"A Global NGO in advocacy for people experiencing mental distress"

Lived experiences in mental health in a diverse world.

Photos from activities sent by members of WAPR Network

World Association Psychosocial Rehabilitation

WAPR

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EDITORIAL
by Marit Borg and Michalis Lavdas

Photo by Roald Lund Fleiner/napha.no

For the first Bulletin in 2020 we wrote: "While finalizing this Bulletin the world is changing from day to day. There are extremely challenging situations related to the of Covid-19 crisis in many countries. Health professionals are overworked, and many are unprotected". We may well say much of the same one year after, although there are some reasons for being more hopeful. Most of us have more experiences in dealing with the pandemic- both in everyday life and in services, an increasing amount of people have had their vaccine and some countries or part of countries are opening up. During this year we have been challenged with new lived everyday life experiences, been forced to take on new roles and new learnings, been more isolated and lonelier. Experience-based knowledge drawing on peoples' hardships, pain and fears have for long been present in the mental health area. Service users have told their stories about what it means and how it feels to have mental health problems, and what helpful help is about for the person. Family members, both parents, sisters, brothers, and children have shared their experiences. User organizations also have a long story. For instance, The Alleged Lunatics' Friend Society (ALFS) was a movement started by former asylum patients and their supporters in England in 1845 (Watson, 2019). ALFS campaigned for greater protection against confinement, for reforming the mental health laws, for improvement of the conditions in the asylums and supporting patients who were discharged. The Society also were concerned with public opinion and attitudes towards mental health problems. Many of the same areas are in critical need for improvement still – 175 years later.

Peer support work also have a long history worth reminding of. The physician Philippe Pinel (1745–1826), recommended the employment of ex-patients as they were thought most likely to refrain from inhumane treatment while being able to stand up to pleading, menaces, or complaining (Davidson et al, 1999). Peer support work is one of the key criteria in the development of recovery-oriented services.

So, in trying to capture the state of the art in our present mental health services, there are good reasons for being reminded of the history and ideas of improvements in earlier days.

In WAPR Bulletin number 1-2021 we want to focus on lived experiences and expert-by-experience knowledge. Contributions from all over the world paint a beautiful mosaic of experiences in different cultural contexts. Decolonizing mental health also means giving voice to experiences and practices that are not typically heard and listened to on an equal basis with dominating voices. Understanding different cultural backgrounds and aiming for the "highest attainable quality of care" in mental health means also adopting an attitude of cultural humility. Such an approach, opens new directions in a dialogue between stakeholders in mental health and addresses gaps in human rights in mental health and the people using services and their families. This bulletin aspires to work as an inclusive forum where different views can be communicated and heard and a dialogue between service users, family members and professionals and policy makers in mental health be enhanced. We believe these are key areas in the further development of our organization and hope to inspire further developments around the world and discussions in various parts of our network.

Michalis and Marit

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President's Message. *Murali Thyloth, President of WAPR*

Murali Thyloth
President of WAPR

Dear esteemed members of WAPR.

This is the season of festivals across the world. I wish all of you a good celebration with safety.
In this Bulletin I am addressing an issue of planning programs during a pandemic. The uncertainties of the pandemic are an important lesson to be learnt by all. If we look at the Spanish Flu (even though not originated in Spain) which lasted for three years, today we have developed vaccine in no time and people got vaccinated. However, we are still not sure whether this is an answer as the virus is mutating. Majority of the countries have been giving vaccines to the vulnerable population, which seems to backfire. It is the younger productive people who are likely to spread the disease because of their work and contacts. I strongly feel governments should take these sections seriously otherwise there is going to be a huge economic breakdown.

In these testing times, as there are waves after waves of infections, misery and deaths across the world, planning an event becomes so difficult.
Issues like containment zones, local lockdowns, curfews, and an entire country lockdown can have devastating effect on economy and mental health status of people.

In this period- how can we plan an event? Technology has helped us to have virtual events, hybrids etc. Sponsorships are not required for these events as the expenditure for organizers are minimal (no breakfast, no lunches, or banquets and no hotel reservations, no flight charges). People find it easy to attend from home. Sometimes it may become embarrassing as videos and audios were on and you are in your home dress or shouting at children etc.

So, planning a world congress or a scientific conference is a difficult task. Physical attendance usually gives some income for associations but the virtual programs?

Now the current wave in India is worse than the first one. I also realize that this is the situation in many other countries. All of us have to go through this pandemic with caution, care and uncertainty. It is a challenging time for WAPR. I am sure many of our members are active in the forefront. Here in our medical college in India, we have started a psychological support service for all the staff and students. The students in all branches are facing one or the other form of stress due to uncertainty of their examinations. Getting classes through virtual means in turn makes them challenged in writing assignments etc.

Today as a World Association we are facing challenges which are new, and we need innovations to tackle this. As head of our WAPR organization in these times I am undergoing tremendous dilemmas on what to do? How can we in a good way make sure that WAPR task forces, world congress planning, election procedures and standard organizational work are efficiently carried out? A large number of people are already developing an aversion to zoom meetings and webinars. However, for the time being we need to find ways of moving forwards in WAPR through digital activities. There are also some advantages worth noticing, in that national and regional representatives from all over the world can meet and discuss common issues in the field of psychosocial rehabilitation.

I would like to end this brief message by hoping for a speedy end to this pandemic and that we soon can have our regular programs for persons with mental health issues.

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ARTICLES

Participation of people with experiences as service users and family members in WAPR

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The Sars-Cov-2 pandemic made us experience uncertainty. The disease was unknown until a few months ago and its various aspects - diagnosis, treatment, prognosis - have been studied all over the world under dramatic conditions. The sense of helplessness was and still is dominant among health professionals. We all have recognized that we are not in control of a health problem.

The viral infection has highlighted deficiencies and weaknesses of health systems. The millennial confrontation between man and nature has been a critical retreat, during which a disease had become globally stronger than us, leaving us helpless and unprotected. We have lost the opportunity to choose, to discuss the treatment plan with the doctors, to say what we want or don't want. And even now we are using vaccines without knowing how long they will be effective and with what possible side effects. We had lost the power to decide and determine our future.

This condition is similar to the one experienced by people with a mental health problem every day. They have often experienced not receiving information about their treatments, not knowing how long they will stay in a psychiatric ward or in a residential facility. They have been in situations when their needs are not adequately met and when they are scarcely involved in the decisions that concern them. Their lives are completely in the hands of the professionals. These aspects that characterize mental health services are critical to the outcomes. The patient's lack of a "voice" in treatment decisions is repeatedly associated with perceived coercion and various studies found a negative association between coercion and improved outcomes (Newton-Howes G. et al., 2011). Evidence indicates that when patients believe that their opinions are taken into account and they are involved in care planning, they feel less coerced, even when treated against their will (Katsakou C. et al., 2011). In fact, services users are clearly asking for changes in two key areas: the way mental health professionals relate to them as people and citizens and the alternative forms of treatment and a variety of service options (Ridley J. et al., 2013). They are asking for opportunities to choose, influence and control their own care plans and lives. This is an important part of the empowerment process which can allow positive outcomes and can act as a protective factor against levels of disease risk. But in a wider perspective service users' involvement goes beyond the strictly clinical dimension. It aims to create the conditions to face the ever-present risk of discrimination and social exclusion, since users frequently encounter social and structural barriers, resulting in stigma and difficulties in accessing work and any other activity (WHO, 2010).

Service user involvement is articulated in various forms and at various levels based on specific experiences and local as well as national and international policies. Starting from the situation in which people attend services as passive recipients and with the help of different tools such as information, person-centered approach, informed decision making, user views and feedback enhancement, participation of associations, it is possible to reach co-production. This means an equal relationship between the people who use services and the people responsible for services who both share decisions and a strategic vision to define policies and services planning (GMMH, 2018). In such a way one could realize a shift of power from professionals and politicians to the public while promoting the growth of democratic participation and the capacity of people to intervene in the management of health care. Despite these political and social dynamics have emerged in all their importance, «has been a neglected topic in global mental health», and most states, regardless of income level, are falling behind in promoting regulatory frameworks and practices that end discrimination in the field of mental health (UN Assembly, 2020).

In this perspective, the involvement of users and family members is put at the very center of the human rights issues since mental health is a fundamental right in itself as an inalienable component of health. People should have the right to access quality mental health services, to express their will, to decide and make choices about their lives without encountering obstacles and social barriers (Patel V. et al., 2018).

Ultimately, users' protagonism go beyond the perimeter of mental health services, aims to overcome social injustices and institutional barriers. It aims to promote the transfor-mation of power relations between individuals, communities, services and governments (WHO, 2010).

WAPR has always collaborated with service user and family associations. However, the awareness of the complexity and importance of these issues urges our Association to make an even stronger commitment. Hence some proposals concerning various organi-zational areas of the WAPR.

Proposals at four levels

Board of Directors.
Since evidence increasingly show the value and relevance of the participation of service users and carers in the planning, monitoring and evaluation of services and in research, we need to enhance the contribution within WAPR. As an international association we must make more systematic use of lived experiences and experience-based knowledge in developing our organization. For this reason, it's essential to strengthen service user and carer participation and influence within the Board. We need to make sure that their vision influences the debate and organizational choices.
For this purpose, we would plan to:
a) Increase the number of representatives of service users and family members with-in the Board of Directors.
b) Establish a Committee to
- suggest initiatives that foresee the participation and influence of users and family mem-bers as protagonists
- draw up programmatic and policy documents that highlight the promotion of community mental health and the full involvement of users and family members

- draw up a document to share with media representatives on how to deal with issues of mental health.
- establish relationships with WHO and United Nations to keep a regular dialogue on the issue of the development of community mental health services and human rights.

Regional activities

- Organize meetings with media representatives to define how to deal with the issue of mental health.
- Facilitate the representation of users and family members in the institutions that have the role of planning and assessing mental health services.
- Promote and support associations of users and family members with initiatives at a social and mental health service level.

Training

WAPR can provide:

Training Programs on the involvement of users, family members and carers within a framework structured in four main levels of involvement: Interactions between service us-ers (self-help); Interactions between users and health professionals (individualized care planning); Local service management opportunities; Service planning (Kennedy L.A. et al., 2017). The main goal is to support professionals in changing the values and attitudes that can be both a barrier to and enabler of engagement.

Training Programs on Peer support, based on the evidence that some interventions provided by people who have experienced mental health problems are of key value both when it comes to supportive relationships and social inclusion (Davidson et al., 2012).

Training programs for service user and family member involvement in research and evaluation. Experiences show that by including people with service user or family mem-ber background, the research questions and process are expanded.

Bulletin

Establish a section dedicated to service users, family members and carers. It could be focused on personal stories of mental health problems and recovery, examples and experiences of protagonism and advocacy of service users and family members, scientific reports about user's involvement, projects and significant documents that deserve to be shared.

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Why you should believe in us?
An account of mental health service user involvement in Ethiopia

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1. Service user involvement: a unique function, yet untapped potential
The importance of involving mental health service users and caregivers in the improvement of the health-care system is being acknowledged by stakeholders around the world, both in theory and in practice with varying pace across countries (Tambuyzer et al. 2014).

In low- and middle-income countries (LMICs), although there are examples of such involvement in mental health system strengthening in various countries, the work that is being conducted is found to be poorly evidenced and there is a lack of high-quality research in the area (Semrau et al 2016). As a person living with a mental health condition for two decades, I have a firm conviction that service users and caregiver play a unique, yet untapped, role in strengthening the mental health system. This role pertains to improving the quality and access to mental health care, the service delivery itself through peer support workers, advocacy at all levels, awareness creation, human rights promotion, policy and strategy, monitoring and evaluation, research, training etc.

The above distinct function comes from the lived experience of mental health conditions. This personal life circumstance provides an immense impetus for service users to carry on the work they do in the health system quite sustainably. Additionally, I have noticed that those who are most passionate about mental health care are often those with lived experience of ill mental health, whether personally or through secondary source such as a family member or friend. This may be why several foundations working on mental health draw their inspiration from some sort of lived experience.

In addition to the candid dedication to leverage, service users also deserve a special place in the system because they bring onboard an expertise that is based upon experience. This is why we refer to them as experts by experience. The stories of personal struggles, recovery, relapses, retrospective thoughts, and coping skills are all full of knowledge and wisdom that cannot be sufficiently articulated in textbooks.

For me, service users' life stories are their branded 'products.' If the latter met the appropriate 'market', they can go a long way in contributing to bring the desired change in the mental health system. I remember someone from Zimbabwe saying "there is no better person to know how comfortable a bed is than the one who sleeps on it every day".

2. Caregivers: busy picking up pieces of dysfunctional health systems

The involvement of caregivers is equally as important as that of service users, and for several reasons. In low-resource settings, alternative treatment options other than medication are quite scarce. For example, for the majority of my recovery journey, I never had the chance to complement my medications with any form of non-pharmaceutical therapy. They were simply unavailable.

 The few minutes of talks with my psychiatrists who are forced to ration their consultation time with a long queue of fellow service users was all that I was offered and this is not even always possible. Conversations are normally restricted to issues related to medication types, dosages, side effects, etc. Hence, the burden of delivering such therapies inevitably falls on the shoulders of caregivers. My parents, my siblings, later my husband were the ones who were there for me when I needed a talk therapy, counselling, or any form of support. The situation, however, is improving slowly, especially in urban centres.

Caregivers' role encompasses that of the community workers, social workers, therapists, counsellors, etc. What is most unfortunate is that caregivers support the service user doing all that they do with no or very minimal support from the system: they teach themselves from their experiences of caring for a loved one, learning from their own frustrations and rising again from desperate situations.

Also, the social health insurance system is at a pilot stage in Ethiopia and understandably not yet available in all areas. Mental health seems to be a sector at risk of being left behind efforts towards universal health coverage (Hanlon et al 2019). The major financial burden of medical treatment and its associated costs are borne out of pocket by the family or the service users themselves (Hailemariam, 2020).

3. Experience of Mental Health Service Users Association in Ethiopia

To illustrate some of the virtues of service user involvement and the barriers to it, it would be interesting to discuss briefly what the experience of the Mental Health Service Users Association (MHSUA) has been in Ethiopia.

Founded two years ago, the MHSUA is an association of mental health care users in Ethiopia, founded and run by persons with lived experience in mental health. The goal of the association is to ensure that persons with mental health conditions in Ethiopia are engaged meaningfully in the health care system focusing on human rights, empowerment, recovery and peer support. The key issues that the MHSUA seeks to address include: increasing community awareness about mental health; reducing stigma and support for persons with lived experience; and empowering service users and their families to be their own advocate in the improvement of mental health care and policies. Some of the achievements of MHSUA are humble indications of the unique function that service users can bring on board as outlined above.

Advocacy

The major innovative element of the MHSUA comes from striving to amplify service user voice within and beyond the health system in Ethiopia. It is the first registered entity representing mental health service users in the country. Most of its activities so far have been related to struggling to grip a fair space amidst the mental health system and to be considered as a legitimate stakeholder. There is still a long way to go in this regard; but, at least some major stakeholders such as the Mental, Neurological and Substance use (MNS) Case Team within the Ministry of Health, research institutions (Addis Ababa University), local and international non-profit entities working on mental health, etc. acknowledge the merits of service users' involvement.

Given the deep historical neglect of the mental health sector in the country, it is obvious that service users' role/voice has also been totally absent from the platform, apart from some family-based advocacy institutions.

The MHSUA has recorded some promising changes in advocating for a collective voice. For example:
• the MHSUA co-chaired, with the Ministry of Health, the national committee organizing the World Mental Health Day celebrated in October 2020;
• MHSUA was given a slot at this national event to present mental health service users' perspective on increasing access and investment in mental healthcare;
• the MHSUA took part in the national Annual Review Meeting of the mental health sector, held for the first time as a separate meeting. Mental health focal persons from all over the regions in the country assessed achievements of the year in terms of mental health services and planning for the next one. This meeting gave the opportunity to discuss with regional representatives on the potential of working in partnership with MHSUA to leverage service user involvement to improve mental health services in their respective regions. Flyers inviting service users to be members of MHSUA were also distributed to regional focal persons to mobilize membership;
• the MHSUA took part in the revision of the National Mental Health Strategy 2020-2025. The participation of MHSUA in this revision allowed inclusion of the establishment of MHSUA as an Opportunity in the SWOT analysis of the Strategy and provide service user perspective in strategic approaches and program implementation activities;
• the MHSUA is involved in reviewing the draft Health Act, which addresses issues related to mental health services as part of this general Health Service Act;
• the MHSUA is part of the drafting team responsible to prepare mental health education materials for health care providers, service users and the community;
• the MHSUA was invited as a stakeholder to voice its perspective on the curriculum of a new PhD program in Counselling Psychology;
• The collective voice of service users was recognized as a promising innovative community-based initiative by Ember Mental Health for 2020 cohort, which provides mentoring and other supports to such initiatives in low-resource settings over a period of 12 months.

Peer support
Members of MHSUA provide peer support to each other beyond the call of duty. The friendship and the common cause have drawn members closer to each other. Members visit each other at hospitals when admitted, and perform home visits or phone calls when members are in distress or having a poor mental health day. Members also met with each other casually as friends to catch up and support each other. The MHSUA has found that this sharing of lived experiences boosts members' self-esteem, and decreases individual feelings of loneliness often experienced during mental health challenges.

In addition, MHSUA uses its social media platform to provide peer support. Followers usually drop private messages requesting information and peer advice.
Awareness creation and anti-stigma
• With 1000+ followers to date, MHSUA uses its Facebook page to raise awareness on mental health and reduce the stigma associated with it. Although this has been on hold for a few months now; the page will be active again to rebuild better with new members coming in
• MHSUA also took part in a discussion on what access and investment mean from service users' perspective in a webinar organized by United for Global Mental Health:

• The MHSUA also contributed to educating the community about mental health through the ARTICULATE documentary film Filling the Gap sharing personal lived experiences and the role of service users by the African Mental Health Research Initiative and also the Our Global Voice project by Global Mental Health Peer Network to reflect on how the way diagnosis of mental health condition is received plays an important role in the recovery process:

Research

Involving service users is important in setting research priorities as well as in the design, actual conduct, implementation and dissemination of research. An example of such engagement included a qualitative study on service user involvement in mental health system strengthening in Ethiopia.. This research was conducted in a rural setting, and explored how to increased service users involvement in the strengthening of mental health systems. A Theory of Change model was produced with a range of stakeholders, including experts by experience and caregivers. Then a Participatory Action Research approach was applied and stakeholders—including experts by experience—identified top local priorities that need to be addressed to achieve involvement. Service users were engaged at all stages of the research process

A smaller Research Participant Group comprising service users, caregivers, and health professionals was then established and worked together to explore in more depth the priorities identified by the stakeholders. An action plan was then developed, in which the Research Participant Group is implementing with assistance from academic researchers. The local service users were also actively involved in disseminating the major outcomes of the research as engaged-owners of the process.

