

Compendium on Habilitation

Part I

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Treatment and rehabilitation

The goal of treatment is to "make healthy" The goal of rehabilitation is to ... Well, what is it?

Ivar Lie

What is rehabilitation?

Rehabilitation actually means: to regain dignity. But if we look at the practice of rehabilitation, it can be difficult to recognize the similarities that can be said to define rehabilitation as field operations, let alone to notice the efforts to dignity. Everything from medical treatment of acute injuries to care of the elderly can be named rehabilitation. What may seem common to much of the business is that it is about efforts to restore or compensate capabilities and features that are permanently reduced or lost by previous injury or incurable diseases. The bulk of this work is focused on training and adaptation of technical aids. Key agents in the business are physiotherapists, occupational therapists, doctors and nurses. These all work on the basis of a medical model in which academic work routines are focused on diagnoses of deviation and normalization of the person's features.

Psychologists have so far not found any natural place within the field of rehabilitation in this country [Norway]. It may be due to factors related to academic content as well as to the field's lack of prestige. The medical work model has provided little space for psychologists beyond a certain demand for specialist services, particularly in the neuropsychological diagnoses. It is therefore not surprising that it has been difficult to work with the recruitment of psychologists to the rehabilitation field.

But the field is now in a melting pot, based on a scientific and social paradigm shift related to that focus has shifted from the normalization of functions to the normalization of the individual life circumstances. There will still be as important as ever to ensure that the individual has the opportunity to regain functions when this is possible, but the main goal of rehabilitation is to be helped to lead the most normal life with the injury and disability one has.

The basis for this paradigm shift is the understanding that the core of what it is to be disabled is to find that something has happened that makes it impossible to continue to practice activities or to implement plans that are important to one's sense of identity and significance as a human being.

"Peter is working as a book illustrator, grows corn on his farm, plays soccer and is one of the nation's premier clay pigeon shooters. In an accident at the farm, Peter is blinded. He realizes quickly that he can not continue with some of the activities that have been important in his life, activities that have been fundamental to his sense of meaning and future planning. Peter is in existential crisis, he knows not what he should do with his life!"

The medical work model

Confronting Peter, the medical work model [in which academic work routines are focused on diagnoses of deviation and normalization] breaks down. Diagnosis and treatment is no longer relevant neither in the effort to understand nor to help Peter in his existential crisis.

Furthermore, in the medical model professionals are put in charge and control of managing both objectives or goals and instruments or means. Now it is Peter's future life that is in question. Nobody has the professional authority to be in charge of neither Peter's nor other persons planning of their future life, provided they are of legal age, that is. It is Peter that must have the management, and it is the rehabilitation work that must adjust to Peter, not the other way around. This means largely a revolution in the field of rehabilitation, where the psychology in a whole new way must be ensured a central role in service provision.

The need of expertise

Why more expertise than before? It will be with Peter as with most others in similar situations; he lacks the necessary expertise to plan and implement a realistic reorientation of his life. He lacks a reasonable understanding of his own needs and feelings to such a degree that he is, without some help, incapable to find new activities that could form the basis for the maintenance of his identity, dignity and feeling of living. He lacks knowledge of the functional aspects of his functional status, the opportunities, the limitations. He knows little about his own "hidden" resources. He may have not have developed appropriate strategies for

coping with difficult life situations. Without such knowledge and insight Peter will not be competent to be in charge of the rehabilitation. The result will be that Peter, like most others in this situation, make a "stripping" of past lives, rather than going into an active planning of new life on the basis of basic needs, values and resources. Peter will gradually come to terms with having to abstain from all the activities he can not continue with and eventually set out to find joy in being able to practice the few remaining activities.

Facing existential problems of this type, the support/service system must position itself primarily with an objective of assisting the person to gain the expertise necessary for that person to re-establish a desirable situation. Such a reorientation of life will involve investigation of goals for the future, identification of problems to be solved to achieve the goals and appropriate plans to resolve problems. The need for psychological expertise comes, naturally, with particular force in connection with assessment of the goals. In reality we are talking here about the profound psychological conditions in which the borderline between the conscious and unconscious forces, ideas and experiences must necessarily be challenged and molded in a clinical setting where the framework ensures trust and openness.

It is not about treatment

This means that psychologists should be able to feel at home in the ongoing reform of rehabilitation services in this country [Norway]. For is it not precisely that building of expertise that is the core of much of modern clinical psychology? Without any statistics to show it seems obvious that the psychologist's client base today is dominated by people with existential issues related to lifestyle, conditions of interaction conditions and material framework. The vast majority of clients are not mentally ill, they are mentally normal people for whom life has become crooked in such a way that they need help to reorient themselves in a new future. In this perspective it is easy to see that is unfavourable that clinical psychology once, and without further ado, adopted the medical model and defined itself as a profession of treatment. Admittedly, the treatment concept is still relevant in parts of clinical psychology. Although the normality concept in psychology is so wide, spacious and culture dependent that it poses great problems to set criteria for recovery from mental illness, there are obviously conditions related to anxiety, depression and confusion that can reasonably be regarded as morbid and where at least part the medical model seems relevant and appropriate. But

problems arise when this framework is also dominant in the face of primary existential problems. Not only because the disease model is inappropriate, but also because it is harmful in involving a frame of interpretation which allows normal reactions to a difficult life being defined morbid. Grotesque examples of this may be found within the psychiatry where the frame of the hospital gives the patient little opportunity to be perceived as both ill and as someone with a difficult life. The use of terms like reactive depression also obscure, in many cases, existential problems and initiate treatment which most of all must be considered as disempowering and violation of integrity. Moreover, the treatment model contributes to the making of clinical psychology and psychiatry exclusive in relation to rehabilitation. In the "rehabilitation patient" the specialist encounter the result of unsuccessful treatment. It can be experienced both provocative and despondently to have failed to make a person healthy. It is perhaps not even necessary to resort to Freud to understand that psychiatrists and psychologists are absent in the field of rehabilitation. This is particularly strongly expressed in the organization of psychiatry, where rehabilitation has not even been recognized as a need. The furthest one has come in the direction of recognition is to talk about the need for aftercare. Aftercare is no prestigious institution that attracts the best professionals. Aftercare is something for hospice hosts and unskilled assistants.

Rehabilitation as an overall framework in mental health care

But the revolution is about to happen also in psychiatry. Decentralization of services is in full swing – with the dismantling of central institutions and transferring of the responsibility for the integration of patients in the community to local authorities. This means that both psychiatry and psychology significantly must redefine their concept of work from treatment to rehabilitation. There is reason to believe that this realignment will be very heavy and difficult for psychiatrists, for whom treatment is the basis of professional conduct. But also many of our well-established clinical psychologists will feel that it is massive expenses for their professional pride when rehabilitation is being made the overall principle also in the mental health care. Yes, that's what we are talking about, namely to implement rehabilitation as overall framework for professional development in mental health care.

In somatic medicine one has for long recognized the need for rehabilitation of people who can not be healthy or fit, people which goes in and out of available treatment regimes, people with reduced premises of functioning that causes problems for living a dignified life.

Treatment of mental disorders is not different. In truth, it is rather rare that people with psychiatric diagnoses is permanent healed so they can automatically go back into, or into, life normally functioning. In the rehabilitation perspective, the question about how well a person can become is subordinate to the question of what assistance the person needs to become able to master the most normal life on his own terms within the framework of the rights and obligations at any time in the community. It is life that counts, not how well or injury-free one is. Here, people with physical and mental deviations must be treated equally in the design of the service providing. In my experience it is neither political nor financial constraints that are the problem in the ongoing process. The problem is the professional culture in the overall health care system, nurtured and cultivated in the medical model of disease. But since the emphasis in rehabilitation efforts is the need for assistance about coping with existential issues, the process is particularly dependent on the necessary renewal of the psychological profession.

The big and exciting challenges in making rehabilitation a primary goal of clinical psychology are today offered to psychology students and young psychologists who have not yet done treatment to a personal value in life. The 50-year anniversary of IMPULS is an appropriate occasion to accept this challenge.

The article was published in Norwegian in the Journal *Impuls No. 4, 1996*.

Habilitation in a time of change

Martinsen, Tellevik

Abstract

The field of habilitation

In a broad sense, a habilitation client is said to have an *interaction problem*, linked to other people and social institutions in the areas of life where the culture regulate the activities and

social behavior of people. Habilitation clients are characterized in that they do not develop so that they can participate in society's normal activities as usual at the usual time. Our culture's frameworks for childhood are inadequate for those children who are in need of habilitation measures in order to participate independently in the culture activities in the usual way. The usual framework of a child's upbringing must be broken, and extraordinary frameworks arranged for them to increase their participation in community activities. For most clients in need of habilitation services, such a break of the normal framework of social participation persists for life. Habilitation work consists in changing the social framework within which people live by facilitating the physical and social living conditions, implementing treatment and systematic training – such that the habilitation clients, as much as possible, can be participants in society's mainstream activities. The overall objective of the habilitation work is that clients will achieve the same quality of life as other people. Work with habilitation clients requires a comprehensive, long-term and individual adaptation of public facilities and services.

In the following, I describe the scope of habilitation work and discuss what knowledge and competence in this field involves. Knowledge and competence is discussed in relation to the guideline that the work with each and every individual habilitation client is considered as a separate project. On this basis, it is discussed how the habilitation work can be evaluated and quality assured, and how the various services and facilities can be coordinated from the perspective of the individual's totality of needs.

Who are the habilitation clients?

The portion of the population in need of habilitation split up into a number of subgroups that have different functional problems and different needs for programs and services from the public. This is reflected partly in the variety of diagnostic groups that comprise the total group. Each of the individual subgroups is few in number, varying from a fraction of a thousand, to nearly one percent of the population. Both internationally and nationally, the population in need of habilitation is complex and poorly defined. This is due to both lack of knowledge about sub-groups with special needs such as changing diagnostic criteria on the individual groups and confusion about how the groups' needs should be cared for and reflected in the structure and organization of the public services.

The single largest group consists of people with so-called mental retardation. This is an *administratively* defined subgroup that does not reflect any academic grouping. Historically, the groups were designed to separate out those who could not profit from regular schooling and, therefore, would be given special training or placed in special institutions. This is an argument which largely cuts across the prevailing cultural and socio-political attitudes in Norway today, where the goal is to involve all in community activities. Functionally, the group mental retardation divides into a large number of subgroups.

The prevalence of mental retardation can be difficult to estimate, and it is common to use the term in such a way that there are varying prevalence in childhood and adult age (Berkson, 1993). In Norway it is in the best survey found a prevalence of 2.6% of school age (Vikan, 1985), while the incidence of adult age is usually estimated at about 1% (Berkson, 1993).

