins a group activity in which he works with wood. It works out well for him to be in a group if he is allowed to have his own space. As soon as someone comes too close, he moves to another area. He chooses pre-cut pieces of wood to work with and needs assistance every step of the way. He cannot determine on his own when a step is completed.

The plan is to also start getting him accustomed to doing certain activities with others. Since he likes playing TV bingo, the staff try to get him to accept watching the programme with a group. The psychologist has begun talking to him about things like sitting on the same couch as another person; he does not have to stand because someone else is already sitting there. If he does not want to sit right next to the person, he can sit a little ways away:

obvious knowledge for most, but not for Jasper.

Future plans are also being discussed in which Jasper will need to have a very structured existence with lots of activities to keep him busy so that he has no time for obsessive thoughts. It also requires that he gets used to passing by the places in his hometown connected with past crimes without triggering the compulsive associations to commit arson.

It is a matter of providing him with alternative thoughts and actions to replace the compulsive ones. He is unable to think new thoughts on his own, or to initiate new actions, which is why it is crucial that the initiation comes from those in his surroundings. The only educational method that will work for Jasper in his current state is that of behaviour modification, because he simply does not have the ability to reflect upon what he thinks and does.

Certain ritualistic activities that Jasper carries out can only be changed through a step-by-step deconditioning process resulting in new behaviours. He also needs to learn new patterns of thinking through rote memorization and in this manner, overlearn alternate strategies. At the same time, one can try to develop his cognitive abilities to gain greater insight. Jasper most likely will need to have a structured life and continued supervision for a long time, along with continued extensive support when he makes the move to municipal housing in the future. His propensity for obsessive thoughts and actions in conjunction with his inability to empathize with others and his difficulties in understanding the consequences of his actions places him in a high-risk category.

what happened then?

Six month after the staff training sessions ended, I interviewed the staff on the unit.

One of Jasper's contact persons related the following:

> Jasper goes to school two days a week now; he has sessions with his psychologist and gym three days a week … and I actually think that things are going much better for him in the group now and he is taking initiative a lot more, which I think is amazing … he has, for example, written to the outpatient unit to request copies of his medical records to see what they have written about him … and there they referred to his problem with alcohol and we have sat up several nights and talked about it because he wanted to … and that is probably the biggest change that has taken place—that he has become interested in himself and how others see him …
>
> We have structured his days for him; he has a schedule and I think that it works well for him now … and his entire facial expression has changed; he smiles more often and looks positive … and you can see that he *is* someone now … it was really necessary that we set aside time together with him; before he just faded away and was afraid and silent … before we waited for the initiative to come from him, but it never came … but since we started to put a little pressure on him, things started to happen … the only thing he could really come up

> with to do on his own before was to ask if he could go to the newsstand …

Herald

Herald is a man in his 30s who has a schizophrenia diagnosis. The personnel on his unit do not think that he is like the other patients with schizophrenia and it is difficult to treat him with the methods available. Herald has been on the unit for shorter and longer periods over the last four years. When the staff training sessions begin, Herald is sharing an apartment in a group home with a young man who has Asperger Syndrome. The staff suspect that Herald also has an autism spectrum disorder and that is what the training sessions will focus on.

What they see is Herald's lack of reciprocal contact, difficulties structuring his time and planning. His mind can be totally blank at times, completely empty of thought. He is impulsive, easily distracted, easily led. He has many "friends" that he hardly knows the names of. These occasional acquaintances can easily involve him in all sorts of questionable activities in which he shows poor judgement. It has been observed on the unit that Herald needs quite a lot of structure in order to function. He has perceptual disturbances, finding it difficult to locate what he is looking for in a cupboard or in cluttered spaces. He can become completely powerless to act and forget what he is doing. On the whole, he has considerable difficulties initiating activities and avoids doing anything he has not done before.

When he does not know what to do, he lies down and goes to sleep. He can also be mentally absent in the middle of an activity or conversation. The thought vacuum, drowsiness and sudden mental withdrawal seem to result in unplanned activities that are not directly motor hyperactivity, but may still be a way of keeping the brain active. This will be observed and documented for the next staff training session.

continued staff training

Since Herald lives in LSS housing, the housing staff will also be affected by what we discus in the staff training sessions, which is why we invite them to join us.

from my notes

The staff have been in touch with Herald's legal guardian who will help him to withdraw money and portion it out every week. The staff relate that Herald finds it exceedingly difficult to learn from experience and that it does not help to talk to him about his inability to plan his purchases. Although he appears to be in complete agreement about his planning problems during a discussion, as soon as the staff member is out of sight and earshot, everything is forgotten. Herald is also described as being extremely carefree. He can be without money for food for several days without it bothering him in particular or causing him to stop and think. Each moment and each experience is as though it were happening for the first time and detached from the past and the future. He has no long-term plans, but lives entirely in the here and now. Still, he manages relatively well because he has charm, which he combines with a superficial pleasantness and an expressive but childish body language. In this way, he appeals to others who lend him money or help him out in other ways. He has an ability to connect with people that appears to be entirely normal and socially appropriate at first. But when observed over time and in different situations, you see that he has a memorized pattern that he always uses, with the same phrases and the same small talk.

Herald has no lasting insight into his own difficulties. On some occasions, when staff members speak with him about it, he seems to understand, but as soon as they have finished talking, the insight disappears. On the whole, he has considerable difficulties in paying attention. A game like volleyball that requires focused concentration is almost impossible for him if there is not someone there all the time helping him to concentrate.

One suggestion was to introduce a notebook to be used for discussions and agreements, so that everything of importance was written down. Perhaps that would assist him in gaining more insight and understanding of the help he needed.

We also went through the points from my educational evaluation that described Herald (Mandre, 1999). Most of them had to do with disturbances in perception, concentration, memory and planning difficulties. Herald has a strategy for managing everyday situations because he has learnt to react to certain signal words that he knows will result in a certain actions. He is particularly good at everything associated with motor activities.

new assessment?

It becomes more apparent how severe Herald’s memory problems and concentration difficulties are. He also tires easily and cannot do as much as others. A new assessment is called for to delineate his difficulties. If he really does have schizophrenia, it cannot be the only diagnosis. He was very disappointed in his poor results on the last psychological test, and it is necessary now that he be given a realistic picture of himself—both of his difficulties and abilities. He has good gross and fine motor skills and co-ordination; he is able to concentrate when someone can get his attention and motivate him.

One possibility would be to involve Herald in computer-based activities. A computer screen helps to maintain concentration. Multimedia programs with visual and auditory input could provide sufficient motivation to hold Herald's attention.

The staff have observed that Herald's best sensory input channel is the auditory one—the spoken word is better than the written. That is probably why he is not very interested in writing down what he has agreed to do in the notebook. The difficulty, though, is that he does not remember what has been said. Perhaps his schedule and instructions should be tape recorded instead; spoken language alternated with a little bit of music, for example, to tell him what his day will be like. It is obvious that he needs to have some kind of aid to help him remember.

The unit supervisor took up the question of a new assessment with the chief psychiatrist. Treatment with amphetamines was also discussed. It is obvious that Herald can no longer live in the apartment he now has, because he is in need of much more assistance than they had reckoned with when he first moved in. They are now going to try and find a placement in a smaller nursing home outside of town.

This, however, turns out to be considerably more difficult than expected and it will be a long time before Herald can move out of his apartment. The staff members are weary and dissatisfied with the effort it takes to make do with the current arrangement. They have tried so much but have now lost all enthusiasm; they are only waiting for Herald to be transferred to a place where there is more structure than they can offer him.

what happened then?

It is quite obvious in Herald's case how poorly the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) addresses the needs of people with specific cognitive and executive difficulties. It presumes that those who are covered by the law are aware of their needs and can decide the services they want themselves. Two of the people from the housing section of the municipal LSS authority who have participated in the staff training sessions provided the following summary in their course documentation:

> We received confirmation during the training sessions of how limited we are in what we can do in complicated cases; how difficult it is for us at the local level to properly serve the needs of a fellow with the problems that Herald has. We are only supposed to support, not take over his life. Herald, with his impulsivity and lack of insight needs framework and structure 24 hours a day, but we are not allowed to infringe on his rights or give him this kind of special treatment. Herald refused all the suggestions and aids we offered, such as a

> blinking light as a time reminder, writing things down in a diary, audiotapes, etc. We will be able to make use of these aids in the future, however, with clients who have insight and who want help.
>
> Today, we have reached an agreement with Rehab that Herald will be placed in a facility with more authority to provide the kind of care that he is unable to get in an apartment on his own. Herald was given the chance he wanted to take control over his own life; he couldn't manage it.

In a follow-up interview, Eva, the nurse, describes what happened to Herald:

> Things haven't gone very well for him … he is on the admission unit and has been there for at least a month now … he was admitted to a residential treatment programme but only stayed there two days and then left … he couldn't have the apartment anymore … he stopped taking his medication … he had not been committed to residential treatment and if you refuse to take your medication, there is nothing they can do … and we really did all we could to stay in touch, but it didn't work out … and so he started using drugs and ended up in a psychosis and then there was no choice but to commit him …

8. The staff training process concerning specific problem areas

The design of the staff training sessions for two of the units differed from that of the others due to particular circumstances, which will be further described. They were the *Forensic Psychiatric Assessment Unit* and *Rallare*.

Forensic Psychiatric Assessment Unit

We were unable to examine individual cases and follow them up because the time the patients were on the unit was too short (3–4 weeks as a rule). In addition, it was not possible for one team to take part in all of the staff training sessions due to staff shortages.

In consultation with the unit supervisor, I decided to take up a new theme at each of the staff training sessions. These themes would offer the staff opportunities to make associations with previous or current patients and to come up with their own examples. The areas included were as follows:

- contact/communication
- nonverbal communication
- pragmatic language disorders
- unusual cognitive processes
- understanding social situations
- understanding emotional expressions
- ability to describe feelings
- ability to exchange ideas and maintain a conversation
- reactions—slow, impulsive, reflexive, hyperactive, extreme, etc.
- difficulties in meta-cognition—ability to reflect upon the way one thinks and acts
- difficulties with abstract concepts—believing, supposing, assuming, intending, etc.

One idea that was also developed in discussions with the chief psychiatrist was that the patients with autism/autism-like conditions could bring a set of “instructions” with them to the unit that was going to treat them, in order to facilitate planning.

A summary of my own documentation on what was covered during the training sessions:

rituals and complusions

What became clear on the Forensic Psychiatric Assessment Unit were the repeated accounts of the patients' rituals, obsessive thoughts and compulsive acts. These compulsions often were the underlying cause of the crimes they had committed. Examples were given of those who committed the same kind of white-collar crimes again and again. Even though the crimes were detected, the person was unable to change strategies. The crimes were a sort of ritual that had to be carried out in exactly the same manner each time. These people also felt completely secure in the ritual that followed which involved discovery, police interrogation, jail, etc. There was one patient who always asked for the same cell when he was detained.

