




I am a person, not an illness:  
Why CSC in early psychosis matters

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A person with a red backpack is walking away from the camera on a dirt path. A dog is walking ahead of them. The landscape is hilly and covered in golden-brown vegetation, suggesting a sunset or sunrise. The path leads into the distance, winding through the hills.

Recovery is a  
pathway into the  
life I want for  
myself

Pat Deegan



**For some, recovery means  
having a job, a paycheck and a  
date on a Friday night.**



# Why CSC Matters

The goal of CSC is to support individual recovery

Stabilization and maintenance is a low bar



# Story 1

I am a person,  
not an illness

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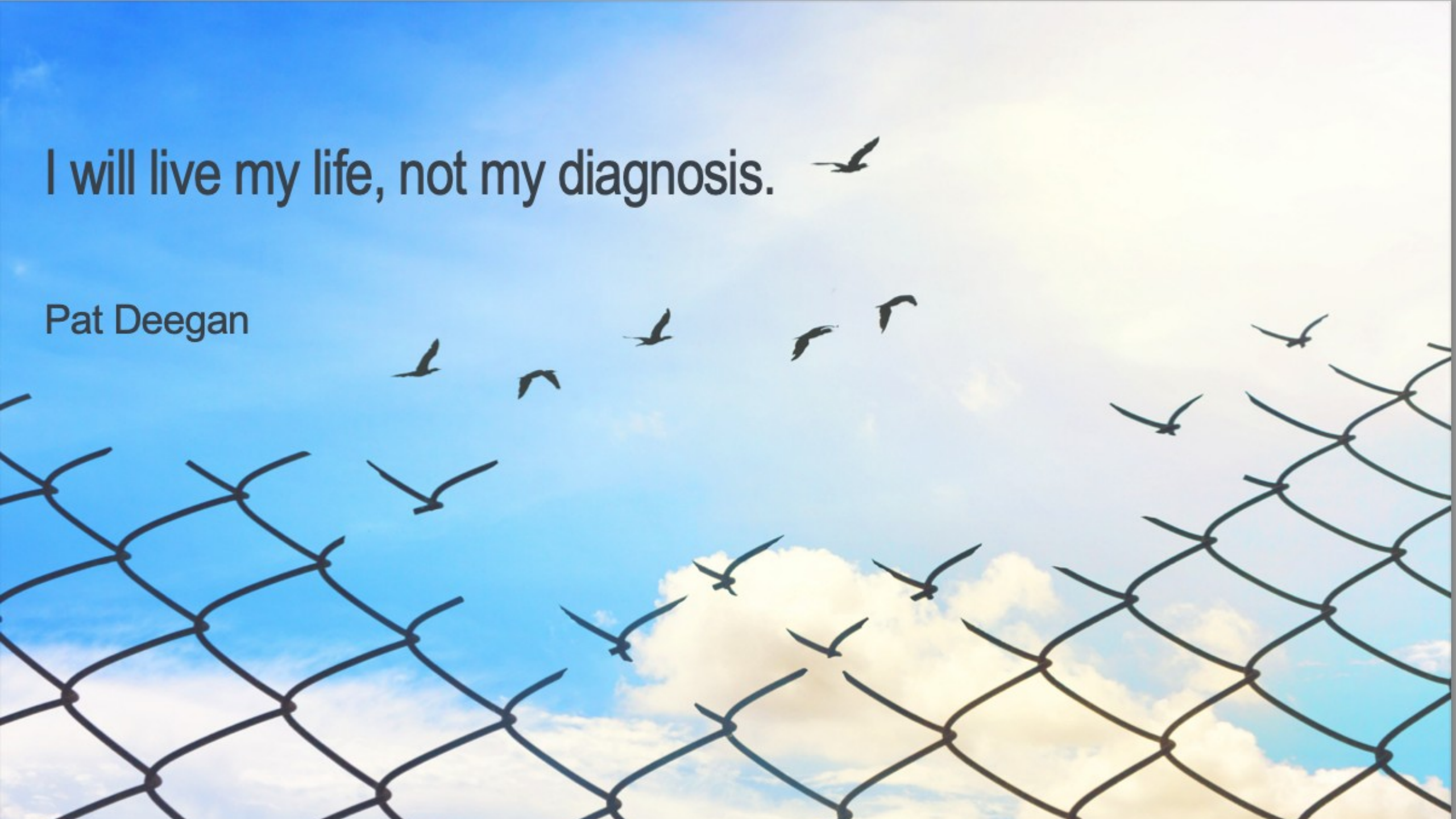
Illnesses do not recover

People do.

Pat Deegan

I will live my life, not my diagnosis.

Pat Deegan





## Soy una persona, no una enfermedad

Nuestro diagnóstico no nos define. Nuestro desafío de salud mental es solo un aspecto de quiénes somos.

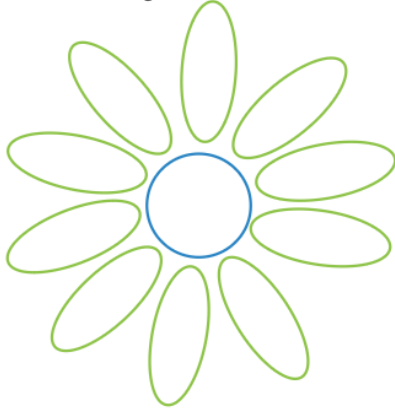
**Paso 1:** Pon tu nombre en el centro de cada flor. En esta hoja de trabajo, tendrás la oportunidad de explorarlo a USTED antes y después de que le diagnostiquen un problema de salud mental. Deja que la flor sea un símbolo tuyo.

**Paso 2:** Complete los aspectos importantes sobre quién era usted como persona ANTES del diagnóstico. Puede incluir ejemplos de sus talentos, intereses, espiritualidad, familia, cultura, esperanzas y sueños, etc.

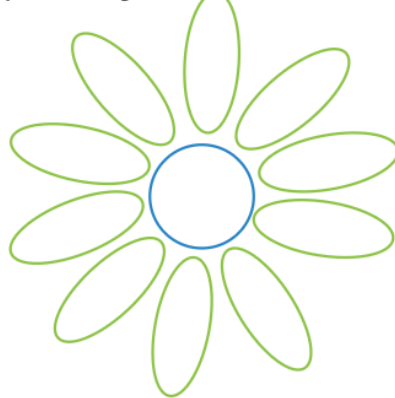
**Paso 3:** ¿Qué ha cambiado en ti desde el diagnóstico? ¿Hay cosas nuevas que quieras agregar a tus pétalos? ¿Hay pétalos que ya no pertenecen después del diagnóstico?

