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# CAN THE FACILITATED COMMUNICATION METHOD SUPPORT AUTISTIC PEOPLE, ACCORDING TO FACILITATORS' OPINIONS?

AAC practitioners and researchers have developed non-speech communication strategies and technology greatly during the past 30 years. This article concentrates on one of them: the Facilitated Communication Method. The aim of this research is to describe the facilitated communication method in the light of the perceptions and experiences of facilitators (N= 11) who have assisted handicapped people with expressing themselves with this method. The purpose is to bring out the use of the method, its preconditions and functionality, especially among autistic people. The data was gathered by semi-structured interviews. The research was based on a qualitative research paradigm with a phenomenographic method. The results show that no common formula for how to make the facilitated communication method succeed can be found, because every communication situation is different. However, the method aids many people with communication disabilities who are searching for a communication method that supports speech replacement.

Key words: facilitated communication, autism, facilitation, facilitator, AAC methods

## Introduction

In this study, we examined facilitators' perceptions on the facilitated communication method. Facilitated communication belongs to augmentative and alternative communication (AAC) techniques aiming to maximize the user's communicative competence in both receptive and expressive communication. It is a strategy for training and teaching individuals with severe communication impairment to use communication aids mostly with their hands. In facilitated communication a training partner, often called a facilitator, helps the communication aid user overcome

physical problems. In this way, the aid user's functional movement patterns also develop. Facilitation is also used when necessary to assist individuals accessing symbol and picture boards, or choosing from real objects, such as toys (Crossley, 1994, pp. 3-6).

This technique has been surrounded by a debate in the broad field of rehabilitation and education in the last decade. The controversy and ongoing debate focuses on the validity of facilitated communication, primarily because of the authorship question.

Examination of facilitators' perceptions on the facilitated communication method is a new dimension in the discourse concerning this method. It has been emphasized that facilitated communication requires research in which the complexity of the very nature of the communication process, the competence of those with autism, and the method's effectiveness is considered (Duchan, 1993).

In this study, the facilitators (11) are conceived as people who have assisted people with severe communication problems (the handicapped) to express themselves with the method of facilitated communication in their work or in their family contexts. Some of the assisted people had significant motor impairments as well. Assistants are usually called facilitators, and this is the name we use.

AAC practitioners and researchers have made a lot of progress in non-speech communication strategies and technology during the past 30 years. There is still a substantial number of individuals, especially among people with autism spectrum disorders, who have not yet achieved functional communication with any available system (Crossley, 1994, p. 3; Mirenda, 2008). According to Crossley (1994, p. 3), some of these people may be helped by facilitated communication training.

#### Theoretical framework

The facilitated communication approach was developed by Rosemary Crossley, an Australian educator. According to Crossley, facilitated communication has been used occasionally with people with autism since the 1960s (Crossley, 1994, p. 5). This was a long time before the method became known as facilitated communication. Almost at the same time, physical support has been tried out by Crossley in Australia, Oppenheim in California, and Hansen and Arnfred in Denmark (Pilvang, 2002). Hansen was the pioneer and pathfinder in Nordic education of autism (Haracopos, 1988). At the same time, the method has been found and used with a few individuals also in Canada, Sweden, and the United States (Kärnä-Lin, 2003; Bogdashina, 2004, p. 236).

Crossley used the method in the 1970s when working among people with cerebral palsy and referred to it as a training program. The development of this training program was stimulated by the opening of DEAL, a center financed by the state in 1986. DEAL was Australia's first center devoted solely to the needs of individuals with severe communication impairments not caused by deafness. 95 % (636) of the

clients of that center were labeled as either intellectually impaired or autistic or both from 1986 to 1990 (Crossley, 1994, p. 5; Kärnä-Lin, 1995, p. 7).

In all the countries where facilitated communication has been discussed and used the response has been controversial. This is primarily because of the authorship question. That includes the question whether the assisted person is typing the message or the assistant. Numerous studies and articles have attempted to investigate this question by using various research approaches. Many of them indicate that assisted persons are influenced by their assistants when composing messages and the assistants do not realize this. Therefore, a lot of published articles raise serious doubts concerning authorship and physical assistance. Many of them use quantitative methods as the research framework (see Eberlin, McConnachie, Ibel & Volpe, 1993; Hudson, Melita & Arnold, 1993; Moore ym, 1993; Szempruch & Jacobson, 1993; Cabay, 1994; Regal, Rooney & Wandas, 1994; Shane & Kearns, 1994; Bebko, Perry & Bryson, 1996; Bomba et al., 1996; Simon, Whitehair & Toll, 1996; Kerrin & Murdock, 1998; Mostert, 2001; Saloviita & Sariola, 2003; Ojalammi & Leppänen, 2005).

In spite of disagreements regarding facilitated communication, there is no evidence or documentation to argue that all use of the facilitated communication method should be avoided. We need more both experimental and phenomenological rigorous research to understand the process of facilitated communication (Biklen, 1990; Duchan, 1995; Horner, 1994; Silliman, 1995).

The role and task of an assistant or facilitator is very important and should be researched. The influence of a facilitator should be tested from time to time. The test could be formal, but also informal, such as having a facilitator ask an assistee to talk about his/her weekend, morning or evening. After that the facilitator could confirm the facts. The results of these personal experiences will hold the real future of this method (Horner, 1994). A number of studies have demonstrated that assisted people could pass on their messages using facilitated communication. Reaching this goal often requires plenty of practice over time, a variety of tasks, practical and emotional support, and assistees' personal goal setting as well (Marcus & Shevin, 1997; Olney, 1997).

