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ABSTRACT

This monograph presents the final report of the Swedish component of TeleCommunity, a nine-nation European project exploring the potential of videotelephones. This particular study focused on the use of videotelephones to increase levels of independence, social integration, and participation in social life among adults with moderate mental retardation (MMR). Twenty-four adults (ages 21-60) with MMR were drawn from six day centers and group homes in Stockholm and Jonkoping (Sweden) to participate, each having poorly developed spoken language and using graphic symbols for regular daily communication. Pictogram symbols were selected for each participant's concept keyboard, and participants were trained on use of the equipment. Data on their subsequent use of the videotelephones were gathered through questionnaires; assessment of communicative ability, telephone protocols, and goal setting; and interviews with family members, participants, and support staff. Results indicated that participants' social networks were expanded, frequency of use of the videotelephones increased, communication was generally improved, and increases were noted in both independence and initiative. Appendices include protocol evaluation forms, communicative ability assessment tools, and interview guidelines. (Contains 90 references.) (PB)





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VIDEOTELEPHONES

A tool for facilitating communication and social integration for persons with moderate mental retardation.

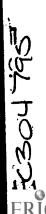
TeleCommunity - Final report.

Jane Brodin and Ingegerd Alemdar

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Jane Brodin and Ingegerd Alemdar

This report is the final report from the European project TeleCommunity, RACE 2033 (Research in Advanced Communications Technologies in Europe). The project was supported by the Swedish telecom Telia and the Swedish National Board for Industrial and Technical Development (NUTEK) in 1992-1994 and by the The Swedish Transport and Communications Research Board in 1995.

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Abstract:

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TeleCommunity is a European project within the area of videotelephony, with nine countries involved. The overall aims of the Swedish ACE (Advanced Communication Experiment) were to get knowledge of and understanding of the issues whether videotelephones could increase the level of independence, social integration and participation in social life. The purpose of using videotelephones was to study if this kind of telecommunication aid would help the participants with moderate mental retardation to use telephones. The aims were to support, stimulate and facilitate communication, to get access to telecommunications, to support independent living and to increase social integration.

Twentyfour persons with moderate mental retardation from six day centres in the Stockholm area and in the Jönköping area participated in the study. The age of the participants were between 21 and 60 yearsparticipants had a poorly developed spoken language and used graphic symbols in their daily communication. They also had many additional impairments. The methods used to collect data were questionnaires, interviews with parents/relatives, staff from day centres and group homes as well as inteviews with the participants themselves, assessment of the communicative ability, goal setting and telephone protocols. The results show that the participants' social network was expanded, the frequency of use of the videotelephones increased, communication was improved and developed, independence and the ability to take initiatives increased.

Keywords: videotelephones, mental retardation, communication, social network, independence



FOREWORD

TeleCommunity, RACE 2033, started on January 1st 1992 and went, with one year's extension, on till December 31st 1995. TeleCommunity was a European project with nine countries involved (Belgium, Finland, Germany, Ireland, The Netherlands, Norway, Portugal, Sweden and United Kingdom). The Swedish project was a cooperation between Stockholm University, Daltek AB and Telia AB, who was the main contractor for the Swedish participation. From January 1st, 1995, the project was transerred from Stockholm University to Stockholm Institute of Education, Department of Special Education. Responsible for the technical development and support were Sven-Hakan Nilsson, Master of Engineering, and Maria Fahlen, Engineer. Their tasks were to look after the technical equipment and assist the day centres involved in the study. It has not always been easy to keep the equipment running, and much trouble which "our" technicians have not been able to influence occurred e.g. with the ISDN-network. Their contribution and knowledge of technology has been valuable for me as a non-technician, although it has sometimes been difficult to understand the different "languages". Teething problems are probably a fact you have to cope with when new technology is implemented.

Many persons have been involved during different periods of the project. The individuals who have formed the basis for the project and who have made this study possible are firstly the 24 individuals with moderate mental retardation and their parents/relatives, secondly the staff at the six day centres involved and the staff at the group homes. I would like to thank all these persons for their assistance and all their efforts made to conduct the project.

I would also like to thank Jan-Ingvar Lindström, Master of Engineering, Telia AB, for his always positive attitude and constructive comments. His knowledge of persons with disabilities and their living conditions and his enthusiasm have been a great help.

Thank you all 'partners in TeleCommunity, especially Leonor Pereira, Coleman O'Callaghan and Jan Heim and their teams, who were all working in the area of mental retardation. Nine countries were involved and the discussions at the meetings have been very useful and giving.

I am especially thankful to John McEwan, NSSL, UK, who has had the hard job of being the uniting link of the consortium. John's always positive attitudes have helped us all to continue the work and he has been a marvelleous leader of the gang and led the group with a lot of humour.



I do admire his ability to keep the partners from the nine countries together for almost four years.

The Swedish project team has during different periods of time involved various members as the the project has been interdisciplinary. Magnus Magnusson, speech therapist, has together with Fredrik Thurfjell, also speech therapist, worked with communication. Magnus has been a colleague of mine since almost 18 years and we have had a long and giving cooperation. He has made the interviews in TeleCommunity and Fredrik Thurfjell has worked with the communicative assessments of the participants and the goal setting. The work with background descriptions, social meetings, staff education, telephone protocols and reporting have been done by Jane Brodin. The extensive data collection have been processed in a computer, analyzed, and documented by Ingegerd Alemdar and Jane Brodin.

It is my hope that this study will be the starting point for many other activities in the area of mental retardation. The study shows that if technology is adapted for the users from the start there are great opportinites for persons with mental retardation to have access to technical aids and to be able to participate in society. Technology and pedagogics must always go hand in hand!

Finally, I would like to thank our financiers, who have given us opportunities to effect the study. In 1992-1994 the project was supported by Telia AB and The Swedish National Board for Industrial and Technical Development (NUTEK) and in 1995 by the Swedish Transport & Communications Research Board (KFB). This last year's financial support has been very valuable in order to complete the data collection and to be able to process data.

Jane Brodin, Ph.D. Project leader



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- 1. Videotelephones for persons with moderate mental retardation. Background description (Brodin, 1992)
- 2. Transmission of moving pictures. People with mental retardation. Protocol for use of telephone. A-form. (Brodin, 1993)
- 3. B-form (Brodin, 1993).
- 4. Assessment of communicative ability of persons with mental retardation. (Thurfjell & Brodin, 1993, revised 1994)
- 5. Protocol for use of videotelephones (Brodin, 1994)
- 6. Interview guide (Magnusson & Brodin, 1994)

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1. INTRODUCTION

1.1 Background

People with mental retardation are people in need of special support for their daily living. In order to have access to services in the community and to be able to participate in social activities at 'normal' living conditions people with mental retardation sometimes require more support than other groups of disabled people due to intellectual, cognitive, motor and social factors as well as the comprehension of additional disabilities. About 70% of this population also have multiple disabilities in addition to the mental retardation (Brodin, 1991; Granlund, 1993). The most common additional disabilities are motor disability, speech and/or communication disorders, visual impairment and epilepsy. This makes the situation extremely comprehensive.

People with mental retardation do not form a homogeneous group. There are of course differences between individuals, but there are also differences between different functions in the same individual, i.e. a person can be very good at perceiving sensory impressions, but not have the ability to organize and interpret the impressions. Sometimes the additional impairments influence the mental retardation per see negatively. In order to understand the consequences of multiple disabilities the difficulties should not be added but multiplied.

In Sweden about 0.45% of the total population is classified as mentally retarded according to legislation. This means that there are about 38.000 persons (about 17.000 are children between 0 and 19 years) in Sweden. In the USA the percentage is twice or in some states six times as high, i.e. 2-3% of the total population (in some states 10%) and in the developmental countries this figure exceed 10% (in some parts of the world 30%) (Bakk & Grunewald, 1986). However, it is reasonable to stipulate that more than 1% of the total population in the western world is mentally retarded. This means that there would be about 5 million persons with mental retardation in the whole of Europe, with a population of 500 million people (official information from the Swedish Institute of Foreign Affairs). The low figure for Sweden (0.45%) depends on the fact that many steps have been taken by the social and legal authorities in order to avoid handicap and to compensate for the disability in the community. Another reason affecting this is that Scandinavia has a well-developed preventive health care and especially for pregnant women this is important. By giving females vaccination e.g. against rubella and good living conditions during pregnancy many problems can be avoided. The living conditions in Scandinavia are good and no children are born with disabilities due to shortage of nutrient supply. The need of support differ between individuals and the concept disability is thus a relative concept.



1

The view of people with mental retardation has varied during different periods, and so has the term used to describe the disability. Many different terms are today used to describe mental retardation, i.e. mental/intellectual handicap, mental/mental retardation, mentally delayed, developmentally disabled/handicapped and slow learners. Many of the national handicap organizations and associations and scientific journals use the term mental retardation, but the various terms are often used synonymously. However, it seems to be important to stress that mental retardation/impairment has no connection with mental illness. I have chosen to use the term mental retardation as this term is internationally well established and involve only people with severe intellectual disfunctions.

1.2 Mental retardation - definition and classification

In Sweden a person is classified as mentally retarded if he or she incurs before the age of 16, a deficiency or injury impairing his mental ability to such an extent that he requires special support and assistance in his daily living in order to participate in social activities in the community. Psychological, social, educational and motorical factors all have to be included in the assessment of the ability. This definition follows the recommendations by the World Health Organization (WHO, 1980).

One reason for defining mental retardation is to work out models to classify, assess and to take measures to facilitate and compensate for the impairment. WHO classify mental retardation in four degrees: deep, severe, modera: and mild and relate these to Intelligence Quotient (IQ).

Table. 1 WHO's definition of mental retardation in relation to IQ

Degree of mental retardation	Deep	Severe	Moderate	Mild
ĪQ	- 20	20-35	35-50	50-70

The distinctions between the different levels are arbitrary and based on statistical lines. These principles for classification can be used for adults with mental retardation, but it is not recommended to use IQ as a base for classification of children as there are great difficulties to measure IQ on children and sometimes also on adults with mental retardation as they can or will not contribute to tests. Another reason might be that they do not understand how to perform the tests. One limitation in this kind of test is that it does not say anything about how the person uses his ability in



everyday life, i.e. the cognitive ability. Although, WHO's classification system is used in many countries, others classify mental retardation into mild, moderate and severe (or profound) retardation. In Scandinavia these latter terms are used. The Swedish researcher Gunnar Kylén (1981) developed a theory describing intellectual development in relation to mental impairment. From table 2 appear the principles for grouping.

Table. 2 Kyléns classification in relation to WHO's definition of mental retardation and IQ (based on Kylén, 1981)

Degree of mental retardation		Deep	Severe	Moderate	Mild
ĪQ		- 20	20-35	35-50	50-70
A-B-C level Kylén	A -10		B 11-45		C 45-70

Kyléns theory is based on Piaget (1962) and thus based on established levels in child development. In reality this means that the A-level corresponds to an age below 18 months, the B-level to an age from 18 months up to seven years and the C-level from seven to twelve years of age. An adult can thus have an biological age of 25 years, but a developmental age of twelve. However, life experience and functional ability must be taken into account when assessing the level of development. Many methods for assessment rely on a comparison of chronological age with a derived developmental age (Granlund, 1993).

Mental retardation can also be classified according to other rules. A person whose intellectual capacity deviates downwards from 'normality' can be described as mentally retarded. The concept normality shall be understood in relation to the average, the normal curve, of the population. The normalization principle originates from the fifties and is based on democracy, solidarity, equality and participation for all citizens in community. The ability to understand what you see, hear and experience and to think in abstract terms is impaired or retarded in people with mental retardation. This is a psychological definition. The social definition includes that an individual who cannot meet the requirements in community, can be described as mentally retarded from a social point of view. The level of the requirements of support and the adaption of the environment where the person live is crucial for classifying people as mentally retarded. If the environment is adapted to a person with an impairment, he or she is not necessarily handicapped. Handicap originates when a person with disability confrontates with the environment (WHO, 1980), and society's demand exceeds the individual



ability. If society is adapted to the needs of the human being, the handicap will decrease or be relieved.

The psychological and social definitions and effects of mental retardation are closely related to each other and cannot be separated. That is the main reason why persons with mental retardation need a comprehensive support from the community.

Today also other methods are used to define and assess mental retardation. The most important way is to make assessments of the functional level of the individual (Seibert & Hogan, 1982; Uzgeris & Hunt, 1975). They have developed qualitative scales for assessment of social communicative skills and child development. These scales seem to be useful for assessment of people with mental retardation and multiple disabilities. Nielsen and Petersen (1984) have developed a scheme to assess the functional level and learning abilities primarily in children. The most important thing is to find out what the child can do and how to give the best support to compensate for the disability. Assessment thus ought to focus on the present level of the cognitive ability (Mirenda & Iacono, 1990). To conclude, this means that qualitative and criteria referenced measures are recommended to be used for assessment of individuals with mental retardation, instead of using the norm referenced IQ-tests (Brodin, 1991).

1.3 Implications of mental retardation in daily living.

In order to define intellectual capacity it is necessary to understand the implications of mental retardation. Intellectual capacity encompasses a concept of reality that is built up by processing sensorial experiences and is organized by the thought process. Symbols (pictures and language) are used to assist the thought process, but they are also important for communicative interaction with the environment.

The first function of the intellect is to structure the impressions. Sensory impressions are organized into five categories: the concept of space, the concept of time, the concept of quality, the concept of quantity and the concept of cause. By structuring the sensory impressions the above categories can be organized. The second function is to make concrete and abstract thought operations and the third is to symbolize objects and events. Structuring, operating and symbolizing can be performed at different abstraction levels (Göransson, 1982; Kylén, 1981). These levels (A, B and C levels) increase during the intellectual development.

People with mental retardation have the same feelings and needs as nondisabled individuals, but their self-esteem and self-confidence are



influenced by attitudes and treatment received from people in the environment.

To conclude:

- A person with mental retardation has a lower capacity of the short time memory than normal. This deteriorates the learning ability. He/she has difficulties to perceive, to treat and to store information (Kylén, 1981).
- The abstraction level is lower than normal. This means that he/she needs concrete operations and a concrete environment. He/she cannot make plans for the future and the concept of reality is simple (Göransson, 1982).
- Speech, language and/or communication disorders are common. About 70% (Johansson, 1981; Luftig, 1982) of all persons with mental retardation and more than 95% of persons with profound mental retardation have communication disorders (Brodin & Lindberg, 1990; Granlund, 1993).
- The ability of perception is often disturbed and he/she has difficulties to discriminate and perceive sensory impressions.
- A person with mental retardation needs more time to learn to understand pictures and symbols and he/she needs more training (Brodin, 1994; Göransson, 1982).
- For children with mental retardation it is obvious that they are slow learners and that they have a slower development than other children (Brodin, 1991). Many researchers today discuss if the development of children with mental retardation follows the same steps as that of children with normal development or if the development is 'handicap specific' (Kraat, 1990; Mirenda, 1990).

Mental retardation cannot be cured, but to some extent compensated. The keywords for compensating mental retardation is training, repetition, structure, continuity combined with social, psychological, educational, medical and technical support.



2. SERVICES IN SWEDEN FOR PERSONS WITH MENTAL RETARDATION

Services for people with mental retardation in Sweden are provided by the government, county councils and municipalities. These authorities are responsible for almost all public services within important sectors such as the employment services, education, medical care and social welfare. Sweden has also a powerful handicap movement which influences decisions in the Parliament with regard to policy and questions concerning people with disabilities. This movement consists of people of and not for disabled people and about 35 associations represent different disability groups. Services for people with disabilities are based on individual human needs and not on a voluntary basis.

The goal of the Swedish handicap policy is to avoid special solutions for people with disabilities as far as possible and instead make society as a whole accessible to all citizens. In contrast to some other countries, Sweden has not, until 1994, had a general law aimed to secure the rights of disabled, but has had special paragraphs inserted into certain laws e.g. the Building Act, the Social Service Act. One exception from this rule was the Act on Special Services for the Intellectually Handicapped Persons (1986), which was substituted with the Law for Support and Services for Persons with Certain Disabilities (LSS), valid from January 1st 1994. The concept certain means severe disabilities. This specific law applies to special services for persons with mental retardation, visual impairment, hearing impairment and motor impairment and is a complement to other laws. The main support obtained according to this law is:

- consultation, individual support from a contact person or specialist
- personal assistance for persons who need support more than 20 hours a week.
- daily activities in day centres or other activities for those who have left school and are not in education any more
- respite care service in the home
- stays at short time homes in order to give parents, siblings and other relatives some spare time and opportunities to rest
- stays for school children older than 12 years at leisure time i.e. before and after school
- residence in foster homes, boarding homes or group homes for children and young people who cannot live with their parents
- group homes for adults who are unable to live by themselves



The law is a civil right and a complement to the support obtained from other legal acts. In addition to this, people with disability can get home help service and transport service.

In recent years there has been a trend towards transferring people from institutions to various forms of independent, integrated housing. This trend is especially obvious concerning children, adolescents and adults with mental retardation. Most children today live with their parents, in foster homes or in small boarding homes for children. There are, however, still about 3.000 adults with mental retardation living in institutions, but the policy of the county councils is to close down all huge institutions and let people move to integrated settings in the municipalities. In the group homes, four or five persons live together in a flat or a house. Each person has his/her own room, but they often share kitchen and living room. There are staff employed to care for and assist these persons if they are not able to manage by themselves.

Dependence - Independence.

Most individuals with mental retardation are dependent on people in their surroundings. It is impossible to say to what extent people with mental retardation can be independent as the variation between different individuals is large. A concrete political goal is to increase the possibilities for all citizens to be as independent as possible. However, it is necessary to have in mind that most people with profound and moderate mental retardation have lived most of their lives at institutions and have consequently not been able to live in a normal setting. This complication will probably be solved over time but all changes in society and to change attitudes to people with mental retardation take time. Another complication is that these people have severe disorders with regard to cognitive and intellectual ability which make them dependent on daily support from people in the environment.

Some people consider it to be a risk that people with mental retardation get too much help, which in the long run can reduce the possibility to take initiatives and that this will result in a learned helplessness (Seligman, 1975). Most of the staff working at day centres are, however, aware of this problem as it has been illuminated during the last ten years, and the consciousness about this will help them to be aware of and as far as possible avoid this problem. On the contrary, there is an obvious risk that people with mental retardation are forced to live independently in order to fulfil political or economical goals (e.g. independent living) and that they may have social problems due to the fact that they cannot fully manage the situation.

For people with mild mental retardation the situation is different and the degree of independence can be higher and also increased more than for



people with moderate mental retardation. The primary purpose must be to make it possible for people with mental retardation to lead a good life and to be as independent as possible. Personal solutions for each individual according to the individual conditions - physical, social and psychological - must be offered

2.1 Medical care and habilitation

The ordinary medical service is intended for all citizens. The county councils are responsible for habilitation and rehabilitation of people with disabilities. There are special technical aids centres for visually and hearing impaired people and they have special consultants employed. Habilitation for people with mental retardation includes medical, technical (e.g. technical aids), psychological, social (e.g. financial support) and pedagogical support. The medical support is attended to by doctors, occupational therapists, speech therapists and physiotherapists and given by the habilitation organization run by the county councils. The pedagogical support for children is given by special teachers e.g. toy librarians or special pedagogues. The psychological support is given to the whole family by psychologists and the social support is given by social workers and advicers. The various categories of service suppliers are working in teams in order to give the child/adult and the family a total support (Brodin & Lindberg, 1990). Two different perspectives on habilitation can be used: the family-oriented and the child-centreed. There is no controversal opposition against the family-oriented view of support as the child is part of the family. In the United Kingdom a more childcentreed approach is used in order to meet the wishes of the child (e.g. Robinson, 1994), but in Sweden the habilitation tends to be more and more family-oriented.

In habilitation technical aids are important. All people with disabilities can obtain technical devices free of charge, i.e. as a principle. This means that technical devices are obtained as a loan, free of charge, from the county councils for the period the individual needs them. A principle is that a user with disability should receive what he or she needs, which means that the individual requirements are the subjectively experienced needs. Due to economical and other limitations it is, however, not always possible for an individual to get what he or she really desires (Brodin & Magnusson, 1993b).

All persons with disabilities can, in principle, obtain assistive devices free of charge. This means that assistive devices are loaned by the county councils for as long a time as the individual needs them. The principle is that a person with a disability should receive what he or she needs, i.e. that the individual's requirements are his or her own subjectively



experienced needs. However, because of economic and other limitations, it is not always possible for an individual to get what he or she really wants.

The technical aids centres test, prescribe, adjust and give information about technical devices. They are also responsible for the adaptation and training which are important parts in the habilitation process of people with mental retardation.

2.2 Education

The main principle with regard to education is that people with mental retardation have the same rights to education as other citizens. Special schools for pupils with mental retardations are as a rule physically integrated in ordinary schools. The responsibility for the schools for pupils with mental retardation in Sweden are being transferred from the county councils to the local municipalities in correspondence with compulsory schools in general. This was due to a decision in the Swedish Parliament in 1991 (SOU 1991:30) and this reform should be completed not later than January 1st, 1996. Education for children with mental retardations is compulsory until grade nine, i.e. between the ages of seven and sixteen. The special schools include special comprehensive schools, training schools and vocational schools. The special schools are thus usually located in the same building as the ordinary schools, i.e. physically integrated.

Today almost all children with mental retardation attend the local preschools or daycare centres, often beginning at the age of one year. The municipality has the responsibility to offer a place to all preschool children (0-6 years), but for children with mental retardation this seems to be extra important due to their needs of special support for their development. Special schools have a ten-year program and focus on deaf and hearing-impaired children, children with speech and language disorders, children with multiple disabilities such as mental retardation in combination with visual impairment or hard of hearing, and who are unable to go to a regular school. For children with severly mental retardation a special program is run in special classes. The education follows the standard curriculum, but is adapted to their needs. When these children go to secondary schools they will have vocational training in specially designed and individual programs.

Many adults with mental retardation have not earlier in life had the opportunities to go to school as they have lived most of their lives in institutions. The Special Act for Persons with Mental Retardation of 1967 for people with mental retardation made it possible also for profoundly



mentally retarded people to go to school and today many adults have got special educational training. To attend school was a legal right also for the most severely disabled people from this year.

Until the age of 20 all persons in Sweden have the right to start secondary school, but after that age they can go to different kinds of adult education. For adults with mental retardation it is possible to attend a special education for adults.

3. COMMUNICATION

3.1 Communication in persons with mental retardation

Communication originates from the Latin word communicare which means to share, to do something jointly. Communication is a social process which involves feelings, experiences and activities, and is based on mutuality and on the activity of the individuals. The ability is not innate, but the child learns to communicate in interaction in a social context (Björck-Åkesson, 1992; Brodin, 1989; Granlund & Olsson, 1987; Söderbergh, 1979). In reality this means that children successively gain the ability to interact from an innate preparedness to communicate. A communication partner who encourages communication and persons in the environment with sensitive ears to support the child are necessary. Step by step the child will learn the benefits to communicate and influence his own situation. At the same time the child will learn the rules for social interaction and communication (Lloyd & Beveridge, 1981).

Communicative interaction can be intentional or unintentional and Kylén (1981) divides communication into presymbolic and symbolic communication. Presymbolic communication, i.e. natural reactions and reflexes is the first step in interaction, and signals, i.e. to use e.g. cry as a signal to get attention is the second step.

Communication was earlier described as a simplified process model with a sender and a receiver, but at present the knowledge of the character and stile of the communication partner are also emphasized for the communicative interaction (e.g. Culp, 1982). Many different definitions of communication have been given by researchers (Brodin, 1991; Brodin & Björck-Åkesson, 1990). Some emphasize the importance of intentionality in order to interpret a behaviour or expression as communication. The majority of these reseachers are in the field of linguistics (e.g. Linell & Gustavsson, 1987; MacKay, 1972). In the field of augmentative and alternative communication (AAC) a broader definition is more appropriate (e.g. Smebye, 1985). Johansson (1988) and Smebye (1985) stress that adults should make conscious over-



interpretations of childrens signals and the child will be prepared for shared attention. By chains of associations the child can build up expectations as an important component in communication development.

A person who is mentally retarded has a simpler and more concrete concept of reality than a person with normal intellectual ability. The difficulties are related to perception, guiding/operating, symbolizing and memory functions. Many people have communication disturbances and disorders. In spite of the fact that great efforts have been made during the last few years, mentally retarded people are a neglected group with regard to communication support and technical aids. This is true especially of adults who have not had access to any alternative way of communication in their lives. Today most adults with mental retardation live in group homes as the huge institutions in Sweden have or are closing down. About 3.000 adults and about 140 children below the age of 20 years are still living in institutions in Sweden. Most of these individuals have severe disabilities, often combined with medical problems.

The lack of a functioning communicative ability will be highlighted when an individual moves to an integrated setting in the community.

However, it has turned out that consistent and well adapted communication training together with suitable communication aids can enable many persons with mental retardation who cannot use speech today, to communicate (Brodin & Björck-Åkesson, 1991; Granlund & Olsson, 1987; Kraat, 1985). Even if their communication is limited, it can contribute to the person's capability to exert influence on his environment and make his own choices, which is important for personal development, independence, participation and the quality of life. It is also of importance for establishing social relations.

The communication process is dynamic, and the various steps interact continuously. The will to communicate depends on motivation, implying that you have to know what you want, how to attain the objective and what you get from reaching the goal (Kylén, 1981). A mentally retarded person has a limited short-time memory, and in many cases a limited motor ability. Even if he/she gets help to get in touch with others, he/she may have no message to bring across.

In the communication field, two prominent schools occur: the process school and the semiotic school. The process school involve the specific act and includes transmission of messages and demonstrates how different channels for transmission are used. The semiotic school defines communication as creation and exchange of meanings. Shannon and Weavers model for communication (1949) belongs to the process school. In their model communication is presented as a linear process with three levels of problems directed to technical problems (A-level), semantic



problems (B-level) and efficiency problems (C-level). The technical problems, i.e. the form, is a question of how exact the communication symbols can be transmitted. This was the original idea that Shannon and Weaver (ibid) tested within the telecommunications area at the research department at the Bell Telephone Laboratories in the United States. The key question was to elaborate a way to use the communications channels within the telecommunications area as efficiently as possible, i.e. to stimulate an increased use and accessibility of the telecommunication network.

The semantic aspect, i.e. the content, is a question of understanding the meaning of the signs and codes that are transmitted and in these respects the cultural and social differences are of significance for interpretation of the messages. The third area of problems deals with the efficiency, i.e. how effectively the received meaning include the behaviour. The three levels are closely related and mutually dependent on each other. They are of special interest in studies focusing on improving the exactness and efficiency in communication (Fiske, 1984). Gerbner (1956) stresses that the access of communication media in reality is a means for exercising power and social control. To have access to an information channel does not necessarily mean to have access to information and to use it. Also Linell and Gustavsson (1987) regard initiating as exercise of power and argue that this is an important aspect-of communication.

In communication difficulties often arise when persons with speech disabilities communicate with non-disabled. The speaking individual dominates the dialogue in most situations, takes more space in interaction, often initiates new topics and transfer more information at shorter time. The person with speech impairment is not seldom put in a reply position where the communication partner expects the individual to answer yes or no (e.g. Light, 1985). The person with speech impairment is often regarded as passive and the result is that the non-speaking person or the person with a poorly developed spoken language is in a disadvantageous position (Rowland, 1990). The passivity occuring in persons with mental retardation has been described in studies by Brodin (1985), Granlund and Olsson (1987), and Orr (1989), but Calculator and Dollaghan (1982) argue that the passivity might be related more to the specific experimental situation than to the indivual's ability.

Communication includes three significant aspects: communicative form, communicative content and communicative use. The communicative form can be described as the tool used to express something verbal or nonverbal. It deals with eye contact, body language, sound/vocalization, gestures, sign communication, picture or symbol communication, written or spoken language. The lowest level of communication is natural reactions, i.e. reflexes and signals (Kylén, 1983). "Various code levels



and different modes of communication can occur simultaneously, e.g. vocalization and gesture." (Granlund, 1993, pp 24). The communicative content deals with the transferred message itself and is based on the individual's experiences, feelings and needs. In order to have something to communicate about, it is necessary to have many and different experiences and Kylén (1983) emphasizes the importance of offering individuals experiences to communicate about. The communicative use deals with the question of how the ability is used, i.e. in what situations the individual uses his skills. The use could be to ask for things, to draw the attention to a specific object, to share mutual attention, and to direct the attention towards subjects and objects. However, it is not enough to draw the attention to a specific object or subject, it is also necessary to be able to maintain the attention.

