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Jönsson, Bodil; Philipson, Lars; Svensk, Arne

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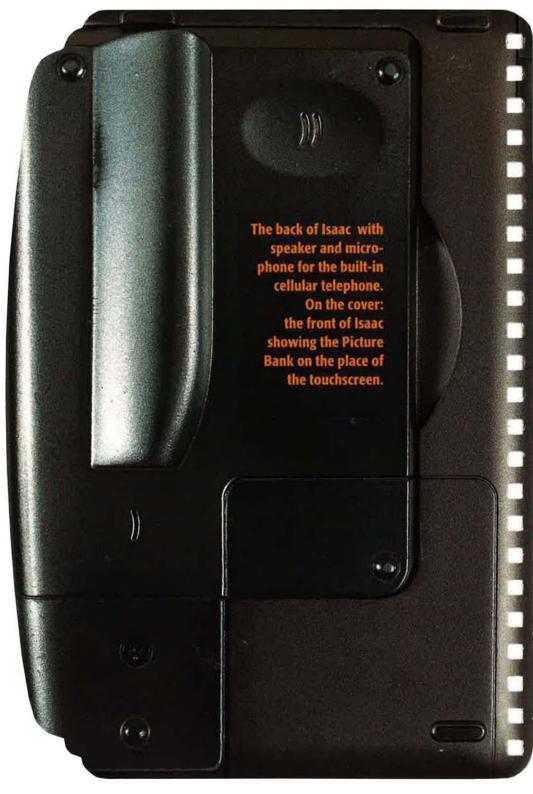
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Bodil Jönsson, Lars Philipson, and Arne Svensk

Certec



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Certec

Certec, Center for Rehabilitation Engineering Research, Lund University

Certec
LTH
P.O Box 118
SE- 221 00 Lund
phone +46 46 222 46 95
fax +46 46 222 44 31
email certec@certec.lth.se
URL http://www.certec.lth.se

Design *Karin Rehman*Cover photo *Bo Wiberg*Illustration p. 15 (to the left) and p. 17 *Johan Bergstrand*Photo p. 16 *Lars Cardell*The other pictures were taken by the Isaac users and have limited resolution.

Printed and bound at Trydells Tryckeri, Laholm, 1998 © 1998 Bodil Jönsson, Lars Philipson, Arne Svensk and Certec ISSN 1101-9956 OUR YEARS AGO, on 15 October 1993, we came up with the idea of creating a personal digital assistant for differently abled users. Our source of inspiration was among other things the Newton, a pocket computer with a touch screen, which had recently been released by Apple. The story of Isaac, as it came to be called, from the first vision in October 1993 up to Science Piction, in September 1997, is told in »Isaac I, Isaac II, Isaac III.«, [1].

The following is a short version of this four-year story. Its focus is on Isaac's impact on users and researchers. The story is about content and method as well as result and process. The most important thing is the significance of digital pictures to the power of initiative, internal relationship perceptions, and the language of differently abled persons. »Action learning«, cf. [2], is a key concept to both users and scientists, separately and for these groups together.

The results are remarkably good and will require extensive analysis. What might be achievable when personal pictures become everyone's property, and our previous restriction to more abstract and impersonal pictures disappears?

An introductory example

Let us begin from an unusual angle: Alan Alda's visit to the main center for Isaac users, The Pictorium, in Lund on August 18, 1997. Alan Alda is the host of the popular TV series »Scientific American Frontiers«, which airs once a month on the American public television network PBS.



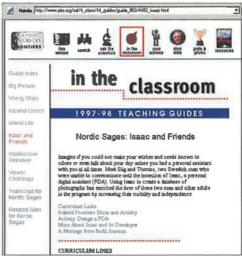
The theme of the program in January 1998 was major research breakthroughs in Scandinavia in recent years. After an extensive search, the producers chose Isaac and its users as one of the two Swedish contributions to the program. The day of filming arrived, and Alan Alda whirled into The Pictorium.

He was unprepared for the huge number of pictures, the bar coding, the bar code scanner and the computers (him not knowing what to expect is part of the program concept). He tried talking to the users and after a while he realized that he could communicate with them by referring to their own pictures. First, he tried to show them what kind of food he likes. He chose a plate of boiled potatoes. When this picture appeared on the screen, S., one of the users, turned immediately, and pointed to a picture of an older lady on his phone list. Not once, but several times and with great emphasis!



