

# *Supporting GAM Practices:* Gaining Autonomy & Medication Management in Mental Health

## A HANDBOOK

### RRASMQ

Regroupement des  
ressources alternatives  
en santé mentale  
du Québec

*Quebec Coalition of  
Alternative Mental Health  
Organizations*

### ÉRASME

Équipe de recherche  
et d'action en santé  
mentale et culture

*Team for Research  
and Action in Mental  
Health and Culture*



This handbook was produced by:

## RRASMQ

### **Regroupement des ressources alternatives en santé mentale du Québec**

*(Quebec Coalition of Alternative Mental Health Organizations)*

## ÉRASME

Équipe de recherche et d'action en santé mentale et culture  
*(Team for Research and Action in Mental Health and Culture)*

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*Supporting  
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Gaining Autonomy  
& Medication  
Management in  
Mental Health*

A HANDBOOK



Gaining **Knowledge**

Gaining **Support**

Gaining **Quality of Life**

Gaining **Well-being**

Gaining **Power**

# A collective production

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Many people made contributions, large and small, to the development of A Handbook for Supporting GAM Practices: Gaining Autonomy & Medication Management. The guide itself is greatly indebted to previously published documents on Gaining Autonomy & Medication Management:

- 1) *Taking Back Control: My Self-management Guide to Psychiatric Medication*, a joint production of the Regroupement des ressources alternatives en santé mentale du Québec (RRASMQ – Quebec Coalition of Alternative Mental Health Organizations) and the Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ - Association of Advocacy Groups for Mental Health Rights in Quebec);
- 2) *Gestion autonome de la médication. Guide d'accompagnement pour les ressources alternatives en santé mentale*, (A Gaining Autonomy & Medication Management guide for alternative mental health organizations) published by the RRASMQ;
- 3) Introduction to Gaining Autonomy & Medication Management training developed by the RRASMQ. Medication users, providers from alternative mental health organizations and advocacy groups, and member researchers from various fields of the Équipe de recherche et d'action en santé mentale et culture (ÉRASME – Team for Research and Action in Mental Health and Culture) have been involved in the collective process of developing these documents.

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## Foreword

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### Gaining Autonomy & Medication Management

The concept of **Gaining Autonomy & Medication Management (GAM)**<sup>1</sup> is part of a much broader school of thought in psychiatry and mental health. To fully grasp the essence of the GAM concept, one must examine the etymology of the word “autonomous,” which stems from the Greek words *autos*, or “self”, and *nomos*, or “law”, from the verb *nemein*, meaning “to distribute or allot one’s due”; hence, “to give oneself one’s own individual law”. Gaining Autonomy & Medication Management involves openness to a range of perspectives and to sharing and discussing the role that medication and other practices play in the lives of users, as well as a willingness to substitute the positions of object of treatment and *patient* for *subject* and full-fledged *person*.

An assumption of dialogue and discussion is the essence of the GAM approach.

Autos  
Nomos  
Nemein  
dialogue  
sharing  
discussion



- 
1. The original GAM name is, in French, “Gestion autonome des médicaments de l’âme” or, literally, “Autonomous management of medication for the soul”. GAM is also referred to in French as “Gestion autonome de la médication en santé mentale”, which translates into “Autonomous Management of Medication in Mental Health”. The current English GAM name was ultimately selected in an effort to keep the original French acronym, “GAM”, hence “Gaining Autonomy & Medication Management”. GAM in Brazil is known as “Gestão Autônoma da Medicação” or “Autonomous Management of Medication”.

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### Excerpt from *Taking Back Control: My Self-management Guide to Psychiatric Medication, 2003*

#### Self Management of Psychiatric Medication: More than a fairy tale . . .

Since their beginnings about twenty years ago, Québec's alternative resources and advocacy groups in the field of mental health have been concerned both with the questions surrounding medication and also with the demands of people who have mental health problems or who have had them in the past. These people want their experience and first-hand knowledge of how medication affects their lives to be acknowledged.

For a host of reasons such as a lack of information on prescribed medications, the burden of their unpleasant side effects (especially with over-medication), continued suffering despite drug treatment, the inability to return to work, and the desire to live without medication, many people try to abruptly discontinue their medication. The vast majority of these people end up back in the hospital and, upon their release, find themselves even more medicated than before. For people working in alternative resources and advocacy groups, the accounts of such trying experiences are deeply moving.

#### Responding to a need for information

Thus in 1995, in response to a real need for information about psychiatric medication, the Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ), in collaboration with the researcher David Cohen and with Suzanne Cailloux-Cohen, published a guide concerning psychiatric medication entitled *Guide critique des médicaments de l'âme*. This book was written specifically for people taking these types of drugs and provides information that helps them exercise their right to free and enlightened consent to psychiatric treatment. In 1997, the AGIDD-SMQ developed a two-day course based on the *Guide critique* entitled *L'autre côté de la pilule* (The other side of the pill). The AGIDD-SMQ ran the program in several regions of Québec, primarily among people experiencing some form of mental health problem. For people wanting to take a more personal approach to their medication, however, this program by itself was not enough.

#### A new model of practice

In recent years, Québec's alternative mental health resources have been exploring a promising new model of practice: self-management of psychiatric medication (former GAM name). The end result of this exploration is that members of the Regroupement des ressources alternatives en santé mentale du Québec (RRASMQ)—a group of about one-hundred organizations with diverse intervention models all over Québec—have made a commitment to support SPM in their practices (*Manifeste* of the RRASMQ, 1999). At the centre of the various forms of support that these resources provide is a respect for people's questions and needs. These organizations are working to create a spirit of openness when discussing medication. From the standpoint of treatment, this helps to give meaning to peoples' experiences that goes beyond the mere control of symptoms sought by drug treatments.

In 1999, the RRASMQ and the AGIDD-SMQ initiated a pilot project involving ten member organizations of the RRASMQ. Researchers from the team for research and action in mental health and culture (Équipe de recherche et d'action en santé mentale et culture—ÉRASME) monitored the project's implementation (Rodriguez and Poirel, 2001). *My Self-management Guide* was born out of the framework of this pilot project. The guide is intended as a practical tool to help people embark on a process of reflection about their medication in order to improve their quality of life.

SPM (GAM) is an innovative idea developed by people who live with or have lived with mental health problems, by advocacy groups, and by alternative mental health resources in Québec\*. The concept was recently included in a document of the Québec ministry of health and social services (MSSS), which supports such projects in order to contribute to reaching its priority goal of empowerment (*Accentuer la transformation des services de santé mentale*, MSSS, 2001). It was with this in mind that the MSSS financed the production of this guide.

\* GAM practices have now been developed in Ontario, Canada and in Brazil.



# Introduction: A Handbook for Supporting GAM Practices

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This handbook is intended for anyone who places (or wishes to place) at the heart of practices surrounding psychiatric medication concerns about quality of life and empowerment of people living with mental health issues, whether these problems are temporary, moderate or serious.

In this sense, it is aimed at all service providers in the mental health field, doctors, nurses, psychologists, social workers, along with others who offer support, such as: relatives, peers and volunteers. Gaining Autonomy & Medication Management<sup>2</sup> (GAM) can be integrated into any process of therapeutic counselling or intervention, psychotherapy, rehabilitation, or reintegration that is oriented toward (re)empowerment and wellness, as well as toward recovery, understood as the possibility of getting back on one's feet in a more livable world.

This handbook is in keeping with the broad thrust of changes to Quebec's mental health system, which, since the implementation of the Politique de santé mentale (Mental Health Policy) (MSSS, 1989), has focused on putting people first, on the need to involve people in decisions that affect them, as well as on the importance of transitioning from a tradition of management to one of empowerment and from a chronicity-based outlook on problems to a recovery-based one (MSSS, 1998a; MSSS, 2005). The concept of GAM has aroused the interest of and received the support of the Quebec Department of Health and Social Services (MSSS) at various stages of its development.

More broadly, both nationally and internationally (WHO, 2001), health care institutions are showing an increasing desire to involve the people who are most directly affected in shaping mental health services and orientations. In this respect, it is generally recognized that the most significant problems and opposition are encountered at the field implementation level, in the effective organization of services and in the transformation of practices (MSSS, 2001a).

This GAM approach was developed gradually using participatory action research involving a variety of mental health practice settings (Rodriguez & Drolet, 2006; Rodriguez & Poirel, 2001) and has matured over many years. It supports and intensifies this new school of thought concerned with legitimizing the voices of people taking psychiatric medications. Indeed, the GAM approach is essentially grounded in the idea of listening to users' perspectives on psychotropic medication. Born of an intensely participatory collective process, the approach draws from a range of experiences and expertise—foremost that of medication users—but also from the knowledge emerging from intervention and practices in the field, as well as from research on mental health treatments (Rodriguez & Drolet, 2004; ÉRASME/RRASMQ, 2003; Rodriguez et al., 2001; Rodriguez & Poirel, 2001).

This handbook introduces the primary guidelines for GAM.



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2. The expression "GAM" first appeared in 1998 amongst a Regroupement des ressources en santé alternatives en santé mentale du Québec (RRASMQ – Quebec Coalition of Alternative Mental Health Organizations) work committee made up of medication users, service providers and representatives from the Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ – Association of Advocacy Groups for Mental Health Rights in Quebec). In 1999, the GAM approach was integrated into the RRASMQ's *Manifeste* as an integral part of (re)empowerment.



## Three GAM pilot projects

### 1999-2004

In 1999, an initial pilot project, launched in ten alternative community-based mental health organizations with a variety of vocations, helped to gradually define the shape of a new approach and a new mental health practice model: Gaining Autonomy & Medication Management (GAM). The Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ – Association of Advocacy Groups for Mental Health Rights in Quebec) is associated with this pilot project. The Équipe de recherche et d'action en santé mentale et culture (ÉRASME – Team for Research and Action in Mental Health and Culture) also guided the experiment, which extended over a number of years (Rodriguez & Poirel, 2001 and 2003; Rodriguez & Drolet, 2004).

### 2002-2005

The second pilot project aimed to create a space for dialogue among the public system, the community network, medication users, and their loved ones concerning the role of medication in users' lives, in mental health practices, and in society as a whole. One aspect of the project involved the development of a GAM training course and its dissemination throughout the different Quebec regions (initially in alternative community-based organizations, but also in the public system in certain regions); the other aspect involved the setting up of pilot experiments in three Quebec regions in collaboration with different partners in the mental health field. An evaluative study was conducted by ÉRASME researchers (Rodriguez & Drolet, 2006). As part of this pilot project, funded by the MSSS, a provincial advisory committee made up of representatives from alternative organizations, doctors, health and social service professionals, as well as medication users was formed in order to guide the experiments and explore future extensions of the project.

### 2005-2007

A third project launched in 2005 aimed more specifically to create support and guidance networks for GAM and for knowledge transfer, which was subsidized by the Quebec Department of Economic Development, Innovation and Export Trade (MDEIE).

