

Assistive Technology Provides Opportunities For People With Psychiatric Disabilities



Hjälpmedelsinstitutet

© **Swedish Handicap Institute 2003**

Author: Marit Grönberg Eskel, Karlstad University

Gunilla Barse-Persson, Human Technology Project in Karlstad

Catarina Brun, Human Technology Project Leader, Swedish Handicap
Institute

Lay-out and illustrations: Jenny Renstrand

Edition: 500

Print: Eo Print 2003

Best nr: 03357

ISBN: 91-88337-88-X

Contents

Introduction	4
Background.....	4
Cathrin explains:.....	5
Carl-Peter explains:.....	6
Psychiatric Disabilities.....	6
What assistance is available?	7
Comments from Users	9
List of references	12

Introduction

Assistive devices make life easier

Cathrin and Carl-Peter participate in the project Human Technology together with 10 other people. Both Cathrin and Carl-Peter greatly benefit from the different assistive devices that help their day to day life. In the film we have chosen to focus on Cathrin's and Carl-Peter's everyday life, on their thoughts and ideas and not on their assistive devices.

In this booklet you will be given more information about:

- The Project Human Technology
- Psychiatric disabilities
- The assistance available
- Comments by participants on their assistive devices

Background

- The Swedish Handicap Institute
- Interest groups for people with schizophrenia and similar psychoses, The Swedish Schizophrenia Fellowship
- The Swedish Association for Social and Mental Health, RSMH

These groups have received funds from the Swedish Inheritance Foundation and together run the project - Human Technology. The aim of the project is to develop new forms of assistance in the home and at activity centres for people with psychiatric disabilities. With the help of different products /assistive devices they are also given the opportunity to take charge of their own lives and become confident, independent and active in their everyday lives. The target group is people with psychosis diseases and/or compulsive behavioural problems. The trial programme is based within the Karlstad City Council and the county of Värmland. The project runs from 2001 to 2004.

”For me the memory message is so important,
it has made my life easier”.

The Memory Message

Cathrin explains:

A new day begins with the loud beeping of my clock radio alarm, 8 a.m. but I don't wake up. Then it is the memory message's turn to try to bring me to life. I find it difficult to wake up. At 8.10 a.m. I hear something, far away but don't know what it is. It is my memory message that repeats my message: "Good morning, good morning, time to wake up" nine times, once every minute. In the evening, after I have programmed in my daily routine for the next day, if I am unsure whether the clock will repeat the message all I need to do is look to see if the black dot is in the middle and then I know that it is set for repetition. After breakfast I can make additional changes if I need to do something particular. I often go out in the morning, and use the clock regularly to make sure I leave on time. This device has quite simply changed my life for the better. Yes, I can plan an ordinary day exactly how I want it – isn't that wonderful?

First I get a message to wake-up of course, followed by: "Now it's time to shower". After that I get messages telling me when I should eat breakfast, when I should get dressed, when I should get ready to leave, pack my bag and put on my shoes. Finally I finish with: "Now its time to leave the flat", and then I go. The memory message has made my life easier. I find it difficult to gauge time. I disappear inside myself, time simply ticks by and I don't get anything done. But now with the help of the clock I get everything done.

I've also tested having the clock programmed in the evening and found that it was as impressive as with the morning routines, I realised that I needed it just as much as in the morning. Unfortunately it hasn't become a fixed routine yet, but it will eventually. It is just that I always believe that I can manage without it. I almost always think: "This evening I'll go to bed early". The thing is I don't always manage to do that, not alone, not without the help of my friend the memory message. Yes, I see it as a friend.

I tend to stay up late every evening, but with the clock's help I get to bed. What makes it a little more fun is that I record my own voice to wake-up to and my own personal message. I usually use my voice differently, a little softer with my wake-up call. Yes, a nice voice to wake up to. But when its time to take a shower, then I am a little harder. I find this fun since I am a rather dramatic person.

Finally I would like to say that I am very grateful to have been part of this project, thank you.

