



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

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September 30, 2024
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Vermont Coordinated Specialty Care Conference
Hotel Champlain, Burlington, VT
September 30, 2024
Workshop #: 1 of 7 I Am a Person, Not an Illness: Why CSC Matters
Planners: Vermont Department of Mental Health Staff
Speaker: Patricia Deegan, PhD


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In support of improving patient care, this activity has been planned and implemented by The Robert Larner College of Medicine at the University of Vermont which is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME) and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

The University of Vermont designates this live activity for a maximum of 5.5 AMA PRA Category 1 Credit(s)[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This program has been reviewed and is acceptable for up to 5.5 Nursing Contact Hours.

As a Jointly Accredited Organization, The Robert Larner College of Medicine at the University of Vermont is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. State and provincial regulatory boards have the final authority to determine whether an individual course may be accepted for continuing education credit. The University of Vermont maintains responsibility for this course. Social workers completing this course receive 5.5 ethics continuing education credits.

This activity was planned by and for the healthcare team, and learners will receive 5.5 Interprofessional Continuing Education (IPCE) credit for learning and change.

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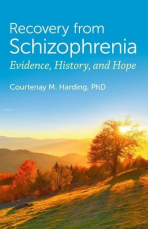



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"I don't believe a word she just said."
Professional colleague to Professor Harding, upon hearing recovery from schizophrenia data from Vermont longitudinal studies

The Maine and Vermont three-decade studies of serious mental illness. II. Longitudinal course comparisons

M DeSisto¹, C M Harding, R V McCormick, T Ashikaga, G W Brooks




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Why CSC Matters

The goal of CSC is to support individual recovery

Stabilization and maintenance is a low bar



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Story 1

I am a person,
not an illness

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Illnesses do not recover

People do.

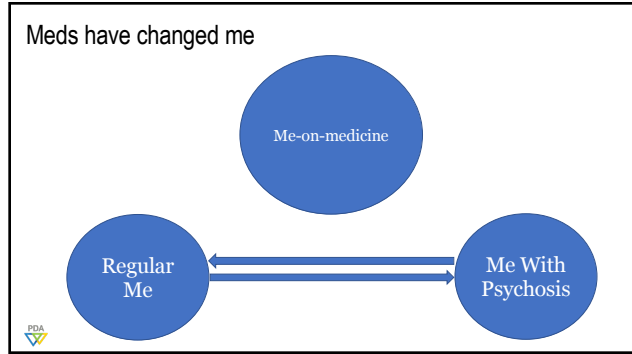
Pat Deegan



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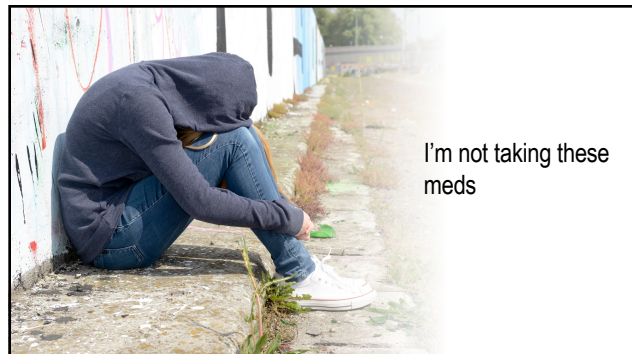
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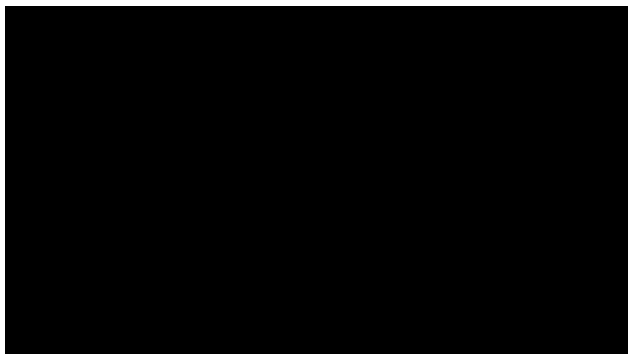
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Me	My Team
<ul style="list-style-type: none"> • I feel sedated • I still hear distressing voices • I can't think clearly • I feel like the meds are controlling me • I'm not myself anymore 	<ul style="list-style-type: none"> • You are not psychotic • You are not shouting at your voices anymore • You are less thought disordered • You are more in control • You have returned to baseline

