

***Not being able to talk is not the
same as not having anything
to say***



**Alternative
Communication
with
Digital Personal
Photographs
for
People with
Cognitive
Disabilities**

Master thesis

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ABSTRACT

Many people are in need of alternative or complementary means of communication. People with cognitive disabilities make up one group who have problems understanding language. The use of digital personal photographs is a fairly new alternative method of communicating and the advantages are many. A photograph is easy to understand, stimulates speech, supports memory, works as documentation of the past and is naturally interesting.

This master's thesis tries to give as complete a picture as possible of the use of digital personal photographs and to connect today's use with the future design of computer-based communication aids. The importance of picture, camera and computer accessibility is emphasised, as well as the need to consider the whole context in all design work.

Keywords: alternative communication, autism, cognitive disabilities, computers, constructionism, design, digital personal photographs

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Ronneby. May 2000

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1 Introduction

This is a master's thesis from the People, Computers and Work Programme (MDA in Swedish) at the University of Karlskrona/Ronneby (now Blekinge Institute of Technology), Sweden. In the MDA Programme half of our studies are in the area of computer science and half in human work science. The emphasis is on design and development of IT and how people use IT.

1.1 Why this subject?

My interest in disability issues derives in part from being related to disabled individuals and from having worked in the area. I also have a university degree in Social Service – Care of the Elderly, Disabled, Mentally Retarded and Multihandicapped, from The Baltic International School of Public Health in Karlskrona, Sweden. The past four summers I have worked as a unit manager in disability care. I wished to combine my previous experience and education with new knowledge, which is why I chose to focus on people with cognitive disabilities in this master's thesis.

The title is taken from the home page of J. Norman-Bains¹.

1.2 Entering the field

In the autumn of 1999 I contacted the Division of Rehabilitation Engineering Research² (Certec), at the Department of Design Sciences, Lund University. I had earlier come in contact with material from Certec in my summer job, since Certec does research in technology for people with different disabilities. I got in touch with Arne Svensk and he invited me to visit Certec to discuss suitable areas of study. The first visit was in November 1999, when I met Håkan Efring and Arne Svensk from Certec and Björn Harrysson from Region Skåne. The meeting was very inspiring and I left with lots of ideas and suggestions. After a conversation with my advisor, Björn Andersson, from the University of Karlskrona/Ronneby, I decided to take a closer look at the use of digital personal photographs.

¹ <http://www.isn.net/~jypsy/notbeing.htm>, May 31, 2000

² <http://www.certec.lth.se/>, May 31, 2000

1.3 Who should read this thesis?

Whom am I addressing? My intention is that everyone with an interest in the area should be able to read and understand this thesis. It can be staff that care for disabled people, relatives or researchers, but I am mainly writing for designers developing communication aids or other computer systems or applications for people with cognitive disabilities. Since those reading this thesis will have diverse backgrounds and experience, it might be appropriate to skip the chapters whose content one is already familiar with.

1.4 Thesis outline

1 Introduction

The first chapter is the introduction you are now reading. Here you will find the reasons for my choice of topic, how I entered the field, to whom I am writing, the thesis outline and finally some comments about the English translation.

2 Questions at Issue

Chapter two contains the questions at issue, i.e., the intentions with which I started my work.

3 Methods

The third chapter deals with the methods I used. They are mostly ethnographical in nature, such as observations, field notes and conversations. There is also a brief description of the day centre (a sheltered workplace for adults with cognitive disabilities) and the special schools I visited.

4 Cognitive Disabilities

In the fourth chapter I provide a short description of what it means to have a cognitive disability. I have also chosen to specifically describe the syndrome autism.

5 Alternative Communication

Chapter five is about alternative communication. I start with an attempt to describe what language is and why we speak. After that I give some examples of alternative ways of communicating and briefly compare them. Comments are included about interpreting pictures and spoken language and about accepting alternative ways of communicating.

6 Digital Personal Photographs

In chapter six I describe the digital personal photographs more closely. Here you will find many examples of the use of digital pictures, examples from my field notes and logs. These examples are slightly edited and presented in a different style than the rest of the text to show that they are from my fieldwork.

7 Accessibility...

Chapter seven is about accessibility, which I consider the most important condition for increased independence, which in turn is a prerequisite for gaining power over one's own life. I write about the importance of picture, camera and computer accessibility.

In chapter eight I write about the significance of the surroundings in the use of digital personal photographs. By surroundings I mean relatives, friends, organisations and society on the whole.

Chapter nine contains a discussion of my methods, technology, cognitive disabilities and prerequisites for good design for people with cognitive disabilities.

The last chapter contains suggestions for further areas of study.

8 The Surroundings

9 Discussion

10 Afterword

1.5 Names in the thesis

I have chosen to use the first and last names of the adults in the thesis with their permission. The children, on the other hand, I have chosen keep anonymous.

1.6 Translation

I have translated this thesis from Swedish to English myself. I have tried to explain notions and the phenomena that are typically Swedish. Some of the quotes are my own translation, even if they were in English originally. I have also translated the Swedish book titles in my references to English, with the English translation in brackets, even if they do not exist in English yet. Since the translation is my own, it might differ from the original.

2 Questions at Issue

The purpose of the thesis is to present the results of a qualitative study of the use of digital personal photographs, i.e., to examine who uses them, for what purpose, in which context and, primarily, how they are used.

There is not much previous research in the use of digital personal photographs. That which exists is often quantitative and with a narrow focus; studies that have been carried out with small groups of people in very specific situations, often a test or lab situation and thus out of context. The aim of the current study is to present a broad description of ordinary daily usage. It provides as comprehensive a description of the use of digital personal photographs as possible.

The thesis examines usage in order to illustrate the existing conditions and limitations of design. Can the knowledge of how people use digital personal photographs be used to develop good design for future communication aids? What are the prerequisites for good design and what are the limitations? Can you generalise the design implications found to apply to other areas of design concerning people with cognitive disabilities? I am interested in the areas concerning current usage and future design.

3 Methods

At MDA we apply ethnographical methods to study how people actually use IT. The word ethnography is derived from the Greek *ethnos*, which means ‘people’, and *grafein*, which means ‘write’ (Bonniers stora lexikon, 1985). Ethnography is, therefore, a descriptive science regarding the study of different cultures (Ely, 1993).

Ethnography

3.1 Field studies

Ethnographical field studies deal with participating in and observing how people work and act. It is a very visual way to work. What you see is what you note (Ball, 1998).

Observations

There are different ways of carrying out observations. Walcott (Ely, 1993) mentions three. The first is when you participate in the work you are observing; participate in the sense that you have your own tasks to perform at the same time as you carry out your research. Walcott calls this ‘the active observer’. ‘The privileged observer’ is a person who is known by the informants before the research begins and as such, easily has access to the information available. The third way is the most common; it is what Walcott calls ‘the restricted observer’. It is when the researcher comes from outside and so needs time to establish relationships and build trust.

‘Participating observations’ is an accumulated concept, that not only represents how ‘the active observer’ works, but also includes interviews, analysis and more (Ely, 1993).

During the observations you take field notes, which means that you quickly write down what is happening. These field notes are the foundation of what Ely (1993) calls a log. The log should contain the data needed to be able to analyse the material.

Field notes

3.1.1 Field notes

I have visited three special schools and a day centre³. During these visits I have made short notes of what I have seen and heard and after the visit I have made a clean copy of my notes. My log contains about 50 hand-written pages and a number of

³ A day centre is a workplace for adults with cognitive disabilities, such as mental retardation.

photographs and other materials that were given to me by my informants.

A closer description of the different places I have visited follows:

3.1.2 Tryckolera

At the Tryckolera Day Centre⁴ in Lund, Sweden, there are five employees with cognitive disabilities and two staff members. Of these people, two of the employees, Stig Nilsson and Thomas Åkesson, and one staff member, Göran Plato, work primarily with digital personal photographs. The other employees use them occasionally but not as much as Stig and Thomas. They have been using digital photos at Tryckolera for a long time.

I spent two days at Tryckolera in January 2000. Göran described the activities for me and showed me the premises. Stig and Thomas demonstrated how they use the digital photographs and I could also observe their work.

3.1.3 Fågelskolan

At Fågelskolan in Lund, Sweden, I visited a special class with six pupils. The staff consists of, among others, Vibe Björfors and Mona Ekelin. The pupils have different mental and physical disabilities. Some have fine motor disabilities and one of them uses a wheelchair. All of them have major or minor difficulties with speech.

I visited the class during two grey days in January and yet another day at the end of March 2000. I participated in different scheduled activities, such as the morning assembly and a music lesson. Both teachers and pupils showed me how they work with digital personal photographs and I had the opportunity to study how they work with computers. I also sat with the teachers as they told me about the activities and answered my questions. During the second visit I had prepared the questions in advanced.

3.1.4 Georgshillsskolan

Agneta Dyberg-Ek is the teacher in a special class at the Georgshillsskolan, in Hörby, Sweden. She has used digital personal photographs in her teaching since 1995. The class has four pupils, all with very different limitations, developmental levels and needs.

I visited the class one day in February 2000. Agneta showed me around and told me about the activities. I observed when Agneta worked individually with one pupil at his desk and with two different pupils at the computer. Agneta showed me other

⁴ <http://www.tryckolera.certec.lth.se/>, 2000-05-31

special classes that also use digital photographs. In addition, I had the opportunity to sit down individually with Agneta and discuss her work, at which time she demonstrated their digital cameras.

3.1.5 Ingrid Christoffersson

After my visit at Georgshillsskolan I went with Agneta Dyberg-Ek to visit Ingrid Christoffersson in her apartment in a group home in Eslöv, Sweden. Ingrid has thalidomide (neurosedyn⁵) damage and has been totally deaf since birth. She communicates through sign language. About two years ago one of the group home staff members, Kristina Nilsson, asked Agneta for help. Since Ingrid always has been interested in pictures and taken a lot of photographs, Kristina thought that Ingrid could use and be interested in digital photographs. They now participate in a project where Kristina and Ingrid work with the digital personal photographs about four hours a week and Agneta serves as their advisor.

I visited Ingrid one afternoon in her home. Kristina and Agneta told me about the work and Ingrid showed me her pictures. I observed when Ingrid, with the assistance of Kristina, worked at the computer.

3.1.6 Spandelstorpsskolan

I also paid a visit to a special class at Spandelstorpsskolan, in Karlskrona, Sweden. In the class there were five pupils, all with different types of mental and physical disabilities. Anna Hallqvist is their teacher.

I visited the class one day in the middle of April 2000 and started out by attending the morning assembly. Then Anna showed me, along with two pupils, how they work at the computer. In addition, all of us – teachers, pupils and myself – gathered around the coffee table and talked.

3.2 Analysing the data

Ethnomethodology is a way of analysing in which you assume that people do not have mental models for what they are doing. Instead you concentrate on analysing what is happening through observations of actions in their natural context (Preece, 1994).

Irrespective of the method of analysis you prefer, it seems correct to say that you, the researcher, have a duty to create meaning, to get something sensible out

⁵ Neurosedyn (thalidomide) was a drug prescribed in the 1960s to pregnant women against nausea. The drug caused physical damage to the foetus.

of your facts. No one else can do this better since you are so intimately connected to the shape and focus of your study and you have such an understanding of what you have studied. In this sense all qualitative research is personal.

