Proximal processes of children with profound multiple disabilities

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To Per
Abstract

In this thesis four empirical studies dealt with children with profound multiple disabilities and their parents with regard to: (a) how parents perceived interaction with their children (b) how observed child/parent interaction was linked to behavior style of the children as perceived by the parents (c) how parents of children with profound multiple disabilities perceived child/parent interaction and behavior style of their children in comparison to parents to children without disabilities matched for communicative ability and age respectively, and, (d) how social networks and family accommodations were linked to child/parent interaction and child behavior style over time for these families according to parental appraisals. The results in study I showed that child/parent interaction occurred throughout the day and constituted of mutual experience and joy. There were two processes in interaction: monitoring interaction and successful interaction. Study II found hypo- and hyper dominated behaviour style of the children to influence interaction differently. The parents were found to be experts on their children in monitoring interaction to achieve more frequent periods of successful interaction. Study III found few differences in wishes about ideal interaction between parents of children with profound multiple disabilities and parents of typically developing children. Study IV showed that the children were communicative dependent on their parents; there were few complete overlaps between the children’s and the family’s social networks; and although family accommodations were child-driven, sustainability of family life evolved around other factors. There was a “contradiction” in results for the whole thesis: child/parent interaction occurred throughout ordinary everyday life and constituted of mutual experience and joy versus the children’s communicative dependency and the distance found between social networks of families and children and child/parent interaction.

Keywords: Children, profound multiple disabilities, interaction, behavior style, family accommodation, social networks, systems theory
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List of studies

The present doctoral thesis is based on the following studies:


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Introduction

Current theories of child development consider children to be competent active agents who participate in constructing their social life (Bronfenbrenner, 1999). Children are perceived to be active receivers and even to be active agents in searching influences from their surroundings (Sommer, 2005). The driving forces for being active are the innate motivation to learn and curiosity to interact with others. Children are competent as they are flexible and resilient (Sommer, 2005). Children are flexible in how they socialize with others and how they adjust, for example, they interact differently with different persons. Children are resilient as they can compensate and adjust to stressful life situations. Specific events cannot directly be the isolated explanations to future developmental difficulties; rather it is the total personal, biological and social adaptability that determine how a child will persevere (Shonkoff & Phillips, 2000). Within this thesis it will be argued that children with profound multiple disabilities have restricted competence and flexibility but can still be considered to be active agents in constructing their social life.

The primary social context of children is the family. The child and its family are interdependent in that they influence each other in development in a reciprocal and binary way. As such one part of the family cannot be fully understood on its own but, rather, must be considered in relation to the whole family (Epstein, Ryan, Bishop, Miller, & Keitner, 2002). Families live in the context of a culture and society with rules and resources to which they must accommodate. Furthermore, families are surrounded by social networks which provide them with both formal and informal support. In ecocultural theory, families with children with disabilities are perceived as more similar than different from typical families (Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

The group in focus in this thesis is children with profound multiple disabilities and their families. The children who participated in the four studies of the thesis all had a combination of cognitive and physical disabilities, some also had severe medical problems. All children had different diagnoses, example of diagnoses were CHARGE, Tetraplexia, Autistic syndrome in combination with physical disability, Trisomy on chromosome 13 and combination of cognitive disability and cerebral palsy. Some children were ambulatory but most of them were not. A few of the children did not have a diagnosis due to difficulties to determine the
disabilities. Furthermore, some children had cochlear implants as an intervention. Most of the children functioned on a non-symbolic communication level, which was pre-intentional. A few of the children had a little more advanced symbolic communication, for example, they knew some signs and/or used object to communicate. In following contemporary interaction theories these children are often considered to be non-communicators as they do not subscribe to the typical way of communicating and interacting. Furthermore, children with profound multiple disabilities may not have intentional communication in the way it is traditionally measured and theoretically defined in research today.

All children and families in this thesis were Swedish. In the Swedish context a relatively high level of availability of services from the society is provided to these children and their families (Björck-Åkesson & Granlund, 2003). The ecology of early intervention in Sweden consists of the family, the preschool/school, Child Health Services (CHS) and the Child Habilitation Center (CHC). The CHC provides family-centered services of advice and support were a team of professionals work in collaboration to enhance the child’s development and skills together with the family. In the CHS the children have free medical and health services. The community has the responsibility to provide special preschool/school placements, respite care and personal assistants if it is needed. In Sweden it is possible for a parent to become employed by the community as a personal assistant for his/her own child. Furthermore, families of children with profound multiple disabilities receive a monthly subvention from the government.

The primary theoretical framework of the thesis is systems theory and theories of early interaction. In systems theory children are always considered in their social context and relations between individuals, and how these influence development and change is the focus. In order to understand how children with profound multiple disabilities interact and how they gain from it, theories of early interaction will be presented and discussed. The main aims of the thesis were to explore child/parent interaction of children with profound multiple disabilities and their parents by investigating (a) how parents perceived interaction with their children (b) how observed child/parent interaction was linked to behavior style of the children as perceived by the parents (c) how parents of children with profound multiple disabilities perceived child/parent interaction and behavior style of their children in comparison to parents to children without disabilities matched for communicative ability and age respectively, and, (d) how social networks and family accommodations were linked to child/parent interaction and child behavior style over time for these families according to parental appraisals.
Family life of children with profound multiple disabilities

Children are born into a cultural context of a family (Lewis, 2000; Super & Harkness, 1999). In contemporary society the traditional view of what constitutes a family is being questioned both theoretically and practically (Sommer, 2005). A modern way to define the constellation of a family is made by Hanson and Lynch (2004): “a family is considered to be any unit that defines itself as a family including individuals who are related by blood or marriage as well as those who have made a commitment to share their lives” (Hanson & Lynch, 2004, p. 5). The family is the central frame in childhood and is the pivotal activity setting where the child learns about how the world functions.

Family level processes- Everyday life

Everyday life of families of children with profound multiple disabilities is organized according to family routines and rituals just as in typical families. Family routines are defined as instrumental communication and acts that are performed regularly holding no specific meaning, for example, the ordinary habits of a day; making up the bed and having breakfast (Spangola & Fiese, 2007). Daily routines serve to maintain family life (Bernheimer & Keogh, 1995). Family rituals are defined as symbolic communication and acts which convey a meaning of “this is who we are as a group” p. (Fiese et al., 2002, p. 382). Family rituals may include celebrations or traditions and family interactions such as a family meal (Spangola & Fiese, 2007). A research review over 50 years of research on naturally occurring family routines and rituals of typical families found that routine practices increase frequently during early childhood and school years for most families and that as children become more competent, they are more actively involved in family routines (Fiese et al., 2002). The review also concluded that routines and rituals may ease the stress of daily living as they can have a stabilizing function in their predictability and regularity. Furthermore, according to ecological theory the cultural identity of a family is conveyed to the child by family routines and rituals (Super & Harkness, 1999; Weisner, 2002). The study of routines and rituals represents a focus on the whole family process;
it gives access to how the family as a group is organized and finds meaning as a collective unit (Fiese et al., 2002).

In being part of a family system, the child receives knowledge about how the world functions as it is included in the everyday life of a family. The child gets to know the habits and routines of the family and can feel secure in the recognition not only of interactions with the parents but also of the recurrent relationships with other family members, settings and activities. Trevarthen calls this feeling to be “at home” (Trevarthen, 2004). In sharing interactions with the parents the child receives knowledge about how interpersonal relationships functions and also receives an extended feeling of the self as a subject on its own. The shared interactions are set in a context of everyday life with routines that are specific to the family and also to a large extent to their culture. Daily routines reflect a mix of personal and cultural values; they reflect the parents’ beliefs about their children and families (Bernheimer & Keogh, 1995). Daily routines are made up of activities and practices and include five features: goals and values, motives and emotions, tasks to be performed, a script for normative or appropriate conduct and who is present (Weisner, 1997). In the daily process of sharing a functional and meaningful everyday life the child is constructing personal narratives and is also part of constructing family narratives (Trevarthen, 2004). Narratives are made up by mutual experiences of the past and present and these are important for the formation of identity and the feeling of belonging (Mason, 2004).

Research about the everyday life of families of children with disabilities and their reactions to having a child with profound multiple disabilities have been studied from different perspectives depending on the appraisals of the concept of disability in society (Ferguson, 2002; Risdal & Singer, 2004). The ABCX model has become classic and extensively used in research about adaptation of families of children with disabilities. In this model and theory, A denotes the child with disability as a stressor, B denotes coping strategies and forms of appraisals and C denotes resources including social support: together they produce X which denotes the outcome in the form of family adaptation (Ferguson, 2002; Risdal & Singer, 2004). The model has been refined and elaborated during the past years and a shift has been made towards studying more salutogenic perspectives on family adaptation instead of pathology (Ylvén, Björck-Åkesson, & Granlund, 2006). In studying families that in spite of stressful life circumstances seem to lead a well functioning everyday life, researchers seek to find what constitutes their specific skills or dispositions that make them able to use positive adaptations. The ABCX model has also been reinterpreted as a dynamic model in the way that every family is unique and has its own developmental life course over time. Each family is constituted by members that in themselves have unique sets of strengths and weaknesses (Epstein et al., 2002). Another important elaboration of the ABCX model has been the
recognition that families have both internal and external resources that may be available to them. In this approach it is acknowledged that families of children with disabilities exist in a normal macro- and exo level societal context as all other families; they are not isolated from the normal demands or anticipations of society (Bronfenbrenner, 1999).

Family accommodations in everyday life of families with children with profound multiple disabilities

Although the ABCX model and research that is inline with its theory have helped to diminish the unrealistic gap of attributions of what constitutes everyday life between families of children with disabilities and families of typically developing children, it can still be claimed that having a child with profound multiple disabilities is an extra challenge to families. By using structural equation modeling and path analysis Keogh et al. (2000) found that the longitudinal relationship between child characteristics and family adaptations for families of children with developmental delays were best explained by a child-driven model and not a transactional model (Keogh, Garnier, Bernheimer, & Gallimore, 2000). This means that the characteristics of children with disabilities influence family everyday life development more than other influential factors in family everyday life do. Each unique family has its own life course and family adaptations are individualized, but, still, as can be seen in larger samples, they are generally driven to a larger extent by child characteristics than not when a child has disabilities. Earlier studies have not focused on families of children with profound multiple disabilities.

There are phases in how a family responds to having a child with disabilities. Early, the family adjusts to the situation. According to McCubbin and McCubbin (in Lin, 2000) the adjustment phase can be described as the interplay between family types and established patterns of functioning, appraisal of the disability and its severity, problem solving and coping and family’s resistance resources. Over time, a family with a child with disabilities will adapt to the situation. Adaptation is defined as “the outcome of family effort to bring a new level of balance, harmony and functioning to family crisis situation” (Lin, 2000, p. 202). According to McCubbin and McCubbin, adaptation is built up by the direct adjustments in the immediate everyday situation but always in the context of existing family appraisal of schemas and meaning as well as the context of social support (in Lin, 2000). The existing family appraisal of schemas and meaning is a product of earlier family experiences and family history. According to Lin (2000) positive family appraisal is a coping strategy which is related to family adaptation, it significantly predicts family adaptation.
In the ecocultural approach to family adjustment and adaptation, the nature and expressions of the child’s disability, the material circumstances of the family and personal resources of the family is combined. The concept ‘ecocultural’ comes from “eco logical + cultural” (Bernheimer & Keogh, 1995, p. 17). Ecocultural theory applies Super and Harkness’ notion of a developmental niche for the child (Super & Harkness, 1999; Weisner, Matheson, Coots, & Bernheimer, 2004). In ecocultural theory family accommodations are used as a concept to explain a family’s functional responses to the demands of daily life with a child with delays (Bernheimer & Keogh, 1995). Accommodations of all families require both adaptations to external factors, for example customs of society, as well as internal family factors, for example the specific age related needs of children (Gallimore et al., 1989). The process of accommodating is often unconscious and the purpose of accommodating is to lead a daily life that fits with the families’ beliefs and values, the needs of family members and perceived expectations from society (Gallimore et al., 1989). Accommodations do not automatically require individual or family stress to be activated (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). The goal is to construct and sustain a daily routine which is satisfying and coherent for the whole family in terms of their views of family and child life (Weisner et al., 2004). In the process of sustainability parents prioritize the accommodations they do and how intensive they are; they make trade-offs that are based on the valence of the accommodation in relation to their views of family and child life (Gallimore, Keogh, & Berheimer, 1999). According to ecocultural theory “a family that has a more sustainable daily routine makes accommodations that 1) fits with available resources; 2) has meaning with respect to goals and values; 3) balance inevitable family conflicts; and 4) provides some stability and predictability for family members” (Weisner et al., 2004, p.3).

The Ecocultural Family Interview (EFI) was developed in order to capture family accommodations in everyday routines and activities in response to having a child with disabilities (Weisner, Bernheimer, & Coots, 1997). It is a semi-structured interview with open ended questions which covers ten domains of parents’ accommodation activities: family subsistence base, use of services, home/neighborhood safety and convenience, domestic workload, childcare tasks, child peer groups, marital roles, instrumental/emotional support, father/spouse role and sources of information (Weisner et al., 1997). The interview is a conversation where the parents are encouraged to describe how they organize, adapt and sustain their daily routines and activities. Examples of questions are: Walk me through your day; why are these important activities, How do you keep your routines going (Weisner, 2002)? Following a specific code book, accommodation intensity is measured on 51 items with possible scores ranging from 0 (no accommodation activity) to 8 (high accommodation activity) on each item, 9 denotes not applicable. There are three levels of measures: 0-2 is low, 3-5 is
medium and 6-8 is high. The 51 accommodations measures are then summarized on three items. On these items a summary estimation is done for each family concerning: meaningfulness of daily routines and appropriateness to family’s goals and values, ecological fit of resources and the ability to keep routine and congruence between daily routine and the competencies and needs of the child as well as other family members. The scale of these items goes from 0 to 8, where 0-2 is low, 3-5 is medium and 6-8 is high meaningfulness, ecological fit and congruence. The higher estimate a family receives the more sustainable are the family routines and thus there exists better possibility for well-being in the family (Weisner, 2002).

Results from research that has used the instrument Ecocultural Family Interview has focused on families with children with developmental delays. Gallimore et al. (1993) studied 102 North American families with children with developmental delays aged 3-4 years. They found that these families made many accommodations in the domains of child care, sources of parental information, and social support. Accommodations were not related to children’s developmental status but to the impact the child had on the daily routine. Number and nature of child problems were related to more accommodations in domains of child care, accessibility of services and subsistence. Gallimore et al. (1996) studied the same sample at age 7 and 11 and found that accommodations of these families were less intense but dealt with more types of accommodations when the children were 11 than they were when the children were 3 and 7 years of age (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996). Although there were differences within the group which were note worthy; many families who had children who were more problematic, less competent and caused greater hassle at 3 years of age accommodated still at age 7 and 11 but in new ways and in more domains. Furthermore, many children who had high medical needs when they were little had stabilized and did not need the same services anymore at age 11. Conclusively, family accommodations from preschool to late childhood presented a mixed picture of continuity and change. In order to capture the reason for type and intensity of family accommodations child maturation, stabilization and family life course theory must be considered in this type of research.

Weisner et al. (2004) used the data from Gallimore et al. (1993) and Gallimore et al. (1996) and studied sustainability of family accommodations. Thus, they studied the sample of 102 families of children with developmental delays which were interviewed with EFI and questionnaires about child characteristics at age 3, 7 and 11, and they also added a data collection at age 13. Over the years, the attrition rate was extremely low, only 9% of the sample dropped out. Weisner et al. (2004) used the summary estimations in EFI; ‘meaningfulness’, ‘ecological fit’ and ‘congruence’ which measure sustainability of daily routines and divided the families on a scale from 1 (multiply troubled- low sustainability families) to 5
(stable/sustainable- highest sustainability) at each time point (3, 7, 11 or 13 years). They found that over 10 years 75% of the families were fairly stable in sustainability of daily routines. Overall, sustainability was considered to be reasonable at age 3, dipped at 7 but increased again at 13. They also found that in common for those who belonged to the lowest sustainability group was that they had restricted and few resources. Single mothers more frequently belonged to the lower groups (Weisner et al., 2004).

In ecocultural theory, families with children with disabilities are not perceived as extremely different from typical families, rather “the activity settings of families with developmentally delayed children will be far more similar to activities of families in this culture with nondelayed children than they will be different” (Gallimore et al., 1989, p. 225). In everyday life parents of children with profound multiple disabilities have hopes for their children’s lives similar to parents of typically developing children. The aspirations of these parents have not been found to differ much from any parent. Parents of children who were deaf blind felt that a ‘good life’ for their children would constitute of a comfortable and stable home, relative good health and comfort, circle of friends, many micro environments and some kind of occupation so that they would feel useful in society (Giangreco, Cloninger, Mueller, Yuan, & Ashworth, 1991). At the same time their concerns dealt with worries about the future when it came to receiving good community services and the attitudes of professionals and teachers in school about the competences of their children (Giangreco et al., 1991; Knox, Parmenter, Atkinson, & Yazbeck, 2000).

There are variations in how families handle to live and interact with children who have disabilities. The variations depend on several factors, as for example, type and degree of disability, the age of the child, family situation and the personalities of the child and the parents (Grant & Whittel, 2000). Most families seem to go from stress reducing coping strategies to cognitive and problem solving coping strategies with increasing experience, for example, involving the social network in solving problems (Grant & Whittel, 2000). In negotiating a problem solving task in families with children with disabilities and in family interviews about problem solving results found that the parents maintained different roles in the family in ways that were consistent with those in typical families (Costigan, Floyd, Harter, & McClintock, 1997). Furthermore, in these families it was not especially the children with disabilities who presented particular challenges but other children in the families could also present difficult or stressful challenges. In some families the child with disabilities was less disruptive than other children in the family. This study indicated that it is not automatically an additional demand to have a child with disabilities as family systems are so diverse and uniquely set up by its members (Costigan et al., 1997). Overall, research has found that it is the problem behaviors of children with disabilities that are important for how the everyday life functions. For
example, by using structural equation modeling, King et al. (1999) found child behavior problems to be the most important predictor of parental well-being. Even though the problem behaviors of children with disabilities were not severe, their behavior was related to how much distress and depression their parents felt (King, King, Rosenbaum, & Goffin, 1999).

