

History of the care of people with mental limitations the Netherlands

“Starting from an arsenal of *impossibilities* is a bad start. It is much more positive to learn to recognize *the possibilities* of people with severely mental limitations”

Introduction

People with a mental disability or we would say today, people with mental limitations, belonged for centuries to the group of “abnormal people”, living at the bottom of society. The mentally ill and the outlaws lived beyond the city walls.

At around 1900 the group of the mentally and physical disabled was separated. The definition as to whether someone was classified as disabled was made on the basis of their intelligence and their social abilities. This group of people was said to be ill. So the help and support they received was the same the ill were given. Care for the disabled was based on a medical model where people stayed in bed all day, were treated by the doctors who were in charge and where everyone was wearing a uniform just like they did in a hospital.

Later some people believed that it would be possible to treat people with mental handicaps and that the right education could help to make them “normal”. During that time the philosophy of educational influence was developed and psychologists took on a strong role. Educational programs, which included punishment in case things went wrong, were developed.

In the Seventies our country was ruled by the waves of democracy and individual thinking was taken up. The circumstances under which mentally handicapped people were living, were strongly criticised.

History

Looking back in time we see a picture with many changes in the attitudes towards the mentally handicapped. In many ancient civilizations, and in the primitive cultures even today, a great number of the mentally handicapped died owing to inadequate medical treatment. At first they used to live among their fellow men, their family. There were times when they were deliberately killed (witch trials). In the Middle Ages the mentally ill who showed maladjusted behaviour were locked up in so-called madhouses. In such places both insane and retarded people were found. There was no distinction made between them. There were no therapies whatsoever.

Treatments in the institutions constantly changed. Gradually people began to understand that insane and retarded people did not require the same treatment. By the end of the 19th century the first institutions for the care of the mentally handicapped were founded. Because mental retardation began to be regarded as a congenital defect the therapy was: bed nursing. This caused many objections because most of the retarded patients were not really physically ill: aggression increased, as well as boredom and apathy. There were also regulatory disturbances to do with sleep. This situation changed for the better at the beginning of the 20th century. The mentally handicapped patients were kept occupied with several activities that required great physical exertion. The aim of this was to change their behaviour: less aggression, regulation of sleep and a good physical shape. In those days there was little attention for the individual.

But slowly it was realized that there were other possibilities to keep mentally handicapped patients busy. They were to be activated at a higher level. For, many of the patients could apparently be brought to do some kind of real work. And this soon turned out to have favourable results. Mentally handicapped people won more respect and, what's more, their self-esteem grew because they did something "useful". The activities began to look like work more and more. But there was the danger that these people would be crushed in the production drive. The aim of occupational therapy, however, is that you try to make the resident function as meaningfully as possible, on his own level, in his work. The insight was gained that many of the mentally handicapped could be approached in the field of their creative possibilities. The value of creative therapy was recognized, aimed at supporting the pupil in exploring his creative abilities, making him familiar with the materials and teaching him the methods.

The care of the mentally handicapped in The Netherlands has experienced a turbulent development. Looking back we can see that attitudes towards our mentally handicapped fellow men have radically changed. Because in the past decades there has been more research on the phenomenon of mental retardation, numerous works on this subject have been published. Fortunately, we can conclude that this knowledge is not only available to scholars but also to those who are, in the first place, responsible for the care and the contact with this group. For example parents, social workers, staff and others. Education first of all takes place in the family. When it turns out that this is no longer possible or desirable, which can be due to several factors, the child will be placed in an institution or visit a day-care centre.

Generally speaking, one might say that the care of the higher-level mentally handicapped is provided by extramural facilities. We can think of day-care centres for children or adults, surrogate family units, etc. Patients of lower levels are mostly taken care of in large institutions, in intramural care. The initially sharp distinction is fading, especially because the larger institutions are increasingly trying to find other forms of housing. This is an effort to give as many residents as possible the chance, if they can handle it, to live and work in society outside the walls of the institution. So called "phase houses" and "socio-houses" have experienced a mushroom growth over the past 30 years. Apart from these aspects of integration, the demand for housing on a smaller scale also plays a role. Institutions will certainly not be built anymore in the future. However, we cannot deny that, as a result of what was mentioned above, the larger institutions will increasingly be admitting the lower-level patients. Besides, there are also problems to do with the ageing population of the institutions, resulting in a growing number of long-term illnesses and bedridden patients.

We were also confronted with this problem in our own work situation. In the past, most of the attention was directed at the higher-level residents. It was not too much of a problem to find suitable occupations for this group, but the problem shifted elsewhere as the lower-level residents began to outnumber them. Parents, staff and consultants were increasingly confronted with the question: what occupations can we offer the severely retarded residents? That question may have been preceded by this one: should we offer any activities at all to these residents? Is it not enough to provide them with good care, from a medical point of view only? Before the fifties only morons and imbeciles were eligible for education and occupational training. The severely mentally retarded were excluded from these efforts. In the institutions there was only care for them and, at the most, some training to teach them to do some of the fundamental things independently. Because they were supposed to require care only, they were (and often still are) regarded as a "remainder" in the care of the mentally handicapped.

A different outlook on the mentally handicapped and care

With the arrival of educationalists and psychologists there was a growing awareness that most of the mentally handicapped had more possibilities than care and some training only. The social sciences indicated a number of possibilities for a certain degree of educability of the severely retarded. Apart from medical abilities the nurses also needed social skills now. There was a demand for activities that could make a meaningful contribution to the residents' existence in their contacts with others. The starting point was: what can we develop? Social feelings, for instance, if possible and desirable. What should we preserve? Mobility, for example, attention for the motor system. What must and can we try to prevent? We could create such conditions that residents grow demented less quickly. Here it concerns activities offering opportunities for social contacts like: independence training, world studies and communication. But also music and song, handicraft sports, recreation, games and drama. Most of these activities have some educational use. For a long time the view prevailed that the mentally handicapped should also be educated, or at least develop. All this in the framework of socialization, normalization, etc. The mentally handicapped had too many obligations and there was but little consideration for their *individuality*. Terms like "operant conditioning" took root. But certainly all this happened with the best of intentions. Today training is not absolutely wrong either, provided that there is an underlying view in which the mentally handicapped person is accepted. In this sense he is allowed to function in other ways too.