(Ely, 1993)

By analysing my material, i.e., my log and previous knowledge, I have searched for examples of the use of digital personal photographs. I have focussed on what is happening, what the persons in question are doing and I have tried to arrange the examples into groups according to use. I have also tried to put forward the prerequisites for use and what would facilitate future use.

3.3 Other methods

I have used other methods in additions to my observations, field notes, log and analysis. From November 1999 to the present, I have kept a diary. It differs from the field notes in that it contains more feelings and unstructured thoughts. It is less official than the log (Ely, 1993).

I have also had access to an Internet-based conference group⁶, started by Henrik Danielsson at Certec. Here discussions are taking place and examples are shown of the use of digital personal photographs.

During certain periods I have had access to a digital camera, which I have used to learn the technique and to take the pictures included in this thesis.

I have studied relevant literature, much of it recommended by my advisors in Lund. I have also searched for literature myself and I have re-read previous course literature.

⁶ <http://www.certec.lth.se/bilder/>, 2000-05-31

4 Cognitive Disabilities

Cognitive disabilities imply difficulties with what are usually called our thinking abilities or intelligence, i.e., the abilities involving perception, memory, learning, language and so on. These disabilities can be caused by a variety of factors and mental retardation is one of them.

Mental retardation is a disturbance in the development of cognitive abilities before the age of 16. Cognitive disabilities can be present without mental retardation as the result of different types of dementia or severe head trauma in adulthood (Kylén, 1981).

According to Gunnar Kylén (1981) there are three different types of cognitive functions that we develop while growing up: arranging and rearranging of sensory impressions, thought operations and symbol function.

4.1 Arranging and rearranging of sensory impressions

Cognition helps us to create a sense of reality by processing and arranging our sensory impressions. The arrangement falls into five different categories: space, time, quality, quantity and cause (Kylén, 1981).

The sense of space answers the question ‘where?’ It makes us able to separate ‘here’ and ‘there’, ‘behind’ and ‘in front of’, ‘under’ and ‘over’ and ‘next to’. We learn to find different places, first the ones close to us then farther and farther away. Eventually we learn how to use different aids to find places, such as maps. Finally we learn about other countries and the solar system (Kylén, 1981).

Space

One major limitation to the sense of space is that we basically live in the here and now. What we can’t see doesn’t exist. The less severe the limitations, the easier it is for a person to find his way in different environments: from the ability in finding one’s way around the home; in a known environment with the help of landmarks; around several known environments with the help of landmarks; to the ability to take short cuts and understand that places exist that one have never been to (Kylén, 1981).

The sense of time answers the question ‘when?’ It makes it possible to separate ‘now’ and ‘then’, ‘before’ and ‘after’ and

Time

'later'. We learn that time is divided into days, months and years. We learn to tell time and that there is historical time, future time and eternity. A well-developed sense of time makes it possible to make plans (Kylén, 1981).

If a person's sense of time is very limited, (s)he has more or less well-informed expectations of what is going to happen. Known objects can trigger these expectations. When the limitation is less severe the sense of time can encompass the notion of days or weeks. One can also have difficulties using a clock, but still understand words like 'before', 'later', 'yesterday' and 'tomorrow'. If the disability is minor one can also tell time, understand historical time and future time. One has an increased understanding of days, weeks and years, which gives a better overview (Kylén, 1981).

Quantity

The sense of quantity answers the question 'how much?' It enables us to separate 'more' or 'less', 'longer' or 'shorter' and 'as much', 'the same amount' or 'the same length'. We learn numbers, to count and words like 'double' or 'half', 'none', 'all' or 'some', 'singular' or 'plurals'. We learn about natural and irrational numbers, integers, fractions and more (Kylén, 1981).

Major limitations in the sense of quantity mean that what a person sees exists and what one doesn't see doesn't exist. The less pervasive the disability the easier it is to separate small from large. One also has expectations about the size of different objects. One often has trouble with numbers but if the disability is less pervasive, one might be able to use the four basic functions of arithmetic. One usually still has difficulty with symbols of symbols, such as in dealing with cheques, which represent money that in turn represents some kind of value (Kylén, 1981).

Quality

The sense of quality answers the question 'what is it like?' We understand that things have a certain shape, colour or size and that this doesn't change. We learn to separate different colours, 'round' and 'square', 'light' and 'heavy', 'high' and 'low', 'hard' and 'soft' and so on. We also learn to separate different categories such as 'dog' and 'cat' and 'tree' and 'bush' (Kylén, 1981).

If a person has major limitations (s)he only knows how to use very familiar objects, for example, that a chair is for sitting and a bed is for lying down. The less severe the limitations, the easier one can actively examine objects as well as use familiar objects in a new way. One may be able to classify them, for example, 'my chair and my table are furniture'; and if the disability is minor one can even classify things one hasn't seen, for example, 'all chairs are furniture' (Kylén, 1981).

Cause

The sense of cause answers the question 'why?' We learn to see connections between different actions, for example, 'If I eat, I

will be satisfied'. We know that we will get wet if it rains, and if we are cold we can put on more clothes (Kylén, 1981).

With a major limitation in a person's sense of cause one might be able to recognise an activity and demonstrate that by laughing, for example. It can also mean that one gladly repeats interesting actions and if the limitation is minor one might try to perform these actions in different ways. Limitations might also imply that one has trouble transferring knowledge. One can, for example, handle ones own stereo but not another model. If the disability is minor one might be able to draw conclusions from earlier experiences (Kylén, 1981).

4.2 Thought operations

Gunnar Kylén (1981) differentiates between manual operations and thought operations. If we are supposed to rearrange the furniture in a room, we can do it either in action or just in thought. To furnish a room in thought is to make a concrete change in a concrete room, which Kylén calls concrete thought operations. Consequently we can also have abstract thought operations, that is, thinking without having a concrete object in mind. Abstract thinking is a problem when one has a cognitive disability. The more severe the disability, the more concretely the person thinks.

4.3 Symbol function

Symbolising means that we realise that an event can be represented by a symbol. These symbols can be sounds, pictures, letters and so on. Picture symbols look like the object we want to represent while semantic symbols, such as letters, have no resemblance to what we wish to represent (Kylén, 1981).

4.4 Autism

People with autism make up a group one often encounters in care for the disabled. Since their set of problems is special, involving the understanding of language and social interaction, I have chosen to describe autism in more detail.

Autism is not a disease but a syndrome and certain symptoms have to be present for a diagnosis. These symptoms are (Gillberg, 1999):

- Major limitations in the ability for social interaction.
- Major limitations in the ability for mutual communication, including limitations in the understanding of language, gestures, symbols as well as difficulties and divergences in

the ability to express oneself, both verbally and non-verbally.

- Major limitations in behavioural patterns and the ability to imagine, with refined ritual behaviours, strange routines or extremely deviated playing behaviours.

Most of those who have been diagnosed as autistic also are mentally retarded, but not all. They have particular difficulties in human social relationships. This does not mean that they do not want or need to have contact, but that they do not understand the rules of social interaction.

They are also limited in their understanding of language, which presents itself in several different ways: some might not understand spoken language at all and some might interpret everything literally. Unfortunately, limitations in language understanding are very common and half of all children with autism will lack or have very poor spoken language abilities all their lives. They may be able to repeat speech, but even if they can do that without any problem, they can still have major difficulties in understanding the meaning of words (Gillberg, 1999).

4.5 Major individual differences

It is important to emphasise that there are major individual differences. Everyone with mental retardation and/or autism does not have the exact same set of problems (Gillberg, 1991; Kylén, 1981). There can also be considerable differences within the individual: major problems in one area of ability do not necessarily generalise to others. The same individual can also function better one day and not so well the next.

As with all human beings, people with autism are in a continuing process of development and gain new experiences that affect their abilities and how they use them, both positively and negatively. All human beings are individuals and should be treated as such.

5 Alternative Communication

What is alternative communication? According to Björck-Åkesson and Lindsay (1997) alternative communication, or ‘Augmentative and Alternative Communication’ (AAC), is when other instruments than spoken language are used to communicate, either as a complement or a substitute. In Sweden we talk about ‘Alternativ och Kompletterande Kommunikation’ (AKK). Bergh and Bergsten (1998) define AKK as: ‘*all the ways of communicating that complement or substitute ordinary speech for people who are unable to express themselves satisfactorily through speech*’.

Charles Hockett established a definition of language in the 1960s. He presented 18 criteria for verbal language, the four most important ones being: it should be referential, syntactical, non-iconic and learned. This means that to qualify as verbal language, the sounds we make should refer to something, that they should have grammatical structure, that they should not be similar to what they are referring to (as for example ‘moo’ is when one imitates the sound of a cow), and that they should not be instinctive (Dunbar, 1998).

Language

Wittgenstein maintains that the understanding of language is not a mental process; it is more about controlling a game and it is the rules of the game that determine the character of the game. When it concerns the understanding of language, these rules correspond to grammar. Being able to use a certain word corresponds to knowing how to make a certain move in chess. Ordinarily we don’t use language according to strict definitions, since they simply don’t exist. To believe that there are strict definitions for every day language is *like assuming that as soon as children play with a ball, they play a game according to strict rules* (Fredriksson, 1994).

Wittgenstein compares grammar with a toolbox, and the many different tools with all the things you can do with language: *give and obey orders, ask and answer questions, describe an event, tell an imaginary story, tell a joke, describe a recent experience, make guesses about activity in the physical world, bring forward scientific hypotheses or theories, greet someone, etc.* (Fredriksson, 1994). He compares ‘understanding’ grammar to preparing your toolbox for the future.

Wittgenstein objects to describing the understanding of language as a mental state. He does admit that certain words can

give different mental conceptions but that does not apply to all words. To emphasise this, he mentions the word 'or' and thus an 'or feeling', which he means is a totally absurd notion. Wittgenstein also states that it is not interesting if, or in that case which mental processes might occur in understanding language. He means that it is nonsense to ask when you have learnt the meaning of a certain word or how long you have understood it. He compares this with someone asking when a person has mastered the art of playing chess. Understanding language is all about knowing how to use the words when you need them. *There simply is no special remedy that helps us to 'understand'. Using language successfully is what 'understanding' is all about.* (Fredriksson, 1994).

Why do we talk?

In the book 'Samvaro, skvaller och språkets uppkomst' ('Grooming, Gossip and the Evolution of Language'), Robin Dunbar (1998) presents a theory of why human beings once upon a time started to talk. He maintains that language arose out of our need to be able to gossip. To put it simply, humans started to talk when they started to live in large groups. If many people live together, it takes a lot of time to maintain relationships, which is necessary to know who you can trust. The apes, who also are social creatures, spend time together while grooming each other. The problem with grooming is that you can only tend to one other creature at a time. Dunbar claims that we use language to initiate and nurse relationships and that it works as some sort of verbal grooming. Studies have shown, according to Dunbar (1998), that about 60-70% of all human conversation time is spent discussing social subjects, who has done what, what you like or dislike, personal experiences and so on. You can even see this in newspapers, even those that claim to present important news are filled with gossip about other people (Dunbar, 1998).

Alm, Waller and Newell (1997) also put forward the social dimension of language. To be able to converse satisfactorily you have to be able to tell stories, tales, jokes and experiences. Our impression of other people is highly dependent on mutual experiences, which in turn makes it important to be able to talk about them. Socialising is very much based on our ability to entertain each other.

5.1 Who needs alternative communication?

The need for alternative communication is motivated by limitations in accessibility (caused by physical, sensory or

cognitive disabilities), according to Loncke, Vander Beken and Lloyd (1997).

