

Art and Science: A different convergence

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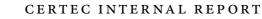
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- A Different Convergence



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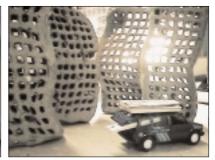






























#### PREFACE

The Pictorium ("Tryckolera" in Swedish) is a day center for adults with developmental disabilities directed by Göran Plato, artist.

Certec is a division of the Department of Design Sciences at Lund University's Institute of Technology directed by Bodil Jönsson, professor.

Göran and Bodil met in 1994, when The Pictorium came to be the main home of *Isaac*, a personal digital assistant developed by Certec. If we had planned 1994–2001 and beyond as a period of joint research from the beginning, the work would most likely have been called a longitudinal project. That was not the case—just the first year was a "project". Since then, The Pictorium has become an integral part of Certec and vice versa.

An overview of what has been published about *Isaac*, The Pictorium and Certec can be found at the end of this report.

How did this interaction originate? And how could we keep it going for seven years without running out of results? *Can it possibly have to do with a special convergence of art and science?* 

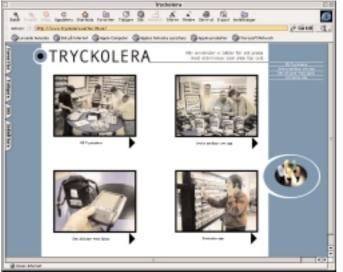
The material for this report is based on the correspondence between Göran Plato and Bodil Jönsson. In pictures and in words. Bodil has provided the overall structure and is the narrator. But when you have finished reading, you will see that Göran is as much an author of this report as the narrator. Consequently, it is not by chance that the authors were put in the order "Göran Plato" and "Bodil Jönsson".

Stig Nilsson, Thomas Åkesson and Anette Hartlow have given their approval for the publication of all the text and pictures.

We would like to thank Region Skåne (the southernmost region in Sweden) and Malmöhus Läns Landsting that have made our cooperation economically feasible.

Lund, Sweden April 2001 Göran Plato Bodil Jönsson







Clockwise from the top: Isaac • Growth Book for Differently Abled People • What Isaac Taught Us • The Pictorium website • Just Give Us The Tools • In the classroom website.

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An introductory picture series from The Pictorium. As you can see, it is not an instructional sequence in how to plant potatoes, nor is it a direct documentary of the excursion on May 10, 2001. The photos serve a dual function. They support and confirm memory as well as working as a written language. In addition, they are a source of inspiration for conversation, that is, they work as a spoken language or support to such. That is why they need to deal with subjects the people involved actually want to talk about.

EVEN YEARS have transpired during which Göran Plato and myself, Bodil Jönsson, have thought together, done things together, laughed and cried together. We are always doing something together, if not every day, at least every week. Not that we have to meet—we most often work on our own and in different places. But there is always something for me that concerns The Pictorium, Göran's place of work. Many times Stig Nilsson and Thomas Åkesson, two of The Pictorium participants, are a part of it.

Göran and I come from two different worlds: care giving and science. Every once and a while of course, we stop and wonder how this long-term joint endeavor has at all been possible. "A longitudinal project" is what it would be called scientifically—but that would not be a fair designation. We have been working together on this for a long time, but it was only in the very beginning that it was a project. After that, no money has been earmarked for it from the University or the local authorities. But grants from Region Skåne and its predecessor have given us the opportunity to be able to continue and that, in and of itself, has been invaluable. This type of cooperation cannot be dressed in the language of applications, goals and means but instead requires a long-range creativity. That the results are of a high standard and demonstrate consistency over and above the ordinary have been observed and confirmed for ourselves and the world. But what is behind it all? What has made it possible and continues to make it possible for us to keep at it for such a long time? Without tiring and without the results leveling off?

TTT, Thoughts Take Time. In this case it took seven years for the thought to mature as to what the actual linchpin really could be. We would like to try and formulate it in words and images. The words are sometimes mine, *Bodil's*, and I am also the one who has structured and chosen the excerpts from Göran's correspondence. But the pictures are *Göran's*. And, believe us, the thoughts are really *ours*. Entirely mutual.

We are a bit odd, Göran and I, because we think not only in words but in images. Not many do that—at least not at a conscious level. For us it adds extra zest to our joint venture; we can always rely on the fact that whatever one of us says or does is coupled to an internal, mental image. So if one of us doesn't understand, we can always ask and then the other can say, "Yes, well, but seen from that direction it's like that, from this direction it's like this..." The internal images are so concrete that they can be turned over and around.

"In this case it took seven years for the thought to mature as to what the actual linchpin really could be."

























It makes a difference having your own photocopier and being able to print pictures yourself.



There are not only similarities but great differences between us as well. Just consider our places of work: Göran manages a day center for adults with developmental disabilities, The Pictorium, and I, a university division, Certec. In his leisure time, Göran gives shape to clay and other materials, creates color and design, produces artistic figures, while I occasionally write articles and books, and make public speaking appearances before large audiences. We are both researchers in the sense that we *seek new knowledge*. But we have entirely different methods. In the process of relating the effects of the convergence of two methods and two people, the end results will be a unique documentation of developments at The Pictorium and at Certec.

#### ART AND SCIENCE

Art and science share many points in common. One of these is that both raise new *questions*. But there is a basic difference in how the questions are used. While science immediately throws itself into finding answers to the questions and then making them public, art takes on the role of finding questions, accentuating them and hanging the *questions* up for people to see. So that people can answer themselves—or continue living with the questions.

This has been quite evident in our different ways of working. At first we are united in the joy of *discovering* the new questions and asking one another: "Do you think that it can actually be like this?!" But then I try along with others at Certec, to find the answers, come up with the technical solutions, etc. Göran also searches for answers and solutions. But above all, he sticks to the question and tries in all the ways he can think of to get Stig and Thomas to see it too.