**Paso 4:** Eche un vistazo a lo que cambió antes y después del diagnóstico para crear su historia de flores.

### Yo antes del diagnóstico



### Yo después del diagnóstico



### Mi historia de flores

#### Resuma lo que es igual y lo que es diferente ahora que tiene un diagnóstico de salud mental

*Ejemplo: solía pensar que era invencible y que solo las personas débiles tenían problemas. Ahora soy más compasivo. Incluso estoy pensando en conseguir un trabajo para ayudar a otras personas que experimentan desafíos como yo.*

### Mi plan para usar Mi historia de flores

**Voy a:** (marque todo lo que corresponda)

- Compartir mi historia de flores con \_\_\_\_\_
- Tomar una foto de mis flores y guárdelas en mi teléfono para recordarme lo lejos que he llegado.
- Recortar mi historia de flores y publíquela en un lugar destacado para recordarme lo que he logrado.
- Crear mi propio arte, música o video para expresar y celebrar quién soy hoy.
- Mirar mi tarjeta y recuerde mi valor si me encuentro con el estigma.
- Otro: \_\_\_\_\_



## I Am a Person, Not an Illness

Our diagnosis does not define us. Our mental health challenge is just one aspect of who we are.

In this worksheet, you will have a chance to explore YOU before, and after, being diagnosed with a mental health challenge. Let the flower be a symbol of you.

**Step 1:** Put your name in the center of each flower.

**Step 2:** Fill in the important things about who you were as a person BEFORE diagnosis. You might include examples of your talents, interests, spirituality, family, culture, your hopes and dreams, etc.

**Step 3:** What, if anything, has changed about you since diagnosis? Are there new things you want to add to your petals? Are there petals that no longer belong after diagnosis?

### Me Before Diagnosis



### Me After Diagnosis



### My Flower Story

#### Summarize what's the same and what's different now that you have a mental health diagnosis

*Example: I used to think I was invincible and that only weak people had problems. Now I am more compassionate. I'm even thinking about getting a job helping other people who experience challenges like I do.*

### My Plan for Using My Flower Story

**I will** (check all that apply)

- Share my flower story with \_\_\_\_\_.
- Take a photo of my flowers and store them on my phone to remind me of how far I have come.
- Cut out my flower story and post it in a prominent place to remind me of what I have accomplished.
- Create my own art, music or video to express and celebrate who I am today.
- Look at my card and remember my worth if I encounter stigma.
- Other: \_\_\_\_\_

# Will I ever get my son back?

The good news is your son never left. He is still here. All of the gifts and values you helped him develop are still with him. He will draw on those strengths, and discover new gifts, as he makes his journey of recovery.



My dreams are the stars that guide  
my journey of recovery.

I will trust my dreams to lead me.

Pat Deegan



# Why CSC Matters

## HOPE In Numbers

### Suicidal Ideation

67% ↓

Decreased from 27% to 9% between program initiation and 12-month follow up

### Employment or School Enrollment

63% ↑

Increased from 43% to 70% between program initiation and 12-month follow up

### Inpatient Hospitalizations

86% ↓

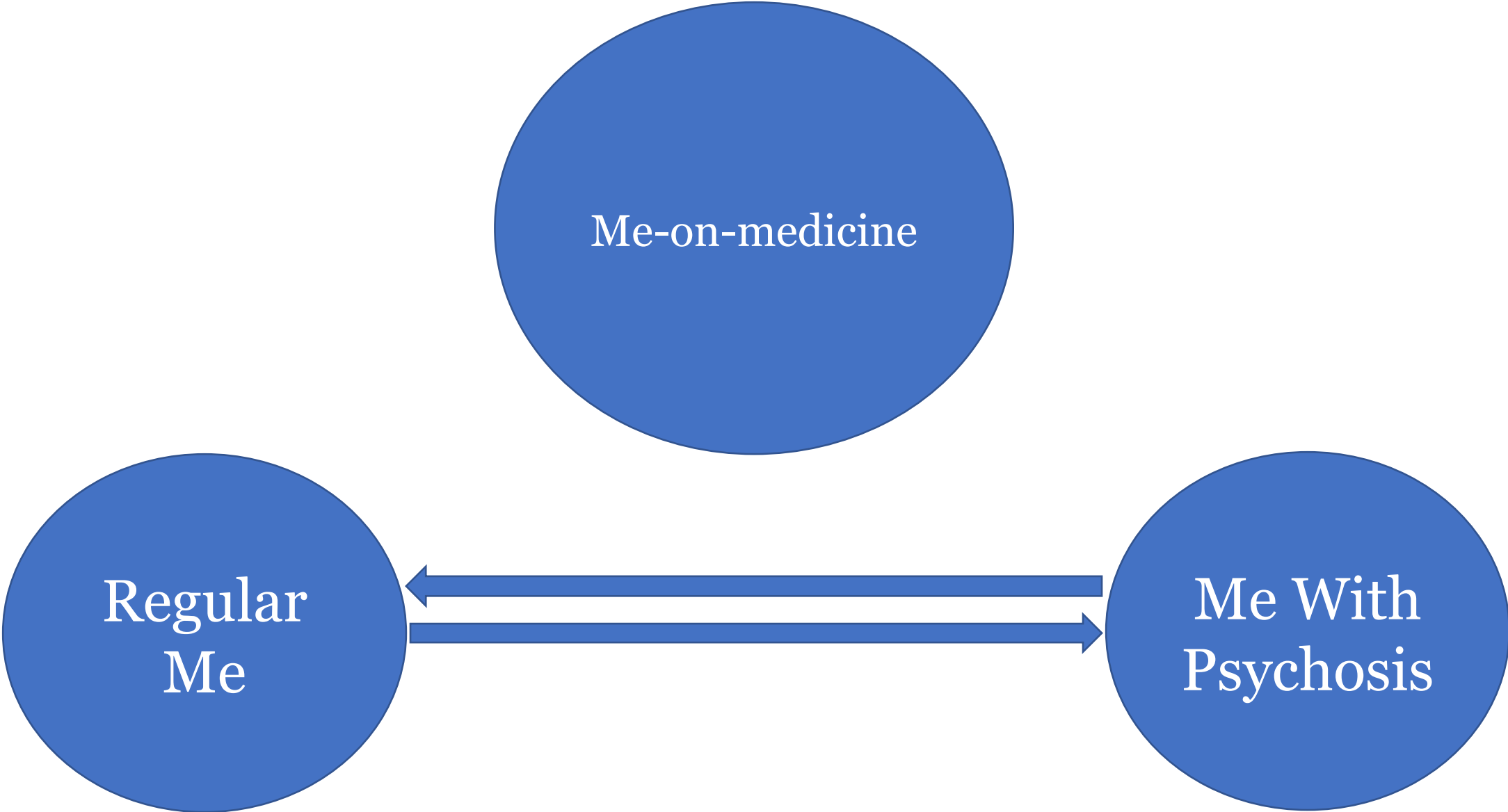
Decreased from 74% to 10% between program initiation and 12-month follow up

