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New Approaches to Supporting Recovery and Improving Wellbeing

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Thank you so much for the warm invitation and thank you for the opportunity to come and share some time with you. I'm really grateful and appreciate the hospitality I've received. So thank you for the invitation and the welcome. I understand Mr. Khoo was involved in setting up the first halfway house in Hong Kong, as a stepping stone to supporting people into everyday citizenship. I think he would be really proud of where we have gotten to now with the things we can do to support that process of recovery. Just before we start what I've come to talk about, I have the task of talking to you after that amazing lunch. I'm going to ask you to do something just to wake up. I want you to just stand up and sit down, but only when I point to you. I will point over there and you will stand up, and then I will point over there and you will stand up. Ready? Stand up! Stand up! Oh , wonderful. Aren't you kind? Shall we go the other way, just to close the circle. So stand up! Stand up! Stand up! Wonderful wave! Thank you so much.

Just for a moment, we were all people together. Just for that moment we were not doctors or patients. We were not social workers or psychologists or peer workers. We were people together. One of the key insights of the recovery approach is that it is reducing the importance of those labels, those titles, so we become more like people together. I'm going to talk about new approaches, and I'm deliberately wanting to give you some ideas about our new research. Some of the things you may know already, but I'm hoping that at least some of the things I'll talk about will be new. And the invitation to you then is: Are there any new ideas which are offered which may have some relevance to you? Are there any things which can be adapted or modified or can be a basis for new developments here? This would be the most exciting outcome from our meeting today.

I'm going to talk about three aspects: Theory, Interventions and Knowledge gaps. I'm going to talk about theory, because without theory we just have an opinion. One of the interesting things about a research perspective is that we can then evaluate interventions. And I'm going to talk about some of the other things that I think globally are knowledge gaps, the things which are the next stages of development in a movement towards recovery.

Theory of Recovery

Just to make sure we are on the same page – we have talked already many times about recovery in this conference. The starting definition came from Bill Anthony and this is widely cited in Hong Kong. "Recovery is the common vision". That is a grand statement, and it was a joy to read as I was learning about Hong Kong services. Of course, don't think you are unique, because recovery is the common vision for national mental health policies around the world. You are part of a global transformation from a traditional understanding that the job of the system is to fix and treat and cure, to a new understanding that the job of the system is to support recovery and promote wellness. They are overlapping but they are different things. Not just at a national level, but also internationally, it is very clear there is now global consensus that recovery as a guiding value

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for the purpose of the mental health system has now reached consensus across most countries. The challenge now is to make that vision a reality. And that is what I will be talking about now.

When we talk about recovery, it is a term which is easy to have lots of different meanings, so my research group did some work developing a framework for thinking about what recovery means. We collated evidence from many people's experiences of recovery, and what we identified is that there are five processes around the world that people often talk about. These we called the CHIME framework, for Connectedness, Hope, Identity, Meaning and Empowerment. The CHIME framework captures some of the things people tell us are involved in recovery. Everyone is different. For some people there are things not in this framework that are really important, but the framework emerges as often important to many people. There are some challenging implications and just to pick out a couple. The CHIME framework starts with C, with connectedness, supporting people to be citizens in inclusive societies. When we have special services for the special group of people who have mental health or substance abuse or learning difficulties, are we helping them to be connected into wider society?

Similarly, if our assessment process when we first meet someone is all about what is wrong with them, are we creating an identity of someone who is damaged or disabled or in need of a diagnosis, when actually, for the recovery process of identity, we should be supporting a much more positive identity? I will come later in my talk to some ways we can do that.

CHIME has gotten some traction internationally. It's widely endorsed and independent research suggests it is in widespread use. Here are just some recent papers I've picked out which cite it. One is talking about recovery in probation services for people coming out of prison. A second is talking about recovery when people play football. I noticed earlier today there was talk about people taking part in football groups. And CHIME has been used to evaluate the impact of sport on recovery. It's also being used to explore cultural adaptations. How does CHIME need to be changed when it's applied, for example, in the country we are in today? That makes some interesting new theories, for example, the idea of relational recovery, putting much more emphasis on the connections to relationships, that in some ways recovery is relationships. Recovery is not something that goes on in the head; it is something that goes on outside in the real world. When I am in my world and I find a place or I do not find a place. When I have a sense of someone who loves me or I have a sense of isolation and being alone. These are what is at the heart of recovery. These cross-cultural adaptations are fantastic, because of course what we don't want is to create some kind of fixed idea. Recovery is very individual. Recovery means different things to different people. So that's something about the idea of recovery.

