

Podcast series “Empowering Minds”

Episode 5: Psychiatric diagnosis – what is it good for?

Transcript

Jonas: Hello and welcome to empowering minds, the Brussels based podcasts from Mental Health Europe. In our podcast series, we discuss all things related to mental health. My name is Jonas Bull. I am a research and policy officer with Mental Health Europe and I am your host today.

Jonas: When we experience mental health problems and seek help from a doctor, psychiatrist or other health professionals, sometimes we receive and are given a diagnosis. This has important consequences, both positive and negative. In today's episode, we would try to approach and unpack the large topic of psychiatry, diagnoses and labelling. Today you will hear from three great speakers how diagnoses and diagnostic manuals were established over time, how the covered pandemic relates to the way we think about mental health and where we can observe drivers for change. But most importantly, we will hear from people with lived experience, having received a psychiatric diagnosis in their lives and how they think about questions off labels and the power dynamics around psychiatry. On our MHE platform, you can also find further information such as the short guide to psychiatric diagnoses. But we have also included some links to articles authored by today speakers. You can find them on www.dmheshme.org - and then search for our podcast.

Jonas: Our first guest today is Lucy Johnston. Dr. Lucy Johnston is a consultant, clinical psychologist, author of the users and abusers of psychiatry and co-editor of the formulation in Psychology and Psychotherapy. Making Sense of other people's problems. She has worked in adult mental health settings for many years, most recently in the service in South Wales. She was lead author, along with Professor Mary Boyle for the Power Threat Meaning Framework, a division of clinical psychology funded project to outline a conceptual alternative to psychiatric diagnoses.

Jonas: Could you maybe explain to us briefly how where psychiatric diagnoses established particular, taking into account all of the, um, the manuals as we know them today?

Lucy: Okay, so this is an important question, because it's really the absolute foundation of mental health practise as we know it today, because it's relatively recently that we started thinking about people`s very real experiences. This kind of happened around about the end of the 19th century when we started to think, whether we need to have diagnostic labels of doctors. So around the 19 hundreds, we had three tables which were called like things that sound very old fashioned, now melancholia and so on. But since then, we've developed gradually over the years of a much larger, more complex system of diagnostic labelling, and it comes in two versions. Essentially one is the Diagnostic and Statistical Manual of Mental disorders, and it's drawn up in America, but it's used worldwide. First Edition came out in 1952 that had about 106 so-called disorders and every so often revised and updated editions. So, the most recent one was in 2013. And a more or less in parallel, we have the international classification of diseases ICD, which has one chapter which is devoted to so called psychiatric disorders, and they have some minor differences between them. The existence of these manuals is very, very important because they are the kind of building block of psychiatry as a branch of medicine off the whole of the mental health system. If you took away a diagnosis, everything else would come under question. Psychiatric drugs play a large role. Well, do we actually need to think about these very real experiences of distress in a very different way? So, you can't underestimate the importance of these manuals.

Jonas: Thank you very much. You mentioned that both ICD and the DSM have been undergoing several revisions. So now we have DSM five, um, from I think, 2013. Could you maybe explain to us, Maybe, why do the manuals keep changing? Why are they being revised?

Lucy: Well, I mean, like all diagnostic manuals need revising. We learn more about diagnoses of physical health problems by undertaking medical research. Certain things like, you know, diabetes, all down syndrome. Whatever has evolved over the years, though I suppose one way of saying that is, well, diagnoses need updating in the light of new knowledge. But from another perspective, you could say, Well, actually, something very different is going on when we're revising these manuals because we're not revising them on the basis of new medical knowledge. And it's important to be clear what kind of diagnosis I'm talking about here. This is a huge bag of conditions, and basically there are some things like Alzheimer's disease and some forms of intellectual disability that everybody would see as you can understand these