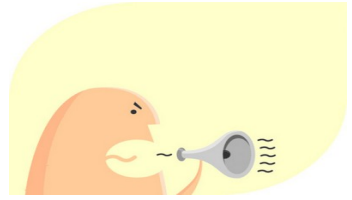


# Story 2

## Psychiatric Meds

# Meds have changed me





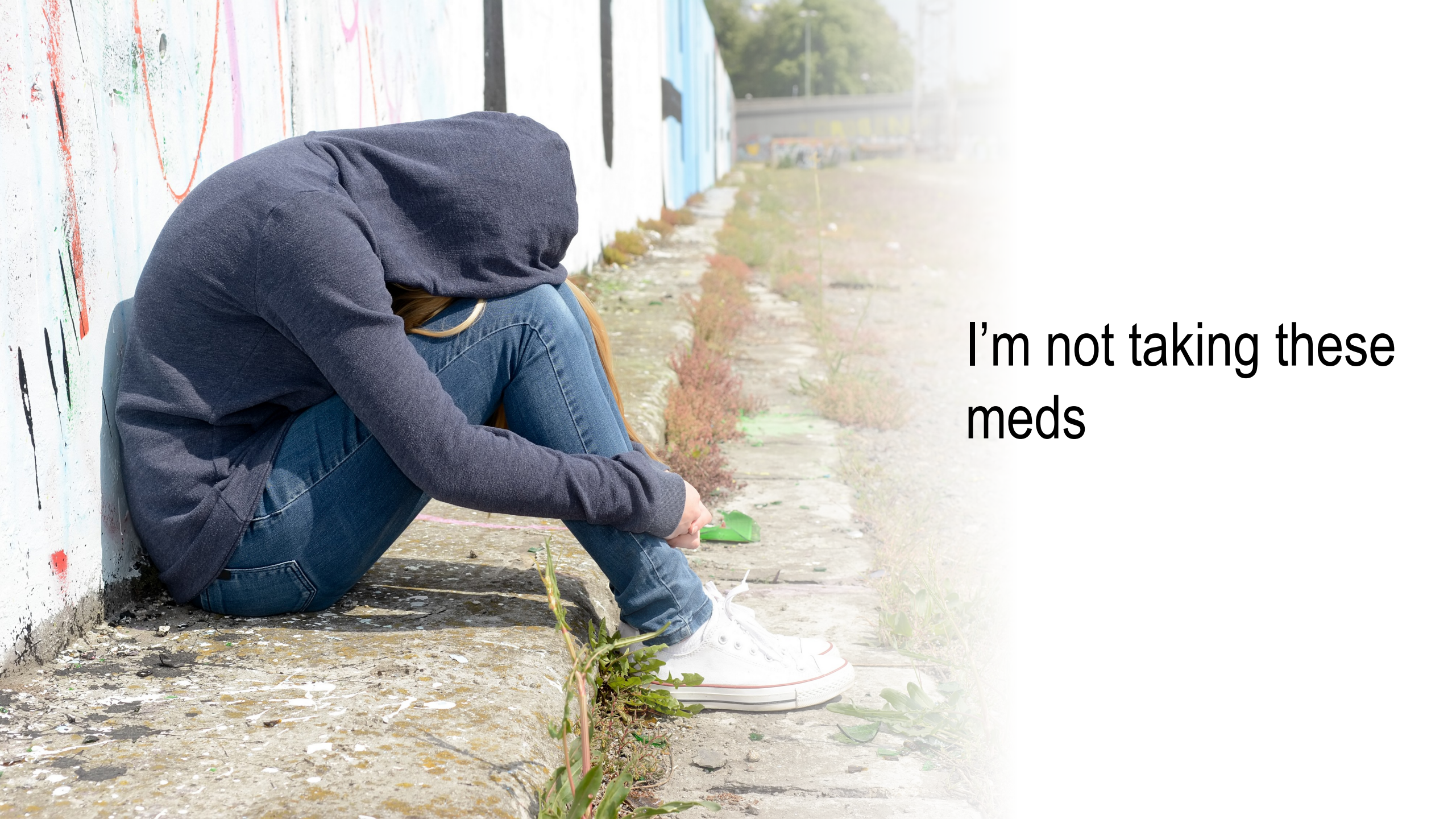
# Me

- I feel sedated
- I still hear distressing voices
- I can't think clearly
- I feel like the meds are controlling me
- I'm not myself anymore

# My Team



- You are not psychotic
- You are not shouting at your voices anymore
- You are less thought disordered
- You are more in control
- You have returned to baseline



I'm not taking these  
meds



It's easy to go off  
MH meds

The hard part is  
coming off meds  
and staying well



### My Power Statement

We will achieve our goals much more quickly if the doctor is paddling in the same direction we are. For that to happen, we both have to agree on where we are heading. A two step Power Statement will help us tell the doctor what our goal for medication treatment is.

Create your Power Statement using these two steps:

**Step 1:** I want to work together to find a medicine that will \_\_\_\_\_

**Step 2:** so that I can \_\_\_\_\_.

Here are some examples of Power Statements:

- ▶ I want to work together to find a medicine that will *improve my concentration* so that I can *focus on my job at the pizza shop*.
- ▶ I want to work together to find a medicine to *help me manage my anger* so that I can *get along better with my family*.
- ▶ I want to work together to find a medicine that will *help me improve my sleep* so that I can *get up on time for school*.

