

# **SOCIAL NETWORKS – INVOLVING FAMILIES AND PROFESSIONALS SURROUNDING CHILDREN AND YOUTH WITH COMPLEX COMMUNICATION NEEDS**

## ***Introduction***

Children with severe communication disabilities are a vulnerable group in the community and are depending on the knowledge, skills and empathy of the people in their immediate surrounding, which include parents, sisters and brothers, relatives and professionals, i.e. the social networks (Klefbeck & Ogden; 1996; Blackstone & Hunt Berg, 2002; Anderson, 2006). The family is of great importance in supporting the communication and language development of the child. The professionals have to create conditions conducive to a positive learning environment, which demands knowledge of disability, language, communication and proximal zone of development (zpd). (Lahey, 1978; Vygotsky, 1986; Bodorova & Leong, 1996). It is significant to consider persons with complex disabilities as active and participating parties in the developmental process (Light & Binger, 1998).

Children with disabilities encounter different hindrance in their daily life, in their communication with others and in their learning. Hindrance can be found by the individual himself as well by the persons in the surrounding and in the situation as in structures and principles of the society (Beukleman & Miranda, 1998; WHO, 2001, 2004; Anderson, 2002; Eriksson, 2006). Another reason can be found in indistinctive goals, effort and responsibility according to communication and language development of the child. Various kind of hindrance can be eliminated, among others by identifying and analyzing them, contextualizing them, illuminating facilitating phenomenon and increasing the awareness of the importance of communication by as well professionals as families.

This project was made on the thesis from Anderson (2002). The results show that there are both possibilities and obstacles that respectively facilitate and obstruct communicative and linguistic development. These can be related to micro-, meso-, exo and macro levels. Informal communication was characterised by participation and mutual exchange, pleasure in communicating and adults adapting to the child's perspective. Formal communication was characterised by adults choosing topics for conversation and being purpose-oriented, asking questions, giving instructions and expecting certain answers from the child. The children's communication was mostly functional, but the adults did not always notice their intentions. The pupils were met by staff members with varied skills in manual signs and it was evident that the children's communicative and linguistic needs were not necessarily accompanied by a supportive environment that facilitated communication development. Adults in the surroundings need education, training and support in Alternative and Augmentative Communication (AAC) to become competent and challenging communication partner (Beukleman & Miranda, 1998; Light & Binger, 1998; Arts, 2000). Another result shows that language use of parents and teachers with respect to prerequisite and needs of the children influence the expectation and treatment of the children.

The starting point of the current project is the social networks surrounding children and youth with complex communication needs caused of, among other things hearing and intellectual disabilities. The target group is children and youth of 6 to 25 years of age and who

communicate in linguistic level, but the communication form is not sufficient to understand or express feelings, thoughts, and aims within the family or in daily life situations.

### ***Aim of the study***

The all-embracing aim of the Social Networks project is to examine the communicative competence in the surroundings and follow and illuminate participation and collaborative learning among participants in social networks (families and professionals) related to children with complex communication needs. An underlying purpose is to develop assessment methods, analysing needs and support and to find suitable forms of cooperation. The project contains two parts.

### **Purpose and result of part one**

The purpose of part one is to survey and analyse families and professionals opinions and experiences of communication, communication use, content and form in different contexts, family advice and support, the responsibility of the communication partners, families and professionals in cooperation and communication needs and efforts.

Questionnaires were sent to parents and professional in preschool, school, rehabilitation and recreation activity in Sweden, a total of 310 forms were sent out. The answering frequency was about 65 %, which may be regarded as acceptable.

To sum up the analysis of the questionnaires the result show:

- Regardless the age of the children adults are the most common communication partner. The truth is that children and youth with disabilities have few or no friends of their own age.

*Table 1      Disabilities and use of communication devices*

<b>Disability</b>	<b>Communication device</b>		<b>Difference</b>
	<b>Yes</b>	<b>No</b>	
Vision	2.2	2.0	Non
Hearing	1.9	2.1	None
Motor	3.4	2.5	p<.05
Concentration	2.9	2.8	None

Every third have some communication device according to motor disability rather than other disabilities.

