



MASTER THESIS

SENDING A MESSAGE INTO OUTERSPACE

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SENDING A MESSAGE INTO OUTERSPACE
*Communication Between Nonverbal, Intellectually Disabled Adults with ASD, and the People
Around Them.*

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Abstract:

Very little information exists regarding the communication of nonverbal adults with severe Intellectual Disabilities (ID) and Autism Spectrum Disorder (ASD). Most research in this area pertains to children. This study poses the following questions: "How do nonverbal, intellectually disabled adults who have ASD and those people who have contact with them on a regular day-to-day basis communicate with each other? What enhances and or strengthens this communication? Can positive development in communication occur?" Based upon the data retrieved from eleven interviews, portraits of the communicative relationships of nonverbal adults with ID and ASD and their caregivers were compiled. The results of the study confirmed the existence of a personalized, functional system of communication between nonverbal adults with severe ID and ASD and their caregivers. The information gathered revealed improvement in communication. It was discovered, moreover, that a key factor in communicative development was the creation of common conceptual ground between caregiver and service user. Several attitudes and behaviors on the part of caregivers were noted to increase this common conceptual ground. The study's conclusion cites the limitations, in methodology and scope, of the current investigation, and calls for more wide-ranging research on the communication of nonverbal adults with ID and ASD.

Key words: Intellectual Disability, Autism Spectrum Disorder, communication, positive development, Common conceptual ground.

Abstrakt:

Det finns idag inte mycket information tillgänglig gällande kommunikation av icke-verbala vuxna med gravt intellektuella funktionshinder och Autismspektrumtillstånd. En stor del av forskning som har bedrivits i detta område gäller barn. Frågeställningarna i denna uppsats är: "Hur kommunicerar icke-verbala vuxna med intellektuella funktionshinder och Autismspektrumtillstånd i sin vardag med de människor som finns runt omkring dem? Vad är det som gynnar och förstärker denna kommunikation? Kan denna kommunikation utvecklas och förbättras? Med information från intervjuer med elva omsorgsgivare skapades fem porträtt av det kommunikativa samspelet mellan icke-verbala individer med gravt intellektuella funktionshinder och Autismspektrumtillstånd, och deras kontaktmän. Studiens resultat visade att det finns ett fungerande, individualiserat kommunikationssystem mellan omsorgstagare och omsorgsgivare. En förbättring i kommunikationen noterades. Man har kunnat se att omsorgsgivarens attityd och förhållningsätt gentemot omsorgstagaren varit betydande för denna förbättring. Resultaten visade att utvidgning av den gemensamma konceptuella grunden [common conceptual ground] mellan omsorgstagare och omsorgsgivare var en viktig faktor i den kommunikativa förbättringen. Flera faktorer visade sig vara avgörande i expansionen av den gemensamma konceptuella grunden. Det påpekas att det fanns uppenbara begränsningar i bredden och metoden i denna studie och det konstateras att det finns behov av mera omfattande forskning om kommunikation av icke-verbala vuxna med intellektuella funktionshinder och . Autismspektrumtillstånd

Nyckel ord: Intellektuella funktionshindrade, Autismspektrumtillstånd, kommunikation, utvecklas, gemensamma konceptuella grunden[common conceptual ground].

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Introduction

When writing this introduction I remembered seeing a model of the spaceship Pioneer 10 in the Smithsonian Institution in Washington D.C. Pioneer was the first space ship to fly through the asteroid belt, penetrating deep outer space. This space vehicle was equipped with a visual message etched onto an outside panel in preparation for any possible encounters with intelligent life forms. Included in this message was a drawing of a naked man and woman. The man is standing with one flat hand raised up showing the palm. This is the same greeting that friendly Indians used in the old classic Cowboy films. When I first saw this picture I thought to myself,

It is taken for granted that whoever finds this will understand this nonverbal gesture or emblem. Space scientists are assuming that the folks from outer space have brains that work the same way ours do!

I chuckled at the thought that those who live and work with intellectually disabled (ID), nonverbal adults with Autism Spectrum Disorder (ASD) have something in common with NASA. We are all trying to bridge a communications gap. The difference is, of course, that NASA has invested huge quantities of time, research and money in preparing for the off chance that we will be able to communicate with someone in deep space. Yet, while it might seem logical to fund a similar effort to improve communication with people right here on earth, dedicated caregivers continue, without the advantage of such support, to attempt communication with adults who do not think the same way we do, and who at times seem lost in their very own deep space.

How does one give a voice to those who have none? Or, barring that impossible scenario (who can truly know another's mind), how can we learn what the nonverbal, severely intellectually disabled need and want? How can we hope to understand an individual who is incapable of verbalization or conventional sign language, and who apparently has a whole different cognitive process? For those who work with, or whose family includes, nonverbal, developmentally challenged people with ASD, this is no easy task. It isn't courage or stubbornness that breeds our determination, but the sheer humanity of the women and men we work and live with. Like all of us, these adults are unique, exciting and complex individuals. And like all of us, they need to communicate!

Disability Studies are the study of disabilities, the people who have them, the society that creates, accepts, denies and or alleviates these disabilities and how they interact with one another. The objective of this science is to legitimize, validate, and provide information concerning this large sector of our society. The people this author's study centers around are an especially vulnerable group within the broad category of "the disabled." They not only lack an official voice, but they also lack the traditional tools for symbolic, linguistic communication. Their disabilities make speaking to and for them a staggering challenge. How can we, as a society or as individuals, meet this challenge? Can positive change occur in the communication between these service users and their caregivers? Is it possible to say what it is that aids communication and why? The ultimate goal of this paper is to develop answers to these questions that may be of assistance to those working with people whom society often alienates and isolates, people trapped in their own inner space..

Chapter 1

The Intention

The questions:

This study begins with a question and the intention is to find the answer in the data collected, an inductive process (Bryman, 2008, p. 11). The question to be explored is: How do nonverbal, severely intellectually disabled adults who have ASD and those people who have contact with them on a regular day-to-day basis communicate with each other? The purpose is to pinpoint the dynamics of these communicative relationships. A vital, related question is, can communication between nonverbal, intellectually disabled adults who have ASD and their caregivers improve? If so, what kind of actions, behavior and attitudes contribute to the positive development of communication, and why?

Background:

I am an Art therapist specializing in working with adults with intellectual disabilities. In this capacity I have often worked with nonverbal adults with ID and ASD and it is this work that has motivated this paper. Working with this population has revealed how vital communication is for functioning and survival. It has also become apparent what a challenge it is for all involved just to establish everyday wants and needs. Admiration for the way in which caregivers and communicatively challenged people functioned together, inspired this study which is an attempt to delve further into what makes such communicative relationships work.

Disposition:

Chapter II begins with a clarifications of the following concepts: Intellectual Disabilities (ID), nonverbal, Autism Spectrum Disorder (ASD), Communication and Key-caregivers. The different theoretical schools considered when developing this project are reviewed in chapter III. In chapter IV, some previous studies involving similar target groups and dealing with similar **questions** are described and compared. Chapter V is a description of the procedures and methods used, and is followed in chapter VI by profiles of the individual communicative relationships. Based on the study's collected data the aim of these profiles is to generate a picture of each relationship, based, not on the disabilities of those involved, but on their communicative strengths and potentials. These profiles are followed, in the second half of the chapter, by a general presentation of all the data collected. In chapter VII, conclusions are drawn as to what kind of communication takes place, if there has been improvement and what actions, behavior and attitudes assist it. In the final chapter, the implications of these conclusions are discussed.

Chapter II

Concepts and Definitions

Intellectual Disabilities:

An intellectual disability can be classified as *limited intellectual functioning and hampered adaptive behavior which restricts an individual's performance of everyday social and practical skills. This disability originates before the age of 18* (American Association of Intellectual and Developmental Disabilities, 2013). In Sweden, the intellectually disabled are divided into three categories based upon a model developed by Gunnar Kylén (1974). The first category consists of people who can read, write and do mathematics to some degree but

have difficulty with abstract thinking and planning. The second group can handle everyday practical duties and routines after coaching but usually do not read, write or do math at more than a very elementary level. The third category, in which the service users described in this paper fall, includes people with severe to profound intellectual disabilities, those for whom the performance of most rudimentary daily activities is not possible without help. This last category of intellectual disabilities if translated to the classification system described by the American Association of Intellectual and Developmental Disabilities would be divided into two categories severe and profound (Schalock, o.a., 2010) For the sake of simplification during the rest of this paper instead of referring to this group as having severe to profound intellectual disabilities I will simple use the term severe intellectual disabilities to include both these categories. Over half of the intellectually disabled population and all of those who are classified as having severe ID also have interactive communicative problems (Grandlund & Olsson, 1987).

Nonverbal, SCI or CCN:

A nonverbal individual is a person who does not use verbal language to communicate. We could also say that the individuals whom this study centers around have Severe Communication Impairment (SCI).

Individuals are described as having Severe Communication Impairment (SCI) and/or Complex Communication Needs (CCN) when their speech and handwriting are insufficient to meet their communication needs. The terms are usually used in relation to people with no speech or very little intelligible speech, but it may also be applied to people whose speech, while clear and fluent, is still not meaningful or representative of their real thoughts, for example, people whose speech is echolalic (The Anne McDonald Centre).

The broad term nonverbal is used in this paper because it is readily accepted and easily understood.

ASD:

The new version of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5) to be released in May 2013 will contain a new classification of ASD. This revised definition will include what was previously seen as four separate disorders: autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome (Connors, 2012). The new definition of ASD because of its wider, more inclusive reach will be used throughout this paper..

Autism is a disorder that usually affects children during their first three years. Autism effects cognition, social interaction, and communication skills (American Psychiatric Association, 2000). Research suggests that it is a neurodevelopmental disorder (Charman, 2003), but recent studies have brought to light influences from different environmental factors (Lathe, 2006). Iris Johansson in her book *En Annorlunda Barndom*, describes how she, as an autistic child, experienced the world:

The child does not know that there exists any other way of being than his own. The child is in a foreign land where he does not understand the language that everyone else is speaking. He sees the world as consisting of things surrounding him but that do not have anything to do with the child himself (2007, p. 360) (translated by the author).

The Autistic individual exists in an extreme state of separateness, of not being in the same space or the same reality as others (Baron-Cohen, 1995). There are many different degrees and kinds of Autism, some being quite manageable and others that make integration into society a major task. Approximately 30 to 50 percent of all children and adults with ASD do not use speech to communicate (National Research Council, 2001).

Communication:

The National Joint Committee for The Communication Needs of Persons with Severe Disabilities in their document, *Guidelines for Meeting the Communicative Needs of Persons with Severe Disabilities*, describes communication as:

Any act by which one person gives or receives from another person information about that person's needs, desires, perceptions, knowledge, or effective states. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes (The National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992).

Another definition, more all encompassing and more appropriate when dealing with the communicative relationships of nonverbal adults with ID and ASD, is used by Buch: "Whenever the behavior of one individual (the sender) influences the behavior of another (the receiver)" (1984, p. 4).

Quality of life and Communication: Not only is it a logical assumption that communication is a requisite for improving the quality of life for adults with severe ID, research has also shown this to be true (Healy & Walsh, 2007, p. 138). The relationships formed and the extent to which people with intellectual disabilities participate in everyday activities is a key measure of their quality of life (Mansell & Beadle-Brown, 2012) and without communication it is very difficult to establish a relationship and even more difficult to participate. In the final draft of *The International Classification of Impairments, disabilities and Health* (World Health Organization Classification, Assessment, Survey and Terminology Team, 2001, p. 12), communication is listed as the third of nine domains used to qualify levels of Participation.

Verbal and nonverbal: Communication can be divided into two categories, verbal and nonverbal. Nonverbal communication has traditionally been divided into three categories: biological or spontaneous, intentional, and pseudo-spontaneous. Spontaneous communication is characterized by biologically motivated, automatic, non-intentional displays that our body emits. Spontaneous displays can consist of facial expressions, gestures, postures, micro-movements, and vocalizations (Buck & Van Lear, 2002). Pseudo-spontaneous communication is when: *The sender intentionally manipulates the displays to send a specific message, or proposition that can be false* (Buck & Van Lear, 2002, p. 526). Communication can also be described as *symbolic and non-symbolic or pre-linguistic* (Siegel-Causey & Guess, 1989). The most obvious example of symbolic communication is verbal communication, and in most cases unaided nonverbal communication is considered to be non-symbolic. Buck and Van Lear, however propose that forms of nonverbal behavior can also be considered symbolic and that these originate in the brain's left hemisphere as does verbal communication (2002, p. 522). Sign language, the use of objects and or picture boards are all examples of symbolic nonverbal forms of communication (Casella, 2005).

Augmentative and alternative communication (AAC): Many forms of communicational aids can be used to facilitate communication with nonverbal individuals. The most commonly used are unaided AAC. Unaided AAC systems are those that do not call for any extra instrument other than the human body. Examples of unaided AAC are facial expression, vocalizations, gestures, and sign language systems. Gestures can be used as they occur naturally, in formalized codes that lack any connection to an already existing language, or as sign languages that have a linguistic base and can transmit unlimited variety of communications.

Aided AAC can consist of simple communication aids such as objects and pictures in combination with communication boards or more advanced technical aids such as computers and speech generating devices. Symbols are used to aid in communication and may consist of graphic, auditory, gestural and textural symbols that represent objects, actions and concepts. The choice of symbols, how, when and where they are used depends upon the individual's linguistic, visual, and cognitive skills (Johnston, Reichle, Feeley, & Jones, 2012).

