

Understanding the parents of children with special needs: collaboration between health, social and education networks

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Abstract

Context In 2003, Quebec's Ministry of Health and Social Services (MSSS) and the Ministry of Education, Recreation and Sports (MELS) concluded the *Agreement for the complementarity of services between the health and social services network and the education network*. The objectives of the current investigation were to evaluate the implementation of this *Agreement* and its impact upon renewal of practices and services, and to investigate the consequences for children with special needs and their families. The specific focus of this article is to describe parents' perspectives regarding the impact of this *Agreement* upon them and their children.

Methods Interviews were conducted with 56 parents of children with disabilities, social maladjustment or learning difficulties across the province of Quebec. Data were analysed using content analysis.

Results Most parents were not directly aware of any contact between school staff and health or social professionals, although discussions might have been held without their knowledge. The intervention plans seemed to be the main vehicle through which some parents perceived collaboration to be occurring. For parents, the impact upon actual practices or collaborative work is either minimal or non-existent.

Conclusion School inclusion of children with special needs is a challenge for all societies. The *Agreement* illustrates the Quebec government's intent to promote an alliance between two complex networks and has the potential to greatly benefit children and their families. However, more concrete action is required in order to realize specific changes regarding work cohesion and service organization for these groups.

Keywords

co-ordinated services, parents, partnership, professionals, school

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Introduction

In the province of Quebec (Canada), about 163 000 school-age children with disabilities, social maladjustment or learning difficulties were identified in 2010 (Journet 2010). In this jurisdiction, education policy favours the attendance by children and youths with special needs at their regular neighbourhood schools in an inclusive setting where they learn with typically developing peers. However, when it is determined that students

are unable to receive educational services within regular schools that adequately meet their abilities and needs, some different options, including education in a special (non-mainstream) school, may be preferred (Ministère de l'Éducation, du Loisir et du Sport 2007).

A considerable number of school-aged children with special needs also receive services from the health and social services network. Since 1974, formal collaboration has existed in Quebec between the education, and health and social services networks.

In 2003, a renewed partnership was established, entitled the *Agreement for the complementarity of services between the health and social services network and the education network* (Ministry of Education 2003). This *Agreement* is applicable to school-aged children but also includes children with disabilities from 4 until 21 years of age and four-year old children who are living in an economically disadvantaged environment.

The *Agreement* was inspired by the general consensus that collaboration between the networks concerned with children's development is the key to offering appropriate services in a timely manner. This collaboration promotes greater dialogue through the definition of common goals as well as better complementarity of services as a result of pooled resources. The *Agreement* is primarily realized by the education network and the health and social services network, which attempt to develop a global vision of the needs of children and their families. By co-ordinating joint projects, all actors involved define specific and common responsibilities to deploy together the resources needed.

Six principles (Ministère de l'Éducation, du Loisir et du Sport & Ministère de la Santé et des Services sociaux 2009) guide the *Agreement*: (1) the child has an active role in his/her development; (2) parents are the primary persons responsible for the development of their child; (3) school is the predominant living and learning environment for youth; (4) school is a major component of the community; (5) provide an adapted response to youths with special needs; (6) develop a continuum of integrated services.

Purpose

The research described in this article was part of a larger investigation that aimed to evaluate the implementation of the *Agreement*, including its effects on practice renewal and service organization in the education network and the health and social network. These findings will be reported in other articles. The current manuscript focuses on parents' perspectives regarding the effects of the *Agreement* on their school-age child and their family. A number of elements relevant to collaborative and cohesion practices have been explored.

Methods

Research design

A survey design, using quantitative and qualitative methodology, was used to collect self-reported data in 2008–2009 from a provincial sample of parents living with their children. The

research ethics committee of the *Institut de réadaptation en déficience physique de Québec* approved the study.

Participants

The participants included parents of school-age children with disabilities, social maladjustment or learning difficulties. All of these individuals were French-speaking and were living within one of five regions in the province (Bas-Saint-Laurent, Capitale-Nationale, Chaudière-Appalaches, Montérégie, Montreal). The parents' participation was solicited via schools' administration and parents' associations. Interested participants contacted the research team and received a letter explaining the study and procedures. Parents were subsequently asked to sign a consent form. A time to conduct the interview was planned according to each parent's schedule.

