Panel T06-P05 Session 1

Governance with the Population: Frames, Measurement Instruments, Strategies and Mecanisms

Title of the paper

Involving and maintaining youth user's participation in design, implementation and policy evaluation: The case of mental health and youth transition to adulthood

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Abstract

Glasby and Beresford (2005) question the assumption underlying the concept of 'evidence-based practice' in a context where policymakers, practitioners, evaluators, and researchers recognize the importance of experiential data; the authors proposed a new concept 'knowledge-based practice'. In fact, there is an increasing call for users' services to participate in the policy-making process (Leung and Larn; 2019) as well as in evaluation and research processes (Breth & al., 2014; Bush & al. 2017). Many authors tried to explore the different venues of research about users' participation (ethical issues, participation impacts on users). Particularly, young users' participation presents more challenges, even if there are a large number of writings from different contexts exploring young people's participation, especially on research projects (Flemming, 2010; McLaughlin, 2005). The young people role in research made huge progress and they become active participants (McLaughlin, 2005). However, many issues remain important to explore, discuss and resolve to optimize young people's participation.

In this paper, we adopted the definition of Canada's Strategy for Patient-Oriented Research (SPOR). The user becomes a partner who collaborates actively to a continuum of research (governance, priority setting, conducting research and knowledge translation). We will present descriptive case studies (EDJeP and AO), and process evaluation of the engagement of youths. The two cases are successful experiences of the participation of youth. The first EDJeP is a provincial longitudinal study interested in the transition to adulthood of youth placed in the youth center. The study focused on their trajectories, the services to which they have access, and how they were prepared for their autonomous life. A youth committee accompanied the project since the project was funded. The youth committee is an important component of the governance strategy since the project design. The second project "Air ouverte (AO)" is an integrated network of youth mental health services 12-25 years. Only three demonstrative projects in Quebec were financed in 2018 to implement and to evaluate those projects. In this paper, we will cover Laval's project. The youth user's participation was a condition of the fund organizations. The participation of youth covered the entire project

continuum. Youth users are mobilized in different governance instances and a youth committee is involved in the implementation of "Aire Ouverte".

Our question research is interested on: what are the successful conditions to engage youth users in a participative process? Analysis of methodological, organizational and practical issues encountered during this process and the solutions implemented to achieve a meaningful, active and continuous participation of youth users will be presented.

Financial issues, ethical issues, and youth coaching seem to be the preconditions of any process of youth user's involvement. However, real life exposes researchers and evaluators to other issues they have to resolve in an innovative way. In fact, the perception of youth participation of all stakeholders, the manipulation of the concept of participation as well as their coaching and training to enhance their self-confidence and self-esteem continuously are key elements to maintain their motivation, interest, and engagement.

Key Words: participation, Youth, Adulthood, Integrated network, cocreation

1. Introduction

Recent years have been marked by a higher enthusiasm for citizens' participation in the various stages of the public policy cycle; politicians, administrators, researchers and evaluators try to involve citizens in their processes. This enthusiasm comes from the need to give citizens a place in the choice of policies, programs and interventions they are concerned in, but also to give them a voice to judge the effectiveness, efficiency and relevance of these policies, programs and interventions. In this essay, we focus our thinking on youth participation as much in the design and development of intervention as in evaluation and research approaches.

The two empirical cases presented here to illustrate youth participation fall into two areas. The first case concerns the EDJeP youth committee, which accompanies a longitudinal study on the transition to adulthood of 1100 young people placed in the care of youth. The second

case concerns the Integrated network of Mental Health services for youth aged 12 to 25, Aire-Ouverte.

2. Youth participation in public policy, research and evaluation: perspective théorique et conceptuelle

Citizen participation in the development, implementation and evaluation of public policies is being increasingly advocated by different stakeholders. We are also talking more and more about the participation of citizens and users in decisions that affect them, for example, medical treatment plans. Public decision makers are appealing and trying to involve citizens in these processes. Experiential knowledge is recognized in the same way as scientific knowledge, and the very relevance of public policies depends on the level and form of the involvement of citizens, and particularly the groups of citizens concerned, more closely with the problem that we try to settle by public intervention.

