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Observation report

59G21 Lille – September 2018

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**SUMMARY**

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**Synthesis**

**Objectives**

WHO QualityRights aims to improve access to quality mental health and social services and promote the rights of people with mental health conditions, psychosocial, intellectual and cognitive disabilities.

The objectives of QualityRights are to:

* Improve quality of care and human rights in inpatient and outpatient mental health services.
* Create community based and recovery oriented services that respect and promote human rights.
* Promote human rights, recovery, and independent living in the community.
* Develop a movement of people with mental disabilities to provide mutual support, conduct advocacy and influence policy-making processes.
* Reform national policies and legislation.

The WHO QualityRights Tool Kit supports countries to assess and improve the quality of care and human rights conditions in mental health and social care facilities.

**Methods**

This report presents the results of the use of QualityRights observation tools in a mental health centre (59G21) of the EPSM Lille Métropole.

A multidisciplinary team composed of users, families and professionals (psychiatrist, psychologist, lawyers, facility director, quality manager) was trained in the use of these tools, and visited the various sites in sector 59G21 in Lille for a three days' observation.

35 interviews with users, carers and families and professionals were scheduled (36 conducted), as well as in situ observations and a document review.

**Results**

Five main themes, broken down into 116 criteria, were investigated and then rated by the observation team according to the following procedures: Achieved in Full (A/F), Achieved Partially (A/P), Achieved Initiated (A/I), Not initiated (N/I) and Not applicable (N/A).

The results for the five main themes are presented in the table below:

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| Thème | Score |
| Theme 1: The right to an adequate standard of living (art 28 of CRPD) | Achieved Partially (A/P) |
| Theme 2: The right to the enjoyment of the highest attainable standard of physical and mental health (art 25 of CRPD) | Achieved in Full (A/F) |
| Theme 3: The right to exercise legal capacity and to personal liberty and the security of person (art 12 and 14 of CRPD) | Achieved Partially (A/P) |
| Theme 4: Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (art 15 and 16 of CRPD) | Achieved in Full (A/F) |
| Theme 5: The right to live independently and be included in the community (art 19 of CRPD) | Achieved in Full (A/F) |

**Discussion, conclusions and recommendations**

This report presents the team's observations, positive points and areas for improvement. Excerpts from interviews or observations are used to qualitatively illustrate the ratings.

Ten recommendations were made at the end of the visit.

**Methodology**

**Selection, composition, roles and responsibilities of the evaluation team**

Particular attention was paid to the constitution of the observation team that will travel within the EPSM Lille Metropole, on sector 59G21. The guiding idea was to maintain multidisciplinarity within the team, in order to reflect the values promoted by the QualityRights program. It was therefore essential to form a group large enough to include users, families and professionals.

The observation team was composed of eight members:

- Marie-Josée Froideval, Vice-President of GEM les Ch'tis Bonheurs (mutual self-help group).

- Marina de Guerry, Member of UNAFAM (national association of families).

- Laurent Burckel, former Hospital Director.

- Ramona Spinu, Psychiatrist, CH Argenteuil.

- Marie Baudel, Lawyer, University of Nantes.

- Adeline Dubois Rigollet, Quality Director, CPA, Bourg en Bresse.

- Agathe Martin, Lawyer.

- Aurora Jeanroy, Psychologist, Lawyer, International Criminal Court.

The members of this team did not declare any conflict of interest regarding their participation in this observation on sector 59G21 of the EPSM Lille Metropole.

Each team member was trained in the use of each of the five documents making up the Tool Kit (main document, interview guide, observation guide and data collection, establishment report, national report). Similarly, each member carried out the three observation procedures provided for in the protocol (in situ observation, interviews, document analysis).

**Preliminary meeting of the evaluation team**

All documents were distributed to each member prior to the working meeting, and telephone meetings were scheduled to list the issues and difficulties encountered.

A presentation of the establishment and the 59G21 sector was made.

Several documents were proposed and subsequently revised:

- Schedule of visiting days (see Annex 1)

- Instructions to interviewers (see Annex 2)

- Consent form (see Annex 3)

- Details of the items for observation and document analysis (see Annex 4)

**The visit**

Work to prepare the observation site was undertaken prior to the observation visit. The QualityRights approach was presented at an information meeting to which the professionals of the 59G21 sector were invited. The documents and an information note were also distributed.

In hindsight, it seems to us that this process of explanation and preparation, both at the level of professionals and users, is an interesting prerequisite in order to facilitate the visit in itself, and should be further developed.

The visit took place from 17 to 19 September 2018, with a team of 8 observers, within the structures of the EPSM Lille Metropole, Pôle 59G21 :

Hospitalization :

- Jérôme Bosch Clinic, Lille University Hospital

Outpatient care:

- SMPP, specialized consulation center, Maison Antonin Artaud, Lezennes

- Don Jackson Intersectoral Centre for Family and Systemic Therapy, Hellemmes

- Frontier Centre$ - Art Gallery, Hellemmes

- SMPP, specialized consulation center, Georges Van Belleghem, Faches-Thumesnil

- André Breton Residence, Faches-Thumesnil

- Espace Alan Turing, Ronchin

- SIIC, Mobile Intensive Care Team integrated in the city, Alan Turing Space, Ronchin

- Habicité (housing team)

- Therapeutic family care as an alternative to hospitalization (AFTAH)

No pictures were taken within the structures and no audio recordings were made.

36 interviews were conducted. The logistical conditions were of high quality, with enough offices for interviews, guaranteed confidentiality and sufficient comfort. Attention was paid to the diversity of the interviewees, both for users (diagnosis, length of hospitalization or follow-up within the service, hospitalization regime, gender, age), and for caregivers and professionals (psychiatrist, health executive, psychologist, peer health mediator, facilitator, qualified hospital service agent, elected official, etc.).

