



What does "lived experience" really mean and why is it important?

May 18, 2023

Patricia E. Deegan PhD
pat@patdeegan.com



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In school we were taught there were how many senses?

2




Do these strawberries dipped in chocolate look delicious?

3


What were the steps we took to get to the lived experience of strawberries dipped in chocolate?

Step 1 - Be willing to suspend [bracket] our belief in the idea there are 5 distinct senses

Step 2 - Reflect on the experience as we live it, even if what we find is different than our "models" would have us believe



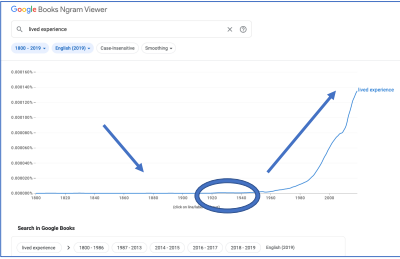
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Part 1:
What does lived experience really mean?

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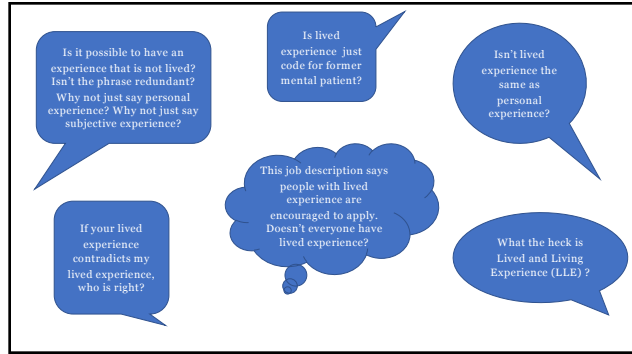
Use of "lived experience" in digitized books 1800 - 2019



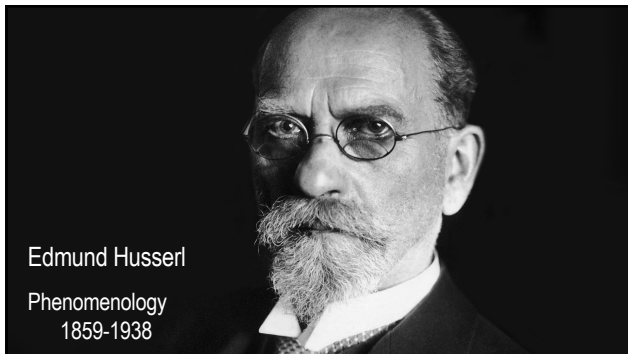
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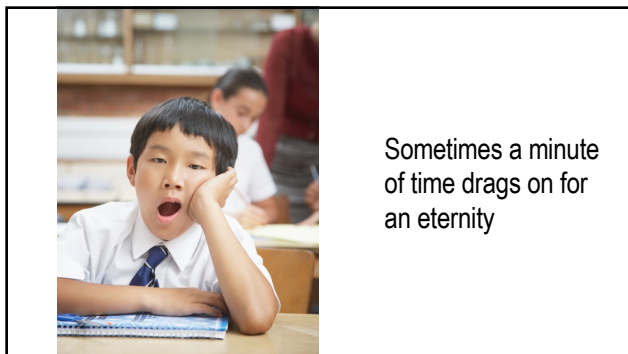
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Lebenswelt
"Life-world"

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Martin Heidegger

Maurice Merleau-Ponty

Jean-Paul Sartre

Simone de Beauvoir

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Lived Experience → Feminism

Simone de Beauvoir
published 1949

COMPLETE AND UNABRIDGED FOR THE FIRST TIME

The
Second
Sex

simone de beauvoir

INTRODUCTION BY JUSTIN FLECKMAN
A NEW TRANSLATION OF THE LANDMARK CLASSIC
BY CHRISTOPHER POLYAK AND STEVE NEWMAN, CHAIRMAN

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Use of "lived experience" in digitized books 1800 - 2019

Google Books Ngram Viewer

lived experience

1800 - 2019

lived experience

1800 1820 1840 1860 1880 1900 1920 1940 1960 1980 2000 2019

Search in Google Books

lived experience > 1800-1900 1901-2019

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Phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it.

Psychology as a *human* science

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Science says:
The heart is a
bio-mechanical pump

Superior vena cava

Inferior vena cava

Right atrium

Right ventricle

Aorta

Pulmonary artery

Pulmonary vein

From right lung

To left lung

From left lung

Left atrium

Left ventricle


To upper body

To lower body

THE HUMAN HEART

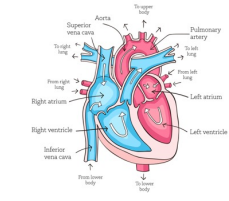
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What is the heart we know before science tells us the heart is a pump?