In addition to mental retardation, the population in need of habilitation include children and adults with sensory damage, extensive mobility problems and extensive developmental disorders (Pervasive developmental disorders), including autism. The prevalence of sensory damage in the population is between 0.25 and 0.5%. A conservative estimate of the prevalence of mobility problems, including severe delayed motor development, cerebral palsy, motor paralysis, coordination problems and diffuse mobility problems linked to birth defects and damage, is of 0.14% (National Institute of Handicapped Research, 1985).

Prevalence numbers for autism, which is the largest of the so-called comprehensive developmental disorders, varies in the different surveys between 0.04 and 0.11%. In addition, the specific language disorders, which have not traditionally been counted among habilitation clients, but who have similar needs.

The various diagnostic groups that make up the population in need of habilitation overlap to a large extent. The overall prevalence is lower than the sum of the various subgroups. Overall, it seems reasonable to assume that habilitation clients make up less than 2% of the total population and between 3.5 and 4% of children in preschool and elementary school age.

What are the framework conditions for habilitation?

Programs and services for children and adults with habilitation needs are dependent of a number of framework conditions. Among the most important are the geographic and

demographic factors, primarily the distance to the communities that will provide services and population in the region where the clients live. Both the supply of programs and services and the quality of these vary depending on residency. In the country's major population centers, there is greater access to specialized departments and individual professionals with specialized expertise, which makes it easy to obtain specialist without going outside their own region. In sparsely populated areas it is increasingly necessary that the group of specialists is engaged in a "self-rescue tactics", which aims to manage without help from distant specialized departments that lack knowledge of local conditions. The demographic framework factors are reflected so that support services are organized differently and have different working methods in different places in the country. Cultural and social policy guidelines, however, constitute the main frame factors for habilitation work, and are reflected in the legislation and the regulations for working with the client groups.

Who are the participants in habilitation services?

Participants in a habilitation service consist of someone close and professionals of various categories. The professionals who are participants have different positions related to the habilitation work, and they are participants to different degrees and in varying time-spans. There is always a wide variety of professional agencies and professionals that to any time are involved in services and measures for children and adults in need of habilitation.

When problems are extensive and complex, and perhaps also include other family members, the number of involved professionals may be very high. This is partly due to the fact that many disabled have complex problems, and that they are more vulnerable to diseases and medical disorders than the general population. In one instance, there were a total of 27 different professionals related to the services of one specific autistic child

The professionals comprise, to a large degree, what we might call the formal network, but habilitation clients must also deal with people in what we may call the informal network. In addition to the immediate family, there may be relatives, friends, employees at the local post office, bank, café or shops, and people that the client comes in contact with through various forms of activities. Such people often need information about how to interact with a client can, or how to facilitate for functional performance of activities. Information and training of

someone close in the informal network is important for the ideals of the involvement in local communities can be realized. The formal network is very important in order to activate and get the informal network involved.

...(…)...

Competence^[1] levels, knowledge and information from close-others

Competence in habilitation work

Competence in habilitation work is generally speaking skills for working with each client as if the client is its own project. Competence includes knowledge of a theoretical, administrative and organizational, generally practical and individual level, as well as many different kinds of competencies. A comprehensive and specialized competence in habilitation work includes thus an extensive and rich and complex pattern of various forms of competencies as modules or components. The competence consists also of a complex web of theoretical knowledge, knowledge of the subgroups of the client population, practical experience in initiating measures for specific client groups, knowledge of support services and experience to implement the organizational framework of measures and ‘close-other information’, i.e. knowledge of the habilitation client’s individual characteristics and needs from the perspective of those who know the client intimately.

To get an overview of some of the competencies that must be made available by various ***forms of competence*** in order for a habilitation service to be comprehensive and quality assured, it is possible to distinguish between

- *general habilitation competence,*

[¹ For the concept competence, see e.g. Dreyfus: What Computers Still Can't Do: A Critique of Artificial Reason, ch. 5; Dreyfus: On the Internet, p. 35.]

- *domain-specific competence*,
- *group-specific competence*, and
- *individual-specific knowledge*.

It is also useful to distinguish between different **levels of competence**. This enables a discussion about what kind of expertise it is realistic and desirable that the various professional agencies should possess. One may distinguished between three different competence levels:

- the level of *involvement*,
- the level of *objectives or goals*, and
- the level of *distribution*.

General habilitation competence

Some of the competencies needed in order for habilitation clients to receive good and comprehensive services can be considered as *general habilitation competence*. This means competencies necessary to define, initiate and implement programs and services for all, or most, of the clients who need habilitation services. However, it is important to emphasize that putting such a competence to use, is based on a plan for a comprehensive service, which requires that other forms of competence already is in place when such overall plans are being made. Other forms of general competence, for example, are knowledge of strategies towards measures, methods and techniques that are wholly or partly used in relation to multiple client groups within the population of habilitation clients.

Domain-specific habilitation competence

Other forms of competence modules or components related to habilitation work can be called *domain-specific* competence. This is competence related to theory and clinical practice in specific fields included in the measures for different groups of habilitation clients. Perhaps the best example of such a domain-specific competence important in the field of habilitation is

knowledge of language and communication. For a large part of the habilitation clients with various disabilities language and communication problems have a central role in their problems to participate in community activities and achieve a satisfactory quality of life. Other examples of domain-specific competence are knowledge and experience with mental health problems in children and adults, theoretical knowledge about learning and practical skills to define, organize and implement various forms of training, knowledge of cognition and assessment of intellectual abilities and knowledge that enable the diagnosis and medical and functional assessment of habilitation clients.

All forms of domain-specific competence means knowledge that is general in the sense that they are necessary for making good services for many, perhaps most, of habilitation clients, and also in the sense that everyone who works with habilitation clients should have some knowledge in the field. For example, it is reasonable to require some knowledge of language and communication difficulties among all professionals in the habilitation field, no matter where they work and what professional role they have. In this sense, domain-specific habilitation competence approximates general habilitation competence.

The domain-specific knowledge is specific in the sense that in most cases requires competence that goes beyond what is reasonable to expect of others than those who are specialists in the field. For instance, special knowledge and experience is required to be able to select and initiate training in use of alternative communication for the habilitation clients who need this. There are now numerous different communication systems, particularly graphic sign systems, and a variety of strategies, methods and techniques for training in the use of the systems. To a certain extent, it is reasonable to say that alternative communication has evolved to become a special field of study. This highlights the appropriateness of talking about domain specific habilitation skills. Even more clearly, this is demonstrated when one looks at the extent to which the clinical use of alternative communication is based on general and theoretical discussions of language and communication. Topics of discussion that traditionally belong in a linguistic tradition are largely defining the content of the measures for different groups of habilitation clients.

As with competence in language and communication, also other forms of domain-specific habilitation competence, has an academic and theoretical "hinterland" or background which is more comprehensive than what can be represented in the habilitation field. This applies for

example for knowledge of mental disorders in children and adults. When habilitation clients are in need of measures for mental health problems, both the specific treatment and the total of services must be based on general knowledge about the causes and treatment of psychological problems. When assessing the extent to which the clients' intellectual capacity puts special demands on services and measures the foundation of the assessment are general knowledge of cognition and the use of ability tests.

Group-specific habilitation competence

Especially important for the design of services and measures are the forms of competence modules in the habilitation field that can be called *group-specific competence*. This is the kind of competence that is specific for certain subgroups of the population. To create and implement measures for blind people which, for example, it is necessary that specific knowledge of vision and vision loss, use of hearing, etiological subtypes of the blind population, common problems associated with loss of vision at different ages, the blind teaching methods and techniques, aids for the visually impaired, practical and physical organization of everyday life, etc. are made available. This group-specific competence include both theoretical knowledge, knowledge of treatment and training programs designed for the group and what experience one has with these, knowledge of practical issues and skills in conducting training and other specific measures the group needs.

In all groups associated with specific subgroups, there is also a special form of knowledge that are part of the group-specific competence and is a kind of *lore knowledge*, i.e. knowledge of the group that is based on practical experiences over time and which not, or only partly or indirectly, is possibly deduced from theory related to disability: a kind of folklore. Examples of such knowledge is what autistic children and adults like and tend to be interested in, how you talk to well-functioning autistic people, the tasks that are suitable for autistic people, how to learn an autistic child to wash the table after the meal, the typical behavior of different subgroups of autistic children and adults and what it means for selecting the training method and form of socialization, etc. Such lore knowledge is developed and maintained within the stable communities that work with the various subgroups of habilitation clients. The communities associated with the NGO's [interest groups, often parent groups; e.g. The Autism Society] of each sub-group are often where lore knowledge is commonly available.

Individual-specific competence

The individual-specific competence include knowledge of and experience with the special characteristics of the individual client and the client's environment that must be taken into account when the sum total of services is determined and the specific measures is implemented. The individual-specific competence also includes the skills that make it possible to translate these experiences and knowledge into practice, when the individual measures are implemented. The fact that it takes special skills to interact with each client, and that these skills only to a certain extent can be conveyed or communicated in the form of information from the relevant interaction situations, makes it appropriate to use the term "competence" instead of merely talking about "knowledge" or "information".

Important in relation to the individual-specific competence is that it incorporates and builds on information from close-others. Close-others include parents, siblings, relatives, professionals with different professional training that have relations with the client on a daily basis and others who review the client regularly. Information that someone close has and can pass on to each other and to professionals who do not have the status of someone close, is knowledge of what the individual client makes during the day, how the social life and communication manifests itself in everyday life, interests, what the client likes and dislike, the client's emotional reactions to various events and conditions, history relating both to how the client has been in the past and what measures have been previously implemented and how – and with what consequences, practical experience and skills to facilitate activities and mingling or socializing with the client throughout the day, practical knowledge of the physical limits and possibilities for the client to be able to make things, etc.

Individual-specific competence also includes professional knowledge about the distinctive qualities of the individual habilitation client in relation to other clients that belong to the same subgroup in the population of habilitation clients. An example of such competence is the knowledge that the client has a special form of visual impairment or difficulty not characterized by the blind or visually impaired people in general, and knowledge of the consequences that specific impairment has for this particular client's adaptation to its environment.

Skills in how to socialize or spend time together with the individual habilitation client is often the main form of individual-specific competence. Close-other information is the basis for acquisition and development of such skills. In order for these skills to be adopted in the current situations requires close collaboration between those who have them and those who need them in order to make measures and socializing work properly. An example of this is illustrated by a brother of an autistic young man named John who were moving into his own home. The brother made "John - a survival guide" for the new staff, containing information of how to facilitate interaction with the young man. In this guide, such things as "how to walk along the busy road" were addressed: "Do not walk in front John. If you do he can hit you in the head. Do not walk to the left of John. If you do he can push you into the ditch. Do not walk to the right of John. If you do he can shove you in front of an oncoming car. Walk two steps behind him, right in the middle of the road, so you can prevent him from running out into the road".

