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# User participation in mental healthcare in Suriname: the implementation of a client council

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# Abstract

User participation in mental healthcare has increased considerably in many countries around the world in the past decades. However, users' voices are still incipient in other countries. This was the case of Suriname where user participation emerged just recently with the creation of a client council at the national mental healthcare service (PCS). The PCS client council was implemented as a result of a project involving a transnational partnership between stakeholders in Suriname and the Netherlands. Employing a qualitative research approach, this paper examines the client council implementation process and analyses stakeholders' expectations for its future performance, benefits and disadvantages. The paper concludes that the client council offers a space from which traditionally excluded users can renegotiate their identities, develop new skills, influence care provision and exercise their citizenship. For genuine participation to emerge, however, it will be necessary to invest in effecting cultural and organisational change in mental healthcare, tackling power differentials between care providers and users, resourcing the council and reducing the stigma attached to mental illness. Transparency, consultation, negotiation and full collaboration are also identified as key elements to foster productive transnational partnerships, especially when they involve stakeholders belonging to countries with a colonial history.

Keywords: User participation, mental healthcare, client council, Suriname.

# Introduction

The need to tackle health inequalities and to develop adequate and sustainable healthcare has highlighted the importance of engaging lay people in defining health priorities and implementing local health services. This was officially acknowledged by the WHO in 1978 through the Alma-Ata Declaration (WHO, 1978). Community and user<sup>1</sup> participation in healthcare has since been increasingly advocated as good practice (White and Harris, 2001; Watters *et al.*, 2003; 2008; Portugal *et al.*, 2007; Padilla *et al.*, 2009) and in countries such as Australia, the UK, Brazil and the Netherlands it is a discernible element of healthcare policy and practice (see De Carvalho, 1998; Sozomenou *et al.*, 2000; DoH, 2000; De Freitas, 2011).

These developments find support in the idea that participation has the potential to increase the level of responsibility of communities for their own health (Blakeney and Patterson, 1972 cited in Sozomenou *et al.*, 2000), enable a more equitable distribution of power (Rifkin, 1990; Dujardin, 1994) and contribute to greater efficiency and quality of healthcare services (WHO, 1989; Zakus, 1998). In addition, governments around the world have felt the need to improve the legitimacy of decision-making and to deal with growing demands by marginalised groups to have their rights enforced (Braye, 2000; Barnes et al., 2004). Finally, there has been an increasing focus on the promotion of more substantive and participatory forms of democracy (Gaventa, 2004) which, among other things, builds on the conviction that citizen participation in decision-making processes improves the effectiveness and responsiveness of public policy, boosts public confidence, fosters political renewal and deepens democracy (Elster, 1998; Avritzer, 2002; Gaventa, 2004).

User participation in mental healthcare began in the early 1970s through two user movements in the US and in the Netherlands that are still active. Aggrieved by the lack of rights, powerlessness and inappropriate care, users and ex-users began to organise, some in search of alternatives to institutionalised mental healthcare and others in search of greater influence over the development of client-centred care (Chamberlin, 1978; Haafkens *et al.*, 1986; Rogers and Pilgrim, 1991). In the decades that followed, user movements proliferated in several countries including Brazil, Australia and the UK (see Sozomenou *et al.*, 2000;

<sup>&</sup>lt;sup>1</sup> The term 'user' is employed to refer to people who make or have made use of mental health services. We also employ the term 'client' because it is the most commonly used term in Suriname and the Netherlands to address this group of people. Both these terms are problematic not only because people may not wish to be identified primarily as service users or clients but also because they are tainted by the stigma associated with mental illness. However, other terms such as 'patient', 'survivor', 'consumer', etc. are also criticised. We employ the terms 'user' and 'client' out of pragmatism, with the goal of bringing clarity to the text. We do not associate in any way to their negative connotations.

Vasconcelos, 2000; Bertram, 2002) and the range of initiatives in which users were involved expanded to include self-help groups, health councils, service management, research and policy-making (Chamberlin and Rogers, 1996; Barnes, 1999; Kemshall and Littlechild, 2000; Rose *et al.*, 2004). At present, user participation in mental heath is viewed as good practice. However, it is far from a "conquered terrain". There are many discrepancies between countries and some are marked by the complete absence of a user voice (Pilgrim and Waldron, 1998). Where participation exists, entrenched barriers (e.g. professional resistance, alleged lack of representativeness, insufficient information and funds, stigmatisation, etc.) often threaten the realisation of its full potential (Lindow, 1999; Webb *et al.*, 2000; Ryan and Bamber, 2002; Summers, 2003; De Freitas, 2011).

Suriname is one of the countries where user participation in mental health was marginal until the mid-2000s. This changed with the creation of a client council at the national mental healthcare service - the Suriname Psychiatric Centre (PCS). Its implementation resulted from a project involving a transnational partnership between stakeholders in Suriname and in the Netherlands. Stakeholders included PCS care users and staff, the Surinamese and Dutch organisations of family members of people diagnosed with schizophrenia and other mental illnesses - Ypsilon Suriname (YSR) and Ypsilon Nederland (YNL) – and the client council of RIAGG Rijnmond, an out-patient mental health service in the Netherlands. This paper analyses the process leading to the implementation of the client council at PCS. It also examines stakeholders' views on the needs for reform of Surinamese mental healthcare and their expectations concerning user participation in a client council. Although it was not an initial goal of this study to inquire about the stigma associated with mental illness, this emerged as a relevant theme during data collection. For that reason, it is included in our findings. In what follows, we provide a description of the project leading to the implementation of the PCS client council and an overview of healthcare provision in Suriname. We then present the results of the study and a discussion of its overall implications for user participation in Suriname.

# **Background of the Project**

The setting up of a client council at PCS was proposed by a Surinamese resident in the Netherlands who is a member of RIAGG Rijnmond client council and YNL as well as the founder of YSR. The first phase of the project entailed a trip to Paramaribo<sup>2</sup> where PCS is located to present the idea and evaluate users' interest in client participation. As a result of this initiative, a preliminary group of users willing to take part in a client council was formed.

The second phase of the project consisted of forming a work team and seeking funds. The RIAGG Rijnmond embraced this venture turning it into a wider project that comprised the following goals:

- to provide training on information technologies and knowledge about user participation to users;
- 2) to set up a client council at PCS;
- to conduct research focusing on the measures necessary to improve mental healthcare, stakeholders' expectations about user participation and the process of implementing a client council; and,
- 4) to establish a partnership between the RIAGG Rijnmond and the PCS client councils.

In April 2006, a delegation of RIAGG Rijnmond client council<sup>3</sup> went to Paramaribo to assist in the setting up of the PCS client council. During that trip, the delegation provided training and information sessions on user participation and several meetings were held between the various stakeholders to define the terms of collaboration, plan the installation of the council and discuss future partnership. This third phase of the project culminated with the launching of the PCS client council during an event that gathered users, family members, care professionals, YSR members and the Netherlands-based partners. The council was set up with a total of seven members all of whom were clients with the exception of the facilitator who is a social worker.

The project was sponsored by several Netherlands-based entities including RIAGG Rijnmond client council, Basisberaad GGZ, the Landelijke Patiënten- en Bewonersraden GGZ (LPR), Okapi Fonds, and the Institute for User Participation and Policy (IGPB)<sup>4</sup>.

<sup>&</sup>lt;sup>2</sup> Paramaribo is the capital city of Suriname.

<sup>&</sup>lt;sup>3</sup> The RIAGG Rijnmond client council delegation included one former client, two family members and the facilitator of the council.

<sup>&</sup>lt;sup>4</sup> All these entities are concerned with the promotion of clients' rights and interests in mental healthcare.

# The Surinamese Healthcare System – an overview

Suriname has a relatively complex healthcare system composed of various management and financing entities, healthcare providers and insurance schemes. The system also embodies a particular set of features<sup>5</sup> which distinguish it from the rest of the countries in the Caribbean region and that can be traced back to the country's political and colonial history (Haqq and Mills, 2002). The management of the healthcare system is a responsibility of the Ministry of Health which is liable for guaranteeing the availability, accessibility and affordability of care through planning, policy development, evaluation, coordination and setting of standards. The financing of the healthcare sector is shared by a variety of bodies including the Ministry of Finance (MOF), the Ministry of Social Affairs (MSA), the Ministry of Health (MOH), the State Health Insurance Fund (SZF), private firms and private individuals' contributions (IADB, 2005).

Access to healthcare providers is bound to individuals' geographical location and type of insurance coverage<sup>6</sup>. In the coastal area, the main healthcare providers include the government subsidized Bureau of Public Health (BOG) responsible for providing preventive care and healthcare education, the Regional Health Services (RGD) liable for delivering primary care to the poor and "near poor", and the public hospitals<sup>7</sup> which deliver specialised out-patient and in-patient care. The coastline is also covered by an array of private providers including private general practitioners (GPs), primary clinics managed by firms and two private hospitals. A fair number of NGOs also deliver services including family planning, blood transfusion and health promotion. Healthcare in the hinterland is provided mostly by the Medical Mission (MZ), an NGO partially subsidised by the MOH and liable for primary healthcare are undertaken by a private hospital in Paramaribo (PAHO, 2002; IADB, 2005).

Although the Surinamese Constitution establishes the right to health for all citizens, free care is not granted by law. Most Surinamese are insured by one of the following: the SZF, private firms or the MSA. The SFZ caters mostly for civil servants and their dependents and grants the use of both private and public primary and secondary care services. Firms'

<sup>&</sup>lt;sup>5</sup> These features include: 1) a separation between service financing and provision; 2) a mixed public-private system; 3) institutions with a high degree of managerial autonomy; 4) a social security system (SZF) with relatively high coverage and no healthcare provision responsibilities; 5) a formal means test for subsidizing care to the poor; and 6) the use of different provider reimbursement systems in the public sector, including capitation and *per diem* rates (IADB, 2005).