## The Quebec Department of Health and Social Services (MSSS) and GAM


Gaining Autonomy & Medication Management (GAM) has aroused the interest and received the support of the Quebec Department of Health and Social Services (MSSS) on several occasions. In 1998, a sub-committee of the *Comité de mise à jour de la Politique de santé mentale* (Mental Health Policy Update Committee) (MSSS, 1989) produced an advisory paper entitled *Pour une gestion autonome de la médication. Mythe ou réalité?* (Toward Gaining Autonomy & Medication Management: Myth or Reality?) under the direction of psychiatrist Michel J. Messier. Three years later, in 2001, the MSSS introduced GAM through a report entitled *Accentuer la transformation des services de santé mentale* (Accentuating the transformation of mental health services), which followed up on the 1998 *Plan d'action pour la transformation des services de santé mentale* (Action Plan on the Transformation of Mental Health Services) (MSSS, 1998a). In the 2001 report, the MSSS committed to supporting projects aimed at Gaining Autonomy & Medication Management in order to help reach the priority goal of empowerment. Shortly thereafter, the MSSS funded the publication of *Taking Back Control: My Self-management Guide to Psychiatric Medication*, jointly produced by the RRASMQ, the AGIDD-SMQ and ÉRASME. That same year, in 2002, a pilot project aiming to raise awareness of and develop practices to support GAM also received funding from the MSSS, and a ministerial representative joined the provincial advisory committee that was formed to guide its development. The MSSS contributed to the funding of the International GAM Forum held in 2007 and participated in the event. In 2012, the importance of GAM practices was reintegrated in the *Appraisal Report of the Performance of the Health and Social Services System* by the Quebec Health and Welfare Commissioner.

## What is GAM?

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“GAM should not even be a question. It should be part of common mental health practices.”<sup>3</sup>

Gaining Autonomy & Medication Management (GAM) is not an end in itself. It is inseparable from an overall perspective of wellness, to which the drugs taken must contribute, lest they lose their essential purpose. The aim of GAM is to help psychiatric medication users reach a level of medication that is acceptable to them and that is part of a broader improvement process.



**GAM is not an end in itself. It is inseparable from an overall perspective of wellness, to which the drugs taken must contribute, lest they lose their essential purpose.**

In this sense, GAM considers the role of psychiatric medication in dealing with mental health problems as simply one tool among many that can help people who are seeking progress and wellness.<sup>4</sup> In a context in which pharmacotherapy appears to be widely favored for dealing with mental health problems, GAM takes other factors into account in the process of becoming well.<sup>5</sup>

*In itself, GAM aims at neither:*

- *an improvement in adhering to a treatment, nor*
- *a reduction or cessation of psychiatric medication.*

The intent of GAM is not to advocate a position regarding psychotropic medication as such.

Rather, based on the assessment of research data and on requests from medication users themselves, GAM promotes and enables a reflection and an in-depth examination of people’s relationships with their medication and of its role and effects in their daily lives and progression. For people dealing with mental health problems, it places the role of medication into a broader context of self-examination in terms of quality of life, of ways to improve it, and of the conditions for significant change in one’s daily life and life trajectory.

For those guiding and counselling people who take psychiatric drugs and who experience the effects of such drugs in their daily lives, this approach entails an attitude of openness and availability, as well as a willingness to place medication users at the centre of the treatment process.

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3. Excerpts from an interview with a participant in the 1999 GAM pilot project implemented in 10 alternative mental health organizations, as cited in Rodriguez & Poirel, 2001.
  4. In a 2001 report, the World Health Organization stated that the “three fundamental ingredients” of an “appropriate treatment of mental disorders” are: “medication (or pharmacotherapy), psychotherapy, and psychosocial rehabilitation” (WHO, 2001, p. 55–59).
  5. When confronted with improvements or deteriorations in a person’s mental health, professionals, family, friends and the person themselves often tend to concentrate exclusively on medication, to the detriment of other factors likely to be involved in the changes (Rodriguez & Drolet, 2006 and 2004).



## Perspectives of medication users on the prescription of psychiatric drugs

Statements by psychiatric drug users highlight both the conditions that allow medication to be a tool likely to be integrated into one's progress toward wellness and toward a greater ability to exist and act in the world and also the practices that, on the contrary, heighten the experience of distress.


"In summary, one might say that the practices associated with psychiatric medication that are most objected to by medication users are:

1. medication presented as the only answer to suffering;
2. the prescription of medications with painful side effects;
3. high doses of medication that hinder working on one's self;
4. the difficulty—or impossibility—of questioning or offering one's point of view on the medication;
5. high-dose and long-term prescriptions that are consequently even harder to call into question;
6. insufficient information;
7. little room for dialogue with doctors concerning medication;
8. insufficient follow-up; frequent feelings of abandonment after hospital stays;
9. little room for alternative therapeutic approaches to medication;
10. interventions focused on controlling medication;
11. condescending and demeaning interventions;
12. the fact that questioning medication is understood as resistance to or refusal of treatment.

On the other hand, under certain conditions, medication can be an instrument that does not stand in the way of empowerment and improved quality of life:

1. when it is accompanied by other forms of working on one's self and support;
2. when it is accompanied by adequate information;
3. when doctors take the time to give meaning to the experience and suggested course of treatment;
4. when medications help reduce or eliminate certain symptoms and restore stability to one's life;
5. when people are too "down" or in crisis, to obtain specific, short-term effects."

Excerpts from Rodriguez et al. "Limites du rôle de la médication psychiatrique dans le processus de réhabilitation du point de vue des usagers" (Limits of the role of psychiatric medication in the recovery process from the point of view of users), *Équilibre, Pharmacologie et santé mentale*, Association canadienne pour la santé mentale, 2006.



**The hopes raised by developments in psychopharmacology in recent decades have tended to push certain aspects, challenges and limitations regarding the use of psychiatric medication to the background.**

In the Western world, particularly in North America and in Quebec, medication now occupies a central role in mental health practices and in the lives of people who are intimately acquainted with the psychic, relational and social suffering that accompanies mental health problems. Indeed, psychotropic drugs (antidepressants, anxiolytics, mood stabilizers, neuroleptics or antipsychotics and stimulants) frequently constitute the first and primary response presented to those who seek psychiatric and mental health services (Rodriguez et al., 2006 and 2001), and such people are often overmedicated (in terms of dosage, duration and number of prescriptions). Psychiatric drug users span all age groups (MÉOS/ Conseil de la santé et du bien-être, 2005; MSSS, 1998b). Over time, the range of application of psychotropic drugs has spread considerably, taking part in and in keeping with a broader tendency of our societies to medicalize human anguish (Collin, 2006).

The special status enjoyed by medication in current mental health practices owes its origins to pragmatic and theoretical considerations. The former relate to the ease of use of psychotropic drugs and the relative rapidity of their effects; these characteristics have enabled such drugs to accompany a significant trend toward deinstitutionalization. The latter relate to the spread of hypotheses and biomedical models in psychiatry that seek reliable and specific biological “markers” of mental disorders, the understanding of which, despite certain discoveries, remains fundamentally elusive (Lalonde et al., 1999).

This rapid spread of the biopsychiatry model has put other conceptions of mental health problems on the back burner, particularly psychodynamic and psychosocial conceptions, which attempt to understand mental health problems as part of a personal and relational history and within a broader social and cultural context. While mental health practices had until recently benefited from the dynamic tension between these different conceptions (Comité de la santé mentale du Québec, 1985), this narrowing of the focus of understanding of mental health problems and their origins remains of concern (Comité de la santé mentale du Québec, 2006).

Combined with the development of increasingly specific diagnostic classifications fundamentally based on symptomatology<sup>6</sup>, the hopes raised by developments in psychopharmacology in recent decades (particularly reductions in hospital stay durations and the presumed impact on the social reintegration of people with serious mental health disorders) have tended to push certain aspects, challenges and limitations regarding the use of psychiatric medication to the background.

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6. The most frequently used classifications in Quebec and North America are those of the *DSM-V, Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatry Association in 2013.



In both the research field and also in certain mental health practice environments, there is increasing awareness of the importance of moving beyond a fragmented view of psychiatric medication and of approaching this question and the issues it raises from a broader perspective (MÉOS/Conseil de la santé et du bien-être, 2005).

The concept of GAM aims to broaden the perspective of psychotropic drugs and to promote this attitude in mental health practices.

## The complex effects and limits of psychiatric medication


The drugs used to treat mental health problems and their effects are hugely complex. Psychotropic drugs are prescribed for certain anticipated effects, and they have a recognized therapeutic role. But they also have certain limitations, as well as adverse side effects that sometimes overlay their beneficial effects. In practice, time is not always taken to weigh the pros and cons of these different aspects of medication.

People who take psychotropic drugs recognize both their importance and their limitations, as shown in qualitative studies on the points of view of people receiving psychiatric and mental health care. On one hand, most of the people questioned felt that at one point or another, the medications helped them feel calmer. On the other hand, many deplored the fact that the regular use of medication or improper medication prevented them from “getting in touch with themselves” and hindered any possibility of personal transformation or deeper recovery (Rodriguez et al., 2006, 2001 and 2000; Corin et al., 1999).

### Roles and limits of psychotropic medication

Irrespective of the medication and of the problem it targets, psychotropic medication does not fall into the category of curative medicine (WHO, 2001; Zarifian, 1994; Turmel, 1990).

While psychiatric drugs do not cure per se, they can help mitigate and control certain symptoms. Hence, in many cases, they can be considered necessary, especially at certain times or at certain stages of problems and of the experience of suffering. However, research and clinical experiments have shown that drugs do not always succeed in alleviating the targeted symptomatology.<sup>7</sup>



**While psychiatric drugs do not cure per se, they can help mitigate and control certain symptoms.**

- 
7. Clinical psychopharmacological research has shown that the effects of medication remain uncertain. In particular, between one-quarter and half of people who have been diagnosed with schizophrenia experience symptoms such as delusions and hallucinations even while on drug regimens. Relapses are also frequent, even among patients who adhere to their treatments (Fowler et al., 1999).



**The complexity of mental health problems affects many aspects of people's lives, including their identity, experience of the world, relationship to the self, and relationships with others.**

Research into the perspective of people who take psychotropic drugs reveals that, for most of them, psychological and interpersonal suffering is not limited to and extends far beyond mere symptomatology (Corin, 2002; Rodriguez et al., 2000). The complexity of mental health problems affects many aspects of people's lives, including their identity, experience of the world, relationship to the self, and relationships with others. In this respect, what help these drugs do provide seems to be insufficient, even when they are recognized as being necessary.

Based on their clinical work in psychoanalysis and psychiatry with people experiencing psychosis, some authors have come to the same conclusions:

*"Despite progress in this area, biological approaches to mental health disorders only affect problems on the surface, by easing symptoms." (Apollon, 1990, p. 14)*


*"This limitation of medication, far from boiling down to a biological or biochemical resistance, or being related to the surrounding environment, stems from a completely different point of view. Medication is ineffective in treating problems related to human issues, intersubjective conflicts, difficulties in coexisting with others, etc." (Turmel, 1990, p. 165)*

*"In some patients for whom psychosis is particularly terrifying, a decrease in psychotic symptoms may be enough for them to feel that they have obtained significant benefits from medication. In many other cases, however, stability comes at too great a cost in terms of overt side effects, more subtle alterations in the patient's sense of self, [and] decreased energy or spontaneity [...]. It seems clear, however, that antipsychotic medications have little to offer most patients in terms of providing relief from deficit symptoms or dealing with their interpersonal and occupational limitations. [...] It is assumed, often without much reflection, that an improvement in psychotic symptoms and the ability to survive outside the hospital is enough. Obviously, our patients do not believe it is enough." (Diamond, 1985, p. 34–35)<sup>8</sup>*

In addition, psychiatric drugs can attenuate the intensity of what may be intolerable suffering. In this sense, for some people, medication may be necessary in order to initiate an in-depth examination, psychotherapy, or another form of therapy.

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8. Similar comments were collected during the second GAM pilot project (2002–2005). In particular, a hospital social worker remarked that "providers tend to forget that people have their own rhythms. Our clients are not supposed to return to the hospital. They're supposed to be well. They're supposed to be stable. At the same time, though they seem stable from society's perspective, we often forget to ask what the cost is in terms of their quality of life." Comment reported in Rodriguez & Drolet, 2006.