Key-Caregiver:

The duties and responsibilities of a key-caregiver in Sweden vary within different institutions, but for the most part it is the key-care giver who has the overriding responsibility for the individual service user's well being. They are responsible for forming and executing their assigned service users' individual plan for development. He or she should also function as a link between the service user, their families, guardians, other staff, administrators and society at large. Establishing communication with, about and around the service user is an essential part of his or her responsibility (Socialförvaltningen Simrishamns; Socialförvaltningen Upplands-Bro).

Chapter III

Theoretical Background:

This study takes full advantage of the inter-disciplinary nature of Disability Studies. The literature consulted and referred to here comes from developmental and clinical psychology, sociology, communication sciences, evolutionary anthropology, linguistics, educational sciences and disability studies. Since the impact of the relationship between the caregivers and service users is of key importance in this investigation and since the service users are seen as individuals with communicative strengths, most of the data is reviewed from the stand point of the Relational Model of Disabilities (Holme, 2000). In line with Antonovsky's Salutogenesis (1987) this study searches for that which moves caregiver and service user towards a healthy, functional communicative relationship. The ability to cope and hence maintain health is dependent upon ones sense of coherence which according to Antonovsky consists of three elements: comprehension, management and meaning (1987). In order to understand, manage and make sense of the world around us we must communicate, hence communication is required for a sense of coherence to exist. This paper has made use of theories that seek to explain what a functional system of communication is and what elements promote its development and growth. Some of the terms referred to are reviewed below.

Human Cooperative Communication:

Tomasello's cooperation model of human communication proposes that humans are unique among animals in that their systems of communication are processes of *shared intentionality*, or

we thinking (2008, pp. 72-108). In this model, human communicative acts are grounded in joint attention and shared understandings of the situation at hand (Tomasello, 2008, p. 107).

Common Conceptual Ground :

Common conceptual ground (Clark, 1996) is joint attention, shared experience and shared knowledge of the physical and emotional world we live in. Common ground makes it possible for us to understand one another (Tomasello, 2008). A very simplified example of this concept involves an individual pointing to the water faucet and then to a glass in an effort to obtain a drink of water. As observers, we would have a hard time understanding his desire if we did not share the basic knowledge that water comes out of the faucet; if we had never been thirsty; or if we were simply not interested in learning about his needs. Hence all variants in personality, upbringing, attitudes and information about the immediate environment, affect intercommunication. Clark (1996) introduces the concept of common conceptual ground in reference to linguistic communication, but Tomasello proposes its relevance to both verbal and nonverbal interchanges (2008). *Common ground is necessary for the recipient to determine both what the communicator is directing attention to (his referential intention) and why he is doing it (his social intention)* (Tomasello 2008, p. 75).

Joint Attention:

Joint attention (also referred to as shared attention) is a triadic form of communication where one attempts to direct the attention of a social partner toward an object or event in order to share awareness of it (Mundy, Delgado, Block, Venezia, Hogan, & Seibert, 2003). Joint attention has been studied extensively in relationship to ASD (Mundy et al., 2003); (Mundy & Crowson, 1997); (Charman, 2003), and is considered a crucial factor in interventions with autistic children (Charman, 2003);(Mundy & Crowson, 1997). Tomasello proposes that joint attention originates in infants with collaborative activities and that it is the predecessor to common conceptual ground and cooperative communication (2008). Baron-Cohen sees it as one of the mechanisms behind mindreading (1995) and Meltzoff, Kuhl, Movellan and Sjenowski, consider it one of the pivotal skills involved in communication and learning (2009).

Theory of Mind:

Human beings have a sense of one another as emotional creatures. For the most part all adults have an innate understanding that other people have intention, desires, feelings and beliefs similar to our own (Meltzoff, 1999). Research shows that 18 month old toddlers are capable of reading another's intentions (Meltzoff, 1999, p. 257). The development of both verbal and nonverbal communication are dependent upon this ability (Meltzoff, 1999). Theory of mind (ToM) is *the specific ability to attribute mental states to oneself and to others* (Baron-Cohen, leslie, & Frith, 1985). Joint attention, empathy and imitation are basic social skills and pave the way to ToM or mentalization (Meltzoff, Kuhl, Movellan, & Sjenowski, 2009).

Affect Attunement:

Affect attunement is a communicative phenomenon that first manifests in humans between mother and child. It originates in imitation and is the building block to empathy (Stern D. , 1984). Stern sees affect attunement as an instantaneous and unconscious form of nonverbal communication, a bridge between pre-linguistic communication and symbolic or verbal communication (1985). The first stage of affect attunement is imitation, but this communicative form extends beyond imitation. It requires that the receiver not only take in the other's emotion, but also that they make it their own and then send it back to the first individual as a true and felt response to the behavior and feelings of the other. It is also important that the original sender

can recognize his or her original feeling in this response. This phenomena is so deeply imbedded in our behavior that it can be difficult to detect (Stern,1984). Attunement can be seen as a form of dyadic shared intention and or ToM that can form a common conceptual ground.

Mixing Theories:

In line with the interdisciplinary nature of Disability Studies, elements from different theories have been chosen to support singular aspects of the findings and conclusions.

Tomasello's cooperative communication module (2008) is seen as a functional communicative form that all social groups including the service users and the informants are striving to achieve. The concept of a common conceptual ground is seen as a communicative necessity that can be cultivated and expanded in order to enhance both verbal and non-verbal communication and achieve the ultimate goal of cooperative communication. Joint attention, ToM and affect attunement are sighted here as specialized communicative tools that contribute to a sense of self and a common conceptual ground. All the information is reviewed from a Salutogenic (Antonovsky, 1987) view point - The ambition is to better understand the communicative abilities of these people and not their communicative disabilities.

Chapter IV

Previous Studies:

Similar, But Not the Same:

Research has been done regarding the nonverbal communication of children with autism (Keen, Sigafos, & Woodyatt, 2005); (Mundy, Sigman, Ungerer, & Sherman, 1986); (Alvarez & Lee, 2004), children with ID, physical disabilities and SCI (Sigafos, et al., 2000); (Ogletree, Bruce, Fahey, & Mcleen, 2011). Others have studied the nonverbal communication of adults with severe to profound ID (Healy & Walsh, 2007); (Granlund, 1993); (Casella, 2005); (Brady, Mclean, Mclean, & Johnston, 1995). Underwood, McCarthy, Tsakanikos, Howlin, Bouras, and Craig, (2012) compared the health and social functioning of adults with ID with those who had both ID and ASD and Furenhed in Sweden studied the existential quality of life of a adults with profound ID (1997). It would seem that very little research has been done dealing specifically with the communication of nonverbal adults with ID and ASD. A quick review of the general research within the realm of communication pertaining to individuals with SCI, ID and ASD reveals that there is a tendency to study children over adults. Needless to say the study of the communicative ability of nonverbal adults with severe ID and ASD seems to be relatively uncharted territory. The IPCA developed by Sigafos et al. (2000) has been used to formulate the interview questions for this study, while the choice of method was greatly influenced by the work of Furenhed (1997). Baron- Cohen's findings indicating the relationship between joint attention, ToM and autism (1995) are considered here and the results of this study have been compared to those of Granlund (1993), Furenhed (1997) and Casella (2005).

Different Approaches:

In his book entitled *En Gåtfull Verklighet [A Mysterious Reality]*, Furenhed's (1997) ambition is to qualify the existential well being of people with profound ID. To do so he uses in depth interviews with both parents and staff. One of the reoccurring themes revealed in these interviews is the strong influence the relationship with caregivers has on the way service users are perceived and treated by others. Furenhed describes what he calls *ordlös tillhörighet* [wordless belonging] (translation by the author) (1997, p. 181). which resembles the concepts

of affect attunement and ToM. Furenhed's soulful and philosophical approach to his subject matter inspires and opens the door to a more passionate and involved method of investigation.

Baron-Cohen in his work with autistic children comes to the conclusion they have malfunctioning SAM (Shared-Attention Mechanism) and or ToMM (Theory-of-mind mechanism)(1995). SAM and ToMM are two of the four mechanisms that form peoples' capacity to mindread or mentalize (1995). SAM is closely related to joint attention and ToMM is equivalent to ToM (1995). Baron-Cohen searches for the missing links in autistic communication, the communicative flaws (1995). He is searching for the cause of mindblindness or the inability to mentalize (1995).

Granlund (1993), and Cascella (2005) both investigated the communicative competence of the severe to profoundly intellectually disabled, although they have chosen different methods of assessment. Granlund's dissertation fits in the category of the *social and relational* model of Disability Studies. All his research is grounded on the communicative competence of persons with profound ID, not on their disabilities. His study is, in large measure, motivated by the quest to find and document the relationship between the communicative competence of persons with ID and their environment. Granlund uses structured interviews and observation to assess the communicative competence of his subjects and the effectiveness of staff training interventions (1993). Cascella uses the results of staff informant reports to evaluate the communicative strength of 14 adults with severe to profound intellectual disabilities residing in group-home settings. The staff informant reports contain a 28-item expressive communication rating scale that categorizes communication according to both form and function. Cascella's results are both quantitative and qualitative. He describes not only what kind of communication takes place but how often it occurs. Cascella, as does Granlund, concentrates on the communicative strengths of his subjects (2005).

The overall conclusion that Granlund draws from his research and study of literature is that persons with profound mental retardation have communicative competence despite their disabilities (1993). He also concludes that this competence is, in great part, dependent on the people in the disabled persons' environment and this in turn demonstrates the importance of concentrating interventions aimed at increasing the communicative competence of persons with profound mental retardation on educating the staff that work and live with these people (Granlund, 1993). Cascella concludes that the subjects of his study have "numerous and diverse communicative strengths"(2005, p. 3) and that the use of context-sensitive rating scales completed by direct-care staff is an effective means of evaluating the communicative ability of individuals with severe to profound disabilities(2005). Furenhed finds existential competence in his subjects and draws the conclusion that this quality is greatly dependent upon their caregivers (1993). Baron-Cohen in his extensive research with autistic children discovers what is lacking in their communicative ability. From these studies we can assume that communicative ability can and does exist in nonverbal adults with Id and ASD and that it is greatly dependent upon their relationship with their caregivers. What has been found to be deficient in the communication of children with ASD has been related to the abilities to perform joint attention and ToM.

Chapter V

Methods and Process:

Participants and Subjects:

Convenience sampling (Bryman, 2008, p.183) was used in the selection of the informants for this investigation. The ambition was two interview at least two different key-caregivers, one from the residence and one from the day center, regarding their communicative relationship with their assigned service user. Five service users, two men and three women from the day center where six of the key-caregivers work were chosen to be the subjects of the interviews. They are all nonverbal, have severe ID and have some form of ASD. At the Time of the interviews they were between the ages of 21 and 37. Five of the interviews with the service users' key-caregivers were conducted at their day center and three at the assisted-living residences. Since two of the service users still lived at home two interviews were conducted with their guardians. One of these interviews took place at the day center and the other at the local library. In addition a caregiver who has worked many years at the day center and knows the service users well was interviewed.

Individual interviewed:	Interview centered around communicative relationship with : (fictitious names)	Work place:	Time they have known each other:
caregiver A (male)	Björn	Key-caregiver residence	3 years
caregiver B (male)	Björn	Key-caregiver Day Center	7 years
caregiver C (female) (C = J)	Anders	Key-caregiver Day Center	1.5 years
caregiver D (female)	Anders	Parent/key- caregiver at home	Service user's whole life
caregiver E (female)	Bjorn, Anders, Lisa, Amanda and Diana.	caregiver Day Center	Worked at the center for 11 years
caregiver F (female)	Lisa	Key-caregiver Day Center	10 years
caregiver G (female)	Lisa	Key-caregiver residence	16-17 years
caregiver H (female)	Amanda	Key-caregiver Day Center	6 months
caregiver I (female)	Amanda	Key-caregiver residence	4 years
caregiver J (J = C)	Diana	Key-caregiver Day Center	1.5 years
caregiver K (female)	Diana	Parent/key-caregiver at home	Service user's whole life

5.1 Interview Chart: Showing the caregivers interviewed and the service users whose communicative relationship the interviews centered around.

Above is a chart showing the caregivers interviewed and the service users whose communicative relationship the interviews are centered around. This chart also shows how long each caregiver has known the respective service user and where they work with them.11

interviews were conducted with ten caregivers. Nine key-caregivers were interviewed regarding their communicative relationship with the service user assigned to them and the parents regarding their offspring. The caregiver who was not a key-caregiver to any of the subjects was interviewed regarding all five of the subjects. One of the key-caregivers from the day center and one from the residence were male. These two men were key-caregivers for the same individual, also a man. The rest of the informants were female. Since one of the informants was a key care-giver to two of the subjects at the same time, she was interviewed twice, once for each service user. The individual informants are referred to as A, B, C, D, E, F, G, H, I, J (C and J are the same caregiver interviewed twice regarding two different service users) and K during the rest of this paper. The service users have been given fictitious names.

Process:

The acting director was contacted and informed of the proposed study. It was requested that the guardians of these service users be contacted in order to inquire as to whether they were willing to consent to the realization of this study concerning their wards. Letters of informed consent (see appendix A) were drafted and sent to the guardians of the service users. The letters of informed consent were written according to the guidelines presented in Codex Rules and Guidelines for Research, Informed Consent (CODEX, 2013). All of the guardians gave their consent and signed the letters. The key-caregivers at the day center attended by the service users and the service-residences or homes where they lived, were asked if they would participate in the individual interviews. All of them agreed and signed the letter of informed consent preceding the interviews.