With the hope to promote ethical and policy-relevant researches, the MHSUA has been contributing to reviewing research protocols, proposals that involve service users (Abayneh et al 2017).

4. Challenges

Because mental health service users' active involvement is novel in Ethiopia, one would imagine the depth and width of the challenges involved in advocating for a collective voice.

Based on the MHSUA experience so far, the greatest barrier to X is the stigma attached to mental health service users. There are many kinds of stigma that impede X. For example, structural stigma includes a lack of policies that promote service users' active involvement in all matters that affect their lives, whether directly or indirectly. The very entities that are expected to fulfil this promoting role find it so bizarre when MHSUA proactively requests to be involved.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is unambiguously clear on the obligation by State Parties to closely consult with and actively involve persons with disabilities, through their representative organizations in the development of policies and legislations concerning issues relating to them.

However, the few engagements of MHSUA with the government outlined above are rarely driven by this obligation, and often come through exhausting and oftentimes frustrating advocacy work by its members.

Public health emergencies such as the COVID-19 pandemic have also provided some evidence of this structural stigma. Yeka Kotebe General Hospital, which has been inaugurated a few years ago to provide mental health services with around 150 psychiatric beds and outpatient service for over 250 patients in a given day. It has now been earmarked for COVID treatment; affecting significantly mental health service delivery in a country with a scarce number of mental health first responders (Hailemariam, 2020).

Psychotropic medicines have been scarce and expensive during the pandemic, as import and distribution have been negatively affected by the new challenges imposed by the pandemic. The societal stigma against mental health in general and service users, in particular, is another challenge to service user involvement. Misconceptions around the causes and treatment of mental health conditions are quite deep-rooted. Not only the public but the service users ourselves have a strong self-stigma.

One of the major challenges for MHSUA to mobilize membership is primarily related to the negative attitude around mental illness. Service users find it quite difficult to disclose their condition and join such a formal association of service users like the MHSUA. Discussions around mental health are not generally normalized in families and communities. This is why it is always a special delight when a service user comes to MHSUA to be a member. They must have gone a long way to come this far and it is indeed a personal achievement to celebrate.

5. Concluding remarks

Advocacy work in any field, let alone a sector heavily stigmatized as the mental health sector, is a huge challenge. All the more demanding would be to empower service users to become their own advocate; however, empirical evidences around the world on service user involvement and the humble steps by the MHSUA so far is an indication that the more service users and their caregivers are involved in a non-tokenistic way, the better the chance to bring about the desired change in mental health care.

#Nothing About Us Without Us is still a call for Our Collective Voice for Mental Health

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Ways of being the experts in peer support in mental health.

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Introduction

A new important change in mental health is going on in Europe and other countries in the world. At nearly forty-five years from the revolution started by Franco Basaglia, and in strong continuity with such revolution, a glimpse opens into a new way to introduce innovative perspectives and practices in mental health care. Such revolution has its ground in the recovery paradigm, like co-production, active presence of people with direct experience of mental illness, who, from being object of care, become an active and responsible subject (Kauffmann e al., 2017).

The peer workers, or experts by experience, are expressions of all this. They are users of mental health services who, thanks to their experience and to a specific training, can understand and support – in a really unique way – other people experiencing mental health problems. In Italian, the name corresponds to "expert in peer support", the ESP.

The most salient meaning of the ESP probably lies in overcoming the dichotomy between those who receive care and those who provide it, either inside and outside the services. An in-between space is therefore identified, where people with mental problems, family members, professionals, associations and services experience a new type of therapeutic alliance and share knowledge, aims and responsibilities. This paper represents a co-production exercise, composed by several voices and points of view, and grounded in trust and hope in doing things together.

Who is the expert?

The ESP is first of all a person who is or has been suffering from a mental health problem and helps and supports other people who are in their recovery process. The ESP helps through his/her sensitivity, empathy, personal abilities, and knowledge - in an equal relationship. He/she works in collaboration with the mental health professionals, supporting the person in everyday life and socialization activities and in mutual help facilitation.

What does the ESP do in more detail? The ESP is a person who is or was in a process of recovery. It is a person who is aware and sensitive when it comes to ways of helping and supporting fellow human beings. Through their lived experiences of recovery, they can offer a structure to their experiential knowledge and put it in place in order to facilitate and support other people's recovery process. The training usually consists of a course, generally co-designed and co-conducted with the participation of experts by experience, and

direct experiences with a tutor in services or projects realized in the community. During the training, the ESP improve their relational awareness and skills, learn how to regulate their emotions and not to burden themselves with others' problems too much. They also learn about ways of managingtheir working hours and also get knowledge about various ways of understanding mental illnessand how mental health services are organized and work.

The ESP can have different tasks. It is important that such tasks are defined consistently with their skillsand resources. They meetpeople in very critical moments as a sort of coach, collaborate with professionals in planning, developing and conducting courses and activities. They also make their personal stories and expereinces available in order to introducenew users tothe concrete mental health service. Furthermore, they can support the persons'need of a more direct informationabout specific topics, like coping with symptoms, financial support, how life works in supported housing, how to enjoy opportunities for education, how to navigate mental health and social service, where to find opportunities for social inclusion outside the services.All in all the ESP can have important roles in keeping hopefulattitudes towards improvement, recovery, and co-production. This means that the ESP do not substitute, rather integrate, the rehabilitation activities offeredby mental health service professionals. One of the most important tasks is being a bridge between the service user and the professionals, and offer and facitiate a dialogue for them when difficulties occur. This means that the ESP works in the team, participate in training and supervision activities. They also need to have self-awareness in relation totheir own limits and strengths.

Personally, I am involved in an activity, named AMIcittà, - a project realized by several partners including the Regional Authority and the City of Milan, that, using the personal health budget, builds the conditions for an independent life for people with mental disorders . I support people in charge of the mental health services in socialization and social inclusion, trying to reducethe isolation of some people with mental health problems. I am engaged inthe cooking workshop, in the editorial board of web radio Radiomenta, and, when possible, in the organization of leisure time activities like happy hour, visits to museums and trips. The team is composed by four experts in peer support and we have frequent and regular meeting with professionals for supervision and discussion of people's ways towards inclusion and recovery. We have continued to work during the restrictions due to the COVID-19.

Representing the point of view of the experts by experience
My name is Paolo Macchia, and I wasted more than 30 of my 57 years with frailty, dependence and marginality. I was in touch with many services, often inadequate, with professionals having no empathy and trust in the person they were dealing with. Nowadays I am certainly a different person. I knew mental health services from inside and understood that my knowledge and expertise can help developing better mental health services.

I am strongly convinced that even those who had to face great difficulties for a long time can then be an important resource for others, bringing the strength of the direct personal experience, and therefore a look of different eyes. In 2014 I was a subscriber of the constitutive act of the Rete Utenti Salute Mentale Lombardia (the network of mental health services users of Lombardy, www.reteutentilombardia.it) which aims to be a direct partner of the mental health institutions and the administrative decision makers. The final aim is to fight stigma, self-stigma, and prejudice and promoting experiential knowledge and mutual help and peer support.

Health and welfare policies and the complex systemsthat regulates the mental health world should take into account the main actors, ie, those in charge the services,. We want to participate in the development andimplementation of recovery-oriented services, more focusing onthe person and the central and key role of the person the recoveryprocess. In order to achieve this, integration of the social and the health sectors is necessary. Recovery happens outside the services- in the local community. What the community, associations, the third sector can provide is essentialfor an improvement of quality of life and a recovery vision of care in the community.

We can say that our voice is more and more listened to, we sit at several negotiation tables, are included in the programs of prominent conferences, and we are confident that, although with some difficulties and setbacks, this will continue. Changes are always slow, but we believe in continuity and perseverance and trust in front of several small setbacks. Gains in quality of mental health services will benefit not only users, but also caregivers and our community as a whole. The professionals themselves, see and acknowledge the new positive achievements of ESP and are therefore more motivated and less frustrated.

Users participation in research and service evaluation
Users' participation concerns also scientific research. Such involvement was the request of the users to be recognized not only as an object to be studied but also as an active subject in the process of knowledge production in mental health, as a need to have a voice in what affects them directly. In fact, it is expectedthat the direct experience of a mental illness can produce and offer a competence different from that of professionals, but similarly useful when studying mental health issues. It is essential that people with lived expereinces can bring their knowledge to mental health services as well as knowledge development There are several reasons why experts by experience and users in general wantto participate to research:

- to have an impact onprovision of service and recovery interventions;
- to have a say in the choice in issues to be investigated so that these are the most relevant for their peers;
- to assure that the studies include users' point of view;
- to offer their personal experiences and knowledge;
- to help the results of good research to be widely known and implemented in practice;
- to assure that participants to a research are treated correctly and that the research is carried out appropriately.

Users are "expert by experience" and therefore "expert of their experience", in particular of physical mental health problems and mental health services and thus they can have a unique role in designing studies in this field. Participation in research also gives benefits to the participants themselves, who express that they gain empowerment and competences.

Participation in research of users, family members or associations varies in type of contribution and level of involvement. Examples are identification of the research question, design definition, data collection and analysis, findings interpretation and dissemination. In particular, there are three possible levels of involvement: consultation typically happen in the very earlyphase of research, when users are asked about their opinions ofthe area or object of research, give prompts and suggestions to enrich the question. However, the professional researchers are free to take such opinions into consideration or not. They keep the control of the research. After the consultation, users are no more involved. The Clinical Antipsychotic Trial of Intervention Effectiveness (CATIE) (Stroup et al, 2003), a clinical trial comparing the effectiveness of several antipsychotic treatments, was an example of the consultation level of involvement in research.

The most frequent type of users' participation to research is partnership working between users and researchers. Users researchers are active partners in the process of research, share responsibilities with the professionals researchers, their opinions are taken in the same consideration as the professionals' ones, and decisions and control over the process are equally distributed. Users are involved in all phases of the research and are informed about the whole project. An example of such type of partnership is a study conducted in the Department of Mental Health of Pistoia several years ago (Barbato et al, 2014) which assessed the quality of the mental health service from the point of view of the users.

User led research is characterized by the control of users over the entire process, management and methods of research. Users researchers decide whether consultation of professionals is necessary and should be included. The quality of the study will depend on the expertise and competence of the users leading the research. An example of such research is the study conducted by Diane Rose and collegaues (Rose et al, 2003) addressing users' opinions about electroconvulsive therapy for depression.

Often, the level of involvement is something in-between the simple consultation and user led research. The integration of the knowledge of the experts by experience is a unique resource for the production of evidence.

Relationship between experts in peer support and services. Strengths and limits
Although several studies and experiences highlight the advantages provided by peer support, others indicate barriers and challenges faced by peer workers. Moran et al (2013) reported that peer workers were hurt by stigmatizing words and prejudices professionals used about patients of the service. Such experience was related to the worry not to be deemed as adequate as other colleagues and professionals of the service. Others stated that they did not have sufficient autonomy and were not recognized in their role, having often been required to do inappropriate tasks. They also reported work overload. The respondents to this study also reported some difficulties in defining clear relationships with the peers. For instance, they were uncertain whether to reveal their story, to whom, and in what circumstances. They also felt to be inclined to be over-involved by people experiences and problems and to overcome their limits in the relationship, engaging in frequent tensions between the wish to help and their need to take care of themselves.

Peer workers can feel responsible in facing people who did not improve or even got worse (Miyamoto Y., Sono T., 2012). These issues clearly suggest the importance for peer workers of receiving more and tailored support and supervision from trained supervisors and professionals. This would help avoiding excessive burden and risks of crisis, as well as facilitate doing a good job. For peer workers, supervision is a necessary condition to perform their work with continuity and a good performance. Peer workers also suggested that a written common agreement should define how the service can provide support to the peer worker, and, in case of relapse, redefine the tasks and a gradual reintroduction into the service activity.

Other studies found that peer workers were not satisfied with their financial reward, sometimes this was even absent. A low pay can prevent persons to get out of the insufficient income provided by a disability pension. This was confirmed in the ESP experiences. Peer workers are financially supported by specific projects that are renewed every year. Such mechanism entails that it is difficult to plan and realize activities in the long term that might give more continuity to the role of peer workers in the services. There is the risk that some peer workers with limited experience hardly bear the burden of such instability. It is not infrequent that in the period of interruption of the activity the peer workers loose motivation and step away from their role. When the activity can start again, it is usually necessary to spend time in dealing with the discontinuity and recovering motivation and trust.

Every service or Department of Mental Health have arranged the training and the financial reward of the peer workers in their own way. It is urgent that the ESP is recognized through a national act which formally and clearly recognizes the specific role of the expert.

Mental health services and the community. What future for the experts by experience?
Since few years, the recovery paradigm is largely present in the language, policies and practices in the mental health field. According to this deep change, experiential knowledge is deemed as valuable as the professionals' one. Those who care and those who are cared for are in a continuum, each with different views and tools, but both necessary to achieving the clinical, existential and social wellbeing of people with mental problems and their families.

We think that the areas where co-production is possible and necessary are:
- implementation and evaluation of the care plans;
- participation of associations, in particular those of users and families, in the planning, management and evaluation of the mental health services;
- participation of the experts by experience in all institutional levels where social and health policies related to mental health are developed;
- establishing educational and training programs shared by users, experts by experience and other professionals.

The aim is to develop an open and flexible system of care where a wide range of resources are invited to participate. Included here is the central responsibility of the community as such, and the public mental health services with the collaboration of the associations and the third sector. In such scenario, the experts by experience can have wide space for useful work and can play an unique role in partnership with service users in the identification of the real needs of people with mental health problems.

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Managing a Residential and Rehabilitation Centre for Homeless Persons with Mental Illness during COVID 19 Pandemic

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Outpatient collecting medicines at entrance to Chittadhama

Chittadhama, the Residential and Rehabilitation Centre for Homeless Persons with Mental Illness (HPMI), is situated at Shantipura Village, HD Kote Taluk, Mysuru District, Karnataka, India. This is a socio economically backward area with a large tribal population.

Chittadhama was established in 2010 and since then it has been catering to the needs of the HPMI in addition to care of the mental health needs of the community. Chittadhama is housed in a 7200sq ft building surrounded by four and a half acres of land that is used for agricultural, horticultural and dairy farming purposes. The rehabilitation program is based catering to rural needs. At present Chittadhama has 41 residents and 14 staff. A team of psychiatrists from Bangalore travel every month to Chittadhama and conduct two out patient services where on an average of 60 out patients are seen during every visit. There are no consultation charges and every outpatient is given free medicines for one month at a time. During these visits, the residents of Chittadhama are also see and medication , rehabilitation and reintegration plans reviewed With the outbreak of the pandemic, there were several challenges that were encountered in following physical distancing, wearing masks and other regulations that needed to be followed to ensure the safety of the residents and staff. New methods had to be innovated to meet with these challenges as the pandemic evolved and Government regulations to control the spread of the virus changed.

Temperature checking and hand sanitising before entering Chittadhama

The largest challenge was trying to keep the residents and the staff safe. Due to the nature of the illness, many of the residents had difficulty in understanding and comprehending the seriousness of the disease. Hence, they were unwilling to keep the mask on or maintain physical distance or follow the protocol of washing hands.

Maintaining physical distance at entry point

Following are protocols followed

• In the initial period of the pandemic during the lock-down phase, strictly there was no entry for outsiders into Chittadhama. Due to anxiety and fear some of the staff were reluctant to come to work. Staff were encouraged to reside in the centre and anyone who went outside for more than three days had to undergo 7-14 days of quarantine in the quarters removed from the main building. To encourage staff to continue working, they were paid an additional 'COVID 19- difficulty allowance'. This placed an extra monetary burden on our stretched finances.

• The Staff were educated concerning the Corona virus giving basic knowledge of the infectivity and spread. Safety principles of Mask wearing, Physical distancing and Hand sanitising was practically demonstrated. Initially there was hesitation and reluctance but very soon the new habit was established.

Simultaneously the staff started training and educating residents in simple terms about the illness, nature of the virus and severity of the problem. This was not easy as residents had difficulty in following instructions because of their illness and cognitive difficulties. The instructions were persisted on and there was improvement in compliance. Still some of the residents continued to be non-compliant, and negative reinforcement had to be used in some instances.

• The need for physical distancing necessitated changes in the ward structure. The number of beds in a ward had to be reduced and the beds were shifted to areas that were not being used. We were fortunate that we had vacant space. The dining hall had to have two batches for breakfast, lunch and dinner to ensure required physical distance was maintained. This meant that more time and effort had to put in by the staff.

• Hand sanitising/ frequent hand washing: Extra soap solution and sanitisers were provided at strategic places- bathrooms, dining hall, office room etc. This procedure continues placing an additional financial burden. In addition, there is extra pressure on the staff to implement hand hygiene.

• It was not possible for the psychiatrist to travel from Bangalore to visit Chittadhama in view of the lock-down. At other times there was hesitation for the psychiatrists to visit as they were travelling from an urban place that had a huge number of positive cases to a place where there were only a handful of cases. Six months into the pandemic visits by psychiatrists had to be abandoned on three occasions as they tested Covid positive. During these times all consultations for residents and outpatients were through tele consulting- video or audio.

Maintaining physical distance in areas marked on ground

• Since a month after the onset of the pandemic, consultation has resumed. Special precautions are taken to see the outpatients. No outpatients are allowed to enter the main building. A temporary structure was put up at the entrance near the entry gate. Patients have to wait outside the gate in spaces marked for them maintaining physical distance. Masks were a must if they have to be seen. Those without masks are sent back. Their temperature is checked before being let into the consultation area. They are given staggered appointments to avoid overcrowding.

