

"Building and Sustaining a Digital Mental Health Ecosystem of Equity"

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[2022/05/13 07:28] Carolyn Carillon: Hello everyone.

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Carolyn Carillon

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The following initials in the transcription record will identify the speakers:

KF: Karen Fortuna

[2022/05/13 07:32] Carolyn Carillon: <<transcription begins>>

[2022/05/13 07:32] Gentle Heron: Good morning everyone. Welcome to Virtual Ability's 2022 Mental Health Symposium.

We hope you will enjoy your time with us today, and that you will learn a LOT about loneliness, isolation, resilience, community, and other mental health topics.

I want to remind our audience that many of our presenters are new to Second Life, so please be patient with them.

Hold your thoughts and questions until they are done presenting so they can concentrate.

Thank you, and have a good day.

Now [I] will introduce our first speaker.

Karen L. Fortuna, PhD, LICSW, is an Assistant Professor of Psychiatry at Dartmouth College and Co-Founder of the Collaborative Design for Recovery and Health. As an international collaborative of patients, peer support specialists, caregivers, policymakers and payer systems, the Collaborative uses community-based participatory research to facilitate the development, evaluation, and implementation of digital tools that leverage mobile health to address needs identified by community members from vulnerable populations (collabrh.org). Dr. Fortuna is co-Chair of the Patient Engagement National Advisory Council to the Patient-Centered Outcomes Research Institute (PCORI), in which

she is currently co-leading a project to update the community engagement standards and integrate these updates to the PCORI Engagement Matrix.

'Building and Sustaining a Digital Mental Health Ecosystem of Equity'

[2022/05/13 07:36] Carolyn Carillon: <https://collabrh.org>

[2022/05/13 07:36] Karenfortuna Resident: Slide 1

Building a Digital Mental Health Ecosystem

Karen L. Fortuna, PhD, LICSW

Assistant Professor. Department of Psychiatry, Dartmouth College

<https://collabrh.org/>

Slide 2 Disclosure

Dr. Fortuna offers consulting services through Social Wellness

Slide 3 Grant Support:

- National Institutes of Health
- PCORI
- Japan Agency for Medical Research and Development
- The New York Academy of Sciences
- American Federation for Aging Research
- Brain & Behavior Research Foundation

Slide 4 Agenda

- Disparities in mHealth access and engagement
- Community-based Participatory Research Approach-The Collaborative Design for Recovery and Health
- Case Example—Efforts to Address Early Mortality in People with Serious Mental Illness
- Current Projects and Future Opportunities
- Questions/Answers

Slide 5 Technology is ubiquitous....But does everyone have equal opportunity to access and engage?

Mobile health (mHealth; i.e., mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices) is a promising approach to facilitate monitoring of mental health conditions, support people, and provide psychoeducation.

mHealth technologies offer a potential opportunity to overcome linguistic and literacy barriers to engaging underserved communities.

Research indicates that use of mHealth tools and resources is related to improvements in mood disorder symptoms,

especially those tools and resources utilizing evidenced-based approaches like cognitive behavioral therapy.

Use of mHealth tools and resources can increase an individual's capacity to self-regulate and monitor mental health symptoms.

Studies have also shown that digital interventions targeting suicidality demonstrate statistically significant results in reducing suicidal ideation.

Additionally, the COVID-19 pandemic has expanded the need to offer mHealth due to lockdown measures, which has impacted access to in-person mental health services.

The use of mHealth has the potential to provide care for patients throughout the pandemic and beyond.

Yet, some groups may fail to benefit despite high need for mental health services, including people representing racially disadvantaged groups, rural residents, those who are socioeconomically disadvantaged, and people with disabilities.

[2022/05/13 07:40] Carolyn Carillon: KF: we can access tech in areas that don't have access

We'll look at helping people get access in places where they don't have it

People who are underserved: black, indigenous, POC

How can we promote equity with tech?

[2022/05/13 07:42] Karenfortuna Resident: Slide 6 The Participatory, Human-centered Design Life Cycle

In 2018, the Collaborative Design for Recovery and Health was established to ensure all people have the same opportunity to access and engage with mobile health.

