Participation of mental health service users and their carers

Some European examples

GCS POUR LA RECHERCHE
ET LA FORMATION
EN SANTE MENTALE

The French World Health Organization Collaborating Centre for Research and Training in Mental Health

The French World Health Organization Collaborating Centre for Research and Training in Mental Health (WHOCC Lille, France) is a functional organization bringing together a network of actions, skills and programmes, related to the mental health policy of WHO.

It is one of the 48 WHO Collaborating Centres in the world specializing in mental health (the only one in France).

The WHOCC gathers hospitals, research centres and universities that participate in implementing this work plan. This is especially based on the animation of a health-care cooperation group which gathers 25 french hospitals.

The Centre is constituted by a network of qualified human resources and a consultative scientific council that share common values.

The WHOCC is part of INSERM (National Institute of Health and Scientific Research) unit U1123 «Clinical epidemiology and economic evaluation and vulnerable populations», Team ECEVE, Paris 7 University.

The Centre is redesignated every 4 years by the WHO, on the basis of a multiannual program.

EPSM
Lille-Métropole

World health organisation
Collaborating Centre for Research
and Training in Mental Health

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Foreword

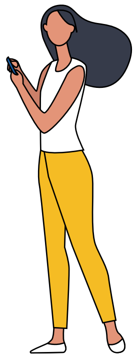
WHO asked WHOCC Lille to achieved guidelines for effective participation of users and carers as well as local elected representatives in the organisation of mental health care and policies at a local level.

Although the participation of users and carers in mental health has been developing progressively since the 1970s, it has been really implemented in care services only for about twenty years, and sometimes much less. It is therefore a very recent development and an important change in mentality that is shaking up the posture of caregivers. Until recently, it was unthinkable to involve users, carers or expert of experience in mental health, in decisions about the organization of the mental health care system. Is the person with a pathology - or a former pathology - able to express his or her views on the care system? Is he or she sufficiently informed to understand how the system works and to discuss it on an equal footing with professionals? Is the person legitimate to represent this or that group? In a very concrete way: how to face the difficulty of recruiting people ready to get involved? Does the political incentive of the authorities encourage participation, if only to finance it?

Of course, participation takes many forms, with widely varying levels of complexity and impact on the organization of the mental health care service.

We can imagine that the impact on people’s care is not the same if we set up a simple satisfaction questionnaire on hospitalization, or mediation for disputes, or if we take participation into account in a transversal way as an essential component of the functioning of a service, declined by a strategic plan, an investment in management, professional training, an operating budget and material means.

The emphasis on participation gives an idea of the policy of the institution concerned. This is the objective of participation: to change attitudes and postures not only of caregivers but of society as a whole, to reduce stigmatization, to consider people suffering from mental health problems as individuals with rights, to orient care towards recovery, and to reduce restraint practices. In this sense, the participation of mental health service users and their carers is a tool for transforming practices, which is in line with what is requested by the WHO and the UN, notably in the preamble of the Convention on the Rights of Persons with Disabilities: “Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,...“.



Methodology

WHOCC Lille has conduct, between late 2020 and mid-2021, 8 interviews in Europe in order to describe experiences of effective participation as well as the identification of the key factors of success or failure of this participation.

Methodology

The experiences of services that have developed an advanced practice of user participation were identified through the WHOCC contacts within its network and with the help of support from partner networks, in particular the European Community based Mental Health Service Providers (EUCOMS).

- These interviews were conducted using a video-conferencing tool. They lasted between one and three hours each. The interview guide (in Annex 1 of this document) was used to prepare the interviews, to guide the interviews and to ensure that no topic was forgotten.
- This guide have been worked with users representatives, professional of the East of Lille Mental Health service (included a peer support worker) and professionals from the WHOCC Lille team. It was used as a tool to help prepare and conduct interviews.
- This tool should make it possible to understand what type of health operation participation fits into, who exactly are the people invited to participate, what are the participation actions, how are they implemented and for what purpose.
- The presentation text drafted at the end of the interviews was then systematically sent to the interview participants for proofreading and possible correction.
- The profile of the 25 people who participated in these interviews is quite varied. Nurses, doctors, heads of service, psychologists, peer support workers, users or ex-users of mental health services were all asked to tell the story of participation in their environment of intervention (see the list of interviewees in the “Acknowledgements“ section).

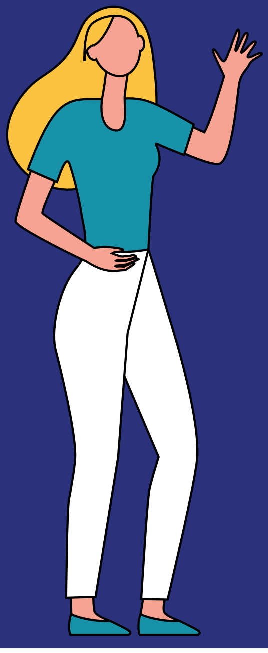
Guidelines

Guidelines for the participation of users and carers in mental health care services

The few guidelines listed below are derived from recommendations made by the people interviewed by WHOCC to describe how users and carers participation is implemented in the area of 8 mental health services situated in 7 European countries. This ad hoc survey is the recounting of a series of experiences with the idea of sharing practices and pooling knowledge. One of the difficulties of a “story telling“ exercise such as the one that follows is to describe the local initiatives of the actors in a national or regional legal and political context that is of course different for each territory. We have chosen to explain this local context only when it has a direct influence on the nature of the participation initiative deployed. Similarly, this document does not contain a systematic review of the literature on participation in mental health. The sources or references in this document are those cited by the stakeholders themselves and some additional resources that could be relevant. The guidelines cited below correspond to the recommendations most often made by the stakeholders (users, experts of experience, carers, mental health professionals).

1 Stay positive, don’t give up!

Participation is not easy to implement. To face the difficulties, whether material, organizational, administrative, financial or human, the leaders of the participation projects will have to show conviction and enthusiasm, as several professional actors interviewed spontaneously testify. As Josep Maria Sole, General Manager of Support, Guardian Foundation, says: “What happen in Gerona is not following any guide, any plan of any ministry. We work like this because we want to.” Because change is often difficult to implement, it is sometimes necessary to think outside the box. This is confirmed by Dick van der Vlugt, peer expert at GGZ Noord-Holland-Noord: “Start the process with peer support workers. Even if the posts are not funded (which is better, of course): do it anyway!” Whether in Ireland, England or France, the actors involved assert it: “Go beyond the legislative requirements” ask Padraig O’Beirne from Cavan Monaghan Mental Health Service, “Stay positive, don’t give up” says Claire Watson Greater Manchester Mental Health, which is confirmed by Laurent Defromont, EPSM Lille metropole: “Believe in the feasibility and mutual benefits of participation, be positive!”.



2 Consider that it will take time

Following the first recommendation, we understand quite quickly that participation necessarily requires time. Not only to get around the obstacles, but also because it can be savior not to want to rush things, as explained by France Dujardin, from CRP Les Marronniers: “The border between caregivers and cared for is impacted by participation. The latter leads to resistance that is not useless. If a professional does not identify with a mental health problem, it is also to preserve himself. The link to madness can be exhausting. Touching that border creates anxiety. We must not deny this either: we must even give it a place.” Another example: Alain Cantéro, from the Hôpitaux de Saint-Maurice: “Integrating participation in a service requires preparation: no matter how much the managers want to, these actions take time. Time to prepare the integration, time to let reticence be expressed (about 9 months of preparation before the recruitment of a peer support worker for example).”

3 Training as a cross interest tool

The added value of participation in mental health and most of the ideas related to it, whether it is empowerment, experiential knowledge, or recovery, are the subject of an abundant international literature and are widely discussed during various events and other conferences. Since not all professionals have access to this information in their initial training, it is necessary to bring it to them in order to modify representations, make relations with users more horizontal and break down the barrier between “them“ and “us“. As it has been said by Claudi Camps, from IAS Gerona: “Our recommendation consists of joint training activities for professionals, users and carers, as well as specific ones for each of them. It is also necessary to encourage professionals in training a more horizontal view in their relationships with users and carers, as well as shared decision-making.”

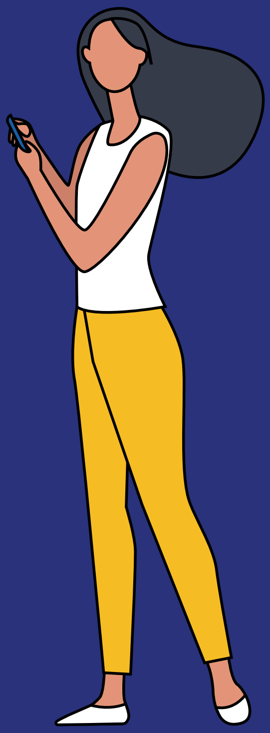
Training is both a means of involving management (a point underlined as essential by several people), and also a means of helping users of care services to get better, in the way to their recovery, by being themselves responsible for passing on their experience, provided that they are given the means to do this in good conditions, as is the case in Manchester where training and support is available across the Trust for service users and carers involved in decision making and service development activities free of charge.

And on top of the concept, training is also a way to put the emphasis on the importance of the personal contact for people who are feeling lonely and vulnerable. “This is frequently underestimated”, think Padraig O’Beirne, from Cavan Monaghan Mental Health Service.

Guidelines

4 Use testimonials

Following the recommendation on training, we can complete it with testimonials. Many stakeholders have found that the best way to overcome preconceived notions about mental health disorders and recovery is to hear from experienced experts. This humanization touches the emotions, of course, but also helps to fight against clichés. The testimony gives hope of recovery to the user (or ex-user) who passes it on, to the families, but also to the professionals who sometimes are in services where they only see people who are in very bad situations. As Alain Cantéro says: “In order to change the way professionals look at things and get them to consider users more as people than as patients, having the main people involved (in particular PSWs working in other establishments) testify is an effective method that makes participation concrete and changes attitudes.”



5 Think about a global approach

“Have a holistic approach to make it work: create various programs help people to work and to co-produce together” says the Irish respondents. If you just have a little action once in a while in a service, people can easily do without it. Anu Putkonen, from Niuvanniemi Hospital, completes this statement: “Launch user engagement in multiple task forces and steering groups to develop patient-oriented care and activities together with professionals and leaders. Provide these members with support, counseling and monetary compensation. Routine patient involvement and patient-oriented care as a value of the hospital are beneficial for all.”
But thinking about participation in a transversal way should not only be aimed at professionals. As France Dujardin, from the CRP in Tournai, points out, “Rivalry between peers also exists: some people are desperate to be recognized and participation gives them a way of existing, sometimes to the detriment of the space that should be left for others to exist in this way. Some users take up a lot of space and impose themselves to the detriment of others, sometimes with violence. We need to be aware of this and imagine organizations that balance participation among users.“

Recommendations

6 Devote resources to participation: financial, material, human

For Hugo Rovira. Responsible of La Foixarda Project and former mental health service user, “If former mental health users are considered experts, then they should be properly compensated.” Managers have to include in the estimated budget both reimbursement of expenses and payment for time worked. From a material point of view, a wide variety of means can be devised to encourage participation. Whether it is a question of reception areas (e.g. for Greater Manchester Mental Health (GMMH), the new building of the Recovery Academy: when users go in it, they feel valued) or materials and time spent on communication, both to recruit people and to publicize what has been done, with posters, flyers, on social networks, or via a user’s newsletter like it has been done in GMMH, or a newspaper, like in Niuvanniemi Hospital.