Routines, rituals and obsessions characterize autism spectrum disorders to a greater or lesser extent. One way they may be expressed is in the collecting of objects. The person collects stones, newspapers, a type of clothing or something else in a manner that has no real purpose. Ritualism can also be expressed in always buying two of a kind or another predetermined quantity, such as always purchasing for a certain amount.

deficiencies in emotional reactions

The results of forensic psychiatric assessments often reveal a number of people who do not react emotionally to situations that normally evoke emotional responses. This comes out in life history descriptions or when a person talks about his childhood by only listing factual information.

These people are seldom aware of nuances in emotional expression and find it difficult to recognize their own feelings. "Why is there water coming out of my eyes?" can be a question asked when someone cries. Feelings and their names can then be taught as whole concepts based on the patient's experiences—emotional expressions are named and paired with appropriate situations through instruction.

Some of these patients are only interested in the factual content of the forensic psychiatric evaluation. They can collect all the legal information imaginable, learn the wording of the law by heart and then lecture the staff and their fellow patients. Among them are those who are always filing complaints and appealing decisions, who always feel their rights are being infringed upon, who try to use the system.

Two of the staff training sessions dealt with a middle-aged man who was described as extremely "empty". The personnel found it difficult to establish any real contact with him. He appeared to only communicate with stereotypic, memorized phrases as if he was totally incapable of spontaneously expressing his own ideas and feelings. He was described as being controlled by routines and got up at exactly the same time every day, sat on the same couch and waited for breakfast. He also spent his days in a state of extreme passivity on the same couch. He was incapable of coming up with other things to do than to watch TV. The staff wondered if he could have Asperger Syndrome. What confounded the assessment even more was a previous report from another psychiatric unit in which the description of him did not fit at all with how the personnel on the assessment unit saw him. This situation called into question the observations and interpretations that are the basis for patient descriptions found in the medical records. Observations made by professionals with different perspectives and interpretations can result in entirely different descriptions of the same person and with that, different diagnoses as well.

At the training sessions, it also came to light that the various teams on the unit could interpret observations in entirely different ways, which is why a patient could be assessed differently and be given a different diagnosis depending on which team it was that carried out the assessment.

Rallaren

The issues discussed at Rallaren will be summarized and described as *problem areas* instead of as cases. Many of the patients on this unit are so unique that descriptions of them could easily lead to identification.

problems with food and weight

One of the most common problems that came up in the staff training sessions on Rallaren was related to food and weight. Some of the patients had previously been treated for anorexia. During treatment, their constellation of symptoms proved to be different from the others and the customary methods had not worked. The problems were of a different nature and what first appeared to be only compulsive behaviour proved to have a number of different causes. One of the reasons why some patients did not eat as they should and were, as a result, underweight was that they simply did not know what "normal" meant in relation to body length and constitution. They had come up with their own, unique concepts of this that proved very difficult to alter. Nor did they have any notion that nutritional needs varied depending on how much a person worked or exercised. Such basic knowledge is necessary before you can try to treat compulsions or other factors connected with them. One way is to construct an individualized, balanced diet chart with the patient in which you list the portions of different kinds of food that she needs to eat every day in order to get all the required nutrients.

Additional factors that result in some people not eating enough can be that they do not enjoy food and never look forward to eating a particular dish. Food is seen as a necessary evil and the body as a machine that always performs in the same way when it takes in the same nourishment.

On one occasion, a married couple that had problems eating regularly became very irritated with Rallaren's personnel for meddling in their lives. Staff members tired to explain the consequences of eating too little food, and food of low nutritional value. The staff felt that they had no other alternative but to step in and try to show the long-term consequences of certain eating habits. The couple pointed out that they were healthy, but the personnel still tried to instruct them on the long-term effects of an unhealthy diet.

In several cases involving patients' poor eating habits, it turned out that the problem did not have as much to do with the actual food as it did with an obsession to save money. Everything they purchased had to be as inexpensive as possible; health considerations were secondary even when they claimed the contrary. Indeed, these patients had no difficulties eating unhealthy food when it was offered free of charge. If anything, free meals resulted in startlingly displays of gluttony.

In the staff training sessions, the personnel also shared examples of attempts to help patients with eating disorders, but in which the help became a kind of imprisonment: They got one woman to start eating by providing her with a meal schedule. She became so tied to the schedule, though, that she refused to go on outings for fear of missing a meal. She had to be given an alternative menu in which the kinds of food she could take with her in the form of sandwiches or fruit were listed; she would then be assured of having something to eat if she was away at meal times. This woman eventually started in a social training group to get additional support and assistance.

Eating disorders are sometimes due to a person's inability to interpret internal signals, not really knowing when he or she is hungry or thirsty. A mother of a young child sought help at Rallaren for the difficulties she had in sensing when she needed to eat. This meant that she did not know when her child needed to be fed either; she wanted help in solving the problem for both of them. In this woman's behaviour there were many other indications that were associated with Asperger Syndrome, which is why it was felt that she should be assessed.

partner relationships when both parties have difficulties changing perspective

There are couples with Asperger Syndrome who are married or live together in which both parties find it difficult to reflect on their own behaviour and understand the other's perspective. One of the nurses at Rallaren has helped and supported a married couple for many years. They have had many heart-rending conflicts for which they have received assistance in structuring the problems and by having a schedule for almost everything they do in common. They also receive educationally designed counselling in which they learn how other people solve similar problems. Their life together is further complicated by the fact that one of them is steered by compulsions in which he tries to involve his partner. The partner finds it difficult to stand up to him and needs support in learning how to assert her rights.

work

Some of the discussions centred on the difficulties arising on the job for people with autism spectrum disorders who are employed. It usually requires a great amount of understanding on the part of the employer and acceptance that these employees have difficulties with the social aspects of the workplace. They can also need guidance to avoid run-ins with their co-workers. At Rallaren, there are several patients with Asperger Syndrome who have jobs on the open labour market and it works out well in those cases in which they have received appropriate job assignments and have a sympathetic management team.

autism or another diagnosis?

Even if the training sessions were not primarily intended to diagnose or re-diagnose the patients, it still became necessary to explain how the various childhood neuropsychiatric diagnoses differ from one another and from schizophrenia. The staff member who is assigned to be the patient's contact person is also an important observer and can contribute opinions about the patient's diagnosis at the time of assessment. In addition, contact people can suggest further evaluation by the neuropsychiatric team based on their suspicions that a patient can have such a diagnosis.

recieving care for somatic illnesses

On one occasion, we discussed the many women with Asperger Syndrome who go to the doctor with somatic complaints. The staff members at the medical clinics are often unable to find anything wrong, even though the patient may be experiencing stomach pains, vomiting and skin irritations, among other symptoms. The patient finds it difficult to manage these situations because she is unable to explain herself in such a way that the doctor or nurse understands her complaints. These women also find it hard to make sense of the answers they are given and often come away feeling that the doctor neither can nor will help them. Nurse Iris at Rallaren has made a concerted effort to establish contact with the nurses who work at the medical clinics concerning patients with Asperger Syndrome.

what is normal eye contact?

At the final staff training session, one of the participants brought up a new topic. There was a young man, diagnosed as having a schizophrenic psychosis with paranoid tendencies. Gunnel, the occupational therapist, thought he might have Asperger Syndrome. The young man thought that people looked at him funny when he was out in town, which is why he avoided going out where he knew there would be a lot of people. On the student corridor where he lived, he also felt that people opened their doors to look at him. In therapy, Gunnel explained that people make eye contact when they walk past one another. She also asked him to think how long he looked at people and how long he maintained eye contact. Gunnel thought that in his case, it was more a matter of ignorance of nonverbal communication between people than of a true paranoia. When it was explained to him that other people were not staring or acting strange just because of him, he understood things better.

After Gunnel had started to teach him about human nonverbal communication, his fear of eye contact disappeared and he even was willing to take a weekend trip to Germany. He had heard about the good-humoured Germans and interpreted it concretely to mean that you had to drink a number of glasses of beer when you got there. When Gunnel asked why he drank so much beer, he looked surprised and wondered if you were not supposed to do that so that you could be friendly and have a good time in Germany. Gunnel described several situations that revealed this young man’s naivety and ignorance when it came to ordinary human communication and the interpretation of everyday situations. This, combined with his stiff body language and non-existent facial expressions, made it obvious that he needed to be reassessed by the neuropsychiatric team.

These examples of difficulties in understanding what other people learn naturally and without effort, show what a tremendous amount of mental effort life involves for a person with autism. The obvious human activities of making eye contact, of understanding emotional messages, of knowing when you are hungry or thirsty, of being able to explain your pains to the doctor—all these are great stumbling blocks. The autistic person tries to discern how to behave in different situations; he guesses but is never really sure that he has understood and acted correctly. There is always a risk that he will make a fool of himself, appear stupid or less intelligent. This feeling of not really being a part of ordinary life and ordinary situations is an element of many people's everyday existence.

9. Staff training documentation

When the staff training sessions began, I presented the personnel with a *dissertation declaration* in which I described the purpose of my work. This included, among other things, that the participating staff members would reflect over what they had learnt during each training session and then document it in writing.

Personnel documentation

About 40 people made up the group that regularly participated in the educational programme for the entire time. Of these, a total of 31 turned in documentation of what they had learnt during the training sessions and some of them were quite ambitious in carrying out the assignment. Many have rewritten their notes and some have turned in substantial volumes. The units that were the most ambitious in documentation were those that had just the right number of participants, most often consisting of an entire team. The sessions with these staff groups were carried out in a dialogue format. There was give and take and the participants were free to ask questions or ventilate problems.

After a survey of the material, I found that it could be categorized under the following heading:

This was new for me
Knowledge of assessment and diagnosis
Knowledge of treatment
About the staff training sessions

this was new for me

In this category, I have assigned items dealing with when the participants acquired information about autism spectrum disorders for the first time and when they understood that another kind of approach was required when caring for and treating these patients. Some of the participants understand that this form of autism is something different from the autism that is a sub-symptom of schizophrenia.

For one mental health assistant it is an altogether new experience to be given training sessions dealing with patient work and he thinks that it was “an entirely new thing for me.”

Many also comment that they now understand that autism is a lifelong disability and that it is from this perspective they have to see these patients; it simply is not possible to understand patients with autism from a normal psychological perspective.

It is new for several of the participants that people with autism spectrum disorders can be so different from person to person and that there are sub-groups within the spectrum.

There are a considerable number who did not know that autism can exist in conjunction with other symptoms such as obsessions and rituals; nor did they know that autism could co-exist with hyperactivity, sleep disturbances, depression and other symptoms that are not direct symptoms of autism. That people with autism can have psychoses was also new for them.

Many thought that one difficulty with the neuropsychiatric diagnoses is that the symptoms can overlap, making it hard to differentiate one from the other.

The thought that normal psychological development does not apply to all is entirely new for one nurse and some of the assistants.