The Collaborative is an international coalition of patients, clinicians, peer support specialists, caregivers, industry, scientists with and without lived experience, policymakers, and payer systems focused on co-producing technologies with disadvantaged populations.

[2022/05/13 07:43] Carolyn Carillon: KF: they may have lived experience

Our partners help us define the problem they want to address in their community

We do the research together and publish & present together

Called community-based participatory research

Leads to higher engagement

Because most people disengage from tech after 2 weeks

[2022/05/13 07:43] Karenfortuna Resident: Slide 7

Populations we work with include: people with SMI, peer support specialists, older adults, native American tribes, caregivers of people with dementia, and low income countries.

Today, we will focus on extending the lifespan of people with serious mental illness.

Slide 8

Developing Trust Through Dyadic Training

The Collaborative offers dyadic trainings in participatory technology development, monthly seminars on community engagement practices, consultation, and access to an open innovation network to engage in idea formation, group discussions, and resource sharing.

[2022/05/13 07:45] Carolyn Carillon: KF: here's how it works

People reach out

Tell us about the problem they want to address

We create work groups of scientists

They partner with the community

There are dyads

That work together to develop solutions

I'll tell you about one of our projects around early mortality

Here's our team

We offer training, resources

We have over 100 peer reviewed publications

[2022/05/13 07:46] Karenfortuna Resident: Slide 9 Overview of Our Approach

We have over 40 members representing multiple patient populations and science areas of study.

Slide 10 How do we ensure accountability to community engagement?

The Collaborative uses accountability surveys to ensure equitable partnerships.

[2022/05/13 07:48] Carolyn Carillon: KF: what normally happens is that people engage with the community

After a few years they do a survey

That doesn't give you an opportunity to make changes

This tool is used every month

To make sure everyone feels respected and valued

We change based on feedback

[2022/05/13 07:49] Karenfortuna Resident: Slide 11 Case Example
Efforts to Address Early Mortality in People with Serious Mental Illness
Here is an example of our work.

Slide 12

- Adults with a diagnosis of a serious mental illness are disproportionately affected by medical comorbidity, earlier onset of disease, and die up to 32 years earlier than the general population.

- Age-related changes in metabolism, physiology, and activity that may contribute to the development of additional illnesses and worse health outcomes.

- High rates of morbidity and early mortality are often linked to poor health behaviors.

Adults with serious mental illness are disproportionately affected by medical comorbidity, earlier onset of disease, and die up to 32 years earlier than the general population.

[2022/05/13 07:49] Carolyn Carillon: KF: we've known this for more than a century!

Lots of approaches to address it

But we need a new paradigm

Because the problem persists

[2022/05/13 07:50] Karenfortuna Resident: Age-related changes in metabolism, physiology, and activity that may contribute to the development of additional illnesses and worse health outcomes.

Their high rates of morbidity and early mortality are often linked to obesity or tobacco use, which prompted the development of a series of interventions to support self-management of physical health conditions in this high-risk group.

Self-management interventions focus on a combination of three tasks:

(1) medical management (e.g., teaching people how to follow through on treatment);

(2) role management (e.g., encouraging healthy lifestyle behaviors); and

(3) emotional management (e.g., learning how to monitor symptoms and identify early warning signs of relapse).

In addition, a series of randomized control trials have also SEPARATELY demonstrated the effectiveness of

psychiatric self-management interventions in improving mental health outcomes for persons with serious mental illness.

Slide 13 Colocation of Services May Not Be Enough to Significantly Affect Cardiometabolic Risk Factors

[2022/05/13 07:50] Carolyn Carillon: KF: So what have we done?

We have co-located services
Co-location improves access
May not be enough!
Best outcomes were around peer support & self-management

[2022/05/13 07:52] Karenfortuna Resident: Slide 14 Digital Peer Support May Address Implementation Barriers

I conducted a systematic review on the effectiveness of medical and psychiatric self-management interventions for adults with SMI. Of 707 studies screened, 17 studies reported on 9 interventions that co-manage SMI and chronic health conditions. While the studies demonstrated feasibility and preliminary clinical effectiveness, there has been limited dissemination and spread of these interventions due to the workforce needs of the interventions, the length of interventions, and related costs.

