



ISPS Newsletter - Summer 2020

Dear members of ISPS and friends,

The whole world is in struggle against the Covid-19 virus. This virus, just a particle that cannot 'live' on his own but needs a host, can destroy the host on whom it depends. Although it shows no respect for borders and it makes no distinction between people, the consequences of the lockdown in the struggle against this virus are so unjust. The pandemic is the hardest for those people who live alone, for homeless people and for those who struggle to survive economically at the edges of our society.



When a person, staying in a hospital or in a nursing home for elderly, cannot survive the virus he is condemned to die without the intimacy of his loving family or friends due to the forced quarantine. Of course he is surrounded by medical staff who make every effort to give a human farewell. Pulmonologists tell us that the dying process of Covid-19 is not so hard because first you sink in to a deep coma. This can give some consolation, but the impossibility to be present and to touch your partner or your family member during the last moments of his/her life makes the farewell process and the mourning much more difficult. I wish the people, who have lost their family members or friends, much love and warmth in this heavy period. But we realize that the virus is the most cruel to those people who die on the street or alone, locked into their houses without anyone around them. The pictures of these terrible circumstances will remain burned on our retina forever and confront us with the value and the need for human proximity during traumatic times.

Not only medical staff, who are seen as soldiers on the front line, but all of us are at war with an invisible enemy that creates a paranoid attitude between people. When a human being is in crisis or feels uncertainty, 'being with another person' is the most helpful method to survive. The paradox is that we all have to keep 'social distance' to fight this pandemic while we need human proximity. My concern goes to **all** those people who live alone and who miss this proximity and the contact with the skin of another human being. We know that all forms of online or telecommunication cannot offer the same consolation and safety that we all need during this crisis.

But besides all these bad feelings we also see good things. We see a new kind of **solidarity** between people: for the first time we are discovering the richness of a good neighbour and so many volunteers who have started to help other persons in need. We see **creativity** in the sewing of mouth masks, the creativity of musicians who reach people at home, the creativity of people who started writing and creating poetry, the creativity of grandchildren who make drawings for their grandparents locked down in their homes. We see more **respect and mainly more awe for nature** that arises again after the winter break. The trees show us their most beautiful blossoms, the birds are preparing their nests and their love songs sound louder than before because they are not disturbed by human noise. The flowers appear in their most variant colours and we can breathe much more healthy air now the traffic does not pollute our sky anymore. But above all we see that **people ask more than ever existential questions**: what are our real needs and real aspirations? What is essential for our spirit? Some people believe that this pandemic has forced ordinary people and policy makers to reorganize life in such a way that true values will continue to exist after the crisis. Does this crisis will give us the opportunity to leave the neoliberal, meritocratic organisation of our Western society behind us? And will a new society grow with inclusion, solidarity, empathy, human proximity, respect and a real awe for nature? No one can predict the future but there is a lot of hope that the virus will change definitively our life in a positive way, despite the misery we are confronted with.

All these existential questions remind us that many people see psychosis as an existential crisis. ISPS has a specific task and challenge during this pandemic. In the letter of the EC, written by Debra Lampshire and Dag Söderström a few weeks ago, we heard: *'On reflection it appears that the world is getting a small glimpse of what it is to be someone with lived experience (of psychosis) for the exclusion from society is part of our norm. The loneliness, the sheer boredom, the assault on our personal rights are concerns that confront us on an almost daily basis. It would seem that loneliness is now an 'issue' for the general population, where it has been a tenant for those of us with lived experience for many years. We would assert that actually people with lived experience are well suited if not even better equipped to deal with this pandemic than our 'chronically normal' compatriots. This is not to infer that all*



CORONAVIRUS STORIES

We are addressing this letter to people with lived experience of psychosis, to their family members, and to professionals.

The corona crisis has brought significant changes to our interactions with each other. While the crisis may be even more challenging for people living with psychosis, we have also heard stories of resilience - that some people with psychosis susceptibility are doing well or even better than others in this period.

We want to gather the experiences of Corona-time - your stories. We want to hear from people with psychosis susceptibility as well as family members and practitioners. These stories will serve as the starting point for an international Webinar, which ISPS will hold in June. Looking further ahead, the stories could provide questions for future qualitative research.

Why are we so interested in your experiences during the pandemic?

One of the objectives of ISPS is to investigate the relationship between psychosis and the environment. Now that there are profound changes in the relationship between people, this is a unique opportunity to learn from experience, including learning about the strengths of psychosis susceptible people.

