

What Sølund taught me

by Grete Obel



Preface

Dear reader,

You may be a student pondering about the field of work you will undertake the future, or perhaps an educationist, a psychologist, or a therapist who in your everyday work is involved with and caring for *nonverbal* people. You may equally be a personnel manager, administrator or politician, who wish to acquire insight into and understanding of an inarticulate group of people, who need your support in order to lead a more meaningful life.

The title "*What Sølund taught me*" suggests a retrospective look, inspired, as it is, by Sofie Madsen, the first Danish educationist to work with nonverbal autistic people, which she describes in the book "*What the children taught me*".

It is my great hope, that I – with my personal account of working as specialist teacher at Sølund – as well as selected valuable comments made by a number of committed, professional people, have managed to lay down some guide lines, so that we can make some progress with the development of our educational work in relation to our *nonverbal people* in institutions all over Denmark.

I shall finish with a heartfelt thanks to all those who have given active support to the *nonverbal people* or, who, in any other way, have contributed to "*What Sølund taught me*".

A special thanks to Maureen Pilvang, from whose project "*Spelling boards – hidden knowledge*" (and/or Assisted Communication Technique [ACT]) I have taken the liberty of quoting particularly relevant extracts.

0-0-0

In order to protect individual people's privacy all the pupils' names have been altered.

The word nonverbal people has been used in stead of: People who are incapable of speaking.

Acknowledgment

Acknowledgment – a clarification of "*What Sølund taught me*".

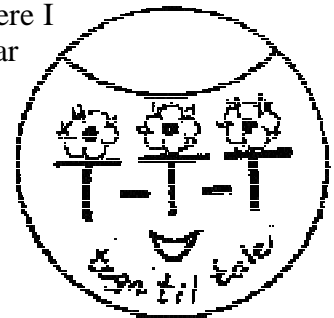
As individuals we cannot just wave a magic wand to make the pain and suffering go away. Suffering, mental suffering, a pain deep inside cannot just be made to disappear into thin air. But we, who are close by the sufferer, have a choice to make because we know we are in a position to help. We can choose to be present in mind and spirit or not. When we choose the former, important boundaries are crossed. It is not an easy choice – but one of the most difficult decisions for human beings – choosing between remaining close to or running away from our suffering fellow human beings. It demands courage to get involved – as one may be frightened or experience opposition. It is brave to remain close by and stand by the sufferer through thick and thin, and open oneself up to what one is experiencing, not being frightened to admit to one's own vulnerability or feelings when faced with the sufferings of another human being.

If one manages to remain close, to stand by, then the miracle will happen – not the next day or even the following day, but the moment the suffering, lonely individual becomes aware that here is somebody, or several people, who are not fleeing, some people who dare remain close by them, and experience and witness the suffering for themselves. Here are some people who are realizing that it is "worthwhile" to stick with them through thick and thin, people who are aware that the reward would come one day, the reward in seeing a liberated fellow human being, a fellow human being who is sharing their feelings – a fellow human being who has learnt to communicate, not a fellow human being who is entering the business community – but a fellow human being who is joining our social community – our Christian community.

"Grete, damn it – our community is completely soaked in Christianity", a colleague said to me one day – a colleague who reflected upon the greater whole, the historical and the social scene. Yes, the community is completely permeated by Christianity – thank God it is – but the fact is that we do not always think about it very deeply. True, we can call it humanism, social involvement, the desire that, although we are all different, we are also all of equal worth.

I had also a social contract when I started in 1975 at the Central Institution Sølund in the district of Århus, situated in beautiful surroundings by Skanderborg lake. Having for many years (1966-1975) functioned as a specialist teacher and school psychologist in a day school for mentally retarded children, Vestergade School in Skanderborg, I accepted an invitation to start working at Sølund. My brief was to try to stimulate, treat and teach a number of inmates, who for years had been left sitting in over-crowded wards – regarded as mentally retarded and without hope of improvement.

This was a big challenge after my exciting time at Vestergade School, where I was fortunate to discover the value of sign language for those who hear well but are without speech – the form of communication which developed to Sign to Speech – a form of communication which became a big support and a relief for the nonverbal people, children and young people who formerly often suffered from psychological problems, due to the stress induced by not being able to express their frustrations, thoughts and feelings.



From Keller Institutions to Social Education.

So in 1975, together with a number of very committed colleagues, I set to work on improving the lives of these unstimulated and deeply frustrated "pupils". The task appeared great and overwhelming, and in a way rather dangerous - who were these people? What were they feeling and thinking?

One thing I was clear about – that Keller institutions like Sølund had for many years been orientated and guided on a medical principle. The inmates were regarded as sick and the illness was often incurable.

However, many of the nursing staff at Sølund showed a clearly positive interest in us as specialist educationalists as well as in our work. I remember, in particular, how, one day, a very imposing matron who lived in one of the old wards – in close proximity to the children, remarked as she was passing by and saw me using the Sign to Speak language to one of the inmates: "Now, isn't that amusing". However, many of the elderly matrons and many of the nursing staff on the wards, appeared to regard our method of speaking directly, respectfully and supportively to the inmates as complete gobbledygook.