Data collection procedures

The interviews with parents were conducted by telephone or in person at home, depending upon their availability and preference. Regarding their child's situation, participants were asked to describe their perceptions of the collaboration between the education network and the health and social services network. The interviews, which lasted between 30 min to an hour-and-a-half, were audio-taped. Only responses to the open-ended questions were transcribed. Transcriptions were verified twice by different research assistants.

Interview guide

The interviews were conducted in French, in the form of a dialogue, with a focus on parents' experiences involving the school and the health or social system. Recognizing that parents are not systematically informed of collaborative work between ministries, institutions and schools, the interview guide was developed to address the impacts of interagency collaboration without associating it explicitly with the *Agreement*. The interview guide included four sections: (1) child's needs and services; (2) parent's participation in decisions and interventions; (3) parent's evaluation of services provided; and (4) suggestions to improve collaboration or partnership. Examples of questions posed in the interview included: Could you describe how your child functions at home? What is difficult for him/her? Currently, who provides help or support at school for your child? What do they do? What activities are carried out by stakeholders at school and those from the health network (rehabilitation and social services) to achieve a common vision of your child's

needs? As well, parents were asked about their level of satisfaction concerning different situations. Items to be rated included, for example: the opportunity to communicate child's needs; involvement in discussions related to services; complementarity of services.

The participants also completed a short questionnaire regarding the child's characteristics (gender, age, grade, type of attended school, principal diagnosis). Information regarding the participant's own situation was requested, for example, level of education, employment status and the number of children in the family.

Data analysis

The content analysis was realized in two phases. First, responses to open-ended questions were transcribed and coded using a template analysis approach (Denzin & Lincoln 2005). Deductive analysis was guided by a coding scheme. Second, the interpretation and search for meaningful themes was guided by Giddens's (1984) Structuration Theory. The focus was upon the understanding of the *Agreement* and the individuals' motivation to explore their own situation.

Structuration Theory supposes that human social actors are always knowledgeable, to some degree, of what they do, why they are doing it, and in what context their actions take place. The duality of structure is the principal unit of this theory; it has both a structural and an agency component, which are inextricably intertwined. On the one hand, the structural properties guide and constrain individual behaviours by establishing conventions that people follow (e.g. rules related to educational or health services' access). On the other hand, these structures also provide resources used to accomplish goals (e.g. *Agreement* that promotes cohesion between networks). The agency component refers to the capability of social actors to act in the world, and to do otherwise than that proposed by the structure. Consequently to the changes in their understanding of activities and structural conditions, social actors modulate their actions (Giddens & Pierson 1998); they can either conform to the rules and constraints or act beyond conventions and take power over their situation (e.g. regarding the services the child receives). Giddens emphasized the importance of power. It is by acting, by mobilizing the rules and resources that actors construct, maintain and transform the conditions of their actions. This research permitted to cultivate the reflexivity of actors on their opportunities and their ability to act, which is their true power.

Consistent with qualitative inquiry, several criteria were adhered to in order to create authenticity in this investigation, for example, audio taping/verbatim transcription for content accu-

racy and participants' actual quotations (translated from French to English) to provide thick description of their experiences.

Findings

Participant characteristics

Fifty-six parents were interviewed (Mothers: $n = 49$; Fathers: $n = 5$; Foster parents: $n = 2$). Six (10.7%) participants had more than one child with special needs. The schooling situation of the 60 pupils was documented; it should be noted that two other children of the participants were not in school at that time. Boys ($n = 39$, 65.0%) were more represented than girls ($n = 21$, 35.0%). The principal diagnosis varied, with a predominance of children presenting a Pervasive Developmental Disorder ($n = 21$, 35.0%). Forty-nine pupils (81.7%) were attending a regular primary or high school, 10 (16.7%) were attending a special school and one (1.7%) was in CEGEP (college). Students in regular settings were either in a regular ($n = 26$, 43.3%) or a special class ($n = 23$, 38.3%) within the neighbourhood school. Among these, 32 children (53.3%) were in primary school and 17 (28.3%) were in high school.