This reflects the paradigm change in public administration of new public management focused on efficiency and effectiveness to new public governance (Osborne, 2006) or to the new public service (Denhardt and Denhardt, 2000), both relying on partnership and the place of citizens as co-producers and co-creators (Baptista & al., 2019; Torfing & al., 2019).

While the participation of users in research and evaluation is already well recognized and used by several researchers and evaluators, the participation of users and citizens in the development, design and implementation of public action requires more recognition. However, the benefits of this participation as much for the policy, the administration and the citizen user is well documented; we are talking about a public value for all stakeholders in this participatory process.

In particular, regarding the importance of youth participation in service development and service delivery, Coates and Howe (2016) demonstrated the benefits of this participation for both youth and the organization. The authors refer to a Headspace Center (Gosford) and its Youth Alliance participation model (YA) in which 12 young people participate in the

development of the service offering through different activities. There are two main reasons for young people to participate. The first reason is to break down barriers so that young people can access the services they need (in particular to counter the stigma that young people may have with regard to mental health problems / consultation of mental health services; youth desire to be 'normal' may also reinforces the reluctance of youth to seek mental health services (Coates, Howe, 2016). Awareness and education about mental health in school environments, then participation allow youth to develop social skills (better confidence and self-esteem), create a social network and be more able to support friends who also have a mental health problem.

The space of participation offered to young people allows them not only to express their ideas, but also to confirm themselves in society. For example, youth participation in decision-making during placement may help them in their transition into adulthood (Cashmore, 2002, and Murray, 2005, quoted in Lacroix, 2016) and increase their social capital and capacity to ask for help later (Gilligan 2007, Hollingworth 2012, and Schreiber Culbertson 2014, quoted in Lacroix 2016). When this participation is collective, its benefits are even greater. Indeed, it facilitates the construction of social networks if young people are involved for example in an artistic, sporting or religious community (Gilligan, 2007, Hollingworth, 2012, Schreiber, Culbertson, 2014, quoted in Lacroix, 2016). For example, collective participation in weekly meetings in child protection teaches youth the basics of citizenship (claim formulation, negotiation, agenda, listening) (Ossipow & al., 2014, quoted in Lacroix, 2016). Participation develops the ability to negotiate (Join-Lambert Milova, 2006), self-confidence, self-esteem, social skills of project leadership, lobbying (Robin, 2010) and also reinforces academic achievement (Gilligan, 2007, Hollingworth, 2012, Schreiber, Culbertson, 2014, quoted in Lacroix, 2016).

Aside from this citizen participation to improve policies and inform researchers and evaluators, more and more care approaches are leading young people to participate in their own clinical choices as part of their interventions. In fact, to promote early intervention for youth mental disorders, it is also important to eradicate the stigma that can sometimes prevent people from talking about their mental illness or that of a family member and their family to get the help they need (Kroes & Watling, 2009). A comprehensive continuum of care

should promote the promotion of mental health and well-being, the prevention of mental illness, the reduction of risk, and the improvement of coping skills. Kroes and Watling (2009) demonstrate the importance of involving young people in their treatment and recovery strategies to ensure that they continue to devote themselves to the treatment process as long as necessary. It is in this perspective that new models of youth-centred care are centred on the patient and family-oriented. In addition, these models are not, in our opinion, well documented from the point of view of health professionals. It seems that an active partnership in problem identification and adherence to treatment is more effective because it ensures the involvement and buy-in of all actors. Young people are actively engaged in identifying health issues that are important to them, setting priorities and developing strategies (prevention, mitigation, treatment, recovery) to address their mental health needs as effectively as possible.

3. Youth Participations: Two Empirical Cases Studies

We will present two youth participation's cases. The first one, EDJeP, youths have participated in the research process. Their participation was planned in the research design. The second case study, Aire Ouverte, youths were implicated in all the policy stages from the design of the integrated network to its evaluation, as well as its implementation.

