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[SPEAKER_04]

How does stigma affect the lives of people experiencing mental health challenges?

And what can we do to change it?

In this episode of Kafe MIRELLE, Sarah Hean from the University of Stavanger talks with leading stigma researchers Claire Henderson and Petra Gronholm about the causes and consequences of mental health stigma, the evidence behind effective anti-stigma interventions, and why lived experience must be at the heart of creating more inclusive and supportive communities.

Welcome to Kafeé MIRELLE and conversations about stigma, discrimination and recognition.

I'm in the studio today with Claire Henderson, a clinical professor of public mental health at King's College London, and Petra Gronholm, an assistant professor at the London School of Hygiene and Tropical Medicine.

Thank you very much, both of you, for meeting with me over the North Sea.

We are meeting remotely, so I hope the technical gods are good for us.

But welcome to the studio here in Stavanger, and I look forward to our discussion.

Thank you.

I wonder if you could just start a little bit about your backgrounds and why you got into this really interesting area of work.

So Claire, maybe I start with you.

[SPEAKER_00]

Sure.

So I started my training in psychiatry in the mid-1990s after studying medicine and

and did a master's in public health in the States.

And it was an interesting time to start working in psychiatry because we were gradually closing our large Victorian institutions, formerly often known as asylums, but closing large hospitals and increasingly setting up community mental health care.

And

This was, I guess, something that was kind of new for us, but obviously new for everybody else concerned as well.

And it became a little bit of a political issue in that when something went wrong, there would be a lot of coverage, for example, on the part of somebody who'd been receiving mental health services and committed a violent act and occasionally a homicide.

there would be a huge amount of coverage of this.

And there was sort of rhetoric about, you know, community care is failing.

And at the time, as I said, I was doing my training and then I started doing a PhD in psychiatry and I was studying something else at the time, but it involved going to see a lot of the people that I was recruiting into my study at home.

So I would

visit people at home and sometimes they would pick up their tabloid newspaper and points where, and there'll be coverage, you know, about something, something that has happened along these lines.

And people would say, this really affects me because now like, you know, all

the people I know will think I'm like this.

So that was really, you know, a kind of a window into the impact of kind of stigmatizing media coverage and kind of stereotypes about psychosis and violence and,

which really brought to life to me something that I had studied as part of my master's in public health.

Actually, I'd done a couple of classes with Bruce Link, who's one of the kind of leading stigma theorists.

But like I said, it really kind of brought things to life.

And so when later on in my research career, I got the opportunity to work more on stigma, I took it, you know, because it's so relevant to the people that I look after as a psychiatrist.

[SPEAKER_03]

Thanks.

For my part, a slightly different route to Claire.

So I don't come from a clinical background at all.

In fact, I have a background in psychology, but more as a field and discipline as opposed to actually anything clinical or being a practicing psychologist.

But what drove me to study psychology originally was I'm just very interested in social dynamics.

And it was really the

the social psychology side, that was of real interest to me.

So I was almost peddling, do I want to understand sociology or psychology a bit better?

But I also was really interested in ideas around identity and what makes us who we are.

And also, obviously, within psychology, you can start thinking about psychological wellness and illness as well.

And then the idea of why do experiences of mental health conditions and psychological

disruptions of some kind affect different people in such a different way and then merging that with the social dynamics of how do other people then start to think about these differences and illnesses potentially.

So that was really my introduction to the field.

After my psychology degree, I was still slightly toying with the idea, would I be interested in something a bit more clinical?

Or would a research group be more of interest to me?

And then during my master's studies, I had an opportunity to really dig into this idea of sociology of illness and societal influences around mental health and understanding those social dimensions of mental illness.

So that really drew me in and I decided to go into that research side of things.

And I've always been interested in perhaps research from a health perspective. So particularly health service research, understanding how do people get to treatment when they need it?

What is it that might stop them?

And also what is the experience of being ill both for the person and those around them, whether that's on a close scale or on a wider societal scale.

So the idea of stigma as a process within this came up quite quickly.

Another element I've been really interested in is thinking about cultural and contextual differences in how illness is understood and in how health care is provided and mental health care and support is provided, both in terms of what it looks like, how illnesses are understood.

what's available, what's appropriate, how do we understand what is best in one context versus another.

So I've been really fortunate to be able to tie these different areas of interest together around this exploration of stigma and discrimination and how that becomes a barrier, particularly when we think about how we seek help, how we talk about our experiences, how we support one another when someone's unwell, and also how we access services.

So coming from it more from a social sciences background and definitely a very strong research angle as opposed to a clinical interest as such.

But that's why it's also so nice to have been able to work with colleagues like Claire and others.

We all kind of come from slightly different backgrounds and can take slightly different angles at looking at these questions together.

[SPEAKER_04]

conceptually, there seems to be a lot of discussion about what stigma is, what discrimination is, the relationship between them.

So from your research work, how do you define stigma?

What is your definitions?

What are the definitions that you choose to use?

[SPEAKER_00]

So I guess for me, I think about it operating at different levels.

And I guess the longer time goes on, I start to think about more and more levels.

Because it is a very multifaceted thing.

And there are a number of different definitions of different ways of thinking about it.

So, I mean, one very important level that sometimes can get a little bit forgotten in terms of the research field, I think, is the kind of structural level where you're thinking about legislation, policies, procedures within organisations.