One of the few longitudinal studies about life course impacts of American families of children with developmental disabilities (Mailick-Seltzer, Greenberg, Floyd, Pette, & Hong, 2001) found no difference in marital status or stability over time between these parents and parents of typically developing children. A meta-analysis on marital adjustment of parents to children with disabilities found that these parents were exposed to an increased level of marital strain than parents of typically developing children, although the difference between the groups were rather small (Risdal & Singer, 2004). The increases were smaller than was previously assumed in research but the results still call for awareness of this in family support. In typical families, marital hostility has been found to be linked to the father’s rejecting parenting (Katz & Gottman, 1996). When unhappily married men withdraw from their marriage, they also withdraw from their child. Research has also shown that male withdrawal is particularly stressful for women (Katz & Gottman, 1996). Single parents of children with disabilities have been found to experience more parent-related stress than two-parent families of children with disabilities (Duis, Summers, & Summers, 1997; Emerson, 2003). Although having a child with disabilities as a single mother may suggest extra demands to be able to be supportive in everyday problem solving, there were greater differences found in problem solving in everyday life between single mothers and two-parent families unrelated to if they had a child with disability or not (Costigan et al., 1997). In a problem solving task single mothers seemed to be more closely knit to their children and practiced more active listening and directiveness, which was analyzed to reflect their attempts to maintain control.

In research about accommodation social economic status of families of children with developmental disabilities has not been found to be related to amount and type of accommodation but rather to values that the families had about family and child life, for example, about the importance of mother’s career (Gallimore et al., 1993). Mailick et al. (2001) studied an American sample and did not find any significant differences in level of social economic status between families of children with developmental disabilities and a comparison group of typical families: not at different measuring points nor over time. Although Mailick et al. (2001) showed families of children with developmental disabilities to be gainfully employed to a lesser extent. Over a period of 15 years, measured at their mid-30s and again at their early 50s, the mothers were employed to a less extent outside the home than mothers in comparison groups and reported higher rates of work-family strain over time. Olsson and Hwang (2002) studied a Swedish sample and
found that parenting a child with an intellectual disability generally had more impact on the life situations and psychological health of mothers. Furthermore, they found that social economic status was not related to sense of coherence in these parents (Olsson & Hwang, 2002). In an American sample, Wang et al. (2004) studied how severity of disability and income interacted to affect parents’ satisfaction with their family quality of life during early childhood years. They found that severity of disability was a predictor of both mothers’ and fathers’ satisfaction ratings of family quality life. They also found that family income was a predictor of mothers’ satisfaction ratings of family quality life but not for the fathers’ (Wang et al., 2004). Also Emerson (2003) and Emerson et al. (2004) found that low social economic status heightened psychological distress of mothers to children with intellectual disabilities (Emerson, 2003; Emerson, Robertson, & Wood, 2004). In their research they found that social economic status appeared to moderate the association between maternal distress and the emotional and behavioral difficulties of children with intellectual disabilities (Emerson, 2003). Presumably the social care structures of specific countries and disadvantaged areas in countries to live in may enable or disable families’ appraisals.

Family everyday life and social networks

Families with children with disabilities are benefited by well functioning formal and informal social networks in their everyday lives. The supportive role of social networks in the lives of these families is significant (Harty, Joseph, Wilder, & Rajaram, 2007). Formal social networks denote relationships with professionals, for example, interventionists, psychologists, doctors and school teachers. Informal social networks denote relationships with persons that are family, relatives, close friends or acquaintances. Social networks do not exist without social interaction and communication (Blackstone, Hunt Berg, & Wilkins, 2006). Optimal social networks include a set of individuals who are outside of the family but who engage in activities and exchanges with the family of an affective or material nature (Cochran & Niego, 2002). Burchinal, Follmer and Bryant (1996), provide some insight into how families’ social networks can be better understood. They explain that the network size refers to the number of individuals within the network or how extensive the network is; the network composition refers to the categories of individuals within the network, for example, spouse, children, grandparents, professionals; the network density then refers to the quality of interactions between the individuals in the network (Burchinal, Follmer, & Bryant, 1996). Burchinal et al. (1996) conclude that it is the size and the component parts of the network that best determine the nature of the network’s influence on the family. Although, it is the composition and
density of the network that produces the most impact on the adjustment 
process in daily life (Trute & Hauch, 1988). Families who have more 
categories of individuals within the network and share quality interactions 
with them are more likely to experience the full positive impact of the 

Studies have shown that families of children with disabilities have 
restricted social networks (Blackstone et al., 2006). Thunstam (2004) found 
that the social networks of Swedish children who were deaf or had hearing 
impairments who used symbolic and/or sign language were smaller in size 
than compared to those of other children functioning on a pre-symbolic 
level. The size of the social networks of these children was generally small 
and also decreased as age increased (Thunstam, 2004). Joseph and Alant 
(2000) discussed the social networks situation of children who were deaf and 
attended signing schools in South Africa. These children’s social networks 
became distal to their families as they more or less lived in boarding schools. 
Furthermore, they found that the mothers of these children had inadequate 
signing skills, which impacted on their ability to communicate effectively 
with their children (Joseph & Alant, 2000). The longitudinal study by 
Mailick et al. (2001) that studied life course impact over 15 years of parents 
of children with developmental disabilities found that these parents had less 
frequent contact with their friends over time than did the comparison group 
parents; they visited their friends less often. As such their social networks 
had lower networks density over time.

Blackstone and Hunt-Berg developed a tool called The Social Networks 
Inventory (SNI) to describe the informal and formal social networks of the 
communication partners of persons with communicative disabilities 
(Blackstone & Hunt-Berg, 2003). The SNI is a structured interview with 
open ended questions and closed questions. The procedure involves 
interviewing two communication partners who are close to the person with a 
disability, in order to map the social networks with particular reference to the 
communication partners. Communication partners are documented in a 
diagram of five concentric circles: the first circle includes the person’s life-
long communication partners, the second circle includes close 
friends/relatives, the third circle includes acquaintances, the fourth circle 
includes paid workers and the fifth circle includes unfamiliar partners (see 
figure 1). Additionally, within these circles, the primary communication 
partner, the most skilled communication partner, the most frequent 
communication partner, the favorite communication partner, the 
communication partner most willing to learn and the communication partner 
most willing to teach others about the person with a disability are chosen. 
The person’s modes of expressions, communicative strategies and type of 
communicator are also discussed in the structured interview. Thus, the 
Social Network Inventory cannot only be used to study the composition, 
density and size of networks, but also the quality and characteristic features
of the communication of both the individuals and their communicative partners and the support provided in and across the circles (Blackstone et al., 2006).

![Diagram of communication circles]

**Figure 1.** Circle of communication partners in Social Networks Inventory (Blackstone & Hunt-Berg, 2003).

Individuals within the families’ social networks provide social support to families. Thus social support can be viewed as a function of social networks. It is clear that for families of children with disabilities, social support play a major role in reducing stress (Duis et al., 1997). Social support is a feature that is entwined at different system levels and can be either formal or informal in nature. Social support has been defined as “the emotional, psychological, affiliative, informational, instrumental, or material aid and assistance provided by personal social network members that influence the behavior of the recipient of the help or advice in a positive manner” (Dunst, Trivette, & Jodry, 1997, p. 501). Formal support denotes support from professionals and informal denotes social support from friends, relatives and acquaintances. Social support can be divided into different components or dimensions, *functional*: type and quality of help, *relational*: the quantity and different types and relationships, *structural*: frequency, duration and
physical proximity of support, constitutional: the actual need and type of support given and support satisfaction (Dunst et al., 1997). Research has shown that there is a strong relation between health of family members in families of disabled children and size and perceived helpfulness of informal social networks (Dunst et al., 1997). Further, research showed that mothers with higher levels of support experienced higher levels of emotional and physical well-being compared to mothers with lower levels of support (Dunst, Leet, & Trivette, 1990). King et al (1999) found that parents who were more satisfied with the social support they received, and whose families were doing well, felt less stressed or depressed (King et al., 1999). Therefore social support can be viewed as a mediator of stressful events. This implies that under conditions of high stress, satisfying social support can blunt the impact of the stressors and reduce the occurrence of secondary stressors.

This first part of the thesis dealt with families of children with profound multiple disabilities. Issues addressed were: everyday family life, family accommodations, social networks and social support. The next part of the thesis will deal with the theory frame, which is systems theory. Specific parts of systems theory will be presented and discussed: the proximal environment of children, proximal processes, niches and individual systems characteristics.
Systems theory

Systems theory is represented by two lines of theory: dynamic systems theory and general systems theory. Both lines mean that the organization of a system is dependent on how its parts interact with each other and that the stability of a system increases by the number of its parts (Thelen, 1990; Wachs, 2000). Systems theory is useful as a theoretical framework to describe changes (Bornman & Granlund, 2007). Dynamic systems theory is also known as chaos theory and can be applied to systems that are not hierarchically constructed and that are sensitive to initial conditions. It can be used to explain unpredictable and quick changes in systems. General systems theory can be applied to explain systems that are hierarchically constructed and in such a system some parts are more important than others for the whole system (Thelen, 1990). According to general systems theory there is stability in a system which can be influenced by internal and external factors. In response to internal or external influences the system will by reorganization try to self stabilize. As such it has to do with self regulative functions (Bornman & Granlund, 2007). In research about children with profound multiple disabilities and their families it is most appropriate to apply general systems theory as this line of theory best explains gradual and slow changes in systems. Furthermore, general systems theory is best applied to individuals with strong and stable characteristics and who exist in structured environments (Wachs, 2000).

In systems theory the family is described as a system, and also the individual child is described as a system (Wachs, 2000). A system is constituted of several parts that make up an entirety. These parts are processes on different levels in the system and are called subsystems; which interact in building up the whole system. The subsystems have their own function but cannot be fully understood unless considered together with the whole system. There is a synergetic effect between the parts of a system, and the entirety of the system is greater than the sum of its parts (Capra, 1997; von Bertalanffy, 1968). The subsystems of a family are the interactive individuals and their own strengths and weaknesses. In systems theory, one part of the family cannot be fully understood on its own but, rather, must be considered in relation to the whole system (Epstein et al., 2002). An individual child has subsystems that are physical (e.g. autonomic- and central nervous system), psychological (e.g. self regulation, self concept) and
biological (e.g. genes). These subsystems function together and make up the child.

**The proximal environment of children**

In the bio-ecological model the activity setting of the family is called the micro environment (Bronfenbrenner, 1999). The micro environment entails the immediate proximal setting of an individual that the individual belongs to and has regular interactions with. In a micro environment the child is directly active and directly influenced by interactions and activities in it. A child can have several micro environments and most often there is an increase in amount with age. Furthermore, other members of the family have several micro environments in which they actively participate, for example workplace or school. All members of a family contribute to the common micro environment with their own experiences and personalities of strengths and weaknesses (Sontag, 1996).

The bio-ecological model describes several distinct levels of influences of which the micro environment belongs to the microsystem. Each level is called a system and except from the micro system of influence there are meso-, exo-, macro- and cronosystems of influences. The child and caregivers in its immediate vicinity can be found at the microsystem, the communication between microsystems, for example, between schoolteachers and parents can be found at the mesosystem. Every time a child enters and is included in a new microsystem an interface is formed between the child’s primary microsystem and the new microsystem. This interface is the mesosystem. Activities where the child is not directly involved is found in the exosystem, these include for example the parents’ workplace. Activities in the exosystem influence the child indirectly, for example, if a parent has a stressful working situation he or she may not be sufficiently available for the child at home. At the same time the child can influence the exosystem, for example, a parent to a child with profound multiple disabilities may be forced to be absent from work a lot if the child’s has a poor immune system and needs to be cared for at home. Beliefs and values in common for a society and a culture can be found in the macrosystem and influence the other levels in the bio-ecological system. Laws taken by a government can highly influence the daily lives of children, for example legislations about extended paternity leave (Almqvist, 2003). These different systems can be found further and further away from the individual and influence the individual’s development more and more indirectly. Bronfenbrenner (1999) also defines the cronosystem, which is the aspect of time in which all individual development exists.

Developmental outcomes are a product of the continual dynamic process between the child and its experiences it has within the family and in other
The child influences its environment and the environment influences the child, there exists a reciprocal and binary exchange over time. This continual dynamic process of developmental influence is called transactional processes and occurs at all levels in the bio-ecological model. Transactional processes are causal chains of transactions between the individual and experiences made in meaningful contexts over time. The outcomes of transactional processes reside in the adaptiveness of the relationships between individual and context (Sameroff & Mackenzie, 2003). The transactional model “is also embedded in an interpretive framework” (Sameroff & Fiese, 2000, p. 142-143). This means that transactions and interactions are always social and thus entails a feature of inference by those involved. People process their experiences; they are not just passive recipients of environmental influences (Rutter et al., 1997). In the transactional model the influence from the environment entails many components, for example, mother-child interaction patterns and parental belief systems. All components together make up the ‘environotype’. By transactional processes, the environotype together with the ‘genotype’ (the biological prerequisite of genes) and ‘phenotype’ (the product of the interaction between the genetic make-up and the environment) determines child development over time (Sameroff & Fiese, 2000). Because there are great variation across populations in the three factors discussed above there can be different pathways to similar outcomes (equifinality) and also similar pathways can lead to different outcomes (multifinality). Furthermore, certain development is more easily moldable by environment than other which can depend upon for example, stable individual characteristics such as profound multiple disabilities or dominant genes (Rutter et al., 1997). In the development of children with profound multiple disabilities it is imperative to elicit those areas which are moldable by environment and to work on them in transactional processes. Such areas could be, for example, regular and qualitatively good interactions and stable personal relationships.

As has been discussed above child development is influenced by genes, culture and the direct social context and are built up by individual and environmental characteristics. These can be divided into risk and protective factors, which are factors that are negative or positive for child development (Rutter et al., 1997). There are environmental risk factors that research has found to be related to negative child development, for example, low social economic status of the family (Letourneau, 1997). Protective environmental features are, for example, growing up in a safe community and to have at least one primary attachment person (von Tetzchner, 2005). Also individual characteristics can be protective- or risk factors for development, for example, persistence and positive sociality are temperament dimensions that can be positive. Individual characteristics can also be risk factors that threaten parent/child interaction, for example, children with congenital heart
diseases have been found to be less responsive in interaction (Letourneau, 1997). When it comes to the importance of communication and interaction for development research has shown that qualitatively good interactions in the early childhood years between the child and important others are positive for child development (Tronick, 2007). In conclusion, it is not the specific risk or protective factors that in themselves influence development; rather it is the accumulated experiences that make up the course of development. It is the total accumulated amount of risk or protective factors an individual has over time that determines the individual’s developmental trajectories and which makes individuals either resilient or vulnerable (Shonkoff & Phillips, 2000).

Niches

Super and Harkness (1999) described that in the *niche* the culture as a whole comes to influence the development of individuals directly. In their theory, the culture denotes the direct context of individuals, where context is built up by settings, caregiver psychology and customs. These three subsystems surround the child and influence development directly through the daily life of actions (settings), the general practices of caregivers (customs) and the ideas and beliefs of the caregivers (caregiver psychology) (Super & Harkness, 1999). The three subsystems reciprocally influence each other to effect change, for example poor economy and a lack of money in one subsystem, will influence family experience in another and so on. Furthermore, the three subsystems can be influenced by external factors, for example, laws and historic events (Lewis, 2000). The concept *niche* expands Bronfenbrenner’s description of the microsystem but goes beyond physical settings and includes “cognitive abilities and skills, interpersonal characteristics and attitudes, that are potentially available to a given individual” (Wachs, 2000, p. 301). Proximal processes and individual systems characteristics are imbedded in the context of children, in systems theory these links operate in the contextual *niche* (Wachs, 2000).

There exists a bidirectional relation in influence between the individual and its niches, especially individuals with extreme traits influence niches (Wachs, 2000). Children with profound multiple disabilities influence their niches due to their specific needs, their restricted communicative abilities and special circumstances around their disabilities. The number of niches available for individuals is limited and each individual has a niche potential. Individual characteristics, biological factors, influences from exo- and macrosystems can open or close niches, for example, a large parental social network opens niches for children while restricted communicative abilities of a child closes niches.
Furthermore, to a varying extent individuals select their niches, although children with profound multiple disabilities have restricted capacities to choose. Those who can choose are assumed to select niches that fit with their interests, talent, goals and expectations. But for all individuals there are contextual processes that also restrict the number if niches available. Depending on individual characteristics and context, an individual’s niches can be homogeneous or heterogeneous. Homogeneous niches work to maintain, for example, the individual’s goals and expectations over time. On the other hand, heterogeneous niches mark the way to more optimal development as an individual with mostly heterogeneous niches must adapt and adjust to many different contexts. Thus, such an individual learns to be more flexible and also observes a wider variation of behaviors of others (Wachs, 2000).

The individual child accumulates experiences through proximal processes in the niches where the child is an active participant; the experiences are stored in mental representations of reality. “The properties of the environment that have the most power to influence the course of development in the individual are those that have the most meaning to the person in a given situation” (Sontag, 1996, p.328). Wachs (2000) describes “temporal moderation” to explain the outcomes of accumulated experiences. There are four dimensions of temporal moderation: buffering, steeling, sensitization and blunting. Buffering signifies that earlier positive experiences protect against later negative experiences. Steeling signifies that earlier negative experiences protect in later negative experiences. Sensitization means that earlier negative experiences increase the sensitivity towards later negative experiences. Finally, blunting, means that earlier negative experiences reduce the probability that the child will profit from later positive experiences. These are four processes acting over time that decrease or increase sensitivity towards sudden changes (Bornman & Granlund, 2007; Wachs, 2000).