I often experienced that communication between the nursing staff and the inmates was one way only, and for the most part nursing staff had a bossy and condescending manner, holding the inmates up to ridicule. The nursing staff on the wards, trained to care for the mentally retarded, were at that time hard pressed by the over-crowded wards and the very poor sanitary and hygiene conditions that existed. There were no lifts and the inmates, living in such dirty and unhygienic conditions, came under increased stress and their condition regressed, as no efforts were made to support them in a sensible, practical way by teaching them about personal hygiene. Everybody was simply too hard-pressed for that.

However, some of the staff were sensitive and loving, and they remained at the institution in spite of being overburdened – I admire them deeply, it must have been a very miserable experience. After all, as specialized teachers we had a basis of experience and special working conditioned making it easier for us to be positive, to stand by the inmates, and to dare to feel and see – what we saw.

It was like entering a foreign country – a country which was occupied by an authoritarian regime, which, for the most part, was not aware that they were dealing with human beings having thoughts and feelings. We had a good working relationship in our group of colleagues, supported by our leader Preben Sønderskov, who today is employed at the Educational-Psychological Counselling Service in Skanderborg.

Preben Sønderskov had encouraged me to start at Sølund as a result of his knowledge of my work in the period (1967-1975), where I functioned as School Psychologist in a school for adults at Sølund once a week – seconded from Vestergade School, where I, as described earlier, was busy using the Sign to Speech method with the pupils.

In our classroom at Sølund, where we among other things had been given a couple of typewriters for use in our teaching, the atmosphere was positive. We believed that our "new" pupils possessed a large amount of unused potential, and that they would point the way to how they could be made to improve their communication skills.

Above all, we tried at all cost to make the pupils feel secure with us, in particular by creating a simple and predictable structure around them. We built up their identity and self-worth by often calling them by their names, and by gently holding them and mirror their inner feelings. If a pupil appeared particularly restless, we would for example say gently: "Lise, I think you are feeling a little upset today, let's sit down here and listen to some music, come on, yes that's fine, brilliant, you can sit there.

0-0-0-0-0

0-0-0

0



What Karen from Kildegården showed us!

One pupil, living at the rest home Kildegården, had lost the ability to speak through a severe traffic accident. She came to us at Sølund to see whether we possibly could discover a way of stimulating her into improved openness and communication.

Karen was a fine, little frail girl, who only walked with the help of the nursing staff. She often appeared withdrawn, very despondent and resigned. But now and then she would stand up tall and look at us with bright eyes, showing much

awareness. Little by little, we discovered a very interesting and exciting personality.

I chose to try to teach Karen some word pictures on the typewriter. On a piece of A5 paper I had glued some pictures from a magazine of clothes and animals, one picture on each piece of paper. On one sheet a cat, another showed a dog, a third a dress and so on.

Then I held Karen's hand, gently but also with acknowledgement and secure presence – so it was not easy for her to avoid contact or escape. "Now, let's help each other to write 'cat'", I said.

At first there was a certain reluctance, but it disappeared quickly – we wrote *cat* many times, and it felt as if Karen was relaxing and enjoying the close contact and working together with somebody. After a while we were busy working on clothing items on the paper, and there was a picture of three shoes and one boot, so I helped Karen finding the B for boots. Then it happened, it was as if she was starting to work on her own, she had strength in her hand and finger, found a G a U M – BOOT. Great was my surprise: "But Karen, that's right, it is a gumboot, isn't that just wonderful, you can spell on your own, that's great. I was so very pleased.

Now we realized that Karen, who had lost her mother in the accident in which she herself had been so badly wounded, would be able to express her feelings and thoughts on the typewriter with psychological support.

We usually began by saying: "Come on Karen, it's so exciting what you want to tell us", and as soon as Karen had found a letter we repeated it – I think it made her conscious of our interest. When she had written the word, for example "*far*" (*dad*), we would say: Well done Karen, that really is wonderful – you can write *far*. That would eventually become "*farmor*" (*grandmother*): "Well that wasn't just "*far*" but "*farmor*" – how exciting!"

I think that after the tremendous trauma of having lost her mother Karen's fear of losing something was greatly increased. The confirmatory presence of my hand signalled to Karen that I was all there.

In order to further build up her confidence we took some photographs of us together and examined these with Karen, so that she could see herself amongst us, the teachers. It was not dangerous to open up because Grete was here and totally involved, or as the first manager of Sofieskololen Else Hansen put it, "Totally engaged presence".

Once Karen wrote: "Mie" – twice in two days, with me and with another specialist teacher, Sine Erbs, who also was able to support Karen in the use of the typewriter. We thought it could possibly be one of the nurses on Kildegården, or they might know there whether Karen had a relation called Mie. But on Kildegården they did not know either who Mie was.

In the meantime we managed to contact Karen's father, who was terribly pleased because he could tell us at once that Mie was his sister – and apart from her dad, mum, granddad and granny, Mie was the one person she was very close to and had often written about.

I will finish this little tale about how Karen was helped to communicate through the typewriter with an experience I had one day I visited Karen in her room on Kildegården, where she did not have a typewriter.

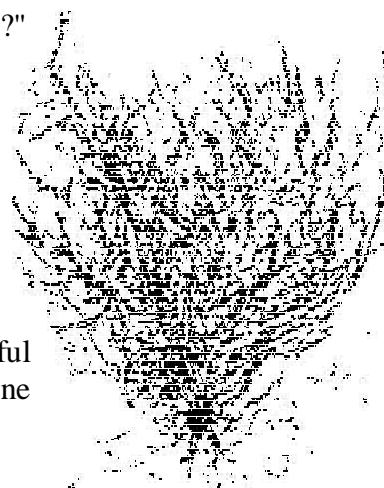
By then we had discovered that we could use a piece of cardboard with large capital letters on it. This was cheap and could be transported anywhere, and the letters could also be transferred onto a piece of paper or a book – it worked just as well.