In practice, it is important for many habilitation clients that certain individual-specific skills are made available when training or other activities is scheduled as part of the planning of the sum total of services. This is a competence it is impossible to acquire only on basis of theoretical knowledge, knowledge of each client group, surveys and clinical observations of the client, or from knowledge of the client which is limited to one or a few interactions.

Different levels of competence

The previous review of the various forms of competencies that is included in an extensive habilitation competence, shows very clearly that it is unrealistic, neither is it desirable, that all the professionals involved in the habilitation services have all kinds of competence. The requirements for competence vary depending on the workplace, and thus the role and responsibilities in the planning and implementation of the totality of the services the individual professionals have. The fact that different professionals at all times will have different competencies, necessitates that responsibilities are clarified as far as possible, and that there is a coordination that highlight the necessary cooperation such that the different forms of competencies are made available in the sum total of the services to the client. This means that it becomes clear which services the first-, second- and third-line providers respectively have responsibility to initiate and implement. Coordination of the various

competencies corresponds, to a certain extent, but not quite, to the usual requirement that the various measures at different arenas of life to be coordinated. Coordination of competencies, however, requires in addition that the necessary competence is made available across various arenas.

In addition to the fact that the various providers or agencies have, and should have, different competencies, it is also meaningful to distinguish between different levels of competence, in a hierarchical order. The hierarchy is shown by the higher levels of competence both possess the competence of the lower levels and an additional particular competence as well. Such a division of competence levels are fertile for several purposes. It makes clear how different forms of knowledge and skills differ from each other and show what a competence in practice entail. In addition, the division is suitable as a starting point for a discussion of the responsibilities, duties and working forms of the various providers or agencies.

In the following, three different competence levels are distinguished:

- the level of involvement (CL-1),
- the level of goals (CL-2), and
- the level of distribution (CL-3).

The three competence levels are shown in Table 1. The competence levels describes professional competence in relation to skills to spend time with clients, skills to review and prepare measures, skills to define a suitable totality of services, choosing strategy, methods and techniques for implementation of the measures included in the total sum of the services, facilitating the activities that the measures involves, choose necessary aids, train assistants in the use of necessary aids, carry out the activities that the measures involve, and coordinate and ensure the quality of the measures comprising the sum total of the services. *Specific administrative and organizational competencies are not mentioned in the description of the competence levels.*

Table 1: Competence levels and procedural knowledge in measures-oriented work

CL-1 The level of involvement

How to obtain close-other information?

- using sources / interview (by professionals and someone close) to provide information about the client and the close-others that exists in the client environment.

How to create measures procedures, workplans?

- creating tasks for the client
- using different kinds of techniques
- organizing the physical environment
- using aids.

How to make framework measures?

- obtaining additional resources
- facilitating and organizing relief/support for care-givers
- implementing two-teacher system.

CL-2 The level of goals

How to make a habilitation/individual plan?

- surveying/mapping the client's skills, activities, etc.
- using information from the survey/map to create a habilitation plan
- using activities as a means to achieve general goals in the habilitation plan.

How to prioritize actions in relation to the objectives?

- prioritizing and coordinating measures/services/activities in relation to the goals of the habilitation plan.

How to prevent continuity break in the habilitation work?

- supervising (when and in what situations).

How to choose/perform the evaluation?

- Evaluating/adjusting goals and measures (activities) in the habilitation plan (when and in what situations).

How to transfer lore knowledge to the level of involvement?

- creating procedures to get people on the CL-1 Level to the CL-2 level through creation of habilitation plans and goals.

CL-3 The level of distribution

How to get people to have ownership of issues and objectives?

- adapting knowledge and language to the recipient's premises, i.e., select, and explain the situation in relation to goals, theory and cultural constraints when teaching knowledge related to the CL-1 and CL-2 level.

How to get people to see the theoretical implications of the work on a habilitation client?

- making procedures that generate the use of adequate knowledge and theory in relation to the goal.

How to get people to see the administrative and organizational consequences of habilitation work?

- creating procedures/facilitate for the roles and responsibilities for both measures, evaluation and for initiating changes.

In Table 1, words to characterize and exemplify the tasks that professionals at different levels of competence are able to perform, and what competence in terms of knowledge and skills required on each level is inserted. The examples are not intended to be exhaustive, but are chosen to illustrate the differences between the competence levels.

CL-1 The level of involvement

On the CL-1-level, competence is associated with important skills to get involved in habilitation work. Some of these are general, in the sense that they are usable for multiple disabilities, while others are more directly related to procedures for clinical practice for a single disability. At the level of involvement one may characterize the necessary competence by differentiating between close-other's information, procedures and measures, and knowledge of framework measures.

Examples of close-other's information are experiences with how the individual tends to behave, what experience the person has, what activities the person participates in, the activities and things that person likes or dislikes, linguistic and communicative skills, and habits the person has and which close-others exist.

Examples of practical procedures are how to create a tasks for an autistic person, how to describe and plan a mobility route for a visually impaired child, how one can implement a sensitive hand-line/hand-support, how to use various forms of techniques, how to manage pictograms, how to use existing registration tools /surveys, how one should physically prepare the environment for the individual and how to use aids.

Knowledge of the framework measures include includes for example knowledge of how to obtain additional resources (e.g. hours in school with pedagogical teachers), two-teacher system, facilitate and organize support and relief for care-givers, personal support, medical examinations, provide overview of social security rights, etc.

CL-2 The level of goals

The competence on the level of goals can be characterized by separating between preparation, prioritization and coordination of procedures and procedures for evaluation and adjustment in relation to defined goals. *Procedures for preparation* defined in relation to goals are for example how to make a habilitation plan. This includes expertise in conducting a survey of student abilities, activities, etc., and on this draw up a habilitation plan and define tasks and activities in relation to the goals of the habilitation plan. In working with visually impaired will be the definition of mobility router is an example of this. In contrast to the routes that have no other purpose than to train to move from A to B, is a mobility route to define a route that is used as a tool for achieving overall goals of a habilitation plan.

An example of how to *prioritize and coordinate* actions in relation to a goal will be to focus on activities that one considers the most appropriate as a means to achieve the overall goals of the habilitation plan. It requires application of knowledge associated with change of behavior in a longer perspective. Such prioritizing includes assessments of adequate measures related to various fields of knowledge such as developmental theory, learning theory, cultural and social constraints in the pupil's environment etc.

A habilitation plan makes it necessary to consider how best to prevent discontinuity in the implementation of the plan. Such knowledge is strongly associated with the procedures on when and in what situation tutoring is necessary. Experience shows continuity violations often happen when there is a shift in goal orientation, environment, personnel and context. This requires that one is sensitive to both the pupil's needs and interests, academic, administrative and organizational frameworks for implementing measures as well as the social and cultural constraints that are active in the pupil's environment.

Evaluation of procedures in relation to the goal should ideally be described in the habilitation plan, and professionals at the CL-2 level should be able to undertake evaluation in relation to the goal, if the situation warrants it. A habilitation plan will always need *adjustment*, often because the activities prioritized at an early stage eventually proves less appropriate. In addition, unforeseen events such as e.g. disease, changes in the composition of the professional personnel etc. require adjustment and evaluation.

When transferring lore knowledge to the level of involvement, the work for those on the goal level is to demonstrate/describe how lore knowledge relates to the goals of the measures. An example of this is to emphasize, when working with adult autistic clients, how important it is to define clearly the beginning and end of a task in order to carry out an activity. These are procedures that stimulate knowledge of the client group that can not be directly derived from the theory. The most important for activating such knowledge is to initiate mapping/surveying routines in conjunction with the establishment of a habilitation plan. Mapping or surveying focus on, among other things, knowledge of the client group that largely is based on practical experience over time. Such experiences are essential prerequisites for habilitation work, to facilitate measures and services that seem meaningful to everybody involved.

CL-3 The level of distribution

The level of distribution describes competence in selecting approaches and procedures appropriate to the overall purpose. In practice, this means that people at this level of competence must have an understanding of procedures, professional background and knowledge among academic staff and close-others, cultural constraints, knowledge and theory in relation to the purpose, as tools. This understanding is often visible in the ability to

customize own knowledge and use of language to the recipient's abilities and skills, the ability to teach it to others.

An important prerequisite for engaging people in habilitation work is, experience has shown, is ownership of issues and goals. In practical situations it means, among other things, that one can select and justify the procedures depending on the situation in relation to the goals, theory and cultural constraints when teaching others the procedures and knowledge associated with the CL-1 and CL-2 levels. The knowledge to be taught must be adapted so that it can be absorbed by the recipients. It is then necessary to take into account the academic and theoretical traditions that are represented in the host communities so that the receivers can accommodate for change from their own knowledge structure. This knowledge is embedded in people who are at the CL-3 level in such a way that it can be communicated differently to different user groups which one wishes raised to a CL-2-level, depending on the communities' academic tradition, special education knowledge and their theoretical background. People at this level of competence not only have an intuitive understanding of the situation, but also an intuitive understanding of action.

Equally important is it to try to get people to see and understand the theoretical implications of the work on a habilitation client. It means, first and foremost that one is able to create procedures that generate the use of adequate knowledge and theory in relation to goals. The procedures are considered to be the nexus of what we call declarative knowledge. Declarative knowledge and theory is largely associated with our actions. Such knowledge is closely linked with our procedural knowledge. Our action procedures are an integral part of our knowledge in different areas of life.

In working with disabled it is also necessary to get people to see the administrative and organizational consequences of habilitation efforts. A necessary precondition for this to happen, is a functioning division of roles and responsibilities. An important element in this context is clarity at different levels. A successful habilitation work requires clarity at the individual level (of one's own and others' roles), at the administrative/organizational level (who are responsible for what, who takes the initiative to change) and on the academic/scientific level (what is professionally important for the involved parties, who has responsibility for addressing this). If such requirements are not met, it may be difficult to meet

unforeseen situations. The result can then easily lead to exclusion and lack of dialogue between the parties involved in the habilitation work.

The participant's need for close-other information

The general public assumption has traditionally been the need for close-other information will decrease the farther away from the client the services are defined. It has been imagined that this need is most pronounced among parents, municipal administration, experts reviewing the client on a daily basis, and other local professionals (e.g. pedagogical-psychological services (PPT)) (1. line), and that it is less pronounced for the habilitation agencies and the psychiatric service agencies on County level of (2. line), and for regional or national competence centres (3. line and above). In practice, however, the experience has often been that the need is related to the roles of the various providers/agencies involved in habilitation work. The need for close-other information is obviously great for those who are directly involved in the daily work, in action-oriented measures, such as parents and local professionals, but to a lesser extent among the providers/agencies in charge of organizational measures. The need is however expressed for those who are often physically distant from the client, but which has the function-oriented specialist and consultancy responsibilities, such as the regional and state/national resource centres. Consequently, often close-other information is found both in those physically closest to the client, and in those who are physically far away from the client, but which must have individual and close-other information to provide their services.

