

Collaborative problem solving in the context of early childhood intervention – the link between problems and goals

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Swedish Child and Youth Habilitation Services (C-YHS) for children with disabilities and their families' build on regular planning meetings involving families and professionals, and appointments and interventions implemented between meetings. This study explores the content of issues discussed at planning meetings, and the relation between content and activities implemented in everyday interventions. Longitudinal data from five families and their C-YHS-teams were used. Data were analyzed using conventional content analysis. The results illustrate a process with a high degree of correspondence between families' concerns, experienced problems, the formal decisions and the activities they generated. *Concerns* were focused on the future, and related actions focused on supporting adults in the environment, mostly the parents, thus indirectly relating to the child. *Problems* were focused on the current situation, and to a larger extent concerned actions directly related to the child. Although a family-centred service, interventions focused on the proximal environment, may be underreported.

Keywords: families; children with disabilities; professionals; early intervention; collaboration

1. Introduction

According to The Convention on the Rights of the Child (UNICEF) children with disabilities do have the right to enjoy a full and decent life. The parents are responsible for the child's development, to facilitate active participation and have the best interests of the child in mind. In supporting children with disabilities parents may need support and services from professionals. Swedish habilitation services for children with disabilities and their families' build on a structure of regular family-centred planning and goal-setting meetings involving the family and professionals, as well as a series of appointments and interventions implemented between planning meetings. A family-centred relationship with professionals providing service and support to children with disabilities and their families has been defined as one in which support impacts the family in a positive way (Föreningen Sveriges Habiliteringschefer 2010; Dunst et al. 2002). From a systems theory perspective (Bronfenbrenner 1979; Garbarino and Abramowitz 1992) this kind of formal family-centred relationship takes place at the mesosystems level. A mesosystem develops when two micro systems, e.g. the home and the Child and Youth Habilitation Services

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(C-YHS), are connected. A functional relationship also builds on defining desired outcomes not only on the child level but also on the family level (Bailey et al. 2006), that is, it recognizes that children live in a social context and that providing support to the context may enhance and sustain the effect of child-focused interventions. A conflict of interest may occur in the relationship between the families and the professionals especially if there are different values or priorities in the microsystems influencing the negotiation at the mesosystem level (Garbarino and Abramowitz 1992). In theory, planning meetings are designed to frame the content of collaboration in terms of child and family goals and interventions implemented with the help of family-centred procedures. However, there is not always agreement about routines for structuring and implementing meetings or about issues related to child and family outcomes. Thus, little is known about how the content of discussions at meetings is related to the implementation of interventions between meetings. The present study is an exploratory study of the content of issues discussed at planning meetings, and the relationship between this content and activities implemented in everyday interventions for children and families who receive services from the C-YHS in Sweden.

General guidelines for the intervention process in family-centred practices have been developed, both in Sweden and internationally (Föreningen Sveriges Habiliteringschefer 2010; Bruder 2010). A 'habilitation plan' in C-YHS is the Swedish form of an Individualized Family Service Plan (IFSP). It is the cornerstone in intervention services for children with disabilities and their families. It should contain descriptions of problems, goals and methods used to reach the goals; and should identify the persons responsible for working with the methods in a specified timeframe. Such a plan is both a process and a document that assists professionals and families to meet the needs of the child (Föreningen Sveriges Habiliteringschefer 2010; Blue-Banning et al. 2004; Jung 2007; Keen 2007; McWilliam, Casey, and Sims 2009; Trute, Hiebert-Murphy, and Wright 2008; Woods and Lindeman 2008). Ylvén and Granlund (2009) studied professionals supporting families' positive coping (Folkman 1997) in planning meetings. Problem-focused strategies were the most frequently used coping strategies in the meetings. Searching for information, solving problems and making goal decisions were all active strategies that were used by family members and professionals. It was also found that negotiation about problems and solutions between parents and professionals was common in planning meetings indicating that planning is a collaborative process (Ylvén and Granlund 2009). Whether collaborative problem solving also characterizes interaction in everyday habilitation involving parents and professionals between planning meetings is not known.

Concerning outcomes, a shift in focus concerning both child and family outcomes has been recognized in recent decades. Regarding the child, the trend is to stress outcomes related to child's functioning in everyday life (Simeonsson et al. 2003). An expression for this trend is the International Classification of Functioning, Disability and Health – Child and Youth version (ICF-CY) (WHO 2007). In ICF-CY, child functioning is described in terms of body function and structure, activity and participation, with impairments describing problems with body function, activity limitations describing problems with performing activities typical for a certain situation or age, and participation restrictions describing problems with involvement in life situations. Björck-Åkesson and Granlund (2005) have suggested that a family-centred collaborative problem-solving approach is easier to apply to participation restrictions than to body impairments. Interventions focusing on body impairments require specific knowledge and may demand a more expert-focused approach to the problem-solving process. Family outcomes need to focus on the family as a whole and not only on the child (Bornman and Granlund 2007), as

well-being is generally recognized as an important family-level outcome of early childhood intervention. Suggestions for other family-level outcomes include family knowledge about the child's disability, family skills in problem solving and service utilization (Bailey et al. 2006). Supportive coaching from professionals may help parents to develop skills and increase their ability to discover solutions to both child and family problems (Graham, Rodger, and Ziviani 2009). Thus, while there has been consideration of family-level outcomes, the content and focus of parent-professional interaction between formal meetings in relation to child- and family-outcomes needs further attention.

