"MADNESS AND HUMAN RIGHTS: IDEAS ABOUT THE PAST AND FUTURE OF MENTAL HEALTH TREATMENT"

A conversation with John Trainor, Jonathan Cohen, and Judith Klein

Moderator: Joanna Erdman

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ANNOUNCER:

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JOANNA ERDMAN:

All right, so-- welcome, everyone. Thanks so much for joining us. We're-- here for Madness and Human Rights: Ideas About the Past and Future of Mental Health Treatment. My name is Joanna Erdman, and I'm the chair of the O.S.F. Public Health Program's advisory board-- and we are hosting the event tonight in honor of John Trainor-- and his many, many years of service-- on our board. So, I'll just quickly-- introduce-- fellow members who are up here at the table with me. Jonathan Cohen.

JONATHAN COHEN:

Good evening. I'm Jonathan Cohen. When I'm not on sabbatical, I direct the Public Health Program at the Open Society Foundations.

JOANNA ERDMAN:

And Judy Klein.

JUDITH KLEIN:

Hi, I'm Judy Klein, and I am-- I've been at O.S.F. for over two decades-- leading the-- the work on mental health here. And-- I'm now a senior advisor to the Public Health Program.

JOANNA ERDMAN:

Great. Thanks. So, I'll do a quick introduction of John and let him then take the floor. So, in 2013, John retired as the director of the Community Support and Research Unit at the Center for Addiction and Mental Health in Toronto, Canada. But through his retirement, we kept a very talented, and I would say wicked advisor. John's worked in mental health for over 40 years, including clinical work-- program planning and policy development.

He's currently the chair of Mental Health Research Canada, which promotes research funding and fellowships in the field. I'd say probably for me, it's his-- service as a policy advisor that's really proved a source of endless learning for us on-- the committee. And what I've learned most from John is the fact that there's something to be understood in everything. So-- I think I would say John says that there are always people behind any policy, and part of great advocacy is really asking not what people should do, but more asking why do they do what they do.

And so, to really engage in injustice in mental health policy not as something to be only condemned, but also to be something to be understood. So, this evening, John's going to help us explore and learn from society's past reactions to mental illness, how they can lead us-- to better treatment strategies for the future. So, John? (APPLAUSE)

JOHN TRAINOR:

Thank you. Thank you very much. And-- and I-- (CLEARS THROAT) want to thank-- the Open Society Foundations and the Public Health Program for the chance to-- to talk tonight-- and welcome everybody here. It's very nice to see you. I'm gonna make remarks and then I-- we're gonna have, I think, some responses and then time for questions and input from-- from all of you.

I do want to talk about madness and human rights. And I've always had-- a tendency to look at these things from a kind of historical perspective. If you look at the history of madness, and I-- I'm working kind of mostly in a kind of western tradition here, but if you look at the history of madness, what you do not see is an arc toward-- more humane and more enlightened treatment over the centuries. You see something that looks more like a roller-coaster.

You can find, for instance, quotes from ancient Greece-- 400 B.C. or 500 B.C., which say if somebody is showing what we would call the symptoms of mental illness, take them to a nice place, care of them, give them lots of light and air, and support them until they recover.

You can fast-forward from that, almost 2,000 years to Thomas Moore, at the time of Henry VIII-- who says people who show the signs of mental illness should be chained to a tree and the devil whipped out of them.

So, it's not-- a line of just progress and enlightenment. It's-- it's much more a mixed story than that. But I think looking at historical perspectives is-- is essential to understand-- where we are now in the treatment of people with mental illness, to use that kind of terminology, but we want to be careful about getting a little too over-confident, again, about our approaches. There was a very interesting series of studies done in the 1980s by the W.H.O. called the Pilot Studies in Schizophrenia.

And they looked at the five-year outcome for what we would call, in western society, schizophrenia. And what they found was that the best outcomes were not in our cities or where there's, you know, up-to-date treatment, hospitals, medications. The best five-year outcomes were in-- some traditional-- villages in the developing world, where they did not have the hospitals and the medications and the professionals.

What they did have tended to be a high level of social inclusion and a way of interpreting the phenomena of what-- that we call mental illness in a way that was much more positive and-- and much more respectful of people who were dealing with that. Now, here's a straightforward way of looking at the past as I'm gonna deal with it, 'cause I wanna look at two primar-- primary eras. One is the moral treatment era and the other is the era that I think we're still in, which is deinstitutionalization.

So, beginning slowly in the late 18th century, but gathering speed in the 19th, a movement called moral treatment developed. And it was really a very new way of looking at how to deal with the phenomena of mental illness in society. Earlier forms of treatment had focused on the body. And there were a variety of approaches-- which were often a bit disturbing to the modern ear. One example was the cupping and bleeding.

Cupping and bleeding was-- either drawing blood or cupping-- this is a cupping and bleeding kit you see. And it involved-- various kinds of blades and knives. And it involved cupping, where you heated the cup over a candle and then put it on the skin, with-- and sealed it on the skin. And as it cooled, it would suck the-- the skin into the cup. And it was quite painful, but it was meant to draw out humors. This is a somewhat older picture of someone in the bleeding.

And I-- if you notice the look on the patient's face, I'm thinking maybe this was a promotional (LAUGHTER) photo for-- for that particular bleeding clinic. But these-- these were all focused physically. And in that sense, how they saw mental illness is not that different from now. We have different types of theories, but we're very much focused-- some professionals anyway, on brain chemistry and other-- other-- physical features or physical factors.

Now, with moral treatment, you had a complete change because the focus became the mind or the person or the person's moral self. Complete and radical change from-- assaulting-- the body. And one of the-- the famous cases that-- (CLEARS THROAT) that sort of illustrated the shift was the case of George III, king of England, known as Mad King George. He was the king of England during the American Revolution. And sometime after that, he went mad, to use the terms of the day.

And at first, they tried the old treatments. They-- they cupped him and they bled him. They almost killed him. They would rub caustic substances on his skin so it-- boils would arise, which were felt to be bringing out humors that were-- and-- and-- fluids that were detrimental to him. But then that didn't work. And it was a political crisis in England and they brought in a moral treatment-- one of the early moral treatment practitioners, named Dr. Willis, who had been a minister-- and decided-- had decided to switch to become a doctor.

And at that time, that-- what that didn't require was going to medical school. So, he-- he re--recast himself as a doctor. And it was felt-- this actually turns out not to have been-- it's historical true, but it's not actually what-- what cured King George, and he was only cured for a certain period of time, but the moral treatment was seen to work and it therefore caught on.

Now, the moral treatment movement was really based on about four foundations. It had a new theory and a new technology. The theory was, again, you approach the mind and the moral self. The technology that was felt to express this was the asylum. So, it was an institutional expression of moral treatment, was the asylum. And remember, asylum then, and to some extent now, depending on how it's used, was a good word.

One of the earliest moral treatment-- asylums was York Retreat in England, opened in the late 18th century by William Tuke, who said he wanted it run like a well-run household, with patients living ordered lives in healthy surroundings. So, they felt they had a theory and a technology. The other driver-- another driver was the Victorian fear of mental illness. By the time you get into the Victorian period, from the 1830s on-- people are really afraid that mental illness is a-- is a growing phenomenon.

There was a lot of social change then. The Industrial Revolution was in its heyday, and there was a great deal of fear that-- that this problem had to be contained. It's-- it's-- there's some similarities to today. And it was felt we need a strategy and we have one. We have the technology and we have the asylum. There was-- a growing belief in humane care. Part of moral treatment was driven by enlightenment ideas about humane care.