There are many reasons for the need to either complement or replace verbal communication: mental retardation, severe physical disabilities, such as cerebral palsy, severe trauma or disease that can lead to brain damage⁷ and other impairments that can lead to difficulty in using speech and writing (Björck-Åkesson and Lindsay, 1997).

Some individuals have alternative communication as their main way of expressing themselves, while others have it as a complement. There are also people who only need alternative communication temporarily, to stimulate the development of speech and language (Bergh and Bergsten, 1998).

According to Alm, Waller and Newell (1997), a common phenomenon is that non-verbal persons often are considered less intelligent than they really are. It is therefore important to have access to one or more modes of communicating.

5.2 Different ways of communicating

So what different ways of communicating are there? Even people without any impairment use different means of communication. Speech can be transformed into text; it can also be transformed into manual signs, signed alphabet and graphical symbols. People use these all the time. We know when it is appropriate and most efficient to write a note or a letter, when it is appropriate to make a phone call or speak face-to-face with someone. Most of the time these decisions are made based on what is most efficient and available (Loncke, Vander Beken and Lloyd, 1997). Our ability to communicate does not start with words; infants communicate long before they learn how to talk. They start with gestures to attract attention, gestures that eventually become more and more symbolic (Smith, 1997).

⁷ For an excellent description of the importance of digital personal photographs for someone with aphasia see Henrik Danielsson's master's thesis 'Bildligt talat – Om hur och varför Gun Andersson övervann stora delar av sin 7-åriga afasi via Science Piction och personliga digitala bilder'. (Figuratively Speaking – How and Why Gun Andersson Overcame Major Portions of her 7-year-old Aphasia via Science Piction and Personal Digital Pictures.) Certec, LTH Number 1:1998. <http://www.certec.lth.se/dok/bildligttalat/abstract.html>

5.2.1 Concrete objects

A person who has a severe mental retardation needs concrete objects to understand what is meant. Swimming trunks can, for example, signal that it is time to go swimming or a paintbrush that it is time to paint. If you also have a visual impairment and a physical disability that make it impossible to feel the object at hand, you can use sound signals (Bergh and Bergsten, 1998; Falck, 1985).

5.2.2 Sign language

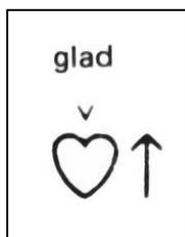
Sign language is not only used to communicate with persons with hearing impairments, but also to complement the spoken language when talking to people with cognitive disabilities. The sign language of the deaf is a language of its own. It is not the same as signed English that hearing people most often use. When you communicate with signs, with people who hear but cannot speak, you use the signs to enhance the spoken language, and you only sign the most important words, not all of them (Falck, 1985). This means that you sign at the same time as you speak and when you can use both your hearing and your vision understanding increases (Bergh and Bergsten, 1998).

We use gestures very early in our development; it is natural to point at what we find interesting. Even children with physical disabilities try to use their hands to communicate. It requires greater fine motor skills to use our organs of speech compared to sign communication. Communication through signing is limited, though, if one has a severe physical disability (Bergh and Bergsten, 1998).

5.2.3 Bliss

Bliss is a graphical symbolic language that is mostly used by people with physical disabilities. These people are often mistaken for being less intelligent than they really are. If, due to physical disabilities, one cannot form words or letters, cannot point or if gestures and movements are spastic, it is not easy to be understood (Falck, 1985).

Bliss, constructed by Charles Bliss in the 1940s, is a system of international symbols. These symbols are divided into groups that are colour coded and placed in a chequered pattern on a pointing board. The symbols can be combined, which means that you have access to more words than the number of symbols (Falck, 1985). The Bliss symbols are very abstract, though, and are therefore not suited for people with cognitive disabilities.



Bliss – happy

5.2.4 Pictogram

Pictogram, created by Subhas Maharaj in 1980, is a graphical way of communicating. Its abstraction level is lower than Bliss. It consists of stylised, and sometimes figurative pictures in white against a black background (Falck, 1985; Bergh and Bergsten, 1998). Pictograms are used very frequently in Sweden for communicating with people who have cognitive disabilities. You cannot express yourself grammatically with Pictogram as well as you can with Bliss (Bergh and Bergsten, 1998).



Pictogram – happy

5.2.5 Drawings

Individuals who communicate by drawing introduce iconic variations of different graphical forms in order to convey sentences. Here the individual is in control of the system that produces the representation of the sentence, which is not the case when he or she is given a predetermined number of ready-made pictures (Grove, 1997).

5.2.6 Digital photographs

Digital photographs differ from ordinary photographs in that you can see the picture immediately on the LCD screen of the camera; you can immediately put them in the computer and print them out. Besides that, you do not have to worry about the cost of developing the picture. You can take as many as you want, look at them and then choose to throw away or save them, as you desire.

5.2.7 Comparison of different alternative methods of communication

An old argument against the use of alternative methods of communicating is that the users can become 'lazy'. What's the point in learning to talk and speak when there are alternatives? Earlier research partially supported this notion; they used to think that there was a contradictory relationship between the different ways of communicating. If you developed sign language it would take resources from the development of spoken language. Current research shows that different ways of communicating stimulate and reinforce one another's development instead. Early introduction of alternative communication does not mean that you have given up hope of the child learning to speak. Alternative communication does not delay or hinder the development of speech in any way; on the contrary the opposite is true. Research has shown that by using alternative communication, you actually increase the number of sounds and words when the pressure to speak is decreased. Alternative communication can therefore both

hasten and ease the development of speech (Bergh and Bergsten, 1998; Loncke, Vander Beken and Lloyd, 1997).

In many cases it is easy to exclude some of the alternative means of communicating. A person with severe physical disabilities cannot use sign language and those with major visual impairments cannot use graphical symbols (Falck, 1985).

Since signing has such a positive influence on the ability to speak, it is important to start signing as early as possible. One advantage of signed communication is that you always have your means of communicating with you. It is easy to attract attention with signs and those who are close to you will soon learn to understand what you mean. The main disadvantage is that people other than the ones closest to you have difficulty understanding. Manual signs are also, just as speech, a dynamic way of communicating; what you say disappears as soon as you have said it. This gives you less time to perceive what is said. To use dynamic methods of communicating requires good memory capacity. *Many children can make a perfect manual sign when you show them a picture of it or when you say the word, but they are unable to make the sign spontaneously. They have difficulty remembering how to make it* (Bergh and Bergsten, 1998).

Many people with autism, which implies limitations in the understanding of language, have difficulty learning manual sign language. It can even be easier for them to understand spoken or written language. On the other hand communication becomes easier with pictures and photographs. People with autism often have sensory disturbances. Their senses of hearing and touch are more disturbed than those of vision and smell. Many children with autism have very well developed visual abilities, but since people with autism seldom or never think in symbols (Gillberg, 1999) Pictogram and Bliss are not suitable.

Bergh and Bergsten (1998) present a list of the abstraction level of different symbols, from the concrete to the abstract:

1. Concrete objects
2. Colour photographs
3. Black and white photographs
4. Miniatures (concrete objects that differ considerably in size from the real ones)
5. Colour pictures
6. Realistic drawings
7. Manual signs
8. Stylised drawings
9. Bliss symbols
10. Written words

Pictogram symbols are placed sixth or eighth in this list depending on how realistic the pictures are. All graphical ways of

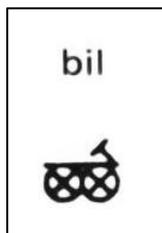


Photography – car

The picture is from the conference group, Arne Svensk, Jan. 20, 2000.



Pictogram - car



Bliss - car

communicating are static, which means that they remain, available, both for the talker and the listener. The fact that the symbols and pictures are available in another form than speech and manual signs supports memory. You don't have to remember all the pictures, you just have to recognise them (Bergh and Bergsten, 1998). That positive feature, that the pictures are static, is at the same time negative. You have to carry the pictures with you; if they are not close by they are not available. To have too many pictures to choose from can be distracting and confusing. It is also difficult to maintain eye contact when you use graphical ways of communicating (Bergh and Bergsten, 1998).

An important factor when looking at graphical AAC symbols, and something that has been well investigated is iconicity, i.e., how well a symbol visually represents something. It turns out that the more the representation looks like the represented item or action, the better it is (Loncke, Vander Beken and Lloyd, 1997). *Something important to consider is that people with mental disabilities many times associate differently than people with no disabilities. For example, they often associate baking not to all kitchens but just to their own.* (Björklund and Wilhelm, 1995)

It is important to keep in mind that every user is unique and that the means of communicating used are personal. Several different methods are used, often in combination with one another. These methods can differ depending on where you are in life and whom you are communicating with. It is the individual conditions that should control the means of communicating (Bergh and Bergsten, 1998).

5.3 Interpreting pictures

One disadvantage with graphical ways of communicating, with the exception of Bliss, is that you are unable to express yourself grammatically according to Bergh and Bergsten (1998). This forces the listener to interpret the pictures according to the context. That ought to imply that it is more complicated, cognitively speaking, to communicate via pictures than via speech.

Hjelmquist also (1997) claims that there is a problem with pictures, compared to speech or writing: a picture is more ambiguous, depending on what it is referring to. For example, in a picture of a man sitting on a chair, are you supposed to focus on the fact that the person is sitting on the chair, that the chair is under the person or that the chair is on the floor? The picture is used differently depending on which information the 'speaker' thinks the 'listener' already has and which information needs to be added. A text can easily be transferred into speech and vice versa, but a picture or icon is not as easy to transfer to speech. This is

due, according to Hjelmquist (1997), to the fact that a picture can be interpreted in many ways. As a result you have to decide in advance which interpretation to give to a certain picture and that interpretation has to be valid in every situation.

According to Barthes you can divide the interpretation of photographs into two parts: one which he calls 'studium', i.e., information and aesthetic values and one he calls 'punctum', i.e., the feeling the photograph evokes from the viewer. He means that the information and the aesthetic values are accessible for everyone who looks at the photograph, i.e., two people from the same cultural background will interpret the same picture in a similar way. On the other hand, the emotions the picture stirs up are completely individual. Lesy also talks about two dimensions of a picture. The content, or motif that can be perceived quickly, while the meaning of the picture is on a more unconscious level. Barnes and Strernberg, on the contrary, have studied how we interpret pictures and their results tell us that there is no universal way. This implies that it is not as simple as Barthes and Lesy claim (Cronin, 1998).

An image can mediate much more than just the motif:

A traffic sign that shows two little children holding hands does not mean to convey an idyllic motif. It means that the user is legally obligated to watch out for children on the road after the sign. Traffic signs and their images have an established use in traffic, and in the traffic game. You as a driver have to learn that game to understand the meaning of the signs. Consequently, it is not enough to just understand the picture's motif.

(Öhman, 1993, p. 148)

Musello says that personal photographs, such as our photo albums, need to be accompanied by verbal explanations to understand their meaning. When you show pictures to others they are imbedded in a verbal context that points out what the viewer should focus on, what is special for just that picture, and to give enough background data to understand the picture (Cronin, 1998).

Also Adelman (1998) speaks of the importance of context; a photograph is interpreted differently depending on the context. He means that you might believe that the interpretation of a picture is obvious, but to make it understandable the picture has to be seen in connection with text or other pictures.

There are two contexts that yield meanings inferred about photographs. One is the context in which photographs are taken;

the other is the context in which they are viewed (Adelman, 1998, p. 148).