Quality vs. Quantity:

Using the data collected and the literature reviewed, the intention was to qualify the communication between the subjects and the informants. Communication is difficult to quantify without the aid of video cameras or constant third-party observation. The possibility of using these methods was considered but rejected on the grounds that they might infringe on the privacy and integrity of the service users. It was felt that an attempt to quantify communication would also place rigid and arbitrary restrictions around the definition of communication. The original premise is that communication does take place between the service users and the informants and the main interest is not in how much but how this communication works and what are the attitudes and behavior that enhance and strengthen this interaction. This is similar to the approach used by Sigafos et al. where the objective was to identify the individuals' potential acts of communication and in what capacity they were used, not how often they were used (2000).

Semi-structured Interviews:

Because the interviews were with highly engaged caregivers and parents, and in some instances we touched upon emotionally charged subject matter, it was deemed important that the interviews be flexible and allow for supportive listening. It was also important that the informants be allowed the time and space necessary to formulate their thoughts. The ambition was that they should feel free to improvise and come up with valuable although maybe unexpected information. As a result an interview schedule (see appendix B) was used but the informants were allowed a certain freedom with their answers and eventual narrations, qualifying this method under the category of Semi-structured interview (Bryman, 2008, p. 196). The interviews were taped and then transcribed. The transcripts were then submitted to those interviewed for their approval. All the interviews were conducted in Swedish. The original interview schedules were also in Swedish and have been translated into English (appendix B). The interview transcriptions were also written in Swedish so the informants'

quotes have been translated from Swedish to English. I believe my 30 years in Sweden have given me sufficient time to enter into the Swedish hermeneutic circle and I believe my translations do justice to the original words of the informants.

Distinguishing intentional nonverbal communicative acts from spontaneous ones is a very difficult task when dealing with individuals with ID, ASD and SCI. The fine line between non-symbolic and symbolic communication is also not easily distinguished. Cascella however does classify behavior such as: leading gestures, request for objects, request for action, asking for help and directing staff actions as intentional. He also distinguishes between symbolic and non symbolic communicative acts (2005, p. 3). The possibility of using this kind of classification was dismissed because it seemed to eliminate the possibility that all communicative behavior could at times be intentional and that any nonverbal behavior can acquire a symbolic meaning and be used as such. This is one of the reasons that the *Inventory of Potential Communicative Acts* (ICPA) (Sigafoos, et al., 2000) was used as the foundation for developing the interview schedules for this study. Sigafoos et al. when developing the ICPA, an interview schedule for nonverbal communicative assessment, chose to use the term *potential acts of communication* (2000, p. 78). In so doing, they eliminated the necessity to qualify communication as intentional, spontaneous, pseudo-spontaneous, pre-linguistic or symbolic. *Potential acts of communication are defined as any behavior interpreted by others as a form of communication* (Sigafoos et al., 2000, p. 79). This includes all personalized forms of behavioral signals and or displays created and used as effective forms of communication that can be responded to accordingly. The word potential, is appropriate in that it implies an attempt to communicate but does not eliminate unsuccessful communication i.e. communication that is partially understood or misunderstood. Another advantage of this approach to qualifying communication is that it is determined by the observations of those who interpret these acts, in this case, the key-caregivers.

In this form of assessment, communicative competence as expressed in pragmatic functions is emphasized (e.g., requesting, protesting, commenting), instead of singular symbolic communication (Sigafoos et al., 2000). The ICPA divides potential acts of communication according to the following 10 functions: Social convention: greeting others and responding to own name; attention to self: getting the attention from others, seeking comfort, showing off; rejection/protestation: rejecting items, indicating no; request for an object: requesting a preferred item; Request for an action: asking for help with a game, dressing; request for information: asking for the name of an item or clarification; comment: how does one indicate different emotions?;Choice making: choosing between two alternatives; Answer: indicating yes or no in answer to a question and Imitation (Sigafoos et al., 2000, p. 80). Seven different categories of nonverbal behavior are listed as potential acts of communication: vocalization, body movement, face and eye movement, breathing, challenging behavior, stereotype movements and symbolic forms (Sigafoos et al., 2000, p. 79). The ICPA was designed to systematically identify and describe the potential acts of communication of individual children (Sigafoos et al., 2000, p. 84). The fact that this is not a standardized test, that it is centered around the individual and that it uses functions to define the different acts of communication, made it applicable for use in this study. Despite the fact that it was designed for assessment in children, the ICPA proved to be a very appropriate source of inspiration when developing the questions for the interviews regarding adults.

The interviews consisted not only of questions based upon the ICPA, but also included questions pertaining to how the caregivers themselves communicate with the individual service users. Questions relating to joint attention and eye contact were added due to the importance of this communicative phenomenon in regards to the cooperation model of

communication, ToM, affect attunement and Autism. The interview schedule also included questions about what special activities might help develop and strengthen communication and about possible improvement. The last question of the interview (see Appendix B), relates to the concept of affect attunement, ToM and common conceptual ground. This is an open question, and I was hoping for a narrative response that would shed light on the possible existence of a deep emotional form of communication between the informants and the service users.

Credibility and Transferability:

Due to restrictions of time and resources, an extensive examination was not possible. Instead, this study was executed on a small but detailed scale. The goal was to retrieve as much information as possible regarding the communication between eleven informants and five service users during intensive hour-long interviews with each informant. By allowing a comparison of two accounts of the same social reality (the service user's communication), the 11:5 ratio of informants to service users increased the credibility of the findings (Bryman, 2008, p. 377). In an effort to bring transferability (Bryman, 2008, p. 377) to this study the focus has been narrowed, taking a close look at the communicative relationships between the individual service users and their key-caregivers. The ambition then was to extrapolate a "big picture" that applies to others in similar situations.

Preconceptions:

Having worked many years with adults with different forms of ID and ASD, I embarked on this project with a strong preconception that these individuals could and do develop, change and grow. In conducting these interviews, I was well aware of my bias in this regard and made a concerted effort to maintain neutrality in both the interview process and the analysis of the transcripts. Despite this, as Malterud points out, there is no such thing as neutrality:

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions (Malterud, 2001, pp. 483-484).

Although this form of preconception can be viewed as a liability when considering the credibility of the results of this study, it is also the original motivation for pursuing an education within Disability Studies and for initiating this investigation.

Analysis:

Consideration was taken regarding the actions, thoughts and motivation of the people involved when analyzing the data collected. In other words, the information was inspected with a hermeneutic (Bryman, 2008, p. 15) magnifying glass. Reoccurring themes were explored that when related to information obtained from the literature reviewed, suggested which elements could be considered catalysts to communicative improvement and why. In the data analysis a Salutogenic (Antonovsky, 1987) stance has been taken. Emphasis has been placed upon a search for what attitudes and behaviors strengthen existing interaction and help create a healthy and functional system of communication.

The interview transcripts were analyzed using qualitative content analysis (Bryman, 2008, p. 529). The data was categorized for each of the service users in order to create a complete picture of the individual's communicative relationship with their caregivers. Information regarding the forms of communication used by the informants to communicate with service

users was categorized and analyzed. Information regarding the communication used by the service users was coded according to the functions of the communicative behavior and then categorized according to the kinds of behavior used, the reported difficulties, when this behavior usually occurred and the caregivers' reaction to this behavior. The information was reviewed in search of data regarding what stimulated different communicative behaviors. Reports of communicative behavior indicating evidence of joint attention, affect attunement and ToM were categorized separately. The data was reviewed to see if there were indications of communicative improvement and if so what this could be attributed to. The information was analyzed in search for recurring themes regarding the actions, behaviors and attitudes that could contribute to the expansion of the service users' and the caregivers' common conceptual ground.

Ethical Considerations:

How do we discern the feelings, frustrations and opinions of those who can't speak for themselves? Sometimes it is possible to interview people with ID or ASD using pictures, sign language and other communicative aids (Danielsson, 2006), but not in this case. The level of their cognitive disabilities makes this an unfeasible task. Furehed, in his study of the inner world of the severely intellectually disabled (1997), used interviews with the parents and those close to his subjects, so that the informants could be: *substitute judges of quality of life* (1997, p.16) (translation by the author). Here very much the same method is used. The informants have been asked to be substitute judges of quality of communication. As in Furehed's study, the informants are not the subjects, they are interpreters who are used in order to gain access to the world of the nonverbal individuals. Normally, of course, all those involved in such a study would need to supply their informed consent. But since the service users are unable to understand and or give consent, it was necessary to request permission from their guardians. This created a difficult paradox: permission was received from the parents, at the same time that it was essential to respect these individuals as adults in their own right. How can this be? How can one ethically justify this study if the participants themselves are incapable of clear and full-hearted consent? One has to assume that, if the legal guardians of the people involved, in this case their parents, believe this study can in no way harm and may help, the individuals involved, that this is in fact the case. It would appear that these guardians share the ambition that this study could become a vehicle through which these people can in some way, be seen and heard. Several other methods other than interviews with caregivers were considered but rejected because of the possibility of compromising the integrity and confidentiality of the service users and their families. The Swedish Research Council's Guidelines suggest that the ethical risks involved in the methods of a research project should not outweigh the gain from the outcome of the research (The Swedish Research Council's Expert Group on Ethics, 2011, pp. 31-32). The ethical flaw in this research, the fact that those who are the focal point of this research were unable to give their consent, is balanced by the intention that the results of this study could give these people a voice and that this voice could in turn help others in similar situations.

Chapter VI

Results from the Interviews

Individual Communicative Profiles:

After analysis of the data retrieved from the interviews, one theme seems to repeat itself in all the informants' answers: the importance of recognizing the individuality of each service user. Comments that suggest that one form of communication work with one individual, but not with

another reoccurred in the interviews. Each one of the informants at one time or another commented on the need to become acquainted or *lära att känna* [getting to know] the service users as individuals. After studying the results it became apparent that each of these service users has their own unique way of communicating and that the findings could be best represented by descriptions of these five special communicative systems and how they work between caregiver and service user. At this point it would be valid to question why there is not equal time given to the individual communicative systems used by the caregivers? First the individuality and uniqueness of the caregivers is not in question here and since the assumption is that the caregivers communicate in a fairly standard fashion for adults *without* ID or ASD, their communicative acts do not need to be so thoroughly described for those reading this paper.

These short, sketchy communicative portraits can't possibly do justice to the very intricate personality and cognition of each individual. As with an actual painted portrait the artists hand is always visible in the final product. The intensity of the colors, the brush strokes and what the artists chooses to accent , all reveal the feelings and attitude of the painter. These descriptions are colored not only by the way they are worded and what has been highlighted but they are also shaded by the feelings and thoughts of the informants who have transferred this information. Despite this, it seems to be of intrinsic importance that an effort be made to create an image of each service user as a distinct communicative human being. The hope is that this will emphasize the fact that these are not just five members of a nonverbal group with ID and ASD, but are, equally and crucially, five distinct people with their own likes, dislikes and their own unique form of communicative strengths. In line with the relative model of disability studies, the hope here is to create an accurate image of each individual, not based on their disabilities, but on their unique personalities and their special communicative abilities. Again using Antonovsky's model of Salutogenesis (1987), the interest is not in these peoples communicative deficiencies, instead the search is for evidence of healthy communicative behavior and how it can be nurtured. Sometimes in social services and care institutions there is a tendency to generalize when it comes to people with certain types of diagnosis. But it is often easy to forget that each person is an individual *with* a diagnosis. The diagnosis is not *who* they are. This kind of description seems to be necessary if this information is to be helpful to caregivers of other individuals with similar communicative behavior.

The five service users were between 21 and 37 years old at the time of the interviews, two men and three women. All have severe ID and ASD. Three have epilepsy, and one, though not epileptic, is prone to seizures similar to those found in persons with epilepsy. One of the subjects needs assistance when walking; otherwise all are capable of moving on their own. Given the information received, an attempt to paint an accurate picture has been made. Fictitious names have been used in the descriptions and some details have also been omitted in order to protect the service users' identities and integrity.

Björn: The caregivers interviewed regarding Björn were A and B. Björn is an intense young man who does not use words to communicate. He is very sensitive to all stimuli, auditory, visual and tactile. He can apparently say some words when prompted. He uses assorted high-pitched humming-- noises, shouts, grunts and screams. He also uses gestures-- holding his hand over his ears and shaking his head to indicate irritation or *no*; jumping up and down and stereotypical movement such as waving both hand in the air which usually indicates happiness and excitement. He is very expressive with his face, showing anger, happiness and sadness very clearly. Both informants (A, B) find it difficult to distinguish his physical pain from emotional discontent or sadness.

Björn uses photographs to communicate. He has a communication book with pictures of himself performing different activities. On each door leading to the room where an activity takes place, hangs a picture of him performing the activity that occurs in that room. Underneath is a space for Björn to attach his picture which matches the one already hanging there. He removes the appropriate picture from his book at the beginning of the activity and places it under the existing picture. When the activity is over he removes it from the door and returns it to his book. In another part of the day center, he can look at his weekly schedule that is depicted using the same pictures. Björn participates in setting up this weekly schedule. The informant (B) says this works well for him because he sees so clearly all the details in the photographs and he recognizes his own image without problem.

Björn is subject to strong mood changes. What usually triggers them are changes in routine, or loud obtrusive sounds; but sometimes the informants (A, B) admit they are at a loss to know what the cause is. Björn likes to swim. He also likes to go for walks, play ball with his key-caregiver, and he definitely looks forward to meals. One of his favorite activities is painting with the art therapist that comes once a week (B). The informants (A, B) use short simple words accompanied by gestures and photographs to communicate with Björn. They both seem sure that Björn understands everything they say to him. They also feel that he participates in joint attention with them, sometimes pointing to objects with his finger and at other times using his eyes then looking back at the caregiver to check for a reaction. When asked which activities seem to benefit communication, one informant (A) thinks that sitting and eating at the table with other service users and staff produces opportunities for communication, and the other (B) thinks that painting with the art therapist and bathing at the public swimming pool fill this function.