Ideally, planning meetings should guide the intervention process between meetings. In Sweden, planning meetings occur every 6–12 months. Within this timeframe, child and family needs will probably change. It may be the accumulation of problems on a daily basis that has the greatest impact on child functioning and parents' well-being (Nezu, Wilkings, and Nezu 2004), and perhaps also on the intervention process. Parents must accomplish several tasks related to the disability of their child and to everyday family life. Thus, interventions implemented during the set time period may not focus on the goals and methods designed in the planning meetings, but rather on the most urgent problems at the moment. Neither will the intervention process guiding interventions necessarily be based on collaborative problem solving for all problems. Knowledge is needed concerning the content and process of family-centred intervention between planning meetings (Jung and McWilliam 2005) in order to plan a successful intervention.

The aim of the present study is to compare the content of issues discussed at planning meetings, with the activities implemented in everyday services provided by the C-YHS between meetings. Questions addressed are (a) 'On what content are the processes focused?'; (b) 'What activities are initiated based on problems identified at planning meetings?' and (c) 'What is the correspondence between plans developed at meetings and activities implemented in everyday services?'

2. Methods

A longitudinal qualitative multiple case study design, following five families in Swedish C-YHS, has been used. Several methods were used to collect data concerning the activities performed and the service provided. The C-YHS are organized in almost the same way nationally and involve professionals from many disciplines: physicians, social workers, physiotherapists, occupational therapists, special educators and psychologists. When a child has multiple disabilities several different specialists need to be involved to meet the child's needs. They form a team around the child and the family (Björck-Åkesson and Granlund 2003).

The data in the present study come from (1) videotapes of planning meetings between families of children with disabilities and the team of professionals at the C-YHS, (2) interviews with the families conducted between the planning meetings, (3) 'memory notes' made by participating families and professionals between planning meetings, in response to pre-printed open-ended questions about the nature of their interactions, including contacts at appointments and telephone calls; and (4) informal information from professionals concerning 'their' family was taped using dictaphones.

2.1. Sample

Data came from five families of children with disabilities enrolled in intervention programmes at the C-YHS in different county councils in the central part of Sweden.

Eligibility criteria for participation in the project were that the children were new cases for the team, and had conditions requiring services from several professionals. Each of the five families had one child with a disability (boys $n = 3$ and girls $n = 2$), and two or three older children without disabilities. When the project started the ages of the children with disabilities was one child 10 months; two children 1 year; one child 2 years; and one child 5 years. Diagnoses were chromosomal abnormalities, spina bifida, metabolic disorder and birth-related brain injuries. Related disabilities were motor impairment, epilepsy, developmental delays, speech and communication problems, feeding problems, hearing impairment and autism. The participating professionals were speech pathologists, paediatricians, physiotherapists, social workers, special educators and occupational therapists. Professionals in the teams around the families changed over time dependent on the interventions needed for the child. Planning meetings, involving the family and the professionals, were held approximately twice a year. At least three professionals participated in each planning meeting. At times the child's personal assistant or special educator at the preschool also participated in the meetings.

2.2. Ethical considerations

The Ethical Committee at the Swedish Research Council approved the project DIIS (421-2001-3837) for a five-year project. The professionals at the C-YHS and the families gave their consent to participate in the project and the study follows the ethics principles in social research (http://www.codex.vr.se/codex_eng/codex/oversikter/humsam/humsam.html, 2006-06-26).

2.3. Procedure

For the project ISB9-266/06, data were collected longitudinally from fall 2002 to spring 2005. The families participated in the project between 9 and 33 months. From a previous study (Ylvén and Granlund 2009) data from videotaped regular planning meetings at approximately six-month intervals were used. In the meetings one or both of the parents of the child with disability participated, together with members of their team. The team was responsible for videotaping the meetings. Data were also obtained from interviews with the families, conducted between the planning meetings by a member of the research group. In the interviews, the aim was to identify special curative occasions occurring in the planning meetings according to the parents. Both the videotapes and the interviews were transcribed verbatim. From the previous study (Ylvén and Granlund 2009) transcribed data from 73 sequences out of 164 were used in the present study. These selected sequences represented problem-focused coping used in planning meetings, i.e. identifying, discussing and solving problems. The data for the present study also included memory notes, collected monthly during the time of the project, with information about every contact between planning meetings concerning; how, by visits or via phone calls; where, at home or at the C-YHS; and the purpose for the contact. The memory notes had pre-printed, open-ended questions (see Appendix 1). Contacts occurred several times during a month; each generated one memory note. All were gathered and mailed to the research group once a month by both families and professionals. Finally, informal information from professionals was audiotaped using dictaphones. Professionals involved in the study had one dictaphone each. Informal information consisted of short narratives taped retrospective of chats with family members, with colleagues, and other professionals involved in the case. Table 1 shows the complete data-set, the number from each data

Table 1. Number of data sources and meaning units from each family and all families together.