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Power Statement	My Power Statement Plan
<p>I want to work together to find a medicine that will:</p> <p><i>Help me ignore my voices so that I can...</i></p>	<p>I will share my Power Statement with:</p> <p><i>My psychiatrist</i></p>
<p>so that I can:</p> <p><i>Focus on my English course at school</i></p>	<p>My next steps:</p> <p><i>I will put this on my phone and read it to my psychiatrist at my next appt.</i></p>

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The Power of Power Statements

Our shared understanding of the goal of my treatment

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Nancy

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Power Statement	My Power Statement Plan
<p>I want to work together to find a medicine that will:</p> <p><i>Help me have energy and motivation to focus on my responsibilities so that I can...</i></p>	<p>I will share my Power Statement with:</p> <p><i>My nurse and my therapist</i></p>
<p>so that I can:</p> <p><i>Be a good mom, breast feed my baby and raise her to succeed in life</i></p>	<p>My next steps:</p> <p><i>I will ask my therapist to come with me when I show this to my nurse</i></p>

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The Power of Power Statements

Our shared understanding of the goal of my treatment

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From what's-the-matter To what-matters-to-me

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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

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Story 3
Patricia, would you like to go food shopping?



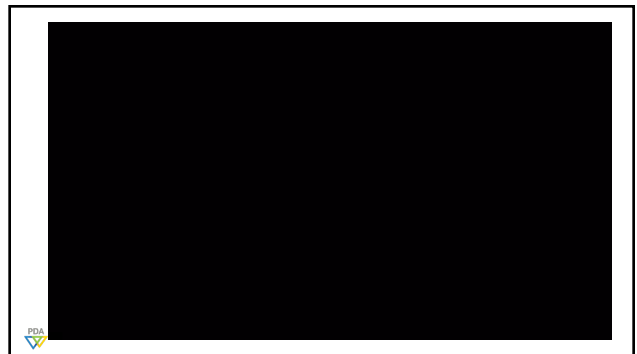
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Why CSC Matters

- ✓ Families are members of the team

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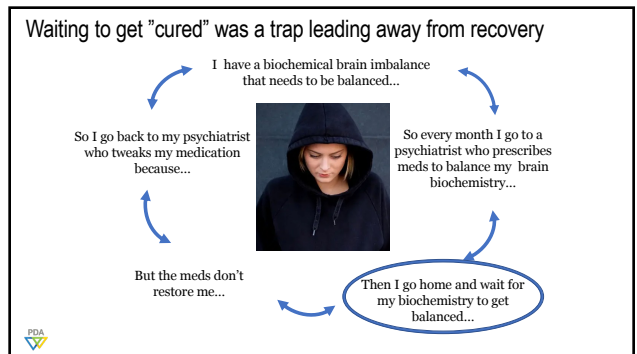
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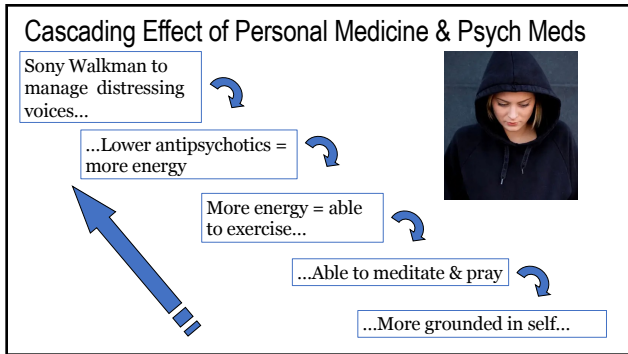
Story 4
Stumbling into self-care

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



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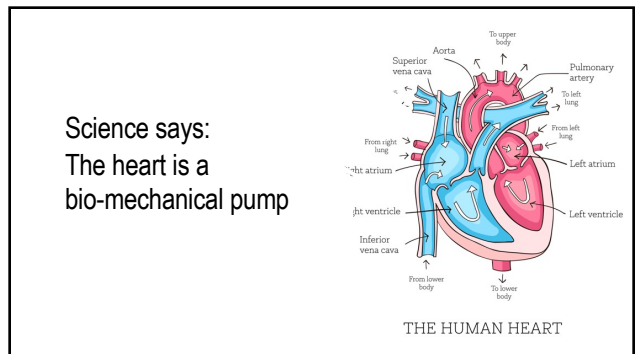
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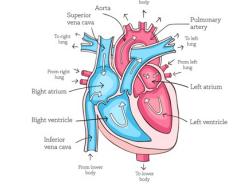
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What is the heart we know before science tells us the heart is a pump?