Both informants felt that communication with Björn has improved over the last three years. They feel this is due to the improvement in Björn's own communicative competence as well as their ability to understand him. As key-caregiver (A) puts it: "He has really improved, and we have become aware of the language he uses to communicate. It is much easier for us to work with him, and it is easier for him when we understand". Both informants feel that they have felt moments of empathetic, emotional closeness or affect attunement with Björn.

Anders: The caregivers interviewed regarding Anders were C and D. Anders is an artist who communicates with his drawings. He loves to draw, and most of the time has complete control and coordination when he puts pencil to paper. He can sit for hours and create one image after another. The pictures just seem to flow onto the paper. When he does something he is particularly proud of, he points to it excitedly and says "Look". If the person with him identifies the object he has represented in his drawing correctly by saying for example; "Anders, you have drawn a tractor!", he reacts with small shouts of joy, waving his hands and a big smile. He communicates with his whole body. His facial expressions are unmistakable, representing joy, excitement, anger and at times disappointment. He has several words that he uses correctly among them are: look, no, food. He also has a large repertoire of grunts, whines, shouts, and some words of his own creation accompanied by gestures, which he uses to communicate what he does and does not want. He often simply pushes away what he doesn't want. He can say no and *Lägg av* [Quit that]. Anders uses pictures and or photographs for communication pertaining to his daily schedule. He has a picture for each of his activities that he can associate with what they represent. He also has a transition card. This is a little plastic card with his name printed on it. When he is given this card, he knows he must go to his daily schedule which consists of a series of pictures stuck to the wall with Velcro and get a new picture for the next activity. The informants (C, D) communicate with Anders using

words, gestures and pictures. They believe that Anders understands a great deal of what is said to him with words.

Anders has no problem with eye contact. He is constantly engaging others in acts of joint attention, as when he points to his drawings, looks into another's eyes and then switches his gaze to his drawing. Both informants (C, D) agree that Anders can also follow another's call to joint attention, if it pertains to something that interests him, following both their gaze and their pointed finger.

Anders communicative ability seems to be improving daily. The informants (C, D) feel that drawing and communicating around it has developed Ander's communicative ability. One informant (D) thinks that all forms of social contact seem to help him, while another (C) points out that the establishment of communication around a regular daily schedule has been of particular assistance. She notes that this schedule creates more opportunities for communication and choice making. Ander's home caregiver (D) believes he has matured within the last couple of years and has become much better at communicating his wants and needs. Anders is currently learning to say more and more words. He has not as yet begun to use them actively to communicate except in relationship to his drawings. The informants (C, D) both feel that there is a great potential for growth.

Lisa: The caregivers interviewed regarding Lisa were F and G. Lisa is a woman with a strong personality. She has a large repertoire of phrases and words that usually come when she is excited or happy. These phrases are, for the most part, not used appropriately, and they resemble some forms of Echolalia. Lisa usually pushes away that which she doesn't want, if it is in front of her. If an object or thing she does not like is not close to her, she can make a gesture that resembles pushing away in the air. If a hand is in her way, that might also be pushed aside. Lisa's facial expression shows when she doesn't like something, but this is not usually accompanied by any kind of vocal signal. If it is food she does not want, she can turn her head away from it. Again there is usually no sound accompanying this gesture. When she is doing an activity, like placing plates or mugs on a shelf in the cupboard, she can sometimes do it with calm concentration; at other times, she throws the plates and mugs. The informant (G) interprets this as a signal that she does not wish to perform this activity. She is not equally expressive about what she wants: she usually takes what she wants, if it is within reach, and if it is not, she looks at it. One informant (F) feels that she breathes in and lifts her head and sometimes even nods to indicate yes.

Lisa loves going for walks outside and usually brings home branches that she finds especially attractive and fascinating. She likes it when people sing lullabies, and she loves to say and hear her own name. She demonstrates her joy with her whole face, as (F) puts it "she smiles and her eyes light up". She can also rock back and forth, say different phrases and laugh, which seems to indicate enjoyment or excitement. Laughter can easily turn into what seems like tears and sadness. Both informants (F, G) find it difficult to pinpoint the causes of Lisa's apparent distress. Is it physical pain, emotional sadness or irritation? One informant (F) feels that Lisa sometimes becomes distraught when the caregiver talks too much. Another (G) feels that changes in routine can sometimes be the cause. At other times, the source of her distress has proven to be weariness or sickness.

When she wants to call attention to herself, Lisa usually makes a lot of noise using all the words and phrases she knows. She may sometimes take hold of the caregiver in order to get their attention. When this happens the caregiver has to look around, size up the situation, take

into consideration what she knows about Lisa and guess what it is she wants or needs. One informant (G) said that she usually tries different alternatives until she gets it right.

At the day center, Lisa uses symbols to communicate about her daily activities. A paint brush is used for her weekly creative session with the art therapist; plastic keys on a ring represent going home; a package of her favorite cookies represents going shopping, and so on. Her schedule calendar consist of two shelves: one of these is at waist height with a wooden stick and wooden rings. Next to this is a plastic container that holds the symbol/object for her next activity. On the shelf above are the objects that represent the entire day's activities and underneath on the floor stands a container with all of Lisa's possible activities. When she is through with one activity, she receives a wooden ring which she takes and places on the wooden pole that rests on the lower shelf. Here she also picks up the symbol/object for her next activity. (F) believes this system works well for Lisa and creates opportunities for her to communicate about what she does and does not want to do. If she is enjoying an activity and she receives a ring indicating it is time to change to a new one, she sometimes throws the ring onto the floor, and in this way can ask to stay a little longer. One informant (F) told me that one day Lisa took out the plastic keys instead of the activity symbol that lay on the middle shelf. The informant interpreted this to mean that she wanted to go home. This also brought to light the fact that Lisa was sick that day and needed to rest.

In general, both informants (G, F) use simple words, combined with gestures and symbols, to transfer information to Lisa. They agree that she is capable of following a pointed finger and engaging in joint attention with the use of her eyes. Both informants feel that there has been great improvement in the last three years. One informant (G) attributed this to better communication between the day center and the residence. She says: "Lisa has always been capable of much more than we were aware of, we have just learned to read and understand her better"(G). The other informant (F) says that Lisa has learned to be more tolerant to change and has become better at communicating. She also proposes that she herself has become better at knowing when is the right time to try new things, how she should talk to Lisa and encourage her in the right way. The informants (F, G) both feel they have experienced moments of attunement with Lisa.

Amanda: The caregivers interviewed regarding Amanda were H and I. Amanda is a responsive young woman who often smiles. She does not use speech to communicate, although she is very vocal, singing, shouting, laughing, screaming and or producing clicking noises. Her different vocal outputs are often interpreted as communication, indicating how she is feeling or what she wants. At other times, they resemble a type of humming or singing, one does for oneself. Amanda gestures often with her whole body, leaning into things she desires or arching away from what she does not want. She can rock back and forth when she seems to be glad or interested, and she can also bang her feet and or hands in order to communicate. It is often her face and eyes that transfer information to others. At times she shouts in a manner that both informants interpret as unhappiness but whether this is due to physical pain or something else they could not say. As (I) says: *One has to be a professional and look at the situation; what did I do? Or what is happening now?*

Both informants believe that Amanda is capable of joint attention through the use of her eyes. They say she can direct her gaze towards the object involved in the triadic communication. Amanda's caregivers do not use much in the way of aided AAC. Occasionally, they will use personalized sign language, and occasionally symbols in the form of everyday objects, but such instances are few and always accompanied by words and gestures. Amanda herself does

not seem to use any form of aided AAC. She has established, however, the otherwise stereotypic movement of banging her chest with her fist which (I) interprets a sign for *yes*. Amanda loves sounds. She is constantly producing them herself, and she loves to hear them. She is also very fond of different tactile sensations. She likes both the sound and feel of water. Music almost always brings a smile to her face. She enjoys being in a social group and seems to really enjoy loud social/musical events such as discos.

How much does she understand? Since the two informants (H, I) say they both communicate fundamentally with simple words and gestures enhanced by some personalized sign language, we can only assume that this is what she understands. Both informants interviewed (H, I) believe that communication with her has improved within the past three years. Both of them think that the advance is due to their own improved ability to understand and interpret her needs and personality. The informant that has been with her the longest (I) also gave credit to an increased sense of trust between her and this service user. Both informants (H, I) describe instances of affect attunement that they have shared with her.

Diana: The caregivers interviewed regarding Diana were J and K. Diana is a sensitive young woman. She seems at times to lose herself in small tactile details such as the edges of the pages in a pad of paper, running her finger over the corner again and again. She finds it difficult and laborious to concentrate and *vara med* [pay attention]. For Diana, direct eye contact does not come easily but the informant from the day center (J) says that her ability to make eye contact has slightly improved since she started there. Diana does not make much attempt to communicate her wants and needs to others. She usually takes what she wants and leaves what she does not want. She makes lots of different sounds, some that sound like talking, sometimes singing, or humming, sometimes shouting and at times screaming. Some of these sounds can be interpreted as communication, while others seem to be something she does for herself. She sometimes shows irritation or a wish not to partake in an activity by physically removing herself i.e. going somewhere else. At the day center, she goes to the couch where she usually relaxes and looks at magazines, here she knows she will be left alone. Likewise at home she retreats to the bathroom, where she knows she will be left in peace.

One informant (K) noted that Diana seems to be bothered by things that happen around her like other people's loud, heated conversations. She demonstrates this by becoming very agitated. At these times it has been noted that it is best to try to remove or stop the source of irritation and let Diana calm down before attempting to communicate with her. The informants communicate with Diana using simple, clear words, gestures and objects as symbols. Both informants (J, K) believe that Diana can understand short sentences and simple commands because she often responds to them.

At the day center an attempt was made to use pictures as a communication tool with Diana but this did not seem to work. A new try was made with symbols in the form of objects to represent different daily activities. The informant at the day center (J) describes how Diana immediately responded to the objects and now uses them with great ease. In Diana's case, only one object at a time is available to her, the symbol of her next activity. She associates this symbol with the activity and goes to the room where it takes place. She does not have access to symbols for all the day's activities, which is deemed to be more than she could handle. This avoids confusion and does not demand too much of her, only that she concentrate on going to the next activity. The symbols used are objects related to or involved in the corresponding activity. For example, relaxing on the sofa and looking at a magazine is represented by a magazine; and drawing or painting in the art room is represented by a paint

brush. This system does not permit her to choose one activity over another, but it does permit her to reject an activity she does not wish to partake in at the moment.

It would seem that Diana likes to be read aloud to. The informant (J) believes that she enjoys the changes in tone of voice when the reader becomes different characters. She also enjoys bathing in a jacuzzi. Sitting together and drawing with other service users in the art room is considered by one informant (J) to be Diana's favorite activity at the day center. When asked what activities promote development in communication, (K) suggests that routinely scheduled activities that relate to life skill training are the most beneficial for Diana.

When asked if communication with Diana has improved within the last three years, both informants agreed categorically that this was the case. Her home caregiver (K) noticed a great deal of improvement within the past two years. She believes that she is now much better at communicating what she does not want. Diana has also become more willful and has gained integrity. The caregiver at the center (J) credits much of the positive change to the use of symbols and to Diana's own improved ability to understand and interpret. She also feels that the increased eye contact has helped communication. Her home key- caregiver (K) describes an episode of empathetic attunement which she experienced with Diana some years ago.

Forms of Communication used:

All the caregivers report that they use verbal language to communicate with the service users. They all stress the importance of using simple, clear language. Some state that they also use gestures and informal sign language to support their words (H, F). Others supplement communication with pictures (A, B, C, D, E). Three of the informants used objects (F, G, J). Eight of the eleven informants use some form of aided AAC, such as pictures or objects adapted to the individual, to assist with communication about daily activities. Five of the informants state that the use of symbols such as pictures and objects make it easier for them to communicate with the service users about their daily activities (B, C, E, F, J).

The caregivers in this study report that service users find it easier to respond than to initiate interaction and often required stimulation or provocation from others (A, B, E, F, G, H, I). All of the service users are reported to use vocalizations, body gestures and facial expressions including eye movement to communicate. Two of the service users use pictures as symbols. Two use objects for symbolic communication and one of the subjects is reported to occasionally use what is interpreted as symbolic gestures (sign language). One of the subjects also occasionally uses words in an intentionally symbolic context. Two of the service users can and do use both their hands and eyes to point. Three are reported to point at objects by shifting their gaze. It was reported that one of the subjects uses her whole body to point as well. Five of the informants state that the use of symbols such as pictures and objects makes it easier for the service users' to communicate about their daily activities (B, C, E, F, J).

Communication with Different Pragmatic Functions: It is reported that the service users have a larger nonverbal vocabulary for communicating what they don't want, than for what they want. The informants have no problem identifying behavior indicating rejection or protest. All of the informants can identify several different behaviors used by the service users to indicate when they don't want or like something. The informants note that most of the service users, when desiring an object, will, if possible, take hold of it. In cases where the object is unreachable, gazing and pointing at the object, sometimes combined with vocal signals, are often used. Nonverbal requests for action, on the other hand, such as asking for help tying shoes or putting on a jacket, is harder for the informants to detect.

Regarding the function of choosing one thing over another, all of the informants report that all of the service users are capable of communicating choice. The choice of one activity over another is according to the informants more difficult to communicate than the absolute refusal to partake in a certain activity. When asked if the service users can communicate “yes” or “no”, all the informants report at least one easily distinguishable signals for “no”, whereas “yes” was reported to be more subtle and harder to detect.

One of the questions posed to all informants was if and how the service user demonstrated curiosity, or requests for information. Three informants report that two service users do sometimes behave in a way that they interpreted as being a request for information. The other seven informants do not report any behavior that indicates a requests for information from the service users.