Interventions in Recovery

What can services do? We developed this framework which is talking about what mental health and social care services and systems can do to support recovery. Currently there are four things services can do. The first is to provide good quality interventions. Recovery as an orientation is not an excuse for, "Oh, we do whatever we are interested in" or "we provide poor quality services". It is not that meaning at all, but the difference is that the intervention, the treatment, the help that is provided is in support of the person's own goals, in support of their recovery - rather than because I as a professional think they need it. My expertise becomes a resource to offer rather than a duty of care to impose. Alongside that then is the emphasis on the working relationship. One thing we know is that there are challenges in which I am very high and the patient is very low in the relationship. We talked earlier in David's talk about shared decision making. That is not possible if there is a big power imbalance. So the relationship needs to find ways of being more equal.

One interesting thing is organisational culture. An organisation which values, for example, compliance from its staff will produce staff who value compliance from their patients. These are called parallel processes. The organisational development literature is very clear the culture within an organisation influences the service

provided by the organisation. But - and this is a big but - recovery doesn't happen in service; recovery happens in real life. There is a much wider challenge about promoting citizenship. The basic question is whether we do anything with the person or if the person's problems are social, in which case maybe we shouldn't be talking with the person but instead should be politically active in society. This is the social and political aspect of supporting recovery. It is not all about individuals. It is also about society and people having a place in society.

So that is something about a framework for practice of recovery, and I'm really pleased we've started to see now the emergence of this policy. For example, in Australia the national framework for recovery-oriented services is built on that four-dimensional framework to try and entrench that as a practice across the country. So we are seeing a link between theory and practice at least at the policy level.

So how can we support recovery? In 2014 we published this article. When we published it, the columns at the top are how many of the interventions had Randomized Control Trial evidence and how many had Systematic Review evidence. The number 20, when we published it in 2014, was 13, so there have been 7 more Randomized Control Trials about peer support work in the last few years. I mention this because it is really important. If there is one evidenced-based intervention which happened in the mental health system to support recovery, it is in fact peer support workers in the work force. If I was being very challenging, I would point out that peer support workers have now 20 Randomized Control Trials almost universally showing various benefits. For example, we heard earlier the importance of self-efficacy. To my knowledge there has only been one Randomized Control Trial done where self-efficacy was the primary outcome, and that was done by Candelaria Mahlke and colleagues in Germany where peer support working was the intervention. They showed a beneficial effect on self-efficacy compared to people not getting peer support work. So it looks like peer support work can go places other interventions can't go. But also, the evidence base for peer support work is at least 20 randomized control trials. The evidence base for psychologists like me or psychiatrists or social workers is zero. There are no Randomized Control Trials showing that we need psychologists. So make of that what you will.

That said, there are all sorts of things that can be done to support recovery. Advance Directives and Joint Crisis Plans put someone in control when crises happen. Wellness Recovery Action Planning is an evaluated approach to supporting self-management. Illness Management and Recovery is a psychoeducational approach. REFOCUS I will talk about presently. We heard a bit about strengths already. There is a whole case model called the Strengths Model which is implemented in a number of countries, certainly including Australia and New Zealand to my knowledge. Recovery Colleges I will talk about. Individual Placement and Support we have heard about already in terms of supportive employment. Supportive Housing is the equivalent for housing that supportive employment is for employment. Supportive Housing has now had its first major trial published, the At Home / Chez Soi study in Canada, a multi-province randomized control trial showing marked benefits for people who are supported to live in an everyday house or home. They stay there longer than people who are prepared to be good tenants in the future. So the big change happening in recovery is we move away from fixing persons so they can get on with their life, get them sober, get them used to managing a budget and then get them somewhere to live. We reverse it and start by getting the person into decent housing and then they are motivated to learn the skills to keep it. Just like supported employment. We start by getting the person into a mainstream job with supportive scaffolding and job coaches to help them to keep the job. Then they are motivated to keep the job. So this is some of the change that is happening.

In German-speaking countries, there is an initiative called trialogues where family members, people living with mental health problems and clinicians come together to do an educational activity where they share their experiences, for example, of schizophrenia, from their different perspectives. It breaks down the barriers, you know, just like when we did the Wave earlier, suddenly we were together doing something

collectively. That creates a different kind of interaction.