7 Engaging also the community

One of the conclusions that emerges from the interviews with the services interviewed for this paper is that participation, once its organization reaches a certain level of maturity, takes on a variety of forms both within the mental health care service and outside it, in the community. As Laurent Defromont, EPSM Lille Métropole says: “…participation in the mental health service has to be apprehend in the broadest sense: integrate professionals with experiential knowledge; include users and carers but also community experts in the operation of the service.” Josep Maria Sole, Guardian Foundation, goes even further by linking participation and prevention: “The notion of involving people with mental health problems can be extended to prevention issues in the context of community mental health. We can’t wait for the person to ask for help, we have to be there. This means talking about mental health everywhere (at school, at work, etc.).” An idea prolonged by Hugo Rovira, La Foixarda Project: “Experts with experience in mental health disorders should also be involved in social services, not just health services.”

If the intentions of the interviewed actors are quite clear concerning the will of cross interactions with the community in terms of participation, we notice that the links of the mental health services with the local elected officials are most often summarized to a presence of the latter in the governing bodies of the structures with a public vocation, or sometimes to a material help (e.g.: loan of rooms). Their presence in a real “round table“, such as the one proposed by the local mental health councils in France, remains quite rare.

Recommendations

8 Document your experience, think about the future

Most of the time, there is one person, often a department head, who is the driving force behind changing practices and participation. While the launch of the dynamic is of course important, participation in a service should not, considering a long-term perspective, be solely dependent on one person. A culture of participation must be spread. This requires not only the guidelines mentioned above, but also the regular production of written material, the formalization of participation, evaluations with all the stakeholders, the production of indicators and finally the dissemination and communication, both internal and external to the service, of these data and results.

While all the actors interviewed agree with these statements, very few actually implement them. From this point of view, the experience of Greater Manchester Mental Health is particularly remarkable, both in terms of the writing of a strategy around participation, its follow-up, the processes put in place to facilitate its development, and the communication actions implemented.

Description of the experiences

In a comprehensive community mental health model, users engagement is central

Cavan Monaghan Mental Health Service, Republic of Ireland
Statut: Public mental health service

Population covered
140.000 inhabitants

Number of people who have had at least one contact with the service during the year
3.500 persons

Intervenes with all age groups: from early childhood to old age.

Orientation

A comprehensive community mental health model, in which an extensive service user engagement programme is considered as a strategic priority. Works with day hospitals and community care multidisciplinary teams. Based on a bio-psycho-social approach, with broad-based psychological and therapeutic interventions in the community. Use the Wellness recovery action planning (WRAP) with mental health service users. Employees are trained to the recovery concept. Do not use seclusion on inpatient wards.

Some key data

70% of the workforce work in the community, 30 % in residential or inpatient services
30% in residential or inpatient services
245 employees, included 4 peer support workers

- Recruitment of a peer support worker “carer“ (who has experience of a relative’s mental health problems) in progress.
- Have a low admission rate per capita to inpatient units (more than twice as low as, for example, services in the region).

Interactions with the territory

on several levels (see below).

Description of the participation in the service

The process started in 2011 with a Mental health Trialogue (see “References”) training between users family members and staff, to facilitate the work between them. Then, the national policy stimulus helped to develop a culture of recovery-focused approach in which users and carers of mental health services are at the centre of attention and consequently participate, in different forms, in the mental health service and in their own recovery journey*.

** See note on page 15.*

Description of the experiences

The basis of this work was the training: many training workshops including service users, carers and professionals were organised, on an equal basis between participants, to learn from each other, exchange and make people aware of the differents perspectives and values. As a result of that process, engagement takes different forms:

PEER SUPPORT WORKERS:

Peer support workers (PSW) are considered as "recovery coachs" and, thanks to their understanding of what it's like to live with mental health challenges, provide a mutually empowering relationship and inspire and support users on the road to recovery. They offer different types of supports: Return to work / education; Identify individual goals and help for empowerment; Connection to community resources (e.g.: community groups, social clubs, support groups, accompany to the library, citizens information office or the post office…). To facilitate the integration of PSW into the teams, an information phase is carried out with the professionals. Following this, the PSW are involved in all the service and in decision making. For example, they are involved in the user's care plans. The PSW have a supervisor (a clinical psychologist) who is not in the care team with whom they can discuss and help them if necessary once a month.

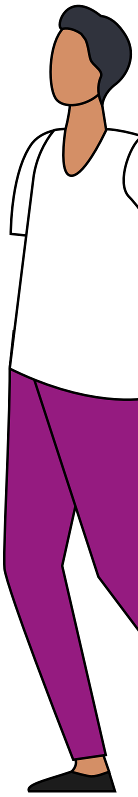
RECOVERY COLLEGE

Innovation recovery project is a cross border Mental Health Recovery College Network between the Republic of Ireland and Northern Ireland, funded through the European Union's INTERREG Programme. The purpose of a Recovery College is to support people's recovery from mental health difficulties through learning and education that is co-produced by people with lived experience and people with professional expertise. Three cross border Recovery Colleges have been established as part of the Innovation Recovery project. One of them is on the territory of Cavan Monaghan Mental Health Service. The Peer support workers employed by the recovery college, who have lived experience of mental health issue, are working with users and professional of the service.

The project has established strong engagement mechanisms with the local communities served and strives to offer courses and programmes which reflect the needs of people with mental health difficulties, and also the wider needs of communities to ensure more awareness of the importance of good mental health and early intervention and prevention.

The recovery college is very important in terms of empowerment of people, to reduce stigma with a freer speech between stakeholders on mental health subjects.

Over the past two years, some of the most popular courses have included: Getting a Good Night's Sleep, the Wellness Recovery Action Plan (WRAP), Understanding Depression, Mindfulness, and Learning to Like Yourself. The courses are delivered both in the community and on-line. This was very important during COVID19 lockdown: most of the people were looking for simple ad basic information on anxiety, trauma, without necessarily having a technical or medical approach, to be able to cope with these problems.



HERE FOR EACH OTHER GROUP

The "Here for each other" group aim to educate as many people as possible about how to cope with the challenges of mental health problems. The group is led by regular attendees and by the peer support workers of the service. 10 to 20 people met 2 hours every week. They can stay 5 minutes if they want. They don't have to talk if they don't want. The guidelines are: Give respect-get respect; No cross talking; Listen when other talking; Switch phone to silent/vibrate; Confidentiality.

Description of the experiences

RECOVERY GROUP

The service runs a network of partners called the 'Recovery Group'. Monthly meetings are organised with community members, service users, their families, NGOs, to promote mental health, share information and put in place joint activities. For example, visits to sports clubs are organised to discuss stigma. The network contributes to change the work of mental health professionals in the territory: everyone works together and is equal to each other in this network.

EXTERNAL EXPERTISE

Former service users attend monthly area management team meetings, together with a family representative. They are not paid, but expenses are reimbursed. Beyond compensation, everyone responds to their own objectives by participating. Padraig Columb testifies: " I want to help in turn as I have been on my road to recovery (…) We can be more objective as an external ".

OTHER ACTIONS

- → As part of a quality assessment process, service evaluation questionnaires were designed with service users.
- → The service has set up a number of Engagement forums, which are a meeting with voluntary groups in the community (family, young, police, elected representative, chamber of commerce…). E.g. "connecting for life" which is a suicide reduction strategy.

Description of the experiences

Successes

- ➔ A national political will that has been translated into several programmes and related resources*.
- ➔ Cross-cutting participation in all actions.
- ➔ Training effort to change behaviours and practices.
- ➔ A recovery college in the territory.
- ➔ For the peer support workers: the supervisory work, very important for them.

Difficulties, points for improvement

- ➔ Resistance and fear from staff: challenging to change the way you work since sometimes decades.
- ➔ A person has been recruiting at a regional level in the context of a National program on engagement. In a way, direct contact with the service has been lost which is a disadvantage. It doesn't work as if it was local. Seen as external of the service.

Recommendations

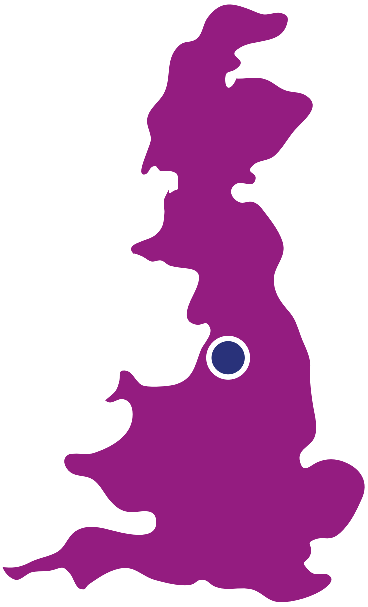
- ➔ Have a holistic approach to make it work: create various programs help people to work and to co-produce together.
- ➔ It takes time to shift from a Hospital model to a person-centred model.
- ➔ The best way to change the culture of care is to hear the story of a person with a leaved experience.
- ➔ The importance of the personal contact for people who are feeling lonely and vulnerable is frequently underestimate: training of staff is essential.

> *"One of the risks that frequently happen with engagement is that it is become tokenistic. We must include it in our day to day practices and go beyond the legislative requirements."*
>
> Padraig O'Beirne
> Area Director of Nursing at Health Service Executive
> Cavan Monaghan Mental Health Service

** As outlined in "A Vision for Change" (a national policy, in place since 2006, that sets out the direction for Mental Health Services in Ireland) and in "A National Framework for Recovery in Mental Health" (launched in 2017, to develop a more recovery-oriented mental health service that is worthy of those who use and provide that service), the promotion of a recovery-based mental health service model in Irish Mental Health Services is a key priority for the authorities. Since then, there has been a growing movement in Mental Health Services in Ireland to shift towards a more person centred and recovery orientated model of mental health service provision. In the intervening years, there have been a number of projects aimed at doing just this, most notably, the Prosper Genio Project (a pilot peer support project), the Refocus Project (laying the groundwork for future peer support in working out the practicalities and intricacies of the role), and the Advancing Recovery Initiative (ARI, to support the development of recovery orientated services).*

Description of the experiences

Engagement as a pathway to recovery



Greater Manchester Mental Health (GMMH), NHS Foundation Trust, England
Statut: Public mental health service

Population covered
2.8 million inhabitants

Number of people who have had at least one contact with the service during the year
53.000 persons

Orientation

GMMH services include Community Mental Health Teams, inpatient services, older adult and dementia services, early intervention teams, primary care psychological services, specialist inpatient services for young people, drug and alcohol users, mother and baby, medium and low secure forensic inpatient services, etc.
GMMH Trust values were launched in september 2017 following extensive engagement with service users, carers, staff and governors, by events and online voting. The values are: We Inspire Hope; We Work Together (with users, family and carers, staff and wider community); We are Open and Honest; We are Caring and Compassionate; We Value and Respect. They are displayed in all services.
Some key data: 6,000 employees in 150 locations. 200 active volunteers, 50 volunteer Peer Mentors including Carer Peer Mentors*, 34 paid Peer Support Workers, 100 supervisors (local staff - it could be a clinical, a psychologist… - who guide volunteers users/carers in their role and are the first point of contact).