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Two Ways of Knowing



THE HUMAN HEART

Knowing through natural scientific method



Knowing through lived experience

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Recovery: The Lived Experience of Rehabilitation

1988

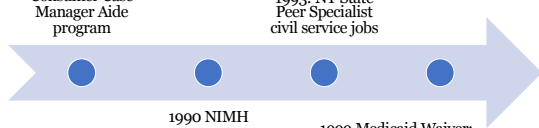
Patricia E. Deegan
Patricia E. Deegan, Ph.D., is a clinical psychologist who is currently living in a community with mentally handicapped adults in Ipswich, Massachusetts.

It's important to understand (we) do not "get rehabilitated" in the sense that cars get tuned up or televisions "get repaired"... Recovery refers to the lived or real-life experience of people as we accept and overcome the challenge of (psychiatric) disability.

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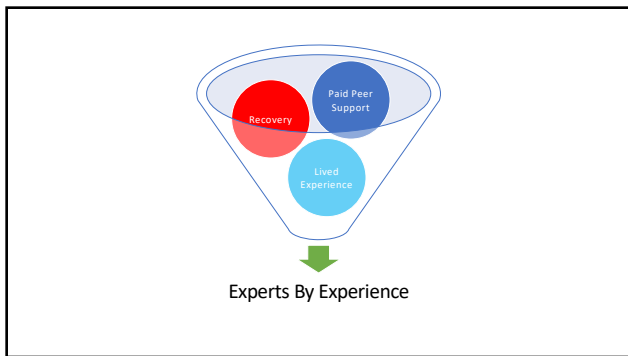
Beginnings of Paid Peer Support in U.S.

(thank you Darby Penney, 2018)



- 1986 Colorado MH Consumer Case Manager Aide program
- 1990 NIMH Peer Specialists on ICM teams, NYC
- 1993: NY State Peer Specialist civil service jobs
- 1999 Medicaid Waiver: 2001 Georgia Peer Specialist certification


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Part 2:

Why is lived experience important?



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1. Lived experience is important because it guides the work of peer specialists

Peer specialists' bracket clinical terms and models, and listen to peers' lived experience and evolving understanding of what is happening in their lives

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Clinical model or clinical way of knowing

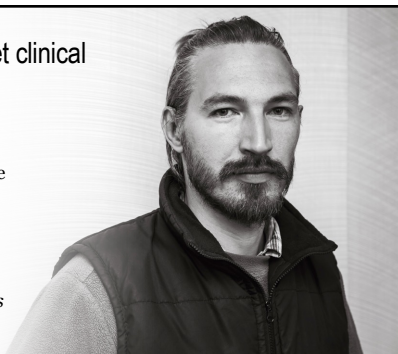
LM is a black cisgender female in her early 20s who began working with the team in March 2022. She is bright, motivated and engaged with the team. She has been experiencing auditory hallucinations prior to working with us. She is currently in college but unable to complete the semester because she is failing her course work. Her hallucinations are preventing her from being productive at school. She recently started responding inappropriately (laughing and smiling) to internal stimuli. She presents as distraught and often cries out of frustration with the voices. In March she was prescribed olanzapine which seemed to help decrease the intensity of the voices. However, for the past 2 weeks LM has refused to take meds stating they are unhealthy for her. Team is concerned she lacks insight.

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Drift. Did not bracket clinical models

A peer specialist was in the clinical meeting. During the discussion the peer specialist said:


LM is home now. I could reach out to her sister to see if she would be willing to supervise LM's med compliance.



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A more complex narrative reflecting lived experience


Some of the voices LM hears are really wonderful. They comfort her and help her believe she's really special. LM chooses not to take the meds because they interfere with those good voices. She doesn't want to get rid of them.



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Peer Specialists

- ✓ Do not use clinical language
 - Decompensate
 - Baseline
 - Lacks insight
- ✓ Do not assess
- ✓ Do not encourage/discourage compliance
- ✓ Do not attribute motive to peers
 - Attention seeking
 - Sabotaging the job



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Keanu told his peer supporter: *Stories about shamans go way back in my culture. Maybe my visions and voices mean I'm becoming a shaman. Maybe I don't have psychosis.*

The peer supporter replied: *Man, your Doc says you have psychosis. It's not your fault. In order to recover, you have to accept your illness. That's the first step.*




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A more complex narrative reflecting lived experience

That's interesting. I don't know that much about shamans. Maybe you can teach me. In the early days I remember thinking I was having a spiritual emergence. Like I was awakening into a new consciousness. It was beautiful.