Power Statement	My Power Statement Plan
I want to work together to find a medicine that will:	I will share my Power Statement with:
so that I can:	My next steps:



### Mi Power Statement

Alcanzaremos nuestros objetivos mucho más rápido si el médico rema en la misma dirección que nosotros. Para que eso suceda, ambos tenemos que ponernos de acuerdo sobre hacia dónde nos dirigimos. Una declaración de poder de dos pasos nos ayudará a decirle al médico cuál es nuestro objetivo para el tratamiento con medicamentos.

Cree su Power Statement siguiendo estos dos pasos:

**Paso 1:** Quiero trabajar juntos para encontrar un medicamento que \_\_\_\_\_

**Paso 2:** así que yo puedo \_\_\_\_\_.

A continuación, se muestran algunos ejemplos de Power Statements:

- ▶ Quiero trabajar juntos para encontrar un medicamento *que mejore mi concentración* para poder *concentrarme en mi trabajo en la pizzería*.
- ▶ Quiero trabajar juntos para encontrar un medicamento *que me ayude a controlar mi enojo* para poder *llevarme mejor con mi familia*.
- ▶ Quiero trabajar juntos para encontrar un medicamento *que me ayude a mejorar mi sueño* para poder *levantarme a tiempo para la escuela*.

Power Statement	Mi Plan de Power Statement
Quiero trabajar juntos para encontrar un medicamento que:	Compartiré mi Power Statement con:
así que yo puedo:	Mis próximos pasos:



I want to work together to find a medicine that will:

Help me ignore my voices so that I can...

so that I can:

Focus on my English course at school



I will share my Power Statement with:

My psychiatrist

fold  
p104  
My next steps:

I will put this on my phone and read it to my psychiatrist at my next appt.

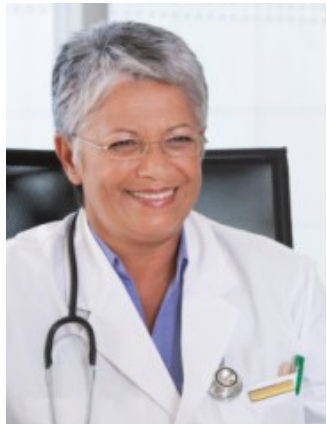




# The Power of Power Statements



Our shared understanding of the goal of my treatment



# My Power Statement

I want you to help me find a medicine that will help my voices quiet down so that I can pay attention to my boy when I have him on weekends



# The Power of Power Statements



Our shared understanding of the goal of my treatment





Nancy





I want to work together to find a medicine that will:

Help me have energy  
and motivation to  
focus on my  
responsibilities so that  
I can...  
so that I can:

Be a good mom,  
breast feed my baby  
and raise her to  
succeed in life



I will share my Power Statement with:

My nurse and my  
therapist

fold  
p109  
My next steps:

I will ask my therapist to  
come with me when I show  
this to my nurse

# The Power of Power Statements



Our shared understanding of the goal of my treatment



From what's-the-matter

To what-matters-to-me



## Enhancing Clients' Communication Regarding Goals for Using Psychiatric Medications

Patricia E. Deegan, Ph.D., Elizabeth Carpenter-Song, Ph.D., Robert E. Drake, M.D., Ph.D., John A. Naslund, M.P.H., Alison Luciano, M.P.H., Ph.D., Shari L. Hutchison, M.S., P.M.P.

**Objective:** Discordance between psychiatric care providers' and clients' goals for medication treatment is prevalent and is a barrier to person-centered care. Power statements—short self-advocacy statements prepared by clients in response to a two-part template—offer a novel approach to help clients clarify and communicate their personal goals for using psychiatric medications. This study described the power statement method and examined a sample of power statements to understand clients' goals for medication treatment.

**Methods:** More than 17,000 adults with serious mental illness at 69 public mental health clinics had the option to develop power statements by using a Web application located in the clinic waiting areas. A database query determined the percentage of clients who entered power statements into the Web application. The authors examined textual data from a random sample of 300 power statements by using content analysis.

**Results:** Nearly 14,000 (79%) clients developed power statements. Of the 277 statements in the sample deemed appropriate for content analysis, 272 statements had responses to the first part of the template and 230 had responses to the second part. Clients wanted psychiatric medications to help control symptoms in the service of improving functioning. Common goals for taking psychiatric medications (N=230 statements) were to enhance relationships (51%), well-being (32%), self-sufficiency (23%), employment (19%), hobbies (15%), and self-improvement (10%).

**Conclusions:** People with serious mental illness typically viewed medications as a means to pursue meaningful life goals. Power statements appear to be a simple and scalable technique to enhance clients' communication of their goals for psychiatric medication treatment.

*Psychiatric Services 2017; 68:771–775; doi: 10.1176/appi.ps.201600418*

Deegan, et al. *Psychiatric Services* 2017

- 17,000 people dx SMI
- 69 public MH Clinics in US
- Peer support prior to med management visits
- 79% created Power Statements to communicate their goal for using psychiatric medicine
- Power Statements are:
  - Efficient
  - Scalable



# Why CSC Matters

- ✓ Protected time for psychiatric care providers to work as members of an interdisciplinary team
- ✓ Individual voice and choice at the center of the care team
- ✓ Shared decision making

## Story 3

Patricia, would you like to go food shopping?





# Why CSC Matters

- ✓ Families are members of the team



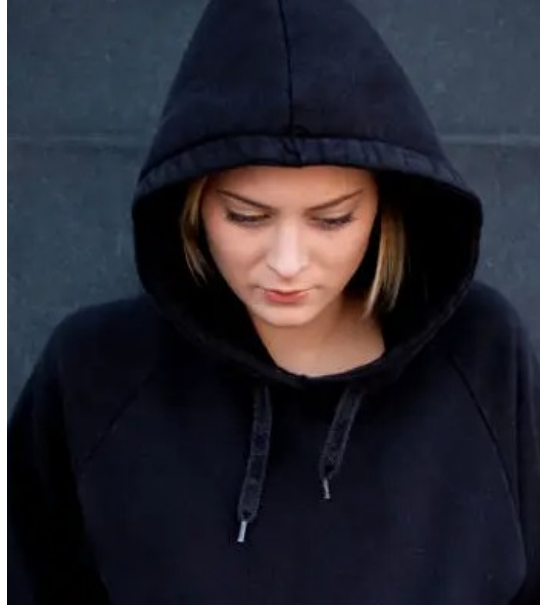
Story 4  
Stumbling  
into self-care

# Waiting to get "cured" was a trap leading away from recovery

I have a biochemical brain imbalance that needs to be balanced...