Some key data

6 000 employees in 150 locations
200 active volunteers
50 volunteer Peer Mentors including Carer Peer Mentors*
34 paid Peer Support Workers,
100 supervisors (local staff - it could be a clinical, a psychologist… - who guide volunteers users/carers in their role and are the first point of contact).

** The role of Mentors in mental health can be compared to mentors of Alcoholics Anonymous (AA): he accompanies a specific person assigned to him. Paid Peer Support Worker roles are a progression route for Volunteer Peer Mentors who do not have access to things like the Trust clinical record system. All peers undertake the Trust Level 2 Award in Peer Support which is mapped to NHS England National Peer Support Competency Framework. There will be a national Peer Support Apprentice vocational qualification in England from 2022.*

Description of the experiences

Interactions with the territory

GMMH's Board of Directors sets the overall strategic direction for the Trust and works closely with the Council of Governors, which is composed of: 11 elected (public elections open to general population) public Governors ; 4 elected public Service User and Carer Governor; 7 elected staff Governors and 5 appointed partner Governors.

On top of that, GMMH work also with local advocacy services, actively encouraging Independent Mental Health Advocates and Independent Mental Capacity Advocates to work with the service users on their premises when required.

GMMH work in partnership with the local voluntary sector and specialist interest groups (LGBTQ etc.) to create opportunities for more people with lived experience to work with them.

GMMH work also with the media by preparing and distributing press releases and feature articles about people with experience of mental health and/or alcohol and drug problems to challenge prejudice and help combat the stigma experienced by people with these issues and their carers.

Description of the participation in the service

Involving service users in their own care is a strategic priority for GMMH. The aim is to make sure that the views of the people who use the services have the chance to be heard and to work together deliver services that take into account real, sustainable changes. GMMH is also engaged, with expert of experience, to make services more relevant and recovery focused. GMMH encourage staff and service users to work together and try to create a common culture between health and social care sector in order to reduce internal and social stigma. Engagement is considered as a significant part of service user's recovery and ensures the care they receive is holistic. Visible engagement is considered as empowering for others: it shows recovery in action. GMMH committed to working and engaging with service users, patients, family, friends, carers and the public in a wide range of ways.

Recruitment process: when services identify that they require a service user, patient, family member, friend or carer to support them, they will develop a role description and person specification and advertise this paid role (by noticeboards, posters, flyers and website). When a vacancy is advertised, GMMH is looking for applications from lots of people who have used GMMH's services, particularly in the last six months, as well as their carers and families.

Service users and people who look after someone can get involved in the following ways: Providing their views as a representative at a service improvement meeting or working group; Getting involved in the recruitment and selection process of staff ; Helping inspect the buildings for the purposes of audit or PLACE Inspection (Patient Led Assessment of the Care Environment); Co-deliver training (as part of the Trust induction or as a Course Tutor for the Recovery Academy); Speaking at events to share their personal experience; Contributing to the development of policies or reviewing information.

People involved are paid for their time. The rate of pay is £10 per hour. Payment for mileage will be reimbursed at the same rate as the staff who use their own vehicle for business mileage (currently 56p per mile). People are not asked to be engaged more than 7,5 hours per week. Firstly to widen participation and engage as many people as possible; secondly, because of the benefit system in England: when volunteers are paid, it can affect their benefit and penalize them.

Description of the experiences

TRAINING

Training and support is available across the Trust for service users and carers involved in decision making and service development activities free of charge. GMMH want to educate service users prior to any involvement, so they are better informed and can therefore feel more equal when working alongside professionals. Many service users report that jargon used in the mental health field can reinforce the separation of ‘us and them’ and leave people feeling undervalued. GMMH also inform service users about legislation changes so they know their rights, and keep them up to date with service developments via newsletters or bulletins.

In January 2013, the Trust’s Recovery Academy was established. The Academy offers a range of free educational courses and resources to support recovery from mental health, alcohol and drug problems for service users, carers and professionals. One of the core principles of the Academy is equal engagement between people with lived experience of mental health and/or substance misuse problems and professionals to encourage shared learning. Collaboration takes place in curriculum design, course delivery and evaluation to ensure the Academy teaches and promotes recovery principles.
There are over sixty tutors involved in the day to day delivery of the Academy, half of whom are service users/ex-service users of mental health services. With over sixty courses on offer, the Academy has over 7,000 students registered (for 2019) and nearly half are service users and carers. Peer Mentors are trained via the Recovery Academy to a Level 2 standard. An assessment of the Recovery Academy shows a reduction of stigma (both for staff and users) and a better return to employment.

CARE PLAN

Genuine collaboration and involvement in the care planning process is a GMMH priority. To involve service users and carers in their care plans, staff are trained and there is a co-design care planning training programme; care planning documentation is service user and carer friendly; GMMH develop resources on their website to support effective care planning; develop a culture where service user and carer involvement in care plans is an always event; provide service users with care planning files; give a copy of the plan to the users.

FEEDBACK

Feedback from service users in all GMMH services is well established via the use of an electronic service user satisfaction questionnaire and paper questionnaires (which include the Friends and Family Test question) given in the services or sent via post. The Friends and Family Test data is submitted to NHS England monthly and services receive a quarterly report. If improvements are required, an action plan is requested and monitored through the Service User and Carer Experience Team. ‘You Said, We Did’ posters are also regularly produced for services to fill in and display locally so that service users can be kept informed of the changes that have been made.
GMMH encourage local services and staff with dedicated link roles to connect with local service user groups on a regular basis to give and receive feedback.

COMMUNICATION

GMMH ensures that decisions and service improvements made as a result of service user feedback is communicated to staff and service users, thanks to the service user forums/ Conversation Cafe’s, and to the service user newsletter.
GMMH share also patient stories across the Trust, and in particular at Board, Executive and Senior Management level, and share learning from compliments, feedback and complaints for services to use and learn from locally.
Progress are published on the Trust website and via social media and best practice guidelines on service user engagement have been developed to complement the Trust policy so that services feel supported and service users feel valued.

Description of the experiences

Successes

- The document “Service user engagement strategy 2018-2021” is monitored via the Trust Service User and Carer Engagement Forum meeting.
- The different roles of experts of experience, to volunteers to Peer Support Workers (via volunteer Peer Mentors) are a pathway to recovery for those who choose this path. The aim is not to call on a person for a specific project and then never have contact with them again, but to involve them gradually, but genuinely, in the service, and at the same time to give them more confidence in themselves and what they can bring to the service.
- Thanks to the different actions put in place, there is less and less stigmatization and a growth in confidence because of the delivering of services responsive to what people need.

Difficulties, points for improvement

- Culture of engagement is stronger in addictions services than in traditional mental health services. Some people are afraid initially that GMMH want to replace staff by service users in order to save money, and worry about things like confidentiality. This type of conversation still exists, but less than they used to. In face of that, exposure to users’ experiences stories and their positivity is the best way to change culture. The Recovery Academy is good for this because it is open for all: staff, carers and service users are learning together, in the same room. Staff are exposed to this environment change their mind, step by step. Sense of humor can also be a good way to breaking down preconceptions.
- Some of the long stay service users reported that they are often asked for further feedback before they hear about improvements as a result of the last feedback they gave. They said this left them feeling undervalued and disillusioned with the whole process. They suggested a newsletter to update them on progress being made, but the emphasis on actually seeing and feeling improvements was more important to them.
- Service managers need to consider practical ways to support such engagement by identifying budgets and supervisors to pay and support service users in these roles within their services.
- Carer engagement not as strong as service user engagement: services asked to complete a carer engagement action plan.
- GMMH have to negotiate with the Department for Work and Pensions, and it can be difficult, because sometimes stigma exists e.g. if people are volunteers, they can have a full time job straight away, while GMMH approach is to move step by step towards recovery.

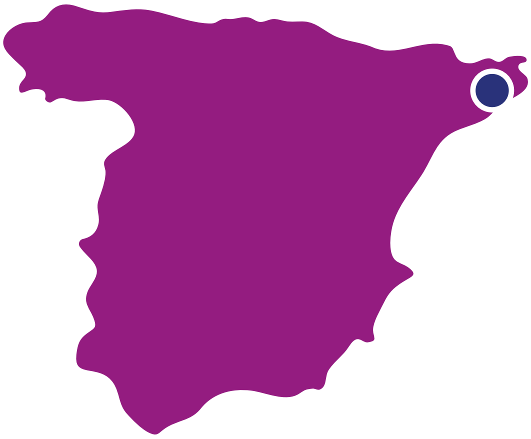
Recommendations

The most important is a board level support at the top of the organization, who will agree to invest money in engagement (e.g. for GMMH, the new building of the Recovery Academy: when users go in it, they feel valued).

> *“8 year after the beginning of this journey, I would say: stay positive, don’t give up. Exposure to lived experience is inspiring! It reminds you what is important and that services should always respond to individual and local need. People who are hesitant will join in eventually, it’s infectious. Empowering individuals and communities to recognize and build on their own assets is the best gift mental health services can give.”*
>
> Claire Watson,
> Trust Lead for Service User & Carer Engagement
> Greater Manchester Mental Health

Description of the experiences

User's engagement through a network of partners and a community based mental health service



Girona mental health network (Institut d'Assistència Sanitària – IAS), Spain
Statut: Public company belonging to the Government of Catalonia

Population covered
743.579 inhabitants

Number of people who have had at least one contact with the service during the year

As far as this is a network based on primary care and which is working on prevention and social issues, this indicator is less relevant than for a sanitary service. However, we can say that 42 000 people are treated in: the Mental Health Collaborative Program in Primary care, 7 Adult and 7 Child/Adolescent Mental Health Centers, 6 Drug Addiction Centres, 7 Rehabilitation Services, a Day Hospital, emergency rooms and in a Mental Health Acute Unit.