Each member of the observation team conducted interviews, visited different structures, and consulted paper or electronic documents.

For some observers, meal times were taken with the users at lunchtime in the hospitalization unit.

**Meeting of the assessment team after the visit**

The observation team met immediately after the various observations and interviews on the afternoon of September 19, in a room at the WHO Collaborating Centre (CCOMS, Lille, France). All eight members were present.

All 116 criteria were rated at this meeting. Some criteria led to a homogeneous rating among the various observers, others led to more debate. The observers were then able to share their individual observations and the content of the interviews in order to stimulate reflection and allow decision-making. If consensus was not reached among the eight team members, with a hesitation between two ratings, the "lower" rating was finally chosen, as recommended in the protocol. For example, if the group hesitated between the "fully achieved" and "partially achieved" ratings, in the absence of consensus, the retained rating was "partially achieved".

The standards and then the themes were then quoted in the same way.

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| The QualityRights protocol provides for a comparison between mental health and general health services. For this assessment, there is no rating for general health services, as no observations have been made in these services.This could be a way to continue the work in the Lille region, or in France in general. |

**Results**

The indicator rating tables will be discussed below. Quotations from the interviews illustrate these results, which are green for the comments of users, orange for families and blue for professionals.

**Theme 1: The right to an adequate standard of living (art 28 of CRPD)**

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|   | Achieved partially |
|   | Achievement initiated |
|   | Not initiated |
| NA | Not applicable |

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**Rating of criteria and standards in Theme 1.**

Care and consultation facilities are generally accessible from the users' homes. The "starred" organisation of activity in the sector, established locally via existing networks and the intermunicipal association (Local Mental Health Council), has made it possible to develop a real non-hospital-centric partnership, and thus to facilitate access to housing and employment for users, who are not "uprooted" from their place of residence.

Accessibility problems for people with physical disabilities have been noted in some care facilities, such as the CMP Maison Antonin Artaud, where steps are present at the entrance, two floors do not have elevators, and the toilets are not adapted. This can complicate access to care for some users, despite the flexibility of the team, which offers consultations in the most appropriate places for their situation.

In addition, there are no facilities on the sites for the benefit of visually impaired people. The welcome booklet at the Clinique Jérôme Bosch is not available in Braille and the clinic secretary seems to be the only one who speaks sign language. At the Clinique Jérôme Bosch, a list of the languages spoken by professionals is available, but it seems that the number of interpreters is insufficient. The general question of the accessibility of foreign language and sign language interpreters is therefore raised:

*"With regard to foreign language interviews, sometimes it's complicated, we have a list of translators but everyone has to be available at the same time"*

The fire training provided to professionals does not seem to be repeated annually, with some professionals present for 3 years who have still not had it.

The condition of the old buildings of the Medical-Psychological Centres and the Alan Turing Space seems problematic, particularly with regard to insulation and heating. Efforts in terms of decoration also seem to be expected. Criticisms have been made of CMP Georges Van Belleghem. The organization of the premises does not ensure confidentiality for users and total security for staff. The layout of the offices within the CMP Maison Antonin Artaud may also need to be reviewed as it may be unsafe for professionals. While the CMP Maison Antonin Artaud seems to be described as a more pleasant place to work than the CMP Georges Van Belleghem, an insufficient number of desktops and computers have been found.

*"It's super hot in summer and super cold in winter"*

*"It's not adapted to the climate"*

*"Some colleagues are forced to bring their own portable heaters to work in the winter"*

*"It was so hot this summer that we did interviews outside."*

*"CMPs lack life and are too old"*

*"These are beautiful, aging buildings."*

*"Inside they lack color"*

*"In some offices there is not enough sound insulation"*

However, some users seem to temper these remarks.

*"I like the garden area, I did my session with the psychologist outside, it's a serene place"*

*"The CMP is pleasant and relaxing, I feel better here than at home."*

*"When you come to the CMP, you have other concerns than the condition of the buildings, what matters to me is the skills of the professionals, and the right level of care."*

Major pest problems are observed in Habicité apartments. In addition, some homes in therapeutic host families have been described as strict, being locked and having closed parks and terraces.

More specifically, at the Clinique Jérôme Bosch, the rooms are well dimensioned and have all the amenities required to respect the privacy and autonomy of users. The personal spaces are satisfactory, both in terms of size and equipment: personal safe and cupboard, independent and well equipped bathroom in each room. All criteria are met for the hygiene of showers and toilets. An art library offers users the possibility to borrow a work of art to personalize their room. During their stay, users have their own personal clothing at their disposal, and therefore do not need to resort to using pajamas. They keep and use their laptops without restriction.

 *"We're at peace here"*

*"The clinic's premises are pleasant and well thought out."*

A very positive point is the existence of two rooms for accompanying family members.

The schedules of activities, the time of waking up and the duration of meals are not imposed, everyone can have their time as they wish. Their movements are free in the Jérôme Bosch Clinic. The unit opens at 8am and closes at 6:30pm, but there is always an agent present to open. The facilitator provides a remarkable service, by offering activities (plastic arts, reading, games, etc...) but without constraint, to those who want it, and when they want it. The activity area is open and offers a wide range of books on the theme of painting. The work of users is really valued.

There are no restrictions on the inter-communication of users. Sexual intercourse between users is not prohibited.

*"They already have what it takes in general, but it's true that there are no condom dispensers available."*

Users have the possibility to use a fridge on request at the Clinique Jérôme Bosch and to have meals delivered.