**Sometimes, taking one or more psychiatric drugs can actually come to be a barrier to the wellness sought by people with mental health issues and by those who guide them.**

From the perspective of people experiencing one or more mental health problems, the ability to work on one's self, one's inner experience and self-image, and the relationships one has with others and the world is what contributes most profoundly to getting better and transforming one's life (Rodriguez et al., 2000). However, while comments indicate that, at certain times and under certain conditions, medication can be helpful in this essential work on the self, the heavy dosages that hinder this progression seem to be especially upsetting.

Thus, certain practice environments are striving to achieve minimum effective doses of psychotropic medication that allow people to pursue other types of treatment, particularly psychotherapy (Turmel, 1990; Sassolas, 2000). However, such drug prescription practices require closer medical follow-up than is generally offered by mental health services.

### Side effects of psychiatric drugs

Psychiatric drugs can also produce different types of side effects, which can be especially debilitating with high doses or when the medication is taken over a long period of time and in combination with other medications.<sup>9</sup> Depending on their nature, their dosage, and people's individual responses to them, psychotropic drugs can affect cognitive ability (numbness, slowing of thought and speech), physical appearance (weight gain, trembling), the ability to connect with others, and long-term health. Hence, medication can sometimes harm people's quality of life.

The visible effects of certain psychiatric drugs, particularly neuroleptics (rigidity of facial expression, involuntary movements),<sup>10</sup> can make social integration difficult, thereby contributing to stigmatization, marginalization, and restricting people to the role of "patient" (MSSS, 1998b; Estroff, 1981).

Hence, sometimes, taking one or more psychotropic drugs can actually come to be a barrier to the wellness sought by people with mental health issues and by those who guide them.


In certain cases, prescriptions stray from the optimal threshold at which the drug is both effective in reducing symptoms and limited in terms of its side effects. When medication causes particularly unpleasant negative effects, reducing dosages and the number of psychotropic drugs taken often helps to attenuate side effects and their negative impact on people's quality of life, social integration, and personal progress.

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9. Taking certain psychotropic drugs can occasionally cause permanent after-effects, such as tardive dyskinesia, which is associated with taking neuroleptics.
  10. The introduction of new antipsychotics said to be "atypical" has helped to change, but not completely eliminate, the incidence of side effects, which particularly affect physical appearance, especially with respect to significant weight gain (Lachaux et al., 2001; Casey, 1996).



## The multiple experiences and meanings associated with psychotropic drugs

The importance of taking into account the experiences and meanings associated with pharmacological, psychotropic and other drugs among users has been highlighted in the increasing number of studies in recent years which reveal the impact of such dimensions on how people relate to their treatments (conflicting to a greater or lesser degree, positive or negative, passive or active) and on how they do or do not adhere to their drug prescriptions (MÉOS/Conseil de la santé et du bien-être, 2005; Collin, 2002; Fainzang, 2001; Groleau, 2004). Palpable in these studies is the fact that this recognition of the importance of meanings and individual experience of treatment for the people concerned is slow in finding its way into care practices.



**In the complex field of mental health, with its various coexisting conceptions of the origins of and best ways to treat disorders, the dimensions of personal experience and meanings associated with treatment take on particular importance.**

In the complex field of mental health, with its various coexisting conceptions of the origins of and best ways to treat disorders, the dimensions of individual experience and meanings associated with treatment take on particular importance.

As so poignantly illustrated by the statements of those directly concerned, the experiences associated with taking psychiatric drugs do not follow any particular rule:


*“At certain times, medication saved my life...” (Comment made during an “Introduction to GAM” training.)*

*“I react very strongly to medication; one day I was forced to take them: it nearly killed me...” (Comment made during the pilot project involving 10 alternative community-based mental health organizations.)*

The effects of medication and the meanings it acquires in the lives of users and their loved ones are also often puzzling and ambiguous:

*“I have trouble figuring out whether taking medication is good or not; it’s an area of permanent internal debate.” (Statement of a medication user cited in Rodriguez et al., 2001.)*

*“My son is psychotic. He has gone through periods of intense crisis. But lately, he has been taking his medication regularly, and it’s reassuring. He seems more stable, but I also have to wonder. My son was very creative; he wrote a lot of poetry, but he doesn’t write anymore.” (Comment made during an “Introduction to GAM” training.)*



**The symbolic aspects of medication, its multiple and often contradictory meanings (sometimes associated with illness, sometimes with health; sometimes seen as a solution, sometimes as a cause of suffering) are as important as its biological effects.**

Psychiatric drugs always mean something to the people taking them, their social circle, and society. While, for some people, they can signify positively managing and effectively controlling the troubles invading their lives, for others, regular consumption of such drugs is a constant reminder of their distress and limitations, due to the fact that they are controlled by others.

The accounts of people who take psychiatric drugs illustrate that the symbolic aspects of medication, its multiple and often contradictory meanings (sometimes associated with illness, sometimes with health; sometimes seen as a solution, sometimes as a cause of suffering) are as important as its biological effects. The symbolic and biological effects of these drugs are tangled together in people's lives (Rodriguez et al., 2001; Rousseau, 1992).

The multiplicity and complexity of experiences and meanings associated with psychiatric medication call for greater consideration in mental health care systems and practices.

### **The reluctance to use psychiatric medication**

In the face of recurring relapses which can occur despite drug treatment, because of unwanted side effects, which are significantly amplified in instances of overmedication, or due to poor listening and follow-up as perceived by those concerned — there is frequent resistance to psychotropic medication. Many users have abruptly abandoned their drug treatment at one time or another without consulting the prescribing physician and without even discussing it with their inner circle or mental health care providers. These brutal withdrawal experiences generally prove to be painful, and in many cases people end up in crisis once again, which often leads to an even heavier drug regimen.

To mitigate the resistance to taking psychotropic drugs, particularly when it comes to treatments intended for people with severe mental health problems, active support practices focusing on compliance with and control of medication have been implemented in recent years in certain community practice settings.

It remains to be seen, however, to what extent these active medication support practices are compatible with taking into account the complexity and multiplicity of people's experiences with medication.



**One's relationship with psychiatric drugs and the role they do or do not play in the process of improvement and recovery are highly influenced by the contexts and methods of prescription and follow-up.**

## **The role of prescription practices and follow-up for psychiatric medication**

One's relationship with psychiatric drugs and the role they do or do not play in the process of improvement and recovery are highly influenced by the contexts and methods of prescription and follow-up.


Yet, the people concerned frequently receive little or no information about treatment goals and side effects, drug interactions, possible risks involved, implications of non-intervention, and complementary and alternative treatments (MSSS, 1998b). The individual experience and meanings associated with taking psychotropic drugs for those concerned are only rarely considered by health care practitioners, who have trouble evaluating their psychological and social impacts, especially in a context in which the duration of medical consultations is very limited.

Indeed, based on psychiatric clinical experiences, some authors have shown that giving people a chance to actively participate in deciding how their medications are used is an essential factor in their cooperation with the treatment (Turmel, 1990; Diamond, 1985). Moreover, this removes the medication's image as a "persecutor." In fact, from a symbolic standpoint, psychotropic medication could bring about a subtle experience of loss of power, particularly as a long-term intrusion into one's body space (Estroff, 1981).

Studies have also shown that, in contexts where drug prescriptions are accompanied by greater availability on the part of the treating physician, and where there is discussion and negotiation surrounding their use, the same effects can be achieved with lower doses than when drug prescriptions are externally controlled (Keith, 1984; Turmel, 1990).

The accounts of people who take psychiatric drugs show that a combination of certain factors appears to favour medication being viewed as a tool to be used to get well. Yet, this positive view of medication only arises when psychiatric drugs are prescribed in the context of a relationship where people feel that they are being heard and that the course of treatment is negotiable, where the use of such treatments does not automatically imply an identity as a lifelong patient, and where medication is not the only response to suffering (Rodriguez et al., 2006; Rodriguez & Poirel, 2001).





**To play a positive role in the lives of medication users, the prescription of drugs must be adapted to each individual situation.**

As a response to mental health problems, medication is at times a necessary measure to attenuate symptoms and relieve distress. However, as shown by both the accounts of users and clinical experiences, medication alone is not usually sufficient and should be accompanied by other practices.

At the same time, to play a positive role in the lives of medication users, the prescription of drugs must be adapted to each individual situation. Finding the right medication and dosage tends to be a slow process of trial and error, one that is often trying for both those concerned and their health care providers and loved ones. Existing practices for prescribing and following up on medication are generally insufficiently adapted to the type of guidance required for this type of process. “We need to be able to use medications creatively, as tools adapted to each person,” stresses psychiatrist Cécile Rousseau (Rousseau, 1992).



## Creating safe spaces for open dialogue on mental health medication

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**GAM [...] calls for a dialogue among the various bodies of knowledge about psychotropic medication and its impacts.**

While psychotropic medication is a significant and complex part of both the lives of people with mental health issues and mental health practices themselves, there are few spaces for talking about these drugs, their effects, their limitations, and their meanings, either between users and providers, or among mental health professionals. In several mental health practice settings, medication all too often remains a taboo subject, and the question of medication tends to be referred back to physicians, who are often reluctant to expand on the question with patients, either due to lack of time or apprehension. Yet, the need for spaces for dialogue and discussion about medication has become increasingly apparent to both the people concerned and service providers, who are all penalized by this silence (Rodriguez & Drolet, 2006).

The goal of Gaining Autonomy & Medication Management (GAM) is precisely to open such safe spaces of open dialogue and discussion about medication, its place and role, its limitations, and its meanings, primarily for the people taking these medications, but also for their loved ones and mental health professionals. Such spaces would allow the various stakeholders concerned with medication to meet and discuss the issues in an open and respectful manner.

GAM also calls for a dialogue among the various bodies of knowledge about psychiatric medication and its impacts: the fundamental and essential knowledge of the people taking the drugs, the knowledge of medicine, the knowledge of the different categories of mental health professionals (psychologists can help clarify the role of medication in working on one's self, and social workers can better identify the impact of medication on the reintegration process<sup>11</sup>, etc.). "We want to promote the sharing of this knowledge rather than substituting one authority for another" (Dr. Cécile Rousseau, cited in Rodriguez & Poirel, 2001).



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11. Aimed more specifically at collaboration with partners, the second GAM pilot project (2002–2005) showed that this approach also resonates well in the context of the organization of services in which medical follow-up of medication such as it is, is often limited. Hence, mental health workers from different categories are increasingly called upon to widen the scope of their practices with respect to medication and to take it into account in order to support people in the community. For several of them, GAM appeared as a more systematic way of doing so (Rodriguez & Drolet, 2006).



## GAM as seen by public sector health care providers\*

**“GAM helps empower people and readjust the relationship with their physician. It allows them to take charge of their lives.”**

Social worker, CLSC\*\*

**“It’s helping people find their own way.”**

Psychologist, mental health team, CLSC

**“It turns out to be much nuanced. We ultimately see all aspects. I strongly believe in self-determination, and I’m very much in favour of such a process. It creates a balance between the biomedical approach and people’s management of their lives. It rebalances the forces involved. We do seem to be heading toward one extreme, and it makes you wonder. If I took psychiatric medication, I would like to be able to question my doctor. I would need to.”**

Physician, mental health team, CLSC

**“It creates openness to the word ‘medication’. It breaks down stereotypes.”**

Social worker, mental health team, CLSC

**“People learn how to listen to themselves more, how to know themselves better.”**

Community case worker, CLSC

**“ It shows that we may not pay enough attention to perceptions and symbolism . . . how people feel about it. There’s room to do more.”**

Nurse, mental health team, CLSC

**“The ‘Taking Back Control’ GAM guide allows people to make a basic assessment of their lives; similar to the ones providers do but don’t share with them. It’s going from being managed to gaining awareness.”**

Social worker, CLSC

\* These comments were gathered during the 2002–2005 GAM development pilot project and throughout GAM training activities. Some of these statements also appear in Rodriguez, L. & Drolet, M., 2006.

