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PUBLIC HEALTH | RESEARCH ARTICLE

“We found a solution, sort of” – A qualitative interview study with children and parents on their experiences of the coordinated individual plan (CIP) in Sweden

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Abstract: Children and adolescents receiving services from two professional parties may obtain support with a coordinated individual plan (CIP). The Swedish law prescribes that CIP must incorporate service user participation. This study aims to explore children and parents’ experiences of participating in CIP-process to generate knowledge with practical implications of how children and parents may be involved in the CIP-process. A descriptive qualitative interview study with 13 service users was conducted during November 2014 to March 2016. Data were audio-recorded and transcribed, and further subjected to qualitative content analysis. Three main descriptive categories with six subcategories emerged. The category “Struggle for coordination” includes service users’ need for participation which are limited by professionals’ lack of consensus. The category “Alliance for coordination” points out the importance of relationship and personal support to accomplish functional coordination. The category “Structure for coordination” shows how the structure facilitate service user involvement on a high level. Service user involvement seemed limited by professionals’ actions, but could be facilitated by support of professionals

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PUBLIC INTEREST STATEMENT

Children and parents with complex needs are defined as families that require simultaneous service from several caregivers, which often are healthcare, school and social services.

The overall responsibility for these efforts is often not clear. The caregivers intend to coordinate the service and invite the children and parents be involved and able to influence the service. But this intention can be hindered by disagreements, differences of intentions and lack of consensus among professionals. Due to these constrains, children and parents may experience confusion and fragmentation of services over a long period of time, which may cause that the child’s needs are not met. To ensure inter-professional coordination, the Swedish government has stipulated a legal obligation of a Coordinated Individual Plan (CIP). This article highlights service-users’ perspective through qualitative interviews concerning children’s and parents’ experiences of CIP.

working in the child's daily life. Structured coordination seems to relieve the pressure on parents, as well as children, but CIP needs to be individually tailored to reach its full potential.

Subjects: Family Policy; Sociology of the Family; Health and Social Care

Keywords: alliances; children; coordinated individual plans; coordination; service user involvement

1. Introduction

The life situation of children with physical, psychological, and/or social problems may be complex, and simultaneous services are needed from several professional mainly from healthcare, school and social services. This support is supposed to be coordinated and given with a holistic perspective and a strong element of service user participation.

Previous research indicate that this coordination and service user participation is hard to reach due to disunity among the professionals (Blomqvist, 2012; Breimo, 2016; Hodge, 2005; Nordström, Josephson, Hedberg, & Kjellström, 2016).

To ensure inter-professional coordination, the government have stipulated a legal obligation of a coordinated individual plan (CIP) for individuals (SFS: 1982:763, 1982; SFS: 2001:453, 2001). The CIP must state what kind of services the individual need, whom is responsible providing the service, and which professional parties bears overall responsibility for the plan, including clarifying that the services are planned, provided, and followed up (SFS 2009:981, 2009).

This article highlights children's and parent's experience of participation in this CIP-coordination process by 11 qualitative interviews.

2. Background

Service user participation, service user contributions and service user involvement are closely related concepts that mean that individuals "are able to be informed of and influence decisions that concern them, or when they are able to influence the design and management of the organisations that provide the services" Swedish National Board of Health and Welfare (2013, p. 46). According to Mannberg (2015), "participation exists when the individual can enter into a committed interaction that is accepted by the other service users based on his or her own decision, where availability is not limited by physical and social barriers" (p. 4). Melin (2013) describes three perspectives on children's participation: in their roles as citizens, in control over their own lives, and participation in everyday life. In relation to the CIP-process, control over one's own life might mean participation in decisions concerning important events affecting everyday life. When the child's expression is taken seriously for consideration and discussion, the child has influence in the decision (Skivenes & Strandbu, 2006). When coordination takes the form of a CIP, it is important for children, young people and their parents to be viewed as fellow service users with the right to participate in the planning, implementation and follow-up of support and services. It is important that expressions from children and parents' is taken seriously according to their state of vulnerability in collaborative situations with more than one caregiver. From a global perspective, individuals have the right to be treated with respect for their self-determination and integrity. The Social Services Act (SFS 1982:763, 1982) contains provisions on children's right to be heard and to have their wishes considering their age and maturity. By the Convention on the Rights of the Child (CRC, 1989), children have the right to exercise, influence, and participate in decision-making discussions concerning their care and treatment as much as possible. The child perspective means that before deciding or act, the responsible decision-maker must consider whether it affects the child/children, and if so, how. If the action or decision is considered to cause consequences for the child/children, their rights must be taken into consideration (CRC, 1989). Due to the Swedish law (SFS, 2001:453, 2001; SFS 1993:387, 1993) children should receive relevant information when a decision is to be made about an action that concerns them.