Long before our trip to Denmark, on a cold weekday, Thomas and I stood and looked out over Öresund. Göran took photos, as usual—his digital camera always ready, almost an extension of his hand. When we got home, we looked at the pictures. "The boat," said Thomas when he saw the two of us in profile. "What did you say?" I asked. "The boat," repeated Thomas. I looked and looked but didn't see any boat, just our profiles. At that moment, I was the one who was cognitively impaired—I was the one who couldn't see what wasn't in the picture, an inability attributed to people who are developmentally delayed. But Thomas could. And after 10 seconds of thought, I realized what he meant: "Göran must have taken this picture when we were looking at the boat..."

## A revealing example:

I had invited the gang from The Pictorium on an outing to Denmark. As the day approached, I started to wonder if I should be making any preparations. So I sent the following e-mail to Göran [May 3, 2000, 15.35]: "Please decide where we should meet and when. What should I bring, more than myself and some money?" And what did Göran answer the same day at 16.50, if not: "Dear Big Sister, you and I aren't making the decisions at all. Thomas has already made them. He pointed out which boat we are going to take and the destination will be revealed when we are underway. 'We are going to a hill in the woods,' according to Thomas. 'And I want a red, Danish sausage and a beer,' says Anette. So it's just to obey. We're in big trouble now that we can't take part in making the decisions."

Stig finds it very hard to concentrate on his work while waiting to give someone information, such as a message about a telephone call. We have solved this problem with picture cases. With them he can confirm and remember. Having the case there in front of him results in him being able to calmly continue working, and with the help of technology tell someone else what has happened.













What you most commonly see at The Pictorium are photos with bar codes. Bar code scanners are used to display the images on a computer screen and Thomas and Stig combine the pictures to ask questions and express thoughts. Sometimes they play with just the bar codes—each one corresponding to a picture in the computer. And sometimes they simply use a finger to point at the photos.



















All good and well. And yet not quite as simple as it seems. Behind it all there has been a personal development among the participants of The Pictorium closely connected to their interaction with Göran, (See Annamaria Dahlöf's film, *Uncommon Friendship*) based on Göran's consistent refusal to live life for anyone else, to decide for anyone else. That was his approach from the very beginning of The Pictorium. He started with rooms that were completely empty. They sat on the floor and talked about what they needed. "Coffee!" someone said. And so they went out and bought a coffeemaker and some coffee. But no one thought about the filters—and Göran said nothing. They returned with the coffeemaker and coffee and discovered what was missing—and they went back to the store one more time to buy the filters. In one way they "lost" a lot of time—whatever losing time means. But they won in understanding of the whole concept in its natural context.

At The Pictorium, the participants are constantly being offered opportunities to discover for themselves *how things are related*. One physical expressions of this is that none of the cupboards have doors with a few exceptions, the refrigerator being one of them. The guiding principle is that everything should be open, visible on the shelves, or picture rollers, walls and racks.

Of course, The Pictorium had come a long way by the winter of 1994 when Göran and I met. But the technology used there since then has revolutionized almost everything. Stig and Thomas needed more than people to give them cognitive support—they also need *tools* and *artifacts* with which to think (See Arne Svensk's licentiate thesis, *Design for Cognitive Assistance*). That is how science can assist: with *solutions* that enable Stig, Thomas and others to think better on their own. For Thomas and Anette to take upon themselves the role of tour guide planners in the example above required self-confidence, imagination and internal images. It did not happen on its own.

## QUESTIONS VERSUS ANSWERS AT THE PICTORIUM

If there is a group of people who is more exposed to training in following directions and repetition practice than others, it is people with developmental disabilities. Learning by transfer. An expressed stimuliresponse situation, an expressed belief in learning-through-repetition, combined with assuming guardianship, that is, others doing things and making decisions for the person involved. This approach has dominated and dominates still. The pattern is deeply ingrained even today, in spite of all the good talk of individual development and the right to self-determination that we have heard for a long time now.

Perhaps the pattern will not be broken until one understands the dif-

We don't just send pictures through the computer. We take the pictures in hand → and show them to one another. Sometimes we use our picture cases with a fixed picture series on one side to help us remember and our own messages on the other.













The walls, furniture and other inventory all have bar codes—coupled to photos with sound that tells, for example, how I painted, repaired or to whom the different items belong. They are "Post-it notes" that help us to recall by using the bar code scanner.





















ference between elevating the questions versus furnishing the answers. There is no doubt that the people we are involved with need support, lots of it, in order to see structure and context. Just think of Henrik Person's black Wednesday as described by Arne Svensk in *Design for Cognitive Assistance*. HP needs help with all the many different situations that he does not grasp. But is it preaching, nagging, reproaching and repetition that he needs? Or a more restricted set of values in society saying that people like HP really shouldn't be allowed to live on their own, shouldn't be allowed to cut the grass, shouldn't...?

What would happen to HP if he was given technological cognitive assistance?

There is a polarization between focusing on questions versus answers in education as well. On the one hand, we find constructivism, that with its view of learning as a searching and creative process, places the main emphasis on questions. The supposition is that people learn by asking questions, searching, creating and finding support in the world and inside themselves, all in order to achieve learning, i.e., internal change. On the other hand, there is the psychology of learning, programmed learning, teaching technology and similar approaches, in which learning is studied as if it were independent of content and environment and as if it could primarily be controlled through situations and instructions arranged in the right manner by the external world.

Repetition has been considered the mother of learning for most of the history of teaching and long before that in the authoritarian era. The world was divided into those-who-knew (teachers and leaders) and those-who-did-not-yet-know (students and other dependents). It was a matter of getting the right answers to more or less *migrate* over from the former to the latter—then the mission was accomplished from the learning-by-transfer point of view.

Many well-intentioned adults think that newborns need help with just about everything. But on second thought, one realizes that even the very youngest do most things on their own: breathe, eat, maintain body temperature . . . And not least of all, search from the minute they come into the world, as well as they are able at that point in their lives. It is this searching process that is the prerequisite for learning, and it is this capacity for searching that can also be found in people with developmental disabilities, and on which all care and educational services should be based.