Integrated medical and psychiatric illness self-management interventions appear feasible and acceptable, with high potential for clinical effectiveness. However, implementation considerations were rarely considered in intervention development, contributing to limited uptake and reach in real-world settings. Peers and technology may address these barriers. Peers and technology may address these barriers.

[2022/05/13 07:53] Carolyn Carillon: KF: imagine having to go to a place to access services!

Also need a trained workforce to offer services

Those are barriers

So we thought

What if we combine peers

And train them to provide services

And use tech

So we can reach people

[2022/05/13 07:53] Karenfortuna Resident: Slide 15 Impact of Digital Peer Support Self-Management Interventions for People with Serious Mental Illness

What is the impact of digital peer support?

[2022/05/13 07:54] Carolyn Carillon: KF: we see improvement in quality of life

When we first proposed this, scientists were skeptical that people could use the tech

We asked peer support specialists

93% used tech

There's a patient-facing version and a peer-facing version

They can communicate via text and video

Can also put in their hours

Can add their own wellness plan

There's curriculum they use around challenges like loneliness

People can access recovery narratives in video

That increases hope and feelings of belongingness

[2022/05/13 07:53] Karenfortuna Resident: Slide 16 National Survey of Peer Support Specialists Ownership and Use of Technology

93% of peer support specialists are willing to use smartphones to promote health behavior change with consumers, N=120

3% of peer support specialists are willing to text message consumers to promote health behavior change

N=146

Gender Female=103 Male=43
Age range 28-72 years
Race White=123
Peer Smartphone Ownership 133 (95%)
85% with serious mental illness own phones

Slide 17 PeerTech
Our app is called PeerTECH.

Slide 18 Digital Peer Support Human Factors
In user-centered design projects, researchers typically lead the entire effort from study design to dissemination.
In contrast, community-based participatory research is an all-encompassing research paradigm that defines purposeful engagement among researchers, intended end users, and other stakeholders throughout all stages of a research project. This broader degree of engagement through community-based participatory research fundamentally alters how technologies are designed, implemented, and translated into wider practice
User-centered design includes end-users in digital mental health intervention development and is intended to increase the usefulness and satisfaction with technology, and hence, impact engagement with technology. Despite efforts to include end users in the usability testing process, disengagement is still highly common. User-centered design methodology alone is not capturing the full potential of end users, and in some cases, resulting in unforeseen consequences of perpetuating health and healthcare disparities for vulnerable populations.

Slide 19 Digital Peer Support Human Factors

- 4th grade reading level
- Limited compound sentences
- Repetition
- Multi-modal
- On-demand videos
- No hyperlinks
- Limited color contrast
- Trauma-informed digital principles
- Recovery model of mental health
- Active tracking instead of passive
- Promotion of patient experience (i.e., stigma, sense of belonging, respect)
- Recovery outcomes (i.e., social health)
- Technology selection and analytical techniques

Human factors that promote engagement in technologies
[2022/05/13 07:58] Carolyn Carillon: KF: here's how patients made it different
They changed the language
It was written at a grade 12 level
Challenging to understanding
We got it to a grade 4 level
We added design features
Around scrolling
We included trauma

Wasn't included originally

90% with serious mental illness have experienced trauma

Added info on how to live with grief and loneliness

[2022/05/13 08:00] Karenfortuna Resident: Slide 20 PeerTech Classes

Here are the classes we came up with for the app

Part 1. Introductions, Smartphone Orientation, and Recovery and Health

Part 2. Good Mental Health Starts With Good Physical Health and Social Health (vice versa)

Part 3. Recovery is a Daily Process

Part 4. How Stress Impacts our Whole Health

Part 5. Living a Healthy Lifestyle

Part 6. Healthy Sleep

Part 7. Dental Health

Part 8. Exercise

Part 9. Developing and Maintaining Relationships

Part 10. Getting the Help You Want

Slide 21 Here is how the app works.

[2022/05/13 08:02] Carolyn Carillon: KF: on the left you see the peer app

We have a dashboard on top

We can see how people are engaging

[2022/05/13 08:02] Karenfortuna Resident: Slide 22 Single Arm Pre/Post Pilot Study N=8

[2022/05/13 08:02] Carolyn Carillon: KF: we ran a study

We trained older adults to use the tech

Peer support specialists

Helped us improve our training

[2022/05/13 08:03] Karenfortuna Resident: Slide 23 Results

Here are our results.