And then...

you know, within organisations that obviously can affect the kind of organisational culture and the kind of interpersonal things that happen either within organisations and the interpersonal level is another one, you know, in terms of how people behave towards each other, either in an organisational kind of context like healthcare or social care or, you know, in workplaces, but also obviously in informal settings, you know, in terms of people's social relationships.

But I think what's emerged for me is another sort of in-between type level, if you like, where, and I think this is because of the way that we often measure stigma, where you're asking people to think sort of about, you know, people with whatever characteristic it is, you know, whether it's mental illness or substance use or people with both or other characteristics, when you're asking people to consider sort of this group of people in general, because that's a different thing to asking about, you know, a particular kind of interpersonal interaction with an individual.

And then at the level of the people affected by this, then there's this concept of internalized or self-stigma where people are thinking about themselves and responding to people around them because of the way that we all learn, I guess, stereotypes at quite a young age.

and that is something that's very difficult to kind of shake off.

[SPEAKER_03]

I fully agree with Claire that we can think about stigma at multiple levels and the more we think and whichever level we potentially zone in on, the more nuance and distinction you can build into what that process of stigma and discrimination might look like on that level as well.

So my take on this tends to be relatively pragmatic, but I think there's definitions of stigma very conceptually that are rooted in sort of sociological literature from the 1960s, talking about something that makes a person different from others, some sort of identifying marker that could be anything. As Claire mentioned, and as we all know, there's a number of stigmatizing characteristics or features about an individual that could be related to anything from mental health to health, to gender, to any other social indicator.

But at its core, I think of stigma and discrimination as that, or stigma in particular, as that difference people have and that impact that difference, the perceived difference makes, whether it's how that person is viewed by others or how a group of people is viewed by others or how others view that person or that group.

And then slightly depending on

how I like to explore this from a research perspective.

You can look at different theoretical frameworks or operationalized frameworks almost that help you then structure theories or approaches around an approach that then helps you dig into this really complex social dynamic that can look different ways.

And I think this is why sometimes

The research on stigma and discrimination can also be critiqued for being quite simplistic because one very common model of looking at stigma and discrimination would talk about stigma in terms of knowledge, attitudes and behaviour.

that behavior dimension in capturing that discriminatory behavior as well.

And that's a really useful way of thinking about stigma and discrimination, for instance, from a research perspective, because we've developed scales that help us assess these different dimensions.

of knowledge attitudes and behavior we can do relatively easy pre-post comparisons and start to capture this really complex social process but that's obviously not to mean that it's possible to capture something as complex and profound and multi-layered and just nuanced rooted in individuals' identities and these group dynamics with a couple of brief questionnaires.

It's also always important to remember why we are thinking of stigma, conceptualizations and models and where they're used.

Yeah, it's a very complex matter that we need to make tangible in some way for our work.

And this is why different people, different groups, different projects can have slightly different ways of trying to grapple.

and sort of operationalize this concept.

So even if you look up my publications, you might well see a couple of different frameworks for which stigma has been considered, slightly depending on the particular angle of projects taken or the type of stigma that's been explored, or maybe the levels at which stigma has been looked at, or from whose perspective, or are we talking about something that's reported as happened or are we thinking about anticipated reactions that may or may not take place so I guess maybe the takeaway I tend to give students in my teaching on stigma as well is don't be worried if you get into the field and

just feel yourself overwhelmed by a number of different definitions and models and conceptualizations because that doesn't mean that there's anyone that would be better than

know the rest or that there's something that's absolutely wrong and something that's absolutely right but it's more thinking about what aligns with how you for this particular question or project or way of thinking what helps you start to put some boundaries and framings on these really difficult and complex dynamics that we're looking at when we talk about stigma and discrimination

[SPEAKER_04]

I suppose going back to, so we're looking at the concept of the experience of stigma, the experience of discrimination.

Why is it important?

What does stigma and discrimination do to people?

Why is it something that we need to counteract?

And how do we monitor it?

Is it important to monitor it?

[SPEAKER_00]

So I guess one way to think about the impact is a kind of vicious cycle, really.

So if people, you know, experience exclusion on the basis of stigma and discrimination from the workplace, from, you know, the family social events or, you know, friendship groups, education, their church, you know, whatever it is, then they, you know, they lose opportunity.

And obviously, you know, the younger that happens, the worse it is in terms of people's ability to

to just develop in terms of getting education, getting employment, all of the kind of social support that people need when they're ill.

The opposite happens sometimes, that people lose social support, whereas obviously what you want is for people to kind of rally around.

So all of those things are going to make people feel worse, but also, as I said, people lose opportunity sometimes.

terms of socioeconomic opportunities social opportunities and that can actually kind of reinforce stigma because one of the kind of stereotypes about you know people of mental illness is the idea that you know people sort of incompetence in some way so if people you know can't complete their education or can't work then that can just feed into those kind of stereotypes you know and with those losses of opportunity obviously you know having not having a job for example is a risk

of a mental illness.

So this is just a thing that goes round and round.

And obviously, as I mentioned before, there's this phenomenon of self-stigma.

So when people experience negative reactions towards themselves on the basis of having a mental health problem, they can kind of internalise that and end up feeling very badly about themselves and also feeling very much defined by the illness.

So whether aspects of people's identity can kind of get engulfed or eroded, again, because if people are only responding to them on the basis of having a mental health problem, as opposed to other aspects of their identity, then those kind of aspects of identity start to get lost.

And obviously, which means that when you're trying to

combat these kind of things, then finding ways for people to kind of recover their identity and develop in different ways become incredibly important.

