

# Facilitated Communication in Denmark

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## The Historical Development and the Present Situation in Denmark.

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Having been involved with all degrees of autism and other related communication and developmental disorders for nearly 35 years as a special teacher, I find it interesting to follow the development of teaching methods and special interventions. Seeing things partly from a teaching point of view, I find it important to include the knowledge and experience of daily life, when discussing different treatment interventions and teaching methods for people with special needs. I find it of great importance to look at, which methods work with the individual child or adult I am involved with. This is why I know that facilitated communication is such an important method to have available when needed.

### Abstract

Facilitated communication is a method to help nonverbal people, with presumed low IQ and lack of pointing ability, to be able to communicate with others. Facilitated communication is a necessary access strategy for some people, as people who do not speak still have something to say. The method was discovered in different parts of the world more or less simultaneously. In Denmark facilitated communication was originally called “hidden knowledge” and later on “assisted communication”. The first term, “hidden knowledge”, was misleading, as it indicated that people on purpose did not communicate, which of course is not so. The disability, not being able to communicate without facilitation, is today recognized as being a neuro-motor problem, which in some cases and to some extent can be remedied by training. This training is today called facilitated communication training.

### The Early Danish History of Facilitated Communication

Facilitated communication has been used in Denmark for a long time, before the method had a name. The method can be traced back to Sofie Madsen, who established a children's home called Himmelev Børnehjem (children's home) in 1920. She concentrated her efforts on children with special needs, especially children whom we today would have diagnosed as children with autism. Sofie Madsen had a special way with these children, and parents were happy to have their children in her care.

In 1962 Else Hansen approached Sofie Madsen, because she wanted help with her own child, and for a period she worked together with Sofie Madsen as a teacher. This inspired her to establish the first special school for children with autism in

Denmark (at that time these children were called “psychotic children”). Else Hansen's school was founded in 1963 and was named Sofieskolen. These two women were the pioneers in dealing with and teaching children with autism in Denmark. Else Hansen also initiated the idea of finding all children with autism in Denmark, so they could receive the type of education that they needed. In 1969 a committee, named “Psykoseudvalget” was set up under the Ministry for Social Affairs to deal with the research of finding out how many children within the state-institutions for children with mental retardation were psychotic (autistic) at that time. Else Hansen was a member of the committee. Psychologist Demetrious Haracopos and psychiatrist Anders Kelstrup were appointed by the committee to do the actual research analysis and to write a report. They travelled around Denmark together with the committee to visit all the state-institutions for people with mental retardation and the results of the research was finally published in 1975 as a book: “Psykotisk Adfærd” (Autistic Behaviour). This book was important inspiration for many professionals for a long time, and some still consider the book of great value. Else Hansen was among those testing the children with a test called “Færdighedsprøven”, based on basic knowledge and skills specifically developed for the research project with the view to reveal the individual child's knowledge and abilities.

Else had in her teaching discovered that the children, also those who did not have a spoken language, were able to show or point at requested pictures, objects, sentences, letters etc. after having been encouraged by prompting or a slight touch by the adult, with other words the children were facilitated. The children, who responded to this approach, were mostly those, who at that time were referred to as being low functioning intellectually as well as practically, those who when tested traditionally were given a very low IQ and often diagnosed as being imbecile. The IQ levels had earlier been based on testing without the children necessarily having a way of communicating, so the traditional testing had not helped to find the children's level of comprehension and cognition.

### **My First Experience of Facilitation**

My first experience of facilitation goes back to 1968/69 where Else Hansen the headmistress of Sofieskolen, taught us young teachers how to teach pupils with autism to write. The method was used in those cases, where a child could not initiate writing by him self. She taught us how to start facilitating at the hand and gradually move up wards along the child's arm to the shoulder eventually fading out completely. Facilitation was also useful, when teaching children with autism other things like getting dressed, doing puzzles, drawing, tying shoelaces etc. if they could not initiate the activity themselves. Moving a child's hands through motions of an activity or skill was a method, which was also known to be used by parents of normal young children, so it seemed quite a natural approach.

These observations were more or less simultaneously described in three different parts of the world, by Lorna Wing (England), Else Hansen (Denmark), and Rosalind Oppenheim (USA) as a possible method of teaching children with autism. Interestingly enough all three women are mothers of children with autism, who

dedicated their lives professionally to try and make life easier for people with autism.

### **Experience in America that Correlates with the Early Danish Experience of Facilitated Communication**

The book "Effective Teaching Methods of Autistic Children" by Rosalind Oppenheim was published in 1974, where she describes her work from the fifties and onwards. She established the Rimland School in Illinois, based on her experience of teaching her own son with autism. Oppenheim taught children with autism without speech. The facilitating method she used was similar to Else Hansen's. The children were taught how to write, so they specifically had a means of communicating in full sentences. In relation to her description of teaching writing Oppenheim writes:

"We find that it is necessary to guide the child's writing hand for a considerable period of time. Gradually, however, we are able to fade this to a mere touch of a finger on the child's writing hand... ultimately however, the finger-touching can be eliminated, and the child does the writing without it, although some children want the touch of a finger on some other bodily surface, such as the head, in order to write." Her school had great success in teaching these children, who became capable of communicating through the written language.