Proximal Processes

The interplay between the child and its context occur in the proximal environment and is defined by individual- and environment characteristics. It is also defined by what happens in the immediate context in the form of interactions between dyads within the family’s activities, routines and rituals. Within the systems of influences presented in the bio-ecological model the development of children occur through proximal processes in niches (Bronfenbrenner, 1999; Wachs, 2000). It is the close interplay between the environment and individual in proximal processes that determine constancy and change in development (Sontag, 1996).
Proximal processes denote interaction between the child and its caregivers, objects and activities that promote development and occur relatively regularly over extended time, for example, closeness to mother, group and solitary play, reading, child-child activities (Bronfenbrenner, 1999). In these processes the emotional and practical experiences are stored in the child’s memory. Already infants represent pre-verbally these episodes in mental representations called internal working models (Stern, 2002; Wachs, 2000). Internal working models are “integrated sets of memories, expectancies, and associations between stimuli and affectual responses” (Wachs, 2000, p. 116). The child interprets current experiences on the basis of what is stored as internal working models of such earlier experiences. On this background the child develops expectancies about how the interpersonal world functions.

Intersubjectivity is also an important prerequisite for proximal processes to function. Intersubjectivity has been argued to be an innate human capacity (Stern, 2002) and it has similarities and associations with the proposed structure of the mirror system in the brain (Rizzolatti & Arbib, 1998). Primary intersubjectivity is defined as the child’s apprehension of the caregiver’s attention and the apprehensions that the child itself can influence the caregiver. Trevarthen denotes this interaction as protoconversation of person-person (Hedenbro & Lidén, 2002; Trevarthen, 2004). Secondary intersubjectivity is when there exists a mutual focus of the dyad to an object outside their twosome (Stern, 2002; Trevarthen, 2004). Trevarthen calls secondary intersubjectivity “co-operative awareness” and applies directly to joint attention (Trevarthen, 2004). Internal working models and intersubjectivity are individual systems processes that underlie how proximal processes work.

Proximal processes are reciprocal in nature and contain gradually more complex interactions over time to be effective; “the characteristics of the person are both a producer and a product of development” (Bronfenbrenner, 1999, p. 5). For reciprocal interactions to occur with objects, these must elicit interest, attention, exploration and imagination. Through proximal processes, apart from biological development, the child’s knowledge of the world, of itself and its position in the world becomes increasingly elaborated. Proximal processes occur within and between each system in the bio-ecological model. Not only parental resources and other resources of the primary micro system influence the proximal processes which a child experiences, but also influences from outer systems become important. Examples of a macro system influence are cultural stability and consistency over time and an example of exo system influence is stability over time in a parents’ work situation.

In proximal processes, the genotypes of individuals become realized into phenotypes (Bronfenbrenner & Ceci, 1994) through transactional processes (Sameroff & Fiese, 2000). This theory of alternative phenotypic outcomes
emanates from research findings about how genes do not produce fixed traits but that genes interact with individual experiences. Through proximal processes individuals’ potentials are actualized in different developmental outcomes. If the proximal processes are weak the actualization of potentials are confined. Proximal processes can be weak as a function of poor environment (low social economic status), restricted individual systems characteristics (disabilities) or cultural limitations (unequal gender beliefs). Profound multiple disabilities are individual systems characteristics that imply low levels of proximal processes as they reduce the possibility for progressively more complex reciprocal interaction. Although, proximal processes have greater impact than hereditability on individual developmental outcome in advantaged and stable environments throughout the life course (Bronfenbrenner & Ceci, 1994).

Individual system characteristics

Children are born with individual characteristics that to some extent determine how they are treated by others (e.g. gender, looks) but also how they tend to react to new stimuli (e.g. temperament, disabilities) (Wachs, 2000). Children’s abilities related to communication and interaction can be described according to Bronfenbrenner’s Developmentally Instigative Person Model (Sontag, 1996). This model is appropriate when studying children with disabilities as it supports the search for protective factors in the development of these children. In the model three types of child characteristics can be identified: physical attributes, personal stimulus qualities and developmentally structuring attributes. Physical attributes denote individual characteristics as gender, age and disability. Personal stimulus qualities denote individual characteristics that either encourage or discourage reactions from the environment, for example, personality and temperament or attractive versus unattractive looks. Developmentally structuring attributes denote individual characteristics that describe the individual’s active orientation and interaction with the environment. Such characteristics are exploration of the environment, intellectual curiosity and initiations in interactions.

Cognitive disability is an individual systems characteristic that belongs to physical attributes. Cognitive disability has traditionally been measured by level of intelligence using measures of IQ. The utility of IQ measures for people with cognitive disabilities have been debated as those measures require abilities to read and write. Tests based on Piaget’s theories of development have been more commonly used for people with profound disabilities (Dunst, 1998). Children with cognitive disabilities relate to their context differently than typically developing children and may be restricted in their interaction abilities. Tallal (1999) argues that people with cognitive
disabilities have difficulties to register and process quick and short changes of information in communication and interaction (Tallal, 1999). Furthermore, research has long claimed that people with cognitive disabilities have restricted short term memory (Kylén, 1974), although recent research has found that children with cognitive disabilities develop more and better memory strategies with age just as typically developing children. The memory strategies people with cognitive disabilities use seem more dependent on meaningful situations and contexts than the memory strategies of people in general (Erez & Peled, 2001). Overall, children with cognitive disability benefit from regular proximal processes in familiar niches as meaningful situations and contexts help them to optimize their potentials (Ceci, Rosenblum, de Bruyn, & Lee, 1997).

Already as infants, children show differences in personal stimulus qualities, for example in temperament as measured by the degree of a child’s emotionality, activity, sociality and reactivity to new stimuli. Emotionality can be described as the amount of positive and negative affects that a child displays. Affects are physiological arousals that infants experience in reaction to internal (e.g., hunger) and external (e.g., cold) stimuli. Differences in activity denote amount and intensity of motor activity, differences in sociality denote interest and joy in being with others and differences in reactivity denote the degree to which children withdraw or approach new stimuli. All these four aspects of individual characteristics can be defined as temperament, and although researchers disagree on many things about temperament (Wachs & Kohnstamm, 2001), these are the four aspects of temperament that they agree upon (von Tetzchner, 2005).

Another aspect of temperament that researchers more and more agree upon to be imperative for personal and social development is self regulation (Shonkoff & Phillips, 2000). Self regulation is the ability to regulate emotionality, physiological arousal, attention, thoughts and impulses. Self regulation starts from birth, when infants first struggle with regulating day-night sleeping patterns, hormones and body temperature. The development of self regulation is biological in that sense but it is also social as it is easily influenced by the environment. In the regular responses and the care infants experience from parents self regulation is successively developed as parents lead children who learn by experience and guidance how they can regulate themselves. When children grow an example of self regulation is when they have to wait for attention and thus practice tolerance. With age self regulation matures and temperament expressions which are displayed in the behavior will by age become more regulated and repressed as the children can handle their feelings, reactions and impulses. Children with profound multiple disabilities may have restricted self regulation, thus they may not be able to regulate and handle themselves. As a consequence their temperament will show in their behavior more explicitly. The tendency children have in
self regulating is a form of temperament dimension (Wachs & Kohnstamm, 2001; von Tetzchner, 2005).

Children with profound multiple disabilities show affective displays and show tendencies in how they react and interact with others (Goldbart, 1994). Children with profound multiple disabilities have idiosyncratic communication and their affective communicative expressions are not always predictable. As these children show restricted behavior repertoires it is difficult to use traditional instruments to measure temperament (Granlund & Olsson, 1999). The instrument Carolina Record of Individual Behavior (CRIB) measures behavior characteristics and behavior style dimensions and was constructed and validated by Simeonsson et al. (1982). It was constructed in response to the methodological limitations of the Infant Behavior Record (IBR) in the Bailey Scale of Infant Development (Simeonsson, Huntington, Short, & Ware, 1982). The methodological limitations of those instruments concerned for example inconsistency of items scales and poor descriptions of items. Furthermore, the IBR was not intended to be measured on children with disabilities. The target group of CRIB is children with disabilities and assessments are “made of generic characteristics and traits rather than task-specific responses” (Simeonsson et al., 1982, p. 45). The CRIB instrument measures states of arousal, developmental dimensions of behavior and behavior style dimensions. Behavior style dimensions are the behavior expressions of a child’s temperament. The behavior style dimensions measured are: activity, reactivity, goal directedness, frustration, attention span, responsiveness to caregiver and/or observer and general tone of body. These dimensions are measured on a scale ranging from 1 to 9: 1 indicates hypo/passive behavior, 9 indicates hyper/extremely intense behavior and 5 is the middle score which indicates behavior style most appropriate to situation and age. CRIB was not intended to be unidimensional (Spector, 1992), but scoring CRIB for one child can be used to give a behavior style profile over several dimensions. Thus, a child can have a hypo- or hyper dominated behavior style profile.

Few studies have measured behavior style of children with profound multiple disabilities. In a sample of 360 children with disabilities, Simeonsson et al. (1982) found that children with severe disabilities differed more from the average score on the behavior style dimensions, 1.5 units, than other less severely disabled subgroups who differed 0.5 to 0.9 units from the average. Bagnato and Mayes Dickerson (1986) studied the developmental and behavioral progress of 17 brain-injured children during interdisciplinary intervention. The severity of disability was moderate to severe for all children. The results showed that only the behavior style dimension attention span showed significant change over the two time points pre- and post intervention (Bagnato & Mayes Dickerson, 1986). All other behavior style dimensions were stable. Granlund and Björck-Åkesson (1998) studied individual differences in behavior style and the relation
between type and degree of disability and behavior style in 48 children with severe and profound disabilities. The results showed that the dimension *reactivity* was most independent from degree of disability. Furthermore, a division was made of the participants into three groups according to hypo/slow, common/optimal and intensive/hyper behavior style. Analyses showed that the subgroup of children who showed hypo/slow behavior style was characterized by disabilities in cognition, vision and motor ability (Granlund & Björck-Åkesson, 1998).

Personal stimulus qualities in the form of behavior style and affective expressions come to influence the interactions the child takes part in (Sontag, 1996). Although children with profound multiple disabilities are difficult for caregivers to read in interaction (Granlund & Björck-Åkesson, 1998; McCollum & Hemmeter, 1997), studies show that sometimes when children have a more extreme behavior style and show an intensive temperament, caregivers find it easier to respond to those children in interaction (Wachs, 2000). This is contrary to results from studies with typically developing children in a typical context as participants where the caregivers find it more difficult to handle children who show an intensive temperament (Wachs, 2000). Furthermore in an overview of studies, Huntington and Simeonsson found that behavior style in the form of temperament was not related to etiology of impairment among children with disabilities (Huntington & Simeonsson, 1993). Rather, their overview showed that several studies had compared behavior styles of children with disabilities to children with typical development and found similar distribution and variability in temperament in the groups. Thus, it is interesting to study the links between behavior style and interaction for children with profound multiple disabilities.

This second part of the thesis dealt with the theory frame. Specific parts of system theory were presented and discussed: the proximal environment of children, niches, proximal processes and individual systems characteristics. Cognition and behavior style were discussed as examples of individual systems characteristics. The third part of the thesis will address communication and interaction of children with profound multiple disabilities. In that section these children’s idiosyncratic and pre-intentional communication, augmentative alternative communication and difficulties to maintain joint attention will be discussed. Furthermore, theories of early child/parent interaction will be presented and also how interaction is perceived to be a bidirectional process between two interaction partners. Challenges of interaction partners to children with profound multiple disabilities will be addressed, and, finally, interaction intervention for these children will be discussed.
Communication and interaction of children with profound multiple disabilities

The distinction between communication and interaction is subtle. Communication denotes when a message is being transmitted intentionally or unintentionally by an individual (Olsson, 2006). If communication is unintentional then the behavior becomes communication when it is interpreted as communication by others. Interaction can be describes as the process of exchanges between an active human organism and the persons, objects, and symbols in its immediate environment (Sontag, 1996). Consequently, in this thesis interaction is referred to as an ongoing turn taking between at least two interaction partners.

Children with profound multiple disabilities have restricted possibilities to communicate or interact typically. The communicative expressions they use and how much they understand of others’ communication differs a lot. Some children only use non-symbolic communication (crying, physical movement) while others use iconic communication (actual objects, photographs, pictographic visual-graphic symbols) and even symbolic communication (supportive sign language, speech) (Romski & Sevcik, 2005). Children with profound multiple disabilities show repertoires of behaviors in interaction that are idiosyncratic (Goldbart, 1994). This means that their behavior is not always shown in conventional patterns and that repertoires are not always consistent from time to time. Inconsistency over time may be due to different levels of arousal or different appraisals of stimuli. Non-symbolic communication denotes the time in typical development from 0 to approximately 7 months of age. The modes used at this level are also used in typical communication, as an adjunct to symbolic communication. The modes used by non-symbolic communicators are for example facial expressions, gaze, gestures, physical movements, vocalization, smiles, laughter and crying. Although the communication expressions are restricted at this level the innate motivation to interact with others may well be intact. And even though it could be disturbed for a child with profound multiple disabilities the child finds itself in interaction with others because of its needs.

Cross sectional studies are frequently performed to find general communicative competencies for specific disability groups. Mar and Sall (1999) studied expressive communication skills of 103 children and
adolescents with severe cognitive disabilities to find profiles of communication. The participants in the study were on a cognitive level where they used simple reactive behaviors or, most commonly, single behaviors (one action conveyed an idea, e.g. sign for eat). Mar and Sall (1999) did not find any clear profiles: most students and children had multiple communication modes including gazes, vocalizations, gestures, reactive behaviors and signs. Neither did they find any relation between chronological age and communication modes and competences (Mar & Sall, 1999). McLean, Brady and Mclean (1996) found similar results when investigating 211 children and adults with severe cognitive disabilities; there was a great variety in distributions of communication modes and abilities among participants (McLean, Brady, & McLean, 1996). On the other hand, they found that communication modes and competences increased by chronological age, although these results may have been biased due to sampling. The results from these studies illustrate the variety of communication modes and competences of individual with profound multiple disabilities and also illustrate the inconsistency of results regarding the relation of communication modes and competences to chronological age. It is important to use a total communication approach where the child’s whole repertoire of communication modes and abilities are considered (McCollum & Hemmeter, 1997; Olsson, 2006). There is evidence that intervention should build on existing non-symbolic skills (Snell, 2002).

Dynamic assessment rests on Vygotskian theory and the principle that “children learn best when adults provide mediated assistance during tasks whose difficulty lies just beyond a learner’s independent performance in his or her zone of proximal development” (Snell, 2002, p.164). Dynamic assessment uses a test-teach-retest model, where the individual’s own communication is tested as a baseline, taught at the proximal zone of development and finally retested to check if the individual has learnt more advanced communication skills. For children with profound multiple disabilities this model for example entails communication temptations, which signifies interactions of a familiar joint attention where the communication partners pauses and holds so that the child is tempted enough to take a turn to get the interaction going again (Snell, 2002).

Coupe O’Kane et al. (1985) developed an instrument that was designed to catch the whole behavior repertoire that individuals with profound multiple disabilities use to communicate. It is called Affective Communicative Assessment (ACA) (Coupe O’Kane et al., 1985). The instrument facilitates detailed documentation of the individual’s positive and negative affective responses to a variety of external stimuli. In interpreting the meaning of affective responses four crucial meanings are in focus: like, dislike, want and reject. The instrument is divided into three stages. First, the individual’s behavior repertoire is documented over a series of observations where the child is exposed to several kinds of positive and negative stimuli, for
example specific food or songs, which the individual has shown clear affective responses to according to familiar people. Secondly, identification of strong responses is documented and more detailed information of these responses is gathered with further exposures to the stimuli and response in question. As a third stage interventions can be formed on the background from the gathering of information on both stimuli and setting that have been identified for the specific individual. By getting to know the individual’s behavior repertoire like this, new ways to communicate can be formulated by using the typical reactions that the individual already performs in a new way (Coupe O’Kane & Goldbart, 1998). Recent studies show that the existing interaction patterns of children with profound multiple disabilities should be taken into consideration when planning communication interventions (Olsson & Granlund, 2003).

Augmentative and alternative communication (AAC) is an international intervention approach that uses for example, manual signs and communication boards with symbols. It is a myth that children must have a certain set of skills or be of a certain age to be able to benefit from AAC. The relationship between cognition and language is bidirectional, if a child does not have access to a communication it may interfere with cognitive development and the other way around (Romski & Sevcik, 2005). The direct goal is to aid the child in its communication so that its full communication abilities are reached; the overall goal is to increase the child’s participation in everyday life (Granlund, Björck-Åkesson, Wilder, & Ylvén, accepted). Augmentative and alternative communication is multimodal as it permits the child to use every mode possible to communicate. Augmentative and alternative communication forms are divided into two groups; unaided or aided forms of communication. Unaided communication means nonverbal natural communication and supportive sign language, and aided communication means that external support is needed, for example, by communication boards or digitized speech. Aided AAC systems have been found to be less spontaneous for children with profound multiple disabilities than signing or nonsymbolic communication (Carter, 2003). Lund and Light (2006) studied long-term outcomes for seven young men with cerebral palsy who had used AAC for 15 years, and who began using AAC as preschoolers. They found that familial support and educational placement were linked to positive outcomes of quality of life. Factors that were linked to both positive and negative outcomes of quality of life were environmental factors, for example access to resources, and factors intrinsic to the individual, for example, level of cognition. Overall results indicated that interaction was a stronger predictor than language skills for participation outcomes related to everyday life (Lund & Light, 2006).
Preintentional communication

From birth to approximately 18-24 months of age, children advance through stages towards intentional communication learning that they can control the world through communication (from prelocutionary/preintentional to illocutionary/intentional) (Volterra, Caselli, Capirici, & Pizzuto, 2005). It is not always easy to know if children with profound multiple disabilities have intentional communication or not. Preintentional communication is when children do not deliberately or intentionally communicate but rather their signals are interpreted by others to have significance as communication (Goldbart, 1994; Iacono, Bloomberg, & West, 2005). According to Goldbart there are three subdivisions of preintentional communication: reflexive-, reactive- and proactive stages, see table 1 (Goldbart, 1994). The reflexive stage is when the child’s reflex responses to internal and external stimuli are interpreted as communication, e.g. different cries for hunger. The reactive stage is when the child’s reactive responses to internal and external stimuli are interpreted as communication, e.g. smiles are understood as pleasure. The final stage of preintentional communication is the proactive stage which signifies when the child’s goal-oriented acts on objects or people are interpreted as communication, e.g. turning away is understood as an individual gesture for dislike, this final stage is very close to intentional communication (Goldbart, 1994).