Orientation

Leader and reference for Mental Health in the whole province of Girona. Girona mental health network closure psychiatric hospital in 2004. The deinstitutionalization roadmap is based on an organization process which involve incorporate psychosocial rehabilitation values, an assessment user's for guiding intervention, flexibility in rehabilitation procedures and a great hope in improving daily living and autonomy of patients. This Community Mental Health Services working closely with a network of stakeholders, and is based on: Adults and childhood Mental Health Centers; Assertives community treatment teams (Early detection psychosis, Homeless mental health team, Case management housing program, Inpatient housing team to avoid hospitalization); Day Care Center; Drug addiction treatment Centers; Flats with support; Home Residence, Social club, return to work, gardening, leisure activities…

Some key data

5,2 beds / 100 000 inhabitants for acute needs
8,5 beds for 100 000 inhabitants for subacute needs

A good assistance continuity rate :

90% of users that have been admitted in a mental health Acute or Sub-acute unit continue their treatment in the community mental health centers

18%: A low percentage of readmissions

70%: A high proportion of community resources versus hospital

IAS has 1900 employees, of which **500** are in mental health.

Description of the experiences

Interactions with the territory

A series of coordinated supports are organized in the community, linked with primary care, social, juridical, education, older people, intellectual disability, employment or other general facilities looking for preventive action with the most vulnerable population. Elected representatives of the regional health department participate in the board of directors. IAS is also involved in Activate for Mental Health (Activat per la salut mental), a Catalan pilot project that aims to provide training and information to mental health service users and families in order to create more horizontal relationships with professionals.

Description of the participation in the service

The user's participation in the Mental Health Network is based in the cross-supported involvement of IAS with independent Foundations and NGOs: Work Foundation (www.fundaciodrissa.com), Family and Users Associations (www.familiaisalutmental.cat), and Guardianship Foundation (www.supportgirona.cat/en). There are two referents for facilitating the involvement in the mental health grid, the chief of Rehabilitation Service in the Hospital, is in permanent contact with main stakeholders to coordinate actions. Agreements have been signed by the professionals to facilitate the cross interventions in each other services. These stakeholders have been essential in the successful deinstitutionalization process.

MENTAL HEALTH STEERING COMMITTEE

All of them are involved in the mental Health steering committee of the Mental Health & Addiction Network and participate in the decision-making process. This is a month meeting where chief of the community mental health centres (adult & child adolescent), addiction centres, community programs and hospital services, work to improve and solve troubles. The participation in the mental health steering committee gives the opportunity to talk about some professionals practices, troubles detected in mental health treatment, dissatisfaction of users related to the care processes. They can propose for example new procedures, and they globally help the reflection about the impact of the interventions. For example, during a recent meeting, on the topic of involuntary treatment, professionals of the emergency units heard a user's representative explanation about Human rights in mental health. And the raising awareness that it should be a last resort decision was important because there is actually no government instruction in Catalonia to avoid involuntary treatment, even if there are few in Gerona.

TO RECOVERY

Users receive training, consultation & support to prepare their participation in conferences. They talk about their experience in "first person", with positive & negative impact of mental health in their lives. It is a non-profit activity with an important recovery component. Users can have access to a training plan, depending on area involvement. They receive a course to develop the skills to be an expert user. They receive support from professionals to manage the "perceived stress" to speak.

Description of the experiences

JOINT COMMISSION

Thirteen years ago, the "Joint Commission" has been created, following a round table with users in a mental health congress in Girona. It is composed of users and professionals to fight against stigma. Various decisions are made to improve services and anti-stigma actions are carried out in the framework of this Joint commission. Users give conferences in all the high schools of the province, and support university students who suffer from a mental disorder, and later, if necessary, connect them with the mental health network. They look for "raise aware" the importance to be honest in recognition of mental disturbances, accepting the "emotional impact", fighting to avoid the social detachment.

AND ALSO...

9 expert users also participate in group therapy sessions, with users who live similar situations to theirs. These experts are former users of the service and they are paid by Fundacion Drissa.

The project named "La Foixarda", included into the mental health network, is a peer-to-peer mutual aid group and social project that have been done with students of the university (agreement between Fundació Drissa & Girona University), promoted by IAS.

Four social clubs are managed by the service and the family association, in different territories, complementary to the community services of psychosocial rehabilitation, for the orientation in leisure and free time. They are financed by a social budget: that is possible thanks to the co-management with an association.

Once a year, a meeting is organize with users of the service and some professionals to ask them what do they think about the functioning of the service.

Recruitment of peer support workers is in process for the future.

Successes

- With the participation in the management of users and carers, IAS succeeded to consolidate among professionals the idea that people with mental health problems and their families have the right to participate more actively in the processes of recovery and improvement of their quality of life; participation which is considered an inherent right to their status as citizens.
- Thanks to users and family involvement, the service is more sensitive to the real needs of users.
- Mental health problems impact many aspects of daily life. Beyond the medical aspects, it is difficult to solve all these problems alone, starting with housing and work. From this point of view, the participation of families and consumers of mental health services has proven it is usefulness.
- The intervention of users in the high schools, in the framework of the joint commission, are going very well and giving good results. Many students have testified that they have changed their outlook on mental health and sometimes even their lives. Users feel valued by telling their experience.
- The obstacles put in place by the syndicates 15 years ago at the Drissa Foundation concerning the participation of users in the Foundation's bodies were difficult to overcome. They had to go to court to win the case. It takes a lot of conviction to get things moving.

Description of the experiences

Difficulties, points for improvement

- Political support is essential. Encourage the development of this participation by law so that it is not simply an exception here or there, depending of some few people who are able to change or not be there at a moment. IAS believe that they must extend and generalize the participation of users and carers in all services of the mental health network, at all levels of management, as well as the figure of the expert user, even in psychiatric emergencies and at the time of hospital admission. For this important legislative changes are needed.
- Not all of professionals are prepared to the users' participation in services. You have to promote a consensus around the participation, because you have to break "the professional fear" to be assessed by an expert user. It took time, but it's possible, step by step.
- Lack of documents, data's, assessment results or formalization, to promote and consolidate the Girona experience and users/family engagement.
- The authorities provide four times more funding for residential setting than for helping someone in the community. So, it's also difficult to provide users/family participation in this context.
- Improve the quality of users and professionals training about Human Rights.
- Lack of national/regional certification for the work of users in the framework of user's involvement.

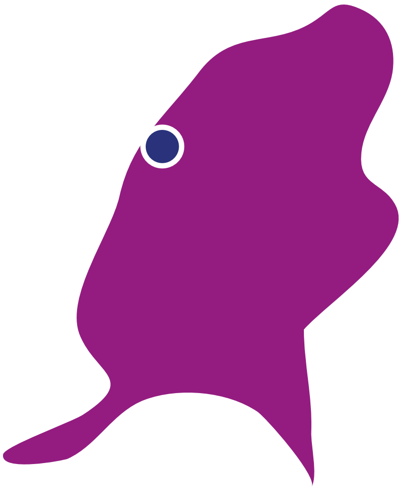
Recommendations

- To developp users engagement, there must be joint training activities for professionals, users and carers, as well as specific ones for each of them. It is also necessary to encourage professionals in training a more horizontal view in their relationships with users and carers, as well as shared decision-making. All of this must be accompanied by the implementation of the least coercive practices possible and the creation of regular spaces for discussion between professionals, users and carers. It is advisable to systematically carry out opinion surveys of users when they have been hospitalized.
- The importance of the leadership from management: users participation involves all of professionals. They need a coordination of actions, to guarantee the safety of the users in the participations, to give support to all of the "misunderstandings" that can be done.
- The notion of involving people with mental health problems can be extended to prevention issues in the context of community mental health. We can't wait for the person to ask for help, we have to be there. This means talking about mental health everywhere (at school, at work, etc).
- If former mental health users are considered experts, then they should be properly compensated.
- Experts with experience in mental health disorders should also be involved in social services (not just health services).

> *"We promote the relationship with the partners of our network and we grow together. After decades of collaboration, it became natural to be flexible between us and to listen to each other. Family and user representatives really help us make the best decisions because they are part of it."*
>
> Jordi Cid, psychologist network coordinator
> IAS, Girona

Description of the experiences

Peer support workers involved in a transversal way



North-Holland-North, Netherlands
Statut: Foundation, a medium size mental health service. Financing by insurance companies, according to government guidelines. Youth care is funded by local government.

Population covered
620.000 inhabitants

Number of people who have had at least one contact with the service during the year

considering the mission of prevention of GZZ, all the population is concerned. But, for direct interventions: **14.000 persons** including youth and forensic.

Orientation

Mental health services in the community, outpatient care as close as possible to the person's home are preferred. Mobile teams are working on the basis of Flexible assertive community treatment (FACT) model. Possibility, for persons with mental health issues, in some special cases and for the shortest time as possible, to receive care in a clinic or to have medical monitoring in housing in the community.

Some key data

2 200 employees, included 30 peer support workers.
3 recovery colleges with 10 workers each, in order to: work with mental health service users (most of the time in groups, less individual) on their wellness recovery action plan (WRAP), organize peer support workers exchange/support groups and groups on different topics (peer support, writing, self-image, yoga...). Peer workers also participate in Recovery Oriented Intakes (explained later).

Interactions with the territory

Once a month, a meeting is organised with representatives of the different stakeholders in the community (mental health workers, but also local elected, police, firemen...). Expert networks (#27), diagnosis and non-diagnoses based, can support the ambulatory teams if needed. Once a month, "Recovery stories" are broadcast "live" and on social networks. On a moderate scale, peer support workers are also doing interventions at school, for children aged 12 to 18 years. Occasionally the local authorities organize a forum for all service providers to meet, talk and exchange.

Description of the experiences

Description of the participation in the service

At GGZ Noord-Holland-Noord, experiential knowledge is taken into account on several levels: User and family participation council, Peer support workers, Expert network and advisor of the Board.

USER AND FAMILY PARTICIPATION COUNCIL

GGZ has had a User and Family Participation Council (CFM-raad) for years, which is composed of both users and family members or other relatives. This is a dialogue body that enables the wishes and needs of people receiving care to be collected. It allows difficulties to be raised and solutions to be found. The recruitment of these people is done orally in the service, and the council also distributes information leaflets. Participants are not compensated but their travel costs are reimbursed.

PEER SUPPORT WORKERS

The service has been employing peer support workers for about 15 years. The first peer workers worked both in the outpatient service (FACT teams) and in the hospital. Since 2017 the peer workers are organized in three recovery centers. The major reasons for this “big” change, are: just one peer worker in a team is (too) vulnerable, and developing quality services require peer workers working close together.

WARM WELCOME

Recovery Oriented Intakes are the latest innovation. When a person arrives for a first appointment in the service, he or she is first welcomed by the peer support worker, who is in charge of the “warm welcome“. This first contact allows the person to feel at ease over a coffee, for example, and to have an initial exchange that allows the peer support worker to introduce himself or herself and possibly build bridges on a common experience. Then, when this exchange is over, both psychiatrist, psychologist or nurse are invited in the meeting. This way, all required knowledge is available (scientific, professional, own experience and the client him/herself) to decide on the right next step(s). Possibly outreached treatment form the FACT-team, activities within the recovery center and in many cases (1 out of three) no specialized mental health seems to be required.

AND ALSO...

