Diversity: Enough to include services users in an evaluation process or not?

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Abstract

Evaluation methods and procedures have undoubtedly evolved in the past years but still remains all-too-often perceived as disconnected from the reality of those who use the services that are evaluated. This paper will present two evaluation processes that explored diversity and included services users. The story of a mental health treatment program and the story of a support group for siblings of autistic children will be told. The combination of conceptual models, of methods of data collection adapted to every type of participants and the involvement of service users from the early stage of the preparation of the evaluation process up to the final report will be discussed. Finally, narratives from the service users will illustrate how diversity in methods and in participants contributed to empower them and how it facilitated the implementation of the evaluation results proving that diversity has its place in the field of evaluation.

Ste-Mary's Hospital

The first evaluation story is that of the mental health treatment program of Ste-Mary's Hospital. Ste-Mary's is a general hospital located in the province of Quebec, Canada between the two major cities of Montreal and Quebec City. There is a multidisciplinary team composed of psychiatrists, general practitioners, nurses, occupational therapists and social workers. It should be stated that most of the psychiatrists, general practitioners and nurses have been working at Ste-Mary's for fifteen to twenty years while the majority of the other health care professionals has been practicing for an average of 5 years. This has to be taken into account when considering the working context and the interactions between team members. There are important differences in expertise, experience, clinical practices and in the consideration given to the patients and their functional capacities.

Over the past seven years, working conditions have declined and more and more complaints have been filled either by staff members or by patients. Management was also unhappy with the performance of the staff. Among other things, the length of stay was too long, the case loads were not satisfactory and the working routine was inefficient. In the fall of 2002, a new administration team was appointed to the mental health program

with, as a mission, the responsibility to evaluate the functioning of the program in order to decrease the number of complaints, decrease the length of stay of patients and increase the productivity of the staff members.

The head of the mental health program decided on an internal evaluation (Love, 1991, Stake, 2004 & Weiss, 1998). This type evaluation was chosen because having someone from the organization and familiar with the culture and the ins and outs of the situation was thought to encourage better communication across the organization, facilitate change and facilitate utilization of evaluation information. This appeared to be a good choice since there was a history of unresolved and unspoken conflicts between team members and the administration leading to strong resistance to changes.

The evaluation was an exploratory process and in this particular case, both team members and psychiatric patients where considered as services users by the evaluator as both groups would be affected by the evaluation process and its results. Since the administration wanted to work hand in hand with the multidisciplinary team members and that transparency was the primary concern, every member had to be aware of what was going on, and be able to follow the evaluation process step by step. That is what motivated the evaluator to choose a method of data collection that would allow the participants to be part of the collection and of the analysis of the data. Therefore, TRIAGE, or Technique for Research of Information by Animation of a Group of Experts, was used (Gervais & Pépin, 2002). It is an inductive and structured method for collecting and analyzing information. It rests on group consensus and one of its goal is to supply, quickly and efficiently, firsthand information to enable decision-making (Gervais & Pépin, 2002).

Specifically, TRIAGE is made up of three different phases. The first phase is one of preparation, in which the evaluator develops a questionnaire targeting the issues addressed in the evaluation process as well as the other material needed to conduct TRIAGE successfully. It is followed by the individual production phase where each participant fills the questionnaire and returns it to the evaluator. The final step is the interactive production phase. It consists of a group session during which data obtained from the questionnaires are discussed and analyzed by the participants. An important visual support facilitates the analysis processes (Gervais & Pépin, 2002).

TRIAGE has many advantages but the most relevant in this particular context are: 1) its ability to simultaneous explore several facets of the phenomenon to be studied, therefore enabling the study of subjects of varying complexities; 2) the rapid and continued involvement of the participants in the analysis of the data. As a result, the participants rapidly realize the importance they play in that part of the process. In deed, the recognition of the participants as experts in their field of expertise and the importance of their continuous participation guarantee that TRIAGE is a technique that empowers all participants. Moreover, the visual support provided by TRIAGE during the group session allow participants to understand the task at hand and offers the possibility to confirm or readjust choices made to date at any moment. (Gervais & Pépin, 2002).