### **"Hidden Knowledge" / Children with "Knowledge Hiding" Behaviour**

The result of the Danish research and the book "Psykotisk Adfærd" (Autistic Behaviour) put focus on a lot of children with special needs, so at this point we were not only talking about children with autism, but also about children described as mentally retarded with possible autistic behaviour.

This facilitating approach was named "hidden knowledge" in the early seventies in Denmark. One talked about the importance of finding the "mainland" or the "islands" of the child's abilities, so that one could find the right level of teaching and make sure of stimulating these abilities. This approach was a success until it was blown up in the media. The approach got out of hand among professionals as well as journalists, and at some point nobody dared talk about the matter any longer.

People misunderstood each other, there were pros and cons, and the approach gradually faded out. The method was torn apart, which was very sad both for the children, who had benefited from the method, as well as for parents and professionals. However some result came out of it: the level of expectation in special education had been lifted to a higher level, both as far as children with autism as well as children with mental retardation were concerned, this in it self was a very positive outcome. It was sad that a teaching method could be twisted to such an extent, and it has not yet been discussed openly again. The intention and the process was constructive, and lots of children had benefited and still do, as far as their general functioning level is concerned.

The professional discussion was never reopened and stopped sometime between 1979 and 1982.

When the concept was introduced initially, it was not meant as an indication, that the children hid their knowledge on purpose. There was full agreement that the “knowledge hiding” behaviour was involuntary and caused by the disability, but at that time there was no theoretical explanation of, why some children could not show their skills, abilities and language comprehension without facilitation.

The term was originally: “Children with knowledge-hiding behaviour”, but accidentally a child psychiatrist A. Arnfred shortened the term in an article to make it easier to read, so it became “knowledge-hiding children”. This leads up to the beginning of the misunderstanding of the term and to the indication of the behaviour being deliberate, which had never been the intention, when the method was originally introduced.

You can read more about “hidden knowledge” in the article: “Intelligence and Cognition” by Brown and Pilvang (1976).

### **The Spellers**

In 1981 a new exciting period started. This was mainly to do with adults living in M-huset (a home for people who were diagnosed as being mentally retarded) and Ishøj Aktivitetscenter (a day center for people with varied disabilities often including lack of speech). People without speech, who earlier had been considered extremely intellectually impaired, started communicating on spelling-boards and typewriters. They proved to be able to communicate their thoughts, wishes and feelings when facilitated. They did so in written language by pointing at letters or typing, although many had not been taught to spell and read. Staff, parents and even the “spellers” were overwhelmed by the communication that happened. People, who had been violent, became easier to deal with, as they now had a way of telling, what they wanted to do and how they felt. They started to have an influence on their own lives, could tell what they wanted to eat, how to dress etc. The knowledge of the discovery spread around the country, the parent's organisation LEV supported the development and parents got very keen, when they discovered, that they could now communicate with their non-speaking child.

Rosemary Crossley came to Denmark to visit M-huset and to give advice on how to facilitate, as she herself had discovered facilitation in 1977, when teaching Ann McDonald in Australia to read and spell. This was the beginning of facilitation in Australia, as described in “Annie is coming out” by Rosemary Crossley. Rosemary is the present days worldwide pioneer of spreading knowledge about the FC-method. During this period many disabled people without speech got the chance of communicating in written language in Denmark. It helped many to express their thoughts, feelings and knowledge in general. The facilitated spelling communication appeared to function with many different types of disabilities and it was used in different parts of the country. The method became known as “assisted communication” (“støttet kommunikation”). Those who were facilitated were called “the spellers” (“staverne”).

During this exciting period a series of booklets (“Serie om kommunikation”) were published by Copenhagen County, and in this way the method of assisted communication became officially acknowledged. In the booklets you can read about

the method and thoughts behind the approach, as well as comments and poems written by the spellers themselves.

The media got involved initially in a positive way, but later unluckily there was an episode, where a speller indicated that she had been misused sexually, this got everybody going, so from being a great adventure, the spelling ended as the "hidden knowledge" debate, it was closed down and was even forbidden in some counties in Denmark. This meant that lots of spellers suddenly could not communicate any longer. Parents did not dare to use spelling boards publicly with their child, and staff could no longer feel free either. Neither staff nor parents felt free to tell about the adventure they had experienced, and the spellers became disillusioned.

A rushed and untenable investigation was initiated in 1990-1991, the spellers were tested and a report came out. The results were one-sided and did not take into account that these, disabled people without speech could not be tested in the ordinary way.

This resulted in some counties not wishing the method used, unless the parents insisted. This was when the FC-method officially stopped being used and acknowledged in Denmark. Since 1990/92 Facilitated communication has therefore not been used officially in Denmark, neither in institutions and special schools nor in homes except for a few individual cases. This you can read more about in the booklets, "Serie om kommunikation" no. 1-6.

The pressure to stop using the method has caused lots of grief and was a disaster for many people.

