


Proceeding Paper

# Recovery, Citizenship, and Personhood of People with Lived Experience of Mental Health Problems during the Pandemic: Two Expert Focus Groups <sup>†</sup>

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**Abstract:** The pandemic has dealt a severe blow to everyone, but especially to people with previous vulnerabilities, such as people with lived experience of mental health problems. Studies on the increased incidence of all types of mental disorders have been published incessantly since the beginning of the pandemic. However, not much has been said about the impact of the pandemic in terms of their rights, already hampered by stigma and social discrimination before the pandemic. The full inclusion of people with lived experience of mental health problems as full citizens is a limitation in all societies, and it implies a burden in their recovery journeys. In these pandemic times, we think the rights of persons with lived experience of mental health problems deserves special attention. We carried out two focus groups with 17 key participants with different mental health expertise from three Spanish-speaking countries (Chile, Colombia, and Spain) to consider possible violations of rights that have occurred in the pandemic context but also experiences of individual and collective resilience that have helped maintain well-being among this group of people.

**Keywords:** citizenship; COVID-19; discrimination; mental health; pandemic; recovery; stigma



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## 1. Introduction

The current COVID-19 pandemic has become a global health crisis that has put many of the social, economic, and political world foundations on the ropes [1–3]. In this context, people with previous experience of mental health problems are becoming one of the most severely affected groups. There is empirical evidence of an increase in anxious, depressive, obsessive, psychotic, and stress symptoms [4–6], in addition to increased alcohol consumption [7] and suicide rates among men [8] and violence against women [9]. All of these phenomena are even more intense in people diagnosed with severe mental disorders [10–12]. In general, vulnerable populations, those who barely survive in our increasingly competitive societies, have been affected by a total change in the societal game rules during the last months [13].

People diagnosed with severe mental disorders are subjected not only to stigmatization outside and within the mental health care system [14], but also to constant violations of their human rights [15]. Some examples are involuntary inpatient and outpatient treatments, forced medication, overmedication, electroconvulsive therapy under duress, mechanical restraints, seclusion, isolation, and arbitrary legal incapacitations and guardianships. The underlying beliefs that enable this degrading treatment appear to be formed, among

other factors, by a lack of awareness of mental health professionals' prejudices [16]. This causes many people affected by psychosocial hardships to be forced to hide their suffering, preventing early detection and adequate therapeutic interventions [17]. We could say that, in general, people with psychosocial impairments are not considered full citizens.

Accordingly, the citizenship framework is an emerging trend in the field of mental health and social inclusion. Citizenship has been for centuries a complex social concept concerning the degree to which a person is a part of and can influence society [18,19]. Lately, it has also become the leitmotiv of a professional and academic movement that, in a similar way to the recovery movement, which has had wide impact on the transformation of services and systems addressed to people with mental health problems [20], it tries to improve the living conditions of people with psychosocial impairments by fully exercising their rights [21]. Although both movements share values and objectives, citizenship explicitly emphasizes social-contextual dimensions such as the importance of social justice and advocacy [22,23]. This might have been eclipsed within the Recovery movement by having become mainstream, as well as by mixing elements of personal and clinical recovery [24,25]. From a 'therapeutic objectives' perspective, in the same way that the Recovery movement proposed to change the focus from the reduction of symptoms to the autonomous construction of a life project in community even with the possible limitations caused by illness [26], the citizenship movement would add a 'rights' component. That is to say, in order to be able to build a life project in a truly autonomous way, one has to be aware and be able to make use of the 5 Rs proposed by Rowe and colleagues: rights, responsibilities, roles, resources, and relationships [18,21,27,28]. As can be inferred, these capital dimensions of our personhood have been affected during the pandemic throughout the population, but probably in a more incisive way among already vulnerable collectives as people diagnosed with mental disorders.

This work intends to explore the impact of the COVID-19 pandemic from the perspective of the citizenship of the people diagnosed with mental health problems. This will be performed by means of the analysis of two focus groups carried out with mental health experts.