And that's really the kind of basis of the whole idea of personal recovery in mental health care.

[SPEAKER_03]

It's obviously, there's many things that are very important when it comes to thinking about how we allocate resources around mental health and mental health care and how we look after people who experience mental ill health.

And sometimes I've come across this argument that is thinking about stigma a bit of a sort of luxury.

Like, should we instead be thinking about, you know, obviously other important things like service provision or quality of services and, you know, like, why should we focus on stigma specifically when there's so many other pressing issues in the field of thinking about mental health and mental illness? but we've done some work looking at what's the actual lived experience of having that mental health condition and how does stigma fit into that broad range of experiences.

And overwhelmingly, we tend to find a result that actually the impact of stigma and discrimination is generally worse than the impact of the mental health condition itself.

So it's one thing to perhaps have an illness, need to find ways of looking after yourself, finding the right help, thinking about getting better or finding ways to

to cope with the fact that you might have a long term condition of some kind. But when on top of that, we add that dimension of the the social prejudice and the ideas and the attitudes that people might have towards you because of that. whether it's a diagnosis label or the symptoms you have or the medication you're taking or the services you're attending or just these general assumptions that others might have about you and in what way you're different because of your mental health condition and that experience of stigma and navigating that whether it's the experience or those anticipated worries or or how you navigate the world and the social world and how you consider the opportunities and the options that you have because of that, that added burden is worse than the experience of the mental health condition itself.

So we surveyed as a part of some work we did nearly 400 participants over 45 countries asking specifically that question. And in our respondents, over 80% said that stigma and discrimination was worse than the impact of the mental health condition they were experiencing. So this is in a sort of marginal side question for those who happen to be interested in understanding these social dynamics around mental illness, but it really has

As Ken was explaining, real life impacts and consequences are overwhelmingly negative, as well as that being a huge added burden to the persons who are experiencing that stigma.

And then we can think about that as well in terms of then going towards concerns around

you know, specifically when health services also towards premature mortality, for instance, if stigma acts as a barrier to care or it's harder to get good treatment or if you have morbid physical health conditions in particular in relation to a mental health condition, often those get less attention because of the fact that a person becomes viewed primarily through the lens of the mental health condition and

other concerns might be dismissed or there might be ideas that someone's just exaggerating their experience or looking for attention to talking about other

symptoms and there's robust data on that as well that there's a very large mortality gap where people who have a comorbid mental health condition alongside a physical health condition die up to 20 years earlier than comparable controls with the same physical health condition but without that mental health condition on the side. So it really you know it sounds very dramatic to say it can be a question of life and death but it really can be. So it's not just a surface level you know like a side experience in people's lived realities but it's a really really severe issue.

[SPEAKER_00]

The answer is what do we do about it?

So I guess the first thing to say is that there's an awful lot more to do and I think different kind of things to explore for this field.

And I guess it probably makes sense to think about these different levels that I mentioned earlier and Petra talked about as well and intervening at these different levels.

On the whole, you know, there's been quite a lot more work looking at kind of reducing, you know, negative attitudes to the sort of interpersonal side or the public attitudes towards people with mental health problems as a whole. And also a rather separate field, although I kind of feel it shouldn't be so separate, but it's different people doing these different interventions, really.

So a separate field, which is mostly kind of different types of psychological intervention to...

trying to address self-stigma and then rather less at the sort of structural level.

And I think that reflects, you know, the difficulty of intervening at the level of things like, you know, legislation policies.

And even if one can, it can be then very difficult to study the impact of it in terms of how does that then kind of, you know, filter down and affect individuals.

I mean, there are some notable exceptions, but I'm not really sure that there are any in terms of mental health care.

So, for example, I'm thinking about the fantastic work that's been done in the States looking at different state level policies in terms of gay marriage legislation and how that's related to suicide rates, you know, amongst LGBTQ people in those states.

So you can, you know, you can look at how policy affects people, but it's often not easy to

So, I mean, in terms of the work that I've been involved with, I started in about 2008 working on a couple of programmes of research that Graham Thorncroft was leading.

And in one programme, there was an intervention to help people think about disclosure in the employment context.

And this was a decision aid that was developed by Elaine Brohan, who was at that point a PhD student.

And obviously this is a complex and very individual decision and it depends partly on how your mental health problem affects you, partly on the type of work you're looking to do, partly on what do you know about the employer, if anything, in terms of their kind of attitudes or what kind of things the employer has in place for people

Partly on your knowledge about, you know, the Equality Act in the UK or

equalities legislation, you know, more broadly, but also obviously on your own sort of personal values and preferences about things like, you know, being sort of open or a preference for privacy.

And so this kind of structured tool help people think through this kind of thing.

because of people's worries about the impact of disclosure on potential workplace discrimination.

So either not being hired in the first place or experiencing discrimination within the workplace, which can take lots of forms, whether it's getting passed over for promotion or not being sent on extra training or even as far as losing your job.

So we did a randomised controlled trial of this recruiting people who were using the employment services within the mental health trust where I work.

Um, and, um, that's, that seemed to be effective in terms of, you know, helping people feel better and more supported about, about their decision.

And the numbers were very small, but it looked like maybe a few more people were getting into work as well.

So that tool is now available along with some other resources from more recent work.

So, um,

And at the same time, so the other research program I was working on was the evaluation of England's Time to Change Stigma Reduction Program, which was run by our two big mental health charities.

It was Rethink Mental Illness and Mind.

And I think they took a very good approach as far as the work that they did was concerned.