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Our acceptance of him should be active; we should not reconcile ourselves to his incapacities but start from his capabilities. Create the conditions under which growth and change are possible. We should also learn to give the retarded person so much room that his experience will be: together we will work it out. In this changing view the hierarchy is also discussed. Because non-mentally handicapped people possess greater intellectual powers they are placed above the mentally handicapped.

“But today it is rather a matter of being equal. In humanity there are no levels!”

These changes can also be found in the terminology. In the early days mentally handicapped people were called patients (the medical model), then pupils and now residents, housemates, visitors, etc. And similarly they used to be called idiots, but now severely retarded, mentally handicapped people with mental limitations, etc. Mentally retarded people used to be considered "really pitiful", because the outside world detected so many defects.

Move to a flat sharing community-model

The community model can be compared to a little village in which mentally disabled people were able to lead a safe and peaceful life. They lived together and could make use of their own church, laundrette and restaurant and some larger institutions even had their own graveyard. About 10 to 12 people would live together in each of the flats. Within the flat a cosy, home-like atmosphere was created in which people can experience nice things as they would do at home. The focus was on doing things together as a group or as an institution as a whole. Even nowadays you can see remains of the collective way of thinking i.e. at big events for the entire institutions.

Changes in the material domain

There have also been changes in the material domain. The rooms of the institutions used to be bare. They were furnished as little as possible because they thought that the severely retarded patients in particular would only wreck the furniture, and they would not care what furniture or attributes there were in the room anyway. They would even see it. Now we know better. It is obvious that severely retarded people are also very sensitive to atmosphere and changes in it; a fact that was long known before Snoezelen was ever heard of. We are very much hindered by our rational attitude. As we pointed out before, this impedes a more primary use of our senses and purer experiences. Instead, we try to analyze them rationally.

Severely retarded people are not laden with such a weight of knowledge. When you observe them carefully you can see that they often act for the sake of acting only. They use their senses and enjoy them in their personal way.

Their reactions are very primary. Their surprise is real and the sensory experiences are authentic, although they cannot explain them in rational terms and may find them strange. Learning is not a must, but they should be given the opportunity to gain experience. It is up to the mentally handicapped person to do whatever he likes with it and, if he learns something in the process, that is a bonus. At any rate his horizon may be broadened.

A mentally retarded person has his own way of playing, communication, etc. From the fact that he probably does not consciously experience this world we may not conclude that he is inferior.

We pointed out that we as staff approach the mentally handicapped too much with our own standards in mind. Many severely retarded people show odd behaviour, which they apparently enjoy. But because we find this behaviour disturbing we label it 'disturbed'. It can be very refreshing for the severely retarded if we go along with this kind of behaviour working with different standards. Obviously, there is a constant appeal to our creativity and inventiveness. Over and over again it has to be stressed that the resident should not adjust to life in an institution, but that the institution and its staff should meet his needs and wishes more.

Already in the Seventies the term 'integration' comes in now. According to the dictionary it means: "bring or come into equality by the mixing of groups or races". In this special case it means that the mentally handicapped person is brought or comes into society outside the institution. This is no passive process. The words 'bring' and 'come into' involve action. This action has to come from two sides.

The mentally handicapped person has to find his place in society, even if he is there only now and then. On the other hand, society should also open its gates for him. It should not be one-way traffic in the sense that: these are society's standards and the mentally handicapped better adjust to them. The other way round is also impossible: the mentally handicapped person imposes his standards (as far as these can be defined) on society

Change of the philosophy

In the meantime the way of thinking had changed from collective to individual thinking. The philosophy says that the mentally handicapped do not have to live in the institutions anymore like in a safe

harbour. Some critics go as far as comparing the system of institutions to "apartheid". They call it discrimination to lock people into institutions just because they are different or have a mental handicap and because of that are not given the same rights as you and me.

It is an interesting point of view. More and more you can see that the whole care system in the Netherlands is influenced by the philosophy of considering our mentally handicapped people as normal civilians. Normal civilians means, they have the same rights as everyone else in our society. Just saying it is not enough, it means a lot will have to change.

The whole system has to change from caring to supporting, from taking care of a mentally handicapped person to give support to a mentally handicapped person.

We will have to learn to support them in parts of their lives and their way of living where others would be able to do it by themselves, but they cannot due to their disabilities.

We have to stop taking over the lives of mentally handicapped people completely.

Because of the philosophy of a life as a Normal Civilian we do also believe that people with a mental handicap should no longer live in an institution. They should be allowed to live in a normal home, in a normal street, in a normal village. They should not live in this wonderful area in the middle of the woods far away from society. They should live like normal civilians in a normal society. They have the right to have their place within society and not outside society.

Here in the Netherlands we are currently undergoing the process of changing from community thinking to the philosophy of Normal Civilians. Lots of parents of mentally handicapped people, and even the mentally handicapped themselves, are not entirely happy about leaving the institutions and with that the safe place they represent. Parents are scared for their children to live outside and to be confronted by new danger i.e. cars driving too fast. Even the institutions themselves are not totally convinced about the new philosophy. How will the mentally handicapped cope with life within society? Will they be all right?

We as carers of these institutions are so used to help, to take over and care for these people. That makes it very difficult for us to let go and hand over the lead to the mentally handicapped and only to support when we are asked to. I think it will take some time before we really know how to act and we have learned how to behave towards our mentally handicapped fellow citizens.