Communicative form, communicative content and communicative use can not be split up into separate parts, but must be considered as a unity, i.e. a holistic model (Bloom & Lahey, 1978).

Gunnar Kylén and his colleagues Alba, Fischbein, Frank and Kylén A. (1995) have delveloped a holistic model of interaction (based on Kylén, 1986), which involves the individual and the environment. The model includes four sciences; psychology, sociology, biology and physics. The psychological aspect involves the individual and covers cognitive and emotional aspects. The sociological aspect involves the social environment and covers the family, group, culture and society. The biological aspect involves the individual and covers heritage, gender, body and health. The physical aspect involves the physical environment and covers materials, objects and technical aids.

As appears from the model below that also other aspects are involved such as social psychology, psychophysics, social mediane, behaviour genetics and physiobiology and politics economy are avolved. The approach is cross-disciplinary.



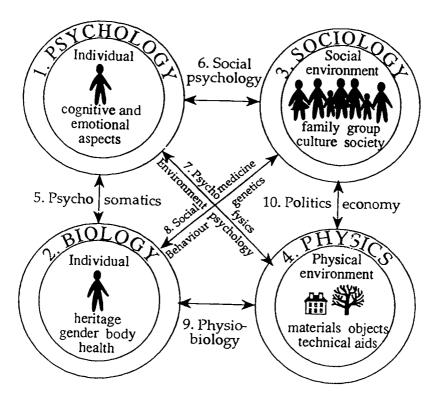


Figure 1. A Holistic Model of Interaction (based on Kylén, 1986).

3.2 Communicative competence

Light (1989) has defined communicative competence in terms of functional aspects, sufficiency and skills. Light stresses that "communicative competence is a relative and dynamic, interpersonal construct based on functionality of communication, adequacy of communication, and sufficiency of knowledge, judgement, and skills in four interrelated areas; linguistic competence, operational competence, social competence and strategic competence." (1985, p 137). "The former two competencies (linguistic and operational) reflect knowledge and skills in tool use, while the latter two competencies (social and strategic reflect functional knowledge and judgement in interaction " (Light, 1985, p 139).

The linguistic competence deals with the linguistic codes. It is necessary to know how to express oneself to be understood and to be familiar with the communicative form (vocalization, body language, gestures, symbols). It is also important to have a communicative content



(something to talk about) and to know how to use the language. The linguistic competence also deals with the complexity in the communication mode, e.g. reflexes, signals, symbols or language with a complete grammar. The concept communicative competence is relative, and might be something different to an individual with impairment than to a non-impaired person.

The functional or operational aspect deals with the limitations caused by the disability and at what respect technical aids can be used to support and compensate the disability. One problem with regard to this is the possibilities to influence the choice of technical aids. The social competence include the social rules for communication in order to develop a communicative competence and the context and the attitudes of the communication partner is then important. There is a question of socio-linguistic aspects e.g. strategies for dialogues and communicative functions but also about sociorelational apsects, e.g. interpersonal abilities. Finally, it is important to work out a strategi to communicate and to learn how to compensate missing or defective functions.

3.3. Telephoning and mental retardation

Most people consider it as a matter of course to be able to use telecommunications and regard it as impossible to live without a telephone. For people with mental retardation speech and communication is often complicated. International research have shown that previous activities within this area have primarily focused on individuals with visual impairment, hearing impairment, motor disability and elderly people. An evaluation of still picture telephones for children and adults with moderate mental retardation showed that if the equipment and the environment are adapted to respond to the user's requirements, the possibilities to use telecommunications will increase also for this population (Brodin, 1993a; Brodin & Björck-Åkesson, 1991). Telephoning is a way to communicate, but can be difficult and complex for many persons with mental reatardation. The ability to communicate depends on the individual's status (physical and psychological), the environment's requirements and status (physical and social), and on the access to AAC (Augmentative and Alternative Communication). Sometimes the individual does not understand that the voice does not originates from the telephone receiver per see, but from a person sitting somewhere else, sometimes at very long distance. When it comes to using videotelephony (transmission of live images) all these aspects are relevant and important to consider. The above study also showed that videotelephony facilitated communication and increased the possiblities to establish social contacts, and consequently increased the quality of life for these persons (ibid).



Telephoning imposes requirements both on the individual and on the environment. A basic requirement for the individual is to increase the motivation to use the telephone. Another requirement is to have access to appropriate social support from persons in the environment when needed. The attitudes of people around are thus of importance. If the support is good the persons with mental retardation will be encouraged and stimulated to use the telephone. Light's (1989) model of communicative competence in terms of functional aspects, sufficiency and skills, has shown that especially the operational and sociorelational abilities are necessary when using a telephone.

There are, as mentioned above, about 5 million individuals with mental retardation in Europe and statistically about 60% of these persons are mildly or moderately mentally retarded. It is reasonable to believe that persons with mild and moderate mental retardation could make good use of videotelephones. Most of these people have difficulties to communicate and often use graphic symbols or 'sign communication' as a complement to a poorly developed speech. Sign communication is a simplification of deaf sign language, and the users are mainly people with mental retardation. For many reasons this population does not use telephones, but by using two channels for information (visual and auditive) at the same time the possibilities to understand and be understood will increase.

Most persons with mental retardation need alternative modes to communicate. One way to promote and encourage communication is to use picture telephones to support the communication ability and by that increase the quality of life. One purpose to use visual communication systems might be to give people with mental retardation possibilites to get access to the same services as other people in the community, but with necessary adaptations corresponding to their level of development. Another purpose would be to give all citizens in the community full participation apart from their disabilities (Brodin & Magnusson, 1993b).

The staff engaged in this kind of activities at the day centres are often occupational therapists, speech therapists and special teachers. To facilitate telephoning a videotelephone could be used to transfer sound and imagages via the ISDN network. The videotelephones could be used at day centres, group homes, family homes, sheltered workshops, special schools, habilitation centres etc. In other words; the videotelephones could be used everywhere a telephone is needed in order to make it possible for people with mental retardation to participate on the same conditions as other citizens in the community.



3.4 Augmented telecommunication

During this century a number of devices have been introduced to make the use of telephones easier, e.g. automatic dialers and loudspeaking telephones. A product possible to attach to a standard telephone is the Panasonic Still Picture Telephone, which consists of a camera and a small graphical display. This device is still in use, but is not longer manufactured. If both parties in the conversation have such a telephone, it is possible to show a still picture of the person who is talking or to transfer drawings, photos and Bliss (Bliss, 1966) or Pictogram (Maharaj, 1980) symbols. The transfer of one picture takes about six seconds. The telephone also has a memory which can store the last six pictures transferred. This type of telephone offers simultaneous auditory and visual information during a dialogue.

For people with mental retardation a still picture telephone can support speech and facilitate communication. People with mental retardation generally have difficulties in using a telephone, for functional, social and cognitive reasons: he or she must be able to operate the telephone, have somebody to call, be able to carry out a conversation over telephone, be motivated to communicate and realize the benefits of using the telephone. These topics are illuminated in literature when discussing the use of telecommunication (e.g. Brodin, 1994; Brodin & Björck-Åkesson, 1995). Graphic-based communication systems are used by many persons with mental retardation and if a visual telephone system is used, pictures can support speech and memory. Picture telephony with concomitant auditory and visual information makes telephoning resemble normal face-to-face dialogues (e.g. Pereira, Matos, Purifição & Lebre, 1992).



4. STUDIES ON TELECOMMUNICATION FOR PERSONS WITH MENTAL RETARDATION

4.1 Still picture telephones and fax communication

Brodin and Björck-Åkesson (1991) studied what use and benefit persons with moderate mental retardation could derive in their daily life from using still picture telephones. The study included three children and five adults who had access to still picture telephones during five months. The telephones were placed in the subjects' homes, day centres or in the homes of friends, relatives or respite care families. Each person had at least one partner to call. A total of twenty picture telephones were used during the experiment.

Concrete questions were if transmission of pictures via the telephone network facilitated communication, if still picture telephones contributed to more and better social contacts and thus improved the quality of life, and if still picture telephones could be considered as technical aids for this population. Central aspects of the study were the communicative competence with focus on the communicative form, contents and use of communication (Brodin, 1991; Light, 1989; Granlund, 1993). Data collected on each subject included age, sex, family situation, housing conditions, social contacts, functional assessments, additional disabilities, communication modes, available technical devices, ability to recognize and understand pictures, symbols, persons and voices as well as familiarity with telephones. For each subject a questionnaire was completed by the day centre staff in cooperation with family members and, for adults, by the staff of the group homes. Every telephone dialogue was registered by the person who helped the subject to make the call, diary notes were made at the end of each week, interviews were made continously with staff and parents during the project period and video recordings were made at the day centres. A total of 607 telephone calls were registered and analyzed (Brodin & Björck-Åkesson, 1991). The results of the study revealed that four of the adult users and two of

the children increased their frequency of using the telephone. They used the equipment more adequately over time, the picture supported their communication and the still picture telephone facilitated communication. The study also demonstrated that persons with moderate mental retardation can benefit from a still picture telephone in their daily life and that this type of telephone can be regarded as a communication aid. Six of the subjects have since used the telephone in a functional way and seem to have made gains in independence and self confidence.

Two subjects did not complete the experiment. One was a six year old girl. Her mother claimed responsibility for not carrying through the



experiment, in that she was too tired to arrange systematic telephone training in the evenings after long working days. A 34 years old woman withdrew from the experiment after only one month. She showed anxiety and tenseness. The staff attributed this to her mental retardation or impaired vision, but it is reasonable to believe that she did not get enough support for the task. The small number of subjects studied is, of course, a reason to be cautious in generalizing the results. Small samples are, however, common in studies on disabled persons, since disabled people constitute a minority of the population. On the other hand, a small sample permits in-depth examination of specific situations. The strength of the study is that the subjects were described in great detail and that each one was observed daily during five months.

Brodin and Björck-Åkesson (1992) also conducted a study of the use of still picture telephones of four adults with profound mental retardation. The aim of the study was to find out if people with profound mental retardation could benefit from still picture telephones in their daily lives. Two of the participants were men and two women, aging from 25 to 39 years. Ten telephones were placed in the participants' group homes and in the parents' homes. The data collection included; background descriptions (questionnaire), telephone records, diary notes, video recordings and interviews with parents and staff. The results from the 123 registered telephone calls showed that the use of still picture telephones for people with profound mental retardation can be assigned to questions related to personal/individual factors, communication, the social network and organization/system. At the individual level, the fundamental condition to be able to benefit from the still picture telephone is that it fulfills a real need. With regard to communication, the telephone contributed to new conversation topics emerging, and to an increase in the frequency of contacts. The still picture telephones gave conceptional training and supported communication. Three of the parents experienced the closer contact with the staff as positive while the staff was uncertain whether this was good or not mainly due to the aspect of "grown-up existence". Finally, the results showed that the staff's education and attitudes to the use were decisive, as the participants needed a lot of assistance.

A similar study with picture telephones was conducted at a special school for mentally retatarded children in a rural area in Portugal (Pereira, Matos, Purificação & Lebre, 1992). The equipment consisted of two TV monitors and videocameras, linked by a coaxial cable. Fifteen subjects aged 8 to 23 years participated. Eight of these children functioned in the mild range of mental retardation, six in the moderate range and one in the severe range. The study was designed to examine whether picture telephones were easy to use for this population, and to observe how this



group of disabled people responded in a learning situation where picture telephone was used.

A key question in this study was whether participation in school work would increase in children and young people, who often stayed at home from school. It was assumed that their absence from school was associated with long travelling distances. The experiment thus included two picture telephones, installed in separate rooms in the school building and the study was based on structured interviews with staff and children and on observations. Only one experiment was made with each subject. Observations were made of breathing, body awareness and posture as well as sense for numbers (sum and subtraction).

The results showed that the children rapidly accepted the presence of the picture telephone. Sound and image quality was satisfactory and the children understood the teacher's questions without difficulties. The benefits of the picture telephones were that children who were often absent from school could be educated in their homes, constituting a relief for those who lived far from school. "The experts also said that the videophone could be a very important means of communication, because it offers the possibility of allowing the parents to participate in the learning process, which increases their understanding of their childrens' needs." (Pereira et al, 1992, p 46).

While one reason for absence was the long travelling distances, another reason which was not discussed in the report was the parents' attitude to what the school could offer the children. If the parents did not feel that school was important for the children, they let them stay at home now and then. Long distances to school is a problem in many countries and there is always a risk that parents who do not recognize the value of school let their children stay at home more often. Children who are restricted to home teaching tend to be isolated and lack the social training they would get in interaction with different teachers and pupils.

The limitations of this study are that it is based on observations on only one occasion per child. Research on children with cognitive impairments shows that their levels of activity strongly depend on their physical conditions and may vary from occasion to occasion to a significant degree (Brodin, 1991; Mirenda, 1990) and on the communication partner. Lindsay (1990) states that 'Communicative competence depends as much on the skill of the person who is interacting with the AAC user as it does on the skill of the AAC user or the effectiveness of the AAC system itself.'(p 112). To record a behaviour characteristic of a child with severe impairments, repeated observations are required. This aspect must be regarded as very important.



In a study on fax communication five adults, four men and one woman, with moderate mental retardation participated for a period of one and a half year (Brodin, 1993b). The equipment used in the study consisted of eleven copyfax machines, placed at four day centres and in group homes. In one case, a parent was the communication partner, in the other staff or peers at the involved day centres participated. The participants selected for the study were, according to the staff, in great need of communicative support and used Pictogram symbols in their everyday communication. The aim of the study was to investigate if the use of fax could facilitate and support remote communication. The techniques used to collect data were questionnaires, interviews and records based on the messages sent. The topics covered in the faxes were food, previous activities and future activities, but for ethical reasons no analyses of the contents were made. Totally, 653 fax messages were sent and the results showed that the use stimulated and developed the participants' communication skills. They asked for more 'words' and their interest in writing letters to friends increased. They also took own initiatives to send faxes. From the participants' perspective, participation in the project was positive and gave opportunities for development. However, a critical aspect occuring, was the reported changing and shortage of staff. The staff's attitudes to the activity was also of significance, and one conclusion from this project was that the participants were entirely dependent on the will, interest and time of the staff. Statements such as "this week we have not used the fax very much because of....". were not unusual (Brodin, 1993b). There were naturally obvious reasons for not sending faxes, but nevertheless it seems as if the possibilities for the participants to make decisions and influence their lives were limited.

4.2 Videotelephones for persons with mental retardation

In the project TeleCommunity, RACE 2033 (Research in Advanced Communications Technologies in Europe) videotelephony experiments with persons with visual impairment, hearing impairment, mental retardation and elderly people were carried through. The nine participating countries started with a pilot study (a minitrial) and continued with a main study. Four of the nine countries participating in the project (Ireland, Norway, Portugal and Sweden) were carried through studies on the use of videotelephones for persons with mental retardations. The project started in 1992 and was after extension completed in December 1995 (McEwan, 1995).

The Portuguese experiment was aimed at identifying transmission needs, user requirements, and to find out if the equipment used was proper for the target group (Pereira, Rocha, Cidade, Lebre & Purificação, 1993; Pereira, Vieira, Rocha & Cidade, 1994). Data was collected by



questionnaires and observations. Three main areas were selected for the trial: remote care, learning and training, and collaborative decision making. Twentyeight persons with mental retardation participated in the study (five with severe, twelve with moderate and eleven with mild mental retardation), aging from 16 to 30 years. The equipment used at each of the two workplaces was a personal computer and a videotelephone prototype, and the ISDN network was utilized. The aim was to examine the possibilities to discriminate, classify, match, describe and name different objects. The results from the study showed that all participants were able to use both equipments, but only the mildly retarded did not show any difficulties in using the videotelephone. The others needed assistance and verbal instructions. With regard to the visual perception the subjects with severe retardation showed more inferior results than the others. No significant differences were observed in the performance of the learning situations compared with face-to-face situations. From this study appears that videotelephones and personal computers may be used to facilitate education (Pereira et al. 1994).

The main study focused on remote delivery of expertise (such as team work and collaboration, supervision and follow-up), learning and training (such as perceptive training, social skills training and recreational activities), interpersonal communication and collaborative decision making (such as counselling and information). Fourtyone children with mental retardation participated (two slightly, fourteen moderately and four severely impaired). Twentyone children "had other situations", e.g. behaviour problems (McEwan, 1995, p 19). The results showed that all children stated they liked to use the equipment and to perform the learning situations. The dialogues at distance were the same as in face-to-face communication.

The aim of the Norwegian study was 'to see if a videophone service could be used to improve the quality of life for clients through a better and more efficient municipality health and social care service' (Heim & Skjetne, 1994, p. 47). The service included remote care, remote response to emergency calls, remote advice and training, social integration, and support for carers. A handful of people with mild mental retardation were involved in the study. Some problems occurred due to difficulties to get the social authorities interested in participating in the videotelephony project. The main study utilized both ISDN and cable network. Both persons with mental retardation and elderly participated in the study.

The Irish study, effected by Neill, O'Callaghan and Healy, focuses on the use of cable TV network for delivering services to 44 adults with mental retardation (four severely, sixteen moderately, and twentyfour mildly impaired) living at two different sites. The services delivered were communication and recreational services. The participants had earlier



attended pre-vocational or vocational training centres and lived in supported community housing. The preliminary results (McEwan, 1995, p 20-21) showed that; the social networks appeared to be enhanced, communication was more effective, communication was at best when interacting with familiar people, younger people felt more comfortable to use the equipment than older, and many participants still needed much assistance to use the equipment. Finally, the equipment was found usable.

The aim of the Swedish minitrial was to evaluate three main factors: the equipment (technical aspects), possibilities to understand how to use the videotelephones for people with mental retardation (user aspects) and general points of view from the staff (staff aspects) regarding equipment, time consumption, training methods etc. Methods used to collect data were questionnaires, ratings, observations and interviews. Detailed background descriptions were made of the two male participants, based on information collected in collaboration with parents, staff of group homes and day centres. The background information covered sex, age, housing conditions, educational background, disability, social network, leisure interests, use of technical aids, way of communication, cognitive level, previous use of telephone etc. Fourty telephone calls were registered, 28 calls between the two participants and 12 between participant and staff. The main results showed that the quality of sound and image had to be improved, that the users were stimulated by using the videotelephone and that the staff were positive, although they experienced the time consumption high (Brodin, Fahlén & Nilsson, 1993).

The overall goal of the main study was to encourage people with mental retardation to use the videotelephones in order to support communication and to extend the social network. Twentyfour adults (23-60 years old), with moderate mental retardation, participated in the study. The participants lived in group homes. The data collection was based on questionnaires and interviews. A protocol for assessment of the communicative ability was developed (Thurfjell & Brodin, 1993/94) and individual goal setting and goal attainment scales were used. The results from the study showed that the participants increased their social network and made new friends. They developed their communicative ability and in some respects, it seems reasonable to argue that the participants have increased their quality of life. The results are presented under the sections Results of the Minitrial and ACE.



4.3 Videotelephones in health and care services

The possibilities to use picture telephones in teaching and instruction of staff, assessing children in need of special support, were investigated by von Tetzchner, Hesselberg and Langeland (1991). Picture telephones were used to transfer information between a habilitation centre for severely disabled children and a local habilitation centre in a small municipality outside the city. The purpose was to find new ways for assessment of these children and guide the local staff during intervention. Both the technical performance of the equipment, a Tandberg 64 kbt/s videotelephone, and the system's "user friendliness" were investigated. The equipment functioned well and the users reported that they were satisfied with the image quality. They compared picture telephoning with ordinary telephoning rather than with personal visits and found that the picture had a sufficient reinforcing effect. A negative aspect was that image and sound were not synchronized

The five children involved in the project were one to five years old. Four of them had been referred to the habilitation centre for assessment. Physiotherapy had a central role in this project while a therapist at the local centre worked with the child, her colleague at the habilitation centre looked at the image and commented her activity. Every child participated on two to seven occasions. The study showed that the need for routine checks could be reduced and the time between visits be extended if picture telephony was used between personal visits. The project also emphasized the importance of knowledge transfer following up the intervention. A comment from parents was that they would prefer picture telephony to routine checks at the habilitation centre, because that would eliminate long and tiring trips. As such this form of knowledge transfer helps to give everybody the same quality of intervention irrespective of where he/she lives. The use of picture telephones can be a valuable complement to ordinary examinations, reporting and telephone contacts. A limitation of the study is that only two videotelephones were available.

Magnusson (1994) reported that fax communication, still picture telephones and videotelephones can be used in training/educational situations for persons with aphasia. He demonstrated that the extra dimension that visual support added increased the quality of communication. "The technology involved also seems to cause no real problems of handling or understanding and is well adpated." (p 57). These results are similar to those reported by Pereira, Matos, Purificação and Lebre (1992).

The special needs of older people and services to meet those needs are of great importance in the future as the population of elderly people



increase rapidly. With increasing age, many older people experience problems in daily living. Health problems are prevalent and many old people are isolated. Some of the problems can be described as follows: "the ability to make and maintain social contacts, provoking a downward spiral of reducing communication, inadequate exercise of communicative and cognitive skills, depression and withdrawal" (McEwan, 1995, p 3). For elderly people videotelephones can be used as a support service. Erkert and Robinson (1994) showed that the opportunities for providing services to elderly people in their homes and in sheltered housing increased by using videotelephony. They stated that videotelephony offered opportunities to give support services in the homes, to encourge and support an independent way of life and thereby reduce elderly people's needs for institutional care. In some respects it also helped to maintain the social competence and prevent isolation, loneliness and dependence. "An integrated service concept can significantly improve the quality of life of the elderly living at home", (ibid, p 81).

4.4 Videotelephony for users of sign language

Holand, von Tetzchner and Steindal (1991) described an experiment with picture telephones to train two autistic children to use sign language. The children were three and five years of age and lived in Northern Norway. The experiment was a part of a rehabilitation effort designed to evaluate, functionally and technically, whether a picture telephone could be used for sign language training. Via the picture telephone 22 dialogues were obtained with the two children, their parents and staff. The image quality made it hard to see how the children performed the signs, and therefore the teachers had to give verbal information. The major purpose was to document how the training was arranged, what method was used, how the children were motivated, how much time was dedicated to the training and in what manner the teacher helped the child. The result of the study showed that picture telephony could be used for special training. The limitations discussed in this study are of technical nature and primarily involved image quality. Although no specific conclusions can be drawn from the study, it is reasonable to assume that transmission of sign language via videotelephony can be a valuable complement to speech.

Persons with severely impaired hearing can use ordinary text telephones, but for those who cannot read or write, the videotelephone has an important function as sign language can be used. Sign language has in Sweden an official status of being the deaf people's first language, and Swedish their second. Most experiments with picture-based remote communication for disabled people have been conducted with persons with loss of hearing (Coninx & Josiassen, 1994; Cullen & Clarkin, 1994; Delvert, 1989, 1994; Lindström, 1994). Adult persons, who are deaf



since childhood, have got the opportunity to communicate via videotelephones in several countries (e.g. Dopping, 1991; Marion & Appendino, 1994; Wilson, 1994; Whybray, 1991).

Blohm and Mühlback (1990) indicated that readability of sign language depended on how much of the communication partner one can see on the picture and that a high image quality was required. The relevance of screen design to readability appears also from a study primarily oriented towards ergonomy, but is of importance to everyone interested in communication via graphic displays (Smedhammar, Frencker, Nordquist & Romberger, 1990). In several studies, the effects of the screen size, illumination and camera position have been investigated. A finding common to these investigations is that added visual information makes up for the loss of auditory information in the dialogue. Supplementary visual information appears to have the same effect on intelligibility as increased volume in a traditional telephone conversation.

Some people emphasize the importance of image quality for efficiency in interaction, whereas others do not note any significant differences in intelligibility or interaction which could be attributed to different image quality (e.g. Frowein, Smoorenburg, Pyfers & Schinkel, 1991). There is, however, also a discussion between researchers about the ergonomic aspects of image quality and the significance of background illumination for perception of pictures (Lo, 1990).

4.5 A minitrial on videotelephony aimed at testing methodological and technical issues.

TeleCommunity, R2033. is a European project within RACE (Research in Advanced Communications Technologies in Europe). In TeleCommunity nine countries (Belgium, Finland, Germany, Ireland, The Netherlands, Norway, Portugal, Sweden, United Kingdom) participated. Four of these carried out projects focusing on persons with mental retardation (Ireland, Norway, Portugal and Sweden). The services in the Swedish minitrial and main study were designed for adult people with moderate mental retardation. Although additional disabilities were common, the primary disability was the mental retardation. The intention was to encourage people to communicate and to use videotelephones in the same way as other people in community use telephones.

The minitrial continued for 12 weeks in 1993, and the empirical study was completed in six weeks. The equipment for the minitrial (see Description of the technical equipment) was installed in one day centre, where two individuals participated. The evaluation of the minitrial



focused on three important factors: technical aspects, user aspects and staff aspects.

Aim of the pilot study

The aim of the minitrial was to evaluate three main factors: the equipment (technical aspects), possibilities to understand how to use the videotelephones for people with moderate mental retardation (user aspects) and general points of view from the staff (staff aspects) regarding equipment, time consumption, and training methods. The results from the evaluation of the minitrial formed the basis for adapting the equipment for the main study (Brodin, 1994, 1995; Brodin, Fahlén & Nilsson, 1993).

Methods used in the evaluation

The evaluation of the Swedish minitrial thus focused on technical aspects, user aspects and staff aspects.

Table 3. Evaluation from three different aspects.

Equipment	User	Staff
size of screen function of concept keyboard parts used in communication quality of image quality of sound how to operate equipment (easy/difficult) quality of document camera improvements	understanding of symbols user's attitude to equipment reason for calling conversation subjects way of communication number of pictures sent number of calls interest/motivation.	use of time number of staff education of staff responsability for calls training methods attitudes to use (equipment, user)

The techniques used to collect the above data included questionnaires, ratings, observations and interviews. A careful background description (Appendix 1) was done for each of the two participants. This was based on information collected in collaboration with parents, staff of group homes and day centres. The background information covered sex, age, housing conditions, educational background, disability, social network, leisure interests, use of technical aids, mode of communication, cognitive level, earlier use of telephone etc. This part is showed as personal descriptions of the two men involved.

Two forms, A-form (Appendix 2) and B-form (Appendix 3), were elaborated. The A-form was completed by the staff at each telephone call and the B-form was filled in by the staff at the day centre after one week's and after three week's use of the videotelephone equipment. Telephoning took place daily during the minitrial. The experiences from the minitrial contributed to avoiding difficulties and obstacles in the main study. The results from the minitrial were compiled and formed the basis



of the main study, the ACE (Advanced Communications Experiments in Europe).

The selection of day centre followed certain defined criterias e.g. continuity of staff, interest in technical aids, interest in learning new tasks, and possibilities to spend time on project work. The choice was a day centre outside Stockholm. The staff involved were occupational therapists and nursing staff. Two persons at the day centre were appointed to work with the task within their ordinary daily activities. The tasks were thus part of the ordinary ADL-training. Two men with moderate mental retardation participated in the study. The selection of participants was made by the staff of the day centre in cooperation with the project leader according to criterias like interest in communication, motivation to learn new tasks, physical possibilities to operate the equipment, a defined need for communication support. The participants used graphic symbols, sign communication, gestures, facial expressions and sound. The spoken language was poorly developed and the aim was to improve the ability to communicate.

The minitrial was based on person-to-person communication and included interaction between participant-staff and participant-participant. Participant means the person with mental retardation. The subjects in the minitrial and main study were people with moderate mental retardation. Many different terms are today used to describe mental retardation, e.g. mental/intellectual disability, mental impairment, mental/intellectual handicap, developmental disorder/disturbance or intellectual retardation/ delay. Sometimes the term slow learners or people with difficulties in reading and writing are categorized as intellectually handicapped and included in this population. Different terms are used in different parts of the world and by different categories of professionals. There i., a risk that this population is mixed up with people with mental illness. In this document I have chosen to use the term mental retardation. Definitions are intended to be tools to facilitate understanding between human beings in order to avoid complications due to language differences as well as cultural and social factors. The evaluation was quantitative as well as qualitative. The use and the function of the equipment were evaluated continously. Due to the mental retardation of the participants the purpose of the project can be described as support for communication/interaction and social integration. The quality of effect was considered to be one of the most interesting and important parts of the Swedish minitrial and showed the personal impact on the participants with regard to factors as skills to operate the equipment, to compensate for the disability as well as the functional competence. The results were based on background information, questionnaires, telephone protocols, observations and interviews. The evaluation covered the following aspects:



Communication/interaction and social integration

changes in mood, motivation

changes in degree of activity

changes in communicative behaviour (turn-taking, initiatives)

changes in communicative competence (communication and social skills)

changes in the way to communicate (picture, sign, gesture, speech)

changes in social interaction (cooperation with staff, peers)

changes in independence

The overall aim will in the long run be to offer opportunities for people with mental retardation to live in society at the same conditions as other citizens. The "videotelephony service" offered was consequently accessibility to existing services in the Swedish community.