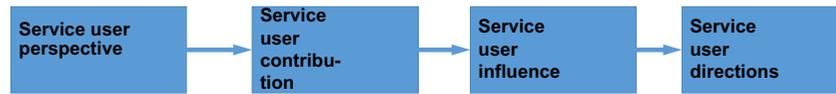
They should then be given the opportunity to present their opinions. To participate in the planning of services, children must understand what is happening, must be allowed to express their opinions and they must perceive that their opinions have a tangible effect on decisions (SFS, 2001:453, 2001). Children have the right to be heard concerning all decisions that concern them. They have also the right not to express their view or opinion against their will (ibid). This means that children must be listened to, but do not need to take sole responsibility for decisions made, based on their own wishes and opinions. The documentation of the planning is often insufficient and children's opinions and wishes might not be visible, or what they said is not clearly stated (Fridh & Norman, 2008; Hultman, 2013). Participation by children and adolescents requires participation by parents. Therefore, it is important to facilitate participation by both children and parents in the case of inter-professional coordination. Professionals in health care, social services and education are responsible for facilitating and offering opportunities for participation in the planning of services (Gallagher, Smith, Hardy, & Wilkinson, 2012; Sahlsten, Larsson, Sjöström, & Plos, 2008). Even young children and children with serious disabilities can participate in the planning of services if the planning is adapted to their abilities and conditions (SFS 1993:387, 1993). Collaboration of individual plans can be viewed as collaboration guided by the wishes of children and their parents, collaboration guided by interaction between professionals, children and parents, and restrictive interaction characterised by conflicts and disagreement. Professionals should view every family as unique and avoid applying a strict collaboration concept (Alve et al., 2013). Therefore, it is of interest for this study to explore if the CIP-process is such a strict collaboration concept or influenced by individual variations.

Research about participation of children and adolescents in planning of individual services is sparse. However in their study, Gallagher et al. (2012) demonstrate that children's and parents' expectations for participation consist primarily of being treated with trust and respect, clear communication and information, and being guaranteed support for participation. Willumsen and Skivenes (2005) state that free and open communication concerning both formal and informal decisions in the collaboration context help create confidence, development and learning. Collaboration with children and parents should have a secure structure and environment that creates trust, as well as awareness of the importance of knowledge, empathy and accessibility (Widmark, Sandahl, Piuva, & Bergman, 2013). Slettebø et al. (2012) found three different power discourses in their study about coordinated individual plans for children in Norway: power in relation to knowledge; power about language; and power to define problems. These power discourses imply that the professionals must be conscious about the power they possess to define the situation for the client when collaboration in individual plan processes. The use of individual plans in a Norwegian context is criticised by Breimo (2016) for a tendency over time to become the care providers' instrument for performing and documenting care rationally, rather than preserving the intention that the individual plan is the individual service user's document. Eklund Nilsen and Jensen (2011) is arguing that coordination should be planned and conducted from a bottom-up perspective, with structures adapted to children's and parents' needs, rather than a top-down coordination governed by existing power structures among the involved professionals. There is a risk that service user participation will become diffuse unless the responsibility of the professionals involved to achieve participation is made clear. Such clarification helps participation develop in a liberating direction (Cowden & Singh, 2007; Stickley, 2006). But, service user participation in this manner may arise questions of power, conflict, and civil rights for the service user in a CIP-process. Service user participation and interprofessional collaboration are closely connected to each other (Breimo, 2014; Langhammer et al., 2014; Slettebø et al., 2012; Willumsen & Skivenes, 2005) why participation in CIP requires service users' involvement in the planning and influence over the parents of this planning.

Because of the interrelation between inter-professional collaboration and inter-professional coordination, it is important to consider their differences. Inter-professional collaboration could be different health care, social care and educational professions who come together and are involved which negotiate and agree how to solve complex care problems or provide services in a more integrated manner. On the other hand, inter-professional coordination means different health, social care, and educational professions whose work together is focused on coordinating care tasks

Figure 1. Model of levels of service user participation.

Source: Modified from Hansen (2007).



between one another (Axelsson & Axelsson, 2006). Coordination can be in a less integrated and interdependent manner. The goal of CIP is to create coordinated efforts and a coordinated plan. The actual situation can be complicated with many caregivers with different standpoints and logics (Grape, Blom, & Johansson, 2006; Nordström et al., 2016).

2.1. Conceptual framework

Hansen (2007) model offer a way to understand participation. The model is constructed as a four-point scale where service user perspective is the lowest degree of participation and service user direction is the highest (Figure 1).

Service user perspective means that decisions have often already been made, and the value of the service user's contribution is more symbolic. The professionals define and decide what the service users need and ask them to confirm this. Professional norms direct the provision of services to a large extent and service users are asked for consent. Previous experience and institutional norms are extremely determinative. Each organisation focuses on its task based on its assignment, and the organisations coordinate with one another by exchanging information. In the case of *service user contributions*, service users are invited to a dialogue about the forms of collaboration and participation, but in practice the final decision on services and how they are to be delivered is made by the professionals. The profession focuses on standardised forms that determine how service users are to participate in planning of services. In the case of *service user influence*, service users are given the opportunity to make decisions within a given framework. There is a focus on dialogue and process concerning subject matter and objectives. In the case of *service user direction*, service users make the decision and professionals carry it out. Service users place orders, and the profession provides support within the given framework if possible. Service users first achieve tangible influence with service user influence and service user direction, and this is the first chance for them to affect services based on ends and means (Hansen, 2007). This study uses Hansen's model of participation to explore how the service user can participate and influence the CIP-process.