The notion that theoretical knowledge is increasing the further away from the client the service provider/agency is, has also been strong. It has to some extent been related to the fact that specialist services have been defined regionally and centrally. In practice, this is not always to be the case. In fact, we often find that parents in many cases have good theoretical knowledge that often, especially when combined with knowledge about their own children and the environment, is more applicable in habilitation work than the theoretical knowledge we find in the local and regional support agencies.

This is particularly striking when one works with low-frequency groups where the incidence of local communities is small, perhaps only every 15 or 20 years. Actually, we are talking not just about theory in the traditional sense, but in theory, together with knowledge of the

disabled. This knowledge is in fact often best in those who are close to the client, and among those who have specialist status in relation to the client. The same picture we also find when considering what we might call lore knowledge, i.e., experience-based knowledge of disability based on practical experience over time. Such knowledge includes what the disabled likes and dislikes, what activities are preferred by e.g. blind children, etc.

The consequences for the work and cooperation is, first and foremost that both first-, second- and third-line services need close-other information in order to deliver their services. In habilitation work it is important that the theoretical knowledge associated with the disability is combined with close-other information and lore knowledge. This means more direct cooperation with parents, someone close and municipal professionals when surveying and when designing a habilitation plan – a form of working that traditionally partly has been considered foreign and sometimes even threatening.

...(...)

Requirements for rehabilitation work in the future

Habilitation work consists in changing the social framework through the facilitation of physical and social living conditions, implementation of measures of treatment and implementation of systematic training, so that the habilitation clients to a high degree as possible, becomes participants in society's mainstream activities, and achieve the same quality of life as other people. For most clients of habilitation work such adjustments may be necessary in all phases of life. That fact provides clear guidelines and requirements for habilitation work. First and foremost it requires a comprehensive, long-term individual adaptation of public facilities and services in relation to disabled children and adults, and lead to that quality control at the best is done by working with each client as if the client were their own project.

The project form has three clear advantages. First and foremost, it stresses that one should have clearly formulated objectives/goals and issues for the development of competence. This makes it possible to ensure that the objectives/goals and issues are appropriate for the clinical work for disabled people and relevant to their needs. Another important advantage by developing competence through implementation of projects is that the project form allows for

prioritizing of the professionals involved in projects based on their professional affiliation. This ensures that in work with disabled people one can target one's clients when developing competence and at the same time make a realistic framework for the development. The third advantage is that the formulation of objectives/goals and issues and evaluation of these – as the project form requires, is an assurance of the competence development. The project form establishes a framework which is suitable for competence development. In general, the project design is chosen from the following recognition of learning: It is easier to learn and make use of theoretical knowledge if the theory is related to one's own clinical practice than to derive a good clinical practice from general theory. It is therefore easier to achieve an interaction between practice and theory and to achieve a learning effect, if one assumes the practical and proceeds to the theoretical – rather than the other way around.

Project work is both a practical approach and a metaphor for how the work should be performed. It is crucial that client work, like in any project, must be evaluated. This assumes that one can formulate the objectives/goals, issues, clinical hypotheses and progress plans for the work with a basis on a long-term totality of services. In order to work project-oriented with the individual client, it is important that knowledge and competence in three different levels are coordinated when objectives/goals, issues and schedule is derived from the client's need for a comprehensive and quality assured long-term totality of services. This comparison between specialized competence in habilitation work and project management/-work demonstrates that two necessary conditions must be present in order for the measures for the individual client to be quality assured:

- Knowledge related to the individual's needs must be made clear, such that the objectives/goals, issues and clinical hypotheses can be formulated and subject to evaluation.
- The working form/design/method must satisfy the general requirements for goal-orientation, planning and clarity in formulation of problems.

Generally, this requires that close-other information, theoretical knowledge and lore knowledge must be integrated into the organization/facilitation of measures. Close-other information necessary to facilitate these measures must be obtained from parents, other relatives and the professionals who have status as close other of the client. This gives clear

requirements for collaboration between parents and professionals in different service lines. Both the second and the third line must develop their services, primarily counseling services, based on such knowledge about each habilitation client. Mapping of close-other information is a prerequisite for the working form/design/method to satisfy the general requirements of goal-determination, planning and clarity in the formulation of the goals.

When important decisions are made for habilitation clients it is important that close others are available to the agency that is responsible for expressing the client's overall needs for services. In most cases this will be the duty of the client's responsibility group. For the plans will be implemented, an intimate cooperation between the agencies that are formally responsible for making and implementing regulations is required. With regard to the project form as a practical approach and a quality assurance for habilitation work, especially two aspects are central: clarifying the formulation of objectives/goals, issues and clinical hypotheses, and the requirement that the objectives/goals, issues and clinical hypotheses will be evaluated. It is important to have goals in the responsibility group that is in accordance with the habilitation plan. This means that the responsibility groups can work more directly in relation to the goals and measures in the habilitation plan. A habilitation plan is meant to have a coordinating function so that all parts of life of the disabled person is seen as a whole and in the long term perspective. By creating a habilitation plan this is ensured, and also that everyone involved in the services in the various areas of life agree on objectives/goals in and for the work.

Agreements of cooperation should actually be incorporated into the habilitation plans in such a way that the professional and organizational goals and services are customized to the content of the plan, i.e. are adapted to the client's needs and functioning. If a habilitation plan is not established, the opposite often happens: the services are adapted to fit the organizational structure of the local or central agencies /service providers, not to fit the client. Then evaluation becomes a paradox. In such cases, what often happens is that the evaluation becomes an evaluation of well one has fulfill one's own goals, not whether one has reached the goals of the client, based on client needs and functioning.

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The full article was published in Norwegian in the Journal
Spesialpedagogikk nr. 3-4, 1997.

Good and bad days in a man with autism and severe attention-related performance problems

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Variations in condition during the day in people with autism and focus-related performance problems

Focus-related performance problems (FRPP) can theoretically be defined by two criteria:

1. Serious problems related to the performance of movements and actions which often results in lowering of functioning.
2. Performance problems are triggered by the person focusing his attention on his performance/execution of the movements and actions.

When people with FRPP focus their attention on specific movements or actions that they perform, they are often unable to perform them. They tend to interrupt themselves, and the movements are often frozen. They are typically awkward and move in a clumsy and staccato way. When they speak, they often seem strained. They get tight throat and neck muscles and begin to whisper or speak with great effort. Their focus-related problems can be seen as "automation" issues. As long as they are not conscious of what they must do, movements and their actions can be normally flexible and smooth.

Most people with autism and focus-related performance problems also have considerable fluctuations of condition during the day. In a survey of 193 children and adults with autism, there were 79 who had considerable fluctuations of condition during the day, i.e., 43 per cent. Everybody in the group who had FRPP, however, had considerable fluctuations of condition during the day. This is a very strong association between the FRPP and considerable fluctuations of condition during the day, and a significant majority of fluctuations, when the population as a whole and the subgroup with the FRPP are compared. The performance problems in people with FRPP are triggered by several factors, but generally the focus-related performance problems are more serious when the person has a bad day. In bad periods, both

the frequency and severity of performance problems increase. In many cases, the execution of movements and actions will be relatively smooth and trouble free on good days, where the person is in good spirits and is fine.

A bad period can be triggered by unusual and idiosyncratic factors in people with autism. Generally, it is typical for people with autism that things easily are "out of order/not as they should be", so that the person is disturbed and stalls. In many, such as violation of their own - often special and unusual - expectations get intense and extensive follow. In high-functioning people with autism and Asperger syndrome, events that others see as unimportant and insignificant, can lead to responses of catastrophe. That negative condition of the day can be triggered by such special factors in people with autism have serious consequences. Presumably, it leads to increasing occurrence of bad days. The fact that it is often difficult to understand what causes a bad day, means that the fluctuations in daily condition is unpredictable and seems random. The problem of understanding is amplified by the fact that discomfort and pain is often expressed in an unusual and unique way. The problem of understanding the causes of a particular response pattern makes it difficult to arrange the services and the physical environment in an appropriate way for people with autism.

Many people with ASD (autism spectrum disorders) are especially hypersensitive to sensory input. In children and adolescents with Asperger syndrome sensory hypersensitivity were found in approximately fifty percent (Martinez et al, 2008). In a survey of 179 children and young people with autism hypersensitivity to sensory input were recorded for 79 of the group, i.e. in 42 percent. Very serious and restraining/inhibiting sensory sensitivity was recorded in 23 persons, i.e. in 13 percent of the sample. It seems that people with autism and FRPP are particularly sensory sensitive. Hypersensitivity to sensory stimulation was, for example, registered in nine of 11 children and adolescents with autism and FRPP, i.e. over 80 percent. A common clinical experience is that sensitivity in relation to sensory input increases when the person has pain, other forms of physical discomfort, and when other factors increases their physiological arousal, for example, anxiety and love. It also seems that those who are particularly sensitive, such as people with autism and FRPP will be even more sensitive to lighting, sound and tactile/haptic stimulation when in a bad period.

Adam – a man with autism and serious focus-related performance-problems (FRPP)

Adam's adjustment problems

Adam has two comprehensive disabilities that limits his life strongly and which gives clear requirements for his services:

1. Autism
2. Serious dyspractic performance problems

Adam's dyspractic performance problems are the greatest limiting factor in relation to his chances of getting a reasonably good life. In general, the dyspractic performance problems are characterized by that he has difficulty performing so-called voluntary movements, i.e. movements that he deliberately tries to perform and that his focus is directed towards. In particular, this applies to transfers between activities and tasks.

History

Adam is a man in his early thirties. He lives in his own apartment. He lived at home with his parents until he was 13 years old. As a child, Adam was very active, and he spent much time trying to collect water in cans and cups. If he was not employed, he was able to get much focus by destroying books, clothing and tearing off wallpaper. Adam seemed happy and satisfied at this time and was rarely angry, upset or frustrated. In his teens he moved to a special institution for people with autism. There he was faced with many demands and there was much special training /drilling on language and ADL (activities of daily life) skills. He had a good language development, but at the same time, he was often frustrated and angry. He also developed a lot of anxiety and resistance. Adam moved into his own home when he was 19 years old.