Regarding the function of drawing attention to themselves, all the informants report that all of the service users have an easily distinguishable behavior for this function, in all the cases this most often involves some form of vocalization. It is reported that only two of the service users do not at some time demonstrate a behavior that could be interpreted as imitation. Regarding the social functions such as greeting and recognizing names: All the informants report that all the service users know their own names and two of the service users react to the names of family members. Apparently only one service user has any behavior that could be interpreted as a social salutation. Four of the service users are reported to respond to simple verbal commands. Regarding the remaining service user, the informants are not in accord. (H) believes that the subject does respond to commands and (I) does not.

Requests for affection: Several of the informants (B, D, E, H, I, J) mention instances where the four of the service users request or initiate exchange of expressions of affection or closeness. In one case this consists of hugs initiated both at times of joy and at moments of distress or sadness (B). Other informants (D, E) report that one service user creates his own special kind of hug that he initiates when he seems to be elated. Two informants (H, I) report that one woman does at times present her cheek to a caregiver and if the other places their cheek next to hers, her “request” seems to be fulfilled. (J) noted that her assigned service user in times of apparent happiness would take the caregivers hand and or stroke them gently under the chins.

Communication Around Emotions and Abstract Concepts: Regarding the function of commenting or showing emotions, all of the informants find it easier to interpret the cause of apparent joy or happiness than to determine the origins of apparent despondence. Several informants reported frustration over often not being able to find the source of behavior that they interpret as distress or sadness. It was also said that it is difficult to distinguish physical pain from emotional distress (A, B, F, G, H, I). It is reported (J, K) that in the case of one service users it is impossible to pinpoint any behavior that indicates sadness and that anger seemed easier to identify. From what the informants report, the only behavior indicating fear shows itself as a reaction to physical danger, such as walking over a high bridge with lots of cars passing under, proximity to dogs and or slippery walkways where one can lose control and fall. One informant (K) describes a spontaneous response to fear with the following words: “Her body showed that she was afraid, whereas she herself could not express this fear.” It was reported that all except one of the subjects can’t request an object that is not visible at the moment.

Joint Attention: Regarding the service users' ability to engage in joint attention, eight of the informants (A, B, C, D, E, F, G, H) report that four of service users can participate in this form of triadic communication. Regarding one service user both informants (J, K) agree that she does not participate in joint attention. Regarding another service user, one informant (H) believes she can engage in joint attention using her eyes, whereas the second informant (I) does not.

Moments of Affect Attunement: Eight of the informants (A, B, D, E, F, G, H, I, K) responded to the question regarding affect attunement with a narrative depicting an incident where they felt the service user had in some way exchanged and or shared an emotional experience with them. In most cases, these are depicted as occurring during episodes of heightened emotions and or feelings of well being. Two informants could not recall having experienced any such phenomena (C, J).

Improvement:

All the informants across the board report improvement in communication with the service users over the last three years (or since their employment, in the case of those who have been working with the service users for a shorter period). Nine of the informants report that they see improvement in both the service user's ability to communicate and in their own ability to understand and or interpret. The informant who has worked with the service user the shortest period of time (H) has only noticed improvement in her own ability as interpreter; and a resident caregiver (K) feels that the service user she works with has improved significantly since attending the day center. One of the informants (G), credits communicative improvement, to an open dialogue and shared information between the service user's residence and the day center. Several others, attributes it to increased knowledge regarding the service user (A, B, E, F). While another informant (I) attributes it to a relationship of trust. Several informants (B, E, G, J) believe the use of systems of aided AAC with objects and pictures have contributed to improvement. Another informant (C) thinks that advancements in communication have been made thanks to expert advice and open communication with specialists consulted in the realms of psychology, pedagogy and Autism.

What Enhances and Strengthens Communication?:

Activities and Opportunities for Communication: Some caregivers (A, B, F, G, J, K) report that a certain kind of atmosphere is conducive to communication, one of calm relaxation without too much input or stress. Others suggest that the service user they work with feels open, relaxed and most receptive to communication at big social events with crowds and loud music (H, I). Others note that the user they are paired with is extremely sensitive to loud noise (A, B). Three of the informants stressed the need for structured routines and life skill activities (C, G, K). All of the informants when asked to name activities that developed communication mention at least one activity that the service user enjoys.

The Caregiver's Role as Detective: One of the informants (I) explains that, when reacting to a potential communicative act, she is often forced to interpret or guess at its meaning. Sometimes a service user can employ the same gesture or vocalization for several different functions (A, B, F, G, H, I, J, K), as in the case of one woman who can use the same wail to communicate several different things. In these cases, the caregivers are dependent upon their own deductive abilities. As one informant put it: "In this case you have to be a professional and think about what is happening in the existing situation. You have to ask yourself, what did I do or what has happened that made her start wailing (I)? It is reported that a caregiver sometimes uses trial and error (G) to discern the motives for a service users apparent

communicative behavior. For example, they might offer the care user different alternatives until she or he accepts one. Sometimes, in the case of behavior that seems to indicate anxiousness or distress, the solution is to let the service user be alone for a while until they calm down (A, B, G, J, K). In such cases, the original motive for the behavior may never be known.

Accumulating Knowledge About the Individual: All the informants agree that the more information they obtain regarding the service users and the more they get to know them as individuals, the better communication between them is. One informant points out that the longer one is with a service user, the better acquainted one becomes with their likes, dislikes, mood swings and what different forms of communicative behavior they use and how it can be interpreted (F). Trust was named as an essential element that contributes to the fact that communication improves with time. One key-caregiver (I) says: “As trust in our relationship grows, so does our ability to communicate.” On the other hand, the same informant points out that working with the same service user for a long period of time does have its pitfalls. She explains that sometimes a caregiver can begin to believe they know a service user so well that they stop experimenting or trying new approaches. “It can be an advantage”, she says : “to have someone come from the outside with no preconceptions as to what the service user can or can’t do”(I).

Timing: The correct timing in relationship to each individual is also mentioned as an important factor in facilitating communication(A, B, E, F, I). Knowing when a service user is calm, relaxed and open to communication is considered to be important if communication is to take place(F). Several of the informants mention the significance of how the service user is feeling that particular day, or in Swedish what they call *dagslägge* (A, B, C, D, E, F, G, H, I, J). A service user can be agitated, uneasy and in need of quiet alone time or they can seem apathetic, out of reach and in need of stimulus and activity. Knowing when to wait, when not to press and realizing when it is necessary to repeat what is said, to try again and maybe again are named as attitudes conducive to better communication (F). The opening that allows all this apparently differs for each individual service user.

Summary:

Data gathered from interviews with informants reveals five very different individual service users who together with their caregivers have developed their own unique form of nonverbal communication. The information gathered regarding these communicative relationships, the attitudes and behavior that make them function, is summarized below.

All the informants communicate verbally with the service users. They all strive to simplify their verbalizations and enhance them with gestures and the use of symbols. Which kind of symbols they use is dependent upon the individual involved. The service users have all developed their own forms of communicative behavior, augmented, except in one case, with a set of symbols (pictures or objects) designed for this use. Symbols in the form of pictures and objects prove to be a great advantage when communicating around otherwise complicated concepts, such as daily activities.

Rejection and protest are reported to be easily communicated and interpreted. All the service users are reported to be able to express the choice of one thing over another although choosing is apparently a harder task than rejecting. Similarly, “no” is easier to communicate than “yes”, and requests for an object present in the room is more easily communicated than a request for action or for an object not present. Most of the service users do not indicate that they are curious or have behavior that would indicate a request for information. The behavior

used by the service users to call attention to themselves is for the most part vocal. The informants report that most of the service users have behavior that can be regarded as imitation. All of the service users react to their own names and a few react to the names of family members. Only one of the subjects is reported as having social greeting skills and all but one of the informants believe that all the subjects are capable of following simple verbal commands.

Communication around objects not present in the room is found to be difficult for the service user to express. The caregiver finds it easier to interpret the causes of feelings of joy than those of sadness. All reported episodes of fear indicate fright of physical threats rather than existential or imagined fears.

It is reported that four of the subjects at times request or initiate exchange of expressions of affection or closeness. The informants judged that four of the service users could engage in acts of joint attention and moments of affect attunement are reported from all informants but one. In most cases, these are depicted as occurring during episodes of heightened emotions and or feelings of well being. It is reported that the activities conducive to communicative development are dependent upon the individual and what he or she enjoys. The importance of routinely scheduled and life skill activities is also mentioned by caregivers.

Definite improvement in communication between caregivers and service users is reported by all informants. This improvement is seen to be a result of the positive influence of the day center, increased communication among staff members, the caregivers increased knowledge concerning the service user, the building of a trusting relationship between caregiver and service user and the use of external communication aids and expert consultation.

The caregivers in many instances find themselves forced to interpret or deduce the meaning of the service users' communicative behavior. Increased knowledge regarding the service users facilitates this process. Knowledge pertaining to the service user, is regarded by the informants as a great advantage in communication between caregiver and service user. Time spent with the service user is also considered an important aid to communication. One advantage of more time spent with the service users, is that it aids in building a trusting relationship between service user and caregiver, which in turn aids the communicative process. Despite the overall positive effects of having a long term relationship with their service users, it has also been suggested that there is a danger that the caregiver may develop a nonchalant attitude towards the service user if they are with them for a long time. Timing or knowing when and when not to initiate certain activities with the service users was also said to be an important factor effecting communication.

Chapter VII

Analysis and Discussion

Relating Reality to Theory:

Theoretically the ultimate goal is full cooperative communication where people can share goals and develop a sense of *we* (Tomasello, 2008). When dealing with nonverbal adults with severe ID and ASD this is a lofty ambition. Functional communication is needed on a daily basis and must be the first step when building a system of communication. This elementary functional interaction, rejecting, requesting and commenting is the base on which all preceding communication will rest. Without first establishing a working functional communication there can be no growth in common conceptual ground and hence no

possibility for cooperative communicative communication (Tomasello, 2008). Hence the first question in this study, does such a basic functional system of communication exist and how does it work? The second question is can this communication change, evolve and perhaps move closer to the ultimate goal of cooperative communication? What behaviors and attitudes on the part of the caregivers promote the expansion of the common conceptual ground and the eventual evolution of this communication? Can we find evidence of the use of such communicative tools such as joint attention, ToM and Affect attunement? Despite the apparent mindblindness (Baron-Cohen, 1995) of these service users can we find hints that it is possible on some level, to cultivate these elements?

Quality of Communication:

Granlund finds that there is communicative competence amongst the profoundly mentally disabled (1993); Furehed (1997) confirms their existential competence while Cascella establishes the communicative strengths of adults with severe to profound ID (2005). The results of this study similarly confirm the existence of a personalized, functional system of communication between nonverbal adults with severe ID and ASD and their caregivers.

Forms of communication: Information from the interviews reveals that each service user has their own unique communicative behavior. Some are more vocal than others, some communicate with their whole bodies, some use their eyes to communicate, while others avoid eye contact. Some use aided AAC in the form of photographs, while others work better with pictures or objects. Another service user uses no form of symbolic communication on a regular basis. The fact that four out of five service users, use symbols to assist in communication can be related to Cascella's results where all 14 of his subjects were reported to use some form of symbolic communication (2005). The caregivers for the most part communicated with words, enhancing them with gestures, and symbols such as pictures and objects. The informants believed that the service users for the most part understood what was said to them. This would indicate that the service users both transmitted and received information nonverbally, but that they only received verbal communication, whereas the caregivers could receive and transmit both nonverbally and verbally.

Functions of communication: The findings that the service users could all communicate choices, requests for objects and rejection coincide with the communicative strengths described by Cascella (2005). These findings are important in that they indicate the subjects' ability to affect their environment (Cascella, 2005), which can be seen as the ability to participate.

The Potential for Change:

It is evident that communication between nonverbal intellectually disabled Adults with ASD, and the people around them can and does improve. The overwhelming conviction on the part of all the informants is that communication between them and the service users is better than it was three years ago (or since they began working with them). They have varied opinions as to how and why this improvement has occurred, but there was no hesitation on their part when answering questions regarding progress. It could be assumed that it is to the caregivers' advantage to report improvement in their own ability to interpret and communicate with the service users since this is their job. But it is important to note that in nine of the eleven interviews it was also stated that the **service user's** ability to communicate had improved. One could attribute these results to optimism on the part of the caregivers, but this optimism can also be part of the catalyst towards improvement. Without their faith in the potential for improvement and their dogged search for new ways of reaching these service users, surely improvement would not have been possible. After analyzing the results of the interviews, it is

clear that there were certain kinds of behaviors and attitudes on the part of the caregivers, including ones of optimism that made this communicative advancement possible. The importance of the caregivers' ability to detect service users' communicative strengths has been noted in previous studies (Payne & Ogletree, 1995). Again referring to Salutogenesis (Antonovsky, 1987) as a model it would seem more appropriate not to call it *optimism* but instead refer to it as - the caregivers' ability to make use of the service users' communicative powers.

The Importance of the Individual:

In the Swedish Law Regarding Service and Support to the Disabled (LSS) great emphasis is placed on the fact that all services should be designed around the needs of the individual (Bergstrand, 2012). In interview after interview, the informants refer to the service users' distinct personalities, their likes, dislikes, their special way of communicating and the special relationship they have with their caregivers. This uniqueness must be kept in mind when devising systems of communication for the individual. Photographs work well for Björn because he can identify them and immediately associate them with himself and his world. For Diana, pictures do not hold any meaning, but she has been able to identify and associate different objects with the activities they represent. Lisa uses objects that she can recognize and identify as part of her daily life. Such tools, of course, need to be adapted to the individual's physical ability. Björn has no problem with fine coordination, and can easily negotiate a communication book with small pictures. This kind of delicate procedure would be very taxing for both Lisa and Diana, who would soon lose interest, yet they find it easy to hold an object in their hands and relate it to an upcoming activity.