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Two Ways of Knowing



THE HUMAN HEART


Knowing through science



Knowing through lived experience

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



Brian scan of a person having auditory hallucinations

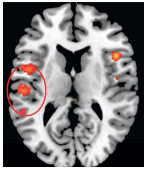
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What is hearing voices before science tells us it is a symptom of mental illness?

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Two Ways of Knowing



Knowing through the scientific clinical applied sciences




Knowing through lived experience

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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



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Clinical	Lived Experience
<ul style="list-style-type: none"> • Safety planning • SDM for long acting injectable • Harm reduction approach for substance use • CBTp • Financial security • Explore daytime jobs to help improve sleep 	<p>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 <u>were</u> 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.</p>

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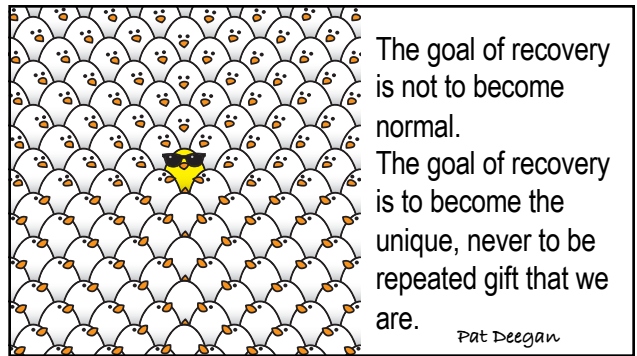


Story 5
I want to go back to who I used to be

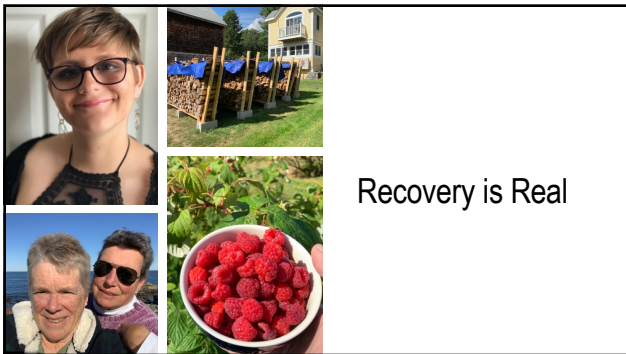
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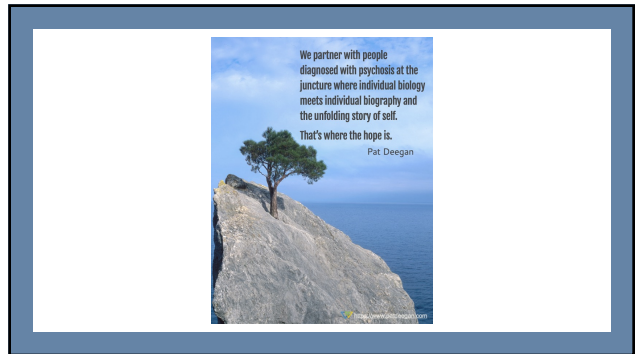
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Join our conspiracy of hope