as developmental disorders or brain diseases or whatever. But there's a whole area of things that are sometimes called functional psychiatric diagnoses. So they're things that form the bedrock of mental health, practise things that we call schizophrenia or bipolar disorder or major depressive disorder or anxiety disorders. It's those disorders that keep being revised and updated and often added to so that we now have apparently, if over 400 ways, which could be so-called disorders. Actually, what's happening in this kind of revision of diagnoses is a very different process because we do not have what are called signs in medicine. We do not have evidence about what's going on in the body to cause these so-called conditions. So, in diabetes we have quite a well-established pattern. They studied medical research about what goes wrong with the function of the pancreas and someone has ways of diagnosing it and confirming or disconfirming it. But essentially what psychiatric diagnoses nearly all are based on is a judgement of the way someone's thinking or feeling or behaving is. You know, one of the results of that is we have very kind of unclear categories. They shift, they change, overlap. There's actually no way of saying this is schizophrenia versus that is bipolar disorder that says there's no way of confirming or disconcerting a diagnosis. And some people would say there's no way of validating in the first place. So, we're left with very loose, unsatisfactory, overlapping categories. And one way of looking at our constant revisions is we're trying to make these look more scientific on reliable - reliable means people are likely to agree with them. So, reliability is one test of a sound scientific system. But in fact, reliability is incredibly low. It's more or less a chance level for many so-called disorders. And actually, reliability is only one of the important criteria, because scientific work is also meant to be valid. In other words, they're meant to represent something of the real world. So, is there really such a thing? The schizophrenia out there in the world that in some sense explains some people's forms of distress. Well, one of the interesting things that's happened in recent years is that even the very senior people who drew up these manuals in committees are saying things like, you know, quite devastating things: "DSM five will radically and recklessly expand the boundaries of psychiatry. The science isn't there, it is totally wrong, an absolute scientific nightmare". Those are actual quotes from senior establishment psychiatrists. So, the interesting thing that's happening nowadays, which is not widely acknowledged or known about and certainly implications already talked about is that there is a massive amount of money and research being poured into developing a new diagnostic system from scratch. Because the people who make the criticisms are not against diagnosis as such but in a way, they're rebuilding. This one really doesn't work. We'll get another one along in a decade or two, and that will be better. To me, that's an ultimate of faith. And there's no particular reason to believe that something that comes along in a decade or two which would be better. A sign we're proceeding on the wrong assumptions of the wrong principles. But one perspective on why we've tried to kind of shore

up and make a more sound and valid and plausible system. We've reached the end of that particular pathway. It doesn't seem to be working well.

Jonas: Yes, I think this is one other question that I had. What other ways have you experienced? What other ways are there at the moment of how we could think and talk about experiences of distress beyond the two manuals and the way psychiatric diagnoses is practised and understood today.

Lucy: Okay, that's a good question, because it's an interesting fact that, in contrast to the complete lack of evidence, the so called chemical imbalances and genetic malfunctions and so on as causing so called mental illnesses there is a huge amount of evidence, a growing mass of evidence for the role of former adversity, discrimination, social factors like poverty and social exclusion in the lives of people who end up feeling distressed. It's kind of common sense in a way that people who have difficult lives are more likely to struggle emotionally and psychologically. There's growing amount of research structural support that. So what is the alternative to diagnosis? In very simple terms, alternative diagnosis is to listen to and understand people stories, their personal stories, their life stories, as in the slogan instead of asking What's wrong with me? Ask what happened to me and as a psychologist, I would say and a lot off, like I would agree with me that however unusual or frightening or risky or eccentric or perhaps overwhelming or longstanding someone's emotional and psychological difficulties are, there is always a way of understanding them, and it's not a quick or easy way. Therefore, in life, you help people put together a personal story. Now sometimes people who know about that already you know, -they know they have had it filled up with things. They know they were traumatised and hurt. But that gets moved into a medical narrative. In the UK, there is quite a strong tradition which I've done a little writing and teaching and training research into called formulation, which is just a way of saying a semi structured way of putting together someone's story. So, a formulation is a kind of constructive narrative. Like all psychologists in the UK and a growing number of professionals use formulation, it has quite a solid base in mental health services. So, it's an evidence based on the story if you like. So, it draws on the knowledge that we already have about the many psycho-social causes of people's distress. It adds to the evidence that the patient or service user brings. You put this together into a kind of personal narrative or very individual hypothesis, if you like. This seems to explain perhaps the reasons I'm feeling down so distressed and that can provide very personal plan for whatever you may need to do whatever support you may need to have in order to move forward in your life. So, all of my practise is formulation-based.