\*\* In Quebec, CLSC stands for “Centre local de services dans la communauté” which translates as “Local Community Service Centre”. CLSCs offer public health and social services to members of the community.

The key Gaining Autonomy & Medication Management (GAM) principles are:

- The importance of subjective quality of life
- (Re)empowerment
- Recognition of the multiple meanings of medication
- Respect for people, their decisions, and their rights
- A broad approach to suffering and wellness

Implementing GAM in mental health practices involves a real and significant consideration of these principles.

### Toward subjective quality of life

“Psychotropic treatment should improve quality of life, not diminish it.”

*Édouard Zarifian (Psychiatrist and author)*

The advent of the concept of quality of life in the mental health field has shifted the objective assessment of needs and services toward an increased concern for the subjective perceptions of those most directly affected (Mercier, 1993). Recent studies have demonstrated the significant impact of mental health services and practices on quality of life for the people concerned, especially those with serious mental health problems (Comité de la santé mentale du Québec, 2006).


Concern for quality of life is at the very heart of GAM. Yet, quality of life remains a highly personal and subjective matter, and there are no precise rules in that regard. “When we talk about ‘quality of life,’ we mean everything that contributes to creating more harmonious living conditions. There is no single ‘recipe’ for getting there” (AGIDD-SMQ & RRASMQ, *Taking Back Control: My Self-management Guide to Psychiatric Medication*, 2002).

There are many aspects to quality of life that must be considered. GAM therefore calls for a personal assessment of one’s overall quality of life.

For people taking psychiatric medication, the drugs are only one aspect of quality of life. Discomfort felt on a daily basis might be due to side effect of medication, but it may just as well be related to a whole other aspect of one’s daily life (sleeping habits, diet, etc.) or personal experience.

While it is not the only thing that affects quality of life, medication does come into play in one way or another, either positively or negatively depending on the different situations and perceptions. GAM practices must take into account the personal nature of these situations and perceptions.





**GAM process seeks a comfort zone in the consumption of psychiatric drugs [...]. GAM has no fixed rules; it is always part of a highly individual process.**

Since drug treatments are often initially prescribed during a time of crisis or acute distress, an overall review of people's quality of life and a projection toward the desired quality of life are often necessary to best identify the role of the current medication and, possibly, any future changes.

Hence, GAM seeks a comfort zone in the consumption of mental health medications, *a suitable level of medication and a quality of life dose*. This comfort zone can shift over time, with progress, and based on different experiences and events.

Reaching *a suitable level of medication and a quality of life dose* can require changes to the pharmacological treatment, changes to one or more of the drugs themselves, a reduction or increase in the existing medication. In certain cases, the process of seeking a better quality of life can lead to a gradual cessation of the medication.

GAM has no fixed rules: it is always part of a highly individual process.

## Toward (re)empowerment

Concerned as it is with fostering the development of an active role toward drug treatment rather than a passive one, GAM is aimed at (re)empowering medication users.

In itself, (re)empowerment is such an individual and personal thing that, considered broadly, it is impossible to define. Nevertheless, certain conditions for its emergence have been identified: gaining greater control over one's life and environment, the ability to fulfill one's potential, the possibility of contributing to one's community, and the ability to make free and informed choices, as well as the ability to defend one's rights (Comité de la santé mentale du Québec, 2006; Comité de Pilotage du Guide, 2004).<sup>12</sup>


The nature of mental health problems—which affect the innermost parts of people's beings and impact several aspects of their lives—on the one hand, the tendency for their treatment to be managed by health care services and practices, on the other hand, often combine to hinder the empowerment of people with mental health issues.

Increasingly, medication users are demanding (re)empowerment and the ability to define and redefine the shape of their own process.

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12. In the process of expanding and building upon the ability of people living with mental health issues to live and act in society, those who support them, including providers, are often called upon to play an important role. While it is an individual process, it is also a relational one and, more broadly, a social one. "(Re)empowerment involves working on one's self through one's work with others" (Comité de la santé mentale du Québec, 2006, p. 97).





**GAM involves a search for conditions that can be adjusted to any situation and that allow drug treatments to become tools in helping people embarked on the path toward recovery and well-being.**

In particular, users of mental health services and psychiatric drugs are making their demands to be fully involved in the treatment process. It means not only recognizing their own experiences and the special expertise this confers, but also having the power to take control of their personal recovery process and medication, assessing its impact on their progress and quality of life.

Concerned as it is with making these demands a reality, GAM involves a search for conditions that can be adjusted to any situation and that allow drug treatments to become tools in helping people embarked on the path toward recovery and well-being.

*Translated excerpt from **Guide pour une réflexion et un dialogue sur l'appropriation du pouvoir individuel et collectif des personnes utilisatrices de services en santé mentale. Paroles et parcours d'un pouvoir fou**, (Comité de Pilotage du Guide, 2004).\**

“A process of achieving empowerment (either alone or with others) is not a recipe; it is not a PRN prescription (i.e. to be taken “as needed” and according to the interests and choices of someone else); it is not an expected and pre-established course toward integration at any cost; and... above all, it is not a uniform to be worn, as if we were all the same—women and men, the elderly and the young, people from cultural, gay, lesbian or Native communities—as if the diversity of our realities, needs and living conditions disappears... as soon as we get stuck with a psychiatric label.


There are differences to recognize and respect. There are differences between ‘taking back’ a power that’s been lost... and ‘taming’ a power that’s never been known.

Empowerment is not a result, it is a process. It is not a destination; it is a journey, along a route that does not always follow a straight line. It is a road on which one loses their way before finding themselves, and on which ‘stumbling’ is just as important as taking the next step. It is wandering... wandering in all directions but never the wrong one. It is the right to try things, to experiment, to learn, to evolve. It is the right to dream...

It is building and rebuilding a life: a continuous process... an endless ‘work in progress’, a construction site. And it is time... the time needed... the time it takes (sometimes less, sometimes more than expected) to become someone, somewhere... or (maybe, one day) a full-fledged citizen.”

Denise M. Blais

\* Title translation: Guide for reflection and dialogue on individual and collective empowerment of mental health services users. Words and stories of a mad power.



**In providing support, it is important not only to respect people's representations of their prescribed medications, but also to work within that world of representations and meanings.**

## **Toward the recognition of the multiple meanings of medication**

For people who take these drugs and those who support them, psychiatric medication is never neutral. It comes with a multiplicity of meanings that can be either positive or negative, and most frequently highly ambivalent. Sometimes a symbol of health, sometimes a symbol of illness, sometimes perceived as the only solution, sometimes experienced as the cause of illness, medication can signify both things at once, as well as come with a host of other meanings.

Sometimes, certain drugs take on specific meanings and, from a symbolic standpoint, a person might tolerate one type of medication poorly while readily accepting another.

For mental health support providers, it is important to be aware of the world of meaning that surrounds psychiatric drugs. In providing support, it is important not only to respect people's representations of their prescribed medications, but also to work within that world of representations and meanings. It is vital to avoid positions of value judgment.

Psychiatrist Cécile Rousseau points out that "None of these representations is true or false, good or bad. They all represent a portion of the truth, and it is all true in the sense that it represents people's experiences, so it is important to take into consideration, even more so than the precise chemical effects of the medication" (Rousseau, 1992).

It is also important that providers be aware of their own representations of psychotropic medication, which inevitably interfere with the support process, colouring one's comments and practices regarding medication. For providers, being aware of one's own world of representations and meanings surrounding psychotropic drugs can help to better understand and respect that of the people taking them.



**Translated excerpt from a presentation by psychiatrist  
Cécile Rousseau: “Neuroleptics in psychiatry: to take  
or not to take, is that the question?” (1992)\***

“I want to speak to you today about medication from the standpoint of what it can represent, especially for people who take it. [...] I won’t be addressing neuroleptics specifically, but rather all psychiatric medication: neuroleptics, lithium, tranquilizers, and sleeping pills. One way or another, regardless of their actions, all of these pills can hold similar meanings.

First, it is important to note that in the representations—in other words, the images people have of medication and what it represents for them—we find images that are totally and even diametrically opposed. And this is what makes the subject both very interesting and extremely delicate. For example, for certain people, medication can represent health, while for others, it represents their illness. When it represents the illness, it represents it as being unacceptable. Taking medication reminds the person every day—or every month, if they take an injection—that they are sick. And this illness is not acceptable: it is something others say, they don’t accept that it is part of them—they don’t consider themselves to be sick—or they don’t consider that the illness is what primarily defines them. So the medication reminds them day after day that other people think of them as being sick. Medication becomes totally unacceptable because it does not represent medication, it represents the illness. This leads to rebellion and to the rejection of all medication, since if it represents the illness and the illness is unacceptable, then medication is also unacceptable.

In a similar vein, we find that other people have the opposite reaction: medication can represent health and any absence or change in that medication reawakens the fear of getting sick again. For these people, it is as if the pill represented health, and they say to themselves: ‘If I don’t have my pills anymore, if I don’t have my medicine, that means I’m sick.’ A reduction or change in medication can also induce this reflex. Sometimes, there are people who have been taking lots of pills for years, but any change means ‘I could start to be sick again, and that’s too painful, too distressing, I just can’t face that.’ So we have completely opposite meanings: for some, medication can mean illness, and for others it can mean health.

There are other opposing representations. For some people, medication represents the cause of their illness: ‘I’m sick and I don’t feel well because I took my pills and it is the pills that made me sick.’ So the medications are responsible for anything that’s not right. In Ireland, a Mr. Zola did a study on patients taking neuroleptics, patients who were often out of touch with reality, so we could say they were psychotic. The study revealed that for people in Ireland, someone who lives in their inner world and who talks to themselves in the street is not a problem, and it doesn’t alarm anyone. But someone with side effects due to the medications, someone who is all stiff and who trembles, that scares people. In this case, when these people took medicine, ostensibly to get well, they became sick people to those around them. So in the eyes of their loved ones, the side effects of medication made them sicker than their actual illness did. This is a good illustration of how medication can be perceived by users and their loved ones as the cause of illness.

(Continued on page 26)

Translated excerpt from a lecture by psychiatrist Cécile Rousseau:  
“Neuroleptics in psychiatry: to take or not to take,  
is that the question?” (Continued)

At the opposite end of the spectrum, there are people for whom medication is the only solution. They're not interested in examining their personal lives; they don't want to talk about what's happening at work, with their families, children or spouses, or in their love lives. The only solution is the medication; they don't want to talk about anything else, which allows them to avoid all the heavy responsibilities in their lives. So these are two other opposing meanings: medication as the cause or the solution.

Here's one last pair of opposites: medication can represent solitude or social connection. For some people, taking medication represents the rejection they feel from the people around them; it represents marginality and isolation. So stopping one's medication or not taking any represents the contrary. But for other people who are also very isolated, medication represents, on the contrary, someone who supports them. I work with a person who told me she always kept her pills in her pocket. For her, just hearing the sound of the pills was like having a companion, as if there were someone who could always be there for her, and that reassured her.