Becker (1998) means that, like all other cultural objects, the photograph gains its meaning from the context. Just as a painting gains its meaning in a world of artists, collectors and critiques the photograph gains its meaning from those who use it.

5.3.1 Speech must also be interpreted

But do photographs differ so much from speech? Doesn't talk need to be interpreted according to person and context? Ball (1998) says that photographs are far from transparent and they have to be interpreted. Just as language is ambiguous so are visual materials and photographs that store representation. Ball hints that language also has to be interpreted according to context.

Wittgenstein says that just because you know what a word represents, doesn't mean that you can use it. He sees the representation as preparation for using the word. As an example he uses two construction workers called A and B:

First when A and B have also been trained in the language game (construction) they really know the meaning of the words. The use of the word 'slab' is that A says 'slab' and then B fetches a slab – it is these actions (saying-plus-fetching) together, this co-operative action, that constitute the use of the word.

(Öhman, 1993, p. 34)

Wittgenstein emphasises that words are a part of the reality in which they are used. A word's meaning is therefore connected to its use, i.e., words are used differently in different language games (Öhman, 1993). The construction activity in the quote above is an example of a language game. To say 'slab' to someone else or in another situation can mean something entirely different.

5.4 Acceptance of alternative communication...

As mentioned earlier, it is important to offer alternative means of communicating as early as possible, though it may be that the individual is not quite ready for alternative communication nor for a communication device. This is most common for people who are injured as adults and who prior to injury had a well functioning spoken and written language. It is also common when doctors and

other experts constantly tell the patient that vocal development will start soon; he or she has been given a good prognosis but speech still does not develop (Sweeney, 1997). Starting with alternative communication at this point can feel like giving up all chances of ever speaking and writing.

5.4.1 ... by the user

Three main factors contribute to our sense of self-esteem: how others see us, how we believe that others see us, and how we see ourselves. Good self-esteem is important for a sense of independence, for how we feel and for how we handle change and trauma. The most basic function for developing our self-esteem is our ability to communicate. So when one has to use alternative communication, a communication device, it can affect self-esteem (Sweeney, 1997).

If you have one or more children with communication problems in your family, then the closest family members soon will learn to interpret the child's different signals. The child can communicate, but only with those who know him or her very well. It can be difficult to introduce a technical device that will complement this communication, since it can be seen as a replacement for human help. The child or immediate family members may feel like they will lose contact with someone close to them if they accept the communication device. The device or system must work at least as well as the already existing alternatives. It isn't enough to wish for and need the device; it also has to be useable (Sweeney, 1997).

5.4.2 ... by the surroundings

How well you accept an assistive device depends on many different factors, not only personal ones. The most common devices in our society are glasses; almost everyone knows what they are and why you use them. But glasses are valued for more than their function. They have long been connected with studies and intellect, and in recent times fashion too. People have been known to use them with 'window glass' just because they look good. Hearing aids are also well accepted in our society, though they are designed not to be seen, not be emphasised. It is hard to predict the acceptance of communication devices and systems. There are many in general use today, such as mobile phones and hand-held computers. These devices are desirable and highly valued. There are major differences, though, between individuals and groups in how the new technology is embraced. Take something as common as a video tape recorder. Most households have at least one, but many owners have never learned how to program it (Sweeney, 1997).

A problem with alternative communication is asymmetry between input and output. Most people who use alternative communication spend time in environments where many of the people they interact with are speakers. Inevitably, the communication form received is primarily verbal. Even when using manual sign language or pictures is it likely that spoken language will dominate (Smith, 1997).

5.4.3 Conclusion

Language is a complicated matter that is extremely important to our social life. Communicating with others is not just a question of transferring messages back and forth, but also about sharing experiences and entertaining each other. Language consists of a number of rules and in each situation one has to know which rules apply and then decide to follow them or not.

It is also a fact that a large portion of the population has temporary or permanent difficulties in understanding and using spoken or written language. There are several alternative and complementing ways of communicating but all of them have advantages and disadvantages. The alternative that is easiest for people with cognitive disabilities to understand is colour photographs, but a photograph has to be interpreted, just as speech, according to its context in order to be understandable and useable.

How does communication via digital personal photographs work in reality? Is it possible to interpret pictures and can they really replace and/or complement spoken language?

6 Digital Personal Photographs

This chapter describes the use of digital personal photographs that has been observed during the field studies. It might be wise, though, to start off with considering how ordinary photographs are used.

Bartlett and Loftus state that for a family, photographs are a description of something that has happened, an event shared. Photographs function as a clue to a common past and a way of recreating what has happened by sitting together and talking about the pictures (Cronin, 1998). Beloff points out that in our photo albums we don't usually find pictures of what is unpleasant in our lives, such as work, arguments, boredom and sorrow. Family photographs give an idealised image of our lives (Cronin, 1998).

So what is the difference between using ordinary photographs and digital ones? As mentioned earlier, the speed is a clear advantage when it comes to digital photographs. You see the picture instantly and you can immediately put the picture in your computer and use it there. You can take as many pictures as you want since you don't have to worry about developing costs. The question is if, and in that case how, the ability to see the pictures immediately and to take many pictures, will affect our photo albums in the future.

Investment costs for digital photographs are greater than for ordinary photographs. Digital cameras are a bit more expensive than ordinary ones, but the biggest cost is the purchase of a personal computer, of course.



Computers are fun!

6.1 The computer

Anna and I sit together with a pupil by the computer. Anna has recorded a short film sequence the day before. The sequence shows how a pupil is being mischievous and how another pupil comes up and pulls him by the ear. All this is done in fun. All three of us laugh as we watch it. The pupil soon understands that he only has to click on the picture to run the film. He watches it several times. His concentration on the scene is total and he watches it over and over again.

Stig has a small communication device. It has some buttons with pictures representing different sentences. If you press the button you hear a recorded voice saying the sentence.

There are several advantages to using computers in education and for communication. Besides reducing demands in social interaction it is also much more patient than human beings. It is common that people with cognitive disabilities need constant confirmation over a period of time. Constantly having to answer the same question time and again can be very frustrating for people, even when they understand the need for it.

When I visit Fågelskolan it is the Friday before Bonfire Night (April 30th), and all the pupils and teachers in the special school gather in the schoolyard to roast marshmallows. I have brought the Department's⁸ digital camera and a little boy, whom I have never met before, soon sits down next to me. He asks a lot of questions about the camera and he wants to try out all the different buttons. When I show him the pictures that are on the disc he immediately understands what he should do to see the next picture. We sit closely together, he pushes the buttons of the camera while I hold it and answer his questions. Eventually a teacher, who I haven't met before, also approaches me and wonders who I am and if I am good with digital pictures.

The question is if the technology brings something more than the ability to take many photographs fast and easy. Something that immediately struck me when I was in the field was that the interest for computers and cameras is very large. It is not only the pupils in school that are interested and amused by the technology but the staff as well.

6.1.1 Constructionism

Anna tells me that they have a computer game, *Toy Story*, that some of the pupils enjoy playing, even though the game is in English. Two of the pupils in particular have been sitting together a lot and playing it. They have spent time together in front of the computer in a way that Anna has never seen before. They have had a great time. Eventually they also began to sit together, looking at each other's photographs on the computer.

⁸ The Department of Human Work Science at the University of Karlskrona/Ronneby, Sweden

Agneta and a pupil open the pictures from the pupil's visit to the woods with his father (at Georgshillsskolan they had a project where the pupils went with their parents to work and took photographs). The pictures are displayed in a slideshow format and the pupil takes the microphone and makes a sound like a chainsaw. 'What are you looking at?' Agneta asks. 'There!' says the pupil and points at the picture. They look at the next picture and the pupil talks into the microphone about what he sees while Agneta encourages him with questions. When we run the slideshow later the picture is displayed as long as there are sounds to it.

At Fågelskolan each pupil has his/her own sequence of pictures (looks like a home page). Here you can click around and see pictures of the pupil with family, friends, at home and so on. Most pictures have sound and it is usually the pupil who is speaking.

Could the pupils in the first example have gathered around any artefact whatsoever? What is the significance of it being a PC through which they interacted? I think that it is significant that it was a computer that functioned as a mediator. The computer awakes a natural interest, it is entertaining and it reduces certain demands on social interaction.

Constructionism is built on Piaget's theories of constructivism. Piaget said that knowledge not just is transferred from teacher to pupil, but the pupil constructs his or her own knowledge. The pupil is therefore not a passive receiver, but very much active. *Children don't get ideas; they make ideas.* Papert has expounded constructivism and says that the construction of knowledge is facilitated if the pupil actively creates some form of external artefact. You can reflect over the artefact and others can also be involved with it. This is what Papert calls constructionism (Kafai and Resnick, 1996).

Papert talks about the importance of creating an external artefact so you and others can reflect on it. The pupils I have met create, among other things, slideshows with their photographs. They often sit together with teachers and other pupils in front of the computer and watch the slideshows repeatedly.

6.2 Personal

When we are at home with Ingrid, Agneta shows Ingrid a paper with pictures from Georgshillsskolan. Ingrid takes the paper with interest and looks very carefully at each and every one of the pictures. When she has looked at all of

them she immediately returns the paper to Agneta. The content has nothing directly to do with Ingrid and she wasn't there when the pictures were taken.

According to Adelman (1998), photographs are not an extension of the technology or the art of photography, but an extension of the photographer. The contents and the photographer are therefore intimately connected with each other. What I have seen when visiting the day centre and the special education classes is how important it is that the photos really were taken when the person was present or that someone close to him or her is in the picture.

6.3 Interpreting the picture

Göran at Tryckolera brings out a big round box, which previously contained a roll of film, and opens it. In the box, called 'the scrap box', are lots of pictures and Göran tells me that they are 'un-interpreted' pictures. When new pictures are taken they print them out, look at them together and talk about them. They need to agree on what the picture represents before they use it. Often Göran only checks that Stig and Thomas understand what the picture represents, but it can also be the other way around. At Tryckolera they have picked stones polished by the sea and painted them in different colours. Göran's interpretation of these stones was that they represent mobile phones, since they are shaped like a phone receiver. But when the stones were painted in different colours, they became a representation of the person who had that particular colour. So Göran had to reconsider and they started to use the stones for different role-plays.



The weekly newsletters

Every Thursday at Fågelskolan they sit down together and discuss what has happened during the week. They discuss one day at a time and talk about what they did then and they write a few lines about it. Then they look at the pictures taken and jointly choose the ones that best represent the week. This is put together to make a weekly newsletter that the pupils bring home. The pictures function as a memory support for the children and the text is important for the parents. The intention is that parents and children will read the newsletter together.

Agneta first hangs up all the pictures in plain view on the wall. Not until the pictures are familiar to the children does she make a book out of them.

This shows that the interpretation of the pictures is important, that together you place the picture in its context. The interpretation is not very complicated but feels natural in the context; you talk about the pictures and get acquainted with them before they become a communication resource.

6.4 Dialogue/Conversation

During the lunch break at Georgshillsskolan, the pupils, teachers and myself are sitting together talking. One of the pupils wants to tell us something and we understand almost everything except for one important detail. Suddenly the pupil gets up, runs quickly to his workbench, grabs a picture and shows it to us. Then we understand and the conversation can continue.

Before I made my first visit to the Tryckolera Day Centre I had the notion that alternative communication with the help of digital personal photographs was almost completely concerned with replacing spoken conversations or dialogues. But it turned out to be much more nuanced than that.