3.1. EDJeP

3.1.1. What is EDJeP?

Youth Leaving Care in Québec and France: A Longitudinal Study (EDJeP). EDJeP was developed by the Canada Research Chair in Evaluating Public Actions Related to Young People and Vulnerable Populations (CREVAJ), in the purpose of filling a lack of knowledge on the post-out-of-home care period, a period that doesn't get the attention it deserves in Quebec. is a longitudinal study (2014-2021) that aims to understand the factors that have an impact on all

youth in care, in Quebec, that are about to leave an extended placement (more than one year) because they have reached their majority. The study focuses on the supports and barriers those young people encounter in their various transitions to adulthood in territorial contexts (metropolitan, semi-urban, rural). More precisely, EDJeP is interested in the living conditions and transition to independent living of youth aged between 17 and 21 placed in out-of-home care and in organizing the first longitudinal and representative study in Quebec on this topic. A follow-up of about 1,000 young people, during a 3-year-period, will lead to a crossed analysis with harmonized administrative data from Child Protection Services, administrative usage data of MESS's and MESRS's services as well as certain population data, all in the purpose of obtaining a better understanding of issues revolving around the transitions youth in care have to face, as well as improving social practice and public policies.

By combining the analysis of the trajectories of youth with social intervention practises related to public policies, institutions and communities, this research study tries to capture the correlation between interventions and the needs of young people. The crossing of these two dimensions will improve the range of services offered to young people leaving care and influence the development of social policies. This project on the future of youths who have been placed is built on international (France-Québec comparison) and interdisciplinary (public administration, social work, education, and several other) perspectives. This project is also built on strong intersectoral collaborations with actors of youth protection and youth frontline services.

Specifically, the project objectives are to: 1) Develop knowledge on the future of young people placed in Quebec and France by conducting a representative longitudinal study; 2) Identify the effects of innovative practices for engaging youth in their transition to adulthood by using comprehensive and evaluative research projects; 3) Support the mobilization of knowledge gained in the first two objectives to improve the institutional and practice community; 4) Strengthen the dynamics of formation for both researchers and social workers on the question of support for youth leaving care. Furthermore, we will disseminate these gains in other sectors of care (hospital, correctional, educational, and rehabilitative).

3.1.2. EDJeP Youth Committee

At the heart of this research project, there's a youth committee composed of 14 young people aged between 18 and 35 years old Those youths have had a diverse placement experience (foster family, youth centres, community group homes) under the Youth Protection Act (YPA) or under the Youth Criminal Justice Act (YCJA). The Youth Committee main motivation is to improve Youth protection services. The purpose of this committee is to offer a space where the voices, experiences and rights of those young people are considered at every stage of the research process. The Youth Committee members are considered as part of the EDJeP team and are presented on the Web site[1]. They had the opportunity to present themselves in a video[2], as well. Youth committee is dedicated to promote the study. Wave two had been implemented this year and youths announced it arrives in a video[3].

Since 2014, the EDJeP Youth Committee structure had been changed and the group has evolved a lot. At the end of the project, the main challenges concerned the coordination of youth and their mandate. The Committee has been stabilized during 2016. The coordination was no more a youth member of the committee, but an external coordinator who facilitates managing the committee. All youth are compensated for their participation.

The Youth Committee was involved in many steps of the first and second waves as participating to validate the data gathering tools and the communication tools that aim to reach and inform the youth targeted by the research. They also participate in the interviewers' selection and hiring process, the interviewers' training, validation of the data collection tools, results analysis and interpretation. For example, regarding the training of interviewers, focus was on the know-what and know-how. In addition to the skills of data collection and interview techniques, and a good knowledge of the youth protection community, it is imperative for interviewers to know and understand the reality of young people in transition to adulthood.