2.2. Study aim

The aim of the present study is to explore children's and parents' experiences of coordinated individual planning.

- What experiences do children and parents have in CIP meetings?
- How is children's and parents' experience of participation and influence in the coordination due to CIP, expressed?

3. Methods

3.1. Study design

Exploring the issues, related to the study aim, a semi-structured interview study, and a qualitative analysis, was used to investigate participants experiences of CIP.

3.2. Setting and service users

Children older than 15 and/or parents who have participated in at least one CIP-meeting, and who speak and understand Swedish, were the inclusion criteria. The participants were recruited through a three-step process. In step one, organisation heads and staff at two paediatric and adolescent psychiatric clinics and three municipal welfare offices in a county in southern Sweden were asked for

assistance in contacting study participants. They were requested to provide a brief description of the study to everyone who had participated in at least one CIP meeting, without using gentle persuasion or any other improper form of motivation. In step two, the staff distributed an envelope with a written informational letter to those who had shown interest in receiving information. The information that was directed to parents and children respectively, contained informed consent forms and an addressed stamped envelope. The informational letter contained information on the purpose, the approach, the voluntary nature of the interview, and that it could be held with children and parents together or separately, as well as the research team’s contact information. In step three, those parents and children, willing to participate in the study were requested to sign and return the consent forms. One of the authors (EN) contacted the participants, and an agreement was made on the time and place of the interview. A total of 13 persons agreed to participate in the study. Three were teenagers and eight parents. Five of the parents were mothers, two were couples who were parents, and one was a foster-mother (Table 1). Eleven interviews were held, nine individual interviews, and two dyadic interviews with two pair of parents.

In all interviews, the causes of the CIP meeting were related partly to factors in the child’s school environment and partly to the child’s aggressive behaviour and neuropsychiatric disabilities.

3.3. Data collection

Data was collected by the second author (EN) from November 2014 to March 2016, through interviews containing semi-structured questions. Open questions were asked concerning the participants’ experiences before, during and after the CIP meeting. “Tell us about your experiences of the CIP meetings”, “What is decisive for effective coordination and a good CIP meeting?” “What is especially important for the staff group to bear in mind/take into consideration at a CIP meeting?” More in-depth questions were asked in relation to what the participants had said. The interviews were audio recorded.

3.4. Data analysis

After being transcribed verbatim, the text was inductively performed following the steps by Elo and Kyngäs (2008), including open coding, creating categories and abstraction. The text was read and reread several times to grasp the whole content of the data. During the open coding step, notes and headings was marked in the text, to identify different aspects of the content, related to the study aim. By comparing codes focusing on key words, phrases and/or recurring sentences in the text, a coding scheme, consisting of categories was developed. Based on how the categories were related and linked to one another, those similar or dissimilar were subsequently organised hierarchically into broader, higher order categories. Finally, the categories were abstracted based on similar and differing descriptions, and divided into subcategories and generic categories. To increase credibility,

Table 1. Description of participants and the child’s level of education

Interviewer	Primary school	Lower secondary school	Upper secondary school
A (Mother)		X	
B (Child)			X
C (Mother)		X	
D (Mother)		X	
E (Mother)	X		
F (Mother and Father)		X	
G (Mother and Father)		X	
H (Child)			X
I (Mother)	X		
J (Foster mother)	X		
K (Child)			X

differences in the coding and the categorization step were reconciled through reflection and open dialogue in the research team, until consensus was reached.

3.5. Ethical considerations

The study was approved by the regional Ethics Review Board in Linköping registration number 2014/34-31. Informed consent was obtained through an information and consent form provided to the children and parents who participated in the study. The interviews were held at a time and place set by an agreement between the participants and the interviewee (EN). It was made clear to all concerned that the lead author would not provide feedback to the affected organisations concerning who was interviewed. The three children interviewed were upper secondary students near the age of 18, and all three expressed their desire to conduct the interview without their parents. The statements of the children were not communicated to their parents in accordance of the Ethical Review of Research Involving Humans (SFS 2003:460, 2003).

4. Findings

The findings describe children's and parents' experiences of their participation in the CIP-process. The participants described that the CIP-meeting was initiated by one of the involved professional organisations, e.g. social services, paediatric and adolescent psychiatry, or the schools, with the overall motive of coordinating all support services for the child in question. The participants were informed before the CIP-meeting about why CIP had been initiated. None of the participants had previous knowledge about CIP, and they perceived this initiative from the professional organisation as something positive.

The findings were described by the participants as a pathway to reach coordination and service user influence, a finding, prominently in all interviews which is described in three generic categories and six subcategories (Table 2) and in the following text.

4.1. Struggle for coordination

The participants described *struggle for coordination*, as their effort to achieve coordination or sufficient support. The category concern participants' descriptions of the prevailing view of inter-professional coordination of children's need-related support services. The category encompasses the subcategories *silo mentality*, described as participants' experiences of professionals focusing solely on their own task, and *border area*, described as efforts to establish coordination despite conflicts.