Table 2 *Disabilities and IEP according to Language and Communication.*

Disability	Individual Education Plan		
	Ja	Nej	Difference
Vision	2.2	1.7	None
Hearing	1.9	2.7	p<.05
Motor	2.7	2.7	None
Concentration	2.9	2.8	None

Two thirds of the children/youth have Individual Education Plans (IEP) according to language and communication, but the formulated goals are rather general than specific.

- As well professionals as parents have opinions about each other. Parents underestimate and give just little credit to other persons AAC competence. The opposite is valid from the professional's point of view.
- Many professionals are involved in the cooperation about persons with complex communication needs but the efforts are not always meaningful and comprehensible according to the parent's opinion
  - 60 % of the parents receive communication advice and support to help their children
  - 40 % of the parents have been informed about AAC devices
  - 60 % of the parents regard the efforts to be meaningful
  - 80 % of the professionals are satisfied about the communication efforts

### Comments from parents and professionals

- *Making IEP demand parents knowledge and point of view (professional).*
- *Some parents don't accept their children's needs of signs (professional).*
- *The family is the foundation and the professionals (in school) are pedagogical Responsible (professionals)*
- *Everyone have to use signs in the communication with the child (parents)*
- *The speech therapist doesn't believe in our story (parents).*
- *The school is fumbling. A lot of talk but no implementation (parents)*

The statements concern competence, knowledge, collaboration, responsibility and credibility.

- Everybody call attention to knowledge and competence of alternative and augmentative communication (AAC) in general and Sign Language or manual signs (sign supported speech) especially.
- The needs of each family are unique and must be considered with respect and mutual understanding.

### ***Purpose of part two***

The purpose is to describe, analyse and understand the Communication Partner's communicative development in relation to the Partner and to each other in the group based on the Social Networking.

### **Some issues**

- Increase participants' understanding and communication skills through social networking – in what ways?
- Does social networking benefits of everyday life for children with complex communication needs– in what ways?
- How to describe the linguistic usage in different IEP?

### ***Method and target***

In focus are participation and activity of the members in six social networks. Every network consists of 4-9 participants, i.e. family members, speech therapists, special educators, teachers, pupil assistants, employment consultants etc. The way of working is a process going on for about 2½ years with in all 9-10 meetings and different tasks in the intermediate period. The way of working is about assessment, reflecting dialogues, IEP, evaluation forms, analysis and video – recording with support and tutor in daily communication situations.

I informed about the project on websites and in magazines for persons with disabilities and parents enter their name and interest to me and later on they choose important partners to participate in social networking surrounding their child. Everyone has given their permission to collect information in different ways.

### ***The process***

By reference to the Inventory Booklet "Social Networks" (Blackstone & Hunt Berg, 2003) an interview with participants in every social networks according to the child with complex communication needs is done. Questions about their modes of expression, skills and abilities, important partners in different environments, the frequency, effectiveness and intelligibility of different communication modes are put. The summary of the interview will highlight relevant findings and developmental areas.

Feedback and reflecting dialogues will be the start of the second meeting. The next task will be to collect information about IEP according to interaction, communication, development and objective for every child/youth. This information is going to be analysed with respect of Activity, Participation and Context, i.e. the concepts used in WHO's International Classification of Functioning, Disability and Health (ICF, 2004) and formulated communication goals.

In the intermediate time both families and professionals will make short video- recordings about the children in communication with others. The purpose is to illuminate and analyse hindrances and opportunities in daily life situations of interaction and communication situations before the intervention. The social network members do entries about their own experiences and knowledge development.

Feedback and reflecting dialogues will be done according to content in the Individual Education Plans. The content of the video - recordings are discussed and the participants get feedback on situations, which are propitious and developmental to the children.

An "Activity schedule" (Carl J. Dunst, 2001) is introduced. Each group decides about adequate activities or communication situations, what activities will facilitate or hindrance children's participation, where and when are the activities implemented and finally the responsibility of the surrounding persons. The intermediate time will be a trial period for each schedule. The social network members do entries about their own experiences and knowledge development.

The implementation of the activity/communication schedule is discussed and evaluated. The participants reflect about their own contribution. Viewpoints on facilitating and limiting factors are given. Further reflections about the video - recordings among the network members will be done. The continuing work in the daily life is planned together. What in the activity/communication schedule can be changed or supplied. Video – recordings of the same activities as prior are requested. Update" Social Networks" interview. Evaluating form with respect to learning and forthcoming expectations is distributed.