Göran breaks with the established culture in his role as the leader of a care-giving facility by systematically opposing the approach that one is only to furnish the participants with *answers and solutions*. Göran wants to assist his charges in finding their own questions. He is there in the background and works with providing structure, structure, and more structure. And it is in offering *feedback* that he gives structure to the people around him, not in the dispatching of instructions to people whom he considers as more or less passive receivers. I have written about this in the



We play with words at The Pictorium because they aren't always self-explanatory for everyone; we twist and turn them to fit, to make them more concrete. "Vegetable soup", for example, starts with planting vegetables (in a pot!) in the ground and ends up as soup in a pot.

books, The Unyielding Desire to Search, and The Power of Thought.

For me it is apparent that Göran is fortunate enough to have cultural developments going in his direction. He has before him, though, a period in which others will question what he is doing. That is because care giving and educational services are not at the forefront in the transition from prioritizing the sender/receiver situation to prioritizing the searcher/giver-of-feedback relationship. If anything, they lag behind. It is good, then, that Göran stands out as a prominent, pioneering figure who can show what is actually possible if one dares to trust in people's innate desire to search and to think for themselves.

#### **OUESTIONS VERSUS ANSWERS AT CERTEC**

In Certec's theories and methods, as they are presented in *Rehabilitation Engineering and Design—Theory and method*, both questions and answers are emphasized—and above all, the relation between them. Research can be based on questions (or well-formulated suppositions, hypotheses) that at the same time can lead to other questions and hypotheses. We are humble on the one hand, in the sense that, "*You cannot know until you have tried*," (See *What Isaac Taught Us*) and on the other, ready to stick out our necks and make the needed effort to ascertain, "*How do you go about testing it?!*"—i.e., implementing the whole idea.

I was the one who at the time of the Isaac technology creation supported the inclusion of a built-in, digital camera, something quite exotic in 1993. It was obviously a "solution" but to what and why? I asked myself: "How does one go about talking to others if one does not have the words?" And you have to say that the possibilities offered by a digital camera answered that question superbly. Yes, it proved to provide a means that was infinitely more successful than anything I could ever have imagined.

I had only understood the half of it (if even that). And how could I be able to understand more—I too learn by searching and creating. In my stupidity, I also believed in the right kind of *instructions*, created through the use of personal photos. It is a bit embarrassing in hindsight. But on the other hand, why "embarrassing" and why "stupid"? By *trying* it out I realized that it did not work, and with that I had reason to contemplate *why*. Some aspects were correctly thought through, e.g., that entire sequences of photos are often needed. But it was not the chains of correctly constructed instructional photos that resulted in success; it was the chains of photos that were built up *while* learning, as a *support* in learning.

#### VARIATION AS THE MOTHER OF ALL LEARNING

Göran has also, step-by-step, become more aware of his method. This is what he wrote me recently in an e-mail: "As you can see, one of our most important things is not to plan first but to build and create ideas direct-

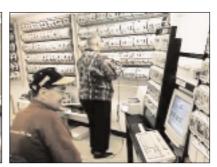
























We are building a picture bank and testing to see how it works. We change photos and make new picture rollers.

"To challenge and be challenged. Reality is perhaps not quite what it makes itself out to be." ly based on imagination and plan according to what we come up with together. We work a lot with altering concepts and doing something differently."

Here I see the artist in Göran. To challenge and be challenged. Reality is perhaps not quite what it makes itself out to be. What if it turns out to be exactly the opposite? Or, at least: What can you see if you pretend it is exactly the opposite? Or do exactly the opposite?

The whole time, all of the many "answers" from Certec that have resulted from our attempts to understand what the questions are, have contributed to a renewal at The Pictorium. On January19, Göran wrote me the following:

"Dear Bodil,

Our motto for December and January has been, 'Let's build'. Stig, Thomas and the others want *changes*. I have noticed that some things we have are no longer used, other too old and in need of renovation or replacement.

"We've changed the Picture Bank, Picturegraph and our Picturegram.<sup>1</sup> Kept the same style but with a new logo and rearranged the rooms. They have participated in and influenced all that has happened.

"Construction of the network station will soon be finished. An important personal aspect has been the building of the Net Bar, with a counter and barstools where we can serve coffee, beer and soft drinks when they are working at the computers. There will also be pillars for displaying photos, since they all 'picture converse' with one another. The response has been positive from everyone. It's become our meeting place. As Thomas said to a visitor: 'Have a seat. Would you like a beer, coffee or soft drink while you see how I work at the computer? I will be filming it on video.' Talk about self-confidence! Just think how great it is for them to achieve serious, meaningful results while having fun, results that make them feel like adults.

"Each morning Thomas comes in and turns on his computer. Then he goes out and asks Johan if he would like some coffee. Thomas has a computer car racing game. Johan has helped him install it and has shown him how it works. It's a real Thomas-experience! As he plays, he uses his whole body, jumping up and down when the car runs off the road. Tells the custodian what he has done, that he has driven on the grass, run over all the trees and that 'the police are chasing me!' He laughs the whole

1. The Picture Bank consists of pictures mounted on large rollers in roller stands. The Picturegraph consists of a computer, photo database, bar coded photos, bar code scanner and printer used to handle smaller selections of pictures. Picturegrams are photo-based letters. See: www.certec.lth.se/english/picturebank/index.html

What do you do with a gray stone? Usually you just leave it on the ground, or you may pick it up and use it as decoration. We try to use things in our surroundings, make something different out of them. Make them important, something to share with one another. To see that it works to bring a "dead" object to life. Suddenly it becomes a living entity. When it's cold outside, we put the stone in the oven, so that it will warm up—seek the warmth. If it is hot out, we put it in the fridge—seek the cold. It becomes a meeting point in our life.



















The Net Bar.













The photos used at The Pictorium are usually 7.5 cm. (3 in.) wide. And the table is 150 cm. (60 in.) in diameter. So we made a picture stick with 20 images on it. It reached all the way across the table.

time. The changes we have made have effected everyone positively, ignited their thinking."

Background information: Thomas just got his own computer and they have built a small computer network at The Pictorium. Björn Breidegard from Certec has come up with different ways for Thomas to control the pictures himself, among them, using spoken words, which gives him additional practice in speaking.

