The mother's voice in inter-professional collaboration in a client support group

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By analyzing videotaped scenes from a meeting in a client support group, this qualitative study investigates the communication between the mother and the professionals. The conversation taking place is not in a spirit of shared ownership and responsibility; the mother's voice is not heard. The study demonstrates that the professionals act from different perspectives to the parents as a matter of routine, and they call for standard solutions. The findings also demonstrate that it is not enough for the professionals to act in an empathic manner towards the mother, if they cannot bring forward expectations of changes that make real differences in daily life in a more material way. The paradigm of empowerment and partnership demands strong consciousness about professional role and practice.

Keywords: inter-professional collaboration; parent's voices; disabled children; professional attitude; professional communication skills; partnership

Introduction

Most families with disabled children have much experience related to accessing public services. There are many different stories told about the families' struggle for better life-conditions for their daughter or son (Tronvoll 1999; Holck 2004; Tøssebro and Kittelsaa 2004; Lundeby 2008). Parents describe lack of coordination between different welfare and health agencies. Parents report that professionals ignore their view and they feel they are not being listened to from their own perspective (Lundeby and Tøssebro 2008). The caring professions, in the paradigm of family empowerment, have to be aware of their new role in assisting families in their social and political struggle for independence and self-determination. Inter-professional collaboration is also challenging the paradigm of family empowerment; hence it is important to study how the parent's voices are heard in this context.

Research in the field of inter-professional teamwork has promoted some key indicators for effective teamwork: To communicate clearly, to interact respectfully, to demonstrate trust, to negotiate different perspectives, to build on each other's strengths and to promote reliability and responsibility (Carter 2001). A key factor as well, seems to be the phenomenon of creating collective thinking among parents of children with special needs, family members and professionals about what is necessary and important in a collaborative relationship (Bishop et al. 1993).

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Collaboration between the service-providers and the family is viewed as a way to improve the service delivery system in a spirit of shared ownership and responsibility.

Seven principles of family/professional collaboration are described in this study: (1) To promote a relationship in which family members and professionals work together to ensure the best services for the child and the family; (2) To recognize and respect the knowledge, skills, and experience that families and professionals bring to the relationship; (3) To acknowledge that the development of trust is an integral part of a collaborative relationship; (4) To facilitate open communication so that families and professionals feel free to express themselves; (5) To create an atmosphere in which cultural traditions, values, and diversity of families are appreciated; (6) To recognize that negotiation is essential in a collaborative relationship; and (7) To enhance a relationship of mutual commitment of families, professionals, and communities (Bishop et al. 1993).

It also seems necessary to be aware of the important factor that shared understanding of common issues is a key variable for success in the relationship (Habersang 1994). In the studies of Carter (2001), Bishop et al. (1993), and Habersang (1994) we can see some outlines of the paradigm of family empowerment and partnership. Partnership can, in this context, mean agreements by contract between equivalent partners working towards a mutual goal. Each participant has his or her own tasks to do according to their own strength. Equivalent partners are not necessarily equal, but they complement each other (Dale 1996; Askheim 2003; Lorentzen 2006; Askheim and Starrin 2007).

In Norway, regulations require that every person in need of prolonged, combined services is entitled to an individual plan. The parents with children below 18 years of age have the right to participate in developing the plan and this is arranged by the local service delivery system. The purpose of an individual plan is to provide a complete, coordinated, and individually tailored set of services and to ensure that one person has the main responsibility for following-up and coordination at all times (Sosial- og helsedepartementet 2001a, 2001b).

The purpose of this study is to investigate the relations and communication between service providers and parents, as spokespersons for their 18-year-old son with severe physical and intellectual disabilities, in a client support group.

The article will, through analyzing videotapes from a meeting in a support group, focus on how the parent's voice is heard and brought into the inter-professional collaboration in the light of empowerment and partnership. In, particular, this article will focus on how the professionals understand the mother's visions and future dreams for her child.