Description of the technical equipment

The aim was to design a videotelephone which could be handled by users with mental retardation. The base was an IBM compatible PC equipped with additional serial communication ports. The video telephone software was designed for a Windows environment. The public ISDN (Integrated services digital network) was used for connections between the videotelephones. A standard H.261 codec was used (Brodin, Fahlén & Nilsson, 1993). The functional block diagram is showed in Figure 2.

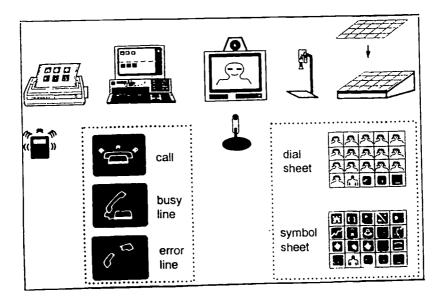


Figure 2. Functional block diagram

The user interface was a 14" VGA colour screen, and a modified concept keyboard with a built-in optical sheet detecting facility. The VGA screen showed the Pictogram symbols received and transmitted during the call.



The television monitor showed the far end picture. The concept keyboard was used for commencing and ending calls as well as for symbol communication. Pictograms were used to support the spoken language. This graphic symbol system was widely spread among people with mental retardation in Scandinavia and it has about 750 symbols available. The additional video equipment included an RGB camera placed on top of the television monitor and a document camera with a built-in camera switch, which automatically selected the picture from the document camera when there was a document or another object present in front of that camera. The audio equipment was a microphone with amplifier and a loudspeaker in the television monitor. A laser printer was included for printing the Pictograms transferred during the call. For the awareness of incoming calls a paging system was used. Every user was equipped with a tactile receiver.

The purpose was to design a videophone with a user-friendly manmachine interface. A standard concept keyboard was the base. The concept keyboard consisted of a flat membrane keyboard in ordinary A3format. The pressure-sensitive area was divided into 128 squares, 8 rows and 16 columns. Some modifications were made to the standard concept keyboard.

A V.24/V.28-port connected the keyboard to the PC, to indicate which keypad was pressed. The user put a symbol sheet, with 32 symbol squares, on the flat keyboard. The symbols on the symbol sheet covered, if correctly placed, the 128 keyboard squares. Every symbol square on the sheet covered 4 squares on the keyboard. Thus, the user could press a symbol square on the sheet and the computer got information about this.

To separate the different user symbol sheets from each other, an optical sheet detector was designed for use with the concept keyboard. Every sheet was marked with a unique digital code, consisting of 8 filled or unfilled circles. Reflex detectors, placed in the keyboard housing, were used to read this code. When no symbol sheet was applied or when the sheet was not properly placed a led on the keyboard was flashing to notify the user. For better support to users with motor disabilities a mechanical redesign was made. The flat keyboard was leant towards the user. The front and the right hand side of the keyboard had borders to make it easy to put the symbol sheet in its proper place.

There were two categories of symbol sheets. The dialling sheet had photos of the persons that the user might want to call. A call was initiated by pressing a photo square. The communication sheet had Pictograms in the symbol squares. During the call a Pictogram was sent to the two screens involved when a Pictogram square was pressed. Both types of sheets had a square for removing the last pictures transmitted and another for ending



the call, as well as squares for obtaining a self-view on the television monitor and for returning to the far end picture. A call was also disconnected if no symbol sheet was applied on the keyboard for more than 30 seconds or if a call goes on for 30 minutes without any symbols being pressed. To answer an incoming call, a symbol sheet was placed on the keyboard or, if a sheet was already present at the keyboard, a symbol square was pressed.

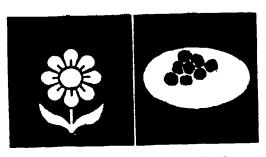


Figure 3. Pictogram pictures of flower and meatballs

The PC used was an IBM-compatible PC 386SX/33 MHz, equipped with 4 Mbyte RAM, a 120 Mbyte hard disc and Windows 3.1. The minitrial equipment had two monitors, a 14" computer colour monitor for the Pictogram symbols and an ordinary colour television monitor for the far end picture. A self view could be obtained by pressing a button on the concept keyboard.

The 14" VGA computer screen showed the received Pictogram symbols on the upper half of the screen on a red background and the sent Pictograms on the lower part on a green background. Figure 3 shows the screen disposition. The far end picture was shown at the television monitor.

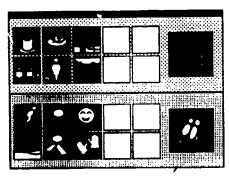


Figure 4. The screen disposition



The codec used was a Tandberg Vision Model 15. The reasons for working with Tandberg Vision was that the Vision offered a data channel together with video and audio transmission. This function was vital for the Pictograms and for paging information. Vision was also approved for use in the Swedish ISDN network. During the minitrial, the Vision with Tandberg software version H installed, behaved reasonably well. The Hayes-like command interface, included in the H software release, was used for dialling. The codec keyboard interface was used for all other control functions.

The audio equipment consisted of a table-placed microphone and the loudspeaker in the television monitor. The main camera was placed on top of the 20" monitor. It did not have a zooming function. The focus was settled at installation, and the user could adjust his/her distance to the screen supported by the self view.

The document camera was specially designed. It included an automatic video switch. When the user put a document or an object in front of the camera the switch selected the document camera picture for transmission until the object was removed. This procedure was followed on the screen in the permanent self view window. The camera used was an industrial type of CCD-camera.

To make the user aware of an incoming call a paging system was used. When connection was established between two video phones a paging command was sent from the originating phone. This command included information about the number of the receiver carried by the answering person. The answering videotelephone requested a paging for that person whose receiver beeped or vibrated. The Swedish Telecom "Minicall" service was used. This required a modem and a telephone line which were used to call the "Minicall" computer to initiate the paging. The time that elapsed between the connection of the videotelephones and the actual activation of the called person's tactile receiver was 30-60 seconds.

When a call was finished the Pictogram symbols used during the call were printed out on paper. An ordinary 300 dpi *laser printer* was used to get a reasonable speed, which was considered to be a few minutes. The received and transmitted symbols were printed on different sheets. If many symbols were used several sheets were produced. The sheets could be used to remember what topics where covered and referred to in future calls by use of the document camera.

The videotelephony service utilised the ISDN network. The basic access rate interface with the two 64 kbit/s-channels was used for codec video and audio signals. The D-channel signalling included interterminal communication with end subscriber code, graphic symbol code and statistical data. The Swedish ISDN network was introduced as a public



service in 1993 when a majority of the population had the possibility to be connected to the network. The restriction for subscription was a limitation of 5 km from exchange or multiplexor. However, a lot of research was going on with the aim to extend the subscriber connection range. An adaptation to the Euro-ISDN was planned in 1994. The equipment was developed, adapted and tested by Daltek AB, Borlänge, in collaboration with the project team.

4.5.1 The participants in the minitrial

The participants in the minitrial were two men, Daniel (32 years old) and Tom (35 years old) both with moderate mental retardation (Kylén, 1981). They lived in different group homes and spent their days at the same day centre. The background information was collected by a questionnaire filled in by the staff from the group homes and the day centre. In the first phase of the project the staff picked out the 50 most frequently used Pictograms for the two participants to be used on the concept keyboard. Daniel had earlier participated in a project with still picture telephones and a change in behaviour and development was noted as to motivation and interest in communication.

Daniel - a personal description

Daniel was 32 years old. He lived together with his parents until he was 12 years old, when he moved to an institution for children with mental retardation. After a year he moved to a nursing home and after another year to a second nursing home. He lived there for eight years until he moved to a group home at the age of 22. Since ten years Daniel has lived in a group home with four other adults. Daniel spends his leisure time watching TV, listening to music, going to dances and parties, playing bowling, swimming, and relaxing. Daniel has spent about 14 years in a school class for children with severe mental retardation. Daniel goes to the day centre by bus and he attends a group for physical activities and adult education once a week. Twice a week he participates in a communication group. This group prepares a newsletter with pictures and is also responsible for transferring written information into pictures giving service to other groups. Daily he is engaged as "postman" at the day centre.

Social network

Daniel's mother is dead since a couple of years. She used to be his closest relation. His father is old and Daniel has only sporadic contact with him. He also has sporadic contact with his sister. Her attitudes towards Daniel has become more positive and the contact has increased since the mother died. His father has a new wife and Daniel has also sporadic contact with her and with a good friend of his father. The family is very important to



Daniel and he often talks about them. Daniel has every day contact with a man who is working in the group home. He has just returned to work after a prolonged illness. Every week he has contact with a neighbour, who is also intellectually impaired and one of the staff from the day centre, to whom he calls in the evenings. A new assistant will be introduced to him for the leisure time. He also has daily contact with staff from the day centre, group home and friends living in the same group home. Daniel has no contact person, which is a legal right for people with mental retardation in Sweden.

Functional disorders

At birth it was evident that Daniel had Down's syndrom. He was assessed and diagnosed by a doctor and a psychologist within the service system for persons with mental retardation in 1964 and 1969, at the age of six and nine. The staff at the day centre and group home regard him as moderately intellectually impaired. Daniel has a visual impairment, reduced hearing, speech and communication difficulties, diabetes and food allergy. He uses spectacles. His gross and fine motor abilities are good, but he has difficulties with coordination.

Pictures/communication/language

Daniel recognizes objects and persons on pictures and photos. He also recognizes Pictograms, and symbols used for communication or for marking objects and places in his near environment. He cannot read digits or letters, but he recognizes the letter group forming his name. Daniel is motivated to commmunicate and uses speech. His speech is, however, difficult to understand and he often misunderstands or does not understand what people say. He reintorces his speech with gestures, pictures, signs and concrete actions. He often initiates communication and often responds. The communication aids used are Pictograms, pictures, diary, day schedule, stamp with his own name, still picture telephone, automatic dialler and photos. When he is working as a postman he has photos of the receivers instead of their written names to be able to identify them. Daniel has participated in other projects on communication and he still uses the communication aid that he evaluated in that project. Daniel has improved his communicative ability since he first participated in the telecommunication project. Earlier, he seldom used the ordinary telephone, but now he uses the still picture telephone daily and he is able to call by himself. He answers the telephone and recognizes voices. At home, he uses a loudspeaking telephone. He presses the button for automatic dialling and also manages to complete the call. If he uses the ordinary telephone he asks the staff to help him dial the number.



Tom - a personal description

Tom is 35 years old. He has lived most of his life in different institutions and spent shorter periods in between in family homes. Since 1985 he lives in a group home. He is interested in listening to music, going to concert halls, visiting cafés and going to the cinema. Tom has spent 12 years in a school class for children with severe mental retardation. He left school in 1981 and started to work at the day centre. One of Tom's daily activities is, together with Daniel, to distribute mail at the day centre. He also attends a communication group and serves the other persons at the day centre.

Social network

Tom has no contact with his mother, father or siblings and has no contact with his relatives or friends outside the day centre and group home. The only person he meets continously, i.e. every week is his contact person.

Functional disorders

Tom has Downs syndrom and he is assessed to be moderately intellectually impaired i.e. at the B-level (Kylén, 1981). He was tested in 1964 with the Merrill-Palmer test and the Vineland Interview. Tom has normal vision and hearing skills, but he has a motor disability. He has difficulties to walk due to stiff hips, but he is not in need of mobility aids. Tom has also a heart disease and speech and communication disorders.

Pictures/communication/language

Tom recognizes objects and persons on pictures and photos. He also recognizes Pictograms, and symbols for communication or for marking objects and places in his near environment. He cannot read digits or letters. Tom is motivated to communicate and uses single words. He cannot communicate with whole sentences. Tom mainly uses sign communication, speech, gestures and sounds for communication. The communication aids used are Pictograms, pictures, photos, diary, day schedule, Pictogram stamps, still picture telephone and loudspeeking telephone. Tom often initiates and responds to communication. He has never participated in a project directed to communication before. Tom calls his contact person using a telephone with a loudspeaking unit. He also calls the day centre and uses a still picture telephone and a loudspeaking telephone. Tom received a still picture telephone of his own in December 1992, but before that he had only used the still picture telephone in the day centre. Tom recognizes voices and he can make calls with the help of an automatic dialler, but he cannot answer the telephone. Tom does not take any initiatives but is interested in telephoning if he is asked to. He presses the buttons, he knows how to use the loudspeaking telephone but he needs help to show the pictures to be sent via the still picture telepone.



Preparation and start of the minitrial

For each participant the 50 most frequently used Pictograms were selected. The selection was done by the day centre staff and gave a view of the participants' interests. It also revealed what topics could be discussed by using Pictograms and concept keyboard. Only 50 Pictograms each were used in the minitrial, but the number of pictures will increase in real life. The participants could also use other pictures, but not via the keyboard. They could show the Pictograms via the document camera or just hold them in front of the videotelephone. The symbols used for the concept keyboards appear from Table 4 and Table 5. The Pictograms selected are listed below. Some of these pictures were not used by the participants, and thus exchanged when the staff after a while noted that this was the case. Some Pictograms (*) were excluded and new added.

Table 4. Daniel's Pictograms. (N = 50)

A People	4 r	man *	D	Inventories	- 5	book
-		woman *	_	211.701.101.105		letter
	9	father			29	radio
	10	mother			34	
	11	friends			35	TV
	12	group*				computer
G Food		meetballs coffee	L	Garden	2	flower
	9	hamburger	M	Weather	1	day/sun*
		hot dogs			4	rain
	18	sandwich			6	snow *
		soup chicken	N	Music	2	guitar
	26	ice cream	0	Leisure	12	pop group
	27	cake pie			24	newspaper
		I	R	Transports	5	bus
P Feelings	2	happy			15	taxi
	_	angry			16	train
S Localities	8	church	Т	Activities	12	dance
	9 (city			28	visitor
		shop			44	rest
		restaurant			59	walk, going place
		home day centre			71	stick together
U Feasts		Christmas	V	Qualitites	16	ill/pain
O reasis	2	Christmas Easter party	Z	Diverse	25	Pictogram

^{*} excluded from the list just before preparation of the concept keyboard



New Pictogram pictures added due to individual interests:

clothes	C36
weep	T67
bowling	02
insulin shot	ZA
draw	T14
visitor	T28

Five Pictograms were excluded and six new were added to the concept keyboard.

Table 5. Tom's Pictograms (N=50)

A People	4	man *	D	Inventories	5	book
- F		woman *			15	letter
	_	friends			29	radio
	12	group *			24	telephone
		0			35	TV.
G Food	ì	meetballs			41	sewing machin
	5	coffee				-
	7	food	M	Weather	1	day/sun *
	8	pommes fries			4	rain *
	9	hamburger			6	snow *
	12	meet				
	13	pancake	N	Music	1	drum
	27	cake	•			
		chips	O	Leisure	6	icehochey
		spaghetti	_		11	break *
		yoghurt				popgroup
	43					L-LD
	73	uiiik				
P Feelings	2	happy	O	Professions	1	dentist
1 rectings	2 6	angry	*			doctor
	U	angry			_	· doctor
			S	Localities	g	city
R Transports	1	aeroplane	~	2300	21	. •
W Transhorts	5	bus			22	
	15	taxi			25	
	13	mvi.				
T Activities	12	dance	[]	Feasts	1	Christmas
Activities		drink *	_		2	
		vistors			4	party
		rest			•	L7
			7	Diverse	24	5 Pictogram
		walk, going places *		Diverse	4-	, recognant
	71	stick together				

* excluded from the list just before preparation of the concept keyboard

New Pictogram sy	mbols added due to	individual interests:	
work	A163	wheelchair	G148
clothes	C36	park	S17
stationaries	D24	day centre	S28
computer	D42	draw	T14
lemonade	G29	сгу	T67
dog	J5	Lucia	U5

Eleven Pictograms were excluded and twelve new were added to the concept keyboard



Starting point of project - installation of equipment

At the start there were technical problems which affected the participants. Daniel made a telephone call in the very start, but it did not turn out satisfactory. He seemed bored and wanted to quit the dialling. He said: "I don't want to use this - I want to use my still picture telephone instead". He probably felt safe and had a basic trust when using the still picture telephone as he knew how to operate it. This new videotelephone made him feel anxious and worried especially as it did not function well. He felt unsafe in this new situation.

Unfortunately, the staff made a mistake. They had been told that the two persons with mental retardation were not allowed to use the equipment until the staff had learnt exactly how to run it. This was based on earlier experiences because if a person with mental retardation uses a technical device which the staff is not familiar with, they cannot get a good enough support. This may influence the whole project negatively. The participants may loose their motivation and a lot of time will be spent to build up their expectations of the videotelephone again. Some technical problems were reported during the first week of use e.g. bad quality of image, echo on the telephone lines, interruptions, difficulties to put the overlays on the concept keyboard.

Staff preparation

Before the start the staff filled in questionnaires with background information about the two participants. It contained information about age, living conditions, educational background, social network, leisure activities, degree of mental retardation, diagnosed by whom and how, i.e. what kind of tests were used. The questionnaire also contained information about additional disabilities, ability and ways to communicate, ability to use a telephone and if they had participated in similar projects earlier. The background information gave a good idea of what could be expected from the two participants and about their possibilities to use the videotelephone. During this first week the staff involved in the minitrial learnt how the videotelephones functioned. They practiced all moments in order to learn as much as possible before the two men, Daniel and Tom, started their use of the videotelephones.

Conduction of the trial

Daniel and Tom were the first persons to use the videotelephones. The first week of the project, the staff filled in a telephone protocol at every call. Each of the two men made at least one telephone call a day. After the first week's use, the staff filled in a form concerning the equipment (questions related to technical outfits etc), their working situation, and time consumption. The same form was completed after the videotelephones had been used for three weeks. It was then possible to



compare the results in order to find out how many of the problems reported at the start still existed after three weeks use. Telephone calls were registered in special telephone protocols (Appendix 4). After the third week the B-form was filled out again, and a report including the results was completed. The data collection from the empirical study was finished almost 12 weeks later than planned due to technical problems.

4.5.2 Results of the minitrial

After three weeks' use the results from the B-form showed that no significant changes appeared over time. It was difficult for the participants to understand when to answer the videotelephone, i.e. when the telephone call was connected. The paging system, the personal minicallers, were not used as the staff found it too complicated for the participants at the start. The equipment had to be changed in different ways e.g. one monitor was to be used instead of two. This was, however, already planned from the start. The following comments appeared in the staff interviews:

The staff stressed that the size of the monitor was too small. It was difficult to see if the partner was signing "too" low. i.e. with his hands on his knees. Tom usually signs at the height of his waist and Daniel did not conceive that Tom was signing. It was also difficult for the participants to understand that the communication partner could see the sender all the time and to explain that pictures sent via the document camera could be seen on the monitor of the partner. It was also difficult to understand and to explain for the participant that objects must be removed from the document camera in order to send new pictures. It seems to be easy to end up outside the monitor e.g. to sit in an angle where the camera cannot zoom in the participant.

Due to the visual impairment of the participants the staff stressed that the screen of the monitor had to be larger. The staff also required one monitor instead of two.

- The concept keyboard did not function acceptably. There were difficulties to change the pictorial sheets and to understand how to put them correctly on the concept keyboard. It did not seem to be natural for Daniel e.g. to use the concept keyboard and this required training.
- When there was a call a picture was shown on the monitor symbolizing a "calling telephone". First of all the participants did not notice the picture on the monitor and the staff had to draw the attention to the picture and tell what was going on e.g. that it sounded like a telephone call.
- With regard to the time used the staff point out that it is important that the videotelephoning is on the schedule. Nobody had taken any initiatives of their own to make a call.
- With regard to staff involvement and responsibility in the activity the staff reported that during the first week three persons from the staff were involved in the videotelephoning, the third week four persons were involved. Two persons of the staff were responsible for the project activity and for the training of the two



participants. The staff also spent "a lot of time" to plan the activity and to learn how the equipment functioned.

The staff spent time daily during the first two weeks to learn how to run the equipment. Every week about three hours were spent on preparation and conducting the calls. (Time for own learning of the equipment is not included). The staff reported that they experienced the work interesting, positive, but time consuming. They stressed that the participants needed a lot of training in order to learn to use the videotelephone and to understand how to benefit from it.

After finishing the minitrial, no changes in staff attitudes towards the use of the videotelephones were found, despite all complications, and the participants were still positive to use the videotelephones according to interviews with the staff.

A total of 40 telephone calls were registered. Daniel and Tom made 20 calls each. They called each other, but during the last week the telephone calls were completed between the participants and one of the staff. A total of 28 calls were conducted between participant and participant, and 12 were conducted between participant and staff. In all cases the staff took the initiatives to call and the reason for calling was to test the equipment (38). In two cases the reason "for training" was indicated. The minitrial went on for six weeks. The personal callers were not used in the minitrial, which means that only five different parts of the technical equipment were evaluated. The equipment consisted of videomonitor, Pictogram monitor, document camera, printer and concept keyboard. In 36 cases out of 40 all parts of the equipment were used during the telephone calls. In two cases the document camera was excluded and in two cases the printer.

Technical aspects of the equipment

The technical aspects of the equipment has focused on quality of image, quality of sound, function of the document camera and function of the concept keyboard.

Table 6. Quality of image and sound

Marks	Quality of image	Quality of sound
Very good	i i	
Good	8	13
Satisfying	10	14
Poor	15	7
Very poor	6	4
No answer		ĺ
	40	40



The results showed that the quality of the image was satisfying in 10 cases, but poor and very poor in 21 cases. Only in eight cases was the quality good, and in one case very good. This showed that the quality of the image must be improved. The quality of sound was satisfying in 14 cases, good in 13 cases and very good in one case. The quality of sound was poor or very poor in 11 cases. In one case there was no reply to the question. This showed that the quality of sound seemed to be better than the quality of image, but both had to be improved.

To the question if the participants experienced difficulties to place the pictures or objects correctly on the document camera 28 answered yes, seven no and five answered sometimes or gave no answer. It seemed to be difficult to understand that the dialogue partner could see the picture of the objects transmitted via the document camera. There was also difficulties for the participants to understand that the objects on the document camera must be removed in order to transmit other pictures. At an early stage the staff found the document camera a problem and wanted to exclude it. At the end of the project they found the document camera useful. To the question if the participants experienced difficulties to put on and change the overlays on the concept keyboard during the telephone calls 23 answered yes, nine no and eight sometimes or gave no answer. The participants had difficulties to place the sheets with the Pictograms correctly on the keyboard, but there was a small change over time which could be the result of training/learning. There was a technical problem which cannot be denied, but there was also a pedagogical. With adequate training the participants would probably learn to place the Pictogram sheets correctly on the concept keyboard.

The aspects of the technical equipment were based on information collected from the evaluation forms A and B as well as interviews with the staff. The results showed that the technical equipment had to be improved, especially with regard to quality of sound and image. The difficulties to operate the equipment e.g. to place the overlays correctly on the concept keyboard have to be attented to. The two monitors should be substituted with a larger monitor as the staff complained about the small size of the screen. All parts of the equipment were used in 38 of the 40 telephone calls, as in two cases both the document camera and the printer were excluded.

Frequency of use

The frequency of use showed how many pictures were sent via the concept keyboard, the document camera and the videotelephone.



Table 7. Frequency of use

Equipment used to send pictures	Number of pictures	
Pictures sent via the concept keyboard Pictures sent via the document camera Pictures sent via the videotelephone	243 105 57	
Total	405	_

Most pictures were transmitted via the concept keyboard (243). One reason for this was probably that the Pictogram pictures were easy to find on the keyboard. The participants used the document camera 105 times, but it was difficult for the staff to explain that the picture or object on the document camera was transmitted to the receiver. There was an increase in number of pictures sent via the document camera and via the concept keyboard in the participant-staff dialogues. This was especially significant for Daniel. Once when Daniel was eating an apple he put it on the document camera to show one of the staff members what he was eating. This was done on his own initiative.

The most frequently used topics for communication were activities, food and feelings. The two participants told each other what they had done, what they were doing and what they planned to do later. When they talked about food they informed each other what they had eaten, what they were going to eat and what they were fond of. The Pictograms for coffee and hamburgers were often used and seemed to be popular to talk about. In connection with food they also talked about the insulin shot Daniel had to take. They often told each other if they were happy or felt angry with something.

The 50 most frequently used Pictogram pictures were selected for each of the two participants at the starting-up process of the minitrial. However, some Piciograms were not used by Daniel nor Tom. These were: radio, dentist, stick together and Christmas. Other pictures which were specific for one of the participants, but not used were e.g. train, aeroplane, sewing machine. Pictogram pictures which were not included in the minitrial and for which there was a need were e.g. postman and hospital. Unfortunately, a change of Pictograms were made by the staff at the start and before preparation of the concept keyboard without informing the project leader. However, to conclude, this showed that it is extremely difficult to pick out the 50 most frequently used Pictograms. From the start Tom did not have the symbol for wheelchair and this symbol suddenly became very important for him. He had a friend for whom he cared a lot. She fell and broke her leg and she had to go to hospital, and she had to sit in a wheelchair. Tom was very worried about her and talked a lot about the hospital, about Mrs Andersson's leg (he



always called her by her family name) and about the wheelchair. Tom talked about the wheelchair ten times and about his desire to stay at home from the day centre and do other things than work nine times.

Hospital also played an important role for Daniel as he had diabetes and sometimes needed to go to the hospital as he did not feel well. He also took insulin shots every day, and naturally the picture of an injection was important for him. Daniel talked about the injection 17 times. He talked about drinking coffee 11 times, about staying at home from the day centre 11 times and that he felt sad seven times. As Daniel and Tom were responsible for the internal distribution of mail the Pictogram for postman had been useful. However, it seems to be difficult to chose the "right" symbols as the interest of the participants change over time and from time to time.

User aspects

One question concerned the participant's attitude to use the videotelephone. The results reveal from the table below.

Table 8. Participant's attitude to use the videotelephone

Expression	Number of marks	Positive or negative
Looks happy/seems to enjoy	17	+
Seems motivated	20	+
Takes initiatives	19	+
Shows expectation/excitement (activity)	16	+
Shows interest	22	+
Shows no interest/looks bored	9	-
Looks afraid/looks anxious	0	-
Looks angry/upset	1	-
Task is difficult/laborious	0	-
Seems unconcerned	$ar{2}$	_
Other	1	

Table 8 shows that most of the notes are on the positive part of the scale. This means that the participants were interested, motivated, took initiatives within the communicative interaction, looked happy and seemed to enjoy the actitivity. It also shows that they showed expectation and were excited to make the calls. With regard to the communication mode, the participants used total communication which means that they mixed many different modes at the same time. For Daniel the spoken language and the Pictogram symbols were the main modes to communicate and for Tom the Pictogram symbols and the signing were the main modes.



The user aspects were based on information from the telephone protocols, observations and interviews with the staff from the day centre. For the users the difficulties were to get access to the right Pictogram symbols, and to operate the equipment. The users had a positive attitude to the videotelephone and showed interest and motivation. They conducted 40 calls and sent 405 pictures via the tele network. The reasons for calling were to train and test the equipment. They used total communication and thus combined different modes to communicate. Both participants had, however, earlier used Pictogram symbols. The conversation subjects were limited as the participants only had 50 Pictograms each on the concept keyboard. The most frequent conversation topics were food and activities. In the main study the number of Pictograms would be at least 100. One obvious problem was to chose the "right" symbols for each participant. The participants had difficulties to understand some of the symbols on the dialling sheet e.g. "the calling telephone".

Staff aspects

The staff from the day centre were positive and interested in using the videotelephones. The technical problems at the start influenced their attitudes to the videotelephones in a negative way, but they tried very hard to get the equipment to function. The work with the videotelephones was time consuming, but as it was on the schedule it was part of their ordinary job. They prioritized the activity highly and spent about three hours every week to make the telephone calls. The staff aspects were based on information from the telephone protocols and interviews. The videotelephony activity was time-consuming and the staff emphasize that it was important to have it on the daily schedule and to decide how much priority to give to the activity. The staff also stressed that it is important to have somebody appointed as responsible for the training. In order to facilitate activities like this it is necessary to give the staff education in communication before the start.