## 2. Materials and Methods

We carried out two focus groups with 17 (12 and 5 respectively) key participants from three Spanish-speaking countries: Chile, Colombia, and Spain. The focus groups were carried out in the context of the preparation of the International Recovery and Citizenship Collective (IRCC) 2020 Colloquium entitled 'Recovering Citizenship IV: Recovery, Citizenship, and Personhood in Public Spaces: Their Link to Mental Health'. These two groups, and others carried out in other languages around the world, aimed at deepening how the key concepts of recovery, personhood and citizenship are understood within the context and challenges that COVID-19 presents to us all as well as the specific difficulties lived by people with the experience of mental health problems. Thanks to the analysis carried out, we brought to the colloquium reports on how the pandemic was affecting the connection of people to their sense of citizenship and personhood.

Participants included mental health professionals including peer support workers, policy makers, health managers, anti-stigma campaigns technicians, and mental health activists. The groups were led by the first author of the current paper in collaboration with another IRCC Spanish-speaking member. Each group was audio-recorded, transcribed verbatim, synthesized, and analyzed using thematic analysis [29].

There were four conversation blocks based on the following questions:

1. In mental health, the concept of recovery can mean different journeys for different people aimed at reclaiming or developing a new sense of self and living up to one's own aspirations. How is recovery in mental health experienced in your region?
2. Citizenship is bestowed to people by the nation state, by birth, or by naturalization. It is both a legal status and a social practice. Citizenship affords the citizen with a bundle

- of rights and responsibilities, inclusion, and a sense of belonging to their co-citizens and the country. How is citizenship experienced in your country or region?
3. Personhood can be described as an identity, and recognition of that identity by others, thereby affording us the same respect as others expect and to be a full and active participant in society. It can involve seeing beyond a particular label or category to see a person with strengths or attributes. How is personhood understood in your region?
  4. How has COVID-19 impacted people's experiences of recovery, citizenship, and personhood in your country or region? What action or actions are needed to promote access? Are there any barriers that need to be overcome?

### 3. Results

Four thematic blocks were identified: Recovery, Citizenship, Digital Wave, and WellBeing.

#### 3.1. Recovery

This thematic block collects all those reflections on the recovery process and the different key elements in it, regardless of whether they were done in the part where the concept of recovery was discussed. Below are the different themes that make it up.

##### 3.1.1. Personal Recovery

This includes reflections where it is evident that the person in recovery decides what they want, what does them well, and what path they want to follow.

"The truth is that for me the term recovery has always been closely associated with a life plan term. That is, to me when a service user, or a patient, is recovered, I have always identified him or her as someone who has a life plan and is integrated into that life plan."

##### 3.1.2. Community Recovery

This theme captures the idea of a community-centered recovery, in which the persons are connected and are part of an environment who counts on them as a member within it.

"When you talk about recovery, you talk about people who are integrated into the social group with whom they live."

"Another second part of interaction with my community. I work, I integrate, I am part and I feel that I am part, and my environment too."

##### 3.1.3. Functional Recovery

It refers to a recovery focused on the person's abilities, which allow them to be able to carry out daily life activities without further support:

"Functional recovery that is, what skills can be maintained and what skills maybe not (...). And, on the other hand, this is a bit of the key element of functional recovery: being able to lead an autonomy, a personal ability to cope with everyday life."

##### 3.1.4. Overcoming Deficits and Going Back to Normal

It refers to reflections made from a clinical idea of recovery based on symptomatic relief and overcoming deficits:

"When you talk about recovery, you talk about recovery (especially for psychiatrists) as very medical: going back to work, going back to the life that was done before."

"A recovered person, even with their family, talking, because it is difficult for them to justify or it can be difficult for them to justify the fact of not working, right? As if this were the case... And the fact of not working not only makes you consider

yourself in front of yours and in front of the Society as an unrecovered person, but also that the fact of being considered a citizen may make you problematic.”

