PHILIP YANOS
'How do people diagnosed with mental illness become written off? How can they overcome it?'
Mental Health Symposium April 21st 2018

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The following initials in the transcription record will identify the speakers:
PY: Dr. Philip Yanos

I am very new to Second Life - I joined two weeks ago, so this is still very new to me.
I am Blind, and using an SL viewer called Radegast, which allows me to access this wonderful virtual world with a screen reader.

It is a privilege to introduce you to our speaker today, Dr. Philip Yanos.
His topic is "How do people diagnosed with mental illness become written off? How can they overcome it?"
Dr. Yanos is a professor of psychology at John Jay College, City University of New York.
He is also the interim Director of Clinical Training for the clinical psychology Ph.D. program.
He is an internationally recognized expert on mental health stigma and its effects on identity, not only through his significant research, but as a published author, editor, and contributor to a multitude of publications.
He is co-creator of a treatment approach called "Narrative Enhancement and Cognitive Therapy," designed to combat the effects of self-stigma on people diagnosed with severe mental illnesses.
In his new book, and his talk today, he aims to make the importance of mental health stigma understandable and accessible to a general interest audience.
Thank you for coming today, I'm sure that we will all enjoy this presentation. As a reminder, please refrain from talking or typing while Dr. Yanos is speaking. There will be an opportunity at the end to ask questions. And with that I am very pleased to present to you Dr. Philip Yanos!

[2018/04/21 09:36] Carolyn Carillon: <<transcription begins>>

[2018/04/21 09:37] Carolyn Carillon: PY: Thank you very much & thanks for inviting me
I'm impressed by the presentations today
The title of my talk is "How Do People Diagnosed with Mental Illness Become "Written Off"? How Can They Overcome It?"
This is the cover of my book
It's the same as the title of my presentation: "Written Off"
I'll summarize a lot of the research
Not about a specific study
Here's a quote from the recent news
"I didn't want to carry around the stigma of a lifelong disease that would define me and potentially end my career."
-Mariah Carey, explaining why she hid and minimized having bipolar disorder for 17 years
The reason why this jumped out at me is that she's a celebrity with a lot of fame & resources
Yet she felt the label would discredit her

The next slide is about what I'll cover
Review extent of endorsement of mental health stigma
Discuss how stigma impacts identity
Discuss how identity impacts the recovery process
Discuss peer-led and professional-led ways of overcoming effects of stigma on identity

What is stigma
Occurs when "elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation" (Link & Phelan, 2001)
The important part of that definition is the power situation
Label (e.g., mental illness) is linked to negative stereotypes, or negative traits generally ascribed to the group
The most common stereotypes are stereotypes of violence, unpredictability, incompetence, and inability to work/function
It can be helpful to put stigma in perspective

The eugenics movement led to an euthanasia program in Nazi Germany
That preceeded the holocaust that we all know
This is an image from the US eugenics movement
It talks about unfit human traits
That run in families and are inherited
It was intended to promote the eugenics movement
That families with more "positive traits" should be promoted and others should be sterilized
The next image shows the contiguous US states that shows how many states had enacted forced sterilization
The majority
This is a picture from Nazi propaganda
The title says "life without hope"
It was used to justify extermination

So what is it like now?
Stigmatizing views have not changed substantially since the 1950's, when surveys first began tracking these views
We know this from surveys
There was evidence that negative stereotypes had increased
Between 1996 and 2006: No decrease (Pescosolido et al., 2010) in Americans’ endorsement of the belief that people with mental illness (schizophrenia especially) are dangerous and in desire to maintain social distance from them
Between 1980s – 2000: Globally, no improvement in attitudes toward people with schizophrenia (Schomerus et al., 2012)
The next slide shows global stereotypes
Findings from a the Stigma in a Global Context study (over 6,000 participants from 16 countries) (Pescosolido et al., 2013) indicate that there is a core group of negative attitudes that persist globally
“likely to be violent to others” (endorsed by 53% on average)
“not likely to be productive” (endorsed by 51% on average)
“unpredictable” (endorsed by 70% on average)
“shouldn’t care for children” (endorsed by 84% on average)
All this indicates that stigma is still with us