A number of parents reported being involved in consultative committees that focus upon the interests of students with disabilities and other special needs. Each School Board has such a committee that includes representatives of designated parents, as well as the school principal and individuals representing teachers, school staff and organizations that provide services to those children. These consultative committees formulate opinions addressed to the School Board regarding the organization of educational services for children with disabilities and other special needs.

Parents' perception of the impact of the *Agreement* on children and families

Five principal themes emerged regarding the impact of the *Agreement* upon children and families.

Always searching (and fighting) for services

The parents of primary school-aged children indicated that they did not have enough support in looking for services, especially at the beginning of their search process. Participants would appreciate receiving information about services at the time of the medical investigations as well as once their child is diagnosed. This information could be general in nature regarding

existing services or precise contact information in order to access services. Parents typically received this information only after months of being on a waiting list. Accordingly, having a diagnosis for one's child is a key element to gaining access to services. One mother explained how important it was to her to obtain the right information:

That document, had I had it eight months ago, would almost have saved my life. I would have known where to go to get help. There is a lot of information that I did not have, but which was available in [the document].

Participants expressed that most of the time they do not know how to access services, having to cope with, for example, different sets of rules and procedures depending on the network or the institution. They lacked information about what they described as a complex system and in that respect, they felt isolated. As one mother reported, *'I feel like I'm still all alone in the boat and that I must, by myself, find what my child needs'*.

For the most part, it is a continuous battle to obtain services each year, especially in regular school settings. As one parent described, *'I feel that I have to beg to get services. Nothing is offered to me, ever'*.

Regarding the high school level, most participants stipulated that some needs are neglected. They emphasized that few services are offered in order to prepare students for the transition between primary and high school, for changes throughout adolescence and for the transition to adulthood. There seems to be a lack of resources to help students develop their social abilities. Sexual education was also a concern. One parent described some life choices he made to offer the best environment possible for his son: *'It was the second or third time that I moved so he could attend a school where there were appropriate services'*. A considerable number of parents reported wanting their neighbourhood high school to provide access to more services, for example, psychology, speech therapy and remedial instruction.

Unaware of collaboration practices

Parents expressed a lack of knowledge about how stakeholders of both networks collaborate with each other. Few participants were directly aware of any contact between school staff and rehabilitation or health professionals. It was difficult to identify examples of joint work involving school staff and professionals from health and social services, although stakeholders might have had discussions without their knowledge. Accordingly, about half the participants believed there were existing collaborative practices. As one parent indicated, *'There must be*

collaboration between school staff and health professionals, but I am not aware of it. They do not tell me'.

Examples of collaboration mechanisms between networks and ways to engage parents through decision making process often reflected similar actions. As schools and health and social services institutions are obliged to prepare an intervention plan for each child with disabilities and other special needs, parents identified this method as the most common collaborative tool through which they become involved. These plans are intended to identify the youth's needs, to set objectives and define the means for their realization. This approach aims to organize an adapted intervention, which can include collaboration between networks. Given the *Agreement's* principles, co-ordination of services is an important priority for both networks. Intervention plans from the two sides should be coherent and share objectives. However, the present research findings suggest that parents and children are not systematically invited to participate in planning meetings. Some of those parents who were interviewed expressed concerns about their lack of opportunity to contribute to the decision making process.

Only 26.7% ($n = 16$) of participants agreed that the network's intervention plans were harmonized and targeting similar goals. On the one hand, some parents witnessed joint work through the intervention plan meetings. For example, some parents mentioned observations that were made of their child's behaviours, in class, by health or social services professionals; these observations were identified as examples of collaborative practices. On the other hand, parents stated that most stakeholders were not involved in any or enough team work through intervention plans or other means. Many of them believed that this situation was mostly due to resource limitations. The point was also made that collaboration practices depend on the opportunity to meet, but also on stakeholders' willingness to accept the points of view and involvement of others. One parent specified that not only should stakeholders communicate more but that their co-ordinators should also contribute to making it possible for them. Although some schools or health and social services institutions are more proactive, others seem more reluctant to share responsibilities. Quantitative data indicated that satisfaction levels concerning this aspect were rather low: 60% ($n = 37$) of interviewed parents thought that collaborative work was inexistent or insufficient. In a similar vein, parents considered that if they want something achieved, they are obliged to motivate both networks to put in place the best services possible for their child. For example, it is often only by their initiative to invite the social worker that collaborative action is possible: *'I realize now that if parents do not get involved, the situation does not evolve much'*.