Several people have begun to understand how perceptual disturbances are expressed. One mental health assistant now understands one of his previous patients, for whom he was the contact person:

> I was the contact person for a guy who didn't want to shower. It was almost like he was afraid of the shower. I never thought that it could be because he was hypersensitive and that it hurt when he showered.

knowledge of assessment and diagnosis

This category was included because the staff members who carry out assessments and diagnosis felt that they too would benefit from these kinds of training sessions. Some psychologists describe their thoughts and what they have learnt in this area:

A psychologist who participated in six training sessions:

> I think that the training has been very inspiring and thought provoking and I understood that we already know a lot about the patient, although we haven't really structured our expertise. Now we have to consider how much we already know and what more we have to find out about the patient. For example, we have to consider if the patient's laughter at inappropriate times can be a form of obsession in conjunction with his other obsessive symptoms, indicating that he may have Tourette's Syndrome.

Other information that is considered important is the need to survey perceptual disturbances and see how they are expressed. One participant, for example, mentions that he has started to wonder if weak physiological signals may be the cause of an adult patient's inability to control his bladder and bowels.

The same psychologist has also realized that they all need to examine, much more systematically the patients' cognitive processes and their ability to evoke associations and memories.

How much help does the patient need in establishing concepts of things he has not experienced himself?

They also understand that the basis of relationships is different—they can be related more to needs than to feelings. One psychologist writes, “You need to differentiate between the *memory of* and *feelings for* a person.”

Another psychologist now sees the value in looking at patients with neuropsychiatric diagnoses from a developmental psychological perspective. He gives Piaget as an example. This psychologist still finds it hard to differentiate between autism and ADHD. Nor does he *really* know how to distinguish between the neuropsychiatric diagnoses and schizophrenia, though he is starting to discern the differences. He also sees the importance of the psychological portion of the assessment reflecting the patient’s true functional abilities and that formal test results need to be weighed in light of clinical observations.

knowledge of treatment

Most of what was documented as new knowledge by the personnel dealt with what can assist them in the treatment of patients with autism spectrum disorders and in the design of treatment plans and strategies.

A nurse who participated in five sessions writes:

> This is the best way to sit down and develop a good, functional treatment plan and a new life for the patient. We have been given a concrete “road map” of what we should do and which treatment plan we should draw up, both for the patient we discussed and for those involved with him. I now understand that he cannot comprehend instructions that are given for an entire week, but has to be given them a day at a time. And I also understand how extremely concrete, detailed and over-explicit you have to be in order for people with autism to understand.

Most of them related that they have learnt the necessity of being very concrete, of finding out what the patient understands and does not understand; that they cannot take it for granted that a patient has understood just because he has been told something. They also feel that they now better understand why discussions with the patients have to be followed up with questions—it is not self-evident that the patient understands the staff members’ ways of thinking and how they express them.

That an educational approach is different is a message that has been conveyed to all participants. They understand that an educational approach means working more systematically than one does with the ordinary fostering that is carried out on the unit. They need to set up intermediate objectives that are followed up and evaluated. One mental health assistant now realizes that, “You can’t give up right away.” An important understanding is that the patients with autism need to have carefully planned, scheduled days with recurring, meaningful activities. They also find it difficult to fill their free time. From that perspective it becomes clear why they just sit passively or go to bed when they do not know what they are supposed to do.

A nurse expressed it like this:

> Structure is important; the day needs to be well planned. What is most difficult is when the patient isn’t occupied; it’s better for him to have something to keep him busy. He can’t come up with something to do on his own, which is why he just ends up sitting there. It was good to be reminded that we have to explain thoroughly for the patient by writing it down, drawing and explaining again what we mean, how things are to be done, how others react and that we have to do it many times.

We discussed extensively in the training sessions the importance of establishing relationships; many commented on this in their documentation. They have understood that the autistic patient does not always know how to make and maintain contact with other people. Because he does not initiate contact does not mean he does not *want* to. It is up to the staff to take the initiative, and they should strive for something more than small talk or talking for the sake of talking. A psychologist has additional reflections about our discussions and the nature of social relationships:

> I’ve understood that the patient actually has the ability to relate to certain people and that he can differentiate between the relationship to a person and the function that the person serves for the patient. The patient, who otherwise has a clearly defined territory, tolerates bodily contact when he is occupied with other thoughts, like when playing a ball game.

A nurse has come to the following insight:

> I now realize that patients with autism find it hard to understand facial expressions and body language. You have to explain all that is inter-personal very explicitly to them. Social rewards don’t work for people with autism.

The importance of systematic observation and documentation was also mentioned as significant knowledge gained from the training sessions:

> The importance of analysing in detail situations that result in different kinds of behaviour, such as violent behaviour.
>
> We actually have a tremendous amount of knowledge about the patient, but few structured plans.
>
> It was good to learn how to make observations–by following an observation protocol, for example.

> It's important to include intermediate goals in your planning. This is really good for the patient's sake. It's also good to see how you perceived the patient, based on the paper you gave us (the educational diagnosis). I thought all the items fit him.

One of the treatment staff reflects on a patient in concrete terms:

> It becomes clearer each time what Herald's limitations are. Can he learn things that are entirely new? He simply doesn't have the ability to convert reminders and suggestions into action. Taken all together, the discussions provide a clear and complete picture of who Herald is and how you can work with him, what you can concentrate on and what you can set aside. You can, for example, find new solutions by letting him eat his evening meal with us on Mondays so that he stays around for football training. If he goes home, he won't return. You can also add to his schedule that he can wash his football-training outfit here on the unit, so he won't forget it at home. We are going to try to find things that Herald is good at. What are his strengths? Maybe computers?

Relationships to relatives also come up in several staff training sessions. What needs to be considered is how to utilize the knowledge and experience parents have of their adult sons or daughters. How can you include parents in treatment so that they know what the plans are and how they can assist in implementation? A new reflection for the majority of participants was that the parents of adult children also go through a crisis and react strongly when their offsprings are given a psychiatric diagnosis and when it dons on them that their son or daughter will never be cured by any form of psychiatric treatment. Parents also need to work through these crisis reactions to avoid the risk of them becoming permanent. The staff had not previously considered that relatives who were always critical had, perhaps, an unresolved grief reaction to such a crisis that the staff could help them with; not to mention the fact that the parents could also be correct in their criticism of the care their offsprings were receiving.

A psychologist trained in cognitive therapy who participated in six sessions explained what he had gotten out of them:

> New for me was that you have to be very detailed in your work.
>
> I have to be much more concrete in what I say and do.
>
> Written information works better than verbal.
>
> I haven't previously considered the fact that you have to clearly explain every step of what you do; that misunderstandings often arise due to information that is not clear.
>
> The importance of structure and the use of educational methods in treatment.
>
> The importance of teaching the patient fundamental human attitudes and rules of social interaction.

> You have to be conventional in a way that goes against the grain of more unstructured approaches that one has learnt.
>
> You feel like a strict parent.
>
> Sometimes it's a bit difficult to realize that the patient doesn't know about ordinary human ways of relating.
>
> Much of what we interpret as unwillingness, sabotage, resistance, etc. can be better understood as functional inabilities and deficiencies.
>
> I was reminded of the many rituals the patient has. That you have to work slowly and be sensitive to the patient's reactions; not push too much.
>
> How easily we get stuck in our own interpretations of the patient's behaviour, which is based more on our views and our ways of functioning rather than the patient's.
>
> That you may not be able to change the patient's ritualistic behaviour, but instead make it more goal-directed

In a follow-up interview with a nurse, she expressed her concern that they now were carrying out thorough assessments when diagnosing these patients, but that they lacked personnel with the required knowledge to follow up on the patients according to LSS or other measures:

> It's very frustrating to see the patients being assessed and diagnosed according to all the recognized, state-of-the-art standards and then they are sent to their hometown facilities, which lack expertise in the area. And I sometimes feel that I'm collapsing under the patient load that I have, because we really don't know what we are supposed to do after the diagnosis … and it takes its toll when you're always thinking "What on earth am I going to do about this and that?"
>
> We have had a *social group* for over ten years now and in that situation it becomes especially clear that some of the patients are very different from the rest … those who only boil potatoes and fix oatmeal and who don't notice that we have made soup fifty times … they don't eat it anyways, because it means changing their habits … they can't go grocery shopping and they can't figure out ordinary things, nor can they socialize with others in an ordinary way … even a very psychotic person can, with training and the right atmosphere, display social skills … they may have their hallucinations to be sure, but are still able to play *Trivial Pursuits*, for example. But the patients that I'm thinking of are always the same no matter who is here or who is doing what … they don't change and that is when you start thinking, "What in heaven's name is this and what are we going to do about it?"
>
> We need specially adapted solutions for these patients … there should be small units with dedicated and knowledgeable personnel who receive training and who understand what they are doing … and they shouldn't have so many patients because it's very demanding to work with them … I've a patient now that I can barely manage to look at and am glad that I'll soon be going on vacation … it requires people who have patience and stamina and knowledge and who have the educational training to teach patients why they have to eat, why they have to sleep, why they have to pay their bills and why you don't just

> tell people the first thing that comes to mind if you want to stay friends with them; that you don't tell people off in the check-out counter at the store, etc.

about the staff training sesesions

What the participants list under the heading, "In addition, I thought . . ." are the practical benefits they gained from being able to discuss their own patients. They also think—when they write their final summaries after the last session—that they really see the difference for the patients.

Two people on the same unit express themselves almost identically:

> It was good to look back now at the end of the staff training. You see what has happened and what has changed. The difference is noticeable after the summer break. That so much can happen in such a short time!
>
> It has been the best staff training in a specific patient situation I have ever had. I hope that we can continue. After the summer break, I saw that great strides have been made in the treatment and the way we approach the patients.

A psychologist who participated in all the sessions reflected on the different care cultures of the teams on the unit. Only two of the unit's four teams have participated in the training sessions and the other teams still have the same way of looking at and dealing with the patients we have discussed:

> The staff training has been a very good support in treatment design and implementation. Today, I was thinking how valuable it would have been if all of the teams had been able to take part in order to reduce the risk for conflicts between the different teams.

Two psychologists who only participated occasionally also turned in documentation:

> I thought it was worthwhile even though I didn't participate so often. It's really good to be able to talk through different thoughts and reflections in the area. I only wish I'd had the time to attend more sessions.
>
> The forms and methods of instruction were very good. I feel that it's been possible to quite freely ventilate questions that are also outside of, yet related to, the "subject"; for example, that autism spectrum disorders are different in nature, or the importance of looking for alternatives. This process of reflecting back and forth in the group without anybody lecturing has appealed to me a lot and provided me with ideas for further consideration.

One mental health assistant had previous experience and knowledge in the area of autism and her documentation reflected this:

> In reality, there wasn't very much that was new because I've had experience working in education at a special high school. I've also studied the subject at school in a 10-credit course. It has, however, felt good to receive confirmation for the methods I use on the job. In the regular staff meetings, there hasn't been much interest for my ideas. In other training sessions, you get the feeling that you have failed. On previous occasions, I've been told that I'm too controlling; now I've received confirmation that you just have to be that way with these kinds of patients.