Source of data	Fam1		Fam2		Fam3		Fam4		Fam5		Total	
	<i>n</i>	Mean units	<i>N</i>	Mean units	<i>n</i>	Mean units	<i>n</i>	Mean units	<i>N</i>	Mean units	<i>n</i>	Mean units
Memory notes	344	328	44	49	55	79	49	96	8	21	500	573
Informal inform	132	108	10	13	2	3	80	66	7	6	231	196
Planning meetings	3	17	1	4	4	17	1	6	1	3	10	47
Interviews	2	14	1	3	1	2	1	5	2	6	7	30
Total	481	467	56	69	62	101	131	173	18	36	748	846

source and the number of meaning units after the analysis. Data are presented from each family and in total (Table 1).

3. Analysis

The empirical data in the present study were analyzed inductively using content analysis (Coffey and Atkinson 1996; Hsieh and Shannon 2005). Data consisted of memory notes ($n = 500$), informal information ($n = 231$), transcribed data from planning meetings ($n = 10$) and interviews ($n = 7$). First, all data were read through several times to get a sense of the whole. Words, concepts and sentences that contained relevant aspects for the research question were then identified and exact words from this text were highlighted. The exact words were sorted in terms of how they were related to aspects relevant for the research questions. The initial coding scheme often emanates directly from the text (Hsieh and Shannon 2005). The exact words that capture key thoughts or concept were labelled for the construction of codes. Most of the key concepts came directly from the participants' words; some were an interpretation from the researcher of what the participants seemed to describe. The numbers of words, concepts and sentences were 573 from memory notes; 196 from informal information; 47 from videotaped planning meetings; and 30 from interviews, a total of 846 words, concepts and sentences. From these 846 words, concepts and sentences, data were extracted. Codes that were related and could be linked together were clustered into 19 subcategories and were confirmed using peer review (Hsieh and Shannon 2005). The 19 subcategories were: body/physical function, activity, communication, nutrition, medical, support, intervening, instructing, assessing, informing, planning, documenting, engaging, consulting, reflecting, hand over, concerns, problem solving and making decisions. Based on relationship among the subcategories, three main categories emerged and were confirmed after further discussion of content using peer review (Table 2). Category 1: *Focus* was related to the content of the concerns, problems, activities, decisions and goals, and on the focus of the intervention. Category 2: *Action* was related to the actions that the concerns, problems and decisions generated as reported by professionals and parents.

Category 3: *Collaboration* was related to the occasions when parents and professionals met face-to-face and discussed concerns, problems and decisions in relation to goals.

Next, the 19 subcategories were placed on a timeline – one for each family. On this timeline, the collaboration (Collaboration-categories) and the problem areas (Focus-categories) were chronologically linked to the actions (Action-categories). Topics identified in the collaboration-categories could often be related to subsequent action-categories. Each of the 19 subcategories had its own character code and a number representing how often the subcategory appeared. This method was used to analyse concerns, problem solving and decisions in planning meetings and other appointments (Collaboration); which topic was in focus (Focus); and what action was performed (Action). In Table 3, an example is provided representing the action *intervening* starting with the month when the planning meeting is held (intervening performed in November is excluded in Table 3). The table shows what parents' concerns, the problem solving, and decision-making are focused on at the meeting, and further, the focus for the intervening the following four month (everyday habilitation). Noteworthy is, the parents' concerns about communication at the planning meeting and the fact that this is found as a focus in actions the following months, and also as a topic for decisions made in everyday habilitation. Several data sources needed to be combined to generate a comprehensive illustration of the topics.

Table 2. The coding process from keywords/concepts to subcategories and categories.

Keywords and concepts, examples of	Subcategories	Categories
Stretching; bending; exercising; stabilizing; strengthening	Body/physical functions	FOCUS
Aids for sitting, standing, walking, moving, orthoses; technical aids; wheel chairs; participate	Activity	
Mouth massage; sign class; aid for getting attention initiating conversation (Big Mac); communication training; pictures as support for communication	Communication	ACTION
Aids for drinking, eating; mincing food; special food; Perkutan Endoskopisk Gastrostomi (PEG)	Nutrition	
Medications for facilitating catheterization, weight gain, decrease spasms; surgeries; tube,	Medical issues	
Respite care; assistant; support in relation to visits and appointments; parent support groups; financial	Support	
Actions to minimize the symptoms of disability in body/ physical functions, activity, communication, nutrition, medical issues, and to offer relevant support	Intervening	
Instructing family, preschool teachers, assistants about how to use and how aids function,	Instructing	
Assessing the child's status and abilities e.g. physical, psychological, communicational, needs	Assessing	
Informing parent, colleagues, personal at preschool, assistant, contact persons, external resources; informing about activities, wishes, treatment, needs	Informing	
Planning for meetings with the team, the family, external recourses, preschool, assessments, appointments for treatment, assessment, follow-ups	Planning	
Dossier for referral; letters of referral to specialists, doctors; training programmes; medical records; protocols; dossier for assessments; assessments;	Documenting	
Asking colleagues about the family; comments about development; worrying; chats with the families; disappointed when families are treated badly	Engaging	
Consulting colleagues; special competence; being a consult; consulting for finding special competence; about aids; advices; external support for the family	Consulting	
Reflecting about own and the team's professional knowledge and competence; reflecting about children's needs and reactions; encountering families	Reflecting	
Bring and fetch aids, materials, orthoses, books, bolls, toys, feeding supplies, documents, computer programmes	Handing over	
Ask for information/knowledge about disability, consequences, health; advices; support; needs;	Concerns	COLLABORATION (parents and/or professionals together)
Emphasize and negotiating problems; express difficulties; discuss conceivable solutions	Problem solving	
Decide about activities, actions, interventions; goal-setting	Making decisions	

Table 3. Timeline showing content focus in the collaboration at a planning meeting; focus for the action intervening performed four month after the planning meeting, together with problem solving and new decisions (Fam1).