Peer workers also participate in a variety of other activities (within the company, national and international). E.g. The peer support workers take part in training courses for professionals on experiential knowledge (e.g.: “From paper to practice“ course). They lead internal workshops on the handling of user complaints, which aim to improve care. They participate, together with the users and carers representatives, in the two strategic meetings organized each year with the directors, managers and administrators.

The Expert Networks (#27, e.g. Trauma, Recovery, Forensic, Autism, Frailty, Domestic violence, etc.) support on an ad hoc basis, as needed, the mobile teams. Peer support workers all participate in one or more expert networks. Regular meeting helps to keep the expertise up-to-date and available across the organization.

Description of the experiences

Successes

- Fifteen years of experience in integrating peer support workers into teams has changed the situation: a real culture has been developed, they are recognized for their work and involved at all levels of support.
- At the beginning, some psychiatrists questioned the role of the newly peer support workers. But as everything worked well, these apprehensions disappeared.
- As with any recruitment, the profile of the person counts for a lot: but if the person is persuasive, communicative, and welcomed into a caring team, then recovery oriented intakes are great.
- The approach allows for the recognition that recovery from a mental health disorder is possible, as professionals work with people who are / have been in this situation. It also breaks down barriers and preconceptions, blurs differences between people and changes perspectives by normalizing interpersonal relationships.

Difficulties, points for improvement

- Difficult to do prevention and to raise awareness of general population on mental health issue.
- For the training of professionals, it is necessary to find the right tone so as not to make them believe that they are doing everything in the wrong way and not to be moralistic.
- For work in the community, need to further improve knowledge of all the actions carried out by the various stakeholders (from the health, social, administrative and leisure sectors, etc.), and to further improve the quality of interpersonal relations in order to be able to deal together with the crisis or emergency situations that can sometimes arise.

Recommendations

- A willingness to innovate and a conviction of the added value of experiential knowledge on the part of the management of the institution/service concerned are required to develop this type of support.
- Start the process with peer support workers. Even if the posts are not funded (which is better, of course): do it anyway!
- Do not start with only one peer support worker in a team: always start with at least two. They will need each other to exchange, to support each other...
- Invite peer support workers to strategic meetings to benefit from their different perspectives on the functioning of a service.

> *"Involving people with lived experience of mental distress in the running of a service completely changes the approach to care and support: the whole system is improved."*
>
> Dick van der Vlugt, peer expert, advisor to the board of community mental health service
> GGZ Noord-Holland-Noord

Description of the experiences

Patient-experts, user and carer representatives, but also peer support workers and family peer support worker

Hôpitaux de Saint-Maurice, Val-de-Marne, France
Statut: Department of a public hospital

Population covered
112 000 inhabitants

Number of people who have had at least one contact with the service during the year

2 500 people per year
are followed up by this unit

Orientation

"Open door" service for all patients, without exception (including the COVID19 pandemic), which favours the therapeutic alliance. No care programmes (French system of compulsory outpatient care), no restraint, rare use of isolation rooms. An internal study shows that violence in the department has decreased as a result. A reduction in stigmatisation is reported by users.

Some key data

2 temporary patient experts for therapeutic patient education programmes
2 peer support workers
1 family peer support worker employed
2 user representatives
2 volunteer carers' representatives participate in meetings of the department

Interactions with the territory

Networking, in particular via a local mental health council, with the region's medico-social, social, political, cultural and private stakeholders to facilitate the social integration of patient-citizens and the destigmatisation of mental illness.

Description of the experiences

Description of the participation in the service

The participation of experience experts takes several forms:

RECRUITMENT OF PEER SUPPORT WORKERS (PSW)

The first PSW was recruited in January 2019, the second in September 2019. The PSW have found their feet and their position, both at the relational and professional level, in complementarity with other colleagues, based on their recovery path and training. The PSWs have a great deal of autonomy in the activities they can offer (recovery support interviews, facilitation of discussion groups, meetings, etc.).

RECRUITMENT OF A PEER FAMILY PEER SUPPORT WORKER

The idea of creating this job came from the family group and became a reality following a response to a call for projects from the ARS on the "Patient Experience". The son of the person who occupies this post is followed in the service. He is therefore familiar with its functioning, which is a plus. The main idea is that he can make the link with families in distress thanks to this experiential knowledge. The recruitment of a second person is being considered.

PATIENT-STAFF MEETINGS

Weekly patient-staff meetings (medical and non-medical) are organised in the outpatient department of the day hospital and in the inpatient department with people who are being hospitalised. This is an opportunity to discuss concrete day-to-day difficulties as well as fundamental issues (experience of the disease, recovery resources, treatments, user status, etc.). The subjects are brought by the users and are discussed for 30 to 45 minutes. For example, it was as a result of these meetings, co-facilitated by a PSW, that locks or curtains were installed on the windows in the rooms to ensure greater privacy, or that a clock was installed in the isolation room.

THE PATIENT-EXPERTS

Thanks to funding from the ARS, within the framework of "health promotion", several sessions of six sessions to raise awareness of mental illness are offered to people who do not work in the health sector, for example staff from medico-social establishments, town halls or social housing, etc.
Two expert patients were trained for 40 hours in the Therapeutic Patient Education programme (training paid for by the hospital). They then co-facilitate these six sessions. They are paid for this, both for the preparation, for the intervention and for the subsequent synthesis, so that this remuneration is sufficiently significant. These interventions, on topics such as "How to intervene in a crisis", are very much appreciated, as evidenced by the evaluations.

Description of the experiences

Successes

The different forms of participation deployed in the service increase the feeling of being truly heard by service users and families. They promote a better therapeutic alliance and self-esteem. They help to reduce self-stigmatisation.
At the level of the teams: once the initial reluctance has been overcome, participation changes the way people look at the disease and their rights. The discourse between professionals changes. Destigmatisation progresses. Having two family representatives and two user representatives in the meetings is a real plus. It was noted that speaking out, especially in front of a large number of people, could sometimes be difficult and that the fact that there were more of them made it easier.
Having two PSWs and a family PSW also facilitates integration and mutual support.
The local mental health council contributes to changing the way mental illness is viewed outside the hospital

Difficulties, points for improvement

- The user and family representatives are volunteers: for the moment, no budget has been set aside in the hospital for reimbursement of expenses or remuneration.
- The integration of a family peer support worker, like that of a peer health mediator, may give rise to reluctance on the part of the teams. It should be noted that the first person who previously held this position was both a user and a family. This proved to be a complicated situation to deal with: the person resigned after a few months.
- Collaboration with partners outside the hospital (elected representatives, other administrations, etc.) is sometimes complicated, despite the organisation of awareness-raising meetings. The notion of professional secrecy is difficult to get across, the language is not the same, there is a lot of stigma attached to it... We need to be educational.
- Difficulty in devoting time to formal evaluation of these systems.

Recommendations

- Integrating participation in a service requires preparation: no matter how much the managers want to, these actions take time. Time to prepare the integration, time to let reticence be expressed (about 9 months of preparation before the recruitment of a PSW for example).
- In order to change the way professionals look at things and get them to consider users more as people than as patients, having the main people involved (in particular PSWs working in other establishments) testify is an effective method that makes participation concrete and changes attitudes.

> *"If given time, the participation of users, ex-users and families changes the way mental health issues are viewed: it shifts lines and brings new thinking."*
>
> Dr Alain Cantero, psychiatrist, head of the department
> Hôpitaux de Saint-Maurice

Description of the experiences

The participation of experience experts in the mental health service

EPSM Lille métropole, eastern suburbs of Lille, France
Statut: Department of a public mental health hospital

Population covered
88.000 inhabitants

Number of people who have had at least one contact with the service during the year
3 536 people per year

Orientation

Recognized by WHO as a good practice in community based mental health service; care oriented towards recovery, respect for human rights, fight against stigmatization. The service was inspired by numerous innovative practices in the international arena to design an organisation centred on the needs of individuals, in close collaboration with all the stakeholders in the region. Everything is done to facilitate access to care while preventing hospitalisation. When these cannot be avoided, they are kept short. The co-construction of a care project with the user aims, from the very beginning of the care, to involve the user in the reflection on the post-crisis period.

Some key data

122 professionals employed

72% of the staff work in outpatient care

- First appointment in 48 hours;
- Almost no restraint practices (no isolation, one restraint in 2020); activities essentially oriented towards the city (10 hospitalization beds);
- The support provided to users involves many categories of professionals, in addition to the usual care providers (doctors, nurses, nursing assistants, psychologists): psychomotricians, social workers, artists, peer support workers, socio-cultural facilitators, educators, occupational therapists, medical-psychological assistants, etc.
- It should be noted that private provision in mental health care is low in the area, which gives the service a virtual monopoly on mental health care provision.

Interactions with the territory

The organization is articulated with the action of a local mental health council that brings together all the stakeholders of the territory (local elected officials, representatives of users and carers, social actors and landlords, primary care actors, etc.) and the many other local actors (associations, mutual aid groups). Low private supply in the territory.

Description of the experiences

Description of the participation in the service

Since 2012, the department has included the participation of experts in mental health experiences at different levels, whether they are people with direct experience of a disorder or their carers:

- 5 mental health peer support workers positions have been created: these are people with lived experience of a mental health disorder, sufficiently recovered, who have been trained and then recruited by the department - after a period of immersion - to accompany people individually on various levels (health education, feeling about the illness, etc.). The peer support workers also facilitate meetings for users of the department with user groups.
- The users' spokespersons are volunteer users' representatives elected by their peers (100 to 150 voters per election, for a two-year term). They participate in department steering committees, working groups and meetings organized with users. They encourage users to express themselves (e.g. via expression forms), report any problems or undesirable events and work with professionals to find solutions. Three elections have been held so far, in 2015, 2017 and 2019.
- Experienced experts lead training sessions for professionals to give them insights into the behaviour and practices that can promote or, on the contrary, hinder a path to recovery. These interventions are facilitated by representatives of carers' or mental health service users' associations. These representatives constitute a network of resources to which users are also referred as needed. Specific consultations are then offered to the user with a service professional and an experienced expert member of the network.
- The users' spokespersons, the experts of experience and the users of the partner structures are systematically associated with the presentations of the service carried out for French and foreign care professionals, national and local elected representatives, representatives of ministries, supervisory authorities... (more than 100 visitors per year).
- "Wellness Workshops", co-facilitated by a professional and a user or carer, take place about 30 times a year. They aim to develop the general population's knowledge of mental health, in order to combat stigmatisation and promote access to care (200 to 300 participants per year).

Successes

The participation of experienced experts modifies practices in a transversal way, both on the priorities of action, on very concrete elements of functioning and also on the training and behaviour of the care teams. The participation of the users helps them to acquire the right way of being, the right behaviour, in addition to their technical professional knowledge.
Participation gives a different role to experienced experts: it improves their own self-esteem and gives a message of hope to both service users and carers.
This participation softens the patient/caregiver dichotomy, destigmatizing mental illness. This has many benefits, for example, when a professional is going through a difficult period, or is himself a carrier of a disorder, he will find it less difficult to talk about it.