It is important to point out that none of these representations is true or false, good or bad. They all represent a portion of the truth, and it is all true in the sense that it represents people's experiences, so it is important to take into consideration, even more so than the precise chemical effects of the medication.

Thus, medication may be a tool that a specific person may use according to their needs, or not use according to their needs as well. It doesn't matter whether the drug's action is clinical, chemical or symbolic. What is important is to respect the representations that people have of their medication and work from there.

Finally, medication can therefore be a tool, if it is not taken in a context of unequal balance of power in which the medical profession or institution possesses knowledge about medication and in which others are supposed to accept such knowledge. In most cases, what prevents medication from becoming an adequate tool, whether they are taken or not—what prevents medication from being used from time to time depending on people's needs—is the fact that it is not possible to talk about it as equals. What person feels or thinks about medication does not have an equal or greater weight to what the medical profession or institution has to say about medication. And I think that this is the main problem that prevents medication from becoming a tool. [...]

\* Cécile Rousseau was involved in the development of the GAM approach.

## Toward respect for people, their decisions, and their rights

“I’m a person, not an illness!”

MSSS, Harnois Report, 1987

The values of respect for people, their dignity, their freedom of choice, and their rights are fundamental for people living with mental health problems and who use psychiatric and general mental health services (Comité de Pilotage du Guide, 2004; Comité de la santé mentale du Québec, 2006).

Gaining Autonomy & Medication Management (GAM) allows integrating these fundamental values into practices. With this approach, the role of mental health professionals is to support people in a process in which choices and decisions are fundamentally up to the person seeking care. GAM reminds us that people undergoing mental health care have the right to be respected in their decisions, even if these may not agree with those of their caregivers, peers, or loved ones.

### GAM from a legal perspective

“GAM is not just a choice, but a fundamental human right.”

MSSS, *Pour une gestion autonome de la médication. Mythe ou réalité?* (Toward Gaining Autonomy & Medication Management: Myth or Reality?, 1998)

GAM rests on one primary and essential principle: the recognition of fundamental human rights (RRASMQ, 2002). In Quebec, fundamental human rights are guaranteed by the Civil Code, the Quebec Charter of Human Rights and Freedoms, and the Canadian Charter of Rights and Freedoms. Among these fundamental rights is the right to free and informed consent, particularly in the area of health care.

The Civil Code of Québec states:

“No person may be made to undergo care of any nature, [...] except with his consent” (Sec. 11).<sup>13</sup>

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13. In this same section, the Civil Code also stipulates: “If the person concerned is incapable of giving or refusing his consent to care, a person authorized by law or by mandate given in anticipation of his incapacity may do so in his place.” In psychiatry, situations of legal incapacity are in fact rare.





**GAM reminds us that mental health providers can actively participate in implementing and updating free and informed consent with respect to psychotropic treatment.**

According to the *Act respecting health services and social services*:

“Before giving his consent to care concerning him, every user of health services and social services is entitled to be informed of his state of health and welfare and to be acquainted with the various options open to him and the risks and consequences generally associated with each option” (Sec. 8).

In 1998, an MSSS working committee<sup>14</sup> looking at the issue of GAM noted:

“The notion of free and informed consent goes much further than providing a list of possibilities. It calls on the prescriber to engage in a process of collaboration and cooperation that not only makes the person aware of information about the medication but, further, also ensures that the person understands this information and is in a position to make a decision that they deem best for them. At the end of this process, the person may decide to take or not take the medication and still have the right to receive the prescriber’s services” (MSSS, 1998b, p. 9).\*

While, as set out in the *Act respecting health services and social services*, “every user is entitled to participate in any decision affecting his state of health or welfare” (Sec. 10), the prescription of psychotropic drugs occupies a particular position in the medical treatment field. Indeed, drug intervention in the mental health field often creates a significant relationship of dependence between the medication user and the prescribing physician. Medication’s hold on the mind has led certain legal scholars to state that, with respect to psychotropic drugs, “no one should risk harming people more seriously” (Me H  l  ne Guay, legal opinion on *Risques l  gaux d’un programme de gestion autonome de la m  dication* – Legal risks of a Gaining Autonomy & Medication Management program, 1997). In certain situations, mental health care providers could play a role of vigilance and assistance.<sup>15</sup>

More broadly, GAM reminds us that mental health providers can actively participate in implementing and updating free and informed consent with respect to psychotropic treatment by regularly informing the people concerned of their rights and by offering them access to relevant information about drug treatments and complementary or alternative approaches,<sup>16</sup> while ensuring that they understand the information and by answering any questions that may arise.

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14. The committee included various mental health stakeholders and was chaired by psychiatrist Michel Messier.

\* Note for the English translation: Free and informed consent laws may vary from one country to another.

15. “Informed consent must be given during a period of lucidity. The person’s faculties must therefore not be altered when they give consent: they must not be in a state of crisis or under the influence of a medication that can produce undue docility, prevent them from grasping information they need to understand or assessing the consequences of their actions.” (*Guide critique des m  dicaments de l’  me* – Critical Guide of Psychiatric Medication, p. 362.)

16. “Free and informed consent presupposes alternatives and/or complements to medication. Offering drug therapy alone to treat mental health problems is extremely reductive” (MSSS, 1998b, p. 9).

## A few guidelines for intervention in crisis and emergency situations

For people living with one or more mental health problems, crisis situations frequently mark the beginning of their contacts with psychiatric and mental health services, often by way of psychiatric emergency, where they are usually given medication, but sometimes by way of community crisis services, which may be better adapted to accommodate people going through periods of intense distress by offering spaces where they can express themselves and be heard.

Save in exceptional circumstances:

- In crisis and emergency situations, the person's consent must be obtained prior to any intervention.
- The person's point of view must be listened to and their decisions respected regarding the solutions offered.
- It is not always necessary to use high doses of drugs as a first-line solution.

Qualitative research and user narratives show that most often, in crisis or emergency situations, their first and primary request is to be listened to and heard, to be accepted and respected as a full-fledged person.


There are legal provisions surrounding intervention in extreme situations:

- A provision of the *Quebec Act respecting health services and social services* stipulates that “force, isolation, mechanical means or chemicals may not be used to place a person under control [...] except to prevent the person from inflicting harm upon himself or others” (Sec. 118.1).\*
- In especially critical situations, interventions imposed on people must be strictly controlled and time-limited. In 2002, the MSSS provided the health services network with a system aimed at setting guidelines for the use of exceptional control measures (chemical and physical restraints, and isolation). A more limited use of these measures starts with the development of replacement measures (MSSS, 2002)\*.

## An ethical position

The backdrop to Gaining Autonomy & Medication Management is a reflection on and commitment to the question of “subject”: in other words, to defend and support the progress of people made fragile by their experience with mental health problems—and, unfortunately, sometimes also by psychiatric care—toward a position of subject in their lives and in the community. In this sense, GAM also involves taking an ethical stand.

\* Note for the English translation: Laws and policies surrounding the use of restraints and isolation vary from one jurisdiction to another.



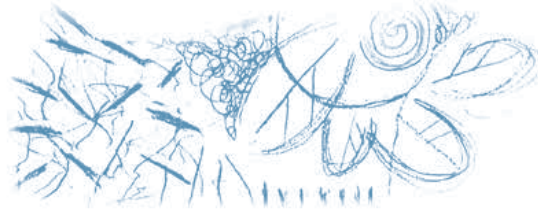
**The GAM approach clearly highlights the limitations of a single, one-dimensional treatment for the various manifestations of mental health problems.**

## **Toward a broad approach to suffering and wellness**


The goal of Gaining Autonomy & Medication Management is wellness, as defined from the perspective of medication users. Its purpose is to achieve a suitable medication for people (type of drug, dosage, and combination), in terms of effects experienced with respect to symptoms and mental health problems, in terms of impacts on their bodies and daily lives and on their relationships with themselves and others, but also based on the meanings associated with medication.

At the same time, the GAM approach takes into account mental health problems, the suffering expressed by the people, and the search for answers based on the meaning they give to their subjective experience—all within a broad perspective that takes personal life story and background into account.

The GAM approach clearly highlights the limitations of a single, one-dimensional treatment for the various manifestations of mental health problems. These problems comprise multiple and complex experiences of suffering, which call for multiple responses.







**Respect for the multiple relationships people have with medication is the one basic requirement for providing guidance in Gaining Autonomy & Medication Management.**

Respect for the multiple relationships people have with medication is the one basic requirement for providing guidance in Gaining Autonomy & Medication Management (GAM).

Mental health providers must always recognize the value of experience with and knowledge of medication that medication users have accumulated.

Actions and interventions aim to create a safe space for expression and choice and to provide resources to guide people in their efforts toward wellness.

As long as it rests on these fundamentals, guidance can take various forms and be adapted to different situations and intervention settings.<sup>17</sup>

### Information on medication

Access to information on prescribed medications is often a basic need for medication users. Access to the most comprehensive and objective information about drug treatment, its benefits and risks, and the various alternative or complementary therapeutic options available is a right for people who are prescribed medicines, psychotropic or otherwise.

In Quebec's current medical practice environment, doctors do not always have the time to provide all the necessary information on the medications they prescribe. It is therefore important that mental health providers who advise medication users ensure that they receive and understand the available information on the drugs prescribed, their instructions for use, desired effects and side effects, drug interactions, and different treatment options, if so desired. There are several sources of information on psychotropic drugs, including pharmacists, reference books such as the *Compendium of Pharmaceuticals and Specialties*, the *Guide critique des médicaments de l'âme* (Critical Guide of Psychiatric Medication; Cohen et al, 1995), *Psychiatric Drugs Explained* (Healy, 2008)\* courses on psychiatric medication,<sup>18</sup> and the Internet\*\*. This information can also be conveyed by different means: during individual follow-up meetings, through workshops on medications, or by way of posters displayed in organizations or establishments.

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17. The GAM support practices discussed here were laid out during the first GAM pilot project, launched in 1999 in 10 alternative community-based mental health organizations. Initially tested with alternative resources, these practices also came out of other practice settings during the second pilot project aiming to broaden the approach to different mental health partners, particularly from the public sector (2002–2005).

\* Sources of information regarding psychiatric medication must be reliable and varied in order to get a full picture. User accounts, information from a critical perspective, along with more mainstream sources, are all useful.

18. For instance, the AGIDD-SMQ offers a course on drugs used in the fields of mental health and psychiatry, *L'autre côté de la pilule* (The other side of the pill). An introductory course on Gaining Autonomy & Medication Management (GAM) is also offered by the RRASMQ/ÉRASME. The GAM training does not give information on psychotropic drugs per se, but rather explores more broadly dimensions such as quality of life in relation to medication, (re)empowerment, and the symbolic links with psychotropic drugs. In both courses, service users are trainers.

\*\* As an example, the Web site [www.davidhealy.org](http://www.davidhealy.org) and the tab "RxRisk Papers" can be consulted as an introduction to the general information and issues surrounding the different classes of psychiatric medication.

## **GAM in an alternative community-based day centre: Brief portrait of one organization's experience\***

Located in an urban area, this alternative community day centre welcomes and guides people living with serious and moderate mental health problems. Most are also receiving psychiatric care and taking medicine. Regular visitors to the centre engage in a holistic approach that deals with self-knowledge, transforming one's relationship with one's self and with others, and integration into the community. As such, the day centre offers various workshops (stress management, health, creativity, social skills, cognitive skills, back-to-work transition, etc.), group therapy, and individual, occasional or therapy sessions. The holistic approach taken at the centre can span several years.

Starting in 1999, the organization agreed to take part in a pilot project to develop a model of practice for Gaining Autonomy & Medication Management (GAM) initiated by the RRASMQ in 10 member organizations.