<sup>&</sup>lt;sup>6</sup> People living in the hinterland of Suriname have no insurance coverage (IADB, 2005).

<sup>&</sup>lt;sup>7</sup> These include three general hospitals and one psychiatric hospital.

employees are provided with insurance packages that give access to the company owned clinics and private care. And the MSA secures the eligibility of the underprivileged to public health services (IADB, 2005). Despite these provisions, approximately one third of the coastal region's population is uninsured. Lack of insurance affects the poor and "near poor" the most (Bitrán *et al.*, 2001) and has a negative impact on the access to care (Giedion *et al.*, 2001).

Suriname's health system's performance and population's health status rank low when compared to other countries in the region (WHO, 2000). In the mid-1990s, during a period of dramatic macro-economic problems that put the funding and provision of healthcare at stake, the Surinamese government acknowledged the need to reform the healthcare system. This was also a reaction to the dissatisfaction expressed by various stakeholders, including the government-insured population on whom the payment system and the poor quality of care delivery were taking a heavy toll, and the state sponsored care providers who claimed better wages and changes in the financing policy (PAHO, 2002). Other problems identified in the meantime include the need for more qualified personnel both in care provision and policy development, more preventive and promotional care, the decentralisation of health services, more efficient use of available resources, greater transparency in the funding process, care quality control, an increase of insurance coverage, a better health information system and more cost-effective provision of pharmaceuticals (IADB, 2005).

In the early 2000s, the MOH established a partnership with the Inter-American Development Bank (IADB) to conduct studies to inform the design of the health reform process. One of their conclusions was the need to promote lay people's participation in healthcare and in the reform process itself. Although an attempt to promote the latter was made by publicly announcing the results of the IADB studies, little feedback from civil society was obtained and used in decision-making (PAHO, 2002). A report compiling the results of the IADB studies confirmed the generalised lack of user participation: "patients have no formal power and are not a discussion partner for the medical profession" (IADB, 2005: 96). There is also an absence of formal mechanisms to measure users' needs and level of satisfaction with care. Thus, the setting up of the PCS client council was one of the first initiatives to give voice to healthcare users.

## **Mental Healthcare Provision**

Until recently, public mental healthcare in Suriname was available only through one psychiatric hospital in Paramaribo, the former National Psychiatric Institution (LPI). In the mid-1990s, the MOH and LPI agreed there was an urgent need to reform the mental healthcare sector. At that time, ambulatory care was extremely limited. Care provision was oriented toward tranquilising medication and most LPI inpatients had been hospitalised for more than 30 years. The majority were over 65 years of age (PAHO, 1998). The increase of access to mental healthcare in the rest of the country and its decentralisation to other services in Paramaribo were identified as the main priorities of the reform. In 2000, the LPI changed its name to Suriname Psychiatric Centre (PCS) reflecting its commitment to the reform process and a shift toward community-based care provision (Liefden, 2005).

One of the early challenges to mental healthcare reform lay in the lack of expertise in policy-making within the MOH. To a great extent, this was caused by the exodus of human capital which occurred as a result of the economic downfall and the socio-political unrest in the 1990s (PAHO, 1998). To solve this problem, the MOH commissioned PCS to develop a mental healthcare plan for reform. In the early 2000s, PCS delivered a reform plan containing several measures: 1) reinforcing the shift from intramural to community-based mental care provision, which was to be implemented through collaboration between PCS, general healthcare services, NGOs and user and carer organisations to disseminate information about mental health and to make mental care professionals (particularly psychiatrists) available in general hospitals in Paramaribo; 2) entrusting the provision of basic mental care to RGD and MZ primary care providers, which was to be accomplished through additional training of RGD and MZ professionals in mental healthcare delivery; 3) making psychiatric care available in Suriname's second largest city Nickerie, which was to be delivered by two PCS psychiatrists travelling twice a month to provide care in situ; 4) creating a more comprehensive curriculum for the Nursing School including training in the field of mental care; and 5) making psycho-pharmaceutics available at polyclinics and pharmacies.

Some of these measures are already being implemented but some quandaries remain to be tackled. Difficulties in assembling and sustaining the necessary funds for healthcare provision play a significant role in the extent to which reform can be achieved. Suriname has been confronted since long with a widespread shortage of qualified health professionals in the public sector. This situation is particularly striking in mental healthcare and relates to two constraints: the inability of the MOH to compete with the wages and work conditions offered by private care providers (PAHO, 2002) and the lack of local training in psychology and psychiatry which keeps the number of graduates in these fields low. Another barrier linked to the shortage of resources is the inability to make second-generation anti-psychotic medicines accessible. Although these medicines are likely to improve users' quality of life and, albeit indirectly, contribute to the implementation of community-based care, the MOH is unable to bear its costs: they are three hundred times higher than those of currently available medicines.

A final consideration on the low socio-economic position of people suffering from chronic illness. In Suriname, people unfit for work due to ill-health are eligible for state financial support. However, sickness subsidies are very low, forcing beneficiaries to depend on their families or on mental healthcare. This situation places a heavy burden on less privileged users and their households putting them at risk of increased poverty. The problem is exacerbated by the fact that people labelled mentally ill are highly stigmatised as society is unprepared to accept mental healthcare users in general care, the labour market and the social sphere itself.

# Use of mental healthcare

The PCS can accommodate 300 inpatients in a total of fourteen departments: two observation wards, two geriatric units, two wings for unstable users, two units for chronic users<sup>8</sup>, one child unit, one drug addiction wing, one night centre, one protected living unit, one day centre and one department to host people with a history of homelessness. In 2006, the PCS had approximately 240 inpatients and 30 out-patient service users. Its staff totalled 430 people including six psychiatrists, one psychologist, two general practitioners, one social worker, two assistant social workers and 170 nurses and nurse assistants. The remaining personnel included administrative, technical and maintenance staff. The average length of stay upon admission is forty-two days. PCS provides an average of 14,000 polyclinic consultations per year (PCS, 2008).

There is little data on mental healthcare use in Suriname. However, there seems to be a marked split in the use of this type of care depending on economic status. While the poor and the "near poor" use public services, the better-off resort mostly, if not exclusively, to private care. The choice of the latter seems to be influenced by two factors. On the one hand, the fear of being stigmatised drives people to seek care where they can remain more anonymous. On the other hand, poor facilities and the shortage of mental healthcare professionals in public

<sup>&</sup>lt;sup>8</sup> These four departments have separate wings for men and women.

care make it unattractive for those who can afford an alternative. The case of psychological counselling is paradigmatic of these limitations. Although there are twenty to thirty psychologists in Suriname, PCS had only one psychologist in 2006. The rest of these professionals work in the private sector. Because psychological care is not included within insurance packages, it is largely inaccessible to those who cannot afford out-of-pocket payments. We have no figures on how many people make use of private mental healthcare.

Referrals and admissions at PCS appear to have decreased in the last years. According to a department director, this results from the investment made in providing community-based care, having psychiatrists at one of the general hospitals in Paramaribo and creating a team of "flying psychiatrists" who travelled twice a month to Suriname's second largest city to provide care to locals and those in the vicinity.

## Methods

This study was conducted in the cities of Rotterdam and Paramaribo where the project to promote user participation in Suriname was designed and implemented. We employed a qualitative research approach. An underlying assumption of the research was that token user participation is likely to occur if the stakeholders on which participation depends are not committed to the participatory project. In this study, there were two groups of stakeholders: 1) Suriname-based PCS users, PCS professionals and YSR family members; and 2) Netherlandsbased RIAGG Rijnmond client council delegates who assisted with the implementation of the PCS client council. Participants were drawn from each of these groups leading to a total of seventeen respondents.

Semi-structured interviews with Suriname-based participants were conducted in Paramaribo during April 2006 in the periods before and after the installation of the PCS client council. Fifteen participants were interviewed, namely six users, two family members, six professionals (two nurses, one psychologist, one social worker, one social worker assistant and one psychiatrist) and the social worker who volunteered to become the facilitator of PCS client council. Users were recruited during an information session on user participation held by RIAGG Rijnmond client council members. Sampling of professionals was purposeful in order to accommodate the broadest range possible of care providers. Family members were recruited during the YSR monthly meeting.

The Netherlands-based participants included two of the four delegates of the RIAGG Rijnmond client council (one ex-user and the council's facilitator). One of the participants was interviewed in the Netherlands and the other answered the interview questions in writing.

The purpose of the study was explained before the interviews and all participants provided verbal informed consent. Face-to-face interviews lasted on average 1 hour and were conducted in Dutch, with the exception of one which took place in English. Interviews were audio-recorded and transcribed verbatim by freelance transcribers.

Participant observation in Suriname took place during the meetings, activities and events that led to the installation of the PCS client council at various sites including the PCS, the Netherlands-based partners' lodging house and the headquarters of YSR. In the Netherlands, observation occurred at RIAGG Rijnmond during project related meetings.

Data analysis involved coding and the identification of themes using MAXqda2 software. Coding was organised in three stages: open, axial, and selective coding (Yin, 1994). During open coding, transcripts were read several times and then divided by identifying units of text related to an idea. In axial coding, ideas were compared between and within transcripts for consistency. This allowed similar ideas to be organised into conceptual categories that were further developed by iteration to eliminate redundancy and generate comprehensive categories. Finally, in selective coding core concepts were identified as overarching themes of the study and conceptual categories were organised in relation to these concepts. The themes identified are illustrated by the English translation of direct quotes from the data. The acronyms SR and NL are used to refer to the Surinamese-based and Netherlands-based participants, respectively. The names aggregated with the quotes are pseudonyms in the case of the users. The client council facilitators, PCS professionals and family members are referred to as such, but the first are differentiated by country and the last two by the use of a number. Naming the function held by professionals could facilitate a better understanding of the results. However, this would jeopardise the anonymity of their statements since some positions at PCS are held by only one professional. For this reason, they are not designated according to profession.