Do people who are diagnosed know those attitudes are there?
Most evidence says they're *very* aware
Studies consistently find that most mental health service users are aware of stigma, and roughly 70% anticipate discrimination (Thornicroft et al, 2009)
In addition, studies find that 60-70% of people diagnosed with mental illness believe that “most people” hold stigmatizing views and would reject a person with mental illness as a friend, etc. (Lundberg et al., 2007; Kleim et al., 2008)
People are quite aware
How do they become aware?
Link’s modified labeling perspective: generally-held stereotypical attitudes about mental illness are absorbed during childhood, take on personal relevance when a person is diagnosed, and gain increased salience
There’s a lot of evidence for this theory
You don't ever have to be treated badly to link stereotypes to yourself because you learn about them as you're growing up

Here's a simplified graphic that shows this
If people become aware, what happens?
If they have social rejection experiences, they can impact you
They can discourage you from opening up to others
Types of social rejection experiences commonly endorsed include being treated “differently” by friends or being aware that friends are uncomfortable (Lundberg et al., 2007)
More overt discrimination experiences are also reported, though less frequently- in a global study Thornicroft et al. (2009) found that roughly 50% reported experiencing discrimination, with most common areas being work (30%), housing (15%), and police (17%)

We're all aware of microaggressions related to race or gender
But people with mental illness experience this too
Concept of “microaggressions” (Sue et al., 2008) may also be relevant here-
everyday unconscious, subtle, and covert verbal, and nonverbal slights
A focus group study (Gonzales, Davidoff, Nadal & Yanos, 2015) found that people with mental illness report experiencing microaggressions in addition to more overt discrimination
Categories reported included: Invalidation, Assumption of Inferiority, Second Class Citizen, Fear of Mental Illness, and Shaming of Mental Illness
Invalidation, for example
“People in my family, if I actually start being happy they’re like ‘Are you sure you’re okay? You look happy today.’ It’s like I’m allowed to be happy sometimes. Or if I do a lot of activities or if I stay up late I’ll have people call me up and say ‘Maybe you’re manic, you stayed up really late. You’ve done a lot more things than you usually do.’”
For this person, even normal happiness gets pathologized
People don’t allow you normal happiness

Here's a candy bar wrapper I saw in San Francisco
It says "Alcatraz Psycho Ward Bar"
This is fairly common
We created & piloted a scale that measures microaggression
It has 3 sub scales
We piloted the scale in a sample of 505 college students and general community members (Gonzales, Davidoff, DeLuca & Yanos, 2015)
3 subscales:
- Assumption of inability
  If someone I’m close to told me that they had a mental illness diagnosis, I would try to talk more slowly so that they wouldn’t get confused.
- Patronization
  If someone I’m close to told me that they had a mental illness diagnosis, I would frequently remind them that they need to take their medication.
- Fear of mental illness
  If I saw a person who I thought had a mental illness in public, I would keep my distance from them.
This is what we heard from focus group participants

The next question is how does this impact someone
Corrigan and Watson (2002) developed a model allowing for three different responses: indifference, righteous anger, and self-stigma
My graphics will explain what leads to each one
The first is "indifference"
That can happen if you don't identify with a group of people with a mental illness
Or you can identify but you dismiss the stereotypes
It doesn't matter
You don't care
The second possible response is "righteous anger"
They may identify with the diagnosis
But reject it & feels it's wrong
The last response is "self-stigma"
They're aware of being in a group
They agree with the stereotypes
It's a toxic combination
Of believing you're part of a group & believing the stereotypes
It affects how you define yourself

