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Collaboration for children with complex needs: What adolescents, parents, and practitioners tell us

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Abstract

Children with complex needs require coordinated care and collaboration between the different sectors in child mental health care. These needs and service issues are individually defined and therefore challenging for the mental health system to respond effectively. Different barriers at the organizational and policy level to initiate and maintain collaborative relationships are reported. This research explores the reality of working with a protocol for collaboration (Client Network Consultation (CNC)) by questioning the experiences of adolescents, parents, and practitioners. A qualitative design with semistructured individual interviews is used, guided by the questions from the Wraparound Fidelity Index. Useful and practical insights on effective collaboration result from the in-depth analysis of the interviews. A neutral chairperson, the presence of specialist practitioners, visualization, participation of adolescents, and parents are among the effective elements reported. Some challenges remain; the principle of equality, monitoring the action points resulting from the collaboration and effective crisis management seem very difficult to fully achieve in practice. These results present experiences from adolescents, parents, and practitioners to support an effective collaborative process for working together with children and families with complex needs.

Keywords

Adolescents' and parents' perspectives, child and adolescent mental health, complex care, collaboration, qualitative approaches

Introduction

Children with multiple complex needs (MCNs) include a diverse population. These children experience multiple and interrelated challenges, medical problems including mental health disorders, and social, educational, and relationship problems (Cohen et al., 2011; Rosengard et al., 2007). The essence of complexity can be described by the multitude of needs and their inter-connection and/or by the severity or intensity of the needs (Rankin and Regan, 2004). These needs require support from more than one agency bringing them into contact with a wide range of professionals, services, and sectors (Brooks et al., 2012).

Interagency collaboration and coordination are important objectives for the health-care system, especially for children with MCN. The need for a 'seamless web' of care treatment and support is evident but difficult to achieve (Carter et al., 2007). Numerous reports describe the advantages of collaboration within the context of health and welfare services: faster access to mental health care, better service coordination, shared knowledge, enhancement of creativity and problem-solving, and improved children's mental health outcomes (Chuang and Wells, 2010; Dagenais et al., 2008; McLean, 2012; Osofsky and Lieberman, 2010). However, effective interagency working remains a challenge. Different barriers to initiating and maintaining collaborative relationships are reported: a lack of information on services available, a lack of knowledge about the role of practitioners in the other agency, confidentiality policies and practices vary across agencies, and the absence of effective liaison structures and guidelines (Darlington and Feeney, 2008).

The practitioners' characteristics and requirements at the organizational and policy level are frequently explored to achieve successful on-going collaboration (Darlington et al., 2004). Meanwhile, research that actually explores the reality of working collaboratively specific to children with MCN and their family is rather scarce. Abbott et al. (2005) report the impact on professionals of working in a multi-agency service. The study of Carter et al. (2007) explores the experiences of families and professionals working with children with MCN and results in best practice statements in multi-agency working. In exploring its effectiveness in practice, collaboration needs to be seen as a process as well as an outcome. Diverse stakeholders need to be asked to acquire a holistic picture (El Ansari et al., 2001).

In Belgium, practitioners expressed the need for a formal procedure concerning interagency collaboration with family involvement for children with MCN and their families. A shared vision and a common value base are essential components to realize a collaborative effort (Gittell et al., 2013; Grace et al., 2017). The practitioners mentioned different basic elements: (1) procedures to guide the planning and implementation of a collaborative care trajectory built around the needs of the child and its family and (2) relevant, achievable in daily practice and accessible for children, parents, and practitioners from different settings/sectors.

These elements require a person- and family-centered approach to put the needs of the child and the family central (Barry and Edgman-Levitan, 2012; Walter and Petr, 2000). Family-centered values and involvement of consumers in all stages of mental health-care service delivery offer the best hope to improve outcomes for children and families (Kuhlthau et al., 2011). Shared decision-making can also ensure that care better aligns with clients' preferences and values (Lee and Emanuel, 2013; Pickering and Busse, 2010). To guide the planning of a collaborative care trajectory, a solution-focused approach can increase positive affect; self-efficacy and can help set goals for the future (Grant and O'Connor, 2010).