Financial structure and person bound budget system

There is help available for the new developments. The existing financial structure is currently changing. So far we had a collective system, where all the financial grants are paid directly to the institutions and they will then have the responsibility of how to spend it. In the new system every person with a mental handicap receives an indication. This indication says how much and what kind of help, care and support the person needs. Based on that, a set amount of money to buy the care and support needed is given to the mentally handicapped person (or the parent). The handicapped person can then go to care providers, such as our Organisation ,s Heeren Loo, (this is the main organisation which the Centre De Hartenberg belongs) and request for the care/support they need or want for a special price. That system is called the "**Person bound budget system**". (**PGB**) The money follows the handicapped person.

For organisations, such as ours, this will be a great change. The mentally handicapped people will become consumers. The essential financial grants will no longer be paid annually to the organisations directly. In future we will have to negotiate with the mentally handicapped or their parents. And if the consumers – the handicapped person and their parents – are not entirely satisfied with the quality of care they receive then they can go to a different organisation and obtain the needed care from them. The change in the financial system does give our consumers the power to be treated like an ordinary customer with the choice to change shops if they are not satisfied with the product or service they receive.

For us as organisation that means a great incentive to make sure the service we deliver is of high quality. It motivates us to listen well to the clients to make sure they are satisfied with what they get etc. I think this is all very exciting. It will be a big change offering lots of new possibilities but also some dangers. We will have to wait and see.

Lastly I would like to talk about the developments in the care and the new care products this new financial system offers.

New products chosen by the consumers/clients are:

Home care

There are different kinds of home care available. Carers do offer their services in the house of the handicapped person. Especially for the handicapped children we feel it is very important to live at home with their parents rather than in an institution. And if the care for the child is too intensive for the parents, our staff can come to their home and support the parents for a few hours. Our help can be a few hours a day or a week, just as the situation back at home demands it.

Part-time-living

Some clients are staying with the organisations for the weekend or the holidays. The parents cannot take the responsibility for their children 24 hours a day, 7 days a week. So we are able to offer them all kinds of part-time support.

Since already more than 20 years there are developments of homes initiated by parents. Parents do have certain ideas and dreams of how they want their children to live, for example, if they have a special religion or if they live in a particular village and would like their child to live close by. Nowadays it is possible for clients or the parents to rent or even buy a home. It will be the home of the client and the parents, they will lay down the home rules and buy the furniture together etc. We, the organisation, have a contract with the clients (or their parents) and that contract is the basis for the amount of care /support they will receive in their special home. I think that this is a way of living where the individualism of our clients is respected and their wishes of how they would like to live are acted on. In these homes they can be themselves as a handicapped person but also as a person with his or her own identity.

Daily activities program

Our daily activities program is very wide-ranging and has grown over the past few years. During the early years of the Centre De Hartenberg, part of the Organisation 's Heeren Loo, the daily activities program was not a major focus of our organisation. It was only available for disabled people who were able to do some sort of production work. The external budget was based on that.

But that has changed over last 40 years. The Centre De Hartenberg started to allocate the budgets, internal departments were partly or completely closed down and the money saved was used it in favour of the daily activities program.

Additional grants

In the middle of the nineties the government made further grants available. These grants can only be used to extend the daily activities program for the severe multiple disabled people.

1 to 1 care

Also at the end of the Nineties the possibility arose to receive further financial grants for disabled people with conspicuous behaviour problems such as aggression or self-harming behaviour etc. These grants are used for 1 to 1 care..

Wide range of activities

We are offering a wide range of activities that are determined by our client's demands. Daily activities can be used by small groups or individually. They can take place in a separate area or amid society, the activities can be aimed at support, can be work-like or creative and they can take place indoors or outdoors.

There are daily activities for children and adults available and there are also suitable daily activities for disabled older people on offer.

We are also offering an extensive range of activities in the surrounding area. In an industrial estate some of our clients are working, preparing toys and tools for dispatch. Some of our clients are helping as a caretaker in a nearby school. Some others are helping in the library in Ede. Other participants of the daily activity program are helping out under supervision in care homes, serving tea and coffee in restaurants, taking care of pets, cleaning etc. Individual work is also done in a large bakery in Ede, several shops, a garage and a Tearoom.

There is also a wide range of products we make ourselves, such as candles, soap, art and promotional gifts. We also pack Christmas parcels with our products for clients.

Integration in society and offering work-like activities are major points in our care politic.

The Centre De Hartenberg

The Centre De Hartenberg is part of the organisation 's Heeren Loo Zorggroep, a leading Dutch organisation for the mentally healthcare. With the help of approximately 1190 staff members (703 full time equivalent, 36 hours) it cares at the moment for 1109 mentally disabled in an area of about 50 kilometres. The centre is situated in vast pinewoods covering 85 hectare.

De Hartenberg was built in 1968 with the intention to offer approximately 800 to 1200 mentally disabled people a place to live. Due to the changed way of thinking about mentally disabled and their provisions, it was decided during the process of construction to accommodate no more than 350 residents. Meanwhile due to faulty building materials almost 80% of the buildings constructed in those days had to be demolished in the mid-Eighties.

Today De Hartenberg is made of different living quarters, partially linked to little day activity centres. The main part accommodates approximately 234 inhabitants. That should increase to approximately to 300 residents in the next years. A change in today's philosophy is that there is still a need for small protected areas with living quarters for the severe mentally disabled and people with challenging behaviour.

In a nearby villages are 15 integrated living quarters with a day activity centre. In other surrounding villages are 10 more integrated living quarters, which are partially linked to day activity centres. In the main part the residential groups are small: 6 to 8 residents. Each group is put together differently, concerning age and abilities. Each of the flats is a self-sufficient unit, doing their own cooking and shopping. All flats have a certain budget available. Each residential group has a very big direct influence on the entire management.

