



TEXAS

I'm back!

A Moment Reflection,
Gratitude and Love...

From **MY** heart to **YOURS**

....And an *invitation*



WHY Didn't I Know That?!?

Hard Lessons
(L)*earned*

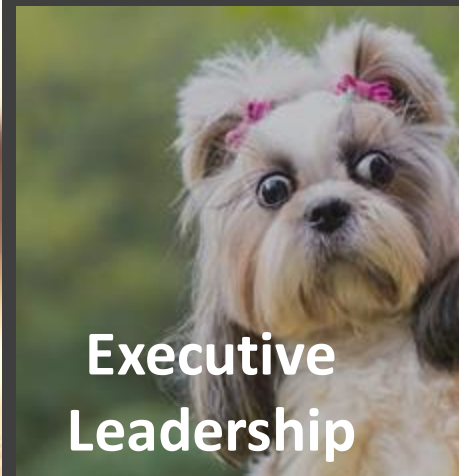
Cherene Caraco,
CEO of Promise Resource Network

Internship



**My first, second,
third job**

IM CONFUS



**Executive
Leadership**

This morning



**Policy &
System
Change**



32 years of professional roles....

Residential counselor
Case Manager
Program Manager
Director
Peer Support Specialist
“Behaviorist”
Grant writer
Policy and System Transformation
Consultant, Trainer, TA
Advisor
Keynoter
Parent (I/DD and MH)
Mental Patient
Current CEO

MH/SUD/IDD/Youth & Families/Unhoused..

In patient, residential, community based

24 states, 4 countries

A photograph of a forest with tall, thin trees and green foliage. A large, dark, semi-transparent circle is overlaid on the left side of the image. Inside this circle, the text "NEVER FORGET WHERE YOU COME FROM" is written in a white, hand-drawn, chalk-like font.

NEVER
FORGET
WHERE YOU
COME FROM

Three thick, purple, hand-drawn style arcs are positioned in the upper right corner of the slide, above the main title box.

My very first (L)earned lesson

**On Power, Hierarchy, and
the Art of Seduction**

i have
~~mental~~
~~health~~
problems
with
oppression
& stigma

“We must dare to talk about help because POWER, including the power to oppress, often disguises itself as help.

Power-disguised-as-help is used to silence [people with diagnoses] disabilities

Oppressive power submerges the consciousness of the oppressed into a culture of silence.”

Pat Deegan

Attention **Connection** ***Seeking***

#labelsareforclothes

(L)earning by *Un*learning



Mental illness is caused by a chemical brain imbalance

People Labeled with SMI can become stable and functional with medications and treatment but can't really recover

People with intellectual or developmental disabilities can't live outside of residential settings

This is what I was taught....

The interventions for people in active addiction is for behavior management and designed to get them to stop using (abstinence)

"Homeless people have anosognosia. They lack insight and therefore need to be compelled into treatment and medications"

If someone with an intellectual or developmental disability can work, it needs to be in a sheltered workshop

Schizophrenia is a chronically debilitating disease

When someone talks about suicide, a risk assessment needs to be done and they need to be hospitalized, even if involuntarily

Research on Recovery began 30-40 years ago.



Yippee...
A Pop Quiz!



Based on research, what percentage of people labeled with an SPMI recover?

Is Recovery Possible? The Vermont Study (1987)

- A **32-year longitudinal outcome study on recovery and how it is impacted by mental health services.**
- Dr. Harding studied the success of a recovery-oriented system in Vermont through a planned deinstitutionalization process, to a rehabilitation program with community supports. Subjects were then followed 32 years later.
- N= 269
- All diagnosed with a “Thought Disorder”- Schizophrenia, Schizoaffective Dx, Psychotic Dx, etc.
- Most severely disabled bottom 19% in their state hospital.
- Lifelong institutionalization; ill on average for **16 years**, totally disabled for **10 years**, and most had been at the hospital for over **10 years**