The Wraparound principles also address these elements: care should be strengths based, culturally competent, and organized around the family members' own perceptions of their needs and goals (Burns and Goldman, 1999). The Wraparound process is a method for individualizing and coordinating the services and support provided for children and their families (Walker et al., 2008). Different advantages are linked to Wraparound: more engagement of families; development of self-efficacy, empowerment, and self-determination; a better fit between family needs and services; more frequent problem-solving and continuity of care (Bruns et al., 2010); and improvement of children's day-to-day functioning (Kazi et al., 2011; Painter, 2012).

A protocol, which focuses on family-centered care, shared decision-making and setting goals, was developed using the Wraparound principles as a framework (Walker et al., 2004) to create opportunities to collaborate and to structure interdisciplinary meetings with children, parents, informal support figures, and practitioners. The protocol, named a Client Network Consultation (CNC), is implemented in practice since 2012. The different steps in the CNC protocol are described in Table 1.

Table 1. Overview protocol CNC.

Preparation	Preparatory conversation: with child, parents, and practitioner who presented the case:
	<ul style="list-style-type: none"> – Information exchange about the CNC – An overview is made: participants to invite, present strengths, needs, cultural values, current and/or past support – The presence of certain specialist practitioners based on the indicated needs/priorities is requested
CNC	Structure: The chairperson questions the child first, next the parent(s) are questioned, and finally the practitioners. The other people present can ask questions for clarification.
Introduction	The chairperson clarifies the goals and basic rules (deontology, equality, rights child/parents).
Overview strengths	The CNC participants identify the strengths of the child and its family.
Overview needs	Next they describe and prioritize the difficulties, safety needs, and concerns.
Overview goals	The goals, associated outcomes, and progress indicators are determined.

<i>Actions</i>	Action steps are assigned situated within the following domains: Child-centered care, support environment (parents, family, school), crisis plan, and care environment of the child
<i>Individualized care plan & care team</i>	The actions chosen are specified in clear appointments (who does what and when). The participants receive a report from the chairperson.
<i>Care manager</i>	Nomination of a care manager with the mandate to: <ul style="list-style-type: none"> – Follow-up of the care plan and the agreements – Indicate team members' responsibilities The care plan is implemented into practice.
Implementation	The progress is reviewed and changes can be made.

Practitioners from the different sectors within youth mental health care (child welfare, child psychiatry, disability care, and school counselling) were able to sign up complex cases (typically when current care was unclear, fragmented, and reached a deadlock).

The CNC process brings child, parents, support figures from the family's network and practitioners together. It creates a clear overview of the present strengths and needs of the child and the family and monitors evolutions. The CNC follows a distinct planning process to create an initial plan of care, to unite a care team, and to implement this care plan into practice.

The CNC takes place in a neutral environment. An independent and trained chairperson moderates the consultation and guards the ground rules. Specialist practitioners from different disciplines may be invited based on the indicated needs/priorities. The specialist practitioners have a supportive and guiding role resulting from their field of expertise. The family's perspectives get priority and the team keeps an open mind to develop creative strategies.

The focus of this study is on the reality of working together for (and with) children and families with MCN and on the present conditions that guide care. A qualitative study using semistructured interviews explored the experiences of the adolescents, parents, and practitioners in depth by questioning the efficiency of a protocol for interagency collaboration and by exploring topics that seem self-evident and connecting them to the Wraparound principles. The research questions were 'How do adolescents, parents and practitioners experience collaboration during CNC?' and 'Which elements support an effective collaborative process according to adolescents, parents and practitioners?'

Method

Design

The content of the interviews provides information about each participant's experience. The Wraparound Fidelity Index (WFI-4; Bruns et al., 2004) guided the semistructured individual interviews to assess the quality of individualized care planning and management inherent to the Wraparound principles (see Online Supplementary Material for the interview questions).

Selection of participants

Adolescents, parents, and practitioners from the same case were asked for the interview. In one case, the practitioner changed jobs and could not be contacted. Two adolescents were not interviewed because their parents did not give consent referring to the adolescents' personal problems.

Characteristics of participants

In total, four adolescents (two male and two female, ages one 13-year old, one 15-year old, and two 17-year olds), five mothers, two grandmothers, and five practitioners were interviewed. The interviews took place on a location of the participants' choice. The participation during CNC was the inclusion criteria.