Jonas: Because it's just so topical, and it's just so all-encompassing - maybe you'd like to just comment on how this pandemic also challenges the narrative of psychiatric diagnoses that we have been experiencing?

Lucy: Yes, we're going through interesting times at the moment. The article I wrote was about all these headlines we're seeing about along with the Covid-pandemic, we can expect, or perhaps are already experiencing a mental health epidemic or pandemic, whatever that is. So, I think this whole coverage of the pandemic has highlighted some of these, I would say, very unhelpful and actually mistaken ways of thinking. Because how much sense does it actually make to stay normal with a worldwide virus? That's one of the biggest threats we've ever faced as a species and is closely linked to climate change and all the other things that are a threat to the whole planet. We, unfortunately, have another pandemic at the same time. What an unfortunate coincidence and since we've all got mental health problems, you know, seldom has it be more obvious that the things that we're all experiencing, like being anxious and isolated and miserable and therefore understand of responses to our circumstances, are understandable signs to the bigger threat and actually the same is that saying this is a mental health epidemic is identifying the reasons for people feeling more anxious or more miserable or more depressed than usual is because they're worried about their jobs. They worried about getting ill. They worried about their sick relatives. They need to stay in an isolated, small, flat obey or not or how they're going to kind of run their family finances. They are worried about the future, so it was never clearer: These are understandable responses to difficult circumstances. So, I really hope this is an opportunity to challenge the mental health narrative. I ended the article by saying we're not facing an epidemic of mental health problems, but we all are facing an epidemic of mental health thinking

Lucy: One of the good things that happened much more over the last 20, 30, 40 years is the growing strength of the user & survivor movement. If change is going to happen, I think it's probably going to happen through the users & survivor movement, through people taking back their power, taking back ownership of their stories, deciding that it's no kind of interventions they want in some cases. Although I'm not saying everything that happens in the current system is unhelpful, but the system itself isn't going to change very much. Radical changes need always come from grassroots movements, and I think it's particularly important to think about that in relation to not just psychiatry in Western societies, but in relation to the global mental health movement. And there's been some very good reports coming out of the U. N about this by the special reporter saying, Really, we need to think very carefully, what we're exporting here. So, this is not about psychiatrists. They say it's not about psychologists. This is another form of colonialism imposing a set of individualising, Western based and actually

even in their own terms on scientific beliefs on cultures, which very often already have their own ways of experiencing and expressing distress, which actually research shows off a much more effective louse. It's little acknowledged facts that Western psychology is much better creating problems than curing them. So that's something really to be very wary of, you need to be thinking much less about chemical imbalance and much more about the power imbalances.

Jonas: Our next speaker is Lea Labaki, and I'm very excited to have her with us on this episode. In this talk, she will share a little bit more of experiences having received psychiatric diagnoses in her life.

Jonas: Thank you very much for joining us again. Maybe to start with: could you tell us a little bit more about yourself?

Lea: My name is Lea Labaki, I'm from Belgium and I identify as a person with a psycho social disability and as a psychiatric survivor, and I also have a background in human rights. This has helped me to read my own psychiatric experiences through the lens of human rights and become an advocate for the rights of people with psychosocial disabilities.

Jonas: What is your experience with diagnoses?

Lea: Maybe to continue what have been the consequences of being diagnosed. My very first psychiatric diagnosis was when I was 13 and I was diagnosed with anorexia because I stopped eating and I really remember thinking that there must be some sort of misunderstanding. But because in my mind, what I was doing was some kind of hunger strike, certainly not an illness. And so, it didn't make sense to me. Why it was being discarded is a pathology and why I was being sent to hospital and given medication for that? So, I really remember at first trying to resist that label. And then in the following years I was diagnosed with many other illnesses and disorders. Kind of every psychiatrist has had their own theory. So of course, this was a bit confusing, but also, I think it was lucky in a way because I know that other people have to deal with one big label being stuck on them, that they have to fight. And this has not been my experience. These diagnoses had been quite easy to shake off one by one. But in my mind, these diagnoses were not even meant to help me. Really. I felt that it was more kind of justification to the coercion that I faced in the mental health system and for the general paternalism that I faced there really a kind of way of saying like this poor woman doesn't know what she's doing. We need to protect her from herself. So, I think what's really important, is that a diagnosis is not a word like any other. It has power when it's pronounced by the right