Thus, there are articles that have reported data supporting the use of facilitated communication (see Biklen, 1990, 1991, 1993; Kärnä-Lin, 1993; Sabin & Donellan, 1993; Crossley, 1994; Janzen-Wilde et al., 1995; Kärnä-Lin, 1995; Sheehan & Matuozzi, 1996; Biklen et al., 1997; Cardinal, Hanson & Wakeman, 1996; Marcus & Shevin, 1997; Olney, 1997; Basler-Eggen, 2000; Otter & Masefield, 2001; Niemi & Kärnä-Lin, 2002; Kärnä-Lin, 2003; Niemi & Kärnä-Lin, 2003a; Tuzzi et al., 2004; Biklen, 2005a, 2005b; Kärnä-Lin, 2005). The linguistic structure produced by an assistee who communicates by facilitated communication has also been examined. The language has unique characteristics compared to the language of the assistants. The atypical characteristics of the facilitated texts were similar, regardless of the time or the assistant (Niemi & Kärnä-Lin, 2002). Tuzzi et al. (2004) have also aimed to identify

the characteristic features of the language produced by facilitated communication. The subjects were autistic and these results showed that they used a special style of writing with the sparing use of words: unusual terms were used, short phrases were preferred, and they talked about emotions, intentions and feelings. The existence of lexis and distributional patterns of grammatical categories are characteristic of this written production of individuals with autism (Tuzzi et al., 2004; Tuzzi, 2009).

In addition to scientific research, there also exists documentation regarding people who have been linked to this discussion. They have learned to type messages independently but still need their assistants near them (see Biklen, 1990, 1991, 1993; Kärnä-Lin, 1993; Sabin & Donellan, 1993; Crossley, 1994; Janzen-Wilde, 1995; Kärnä-Lin, 1995; Sheehan & Matuozzi, 1996; Biklen et al., 1997; Cardinal, Hanson & Wakeman, 1996; Marcus & Shevin, 1997; Olney, 1997; Basler-Eggen, 2000; Attwood, 2001; Blackman, 2001; Otter & Masefield, 2001; Niemi & Kärnä-Lin, 2002; Kärnä-Lin, 2003; Niemi & Kärnä-Lin, 2003a; Tuzzi et al., 2004; Biklen, 2005b; Kärnä-Lin, 2005; Kontu & Rämä, 2006; Sajaniemi, 2007; Mirenda, 2008; Iversen, 2006).

Also those people who are labeled as having significant and severe intellectual disability can develop high-level language skills and can learn to read, spell and write. Such people who have gained publicity include Sharisa Kochmeister (1994), Sue Rubin, Tito Mukhopadhyay and Lucy Blackman.

At age 7 and 12, Rubin achieved intelligence and adaptive behavior scores placing her in the 1- to 3-year "mental age" range. She was considered to have both autism and a severe intellectual disability. She engaged in severe self-injurious, aggressive and self-stimulatory behaviors as many people belonging to the autism spectrum often have. Rubin began to communicate using FC at age 13. With time, she took a full load of academic classes in high school and became a disability rights activist and keynote speaker at many disability conferences (Biklen, 2005a, pp. 80-81). She was also featured in a 2004 documentary entitled *Autism Is a World* that was nominated for an Academy Award (Wurzburg, 2004).

Mukhopadhyay, who is from India, has written the books *Beyond the Silence: My Life, the World and Autism* and *The Mind Tree.* In spite of his high-quality writing, Mukhopadhyay has plenty of very difficult behavior problems that restrict his life (Biklen, 2005b, pp. 110-143; Iversen, 2006).

Developing into an independent writer without an assistant's physical support takes a long time. For Blackman, it took nine years (Otter & Masefield, 2001). Blackman has written a book about her life (*Lucy's Story, Autism and Other Adventures*). Her behavior has the features of classical autism and she has done her BA (Hons) in literature at Deakin University in Geelong (Attwood, 2001; Blackman, 2001).

# Research questions

The aim of this research is to describe the facilitated communication method in the light of the perceptions of facilitators who use it. The purpose is to bring out

the perceptions about the use of the method, its preconditions, and the functionality of people who have experience with this aid as well as to describe the meanings given to this phenomenon by this group of facilitators that is considered here as a group of experts.

The following research questions are set for this research:

- 1. What kind of ethical values guide the facilitators' use of the facilitated communication method?
- 2. How do the facilitators describe the construction of the interactional relationship with the assistees provided by the facilitated communication method?
- 3. What has to be taken into consideration when practicing the facilitated communication method, according to the facilitators?

### Data

In this study, the data was gathered by interviews. The interviewed participants were facilitators (11) conceived as people who have assisted handicapped people with expressing themselves with the method of facilitated communication in their work or in their family contexts. Three (3) of the participants were the assisted persons' parents and eight (8) of them worked in the field of education, rehabilitation or therapy. The study was carried out by interviewing the facilitators, twice each. The first interviews took place in 2000 and the second ones seven years later, in 2007.