Table 1. Parents' level of satisfaction regarding services offered by both networks for each child ($n = 60$)

	Do not know		Very dissatisfied		Fairly dissatisfied		Fairly satisfied		Very satisfied	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Identification of the child's needs by stakeholders	–	–	4	6.7	19	31.7	25	41.7	12	20.0
Clarity of stakeholders' roles	–	–	7	11.7	17	28.3	19	31.7	17	28.3
Complementarity of services from both networks	7	11.7	23	38.3	14	25.0	8	13.3	7	11.7
Collaboration between school staff and health professionals	5	8.3	18	30.0	19	31.7	12	20.0	6	10.0

With respect to the impact of the collaborative practices on children, most participants did not witness sufficient results from co-ordinated actions to be able to identify specific outcomes. They suggested that more concrete and realistic interventions are necessary. Some participants reported that the intervention plan meetings enabled them to express their opinions and to make requests, while others declared they were not able to discuss the goals of the plan. For example, some informants mentioned that the objectives of the individualized education plan were determined in advance prior to their arrival at the meeting; they were simply asked to sign the plan without discussion. These parents perceived unwillingness from stakeholders of the two networks to integrate them in planning procedures. For a majority of parents, involvement in the decision making about their child is a major priority.

More than half of the parents interviewed were not satisfied with the complementarity of services across the networks (Table 1). The majority were dissatisfied with the collaboration between school staff and health professionals. The findings also revealed a range of opinions regarding the clarity of stakeholders' roles.

Parents caught between two networks

Most parents noted both networks' tendency to *pass the buck* regarding problems with services, avoiding taking responsibility and arguing that the obligation is not theirs. In a similar vein, the roles of stakeholders from the two networks are not always clearly defined, which is in itself an obstacle to collaboration. Many parents found themselves caught in the middle, having the burden of transferring the information from one network to the other. In this context, another parent indicated that it would be helpful for families and children to have people from the two networks collaborating:

I believe that if the health environment and the school environment work together, it would be a plus for the families and the children as well. It's so unpleasant to be in between two things that are opposing each other.

However, it should be noted that some participants, like this father, are at peace with the role they have to play: *'The parent should be the coach of everyone who works with children and also the motivator'*.

A considerable number of parents, referring to their experiences with primary and high schools, declared that support from stakeholders of the health and social services network is insufficient and that they mostly have to take the steps by themselves, without any help. However, some participants whose children are in high school reported they were supported when they made precise requests. On the other hand, parents of youth who are reaching adult age find themselves in an urgent situation; in their view, nobody seems to assume the role of providing services for young adults with disabilities. The discontinuity in services gave those parents the impression that they constantly have to fight to obtain and keep the services that their children require.

Different settings mean different types of support available

Many parents reported that complementary services were more readily available in special schools than in mainstream schools. This is perhaps not surprising, considering that rehabilitation professionals already work on-site and that their services are co-ordinated by the school principal. One parent alluded to the ease of access to services:

It [resource allocation] is automatic because they [children] have heavy issues. As soon as a child enters the school, he gets a lot of resources on site.

In this context, parents also appreciated the stability and continuity of services for their child. However, a few parents whose children attended a regular primary school reported that they had been supported by health and social services stakeholders to assure services at school. Two parents revealed the helpful aspects of being supported by the health and social services network:

There is no doubt that the support of the rehabilitation center helps a lot to make our case. When things are

explained by a professional, sometimes it works better or arguments are better heard. Knowing we have the center's support also helps us to express ourselves more. It feels good to know that we are not alone in our battles.

From the moment I was supported by these people, it was seen that I was serious, that there was no means of telling me to calm me down or try to push me in a corner any more.