Table 1(p. 18 in Goldbart 1994). Continuum of Early Communication

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There are difficulties in distinguishing between the reflexive and reactive stages of preintentional communication by support workers, professionals and researchers (Iacono et al., 2005; Olsson & Granlund, 2003). Olsson and Granlund (2003) discussed four levels of awareness of one’s intentions and the first level called ‘unawareness of any intent’ fits the reflexive and reactive stages of Goldbart (1994). They define this level as “the intentions of the organism rather than that of the mind” (Olsson & Granlund, 2003, p. 305). Along with systems theory this stage or level has to do with the body as a system and the intention to keep balance in it. As a consequence of the
results from a larger quantitative study investigating the internal consistency of the Triple C instrument Iacono et al. collapsed the reflexive and reactive stages and called the new combined stage “unintentional passive communication” (Iacono et al., 2005).

The proactive stage is the most important to identify in children with profound multiple disabilities and work on in intervention and training if the communication is to develop further (Goldbart, 1994; Olsson & Granlund, 2003).

If definitions of what signifies communication and theories of intentional communication are too narrow, then individuals with profound multiple disabilities will frequently fall outside the definition as communicators (Goldbart, 1994; Iacono, Carter, & Hook, 1998; Olsson & Granlund, 2003). There are conventional qualitative indicators of intentionality, for example, alternating eye gaze and smiles (Iacono et al., 1998). Depending on the frequency, persistence and specific reoccurring situations where these communicative expressions are used by individuals with profound multiple disabilities emerging intentionality can be measured (Iacono et al., 1998). But there are also other communicative expressions that are part of an individual’s behavior repertoire which can be considered components of communicative expressions depending on how narrow researchers choose to define communicative expressions. Björck-Åkesson (1992) studied interaction between young children with profound multiple disabilities and their parents. She studied the dynamics of interaction over time in seven dyads and focused specifically on discourse status, communicative function and form. In the analyses she used a model constructed by Light (1985) and modified it to her target group in the way that the communicative components that were considered in the analyses were more tentative and attempted to capture the children’s entire behavior repertoire (Björck-Åkesson, 1992; Light, 1985). In the modified model the children’s and the parents’ motor and verbal behavior, smiles and laughter and direction of gaze in the interaction were considered in detail to be components of interaction. The analysis took into consideration the function of each turn in relation to the preceding and following turn. Different amounts of interaction components and how many seconds a turn taking prolonged were determinants for strong or weak interaction turns. Patterns of the children’s interactive styles were explained according to frequency of weak or strong initiatives, responses and endings in interaction. This is an example of how very detailed interaction analyses can yield information about communication and interaction of children with profound multiple disabilities that can be used in communication interventions. It is important that attempts are made to capture the children’s entire behavior repertoire and that it is analyzed in the context of typical interaction with familiar partners as it is in that way these children’s preintentional or intentional communication is elicited.
Joint attention - Pivotal interaction behavior

Researchers have found pivotal behaviors that are related to child developmental growth (Koegel, Koegel, Harrower, & Carter, 1999; Mahoney, Kim, & Lin, 2007). The definition of pivotal behaviors is “behaviors that are central to wide areas of functioning such that a change in the pivotal behavior will produce improvement across a number of behaviors” (Mahoney et al., 2007, p. 311). Identified behaviors that are considered to be pivotal in interaction for children with disabilities are: attention, persistence, interest, cooperation, reciprocity, self-regulation, initiation, affect and joint attention. These behaviors have been found to be related to child developmental gains in for example, communication and social emotional functioning (Koegel, Koegel, Harrower et al., 1999; Mahoney et al., 2007). These behaviors are also related to temperament characteristics of children (Simeonsson et al., 1982). For children with autism, in intervention studies focusing on maternal responsiveness the children's pivotal behaviors were found to improve. Mahoney et al. found that pivotal behavior mediated the significant relation between maternal responsiveness and child developmental gains (Mahoney et al., 2007).

One prerequisite to attain mutual interaction is the ability to achieve and maintain joint attention, which corresponds to secondary intersubjectivity as described by Trevarthen (2004). Joint attention is defined as “the ability of the infant to coordinate attention to an object or event and to another person within a single communicative act” (Watson, Baranek, & DiLavore, 2003, p. 205). Many children with profound multiple disabilities have difficulties to achieve joint attention and to maintain it (Brodin, 1991).

Children with autism have difficulties with joint attention as their disabilities concern sensory processing, self-regulation and affective development (Watson et al., 2003). Joint attention is also social communication, which is difficult for these children to handle (Koegel, Koegel, Shoshan, & McNerney, 1999). Improved joint attention skills for children with autism are important because sharing a focus of attention with others allows the child to acquire the types of skills that are socially learned, for example language and play with peers. Positive changes in joint attention skills have been found to improve speech and language for children with autism (Kasari, Paparella, Freeman, & Jahromi, 2008). In interaction with children with autism it is important to direct them to relevant objects and events, these children do not seem to have problems with shifting attention but rather in following the attentional directions of others (von Tetzchner, 2000). To help these children to establish joint attention it is more appropriate to use manual or graphic signs than speech, as explicit visual cues help guide their attention in the communication situation better than speech (von Tetzchner, 2000). Implicit in this discussion lays the most
important knowledge which the parents often have of what motivates a child and what he or she perceive as relevant and interesting.

Children with visual impairments on the other hand need other kinds of cues to be able to achieve joint attention. In their case parents must be sensitive in seeking proximity and to use cues for other sensory orientation (van den Broek, Jansen, van Ramshorst, & Deen, 2006). Reaching and touching is linked to the development of intentionality, and for children with severe visual impairments who do not perceive any visual feedback acquiring intentionality is difficult and may be considerably delayed (Bigelow, 2003). It is common that children with profound multiple disabilities have visual impairments. A prevalence study performed by van den Broek et al. (2006) among 76 adult persons with severe and profound multiple disabilities who were clients in a typical Dutch care organization showed that 92% had visual impairments (van den Broek et al., 2006). In this sample only 30% were known to have visual impairments. This can be explained by their inability to express their needs to others and also that it is difficult to measure vision in persons with profound multiple disabilities. As an implication of their results, van den Broek et al. argue that all people with severe and profound multiple disabilities should be perceived to have serious visual problems until proven otherwise (van den Broek et al., 2006).

Children who are deaf blind belong to a small and very heterogeneous group. In this group there are great variations in degree and type of hearing- and visual impairment, as well as in cognitive and communicative abilities (Preisler, 1998). The prevalence of individuals who are deaf blind is very low (app. 1 200 individuals of 9 million inhabitants in Sweden) and most of them are elderly people (Preisler, 1998). Many children who are deaf blind have remnants of vision and audition to a differing degree and the needs of AAC must be evaluated individually. In interaction partners must follow the child who is deaf blind and support the already existing behavior repertoire (Nafstad & Rodbroe, 1999). For the quality to be good in interaction it is also important that the goal and experiences of interaction are feelings of mutual joy of being together. These two strategies make up the backbone in the development of further more complex interactions and experiences of children who are deaf blind (Nafstad & Rodbroe, 1999). In the everyday interactions of these children the meaningfulness of context is highlighted as well is the creativity of interaction partners. The children’s exploration of the environment is very intense and can be rather unconventional, for example, one child explored a threshold by carefully walking passed it 250 times (Nafstad & Rodbroe, 1999). Children who are deaf blind use their whole body to perceive and feel their surrounding world. They especially use their hands, their mouth and face to explore and the nature of use make these body parts a zone of their own which partners must be especially aware of not to intrude on in interactions. At the same time a careful familiar partner can use
the children’s use of their hands, mouth and face to engage the children in joint attention.

New technology has made it possible for children who are deaf or hard-of-hearing to have cochlear implants (CI) by operative surgery as an intervention. CI are hearing aids which function is to repair the disrupted connection between the nerves in the ear and the auditory centre in the brain by electronic impulses. The effects of the implants are good when measured as perception and production of speech in a laboratory setting (Preisler, Tvingstedt, & Ahlström, 2002). However, these effects say nothing about symbolic comprehension or the use of language in everyday life. Preisler et al. descriptively, longitudinally and qualitatively studied patterns of communication and interaction between 22 children with CI and their parents at home and with teachers and hearing as well as deaf peers in the preschool setting (Preisler et al., 2002). Detailed observations by means of video recordings showed that meaningful oral communication was more easily obtained in the home setting than in the preschool setting. Supportive sign language was important as a complementary means of communication for these children. As time passed, all parents introduced more spoken language in their conversations with the children. This did not benefit all children. When parents used a child-centered communicative style, as opposed to an adult-centered directive style, the children used both oral and supportive sign language and could develop their conversations in complexity. There were no clear patterns found in effects of variables such as time for and cause of deafness, time with implant or age of operation on how well and how much the children used their CI (Preisler et al., 2002).

Another issue to consider when the goal is mutual interaction and joint attention is behavior state and especially levels of arousal and alertness of children with profound multiple disabilities. There are 8 different stages of alertness: inactive sleep, active sleep, drowse, daze, awake inactive-alert, awake active-alert, awake active-alert with stereotypy and crying/agitation, which also includes self-injury (Guess, Roberts, Siegel-Causey, & Rues, 1995). A study of the percentage state occurrences of a sample of 66 children and youths with profound disabilities found participants to be mostly in awake inactive-alert state: 46% of the time (Guess et al., 1995) independent of chronological age. The level of alertness in which children are most likely to participate and learn is the stage of awake-active-alert (Roberts, Arthur-Kelly, Foreman, & Pascoe, 2005). In the study by Guess et al. (1995) the occurrence of that state within the sample was very low across chronological age, only 13-24% of the time measured. Several studies highlight the often rather low rate of optimal alertness and shifting nature in stages of alertness for children with profound multiple disabilities during typical everyday life (Roberts et al., 2005). Arthur (2003) studied socio-communicative variables and behavior states of ten students with profound multiple disabilities in school settings (Arthur, 2003). During one day in
school these students were observed over a variety of settings, for example, classroom, bathroom and playground. Behavior states were documented on a continuum from asleep-inactive to awake-active-self injury, with awake-active-alert as the most common state. Findings showed that the students had individual variations in behavior states across the day and also that they were in interaction with other persons to a varying extent. Critical findings were that students who were in an optimal behavior state for interaction and activity spent time in solitude and were not engaged in communication from teachers during that state. At that time, neither did the students receive responses to cues of communication they themselves initiated. Overall, there was quite high proportion of time during which no activity or communicative interaction occurred for the students. As this group has such a low prevalence of time spent in the optimal behavioral state for interaction and learning it is vital that they are engaged in proximal processes during that time. This has important implications for teacher training and education for children with profound multiple disabilities.

**Interaction- Mutual regulation**

Interaction is a continuous process system where partners co-regulate their actions depending on the interpretations of the others ongoing and anticipated actions (Fogel, 1993). In this process a consensual social frame is created and elaborated over time. Fogel argues that in the process of interaction partners are creative and not governed by rules. There is openness between the partners and as long as the frame is mutual the interaction in it can elaborate in all directions. It is unnecessary for the interactive partners to share a goal in interaction. Consensual social frames denote mutual agreements between the partners about what to communicate about, when and how interaction takes place and for how long. Frames are established through negotiation processes, which can be established by attentions direction, spatial location, postural orientation and topic (Fogel, 1993; Olsson, 2006).

There is also a generative characteristic of language and interaction competence of partners that make it possible to create new words, new gestures and new languages (Corballis, 2002; Tronick, 2007). The generative capacity also makes notice in the immediate interaction between children and caregivers. The dynamic turn-takings in interaction is interpreted by the interactive partners and made new with every turn, it is a spiraling process of mutual regulation and interdependency (McCollum, Ree, & Chen, 2000; Tronick, 2007).

The Mutual Regulation Model (MRM) constructed by Tronick is similar to Fogel’s concept of co-regulation and proposes that the interactive goal of child/caregiver interaction is to achieve mutual regulation, also described as
reciprocity (Tronick, 2007). Mutual regulation is a “feedback-regulated control system process” (Tronick, 2007, p. 178). In mutual regulation there are two goals present simultaneously: physical goal and intersubjective goal. The physical goal is the physical positioning and behavior that enables interaction. The intersubjective goal is the experience of a mutual sensing of each other’s motives and desires. These two are both primary goals but in interactions there is a pendulum in prioritizing one of them at times in the background or foreground (Grove, Bunning, Porter, & Olsson, 1999).

To achieve mutual regulation both partners in interaction adjust by regulating their interactive behaviors (Hedenbro & Lidén, 2002). In interaction Tronick (2007) describes two regulative functions that individuals perform: self-regulation and interactive regulation. As discussed earlier, self-regulation is the ability to regulate emotionality, physiological arousal, attention, thoughts and impulses. The second regulative function, interactive regulation, is the regulation that occurs in interaction, achieved by the adjustment of interactive behavior. In the mutual regulation model, interactive behaviors are considered to be primarily affective communicative expressions. Affective communicative expressions are responses to the achievement or non-achievement of intersubjective goals of mutual regulation but also to physical goals. The function of the responses is that the infant’s appraisal of the interaction is expressed in the affective displays. In this way the infant can direct, modify and maintain interaction: this is a significant communicative power (Tronick, 2007).

Interactions of reciprocity and mutual joy are most important for the development of children. The goal in interaction is to reach mutual regulation, obviously it is not always possible to achieve. Mismatches in interaction are common and successful resolution of mismatches is central for the development of interactive skills and the sense of self (Stern, 2002; Tronick, 2007). It is also important for the development of self-regulatory skills (Tronick, 2007).

Challenges for interaction partners of children with profound multiple disabilities

Children with profound multiple disabilities are communicatively dependent on their parents as mediators, and caregivers must be especially sensitive when guiding these children in interaction and social life (Brodin, 1991; McCollum & Hemmeter, 1997). Interpreting a meaning to another person’s communication is something that is included in all interaction. As discussed previously, mutual regulation or co-regulation is the functional form for interactive behavior in the immediate situation to achieve successful interaction and mutual joy between two interaction partners (Fogel, 1993;
In this spiraling process, the assignment of meaning to the other’s interactive behavior is made all the time. When one interaction partner has profound multiple disabilities the assignment of meaning becomes difficult (Grove, Bunning, Porter, & Olsson, 1999). In assigning meaning partners use their prior knowledge of the individual, knowledge from previous interactions with this individual or others and knowledge about the context (Tucker & Kretschmer, 1999). In accordance with a transactional perspective of development it is important for professionals who work with individuals with profound multiple disabilities to have a thorough understanding of the whole communication repertoire of the individual with disabilities, the individual’s communication partners and environments. Meaningful interaction is the key to more complex and advanced communication and social interaction (Snell, 2002).

It has been demonstrated that parents of typically developing children have regular and predictable interactive behaviors of which they are not aware that are aimed at supporting children’s development (Waxman, Spencer, & Poisson, 1996). Although parents seem to be more responsive to infants who are developmentally delayed or have serious illnesses (Bronfenbrenner & Ceci, 1994), this ‘intuitive’ parenting is not enough in interaction with children with profound multiple disabilities to ensure reciprocal interaction and optimal development (Nafstad & Rodbroe, 1999; Waxman et al., 1996). Waxman et al. (1996) found that hearing mothers to deaf children did not change their communicative and interactive behaviors in consequence of the child’s communication abilities. Modifications of interactive behaviors did not transfer spontaneously to another modality different from the one the mothers’ habitually used. Waxman et al. (1996) argued that this could only be changed by direct interaction intervention. Furthermore, there can also be practical challenges in everyday communication and interaction of parents to children with profound multiple disabilities. Parents of children who used aided AAC reported that their own lack of skills in dealing with, for example, technology breakdown was great challenges to make everyday interactions to work (McNaughton et al., 2008). These parents perceived support from clinicians to be very important for intervention sustainability.

Parts of systems theory state that culture has a direct influence on child development through the psychology of their parents (Lewis, 2000; Super & Harkness, 1999). Some parents, irrespective of if they have a child with profound multiple disabilities or not, have the opinion that they should have an active role in promoting the interaction with their children while others have the opinion that children interact spontaneously if provided with adequate opportunities (Booth, 1997). Thus, parents consider interaction abilities to be either innate qualities that lies within the disposition of the child or abilities that are moldable by the environment to a greater extent (Booth, 1997). The contexts of the cultural value system parents have about
communication are building blocks for how they as interactive partners view interaction of children with profound multiple disabilities and make their inferences of communication cues (Kelly & Barnard, 2000; Tucker & Kretschmer, 1999). In accordance with Waxman et al. (1996), in a case study Tucker and Kretschmer (1999) found that a mother and a physical therapist interacted differently with the same child with profound multiple disabilities depending on their pre-conceptions and beliefs about communication. The physical therapist responded to and used more atypical cues of communication; she believed that the small movements and vocalizations were as valuable as the end product of an act. The mother, on the other hand, viewed the end product as the valuable goal and thus did not see the small steps on the journey as important communication. Furthermore, McCollum et al. (2000) investigated parent/infant interactions cross culturally of white American mothers and Korean mothers and found that the way mothers viewed parent/infant interaction with objects and parent/infant social interaction differed with cultural background. As the cultural meanings of the two interaction situations were different also the way they would present objects and play with the objects together with an infant in intervention could come to differ (McCollum et al., 2000).