Because of her previous experience in special education, she had been frustrated when her psychologist colleagues showed no interest in what she had to say. It took a teacher coming from the outside for them to do so.

The interviews

I have used the material that came out of the interviews for two purposes: 1) to gain background information about psychiatry as a care and treatment environment, 2) to add, throughout the entire dissertation, a more individualized and personal touch to my presentation of psychiatry by using the actual words and narratives of the people who work there. In the case of Emil, I have also carried out longer interviews concerning changes in the way the personnel approached him. I go on to give a thorough account of most of these to show who Emil was and who he became in the eyes of the staff.

altered approach to emil

Ester, nurse and contact person, relates:

> I think that it all has to do with the filter through which you see things … previously we saw much of his behaviour as being aggressive, but now we see it as being compulsive and that he has rituals that he has to follow. He also needs clear and explicit instructions about things and he wants to know all the facts … he can really be irritating with all of his factual questions and you can interpret that as a form of compulsive behaviour, if you want to see it from that angle … when he came here from the large mental hospital, we interpreted it more as the result of long-term hospitalization … I thought the descriptions in his medical records were full of awful clichés that we really made an attempt to disregard.

I asked Ester what she thought would happen if they tried to break Emil of his rituals and compulsions—would he become aggressive then?

> If anything, it would drive him to despair, but I don't think he would become aggressive … and I think that he would be more persistent now; he doesn't withdraw anymore … and he probably would go to another staff member when the first didn't understand him … now he doesn't give up until he gets proper and satisfactory answers to his

> questions … and we've interpreted this development as something positive.

I continue to ask: *Do you think that his lack of facial gestures and body language can result in people misinterpreting him? That was the explanation I got when I first came to the unit, that he was extremely dangerous because he didn't express any feelings but kept them all inside and was like a time bomb who could do just about anything when his controlling exterior burst.*

> I don't see him like that at all; he has no problem telling you what he thinks about things, but it's on a more factual level … it's not at all difficult to make contact with him …

But before, when he was at the big hospital, he was considered to be unreachable … how has the change occurred?

> I think it has to do with respect—to *truly* respect a person. And it has to do with taking notice of the patient and not just letting him be—as with Emil. With him, I had to start from the beginning when he came from the large mental hospital. The room he had lived in was entirely bare because he had "chosen" not to have anything. He said the same thing when he came here ... that he didn't need anything. But I thought, "Dear God, no one can live like this!" So we put in a little furniture for him—a bed, a nightstand and a chair. He also had a plant in the window. Then, when he got used to that, I knocked on the door and went in with some pictures. I didn't ask *if* he wanted them, but *where* I should hang them up. "Yes, they're nice!" he said and turned away from me as was his way then when you spoke with him. And then he showed me where he wanted them hung. And that's the way it's been … one thing after the other has been moved into his room and now it looks entirely normal.

I remind Ester of what I had first heard about Emil when I wanted to include his case in the educational project: *I heard that he was paranoid; that he believed that there were rays coming from people's eyes and that was why he always put his arm over his face when he met others … it's also mentioned everywhere in his medical records … where did that idea come from?*

> Who knows?

Can his difficulties in making eye contact have to do with his extreme over sensitivity to light?

> Oh, yes, he is sensitive to light … I've suggested that he buy dark glasses because he finds sunlight so hard to tolerate …
>
> The way he's described is based on a schizophrenia diagnosis and it sometimes feels as though they really had to make an effort to find symptoms in him that fit the diagnosis … personally, I don't pay much attention to the diagnosis … it is more important to describe the person … that is what I try to do when I draw up a treatment plan

> … it's also important to know what drives a person … it has to be a living description of a person …

I also ask Buster, one of the mental health assistants: *Why do you think Emil was considered so dangerous before?*

> I've always seen him as a very withdrawn person who is tremendously curious … I can't understand how anyone could have considered him to be dangerous or aggressive … I was on a trip with him early last summer … to Hälsingland … another assistant and I, and then I got to know him really well. I never detected any kind of aggressive behaviour, none at all … he was cool as a cucumber and very curious about everything … we went fishing and on excursions and he had a good time …
>
> But then there are his perceptions of the world; he doesn't really seem to understand what the world is like … I think that it is the result of his isolation, because he can take in new information if you explain it to him, but he knows very little about the world … like in the beginning when we started to talk to him about going on outings and he didn't want to go at all … he claimed that the world was no more than the size of a potato patch … we showed him pictures of places we could travel to … he looked at them and still maintained that the world was a potato field and that the buildings were made of blocks and Lego pieces that people moved around like sets from place to place ...
>
> I find his diagnosis of paranoid schizophrenia really hard to swallow, now that I've started to look at him from an autism perspective … one thing that I've wondered about is that he sometimes just shouts or cries out when he is alone in his room … I've asked him about it but he says it's nothing … I've wondered what it can be …

Eve: *What spontaneously comes to my mind is the combination of his tics; he has quite strong ones you know, and his compulsiveness … along with the shouting. Is it possibly that he also has Tourette's Syndrome?*

How would you describe Emil? Who is he?

> A man in his 50s … very limited when it comes to doing things, easily ends up in a routine. But we've really worked at modifying small aspects to get him to realize that there are several ways of doing things … he was very routine bound when he arrived here … at first he wouldn't even listen when we tried to tell him there were other ways of cleaning … everything had to be done in a certain way; when we explained, "You can do it like this too," he wouldn't hear of it. Anyways, we gradually were able to show him that certain things could be done in several ways. If he then still chooses to do it his way, that's up to him, but he knows, in any case, that you can do it differently …
>
> That others have left him alone in the past can be due to fear, perhaps, or misguided "respect", because I didn't think he was easy to make contact with in the beginning either; it requires an awful lot before you have established the level of contact necessary to increase the demands on him … and he also indicates his limits quite clearly—here but no further … and it's always much easier to make contact

> with him if you have something concrete to offer … for example, a picture of a fish and say that we are going fishing tomorrow …
>
> And it's also the case that you can't come to him the same day and say that we are going to do something. Instead he needs to be told at least one day in advance so that he has time to get used to the idea … when his curiosity about something is aroused, the questions start coming and then things are under way and there's no problem doing things.

Lena, mental health assistant:

> For me it's inconceivable that he could be described as being dangerous, but I can imagine that others haven't understood his odd behaviour … what it says in the medical records mostly has to do with how dangerous he was … from the time he came to our unit until now he has been an entirely different person than the one described … but, of course, we've been a bit harder on him. We've made a point of intervening so that he wouldn't be able to become isolated. He's certainly been allowed to do what he wants, but he's also been forced to adapt to certain things such as getting dressed up for special occasions at Christmas and other times … and he's also been introduced to completely new things such as a computer and digital camera which aroused his curiosity and interest. And he's been able to use tools such as a hammer, nails, screwdriver, drill and everything we have … he's been allowed to tinker with everything at his own pace and according to his ideas and has been given the responsibility of returning them to us on the unit when he's finished … we have never stood over and supervised him.

Lena continues:

> He's shy, really like a shy, withdrawn child who wants to try out mamma and daddy's things … and he likes to putter in the kitchen on his own, but he almost always carries things too far … like the other evening when the staff were sitting in the kitchen eating dinner and we said to him that we would do the dishes. But he was very stubborn about doing them himself. We suggested that he could do something else, but he sat outside the kitchen and waited until we had finished eating and then he came in and washed the dishes, exactly as he always does. You just can't change Emil's routines … and he's so punctual that you can almost set the clock by him.

I ask others among the personnel and Johan, a mental health assistant, gives his version:

> He's stuck in his routines and wants to do everything as he usually does it, in the same way as usual and in the same amount of time as usual; but what has happened recently is that he has started to loosen up his routines more and more. He can, for example, wait a while for something to happen; it doesn't have to be immediately. He can also do things in a different way, even though he sometimes is a little disturbed or anxious about it. But at the same time, he sees that nothing bad happens if he does things in a different manner … he has actually become more flexible … and now he can also let you know if there's something that he doesn't like … before he just walked away.

Who takes the initiative to all the new things you do?

> Well, it has to be us; he could never come up with something on his own. He really doesn't know what there is. You can't just come up to him and say, "Shall we go out and do something now?" Instead you have to prepare him several days in advance and we show him pictures or brochures of what he can choose from so that he can get an idea of what it's like. It took quite a long time to motivate him the first time. He fought against it for a long time and said that he wasn't going to and things like that, but when we finally convinced him to come along a few times and he saw that there were lots of things to see out in the world, it has become bigger and bigger for him … among other things, he has asked us what it would be like to go sailplaning …

What is his self-image like? Do you think that he has a complete picture of himself and can reflect on who he is in terms of his life history?

> No, he lives very much in the here and now; extremely so, actually … sometimes you can get him to talk about something that happened earlier in his life, but it never happens spontaneously; it's always in response to questions … his way of thinking is different too; it's like his world consists of a series of scenes that aren't related to one another … he says, for example, that the world has come to him in such a way that it could just as well move away from him again and everything would be as empty as it was a moment ago.

views on continuing education

In the interviews, some of the respondents also had much to say about the educational programme I offered on their units as well as what they desired in the future. I am including this because it is of value for subsequent educational efforts. They also confirm the assumption that learning is an active reorientation process that always has to start from the individual's current level of knowledge, that it is not just a matter of a transfer of knowledge.