The Importance of Common Conceptual Ground:

Granlund finds that the communicative competence of people with profound mental retardation is greatly dependent upon their caregivers (1993); Cascella acknowledges the importance of staff members' sensitivity to communication strengths (2005) and Furehed (1997) comes to the conclusion that the service users he studies are individuals who have a valid inner emotional life that is greatly reliant upon the understanding and support of the people around them. This study, also reveals that the communicative competence of the service users is dependent upon their relationship with the caregivers who stimulate, interpret and validate their communication, in so doing increasing the common conceptual ground shared between them and moving them closer to a cooperative model of communication or a sense of *we* (Tomasello, 2008).

The results from the interviews indicate that communication takes place in the area where caregivers' and service users' conceptual grounds overlap. Cultural differences, the quality of early childhood attachments or the lack there of, our physical and mental state, education, all experiences including possible traumatic incidents, our perception of ourselves and others plus the way we perceive our immediate environment are what build our conceptual ground, which will in turn influence our ability to communicate with each other (Tomasello, 2008). When dealing with nonverbal intellectually disabled adults with ADS, therefore, we must also consider variants such as the quantity and level of disability and the fact that the individuals involved perceive the world from a unique cognitive viewpoint. Tomasello states that the common conceptual ground is constructed from shared, joint attention shared experience and shared knowledge of the physical and emotional world we live in (2008).

The illustration 7.1 is a visualization of the communicative relationship that was found to exist between the caregivers and the service users. Here the caregivers are capable of both

transmitting and receiving verbally whereas the service users can only receive verbally and even then on a limited level. The area where conceptual grounds overlap is where it is possible for communication to take place. The more the caregiver is capable of expanding her or his conceptual ground and the farther they can move it towards that of the service user, the larger the common conceptual ground becomes, thus increasing the areas available for communication. This whole system is open and susceptible to influence from the environmental context and or the situation at hand.

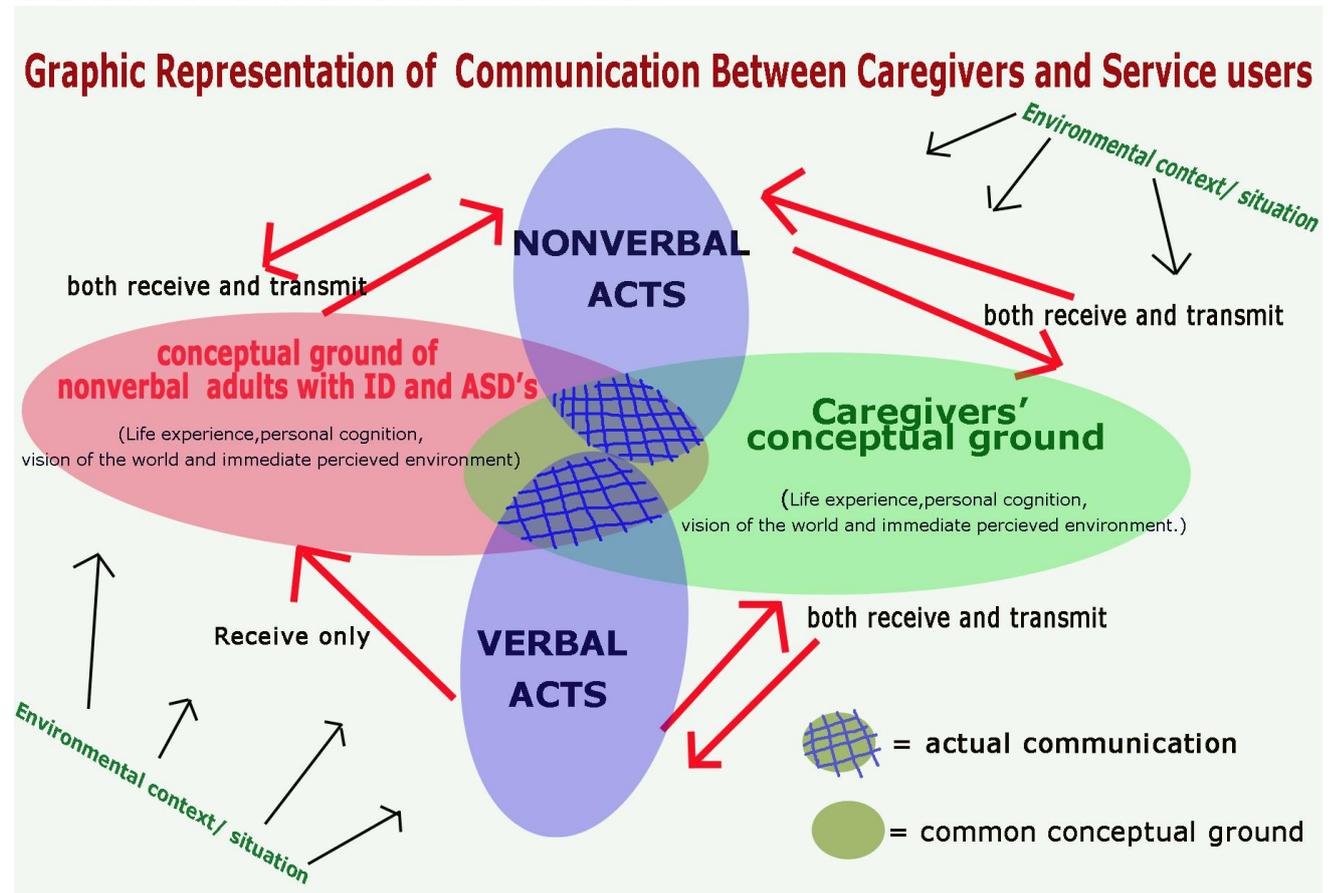


Illustration 7.1: *Graphic Representation of Communication between Caregivers and Service users.* Jane Hawes, 2013.

The following description of a communicative incident reported by one of the informants (J) demonstrates the dynamics of the common conceptual ground in a very simple manner. Everyone knew that Diana likes sweet things like cake and cookies, but she never ate her cake on Fridays. She did not complain or make any kind of attempt to communicate a dislike for the cake, she just left it. Why? Was it the surroundings in the dining room that put her off? Was she not hungry at that time of day? Did it make any difference if a different person sat next to her? The mystery was soon solved when someone found out that Diana did not like bananas. The cakes that had been baked were all banana cakes. Next Friday, Diana was offered an apple cake and she ate it! This story serves to demonstrate the importance even seemingly insignificant information regarding the service users can be. Caregivers could have easily understood if Diana had pushed away the cake and made a face indicating dislike. This would have fallen within the area of the caregiver's conceptual ground i.e. one pushes things away and makes a face when they do not think they taste good. However, caregivers could not understand when Diana did not want the banana cake, since they had no common knowledge of her dislike for bananas, and she had not communicated this to them.

The difference between emotional sadness and a reaction to physical pain was difficult for the caregivers to distinguish because they and the service users had established little common conceptual ground in these areas. Usually, both parties in a communicative relationship strive to increase their common conceptual ground, i.e. try to understand each other. But in the case of the relationship between these service users and their caregivers, the responsibility to increase the common conceptual ground lies for the most part on the shoulders of the caregivers. The results of my interviews reveal that one of the most important goals of a caregiver in this circumstance is to expand the common conceptual ground between themselves and their service users. This would confirm Granlund's conclusions of the importance that caregivers have in regards to the communicative competence of the profoundly disabled(1993).

Increasing the Common Conceptual Ground:

A Constant Effort to Increase Opportunities for Communication: The caregivers in this study report that service users find it easier to respond than to initiate interaction and often required stimulation or provocation from others. Similarly, Granlund found that the initiation of communication was much more demanding than responding (1993). Hence, the more the caregiver is capable of prompting communication with questions and options for response, the more opportunities for communication they make available to the service user. Every time the caregiver reaches out with word, gesture or symbol; every time she or he stimulates the service user to engage in activity with others, the common conceptual ground between them is increased, and their store of shared experiences grows.

Exercises and activities that stimulate mentally and physically can both promote communication and increase conceptual commonalities. If a caregiver is attentive, responsive and open to the service user's reactions and behavior during these activities, there is great potential for improved interaction. The results from all the interviews indicate that it is not important what these activities are, but rather that they be stimulating and enjoyable for the service user and that the caregiver have an open, playful attitude, free from judgmental restrictions. Again, the importance of seeing the service user as an individual is primary.

A Common Language: The service users in this study have learned to understand spoken language, to some extent, if only to receive limited but basic information (all the service users understand short simple words and or commands). So it stands to reason that the caregivers, in their turn, have learned the service users' own nonverbal language. Tomasello states that unintentional nonverbal communication in small children is the stepping stone to intentional verbal communication (2008). Behavior used by a service user, regardless of whether it is deliberately used to communicate or a spontaneous reaction to stimulus, can if continuously responded to as communication, result in the individual's intentional use of said behavior to communicate (Sigafos, et al, 2000). This would support the importance that all the informants give to learning the different communicative behaviors of each individual and trying to respond to them accordingly.

Together, the service user and caregiver create a new language they both understand and use to transmit and receive information. One informant (J) describes this process in the following way: *When we began using real objects as symbols, for example a brush to represent painting, we saw that her ability to communicate changed from night to day! Now she knows what activity she is going to and can communicate with us around this* (J). If this new language is adapted to the individual's own special form of cognition and also takes advantage of already existing nonverbal behavior, it can join together the service user's and the caregiver's conceptual grounds.

An Attitude that Builds a Trusting Relationship: Several of the informants (E, I, F&G) pointed out to me that, in working with this population, it is important to have patience and not expect things to happen overnight. (I) expressed the importance of building up a feeling of trust between the service users and themselves. As (I) says: *Communication in itself is a form of trust.* We all know how scary it is to go to a foreign country and attempt to communicate with a handful of mispronounced words. It is much easier if you feel comfortable and safe with the person you are talking to. Similarly, communication between service users and caregivers is much easier for both if it takes place in an atmosphere of trust and confidence. In order to gain trust, it is necessary to establish a stable relationship. This relationship should be a building block that gives the service user the tools to establish other relationships. It should be a safe, reliable support that can be the doorway to other social interactions. The attitude needed on the part of the caregiver in order to establish such a trusting relationship is described in detail by Podvoll (1990). He also gives it a name: *Basic Attendance* (Podvoll, 1990, p. 247). I am borrowing this term from Podvoll who uses it to describe the special approach needed by staff working with psychotic patients. I will take the liberty of simplifying his concept and describe it here as an attentive, open, understanding and allowing attitude.

Time Together: We can't communicate unless we have some form of shared experiential information. It is very difficult to build up a registry of shared information regarding abstract concepts with someone you can't talk to. Yet a mother does this automatically with her pre-verbal child. Together, they create a repertoire of what Stern refers to as RIG, representation of interactions that are generalized (Stern D. , 1985, p. 25). When a toddler first picks up an object and gives it to his mother and she smiles, claps and hugs him he then generalizes this experience: *Every time I give something to mommy she will be glad and she will do things that make me feel good.* Stern sees these RIGs as the first steps to building a sense of self (1985). The sort of shared interactive experience that produce RIGs can help enlarge any two people's common conceptual ground. To build up this reserve of shared experiences, though, requires time spent together. All the informants report that their ability to understand and interpret the service users has increased with time. The only problem, noted by one caregiver, is the possible development of a blasé attitude on the part of the caregiver. To remedy this, one can say that time spent together is essential, providing that the relationship is constantly stimulated with new input from outside i.e. new activities, caregiver education, and new people interacting with both the caregiver and the service user. It is not only the service user, then, who needs to be challenged and stimulated. The caregiver must sometimes be forced into expanding or changing his or her assumptions regarding the service user. Education and information concerning the target group of service users can be part of such expansion, and is discussed under the caption below.

Shared Information: When conducting these interviews, I discovered that all the informants felt a great need to communicate. The eagerness with which they shared their knowledge with me suggests this is something they would benefit from on a regular basis. Meetings between different groups of caregivers to compare notes, receive/give support, and acquire new information, would surely benefit all. Laws regarding confidentiality are of crucial importance for the protection of the service users, but they sometimes stand in the way of open communication between different caregivers working with the same individual. The more caregivers can communicate around the service users, the more information is shared and compared, the greater the common conceptual ground among them. A constant exchange of information from previous and current caregivers, with a chance for dialogue and discussion

combined with education and information concerning the target group of service users, is essential for improving communication and enlarging the common conceptual ground.

A Shared Daily Routine: One of the major contributing factors to growth in common conceptual ground between service users and caregivers is the establishment of a daily routine that both parties can relate to and communicate with each other about. Informant (C) notes, “We constructed an environment that was more structured and conducive to communication”. An established daily routine provides service users with many opportunities to communicate. The variety of daily activities that service users can attend, along with symbols to make these activities tangible, give them opportunities to reject, protest, accept, comment and, at times, choose.

Joint Attention, ToM and Affect Attunement: The fact that eight of the eleven informants interviewed feel that all but one of the service users are capable of some form of joint attention is another indication of an untapped potential for communicative development. Mundy and Crowson conclude in regard to children with autism that not only are disturbances in joint attention and other social nonverbal communicative skills a key to understanding the development of ASD, but they might also be pivotal to successful interventions (1997). Charman (2003) reports that joint attention is crucial to understanding the development of ASD, and to its diagnosis and early intervention with children. Baron-Cohen sees joint attention as one of four mechanisms leading to the ability of mindreading (1995). Since mindreading is also the key communicative tool lacking in people with ASD, it would seem that the ability to engage in joint attention is a major missing piece in the puzzle of ASD and communication. Tomasello considers joint attention to be a part of the common conceptual ground (2008). Hence, if the caregivers interviewed in this study have observed accurately, and if these individuals are capable of joint attention, this ability may be an important link in the chain of their communicative competence. Creating opportunities for and simulating acts of joint attention can also expand the common conceptual ground.