In 2000, the number of assisted people was thirty (30). All the individuals that our participants had assisted had severe communication problems. Apart from communication problems, some of the assistees also had significant motor impairments. Except for two assistees, all of them had autistic features or they had been diagnosed as affected by ASD (= autism spectrum disorders). At the time the facilitators started to use the facilitated communication method, the assistees were aged between 5 and 25 years.

The facilitators who were interviewed in this research lived in different parts of Finland, at distances from one another of 800 kilometers at best. They were selected and asked to participate in the research with the help of work and study contacts. All of them were willing to participate in the research. We contacted them in work situations or by phone. We met three (3) of them for the first time in the interview situation. With the others (8), we had discussed the facilitated communication phenomenon before the interview.

#### Research method

The study is based on a qualitative research paradigm and attempts to understand the world from the points of view of the subjects. In this paradigm, one of the basic goals is to use the same terms that the subjects use (Denzin & Lincoln, 1998, p. 3).

The form of the study was phenomenographic. As a research approach, phenomenography occupies a space somewhere between natural science and traditional social sciences (Marton, 1986, p. 32). There has been an abundant discussion among researchers in which the methodological concepts of phenomenography have been considered. It has covered the paradigm, research approach, research method, methodology, framework and also methods of analysis. According to Marton and Booth, there are methodological elements associated with phenomenography although it is not a method itself. Furthermore, it is not merely a theory of experience although there are theoretical elements derived from it. Rather, phenomenography is a way of or an approach to identifying, formulating and tackling certain kinds of research questions (Marton & Booth, 1997, p. 111). Phenomenography does not give strict and structured guidelines for analysis, and because of that it can be considered a research approach (Uljens, 1991, p. 89).

The main focus of phenomenographic studies is to address the content of thinking. Phenomenography is interested in the qualitatively different ways in which people experience, conceptualize, perceive and understand various aspects of the world around them. People are seen as the bearers of different ways of experiencing various phenomena (Marton, 1986, p. 32; Marton & Booth, 1997, p. 115; Niikko, 2003, p. 20).

In phenomenographic studies, the most usual way of bringing out people's perceptions and experiences is an interview as a form of data collection (Marton, 1986, p. 42; Marton & Booth, 1997, p. 132). In an interview conversation, a researcher learns about the interviewees' points of view by listening to them telling about their lived world. The research interview attempts to understand the world from the points of view of the research subjects and to uncover their lived world prior to scientific language and explanations (Kvale, 1996, pp. 1-2; Robson, 1993, p. 227).

What questions are asked and how this is done, are very important aspects of the method. An interview is always a social interaction and the interpersonal relation of the interview situation is at the focus of this investigation. One of the main aims is to maintain an understandable discussion and to support the interviewee so that it is possible for him/her to express himself/herself in a way he/she is willing to.

In this study, we gathered information by semi-structured interview. This can be located somewhere between thematic and open interview. Like open interviews, our interviews were as open and natural as possible. This was very important especially because of the delicacy and confidentiality of our subject, facilitated communication. In connection with the interview themes (see below), there was plenty of room for the subjects to express their experiences, feelings, memories, opinions, reasons and justifications. Therefore, the research interviews turned into discussions and dialogues about other things connected to facilitated communication and that the interviewer asked about (Kvale & Brinkman, 2009, pp. 84-88).

# **Analysis**

In the first phase of the analyzing process, the interviews were written down verbatim. The transcript comprised 263 sheets in total. Then the interviews were read carefully and during the whole process the aim was to distinguish the participants' opinions. At the same time, the units of analysis were chosen. The unit of analysis is the content of a thought or idea and it could be a part of a sentence, the whole sentence, many sentences or a statement. During this process, we were searching for important expressions and clustering them as well.

After that, we re-clustered the important expressions and searched for significant utterances and expressions. In this phase of the process, the data was analyzed as a whole, not interview by interview. During this analysis, we also searched for similarities, differences and borderline cases among the significant expressions.

In 2007, we contacted the participants and asked if they wanted to continue participating in this research. Everybody was willing to participate. Therefore, contextualization took place, interview by interview. Every participant read our interpretation of his/her intensions. This interpretation was the first analysis for each interview with the adaptation of preliminary categories. After that, we complemented the material with the help of the control of interviewees. This contact was made by phone and two of the participants also added material by e-mail.

Then, the second interviews took place and they were also controlled by the interviewees afterwards. This completion was made by phone and e-mail. The last analyzing phase was to sharpen the main categories and subcategories. Finally, the specific contents of the subcategories that made them lucid were found.

#### Results

In this article, we illustrate one of the main results included in the category of individuality of facilitated communication. When people use facilitated communication as a method for communication, every situation is individual. Every session is a unique moment between the facilitator and the assistee.

#### The ethics of facilitated communication

The ethics of facilitated communication formed the basis for the facilitators' work. Ethical principles emerged in many different aspects of the interviews. The ethics is divided into five elements according to the perceptions of the facilitators interviewed. These elements are the value of facilitation, abstaining from publicity, confidence, suspicions and defending factors.

# Value of facilitation

The basis of the work of a facilitator is focused on the most original and exhaustive question of ethics: the question of what kind of life is a good life to live

(Lindqvist, 1985, p. 38). According to the interviewed facilitators, facilitated communication supported the good life of the people with whom they used the method. The facilitators' perception was that there was ethical dignity and importance every time there emerged possibilities to communicate.