At the end of that time Adam lived in the special institution, his performance problems was so large and resistance so extensive that he almost failed to conduct any activities, even those

that he most appreciated. He was very passive and was living a boring life, with few or no highlights. Adam had problems and spent a long time:

- Passing doorways
- Passing lines in the pavement
- Passing divides between sun and shade
- Walking up and down stairs
- Getting dressed
- Moving from chair, sofa or bed
- Sitting up
- Entering and exiting a car

On the worst days Adam was not finished the morning ritual (washing, toilet, getting dressed etc.) before - at the best - far into the day. This led, among other things, to that he often didn't:

1. arrive school until it was almost over,
2. failed to carry out daily activities, and
3. failed to do things that were planned, such as going to the cinema or to circus performances.

Daily life was marked by much yelling, screaming and challenging behavior; both aggressive outbursts /tantrums, self-injury and causing injury to staff.

Requirements to persons close

The dyspractic performance problems puts special demands on staff around Adam and other's close to him. This applies to the daily companionship with him, the ability to help him to carry out the daily activities and in preparation of the daily services. The dyspractic performance problems require high standards of competence in the personnel who will work

in relation to Adam. It requires both a special insight into dyspractic problems and an integrated understanding of the requirements the problems pose to those who are employed as service providers. The dyspractic problems are getting more difficult to deal with by the fact that the the form and methods of teaching skills, required by the dyspractic problems, runs contrary to what usually is best for most people in the autism population.

In addition to the requirements of autism and of the issues by the dyspractic performance problems, Adam has individual characteristics that affect what is suitable service. Some of these characteristics must be seen as ordinary temperament and personality-related, while others are easier to see as created at the intersection of autism, the dyspractic problems and Adam's temperament-related characteristics. The important thing is that Adam easily comes into mental imbalance. Among other things, he has a depressive orientation. "Black thoughts" and fears for the future tend to come when he is put in an inactive state. Negative thoughts and worries can stick to and color the days, if someone close does not immediately react in a suitable manner. If they are allowed to develop, the problems grow in scope and become long-lasting. To respond in a positive way, however, requires an understanding of Adam's problems, way of communicating and special features.

Adam's way of speaking and communicating

As a result of his autism, Adam has particular problems with language, communication and relationship with other people. He has idiosyncratic language and communication, and it requires good knowledge of him to understand him. One must know his everyday routines, history, family, peculiar behavior, condition of the day, what he likes to do and what he dislikes.

For example, Adam often expresses that he will travel by the ferry - which he is particularly fond of - either by saying: "Moss", which is the name of the city where there is a car ferry to the city Horten from, or sometimes by pointing in the direction of the road to Moss and say: "There" when it is time for a ride and he's sitting in the car. Adam also uses the "Yes" not as an affirmative answer. After showering, he stands with the towel in his hand and says "Yes". Then "Yes" is a question if he may put the towel down on the floor. In general, he often says "yes" to confirm or consent to something he wants - both when his wish is already

communicated and in situations where it is required that someone close understand what he wants without any previous communication on the subject.

In some situations, Adam communicates only with his eyes. For example, it is difficult for him to go to the bathroom on his own initiative, and if he really must go, he looks at the staff with a pleading, empty look, begging the staff to give him an instruction to go to the bathroom. Adam also sometimes says things that one must know him well to understand what he means by. For example, he often says "Hello rice". This means he is looking for fried rice, preferably from a specific local fast food restaurant. The term derives from a period he had great difficulty getting out and could not have gone to the fast food restaurant himself, so that the rice was ordered over the phone and delivered at the door. To understand him, one must thus interpret things other than the literal meaning of what Adam says. If communication with someone close fails, he is frustrated, and usually he's experiences with not being able to communicate well causes uneasiness and increasing of his performance problems.

What Adam understands of what the staff say to him, differs greatly from day to day. On bad days he spends much effort and focus to carrying out daily routines and understands little of what staff is trying to convey. If the staff tries to make things easy and instructs him with single words - for example, say "glass" when he's about to prepare the table for a meal and forgot to put glasses on - he will, on a very bad day typically fail to follow the instruction but just wander about. On good days, especially when he is motivated to do what he is doing, he understands complex messages from the staff. One winter, for example, he had only put on his shoes, but no coat, when about to go for a drive. But because it was a good day the staff said, "Maybe it's a good idea with sweater and jacket", and Adam took the jacket out. When the staff added: "Maybe it's good to have a sweater too? What about the red sweater that is laying in the bathroom? ", Adam laid his jacket down again, went to the bathroom, put on the sweater, went back to the entrance, took the the jacket on, and moved towards the door. All this without getting confused, upset to be corrected or stall. He seemed completely unstriking, only slightly distracted.

Specific responses to the environment

Adam has especially three idiosyncratic reactions to the environment which puts demands on the services he is given. This is his:

1. Preoccupation with what will happen.
2. Hypersensitivity in relation to light and heat, and
3. Negative reactions to snow and slippery roads.

Particularly important is his preoccupation with what will happen. This is a feature that Adam shares with most people with autism, but Adam's special performance problems, behavior and unfortunate history makes attendance to the need for transparency, predictability and control more challenging for Adam's close others than for the close other's of ordinary cases of autism.

Adam asks very often about which of the staff is coming the following days, and what will happen when. Previously, he constantly asked about this, and would have an overview as many hundreds days ahead as possible. It was neither desirable nor possible to give him such an overview, and Adam eventually stopped to ask many months ahead and just used a lot of energy of asking over and over again about the next few weeks.

Adam has a strong seasonal fluctuation in daily form. In the winter he reacts negatively to snowing. He is light-sensitive, and light reflecting from the white snow bothers him. In addition, he dislikes that the snow makes it smooth and easy to slide. In the summer he is bothered by the sunlight on cloudless days. Partly by the strong light, but it also hurts to feel that the sun warms - especially when the sun falls only on one part of his body. He dislikes also when strong light creates deep/fuzzy shadows, so badly that he must cross clear/sharp distinctions between black and white when he walks.

Summer is the worst time for Adam. He cannot stand sunlight and warm summer days. On a bad day he is very disturbed when the light shines in certain ways and creates sharp transitions between sun and shade, whether it's on the arm, the leg, on the floor, wall or anything else. He can sit in his living room and get something resembling panic anxiety attacks just by seeing sunlight; he then hits himself, jams his fits into the walls, screams, howls, cries, hyperventilates and makes grimaces. He never likes to get sun into his eyes and rather looks away.

Shadow and overcast weather is the best. On the other hand, although he often stimulates himself by staring into a bright halogen lamp, and earlier he had a habit of pressing a finger

halfway into his eye, which probably gave lighting experience. If he has a very good day he can move almost effortlessly out in the finest and warmest summer weather.

Neither wind is Adam usually very excited about, even if he can he laugh and enjoy when driving a car with the window rolled down. Minutes later he can be hit by sunlight and throw himself violently forward and backward in the car seat.

In winter, it is the smooth surface that causes Adam the greatest upsets. He has poor balance and is often left perplexed when there is ice on the road. If staff are in range he clings to them and struggles to get over to a less slippery area, fearful of falling. If he falls, he can cry, yell and be angry. The same is true if snow falls a bit skewed on him.

Variations in situations and daily condition

Rules for interaction and companionship, and states of daily condition

Adam's special way of being and special dyspractic problems is well presented in the 15 rules of conduct that staff should follow in the company of him. The rules of conduct are also explained so that the purpose of them will be easier to understand, especially for new staff. In this way, the general rules of conduct provide a quick overview of Adam's problems, what his difficulties means and the principles that apply to companionship with him.

General rules for interacting with Adam

The objective of the rules of conduct is that staff will work in the same way with Adam. The rules of conduct will be of assistance to other staff who works with Adam, when those who know him well are not present, and in order for all staff to relate to a fixed structure. The rules of conduct should be the starting point for all work with Adam.

1. Adam is supposed to take part in practical work in the home. Use the time when he needs you for example to prepare the table for a meal, do the laundry, water flowers, wash clothes, etc. It is important to activate Adam so that he does not loose contact with the here-and-now. When he is sitting passive for too long, he can begin to get

2. Avoid controlling Adam physically. You need to be aware of the condition he is in and able to cope with the consequences. Do not push / pressure on Adam if he howls, cries or has started with "starting movements". If you have to tilt Adam out of the chair / bed, go behind him and say, "Now I'll tilt the chair, Adam" and wait a few seconds before you tilt while you repeat the warning. Tilting the chair or bed has not been used for many years, but might be necessary.
3. Adam must get time to prepare himself for things about to happen, so he does not perceive what is happening as a punishment. Prepare Adam about what he shall do and when he is finished. Example: When he is in the process of completing a task, tell him what to do after the current task. This must be done such that Adam will have time to finish a task and at the same time bring his focus on a new one.
4. If Adam loose contact with the here-and-now when engaged in an activity, you need to regain his focus and repeat the instructions. This is done in order to prevent him to start thinking about how difficult things can be.
5. Hold on to the instructions. Do not split up behavior. Example: When Adam has stopped in front of a door, do not ask him to take it one foot in front of the other or the like. If you split up behavior, you are only providing even more things he must get in order before he gets done with what he's about to do.
6. Keep in touch with Adam when he's in a break, and don't let him disappear into imagination.
7. Get Adam to use his language as much as possible, and demand questions and answers with complete sentences. Example: Adam says "time". Get him to say "What time is it?" Adam needs a clear language so that we can understand him and so that he won't need to be frustrated that we do not understand him. BUT: we do not pick on the language if he is not in good shape (see state descriptions).

8. Do not correct words that are not properly pronounced. Rather repeat the sentence correctly when it is pronounced in a bad way. Example: Adam says: "Two pooofff" Say: "Yes, Adam. In two days, you're working at the post office". There are many words Adam is struggling to say, and when he is in good shape (see stage descriptions) we can pretend we do not understand, and get him repeat himself more clearly.
9. Do not try to persuade Adam to get through a stop using reinforcers. Then things gets even worse. It gives him only one more thing to think about in the chain of things that he should do.
10. Adam can sometimes be upset and stressed (howling and screaming). Let him have time to recover before you repeat the instructions. Things are awful inside Adam's head. He is unable to perform what he should and cannot see where to begin to achieve it.
11. Sometimes Adam asks about "horrible things" he has to do, such as washing clothes. Say that he will not, but that he should continue with what he is doing. If Adam asks for good things - such as watching a video or listening to his iPod - you can say that he can do it when he is finished with what he is doing. In other words: You have to respond affirmatively to the things he likes, and the negatively to things he dislikes.
12. Adam needs to direct his focus away from things he knows are difficult to perform, to be able to get started. He puts less demand on himself when the activity he is doing is nice.
13. The staff must understand Adam well and have good knowledge of his various conditions. This is to avoid that Adam is frustrated and scared, which can lead to self-injurious and challenging behavior.
14. Do not touch Adam (give him a hug, or the like) without making him aware of it beforehand. He needs to have control over himself and his surroundings. A pat on the shoulder can feel completely horrible for him.
15. Adam must not be corrected for his walking or other movements. He can start making parts of actions with accompanying rituals. Adam has many movements that look

Stages

Variations in Adam's daily condition are described as three different stages, where he is in the best condition in stage 1 and in the worst condition in stage 3. For each stage, a general description of how Adam looks and behaves is given, and a description of a typical morning situation. The descriptions were made so the staff should learn to distinguish between good and bad periods and know what they should do depending on Adam's condition of the day. An important goal was that new staff quicker could get to know Adam. Morning situations are described because this is something all staff encounters. Specific/concrete situations of how staff should interact with Adam when in his different stages are described, with references to the rules of conduct, and it is explained why the interaction with Adam has to be as specified by the rules of conduct.