Starting point for that philosophy is:

-“as normal as possible, specific only if needed”-

The smaller living quarters are different in their planning: Detached houses or chalet-like bungalows, which go well with the scenery. Every resident has his own living room mostly with a separate bedroom and his own bathroom. When necessary his apartment is totally equipped with advanced technic and ceiling lift systems. These flats surround a little square, which serves as a meeting point at the same time. For the living quarters are facilities available such as a big swimming pool, hydrotherapy pool, gymnasium, departments for the physiotherapy, logopedics, Snoezelen rooms. The centre does work with its own doctors, teachers and psychologists.

The day activities in the main part take place in 3 different buildings, which are spread over the grounds. That way traffic takes place and brings liveliness in to the area.

Principally all residents are at their workplaces outside the flats during the day. That is based on the philosophy of a daily routine: Living – Working – Relaxing, which plays a role in everybody's life. - Outside the flat one can meet other people, the coffee tastes different, the building smells different etc.- One should make the effort to go somewhere, once one is on the way one can experience so much, one can feel that the sun is shining, that it is raining or that the wind blows. One will meet other people, feels warmth or cold etc.

Snoezelen - “nothing has to be done, everything is allowed”

Snoezelen was originally conceived as a leisure activity for people with severe mental handicap, where they can relax and find themselves.

To do that a situation is necessary for which in contrast to every day life the senses are not addressed simultaneously but where they have to concentrate on individual sensory perceptions for example to touch only. The senses shouldn't be addressed in width but in depth. To achieve that, we try to offer stimuli in a selected way and reduce unnecessary stimuli at the same time. The offer of stimuli should be chosen in such a way to make nice and pleasurable sensory perceptions possible for a disabled person as well as to offer special experiences that can't be made in every day life. One should feel good and safe.

It applies the principle to give the disabled the necessary space and time, to choose for himself or indicate which stimuli he enjoys, what he wants to concentrate on for longer or what he wants to do. The encouragement of the residents shouldn't come only from staff but from the things in the room: material and environment should be inviting and stimulating to activate the disabled person to for example reach for something or lie on a soft mat etc. At the same time the environment should bring

the necessary peace and quiet to make relaxation possible because experiencing the direct environment, taking it all in and passively enjoying it are already enough aims.

Snoezelen with its dream atmosphere is meant to be a place where one can leave everything behind and find complete relaxation.

Accordingly calm music and dimmed lights should help to create a special atmosphere. Other institutions state besides or instead of our aim of rest and relaxation the stimulation of the development or therapeutic intentions for example consciously to use Snoezelen to make worried clients well balanced again.

The basic principle in Snoezelen is:

“niets moet, alles mag” which means, “nothing has to be done, everything is allowed”

Unlike in the housing group where certain restrained ways or activities are demanded from the disabled, during Snoezelen he should be allowed to be himself and to do whatever he likes. The accompanying members of staff should therefore distance themselves from their own ideas and expectations and let the clients have their own way, even more so than ever. Free use of Snoezelen material is permitted. If for example someone does not want to smell a smelling device but would like to rotate its stand that would be accepted. The voluntary intention of the offer is particularly important. It is not about a collection of material experienced according to course but about a varied and atmospheric offer of sensual impressions that should be used voluntarily and gladly. Who does not like it after a settling in period does not have to take further part in Snoezelen.

After the construction of the first Snoezelen-room in the early seventies the design of the materials and implementing the ideas was pioneering.

There was no experience available at all for the practice of Snoezelen that could have supported our work. We could merely orientated on the theoretical medical model and searched in discussion for general consent. That was very time-consuming and there was always one person not present at such a discussion, which meant we often had to start all over again to explain the basics. We could have talked for many days and nights about our experiences with multiple disabled people, but that was not realistic. Because of that we decided to simply try Snoezelen but to make sure to reduce or avoid the risk to undergo unpleasant experiences. We observed the disabled people, how they reacted to the various stimuli and we realized, that every person reacted individually to the different types of stimuli of light, colour, vibration and sound. It was important to make notes of our observations and to reflect on them in meetings afterwards. The result was a structured model which led us to realize that Snoezelen was not only a relaxation offer but could also be a therapeutic influence.

There we were with our working method in contrast to treatments and methods based on scientific backgrounds. We followed the theory, that a person with deficits should not be treated like a frail porcelain doll but confronted directly with something new. I have to emphasize, that as a matter of course risks and dangers are and were eliminated.

In the early stages we tested particular objects directly at the bedside of a person. We build mobiles, used lights and different sounds and exchanged these materials on and above the bed again and again. We recognized that Snoezelen should not just be relaxation but also an experience. It doesn't have to have a direct objective, i.e. to learn or rediscover something. Snoezelen is generally about experiencing and predominantly about relaxation.

In Snoezelen the focus lies with the companion who supports people equally. In daily practice there is always the danger that one directs and steers too much. During Snoezelen it is much more important, to observe carefully, how a disabled person responds to his/her surroundings. A person in a wheelchair for example will not oppose when she's moved somewhere, she will not complain, one could move her anywhere without her resistance. But we don't know very much about that disabled person, she can't tell us what effect her surroundings have on her, what she experiences and feels within her body. It could be very disappointing when an offer is planned and designed vigorously but then suddenly it is not accepted. One had studied everything, made experiences and now one has to step back a few steps and start again. One is trained in methods, in specific didactic, has learned to work with verbalized objectives and then one has to forget all that for the time being. For many members of staff that represent a big problem. We have to learn to adjust to the level of a disabled person and to relax as well. That also causes problems for many staff members.