...I think it would be a very good thing that everybody could communicate in some way, the method can be facilitated communication or whatever else... (Line 5205, F)

...I think, however, that it would be an extremely good thing if all people had a means to communicate; although it was facilitated. (Line 5205, F)

The facilitators were open to all alternative and augmentative communication (AAC) methods. The communication of the assisted people also included other things than facilitated communication. Many kinds of pictures, symbols, signs, speech, written words and expressions as well as gestures were used.

We do have... other pictures too, photographs and then also signs to support speech and some objects as well. (Line 1742, B)

In addressing ethical dilemmas, the theory that was the most familiar to the people working in the field of special education might be called *meaningful choice*. This is not a dilemma of being right but being responsible (Paul et al., 2001). The Finnish Association of Speech Therapists issued a statement about ethics and facilitated communication training in 1996, 2000 and 2004. This statement addresses responsibility and meaningful choice and points out that a therapist has to inform the client that there are contradictory concepts of this technique. If facilitated communication is used in rehabilitation as a method of communication, it has to be done with the client's consent (Launonen, 2005). Launonen emphasizes that a therapist who uses facilitated communication has to familiarize herself/himself with this technique and on the other hand, with the content of the debate surrounding it. It is everybody's responsibility to make choices by using the best knowledge and experience they have (Launonen, 2005). The facilitators interviewed in this study had expressed their opinion by choosing to work with the facilitated communication technique.

Two of the eleven interviewed facilitators did not have any knowledge about the technique when they started to use physical facilitation and realized the benefits for the assistees. Later on they found the name of the technique and information about it. All the interviewed people had knowledge about and experience of the technique and they knew about the controversy, suspicions and study results.

Ethical issues are concerned with what is valuable and what has to be done (Airaksinen & Kuusela, 1989, p. 29). The interviewed people had made their decision to use facilitated communication. This decision involved these facilitators' real values. The cornerstone of their work was the assistees' individual needs

and functional skills as well as the aim to support the assistees' development (see Räsänen 1993, p. 186).

# Abstaining from publicity

The facilitators were working with their assistees and people near them. They had decided not to participate in the public debate on facilitated communication. They had made this decision because they did not want to expose their assistees to public evaluation or criticism. When thinking about ethics, this argument refers to "the things not to do" (Airaksinen & Kuusela, 1989, p. 29).

At that time, I thought that I was the wrong person for it... to defend this method. And to defend anything... as the aforementioned pupils and their families are involved in this too... (Line 509, B)

# Confidence between an assisted person and a facilitator

According to the facilitators, the absolute and strict basis of their work with the facilitated communication method was a confidential and respectful attitude towards the assistees. Conveying confidence to the assistee is an important thing when starting to use facilitated communication (Biklen, 1993, pp. 196-197; Kerola & Kujanpää, 2000, p. 45). The facilitators thought that this situation had to be mutual, as also the assistees had to respect the facilitators.

It is so that there has to be some kind of confidence and it can be used somehow successfully..." (Line 5807, G)

In order to make the facilitation succeed, the belief in an assistee and his/her possibilities is of primary importance.

...and I also think that if I don't believe in it, it will be difficult to make other people believe or show their talents (Line 4816, F)

The assistees were sensitive to a doubtful attitude and atmosphere. When sensing this, they could totally refuse to communicate.

They sense your doubts. And then they won't do anything at all. (Line 7125, H).

# Suspicions regarding the method

The facilitators were perfectly aware that there were plenty of doubts and controversy regarding facilitated communication as well as contradictory scientific results. They thought such controversy and emotional attitudes towards the method were natural. Sometimes, they also wondered about the knowledge and practical experience of the people who were very negative about the method.

 $\dots$  but there is not a thing in the world of which all the people would think in the same way... (Line 492, B)

The facilitators thought it was not easy to see who was leading the movement in facilitated communication when the facilitation was very strong in the assistees' hand or palm.

When you are looking at facilitation you just cannot say who is the leader... (Line 6766, H)

And there is also that thing that if you look at facilitation... it looks just different than it is. It looks as if the assistant is leading the assistees' hand. (Line 493, B)

The facilitators said they felt the movement of the assistee when they were using the method.

 $\dots$  I am really resisting the assistee's hand movement and the boy is just leading his hand to the point he wants himself... (Line 5210, F)

The assistees were also very willing to enter the communication situation. Therefore, it was clear that they showed a need to communicate and this was a good incentive to use the method even though it was a slow method.

And that too... I don't believe that they would come so willingly and just force their way into the situation... and be there such a long time... never... (Line 664, B)

Moments of suspicion were part of the work. Starting to use facilitated communication sometimes took a long time. Sometimes, the assistees could not start the movement fluently. This made the facilitators uncertain. After assisting the same assistee several times, the facilitators found it easy for the assistee to communicate with the method. This brought certainty to their work as a facilitator.

On a good day, you can sense that their own will is present and the hand really moves... (Line 5402, G)

# Supporting the method

The facilitators saw many positive changes taking place in their assistees' lives. They thought those changes were linked to the use of facilitated communication. For example, the cheerfulness of one assistee had returned at the same time he could use the method and be communicative.

... he was very cheerful when he was a baby but when the autistic features became stronger he became so very sad without any smile on his face.... When

the communication possibilities became better his cheerfulness came back again... (line 6025, H)

The behavior of many assistees became more controlled and the amount of challenging behavior became smaller at the same time they began using the method. Niemi and Kärnä-Lin (2002) have reached the same conclusion.