Description of three stages

Be aware that Adam's states change quickly. A bad day can easily become good if you use the right tools (the rules of conduct). Similarly, a good day may quickly turn into a bad one if you start to take shortcuts and ignore the rules. Remember that time doesn't matter in the perspective of getting through a task. What matters is that the activity is carried out with minimal problems for Adam. Adam should not be stressed or bossed around because the staff has made goals or dates for Adam to satisfy.

General description of stage 1

Adam is very happy, smiles, laughs and seems to be in full control of himself, his performance problems and compulsive actions. He walks, almost runs; - often with his hands up at shoulder height. He has no visible movement problems. He talks and asks a lot about "cool" things, things we know are on his top 10 list, which is to visit his mom,

go on vacation, go on a ship to Denmark, drive car, go by car ferry and visit staff at home. This is a stage to make the big and difficult, but fun activities such as going to the movies or travel with the underground. This is also a stage to practice language in natural situations. If Adam is talking really fast and unclear, pretend to be a bit dull and do not understand what he said (say "Huh?" "What did you say now?"). You can also work on new stuff if you know Adam well enough (cf. rule of conduct no. 12). See example of this later.

In stage 1, Adam may be wandering about and apparently not knowing what to do. He can be high, look almost drugged, and having crazy fun. Typical of such days is that the staff assists as little as possible in the morning, care, cut two or three slices to him and wait in the kitchen until he is ready to dry off after showering. Then he often laughs while getting dressed. It may seem as if he thinks the absence of instructions is noble, challenging and alluring. These days, he usually goes through breakfast on his own - even if it takes some time before he gets buzzed up and prepared the table, taken out the food, etc.

All the time he seems euphoric. Other days, the staff must help him a little, especially if he is standing and laughing and wandering about in the kitchen for several minutes. Then staff hints that we need to prepare the table. Sometimes, the staff judges that he needs a clear message, e.g. "plate in the cupboard", and he may respond by laughing open the cutlery drawer, without being depressed by making mistakes, and almost dance around on the floor - often with waving hands and while he often rubs his ears. (The focus is then on something other than performance!) These "errors" should not be corrected, but the staff may laughing, in a humorous tone of voice, say things like, "He-he. Oh well. Plates in the drawer - that would have been crazy!".

Morning Situation with the use of the rules of conduct in stage 1

Adam is woken by knocking on his bedroom door. One opens the door and says "Good morning Adam, do you want some juice?" In this stage he jumps without problems out of bed and walks/runs into the bathroom. When he is in such condition, it is wise to ask Adam to poop in the toilet. Wait until he has peed before giving instructions. If nothing happens, repeat the instructions (see rule of conduct no. 5). Ask Adam what he's

supposed to do (rule of conduct no. 4). Use about 3 min. intervals between instructions. If he does not poop within 15 minutes, give up and say: "When you're finished at the toilet, you can go in the shower" (cf. rule of conduct no. 3).

When Adam is sitting on the toilet and in this stage, you may want to cut his nails, if needed. Say: "Adam, now we're going to cut the nails." Wait for a while before you start. Start with toenails (see rules of conduct no. 3 and 12). Adam is a little afraid of this, so take it easy. When he sticks out his leg, you can begin.

When Adam showers he uses a fixed counting system. When he goes into the shower he gets a cloth and washes himself after counting principle. He strokes 5 times under his arms while counting to 5, 5 times between his legs while counting to 5 etc. When he's done he hands the cloth to the staff. Say: "Now I'll wash you, OK?" (cf. rule of conduct no. 3). The hair is done in a similar way. Say: "Now you wash your hair." Shower his hair with water and give him the shampoo in his hand, and he washes himself. Then say to Adam that now you'll wash his hair (see rules of conduct 3 and 13). Wash his hair and turn off the shower. Wipe his hair. Give him a towel and he wipes the rest of his body himself. If he stays laughing in the bathroom for a long time, asks him what he's about to or supposed to do (cf. rule of conduct no. 4).

When he says "Eat food", verify this by saying "Yes, you are." Slices off three lumps of bread and put them on a plate, say to Adam that he may prepare the table and that he have to find knife, glass, juice and bread spread/topping (see rule of conduct no. 1). He always chooses liver pate. If you want him to eat something else than his usual (for health's), hide the spread you don't want him to eat. If he asks for this spread, then say that it is empty and that we will buy new. Remember that preparing the table and finding spread may take time. Remind him to clear off the table when he is finished eating (cf. rule of conduct no. 3).

Adam goes to the bathroom to brush his teeth when he has eaten. He takes out a toothbrush and toothpaste, puts paste on the brush, and begins brushing while the staff counts to 10 and points to oneself where Adam is supposed to brush: right upper, left-upper, etc. The staff brushes when Adam finished. Say "Now I'll brush" (see rule of conduct no. 3 and 12). Tell Adam that he may sit in the living room and watch TV,

listen to music or do something else before heading for work. Cf. rule of conduct no. 3. When Adam must head off to work say, "Now you may sit a little longer, then we will go to work." When in this stage, it is wise to shave Adam. Say "Now you may sit a little longer, then we'll shave before we go to work." Start shaving by saying "Now I'll shave you, okay?" Adam says "yes" or "OK" (see rules of conduct no. 3, 5, 13 and 12). Adam dresses himself before he goes to work. He needs a little help with tricky shoelaces and the like.

General description of stage 2

Adam is very quiet and has more or less lost contact with the here-and-now. His gaze is empty and his postures very limp. Adam ends up in this stage when he is sitting too long without activity, is ill, has slept very poorly or is very in need of the bathroom (poop). In stage 2 it is very important to help Adam as much as possible by facilitating the performance of activities in the simplest possible way, for example, by preparing his food, tying his shoe-laces, opening the doors for him, etc. Use rules of conduct 2, 3, 4 and 9. If you push, nag or ignore rules of conduct, he often falls quickly straight down into stage 3.

Morning Situation with the use of the rules of conduct in stage 2

Adam is woken by a knock on the bedroom door. One opens the door and says "Good morning Adam, do you want some juice?" He does not answer, but will remain completely quiet in bed. Repeat until he answers yes, or say "juice" (cf. rule of conduct no. 4). Put the glass on his cupboard. If he is lying in bed, you need to connect with him and give instructions that he should go to the bathroom (see rules of conduct no. 4, 5 and 6). If Adam sits too long on the toilet, you must give instructions that he should go in the shower (see rules of conduct 3 and 4). In the shower Adam gets a cloth and washes himself after counting principle. Do not correct him if he counts or washes badly. Pretend as if nothing (cf. rules of conduct no. 8 and 14). When Adam is finished, wash him. Say "Now I will wash you." Wash him, turn off the shower and give him a towel (see rule of conduct no. 13). If he stays without doing anything, you have to say "When you are finished in the bathroom, you have to eat food" (cf. rule of conduct no. 3).

Prepare food for Adam when he is in this stage. Is Adam just sitting without doing anything, one must say that when you are finished you can sit in the living room and watch TV / listen to music until you're off to work (cf. rule of conduct no. 3). Here you have to consider the idea whether Adam should go to work or not. He may be sick. Ask Adam if he hurts. If he answers "Neck", it means that he has headache. Let him stay at home. Say: "Now you can sit with ... (some things he likes) to you .. (an activity) ". See list of activities. (cf. rule of conduct no. 3)

General description of stage 3

In stage 3, disease is often involved, such as headaches or colds. Adam is very passive, have narrow eyes and irritated skin. Everything is hard for him, which is clear to see and hear. He makes loud noises and has a number of movements that look strange and unnatural. Adam nags too much about different things. Answer as best you can, but do not make agreements you cannot keep.

In this state, Adam tolerates no errors, either from staff or himself. He is highly focused on doing things right by his own rules. He shall have the right leg out of bed first, put down the glass of juice with the right sound and feeling, sit down right, walk right and all movements should be correct. Clothes shall feel right on the body, the cloth shall feel appropriate when he washes itself, the knife must hit correctly on the sandwich, etc. Much is compulsive performance problems, i.e. expressions of visible or invisible rituals. In this stage, Adam is very concerned about his rituals, and he takes no shortcuts. If he has forgotten something or made a mistake, he begins over again. Activities in this stage is very time consuming. And you can do anything but wait. You can only give starting instructions if you know when the ritual begins, what the start of the ritual is for Adam and if hitting precisely this beginning when you try to help. This is so difficult that it is usually not worth trying.

Do not stand and look at Adam when he stops. Be in motion, do things around him, tidy up a bit, chat with yourself, drink coffee. All sorts of distractions that are not directly aimed at Adam or his performance may help to get him started. You are guaranteed to provoke tantrums or self-injurious behavior if you do not follow the rules of conduct.

Morning Situation with the use of the rules of conduct in stage 3

Adam are woken by a knock on the bedroom door. One opens the door and says "Good morning Adam, do you want some juice?" He is passive, makes some noises, but does not stand up. Already, you notice that the day is a bit difficult. Say to Adam that he can stay a little longer in bed, and then he must go to the bathroom. Repeat this instructions, and only this one (see environment Rule 5). If Adam is sitting too long on the toilet, say "When you've finish on the toilet, you can go into the shower" (cf. rule of conduct no. 3). If Adam does not respond, ask what he's supposed to do. If he does not know it, repeat the instructions (see rule of conduct no. 4). Do not try to persuade with reinforcers, like promising him Coca-Cola if he does what he's supposed to. This makes it much worse.

Do not correct him when he is in this condition (see Rules of conduct no. 8 and 14). When Adam is finished washing himself, he is washed by the staff. Say "Now .. (your name) .. washes you, OK?" When Adam responds "OK" you can wash him (cf. rule of conduct no. 13). It may be that he takes hold of your hand. Let him stay until he release your hand. This allows him the control. Turn off the shower for him. You can run the risk that the water gets very cold if Adam halts while showering. Adam towels and dresses himself. If he stalls when dressing, then say "When you are finished get dressed and go and eat breakfast" (Ref: Rule of conduct no. 3).