	November	December	January	February	March
Action: intervening	Planning meeting	Everyday hab	Everyday hab	Everyday hab	Everyday hab
<i>Focus</i>					
Ph – Body/physiological				2	3
A – Activity		1		3	2
Com – Communication		2	4	5	4
N – Nutrition					2
M – Medicine					
S – Family support		1			1
<i>Collaboration</i>					
Parents' concerns	2Com; 2S; 1N				
Problem solving	1N		4S; 1N		
Decision	1Ph	2Com	2Ph	1S	1Ph; 1Com

4. Findings

All children in the present study had diagnoses with severe-related impairments and serious health problems. Thus, every child had a number of problem areas that were in focus, a number of people from various professional groups involved, and several simultaneous, ongoing actions. Some of the issues of concern were short term, while others remained over a longer time span. Minor concerns, such as the need for instrumental support, were solved at the planning meetings or in contact with professionals, during an appointment or by phone. Issues experienced and raised by the families that remained over time were: possibilities for their children to be active, physiological consequences of the children's impairments, facilitation of the children's communication, support for the family and medical needs of the children. When issues were identified, actions and collaboration started early in the process with the aim of reducing the problem or concern. *Collaboration* and *actions* were the two categories describing processes, and *focus* concerned the content of the process.

Category 1: Focus – The first question to be addressed is ‘*On what content do the processes focus?*’ The category focus consisted of six subcategories: *body/physiological functions*, *activity*, *communication*, *nutrition*, *medical issues* and *support* (see Table 1). Each of the subcategories described the problem areas identified in relation to each child's difficulties and was the focus for actions and collaboration. Because the children had several impairments, e.g. motor impairment, epilepsy, developmental delays, speech and communication problems, feeding problems, hearing impairment and autism, activities concerning the child had to focus on more than one of the problem areas to solve one problem. One problem area, *support*, was only partly related to child-driven issues, *support* frequently concerned the whole family; e.g. emotional, instrumental, appraisal and information.

Category 2: Action – In the responses to the question ‘*What activities are initiated based on problems identified at planning meetings?*’ two process categories emerged, actions and collaboration. The category action consists of 10 subcategories – *intervening*;

instruction; assessing; informing; planning; documenting; engaging; consulting; reflecting; and handing over (see Table 1). Parents' concerns, identified problems and desired goals generated a chain of actions performed mostly by professionals at the C-YHS. This chain of actions was constantly infused by matters raised in the collaboration. Actions varied depending on the current concerns, problems and decisions, but often one issue resulted in several actions. In Figure 1 under the label *process*, the actions performed by professionals (as reported by themselves and parents) in everyday intervention are presented. Data from professionals verify that several different actions were performed between the planning meetings and other appointments with the parents (Figure 1, the broad arrows).

Intervening was the first and most important action. In the present study, the concept *intervening* relates to activities performed by professionals with a special competence in impairment-related problem areas, and in appropriate therapies and treatments needed to minimize delays and maximize development, and the participation of children with disabilities (e.g. physicians, social workers, physiotherapists, occupational therapists, special educators and psychologists). *Intervening* refers to actions focused on communication, activity, physical treatment, nutrition, medicine and support.