When I visited Karen in her room she being feed by tube, so I decided to help another patient, Mrs. Caspersen, who was standing by the door the whole time calling out for the nurse: "Aren't you

going to come and help me? – Aren't you going to come and help me?" I went and helped Mrs. Caspersen into her bed and tugged her under the duvet, she was very pleased.

When I returned to Karen, who wasn't being fed anymore, we started our communication. I was very surprised – Karen wrote: "It annoys me that you are helping Mrs. Caspersen" – forgivable, one understood that Karen needed me as "her own", and not everybody's property.

Together with Sine Erbs I have later often relived that powerful moment, where we were privileged enough to reach Karen, who, one had feared, was never going to be able to communicate.



Jytte and Jørgen

Karen was a delicate and in many ways an amenable pupil.

It was a totally different case with Jytte and Jørgen in the beginning. Jørgen was hyperactive and could, if he was not been kept occupied by an activity supervised by the staff, spin around and around for up to half an hour, for example when the staff had let him out into the fenced in playground. At certain times he would bite everything, and unfortunately at very bad moments he would bite his fellow patients and the staff.

Jytte, with her constant "handballet" and strong eyes, was also a very intense character. Jytte expressed herself like Jørgen by biting and screaming. She did, however, manage to find reasonable ways of distracting herself, for example when she was angry about having her "school" interrupted because it was lunchtime and she had to go home and eat her lunch, she would bite her padded jacket.

The period from 1975 to 1981, when I worked daily with Jytte and Jørgen, was a very demanding as well as developing period for the pupils and for myself and my trainees.

After a while, it became possible with the help of communication by typewriter and supportive sign language for Jytte and Jørgen to give expression for their feelings and frustrations.

As was evident from the weekly report I made of Jytte and Jørgen, there were periods where everything was going very well, and Jytte and Jørgen were making good progress – became more open, calm and ready to seek contact, but then suddenly you could have a period when they were entirely restless, which was truly extremely demanding, in particular as we were unable to confer with the overworked staff. We held a meeting once a month and it was often cancelled. The conditions for collaboration were very unsatisfactory.

In the record book I described, of course, the episodes which supported and demonstrated clearly the progress made by communicating by typewriter.

The staff on the ward doubted the wisdom of the way we chose to communicate with Jytte and Jørgen, and did not have the extra energy to get involved in something which came into direct conflict with what had been laid down to them as determining the identity of the mentally handicapped and their development prospect.

One example: Ann Rahbek Hølund, a long-term unemployed, and I were on a camping trip with Jytte and Jørgen. Jytte, who frequently had a problem with constipation, had been given a laxative

for the trip. But Jytte refused point-blank to take the medicine – lips firmly together, there was nothing to do.

Now how do we handle this? – Ann and I talked much about how harmful it would be if we decided to force Jytte to take the medicine, but on the other hand it was important for Jytte that she took her medicine. Suddenly, Jytte reached out for the spelling board lying on the table. She wrote: "If you are going to make such a fuss about it, then I'll take it. "After that she took her medicine without protesting.



Jørgen was at times incredibly bright and happy and expressed many exciting things with the help of the spelling board – it appeared that he had an open and loving nature, but also that he needed people who would remain close to him, who were mirroring and support him.

Useless structure.

Our leader, Hans Steensig, was very supportive of our work, believed in the potentialities of the pupils and our communication by spelling board. He was, however, in a very difficult position, because at the Central School we were an open invitation to the inmates on the ward – in the sense that the ward could enrol the pupils as to an ordinary evening class, according to what was on offer. In other words – if we at the Central School had discovered communication possibilities and resources, which the ward at the time, for understandable reasons, could not manage or relate to – well, then we had to accept the fact that the ward would not refer the pupils to us.

They were unacceptable conditions. Regrettably, I did not manage to impress on the powers-that-be with sufficient vigour that, when one was concerned with such disturbed youngsters as Jytte and Jørgen, who had great difficulties in relating to and communicating with anybody, it was essential that these working conditions were altered. For this type of pupil, where the contact with a reliable and committed grown-up was the most central requirement to their development, it was catastrophic that the structure was of so little use in achieving this aim. Smaller units with no more than three inmates and a permanent staff, plus contact people and good possibilities for supervision, would be the optimal model. Fortunately, today such a model exists in several departments of Sølund.

Under such a structure, it would have been possible for specially trained educational psychologists to convey the pupils thoughts and feeling, through the use of communication by the spelling board, to the employees of the ward. After a time, it is very likely, as happened in *M-huset* in Copenhagen, that several of the employees would have been able to take over the support with the spelling board and thus be able to communicate with the non verbal pupils.

As far as the development of Jytte and Jørgen is concerned, the previously described useless structure was catastrophic.

My trainees and I had fought hard to make Jytte and Jørgen feel secure and accepted, but at the very moment, when their sense of security was beginning to develop so well that they were making real and fast progress in their development, the ward decided that I should no longer teach these two pupils.

Our structure was, as previously described, built up in such a way, that the decisions about the length of a teaching programme were in the hands of overworked employees on the ward.