Okay, let me talk about a couple of specific approaches. REFOCUS is an intervention we developed in England. Essentially there are two parts. You remember the dimensions we talked about earlier. This is tapping into the working relationships and supporting recovery. How do you support recovery? You do three things. We call these working practices. The first practice is that you start with the person's values and preferences. So you don't start with what's wrong with them. You don't start with a careful assessment of every disability they have, their functioning problems and their deficits. You start with who they are. You start with personhood, their values, what they want in life, what if anything they want from you. This approach doesn't start with an assumption that the mental health worker is necessarily the person that should be giving help to the person. So values and preferences is the starting point. The second working practice is that the assessment moves not to what the person's problems are but what their strengths are. Strengths are both individual level of resources the person has but also community resources, for example, the cultural capital that they may have, the extent to which they are in a community that cares for them and recognizes and understands them. Then the final working practice is to support goal striving. So this is like planning care, but instead of the worker's goals being planned, the individual's goals are planned. You know, you can easily tell the difference. A worker's goals are things like, "reduce relapse, keep out of hospital, reduce symptoms, improve functioning, reduce disability". Those are worker goals. The user's goal are things like, "swim with dolphins, or learn the piano, or go back to church, or talk to my brother again". Some very different things. And the job of the worker is to support goal-striving by the individual towards their own goals. That can look very different in terms of the role expectations on workers.

So those are the three REFOCUS working practices. I've talked about the balance of power in relationships. The way that balance of power is changed in REFOCUS is by training workers to use coaching, rather than traditional doctor-patient relationships, with the people they are working with. Supporting persons to find their own solutions, their own ways forward, in ways that work for them. So that is the REFOCUS intervention. We published an intervention manual, and it's all free to download, so feel free to download this.

The REFOCUS intervention was taken up for example in Australia, in Melbourne, was a replication study that's been completed called Pulsar REFOCUS. This is extending the intervention from secondary care, where we tested it in England, into primary care, working with family doctors. Both of the trial reports have been published in Lancet Psychiatry articles. Essentially what emerged is that REFOCUS is an effective approach to supporting recovery when implemented. The challenge is one of low expectations of workers. In other words, do workers feel it is their job to support the person's recovery, which might mean doing things differently to what they're used to doing, or do they feel that their job is, for example, to address symptoms? Or to get medication into the person or to get them to out-patient clinics? So there are real pushes on staff in terms of what their role is.

Mental Wellness

I want to turn now to well-being. That is something about recovery. Well-being, or wellness as it might be called here, is an interesting idea which to some extent has come entirely outside of the mental health space. Recovery is an idea which has emerged in relation to mental health. Wellness or well-being is for everyone. It's something we are all interested in. I mean, who wouldn't want well-being? And yet when we did a study asking staff who work with people with a diagnosis of schizophrenia, we asked them two questions. Firstly, what do you, the staff member, need for your well-being? And they said things like, "a good job", "friends", "alcohol", "sex", "poetry", "nature". They had a long list of things that they needed. The second question, "What do the people you work with, your clients, your patients, what do they need for their well-being?" Not always, but often staff said things like they need to not have symptoms, they need to stay out of hospital, they need to take the medication, they need to attend the psychological therapy. Can you see the difference? It speaks, I think, of this wave; how we are yet to fully engage with the idea that people with mental

health problems are fundamentally people. And therefore what is good for everyone else in society is generally just as good for people living with mental health problems. That is the idea at the heart of thinking about the relevance of wellness and well-being to people with mental health difficulties.

We did some work taking an existing intervention called Positive Psychotherapy, which is an intervention developed for the general public based on positive psychology principles, and we modified it for use with people living with psychosis. What we ended up with is a 13 session group-based intervention which had these aspects being covered in various groups. Some components were already being used; many people, for example, will have the experience of a positive psychological exercise of just noticing the good stuff in your life and being grateful for it. Sometimes though we found when we tested a component that some aspects needed to be modified. For example, people with psychosis often have a very difficult time with past experiences, not always but often. And so the task around forgiveness we found needed to be slower and more gentle and more managed than that for the general population. So there were differences between what people with psychosis needed compared to people from the general population. They were not big differences but sort of marginal differences.