6.4.1 Being able to gossip

Göran told me about one occasion when Thomas, who is very interested in clothes, approached him and said that he wasn't allowed to wear the clothes he wanted to. They went to the group home where Thomas lives and found that most of his clothes were kept in a locked area in the basement. They took the clothes out and photographed each and every garment. Now Thomas was able to decide what he was going to wear the next day with the help of the pictures at Tryckolera. They became so important that when a garment was torn Thomas showed this by ripping the picture apart.

A person with mental retardation told me one day, with the help of digital photos, that he hadn't got any coffee at breakfast that morning. His work supervisor then called up the group home and wondered what the reason was. The staff at the group home was very surprised at how the supervisor knew this since the person at hand couldn't talk.⁹

⁹ Notice in the conference group (<http://www.certec.lth.se/bilder/>) by Arne Svensk, Nov. 25, 1999.

Whether language is a psychological process or not, how we use it is greatly influenced by the context, and lack of language understanding can have major social consequences. To be able to gossip is to have power over your own life. If you can't gossip you are at the mercy of other people's good will.

6.4.2 Being able to tell a story

At Tryckolera they photograph all stages in a work assignment. One example is the growing and preserving of cucumbers. The work is documented with photographs from beginning to end, from seed to the jars filled with pickles. One wall in the dining room is covered with small pictures that show last year's gardening. Here one can find images from the first visit to the garden plot in the spring to the harvest in the autumn.

In this case personal photographs are superior if you are unable to use speech or text. You can have a series of photographs of a situation that clearly shows other people what you have experienced and even how you might have felt. Also a text will be easier to understand and more entertaining if you also add pictures.

6.4.3 Initiating conversation

The second day at Tryckolera Stig suddenly grabs my arm and leads me to the Picture Bank. There he starts to pick out pictures of different people who work at Certec with the help of the bar code scanner. Then he looks at me, chooses a picture of Arne Svensk and points to me and then himself. The day before we had sat together at the dinner table talking and I had told that I was going to visit Certec some days later and meet Arne and the others. Someone else told me to greet Arne, and Stig asked me to do the same for him. He did this by lightly pulling the sleeve of my sweater during the conversation, and pointing to himself. So the day after he could quite easily remind me to greet Arne when I met him. The fact that the pictures were highly visible on the wall made it much easier for Stig to refer to Certec with pictures of the people working there.

To be able to initiate communication is crucial to becoming independent and to gaining power over your life. A prerequisite to taking initiative yourself is that the pictures are available when you need them.

6.5 Knowing what is going to happen

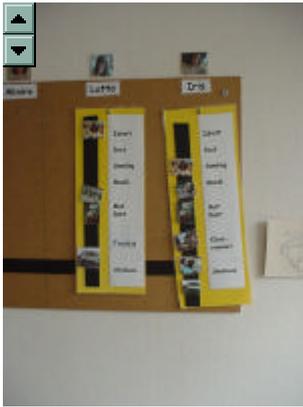
On the round blue table at Tryckolera there are a number of pictures. Among them are some students from a nursing school and a project they carried out with Göran, Stig and Thomas. The three of them are standing close together by the table looking at the pictures, Göran with his arm around Thomas. Göran points at the pictures and reminds them of the picture quiz walk¹⁰ that the students had made for them. They study the photographs that were taken when Göran, Stig and Thomas took the quiz walk. 'There is Thomas!' says Thomas and points to a picture. 'Yes, Thomas and Stig', says Göran. Göran asks which street the picture is taken on and Thomas answers, 'Bicycle'. 'Yes', says Göran, 'you can only ride a bike there'. (The picture is of a street with a sign showing a cycle path). 'There is Thomas again', says Thomas. 'What is that?' Göran asks. 'Swings', answers Thomas. Stig follows the conversation with great concentration all the time. They look at the pictures of what is going to happen during the afternoon and they talk about it. (They are going to the nursing school to meet the students.) When they look at the last picture Thomas says happily, 'Coffee!'

At all the places I have visited, one of the most important tasks is to give the individuals knowledge about what is going to happen next. Not knowing anything about what is going to happen, not knowing the plan, renders you powerless and insecure. It is not until you know something about the future that you can influence it. One way to structure the future is to make a schedule.

6.5.1 Schedules

At Fågelskolan the pupils start every day by making their own schedule for the day. The activities are written on paper and the pupils match the right picture with the text. Every pupil has a jar of their own personal pictures and the pictures are attached to a magnetic strip. After all the pupils have finished their schedules, they have a group assembly and talk about the coming day's activities. They also put a common schedule on the whiteboard.

¹⁰ The students had photographed the grounds surrounding Tryckolera and the task was for Göran, Stig and Thomas to find the places on the photos.



Schedule

At Spandelstorpskolan they start most days with an assembly. They sit together and talk about which day it is and what is going to happen. They put up a schedule with pictures on the wall. They see pictures of what is going to happen at the same time as they talk about it and the speech is reinforced with manual signs.

According to Gillberg (1999) structured activities are important, especially for children with autism. To know what is going to happen creates security. Therefore the schedule is an important part of everyday life. The schedule should be easy to understand and easy to access.

6.5.2 Dealing with changes

Last week I accompanied Agneta Dyberg-Ek when she visited her pupil at home. When he comes home from school he usually puts on his painting coat and paints with watercolours on a table that is on the glassed-in balcony. This day it was so cold that the assistant was freezing even though she had put on as many layers as she could. Agneta decided to move the table from the balcony into the kitchen. It had to be done sooner or later since winter was coming on. Whenever the table was moved the pupil would throw a tantrum. Agneta moved the table. The pupil screamed and kicked wildly. When the table was in place with paper and paints and everything that should be there, Agneta took a photo of the pupil next to the painting table at the new location. When he saw the picture of himself in the digital camera, he immediately calmed down and started to paint.¹¹

Children with autism are often particular with routines and they become very disturbed over changes. Even small changes can lead to violent emotional outbursts. Gillberg (1999) tells of a 5-year-old boy that ‘screaming wandered back and forth in the apartment’. When the mother remembered that she had moved a book in the bookshelf and put it back, the boy calmed down immediately. The same boy could manage to travel abroad and change places to stay without problems.

¹¹ Notice on the conference group (<http://www.certec.lth.se/bilder/>) by Eve Mandre, 1999-12-16.

6.6 Supporting memory

The day before my next visit to Tryckolera, Thomas had started to learn where the different keys on his key ring go. They had photographed the keys one by one as well as the locks they belong to. Thomas shows me the pictures, points to the different keys and talks about where they fit. He knows them all if he takes it slow and reflects: that one to the new bike, that one to his home, that one to the mailbox and that one to the old bike.

The use of techniques to support some of our cognitive abilities isn't anything new. Different memory aids and calculators have been around for a long time. Memory was probably the first cognitive ability that was discussed and we use many external artefacts to make things easier to remember. The written word is one (Alm, Waller and Newell, 1997).

Edwards and Middleton (Cronin, 1998) state that memory is crucial for our relations. By talking about the past, about what has happened before, we can define, negotiate and discuss our relations. We define what is worth remembering and how the things we remember are connected with each other.

Pictures are especially important for people with cognitive disabilities since their short-term memory is often poor. The photograph functions as evidence that something actually has happened.

6.6.1 Access to your own history and future

At Tryckolera they not only use new pictures, they have also searched for old ones, pictures of Stig and Thomas as children. When they found old photographs of Thomas' mother they discovered that Thomas was born in Scotland.

Kristina and Ingrid are documenting Ingrid's history at the moment. They do it by visualising the different years that have passed. When the work is done they will burn a CD for Ingrid so she will always have access to her own history.

Barthes thinks that a photograph, unlike a painting, cannot simply be dismissed as fantasy. Photographs act as evidence that something has existed (Cronin, 1998). Boerdam and Martinus go as far as to say that a photograph works as protection against the passage of time. It can shield us from the sadness we feel over times that have passed, either by working as a replacement or as a support for memory (Cronin, 1998). Kotkin claims that the

perception of time has a social dimension. We divide our life into different parts and our photo albums reflect these different periods. (Cronin, 1998).

The individual's history often is missing in the care of the disabled. It is especially common among older people because they have spent a long time in care and because they do not have any older relatives left to tell their story. Sometimes the death of a close one involves the disappearance of all the knowledge about an individual's history.

6.7 Understanding your surroundings

When one of the pupils at Georgshillsskolan started in the class he became upset if he didn't know who else was in the building. He was therefore allowed to start every day by walking around and greeting everyone. After a while they took photos of all the pupils and teachers working in the building and made small class books with photos and names. Then it was enough for him to look through the books every morning and now he only uses the books once in a while. They are kept on the pupil's shelf and he can look through them whenever he wants to.

Another pupil at Georgshillsskolan has a disease that makes it necessary to visit the hospital for treatment several times a year. For him to better understand what is happening, Agneta asked the parents to photograph him at one visit, because he hadn't seen himself in that situation before. The result was a small book and they now look through it before every hospital visit. They talk about what is going to happen and sometimes the pupil himself takes the initiative to talk about the hospital treatment by bringing out the book.

6.7.1 Immediate confirmation

During my visit to Georgshillsskolan, Agneta is working with a pupil. He picks up a piece of driftwood and Agneta compares it to a pike. (It is most certainly something they have talked about before and it actually has a pike-shaped form.) But the pupil makes a fast movement like he is loading a gun and lifts the driftwood to his eye, aims and presses the trigger. Agneta asks what he is doing and he answers quickly: 'I shot your bag!' They talk about what the wood really represents and Agneta brings out the camera and takes a picture of the pupil when he aims, with the

former 'pike' that now is a 'shotgun'. Together they look at the photo in the camera's LCD screen.

To be able to give immediate confirmation is one of the biggest advantages with using digital photographs. You can look at the picture right away and talk about it. In addition, you can easily connect the camera to a VCR and view the photograph on a TV screen, making it possible for many to sit together and look at the same picture.

6.7.2 Self-image

Agneta tells me that one of her pupils on one occasion took her glasses and put them on. When Agneta looked at him he put his hands in front of his eyes so she would not be able to see him. She then took a photograph of him and could immediately show him that even though he didn't see anything, the camera saw him.

On a wall at Tryckolera there is a big paper figure representing a human body. On the different parts of the body there are bar codes. When you scan them you see a photograph of that particular body part.

Göran and Stig have recently started to photograph different feelings. They are making a series of pictures of Stig when he is happy, sad, scared and so on.

People with different disabilities often have problems with their own body image. They can have difficulties understanding that they are a person in their own right or perhaps they are paralysed or spastic and so do not have real control over some parts of their body. Then the camera can be an excellent aid for looking at oneself.

6.8 Time

Agneta is teaching the children to understand the time frame of a year. She has made annual rings of paper to which pictures can be attached. She has given every month a colour, as well as the days of the week.

The work that Kristina does with Ingrid has led to Ingrid now having a better understanding of time. They take photographs every day and put them in different folders, one for each month. This is done to make the concepts of 'year',

'season', 'month' and 'week' more visible. Ingrid has now learned that some events are repeated in a certain pattern.

In Anna's class they are also working with understanding the year. They have made a round wooden plate divided into twelve different 'pieces of cake'. Every season is marked with a colour and every month that has passed or is current is marked with a symbol. The symbol for April is an Easter egg.