Slide 24 Single Arm Pre/Post Pilot Study N=30

-A total of 30 participants completed baseline and 21 completed the follow-up assessment.

-Among the 21 participants assessed at the follow-up visit, 71.4% were female (n = 15), with a mean age of 39.85 (SD = 12.41).

The majority of participants were white (n = 20, 95.2%), had never been married (n = 11, 52.4%), completed high school/GED (n = 18, 85.8%), lived independently (n = 12, 57.1%) and were unemployed (n = 15, 71.4%).

Participants had a primary mental health diagnosis of: schizophrenia spectrum disorders (n = 12, 57.1%), bipolar disorder (n = 6, 28.6%), and major depressive disorder (n = 3, 14.3%).

The 8 participants who were not assessed at follow-up were not significantly different from those who were assessed in baseline age, gender, education, or psychiatric diagnosis.

Slide 25 Results

Slide 26 Results

We saw improvements in medical self-efficacy and empowerment.

Slide 27 Results

We saw improvements in medical self-efficacy and empowerment.

Slide 28 mHealth Ecosystem For Equity

Promote digital literacy

Embrace adaptive-technology

Facilitate informed decision-making in technology selection

Promote inclusivity via mHealth design features

Reduce bias in machine learning analytics techniques

Consider the participatory, human-centered design life cycle

Facilitate access to mHealth

[2022/05/13 08:05] Carolyn Carillon: KF: how do we train people who may have cognitive deficits or may have symptoms of mental health issues

People are trained over 3 months

Then people practice and we provide support and feedback

How do we create this ecosystem?

People can use tech if they're taught

It helps to have a peer train another peer

Create technology that operates on low or no-wifi signal

Like WhatsApp

We have conversations to facilitate informed decision-making

Base design on universal design principles

We train people around policies that give people free access to phones in the US

[2022/05/13 08:10] Karenfortuna Resident: Slide 29 Pilot Randomized Control Trial
Current study we are conducting with a larger sample.

Slide 30 Collaborative Design for Recovery & Health

Other scientists on our team, working with recovery coaches and OUD, service users in developing countries, caregivers of people with dementia, native American populations, and people with Parkinsons & dementia

Slide 31 Thank you

[2022/05/13 08:11] Carolyn Carillon: KF: let me talk about our future work and then I'll take questions

Our first study is implementing the tech in Norway

You can see our team

We have another project where we're integrating natural language processing

Taking the text in text messages & audio from conversations

Using that to support peer support specialists

To deliver evidence-based practice

Another tech we're developing is a bio sensor

To identify neuropsychiatric disorders 10 years before they appear

Dementia, Parkinsons

So we can offer an intervention

Another project is supporting older adults remotely

I'm leading this with another colleague

To support people to stay in their home

Also have a caregiver app

For those with dementia

Also developing a research agenda around mental illness

By gathering people around the world

A patient-centred agenda to develop life-prolonging interventions
Here's one of our teams
It's a pleasure to work with all these people
They've pushed us
We're open to collaborations
This is just the beginning
We want to dive into other types of disability states
To promote equity of access
Thanks!
I'm open for questions

[2022/05/13 08:15] Shiloh e. (Shiloh Emmons): Is your organization working with projects/ programs like TeleDoc?

Can you describe a little on the difference?

Wonders if programs like this could also have access provided at rural public libraries.....
the difference from TeleDoc

[2022/05/13 08:16] Elektra Panthar: KF: Good question - we're developing something different to support people in the community who provide mental health services

I can share more if people reach out

Thank you, I appreciate that

Yes, that's already happening in the case of people using wifi

I can't [discuss here] because it's part of a patent pending process but send me an email and we can talk about it after that

[2022/05/13 08:23] Shiloh e. (Shiloh Emmons): ahhh... ok

Thank you for sharing your research.

[2022/05/13 08:15] Mook Wheeler: COMMENT & QUESTION : Engagement levels for any health intervention are influenced by a self-stoking spiral: Comfort level <-> level of need.