Is Recovery Possible? The Vermont Study

Recovery was based on the following criteria:

- Having a social life indistinguishable from your neighbor (being integrated into the community)
- Holding a job for pay or volunteering
- Being symptom free (no current signs and symptoms of mental illness)
- Being off medication

Results

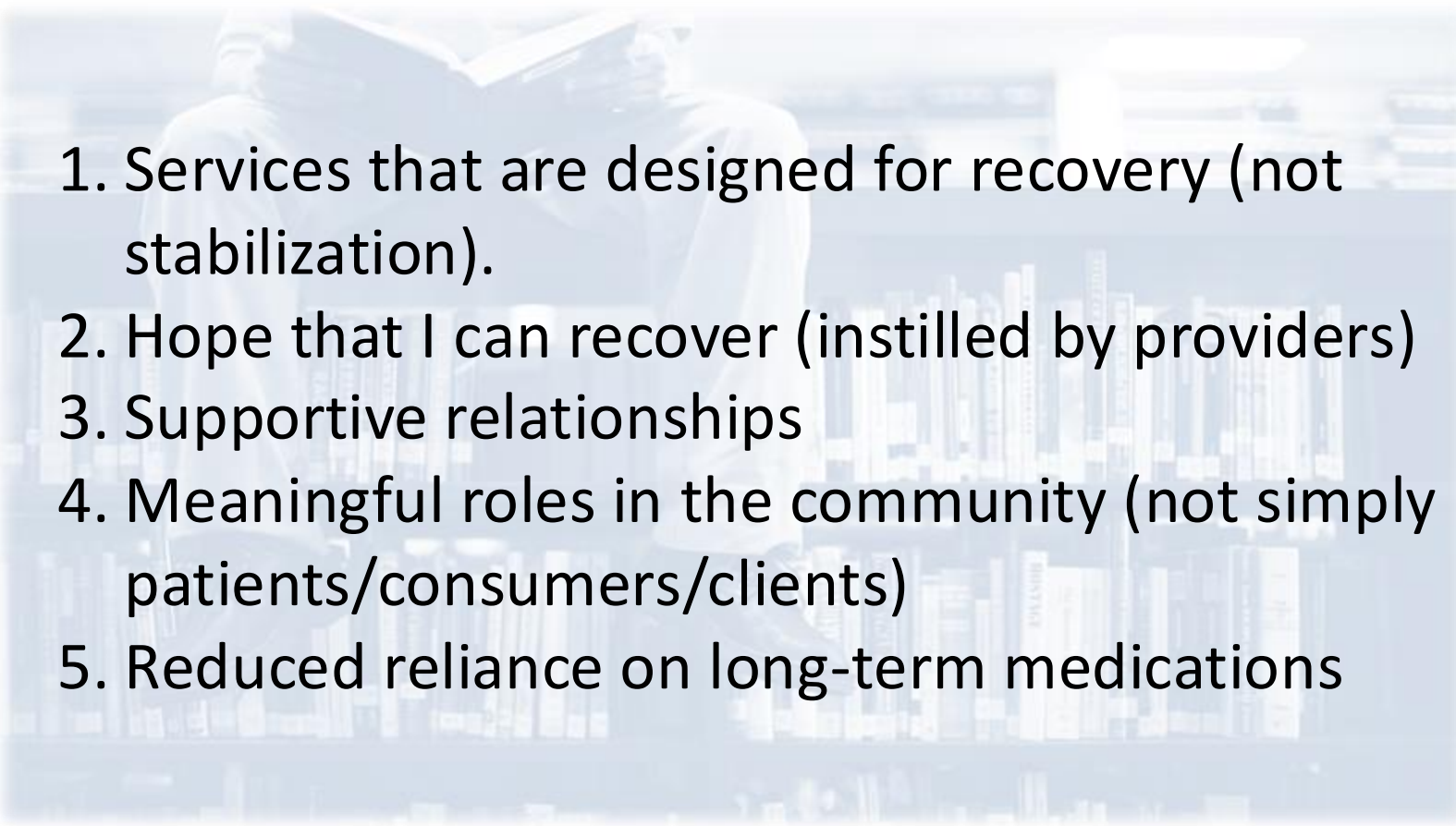
32 years later, 97% of the original 269 patients were involved in a follow up study:

- **62-68%** fully recovered or significantly improved. **Only 25%** were considered severely disabled.
- **20%** were fully recovered (working, living independently, symptom free without medications)
- **34%** of those people with a diagnosis of schizophrenia experienced full recovery in psychiatric status and social functioning.
- An additional **34%** of the people who attended the rehabilitation program were significantly improved in both areas.

Of the 62-68%, **half** met all **four** of the recovery criteria, the other *half* met **three out of four** criteria, usually continuing to take medications while meeting the other criteria.

It should be noted that this cohort is the *least functional* ever studied, there are 13 additional studies

What helps people recover?

- 
1. Services that are designed for recovery (not stabilization).
 2. Hope that I can recover (instilled by providers)
 3. Supportive relationships
 4. Meaningful roles in the community (not simply patients/consumers/clients)
 5. Reduced reliance on long-term medications

In November, my Unlearning
continued in Trieste, Italy

“The Best Place in the World,
to Have Mental Illness”

From over
the psychi
hospital to
mental he

SONO S
VORREI
PER PETTINARMI
HO BISOGNO D
MA NON POSS
HO DIRITTO
VOGLIO U





**Why is Trieste
“The Best Place
in the World to
Have Mental
Illness”?**



Founded in 1968 out of “The Radical Psychiatry Movement” from psychiatrists committed to closing down hospitals and ending the use of forced treatment

(<https://pmc.ncbi.nlm.nih.gov/articles/PMC4430803/>)

A value based service

The services are value-driven, in that their focus is on:

HELPING THE
PERSON, NOT
TREATING AN
ILLNESS



Value 1:
Help the Person,
Don't' Treat an
Illness

FOSTERING
RECOVERY AND
SOCIAL INCLUSION



Value 2:
Foster Recovery
and Social
Inclusion

ADDRESSING
PRACTICAL NEEDS
THAT MATTER TO
SERVICE USERS



Value 3:
Address
Practical Needs
that Matter
Most to the
Person

CHANGE THE
ATTITUDE IN THE
COMMUNITY



Value 4:
Change the
Attitude in the
Community

RESPECTING THE
SERVICE USER AS A
CITIZEN WITH
RIGHTS



Value 5:
Respect the
Person as a
Citizen with
Rights





The Approach

1. Relationships, Relationships, Relationships

- **Radical Hospitality:** everyone connected to the person **KNOWS** the person and establishes mutual trust. This is very recognizable with the way their psychiatrists talk, view, and work with people
- **Relentless Negotiation/Open Dialogue/Confronte:** Interplay of idea sharing with the person and their trusted social networks and support services are HOW decisions are made. They are led by the person and/or the people they trust the most

As a result, people **TRUST** the service providers. They call the hospital staff just to talk. Their psychiatrists are viewed as allies and champions and operate more like really good social workers. The “tension” of compliance is NON-EXISTENT



The Approach

2. Medications are an Optional “Tool”

- **Trauma:** distress viewed through the lens of life, not biology
- **Quality of Life:** only 30% of people take psychotropic medications
- **Harm Reduction:** A plan for titration begins at prescription and long acting injectables are the exception

3. Serve in the Community, Zero Force

- **Community Access:** Psychiatrists are community based and work in people’s homes, go the hospitals every morning, and have offices in the 24/7 regional mental health centers
- **Human Rights/Voluntary:** 6 unlocked hospital beds for 350,000 people

Dr. Mark Ragins, MD (The Village)