4.1.1. Silo mentality

The participants described that collaboration with the professionals exhibited a silo mentality related to each one's area of responsibility. The participants described that professionals' view of coordination differed and was characterised by disagreement among them. They perceived that professionals' assessment of the children's needs was diverged, which gave them an impression of that the needs of their children's needs become fragmented and unclear. The participants described the professional actors, involved in the CIP meeting, bringing separate views of what kind of support services should be planned for the child, and that no professional actor was willing to take an overall responsibility. One parent said:

Table 2. Summary of generic and sub-categories

Sub-category	Generic category
Silo mentality	Struggle for coordination
Border area	
Go between	Alliance for coordination
Spoke person	
Allocation of responsibilities	Structure for coordination
Ability to influence	

We've called the school and social services at different times, and everyone shifts the blame elsewhere, saying someone else is supposed to do something. We've had to call everywhere twenty times because no one wants to say anything or deal with it. But if you have a meeting like this, something real will come out of it (G).

The participants described their understanding of the coordination as something that was based on specific support services, laying within each professionals' own domain of responsibility. When the participants expressed for example the need for a support service for the child, they perceived that none of professionals took responsibility for providing it., of How the professionals managing the situation brought up feelings of confusion and alienation. However, their frustration motivated them to seek out new options to bring about change. In the words of one of the participants:

Everything was so jumbled. No one cooperated with anyone else. They just threw crap at each other and blamed each other...// I felt I couldn't stand to listen to it (K).

4.1.2. Border area

The participants described that they had to work hard on their own, and wait too long to obtain the needed service. Although the participants once had been promised a specific service they did not note if the service was delivered. Some of the participants defended the undelivered service on insufficient resources and change of staff. The participants felt alienated and started to find new options when they described that the professionals didn't treat the problem of the child seriously. The participants perceived that the collaboration was strictly limited to professional core mission. The participants felt objectified when the professionals marked out boundaries such as personal chemistry, lack of time and staff shortage. One of the participating children described her first CIP-meeting as meaningful, but experienced a sense of social exclusion:

They talked about me as if I wasn't there. I wasn't a NAME, but rather the patient (K).

The participants described how they perceived boundaries being drawn between themselves and the professionals when they requested for example a specific support service. Some of the participants felt themselves questioned of whether their request was reasonable or not. The parents perceived the same type of repudiation when their child's problems were denied or minimised by the professionals. The parents perceived a power asymmetry related to the professionals' sensitivity for opinions or decisions raised by other professionals. The participants describe how they might end up in the middle of the power field. One parent describes this:

The school wants to make decisions alone, they act offended if anyone goes to them and decides what they should do. It's a forceful centre that you can feel the consequences of, and no one wants to get their toes stepped on, and then as a parent you're sitting between them (E).

The participants expressed that their needs were questioned by the professionals, when the professionals exercised their power by challenging the participants' need or desire for services. There were also participants who expressed satisfaction about the attention towards their life situation. When the participants were treated without a challenging attitude and exhibition of power on the part of the professional actors, their sense of denial from the professionals was replaced by validation of their needs and a secure coordination environment. One of the participants described the CIP meeting as important and validating:

Everyone came in and introduced themselves and so on, and [told us] what they did and what they thought. And I thought, when I came in and oh shit there were so many of them, almost thirteen. Everyone here for my life ... (B).

4.2. Alliance for coordination

Overall the category alliance for coordination, concerns the participants' experiences of relationship with someone they trust. This category contains of the participants' need for support, as well as the importance of the relationship. This category encompasses the subcategories *go-between*, described as a transformation of the coordination, and *spokesperson*, described as a person who acted accordingly to the child's needs.

4.2.1. Go-between

The participants described how they before the CIP process was initiated, battled alone by overseeing their children and their need for support. The lack of information, staff turnover, ad hoc solutions and insufficient knowledge of their child's set of problems took a great deal of energy. But this kind of struggle could somehow be reversed. One parent put it like this:

I was at the BUP [paediatric and adolescent psychiatric clinic] when I broke down, and they said, "why don't we get in touch with social services" and then I got to meet with them, and they said, "do you want this or do you want that", etc. and I just said, this all just too much... (A).

The participants described how they were listen to and paid attention to, when they appealed for professional support, and got help to coordinate the child's need of services. Children who were involved in identification of their problems did not have the same need for go-between. Instead, these children were informed at an early stage about the option of the CIP process, which meant that the CIP meeting could be perceived as more open and straight to the point per expressed needs. One adolescent put it:

So, after everyone had said what they thought, we found a solution, sort of (H).

4.2.2. Spokesperson

The participants described how a form of alliance could arise between themselves and a person who served as a go-between. This person could be a spokesman for a parent or a child during the CIP-process. One participant described how the alliance began:

... when I have a meeting with the school from now on, I want you [the psychologist] to be there too ... this must be managed better (C).

The participants describe how they met the spokesperson before the CIP meeting, and together formed their strategies for the meeting. The relationship to the spokesperson was described as a form of "us against them" in relation to the other parties in the CIP-meeting and the spokesperson made the possibility to reach a common goal. The participants described how they felt less vulnerable when a spokesperson was available for support, specifically when the professionals were driven by power. The participants expressed satisfaction about being believed, where they had previously been challenged and had to fight to change things, with guidance of the spokesperson.