We grew up in a society, in which everything is aimed at a goal and at the end of the work there has to be a product. Everything is controlled and measured and results validated. The staff working with

disabled people also has the goal to achieve something, to create a product and to be active. Now all of a sudden they have to step into the background and sometimes simply watch over a long period of time in when nothing happens with the client. That makes a caregiver restless.

A practical example should illustrate that:

Imagine, there is a caregiver and he walks into the Snoezelen-room with Georg, a disabled man. They both lay down on the waterbed. It feels pleasant, relaxing and warm. A colleague looks into the room and sees both people resting on the bed. He doesn't say "Don't you have anything better to do?" but his look speaks for itself. That unsettles us. It is not about justifying ourselves to the disabled person but to our colleagues with the same education. One feels that he now pictures me as being not active myself whereby everybody else at work is struggling.

A different situation: Georg enters a therapy room for occupational therapy. He lives at home and one of my colleagues escorted him on the bus journey. Of course he's greeted with "Good morning Georg, have you slept well, did you have a nice breakfast?" But Georg can't talk and consequently the conversation is one-sided. To begin with Georg stays in his wheelchair. But when he's instructed "Sit down", he gets up slowly and moves towards the table and takes a seat on a chair. Because of a long lasting relationship he knows, that "Sit down" means, to sit down in a adapted chair, to chose from the materials provided, to look around and even to relax sometimes. Music is played quietly in the background and I am chatting to Georg: "How was your evening? Did you watch TV" I don't expect a reply but that is the usual communication. Suddenly the door opens and a colleague comes in to remove some objects that had been left in the room. She says: "Sorry, I am a bit forgetful. Can I get the materials?" No problem, she greets Georg "'Good morning Georg, have you slept well?" Then she goes to the cupboard, takes the materials and leaves the room. Nothing special – but the same colleague returns 30 minutes later with the same excuse. When passing, she keeps looking into our direction and I am still sitting there with Georg, without us having moved from our spot. In front of him are craft materials and everything seems very harmonic. The music plays quietly in the background but up to now nothing has changed. 45 minutes later the colleague returns with a different excuse. But now comes the question: "What are you actually doing?" In her mind she pictures an activity room where the therapist works with his happy client, but all the time she couldn't see any activity.

The example may seem very blatant, but that's the daily practice of our work. There are two possibilities to answer the question: A: "Yes, we enjoy just sitting here, don't we Georg?", but Georg wouldn't say anything. He looks around and finds it all quite nice. He doesn't complain. Or Answer B: "Yes, I am busy and my aim is it, for Georg to discover the materials by himself." I am not adding any more targets yet. Again Georg is not complaining

Another situation. Again Georg enters the room in his wheelchair; I greet him, as well as another colleague who enters the room. This time I am not saying "Sit down" but I just wait and see what Georg will do. After about 5 to 10 minutes Georg climbs arduously and completely unexpected out of his wheelchair and walks with difficulty to a window that is about three metres away. There he stops, supports himself with one hand on the window sill and looks out of the window. He always does that – as I discovered in the meantime – when I don't say "Sit down". Something forces him, to look outside. I don't know, why. I stand next to him and look out of the window as well. Yes, it is a bit cold, I realised it this morning. There are trees, green meadows, but apart from that nothing special to see. I realise that I get bored, since I know the picture in front of the window. From my experience I know the outside temperature, the green trees; I know they are pine trees. Same situation as before. The forgetful colleague comes in again and gets the things she'd forgotten. Again she expects us to be active. She didn't see any activity when she entered the room 25 minutes ago. As with her previous visits she doesn't ask the question yet, why we were standing at the window. Only 45 minutes later when she returns to our room she asks: "Why are you standing in front of the window all the time?" Answer A could be: "We enjoy standing here, don't we Georg?" Georg doesn't say anything but he doesn't complain either. Answer B could be: "Yes, I am preparing for the forest therapy." "Oh", says the colleague, "that's new, I haven't heard about that before."

With the help of these examples I am trying to demonstrate, how the attitude towards dealing with disabled people can be different. It would have been easy to sit down at the table with Georg, to give him sandpaper and to animate him to sand the logs. We would have

had a product and after approximately 45 minutes we would have had about 40 smooth logs on the table. For the companion that would be a very safe and putatively satisfactory situation. It shows that the disabled person has been supported, that he learns something, that he can create something and that I am capable of animating a person. But suddenly the situation changes: We stand in front of the window and after 10 minutes I am already bored. Next to me is a disabled man, who can't tell me anything, for whom it is difficult to move away from the wheelchair towards the window. But there is something that motivates him to that activity, but I can't recognise and capture it. Apparently Georg enjoys standing in front of the window, but I find it difficult to linger for such a long time. Nothing forces me, to stand there and linger. But for me it is the disabled person who is my guideline. After 45 minutes I standing there empty handed, have nothing to show for, no product, no result and that's the problem I am oppressed by.

These examples illustrate the thoughts we had during the first few years of the daily practice of Snoezelen.

We were confronted with things we were not familiar with. We didn't know very much about the world of a disabled person. We had to start to put ourselves into a severely multiple disabled person's position and had to learn slowly to discover the tasks for the practice. What could we offer? How do disabled people react to it? The first step was to simply try things out, to apply them and observe how a disabled person reacts to particular stimuli. Above mentioned examples are certainly showing the different worlds, in which a severely multiple disabled person and the companion or therapist – or whatever we would like to name him – live.

Companions support the disabled, they accompany them and the activity is always subjective. With other people we can have discussions, can exchange and receive replies. If we have communication problems among colleagues, we can explain things further and discuss them for days. That is impossible with severely multiple disabled people who are not capable of expressing themselves through speech. Mimic and gestures, that is a person's body language, can be of help. But to make use of that, experience is needed and most of all guidance by people, who have been practicing for years. In our thirty years of practice we have learned to accept people just the way they are. Their reactions have to be recognized and taken on board. It is our job to accept their behavior, steer it if necessary and offer the disabled person – not only in Snoezelen – a comfortable, happy and secure atmosphere.