Dr Thyloth Murali interviewing

• It is mandatory for staff who came in contact with patients to wear masks, face shields and gloves. They sanitise their hands after seeing each patient. After seeing the patients this opportunity is used to educate them about the pandemic.

• The admission process was stalled because protocol for admission of HPMI during the pandemic was unclear. Request for admission had to be referred to the Public Mental Health Establishment. However, five patients were admitted as they were sent by the Mysuru City Corporation, after due legal process and an assurance by the Medical Officer that they had completed the stipulated quarantine period.

• Prior to the pandemic all general medical care of the residents was taken care at a local hospital- the Vivekananda Memorial Hospital, Sargur. In the new normal, this became difficult as the hospital was declared a Covid treatment hospital. Hence it necessitated changes in treatment protocol with tele consultations.

• Seven months into the pandemic the Taluk Health Officer recommended that a Covid RT-PCR test be done for all the Residents and Staff of Chittadhama. No tests were positive.

• A request has been made to Taluk Health Officer and the Tahsildar that the residents and entire staff of Chittadhama be considered on a priority for anti Covid 19 vaccination.

We continue to follow our protocols and have so far managed Chittadhama without any untoward events.

Lessons from the lockdown: A space for change

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Despite many efforts, the field of psychosocial rehabilitation is still struggling to find ways to support recovery. This article is about what happens for some service users, when what is usually done, is not done at all. The aim is to search for new answers on how to support recovery.

The Danish user-led organization Outsideren did a survey among service users about the role of their lived experiences during the first national Corona-lockdown in the spring of 2020 and the impact of the lockdown in their current everyday life.

Contrary to the general assumption, a majority of the mental health service users in the survey found the lockdown positive for their mental health and wellbeing. External demands were replaced with a sense of space and autonomy that made it possible to experience one's own strengths and values in new ways. Often for the first time in a long while. The initial findings were explored and elaborated in a qualitative study in the autumn 2020.

The conclusion is complex, yet clear. The 'new normal' during the lockdown offered a unique opportunity for exploring the empowering potential in replacing predefined individual interventions with a space for change.

Empowering service users has become a main priority in the field of psychosocial rehabilitation, after the paradigm shifted towards recovery. This has made re-orienting services to support recovery and social inclusion, a central focus in most planning and service delivery in the mental health area.

But progress has been surprisingly slow and difficult. No one has yet identified an intervention showing a significant effect in promoting personal recovery. This has led both practitioners and researchers to conclude, each in their own way, that we have "failed to achieve consensus on how to realize the vision" of recovery .

At the same time, initiatives such as Relational Welfare have shown how ecosystems like the psychosocial and psychiatric services, as a whole can have severe side-effects. We know some of them, like stigma and "clientization", but these are focused on the individual. Relational Welfare looked the other way and has shown how the combined effort across services, in this instance family-services, can act as 'a gyroscope spinning around the family, keeping them stuck exactly where they are'. Making no difference at all. Apparently, the gridlock of interactions and counter-interactions between many different organizational aims, practices, and cultures, manage to grind every new and hopeful approach into not really changing that

much for the service users. Any movement in a meaningful direction in the field of psychosocial rehabilitation, seems as difficult, as necessary.

But then came Corona and took it all away, and thus creating a the biggest and most unique learning opportunity we (hopefully) will ever see. Showing us what surfaces, when everything is very different and what we normally do, is no longer done at all.

This article describes the experiences of mental health service users during and after the national lockdown in Denmark due to COVID-19 in the spring of 2020.

It is based on a survey with 83 respondents with various mental health issues. The initial survey was followed up by collecting nine personal stories and finally exploring unexpected outcomes of the lockdown at an explorative workshop with eight service users and one staff in October 2020. The story-collection and the workshop were conducted in collaboration with the Danish Social Development Center, SUS.

The initial survey was designed by people with lived experiences and reflected that our personal experience of the lockdown didn't fit with the dominant story of 'crisis'. Thus, in the survey we chose a strength-based approach. It focused on lived experiences during lockdown in two ways. It asked if peoples lived experiences made a (positive or negative) difference in their lives during lockdown. And it asked how they experienced the lockdown itself, with a main focus on the absence of meetings with professionals.

The aim was to make room for broader spectrum of answers than the 'automatic' understanding of lockdown as a time of hardship. We acknowledge that some people were left alone with a lot to deal with. But we also know that ultimately recovery is about standing on your own two feet.

So, what happens, when you suddenly find yourself in a situation, where you have to do exactly that?
In the following, we are interested in highlighting the strengths and surprises that became visible during the lockdown in spring 2020, when you are an expert by experience, and the biggest service design change in recent history, happened almost overnight.

March 2020
"Being sick and hospitalized was unbearable and painful. It is not unbearable that the daily routines are a little bit different – that I can manage" – comment from survey

When Corona hit Denmark in March 2020, all non-essential functions of the public sector, including many mental health- and social services, unemployment services, GPs and more were shut down for more than three months.

The pandemic was followed by heavy concerns for people with mental health issues in the public debate, with a general consensus, that we were among the defenseless and needed to be shielded. When the number of admitted psychiatric patients dropped below half, even though the wards were kept open, the missing patients were explained with people 'biting their teeth', 'staking it out,' battling an ever-worse depression or anxiety without help and being 'too afraid' to contact their GPs.

It took the service-user community a week or two to realize, that for many of us, the lockdown surprisingly led to a sigh of relief. It became clear at our first big online meeting in our association Outsideren into the lockdown. Generally, we were not worse. In fact, we – 'the vulnerable' - were actually doing better than usual. We did not feel increasingly anxious, depressed, worried, or stressed. Quite the contrary.

When the box disappears

During the explorative workshop, we held half a year later, most participants described how the lockdown had led them to experience newly found strengths and opportunities.

"Before the lockdown, I was stuck in a box, I couldn't get out of. There were so many demands, and I could not see any hope for my future. Now I am studying to become a nurse. Almost everything fell into place during the lockdown. It is so surreal." says Alexandra, a young woman who has been hanging around psychosocial and psychiatric services the last twelve years.

"There were so many disturbances all the time before the lockdown. My work trial and all the hassle from different services were stressing me out. The night everything closed down, everything became calm." says Alexandra, who started helping her mother buying groceries when the lockdown began. This led to helping a friend move. Which again led to further change.

"It was like a snowball. I felt stronger and stronger." says Alexandra.

The workshop participants connect the new roles and new strengths they discovered in themselves, with the quieting of external demands and activities during the lockdown. Exactly which demands or activities, varies. For some it was suspension of demands for receiving benefits. For others it was changes in their job or study activities or something else. The best way to describe it, is really just space. The lockdown created space for something else to happen.

For some it was terrifying. Especially in the beginning.

"When the lockdown came, I was writing on my thesis and had just been in a psychiatric ward for three months. At first, I really felt bad, but I had to learn to cope. As long as I can remember, I have been afraid of being alone, but during the lockdown I had to learn how to deal with it, and I did. It was hard but important. It also made me realize how much I conform to what other tells me is important, and expect of me." says Majken, who – after the initial crisis – continued working on her thesis during the lockdown.

Majken was part of an online group, who met once a week. She describes the group as a cornerstone in her everyday life during the lockdown. There was no agenda for the group. Often it was just checking in and sharing stories.

Zayra, attended the same online-group; "you could just talk about what you felt like. The was no obligation to work with specific topics. We got really close and learned a lot about each other. At the same time, it was possible to reflect about myself and what is important to me. As soon as the lockdown ended, I lost contact to the group, because my studies demanded my attention," says Zayra about her experience of the online-group, which was held by Fountain House Copenhagen, during the lockdown.

The space that made it possible to discover new and stronger sides of oneself during the lockdown, including time to reflect about values and priorities, is not described by any respondents as a space of isolation. Central to it, was experiencing oneself relative to others in a new way.

To lend a bit of language from Putnam's social capital, the lockdown cut ties to all sides. But at the same time, everybody was available to each other because nobody was doing anything. The lockdown was a shared experience, regardless of one's mental health and vocational situation. In that sense, the lockdown was a period of exceptional possibilities to create new ties and discover oneself in new roles.

This brings into mind the work of Alain Topor, who emphasizes the social basis of the recovery-process. Topor argues, that to create environments that support recovery, it is necessary to look at individual aspects but also at ties to others and living conditions, because recovery is a 'deeply social, unique and shared process' . At the core of Topor's definition of recovery, is the need for a space in which it is possible to experience and act in new ways. However, what is social and shared, is not just what happens between you and me, but also a broader question of identity and how we perceive ourselves as belonging or not belonging to the contemporary world.

For Nanna, who has retired early because of her mental vulnerabilities, the fact that the lockdown didn't really change anything, strengthened her feeling of living outside society.

"When people started talking about how the lockdown turned everything upside-down, I felt very lonely, because nothing in my life was different. It made me feel like I had no value at all. It was difficult. No one expected anything from me and there wasn't anything I had to stop doing or return to," says Nanna, who experienced anxiety over the arrival of the pandemic, but stayed on top of it together with her friends.

The characteristics of the space of possibility that was created by the lockdown, to discover oneself, to act, to breathe and feel hope and to interact with others in new ways, is in line with Topor's definition. However, the lockdown was an exception and not a solution, and thus it is necessary to look closer at what service users point to as specific strengths during the lockdown. For this we turn to the survey conducted one month into the lockdown.

The strengths of lived experience

In the survey 60% of the 83 respondents replied, that their past experiences with mental illness actually made them stronger and improved their wellbeing during the Corona-lockdown.

Especially firsthand knowledge that any crisis is temporary, and the intimate relationship with social isolation, was emphasized as empowering. Many found themselves doing better than friends and family, who were much more dependent on external activities to feel well.

"I've been in crisis before. And I learned that I survive. Also, I have learned what I need to pay attention to, in order to stay well." – comment from survey.

What difference does your experiences with mental ilness do during the Corona-lockdown?

Neutral 11%

Negative 29%

Postive 60%

■ Postiv ■ Negativ ■ Neutral
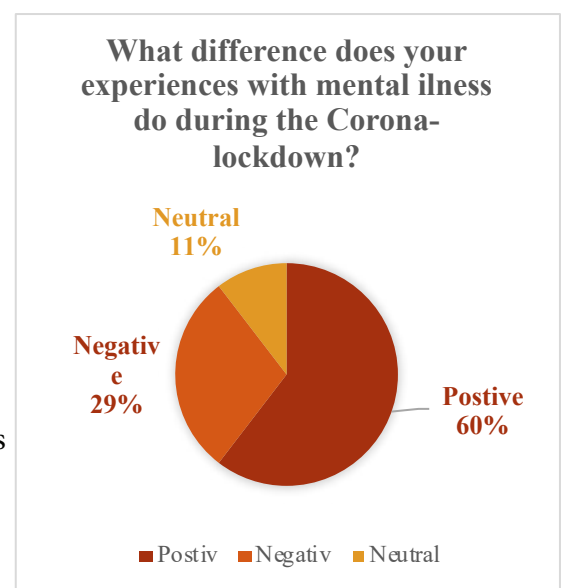
Considering it, it is quite simple. The general population may be unfamiliar with something beyond one's own control creating uncertainty, isolation, and setting boundaries for your life. But if you are a mental health service user, a lockdown is really not that special. You have tried something like it before, and probably much worse.

At the workshop we held, knowing that any crisis is temporary, was also a central theme.

"When the lockdown came, my days became far more meaningful. I had time for my daughter and suddenly I was the strong one in the family. I knew crisis, and could tell everybody to relax, because it would pass. It changed the perception of myself, and I stopped viewing myself as sick. I was surprised how quickly everything turned back to being as before, when the lockdown was lifted." says Loucia, who is part time employed as part of her recovery- process.

For Loucia and many others, the lockdown created a connection between personal firsthand knowledge of a crisis and a new experience of oneself as better skilled than others, to handle the changes and circumstances. This meant that not only did the lockdown create possibilities to recreate ties, but it was also much more constructive roles, that were available for service users.

The new normal
"I don't have a very active social life, and I feel better, when I am alone or with only a few people. So, my everyday life now, is much like before the Corona-virus came. Actually, my everyday life almost is better, because I have time to do things in my own pace and in my own way. I don't feel the same pressure and anxiety as usual."
– comment from survey

What was really missed during the lockdown?
Unsurprisingly 62% felt better or much better not having to show up at the unemployment services or being sanc-tioned for not applying for jobs. 80% replied that it made no difference for them, whether or not they could be hospi-talized if needed.
What was really missed was that one social worker/peer/ community worker, that generally was described as the anchor point in everyday life.
Half of the respondents described negative consequences from missing that meaningful support person in their life during the lockdown, and only one in ten experienced it made them feel better.
Source: Questionnaire on lived experience during the lockdown. Outsideren, 2020.

It is well-known that mental health service users are more isolated and lonelier than the general population. Thus, when being socially isolated suddenly became good citizenship during the lockdown, it was a big relief for many service users. In our survey, it is generally described as a big burden being removed.

"It is a relief, that there are so few people on the streets, and see on Instagram, that other people are getting to know my everyday life, with all in uncertainty of what is going to happen." – comment from survey

There are many reasons for being less social active when you live with mental health issues. Anxiety, exhaustion, no love for yourself and not wanting to let others down, are some of them. But the respondent's main emphasis was the relief they felt, when everybody for a while was living like them. No social activities. No fancy vacations. No expectations.

From the survey it seems as if solitude and the feeling of non-belonging are two very different qualities. Solitude is easier to enjoy when socially acceptable, but sometimes you have to live in solitude anyway, when mental health issues demand it. The feeling of social exclusion on the other hand, seems much closer tied to interaction – or comparison - with others and in is many ways beyond one's own control.

The experience of being 'normal' or socially equal, that many service users felt during the lockdown, is hardly one that can easily be transferred to a post-Corona society. However, as social inclusion is a core element of psychosocial rehabilitation, there are still important takeaways.

"I felt a huge grief when the lockdown was lifted. Before the lockdown I felt a lot of pressure of being part of a community and having very little choice in my part time job. I was caught up in having to do so many things and felt no real choice in my everyday life." - Loucia, workshop participant.

In the survey, the theme of belonging is of such major significance for the respondent's experience of wellbeing, that it brings into question if it really makes sense to spend time perfecting specific interventions aimed at changing the individual persons lives. A more relevant question might be: How does what we do, contribute to feeling more like a human being in everyday life, and less like a part of some problematic target group? One third felt abandoned

Not everybody welcomed the lockdown. In the survey, one third stated that they experienced a negative impact from the lockdown on their mental health and wellbeing. Commonly was a sense of feeling abandoned with a vulnerability or issue, that was scary and unfamiliar to manage just by yourself. This experience was generally connected to a feeling of a general vulnerability in everyday life, that became worse when the Coronavirus arrived.

"I am much more vulnerable now. I get panic attacks and feel much lonelier that before Corona. I cry all the time, and worry about how this will end? How will my friends make it?" – comment from survey

Secondly, many in this group were still in an acute crisis of just coming out of it, when suddenly they were left to themselves. When most appointments and non-acute services shut down, it became unclear what help was available and when, creating a fear of relapse or loosing what had been achieved.

"I thought I was taking control over my life. But the clinic for eating disorders is shut down. I am waiting for a debt counsellor, but now I don't know when that will happen. Everything is on hold."
- comment from survey

Thirdly, many of the respondents in this group describe how they spent a long time building trust to others and getting the help they needed. With the lockdown followed a sense of losing the momentum and progress, and concern about not being able to achieve the same later. While many felt everything fell into place during the lockdown, some feared everything would fall apart.

Finally, this group seemed especially affected by not having their everyday life structured by appointments and meeting other people. It created an unmanageable space for negative thoughts and unease.

"Everything inside me, takes up more space, because I have nothing else to focus on, like being with other people. It is very demanding" – comment from survey

Summing up the lessons

The main story from the lockdown, which must not be forgotten, is the story of the strengths you build when you are mentally vulnerable.

One core strength seems to be the ability to create a meaningful and enjoyable daily structure (when necessary), even when you may be on your own and there is nothing outside yourself, creating it for you. This ability seems to be the central difference between those in the survey, who experienced greater wellbeing during the lockdown of spring 2020, and those who felt worse.

As such, everyone in the field of psychosocial rehabilitation, must ask themselves, what is done, outside a lockdown, to make these personal strengths visible and build on them? Repeatedly in our findings is a narrative of how the lockdown led to exploring one's own skills and finding new inner strength, even though the respondents were long time service users. Why is it, that psychosocial interventions do not achieve the same outcomes?

Secondly, it is beside the point to reduce these skills to an individual 'toolbox.' The empowering part of what Topor calls a shared process, seems to unfold when it is possible to create or recreate ties to others in a constructive way based on your skills and knowledge, and not hindered by limiting cultural stereotypes of being normal or not normal.

At such this supports the argument for the current agenda of social inclusion, to which the lockdown created an unprecedented open space allowing everyone to be part of it and experience oneself in new ways.

A big part of the shared process during the lockdown was related to everybody having to put their social life on stand-by and can hardly be extended beyond corona.

But another part, we can and will have to rethink is the 'the box' created by combined demands, evaluations, and interventions across services, whose disempowering characteristics became visible when they were shut down. The pausing of these demands made it possible for service users to radically experience themselves and their abilities in a new and positive way. At the workshop six months after the end of the lockdown, it had led to a deep shift in the perception of oneself and the life it is possible to live. Even with the same symptoms and limitations.

Also, we cannot separate the experiences of empowerment during the lockdown and 'the box.' As Foucault pointed out, any modern society produces 'truths' that affect how we act and perceive ourselves and others. The 'truths' about who we are as service users, came out very clear and loud at the beginning of the pandemic: helpless, vulnerable people, that needed to be shielded.

For some, this may be a truth, they can relate to. For others, the truth appears to be quite the opposite, and thus the 'truth' of help-needing 'vulnerability' becomes disempowering epistemic violence. It makes it harder for service users to do what any person and all services dream of; Stand on your own two feet in everyday life. But especially for professionals and services this 'truth' is toxic when it stands in the way of creating interventions building on strengths and supporting recovery.