They worked on, again, multiple levels with employers.

but also with a big social marketing campaign, which for much of the time was really sort of aimed at, you know, skilling people up a bit in terms of supporting people that they knew.

So first of all, you know, getting people to realise that they probably knew somebody with a mental health problem or might have experienced it themselves.

And then encouraging people to, you know, in terms of taking supportive behaviours, you know, so staying in contact with people.

Because obviously it can just be counterproductive if you sort of accused people of being stigmatizing and tell them to be aware of stigma, because then the question is, OK, so stigma is a problem.

Like, you know, I don't want to be stigmatizing.

Like, what do I do instead?

So it was very much about, you know, not not feeling like you have to you have to kind of avoid people and worrying about, you know, I'm going to say the wrong thing to them.

but just being supportive and doing kind of normal things together.

And so we studied the kind of change over time in terms of public attitudes, which did look like they were improving.

And also we did a survey every year of people using mental health services to ask about discrimination in a whole raft of, you know, kind of life areas from the sort of interpersonal relationships to people things like the workplace context, healthcare, mental healthcare.

And those experiences did lessons.

We're asking people like over the last year in terms of discriminatory experiences, and there were fewer of them, particularly in that kind of area of social relationships.

So family, friends, dating, all of that, those kind of life areas got better. To some extent, it's easier to perceive those changes because, you know, everybody pretty much has some kind of social life, family, friends, et cetera.

And so you get to, you get to count that in more people and you can detect a difference more easily.

Um, but it's also very much in keeping with the emphasis that time to change placed on those kind of, you know, informal social relationships, you know, how do you support a friend or a family member?

Um, so, um,

So that was great in terms of positive change.

I have to say that since then, things have deteriorated.

And I know we can talk about that in due course in terms of, well, what has deteriorated and what seems to have held up because it's kind of a mixed picture.

But while I was working on Time to Change, it really made me think about mental health care and the kind of discriminatory experiences people were talking about in terms of mental health care.

And as a mental health professional, you know, what we should be doing about that, because it's not really something that mental health charities can address.

You know, it's something that we have to do ourselves.

And so I initially developed a bit of training for medical students as future health professionals, you know, in general about stigma issues.

and discrimination, you know, particularly in the context of healthcare and, you know, what we can do to kind of avoid being stigmatising.

And I delivered that along with other health professionals who had their own lived experience.

And then from that, that was an unfunded piece of work that we then did in multiple different sites.

And this is what Petra was referring to earlier as the READ program.

So that's responding to experienced and anticipated discrimination.

So it's really when patients are talking about not wanting to do something, which would actually be maybe helpful in terms of their recovery because of their anticipation of discrimination.

So for example, not wanting to seek either paid or voluntary work or take up some kind of social opportunity.

And then obviously the experience discrimination part is how do you respond when people tell you about discriminatory experiences, you know, because that could be something where you actually might need to involve the police if it's, you know, in some ways.

Or, you know, it could be something where you need to contact another professional and say that this person's, you know, being affected as far as their social care or employment is concerned and what can we do about this. And that could involve a difficult conversation with another professional who may have perpetrated the discrimination.

And that's a very fine line to tread, obviously, because you don't want to get cross with people because you have to maintain a professional relationship, but also you can't just let it pass.

So I developed that more in training for mental health professionals.

And that's the READ-MH bit, which was part of the Indigo program.

So that's really the most recent

um, thing that I worked on.

Um, and my, I am really not an educator.

So I was very lucky to find someone, a psychiatrist who is very much an educator and who could sort of bring these ideas to life better than I could. So that's Uta Wali, um, who at that point was working in, in Tunisia. And that was one of our sites, um, for the Indigo program. So, um, so she made it a lot more kind of interactive in terms of, uh, you know, a piece of education. And at all the sites where we were working, we involved people with lived experience to talk about their experience of mental health problems and of stigma and discrimination to really help professionals think through what they can do as part of their professional role as mental health professionals. And even the fact that helping people to address stigma and addressing it within one's workplace is actually part of your professional role, because that's not necessarily something that one learns when... when training to be a mental health professional.

[SPEAKER_03]

I can jump on to slightly expand on the Indigo project that Clay already mentioned here.

That's another large piece of work that we've been involved with together. So traditionally, when we think about evidence on how we best reduce stigma and discrimination, a lot of the information we look at and the studies that we draw on in terms of understanding what works and where and how and for whom, These studies tend to be conducted in what we call the global north and sort of Western high income settings, generally Europe and the US, also Australia to some extent, but nonetheless not particularly globally representative. And we obviously also know that the vast majority of the population on this planet does not live in these high income Western settings.

So Indigo was

The Indigo Partnership specifically was a study where we were looking to generate evidence on effective anti-stigma strategies from different types of settings to understand how stigma reduction works best in different cultural settings and different social contexts and different healthcare contexts. So for this project, we worked specifically in what we would categorize as low and middle income countries, so countries that are lesser resourced. And we had seven different research sites in six different countries. So we worked in China, Nepal, India, Tunisia, and Ethiopia. Those countries and two sites in India, two sites in China, obviously as they're such large geographical context that it was interesting also to think about geographical differences, North and South within these very large countries.

And what we did through Indigo was, first of all, some work to just understand how does Stigma actually operate in these settings?

What exactly is stigmatized?

assume that the theories and the assumptions and the models that we have around stigma and specifically what are the particular driving beliefs or experiences around stigma and what are the specific impacts of stigma.