He was always swinging the doors and many times he had his fingers between the hinges....the boy was a real poet and he stopped swinging and banging doors just after the time he could say his thoughts out. (Line 1721, A)

The facilitators also thought that with time, assistees became more mature in a natural way. Thus, other things than just communication were also affected.

Using the method was helpful in many normal life situations. It was possible to ask things they did not know and so the answers made them more tranquil and controlled. They could also handle difficult situations and distress in a new way by using the method to communicate.

When he was just distressed and his behavior was very challenging and then he, for example, asked with whom he would go shopping or eating.... then he heard the answers and he just became calm and controlled... (Line 2070, A)

Because of facilitated communication, the assistees could be involved in ordinary life by communicating their opinions and hopes. This was a new dimension in their lives. Looking in the context of rehabilitation, this is a modern and ethical ideal value addressing customer-orientated action and quality of life (see Järvikoski & Härkäpää, 2008, p. 53).

So, we were shopping and wanted to buy shoes for him... I first chose them and asked the shop assistant to give me some paper and a pen... I wrote if the shoes were good or bad, if we should take them or not ... and I assisted him a bit and so he could choose the shoes he wanted... (Line 9083, 7)

Once he wanted to introduce our family... I asked if he wanted to introduce himself... he nodded and introduced the whole family too... (Line 8586, I)

# Interaction between a facilitator and an assisted person

When the facilitators spoke about their perceptions of the facilitated communication method, building an interaction between the assistant and the assistee seemed salient. It is hard to define the development of an interaction between two people in a distinct way. It has been compared with, for example, a house meant to be built together. Both parties have plenty of materials for the house and they have to adjust these together.

The beginning of practicing the method was considered in terms of experimentation with just one way of communication. It was supposedly expected to function well but it could turn out to be unworkable as well. Therefore, it was considered understandable that the method might have failed.

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Well, I'll try and so what if it doesn't work... (Line 8011,1) ...so that you have to have that attitude, you know, be willing to try. (Line 8005,1)
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#### Non-verbal interaction

Creating an interactional relationship between facilitator and assistee started already before the facilitated communication method was tried and used. The basic material for constructing this relationship was listening to the assistee and sensing as well as observing his/her action.

Before using the facilitated communication method, I consider the creation of non-verbal interaction between a child and an adult of primary importance. One has to "listen to" a child by sensing, observing his/her action. (Email, C)

They did not have any directions or a manual for this work. The prerequisite for the method and interaction it demanded was the thought of a facilitator having sufficient readiness and ability for physical contact. At the beginning, in order to create the interaction a great deal of physical support by the facilitators was needed but reducing it was regarded as an important aim.

# Changing communication needs

Interaction had to be taken care of during the whole process of practicing facilitated communication. The facilitators learnt to notice the assistees' changing communicative needs in different situations and times. How easy it was for a facilitator and an assistee to get along with each other could vary from time to time, but mutual trust was regarded as the fundamental element in their interaction. Cooperation between home and other educators who worked with the assistees was considered important for widening their perceptions. Shared positive experiences enhanced development.

...So whether there was something that Jesse noticed that we sort of...collaborated for his good... So that there was a great difference in that in the next week in other activities as well and not just in this FC. (Line 4799)

The learning possibilities of the assistees who used facilitated communication were hard or even impossible to define beforehand. The interviewees thought that they had not even defined the limits of the assistees' ability to learn in their mind but instead they offered the assistees an opportunity to train themselves in

interaction with the facilitators. Some of the assistees had to be almost forced to learn new things but even then maintaining a positive atmosphere was important.

# Compulsion and freedom

On the one hand, pedagogical interaction is about pursuing mutual understanding, while on the other hand it is about issues of exercise of power, freedom and compulsion. It is a constant maneuvering between striving for the exercise of power, the inevitability of compulsion and giving freedom (Latomaa, 1994, p. 70). This was also the question in the interactional relationship between the facilitators and assistees. Pedagogical virtuosity was tested. One had to recognize the limit of one's demands that defied a child's abilities in various situations.

So in that way he thinks about things and is able with words, these thoughts with words, to bring them out with words; I have to compel him to write it..." (Line 9190, J) An adult has to have a certain kind of sensibility to receive the child's message and in every action things have to proceed on his/her terms. On the other hand, one has to be sure and brisk at guiding /demanding. An adult has to know the line (familiarity with the pupil!!) when a demand surpasses the child's abilities or when a fear is unbeatable. (Email, C)

Along with time, the interactional relationship between facilitator and assistee might change. This was considered as being typical of relationships between human beings.

But I think that it has always been in a human being's life that relationships change too. And we are not equally open to everyone whom we told about some serious matter years ago, either. It can and will change. It is... in my opinion, it is the same in facilitated communication... The relationships either develop or shrink. (Line 9488, 7)

Facilitation was seen as the facilitator's and the assistee's shared training process. In this case the facilitator, together with the assistee, looked for concrete ways to meet the assistee's growth and developmental needs as a user of the facilitated communication method.

When starting to use the facilitated communication method, plenty of concrete operation between facilitator and assistee was required in order to create interaction. One of the starting points for action was physical support given by the facilitator. Little by little, they pursued the goal of the assistee becoming independent so that he/she could be free of both physical and other support provided by the facilitator. The assistees' individualistic development was not straightforward, nor did it proceed in the same way in all the assistees. One assistant compared the first steps of gaining physical independence with learning how to ride a bike. Sometimes it

succeeded without physical support but the overall ability was not yet sufficient for total independence for a longer time.