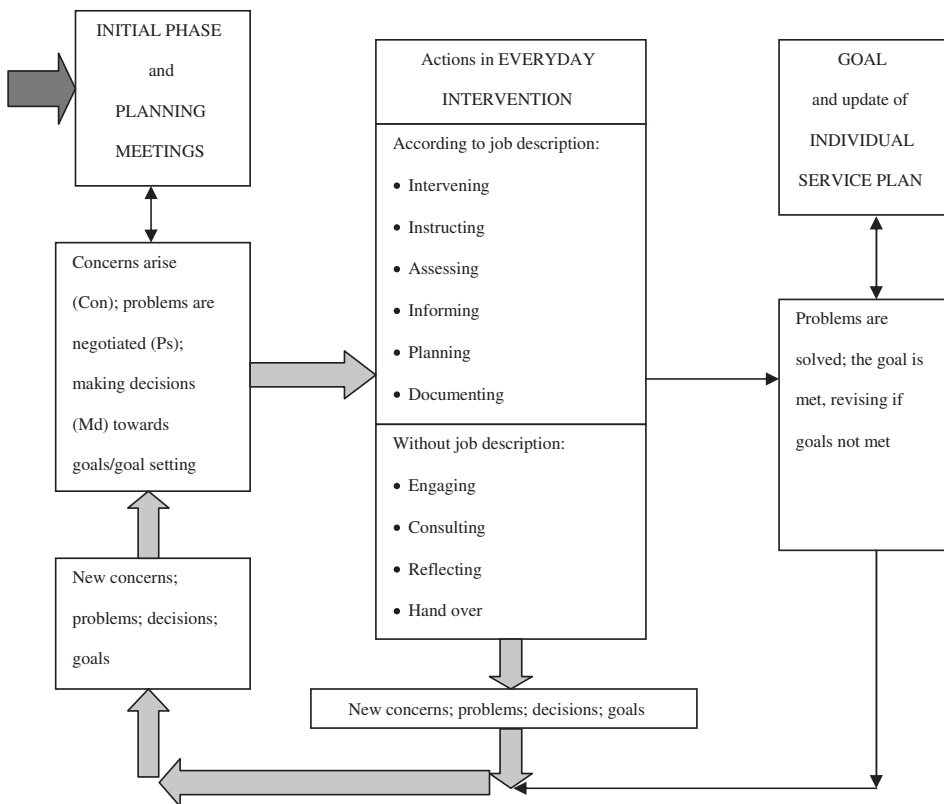


Figure 1. The broad dark arrow illustrates when families enrols in the C-YHS. The process of collaboration and actions performed in everyday interventions is represented by the broad arrows. The update of the IFSP made every six months completes the process and is represented by adding the narrow arrows.

Another action performed by professionals was to provide *instructions* to family members, assistants, personnel at the preschools and colleagues about how to use, adjust and adapt devices. Some of the aids and orthotic devices were complicated, requiring a number of functions and adjustments. *Instructions* were also given about how training programmes, physical training, i.e. new movements for stretching/strengthen the child's muscular system, and new signs for communication, should be implemented and performed at home and in preschool.

Assessment involves both an initial action with the aim of learning about the child's development and functioning in order to accommodate interventions and continuing action monitoring the child's progress.

To provide and gather *information* related to problem areas resulting from the children's impairments was another action. Soon after the enrollment in C-YHS, parents asked for information. Sometimes professionals had to search for information, from colleagues or experts outside the C-YHS.

The action that was most time-consuming for professionals, besides intervening, was *planning*. All activities related to the case had to be organized, scheduled and coordinated. Every meeting with team members, families, preschool personnel, professionals and specialists outside the C-YHS had to be planned. Common sense suggests that the greater the number of people involved in the meetings/activities, the longer the planning time needed to find a suitable date for all. Planning meetings with both parents had to take the parents' job schedule into consideration. Appointments at the C-YHS for treatments, assessments and trying out different aids and devices had to be planned. Over time, interventions were also performed at preschool. Visits, treatments and assessments carried out by the members of the family's professional team then had to be planned together with preschool staff and also with the parents if they wanted to attend.

Documenting is an action related to legal security and quality assurance. Several protocols were produced at C-YHS, for example letters of referral to specialists, inventory lists of aids and devices for the child at home and at preschool, training programmes, medical records, dossiers, assessments forms, documentation of decisions and outcomes from planning meetings, including the habilitation plan and applications for support to the family. A number of the documents had to be signed by the parents.

Engaging in the families' life situation was an action expressed by the professionals in relation to all problem areas. Two kinds of engagement were identified in the present study. One was to follow the children's development in the problem areas. The other was engagement of team members in the concerns about the families.

Consulting with other professionals was a common action. Hesitations or uncertainty in complicated situations caused team members of different professions to consult each other concerning assessment results, special requests from the families, second opinions, or support in solving challenges. Team meetings were important forums for sharing special knowledge. When there was a lack of knowledge, i.e. about rare or complicated impairments, the team members consulted experts outside the C-YHS.

Reflecting is an action generally associated with professionalism. Reflecting means to be aware of your own actions and knowledge. In the present study, a C-YHS team leader expressed a concern over the team members' limited knowledge about visual impairments, and considered in-service training for the team members. Another reflection was a team member's perception that the parents' perspective was not considered, based on the belief that the wrong questions were asked and that the team members had not listened to the parents. The professionals also suggested the need for better communication skills through supervision.

A time-consuming action was *handing over*. As children grew and developed their needs for technology changed, and equipment, aids, and devices had to be replaced or adapted. Handing over such supplies was done mostly by team members, but personal assistants and parents were also involved in handing over, delivering equipment and aids between C-YHS, the preschool and the home.

Category 3: Collaboration – The category *collaboration* consisted of three subcategories: *concerns*, *problems* and *making decisions* (see Table 1). Parents' *concerns* involved reflections and speculation on the impact of the disability and impairments on their child's *future*. The concerns regarded facts and were a means of exploring how to continue to support the child, and what everyday life might be like in the future. Parents' *problems* referred to *existing situations*, conditions or issues that were unresolved. *Decisions* were always formalized and written down in the habilitation plan. Decisions were made as agreements between the family and professionals, or initiated by the professionals. The subcategories *concerns* and *problems* were the key to the collaboration and constituted the foundation for activities and interventions. Further, new concerns and problems caused changes in the focus for activities and interventions and new decisions.

To answer the question 'What is the correspondence between plans developed at meetings and activities implemented in everyday services by the Child-Youth Habilitation Services?' a timeline was created for each family. On this timeline, the collaboration (Collaboration-categories) and the problem areas (Focus-categories) were chronologically linked to the actions (Action-categories), based on what was discussed at the planning meetings and what happened between the meetings. In the analysis of correspondence, critical issues included whether or not a formal decision for action was decided on in the meeting, and also whether professionals or parents initiated a different focus of content than what had been discussed in the planning meeting. After an introductory meeting at the C-YHS, the initial phase of the collaboration between families and professionals began with the first planning meeting. The collaboration continued through everyday intervention, and through the activities performed between the planning meetings. In the subsequent planning meetings (second, third, etc.) the professionals' followed-up concerns and problems discussed at the previous planning meeting and also examined if new concerns or problems had appeared between the planning meetings. This approach provided families with opportunities to express their perceptions about problems and problematic situations, and facilitated further collaborative problem solving. Questions about new habilitation activities were sometimes asked by the families, and sometimes by the professionals during the planning meetings. When parents asked for an activity it was most often in relation to recently experienced problems or concerns, in contrast to the professionals, who initiated activities according to 'a check list of problems' or by asking about earlier experienced problems. Collaboration between the professionals and the families was a process, driven by how the children's disabilities affected the families' everyday life and the accumulation of daily hassles (see Figure 1).