It also includes narratives about past and losses.

“The problem is that everything we mean by ‘recovering’ often makes you look back.”

“Recovery: literally take back or acquire what you had before.” But there are persons who have never had anything, because they were born semi-ill, has grown up, has never had a job, has never been socialized... What is the name of that person who has had nothing and they put it right? Recover? The re prefix already means that there was something previous, something you had to recover.”

### 3.1.5. Professional Malpractice

“From our violence and from our practices in preventing the empowerment of the people we take care of. In other words, recovery would have much more to do with reviewing our privileges and our violence. And I think that what we have many difficulties with, and for me the recovery model has been one of them, is to think critically and look within ourselves. And in the end it’s one thing, right? My feeling, for example, with terms like empowerment, in all these things, is that in recovery, in the end, we run the risk of focusing on the other person and forgetting a bit about what role we have. And if I expand it more, not only as professionals but as friends or as other roles that we have in the community and from which it is also very difficult for us to think about ourselves.”

“We are finding, when people who have suffered involuntary admission, for example, what they are finding is that they are citizens whose psychiatrist can proceed with the deprivation of their liberty with a very little legally motivated argument.”

### 3.1.6. Support Network

It refers to all those narrative fragments in which special importance and emphasis are given to the role played by support networks (family, friends, neighbors, etc.).

“The neighborhood, even the police, the emergency medical personnel, the environment, the extended family, were part.”

### 3.1.7. Personal Process

Aspects that can or should be given to the person as a result of the situation in which they find themselves, recovery, citizenship status, etc. Importance is given to the fact that the person feels satisfied with what they do and to fulfill their needs.

“Experience of satisfaction on the part of the person. If the affected person does not live satisfactorily that participation, they will not feel like a full citizen.”

### 3.1.8. Giving Up

It refers to the process of giving up on some aspects that the person must go through in order to be able to move on and recover.

“It will be necessary to give up the best, in some cases, certain things and that process of giving up is really complex.”

### 3.1.9. Resilience

It captures the ability of people to overcome problems, to adapt to the setbacks of life.

“Well yes, this is fatal, but people find ways to fight and get out of this story, even people who have been sicker and have had more problems are able to fight this story.”

### 3.2. Citizenship

This thematic block deals with all the narratives in which the participants reflect on the issue of citizenship in relation to people with mental health problems, regardless of whether they were given in the part where the concept of citizenship was discussed. Below are the themes that make up the elements covered in these citations, with their examples.

#### 3.2.1. Citizenship Status

This includes where the person is located in society and their position on the social scale. It includes reflections on excluded groups:

“The groups or people in situations more outside the circuits of citizenship, I speak about the immigrants, from the illegal immigrants or in irregular situation, I speak of the people who are in the street, of extreme poverty and exclusion, the homeless . . . ”

“From our side because many people with more or less persistent problems, chronic, serious, etc., in the area of mental health, as they have been excluded from citizenship.”

This also includes discussions about rights.

“Citizenship is a concept in which a person has rights and obligations against a rule of law.”

“For me, citizens inevitably go through an equality of obligations, rights and opportunities. And as a group it is very difficult to talk about citizenship if your reproductive rights are violated, if you do not have the right to vote as happens to many people with disabilities, people who have a diagnosis in mental health, 85% of people are unemployed . . . ”

In addition, of course, it includes discussions on exclusion from full citizenship.

“There are probably Services that have mechanisms by which those people who meet or do not meet minimum requirements to be, to enter the circuits of interaction, by language, by culture, be they economic or symbolic, are at risk of being more out of the circuit and more out of focus.”

“If I feel little citizen being . . . white and being a psychiatrist . . . Well I don’t want to think about how a person who has fallen can feel like a citizen . . . how a machinery of diagnosis, positioning, subordination gives them . . . And everything has happened to them that for the body, for the look, and for the place that is socially deposited there.”