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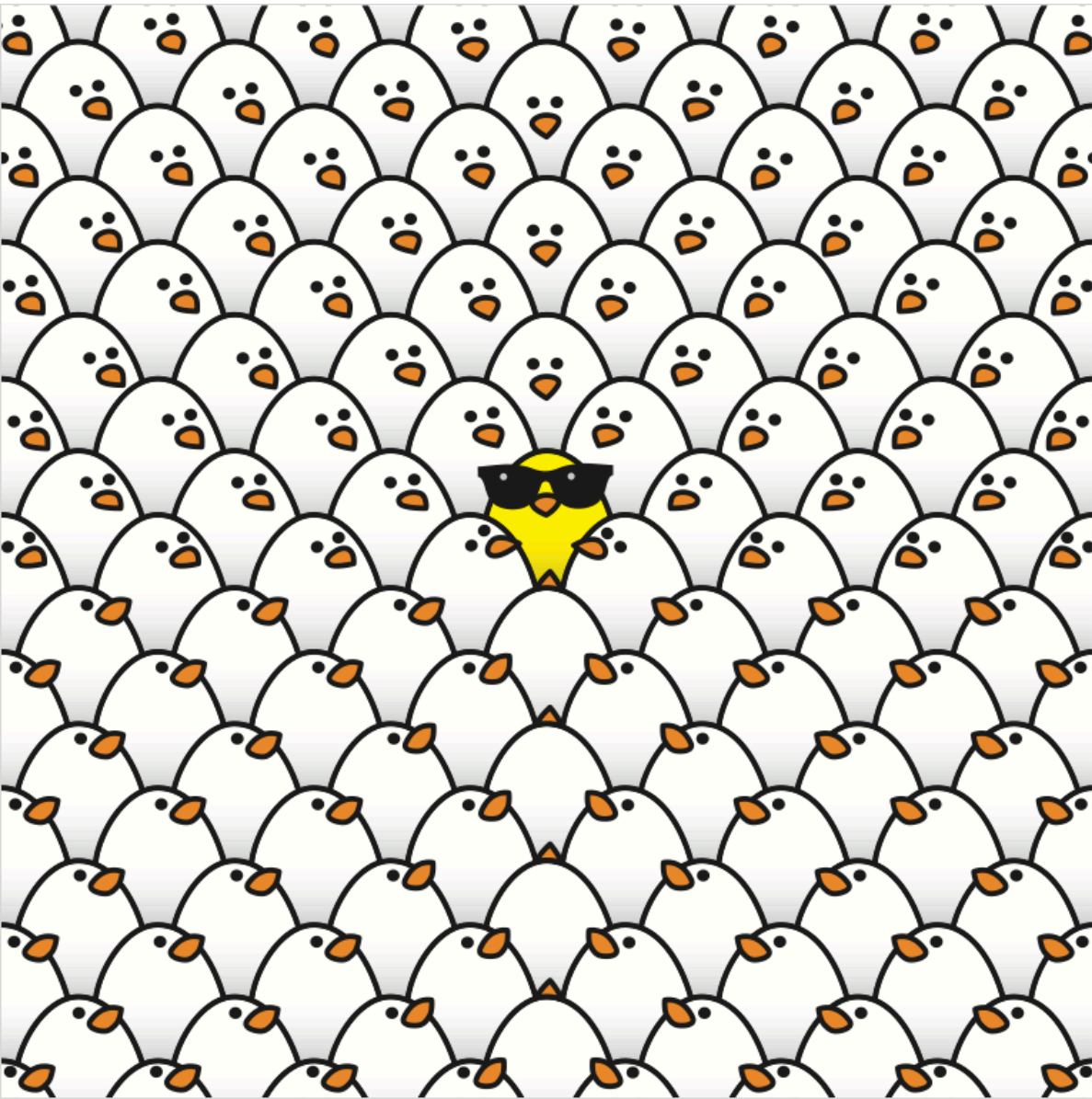


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I am a person,
not an illness

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



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

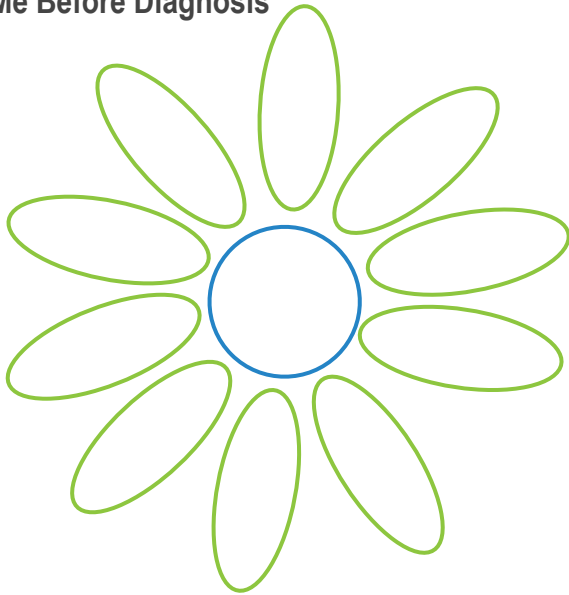
In this worksheet, you will have a chance to explore YOU before, and after, being diagnosed with a mental health challenge. Let the flower be a symbol of you.