The context and processes

This study was done during one year, in a client support group. The main purpose of the group was to contribute to a situation of life as independent as possible for a young man, in this study called Per. Per is a young man, age 18 years old, with severe physical and intellectual disabilities. His mother and father speak on his behalf as guardians, because Per's diagnosis influences his ability to attend the meetings. The support group consists of his parents and an interdepartmental and inter-professional group which coordinate the services offered and make inter-professional and user-based evaluations and decisions. The decisions made in the support group will hopefully lead to a better life for Per. The particular meeting, this study was based

on, was one out of four videotaped meetings in the process of preparing an individual plan for Per. The meetings lasted between one and two hours.

Members of the support group

Through informed consent from the parents and the other participants, I got permission to make a video study and follow this particular support group in four meetings. The study was approved by The Norwegian Data Inspectorate. This particular group was chosen because I knew the mother beforehand.

The support group at the meeting, which was videotaped at Per's school, had the following professional members: From the County's Health and Social Department, an Advisor for Disabled People (Social Educator) and a head of relief apartment buildings (Social Educator); from the School Department, two teachers (special educators); from the Community Health Services, a general practitioner and his intern; from Per's home base, his mother, who is also trained as a special educator; and a student from the Faculty of Health and Social Sciences, Bergen University College. She is associated with her home-based practice for 12 weeks, as a part of her BA degree. Totally, there were eight persons at the meeting. The GP and his intern were only present during the first part of the meeting. The father of the young man was out of town in a work-meeting, and could not attend, so the mother became the main spokesman for Per in this meeting. Only one male was present, the GP, the rest of the group was composed of women. Per, himself, was not present.

Method

This study has a hermeneutical and phenomenological approach. The relationship between the professionals and one parent in one particular meeting has been studied in depth. The meeting was videotaped. One meeting out of the four meetings was selected as the basis for my in depth analysis. This was done for a practical reason. By using the methodology from microethnography (Erickson 1982), it would be necessary to keep the transcribed text in a format that I could handle. In a case-study like this, I am looking for the understanding of the interpretations of meaningfulness held by the actors in the concrete scenes. This demonstrates some of the limitations of this study: The findings are related to situations taking place in taped sequences from one meeting, and cannot be a subject of generalization.

This particular meeting and scenes were chosen because they had some qualities that could illustrate the relations and communication between service providers and the mother in a clear manner. The mother was well-prepared for the meeting. The selected dialogue with the professionals illustrates issues of particular relevance to my study.

I chose to use a tripod with one camera and play the part of 'the fly on the wall'. I seated myself on a chair next to the camera. The camera caught all participants, but some participants were shot from behind. Since I used only one video-camera, I realized afterwards that my data was insufficient in some respect, and my opportunity to use the non-verbal communication properly, when analyzing the transcribed text, was affected. I could see one person's face and body-language, but only the back of the person who was responding. I consider it more important to be unobtrusive during filming rather than to film the activity perfectly.

One of the obvious problems with video recordings is that people may act differently from their normal behaviour. Critics claim that filming increases the distance between the observer and the observed. The participants' awareness of being observed leads to staged behaviour. Several scientists (Erickson 1982; Alrø and Kristiansen 1997) claim that the purpose of the meeting will override the disturbance and eventually make the actors behave the way they normally do. My own experience told me that although recording equipment may be disturbing at first, those effects will decrease as the group shift focus to the case and content of the meeting.

Video recordings in general allow observation of both the verbal and non-verbal communication. By using video recording I can recall events and study them more closely by rewinding the film and studying it repetitively. This method is more accurate than recalling things from memory and personal notes. This is one of the main advantages that videotaped scenes have. I was able to put myself near the context in a very 'experience near' manner, by playing the scenes again and again. When I was in the interpretive process, I could recall and check my interpretations in a critical way.

When analyzing the video-scenes I looked at the whole meeting in an open-minded way asking: What phenomena do I identify? I tried to understand which factors influenced communication and relations in a positive or negative way.