So I go back to my psychiatrist who tweaks my medication because...

So every month I go to a psychiatrist who prescribes meds to balance my brain biochemistry...



But the meds don't restore me...

Then I go home and wait for my biochemistry to get balanced...

# Cascading Effect of Personal Medicine & Psych Meds

Sony Walkman to manage distressing voices...



...Lower antipsychotics = more energy



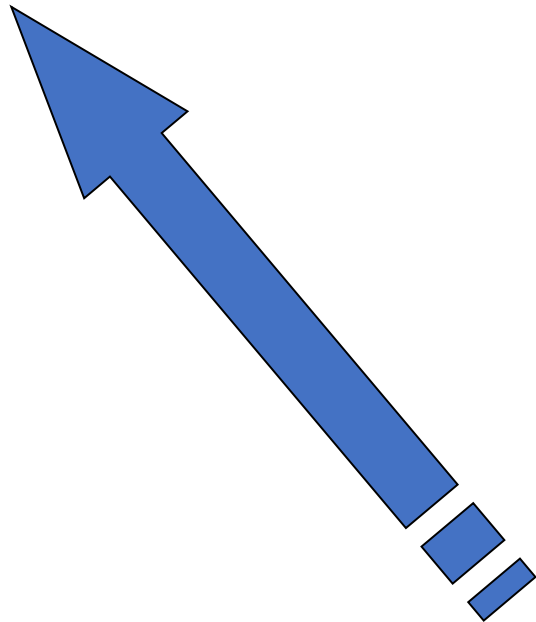
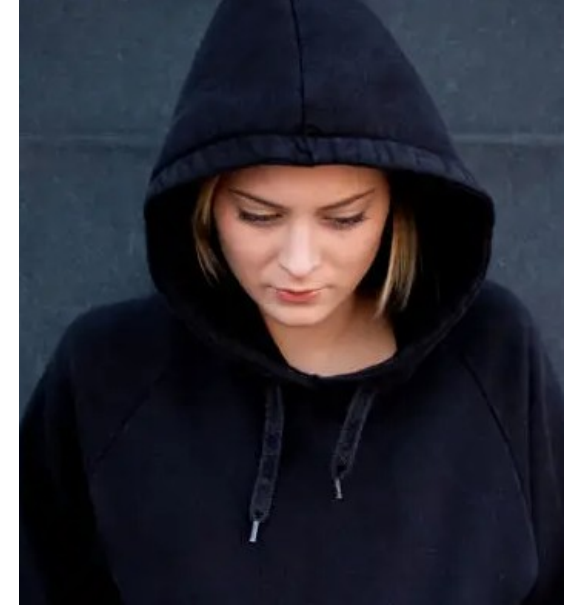
More energy = able to exercise...



...Able to meditate & pray



...More grounded in self...

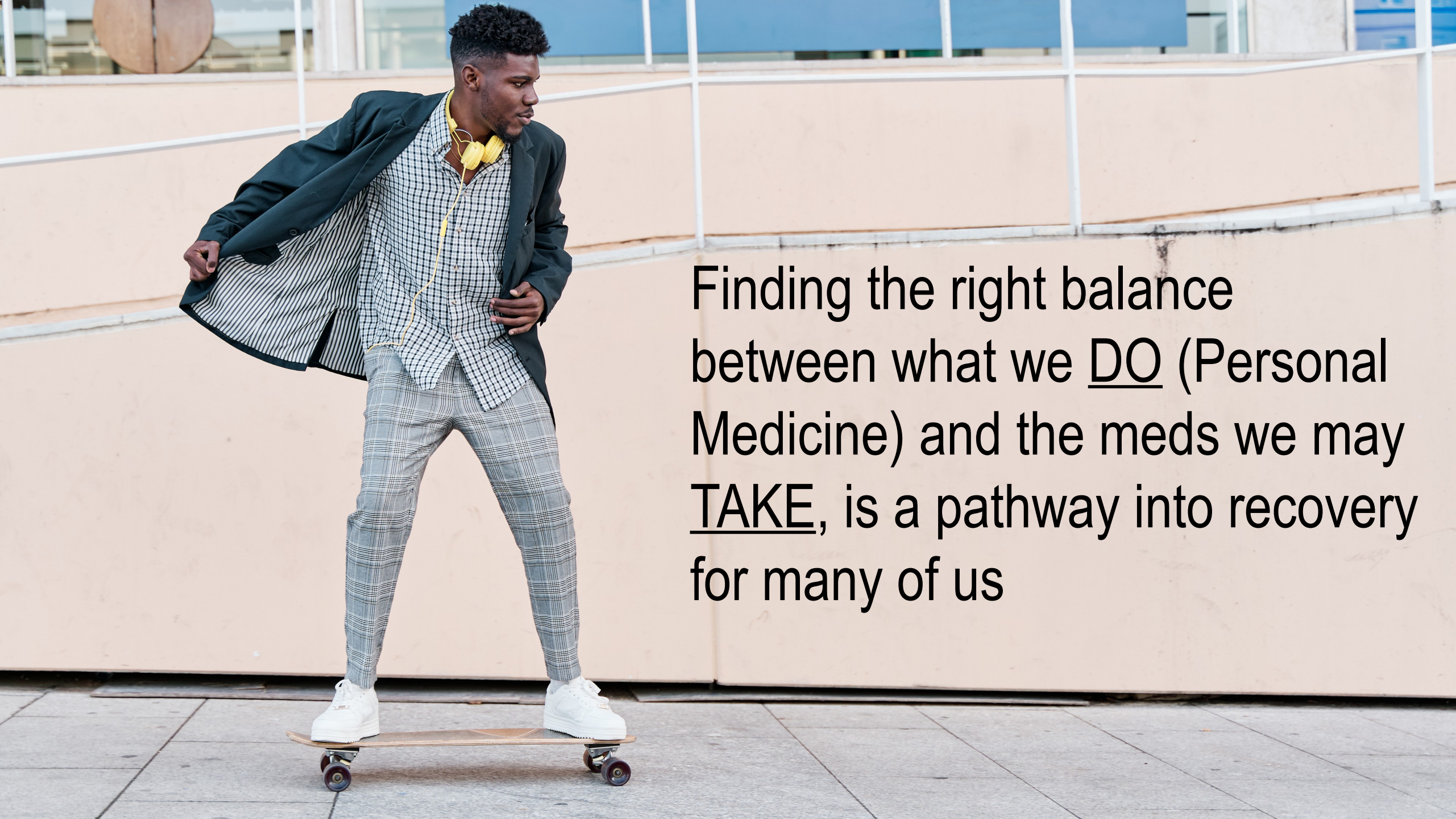


# Personal Medicine

The things we do that put a smile on our face and bring joy and meaning to our lives.