What was S. trying to tell Alan Alda? What would Alan have understood if he had known more about S.? Simply that the users at The Pictorium grow their own potatoes, that they grow them in the lady's garden, and that the next day they were going to harvest their potatoes! Not a bad chain of thought for a person who has a developmental disability, who lacks a spoken and written language, and who has a very limited sign language. As this example illustrates, S. has grown tremendously through the use of Isaac. He is able to handle a visit from an English-speaking actor and can tell his visitor about one of the many new internal relationship perceptions he has acquired. Before Isaac, this would have

The above question, »Can you actually be certain that you understand what S. means?«, was asked of Bodil Jönsson in »Ask the scientist« at www.pbs.org/saf. The site also contains all the other questions and answers about followed the Scientific American Frontiers feature »Isaac and his friends«.



been completely impossible. S. was unable to show those around him what he wanted to say and they were unable to guess. But with about 10 000 digital photos of his own, he has turned the pictures not only into words but into a language.

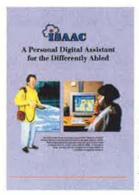
Can you actually be certain that you understand what S. means? Well, it depends on who 'you' are. The advantage of digital pictures to strangers who meet S. for the first time, is that they can immediately carry on a superficial conversation with the aid of the pictures. But to those of us who already know S., the pictures constitute a different kind of progress, as can be seen in the example given above. Now, S. is telling us that the instant he sees a plate of boiled potatoes, he thinks of the potatoes growing in the soil, of the garden where they are growing, of who owns the garden and of when the potatoes

will be harvested. Accordingly, we are able to discover complex internal relationship perceptions in a way that outsiders cannot. We can ask him questions, and we can carry on a completely new kind of conversation with S. There is no magic to this – the difference between communication between strangers and communication between confidants is of a similar nature whether you communicate with pictures or with words. In our opinion, the risk of misunderstanding S. when communicating via pictures is actually smaller than the risk of misunderstanding other people when communicating with words. The reason is that S. is not satisfied until he knows that we have understood.

Was there a need for Isaac?

Isaac was created entirely at the initiative of engineers and scientists. No user had expressed a »need« for an Isaac and neither had parents or staff or even researchers in cognition,

habilitation, or education. The only real indication of the possible creation of an Isaac was an article by Gregg Vanderheiden of the Trace Center, Wisconsin, USA, describing »The Companion« [3]. This was a somewhat science-fiction inspired tale of the support which a technological »companion« might provide to a differently abled person



Technical brochure about Isaac, 1994 in the future. The story did not play an active role in the creation of Isaac, but to some of us who were involved it was a stimulating background story.

There is no doubt that the initiative was on our side, rather than with the users, and that we retained it for the first year. Now, however, it's impossible to distinguish between ideas generated by us and those coming from users. There is a recurring criticism of engineers that they make technological developments for their own sakes. The Isaac project has certainly not escaped that criticism. It is true that we had almost no results at the user level for the first year. Certainly, user results are not necessarily generated by the mere existence of attempts to create technological solutions. Now, however, there are numerous results and the project is largely user-controlled, earning it a great deal of respect and giving it an ever wider audience.

We believe that it is important to emphasize that one cannot rigorously apply the principle of user initiative to the initial development stage. If the only respectable and relevant needs are to be those formulated by the user at the outset, we may deprive people with disabilities (and in particular people with developmental disabilities) of the opportunity to use technology as one of their languages. On the other hand, it is essential to insist on a gradual transfer of initiative and control to the user. An evaluation of whether or not this requirement is fulfilled is an important part of the outcome of a project. Consequently, this aspect must be thoroughly documented.

You cannot rely on needs to be formulated by the users just because they exist. By providing a solution, technology is a very good means showing that a problem exists and what it consists of.* In the very beginning, it may be difficult, sometimes impossible, to involve the users. On the other hand, later on in the process, the initiative may shift making it difficult for those with the original initative to keep up with all the ideas which are being generated.

^{*}See »Certec's Core, [5]«



Don't leave home without it!

What really happened?