Although Hans Steensig had many meetings with the employees on the ward during the year, in order to try and make them realize how unfortunate it was to break up the teaching course, he was unable to alter the situation.

I asked Hans to inform Jytte and Jørgen that it was against my wish to stop the teaching course. He agreed to do that, and I remember his words to Jytte and Jørgen that now they should show the employees on the ward how capable they had become, because he knew very well how much they had achieved when communicating with us. That was unfortunately precisely what they could not do.

I saw Jytte and Jørgen as a little girl and a little boy who were standing in a large hall holding their big sister by the hand; on the other side of the hall they had recognized their mother. They clearly wanted to cross the floor and go over to her – they could cross the floor – they had the use of their legs, but they hid, not having the courage and energy to, by themselves, cross the big void of "the open room", if a grown-up would not take them by the hand and "stand by them".

Ann Hølund and I had a couple of awful days of confusion, despair and sadness. I had been close to Jytte and Jørgen for six years and Ann had joined for the last six months. We very genuinely concerned about the future of our two pupils. I was hoping that they, after all, knew that there was somebody who had "seen" right inside them – and knew many of their thoughts and feelings, and that this mirror and activity had gone on for so long, that it would have left permanent and comforting impressions on their vulnerable minds, so comforting that it would enable them to continue later with other people going down the same route.

At present, in 1998, I have one year left working part-time at Sølund – 200 hours a year – and I am very happy to say that, for the last couple of years, I have again been working with Jytte once a week.

Jytte was no longer in the old ward in "the original Sølund". That ward had been closed down, and all the grown-up patients had been moved into new houses around a courtyard, semi-detached houses with room for 12 patients in each.

Jytte had not lost her trust in me in spite of "the break" – we were quick to get going again, possibly helped by the fact that she had been visiting me at home a couple of times.

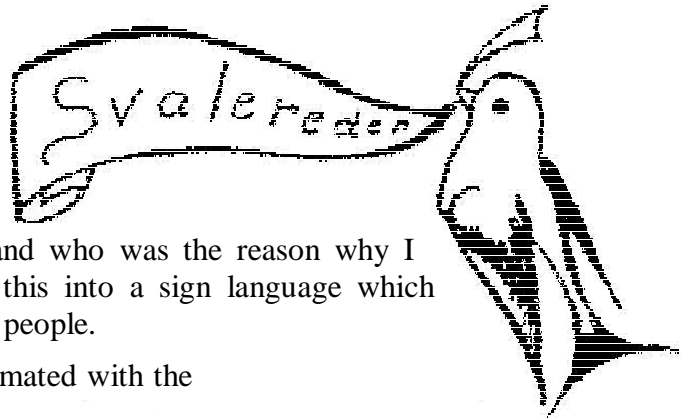
She had even at the odd moment mentioned with pride to the trainees and visitors that I had especially sought out "Jytte's house" when I had the chance, because I wanted to continue "working" with Jytte and would like to be with her.

I remember the first time I visited Jytte in the new ward, before I had again established a weekly programme. A young trainee was present, and I was anxious to find out whether Jytte would write on the spelling board with me. Everything went well – suddenly Jytte deliberately removed her hand and moved it gently over her chest, (I followed suit, of course, so that she could feel that I was all there "by her") – great things were happening with her hand, and mine too following quickly after - Jytte decided the movements I followed suit – constantly trying to signal to her with my hand movements:

"Dearest Jytte, I'm here, following you – do tell me, do tell me – don't be afraid, don't be afraid." So, to my great surprise, Jytte stroked her chest gently and then returned to the spelling board: D-E-N-M, "Oh! you remember the sign for Denmark." Jytte's body language and mimicking was very exciting. She was sitting, her nose in the air, and glanced slyly at the trainee, who now was in no doubt that Jytte, a long time ago, had, amongst other things, learnt the sign for Denmark, (three fingers in waves over the chest – (the three great straits in Denmark)). So it was clear, that it was extremely comforting and encouraging for her, that one acknowledged and followed her sign language.

New group in the "Swallow's nest".

When Jytte's and Jørgen's ward had rejected my "school offer", I was given a new group with, amongst others, a deaf woman, Birgitte, whom I had come across before, and who was the reason why I learned sign language, and later developed this into a sign language which could be used with the nonverbal but not deaf people.



The Central School had by then been amalgamated with the Activity Center.

There were 4 pupils in Birgitte's group – 2 of those were able to communicate on the spelling board.

A productive period followed, when I was busy making sure that there were plenty of opportunities for our pupils to communicate and make contact – as long as we made them feel safe and supported, and we dared listen carefully to them.

Mette, the second girl in the group, who had lost her mother at an early stage, could now and then be chaotic. She gave the impression that, the fact that the employees on the ward did not believe she could express her own thoughts and feelings, made it difficult for her.

A night duty nurse spoke harshly to her and that was a great strain on her. I was at my wits' end – knew very well that the particular night duty nurse expressed herself in a very authoritarian manner. I knew that, on her return from a visit at Christmas, Mette had been received in a bossy and unfriendly manner: "Just you come in now and get your clothes off!" No sympathetic understanding or inquiries about her evening out. I also knew that, if I chose to go straight to the person concerned or the ward manager in order to have the manner in which the night duty nurse communicated, it would be in vain.

I knew from previous experiences that, the old authoritarian way of communicating involved the sort of people who had an almost explosive temperament, whose psyche did not manage dialogue and exchange of views and attitudes in a mutually respectful way.