As transparency was a major issue to consider in the evaluation process, multidisciplinary team members were continuously informed about the evolution of the evaluation process. Information was passed on through written reports but also verbally as it was suggested by team members. When asked how and when they wanted to receive information about the evaluation process, they identified multidisciplinary team meetings, lunch hours and coffee breaks. As sharing information and making team members part of the elaboration of the evaluation process proved to increase their desire to be part of this experience and decrease resistance to change, the evaluator raised the following questions: "How about the patients using the services?", "Why not make them a part of the evaluation process as well"? and "How could they become involved?"

Interestingly enough, there was much resistance both from the administration and the team members when involving the patients was brought up by the evaluator. Administrators thought patients had no say in the evaluation of the program, they thought they would not understand what was being studied and that patients would focus on their own problems or even that having a mental illness automatically meant that patients were not suited to participate in the evaluation. As far as the staff was concerned they were worried about the mental status of the patients and feared that the whole process of evaluating the functioning of the program would increase anxiety level and led to flair up of the symptoms. Thankfully, after discussing and addressing everybody's concerns regarding the participation of the patients it was decided that they would take part in the evaluation process. Specific inclusion criteria were established as the patients' condition had to be stable; patients shouldn't present any positive symptoms such as delusions, hallucinations, etc., and had to be able to sustain group activities and interactions. Psychiatrists, nurses and occupational therapists were responsible to recruit patients that met those criteria.

Just as the team members were part of the process and informed about its evolution, the patients would be updated on what was going on as well. It is believed that the fact that the evaluator was part of the organization and had experience and knowledge of the clientele contributed to reassure administrators and team members as far as involving patients was concerned.

Thus, patients were met just before lunch as this moment appeared to be best suited to their level of functioning and to the side effects of their medication. During this time, they were told about the evaluation process that was going on, its purpose and its implementation, the eventual use of the results of this process as well as the impacts it could have on the daily functioning of the program. As it was expected, the patients had a lot to say. Obviously, they had noticed that something had been going on because of increased visits from the administration team, increased meetings as well as some changes in the staff's attitudes from day to day going from "quite upset" and "ready to go to war" to "cool off" and "in a better mood". The following comment illustrates the effect being included in the evaluation process had on the patients:

"I couldn't believe it! They actually took the time to explain what was going on…we're not stupid you know, we're ill…we know something is wrong. And they even asked for our opinion! Just like they do with normal people!"

<div align="right">John Doe, chronic schizophrenic, 41 years old</div>

Because of its advantages, TRIAGE was also used with the patients. Its visual support and interactive aspect were the main reasons. Due to performance capacities of the patients, there was no individual production phase. Instead, they were asked during a group activity what were the five best things about the way the ward was functioning. Then, they were asked to identify five things to improve and five strategies to deal with the different problems they had previously mentioned. Having a familiar face leading the group, the evaluator being known to the patients, it was possible to redirect them when they were starting to discuss their own illness and treatment instead of the more global functioning of the ward. Afterwards, the visual support specific to TRIAGE was used for the data analysis. It enabled the patients to understand what had happened to their initial comments and where the final results came from.

After TRIAGE in its adapted format was conducted with the patients, it was used in its original version with the team members. They were given a questionnaire to fill for the individual production phase in which, just like the patients, they were asked to identify five strengths and five weaknesses in the organisation of their work in the program. Then they were asked to think of five strategies to implement in order to deal with the problems previously identified. Then, the questionnaires were returned to the evaluator. Between the strengths, weaknesses and solutions, some 323 issues were raised by the staff members, including psychiatrists and general practitioners. However, these two categories of people refused to participate in the interactive production phase of TRIAGE. Nevertheless, four groups were held (n=8, n=9, n=10, n=13).

One thing that should be pointed out is that several comments reported in the questionnaires expressed the lack of respect felt by the multidisciplinary team members and how frustrated they were with the administration's attitude towards them. And interestingly enough, they could identify only three strengths of the treatment program and its functioning. Here are a few comments made by staff members illustrating their state of mind before and after the evaluation process:

"At first, I thought she (the evaluator) had turned on us. Then I thought she would know what is really going on even if things are not said as they truly are."