Stig is also improving his language skills. This is what Göran writes in the same message:

"Stig has new opportunities and is taking advantage of them. He tests, tests and tests again with photos and sound. New word-like sounds are issuing forth from Stig: 'Ooooooja; Ja; Va, va va; Na-na-na; Mu, mu, mu'. This happens when he is the one controlling the bar code scanner and picture rollers.

"To help them, we have our new printer, which is a combined printer, scanner, and photocopier. When we have developed different events as photos, they are able to decide for themselves when they will have them on paper.

"Stig and Thomas copy their own pictures. Stig usually sits at the computer, looks at his pictures and tries to imitate the sounds I make. He's using many new words that I find difficult to understand."

For those of you who do not know The Pictorium participants, it wasn't all that long ago that Thomas hardly spoke at all, even though he actually had a vocabulary, limited though it was. And Stig only said "Ig" (Stig) and "Jaa" (Yes).

#### HOW THINGS ARE RELATED

All the participants have exploded in their abilities to see new relationships. It is most evident with Thomas since he has become so much more verbal at the same time. Just take the following example (from Göran's email):

"When we drove past a neighboring high school, Thomas said: 'Everyone's started school again.' I asked him how he knew and he replied: 'All the cars are here again,' pointing at the parking lot. Another day: 'Many are free today. Few cars'"

And an example of Christmas logic: "Happy New Year. Everyone here sends their love and thanks for the Christmas presents. As Thomas said: 'I've been very good, got lots of presents. Bodil's been very good too, so she also gets many.'

"Some new Thomas-talk. He is using many new words and sentences. I have never heard these before:

'I have to have' 'Don't you want?' 'Come over, sit here' 'What are we gonna do now, today?' 'Am better now' 'That's not right, it's wrong' 'I wanna go home' 'Good, you're nice, you coming tomorrow?' 'Don't wanna, do it yourself' 'Will you get me tomorrow?' 'Who's driving tomorrow?' 'Shall I get something?' 'Damn it, stop fighting!' 'What does this say?' 'We need to shop, we're out of a lot.' 'Do it yourself!' 'I wanna call someone' 'Shall we work?



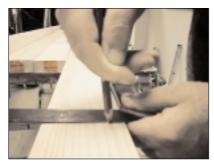
















For a period of time, Thomas was fascinated with measuring the diameter of a round table with a yardstick—literally translated as "inch stick" from Swedish. "Tum", which means "inch" in Swedish, also sounds a lot like the Swedish word for "thumb". (The story is told in What Isaac Taught Us <a href="www.certec.lth.se/doc/whatisaac/index.html">www.certec.lth.se/doc/whatisaac/index.html</a>). Afterwards, Thomas started to contemplate the relationship of the words "thumb" and "inchstick".









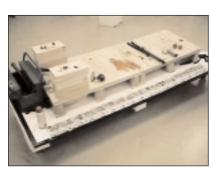


























































Thomas has always said that he would like to have a black bike. He even claimed that he had one. Well, he did have a bike key. And once he actually showed Göran an old, old bike—to which the key fit. They brought the bike to The Pictorium, took it completely apart and bought new parts where needed. Finally, Thomas had his black bike; much, much nicer than anything he could have purchased brand new, because he knew exactly how this one was built.



















NOTHING IS IMPOSSIBLE. We always have our technology with us, as if it were another person on the trip. We use it in order to remember, document and talk with people around us.

"On the way to Stockholm. We started driving early in the morning. It was dark; car headlights were all that we could see. Then it started to rain. Stig and Thomas got comfortable and tried looking at their magazines. After a while, the fellows nodded off and slept until it started to get light. We took a number of breaks to stretch our legs. Henrik and I took turns driving. When Thomas saw the pictures we took of the road while driving (to mark the time when nothing happened), his explanation was that we drove, drove, and drove. He said that about every picture until an ordinary one appeared again. Of the photo taken in the dark, he said that it was dark when we drove off. The light pictures: 'Now it's light again, now we are able to look at the magazines and see things through the window.'"



GÖRAN QUESTIONS—AND BODIL COUNTER QUESTIONS

"I have started pushing the limits a bit here. Have you spoken to Arne about it? I have tried for a week to show no interest in taking pictures of the days' events.

"The first day went quite well, a few raised eyebrows but nothing more. The second day the guys started grumbling a bit. They sat there wondering and looking at me as I went around doing other things.

"The third day, when I went to pick up Stig in the car, one of the staff members from his group home came out and asked me if anything had happened. Stig had started acting out in a way he hadn't done for a long time. He explained that he didn't want to go to work. But when the staff said he could stay home, he didn't want to do that either. He became more and more obstinate, as he had been before. When we arrived at The Pictorium, had finished our morning coffee break, all of them let me know what was on their minds.

'Why is it like this?!'

'What do you mean?' I asked.

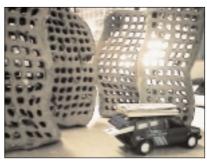
"Thomas explained: 'TODAY I WANT TO HAVE LOTS OF PICTURES, OR ELSE...!' And then he laughed and blushed. Stig also answered in his own way. Annette said: 'I thought there was something strange going on!' I promised that I would go back to taking pictures. Was it wrong to test them like this? It was a kind of role play."

Bodil: "Göran, why in heaven's name would it be wrong?! You tested in order to find out. And you say yourself all the time that your work with pictures needs to result in change. In what you did, not only you, but Stig, Thomas and Anette also realized that taking pictures of the day's events — that's the important thing. Fundamental. Altering that isn't done with impunity.

"At the same time, I understand what you mean. It feels ethically wrong to deliberately stop doing something that you now believe is necessary for life to be fun and meaningful. And of course it is right and good and typical that you are the one who feels so. But you didn't think so early on—before you had the ideas, before you had the possibilities, right? Perhaps it was considerably more unethical at that time to, day in and day out, *not* deal with Stig and Thomas through pictures of the 'day's events' so that they could better understand the world and themselves. On the other hand, the technological prerequisites did not exist. What is to be said today, concerning ethics, of all those other organizations dealing with people like Stig and Thomas that haven't yet made any attempts to use personal digital photos for self-determined feedback and memory support?"



