4.1. Concerns

All participating families had a number of concerns, often about the impact of the disability on their child's future. The parents also had concerns about communication, support to the family and medication. Such concerns were raised by families at planning meetings and set the agenda for several activities and actions. There was a strong correspondence between the concerns families raised at planning meetings and the actions taken between the meetings. This was confirmed in retrospect by parents in interviews.

The results showed that all concerns the families raised at the planning meetings were met with formal decisions. For example, one family had experienced communication delays with an older child. Their concerns referred to their younger child with an established disability. Because they did not want to lose time for interventions for their young child, the family asked very early for communication intervention. A formal decision was made to begin by assessing the child's communication skills. Another family's concern referred to the manual signs they had to learn at a course in sign-as-support. The signs chosen were not seen as relevant by the family, and did not fit into the family's everyday routines, and therefore they did not use them. They asked for the option of choosing which signs to learn. A formal decision was made to present the material to the parents with the aim of letting them choose signs; the actions following this decision were informing, planning and consulting. The child's medical needs were a major concern for another family. The formal decision was to include a nurse on the professional team. The action was to invite the nurse to inform the parents and the professional team at a planning meeting.

4.2. Problems

The problems were experienced as obstacles affecting the child's daily life and family functioning here and now, i.e. a difference between the actual situation and the desired situation. Sometimes the nature of the problem implied that it had to be solved quickly. When the families described problems at the planning meetings, available solutions were discussed in collaboration. An important problem for more than one family was that the child had difficulty in sitting properly. The problem was twofold: on one hand it was a practical concern when the parents fed their child, and on the other hand parents wanted to facilitate the child's participation during daily routines and activities at home and in preschool. The formal decision was to provide adapted sitting aids for the child such as pads and high chairs.

Problems' concerning support to the families was another topic raised by all families, both in planning meetings and in everyday intervention. Depending on the support required, action focused on informing the family about available benefits; consulting by contacting the municipal school system to find a preschool with the special educator competence required; planning appointments to accompany and support the parents when informing preschool teachers about the child's disability and medical needs; documenting by helping the parents to prepare applications for benefits; engaging in emotional support to the families during hard times; assessing the aids needed in the home to care for the child; handing over by delivering a special high chair directly to the preschool to save time for the family.

Families, however, also initiated and raised problems in the planning meetings that did not generate any activities or actions. For one family their child's medical problems were a major concern. The problems were raised by the family in two planning meetings, but in this case no related activities or actions could be identified in the present data.

4.3. Decisions

The results showed that formal *decisions* in planning meetings were most often decisions related to the concerns or problems experienced and raised by the families. Some discrepancies, however, could be identified. For one family, even though their most

important concerns had to do with their own need for support, all formal decisions made at planning meetings as well as decisions made between meetings were focused on activities related to communication. Activities following decisions, however, were directed both towards providing support to the family and on communication. In an interview, this family stated that the formal decisions focused on activities directed towards supporting the family and the child's activity. This suggests that having the chance to talk about concerns may be more important than a formal decision. The formal decisions made at the planning meetings were focused on physiological factors, activity, support and communication problems and were all focused on interventions and activities. Formal decisions concerning body/physical functions and activity were made even when these problem areas were not family concerns or focused in the collaborative problem solving at the planning meetings. Actions in relation to the formal decisions consisted of informing, planning, consulting, assessing and documenting.

The result showed that new decisions made between planning meetings could be identified in the everyday intervention. These new decisions affected the actions and the activities performed between planning meetings; sometimes even the focus of problem areas changed. Furthermore, some activities that were performed between meetings were not identified as formal decisions at the planning meetings or as new decisions between the meetings. These activities primarily concerned long-term interventions focusing on physical impairments and child development. Actions by professionals related to physiological problems were: instructing families, assistants and preschool personnel about how to perform recommended training programmes; assessing and documenting children's physiological functions; and consulting other professionals about assessment results. In conjunction with these actions, the actions informing, planning, engaging and reflecting occurred.

5. Discussion

The aim of the study was to explore and compare the content of issues discussed at formal planning meetings with the activities implemented at the C-YHS between formal meetings. The results reveal that the intervention process is multifaceted and complex with several parallel lines of intervention continuously addressing identified concerns and problems. Parents' concerns were focused on the future and everyday life of both the child and the family indicating the importance of seeing the child as a part of a social system in intervention. Concern-related interventions were many times diffused and concerned social context (e.g family life) or social systems (e.g preschool) and thus the effects of concern-related interventions were difficult to evaluate on child level. On the other hand, problems were focused on the present, and were solved both immediately and with several interventions over time. Some of the actions and activities implemented by professionals concerned issues, especially physical impairments, not discussed and/or formally decided upon in planning meetings. New problems that needed attention also appeared between planning meetings. These could change the focus of the intervention.