Understanding time is one of the most difficult concepts for those with a cognitive disability. Time is very abstract and there are a number of different ways of measuring it, such as 'seconds', 'hours', 'days', 'weeks', and 'years' or 'soon', 'in a while' and 'recently' or 'future' and 'history'. Photographs can be used to show that certain events reoccur. For example, you can show that you go swimming every Thursday or that Christmas comes once a year.

6.8.1 Documentation

Agneta documents much about every pupil. She does it mostly for her own sake, to see and reflect over how she works. In this way she visualises the development of the pupils and gives other people around the pupils an opportunity to feel more involved in the effort. Documentation is also important if the pupil should move or change class, so that the new staff does not repeat a lot of mistakes. The problem with extensive written documentation is that you need to have the time and energy to read it. Agneta adds a lot of pictures as a complement, which makes the text easier to understand and remember, as well as more fun to read.

The weekly newsletters that they make at Fågelskolan do not only function as communication with the parents and support for the children's memory but also as documentation for the teachers.

A personal experience of my own, both as an employee in care for the disabled and as a relative, is the lack of documentation. We are so eager to comply with the policy of confidentiality that we sometimes even hurt the ones it concerns. A thorough documentation that stimulates reading can avoid mistakes being repeated.

6.9 Stimulating speech

Thomas at Tryckolera has started to talk since they began to use pictures. Now you can clearly see how stimulated he is by the pictures; he likes to look at them and talk loudly. On one occasion we are all watching a recording of Stig, Thomas, Göran and Bodil Jönsson's (professor at Certec) visit in TV4's morning show, and Thomas is constantly commenting on what is shown on the TV screen. When Bodil, on the TV, phones and Stig answers the phone, Thomas says loudly and with a deep sigh, 'Is she calling now again?' Thomas, as mentioned earlier, started to talk after they began to use the digital personal photographs. Stig hardly speaks at all but he says 'yes' and the goal for Göran is for Stig to also start saying 'no' more frequently.

One of the pupils at Fågelskolan shows me his pictures on the computer. He clicks very quickly to get to the next picture and I barely have time to see them. When a photo of his mother shows up on the screen, he stops and starts talking to her. He tells the picture of his mother that this afternoon they are going to McDonald's, and he is going to buy a large hamburger, large fries and a large soda. He emphasises the word 'large' and at the same time shows with his hands just how large it will be.

Just as manual signs stimulate speech, because speech and hand mobility are connected to each other (Falck, 1985), the photographs also seem to stimulate speech.

7 Accessibility...

7.1 Design

When you create a design you make something new. According to Löwgren and Stolterman (1998) design is not the same as problem solving, since a prerequisite for problem solving is that the problems are already known. During a design process the problems and their solutions are formulated at the same time and continuously, which makes every design process unique. Therefore design is not only about the development process and the end product, but also about how the human being is affected by using the product (Jönsson and Anderberg, 1999). Löwgren and Stolterman (1998) also mention the ethic and political role of design. All design effects and determines how we use the product and consequently what room for action we have.

7.1.1 Useable

When you construct computer systems and applications you often talk about usability and user-friendliness as a measure of how good the product is. According to Preece (1994), the definition of usability depends on how easy the system is to learn, how safe and efficient it is and how the user experiences the system. Preece (1994) does not want to use the term 'user-friendly', as she sees it more as an expression for something that is extra usable.

7.1.2 Useworthy

Useworthiness is a new concept presented by Efring (1999). He defines it as *the individual user's assessment of the extent to which the technology meets the user's high-priority needs*. The product should consequently respond to the needs to which the user sets the highest priority. This means that a product can be useworthy even if it is not very usable and the other way around. Being able to offer a useworthy product, consequently, requires knowledge of the needs the user herself views as most important to fulfil.

It is very hard for people that have problems with abstract thinking to wish for an aid without first having the opportunity to test it. This means that the disability has a direct impact on the user's opportunities to influence future development (Lundman, 1997).

Thus is it especially important for people with cognitive disabilities that they are offered an opportunity to test aids so that they can find out what they want and what they prioritise the most.

The key word here is ‘accessibility’. It is not until the technology and the alternatives are accessible to the individual that they can use them and then express the needs that exist and their order of importance.

7.2 ... to the picture

Vibe tells me that she used to have a pupil that needed constant confirmation of what was going to happen later. They constructed a bracelet of Velcro where they could attach pictures that represented the schedule. When he asked what was going to happen next, they could just answer by making him attentive to his bracelet. He soon learned to look there instead of asking and was happy with that. The pupil used the bracelet for about a year then he felt so secure that he managed with the ordinary schedule on the whiteboard of the classroom.



Thomas by the Picture Bank

The picture is from the home page of Tryckolera

The first thing you notice when entering the Tryckolera Day Centre in Lund, is that two of the walls are covered with big rollers filled with photographs. There are several rollers with many pictures on each. All the pictures have bar codes and a bar code scanner with a long cord lies on a table nearby. Next to this Picture Bank is the Picturegraph, which consists of a computer with a touch screen, a printer, a keyboard, mouse, and shelves on each side of the screen. Since the pictures are on the wall you have to use your body when looking at them; you roll the rollers and stretch or bend to find the right picture. Using the body and spatial memory makes it easier to remember the different pictures. That they are visible all the time also makes it easier to create new combinations.



Pupils at Fågelskolan looking at pictures together

The rooms at Tryckolera contain many different installations of the projects that they have been working on. On every object there are pictures with bar codes or only bar codes. There is for example a big, beautiful pumpkin with a number of bar codes attached. If you scan them you see a picture and a voice tells you about one step in the process of growing the pumpkin. Thus, you connect the pictures to the concrete objects that they represent.

Every pupil in the class at Fågelskolan has a folder with photographs. These folders are used frequently and they often sit together and look at the pictures.

At Georgshillsskolan they have many pictures in the room. The pupils have pictures of themselves and their family at their workstations, including all sorts of animals. They also make small books with pictures about things that interest the children. These books are available so they can look at them whenever they want.

At all the places I have visited every individual has at least one folder of his or her own with photographs. These folders are used frequently and are always accessible. There are also pictures on the walls of the room. All the staff members that I have met are very good at making the picture consistently available. This is especially important for people with cognitive disabilities, since the handicap itself means that they have a hard time imagining what they cannot see as well as a reduced short-term memory span.

7.2.1 When the picture is not accessible

The first day I visit Tryckolera, Stig is in a bad mood. He greets me and shows me something quickly when Göran asks him, but he doesn't seem to be interested in communicating with us. Both Göran and I are convinced that this is because I am 'intruding'. Furthermore, I was there before Stig and Thomas that morning and as a result they didn't get to open the door and greet me. Stig's somewhat awkward behaviour lasts all morning but after lunch he walks up to the Picture Bank and points to a picture of a cake. Göran reacts immediately and starts to ask Stig what he means. The result is that one of his fellow group home residents is having a birthday today, and Stig is counting on getting some cake when he gets home. Once Stig has succeeded in communicating what he wanted, his whole attitude changes. He grabs me to show me around; he uses the pictures to tell me about himself and I get several spontaneous hugs. Of course, we can't be sure why Stig reacted as he did, but both Göran's and my interpretations are that all morning Stig has been thinking about how to tell about the birthday. There simply was no picture of the man having the birthday.

Those who use graphical systems need to develop a strategy to compensate for symbols that are lacking and the inability to create new symbols when needed (Soto, 1997).

Thus, a problem with the digital photographs is that if there is no picture, there is no alternative. So you have to have the ability to immediately take new pictures and also to have a basic

individual collection of pictures. That the pictures are easily accessible increases the chances of creating new combinations of pictures if a picture of what you are trying to talk about is lacking.

7.2.2 Mobility

Accessibility to the pictures at the Picture Bank is very extensive, but only if you are in the same room. When you are somewhere else you have no access to the pictures.

On one occasion at Fågelskolan they solved the problem with the help of a folder, the same size as a Filofax, that contained small strips of Velcro. Here you could attach small pictures, and carry them with you. You could have about twenty pictures in a small picture bank and it was possible to arrange some of them in a row.

Even if the pictures on the rollers are not directly mobile you can print them out and take them with you. You can also have pictures stored in a camera. The problem is that you have to decide beforehand which pictures to bring. Even if the folders with the pictures contain most of those stored in the computer, they are rather clumsy to carry around.

7.3 ... to the camera

At Tryckolera they are planning to decorate a room as a workshop for inventions. They have invented several items together; one is an armband for the camera. You wear it like a wristwatch and in that way you can always have your digital camera on your arm, always accessible.

The camera has been, and still is, an instrument for a cultural elite within art and research. At the same time, developments have gone towards a democratising of camera ownership, and almost everyone (at least in the western world) can afford their own camera (Cronin, 1998).

The development of the digital camera has radically changed people's access to that technology. A digital camera is now not much more expensive than an ordinary camera.

7.3.1 Camera requirements

None of those I have spoken to think that the quality of the picture is the determining factor in buying a camera. Of course, good quality is something to strive for, but it is not what is most important. Often a cheaper camera is preferred since one does not

have to be too careful with it, which is an advantage if children are going to use it.

To be able to photograph yourself, a camera with an adjustable lens is preferred. It makes it easy to photograph objects on the floor or on the ceiling. It is also good for people who use wheelchairs; they can easily see their own feet.

Most cameras require special software and that the pictures be transferred to the computer via a cord. Currently there is only one camera manufacturer on the market that produces cameras in which the pictures are directly stored on a diskette. They are saved as JPG files and do not need to be converted to be able to use them more flexibly. Cameras with a diskette are preferable if you use the pictures on many different computers because you avoid the problem of installing software and such. The disadvantage with this kind of camera is that it tends to be rather clumsy, creating problems for children's small hands and for those with disabilities involving weakness in the hands.

It is important that the camera can be connected to a VCR so that the images can be viewed on a TV screen, allowing a group to look at the pictures together. This is becoming a standard feature in most of the cameras on the market today. You can also record the pictures on videotape and show them when you do not have access to a computer or camera.

With the latest camera models can you even take motion pictures. The quality is rather poor, but there is an advantage to seeing movement in some situations. At the Georgshillsskolan, for example, they had photographed a teacher swimming. Seeing the strokes demonstrated before one is supposed to do them makes it easier to learn.

It is also important for people with concentration difficulties (short attention spans), that the recording time of the pictures is not too long. By recording time I mean the time between taking the photo until it is saved in the camera. If that interval is too long, you cannot take the next photo immediately, having to wait a few seconds, which can be enough to disturb the photographer's concentration so that he or she loses interest.

7.3.2 Being able to photograph on your own

Most of the users I have met are able to take photographs on their own, although some have problems keeping the subject in focus when pressing the button. One prerequisite for being able to take pictures yourself, besides camera size and weight considerations, is that it is reasonably cheap and not the only camera available. If you only have one and it breaks, you are without it for a long time, which can be worse than not letting the users take photographs themselves.



The favorite toys

7.3.3 Different interests

The camera stimulates different interests with different children. On my last visit at Fågelskolan, I brought a camera to take some pictures for myself. One pupil was very interested in the camera and wanted to try out all the functions. Several other pupils came up and wanted me to take their picture, while yet another pupil wanted me to photograph a brochure with pictures of his favourite toys.

7.4 ... to the computer

At Tryckolera Stig has his own computer. He has just moved it there from home where it was placed in a staff room. Göran's plan is that Stig will learn to handle his computer himself, i.e., turning it on and off, choosing pictures and printing them. When he can do this without help he will take his computer home again. Thomas is also thinking of buying his own computer.