<div align="right">Nurse, 25 years of experience in the mental health program</div>

"Usually, I don't bother and don't get involved in these things because, they never take into account what I say. But when we started to have information about what was going on, and we had access to these things all the time, I said to myself, it's a change!"

<div align="right">Nurse, 16 years experience in the mental health program</div>

Always keeping in mind that transparency was a major concern for all parties involved, results from the patients' interactive production phase were told to the team members just

as the results from their own interactive production phase was summarized and told to the patients. Team members were surprised to see so many similarities between their concerns and those of the patients. For example, they shared common concerns about improper prescription and management of medication, insufficient visits made by the psychiatrists and the uninviting and disorganized working environment. This contributed to decrease the tension on the ward as several people shared many of the same preoccupations leading to a better understanding of each other's reactions.

In this story, a data collection technique promoting the involvement of the participants in the data analysis proved to be successful. Being able to adapt this data collection technique to fit the functional capacities of the patients had a positive effect on their self-esteem and on the quality of their interactions with the team members. Also, conducting an internal evaluation facilitated its implementation as well as the data collection process because in this situation having a good knowledge of the context was very helpful. The elaboration and implementation of a system to share the information about the evaluation process on a regular basis promoted better communication and interactions between team members and administrators and within the multidisciplinary team as shown by this comment:

"I admit I was ready to react to any negative comments made about me or my work. But the visual support and the images used during the group meeting made this not so formal. We even had fun and laughed at times. We had a chance to talk about our differences. We worked together for a change…and that include myself…"
                    Occupational therapist, 7 years experience in the mental health program

In other words, the bottom up approach often mentioned and discussed in the field of evaluation applied in this context facilitated the evaluation process and, to a certain point, the implementation of the some solutions.

Support group for siblings of autistic children

The situation of siblings of a physically and mentally challenged child has been documented in the literature only recently (Lobato & Kao, 2002, Nixon & Cummings, 1999). But already, it appears that these children present more mood disorders, behavioral problems and an overdeveloped or underdeveloped sense of responsibility than other children (Lobato & Kao, 2002, Nixon & Cummings, 1999). Despite the few researches conducted with this clientele, the findings were serious enough for researchers of Southern Quebec to elaborate a support group for siblings of children suffering from autism and other pervasive developmental disorders (PDD).

The support group has been held on Saturday mornings for a period of seven weeks since the winter of 2003. It is offered to siblings of children suffering from autism and other pervasive developmental disorders aged from 7 to 10 years old living in the region of Southern Quebec. The content of the group was elaborated following an exhaustive

literature review of the impacts autism and PDD have on family functioning and especially on the siblings of the child suffering from one of these disorders (Lobato & Kao, 2002, Nixon & Cummings, 1999). The objectives of the group are: 1) increase knowledge about autism and other PDD, 2) increase understanding about autism and other PDD, 3) decrease siblings' psychological distress, 4) promote positive modifications in the perception and attitude regarding the brother or sister suffering from autism and other PDD, 5) express and deal with emotions brought by extreme behaviors related to autism and other PDD, 6) develop better communication and interaction skills with the autistic child, with the rest of the family and with peers, 7) promote mutual help within the group.

Each week, one objective was addressed during the group session through specific activities such as role playing, treasure hunts, group discussions, educational sessions, etc. When the children attended the first group meeting, they were presented with 7 doors, one for each objective. And at the end of each meeting, the children received a key allowing them to open the door of "better knowledge about autism and other PDD" or of "better understanding about autism and other PDD" until they had in their possession all the keys they needed to deal with the illness of their brother or sister as best as they can.