It was a *very long process*. We were warned that it would take a long time for differently abled persons to get used to new possibilities. But this turned out not to be the case. On the contrary, where Isaac took root, things moved quickly. What make it a very long process is that every new application of technology results in the sudden appearance of abilities and wishes which were not previously perceived. Often, it really is as simple as this: *you cannot know until you have tried!*

You cannot know until you have tried!





http://www.certec.lth.se/publications/books/technology/ http://www.certec.lth.se/publications/books/tools/

The Isaac project has been documented continuously. It appears in its preliminary stages in the book »Technology and Differently Abled Persons« [6]. Later, we described some of the insights it whirled up in »Just give us the tools« [7]. This book generated many strong emotions, positive as well as negative, and it spawned a healthy debate. Unfortunately, however, Isaac's detractors did not come to observe users in action. They believed that they could make an assessment from a distance, which necessarily limited the debate.

The importance of inner pictures

The mock-up of Isaac – the first concrete technical model – enabled us to communicate the project to grant givers and other interested parties and it played a crucial role in our work. The first finished product, Isaac I, turned out to be exactly like the mock-up in its shape, weight and everything.

To a high degree we are controlled by inner pictures: the end result often turns out to be amazingly like the original picture. Consequently, one has to make one's inner picture visible, for example in the form of a mock-up, so that others can see it, too, and criticize it as early as possible.

Lesson 4

When a high-tech idea is introduced into a no-tech environment (without even passing through a low-tech one) and finds its place there, almost anything can happen.

But you need a »computer custodian« and a group for brainstorming.

Continuously.

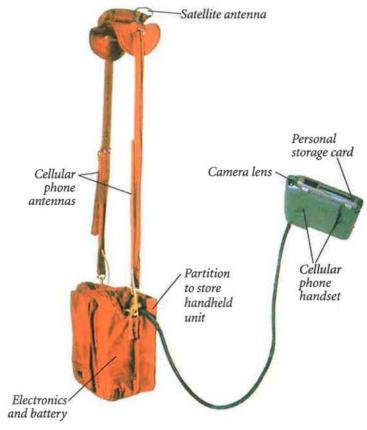




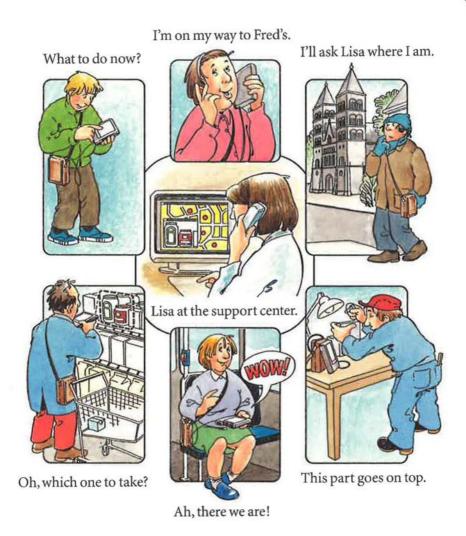
The simularity betweed the mock-up and its implementation, Isaac 1, is obvious.

Initially, neither the mock-up nor anything else helped elicit suggestions from end users, friends, parents, or staff. Later however, they were brimming over with ideas. *Continuous technical support* is needed if we are to make use of these ideas. It must be possible to turn new ideas into reality. Continuously.

Why were there so few initiatives from the users and those around them? We do not believe that it was because of their unfamiliarity with technology as such. Rather, a high-tech and a no-tech environment are based on completely different underlying thought patterns. This coming together needs to be given time. TTT – Thoughts Take Time.



Isaac combines in one unit a pen-based computer, a digital camera, a GPS satellite navigation receiver, and two cellular phone channels for both voice and data. A number of such mobile units can be in wireless contact with a remote mental companion who can give advice over a cellular phone, wich is also part of Isaac. At the same time, the user can be located on a map, thanks to a satellite navigation receiver. However, the GPS-registration is optional – the user decides whether he wants his location to be known or not.



What took root?

Isaac combined four functions: digital picture communication, a simplified clock and calendar, a telephone facility, and localization via GPS. Only two of these caught on and were developed further: digital pictures and the clock/calendar. But »only« is not really the right word, these two functions took off in a way we would never have imagined!

Isaac's clock function was made available through Clock o'clock [8].