But it also brought in a new kind of power. It wasn't just a story of humanitarian concern. There was a new kind of power. This is what's discussed by Michel Foucault-- years ago in his book, *Madness and Civilization*, and that is that, okay, we weren't going to control your body in the same way, but we are gonna use a disciplined approach and a disciplinary approach to dealing with your mind.

Now, the asylum idea was based on two things. One was their theory of what led to people being mentally ill. And what they felt at this time was that it had a lot to do with problems in the community. It's sort of the opposite of now, where we think people need to get out of institutions and into the community. They felt that the-- that-- that situations in the community created problems. And if you look at 19th century admission records to asylums, you get, and I'm quoting-- causes for admission such as loss at love-- living in squalid conditions, or political excitement.

You don't see that in Canada as much as here, but-- (LAUGHTER) there was some of it. So, it was felt that we want to bring people away from that, into a protected setting, and that's the asylum. But the asylum, itself, was also felt to be a machine for curing mental illness. And its curative potential was based on putting moral treatment principles into play.

Now, here's an example. That is an institution that was in Toronto. It opened in 1849. It's called the Lunatic Asylum of Upper Canada. I was actually in that building-- not when it opened, but-- later, when it-- when-- the year before it was torn down in the 19-- late 1970s. The moral-- treatment approach was reflected in a number of ways. The architecture had a lot of Greek features, which were felt to represent reason. It was built within sight and overlooking water, Lake Ontario, which was felt to be calming for people.

The first-- administrator of the hospital, and head of it, was Dr. Joseph Workman. He lived with his family in the center of the center block of the hospital. And it was felt that that created a moral example for the patients in the hospital and that influence would been seen directly. It was, in 1850, the largest and most expensive public building ever built in Canada. That's the degree of commitment to this kind of-- of asylum. And it was the first building actually in Toronto that had central heating and running water. So, it was considered a high-tech operation and it was-- you-- you find this in other asylums, where there was not only the-- the physical plant, but there was also this spirit of it.

In Massachusetts, in an institution, they would bring patients in when it was opening, who had come from jails, where they had been essentially chained in cells, and the chains would be struck from them. At dinner, there was a great hall and the patients ate with the senior staff in the great hall every night. And they would take the patient in in his chains. They'd be struck off at the table and he would sit down and have dinner with the senior staff as a symbolic representation of his return to the human community.

So, you had some real spirit to this movement. And it's really hard to overstate how much it changed the approach. The scale at which it was bought into, I-- it was really-- to me, you can sum up with one fact, and that is in the 19th century, in Britain, they spent more money and put more resources into psychiatric hospitals than they did in the British Navy. And if you know your British (LAUGH) history, the navy there was pretty much number one. So, it was-- it was a very large commitment.

Now, when we look at moral treatment, what does it show us about rights and about what creates open society for people with mental illness? Obviously, from our perspective now, when you talk about mental institutions or mental asylums, people think of terrible conditions-- warehouses to exclude people, and that in fact is what happened to these places, but they didn't start out that way.

At-- at its best, moral treatment could be seen as a humane envelopment of troubled people-- and an attempt to bring a higher degree of order and care to their lives. It-- it was-- you-- you-- you didn't have a right to care in a modern sense, but it was felt that we should do this for people who are suffering. And so, ideas of individual human rights did not arise. And one side of moral treat-- treatment that, I think, bedeviled it was that this was-- these ideas were not put in place in terms of human rights.

Really, the thing was these people are chattels of the state: let's be nicer to them than we have been and let's try to do it in a way that'll work. It was reform without rights and it was a belief in the technology of the asylum and its ability to cure, which did not come true. In other words, their theory of mental illness was not entirely correct. It had some good features, but it was not the whole story and the system began to break down.

If you look be-- by the time you get to the 1870s and '80s-- it's-- it's going downhill quickly. And-- the kind of institutional disasters we're used to-- are really coming true. Here's an example of the scale we got to. That's Pilgrim State Hospital, one of 75 buildings of Pilgrim State Hospital. This is a picture that I think was taken in the 1960s. Pilgrim State, in 1954, reached its peak census of 13,875 patients in its 75 buildings.

It had a fire department, courts, post office, Long Island Railroad station-- it was on Long Island, power plant, farm, church, cemetery, and its own water system. In-- in an interesting historical note-- actually-- the poet Allen Ginsberg's mother, Naomi Livergrant (SP) Ginsberg, was in there. She suffered from schizophrenia. She died there in 1956. And Pilgrim State is mentioned in his poem, *Howl*.

But this is the kind of-- this was the peak of the total institution. And within ten years of-- of that peak, the system began to change. And it started to change in North America and Canada oddly enough as the result of a fire. I think it was 1955, there were two mental hospitals in the province of Saskatchewan in Canada and a patient burned one of them to the ground, lit-- lit a fire, the place burned down, and the-- the province was faced with a decision: Are we gonna rebuild the hospital or do something different?

At that time, there was a very progressive government and-- in fact, the father of Canadian Medicare-- was the premier of the province. And they decided that they would do something different. Instead of rebuilding an asylum, they would divide the province into grids, they would set up community teams in each grid, and they would treat people in the community.

And they started that and it became very well known. In fact, for a while, Saskatchewan was world famous. It's-- it may hard to be-- it's a little hard to believe, but-- but it was in the mental health area. But that was just the beginning. It really caught on in the 1960s. And if you fast-forward to now, over 95% of-- of the mental health beds in Canada have been closed. And that's-- it would be a similar figure probably in the States.

And the new rallying cry, unlike save people from the community, it was let's get people back to the community. And the asylum went from a place of protection and care to-- to-- to a place which was actually harmful and the main problem was seen as incarceration. Now, this led to very dramatic action. New York state was actually one of the most dramatic jurisdictions. They hired people from Saskatchewan and they closed 50,000 mental hospital beds in five years in New York state, from 1967 to 1972.

And unlike moral treatment, deinstitutionalization did have a major human rights component. Most jurisdictions rewrote mental health laws. And by the time you get into the 1980s-- most jurisdictions had mental health laws that respected human rights, rights of due process, and being mentally ill was no longer a reason to be detained. It was based on behavior now and the phrase, you know, dangerous to yourself or others came into widespread use.

Prior to that, you could and would be put in a-- in-- in a psychiatric hospital just for being mentally ill, no matter what your actual behavior was. Now, most historians of this period would say that human rights weren't really the main driver of this. The main drivers were cost-- there was new medications that came on the scene, but human rights did play an important role. And deinstitutionalization, like moral treatment, had this ideology, but it also had the technology.

And the technology was-- psychiatric medications. That was seen as the saving technology. So, it wasn't-- if moral treatment was about envelopment, deinstitutionalization was the opposite. And if the humane side of moral treatment was a desire to treat people decently and to help them recover, the humane side, the good side of deinstitutionalization, was to free people from what were called, you know, in some movies the snake pit, and free them from detention.

So-- and you know, and some movies came out that really supported this way of looking at it, particularly the *Snake Pit* in the 1950s, with Olivia de Havilland, and then *One Flew Over the Cuckoo*'s *Nest* was the-- the-- the most influential. Here's the problem. The limited scope of this humane impulse to get people out of hospitals was a good start. It was a genuine contribution, of course, to their ability to live in-- in a freer way.