# Findings

This section presents the four themes derived from the data: a) perceived need for change in mental healthcare; b) lay people's participation in mental healthcare; c) the implementation of the client council; and d) stigmatisation of mental illness.

## A. Perceived need for change in mental healthcare

User participation is often inspired by a perceived need for change. As observed earlier, the performance of the Surinamese healthcare system lags behind that of other countries in the region (WHO, 2000) due to insufficient funding and brain drain, among other factors. These factors also appear to have a negative impact on mental healthcare. To understand how they may be affecting this care sector, we asked the Suriname-based participants about the changes they consider relevant to improve the quality of mental care provision. The changes suggested are grouped under the following sub-themes: 1) ideology and organisation of mental healthcare; 2) access to mental healthcare; 3) mental healthcare delivery; and 4) client participation in treatment.

## 1) Ideology and organisation of mental healthcare

Participants expressed the need to decentralise mental healthcare provision, develop community-based mental services and implement a biopsychosocial approach to mental ill-health. These amendments are in consonance with those proposed in the mental healthcare reform plan delivered by PCS.

Decentralisation of mental healthcare was considered particularly necessary as a means to increase access to mental care. Public mental care in Suriname is mostly available in the capital city through one mental healthcare service (PCS). Meagre financial resources often pose a barrier to those seeking this type of care. A journey to Paramaribo is something many living in the periphery cannot afford. Aside from that, the stigmatisation of mental illness is a serious problem in Suriname. Shame and fear of exclusion hamper people's use of mental care services. Making mental care widely available at general hospitals and healthcare centres could help curb the problem of accessibility caused by stigmatisation. Going to a general service offers greater anonymity to mental healthcare seekers. Furthermore, placing mental care side by side with other specialisms may lead make people reappraise what this sort of care entails and whom it targets, generating more understanding of mental ill-health and perhaps a reduction of the negative stereotypes associated with it.

Participants also stressed the importance of making care available within people's social, psychological and existential environments, i.e. to foster community-based care. Efforts to promote this type of care led to the creation of a social psychiatric service centre at PCS. This service aims to provide out-patient care and to downsize long-term hospitalisation. Although participants considered this a good initiative, they stated the need for professionals to go beyond PCS and adopt an outreaching approach including also social care. This implies the creation of a mobile team composed of a diversified set of professionals who can extend the work carried out at PCS to the community as well as the development of a closer collaboration with health care centres. Additionally, it is crucial to make psycho-education available to users, care professionals, family members and society at large in order for users to become more accepted and integrated in society.

The implementation of a biopsychosocial approach to mental ill-health will require combining the prevailing biological perspective with psychological and social perspectives of mental distress. Participants stated that the recognition and incorporation of all kinds of professionals (i.e. social workers, nurses, psychologists, occupational therapists, etc.) as equal providers in care is critical for this to occur. Even though this standpoint has a growing numbers of advocates at PCS, it has been somewhat resisted by psychiatrists: "(...) things are changing but people are approached from a medical perspective because psychiatry takes up leadership here. They [psychiatrists] determine what happens and they don't have a multidisciplinary way of thinking about the client" (Professional 2 SR).

Psychiatrists also opposed the re-implementation of periodic staff meetings. These meetings were common practice in the 1980s and can be used to promote a holistic approach to care users through the sharing of various forms of professional expertise. Perhaps the new social psychiatric service will serve as an impetus for the exchange of different kinds of knowledge. Nevertheless, the adoption of structural measures such as the inclusion of social and psychotherapeutic care in health insurance packages also seems to be necessary. If these types of care become affordable and accessible, and psychiatric care is no longer the only subsidised specialism, there are better prospects for a re-equation of power relations and the recognition of all forms of expertise.

#### 2) Access to mental healthcare

According to participants, access to public mental healthcare is undermined by several barriers: poor information about mental healthcare, the stigmatisation of mental illness, the lack of insurance coverage for social and psychotherapeutic care and GPs' reluctance to make

referrals to PCS. According to Professional 5 (SR), the latter originates from a misunderstanding which led many GPs to associate PCS exclusively with care for severe mental illness. This, together with an attempt to protect their clients from stigmatisation, prevents GPs from sending people with mild mental problems to PCS.

Participants proposed various measures to improve access to mental care: the decentralisation of mental care provision, training primary care professionals to recognise mental problems, adopting a biopsychosocial approach to mental ill-health, psycho-education, campaigning against stigmatisation and the mobilisation of both professionals and lay people to lobby for the inclusion of psychotherapeutic and social care in insurance packages. These measures, with the exception of the last two, are being implemented through the joint efforts of PCS and MOH. YSR has also been an important partner in this endeavour, collaborating on the dissemination of information about mental-ill health and mental care and supporting family members and clients dealing with psychosocial distress.

#### 3) Mental healthcare delivery

Concerning the delivery of mental healthcare at PCS, participants indicated a number of aspects requiring change. These include users' isolation, the way in which users are approached on a daily basis, the type of medication and facilities available, the shortage of qualified professionals and communication among professionals and between staff and clients.

Isolation upon admission is common practice at PCS and all the interviewed users experienced it at least once. According to participants, isolation is meant for those showing aggressive behaviour upon arrival but it is not always applied under these circumstances. One participant explained how he had to endure seclusion even though he had offered no resistance to admission:

I don't understand why I have to go directly into the isolation room every time I go there [PCS] if I'm quiet. All those times I was admitted I never reacted. I'm a very quiet patient. But each time, I have to first go into isolation and after three or four days they place me in a room. I would really like this to change. You shouldn't be sent straight into isolation every time you are admitted. (Rodney, SR)

Users stated that isolation puts them in a situation of extreme deprivation and discomfort: "your clothes are removed. You have to sleep in the isolation room without a mattress, on the cold floor. You urinate and defecate in the same room where you sleep" (Sonja, SR). All the interviewed users expressed a strong dislike for this practice and the need to eradicate it or, at the very least, make it less frequent. These views seem to be increasingly supported by some professionals: "I want the word isolation to vanish from here. The whole idea must be abolished" (Professional 2, SR). According to this professional, nurses are the biggest opponents of the eradication of isolation due to fears of becoming unable to handle aggressive users. He noted the need to give them training focused on the development of competences to deal with situations of conflict and aggression and to promote a holistic, integrated and respectful approach to dealing with users.

One of the most criticised aspects of care delivery was the way in which some nurses address users: "they scream at us: 'you idiot. Shut your mouth'. They hit us. I don't like that (...). I'm a *mondige* [outspoken] patient but the other patients take whatever the nurses say without reacting. They don't answer" (Glenn, SR). When asked about why nurses treat them that way the same user answered: "due to lack of power. And because they have no love for the job. They can't find anything else so they end up at PCS" (Glenn, SR). Other factors which seem to contribute to the maintenance of that kind of conduct are insufficient training, poor communication between professionals, the low wages and recognition awarded to nurses, lack of care quality evaluation and the fact that most users are not aware of their rights and, therefore, do not dare to dispute that kind of "treatment".

As mentioned earlier, Suriname endured an economic backlash in the 1990s that led to a drastic reduction in the budget allocated to the care sector. Participants noted the negative impact of meagre financial resources on mental healthcare delivery particularly in relation to the availability of qualified professionals, the accessibility of second-generation antipsychotic medicine and the quality of facilities.

At the time of our fieldwork, PCS had one psychologist, one social worker and two assistant social workers for a population of approximately 240 inmates and 30 out-patient care users. Aside from the poor recognition given to these categories of professionals, the low wages make work in public mental healthcare unattractive. Most psychologists in Suriname prefer to seek employment in private companies where earnings are much higher. Social work is a relatively recent degree and even though the number of interns at PCS has been increasing, most end up taking jobs in other sectors where they are better paid. The same applies to specialised nurses who migrate to other countries in the Caribbean region. Overall, these circumstances pose a barrier to the hiring and permanence of qualified healthcare workers in public mental healthcare. PCS is equipped with a pharmacy that provides its users with government subsidised medicines at a lower cost. This is an essential service. Many users are otherwise unable to afford these medicines given the low sickness subsidies to which they are entitled. Although PCS usually has a stock of essential medicines, it falls short at times leaving some users with no alternative but to interrupt medication. Scanty financial resources also impede PCS's from acquiring second-generation antipsychotics. Participants stated that the availability of second-generation antipsychotics could foster an improvement of users' treatment and quality of life but they expressed little hope of that becoming possible in the near future.

Participants also stated the need to improve the quality of some facilities. Some PCS wards lack good sanitation conditions and long-term inmates could benefit from the availability of a "shop" providing utilities at low prices as well as from the expansion of the range of activities provided within occupational therapy. These aspects have been under consideration but the pace of implementation is slower than desirable due to limited funds.