Urgency of finding appropriate services corresponding to the needs of children

For informants, various services did not correspond to the needs of their child; the lack of cooperation between the two networks was part of the problem. Some services were not available while others were duplicated. One parent describes the situation:

When [children] reach school-age, when they get in first grade, services are cut off. We were told that the school must provide services, but at school, they do not have speech therapy and occupational therapy, so we lost everything. From that moment on, my daughter did not receive any service.

Children sometimes received the same service twice, provided by different organizations. While parents believed that teamwork takes place between the two networks, most concluded that services were not ultimately improved. Participants insisted that stakeholders, in partnership, should offer services that better meet their children's needs.

Discussion

The purpose of this study was to explore parents' perceptions regarding collaborative practices between the education network and the health and social services network in Quebec, within the framework of the 2003 *Agreement* that was developed to promote complementary services. The major findings suggest that families did not benefit much from the policy, believing that the outcomes of collaborative practices among the school and the health and social professionals were not very noticeable. Those limited effects of shared responsibilities towards children with disabilities have been previously observed by Carter (2010) and Elkins and colleagues (2003). The publication of partnership programs is not necessarily followed by the allocation of necessary resources (Bhagat 2007). Other authors also have noted the challenges of multi-agency working and remind profes-

sionals that it is not easily achieved (Atkinson *et al.* 2005). To our knowledge, the *Agreement* is one of only a handful of inter-departmental attempts to establish formal collaborative practices meant to promote all children's development, including those with special needs (Department of Education & Department of Health, Social Services and Public Safety 2006; Ministry of Health 2008). These joint actions, despite their limited application to date, are necessary as they aim to address complex problems that cannot be resolved within separate networks. This objective is congruent with the observation by some participants in the present investigation that in certain specific contexts, motivated stakeholders were successfully able to realize their good intentions in concrete, small-scale collaborative systems that functioned. Nicholson and colleagues (2000) concluded that organizations have opportunities to support partnership by offering an environment that is conducive to collaborative work, although most joint actions rely on individuals. Given that the co-ordination of action with partners may not necessarily come naturally to professionals, it is not surprising that additional effort is required to provide a more integrated response to the most complex needs of children with disabilities, social maladjustment or learning difficulties. The complexity of the two networks also must be acknowledged (Green 2006).

One important finding of this investigation is that the education of children with special needs must be addressed with the participation of both networks. These networks have complementary knowledge and they agree that it should be shared. They need not only to exchange information, but also to develop common projects with the participation of parents. These changes paired with new ways of working together are encouraged by the *Agreement*.

More extensive research is required to explore new ways to involve families in the process of interagency collaboration. It is also essential to solicit youths' point of view (Gordon 2010). They must be fully engaged in the planning, and their needs, wishes and aspirations must be taken into account (McConachie *et al.* 2011).

Limitations of the study

Some methodological considerations may limit generalization of the findings. The study sample was small and the participants were selected based on convenience sampling procedures. Consequently, the sampling may not be representative of all parents of children with special needs. Another limitation concerns the difficulty of evaluating the situation in different regions of the province of Quebec, considering that each school functions as a microsystem with its own internal rules and resources. As well,

the diversity of service organizations is so broad across the province that it can be difficult to collect opinions concerning all types of situations. Despite these limitations, this study is the first to examine the *Agreement* with respect to parents' perspectives.

Conclusion

Being a parent of a child with special needs can be very challenging. Additional burdens are associated with the beginning of school (Keller & Honig 2004). This investigation's findings suggest that the *Agreement* has the potential to help parents because it promotes the development of links and common objectives between the two networks. Such development is critical to support the education of children and their development process. Furthermore, the findings should encourage all education, social and health professionals to actively work with common goals. Informing parents of available services and inviting them to actively join the discussions should be considered. The investigation reveals that parents are important actors in the development of children with special needs. They are motivated in different ways to create alliances with professionals. This *Agreement* is unique and provides guidelines to support collaborative practice between two networks, including parents and children.

Key messages

- The education of children with special needs must be addressed with the participation of both the education network and the health and social services network.
- Most participants did not witness sufficient results from co-ordinated actions to identify specific outcomes.
- Additional effort is required to provide a more integrated response to the most complex needs of children with disabilities, social maladjustment or learning difficulties.

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