Conclusions

The project plan was impossible to follow due to technical disorders. The starting point of the minitrial was postponed about 12 weeks. The main activity at the day centre involved was augmentative and alternative communication and the staff had long experiences and good knowledge of this kind of tasks, and also knew the participants well. Although the minitrial was time-consuming, the staff were interested and positive to conduct the study.

The minitrial was effected with only two participants and focused on technical equipment, user aspects and staff aspects. The experiences contributed to avoid some mistakes in the main study, e.g. in the ACE. The methods used in the minitrial were useful for this special purpose,



but would be too detailed for the ACE. The final and adapted equipment for the main study were to be installed at the six day centres.

Summary of studies in the videotelephony area.

Few studies have been effected in the area of telecommunication for persons with mental retardation. Many studies related to telecommunication in the area of disability stress the opportunities to increase the quality of life by expanding the social network and the communicative skills.

The effects for the individual will primarily appear on the micro-level (Bronfenbrenner, 1979). Bronfenbrenner's ecological model for human development includes four levels of importance for an individual: the microsystem, the mesosystem, the exosystem and the macrosystem. The microsystem involves the family, home, different patterns of activities, roles and relations affecting the individual. The mesosystem links various microsystems together and the relations between different groups e.g. group home, day centre, service staff. The exosystem involves the local authority, systems for case management, decisions taken in the social board. The final level is the macrosystem and it involves culture, class structure, ideology, legislation. This theoretical model for assessment of social network e.g. can be useful as the systems effect the individual on different levels.

Studies of graphic-based, picture communication for persons with mental retardation are mainly in the areas of communication, ADL (adaptations to daily living), education, learning and care. Few studies are in the area of telecommunication for this population.

Tables 9 and 10 demonstrate the areas/aims and findings of the studies of picture communication for persons with mental retardation reported above.



Table 9. Studies on telecommunications for persons with mental retardation (= mr).

Authors	Subjects	Experimental feature No of calls/exchang	Settings
Brodin & Björck-Åkesson 1991	N=8 3 children CA 6-12 years 5 adults, moderate mr	Use of 20 Still Picture Telephones	Day centres Group homes Parents homes Friends
Brodin & Björck- Åkesson, 1992	N=4 adults with profound mr	Use of 10 Still Picture Telephones 123 calls	Day centres Group homes
Brodin, 1993b	N=5 adults moderate mr	Use of 11 Copyfax machines 653 faxes	Day centres Group homes Parents homes
Brodin, et al, 1993	N=2 adults moderate mr	Use of 2 Vidoetelephones 40 calls	Day centre
Brodin, 1995	N=24 adults CA 23-60 years moderate mr	Use of 6 Videotelephones	Day centres (6 sites)
Heim & Skjetne, 1994	N=10 adults mild mr	Use of 2 Videotelephones	Service centre 'Mini service centres'
Neill et al, (see McEwan, 1994)	N=44 adults 4 profound mr, 16 moderate, 24 mild	Use of 10 Videotelephones	Pre-vocational centres, Houses (two sites)
Percira, et al, 1992	N=15 children CA 8-23 years 1 profound mr, 6 moderate, 8 mild	Use of 2 Picture Telephones Closed cable network 15 calls	Special school
Percira, et al, 1994	N=28 children CA 16-30 years 5 profound mr, 12 moderate, 11 mild	Use of Videotelephone and Personal computer cable network	Special school Institution
Percira et al, (see McEwan, 1994)	N=41 children 4 profound mr, 14 moderate, 2 mild, 21'other'	Use of Videotelephones	Institution for mr. (3 sites)
von Tetzchner et al, 1991	N=5 children CA 1-5 years severe mr	Use of 2 Picture Telephones 2-7 occasions/child	Habilitation centre Local habilitation centre



Table 10. Areas/aims and findings of studies in telecommunication for persons with mental retardation

Authors	Areas/Aims	Findings
Brodin & Björck- Åkesson, 1991	Evaluate use of picture telephones Communication, Access to telecommunication, ADL	Facilitatedcommunication. Social contacts increased. Both visual and auditory information at the same time positive. Still picture telephones can be regarded as a communication aid.
Brodin & Björck- Åkesson, 1992	Evaluate use of picture telephones Communication Access to telecommunication ADL	Facilitated communication. Increased level of activity. Personal/individual support and attention positive Emotional and social aspects dominated. Organizational/system/staff factors decisive for use.
Brodin, 1993b	Communication Access to tele- communication, ADL	Communication facilitated. Initiative increased. Frequency of use and independency increased. Social network extended.
Brodin, et al 1993	Communication Minitrial	Quality of sound and image needed improvements. Users and staff positive to use. Time-consuming.
Brodin, 1995	Communication Social network	Communication increased and developed. Ability to take initiatives and independence increased. Social network extended. Staff and participants positive.
Heim & Skjetne, 1994	Support services Quality of life	Results not yet available.
Neill et al (see McEwan, 1994)	Communication Recreation	Social network enhanced. Communication more effective. Equipment useful. Participants need much assistance to use the videotelephone
Pereira et al, 1992	Use of picture telephone. Learning, Education Participation in school	Children accepted use rapidly. Children understood questions from teacher easily. Quality of picture and soun acceptable.
Pereira et al, 1993	Learning Distance education Obtain self awareness	Videotelephony gave better control of learning situation
Pereira et al, (see McEwan, 1994)	Support Service Learning, Training Communication	Children liked equipment and to perform the learning situations. Diaglogues similar to face-to-face communication.
von Tetzchner et al, 1991	Habilitation Supervision	Participants satisfied with videotelephone. Supportive tool for exper supervision in distant areas



5. TELECOMMUNITY - THE SWEDISH ACE

TeleCommunity started on January 1st, 1992 and went on till December 31st, 1995. The empirical study, the Swedish ACE, was carried out in 1994 and continued for nine months in the Stockholm area and eight months in the Jönköping area. The equipment for the ACE was installed at six day centres and four individuals with moderate mental retardation (see Kylén, 1981) at each day centre used the videotelephones. A total of 24 persons participated in the study and the communication was primarily based on person-to-person communication. The participants received personal support in order to stimulate and encourage their communication and to extend their social network. This was mainly based on natural, social relations, but in order to try to expand the social network the task of the staff was also to stimulate contacts between the individuals of the day centres involved.

A presumption was that the use of videotelephones would promote communication and increase the opportunities for people with mental retardation to participate in social life. Earlier studies with regard to still picture telephones for people with moderate and profound mental retardation showed that there are great benefits to be able to use telecommunications (Brodin, 1993a; Brodin & Björck-Åkesson, 1991, 1992; Pereira, et al, 1992, 1993). The participants in the still picture projects used alternative communication as they had no or poorly developed spoken language, and used gestures, body language, Pictogram graphic symbols, and sign communication (a simplification of deaf sign language) in their daily communication. The results showed that the still picture telephones facilitated communication and contributed to increase the possibilities for social contacts both with regard to quantity and quality. The above studies demonstrated that fax and visual communication systems were adequate communication aids for people with mental retardation. The above studies and the minitrial (Brodin, 1994; Brodin, Fahlén & Nilsson, 1993) formed the basis of TeleCommunity.

5.1 Aims of the study

The overall aims of the Swedish ACE (Advanced Communication Experiment) were to get knowledge of and understanding of the issues whether videotelephones could increase the level of independence and social integration, improve communication and increase the quality of life in terms of communication and participation in social life.

The purpose of using videotelephones in the ACE was to study if this kind of telecommunication aid would help the participants to use a telephone.



The aims were:

- to support and establish social relations in order to extend the social network
- to stimulate and encourage the participants to communicate more
- to facilitate, support and improve communication/interaction
- to have access to telecommunications in an ordinary way
- to support independent living
- to increase social integration.

The most important purpose for using the videotelephones was the accessibility to ordinary telecommunications on the same conditions as other citizens in society.

5.2 Service classification and staffing

The service was provided as elementary telecommunication, and as a support for social integration. This means that the service was part of the ordinary telecommunication services in Sweden and that it was based on person-to-person communication and included participant-participant and participant-staff communication. It was also possible for the whole group (four people) at each day centre to communicate with a group at another day centre. At each day centre the four participants could thus call five other day centres. The service was designed for adult persons with moderate mental retardation with no functional spoken language, but in need of communication support for their daily living, i.e. a dialogue service. The day centres in Sweden are responsible for the ADL-training (adaption to daily living) for adults with mental retardation and communication is considered as an important part of this training. The tasks were therefore integrated in the ordinary training programs for daily living.

The procedures to use the videotelephones required achievements from the ordinary day centre staff. At the start of the project the staff were encouraged to take initiatives to use the telephone, but one goal was to stimulate the motivation of the participants in order to increase their interest to use the videotelephones spontaneously. This was especially important with regard to independence. From the minitrial appeared that the videotelephoning was time consuming for the staff, but as their attitudes were positive, this task was experienced as a stimulating and meaningful activity. The time to use the videotelephone for each individual was not restricted, but two calls a week during the main study seemed reasonable to ask for. The quality and size of the image seemed to be of less importance (Brodin & Magnusson, 1992), but it seemed to be significant that sound and picture were transmitted synchronized.



6. METHODS

TeleCommunity went on from 1992 to 1995. The ACE continued for three years with a one year extension due to technical problems with the ISDN-network and with the equipment itself. The project consisted of a minitrial, aimed at testing technology and methodology, and a main study.

Problem inventory

TeleCommunity started with an introduction phase where the tasks were to identify and describe the requirements of persons with mental retardation and to define important concepts. What does mental retardation mean, what methods are used to assess mental retardation, what are the implications in daily life and what kind of assistance do this population need in order to avoid obstacles. The next step was to identify and describe services available for persons with mental retardation. Sweden is a society with a long tradition and a good reputation of equality and social welfare for all citizens, but what has actually been done to adapt the environment to suit all citizens and what kind of legal systems are working in Sweden? The keywords for all inhabitants are equality. democracy, communication and participation in social life, and normalization and integration are the ways to reach the goals. These questions are answered in the introduction of this report. Two literature surveys were made (Brodin & Magnusson, 1992; Brodin & Magnusson, 1993a) over time, and a follow-up was made at the end of 1994.

Literature research in databases.

In the start-up process of TeleCommunity two literature surveys were thus effected in the area of telecommunication for people with disabilities. The main interest in these literature surveys were to find out what had been done and what was going on in the area of telecommunication for people with mental retardation. The data were collected from some of the most frequently used and largest databases in the area of telecommunication, videotelephony, disability and closely related fields. The most comprehensive databases with regard to special needs were included.

The first literature survey was based on research in Europe (Brodin & Magnusson, 1992) and was done in January 1992 in the following databases: Libris, Pepsy, ERIC, PsycLit (PsycInfo) Tudor and Medline (Medlars). Most references available were in the area of technology and only a few references were found concerning videotelephony and disability. The second survey was based on international research (Brodin & Magnusson, 1993a) and was effected in 1992/93 in ten databases in the area of videotelephony (picture/image telephony) and disability. The literature research was summerized in a bibliographic report covering a total of 78 references concerning disability. The survey covered the same



6:

databases as the first one, but four new databases were added: ECER, Pascal, Articificial Intelligence (ARTIF) and Inspec. The most extensive database in this literature research covered 9 million references (Pascal) and the smallest 14.000 references (ARTIF). A special interest was directed to studies on people with mental retardation, but the results showed that few studies had been carried out on this population within the telecommunication area. The results were compiled and published in "Videotelephony and Disability. A bibliography" (ibid).

The keyword videotelephony resulted in totally 664 references (Pascal and Inspec). When videotelephony combined with disability was used the number of references decreased and was limited to 27 (Inspec). The results of the literature research showed that there were few references in the area of videotelephony for people with disabilities, especially for people with mental retardation. Few activities had been effected and the need for further research in this area seems to be of high priority in the future. A follow-up at the end of 1994 showed that few new references were added.

Equipment and network overview

The minitrial formed the basis of the Swedish ACE. In the minitrial the user requirements, the staff requirements and the technical equipment were evaluated. The results of the pilot study gave valuable information about necessary improvements of the equipment and of significant aspects of the participants' and the staff's needs. The ISDN-technology was utilized in the Swedish ACE. The equipment used was six Tandberg 64 kbit/s videotelephones (according to the 2x64 kbit/s ISDN standard). A modified standard videotelephone, concept keyboard with automatic dialling, document camera, personal caller and printer were used. The videotelephones at the six day centres were identical. Special adaptations with regard to the technical equipment were made when the minitrial was conducted. The Swedish ACE was carried through within a distance of 500 km from Stockholm in order to keep costs down, but also in order to provide assistance to the staff at the day centres in an easier way.

The equipment was adapted to suit both the requirements and the cognitive level of the mentally retarded persons and the environment. One condition was that the videotelephones were easy to use. Generally it is a benefit for people at early developmental levels that few moments are involved when operating the equipment (see technical description of the minitrial for details). Evaluation of the technical equipment was carried out continuously. In February 1994 the technical equipment was evaluated and this was followed by a more extensive evaluation in November 1994 (Brodin & Alemdar, 1994), just before the empirical study was completed. The reason for this was a desire from the project team to convey the videotelephones to the day centres in a good condition.



6.1 Selection of day centres, staff and participants

The videotelephones were thus installed at six day centres, three in the Stockholm area, and three in the Jönköping area, which means within a ratio of 500 km.

The first step was to choose the six day centres for participation. Eleven day centres in Stockholm were contacted and three of these were selected to participate. Four day centres did not accept to participate as they were re-organizing their activity, had a shortage of staff, or had too few persons with moderate mental retardation at their centre. Four day centres were excluded as their activities did not correspond to the goals of TeleCommunity, e.g. gardening, running a restaurant etc. Six day centres in Jönköping were contacted and three of these were interested and selected to participate in the project. The reasons for not being able to participate were in Jönköping a shortage of staff and re-organization.

One of the day centres in Stockholm had participated in previous projects in the telecommunication area, led by the project leader, and the employed staff had proved to be reliable and competent. The other two day centres were selected because they had a reputation in the county council as competent and interested in communication. The staff at the selected day centres were well educated and interested in technical aids for persons with mental retardation. They all had a continuity of employed staff and most of them had worked at the day centre for many years. The three day centres in the Jönköping area were selected on the same basis. To sum up, the following aspects were considered:

- an interest from the head of the day centre to be involved
- access of four persons with moderate mental retardation
- experience of new technology and technical aids in general
- motivation and willingness of staff to attend the project
- a reputation of interest in augmentative communication
- time to effect the training.

The staff involved in the project were the ordinary staff at the day centres. No extra staff were recruited and no extra costs were involved. For this reason, it was necessary that the project was anchored to the head of the centre as well as to the county councils. Most of the staff involved were occupational therapists, speech therapists and nursing staff/personal assistants. One of the staff members was responsible for the conduction of the project from each day centre, and the task to make calls was on the daily schedule of the centre. The staff (one main responsible and at least two or three others as co-trainers) were selected by the head of the centre.



The criterias for selection of staff were:

- interest in learning how the equipment worked
- motivation and positive attitudes to teach and train the participants
- willingness and ability to spend time on training
- willingness to document the work in writing
- willingness to produce diary notes according to a special schedule.

The specific task for the staff was to be the "helping hand" of the participants with moderate mental retardation. The maximum time to use the videotelephone for each individual was not restricted, but minimized to two calls a week. Professionals from the day centres were included in the project team, but parents, relatives and group home staff were also involved. When the day centres and staff had been selected, the users were selected and invited to participate in the project.

The four participants from each day centre were selected by the staff in co-operation with parents, relatives and friends. The requirements of the participants were that they had a moderate mental retardation, were in great need of support for their communication, had a limited social network, and were interested in persons in their environment. A total of 24 persons were selected to participate, 12 from Stockholm and 12 from Jönköping. The participants selected for the ACE were adults in the range of 21 to 60 years of age with moderate mental retardation. Twelve women and twelve men were selected to participate. The following criterias for the participants were set:

- poorly developed spoken language
- graphic symbol users, combined with other methods
- in great need of communication support
- motivation and will to communicate
- interest in learning new things
- not too severe additional disabilities
- in need of expanding the social network
- acceptance from the close social network to participate, i.e. parents/relatives.

At the participant's first confrontation with the videotelephone equipment the participant decided if he/she wanted to continue to participate. Nobody rejected the invitation, but found it exciting to use the telephone.

The next step was to select the Pictogram symbols for each participant and to start to make the overlays (the dialling and symbol sheets) for the concept keyboards. This was based on the background descriptions with data from questionnaires and medical journals completed in collaboration with parents, staff from group homes and day centres. The selection of



Pictograms were effected parallell with the other activities going on i.e. collection of background information and conduction of staff eduction/inservice training.

6.2 Staff education

In the introduction phase written information about the project was sent out to all day centres and to parents. This letter gave information on the aims of the project, the methods planned to be used, and what other participants were going to attend. In this letter the project team also offered the day centres a brief basic education, which they all welcomed. At the project start the team members thus gave a one day staff education/training at each day centre about communication, telecommunications and on-going activities in the area, and about the TeleCommunity project. It seemed to be important to give the same message to all persons working at the day centres. The presentation was audio-visual and at this time the staff members had a chance to ask questions about the different steps in the project and what the results would lead to. All the staff members at each centre participated in the education and this increased their involvement in the project and probably influenced their attitudes to participate.

6.3 Introduction meetings with participants and staff

Two separate meetings were arranged, one in Stockholm county council and one in Jönköping county council. One purpose of these meetings were to inform the participants, parents and the staff of TeleCommunity and to give the project participants an opportunity to meet and see each other before the project started. The meetings went on for three hours at each place. Another purpose of these meetings was to give the participants an opportunity to introduce themselves to each other and to find out who else was participating in the project. The staff introduced themselves by telling their names, which day centre they represented and their positions. After that the participants described who they were, what kind of job they had and what were their leisure interests in order to find mutual references. The participants were main actors and got all the time they needed to introduce themselves without restrictions. It turned out that the participants had many mutual interests. A result of these meetings were that the staff undertook to transfer written information about each individual's interests in order to facilitate communciation via the videotelephones. Data were compiled och processed for all participants.



6.4 Background descriptions

The background descriptions were based on a questionnaire (Appendix 1) covering information from:

- medical journals
- * parents
- staff from group homes
- * staff from day centres.

Areas covered in the background descriptions were: sex, age, housing conditions, previous and present schooling/education, main activities at the day centre, social network, leisure time interests, degree of mental retardation, assessment and diagnosis, additional functional disorders, use of assistive devices, gross and fine motor skills, understanding of pictures, functional level of communication, telecommunication, skills to send messages plus a description of everyday life.

Some questions were open e.g. the question about the description of the participants' everyday lives, but most questions were structured or semistructured with multiple choice alternatives. The parents, in some cases the relatives, and the staff from the group homes were invited by the day centres to meet and collaborate on the questionnaires. Most of them accepted to participate. On this occasion, and after permission of the parents or relatives, the medical journals were penetrated. information of the medical journals contributed insignificantly to the data collected collaboratively for the questionnaire, as the journals were incomplete in many respects. Expressions like "not contactable" or "no functional communication" can exemplify that. Background descriptions based on information from several sources are often more reliable, than data collected from only one source (e.g. Brodin, 1991), in spite of the fact that the informants may have different perspectives and experiences. Bogdan and Taylor (1975) stress that "One person may describe an experience in one way and another person may describe that same experience in quite another way. Yet both may be 'telling the truth' according to their own perspectives: Their own interpretations, rationalizations, fabrications, prejudices and exaggerations" (ibid, p 9). This is actually a question of the researcher's perspective and how the questions are asked, but it is reasonable to believe that the opportunity to collaborate about the completion of the questionnaire concerning the participant's communicative ability, increased the awareness of the difficulties and gave a more integrated view of the ability. In this part of the data collection the participants were not personally involved, as this would not be possible due to their cognitive and intellectual disabilities.

Another way to judge the reliability of the results is emphasized by Polkinghorne (1989). He argues that a longitudinal study with several



occasions for data collection increase the possibilities to revert and deepen the discussion about the same topic over time.

In this study the parents together with the staff from the participant's group home and day centre contributed to the study by completing a questionnaire on background data, by giving interviews, by completing a questionnaire on the communicative ability, by taking part in the goal descriptions and goal attainment. Data were also collected by telephone records and at social meetings. Kvale (1989) stresses that repeated meetings make it possible for the researcher to check if he/she has understood and interpreted the statements correctly. By meeting the participants continuously the knowledge of each individual increases and this helps to judge how reliable data are.

The three day centres in the Stockholm area (group 1) and the three day centres in the Jönköping area (group 2) formed two separate groups. The data from each group were separated, and later compiled for all six day centres. This made it possible to focus on variations in data and to compare the results. The background descriptions formed the baseline for the study.

6.5 Interviews

Interviews were made on two occasions; in 1993 (October-December) and in 1994 (September-December). A total of 123 tape-recorded interviews were made. The questions were open and put in a conversational form as there was a need for flexibility. The interviews were transcribed word for word from the tape and each question was processed separately and for each group of informants. The interviews were also compiled for each individual. The interviews took in general five to thirty minutes per person.

The following groups were interviewed:

- * parents/relatives of the participants
- * staff from group homes working with the participants
- * staff from day centres working with the participants
- * the participants (18 of 24)

The interview questions focused on the participants' functional communication skills (e.g. initiation and mode), social network and friendship (e.g. relatives/close friends outside and at the day centre). The interview questions also included if the participants usually visited people outside the day centre and if he/she received any visitors at the centre. A further question was if the participants were interested in technology and if he/she had any experiences of technical devices. Other questions of



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interest included education, additional disabilities, use of telephone and self-image.

The same person made the interviews with all informants and also typed them out as the first step in the data processing. Later on the interviews were transcribed step by step and more and more in detail as part of the analysis and processing of data. The results from the interviews were put together as brief notes and constituted a complement to already collected data from the background descriptions. The quality of the interviews differ, especially with regard to the interviews conducted with the participants.

The technique used when interviewing persons with mental retardation must be developed as this kind of research demonstrates many difficulties e.g. how reliable are the answers of the participants? Many persons with mental retardation have lived most of their lives in institutions and they have had no possibility to talk for themselves. It is reasonable to believe that the answers they give on direct questions might be based on their experiences of what they belive people expect from them. Their voices have not been heard and nobody has really asked for their opinions. Another issue is that they might not understand the questions and therefore avoid to reply. "In order to make intelligent judgements about the significance of the communication skills that subjects may have gained through intervention, we need to know exactly how they communicate, how frequently, in what settings, and with what clinical background" (Rowland, 1992, p 18). This focus on the methodological difficulty in assessing the communicative ability in disabled persons and support the importance of collecting data from different sources.

Patton (1980) stresses that one way to test the reliability in qualitative studies, and especially in interviews, is to go back to the informants and check if they recognize the description of themselves. He proposes two ways to check the reliability. The first is to validate how the researcher judges the collected data, the second deals with other researchers possibilities to verify and validate the data. However, Kvale (1989) means that the reliability can easily be tested just by asking the same questions at different times and in different situations. He claims that there is no validity problem with respect to the interview method as such; it is the results of an interview study which must be validated in a concrete situation. The question about replication is difficult to discuss as researchers have various backgrounds, knowledge, references and interests and it is almost impossible to arrive at the same conclusions, especially when talking about interpretations of the results.

Bogdan and Taylor (1975) state that the methods used when studying people affect how we view them. They state "Qualitative methods allow



us to know people personally and to see them as they are developing their own definitions of the world" (p 4). However, the most important task for a researcher seems to be to be open-minded and to try to collect data on the same phenomena from many various sources and to compare the results and try to figure out and discuss with other researchers what are the reasonable conclusions.

6.6 Assessment of the communicative ability

Communication is difficult and complex for many persons with mental retardation and about 70% of all people with this disability have no or poorly developed spoken language, and use augmentative and alternative communication in their daily lives (Granlund, 1993; Mirenda & Mathy-Laikko, 1989). Before being able to use videotelephones as a means of communication, assessments of the communicative ability of the participants had to be effected. A questionnaire specially designed for assessment of the communicative ability (Appendix 4) was elaborated (Thurfjell & Brodin, 1993).

The questionnaire on the communicative ability constituted the basis for the individual assessment made in collaboration with staff and parents/relatives. The assessments formed the baseline for the participants ability to express themselves in everyday situations and to communicate via videotelephones. The purpose was to design an individual training-programme for the concrete work with the telephoning sessions during the project. The results of the training programme were particularly interesting to study, not the least with regard to determination of the communication mode, turntaking and other interaction-roles. The questionnaire was based on indirect assessment by persons who were familiar with the participants. The assessment form 'Assessment of Communicative Ability in Persons with Mental Retardation' (Thurfjell & Brodin, 1993), was a revised and modified version of 'Assessment of Pragmatic Ability' (Nordström Walder & Åström, 1993) in order to suit the aims of TeleCommunity.

Design of the assessment form

The form was designed to assess each persons communicative skills; form, function and use, and was divided into three parts: interaction-roles, use/aim and alternative communication. Within every part of the form, separate abilitities were assessed and exemplified by the staff with concrete experiences of how the assessed person expressed him/herself in everyday situations.

Under the section interaction-roles the assessment was made of the ability to take initiatives to interact, to respond to communicative initiatives



made by others, to maintain a contact, i.e. turntaking and a cohesive function, and if the person in question normally finished an interaction. For each ability was indicated whether the ability usually existed or only occured occasionally.

Under the section use/aim the functional content of the communicative expressions was assessed, i.e. the purpose and meaning behind what the staff conveyed. This was the most comprehensive part of the test, and reflected a new dimension on how language and communication abilities are usually assessed in persons with different types of functional impairments. The focus was on the content of what was expressed rather than how it was done and what form was used.

The test assessed the ability to accept and reject offers of an object or an activity, the ability to choose between two objects/activities and whether the person usually asked for a certain object/activity. Indications to whether the ability existed or only occured occasionally were also made for each part concerning form and situation. Also social purposes as to greet/say goodbye, attract attention, turn the attention from a person to an object/activity were assessed as well as what emotional expressions the person had and if the persons in the environment usually were able to interpret those expressions. The personal knowledge of each assessed individual was indispensable and a condition for the assessment process, not the least regarding the expressions interpreted as based on emotions. Furthermore, the test assessed the ability to understand and follow instructions and if the person understood everyday conversations, asked for and gave information to the conversation partner, spontaneously commented objects and events and how this was done. Other abilities assessed were how the person could be more evident when he/she was not understood by the environment, and whether the person him/herself asked for elucidation when he/she did not understand what had been said. The ability to repair an interaction is necessary to establish, when considering the importance of the success of a telephone call. Significant for a telephone call is that the information, e.g. glances and emotional expressions, are no visible. It is not obvious that the same factors influence calls over the visual telephone system as over the ordinary telephone.

The second part of the form assessed in what situations the person communicated the most, in other words used most expressions, and in what situations and with whom he/she communicated most frequently and optimally. The latter was of value to establish as the communicative ability and intention always vary from situation to situation and from person to person. It was also valuable to get information from persons familiar with the participant and who were able to give examples from everyday situations. The last part of the form concerned alternative



communication such as signs, picture and symbol based communication and use of technical communication aids. The questions concerned if alternative expressions were used, in what settings and with what persons these expressions were generally used. The questionnaire gave a wide and clear picture of how the person in question communicated, what means of expression he/she used and around what topics, needs and aims the person usually communicated.

The assessment has the character of a general description of the linguistic and communicative ability (Brodin & Thurfjell, 1995) and can be used in different situations, not only in terms of telecommunication. The form was also tested and evaluated by ten speech therapists. They gave their opinions on the form and suggested changes so that the form could also be used in other contexts. Most of them were positive to the procedure of the test and found it useful as a description of mentally retarded individuals' way of understanding and communicating with the environment. The test takes approximately one to one and a half hour per person to carry through, and at the same time it raises a lot of new questions, which might be fruitful and developing for everybody involved. It raises the question of each persons' individual prerequisits to understand speech and communication and is at the same time introspective. The people consulted, such as staff at day centres or group homes must reflect on situations which normally get little attention. During the process of the test, discussions occur about the importance of awareness, communicative contexts, conditions and prerequisits. The form has also an educational and knowledge increasing side effect which varies from one occasion to another, but which none-the-less is well worth considering. The person who carried out the assessments started off by making a general survey of the main principles behind the design and content of the test.

The assessment was the basis for the individual goal setting. The results were compiled for each person, for each group and for all participants in total, but only the results from the whole group are revealed. Examples from a few cases will illustrate how data were processed for each individual.