I believe that Mette was aware of my thoughts and despair, and I remember also that I, as a Christian, prayed for the nightwatch nurse concerned, and said the following: "Mette, I am sure that the nightwatch nurse has a little girl like you deep within her, who once has been treated just like you are being treated by her now". "Isn't it terrible that somebody can have treated her like that," wrote Mette, and looked at me with calm, penetrating eyes, – "I will try not to tease her any more."

Later Mette reported, that she and the nightwatch nurse were getting on fine - - - "I give her a smile, and then she becomes happy."

Others were using the spelling-board.

I remember that, after we had worked with the spelling-board – at the end of the seventies, (incidentally, I called it a pointing-board), I discovered that people were working in a similar way in the Copenhagen district.

You could read about it in articles and watch it on the TV, in which Lise Lind, who was the first to start in Copenhagen, recounted in an exciting way her results and experiences. M-Huset at Vangedehuse and the activity-centre at Ishøj were particularly prominent in recognizing and recommending the use of this supportive form of communication.

Axel Arnfred, whom I had experienced as an incredibly open and competent child psychiatrist, managed to put in writing what was involved in the use of the spelling-board. He had previously held some seminars at Sølund in which he, with his deep compassion, humanity and respect had managed, in a wonderful way, to communicate his psychological insight. I owe him much, and am very grateful for his gentleness, courage and insight.

In Nadja Mac's book "Mentally retarded children" from 1974 Axel Arnfred writes:

Some mentally retarded children do not have the vigorous interplay with us, that one would expect from the rest of their psychological development. They are impoverished as far as ability to make contact is concerned, and disclose only a small amount of what they can do and know". "Many psychotic (autistic) children behave under normal circumstances as moderately, strongly or deeply mentally retarded, although they, when they are with people who understand how to treat them, betray "islands" of skills, inner language, knowledge and learning capacity, all of which are clearly more advanced than their behaviour indicates."

"The children's behaviour is well behind that of their age-group."

"New skills, which a child must have at its disposal, has to be mastered within a framework of a balanced interplay, in which the teacher handles the child in such a way, that the child is recognized as having its own individual personality - and especially is able to develop its trust in the teacher."

M-Huset

The contact with Pia Bentsen from M-Huset has also been a great help and support.

At one of Århus Amt's Special Schools' yearly meetings several themes were on the programme. One of the themes was the general atmosphere in *M-Huset*. Pia mentioned the general attitude and ethics in relation to the educational work with mentally retarded, speechless grown-ups – especially the individual patient's possibility for influencing matters, making choices, being accepted as a human being with opinions, desires and dreams.

This educational work requires a well-known and accepted method of communication, not to mention the general surroundings which emphasize that the mentally retarded person has opinions too.

The employees really should be ready to listen to the inmates' thoughts and feelings and to involve the inmates in decision processes, to the fullest extent possible, concerning their own person --- seriously consider the mentally retarded person's abilities.

"Public Opinion"

At the same time, there was much positive published in the daily press about *M-Huset's* manually supported communication method (the spelling board).

It was as if a warm, light and liberating wave was entering Educational Circles, and people in general often pointed out to me that they now had read here and there about the spelling board ---, and - I believe that it is, in fact, the very same spelling board I have been working with for years at Sølund. I had to confirm over and over again, that I had, by reading about and visiting *M-Huset* discovered that we had found our way to the same methods at just about the same time – independent of each other, which is often the case with new initiatives all over the world.

It was a wonderful and enlightened period. --- I remember that an acquaintance of mine, a middle-aged woman with a sense of humour, studying theology, had said: "Grete, I just want to tell you,

that people are now saying that that woman Grete Obel, who was a bit mad with all that talk about the spelling-board, she was perhaps ahead of her time."

I reflected quietly – that that sort of public opinion is not much use to me, because it is the same, understanding but superficial debate, which often ruins and belittles genuine and honest research, among other things through the sensation-seeking press.

It was, I believe, at the same time that Rose Mary Crossley from Australia, who wrote the book "Annie is coming out", visited *M-Huset*. Rose Mary contacted me by telephone and thanked me for a letter I had sent her. It was very pleasant to speak to a person from the other side of the globe, who also had achieved the same insight into supported communication.

During this period, there were, naturally, many people who had difficulties in keeping up with the new spelling-board movement. It was too much to take in and too fantastic.

A difficult and chaotic period.

One mother, who apparently had made use of her right of access to documents – and through these had learnt that her grown-up daughter had uttered something about incest in relation to her own mother, and had, not surprisingly, become very upset. It was most unfortunate, that this lady turned to the press, and thus, sowed the seeds in all Danish people's minds, the uncertainties in relation to incest accusations by use of communicating on spelling board – and thus discrediting its use. It was alright that Danish Institutions decided that statements made on spelling boards were not valid as evidence, but sad that grown-up inmates in Institutions were not allowed to have private conversations with the employees, conversations to which parents had no access. In my opinion that is discrimination against nonverbal grown-ups.

If the young daughter's utterances had not been brought to the mother's notice, it is probable that sensibly supervised employees, through further conversations with the girl and with the support of a psychologist, had become aware that, many borderline psychiatric cases can have fantasies about incest.