The problem was when you got out of the psychiatric hospital, you were still a person with issues, perhaps with a disability. It might be from an illness, it might be from having been locked up in a mental hospital, and that became a syndrome, it was called institutional syndrome, which was the damage caused by the hospital, itself, and being locked in there.

But you now had many more needs than just your mental healthcare to be dealt with. And although you were going to the community, sounds nice, the community-- the community was not always happy to see you. We were just coming out of-- of an era of social hygiene and the doors were not always open. I worked on in-patients wards in-- in the late 1970s and '80s and in discharge meetings people would say, "Well, where's-- where is this patient going?" "Well, they're going to the community." It sounded so nice, you know, the community, mom and the picket fence and the dog.

But of course, if you were working in the community, which I was, you realized they weren't going to your community because your community was gonna march in the streets if somebody tried to set a group home up. They were going to much poorer districts and-- and places that had a lot less support for them. Now-- an American sociologist, Leona Bachrach, did the classic analysis of this problem with deinstitutionalization.

She said the old asylums, as bad as they were, did carry out a lot of functions. They housed you, they fed you, they had some kind of medical care. There was often activities or workshops or farms to work on. And when deinstitutionalization was planned, because of the focus on releasing people, and that was the biggest goal, there was only planning for treatment in the community.

In the States, in 1963, I think it was the Community Mental Health Centers Act, and similar legislation in other countries, did put some infrastructure in place for treatment, but all the other things, you were now a disabled person in the community and what about your housing? What about your-- chances for work or school? We were in-- in-- in a world where there was a better social safety net, but I can tell you it wasn't good enough and it wasn't even close to being good enough.

And that brought the era of mentally ill street people, homelessness, and a lot of despair. So, where are we now? Well, I think it's like politics. We're in-- in a trend-- trend-- we're kind of in a situation with extremes. I come from Ontario. Six months ago, we had a progressive premier. She was s-- supporting a progressive agenda. She was openly lesbian. She had won a majority.

Now we've got-- six months later, we have a Trump retread-- named-- named Doug Ford. You probably remember our illustrious mayor of Toronto. This is-- this is what really, you know, beware what puts you on the map-- because for us it was Rob Ford. But this-- his brother is now premier. So-- there's so many extremes. In mental health, I'll give you a couple of examples, we are now in a situation where we can support even the most disabled people because of years of work on community programs and technologies around supporting people.

Even people with very high disability levels can live successfully in the community. And every time the envelope has been pushed, like could they live on their own, in their own apartment? Could they finish school? Could they have a job, at least part time? The answer's always yes. When we've tried it, it's always yes. This has been an ex-- exploration and the results have been excellent.

But while that is going on, we also, in almost every jurisdiction, have insufficient funding and commitment to these kinds of programs, and now, open calls for a return to the asylum era. Two years ago in this room, we had a workshop on this-- or a-- a forum like this about c-- because there are now public calls, let's open the asylums again. And there was a piece in the t-- *New York Times*, I think just a couple of months ago, about that. So, we've got that kind of contrast.

We're in a position now where there's excellent news around the understanding of the social determinants of health and how they affect mental health and mental illness issues.

(CLEARS THROAT) But while this understanding has become so much richer, psychiatry, as a discipline, is becoming more and more reductionist, and both drug and illness focused. There's a lot of driving of this by the pharmaceutical industry. And major projects now, N.I.M.H. is doing one-- and there's-- there's reasons to do these, but that-- really, really have a reductionist feel to them, that we're gonna bring everything back down to neurochemistry and cognitive science. The risks are high now with the rise of populism.

When it comes to creating targets, whether they be immigrants, Roma, ethnic groups-- disabled people often are on that list. And we're-- we're only 75 or 80 years from where people with mental illness were a direct target and were murdered in the Holocaust in large numbers. So, what can we do? Retire is what I'm doing, but-- (LAUGHTER) I think one thing is we have to fight for the real-- the real story. In mental health, and if-- if you work in the field, there's of-- there's an effort-- often efforts to distort what you might call the real story.

And there-- it's used in two ways to-- to be oppressive to various groups in society. One is objectifying and harming people with serious mental illness. People with serious mental illness are never that far away from being objectified, stigmatized, and-- and rejected. And you-- that's-- that's a very real risk. But-- but the other one that's-- mental health has been misused for, is the conversion of social justice issues into illness.

And the real story here-- is that unjust and oppressive social conditions-- can lead to mental distress. And that is not just reducible to biological models. I'll give you a couple of examples. This is one-- I couldn't resist this one even though it's from way, way, way back. This is Dr. Samuel Cartwright, who was a physician in Louisiana before the Civil War. He looked at this phenomenon-- this is a painting by Eastman Johnson called *The Fugitive Slaves*-- their ride for freedom. If you want to see it, it's in the Brooklyn Museum. And when Dr. Cartwright looked at this reality, this is what he came up with. These people were not just riding for freedom; they were mentally ill. And they had a mental illness called drapetomania, and the chief symptom is an insane desire to run away from home.

So, you couldn't get a better example for converting a real human situation into-- an alleged illness. Another one, psychological problems in women, and this goes way back. Even in the-- in the asylum era, they-- you look at admission records and some of them, they're terrifying to read. Some of them talk about women-- well, this-- she was rebellious. So, well, something wrong, so let's get her to the hospital.

Everybody's watched *Mad Men* in the world, right? Okay, if you haven't, that's from the show *Mad Men*. That's-- Don Draper's wife-- he's the pro-- chief protagonist, on the couch with her psychiatrist-- and-- who-- who would them t-- talk to Don in the evening about his wife, so privacy laws were a little different then. But if you think of what's really going-- what's the real problem with her? Well, (LAUGHTER) if you've watched the show, Don was-- not exactly-- a well-balanced, warm and fuzzy, nurturing fellow. Quite the opposite. So, I think another-- a second one I would say, and I'll close with a couple of these is-- is fighting for human rights and keeping that-- there's been-- so much progress in that area for people with mental illness-- that I think it's-- it's-- it's a priority just to be very vigilant about things that go on. And another one, the third one, is give tools to the people, themselves.

One of the-- very interesting things about looking at the history of mental illness and including, say, recent debates in the '60s where these radical theories were put forward, you had R.D. Laing and a psychedelic theory of psychosis, and you had Thomas Scheff and labeling theory. What's absent from all of these is hearing from people who have mental illness and have used the system and have, believe me, a great deal to say about what's going on and what some of the priorities are.

In Ontario, s-- in the 1990s, we created a funding stream for these organizations and funded 40 independent non-governmental organizations governed and run by people with mental illness. A part of the reason was for self-help and support, but part of the reason, for some of us who were involved, was defense, so that these groups could better defend themselves. And you don't have to look too deeply into the history of psychiatry and mental health to realize there's a lot of risks there. And finally, truth and re-- reconciliation process, I'm not sure. But there are certainly things that have happened that are not socially recognized and have not been taken into account.

So, I think now we have-- we have new tools, we have innovative program models, we have a human rights foundation, we have useful medications in the right-- you use them properly. We have understanding of the social determinants of mental health. The challenge is to put these together to build inclusion and dignity for people who suffer from mental distress. Thank you. (APPLAUSE)

JOANNA ERDMAN:

So, thanks so much, John. I was thinking about your title as you were talking, *Madness and Human Rights*, but I think it's social madness and human (LAUGH) rights, a question of-- who exactly is mad. So, I want to welcome and invite-- Judy Klein to open our discussion.