We are all born with a biological, existential common conceptual ground. The ability to tap into this common conceptual ground is sometimes referred to as ToM (Meltzoff, 1999). Despite their very different cognition, adults with ID and ASD also share with their caregivers the basic conceptual ground of being human beings. Unfortunately, the special way they perceive, feel and react to the world around them makes it difficult to come in contact with this shared humanness (Baron-Cohen, 1995). Spontaneous moments of attunement seem to be those instances where, for a short time, two people can come in contact with this basic human common ground. Stern believes that attunement helps pave the way to a *sense of self* (1985). This *sense of self* confirms one’s existence in connection to other human beings (Stern, 1985) and so increases the common conceptual ground. Nine of the eleven informants could name at least one instance of attunement. We can only hope and or guess that the service users were participating in these moments of closeness. Possibly greater awareness of the existence and the value of such moments of attunement could help caregivers take greater advantage of this unique tool for increasing common conceptual ground.

Preconceptions and Misconceptions:

We all have preconception that help us negotiate in the world around us. They are part of our conceptual ground, and include defensive conceptions we need for survival. If I eat a rotten apple and then get sick, I can anticipate that eating another rotten apple will have the same result. These preconceptions can be tested, and if they are, in fact, misconceptions, they can be changed or adapted to reality. If they concur with what we experience, though, we hold on

to them and reinforce them. Adults with ID and ASD, like all of us, have preconceptions and misconceptions. It takes a long time and repeated retesting, however, for this group of people to revise or change a misconception, but it can be done. (F) reports that Lisa tended to get very upset when there were many items out on the table; she had a misconception that this was bad and pushed everything off the table. But with much patience and repetition, the caregiver has shown Lisa that, when they are baking a cake many items can stay on the table and that, as they are used, they will be put away, one by one. Of course, it is not just service users who need to change their misconceptions; caregivers must constantly test their own preconceptions, such as, “he can’t do that”. The banana cake story shows that the preconception that Diana would like Banana cake, was proved to be false and was therefore revised. Revising or clearing away our own misconceptions and helping service users do the same, is a valuable path to increasing common conceptual ground.

In addition to individual misconceptions, there exist cultural misconceptions that can impact the communicative relationship between caregivers and service users. Many such misconceptions have formed around Autism. In the first half of the twentieth century, ASD did not exist, and Autism was a new and mysterious disorder. It wasn’t until the 1970’s that the term *Autism* began popping up in the popular media (Pollack, 1997). Our lack of knowledge regarding this cognitive disability brought about some false generalizations regarding its origins, those who had it and their families (Pollack, 1997). Here again the importance of the individual service user’s personality makes itself clear. People with ASD are individuals, and as such, their disability manifests itself accordingly. It’s vital that caregivers do not let cultural preconceptions about autism reduce the common conceptual ground they share with their service users.

Limitations and Advantages:

This study is limited in its scope, involving only five service users and 10 caregivers. It would have been preferable to have interviewed a larger group, as well as similar groups in other institutions in order to have a greater variety of comparative results. Another Day Center that worked with a similar group of service users was located and contacted but they were reluctant to participate in this study. Due to restrictions imposed by time and geography the ambition of including larger groups and several institutions in this research, was relinquished. Despite the limitations in the scope of this study the expectation is that transferability (Bryman, 2008, p. 378) will be increased by the use of thick description i.e. making a deep and thorough study of each communicative relationship (Bryman, 2008, p. 378).

Familiarity with this population of service users proved to be, overall, a distinct advantage. The literature studied revealed that others performing research involving nonverbal communication with people with ID had similar experiences (Martin, O’connor-Fenelon, & Lyons, 2012, p. 16). Due to the extreme vulnerability of this group, it is only logical that both staff and relatives find it difficult to relinquish information to those who are not familiar with this specific target group. Because the informants knew that I work with the same type of individuals they do, it was easier for them to communicate their desires, frustrations and uncertainties to me.

Further, I found my familiarity with nonverbal adults with ID and ASD helped me formulate the right kinds of question in the right way and analyze the answers afterwards. In short; our common conceptual ground regarding the service users made it easier for the informants and myself to communicate and easier for me to interpret their answers from a hermeneutic stand point.

Summary:

This study indicates that nonverbal adults with severe ID and ASD have a rich repertoire of communicative tools that are very much dependent on the interpretation and interaction of their caregivers. It also reveals a potential for improvement in the communication of nonverbal adults with ID and ASD. The importance of considering each service user's communicative ability as unique was established. The positive communicative development can in part be attributed to the enlargement of the service users' and the caregivers' common conceptual ground. It is clear that many aspects of the caregivers' attitudes and behavior can increase this common conceptual ground. Caregivers' continual efforts to present service users with stimulating activities that promote opportunities for communication, plus the creation of a common shared language that both parties understand, are vital to creating new common conceptual ground. A secure relationship, based on trust, shared experiences and time spent together, is also a building block of mutual conceptual ground. The importance of increased knowledge regarding all aspects of the service users' lives, combined with a shared daily routine, are also of key importance in expanding common conceptual ground. Creating opportunities for and stimulating the social acts of joint attention and moments of affect attunement will also increase the common ground. Lastly, because misconceptions hinder the development of common conceptual ground and close the door to communication, caregivers must strive to eliminate their own as well as to help service users overcome theirs. In addition to individual misconceptions, there also exist cultural misconceptions that can impact the communicative relationship between caregivers and service users. Finally the limited scope of this study was noted and the advantages of previous knowledge regarding this specific population of service users was reported.

Chapter VIII:

Reflections and Conclusions

A personal Experience of Common Conceptual Ground:

In my work as an art therapist I have been able to witness at first hand the communicative power of common conceptual ground. One such occasion was when I first began working with a nonverbal woman with ID and ASD, I felt from the beginning that we had a special connection. She loved to draw and did so all the time. We would draw together, laugh together, and be excited by the same small miracles of color, texture, line and shape. It took me a while to realize what was happening. She and I were both artists. We had a huge overlapping area in our conceptual grounds, that region of understanding shared by all who are passionate about drawing and painting. In an artistic context we were engaged in mentalization and we partook in many small moments of affect attunement. I would draw a figure and she would watch my every move, fascinated, excited and sharing the experience with me. I likewise was fascinated by the way the images just seemed to roll off her pencil, one beautiful image following another. Whereas it usually takes a while to establish a relationship with an adult with ID and ASD, she and I found each other immediately. I am sure this happens with other specialized areas of conceptual ground. Was there a special immediate form of ToM taking place between us? Surely two people who love plants, music, trains, horses or any other shared passion, will find it easier to connect and understand each other. This is yet further proof of the importance of knowing the individual, what his or her preferences and inclinations are, and how we can connect them with others who share this specialized conceptual ground.

Why Adults?:

It is of particular importance that this study deal with adults. In my work with adults with different degrees and forms of intellectual disabilities, I've frequently confronted a deterministic attitude towards this target group. The common supposition is, "*You can't teach an old dog new tricks*. This belief seems to stem from a sentiment I often hear voiced, the idea that, while growing children can still be molded, trained and helped, adults are too rigid and set in their ways to change. Phrases such as, *It's too late*, or *They can't change*, are often used in regard to adults with intellectual disabilities. But despite such negative evaluations, I have seen again and again the *teachability* of these people. In most cases, they exhibit a huge potential for development and change if only the time, patience, engagement and energy can be found to stimulate and start growth. The more Disability Studies bring to light the existence of this potential, the greater is the possibility that we can erase the preconception that adults with cognitive disabilities are beyond hope of growth and change.

Implications:

The common sense, intelligence and humanity displayed by the informants were a source of constant surprise and delight when analyzing these interviews. These caregivers have important insights and observations that could surely help others in similar situations. It is also evident from the interviews that there is a definite need and longing to exchange information and ideas with others. This leads me to wonder, in this age of networking and social media, why it would not be possible to build a support and education network that does not compromise confidentiality? This is an important mandate I hope will be taken up in future research projects.

As to the validity of my own project, I am aware that information from interviews is always problematic. After all, my observations here are based, in large part, on other peoples' observations. Although the informants have been careful to qualify their opinions and to make it clear when they are unsure of certain facts and events, I have been unable to corroborate their reports via other methods. [Sigafos confirmed the information gathered from interviews with direct observations and structured assessment trials (2002).] In the case of a study such as this one, analysis of video footage would be an appropriate system for verification, and it would most likely be beneficial if future studies of this target group involve both interviews and direct observation from video filming. If we are to build up a common conceptual ground in order to facilitate communication with ID and ASD populations, we must know more. Scholars, like caregivers, can only piece together the clues and information given us in order to puzzle together a rough picture of who these service users are. As stated earlier, very little research seems to have been done regarding the nonverbal communicative skills of adults with ID and or ASD, especially regarding the importance of joint attention and other nonverbal social skills as methods of intervention. We need more studies to help us understand the needs and the developmental potential of these people.

In Closing:

During the course of this investigation, not only did I develop a huge respect for the caregivers who work and live with these service users, but also for these people themselves—their creativity, their determination and their potential for joy. We are not sending a message into outer space, although at times it might feel that way. Yes, sometimes these unique individuals do disappear to a place where we can't reach them but we are here together on earth and we are all humans. We are different, but we do have our shared humanity, and with time and effort we can collect a repertoire of shared experiences. Together we can construct a new language, a common conceptual ground which can help bridge the gap between us.

This study has not brought to light any great revolutionary ideas or theories. It has only reinforced some basic truths about how humans communicate and interact with one another. We are all individuals and must be seen as such, and our communication with each other can be improved by expanding our common conceptual ground. We are all, old or young, disabled or not, capable of change and improvement. The information gathered here reveals the critical mission of caregivers in developing and enhancing the communication between themselves and their service users. If we are to achieve a better quality of life for nonverbal adults with ID and ASD, we must find ways to better equip caregivers in their roles as communicators. Information and education that stresses the importance of the service users as individuals and that also introduces methods and approaches to increase common conceptual ground are essential. Such education is important on a cultural level, too. Our society needs to share the knowledge and conviction that change is possible. And action must follow awareness: we need to invest more time, money and education in making sure that nonverbal adults with ID and ASD are not lost in “outer space,” but can reach their full potential and share their individual gifts with the rest of us.

References

- Alvarez, A., & Lee, A. (2004). Early Forms of Relatedness in Autism: A Longitudinal Clinical and Quantitative Single-Case Study. *Clinical Child Psychology and Psychiatry*, 9, 499-518.
- American Association of Intellectual and Developmental Disabilities. (2013). *Definition of Intellectual Disability*. Retrieved January 15, 2013, from American Association of Intellectual and Developmental Disabilities: http://www.aaid.org/content_100.cfm?navID=21
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4 ed.). Washington D.C.: American Psychiatric Association.
- Antonovsky, A. (1987). *Unraveling the Mystery of Health; How People Manage Stress and Stay Well*. San Francisco: Jossey-Bass Publishers.
- Autism Speaks. (n.d.). *Autism Speaks*. Retrieved January 13, 2013, from <http://www.autismspeaks.org/what-autism>
- Baron-Cohen, S. (1995). *Mindblindness: an Essay on Autism and Theory of Mind*. Cambridge, MA: MIT Press.
- Baron-Cohen, S., Leslie, A., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition*, 21 (1), 37-46.
- Bergstrand, B. O. (2012). *LSS 2012*. Helsingborg: Komlitt AB,.
- Bhaumik, S., Branford, D., McGrother, C., & Thorp, C. (1997). Autistic Traits in Adults with Learning Disabilities. *The British Journal of Psychiatry*, 170, 502-506.
- Bowlby, J. (1983). *Attachment* (2 ed.). New York: Basic Books.
- Brady, N. C., Mclean, J. E., Mclean, L. K., & Johnston, S. (1995). Initiation and Repair of Intentional Communication Acts by Adults With Severe to Profound Cognitive Disabilities. *Journal of Speech and Hearing Research*, 38, 1334-1348.
- Brattberg, G. (2009). *Innanförskap, autismspektrumtillståndets funktionshinder inifrån [Being inside, autism spectrum disorder from the inside]*. Stockholm: Värkstaden.
- Bryman, A. (2008). *Social Research Methods* (3 ed.). Bangladesh: Oxford University Press.
- Buck, R. (1984). *The Communication of Emotion*. New York: Guilford Press.
- Buck, R., & Van Lear, C. A. (2002). Verbal and Nonverbal Communication: Distinguishing Symbolic, Spontaneous, and Pseudo-Spontaneous Nonverbal Behavior. *Journal of Communication*, 53 (3), 315-324.
- Cascella, P. W. (2005). Expressive Communication Strengths of Adults With Severe to Profound Intellectual Disabilities as Reported by Group Home Staff. *Communication Disorders Quarterly*, 26 (3), 156-164.
- Charman, T. (2003). Why is joint attention is a pivotal skill in autism? *Philosophical Transactions of the Royal Society*, 358, 315-324.