We can't assume that those are the same in the more Western or Northern research context in Europe, for instance, versus exactly what it is stigmatized in a completely different cultural context.

So we did

quite a bit of work to understand those dynamics and consequences and then we took those into a multi-level stigma reduction set of interventions that were implemented in each of our research sites and that would link to this idea as we've discussed already that stigma operates on multiple levels so sometimes we

might need to also tackle it on multiple levels to really see a difference
And with this programme, the particular consequence of stigma we were most interested in was access to good mental health care.

So in view of that, we had a multi-level approach where we had one intervention that was targeting community level influences and community health workers and essentially running

awareness raising and training campaigns within communities to increase understanding around mental illness and promote help seeking.

And then we had another intervention that was tackling the primary health care level.

Obviously, often primary health care providers might not have a great deal of training or understanding around mental health and might in themselves be stigmatizing.

So this intervention was providing mental health training to primary care providers with an added component of integrating a lived experience perspective.

So this is something the evidence shows is incredibly effective when it comes to reducing stigma to not just provide information and numbers or sort of talk about what's a helpful belief versus what's not.

But it's something very powerful.

about having the perspective of coming to understand the lived experience and the perspectives of persons who are themselves affected by stigma and experience of a mental health condition.

So we incorporated that lived experience dimension into the training that was provided to the primary health care providers to really generate a true understanding of these impacts of stigma.

And that was found to be effective.

And then the third intervention within Indigo was the READ intervention that Claire just described.

So once we've moved to the community level and gone to the primary care level, then obviously if needed, we might progress to mental health specialists, whatever they might look like in a given geographical and societal setting. and then sort of how we can make sure that also when a person starts engaging with that level of health personnel that they're not met by stigma and discrimination from within the health service.

And so that was a really interesting piece of work.

And we're just having our final results papers coming out.

And it's been really exciting to see that all the interventions are having the expected impact.

So they're all reducing stigma and discrimination, improving attitudes, improving knowledge in the various ways in which these interventions assessed it.

And to kind of capture the true complexity of stigma, we did not only do the quantitative questionnaire based assessments of what happened before versus after treatment, but we'd also conducted some qualitative work with whether it was persons who had been trained in the intervention or who had, you know, then ended up engaging with health services as a result of that intervention also being delivered.

And also in that qualitative evidence, interventions in all settings seem to be very, very effective, very welcome, very appropriate.

So that was fantastic to see.

And as a next step, we hope to have opportunities to build on this work, to do comparable work on a larger scale, perhaps in other settings as well, because

now we have a very good understanding of how we can contextually and culturally adapt these broader stigma principles and perhaps intervention principles to special localised contexts, thinking about that local nuance, local diversity, local influences, cultural considerations, understandings around health and illness.

practically what is available in terms of health care provision and mental health care provision, how do we conceptualize mental illness and mental health conditions, taking all of that into account to develop and then implement interventions that actually are meaningful for that particular context. And some of these learnings are synthesized in the Mosaic Toolkit that you spoke of earlier.

So this is a resource that we developed in collaboration with the World Health Organization and the European Regional Office, as well as lived experience representatives from an organization that was called the Mental Health Peer Network at the time, but they're now called Aves Mental Health.

But it's a group of

I think the tagline is unapologetically experts by experience.

So they're all coming with lived experience of mental health conditions and are a fantastic group to work with on a range of initiatives such as this toolkit. So with this toolkit, we provide practical guidance on a little bit on setting the scene.

Why do we need to tackle stigma?

Why is it important to work in this space?

but not so much making the case and more very practically thinking about, okay, so what can we actually do?

So the toolkit outlines some background on the sort of three core principles that we recommend any anti-stigma intervention should include.

And one of those and the central one is lived experience, meaningful leadership or co-leadership by persons with a lived experience of a mental health condition should always be

built into any anti-stigma program.

Then there should be a dimension of social contact.

So this is one of these sort of evidence-based principles that research has shown

time and time again, coming from the sort of early sociological work in the States as well around racial discrimination and segregation in that if we bring people together in terms of all sorts of social psychology principles, like have social contact that meaningfully helps

these sort of in groups and out groups, which in this case would be the people who are different versus the people who are quote unquote normal or not different or persons who have a mental health condition that sets them apart from the others in some way that we can discuss whether that's right or wrong. But nonetheless, we have these two different groups.

And if we facilitate social contact between them, that's a very powerful way of

of diminishing discrimination and combating some of these false beliefs and understandings that we might have about this other group that they lead to negative attitudes and stereotype beliefs, etc.

So social context, the second principle alongside the first principle of lived experience involvement.

And the third principle the toolkit emphasizes is inclusive partnerships.

So when we conduct anti-stigma work, we should always think about the broad range of stakeholders that needs to be

involved, you're going to have a more effective program if you involve health care providers, if you involve local stakeholders, maybe cultural leaders,

perhaps policymakers, whether it's employers and school personnel and academic partners and clinical partners than if any of these groups alone tried to do something.

So those principles are in the toolkit.

And then we also have a four-step process model that is not a sort of off-the-shelf resource that you should just implement as an intervention, but it's more stages that you need to think about when you start defining what stigma focus your work is taking.

Then when you start thinking about, okay, what would an intervention then to achieve change in that specific area look like?

Once you're actually implementing it, what would that look like?

What should you be monitoring as you're going along to understand if it's working or not and how you might need to change it?

And then the final step is like afterwards, what do we do then?

Do we want to build on this work?