Does stigma impact identity
Identity: social categories people use to describe themselves and that others use to describe them
“I am a ______” (e.g., “father,” “professional,” “gangster”)
“S/he’s a ______” (e.g., ‘great parent,” “criminal,” “spiritual person”)
Our own identity is often influenced by the categories that others impose on us
Self-Stigma = Stigmatized Identity?
Through a variety of processes, identity of having a mental illness takes over and supersedes other identity categories (e.g., musician, parent, spouse, veteran, spiritual-person, etc.)
People who've been diagnosed have many identities
But the stereotypes associated with the mental illness take over
Lally described the process of "role engulfment"
Transitional events leading to this include hearing a diagnosis, applying for disability and resigning oneself to the permanence of the diagnosis/illness
The statements of mental health professionals may also be important- making statements and taking actions that reduce people to diagnoses, ignore their strengths, and discount or minimize their successes, leading to "spirit breaking" (Everett, 2000; Deegan, 2000)
It hasn't been studied but reported in personal accounts

Here's the first account of personal self-stigmatization
"I perceived myself, quite accurately, unfortunately, as having a serious mental illness and therefore as having been relegated to what I called "the social garbage heap."… I tortured myself with the persistent and repetitive thought that people I would encounter, even total strangers, did not like me and wished that mentally ill people like me did not exist. Thus, I would do things such as standing away from others at bus stops and hiding and cringing in the far corners of subway cars. Thinking of myself as garbage, I would even leave the sidewalk in what I thought as exhibiting the proper deference to those above me in social class. The latter group, of course, included all other human beings." (Kathleen Gallo, “Self-Stigmatization,” 1994)

A very negative self-image
How do we know if this happens
There are a number of scales
Ritsher: Internalized Stigma of Mental Illness Inventory (ISMI)
Corrigan: Self-Stigma of Mental Illness Scale (short-form also exists)
McCay: Modified Engulfment Scale
Barney: Self-Stigma of Depression Scale

To give you a sense of the first scale, here are a couple of items
"Mentally ill people tend to be violent." (Stereotype Endorsement)
"I am embarrassed or ashamed that I have a mental illness." (Alienation)
"People with mental illness make important contributions to society." (Stigma Resistance)
"Because I have a mental illness, I need others to make most decisions for me.” (Stereotype Endorsement)

How many people endorse having a stigmatized identity?
Using predetermined cutoff totals on the ISMI, findings consistently hover in the 20-40% range

The largest study:
Brohan et al. (2010) surveyed 1229 mental health consumers diagnosed with schizophrenia in 14 European countries and found that 41% had elevated internalized stigma
Among 1182 diagnosed with bipolar disorder or depression, 22% had elevated internalized stigma

There's evidence it's a common phenomena
Findings demonstrate that, while most mental health service users do not develop stigmatized identities, a significant subgroup (roughly a third) do, and that people with schizophrenia may be at greater risk for elevated self-stigma

Are some groups more prone?
Consistent predictors of self-stigma related to age, ethnicity, gender, etc., have not been identified
There's a connection between community attitudes & self identity

So here's the crux
How does this affect people?
My colleagues and I came up with a model
Corrigan and Watson’s model proposes that self-stigma leads to diminished self-esteem (belief in one’s own self-worth) and self-efficacy (belief in one’s ability to handle problems and accomplish goals)
My colleagues (Roe, Lysaker) and I have developed a model proposing a more profound and pervasive effect of self-stigma on the recovery process
Self-stigma can have an impact on suicide risk
Ability to cope
Social interaction
Vocational outcomes
People withdraw & become more isolated
It has an effect on symptom severity
It can make symptoms worse

I don't want to get bogged down in stats
But I'll explain it
The first paper we did on this was
Towards understanding the insight paradox: Internalized stigma moderates the association between insight and social functioning, hope, and self-esteem among people with schizophrenia spectrum disorders. We wanted to know when insight has a negative impact. We believe it does when it's combined with self-stigma. If you don't endorse self-stigma, it can be positive. Insight has been found to be associated with both positive outcomes (better functioning) and negative outcomes (greater depression/hopeless), depending on the study. Here's a table that shows where people fall in terms of self-stigma. The differences between groups matter. There's some benefit to having low insight if you don't endorse self-stigma. You had better self-esteem & more hope.