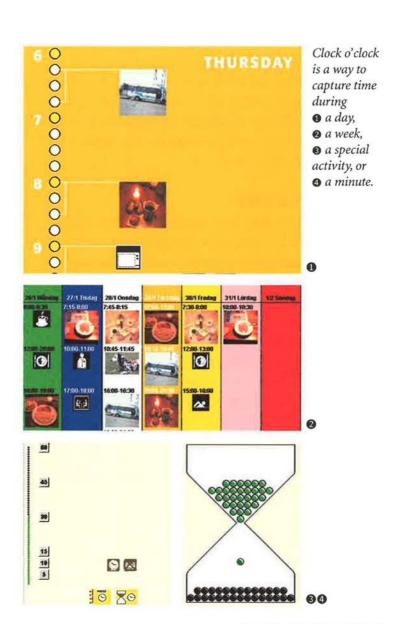
To capture time

Clock o'clock's dependence on Isaac is merely an historical one. An ordinary powerful computer and software are required in order to use Clock o'clock in its existing form. Features include:

Every day has a color. Time is shown as length. The vertical clock (the top always represents the present time) shows the hours as numbers or symbols (the user's choice). The screen includes 4 or 8 hours (the user's choice). Events may be incorporated as a pictograms (large selection) or as personal pictures (jpeg format). An analog or digital clock can be placed next to the clock.

It is easy to create weekly diaries for the desired number of weeks. Everything can be printed out.

Clock o'clock also includes an »Hour Bar« which can be used for learning how long an hour is. The Hour Bar is shown as 60 lamps turned on. With each passing minute one lamp is turned off (thus, time is shown as length, just like on the Isaac



19 · WHAT ISAAC TAUGHT US

clock). The time bar can start at 60, 45, 30, 15, 10, or 5 minutes. The Minute Glass: If you click on the upper part of the Minute Glass it is filled with 60 seconds (60 balls). The balls fall down through the middle of the minute glass at a rate of one ball per second. The experience is enhanced through the use of sound.

A multitude of pictures

As for the pictures, there were soon so many that the users could not keep track of them despite having excellent database software. *They lost power over them*. The first makeshift solution was the software program »Mymories«. But it was too small and too complicated. Or rather, it was too limited: the user had to fit into its framework. The next step was *the Picture Bank* [9].

We opened Isaac's picture database to pictures taken with a Casio digitalcamera (a color camera with a viewfinder function and a large bright display). In this way, the Picture Bank became *available to many*. The picture/computer interface was simplified by bar coding the pictures automatically when they were downloaded from the camera. The pictures were also printed and made physically available in the room (the database includes thousands of pictures). As a result, the users were able to regain the upper hand – they are very good at handling bar code scanners, printers, etc.

We have managed to attain our goal of making the Isaac concept available to many. We knew that we wanted to use the few original Isaacs to gain new knowledge about the user

Lesson no. 2 (again)

You cannot know until you have tried.

Lesson no. 5

Things start happening when empowerment works.
Otherwise not.

Technology always
develops more quickly
than you can imagine.
And then it turns out to be
completely different
from what you expected.



Göran Plato and the Picture Bank

group. In that way, we might be able to contribute to making the concept widely available. But, we had no idea that technology would enable us to make many of Isaac's capabilities available as bits rather than gadgets. As usual, the technological development was much faster than expected, and – even more importantly – it differed significantly from predictions. (See [10] for an advanced historical survey on this subject.)

Isaac has now come as far as Isaac III, the Science Piction concept [11]: the possibility of picture communication over the Internet. At the moment, we have no idea where this might lead. But we do know that the Isaac users at The Pictorium were able to reach millions of American viewers in January, 1998, and that the contents of http://www.tryckolera.certec.lth.se [12] became widely known.

What has happened to the users?

The early changes were described in »Just Give Us the Tools« [7]. These changes have not stopped, but rather expanded.

Spoken language development

One of the users, T., has developed his verbal language and his personality in a way which was previously unimaginable. He is working with a speech therapist to develop and document his language.

An example: previously, T. would rarely say anything without being prompted and what he did say, he kept as brief as possible. If someone asked »What did you have for lunch today?« he would almost always answer without reflection: »meat and potatoes«. (Which surprisingly often was the case. And, anyway, the person who asked would usually be satisfied with that answer whether it was true or not).

In the spring of 1997, without even being apostrophized, the same T. said: "The beef soup was very good yesterday, Plato. Thank you for making it!" This is just one of many examples of significant changes. T. now takes the initiative, he is able to express himself, he remembers, and he can plan for the future.