It was very sad for the unhappy mother, who naturally stuck up for herself – and also for the poor employees, who, as I understand it, of course are well aware that nonverbal inmates (often borderline psychotics) and others, who have not been able to come to terms with their feelings and sexuality, can come forward with incorrect and confused utterances in connection with the people who are closest to them.

In the book "Dynamic Psychiatry" by Johan Cullberg these phenomena are well described.

Well, it really was unfortunate and very destructive for the mother, not to mention for the serious-minded employees, that this case received such an overblown Media coverage, and was followed up by superficial and incompetent psychological research. We know from similar complaints about incest from young people that, of course, in common with other statements with or without a spelling-board, incest may have been committed, or, it can be complete fabrication in the young person's mind - that's how it is, anybody who is working with mentally retarded people knows that.

When we are dealing with nonverbal people – like at *M-huset* or at *Sølund* – we must always be very conscious of the fact that we are dealing with very seriously handicapped and vulnerable people, whose utterances, naturally, have to be treated with the utmost care and consideration, and must be analysed in a positive and supportive manner.

The employees must have at their disposition the possibility of supervision by well-educated psychologists with an understanding and interest in ACT (Assisted Communication Technique).

Work on attitudes

I think there has been a failure to face up the fact that, for perfectly good and understandable reasons but nevertheless in the long term unacceptable, there has been opposition from a number of those employees who do not work with spelling boards, and do not wish to see any changes in their understanding of the nonverbal people's identity.

One kind and caring colleague who had been working in one of the old wards said, after we have managed to get a couple of young and bright Media people to make a video about Jørgen and Jytte: – "If what that film says about Jørgen and Jytte is true, then I can hardly bear the idea that I worked in their ward, where we regarded them as being severely mentally retarded".

That was a very honest message, and I understand very well that such a message and what it implies, is one of the reasons for the employees' opposition towards communicating by spelling boards.

I have myself had difficulties in swallowing hook, line and sinker, which, nevertheless, had to be swallowed as we went along. I had, as mentioned earlier, acted as school psychologist at Vestergade Skole. Here I have had pupils who I could not manage to involve in the test situation, and who were therefore difficult to assess.

When I later were able to make another attempt at communicating with these pupils, for example Mads and Mikkel, it transpired that they were bright but very frustrated nonverbal youngsters.

Mikkels's father, who was from Djursland, dutifully took the train and bus with regular intervals in order to visit his son at Sølund.

One day, when I, after such a visit, drove him to the busstop and told him that I corresponded with Mikkel and that I thought Mikkel was a wonderful, bright lad, who was able to express amusing and exciting thoughts and feelings, as long as he received the necessary support. Mikkel's father came forward with some interesting information and insights. – When Mikkel was at home on a visit he wanted to "read" the newspaper. But what had really surprised Mikkel's father was, that Mikkel always found the day's paper, although it was at the bottom of the pile of newspapers. He had then come to the conclusion that Mikkel had taught himself to read. But then he said: "I told this to the consultant, (who had not worked with Mikkel for a long time) and he said that that could not be right". Mikkel's father had therefore thought – the consultant knows best – and had therefore given up his belief in Mikkel's undiscovered abilities.

I personally coped with it all, because I kept a low profile and had good leadership at Sølund.

One day I met the manager of Sølund, Maurits Eijgendaal, who also felt dejected about the lack of progress in the struggle for assisted communication in the Copenhagen District. We had both listened to a touching radio programme in which a mother had corresponded with her nonverbal daughter, Lone, over a long period. She explained that after the incest case she had received many sceptical looks, for example when she went shopping for clothes with her daughter. The shop assistant regarded the mother as a cruel pedagogue leading the poor handicapped child's hand. What made the programme even more exciting was, that two of the staff making the programme on the radio, made an attempt to communicate in writing with Lone and succeeded – so here was proof of the genuine nature of the programme.

Lone wrote about a person called "Lola" and the employee did not know about whom Lone was talking. The mother explained that it was her sister, who is married and lives in Germany.

These well-documented proofs from "natural test situations" is not discussed anywhere, and least of all on the front page of BT (a Danish newspaper) – such stories are not sufficiently sensational and do not take into account people's enormous appetite for scandals, and therefore they do not motivate the sensation-seeking tabloids into publishing them.

New Insight

In this connection, perhaps a little episode I experienced one day, when I was having lunch with one of the inmate's parents, will clarify the problems surrounding the use of spelling-boards in Denmark.

I talked a bit about the spelling-board's potential. "No", he said, he did not believe in it. "But you haven't actually seen it in use – why not drop in and see how it works?" I said. "I've no problems about believing in something I haven't seen, for example that New Zealand is situated where it is", he said. "Well, you are teaching me something", I said, "does that mean, that all you need is for some sort of authority to tell you what is right?"

"Yes, of course, I can't damn well check up on everything myself."

I had listened and learnt much during this lunch break.

Genuine Qualifications

For many years my work consisted of researching, watching and believing in what I saw and experienced. That is why I now had to realize that there were people, understandably, were dependent on that we got valuable authorities:

Really recognized as authorities,

I am in particular thinking about Lone's mother, the radio assistant Lisbeth Jessen, who saw the truth about Lola for herself, and also the author of the well-documented publication No. 6 (page 21) from the Copenhagen County Authority, not to mention the child psychiatrist Aksel Arnfred, Pia Bentsen and Jette Lundgaard, who have worked seriously with nonverbal people and the use of assisted communication for years.