Description of the experiences

Difficulties, points for improvement

- Recruiting user spokespersons remains difficult, despite the information that is provided by professionals and the information tools deployed (posters, leaflets...).
- It remains complicated to maintain the commitment of the most motivated in the long term, even though a budget is provided for the reimbursement of their travel expenses, through the local mental health council. The question of compensation for time spent at the meeting arises. However, not all users necessarily agree to be paid, for fear of losing their freedom to speak. Other methods of remuneration, by an independent organization, are being studied.
- For the users involved, the strengthening of their skills must be accentuated so that they feel even more legitimate to express themselves without apprehension.
- Mental health peer support workers: the acceptability of this new profession has required time and explanations, both at the team level and at the institutional level (hospital and funders).
- Take the time to train the newly recruited professionals in the philosophy of the department and the principles underlying its action.

Beyond participation in the department, self-support dynamics are encouraged. Thus, expression workshops are organized by the department in a citizen’s café, on themes such as “What are your projects? “How to fight against isolation? “.

Concerning local elected representatives: direct communications are regular. Elected representatives in the area have the phone number of the doctor on call, they sometimes call the department when faced with a difficulty or in connection with current events, they are involved in the local mental health council where dialogue is regular. At the beginning of their mandate (every 6 years), they visit the department.

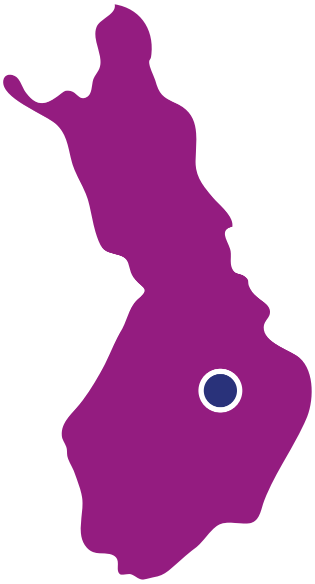
Recommendations

- Apprehend participation in the broadest sense: integrate professionals with experiential knowledge; include users and carers but also community experts in the operation of the service.
- Devote resources to participation: financial, material, human.
- Believe in the feasibility and mutual benefits of participation, be positive!

> *"We must not be afraid to be directly observed by the users: the resulting gains in the improvement of the quality of our organization are very important. Finally, the most difficult thing is to decide to do it..."*
>
> Laurent Defromont, psychiatrist, head of department
> EPSM Lille métropole

Description of the experiences

Promotion of dialogue, communication and mutual understanding with the service users' participation in a forensic psychiatric hospital



Niuvanniemi Hospital, Kuopio, Finland
Statut: Public (the larger of the two state hospitals)

Population covered

6 500 000 inhabitants

Number of people who have had at least one contact with the service during the year

288-296 patients
including 13 adolescents
100 000 patient-days/year

Orientation / key data

Niuvanniemi Hospital is a state forensic psychiatric hospital with The Department of Forensic Psychiatry in the University of Eastern Finland, Kuopio. It is also a training hospital for medical students and health care students. The hospital and its 500 professionals provides forensic psychiatric in-patient care and examinations (2% of patient days in 2020) for the whole country. The majority of patients have committed violent crimes and found non-guilty for reason of insanity (55% of patient days), and the rest have been considered too dangerous and/or difficult for prison hospitals or local psychiatric care (44%). Practically all service users (96%) suffer from schizophrenia-spectrum disorders, usually with co-morbid with substance use disorders and personality disorders. About 80% of patients are males. The mean treatment times are 7,5 years (criminal patients) and 5,5 years (other patients).

Description of the participation in the service

The active participation of the patients in the development of the services begun during 2008-2009 randomized controlled study of coercion reduction. An academic multi-professional task force was educated in the Pennsylvania and South Florida State hospitals, by the professionals who had developed the most successful published restraint/seclusion reduction projects. The method is called The Six Core Strategies (6CS) for Reduction of seclusion and restraint (S/R). These strategies define the most important factors to improve according to local needs, for effective reduction of both crises and coercion. This development of the culture of care is based on mutual communication and understanding of the individual needs of each service user.

Description of the experiences

The cultural anthropological observation revealed that e.g. the nurses, doctors and patients had their own closed subcultures and restrictions of communication with other groups. Since fear and distrust made the recommended discussions of all members of the unit around the same table impossible, the academic team met each group separately, participated weekly ward meetings to increase communication, and initiated both "patient expert meetings" and staff training in the two study wards (allotted of the four units with highest S/R rates). They also informed leaders of the hospital who discussed and tailored the tools in the monthly coercion reduction steering groups. All these groups discussed e.g. violence, coercion and problematic practices, and provided the task force with important information to communicate openly. Employees had considered physical restraint and seclusion as care, and trained it monthly in "Safe treatment-training". The information of the traumas, risks and harms of restraint/seclusion to everyone was a shock to many persons.

The co-work of patients and staff was initiated with a book project in the study wards. The patients wrote texts with the help of occupational therapists, and photographed their experiences of S/R with staff. The book "Behind Locked Doors" was published by the hospital. The task force participated ward meetings and organized weekly coffee breaks with cake catering for all who could sat around the same table. The obtained information of service users' and nurses' perspectives and needs were precious in the development of the effective supported intervention of the study wards, and also for the hospital-wide coercion reduction project. The cluster-randomized study demonstrated that 6CS is an effective way to reduce coercion without increase of violence.

THE SIX CORE STRATEGIES:

1. Leadership of change (support and supervision)
2. Active involvement of patients and families
3. Development of staff
4. Use of data to guide the practices
5. Post-event analyses/debriefing
6. Coercion reduction tools (e.g. individual crisis plans)

The hospital-wide coercion reduction was initiated in 2011 with the 2-day seminar of the developers of the method (KA Huckshorn and J. LeBell), including the presentations of the current in-patients. Since 2011 the entire hospital has used the 6CS in the common services/rehabilitation, in each ward, and with each patient. The senior doctors and ward sisters of each unit are responsible of the constant development of the strategies in the units. The leader of the hospital also monitors the reports of harms and violence, and the statistics of seclusion/restraint. Patient participation and co-work with staff are an important part of the constant, evidence-based improvement of the practices, safety, and patient-oriented culture of care. Patients work in all multi-professional task forces and steering groups of the hospital. They have an essential role in the improvement of the services.

The current patients work in the training of staff, peer supporters and e.g. as group leaders in occupational therapies. Ex-patients, including many prized authors and artists who have survived psychoses, coercion, or other hardships of life, talk of their experiences and surviving strategies in the theme days, thus providing shared experiences for all members of the hospital.

The co-work of staff and patients, for example in recreative therapies, e.g. music and theatre groups, creative building projects or care of the animals in the hospital area, improves the communication and mutual understanding. The variety of therapeutic, recreational, occupational and vocational activities are constantly developed in the numerous steering groups with service user members. Communication is the basis of e.g. development of an effective crisis plan to prevent violence and substance abuse

Description of the experiences

Staff skills and professions have been developed to meet the new therapeutic needs. The proportion of academic and female staff has increased. E.g. the old state positions of mental wardershave been replaced with occupational therapists, psychologists and registered nurses. Today, each of the 14 wards have both an occupational therapist and a psychologist. The ratio of registered vs. unregistered nurses has increased to 189/140, and all staff are educated professionals. E.g. cognitive therapies, music therapies and trauma- and recovery-oriented therapies have increased. This has not improved the economy. The frequent injuries and long sick leaves associated with traditional physical training are no longer a problem after the training of prone restraint was replaced with a new proactive training since 2011. The local proactive AKO training was developed for prevention of crises with 6CS, and for coping with aggression without restraint.

ETHICS AND LEGISLATION

The respect for human rights, laws and human values is the cornerstone of the operations. The freedom of communication includes all media, e.g. smartphones and own computers, if no legal reasons for individual restrictions arise. The hospital also respects the patient's privacy and individual needs. The patient plans his/her treatment with professionals. He/she can ask e.g. a relative to participate in these meetings. The hospital has a booklet of the variety of therapeutic activities available in the hospital. Each person is viewed holistically, as a biopsychosocial entity.

INTERACTIONS WITH THE TERRITORY

In the end of the treatment time some patients visit the clubs for persons with mental health problems, and/or train independent living in the local rehabilitation homes.

INTERACTIONS WITH PEER-SUPPORT ORGANIZATIONS

Training for peer-supporters is organized by experienced experts of the Central Organization of the Mental Health organizations in Finland. Some service users participate the local peer-support group meetings. E.g. Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and Gamblers Anonymous provide valuable help for fighting the lifelong addictions.

SERVICE USER PARTICIPATION IN THE PLANNING OF CARE

Service users participate in the planning of their own care, including the strategies for coping with crises. They can ask the family members to join their multi-professional care planning meetings. According to the law the decisions of e.g. medication are made in co-work with the service user, even during involuntary care, with the exception of a severe danger without it.

CRISIS PLAN

A crisis plan of a service user is based on the mutual knowledge of the individual triggers to avoid in treatment, the calming strategies to train for coping with difficult emotions, and the service user's preferences of the measures to use. A crisis is considered a possibility to improve the strategies, rather than a failure of the patient. "How could we help you better next time to avoid this?"

Description of the experiences

PEER SUPPORTERS

Voluntary patients who visit co-patients who want such support. The supporters have been evaluated to be able to cope with the task. They participate in training and counselling. These more recovered in-patients provide precious help and discussions for all persons who want it, e.g. new, lonely or troubled patients who have difficulties in trusting the staff. Financial compensation is provided for in this case.

SURVIVERS

Ex-patients and famous persons and authors from outside of the hospital provide lectures for all patients and staff of their experiences, coping strategies etc. Financial compensation is provided for in this case.

PATIENT COUNCIL OF THE HOSPITAL

The patient council of the hospital has representatives of most wards, and works without staff, with the help of the councellor. It helps the leaders of the hospital by suggesting new practices and activities, and by giving the patient opinion of issues important to patients, e.g. participated in the choose of the producer for the cloths and textiles. The chair and another member of the patient council are now also members of the extended steering group of the hospital. Financial compensation is provided for in this case.

TOITYKE GROUP

Two patients work as members of the multi-professional task force for planning occupational and vocational therapies and activities. E.g. possibility to earn more by learning new skills in the voluntary work therapy in the garden and janitoring group. This groups serves about 100 patients and has own gym times, excursions and cinema days for the participants. Hundreds of salmon have been annually planted in a pond, to both provide excitement and joy of fishing, cooking and eating, and to replace antisocial excitement-seeking. Financial compensation is provided for in this case.

A THEME DAY STEERING GROUP

The multi - professional theme day steering group has patient members. It organizes program for days of shared experiences for both staff and patients, of e.g. literature, poetry and recovery. E.g. Relatives' day, Women's day, Christmas, Independence Day, and the Literature day twice a year by voluntary famous authors, artists, former patients and other survivors. Financial compensation is provided for in this case.