In most of the classes I have visited they only have access to one computer in the classroom, which means that the pupils do not have immediate access to the computer when they want or need to. The classes are rather small, though, from 4 to 6 pupils.

7.4.1 Mobility

The computer that contains all the individual pictures is not very mobile. Everyone keeps their pictures in stationary computers. The ideal would be a handheld computer with a wireless connection to the database where the individual's pictures are stored. The problem is what the software in that kind of handheld device should be like.

The great interest for digital photographs is based on a project called Isaac¹². In 1993 the people at Certec developed an electronic assistant for people with mental retardation. This assistant was a small handheld computer with several functions, where the digital camera turned out to be the most important one (Jönsson, Philipsson and Svensk, 1998). One can learn from that project and develop a product that is based on the use of digital photographs.

¹² <http://www.certec.lth.se/isaac/>, May 31, 2000

7.4.2 The application

Even though Ingrid has her own computer at home, she never touches it unless Kristina is there to help. She is afraid of ruining something. But when someone is sitting next to her she is very confident in what she is doing. She moves pictures from the camera software (QV link) to PowerPoint, she changes picture size and puts them in the right place without any major problems. Ingrid learned how to move the pictures between the different programs in one day. One problem is that she has access to so many other programs and icons that she does not need to use yet.

The fact that even Ingrid who has her own computer at home, is afraid to use it without assistance is a major problem, in my opinion. Both Agneta and Kristina desire a user interface where Ingrid only has access to the few applications she actually uses. Not until then will she have a chance to learn to turn the computer on and off and use the applications without the help of someone else. When she has done that a number of times so that she feels secure, she can use her computer more independently of others.

The application that is used at Tryckolera has been specially designed for them in co-operation with Certec. Here you can easily choose pictures with the help of the bar code and then print them out by just pushing a button. Since they have a touch screen, they don't have to be able to use either a keyboard or mouse to print the sequence of pictures chosen. The program arranges the pictures automatically, 2 x 4, and assigns them a bar code. This allows Stig and Thomas to choose the pictures themselves and print them out without asking for help. Their sense of integrity increases enormously since they neither need to show or explain the pictures to anyone else. Göran tells me that it's not unusual that they print pictures and take them home without showing him.

'Often the interpretation is individual and that is solved by an adaptable personal user interface where you can choose the representation that suits the user best.' (Björklund and Wilhelm, 1995, p. 34).

This, in addition to your own profile is something that almost everyone I have spoken to requests. There should be photographs on the screen representing user profiles. By choosing your own,

you gain access to the programs that you need. Such a program exists, and they are planning to acquire it at Fågelskolan. It is called *Kidsafe*, but I have not yet examined it.

Screen layout

There shouldn't be too many choices per screen, but what is too many depends on the individual. That is why it is important to have a personalised user interface, but consistency in the layout is of even greater importance; buttons that have the same function, such as the 'Exit' button, should have the same icon and be in the same place on the screen. It is also easier for people with moderate mental retardation to perceive information that is placed in the middle of the screen. Consequently, a big screen can confuse the users (Björklund and Wilhelm, 1995).

It should be emphasised, though, that the problem with a big screen ceases to exist when you are looking at photographs. To be able to sit together and see a picture on a big screen is important.

It is also important that there is no inactive choice visible on the screen, to avoid confusion (Björklund and Wilhelm, 1995).

Pictures/Icons

One of the pupils at Fågelskolan really wants to show me a photograph of a special person. We look at her pictures, which are shown as thumbnails on the screen. I am having trouble seeing what is on the pictures but the pupil browses through all of them quickly. She says something and makes a movement with her hand to show us that we have to scroll down so she can see the rest of the pictures. First, she points at one with lots of blue on it and then at the right one. It turns out that the picture we were looking for was taken on an outing. The picture with lots of blue on it was of a blue sky.

According to Björklund and Wilhelm (1995) icons/symbols should be at least 4x4 cm so you can see the contents. Thus the screen size limits you. The larger the pictures the fewer you can fit into a display. The most important factor, concerning size, is that the picture is large enough for everyone involved to see it (Loncke, Vander Beken and Lloyd, 1997).

The example above shows that it is not at all necessary that the pictures are large. Ingrid also used thumbnails without any problems. I believe that it is the interest in the content that is the determining factor. I have noticed that the same persons that easily find the right picture among many others have great difficulty in finding the right icon to open a program. Of course, there could be several reasons for this, but I think that when the picture means something special for a person it makes it much easier to find. It is

important, though, that you are able to look at the photographs in a larger size when you want to look at them with someone else.

Björklund and Wilhelm (1995) mean that there can be an advantage if the symbols are animated: *We have tested a representation for 'Exit' that consists of a filmed hand waving. It turned out that the users found it easier to associate this with 'Exit' than a simpler symbol.*

According to Björklund and Wilhelm (1995) a hierarchical structure is the form that suits moderate mentally retarded people the best. This is because it allows program designers to limit the number of choices.

Agneta wishes that the folders containing the pictures could be represented on the desktop and have different colours depending on which month they represent, instead of in a regular tree structure. This does not support Björklund and Wilhelm's (1995) idea that a hierarchical structure is best. I believe that if the choices are not more than what easily fits on the screen, it is to be preferred to see all at once. One condition, though, is that the icons clearly represent what they are supposed to symbolise, for example with a colour or photograph.

Hierarchical structure

At Tryckolera, Göran is very particular about every picture having a distinct black frame around it. The frame makes it easier to look at one picture at a time, the borders between the different pictures become clearer and you can more easily focus. Göran even brings ordinary black frames with him when they are out somewhere. Then he can simply put the frame in front of the object they are looking at, making it easier to focus.

Clear frames

Symbols and pictures should be enclosed by a black frame (Björklund and Wilhelm, 1995).

Everyone at Tryckolera has his or her own colour, Stig has red and Thomas has green. The pictures that are personal are colour coded, just as the desks and chairs. They also have a common symbol; a blue ring with a black dot on it, which represents an eye. The round, common worktable in the middle of the room is also painted blue with a black dot on it.

Colour

The use of colours in a user interface usually is not very consistent. People with mental retardation often use colours to represent different things. The weekdays for example are represented in this manner (Björklund and Wilhelm, 1995).

It is important that you do not use colour coding with colours that are already being used to represent something else. It is common within care for developmentally disabled people, that colours represent weekdays and months and at Tryckolera every individual has his/hers own colour.

Feedback Ingrid often turns to Kristina to get confirmation that she is doing the right thing.

Visual and auditory feedback are important for people with moderate mental retardation. Feedback is necessary so they really understand that the computer is reacting to the action, to know when they have done something wrong and because it simply makes it more fun to use the computer. Recorded speech often gets a very positive response. It has to be possible, though, to inactivate the type of feedback that is not currently needed, such as inactivating sound for people with severe hearing disabilities (Björklund and Wilhelm, 1995).

Receiving positive feedback, a confirmation that what you do is right, is very important. If the application cannot offer that, another person has to. Even if the application offers feedback you might need confirmation from a person for a period of time, until you feel secure enough in using the computer.

I am sitting with one of the pupils at Fågelskolan. She is handling the mouse but is so eager to show me her pictures that she clicks too quickly. I continuously have to try to make her wait until the picture is finished loading.

It is important that you don't have to wait for the feedback, that it is immediate. If the computer needs time to perform a task, a kind of 'waiting symbol' should be shown. The most common such symbols are an hourglass or a rotating clock, two symbols that often don't have any major value for people with mental retardation. Björklund and Wilhelm (1995) have another suggestion: *We suggest a sequence where an animated or filmed person walks back and forth 'waiting'. We tried this by filming a person walking back and forth looking at his watch at the same time as a spoken message said, 'Wait'. This auditory feedback should be repeated about once every 10 seconds.* (Björklund and Wilhelm, 1995)

I am sitting with a pupil at Spandelstorpsskolan who is colouring pictures from a colouring book on the computer. He has, by himself, found a picture of a flower and he is colouring with great concentration. When it is finished he wants to click on the print symbol but accidentally clicks to close the program instead. The result is that the picture doesn't get printed. We open the program again but now he can't find the flower after looking through many pictures. Eventually he gives up and starts to colour a floor lamp instead.

Handling errors



Pupil colouring a flower

'Preferably you should avoid any error occurring, though this is almost impossible. This is important for a normally gifted user, but even more so for users with moderate mental retardation. When errors occur, these users become upset because they don't understand why the system doesn't behave as intended. This creates a feeling of insecurity that is reinforced when the user doesn't get any reasonable explanation for the behaviour.'

(Björklund and Wilhelm, 1995, p. 31)

A pupil at Fågelskolan is writing a letter to his teacher Vibe, who is on leave. He and Mona have already decided what the letter should say and they have spelled it out with blocks of letters. He is writing slowly and has to look at the letters almost all the time to know which one to write. Sometimes, though, he knows what the next letter is and he doesn't look at the blocks. The keyboard is set so that if you hold down a key too long the same letter is typed repeatedly. This happens several times, but he really seems to find it fun to erase the extra letters. When the letter is finished and we are going to print it out, the printer doesn't work. The pupil soon loses concentration and interest in the printout and starts to do something else.

In a study where they interviewed fathers of persons that use alternative communication technology about their needs, the question of maintenance, programming and repair of the device is ranked as high as second or fourth place (Sweeney, 1997).

Difficulties with handling errors and technology that does not work as intended, is precisely the problem that several of my informants address. It takes a lot of time to figure out what the

problem is and then solve it. None of the staff at the day centre or the schools have any special training concerning computers.

Sorting and storing of pictures

Göran wants one picture to work as a 'picture in one's mind', i. e., as a key to other pictures. Beneath this 'picture in one's mind' there will be several other pictures, a whole sequence (or more) that shows a particular event.

Everyone I have visited sorts their pictures after person and then chronologically or after event. Most of the users have their own folders and inside them, one folder for each month. The problem is that the only thing identifying the separate folders is the title, mostly given in year and month. If you have problems with reading, it becomes almost impossible to find the right folder by yourself. One solution, that many of my informants have suggested, is to simply give the folders different colours. To represent the months by colour is nothing strange since almost everyone in care of the disabled already uses different (standardised) colours for the different days of the week. If each user then has his own profile, and so doesn't have to start by searching for his name on a folder in a file system, it would increase accessibility considerably.

7.4.3 Hardware

Screen

One of the pupils at the Fågelskolan had recently got his own communication computer when I make my first visit there. At the moment there are only a few PCS¹³ pictures stored but you can add your own pictures/photographs and sound. It is a small computer, like a laptop, that the pupil is supposed to carry with him and use both at home and in school. We sit down together to look at it, Mona and I on either side of the pupil. The problem is that to be able to see anything at all on the screen, you have to sit right in front of it. For us to see anything together I lean towards the pupil and Mona stands behind him. And this is supposed to be a computer for communication!

One basic requirement of a screen, in my opinion, is that you can see what is shown even if you are looking at it from the side. This should be especially important if it is a computer that should be used to converse with others.

¹³ Picture Communication Symbols

I sit next to a pupil at Fågelskolan. He is showing me his pictures and he has no problem whatsoever handling the mouse. He opens up new pictures quickly and closes the old ones with the help of the x box, fast and easily. Another pupil at the school has a hard time lifting and moving the mouse when she gets to the edge of the mouse pad. 'Help me!' she says. It is enough though that I lift the mouse and place it in the middle of the mouse pad.