“I think my approach to citizenship is that we all have a bit of an origin: first-class citizens and second-class citizens. And so it is based on economic status. I already put the disability in the Third Division.”

#### 3.2.2. Otherness

It refers to the process by which one constructs an identity through the identification of the other as someone completely different. In this way, an image of the other is constructed as someone radically different from us and that we can never become, and at the same time, therefore, we are constructed as we are.

“Denying the other I constitute myself, I build myself.”

“When I went to the first peer support environments, I would come in with mine and look at the rest and say, ‘Jo, you’re not as bad as they are, calm down, yours isn’t that bad.’”

#### 3.2.3. Change of Gaze

Aspects through which change can be humanized and facilitated in the way people diagnosed with mental disorders are seen and treated. It includes:

### Equity (Giving Everyone What They Need According to Their Conditions, Situations)

“Reverse care law: more care, more services, more options for those who need it most. Not necessarily for those who more or better ask for it, but for those who need it most and who are at serious risk of being left out of the inclusion circuits.”

### Humanization (Showing That We Are All Equal and That We Can All Have a Mental Disorder without This Changing Our Condition in Life)

“If tomorrow I have a very serious traffic accident and suddenly I develop a mental health problem, then how am I going to be treated as a citizen? In other words, none of us is outside of that, we are all exposed to that happening to us at some point in our lives and it seems important to take it into account.”

“Making people understand, empathizing that health is a process, is a continuum in which we all go through at some point and . . . Through any of these points.”

### Equality among All Persons, Whether or Not They Have a Mental Disorder

“Citizenship is that through which the person feels a member of a collective, of the community, of a group . . . , and participates with full right in all this, in equal conditions.”

“To me all that of the citizenry without regulating or without doing a job in pursuit of the equal rights of people who have mental health problems and those who do not have them because it is like a debate that . . . ”

### Empathy

“Perhaps the person, that category implies seeing the other as an equal, as a human being, as a pack, regardless of racial, socioeconomic differences... As of those other accessory elements I think that perhaps the differential element would be that I recognize the other, another integral human being who would have rights and possibilities for the development of autonomy that may be divergent from mine, but which are other possibilities.”

### Awareness [Considering How Our Value as a Person Does Not Change Due to Having a Mental Disorder (“Humanity”) and How Therefore There Should Be an Equality of Conditions (“Equality”), and Thus Vindicating When Not Is Given (“Awareness”)]

“Is a person with an intellectual disability less of a person?”

“It started like being able to talk about the fact that there were people who didn’t feel good about being incarcerated, that’s the paradox, right?”

### Needs

“Ask them things about whether emotional relationships are important to them, whether it was important for them to have their emotional needs covered, to have a partner, to have a job, and so on. These questions, which were asked anonymously, were the first time that a survey was conducted in Spain and, obviously, in the affected people who answered, they have the same emotional needs as any human being.”

### 3.2.4. Stigma

Discrimination that is carried out towards people with mental health problems as a result of prejudices and stereotypes.

“This stigma and this social discrimination that exists, or sometimes even this self-stigma that can be generated, does not help this concept of citizenship either.”

“( . . . ) all these prejudices, all these stereotypes, I believe that the society in which we are has them.”

### 3.3. Digital Wave

This thematic block includes the aspects that have occurred as a result of the forced digitalization that has accompanied the COVID-19 pandemic.

#### 3.3.1. Digital Future

This includes the idea that there will be a continuity to this use of technologies, as well as the good they have done during the pandemic.

“The digital change that I believe has come to stay. Now because we need it, but in the future it will be.”

“But also a little in the sense that I think that digital care is here to stay and really, for example, throughout the de-escalation we have carried out both face-to-face and online activities, because they have been maintained in terms of people’s preference.”

Discomfort development.