Ethical considerations

This study protocol received the approval of the Commission for Medical Ethics of the University of Antwerp. The participants received a phone call from the researcher, explaining the rationale behind their involvement. Participation was voluntary. Informed consent (from parents and adolescents) was retrieved before the interview took place.

Compliance with ethical standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Data collection

Fourteen face-to-face interviews were conducted by the same researcher. During one interview, both mother and daughter were interviewed together (on the adolescent's request) and two other interviews took place with mother and grandmother (both participated during CNC). Audiotapes were transcribed verbatim.

Data analysis

Two researchers independently analyzed the transcripts to create a wider analytic space using systematic text condensation (Malterud, 2012). This approach is a descriptive and explorative method for thematic cross-case qualitative analysis. First, an overview of the data is acquired, the researcher reads the full text, and then looks for preliminary themes. Second meaning units are systematically identified and classified; a meaning unit is a text fragment containing some information about the research question. These units are sorted by codes; a code connects related meaning units into a code group. Third each code group is further abstracted by condensation of content. The nuances and different aspects of meaning within a code group are explored and sorted into subgroups. Finally, data are synthesized; descriptions and concepts are developed reflecting the validity and wholeness of their original context (Malterud, 2012).

Results

Three major themes from the interviews, together with verbatim extracts of the participants' contributions, are outlined in this section (adolescent 1/4 A; parent 1/4 P; and practitioner 1/4 PC). The participants report different challenges to pursue equal partnership. Secondly, advantages and difficulties of the CNC protocol are mentioned. Thirdly, monitoring of agreements and decision-making is an important theme.

Equal partnership

The data reveal an imbalance between adolescents, parents, and practitioners concerning the perception of a thorough and equal preparation. Information exchange and the invitation of persons to a CNC are subthemes.

Information exchange. Adolescents and parents report a limited or absent preparation. They also report an incomplete or incorrect explanation about the CNC. Adolescents say they are informed late about the meeting. All these things make it more difficult for them to contribute during CNC. Also the parents mention a lack of information as discouraging. They express concerns about the consequences of the CNC and about the people present. According to the parents, some practitioners are unfamiliar with the process and could not give a full explanation. One parent suggests letting a neutral person familiar with the CNC do the preparatory conversation.

No they did not prepare the meeting with me . . . My social worker said we have a CNC, but she said no more than that. (A2)

Until the moment of the CNC I did not know what it would mean . . . I can image that many people would be discouraged to participate when they have questions like: what is it, can they take my child away.... (P3)

Practitioners report an adequate preparation. When the practitioner has insufficient knowledge, they inform themselves about CNC. The practitioners indicate the importance of a person close to the family doing the preparation. Some practitioners state that difficulties in guidance hinder a proper preparation.

There was a preparation with the mother. I do not know if there was enough space for the daughter'. Interviewer: 'Was this a choice to focus on the parent?' It was difficult with the youngster; her guidance was difficult. (PC3)

CNC invitation. The adolescents report that they had no say in the selection of the people present. The parents report that they could suggest CNC participants, but they feel that a great deal was already decided by the practitioners.

In most cases, the practitioners seem to select the persons present and the parents give their consent. According to the practitioners, most people are motivated to participate.

The majority of the CNC participants are professionals. One parent says she did not invite friends or family members because they do not understand their problems. Practitioners say it is difficult to involve the informal network; it only succeeds when the parent takes the initiative.

It was meaningful because suddenly there were a few people, a friend of the mother and a former foster mother, we were not able to reach during a year of guiding this family. (PC3)

A protocol for active collaboration

The presence of the adolescent and the parents during CNC is perceived both positive and challenging for practitioners. Also, the presence of different practitioners is perceived as a duality for adolescents and parents. Furthermore, the participants discuss the different elements of the CNC protocol.

The presence of adolescents, parents, and practitioners. Adolescents report that the presence of a lot of unknown people makes them uncomfortable. The parents experience it as positive that a lot of people participate, including the presence of specialist practitioners. The practitioners state that the specialist practitioners contribute by their neutral position and their distance to the family. As a result, practitioners involved seem to let go of their history with the family.