For some years now, the field of psychosocial rehabilitation has worked towards supporting recovery. But professional interventions are still struggling to create a profound change of practice. The lockdown highlighted the need to focus on creating spaces in which people can change their lives, rather than defining interventions that changes people.

When working with our data, we could not help having the asylums and their almost static focus on peace and recreation in the back of our mind. How was the space created by the lockdown different? How come people didn't just fall into a disempowered passive state?

To us, it seems that what makes the difference between a difficult situation or crisis becoming either disempowering or positively lifechanging, is the surroundings and relations around you.

If that is true, then the main questions for future services are: How do we strengthen our ability to create a social space, in which people can change their lives? How do we do it in ways, where people's strengths rather than their neediness become visible and useful? And when are we misleading ourselves to stand in the way in our eagerness to protect, fix and change people?

About us
Outsideren is a Danish volunteer association run by current and former mental health service users. We were established in 1995 and focus on communication and social inclusion.
www.outsideren.dk – for more information contact Klavs Serup Rasmussen, ksr@outsideren.dk

About the authors
Klavs Serup Rasmussen is a volunteer in Outsideren due to his former experiences with long time hospitalization, schizophrenia, and early retirement. Currently he is the project manager of a randomized trial, documenting the effect of community based peer-support. His educational background is in political science, leadership and a master's degree in social entrepreneurship.

Agnete Neidel has a PHD degree in recovery-oriented social work. The cornerstone of her work life is to facilitate new knowledge and new practices which can strengthen (and make visible) the power, participation and possibilities in the lives of marginalized groups.

Data sources
The article is based on:
• a survey with 83 respondents with various mental health issues
• 9 individual stories on life during lockdown
• a dialogical workshop with 9 people (8 experts by experience, 1 staff), facilitated by the authors.

All empirical work was designed to explore unforeseen strengths and possibilities happening during lockdown, but made room for negative and life confining experiences as well.

Respondents
The service users participating in the various collections of data, live with a broad range of mental issues, from psychosis, depression, anxiety, autism, PTSD, eating disorders, personality disorders and so on. Two-thirds were receiving support from community services or psychiatric treatment, at the time of the questionnaire or workshop.

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Mental distress in Afghaninstan and suicidality: Data from a National Survey

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Mental Distress in Afghanistan

National Mental Health survey conducted in 2018 (Afghan Ministry of Public Health & Mental Health Working Group, 2019) indicated consistently high levels of mental distress Afghanistan. According to this survey, one out of two people (50%) is suffering from psychological distress and one out of five (20%) is impaired in his or her role because of mental health problems. Almost 10% of children are impaired in their daily roles by a mental health problem. Underlying mental health issues will only be further complicated and exacerbated by COVID-19.

Being a woman or a girl, as a risk factor.

According to recent studies, about 1.8 million Afghan women have been diagnosed with depression, due to the massive psychological pressure. Dr. Mohammad Ashraf Rawan, who offers psychiatric support in the northern province of Balkh, argued that "violence against women and restrictive conditions are potentially fatal". According to the World Health Organization (WHO, 2014), the estimated number of suicides in Afghanistan for the year 2012 was 1,205 (males: 562, females: 643), representing an age-standardized rate of 5.7 per 100,000.

Most factors contributing to self-immolation of women are forced marriages, early child marriages, multiple marriages, lack of societal awareness of women's rights and the psychological impact of 25 years of war. Additionally, customary practices such as high marriage portion (Tuyana) or (bride price) and family violence are the main risk factor of self-immolation too (AIHRC, 2008). However, most of the victims were young generation, especially women (95%), between ages of 14-19 years old (Medica Mondial, 2006).

Countrywide investigations showed that the vast majority of suicide cases in Afghanistan were amongst women and young girls experiencing physical abuse, according to the United Nations Assistance Mission in Afghanistan (UNAMA) which also presented that Afghan women experience some of the highest rates of domestic violence in the world.

So, it is assumed that the real prevalence may be higher than what was mentioned, because of general collusion of silence, taboo and stigma following this issue. Suicide is a criminal act in Islamic 'Sharea' and also in the Afghani civil and criminal laws. Suicide amongst men may remain hidden because according to the Islamic beliefs, suicide is a great sin. Men with suicidal ideation or attempt, may divert their belief toward the idea, that: if a person die for the sake of Allah, no one will ask him/her during doomsday and for them heaven is always open. Consequently, many men with suicidal ideation or attempt are going to die in a purposeful way rather than a condemned way, through participation in holy war (JIHAD) or suicide attack either inside Afghanistan or outside e.g. Syria, Iraq etc. However it is important to take into consideration the positive and negative aspects of religious believes during developing a suicide Prevention Strategy.

Suicide data in Afghanistan

There is evidence for inaccuracies of suicide statistics due to the criminalization of suicidal behavior, i.e. in countries where suicidal behavior is considered a criminal offence; cases involving suicidal behavior are often not reported to the police (Khan, 2007). The HMIS report in 2013 showed 1,146 cases of burnt, 1,445 cases of poisoning and 4,466 cases of only drug poisoning, and data was collected from only 5 hospitals in the Capital Kabul.

A Study of self-immolation by women on 2006 done by Medica Mondiale in three provinces (Kabul, Wardak and Herat) showed an estimated 2,300 women or girls were attempting suicide annually (2006). Cases of self-immolation, hanging, poisoning and exsanguinations were all registered this year. Although they did not go into further detail, Public Health officials said that cases of suicide have increased in Afghanistan.

Vulnerable groups:
*   Women especially young girls between age of 14 -19 years, which are most vulnerable due to gender base violence and violence against their rights.
*   Drug users: nowadays data showed 11% of general population is using some kind of drugs such as opiates, opioid, heroin, sleep pills or pain killers and hashish (INL Afghan rural drug survey result 2015).
*   Returnees and displaced people with facing acculturation.
*   Disables, family of martyrs.
*   Poor people/ jobless.
*   People with mental disorder and psycho-social problem.
*   People affected by serious infections such as HIV/AIDS, HBV and HBS.

Suicide and Psychosocial Support

The overall underreporting of suicide in Afghanistan is further evidenced by figures from the Health Management Information System (HMIS), showing that in the first 6 months of 2014 approximately 4,136 burn cases from 34 provinces were reported by HMIS, which according to health providers working in these settings, the majority of these cases represented self-inflicted harm or self-immolation.

Medica Afghanistan (an Afghan NGO) which was Medica Mondiale in the past (a German NGO) offers psycho-social support to women survivors of self -immolation cases in Kabul Rabia e Balkhi female hospital, Burnt Unit of Herat Regional Hospital since 2005. Afghan women and girls, continue losing their lives through committing self-immolation suicide (Medica Mondiale, 2006).

As part of the Mental Health System, there are community based programmes in Herat and Balkh, which are being implemented by the International Assistance Mission (IAM) and MoPH which is providing out-patient Mental Health Services and psycho-social support for people in need since 2003 (IAM, 2015).

Psychosocial Support Case

An Afghan woman, 23 years old, from Nangarhar province at the first time when she came to the mobile health team, working site, she had a small son with 3 months age, her husband went to Iran for work one and half year ago and she is currently living her father's home.

She came to the MHT site with signs of depression and she told her story like this:

When she gave birth her last child through cesarean operation, her husband's family had taken her out of the house and sent her to her father's house. In this time her husband was in Iran. She lives with a lot of life related problems in her father's home and her husband did not contact her since for one and a half year. She eventually got depressed, had sleep problems, lack of appetite, social withdrawal, anger, she had lost hope in life.

After she was referred to the program for Psychosocial support (PSS), the PSS counsellor provided her the primary consultation. In the second visit she seems very good psychologically and hopeful effects were visible on her face. She was able to bring changes to her life.

In the 3rd visit she was very happy and informed the counsellor that now she has good appetite, can sleep easily, can take care of her child who is of 3 months, her stress was reduced, she was able to perform her daily activities and identify her resources and abilities.

Besides, she informed the counsellor that 5 days ago she talked with her husband over phone and he will come back to Afghanistan after one month and will take her back to his house and that was very good news for her.

In the last visit she was feeling very good (physically and psychologically), was able to do self and childcare after the consultation. She was successfully discharged from the program and thanked (PSS counsellor) for effective and useful psychosocial support counselling, in this difficult time she was going through.

When we focus on the mobile team effectiveness especially, we realize that we can meet the minimum necessities for hundreds of people in need, in the remote areas of our country and people see it as a positive step in their life.

Conclusion

After almost 40 years of conflict and crisis, the vast majority of the Afghan population suffers from some form of psychosocial distress. The Mental Health and Psychosocial Support Service Working Group (MHPSS WG) is looking forward to continue working together, enhancing collaborative effort with all stakeholders, to strengthen MHPSS services & improve the quality of those services to save many Afghan lives and alleviate suffering.

Action Against Hunger has the responsibility of leading Mental Health and Psychosocial Support Working Group in Afghanistan. Around 30 NGOs who are implementing MHPSS are members of the MHPSS WG. The purpose of the (MHPSS) Working Group (WG) is to address the MHPSS needs of the various populations in Afghanistan, by providing overall guidance and coordination of MHPSS services, activities, and assessments, and advocating for minimum standards and sharing of best practices. The WG adheres to the general framework of the global Inter-Agency Standing Committee (IASC), following the IASC (2007) MHPSS in Emergency Settings guidelines, and collaborates with the Mental Health Technical Coordination Committee (MHTCC) in Afghanistan. The WG works to ensure that all stakeholders remain in line with the National Mental Health Strategy (2018-2023), as laid out by the Department of Mental Health and Substance Abuse (MHD), under the Ministry of Public Health (MoPH). The WG maintains a commitment to emergency preparedness, inclusive programming, and a sustainable, responsible, and minimum response.

Thirty NGOs who are implementing MHPSS are members of the working group and regularly participating in monthly MHPSS WG meetings.

The WG intends to address the various barriers and challenges in the provision of mental health services in Afghanistan, ensuring MHPSS is prioritised and mainstreamed, as an integral component, in humanitarian interventions.

In response to high level of mental health problems in Afghanistan, NGOs are providing psychosocial support through psychosocial support center well as online psychosocial support and through websites and phone calls. The NGOs conduct awareness campaigns on mental health and psychosocial issues, through multimedia, radio, television, IEC material, official webpages and platforms. MHPSS WG, NGOs in coordination with Mental Health Department Directorate of Ministry of Public Health of Afghanistan, is consistently working for capacity building training of frontline workers and MHPSS staff to better support the client and affected population in Afghanistan.

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"When I see him, I feel a sting to my heart". Children and young people whose parents struggle with substance use problems – short report from a qualitative study of living conditions

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Introduction

The title above is a quote from one of the participants in a Norwegian qualitative study on living conditions of children and adolescents (henceforth referred to as children or young people) with parental substance use problems (Kufås, Faugli and Weimand, 2015). All the participants had one or two parents with substance/ alcohol abuse. In this short report, we will briefly describe the context and findings, and then we will reflect on the findings and their implications for practice keeping in mind the present Covid 19 pandemic world- wide.

Better support for children

Since the early1990s, there has been a growing awareness internationally in legislation, policy and practice on the so-called "invisible children" (Ruud et al., 2015; Skogøy et al., 2018); young people with parental mental illness and/ or alcohol- or substance abuse (henceforth called substance). Greater awareness of the situation of these children led to an amendment to the Health Personnel Act, which came into force in Norway in 2010. This placed health personnel under the obligation to ensure better support for children of parents who suffers from substance abuse, somatic or mental health problems (Health Personnel Act- § 10a). The purpose of the legislation was to provide ill parents and their children relevant information and knowledge about the family situation, and to ensure children's safety and care during the parents' illness and recovery process (UN Convention on the Rights of the Child).

Alongside this Norwegian legislative change came a development of a considerable number of projects and programs to support these children and families in Norway (Kallander et al 2011). However, only minor changes have taken place in the relevant health services (Werner & Malterud, 2016; Skogøy et al., 2018). When the legislation came into force, service user organizations started the process of producing research on how these children experience their own, and their family's life situation, as well as their needs for support or help. Patient organizations argued that young people have experiences that surveys with pre-defined questions and responses had not been able to explore.

Within this context, the Norwegian Directorate of Health funded the present study in 2013 as additional funding to a Multicentre Study on children as next of kin (the Children of Ill Parent (CHIP) study) (Ruud et al., 2015), mainly funded by the Norwegian Research Council.

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The study – exploring children's life situation

The objective of this study was to explore and describe the life situation, living conditions, and need for help and support, from the perspective of children with parental substance abuse.

The study had a qualitative design. Participating organizations were the Organization Children of Drug Addicts (Barn av Rusmisbrukere -BaR), the National Association for Child Welfare (Landsforeningen for Barnevernsbarn LFB) and Adults for Children (Voksne for Barn - VfB). They participated in preparation of the interview guide, recruiting process and discussion of findings. Fourteen participants, young people aged 10-17 years from the southeastern part of Norway, were interviewed. One of the researchers (EK) met the participants in places according to their own request. Both the children and their parents gave written, informed consent of participation beforehand. The semi-structured interview explored the young people's everyday life that enabled them to give deepened descriptions of the questions under study. The themes revolved around typical regular days, positive experiences; their health and safety, school situation and friendships, the family's material situation, housing and economy, persons or places for support, if adults in the family was present or absent, and any topics the participants wanted to add. The participants were frequently asked to share "examples". To explore variations in the participants' experiences, the researcher could ask – is it always like that? - when the participants described their experiences, Other times they were asked to reflect back on earlier episodes.

The transcribed interviews were analyzed using a qualitative content analyse (Elo &Kyngäs, 2007; Malterud 2011/2013). Well-known research on children's living conditions (Unicef 2013) was a starting point. During the analysis process, an overarching theme emerged:"The context they are living in – whether the parents are intoxicated now or not". Issues, such as if the parent was in an active phase with substance abuse problems; to what extent the child was living in the same household as that parent in question;- whether other adults were at reach; and if the child was living somewhere else under safer conditions were of great importance for how children described their everyday lives. Furthermore, the analysis revealed three general categories of daily life experiences: "Handling everyday life in the family", "Participation outside of home" and "In need of help and support"

Handling everyday life in the family

The findings showed both struggles and coping with the situation, which seemed related to the present situation as described above. Example of statements showing the young people's resource, fullness and coping, were for example:
"Really – I'm leading a quite normal life"
"The only thing you need really, if you're in a situation like that, is someone you can go to"

The housing situation affected the participants in different ways. Most participants described their situation dependent on the conditions in the home, and if they had safe adults to turn to. A few talked about living in a poor residential area. In Norway, the welfare state must ensure that families with children have proper housing.

Handling everyday life in the family reflected relations with family members, the person's inner thoughts and inner conversations about hard feelings and safety. Several participants talked about how they never got any answers when asking parents or other adults   about their parent's substance abuse. No one gave them information, nor had they experienced that someone acknowledged their challenging situation.

"I had no idea, - not much knowledge- Then, about when I was in middle school age I got some information – I think that was when I understood-"

The oldest participants described their experiences of acknowledging negative consequences from growing up with parental substance use problems, and of sadness, anger and loneliness. These feelings were strongly related feeling as being victims of the parent's addiction, which could make them feel almost like an outcast. Further, albeit they could feel as belonging to a group sharing the same interests like sports, they also felt being different from friends. This made it almost impossible to share their experiences with their parent's problems with their peers, underpinning exclusion from the community of friends:

"Especially when it comes to the problems, I've felt that I was the only one who had it like that: who has a dad who's like that. The only thing I remember is that I'm sitting and crying somehow - I kind of don't remember why I cried, but I remember crying a lot then ..."

Several participants particularly described being very lonely:
"I sat in my room and cried."
The sadness and anger were among others tied to constant disappointments:
"When I came home and asked why she kept on (drinking), she said it would never happen again, but I knew that was just nonsense, since she had said it so often".
"I was very disappointed ... because Dad was going to attend to things that were important to me, he was going to give me things – it never happened. It made me disappointed! - Yes - I actually believed he would do something it (the drinking problem) - that he would fix it - or that he had fixed it. But he never did anything about it".

A recurring issue was unpredictability – The participants talked about how difficult they found it to not knowing what would happen from one day to the next. There were descriptions of unsustainable situations where the children's need for security was not taken into account by their parents. One example was untenable situations where the child lived with one of the parents who was addicted to drugs, and difficult conflicts between the parents. Such situations often led to insoluble dilemmas for the children regarding where to go: to the parent providing greater security or to the parent who could not provide care and safety, but who, in the child's opinion, needed him or her more.
"Mum told us to call, but we don't. If we did, we would feel guilty towards our dad."
"…It would have been better, I think, if I was less than a week together with him - It would probably have been nicer and maybe I wouldn't have experienced that many bad things –".

There were also stories of violence and neglect. Some children and young people experienced strain on their health and a threat to their safety because they had to assume the adult role in their families.
"She's someone who can just beat me – it was like that during my entire childhood –"
"In a way, I'm the dad – like, his role, then – and that's a bit disgusting - I had to do everything for my siblings-cooking and like that - I was ill with a fever and no energy order to do anything at all-"

In contrast to the burden of being responsible for siblings that some participants described, we found that participants without siblings in the household described experiences of deep loneliness. A significant factor of feeling safe and supported in everyday life for those who lived permanently or part-time with the addicted parent was the availability of a safe adult whom they could turn to, such as a relative, friend or stepparent without substance use problems.

Participation outside of the home

 "I got to know a boy before I started first grade. He's still my best friend and he knows all about everything…"
All participants attended public school. Some established long-lasting friendships in school, others described school as "straightforward", and yet others experienced school as an additional burden.
"It was difficult for me since there were many worries which affected school and friends"

Some enjoyed, and did well in academic subjects, while others highlighted activity, creativity and recess as more attractive. For some participants, the school was problematic both socially and academically. Some needed extra help to be able to concentrate, due to thoughts about the problems at home. Several informants had experiences with teachers as confidants, a person in their lives who would care and support them when they had a particularly difficult time. Through such descriptions, it became clear that these teachers were important for how the child managed these difficult situations.