The smaller things we do that help us manage symptoms/distress





Finding the right balance between what we DO (Personal Medicine) and the meds we may TAKE, is a pathway into recovery for many of us



# Personal Medicine Workshee

What do you do to feel  
read holy  
better scripture and how  
does it help?

when I'm anxious, it helps me  
know that God is with me

---



Just like a cast can't heal a broken leg, psychiatric meds can't do all the work of getting us through mental health challenges. Meds can help us achieve our goals, but we have to get active too.

Ask yourself: What do I do to feel better \_\_\_\_\_ and how does it help \_\_\_\_\_.

Here are some examples:

- ▶ What I do to feel better *is read spiritual teachings* and it helps *bring me peace so I feel less anxious.*
- ▶ What I do to feel better *is weed my vegetable garden* and it *gets my mind off my troubles.*
- ▶ What I do to feel better *is look at photos of my friends* and it *reminds me I'm loved when I'm feeling bad about myself.*

All of these are examples of Personal Medicine. Personal Medicine is what we DO. Psychiatric medicine is what we TAKE. They work together to help us through our mental health challenges.

Now it's your turn to discover your Personal Medicine and to make a plan for using it.

My Personal Medicine	My Personal Medicine Plan
<p>What I do to feel better:</p>          <p>how it helps me:</p>	<p>I will use this Personal Medicine when:</p>          <p>I will share my Personal Medicine with:</p>

My Personal Medicine © 2020 Pat Deegan PhD & Associates, LLC My Personal Medicine © 2020 Pat Deegan PhD & Associates, LLC



# Personal Medicine “hidden” within a CSC

## intake note

Upon our evaluation, Cindy reported onset of paranoid thoughts a few weeks prior to the end of her spring semester. Very afraid her computer and accounts had been hacked as retaliation for religious beliefs. Cindy reports paranoid beliefs related to celebrity figures as well and believes a chip has been implanted in her teeth via the milk she drank in high school. She endorses thought broadcasting and thought insertion by “billionaires”. Following hospitalization, she notes that residual paranoid thoughts continue but reported “I fight against them”. She indicates having challenges with sleeping...

# Why CSC Matters

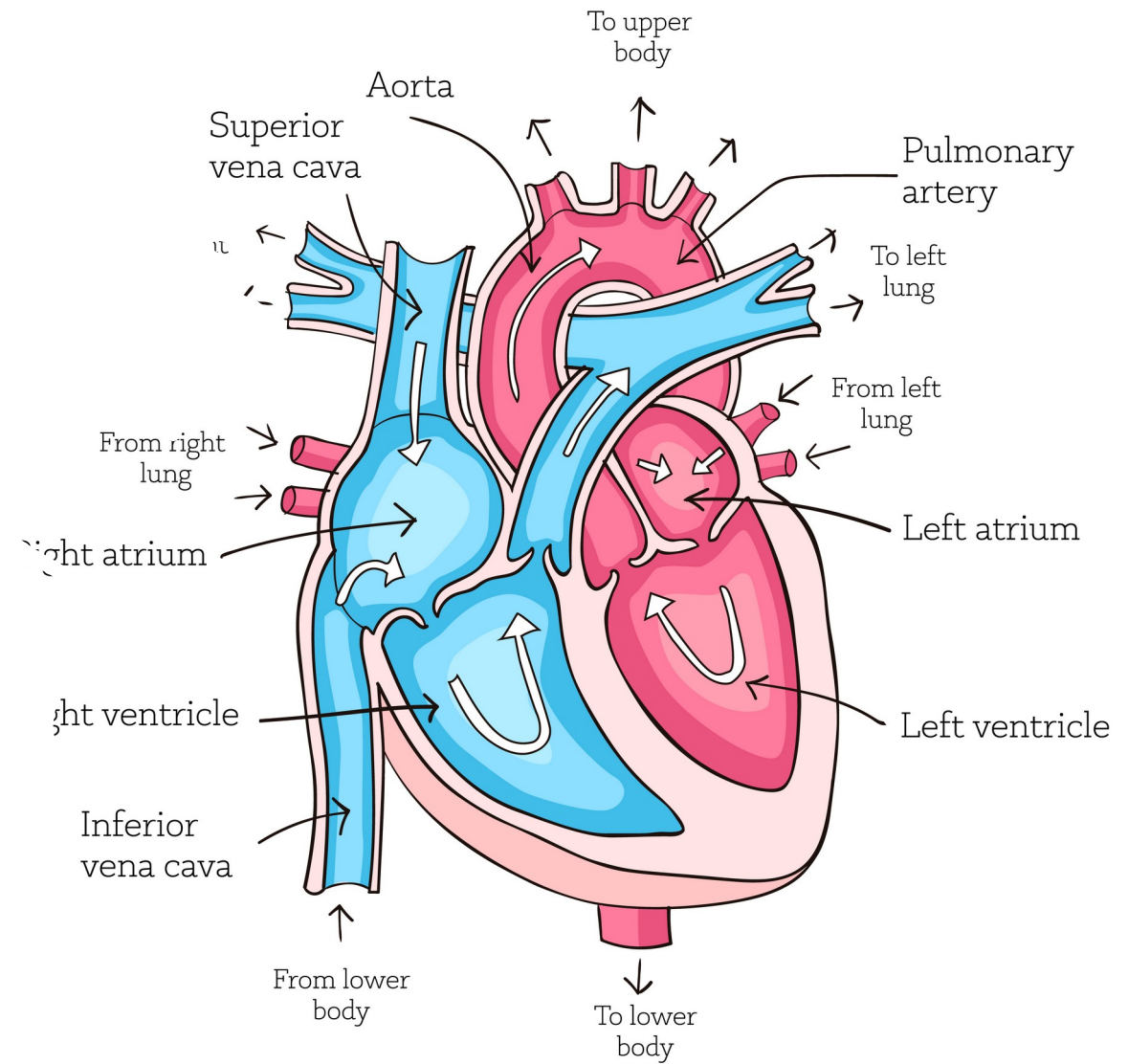
- ✓ Multidisciplinary teams
  - ✓ CBTp
  - ✓ Harm reduction
  - ✓ Motivational interviewing
  - ✓ Supported employment
  - ✓ Supported education
  - ✓ Psychiatry
  - ✓ Wellness nursing
  - ✓ Peer support