PROFESSIONAL EXPERTS BY EXPERIENCE

The hospital trains voluntary experts of experience with the help of the Central Organization of Mental Health Organizations*. Additionally, they visit the ward meetings to inform and discuss peer support work with all members of the unit. The experts of ethnic minorities have been very helpful with persons of their ethnicity or language.

**There is also a national training program for experts of experience in Finland.*

Description of the experiences

PATIENT COUNCIL

Each ward can nominate a member to the patient council chaired by a patient. It helps the steering group and leaders of the hospital by informing of problems in the wards and therapeutic, material and other needs of the patients.

NEWSPAPER

The patients produce (write, edit and illustrate) their own newspaper with an occupational therapist, including e.g. articles, news, interviews of new professionals, pictures and photographs.

Successes

- Patient-oriented care is a main value of the hospital.
- Patients participate in most steering groups and planning of activities.
- Service users can reveal and improve unfair or humiliating practices.
- Huge reduction in seclusion/restraint.
- Huge reduction of person-related staff injuries and sick time.
- The barriers between nurses, doctors and patients have diminished.
- Co-work and communication have increased.
- Many common interests and shared activities: role-models and increased self-respect.
- Possibility to learn new skills, earn money and have active role in work therapies.
- Patient-participation brings on meaningful activities to replace antisocial excitement seeking.
- The randomized controlled study demonstrated that it is possible to reduce coercion in care without increase of violence.

Difficulties, points for improvement

- Psychiatric care systems are prone for mutual fear, distrust and poor communication. The traditional culture of care is distressing and dangerous for all, but difficult to change.
- Effective improvement of the culture of care requires constant support, supervision patient participation and multi-professional development of many key elements of coercion reduction together.

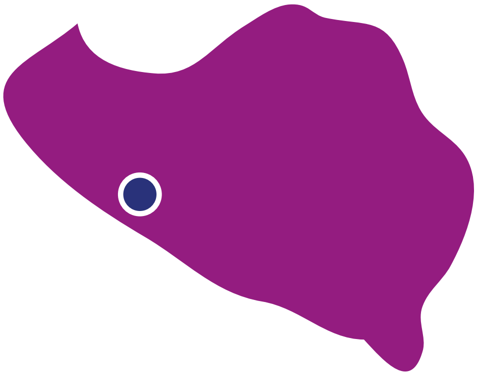
Recommendations

"Systematic increase of patient participation and communication with 6CS may improve the safety and well-being of both service users and employees."

Anu Putkonen, MD, PhD, psychiatrist, forensic psychiatrist
Niuvanniemi Hospital

Description of the experiences

Outsourced participation in the city, but also in the Secure Psychiatric Hospital



Centre Régional Psychiatrique (CRP) Les Marronniers, Tournai, Belgium
Statut: Public - financed by the State, the federal level and the regional level

Population covered

3 600 000 inhabitants

The whole of Wallonia (3.6 million inhabitants) for the Specialised Hospital Centre (CHS) and the Secure Psychiatric Hospital (HPS). Users of the outpatient sector mainly come from the Tournaisis care basin (70.000 inhabitants) but may come from the whole of Wallonia-Picardy (330.000 inhabitants).

Orientation

Created in 1881, this hospital offers a diversified range of services (prevention, outpatient care, rehabilitation, planned or crisis hospital care, accommodation) and welcomes anyone with a mental health problem. Its actions are based on strong values: respect, quality, humanism, trust, openness, recognition.

Some key data

The hospital comprises three main units:
- A Specialised Hospital Centre (CHS);
- A Secure Psychiatric Hospital (HPS);
- An outpatient sector, including the Psychiatric Care Centre (MSP);
- It has a capacity of 735 places: 234 beds in the CHS, 381 beds in the HPS, 120 beds in the MSP. This represents more than 230,000 days of hospitalisation per year, and nearly 1,900 admissions per year. More than 1,000 people are employed there. Some twenty out-of-hospital services are offered (mobile teams for children and adolescents or for adults, activity centres, etc.).

Interactions with the territory

In addition to the local, provincial, community or cross-border care offer, the CRP also has a medico-legal mission to protect the patient and society, as well as an educational and research mission.

Description of the participation in the service

The CRP Les Marronniers advocates the participation of users, whether it is for their care, the organisation of services and the more global organisation of care.

Description of the experiences

THE HPS USERS' COMMITTEE

People admitted to the HPS are admitted on the basis of a court decision following crimes and offences. However, participation exists in this unit, as a users' committee was created two years ago. This committee is composed of 16 members: 1 member from a patient family association, 10 members elected by users currently receiving care in the hospital, 2 members from the heads of department of the HPS, 1 member from the CRP Les Marronniers who is not attached to the HPS and who acts as moderator of the committee, the logistics manager and the quality coordinator. A charter governs its operating principles. The committee meets four to five times a year, where it discusses collective problems of daily life to which the professionals try to respond. For example, following these meetings, users can now use their personal mobile phones, replacing the collective phone box. This committee is also a forum for dialogue. For example, still on the subject of mobile phones, it was explained to the management of the establishment that the few abuses that had occurred (unwanted calls to the social service, etc.) were only made by a few people and did not justify calling into question the possibility of all users having a telephone.

Once a year, this users' committee meets with the management and makes recommendations, as was the case recently for a major building project, in conjunction with the architects.

In addition, six-monthly working groups bring together kitchen professionals and users from the MSP and the HPS to improve hotel quality, which is all the more important at the HPS where the average length of stay is 8 years, given the nature of this hospital.

"LE B'EAU B'ART": A THERAPEUTIC BISTRO

"Le B'Eau B'Art" is a therapeutic bistro located in the town centre. It is co-managed by the people who use it and health professionals, some of whom are CRP staff. A two persons team user-professional is present every day. Anyone is welcome. You can go there whenever you want, as often as you want, in complete autonomy. 1,200 people use this place every year. Alcohol is not served, in accordance with the place's operating charter, but the drinks menu is varied and it is possible to have lunch. Newspapers and board games are freely available. Outside activities are organised, either by a volunteer co-manager or by a professional co-manager. People sign up for them according to their interest. Professionals do not systematically participate in these activities.

B'Eau B'Art can support people between hospitalisations, before or after hospitalisation, or simply people who wish to (re) create social links, to be less lonely. Spontaneous mutual aid develops there. Similarly, early detection of the first signs of a deteriorating situation is facilitated, particularly by the users themselves. As the professionals are in fact present during working hours and the opening hours of the structure, the links created between the people enable vigilance and mutual support to be extended outside these hours. The ramifications of these links showed their importance during the COVID19 pandemic, when the bistro was mostly closed.

PARTICIPATION LUNCHES

Once a quarter, a department of the institution may present to the others the initiatives it has put in place involving the participation of users. An example of an initiative shared on this occasion: a service organises breakfasts for and with teenagers which encourage informal exchange.

TRAINING

The CRP Les Marronniers has developed a training programme with the University of Mons, which will be delivered to the establishment's professionals by pairs of professionals/experienced experts, based on the results of an analysis of the professionals' needs. At the time of writing this document, it has not yet been possible to start this training.

Concerning the training of users to the participation in institutions, the association Psytoyens offers one (on a national scale), on themes such as speaking out or the functioning of the care system. Users can access it free of charge.

At the time of writing this document, only trainee peer helpers have been integrated into the care teams. A project is underway to welcome professional peer helpers.

Description of the experiences

THE RESIDENTS’ COUNCIL AT THE MSP

The Maison de Soins Psychiatriques (MSP) offers residential care to people who have previously had a long hospital stay. The average length of stay is one year. A residents’ council has been set up. It formulates opinions and suggestions and makes observations on all matters concerning the quality of care in the MSP.

Successes

- Participation is real at the Secure Psychiatric Hospital, despite the constraints linked to the security context of this establishment. It brings real progress in terms of users’ rights.
- The B’Eau B’Art is an excellent tool for fighting isolation and promoting social inclusion. The “knowing“ postures between users and professionals can be reversed in the context of this therapeutic bistro, where the undifferentiated welcome facilitates destigmatisation.

Difficulties, points for improvement

- At the Centre Hospitalier Spécialisé (CHS), where hospitalisations are shorter, there is no users’ committee, despite several attempts. Generally, the people hospitalised were not well enough to participate, and when they get better, the hospitalisation ends. People then don’t want to come back to the hospital to participate.
- Real political support at national level is sometimes lacking for participation: for example, public support for mutual aid groups in France has no equivalent in Belgium. Local initiatives, such as the B’Eau B’Art, exist, but they are disparate and sometimes place institutions in a position of omnipotence given the financial support they provide.

Recommendations

- The border between caregivers and cared for is impacted by participation. The latter leads to resistance that is not useless. If a professional does not identify with a mental health problem, it is also to preserve himself. The link to madness can be exhausting. Touching that boundary creates anxiety. We must not deny this either: we must even give it a place.
- Rivalry between peers also exists: some people are desperate to be recognized and participation gives them a way of existing, sometimes to the detriment of the space that should be left for others to exist in this way. Some users take up a lot of space and impose themselves to the detriment of others, sometimes with violence. We need to be aware of this and imagine organizations that balance participation among users.

> *"Participation helps all service users. It gives them hope for recovery and offers them a perspective of active social inclusion. It is also useful for professionals who, in some services, only see people who are not doing well: for them too, the prospect of recovery is life-saving. Finally, it is useful for families, who can imagine a way forward in a very complicated life."*
>
> France Dujardin - Coordinator of the therapeutic club
> Centre Régional Psychiatrique Les Marronniers

Conclusion, perspectives

The result of this work, carried out by the WHO Collaborating Centre for Research and Mental Health in Lille at the request of the WHO, is a description of some European initiatives led by organisations that have decided to make the participation of users and carers an essential component of their organisation. These examples and presentations of the experiences of those working in the field may inspire the readers of this document and give them ideas for action based on experiences already implemented elsewhere.

However, this snapshot of situations is not intended to be representative of participation in Europe, nor of participation in the countries where these experiences are taking place, nor even sometimes of the participation of the entire structure to which a particular service belongs.

Moreover, even though these are European countries, the context in which these initiatives have been set up is quite different from one country to another, from the point of view of territorial organisation, the status of the actors and the competences devolved to them by law, the history and local culture, or the presence or absence of political incentives. The latter, when it exists, can be translated into a national strategy, legal obligations, contents of school and university education or professional training, or funding dedicated to participation.

Finally, there is an overall lack of indicators and assessment of the effectiveness of these participation processes and the improvement in the quality of care that is supposed to result from them.

To complete this first approach, future work could focus on the definition of the different forms and levels of participation in mental health services and their implementation in Europe, and on the evaluation of the contributions of these different participations, both from the point of view of the persons concerned and from the point of view of the care providers.

Finally, a future project could aim at defining up to date recommendations for policy makers in order to provide the components of a legal framework that promotes and stimulates participation. This implies the prior completion of a monograph on the existing legal frameworks and policy contexts around participation in mental health in European countries (territorial organisation, status of actors and competences devolved to them by law, local history and culture, presence or absence of political incentives involving a national strategy, legal obligations, contents of school and university education or vocational training, or dedicated funding for participation).