An acute level of need will motivate the user to reach for digital mental health intervention (DMHI) even if the discomfort level of using DMHI is high; yet high levels of discomfort in using DMHI will discourage users unless their needs are acute. If our need is high enough, we will reach out even if we are uncomfortable doing so.

Mental discomfort/distress in using digital mental health intervention is therefore an unfortunate irony, but it points to a hypothetical question: Could this mean that in your low-engagement situation, current DMHI usage levels are actually identifying the section of users with THE most urgent mental health needs?

[2022/05/13 08:18] Elektra Panthar: KF: Wow, that's fascinating

[And it's a very interesting research question

If you have any interest in us studying that, just reach out, because that question hasn't been answered

I do wonder, what happens is in some of the commercially available products, people download these apps, they use them like a gym membership, they go when they need to, so they may check in once a month. People have said to us that it's nice knowing that someone is there for them, and it's just on the app and they can engage at any time. And that's potentially the working well, who maybe don't have these acute mental health challenges. It's a fascinating research question, yeah, if you have any interest and you want us to study it just reach out and we'll make that happen]

[2022/05/13 08:16] Polaris Grayson: Question: How has the socio-economic differences in the demographic topography caused issues and barriers in the peer groups?

[2022/05/13 08:20] Elektra Panthar: KF: We didn't see differences in status because organizations luckily provide the technology

Around 88% of people with severe mental health issues have a cell phone - people are increasingly using the tech

Providing people with the tech helps people enormously

There are plans to allow people to access data at very little cost

So the number increases every day

[2022/05/13 08:21] Polaris Grayson: TY 😊

[2022/05/13 08:19] James Heartsong (PeacefulJames Heartsong): does talking with others who have PTSD help us to work through our PTSD? i.e., peer support

[2022/05/13 08:22] Elektra Panthar: KF: when we talk about trauma maybe we don't talk about the details so we don't exacerbate the triggers of the person

For example playing video games helps people with PTSD

So that might be a useful route to choose

[2022/05/13 08:23] Gentle Heron: Thank you Karen. Those are interesting projects.

Audience, please click on the box by Dr. Fortuna's feet to get notes from her presentation.

QUESTION- You're including a wide swath of people for your projects not only from multiple countries but from multiple societal roles. How do you help scientists, for example, learn to communicate well with insurers, or help patients find a voice with policy makers? I'm wondering if cross-role communication is perhaps more difficult than cross-country communication? I'm not asking about peer-to-peer communication, because that training has been well established.

[2022/05/13 08:24] Elektra Panthar: KF: that's what we do in dyadic structures

We talk about experiences, and sharing yourself, and what you bring to the table

We integrate our accountability to multiple points

There's always training for the 'patients', but rarely for the scientists to help them understand the 'humanistic' side of the study, how to deal with people more effectively

We offer tech assistance as well to help these groups with their research

Thank you for joining

Please reach out, we are very collaborative and there are so many things we'd like to change

[2022/05/13 08:27] Elektra Panthar: Any more questions for Karen?

[2022/05/13 08:26] Slatan Dryke: great presentation, thank you !

[2022/05/13 08:26] RoXkSie (Roxksie Logan): /me .:{APPLAUSE}:.
thank you :)

[2022/05/13 08:27] Suellen Heartsong: /me applauds

[2022/05/13 08:27] Buffy Beale: yes really great information, thank you!

[2022/05/13 08:27] Gentle Heron: Great presentation, Thank you.

[2022/05/13 08:27] Eme Capalini: Great job!

[2022/05/13 08:27] Psyra Extraordinaire: Very informative. :>

[2022/05/13 08:27] Zzri Avian (Zri Portal): Claps!

[2022/05/13 08:27] PEACE (Peaceful Harbour): *****

APPPPPPLLLLLAAAUUSSSSSEEEEEEE*****

[2022/05/13 08:27] Lyr Lobo: Great session! Many thanks!

[2022/05/13 08:27] Karenfortuna Resident: THANK U!

[2022/05/13 08:28] Elektra Panthar: Thank you Doctor Fortuna, please take a quick break everyone!

[2022/05/13 08:27] Gentle Heron: Audience, please take a quick break.

[2022/05/13 08:28] Carolyn Carillon: <<transcription ends>>