Despite the popularity of the group among the children, many parents commented on the difficulty they had to juggle with time management, having to drive one child to the group while having to do their usual chores and care for their other child's special needs. Group leaders and researchers decided to adapt the group format to the daily context of the families involved. That's how the support group was adapted to fit into activities offered at a well known summer camp located near the St-Lawrence River in Eastern Quebec. The group leaders and managers of the summer camp found common grounds and the group in its new format was going to be held during the second week of July 2004. Group sessions would be held every day during a week. Specifically, the children would attend group activities in the mornings while they would be free to participate in the camp activities during the afternoons and evenings. For example, they could do hiking, horse back riding, swimming, sailing, etc.

As it was mentioned previously, the support group was popular among the families dealing with a child suffering from autism or other PDD and known and appreciated in the community. Once it became official that the support group was going to be part of a summer camp, it was advertised in the region of Southern Quebec. Then, something quite unusual happened. Some children, on their own, contacted the group leaders with a few questions about the new format of the group. In fact, they expressed concerns about the impacts these changes would have on the content of the group and its capacity to reach its goals. They asked questions such as: "How will you make sure we learn what we came to learn about our brother or sister?" or "Summer camp is great but that will not tell me what to do when my sister goes crazy on me" or "If the activities take place in the summer who will want to work and teach us stuff?".

That was the starting point of an evaluation process to explore the effects of the support group on the participants. But, while group leaders and researchers focused on evaluating the effects of specific interventions or activities, it seemed appropriate to have a global

look at the entire program. For example, if an activity was supposed to increase the knowledge about autism, after having completed the activity, the children were asked to answer specific questions about the illness to "measure" their knowledge. But, no one ever considered the entire program, in this case, the support group and its different dimensions. Therefore, much thought was put into finding the best conceptual framework to evaluate the effects of specific activities while documenting the functioning of the entire program. After consulting recent studies and keeping in mind the attention paid to the service users, especially since they were the one expressing concerns about the capacity of the group to reach its goals, one conceptual model stood out. This model is the Model of the Dimensions of a Program (MDP) (Gervais, 198).

The MDP (Gervais, 1998) reflects the effort of modeling the complex interactions existing between a program, the environment and the individuals involved. The model is holistic and takes into account the functional, systemic and human elements conveyed by traditional evaluation approaches. It embodies the individuals and systems in place and makes an effort to incorporate the political and technical aspects of efficiency. This model is dynamic. It has active feedback loop and is flexible enough to enable a program to maintain its uniqueness and to accommodate any changes. The author demonstrated that considering several dimensions is necessary to fully understand and explain the stakes of the program under study. Once they're documented, the dimensions provide a complete image of the program, its strengths, its limits, and the area to develop and to consolidate as well as those that could serve as models for their relevance.

The dimensions of a program though by Gervais (1998) are: 1) structural; 2) operational; 3) strategic; 4) systemic; 5) specific. The structural dimension covers the physical, material, financial, information and human resources available or needed to provide the services. The operational dimension includes the program's activities and the behaviors of its members. It includes professional practices, activities scheduling and programming. The strategic dimension encompasses the activities of a program related to its management policies and practices. Activities associated with managing the program and its constraints, mediation, strategic planning, time management, decision-making process, supervision, coordination, leadership, evaluation, creation of a performance-oriented work environment, respect for standards, and ethics are primarily covered in this dimension. The systemic dimension looks at the activities of a program in connection with its external environment. It covers the manner in which the activities of the program relate to other resources, services or activities already in place. The focus of the systemic dimension is therefore how a program interacts with and adapts to its environment. Finally, the specific dimension pertains to the activities of a program in terms of generating results. It is primarily a matter of meeting program objectives, meeting expectations and providing services. The degree and capacity of achieving the objectives specified by the program, the quality and quantity of products and services provided, customer satisfaction and product durability are covered by this dimension (Gervais, 1998).

In order to take into account the questions asked by the children considered here as the services users, the group leaders decided to have a meeting before the summer camp started. The children and their parents were invited to meet the group leaders and the

researcher after school for a light snack. There, the changes in the group format were discussed and each dimension of the support group was explained and presented. The details of the activities (operational dimension) were not told to the children to keep the surprise and their interest but their goals and purposes were mentioned. Then, the children and their parents were asked to comment on the support group as it had been presented. The children provided the group leaders with very relevant comments and suggestions and took that part very seriously as illustrated by the following comment made by Marie, 8 years old:

"It is serious you know…when adults tell you they need to know what you think. They were even taking notes about what we were saying. But it makes sense because they don't know my sister so how can they know what it's like to live with her!"