In this stage, the staff prepares the breakfast table, puts spread on the bread and fills his glass with juice. When he is finished eating, brush his teeth. In this stage, the staff puts on toothpaste for Adam. The staff counts and points. Here it can halt. Let Adam have time to get started again. He does not need instruction or reminders when he has toothbrush in his hand. When Adam is finished brushing his teeth, he can sit in the living room and listen to music or watch TV. Say: "Now you can sit in the living room and listen to music / watch TV, and then you are going to work." (Ref: Rule of conduct no.3).

Changes of stage

Diary entries

The staff who work with Adam write diary entries about their experiences and document everyday life with images and text. Some of these diary notes illustrate Adams's difficulties and the practical challenges faced by close-others. Three diary entries are presented because they explain the circumstances leading to stage changes. The third entry shows how good emotional atmosphere, respect for Adam's problems and application of the rules of conduct can make a bad day into a good day. The second entry describes how excessive attention to details can ruin a day, and how the rules of conduct can be applied to remedy the damage. The first entry shows how one of the staff is trying to raise the requirements for Adam's performing skills. This entry brings out a dilemma that all close-others to people with FRPP is presented with: On the one hand, one very often must lower the demands to avoid performance problems. On the other hand, the person becomes passive and loses experiences of mastery and a source of independence if activities ceases, or one perform the tasks for the person. Passivity is in itself a performance problem, which is linked to low well-being and poor quality of life. In addition, if the others do most of the person's daily activities and makes the person dependent, the likelihood of focus-related performance problems increases also on the activities that remain. The activities that are still carried out independently are more important and strongly focused on by the person. At worst, there may be a vicious circle: performance problems increases in a few activities and demands are lowered for more and more activities. Many close-others to people with FRPP experience this as a virtually hopeless dilemma - it is wrong no matter what one does. The diary entry argues that the demands for the performance can be increased on a good day, if the assistant knows Adam well and are conscious about the fact that Adam has FRPP and special individual characteristics. The intention is that Adam will become more independent, get more experiences of mastery and get more initiative. It is hoped that this will have a positive effect on his well-being and quality of life. It must be emphasized strongly that the increase of the demands for performance must be implemented only if one is absolutely sure that Adam has a good day and that other factors also are well prepared. One must be sensitive to Adam's reaction and changes in his condition during the whole experiment, and cancel if Adam shows signs of moving into another stage.

Raising of demands

Raising of demands in stage 1

Adam has difficulties to perform. He is therefore learned helpless. The demands was virtually removed to minimize the discomfort he experienced. It was, and still is, a struggle for him to do things. Anyway, Adam has now, as far as I can see, become more robust - on good days! But he has little experience in making even the most basic things on his own. For example wash himself. It is common for staff to wash him. It is desirable that he should be more independent. It is no longer enough that he washes symbolically. Although Adam sometimes washes a little bit more than just symbolic, this is not enough to get sufficiently clean in a hygienic sense. Thus all washing sessions ends with the staff in practice washes him. The problems with changing the symbolic washing to an actual washing has to do both with Adam's performance problems and his general difficulties. I also think that Adam needs the experience that what he does is good enough. These days however, I guess that his experience is something along the lines of: "What good is my washing when they wash me anyway ". The symbolic act, in my opinion, has no value in terms of mastery and autonomy. What is needed is that he actually washes himself. But how to achieve this? The experience of mastering washing hang, I think, closer together with actually having washed oneself, than with not having been helped. It is important to master washing oneself, and this can be achieved despite a lot of non-physical assistance if help is given correctly. As I see it, it is no contradiction between the experience of coping and receiving of assistance. It is the end product is crucial.

When I wash Adam, I use a normal voice when giving instructions. I'm talking quietly without raising my voice. The routine is so established that I really don't need to say anything. Both Adam and I know this routine; - it's in the spinal cord and is completely automatic. But what is needed is an effort. A focus, a challenge. I have previously tried to raise the demands on him, raise my voice and give instructions. Fear of micromanaging and that he will become too dyspractic, stall and get hurt, have always previously put an end to this. But knowing that Adam enjoys tremendously well not get help and to do things himself, along with the desire to end something that probably even he sees as a fraud, should overcome the fear of failure. One must take some chances. If

one doesn't fail now and then, one can not say that one has succeeded in anything either. In practical terms it is difficult to get Adam to wash himself properly, especially in such critical areas as in the crotch, the buttocks and in the face. Adam never washes his face. In the past I have tried to raise the demands on good days. I have raised my voice, pointed out, claimed and demonstrated with my own body as a model (fully clothed of course) that he has to stretch his body and wash, not just with one, two, three, four, five small and easy pats. I've said things like: "Oh come on. Stretch out your legs and wash in the butt!") I have left out the cloth. It only makes it difficult. I use plenty of soap. I get Adam to stretch out both his hands and I spray soap into them and commands with high voice to focus. And Adam actually manage it. He washes as it should be done, and gets clean without help. I keep the same clear focus when washing hair and face. I say: "Wash your nose" and he jams soap into his face and rubs. Perfect – in hugh contrast to the typical standing and looking uncommitted while stroking, or rather patting, while in a monotone way saying "one, two, three, four, five "

Adam also wash his hands very poorly. Usually he uses only a small squirt of soap on the tip of his fingers and rubs gently together under a little bit of water. He folds his hands together and that's it. Therefore I command him also to wash properly. And everything goes fine and for Adam, it seems, everything is fine. Then I give him a towel and head for the kitchen. When he is finished drying and saidy "Yes ", which is a question whether he can put the towel on the floor, I reply that he must remember deodorant and then go and get dressed. I also stopped to arrange underwear, socks and t-shirt for him. He comes into the kitchen, and I say that he'll have to find underwear, socks and t-shirt in his bedroom. He walks to his bedroom and comes back dressed. However, without t-shirt. I say "There is certainly a t-shirt in your closet." He goes back into the bedroom and comes back with a t-shirt on. Then there is the same procedure with jeans. I think this is a way for Adam to become more independent and independent. But it is absolutely necessary to take the condition of the day into account, make sure that the emotional climate is good and not try this on a bad day or in an unpleasant, authoritarian manner.

From stage 1 to stage 3

Many things can cause a good day to turn bad. Sometimes the cause is a combination of Adam's sensitivity to weather and that the staff by unlucky attempts to make good forms of companionship causes insufficient mastery and performance of favorite activities. If one facilitates for performance by following the rules of conduct, Adam's tolerance unpleasant conditions. Episodes like the one described in this example can and should be avoided. But one should not underestimate that Adam is very vulnerable, and things are going on so fast that it is often difficult to think and react quickly enough in the heat of the moment. In the following example, presented by the staff experiencing it, the setting aside of the rules of conduct causes a good starting point to end up with an unfortunate outcome. The example shows the fragility of Adams daily condition and demonstrates some of the special competence needed in the company of Adam. This competence is embodied in rules of conduct.

Exaggerated demands and vague communication creates fuss

The day starts good. I knock on Adam's door, opens it and sees that he is wide awake and smiling. The clock has barely rounded 9. It's Saturday. I say "good day" and Adam stands up. He goes to the living room window where the curtains is closed and looks through a crack between them. He does not indicate to close them further as he would have on a bad day. I find myself in the kitchen. Adam goes to the coffee table, picks up the clock and look at it: - still smiling. He goes to the bathroom and sits down on the toilet. I tell him that I have to go myself, and go to the staff toilet. When I get back Adam is still in the bathroom smiling. I go to the kitchen and cut three slices of bread that I put on the chopping board. I do not prepare anything else. Then I go and sit in the living room.

After about five minutes, I shout to Adam that he must shower when he is finished doing the toilet. I put on a CD and eat some bread. Then I go to the living room again. After about 10 minutes I hear Adam pee, pull down and go in the shower. He turns on the water, and I go to the bathroom. Adam is waiting a bit, then sticks his head under the water. Usually I wash him with a cloth the usual way, but in the past I have on good days tried to get him to wash himself. I do the same now. I tell him that he must wash himself and give him shower gel. He stretches out his left hand, and I squeeze out a

good bit. He washes his hair with one hand and use the other to get rid of soap from his face. Again I give him shower gel. Again he stretches out his left hand. I squeeze a little soap in his hand and tell him to wash under his arms. He begins to wash his right arm and looks at me. I pretend I wash myself, moving my hand from under my other arm and over my chest and stomach. Adam does the same. Then the same procedure with crotch and buttocks.

Then soap in the right hand and washing of the left side of the body. I pretend that I wash myself and make a little show where I hum and sing "in the shower". Adam is OK. He seems happy and hums and laughs a bit. Finally, I rinse him to get off all the soap. He takes the shower head from me and put it in place. He makes some small, strange, staccato movements. Then he turns off the shower. I give him a towel and find his pants, t-shirt and socks. Jeans and hoodie is already in the bathroom. When I come back, he has finished drying himself. He has finished very quickly but his hair is almost soaking wet, and is certainly something wet in other places too. I put his clothes on the bench in the hallway and tell him that I so did. In the corner of my eye I see Adam put the towel on the floor (without saying "yes" as he tends to). I say: "Remember deodorant" and pretend I'm putting on deodorant. I turn away and move toward the kitchen. Adam puts on deodorant.

In the kitchen I start to clean some dishes from yesterday. Adam comes out fully dressed and takes out a plate from the cabinet over the bread box. He then puts the three slices I cut up earlier on the plate. Then he opens the refrigerator. In the corner of my eye I see him explore what the fridge is offering, but cannot quite figure out what he chooses. He puts the spread on the table and takes out a carton of orange juice from the refrigerator. Then he takes a knife from the cutlery drawer. Adam sits down and begins to eat. He has, as usually, forgotten that glass, and I put a glass next to his plate. He eats fast, but not hectic, and I see that he has chosen brown cheese (sliced). He takes a glass of juice as I am finishing putting away the dishes I just cleaned. I put his daily tablet on his plate and he takes it. Everything happens without instructions - without me saying anything.