This finding also show the importance of good friendships and social participation with peers.
We found descriptions of friends and peers having played a significant role and even could be said to having saved them during crucial times. Not all informants were as open to express their feelings and the situation at home. Descriptions showed that although the participants had friends, they were not hanging around with friends so often. The explanations given were shame, inferiority and fear of not being understood. Furthermore, some described a fear of exclusion from the peer group should anyone found out how things were at home.

"However – there are others who have it like... - the mother and father living together, lots of siblings and such things - what then; will they think about my family and me?"
Both organized and unorganized activities were highlighted, ranging from sports to just "hanging around". Many informants preferred exercise and various sports activities. However, the family economy reduced the opportunities for some to participate.

In need of help and support
This category reflects that although an untenable situation had lasted for a long time; the participants found it hard to know where to turn to for help and support. There were stories of how they spent time with heavy family caring tasks. One participant described that despite of own difficulties, he/she did not want to be involved in meetings with parents and his/her psychologist because he/she did not want to be forced to listen to the parents' excuses. The participant further described a lack of information and support, and not to be listened to; the psychologist only listened to the parents' story.

"Children have to talk to other adults – I simply wish they (other adults) knew what was going on … Wish there had been someone to talk to …"
"At least I have learned that you should never trust an alcoholic"
The participants gave a wide range of descriptions of needs and thoughts about life. The need for support was related to the present family situation, and in particular if the parent presently was misuseing or not. They described how having a parent with substance use problems is always on their mind. Furthermore, there was considerable conformity among the participants about the need for help and support. For all participants it was essential that parental substance abuse had to stop! Albeit help and support could have a positive impact, the main problem did not disappear.

The participants described in various ways a wish to take part in the professionals making decisions concerning support to the family or their own situation. Some descriptions were about experiencing that more knowledge about the parent(s)'condition could lead to better coping with their own situation and increased understanding of the parents' behaviour. In their everyday life's tough choices and challenges, such knowledge sometimes seemed helpful.

Experiences with different kind of peer groups and meeting places for children and / or families with similar problems were a recurring theme in the participants' descriptions of what they found to be supportive and essential, and that such meeting places could mean a huge difference in their life. Such arenas also meant that they could experience belonging and normality, which the participants' stressed as being essential. The participants further explained a need for places where they can share experiences regarding substance-use problems in the family, learn ways to cope, be strengthened, belong, and have fun together. The importance of "having fun" was a repeated statement.

Participants talked about Child protection services (CPS) and about dilemmas. They talked about positive and negative experiences:
"CPS – not so much for help – really - just a little worse -. When they got to school, it makes so much trouble for me. However, it was something good - a kind person was helping my mother painting a wall. She invited us out to eat and then talked a bit –
CPS can be helpful in a way – children want to play football, but it was so much money – then CPS pay the bill."
"I remember that I was afraid of being taken from my family –"
"If the child does not want to live with their parents, for example if the child is beaten, then it is not wise for parents to know where the child is protected - it depends on the situation ..."

Final reflections – implications for practise
The main message from the children in our study was that parents have to stop their abuse and search for help. Therefore, it is crucial that health services can offer effective treatment programs to parents with substance use problems and their families (Birkeland et al 2018). Another important message from the children in our study was how difficult it was for them to choose where to stay if the parents were divorced. To choose between the parents may be difficult, especially if the parents are in conflict and one has ill health. The final important message from the children in our study to be mentioned in this short report is the warning about domestic violence, loneliness and neglect. As they claim, this implies that children and young persons who have parents with substances use problems in some situations are in need of secure homes and safe adults.

Since the Covid – 19 pandemic reached Norway in March 2020 and the society locked down, many schools and other arenas were children and young persons in need can seek help or respite have been closed most of the time. The findings in our study show that children in families with substance uses problems run "under the radar". Lack of respite and visibility of these children and young persons may have a number of negative and dangerous consequences to them. Johnson et al. (2021) reported concerns from UK mental health personnel that social isolation among the service users contributes to poorer physical and mental health, less availability for mental health care, and increased risk for persons being exposed to abuse and domestic violence. Recently, in March 2021, the Norwegian Institute of Public Health published a "rapid review" on the effects of Covid – 19 on children and youth's wellbeing (Nøkleby et al 2021). The review emphasizes an increased load on already vulnerable children who experienced exacerbations in most areas of life. According to a recent Norwegian newspaper report, the police in Norway reports higher rates of domestic violence and neglect against children during the pandemic (VG, 2021).

More neglect and violence at home while lock down is for many Norwegian children with parental substance use problems becoming increasingly dangerous (BaR 2020). Their loneliness is increasing and they become more and more frustrated. The severity of the present and post-pandemic situation for these children is growing.

There is still much work that needs to be done. The findings in our study and the impact of the pandemic show that children in families with substance use problems run "under the radar" for various reasons. In the pandemic context, the findings in our study are of huge importance. Children of parents with substance use problems need the possibility to seek for resources and arenas outside the home, with friends, and in different social contexts. Unfortunately, the possibility for a respite outside home disappears while the community is handling the pandemic situation. Implementation of helpful solutions for children with a parent abusing substances and their families in health services is an ongoing challenge. Opening schools, organized sport activities and other healthy arenas with safe and caring adults and more social- and health personnel available may be one first step. Adults must be aware of that there are vulnerable children coming back to school and other arenas when the society opens up. They need a place where they can flourish and play as other children.

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The Open Dialogue pilot project in a Day centre in Athens: the role of mental health professionals in democratising mental health care

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Introduction

The Open Dialogue approach constitutes an alternative to traditional psychiatric care for individuals experiencing mental health difficulties, particularly psychosis. Open Dialogue marks an inherently democratic shift in mental health care by introducing service user social network (including mental health professionals) as an integral element of their recovery and psychosocial rehabilitation. The Open Dialogue approach attempts an understanding of mental illness on the basis of social co-construction whilst utilizing notions of polyphony and dialogue as underpinning the development of an essentially dialogical self. In this context, psychosis is viewed as a violent rupture of the person's personal narrative whilst the network's reflective function provides containment, regulation and mentalisation of the psychotic symptom and a reconstruction of the service-user's psychotic narrative, through the provision of meaning (Stylianidis, 2019b; Issari &Polyzou, 2013; Martindale, 2015; Lorenzini, Campbell & Fonagy, 2018). Existing limitations of the biomedical model and the often ambivalent attitudes of professionals with regard to service user rights further highlight the need for a structural reform in psychiatric care aiming at the democratization of mental health care (Stylianidis, 2019a).

The Open Dialogue approach re-conceptualizes dominant notions of mental illness and underpins an essential move towards psychiatric reform and service user empowerment, in accordance to WAPR's mission that values service user and family member experiences as important knowledge bases (Gordon et al, 2016). Within the context of the ongoing dialectic between service users, their families and society, the role of mental health professionals is being acknowledged as increasingly vital in promoting the psychosocial integration of service users and in challenging social stigma. In that respect, mental health professionals are at the frontline of any meaningful psychiatric reform through the assimilation and promotion of democratic, humanistic paradigms aiming towards a change of culture in psychiatric care across different contexts. In Northern Europe and the UK, the integration of mental health services and within them the implementation of practices such as Open Dialogue, seem to be effective particularly in young people during serious, acute psychotic relapses as compared to treatment as usual (TAU); effectiveness is assessed on the basis of

social functionality, return to employment or education, reduction of days spent in hospital and the individual's overall psychosocial rehabilitation (Seikkula &Olson, 2003; Seikkula et al, 2006; Seikkula, Alakare & Aaltonen, 2011). On the contrary, in Greece the model is far from being widespread with very limited active Open Dialogue networks (including various organizations and trained professionals) and a complete lack of research with regard to its implementation in existing mental health services.

The present research is part of a large-scale action-research project attempting to assess globally the introduction and implementation of the Open Dialogue approach within a multidisciplinary team of mental health professionals in the EPAPSY "Franco Basaglia" Day Centre for Psychosocial Rehabilitation in Athens. This comprehensive action-research (Issari & Polyzou, 2013) in collaboration with Panteion and NKUA Universities (Laboratory of Psychopathology, Social Psychiatry and Developmental Psychology and Laboratory for Qualitative Research in Psychology & Psychosocial Well-being respectively) aims towards an in-depth understanding of the impact of the Open Dialogue approach on service users and their families, mental health professionals involved in their care as well as the wider patient-network- professional constellation within an established mental health service. Since any change of culture in psychiatric care is plausible only when individuals that are directly involved (patients, family and professionals alike) feel actively engaged in the process of change, the present part of the project focuses on processes affecting mental health professionals and the organizational aspects of the reform. Taking on board earlier findings of the present research (Skourteli, Stylianidis &Issari, 2019), it is maintained that Open Dialogue requires a radical change of culture, both organizational and professional in order for it to be effectively applied; equally, a top-down introduction of the approach has been reported as being effective in the UK (Tribe et al, 2019). More specifically, the present paper presents findings emerging longitudinally from the introduction and integration of the Open Dialogue approach within an established mental health service in September 2018. There is a particular focus on the attitudes, dynamics and reflective function of the multidisciplinary team as well as the challenges and needs that emerged as a result.

The role and function of mental health professionals

Drawing from the constructivist paradigm and Mikhail Bakhtin's views on dialogism and polyphony (Anastasiades & Issari, 2014), the Open Dialogue approach proposes dialogue as the primary vehicle for constructing meaning and integrating psychotic experience into the dynamic reality that unfolds during network meetings. Within that notions such as capacity to contain uncertainty, respect, transparency and capacity for self-reflection emerge as principal aspects of the Open Dialogue approach that support the participation of all parts (service users, family, professionals) in the individualised care plan and overall decision making (Olson, Seikkula & Ziedonis, 2014; Freeman et al., 2019). Such traits do not refer to structured techniques or skills that can be conventionally taught but rather reflect humanistic qualities that may be cultivated and acquired experientially within the context of a democratic and ethical stance towards mental health (Seikkula & Olson, 2003). The creation of safety and trust within network meetings is facilitated by an accepting attitude of all views and regardless of therapeutic outcome. Mental health professionals are asked to participate in the dialogue not from a traditional 'expert' stance but through their authentic thoughts and feelings; they ought to avoid being directive, suggestive or interpretive and to contain any emotional response that may interfere with the network interaction and the reality that is being constructed through ongoing dialogical processes (Seikkula & Olson, 2003).

Dialogue and polyphony constitute the foundation of the Open Dialogue approach and essentially safeguard one's capacity to be heard in the uniqueness of their subjective experience, including psychotic ones (Bakhtin, 1986; Seikkula & Olson, 2003; Seikkula, 2011;

Olson, Seikkula& Ziedonis, 2014; Pavlovic, Pavlovic & Donaldson, 2016). Every participant, brings their own view of reality and through the tapestry of different views, a new commonly shared narrative evolves (Andersen, 1987); such polyphony both requires and promotes mutuality in respecting and valuing others' experience whilst viewing conflict as a meaningful opportunity for growth both for individuals and the network. In that respect, mental health professionals need to be engaged into active listening, promoting space for whatever emerges from the dialogue, without censoring it. They reform existing network narratives and promote every view, including their own, not from a position of privilege or expertise but as participants in the dialogue. According to Seikkula (2011), a significant portion of experienced and skilled mental health professionals present difficulties with the notion of dialogism; he goes on to re-iterate that a dialogical stance is not a method or a technique but a way of being with others. In that respect, therapists are required to participate in a meaningful, embodied and genuine way in the here-and-now in order to be able to respond dialogically in whatever emerges through network dynamics.

Therapist reflective capacity lies at the core of the approach and is crucial for mediating the triadic relationship between service users-family- professionals through openly discussing issues regarding individualized care plans, including medication or indeed in responding to the network's reflection upon their own (Olson, Seikkula & Ziedonis, 2014); in that process, mental health professionals of different disciplines need to challenge their own assumptions around hierarchy and to work towards the cultivation of a democratic culture within the organization (Seikkula & Olson, 2003). Therapist experience and specialization in a specific discipline may indeed be challenging for mental health professionals that are members of a multidisciplinary team as they may actively aim for targeted interventions or solutions perhaps as a means of regulating their own anxiety and need to control therapeutic outcome (Buus et al, 2017; Stockmann et al., 2017; Borchers, 2014; Schubert, Rhodes & Buus, 2020). Mental health professionals may indeed face challenges in integrating practices that are not taught but rather experientially acquired and require the adoption of a new modus operandi where transparency and acting from a non-expert stance are elementary; further research seems to confirm that Open Dialogue principles may often cause insecurity in mental health professionals that may lead to reduced participation and questioning of the model (Holmesland et al., 2010; Buus et al., 2017).
The introduction of novel practices within organizations

Organizational change transcends through different stages and impacts employee values and dynamics (Hussain et al., 2018). The success of any meaningful change depends on the access that employees have to information about new practices as well as the clear gains that are to be acquired from their implementation. As a result, new practices are assimilated and established in organizational structure and culture; the outcome of such a reform is mediated by professional attitudes towards change, anticipated gains, the complexity and nature of the change itself, the quality of the management in containing tension as well as traits and dynamics within the multidisciplinary team. Organizational change is processed on the basis of the pre-existing organizational culture, employee representations of change and fears regarding stability following that change; it is particularly helpful during this process for facilitators of change to maintain ongoing communication and transparency amongst everyone involved, particularly when the change is imposed in a top-down manner, in order to disseminate information, reduce team anxiety and promote a sense of inclusion as well as psychological and practical commitment (Armenakis et al, 1993; Herscovitch & Meyer, 2002; Weiner, Amick & Lee, 2008; Tribe et al., 2019).

Methodology of the present research

A complete account of the research setting within which the present project is being undertaken is presented elsewhere (Skourteli, Stylianidis &Issari, 2019). Data collection was undertaken through participant observation of the monthly Open Dialogue team meetings of a Day Centre's multidisciplinary mental health team from January 2019 to January 2020. The Open Dialogue team had been composed for educational purposes and in order for participants to familiarize themselves with the theoretical bases of Open Dialogue, to design and establish the strategic implementation of the approach, to experientially develop the team's reflective function and to observe and evaluate the introduction and integration of Open Dialogue within an established mental health service. Participant observation provided researchers with the flexibility to follow different groups of professionals within the organization and explore their thoughts, feelings and behaviour both implicitly and explicitly (Willig, 2015; Paschaliori & Milesi, 2010). One of the researchers kept analytical notes in every meeting for a duration of 12 months, including noting non- verbal behaviours and group dynamics; during initial stages of the research procedure, notes were mostly descriptive and data was collected prior to being analyzed however, following the emergence of initial themes new data was assimilated into existing thematic categories or were kept on hold to be interpreted at later stage in the process. The validity and reliability of the qualitative methods utilized were safeguarded through the participation of more than one researcher that ensured a multitude of views on analysis and interpretation of results as well as researcher reflexivity (Robson, 2007; Willig, 2015). In terms of methodology it is important to emphasize that the object of participant observation was the multidisciplinary team as a whole and the dynamics and interactions within it and not each participant separately; this further safeguards participant anonymity and confidentiality. Data were analyzed using Thematic Network Analysis aiming to identify themes or patterns that emerge from different levels of analysis that compose a whole network of local and overarching units of meaning thus synthesizing a comprehensive story with its constituent parts (Issari &Pourkos, 2015; Attride-Stirling, 2001). At some point during the research study, researchers decided to share some preliminary findings with participants in order to promote equality within the team, to inspire trust in the research process and to reduce anxiety levels within the team related to the research process.

Discussion of findings

Thematic analysis of the data revealed two distinct superordinate themes that correspond to two separate time periods with regard to the introduction and implementation of the Open Dialogue approach that reflect the longitudinal progression of the multidisciplinary team in relation to the new model. The first period referred to as 'Introductory- Exploratory' (January- May 2019) reflects the attitudes, practices, emotional responses and group dynamics during the initial acquaintance with the model whilst the second period referred to as 'Introductory- Systematizing' reflects dynamic changes regarding the professionals' attitudes, practices and emotional responses towards the Open Dialogue approach between July- January 2020. Organization of the data longitudinally is approximate and aims at highlighting the global ongoing changes of the professionals' team in relation to the introduction of the new model. The proposed time distinction seems to be facilitated by the decision from the part of the research team to disseminate preliminary findings with the rest of the participants; this opportunity for sharing and reflection as well as some changes in the organizational structure seem to have facilitated the multidisciplinary team's move from a passive and frightful position regarding Open Dialogue to an active and extrovert position of active and systematic implementation of the model to clinical cases. Taken together, superordinate themes and subthemes reflected within the two analytical models create a coherent story about the team's journey with Open Dialogue over time; this journey illustrates the readiness of mental health professionals to adopt a radically humanistic approach as well as the challenges and main issues that emerged throughout this process.

Preliminary findings of the first 'Introductory- Exploratory' period regarding introduction of the Open Dialogue approach in the Day Centre have been extensively reported elsewhere (Skourteli, Stylianidis &Issari, 2019) and will only be referred to briefly in the present paper in order to better highlight change over time. In summary, the 'Introductory- Exploratory' period revealed themes such as 'the multidisciplinary team as an agent of change', 'ambivalence towards the Open Dialogue approach', 'practical difficulties with implementation' and 'participant identities'. The second 'Introductory- Systematizing' period again included the ever-changing themes of the 'multidisciplinary team as an agent of change', 'critical acceptance of the Open Dialogue approach', 'clinical implementation of the Open Dialogue approach', 'extroversion' and 'emotional openness'.