Much of the material at The Pictorium has been remolded by nature, such as bricks exposed to the transforming power of the sea. Some look like telephone receivers and we call them "brickphones". Others, like those in the pictures on this page, are used at The Pictorium to simulate tall buildings. The lamp shining from behind activates the observer's imagination: "It's dark", "There it's light", "It's probably moonlight", "The sun is shining through".

#### PUSHING THE LIMITS

"We still have picture-miming exercises every day, using both photos and film. The conversations are getting longer and longer, we talk louder and louder, the body language is bigger and bigger.

"We'll send you pictures of our nifty new bar and barstools, where Stig and Anette drink coffee and watch Thomas work at his computer.

"Can you imagine Stig getting up on the barstool himself? If you are motivated, you can do anything. Miracles happen everyday when you create, play, imagine, build and believe in yourself, and that nothing is impossible."

It is as if we had found forms for collaboration in which Göran's sensitivity, artistry and innovations together with Certec's wealth of ideas, innovations, answers and solutions are continuously reinventing the entire environment. The participants at The Pictorium are very much involved in the whole process.

It is all so unique that I resist putting it in a category as an example of something more general. An attempt, anyway: Schön's, *The Reflective Practitioner*, can hardly be more powerfully illustrated. It is in the *doing* that one then can and should listen to how the situation responds or *talks back* (reflection-in-action) and proceed from this. *That* is what happens in our collaboration.

To build

"Hello again!

All of a sudden the word 'build' has become a new concept for Thomas and Anette. Thomas talks about it everyday.

"Let me tell you what he said at home. A new staff member was preparing breakfast when Thomas came up to him and explained that, 'At work we are building and making fantastic sandwiches and food every day because I'm on a diet.'

"Thomas is losing weight. During the Christmas season he lost two kilos (in spite of all that Christmas food).

"Back to the bar: Stig and Anette have talked about different things using pictures. They have had their morning coffee and have hugged one another. Stig also gave Anette a kiss on the mouth, all this while they sat on the bar stools. What technique! Stig, who at times finds movement and balance difficult—he can do it. When he wants to.

"We often watch the film from our Stockholm trip. There is one sequence I find particularly interesting. Thomas was sitting by a window and looking at a building. 'Plato,' he said, 'look at all the window-pictures there are in that building.' He pointed back and forth at the building. I asked what he meant by 'there is a picture in each window'. We video taped it and I helped Thomas to get a close-up by zooming in on the window, so he could see what they were doing inside. There was someone



















Arne Svensk at Certec sends photos to Thomas and asks him to imitate what Arne is doing in the pictures. Observe Thomas's ability to mimic. He doesn't miss a thing repeated trials have demonstrated that he doesn't even make a mistake with right and left.

sitting at a computer, someone making a phone call, someone drinking coffee, etc. He sat for a long time and looked at it."

I believe that we have been given an example that shows we have come full circle. One of the things we discovered a long time ago was that Thomas could not clearly see a picture if it did not have a frame. So we started to frame in all the pictures, of course. That gave Agneta Dyberg-Ek, a special education teacher in Hörby, sudden insight: The reason that sitting by a window has such a great effect on some students has to do with the *frame*. The window provides them with a frame through which to see the world. And in that way, one and the same slice of real life becomes easier to handle than the complex, three-dimensional, constantly changing world.

For Thomas, though, it was not a matter of the picture frame or of the view through a window. No, with him it had to do with in-sight—Thomas now saw the windows from the outside as pictures. He even said so: "there is a picture in each window". That it was also possible to zoom in and show what was actually in the picture—that was fantastic.

#### HISTORY

Each one of us is part of our own history. But are we really if we do not have anyone who knows what we mean with words, and if we do not have so many pictures either? Many refugees have related what it is like to be cut off from their childhood, not having anyone else with whom to share their memories. People with developmental disabilities can have even greater problems with this: the staff members that know something about their past have quit, and they may be unable on their own to organize their thoughts, in which case they will be unable to share them with anybody.

Göran has made a great effort to document, step-by-step, Stig and Thomas's personal history. You can read about it in *Just Give Us the Tools*. But there is still a lot that Göran has not been able to get a hold of. Thomas can relate some of the things on his own now. It happens that he suddenly remembers something from the past, which seems to surprise him as much as those around him. Such was the case when he remembered that he had once worn a cast and sat in a wheelchair. The recollection came when he was looking at pictures of Stig at the dentist (!). Thomas talked and talked—and sure enough, when Göran checked it out, he found it to be true. A few decades ago.

Now Göran writes:

"I told you that I am working with Thomas's pictures and his history. You know that he always has talked about a person named 'Brant'. 'Brant's done that,' says Thomas frequently in both positive and negative contexts. Now I have found a picture of Brant! He worked with Thomas at Blinkarp. Thomas has also said that he has ridden a horse. No one real-



Thomas was right all along.





























And then Thomas remembered that he had once worn a cast!

ly believed it was true. Now, Thomas and I have evidence: a picture of Thomas riding a horse."

#### FEELINGS

It is easy when working with pictures to grasp the meaning of nouns. Pictures also work well with verbs, events and adjectives. Feelings are more difficult and more important. That is why Göran works with them, of course:

#### "Dear Bodil,

I have started to work with each and everyone's personal pictures of emotions. Started with Stig's. Together we have gone back a year and a half and found 480 pictures of emotions that deal with positive and negative feelings, common and uncommon. I will continue a few more years back and see how many we come up with. Have seen an increased interest in using these photos in picture-talking. What's interesting is that the sound telling what the picture is about is also important.