6.7 Individual goal setting and goal attainment

The goal setting was made on the basis of the background descriptions, the interviews, and the communicative assessment. The first goal setting took place in February 1994, and shortly after that the proposed overall goals were sent to the parents and staff for approval. Each goal was described in concrete terms and had to be completed within a certain period of time. At the same time it was described how the staff methodologically should work to reach the goal. Generally, the goals



were accepted with a few alterations. Later on more detailed goals and subgoals were prepared for each participant and they were sent to the staff for approval. Concrete goals based on each of the particpants prerequisits, were thus elaborated. These could consist of quantitative standards e.g. to make a certain amount of calls during a week, to learn to listen to the communication partner, and to gradually get more involved in the subject or object the conversation partner talked about. The qualitative measures could involve the content of the conversation, choice of partner, choice of picture symbol and topics, turntaking and ability to initiate communication. A goal could also be to develop more evident expressions in order to be understood easier, or to offer more opportunities to use existing communication. When the goals were considered and finally accepted by the staff at the day centres, the staff started to support the participants according to the described goals and methods before and at each telephoning session. The staff worked with the goals during a limited time period varying from two to three weeks for each participant.

Goal attainment

The process was based on regular and continual evaluation of the goals, methods and modification of the goals if necessary. The goal attainment scales were assessed and new goals were set up. The staff had to judge if the goal had been "attained optimal in this context, better than expected, as expected, worse than expected and as inferior as possible in this context". If the goals were not attained the work was to analyze if the previous goal was set too high, or if there could be another reason for not attaining the goal. The goal was then re-formulated.

6.8 Telephone protocols

A special protocol, "Protocol for use of videotelephones", to be completed by the staff at each telephone call, was elaborated (Appendix 5). This protocol included information on day centre, name of participant, communication partner and the signature of the staff who had completed the form. The signature was important if any questions arose concerning the telephone call.

The protocol also included date, approximate length of the call (in minutes), initiator to the call, modes of communication and what kind of pictures were sent i.e. if they concerned activities, food, events, feelings or needs. These topics often take up a big space in the lives of persons with mental retardation (e.g. Brodin, 1993b; Brodin & Björck-Åkesson, 1992; Brodin & Thurfjell, 1995). The protocol included questions of what parts of the equipment were used, as the equipment consisted of videotelephone, concept keyboard, document camera, personal mini caller



and laser writer. The quality of image and sound was also included in the protocol. Another significant question focused on the expressions describing the participants' attitudes to use the telephone, e.g. if he/she was interested, bored, active, afraid, anxious, angry, upset, or if he/she found it difficult to use the equipment or felt frustrated.

The protocols were first compiled in detail for each individual. It appeared how many registered calls each individual made, and to whom. However, many calls were not registered at the end of the project, when the participants spontaneously made calls by themselves. Finally the protocols were compiled for the whole group of participants.

6.9 Parties and social meetings

The first meeting in each group (Stockholm and Jönköping) was the introduction meeting arranged by the project team. This was the starting point for TeleCommunity. The introduction meeting helped the participants to recognize each other and made it easier for them to make telephone calls to each other. It is reasonable to believe that it had not been possible to benefit from the videotelephones if the participants had never met before. After these first meetings and after the participants had started to use the videotelephones the staff and the participants arranged social meetings at leisure time. A couple of times a year the staff at each day centre arranged parties and invited the participants and staff from the other day centres and the project team. The participants who hosted the party, assisted the staff to prepare food and to chose music for the dance. The relation between the participats were strengthened by these informal meetings.



7. RESULTS

7.1 Background information

When the six day centres, the staff and the participants had been selected for the study, and the staff education and the first introductional meetings had taken place, the equipment was installed at the day centres. The participants lived in the Stockholm area and in the Jönköping area. In the study 12 women and 12 men were included. The participants were between 21 and 60 years of age. The average age of the the participants was 38,3 years. For the women of the Stockholm group the average age was 36,2 years and for the men 29,4 years. The average age of the women of the Jönköping group was 37,4 years and for the men the average age was 42 years. In total, the average age of the women was 36,8 years and for the men 35,7 years. The participants from the Jönköping area (group 2) were thus a little older than the participants from the Stockholm area (group 1).

The results from the background descriptions based on information from parents/relatives, medical journals, staff from the group homes and staff from the day centres were compiled both for each group and in total. From table 11 appears the results of the functional impairments of the participants.

Table 11. Functional impairments of the participants in addition to moderate mental retardation (N=24)

Group 1	Group 2	In Total
6	8	14
6	5	11
3	4	7
	2	2
6	5	11
0	2	2
4	6	10
6	9	15
8	8	16
2	6	8
3	3	6
3	3	6
12	12	24
9	1	10
á	3	6
	6 6 0 4 6 8 2 3 3 12 9	6 8 6 5 3 4 2 6 5 0 2 4 6 6 9 8 8 2 6 3 3 3 3 12 12 9 1

^{*}Heart-disease, diabetes, cerebral palsy, paralysis of the pharynx muscles, atetos with tonus variation, heart murmur, cronic nasal catarrh, gastric catarrh.



All participants were assessed to be moderately mentally retarded according to Kylén's theory (1981). The grading of the mental retardation was made by parents, doctors and staff working with the person in question. There are few details on how and when the diagnoses were made except for those, who were diagnosed at the maternity hospital. Eight of the project participants had Down's syndrome, which means one third of the whole group. In most cases it appears that the diagnosing was made in the early childhood. Among "experts/people in the field" it used to be an opinion that it was impossible to perform reliable vision and hearing tests on people with mental retardation, as they often find it difficult to take part in tests. However, we know today that i.e. hearing tests can be made with audometri. Even if a person is unable to take part, there are possibilities to perform reliable vision tests. As a consequence, many people with mental retardation have been tested, but others have not yet been offered to do so.

Table 11 illustrates that 14 of the participants have impaired vision. Eleven of those have been prescribed eye-glasses, but only seven use them regularly, according to information from the staff. Two persons are in need of enlarged text/picture to be able to discriminate. There are 11 persons with hearing impairment, but only two of them use hearing aids.

Ten of the participants have severe motor impairments, which affect both fine- and gross motor abilities. Table 11 illustrates that 16 of the 24 participants have gross motor difficulties and 15 have fine motor difficulties. A reduced motor ability is often linked with some kind of motor impairment and the number of people with motor disabilities is probably higher than mentioned, i.e. 10. Furthermore, three of the participants have difficulties in the fine- or gross motor ability only, which increases the stated figure, namely 15 or 16, even more. In reality this means that motor impairment in some forms or to some extent is to be found in 18 or 19 of the participants.

Six of the participants suffer from epilepsy and all of them take medicin to avoid fits. The participants have in addition to this particular medical handicap, several other additional handicaps of medical character, which further complicate their possibilities to actively take part in interaction. All the participants have speech and communication disorders to some extent. Some of the participants use a poorly developed speech, or a language functioning only with people familiar to her/him. Difficulties occur in the interaction with people who are not familiar with the person in question and do not know what it means to be a person with functional impairment or communication disorder.



Housing conditions

Seven of the twelve participants from the Stockholm area have lived with their parents when they were small and have later moved to residential homes for children when the parents no longer could cope with caring for them. Several of them have at the age of seven to 14 years moved to residential homes or nursing homes. Three of the participants have grown up in a nursing home before they moved to a group home. Ten of the participants are today living in group homes, one with foster parents and one is still living with his parents.

Ten of the participants from the Jönköping area have grown up in their parental homes, one in foster home and one in a residential home. Four of the persons who live at home have for shorter or longer periods stayed at a short-term home in order to give their parents relief. At present eleven individuals live in group homes and one with his parents.

The majority have moved to group homes during the latter part of the 1980s. Many of the nursing homes were closed down during this period and the transfer can be considered as a step in the societal development. Another reason for the transfer from the parents home to a group home can be seen as a step towards the person with mental retardation growing up in exactly the same way as 'ordinary' adolescence, i.e. leave their parents and move from home.

Schooling/education

The majority of the 24 participants have attended some kind of school or education. On average they have attended between 10 and 11 years in special schools for mentally retarded children, attended special classes integrated in ordinary schools or have had vocational training. Four individuals have not had access to school/education. They are between 46 and 60 years old, and at the time for their education, school was not compulsory for persons with mental retardation in Sweden. The compulsory school for persons with mild mental retardation was introduced in 1944, for moderately retarded in 1954 and for persons with profound mental retardation in 1968.

Communication

From the background descriptions appear if the participants recognize pictures of objects and subjects, graphic symbols, digits and letters. It also appears if the participants use pictures/symbols in their daily communication and if symbols are used to mark the environment to facitilitate orientation. The modes of communication also appear from the background descriptions as well as the usage of ordinary telephones.



Tabel 12. Understanding of pictures (N=24)

Recognition and use	Group 1	Group 2	In total
Recognizes objects on pictures/photos	12	10	22
Recognizes persons on pictures	12	ii	23
Recognizes symbols (Bliss, Pictogram)	12	9	21
Recognizes digits, letters	5	6	ĩi
Uses pictures/symbols for communication	8	ă	12
Uses pictures to mark the environment	š	Õ	8

From table 12 appears that 22 of the 24 participants recognize objects on pictures, 23 recognize persons on pictures/photos and 21 recognize graphic symbols such as Bliss and Pictogram. It seems more difficult to recognize digits and letters and only half of the participants can do so. For those who are using symbols as means of communication, pictures or symbols are often used in order to mark the local environment, such as marking the drawers of the cabinet with Pictogram symbols, and to mark the various common rooms at the day centre and the group home, e.g. the toilet, bedroom, kitchen.

Table 13. Assessment of the participants communication/language based on the background description (N=24)

Communication	Group 1	Group 2	In total
Is motivated to communicate	12	12	. 24
Communicates by means of speech		12	2-4
(sentences of more than one word)	8	5	13
Communicates by single words	9	7	16
Communicates by means of signs	7	4	ii
Communicates by means of pictures/symbols	8	2	10
Uses communication aids	9	1	10
Responds to communication		-	
always	5	8	13
often	6	2	8
sometimes	1	2	3
seldom	0	0	Ō
never	0	Ö	ŏ
Has participated in other projects regarding			ŭ
communication	2*	0	2

^{*} Both of them completed the project and are still using the communication aids they evaluated in the project.



From table 13 it is evident that the 24 participants are motivated to communicate. The assessment is made by staff at day centres and group homes in collaboration with parents. Thirteen participants communicate by speech using sentences of more than one word, but this kind of speech is often impossible to comprehend for people who are not familiar with the person in question. However, the most frequent mode of communication is to combine several means to reach a goal. Various combinations are used for different purposes and for transmitting messages by quickest possible means. Approximately half of the participants communicate by using a combination of signs, symbols, pictures and speech, i.e. total communication.

Table 14. Use of telephones (N=24)

Telephone use	Group 1	Group 2	In total
Uses the telephone			_
daily	6	2	8
occationally	4	3	7
seldom	1	2	3
never	ī	4	5
Recognizes voices of familiar persons	_		
on the telephone	12	10	22
Is able to make a telephone call by him/her self	7	4	11
Is able to answer the telephone on his/her own	8	6	14

From table 14 reveals that the participants' experiences of using the telephone to establish and maintain contact with people in the environment vary considerably.

Eight persons use the telephone daily, seven occasionally and eight seldom or never. It is probably not a matter of ability to use the telephone, but rather a question of having somebody to call and something to talk about. In two cases it is not known if the person recognizes voices on the telephone, as do the other participants.

The telephone calls are primarely made to the mothers and fathers (18), but three calls are adressed to other relatives and in a few cases to friends from the day centres.

Main activity at the day centre

The participants of the Jönköping group are during daytime active with industrial work, packeting, cleaning, weaving, textile printing, participating in a sewing group, measuring material, filling cushions, painting, sensory stimulation and social training.



The participants of the Stockholm group are during daytime occupied with distribution of local mail, making mail rounds outside the day center, doing subcontract work, office work, work at a coffee shop, lawnmowing, handicraft, household duties, participating in a communication group, physical exercises, mobility training, adult education, swimming, ADL-training, painting and listening to music.

Table 15. Main activities at the day centres (N=24)

Activity	Number of persons
Work with computer	6
Bake, cook	7
Wash clothes, clean the houses	6
Shop, lay the table, wash up	3
Office work like copying, sorting papers	5
Post distribution	3
Sew, weave things for selling	4
Subcontract work for companies	5
Carpentry	3
Go for a walk/excursions	7
Drama, theater, aesthetical actitivities	10

Both the Stockholm and the Jönköping groups are doing subcontract work. It seems like it is mostly the men who are taking part in such tasks, while the majority of the women are doing traditional female work such as sewing, printing of patterns, cleaning and household duties.

Leisure time interests

The participants of the Jönköping group are interested in music, dancing, TV, cooking, embroidery, physical exercise, club activities, activities at church, outings, visiting parents, boat trips, car rides, going for walks and to spend time out of doors.

The participants of the Stockholm group are interested in music, dancing, TV, cimena, bowling, s imming, conserts, animals, nature, technics, photography, social life, horse riding, outdoor activities and painting.

Even if quite a lot of the leisure interests correspond between the participants from the six day centers, the similarity is higher within each group.



Social network

Many persons with mental retardation have moved from huge institutions to group homes in the society. Table 16 and 17 show the social networks for each group, and in table 18 the results of the social network for all 24 participants are compiled.

Table 16. Social network for Group 1 - The Stockholm group (N=12)

Has contact with	Daily	Every week	Sporadically	None
Mother		3	-	4
Father	ī	3	4	4
Siblings	ĩ	-	7	4
Relatives	-	1	-	11
Staff at leisure time	2	3	-	7
Friends outside work	-	_	-	12
Contact person	-	1	2	9

Table 16 reveals that none of the participants have friends outside work or outside their 'ordinary' environment, i.e. the group home or the day centre. Nine of the participants have no contact person, which is a legal right for persons with mental retardation. In three cases their mothers are dead, in two their fathers. In one case both parents are dead.

Table 17. Social network for Group 2 - The Jönköping group (N=12)

Has contact with	Daily	Every week	Sporadically	None
Mother	3		2	2
Father	I	3	4	8
Siblings				
1. first	1	-	-	11
2. second	-	2	8	2
3. third	-	1	1	10
Relatives	-	-	4	8
Staff at leisure time	9	-	1	2
Friends outside work	4	-	-	8
Contact person	-	-	1	11

Table 17 reveals that four persons have daily contact with friends outside their 'ordinary' environment, i.e. the group home or the day centre. Eleven participants have no contact persons, despite the legislation. The leisure time is often spent with family members or with staff from the



group homes and day centres. In two cases their mothers are dead, in four their fathers. In two cases both parents are dead.

Table 18. Social network for Group 1 and 2 (N=24)

Has contact with	Daily	Every week	Sporadically	None
Mother	8	8	2	6*
Father	2	6	4	12**
Siblings				
1.first	2	•	7	15
2.second	_	2	8	_
3.third	-	1	1	-
Relatives	_	1	4	19
Staff at leisure time	11	3	1	9
Friends outside work	4	•		20
Contact person	-	1	3	20

^{*} In five cases the mothers are dead

From table 18 concerning the social network covering group 1 and 2, it is evident that the participants have a limited social network outside their families. Family is in this respect referred to as the biological family (parents and siblings). Most of the participants are at present living at group homes and approximately two thirds maintain daily or weekly contacts with their parents. As some of the participants are quite old their parents are sometimes dead (11). In three cases the participants have lost both their parents.

Bronfenbrenner (1979) divided the social network in four different systems from an ecological point of view: the microsystem, the mesosystem, the exosystem and the macrosystem. The microsystem is the most important level and cover the relations between parents, siblings, friends, and staff and peers at day centre and group homes. Different patterns of interaction, e.g. activities, roles and relations are included in this system. The individual is influenced by the social interaction in different systems. For this reason it seems important to include parents. relatives and other persons in the individual's immediate environment when assessing the communicative ability and when offering persons with mental retardation support. Studies on the communicative ability of children with profound mental retardation (e.g. Brodin, 1991) and of children with cerebral palsy and speech and communication disorders (e.g. Björck-Åkesson, 1992) have shown that the communication partner as well as the context are of great importance. The interaction between the different actors in the microsystem are thus significant. The project



^{**} In six cases the fathers are dead

participants have daily contacts with many different persons, e.g. the staff in group homes and day centres and other persons with mental retardation living in the same group home and working at the same day centres. Six of the participants have no contact with their mothers and twelve have no contact with their fathers according to table 18. Fifteen of the 24 participants have no contact with their siblings. In the microsystem friends and contact persons are also involved, but twenty of the participants have no friends outside their daily working site and they have no contact person despite the law LSS (1994). This shows that the immediate social network is very limited and most contacts involve persons they meet in their housing and daily activities.

The mesosystem deals with the relation between different microsystems which are linked together. The relations between staff at group homes, day centres and other service providers seem to be significant for the participants. In TeleCommunity the assessment and the goal setting are based on a collaborative work between parents, staff at group homes and day centres and this means that the different parts in the system are linked together in order to suit the individual. One result of this project is that the staff members in the group homes and day centres have started to cooperate, another that parents and relatives feel more involved in their "adult children's" daily activities.

The exosystem involves the day centres as a working place and decisions which the individual cannot influence in the municipality, e.g. the case management for persons with mental retardation in the habilitation teams with staff members with competence in many different areas. Bailey (1989) has showed the importance of having a functioning case management system and stress that cooperation between different levels and systems are necessary.

The macrosystem involves ideology, systems for service delivery, the financial situation in a country, legislation, culture and sub-cultures, and structure of social classes. Since the 80's the aim of the Swedish handicap policy has been to integrate persons with mental retardation in society in order to attain equality and participation in social life. This means that the huge institutions were abolished and that adults moved to group homes. This is mainly an ideologic issue, but probably also an economic, as the costs for care decrease if persons with mental retardation live in group homes. Another aim has been to normalize living for persons with mental retardation. Of the 24 participants 21 live in group homes and the remaining three live with parents or in foster homes.

Also the holistic model of interaction based on Kylén (1986) shows that many aspects are involved when assessing the communicative ability in individuals with mental retardation. The sociological aspect involves the



social environment and includes the family, group, culture and society (Kylén, G., Alba, Fischbein, Frank & Kylén, A., 1995).

7.2 Interviews with parents, staff and participants

A total of 123 interviews about the participants communication were carried through with parents, staff and participants. The interviews were tape-recorded and made at the end of 1993 (85 interviews) and repeated at the end of 1994 (38 interviews). All interviews were made by the same person with open questions (Appendix 6) and transcribed word for word. The interviews made a complement to the background descriptions, the social meetings and the communicative assessments in order to get a more holistic view of the participants. The data collected from many different sources formed a description of the participants abilities. A two day visit at each day centre was made and the staff of each day centre made schedules for the interviews at each visit in order to make them as effective as possible. Four interviews were effected with the participant, his/her parents, staff at group home and staff at the day centre. In some cases the parents were dead (11), or did not want to have any contact with the participant, in other cases the informants were ill and could not participate. In a few cases people refused to be interviewed in the second interview round, as they did not have "anything to contribute with". It was a decline from 85 to 38 interviews in the second round.

Ouestions for the first interview round and for the second interview round were elaborated (Appendix 6). The interviews were integrated in the conversation, i.e. in the dialogue between the informant and the interviewer. The reason for this was mainly that dialogue interviews give a more equal relation between the interacting parties (Kvale, 1989). In general, conversations will give more and deeper data of the persons, and give possibilities to explain difficult questions, which was important in the interviews with the participants with mental retardation. This interview technique put great demands on the documentation. This problem was partly solved by the tape-recording of the interviews and the transcription word for word. A database was created to process the interviews and the replies related to the interview questions were put into the database, where it was possible to process data and find more general answers in relation to the different groups of people interviewed. Much time was spent on typing, editing, processing and analyzing the material. The material is written in Swedish and translated into English.



7.2.1 The first interview.

The first interview round was made in 1993. Most of the interviews were made individually in face-to face situations, but some interviews were made over the telephone (7). The interviews took between five and 30 minutes. Due to the geographical distance between the day centres (Stockholm and Jönköping), much time was spent travelling. The main goal of the interviews was to collect information of as many representatives of the participant's immediate environment as possible to obtain a more holistic view of the participant. The questions covered modes of communication, and familiarity to technology.

The interviews were organized by the staff at the day centres, where most of the interviews took place. Every interview was individual, but in most cases, the interviews with the project participants required support or an interpretor - mostly someone from the staff. No one refused to be interviewed. In one case, one of the persons interviewed misunderstood the aim of the interview and thought that the interviewer was a salesman, intending to sell expensive videoconferencing systems. The misunderstanding was cleared out. In another case a relative reacted very strongly to an incorrect pronunciation of the last name of the participant and the interview became "hot", before apologies were accepted. The form of the interviews was open, although there was a set of fixed questions to be answered, and sometimes the conversation developed in another direction than planned. This meant that the persons interviewed had possibility to ask questions, or just chat. A general feeling of openness and personal engagement was experienced.

Since the day centres were responsible for organizing the first interviews the day centre staff were important. One staff member of each centre, was appointed the main responsible and coordinator. This person was interviewed as he/she was supposed to know the participant(s) best. During the sessions with parents and staff of group homes, it was necessary to start every interview with a brief presentation of the project. At every centre, a special room was let up for the videotelephone. In some of the day centres, that room was functioning as a technical resource centre with computers and electronical communication aids. In one centre they used the computer of the videotelephone equipment for training of all mentally retarded persons working at the centre.

7.2.2 Results from the first interview round

Two questions concerned the *contacts* the participants had within and outside the centre. It appeared that the relatives and the group home staff lacked information on the contacts the participants had with peers at and



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visitors to the day centre during the working day. The borderline between day centre (working site) and the group home (housing) seemed obvious. Only in few cases, could the informants give information of contacts outside work or leisure time. The only situations where they could give information about contacts were when talking about organized leisure time activities, e.g. monthly dances etc. The participants did not separate the various contacts in time and most of their answers concerned activities at the day centres. The day centres seemed to be the place where things happened.

From all answers appear that the participants lives are based on routines, and few unexpected events are described. There is a risk that the use of the videotelephones might be a new routine, as it might be difficult to make telephony spontaneous. The interaction of the participants seems to consist of planned and fairly regular occasions of communiction with people that are given and expected. In a few cases, the staff cannot imagine a situation where the participants would experience anything, but routines in the company of wellknown people. In some cases, I: is used in the examples below to show when the interviewer is talking. All quotations are selected from the interview and are typical statements without being statistically selected. The numbers below are related to the coding of the day centre and project participants.

A few examples of quotations from the interviews regarding contacts:

13. A 32 year old man

"NN is the one who has most contacts outside the group home"..."He finds it easy to initiate contacts with others and does it most sponaneously. He has three or four friends, whom he meets now and then." (group home staff).

32. A 50 year old woman

"She does not have many visits at the day centre. At home we do not know. I only know that she has a contact person, who she visits quite often."..."She continuously calls a relative on Gotland." (day centre staff).

"She travels to a relative on Gotland twice a year." (group home staff).

11. A 33 year old man

The question if NN contacts other persons and is curious, was answered as follows:

"No, not spontaneously (oh no). It depends perhaps on where, i.e. in what situation he is. I would rather think that if he is (hmmm) interested - yes, then he would." (group home staff).

24. A 24 year old man

I: Does NN take contacts by himself?

"No, not if it is not allowed, I think." (day centre staff).

1: And what does allowed mean?

"Well, as in this working situation, he does not know what the coditions are, that he is allowed to take responsability for his answers. He does not take initiatives in relations with strangers." (day centre staff).



41. A 35 year old man

From a telephone interview with NNs mother appears: "His contact network is limited to the parental home, the group home and the day centre. He has no problems to get in touch with people."

To sum up, most participants do not take initiatives to communicate with strangers. They are often interested in other persons, but need support from persons in their immediate einvironment to get in touch. As soon as the "ice is broken", they seem to be very pleased to have someone to communicate with. Very few of the participants are afraid or negative to strangers. A normal pattern of contact is that the visitor first initiates the contact, then the participant reacts positively. The interviews also confirm that the informants do not know much about the activities the participants have at the "other sites". The participants do not meet many vistors or unknown persons at the day centres or the group homes and their social network is limited.

The answers regarding familiarity to technology and the use of telephones show that handling a telephone seems decisive of the participants' ablity to handle technological equipment in general. The most initiated and detailed answers come from the staff at the group homes. They give many examples of equipment used by the participants. Most of the participants seem to have some technological equipment, mostly gramophones, tape-recorders and in some cases TV-sets. However, the TV is seldom private, but belong to the group home and is often placed in the living room. Few participants have their own telephones. To make telephone calls seem to be an activity outside the workplace for most of the participants, although telephones are available at the workplace, it does not seem to be expected that the participants should use them.

In most cases it seemed as if the staff and sometimes the parents helped the participants to get only the type of technology they expected the participants to handle on their own. This viewpoint excluded telephones since a telephone conversation involves two users. In a few cases, a relative had arranged telephone facilities for their son or daughter in order to be able to communicate with them. None of the staff were of the opinion that the participants would not understand that the telephone is a means of communication. Technology also seems to conserve boundaries, i.e. to maintain routines. In few cases there was an expectation that new patterns of communication would arise. At the initial information meetings, the participants' interest in the project, surprised many of the staff. - "Who would expect that he/sheetc.". The staff at the day centre expressed strongly that this project would give something totally new to their centre and that it was extremely important for them to participate. It appeared that they expected the project to initiate spin-off activities, e.g. use of computers and fax communication.



A few examples of quotations from the interviews regarding technology and telephoning:

24. A 24 year old man

"He uses an 'Alfa-telephone' which he is very interested in"..... "He is calling and asks all the time if he may call. I have to keep him back." (day centre staff).

i: Can NN handle different types of technological tools?

"Yes without problems and with great interest." (day centre staff).

It appears that he often uses the telephone spontaneously.

54. A 35 year old man

"Normally technology require good motor skills but his motor ability does not prevent him to handle the TV, the remote control and the record player. Oh yeh no problem!" (day centre staff).

"We have knowledge of computers, but not of videotelephones, and we are pleased that NN is a pioneer and will be one of the first to influence the development a little. (father).

52.

A 43 year old woman "I don't think that she uses the telephone from here but she calls from home. She needs help to call. Her siblings call her and she answers the telephone and recognizes the communication partners." (day centre staff).

64. A 32 year old man

"He uses the telepone occasionally."....."He cannot use any instruments, a remote control or a keyboard." (sister).

"He likes to press buttons to change channels on the TV. If he despite his motor disability can hold the control in a steady grip, he is happy to press the button." (group home staff).

43. A 48 year old man

"He has not used a telephone. We talked to his mother about it and we were going to try if he could listen in the telephone"...."He has had a small tape-recorder and I think that he can operate it". (day centre staff).

To sum up, most of the participants are used to home technology, but not to use a telephone. The staff meant that the technological awareness included telephone, radio, music-machines and TV, tools which demanded the same kind of skills from the participants. However, a telephone did not seem to be generally available for the participants at the day centers, only in their group homes.

Questions about relations with friends, and acquaintances and staff at the day centre were involved in some of the interview questions.



13. A 32 year old man
"He socializes with everybody in the group home and he has taken on the role of taking care of everything and everybody."(group home staff).

12. A 34 year old woman "She turns more to us, the staff, but this could also mean that the other mentally retarded peers have difficulties in understanding her. She uses her own signs and it is not always easy to understand those signs." (day centre staff). "NN has quite an extensive network, especially when she lived at the X institution." (mother).

14. A 35 year old man
"He has no contact with his family, but he has some other social contacts now and then." (day centre staff).

"He has few contacts outside the group home but he has a contact person who has continuous contact with him and whom he likes very much". (group home staff).

34. A 34 year old woman

"She has contact with all the staff here. Everybody understands her and also staff from other working groups assist her when eating. If only two persons are involved and understand her communication, the situation is very vulnerable."

(day centre staff).

"Her immediate relations are rather limited to the family and to the day centre and group home staff." (mother).

31. A 23 year old woman

"Sometimes she calls her mother two or three times on Saturday mornings before going out. She has a wonderful mother who is always supportive. She has also siblings but 1 don't know if she has any peers."..... She is rather contact seaking. She wants to hug everyone, and she waves to people she recognizes" (day centre staff).

"When NN can talk to all of us at the same time, then it is happiness! - To be together with all persons you love." (mother).