The questions related to human resources available during the summer (structural dimension) brought up by the children was addressed as the group leaders presented themselves and explained in details their role in the group. Concerned with being distracted by the summer camp activities and not focusing enough on learning how to deal with their brother or sister because (systemic dimension), the children suggested that they meet every evening around a camp fire to discuss what they had learn during the morning sessions (operational dimension). To them, it was a strategy to make sure they would remember and maintain their new skills or knowledge (specific dimension). With respect to the effects of the activities, the children were satisfied with the strategies proposed to evaluate if the goals were reached and to what extend (specific dimension). But, they suggested that the same evaluation should be repeated once school had started to make sure they would maintain their new knowledge and skills and most importantly, if they could apply what they had learned to different contexts (specific dimension). After discussing the ways to evaluate the effects of participating in the support group over time (specific dimension), it was decided that the parents would take part in the data collection process. They would be involved at the beginning and at the end of the group activities as well as in the re-evaluation process in order to provide a more objective point of view of their child's experience and of their use of their new skills and knowledge. As a matter of fact, here is what Simon; 10 years old, had to say about transferring his knowledge in other contexts:

"It's tough in school sometimes. People make fun of my sister and stuff. They think she's crazy and sometimes they think I must be crazy too since she's my sister. Now, I know what to do but what if I forget what to say once I'm back in school. I just want to make sure I didn't learn all this for nothing you know…"

In this particular case, involving the children before the program took place and keeping an open mind about their concerns proved to be helpful in providing a service that could answer their needs. Listening to them and taking into account the suggestions they made contributed to truly include the service users in the implementation and evaluation of the support group. Also, the conceptual model used helped in considering all aspects of the program. Actually, the children's suggestions were integrated mainly in the operational dimension by adding new activities and in the specific dimension by developing

strategies to make sure the skills and knowledge were maintained over time. By asking about the availability of human resources, the children's concerns addressed the structural dimension while the importance to keep the focus on the support group within the summer camp and its activities referred to the systemic dimension of the program.

The summer camp and the support group took place as planned during the second week of July and the content of the program was adapted as suggested by the children. Measurements were taken with regard to the seven objectives of the group. The preliminary results show that there was an increase in the knowledge and in the understanding about autism and other PDD. It also appears that children increased their ability to express the emotions brought by extreme behaviors related to autism or PDD. Currently, is it impossible to comment on the modifications in the perception and attitude regarding the brother or sister. Upon re-evaluation, the group leaders and researchers expect to be able to document that aspect as well as the capacity to deal with the emotions on a day to day basis and the development of better communication and interaction skills with the autistic child, with the rest of the family and with peers and modifications in perceptions and attitudes. Finally, it seems that the group didn't promote the development of mutual help. These preliminary results will be analyzed keeping in mind the changes in the group format and the consequences on the ability to reach the objectives. Post-group data collection is schedule to take place during the third week of October.

These two stories were told to illustrate how including service users can be a positive aspect in program implementation and program evaluation and how enriching having such people as partners can be. This paper puts forward some specific interventions and methods that facilitated the implementation and evaluation process in these specific contexts. A data collection technique that promoted the involvement of all participants contributed to better collaboration and decreased resistance to change. Listening to the comments made by the services users and adapting the content of the program in response to those comments was also a successful strategy.

Choosing the proper data collection and data analysis strategies, using a good conceptual framework to develop an implementation or an evaluation design, maintaining the capacity to adapt the content of the program with regard to services users' needs are all part of an evaluator's knowledge and competence. But going beyond what is usually done, going outside our comfort zone as evaluators, going beyond prejudice about the capacities of certain categories of service users and actually making them equal partners in an implementation or an evaluation process, that is the art and science of evaluation. That is the art and science of diversity.

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