Ingrid sits by the computer arranging pictures. She works in total concentration and moves the mouse slowly but confidently. She moves the picture from one program to another. Waits until the cursor changes symbol and changes the size of the picture. Waits again for the cursor to show the right symbol and moves the picture to the right place. She is careful and doesn't give up until the picture is exactly where she wants it. Every once in a while she turns to Kristina to get confirmation that what she is doing is right.

One of the pupils at Spandelstorpsskolan is sitting in front of the computer colouring a picture of a flower. He has the mouse right in front of him on the table and handles it with both his hands. (The whole table ought to work as a mouse pad!) It looks difficult but he succeeds colouring even the thinnest areas.

You should be careful in making too many adjustments. There should, of course, be alternatives if you can't handle an ordinary mouse. But if you depend on alternatives they have to always be available if you are going to be able to use the computer. Several of the people I have observed have given the first impression of needing some sort of adapted mouse instead of the regular one, but when I have seen them work for a while I realise that they can handle much more than I first thought. Besides that, several of the pupils have siblings that use the computer to play games and they learn from them.

Mouse



Pupil handling the mouse with both hands

8 The Surroundings

As in every other case concerning introduction of new technology and use, it is not enough just to focus on the individual or group level. The rest of the organisation and surroundings are also affected by and affect the chances for a successful introduction.

8.1 The organisation

Agneta Dyberg-Ek tells me that nowadays not only all special classes have at least one digital camera each, but that the interest for digital pictures is starting to spread to the 'regular' comprehensive school.

A common problem in the municipalities is the 'principle of fairness', in my opinion. Do not give extra resources to anyone; everyone should have the same. But everyone isn't the same and you have to give extra resources to those who need it, so they can have the same basis as everyone else. It also is not so that everyone can be in the forefront of development; you have to let some go ahead. As in this case, letting the special school lead the development and then spreading the knowledge to the others is an excellent example to follow.

8.1.1 Resources

'We only have 600 SEK per pupil and year and that should be enough for everything. Since we have few pupils there is not much money left for new equipment. It "takes" two pupils just to buy ink cartridges'.

The economic resources available, unfortunately, depend on the municipality in which you reside. Many of those I have met have very poor access to resources, while some have no problem at all getting the necessary equipment. It is possible to apply for extra funds through different trusts and projects, but it takes a lot of time to apply for money.

8.1.2 Technical support

Many of those I have spoken to wish for better technical support. Often they have to try to solve the problems that occur themselves.

If you do not have any special computer training and many other duties besides, the problems can be so great that you simply do not see yourself having time to use the computers. Neither should it be the case that those in technical support set up rules and complicated demands that impede usage, such as difficult passwords.

8.2 Home and family

Agneta makes sure that each child brings home at least one picture every day. It doesn't happen very often, though, that the children bring pictures back with them to show, but it is becoming more and more common. One of the pupils now has his own digital camera and he takes photographs both in school and at home. Agneta thinks that it is important to include relatives so that the pupils can show what happens during their spare time in pictures. Dialogue demands activity from both sides, says Agneta.

Göran drives Stig and Thomas home every afternoon. Then Göran often takes the opportunity to talk to the staff at the group homes about what has happened during the day. There is still not much contact between the day centre and the group home. Neither Stig nor Thomas uses their pictures very much at home.

Anna tells me that one of the most important changes after they started to use the digital camera, is that the parents feel more a part of the work in school. To receive a weekly report with lots of pictures makes it easier to understand what is happening in school.

Contact between school or work and the home is very important. Historically, there have always been difficulties in the contact between the day centre and home. They don't work in the same way, don't communicate with each other and therefore have difficulty understanding each other. Here I think the digital photographs can be a big help. Just the fact that you have seen a person's pictures makes it easier to establish contact or initiate a conversation when you meet. One condition for the dialogue between work or school and home to function well, is that every user has his/her own camera.

9 Discussion

9.1 My methods

So how have my methods affected the results? I believe that ethnography and ethnomethodology can give many important answers particularly in the area of alternative communication. According to Wittgenstein, the understanding of language is the same as being able to use the language and ethnomethodology is derived from this. Ethnography is also a very visual science, it is about 'looking at' what people do, and I suppose there aren't many artefacts that are more visual than photographs.

9.1.1 My role

My own role as a scientist has been the one that Walcott calls 'the restricted observer'. I hadn't met any of my informants beforehand and I had very little time to gain their confidence and establish a relationship. My meetings were made easier, though, by the fact that Arne Svensk at Certec mediated the contacts with the informants.

My own experience of care for the developmentally disabled also facilitated the contacts and made me to some extent 'privileged'. I didn't have to put time and effort into thinking about how I would treat these people. At my first meeting with Ingrid she walked up to me and signed 'What is your name?' That I was able to spell my name in sign language felt very good. On another occasion in one of the schools, one of the pupils grabbed hold of my sweater and put his head down my neckline, to see if I really wasn't wearing anything yellow. It was a Friday and Friday is colour-coded yellow. I didn't react, but just said 'No, I don't have anything yellow there either'. He looked for a long time and then said 'You look like mother' and let go of my sweater. The teachers who were sitting with us, and who had held their breath, sighed with relief and said 'How good it is with people who are accustomed!'

Something that is emphasised in the literature of ethnography is the state of being 'innocent'. You can enter a workplace and ask 'stupid' questions since you are coming from the outside and aren't supposed to know anything about the domain. This is a problem for us who are studying computer science. Many see us more as computer experts, who are supposed to come out and tell how things should be, instead of playing the role of 'innocent'

To be 'innocent'

ethnographer. My goal was to enter with my senses as open as possible and not to think design and data analysis during the field studies. Even though I had in my initial contacts via e-mail with my informants explained that the purpose of my visit was only to see how they worked, I do believe that there still were some expectations placed on me. My opinion is that this resulted in decreased trust from at least one of the informants. I should have been clearer about my role than I was. All the places I studied were used to visitors and some of them received many requests. Even if a visitor tries not to disturb the activity, it takes a lot of time to inform and show others how they work. It is natural that something is expected in return.

I have also used a digital camera in the study. To be able to gain experience of your own, even to a limited extent, gives information that can lead to further questions. It was exciting to see the interest the camera stimulated, not only in my field of studies but also privately.

9.1.2 The role of the staff

Ball (1998) says that of course the scientist's actions influence the results. One problem with ethnographical studies of foreign cultures is that the researcher doesn't speak the same language as those he observes, at least not in the beginning. If you use an interpreter everything you hear is filtered through translation.

Due to my relatively few visits I have got most of the direct information via the staff. The question is what this has meant for the results? It would be interesting to carry out a longer study of one individual's use of digital personal photographs.

9.2 Technology and cognitive disabilities

Lundman (1997, p. 152) says that *'though we have through millenniums developed and used "brain tools", i.e. tools to remember, calculate, plan and measure time, we haven't been very good at developing these "brain tools" for people with cognitive limitations.'*

Here I see a challenge for those who work with new technology. I believe that developing services where you can easily access a picture database via a handheld device or mobile phone, for example, can have a positive effect, not only for people with cognitive disabilities. I am convinced that an investment in technology and disabilities can direct this development and service for everyone. Considering the creative and innovative people I have met during my work on this thesis, co-operation between

people in the care of disabled people and designers could be very fruitful for both groups.

9.2.1 Digital personal photographs

When I have looked at the use of the digital personal photographs, I have noticed that they are both more public and more private than ordinary family photographs. You get your picture taken at work, when you are tired, happy and sad, in all situations. The digital photographs don't only show an ideal world, but also the trivialised weekdays. At the same time the pictures becomes more public, they are visible in the room, many people have access to them, and they are not hidden in a family photo album.

The advantages with using digital personal photographs compared to, for example, the much-used Pictogram pictures are many. First of all the photographs are much easier to understand if you are cognitively challenged. They represent the reality directly and not via symbols. I have mentioned that people with cognitive disabilities do not always connect, for example, the act of baking to any kitchen, but to their own.

It is also much easier to awaken interest with a photograph; we are all social beings, interested in each other. *'If being a human being is only about talking, then it is our small talk that makes the wheel spin, not the words of wisdom uttered by an Aristotle or an Einstein. We are social beings and our world is characterised – just as the monkey's and the ape's – by every day pleasures and little tasks. They fascinate us very much.'* (Dunbar, 1998).

9.2.2 Acceptance of alternative communication

I have previously mentioned that it can be hard to accept alternative communication and communication devices. The use of cameras and computers is already accepted in our society and using a digital camera often arouses a positive response from the surroundings. I also mean that it is easier for both those in the surroundings and the user him/herself to accept photographs as an alternative way of communicating than Pictograms, for example. Everyone knows what a photograph is, they are not strange to the world outside of care for disabled people, which Pictograms are.

9.2.3 Status

Kristina tells me that on one occasion, when one of her acquaintances started a conversation about digital cameras, she said: 'I use it in my work'. Her friends were positively surprised that she, who works with disabled people, had access to such new technology.

Another important aspect of technology is the ‘increase in status’ for those who are ‘at the bottom’ of society. The integration of people with cognitive disabilities is made easier in part because of the increase in communication possibilities, and to the ‘rise in status’ the technology means. Perhaps working with disabled people will be valued higher if it requires a certain amount of technical expertise as well. We do, unfortunately, value technology higher than people.

9.3 Design

So what do you need to think of when developing communication aids for people with cognitive disabilities? The most important is that you start off from the premise that the users are individuals; just because they have the same diagnosis doesn’t mean that they have the same needs. It is easy to view people who already have been categorised by society as a group and not as individuals.

9.3.1 Useworthy

To make the technology not only usable but also useworthy, you need to know the needs that exist and how important they are to the users. Ethnography is an excellent method for visualising needs for people who cannot easily verbalise them themselves.

It is also important to let the user test the product at an early stage. If you can’t imagine what you haven’t seen or experienced, you can’t wish for something that you haven’t tested. A method where you quickly develop prototypes as you go along and let the user try them out, called ‘rapid prototyping’, is suitable when you are developing technology for people with cognitive disabilities. If you combine this method with ethnographical studies, I believe that you can achieve very successful results.

Rapid prototyping

9.3.2 Accessibility

It is also important that the product facilitates independence and here the keyword is accessibility. The technology doesn’t only have to be accessible in a physical way; it can’t be too complicated either. The applications may need adjustments to reduce the risk of making mistakes. It is more often the case that a user is afraid to click on an icon, than dare to try it on his own.

To make the pictures accessible a person has to try to visualise what is in the computer. One way to do this is to let one picture represent a whole sequence and in that way one can easily see where the pictures are stored. A compact, hierarchical structure is not to be recommended. It is also important to be able to represent folders with photographs or colours and not just with text and numbers.

9.3.3 Co-operation

Since communication always takes place between people, it is essential that communication aids support co-operation. It should be possible to see and work with the pictures along with other people.

10 Afterword

My ambition was to present as comprehensive a view as possible of the everyday use of digital personal photographs. I have seen how people use them in school, at work and at home and I have studied many different users, both with and without disabilities. I believe that I have been able to lay a foundation for further studies. I believe that a longer study of the use of digital personal photographs can give more insight.

It would also be interesting to proceed with developing a good personal user interface, where a person only have access to the programs he or she really uses. An application is also needed that stores pictures in a simple and conspicuous way, and in which icons are not abstract symbols but photographs and colours. To increase mobility it would be interesting to use a handheld computer with access to a personal picture bank.

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