The spellers were not only people with autism, but also people with mental retardation, physically disabled people and people with Down's syndrome. What the spellers had in common was that they could not talk, were labelled with a low IQ and referred to as low functioning. The debate was now once more about, whether these people were able to understand and communicate, when they could not express themselves verbally. The method is still remembered by some, and a few parents and professionals still make use of the method in Denmark, but people do not talk about it, or if they do, then discretely.

### **The Present FC-Situation in Denmark**

Grete Obel, inspired by the original thoughts on "knowledge hiding behaviour", had in a quiet way (as described in "What Sølund taught me") been using the FC-method for 20 years in Århus Amt with disabled adults, who couldn't talk. Three years ago she tried to initiate an interest group of professionals, who had practical experience in using the method as well as theoretical knowledge of the FC-method. We were 4 who responded: Pia Bentsen, Jette Lundgaard, Lasse Herbst and Maureen Pilvang. We established ourselves as FC2000DK (facilitated communication 2000 Denmark), and decided that our aim would be to re-introduce facilitated communication in Denmark based on information from abroad, by collecting information and spreading knowledge and experience.

On the Internet our group found out that during the last 10-12 years the concept Facilitated Communication Training had been introduced internationally instead of Assisted Communication Training. We were thrilled to find lots of information on the Internet and to get in touch with FC-professionals, among others Rosemary Crossly at Deal in Australia and Professor Douglas Biklen at Syracuse University in New York. Douglas Biklen had his disbelief changed to belief after having been to see Rosemary Crossly work in Australia; he also visited the M-house and Ishøj Aktivitetscenter to learn. After having looked into the matter he became convinced of the effect of facilitated communication and has since then been a strong advocate of the method.

Biklen's documentation, based on his earlier scepticism, makes it easy for us to take up the method again here in Denmark. His scepticism has helped to verify the method. The method has proved a lot of successful results, and by this enhanced the quality of life for many people without speech. The newest results are, that some people, who have been facilitated for a long period, develop some speech.

Our group has established a formalized co-operation with LEV (the Danish National Association for people with learning disabilities), with the view to reintroduce the FC-method in Denmark, which we partially do through our web site. We are in the process of initiating pilot projects partly in a special school for children with learning difficulties and partly in a community for adults.

We have had some films translated into Danish and are having Rosemary Crossley's book "Facilitated Communication Training" translated as well. The translated FC-films are one of the ways we are reintroducing the FC-method in Denmark. With these films we are at the same time introducing some technical terms in conjunction with FC to be made use of in the Danish language.

The FC-films we have had translated are from Queensland and from Syracuse University.

Apart from the practical introductions of how to get going with the method, the Syracuse films are based on some people being facilitated over a long period of time. Finally the films show how some people becoming independent with their typing, this proves the method's authenticity and usefulness. So I see the Syracuse films as verification of facilitated communication training.

Going back to my introduction of the importance of looking at different treatment interventions and teaching methods, I will finish off my account with the following comment: Communication is a human right and must be offered to every human being. This is why FC is necessary in some cases, when other approaches do not seem to succeed.

I will finish the proceeding with this beautiful poem written by Sharisa Joy Kockmeister, who has been helped tremendously by facilitated communication. The poem sheds light on the feelings of a person in need of facilitated communication:

FC is like a lifeline  
For those who cannot speak,  
It enables us to start to find  
The answers that we seek.

A voice for giving meaning  
To our inner thoughts and dreams,  
For showing other people  
That not all is as it seems.

FC is not a miracle,  
A simple kind of thing.  
It's more like giving freedom  
To a heart that yearns to sing.

FC is an oasis  
In a desert long and wide,  
A healing drink of water  
For the dryness deep inside.

I was so sad and lonely,  
Empty as can be,  
Until my mind was opened  
By this very special key.

Now the light and sound within  
Are there for all to see.  
I have been given something  
That brings meaning out of me –  
Something very special called FC.

Rosemary Crossley summed up in her talk on epistemology at Isaac 2002, that the validation issues of a new method or strategy go through certain phases:

Unsystematic intervention  
Introduction of new communication system  
Positive community response  
Negative professional reactions  
Battle for “truth” and acceptance

I am inclined to agree with her, as it seems to be what has been happening to facilitated communication in Denmark.

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## Terminology

Facilitated communication (FC): an assistive communication technique in which the primary message receiver makes physical contact with the aid user to help overcome motor or emotional problems i.e. poor muscle tone or lack of confidence. The message sender is solely responsible for the direction of movement. (Crossley.1994)

Facilitated communication training (FCT): is a strategy for teaching people with severe communication disabilities to point and to use communication aids with their hands.

The aid user is helped by a facilitator to overcome physical problems and develop functional motor patterns. The training aims towards the aid user getting as independent as possible.

Facilitator: the helper who initially uses his hand(s) to support or inhibit the aid user and later might just have to sit by the aid user giving "moral support".

Facilitation: the support given by the facilitator. The facilitator facilitates the aid user.

Fading: gradually reducing the amount of facilitation.

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