Do we want to stop this work?

Do we want to adapt it?

How do we make sure that others can learn from what we've done?

So that's a really exciting resource that was published coming up to two years ago now on mental health day in 2024.

And it's had a lot of really good feedback in terms of just.

The aim was to demystify the process of, okay, if we want to work in the field of reducing stigma and discrimination, how do we go about it?

There's so many valuable and valid targets to do, so many types of stigma, so many angles from which this problem could be grappled.

So how do we define what we do and then plan an actionable strategy around that?

[SPEAKER_04]

So I was reading it and I really liked the practicality of it.

And I was wondering from both of your perspectives, so that is an amazing toolkit very much designed for people with mental health challenges.

Do you think this is transferable to somebody?

So if we are interested in a group that have both, say, substance use and mental health, do you think it's a transferable tool?

[SPEAKER_03]

Yeah, I would say so.

The evidence base that we talk about in the background of the toolkit, that references another resource that we can mention here quickly, which is the Lancet Commission on Ending Stigma and Discrimination, which is a great resource that came out in 2022 that really synthesizes a huge amount of literature on

impacts of mental health related stigma specifically, and also talking about effective strategies for countering stigma within the mental health field.

But that does not necessarily always exclude substance use.

So sometimes we have these very broad mental health umbrella within the research that's being done.

And Clare and I have worked on a number of evidence synthesis in terms of looking at effective anti-stigma strategies.

And very often the condition in focus is simply mental health.

And sometimes that does include substance use as well.

Sometimes there's interventions that look at particular mental health diagnosis or also substance use on its own.

Sometimes that's split into alcohol use and other drugs.

Sometimes there's smoking included.

So it's quite challenging to

find any evidence that would pinpoint to any very, very specific diagnosis.

So from that perspective, given that that's the broad evidence that we're kind of talking about in the toolkit before going into those practical principles, it would be applicable.

But the first step when we talk about those practical steps of how do we actually

you know work to to reduce stigma that the toolkit outlines is really understanding what is in focus here so so that process of within the team that's looking to implement some type of work to really think about okay what exactly are we exploring here what is the type of stigma who are the people who are affected how are they affected in what settings because of what types of beliefs where does the stigma come from a lot of that sort of applied nuance comes through at that stage where you yourself need to think about how or whoever it is who implements the work needs to think about what exactly are we looking at here.

And those broad principles of social contact and involving lived experience and sort of the poor partnerships, the social contact

as you mentioned, comes originally from racial prejudice.

So that's not anything specific to mental health as such.

It's more of a social idea of sort of the in-group and the out-group.

And there's a number of different characteristics based on which we can separate our world into these in-groups and out-groups.

And it could involve different types of diagnosis and conditions.

So it definitely can be applied to different conditions as well.

[SPEAKER_00]

The kind of contact interventions that Petra was talking about, where you've gotten two groups to interact socially together, that is one type of intervention.

I guess it's been kind of applied in a slightly different way in terms of mental health related stigma.

where you have contact-based education, where instead of sort of two groups kind of socially mingling, you've got one or more people with lived experience really giving kind of testimonies.

And that allows, you know, learning, you know, so that's the sort of education piece about what it's like to have a mental health condition and experience stigma and how do people recover and what supports their recovery.

But it also makes people who haven't had very much contact.

So for example,

you know, healthcare students who are just starting out can make them feel less anxious about, you know, having that contact as they do their training.

And it can also generate greater empathy for people.

And that's probably how, you know, these kind of testimonials work.

In terms of substance misuse, I mean, the ones that those kind of, you know, testimonials that I've come across, whether they be live or filmed, they've tended to be

on the part of people in recovery.

And I think, you know, that can work very, very well because people can, you know, talk about what it's been like receiving healthcare, mental healthcare as a person, you know, with the substance use disorder and really kind of generate, you know, therapeutic optimism and hope and kind of counter the

stereotypes that professionals have when they're just seeing people you know, when they're, you know, intoxicated or really struggling with substance use.

Because obviously when people are in recovery, you know, we don't see them because they don't need us anymore.

And this sort of speaks to the kind of issue about contact.

And sometimes people question that, you know, how can contact possibly be effective when health professionals have contact with people with mental health problems and substance misuse all the time?

You know, how can it be effective?

Because obviously health professionals you know, have stigma too.

And this is really about the type of contact that we have.

And like I said, you know, we have this bias because we see people when they're most severely affected and when they're in crisis typically.

And this doesn't, you know, so this creates a bias which then, you know, needs to be countered by having more positive types of contact.

And I think as health professionals and mental health professionals, you know, we kind of need to be working

alongside people with lived experience, you know, all the time to keep reminding us of, you know, for the ability for people to recover and, you know, have really important contributions to make.

And actually that, you know, that comes from substance, the substance use field, you know, the employment of, you know, peer workers, people in recovery that started in that field rather than in mental health.

services specifically.

I guess in terms of mental health professionals, we not only need to be working alongside these people all the time, but I think in terms of stigma reduction, Petra was talking about the measurements of knowledge and attitudes improving in the indigo studies.

But with READ, for mental health professionals, what we're really looking at, as I said, is

professionals' ability to kind of embrace helping people address their anticipated stigma and also their experiences of discrimination as part of our professional role.

And here we come back to actually the issue of disclosure.

So I mentioned the CORAL, so the Conceal or Reveal tool to help people think about disclosure in the employment context.

The other context where people really struggle with disclosure is intimate relationships.