In guiding members throughout their efforts toward social reintegration, particularly toward returning to work, professionals at the centre have noticed over the years that the question of medication often, if not always, arose at some point in the reintegration process. This was particularly true in cases where the medicine, especially when taken in high doses, was perceived by people as hindering their progress.

Guidance in GAM has gradually become standard practice at the centre. Regular visitors know that they have a place where they can work on their relationship with medication if they so wish. A GAM discussion and support group has been integrated into the regular activities offered by the organization. In addition, for those interested, individual sessions on GAM are offered, the intensity of which is adapted to the needs of each person and can vary throughout the process. Whether in individual or group sessions, guidance for GAM works on one's relationships with medication from a broad perspective of wellness for the people concerned. The book *Taking Back Control: My Self-management Guide to Psychiatric Medication*, which focuses on thinking about and working on one's quality of life, is frequently used in both the discussion and support group as well as in the individual follow up.

While the GAM approach is supported by all of the day centre's providers, one of them took to the approach especially strongly. She is the person who leads the groups and provides individual GAM follow up. She does not claim to use a recipe: "It's a different journey that I embark upon with each person," she notes. She has also become the resource person at the centre for information about psychiatric medication.

Her experience with the GAM approach has shown her that it "does not lead to more crisis events; on the contrary, it can prevent people from discontinuing their medication suddenly. We're frightened of madness. But what we really fear is that people's lives become disrupted. Oftentimes, talking about quality of life has the opposite effect. It helps to open a dialogue."


\* This portrait was created thanks to observations carried out by ÉRASME researchers during a follow-up assessment of the first GAM pilot project.

Access to information about the medication one is taking can, in certain situations, be distressing and confront people with difficult decisions (e.g. when a person learns that a drug they thought had no choice but to take, can seriously harm their health). Mental health providers can be of great service in such cases.

However, non-physician providers must not replace the prescribing doctor. In this sense, they must not give advice on taking, stopping or reducing medication, since providing such advice requires medical training.

## Individual support

The needs expressed by people about their medication are numerous and complex. Individual support is often a means to deal with the various needs and dimensions surrounding people's relationships with psychotropic drugs.



**Individual support can also prepare people for establishing a better dialogue with their treating physicians.**

Individual support can help people initiate the process of assessing their quality of life, including the place and role of mental health medication in this regard (*Taking Back Control* is a good resource to draw on for this purpose). It can also help people better understand the symbolic relationships they have with the drugs they take, and their roles in wellness or lack thereof (for some people, taking certain drugs may be very painful due to their associated meanings, while taking another type of medicine may be much better tolerated). Individual support and open dialogue can help people to explore more broadly their relationships with medication on their personal path toward improvement.

Individual support can also prepare people to establish a better dialogue with their treating physicians and, if necessary, to negotiate possible changes to their treatment, either during a regular visit, upon discharge from the hospital, or when they have less control over their medication (e.g. when the medicine is given by injection).

Individual support can be a means of exploring complementary treatment or alternatives to medication that may contribute to wellness and improvement. There are many complementary treatments and alternatives to be considered that meet different needs: psychotherapies and other therapies, alternative medicines, art, personal strategies (writing and other creative activities, physical activity, etc.).

## **GAM in a peer support and self-help group: Brief portrait of one organization's experience\***

Located in a semi-rural region of Quebec, the peer support and self-help group in question is, for regular visitors (several of whom have serious mental health problems), one of the few resources available to them in the community. As such, it represents a very important reference point in these people's daily lives and for their guidance.

Since 1999, the group has been taking part in the pilot project launched in 10 alternative mental health organizations aiming to develop a Gaining Autonomy & Medication Management (GAM) practice model.


One particular staff member took an interest in the project and its underlying concerns and took charge of implementing it into the organization. When asked about her understanding of GAM, she answered that it helps people answer questions such as: "Why do I take psychiatric medication?" "How long have I been taking them?" "What am I taking?" "What are the side effects?" and "Do they still meet my needs today?", so that they can discuss them with their doctors.

In fact, introducing GAM into the peer support and self-help group did not lead to a major change in practices. The organization has always been concerned with the impact of medication on the daily lives of its members and the importance of (re)empowering them. The group has long provided information on medication to people as needed and assisted those who sought help in discussing and negotiating their treatment with their doctors. Previously, this type of assistance was provided in informal individual meetings.

The more formal introduction of the GAM approach within the organization has led to a broadening and consolidation of practices in this regard. The organization set up a discussion group on quality of life and medication's place in it and regular meetings were held. It was immediately clear that there was an enormous need to talk about the issue; participants spoke about their experiences with medication, their experience with psychiatry, but also about themselves and their relationships with others, their daily lives, their difficulties and desires. Hence, throughout these meetings, the question of medication was never isolated from the participants' broader life experiences. In terms of participation, this discussion group has been very constant.

This discussion group on quality of life, which regularly brings up questions related to medication, is now part of the organization's regular activities. "I notice that people are much more interested in their quality of life now, and I see that people who have made progress, who are feeling better, also want to help others," remarks the discussion group facilitator. More broadly speaking, this activity of sharing and discussion has contributed significantly to strengthening peer support within the organization.

\* This portrait was created thanks to observations by ÉRASME researchers carried out during a follow-up assessment of the first GAM pilot project.



**By helping people become more aware of the active role they can play in their own quality of life, well-being, and medication, *Taking Back Control* is a tool that facilitates (re)empowerment.**

## Discussion groups

Discussion groups about psychiatric medication that highlight the value of the experiences and knowledge of medication users are places where people can share their multiple experiences with respect to taking medicine. For some, this can be a first step toward feeling ready to undertake a process of individual follow-up.

The topic of medication in group activities can also arise within broader discussions of quality of life.

## *Taking Back Control*

*Taking Back Control: My Self-management Guide to Psychiatric Medication*, a document available since 2002 and written expressly for psychotropic drug users, can also be a very helpful tool. By way of concrete questions, it can help promote dialogue in that regard between users and providers, and it can help the latter better understand the point of view of medication users the former, as well as the issues associated with taking psychotropic drugs.

This guide explores more particularly one of the fundamental dimensions of GAM: quality of life. Readers are asked to assess their lives and target aspects that could be improved. Throughout this process, medication may or may not arise as one of these aspects.

For people who, after this assessment, arrive at the conclusion that their current medication has negative repercussions on their quality of life, *Taking Back Control* offers a method for very gradually diminishing the medication, to be undertaken in collaboration with a doctor. The suggested end of the process is the point at which a personal comfort zone is reached. To guide people in this process, *Taking Back Control* also includes self-observation tools and provides suggestions for creating a support network. By helping people become more aware of the active role they can play in their own quality of life, well-being, and medication, *Taking Back Control* is a tool that facilitates (re)empowerment.





## **GAM in a community-based therapeutic intervention agency: Brief portrait of one organization's experience\***

Located in a semi-urban area, the community therapeutic intervention agency described here is the only “milieu de vie”<sup>\*</sup> type of mental health organization in the immediate area. It accommodates both people with serious mental health disorders and people with more short-term problems. The agency offers a varied range of activities, including a therapy division (group therapy and counselling) and an artistic creativity division. It provides people with “an alternative to medication and hospitalization.” Some people choose to attend the organization precisely because they refuse to take medication. Most, however, are receiving psychiatric care and taking medication.

This community therapy agency took part in the 1999 pilot project to develop a Gaining Autonomy & Medication Management (GAM) practice model launched in 10 RRASMQ member organizations.

The more formal introduction of the GAM approach at the agency did not give rise to specific new activities. Rather, GAM was naturally integrated into the agency's existing therapy practices, particularly with respect to the counselling that is offered.

For those seeking it, the counselling services provided by the agency can take the form of in-depth therapy. In this context, the issue of medication is rarely brought up straightaway unless it is raised by the client, notably by those who specifically do not want to take any. “People come here to make progress on a personal level, and not initially to deal with their medication,” notes one of the agency's counsellors. But for those who take medication, the issue usually comes up at some point during the therapeutic process, especially in situations where people realize that their drug treatment is no longer appropriate for their situation. “The question of medication is always secondary; it's more about a person's mental state: how they're doing, how they feel. As soon as they're better, or feel better, the process starts on its own,” stresses that same counsellor. Hence, it is especially from then on that counselling integrates questions related to medication.

\* This portrait was created thanks to observations carried out by ÉRASME researchers during a follow-up assessment of the first GAM pilot project.

## Assessment of the GAM approach from the perspective of medication users\*

Équipe de recherche et d'action en santé mentale et culture  
(ÉRASME – Team for Research and Action in Mental Health and Culture)  
Lourdes Rodriguez Del Barrio, lead researcher, professor at Université de Montréal  
Marie Drolet, community researcher

“We are presenting the primary results of an exploratory study undertaken with some 20 users of alternative community-based organizations who used the Gaining Autonomy & Medication Management (GAM) approach to examine their medication in order to assess its impact on their quality of life and progress toward wellness.

We were struck by the depth of the statements of the interviewees. They spoke at length about the place of medication in their lives, its limitations, the conditions under which it becomes a tool that promotes wellness, and of what GAM means to them. Moreover, they described in detail the diverse strategies they have developed in order to achieve an appropriate level of medication and/or to find the help necessary to change it.

Using this approach and the principles it embodies, people came to realize that they could have input into the treatments prescribed to them and be full-fledged participants in their recovery. For instance, one person told us:

*GAM means being able to make your own decisions and choices, to have a perspective on the thing as more than just a little magic pill. [...] It gives you back power over your life. Once you are able to make your own decisions, you have taken a big step forward.*

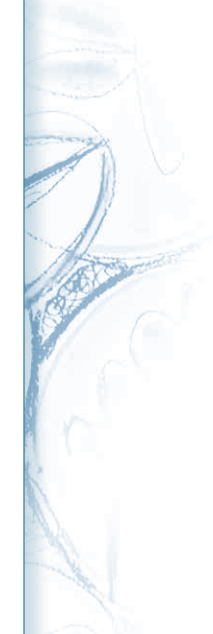
One of the ways in which the GAM approach helps people take control of their treatment is by giving them access to information about their medication. The study showed that the great majority of people interviewed were very knowledgeable about their medications and where they could find information in this regard, such as pharmacists, reference guides (Guide critique des médicaments de l'âme – Critical Guide of Psychiatric Medication, Cohen et al., 1995; Psychiatric Drugs Explained, Healy, 2008; Compendium of Pharmaceutical, CPS, 2005), and the Internet. Better knowledge of their medications helped people to better understand how they affect them and to more easily identify any side effects. For example, one of the interviewees told us:

*It's about knowing what they are and not saying 'I take a blue pill and a red pill.' No, no. It's about knowing your medication, your Rivotril, your Paxil, what the side effects are, what their other effects are. It's about knowing the drugs you're taking, to see if you're having problems with them, whether it's sleep or certain problems that arise, you see if they're among the side effects, and then you can talk about them. It's about really knowing your medication so you can deal with it.*

This also enables people to feel better equipped to negotiate their medication with their doctor. In fact, another one of the main findings in our study was that most participants were under the care of a physician with whom they had established a true dialogue about medication. They stated that they were able to discuss their concerns about their medications and their effects on their mental health with their doctors. Moreover, many received the support of their doctors in the drug reduction process, and others were able to have one drug replaced by another that had worked in the past or whose physical effects or symbolic meaning was less alarming. Hence, users seem to be proactive with their doctors, and the doctors, some more than others, seem to respect their wishes.