Gunilla, nurse:

> During these training sessions, I've also learnt a lot by hearing Hans and Lotta present their cases. There is much that I wasn't aware of before, that it's a matter of a very concrete and firm educational method that you have to use with these patients. And you see once you start working with this approach that it's true … and I can also see that this is something that can be used with many other patients … it's about developing the healthy traits of the person while also understanding what their disabilities involve … that you don't try to correct what can't be corrected and that you don't place the wrong demands on people. You need someone who has mastered this educational method to teach you how to work with it; it doesn't come on its own. And that's the way it is with many of our patients, where you have tried to wait them out and thought that she will mature if left in peace a while and then you see that as soon as you are not there to remind her, to show her, everything falls apart; she doesn't do her job, doesn't clean, everything just falls apart … I feel that it is in this area that I need more guidance … how can I do things in a better way

> so that her life doesn't fall apart as soon as I pull away a little? … I have many patients who have lifelong disabilities and who now are being moved out into different kinds of municipal housing … I have a man, for example, who lives in his own apartment and has some support there, but where it still doesn't work … he is dirty, smells bad and needs a lot more care and attention in his daily life … and it's hard to know how I should tackle it when he comes to me … how do I tell him that he has to shower? … I don't know how to say it to him even though we have close contact …

Hans, psychologist and cognitive therapist:

> What I am used to from cognitive therapy is that the patient and I together define a problem. We both look at the problem and ask, "How can we find a solution to these difficulties?" Defining the problem together is the first step: "You came here because you are afraid of other people and how can we find methods to deal with that?" But we do encounter patients where it is others who are saying that they have a problem, while the patients themselves don't think so and it's with this group that I feel we can benefit immensely from your approach. But that also means that we have to be much more conventional as therapists, you see, because we are claiming things about the patient that in normal cases we don't usually do and it's difficult then to start teaching them, "That these things are connected like this and like that" … or "Do it like this and it will be like that" … regular cognitive therapy is not based very much on that, you know.
>
> What was most difficult in the beginning when I tried to use the new approach was that the patient and I were not able to talk things through, to find out what the problem was. Instead, I had to explain to him, "If you do this, than that will happen … and you can do this instead." It's also much more practical too … it involves writing down "Look at this!", "Do it like this!" and you have to offer alternative suggestions, "If you go to bed when you are in a state of anxiety, you'll just make it worse; instead you can … "
>
> In most therapeutic work, we assume that the client possesses the knowledge and that I am there to bring it forth, but here you often have to assume that the person actually does not have the knowledge in the first place, but that I as a teacher have to teach him … and the lack of knowledge can be at such a primary level that you can't even imagine that it can be like that … you still assume that grownups are going to function at an adult level … for example, when someone from municipal housing says to a person, "Call me when you need help!" and the person never calls even though he needs help … in that case we have to re-think … we assume that we all function alike; it is so deeply ingrained in us that people think and experience things the same, but as a therapist, I have to also understand that something is locked in the other person that I have to help him unlock … it is perhaps a little more of a fostering method, when it basically is a matter of abilities the other person lacks … I think that in order for psychiatry to progress, we must start educational programmes and offer sound guidance in new ways of approaching and treating, but it also requires genuine organizational changes … you also have to start looking at which methods suit whom … and perhaps that special units are needed for certain groups …

Vanja, social worker in forensic psychiatry:

> Learning to see things from a new perspective has been a long process. I became interested in autism and the other childhood neuropsychiatric syndromes in 1992 when I was at a conference in Göteborg and heard Christopher Gillberg lecture on autism … a year later when I was on my way to a social workers' conference, I borrowed Gillberg's book on autism from a colleague who was on the train … I was a bit confused at times over the next three years … when I thought that one behaviour fit the diagnosis, there was always something else that didn't … one thing, for example, was all this about imagination … the diagnostic criteria state that they don't have any imagination or that they have deficiencies in it, and that wasn't the case with some of my patients who were clearly autistic but had enough imagination for a whole regiment … I just couldn't get it to fit together and was unsure of myself … during these years, every time I had a patient I suspected of having autism, I always had to look up in books and read and reread, for example, descriptions of autism … now it's firmly established, I know it more intuitively … it has probably been in the last two years that I've also realized that autism can express itself differently and that the diagnostic criteria are not the absolute truth … you could say that meeting so many patients, in and of itself, is a process of acquiring knowledge. I've now worked with so many who have an Asperger diagnosis, for example, that I can think it through on my own and see how it expresses itself … I carry out about 28 assessments a year and among them there is always a few who are diagnosed as having Asperger Syndrome … we perform about 600 assessments a year and we discuss the patients with one another, too, when there is uncertainty or doubt about something … and we run through our cases once a week, you know, and then we can hear what others are doing … But it's still the case that everyone hasn't accepted these diagnoses and they don't really want to discus them … and then there are those who are interested but a little cautious … those on the staff who have expertise in these diagnoses and recognize them without having to refer to the reference book can be counted on the fingers of one hand so far … you first learn to recognize the classic examples, those who have very clear, characteristic traits … I actually believe that you have to go back to school again. We see so many of these disturbances and I also see that autistic conditions can be behind serious crimes and when you realize that, you have to do something about it … you can't just verify that this is the case and then let it be.

These accounts clearly illustrate how long the learning process can take when you start to examine a phenomenon from a new perspective. First, you understand *that* it is new and you learn factual information that changes your perspective. It is difficult in the beginning to incorporate the new ways of thinking into the old. Hans goes as far as to speak of unlearning the old approach to doing and perceiving things. As time goes by, you also understand that there are significant discrepancies between how autism manifests itself in different individuals and that what is stated as fact in the literature is really variable in nature. Vanja, who acquired more knowledge and experience on her own, has not had the same support from her co-workers that Hans and Gunilla have. Their team members have a common educational background; they know or are familiar with each other's patients and in that way learn to see problems from new angles. All three are in agreement that this requires a substantial educational investment involving specialized expertise of patients with autism and other neuropsychiatric diagnoses so that they receive focused treatment based on their particular requirements.

The questionnaires

The questionnaires were to provide additional information about previous knowledge and interest in the area of autism. Moreover, I wanted to find out the fate of the patients that we had discussed during the staff training sessions. "Did the new perspectives and new knowledge have any effect on the patients after completion of the staff training?" "Could you imagine using an educational approach with other patient groups?" (The questionnaire can be found in Appendix 2.)

The aim of the questionnaires was to provide supplementary information that I could not acquire in other ways. In reality, it was not meaningful to use a questionnaire on some of the units because they, for different reasons—among them two comprehensive reorganizations in a period of two years on one unit—did not fit into the experimental design I had drawn up in advance.

In general, I can say that the questionnaires did not supply as much information as I had hoped. The staff training sessions had to be tailored to the particular needs and possibilities of the different units in a way that I had not anticipated. The questionnaire as an instrument for obtaining information simply was not suitable for all of the units. Instead, I resorted to interviews in order to gain the supplementary information for which I had planned to use the questionnaires.

10. Overall results

The main purpose of this dissertation was to increase the understanding psychiatric personnel have of the specific difficulties in contact, communication and cognition that can be found in patients with an autism diagnosis. I also expected that as the result of education, I could contribute to the patients receiving individual treatment based on their specific difficulties.

In choosing my practical methods, I formulated thee questions that I wanted to answer. They were:

- Why are patients with autism spectrum disorders more difficult to understand than other psychiatric patients?
- Can you better understand the patients' specific difficulties by applying theories of the significance of early social learning for later personality development?
- Based on a better understanding of the patients' difficulties, how can you establish more individualized and focused treatment for them in a psychiatric care context?

Staff reorientation

Through the information that I gathered from interviews and from the personnel's own documentation, I have been able to demonstrate that the psychiatric staff members who regularly participated in the staff training sessions gained new knowledge of autism as well as of educational approaches and methods. As a result, they have been able to better understand the patients' problems and, consequently, to also treat them in a different manner. The educational-psychological theories on the importance of early social learning have demonstrated that it is possible to apply developmental psychology, valid for normally developing children, in order to understand children with autism. Some functions develop normally in autistic children, while others, which are dependent on social learning, develop in another manner. This has consequences for the entire personality development of the individual.

During staff training, the personnel have often spoken of "unlearning" previous knowledge when it comes to patients who have autism. Their treatment requires another kind of knowledge than that which is currently offered in educational programmes for careers in psychiatry. These programmes assume that all people follow the same pattern of psychological development; students do not learn that it progresses differently in individuals who have a congenital or acquired disability.

When staff members have well understood that you need to observe and take into consideration other factors in patients with autism than in those who they have traditionally cared for, a reorientation process begins. Being able to try out new knowledge in action and receiving feedback in staff training session, increases the staff's behavioural repertoire and they start to think and see in new categories. One tool that several of the units used to learn how to observe the new categories was the educational diagnosis inventory that I had developed and presented in my licentiate research.

What were the results for the patients?

As described in chapter 7, *The staff training process concerning individual patients*, the results for the patients were concrete and evident. This chapter contains a brief summary of the results. Some of the cases will be examined further in the discussion chapter.

emil

The altered view of Emil results in the staff starting to question his placement in forensic psychiatric care. Emil's psychiatrist also has an entirely different perspective of Emil's strange ways of reasoning; he sees the logic in it based on Emil's own misperceptions of how the world is constructed. Emil lives in a concrete reality and is tremendously curious about the new worlds he is gaining access to. He wants to know more about the world and tries to understand it, but cannot manage with his own resources. He needs people around him to help him acquire new thoughts and experiences.

Emil's schizophrenia diagnosis, which the staff believed had been kept under control with medication, takes a final blow when they find out how Emil has "taken" his medicine: Every morning at 7, Emil has stood at the nurse's desk and waited to be given his pill. No one has ever questioned that he actually took it because he was always so punctual in fetching it. One day, his contact person finds a pill in Emil's wastebasket and asks him how often he throws his pills away like that. Emil explains that he has always done so.

In April 2000, the county court hearing takes place in which it is decided that Emil no longer is in need of forensic psychiatric care. As long as he was at the large hospital, the thought never crossed anyone's mind that Emil might be capable of attending the hearings himself. As far as Emil was concerned at the time, there was never any real meaning in the issue of him wanting to be discharged either. After his time on the Wild Goose Unit, though, he participated and spoke for himself at the hearing with a little help from his contact person and this time he knew that a world existed outside the hospital walls and that it concerned him.

The personnel had an entirely new view of Emil from the autism spectrum perspective. They better understood his peculiar way of thinking, his ritualism and compulsive behaviours. The technology that came into his life in the form of a digital camera helped him to dare to go out into the foreign and frightening reality from which he had been cut off for over two decades. Attempts were made to assess him for a new diagnosis, but Emil did not see the value of that and refused to participate. Emil was discharged from forensic psychiatric care after 25 years and plans are being made to move him into a group home.

jan

The case manager who had dealt with Jan for a long time went through a reorientation concerning Jan's difficulties. From an autism spectrum perspective, it became clear that Jan was not trying to fool those in his surroundings when he did not understand simple, everyday information. His case manager found that the educational approach of explaining and teaching concrete information was accepted by Jan and that it was a functional procedure for working with him. Jan's behaviours better fit the autism criteria than the schizophrenia diagnosis that he currently has.

kerstin

Kerstin's case manager received confirmation that the educational approach she used worked. She wanted a new assessment of Kerstin, but knew it would be difficult since Kerstin herself was unable to accept any psychiatric diagnosis at all. In order to receive the assistance that she needed under the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), a new diagnosis was required and Kerstin's case manager tried to motivate her to have one.

christina

Christina and her assessment resulted in a conflict in the team that was to assess and diagnose her. The two psychologists had entirely different theoretical approaches and interpreted her in diametrically opposed terms. For her case manager, Christina was much easier to understand from an autism perspective and Christina also recognized herself in the description of Asperger Syndrome. She was considerably happier when she knew that there could be another explanation for her different way of thinking than that she was stupid. She had always heard that when she was growing up and had been bullied because of it. She is now planning, after the assessment, to resume her studies at a high school for students with Asperger Syndrome.

michael

Michael was reassessed and given an autism diagnosis. His sleep disturbances and hyperactivity were documented and he was medicated for them without success. The sleep disturbances will be further assessed at a clinic specializing in the area. His medical records from child psychiatry were requested and indicated a possible brain injury that the current staff had no knowledge of. He falls under LSS and plans are being made to move him to a group home in his hometown. He will also have the right to a day activity programme according to LSS.

jasper

Jasper already had an autism diagnosis, but the staff had never been able to figure him out and did not know how to treat him. After learning how people with autism function, Jasper's behaviour was more understandable to them. They realized that they were the ones who had to initiate contact, keep up communication, suggest activities and explain situations and relationships that he was not familiar with. Jasper's treatment programme was changed entirely and he soon started to show that he was *somebody* and began taking the initiative and to reflect on himself.

herald

For a little over four years, Herald had puzzled the personnel on Rehab. He was diagnosed schizophrenic, but was not like the other patients with that diagnosis. He was suspected of having an autism spectrum disorder. After I carried out an educational diagnosis (Mandre, 1999) with the personnel, it became obvious that Herald's problems consisted of concentration difficulties, hyperactivity, memory problems and difficulties in executing activities; not autism. This explained why Herald had been unable to manage living in his own apartment with the limited support he was entitled to under LSS. Herald was placed in a treatment facility on a voluntary basis. He left a short time thereafter, which resulted in him being placed on an inpatient unit again. What came to light in the staff training sessions were the considerable difficulties he had, which the staff had been unable to define previously. Now it was obvious that a person with such great deficiencies in a number of areas could not be expected to live on his own with the limited support the local authorities had to offer.