Communication between and within different classes of professionals and between care providers and clients is another issue in need of thorough consideration. The following quote illustrates the main limitations encountered at this level:

Consultation is always necessary, especially in a profession where you depend on each other. That's certainly the case in the healthcare sector. Here you depend on your colleagues and the information they hold, particularly regarding the care of patients. If you have to look after a patient who I have been accompanying previously and I keep the information to myself, there is a problem because you have to start from scratch while that is absolutely unnecessary. (...) We need to improve our communication. We need to verbalise more, to talk more with each other, to exchange information and to dare talking about our patients' conditions and wellbeing. We spend hours chatting but we don't talk about our work. So we need to improve that. But we also need to improve the communication with the actual client. I'd like to sit down with the client and make a [treatment] plan together with him/her but that does not happen. (Professional 4, SR)

Poor communication between different categories of professionals may be explained by the existence of a deep-rooted professional hierarchy that perpetuates distance and incommunicability between different fields of knowledge and, consequently, professionals. This was particularly noticed by professionals who were educated abroad and who occupy the lower ranks of that hierarchy:

Many of the people who work in this field have been educated overseas. For instance, I was educated in the Netherlands. What you get is a discrepancy between the people educated here and those educated abroad. First, you don't speak the same "language". Second, I was educated during the times of anti-psychiatry. Third, I haven't developed my competencies in healthcare within a hierarchical system. I'm accustomed to a horizontal system where all specialisms have their place. The education here is more or less the same but the mentality is different. It'll take a while until doctors here realise that: "you are a part of the happening, not *the* happening". And that's difficult. I think they want it but if the client sees you as a God, the chances are you'll perceive yourself as a God as well. (...) So the patient also attributes a certain role to the psychiatrist. (Professional 2, SR)

The existing divide between different classes of professionals and the even stronger divide between care providers and users undermines the possibility of "dialogue" between distinct kinds of expertise. This divide results from the primacy of a biomedical perspective over mental ill-health and of a solid hierarchy which favour the supremacy of the knowledge and practice of medical doctors over all the others. This is further substantiated by the limited accessibility of other types of care (e.g. psychotherapy, social care, etc.): its reduced availability and affordability increases dependency on the care provided by psychiatrists. In addition, the majority of users remain poorly informed about their conditions and rights. This generates an unbalanced power relationship where users turn to professionals, and especially to the doctor, as the only entity able to sort out their problems. The doctor's abilities and persona are, therefore, deified. All in all, these circumstances favour a dynamics by which those at the top and those at the bottom of the hierarchical ladder act to confirm each other's position of superiority and inferiority, respectively. This is not to say there are no dissident voices – the quotes above are good examples of this – but structural measures appear to be necessary to foster communication between professionals. The implementation of a biopsychosocial approach to mental care and the development of a framework emphasising teamwork (for example by creating regular staff meetings) could be a good starting point.

As stated above by Professional 4 (SR), communication between professionals and clients and their inclusion in the decision-making on treatment plans also requires reappraisal and improvement. We address this issue in the next sub-section.

# 4) Clients' individual participation in treatment

Studies show that users who participate actively in their own care plans are more likely to have a better self-image (Brown and Goldenberg, 1993), to be more satisfied with the

care they receive (Chinman *et al.*, 1999) and to feel more empowered (Linhorst and Eckert, 2003). Most participants stated the importance of users being involved in their treatment. However, many PCS users remain *onmondig*, i.e. disengaged from their care plans, unaware of the particularities and implications of their conditions, the medication they take and, sometimes, even of their diagnosis.

Information about treatment flows with difficulty between providers and appears to stumble even more where users are concerned:

There is no tradition [of sharing information with clients]. Sometimes I ask clients: "do you know what's ailing you?" They experience the symptoms but they don't know where they come from. They don't have any information about the medicines [they take]. Sometimes I tell them: "ask the doctor". Most won't do it and those who do don't get the information. Maybe the client council could stimulate this. (Facilitator, SR)

When asked about the reason users are so little involved in their treatment, a professional explained:

Professional: (...) we are still working under a strong hierarchy. (...) Like my sisters, my nurses... they treat me like royalty. They don't have to but they do. That's Suriname. It [hierarchy] is still there. It also happens with the client. The doctor is still the doctor. (...) It's not like they have to bow to me but I'm the doctor.

Interviewer: And where does that sense of hierarchy come from?

Professional: It's like what I felt when I was a young boy and I saw the police. It's not like I'm going to bow to them but you see an authority.

Interviewer: (...) And do your clients let you know when, for instance, the medication does not work for them?

Professional: They would but very, very cautiously. They don't want to hurt you. But they would [tell you]. (Professional 2, SR)

Another professional supplemented this explanation in the following way:

There's no communication in the good sense of the word. You [provider] talk but they [clients] have no say. You have the psychiatrist and then you have the nurses and then you have the client, there, at the bottom. It's not a talk *with* the client but a talk *about* the client. You don't speak to him/her. You don't make any plans with him/her. You get the feeling that you don't know what's happening with the client. You observe his/her behaviour. You report it and there

is a reaction. But there isn't an hour for the client where he/she can "unload" and say: "now it's my turn to speak. These nurses are rude. You should not treat me this way". This isn't possible. It's an absolute hierarchy. I think there should be psycho-education for everyone because the client is "onmondig", stays "onmondig" and I think this should change. (Professional 2, SR, our emphasis)

The last two quotes illustrate the presence of a highly paternalistic way of care provision at PCS. Perceived as an "authority" by some users and handled as "royalty" by some of the other professionals, psychiatrists' discourse and practice is particularly difficult to question. From a user perspective, this also extends to other care providers, i.e. most users consider that staff's directives are not open for discussion. This kind of perception, and the dynamics they ensue, leaves little opportunity for choice, shared decision-making and joint responsibility over treatment. This is further enhanced by an organisational structure that makes no room for user participation. Together, these circumstances favour the dismissal of users' experience, knowledge and wishes regarding their health and life goals over professional expertise. Awareness about and recognition of users' own expertise is, in this way, thwarted. This poses an obvious barrier to users' participation in care plans.

Low *mondigheid* also impairs users' involvement in their treatment. Most users are unable to articulate their care needs in an independent and assertive way. Aside from an unfavourable care environment that devalues their lay expertise and does not encourage the acquisition of knowledge and new competencies, most users have a low socio-economic status that undermines their access to information through channels such as the Internet. This limits their ability to become emancipated users who dare to ask questions, dispute inappropriate work conduct and actively engage in treatment.

There are some voices on the rise, however. Several interviewed users framed their complaints and wishes and pointed out their willingness as well as the need to stimulate other users to promote user participation in mental care, both individually and collectively. These intents are supported by some professionals and family members from Ypsilon Suriname (YSR) who recognise the potential benefits of user involvement. However, user participation intrinsically implies a challenge to the current dominant paradigms in mental care provision and to existing power relationships. This is likely to generate different perspectives on the extent to which participation should occur. For this reason, we asked participants about their expectations regarding user participation, particularly through a client council. These are presented in the next section.

## B. Lay people's participation in mental healthcare

Lay people's participation in healthcare is very incipient in Suriname, particularly where care users are concerned (IADB, 2005). An exception to this is the participation of family members of mental healthcare users in Paramaribo. Their involvement takes place mostly through initiatives carried out by the organisation of family members of people diagnosed with schizophrenia or other mental illnesses – YSR. Although YSR focuses primarily on advocating for family members' interests, it includes mental healthcare users in its activities and strives to promote their rights.

The setting up of a client council constituted an unparalleled venture concerning user participation in Suriname. To gain insight into stakeholders' views about this type of participation, we inquired about their expectations regarding the installation of the council. All participants stated it was unquestionably relevant. However, their opinions differed on the extent to which users' participation and influence in mental healthcare should occur. Before presenting these results we provide a general description of the organisation YSR.

#### 1) Ypsilon Suriname

Ypsilon Suriname was set up in 1998 by Juanita Slengard, a Surinamese member of its counterpart organisation in the Netherlands – Ypsilon Nederland (installed in 1984). YSR started by bringing together family members, clients and professionals at information sessions about mental illness and mental healthcare. Later on, it became an organisation of family members of people affected by mental problems. It is led by four board members: Joyce Dawson-Smits (chairwoman), Nadya Chin Ten Fung (vice-chairwoman), Stanley Sovan (treasurer) and a secretary. Its main goals are the dissemination of information about mental ill-health and the promotion of family members' interests in the field of mental healthcare.

YSR also advocates for clients' rights. Its initiatives and proposals for change are framed in the best interest of all parties concerned including PCS, with which Ypsilon has established close collaboration. Partnership with clients and PCS is considered valuable to the dissemination of information, the formulation and implementation of reforms and resource management.

A good example of this was the acquisition of a bus by YSR which became a joint initiative by YSR, PCS, and users. YSR received a donation from a Dutch organisation to purchase a bus to transport family members and clients to its monthly meetings and other events. Inability to pay for travelling was a key barrier to participation in events and having a

vehicle easily resolved the problem. However, using the bus exclusively for this purpose would have wasted a great deal of its potential. Moreover, the bus maintenance required a number of resources which YSR could not provide on its own. One participant explained how this problem was solved in cooperation with PCS:

Since we have only one psychiatric hospital, we chose from the start to do it together with PCS. We ordered the bus and arranged for the funding and PCS found a garage and took care of the insurance and the driver. We went to the notary and made a contract referring the conditions of use. (...) The bus isn't used only by family members to attend our meetings but also when families or clients want to have a day out, go to swimming lessons or on a course. It can also be used by nurses to attend training and in situations like your [Netherlands-based partners] arrival from the Netherlands. (...) When we want to use the bus, we inform PCS and make an arrangement and they do the same. (Family Member 2, SR)

This approach to resource management, i.e. the maximisation of output at the lowest possible cost, is particularly relevant in countries such as Suriname where there is a shortfall of resources. By sharing the bus with PCS, YSR avoided its under-use, diminished its costs (e.g. the bus is parked in a free-of-charge and secure area), maximised its value by making it available to a wider range of stakeholders and prevented it from becoming a burden for the organisation. YSR found a sustainable and beneficial way to manage this resource that contributed to the improvement of the facilities available to its members, PCS and mental care users.

Examples of other initiatives undertaken by YSR in partnership with various stakeholders include the upgrading of PCS's library, the development of occupational therapy (through the creation of a handicraft department within PCS) and the creation of a day centre for clients. YSR also organises monthly information sessions with a variety of guest lecturers including mental healthcare professionals, GPs, policemen, lawyers, religious leaders, traditional healers, etc. These sessions are usually attended by fifty to eighty people including family members, clients and mental care providers. They are held at PCS which minimises rental costs and works as a bridge between the institution and "outsiders". In addition, YSR mediates between family members and professionals when problems arise, organises outings for clients, offers printed information, provides a help line, participates in anti-stigma campaigns and lobbies for clients and family members' interests with the MOH.