4.3. Structure for coordination

The participants described the structure for coordination, as how coordination was developed. This category deals with the participants' reflections about how the structure of the CIP-process influenced collaboration of the decided services. The category encompasses the subcategories *allocation of responsibilities*, described as participants' experience of how professionals distribute responsibility to each other, and *ability to influence*, described as participants' experiences of getting space for participation.

4.3.1. Allocation of responsibilities

The participants perceived that neither the coordinator nor any of the other professionals confronted a professional that repeatedly not fulfilled the objectives that was planned within a CIP-meeting. One participant said:

The coordinator should have been more to the point about why various things hadn't been done. He would've been able to ask follow-up questions about what had not been carried out (F).

The participants perceived that the CIP-process had a clear structure that laid the groundwork for the meeting. So even if they had negative experiences from previous CIP-meetings, the participants felt that the present form of the CIP-meeting was clear and that the subject matter was good. Participants who had been the subject of several CIP-meetings described them as increasingly effective in meeting their objectives concerning support services that had been decided upon. The participants perceived the CIP-meetings as a form of knowledge dissemination, as they gained familiarity with what different professions function is and how their child's set of problems is managed by each professional organisation. One participant said:

You should have preventive meetings, not meetings once there's been a crisis. Another thing is that people should listen to the young people more and not take things for granted (K).

The participants described the structure of the CIP-meeting as meaningful, with clear areas of focus that prevented opinions not based on fact. The structure created a sense of security and clarity, and reduced frustration. There was a space for participants to decide on beforehand which subjects were not relevant, for example evaluation of their parenting, and that they felt secure that these issues should not be brought up at the CIP-meeting. The participants perceived a clear distribution of roles and a more precise delineation of everyone's responsibility in the coordination of CIP. The parents pointed out that the burden of coordinating and keeping everyone informed was lifted from their shoulders when the professionals took responsibility for collaboration. The parents could be just a parent. The participants perceived that during the CIP-meetings, the professional actors should prove that they had done their part, since decisions on services were documented and would be followed up. One participant put it like this:

But I think that through the CIP they're forced to behave since they know that it will be followed up. Someone will be writing this down, and it would be a bit embarrassing if they hadn't done what they were supposed to do then (E).

4.3.2. Ability to influence

Participants described that over time it appeared that the CIP-meeting had developed towards a collaboration that met the participant's individual needs and ability to influence the subject matter. The individual needs could be about the length of the CIP-meeting, the place, participating persons, and various needed support measures. The participants expressed that they had the ability to decide who they wanted to participate in the CIP process. They also stated the importance of being able to choose a location for the meeting they felt safe and secure. All parents had chosen to participate in the CIP-meeting without their children for various reasons. One reason was that their child had been invited but didn't want to participate. Other reasons were that the parents wanted to protect the child from the stress that participating might entail. They didn't want to subject their child to a situation where many people were present and the focus would be on the child. It also appeared that parents had been advised by professionals not to let their children participate in the CIP-meeting, but that the parents had informed the children of the meeting's subject matter afterwards. The parents felt that even if their child was not physically present, it was important for the professionals to emphasise the child's perspective in the meeting.

It was never even brought up that he would be there. Never that he would sit at a meeting like this. Nothing was kept from him. But that he wasn't supposed to be there was part of the problem... (F).

5. Discussion

The findings illustrate how children and parents experience the CIP-process, and the importance of participation in planning of coordinated services is put to the fore. The study demonstrates that children's' and parents' participation may be surrounded by struggle, alliance and structure for coordination indicating difficulties remaining in involving service users in coordinating activities with professional parties. The parents indicate that previously coordination between professional representing different organisations had obstructed service user participation. One reason could be the differing assumptions and perspectives of the professions (Nordström et al., 2016). The relationship between the service-user and a professional "spokesman" could not guarantee participation.

Struggle for coordination illustrates the service users' perceptions of different views on the set of problems at issue, as well as on the service user's needs and wishes. The service users' experience that the professional parties act based on their respective agendas, and the boundaries between different support services become fuzzy for them. The service users' descriptions, intend that the support services are fragmented and difficult to understand. The professionals' ambition to plan and implement their coordination is time consuming, which might delay the services to a child whose situation therefore could remain unchanged (Blomqvist, 2012). Additionally, Breimo (2016) points out that the CIP-process runs the risk of becoming primarily the professionals' duty due to their core task. The service user is objectified, becoming a task to manage. From the service user's horizon, collaboration appears to have an emphasis on control to the benefit of the profession (Cowden & Singh, 2007; Stickley, 2006). The lack of consensus impairs service users' prospects for participation in the decisions that are involved in the CIP process. When the professional parties focusing on their own tasks, based on their own assignments, the service users' contribution seems to have only symbolic value.