32. A 50 year old woman.

"This woman is going out a lot, she loves dancing and takes part in many leisure activities". "I don't think that she meets many visitors at the day centre or at home." (day centre staff).

62. A 31 year old woman
"She socializes with everybody living at the same group home and her parents."
(group home staff).

22. A 31 year old woman
"She has first of all contact with the people from the same group home and then
she is in touch with her parents and relatives"..... "She has also contact with other
people with mental retardation, e.g. some persons she met on a summer camp"
(group home staff).

21. A 47 year old woman
"I am the only relative she has left but she has a sister with whom she has sporadic contacts. Her social network consists of those who live in the same



group home and work at the same day centre. She has also contact with one of the staff from the old institution where she used to be." (father).

A 35 year old man
 "His social network is limited to the parents home, group home and day centre"
 (mother).

From the above statements appear that almost all participants have few friends outside the family, group home and day centre.

The questions about educational and leisure activities were often treated as one by staff and relatives, meaning that educational activities like evening courses were described as leisure activities. "Leisure" was in those cases not interpreted as something you choose yourself, but something you do on your leisure time, even if someone else made the choice for you. The leisure activities are reported in the background description. It appears from the interviews and from the background description that the main interests are cooking, horse riding, shopping, dancing, playing and listening to music, going for walks, going to chinema or restaurants, technology, to watch ice hockey, TV, and to interact with people.

The manner of communication was described in various ways by the informants. For the participants it was difficult to give an answer to questions about their own communication. The word "talk" or synonyms was used to describe any form of contact with other persons and for those non-speaking it was sometimes difficult to understand if they gave any answers at all to the question. Otherwise, staff and relatives interpreted communication as wider than speech. Many were familiar with augmentative and alternative communication and many questions about methods and communication abilities arose during the interviews. The information from this question correspond to the information collected in the background descriptions and no deviations from the previous information were given by the informants. The results from the interviews supported and confirmed previous results from the data collected by the questionnaires for the background descriptions and the communicative assessments. The question about initiatives was also difficult to answer. In what situations did the participants take initiatives, with whom and in what ways? Most answers exemplified that initiatives were taken in familiar situations with familiar people. This was hardly unexpected since the results of earlier questions showed that very little communication with people outside the daily routines were expected from the participants. A few participants could answer questions about concrete experiences such as: "Did you go downtown yesterday?" or "did you see something exciting there?" or "did you meet someone new?" or "did you talk to that person?".



There were also spontaneous questions about the intent of the project and the technology in general.

Comments to the interviews with the participants

Interviewing the participants was different from interviewing the staff and relatives. The questions had to be shortened and formulated in concrete descriptions. In several interviews there was a long introduction. In a few situations, it was impossible to make a complete interview since the participant did not totally understand the questions. All of the participants cooperated in the interviews in the sense that they wanted to talk with me. Some of them, however, did not cooperate and did not answer the questions put, or in two cases, did not answer any of my questions, instead they wanted to just chat. In most cases, an interpretor who knew the participant well, was present. He/she interpreted each communicative expression of the participant. The following exemplifies how an interview could look like.

11. A 33 year old man

I: Where is the videotelephone?

NN: Hm-hm

(Can you point at it NN? That's the microphone [interpreter])

1. Yes, that's right we can test that too. Where is the videotelephone?

Yes, that's a computer. We can switch that on. Not like that. Before switching it on - where is the videotelephone? Can you point at it? Which direction? In another

(There is a telephone over there on the wall [interpreter])

The man is evidently not interested in answering the questions. The interviewer and the interpreter communicate.

33. A 23 year old man

I: Do you have any pals who does not go to the day centre?

NN: Yes, not so many

I: Not so many?

NN: No. no

I: Is there anyone you use to talk a lot with?

NN: Yes, I use to talk to John.

I: John, Where does John live?

NN: He lives on the X-island

I: Okey, Do you talk to him on the telephone?

NN: Yes

I: Do you call each other? Often?

NN: Yes, yes

I: Do you have long tarks with each other?

NN: Long talks

I: Do you meet each other as well?

NN: Yes we do

I: Hm, hm. What do you do when you are not here at the day centre?

NN: I go home. I work hard at home.

I: What do you do when you work hard?

NN: I watch TV and listen to music and play drums and synthesizer.



As appears the informant just answers the questions and add little information to the conversation. This man has a good vocabulary in daily communication, but did not use it when being interviewed. One reason for this might be that he was alone with the interviewer, whom he did not know before the interview.

61. A 35 year old man

The conversation is about a friend NN has in Gothenburg.

I: Is it a relative in Gothenburg?

NN: No it is not.

I: Is it someone called Nana?

NN: Yes

I: It sounds like a girl?

NN: Yes

I: It is not a boy?

NN: Yes

I: Is it a boy?

NN: No.. it is......

I: Do you use to call?

NN: ves, I do

I: Whom do you call?

NN: Home

I: Do you call from home

NN: Čall - I do

I: Do you call Nana or here?

NN: No, I work.

As appears from the above interview the informant separates between work and home. When the interviewer asks questions the informant seems to try to give the "right"answers", but he was probably mislead by the interviewer. When the interviewer says "it is not a boy?" then the informant was not sure what to answer any more.

23. A 34 year old woman

The first part of the interview when they talked about all kinds of things NN was silent and just answered yes and no. Then they talk about TV and music.

I: So you don't have a tape-recorder after all?

NN: Noo, I have nothing on my tape-recorder either

1: So, do you like music otherwise?

NN: Yes I do

I: What kind of music then?

NN: Abba

I: Do you like Abba?

NN: Pop, rock, hardrock

I: Do you like hardrock?

NN: Yeeeccehhh

As appears from the above interview the interest to communicate change when talking about issues of personal interest. e.g. music.



52. A 43 year old woman

I: Do you work here at the day centre?

NN: No I work at the day care centre

I: What are you doing there?

NN: In the kitchen I: Do you like it?

NN: Yes I do

I: Okev

NN: It is windy and cold outside today.

I: Yes, it is autumn.

I: May I be curious and ask if you have a best friend here?

NN: Yes

I: Who is that?

NN: There are many

NN has a job in day care for children and work in the kitchen. She lives in a flat together with another woman who is also mentally retarded. From the interview appears that when the conversation deals about areas of interest she talks and listens and she also initiates communication e.g. talking about the weather. When the interviewer asked her about her friends she did not give much information, as she probably did not want to.

The first interview intended to mirror the expectations before the empirical study started and to give a view of the interaction structures of the people that were going to participate in the project.

7.2.3 The second interview

The second interview round was made in 1994. The interviews were made in the same way as the first one, with most of the sessions organized by and at the day centres. The main goal of the second interview was to get information about experiences in terms of communication initiatives, new contacts, patterns of communication, establishment of friendship and functions of the technology. One of the participants and a few of the relatives did not want to be interviewed. Due to technological difficulties and errors, it was not possible to make any interviews at one of the day centres. A total of 38 interviews were made. Several persons stressed that they wanted to be interviewed in a group. One reason for this could be that they experienced the second interview more as an examination, than an interview. Another reason could be that they wanted to save time.

In this interview session it was clear that the day centres had, in accordance with the project plan, taken complete responsibility for the trials and also appointed one person responsible at each centre. The staff at the day centres had continuous experience of the videotelephones and could therefore answer questions about the usage of the technology. A



few relatives and staff of the participants' group homes had attended demonstrations of the videotelephones.

7.2.4 Results from the second interview round.

The way that people had experienced the trials were unanimous. Those persons who expressed any opinion at all were disappointed that the equipment had not been working as expected. Very few persons, however, thought that the equipment was difficult to learn to operate. In the first interview session many of the staff expressed ideas about different possibilities with the equipment. In the second interview these ideas were fewer. However, all centres wanted to keep the equipment as promised at the project start. In a few interviews, the staff expressed a little irritation that the project had created more work and had become an obstacle for the real work at the day centre. This, however, was not a general idea. Some of the staff were disappointed that the communication was organized. They meant that communication has to be spontaneous to lead to contacts between people. All persons who expressed viewpoints of the medium, except one of the participants, expressed personal satisfaction with the medium and thought that videotelephony offers great possibilities of quality in communication.

The question about changes in behaviour during the project time was difficult to answer in most interviews since few persons were definitely sure if the changes were a result of the project. Only a handful of the staff could be sure that NN had changed because of the project. When interviewing the participants, the responses were mostly demonstrations of new routines and activities. A few participants had established new routines e.g. to go to the videotelephone and make calls, either on their own or with a staff member. The quotations and comments below illustrate some viewpoints from the staff and relatives:

- * "the more you do the more sure they become and the more fun they think it is. It is good to have continuity and repeat it all the time"
- * "she makes the calls all by herself. She has got a close friend at another day centre. They are very fond of each other"
- * "She turns into the room and sits down in front of the videotelephone. It is often switched on. Then I pick out the overlays and she decides whom she wants to call"
- * "sometimes she takes initiatives sometimes she does not"
- * "she gets a little disturbed by seing herselt in the monitor"
- * "she is more open and easy going than earlier"



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- * "we had an idea that the communication would be freer so to speak but this is more dependent on our situation than anything else"
- "very much has happened, but we do not know if it is a result of changing housing or the videotelephone"
- * "the participants are more aquainted than me with the equipment. They have to teach me how to use it"
- * one of the parents say "I don't believe in this trial very much but I am flattered that NN may participate"

The staff's opinion of the possibilities to benefit from telecommunication for people with mental retardation was undiminished, in comparison with the expectations from the first interview. None described any difficulties in learning how to handle the equipment. Difficulties only existed when the equipment did not function and when the trials were not functioning, they begun to experience the equipment as difficult in the sense of being difficult to understand, being unreliable etc.

Comments

The main comments had to do with the problems with the equipment and the delays this caused. One day centre had considered the idea of leaving the project, because of the problems, but decided that it was too important to quit. The other type of spontaneous comments had to do with the possibilities that this technology seemed to open for people with mental retardation. All people interviewed experienced the technology as positive and expanding for mentally retarded people in general and most of them thought it would be valuable for the participants. Very few of the new staff had made any trials of their own to test the equipment. Several of the interviewed members of the staff said that since it was an equipment for the participants they felt that they should not use it on their own, not even to train themselves. The general attitudes towards the project was positive, but changes of staff created difficulties sometimes. The interviews present detailed and multi-faceted data.



7.3 Communicative Assessment

A questionnaire for assessment of the communicative ability (Appendix 4) was designed (Thurfjell & Brodin, 1993). The assessment included form, function and use and was divided into interaction roles, use/aim and alternative communication. Within every section of the form separate abilities were assessed in everyday situations. The questionnaires formed the basis of the personal visits and interviews (Brodin & Thurfjell, 1995).

The assessments were made through personal visits at each day centre and on that occasion the questionnaires were filled in. Each assessment was made by the speech therapist of the project team in collaboration with the day centre staff who had the best knowledge of each project participant. After the assessment a short summary of the results were made, which gave a view of the participants communicative ability. The summary is short and generic, but includes a rich variety of examples of communicative expressions from daily life. The assessment shows now the participants use body language e.g. glances, gestures, sign communication and in some cases alternative communication such as Pictogram and Bliss-symbols. In a few cases technical aids such as Macaw and Quarter Clock were used. The majority of those using alternative communication used sign communication and Pictogram symbols. Some of the participants were used to Bliss, others had previously tried to use Bliss symbols, but had stopped, as they found it too difficult. The level of abstraction was too high for their level of development.

The ability to communicate was related to personal factors, intelligence, communicative awareness i.e. ability to take initiatives and a desire to talk to people in the environment, and to physical prerequisits. Many of the project participants had apart from the mental retardation also additional disabilities, e.g. motor impairments, visual impairments, hearing impairments and epilepsy. All participants had significant difficulties in communicating. The additional disabilities, especially the motor disabilities, were of importance for people in the environment and influenced the possibilites to interpret their body language, signals, gestures and signs. There are in general great demands on the social environment to correctly interpret and decide what is intentional or unintentional expressions in persons with mental retardation. Incorrect interpretations and over-interpretations are often made of disabled persons' expressions. This is often experienced as frustrating by the staff. It is reasonable to believe that the same aspects apply to persons with mental retardation, especially if the individual is under interpreted by people in the environment e.g. if staff is not receptive enough to attempts to communication.



The staff who made the assessment were interested in the project participantsn and made great efforts to understand individual expressions and small initiatives and signals to communication. They also showed great knowledge of each individual and his/her personal means of expressing him/herself. The concrete experiences of use, particularly the forms of expression, were put in relation to new tions brought up by the test (interaction-roles, aims/use). The star 'enowledge of the isly unknown or individual could be used to clearify aspects pre. unreflected. The individuals' means of communication got a new dimension especially as the staff had to answer questions on the modes, in what situations it was used and at what aims. The different interaction roles were also highlighted. The most vital aspect that takes place through this kind of communication assessment is therefore the systematized knowledge of the individual carrying out the test. The abstract discussion becomes more concrete through the individual example, which sometimes can be generalized as common knowledge on how the expressions occur in different situations with different goals.

This means that a person who has only a few expressions, for example gestures and body language, can nevertherless communicate on a great number of topics. Knowledge of the individual and context lead to a better understanding of each expression. The context decides. A gesture with an arm can in one situation mean "Come here and give me a hand" while in another situation the same gesture can mean "Look over there" and in the third instance "How are you?". It can also be an answer to a question. It is not necessary to have many various expressions/forms to communicate. The most important is that persons in the environment can imagine that the expressions have different meanings, aims and intentions.

These kind of questions, put the individual communicative expression in a relative context. The meaning of the situation is decisive and it is mainly a question of interpretation. This is significant in all kinds of human communication and interaction, not only concerning persons with mental retardation. As a rule, the contextual understanding depends on how successful a conversation is. Normally we interact with humming, winks and head movements and a twitch of the shoulders from the counterpart indicates a certain impatience and a non-desire to listen any longer. This puts special pressure on persons working with disabled people, particularly as these small hints are decisive of an expression's apprehension and often occur in a non-conventionalized manner. A turn of the head could be an expression with a particular meaning, just as well as a head movement!

Most of the project participants used sounds, speech and gestures in order to get contact and to answer to other peoples initiatives to conversation. Most of them were able to choose between two alternatives offered, but



only a few participants asked for a certain activity or for an object. From table 19 appears a compilation of the results.

Table 19. Interaction roles and use/aims (N= 24)

Function assessed	yes	no
Communication/function		
Takes initiative to interaction	22	2
Responds to others initiatives to interact	24	0
Maintains interaction with others	16	8
Finishes interaction	14	10
Communicative use/aims		
Has method to accept/reject objects/activities	24	0
Can chose between two or more objects	24	0
Asks for objects/activities	21	0 3 0 2 6
Greets/Says goodbye	24	0
Draws attention to objects and subjects	22	2
Changes focus between subjects and objects	18	6
To understand and to be understood/To ask and inform		
Expresses feelings	23	l
Gives information to conversation partner	22	2
Asks for information	18	1 2 6 2
Comments spontanous events	22	2
Tries to explain if he/she is not understood	14	. 10
Asks for explanations if he/she does not understand	9	15

From table 19 appears that most project participants take initiatives to interaction and respond to interaction. Most participants can maintain an interaction, but find it difficult to finish a conversation in a commonly accepted way. The ways used to take initiatives, respond, maintain and finish interaction vary and partly depend on motor ability, cognitive and communicative ability. All participants have established ways to accept and say no to offers of objects and activities. The ways to express themselves vary, but the staff indicate that they mostly understand and can interpret the participants' communication.

Most of the project participants use some kind of alternative communication, i.e. signs, Pictograms, Bliss or pictures. Most of them have used the same communication mode for more than three years, but use a limited number of "words", e.g ten to twenty pictures/symbols or signs. Two persons use fifty to hundred symbols.



Goal attainment scales

The aim of the assessment was to form the basis for the continual work when using the videotelephones. From the participants' needs, individual goal descriptions and conrete goals were set. They consisted e.g. of clearly quantitative standards as to make a certain amount of calls during one week, or to be more qualitatively directed. One goal could be to get more involved in the subject or object, that the conversation partner talked about. Sometimes a person had the tendency to communicate frequently, but did not care about what the counterpart had to say. The more qualitative measures could also involve the content of the conversation, choice of picture symbols and thereby topics, turn-taking and ability to initiate etc.

Goal descriptions for each participant were made. A more general description pointed at the strong and weak points in the individual's communication ability, according to assessments made. An examble could be that NN should develop more expressions to easier be understood when talking. The goal did primarily concern form and content of the communication. Another goal emanated more from the use of communication and was aimed at giving NN possibilities to use existing communication. NN needs to have an opportunity to get more friends and develop the social network.

The general descriptions were sent to the staff at the day centres for their comments and modifications. Generally, the goals were accepted with a few alterations. After that more detailed goals were prepared for each participant and these were sent to the staff for acceptance. Each goal was set in concrete terms and concerned a certain period of time. At the same time it was described how the staff methodically should go about to work towards reaching the goal. The goals and methods for two persons Tore and Greta will constitute examples of the work.

Example 1. Tore:

The goals are generally concerned with widening existing expressions, to tempt Tore to continue to communicate despite his problems and to succeed in making himself understood.

Goals

Tore should by time;

* Be able to communicate with more than one participant in the project and to adjust his topics and use of conversation (i.e. to tell things, to comment what the partner says, to ask questions and to answer) to the person he talks to.



- * Through support be able to see his possibilities and resources to pass over a conversation.
- * Not give up conversation when problems occur.
- * Be able to talk about new subjects by changing the overlays on the concept keyboard
- * Use other means of expression.
- * Another goal is to make him start to ask questions to the counterpart.

Method.

- * Adjust picture overlay and make new ones according to needs.
- * Prepare for a call by talking about what he would like to say.
- * Plan what overlay can be used, depending on conversation partner and subject.
- * Give support to begin with desired, but in time more of a psychologial support and emphasize his strong points and possibilities to bring in new topics.
- * Change overlay and make use of all his abilitites of expression.
- * Encourage Tore to raise questions.

Example 2. Greta:

Goal 1.

- * The first goal is to increase Greta's initiatives to conversation
- * To make her initiate more calls.

Method.

- * Encourage Greta to call by asking questions (whom would she like to call, what would she like to tell).
- * Look at the picture overlay and talk about what pictures she could use in order to tell about a certain issue.
- * Over time decrease the direct support and wait for Greta's own initiatives. (If it takes time, push her by asking questions and by urging her).
- * Adjust the support according to the situation.

Goal 2.

* Adjust Greta's topics to the content of the call.

Method.

- * Encourage Greta to look at what the counterpart says/what pictures are transmitted.
- * Be sure that she understands the picture and the context.



* Encourage her to answer with a relevant picture from her own overlay

Give Greta support in order to develop the call to give her new

dimensions.

* Change the picture display if necessary during the call.

* Point out to Greta that she is able to communicate with pictures from another overlay (Perhaps she will eventually take initiatives to change the overlays by herself).

The goals were considered and approved by the staff at the day centres. The intention was then that the staff should work with support for the participants according to the described goals and methods before and at each telephone session. The process was based on regular and continuous evaluations of the goals, methods and modifications if necessary. The staff should, according to the agreement, work in accordance with the goals during a limited time period varying for each participant, from two to three weeks. After that the goal attainments were evaluated and if required new goals were set up. If the goal were not attained, the work was analyzed to find out if the previous goal was too high or if the negative result had another reason. The goal for the continuous work was afterwards re-formulated according to the analysis.

The realization of the work depended on several factors, i.e. different prerequisits of the relevant day centres, problems with the technical equipment, e.g. interruptions or disturbances. Other factors influencing the work were the participant's engagement and presence, and individual factors due to disabilities and present life situation. As time went on it was clear that some of the participants had not been able to make many calls during the goal attainment period for various reasons, and the goals had to be adjusted or reformulated. One of the participants had been ill during most of the autumn and could therefore only take part on a small scale. The data for this particular person was limited as well as for some other participants.



Table 20. Form, content and use of communication (based on the communicative assessment) (N=24)

Communicative disorder	Number of participants	
Form	2	
Form and content	1	
Form and use	6	
Form, content and use	2	
Content	0	
Use	12	
Use and content	1	
	24	

Table 20 illustrates disorders in the communicative form, communicative content and communicative use. The most common communication disorder concerns the use (12). A disorder in form is often combined with a disorder in use (6) or in some cases with both content and use (2). No one has a disorder in the content only.

The goals with regard to the communicative use, could be to stimulate the communication ability in order to be better understood, but also to develop the communication ability to more clearly express himself/herself. The basis for the goal setting was to start from the existing mode of communication.

Another goal could be to promote the individual to take initiatives, to promote the participants not to give up so easily or to find ways to decrease a non-acceptable behaviour in communication, e.g. destructive or violent behaviour. Some persons need an augmentative or alternative communication and this could also be listed as a goal. One important goal was to extend the social network, as many of the participants had very few friends to communicate with (see table 18).

7.4 Goal attainment

The results from he goal attainment scales appear from table 20. The results are based on 22 participants as two of the men left the project. One was a 48 year old man who never really was interested in participating. He was confused when using the videotelephone and sometimes destructive. It is reasonable to believe that the degree of his mental retardation made it difficult for him to benefit from the use and the staff gave information about the problems at an early stage.



The other man who declined was a 35 year old man who probably due to the technical problems at the start got bored and found it frustrating to plan and prepare a telephone call when there was no result. At the start of the project there were many problems with the technical equipment and this man found it too difficult and felt frustrated. He normally wants control of the course of events and in this respect he could not influence the situation. It is reasonable to believe that he felt unsafe and unsufficient for this job, when the technology did not work. This man was a man with many talents and for his development it would probably have meant a lot to participate in the project. The staff asked him to continue, but he did not want to, and we had to accept his refusal.

Table 21. Compilation of results from the goal attainment scales for all participants (N = 22, a decline of 2 persons)

Ifilment of goals	Number
2 Optimal in this context	2
Better than expected	8
As expected	8
Worse than expected	3
Worse than expected As inferior as possible in this context	1

Table 21 illustrates that eight participants had managed to attain the goals as expected, eight had managed better than expected and two participants had managed optimal in this context. One person had managed inferior as possible and three worse than expected. The context is of great significance and necessary to consider when assessing the communicative ability. The results of the fulfilment of the goals were mainly positive as 18 of the 22 participants had succeeded as expected (8) or better than expected (10). The improvement over time appeared in several respects, e.g. with regard to operational aspects and from the points of view of content. The reasons why the four participants did not manage to fulfil the goals were that they had a low participation in the telephone sessions and that their experiences of using the videotelephones thus were limited.

The carrying through of the project was made in collaborative work with the day centre staff and they have contributed with viewpoints of working methods, goals, goal attainment scales and completion of the study. They have been positive to the methods used and experienced that the working method has been useful in their daily work, not only with regard to communication, but also with regard to related areas. This can be considered a side-effect which means a transfer of the training effects and a possibility to generalize the participants' abilities to other situations.



7.5 Telephone protocols

A specific protocol was designed to be filled in by the staff assisting the participants at each telephone call (Appendix 5). The protocol included information on date, day centre, name of the participant, communication partner and signature of the staff who completed the form. The protocol also included approximate length of the calls, initiators, modes of communication and what kind of pictures were sent.

A total of 434 registered calls were made during a one year period (1994). This means that several calls were not registered as some of the pariticipants at the end of the project made calls independently, without the staff. About 25 protocols arrived too late for being included in the study. Table 22 illustrates the length of the calls in minutes. For each participant the shortest, longest and average time is indicated. Each day centre is coded with a number (1-6), and so are the participants (11-64) to facilitate the analysis. Participant number 1 from day centre 1 is thus coded 11. Italics is used in the table to indicate the females.

Table. 22. Length of calls (N=24)

	Day	Number of	Tim	e of calls in mi	nutes
Participant	centre	calls	Shortest	Longest	Average
Stockholm					
11	1	11	5	30	14.1
12	1	18	2	20	7.3
13	1	8	5	20	12.1
14	1	6	5	15	12.0
21	2	30	4	20	12.2
22	2	13	3	20	8.2
23	2	22	2	17	7.7
24	2	8	5 2 5 5 4 3 2 5 2	13	8.1
<i>31</i>	3	43	2	12	6.5
32	3	15	1	15	7.1
33	2 2 2 3 3 3	8	ī	30	16.4
34	3	18	1	15	7.0
Jönköping			-		7.0
41	4	12	10	20	14.3
42	4	44	2 6	25	12.4
43	4	26	6	15	11.9
44	4	31		13	12.9
51	5	21	3	15	10.7
52	5 5 5 5	17	7 3 2 8 15	25	13.4
53	5	14	8	15	12.5
54	5	2	15	20	17.5
51	6	16	4	20	12.9
52	6	22	5	30	18.1
5 <i>3</i>	6	12	10	20	15.5
54	6	13	5	20	11.5



A total of 434 calls are registered. In table 22, 200 calls from Stockholm and 230 from Jönköping are registered. Four calls are missing in this table as the information required was not filled in on the protocols. In a couple of cases this is due to the fact that temporary employed staff did not regard this information as important. The length of the calls varied between one and thirty minutes. The shortest calls varied between one and fifteen minutes with an average of 4.7 minutes. The longest calls varied between twelve and thirty minutes with an average of 19.4 minutes. An average telephone call was approximately 12 minutes.

From table 23 appears the initiator of the calls. Each group of participants (Stockholm and Jönköping) made the videotelephone calls within their own geographical area. This means that there were twelve participants in each group and that each individual could contact eleven others with mental retardation. Besides, they could contact the staff at the day centres. The intention was from the start of the project to widen the videotelephone contacts "across the borders", i.e. to have regular contacts between Stockholm and Jönköping. The decision to keep the calls within the area depended on the difficulties with the technical equipment, e.g. interruptions of calls and disturbances on the ISDN-telenet.

Table 23. Initiator of the calls (N=24)

	Initiated		Initiated	
Participant	number of calls	Participant	number of calls	
11	4	41	10	
12	17	42	41	
13	2	43	20	
14	2 3	44	28	
Staff	20	Staff	1	
21	31	51	8	
22	10	52	6	
23	19	53	9	
24	7	54	4	
Staff	17	Staff	28	
31	40	61	12	
32	10	62	21	
33	5	63	14	
34	17	64	10	
Staff	4	Staff	9	
No informa	<u>tion 7</u>			
	213		221	
Total numb	per of registered calls	434		



From table 23 appears that the staff were the main initiators to the telephone calls at day centre 1 (20 occasions) and 5 (28 occasions). At the other day centres one or two of the participants were the main initiators. However, this question has probably been difficult to answer as many of the participants do things together with the staff - in collaborative work. In general, the female participants seem to be more active in intitiating the videotelephone calls, with a few exceptions. There is a considerable range of variation in taking initiatives between the participants. At day centre number one for example, the participant coded as number 13, seems to be passive in initiating, but this person was a very popular communication partner who received many calls from of the others (34 calls). One woman (No. 12) received 43 calls, which was the highest number of calls in Stockholm. Also in Jönköping a woman received most calls (22). The variation between the received calls are less in Jönköping than in Stockholm.

Table 24. Parts of the equipment used besides the videotelephones

Equipment	Number of occasions		
Concept keyboard	364		
Document camera	132		
Personal caller	50		
Printer	343		

Table 24 reveals that The concept keyboards were used at 364 occasions, which means that they used the document camera or the videotelephone only at the other occasions. The personal callers were used in only 50 cases which is partly due to the fact that telephoning was on the schedule and the callers were not necessary. The printers were used on 343 of the 434 registered calls, but as printing out is an automatic function, the low figure may be that the printer was not on.

Table 25. Mode of communication used by the participants (N=24)

Mode used	Number of occasions	
Speech	311	
Pictures/photos	46	
Pictogram	406	
Body language	252	
Body language Real objects	35	
Signs	24	



As appear from table 25, Pictogram is used on most occasions. Speech is on the second place and body language on the third. Most of the participants use more than one mode to communicate at the same time.

Table 26. Quality of image

Table	27.	Quality	of	sound
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Image		Sound		
Very good	113	Very good	119	
Good	212	Good	184	
Satisfactory	67	Satisfactory	71	
Bad	22	Bad	35	
Very bad	7	Very bad	14	
Information missing	13	Information missing	11	
Total number of calls	434	Total number of calls	434	

From table 26 appears that the quality of image was very good or good in 325 of the registered videotelephone calls and satisfactory in 67. The image was bad or very bad in 29 cases. From table 27 appears that the quality of sound was very good or good in 303 of the registered videotelephone calls and satisfactory in 71 cases. The sound was bad or very bad in 49 cases.