Inquired about the sort of change fostered on the account of YSR initiatives, one participant replied:

They [family members] have much more information. At first some of them could not pronounce the word schizophrenia properly, they didn't know what anti-psychotic [medicines] were (...) and now they are informed. They have much more contact with their peers. They also deal with the illness in a freer way. We used to have our meetings in another place but then the rent increased. So we asked PCS if we could use one of their rooms and in exchange we could make it nicer together with them. They thought that was great. We didn't have to pay rent anymore and the threshold was lowered for the families that hardly ever went [to PCS]. And then it became easier for them to see what it's all about and to meet other people. They also became more *mondiger*. They started daring to make questions, to talk about problems but also about the things they thought could change at the hospital and at home (...).

The treatment. They [PCS] have new ways to do the screening/ intake, to formulate the diagnosis, to provide training for the nurses. The social workers visit people at home, they look at the situation at home. Those things were there before but now they are a little more structured. And also they are more open to the family. (Family Member 2, SR)

Lay people's participation through YSR had a number of positive effects both on mental healthcare (e.g. contributing to its modernisation and diversification and making it more out-reaching) and on lay people (e.g. helping them become more informed, outspoken and engaged). YSR strives to stir up change in a collaborative way, favouring the cooperation of all stakeholders and joint decision-making. Over the years, it built a relationship of mutual trust with PCS that laid the foundation for shared consultation and joint deliberation. Both parties had their share of responsibility in fostering this productive partnership. YSR respected PCS's ability and timing to enable change and adopted a positive attitude that leaves out blame and negative publicity when dealing with arising problems. PCS showed willingness to accommodate lay people's views and wishes regarding mental care provision and to become an increasingly responsive and open institution.

Despite these positive accomplishments, YSR faces some problems. One of its main challenges lies in finding enough volunteers to carry out activities. Time and financial constraints impede people from engaging more actively. But according to YSR's members, the hardest obstacle to circumvent is lack of motivation. Most people are enthusiastic at first but when they get in contact with users they feel disheartened by the conditions in which they live and withdraw their commitment. 2) Expectations regarding the setting up of a client council

User participation in mental health can take place in a variety of ways including individual participation in treatments and collective participation in service design, management, delivery and evaluation, research, training, user-led projects and policy-making (Braye, 2000). Client councils may be described as organs set to enable collective user participation within healthcare services (van Haaster, 2001). In the absence of legally established directives, the scope of intervention of these councils usually depends on its members' initiatives and the extent to which they find support from the service direction and its professionals.

All participants considered the client council pertinent but they shared different views about the input and degree of influence of future councillors. To understand their position, we asked participants about their expectations regarding the scope of intervention of the client council and the benefits or problems for users and mental healthcare that may arise as a consequence of this type of participation.

## 2.1) Scope of intervention

Participants stated that the client council should act as an advocator of clients' interests. However, their opinions about the actions to be undertaken by the council differed. Participants pointed out nine functions that could be adopted by the client council: consultation and advice to both users and PCS (indicated by ten participants), information provision to users (seven participants), mediation between users and professionals (seven participants), design of proposals to improve mental healthcare (five participants), support for users when dealing with problems (four participants), development of mental healthcare policy (two users), organisation of leisure activities for users (two participants), care delivery to other users (one participant) and research on mental healthcare quality (one participant).

No marked differences were found between the different participant clusters on the functions indicated. The only exception was that the Suriname-based clients only outlined functions to be undertaken immediately after the setting up of the council, while six participants from the other clusters (three PCS professionals, two family members and the Dutch and Surinamese client council facilitators) also indicated functions to be effected in the future, after the council had acquired knowledge, experience and stability. This included functions such as the design of proposals for improving care, the development of policy and research on care quality. The latter reasoned these functions should only be incorporated at a later stage in order to prevent disappointment arising from inappropriate performance. They

felt the client council needed to reach some maturity before adopting them. In addition to requiring the command of several competences, the exercise of these functions implies that clients take over a higher degree of power. The professionals and family members who espoused these views stated that clients should take power gradually and they stressed the importance of preventing conflict and maintaining a close dialogue between all stakeholders while that process unfolded.

# 2.2) Benefits and negative consequences

Participants stated participation through a client council could deliver a set of benefits for council members (users and ex-users) and mental healthcare users at large as well as for mental healthcare itself.

# Members of the client council can benefit by:

- becoming informed about mental healthcare, medication, mental ill-health, rights, etc.
- becoming more *mondig*
- becoming more independent
- becoming more able to claim their rights
- advocating for their interests
- becoming empowered
- participating more in treatment
- getting better treatment, as a result of more information, higher *mondigheid* and more participation in care plans
- developing the ability to seek funds
- being able to find advice and feel more supported in dealing with problems
- having a peer group
- being able to exchange their experiences with other users
- finding a meaningful occupation
- reaching a higher social status
- developing a larger social network

# Mental healthcare users in general can benefit by:

- becoming informed about mental healthcare, medication, mental ill-health, rights, etc.
- becoming more mondig
- becoming more able to claim their rights

• being approached as a "collaborative subject" instead of a "suffering object" as professionals shift their perceptions of users

participating more in treatment

• getting better treatment as a result of more information, higher *mondigheid* and more participation in care plans

• finding advice, support and help through the client council when dealing with problems

• feeling more protected because their interests will be advocated for and the client council can work as mediator between users and providers and take part in care quality evaluation

• benefiting from more responsive mental care services, as services and policy-makers might become more informed of users' needs and wants through the client council

• suffering less from the "revolving door effect" as a result of better treatments and support

## Mental healthcare can benefit by:

• achieving better treatment outcomes as users will be more informed, *mondig* and involved in care plans. This will allow professionals to get feedback on the care provided and to adjust it according to users' needs

- gaining an additional party for consultation – the client council

being perceived as more trustworthy by being open to scrutiny

• gaining publicity and getting more researchers interested in mental care as a result of being linked to a new initiative, i.e. the implementation of a client council

• lessening the "revolving door effect" which might raise professionals' sense of accomplishment and motivation, reduce costs, and increase the reputation of mental healthcare institutions

• generating more opportunities to attain subsidies since the presence of a client council is a step further to coming more in line with international standards and directives on mental care provision

• improving its overall quality and performance as a result of the benefits mentioned above.

Only five participants stated that participation in the client council could have negative consequences. These included three clients, one professional and one family member. Their concern lay in the reactions from others as well as the reactions of clients that were to become councillors as they set to incorporate the roles and respond to the possible demands of such an endeavour.

(...) I hope it [client council] won't become too heavy for them or that it stagnates or becomes a reason for fighting [with each other]. (Family Member 2, SR)

Maybe they [members of the council] need to be a bit careful with what they do so they don't get ill again. (Dorothee, SR)

The only thing I see is... but that depends on each person... is that they shouldn't get overexcited with the role they'll have [as a member of the client council]. They shouldn't become impertinent, or think more or less of themselves because of the key role they'll get. (Professional 5, SR)

Family member 2 (SR) expressed concern that the experience of belonging to a client council could become overwhelming, potentially leading to one of either two negative consequences: inertia or conflict. Dorothee (SR) noted the need for councillors to be prudent in relation to the demands posed by partaking in the council as a necessary precaution to avoid relapse. And Professional 5 (SR) showed concern about councillors becoming defiant. These reservations highlight the fact that user participation is not a seamless process and that clients need to be supported in getting involved. Client council facilitators can have an important role at this level. One of his/her functions is to offer clients support when they encounter problems. Another is to secure the continuity of the council during periods in which its members are unable to participate. These two forms of assistance may contribute to easing the strain caused by participation, fostering its re-commencement once users feel prepared to do so.

Three participants were also concerned about other people's reactions to their participation in the council:

I'm not sure if I want to be a member of the client council. I'm afraid that if I have complaints [about my treatment], the doctor will be rancorous with me. (Rodney, SR)

For instance, we [client council] are going to make the patients more *mondig*. Imagine that I'm admitted [to PCS]. Then they [nurses] can say: "oh, you are from the client council!" And then they will make it even harder for me, like: "You have made patients more *mondig*" and clap... you get slapped in your face. (Glenn, SR)

People stigmatise [people with mental problems] here. I don't want to do it [take part in the client council]. Let the people who dare do it. I don't dare. (Dorothee, SR)

While Rodney (SR) felt his future participation in the client council could jeopardise his treatment and so was unsure about whether he wanted to become a member, Glenn (SR) stated she was not afraid of possible negative reactions from professionals because she was committed to preventing relapse: "I always take my medication on time and I will *never* be admitted again". Dorothee (SR), in contrast, was determined not to take part in the council out of fear of exclusion. These quotes illustrate some of the potential barriers to participation in a client council. We address this issue in the next section.

Most participants were positive about the implementation of a client council: the expected benefits by far outnumber its negative consequences. Those who felt there would be no negative consequences were nevertheless keen to assert the installation of the council should occur slowly in order for the council to be accepted and pursue its goals. They also noted the importance of making the subject of user participation part of educational programmes, preparing mental health professionals for user participation and an attitude of transparency and partnership between councillors, PCS and other stakeholders such as YSR. This demonstrates participants' concern about seeking cooperation between all parties when implementing the client council. The fact that the *status quo* between users and professionals is likely to be challenged through user participation makes it even more relevant that all stakeholders are informed about and motivated to welcome this initiative.

#### C. The implementation of the client council

The client council was set up in 2006 by a total of seven members, all of whom were clients except the facilitator. The installation of the client council was assisted by a delegation of four members from the Netherlands-based RIAGG Rijnmond client council, which formed a partnership with the Surinamese client council.