We have drawn up three broad questions to enable you to tell your story:

1. What have your experiences been since the beginning of the pandemic and did your experiences change over time?
2. What changes did you notice in the relationships between people with psychosis susceptibility, family members and other loved ones, and practitioners? What was the effect of less contact with the environment and social distancing? What was the effect of other ways of contact that came into use, such as video and phone calls, greetings across the street, etc.?
3. What changes would you like to take forward into the future?

Your story can be up to 2 pages long. Please include a summary of a quarter page. You can also create and send an audio recording. All these stories will be presented, anonymously if you wish, on ISPS website (provided that you give us permission for this).

Please send the stories to isps@isps.org by 6th June.

If a qualitative research project is initiated from this material, we will contact you in order to get your acceptance to use it in the research.

SAVE THE DATE!

A webinar: "Learning from experience, from each other in Covid-19 time"

On 25th June 2020, 21:00-23:00 (CET)

More information coming soon

THE STORIES SO FAR...

Our recent call for stories, about your experiences during this Corona-time, have resulted in us receiving nice stories from people with lived experience, their family members and professionals. They are very interesting and very diverse, as you can see below. A summary is difficult, so with the consent of the writers we are publishing them in full here and on our website.

My Story

Both my wife and I have a susceptibility for psychosis. My last psychotic episode was 5 years ago. The corona situation is, personally speaking, an opportunity to counter my side effects of psychosis, like being afraid to call or pick-up the phone. The crisis forced me to be more communicative and it goes just fine. Moreover, I feel a bit protected against the negative effects of isolation, just because I have known this kind of isolation during the years in which I had my psychoses.

My wife just had an episode of psychosis two weeks ago. It's difficult to describe why, but a provoking factor was the sense of urge to help other people with psychiatric problems, especially during these corona times. The helper loses herself in helping. Nevertheless I am delighted to see that her resilience has improved over the years. She recovers quickly."

Miguel van den Bedem,
Belgium

“BECAUSE ME, I AM OFF THE MAP”: A short first person narration about the experience of quarantine by a woman with severe psychosis in Greece

I'll tell you, being in quarantine (...) I feel anxiety, but I also celebrate it. There is both weakness and anxiety, and the best antidote for them is indifference.

But everything will be fine. The devil is very strong, sickness, the rotten thing, is very strong. This time, however, I say, no, I like it at home, (...) I feel secure, there was a time when I couldn't stand it, and felt like committing suicide. Now I'm fine, as though a miracle has taken place.

Before the quarantine, I was in very bad shape.... But now some day I thought: Why should I commit suicide since I can be well? On the other side, my anxiety is worse than everybody else's anxiety. Because me, I'm off the map.

The good God puts these anxieties out here, to test the people and make them stronger. God will punish the sickness one day.

Anonymous, Greece

A Carer's experience of lockdown during the Coronavirus crisis

I would like first to give you some background against which I am responding to your email. We celebrated my son's 40th birthday on Thursday. He had a diagnosis of paranoid schizophrenia at age 21, and has been detained more than once. I became a member of ISPS in the hope that he might be helped by a psychological approach and had years of misgivings and challenges with Psychiatrists about medication. He was prescribed clozapine within a few weeks of first admission, and has now been back on clozapine for several years. As his mother, I am resigned to this being the best compromise for his quality of life. After a flat on his own, he had several years in a MIND rehabilitation centre in the previous city from which we moved in November 2018. I was able to arrange for him to live in a shared house with an organisation providing care for people with serious mental health conditions. As previously, he was spending 3 nights every weekend with us. During the week he had the opportunity to attend a variety of sessions including Music, Art, Creative Writing, and going out into the Community for City Farm, allotment, and swimming. Staff are impressed with his attendance and commitment. Now, both we ourselves and the organisation with which he lives and are in lockdown, with no sessions. Staff arrange for him to Skype me once a week. My husband is 82 and has bronchiectasis and I will be 80 in June. However, one of our daughters (the reason for our move) meets him every Saturday, observing social distancing, although she finds it stressful to have to keep reminding him to "keep away" due to cognitive 'damage' he has suffered. They go to our family allotment and then on to talk over the garden wall with us. On his birthday we celebrated with a meal and cake in the garage, our son seated at the back surrounded by candles and a happy birthday streamer and our daughter with 2 young children near the door, and my husband and I just outside. His other sister and 3 young children in London joined us via Zoom.