I'm shifting to my new set of slides. Do you see the first slide? I want to make sure it's working.

[2018/04/21 10:07] Carolyn Carillon: PY: This slide summarizes what I just said

"Advantage" of insight is lost when it is combined with self-stigma.
People with high insight and high self-stigma have greater symptoms, less hope, lower self-esteem, and worse social relationships than both people with high insight/low self-stigma, and people with low insight/low self-stigma.

We did another study: Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders.

I'll skip to the diagram of it. We had significant relationships between things we thought would be related. Internalized stigma can impact hope & self-esteem, coping, etc. We thought we were on to something. We did another study. Internalized stigma as a barrier to improvement in vocational functioning among people with schizophrenia-spectrum disorders. Examined the effect of self-stigma on vocational outcomes using longitudinal data. Data came from a vocational rehabilitation project where all participants were offered work opportunities and followed up 5 months later. People who think that the mental illness is associated with the ability to get better are less likely to get better even when they're offered opportunities to work. This has been studied by a lot of people.

Replication of association with lower self-esteem (Corrigan, Watson & Barr, 2006; Werner et al., 2008)—USA; Israel; Internalized stigma is associated with avoidant coping and lower self-efficacy (Kleim et al., 2008)—Germany. Internalized stigma is associated with poorer medication and treatment adherence (Adewuya et al., 2009; Tseng et al., 2009)—Nigeria; China. Internalized stigma is associated with impaired social functioning (Munoz et al., 2011)—Spain.
Replication of finding that insight moderated impact of self-stigma on “demoralization” which in turn impacted functioning (Cavelti et al., 2012) - Switzerland

It's being replicated everywhere & not just in our studies
This is a meta-analysis of the impact of self-stigma
Livingston & Boyd (2010) conducted a meta-analysis of 127 studies examining consequences of self-stigma
Significant effects were found for hope (-.58), self-esteem (-.55), self-efficacy (-.54), quality of life (-.47), symptom severity (.41), treatment adherence (-.38), and social support (-.28)
This indicates that self-stigma has a significant impact
Evidence is accumulating for our model
We need to do something about it
Findings consistently emerge even when controlling for symptoms
Most studies are cross-sectional, but some prospective findings are emerging

So what can we do?
Is it possible to change identity?
Back in the 90s when I was getting into the field, I was influenced by this article:
Davidson and colleagues (Davidson & Strauss, 1992; Davidson et al., 2005) studied individuals who displayed significant improvement in global functioning over time.
They found that these individuals described how constructing a new “sense of self” was an important part of the process of recovery from mental illness
My friend did a similar study
A separate qualitative longitudinal study found that individuals who improved functioning over a 1 year period showed a progression from the identity of “patient” to “person” in their narratives (Roe, 2001)
This suggests that people do change over time
And that change is connected to identity
There is hope
People significantly improved in self-stigma over 5 months (Lysaker et al., 2012)
also significantly improved in self-esteem
Improvements in self-stigma over time are also significantly related to improvements in functioning (Yanos et al., 2012)

How?
Peer support makes a difference
The peer support movement has started the conversation
They initiated the discussion that I'm talking about here
Theoretical discussions of how peer-led services work emphasize the importance of developing alternatives to the “patient” identity (Mead et al., 2001)
Qualitative research on the impact of participation in the mental health peer/user movement supports that participation in these organizations can facilitate recovery by encouraging participants to transform identities of “mental patient” to “advocate” (McCoy & Aronoff, 1994; Onken & Slaten, 2000).
Quantitative research indicates that participation in peer/user-led services is related to increased personal “empowerment”

Here's a diagram from the Icarus Project
It says "you're not alone"
We decided to study this
Our paper: Participation in peer support services and outcomes related to recovery
We looked at people who were participating in peer-led support groups & followed them over 6 months
We found that, among “new participants” in peer support services, persons who regularly attended services showed a significant decrease in self-stigma as well as an increase in self-esteem in comparison with those who did not regularly attend
We can't say anything about those who never came
There's an impact in participation in peer support