After developing the intervention, we published an intervention manual and then tested it in a randomised control trial, again showing a positive effect, especially, which surprised me, a positive effect on symptomatology. My sense is, where people have some other place to put their attention, for example, in mindfulness, perhaps there is some respite from symptoms. And I suspect one of the areas to come is evaluating that more formally and looking, for example, whether flow experiences, the experiences people can have of the moment when they are fully engaged in what they are doing, is in some ways an antidote to experiencing mental health symptoms. So we then published a treatment manual – you can look at that – and I'm really pleased colleagues have translated that, so it's available locally and again, it is free to download from my website. And I've also published a book, a scholarly case for why well-being and recovery have lessons to teach each other. So for example, one thing we can learn from recover is that there is such a strong evidence from the peer support world, from peer support workers. What does that mean, for example, when we employ people in our society as police officers? Maybe we should employ people who have a criminal history. Just a provocation idea!

Talking about Recovery Colleges now. This has had a major impact on the landscape in the past 10 years. In 2009, there were no recovery colleges in England. Today there are 77 recovery colleges. They've opened in 22 countries around the world – you have the Mindset Recovery College here. I'm just going to talk briefly about a larger piece of work, one aspect of which is that we developed a fidelity measure. One of the interesting things about recovery colleges there is an uncertainty at the heart of what the key features are. So we did a 39-college study, which we reported in this paper, and we developed a fidelity measure which you can download for free researchintorecovery.com/recollect. I won't go into detail but I'll be happy to take questions on it. Essentially I think that it provides the foundation for some of the questions which were coming up earlier about Mindset, and whether it's been rolled out, and what it is and how it applies in different districts and so forth.

Let me move on to a slightly more innovative area. NEON – Narrative Experience Online. This is a new study we've been doing for two years now. The central idea in NEON is that recovery stories of individuals are a resource for other people. Anyone here who has worked with peer support workers will know that peer support workers will tell some of their stories to the client they are working with. And that may be helpful. What is interesting is that story may not be the right story for that client. The big idea in NEON is to say, "Can we do better than a random peer support worker with a random client? Can we match individuals to stories which may make a difference in their lives?". Because I bet if I asked everyone in the room, you would all say that someone else's story has changed you. Stories are transformative. They are powerful things and they are an underused resource. We use them haphazardly in the mental health system at the moment, if a peer support worker happens to be the right person to tell their story.

We did some work first looking at trying to understand what a recovery narrative is, what your recovery story is. A couple of things from what we found. In terms of positioning, as we call it, for some people recovery happens within the mental health system, but we very clearly found that with some people recovery happens despite the mental health system. In other words, the mental health system gets in the way of people's recovery. And for other people, recovery happens outside the mental health system. If that is the reality of people's experiences, then we need, I suggest, to reflect very thoughtfully on how we design and create mental health systems and the ethical notions we employ, such as duty of care. How applicable is that if some people are actually doing better outside of the system than within the system? So it is very challenging from a medical ethical perspective.

The second point, trajectory. Some people's recovery gets better and better but some people have all sorts of journeys, up and down and horizontal, and of course all of those are valid by definition. So we need to avoid telling people how recovery should be right for them. That's one of the challenges about stories, I think.

We also did some work looking at impact and I'll just mention this in terms of the different types of impacts that recovery stories can have. We've done – and I'm not going to talk about it – some experimental studies to try and really develop a causal change model, so trying to be strong on the research side, to understand how stories impact on people. We worked on narrative theories in a very multi-disciplinary research project. So where are we going? We now have a repository of recovery stories, so we have several thousand people recorded telling their stories. There are all sorts of ways people tell their stories. Some talk, like I am, some show their story as a picture. We have one which is a dance video, so someone dances their story. So, you know, there is a whole range of ways that people can tell their stories. We then implement what is called a machine learning algorithm, which I will happily talk about if anyone wants to ask about, but essentially it is an artificial intelligence approach to matching an individual patient, a service user, to a story based on what's most likely to be helpful to them. Next month we start a randomised control trial across England to evaluate this.

I mention NEON as a study because we designed it so it is language-free, that is to say that all the language can be swapped out into a module, different language inserted and then swapped back in. Then you have NEON in Cantonese. I would love the opportunity to collaborate with people around developing this as an approach in other countries and cultures.