Snoezelen has a lot to do with body language and experiencing the body. We get very close to a person we are taking care of. But in our society touching a body without permission represents a big problem and is partly forbidden. However, many disabled people only react to direct contact. Tactile experiencing plays a very important part and I would like to demonstrate the case of a blind man, called, lets say John, from our institution. When he enters the white room, he always takes his seat on the wooden platform with the three bubble units. We thought about what we might have done wrong and only through our own experiences we then realized, that the air pump releases vibrations. The man seems to love these vibrations. Usually a companion would lift the less mobile people from the wheelchair and put them on a mat One day the companion forgot about John who was left behind in his wheelchair in the hallway. About half an hour later they looked for him but the wheelchair was empty. John had jumped like a frog to the wooden platform and sat next to it. That is a nice example but it also demonstrates our work and the need to wait and see. In the meantime we let the blind man act independently. After 15 to 20 minutes waiting in his wheelchair, whereas John locates the individual sounds and moves his head back and forth, he drops to the floor and crawls along the hallway like a frog. The heated areas of the light floor with different temperatures and the touch boards help him to orientated to find the white room. Here he presses his body against the wooden platform and starts tapping it with his palm. His position is always the same and the tapping lasts with precise regularity over 1.5 to 2 hours. Once the bubble units are switched off, he presses his body harder against the platform and stops tapping the wood.

The discussion with the other companions within the room is surely necessary. The knocking does disturb the quiet atmosphere, but that might only be perceived subjectively. Some of the people in the room are not annoyed at all. The blind man – like many other group members – can't give me any feedback on what he experiences as pleasant or unpleasant. We have to learn to wait and see, not to jump in to help a disabled person and to look more closely. That demands much more time and additional members of staff.

Many devices within Snoezelen were developed from daily observations and practice. One example is the bubble units, one of our first equipment. These water columns exert strong visual stimuli on us. 60 to 70% of our world is perceived via the visual system. But the example shown above demonstrates that for the blind man the bubble units are not of interest because of the visual but because of the tactile or vibrating stimuli. The same applies to the platform which is usually covered with a soft material. We have noticed that that is not necessary, since many of our severely disabled people prefer to feel the vibrations directly through the board. Another example is a touch wall which the disabled people didn't feel with their palm but with their heads and finger tips. They could feel the vibration better through those body parts than with the palm of their hand.

In the early years we recorded many videos to capture the reactions of disabled people. We analyzed them then adjusted the materials and the production of new objects to the needs of these people. We discovered that Snoezelen offers predominantly relaxation but in the case of people with conspicuous behavior and aggression it leads to positive changes. Slowly the idea grew, to structure the offer more thoroughly with the help of trained therapists. One example is a man of about 50 years with severe aggressions. He destroyed many items in his living area, which meant that the entire area had to be secured. My colleagues suggested that within 5 minutes he would destroy the sensitive materials in the Snoezelen-room as well. In the Snoezelen-room he displayed a completely different behavior and so far he hasn't damaged anything at all. That might be down to all the different stimuli, which have a very complex impact on visitors. Maybe because of so many impulses he felt released from the pressure to having to destroy something. The waterbed played a very important part for him, because it calmed him down and had a positive influence on his behavior.

Atmosphere

While listening to the description of the rooms and the individual elements one could easily get the impression, that these things are simply available in the room and one just has to chose anything like one would take a toy from a shelf or use a the activity on a play ground.

But, based on my own experience, as soon as one opens the door and enters a Snoezelen room it feels like diving into **another world**. The first impression is one of the complex atmosphere without recognising the individual elements or reasons for the effects straight away. Once one let the impression take effect and get used to it gradually only then individual objects one is interested in come in to the foreground and stimulate to see, feel, hear and experience.

The impression is probably comparable to entering a disco, a fun fair or a church where at first the entire atmosphere and mood will be taken in and only later visual, auditory and olfactorisch sense perceptions can be differentiated and put in order.

In Snoezelen it is the impression of a dream world in which one can dream and relax and by experiencing the environment one will be able to perceive ones own body more consciously. Very important elements of Snoezelen are colours, light, movement and most of all music.

The Snoezelen Complex in the De Hartenberg Centre

Since February 1983 in De Hartenberg near Ede is a big central Snoezelen complex in operation. This Snoezelen Centre was intensely used up until September 2000. Since September 2000 a completely new room of approximately 410 metres square was in operation. In 2017 the whole Snoezelen complex is renovated and up graded with the most modern and advanced technical equipment. All the light bulbs are changed in LED lights

One then decided consciously, for central Snoezelen premises as part of the daily activity concept. The centre is open daily from nine in the morning until five in the afternoon. There is no set timetable. The groups from the living quarters and from the daily activities can come into the room at any time they want. The size of the groups is decided by the caregiver, but one can also come alone. The size of the groups and the frequency of visits do depend on availability of personnel, the degree of disabilities, the behaviour of individual visitors, different activities as well as the weather. Since one is at liberty to use the room at any time one can spontaneously decide to practice Snoezelen. There are no restricting timetables one has to stick to. That makes it easier to respond to clients' activities more consciously. At the same time parents have the chance to practise Snoezelen with their children at any time without having to make an appointment. They make great use of that.

Besides the permanent available Snoezelen Complex there are enough opportunities to practise Snoezelen in natural living and life situations in the daily contact with the residents as well as in temporarily installed Snoezelen rooms in the living quarters.