“In the US, the idea that a great deal of mental symptoms and deterioration were the result of institutional practices, was considered naïve because it ignored the grim reality of the severe underlying biological conditions these people had to deal with regardless of how we treat them. Considerable efforts, mostly unsuccessful, have gone into demonstrating these underlying biological conditions. Repeated studies where people were withdrawn from their antipsychotic medications without any other alternatives were published to show how poorly they did and studies that demonstrated high rates of recovery from schizophrenia without relying on medications both acutely (like Soteria) and over many years (like the Vermont longitudinal study) were largely ignored and repressed.

If someone does not believe they have an underlying biological condition that needs lifelong medications, they are either ignorant, and widespread psychoeducation had been promoted, or they are too ill to realize they are ill, they have “anosognosia”, and therefore need involuntary medications to treat it.

In Trieste only about 30% of their patients take medications, especially those with the most serious, disruptive symptoms and especially at times of greatest need, rather than widespread lifelong medication maintenance.”



The Outcomes

- They closed down the psychiatric hospitals and use **no force**
- They decreased suicide rates by 40%
- They significantly decreased costs while increasing employment
- They brought homelessness down to zero
- They created an integrated system, centered around core beliefs, that is designed to advance *Recovery*, community connection, employment, health, and quality of life
- They established an example for the world to learn from and potentially replicate

<https://www.livingwellsystems.uk/trieste>

***Next Lesson (L)earned...from friends,
family, and others with I/DD***

LENS SHIFT:



Shift
HAPPENS

**It's NOT about
the BEHAVIOR!!!**

Behavior is ALWAYS Communicating Something...


An emotion

A response or reaction

An unmet need



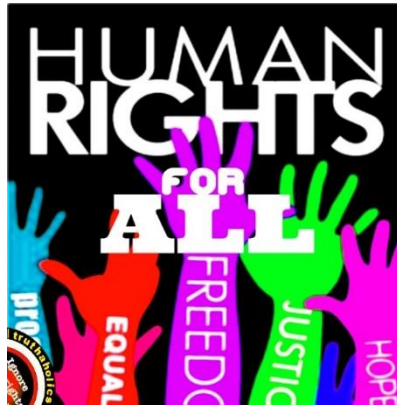
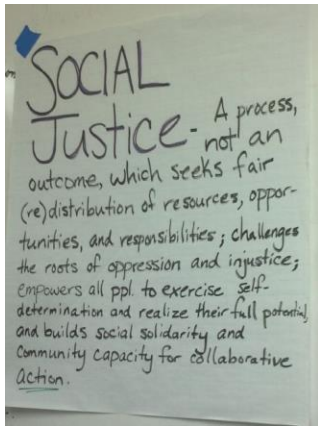
The behavior is the “symptom,” not the problem



(L)earning: To my younger policy self...

“you’re playing the wrong game”

- Laura Van Tosh



A background image showing a close-up of a watering can's spout pouring water onto two small green seedlings growing in a field. The water is captured mid-pour, creating a white, misty spray. The seedlings are small with two leaves each, and the soil is dark brown. The overall scene is bright and natural.

As a CEO (L)earning:

What We Grow, is What We Water

The ILLNESS business

The WELLNESS business

We can choose to plant, seed, water and grow illness or wellness

WHEN AN ORGANIZATION EMPLOYS
PEER SUPPORT WORKERS, THE
ONLY
THING THAT SHOULD CHANGE
EVERYTHING!

Employ people with lived experience in peer support roles and outside peer roles.