By using the software Qualitative Media Analyzer (2001), I have transcribed the dialogues in a more detailed way. Inspired by Erickson (1982) and Ekman et al. (1995), I have analyzed the scenes in an inductive way and tried to understand what the dialogue expresses. What kind of meaning do the members of the group create together or separately in each position as a professional or as a mother?

There are important limitations to be aware of when analyzing videotapes as a primary source of data. I can only interact with data as secondary data source and cannot test my interpretations by interaction. Contextual information that is not obvious in my data on the videotapes, make up another limitation. I am dealing with frozen scenes that are removed from their natural settings. The next limitation is my own personal background as a special educator. I have been a member of a support group which created an individual plan for a girl with severe physical and intellectual disabilities. In other words, I am not a stranger to the culture and professional procedures that take place. This is beneficial in that I am aware of procedures and can easily understand what is communicated and the context. At the same time, because of my background, I am integrated into the 'culture', and therefore perhaps did not ask sufficiently critical questions.

An ethical consideration I will illuminate is that the mother in the support group was my earlier colleague and a friend. She was my gatekeeper into the study. I am aware that this requires special demands on my insight regarding my own role according to the research and knowledge found. My own branch of knowledge about empowerment and partnership was affecting the way I analyzed the dialogues. But this was a conscious choice to use this as a reference to my interpretations.

Another aspect to consider is that the mother in this study is a mother with the specific competence as a special educator. This can be both a strength and a weakness when it comes to building relationship with the service providers. The mother can act with a more professional attitude and more as a peer. Another possibility is that the professionals felt pressured into achieving good results because they know about her profession. This may lead to insecurity in the professionals for not being clever enough (Fjæran and Rusten 2006).

Disability and social network

The topic in focus in this particular meeting is: *What about Per's network when he moves into his own apartment?* The Norwegian literature about people with disabilities and their social networks indicates that family relations are not different from the relations that ordinary children or youngsters have. But when it comes to friendship, only 58% of the disabled people state that they have a friend compared to 91% of regular people (Tøssebro 1996). Disabled people often have friends who are disabled as well, but have less contact with their neighbours than regular people have (Tøssebro 1996). Newton et al. (1994) confirm these studies and show that many disabled people lack friendship and support beyond their own family members or service providers.

Per is, at the moment of filming, still living in his parent's house. He takes part in the family's network, and is a user of some municipal services. The meeting referred in Extract 1, 2 and 3 is the first meeting concerning Per's future network when he is moving into his own department.

The mother's voice

I have chosen a scene where I want to reproduce the mother's voice. This is to clarify her message and to use this part of the meeting to start understanding the mother's perspective. I have translated her speech carefully into English.

The mother has prepared well for this meeting and has written down her thoughts about this new situation where Per is moving into his own apartment:

Extract 1

Mother: *I have been thinking a lot about networking, and I really want to do something about it related to this meeting. I don't want that it's only me who want to visit Per and that it's only me who will be his real network in the future. Neither do I want that the service providers should be his only network. And then I ask: How do we make it?...*

And I have been thinking a lot... Per will get his basic needs covered related to food, house, warm clothes and so on. But the question is: What does Per need to have a real good life? Focusing on Per, which requirements is he in need of to get a dignified role? The system is easily thinking in groups, that we know for sure. They are focusing on resource matters, plans and other administrative stuff. In a way we forget the person, the person in the middle and this particular person's needs...

How can we transfer his social contacts from our home to his own apartment when he is moving? How are we going to create the social meeting-points? There are thousands of questions and many answers...

I have a dream of people who are dropping in and want to visit Per when they are in the neighbourhood. I have a dream that shows service providers appreciating unexpected visitors. I have a dream that it shouldn't be difficult to visit Per. I mean: in a natural way, not binding...

I also have a dream that we can stay as parents and that we don't need to have compunction because we don't visit him every day.