It is about empowerment and the power of initiative. It is not common for differently abled persons to take the initiative to communicate through pictograms, for example (unless somebody else has supplied the pictograms). But there is no end to their initiative when it comes to using their own pictures. It is as if your own pictures get something going inside you.

Internal relationship perceptions

In [13], Justin Leiber describes so-called internal relationship perceptions. He maintains that breakthroughs in internal relationship perceptions can create an explosion in an individual's inner world. He puts forward the example of Helen Keller, who became deaf and blind at the age of 18 months and was unable to communicate with the world around her for many years. But with her classical discovery of the sign for water (while by a pump where the water overflowed her cup) her language began to develop at break neck speed. In describing her life before this event she claims she was not even aware of her own existence:

»Before my teacher came to me, I didn't know that I am. I lived in a world that was a no-world. I cannot hope to describe adequately that unconscious, yet conscious time of nothingness. I did not know that I knew aught, or that I lived or acted or desired. I had neither will nor intellect. I was carried along to objects and acts by a certain blind impetus... I can remember all this, not because I knew that it was so, but because I have tactual memory. It enables me to remember that I never contracted my forehead in the act of thinking. I never viewed anything beforehand or chose it. I also recall tactually the fact that never in a start of the body or a heart-beat did I feel that I loved or cared for anything. My inner life, then, was a blank without past, present, or future, without hope or anticipation« [14].



It was Torsten Hägerstrand, legendary professor emeritus of social geography at Lund, who directed our attention to this article and to the analogy between what we are observing with respect to S. and T. and the Helen Keller experience. We are greatly indebted to him for inspiring us in this way.

We believe that somewhere in the phenomenon of internal relationship perceptions lies the key to development. Perhaps the importance of internal relationship perceptions is the reason why The Pictorium became the main home of the original Isaac. One might be led to believe that it was the creativity and work capacity of their mental companion, Göran Plato, which lifted the participants. But the most important reason was probably that during its ten year existence (seven of which preceded the introduction of Isaac), the aim of The Pictorium has always been the creation of such perceptions (the participants have gone to get clay and made their own cups, they have grown their own potatoes, made their own pillows, etc., etc.). When the Isaac project opened up a new opportunity to develop internal relationship perceptions to an extent which so far had been unimaginable, a development explosion became possible.

There may be hidden conditions which explain why the use of Isaac has developed so successfully at The Pictorium. One of these may be the way pictures were used by the participants before the advent of Isaac. They had never used pictograms, always real pictures, mostly from newspapers and magazines. The object has always been that the world outside the care services should be familiar to the participants. Therefore one should avoid using symbols, went Göran Plato's thinking.

An example: During the past few years there have been many study visits to The Pictorium. Thousands of visitors have passed through its doors. Some of them have been journalists. Lena Nordlund of the Science department of the Swedish Broadcasting Corporation first visited The Pictorium more than two years ago. She returned in August, 1997, to do a feature for her radioshow (available in Swedish [15]).

A new language will not take root with its users unless it can also be used outside its specific environment.

When Lena arrived, one of the Isaac users immediately found a picture from her previous visit among the several thousand pictures in the Picture



Bank. It is important to be able to show how things are related.

In [16], Dunbar emphasizes the emotional rather than informative character of language. The emotional side is about a kind of small talk, about confirmation of the existence and environment of every individual. Naturally, differently abled persons need an equivalent to the way other people may meet somebody who asks »Where do you live?« and when the answer is »Plattsville« react by saying: »Then you might know Mr Brown«. They can have an equivalent in many, many, many pictures which depict themselves and others in the relevant context.

This insight may also be important for older people. The time in life when the fewest photographs are taken is when people are past sixty or seventy. Perhaps many more photos ought to be taken in senior citizens' homes to keep old people's memory alive when it is breaking down? It would be simple to have your own »Sweet Memory Channel« on your TV with pictures from your past, and an »Events of the Day« or »Events of the Week« where you could see things which are closer in time, yesterday and last week.

The picture's importance to accessing the past

Through their own pictures the Isaac users were able to bring the past concretely into the present. Suddenly, it was possible to talk about yesterday's events – today! This provided a basis for variation which is a necessary condition for an explosion in learning. Learning *is* variation and it requires something to base the variation on [17].

T's sudden language development began with a stage where he would stand and talk to the pictures. It was as if the external pictures brought internal pictures of yesterday to life, pictures that he must have had before but which perhaps he had been unable to reach.