Alliance for coordination indicates necessity of creating a relationship with a spokesperson who inspires confidence. Such person can assist service users with coordinating services, especially in the beginning of the CIP process. Collaboration that is characterised by restrictive interaction and disagreement among professionals within different organisations (Alve et al., 2013), could causes feelings of insecurity among service users. A field of force can arise as one organisation affects another (Blomqvist, 2012). The findings in this study, about the important relationship between a parent or child and an ally, is showed also by Buckley, Carr, and Whelan (2011). However, the statutory right to receive support with CIP-coordination when needed should not be something that a parent must qualify for, nor should the parent have to be dependent on good relations with a spokesperson. In this study, polarisation of viewpoints between the service users and the professionals emerged, which is confirmed by a study of Biggs (1993) about an "us versus them" attitude.

In the findings two of the lowest levels of service user participation, according to Hansen (2007), could be recognized in the categories of *Struggle for coordination* and *Alliance for coordination*. The service users did not seem to have been regarded as collaborative partners. They rather felt that the services were decided upon and planned based on organizational norms. Eriksson (2015) mean that there is a certain type of participation and degree of influence that takes place within an institutionally designed framework. The parents demonstrated how this type of management manifests itself as a feeling of lack of confidence to the professionals. The service user was invited to a dialogue of how to achieve goals through the power of professional discourse, which is in line with previous research (Hodge, 2005). It seems due to the professional discourse that the service users' have little ability to influence the choice of service related to individual plans (Hansen, 2007). Even if the professional parties promote and affirm user participation, the professional discourse might hinder the intention for participation (Hodge, 2005). Unless the professionals take responsibility for developing participation in a liberating direction, there is a risk that service user participation will become diffuse (Cowden & Singh, 2007; Stickley, 2006).

Structure for coordination seems to facilitate service users' participation in CIP. In contrary, Eriksson (2015) states that the service users can only exercise influence over services provided

within an institutionally defined and restricted area where the fundamental decisions have already been made. In this study, the user participation concerned who would participate in the meeting. In several of the service users whose experiences we took part of, the parents represent their absent children in the CIP meeting. Thus, the parents could express their own opinions while having the mandate to speak for their child. The parents gave several explanations for their children's absence from CIP meetings. Stenhammar (2009) states that children can participate in planning and decisions on services that affect their daily lives by an early age. On contrary, children who are involved in decisions on services seem to benefit more from the effect of these services (Gallagher et al., 2012; Mannberg, 2015; Vis, Strandbu, Holtan, & Thomas, 2011). The findings indicate that children and parents may have different expectations on participation. While the parents expected to be listened to, and to be met with respect and empathy, one child expected to get some concrete type of action plan. This is in line with previous research by Gallagher et al. (2012), stating that expectations for participation primarily consists of being treated with trust and respect, clear communication and information, and being guaranteed participation through relevant support. The service users in our study also pointed out the importance of having influence over the location of the CIP meeting. Being allowed to influence the structure and setting of the meeting has previous been found as an important component for making the coordination secure and creating trust, along with knowledge, empathy and accessibility (Widmark et al., 2013). Willumsen and Skivenes (2005) illustrates the importance of free and open communication concerning both formal and informal decisions in the collaboration to create confidence, development and learning. Based on what the category of structure for coordination covers, it is possible to speak of service user participation in the form of real service user influence through the service users' description of the dialogue between the meeting service users. As Hansen (2007) points out, the dialogue still takes place within a given framework, where the professionals have identified and addressed the need that the service user has called attention to. Further, the service users do not perceive the services as coordinated due to the legal intentions for CIP until after they have participated in several CIP-meetings, which indicate that the teams of professionals have disagreements concerning collaboration (Övretveit, 2013). In this study, service user participation could assume a form of service user direction, where the service users in coordination with professional parties had opportunities to state their needs, plan, implement and follow up on the services.

This study has some limitations. The data was collected from a small number of service users whom had the capacity arguing their case and clearly run their needs and desires, and able to carry them and complete the collaborative process. The recruitment process may have missed those who have not received appropriate coordination of support and/or not been able to take the initiative to agree to the interview as well as those who were so pleased about the coordination that they lacked motivation to undergo an interview. Information about the drop outs, with information about the study, is missing, why it is unknown what characterizes the participating participants, compared to those who refrained from participating. Those limitations might reduce the credibility of this study that therefore not is representative of the entire group of children and parents with experiences of CIP. It was not possible to recruit children and parents from the same family, which could have brought a family perspective on CIP.

6. Conclusions

- Children's and parents' participation is restricted by differentiated viewpoints among the professionals, with a risk that support will not be provided and a lack of inter-professional coordination.
- A cooperative alliance strengthens the services users' position vis-a-vis the CIP meeting, which facilitates service user participation.
- Parents are relieved of the informal responsibility to coordinate the combined services through compulsory legislation.

- Coordination in the form of the CIP can evolve over time to become more customised based on children's and parents' needs and wishes, why the CIP process should be used in a more proactive way.