According to the videotelephone protocols the participants recognized the communication partner on the screen in 347 cases. In 12 cases the participant did not recognize the partner, and in 42 cases the staff answered that they did not know. In 33 cases no information was received.

Table 28. Participants attitudes to use the videotelephone (N=24)

Attitude	Number	
Fun/interesting	377	
Active	286	
Seems afraid/anxious	2	
Finds if difficult	38	
Shows no interest/looks bored	24	
Looks angry/upset	4	
Experiences frustration/situation too demanding	4	
Takes initiatives within the interaction	131	
Other reactions	19	



From table 28 appears that most of participants experienced the videotelephone calls fun and interesting (377 occasions). They were active (286 occasions) and some of them also took initiatives within the interaction (131 occasions). As a whole there seems to be a positive attitude to the use. On few occasions the staff reported that the participants found it frustrating (4 occasions), were upset (4 occasions) and seemed afraid/anxious (2 occasions). On 38 occasions the staff reported that the participants found it difficult or were not interested (24 occasions). Other reactions could be that the participants did not want to talk - just wave to the partner, were ambivalence or confused. Most comments on this section was about positive reactions such as "very much fun", "positive after support", "takes initiatives by herself for the first time ever".

Table 29. Pictures transferred via the telephone network

Pictures	Number used	
Food/to eat and drink	238	
Activities/to do things	377	
Events/episodes/to happen	186	
Feelings	73	
Needs	12	

Table 29 shows how often the participant use pictures to symbolize food, activities, events, feelings and needs in their videotelephone calls. The results show that the most popular topic is to talk about activities, i.e. what they have done, what they are doing at present and what they are going to do in the near future. The second most popular topic is about food and what they like to eat and drink. The participants seem to talk very little about their own needs (12 occasions) and about their feelings (73 occasions).

Besides the telephone protocols, the project team was informed by the staff of the participating day centres, that there were many problems regarding the technical equipment. The videotelephone calls were interrupted or there were extensive disturbances on the lines. On some telephone sessions there was only an image, on anothers there was only sound. The staff at the day centres were worried about the participants as it was difficult to explain for them what really happened. Some of the participants were frustrated and this was especially evident with regard to day centre number 6 in the Jönköping area. The technicians searched for the error and finally they found that something was not functioning with the ISDN-network in that area. The telecompany responsible for the network could not give an acceptable explanation of the disturbances. The



ISDN-network was first introduced in Sweden in the middle of 1993, and at the time for the project start the network was quite new and evidently suffered from "teething troubles".

7.6 Social meetings with the participants

Some of the participants have met at "county dances" which is usually arranged once a month by the county councils or the handicap organization for persons with mental retardation. Two separate meetings were arranged at the project start; one in Stockholm and one in Jönköping. The project leader and one of the speech therapists were present at those meetings. The participants were excited and curious about what would happen at the meeting. They travelled quite a long distance in order to participate. Coffee and cakes were served at the meetings and the participants experienced the meetings as pleasant social parties.

Each meeting started with a short description of the project by the project leader followed by a very short presentation of the staff including name, day centre and function/duty. After that the main activity began, i.e. to give the project participants space and let them introduce themselves to one another. It was exciting for the staff and the project team to notice how to cope with this new situation and how to keep the participants engaged and concentrated during the presentations. The project leader turned to one participant at a time and asked questions about his/her daily worksituation, what duties he/she had and what he/she liked best out of those duties. After that questions about leasure time and interests/hobbies were raised. At the interview, each person was allowed as much time as was neccesary. When the questions were put and the project leader was satisfied with the answers, the speech therapist summerized the outcome of the interview. The project leader then asked the participant to confirm that we (staff and project team) had understood everyting correctly and then asked the participant if he/she had anyting to add. The interaction that took place was made directly between project leadership and the participants. In some cases, when the imagination was not sufficient in order to understand what the participant wanted to say, the staff helped to interpret, but the team tried us much as possible to sort out the situation without support of the staff. The disadvantage was that the team was only able to communicate with a few simple words in sign communication.

On a couple of occasions, the participants took initiative to add something they had forgotten to mention at their presentation. One of the men added that in the summer he used to spend time with his parents at the sea side and he very much liked to go for boat trips. Another man added on his own initiative that he used to help his parents to cultivate the vegetables at their farm house. These were important issues and showed that the



participants took their tasks seriously. The participants listened to each other with great interest and sometimes a little laughter burst out when they recognized something they also liked. The team summarized topics that several of the participants had in common. This made them understand that there were others within the group with the same interests as they had.

When the participants parted after having spent nearly three hours of concentrated social togetherness, they hade contributed with valuable information for the project leadership, other participants and staff at the day centres. Principally, they had had the opportunity to "show themseves" and be important persons. In some respects the staff were also able to get a different viewpoint of the participants. Group photographs of all the participants and staff from each day centre were taken on both occasions. This was done in order to facilitate recognition of the other participants. These photographs were enlarged and sent to all six day centres with a suggestion to put them up close to the videotelephones.

These gatherings took place in the same way at both sites. At the Stockholm group it was evident that the interest for dancing and music were common for most of the participants and it was therefore decided that a party with dancing should be arranged. One of the day centres arranged a party where the project leader and one of the speech therapist were present. The 12 participants had the opportunity to get to know each other a little better about two weeks before the videotelephoning started.

At the county council of Jönköping there was a techical problem, which delayed the project. As a result of this yet another gathering was arranged for the participants, as the participants could not possibly remember the other participants.

Informal social meetings with dancing were after the project start arranged two or three times a year in 1994 and 1995. At the parties in Stockholm the project team participated and observed the relationsships between the participants. Some of the participants have made friends as a result of the videotelephoning. These parties also gave a complementary view of the participants and contrubuted to a better knowledge of the staff.

7.7 A case study - An example

The data collected of each of the 24 participants make a view of what has been achieved for each individual. The material give good opportunities to be processed and analyzed on an individual level as well as on a group level. The personal description below gives a view on what kind of



information have been collected of each participant and how data can be compiled from the different techniques used.

7.7.1 A personal description of EVA

The personal description of Eva formed the baseline, and was based on information collected by a questionnaire completed in collaboration between Eva's mother, the staff at the group home, the staff at the day center and facts from the medical journals, after permission of Eva's mother.

Eva is 34 years old. She has grown up at an huge institution outside Stockholm. She used to live in a house with 18 other mentally retarded persons, but they were only five in her group. At present she lives in a group home together with three other persons with mental retardation. She has attended the training school (a special school for persons with severe mental retardation) for twelve years and left school in 1980. Every morning she goes by taxi to the day centre where the working day starts with planning och talking about the daily activities. She participate in several groups e.g. a communication group (to train her communication ability), a music group (to listen to music), a nature group (going out for walks in the forests).

In the group home she helps to cook, to lay the table and to wash clothes. She often spends the evenings watching TV. Eva's leisure interests are dancing, listening to music, going to the cinema, watching video, shopping, fashion clothes and taking walks.

Eva's social network. Eva has every week contact with her mother and brother. Her father is dead. She has also contact with her grandmother once a month and with a cousin and an aunt a couple of times a year. She spends her vacation and leisure time mainly together with staff from the day center and the group home. She has few personal friends. From the background description appears that Eva has a socially well adapted behaviour and she is interested in interacting with her peers at the day centre and in the group home. She has a positive attitude and is interested in other persons in the environment. Her network is as appears from the data collection very limited.

Eva's functional impairments. Eva has a moderate mental retardation. She is visually impaired, motor disabled, has epilepsy and speech and communication disorders. Eva has difficulties with her fine and gross motor skills and she has difficulties in coordinating eye-hand and her movements are unexact. She has no spoken language primarily due to the fact that she has partly a paralysis in the muscles in the pharynx.



Picture/Communication/Speech. Eva recognizes objects and persons on photos and pictures, e.g. Pictogram symbols. In the beginning of the 1980's a speech therapist introduced Bliss symbols to Eva, but the level of abstraction was too high and she failed to use it in a functional way. Today she uses Pictogram symbols in her daily communication and the staff use these symbols to mark the environment. Eva communicates with sign communication and symbols. She has used Pictogram symbols for about nine years and uses about 200 symbols actively. About 50% of her total communication consists of symbols. Eva often initiates and responds to communication. At the project start she used the telephone very occasionally as she could not express herself in a functional way.

7.7.2 EVA - One of the participants in TeleCommunity

At the very start of the project all participants from the three Stockholm day centres met at an introduction meeting together with the staff from the group homes, the day centres and the project team. The project leader informed about the project and how the work was planned to be effected. This was followed by a short presentation of the staff with name, day centre and profession i.e. function and duty. Parents and personal assistants were invited, but few turned up. At the meeting the participants introduced themselves, sometimes with assistance of an interpreter, as many persons did not speak, but used sign communication or symbols. Every participant told his/her story and had as much time as he/she needed.

Eva wore a pink dress which she had chosen for this special event and a beautiful necklace. Eva is very fond of beautiful clothes in intensive colours and she is aware of the impression this makes on persons in the environment. She sends a clear signal "Here I am. Look at me!". At the meeting she looked happy, smiled and laughed. She was according to information from the staff curious on the other participants and she really enjoyed the occasion to talk about herself. Eva told us about her daily activities at the day center and what she was fond of doing. She had no spoken language, but used Pictogram symbols most of the time. When she was too excited she used her whole body to express herself. She said that she was interested in baking cakes, working with the day centre newsletter, making postcards, telefaxing Pictogram messages, making the weekly activity schedule at the day center and to have coffee breakes. At leisure time her interests were nice clothes, singing, music, parties and dancing.

The first meeting went on for three hours and the reactions of the staff were that they were surprised that the participants could concentrate for



such a long time and sit, wait and listen when their peers were talking. One reason for this was probably that the participants had the floor all the time. Nobody talked for them or over their heads and nobody interrupted them. They had all the time they needed. Eva seemed to be satisfied and she was very active during the whole meeting.

The participants met for a light meal, listened to music and danced. Eva is very fond of dancing and danced all evening. She preferred to dance with one of the women from one of the other day centers, a woman she had got to know through the videotelephone project. They call each other quite often and chat about daily activities, about clothes and about whatever interests them at the moment. They are about the same age and the woman she is talking to is Mary, who is also living in a group home. Mary often talks about her mother who she is longing for, but not see as often as she wants. Eva talks about her mother when she has met her over the weekends. The two women often laugh together. When they meet in reality. Eva shows happiness by jumping with both feet together and shouts. Mary is a bit shy when they meet face-to-face, but not when they talk on the videotelephone. This illuminates an important aspect of distance communication, i.e. they feel close when they chat on the videotelephone, but still experience the distance when they meet. Once when these two women talked on the videotelephone, Eva did not get Mary's attention. She then knocked at the monitor in order to get attention. Another time Mary stroke Eva's cheek on the screen, as she was very happy to see her again. This supports the assumption that distance communication cannot substitute face-to-face communication, but could constitute a complement.

Interveiws were conducted with Eva, her mother, the staff at the day center and group home. The interviews covered the same areas that had been discussed in the questionnaire, i.e. about leisure interests, communication etc. The interview with Eva showed that it was difficult to complete an interview with her, as she was most interested in the tape recorder and the computer and chose to talk about that instead of answering the questions. Eva has difficulties to receive, process and store information and she has a concrete concept of reality. In order to make it possible to influence her life and to be able to participate in society on the same conditions as other citizens it is important to ask about her points of view. This is often a neglected aspect as most studies concerning persons with mental retardation deals with aspects from parents/relatives and staff.

Assessment of Eva's communicative ability was done with a specially designed tool. The assessment was effected by a speech therapist and showed that Eva takes many contacts to interact and to converse by using signs, sound and gestures. She responds clearly to invitations of



interactions made by other people. If the communication partner lose his/her interest, she literally takes hold of the person's head. She manages to draw other peoples' attention to herself and she is by the staff regarded to be a socially aware and receiptively talented person. She shows what she wants and she also shows when she does not want to do something. When Eva is occupied with something she is concentrated and reluctantly looks up from what she is doing. Her expressions of emotions are distinct and strong, but she seldom shows that she is sad. By pointing at objects and making noices she comments waht is going on around her. Most of the time she is eager to make herself understood, but if it takes too long a time she may well give up.

The overall goal setting for Eva refers to communicative form and communicative content. The goal was primarily to use and develop her strong sides and to extend her social network. The goals were set in collaboration between Eva's mother, the staff at the day centre and the staff at the group home. When eveybody in Eva's immediate environment had agreed to the goals and a special training program "how to reach the goal" was developed by the speech therapist, the training started. Direct hints of how to stimulate Eva in certain situations were given. In order to find out if the intervention was relevant, goal attainment scales were elaborated and after about one/two months work the results were evaluated. Sometimes minor adjustments had to be done and sometimes new goals had to be set.

At each videotelephone call a special protocol was completed. From this appears whom Eva has been talking to and how often. It also shows what they have talked about. It is evident that Eva has been a very popular communication partner. Many of the other participants have called her and this is probably due to the fact that she has a very positive attitude and that she is interested in interacting with the others. She has talked a lot about activities, what she has done, what she is doing and what she will do in the future. She also talks about what she is doing in the group home and mainly this is about taking care of and running the home, in other words typical household activities.

7.7.3 Results of the case study

The study reveals that Eva has reached the goals set by the persons in her immediate environment. She has got new friends and has extended her social network. She has not only got new friends at work time, but also at her leisure time. When she attends the local dances she meets the videotelephony peers and they form a group with a special relation. The participation has also resulted in a general and deeper interest in communication. She does not give up as easily as she used to do and she



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has increased the number of Pictogram symbols for active use. Videotelephony gives good support in communication and Eva has managed to establish new social relations.

At the project start she used the ordinary telephone occasionally, but the vidoetelephone has changed her attitude and she is today more interested in using the telephone, as she knows that she can make herself understood and that she can also understand what the partner is saying. She also makes videotelephone calls by herself and sometimes she calls some of the other participants without knowledge of the staff. The frequency of use has also increased and she sometimes tells the staff that she wants to make a videotelephone call and also who she wants to talk to. Eva has also been stimulated to communicate more.

The videotelephony equipment with the concept keyboard for symbol communication has facilitated and improved her communication. She has been able to use total communication i.e. sign communication, symbols, sound and body language at the same time and this has been a good support. One purpose of the Swedish ACE was to make it possible to use telephones for persons with mental retardation and the ACE equipment made it possible to have access to 'ordinary' telecommunications facilities.

In the future, Eva will continue to keep in touch with her new friends via the videotelephone. The equipment will be kept permanently at the day centre and this makes it possible for her to develop and deepen her relations with some of the other participants. Also other persons with mental retardation will be able to use the equipment in the future and this makes it possible to extend the social network even more.

7.8 Evaluation of the technical equipment

The videotelephones were continuously evaluated. The first evaluation of the technology took place in 1993 and is described in chapter 4.5 "A minitrial on videotelephony aimed at testing methodological and technical issues". The technical problems highlighted in the minitrial were primarily concerning sound and image (Brodin, Nilsson & Fahlén, 1993). These problems were as far as possible attended to in the main study.

The modified and adapted videotelephones were delivered in December 1993, but due to technical problems the technicians of the project had to withdraw the videotelephones for further controlwith his parents. This was really the situation we had tried to avoid. Before delivery of the videotelephones the minitrial had been effected to search for eventual errors, the staff had been educated, the participants had met, the equipment had been tested in a laboratory and everything was well



prepared for making a good project starting point. The data collection for the main study did not start until March 21st, 1994, in Stockholm and April 25th, 1994, in Jönköping, when the technical equipment was regarded as solid. The start of the main study was seven months late in Stockholm and eight months late in Jönköping. Furthermore, there was another break down with the equipment in day centre no 6 in the Jönköping area before the definite start. The problems were the software. The producer of the codecs (which were imported) did not inform the Swedish technicians about the changes in software and that caused the problems. The videotelephones were delivered again in February 1994 and the staff started to prepare the Swedish ACE (Advanced Communications Experiment). The participants with mental retardation were to avoid frustration not allowed to use the equipment until March/April as mentioned above.

In February 1994, before the main study started, telephone interviews with a representative of each day centre were effected by a member of the project team. Three questions were raised;

1) How does the equipment function?

2) Have you made the overlays for the concept keyboards for the participants?

3) Can the day centre staff involved run the equipment?

The results from the brief survey showed that at four of the six day centres the videotelephones did not work satisfactorily. There were recurrent disturbances and interruptions on the lines.

All six day centres had made overlay sheets for all participants both for dialling and communication.

All staff at five of the six day centres knew how to operate the equipment well. Later on the reason for this was discovered. The error was to be referred to the ISDN-telenetwork and the technicians were not informed by the telecompany involved. Day centre No 6, was the one with most problems, and they had not been able to learn how to operate and use the equipment as they had still technological problems. This day centre also complained about the difficulties to keep the participants and the staff motivated to continue. Also from the telephone protocols appeared that more or less all sites had technical problems, but the day centres in Jönköping, had extensive technical problems with interruptions and disturbances on the videotelephones. The staff experienced this as very frustrating for the participants who often were well prepared to make a call and then could not be connected. There was a frustration and disappointment.



A final evaluation was made in October (Period I) and November (Period II) 1994, before the project was finished, as many of the staff members from Stockholm and Jönköping complained about the technical disorders. The questionnaires were sent out to the day centres with one weeks in between (Brodin & Alemdar, 1994) and according to plan ten telephone calls were to be completed from each centre each week. Of 120 possible calls 117 were completed. The results appear from table 30.

Table 30. Use of equipment - Period I and II. (N= 117)

Day centre number	Concept- keyboard	Document camera	Personal caller	Printer
lo. 1	16	16	11	16
No. 2	18	18	8	18
No. 3	21	21	16	21
No. 4	17	18	5	10
No. 5	19	12	1	17
No. 6	20	19	15	16
Fotal	111	104	56	98

As appears from table 30 the concept keyboard was used on 111 occasions, the document camera on 104 occasions, the personal caller on 56 occasions and the printer on 98 occasions. During six calls only the videotelephones were used, i.e. not the concept keyboard or the document camera. On one occasion the printer did not work. Day centre No. 2 reported that the symbol for pause only appeared on six of ten occasions.

Table 31. Quality of image during the telephone calls - Period I and II (N=117).

	y of images durin Very good	Good	Satisfactory-	Bad	Very bad
No. 1	5	5	3	2	0
No. 2	0	16	2	0	1
No. 3	18	1	0	0	0
No. 4	1	18	0	0	1
No. 5	2	16	1	0	1
No. 6	5	10	2	2	0
Total	31	59	6	4	4

The quality of image was good during 90 calls, satisfactory during six, bad or very bad during eight calls.



Table 32. Quality of sound during the telephone calls - Period I and II. (N=117)

	Very good	Good	Satisfactory-	Bad	Very bad
No. 1	2	8	3	1	0
No. 2	0	16	4	0	0
No. 3	19	1	0	0	0
No. 4	2	18	0	0	0
No. 5	5	8	1	5	1
No. 6	2	15	1	1	0
Fotal	30	66	9	7	1

The quality of sound was good or very good on 96 occasions, satisfactory on nine and bad or very bad on eight occasions.

Table 33. Conduction of the calls - Period I and II (N=117)

	Stockholm group	Jönköping group	Total
The call was completed	42	54	96
The call was interrupted	3	4	7
The sound disappeared	21	2	23
The image disappeared	1	4	5

The call was fully conducted on 96 occasions and was interrupted on seven occasions. During 23 calls the sound disappeard and during five the image disappeared. On some other occasions the image disappeared or was fluctuating, but this was only indicated as marginal notes.

Table 34. Image and Picture - Period I and II (N=117)

	Stockholms- group	Jönköpings- group	Total
Sound			-
Without disturbances	4	35	3 9
Satisfactory	32	12	44
With minor disturbances	19	7	26
With considerable disturbances	()	2	2
Image		•	
Without disturbances	24	38	62
Satisfactory	24	9	33
With minor disturbances	5	5	10
With considerable disturbances	<u> </u>	7	8



In some cases the quality of the picture changed during the call and it has been difficult for the staff to know how to answer the questions. The sound was without disturbances in 39 cases, satisfactory in 44 cases, with minor disturbances in 26 cases and with considerable disturbances in two cases. The image was without disturbances in 62 cases, satisfactory in 33 cases, with minor disturbances in ten cases and with considerable disturbances in eight cases.

The results from these two test periods showed that at the end of 1994 there were still problems with the technical equipment. In three cases the informants have not been able to judge the calls in accordance with the ratings and therefore rejected. They indicated that the picture quality varied during the call. On a few occasions they were not able to complete the protocols. Day centre No. 3 seem to have had the best quaility of image and sound. The conclusions from these test weeks were that quailty of sound and image must be improved in the future. When the staff at the day centres received the written report from the evaluation, they did not recognize the situation. They stated that the test periods were not representative for the "normal" situation, as they normally experienced much more problems in the videotelephoning. The staff might not have conveyed their problems strongly enough to the project team and the telephone protocols did not reveal the difficulties. There is always a risk that participants in this kind of projects do not want to be too negative as they are pleased to participate in various project activities. It is reasonable to believe, that the project team should feel responsible for not having seriously enough regarded this aspect.

7.9 A summary of the evaluation focus of the Swedish ACE

As TeleCommunity was a European project within RACE 2033, there were some mutual aspects to be evaluated. The nine countries involved in TeleCommunity had minor differences in focus, but all except Sweden intended to offer a service to persons with disabilities or elderly people. In order to facilitate the description of the Swedish project, the term service is used although it is not a service as such. The purpose of the Swedish ACE was to support communication and to increase the social integration as part of ordinary social legislation and accessability in society. The variables related to the mutual evaluation appear from below.



7.9.1 Quality of Service

Service Organisation

Organisational Structure

The responsibility for day centres for adults with mental retardation is at present transferred from the county councils to the local authorities.

Six day centres, three in the Stockholm area and three in the Jönköping area were involved in the Swedish ACE. Four adults with moderate mental retardation participated in TeleCommunity.

Organisational Functions

Most individuals with mental retardation in Sweden attend a day centre or a sheltered workshop. According to Swedish law a daily activity is a legal right for this population. Different actitivities are carried out at the day centres, e.g. ADL-training (such as cooking, cleaning, washing), communication training, music groups, subcontract-work etc.

Organisation of Service Delivery

The service was delivered in the framework of ordinary daily activities, which means that it was included in the daily work and not offered as a separate activity. The purpose was to support and facilitate communication by using videotelephones and to increase independence and social integration.

Training, Selection, Recruitment

Before the project started the staff were trained in using the equipment and educated in communication in general and in telecommunication in special. The six day centres included in the project were selected in two different counties and all day centres in these areas were asked if they were interested in participating. Only six day centres showed interest and/or could fulfil the criterias of the participants with moderate mental retardation and with a poorly delveloped spoken language.

Service Schedule and Delivery Profile

The service was given at day time when the participants attended the six day centres and had possibilities to communicate with each other. Every day centre had a fixed time schedule when to make calls and most of them had two mornings a week for videotelephoning. Various models for making calls were tested. At the day centres in the Jönköping area the staff made the choices of the communication partners. This means that the staff influenced and made the decisions based on their knowledge of the participants' interests. In the Stockholm area the participants themselves chose their communication partners from the dialling sheet and from photos of all the participants.



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Staffing Profile

The staff involved were the ordinary staff already employed at the day centres and most of them were occupational therapists. They were selected by the heads of the day centres and they had a documented interest in communication and technical aids. They also had a good knowledge of the individuals with intellectual impairments participating in the project.

Delivery Style

The videotelephony equipment was used for person-to-person communication and adapted for the participants with moderate mental retardation. The diaglogues took place between the participants and between participant and staff. A member of the staff was most of the time present in order to support the transfer of messages.

Service Transaction Tasks

The videotelephony support service followed the handicap policy in Sweden, i.e. to make it possible for all citzens to participate in social life and to have equal living conditions to other individuals. The tasks were to support communication and extend the social network. Communication was based on interpersonal communication and the videotelephone helped clarify the interpretation of communication due to transfer of live images. All participants needed a lot of support and the flow in communication depended on the cognitive levels of the participants. The participants were interested in communication and developed their communicative and social abilities. The equipment worked well for communication and the adaptions turned out to be useful. The participants learnt how to operate the equipment and also learnt many n v ways to express themselves. The participants also increased their under anding of the communication partners. The usage of the controls and displays were well functioning and the suitablility of the tasks were good. The attitudes were in general positive by the staff and the participants.

Service Network

The ISDN network was in the middle of 1993 accessible for private users in the whole of Sweden. However, it seemed not to be very solid as many disturbances and interruptions occurred.



7.9.2 Quality of Support

At present few individuals have access to the videotelecommunication support services, but in future the requirements for this kind of service will increase as most inidividuals with mental retardation are today integrated in society and need to get in touch with others in the environment. The needs for support for this population is extensive in everyday life and particularly communication support. The service must be flexible in order to increase the accessibility. The staffs' attitudes are of great importance and especially concerning the understanding of the perceptions of the clients benefits.

7.9.3 Quality of Effect

Personal Impact

The study revealed that many of the participants reached the goals set by the persons in the immidiate environment. Many made new friends and extended their social networks. The participation also resulted in a general and deeper interest in communication. Many of the participants increased the number of symbols for active use. Videotelephony gave good support in communication and made it possible to establish new social relations. The frequency of use of the videotelephones increased and the participants were stimulated to communicate more. The videotelephony equipment with the special concept keyboard with Pictogram symbols facilitated and improved their communication.

Social Impact

The equipment will be kept permanently at the day centres and this makes it possible for the participants to maintain and develop their relations with some of the other participants. Also other persons with mental retardation may use the equipment in the future and this makes it possible to extend the social network even more.

One purpose of the Swedish ACE was to make it possible to use telephones for persons with mental retardation and the Swedish ACE equipment make it possible to have access to telecommunications facilities.



8. DISCUSSION

The overall aims of the Swedish ACE (Advanced Communication Experiment) were to get knowledge of and understanding of the issues whether videotelephones could increase the level of independence and social integration, improve communication and increase the quality of life in terms of communication and participation in social life.

The concrete aims were:

- to support and establish social relations in order to extend the social network
- to stimulate and encourage the participants to communicate more
- to facilitate, support and improve communication/interaction
- to have access to telecommunications in an ordinary way
- to support independent living
- to increase social integration.

Six day centres, three in the Stockholm area and three in the Jönköping area, participated. From each centre four individuals with moderate mental retardation took part. The degree of mental retardation was related to a theory developed by the Swedish researcher Gunnar Kylén (1981). Moderate mental retardation thus means a developmental level of one and a half to seven years and the participants' measures in IQ were between 10 and 45. However, IQ does not form a useful tool to describe the implications of mental retardation and functional measures have therefore shown to be more relevant (e.g. Seibert & Hogan, 1982). This implies that assessment should focus on the present cognitive level. The participants in the project lived in group homes or with parents and attended a day centre at day time. The participants in TeleCommunity had no functional spoken language.

Twelve men and twelve women between 21 and 60 years old participated in the study. The average age was about 36,5 year. About 67% of all persons with mental retardation have additional impairments (e.g. Granlund, 1993). Of the participants in TeleCommunity 100% had additional impairments. The participants had functional impairments such as visual impairment (14), hearing impairment (11), severe motor impairment (10), and speech and communication disorders (24). Of the 14 individuals with visual impairment eleven had been prescribed glasses, but only seven used them. Of the hearing impaired only two used hearing aids, of the motor impaired eight used mobility aids, and of the 24 individuals with speech and communication disorders less than half of the group used technical aids (10). This means that even if technical aids are prescribed, it does not mean that the individual use them. One reason for this might be that the person has not been trained to use the aid in question and therefore finds it uncomfortable, another that the user does



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not realize the benefits of using aids. It normally takes quite a long time to get used to wearing glasses for example and if the individual is not encouraged to do so, he/she will probably not do it spontanesously. With regard to the motor impairment, 15 individuals have fine motor difficulties and 16 gross motor difficulties, but only ten of these have severe motor disabilities according to the background descriptions. One third of the participants had Down's syndrome, but many of the other participants had not been diagnozed or followed-up since childhood.