Prior to discussing the results, some methodological concerns will be highlighted. First, the present study is focused on the intervention process *between* planning meetings rather than on the documented content of planning meetings. Written documents, habilitation plans or actual observations of treatments performed were not gathered as part of the present study. Thus, conclusions about the actions the professionals performed are primarily based on their own and parents' reports. One way to validate the data in the present study would have been to compare the collected data, such as gathered in the

present study, with written documents prepared in the same context. In the study, decisions, activities and goals emanate from spoken utterances, but it is not known how these are evidenced in the planning documents. This implies that whether the documented outcomes are related to the participating families' priorities and concerns or to professionally driven concerns is not known.

Another concern is that the data collected are now at least seven years old. However, given that the system of planning meetings is still the same and has the same purpose of solving everyday problems and meeting the needs of children with disabilities and their families, the data are probably still valid.

The collaborative intervention process that was studied continues over time and involves both formal contacts between the parents and the professionals and informal, usually undocumented, contacts between professionals. The focus on everyday practices made it necessary to collect several kinds of data from both the family and the professionals for each case. It also required an analysis based on one timeline for each case. Thus, a multiple qualitative case design was a functional choice. The data from videotaped planning meetings and the interviews primarily contained information about what was planned and decided. The memory notes and the informal information frequently addressed what was happening in everyday habilitation. In analyzing the intervention process over time these different forms of information were merged. Only observational data provided direct information on what took place. Interviews as well as memory notes and informal information related to how professionals and family members perceived what was happening. The fact that correspondence tended to be found between the content in the different types of data provides support for the validity of the process. Triangulation between different perspectives, and the different data sources, was implemented strengthening the ecological validity of the results obtained.

The analysis was an iterative and reflexive process that involved going back and forth between the abstract categories and the empirical data. All categories were peer reviewed and discussed until consensus was reached. This suggests agreement about the solidity of the categories and their relationship to the data. The inductive nature of this process made it difficult to calculate inter-rater reliability. The chosen design does not allow for empirical generalization but highlights important aspects of the collaborative intervention process in everyday practices not captured by studies of planning meetings or studies focusing on outcomes of early intervention. A final methodological issue has to do with whether the families received more attention from professionals because of their participation in the study. It is not known if the professionals engaged more with the participating families or reflected more on their own performance than would typically be the case.

On what content does the process focus?

In the category, *collaboration* a difference was found between issues related to the future, *concerns*, and issues related to the current situation, *problems*. Professionals acknowledged and implemented activities related to both kinds of issues. However, *concerns* and *problems* lead to different actions. The content of concerns related primarily to preparing the child for new environments and challenges or family needs, which are the difficulties related to participation, environment and everyday life in ICF-CY terms. It indicates that these interventions concern social systems rather than only the child. *Concerns* seem to lead to system-focused actions that indirectly affect the child, such as informing or

instructing parents or preschool staff – while *problems* seem to lead to actions that directly affect the child, such as interventions.

Regarding the children, the content of most problems concerned the child's everyday functioning and participation rather than body impairments. These problems were explicitly identified early on, at the planning meeting. The results show that parents were most engaged and contributed most to the problem-solving process when it concerned such everyday topics as the child's activity, communication, nutrition and support for the family. Topics directly related to the impairments such as physiological and medical problems may be more difficult for parents to understand; thus they leave the responsibility for such issues to professionals. A tendency that was identified was for physiological problems to be addressed by professionals without an explicit discussion with the parents. It may be that problems related to everyday functioning correspond better with a family-centred collaborative problem-solving process, while 'pure' medical problems can be handled as well within an expert-centred process (Björck-Åkesson and Granlund 2003). It confirms the hypothesis put forward by Björck-Åkesson and Granlund (2005), that family involvement may redirect the focus of intervention towards participation rather than a strong focus on body impairments.

What activities are initiated by problems identified at planning meetings?

The link between problems and goal attainment is crucial in everyday intervention. The habilitation plan is a document written on one occasion; in Sweden this planning meeting occurs once in about six months. The plan contains decisions related to problems experienced at that moment and to the current state of the child's health. The habilitation plan is an agreement between the family and professionals about the intervention activities to be implemented. It is also a starting point for a process aimed at facilitating the quality of everyday life for children with disabilities and their families. The present study shows that the topics discussed and the decisions made at the planning meetings start a chain of reported activities and actions. First, there are activities directed both towards problem areas related to the children's impairments, and towards support to the families. Second, there are several actions related to the implementation of activities.