The new Snoezelen Complex has four rooms: a projector room (White room) of 6 by 11 metres, a room for tactile and with sound effects (auditory room) of 6 by 11 metres, a corridor of 18 by 2.5 metres with different materials and a ball pond room of 6 by 11 metres. The centre is accessible through a wide door. Once through that door you come into the corridor with two light effect floors and a foot carillon in between. Opposite the carillon is a combined warm and cold air scented wall. In the corridor one can also find a scented tube stand, different touch boards and feel boxes. In the corner is a mirror wall which, combined with the light floor, does supply a vast offer of effects. From the corridor you can enter into all the other rooms.

The projector room is completely covered in white soft flooring. In there is an embedded sort of an island with three bubble units. As well as the floor, ceilings and walls are white too. Liquid-, Slide- and film projectors, mirrored glass balls, can be served with a remote control.

The tactile room also has a soft floor. There are tactile boards on the walls as well. At different places there are soft tactile objects one can crawl through.

In the studio the importance lies with the combination of light and sound. In a wall across the room is a light screen installed, that translates every sound into a light picture. In front of the distorted mirror, the light organ and the drapes is a vibrating floor that invites to feel the different sounds. An echo sound system does add an extra dimension to the room. With the help of computer music can be played. If one uses cordless headphones, the great effect can be enjoyed even more, it feels like being in a huge grotto. A seating element does provide the comfort needed.

A soft border along the walls surrounds the ball pond. It serves as a seating or lying down area as well as padded protection between wall and balls. On the ceiling above the ball pond is a semi-circular mirror and along the walls are mirrors too. One can keep occupied by simply observing oneself and the depth effect of the room is increased. Sound and light apparatus are as far as possible based in a separate central room, to avoid, visitors handling them wrongly unintentionally. That measure was also essential for fire safety.

Experts have installed the entire Snoezelen complex in De Hartenberg. That was necessary to meet the terms of fire safety, servicing and maintenance etc. Meanwhile the higher investment costs have been proven to be justified

The cleaning does take up relatively little time; only the ball pond requires half a day of maintenance once a fortnight with a special ball pool cleaning machine. Defects are rare up to date, the biggest cost factor as ever is the regular needed change of projector and light bulbs.

There is a huge interest even beyond the De Hartenberg Centre. At certain times groups from other institutions have the chance to come to us to practice Snoezelen.

Many non-disabled children make use of our Snoezelen rooms too, for a birthday party for example.

Description of the Snoezelen room in De Hartenberg Centre

In De Hartenberg are three rooms and a corridor to link them available but one does only talk about "the Snoezelen room". One can expect that in each of the rooms a certain atmosphere will be present or rather a certain area of perception will be addressed. An exact separation between the senses is not given and can hardly be realised anyway. But that is not the aim, but the elimination of unnecessary, unpleasant and distracting stimuli

To get a better picture, I will describe the rooms' one after the other with their special possibilities and difficulties. A few overlaps cannot be avoided.

Ball Pond

In the 6 by 11 metres big room, painted yellow, are two ball ponds. Surrounded by a 70 centimetre high yellow and red border of soft play material there are approximately 60 000 transparent balls each with a diameter of 6 centimetre. By special light equipment (LED)at the sides of the ball pool you can change the light in different colours. One can lie on top of the balls, bury oneself or other people in them completely, throw the balls, feel them individually and play with them. A slow approach to the unknown situation is possible since there is enough free space in the entrance area (also important for wheelchair access) to simply watch the ball pond and those already present. It is possible to walk around the pond on the 50 centimetre wide edge. It is also possible to approach the balls by simply sitting on that edge and allowing the legs to dangle and play with a few balls. To glide into the balls is unusual since they will move in to all different directions and one will sink in faster the more one

moves. Many residents have fun; others do feel frightened that the ground underneath their bodies is so uncertain. Experiences made here are of a more tactile nature.

The PVC mirrors on the walls as well as the semi-circled mirror on the ceiling above the balls offer additional stimuli.

One can observe oneself in the mirror on the ceiling while lying on the balls and throw the balls towards the mirror. They will seem to get bigger the closer they get to the mirror.

A passive experience of the situation as well as all sorts of playing activities, are possible in this room.

The white room

The room measures approximately 6 by 11 metres, is 5.5 metres high and completely white.

Here mainly visual stimuli in the form of light effects are offered. Due to the white interior the room is suitable as a projector screen for:

-Liquid projectors

The apparatus produces a round, slowly rotating picture, in which multi coloured objects shaped like water drops float into one another

All these projectors are kept in a separate little room on the first floor of the building and point into the white room through a window in such a way, that they can be projected onto three walls. One feels like standing in the middle of the play of colours and lights.

Further light effects are achieved by illuminating rotating mirror balls as well as so called bubble units and fibre lights.

-Bubble units

Bubble units are perspex tubes filled with water; underneath each one is an air pump and lighting fixtures attached.

With the incoming air, air bubbles rise constantly and are illuminated by a light which has a multicoloured disc and changes colour every 15 seconds.

There are three of these units in the room, all of them embedded on a hexagonal stage. Two of the tubes are 1,80 metres high and the third one is 2,30 metres. They each have a diameter of 20 centimetres and can be switched on individually or in combination.

-Mirror balls

There are two balls of different sizes, which are covered in little mirror tiles and rotate with the help of a little engine. Spotlights illuminate them.

This creates the effect of slowly moving light spots over wall and ceiling, which can constantly change their colour because of the multicoloured rotating disc moving in front of the light. These balls are also known as Disco balls.

The described apparatus and lights can be switched on and off via a control panel, using a remote control. The fibre lights can be switched on and off using the switch beside the lamps.

By choosing varied combinations of the activities one can create all different effects.

In the white room half way up the wall are besides the mentioned mirrors other objects attached to adjustable rails, which serve the purpose of decoration as well as play, for example big wooden birds which swing once someone pulls on the string. There are also long PVC tubes filled with air hanging down almost touching the floor.