## 1) Conditions for the implementation of the client council

Participants indicated three key conditions for an effective implementation of the client council: motivation and availability of clients to take part in the council; support of all stakeholders (i.e. PCS, YSR and the RIAGG Rijnmond client council) in installing and developing the council; and, the adequate facilities and funding to support the council's initiatives.

Clients who took part in the preparatory meetings preceding the set up of the client council were aware of the implications of their participation in such a council. On average, ten participants attended these meetings. This is a small faction of the total number of mental healthcare users which exceeds 250 people. Seven out of the ten participants got involved in the client council. Their awareness of the implications of user participation was enhanced by two delegations from the Netherlands-based mental healthcare clients that visited Suriname in 2003 with the goal of exchanging experiences and expertise and promoting user engagement in mental care.

Respondents were motivated to either support or sit on the client council by an aspiration to improve mental healthcare, advocate for users' interests and support them in reaching recovery. However, their availability to participate actively in the council varied. Two stated they were unable to participate. One feared stigmatisation and increased stress caused by a heavy workload. The other felt limited by constraints posed by illness. Three participants showed full availability and one expressed the wish to be engaged in functions which did not demand leadership or too much time. As noted in the previous section, some clients feared their participation could have a negative impact on their care or in their daily lives. For those who decided to get involved, their drive to achieve change in mental care outweighed their reservations.

Obtaining support from all stakeholders was also considered a fundamental condition to guarantee the installation and the sustainability of the client council.

They [care providers] must support the client council. Cooperation is important because otherwise it makes no sense to set up the client council. There should be cooperation from the nurses, the patients and the doctors. Thus there should be contact with them on a daily basis. They also have experience and they should support us.

(...) I'm not sure if the client council can function without their cooperation. Maybe it can function but not in its totality. So cooperation must be there. Like what happens with YSR... everyone can attend their meetings whilst in the Netherlands only the parents attend YNL meetings. But here it's different. Nurses, interns, patients, doctors, parents, they all go to the meetings. Because they are all invited. They are all necessary. And I think the same should happen with the client council. (Rodney, SR)

Support and collaboration from all parties was considered important for the following reasons: it would increase the chances of implementing changes in mental care since greater know-how and resources could be activated to pursue reform; it would foster better communication between the different parties, increasing their awareness of the potential benefits of the council's initiatives and preventing misunderstandings and opposition; and, it

would allow proposals to be shared and negotiated which, in turn, would foster more transparency and diminish concealed resistance.

The YSR family members who were interviewed stated that the client council should be independent from the other stakeholders and its management and the formulation of proposals should occur autonomously. Most participants agreed that the client council should work in close dialogue with the other parties while staying independent from them.

Finally, the availability of adequate facilities and funding were considered essential conditions to secure the feasibility of the councils' activities. Mental healthcare users in Suriname are highly discriminated in the labour market and sickness subsidies are too low to allow economic independence. Perhaps for this reason, three participants from the client cluster stated that client council members should be paid for their work. Several other participants noted the need to raise funds to pay for facilities (e.g. office, access to the Internet and phone, etc.) and to sponsor events and activities. It is unlikely public health authorities would provide enough funds for these purposes since the MOH has a small budget. Some participants proposed converting the client council into an association as an alternative solution. This would enable the council to organise fundraising initiatives, request subsidies and receive donations.

## 2) The client council implementation process

The implementation of the client council was a key goal of a wider project developed by the RIAGG Rijnmond client council which began approximately one year before the actual setting up of the council. This was a transnational project that involved different stakeholders in both Suriname and the Netherlands. Next, we describe the activities, meetings and events that took place during that period in preparation for the implementation of the council.

## 1<sup>rst</sup> phase

The idea to set up a client council in Suriname was brought up by the founder of YSR – Juanita Slengard, a Surinamese resident in the Netherlands who is a member of both YNL and RIAGG Rijnmond client council. In 2005, she went to Suriname to present the proposal and evaluate clients' interest in creating a client council. An advert was placed on a local newspaper inviting participation in a meeting where more details about this form of participation would be provided. A first group of users interested in taking part in the client council was formed as result of that meeting. Preliminary discussion about user participation had taken place in 2003 during the visit of two delegations of clients of mental healthcare

services in the Netherlands to Suriname, including clients from the Maastricht RIAGG client council and representatives of the *Cliëntenbond*, the Dutch clients' union. The meeting of these delegations with Surinamese mental healthcare users was a breakthrough for user participation in Suriname, raising awareness over this process and sensitising users to their rights.

## 2<sup>nd</sup> phase

On return to the Netherlands in 2005, Juanita Slengard started seeking partners and funding to facilitate the implementation of the Surinamese client council. The RIAGG Rijnmond client council expressed its interest in carrying out this initiative. It turned it into a wider project including four different components: training, research, implementation and partnership.

Contact between Suriname- and Netherlands-based stakeholders was held in order to prepare a visit from a group of representatives of RIAGG Rijnmond client council with the intent of carrying out the project. The purposes of research were discussed by RIAGG Rijnmond client council members and the researcher. Just before departure, the RIAGG Rijnmond client council and the researcher met with RIAGG Rijnmond's director to report the status of the project and inform him about the implementation plans. During this meeting, the director expressed concern that tension could emerge between the Netherlands- and Suriname-based partners if one failed to consider history and, in particular, the colonial ties between the two countries. As we will see further on, this proved a legitimate concern.

In April 2006, a delegation of four members of the RIAGG Rijnmond client council and the researcher travelled to Suriname with the goal of assisting in the installation of the Surinamese client council.

## 3<sup>rd</sup> phase

In Suriname, a first meeting was held between the Netherlands-based partners and the Surinamese clients to share information about mental healthcare, discuss Surinamese concerns on mental care provision, identify potential client council members and organise the setting up of the council. During this meeting it was agreed that the Netherlands-based partner would provide a workshop about user participation. The next day, the workshop was announced in a local newspaper. Those interested in participating were asked to contact Juanita Slengard for more details. This initiative almost led to a conflict between the direction of PCS and YSR, on the one hand, and the Netherlands-based partner, on the other hand. The former stakeholders claimed that the workshop was also in their interest and that activities in the field of mental

healthcare in Suriname were carried out in close collaboration between all the stakeholders. Information sharing and consultation were perceived as pre-conditions for the development and implementation of new projects and the Netherlands-based partner should respect this form of work.

This is a good example of the difficulties that can emerge in transnational partnerships when the cultural, political and historical backgrounds are not taken into consideration either through neglect or lack of awareness. In the case at hand, it appeared to be a result of the latter. Since its creation, YSR had been working in direct cooperation with PCS, always informing the institution about its intents and jointly deciding its course of action. PCS responded in the same manner, consulting YSR about new initiatives and inviting it to participate in the execution of proposals for change. In addition, the Surinamese partners were cautious about foreign intervention in their services, particularly if that was to be operated by actors based in the Netherlands. Independent from the Netherlands since 1975, Suriname is still recovering from the social and economic hardships generated by the civil war that broke out in the early 1990s. Participants in this research often commented on the importance of "standing on their own feet", valuing their identity and know-how and reducing their dependence on foreign aid. Although they were willing to embrace support from the Netherlands-based partners, that was only an option if they were full partners in the whole process. When the Netherlands-based partners became aware of this, they tried to resolve the conflict by seeking contact with PCS and YSR both to include them in the installation of the client council and to evaluate other possibilities for collaboration (e.g. assisting in making a website for YSR).

Meetings were held between all stakeholders and another aspect pertaining to the conflict became evident: the direction of PCS had some difficulties dealing with the founder of YSR. This dated back several years when she decided to emigrate to the Netherlands to pursue what she considered to be better mental care for her son (diagnosed with schizophrenia) and began to criticise Surinamese mental healthcare. Her "overseas critique" had transformed her into an outsider in the eyes of both the representatives of PCS and YSR. When the announcement for the user participation workshop was published offering only the contact of the founder of YSR (she was the only member in the Dutch delegation who had a Surinamese mobile number), the management of PCS inferred the initiative was hers alone. This generated the feeling that she "was back to give us a lesson". Acknowledging this misunderstanding, the Netherlands-based partners hurried to resolve it by explaining their intention was to be mere facilitators in the creation of the Surinamese client council and

agreeing to the importance of involving all stakeholders in the process. From that moment onwards, a dynamics of mutual briefing was built and the different stakeholders started collaborating in a productive way. Several meetings were organised to evaluate how each stakeholder could contribute, to form a final group of clients and choose a facilitator for the client council.

The user participation workshop was also carried out bringing together approximately sixty participants including mental healthcare clients, family members, students and professionals. The audience raised many questions about the membership, sponsorship, and actions carried out by client councils. It also became clear that the particularities of the Surinamese context had to be taken into consideration: it was unlikely that the council could get funding from health authorities which meant finding alternative sources of sponsorship; it was improbable that family members would join the council because they felt clients should have a council of their own; and, it was unlikely that the council would have an office at PCS because most stakeholders believed clients should seize this opportunity to become more autonomous and integrated in society. This was likely to influence the creation of a client council in Suriname fairly different from the RIAGG Rijnmond client council, something that reflects the intrinsic variability that characterises the phenomenon of user participation.

The client council was set up by seven clients and a facilitator during an event at PCS that gathered, once again, a large number of participants including mental healthcare clients, family members, students and professionals. The members of the client council stated the need as well as their commitment to promote users' rights, fight stigmatisation and improve mental care provision. The statement of one PCS professionals during the installation of the client council summarised both the acknowledged value of user participation and its potential challenges: "We have an awareness problem. Society, but also our staff, needs to be more aware of the position of clients. Client participation is a beautiful word. It demands a lot from you and I'm not ready for it but I wish to get involved and support you".