I have a dream that Per will get mail and postcards and I also don't want him to be a 'resident' only, and that his residence is not only a 'place'. And the greatest dream of them all is that Per should not be forgotten!

> *And then again: How do we do it? Anybody who feels responsible to start the process? Anybody who want to come along? Or is it unattainable? It doesn't work. 'It's only a mama with her unrealistic dreams'. Maybe . . .*
>
> *I think this can happen. But it demands an effort and it demands cooperation. Clarification about roles, key-persons, relations, distinctness, honesty, and cooperation are the keywords in this process. But the greatest challenge is how to catch Per's needs and desires. And here the student has taken the challenge and has written about the attempts in her assignment.*
>
> Student: *I have taken several assignments with me, so you can see what I have written.*
> Mother: *I read it bedside and I was thinking: Oh, how wonderful! When she was writing about Per's homesickness, then I nearly cried. He suddenly came clear to me as a person with his own needs, and not only like my desires and dreams in this process. . . .*

Distance and nearness

Extract 1 is about both the mother's anxiety and her expectations for her son. The mother presents an analysis from her point of view, on both a system level and an individual level. She is well-prepared, and has done it in writing. This underlines how important it is for her to make a statement. She, as both a mother and a special educator, keeps a balance between these two positions. By looking carefully at the spoken text, she is more in the role of the mother, when she is trying to take Per's perspective. She talks especially about his personal needs to have a good social life. We can see the *nearness* to Per coming through the letters: She want us to see him like a *person* with his own desires and needs. We can also see in her last expression that she is making a distinction between her and Per's needs. However, the interesting thing is that she needed the student's perspective to get the consciousness about the differences between *her* needs and *his* needs. Perhaps she needed some *distance* to be aware of it.

The content of the message: asking for responsibility

The main message in the dialogue quoted above was that the mother wanted the professionals to build a system for helping Per to keep his network intact and perhaps get new friends in his new apartment. She wanted to end her responsible role and asked the professionals to take over. She asked several times during the meeting for someone to take the responsibility for arranging the network-meeting, both spoken in terms of a professional and in terms of a mother's wishes for her son.

Different perspectives

The next part of the dialogue in the meeting demonstrates how the two sides, the mother and the professionals, communicate. The professionals in this scene are from the county's Health and Social Department: Professional A: Adviser for disabled people (Social Educator) and Professional B: A head of the relief apartment buildings (Social Educator).

Extract 2

> Professional A: *At the same time, I couldn't see it as my role to be the person who coordinate and start these processes right now. By the way, I have so many unsolved problems simultaneously...*
> Mother: *Ok well.* [waving her hands]
> Professional A: *But the primary person, she will probably be a very central person when it comes to facing the future.*
> Mother: *I feel both puzzled and challenged to be the person who is asking people to come to a both formal and informal network meeting at the same time. And people will think it's odd that it's me who is doing it, or is it a more structured person who can get people to come?*
> Professional B: *When anyone moves away from home, what do they do then? They have a party at their new apartment.*
> Mother: *Yes, they have a party, but I want this to happen before the party.*
> Everybody gives their agreement by nodding and concludes: *So you want it before!*
> Mother: *Yes, I will 'lay the table' before!*
> Professional B: *Because, when having a party, it is a nice way of inviting, and then we follow the usual way of doing it.*
> Mother: *Yes, but then we have already moved, and when the party is over, everything is over.*

This part of the dialogue shows that the professionals have some difficulties understanding the mother's need to have some professionals to lean on in this process. She wants them to arrange an informal network meeting to discuss the roles of the persons in Per's network. Instead, they give alternatives that do not fit with the mother's perspective of preventive action. The mother gives a clear statement at the end about what she thinks of their initiative: 'When the party is over, everything is over!'