Each user has the necessary badge to open all the doors.

Exit possibilities are necessarily limited in a unit designed to receive people in critical phase. However, activities are offered on weekends at the Clinique Jérôme Bosch as well as regular information on outdoor activities that may be of interest to users.

The presence of a sports coach to lead or propose physical activities is noted. On the other hand, the small size of the room dedicated to sports activities was noted, although it was also equipped with quality equipment. State-of-the-art balneotherapy equipment is present in the premises, but has been closed for several months due to a lack of staff. Indeed, a psychomotor therapist must be present to supervise its use according to the team. Couldn't another professional take on this function?

Infiltrations related to a waterproofing defect in the green flat roof have been observed on the walls in the clinic, and the building's thermal insulation appears to be moderate. Problems with humidity and water leaks, heating and air conditioning, particularly at ground level, which are rapidly deteriorating, have been described and observed in some rooms.

*"It's hot in summer and cold in winter"*

*"It's true that in winter some rooms are cold when users enter them"*

The lighting is automatic in the clinic's offices and switches off very quickly if it does not detect any movement, which hinders the conduct of interviews.

There is a gap between the activity areas and the vast central reception hall, which is certainly very bright, but which seems almost disproportionate, especially when there are not many users. They often wander around there, apparently without knowing what to do.

*"I know what boredom is."*

*"The clinic's premises seem cold, impersonal and sad."*

The patio is rather sad and not very well highlighted, especially because of the absence of plantations. Several users pointed out that the outdoor space proposed in the clinic could be better arranged, with flowers in particular. Butts are embedded in the wooden racks. The arrangement of the smoking area facing the glass window of the communal living space generates a tobacco smell in the unit.

Despite a clear desire to adopt a non-institutional care model within the Clinique Jérôme Bosch, some points were raised, in particular the fact that the nursing staff wear gowns, whose usefulness can be discussed and which reinforces the medical aspect of the structure. A badge would seem sufficient for users to identify them. Staff and user toilets are separate. Staff have special keys for their own toilets.

*"Patients don't like gowns, but some of the staff don't want to take them off because they feel it fits with their role, for example, for nurses when they take blood tests.*

*"Some staff members ask to keep the toilets to themselves"*

*"This is a request from the staff, but the department psychiatrist still uses the users' toilets in the common room.*

Due to the loss of access cards by users, they are regularly forced to ask staff members to open their rooms for them over several days.

A supply of clothing has been made available to users who may need it, but it does not seem sufficient. On two occasions the service ran out of clothes to lend to users. Sometimes professionals donate clothing that they no longer need.

*"There is a recycling of unused clothing*

Access to Wi-Fi in the clinic is regularly interrupted, which compromises the possibility for users to get in touch with their relatives and benefit from a link with the outside world, especially since no newspapers or periodicals are made available in the common areas. Users can, on request, use computers from the unit's offices to connect to the Internet, but there is no constant availability of a computer.

The fixed telephone set made available to users is located in the middle of the collective space, which hinders privacy during calls.

Users cannot open and close their room windows themselves and must ask the carers, as the handles have been removed for safety reasons. A handleless opening system could allow users to regain more autonomy in this regard.

Some users also pointed out that they would like to have direct access to drinks, refrigerators or vending machines, so as not to have to solicit staff, as the facility currently provides them with bottled water on request.

*"I keep an average memory of the quality and variety of the meals"*

*"Food depends, some people like it, others don't like it at all."*

*"I sometimes hear some staff members or security guards who are not trained familiarize patients with each other and deny them access to food outside of meal times. I heard "ah no, no chocolate for you you just ate". Everyone should be trained to be aware of these issues".*

On another level, it appears that users appreciated the services offered by Frontières, particularly through the Sagacité scheme, which aims to help them gradually resume activities proposed within the community. Professionals from different services stressed the availability of Frontières, the fact that a follow-up could be quickly organised in cases where they considered it necessary for the user.

However, comments could be made on the budgetary restrictions that would tend to limit the activities offered.

Habicité professionals and peer health mediators also offer to support users in their activities. However, difficulties have been described by these professionals, who may feel destitute in the face of great social isolation or a "lack of motivation" on the part of the user.

**Theme 2: The right to the enjoyment of the highest attainable standard of physical and mental health (art 25 of CRPD)**

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|   | Achievement initiated |
|   | Not initiated |
| NA | Not applicable |

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**Rating of criteria and standards in Theme 2.**

The multidisciplinary team supports users who do not have open rights in their procedures, which guarantees their care. A change of referent professional upon request of the user or professional is possible.

Tutoring and mandatory arrival training are very much appreciated. OMEGA training is carried out very quickly and is directed at all staff. Additional requests for training are often met, to the extent of the resources allocated.

There are no direct restrictions on access to care. There is a free choice of practitioner and they respond very quickly to any request for consultation. Thus, a maximum of 24 hours separates a request for consultation with the SIIC from the first interview in order to determine the urgency of the request and to implement immediate follow-up, if necessary. Also with regard to SIIC, the decision to follow users who have hitherto benefited from SMPP services is taken on the basis of broad criteria, which allows easier access to services and relative flexibility in care.

In general, coordination between the different services is described as optimal.

*"Our priority is access to care. Once an assessment is completed within 48 hours of submitting an application, a follow-up by the SMPP team is organized. On a case-by-case basis, after a prioritisation of needs, regular monitoring is organised no later than one month following this initial assessment".*

However, a sometimes too fast pace seems to be expected from professionals and peer health mediators, which can lead to staff burnout, affect the quality of follow-up and, a fortiori, access to care for users.