The picture's importance to accessing the past cannot be overemphasized.

Our awareness of its importance is not very developed (if at all).

The Norwegian linguist Julie Feilberg claims that monologue is very important to children as a precursor to dialogue [18]. This fits very well with our observations of T., with how he first puts his thoughts together and then likes to talk to others about them. He is at his best with both pictures and language but, now, he speaks without pictures as well.

The pace

Science Piction makes it possible to strech time like an elastic band. If you have difficulty finding pictures or words, you can keep at it for almost as long as you wish. You can put together what you want to say surreptitiously if you wish (with the right to make a mistake without being observed), and then experience the triumph of being understood by those around you.

The time line

Both the young and the old need a timeline with fixed points representing details in life. Pictures make it possible to relate to the time line: it happened when Göran had a beard«, when Sverker worked here«, when Karin was wearing her red dress«. »It must be our second trip to Stockholm, not the first: my hair was long«. How can you manage this without pictures if you do not have words?

The milestones of life

There are a number of major events in life, the ones that become milestones. The Pictorium's recent move to new



premises is a perfect example of a milestone for some of the Isaac users. How could they talk to each other about this move without all their pictures?

Precision

Imagine that somebody was showing you a pictogram of a car, and that when he did, he would have to face more than twenty questions:

Do you want to go for a car ride? Shakes his head

Do you mean that you went for a ride

yesterday? Shakes his head

Do you mean that Charlotte didn't

have a car today? Shakes his head

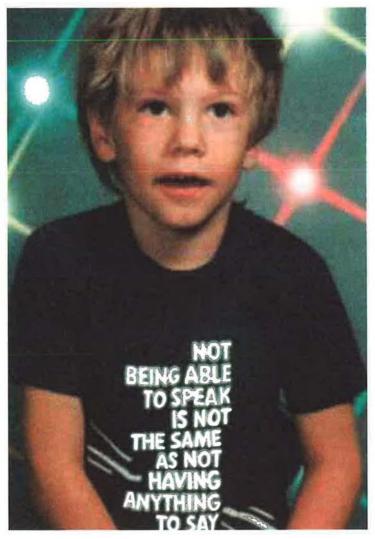
Do you mean that the car from the

day center has broken down? Shakes his head...

Exceedingly frustrating for both parties. If you are used to the *precision* which can be achieved by communicating through concrete, specific pictures, it must be very difficult to be without them from time to time. It is almost like losing your voice to a person who speaks. A person who is temporarily mute can manage the essentials, the main points, by writing notes. But all small talk disappears. The situation is the same for a differently abled person if she does not have her pictures. She might be able to manage the main points with pictograms, but nothing more. She will not be able to relate small events or associations (like Alan Alda's potatoes). Earlier, nobody, not even S.'s mental companion, had a ghost of a chance of divining all the things S. wanted to tell. Because he had so much inside himself. And now much of it is coming together for him.

An example: I, Bodil, often phone The Pictorium and usually S. or T. answer the phone. Previously I always had to ask for their mental companion. Now I can tell S., for example, what I want. Of course, I am not able to keep track of all their pictures and adapt my message accordingly. But when we have finished talking, I know that he will point to pictures for his mental companion until he in turn has understood what I wanted. If I talk to T., he can usually use words to relate what I have said.

Moreover, when the users at The Pictorium do not have access to their pictures, they also experience another kind of imprecision – the uncertainty about what those around them mean by what they are saying. How can you know it is *that* cottage we are going to, if there is no picture of the cottage?



Not being able to speak is not the same as not having anything to say. http://www.home.aone.net.au/lindsay/

It isn't just any cottage, it is *that one*! *She* is the one who is coming for a visit, the woman in the picture. Etc.

Not always a smooth ride

Naturally, it has not always been a smooth ride for the Isaac project, neither externally nor internally. Internally, however, it was a matter of the pleasant challenges created by the fact that the participants are growing so quickly that those around them cannot keep up (a classic problem when development work is concerned, it is those around them, not the people concerned, who think that things are moving too fast). It is most noticeable when it comes to housing. One of the results of the project is that the participants might be ready (or perhaps even more than ready) to move into their own accommodation with a personal assistant. Their newly gained independence does not fit in well with the collectiveness of their present living arrangements where "everything" is taken care of for them.