As Judy mentioned, she's a senior advisor-- to the Open Society Public Health Program, but she's a human rights lawyer who founded and directed the Mental Health Initiative at the Open Society Foundations since 1995, and whose decades of work-- to end unjust institutionalization of-- people living with disabilities and continued global efforts to pioneer community-based living-- in dignity and equality, I think it's a history of its own-- worth writing. So, Judy?

JUDITH KLEIN:

Thank you, Joanna. It's-- it's-- it's good to see such a nice crowd here for-- for an event on mental health. We're-- we're so used to being ignored in this field and-- and it looks like things have really moved. John-- thank you so much for-- for-- for that talk. Of course, it resonated very, very deeply with me. I've worked with John. I've had the privilege of doing that for the past 20 years.

And-- and one of the things-- that we talk about a lot is that, you know, we talk about programs. We talk about institutional programs and whether those are good, and community-based programs, and whether those are good, but what about the people? I-- you know, I think we-- we still don't talk enough about the people. And you know, you-- you-- I know that you-- have talked about funding consumer initiatives and-- and-- and how important that's been in-- in Ontario, certainly, but what do we do about really getting people's voices-- consumers' voices, people who are actually using these services and whose lives are deeply affected by the way those services are delivered? How do we get them really involved? And not tokenistically, but really in-- in policy making and-- and programming?

JOHN TRAINOR:

Well, that's-- that's an excellent question. I mean, (CLEARS THROAT) the example I gave in Ontario, we-- we thought, you know, rather than just inviting people to be on a committee or-- or to, you know, join a policy group, they-- they need a foundation of organizations over time, where they can work on positions.

They can have the resources to-- do research and that kind of thing and have a voice that's-- that's more ongoing. What we found was five years after that funding had been put in place-- 90-- over 90% of these groups were involved in local planning groups, in-- in, say, the h-- working with the hospital around the psychiatric services in the hospital.

So, I think that-- that structure-- a structural component to the system that is controlled by people who have used the system is-- is important. But you know, a lot of the reason that people weren't involved was-- was just good old-fashioned stigma, you know. It is amazing-- when you read some of the radical theory-- through the years and you just-- it-- it just doesn't seem to have crossed people's minds.

And then it turns up around-- in the 1980s, you start to see it coming more. Earlier than that, people who-- who had used the system themselves were talking. They were talking, but they weren't getting listened to. So, it's-- it's-- there's multiple strategies.

JUDITH KLEIN:

Great. So-- thank you. Yes-- and-- and-- and I think-- we continue to-- to have the need really to deploy so-- really a myriad of strategies because it's not one-- one solution that is-- you know, gonna get us there obviously. You know, the-- the other thing I've been thinking about is-- you know, that we-- we-- John and I started-- working together in the Baltics actually, in-- in Estonia, Latvia, and Lithuania 20 years ago. And-- and-- and we got funding-- we-- we jointly funded with C.D.A., the Canadian Development Agency, at that time-- deinstitutionalization program in Estonia that was really very successful and that was sustainable.

The government took it on-- and it's-- it's still alive today. And you know, there was an-- enormous amount of progress over the past 20 years, including those beginnings, but-- but all-- all of the things that we've done-- you know, to build on-- on that kind of work. And I guess I'm impatient.

And I'm tired of waiting for the, you know, the-- the change that I really-- want to see, which is real community inclusion for everybody and the end of this-- this nightmare of-- of us and them-- which-- which is one-- one of the-- the words, you know, the terms that I use to-- to talk about-- the real problem in this field, which is very simple. There shouldn't be an us and them. And-- and what do you think-- maybe are-- are-- you know, some of the levers that-- that might help us push forward this-- the-- this agenda? Because, yeah, we've made progress, but God, it's not enough. What are we doing in 2018-- treating people this way still?

JOHN TRAINOR:

Yeah, no, it's-- it's-- it's a complicated environment now for these sorts of things because, on the one hand, you've got this retrenchment in psychiatry. Some people call it neo-liberal psychiatry, which is-- an attempt to reduce things to-- to a level that is sub-political-- to-- to get the politics of it off the table.

And I think that's kind of working against us. But there are lever-- levers we have. One is that if you-- if you do things the better way-- governments experience something. They experience lower costs and they experience fewer people on disability and more people in the workforce. And that is a-- you know-- something that is very appealing to government.

So, you've got the success of the approach is one of the levers. The other thing, I think, is that there are more people now speaking up. More people are interested and are speaking up about mental health and mental illness than before. And there's more power, I think, being experienced by players like family members and others. Less respect in some way for-- for experts. That can cut both ways.

But the history of psychiatry-- I'm not a psychiatrist, but is-- is a history of expertise really in many cases gone really, really south-- and-- and-- and has brought up approaches to care and everything which-- which are terrible. I think now there's a much more balanced picture. In-- in most systems, I'm sure it's true here, it's true in Canada, a big player, for instance, in mental health systems is non-governmental organizations. And there are-- there are hundreds, and some are huge in Canada now.

And they are governed by boards of citizens. And often most of them on those boards have substantial representative of people who have used the system. So, that's a lever for-- for (UNINTEL) the system has become more complex now. So, I think there are some levers that we can use. That's a couple.

JUDITH KLEIN:

And my last question before-- I'm sorry, thank you, before-- we open it up to-- to the Q&A-- I can't help-- the fact that we're-- we're in New York, I have to ask a political question. We-- you know, we are at the Open Society Foundations and we believe in-- in human rights and we believe in human dignity and pushing that forward through-- through our agenda.

How do you talk to people who have a conservative political agenda about mental health because, you know, we know what we believe, but-- but how do you build a bridge between, you know, kind of the left and the right, to put it in a crude f-- which I didn't mean to, but I just did, way-- to-- to-- to really come together on something that is so much about fundamental humanity?

I mean, mental illness is not something over there; it's something that affects all of us, right, in one way or another, whether it's a family member, a friend. So-- so this is not a foreign issue. And-- and how do we bring the-- the two sides together to-- to make things better for-- for people?

JOHN TRAINOR:

Well, one-- one thing I've certainly learned from being involved in the public health program is how much careful thought is put into-- into tactics and how do you get a message, whatever kind of rights we're dealing with, and-- and the intersection of health and rights? How do you get that to appeal? In-- I-- I think in this area there is-- there's one obvious one, and that is that if you look at some of the priorities of more conservative thinkers, they are things like-- a high level of participation in the workforce, reduced reliance on welfare or disability rolls, that sort of thing.

Those really do dovetail with a lot of the goals of the Community Mental Health System. If you talk to people who have used the system, they want to work, right? They want to finish school. And as I was saying in my talk, there's now so many successful programs that have allowed that to happen.

So, in some senses, the idea of an active contributing person in society is very appealing to a conservative position and it's very appealing to people who have used the mental health system. So, I mean, I think that's one example of where you can get the agendas to mesh-- if-- if you put the message in a certain way. But I think that-- that's a big one.

JUDITH KLEIN:

Yes. I-- I-- I agree. And I think that also goes a long way to-- to kind of deleting this us-and-them dichotomy that-- that we need to-- to get to, because we'll-- we'll never reach our goals, I think, in-- as-- as long as we see people as on the margins and-- and not-- not us. You know, we're all us. There's only one us. And I'll end with that-- and open it up to-- to Q&A?