*"Here it's always on the move"*

*"It's going very fast"*

*"Wanting to do a lot, you lose quality"*

*"I agree to do otherwise if the follow-up remains of high quality. I have the feeling that the needs are increasing, but that the services offered remain constant. »*

*"It's difficult when I go through complicated times. I don't feel like I'm really supported, the appointments are too far apart.*

*"At home, I wouldn't want to receive services. There's a lot of mess, it's embarrassing, I didn't want to talk about it. There is a lot to say and little time to do it. «*

Some people may have noticed a certain difficulty in obtaining follow-up appointments with professionals who form the care team and with whom they would have privileged contact, due to busy schedules. On this point, however, professionals have expressed themselves:

*"If a user expresses the need to meet a professional as a matter of priority, as far as possible, he/she will be given access to his/her request, according to availability. For minors in particular, a referent is chosen. »*

At the Jérôme Bosh clinic, there was a regular presence of a general medical intern, who provides somatic consultations at the entrance, and supervision during hospitalization. Links with services and independent practitioners for discharge follow-up are well established. In addition, contacts with associations accompanying people wishing to quit smoking or adictologists were given to users, and services were arranged to accompany users to external medical consultations.

The character of the teams is very multidisciplinary, and each team has a specific role in them. For example, at SIIC, nurses, psychologists, doctors, educators, psychomotor therapists, occupational therapists, sports instructors, health professionals and external interveners are employed.

*"The psychiatrist's role is primarily that of a prescriber. A great collaboration is established with other professionals: psychologists, psychomotricians, peer health mediators..."*

There is constant communication between the different categories of professionals, which gives the impression of a very global approach to the situation of users.

*"In AFTAH] a systems psychologist comes regularly, she has a special place. »*

At Habicité, a synthesis is carried out each week in a team to approach mainly people in high-risk situations but also, in alphabetical order, all other users. More generally, this feeling is confirmed by the content and density of the exchanges on each case in the telephone tour.

*"I'll have a daily visit to my home, that's great"*

*"You can reach the CMP at any time, including at night, you never go unanswered"*

*"There's always someone answering the phone"*

However, some reservations regarding the organization of work within the teams were highlighted. They mentioned a communication that was sometimes complicated by the high mobility of the professionals or an excessive diversity of tasks required of them, which could lead to them being distanced from the missions traditionally associated with their profession.

*"The role of auxiliary nurses in our service is still not well defined. «*

Staff are responsive to medication adjustments. Users who so wish can be accompanied to the stop of treatment.

*"The treatment tries to be dynamic and not static".*

According to the health care team, users are informed of the side effects of the treatment, there is even an application (PIC network) that provides a descriptive list of treatments to users, which can be a good complement to a discussion with prescribing physicians. Nevertheless, *"they do not always know their treatment"*. One user interviewed stated that he had never been informed of the side effects of his treatment.

Others, on the other hand, say they have been clearly informed of the nature and effects of the drugs prescribed to them.

*"On care and support they do things gently"*

*"I am very satisfied with the effects of my treatment."*

Between these two situations, users are sometimes aware of their treatment without having *"enough information on side effects".* With the treatment *"I feel like I am in another consciousness like no other".*

About the information related to the different options available, some users are interested in themselves and ask questions, others *"are not really"* informed. Professionals, trained to consider non-medicinal methods in care, do not generally consider the drug as the centre of services offered to users. Alternative methods to treatments are thus proposed according to the situations proposed, such as hydrotherapy, herbal treatments, sophrology, work with a psychomotor therapist, etc. However, alternatives to medication treatments are not systematically proposed.

 *"Treatment is seen as a help, not a miracle solution.*

*"It is recognized by the team that the management should not be entirely medicalized/ that it is necessary to have different interventions in parallel with the treatment".*

 *"We know what corresponds to a person, we will only offer alternatives if we feel it is necessary. »*

There is a deficit in the training offered to foster therapeutic families who do not benefit from OMEGA training, nor from training on the subject of medicines or suicidal risk. Peer health mediators would consider it interesting in this sense if they could have the opportunity to have systematic discussions with them at the end of a user's stay. So far, only one interview is planned with the latter. Users housed in foster families usually participate in the preparation of their pill box, even if sometimes the family does so alone, as the user is not considered fit.

*"I return the pills at the end of the stay but I keep some of them"*

In addition, the important role that families play in the recovery of users, in the context of outpatient care, must also be highlighted. However, professionals deplore the fact that no meeting and education workshops are organized with them, even though they believe that such a service could be complementary to the support offered by UNAFAM.

More generally, a lack of access to training could be felt and recognized, particularly because of the difficulty of obtaining information about it. During our interview, two peer health mediators learned of the existence of training courses on "motivational" strategies, even though they expressed the feeling of being too much left to their own devices on this point in their work.

*« For the past three years, professionals have been trained in motivational interviews, 50% of professionals are currently being trained.*

*"We can't do as much training as we would like, otherwise we would spend our days in training... and we don't have enough money anyway.*

Users who have been followed for a long time in psychiatry may feel that they are no longer being listened to.

*"What bothered me was to be received by 5 different people the first few times and to have to say the same things over and over again. So I quickly stopped calling because I didn't want to talk to people I didn't know."*

*"Why do they refuse to talk to me when I say something's wrong? »*

*"I would like to put words on "what's wrong" but I can't get there"*

*"I'm treated like a handicapped person"*

*"My privacy is not respected, they ask me a lot of questions but they don't help me that much"*

*"I was also embarrassed by the presence of interns whom I accepted out of courtesy and regretted accepting."*

Regarding the individual recovery plan, users and staff do not always seem to be informed about it. The notion of psychosocial rehabilitation remains an imprecise, if not unknown, notion, even if what is said by the staff proves that it contributes to it without putting the name on it. The rights of users under the Convention on the Rights of Persons with Disabilities are also not precisely known, but provisions are de facto taken into account. There is no real training on the subject. The notion of advance directives is not really known to users, nor is the term recovery plan, although some users have completed a crisis plan or in some cases have established wellness plans.