What the users find most difficult at the moment are holidays and vacation periods when they do not have access to the technology. One of the participants has a computer at home, but so far, he has not been able to get enough out of it on his own. Perhaps he never will, which may not be his fault: he has an extremely outgoing personality, but he needs people around him who are prepared to communicate with him through pictures. Because, now, he really can *talk* to us through pictures.

Lesson no. 10

The pictures, the language, the communication has become crucial to the participants.
Interruptions, for example during Christmas and vacation periods, cause obvious distress.

Concept formation

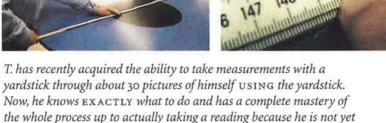
It takes many pictures to form a concept. Not only for us but also for differently abled people. Rather than having simple pictures and reserving *one* picture for *one* concept, we have found that what is needed is a multitude of pictures for communication inside the individual and, above all, for communication between the participants. This is not a very surprising conclusion: a child will see many lamps before acquiring the concept »lamp«. And a wealth of pictures are needed, not only for concept formation, but to an even greater extent for internal relationship perceptions to develop. A language is not only words, but also links between words.





able to say »151 cm«. Thomas has gained his understanding of the

yardstick thanks to a multitude of pictures.



(15) 152 kg

Lesson no. 11

Many pictures, illustrating the same thing or event, are needed for communication to occur inside or between individuals.

It is impossible to know which picture tells a user the most from the beginning.

But, even if one picture turns out to be better for a certain user in a certain situation, it is as if the other pictures are needed too, perhaps precisely because they generate internal relationship perceptions and concepts.

Lesson no. 12:

Many differently abled people are able to manage long chains of thought when they can create them themselves through picture representation. This is partly because it is possible to approach a chain one step at a time - many times. But often users have been able to develop complete chains of undreamed internal relationship perceptions and whole concepts.

Isaac user group

An Isaac User Group was formed in October, 1997, whose members are the beta testers of the Science Piction concept. The main participants are children and teachers in three schools. Freya [19], an adult woman who has autism and who has spent almost her entire life in closed psychiatric care, is another participant. Both the schools and Freya and those around her have a long-standing relationship with Certec, and we are eagerly anticipating the results of their involvement in Science Piction.

Inspired by our work, the user group members have been using digital pictures for well over a year. Some of their activities involving the pictures can be seen in the video »I did it!« [20]. They span a broad field, from providing security and the possibility of co-determination in time and space, to a special needs education class actually gaining appreciation as a resource because of their expertise in digital pictures.

In one of the schools, the *multiplicity of identical pictures* has proved important. For example, it was a revelation to A. when eight sleep pictures appeared on the Certec clock. It made him realize for the first time that we sleep *all* night. Moreover, he also needs a schedule for the whole week, the whole year, even, from the start of each school day. The computer makes it simple to have such identical pictures come back when they are needed. They seem to provide a sense of security which cannot be conveyed in any other manner.

A.'s teacher wrote to us at the start of the 1997 fall semester:

»We have been back at school for little more than two weeks It has been total CHAOS! We all know that a person with autism has the ability and the will. What I did not imagine was that a six-year-old boy would be able to muster so much muscle power that I would be out for the count, completely exhausted, every night.

He is capable, he is probably a very wise little boy, and I haven't doubted for a second that things will get calmer and more pleasant. Nor do I doubt that all the energy he has been using during these first school days to test me and find out how far he can go soon will abate. It hasn't been easy to take photos, run a thousand meters, roll around on the grass slope making sure nobody gets hurt and at the same time keep things pleasant for the rest of the students. Thank heaven for my excellent colleagues who put up with working non-stop and for a principal who agrees to help doing rounds during the breaks and who tries to provide some encouragement.

But, now, in the third week of school, we have pictures of the boy in most of the situations we encounter each day and CALM is reigning and things are getting better by the minute. I don't know what I would have done without the camera, without the computer, and without the belief that having their own pictures for every possible situation is necessary for these children. Think of the effort we used to put into believing that circumstances in the child's environment were responsible for this power struggle!

This is a very short summary of my day at present.«

Certec, too, is looking forward with confidence. We are particularly pleased that there are users and staff who are beginning to believe that problems which earlier seemed insurmountable can be solved with the help of technology.

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