JOANNA ERDMAN:

Sure, yeah. So, if you want to just raise your hand and I'll call on you. Please.
(OFF-MIC CONVERSATION)

QUESTION (MALE VOICE):

Hi-- John-- in your historical overview, I wonder if-- if you could give a *Reader's Digest* critique of legal advocacy. And my experience, which is-- doesn't go back to the 19th century, is that-- the-- the legal advocacy piece is particularly troubling with regard to number three. And the-- the gulf between the lawyers and those who the lawyers purport to represent, I think, is arguably a greater-- larger gap than you saw in the Civil Rights Movement, for example, in the United States, where you-- at least you had African-American lawyers in the system fighting for the rights of-- of-- of African-Americans.

And of course, the recent example that we had at-- Open Society, when I was here and supporting the development of the Mental Disability Advocacy Center-- and-- and the trouble that that organization had in really including the voice of people-- with-- the people who they were trying to serve. I wonder if you could offer some thoughts? And Judy, I would invite yours as well since you've-- also seen a lot of that side of the picture.

JOHN TRAINOR:

Well, it's interesting, yeah-- you set me a high bar-- bar there, Rob, with-- a *Reader's Digest* version. I-- I was actually aiming for *The Onion* or something, but-- (CLEARS THROAT) I-- I'm not sure. I mean, I-- I-- certainly I think now it's getting easier and easier to find advocates-- whether it be lawyers or other kinds of advocates, who have used the mental health system-- or professionals.

I've just been recruiting people for the board of-- of Mental Health Research Canada, which is a fairly new organization. We want a serious representation from people who have used the system. And the people I've recruited so far who have used the system as patients are things like Canada (?) research chairs in-- in-- various disciplines.

So, that's-- that's helpful. Legal advocacy has had a big of a checkered-- outcome. I mean, the famous case I know of in the States is-- there's-- it's a real famous case. It's called Wyatt v. Stickney. It was in Alabama and it was a right-to-treatment case. So, there was a psychiatric hospital there. They were taken to court because the treatment was so bad and the staff ratios were so low.

And the judge ordered the hospital to meet certain treatment ratios, so a number of staff per patient or, you know, so that it was more reasonable. The response of the state of Alabama was to discharge half the patients to meet the ratios. And they just dumped them into the streets of Mobile and it was a disaster. So, you've always gotta temper legal advocacy with other program stuff.

But I think if we keep supporting consumer-- organizations and-- we did a lot of work with-- supporting consumers to complete university and complete college, that the ability of-- of-- of them to take over this is going to grow very quickly. Judy, do you want add?

JUDITH KLEIN:

Yeah, I would just build on that, I guess, and say that I-- I think there has been-- poor collaboration between consumers and lawyers. You know, I-- what we-- we could have done better, and we continue to need to do better, is involve consumers for real. Like, you know, we're not representing them-- I mean, we are, as-- as lawyers.

And-- and that's how I started my legal career, representing people-- who have mental illness or intellectual disabilities in-- in court. But-- and-- and-- and you know, I remember, as a young lawyer, that the judges would be shocked that I actually knew the client's name and was able to make an argument, 'cause I was court appointed, making five cents a day do-- you know, doing that job.

And so, people would show up in court and, you know, the client would be there and-- you know, the lawyer had never seen the client before. So, I won every single case, every case-- in guardianship or involuntary commitment because the judges (LAUGH) were so shocked that I actually consulted with the person and was really advocating on their-- their behalf.

And I think that's been part of the problem, is that the lawyers have also taken-- even in the best intentions, you know, a paternalistic attitude, where it's like, well, we're taking this case to a local court or, you know, to a European court for that matter-- but-- but where are the people who are really affected by-- by that litigation? Well, you know, they're in the background.

Well, we interviewed them, but you know, none of them are here in the courtroom. Well, my clients were sitting next to me, you know, in the courtroom-- as dangerous or as, you know-- disabled as-- as they were perceived. And I think that-- that-- has an impact actually in-- in-- again, we're coming back to the same thing. It's about really involving people-- in-- in a way that-- that's meaningful and where their voices are-- are real and-- and we're not-- you know, they're not in the background.
(OFF-MIC CONVERSATION)

QUESTION (FEMALE VOICE):

I really appreciate the conversation and-- and I guess I wanted to-- offer something that I've been involved with for a while, and kind of working with-- we're an international-- we're New York based, but we work internationally with people who are, generally speaking, attempting to create new psychologies that particularly break with a kind of broader diagnostic framework, of which there are many, and I'm not here to (NOISE) plug that particularly.

But I-- I think I was struck by what you were saying about the involvement question, of who you involve. And I guess I would really urge that we even go beyond people who, quote/unquote, use the system. And what we did and tried to get other people (LAUGH) in the field to do, but there wasn't a lot of interest, is we took a survey about diagnosis and the impact of mental health into communities here in New York and around the country, and online around the world.

But we literally stood on street corners and just spoke to anyone who was willing to speak to us. So, it wasn't-- you know, it wasn't a self-selecting group-- other than if they were willing to talk. And it was a fascinating conversation because we learned a lot about, one, in kind of the unofficial ways diagnosis and that model permeates everyone's life.

So, most of them wouldn't know a psychiatrist or a psychologist or a therapist from a hole in the wall. They don't particularly, in that sense, interact with it. But their children and their grandchildren, and particularly-- are all getting diagnosed with ADHD. Or their-- you know, they-- so they have plenty of stories. And-- and-- and in all honesty, a fairly conflicted view of-- of diagnosis.

It wasn't this kind of, "Oh, yes, we hate it," or, "Oh, no, we--" and but they also-- what was striking is they simply have no access to and very little-- are just never a part of the conversation, not even in the most-- more traditional stuff, but certainly never get introduced to anything that's even remotely innovative, that's outside.

And even though at some level they also understood that there were a lot of ways to improve people's emotional health outside of, if you will, the mental health system. So, it was grappling with that contradiction, too, that I think in a funny kind of way made it-- was both in-- very moving, but it also, in a funny kind of way, made it more difficult because it's-- it's easy to want to characterize all of this as good or evil or bad or good or helpful or not helpful, but-- (LAUGH) but in mostly saying this and, you know, in-- and over the last couple of years, I've been leading the conversation in-- largely in impoverished communities around creating our mental health.

And really putting the question to people honestly and openly, "What do we need?" Because again, in a funny kind of way, the traditional psychology totally overturn-- determines how we all see ourselves. And we all-- I mean, we're endlessly labeling each other. I mean, it's not as if that model hasn't taken hold. They could-- psychiatry could disappear tomorrow and (LAUGH) we would still be in its thrall.

On the other hand, people are kinda saying, hey, we need something else. This isn't working. It's not working for us, it's not working for our children. And so-- and again, there's no easy answers. I'm not offering easy answers. I mean, I-- we've written up the surveys and things. I'd be happy to share it with people. But-- but I guess I'm just kind of (UNINTEL) in-- in a friendly offering, of really wanting to support this, that I just think we really, really broaden the conversation 'cause everybody's being hurt by the mental health system, regardless if ever-- they never, ever, ever step inside a mental health asylum.

JOANNA ERDMAN:

Thanks very much. Do you have any comments or reflections? Yeah, the gentleman in the back?

QUESTION (MALE VOICE):

Well, I have a question, not a statement. How you would explain, among American veterans who serve in armies, like in Afghanistan, Syria, Iraq, about 10% have acute post-traumatic stress disorder? After first war-- after Second World War, where casualties were on a much higher level, conditions in every possible way were much worse-- it was nothing like this.