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The unique contribution of peer specialists on clinical teams is to help deepen the clinical narrative into a story of resilient human beings. PS help teams understand how individuals' makes sense of their experiences. PS are guided by lived experience, not clinical models

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2. Lived experience is important because it is a source of wisdom that can be helpful to others

Sometimes the wisdom of lived experience compliments clinical knowledge. Sometimes it challenges

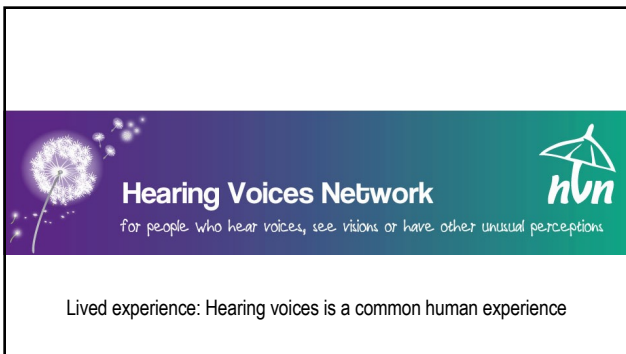
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Julissa has auditory hallucinations

Clinical model: Voices are a symptom of underlying mental disorder

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Hearing Voices Network
for people who hear voices, see visions or have other unusual perceptions

Lived experience: Hearing voices is a common human experience

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Medicine is a pill that you must take everyday as directed

The clinical model

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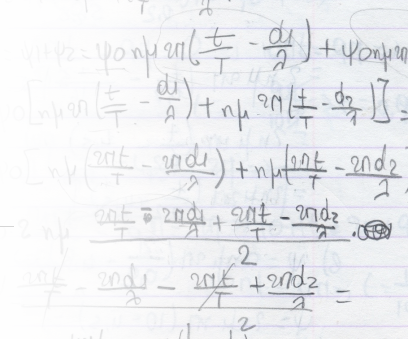
Joe

I think there's a lot of other things that's medication that's maybe not considered medication. There's things that you can do that does change what your body does and it may not be medicine. I still think one of the best mood stabilizers there is in life, maybe not for everyone, but for me, is math.



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Math: A mood stabilizer



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Medicine can be what I do, not just what I take


Lived experience: Certified Personal Medicine Coaching (CPMC)



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Joel is suicidal


Clinical model: Suicidal behavior is a symptom of underlying mental disorder



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Lived experience deepens and sometimes challenges the clinical story

Just a handful of the many reasons and meanings...



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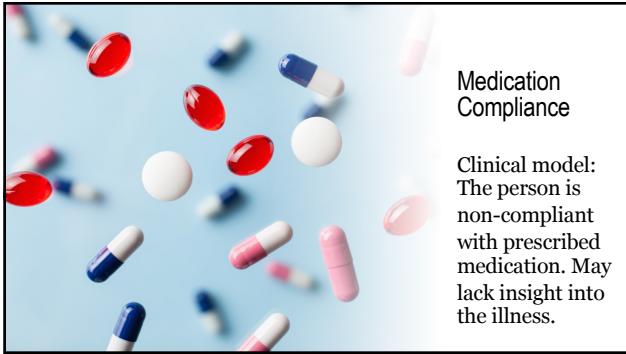
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Wildflower Alliance



Alternatives to Suicide

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Medication Compliance

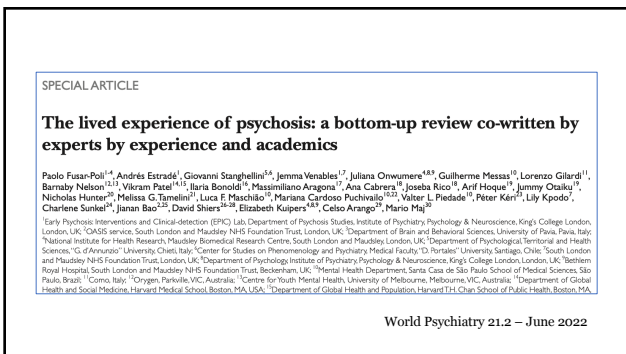
Clinical model:
The person is non-compliant with prescribed medication. May lack insight into the illness.