*"I must have been told about it on the first day [advance directives]. However, we have never talked about it since. I thought it wasn't necessary for me, I didn't really see the point. »*

Informally, however, a life project is developed with the user. In addition, a care project/programme is established before each discharge, requiring in particular a partnership with independent professionals. At the Clinique Jérôme Bosch, crisis plans are not made except possibly in preparation for discharge, but a care project is launched before each discharge from the clinic. There does not seem to be any training on users' rights except for information given by managers on French law and not on international standards.

The implementation of such tools in a systematized way could be considered. Regarding recovery plans, the head of service pointed out that the sector has been working for the past year to develop understanding and use of them.

 *"I don't know about recovery, I don't know, what is it? »*

*"My needs are half taken into account"*

*"There is no real psychosocial rehabilitation program"*

*"There is no oral presentation of recovery information."*

*"We would like to see the establishment of a "university of recovery" so that this idea can be better explained. At present, there is no oral information on this topic, little or no real knowledge of the concept, as well as on the possibility of using it. Little knowledge also about the trusted person, and few people able to understand and fill in proposal forms. »*

A majority of professionals are trained in the Barometer project (90%). This one seems interesting from the perspective of the recovery of users. However, it is rarely used, mainly because of its excessive complexity, such as the fact that it may seem unsuitable for housing for users who do not always have a computer or an appropriate Internet connection.

*"The idea is to create an opportunity to exchange, prioritize, to start from the needs of the user, who is always at the centre"*

*"Even if I was very enthusiastic at first, it is difficult to address and implement, especially because of the complicated access to the tool.*

*"Barometer is rarely used in inpatient settiong because it requires the patient to be stable"*

*"Barometer is not obvious to patients, it's a little long and difficult for them"*

*"Barometer it works well with the motivational interview question, I'm one of the only ones to be trained and to use it"*

*"Very good tool but not for everyone. I understand it but I don't yet have this reflex.*

*"Complex, boring, too systematic, it doesn't make you want to be used"*

*"To use it in a humane way, you have to master it well. »*

Some users or professionals do not perceive/no longer perceive the usefulness of this tool, particularly because it is used too systematically.

*"I don't think about it afterwards, I don't feel it really helps me"*

*"Anyway, it doesn't change the fact that I don't feel competent."*

*"It makes it possible to report on difficulties, but its use should be preferred on a case-by-case basis and it should be expected that the person will be able to ask questions for this purpose. Otherwise, there is a loss of meaning, and it is difficult to work within this framework. «*

It seems that health care teams rely heavily on the users' network. The SIIC states that in the event of difficulties encountered in the relationship with the user, the trusted person, family or friends can be of great help. However, it is specified that family members are never given the first taste. Thus, no intervention is possible at the request of the latter without the user himself/herself being aware of it, in order not to break the therapeutic alliance. Habicity states that there is a real difference between users with and without families. A user in this sense confided to us a feeling of loneliness:

*"I have no one close to me. I went to the GEM in Lille "La belle journée" but it's too far away, I work".*

Finally, institutional plans are implemented in the event that a user is not satisfied. The latter may refer to the elected representatives of the users. However, it seems that, in practice, few comments are made by the latter. In this sense, one user admits that he is not very well informed about the existence of such representatives, even if he admits that posters explaining their role are present on the walls.

In AFTAH, a systematic collection of the user's impressions of his or her stay is carried out by the Peer Health Mediators, at the latest 15 days after the user's departure. Feedback, both negative and positive, is given by the Mediators to the users' representatives and the head of the unit.

**Theme 3: The right to exercise legal capacity and to personal liberty and the security of person (art 12 and 14 of CRPD)**

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|   | Achieved in full |
|   | Achieved partially |
|   | Achievement initiated |
|   | Not initiated |
| NA | Not applicable |

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**Rating of criteria and standards in Theme 3.**

Users' preferences regarding the location of care are taken into account and, as far as possible, respected. Thus, even if the priority of the sector is to *"leave users in their homes"* in order to *"respect their environment, their space"*, which seems to be in line with users' preferences in most cases, users refusing home visits may ask to be followed up in a structure. Similarly, in AFTAH, if a family or user expresses difficulties, a change can be organized.

A systemic logic has been adopted by the teams. A user cannot get better if his/her environment is not doing well. For example, exchanges are planned between the Peer Health Mediators and the curators. Similarly, SIIC doctors try to meet families in order to offer them support through the UNAFAM (national association of families) or wellness workshops if the need arises.

Assistance is provided by the teams (Habicity, SMPP...) to enable people to live in their community, in particular by accompanying them in their daily tasks (shopping...) or by bus or taxi as appropriate to their activities.

*"We have long fought against this representation of "first heal yourself" and then we will see what we can do for you. «*

However, difficulties were noted, as some users no longer perceive any limits in the services they can request from the teams. Paradoxically, this could affect their autonomy.