In Russia, who lost 25 million during the Second War, where 80% were killed or received very hard, very dangerous injuries, also nothing like this. You would mention, of course, better diagnostic now, but besides psch-- psychiatric evaluation, this suggests from statistics from ordinary life how behave-- veterans now and before. Why-- how you explain such transformation-- why it become a nationl problem and it was not something like this before?

JOANNA ERDMAN:

The question is on contradictions or-- or--

JOHN TRAINOR:

I was gonna invite you to answer that question, but I-- 'cause I really don't know. I mean, I-- I think it relates a little bit to-- to this-- there's-- there's-- much more of a tendency now to-- to diagnosis people with things and-- to turn conditions that seemed more like, you know, aspects of normal life into a diagnostic category.

And there's been a lot of concern that the diagnostic manuals, like particularly the-- the DSM-5 of the American Psychiatric Association keeps adding new-- new things and new syndromes, driven in part by-- by issues of-- of phar-- pharmaceutical company pressure and-- and billing, and-- and-- and the need to have things that-- officially recognized so you can bill for them.

So, but you know, why-- if it's the case, people who-- who are involved in-- in the armed forces now would be-- more likely to get this-- we have the same problem in Canada with veterans from Afghanistan. I really-- I really don't know. I-- I would invite some-- if anybody else in the audience wanted to comment on that-- to-- would you-- should we get you a microphone? We'll just give you a microphone.

QUESTION (FEMALE VOICE):

I'm from Japan. And in Japan, average if you are in institution, 30 years in a institution. And it started to happen when young man stabbed an American diplomat after World War II and the society said we need a bigger budget to put them in institution.

That's how government put the big budget for them. And that has been like this for a long time. So, there's many people who have been in institution like 20, 30 years. And then after the earthquake of northern Japan, many people has no place to go. And then all the psychologists started to interview them and they found out you really don't have to be in an institution.

So, they were in, like, a community. And then they said, "Oh, you know, I could have been married. I could have-- had children. Now I'm, like, 60, 70 years old." So, they-- they-- like, their right of living a normal life has been ignored. On the other hand, well, in Japan we call the younger people who couldn't adjust in society and they locked themselves at home, and we call it a NEET. And those people go to, like, a total rural area and they started to live in-- (UNINTEL) communities.

And then they function with local people, like older people. They get a small job and pick up the grocery for older people, and then they are very happy. And then for some reason, they can recoup. So, I think the Japanese-- in our case-- funding by government really would influence the institution like hospital, asylum want keep them in the hospital how long. I mean, is there any screening, like a third party, to say, "Do they really have to be in a hospital?" Do you have any answer to it?

JOHN TRAINOR:

Not a final one, but there-- it certainly depends on the jurisdiction. I mean, it used to be, in-- in many provinces and states in North America, if you go back far enough, that families could commit people-- or a family doctor, and there wasn't due process. In many jurisdictions, there now is. In Ontario, you have things like the Consent and Capacity Board, it's called, where if you're put in the hospital against your will, you have an appeal to this legal tribunal, which is independent of the hospital. But-- so there are better due process protections in some jurisdictions, but I don't know, does anybody else want to--

JOANNA ERDMAN:

I wondered if this linked to-- and we didn't hear too much on the final point of truth and reconciliation. I wondered what aspects of the reconciliation is in the sense of lives lost or what they could have been or people's sense of themselves?

JOHN TRAINOR:

Yeah, no, I-- I-- I've always wondered about that because there's so many-- examples of-- of abuse, such as being-- and-- and Japan was-- was-- had a different trajectory. When beds were closing over here, they were opening in Japan. And I-- I was there in 2000, I think, or 2001, and-- and the-- the bed ratio there was ten times as high as-- as Ontario.

But it's not just-- it's not just being put in hospitals. There's-- there's other kinds of things that have been done. Dramatic-- dramatic overuse of medications, which led to permanent-- neurological problems, tardive dyskinesia and other things. And I mean, I think if-- some process to bring justice to this. In Canada, we've experienced in the last maybe, I don't know, decade in another area, which is the First Nations and-- indigenous people-- who were treated very badly and were really ignored.

And there has been a more formal truth and reconciliation process and public-- public eve-- and public acknowledgement of what went on. I think it's been very important. The chief justice of the Supreme Court of Canada said that Canadian treatment of indigenous people was cultural genocide. So, and I think those are powerful things for people to hear who have been through it. Even if it's too late to recover s-- or recapture certain parts of your life, at least you get some sense of justice.

QUESTION (FEMALE VOICE):

Just to speak a bit to the progress that has been made and, of course, still has to be made-- I'm a social work student at New York State Psychiatric Institute and with that we-- there are a lot of peer specialists who were once in-patients on our units who are now hired with a salary to be an advocate for other patients on the units.

And with New York state now mandating mental health education in its schools, starting I believe this year-- we can see the progress that has been made. So, what do you see as the next steps for stigma and for treatment considering where we've been and where we want to go-- or where we might want to go?

JOHN TRAINOR:

Well, I mean, I think your example is a good one of-- it's an increasing proportion of the mental health workforce is now people who have used the system. If you want to see something that'll change the conversation in the lunch room of an agency or a ward-- and how, say, the patients are talked about, put some people on the staff who have used the system and you'll see a big difference.

I think one-- one of the issues I see is that there's a lot of agencies or organizations like yours that are doing this, and I think that's great, but the other thing is these independent foundations for consumers to be involved-- that are separate from that.

In some ways, you've gotta watch mainstream agencies absorbing these things, you know. I think that what you're describing is good. I-- I think that's very important, but in some ways the mental health system is-- is-- is absorbing some of these things and it's-- it's-- it's-- in addition to that you need this independent base of consumer organizations to-- to fight for their rights and their-- yeah. But I think those are important things.

It's coming together now-- for a lot of people. I mean, we did work in Ontario on early intervention in psychosis, where instead of waiting till some-- for somebody to deteriorate, you-- you try to identify it very early and-- and intervene, not just with treatment, but also with support for families-- a lot of counseling support for the person to deal with what's going on with them.

And you now see people, even with what you would consider serious cases of schizophrenia, and a lot of first rank symptoms and-- and not fully controlled by medication, and they'll be 30 and they've never been in the hospital. They're working full-time. Some of them are married or living other kinds of-- of social lives that they find rewarding. So, I think the next step is-- it's kind of-- things are coming together. And we're gonna get more of those stories and they're going to-- I think they're gonna be powerful.

QUESTION (FEMALE VOICE):

Thank you. I was interested-- in the beginning, you had-- spoken about non-western societies and the meaningfulness of social inclusion and that approach. I was wondering if you could provide some examples of innovations in non-western countries around rights and-- and mental health, like the grandmothers on benches for people with depression in Zimbabwe that's kind of-- approaches that have kind of organically come up with-- because many people don't ever get to the system. So, I was just wondering if you could speak to that. Thank you.

JOHN TRAINOR:

I-- I know about that one. And-- I think that's-- that's a great example. I don't really know about that many others-- but I wonder if other people in the audience might, or on the panel, have examples of that? Things that are really different. There is-- there is a psychiatrist in London, Vikram Patel, he's very prominent in international mental health.