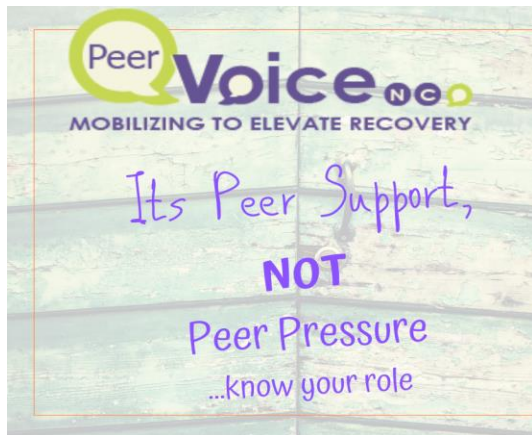
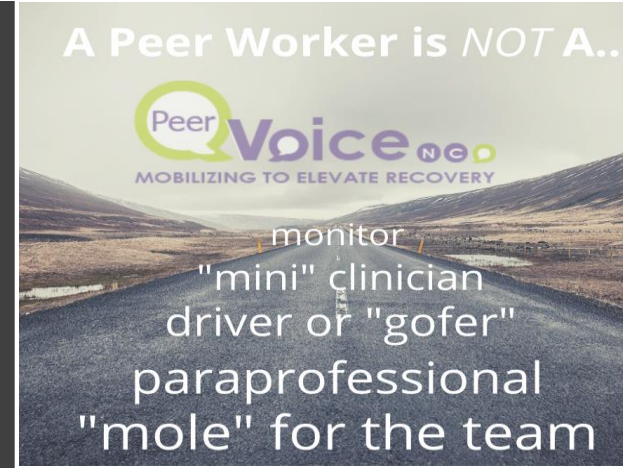
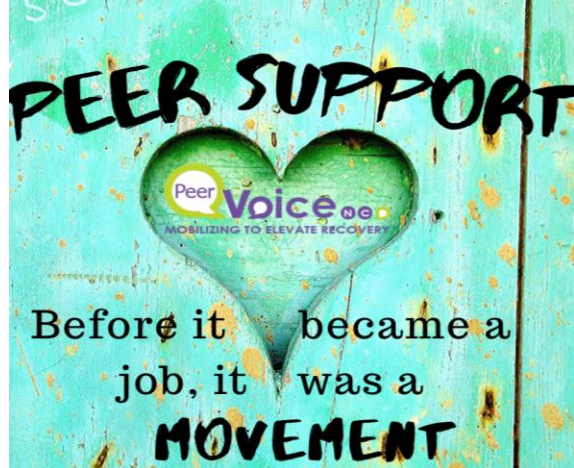
... and a clinician, case manager, driver, CEO with lived experience is NOT a peer supporter

Lean into the tension. It's necessary!



**Not capitalizing on the unique
perspective, wisdom, and skills that
can only be earned through lived
experience,**

**not only to provide peer support, but
to change organizational practices and
policies**



THE DIFFERENCE BETWEEN
SUPPORT AND ADVICE?

...POWER

Peer Supporters, know your role

(L)earning as a PSS

Peer Supporters...
Know your role,
know our history,
use your skills



5 Signs of Co- Optation of PSS

- ▶ 1. PSS don't have relationships with people being supported. Real connections, not just transactional (only teaching curricula for example)
- ▶ 2. PSS talk like a clinician, case manager, use clinical language and labels
- ▶ 3. PSS don't challenge the team or organization to understand through a non-clinical lens because they view people through the lens of symptoms, diagnosis, compliance and non-compliance
- ▶ 4. PSS don't question policies and practices that are not centered in human, civil, or disability rights (the use of coercion or force (involuntary commitment, threats))
- ▶ 5. PSS is doing busy work

And my **FIRST** and most important role as a
mental patient....