Interviewer: 'Did they ask your opinion?' 'Yes, but I thought it was stupid. There were a lot of people I did not know and it bothered me'. (A3)

I felt supported; the specialist practitioners also said give this mother and daughter the chance to live together. (P3)

Adolescents and parents report that everyone present listened, that their opinion was asked and also taken into account. The different interviewees report equality during CNC. One parent assumes that the practitioners can better formulate the family's needs.

Interviewer: 'Was your opinion important to the people present?' 'I think so, we already worked with a lot of people and they know where we came from and where we are now. So, they could formulate it better than us'. (P5)

Adolescents and parents say that decisions are made in their presence. Both a parent and a practitioner mention that the adolescent dared to say more during CNC than during other consultations, where they seemed more on their guard. Practitioners mention that they talk differently when clients are present; it seems more difficult to talk overtly.

I think I had to be present, because they did not want to take decisions without me. If they would decide things behind my back, I would be very angry and I would make it very difficult. (A3)

X collaborated very well; the practitioner from juvenile court also mentioned this. When we have to go to juvenile court, he acts as a big, tiresome child. (P2)

Other practitioners want to hear arguments I cannot give; it is not appropriate, the client does not need to hear this. (PC1)

The practitioners mention that during CNC more attention, respect, and space are present for the clients than during a regular meeting. By organizing a CNC you also seek support as a practitioner; to call over other professionals sometimes seems to feel uneasy.

To discuss your guidance in the presence of the specialist practitioners feels intrusive. It feels unpleasant; asking for assistance as a practitioner is like considering your professionalism. (PC3)

The CNC protocol. From their point of view, the participants discuss several conditions facilitating a CNC. The parents and the practitioners describe the chairperson as important. The chairperson monitors that all participants can contribute equally in the decision-making process. The parents and the practitioners mention that the visualization, by writing everything down on a flow chart, is helpful to get an overview. The practitioners use understandable language or try to explain difficult words according to the adolescents and the parents. The parents say it is important to take enough time for the consultation, whereas the adolescents report that it is not easy to sit still for such a long time.

According to the different participants attention is given to the strengths and accomplishments. Some adolescents say that hearing these compliments at the beginning of a CNC gives them a good feeling; others want to start with the difficulties and finish with the strengths. Adolescents mention that certain practitioners focus on the difficulties.

It seems unclear how these strengths are implemented into the care planning. Some parents said that things were formulated too positively in the presence of their child and certain difficulties were not emphasized enough. It was confronting for the adolescents to hear these difficulties. The practitioners say that a strength-based approach gives parents responsibilities and opportunities. A belief in the parents and the adolescents is pronounced. During CNC, the chairperson and the protocol help to see the positive things again, practitioners report a previous focus on the negative when guidance was inhibited.

I think it would be better to finish with [the strengths], because now you end with the negative things. (A3)

First you had to say positive things, so X could hear that he had a lot more positive than negative characteristics. (P4)

According to the different interviewees everyone can propose solutions and strategies. Adolescents and parents say that hobbies and ways to get the adolescent involved in the community are discussed, but practical limitations seem to obstruct this, for example, distance, financial reasons.

In some cases, the focus during planning seems to be program directed, namely looking for placement. With this goal as a starting point you can't make progress without certain resources. Some practitioners say that in this case a CNC has no added value. Others state that a CNC can help adolescents in accepting placement because they hear the reasoning of the practitioners. A practitioner comments that organizing extra CNCs gives adolescents room to discuss care plans and that they will keep focusing on their wish to go home. It is unclear whether the plan of the family has the full support.

I am glad we tried their [1/4family] solution first. So they could see we tried and it did not succeed. Not because we did not want it, but because we couldn't manage. It made the transfer to residential care easier. (PC1)

Most practitioners report the presence of enough resources to get the support needed. In one case, the mother said that her son's solution was actually the best one, but it seemed unrealistic. Adolescents and parents mention that the care plan often lacks concrete strategies.

My son suggested staying at a farm where he could work.' (P6) Interviewer: 'Which solution would you choose as a mother?' 'Something like that, but he needs something very specific according to his problems. (P6)

The parents and the practitioners mention that not all team members have a role in implementing the plan. The practitioners also mention difficulties dividing tasks and responsibilities. By delegating they report the feeling as pushing off tasks.