And he's done things in-- in Goa where they train people to be mental health support workers in communities, who are often illiterate even. But they're-- they-- they're just the right type of person, you know, the supportive person in the community. They've had a lot of success with that and moving away from the idea that, you know, the real problem with mental health in this country is they just don't have enough psychiatrists or social workers. Of course, you want people with certain kinds of training. That's important, but it's not the only-- the only thing. But does anybody else know of any-- any other examples?

JOANNA ERDMAN:

I was also wondering, John, and it might be a similar type of question, but given the way in which social dysfunction played into the definition of-- mental-- ill health or madness, all the examples now are instances of s-- high social function as a measure of mental health, that you can hold a job, that you can graduate school, that you can-- but these are quite traditional markers of a kind of, quote, normal life or accepted life, or something where we deem things being okay.

And I wondered if there are other models by which people define what is a good life-- that really-- depart in significant ways of what we think of as the major mile-- you must buy your house, you must have your children, and marry, and so forth. And so, are there programs that really take that, the very definition of what it is to live a good and healthy life, as being something very different?

JOHN TRAINOR:

Well, I don't know, I mean, I think e-- even-- even some aspects of traditional mental health work really did listen to people and say, you know, the degree to which we think we have to intervene is based a lot on your reports of-- of distress.

There was an interesting-- qualitative paper done in Montreal quite a few years ago where they looked at two clients-- (CLEARS THROAT) both of whom, if you just looked at the numbers, say how much social contact or how many close friends, were-- were-- were quite isolated. But when you looked at their actual stories, you got two completely different stories.

One of-- one of these people was a very devout Catholic-- and was in-- living a life that was considered to be in a state of retreat. This is a recognized-- social status in the Catholic church. And he-- his connection was with the church and priest. He was not in distress. The other person was just an isolated guy with no friends who was lonely. And they unleashed case managers on both of these. And of course, for one, it was great because he got lots of hands-on help, and the other one it was like, you know, I'm-- I'm changing my number. I mean, I don't want to see you again.

So, I-- I think you do have to do that. And I think that-- you-- you have to watch whatever straight-jacket you're gonna put people in, if I can use a mental health term-- in terms of how they live. And-- you know, certain phenomena, like even psychotic symptoms, are much more common in the population than people think. If you look at-- at surveys in Brazil, something like 20% of the population has had psychotic experiences.

It doesn't mean they're mentally ill. If you look at people who-- there's a study in Britain that says middle-aged-- people who have lost their spouse, the number who hallucinate that spouse on a number of occasions over the next year, well, it's very high, right. So, you-- we do have to be open to a broader range of-- of territory before we pull out the DSM-5 or-- and-- and start labeling everybody.

JOANNA ERDMAN:

The question in the back?

QUESTION (MALE VOICE):

Hi. So-- I just wanted to add here-- while the conversation around veterans was going on, that-- I just came through that. There is a new program that's been launched-- two years ago-- by some of these veterans-- because they were really concerned about the suicide rate of-- people with-- post-traumatic stress, and that is four per day in the U.S.

So, what they-- what they've done is that they're-- this-- this group of six, seven veterans, they're taking wild mustangs from the Midwest U.S. in thousands-- thousands-- numbers. They're transporting them to down in Mexico, where they take them on a 500-mile journey-- up north. And they sort of break those wild horses because before you can get on a horse, it needs to be broken down and need-- it needs to be (UNINTEL) quite a few-- times, if you're familiar with those horses.

So, once they sort of break those horses, they find people-- veterans who are coming back from Iraq, from Afghanistan, and they try to match those horses with the exact personality type of that veteran who can take care of that horse, because spending time with that horse, it really allows them to connect and sort of, like, see themselves in that animal because it's-- it's a program that's been developed that they're not gonna just take care of that horse.

They're gonna take responsibility of that horse. They're gonna make it a part of who they are. And this program, it's been-- really successful in the past two years. There's a documentary out there that's called *500 Miles*. Everyone should sort of like-- check that documentary out. It's great. But-- yeah, then on that-- coming baxk-- I also had a question. So, as you mentioned, you were in New York, so there's-- there's gonna be some sort of a political aspect to it.

So, I just wanted to ask you that you mentioned that, the Canadian society, they've sort of-- really brought in those processes which integrate the society there. And-- you can integrate successfully anyone into the-- the society. Looking at the collateral (?) that we have coming of refugees from the Middle East, from Syria, down in-- South America, all of these refugees that are pouring in, these-- these are basically poor, honest people trying to, like, free-- flee their existing circumstances, just like you showed that picture of-- drapetomania.

That it's-- it's not a symptom that people are just-- they have this mental ill-- illness, that they're just-- they have this urge to jut run away from home. It's not that. So, how do you think-- the conservative thinkers and policy makers responsible for-- for reforming the health reforms and the overall well-being of society in the U.S.-- how do you sort of explain this-- viewpoint to them? That integrating these refugees, it's-- it's gonna benefit for the society if you sort of make those-- if you have a framework to integrate these people in the society?

JOANNA ERDMAN:

So-- and let's just take-- we have-- two final questions on this side, yeah, and then we'll take--
(OVERTALK)

QUESTION (FEMALE VOICE):

Well, I mean, I didn't really have a question, but-- I just-- sort of comment that-- so I represented-- people in-- trying to get out of psychiatric facilities in Buffalo, New York, in the '80s, and it was a really horrible place. (LAUGH) But it did also have on the property one of these beautiful asylums like you showed in the beginning. It was a Richardson-designed building, and he designed our state capitol.

And that's now been made into a hotel. But-- I had lived in the Philippines, where people who are loco loco, they were still part of the community and they hung out in the town square. And if you came into the town, people would tell you, you know, don't-- you-- this is-- don't worry about this person, or you know, whatever. So, they were s-- they were still part of the community. We didn't-- they didn't lock them away. (LAUGH)

So, I-- I was in law school at the time, so I was-- I-- and-- and I had this cross-cultural-- seminar, and I tried to investigate how other cultures-- look at psychi-- psychiatric illness. And-- some cultures don't really see that the individual is the one that's sick. They really see that it's the community that's sick. And the treatment that they-- this was, you know, a long time ago, but the treatment involved treating the whole community, and not just the individual. (LAUGH)

So, I mean, I just thought that was interesting. And-- and this was, like, you know, this again was in the '80s that I was trying to research this-- this subject. But-- I mean, all of this was-- now we have a lot more drugs. I mean, back then they were just using Haldol and, you know, horrible drugs. And-- I think pharmaceutical-- the pharmaceutical industry has really, you know, taken over certainly here. And that's-- you know, that's a lot of it. So, that's my-- just a comment.

JOANNA ERDMAN:

I think we have-- a little bit of time, so, yeah-- the woman in the black sweater.
(OFF-MIC CONVERSATION)

QUESTION (FEMALE VOICE):

Hi. Thank you so much for summarizing such important topics. And I have a very basic question and I wonder if you can provide an outline or references-- about the definition of mental illness, how it relates-- how it's contextualized in different-- social-- historical reality. Because I think starting from the definition, we can really get-- into answer, which are, of course, relative to different-- social contexts, socio-political-- historical contexts-- or from where the treatment should be coming from. So, really going back to a semantics and very basic definition, if there is-- such an outline that can be retraced.

JOHN TRAINOR:

You know, there isn't that I know of. (CLEARS THROAT) It's such a contested area-- in my experience. And-- and efforts-- to nail it down, whether it be a diagnostic system or the current one the N.I.M.H. is doing in the States, where they're trying to nail it down-- as with neurological and cognitive markers.