The 'Introductory- Exploratory' period

The notion the multidisciplinary team as an agent of change, as emerging from participant data, essentially refers to the notion of responsibility and the associated fears for impending changes in the team's usual ways of working. During the initial introduction of the model, the multidisciplinary team feels that is in a position of passivity and disempowerment and has no choice but to accept a top-down implementation of the Open Dialogue approach. The research itself is viewed as part of a vertical hierarchy that imposes the new approach; group dynamics are affected, and initial stages of the introduction are marked by anxiety and suspicion. Within the context of the democratic nature of the Open Dialogue approach, it is important to note that issues of power and control seem to dominate during the introductory period with pre-existing power dynamics amongst professionals being re-evoked thus creating a fragile, antagonistic and fearful climate among the professionals in the team. Ambivalence towards the new model seems to be particularly prominent within the team and reflects a desire to both expropriate and to challenge the newly introduced approach. The team initially attempts to manage the introduction of the Open Dialogue approach by equating and assimilating it to already existing representations and practices by actively seeking points of convergence between established and novel approaches perhaps as a means of maintaining a sense of control within a highly insecure period. At the same time, introduction of the Open Dialogue approach is accompanied by significant mistrust both with respect to its principles as well as the possibility of its clinical application, which seems to be characterized by fears of being criticized as well as about the model's efficacy. This ambivalence by the team is expressed through limited participation in Open Dialogue initiatives such as inconsistency in being prepared with reading materials, late arrival in meetings and procrastination with ongoing issues; the team views the initiative as a necessary evil that has been imposed by management. There does not seem to be a binding substance that facilitates a deeper engagement of the team with Open Dialogue. Instead, during this initial period, the team is preoccupied with various realistic obstacles in implementing the approach on one hand (limited infrastructure, staff availability, lack of formal training), whilst beginning to experiment with applying it in some of the service's most difficult clinical cases, perhaps in an attempt to prove the impossibility if its implementation in Greece and thus to defend itself against overwhelming feelings of uncertainty. In short, during the 'Introductory- Exploratory' period, it appears that the multidisciplinary team's sense of identity is being threatened, as employees in the Day Centre, as experienced mental health professionals and mostly as social subjects along the axis of mental health and illness. It appears that although attractive, the democratizing and deeply reforming nature of Open Dialogue is challenging and evokes deep insecurities within an established team of mental health professionals, who feel unprepared in engaging with it (Skourteli, Stylianidis &Issari, 2019; Schubert, Rhodes & Buus, 2020). Symbolically, the sense of disempowerment expressed by professionals in this instance may indeed reflect the sense of disempowerment service users often experience, when not meaningfully included in their psychiatric care.

The 'Introductory- Systematizing' period

Over time and following some structural changes within the service as well as the dissemination of preliminary findings by researchers, the team seems to gradually move from a position of passivity to one of responsibility and agency with respect to the introduction of the Open Dialogue approach. Whilst during the initial period the team has been characterized by passivity, inertia and a lack or initiative, over time it seems to move into an active position and reform into an agent of responsibility and change. Team dynamics seem to change, and a common sense of purpose emerges that evokes collaboration and partnership. In-group conflict subsides and there is a move away from issues of power and authority and towards the creation of a common identity inspired by Open Dialogue principles. Monthly team supervision, introduced as part of the research protocol from the onset of the project and consistent with Open Dialogue principles of polyphony and dialogue, has significantly facilitated the necessary space for reflection on group dynamics, containment of anxiety and ultimately the creation of a collective vision for the implementation of truly humanistic practices in psychiatric care. Although there may still be doubts and fears among professionals about how to work in an openly dialogical way, this no longer constitutes an adverse factor for its implementation. Reading and reflecting actively on the way that the team relates to the new model provides invaluable opportunities to systematize the approach, explore what works and what doesn't without fear of criticism and respond adequately to practical challenges. The Open Dialogue team becomes more defined, empowered and seems to develop its own separate identity. As a whole, it becomes more extroverted and confident in liaising with other Open Dialogue networks, both in Greece and internationally and actively seeking opportunities for formal training. Ambivalence is also replaced by an attitude of critical acceptance that seems fertile and further promotes the emergence of different views; although the model is still not fully accepted by all, the team assesses its potential and sincerely attempts to incorporate it to existing practices. Team members are interested in understanding the philosophical basis of Open Dialogue and openly participate in meetings, which are now clearly defined in terms of structure, purpose and regularity. The addition of a new colleague, trained in the Open Dialogue approach, within the team, is particularly important as it seems to facilitate others' reflection and interaction within the group without assuming an expert position. Such extroversion reflects the professionals' team openness to reach out to other organizations, networks and individuals that share the same view on Open Dialogue as well as promoting their own work outside the context of the Day Centre, with increased presence in national and international workshops and conferences. New ideas rush into established practices and inform a more dialogical view that expands beyond clinical practice but into the common identity of the Open Dialogue team that moves from dichotomy to integration and from a position of passivity to one of empowerment and responsibility. At the same time, members of the Open Dialogue team are more involved in aspects of clinical implementation, effectiveness of the models (thus more accepting towards the notion of research) as well as maintaining good practice and group supervision in work with service users and their networks. Open Dialogue cases are closely monitored and reflected upon; the issues of diagnosis, interpretation and practical dilemmas in working with the service user network are not absent but are viewed more dialogically; clinical implementation allows professionals to realize that Open Dialogue is not a matter of technique but rather a way of being with another. Participants report experiencing being more present and authentic during network meetings whilst moving away from fears of being criticized; their sense of professional identity is integrated with Open Dialogue principles without the conflict that characterized the first introductory period. Importantly, the Open Dialogue team is able to reflect upon and assess their journey throughout this process, to gain confidence and insight whilst maintaining a realistic view of their practices and ongoing needs.

Conclusions

The present paper aims to highlights the pivotal role of mental health professionals in cultivating a new philosophy and practice in psychiatric care though presenting a multidisciplinary team's journey with Open Dialogue and its transition from a monological to a dialogical epistemological stance. It seems important to highlight that even within innovative mental health services that are committed to the principles of recovery and empowerment (such as the Day Centre), there are still significant collective defenses that may stem both from the threat to one's professional identity and the deeply rooted impact of the paternalistic model in psychiatry (Stylianidis, 2019a). Nevertheless, the team's ambivalence and critical attitude towards the model seems to have facilitated the emergence of a new way of being both with service users, their network as well as with peers within a mental health service (Hussain et al., 2018). The present action-research project is ongoing and seems to have advanced the implementation process not only on a theoretical and clinical but also a personal experiential level for both researchers and participants alike. The perspective of consolidating and embracing the Open Dialogue approach may further advance ongoing attempts towards mental health reform and a change of culture in mental health care with benefits on a micro, meso and macro- levels of society.

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Perspectives in mental health

NEVER JUDGE WHAT YOU DO NOT UNDERSTAND

i may behave weirdly aggressively or rudely

in your eyes

some may judge it like that
and blame me for that as well

i do not tell lies
i speak facts
without emotional entanglement

i only see the world from a different angle

you may have misunderstood what autism truly is

i am autistic
with a complex post traumatic disorder

to small talk, to hug and to socialize are not my favorite activities at all

too much of it makes me melt down
it overstimulates me
even if sometimes it feels pleasant
and i am enjoying

i appreciate and need silence
a lot of alone time
to regenerate
to tap into grace

i enjoy thinking reflecting analyzing
and to dedicate my entire life to my interests
most of the time alone
peacefully and gracefully

alone does not mean lonely
i never feel alone
but
i feel the loneliness, the emptiness of our societies where acceptance is almost absent. a sad reality where
mindless behaviors have taken over and chained hands and hearts of many

hands and hearts full of hidden agendas
bathing in money
suffocating to the last champagne bubble

many have lost themselves in mindless activities
it looks like a collective spiritual suicide
magic pills and vaccines everywhere
what a deluded humanity
when animals on their own continue to live peacefully, as nothing happened, unworried about what will be
food or not
owner or not
shelter or not
only pure love
i bow to that knowledge

people do not know anymore what is violent and what is not

yes i am autistic
i do not need any fix

because i already work hard on myself
every single day i aim for non-violence
in a so violent world that purpose is needed
i am a perfectionist
no one can do my work for me anyway

i am passionate about learning
about knowledge
i am highly curious
extremely sensitive
i see and understand differently
i function, respond and learn differently
because my brain functions differently, it is autistic

nobody can change me - change my brain structure

i am born autistic
there is no need to change me either

i am autistic

i am happy

you can think whatever you want about me

others opinions never define who i am

notice that in life
i always follow my heart, my passion - what makes my music play beautifully

i am not a people follower

i am a free being

an independent thinker

i am autistic
artistic if you prefer

i do not care about what others think about me

life is magic because i make it magical majestic magnificent

i paint me free

i ride me free

i sing me free

i dance beautifully
to my own colorful tune

i am rainbow
thinking in both black and white
in all gray nuances

amazing

keep all the gifts i give you

for
freedom cannot be bought anyway

i appreciate everything
given unconditionally
understood and worshiped for its true value
for what it is
its great possibilities
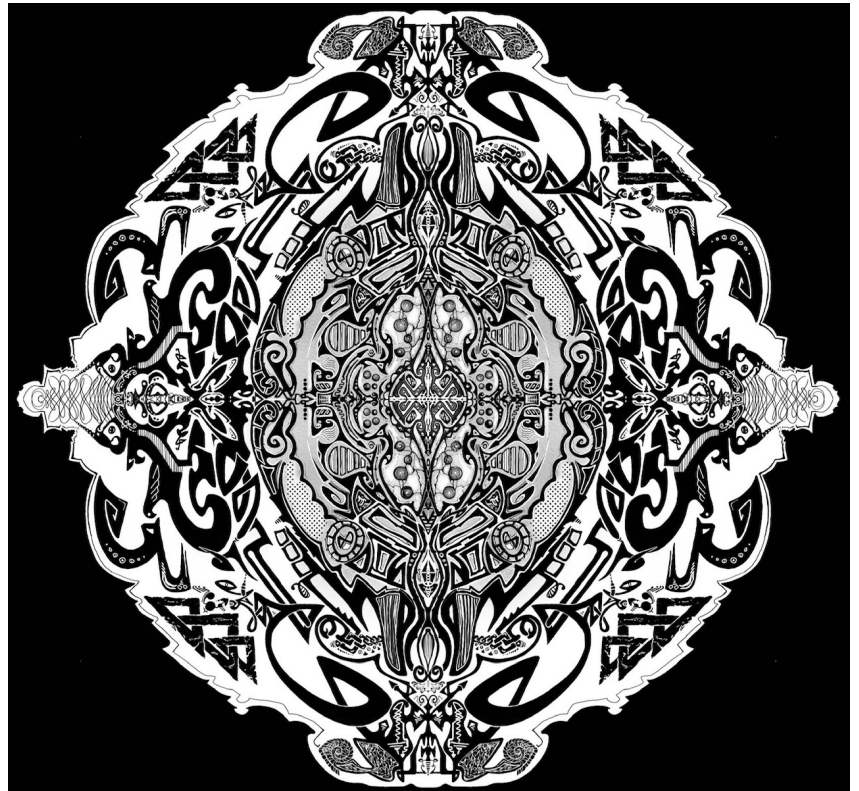not limitless for sure

less is more

thank you

be well
keep well

☀ ☀ ☀

micah oliver clémence
mic♡ārt

Thinking in both black and white - **mic♡ārt**

I am rainbow - **mic♡ārt**

Recent Research
by Esther Ogundipe, Assistant Editor / PhD Research Fellow, University of South-Eastern Norway

Recent Research
Esther Ogundipe
Center for Mental Health and
Substance Abuse
Department of Health-, Social-
and Welfare Studies, Faculty of
Health and Social Sciences.
University of South- Eastern
Norway

Introduction: "Dugnad" is a Norwegian word, which refers to a collective effort/job, that is unpaid for but still done in order to aid the community or an individual person. During this pandemic, the word has been tossed around a lot. The politicians are using it frequently and so are the leaders in my local community. The word has even found its way into my child's kindergarten. I am not complaining, but I am wondering where the spirit of dugnad is when it comes to addressing other issues in the community. For instance mental health and substance abuse. In the recovery literature, we see a somewhat disappearance of the spirit of dugnad as well. In the sense that, although recovery has for the past decades received a growing interest in mental health and substance abuse services, the social aspect of recovery, where the contribution of the community is in focus, has remained a relatively neglected dimension. With this in mind, I wanted to give attention to papers that focuses on social recovery. Both papers presented in this issue focuses on initiatives within the community that has the potential to promote recovery.

This article explores the use of community sport as a means to enhance levels of social capital, positive social identities and social inclusion within the community. More specifically, the article explores the specifics of a community mental health football project, through the utilization of the personal and social recovery frameworks within the mental health evidence base. In this study seventeen semi-structured interviews with participants and staff were conducted. Furthermore, and, as a deliberate departure from existing research, the authors chose to adopt a deductive, theoretical approach to the analysis that located the data within the personal recovery and social recovery literature. Both participants and staff were considerably positive about the football sessions, and data suggested an adherence to the empirically based CHIME personal recovery framework. In terms of alignment with the social recovery concepts, the data was particularly robust in supporting active citizenship processes, which can increase levels of social capital and enhance social identities. The authors concludes that future work is required to further explore the contextual impact of poverty and employment, and the role that sport can potentially play.

Benkwitz, A. & Healy, LC. (2019). "Think Football": exploring a football for mental health initiative delivered in the community through the lens of personal and social recovery. Mental Health Phys Act., 17, 1–9.

Recovery on the Pitch: Street Football as a Means of Social Inclusion.

This paper focuses on the value of street football teams in recovery. In this paper, persons with mental health and/or substance abuse problems experiences with participation in street football teams are

"Think Football": exploring a football for mental health initiative delivered in the community through the lens of personal and social recovery

explored. In total, 51 persons experiencing mental health and/or substance abuse challenges who played in street football teams, in Norway, participated in focus group interviews. Data were analyzed using thematic content analysis, and resulted in three major themes: (1) The spirit of the football team, (2) More than just a pitch, and (3) The country's best follow-up system. Overall, the paper highlights the importance of community and communal efforts through acts of citizenship, in facilitating and promoting social inclusion for persons in challenging life situations. The paper shows how street football is one measure than can be helpful in this context. The authors recommends that communities, policy makers and funders should acknowledge and

gain more insight and understanding of the value that street football teams represent. They also note that there is a need for further studies exploring what contributes to community in our highly individualistic society.

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Life during the Corona Virus: View from the Ground
Marianne Farkas

Some countries are ending their «stay at home» policies and now have had some time to experience what it is like to reopen. Some countries are seeing a resurgence of the virus, just when they thought it was over. Some are seeing an increase in infections and deaths in parts of their country, that had escaped the brunt of the pandemic until now. World wide protests about racial and social injustice have sprung up, underscoring the upheaval of this period. By this point, we have all been living with the uncertainty of this crisis for some time.

The newsletter «Life During the Corona Virus: View from the Ground», reflects a compilation of experiences through the pandemic collected by myself, Marit Borg and Michail Lavds from WAPR members, their colleagues and friends. Through the 3 issues completed since March 2020, we have collected stories reflecting how stakeholders in mental health and rehabilitation are managing their lives during the pandemic. For example, how people with lived experience of mental health conditions are being served and are living with the pandemic? How professionals, families, communities are managing, and what innovations are being created to manage the effects of Covid?

We hope to continue to share these brief snapshots, including some humor and resources, with our global community to keep us connected and perhaps even inspired by each other's stories.

Note from the editors:
The stories that follow were submitted by the authors between June 2020 and January 2021. Since they were part of the newsletter, which was published in the form of "diaries", they were posted with the first names of the authors. Since, they are now included in the Bulletin, full names were used along with titles where submitted. We are deeply valuing equally personal experience from all those who trust us to publish their stories.

You can access the newsletters already published here: http://www.wapr.org/covid-19-resources-and-experiences/ or you can click on the following covers:
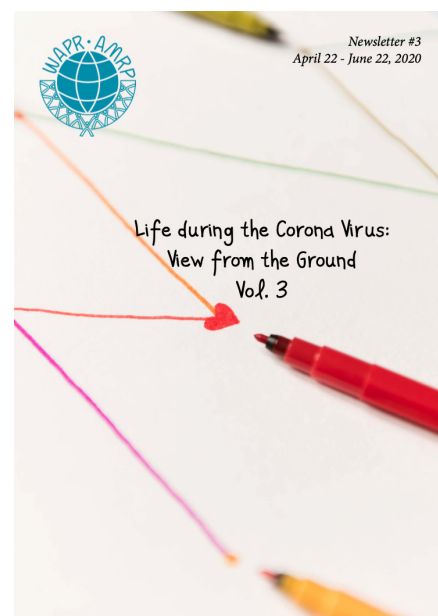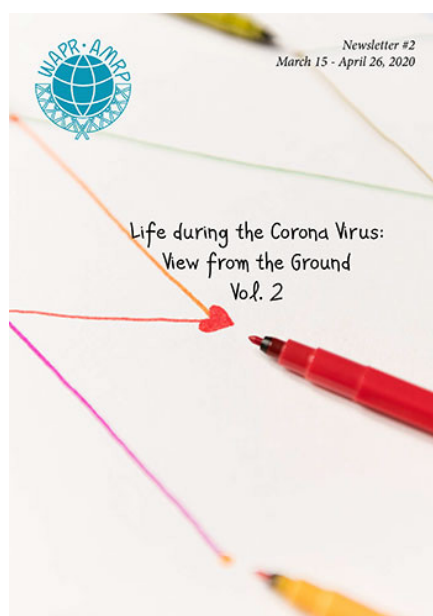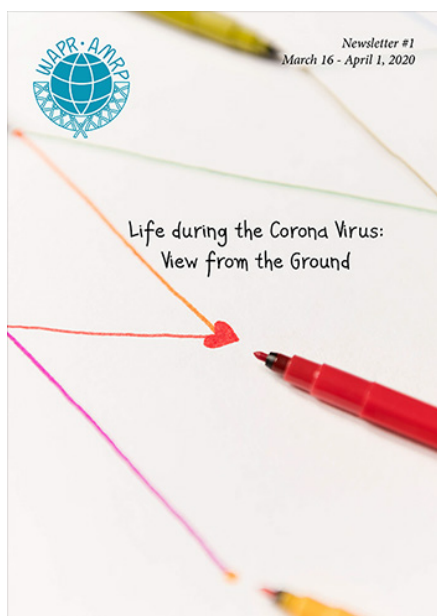
View from the US (Boston)
by Courtney Joly-Lowdermilk

College Mental Health Services at the Center for Psychiatric Rehabilitation, Boston University, offers programming for college students, living with mental health challenges. Individualized services, on campus and distance learning opportunities are designed to help students develop the health, supports, resilience and academic skills needed to thrive and achieve their academic, personal and wellness goals.