*"I have a feeling that he perceives our meetings as courtesy visits.*

*"They need a boost at some point in their lives, but follow-up should be stopped more quickly when it is no longer needed.*

*"It must not become like too often" Hello Habicity, you can come with me because I want to go out".*

*"They sometimes play exclusive, because we are available from 8am to 8pm. This can be at the limit of harassment and you can't say no.*

 *"They are afraid of autonomy."*

*"One of the people followed had a panic attack and it was necessary to call the SAMU because she had been asked to make coffee in the morning"*

*"They know how to do it but don't want to anymore. »*

*"Associative housing should really be a short-term stepping stone".*

*"We create a relationship that must always have an end."*

User preferences regarding follow-up seem important to the teams. Projects are thus determined with the users - without this being part of a recovery plan stricto sensu - in several stages, so that they are the result of a real reflection by a user who has had the necessary time to plan for the long term. Visits are scheduled at times that accommodate people as much as possible and people designate if they do not have a treating physician with whom the teams will contact.

*"Women are privileged to be part of the team if a monitored woman has been a victim of sexual violence in the past and expresses the need for it".*

*"At the first meeting the objectives are set, because that's what users expect.*

*"Decisions are made in a humane manner, adjustments to the rule can be made with the approval of the framework"*

*"We're trying to make them actors in recovery."*

However, the feeling of lack of time to talk to professionals, expressed by users, can make it difficult, in some cases, to collect and respect people's preferences regarding their follow-up.

*"I don't have time to express my needs. »*

In general, admission and follow-up seem to be subject to the user's consent. As a matter of principle, no one will be admitted at the simple request of the family, unless they have been informed and their consent has been obtained. In addition, several professionals specify that the follow-up ends or gives rise to another management *"if there is no longer any enthusiasm on the part of the users"*. In this sense, effective relays are organised between the services.

However, in some cases, consent, although sought, will not go so far as to be obtained to give rise to care. Thus, persons for whom follow-up is necessary and who would not accept SIIC support will be admitted to the clinic *"after having sought their consent as much as possible through negotiation".* One user also mentioned that he did not feel involved, perhaps because of a lack of information about his freedom to express his preferences or questions.

*"I feel like I don't have much choice."*

*"If I understood correctly, this is part of the care pathways, they [psychiatrists] have a hierarchical position. If I have to, I'll go [to the meetings]"*

Information and consent to treatment seems to be functional, even if there is no formally organized therapeutic education. This is done in particular via the PIC network, which provides information about medication to the user and can then be discussed if necessary. The refusal expressed by a user regarding his treatment thus gives the SIIC a discussion with the doctor and the nurse.

*" The only case where these rights are not respected is the strong agitation requiring an injection."*

*"No matter who prescribes it, I know I'm free to go."*

Reservations can be expressed regarding the information given to users on alternatives to treatments that could be more systematic, currently only those users for whom the teams feel a need. Moreover, diagnoses are not always given to users.

*"We do not have to give complete information to users, but proportionate and appropriate information. We assess compliance with these conditions on a case-by-case basis. »*

More generally, Peer Health Mediators feel that users confide in them much more easily. The latter then summarize what has been said with the doctor. The schedules are also flexible, in order to correspond as much as possible to the user's expectations, not to prevent him/her from carrying out his/her other activities.

However, users were able to criticize the feeling of a one-way discussion, the lack of attention paid by some professionals to their words, sometimes due to lack of time, as well as *"inappropriate"* remarks.

*"I feel like I'm constantly being reprehended. She is in a hurry.*

*"And then she said to me, "You should move a little bit! ».*

*"He only prescribes."*

*"He asks me questions that look like a protocol ("do you have any black thoughts"). I have a feeling he's filling out a fact sheet, it's cold.*

*"The psychiatrists' attitude reinforced my impression that I already had about them. With psychologists it's easier.*

Perhaps it could be considered to give more information to users about the role of each of the stakeholders, the fact that psychiatrists at G21 collaborate with many other professionals and therefore have as their main mission to prescribe treatments.

In terms of support, carers and the support person can participate in interviews with the agreement of the users and are well accepted and welcomed by the professionals. Peer health mediators also meet with the curators, if they exist. Users feel listened to in their requests.

*"The choice of the person is a priority"*

*"On an outpatient basis, the support person plays a very important role.*

*"Refusing care completely is rare. We are flexible, we try to understand a refusal"*

*"You have to manage the time of action according to the needs of the patients, at the entrance patients have to feel comfortable"*

*"Doctors choose but listen to what I propose and apply what I wish"*

One caveat was raised by a user who did not receive the help he might need in appointing a trusted person. However, the services stressed that they strongly encouraged users to designate such a person.

*"I think I was made to sign something on the first day, but anyway I didn't have anyone around me I could have pointed to. »*

There is a high level of attentiveness and responsiveness of services to user requests, particularly via the quarterly user forum. The proposals/complaints sheets are forwarded by the mediators, but the information is not always well relayed.

A very complete welcome booklet is given at the reception desk of the Clinique Jérôme Bosch and many information documents are posted in accessible places. However, it seems that too little information is given in oral form. In the case of forced care, an explanation of the user's rights is *"sometimes"* provided by the health care team, but in some cases the information is only given in written form. The establishment of an oral information session on this subject could be systematized.

Confidentiality seems to be guaranteed at the Clinique Jérôme Bosch, no medical files *"hang around"* in the corridors.

Decision-making by host families raises questions about certain topics: medical prescription and treatment management for users, hours of discharge for users, visits by family members of users. The crisis plan can be discussed with the host family when it is available, but it is not systematically discussed.

*"It is difficult to make families understand the philosophy of the G21"*

The reassessment of the designation of the trusted person seems to be irregular.

Staff sometimes initiate a judicial protection measure even if the person is opposed to this solution.

Contractual alternatives such as MASP are very rarely available and therefore not used.

The most frequent complaints from users concern the delay of practitioners, the too low frequency of meetings, and the lack of respect for anonymity when waiting for consultations.