All of the people who took part in the study are trying to achieve, or have successfully achieved, a suitable level of medication, in terms of both its impact on their quality of life and its physical effects and meaning—these three aspects being inextricably linked. For example, one person asked his doctor to replace an antipsychotic with lithium to potentiate his antidepressant because the former category of drugs scared him. Another refused to take a drug that required a weekly blood test because it would make it harder for her to achieve one of her goals of getting a full-time job.”

\* Text submitted to the Parliamentary Commission on Social Affaires examining drug policy on August 30, 2005. It summarizes the broad lines of Rodriguez L. & Drolet, M., 2004, *Évaluation de la gestion autonome de la médication du point de vue des personnes usagères: Étude exploratoire* (Evaluation of Gaining Autonomy & Medication Management from the perspective of users: Exploratory study), ÉRASME/RRASMQ. This study was carried out in alternative community-based mental health organizations that took part in the 1999 Gaining Autonomy & Medication Management pilot project.





### A few examples of GAM experiences (case studies): Excerpts from interviews with providers\*

One client said “I don’t seem to have the motivation to do things.” [...] So she slowly cut down on her Seroquel, which is a neuroleptic, and she said “Now I hear a few voices, but I can live with these ones because I realize that I’m more motivated, I can get myself going, I’m better able to ground myself. And when I get anxious, I replace it with an Ativan when I need to.” [...] Now, she’s a very lively person who’s involved in many things. Sometimes, she goes through rough patches [...] She says “It’s now at a level that I can live with.” She does it on her own, with her doctor. She went to see her doctor and they negotiated it together. He prescribes the anxiolytic Ativan as needed. That’s how she manages things, and for the time being, she tells me “For me, it suits me just fine like that.”

Provider at a community drop-in centre

One of my clients has a personality disorder. The plan was to use Risperdal, which is an antipsychotic, but that’s also often used to treat impulsiveness. [...] But the client would say, “Those damned pills, I’ve tried this, I’ve tried that. . .” and they want to stop everything. [...] He was depressed. [...] So I said “Let’s make an appointment with the psychiatrist.” So we go and see the psychiatrist and we work together. The idea is to also bring up the subject of medication because we have to tell him it’s an antipsychotic; we can’t lie to him. [...] We have to say “Look, if your relationship isn’t going well and you’re depressed, it’s because something else is going on, and we have to work on it, and for that, we need to use drugs. You can decide not to take it; you can decide not to take anything. But you haven’t taken anything for a long time and look where it’s gotten you. We’re not saying it’s a miracle cure, but we want you to take it for a certain amount of time. But at the same time, we’ll work together. We’re not saying, ‘take this pill and it’s over, we won’t see you anymore.’ It’s not a miracle cure.” We negotiate by saying: “Try it for a while; we’ll see how it works. If you decide to stop, there’s no problem, you’ll stop.” And now it’s going well. He started taking it at a very minimal dose where he won’t have any side effects, and even better, he can stop anytime. [...] It’s saying “Take this, but we’ll work together too. We need to give you another tool so you can learn how to manage your anger and impulsiveness.” So we’re working on all of that. [...] We also gave the guide (Taking Back Control: My Self-management Guide to Psychiatric Medication) to both him and his wife [...] because they were people who could look and work at it together. [...] You have to raise awareness by the patient’s loved ones, not just use the guide with them alone. Others have to change their attitudes too.

Social worker at a CLSC (Local Community Service Centre)

(Continued on p. 40)

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\* These interviews were conducted as part of a follow-up of the two GAM pilot projects carried out between 1999 and 2005.



# “Facilitating” conditions for the development of GAM practices

Certain conditions facilitate guidance in and the introduction of the Gaining Autonomy & Medication Management (GAM) approach in practice environments.<sup>19</sup>

## A relationship of openness and dialogue with the physician



**For people who take psychotropic drugs, the prescribing physician’s openness to their concerns about their experience with mental health problems and the response to these are fundamental.**

For people who take psychotropic drugs, the prescribing physician’s openness to their concerns about their experience with mental health problems and the response to these are fundamental. They want to establish and maintain a dialogue with their doctor about their problems and the suggested treatment or treatments, and about any questions and concerns that these treatments may raise. They want to establish a relationship with their doctor in which their point of view is taken into consideration.

The doctor and the person concerned can have different, and sometimes completely opposite, viewpoints on the conditions for the person’s wellness and on the role that such and such drug treatment is likely to play (or not play) in it.<sup>20</sup> When there is a significant disagreement between the doctor and the person (whether it be regarding a new prescription or a request to change a given medication), they can agree that the opinion of another doctor is warranted, then reassess their differences in light of this second opinion. The prescribing physician must nevertheless respect the limits established by the person.

A relationship of openness and dialogue between the prescribing physician and the other personnel involved in the person’s care also facilitate guidance in the GAM process.

## Support from the organization or establishment’s administration\*

It is not always easy to raise the issue of psychotropic medication in practice environments. When met with resistance, the desire of certain mental health providers to remove the taboos surrounding psychiatric drugs so they can raise the issue of medication with clients who wish to discuss it, can sometimes be extinguished.

19. These “facilitating” conditions were identified and born of the follow-up assessment of the two GAM pilot projects carried out between 1999 and 2005.

20. The *Code of ethics of physicians* states that: “A physician must, except in an emergency, obtain free and enlightened consent from the patient or his legal representative before undertaking [a] [...] treatment” (Sec. 2.03.28) and that “A physician must ensure that the patient or his legal representative receives explanations pertinent to his understanding of the nature, purpose and possible consequences of the [...] treatment [...]” (Sec. 2.03.29).



More examples of GAM practices (case studies):  
Excerpts from interviews with providers (Continued)

It was because in the guide (Taking Back Control: My Self-management Guide to Psychiatric Medication) there was the question “Why are you taking that?” and there were people who couldn’t remember why, and they were finally able to remember. One person told me that she took a sleeping pill, but she said “It doesn’t help me sleep.” So I asked her how long she’d been taking it and it turns out that she’d been taking it every night for 10 or 15 years and she still couldn’t sleep. I asked her if she’d talked about it with her doctor and she said she hadn’t. So I told her it was important that she tell him about it if it had been 15 years. She wasn’t tolerating it well either. She finally talked to her doctor and he took her off it. A little later, he switched it for another one because she was still having problems. So we took a look at what she could do improve her quality of life. Maybe it was to take a walk after supper because she had trouble with her digestion. She said she drank a lot of coffee in the evening. We tried to change that to drinking only one cup after supper, but then maybe switching to herbal tea or chicken broth, things like that. Just changing that helped her to sleep and she started feeling better. At some point though, she went through a rough patch and asked for a sleeping pill again. But I recently heard that she’s finished with them. She has started exercising again, and her quality of life has improved, so she didn’t need that particular medication.

Facilitator for a self-help group (peer support group)

There is one woman I’ve known for five years because I helped set up a grief counselling group. This woman’s son committed suicide five years ago. [ . . . ] So she started taking antidepressants. [ . . . ] With the grief counselling group, [ . . . ] a group that was set up with the help of other parents, of course she doesn’t need to seek private mental health care as much, and she’s more able to talk about what she’s going through. Last year, she said, “I don’t think I need the antidepressants anymore. I’m done with them.” [ . . . ] So she decided to stop taking them. She did it with the help of her doctor, and it went really well. The doctor agreed with her.

Social worker at a CLSC (Local Community Service Centre)

We always say “talk about it with your doctor.” One of my therapy clients is also seeing a psychiatrist because he attempted suicide. She gave him some antidepressants. Recently he talked to her about them and she reduced the dose. He’ll have taken them for six months. He received follow-up care, and that helped him feel better, feel that he didn’t need them anymore, that he was no longer depressed. The psychiatrist is open-minded. [ . . . ] She didn’t say “You have to take them for a year or two.” [ . . . ] I know that she’s a psychotherapist too, so she’s not just someone who only prescribes medication. When they get that kind of support—and I think the centre has a good reputation for psychotherapy—when the doctors know that people come here, I think they’re less hesitant when it comes to extending medication, at least when it’s a first-time depression.

Psychotherapist at an alternative mental health community organization

In addition, for mental health care providers who wish to guide people in the GAM process, raising awareness of the approach and its foundations (subjective quality of life, (re)empowerment, attention to symbolic aspects of medication, respect for people and their rights) among the mental health organization or establishment's managers can be an extremely important if not necessary step. (The GAM training course can be a useful tool for raising awareness with managers.)\*

## Internal and external collaboration

GAM practices are greatly facilitated by the development of working relationships with other stakeholders, both within the organization or establishment and outside of it; this allows those undertaking this process to receive all the support they need.


Such collaborations are even more necessary when the GAM process involves a change in the person's medication to improve quality of life and promote wellness.

In such cases, it is particularly important that counselors identify the community support services needed and develop connections with providers and users in other organizations. In this way, they will be in a position to suggest other types of support for the person to continue making progress (with an alternative community-based organization, at a CLSC or community clinic, a women's centre, etc.) or to use in times of trouble (crisis centre, telephone hotline and warm line, shelter, etc.).

In particular, non-physicians who guide people in the GAM approach should, as they gain experience, build a network—whether formal or informal—of psychiatrists and general practitioners open to GAM, and of pharmacists interested in and willing to provide information on psychiatric drugs, their effects, their drug interactions, etc.

## Availability of other therapeutic practices and support

Because it is part of an overall perspective of wellness, GAM usually requires that other therapeutic or support practices come into play, used in association with medication or as an alternative to it. Individual or group psychotherapy is fundamental for a great many of the people who live with one or more mental health problems. Other practices can also contribute to wellness and improvement, such as other forms of therapy (art therapy, body work), counselling and peer support, personal growth workshops, etc.



**Because it is part of an overall perspective of wellness, GAM usually requires that other therapeutic or support practices come into play, used in association with medication or as an alternative.**

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\* The original implementation of GAM in Quebec took place in small community-based organizations. In these small-scale agencies, the board of directors is close to its members, workers, and the activities and practices that take place. A different context such as large-scale organizations, whether community-based or in the public sector, may not find it as pertinent to involve its administration or different hierarchical levels of the organization.

These complementary and alternative practices may be offered in the intervention setting itself or at other community organizations. Collaborating with various other stakeholders who play a role in counselling people with mental health problems is fundamental to enabling access to a range of practices in the community.

## Training and information on mental health medication

A thorough understanding of the different drugs used in psychiatry and mental health is not absolutely necessary to develop GAM practices. It does, however, facilitate the guidance process.

It is possible to acquire knowledge of psychiatric medications, their expected effects, side effects, and drug interactions as one gains experience with the GAM process in their day-to-day work with medication users. This information can come from various sources, such as the *Compendium of Pharmaceuticals and Specialties* (CPS, 2005), *Guide critique des médicaments de l'âme* (Critical Guide of Psychiatric Medication; Cohen et al., 1995), *Psychiatric Drugs Explained* (Healy, 2008), medical and pharmacological journals, the Internet, the training course "L'autre côté de la pilule"\* , directly from pharmacists, etc.

## Support from people's own networks

The multiple meanings associated with taking psychiatric medications and its various impacts concern not only medication users but also their loved ones. People taking medication or changing their medication affects their relationships with others. GAM guidance implies that these interactions are taken into account by providers or others who support users, and that the latter help their clients inform, raise awareness among, and possibly mobilize their natural support networks.

Providers who offer GAM support may also be called upon to help their clients develop their own support networks. *Taking Back Control* contains tools to help people create support networks and to diversify help resources so as not to overtax them.