3) Expectations about a partnership between the Surinamese and RIAGG Rijnmond client councils

The establishment of a partnership between the Surinamese and the RIAGG Rijnmond client council was seen as beneficial for both councils. The Surinamese client council could resort to the RIAGG Rijnmond council as a source of information and advice, relying on its experience to facilitate knowledge and insight on how to develop initiatives and deal with problems. The RIAGG Rijnmond client council could resort to the Surinamese council as a source of inspiration for future projects and a "pool of new experiences" on which to reflect and pursue client participation further.

Acknowledging the difficulties to obtain material resources, participants also stated that the RIAGG Rijnmond client council could facilitate contact with potential donors in the Netherlands and assist the Surinamese council in equipping its facilities.

## D. Stigmatisation of mental illness

The stigma associated to mental illness emerged spontaneously in the interviews. Although not directly asked about it, two thirds of the participants referred to the effects of stigmatisation with great concern.

Stigma can be defined as the "co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination" where "for stigmatisation to occur power must be exercised" (Link and Phelan, 2001: 363)<sup>9</sup>. One of PCS out-patient clients who had a history of various admissions explained how this process permeates everyday life:

(...) when I was fired I began to apply [for new jobs], right? I have my diploma and I started applying but then... it's like with AIDS patients, you can't find any work in the community. And people say... if they know you have been to PCS, they say: 'You *lawman'*. *A lawman* or *laupie* is a mad person, a madwoman. (...) I drifted through the streets for a while. And I have also begged for money. People look down on you. It's as if you were not a human being. (Glenn, SR)

The labels *lawman* and *laupie* in the local Sranantongo language are highly depreciative. They are employed to indicate a qualitative difference, and in this way establish an insurmountable border, between the fit and the unfit, those worthy of trust and respect and those who are disdained and excluded. As described by Glenn (SR), being a *lawman* equates to discredit, status loss, dehumanisation and discrimination. Once a person has this label, it is hard to escape a downward spiral of losses including one's integrity, work, and social network. This has a tremendously negative impact on clients' wellbeing, access to care, psychosocial rehabilitation and participation in mental health.

<sup>&</sup>lt;sup>9</sup> According to Link and Phelan (2001), stigma entails four components. The first component consists of distinguishing and labelling human differences. The second regards the association of undesirable characteristics, i.e. negative stereotypes, to the defined labels. The third lies in producing categories which can create a distinction between an "us" and a "them" and separate the former from the latter. The fourth regards the construction of a rationale for devaluing, rejecting and excluding the labelled, negatively stereotyped and separated which results in their discrimination and loss of status. All these processes are contingent on access to social, economic and political power by those who stigmatise.

Stigmatisation of people affected by mental distress is not a problem exclusive to Suriname. Throughout history, a considerable number of denigrating characteristics were framed to describe the "mad" and to set them apart. They have been perceived as ludicrous, dangerous, deviant, inhuman, contagious, immoral, etc. (Foucault, 1965). These kinds of stereotype are powerful and remain deeply rooted in Western culture (Gilman, 1985). They are attributed to people suffering from severe mental illness, especially those diagnosed with schizophrenia (Schulze and Angermeyer, 2003). Most clients who participated in our study have this diagnosis. Several of them described instances of discrimination at work, by lay people on the streets and even at home. According to the future facilitator of the client council, this occurs because "the Surinamese society is still afraid of psychiatry and psychiatric patients. People don't understand them. (...) People only have contact with them in the streets when they see the drifters. That's where they are confronted with them".

In Paramaribo, drifters wander the streets poorly dressed, hair in disarray, undernourished and dehydrated, at times talking to themselves, other times shouting. Some are beggars. Others just stroll around looking for food and shelter. Some have a problem with drug addiction, others are affected by severe mental illness, and some combine both. The lack of sufficiently responsive programmes to tackle homelessness in Suriname makes it difficult to offer these citizens protection and care. Their disenfranchisement is not only visible but unstoppable. The unpredictability of their sometimes strange behaviour inspires fear in the rest of the society which seeks safety through avoidance. However, there is often just a thin line between avoidance and exclusion.

As noted by Glenn earlier (SR), the *lawman* and the drifter fuse in the collective imagery as the ultimate representation of mental illness. The danger attributed to drifters passes on to the *lawman*, and so does the stamp of marginalisation.

Lack of acceptance and discrimination pushes psychiatric clients into the fringes of society and more often than not into disquieting isolation. This seriously hinders their wellbeing leading some to experience the "revolving door effect", i.e. multiple readmissions which might otherwise been avoided:

(...) it is difficult for them [mental healthcare users] to find a job, to be accepted, to fit in society... and then they have a relapse... because the only safe place to go is PCS again. It's a sort of attraction force... and the cycle starts again. (...) If you go to PCS now you will see them together. They search for each other because society treats them in a cold way. (Facilitator SR)

For those who have not yet been labelled "mad" however, PCS works as a "repulsion force". Being seen at PCS might be enough evidence to others that a person is *lawman*. Paramaribo is a small city and information travels fast. The fear of stigmatisation makes both lay people and general practitioners<sup>10</sup> reluctant to resort to public mental healthcare, i.e. PCS. When this type of care is necessary, some prefer to consult with the psychiatrists at general hospitals. This proved to be a positive innovation of the mental care reform underway: people feel more comfortable seeking mental care when knowing they will not be directly associated with mental illness. Yet the psychiatric care available at these hospitals is still insufficient to cater for all the demand. While the well-off are able to find alternative solutions within private care services and keep their problems (literally) out of public sight, the underprivileged endure long periods of suffering without assistance. In the case of the latter, help is sought at a late stage when problems become too impairing or behaviour too disturbing. In these situations, there is often police intervention converting the first contact with mental healthcare into a dramatic experience.

For those already under treatment it is not always possible to benefit from all its facets. As a professional stated: "sometimes I want to visit a person at home but they ask me not to go because if the neighbours see the PCS bus they will know that person is a psychiatric patient. So these people do experience stigmatisation" (Professional 6, SR). Stigmatisation thus not only limits the access to mental healthcare it hinders the successful completion of adequate treatments.

The fear and shame associated to mental illness is so deeply enrooted in some people that when admission to PCS is necessary some families use false names to avoid being traced back when their relatives are dismissed. This places people with mental problems in a particularly hazardous position. When abandoned by their families, clients are left in a situation of emotional, social and economic deprivation. Sickness benefits in Suriname are insufficient to grant their holders economic independence (100 SRDs)<sup>11</sup>. Furthermore, the labour market is particularly hostile to people with a psychiatric history and society at large either avoids or excludes them. This makes the return to community life very difficulty. It conditions (former) clients to a low socio-economic standard of living, impeding the development of the necessary skills and social support to deal with the illness and eroding

<sup>&</sup>lt;sup>10</sup> General practitioners in Suriname have a gatekeeping function, i.e. contact with other medical specialists is only possible through their referral.

<sup>&</sup>lt;sup>11</sup> At today's rate, 100SRDs correspond to a little less than 25 €.

one's hope in recovery. In other words, it severely impairs their psychosocial rehabilitation (Anthony *et al.*, 1990).

The stigmatisation of people affected by mental illness also has a negative impact on the promotion of client participation. After one of the clients had participated in all the preparatory client council meetings, I asked what sort of function she would like to have within the council. To my surprise, she replied she had no intention of participating. When I asked why she said: "They stigmatise here. People talk about you and I don't want that. Let the people who dare do it. I don't dare." (Dorothee SR).

Taking part in the client council would undeniably function as a sort of "certificate of madness" for the community (De Freitas, 2008a) and that would most likely be followed by exclusion. Yet this is also the reason why setting up the council was so relevant: "People discriminate against the patients admitted here [PCS]. It's good to get a client council. This way if something goes wrong, patients have someone they can trust, who can stand up for them" (Professional 6, SR). The people who sat on the newly formed client council had the courage to make their problems public and to face the consequences. These pioneers hold the chance to have a ground-breaking impact on Suriname's fight against the stigmatisation of mental illness.

Finally, it is important to note the actions undertaken by PCS and YSR to challenge the myths and reduce the stigma attached to mental illness. YSR provides information sessions about mental problems, distributes information though libraries, other organisations, schools and individuals and attempts to foster local knowledge by stimulating university students to write theses about topics related to mental illness. This seems to be having a positive impact: "(...) people speak more easily about it now. They dare to go to the psychiatric hospital [PCS]. The people who came yesterday [to the YSR monthly meeting] for the first time were afraid but now they see there is nothing to be afraid of "(Family Member 2, SR).

The PCS has raised awareness about metal ill-health and mental care and has made itself more open to the general public by promoting "open days" and information sessions and allowing guided tours through the institution. It also organised social events (e.g. collective walk). This not only made the institution more visible and known, but it also gave it a more positive connotation: "the de-stigmatisation process is far from complete but people now say more openly they have a mental problem and they need help" (Professional 4, SR). One of PCS inmate clients<sup>12</sup> was a good example of this. He walked around the city wearing a cap with "PCS" embroidered on it. Curiously, his given name means "to forgive" in Arabic.

# Discussion

This study set out to identify perceived needs for change in Surinamese mental healthcare, to examine stakeholders' expectations concerning user participation and to investigate the implementation of a client council at the national mental healthcare service resulting from a transnational partnership between Suriname- and Netherlands-based partners. Participants were generally favourable to user participation. However, as several studies show, user participation can become tokenistic, failing to move from rhetoric into practice when implemented in settings marked by a reluctant organisational and professional culture which perpetuate power differentials between different categories of professionals and between professionals and users (Bowl, 1996; Lindow, 1999; Rutter *et al.*, 2001). As evidenced by our findings, these are all pertinent aspects in the context of Surinamese mental healthcare provision. A follow up study about stakeholders' attitudes, clients' perceptions regarding the functioning of the client council and its actual performance is therefore necessary to evaluate the extent to which users have gained a voice in Suriname.