Descriptive researches of parent-child interaction between parents and children with severe disabilities indicate that parents are more directive in interaction and take on a more dominant role in interaction in comparison to parents interacting with non-disabled children (Kelly & Barnard, 2000; McCollum & Hemmeter, 1997). It is argued that interaction partners of children with profound multiple disabilities must be sensitive as to not become ‘the owner’ of the communication. It is a difficult act of balance which can make both interaction partners in a dyad insecure. Those who are interpreting the communication of children with profound multiple disabilities must be aware of what they may be inadvertently reading into the situation (Grove et al., 1999). In order to balance the act of interpreting a child with profound multiple disabilities it is necessary to share similar frames with the child in interaction. A structured context, for example with a set number of choices or acts of habits, can be facilitators.

The less explicit the communication is the more the interaction partner must rely on its own inferences. Also the expectations and wishes the interaction partner has on the child’s interaction will determine the outcome. The process of interpreting communication involves two levels of inference: inference regarding the meaning of the message and inference regarding the intentional state of the communicator (Grove et al., 1999). In interaction with children who function on a non-symbolic level the possibility for misunderstanding and breakdown of interaction increases and it is of interest to investigate what happens during communication breakdown. In accordance with Tronick’s theory about resolving mismatches in communication (Tronick, 2007), it can be helpful to explore what the repair
efforts in interactions with children with profound multiple disabilities look like, to get to know more about how to proceed into more complex communication (Snell, 2002).

**Interaction intervention for children with profound multiple disabilities**

In research focused on interaction interventions for children with profound multiple disabilities, interventions have focused on interactions between specific individuals in the family without taking the perspectives of the whole family system (Granlund & Wilder, 2006). Traditionally, interaction interventions have focused on parental directiveness, amount of stimulation and contingent responding by parents as these qualities have been found to be related to less optimal developmental outcomes for children without disabilities (McCollum & Hemmeter, 1997). In this way interventions were focused on behaviors that either the parent or the child with disabilities lacked or performed incorrectly (Koegel, Koegel, Harrower et al., 1999). Researchers have postulated cautions against basing interventions for children with profound multiple disabilities on research from typically developing children. Research about interaction intervention for children with autism have identified a pivotal response model which entail four areas to focus on for intervention to be pivotal (Koegel, Koegel, Harrower et al., 1999). These areas concern; providing intervention in the most inclusive setting, providing the most effective intervention within a relatively small number of hours of direct contact from highly skilled specialists, interventions should be spread across different interventions agencies and, finally, targeted behaviors should be individualized. Furthermore, the targeted behaviors should not be specifically behaviors that the interactive partners lack but should rather focus on pivotal behaviors (Koegel, Koegel, Harrower et al., 1999; Mahoney et al., 2007). In an overview of research of interaction interventions for interactive partners of children with profound multiple disabilities McCollum and Hemmeter (1997) found that interaction interventions have been highly individualized and focused on, for example, increasing parental responsiveness, promoting parental turn taking, parental adjustment to the child’s skills, increasing positive aspects of interactions, following the child’s lead and amount of stimulation from parents. Furthermore, children with severe disabilities are overall most likely to benefit from effective augmentative and alternative communication (AAC) interventions (Snell, Chen, & Hoover, 2006). In their review of interaction intervention concerning AAC for children with severe disabilities Snell et al. (2006) found that interventions frequently used child-directed approaches which include, for example, following the child’s lead, creating
opportunities, proximity of partner and materials and embedding instructions in activities.

The targeted individuals in interaction interventions have most often been the child with profound multiple disabilities and/or teachers at preschool/school and/or the children’s parents (Snell et al., 2006). Siblings have been the target group, but to a much lesser extent. One example is the study conducted by Trent-Stainbrook et al. (2007) who trained older siblings of 3 children with Down syndrome to use responsive interaction strategies (Trent-Stainbrook, Kaiser, & Frey, 2007). The 3 older siblings were 10, 9 and 9 years of age and the focuses for the interaction training were to increase verbal responsiveness and nonverbal mirroring of the siblings. Outcomes were measured on the interaction of the siblings with Down syndrome who, as a result, increased commenting but not requesting in interaction after intervention. One of the siblings with Down syndrome did not benefit from the intervention much and this was argued to be due to the low level of communication abilities that she had from the start. The review conducted by McCollum and Hemmeter (1997) concluded that interaction interventions for children with profound multiple disabilities are few, very individualized and outcomes difficult to generalize across studies.

Outcomes from interaction interventions are in differing details measured on child level, dyadic level or parental level at different time points after the intervention depending on the aim of the intervention. A systematic review of communication intervention in which interactive partners to children with cerebral palsy were trained in strategies that facilitate interaction and communication development (Pennington, Goldbart, & Marshall, 2004) revealed that the effects of training on children seldom is documented. In the intervention study by Trent-Stainbrook et al. generalization of won abilities to other activities than the ones used in training sessions was almost nonexistent (Trent-Stainbrook et al., 2007). Overall in research about interaction interventions there are concerns about the generalization of outcomes and also maintenance of skills learnt in interaction intervention (Mahoney et al., 2007; McCollum & Hemmeter, 1997; Snell et al., 2006). These are important issues when measuring the outcomes of intervention. Long-term maintenance of outcomes can be defined as skills learnt which still remain 6 months after intervention (Snell et al., 2006). To stimulate generalization and maintenance interventions should be performed across multiple stimuli and in naturally occurring interaction contexts (Snell et al., 2006). Also video self-modeling on parents’ interactions have been proven effective to stimulate generalization (Reamer, Brady, & Hawkins, 1998). In this model of intervention, video is used with parents and children to reflect upon progress in training sessions. Furthermore, consideration of family context and implementing interventions into family routines may contribute to the stability and
durability or reductions of challenging behaviors of children with autism achieved in interventions (Moes & Frea, 2002).

Mahoney et al. (2007) and many other researchers argue that as the family is the primary place were children learn to function in the everyday life it is in that environment and in family routines that interventions should take place. In family centered intervention the family is stressed as the primary context for interventions (Bailey et al., 1998; Singer, 2002). The goal is to make the family part of decisions about interventions and to enable and empower the family in an emancipatory way (Ferguson & Ferguson, 2000). Studies show that family centered services not always appear to affect either family or child functioning (Mahoney & Bella, 1998) and that few or no studies have evaluated the effect of interaction interventions on family functioning, for example everyday functioning, network support and optimistic belief in the future (Bailey et al., 1998). For children with profound multiple disabilities the family is the most inclusive setting and also the most important setting because it is within the family that proximal processes primarily take place.

The third part of the thesis addressed communication and interaction of children with profound multiple disabilities. In the section these children’s idiosyncratic and pre-intentional communication, augmentative alternative communication and difficulties to maintain joint attention were discussed. Furthermore, theories of early child/parent interaction were presented and also how interaction is perceived to be a bidirectional process between two interaction partners. Also challenges of interaction partners to children with profound multiple disabilities was discussed. Finally, interaction intervention for children with profound and multiple disabilities was discussed. The forth part of the thesis will present the empirical studies.
The empirical studies

In this thesis, the target group of participants was Swedish children with profound multiple disabilities, their parents and their families. This group of children is very diverse in characteristics and circumstances and there are very few in Sweden. The children had profound multiple disabilities, which was defined by Ware (2005, p. 68) as individuals having “at least two severe impairments, one of which is profound learning difficulties” (Ware, 2005). In this thesis children with profound multiple disabilities were considered to be children having a combination of both cognitive and physical disabilities. All children had different diagnoses, example of diagnoses were CHARGE, Tetraplexia, Autistic syndrome in combination with physical disability, Trisomy on chromosome 13 and combination of cognitive disability and cerebral palsy. A few children did not have a diagnosis due to difficulties to determine the disabilities. Furthermore, some children had cochlear implants as an intervention. Most of the children functioned on a non-symbolic communication level, which was pre-intentional. Some of the children had more advanced symbolic communication and also more intentional communication, for example they used single signs and proactive intentional communication.

Methodological choices

The aims of the thesis were to explore the subjective views of the children’s parents about interaction, child and family characteristics and to study the patterns of child-parent interaction. The explorative approach of the thesis and the target group per se automatically implies a qualitative research approach. A random sample was not taken for the studies; rather a purposeful sampling strategy was used. Taking a random sample of this group would not add statistical security because a random sample would not be representative. For this thesis four studies were performed: three qualitative studies (I, II and IV) and one quantitative study (III). In the qualitative studies interviews, video observations and questionnaires were used at home visits to capture the child/parent interaction. In the qualitative only children with profound multiple disabilities and their families participated. In the quantitative study three groups of children were compared: one group with children with profound multiple disabilities, one
group of typically developing children who were matched in communicative ability to the first group and one group with typically developing children who were chronologically age matched to the first group. In study III data was collected by questionnaires and a structured telephone interview about parental perceptions of child interaction.

The participation of the participants in the studies was stressed throughout the studies in the thesis. This is an important part of interpretative research in order to make sure that data is collected very close to the natural context and reality (Ferguson & Ferguson, 2000). The participation of this specific target group is especially important as the close caregivers of these children function as mediators and advocates; they are the experts (Granlund, Björck-Åkesson, Olsson, & Rydeman, 2001; Landsman, 2006). For the quantitative study questionnaires and a structured telephone interview were used as data collection methods. Parental perspectives for all groups in study III were stressed in the interviews, and the questionnaires were filled in by the parents. For the three qualitative studies home visits were used as the setting for data collection. The home visits were arranged according to the families’ schedules and flexibility was taken by the researcher. During the times of data collection the importance of the families’ point of views and involvement were stressed in the interviews and also by the choice of instruments. The procedures of collecting and analyzing data were open and accessible for the participants. Member checks were done of transcribed interviews, compilations of descriptive data were sent to the families and the parental interpretations of their child’s interaction were sought for at the home visits and also by telephone during data analyses. The families had full insight in the research material of their own family at all times. In planning the home visits it was explained that the researcher was interested in the views of the whole family but that only one of the parents would be needed in the interviews and video observations. It was explained and stressed that this parent would talk for the whole family as a family representative. This approach was chosen so that participating in the studies would not take up too much of the families’ energy and time as the home visits and instruments used were rather extensive. During interviews and questionnaires the researcher reminded the mother or father that they were talking for the whole family and in interview situations the researcher intentionally asked of the interpretations, activities and adaptation of the whole family.

### Video observations

In study II video observations were used to study how the dynamics in child/parent interaction related to the children’s behavior styles. Video observations of interaction are very useful when studying children with profound multiple disabilities as their behavior in interaction is idiosyncratic, subtle and difficult to interpret (Björck-Åkesson, 1992; Brodin, 1991;
Olsson, 2006). In study II detailed analyses were performed for each second of both child and parent interaction. Video observations were made at the participants' homes and the recordings amounted to approximately 40 minutes per dyad. The first 10 minutes of the video recordings functioned as a warm up for the dyad and were not included in the sequences that the parents later chose. The children did not show any reaction to being video recorded; they did not seem to notice it. The parents said that they had been recorded before for purposes of interaction interventions and that they did not mind being recorded. The parents were informed of the purpose of the recordings and seemed comfortable in the situation. After the video recording session the parents and researcher sat down and viewed the whole film together. The parents chose three sequences which they thought were typical interaction to something known, something unknown and typical interaction with a stranger. Then the instrument ACA was used to discuss and explain how the parent interpreted their child’s behavior. In the mutual discussions the parents gave their interpretation of the children’s different ways of affectively communicating. They also chose how they would phrase the reaction in words, for example, total enjoyment or great discomfort. In this way ACA functioned as a direct instrumental standardization of the video recordings at the home visits and gave the researcher more knowledge about the children’s behavior repertoires. In data analyzes the researcher used the chosen sequences of interaction to something known because according to ACA the children used most of their behavior repertoire in these interactions.

Data analyses

The processes of data analyses were also of exploratory kind. Data analyses in study I of the semi structured interview used meaning concentration and categorization (Kvale, 1997). Data analyses by meaning concentration can be described as a circular process and a pendulum between the parts and the entirety by asking questions (Kvale, 1997). By asking questions emanating from the aims of the study to the raw data, data were compressed into shorter loaded units of meaning. In this process several central themes appeared in each interview. These central themes were investigated further by a method of categorization where categorizations were formulated on a continuum from concrete to abstract and also categorized into main themes. As such this method is related to thematic networks analysis (Attride-Stirling, 2001). Thematic networks are web-like illustrations that summarize the main themes constituting a piece of text (Attride-Stirling, 2001).

In study II the questionnaires were analyzed descriptively and video recorded interactions were analyzed in detail using a model and method constructed by Light (1985) and adapted by Björck-Åkesson (1992). According to this model the dynamics in the interaction are analyzed by
studying the turn taking process between the parties in the dyad. The analysis takes into consideration the function of each turn in relation to the preceding and following turn. The children’s and the parents’ motor and verbal behavior, smiles and laughter and direction of gaze in the interaction are considered in detail to be components of interaction. In coding a sequence, different amounts of interaction components and how many seconds a turn taking prolonged are determinants for strong or weak interaction turns. In this way interaction patterns over several turns and entire sequences can be reached for each individual in the interaction. Patterns of their interactive styles can be explained according to frequency of weak or strong initiatives, responses and endings in interaction as well as pauses and accord. This is a very detailed method where interaction is transcribed and analyzed per second for both the child and the parent. In the analyses a second researcher viewed the video recorded interactions and the analyses of interaction were discussed. Also the parents’ interpretations of their children’s interaction behavior as noted by the instrument ACA was helpful in the detailed analyses of interaction. No inter rater reliability was obtained. As a final step of data analyses in study II data about the children’s behavior styles and the parents’ wishes for change in interaction as collected by questionnaires were compared with the results from the video recorded interaction in search for patterns. Hypo- or hyper dominated behavior styles were found to determine interaction in different ways. Furthermore, a triangulation was found between the wishes for change in interaction and what the interaction actually looked like according to the analyses.

To explore differences between the groups in study III data from questionnaires were compared using SPSS for Windows and descriptive analyzes, one-way ANOVA, Scheffé post-hoc test, Pearson’s correlation coefficient and Chi square were performed (Brace, Kemp, & Snegler, 2003; Howell, 2002). In this way significant differences were found between the groups as well as descriptive results about emotions.

Study IV contained extensive amount of qualitative data and the data reduction in data analyses can be likened to manifest qualitative content analysis (Graneheim & Lundman, 2004). Data reduction was deductive. The aim was to obtain the most central factors around which family life evolved. In the data analyses searches for patterns of change and stability over time across and within cases were in focus. There were five steps in analyses. First, during the time of data collection, data were summarized into descriptive results and interviews were transcribed. As a second step, all data were analyzed according to manuals and codebooks of the chosen instruments for each year. In this phase, data were analyzed within and across cases for data from each specific instrument per year. Thirdly, data were analyzed within and across cases for all data collection methods over the time of both years. Data were compiled according to guidelines for qualitative data reduction and data visualization in tables and diagrams.
(Miles & Huberman, 1994). During the third step the analyses were discussed with another researcher at three time points. This third step emanated in an aggregation of variables into indices of ten central factors for change and stability over time. As a forth step in data analyses an extensive result document was sent to the previously mentioned researcher for verification of the ten central factors. The verification between researchers resulted in a reduction from ten to eight factors. The fifth and final step in data analysis was to assess each family on the eight central factors for both years. In order to do so, assessment rules were put down for each factor using individual versus group measures and also the suggested methods of analyses for the existing data instruments.

Ethical considerations

Ethics for all studies in the thesis followed the recommendations of the Swedish Research Counsel (Vetenskapsrådet, 2002). The studies did not entail intervention or manipulation of participants but included a group of subjects which is extra sensitive. No ethical approval was applied for from the Swedish regional ethical boards because data collection was started before the law of ethical approval was instituted. Although, due to the vulnerability of the participant group, approval of the longitudinal study IV was applied for and granted by the ethical committee at the Department of Psychology, Stockholm University. Participants were recruited by posting an information letter on the home websites of two disability organizations in Sweden. Participants were also recruited through counselors at the Special Education Institute in Sweden. The parents of the children functioned as advocates for their children in choosing to participate in the studies. The parents received written and oral information about the studies and about the aims of the studies, and they gave informed consent. The participants have been given total confidentiality. They were informed that they were to participate in research and that the data were only to be used for research purposes. Furthermore, video recorded data have been stored in locked cabins and a safe all the time except when data were analyzed. The participants were also informed that their participation in the research projects was voluntary and could be terminated at any time. During the time of executing the studies, the participants received information about how the studies proceeded and also received member checks of interviews, compilations of descriptive results continually and they received a copy of each video recording in which they participated. They have also been informed of how to get access to final reports of the studies.

Children with profound multiple disabilities and their families are a vulnerable participant group in many ways. It is important not to intrude too much in these children’s routines due to their disabilities and sometimes
factors fragile health. The families’ integrity must be respected and consideration must be taken to their own choices of public display. As data was collected primarily by home visits the researcher entered the primary micro environment of the families and children. As such ecological validity was practiced and obtained (Hayes, 1997). Furthermore, being invited into someone’s home and keeping an objective role as a researcher is an act of balance. In this situation it is important to form correct relationships and that there does not exist any state of dependency in the relationship; “Although friendship is not required or even expected … real human connection is” (Ferguson & Ferguson, 2000, p. 183). The importance of relationships to participants lies in the believability and accuracy of the data (Ferguson & Ferguson, 2000). The parents in the studies of this thesis reported that they had appreciated being participants and that the interviews and video recordings also helped them to see new things.

**Instruments**

In the four studies of the thesis several instruments were used, some were used in more than one of the studies. These instruments will be presented and discussed below in alphabetic order.