- Clark, H. (1996). *Uses of Language*. Cambridge: Cambridge University Press.
- CODEX. (2013). *Informed Consent*. Retrieved April 15, 2013, from CODEX Rules and Guidelines for Research.: <http://codex.vr.se/en/manniska2.shtml>
- CODEX. (2013). *Professional Ethics*. Retrieved may 2, 2013, from CODEX Rules and Guidelines for Research: <http://codex.vr.se/en/forskarensetik.shtml>
- Connors, E. (2012, 3). *The American Psychiatric Association, DSM -5 Development*. Retrieved march 18, 2013, from <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20>
- Danielsson, H. (2006). *Facing the illusion piece by piece : Face recognition for persons with learning disability*. Linköpings: Linköpings Universitet, Institutionen för Beteendevetenskap.
- Ekman, P. (1999). Emotional and Conversational Nonverbal Signals in Gesture Speech and Sign. In R. Messing, & L. Campbell (Eds.), *Gesture Speech and Sign*. London: Oxford University Press.
- Feeley, K., Johnston, S., Jones, E., & Reichle, J. (2011). *AAC Strategies for Individuals With Moderate to Severe Disabilities*. Baltimore: Brooks Publishing Co.
- Furenhed, R. (1997). *En gåtfull verklighet, att förstå hur gravt utvecklingsstörda upplever sin värld [A mysterious reality, understanding how the profoundly developmentally disabled experience their world]*. Stockholm: Carlssons Bokförlag.
- Gerland, G. (2010). *En riktig människa [A real person]*. Lund: Studentlitteratur AB.
- Goode, D. (1994). *Quality of Life for Persons with Disabilities, International Perspectives and Issues*. Northampton: Brookline Books.
- Gradin, T. (2006). *Thinking in Pictures and Other Reports on My Life with Autism*. New York: Vintage Books.
- Grandlund, M., & Olsson, C. (1987). *Talspråksalternativ communication och begåvningshandikapp [Alternative Communication and Mental Retardation]*. Stockholm: Stiftelsen ALA.
- Granlund, M. (1993). *Communicative Competence in Persons with Profound Mental Retardation, Intervention Focused on the Social Context*. Uppsala: Uppsala University Press.
- Halliday, M. K. (1977). *Learning How to Mean: Explorations in the Development of Language*. New York: Elsevier.
- Healy, D., & Walsh, P. (2007). Communication among nurses and adults with severe and profound intellectual disabilities: Predicted and observed strategies. *Journal of Intellectual Disabilities*, 11, 127-140.
- Hinde, R. A. (1972). *Non- verbal Communication*. Cambridge, UK: Cambridge University Press.
- Holme, L. (2000). Begrepp om handikapp. En essä om det miljörelativa handikappbegreppet [The concept of disability. An essay on the Relational Concept]. In M. Tideman (Ed.), *Handikapp synsätt, principer, perspektiv*. Lund: Studentlitteratur AB.
- Johansson, I. (2007). *An annorlunda barndom [A different kind of childhood]*. Stockholm: Forum.

- Johnston, S. S., Reichle, J., Feeley, K. M., & Jones, E. A. (2012). *AAC Strategies for Individuals with Moderate to Severe Disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- Keen, D., Sigafos, J., & Woodyatt, G. (2005). Teacher Responses to the Communicative Attempts of Children with Autism. *Journal of Developmental and Physical Disabilities* , 17 (1), 19-33.
- Kylén, G. (1974). *Psykiskt utvecklingshämmades förstånd. [Cognition of the Psychologically Developmentally Disabled]*. Stockholm: stiftelsen ALA.
- Kylén, G. (1981). *Begåvning och begåvningshandikapp [Intellectual ability and intellectual disability]*. Stockholm: Stiftelsen ALA.
- Lathe, R. (2006). *Autism, Brain and Environment*. London: Jessica Kingsley Publisher.
- Malterud, K. (2001). Qualitative Research: Standards, Challenges and Guidelines. *The Lancet* , 483-488.
- Mansell, J., & Beadle-Brown, J. (2012). *Active Support*. London: Jessica Kingsley Publishers.
- Martin, A., O'connor-Fenelon, M., & Lyons, R. (2012). Non-verbal communication between registered nurses intellectual disabilities and people with intellectual disability: An exploratory study of the nurse's experience. *Journal of Intellectual Disabilities* , 16 (1), 61-75.
- Meltzoff, A. N. (1999). Origins of Theory of Mind, Cognition and Communication. *Journal of Communicative Disorders* , 32, 251-269.
- Meltzoff, A. N., Kuhl, P. K., Movellan, J., & Sjenowski, T. J. (2009). Foundations for a New Science of Learning. *Science* , 325 (5938), 284-288.
- Mundy, P., & Crowson, M. (1997). Joint Attention and Early Social Communication: Implications for Research on Intervention With Autism. *Journal of Autism and Developmental Disorders* . , 27 (6), 653-676.
- Mundy, P., Delgado, C., Block, J., Venezia, M., Hogan, A., & Seibert, J. (2003). *Early Social Communication Scales*. Miami: Department of Psychology, University of Miami.
- Mundy, P., Sigman, M., Ungerer, J., & Sherman, T. (1986). Defining the Social Deficits of A: The Contribution of Non-verbal Communication Measures. *Association For Child Psychology and Psychiatry* , 27 (5), 657-669.
- National Research Council. (2001). *Educating Children with Autism*. Washington D.C.: National Academy Press.
- Ogden, P. M. (2006). *Trauma and the body*. New York: W.W. Norton Company.
- Ogletree, B. T., Bruce, S. M., Fahey, R., & Mcleen, L. (2011). Recommended Communication-Based Interventions for Individuals with Severe Intellectual Disabilities. *Communication Disorders Quarterly* , 32, 164-175.
- Payne, H., & Ogletree, B. T. (1995). Training Team Members to Respond to the Communicative Behaviors of Children with Profound Handicaps. *Focus on Autism and other Developmental Disabilities* , 10 (5), 1-15.

- Podvolf, E. M. (1990). *The Seduction of Madness*. New York: HarperCollins.
- Pollack, R. (1997). *The Creation of Dr B: A Biography of Bruno Bettelheim*. New York: Simon and Schuster.
- Rimland, B. (1964). *Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior*. New York: Appleton-Century-Crofts.
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, L. M., o.a. (2010). *Intellectual Disabilities Definition, Classification and Systems of Support*. Washington D.C.: AAIDD.
- Schalock, R. L., Borthwick-Duffy, S., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Ellis M. (Pat) Craig, P., et al. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports (Eleventh edition)* (11 ed.). Washington D:C.: AAID.
- Siegel-Causey, E., & Guess, D. (1989). *Enhancing Nonsymbolic Communication Interactions Among Learners with Severe Disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- Sigafoos, J., Woodyatt, G., Keen, D., Tait, K., Tucker, M., Roberts-Pennell, D., et al. (2000). Identifying Potential Communicative Acts in Children with developmental and Physical Disabilities. *Communication Disorders Quarterly*, 21, 77-86.
- Socialförvaltningen Simrishamns. (n.d.). *Att vara kontaktman i Simrishamns kommun*. Retrieved Mars 10, 2013, from Socialförvaltningen införmerar: http://www.simrishamn.se/upload/SOC/Dokument/vard_omsorg/kontaktman11.pdf
- Socialförvaltningen Upplands-Bro. (n.d.). *Enhet för Gruppboende LSS, Socialförvaltningens kvalitetsplan 2012*. Retrieved Maj 2013, from Socialförvaltningen Upplands-Bro: <http://www.upplands-bro.se/download/18.1e0358dc13b2d5231b62990/1355167954881/2012-Kvalitetsplan-Gruppboende-LSS.pdf>
- Stern, D. (1984). Affect Attunement. In E. Galenson, R. L. Tyson, & J. Call (Eds.), *Frontiers of Infant Psychology* (Vol. II). New York: Basic Books Inc.
- Stern, D. (1985). *The Interpersonal World of the Infant. A View from Psychoanalysis and Developmental Psychology*. New York: Basic Books Inc.
- The Anne McDonald Centre. (n.d.). *Severe Communication Impairment*. Retrieved February 18, 2013, from The Anne McDonald Centre: <http://www.annemcdonaldcentre.org.au/severe-communication-impairment>
- The National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). *Guidelines for Meeting the Communicative Needs of Persons with Severe Disabilities*. Retrieved February 13, 2012, from The American Speech-Language-Hearing Association: <http://www.asha.org/policy/GL1992-00201.htm>
- The Swedish Research Council's Expert Group on Ethics. (2011). *Good Research Practice*. Retrieved May 6, 2013, from Vetenskapsrådet: http://www.vr.se/download/18.3a36c20d133af0c1295800030/1321519981391/Good+Research+Practice+3.2011_webb.pdf

Tomasello, M. (2008). *Origins of Human Communication*. Cambridge, Ma: MIT Press.

Tomasello, M. (2000). The Social-Pragmatic Theory of Word Learning 1. *International Pragmatics Association* , 10 (4), 401-413.

Underwood, L., McCarthy, J., Tsakanikos, E., Howlin, P., Bouras, N., & Craig, T. K. (2012). Health and Social Functioning of Adults with Intellectual Disability and Autism. *Journal of Policy and Practice in Intellectual Disabilities* , 9 (2), 147–150.

World Health Organization Classification, Assessment, Survey and Terminology Team. (2001). *3rd International Classification of Impairments, Disabilities and Handicaps(ICIDH)*. Retrieved April 10, 2013, from A Sustainable Design: <http://www.sustainable-design.ie/arch/ICIDH-2Final.pdf>

Halmstad University, Department of health and Social Sciences. Disability Studies -
Magister's program

Student Thesis:

How do nonverbal adults with Neuropsychiatric disabilities communicate with those
around them and what enhances this communication?

This letter is to inquire if you would be willing to partake in a study that is undertaken in
connection with the Masters Program in Disability Studies at The University of Halmstad,
Department of Health and Social Sciences. New knowledge regarding nonverbal adults
with neuropsychiatric disabilities and their communication can hopefully increase
societies' interest and investment in this population.

**Take your time and read all the information carefully. Please ask questions if
anything is unclear.**

Candidate:Jane Hawes, tel 073 – 977 9792, janehawes@live.se.

Supervisor: Carin Nyman, Universitetslektor, M.D, Department of Health and Social
Sciences, Halmstad University. tel. 035 – 16 73 87, carin.staland_nyman@hh.se

Purpose:

The main goal of this project is to investigate how nonverbal adults with neuropsychiatric
disabilities communicate on a daily bases with those around them. A secondary goal is to
see what enhances this communication and why.

Process:

The study shall begin autumn 2012 and is planned to be finished in the spring of 2013.
Data will be gathered from interviews with personnel at the day center, residence and with
some of the guardians. All information that can reveal the identity of those involved will
be removed from this thesis. After the interviews the transcripts from said interviews will
be made available for revision and approval by the informants. All information gathered
will be destroyed after the thesis is completely finished, at the latest in September 2013.
The thesis will be available to the public at the University of Halmstad's webb sight.

Participation:

Your participation is completely voluntary and you may at any time, without explanation
withdraw from the project.

I am informed and agree to participate:

Signature.....

Name.....

City and Date:.....

Appendix B- Semi-Structured Interview schedule

The interview begins with a brief explanation of how there is no right or wrong answer to the questions. The ambition is to hear the informants' observations, impressions and feelings.

Questions:

1. How old is X?
2. Does the service user live at home, how long have they been at the day center/ residence?
3. What is your relationship to X? How long have you known, worked with X ?
4. How do you know that X does not like, or does not want to do something? (Sound, gestures with hands and or body, sign language, physical contact, facial expressions, eye contact, breathing, or using picture and or other communicative aids.)? When does this happen? How do you react? (Reject-protest)
5. How do you know when he or she is glad or thinks something is fun? When is he or she is sad? Afraid? When does this happen? How do you react? (Comment)
6. What does X do when he/she wants something? When does this happen? How do you react? (request for object)
7. What does X do when he/she wants help or wants you to do something? When does this happen? How do you react? (request for action)
8. What does X do when he/she is curious about something or wants to know more about something? When does this happen? How do you react?(request for information)
9. What does X do when he/she wants to get your attention? Does he or she often initiate contact? Describe the situations when this occurs. (Attention to self)
10. Does X sometimes repeat what you or others do or say? Describe the situations when this occurs. (Imitation)
11. How does X show that he/she chooses one activity or a certain object instead of another? Describe the situations when this occurs. How do you react? (Choice making)
12. How do you make contact with x when you want her/his attention? Describe the situations when this occurs. Does X react to his/her name? Others' names? (Social convention)
13. Does X have any form of greeting or way of saying good-bye? (Social convention)
14. Can X answer questions? Answer *yes* or *no*? Follow commands? Describe the situations when this occurs. (Answer)
15. Are there times where you and X can engage in joint attention i.e. both of you together regard an object and are aware of each other regarding the object.(give example of joint attention: x looks/ points or both at object, then caregiver and then object. Caregiver looks/point or both at an object and X follows her/his gaze or finger then looks at object. Describe the situations when this occurs. (joint attention)- (comment)
16. How much eye contact do you and X have? Describe the situations when this occurs. Who initiates this contact?
17. When you communicate with X what do you think you use the most: words, gestures (body/hand), facial expressions, sign language, pictures or other communicative aids?
18. Do you believe that communication between you and X has improved within the last 3 years* Describe how. Do you feel you have become better at understanding? How? Has X's communicative ability improved? How?
19. Are there some specific activities that X participates in that you think help improve his/her communicative ability? Why?
20. Have you felt at any time a strong human bond with X - moments where you have felt like the two of you share a deep sense of belonging and understanding? Where you feel that you are sharing the same emotions? Describe the situation when this occurred. (Attunement, ToM)

*or since you have been working with X if the caregiver has been working with X less than three years

Jane Hawes is an Art Therapist who uses painting and drawing to enrich the lives of adolescents and adults with developmental disabilities in schools and group living situations. In her private practise she works together with her clients helping them realize their own creative potential and improve their lives and the lives of those around them.