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

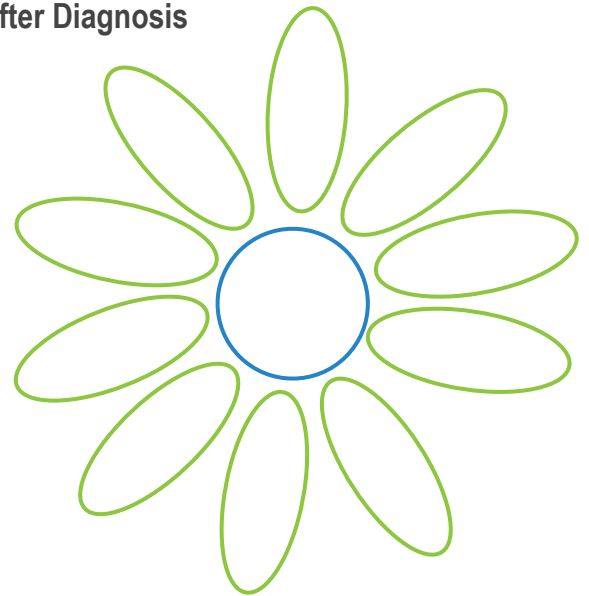
Step 2: Fill in the important things about who you were as a person BEFORE diagnosis. You might include examples of your talents, interests, spirituality, family, culture, your hopes and dreams, etc.

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: _____



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

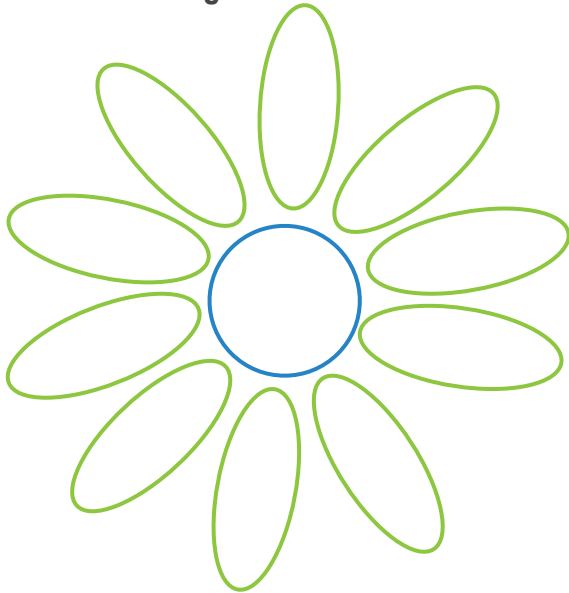
Paso 1: Pon tu nombre en el centro de cada flor. En esta hoja de trabajo, tendrá la oportunidad de explorarlo a USTED antes y después de que le diagnostiquen un problema de salud mental. Deja que la flor sea un símbolo tuyo.

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.

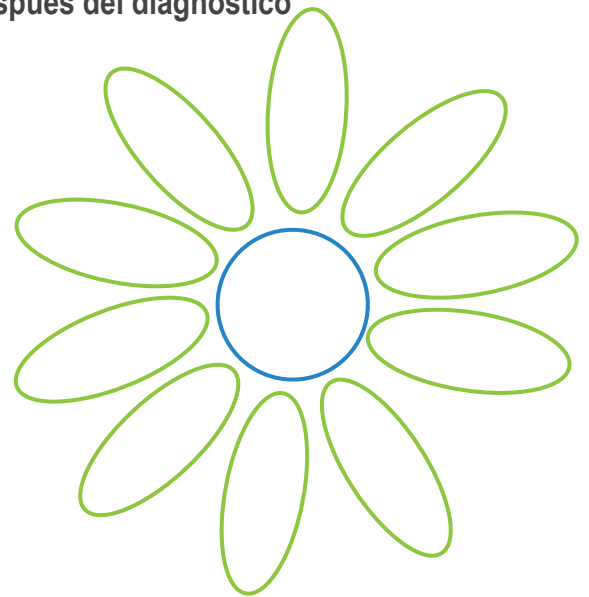
Paso 3: ¿Qué ha cambiado en ti desde el diagnóstico? ¿Hay cosas nuevas que quieras agregar a tus pétalos? ¿Hay pétalos que ya no pertenecen después del diagnóstico?

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: _____



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

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

so that I can:



My Power Statement Plan

I will share my Power Statement with:

fold
line

My next steps:



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

Quiero trabajar juntos para encontrar un medicamento que:

así que yo puedo:



Mi Plan de Power Statement

Compartiré mi Power Statement con:

Mis próximos pasos:

doblez
zebbop