A number of actions were identified that could be expected to be general tasks and responsibilities for professionals at the C-YHS. These actions were *assessing*; *intervening*; *instructing*; *informing*; *planning*; and *documenting*. These are actions that are typically included in job descriptions. In addition the actions *engaging*; *consulting*; *reflecting*; and *handing over* were performed by the professionals in the C-YHS. These actions are not typically included in job descriptions (Figure 1). All the actions except *assessing* and *intervening* refer to prerequisites for coordinated intervention services. One time-consuming prerequisite was to organize all activities through rigorous planning. In addition, professionals at the C-YHS were involved in more than one case. The data sources in the present study provide an insight into the comprehensive work 'off-the-record' that is not often documented in research. Many actions were focused on supporting the adults in the environment, primarily the parents, rather than the child. Such actions may not be well-documented in a record that is designed to document child-specific information, and may lead to under-reporting of interventions focused on the proximal environment. Thus, services may appear to be less family-centred than they are in reality. From a systems theory perspective family-centred service must consider the whole system. When intervention is focused only on the child it may not benefit the whole family (Bornman and Granlund 2007). The results indicate the need for better

definition and measurement of family-related outcomes of intervention, such as changes in parental knowledge about the child's disability, or skills in adapting the home environment to the child or communicating with the child (Bailey et al. 2006). Jung and Baird (2003) examined the outcome statements in IFSP's and found that more than half of the family concerns were written in professional language and were child-focused, rather than defined by the family or defined as an outcome for the family. The results of the present study support the importance of seeing the child and the family and other individuals in the child's proximal environment as a system to be included in intervention for the child. This implies that the process and outcome of intervention should address both child-related and family-related factors.

What is the correspondence between plans developed at meetings and activities implemented in everyday services by the Child-Youth Habilitation Services?

The results in the present study illustrate a process with a high degree of correspondence between families' concerns, experienced problems, the formal decisions and the activities they generated. Most of the concerns that families raised at planning meetings were emphasized and served as the focus for formal decisions. Interventions, activities and actions following the planning meetings were directed to family concerns and to decreasing parental stress. Several problems and concerns related to the child's impairment and to the need for family support tended to remain over time. Some problems identified by families did not result in formal decisions, actions or activities even when conversations about the problem were frequent. Families may perceive the opportunity to express and discuss problems with professionals as more important than actually solving problems (Wilgosh et al. 2004). Parents may learn to solve problematic situations through supportive relationships with professionals (Graham, Rodger, and Ziviani 2009).

The results of the study revealed that new decisions that generated actions not related to the planning meeting were made when the professionals met with families between planning meetings for child treatment or other appointments (Figure 1). There are several possible reasons that new decisions were made between planning meetings. The goals may have been achieved, the expected outcomes may have been too high, or new issues may have become more important. This finding suggests that planning meetings held in six-month cycles may not be effective for developing habilitation plans linked to specific goals, as the time period may be too long to effectively monitor and evaluate the intervention process.

6. Conclusions

The habilitation plan sets the frame for activities performed with a focus on the child with disabilities, and also for activities to support the family between formal planning meetings. Due to parents' concerns and upcoming and unexpected problems experienced by the families, decisions are made between formal planning meetings. These decisions may re-direct the activities. The actions performed most often between meetings have child-focused outcomes as their aim, although they often involve instructing or informing others. However some actions are also focused on the parents, the family and the preschool environment. Indirect, child-focused and family-focused actions, especially informing, instructing and handing over, are probably not adequately documented in the habilitation plan and may be underreported. It indicates that an organization such as the C-YHS, founded on a family-centred philosophy, does not document actions aimed at

supporting families. It seems that actions or goals in the habilitation plan are not formulated at a family level, even when such actions are performed in practice. Family-focused actions, offer the family the possibility of enhancing their competence and family well-being, and therefore documentation of family-focused actions and use of family outcome measures are needed (Bailey et al. 2006).

The correspondence between what is discussed at the planning meetings and what is carried out in everyday intervention is high regarding concerns, problems and formal decisions. However, actions generated from concerns are future-directed and thus difficult to operationalize in child behaviour terms. This may lead to difficulties in evaluating and documenting the effects of such actions and calls for developing family outcome measures.

One exception from the high correspondence between discussions and actions is interventions focused on treating the child's impairment. Professionals tend to monitor and intervene to address the child's physiological impairments continuously over time, independent in part of explicit decisions made at planning meetings. Because such interventions require expert knowledge, something that maybe acknowledged by parents, time was not spent on discussing such issues at planning meetings.

Finally, it seems that when there is a high degree of correspondence between families' priorities regarding concerns, problems and outcomes, and actions taken, the family's level of engagement and involvement in implementing interventions increases. The result may suggest that family-driven outcomes facilitate collaboration between professionals and families. At the same time professionals' engagement in the family's situation, and their willingness to address practical everyday problems, contributes to strengthening the link between problems and goals, making intervention useful for the child and supportive for the family.

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Appendix 1. Parents memory notes

Down under are questions used as a support for your memory, when situations changed and/or if you have been in contact with your team at the Child- and Youth Habilitation center (C-YHS). After every occurrence, please fill in the memory note, there could be several during a month. Send the filled-in memory notes to the research group in the end of every month.

Have there been any changes in the family or its environment?.....

Information about progress or changes in the child?.....

Is there anything experienced as important to talk about with the C-YHS team?.....

The family has been in contact with C-YHS via phone call, date.....

What was decided during the phone call?.....

Show with a cross on the line how well the phone call met your expectations.

Not at all Yes, absolutely

I _____ I

Please leave a comment.....

The C-YHS team has visited you at home/you have visit the team at the C-YHS? Date?

How long was the visit?

What was decided during the visit?

Show with a cross on the line how well the visit met your expectations.

Not at all Yes, absolutely

I _____ I

I 10

Please leave a comment.....

Have you established any new contacts at the C-YHS?.....

Family name:

There have not happend anything during the month of.....and we have not been in contact with the C-YHS team, via phone call or visits