Appendix

1 INTERVIEW GUIDE

This guide have been worked with users representatives, professional of the East of Lille Mental Health service (included a peer support worker) and professionals from the WHOCC Lille team. It was used as a tool to help prepare and conduct interviews.

The presence of users/carers in a mental health care service makes it possible to mobilise experiential mental health knowledge at different levels. We try to find out how you have mobilised it.

Key elements of the service:

- Status (private/public):
- Population covered:
- People who have had at least one contact with the service during the year (e.g.: 3 passages of 1 people= 1 contact)
- Key figures:
- Main feature / orientations:

WHO?

1. Are experienced experts in mental health, users, carers of users or recovered users of mental health services involved in the operation of your service?

☐ Yes (☐ Users / ☐ carers / ☐ recovered users)
☐ No (go to elected representative involvement questions)

2. If yes, since when?

3. Who are these experienced experts involved in the service?

☐ People currently in care in the service (or whose loved one is in care)
☐ External persons who have recovered and have received care in the past (or whose loved one...)
☐ People who are members of an organisation outside the service (user/helper association-NGOs, etc.)
☐ People from groups run as part of the service (self-help groups, discussion groups, etc.).
☐ Individuals solicited (experts, etc.)
☐ Professionals/Service Employees (Peer support professionals)
☐ Others

4. Can you give details of the recruitment process (posters in the service, personalised letters, individual information orally or during meetings, information during public meetings, support from local networks, etc.)?

Appendix

WHICH ACTIONS

5. **Are experienced experts invited to build projects with the service?**
☐ Yes
☐ No
☐ If so, which ones?

6. **Are the experienced experts involved in the care and/or support of the people followed by the service? (access to housing, leisure activities, dialogue spaces, therapeutic education of the patient, etc.)**
☐ Yes - Can you give some examples?
☐ No

7. **Are experienced experts involved in the treatment of "adverse events", and/or the analysis of satisfaction questionnaires?**

8. **Do experienced experts offer training courses for professionals (presentation of associations, interventions related to a pathology, living environment, social assistance, users' rights, stigmatisation, etc.)?**
☐ Yes If yes, which ones?
☐ No

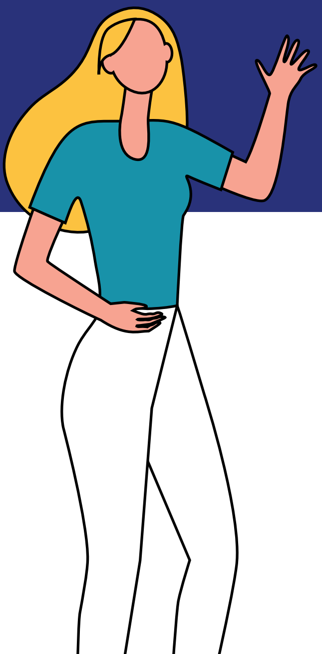
9. **Can you give other concrete examples of how the expression of experienced experts is effectively taken into account in the functioning of the service(s)?**

10. **Have you encountered any difficulties in setting up such an approach? If so, what difficulties? What solutions have been proposed?**

11. **What are the main benefits/added value, in your opinion, of such an approach? (to be specified, according to the public, users, carers, professionals, others)**

12. **Can you give advice, based on your experience, to services that wish to take the approach?**

13. **Would you like to add a comment (on the current situation, your plans...)?**



Appendix

HOW?

14. Does this participation exist

- ☐ service-wide
- ☐ on a part of the service, of a unit?
- ☐ on the scale of the whole hospital, association…?

15. Have you defined the framework of intervention with the experienced experts?

- ☐ The values and ethical principles underlying the intervention (mutual recognition, sharing of knowledge and power, respect of the rights…)
- ☐ The objectives of the intervention (to improve the quality of care, respect for rights, other...)

16. Do experienced experts speak in the name of experienced experts in the service?

- ☐ Yes
- ☐ No

Can you elaborate on this point, explaining (for example, whether elections of representatives are held within the service or outside).

WITH WHAT MEANS?

17. Do the experienced experts have an identified and nearby place for mediation and information (such as a Users' Centre)?

- ☐ In the service?
- ☐ In the city?
- ☐ Specify

18. What are the means of expression and dialogue between experienced experts and professionals in the service?

- ☐ Participation in service meetings (e.g. steering committee)
- ☐ Participation in meetings facilitated by the service (e.g. self-help group)
- ☐ Mails, letters, posting,
- ☐ Suggestion box
- ☐ Transmissions
- ☐ Other (specify)

19. Do users/carers have access to all areas of the service and therefore to all users?

- ☐ Yes
- ☐ No

If not, can you explain?

Appendix

20. Are users/carers compensated for participating in the operation of the service?
- ☐ Yes
- ☐ No

If yes:

Reimbursement of expenses:
- ☐ Yes
- ☐ No

Remuneration of intervention time:
- ☐ Yes - If yes, how much?
- ☐ No

21. Is training for experienced experts offered to facilitate their involvement in the operation of the service (organisation of the hospital, the health system, public speaking, users' rights, etc.)?
- ☐ Yes, If yes, please give details
- ☐ No

22. Have you undertaken any other actions to integrate experienced experts in order to facilitate their involvement in the operation of the service?

23. Is there any communication on the existence and/or results of this participation?
- ☐ Yes, If so, in what form?
- ☐ No

24. Is an evaluation of the participation of experienced experts in the service carried out?
- ☐ Yes, If so, how? (can you send us the results?)
- ☐ No

INVOLVEMENT OF ELECTED REPRESENTATIVES

1. Are local elected representatives involved in the organisation of your service?
2. If so, why? If not, why?
3. How do you work with them? (give some examples)
4. What do you gain from working with elected officials in the organisation of mental health in the community?
5. Are there any obstacles to this collaboration? If so, what are they?
6. In your opinion and based on your experience, what are the success factors for involving elected representatives?
7. Do you have any ideas on how to make this collaboration even more effective?

Appendix

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- Irene Kerr, Peer support worker
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- Nuria Martinez, General Manager, Drissa Foundation
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- Anu Putkonen, MD, PhD, psychiatrist, forensic psychiatrist, Niuvanniemi Hospital
- France Dujardin, Therapeutic club coordinator, CRP les Marronniers (Tournai); Coordinator of peer support training, University of Mons

Appendix

3 REFERENCES

- Amering, Michaela, Mikus, Monika, Steffen, Sigrid, 2012/02/01, International Review of Psychiatry.Recovery in Austria: Mental health trialogue.
- Arnstein, S. R. (1969). A ladder of citizen participation. Journal of the American Institute of planners, 35(4), 216-224.
- Bee, P., Brooks, H., Fraser, C., & Lovell, K. (2015). Professional perspectives on service user and carer involvement in mental health care planning: A qualitative study. International journal of nursing studies, 52(12), 1834-1845.
- Beetlestone E. " La participation des usagers : qu'est-ce que ça change pour le psychiatre ? ", Pratiques en santé mentale, 2016, n°2, p. 19 à 22
- Beetlestone E., Demassiet V., Olivier F., Defromont L., Daumerie N., Chabane R.; " Une expérience de partenariat entre élus, professionnels, et usagers pour favoriser le rétablissement en santé mentale " - " L'information psychiatrique " - 2015/7 Volume 91 | pages 578 à 585
- Boisseau A., Defromont L., Guilloy B., Labey M., Noel C., Olivier F., Provost E., Vasseur-Bacle S. "Des usagers acteurs de la démocratie sanitaire", Santé Mentale, Novembre 2016, n°212, p.46 à 52
- Chris J. Gibbons, Penny E. Bee, Lauren Walker, Owen Price and Karina Lovell; Service user- and carer-reported measures of involvement in mental health care planning: methodological quality and acceptability to users. Front. Psychiatry, 11 December 2014
- Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. Bmj, 325(7375), 1263
- Crepaz-Keay, D. (2014). Effective mental health service user involvement: establishing a consensus on indicators of effective involvement in mental health services (Doctoral dissertation, Middlesex University).
- Encouraging user involvement in mental health services; Published online by Cambridge University Press: 02 January 2018.
- Ham, A. J., Erp, N., & Broerse, J. E. (2015). Monitoring and evaluation of patient involvement in clinical practice guideline development: lessons from the Multidisciplinary Guideline for Employment and Severe Mental Illness, the Netherlands. Health Expectations.
- Health and Social Care Act 2012; NHS England Transforming Participation in Health and Care (2013); NICE Guidance Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (Dec 2011); Government White Paper Equity and Excellence: Liberating the NHS (July 2010); The National Co-production Advisory Group – Think Local, Act Personal Ladder of Co-production NSUN (National Service User Survivor Network) – 4PI National Involvement Standards
- Hunt, E., & Byrne, M. November 2019. Peer Support Workers in Mental Health Services: A Report on the Impact of Peer Support Workers in Mental Health Services.
- Kent, H., & Read, J. (1998). Measuring consumer participation in mental health services: Are attitudes related to professional orientation?. International Journal of Social Psychiatry, 44(4), 295-310.
- Labey M; Defromont L; Noël C ; Boisseau A ; Intégrer les savoirs expérientiels aux soins, Revue Santé mentale septembre 2017
- Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. International Journal for Quality in Health Care, 24(1), 28-38.
- Munro, K., Killoran Ross, M., & Reid, M. (2006). User involvement in mental health: time to face up to the challenges of meaningful involvement? International Journal of Mental Health Promotion, 8(2), 37-44.
- Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: impact and participation: a survey of service user and staff perspectives. BMC health services research, 14(1), 491.
- Putkonen A, Kuivalainen S, Louheranta O, Kautiainen H, Repo-Tiihonen E, Tiihonen J.
- A Cluster-randomized Controlled study of the Six Core Strategies. Psych Services 2013.
- Rhizome n°58, novembre 2015 – "La participation des usagers en santé mentale"
- Service User, Family Member and Carer Engagement in Mental Health Services: A Review of the Literature. Centre for Effective Services (CES) and commissioned by the Mental Health Engagement Office, HSE. May 2018.
- Simpson, E. L., & House, A. O. (2003). User and carer involvement in mental health services: from rhetoric to science. The British Journal of Psychiatry, 183(2), 89-91.
- Wallcraft, J. A. N., Amering, M., Freidin, J., Davar, B., Froggatt, D., Jafri, H., & Steffen, S. (2011). Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World Psychiatry, 10(3), 229-236.
- World Health Organization. (2010). User empowerment in mental health: a statement by the WHO Regional Office for Europe – Empowerment is not a destination, but a journey. Copenhagen: Regional Office for Europe of the World Health Organization.

*World Health Organization Collaborating Centre for Research
and Training in Mental Health*
211 rue Roger Salengro
59260 Hellemmes
FRANCE
Tél. : + 33 (0) 320 437 100
E-mail : ccoms@epsm-lm.fr

www.recherche-sante-mentale.fr

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