They feel that's getting away from the-- the sloppiness of the DSM-5, which is really syndrome based. This is-- this is, you know, well-- if somebody's got these symptoms, what appears on the scan or-- there's been so many efforts and there's been a lot of efforts to sort of weed out-- definitions that are based on being socially marginal or s-- considered socially dangerous.

I mean, the DSM-2, I think, had homosexuality as a mental illness, right? So, you can see, this is-- this is always a contested boundary. And you know, the-- I think a lot of the work-- there's-- there's the genuine work of trying to help people who are in distress and there's the social control work-- which has always been a part of the mental health system.

I don't-- I don't personally know of any, you know, real answer to that other than to continue to have it as an open issue and to continue to unpack things that we see as diagnostic categories. Now, a lot of the talk in Canada is the soaring rates of anxiety and depression in young people.

Well, that's very important. You're not gonna explain it if one of the things-- or if-- or if you miss looking at things like the rise of insecure work and the deteriorating social safety net in Canada. If you don't look at those things, you're not going to, you know, you're not gonna fully explain it. You get into what Daniel Dennett calls greedy reductionism, where instead of looking at something at the right level, you always want to drag it down to say the biological level.

Somehow that seems more real to you. This is-- this is a false way to go. But I-- I-- I just don't have an answer, so that's why I'm talking about something else. But-- (LAUGHTER) I-- I just don't have an exact answer. So, maybe somebody else does.

QUESTION (FEMALE VOICE):

(UNINTEL) answer. My-- I was thinking of the question of diagnosis or trying to be precise about that-- I'm a medical doctor, but I-- it's-- comes, I think, into the whole arena of psychiatric diagnosis is I think we have to ask the question, well, what hangs on it.

What-- what different-- you know, if young people are clearly anxious and depressed, does it make a difference for them to have a blah-blah-blah diagnosis or-- (LAUGH) I work in-- with people a lot with dementia or in that field, and I'm not sure that most of the diagnosing of memory loss much hangs on it in terms of really helping people. Just-- I was just thinking about that.

I also had a question about-- alternative (LAUGH) treatments and stuff. We have a number of colleagues who work internationally with us, who are using just the wonderful approaches of play and performance in-- in refugee camps and with mentally ill p-- groupings of mentally ill people in Zimbabwe.

And I just wondered if other people had-- had experience with that because this has been-- it's-- a community-building activity as well as the individual. Patch Adams brings soldier-- veterinarian (SIC)-- vets with PS-- post-traumatic stress disorder to clown in South America and finds it enormously therapeutic for them. So, just would be interested in that.

JOHN TRAINOR:

You know, we saw something-- and Judy and I were-- in Thailand a number of years ago, but-- the refugee camps on the border. And we were working-- or meeting with some people who were from an agency-- it wasn't an agency, it was really a group of ex-prisoners of-- of Myanmar's prison camps under the military dictatorship.

And they had formed an organization and they were doing exactly the kind of thing you were talking about, you know. They were using plays and theater and-- and things at the village level, also at the-- at the whole village kind of level. And it seemed great to us.

And I-- I-- I think Judy ended up provide-- providing support for them. What was kind of sad to see at the time was that there was funding that had been offered to them, and which they had accepted because they were pretty desperate for money, which had come through-- I think-- U.S.A.I.D. and-- and Johns Hopkins, but this required them to use a very specific cognitive behavioral model that came from here, right.

And they were-- I think they were doing some international comparative thing with this, but it was a real pity. It was a real pity to see that they had worked this out in their own context. Now, they were doing some of it, but that they were getting dragged towards these models like cognitive behavioral therapy, which-- which can be great in its own right, but it wasn't for that setting. So-- good-- yeah.

JOANNA ERDMAN:

Thanks so much. I'm sorry that we don't have more time-- for questions. You can appreciate why we love having John on our advisory board. These are exactly the kinds of conversations-- that-- that we so enjoy having. So, I want to just close the event-- welcome you to stay a little longer and enjoy-- some of the food outside and to chat with John. But to close the event, I want to give the last few minutes to Jonathan Cohen. As he mentioned, he's the director of the Public Health Program here at O.S.F.-- to say some-- words about John.

JONATHAN COHEN:

Thank you, Joanna. Hi, everyone. John, I have the privilege of thanking you on behalf of the entire Public Health Program and the Open Society Foundations for over a decade of service on our Global Health Advisory Committee. And for those of you who came to hear the talk, I just hope you'll indulge me for a few moments while we all thank John.

You've been on our advisory committee for a long time, and the truth is you haven't just advised one program; you've advised several. We're a very different program than the one that we were when you began on the Global Health Advisory Committee. I think almost every single person, with just a couple of exceptions, is new. The whole face of the program has changed.

You've seen us through multiple leadership changes, three program directors, three chairs of the advisory committee, three presidents of the foundation. And through that, you've been a real compass. You've helped us stay true-- to our values and to who we are-- and you've embodied so many of the foundational ideas and commitments of the program. I think one of those-- which we heard tonight, whether it was through the Myanmar example you just gave-- or the comment about independent user organizations-- is your commitment to independent civil society.

You are always concerned that the organizations that we fund not be bought and not be co-opted by us or by anyone. And you're probably imagining the example that I'm thinking of, which I won't go into too much detail about, but it had to do with-- organizations that we fund accepting money from the pharmaceutical industry. And without going into all the details, your interventions on that, John, and the conversations you forced made me a better grant maker, I think made all of us better grant makers.

I think you also understood who we are as a foundation, who our founder is-- what our origin story is and why we're here. Your wife, Judy, is here with us tonight. And you shared with a number of us a few years ago, John, her experience-- as a relative of Holocaust survivors, giving expert testimony in one of the final trials in Germany-- of a guard in Auschwitz.

And it was a very intimate family story that you shared. And I-- I felt a sincere empathy in your sharing that story with me and with us, as staff of a foundation whose founder, George Soros-- is, himself, a Hungarian Jew who survived Nazi persecution. And it said to me that you understand who we are-- who leads us, and where we're coming from.

And when you talk about truth and reconciliation in the mental health field, I know that you're aware that truth and reconciliation has a much broader resonance in the field of human rights and in the field of accountability for mass human rights violations, from genocide to apartheid-- to the institutionalization of-- of people-- with mental disability. I do want to end with a word about your field. I'm fond of saying that there would be no field of health and human rights without the field of mental health and human rights.

It was practitioners in your field who were among the first to recognize social exclusion as a determinant of health. It was users of the mental health system who were among the first to demand inclusion and nothing about us without us. And so many of the foundational ideas that animate health and human rights and our program are ones that come from the mental health and human rights community.

The idea of not pathologizing people who are different or perceived to be different, the idea of not over-medicalizing issues that are as much social as they are biological, the idea of not over-pharmaceuticalizing medical challenges and issues and over-relying on prescription drugs, the idea of not over-institutionalizing people who appear to cause an inconvenience-- to social norms and lead many to just want to sweep them under the-- under the rug.

So, I think your expertise in what was really a pioneering area of health and rights-- it gave you two things. It gave you a grounding and it gave you a breadth, and that explains why, you know, with your characteristic-- grace and humor and generosity, and also anger, you were able to advise us on everything that we undertook as a program. So, John, please accept this gift from the Public Health Program, to you, with our sincere thanks. (APPLAUSE)

JOANNA ERDMAN:

Great. And thank you all so much for coming.

* * *END OF TRANSCRIPT* * *