person in the right context. It has this power to sort of transform your status in society from regular citizen to a person whose rights can actually be limited in some cases in the name of care of protection. And so, this is why the diagnosis is really central in all the laws allowing involuntary treatment or hospitalisation or the profession of legal capacity. And this is also what happened to me because the different moments have been either forced to go to hospital for us to take medication or put in isolation or its trains. And all this was made possible by the fact that I had a diagnosis. The diagnosis is what allowed doing things to me and to other people that are usually not allowed to do to anyone except maybe criminals. That happened to me with being diagnosed as mentally ill.

Jonas: Thank you for sharing. Thank you. And based on your experience, what is it about mental health diagnosis, then that needs change?

Lea: I think the main problem with diagnostic system that we have is that it's based on this idea of illnesses and disorders. And that's not a neutral accepting way of describing who you are or how you react to life. I mean, it's an idea of pathology. There's no way it can be positive. It's inherently negative. It means something. It means that you're wrong, that it's an inadequate response. And that's not how I experienced things at all, because I always knew that deep down what I was doing or saying that was seen as evidence of having a mental illness. In fact, it made sense in the context of who I am and how I experienced life. It's in fact adequate to react like this. If they had access to all these perimeters about me and my life, they would totally understand and they would actually think that I'm right and so I think it's an illusion to try and draw a line between those reactions of distressed that are normal and acceptable and rational, and those reactions of distress that are pathological and don't make sense in fight. I think there is meaning in everyone's distress. And this has, of course, huge implications on how you try to address and to the treatment of those challenges.

Jonas: And do you think it is also possible for diagnoses to serve a positive purpose?

Lea: Yes, because so actually is going to sign, maybe, like a contradiction. But at different points in my life, I have also been wanting a diagnosis and actively seeking one, because I knew there was something different about me, and I knew I faced challenges that most people did not face. And so, I thought that finding the right diagnosis or the right term for this would allow me to identify it but nuts as a way to fight it. But whether the way to accept it or as a way to even befriend it, if that makes sense and I know that for some people in some communities diagnosis had really played a positive role in to answer actually developing a positive identity around the diagnosis, and this is what has been a tool for them, an element for pride, for

building a sense of community. I know, for example, this is a case with the autistic community. It's also a kind of concept of pride. And so, I don't think classifications aren't necessarily bad because we have to recognise that diversity exists and in order to be counted and to count in a society that often refuses to listen to us. Then we need to regroup under some kind of label. But I think the problem is really when we start seeing these labels as a natural truth that cannot be questioned and when. We also don't question the implied values and hierarchies behind them. So, I think what's really needed is to move from this illness and disorder model to the model around this idea of diversity, where mental health conditions for lack of a better word are not seen as pathology. But it's just a way of reacting to life that just as valid is any other way, which is not to say that it's not hard or that you don't need help, but just the way we understand this help is different. because instead of being, an object of medical care, we become a subject with rights, including a right to support and to recommendations that we need to have this fulfilling life and be included in society. So, I think the first step is to stop giving this authority to psychiatric diagnosis, to divide people between who is sound and who is faulty and to use them to, in a way, distribute power between people and allow some people to take away the rights of other people. Because that's what it is.

Jonas: Our final speaker for today's episode is Jasna Russo. Dr. Jasna Russo has been working the fields of research and training for many years. Her special focus is the further development of the participatory and survivor-controlled research approaches. She's co-editor of "Searching for Rose Garden, Challenging psychiatry. Fostering Mad Studies." Earlier this year, and in collaboration with Stephanie Wooley, she published the article "The implementation of the Convention on the Rights of Persons with Disabilities. More than just another reform of psychiatry", which is the basis of our talk.

Jonas: When we talk about human rights and mental health, we often speak about the shifts of paradigm and could you explain to us what that means?