Service-provision as a matter of routine and standard solution

The discussion between the mother and the service providers in Extract 2 shows us that the professionals, in a way, call for standard solutions instead of carefully listening to what the mother really wants. The professionals continue to talk about the house warming party that everyone has when they move away from home as if it is a normal routine. It was far from the mother's expectation that they were using normal standards for her son who was far from fitting into normal standards in his character and attitude. In other words, the professionals lack some relational skills like 'active listening' (Rogers 1951; Eide and Eide 2007). The dialogues are characterized by different understandings of reality and that service providing looks like a matter of routine and standard solutions. The professionals were not acting according to Lorentzen (2006, 77): 'Every new situation demands personal, active presence with engagement, responsibility, sensitiveness, and awareness of the particular situation. The responsibility should cover both the actual and unique situation and the unique person one is interacting with' [author's translation].

Empathy is not enough

At the end of the meeting, the members of the support group were still discussing the informal network meeting. They understood that they had different points of view

about who should take the initiative to an informal meeting. In a way, through the meeting, the mother understood that she had to take the responsibility herself. Meanwhile she managed to explain *why* it was so important to have this informal meeting before her son moved away from home. The service providers got a new understanding of *the purpose* of the meeting. They understood that the main issue for the mother was to meet persons from Per's network and get really honest answers about their future roles concerning Per.

Extract 3:

> Mother: *I can give you an example from Stovner [A place in Norway, authors comment]. They had a meeting every second week with service providers because there was a lot of things to discuss about family, brothers and sisters and so on. But we don't really need this. But therefore I was thinking; how do I get people involved so they can feel free to be honest to refuse and feel free to admit that they would not participate in Per's future network. Do you think they would be honest with me?*
> Professional B: *I think they will be honest with you.*
> Professional A: *No. I'm not quite sure. If I were your best friend and you wanted me to be a part of Per's future network, I would be afraid of hurting your feelings, so perhaps I would go for something that I don't really want because it will be too much for me.*
> Mother: *Yes mmm.*
> Professional A: *It's not certain that I would say no directly. But I'm sure it will hurt your feelings.*
> Mother: *No, I want this kind of conversation: Directly asking: What kind of role can you play?*
> Professional B: *Wouldn't it be obvious because you already know who is visiting him today?*
> Professional A: *I think of the first meeting …*
> Mother: *I was thinking of an informal meeting, but that someone else could arrange and lead the meeting. Put the cards on the table and ask directly: What do you mean? Like that. Of course I can give the student the challenge.*

In Extract 3, the professionals have still not taken responsibility for action. Nobody has taken leadership towards the future network meeting. In particular, Professional A seems to have a clearer understanding for what the mother really means and thinks. Professional A tries to enter the mother's perspective by following her feelings and her anxiety for Per's network in the future. She even goes so far in empathise that she says: *If I were your best friend …, then I will at the same time be afraid of hurting your feelings …*

Interpreting this extract, I find that one of the professionals changes her position at the end of the meeting. I notice more empathy as she even took the position of best friend of the mother. In an external way, this can look very empathetic. But as we can see, the mother did not respond with appreciation. She hardly noticed it and continued to ask for action and responsibility from her perspective. This is an interesting observation. It shows that empathy is not enough to construct common meaning and to reach a common solution. Empathic attitudes by the professionals are not enough if you cannot bring forward expectations in the future of important changes. Sudman (2006) characterized this kind of empathy as 'sugar coating' and that it turns too sticky.

Lack of action and responsibility or shared decision-making?

In these analyses of the dialogue in the support group I found a lack of relational skills by the professionals and different understandings of reality. We can see some mark of service-provision as a matter of routine and standard solutions.

There is a breakdown in the dialogue between the mother and the providers in the middle of the meeting. (Extract 2) They act from different perspectives and are not really on the same 'channel'. The mother asks the professionals to be more responsible for Per's network in the future. They are not eager to attend and have different issues and perspectives to contribute instead of dealing with the practical aspects that the mother outlines. In a way I can say that the professionals are not clever enough to create relationships that promote common understanding and good interaction with the mother. Their communication is not based on shared decision-making and in the spirit of shared ownership (Mead and Bower 2000).