On a cold and windy fall afternoon in October 2019, the College Mental Health Programs (CMHP) team at the Center for Psychiatric Rehabilitation, in collaboration with the Yellow Tulip Project, invited the Boston University and Boston-area communities to build a Hope Garden, sowing hope for all those who live with and love people who live with serious mental illness. Together 500 yellow tulip bulbs were planted. Until the heavy snow set it on Boston, 500 yellow flags symbolically waved, signaling to passers-by that we were holding hope for all. Our message was simple: change does come and recovery and thriving are possible.

We had no idea then how greatly we'd value the reminder of hope and hopefulness come spring when we would all be in recovery… "developing new meaning and purpose in our lives as we grew beyond the catastrophe…" of COVID.

A reality of holding hope is the uncertainty you sit with, over the passage of time. Throughout the dark winter months and into the spring, the CMHP director and Community Hope Garden project coordinator, messaged the community of planters and gardeners, students and colleagues, reminding them that while we can't observe the "growth beneath" it was happening. A video of the budding bulbs circulated at the same time the world was beginning to understand the scope of the outbreak of Coronavirus Disease 2020. Through the darkness and hopelessness of March, April and May 2020, 500 tulips peeked through the ground, reminding us to hold on.

On Saturday, March 14th, 2020, more than 90 workers, students, and family members who were actively enrolled in the in-person, Boston-based NITEO and College Coaching programs, were informed that effective Monday, March 16th programming would move online. In those approximately first 48 hours was drafted in the ink of compassion. The plan laid out how to support and encourage students and families through the remainder of the spring semester remotely, a plan that would be coined, "Plan C". We listened deeply to the quickly shifting and emerging needs of the community, and what students and families were experiencing, amid the loss of familiarity, security, and normalcy. We listened on weekend phone calls and late-night Zoom meetings. We listened through texts, emails, and socially distanced front-lawn visits to drop off technology to families in need. We listened, and what we heard was the disappointment of wanting to learn in person the fear of moving home when home life was unstable, and the anguish with all the uncertainty. Many of these complex challenges were out of our control. Still we created spaces for people to share and through the sharing connect and belong. We first "opened the door" by picking up the phone, offering community listening sessions, and hosting town hall meetings. The trusting relationships we built were, and remain, the foundation of "Plan C". The relationships help people hold on. The relationships help us move on.

From listening, we built a wide range of virtual, online programming. The programmatic adaptions we made were co-authored with our students and families and often in real time and just a half a step ahead. We were building the plane as we flew it. To an outsider, this can seem unsettling, even irresponsible. To a true believer in psychiatric rehabilitation steered by the principles of personhood, choice, and empowerment, it makes perfect sense. Involving our students and families in the planning and construction, we reminded them their voices and choices matter, we are listening, and we believe in you. With students, we built out new classes and curriculum, staff office hours (Zoom room drop-ins for anyone looking to chat, share, ask), study halls (quiet Zoom rooms for writing or working with company), staff-led workshops (on cooking, comedy, and more), and student-led activities (JackBox games, Harry Potter club, and more). From our kitchens and living rooms, we continued to provide the same authentic learning environment and experience students had in person. These spaces, built with students for students, generated further belonging and hope, and the creative process breathed new life into CMHP altogether and harkened staff back to the roots and core values of psychiatric rehabilitation.

Despite the occasional stopped video share, despite different time zones, and the despite the bumpiness that is inevitable when you're innovating, we've persevered. The programmatic and organizational thriving we celebrate today is a lot like the celebration of the tulips in full bloom. We hold hope, and hope carries us through.

Link for the in-text video: https://www.youtube.com/watch?v=0JITuZY38_g

View from England (Nottingham)
Being physically ill with mental health problems during a Pandemic
by Debbie Butler

The few weeks before Christmas I was aware that I was exhausted all the time, my mood was dropping and everything was becoming too much to bear. It was like clinging on by my finger tips to the edge of a very high cliff edge. However, I did hang on and bore the tiredness until two days before Christmas when I discovered a rash. It developed really quickly, one minute it wasn't there the next it was. My initial thoughts were that it looked like Cellulitis which I had in the same place a few years ago for which I was hospitalised for a week. It was quite late in the evening when I discovered the rash so it impacted on my fear of the dark. That may sound daft but a grown woman being afraid of the dark but I have lived with the fear all my life, it starting with nightmares as a child that the house would set on fire every night when I went to bed. Following the discovery of the rash I rang 111 to get their opinion. They were quite concerned when I said that my previous experience of cellulitis had me hospitalised. The next step they were to take was to get a doctor to ring me. They said it could be up to six hours' time. By that time, it was 11pm and I was pretty worried about being woken up in the night by a phone call from a doctor that could diagnose me over the phone. Off I went to bed, preparing myself for a disturbed night. Luckily the night wasn't too bad as a doctor called within 30minutes of me getting into bed. I was still awake so it wasn't too bad. She was very polite but said it didn't sound serious and recommended that I call the GP practice in the morning. This I did. This was the first time I had called the doctor since before the pandemic set in and I wasn't sure of whet the procedure was for getting to see a doctor. The initial call I spoke to a receptionist who was very good at explaining the route my call would take which did put me at ease. Again, however I was to wait for a call back from the nurse at the surgery. Again, I had to entertain myself whilst waiting for the call. It was midmorning by now so my partner and I went out for our walk. By the time we got back the nurse had rung and asked me to send some photos of the rash. This was quite embarrassing as the rash started on my bum my hip and the top of my leg. The nurse rang back with a diagnosis of Shingles. I was grateful it wasn't cellulitis as I was pretty scared of going to a hospital. Hospitals to me at the moment are places to fear. All my life I haver been in and out of them and always felt very well cared for, now however the thought of attending brings about very dark thoughts. The diagnosis of Shingles therefore came as quite a relief. The nurse prescribed me some medication which we picked up the same day and we were off on the road to recovery. Little did I know how low it would make me feel. Shingles is a painful condition as it runs a long a nerve The tablets were ginormous and I knew I would have trouble swallowing them I remember my mum saying you shouldn't cut tablets up. (Don't know the reason why) I have great difficulty swallowing following a minor stroke a few years ago so had no alternative but to cut the tablets I had been given.

The above took place two days before Christmas. When the big day arrived, we were able to spend the day with my daughter and her family, her husband and their two children. I was in a lot of pain but didn't want to spend the day at home. I wanted to see the children open their presents.

So, on reflection, being physically ill during a Pandemic with something other than the pandemic illness has been a difficult time for me and my family. My Anxiety has been heightened, my mood has been low and I have lost a lot of confidence Its difficult to see people have other illnesses in this difficult time but having lived with another virus other than COVID-19 has been difficult. But you must reach out and get help to aid your recovery from normal health issues.

Stay safe,
Debbie Butler
Nottingham England

View from Denmark
When the world is upside down - the strengths of lived experience during the COVID-19 crisis
by Nis Bjarnhof

*The Outsider is a NGO run by service users, where you can do volunteer media-work. We have 200.000 –
300.000 annual readers.*

To broaden the Danish discussion about 'the vulnerable' during the COVID-19 crisis, we asked the question
no one else dreamed of: Can you actually feel stronger in a crisis, when you have lived experience?
*"Being sick and hospitalized was unbearable and painful. It is not unbearable that the daily routines are a little
bit different – that I can manage"* - questionnaire on lived experience during the lockdown.
To prevent the spread of COVID-19, Denmark was among the first countries in Europe to lockdown.
Presented as a means to 'take care of the vulnerable', 'protect the elderly' and 'shield the defenseless', the
lockdown included all non-essential functions of the public sector, including many mental health services,
unemployment services, general social services, GPs and much more.

Following the lockdown, the number of admitted psychiatric patients dropped below half, even though
the wards were kept open. In consequence, the Regions of Denmark, a central representation of the Dan-
ish healthcare system, 'sounded the alarm,' foreseeing significant and critical problems if those in need kept
staying at home[1].

All levels of the Danish health authorities and interest groups voiced heavy concerns for people with mental
health issues. Among others, the Danish professor and leading psychiatrist Poul Videbech offered a hasty
explanation of the "missing patients". According to the professor, people were 'biting their teeth', 'staking it
out,' battling an ever-worse depression or anxiety without help, and were 'too afraid' to contact their doc-
tors[2].

The general concern uttered was that the socially vulnerable would 'fall like flies' without the usual support
from the social services. In other words, the empty beds in the wards were just an 'eerie silence before the
storm.'[3]

Better – not worse!
At The Outsiders first big online meeting after the lockdown, we were surprised to hear that most of the
volunteers were far from worse. In fact, we – 'the vulnerable' - that everyone was so eager to protect, were
actually doing better than usual! Contrary to what many politicians, mental health experts and the general
opinion had concluded (without asking us!), the volunteers did not feel increasingly anxious, depressed,
worried, or stressed. Quite the contrary!

We decided to investigate the matter further by conducting a questionnaire via our Facebookpage. We asked
mental health service users to share their experiences during the corona-lockdown. We chose to explicitly
focus on what difference their lived experiences with mental illness made.

83 respondents helped cast further light on our initial experience and some further themes. Six out of ten
felt that their lived experiences were an advantage during the lockdown. The respondents mentioned is-
sues such as being more in control and knowing how to structure time when the world doesn't do it for you.
Also, having already gone through crisis before, many were secure in the knowledge that it will pass. Only
one out of four respondents described increasing anxiety due to feeling more alone with their problems.
A common theme among the respondents, pertained to the lessening of expectations from their surround-
ings: many experienced less weight was put on their shoulders – both from their peers and from the support
systems. No more family get-togethers, no more expectations of fancy vacations, no more calls from the
unemployment office, and no appointments with many different case-officers, each with their own idea of

how to help. Overall, this meant that many appreciated the lockdown measures as a welcome break from the daily hassles and a possibility to 'move at their own pace'.

Additionally, the respondents repeatedly mentioned the 'liberating feeling' of knowing that the lockdown meant that everyone else was living the same way as them. Many with mental health issues live more isolated than most. Being physically and socially isolated was normalized during the pandemic. Under these exceptional circumstances, staying home felt more like a contribution to society than something to be ashamed of.

Our questionnaire did show, that many with mental health issues are dependent on one person being there for them. It doesn't matter if it is a neighbor, a case-worker, a peer – just someone to share the real burden, which for many was not the virus, but the general doubts about living on the outside, combined with the stress from the normal high life space.

What stands out to us, is how the system and general opinion refer to service users as weak and itself as the only helper. Maybe we need to be more aware of how the help sometimes can be the problem and how much people can do themselves. We hope we remember everything we learned from Corona.

Nis Bjarnhof,
The Outsider
Denmark

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(1) https://politiken.dk/forbrugogliv/sundhedogmotion/art7751999/Danske-Regioner-sl%C3%A5r-alarm-Hvor-er-de-sindslidende

(2) https://ugeskriftet.dk/videnskab/stilheden-stormen-om-psykiatrisk-sygdom-i-coronaens-tid?fbclid=IwAR3AtrqjILQYSewnMnw1mQj-UMSQOmZGtEreOs1nJGapAdegw8aUut62W5Y

(3)https://www.berlingske.dk/kommentarer/mikkel-rasmussen-er-laege-i-den-akutte-psykiatri-der-er-en-uhyggelig

View from Kenya
Mental health services in woodley kibera pre and during covid-19 pandemic
by
David M. Ndete
Frida Kameti

Over the last few decades, the growth of mental health services in Kenya has been fueled by educational, economic, and political events. Early national campaigns addressing the need for family planning, HIV/AIDs education, and post-election trauma services increased awareness about the lack of mental health services across Kenya. In 2007, after the post-election violence in Kenya, Africa Mental Health Research and Training Foundation (AMHRTF) formed a partnership with the Woodley Clinic, which serves Kibera residents, the world's second largest informal settlement after Soweto in Johannesburg, South Africa. Over the years and with the support of the Peter C. Alderman Foundation (PCAF), AMHRTF established a thriving mental health clinic in the Woodley Clinic to help address the mental health difficulties of local Kibera residents.

I have been running the Woodley clinic providing individual, family, couple's and group counseling. I have also been providing psychoeducation to increase mental health awareness in a bid to reduce stigma. Until recently, services were running smoothly and many people were getting the help that they needed at the clinic. Before COVID-19, people were oblivious of things like social distancing, quarantine and isolation. As seen on the picture, clinics sometimes felt like one big happy family gathering.

Due to COVID-19, we have had to change how the clinic is run. As people come through the main gate, their temperatures are taken and recorded. No one is allowed into the compound without a mask. We have a huge water barrel, soap and sanitizer at the main gate where individuals are asked to queue while maintaining social distance to wash their hands. We have seats arranged outside and people sit waiting while observing social distancing. Clients answer a brief questionnaire during triage/intake to establish if they have been in contact with any infected person or if they have traveled recently. Only two people can be served at any given time in the mother and baby clinic. They have also reduced the number of services they are offering to prevent any spread of the Corona virus. For instance they do not recommend a parent bringing a child to the clinic just to have their weight taken. They are only offering urgent services such as immunizations, HIV counseling and testing, pre-natal and postnatal services. A lot of public health sensitization has been done at the clinic regarding the spread, myths, and prevention measures of COVID-19. Clients continue to be given opportunities to share their diverse and complex stories and process the impact that COVID-19 has had on them and their livelihood. Talking to the nurses, clients report an increase in intimate partner violence, unemployment, gender based violence, substance abuse and complicated grief arising from those they have lost to COVID-19.

Like many new initiatives, the mentalley Clinic is overburdened by the compandemic has intensified the situation. government has been of great help in the clinic by providing supplies needed period. Staff members have PPE and are needed. With strong partnerships and AMHRTF is hopeful that sustainable

A picture of the clinic since the outbreak of Corona Virus. Such a contrast from above due to social distancing.

health team at the Wood-munity's needs and the However, the national supporting the running of especially during this able to offer the services government support, and long-lasting change will be possible for the Kibera community long after COVID-19.
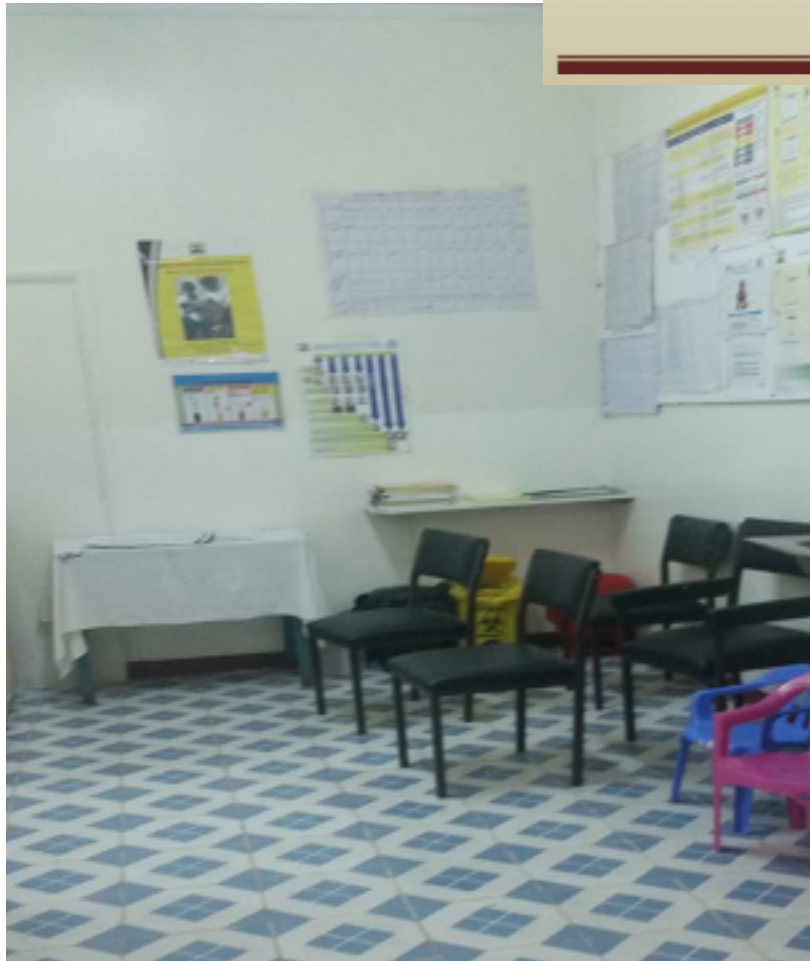
Although the stories of this community can feel overwhelmingly heartbreaking, there is an underlying sense of resilience and hopefulness in the community. Clients convey their thankfulness towards the AMHRTF presence through sincere words at the end of sessions, by referring neighbors and family members, and sometimes simply by returning time and time again. We are truly humbled to be part of this community in our own little ways.

David M. Ndete
Frida Kameti
Nairobi Kenya

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View from Bangladesh
Life during Corona Virus
by M. Tasdik Hasan

I am trying hard to cope in this changed scenario. Working from home is not a new thing for me but with the overwhelming stressors induced by the pandemic are making everything exceptionally challenging in this trying times. Being a mental health professional, I often feel stressed, helpless but at the same time when I complete a relevant activity (i.e. contributing in a paper related to COVID-19 and mental health, presenting in a webinar, mental health advocacy activities etc.) I feel content. I assume any relevant contribution in COVID-19 response is making me happy whilst all regular work assignments are sort of exhausting and tiring considering uncertainty around those projects now. I am deeply affected with unpredictability around the progression of the pandemic and the inconsistent responses from the policy makers of my country. I do not visit patients directly being a researcher, though in this pandemic I am attending a couple of patients, referring them to experts and organizing series of basic stress management workshops mainly for front-line health care workers. They are extremely stressed; clinical depression is evident and many of them are having continuous panic attacks. COVID-19 patients (either recovered or under treatment/isolated), their families are suffering to a great extent. Many of them have expressed their concerns on financial insecurities in relation to mental health in this hard time. Lack of insufficient mental health care services and limited telemedicine facilities to support such disorders have widened the treatment during the lockdown. Whilst researching on the issue, I felt an intense need of implementing remote and periodic stress management interventions with effective delivery of social media-based advocacy materials to teach people on basic sign/symptoms of anxiety, panic attack, suicide, depression etc. with proper (clear and directive) guidance of referral (when to report & where) for SMDs (severe mental health disorders). Psychosocial skills are much needed to be delivered using mass media though these need to be culturally adapted and linguistically accepted before dissemination. I am following only authentic information sources (WHO, CDC, IEDCR etc.) relevant to the pandemic, avoiding all misleading or unauthentic information and suggesting the same using my social media handles repeatedly. I do believe we need to continue our efforts and contribute in our respective field of expertise to effectively address COVID-19 induced consequences. There is a life beyond this pandemic & we should believe that we will win over this virus.