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[1] http://edjep.ca/en/youth-committee-fr-v-o/
[2] https://youtu.be/x0ZVJV6QE38?t=4
[3] https://youtu.be/8cKxrztjZNM?t=22

The Youth Committee has been very insistent on the latter aspect, which they believe may be determinative in an interview. This is why they decided to make a video capsule to help the interviewer to better understand the reality of youth in care or those who were about to leave their placement settings and also to promote positive relationship with these youths. They expected that interviewers would face several challenges while meeting youth, hence how much it is important to be well prepared sensitized and aware of youth difficulties in order to ensure maximum retention of young people for the next phases of the longitudinal study, but above all to ensure a valid and reliable data gathering process that allows them to understand the complexities of youth in care realities. The youth received financial compensation ($20) for taking part in the video capsule.

EDJeP had allowed the youths to explore and participate in other activities and entities. For example, youth committee members have participated in an artistic project who won the public's favourite prize[4.] Youths are invited to participate by many other organizations as INESSS, Centre jeunesse de Montréal, etc. to represent youths who have had a placement experience in youth protection. Lastly, those youths are very active publicly. They are solicited to comment on public topics in the media[5].

3.2.   Aire Ouverte

3.2.1. What is Aire-Ouverte?

Aire Ouverte is an integrated service network that provides mental health services for youth ages 12 to 25. The offer is adapted, flexible and adjusted to the needs of young people. AO aims to respond to the concerns of young people and accompany them to the right resources

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[4] http://edjep.ca/le-projet-porte-voix-et-le-comite-jeunes-edjep-ont-remporte-le-prix-droits-et-libertes-2018-ainsi-que-le-prix-coup-de-coeur-du-public/

[5] https://youtu.be/83z6vZB5A5Y?t=4 &
https://www.google.com/search?q=jessica+cot%C3%A9+guimond&safe=strict&rlz=1C1GCEU_enCA846CA848&source=lnms&tbm=vid&sa=X&ved=0ahUKEwiytaPT5t_iAhXEjVkKHe0_C1kQ_AUIEygE&biw=1680&bih=858

if necessary. A multidisciplinary team at the same point of service is available to answer the requests of these young people.

3.2.2. Gouvernance structures of Aire Ouverte

Throughout this process, several actors have been involved. We present the main committees and working groups that have contributed to and contribute to the deployment of Aire Ouverte at Laval. When the grant application was submitted, the vision of governance focused on the egalitarian place to be given to all the actors involved.

The Continuous Improvement Committee consisted of the user partner[6], the work team, the department head and a community person. An update of the project's developments was made. The actions of the team, the reflection on the presentations made in the community organizations, concrete actions were undertaken following this committee which ended when Laval was chosen as a demonstration project.

The CISSS Clinical Coordination Committee brings together the clinical directors of each CISSS director. They are responsible for following the evolution of the project, but at the strategic level and not in the operational clinical aspects. Very few links are made between this committee and the other committees.

In a first meeting with the partners (partner committee), following the receipt of the grant, a proposal for a governance structure for the Aire Ouverte project was presented and adopted. This structure takes into account the CISSS-Laval's responsibility for the deliverables associated with the project and provides the link between the project and the Clinical Coordination Committee of the CISSS-Laval. It also provides for the presence of various working bodies to ensure implementation at the strategic and operational levels of the project. This committee reconverted to a steering committee in September 2018.

6

The steering committee regroups 22 members and includes the CISSS-Laval (public health, mental health and addiction, specific and specialized services for young people aged 13-17) and the partners of the health network (community organizations, school network, the city of Laval), the CRÉVAJ research team and two partner users. The mandate of this committee is to guide the activities related to the implementation of the Aire Ouverte project by contributing to the sharing of the concerns that affect the clientele targeted by the project. To do this, the steering committee aims to: validate the project structure; contribute to meeting objectives, work plan and deliverables consistent with departmental expectations; ensure links with the relevant regional consultation networks; to help identify promising strategies for reaching young people and adapting practices; to contribute to the mobilization of young people in connection with the project as well as to validate the criteria for the granting of financing for the development of privileged places of reaching-out.