In the above-mentioned situation, interaction is comparable to Vygotsky's (1978) zone of proximal development. A child solves problems with the support of an adult or a more mature friend in the interactional zone needed. A child's skills develop or sprout little by little (Vygotsky, 1978, p. 86). The child-environment system is reorganized constantly in a way that the interaction between people creates an individual's zone of proximal development. The next quotation illustrates the zone of proximal development and breaking away from it for a brief moment.

But momentarily like that – it is a little bit the same as riding a bike; that it goes but when he/she notices that okay, good, so this is it, then he/she would be like Hey, catch me! And that's the end of it. But it is just like riding a bike, so that when the adult is not supporting it, it's like oops! (Line 278, B.)

Specific situations when training in facilitated communication

Individual situations of training in facilitated communication were varied. Training falling into place was not obvious, nor is it possible to show a common formula for making it succeed. However, nine different situational factors occurred in communication and practicing it.

1) The facilitators' ability to control the situation included perceiving the situation beforehand, the way the situation was started as well as persistence in the work and overall control over the situation.

A sort of confident... grasp by the adult; that I know how this situation is controlled and now we will do it like this and there are no choices. (Line 3380-3384, C) Namely, he will try. He tests your nerves; first of all he will test your nerves. You know, how someone can tolerate this. And if he will, okay, let's try a little bit of this... and then it, you know, gets easier. What is that when he/she is sometimes difficult ... his being difficult has to be tolerated because he can't help it yet you know. (Line 7165,H)

2) The way the situation was started was crucial. The first step of practicing the situation was often learning to keep still.

...sometimes it requires more time to get this boy to sit and start and then there will be breaks... one word may come, one syllable at a time, and sometimes, more words come... (Line 1670, A)

Starting to use this method could be troublesome with some assistees although they had used the method for years. Difficulties with getting started and getting stuck in situations were usually seen as evidence of neurological problems.

And then he would tap the same thing and get started; so he gets stuck on these things, which shows that it is about something neurological. (Line 1224, B)

The facilitators also sought and practiced appropriate ways of providing physical support. The aim was to find out how to elicit the assistees' spontaneous movement and how to feel it. This initial stage of work often took a long time and it was not necessarily an easy collaboration with the assistees.

...so it took a long time for me to find the certainty how hard I can hold on to him. And that his hand will make the movement. That took quite a long time. (Line 6281, H)

- 3) Suitable communication aids varied from objects and pictures to computers, communicators, pointer sticks and lamps. In addition, other aids were needed to help with the use of those aids and to enhance the conceptualization of one's body, motor functions and control over one's own action. Such aids included, for example, various rests, helmets and gloves.
- 4) In an individual facilitated communication situation, the facilitators used the tasks comprehensively and tried to find suitable exercises for each assistee. New facilitators were familiarized with the task by having a situation practiced together with the facilitator and the prospective facilitator. Practicing pointing was the first task for training basic skills. The skills did not become automatic easily and the use of support often had to be practiced in new situations and operations again and again. Both verbal and motor exercises as well as those related to sensory functions were carried out with the assistees. Practicing the method often concerned a work group and the power of cooperation was considered as enhancing the training.
- 5) Various working places and positions were sought to make the training easier for the assistees. It required separate training just to find the most ideal sitting position and place.

So you really have to try whether you should sit next to him/her, or behind, where you should hold on to him/her, or how you will react to the various situations. You have to figure it all out and try by yourself... (Line 2236, C)

Some assistees worked best when standing. The location between the seat and the aid was regarded as being of primary importance for successful work.

...it was extremely important how high he/she will sit and where this is when he/she writes. You have to be careful with these things. (Line 5991, H)

6) The individuality of the assistees was shown in their behavior, presence, language and other bodiliness. These matters had to be taken into account compre-

hensively and individually. Even the muscle tone, the speed of using one's hand, and the whole body could vary on different days. Many assistees' mood, excitement and motivation had an influence as well. Both joy and anger were expressed in the power and motor functions of using their hand.

The use of the pointing hand and finger differed between various assistees. Most of the assistees pointed with their forefinger but some of them used their middle finger as the pointing finger. Some used both their hands in communication. According to the facilitators' descriptions, some used their hand in a delicate or pianist-like manner, whereas others would do it more intensely, like hammering.

Then there are those who are pianist-like, with vigilant fingers... (Line 1137, B) And it really shows if he is excited... it shows in writing, he is so powerful, he would tap at a fast speed then. (Line 7257, H)

Therefore, an assistee's whole body tone and hand tone as well could vary (see Crossley, 1994, pp. 19-20).

It varies, yeah. Well, I don't know what the diagnosis is at the moment but when I met Eero, the papers had the reference that Eero changes his tonus; that he changes... (Line 1231, B)

7) An undisturbed environment and personal suitability affected the facilitated communication situation. Lights, voices, temperature, smells and touch could both disturb the assistees and make it easier for them to concentrate. Their sensibility to some certain stimuli could vary on different days.