The entire floor is covered in a soft play material. Two of these mattresses close to the door can be removed to allow wheelchair access if one does not want to lift residents out of their wheelchairs.

One thick air filled PVC tube is moving on the floor along three of the walls to allow a comfortable position that makes it easier to observe the light effects on the walls.

The room does impress with its height and white interior alone and is very popular with the caregivers and residents. The different light effects change by colours and movements never get boring and invite you to dream and simply switch off. In there the feeling to be in the middle of a dream world is the strongest.

Similar to the ball pond here the different demands of the individual visitor can be met too. The fascinating atmosphere alone does have the effect on people to feel very relaxed and invites you to just watch and be amazed. Some people do only react to strong light and dark contrasts, which can be created by switching on and off several devices at the same time.

Others just walk about the room and touch the different air tubes hanging down from the ceiling, playing with them or approaching the lights and bubble units to investigate those. Some do even understand the link between remote control and light effects and try to experiment with them. The devices used in that room like bubble units, liquid projectors and mirror balls are also used for Snoezelen in other institutions, since they are very stimulating. In the meantime they are a permanent part of a typical Snoezelen atmosphere.

Anteroom

Between the corridor and the white room is a small anteroom (2 by 2 metres). In the centre a curtain of phosphorescing PVC strings is hanging down as well as a perspex mirror that is put up the wall with the same strings attached to it. By illuminating them with black light they shine in very groovy colours.

These coloured strings are for the non-disabled a rather optical, nice decoration whereby many of our visitors often grab them and play with them shaking them back and forth, to hear the rustling noise, put them around themselves or put them into their mouth etc. The thick knotted woolly ropes in the corridor are treated in a similar way.

Tactile and Auditory room

This room is covered in soft play material apart from one space. In there are two waterbeds with a sound floor embedded. The water temperature can be regulated. The waterbeds are the most attractive and most used object in the room. Attached to the walls are boards covered in all different materials and furs. They offer various tactile experiences. There is also sort of an igloo made of soft play material, one can crawl into.

Hanging down from the ceiling and almost touching the floor are various soft and sound toys, attached to elastic rubber strings. The strings are meant to make it easier for the disabled visitors to reach the toys even if they let go of them once in a while. There are more soft toys on the floor. The earlier mentioned wooden birds can be found here as well hanging from the ceiling. Many different coloured ceiling lights, whose brightness can be regulated with a dimmer, provide light.

In the same room a vibrating floor is built in and linked with the light screen. This combination makes a conscious experiencing of music and sounds and the playful use possible.

The lights of a big light organ are linked with the sound system and pointed at the perspex mirrors on the wall, which then project lights onto a screen. The observer can see the music matching light reflexes on that screen which measures approximately 3 by 5,50 metres.

The light organ can also be linked with an echo-microphone so that the light effects can be triggered by ones own voice, musical instruments or other sounds, which then can be heard strongly delayed. The acoustic impression when using headphones is extremely fascinating. For residents who perceive very slowly, the delayed playback of their own voice is quite an experience. Once they realise the link between their own sounds and the light effects, they become very motivated to make new noises while under normal circumstances not everybody would have been up for that.

In the room a vibrating floor is built that swings in such a way that the music can not only be heard and seen through the light effects but the vibrations can also be felt with the entire body.

The corridor

The corridor does link all the rooms described so far and does offer many more interesting perceptions. For example a so called living surface, this is a interactive beamer projection which react when a visitor is interfere the projection ,by example a floor with autumn leaves, a fish pond, a meadow with flowers and butterflies and the coloured balls of the ball pool. Also people with severe mental limitations can interact with this floor

A small light floor brings constantly changing combinations of the lights do first of all create very interesting light effects and secondly heats the floor in the different areas to give a warm feeling.

In the middle of the aisle is the carillon. It is made of nine 40 by 40 cm PVC tiles, which are embedded in the floor. Stepping on one of the tiles activates a bell to ring and a light to flash. Bells and lights are located in a light panel on the wall and can also be activated by touching this light panel.

There are also touch boards with sponges, brushes and other materials as well as a PVC mirror in one corner. As already mentioned, thick knotted woolly ropes are hanging down from the ceiling. In the corridor besides these visual, auditory and tactile stimuli are also so called "sniff snakes" to stimulate the sense of smell. These are two rotating stands each of them has a wooden board attached to them with coloured P-traps known from pipe work fixed onto them. Attached to those are elastic PVC tubes, similar to those used for cooker hoods. A concentrated scent will be placed on the wooden board, which can be smelled intensely through the tubes. Due to the flexibility of the tubes it is possible to reach different positions to allow wheel chair users and tall people the same comfortable position to make use of the activity.

The equipment of the described rooms is only one of many. Which devices, materials and playing materials will be chosen for the equipment of a Snoezelen room does depend on the individual views but also very much from financial resources and spatial possibilities.

Today we can use all our experiences and consider them in our meetings. We have learned to step back and observe the behaviour when our residents visit the room for the first few times. What is the muscle tension like, how tense are they generally, to which signals do they react first and what kind of reaction do they show? We receive many different signals and often we will need help from relatives to make sure we interpret the signals correctly. Now we have some kind of "personal dictionary" for each of our clients. It is some sort of archive in which we save pictures, video clips and reactions. Such information are very important for so-called activity companions and other staff members as well as the dialogue with relatives. A long lasting relationship with these disabled people does certainly help to be able to do the right thing. But new colleagues have to be introduced and instructed for them to be able to quickly adjust to the needs of a disabled person. Our institution has a very low fluctuation, which of course is very positive. Most of our staff members stay for many years and they emphasize the fact that working with disabled people has also influenced them personally. Working in a Snoezelen environment brings harmony for the staff; they are often in unison with the disabled person.

And that is also what our philosophy is all about.

Ede, the Netherlands, 2019

Ad Verheul