Jasna: Paradigm, refers to a set of assumptions, concepts, values and practises that constitute a way of viewing reality. You can also call it model or a pattern. So, what we have in psychiatry is a so-called biomedical paradigm, meaning that the dominant view of mental health problems, challenges, whatever people bring into psychiatric services, whatever they come with – the medical paradigm places the problems within bodies and minds of people who enter the system and also treats those problems in that way. I mean, this is how they're located within – I'm saying bodies and minds as opposed to life of individuals. I think it's slightly different but like the biomedical paradigm refers to this, okay, if I'm honest, I call it a belief

system because the problems of living, everything that we experience can be solved by the virtue of medical intervention - that is the dominant paradigm.

And then we have the Convention on the Rights of People with Disabilities, that also covers people with mental health problems, with psychiatric diagnosis etc which focuses on human rights. And there's a big gap between these two perspectives if you like. So, when we talk about paradigm shift in psychiatry and mental health, it means that the medical paradigm needs to be abandoned. There should be a shift, there should be a new way of looking at what is now diagnosed as mental illness or psychiatric disorder. There should be new concepts, new theories, another way of looking (...). I mean the paradigm shift means a need to change the dominant way how mental health problems or as I say what is now diagnosed with mental illness is being looked at, is being approached and is being treated.

When I think in terms of human rights in psychiatry we usually think of the right to be physically safe, not to have things done against your will, not be detained, detached from the rest of society, etcetera. There's also a human right that I personally find very important and many other people, that is the right to name and to understand your own experiences. And if you can't name them and if you don't have a name - then the right to have a process in which you can name what you are going through and in which you can understand it. So, I think the diagnosis and the way it is done now takes that right away from people. I'm speaking now for people who found that very damaging because it's the whole, you know, it is not just a matter like somebody gives you... somebody tells you what you have. It's not somebody. It is a medical authority. What they tell you is an entry card to treatment, many times this is unwanted treatment. Without that diagnosis, you could not be subjected to such treatment. So I am speaking here for people who are not happy with that whole procedure and who think that they should have a right, you know, to understand what's going on, and to have a professional who was going to help them understand that rather than put a medical label on on the experience and say "this is what you have, and this is how I'm going to treat it". There are many self-organised projects of people where there's mutual support that is taking place outside of the mental health system. So, you have peer-respites (such as in the US), there are many of those.

Recently we completed one research project. We researched one such project in Germany that operates for more than 20 years. They have crisis rooms there where they can accommodate up to two persons at the time for about three months. And in this research project we really tried to see what is the approach they're taking, how people understand crises. We didn't find... It is not only that they work without diagnosis, but they also work without any definition of psychosocial crises. They say "each person needs to define for themselves, what they need, so when they come here, we look at what's going on, what the person is able to tell her about it and what is needed." So, I think that there are many such

practises that are not really recognised as practice, that are not seen as viable alternatives to what is in place. But there are those practices.

What I personally notice is that there is still this, you know there's still expertise imposed on people's lives. And even if that expertise is not psychiatric expertise, but this time coming from psychologists and probably coming closer to the issues at stake, it is still a so called third-person approach. I mean it is still like...For my understanding and for what I aspire I would really like to see people at the centre of any kind of intervention; people who really stay in charge of their lives without any... How to say... It's a very subtle process and I really think...Personally, I'm not against diagnosis. I'm against the direction of diagnosis. Because I think we diagnose all the time but the question is, you know, what are we looking at? For example, I worked as a counsellor in a shelter for battered women for six years, and women were coming there with different problems. So of course, you diagnose, but you don't diagnose the person. You don't focus on her state of mind and body. You diagnose together what is needed, what's going to be the next step. So, if there were diagnoses such as poverty, racism, violence, isolation, I think those would be helpful diagnoses to help us see what needs to be addressed.

But it is a huge shift, it is a very difficult shift to make because we are all used to looking at - I mean, also people who are psychiatrised - very much they're used to looking at "what's wrong with me, what can I do to improve?" It's a foreign concept (to look at the surrounding and to say what is wrong in my environment. What is wrong with my immediate surrounding, what is making me feel miserable? What is causing me distress and what needs to be done there? It's very unusual. It's unusual for everybody.

Jonas: With these final thoughts our fifth episode has come to an end. If you enjoyed listening to the podcast, feel free to share it with friends, family and colleagues. Thank you and goodbye.