Initially nobody responded, but the chairperson insisted that someone took on one task, someone an other and so on. It was a difficult moment for me, I asked myself: what will happen, what now? Finally they took on the different tasks. (P1)

According to the different respondents, past crisis situations are not analyzed and crises are responded to when they occur. When the parent reported the presence of a plan for crisis the adolescent stayed in a secured, residential setting. Residential settings for the adolescent or the parents managing the situation at home are the solutions proposed to a crisis. Practitioners mention no need for a plan when they experience a good collaboration with the family.

Some families are satisfied with the outcome of a CNC as the care plan meets their needs. Others are positive about the course of the CNC but report a lack of concrete solutions.

I already had guidance for over a year, and I learned more during those two CNCs. From that moment on it all went more positively. (P3)

Monitoring of agreements

Almost all participants say that they received a report after CNC with goals and agreements. In some cases, these agreements are experienced as unclear or insufficient. The parents and the adolescents mainly report a lack of clarity about further monitoring.

There were agreements, but...no clear plan for the future, this was very difficult for my son. He expected this clarity.(P1)

The practitioners describe the follow-up of agreements as a tough assignment. Some practitioners say they felt pressured to take on the role of care manager. They perceive this as part of their job but don't have the time and means to fully carry out this task.

Most of the time I [counsellor juvenile court] took on the role of care manager. We have the task to coordinate, but we don't have the time to contact everyone involved. (PC5)

It is not clear how practitioners decide that a family is ready to move away from formal support systems. In some cases, the practitioners mention that their possibilities ended (e.g. because of age, duration of guidance) and the parents still report a need for monitoring. In other cases, practitioners seem to doubt the chance of success without guidance and adolescents and parents report no need for further assistance.

The respondents generally stick to the first care plan and little new ideas are considered. To pass on tasks to new CNC participants is motivated by the feeling that the practitioner already tried out every possibility or by a difficult collaboration with other practitioners involved. Parents believe that care can 're-start' when they need it. Practitioners doubt the added value of another CNC.

I don't know if there will be a next CNC; all those appointments were made by one organisation, they kept everyone together. But now this principal person is gone. I don't know how we will manage. (P5)

We don't have further appointments with the practitioner, I think this means that she has confidence in us. (P3)

Discussion

The analysis of the interviews gives us useful and practical insights on effective collaboration. Three main components are discussed: preparation, active collaboration, and monitoring.

The first component, preparation, seems crucial for the succession of the further components. The parents report a limited preparation; the adolescents report no preparation at all. This lack of information or an incorrect explanation discourages them to fully participate. Generally, the practitioners assumed that their clients received an adequate preparation. The reasons for this imbalance can include adolescents and parents may not understand the information because it is too complex; they may not absorb the information because they are anxious and nervous; they may not believe the information because they do not consider the information or the provider to be credible. To give information effectively and to avoid miscommunication, a range of skills and resources available for the practitioners is needed (Caress, 2003; Mills and Sullivan, 1999).

Some practitioners state that difficulties in guidance hinder a proper preparation. Elements of a thorough preparation mentioned are correct expectations, who to invite, the presence of different practitioners and their roles. Generally, the practitioners select the team members and the parents give their consent. The adolescents and the parents reported that few natural support figures were present during CNC. The absence of social networks can be explained in various ways: logistical difficulties and limited individuals who are able and/or willing to participate (Epstein et al., 2003; Walker and Schutte, 2005). Regardless, a better planning and communication can increase the attendance of informal support (Epstein et al., 2003). In addition, we should also think of family and youth peer support workers. These individuals with lived experience in caring for a child with MCN or lived experience in youth mental health care, can offer social, emotional, and instrumental support (Painter et al., 2011; Repper and Carter, 2011; Santelli et al., 1997).

During a good preparation the values and beliefs of the child and the family need to be questioned, this can strengthen adolescents and parents to give their own opinion during meetings; especially for adolescents, it is important to express themselves among adults. For example, the Wraparound Process User's Guide (Miles et al., 2006) contains a guidebook for the family; this seems useful for any form of collaboration. If adolescents and parents are addressed as partners, they have a right to the same information the practitioners receive.

The CNC as a protocol for active collaboration is helping, but some points of attention remain. The respondents mention several necessary conditions. A neutral chairperson is important to guard the equality between the participants, the protocol, the focus on the strengths, and the vision of adolescents and parents. The presence of the specialist practitioners has an added value, because of their neutral, unattached position that gives them a more objective approach. The fact that the things said are visualized gives the participants a clear overview. After every CNC, the participants received a report; this is important for adolescents and parents as they mention it explicitly.