Furthermore, Frank Ulmer Jørgensen (psycholinguist) and Birger Perlt, as is indicated by Maureen Pilvang's publication, have carried out detailed research, in a very ethical and responsible way, into the problems and potentials of these nonverbal "spellers".

At that particular period of time, I was very preoccupied by my daily work, as many pedagogues who work with assisted communication – it demands all your attention. That is why today, with only a few hours work at Sølund, I am delighted to have the time and energy to make public my considered thoughts and experiences in relation to those people without speech.

ASSISTED COMMUNICATION (FC/ACT)

It has for a period of time been of great importance to my work having cooperated with dedicated students.

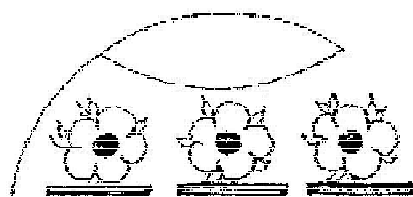
I was supervisor of teaching practice at the Peter Sabroe College of Education in Århus, (1981-1996), where I had a close and useful working relationship with the teachers of the College of Education concerning our trainees.

In the late summer of 1998 I was, to my delight, contacted by a student of education, Lise Andersen from Århus, who had experienced ASSISTED COMMUNICATION (ACT) in an institution in Germany. She was now busy writing a report on the subject. Lise visited me in Ry and experienced my work with the pupils there at first hand.

We exchanged literature and articles, and Lise pointed out an article to me: Publication No. 6 "HIDDEN KNOWLEDGE – SPELLING BOARDS" (and/or assisted communication technique (ACT) in the series about communication from the Inspectorat for Social – and Health Services in Copenhagen District Council.

The publication, written by Maureen Pilvang, is extremely comprehensive with much valuable information.

Furthermore, I would recommend anybody who is interested in the subject to read it and to obtain it for their institution.



Quotations from Maureen Pilvang's publication No. 6:

**"HIDDEN KNOWLEDGE – SPELLING BOARDS"
(and /or assisted communication technique (ACT))**

Introduction by René Aagaard, Director of Social Services:

Publication No. 6 "Hidden knowledge – spelling boards" is an assignment written in 1990 in connection with the special teacher training at "Danmarks Lærerhøjskole" (Denmark's Teacher training College).

The author, Maureen Pilvang, is a teacher at Ballerupcentret, a special school in Copenhagen County, and has worked with psychotic/autistic children for more than 20 years.

This publication gives excellent insight into and summary of the debate about hidden knowledge and communication via spelling boards.

A warm thank you to Maureen Pilvang for letting us publish the assignment

Page 34: In his introduction to the book "Better late than never – the communication environment in the "M-house" as seen from the outside"

René Aagaard, the director of Social Services, concludes that the ideology behind the work with the spelling boards is:

1. All communication is important!
2. Without mutual trust no communication!

He continues: "Communication can (must!) affect the whole attitude to and work with people with extensive physical or mental handicaps. Their legal status will also need to be re-evaluated".

Page 54: **Can it be proved that the spelling boards work?**

Frank Ulmer Jørgensen (psycholinguist): "We are faced with a **phenomenon**. The phenomenon affects the mentally handicapped's daily life, they feel better and we must, therefore, support the phenomenon. (We are talking of a group of people who have previously been destructive and self-destructive – now they are less so)".

"First of all they point to letters, and are being supported in that, and secondly they are approaching something resembling our writing. This is exceptional compared to the way the group has previously been regarded".

"Ethically it is quite irresponsible if we as scientists conduct tests and control tests, test people without first having obtained their approval. How many of you would like it if I turned up at your home one day telling you that you had better participate in this, that or the other experiment!"

"Every time we try to make control tests they become mentally unbalanced". – **As far as I am concerned it is ethically irresponsible if as a scientist I do not accept their disapproval irrespective of whether it is expressed verbally or physically**".

"The day they are willing to take part in a test, it is acceptable for us to conduct such".

Page 55: **Frank Ulmer Jørgensen:**

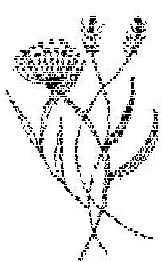
"What about our own children, are we going to wait till they are adults and all their faculties fully developed before we accept their communication? We read them all the time, support them in their efforts to do their homework whilst they are little so that they can learn to e.g. read. Should we not support them just because they have to do the work themselves? Of course we should, it is part of their development. The only way they can learn is by us supporting them".

"It is the same sort of problems we have here. For the group to develop we have to support them".

Birger Perlt:

"It is quite possible that the knowledge we possess to-day about mentally retarded people need to change. It may be more a question of **retarded communication being a psychologically and socially determined** layer on top of very specific physical retardations".

This would be a most interesting field to study.



Pages 55-56: **Interview with Lise Lind from "De tøver ikke" (They do not hesitate) in Press (a magazine) No. 27/88.**

Lise Lind has been a special teacher for 20 years, she was the one who worked with the first "M-house" inhabitant and convinced the "M-house" teachers that Helle was able to spell.

Helle would only write with Lise Lind, her teacher, and therefore nobody believed that Helle could spell and read. Everybody thought that Lise Lind guided Helle's hand. Had Lise Lind and Helle not been so persistent and continued for years (from 1979 to 1984) the "spelling" may not have spread as quickly as it has. Helle was the one who "introduced" the spelling at the "M-house" thanks to her teacher.