What can we do in the professional system?
I developed an approach with my colleagues
Although the area is in its infancy and none are yet "evidence-based"
Treatment approaches developed that show promise include Narrative Enhancement and Cognitive Therapy (Yanos, Roe, & Lysaker, 2011)
The elements our intervention:
1. Psychoeducation to help replace stigmatizing views about mental illness and recovery with empirical findings
2. Cognitive restructuring geared toward teaching skills to challenge negative beliefs about the self
3. Story-telling exercises (narrative enhancement) geared toward improving one’s ability to integrate empowering themes into one’s life story
This is an image of the manual cover, Narrative enhancement and cognitive therapy for self-stigma: Group treatment manual (Participant's workbook)
Here's the Swedish version
It's been translated
There's evidence that narrative is important in how we define ourselves
Researchers and service-users are increasingly pointing to the importance of narrative (or story-telling) in helping people to make sense of their experiences
A classic book: Jerome Brumer. Actual minds, possible worlds

Here's an image of a poster: The schizophrenia oral history project
I'm running out of time so I'll give a quick summary of the evidence on NECT
Evidence comes from 5 studies:
A quasi-experimental study conducted in Israel
A small RCT conducted in the US
An uncontrolled follow-up study conducted in Gothenburg, Sweden
An RCT conducted in Gothenburg, Sweden
An ongoing RCT being conducted in the US
(NECT = Narrative Enhancement and Cognitive Therapy)
RCT = Randomized control trial
The most compelling evidence comes from the Swedish study
The effect size is medium large
That NECT works
Conclusions Regarding NECT
Findings from Gothenburg RCT and Israeli non-randomized trial suggest that NECT impacts self-stigma and self-esteem in comparison with treatment as usual with an effect size of roughly .5 (this is considered to be a “medium to large” effect)
What remains to be seen is if effects persist over time, and when compared to an “active” control group (findings from the US RCT suggest that they will) Effects on objective domains (social functioning) need to be examined There’s something to it & it can help people It’s more common in Sweden The last thing is a peak at other interventions that exist

The take-home messages are:
Stigma impacts the lives of a significant number of people with mental illness Stigma restricts opportunities for community participation, but also impacts identity Identity and identity change play key roles in the recovery process There is evidence that stigmatized identities can be changed by peer-led and professional means, though best practices have yet to be determined Questions?

[2018/04/21 10:23] Gentle Heron: Dr. Yanos, thank you for sharing your work with us today. QUESTION- What can we who witness these microaggressions do to help the victim? to (politely) educate the aggressor?

[2018/04/21 10:24] Gentle Heron: [10:23] Mook Wheeler: QUESTION: Self-stigma, on average, would not take effect with one negative event – it is unlikely to be a singular ‘imprinting’. Such a change of self-image takes sustained repetition, repeated occasions to take hold. Can reduction/reversal of self-stigma through therapy be maintained if the person continues living in the same environment which encouraged self-stigma in the first place?
[2018/04/21 10:24] Carolyn Carillon: PY: That’s a great question If we’re trying to improve people’s self-image but if people aren’t being validated in the real world, can it work It can But it’s a complicating factor We’re not trying to deny that stigma exists We’re not trying to say it’s not real We’re trying to help people see themselves differently And give people strategies to respond when they encourage stereotypes To discount some of the expectations they have Strategic disclosure with trusted people But you can’t control what other people do That may be why some people are afraid of disclosure


[2018/04/21 10:26] Gentle Heron: [10:23] Kitiara Borzage (ladykitiara): as a Blind individual, I really appreciate, that you were very descriptive of your slides, I respect that. It has been a huge honor to meet you!

Other questions?