"We have about 100 such pictures with sound. Stig is going to have his own board where he can gather the pictures he wants in a picture conversation. We tried it out at a study visit. When Stig showed the pictures to the visitors with the bar code scanner, the picture conversation went like this (picture and sound):

1. Hi, my name is Stig Nilsson. 3. Ch

3. Christer is sick.

2. Christer is my supervisor.

4. Christer has a pain in his heart.

A new picture conversation:

1. I have a sore arm.

3. I have to wear it for a week.

2. The doctor has put my arm in a cast.

The visitors applauded Stig and thought he was very clever. You could see in his eyes that he was quite moved by it all.

"Then Thomas interjected: 'I can also do that; I can laugh and cry too!' And so he showed it through body language. I'll send you the pictures."

## From another message:

"Have a good example with Stig. He's sick, can't talk because he has a sore throat. And he has also stumbled and twisted his arm so that it is in a sling. His supervisor, Christer, is sick too. He has a heart problem so he's on sick leave for at least a month.

"It's all had a great effect on Stig. He wants to be on sick leave as well. Just think, Bodil, how Stig has developed. I have never seen him show such emotions about himself.

"An important reason why he wants to stay home is that I have promised that he will be kept up to date on all that is happening here. This opens up a new area: the new *Picture Emergency Kit with First Picture Aid*. Stig will get it every day. Have started with a packet of pictures

































Stig's pictures of feelings.



















Göran and Stig construct negative emotional events. The first picture starts with the event and the last finishes with "I'm well again".

1. I have fallen and hurt my arm.

2. The doctor has put my arm in a cast. 3. I hope that I will get well soon. 4. I have been at the doctor's today and he checked my arm. 5. The cast is being removed. 6. The cast is off. 7. Look, only a few black and blue marks left. 8. Now I can move it as usual. 9 Now, everything is back to normal.

For Stig and Thomas it has often been difficult to understand that most things work out. But if you don't understand how a difficult time can have a happy ending in one situation, you are unable to transfer that expectation to the next. That is why Göran started making series of pictures that deal with traumatic events—and how they resolve themselves. He does them while they are in progress (as in the next series about Stig's pneumonia). The series ends with the healthy picture (a photo of Stig, fit as a fiddle). The empty spaces are for the pictures that will be taken to document his recovery.

1. I feel ill, have a sore throat. 2. I'm sick. Want to go home. 3. Have to go to the doctor's. 4. The doctor takes my temperature, 39°. 5. I get some medicine... 6. and I should get some rest... 7. because I have pneumonia. 8. Göran comes and visits me with pictures of what has happened at work. 9. Also gives me some sweets and magazines. 10—11. Christer and I have written a letter and drawn pictures of my first week of illness. 12—14. Empty spaces, because I... 15... will be back to work soon.









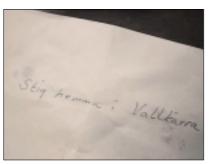






















that looks like a seed packet. There are pictures on the front and back of the packet, telling what the contents are about. Inside the packet is a folded strip of pictures, showing the whole chain of events in order. For example, if Stig wants to check on someone who is coming to visit, as to when, where, how, how long—he pulls out the contents. If it is a matter of how many days are left, he can clip off one day at a time and in that way be able to keep track of time himself."

"Thomas dropped his glasses and they broke. As if that wasn't enough, the handle on his briefcase was loose. As a result, the briefcase got caught between his legs, he fell on the pavement, cut his elbow, hand and knee. His hand was so swollen that he had to go to the clinic.

"And Stig had just had his cast removed when he was going to show a group of visitors a picture. He fell—and his arm swelled up again. What an unfortunate set of accidents the guys have been through.

"My recipe: I recreate the events through *pictures*. Build up how they happened. What we are going to do. And see to it that they end with *a positive event*, when everything is fine again.

"I've started with pictures of the actual injuries. When the fellows saw them they started laughing, started talking about them with everybody and explaining or trying to explain. In that way they started to recreate what had happened and you better believe that they were very good at doing it all over again in pictures; so that they could see for themselves what had happened and tell others on their own. The more they are able to picture-talk about it, the less of a problem it is. Just imagine how little is needed to increase quality of life for them!

"To document a negative event in pictures has changed it to a positive, healing one. It has been a kind of first aid. As soon a Stig has a pain or thinks about it, he takes out the pictures and explains how it happened. What we have done. How it will turn out: 'I will be fine!'

"They have managed their problems on their own. Fantastic! They have laughed over their accidents. It's terrific that pictures can heal."

"Other people write, 'No advertising, thanks'. But we want advertising, so it says just the opposite on our mailbox: 'Advertising, please!' Advertising is important for us. One day Thomas came in with a flyer about clothing from Malmström's. Explained to me that he wanted to buy a shirt. I said that we could do that—'but do you have any money?' 'Yes, I do,' said Thomas and took out his wallet. Showed me that he had 30 crowns in coins. I said that was too little. Then he said that he had some more—and pulled out a 100-crown bill. We decided to go shopping the next day. He wanted to make a board like Stig's, where he could put up pictures, and we did that right away. The first picture showed Thomas's flyer with the shirt, and in the last he would be wearing the shirt. In between there were 5—9 empty spaces for pictures. Thomas was satisfied and we went home.

"The next morning I had promised myself not to say anything.



















An emotionally negative experience that isn't over yet. Thomas constructs a series of photos after the fact. It gives him a sense of security when he can see that something is happening and that it will soon be completed.

- 1. I, Thomas, have glasses.
- 2. I dropped my glasses and they broke.
- 3. One of the lenses fell out.
- 4. The frame is also broken.
- 5. The glasses are going to be turned in for repair.
- 6.
- 7. Empty spaces for pictures of what is going to happen.
- 8.
- 9. This is what my glasses will look like when they are ready.

Thomas came as usual, drank his coffee and started talking with Ann-Christine about this and that. 'What are you going to do today?' she asked. 'I'm going shopping with Plato and I'm going to buy a shirt,' said Thomas. He hadn't forgotten by any means.