Certified peer specialists are professionals who use their lived experience of recovery to support others in reaching their goals for their lives



Science says:  
The heart is a  
bio-mechanical pump

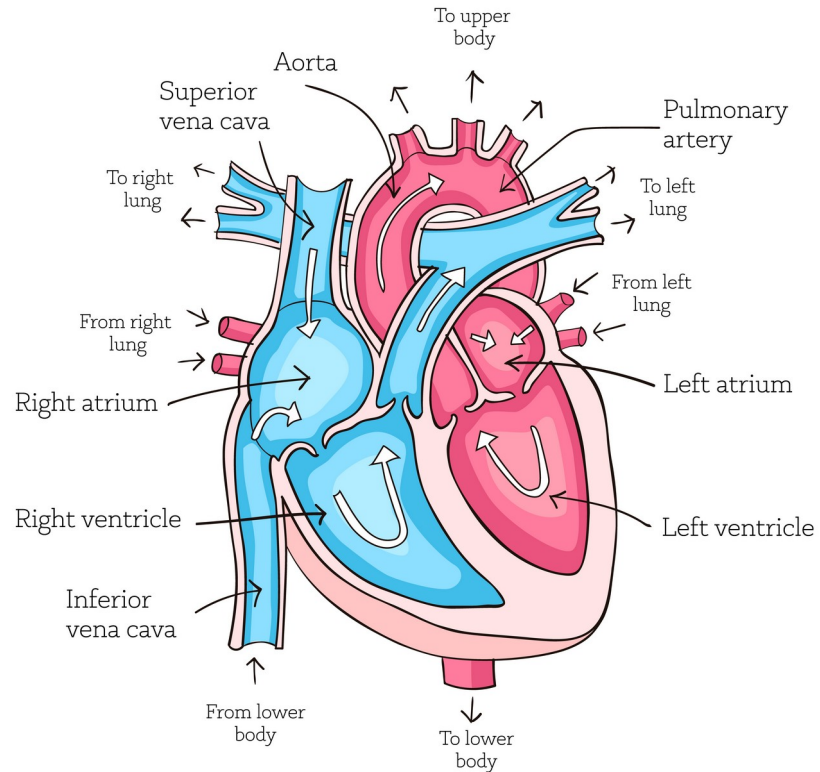


THE HUMAN HEART

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



# Two Ways of Knowing



THE HUMAN HEART



Knowing through science

Knowing through lived experience

Clinicians, informed by science say:  
Auditory hallucinations are often a symptom of mental illness



Brain scan of a person having auditory hallucinations

What is hearing voices before science tells us it is a symptom of mental illness?

*Some of my voices are really helpful and remind me God made me and God doesn't make junk*



# Two Ways of Knowing



Knowing through the  
scientific clinical applied  
sciences



Knowing through lived experience



# Myra

- Works solo and has kept job for a couple of years
- 2 previous hospitalizations
- DX alcohol abuse; unspecified psychosis
- Experiences meds as helpful but can be inconsistent w/ oral; willing to discuss LAI
- Fears for her life; strangers want to get her; sleep deprived
- Good, consistent connection w/ primary clinician; exploring sexual orientation
- Shares she is considering buying a knife to protect herself and recommends therapist get one too



# Clinical

- Safety planning – (concern about knife)
- SDM for long acting injectable
- Harm reduction approach for substance use
- CBTp
- Financial security
- Explore daytime jobs to help improve sleep

# Lived Experience

I grew up queer and often felt people staring at me, trying to figure out my gender. That got tangled up in my experience of psychosis. The threat was real. People were staring at me and in our society, there is terrible violence against non-binary folks like me. I started to explore how to defend myself. I decided not to get a knife because it is illegal to carry one. I settled on pepper spray, and I took self defense classes. Myra might be interested in exploring how she can safely defend herself too.