This paper make an empirical contribution, providing new knowledge on children's and parents' experiences of CIP. They express essentially positive experiences of CIP, since it represents a progress compared to their previous situation. Positive features are that children and parent raise, is that all professionals involved are there at the same time. Service users' usually have cooperative alliances with a professional that stands up for them. Service users are relieved from the task of coordination, and they might feel that they try to meet the needs of the child. Despite this, there are also several challenges for CIP to exhibit a true potential as creating service user participation. Children and parents experience a lack of coordination and even conflict among professionals from times to times. The theoretical contribution to participation research is by confirming that structures and processes aiming at creating participation, is not enough, they need to be complemented with relational qualities among professionals exemplified through communication. It takes deliberative efforts among professionals to reach the higher degrees of service user participation.

7. Implications for practice

To facilitate participation and influence by the individual, the professionals must have the courage to release their grip on control and invite the service-user to the greatest possible extent of participation. It is important for representatives of professional groups to have an in-depth dialogue with the service users about participation in collaboration situations. They must understand that even young children can participate in decisions about services that affect their daily lives, and they should free up the service users' resources by accepting and accommodating their proposed solutions. The CIP is a standardised form of coordination enacted by legislation, which can evolve to become more customised based on service users' needs and wishes. The CIP must be adapted to the service users rather than the reverse. Professionals must be able to identify and support the service users' need for cooperative alliances. Further research is needed on the CIP and how the interaction between the professions and the service users takes place based on the connection between service user participation and the professions' integration, consensus and attitudes on the CIP.

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References

Alve, G., Madsen, V. H., Slettebø, Å., Hellem, E., Bruusgaard, K. A., & Langhammer, B. (2013). Individual plan in

rehabilitation processes: A tool for flexible collaboration? *Scandinavian Journal of Disability Research*, 15(2), 156–169. <https://doi.org/10.1080/15017419.2012.676568>

Axelsson, R., & Axelsson, S. B. (2006). Integration and collaboration in public health – A conceptual framework. *The International Journal of Health Planning and Management*, 21(1), 75–88. [https://doi.org/10.1002/\(ISSN\)1099-1751](https://doi.org/10.1002/(ISSN)1099-1751)

Biggs, S. (1993). User participation and interprofessional collaboration in community care. *Journal of Interprofessional Care*, 7(2), 151–159. <https://doi.org/10.3109/13561829309014976>

Blomqvist, C. (2012). *Samarbete med förhinder: Om samarbete mellan BUP, socialtjänst, skola och familj* [Collaborations with counterchecks: On collaborations between child psychiatry, social services, school and family] (Doctoral Thesis (PhD)). Göteborg University, Göteborg, Sweden (in Swedish).

Breimo, J. P. (2016). Planning individually? Spotting international welfare trends in the field of rehabilitation in Norway. *Scandinavian Journal of Disability Research*, 18(1), 65–76. <https://doi.org/10.1080/15017419.2014.972447>

Buckley, H., Carr, N., & Whelan, S. (2011). 'Like walking on eggshells': Service user views and expectations of the child protection system. *Child & Family Social Work*, 16(1), 101–110. <https://doi.org/10.1111/cfs.2011.16.issue-1>

Cowden, S., & Singh, G. (2007). The 'User': Friend, foe or fetish?: A critical exploration of user involvement in health and social care. *Critical Social Policy*, 27(1), 5–23. <https://doi.org/10.1177/0261018307072205>