**Abilities Index**
The Abilities Index was used in study II and III. The Abilities Index measures the physical and cognitive abilities of the children dealing with vision, audition, motor ability (use of hands, arms and legs), intellectual functioning, behavior/social skills, communication, health and tonus (Bailey, Simeonsson, Buysse, & Smith, 1993). The communication item denotes the sum of both implicit and explicit skills as it measures both language usage and understanding. The scale range from 1 to 6 where 1 denotes normal ability and 6 profound impairments. The Abilities Index was translated into Swedish and used in an extensive Swedish study (Roll-Pettersson, Granlund, & Steénsson, 1999).

In study II the parents filled in the questionnaire. In study III the Abilities Index was filled in by the parents of group 1, which were 30 children with profound multiple disabilities. In study III, Cronbach’s Coefficient Alpha was measured to $\alpha = 0.73$ for this instrument.

**ACA (Affective Communicative Assessment)**
The instrument ACA was used in study II. ACA is divided into three stages: observation, identification and intervention stage (Coupe O’Kane et al., 1985). First, the individual’s behavior repertoire is documented over a series of observations where the child is exposed to several kinds of positive and negative stimuli, for example specific food or songs, which the individual
has shown clear affective responses to according to familiar people. Secondly, identification of strong responses is documented and more detailed information of these responses is gathered with further exposures to the stimuli and response in question. As a third stage interventions can be formed on the background from the gathering of information on both stimuli and setting that have been identified for the specific individual. By getting to know the individual’s behavior repertoire like this, new ways to communicate can be formulated by using the typical reactions that the individual already performs in a new way (Coupe O’Kane & Goldbart, 1998).

In study II the observation stage was used at the home visit. At the viewing of the video recordings of child/parent interaction the parent filled in an observation sheet together with the researcher and interpretations of the child’s interaction behavior was documented.

CCI (Child and Caregiver Interaction)
The questionnaire Caregiver - Child Interaction (CCI) was used in study II, III and IV. CCI measures parent and child interaction (Granlund & Olsson, 1993; Light, McNaughton, & Parnes, 1986; Rowland & Schweigert, 1992). In CCI interaction is measured according to the parents’ perception of the immediate interaction and their perceptions of ideal interaction; as such the difference between the immediate interaction and the perceptions of ideal interaction functions as a third measure. The questionnaire measures interaction patterns on a five-point Likert scale from seldom to common (seldom, rather seldom, in 50% of the time, rather common and common) for 18 items, 9 about the child and 9 about the parent. The items are concentrated on turn taking, focus, time and interest in interaction, e.g “The child can direct the parent’s attention toward a shared topic”, “The child initiates interaction”.

In study II, III and IV the parents filled in the questionnaire. In study III, Cronbach’s Coefficient Alpha was measured to $\alpha=.82$ for the immediate interaction and $\alpha=.72$ for the perceptions of ideal interaction.

CRIB (Carolina Record of Individual Behavior)
Part B of the instrument Carolina Record of Individual Behavior (CRIB) was used in all four studies. It was constructed and validated by Simeonsson et al. (1982). It is a parent- or observer administered questionnaire that measures basic behavioral characteristics of children with disabilities. It is intended to be scored by observers on the basis of systematic observation: either in the context of an evaluation session and/or a period of systematic observation in which the child has opportunity to display a range of behavior. It is constructed to be user friendly. Part B is constituted of seven items inquiring about the children’s behavior style measuring the levels of activity, reactivity, goal directedness, frustration, attention span,
responsiveness to observer/parent and general tone of body. These dimensions are measured on a scale ranging from 1 to 9 where 1 denotes hypo/passive behavior, 9 denotes hyper/extremely intense behavior and 5 is the middle score which denotes behavior style most appropriate to situation and age.

In all four studies the parents filled in the questionnaire. In study III Cronbach’s Coefficient Alpha was measured to $\alpha=.64$ for group 1, $\alpha=.52$ for group 2 and $\alpha=.67$ for group 3. In study III general tone of body was only filled in by group one.

EFI (Ecocultural Family Interview)
The ecocultural family interview (EFI) was used in study IV. It is a semi-structured interview with open ended questions that measures family accommodations in everyday routines and activities in response to having a child with disabilities. It covers ten domains of parents’ accommodations activities: family subsistence base, use of services, home/neighborhood safety and convenience, domestic workload, childcare tasks, child peer groups, marital roles, instrumental/emotional support, father/spouse role and sources of information (Weisner et al., 1997). The interview is a conversation where the parents are encouraged to describe how they organize, adapt and sustain their daily routines and activities. Examples of questions are: Walk me through your day; why are these important activities, How do you keep your routines going (Weisner, 2002)? Following a specific code book, accommodation intensity is measured on 51 items with possible scores ranging from 0 (no accommodation activity) to 8 (high accommodation activity) on each item, 9 denotes not applicable. There are three levels of measures: 0-2 is low, 3-5 is medium and 6-8 is high. The 51 accommodations measures are then summarized on three items. On these items a summary estimation is done for each family concerning: meaningfulness of daily routines and appropriateness to family’s goals and values, ecological fit of resources and the ability to keep routine and congruence between daily routine and the competencies and needs of the child as well as other family members. The scale of these items goes from 0 to 8, where 0-2 is low, 3-5 is medium and 6-8 is high meaningfulness, ecological fit and congruence.

EFI was used in study IV where the EFI instrument was modified for the cultural group of Swedish participants and to fit the children’s profound multiple disabilities. Items number 9 concerning insurances was modified. It was rephrased to: Does the child have insurance and to what extent can the family benefit from it; do they for example receive money? Item number 10 (insurances for other family members), 46 (child needs protection due to sexual development) and 47 (evidence of ethnic and cultural diversity in the family social network) were omitted. Two new items were included that considered (1) participation and emotional support from disability
organizations, (2) emotional support from friends and family. The modifications were done to fit EFI to the Swedish participants concerning reasons of culture, social system and child characteristics (age and severity of disability). Inter rater reliability for EFI was calculated according to agreement divided by (agreement plus disagreement) all times 100%. Inter rater reliability came to 0.85 in this study. The inter rating was assessed on low, medium and high level of EFI measures and was assessed on 25% of the total sum of interviews. The inter rater was a researcher with a PhD with competence in analyses of interviews although she had not worked with this instrument before and had no specific training in EFI.

ESCS (Early Social Communication Scale)
ESCS was used in study III. It is a structured telephone interview measuring early social communication (Seibert & Hogan, 1982), translated and modified by (Granlund, Karlan, & Olsson, 1988). Validity and reliability of the instrument have been reported as satisfactory (Granlund & Olsson, 1988). ESCS measures the complexity, frequency and width of the children’s communicative skills dealing with three areas: the children’s ability to create social contact, to create joint attention and to show regulative behavior. They are measured according to how the children can respond, initiate and maintain social contact and joint attention and how they can respond and initiate regulative behavior. The complexity is measured according to a scale from 0-4. The width is calculated by dividing the frequency that the child shows in each area and complexity level with the amount of frequency that is possible to master at the certain complexity level. A high complexity and a wide width denote well functioning communicative ability.

In study III ESCS was only used with the families of group 1 and 2 as the children of group 3 were considered to have passed the early communicative stages. In study III, Cronbach’s Coefficient Alpha was measured to $\alpha=.84$ for the children’s abilities to maintain, respond and initiate social contact, Cronbach’s Coefficient Alpha was measured to $\alpha=.81$ for the children’s abilities to maintain, respond and initiate joint attention and Cronbach’s Coefficient Alpha was measured to $\alpha=.61$ for the children’s ability to respond and initiate regulative behavior.

Semi-structured interview
In study I a semi-structured interview was constructed that measured parental perspectives of child/parent interaction. The aim of the interview was to present the frame in which the interaction between the parent and the child worked. It was formed to give information about how the parents perceived the interaction to function within the dyad. The interview was semi-structured with five set questions, although there was room for the interviewer to explore issues and to probe further on questions when
considered appropriate (the interview questions can be found in the appendix of paper I). The questions were identified by the primary researcher according to the aims of the study. A researcher familiar with the purpose and the literature background of the study reviewed the initial format of the interview questions. A researcher unfamiliar with the area also reviewed the initial format. The interview questions were modified as a result of this input. Topics that were considered in the interview were the parents’ strategies for the interaction, how the parents perceived the roles of the children and their own roles in interaction, the parents’ opinion of what an interaction constituted of and the parents’ aims and aspiration for interaction. The interview was performed at home visits and took approximately 40 minutes.

SNI (Social Networks Inventory)
The Social Networks Inventory (SNI) was used in study IV. It describes the informal and formal social networks of communication partners of persons with communicative disabilities (Blackstone & Hunt-Berg, 2003). The SNI is a structured interview with open ended questions and closed questions. The procedure involves interviewing two communication partners who are close to the person with a disability, in order to map the social networks with particular reference to the communication partners. Communication partners are documented in a diagram of five concentric circles: the first circle includes the person’s life-long communication partners, the second circle includes close friends/relatives, the third circle includes acquaintances, the fourth circle includes paid workers and the fifth circle includes unfamiliar partners. Additionally, within these circles, the primary communication partner, the most skilled communication partner, the most frequent communication partner, the most willing to learn and the communication partner most willing to teach others about the person with a disability are chosen. The person’s modes of expressions, communicative strategies and type of communicator are also discussed in the structured interview.
In study IV, the SNI was filled in by the parent together with the researcher at the home visits. In this procedure the researcher lead the structured interview and the parents filled in the circles of communication partners (CCP) systematically. The parent representing the family were asked to fill in the CCP for the family as a whole and then for the child. The parents also filled in the primary communication partner, the most frequent communication partner and the favorite communication partner for the whole family. For this study, SNI questions about technical AAC devises and advanced communication were omitted.
Questionnaire about emotions
In study III a questionnaire was constructed that measured how many of 14 emotions the children exhibited (curiosity, joy, expectation, anger, fear, irritation, interest, sadness, disgust, approach, avoidance, anxiety, calmness, excitement). The parents were asked to encircle the emotions on the list which they perceived their children expressed. In this way amount of emotions and emotional span was measured. It was also possible for the parents to add emotions they thought their child exhibited but that was not mentioned in the list above. This questionnaire was used with all three groups in study III.

Structure of the empirical studies
In total 36 children with profound multiple disabilities and their families participated, and 60 children without disabilities and their families participated in the four studies of the thesis. In study I and II the same seven children with profound multiple disabilities and their families participated. In study III 30 children with profound multiple disabilities and their families participated of which seven were the same as in study I and II. In study III also 60 children without disabilities and their families participated. In study IV eight children with profound multiple disabilities and their families participated of which two families had participated in the previous studies. Thus, in the qualitative studies 13 distinct children and families participated.

The whole research project of this thesis began with an unpublished correlation study of a sample of 30 children with profound multiple disabilities which investigated the relations between the children’s behavior style, functional abilities, interaction and communicative competence (Wilder, 2000). The participants were recruited by posting an information letter on the home websites of two disability organizations in Sweden. Data were collected by questionnaires and a telephone interview. From this sample seven children also participated in study I and II and parts of the results from the correlation study are presented in study III.

Study I: Behavior style and interaction between seven children with profound multiple disabilities and their caregivers

Background and aim
Children with profound multiple disabilities exist in the centre of influences from the bio-ecological system and it is through the dyadic twosome the
child meets social and physical environments with the parent functioning as a mediator (Wachs, 2000). As children with disabilities are difficult to read in interaction it is especially important that interaction partners are sensitive as qualitatively successful interactions can boost the development of the child (McCollum & Hemmeter, 1997). The origin of personal stimulus qualities of children with disabilities, for example temperament dimensions, and its role in interaction has been debated among researchers (Guess, Rues, Roberts, & Siegel-Causey, 1993). Studies have shown behavior style of children with profound multiple disabilities to be more related to the parent-perceived interaction than communicative skills and functional abilities of the children (Wilder, 2000). The aim of this study was to inductively explore how parents to children with profound multiple disabilities perceived interaction in parent-child dyads and how behavior style was perceived to be related to interaction.

Method

Seven children with profound multiple disabilities and their parents were purposefully selected depending on the variety of the children’s behavior style dimensions. An acceptable range from hypo to hyper-dominated behavior styles across dimensions were represented in the sample. The study was undertaken by means of home visits where the parents participated in an interview about the child/parent interaction. The interview was open-ended and semi-structured and asked about subjective experiences of ordinary interaction, successful interaction and the qualities of the dyadic interaction. The interview questions can be found in the appendix of paper I. The data analysis was performed by meaning concentration and categorization through a pendulum between the parts and the entirety of the interviews. Main themes crystallized through the shorter loaded units of meaning and the categorizations. The main themes that appeared returned in each interview as the theory of how the seven parents perceived the interaction between them and their children. In this way thematic analysis was being practiced and a hierarchical network of abstractions were found (Attride-Stirling, 2001; Kvale, 1997).
In order, the themes were: sharing of experience, successful interaction, role of the child, role of the parent, interaction methods, obstacles and facilitators and aims and aspirations. Interaction took place as a sharing of experiences in the everyday life of the dyad and the family and was described as mutual responses and reciprocity. Interaction was practiced as turn-taking where the disabilities of the children influenced the form of interaction although the children’s focus in interaction and wishes came to form the content of interaction. Successful interaction was when the dyad shared joint attention and experienced a moment of appreciation in the participation of both parties. The roles of the children were initiating, responding and showing their inner will. The parents had a more responsible role and sensitivity was highlighted. Interaction methods of the children were based on their abilities as they used communicative expressions according to their level of ability. Interaction methods of the parents were to match the children’s expressions, to confirm and reinforce the children’s interaction through observation. They communicated by talking and showing and used these methods as a response.
to what the children needed in the interaction. Obstacles were perceived by the parents to be the children’s physical impairments and consequences of existing in an environmental context. Facilitators were perceived by the parents to be the children’s reactions, expectations and inner will. All parents had aims and aspirations in interaction: they had hopes of better understanding between the parties and of increased participation from the children. They also wanted individuals in the children’s other micro systems to understand the children better in interaction.

Discussion

Interaction was perceived as a sharing of experiences and occurred throughout the everyday life. It was operationalized as mutual response and reciprocity. In successful interaction participants felt appreciation and contentment and it was constituted of prolonged activity, concentration, understanding and joy. The parents were well aware of their strategies in interaction. They perceived their own role in interaction to be of a sensitive leading kind. The parents lead the interaction by using their knowledge about the children’s usual way of interacting, the children’s behavior styles, functional abilities, the children’s current mood and situation as well as the whole context. They monitored the interaction such that, throughout an interaction sequence, the parents always tried to optimize the interaction between the parties in the dyad. The behavior style was a background factor that the parents had knowledge of and scanned in their everyday turn taking. The behavior style became a facilitator for the whole interaction, it forced the interaction in certain directions and it made the interaction more complete with turn taking of different kinds from both parties. These findings show that it is imperative to see parents as experts on their children and to make them assertive in this in relation to professionals. Furthermore, as a successful interaction can boost the development of children, these findings show that it is essential to direct interventions to the everyday interaction in parent-child dyads. Furthermore, behavior style can be a “cue” in parental support.

Study II: Video observations of dyadic interaction: behavior style of pre-symbolic children

Background and aim

Children who function pre-symbolically are most dependent on their families, and parents must be especially sensitive when guiding these children in interaction and social life (Waxman et al., 1996). In a
communicative situation, parties need to share referential frames and schemas for interaction to be mutual and to function successfully (Fogel, 1993). Recent research showed that interactions occur in the everyday life between parents and children with profound multiple disabilities and those parents are well aware of their strategies in interaction (Wilder & Granlund, 2003). Two processes were anticipated to occur in interaction of these dyads: monitoring and successful interaction. Children with profound multiple disabilities are difficult to read in interaction (Granlund & Björck-Åkesson, 1998; McCollum & Hemmeter, 1997), but studies show that when children with disabilities show an intensive temperament, in other words a more hyper-dominated behavior style, parents find it easier to read the children in interaction (Wachs, 2000). Furthermore an overview of studies found that behavior style in the form of temperament was not related to etiology of impairment among children with disabilities (Huntington & Simeonsson, 1993). The aim of this study was to investigate the patterns for how parent-child interaction would present itself for dyads where the child had profound multiple disabilities and communicated on a pre-symbolic level. The aim was also to study how a personal characteristic such as behavior style influenced dyadic interaction.

Method

The participants were the same seven children with profound multiple disabilities and their parents as in Wilder and Granlund (2003). Video observations of dyadic interaction were performed at home visits. The researcher and parent watched the video recordings together and the parent selected sequences of typical interaction. These sequences were at the home visits collaboratively analyzed using the observation stage in the instrument ACA, where the parent gave his/her interpretation of the child’s different ways of affectively communicating. Data of the children’s interaction, functional abilities and behavior style were collected by the questionnaires CCI, Abilities index and CRIB, which the parents filled in.

Data analyses were concentrated on looking for patterns of different variables from the video recorded interaction data and the questionnaire data. Data analyses of video recorded interactions were focused on parent-selected sequences of typical interaction to something known because according to ACA the children used most of their behavior repertoire in those interactions. The sequences were transcribed per second and the turn taking was coded according to a model constructed by Light and adapted by Björck-Åkesson (Björck-Åkesson, 1992; Light, 1985). The analysis takes into consideration the function of each turn in relation to the preceding and following turn. The children’s and the parents’ motor and verbal behavior, smiles and laughter and direction of gaze in the interaction are considered in detail to be components of interaction. Data analyses of the questionnaires
were descriptive. In the final stage of analyses, in-group comparisons over all data were made in search for patterns.

Results

The results showed that the children overall initiated turn taking less often than the parents, the children ended turn-taking more often than the parents although the responses in interaction were rather even in frequency for each dyad. Overall, the parents used stronger turn-taking than the children but they did not use strong turn-taking all the time. Accord occurred more often and among most of the dyads compared to pauses. The results showed that all children had distinct behavior styles and interactions. Some tendencies surfaced indicating influences of hypo- or hyper dominated behavior styles: hypo measures tended to influence turn-takings to be short and rather slow while hyper measures tended to influence turn-taking to become longer in duration and quite fast. Hyper-dominated behavior styles made the children more readable. Readability also contained other child characteristics; directed gaze, smiles, directed vocalizations and strong initiatives and responses. There were similarities between the individual parents’ wishes for change in interaction and the nature of their turn taking in their dyad. The parents’ strategies in interaction were linked to their overall knowledge of the children’s behavior style, readability and the parents’ wishes for change in interaction.