Adam gets up and sets the plate, knife and glass on the bench where the bread box is. He aims for the couch. I say he must clean up. He places the bread spread and juice carton in the fridge and aim for the couch. I say that he must throw the paper sheets separating

cheese slices. He does it and sits down on the couch. I drain the water to do the dishes. After that I join Adam in the living room. Adam looks at me with expectation. I say "Would you like to go for a car ride today?". Adam says "Underground?". I say "OK. All right, we can run the underground today". "First I'll have a cup of coffee. You can sit in the living room for a while, and then we'll go to the subway." I repeat: "First we sit in the living room for a while, then we brush teeth, and then we run the subway. OK?" "OK" replies Adam happily. I walk upstairs, fetches a cup of coffee and goes down to Adam after 5 minutes. Adam looks at me with expectation and I say 'OK, then we'll brush teeth?' Adam gets up and goes laughing into the bathroom. On the way out I say "You can take the shoes on first, so you don't get water on your socks." Adam put on the shoes, goes to the bathroom, takes toothpaste on the toothbrush and comes out to me which stands in the hallway. He looks at me and expects the usual routine of counting to ten while brushing. I count in the usual manner; somewhat rhythmic, but not monotonous. "You flush with water" I say when the brushing is over, and goes into the kitchen to fetch the wallet and keys. Adam follows me and is a bit puzzled. I repeat the last message, and Adam takes aim at the kitchen tap before he changes his mind and goes into the bathroom and drinks water there. Everything is fine, and Adam smiles and laughs. I ask if I can look at him, and Adam stands up in front of me. I correct some of his clothing. "Ok, put on a jacket and let's go" I say and walks towards the front door. He puts on a jacket and we walk out into the hallway. In the hallway I turn to him and see that his face is poorly washed. Moreover, he still has very wet hair. It is not very hot outside, and it blows a lot, so I say we should go and wash his face a little and dry his hair a bit. No protests, but during the wash of the face, he stops me and holds my hand (with cloth) to get the right touch: he adjusts a bit before he takes my hand, holding the cloth, to his face. I wash a bit. He makes a little sound – small noises of discomfort. Then I give him the towel and say he must dry his hair. I'm stupid enough wanting to help. This last intervention is the drop, and Adam dismisses me with a mixture of sounds (beeps) and avoidance movements. Me on the other hand, is pleased with the hair drying and says "Okay, let's go to the subway." But the damage is already done, and Adam has been driven in disarray. He is frustrated and uncomfortable already on his way out through the hallway. But I think it's going to be OK on the way to the subway station. Subway is so fun, and from experience I know that he manages through some frustration when there is something really fun coming along. On the way up to the

subway station, I say as little as possible. Adam struggles with frustration and march on. I hang on. At the station, I need to inform him where to buy the ticket, for Adam has passed it. Relaxed and neutral I talk a bit to myself as I buy two full-day tickets on the machine. Adam is still pretty frustrated - actually more frustrated; almost cracking and so unstable that I think it's best to head home and calm down a little before taking the subway – because I am afraid that I cannot handle the situation that may occur. I say, "Let's walk home first, and then take the subway" as I turn around and walk. Adam follows frustrated. On the way home he stops a few times and jumps up into the air. Once I tell him to go to the sidewalk because of a car. Then he stops and jumps up into the air again. He is clearly frustrated. It doesn't affected me and I keep walking, almost as if nothing has happened. Adam takes overtakes me and march home, stops in front of the front door before he slips in, throws off his shoes and jacket and crash down on the couch. There, he sits wiggle and make noises, but no loud noises. He says "Subway". I answer, "Yes, afterwards. First we shall relax a bit." He sits rocking and hyperventilating. I give him a glass of juice. He doesn't drink it. Occasionally Adam groans, and sometimes he gets up and looks out the window. It's sunny.

I sit down and write this. The time is now half past noon. The subway day-cards are unused. I ask whether Adam will eat. He confirms and I prepare three slices with of liver pate for him. He also gets a glass of orange juice. He eats and drink the orange juice. The other juice is still untouched He asks whether we should drive and ferry tomorrow night. "Yes" I say. He says: "Thomas home ". "Yes," I reply, "Soon I'm going home ". "Maybe you and Sophie could take a ride with the subway?" I continue. He makes noises – apparently he doesn't like me mentioning the subway. Nobody likes to fail - especially not to be made a failure, perhaps. We are both failures.

Time is now half past one, and his condition is somewhat better. He has stopped hyperventilating, and the sudden runs to the window to check the weather is over. Adam rocks and is still breathing heavily. He picks up a stack of papers as he folded the other day. I hear the sound of the toy box. I join him in the living room. He smiles carefully. Another one hour now, and life is probably worth living again.

From state 2 to state 1

Professionalism in the work with Adam is a prerequisite for turning bad days into good. This professionalism comprise practical application of the rules of conduct. Initiative, courage and good humor may also be crucial components. Obvious enthusiasm may have a negative impact, because excitement can lead to a strong focus on the successful completion of a task. In stage 2 both Adam and the staff balances on a knife's edge between stage 3 and 1. Adam is tired because he had slept poorly the night before, but the staff manages in an exemplary way to be resourceful in a moderate and subdued manner.

Activity and coping provides a peak day

The day started pretty normal. Adam sat in the living room with his iPod safely in his hands, - no one can take it from him! I said "hello!" and asked for a hug, as I always do. After a while we made a deal that he was finished with the iPod and was to go to the bathroom. It took awhile, but eventually he let go of the iPod. He jumped off the couch and saw that I had started to make some food. And Adam wanted to join! I said he had to go to the bathroom first, and then we could cook together – when he was finished. He had done what he should, washed his hands – and then it was cooking.

When he was finished eating, he cleaned after himself, sat in the living room and watched television. After a little while I asked if we should play some lottery. He did not seem reluctant, so I found the lottery game and said we could sit in the kitchen and play. We played a game, and it was enough. When I asked if we were to play another round, he said simply no, got up and sat in the living room again.

Adam sat and dozed off a bit. I said after a while that we were to go and play ball, he said "Sleep". I had gone through the process of "now you can sit a little longer, and then we're ..." ... I must admit I thought a bit about staying home. We were supposed to go to a local gym. What was Adam really doing there? Lots of people running around with a ball and clubs – was that something for Adam? But we could at least try. The worst that could happen was we ending up sitting in the car and then drive home again. So I said "Come on, Adam, we're going for a drive now." He replied: "Long trip!" "Nooo" I said. "We shall only drive to the gym and play ball and stuff", and "What are you going to do now?" Now, Adam came along, and his condition was good!

When we arrived, we warmed up with the hawk and dove. Adam went over the whole pitch and we did it quite a while. When we were finished with it, I took Adam over to the other court. We went into the machine room. Adam found a basket ball and threw it to me. I threw it back; - excited to see if he would catch. Sure! He caught without any problems. His hands were tied, however, and I said that it might be easier if he stretched his fingers out. But there was no reaction. It did not really matter, he kept throwing and catching. I was overjoyed, but only smiled to Adam and said this was fun. We continued to throw to each other, and eventually I thought we could try us on the curve. Oh my, he managed that too. I was very impressed. Had it not been for the ears, my smile would have gone all the way round. This was fun! I ran around after the ball because Adam moved away from it as it bounced back the times he missed. We threw to each other and at the basket. Now I saw that Adam had straightened out his fingers and threw and caught properly! And not only that. When I calmed down and didn't run after the ball, then Adam did it! He bent down to retrieve the ball, walked and sometimes "raced" to get it. I was mega-impressed and promised myself that I should not underestimate Adam ever again! We threw three times in one basket, "raced" over the pitch to the other basket and threw three times in that too. We needed after all, a little exercise. In between the ball playing we threw a bit with the medicine ball (4kg). It's great exercise. Adam smiled and laughed, and it was obvious that this was something he liked doing and thought was fun. I hope we can continue with it? Every Tuesday 19.00 in the gym.

When we got home he sat on the sofa and got a glass of juice. I went out to wash the dishes. When he came into the kitchen he said, "Take off pants." The training pants are apparently no "good-pants." Hehe. He took it off himself and sat on the couch with a blanket around him. He went to bed tired at 21.30. And I must say he had been good, for he had asked to go to bed already 18.45. This has been a great day with Adam.

Summery and discussion

Everyday life is usually very stressful for Adam and other people with focus-related performance problems. Their life is often tiring, monotonous and boring. People with FRPP are completely dependent on close-others to understand and master a companionship form that is appropriate to their performance problems. Close-others should *never* focus on the

person performing the actions and movements. A good advice to prevent the person experiencing problems in carrying out activities is to move the focus from the current activity to the target or goal of the activity, or to the next activity. Common strategies that we often use to help people with autism to perform actions and activities can make the problem bigger. Many people with FRPP have e.g. experienced professionals have treated their problems as a learning problem and not as a problem related to the negative effects of having focus fixed on the execution. This has meant that actions have been broken down into parts of actions, with the result that performance problems have been moved down into ever smaller parts of actions in a behavior chain. Generally there is a need for good rules of conduct governing the companionship of close-others and people with FRPP, and which provides a practical description of the conditions that trigger the performance difficulties. The rules of conduct formulated for Adam may be a good example of how such rules can be designed. The high incidence of big fluctuations in condition during the day means that also a good assessment of different conditions during the days in people with autism and FRPP is required. The description of the various stages of Adam is given to illustrate such as assessment.

People with the FRPP is also easily made passive. They are often spectators and not participants in their own lives, and as spectators they get lots time to focus on what is difficult. Thus their performance problems may evolve to become increasingly more and more problematic. It often seems to be difficult to break out of this vicious circle, but if close-others teaches the person to feel well and are aware of the daily fluctuation in condition, it is still possible to spice up life with activities and experiences of coping. Implementation of activities and experiences of coping is important for the well-being and quality of life.

At Adam and other people with FRPP can change condition quickly. Being attentive one can grab the moments when the condition is good, and respond quickly and positively to initiative. A conscious *carpe diem* - seize the day - strategy is often successful. However, it is important to follow good rules of conduct and not be impatient when the movements and transitions between activities and tasks are late, or to act in hectic situations with time pressure and when things go unexpectedly well. It is wise to always remember that implementation of even a favorite activity easily may end up in difficulties and failures. It is not a good idea to fill the day with activities that it is not certain that one is able to carry out, even if the activities are in Adam's top 10 list.

Currently Adam no longer has long periods in stage 3, which previously dominated his life. He also thrive better than ever before. This demonstrates that good deals are helping people with FRPP, even when they have such serious problems as Adam. Adam is still very vulnerable. It is crucial that he has people around him who understand him and follow the rules for the preparation of his everyday life (rules of conduct). In a longer perspective, Adam's vulnerability is represented by the dilemma of either lowering the requirements to avoid performance problems, or to suspend him to inaction. If Adam is put in a state of inactivity, there is a real risk for depression and that his problems will increase in scope and become long-lasting. The main challenge is to find a good balance and pave the way so that Adam will have a good life.

Published in Norwegian in Jensen, Johannessen, Martinsen: "Good and bad days in a young man with autism and focus-related performance problems". In Autism Today, 4/2008. The Norwegian Autism Society. Oslo: 2008