The advisor committee is composed of the CISSS-Laval stakeholders (project manager, youth program director, mental health / addiction, public health and the university education and research directorate). In addition, the representatives of the CRÉVAJ and the two users' partners are members of this committee. The mandate of the advisor committee concerns the coordination and implementation of the Aire Ouverte project which includes ensuring compliance with the objectives, work plan and deliverables in line with departmental expectations; implement the recommendations of the Steering Committee; support the work of the Steering Committee; liaise with the Clinical Coordination Committee and liaise with CISSS Laval's various programs. The advisor committee has met five times since June 2018.

The youth committee was created in October 2018. To this end, the committee members were approached to launch an invitation to young people who attend their organizations. In order to be able to create a diverse group, no exclusion criteria were part of the incentive other than age (12-25 years). As a result, 38 young people participated in the first meeting of this new Aire Ouverte Authority. After only two meetings, a group of 20 young people settled in the Youth Committee (Youth choose their name CAO for **C**ommittee of **A**ire **O**uverte). Taking into account the need to create a dynamic group, this committee is currently a closed group, and therefore no new members can, for the moment, be admitted.

The CAO's mandate is related to activities related to project planning and implementation. It represents young Laval residents to ensure that services adapt to their needs and are friendly and warm; provide opportunities for partners to advertise with youth living in a vulnerable situation to facilitate the creation of trusted relationships with services; adjust for a general assessment, the advisor of the instance.

12 meetings have been held since October 2018 and CAO has work-to-be diversified and this in connection with the Aire Ouverte service. Aire Ouverte information pamphlets; reception procedure for young people arriving for the first time at Open Area), but also in connection with the research project (consent form, entry questionnaire, etc.)

3.2.3. The place of youths in Aire Ouverte

3.2.3.1. Youth user partner

A young partner is integrated in several governance structures of the project which is composed of CISSS Laval stakeholders, intersectoral and community partners (see 3.2.2). The young partner is therefore involved in all stages of the project. He also attends all provincial meetings, subcommittees, etc. with different stakeholders including with the MSSS. He was integrated into the team before several other actors. As part of the project, the goal is to recruit to other young people who will join this young person so that he is not isolated, alone in front of experts (Dupuis and Mann-Feder, 2013).

The partner user had a direct link with the intervention team. Together, they were involved in all the initial thinking around the integrated network. However, once the funding has been obtained, the partner user has lost contact with the field team; no meeting has been scheduled. That made, the partner user continued to visit the team to keep a minimum of contact with them.

While the partner user is considered as a full member of the various committees that he integrates (director, steering, etc.), he was not included in the co-construction of the entry questionnaire.

Different interpretations of the role of the partner users coexist at the level of the different actors of the institutional, which can make their implications complex. Following the meetings of the various committees where the partner iser was present, concrete actions must be taken, but rarely are they involved in the implementation of these actions. When should we involve them? How to avoid using them? To over-solicit them?

3.2.3.2. CAO in Aire Ouverte

The idea of setting up a youth committee was planned during the grant application. The team planned to set up a committee of 15 young people taking into account the principle of diversity of service experiences, issues, gender identity, ethnicity and age, etc.

Indeed, as explained above, a group of 20 young people had formed the Young Aire Ouverte Committee (CAO) since autumn 2018. It meets on average once a month. Our other experiences on youth participation and evidence clearly show that building a collaborative dynamic among young people takes time to build a "hard core"; that there is a turnover in the first months, if not the first year, of youth committees implementation and that the activities of the governance structure require a regular recruitment process for young people. Taking into account this diversity is nevertheless essential (Goyette, 2019; SansFaçon and Bellot, 2016). This was not the case for the CAO, because the group of 20 young people has been fairly stable for a few months and the group is now closed to new hires.