## Story 5

I want to go back  
to who I used to be

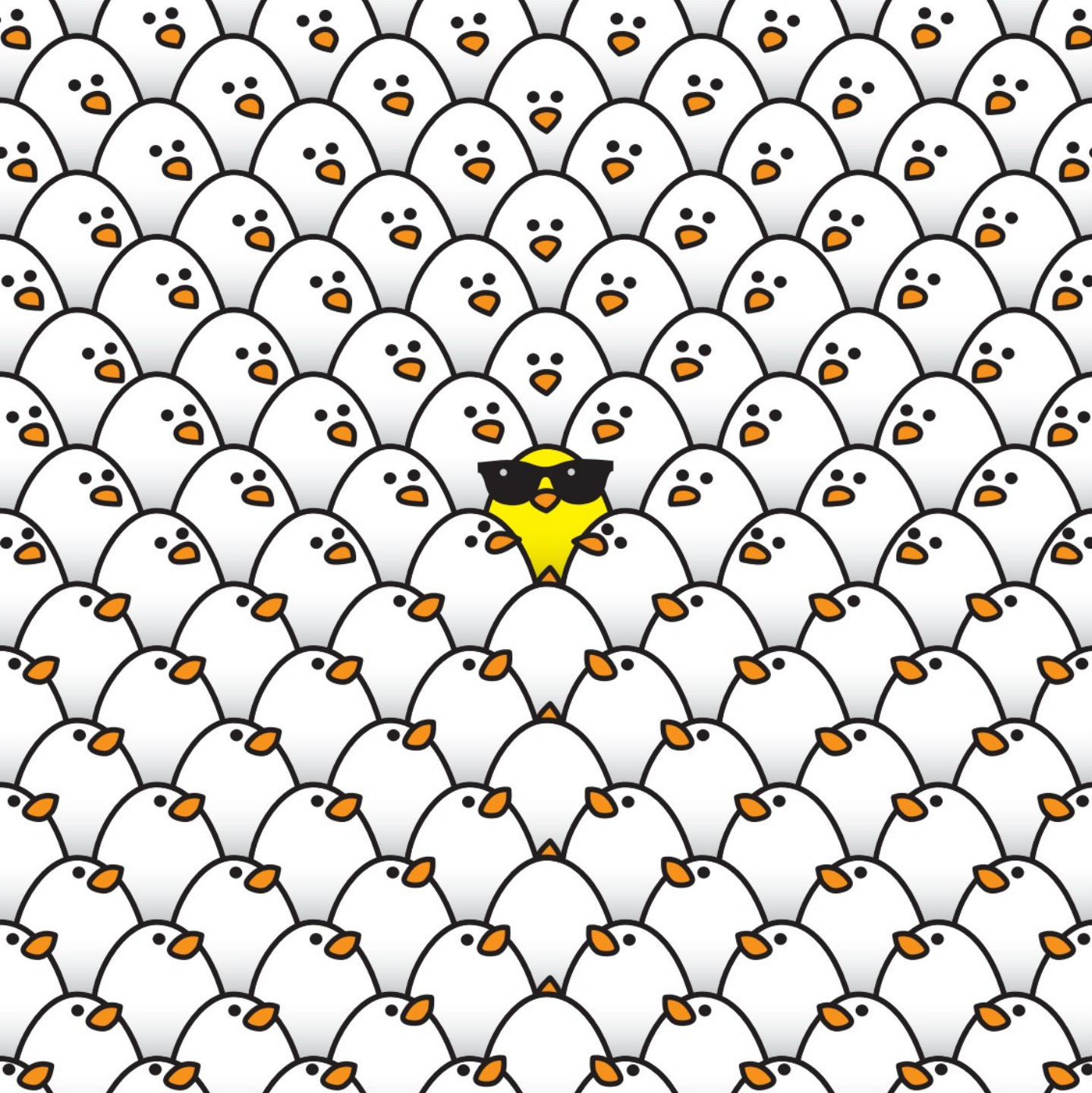


**Recovery is not a story of going  
back to who I used to be.**



**It's a story of becoming  
something new.**

Pat Deegan



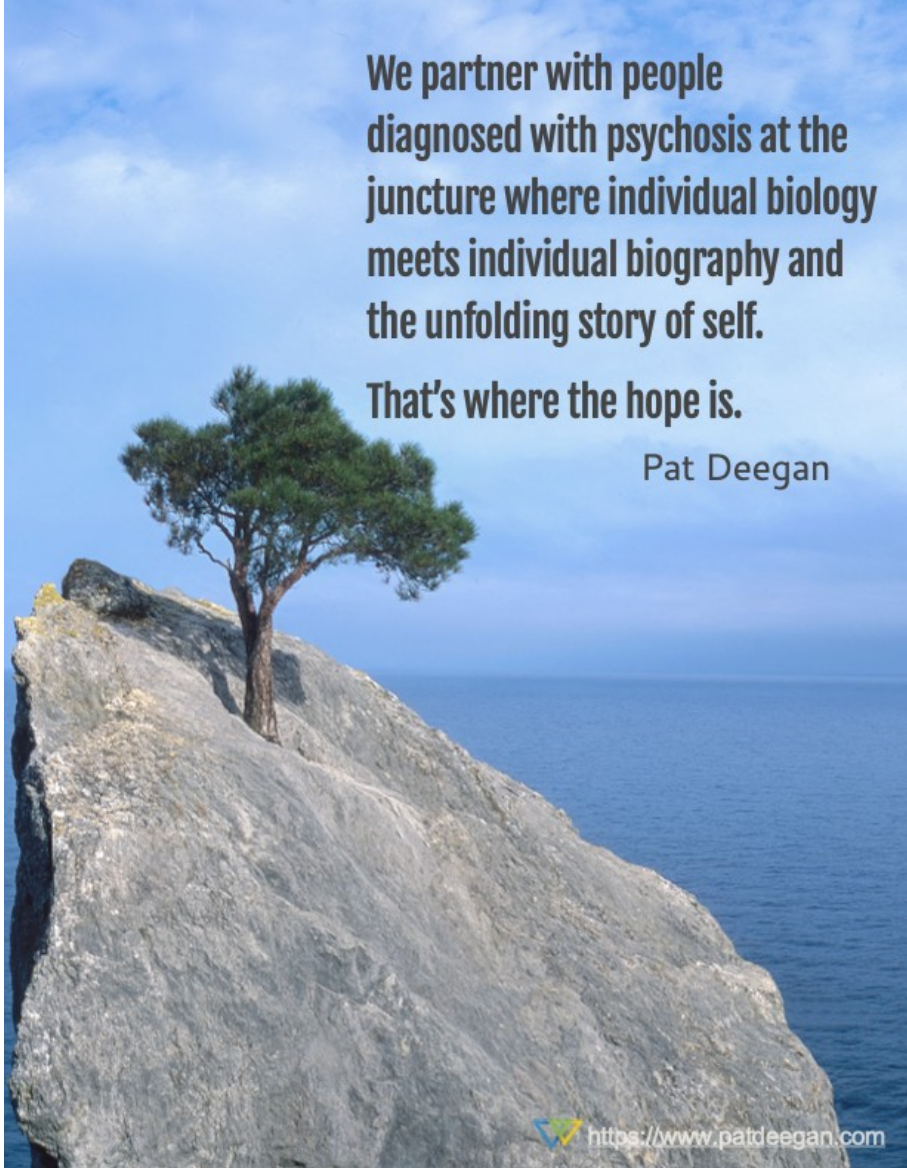
The goal of recovery  
is not to become  
normal.

The goal of recovery  
is to become the  
unique, never to be  
repeated gift that we  
are.

Pat Deegan



Recovery is Real

A photograph of a lone tree growing on a rocky cliff overlooking the ocean under a blue sky. The tree is a small, dark green conifer with a thin trunk, standing on a large, grey, textured rock formation. The ocean is a deep blue, and the sky is a lighter blue with some wispy clouds. The text is overlaid on the right side of the image.

**We partner with people  
diagnosed with psychosis at the  
juncture where individual biology  
meets individual biography and  
the unfolding story of self.**

**That's where the hope is.**

Pat Deegan

# Join our conspiracy of hope



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