#### 3.3.2. Negative Consequences of the Use of Technologies

There is also the idea that the forced use of technologies has had negative consequences in some vulnerable persons.

“Apart from that we are also observing a lot of difficulty for people, who are developing more fears, more anguish, more loneliness, for all the messages we are receiving in relation to this pandemic.”

“There have been a lot of patients and people with mental illness who have a special fragility and who have really had a very bad time, and we have lost contact... There are things that cannot be done by phone or by videoconference and families have really struggled, because it is always the family who ends up taking care of this type of patient.”

#### 3.3.3. Digital Divide

This captures the difficulties that have arisen from this dependence on technologies to stay in touch, as well as the limitations it has.

“If before there were already difficulties to connect, to be linked to groups, to be in contact with other people, now it is more acute. And one of the difficulties that I am seeing more clearly is that the digital divide is wreaking havoc, because there are many people who have no connection with other people or with peer groups or in health spaces. And also to break the loneliness a little. This is the most serious and the most difficult thing that I am experiencing right now in Community Mental Health Recovery Work. With the people with whom we have the most difficulty, we go directly to the phone and call each other.”

### 3.4. Wellbeing

This last thematic block includes those contributions in which the participants reflected on necessary aspects to consider that a person is in a situation of comfort and that they can get to feel good and have a satisfying life.

#### 3.4.1. Empowerment

There are situations in which there is evidence that there has been a process of personal growth, where the person is in control.

“Recovery necessarily involves, for me, personal empowerment. If a person cannot be empowered, it is very difficult for them to start thinking, to take the reins of their life, what they consider to be good for them in their life, what not and to be able to start choosing their path.”

### 3.4.2. Self-Confidence

It refers to the fact that the person has confidence in their plans and their success, that they are confident and that they are competent in some or any area.

“When it comes to opting for a life plan, it seems good to me not only to have it, but to trust in being able to have it.”

### 3.4.3. Self-Determination and Autonomy

It refers to the person’s ability to decide any aspect of their life (treatment, life plan, etc.), as well as to be able to carry it out without any help, independently.

“It’s the person who directs the treatment.”

“How I want to be in my life, what I need to be able to recover from this psychic suffering.”

“A person who can live independently, who can access leisure, who can be adapted to their circumstances.”

### 3.4.4. Self-Esteem

This includes fragments in which self-valuation appears as an important determinant of wellbeing.

“People with mental health problems have felt like they have been considered themselves socially as experts. ( . . . ) and then it has generated a point to some people who have felt [...] interpellated in a positive way.”

“On the second occasion I worked on the aspects of self-esteem, self-stigma, stigma and others, and I think I set a turning point, a before and an after in the evolution of the problem.”

### 3.4.5. Active Participation

“It’s very difficult to feel like a citizen if you don’t participate. It is clear that many times, recovery is linked to that element of active participation, and connected and, moreover, with an experience of satisfaction on the part of the person. If the affected person does not live satisfactorily that participation, he will not feel like a full citizen.”

### 3.4.6. Integration

There are narratives where being part of a community or society as a whole is seen as capital for wellbeing.

“When you talk about recovery, you’re talking about people who are part of the social group you live with.”

## 4. Discussion and Synthesis of the Conversations

In this work, we have analyzed the contents of two focus groups using a framework based on Rowe’s [19] citizenship framework which tried to deepen on the concepts of recovery, citizenship, and personhood during the COVID-19 pandemic among people with psychosocial impairments. We have been able to see how experts understand these concepts and how they have been affected during the pandemic. Despite some positive aspects and the awareness that all of us have had that confinement and loneliness cause distress, it is clear that the pandemic jeopardizes the lives of many people and, at the same time, their support systems. We should not ignore the many voices warning that the consequences of the pandemic at the psychosocial level will extend for years [13].