As a result, we expect that once the Youth Committee has been established as a grant application, it will become the central youth participation forum, and all important decisions regarding the direction of Aire Ouverte and its evaluation will have to be submitted to youth. Thus, starting from an iterative and bidirectional dynamic, the youth committee will in turn be able to solicit the opinion of other governance structure members. Finally, this youth

committee will be at the heart of the reflection and implementation of the mobilization of young Laval residents, and the implementation of the RSIJ and the aspects related to evaluation (supported by the creation of the site web, using digital literacy and video, etc.).

In fact, shortly after the creation of the CAO, requests were made to young people to express themselves on various topics. The CAO was involved both in the development of the questionnaire and the procedures to obtain the consent of the participants. Regarding the questionnaire, the CAO was able to decide in two meetings. The first meeting was more about the process, ie how the input questionnaire could fit into the process of welcoming young people to Aire Ouverte (when to submit the questionnaire and how). At the second meeting, we discussed the content (more in a consultation perspective and not in co-creation). The comments were incorporated into the questionnaire and reported to other instances. In addition, the CAO was consulted regarding the consent form and the aide-memoire that accompanies this form. Once again, this was done in consultation to improve already existing documents.

Even if many of their ideas have been translated into concrete actions (for example, the development of a walk-in schedule), several other pieces of information do not always seem to have been transmitted to all the actors concerned. For example, young people expressed ideas to make the premises more welcoming during one of their meetings (purchase of furniture, equipment, etc.). Even if some purchases were made (bean bags), no follow-up was given regarding the other ideas. It was only four to five months later and at the Aire Ouverte Team meetings that the team expressed the need to redevelop the premises - all that was proposed was part of the CAO's ideas-, so it seems that the ideas expressed by the CAO have never landed to the team.

In addition, the call for interest in reaching-out places (funding of community resources for redevelopment) provides, in the criteria for analysis, support by the youth committee. Although several projects were pre-selected, no consultation was conducted with the CAO. Following a recall by the research team, discussions will be initiated to decide the role of the

CAO. It should be noted that the CAO's mandate described above is the result of a research team proposal that was made by the CAO Facilitator and the evaluation team.

It should be noted that many young people have expressed a desire to become more involved in the research process, particularly with respect to data collection. For the moment, their involvement in the research component is not defined, but it is certain that a reflection must be made to better define their place in these procedures.

Also, the reality of the CAO does not seem to be taken into consideration yet, especially the agenda of their meetings, the time they need to be in a position of co-creation, etc. Indeed, several activities proposed to the CAO require several meetings because of the diversity of the profiles of young people (levels of education, comfort to express themselves, ability to make decisions, etc.). The trend is towards a need for the CAO to adapt to the CISSS reality. We seem to want to consult the CAO when we need the opinion of young people, but do we give them real decision-making power? Are we ready to deal with their realities? Or is their presence symbolic?

4. Conclusion

Youth participation is an opportunity for all the stakeholders involved in this process. However, this process requires a lot of effort, time and funding to be able to create a space where young people are comfortable to participate. These young people need time, support and coaching to develop their communication skills, to express themselves in groups and to take a stand and make decisions.

Indeed, it is a process of empowering young people to participate in this process and fulfill their function. Most of the activities deserve to be prepared with young people in advance, especially to popularize the content and keeping in mind that these young people are experts in their own lives and not experts in the traditional sense of the word. In short, we need to create the right conditions to make informed decisions. To this end, Brett and colleagues (2014) remind us that lack of preparation and learning time can result in a sense of being

unable to contribute actively and effectively. It is certain that many researchers, even those who advocate the participation of users, raise financial difficulties and lack of time as obstacles in order to meaningfully involve users.

Also, those youths need support before and after meetings of a committee as well as throughout their implications within evaluation, research or planning meetings they are invited to. Aire Ouverte and EDJeP guarantee young people will benefit from support, if necessary. The young people can be guided, according to their needs, with a partner user, another person from the research or the evaluation team or a follow-up professional. Having access to this support is a critical issue in terms of evidence (Barry 2014, Coates and Howe 2016, Day 2008).

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