WAPR NEWS AROUND THE GLOBE

WAPR Brazil

Despite the bleak scenario of the pandemic, WAPR Brazil seeks to build partnerships in South America

The entire world is devastated by the Covid-19 pandemic. In Brazil, the daily number of deaths has been increasing, with the terrible average of 2,500 daily deaths in the months of March and April 2021. "April is the cruelest month", we can read in the poem The Waste Land, by T.S.Elliot. In Brazil, the devastation of the pandemic is becoming more serious, due to the adverse political situation, with a far-right government that is destroying the public health and education system, devastating the environment and stimulating violence, through laws that increase the distribution of weapons to the population.

In addition to being the global epicenter of the pandemic, Brazil has been seen by the countries of the world as a country marked by the accentuation of social inequalities, with an unemployment rate of 14% of the economically active population, and an extremely fragile policy of distributing financial support. for families affected by the economic recession caused by the pandemic.

In the midst of such an unfavorable scenario, community mental health services remain in operation, albeit precariously. There are 2,600 Psychosocial Care Centers (known by the acronym CAPS). They are open, public services, that provide care to patients with severe mental disorders, and are distributed throughout all regions of the country, and continue to provide care, in person or remotely, to their users. Remote service has expanded to all municipalities, with face-to-face service restricted to the most urgent situations.

In all this scenario, the Brazilian chapter of WAPR, WAPR Brasil, has been participating in health education activities, through the promotion of online debates, bringing together professionals, users and family members from various regions of the country.

The main question discussed has been : how to ensure mental health care despite the barriers to access caused by the pandemic?

In September 2020, the debate "Psychiatric reform in times of pandemic and democratic collapse: resistance through local experiences", brought together participants from different regions of the country, and was accompanied by more than 800 simultaneous spectators. It was the start over of the WAPR participation at a national level, since experiences from Amazonian, Northeastern states and the central-western region of the country were reported.

In February 2021, WAPR Brasil held a National Seminar with the theme "Psychosocial Rehabilitation in Brazil today", which was attended (by remote means) by more than 200 professionals, users and family members from all over Brazil. The entity's board of directors was restructured, expanding to include representatives from the South, Southeast, Northeast, North (Amazon region) and Midwest regions.

Despite the restrictions of the pandemic, this has been a moment of revitalization for the Brazilian section of WAPR.

In addition to expanding its connections between the various states of the country, the Brazilian section of WAPR participated in two activities carried out in partnership with colleagues from Peru, Chile, Argentina and Spain, to discuss the theme of "Mental Health Care Systems and the Pandemic: Asylum vs Community". The Seminar, in two stages, took place on September 23th and 30th, 2020, and had the support of the Manantial Foundation, in Madrid, Spain (a philanthropic organization that is part of WAPR).

As an action to strengthen the partnership, the national sections of WAPR of Brasil and Chile formed a permanent working group to organize initiatives aimed at Social Cooperativism and Mental Health. The theme of social cooperativism and the conceptions and practices of the solidarity economy have been recognized as an important component of the vast field of Psychosocial Rehabilitation.

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WAPR Egypt
Report of the Egyptian Psychosocial Rehabilitation association (EPSR) activities 2013 - 2020

The Egyptian Psychosocial Rehabilitation Association, EPSR, was established in 2013 in Cairo, It includes a distinguished group of personalities working in the field of psychiatry and psychosocial rehabilitation, It started its activities during those years, and a five-year action plan was drawn up in the following fields:

Psychosocial rehabilitation of the following :
1. Cognitive deficits in chronic schizophrenia
2. Learning disabilities
3. Cancer Patient (Post-operative and after chemo. Or radio therapy)
4. Out Patient addiction rehabilitation program (the Matrix Model)
5. Chronic viral hepatitis patient (HCV, HBV)

Research has been completed in fields 1,2,3. An applied programs had been developed and implemented for the psychological rehabilitation of psychiatric patients and those with developmental disorders from children and adults, such as:
a. Program for developing cognitive abilities of troubled children.
B- Program to develop the mental abilities of schizophrenic patients.

Both are used for outpatient clinics and inpatient departments in psychiatric hospitals. Tangible positive progresses are reported and final results are being drawn on it.

Work is in progress to complete the last two fields 4,5.
- The Foundation arranged Art Therapy Training course in cooperation with Abou EL azayem Hospitals and the Canadian International Institute for Art Therapy (CiiAT) for nine consecutive days, with a total of 80 training hours Implemented by each of:
1. Dr. Lucille Proulx a Canadian art therapist, artist, and published author 2. Dr. Michelle Winkel CiiAT Clinical and Academic Director, Art Therapist.

- Work is underway with the acquired skills in dealing with candidate cases.

Preparation for the implementation of (2) training courses for workers in the field of psychological rehabilitation under the title of :
"Certified Psychiatry Rehabilitation Practitioner - CPRP"

"Certified Child and Family Resiliency Practitioner - CFRP "

In cooperation with:
Prof. Dr. Veronica Carey- professor of Psychiatry& Rehabilitation Drexel University Philadelphia – USA.

But we were not able to actually implement them due to the world's exposure to the Coronavirus pandemic, which caused the suspension of all means of transportation and the cessation of all activities that include gatherings, including scientific courses all over the world, including Egypt, as a precautionary measure to reduce the spread of the epidemic, so the two sessions were postponed to a date to be determined later, As soon as health conditions allow it.

During this year 2020, focus was placed on work in the field of the Coronavirus (SARS- COV. 2) pandemic, and a working group was formed of specialists under the name (Crisis Intervention Team) that includes specialists in the following fields: Virology / Epidemiology / Virtual Learning, which ended with a research protocol. Concerning awareness raising activities about the pandemic including the following elements:
1. An epidemiological study to monitor the frequency of numbers of patients admitted to psychiatric hospitals during the pandemic and the results of screening cases complaining of corona among them, in conjunction with hospital laboratories. Four psychiatric hospitals were chosen in the governorates of Cairo (Nasr City - New Cairo), Giza (Ayyat City) and Sharkia. (Tenth of Ramadan City), which has a distinct demographic diversity between urban, rural and industrial cities. All hospitals are affiliated with Dr. Gamal Abu El-AZAYEM Psychiatry hospitals.
2. Awareness-raising educational seminars were held for specialists and non-specialists in the field of awareness of the emerging virus, methods of infection, symptoms and means of infection control, through various social media platforms such as ZOOM and Microsoft Teams applications.
3. The Foundation, in cooperation with Abu Al-Azayem Hospital and Edraak Psychiatry Clinics (private outpatient clinics specialized in the field of psychiatry), carried out a number of scientific and educational meetings to rehabilitate patients with the Corona virus and those who had contact with them who suffered psychological damage because of that.
4. A cooperation protocol has been set up with two schools, one of them for general education (Al-Muukhtar Language School) and the other for people with special needs (Abu

Al-Azayem School for Mental Disabilities) to train educational staff to make educational cartoon films and to use appropriate educational methods and means to educate students about the pandemic and how to deal with safety measures in society during this period.

5. The application of investigative field research for isolated patients infected with the Coronavirus under the title ((Self-report of the most urgent ideas during the isolation period for Corona patients)) has been started to monitor and explore the pathological conditions and accompanying psychological changes so that these results can be published under WAPR auspices.

6. Arabization and standardization of the IMR (illness management and recovery) program, in order to standardize concepts and therapeutic steps in the field of psychological and social rehabilitation for chronic mental illnesses. This program is being implemented in preparation for monitoring results.

These axes are still in progress, and the necessary statistics for the results have not yet been made, and this will be done at the end of the year.
1. Conference activity during the previous five years: Establishing the integrated psychiatry conferences for the previous four years in association with The Egyptian Branch of WAPR, Al-Azhar Medical College (psychiatric department), Ain Shams Medical College (psychiatric department) and Ministry of Education, ARE.
April, 2014 Multi Axial Approach in Psychotherapy : Honorable president prof. Dr. Hashem Bahary, professor & head of psychiatry department, Al- Azhar University .
President Dr. Hanan Ghader, director of community mental health department, mental health secretariat.
March, 2015 (Integration of Biological and Psychological Factors in Psychiatric Management).
Honorable president prof. Dr. Safia Effat professor & head of psychiatry department, faculty of medicine, Ain shams university.
President prof. Dr. Tarek Asaad professor of psychiatry department, faculty of medicine, Ain shams university.

March, 2016 (Recent Therapeutic Approaches in Mental Health, integration of Drugs and Psychosocial Rehabilitation Approaches).

Honorable president prof. Dr. Ricardo Guinea, president elect of WAPR .

President prof. Dr. Ahmed Saad professor & head of psychiatry department, faculty of
medicine, Ain shams university.

April, 2017 (Neuro – Biological Basis of Rehabilitation).

Honorable president prof. Dr. Ricardo Guinea, president elect of WAPR .

President prof. Dr. Ahmed Saad professor & head of psychiatry department, faculty of
medicine, Ain shams university.

September, 2017 (The first Regional Conference of Educational Psychology: (Confrontation of Contemporary Problems of Education))

Honorable president prof. Dr. Adel Abdulla Mohamed, Ph. D.& Dean of faculty of disability Sciences and rehabilitation, Zagazig University.

President prof. Dr. Amany Saeida professor of educational psychology, vice dean faculty of graduate studies, cairo university

March, 2018 (Stress and Mental Health)

Honorable president prof. Dr. Ricardo Guinea, president elect of WAPR .

President prof. Dr. Ahmed Saad professor & head of psychiatry department, faculty of
medicine, Ain shams university.

September, 2018 (The Role of Educational Psychology in Developing the Contemporary Educational System)

Honorable president prof. Dr. Abdulla Askar, Prof. of Psychology & Vice President of Zagazig University.

President prof. Dr. Amany Saeida professor of educational psychology, vice dean faculty of graduate studies, cairo university

April, 2019 (Preventive Psychiatry)

Honorable president prof. Dr. Ahmed Saad professor & head of psychiatry department, faculty of medicine, Ain shams university.

President Prof. Dr. Muraly Thayloth Professor of Psychiatry, President of World Association for Psychosocial Rehabilitation (WAPR).

September,2019 (Integration of the Branches of Psychology to Promote Mental Health: Clinical Psychology, Educational Psychology and Preventive Psychology)

Honorable president prof. Dr. Safaa Al Aaser Prof. of Psychology, Girls Collage, Ain shams university.

President Prof. Dr. Emad Mekhemar Dean of Fuclty of Art, Zagazig University.

providing scientific and administrative support in the international scientific conference for measurement and Evaluation, which was held by zagazig university(Chief, prof. Dr. Mohamed El-Morry).

scientific and administrative participation in the clinical medicine conference, held by faculty of medicine for males Al- Azhar University.

Scientific participation in the AUC conferences regarding the cognitive behavioral therapy (CBT) .

The Association had a scientific research center and a periodic cultural scientific journal (Reassuring Soul Journal - مجلة النفس المطمئنة) to publish its researches.

Examples of this research:
Research in learning difficulties.
Research about (developing cognitive skills program for troubled kids) .
Program to improve mental functioning and cognitive impairment of schizophrenic patients.
The cognitive behavioral therapy for sexual obsessions.

ALL the Documents available upon request.

Honorary President:
Egyptian Psychosocial Rehabilitation Association

Structure Of The Association
P. Dr. Ahmed Saad, Head of psychiatric Department, Ain Shams University. -President:-
P. Dr. Naglaa Abo El-Azayem, P.Dr at faculty of medicine, Al- Azhar University. -Vice President:-
Dr. Mohamed El-Kady, Clinical psychologist PHD .
Committee Members:
Dr. Hanan Ghadiry, Psychiatric consultant & Eastern Mediterranean Reg. Deputy V. P. of WAPR .
Secretary
MR. Ehab Mahmoud El-Bindary, lawyer .
Members of Board
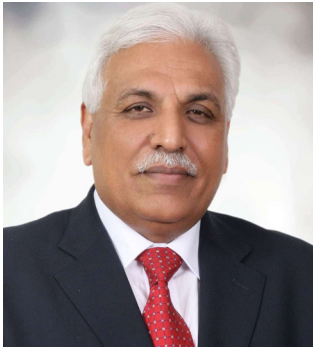- Dr. Manal Elewah, Representative of the Egyptian Society of Cancer Rehabilitation .
- Dr. Mona El-Sharabasy, Psychiatric Consultant .
- Dr .Somia Abdel Hafiz, Pharmacist & Human development consultant .
- Ms. Mona Abdel Salam, Clinical Psychologist.

Report from the World Psychiatric Association
Afzal Javed, WPA President, WAPR Past President

World Psychiatric Association is extremely happy about the success of 20th WPA Congress (WCP20) that took place from 10-13 March 2021. WCP20 was WPA's first Virtual WPA Congress, but it was truly a unique experience for more than 3000 participants.

Just like WPA's normal congresses, we found experts from all around the world discussing the latest trends and developments in our field using the latest virtual technology.

WCP20 highlighted inter-organizational collaboration by inviting various professional organisations, non-psychiatrist groups & many NGOs to participate in the scientific programme. WAPR & WPA Section on Psychiatric Rehabilitation leaders participated in many invited, special & submitted sessions including:

• Panel discussion: From failure to success in working with family carers
• Interorganizational Symposium in collaboration with The World Association of Psychosocial Rehabilitation: Rehabilitation and recovery: future perspectives
• Interorganizational Symposium in collaboration with Fountain House & Club House Europe & International: Working with persons with serious mental illness in the Community
• Global psychiatrist associations joint session – Strengthening alliances
• Panel discussion: Mental health and public health
• Presidential Symposium: The impact of Covid 19 in immigrants, refugees and asylum seekers

Thanks to WAPR & Section leadership for their support and participation in this academic event.
Their participation in sessions covering many topics related to recovery, rehabilitation, service developments, strengthening partnership with patients, families and carers groups and many other related topics were rated as sessions in demand.
Please note that these and many other sessions are still available to the registered participants in our recorded sessions on the congress website.

Some of the other salient features of the congress were:

• The participants enjoyed a truly immersive and personalised virtual experience. We were able to share the new, fully personalised, interactive virtual platform with more than 3000 participants from wherever we were in the world.
• WCP20 was spread over 4 days filled with inspiration, learning and networking along with several symposia, scientific presentations, e-posters. Debates, panel discussions and virtual exhibition and networking with colleagues. Thanks to Prof Norman Sartorius & Prof Helen Herrman for their efforts to shape the programme of the congress that has certainly met the expectations of our membership.

• Live Sessions and pre-recorded sessions. With over 190 sessions (including, plenary, accepted symposia, special lectures, panel discussions, presidential symposia etc.), the scientific committee prepared an exceptionally interesting and diverse scientific programme that was all available live and on-demand to watch at participants convenience!

• Networking with peers: Even though we were virtual, participants still have the chance to engage with and learn from world-renowned international practitioners, researchers, and professionals. We joined in chats and video groups, sent questions to presenters, and of course, connected via social media.

• The Virtual Exhibition hall discovered the latest developments from the industry at their booths and were available to speak directly with the organisation's/company's representatives.

• Learn on-demand was an exciting experience from the virtual platform. Registered participants were able to access the entire scientific content whenever and wherever they want for up to 3 months after the congress.

• CME credits: Participate in the scientific programme were eligible to receive 31 CME credits attributed to the WCP20 Virtual Congress.

• WPA TV: Through our new virtual studio, a unique and exciting experience, we were able to view the worlds' leading mental health experts discussing current global challenges.

• And last but not the least, Social Event with mind reader - Shane Black was a fun congress experience, still available on congress website to all registered delegates. From astounding feats of mind-reading to unbelievable demonstrations of influence, not only we were amazed, but were inspired to implement some of these tactics in your daily practice!

Whilst WPA would of course prefer to meeting congress participants in person, I am confident that this virtual congress is still an important scientific event contributing extensively to the psychiatric and mental health world.

Furthermore, WPA continues in strengthening its link with other organisations. This will indeed be a step forward in achieving excellence in mental health & promoting joining efforts for our mutual work.

Thanks for your patronage
Afzal Javed
WPA President
Past President WAPR

World Association Psychosocial Rehabilitation

WAPR

USEFUL LINKS

In this section we offer links important for our field. If you have suggestions for websites and links, please mail the Editor: *marit.borg@usn.no*

Convention on the Rights of Persons with Disabilities:
http://www.un.org/disabilities/default.asp?id=150

Toolkit and information about policy and implementation of human rights and recovery perspective can be found in:
http://www.who.int/mental_health/policy/quality_rights/en/

Implementing Recovery through Organisational Change:
http://www.imroc.org/

Yale Program for Recovery and Community Health:
http://www.yale.edu/PRCH/

Movement for Global Mental Health
http://www.globalmentalhealth.org/

The Gulbenkian Global Mental Health Platform
http://www.gulbenkianmhplatform.com/

The Mental Health Innovation Network (MHIN)
http://www.mhinnovation.net/

Mental health publications can be downloaded from the links below or ordered from the WHO bookshop:

The WHO Mental Health Gap Action Programme (mhGAP):
http://www.who.int/mental_health/mhgap/en/

The WHO Mental health action plan 2013 – 2020:
http://www.who.int/mental_health/publications/action_plan/en/

WHO QualityRights Project:
https://www.who.int/mental_health/policy/quality_rights/en/

WHO MiNDBank (online databases of good practices worldwide):
http://www.mindbank.info/

World Association Psychosocial Rehabilitation

WAPR

WAPR 2018 - 2021

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World Association Psychosocial Rehabilitation

WAPR

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