The network participants go on working with another activity/communication schedule and video – recording during the intermediate time. The social network members do entries about their own experiences and knowledge development.

Feedback and reflecting dialogues about video sequences are done. The "new" activity/communication schedule is discussed and evaluated. The participants reflect about their own contribution. Viewpoints on facilitating and limiting factors are given. What have been possible to implement? The social network members do entries about their own experiences and knowledge development.

This time the network members devote time formulating goals and efforts based on ICF's conception. Retrospect and discussion over time passed and different moment in social networks meeting. The original questionnaire will be answered once more.

Follow –up goals and efforts after six month.

### ***Part time outcome***

The social networks meeting are under process but part time outcome from the first 1½ year is like follows:

#### **Social Networks**

The Social Networks is unique both in group composition and to their conditions and needs and there are different demands of social services. The children and young people who are in focus are of different ages and have different disabilities (Down Syndrome, Hearing loss, Angelman syndrome, Autism), they have multi-modal communication needs and the needs of different forms of tool and attend to different types of school. The engagement and activity of the networking differs from time to time and all this parts leave marks on issue discussing, planning, decision making etc. The characteristics of the families are that they struggled and searched for help and support to facilitate the child's communication. They have also called for cooperation that can provide a holistic approach to child. One mother says:

As a parent, you are usually the spider in the web that will have control over so much when you have a child with disabilities. The big difference from before is that we can meet and talk to them all at once, without stress.

#### **Inventory Booklet**

This assessment and intervention planning tool is designed to help professionals work with family members and individuals with complex communication needs to determine the most appropriate technologies and communication strategies for communication with partners in various context ([www.augcominc.com](http://www.augcominc.com)). The assessment content areas: Language areas – skills and abilities, related areas, technology use, Circles of Communication Partners (identifying of important partners, modes of expression, effective strategies that support expression/ comprehension, topics of conversation, types of communication) Summary and Intervention planning. The inventory process gives a common overview and a foundation to further dialogues and planning. To discuss communication circles highlight the opportunities and obstacles in the environment around the child and clearly show where support needs to be done.

#### **Individual Education Plan according to ICF's conception**

Regardless to education plans in school or rehabilitation plans description and formulated goals are on structure and function (ICF, 2004)), i.e. focus on body and training inability, seldom activities, capacities of the child, participation or engagement in activities. The formulated goals are to extent. The method are usually focused what the child should do. Professional tasks and achievement are unclear and they often commingled methods with goals. Unclear goals result in continuing goals and methods, i.e. the more of the same. There is seldom reflections about why or changing of methods. A returning dilemma is to formulate specific and realistic goals, reflecting about the methods and evaluating.

#### **Video-recording**

Video – recordings, analysis and feedback are the main tasks in the project. The parents or the teacher are sending me video-clips videos from everyday situations in home or school. I analysing according to Marta Meo criteria before our meetings. During the meetings we look at and discuss the sequences together. During these sessions something happens about the

communication comprehension, competence and skills, i.e. the video does the real communication visible. What do the interpersonal analyses show?

Parents are good in confirmation, joined attention, understanding messages and body language, relationship and making comments. Parents have much tacit knowledge.

- Parents need to develop AAC knowledge and skills
- Naming what is happening
- Expand sentences
- Pay attention to the child's interest to an increasing extent.

Teachers and assistants are good in interaction, structuring way of working, create motivation and pay attention to at the pupil's initiative.

- Teachers / assistants need to develop AAC knowledge and skills
- Naming what is happening
- Reduce asking
- Check the pupil's conceptual comprehension
- Create activities to facilitate generalization
- Communicate more in informal situations
- Formulate clear and specific communication goals

The participants have formulated some opinions about collaboration and activity.

Why couldn't we work like this when P was a little child?

Exchanging experiences and knowledge in connection to AAC and abilities are really important.

A positive aspect of this project is our own observations instead of just receiving expert advices to do or not to do.

Every Social Network is unique and there are no general solutions. Processes take time. Initially there is a need of coordination but Social networks is a mode to develop communication competence, getting common attitudes and skills in concern to children with complex communication needs.

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