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Lived experience: Using meds to help me get the life I want is a journey on which there are many challenges

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SPECIAL ARTICLE

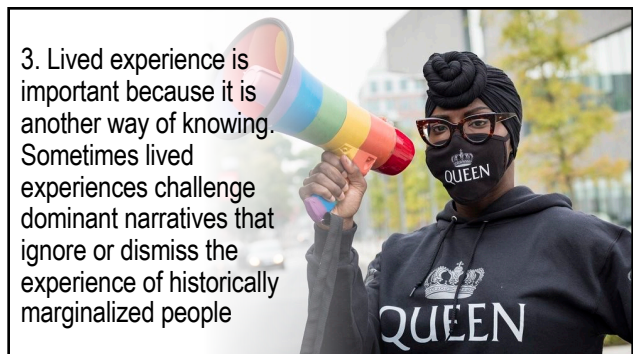
The lived experience of psychosis: a bottom-up review co-written by experts by experience and academics

Paolo Fusari^{1,4}, Andrés Estrada¹, Giovanni Stanghellini^{2,5}, Jenna Venables^{1,7}, Juliana Onwumere^{4,8,9}, Guilherme Messa¹⁰, Lorenzo Gilardi¹¹, Barnaby Nelson¹², Vikram Patel^{13,14}, Itaria Bonaldi¹⁵, Massimiliano Aragona¹⁶, Ana Cabrera¹⁷, Joseba Rico¹⁸, Arif Hoque¹⁹, Jimmy Otaliku²⁰, Nicholas Hunter²¹, Melissa G. Tametin²², Luca F. Reschilio²³, Mariana Cardoso Puchvalgo²⁴, Walter L. Piedade²⁵, Peter Ken²⁶, Lily Kpodo²⁷, Charlene Sunkel²⁸, Jianan Bao²⁹, David Shiers^{30,31}, Elizabeth Kuipers³², Celso Arango³³, Mario Maj³⁴

Early Psychosis Interventions and Clinical-detection (EPIC) Lab, Department of Psychosis Studies, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; "OASIS" service, South London and Maudsley NHS Foundation Trust, London, UK; "Department of Brain and Behavioral Sciences, University of Pavia, Pavia, Italy; "National Institute for Health Research, Maudsley Biomedical Research Centre, South London and Maudsley, London, UK; "Department of Psychological, Territorial and Health Sciences, "G. d'Annunzio" University, Chieti, Italy; "Center for Studies on Phenomenology and Psychiatry, Medical Faculty, "D. Portales" University, Santiago, Chile; "South London and Maudsley NHS Foundation Trust, London, UK; "Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; "Beecham Royal Hospital, South London and Maudsley NHS Foundation Trust, Beckenham, UK; "Mental Health Department, Santa Casa de São Paulo School of Medical Sciences, São Paulo, Brazil; "Como, Italy; "Orygen, Parkville, VIC, Australia; "Centre for Youth Mental Health, University of Melbourne, Melbourne, VIC, Australia; "Department of Global Health and Social Medicine, Harvard Medical School, Boston, MA, USA; "Department of Global Health and Population, Harvard T.H. Chan School of Public Health, Boston, MA, USA

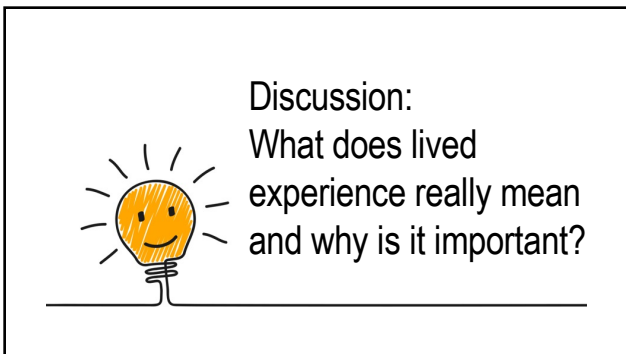
World Psychiatry 21:2 – June 2022

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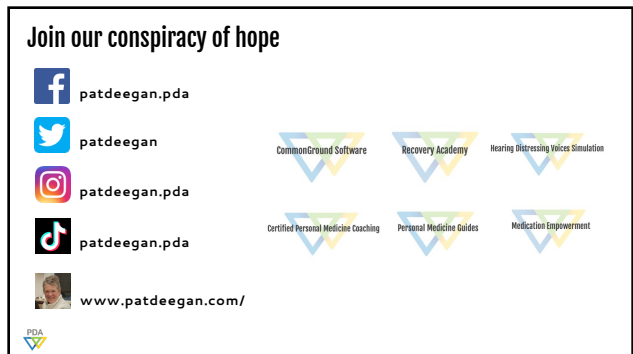
3. Lived experience is important because it is another way of knowing. Sometimes lived experiences challenge dominant narratives that ignore or dismiss the experience of historically marginalized people

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Discussion:
What does lived experience really mean and why is it important?

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