The purpose of the project was thus to use videotelephones in order to encourage and improve communication, increase the level of independence and enhance the possibilities for persons with mental retardation to participate in social life. The telephone equipment consisted of a videotelephone, a concept keyboard for dialling and graphic symbol communication, a document camera, a personal caller and a laser printer. One reason for using videotelephones was to make telecommunications accessible on the same conditions as for other citizens in society as the majority of persons with mental retardation have difficulties in using ordinary telephones (Brodin, 1994; Brodin & Magnusson, 1993b). Only eight of the 24 participants used the telephone daily at the project start. This does not mean that they talked on the phone, but that they just used the telephone for listening to well known voices e.g. of parents or peers. Eight of the participants never or seldom used an ordinary telephone, despite that all participants were motivated to communicate in face-toface situations. Just to have accessibility to a telephone is not enough for using it. Many persons with mental retardation have learnt to be helpless (Seligman, 1975), which means that they do not take any initiatives of their own. This might be due to the fact that people in their environment have taken too much responsibility for them and done things over their heads or for them.

The study refers to different aspects of communication, social network, accessibility, independence and social integration. The data collection covers many different techniques: questionnaires, interviews, pro ocols, communicative assessment and is based on a collaborative work between parents, staff at group homes and staff at day centres and information from the participants with moderate mental retardation themselves.

The problem when using this kind of method when collecting data, is that you will get too much information. The benefit is that you can compare information from different sources and over time. All information is not useful for drawing conclusions, as for instance interviews with open questions made in a conversational form, often make people talk about things that are not relevant to the research questions. However, as the study went on for almost four years there have been many opportunities to revert to the informants and check the reliability of the information



received. It has also been a great help to get to know the informants for a long period of time as it is then easier to judge how reliable their utterances are. Validity is not a problem in this kind of study as you have opportunities to repeat your questions several times and make sure that the informants have understood the questions (e.g. Kvale, 1989). The informants also have possibilities to ask questions if they want an elucidation. As the interviews were tape-recorded and transcribed word for word, it is also possible to revert to the material and check if something is unclear. The questionnaires for the background descriptions, which formed the baseline for the study, were completed by staff and parents in cooperation, which in reality means that they met at the day centre and decided together how to fill in the form. This does not mean that the informants agreed all the time, but it probably gave a more correct view of the participant and his/her abilities than had otherwise been possible.

The discussions at present about participation and empowerment is interesting in this kind of studies, as individuals with moderate and profound mental retardation have difficulties to speak for themselves. In order to be able to influence your own life you need to have a functional communication, i.e. an adequate communication for everyday life (e.g. Light, 1989). The participants' abilities to communicate varied and six of the participants could not be interviewed. They did not answer any questions and it is not sure that they understood why they really should. Three important factors may influence the outcome: the informant him/herself, the interviewer and the context. The interviews took place at the day centres, a familiar place for the informants. The informants had earlier met the interviewer a couple of times, but they had not formed a real relationship. The basic idea was that one videotelephone should be used by the project team, but due to technical disorders this equipment had to be used as spare parts. If the videotelephone had been used in communication with the participants at the day centres, it had been a solution as it would have helped the informants to recognize the interviewer. From one of the day centres the participants selected by the staff were too severely disabled. The motivation for their choice was that these participants had not earlier in life received any communication support and the staff found the participation in the project a good opportunity for them.

A total of 123 interivews with parents, staff and the participants were made. Some persons refused to be interviewed a second time and some of the mentally retarded participants were excluded as the results of the first interview showed that it was too difficult. The interviews had the form of conversations and the informants could influence the interviews. Some of the participants were for instance more interested in the tape-recorder than answering questions. This supports the idea that it is difficult to make



interviews with persons with mental retardation as they have a more conrete way of thinking and often refer to things "here and now". All interviews were carried through by the same person in order to facilitate, especially for the mentally retarded participants. In one case, one of the parents was quite annoyed when the interviewer used the wrong surname of the participant. This was a minor source of irritation that probably influenced the interview negatively. In another case, one of the parents thought that the interviewer was going to sell expensive technical equipment, which shows how difficult it is to keep people informed. All persons involved in the project (parents and staff) were informed of the aims of the project and the procedures several times by written information and at personal meetings.

The interviews with the participants were thus difficult to effect. This was a limitation in the study, as the method for interviewing people with mental retardation was probably not fully suitable. There is a need for developing methods for interviewing this population as their opportunities to influence their daily lives are limited. Few interview studies are reported which illuminate the methodological difficulties and this urges the need for this kind of studies. The first step to empower people with mental retardation is to ask for their opinions and to teach them to formulate their thoughts. As a consequence of this the methodological issues must be developed.

Communication

Persons with mental retardation often have a poorly developed spoken language and are therefore in great need of support for their communication (e.g. Granlund, 1993). The participants used total communication, which means a combination of pictures, symbols, body language and signs as a complement to speech. This mode of communication implies a need for visual support in telecommunication. Less than half of the participants were able to make a telepone call themselves and about half of them were able to answer the telephone on their own. If a person is motivated or not to use the telephone often depends on how active he/she is in daily life, but also how interested the communication partner is to listen (Björck-Åkesson, 1992; Lindsay, 1990; Mirenda, 1990). To be motivated does not only mean to have someone to communicate with it also means to have something to communicate about. The participants in the study attended a day centre every day and worked with ADL-activities. A few of them had subcontract work for various companies. Consequently, the topics of conversation were referred to their daily lives e.g. food, work, events, activities and feelings. Many persons with mental retardation live in a restrained environment and do not spend much time outside the group home and the day centre. This might be one reason why the topics of conversation are limited.



Most persons recognized objects (22), pictures (23) and Bliss and/or Pictogram symbols (21), but only in eight cases the staff used symbols to mark the environment in order to facilitate orientation for the participants with mental retardation. Many had difficulties to show their communicative competence to make people in the environment understand what they meant. Communicative competence implies to function adequately in daily life and can be assessed as to linguistic, functional, social (socio-relational) and structural aspects (Brodin, 1993b; Björck-Åkesson, Brodin, Granlund & Olsson, 1992; Light, 1989). In this respect the significant parts are: communicative form, communicative content and communicative use. One difficulty in communication is when persons with speech disorders communicate with non-disabled persons. The non-disabled person always dominate the dialogue and the person with disability is often put in a reply situation.

From the interviews with the participants with mental retardation appears that the interviewer asks questions and the informant answers. In few cases the informants take initiatives or say more than they are asked for e.g. when a 43 year old woman is interviewed about her daily activitities. She tells the interviewer that she works in the kitchen in a day care centre. The interviewer asks if she likes it and she says "yes, I do". He confirms by saying "OK" and then she changes topic and says "It is windy and cold outside today". What really happened was, that she looked out through the window and just found out that it was windy. Normally, persons with mental retardation have a concrete conception of reality (e.g. Göransson, 1982) and this statement reveals this.

From the quotations appear that the answers of the participants mainly consist of single word sentences. Few utterances consist of several words. In the cases, where this occurs it is only a repetition of the inteviewer's questions. In one of the interviews with a 35 year old man (page 80), it appears that the informant does not maintain his opinion when the interviewer questions the reply. The informant does not seem to be sure of his own conception, and experiences confusion.

In general, the dialogues thus consist to a great extent of questions and replies and it appears that the participants often answer yes or no. It is also reasonable to believe that expectations are of great importance. If nobody expects anything from a person, it is easy that he/she will fulfil these expectations. This might depend on the fact that they are used to answer this way, but it might also be that they have no or few alternatives. Another reason might be that they do not bother to state their opinions as they are not used to people in the environment really caring about their views. Persons with mental retardation might sometimes be regarded as passive (e.g. Calculator & Dollaghan, 1982; Orr, 1989). The



difficulty in communication may also be a reason for not answering and sometimes they do not concentrate and listen to the communication partner. The context is also of importance as well as the relation to the interviewer. It is easier for a person with mental retardation to be interviewed by someone he/she recognizes than by a non-familiar person.

With regard to the communicative assessments one difficulty concerning the function of communication appears. Eight of the participants cannot maintain an interaction and ten cannot end an interaction. Another critical factor is that fifteen of the participants cannot ask for an explanation if he/she does not understand. The communicative disorder is firstly affecting the use of communication, secondly a combination of use and form. None of the staff has regarded the content itself as a problem.

The staff were in principal positive to the work-procedure with the communicative assessments, the goal settings and the goal a tainments and experienced them as a good help. The staff have also been able to work independently with the model and have also been able to adapt the methods to the participants' needs. At the end of the project, the staff stated that the support received during the project concerning the participants' communication in general stimulated and supported interaction and increased the ability to respond as an indirect result of the videotelephoning. These side-effects showed that the results of the training were spread and the abilities generalized to new situations.

The total number of calls registered were 434, but the variation is extensive. Some participants initiated 2 calls, others 41. The average length of the calls varied from 6.5 to 18.1 minutes. One problem is that some items are missing in the tables, e.g. in one case 434 calls are registered, but only in 430 protocols the length of the calls is indicated. In some cases the initiator is not indicated and therefore the staff is registered as initiator of the call. However, these items are not very reliable as there has sometimes been a problem to judge who really was the initiator. Often, the participants made the calls in cooperation with the staff. There are also calls that are not registered due to the fact that some of the participants made calls by themselves at the end of the project.

Social network

One of the aims of TeleCommunity was to give people with moderate mental retardation opportunities to maintain and increase their social network. Participation, communication and equality form the political goals for people with disabilities in Sweden (LSS, 1994). To establish a new social network is often difficult for people who are not young and this difficulty is naturally strengthened for those who in addition has a mental disorder. For a person with mental retardation it is not a matter of course to take initiatives to find new friends and to try to get in contact



with other people. This is partly depending on the fact that this population is often surrounded by staff both from day centers and group homes, partly that their daily lives are often based on routines. Their possibilities to make own choices can in this respect be limited as they are used to other people planning their everyday lives. This does not necessarily mean that it is unimportant for persons with mental retardation to establish new social relationships.

The social network is thus often limited for persons with mental retardation. Twenty of the participants have for instance no friends outside work or outside their group homes and they have no contact person despite the Swedish law for persons with severe disabilities (LSS, 1994). In Bronfenbrenner's model of ecological development (1979) the social network consists of the immediate environment, i.e. family, siblings, group home staff, day centre staff and peers living and working at the same place. First of all it seems to be difficult to make new friends, secondly it seems as if many of these individuals have lost the contact with parents, siblings and acquaintances. One reason for this might be that they have moved from institutions to group homes, sometimes located in another part of the country. Of the 24 participants 21 live in group homes and three with parents or in foster homes. Most individuals with mental retardation need support in their everyday lives and are dependent on people in their immediate environment. It is, however, impossible to say to what extent people with mental retardation can be independent as the variations between individuals are significant. When the responsibility for persons with mental retardation was transferred from the county councils to the municipalities, many persons moved back to their home municipalities despite they had not lived there for many years. People they used to know might not live there anymore.

This study showed that the participants increased their social network and made new friends. However, it is difficult to be sure that the friendship did not depend on the social meetings instead of just the videotelephoning. They met over the videotelephone and later on at parties. The main question is if it had been possible to establish a good social relationship only by using the videotelephones regularly once or twice a week, or only with social meetings two/three times a year. It is reasonable to believe that it is the combination of both that gave the good results. Although people in general realize distance when using videoelephones, persons with mental retardation may not experience the videotelephone conversation the same way. An example of this is when two of the women were talking on the phone. One of them knocked at the screen when the communication partner was not listening in order to call for attention.

According to the staff some of the participants seemed to be more interested in other persons than before the project started. If any of the



peers at the day centre was not present, the others started asking where he/she was. Some of the participants also took initiatives to call one of his/her new friends on the videotelephones. One important aspect of this is that the videotelephones are put in a room accessible to the participants. A previous study on fax communication e.g. (Brodin, 1993b) showed that this was significant. Some of the participants know how to operate the telephone equipment and may go up to the videotelephone, put on a dialling sheet and make a call to one of the other participants without assistance of the staff. It is also evident, that they developed their communicative ability as they expressed themselves more distinctly when interacting with their peers and they also used more 'words'. Sometimes they asked for new words (Pictogram symbols) which were not included on their communication sheet. In many respects, it seems reasonable to argue that the participants have increased their quality of life as communication is decisive.

Conclusions

There were great interpersonal differences between the participants regarding intellectual ability, experience, social skills and communicative ability. For persons with mental retardation it seems to be of great importance that there is a good cooperation between the different settings where these individuals live, especially as they show different skills with different staff members. It is also necessary that the various settings have the same framework of references.

Few studies have as a matter of fact been effected in the area of telecommunication for persons with mental retardation, and all studies found, involve a small number of participants and focus on the communicative ability and stress the importance of communication to increase the quality of life. Videotelephones might, however, be used as support in various educational situations. The use of videotelephones for persons with mental retardation often requires support from staff, and of course a partner to communicate with (e.g. Pereira, Matos, Purifição & Lebre, 1992).

To conclude, the study on videotelephony for persons with moderate mental retardation revealed that the social network was expanded and that the participants had made new friends among the staff and the mentally retarded peers at the other day centres. This was reinforced by the social meetings. The frequency of use also increased. At the start of the project they only used the videotelephones at fixed times, but later on many of them initiated and made calls by themselves. It is evident that the participants have improved their communication with regard to the extension of new words and that they are more clear when expressing themselves. They have also been more interested in other persons in the environment.



One remaining question deals with the technology used. There were difficulties of technological character which could not be influened by the technicians involved in the project. The suppliers changed software without informing the technicians and the ISDN-network did not function satisfactory. At the end of the project the day centre staff were asked if they were interested to continue to work in a new project with the videotelephones and all of them accepted. This might be understood as although there were a lot of problems with the equipment they still wanted to continue to participate. On the screen there is an image of both the sender and the communication partner visible at the same time. The diaglogue consisting of Pictograms also comes up on the screen. At the start of the project we discussed if it would be a problem for the participants to see him/herself on the screen when he/she was talking as this is not usual in face-to-face communication. However, this does not seem to have been a problem at all. Only one of the staff reported that one of the participants was distracted by seing herself on the screen, when she was talking.

Most benefits have been gained on the individual level, but also on a social level as the participants have got access to telecommunication as all citizens in Sweden. Both participants and staff have been positive to take part in the project despite all difficulties with the technology. There are still many questions to be answered and future research should be directed to methodological issues, but also to the social network as many questions remain with regard to this issue. Detailed studies on social network and friendship between individuals with mental retardation seem to be of high priority for the future.



Andreas Albertsson calling one of his friends on the videotelephone. Foto: Jane Brodin



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VIDEOTELEPHONES FOR PERSONS WITH MODERATE MENTAL RETARDATION

BACKGROUND DESCRIPTION

Day centerTelephone				
PersonSexAgeAge				
Housing conditions				
Earlier (for persons living in an institutions, please indic	ate approximate size)			
Present				
Schooling				
Class for mentally reetarded children Class for severely mentally retarded children Other	No of years No of years No of years			
None Schooling finished	Year			
Main occupation at day activity center				



TeleCommunity/RACE 2033 Brodin/Oct. 1992

Social contact network

Has contact with:

(Tick relevant alternative)

	Daily	Every week	Sporadically
Mother			
Father			
Siblings			
1.			
2.			
3.			
4.			
Relatives			
1.			
2.			
3.			
4.			
5.			
Friends (or staff			
during leisure time)			
1.			
2.			
3.			
4.			
5 .			
Contact person	•		
Degree of mental retard Assessed by	•••••••		
Basis for diagnosis (if pos the assessment has been made	ge) · · · · · · · · · · · · · · · · · · ·	•••••	• • • • • • • • • • • • • • • • • • • •
************	•	*****************	• • • • • • • • • • • • • • • • • • • •
Additional functional dis	sorder (Please tic	:k)	
Visual impairment		YESN	!O
Type of visual		1 231	10
impairment	• • • • • • • • • • • • • • • • • • • •		
Glasses have been prescribe			NO
Uses glasses daily	_		NO NO
Needs enlarged text		YES	
· · · · · · · · · · · · · · · · · · ·		YES	NO
Hearing impairment		VEC	NO
Type of hearing inspairment	•	YES	NO
Hearing aid has been prescri	hed	Vre	NO
Uses hearing aid	U-C-L		NO NO
Coro issuint aid		YES	NO



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Motor impairment	YESNO	
Type of motor impairment		
	VEG NO	
Uses mobility aid Type(s)		•••••
Epilepsy	YESNO	
Medication	YESNO	
Speech impairment	YESNO	
Medical disorders	YESNO	
Type		
Other		
Gross motor impairment	YES NO	••••••
Gross motor impairment Type		
Comments		
Fine motor impairment Type	YESNO	
Type		• • • • • • • • • • • • • • • • • • • •
Comment		
Pictures		
Recognizes objects on pictures	YES NO	
Recognizes persons on pictures	YES NO	
Recognizes symbols (Bliss, Pictogram)	YESNO	
Recognizes digits, letters	YESNO	
Uses pictures/symbols for communication	YESNO	
Uses pictures to mark his/her environment	YESNO	
Communication/language	rana No	
Is motivated to communication	YESNO	
Communicates by means of speech	YESNO	
Communicates by means of signs	YESNO YESNO YESNO	
Communicates by means of pictures/symbols	YESNO	
Principal way of communications (please also in	licate combinations)	
Use of communication aids Type:	VEQ NO	
Initiates communication:		
alwaysoftensometimes	seldomnever	
Responds to communication:	seldom never	



TeleCommunity/RACE 2033 Brodin/Oct. 1992

Has participated in other projects directed toward communication Completed the project without interruption Uses the communication aid today	dsYESNOYESNOYESNO
Telephoning before the start of the projectives the telephone:dailysometimesseldom	
Calls the following persons:	

••••••	
Recognizes telephone voices of persons close to him/her Recognizes different telephone signals Can make a call by him/her self Can answer the telephone on his/her own	YESNOYESNO
Please describe the normal procedure fo	r telephoning:

•••••	• • • • • • • • • • • • • • • • • • • •
•••••	
••••••	• • • • • • • • • • • • • • • • • • • •

Thank you for your cooperation. Please send the	completed form to:
Jane Brodin Department of Education Stockholm University S-106 91 STOCKHOLM	



TRANSMISSION OF MOVING PICTURES PEOPLE WITH MENTAL RETARDATION

PROTOCOL FOR USE OF TELEPHONE A-Form							
Day activity center/Station							
	Date						
Inc	IncomingOutgoing Filled out by						
1 .	Dialogue partner	الله ومناه شده فرانه ماري وبلك نسب سيب ومياه وشاه وميا					
<u>2.</u>	Initiator						
3.	Reason for the call						
4.	The following parts of the equipment were used after the alternative)	(fill out x					
	Videomonitor Pictogram monitor Doc Concept key board Personal Mini caller Pri	ument camera nter					
	Conversation Topics Fill out the expressions describing the particip	pants' attitudes					
	to use the telephone:						
	Looks happy/seems to enjoy Seems motivated Takes initiatives	0 0 0					
	Shows expectation/exitement (e.g. strengthens body/ becomes active) Shows interest	0 0					
	Shows no interest/looks bored Looks afraid/looks anxious Looks angry/upset	0 0 0					
	The task is difficult/laborious Experiences the situation as heavy demands Seems unconcerned	0 0 0					
	- Other	0					



8.	The participants mode indicate all)	e of communicati	on when	calling (please				
	Spoken language	0						
	Picture communication	Ö						
	Pictogram symbols	Ö						
	Other pictures	Ō						
	Real objects O							
	Comments (please ind most frequently used)	licate which mod	e of comi	munication was				
9 .	The quality of the pic	ture/monitor was	during ti	he telephone				
	Very good O Good C	Satisfying O	Bad O	Very bad O				
10.	The quality of the tra	nsmission of sou	nd was di	uring the				
	Very good O Good C	Satisfying O	Bad O	Very bad O				
11.	Did the participant he correctly on the document	ave any difficultion ment camera?	es to place	the pictures				
	Yes O No O							
	If yes, please indicate	in which way						
12.	Did the participant has overlay on the concep	ive difficulties to t key board duri	put on ar	nd change the ephone call?				
	Yes O No O							
	If yes, please indicate	in which way						
13.	Please indicate how madifferent ways	any pictures were	transmit	ited in				
	How many pictures were How many pictures were How many pictures were	transmitted via the	document	camera				
	Comments			/				



TeleCommunity/RACE 2033 Brodin/January, 1993

B	- Form	To be	filled	out at	two	occasions	(after	one
	and afte	erthree	weeks	use o	f the	telephone	e)	

B1.	How do you consider the time interval when calling (i.e. does the searching/calling up take too long time) Yes O No O							
	If yes, how do you estimate the importance of this for the participant							
	Does not matter O	Acceptable O	Has great importance O					
	Comments							

B2. The size of the screen is

Too small O Satisfying O Too big O

B3. Has the concept key board functioned satisfying during the minitrial

Yes O No O

Comments

If no, please indicate what the problems have been

B4. Do you have the opinion that the participants have understood the symbols when making a call (e.g. the picture of a "ringing" telephone which is shown on the screen)

Yes O No O

If no, please indicate what the problems have been

B5. Has there been a schedule made out for the participants of using the telephone

Yes O No O



B6.	Do you consider it as important to have a made out for this purpose	special schedule
	Yes O No O	
B7.	How many persons from the staff has in o been involved with the telephoning with the (please indicate the number of staff involved).	ie two participants
B8.	Does any of the staff at the day acitivity comain responsibility for the project acitivity	
	Yes O No O	
	Comments	
В9.	Does any of the staff take the main respo use of the telephone for each participant	nsibility for the
	Yes O No O	
	Comments	
B10.	. How long a time has totally been spent by the first week to learn how the equipment the activity for the participants	the staff during works and to plan
	Abouthours	
B11.	. How long a time for the staff who works has totally been used for conducting the moments - also time for preparation). Thi the time when the staff is working with the learning/training.	calls (including all s does <i>not</i> include
	Week 1 Week 2 Week 3	
	Comments	
B12.	What is the attitudes of the staff towards t the adequate alternatives)	he project (fill out
	Interesting/positive Time consuming Difficult to find time for telephoning Demanding/Demands for heavy efficiency Laborious to fill out the forms	0 0 0 0
	e send the form to	ation 106.01 Stockholm



APPENDIX 4

ASSESSMENT OF COMMUNICATIVE ABILITY OF PERSONS WITH MENTAL RETARDATION

Based on M. Nordström Walder & U. Åström (1993) Bedömning av pragmatisk förmåga [Assessment of Pragmatic Ability] and J. Light, D. McNaughton & P. Parnes (1986) A Protocol for Assessment of Communicative Interaction.

Revised version by F. Thurfjell and J. Brodin for TeleCommunity 1994.

Day center			 Source	Age
Completed	by			
A	Interactio	n roles		
1. Does X to	ake his/her own initia	tive to interaction?		
	yes	no		sometimes
If the answe words) and in	er is yes, please indic n what kind of situation	cate how (glance, pons X takes initiative	gesture, mo e.	vement, sign, picture,
2. Does X i	respond to initiatives	o interaction made	by others?	
	yes	no		sometimes
If the answe	r is yes, please indicat	e how and in what	kind of situa	tions.
3. Does X u	usually keep up an inte ersation"?	eraction, in other we	ords take mo	ore than one turn in "the
	yes	no		sometimes
If the answe	er is yes, please indica	te how and in what	kind of situa	ations.
4. Does X	usually end a convers	ation in progress?		
	yes	no		sometimes
If the answe	er is yes, how and in v	vhat kind of situation	ons?	



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В	Application,]	ourposes	
5. If X is coffer?	offered an object/an act	tivity - does X have a	way of accepting/rejecting this
	yes	no	sometimes
If the answe	er is yes, please indicate	e how and in what kind	d of situations.
6. Does X	usually choose from tw	•	
If the answe	yes er is yes, please indicate	no e how and in what kind	sometimes I of situations.
		•	
7. Does X	usually ask for a specif		
	yes	no	sometimes
If the answ	er is yes, please indicate	e how and in what kind	d of situations.
8. Does X	usually greet others/sa	y good bye?	
	yes	no	sometimes
If the answ	er is yes, please indicat	e how and in what kind	d of situations.
9. Does X	usually call for attention	on?	
	yes	no	sometimes



	:Community/RA		••	
If the	answer is yes, p	please indicat	te how and in what kind o	of situations.
10. I	Does X usually	switch his/he	er attention between object	ets and people?
		yes	no	sometimes
If the	answer is yes,	please indica	te how and in what kind	of situations.
			Tr. O I I and the day of the same of the s	-u overessed?
11.	What kind of e	emotions doe	s X express? How are the	ey expressed:
12.	Is everybody a	round X able	to interpret those emotion	onal expressions?
		yes	no	sometimes
			0.77	averaged?
13.	What kind of	needs does 2	K express? How are they	expresseu:
_				
14.	Is everybody	агоund X abl	le to interpret those expro	essions?
		yes	. no	sometimes
	•			titute a summandings?
15.	Does X unde	rstand instru	ctions given by people in	
		yes	no	sometimes
16.	Does X under	rstand the co	ntent of conversations he	ld in everyday situations?
		yes	no	sometimes
		•		
17.	. Does X give	information	to the conversation partn	
		yes	no	sometimes



		<u> </u>	
8. Does X as	sk for information	from the conversation	partner?
	yes	no	sometimes
f the answer i present/absent.	s yes, please indica	ate how and in what k	ind of situations? Regarding t
9. Does X n	nake spontaneous c	omments around obje	cts or events?
	yes	no	sometimes
resent/absent.			ind of situations? Regarding t
20. If X is no	t understood, does	he/she try to be more	clear?
20. If X is no	t understood, does	he/she try to be more	clear?
	yes	-	sometimes
	yes	no	sometimes
f the answer is	yes s yes, please indicat	no e how and in what kin	sometimes
f the answer is	yes s yes, please indicat	no e how and in what kin	sometimes ad of situations.



order to commu	tind of situations does X communicate municate)?	
23. In what k reach his/her g	cind of situations does X communicate becoals)?	st (most functional in order to
24 With wha	t person/persons does X communicate mos	st?
	nat person/persons does X communicate be	
26. Does X so in comm	Alternative Communication have any alternative way of communicatin the past? (signs, Pictogram, other picture sy nunication aid, communicator, computer)?	g at present, or has he/she had
	ic yes, indicate what kind/what way? ong has X been using that?	
	nany symbols/signs has X got/did X have?	At present



	How much has X been using the alternative way, and in what kind of situations?
	and the way, and in what kind of situations?
3 0. W	ith whom has the alternative mode of communication been used?
Inform comm	nation of importance for assessment of the communicative ability or use of unication aids.



PROTOCOL FOR USE OF VIDEOTELEPHONES

TRANSMISSION OF MOVING PICTURES FOR PERSONS WITH MODERATE MENTAL RETARDATION

Communication partne	Name of participant
1. Date	
2. Approximate length of	call (in minutes)
3. Initiator to the call	
4. The following parts videotelephone (plea	of the equipment were used except the e tick the proper alternatives)
Concept key board Personal Mini caller	Document camera
5.Modes of communicat	on (please tick all alternatives)
	pictures/photosPictogram
	ative was most frequently used
6. The quality of the i	nage was during the call
Very goodGood	SatisfyingBadVery bad
7. The quality of the s	ound was during the call
Very goodGood.	SatisfyingBadVery bad
8. Does NN recognize t	ne communication partner on the image?
Y es	No Don't know
9. Fill out the expressi use the telephone:	ons describing the participants' attitudes to
fun/interesting	0
is active seems afraid/anxious	0
difficult	ŏ
shows no interest/look	bored 0
looks angry/upset	situation too demanding 0
takes initiatives within	he ineraction 0
other reactions	0



	pictures	were	sent	via	the	telenet	work?	(please	tick
altern	atives)							-	

Food/to eat	Activities/t	o do	
Events/situations/to	happen	Feelings	Needs
		ويشتر بسبب ومدوويشتر الحدة الحدة ومدة ومنته ومنته ومنته المنته المنته المنته المنته المنته	

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APPENDIX

6

INTERVIEW GUIDE

First interview

- * Does NN meet many visitors at the centre from outside?
- * Does NN encounter any stangers during visits outside the centre?
- * Who are NNs friends and acquaintances at the centre and outside?
- * Who from the staff is closest to NN?
- * During free time, does NN have any special interests?
- * Does NN use the telephone regularly and spontaneously at the centre?
- * Can NN handle different types of technological tools? (give example)
- * Does NN take any initiatives to commuicate, in what manner?
- * Describe NNs manner of communication
- * Does Nn participate in any educational actitivities?

Second interview

- * How do you think that NN has experienced the project?
- * Have you noticed any changes in behaviour during the project time?
- * Does NN has any new contacts compared to earlier?
- * Could NN have any possibilities to create new contacts without telecommunication technology in a functional way?



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