Knowledge Gaps

Let me in finishing, talk about two more knowledge gaps. One is about the Global South. This is not a term I've heard very much used so far, but some of you will know that a term which has emerged is a distinction between the Global North, which is countries typically in North America, Western Europe, Japan, Hong Kong, Singapore, Taiwan and Australia and New Zealand. They are collectively called the Global North, and the Global South means the remaining countries. One of the knowledge gaps is about learning for most settings.

I'll mention Peer Support. Cochrane did a review in 2013. They highlighted that peer support work produced the same level of outcome as case managers or traditional mental health professionals. Peer support work is to some extent an established intervention in the Global North. Of course some of that has come from here, so I just mention this study by Samson Tse and colleagues here in Hong Kong, contributing about peer support. So in the Global North, the case is made, the evidence is clear, but it comes from particular areas of the world, this evidence base for peer support work.

There is a study called UPSIDES. What we are doing is evaluating peer support work as implemented in other countries in what may be called the Global South. So we are testing peer support work in Uganda, Tanzania, India and Israel, among others. What we want to do is to learn what's the same, what's different, what works and what doesn't work, and so forth. One of the early findings from UPSIDES is about implementing peer support work. What's the key influence? Organisational culture. Again. Do you remember

that came up earlier, organisational commitment? The organisation you run – and here I am speaking to leaders of the organisation – the culture in the organisation you run is central to the service that is provided by the organisation. What is said is not as important as what is done. If the leadership has a particular value, that value will be transmitted in the way workers in the organisation work with the people they are working with. So, go leaders!

The second knowledge gap I want to finish with is the idea of transformation. Why do we need transformation? Can't we just simply carry on developing evidence-based interventions? Well, I think the United Nations nailed it. The United Nations is an interesting organisation, not normally very radical. In 2017, they published a report by a Special Rapporteur on mental health and human rights, who concluded that we have a problem. The way in which we have structured our services is contributing to exclusion, coercion, neglect and abuse. These are strong words. They are very challenging. So what is the way forward from that? I would suggest one way is that we need alternative ways of making sense of experience. One way that our group has been researching experiencing is in terms of post-traumatic growth. People with a diagnosis of schizophrenia will often have a whole range of life experiences, either early in life that have been adverse experiences or current experiences of symptoms, or stigma or not having a place in society. All sorts of challenges. And how do you move forward in terms of moving towards a positive identity? While in other areas we talk about post-traumatic growth. So for example, for someone who has experienced a very bad incident in their life. They grow from that, and they change in useful adaptive ways that they value. They find, for example, new meaning in life. In this setting we were interested in whether post-traumatic growth is evident in the accounts of people with psychosis. What we found was that they very strongly were, with an extra emphasis on integration of all these experiences into identity. So it's not the same as everyone else, but it's very similar to everyone else with a bit of extra emphasis on illness aspects.

We published this paper in World Psychiatry, which is the highest impact psychiatric journal in the world. In the editorial we said supporting people with psychosis to make sense of what is going on for them is not the same as promoting insight. Actually, we may need different skills as clinicians, as workers, to support people to find positive post-traumatic growth in their experiences.

Of course that links to the wider question of the person as citizen. I am sure you are well aware there is a widening discourse internationally about mental health and human rights. Again, in 2019 the United Nations published a document by the same Special Rapporteur, who essentially highlighted that our current practices deflect political attention away from rights violations. We have a framework, a shared framework – The United Nations Convention on the Rights of Persons with Disabilities. Hong Kong signed up to that in 2008. The United Kingdom signed up to it as well, as has Australia, so pretty much every country represented in this room, I suspect, has signed up to it. So we have a Rights-based framework which we routinely are not implementing. The United Kingdom is non-compliant with the Rights framework it signed up to. I believe the same may be true here.

The World Health Organisation to address this has developed an approach called the QualityRights toolkit. I encourage you to have a look at this because this is a validated approach to institutional transformation, to really grappling with what it means to transform organisations to supporting recovery and wellness. If you like, that's top-down pressure from an international institution, the World Health Organisation. What's interesting is that it is meeting bottom-up pressures coming from the emergence of new academic disciplines like Mad Matters, coming from the emergence of new consumer movements like Mad Pride, which are grassroots activism approaches to developing political change through collectivist identity around experiences that are labelled as madness. So I'm really optimistic that in the future we will see that organisational transformation happen as those two pressures cohere.

So with that, thank you very much!