With one assistee, I have been thinking how this fluorescent lighting affects... It came to my mind that he is hypersensitive to light and may even see it fluttering. (Line 1103, B)

- 8) Because their ability to concentrate varied, the facilitators tried to support their concentration. The facilitators thought that a calm and patient attitude as well as looking for motivating situations enhanced concentration.
- 9) According to the facilitators, certain turning points enhanced facilitated communication and practicing the tasks. These turning points were connected with various emotional states, shared experiences, everyday conflicts and new aids.

One assistee could write – using both a computer and a pen – various lists by himself, such as week days, months or TV programs. After a conflict and a surge of emotion, he was able to write about his own needs and things that mattered to him. The content of the writing changed significantly.

...after the huge surge of emotion that we had fought with... you know, he has written by himself. You know, basically most of the handwriting is still like copying. Then there are these compulsive needs about which he has written by himself. (Line 3144, C)

Conflicts were seen as helping to develop the cooperation with the assistees in other ways as well. The assistees had a great need to express themselves and explain situations. This worked as a step towards better cooperation in the use of the facilitated communication method.

Well, then it started to go well that writing after we had some horrible conflicts and... we sat by that tool and I was like 'now you have a chance to explain what's wrong'... then it started you know... text started to be generated... at first, there were just two or three words that came out... and then longer explanations and sentences. (Line 5627, G)

#### Conclusions

# Reliability and ethicality

Next, we will assess the reliability of our research from the perspectives of qualitative research, one of which is the publicity of the research process. In this article, our aim was to report the process in detail. In addition, we let our research colleagues read our texts, received feedback and introduced even our incomplete research results at educational and informational meetings. The facilitators as the source of information for the research have also evaluated our conclusions. This supports the credibility and reliability of the results because research has to show that the reconstructions made of the reality of the research subjects correspond to the original construction, in other words how the subjects perceive the research phenomenon (Lincoln & Guba, 1985; Tynjälä, 1991).

In addition, we have had to analyze the sufficiency of the data. We examined the perceptions of 11 facilitators as users of the method in their everyday life, not the whole phenomenon of facilitated communication as such. Even if the saturation point was not met in the data, similar notions occurred repeatedly among most of the interviewees. The interview data was sufficient in the sense that we were able to create the main categories at the beginning of the analysis and other related concepts found their exact places at the end of the process (see Kärnä-Lin, 2006). We did not consider acquiring more data as being justified, although assistants who used the facilitated communication method contacted us.

When evaluating the scope of the analysis, we concentrate on the validity and objectivity of our interpretation. The analysis was carried out carefully with a

manual process, keeping in mind that the interpretation must not be based on any contingent citations (see Silverman, 2005).

We have pursued securing the evaluability and repeatability of our analysis so that the reader should be able to follow the researchers' reasoning and the categorization and interpretation rules used in the analysis. We know that other researchers should be able to make the same interpretations of the data by adopting these rules. However, this being such a conceptual and personal interpretation, achieving this goal is hard. Specifying the interpretation rules is possible by showing readers the citation from the data based on which the interpretation is made (Eskola & Suoranta, 2001, pp. 215-219). With this criterion in mind, we have added plenty of citations from the interview data in the text.

This research took a long time, offering the possibility to get to know this phenomenon in many other ways in addition to the interviews. The first author, working as a supervising special teacher among the full range of autism, had the opportunity to observe many sides of using the facilitated communication method. The reflective approach to research work was realized, for example, through numerous conversations both with those professionals and laymen who have a positive attitude towards the method and those who are suspicious of it.

We tested our success in the research task by letting every interviewee check the analyzed summary of their own interview. This could increase the reliability of the research although this is not certain as the subjects could have become blind to their experience or situations or have changed their opinions (Eskola & Suoranta, 2001, p. 211). After evaluating our summaries, they totally accepted them with the analysis categories and considered our way of categorizing and understanding their speech to be correct. Therefore, according to the subjects, the reconstructions of their reality produced by the research corresponded to their original constructions.

The transferability of results cannot entirely be achieved when doing research on the perceptions that arise from people's experiences. Indeed, it is better to compare the results with previous theories (Lincoln & Guba, 1985, p. 316; Patton, 1990, p. 489; Tynjälä, 1991). There are scarcely any theories on the facilitated communication method but we have referred to existing research results and other related information during the whole research process by confronting them with the research phases and results. This has been an important part of the research process. Patton includes possible research funding arrangements in the contemplation of reliability (Patton, 1990, p. 472). We did not get any funding, therefore there were no financial supporters behind the research.

The ethicality of research means being responsible. This concerns the whole research process. Research has to be reliable for the research subjects, readers and the scientific community. Ethical considerations begin from the selection of the research topic and continue all the way to the research permission, data collection, and being honest towards the research subjects, data and reporting (Tuomi & Sarajärvi, 2002, pp. 122-130).

The topic of this research, facilitated communication, has been criticized as a waste of money, time and energy. Empirical research results have been claimed to discredit this method that has features that offend the fundamental civic and human rights of autistic people (Fried-Oken, Paul & Fay, 1995; Green & Shane, 1994; Levine, Shane & Wharton, 1994; Shane & Kearns, 1994; Schopler, 1996). On the other hand, the scientific community's creative curiosity to study people within the spectrum of autism, their communication and the facilitated communication method, has been seen as threatening (Sajaniemi, 2007; Mirenda, 2008). Regardless of the criticism, the selection of the research topic was clear. The selection was supported by the interviewees who considered the phenomenon of facilitated communication to be an important research theme. They also wanted to learn more about it.