"It's iterative. And that doesn't change much. »

It is not systematically specified to users that they have the right to consult their medical file, this is done only on a case-by-case basis. Some professionals are not aware that it is possible for users to add information to their files. For them, the computerization of medical records makes it impossible to exercise this right. However, this is an integral part of the rights of people in care. There is therefore a gap between written and posted information (because this possibility is clearly posted, as is the Recovery Charter) and the actual knowledge of rights, concepts, by some users and staff members.

Finally, there are limits to this theme inherent in the national context. Some users are subject to a judicial protection measure (curatorship, guardianship). Such measures can sometimes hinder their autonomy and recovery projects (renovation of housing, access to food, etc.).

**Theme 4: Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (art 15 and 16 of CRPD)**

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**Rating of criteria and standards in Theme 4.**

The sense of freedom they enjoy is often mentioned by users. A quality care provider-user relationship is also regularly observed. Users very largely stressed that relations with staff were positive and based on trust. The users we met agree on the "understanding, extreme patience" of the staff towards them, even in the event of "very painful" behaviour.

 *"With what little they have, they give everything they can"*

*"This is the best place to get treatment, if I had known it was done here I would have come here younger, I would have moved as soon as my illness started to come to this area, I tell everyone"*

*"You realize, here there is no isolation and restraint! »*

The testimonies of the G21 teams interviewed are in the same vein:

*"When a user is vehement, staff do their best to remind themselves that the person is suffering, that it is not directly about their personality, and try to implement calming techniques.*

*"We are looking to talk to users on an equal footing, which can take time. We try to encourage talking with doctors and nurses.*

*"From the beginning of the relationship, we strive to treat users with dignity and respect. »*

On the other hand, feedback has been received from users about a foster family imposing very strict rules. Some of them were thus confined to their rooms. End-of-stay interviews with peer health mediators aim to reduce the occurrence of such situations.

Incidents of verbal, physical, sexual or psychological abuse (criterion 4.1.2.) are quickly rectified by the service, then systematically debriefed and discussed with the team.

There is good traceability of the health status of users in the files, and information is shared by all staff as part of the daily telephone tour and very complete follow-up sheets. Adverse event sheets can be completed and sanctions can be taken against abusive families after feedback from users has been forwarded to the head of the unit.

Within the Clinique Jérôme Bosch, everything is done to avoid violence and abuse, even in the protection of other users: training is generalized on OMEGA for the control of the de-escalation process, and there is great vigilance towards people whose behavioural evolution is unpredictable. Thus, the permanent accompaniment of persons who have engaged in dangerous behaviour by a security guard is set up. This is surprising at first glance, but is presented as a calming factor, avoiding the use of restraints by staff. Other de-escalation strategies are being implemented, particularly through negotiations.

There does not seem to be a de-escalation protocol established with users, but professionals are working with them to detect everyone's triggers and think about ways to calm them down if necessary. The establishment of crisis plans or shared prevention plans is becoming more and more systematic.

*"I was informally helped to identify what external events were triggering a difficult time for me. A psychologist pointed out to me that I start to get sick when I feel rejected. »*

There are no isolation rooms. Restraints, only physical, are performed on rare occasions, one this year, two last year. This could have occurred, in particular, during the journey to the clinic, in the ambulance, even though de-escalation techniques had tried to be implemented.

*"We're not allowed to lock up patients, it's forbidden and it's never happened"*

*"Sometimes mechanical restraints are less invasive because they do not induce physical closeness and touch."*

Seismotherapy is not practiced at the EPSM, but within the University Hospital, there does not seem to be any problem in obtaining consent from users on this subject, and there are few prescriptions.

*"Some medical interns come in and want to test their new treatment ideas, they always ask patients for consent but they are charismatic doctors and sometimes it sounds a little like manipulation"*

Users are informed of their right to lodge appeals and existing user associations, but little information has been collected on the reality of the legal aid available to lodge possible appeals. The G21's unique working philosophy can sometimes isolate it from other sectors of the EPSM.

"We don't work the same way in other departments, it's hard to go back. »

"Mentally and morally it can be hard"

"There is an inability to integrate, to join other sectors after experience in the G21"

"It’s sometimes hard, but I prefer this way of working."

It seems, in general, that team members may feel a certain exhaustion, due to the high pace imposed on them and the high expectations they must take into account, as well as a feeling of insecurity sometimes when they go home, which are not conditions that favour a calm discussion with the user. However, episodes of verbal abuse have not been reported.

A procedure can be put in place when a professional does not feel like going alone to a user's home, but it is recognized as impractical. Professionals prefer more informal prevention strategies: the visit can be done in pairs, by men if necessary, at specific times. If a user is not receptive , *"I warn him/ her that I'm leaving, that we'll come back later to assess his/her situation. «*

**Theme 5: The right to live independently and be included in the community (art 19 of CRPD)**

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| NA | Not applicable |

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**Rating of criteria and standards in Theme 5.**

At the clinical unit level, the liaison work and the "social" mission are carried out by the educator: collection of wishes, administrative procedures with organizations (Disability Regional service for example), donors and companies. This option would be guided by the concern not to "close" this part of the activity on the sector alone - there is only one social worker for the unit - and to personalize the procedures, while keeping a real link with the care team, with information on users being well shared.

The work process for users is thus strengthened by an occupational therapist and an occupational psychologist offering competence assessments. Peer health mediators can also accompany users for interviews, particularly at Cap Emploi (employment service for peole with disabilities).

*« Autonomy is our professional goal"*

The Jérôme Bosch Clinic has good practices in the physical accompaniment of users outside the clinic, according to their needs. For example, even if a person was hospitalized, he or she could be accompanied home to continue to care for his or her animals. Access to voting is also ensured by accompanying users to the outside world, and by facilitating their access to the proxy mechanism for those who so wish.