"We drove to Malmström's clothing store. I saw a rack with shirts on sale. They cost 99 crowns each. I left Thomas alone so he could decide which one he wanted. Listened to him talking to himself. Suddenly he called me over: 'Plato, I want either this one or that one.' One was red and the other blue and white striped. 'You decide,' I said. 'I'll take this one,' Thomas replied, pointing at the blue and white one. He took it to the counter and said to the young man standing there: 'This is the shirt I want'. He took out his wallet, pulled out the money and asked how much it cost. He was entirely confident in his manner and quite polite in his actions. I was very proud of him. When he left the store, his eyes were glowing. He came up to me, hugged me and said: 'Thanks so much, Plato, for everything.' Why did he do that? As he walked ahead with his shopping bag, he turned around and asked me if I had taken many pictures of him. And that I had, I can assure you.

"When we got home, the first thing he wanted to do was print the photos, so that 'the episode would be ready before I go home.' The next day he stood at the door with his new shirt on and his whole face lit up. When we got to The Pictorium, he wanted me to take more pictures of him in the shirt. He went on to picture-talk the entire morning about the event. With everyone. All at once he called out to me: "Plato, can we go shopping for a tie and socks next week?!' I've promised him that.

"P.S. I forgot to tell you that it was also a negative event. He dropped his glasses on the floor and one of the lenses popped out. I thought that the day would be ruined, but that was not the case. Thomas's reply was: 'Let's take a picture of it and put it up on the board. Then we'll get them repaired and I will have pictures of that too.' So, now we have put up the first photo of the broken glasses and a final one when they are in one piece. And in between there are 5—9 empty spaces for pictures to be taken.

"Have a nice weekend!, Göran"

### RIGHT TO TAKE THE INITIATIVE

One thing is for certain, Göran does not want to make decisions for Stig and Thomas more than is absolutely necessary. It has resulted in Göran signaling them with a wave of the hand about things they can do on their own, at times even waiting them out. But all the new possibilities have resulted in Stig and Thomas starting to take the initiative entirely on their own.

"Thomas asked me: 'Plato, you don't happen to have a bag at home that I could borrow?' It's as if the more information pictures we make and the more we create, the greater the new initiatives they start taking themselves.

"Stig didn't have any bandages left on his arm when he came today,































but suddenly he wanted one. I asked why. He pointed at the picture of Christer and explained that he had a bandage and so Stig wanted to have one too. Maybe to get a little attention?

"Thomas just got his new computer. He's decided where he wants it. The next day he all of a sudden came rushing in and said: 'Plato, Plato, there aren't any outlets in the room!' His next question was: 'When can I get pictures in my computer?' He can talk and wonder about all sorts of things."

#### ATTENTION

Closely related to taking the initiative is one's own attention, judgement, and desire to try something new. An example among many:

"We drive the same route from the area where Thomas lives every day. Thomas has seen a motorcycle there that he likes. One day when we drove by he said: 'Plato, the motorcycle isn't there today.' I hadn't really noticed myself so I had to turn and look and sure enough, there was no motorcycle!"

#### WHEN-NOTHING-HAPPENS PICTURES

There is so much we do not talk about and because of that, in a way, does not exist. Even though we know it does. All the time spent waiting, all the pause time, for example. But how is it for Stig and Thomas? What do they grasp of all the time when nothing is happening? All those long eventless miles to Stockholm, for instance? The gang from the Pictorium continually documented the entire trip. Driving to Stockholm, as well as what appeared to be an eventless beginning of the trip is something they talk about.

What is experienced as eventless and non-existent contrasts sharply with the pictures of emotions and feelings. Or, as Göran wrote: "When I picture-read a year of Stig's emotional photos, I notice that I remember events related to them. But I also find it difficult to express feelings about them in all I see."

# THOMAS'S WEIGHT WATCHER SPECIAL

Thomas is overweight. For many, many years others have tried now and then to get him to lose weight: they have reduced the portion sizes, given him fewer portions, healthier food—and in between a lot of food to comfort, food to scare him from eating, especially from inexperienced staff. The results have been that Thomas has grown heavier and heavier. He finds it hard to walk, cannot bend over to tie his shoes, etc.

It took a while for Göran to understand that the road to success would be through pictures: pictures to display attractive dishes and to show Thomas how to go about losing weight. One day Göran sent the following e-mail:

"Thomas wants to send some new pictures of himself. His new

























Thomas watches his weight.

weight is 87.5 kilos. He was up to 102. He has really gone all out for this. Wants to have pictures of appetizing food. Some of your co-workers from Certec were here yesterday and we invited them to stay for coffee. But when it was Thomas's turn to take a piece of cake, he said he doesn't eat it anymore. 'I have my own.'

"He can now put on his own socks again. And today he picked out a picture of food he had eaten before and asked if he could have it again tomorrow. What progress he has made! I am really touched by it all.

"I forgot to tell you about Thomas's morning coffee break. He was able to choose between a baguette with marmalade and a cracker with lettuce, tomato, cucumber and a little slice of low fat cheese. Thomas chose the cracker. That one looks really appetizing. I'll take it. Mmmmmmm good,' he said and laughed.

"I've started planning a diet for him consisting of 1500 calories a day. In pictures, of course."

#### CONCLUSION

Now I have related and recounted. Primarily by cutting and pasting from Göran's e-mail and all of the photos he sent. While I have been writing, I have contemplated memory, among other things. And how we all have the need for documentation stored outside of our heads. Göran has always told me a lot about what was happening at The Pictorium, and I have certainly seen a lot myself. Otherwise we wouldn't have been able to create so much together. But what a difference it has made since Göran also started writing to me about it this last year, e-mail messages with text and lots and lots of pictures. It has provided a better basis, a more stable foundation upon which to stand. The better the foundation, the better the chances are for creativity.

It does not take much imagination to realize that the same goes for Stig and Thomas—but to an even greater extent. For they are unable to always say what they want, *even at the moment*, unless they have access to their documentation (in their case, pictures.)