Our son appears no different from usual. Can his condition be understood as due to his psychosis, the effects of medication, and how far the result of experimenting with street drugs in his youth, I still wonder. Yes, I always have a sense of a wall and limited communication since the development of his "illness". When he spent weekends with us prior to lockdown, I was aware of his frequently responding to voices sub voce. The present situation does not seem to have facilitated any increase in dialogue. He doesn't seem to have the capacity to say "Now you understand what it is like to live like me" However, he does not seem unhappy and when leaving often indicates he is looking forward to the time when he can return to the routine of spending weekends with us, which he expects to happen "in a few weeks". He seems also to like spending the week where he lives.

I took the liberty of forwarding your invitation to the organisation with which he lives and this is the Manager's response:

"Thank you for sending this article through, it is a very interesting insight and perspective. I will pass this on to the team as I think it's a useful topic for us to consider during this time."

Anonymous, United Kingdom

What Experts by Experience have to teach us: A Mom and son perspective by Pat Wright and Gabe

As I pondered this question that was recently sent in my email I decided to have a talk with my son, an "expert by experience" in the world of "extreme states and unusual beliefs". I was grateful our timing was good, a lucky break for me as our communication is not always easy.

He talked to me about the following ideas:

Having a caring person to talk to was the first priority, meaning an available person able to listen to whatever is going on even though it may be difficult. I confess to numerous times where I felt unavailable to listen to what my son was saying, I was reacting to my own feelings of either "how did I cause this" or "how can I fix this?"

Being able to do some problem-solving for example in order to get his state rent rebate \$, which I told him I would help him with, he needed to get a few other papers first.

Doing something fun can be a great escape, in my son's case coming over to grill a steak with asparagus, one of his favorite meals. (He put the gas grill together a few years ago even though he'd never even grilled) He continually amazes me with his unfolding talents.

Being reminded of hope, "this too shall pass" is a good slogan.

My son has felt my home a "safe" place which I want to preserve so he has a place to visit in a time of crisis rather than having to leave it if he lives here because he's no longer feeling safe. We still have tension on this issue at times which I think is a major theme with families of transitioning young adults.

There are no easy answers on this topic and each family decides what's best for them.

Being reminded of hope, "this too shall pass" is a good slogan for all of us.

When I feel insecure I appreciate being affirmed and hearing about my positive attributes which I tend to forget when I'm stressed-my son agrees this helps him.

When powerless and despairing there are some special points to remember:

Having flexible boundaries as we communicate can be invaluable, practicing the art of forgiveness is crucial with all the damage that can be done in particular when being pitted against each other in some systems and at times being ignored in others.

Honesty, even though someone's feelings might get hurt in the process is key. Even though my intention is not to take something personally at times it's difficult to do.

Respect for where each of us is at can lead to empathy especially given that we've each had more than our share of health issues along the way.

We're only in the beginning months of this global tragedy and yet we all have so much to learn and grow from if we take the opportunity. Let's listen to those around us who have been practicing these skills to survive for a very long time and appreciate the gifts they have to offer us.

Pat Wright, USA

"Virus and Psychosis"

I work as a psychologist at a psychiatric community in Ugrnano in the province of Bergamo (the European epicenter of contagion). I want to share a reflection after a long discussion with hospitalized patients (schizophrenics and serious personality disorders).

There is a widespread belief among guests at the facility that Covid-19 was created by a "bad scientist" in a Wuhan laboratory. The predominant primary defensive mechanisms are evident: the projection (the bad part is "outside me") and the denial (reality cannot be so unpredictably terrifying).

The interesting fact is that a SWG survey of April 24 on a sample of 800 Italians says that 47% think the same way as patients. It can therefore be said that when external reality becomes extremely threatening, the use of primary defensive processes spreads indistinctly throughout the population and the boundary between normality and pathology thins.

Mario Apicella, Italy

An example of filial pietas

R., up to 30 years of age, led a rewarding life, made up of work, friendships, passion for motorbikes, beach holidays. He also had fond memories of the military service, carried out at 20 years in Salerno, an experience that a person of his frailty would have had to go through painfully and that instead represented a pleasant experience for R.

R. decompensated 20 years ago, due to repeated harassment at work. He never fully recovered, developing a marked persecutory symptomatology. I met him about 3 years ago, in a new critical phase and I started seeing him weekly, with progressive good results.

R. A month ago he lost his mother, who died of a recurring tumor. R. visited his mother in the hospital twice a day, until the last minute. Not even the fear of Covid-19 has slowed him down.

I thank him for the example.

Oberti Marco, Italy

Welcome to Perugia for ISPS 2021!

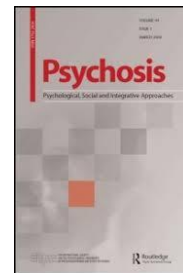


What's new?