”I have grown as a person and feel that I am more independent”

Finding the right assistive devices

Carl-Peter explains:

Since the late summer of 2002 I have tried different assistive devices within Human Technology. I have tried the memory message, pocket computer, shake-awake and assistive devices that are not directly technical solutions, for example filofax, structural solutions for keeping the home in order and a calculating sheet for my economy. My mornings are still as difficult, but I feel I have had some help. The needs change with time. It is a bit of a “fresh produce” I think. Even if I don’t jump up in the morning, keen to make the most of the day, I have still grown as a person and feel I am more independent. It takes time to find just the right assistive devices I need. But when I begin to do that then I cope more and more myself, and the satisfaction that gives also makes me feel better in myself.

Psychiatric Disabilities

In order to understand the difficulties that can arise in everyday life for the participants in the project, a brief account of what psychiatric disability means is presented here according to Lennart Lundin’s and Ove’ S Ohlsson’s (2002) reasoning in the book ”Psyiskt functionshinder – Stöd och hjälpmedel vid kognitiva funktionsstörningar” (Psychiatric disabilities – support and assistive devices for cognitive disabilities). They believe that it is important to distinguish between the terms psychiatric disability and psychiatric handicap. The psychiatric handicap arises when a person with psychiatric disability meets a society that places impossible demands upon them. The causes of the psychiatric disability are functional injuries that have arisen after a person has had a psychiatric illness.

A person could contract a psychiatric illness when they are exposed to psychiatric ill-health, which often reveals itself in the form of early disabilities already in childhood. In order to be able to help people in the right way one requires an understanding of the underlying causes of the disability. Otherwise there is a risk that treatment and support do not focus on compensating the person’s disability but focus instead on the surrounding society and the person’s ability to adapt to it. Thought process disabilities or cognitive disabilities in the executive functions are an underlying cause of the functional disabilities of people with psychiatric disabilities.

Executive functions are: ability to take initiative, cause/effect understanding, planning and organisational ability, ability to motivate oneself, ability to automatic actions, ability to focus attention. Loss or deficits in these abilities result in an inability to acquire an everyday experience and automatic behavioural pattern that most other people make. It concerns the ability to automatically carry out everyday activities that are recurrent and important for a functional social life (a.a.s. 62). This functional deficit can result in people regarding the person as slow, lazy and careless, which is not the case. Cognitive disability of central coherence (to keep and combine a large number of details) (a.a.s. 79) is a disability that results in an inability to interpret social and emotional contexts.

Oversensitivity to stress and other types of disabilities in body conception also occur in people with psychiatric disabilities. The cognitive disabilities increase with stress, and following exposure to stress, people with psychiatric disabilities can have difficulties returning to a normal resting level. Instead the body remains at a high stress level resulting in the person being trapped in a flight/fight behaviour for long periods, leading to, for example, difficulties with perception; an over sensitivity to sensory impression and difficulties with a natural sleeping rhythm. It is also common that people with psychiatric disabilities have difficulties with the memory function, which is associated with concentration difficulties. This is illustrated by the fact that many psychiatric disabled people have difficulties using the right memory, remembering the right thing. It can also be difficult to generalise knowledge/convey learnt knowledge from one environment to another.

What assistance is available?

In the Human Technology project, “psychiatric disabilities and assistive technology devices”, we have tried a number of assistive devices during the course of the project, both low and high technology. The products are chosen according to the supportive and assistive function they provide for the person using them. This means that all the products tested in the project are not necessarily approved assistive devices but they are beneficial in the forms they are being used.

Time and Structure

For those problems that concern the ability to create an understanding of how much time is needed for different activities a **Memory Message** can help. It works by the person itself recording messages and requests which are then replayed at desired times. An example can be when the person knows they are going to do a particular activity at a certain time. The person records a message about getting ready in

time, which is then replayed at an appropriate time before the person must leave. Pocket computers can also be used to create structure. A day can be clearer to envisage on a screen, making it easier to see how much time there is to do everything and it can also help to reduce uncertainty about forgetting or missing appointments. Those people that do not trust in their own ability to keep time can utilise any of these assistive devices as alternatives to loose bits of paper that can easily disappear, or relying on help from others to succeed. It gives satisfaction to be able to manage by yourself without being dependent on someone else to cope with everyday life.