- CRC. (1989). Convention on the right of the child. In CRC becomes incorporated in Swedish law. Retrieved August 8, 2016, from <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>
- Eklund Nilsen, A. C., & Jensen, H. C. (2011). Coordination and coordination around children with individual plans. *Scandinavian Journal of Disability Research*, 14(1), 1–14.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Eriksson, E. (2015). *Sanktionerat motstånd: Brukarinflytande som fenomen och praktik* [Sanctioned resistance: service user involvement as phenomenon and practice] (Doctoral thesis (Ph.D.)). Lund University, Sweden (in Swedish).
- Fridh, B., & Norman, G. (2008). *Att utreda när barn far illa - en handbok om barnvårdsutredningar i socialtjänsten* [To investigate when children are at risk – A handbook about children investigations in the social services]. Gothia förlag, Stockholm (in Swedish).
- Gallagher, M., Smith, M., Hardy, M., & Wilkinson, H. (2012). Children and families' involvement in social work decision making. *Children & Society*, 26(1), 74–85. <https://doi.org/10.1111/chso.2011.26.issue-1>
- Grape, O., Blom, B., & Johansson R. (2006). *Domänkonsensus eller domänkonflikt?: Integrerad samverkan mellan myndigheter. Organisation och omvärld: Nyinstitutionell analys av människobehandlande organisationer* [Domain consensus or conflict?: Integrated co-operation between authorities. Organization and environment: New institutional analysis of human service organizations]. Lund: Studentlitteratur (in Swedish).
- Hansen, G. V. (2007). *Samarbeid uten felleskap: om individuelle planer i kommunalt psykisk helsearbeid* [Collaboration with community: About individual plans in municipality healthcare] (Karlstad: Doctoral Thesis (Ph.D.)). Karlstad University, Sweden (in Swedish).
- Hodge, S. (2005). Participation, discourse, and power: A case study in service user involvement. *Critical Social Policy*, 25(2), 164–179. <https://doi.org/10.1177/0261018305051324>
- Hultman, E. (2013). *Barnperspektiv i barnvårdsutredningar-med barns hälsa och barns upplevelser i fokus* [A child perspective in child welfare investigations – With children's health and experiences in focus] (Doctoral thesis (Ph. D.)). Linköping University, Sweden (in Swedish).
- Langhammer, B., Madsen, V. H., Hellem, E., Bruusgaard, K. A., Alve, G., & Slettebø, Å (2014). Working with individual plans: Users' perspective on the challenges and conflicts of users' needs in health and social services. *Scandinavian Journal of Disability Research*, 17(1), 26–45.
- Mannberg, L. (2015). *Barn och ungas delaktighet och inflytande vid planering av insatser* [Children and adolescents' involvement with planning of operations]. Delrapport 2015:1 från FoU i Sörmland (in Swedish).
- Melin, E. (2013). *Social delaktighet i teori och praktik - Om barns sociala delaktighet i förskolans verksamhet* [Social participation in theory and practice – About children's social participation in the preschool organization] (Doctoral thesis (Ph.D.)). Institutionen för pedagogik och didaktik Stockholms universitet, Sweden (in Swedish).
- Nordström, E., Josephson, I., Hedberg, B., & Kjellström, S. (2016). Agenda för samverkan eller verksamhetens agenda? Om professionellas erfarenheter av samverkan enligt samordnad individuell plan (SIP) [Agenda for cooperation or the professionals' agenda? About the professional experience of the interaction under coordinated individual plan (CIP)]. *Socialvetenskaplig tidskrift*, 1, 1–22.
- Övretveit, J. (2013). *Samarbete, klinisk samordning och integrerad vård: Evidens och praktiska förbättringar* [Coordination, clinical coordination and integrated care: Evidence and practical improvements]. In R. Axelsson & S. Bihari Axelsson (Eds.), *Om samverkan: För utveckling av hälsa och välfärd* (pp. 77–90). Lund: Studentlitteratur (in Swedish).
- Sahlsten, M. J., Larsson, I. E., Sjöström, B., & Plos, K. A. (2008). An analysis of the concept of patient participation. *Nursing Forum*, 43(1), 2–11. <https://doi.org/10.1111/nuf.2008.43.issue-1>
- SFS (1982:763). (1982). *Health and medical service Act*. Stockholm: The Swedish Parliament.
- SFS (1993:387). (1993). *Act on support and service to certain disabled persons*. Stockholm: The Swedish Parliament.
- SFS (2001:453). (2001). *Social Services Act*. Stockholm: The Swedish Parliament.
- SFS (2003:460). (2003). *Act on the ethical review of research involving humans*. Stockholm: The Swedish Parliament.
- SFS (2009:981). (2009). *Law amending the Social Services Act*. Stockholm: The Swedish Parliament.
- Skivenes, M., & Strandbu, A. (2006). A child perspective and children's participation. *Children, Youth and Environments*, 16(1), 10–27.
- Slettebø, Å., Hellem, E., Bruusgaard, K. A., Madsen, V. H., Alve, G., & Langhammer, B. (2012). Between power and powerlessness – Discourses in the individual plan processes, a Norwegian dilemma. *Scandinavian Journal of Disability Research*, 14(3), 270–283. <https://doi.org/10.1080/15017419.2011.574846>
- Stenhammar, A. M. (2009). *Lyssna på mig! Barn och ungdomar med funktionsnedsättningar vill vara delaktiga i möten med samhällets stödsystem*. [Listen to me! Children and adolescents' with disabilities want to participate in meetings with community support system] (Master thesis). Högskolan i Halmstad, Sektionen för hälsa och samhälle (HOS), Halmstad, Sweden (in Swedish)
- Stickley, T. (2006). Should service user involvement be consigned to history? A critical realist perspective. *Journal of Psychiatric and Mental Health Nursing*, 13(5), 570–577. <https://doi.org/10.1111/jpm.2006.13.issue-5>
- Swedish National Board of Health and Welfare. (2013). *Att ge ordet och lämna plats: En vägledning om brukarinflytande inom socialtjänst, psykiatri och missbruks- och beroendevård*. [To hand over the word and make way: a guide to service-user involvement in the social services, psychiatry and addiction and dependency care]. Stockholm: Socialstyrelsen (in Swedish).
- Vis, S. A., Strandbu, A., Holtan, A., & Thomas, N. (2011). Participation and health—a research review of child participation in planning and decision-making. *Child & Family Social Work*, 16(3), 325–335. <https://doi.org/10.1111/cfs.2011.16.issue-3>
- Widmark, C., Sandahl, C., Piuva, K., & Bergman, D. (2013). Parents' experiences of collaboration between welfare professionals regarding children with anxiety or depression—an explorative study. *International journal of integrated care*, 13(4), 1–11.
- Willumsen, E., & Skivenes, M. (2005). Collaboration between service users and professionals: Legitimate decisions in child protection – A Norwegian model. *Child & Family Social Work*, 10(3), 197–206. <https://doi.org/10.1111/cfs.2005.10.issue-3>



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