Discussion

Each dyadic interaction was specific and in itself related to the characteristics of the interaction partners. The parents observed and arranged the interaction according to the dyadic specific conditions. The children influenced the interaction by the way they responded and ended interaction. This came to influence the way the parents’ monitored interaction; if they could read the response they adjusted according to it. If they could not read the children’s responses the monitoring was still influenced. As such, two parallel processes occurred in the interaction of each dyad that was circular rather than linear in form: monitoring interaction and successful interaction. The results showed that these children’s behavior style and how easy the children were to interpret were factors that the parents used to monitor the interaction into more frequent periods of successful interaction. Hyper-dominated behavior style and a good readability in the children seemed to be facilitative factors in interaction. Furthermore, a triangulation was obtained of the instruments CCI, ACA and video analyses that showed the parents to be well aware of the roles children and parents had in the dyadic interaction. When considering the triangulation it is clear that the parents know their children very well and that they use their knowledge in the everyday
monitoring of interaction. These results show that the parents know what to strive for in the interaction and they know their children’s limitations and characteristics. This expertise should be acknowledged and effectively used in interaction interventions.

**Study III: Parent-child interaction - A comparison of parents’ perceptions in three groups**

**Background and aim**

In planning communication intervention for pre-symbolic children with profound multiple disabilities within the framework of ICF it is important to establish how the parents perceive the interaction with their children in the immediate setting as well as their desires regarding the ideal interaction (Olsson & Granlund, 2003). It is also important to investigate if parent’s perceptions of interaction are related to the child’s body impairments and activity limitations. Recent research indicates that parent’s perception of interaction in the immediate setting is related to the child’s type and degree of disability as well as to the emotional expressions and behavior style of the child (Wilder & Granlund, 2003). How parents to pre-symbolic children with profound multiple disabilities perceive ideal parent-child interaction is not well known. Neither if it is dissimilar to parents to children without disabilities.

The aim of this study was to survey and compare parental perceptions of interpersonal interactions with their children between three groups of families: (1) 30 families with children from 2-10 years of age with profound multiple disabilities, (2) 31 families with normally functioning infants of 4-16 months of age and (3) 30 families with normally functioning children of 2-10 years of age. The aim was also to study differences in disability, behavior style and emotional expressions of the children in the three groups.

**Method**

Three groups of families participated in the study: (1) 30 families with children from 2-10 years of age with profound multiple disabilities, (2) 31 families with normally functioning infants of 4-16 months of age and (3) 30 families with normally functioning children of 2-10 years of age. All families were selected through a mix of convenience and purposive sampling. Data was collected by questionnaires (CCI, CRIB, Abilities index and a questionnaire about emotions) and a semi-structured interview (ESCS). Data were focused on similarities and differences between the three
groups and statistics used were one-way ANOVA, Scheffé post-hoc test, Pearson’s correlation coefficient, and Chi square.

Results

The results showed that the children in group 1 showed difficulties in expressing complex emotions. The children of group 2 and 3 showed curiosity, interest and approach more frequently than the children of group 1. All parents perceived the children’s behavior styles in similar ways. The only dimension of behavior style that showed a significant difference between the groups was attention span where the children in group 1 showed a tendency to give attention to stimuli for longer time than was demanded in the situation. In the immediate interaction between parents and children there were several differences between the groups. These differences mostly concerned the children’s ability to initiate interaction, maintain interaction and communication. The results showed few differences concerning the parents’ desires for the ideal interaction, which indicate that the parents wished to improve the interaction they had with their children in a similar way.

Discussion

The results showed some differences in perceived participation, especially related to joint attention and turn-taking in perceptions of immediate interaction between the group with pre-symbolic communicators and the comparison groups. Only one difference in the performance of communication activities (number of situations in which initiating joint attention skills were used) was revealed between the group with pre-symbolic children with profound disabilities and the group with pre-symbolic infants. Only a few differences were found when the groups were compared regarding parents’ desires for an ideal interaction. These differences concerned desires for improved joint attention in the group with pre-symbolic children. The otherwise common parental hopes for improvements of the child/parent interaction indicate that there exists a consensus constructed of ideas about that it is possible to improve interaction and that a reciprocal exchange between the parties in interaction can take place. As implicated by the ICF model, the result indicates that the participation in interaction in the immediate setting of pre-symbolic children with profound multiple disabilities only partly can be explained by body impairments of the children. Differences in activity seem to be less important for participation. Concerning parents’ desires for ideal interaction other factors than the communicative disability of the children seems to be of greater importance. Thus, to focus communication intervention on
participation and interaction, assessment and questions to parents have to be focused directly on these issues.

Study IV: Children with profound multiple disabilities: A longitudinal study of family accommodation, social networks and child characteristics

Background and aim
Families of children with profound multiple disabilities exist in a macro- and exo level societal context; they are not isolated from the typical demands or anticipations of society (Bronfenbrenner, 1999). In order to keep a sustainable everyday life, families accommodate according to their resources (Weisner, 2002). Successful accommodations of families of children with profound multiple disabilities require both adaptations to external stressors as well as internal family stressors, for example the disability of the child. Research shows a strong relation between health of family members in families of disabled children and size and perceived helpfulness of informal social networks (Dunst et al., 1997). Families who have more categories of individuals within the social network and share quality interactions with them are more likely to experience the full positive impact of the network (MacPhee et al., 1996). Few communicative interventions for children with profound multiple disabilities reported in the research literature have been evaluated in a family setting and knowledge concerning the fit between intervention format and content and family environment is scarce (Granlund, Björck-Åkesson, Wilder, & Ylvén, accepted).

The aim of this longitudinal study was to investigate how eight Swedish families of children with profound multiple disabilities accommodated everyday life, the social networks of the families and children and to see how these were related to child/parent interaction and child characteristics. The aim was to investigate the most central factors around which family life evolved.

Method
Eight families of children with profound multiple disabilities were strategically sampled. The families had different structures and the children had a combination of physical and cognitive disability. At home visits at two time points over two years the families filled in the questionnaires CCI and CRIB and participated in the interviews EFI and SNI. Data analysis was a qualitative process where search for patterns of change and stability over
time across and within cases were in focus. The aim was to obtain the most central factors around which family life evolved. The process was deductive in reducing data and can be likened to manifest qualitative content analysis (Graneheim & Lundman, 2004). Data analyses emanated in an aggregation of variables into indices of eight central factors: verification was made with another researcher. The central factors were: EFI; father’s involvement, connectedness between the parents and informal emotional support, SNI; overlap between the families’ and children’s social networks, density of able communication partners in the children’s social network circles and the children’s communicative dependency, CCI and CRIB; parental focus in interaction on joint attention and behavior style as a specific within family construct where hypo measures seemed to be non facilitative.

Results

The results showed variations in change over time across families in the summarizing items of EFI of how meaningful and appropriate the daily routines were to the families’ goals and values, how congruent daily routines were to the competencies and needs of the child as well as other family members and the ecological fit between resources and the ability to keep routines. The families that changed towards lower sustainability over time on the summarizing items also had low to medium measures over time in the factors from EFI. The other families that were stable or changed towards higher sustainability over time had medium to high on those measures. Differences were found between the children’s social networks and their families’: not exactly the same persons were included in the respective circles; sometimes there was no overlap at all. The density of able communication partners in the children’s networks was low and their communicative dependency was high. These tendencies were stable over time. The parents’ wishes for change in interaction were concentrated on extending the time spent in interaction and on wishes about joint attention. For those families that had a change towards higher sustainability over time in the summarizing items of EFI the wishes for changes in interaction was not as great the second year. For the families that had a change towards lower sustainability over time in EFI the wishes for change of the parents’ interaction increased the second year. The results from CRIB showed behavior style to be a within family factor which was specific to each family and child. There were variations in measures on behavior style dimensions across children and over time. In the families where the children showed many hypo measures the parents’ wishes for change in interaction were greater.
Discussion

The overall results from this longitudinal study show that the social networks of the children and their families were different; a difference that was stable over time. These results indicate that the children had micro systems and niches that the family did not participate in and vice versa. Furthermore, the communicative dependency the children had to their parents was extensive and, over time, also the density of able communication partners was low in the children’s circles. Although family accommodations for these families can be considered to be child-driven, the family accommodations that were qualitatively related to sustainability of everyday life were: father’s involvement, connectedness and emotional social support. Overall, there were no strong or direct links between family accommodations and child/parent interaction or child communicative dependency. The only links found between family accommodation and child/parent interaction was that parents showed a heightened awareness of their own interaction style when family accommodations changed towards a lower sustainability over time; when it changed towards higher sustainability parents seemed to be more content about the overall interaction.

In conclusion, there seemed to be a distance between the children’s everyday life, their social networks and interactions, and the everyday life of the families. Individual systems characteristics (behavior style and child characteristics) and dyadic specific processes (child/parent interaction) were not clearly discernable at processes on family level (family accommodations and social networks). The distance remained over time although family situations changed. This is an indication of that the children were not fully participating in family life, which is contrary to typically developing children who are more actively involved in family routines as they become more competent. Future intervention research should focus on how to get children with profound multiple disabilities to participate more in the everyday activities of their families.
Discussion

The main aim of the thesis were to explore child/parent interaction of children with profound multiple disabilities and their parents by investigating (a) how parents perceived interaction with their children (b) how observed child/parent interaction was linked to behavior style of the children as perceived by the parents (c) how parents of children with profound multiple disabilities perceived child/parent interaction and behavior style of their children in comparison to parents to children without disabilities matched for communicative ability and age respectively, and, (d) how social networks and family accommodations were linked to child/parent interaction and child behavior style over time for these families according to parental appraisals.

The main findings were that (a) child/parent interaction occurred throughout the day and constituted of mutual experience and joy (b) there were two processes in interaction monitoring interaction and successful interaction, where the parents used their overall knowledge of the children’s behavior style, mood and the setting and situation to lead and monitor interaction into successful interaction (c) the children initiated less frequently in interaction, hypo-dominated behavior style made the interaction slower and the children ended turn-takings more, while a hyper-dominated behavior style made interactions faster (d) there were few differences in wishes for ideal interaction between typical parents and parents of children with profound multiple disabilities; there were more differences in immediate interaction, children with profound multiple disabilities showed less complex emotions (e) for parents of children with profound multiple disabilities wishes for ideal interaction changed differently depending on level of sustainability of family accommodations (f) central factors for family accommodations were fathers’ involvement, connectedness between the parents and amount of emotional social support, (g) the children were communicative dependent on the parents and there were few complete overlaps between the children’s and the family’s social networks (h) behavior style was found to be a within family construct and hypo measures were found not to be facilitative for interaction and everyday life.
Everyday interaction- Two processes

Although children with profound multiple disabilities often are considered to be non-communicators in research (McCollum & Hemmeter, 1997), results from the studies in this thesis show that parents perceived interaction with children with profound multiple disabilities to occur throughout ordinary everyday life. Just as parents of children without disabilities (Tronick, 2007) the parents of children with profound multiple disabilities in study I perceived that interaction took place all the time during a day and was built up by mutual responses and reciprocity in the sharing of experiences. Interaction was described as a process of turn takings where the disabilities of the children to a large extent determined the form of interaction although the children’s focus in interaction and wishes came to form the content of interaction. A successful interaction was perceived by the parents in study I to be built up by mutual participation and understanding where both interaction partners felt appreciation and contentment. A successful interaction was perceived to be constituted of concentration, understanding and joy. The dyad shared joint attention and experienced a moment of appreciation in the participation of both parties when the interaction functioned well. In successful interaction the consensual social frame is set and creativity can have total playroom so that interaction can elaborate in all directions (Fogel, 1993).

In this way two processes occurred in interaction of each dyad that was circular and spiraling rather than linear in form: monitoring interaction and successful interaction. In the process of monitoring interaction, in study II, the parents lead the interaction by using their knowledge about the children’s usual way of interacting, the children’s behaviour styles, functional abilities, the children’s current mood and situation as well as the whole context. They monitored the interaction such that, throughout an interaction sequence the parents always tried to optimise the interaction between the parties in the dyad. As such the turn takings were dynamic and circular in character and were made new with every turn (McCollum et al., 2000). The process of monitoring corresponds to the theory of co-regulation (Fogel, 1993) and mutual regulation (Hedenbro & Lidén, 2002; Tronick, 2007) discussed in theories about interaction in typical dyads.

In the two processes that occurred in interaction, the children did not influence interaction with intent although they did influence interaction. All children inhabit internal working models of what an interaction usually exists of with the parents and, therefore, they have expectations (Stern, 2002; Wachs, 2000). Their interaction is dependant on their own experiences and personalities, which, in effect, influence the interactive partner. In study II, the children influenced interaction by the way they initiated but especially how they responded and ended interaction. This came to influence the way the parents monitored interaction; if they could read the response they
adjusted according to it to accomplish a successful interaction. If they could not read the children’s responses the monitoring was still influenced, as corresponds to the theory of resolving mismatches by Tronick (2007) and Stern (2002). Thus, when the children ended interaction the parents adjusted their interacting methods accordingly. In the effort to accomplish a prolonged period of successful interaction the parents ended interaction rather infrequently, as can be seen in descriptive data in study II.

Descriptive results from study II showed that different ways of interacting were found to be necessary for different dyads in order for the interaction to function well. Parents are experts on their children’s characteristics (Granlund et al., 2001; Landsman, 2006) which was confirmed in study I and study II where the parents were sensitive to changes in the immediate interaction situation. They observed and arranged the interaction according to dyadic specific conditions and they were well aware of their role in interaction.

Individual systems characteristics- Affective expressions, behavior style and readability

In this thesis behavior style, affective expressions and expressions of emotions of children with profound multiple disabilities were considered to be behavioral expressions of temperament. In the analyses of their link to interaction these were considered to be the tools of the children to perform interactive regulation, which is one of two regulative functions in interaction (Tronick, 2007).

The results from the studies of the thesis confirm that children with profound multiple disabilities show affective expressions in interaction which are interpreted by parents to be communication. In study I the results showed that affective expressions and reactions from the children were perceived to function as facilitators in interaction, and were specified as the children’s way of showing their inner will and expectations. The parents perceived the children to manifest their inner will by showing affect or by using their abilities when they could to make the partner do as they wished or understand what they wanted. In this way the children used proactive intentional communication, which has been found to be the pre-intentional communication to work on for communication to become more complex (Goldbart, 1994; Olsson & Granlund, 2003).

The results from study II showed readability of the children to be important to how the interaction functioned. Readability is dimensions of the children’s characteristics that together with their behavior styles come to influence interaction. If a child is difficult to read it is difficult for a parent to monitor in a way that alleviates or improves the interaction. Study II found
that components of behavior that made interaction more readable were
certain dimensions of behavior style, for example hyper levels of *reactivity*
and *activity*, and individual characteristics, for example, smiles, vocalization
and gazes. These findings replicate earlier research and theory about
interaction with this target group of children (Iacono et al., 1998; Wachs,
2000). Study II also found that when a communicative behavior is longer
than one second it is also easier to read, it is more readable when
communicative expressions come in conjunction with other communicative
components or directly following the other partner’s turn taking. This has
also been found by Light (1985) and Björck-Åkesson (1992).

In study II, profiles of behavior style were found to be linked to
interaction when it was observed and analyzed by the researcher. For
children who had hypo-dominated behavior styles the interaction became
slower and the children ended turn-takings more. For children who had
hyper-dominated behavior style interactions became faster. Furthermore,
hypo-measures on dimensions of behavior style were found to be non-
facilitative in interaction: the parents of these children in study IV had
greater wishes for change in interaction over time.

In reviewing the results from the studies in the thesis it is difficult to find
clear patterns for how specific dimensions of behavior style influenced
interaction, although some tendencies could be found. When investigating
stability over time study IV showed that overall there were variations in
measures on behavior style dimensions across children. *Reactivity, general
tone of body, frustration, goal directedness and attention span* were unstable
dimensions over time. The dimensions *responsiveness to parent* was stable
over time and the same for all children (normal measures), while the
dimension *activity* was stable over time but varied in if it was hypo or hyper
for each child. Study II found that the dimensions of *activity and reactivity*
seemed to be especially influential factors for interaction. High measures on
these dimensions made the child more readable. Furthermore, in study II, a
wide *attention span* and high *goal directedness* appeared to make it easier
for the child to engage in joint attention. Also in study IV these two
dimensions stood out as they changed in a systematic way over time for most
children. Earlier research found that the behavior style dimension *attention
span* significantly changed as a consequence of intervention (Bagnato &
Mayes Dickerson, 1986). Furthermore, when parental perceptions of
behavior style of children with profound multiple disabilities were compared
to parental perceptions of behavior style of children without disabilities
matched for communicative ability and age respectively in study III, all
parents perceived the children’s behavior styles in similar ways. Irrespective
of group the children showed similar distributions of behavior styles in in-
group analyses. The only behavior style dimension that showed significant
differences among the groups was the behavior style dimension *attention*
span, where children with profound multiple disabilities had a narrow attention span.

Conclusively, the behavior style dimensions activity and responsiveness to parents were stable dimensions over time. High measures on behavior style dimensions activity and reactivity made the children more readable in interaction. Furthermore, the behavior style dimensions attention span and goal directedness seemed to be more indirectly entwined in influencing interaction and these dimensions might be more susceptible to maturation and training than other dimensions over time.

The thesis confirmed that personal stimulus qualities in the form of behavior style and affective communicative expressions come to influence the interactions children with profound multiple disabilities take part in (Sontag, 1996). Overall, the results showed that behavior style was an individual system characteristic that to some degree changed depending on situation and time. Furthermore, the distributions of behavior styles in the different groups of children in study III clearly support the findings of Huntington and Simeonsson (1993) who found that differences in behavior style was not related to etiology. The ways in which children can direct, modify and maintain interaction are the behavioral and affective expressions of their behavior style. As such, it is through behavior style the children show their inner will and their expectations and this gives them significant communicative power (Tronick, 2007).