Another assistive device is the "**shake-awake clock**", a type of alarm clock with both a conventional alarm and a vibration plate which is placed under the pillow to wake the person in a more hands-on manner. There is a snooze function built into the alarm clock which is appreciated by the users: "It lets you slumber a little."

In order to get an overview of the week's engagements a **white board** can be of help. Activities and engagements can be noted on the white board which the person can view whenever he or she needs to.

Worry/Stress/ Restlessness. Worry and restlessness are other problems that can be helped by assistive devices. One example is the **computer** that can be used in many ways. It can be used both for work and to play games or quizzes or similar programmes. Quiz programmes can also help increase self confidence: "Its very satisfying when you know the answer" and "it helps improve your general knowledge".

It can also be used to write down your feelings, your worries and concerns and you can then judge how relevant these are in a longer perspective or whether the person can talk through them and end up feeling more at ease with them. A computer can also increase self-esteem. Not "keeping up" with social developments creates a distance to the rest of society.

Socialising with other people

There is great hope among the participants that the **Internet** will help them in their everyday life, for example in contact with other people. Another hope shared by the participants is that they can use the Internet to get a better understanding of society and all "the new stuff" that is coming.

Lack of initiative

A pocket computer or a memory message can be used to help a person that has difficulties motivating themselves to do things that need to be done. Using the person's recorded voice it encourages the individual to

tackle certain tasks. It is the same assistive device that is used to create structure but here it has another function.

To start cleaning is a task that can be difficult, but it is made easier if it is made easier to clean and if there is a clear order in the home. An example can be to label cupboards and drawers in the kitchen and bathroom etc. so that the individual can find things. If they know where things should be placed it is easier to keep everything in order and avoid “making a mess”.

Sleep

Many of the participants have trouble sleeping at night. To improve sleeping patterns a tactile stimulation quilt filled with plastic balls the size of tennis balls has been tested. The weight of the quilt provides a feeling of safety. One of the participants that had tested it said: “It feels as if you are being hugged, the weight gives a sense of peace and tranquillity, you sleep much better”. It is not known what creates this positive effect but according to the participant one reason could be that “it holds you in place”. The tactile stimulation quilt does not help everyone to sleep better, but is generally considered pleasurable. The tactile stimulation quilt has also been used during the day to calm and relax someone who feels stressed or anxious.

The text on pages 11-22 are from Grönberg Eskel, M. (2003) HumanTeknik, hjälpmedel och vardag. Delrapport 4 Karlstads University. (Human Technology, assistive devices and everyday life.)

Comments from Users

The following comments are on the assistive devices tested by the participants in the project. The material was collected and documented by the project group in Karlstad.

Pocket Computer

An electronic calendar with a reminder alarm and opportunities to make notes

- Daily and weekly planning of activities
- Small, can easily fit in a pocket
- Easy to programme, reliable
- Can be used as a calendar, calculator, address book, to make reminder notes, to structure and plan
- Easy to be able to carry notes around with you and can help structuring the week and day.

I can thereby relax better because I can differentiate between meaningful things and discover in time when I begin to loose

perspective. Before I often mixed up which days and times an activity was supposed to take place.

Memory Message

Tells you what time it is and you can record your own personal messages.

- To wake up to, start routines.
- Remind me what I should do now and during the day.
- Can plan activities, start the evening routine in order to get to bed.
- Works well, is easy to programme
- It is easy to hear and I record my own messages to encourage me and "nag at myself"

Wristwatch

With alarm and text messages.

- With the watch I can make my routines work, for example so that I eat when I should, clean etc.
- The watch is easy to wear and it contains a lot of information. It is useful that it beeps and shows me what I should do, that helps me think. I usually call it my "food-and sleep watch".
- It is good that it looks like a normal watch.

Time Rule

Clear count-down of time via a LED display. When it is started a column of lights appear. These turn off in sequence one by one and when they have all disappeared a signal sounds.

- Used it a lot, mostly with TV- programmes otherwise I miss the start.
- It helps when I should start an activity. Helps me get up.
- It is good with the column of lights, it helps practise an understanding of time.
- Good for my breaks during the day so that I do not rest too long.
- Helps with keeping time at the computer, washing-up, tidying, cleaning, showering.
- Security and support, helps me pace myself so that I don't become exhausted.
- Simple, easy and useful, a good friend.