[2018/04/21 10:27] Gentle Heron: [10:24] Guana Victor Daredso (guanadaredso): How do people like me with bipolar identify with the stigma thing you were discussing?
[2018/04/21 10:27] Carolyn Carillon: PY: Well bipolar disorder is one of the more stigmatized disorders
Self-stigma does occur
[2018/04/21 10:27] Carolyn Carillon: PY: it depends on what one’s history is with the mental health system
There are two types
Bipolar I tends to include psychotic experiences during the manic phase
That can lead to involuntary hospitalization
Those experiences tend to be more stigmatizing
It depends on the presentation
And whether psychotic experiences are occurring
[2018/04/21 10:28] Carolyn Carillon: PY: that doesn't happen with everyone
It's a difficult experience
When I work with people with bipolar disorder, I try to see both sides of the person
But shifting between extremes is a challenge
[2018/04/21 10:28] Zombie doggie (tarquin.evermore): Oh that reminds me you weren't here for it Guana, but Mariah Carey just came out with being Bi Polar, but kept it hidden for years due to fear of stigma and effects on her career.

[2018/04/21 10:27] Dhira Giha: You mention recovery quite a lot. What about using successful management as the outcome?

[2018/04/21 10:28] Gloriejoy (joycie.string): QUESTION: Friends outside of a clinical setting are very important. They are fantastic supports and provide many avenues of positive activities, etc. Agree?

[2018/04/21 10:29] Dhira Giha: how can we get a copy of your slides?

[2018/04/21 10:29] Gentle Heron: [10:26] Zombie doggie (tarquin.evermore): I have noticed that fellow disabled people have a tendency to come together, and is more accepting of friendships with each other. Do you think it's because we know the feeling of stigma, or because we are disabled, we have a tendency to be more accepting and understanding of other people's disability even if it's different?
I think that's due to the disabilities movement
That required a coalition of people with different kinds of disabilities
That's not always the case
Sometimes within organizations there can be a hierarchy
Mental illness can be looked down on even in disability communities
But it's had positive results including the American Disabilities Act

[2018/04/21 10:30] Vulcan Viper: We, Dutch, say "soort zoekt soort", meaning "kind looks for kind".


So the issue of culture is interesting but understudied
There's some discussion in my book
About the connection between culture & stigma
https://www.amazon.com/Written-Off-Mental-Health-Potential/dp/1107196957
My colleague has studied this in the chinese community
The focus on face & reputation seems to have an impact on the experience of feeling like you've failed your family or your family's expectations
There can be advantages in family support
But it has its downside in this regard
Not much different than the Greek community
Where we put emphasis on the family
There's a heavy sense of having failed if you can't meet your family's expectations
It's an interesting area that needs further study

[2018/04/21 10:33] Zombie doggie (tarquin.evermore): yes I agree to both. If a family supports you, that's all great! But if you have a family that doesn't support you due to your disability, it can be very hard. I know of a case IRL with an IRL friend that was "Disowned" by her family a few years ago for "acting like a child" when that's really part of her disability.

[2018/04/21 10:31] Zombie doggie (tarquin.evermore): We have been hanging out for so long, Guana can tell if I am off my meds lol
(or need a good guinea pig cuddle)

[2018/04/21 10:32] Gentle Heron: We will have to ask Dr. Yanos to return. We have many questions and he has so much to tell us. Thank you Dr. Yanos this has been wonderful.
The whole transcript?
In case I missed part of it?
[2018/04/21 10:33] Carolyn Carillon: PY: The slides are available for everyone, right
[2018/04/21 10:33] Gentle Heron: Slides are available
[2018/04/21 10:33] Mook Wheeler: Both transcript and slides will be posted on the VAI site
[2018/04/21 10:33] JJ Drinkwater applauds!!!
[2018/04/21 10:33] Eme Capalini: Thank you !
James Heartsong (peacefuljames): ☆Applause☆
Sister (sister.abeyante): Nice job- thanks.
Suellen Heartsong (suln.mahogany): *:-(_.·:*::*Yayyyyyyyyy!*:-
Carolyn Carillon: <<transcription ends>>