Educational diagnoses

In my licentiate research, I developed a format for systematic observations of behaviours that could require educational remediation as treatment (Mandre, 1999). On several staff training occasions, the personnel related that these educational diagnoses had been of considerable help in delineating a person's difficulties, and that the staff used them when they formulated treatment plans. Several psychologists who participated in the staff training sessions also thought that they could be used as the basis for recommending psychiatric assessment and diagnosis. It helped them to structure their observations and to be more systematic in describing the patients' difficulties. Since they were being used in the assessment process, I considered how a reworking of the educational observations could also indicate, in specific cases, that the person was in need of such an assessment.

One of the patients who we discussed had previously participated in a trial application of the educational observation items. Later, when the staff understood that he needed a new assessment, the educational diagnosis was presented as the basis for the request. A deficiency in the educational diagnosis was, in this case, that it lacked observations points for compulsive thinking, tics and similar behaviours that the patient in question had. As I became aware in the course of the staff training sessions that these symptoms were more common than I had imagined, I understood that the observation items had to be reworked.

Thus, you can say that one result of the training sessions was that I received additional confirmation that the instrument I had developed was useful and would be even more so if I changed some of the items.

What also came to light was that the instrument, which was originally compiled to form the basis for educational treatment and not for psychiatric diagnostics, in individual cases revealed clusters of learning difficulties that coincided with the diagnostic criteria for neuropsychiatric syndromes. With this in mind, I further developed the instrument at Certec with Björn Breidegard, MscEE and Licentiate in Engineering. He developed software based on my ideas that produces a personal learning profile in which the statements on perceptual disturbances, reaction patterns, cognition, contact and communication are presented in different colours. For example, the intensity of green in a given case *can* indicate the strength or weakness of autistic traits. Red shows that there can be ADHD traits and blue indicates obsessions/ritualism or Tourette's Syndrome. If the colour intensity is high for traits that collectively indicate one or more of the neuropsychiatric syndromes, a psychiatric assessment is recommended. Along with the educational recommendations that were presented in my licentiate thesis, *Designing Remedial Education*, the new special educational diagnoses can also be used as an educational tool in the establishment of treatment strategies or in the drawing up of treatment plans.

This outcome can be seen as a fruitful by-product of the research for this dissertation and can be found on the included CD-ROM.

11. Discussion and conclusions

In this final chapter, I will attempt to pull together the threads I have spun in the other chapters of the dissertation. I will also try to shed light on possible obstacles to better treatment of patients with autism in adult psychiatry and discuss measures to be taken in specific areas.

The measures I see that need to be included:

- Increased understanding of what it means to live with autism
- Diagnostics that constitute the basis for treatment
- More carefully planned psychiatric environments
- Treatment methods that are based on the patient's individual disabilities and the effects thereof

Theories of social learning

I stated in the purpose section that theories on social learning in early childhood can increase the understanding we have of adults with autism and the difficulties they have in contact, communication and cognition. How can the knowledge that I have acquired be useful for psychiatric personnel responsible for the care and treatment of patients with autism?

The combined theories I have presented include, above all, practical pedagogical implications and thus can be directly applied to an educational treatment programme based on *learning in interaction*. It is, in other words, the interactive aspect of learning that I want to highlight through these theories, which demonstrate that humans, to a great extent, are formed by and through other humans. This aspect is also a complement to what I presented in my licentiate research in which structured observations constituted the basis of education (Mandre, 1999). This basis, of course, is still just as important and shows how you can come up with an individual educational design. But in the observation phase as well as in the later planning phase, the interaction aspect is exceedingly important in the observations you make of the individual. It is through interaction with the individual whom you are observing that you have to create situations in which his or her abilities and learning difficulties emerge. If you do not succeed in creating a positive interaction with the patient, you risk ending up with long lists of “objective” deficiencies to report, but which can hardly become the basis for an educational intervention from a developmental perspective.

For educational intervention to work, it requires that you establish contact with the person and find avenues of communication even if they are unconventional and different. For people with autism, their ways of making contact and communicating are seldom the same, as they are for *normal spectrum people* who have trained their social skills throughout their entire childhood and adolescence years.

Psychiatric treatment, as it has been described to me, deals to a large extent with the fostering of patients. They are to learn how to behave so that they can be with other people in society. I find this to be a particularly interesting fact, when you look back at the history of psychiatry. The incurables were sorted out from the hospital—they were to be disciplined and fostered. Today, it is exactly this kind of fostering that is the primary treatment method, next to medication, in psychiatric care. Fostering is a matter of learning—the patients are to learn what they do not know or what they have forgotten. This is an educational issue, but is expressed in the terminology of care and treatment. Regular education and training is also based on the concept that all people have the same mental structures, and thus know what is normal and what is expected of them. These concepts of learning do not take into consideration adults who actually do not know what is normal according to most peoples’ standards.

By applying theories of normal development and learning to people with autism spectrum disorders, you realize that you cannot expect these patients in adult life to learn in the same manner as patients whose early childhood development was normal. It is a matter of two parallel psychological developments, the scope of which you need to understand for the individual. By highlighting significant areas in the child’s early social development and comparing them to the adult patient who did not advance to an adult level in many of them, you also establish the basis of the educational treatment. In addition, you have established a theoretical foundation for the measures you take to initiate positive interactions with the patients for the development of contact, communication and cognition. Practitioners need to be made aware of the fostering involved in treatment; it needs to be explicitly stated and defined so that it is elevated to the level of a *method*, rather than something you do based on some sort of common knowledge of what adults should know and be aware of to live in society.

Through the combination of psychological and learning theories that I use, it also becomes more understandable why autistic adults have such large gaps in cognition, in language comprehension, in their ability to communicate, in social skills and all the other areas that are dependent on the learning that takes place in interaction with people. Thus, even educational practices at the adult level have to be based on a *one-to-one* relationship for learning to occur. If you want to help a person develop his or her mental processes, you have to start from the person's own way of thinking. In psychiatry, such one-to-one relationships are called therapeutic, and I would use the same term in this case if there was not the risk of confusing these learning relationships with those of psychodynamic therapies or other forms of treatment counselling which have different goals.

When I started working with this combination of psychological and pedagogical theories in order to find a better explanation for the contact and communication difficulties in people with autism resulting in different mental processes, I had the impression that I was fairly alone in thinking along these lines. In the final stage of this dissertation, though, I came across a book (Kristiansen, 2000) in which similar ideas were presented based on a combination of Stern's and Vygotsky's theories. Kristiansen's intentions are, however, different from mine—he is looking for explanations of the causes of autism—while I want to establish a theoretical basis for the design of practical educational treatment for a group of adult psychiatric patients.

Patients and their diagnoses

What became apparent in the staff training sessions and in the interviews with psychiatric personnel were the enormous difficulties they encountered in designing treatment from the existing diagnostic categories. Many did not feel that the categories were of any use at all. Others thought that a diagnosis was good to have as an indication of what the underlying problem was. Still, other judgements were needed in order to set up a treatment programme. The existence of comorbidity problems also illustrates today's ever-increasing tendency to give a patient more than one diagnosis. When we discussed the patients in the training sessions, it became apparent what complex symptom constellations some of them displayed.

In many cases, just assigning a new autism diagnosis did not explain all the difficulties the person had. Instead, considerably more systematic observations of the person were needed to determine which were the primary symptoms and which were secondary in treatment. Further evaluation was needed, for example, of perception and sleep disturbances, compulsive thoughts, tics and hyperactivity. It also became clear that the contacts between child and adult psychiatry did not function. The patients who had been treated in child psychiatry were given new diagnoses in adult psychiatry; no time during their long-term residence in inpatient care did anyone bother to request their medical records from child psychiatry.

Some of the patients had been diagnosed as schizophrenic several decades ago. Now, when a new assessment was to be carried out for autism, the patient himself did not always consent to it. Emil was entirely unaware *that* he even had a diagnosis, and consequently never reflected on it. Kerstin had never chosen to accept a diagnosis. The one she had been given was *schizophrenia*. She was of the opinion that she had not been brought up right—she had not been taught what other people at her age knew. She stubbornly maintained that her problems were the result of the actions of others against her and not because she had deficiencies of any kind. The question of a diagnosis in these cases was not that significant as long as it concerned understanding the individuals involved. On the other hand, it became significant in the application for resources based on the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). When staff members viewed them from an autism perspective, they both were more understandable and the way the staff approached them changed too—but the LSS officer required certified diagnoses.

Kerstin's case manager received confirmation that her educational method was correct. She had seen the positive results, but her colleagues found it difficult to accept because it was not a recognized method in psychiatry. However, when they also saw that the explicit and concrete educational practices produced results in other patients who had difficulties similar to Kerstin's, they accepted her method. An even greater challenge was getting the psychodynamic oriented psychologist on the team to accept the different psychology of one patient group. In the case of Christina, the psychologist could see that a new approach was needed, but it was just too difficult for her to reorient. Hopefully, though, such a process was initiated.

Emil, who had been a patient in forensic psychiatry for 25 year when I completed the staff training sessions, was discharged because the perspective of him had changed. He was no longer considered dangerous after the staff had been given a reasonable explanation of his different thought processes. He was treated in an entirely different manner than he had been at the large mental hospital. A small team of interested staff members was established who wanted to work with education and the technology I had introduced on the unit, which resulted in Emil improving quickly. Nor was it the case that Emil's symptoms could be entirely explained by an autism diagnosis. He also had tics, ritualism that bordered on compulsion, a variety of sensory modulation problems, misconceptions that were not delusions, etc.