Shake-Awake Clock

An alarm clock with sound and vibration

- The alarm clock wakes me up with a loud bleeping and vibration in my bed. It is the first and only alarm clock that has helped me wake-up, it is easy to set, and looks like a normal alarm clock.

Tactile Stimulation Quilt

A quilt with balls sewn into it. Soothing, as the weight of the balls stimulates the central nervous system and gives the body tactile stimulation.

- Safety, keeps me in place.
- Pleasant, wonderful to be covered in something heavy, it gives me a feeling of mental wellbeing.
- You feel as if you are being hugged, a feeling of warmth.
- I fall asleep quicker, sleep deeper and don't wake up as often as I did before.
- Better sleep, I have cut down on my sleeping pills and eat less at night.

White board

For mental notes, easy and provides an overview.

- I use it to write the date each day, meetings with people, daily tasks, what I need to buy.
- It is very useful when someone rings and leaves a message, then I can quickly write it down.
- I use it a lot to help me stop checking the door. I write: check the door once – now it is locked! if I feel worried I look at the white board and feel calm when I see that I have checked it.
- I write funny things as well as good night and sleep well!

Computer and Printer

The computer is at the top of the list of assistive device that the participants wish to have. To use the computer to document what has happened during the day, confirm the activities of the day and write about their life in order to piece together events and contexts, is of great importance. Familiarity with computers varies, some participants have been on computer courses and have their own computers whilst one person had no previous experience with computers. There are many advantages with computers, they are relatively easy to use, predictable and do not require conversation. Having a computer at home allows someone that has difficulties concentrating in different environments and among different people the opportunity to undertake an activity in a safe, stress-free environment.

The computer stimulates activity, daily planning, Internet use and participation in society through seeking knowledge, e-mail contact and taking part in discussion groups.

- Writing a diary helps me a great deal, I become more aware, develop and gain a broader general knowledge.
- Better self confidence, improves my concentration, I feel good when I write, using the computer has given me a lot of pleasure.
- Writing, playing cards and other games.
- I can't describe in words what it means to me to have a computer at home or express in words how I feel. The printer is the best since it allows me to see what I have written.
- I feel less alone when I can send e-mails and have contact on the Internet.

List of references

Grünewald, K. (2000) Psykiska handikapp. Stockholm: Liber
Grönberg Eskel, M. (2002a) HumanTeknik, en första beskrivning. Delrapport 1. Karlstads universitet
Grönberg Eskel, M. (2002b) HumanTeknik, projektets deltagare och fortsatta arbete. Delrapport 2. Karlstads universitet
Grönberg Eskel, M. (2002) HumanTeknik, omvärld och lokalsamhälle. Delrapport 3. Karlstads universitet
Grönberg Eskel, M. (2003) HumanTeknik, hjälpmedel och vardag. Delrapport 4. Karlstads universitet
Lundin, L. & Ohlsson, O. S. (2002) Psykiska funktionshinder – stöd och hjälp vid kognitiv funktionsstörning Stockholm: Cura

www.hi.se

www.humanteknik.se

www.RSMH.se

www.schizofreniforbundet.se

The Swedish Handicap Institute (SHI) is a national resource centre on assistive technology and accessibility for persons with disabilities.

SHI work for full participation and equality for persons with disabilities by ensuring access to high-quality assistive technology, an effective provision of assistive devices and an accessible environment.

The activities of the Swedish Handicap Institute cover:

- testing and procurement of assistive devices
- research and development
- analyses of needs, knowledge and method development
- training and capacity building
- international cooperation
- information

The Swedish Handicap Institute is run by the Ministry of Health and Social Affairs, the Federation of Swedish County Councils and the Swedish Association of Local Authorities.



Box 510, 162 15 Vällingby
Tfn + 46 8 620 17 00
Fax + 46 8 739 21 52
Texttfn + 46 8 759 66 30
E-post registrator@hi.se
Webbplats www.hi.se