And one of the ways that we wanted to assess responding to experienced and anticipated discrimination was to have clinicians do role play, talking to people about some aspects of experienced or anticipated discrimination and helping people with that.

And where we landed after talking to the people at all of these different sites that Petra mentioned, to have a role play where somebody came in and said, I'm thinking about getting married.

My family is very keen for me to marry.

There's a potential kind of marriage partner in my life.

My family don't want me to tell him or her about the fact that I've had a mental health problem and I'm still undergoing treatment.

But I really don't know what to do about this because I don't know if I can keep this a secret for the rest of my life.

And then how does the mental health professional help support that person to

think this through?
And it's not about telling them to disclose or not disclose.
It's really just...
thinking through the implications of doing so or not doing so.
And if they are going to say something, what is it that they say?
How do they approach this?

[SPEAKER_04]

Disclosure is a decision that somebody needs to make and they have various alternatives.

And if you come from an alternative decision, you only have two to disclose or not.

But a lot of the work around quality decision making is actually to start with values and then you

When you associate, start with values, then you're able to have a broader set of alternatives that you can then help the person work through.

You mentioned earlier that decision aid, for example.

Yeah.

[SPEAKER_00]

I mean, I think it's a potentially very fruitful approach, essentially.

And it is really interesting that we've done a bit of work on this in terms of people with lived experience.

They're

decision making and help people helping people to sort of clarify values that they might lead to a decision along with you know a whole bunch of other considerations i mentioned in terms of you know how the illness affects them and what kind of job they're going to be doing kind of thing and then a decision and and like i said disclosure is not not a sort of yes no thing it's it's really about you know what what you say and when and to whom and and yeah and what that might lead to

But yes, on the other hand, you know, there's health professionals and their decision making.

And I think going back to what Petra was talking about in terms of diagnostic overshadowing, where, you know, people make an assumption about, you know, a problem being related to a pre-existing illness, which could be the mental health condition or, you know, substance use disorder and then missing something else.

You know, this is it really kind of is, I guess, like a patient safety issue.

terms of professional values, then obviously professionals want to get the diagnosis right and they want to give the right treatment and they want to behave towards people in line with their professional values and obviously what can happen in conditions of either short-term stress.

So we know that when people are cold or when they're tired or when they're hungry,

You know, their decision making kind of gets worse or they behave more in line with kind of prejudices or their thinking can get more biased.

So they are less likely to behave in line with their professional values or whether the stress is more long term.

So where you have long term work stresses.

For example, if you're working in a way that makes you feel like whatever you do actually doesn't help very much because the people that you're seeing don't seem to be recovering.

This is what I was saying before about the importance of generating therapeutic

optimism by reminding everyone that people do recover and then you stop seeing them.

With that short-term stress or long-term stress, those things can really erode your kind of quality of decision-making and your behaviour in terms of behaviour that's in line with your professional values.

And I think, you know, this really operates in different fields as well.

And so thinking about, you know, other professionals that, I guess, only see people with mental health problems or substance use disorders, you know, when people are in crisis, that, you know, actually brings to mind the police.

And actually, one of the earliest studies that was done on the effects of contact-based education was with police.

So a colleague of mine, Vanessa Pinfold, did some work with a police force.

And that really was a testament to the power of lived experience testimonials, because her follow-up work showed that that was the that the police officers remembered best and had the most impact on them rather than the kind of learning that was delivered at the same time.

So as I said, I think, yeah, this is applicable to people working across the public sector as they encounter vulnerable people.

And actually, it's something that is being used a little bit as a result of some work of colleagues of mine who are cognitive psychologists developed a tool for social workers to help them identify cognitive biases and also think about relevant aspects of the law in relation to child and family social work.

So decisions about whether children are at risk and how to respond to that.

And it's just been used in one local authority at the moment.

And the evidence so far is that it is kind of leading to social workers sometimes keeping cases open for longer, so not making a sort of premature decision that might lead to a bad outcome.

And obviously the hope is that this might in future help to avoid some of the really kind of catastrophic cases that have happened in terms of child and family social work.

This is actually an email that I've just sent to the person who contacted me about helping with this work in terms of looking at implementation within services, which is something that I work on a bit.

Within the stigma reduction work, obviously, we have contact-based education.

There's a lot of studies on it now showing that it can have an impact, but you know, it's often rather a short-term impact and can be, you know, something that's hard to really kind of embed and provide in a long-term way that, you know, that perhaps in some contexts, yeah, instead kind of getting people to think about, you know, their decision-making and are they being affected by any of the cognitive biases that, you know, we all have, then this could be another kind of fruitful approach potentially.

[SPEAKER_04]

if our work with MIRELLE carries on our long-term goal would be to establish a PhD network of PhD students to really study or take this area forward or be the leaders of the future so to take over from people like yourselves

And I was wondering if you had one of those students in the future, have you had something that you say, well, here's a juicy project for you to get your hands into.

What would you say to them?

[SPEAKER_00]

So I guess for me, you know, as a health professional, you know, I would get

them to start with health care and in, I guess, services where we know that, you know, these problems of diagnostic overshadowing can take place.

One setting which is really important is the emergency department.

And I've done a little bit of qualitative work with other colleagues, you know, talking to physicians and nurses who work in the emergency department.

And they, you know, they're aware of this problem.

Obviously, you know, they want to get diagnosis right, but they can all tell you about cases where, you know, diagnosis has been delayed or not spotted until it's really too late.

And so that's one setting.