Göran writes now and again that it moves him to see all that they are capable of. I am moved more by the fact that pictures are so important for them, that talking with pictures surpasses real life. The telling is more important than the events—perhaps because it remains after the telling



There are more participants than Stig and Thomas at The Pictorium, but none of them have been so drawn to using pictures as spoken and written language to the extent that Stig and Thomas have. For Annette, who already has a spoken and written language, it was certainly fun to have pictures of her cat, Putte, but that was all. Until they started to construct bouquets, each with its own special significance. Then Anette developed an interest in pictures too.



























in the form of pictures. Perhaps because it does such a good job of keeping track of the cause-effect relationships in the chronology it presents. Just consider Thomas's desire to have the picture of the shirt-buying event prepared before it was carried out. Not so that he would dare to do it, not because he needed to be prepared, but because in that way it existed before it actually happened—and would certainly have a happy ending. Trying on the shirt immediately after purchasing it was not the most important aspect. No, the most important was: "Have you taken a lot of pictures?" And breaking his glasses was not a catastrophe. Not at all. Their falling on the floor gave him an opportunity for yet another dramatic picture story, from catastrophe to full restoration.

*Does* all of this really have anything to do with art and science? That was how I began. My answer is: Yes, as a matter of fact.

This is how I see it:

Art and science are two human forms of expressions and activities. They push the limits, they challenge the existing way of thinking. Stig and Thomas and all other differently-abled people do the same. But according to the prevailing view of the authoritarian culture, it was a matter of imposing *its* pattern of interpretation on everyone and trying to make Stig and Thomas and others like them over, so that as far as possible they would be like the rest of us. And to the extent that they couldn't, we would take care of them and all that they needed.

But look at what they have taught us—when they can listen, when they can see, when they can search and seek. When they have the tools. For tools help to counter the most negative consequences of developmental disabilities for Stig and Thomas and many others, namely, their language disability.

Have you considered that without language it is almost impossible to learn anything? And if you cannot learn anything you become more and more abnormal as the years go by. On the other hand, even when people like Stig and Thomas gain access to language when they are in their 40s and 50s, almost anything can happen. *Their cognitive development over the last seven years widely surpasses what is normal for middle-aged people.* 

But the questions? And answers? And the relationship between them? Well, they are all included there in a constantly changing mixture. Let me start with the very deliberately structured cognitive environment at The Pictorium as is apparent from the many photos in this report. There is much that is so clear while at the same time being so beautiful—and they have all participated in doing it themselves. But suddenly Göran *changes* something in the environment or in a concept—and those around cannot help but react. They see variations, are challenged, have to continue thinking.

On top of it all are all these blessed study visits (that at times are a lot, but still!), and Stig and Thomas are given the opportunity to talk and talk and talk. That is, the feeling that they can give their *own* answers, and

























Cooperating on their own in the new café.



Stig was institutionalized when he was a child. Since then, he has not had a place of his own. They recently started building a new apartment building where Stig will soon have his own apartment.

that others can understand them. This leads to their own question—in order to tell more and more and more they have to know more and more and more, and so more and more has to happen that they can take pictures of. Even the existential exits: feelings, emotions, thoughts, Who am I?, Why did it end up being this way?, What do I do after that?

## From one role to four

Stig and Thomas have gone from being *receivers* to mastering the roles of being:

*Senders* (to those nearest, to all who come for study visits . . .) with the help of pictures.

Searchers (inward and outward) with the help of pictures.

*Givers of feedback*—they can give feedback to all who ask for it. With the help of pictures.

## Spoken and written language

It is important to see that pictures are just as important for Thomas as for Stig. For even though Thomas has now acquired a rich spoken language, he has no other written language than pictures. They are there as fixed point when he is looking for new variation and taking the initiative.

#### Know the World

A long time ago, Certec attempted something based on a gigantic idea. *Know the World* was the name of the project. The basic idea was that people with developmental disabilities are just as dependent as the rest of us on receiving assistance in thinking and remembering from outside of our own heads. So they should also have access to reference books, right? Their own encyclopedias. The Swedish National Encyclopedia has been made accessible to a great extent for blind users, for example. But who has thought of the needs of people with developmental disabilities?

Know the World was a great idea. But it was ahead of its times—and the project was too limited in scope. But we got as far as the realization that Know the World needed to be individualized, based on the user's own experiences, own pictures, and own environment. Because when it exists out there, reliably documented, a person has a foundation from which to progress. Our metaphor in Know the World was a bookshelf on which each and everyone had his or her own book. Each time a person opened their book, they could choose to remain with the material that was already there or add something new.

Now it strikes me: is it perhaps this that is happening at The Pictorium, even though we had never thought in terms of constructing reference books? Perhaps the *Know the World* metaphor should be revived, at least as a form of thought support. Besides, it has in practice an entirely different potential for success now than 5—10 years ago. For now the































information technology *exists* that makes it possible to start more with the questions instead of the answers.

Who knows? Perhaps in the future we all will have more or less individually adapted "reference books": encyclopedias that have a structure and logic which are not the same for everyone, but are instead suited to just that person. Today there is still a considerable difference between free searching for information about a subject on the internet and looking it up in a reference book. That difference, I believe, paves the way for something else that will arise, something new: something that is more user steered in content, form and function than the old encyclopedias,.

We just may be saying in ten years' time: It actually *started* at the Pictorium!

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In today's world, so much knowledge is developed through a steady stream of short research projects that longer ones are becoming more unusual. That is why we decided to pause and look back over the seven-year-long joint endeavor between The Pictorium and Certec. This was also seen as a short-term project from the beginning. What has sustained it over the years? The answer surprised even us: its staying power has arisen from its core, in the convergence of art and science.

Such a meeting is part of what our culture and society often advocate in comprehensive terms. Conscious efforts of a similar nature are at times carried out from within the worlds of art and science. But in this case the convergence was not at all part of the original intention, and we who have participated in the work have not actually considered it in those terms from within the project's framework. After so many year of not seeing what was staring us in the face, it is thus exciting to raise the question about what is holding it all together, what the linchpin can be. Is it perhaps so elementary and at the same time so exquisite that the questions of art, and the questions-and-answers of science have happened to find a meeting place, unusual though it might be.

You can also find this report at: www.certec.lth.se/doc/artandscience

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