Ethicality towards the research subjects is always fundamentally important. In this research, it is emphasized because so much scientific and popular debate and writing with strong arguments is connected with facilitated communication. The subjects' anonymity has been preserved in this study and this was explained to them already in the first contact with them. At the time, the interviewees were also informed of the nature of the research and the principles of data usage. The recorded data was destroyed according to the agreement during the analyzing process and the research subjects were informed of this by letter. According to good scientific practice, this research has aimed to report previous studies and articles carefully and fairly (see Tuomi & Sarajärvi, 2002, p. 130).

# The limitations and possibilities of facilitated communication with personal adaptations

Communication falling into place is not obvious, nor does our research show any common formula for making it succeed. Every communication situation is different. Even the same person can benefit from the method communicatively at one time and then not benefit at another time. It is also worth remembering that there are always at least two parties present in a communication situation. In a facilitated communication situation, these are the facilitator and the assistee. An assistant's skills, actions and success in various situations affect the outcome. This point of view is also highlighted in Kent-Walsh and McNaughton's article that discusses the facilitators of the AAC method's users and the strategies meant to improve their interactional skills (Kent-Walsh & McNaughton, 2008). In addition, Palmer studies the part of an assistant and the whole work group as one element for the functioning of a facilitated communication situation. According to the subjects' perceptions in this research, facilitating skills can be learnt in collaboration with an assistee. They all had years of experience with this. Basler-Eggen has reached a similar conclusion in her research on the significance of training. Both the facilitator and the assistee can learn the skills of using the method. The longer the experience, often the better the results. The significance of the cooperation between facilitator and assistee was regarded as principal (Basler-Eggen, 2000, pp. 193-195).

The facilitated communication method does not make the assistees' communication problems disappear and complete independence, being free of a facilitator's occasional physical support and presence, is hard to achieve. Nor does this method exclude the simultaneous use of other communication (Biklen, 1993). Indeed, every interviewee highlighted that they used other communication aids with all their assistees as well, such as picture folders, support signs, gestures and other visual aids.

People tend to have a doubtful or skeptical attitude towards the facilitated communication method because they think that there is a lack of strong evidence of its usefulness. The position of the method is not distinct and some professional organizations such as the North-American ASHA (American Speech-Language-Hearing Association) and the Finnish Speech Therapist Association have issued a statement regarding its use. These statements either recommend refusing to use the method or using it very carefully (Launonen, 2005; Mirenda, 2008). No wonder that in the field of AAC facilitated communication has been largely ignored (Mirenda, 2008).

This understandable situation can result in a vicious circle. If the method is not used, no results are obtained, one way or another. The method's possible weaknesses and advantages as well as limitations or uselessness remain unrealized both by scientific means and in everyday life. Nevertheless, it is easy to understand that many of those who are considering trying the method would like it to have strong scientific backing. If the method is not used, it cannot be developed either. The subjects in this study had some development suggestions for the use of the method. Also Basler-Eggen in her doctoral thesis ends up describing the need for increasing professional competence both at the basic level and in the in-service education as well. She thinks that the facilitators' awareness of the method's inconsistent position and their own possibilities to influence the communication situation are especially important (Basler-Eggen, 2000). The results of this research show that the assistants were aware of these issues.

The cautious use of the facilitated communication method can thus partly be explained by the scarce scientific evidence that would encourage experimenting with it. Let us think about children's remediation in general terms. Koivikko and Louhiala point out that a great deal of it would be discarded if activity was discontinued based on so-called strong evidence (Koivikko & Louhiala, 2001). Evidence-based medicine (EBM) promotes nursing that relies on the best and most recent research knowledge and preferably on randomized tests. Koivikko and Louhiala (2001) noted that based on the principle of strong evidence, drawing up nutrition recommendations and most of preventive medicine as well as surgery should be discontinued. Similarly, the means in general practice would remain minimal if very strong evidence was required (Koivikko & Louhiala, 2001). This situation can be compared with the use of facilitated communication. It is obvious that the method does not help all people with communication disabilities searching for a communication method that would support or replace speech. Without trying the method, it seems hard or even impossible to find out its advantages and weaknesses

for different individuals. Every user has to create sufficiently strong evidence of the method through their own experiences of it.

Mirenda (2008) encourages practitioners and researchers to invent and investigate new ways of supporting people with autism to communicate. She points out that we need to pay attention to the stories of FC users like Sue Rubin and her contemporaries, to mention Tito Mukhopadhyay (e.g. Mukhopadhyay, 2000, 2003), and learn from them (Mirenda, 2008). We can also learn from facilitators and their perceptions on the method. Therefore, there are good prerequisites for developing the method. Even this research brings forward tacit knowledge from the field that can be used in development work to enhance both the assistees' communication and other activities such as the facilitators' work.

Most of the people who benefit from the facilitated communication method belong to the spectrum of autism or they have autistic traits as did the assistees in this research. Therefore, it is justified to discuss the research results in the light of the research on autism. Mirenda (2008) dissects the development of AAC methods during the last two decades and sees enormous improvement. Many people who belong to the spectrum of autism can use signs, PECS (the Picture Exchange Communication System) and a variety of speech communicators. However, Mirenda thinks that this is not enough. Paths to better communication will always exist if autistic people are considered capable of it (Mirenda, 2008). The subjects of the present study were also confident about their assistees having a chance for communication with the facilitated communication method.

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