Next, a few critical comments are in place. The principle of equality seems very difficult to fully achieve. There seems to be an imbalance between the solutions suggested by practitioners and solutions suggested by the adolescent or the parent. A solution from an adolescent is not pursued when the adults perceive it as difficult to realize. The involvement of adolescents and parents during decision-making seems insufficiently implemented in practice, despite the link with improved satisfaction, involvement, and less decisional conflict (Aarhun et al., 2017; Chong et al., 2013; Shay and Lafata, 2015). Practitioners mention hesitations in the presence of the family, namely difficulties to express themselves and not being able or willing to put all information on the table. More client involvement has implications for academic training programs; collaboration skills, intervention techniques that respect and strengthen families, multicultural competence and understanding of child growth and development in a broad sense need to be emphasized (Tracy and Pine, 2000; van Bijlevend et al., 2015). Practitioners' competences need to be kept up-to-date, with supervision and wide organizational support (Secker and Hill, 2002).

The component monitoring seems the most challenging. The final agreements in the plan of care seem unclear for the parents and adolescents as they find it difficult to summarize the concrete elements. Clear goals and a care coordinator are necessary to be able to monitor and divide specific tasks (Bruns et al., 2010). The respondents mention difficulties in dividing the tasks and in following up the agreements. Practitioners seem cautious in collaborating with families and other practitioners, but sometimes they may be too cautious. Most conflicts involve interpersonal concerns and concerns about team member follow-through. Conflicts involving service providers increase the likelihood not to achieve the team goals; conflicts between service coordinators and family members have the reversed effect by not avoiding discussions (Wright et al., 2006).

There seems no culture of preventive thinking. Practitioners seem to associate thinking about possible crisis situations with being pessimistic, as past crisis situations are not analyzed, and crises are only responded to when they occur. The solutions to crisis seem extreme, either the adolescent is secured in a residential setting or the parents have to manage it at home. However, in the literature safety planning (e.g. Signs of Safety; Turnell, 2008) empowers families, facilitates the connection between families and practitioners, and minimizes the need for admissions (Bickerton et al., 2007).

It is unclear which conditions determine whether care has succeeded or discontinued. Participants reported an imbalance, on the one hand, the desires and the needs of the family are mentioned, and on the other hand, the beliefs of practitioners and the possibilities within child (mental) health-care play an important role. This points out a need for a more objective tool that can help to balance the resources available and the individual clinical needs (Fallon and Dogin, 2005).

In this study, the perspectives and voices of the participants are prominent. Qualitative research can contribute to understanding how an intervention works in practice, to developing appropriate procedures, and to interpreting results (O’Cathain et al., 2014). A limitation often mentioned with qualitative research is a small sample size and difficulties generalizing the results. The goal of systematic text condensation is to present vital life-world experiences not to cover the full range of potential available phenomena. A limited number of participants provide sufficient data for analysis, as transcribed recordings of interviews or focus groups can produce vast amounts of data (Malterud, 2012; Pope et al., 2000; Sandelowski, 1996). It is important to establish an adequate and information-rich sample (Malterud, 2012).

Further research is necessary on the process to develop an effective care plan for families with MCN and the effects of these care plans on the different domains of functioning of the child and the family. However, the in-depth analyses of this study reveal useful elements to support an effective collaborative process that can be translated into practical points of concern:

(1) The use of a guidebook can better prepare adolescents and parents whereby everyone receives the same information and is perceived as equal partners; (2) adolescents and parents need to be supported in actively selecting CNC participants; (3) facilitate an active and full contribution by providing support for adolescents and parents; (4) structure meetings by using a standardized protocol, a chairperson can monitor this protocol; (5) external specialist practitioners can bring in a more objective approach to a complex situation; (6) visualize the sayings during and after meetings by making up a report; (7) crisis situations can be managed by making up an action plan beforehand; (8) continuous evaluation of the level of care can keep the care plan adjusted to the families’ needs; (9) regularly evaluating the collaborative process can guard continuity; and (10) regular training and supervision can keep practitioners’ competences up-to-date.

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