**Immediate interaction, wishes for change in interaction, and ideal interaction**

The children with profound multiple disabilities who participated in the studies for this thesis had difficulties in achieving and maintaining joint attention. This could be seen in the analyses of video recorded interaction, in their limited attention span, in immediate interaction and also in the wishes for change in interaction as perceived by their parents.

Study III found that there were several significant differences between the groups in the immediate interaction between parents and children. The children with profound multiple disabilities initiated interaction to a significantly lower degree than the typically developing children. Their communicative abilities were comparatively limited, for example, in answering communication, in directing parents’ attention to something specific, in choosing topics to communicate about and in making themselves understood the children with profound multiple disabilities were less able. The typically developing children irrespective of age had a more obvious communication and gave clearer responses. Also in study II and IV the immediate interaction for the children were restricted.
The wishes for change in interaction of the parents of the children predominantly concerned abilities of joint attention. The results from study IV showed that the parents wished that the children would improve interaction related to sharing focus of attention. Also the parents’ wishes for change in their own interaction were related to joint attention. The predominant weight of these kinds of wishes prevailed over time in study IV. The wishes for change in interaction of the parents in study II also concerned abilities of joint attention.

Although, when investigating wishes for ideal interaction between the groups in study III few significant differences were found: all parents wished for the interaction to be improved. The common parental hopes for improvements of the child/parent interaction indicate that there exists a consensus constructed of ideas about that it is possible to improve interaction and that a reciprocal exchange between the parties in interaction can take place. Some parents believe that it is important to take active part in children’s learning process while others believe that children should learn by their own experiences (Booth, 1997). Parents of children with disabilities do not have the opportunity to choose and may be forced to take an active and practical part in the life of their children (Booth, 1997). Nonetheless, parents’ commitment in their children is marked by hopes for a positive development for their children independent of if the child has a disability or not (Giangreco et al., 1991).

Family level processes and interaction

At family level, processes are at work in the everyday life which incorporates the members of the family to differing extent (Gallimore et al., 1999; Wachs, 2000). Family level processes are the processes that make up a functional and sustainable family everyday life, for example family accommodations and relationships in social life (Weisner et al., 2004). Study IV investigated how social networks and family accommodations were linked to child/parent interaction and child behavior style over time for these families according to parental appraisals.

Social networks and interaction

The communicative situation of the children with profound multiple disabilities in study IV was found to be stable over time and also similar for all children. The everyday life of these children evolved around the persons that could understand them, persons they had a close relationship with, everyday routines and the different settings in which they existed. The results from study IV showed that the density of able communication partners was very low over time for all children. Furthermore, the able communication partners were few and the children were very
communicative dependent on them: these were mothers, assistants and fathers. Persons that took care of these children in the everyday routines were especially mothers and assistants.

A consequence of the children being so communicative dependent on their parents and their assistants is that opportunities for proximal processes in, for example, the form of qualitatively good interactions with several familiar partners become limited. Proximal processes of these children can be considered to be weak (Bronfenbrenner & Ceci, 1994) and thus the actualization of potentials of these children are confined. Profound multiple disabilities are individual characteristics that imply low levels of proximal processes but the overall communicative situation these children also add to make their proximal processes weak.

When comparing the social networks of the children to the families’ social networks as a unit few complete overlaps were found. This meant that many of the children had micro environments and relationships that the families did not share and the families had micro environments and relationships that the children did not share respectively.

![Figure 3](image-url)  
*Figure 3. Examples of non-overlap in circle 1 (close family) and circle 2 (close relatives and friends) for two different children and their families.*

The non-overlap between the children’s and the families’ social networks and the overall differences found in the social networks imply that the children were not always part of the everyday life of the whole family. For example in figure 3, according to the mother of child nr 2 the family as a unit perceived and appreciated the grandfathers, the aunt and mother’s 8 friends as close friends and relatives which they met rather often in everyday life. According to the mother child nr 2 did not perceive these persons in the same close way and in consequence, the child did not share those relationships or experiences together with the rest of the family. On the
contrary child 2 had other close friends: 5 children with disabilities, 9 professionals and a horse. Thus, the child is not perceived by the parent to take part in family experiences. As a consequence, this child had fewer niches than its niche potential admitted (Wachs, 2000). This is a result that fits overall for all children over time in study IV.

Furthermore, the social networks of the children and families in study IV were different in other respects. The children had fewer persons in their social networks than the families had. The children had few children without disabilities in their networks, the children had few friends of the family in their networks and the presence of grandparents in number and place in circles differed in the children’s and the families’ networks. The children had more professionals closer in the circles of social networks while in the families’ networks they were found in the fourth circle. Over time, these tendencies were stable.

As a summation, there existed a double vulnerability for these children as they were so communicative dependent on their mothers, assistants and sometimes fathers and did not participate fully in everyday life activities of the families. Furthermore, the children found themselves in other micro environments and niches than their able communication partners but could not benefit from them fully as they could not engage in proximal processes.

**Family accommodation and interaction**

Study IV also investigated how family accommodations were linked to child/parent interaction and behavior style over time. Confirming earlier research (Keogh et al., 2000), the everyday accommodations of the families in study IV were found to be child-driven. This could be seen in that all families accommodated multiple service involvements, the complexity of childcare and everyday schedule was extensive and on average the children were estimated to be difficult to care for. Furthermore, the mothers were highly affected in their career and job decisions by having a child with profound multiple disability. The mothers were the coordinators of the families’ everyday lives.

The most central factors for how the families in study IV achieved high or low sustainability in everyday life accommodations were fathers’ involvement, connectedness between the mother and father and informal emotional support. The results from study IV showed variations in change over time across families concerning sustainability. Sustainability of everyday life was measured in how meaningful and appropriate the daily routines were to the families’ goals and values, how congruent daily routines were to the competencies and needs of the child as well as other family members and the ecological fit between resources and the ability to keep routines. The families that changed towards lower sustainability over time also had low to medium measures over time in the central factors; fathers’ involvement, connectedness, and informal emotional support. The other
families that were stable or changed towards high sustainability over time had medium to high on those factors.

There were few links found between family accommodations and child/parent interaction. The analyzes of family accommodations did not find any specific or overall accommodations nor outspoken concerns about the communicative situation of the children. The only link found between family accommodation and child/parent interaction was that the families that changed towards lower sustainability over time had more wishes of change in the parents’ interaction over time. This increased concern might be analyzed to be that the parents’ experience of change towards more non-sustainable routines affected their interaction with their children in the way that they were less focused in interaction and had less energy to devote to those interactions. Those families that showed a change towards higher sustainability over time had less wishes for change, they were more content about how the interaction functioned over time.

It is a fact that the child/parent interaction was not found in analyzes of family accommodations to be significant for how the families experienced their everyday lives to function. This indicates that there are several aspects for these families to consider in everyday life as there are many things that influence a family. The accommodating process is built up by a complicated net of external and internal influences and responses. In the holistic view of sustainability (Weisner, Matheson, Coots, & Bernheimer, 2004) parents prioritize (Gallimore et al., 1999). How they prioritize is individual and, for example, depends on their beliefs and values of what constitutes a well functioning family and how well they cope with stressors. It is also probable that the social system from macro- and exo level of professionals, rights, possibilities and demands make it more prominent for these families to focus more on for example, physical aids, service delivery and functioning special preschools/school.

General considerations

Conclusions drawn from the results from the studies in this thesis should be made with caution due to limitations. The sample of children with profound multiple disabilities and their families was rather small. Most of the data collection and analyses was performed by one researcher and inter rater reliability was not performed extensively, although other ways to ascertain the reliability was made.

To measure parents’ perceptions of child and parent immediate interaction, ideal interaction and change in interaction the questionnaire CCI was used. This thesis confirms the utility of the questionnaire as it was found to be easy to use by parents and also to very well capture parentally perceived problems in dyadic interaction. In study II, there were similarities
found between the parents’ wishes for change in interaction as measured by
the questionnaire CCI and the nature of their turn-taking in their dyad as
observed and analyzed by a researcher according to video observations and
as measured by the instrument ACA. The similarities imply that what could
be seen to occur in the video recorded interaction was also stated by how the
parents filled in the questionnaire CCI. Furthermore, this confirms earlier
research that show parents to be experts on their children (Granlund et al.,
2001; Landsman, 2006). In study IV, links were found between wishes for
change in interaction as measured by CCI and if the families had
low/moderate or moderate/high sustainability of family accommodations
over time. Those families that showed a change towards lower sustainability
over time also had more wishes for change in interaction, especially
concerning the parents’ own interaction behavior. Those families that
showed a change towards higher sustainability over time had less wishes for
change, they were more content. These findings from study II and IV show
the validity of the questionnaire CCI to be good as it captures the problem
areas the parents perceive to exist in child/parent interaction and which were
also found to be linked to data collected by other methods.

Another questionnaire that was used in the studies of the thesis was
CRIB. Although the measures from CRIB captured the children’s affective
contributions in interaction in a useful way, the CRIB instrument has its
limitations. Parents found it difficult to use, they did not find it easy to
describe the child’s way of reacting and behaving in the wordings used in the
instrument. Also the steps of the scale were difficult to decipher in their
difference from each other. The vocabulary and phrasings were considered
to be too theoretic. It was also hard for the parents of these children to give
answers on an average level as the children’s behavior and reactions varied
in a non-typical way and also varied on average. Thus, there is a need for an
instrument that is even more sensitive to the behavior conditions of children
with profound multiple disabilities.

Another limitation of the studies in the thesis is that the analyses of video
recorded interaction were not inter rated in study II. In consequence of the
pre-understanding of the researcher together with the triangulation of the
instruments ACA, CCI and the video recordings another researcher was not
engaged in the analysis of the interaction. This could be considered to be a
limitation of this study. During the data collection of study IV video
recorded interaction was collected during 4 time points for each family. In
total 36 video recordings were performed and collected. These recordings of
interaction sequences of typical interaction followed the same procedure in
collection as in study II and was also analyzed using the same detailed
method. Because of time restrictions the results were not included in study
IV. Although, in preparation to be included in study IV, inter ratings were
made by a researcher with a PhD familiar with data analyzes of video
recorded interaction of children with profound multiple disabilities. Inter
ratings were made on 25% of the video recorded interaction sequences. These were calculated according to: agreement divided by (agreement plus disagreement) all times 100%. The inter rater reliability was found to be 63% on level of initiation, response, ending, accord and pause. The more detailed level of analyses of strong/weak initiation or response and the two types of ending interaction (ignore behavior or parallel behavior) were not considered. Thus, it was the same researcher who analyzed the video recorded interaction in both studies, the same method was used to analyze the interaction sequences in both studies and a triangulation was found in the results between data collection methods.

Furthermore, in study IV, in the data analysis of central factors no inter rater procedure was executed although verification of the results between researchers was made. Verification was performed in several steps; the two researchers met three times and discussed the analyses and as a final step an extensive result document was reviewed by the second researcher and an agreement was made to reduce the central factors in number from 10 to 8.

Furthermore, in study IV, SNI interviews were made with the family of the child and with a professional who worked with the child and the family, as is suggested by Blackstone and Hunt-Berg (2003). Although, in study IV the interviews with the professionals were not included in the results because most of them could not answer questions about the families’ social networks only the children’s, nor could they answer questions about the fourth circle in the social networks of the children sufficiently extensive. As an inventory SNI requires a second opinion of the child’s communication situation in its social networks from a professional. This probably functions very well when SNI is used as an inventory and when the purpose is to use the results in intervention; not in research.

Conclusions

The results from the empirical studies of this thesis supports that theories of interaction applies also to dyads where one party has profound multiple disabilities. In these dyads interaction can be illustrated as a spiral where two processes occurred; monitoring interaction and successful interaction. The children contributed and influenced interaction in the way they reacted and showed their will and affective expressions through their behaviour styles. These studies found that parents of children with profound multiple disabilities saw their children as intentional communicators in the immediate interaction; they considered the children’s affective expressions, bodily expressions and behavior style as communication. For children with profound multiple disabilities the function of communicative expressions in interaction are the same as for children without disabilities. For dyadic interaction to occur it does not matter if the communicative expressions are
affective expressions and behavior style, or if they are signs or spoken words. The difficulty in interaction that comes with profound multiple disabilities is the readability of the communicative expressions. Furthermore, the parents were experts on their children as they used their knowledge about the children’s usual way of interacting, the children’s behaviour styles, functional abilities, the children’s current mood and situation as well as the whole context when they monitored interaction to achieve more frequent periods of successful interaction. Also, the parents’ hopes for ideal interaction reflected similarities to hopes of parents to typically developing children.

The development of shared contexts is the core of human culturalization and activities involving joint attention may be regarded as a starting point for culturalization and optimal development (Tronick, 2007; von Tetzchner, 2000). It is important for children to have common family narratives with their families for formation of identity and for the feeling of belonging (Mason, 2004), mutual experiences of the past and present make up family history and family narratives. Family narratives can help children to understand their context, events and surroundings (Vygotsky, 1978), which is very salient when children have disabilities. When reviewing the results from the studies in this thesis there seemed to be a distance between individual systems characteristics and dyadic interaction versus processes on family level, see figure 4.

According to the studies of the thesis, the distance remained over time although family situations changed. The distance was shown in for example the non-overlap between the children’s and the families’ social networks and the child communicative dependency or the child/parent interaction that did not seem to influence family accommodations. The children were active agents in their everyday lives, but the children’s activity settings were somewhat different from the families. Furthermore, the children had different micro settings that the family did not participate in and vice versa. This is an indication of that the children were not fully participating in family life, which is contrary to typically developing children who are more actively involved in family routines as they become more competent (Fiese et al., 2002).
A “contradiction” in results for the whole thesis can be seen in that child/parent interaction occurred throughout ordinary everyday life and constituted of mutual experience and joy vs dependency and the distance or non-relation that was found between family accommodations and child/parent interaction. Furthermore, the children were in a way isolated in their own families as the niches of the children were different from the families as a whole to a large extent, which could be seen in the non-overlap of social networks.

Practical implications and future research
In research focused on interaction interventions for children with profound multiple disabilities interventions are frequently studied without taking the family system and the impact of the system on child/parent interaction into consideration (M. Granlund & Wilder, 2006). Snell et al. (2006) in a systematic review of communication interventions for children with severe disabilities report that parents seldom are involved in deciding intervention goals and in implementing training. Although therapy sometimes is performed at home, recent research indicate that professionals do not execute parental participation based interventions but rather exclude the parents and instead continue to practice more traditional like services (Campbell & Brook Sawyer, 2007). Parents report lack of support in adapting interventions to everyday contexts and in maintaining intervention when circumstances change (Marshall & Goldbart, 2008). Studies of the natural learning environments and early intervention of children with disabilities report that early intervention has better effects when it is applied in natural learning activities identified by parents than in activities chosen by professionals (Dunst, Bruder, Trivette, & Hamby, 2006; Dunst et al., 2001). Also Albin et al. (1996) found that when a goodness of fit was accomplished between early intervention and family everyday life routines early interventions had better effects (Albin, Lucyshyn, Horner, & Flannery, 1996). Also ecocultural approach to intervention maintains that interventions fail to be implemented and sustained when they do not fit the daily routines of the family, especially when the intervention is not compatible with the goals, values and beliefs of the parents (Bernheimer & Keogh, 1995). This approach emphasizes that intervention that lead to positive effects for the family as a whole is most likely to be implemented.

Future research and future interventions should focus on how to make family activities more accessible for children with profound multiple disabilities in order to make it easier for them to participate more in the everyday activities of their families. The distance found in the results from the studies in this thesis between child and family niches calls for future research to study how this can be bridged. In this work the subjective views
of parents about their everyday life and their expertise of knowledge of the
interaction and lives of their children is the key for sustainability of
intervention. In order to gain knowledge about how to make children more
participative in family activities and important family relationships in a more
sustainable way it is important to study the way families make meaning in
their lives (Knox et al., 2000). By studying the reasons for how families
structure their everyday routines the way they do knowledge about how to
integrate the children in a sustainable way can be gained. Family narratives
can be studied in order to understand how families have control over their
lives depending on their history and not just on how they adjust and adapt to
external influences (Fiese et al., 1999). In this way coherence, togetherness
and meaningfulness of family life, how it is constructed and how it can
enhance well-being of the family can be studied.

For children with profound multiple disabilities the family is the most
inclusive setting and also the most important setting because it is within the
family proximal processes primarily take place. As children learn and
develop through the everyday activities they participate in, the interaction
between children with profound multiple disabilities and other individuals
within the family is an important area for future research and interventions.
Interaction interventions in the immediate interaction for these dyads should
focus on behavior style dimensions that can enhance joint attention. In this
way proximal processes would become stronger and have more impact on
other processes in the children’s and families’ lives. Pivotal behavior style
dimensions may be attention span and goal directedness. Furthermore, as
this thesis has found that behavior style is a way in which children influence
interaction and parents to be experts on their children’s interaction, new
methods to measure behavior style in a more approachable way for families
is needed.

The communicative dependency of children with profound multiple
disabilities calls for interaction interventions to focus on increasing the
amount of able communication partners of these children and also to expand
the categories of persons who are able communication partners of these
children. In order to achieve this, the structure, function, social and
emotional quality of relationships in the children’s and families’ social
networks should be studied. In this process it is important to identify the
children’s niche potential and to work within them.

The optimal goal for future interaction interventions should be to make
children with profound multiple disabilities fully participating in the family,
see figure 5.
Future research should focus on how to enhance proximal processes and make them stronger for children with profound multiple disabilities and also on how to integrate proximal processes in the family level processes so that both the children and families share mutual experiences in shared niches to a great extent as possible.

Figure 5. Proximal processes integrated in family level processes.
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