Jasper already had an autism diagnosis and had his own apartment and employment according to LSS. The support he was receiving, though, was entirely insufficient for his needs. He isolated himself in his apartment, watching violent videos and drinking beer; he was living in a perverted world where real life and video violence merged. This eventually resulted in him starting to set fires in a ritualistic manner and he was sentenced to forensic psychiatric care. He had continued to live alone and isolated even on the unit. The staff waited for him to take the initiative, but it never happened. The contact person as well as the unit's psychologist felt perplexed and did not know how they should deal with this man who never said a word spontaneously and whose only communication was answering questions, nothing more. As the personnel learnt more about autism, they began to understand him and realized that he had to be treated differently than the other patients.

Herald and Jasper are both examples of people who expose the shortcomings in the types of housing services offered under LSS. The support measures need to be based on considerable knowledge of the person's problems so that they are individually adapted and not just connected to a diagnosis.

About the education

When I now attempt to summarize my experiences of teaching and advising personnel in psychiatry, I have—apart from the concrete results already presented—gained considerable knowledge and experience that can be utilized in other continuing educational efforts for psychiatric personnel. I have modified quite a few of the preconceptions I had about this kind of teaching. When I started, I assumed that I could use the same design for all the training sessions. I visualized the personnel on a unit as a group that would participate in all the sessions.

I soon realized that the training had to be individually designed because the opportunities to meet regularly differed from unit to unit; the training sessions were not like the ones I had planned because *everyday reality* does not always correspond to *planned reality*.

the forensic psychiatric assessment unit

Before starting, I had drawn up a detailed plan with the unit supervisor: One of the teams would participate in the staff training and we set the dates based on the team's scheduling. During the actual training sessions, though, the unit was constantly short of staff, which is why only a few people showed up on some occasions and many on others. Different constellations of personnel attended almost every meeting, so that there was no continuity. Basic information had to be repeated and the same questions came up on several occasions since there was always someone who had missed one or more sessions.

the inpatient units

On one inpatient unit, the staff training was scheduled directly before a general staff meeting. That was when most of the personnel were assembled so that as many as possible would be able to participate. It was a good idea, but because of the large number of people who worked on the unit, the group was so big on occasion that I ended up giving lectures rather than having discussions with individuals. Nor was I able, with a group that large, to gain an idea of the differences in educational background and thus adapt my advising to the needs and qualifications of the individuals. Another factor connected with the time and place for the training sessions on this unit, and which impeded documentation, was that the 15 minutes set aside for documentation turned into a break between the training session and the staff meeting. Staff members put off doing the documentation under the pretext that they would do it later; just then they needed to smoke, use the lavatory or get some fresh air. Consequently, little documentation was turned in from that unit. I tried to compensate for this with more interviews.

It also quickly became apparent that there were differences between various personnel categories and in various individuals' attitudes to the patients and in the knowledge that they had as the basis for treatment. These differences created a certain dynamics in the training sessions and such group heterogeneity resulted in questions that most likely would not have been asked in a more homogenous group. I saw such groups as being fruitful from a learning standpoint as long as the size permitted me to carry on a dialogue with the group members.

rallaren/case managers

Both of the outpatient units had small staff training groups, with the same people coming nearly every time. This enabled us to talk quite freely about different patients in our sessions and discuss a variety of current problems in a much more open manner than on the units where we consistently focused on one patient. The staff could also learn from one another's case studies.

different conditions

One of the most important results of what I have so far just described was that I realized the difficulties involved in organizing regular, continuing education courses in inpatient psychiatric care. It required considerable awareness on the unit of the significance of the course so that all the necessary schedule changes would be made and substitutes called in, etc. The patients on these units are there 24 hours a day and their lives have to go on as usual, even when staff members are attending courses.

When it came to staff needs for further education, the neuropsychiatric diagnoses were something they prioritized highly themselves because they felt this was a new and difficult area. Treating these patients in the conventional manner was not working and the personnel did not know what to do instead.

Some of the psychiatrists were also of the opinion that for these patients in particular, but for many others as well, they needed to set up learning environments, with a more deliberately designed educational approach than the fostering they now had on the units. To this end, they also wanted to include other personnel categories—such as special educators, recreation instructors and more occupational therapists.

I also saw examples showing that it is not only through courses that staff members learn how to use an educational approach on the job. On one unit there was a nurse who worked extremely pedagogically without being aware of it herself and without really being able to explain what she did or how. In her case, it was natural and obvious because at home in Chile she had worked with groups of underprivileged children and had learnt to create learning situations with limited resources.

Personnel—their environments and patients

At the end of the 1990s, I participated in developing a special unit for two very unique patients in long-term, inpatient psychiatric care. The large mental hospital that surrounded the small unit was being phased out and some of the buildings were demolished during the time we were there; they lay as enormous smoking piles of concrete outside our fenced-in exercise yard. Our patients eventually moved out to a freer environment within the framework of the LSS and the building we had occupied was also levelled. With that, the last bastions of the old psychiatry should have been obliterated.

In the beginning of 2000, when I stepped back into the world of psychiatry, I expected to see signs of the effects of institutional closings and of an updated psychiatry from that of the 1970s and 80s. Much to my surprise, I observed that the patients' living environments and the staffs' work settings were still, to a great extent, those of the large mental hospitals. The hospitals may have been closed down, but the premises were still being used under other designations. In many cases, the personnel have been very creative, expending considerable time and energy in spiriting away as much as possible of the institutional setting. The fact remains, though, that it is the old mental hospitals that are again being used in the new psychiatry.

Nor did I see in the design of the units any acknowledgement that the people who were cared for there had perceptual disturbances, planning difficulties or other cognitive disabilities requiring an explicit, inspiring, yet self-instructive setting. On some of the units there were patients with severe visual impairments and brain injuries where, as a researcher from a rehabilitation engineering division, I immediately thought in terms of environmental adaptations where none existed.

Practically all the personnel that I interviewed said that they liked their work as such and the patients too, even though they often had to deal with very severe cases. On the forensic psychiatric units and the units for patients with severely challenging behaviours, there are mixtures of patients with severe drug abuse problems and psychoses. There are very violent offenders side by side with young autistic men who were in high school not all that long ago. The existence of these kinds of mixed units makes it difficult to provide individualized treatment. The personnel are under the impression that they have to treat everyone equally so that no one receives something that someone else does not. In a way, the patients on the unit resemble a group of siblings, jealously keeping an eye on one another. When we wanted to see if increasing Michael's coffee intake would reduce his drowsiness, it was not allowed because it would not be fair to the others.

For these kinds of reasons, most of the staff members were of the opinion that it would be better to have units that specialized in autism spectrum disorders. They also thought that these patients were often taken advantage of by the more social patients, particularly those with criminal backgrounds or who were chemically dependent. It was difficult for the personnel to see this kind of *manipulation* that was taking place on the unit and to protect the more gullible and naïve patients from the more cunning.

The personnel who did not think that there should be specialized units for patients with autism reasoned that it would be impossible to recruit staff to units that only dealt with that patient category. It was such difficult and unusual work that no one would be able to put up with it.

In the interviews, there are many who take up the difficulties in providing different kinds of treatment for different patients. They have learnt that those with autism need to be handled in another manner, but find it hard to switch from one treatment approach to another when interacting with a variety of patients. Some patients require that you turn on your feelings, while others require that you turn them off and only use your intellect. Patients with autism who also have strong rituals and compulsions are a special group who wear out the staff. It is hard to resist their obsessions and compulsive acts, difficult to get a large team to agree on a uniform way of dealing with the patient. This means that a compulsive person can increase his compulsiveness until it becomes unbearable for the staff, without bothering the patient himself in the least. What the personnel describe is that they enter into a total concentration, a kind of tunnel vision when they are working with these patients. They try not to do anything that will interfere with the patient's compulsions and that they know can result in agitation and outbursts. They balance their movements, weigh their words and still are not always able to avoid strong reactions from the patient when they have committed a transgression regarding a ritual. These patients are also often moved between different psychiatric units in the country for patients with severely challenging behaviours.

What is striking in what the personnel relate about their work is the pride in what they do. They feel that they are doing a good job; no one is afraid in the locked units where the serious offenders are cared for. When they explain why they are not fearful, it has to do with their trained ability to detect small, insignificant signals they feel it in the air when something is up and react immediately so that violence can be averted. One of the young mental health assistants, a woman who recently started on the forensic psychiatric assessment unit, felt that she had landed a job in the most qualified area of psychiatry and was proud of it.

Good or poor learning environments?

When I examine the units from the perspective of how they functioned as good or bad learning environments for the personnel (see Ellström in the section *Professional lifelong learning,* chapter 6), some were better than others. The unit that had the fewest prerequisites for a good learning environment was the Wild Goose. It was a unit in constant reorganization for a variety of administrative reasons. The personnel experienced these as being decided by "those guys in the X hospital." The people who determined the goals for the organization were far away, no one they had contact with, other than when a representative came to *inform* them. In general, they heard about it first through rumours.

These set the employees imagination in motion and a sense of indifference spread towards those who decided. The staff knew that when the actual information was presented from management, the decisions had been made. During the total of three years that I was in contact with the unit, there were two major reorganizations in which the staff saw no point. It also meant that a good part of their time and energy was spent in worrying about the patients and their fate after the transfers, as well as worrying about their own job situation. After the second reorganization, a large portion of the staff quit and looked for work outside of the organization.

I observed from several quarters that reorganizations and transfers were experienced, on the whole, as a problem in today's psychiatry. A nurse on one of the units lets out a deep sigh when I start to ask questions about improvements on the units. She sees the constant reorganizations as an obstacle:

> Oh, there are so many reorganizations and I am so tried of them … about every other year it seems … the first big reorganization I participated in was the move from the large mental hospital … it was when the patients were to be moved to their home communities … after that came deinstitutionalization in the middle of the 1980s … those were the big reorganizations and in between were the clinic reorganizations in which they renamed A and B to 1 and 2 and stuff like that, but these didn't affect me very much … I worked away and took one day at a time … but somewhere along the line that feeling arose every time there was a reorganization of, "Oh no, not again … and now we aren't going to be part of the same unit anymore, now it's going to be something new again, etc." … Some of these reorganizations have, with time, turned out to be quite good, although it was traumatic being thrown together with new people … and when our current unit merged with another, no one wanted to and it felt just terrible, and that could also have been done in a better way. But over time it has turned out fine … and in recent years, of course, all reorganizations have been due to budget cuts and not to improvements in the organization or for the sake of the patients or their relatives … money determines everything … but the most recent reorganization, where we skipped decentralization, and which I was so against myself, has turned out quite nicely for our sake; we have good supervisors and that means more now than ever … and when this reorganization started, the board that ordered it didn't want to talk to us, the personnel … even though we are an extremely competent group, some of whom have worked for ages and then it feels strange that they didn't even want to listen to us, the ones who are going to be working in the new organization … of course, you have to listen to the user associations and the relative associations, but not *just* them …

Most of the units had experienced some form of reorganization or transfer during the time—a little more than a year—that I was in contact with them. Rehab and Unit 99 moved to new premises. Rallaren was reorganized. Unit 11 and 12 were included in a bigger division that was carrying out forensic psychiatric assessments. The plan was to establish units with greater specialization, with particular consideration for the special needs of autistic patients, which were often incompatible with other patients' needs. The personnel felt that the changes that took place were meaningful because they were based on a treatment concept and not just decided and imposed administratively from above. It was also this forensic psychiatric unit that had the most satisfied staff when it came to educational opportunities.