The establishment of trust within overseas partnerships must not be taken for granted. Rather it must be seen as a goal to be realised and watchfully sustained. This was particularly salient when the RIAGG Rijnmond client council announced a workshop about user participation after consulting exclusively with Surinamese users. PCS and YSR reacted with discontent and argued that if a dependable partnership was to be built, it had to entail information sharing, transparency, consultation, negotiation and joint implementation of initiatives by all stakeholders. This shows a clear rejection of the role of "beneficiaries" by the Surinamese stakeholders who instead acted as "makers" and "shapers" of the decision-making processes that affect their lives (Cornwall and Gaventa, 2001). It also indicates the presence of a critical stance on foreign-induced "development" challenging the much contested division between rich knowledgeable donors and poor passive recipients. Once the Netherlands-based partner began to act in accordance with the partnership standards adopted by the Surinamese stakeholders, distance was reduced, trust was built and collaboration commenced.

<sup>&</sup>lt;sup>12</sup> Many inmates of PCS have no permission to leave the premises. This client has been living at PCS for several years and is one of the people with the greatest freedom to go out of the institution.

PCS and YSR willingness to take part in the process leading to the installation of the client council should not mask the presence of marked power differentials between professionals, family members and users or the reservations felt about a possible reduction of that gap as a result of the emergence of a user voice. Many of the professionals interviewed felt that an independent full-blown user-led initiative (i.e. an initiative exclusively developed and sustained by users, like a client council) was premature in a context with no history of user participation. What few expressed openly is that it also posed a major challenge to the *status quo*. Both professionals and family members were keen to have a say on the extent to which power was to be shared. We return to this issue below.

Participants identified the need to change several aspects of mental care provision including its organisation, access, delivery and user participation in treatment. Public health authorities have already started reforming mental healthcare with the collaboration of PCS. However, limited funding and the shortage of qualified experts capable of informing, designing and implementing new health policies together with the Ministry of Health pose a limit to the pace of reform. Not only can engaging lay people in this process boost its pace but it can also make it more need-driven and effective. Users and carers hold untapped resources that can be mobilised to disseminate information about services, raise awareness about neglected health problems and generate new and more comprehensive care solutions (Frankish et al., 2002) as their knowledge comes from direct experience with policy and care provision at the receiving end (Beresford, 2000). They can also organise into pressure groups seeking to foster the government's responsiveness to their needs. Another domain where users' and carers' collective action can contribute to stirring change is the funding of mental healthcare. As noted earlier, health insurances do not cover for psychotherapeutic and social care. Users have the power to change this situation if they lobby and request the formulation of new health legislation enforcing the creation of more comprehensive insurance plans. The inclusion of these types of care in insurance packages is likely to promote their availability, affordability and accessibility which may, in turn, foster the implementation of holistic community-based mental healthcare.

Users can also contribute to increasing the quality and effectiveness of mental health services by identifying and seeking responses to unanswered needs, supporting other users dealing with mental problems, participating in treatment plans, accessing, planning and evaluating care, etc. (Zakus and Lysack, 1998; Kahssay and Oakley, 1999; De Freitas, 2008b). These forms of participation can be practised through a multiplicity of spaces (e.g. user movements, councils, interest groups, self-help groups, etc.). The creation of a client council is the first initiative in Suriname through which users may come to develop a "space of their own" (Fraser, 1992), where common interests can be identified, the sense of a legitimate voice can be achieved (Mansbridge, 2000) and grassroots leaders can come to the fore. However, for genuine participation to occur and for its potential benefits to be reached, several aspects need to be considered: a change in the organisational culture of PCS, the reformulation of power relationships among providers and between these and users, capacity-building among users and the availability of resources.

Cultural change within healthcare services may be defined as shifts in the values, beliefs, and assumptions that support patterns of behaviour in the delivery of care (DoH, 2002). PCS mental healthcare professionals appear to view users as "passive recipients of care" (Barnes and Shardlow, 1997) who are at the bottom of the organisational hierarchy. This belief tends to materialise into a paternalistic, at times improper, everyday approach to users which can range from excluding them from treatment plans to literally slapping them when their behaviour is considered inappropriate. For the client council to stand a chance of making a difference, it is urgent for a new perspective on users to be adopted. To use the words of one of the professionals interviewed, users must no longer be perceived as "suffering objects" but, instead, approached as "collaborative subjects". This type of change implies undertaking actions such as making user participation a part of educational programmes, preparing mental care providers to acknowledge and accommodate a new sort of expertise that of experts by experience, adopting a biopsychosocial model of care provision, promoting psycho-education, making mental ill-health information available to professionals, users, family members and society at large, organising anti-stigmatisation campaigns, etc. It also requires power differentials to be realised, understood and tackled in a sensitive way.

Power imbalances are an inevitable result of both the mental health system and wider structural inequalities in society (Rose *et al.*, 2004). People who use public mental healthcare in Suriname usually belong to the most disadvantaged social groups (due to low socioeconomic status, stigmatisation, etc.) while those who define care plans are usually at the opposite end of the social ladder. This is particularly illustrated by the distance separating "deified doctors" from "*onmondig* patients" that appears to permeate mental healthcare provision at PCS. In between these two extremes are other categories of professionals whose knowledge and practice are not yet recognised as equally valuable to psychiatric care, i.e. nursing and social work.

Professionals at PCS affirmed their support for user participation. However, discrepancies between expressed support and actual practice may arise in the future as a result

of professionals' resistance to accepting users' experiential knowledge and transfering power to them (Campbell, 2001; Summers, 2003). Insufficiently trained and resourced and often overworked, nurses at PCS may come to resist the users' claim for a voice. That is likely to demand increased attention from nurses and to be interpreted as a challenge to the maintenance of their already low hierarchical position in the institution. Psychiatrists may also think that if they allow the distance between them and their clients to lessen, their authority and the quality of their treatments will be compromised. For user participation to thrive, it is crucial that power differentials become a subject of discussion and that the roles of both professionals and users can be renegotiated through continuous dialogue. Periodic staff meetings can foster this process by enabling different categories of providers to discuss their viewpoints, approach their differences and develop a sense of equally valued teamwork. Where users are concerned, there is a need to build on dialogue focused on the reassertion of their identity as citizens with a vested stake in mental healthcare. The client council can provide an empowering space for this process to unfold and for collective interests to take shape. Alongside this, sessions with the other stakeholders can be held to discuss problems, point out solutions, evaluate opportunities for collaboration and promote a shift toward more balanced power relationships. These encounters may cause some discomfort at first. As observed in other countries (see Barnes, 1999), clients in Suriname have been traditionally excluded from decision-making and professionals are unaccustomed to having their practice scrutinised by users. Given the particular context of Suriname, where lay people's participation was initiated by family members, YSR can play an important role in mediating between users and mental healthcare professionals, reducing the distance between them and keeping dialogue flowing. But, as observed by Barnes (1999), it is also necessary to build users' capacity to act.

The acquisition of communication, technical, organising and advocacy skills are essential tools for taking over power and participating in a meaningful way (Postle and Beresford, 2007; De Freitas, 2011). Capacity-building can also boost clients' confidence. However, for this to be achieved, programmes must be designed to accommodate the needs of all users, from the most vocal to the least empowered. The clients who participated in this study are likely to be amongst the most informed and articulate mental care users in Paramaribo. In the future, it is important that the initiatives set to enhance participation involve the widest possible range of users.

Access to financial and administrative resources is another essential element to foster transformative participation. The client council will most certainly require these resources to

facilitate its activities. It is unlikely that enough funds will be gathered through the Ministry of Health. Inasmuch as this possibility should not be discarded, it is necessary to seek more immediate alternatives. By becoming an association, the client council can secure the possibility of organising fundraising activities, receiving donations and requesting subsidies. However, if user participation is to be taken as a serious goal of health care reform, the state must not disregard its fundamental role in issuing legislation to promote it and in providing the resources necessary to enforce it.

Finally, it is important to address the negative impact of the stigma associated with mental illness on users themselves and on their participation in society. Being labelled mentally ill in Paramaribo corresponds almost instantly to exclusion from the community. Lawman are dehumanised, silenced and pushed into isolation. The stigmatisation of mental problems also reduces the accessibility of mental healthcare, blurring the path to recovery and undermining the emergence of a user voice. The client council has the potential to fight exclusion by generating a space where identities can be redefined, peer support can be sought and campaigning can be organised. It is fundamental, however, that public officials and professionals themselves discard the image of mental healthcare users as passive recipients of care and approach them as citizens instead (Barnes, 1999). By supporting the client council, mental healthcare services have an unprecedented opportunity to foster change toward more inclusive and responsive care and to actively enable and participate in the struggle against the stigmatisation of people affected by mental illness.

# Conclusion

Following an ever-more common trend in both the north and the south, user participation has become a goal of healthcare reform in Suriname. The creation of a client council constitutes an unparalleled venture to promote user participation in mental healthcare. Traditionally excluded and powerless, mental care users have achieved a space from which they can renegotiate their identities, develop new competencies, influence care provision and exercise their citizenship. The potential of the client council to function as a laboratory for genuine participation is, however, largely dependent on how much investment will be made to effect cultural change in mental healthcare, tackle power differentials between providers and between these and users, promote users' capacity-building, allocate sufficient resources to the council and reduce the stigmatisation of people diagnosed with mental illness. The development of new legislation and comprehensive directives in the field of mental healthcare and on user participation may be critical to reach these goals.

The setting up of a client council through an overseas partnership has also served to realise the importance of cultural, political and historical aspects in shaping the relationships between stakeholders and in determining the success (or failure) of new projects. Transparency, consultation, negotiation and full collaboration have all been defined as key elements to foster a productive transnational partnership.

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