Access to the various religious denominations is provided on request and permanencies are organised on the EPSM.

Professionals are involved in raising users' awareness of the need for activities and help is provided to find what they like. It seems that some associations are invited so that professionals can be aware of the activities and services that each of them offers in the community.

Networks with the various actors are particularly well developed to provide users with access to a very wide range of activities. Formal and informal meetings with partners are organized without frequency, and contact is always made with the user and with his/her agreement. For example, a call to peer health mediators can be made after discussion in a meeting, sometimes directly, even if a medical prescription is required. For example, users are connected with associations, GEMs (mutual self help groups) and a citizen café near the CMP Maison Antonin Artaud. Frontiers is cited as a highly valued entity.

*"Frontieres is great - it fully meets my request. I am free to go to the activities. They tell us to come to the activities and it feels good for us"*

The family is also contacted with the agreement of the user.

The sector offers a very high availability for families and facilitates contact with UNAFAM.

The training provided by experienced experts is described as fundamental for staff and could be systematized.

*« It completely changed the way I see things. »*

*"It was the most useful training I could get. »*

In the context of rapid care responses, particular attention may be paid to not disinvesting in long and complicated care.

*"There are other people who are better cared for than I am."*

The local and communal relays appear numerous and solid, the local presence is strong.

*"The particularity of this service [Habicité] is precisely to use external service providers"*

*"In the context of Habicité, cooperation with town halls and donors is important to fill a real gap, the fact that there is no particular way of returning to housing for people with disorders"*

Nevertheless, sometimes it seems that it is "the sector that does everything": housing, employment, social support, and this at the cost of a very demanding investment in terms of working time and collective but also individual availability for all: is there not a potential risk of "overload" for staff? And a possible factor of fragility for networks?

Meetings with some partners sometimes appear difficult to organize/plan. The role of the Intercommunal Association is very important, we regret not having been able to exchange with one of its members. Synthesis meetings seem difficult to organize with partners.

*"There are some partners who are a little sluggish"*

*"An additional set of communication tools (tablets, mobile phones, etc.) would be welcome. »*

There also seems to be no median solution between home care and hospitalisation, such as respite homes.

**Conclusions et recommendations**

*"We're very spoiled in the area"*

*"We've long fought against this representation of "first heal yourself and then we'll see what we can do for you"*

The observation team observed a philosophy of care focused on users' rights that is unique in Sector G21, highlighted by many positive feedback from users. It may be a model of good practice to inspire other sectors through its approach.

The QualityRights program has highlighted several ways of reflection that we will outline below in the form of recommendations. It is important to recall here that these recommendations echo the results of the observed indicators, and that these indicators are themselves derived from the Rights enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by France in 2010.

These recommendations are not prioritized.

Finally, the QualityRights program offers training modules on targeted themes (alternatives to seclusion and restraint; development of individualized recovery plans; training on Mental Health Rights), in relation to the CRPD and the criteria observed.

The recommendations formulated below can be accompanied by the implementation of selected training modules.

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| ***The observation team would like to thank all the users we met for their participation and their testimonies.******We also thank the families and carers we met, the professionals for their availability and the Management of Sector G21 for allowing and facilitating this work.*** |

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| **Recommendation 1:** Systematize the training of professionals on the concepts of recovery and decision support. **Recommendation 2:** Systematize the development, use and regular updating of recovery plans and the Barometer tool, ensuring the central role of the user in this process and guaranteeing their support by professionals previously trained in this tool.**Recommendation 3:** Systematize the development, use and regular updating of advance directives and crisis plans and train professionals in these tools.**Recommendation 4:** Systematize oral information to the user on his or her rights, contacts of user representatives and care, including medication, their somatic consequences and possible alternatives to them. **Recommendation 5:** Systematize the interventions of experts by experience, information and awareness of all staff on their missions.**Recommendation 6:** Develop training on the rights of people with psychosocial, intellectual or cognitive disabilities on international standards such as the CRPD for users, carers and professionals.**Recommendation 7**: Improve heating and cooling in CMP premises. **Recommendation 8:** Ensure that users of the Jérôme Bosch Clinic can effectively use the equipment (room access badges, wifi, balneotherapy). **Recommendation 9:** Provide a place of comfort and expression within the Jérôme Bosch Clinic that can be used by users and professionals. Such a space could provide several forms of sensory stimulation: dimmed lights, cushions, blankets, music, etc.**Recommendation 10:** Improve training for foster families and other partners (SAMU, caregivers, etc.) and exchange on recovery issues, decision support and crisis management. |

The *WHO QualityRights tool kit* provides countries with practical information and tools for assessing and improving quality and human rights standards in mental health and social care facilities.

The Toolkit is based on the United Nations *Convention on the Rights of Persons with Disabilities.* It provides practical guidance on:

• the human rights and quality standards that should be respected, protected and fulfilled in both inpatient and outpatient mental health and social care facilities;

• preparing for and conducting a comprehensive assessment of facilities; and

• reporting findings and making appropriate recommendations on the basis of the assessment.

The tool kit is designed for use in low-, middle- and high-income countries. It can be used by many different stakeholders, including dedicated assessment committees, nongovernmental organizations, national human rights institutions, national health or mental health commissions, health service accreditation bodies and national mechanisms established under international treaties to monitor implementation of human rights standards and others with an interest in promoting the rights of people with disabilities.

The *WHO QualityRights tool kit* is an essential resource, not only for putting an end to past neglect and abuses but also for ensuring high- quality services in the future.

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