Lise Lind had to convince Helle to prove what she could do as otherwise Helle would have had no one with whom to communicate as an adult.

The "M-house" personnel admits that they laughed at Lise Lind and thought she was mad, but Lise Lind knew from her own childhood experiences what it meant to be considered stupid as she was born a spastic and only learnt to walk and talk rather late in life. "I learned very early in life what it

means to be belittled". "We have to take the pupils seriously, to take whatever time it takes and be patient".

Lise Lind: "I firmly believe that each and every child has within it the possibility for development and furthermore that should a doubt arise, the child should benefit from such doubt".

Page 62: **The initiative.**

"Hidden knowledge disclosure" was made at the initiative of teachers with a view to better understanding of children with very special handicaps. Initially it was not the children who wanted to show what they contained (they hardly knew themselves), it was the adults who wanted to know on what to base their training/teaching.

The spellers are primarily adults, they are the ones who wish to communicate with the outside world now that they have discovered the possibility.

Page 62: **Luria.**

When the hidden knowledge debate was at its height no one thought along Luria-lines. One does to-day so that both "the spellers" and "the knowledgehiders" can now be explained/justified based on his theory.

Based on Luria's theory "the knowledgehiders" as well as he spelling nonspeaking people are supposed to have an impressive vocabulary which is completely intact (block2), i.e. there is nothing wrong with the inward going part of the brain.



Page 64: Finally I should like to quote Axel Arnfred: "We ought to develop training methods which give the personnel in the group an insight, openness and ability to act that make the pupils feel they are understood and respected and that they are being supported in a way which they can use".

Results from work with spelling boards should be made public.

I was delighted to read the above article by Judith Betak in "Berlingske Tidende" (conservative daily Danish newspaper) on 16th February 1998.

"Communication: The national association LEV is sympathetic towards the teachers' continued use of the severely criticised spelling boards. The results should be re-evaluated maintains the association.

The national association LEV is pleased that the teachers in the "Aktivitetscentret" (the centre for activity) at Ishøj has continued using the much discussed spelling boards.

"We are sorry at the turn of events the discussion about spelling boards took earlier on. The fact that matters of incest were effectively ensured that it was impossible to examine what possibilities spelling boards may or may not have had.

And the investigation, which was subsequently conducted, was anything but scientific", according to **John Møller**, director of Landsforeningen LEV, as the association for the wellbeing of mentally handicapped is called to-day.

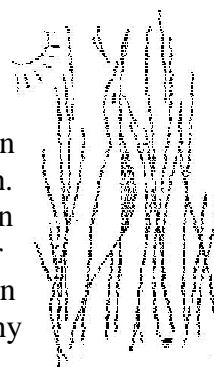
"But worst of all, the investigation made the spelling boards invidious. We have heard from parents who felt ill at ease when they used spelling boards in public to communicate", says John Møller

Also **Jette Lundgard**, who is in charge of the "Aktivitetscentret" at Ishøj, knows the attitude well which is why the teachers at the centre do not publish the fact that they continue to use the spelling boards.

"We are very pleased indeed that the teachers continue to use them. There are quite a few of us who are interested in the spelling boards. We meet regularly to discuss the matter and we have heard of many good results. I am sure that "Aktivitetscentret" at Ishøj also has many positive results, and it would be very good for all concerned if the institution now brought forward their results so that the matter can be demystified", says John Møller."

Considerations year 2000

In December 1998 **Pia Bentsen** (preciously at the "M-house") stated: "It is strange (but wonderful!) that nobody questions the educational communication work that is being done with many quite small multi-handicapped children. Everybody seems to accept that these children "understand" and can/will learn other forms of education than the verbal form. I will be interesting to see whether the future for these children will be easier than it was for the adults who only late in life were "taken seriously" after having been considered stupid, dumb etc. for many years".



We know:

"that based on our qualifications and conditions we have all done our best".

We know:

"that things take time".

Nevertheless I think it would be a good idea to ponder Pia Bentsen's comments.

As Maurits Eijendaal, the head of Sølund, pointed out after having read my report: "It is important that we look at the inhabitants as

people with a handicap

and not as handicapped people".

Precise use of language, concepts and ideas are important for positive development of our teaching practices.

When, to make it easier for ourselves and each other, we use the term nonverbal, we should be quite aware that in reality we are talking of

people who are not able to speak

a handicap for which management, teachers and psychologists together should try to find methods which will assist these people, make their lives easier. Supported communication, FC, may be an excellent tool.

Meanwhilde I got a personal contact to **Maureen Pilvang** through my work with "What Sølund taught me". This contact has resulted in a wealth of correspondence on experience and intellectual contemplations in relation to FC.

At the same time I made contact to Lasse Herbst, Pia Bentzen, Jette Lundgaard who all three have a comprehensive theoretical background and practical knowledge of FC as they have functioned as helpers. It appeared that they as well as Maureen and I wished to promote own and other's FC-experiences and to make these apparent/known to others. With this background it therefore became

quite natural to start an interest group with the view to tell about the methodical experiences one has had in U.S.A. and in Australia, which include the possibility of decrease and elimination of physical support.

This is why it is a great pleasure for me here in May 2000 to be able to finish of "What Sølund taught me" with a reference to FC2000's e-mail and homepage address:

E-mail: fcgruppen@fc2000.dk

Homepage: www.fc2000.dk

Warm regards

Grete Obel

May 2000