ISPS journal PSYCHOSIS

Print versions of the ISPS journal PSYCHOSIS were suspended for several weeks due to the pandemic, but have just restarted, so members will be receiving issues 12-1 and 12-2 shortly.

The latest edition of the journal included an article by Rai Waddingham, Chair of the Hearing Voices Network-England (and previously on the ISPS international Executive Committee) providing lots of information and sources of support for voice hearers, and others, in relation to the COVID pandemic.



The publisher kindly made it open access so it is available, free, to the public [here](#)

Rai Waddingham (2020) COVID-19: how can we support each other (and ourselves)?, Psychosis, 12:2, 101-105

The Journal received 43,326 article downloads in 2019, which is 51% higher than downloads received in 2018.

The most downloaded article is 'Antidepressant tapering strips to help people come off medication more safely' by Jim Van Os et al, with 2,416 downloads.

The Impact Factor (measuring number of citations in other journals) improved from 1.15 in 2017 to 1.21 in 2018, positioning our journal as 90th out of 130 in the 'Psychology, Clinical' grouping. The top cited article was 'Does childhood bullying lead to the development of psychotic symptoms? A meta-analysis and review of prospective studies' by Twylla Cunningham.

John Read
Editor of the ISPS journal Psychosis

ISPS Regional Group News

ISPS Lowlands 2020 conference

The regional conference of ISPS Lowlands is planned to take place on Friday, October 16th, 2020 in the UPC campus Kortenberg (Belgium) with the theme: **Family connections in psychosis: Spores and tissues**. You can find the provisional programme [here](#).

We are keeping in mind that due to the COVID-19 pandemic, the day may not take place as planned. Alternatives are thought to be either a postponement until the spring of 2021, or a 2-hour webinar with keynote speakers on October 16th, or a combination of the two options. Not only for the keynote lectures but especially for the workshops, which will take place in a smaller group, we would be very sorry to be unable to let the discussions take place live. You will be informed just as soon as there is more clarity about this.

Best wishes from the whole organizing committee,
Ludi Van Bouwel, Martine Lambrechts, Leen Lambrechts, Jef Lisaerde, Niel Van Cleynenbreugel, Saskia Verbesselt



Report from the annual Norwegian ISPS conference, 6-7th February 2020

The annual Norwegian ISPS conference was a success. Nearly 200 professionals, service users and family members met up in the city of Hamar at the beginning of February for two days of inspiring professional input and networking.

In a myriad of different conferences, the annual Norwegian ISPS conference seeks to stand out by offering a specific focus on psychosocial treatment methods, professional trends and strategies for people experiencing psychosis. Our aim is to create an annual meeting place for professionals, service users and family members interested in this approach to be inspired, motivated and hopefully create new networks.

The theme of the conference this year was "**Back to the future – psychotherapy for psychosis anno 2020**". The purpose was to acknowledge that all new knowledge is based upon and developed from old knowledge and that we "stand on the shoulders of our predecessors".

We enjoyed inspiring lectures from local professionals and service users on the development of mental health problems in young people and adolescents, self-disturbances in adolescents, the impact of psychoanalysis on treatment today, dialogue therapy, VR-simulation, cognitive training methods, early intervention, family work and occupational therapy.

Matteo Cella and Rachel Brand came from England and Australia in order to update us on the latest research on new treatment methods: cognitive remediation and psychological treatment methods for psychosis respectively.

We were lucky that the conference was completed just before the Covid-19 virus came to our part of the world and put everything on hold. Planning for the next conference in February 2021 is well under way, and we are hoping that the virus situation allows us to meet up with new and old friends of ISPS in Hamar once again then.

Cecilie Brøvig Almås
Chair of ISPS Norway

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NEW! in the ISPS series

Upcoming Events

The ISPS has over 20 regional networks around the globe, many of which organise annual events. Take a look at the impressive range of meetings and conferences taking place in 2020

ISPS events listing

SAVE THE DATE
ISPS 2021: The 22nd International Congress of the ISPS
Wednesday 1st - Sunday 5th September 2021
in Perugia, Italy
More information coming soon at www.isps.org

Haven't joined ISPS yet?

Here are 4 good reasons why you should join us!

- 1) Members enjoy reduced delegate fees for ISPS conferences such as ISPS 2019 'Stranger in the City' in Rotterdam this summer.
- 2) Members receive 4 issues of Psychosis per year and also have online access to previous issues of the journal
- 3) 20% discount on books in the ISPS series published by Routledge
- 4) By joining ISPS you can connect with over 1,500 people around the world - who share your interest in psychosocial treatments for psychosis - through our email discussion groups and regional meetings



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