What about the empowerment of the mother? She wanted to be free of the responsibility of arranging the first network-meeting and asked very clearly the professionals to be accountable. However, they refused to arrange it by themselves. At first glance I interpret this as an escape from responsibility by the professionals, but we can also look at it as an attempt to share some responsibility and decisions with the mother. On the other hand we can identify the classical dilemma by the professionals to give enough support or to take the full responsibility when it is needed.

At the same time this leads to the discussion about how to empower people and let them be their own architects to solve their own problems with assistance from the service-providers. Hernes (2002) talks about professional users and modern providers. The new kind of users, with great knowledge and expectations, are a resource and could be used to make the services much better with higher quality. The traditional asymmetry between the user and the public service provider is moving towards a more equal relationship. Professional users can, as Hernes (2002) describes it, create a learning environment where the providers and the parents are learning *from* and *with* each other. They can create a common understanding instead of having different understandings of the child's reality. In Extract 3 we can see some moves from both the mother and Professional A towards a common understanding of the *intention* of the informal network meeting. The dialogue between the service provider and the mother created a common understanding in this particular issue.

When analyzing the conversations in Extract 2 and Extract 3 in the light of terms like empowerment, shared ownership, and partnership (Dale 1996; Askheim 2003; Askheim and Starrin 2007), this paradigm will influence both the role of the professionals and the service users (in this context the mother). The professionals need to involve the users closely in decisions, treatment, or management and need to take a person-centred approach, which means to understand the user in a wider context, as a private citizen. The users need to be recognized in accordance with their perceptions, values, social, and psychological circumstances (Askham and Chisholm 2006). This paradigm indicates several dilemmas and both the professionals and the users demand strong consciousness about roles and practices.

Modern helpers, like Fossestøl et al. (2004) describes it, have to understand the needs of the Other, but need also a consciousness of their own role as professionals in a paradigm of family empowerment. That means that in addition to their specialized

professional competence they need relational competence. Relational competence can be described as making the dialogue in a spirit of shared ownership by using more specific communication skills like 'active listening', open questioning, regular reflection, and very open-minded and inquisitive behaviour (Bae 1992; Bae and Waastad 1992; Schibbye 2002; Eide and Eide 2006).

These findings, as mentioned earlier, have the limitation that the analysis is based on data from sequences in *one* particular meeting. Different studies refer to the fact that the professionals are in need of upgrading the value of parental knowledge in many situations. (Dale 1996; Keen 2007) They also bring up the question of user-participation: Who should have the power to have the final say when faced with different understandings of a situation (Backe-Hansen 2001)? Many parents report that they often have not been listened to carefully by the professionals (Lundeby and Tøssebro 2008). The professional dominance is one of the findings in a study from Sweden among 'user-centred' team meetings. They also find that parents have a great influence on topic control (Karlsson and Hyden 2007). It can be noted that in this research the parents have not been included as a representative of the user, and the user himself has been present at the meeting. They confirm in a way the qualitative problems in the relationship between the professionals and the parents of disabled children, especially when it comes to thinking partnership. On the other hand, we have research which tells about parent's meetings with professionals that are embossed with respect and recognition. This relationship is often based on personal chemistry, and the same parents often tell about less respect in earlier meetings with other professionals in the service-system (Lundeby 2008).

Conclusion

The support meeting in this study had the main purpose of bringing forward the processes for a better life for Per. By analyzing dialogues between the mother and the professionals we can see that there is not enough relational competence by the professionals to communicate in an acknowledging way and to recognize the perspectives that the mother brings into the dialogue. Her visions and dreams for her son are not fully respected and honoured by the professionals. They are not acting like partners sharing responsibility and do not create a common understanding about how to organize this network meeting.

This demonstrates that professionals in the empowering paradigm need to improve their professional performance and learn to interact in an acknowledging way with families with disabled children. This also demonstrates reflections about their own attitudes and differences so that professionals are able to create an atmosphere where family members and professionals work together to ensure the best services for the child and the family.

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