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\* Note for the English translation. The two-day Quebec course called "L'autre côté de la pilule" (The other side of the pill) is delivered by two trainers, at least one of whom is a user. The pharmacological profile of each class of medication is covered along with alternatives and rights.

## Conclusion: GAM issues and challenges for the future

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The Gaining Autonomy & Medication Management (GAM) approach is evolving within a healthcare system and, more broadly, a society that is ever-changing. Hence, a number of major issues and challenges for the future have emerged: for our mental healthcare system, in terms of openness to multiple approaches; for our society, in terms of its ability to question and broaden the understanding of distress and the various responses to it; and for GAM itself, in terms of its ability to be heard and understood and to usher in a significant renewal of mental health practices.

### Accessibility to a range of therapeutic approaches and practices

GAM calls into question the limitations of a one-dimensional treatment of psychological and relational distress. Accounts by those most directly concerned are eloquent illustrations of the need for multiple responses. Wanting to work on one's self in depth is a basic desire expressed by people who live with mental health disorders and whose psychological and relational distress affect them both mentally and physically.

Mental health medication must be used as a tool in this desire to work on one's self, rather than supplant it. Yet, non-drug therapies remain the poor cousins in our mental health care system. This is more than just a paradox. For a number of years, Quebec's mental health care system has come out in favour of (re)empowerment as a guiding principle in the transformation of how mental health services are organized. However, one of the unavoidable conditions for a system of care oriented toward (re)empowerment is precisely to offer people medication users a real choice among different options.

“People's freedom of choice and the possibility of taking their own path through a range of approaches are highly limited by the implementation of a single intervention model based on essentially medical responses” (Comité de la santé mentale du Québec, 2006, p. 122).<sup>21</sup>

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21. In addition, in our health and social service system, pharmacological diagnosis and treatment are often the only available options in order to access the financial resources (social assistance or private insurance payments) that these people need to live on (Rodriguez & Poirel, 2001).



## Serious mental health problems

While the GAM approach must be adapted to different situations, its scope is not restricted to only certain people and disorders. Indeed, how is it possible to restrict access to a better subjective quality of life, to expanding one's ability to live and act in society, and, more broadly, to getting better? Everyone is affected by these dimensions, which can make life worth living despite the extreme ordeal of psychological and relational distress that is usually at the heart of mental health problems.

Psychosis poses particular challenges for guiding the GAM process. These follow-ups may be much more demanding and require much more investment in terms of time and availability in a broader sense. They may require bringing into play complementary and alternative approaches. As psychoanalyst and co-founder of a treatment centre for young psychotics, Willy Apollon, remarks:

*To be honest with patients, we should, with the experience we have today, admit the truth to ourselves concerning the necessity of medication to treat symptoms, but that it remains urgent to develop complementary methods of approaching the fundamental human problem raised by psychosis which goes beyond the catastrophic symptomatology that it produces and that does not really convey its true dimension (Traiter la psychose, p. 14).*

In this sense, GAM is in line with numerous appeals in recent years for a return to psychotherapy for people with serious mental health disorders\*, given the limited results obtained by the use of biomedical treatments alone (Comité de la santé mentale du Québec, 2006; Lauzon & Lecomte, 2002; Sassolas, 2000). Research has shown that the outcome for people diagnosed with schizophrenia is, in many cases, much less bleak than the frequently cited prognosis for the progression of schizophrenic disorders, and that a great many of the people recover (Lauzon & Lecomte, 2002; Harding et al., 1994, 1988).

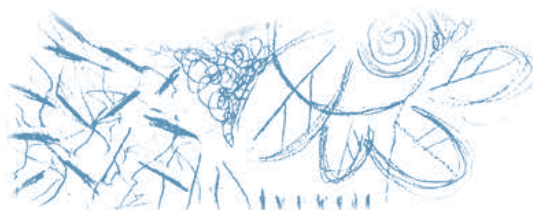
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As a reference: The International Society for Psychological and Social Approaches to Psychosis at [www.isps.org](http://www.isps.org).

## Mental health medication and social suffering

Our society is a source of exclusion and dysfunction, which are themselves sources of suffering for people who find themselves rejected on its margins, and our society's performance and adaptability requirements toward individuals are always potential sources of distress (Ehrenberg, 1998). Many are calling into question the increasing prescription of psychotropic drugs in modern Western society (Collin, 2006; MSSS, 1998b). It is sometimes difficult to draw a line between individual psychological suffering and social suffering. People in distress who are prescribed psychiatric drugs to "hold on" sometimes bear the weight of social failings and inconsistencies. When psychiatric medication is used as a response for social distress, we must ask ourselves questions. Other people, sometimes the same, worry about the increasing influence of pharmaceutical companies, whose interests are not necessarily in line with people in distress and those who support them in their efforts toward wellness (Pignarre, 2003; Saint-Onge, 2004; Cohen et al., 1995).

Grounded in practice, in the here and now of intervention, of peer support, the GAM approach also harbours these broader concerns surrounding social suffering.







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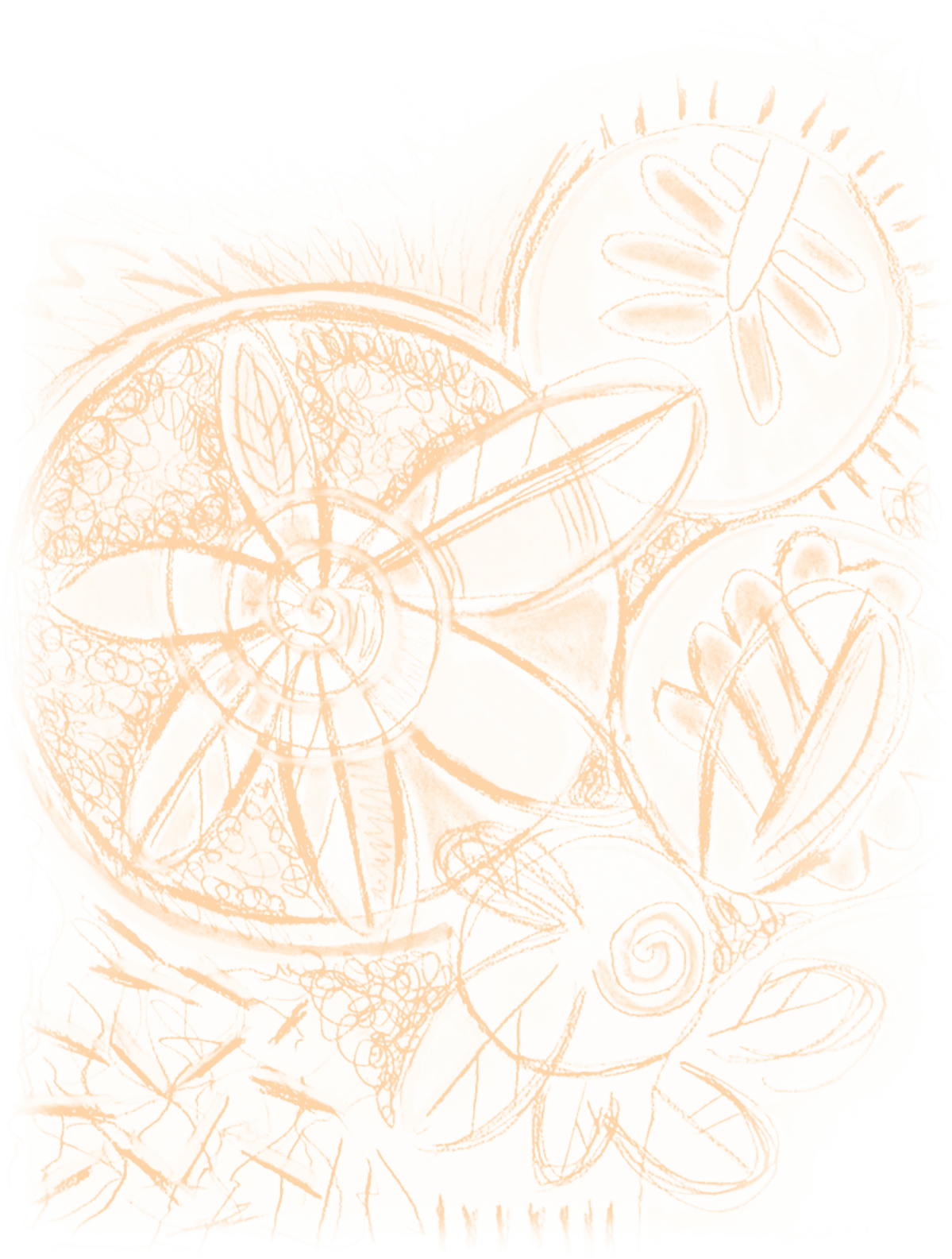


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Founded in 1983, the **Regroupement des ressources alternatives en santé mentale du Québec** (RRASMQ – Quebec Coalition of Alternative Mental Health Organizations) is a non-profit coalition of 113 alternative mental health and community agencies throughout Quebec.

These human-scale organizations are rooted in their communities, socially committed, and stand out by their welcoming atmosphere, versatility and structures that promote equality-based relationships between people. They are organizations such as crisis centres, self-help groups, therapeutic resources, shelters, halfway houses, drop-in centres, employment reintegration resources, and telephone help lines.

**L'Équipe de recherche et d'action en santé mentale et culture** (ÉRASME – Team for Research and Action in Mental Health and Culture), funded by the Conseil québécois de la recherche sociale (Quebec Council for Social Research) and the Fonds de recherche du Québec – Société et culture (Research Fund of Quebec – Society and Culture), is made up of 11 academic researchers from several universities (Université de Montréal, UQAM, University of Ottawa, Université Laval, and McGill University) working in various disciplines (medical anthropology, psychiatry, psychology, sociology, social work, and political science) as well as three community partners. Three researchers have been more specifically involved with the GAM project: Lourdes Rodriguez, Ph.D., professor, Université de Montréal, School of Social Work; Ellen Corin, Ph.D., associate researcher, professor, McGill University, Depts. of Psychiatry and Anthropology, Douglas Hospital, Psychosocial Research Division; and Cécile Rousseau, M.D., associate researcher McGill University, Dept. of Psychiatry. The **ÉRASME** and **RRASMQ** have worked in partnership for the past dozen years. From 2009 onward, GAM research continues in Quebec and Brazil through the partnership of the Alliance de recherche communautés-universités Santé mentale et citoyenneté- ARUCI-SMC (Community-University Research Alliance – Mental Health and Citizenship – CURA-MHC), funded by the Conseil de recherche en sciences humaines/ Social Sciences and Humanities Research and International Development Research Centre (CRSH/CRDI).  
ARUCI's Web site: [aruci-smc.org](http://aruci-smc.org)

## Supporting GAM Practices: Gaining Autonomy & Medication Management in Mental Health

### Guidelines

This handbook is intended for anyone who places (or wishes to place) at the heart of practices surrounding psychiatric medication concerns about quality of life and expanding the ability of psychiatric medication users to live and act in society — whether the mental health problems they are experiencing are temporary, moderate or serious. In this sense, it is aimed at all mental health care providers, doctors, nurses, psychologists, social workers, along with other support workers, relatives, and volunteers. Gaining Autonomy & Medication Management can be integrated into any process of therapeutic counselling or intervention, psychotherapy, rehabilitation, or reintegration that is oriented toward (re)empowerment and wellness, and toward recovery, understood as the possibility of getting back on one's feet in a more livable world.

Gaining Autonomy & Medication Management in Mental Health calls for a dialogue between the various types of knowledge of psychotropic medication and its impacts: the fundamental and inescapable knowledge of medication users, the knowledge of medicine, and the knowledge of the different categories of mental health professionals.

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