The results of our analyses show how participants consider recovery to be a polysemic term linked to empowerment and resilience. It involves a shift from classic biomedical views based on symptoms still very present in mainstream care. It has its roots in the



rehabilitation movement but has gone beyond, influencing different settings and professional thought. There is a consensus on the need for the participation of affected people and their families. However, sometimes it is problematic as can be linked to productivity and normality instead. In addition, some survivors sometimes say they do not want to 'recover' their former life, as it was not full of meaning at all. Additionally, some relatives sometimes say that it is a model designed for those who can recover, there are other affected people who might need intense support that they say it is not fully acknowledged by this framework. In general, the groups showed that, in the Spanish-speaking context, there is a general understanding of the concepts generated by the North American Recovery movement supporting collaborative and person-centered approaches, and therefore adapting to the circumstances and priorities of each individual as opposed to the typical approach of seeing service users as subjects of medical treatment [30].

The debate on citizenship was influenced by mental health concepts as it was discussed after recovery. There was a consensus that people with mental health problems are denied a part of their citizenship. In accordance with previous works involving providers focus groups [31], it can be considered an important concept for mental health and social professionals because there are people who are denied citizenship even though it is supposed to be innate. When talking about citizenship, one should reflect on whether to be a citizen one must participate in some kind of activity or it is something independent of what we do. We could think that it is very difficult to feel like a citizen if one does not participate in society. What is clear is that currently there is a crisis of values in today's society that affects the citizenship status of many people.

The concept of personhood, which was much overlapped with citizenship, introduced the discussion of the role that humanity as a collective play in the mental health of individuals. For some participants who happened to be mental health professionals, the concept of person can be better understood than citizenship. Others said that sometimes not recognizing the other is needed to constitute oneself. Denying the other's personality allows some to build themselves. In general, participants found it an interesting concept because, if a person with a mental health problem feels like a 'person', there are things related to coercion that cannot be done. Regarding otherness, people with mental health problems often do not consider themselves people because parts of their socially recognized identity (profession, possessions . . . ) are missing.

Regarding the pandemic and its adaptations, mainly digital adaptations, participants confirmed that there were a lot of contradictions in the field of mental health services within the pandemic period. There were a lot of tensions on the table as many decisions had to be made very quickly to meet the needs of people with mental health problems during the lockdown. There was a lot of improvisation, but many good things came out of the way it was managed, such as the ways in which contact between practitioners and service users was maintained, or how users of certain services were able to continue in treatment.

Some agreed that the best and worst of people have come out. On the good side, it can be said that many crisis situations were faced in a more collective way than is usually adopted, finding multiple allies who were stimulated by an atmosphere of solidarity. For instance, regarding homeless people, there was suddenly accommodation for everyone. However, this also makes us wonder why this was not the case before the pandemic, why we had to wait for such a crisis to remember homeless people. As was seen within the professional malpractice theme, there were controversies arising from the inpatients' permits to leave. In some places, it was managed very well, but others were very restrictive, and there were people who could not leave for a long time, which negatively affected them. In addition, there was a paradoxical effect since many people, including mental health professionals, have understood that being locked up is bad for mental health, so maybe it cannot be considered a treatment. There was also the case of people with diverse relational patterns who could finally stay home without having to justify themselves.

However, on the downside, the digital divide is wreaking havoc. Although the technification of care has made it easier for many to receive psychosocial support, those

who do not have access due to lack of knowledge or due to financial difficulties are being left behind. On the other hand, on the side of the most excluded, we can find people with increased difficulties during the pandemic. For instance, people that live in very little spaces, such as whole families sharing a single room, faced very complicated living situations.

## 5. Conclusions

Although there has been a large amount of research on mental health symptomatology during the pandemic, respect for the rights and consideration as full citizens of people with psychosocial impairments is an unexplored topic. With this work, we have tried to take a first step in this direction. We have seen that the pandemic is both an opportunity and a challenge for this collective. We must continue trying to analyze the reality of the people with mental health problems from this perspective of rights and not only of ill-being, to promote their empowerment and autonomy.

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