When I asked about the opportunities they have for continuing education, I can also confirm the veracity of Ellström's survey. Staff members who think that they can influence their working situation and who, to a large extent, receive the continuing education they feel they need are much more involved in the staff training I offer. They come regularly, some even on their days off, and they take it much more seriously than other units. In these clinics, there is also a relatively direct correlation between the staff's everyday work and the aims of the clinic supervisors. They do not feel as though the aims are formulated somewhere *over there* and that they are contrary to the work the staff carry out *here on our unit*.

In a big city clinic, when I ask about educational opportunities in autism and other neuropsychiatric conditions, the personnel answer that there are, indeed, courses listed in a course catalogue they get now and then, but that much of what is offered is not suitable for them. It has just been in the last two to three years that they have started to see courses offered that have relevance to their daily work. They say that they lack in-depth education in the neuropsychiatric syndromes, in recent research and new treatment methods. One nurse mentions that all the time she has spent in continuing education in recent years has involved learning to document. This nurse is also very pessimistic about the development of new methods in psychiatry. She has worked as both a mental health assistant and a nurse for several decades and thinks that all improvements now have to do with making money and do not have anything to do with the actual content of the operations. When I ask her if it really is possible to work for your entire career on one unit without taking part in any further education, she answers unconditionally, "Yes."

At another clinic the situation is entirely different. This forensic psychiatric clinic is located in a smaller city where the personnel are very satisfied with their continuing education. One of the mental health assistants relates what it is like:

> I myself am attending a psychiatry course at the moment and these diagnoses are included. It's a course that runs one day a week from September to June and involves lectures on the different diagnoses.

> The clinic arranged it and only those who signed up can attend. Otherwise, the situation is good here with a variety of lectures too. If you want to further your education, you can do it here. Things don’t really stand still here, and then there are going to be a lot of changes in the future as well. We’re going to divide the patients up so that we have more specialized units: one for psychosis, one for the chemically dependent and one for autism. And then we’re going to receive training in all of these areas.

When it comes to the development of psychiatric organizations, it is quite evident, at least in my material, that development means reorganization and that these reorganizations of the staff, for the most part, are experienced as something outside of their influence and completely steered by administrative and financial motivations. Personnel who have worked in health care for over twenty years talk about “the good old days” when the treatment concept steered operations. To be sure, they can also speak of treatment concepts that would be considered totally preposterous today, but it was still the concept of good treatment that determined operations. There is not much positive to be said about continuing education either; you toil away and work with your patients, turn a deaf ear to management and politicians and do your job properly.

In only one of the regions where I taught was the organization steered by plans based on new treatment concepts. These involved creating units with specialized care environments suited to the needs of particular groups. The psychologist on the two units that participated in the educational programme was a driving force in this process of change.

Two chief psychiatrists who I interviewed also had ideas of how to redesign the wards so that they would be better learning environments. They thought that some of these changes would come about by hiring staff trained in education. One of these wards, the one that is going to have specialized units, has already put its plans into action by employing a part-time teacher, who also instructs at the school of health sciences at a nearby college.

Reflections on outpatient care

Before starting the staff training sessions, my contact with psychiatry had primarily been with inpatient units, especially those with patients with severely challenging behaviours. My notion of outpatient care was that it dealt with much milder cases. To a certain extent this was true, but in surprisingly many cases, outpatient work was not any easier. A complicating factor was that care was voluntary, even when patients were a real danger to themselves and others. Where to draw the line for involuntary commitment was difficult and the staff manoeuvred between supporting, teaching and persuading people who had obvious difficulties in judging the risks involved in living as they did. And yet, the patients that we discussed in the staff training sessions were neither drug or alcohol abusers. Nor were they what you would call *mentally ill*. As good as all the cases had either established or suspected autism spectrum disorders and were of normal intelligence. On the basis of their diagnoses, they were entitled to services according to LSS. Since these services need to be applied for by the individuals themselves, it requires that they have insight into their own needs for support and that they understand what these support services involve. Many of these patients have deficiencies in the ability to self-reflect. They also find it hard to understand everyday situations and ordinary communication and consequently cannot be expected to apply for support services on their own, or they may have entirely mistaken notions of what this kind of support implies. This presents particular difficulties when the children involved are badly treated or neglected, even though their parents are doing their best but simply lack the necessary judgement. These circumstances are not only a problem on the units I have been in contact with, but also for many more, in part because the intentions of different kinds of legislation collide with one another and because of the knowledge rivalry that exists between the various authorities involved. These situations are described and analysed in a sociology of law dissertation from the Sociology Department of Lund University, Sweden (Pfannenstill, 2002).

Further research and development

The research carried out and presented in this dissertation and in my earlier licentiate thesis is based on knowledge from the areas of education, psychology, rehabilitation engineering and design sciences. Using a multidisciplinary approach, I have entered into the world of psychiatry and observed it both from the inside and with the eyes of an outsider. What is striking when you observe the care and treatment provided, is how little of it is evaluated. The concept most often used to describe the care given is “environmental therapy”. This therapy, however, is in no way consciously defined; it comprises almost any kind of treatment in which environmental factors are considered to influence the patients.

When it comes to further research, a primary need is to define what actually constitutes care and treatment. It requires that psychiatric personnel become conscious of what they are doing when they care for and treat patients. In addition, evaluation is needed of the methods so that the staff is better able to determine which patients will benefit from what types of treatment.

A survey and evaluation of psychiatric settings is another research project that I can see taking place between psychiatry and a design department, for example.

The overall impression I have of the psychiatry I encountered is that patients in inpatient care today are in a predicament similar to that of cognitively limited people in the 1970s when I worked in a large care facility. For large groups of psychiatric patients, the curable criterion has also been dropped in favour of the designation *disabled.* The disability perspective calls for other kinds of expertise and approaches than does the curable perspective. Disabilities require settings that are adapted, that provide cognitive assistance for people with executive difficulties, concentration and memory problems. There is a need for a survey of these problems as well as research on them and design of different living environments for patients forced to spend large portions of their lives in these inpatient, institutional facilities.

Among the forensic psychiatric patients that I have met are young people sentenced for serious, violent crimes. Their disabilities mean that for a good while into the future, they will be considered dangerous and will not be allowed to live freely in society. These patients, as well as others that society at present cannot place in more normal settings, have to be offered very focused forms of treatment. What is needed is a combination of educational as well as psychological methods and some methods previously considered taboo in psychiatry—behaviour modification, for example—are, in certain cases, not only justified but necessary. These patients need secure settings that are adapted to their disability and yet are as homely as possible, since long-term treatment is often required.

In a report from the Swedish governmental committee responsible for psychiatry (Swedish Government Commission Report 2002:3), similar thoughts are expressed about people who have neuropsychiatic disabilities and fall under LSS legislation. The report ascertains that this forensic psychiatric group is growing as knowledge of them increases and that certain criminal classifications are considerably more common among them than other groups. The committee also has a proposal regarding care of *certain disabled offenders.* It involves care that can be provided based on the model for group living arrangements provided for in LSS. They emphasize that such units have to be staffed by personnel with specialized knowledge and training in habilitation and rehabilitation. Putting this proposal into practice would improve the situation substantially for people like Jasper and many others.

As an educator who worked with children and adults in the Swedish schools, I still observe great deficiencies in a system that excludes the group of people classified as *mentally disabled* from adult education. Adults with cognitive limitations have had their own special schools for ten years now. In fact, the mission statement for this form of educations includes adults with autism, but this is not the case in practice because it is not suited for autistic peoples with normal intelligence. Many have normal intelligence or can be extremely gifted in certain areas; what they are in need of is other kinds of knowledge at a much more basic level. For them, another school form based on a different curriculum is necessary.

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Appendix 1. Interview Plan

What does psychiatric care mean to you? What do you do in concrete terms to care for and treat patients in psychiatry?

How has your view of care and treatment changed during your career?

How do you learn to deal with new problems that arise when new ideologies and new treatment methods are introduced?

What is your view of the relationship between diagnosis and treatment?

Does a psychiatric diagnosis give you enough information to know what kind of treatment the patient needs?

Which treatment methods do you have to choose from?

When and how did you learn about the neuropsychiatric syndromes?

Have you received any continuing education dealing with these groups of patients from your clinic?

What is continuing education like in your clinic? Do you receive the continuing education you think you need for your work?

Have you changed anything in your view of the patient we have discussed during this staff training programme?

What has changed in your approach to the patient?

Has the change in approach had any effects on the patient concerning new treatment, new assessment or anything else?

Is there anything in the work methods of the clinic that hinder the implementation of an educational approach?

Is there anything in the organization that hinders the educational approach we discussed in the training sessions?

Appendix 2. Questionnaire

1. Which professional group do you belong to?
   Nurse Mental health care assistant Psychologist
   Occupational therapist Physical therapist

2. I completed my education in (year) _____

3. I have no formal training.

4. Altogether, I have worked_____years in the profession.
   I have worked_____years on this unit.

5. Did you study any of the following conditions during your training/education?
   Infantile autism
   Asperger Syndrome
   ADHD (Attention Deficit Hyperactivity Disorder)
   DAMP (Deficits in Attention, Motor control and Perception)
   Tourette’s Syndrome

6. Do you remember any of the literature you read on the subject?
   Yes, it was ____
   No, don’t remember exactly, but it was:
   several books
   one book
   some articles
   saw a film
   got information from another source

7. Before I started the training programme on your unit, had you read about or in some other way shown an interest in autism, Asperger Syndrome, Tourette’s Syndrome, ADHD or DAMP?
   Please underline the syndromes that you already knew something about.
   No, I knew practically nothing about these syndromes previously.

8. *Please underline the following statements that are true about you.* The staff training programme has made me more aware that what are referred to as childhood neurospychiatric syndromes can also be found in adult psychiatry. I have personally become more interested in:
Autism
Tourette's SyndromeADHD
DAMP
Asperger Syndrome
All syndromes

9. After the staff training programme I have read more about these conditions in:
text book/s
biographies
journal articles
newspaper articles
film/documentaries on TV

10. The patient/s that were discussed in the staff training sessions have now:
a. been assessed and assigned a new diagnosis
the previous diagnosis was ________________________
the new diagnosis is___________________________

b. will be assessed for a new diagnosis in the near feature

11. It will be much easier for me in the future to recognize a person with:
Autism
Asperger Syndrome
Tourette's Syndrome
ADHD
DAMP

12. I understand how to observe a person who I suspect of having one of the neuropsychiatric syndromes.

13. I have understood that treatment has to be different for a person with a neuropsychiatric syndrome.
I have understood that the most important difference between treatment of patients with childhood neuropsychiatric syndromes and other patient categories is ____________________________
____
____
____

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