I think it can also happen within mental health care, obviously, because people complain about physical symptoms to us and obviously within general practice.

So that's where I would feel best positioned to start, I think.

And like I said, because...

You know, there's probably helpful literature in the sort of patient safety arena about this.

You know, it's an area where there's probably useful work that they could build on.

[SPEAKER_03]

I think from my side, what I think is always really important to consider and something that, you know, we might not dedicate as much time to because we're so keen to get started and do something is to

to think about what is that formative work you need to do to truly understand exactly what you are addressing, with whom, in what setting.

So the idea of the sort of contextual appropriateness and adaptation of the work that's been done and in really, truly considering the cultural fit as well.

I think it's, you know, we've moved to a stage where we are often thinking about cultural adaptation and we're thinking between countries or, you know, work has been done in one region and we're looking to implement it in another.

But these cultural influences occur also at very small levels and even you know within a community we have different cultures and persons coming from different cultural backgrounds that might have different understandings and experiences and different types of worries and whose impacts might look different from another person who has a slightly different set of whether it's ideas or values or traditions that are shaping their understanding of their world and how they operate within that and with their communities and families and others around them.

So to never assume that something is directly appropriate in another setting, but always

taking time to explore the specific context in which you're going to conduct your work and also to think about who you are and what assumptions you're bringing along these ideas of values and how we operate and what do we believe and what do we assume to be a fact that doesn't need to be adjusted or potentially contextualized in some ways.

Always think about what work you're doing and where.

And another aspect I find really interesting is just we all know that contact and social contact is hugely valuable for stigma reduction.

And there's already a lot of work on this, but I think there's a lot more work to be done in terms of just stigma.

the digital domain in which we live our lives nowadays and how so much interaction is happening online and how do we start to categorize these ways in

which we're interacting with one another in non-physical spaces. And there's a lot of literature around parasocial relationships and sort of connections we feel we have with people who may or may not know our existence. But I think it's getting more and more nuanced in terms of how we're navigating virtual spaces, for instance, and how we're shaping up connections there and how that works both ways.

both to perpetuate and to diminish stigma.

So I believe there's a lot more work to be done and we're getting more and more of these platforms where stigma reduction can take place as well in terms of how strategies are disseminated or where voices are being heard or where we are sharing information and narratives and where we are shaping opinions and where our opinions are shaped.

So I think it's...

I feel like it's one of those fields where it's evolving so fast that however we're trying to keep up, we're still lagging a little bit, but I don't think it means that it's not worth trying to fully harness and understand.

[SPEAKER_04]

But thank you so much.

An ending message from both of you maybe might be a nice way to end.

[SPEAKER_03]

Yes, I always like to emphasise to everyone that

It can feel intimidating to work in this space and it might feel complex and there's a lot to consider and we might be held back by the sense that we don't have the right funding or the right project structure or similar, but I think action starts on an individual level as well.

And I don't think there's any anti-stigma action that's too small.

And we can, if we want to reduce stigma and discrimination, we can start even on an individual level, think about how we ourselves operate in the context where we are.

And as individuals, we have the power to shape the structures and societies that we live in.

So even one person can eventually make a large change.

So just for everyone to not feel discouraged that they have to wait for a certain point or a certain resource or a certain something in order to get started.

But we can definitely all make a difference in this field in our own way, even starting today.

[SPEAKER_00]

I think on my side, I'm thinking about a meeting that I went to in the summer of stigma researchers, many of whom were from the US.

I'm thinking about how affected they are at the moment by the kind of political nightmare that they're in, and to the extent that some of their funding has been cut, there are certain

Things that you are becoming very, very difficult to study, you know, questions that aren't allowed to go into surveys that used to be able to ask this kind of thing.

And whilst you can still study stigma, it's not as easy as it was because of sort of related questions that are very difficult to ask now. and the difficulty of getting any funding.

And it feels like a lot of the funding now for research is just through philanthropy, you know, rather than the sort of more traditional kind of

government type fundings, whatever.

And whilst, you know, we're in Europe, not in quite such a kind of extreme situation, there is evidence that, you know, in terms of surveys that we do, that public attitudes in some ways, you know, have increased.

gone back to baselines in England as far as the attitude survey that we used to evaluate time to change.

However, we've also found that if you get people to think about interacting with a specific person, that behavioural intentions have improved and have stayed at that improved level so far,

So there is a real difference between asking people about, you know, people with mental health problems in general, where their attitudes seem to have kind of got worse.

And how would you behave towards a specific individual?

So I think that, you know, the impact of contact and getting people to think about the fact that they probably know somebody with a mental health problem and how you can support them.

I think, you know, that that has been effective and it's continued to be effective, even though recently.

you know, the Time to Change programme finished at the beginning of 2021.

So that's more than five years ago now.

So whilst, you know, there is kind of some disheartening rhetoric, I think, for example, about, you know, young people on benefits and do they really have an illness and this kind of thing, then there is also, you know, cause for, you know, hope and

and evidence that we've got a better understanding now, at least as far as people with kind of common mental health problems are concerned.

I think the real focus needs to be on support and stigma reduction for people with more severe illnesses, because obviously one is less likely to know someone.

So that approach about getting people to think about the fact they probably know someone and how do they support them, that doesn't have quite the same reach or potential for success you know when you think about people with less less common problems um and that's really yeah the area where we need to think think carefully about yeah how do how do we help people along with as you say the more sort of complicating factor of substance use thank you for listening to an episode of Kafe MIRELLE