HELLO
MY NAME IS

Anorexia

Major Depressive Disorder with Suicidal Ideation

Obsessive Compulsive Disorder

Generalized Anxiety Disorder

Panic Disorder

Social Anxiety Disorder

Post Traumatic Stress Disorder

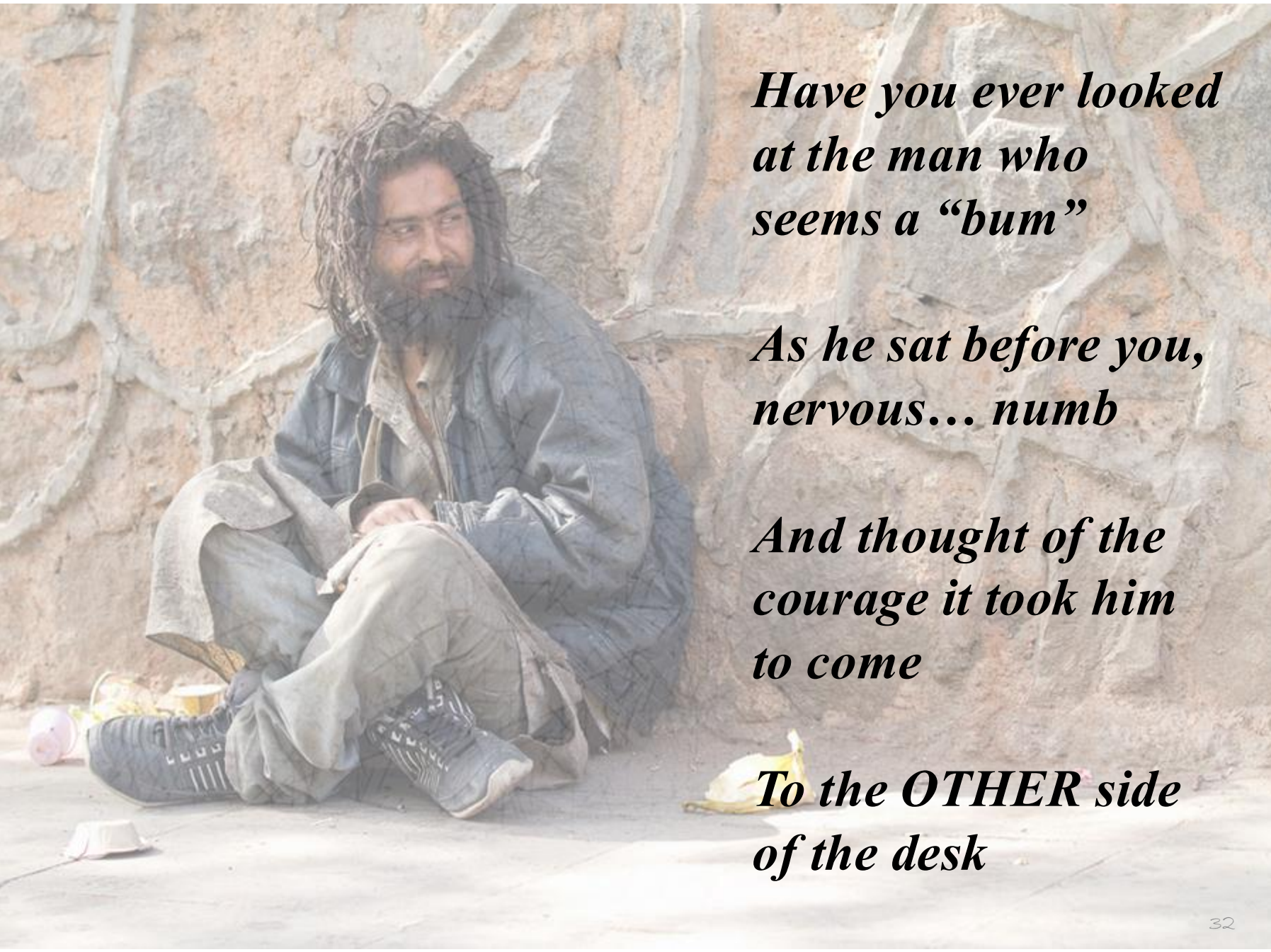
CRAZY

“Cherene, pick up the keys. They’re right in front of you”

Love, you in recovery

The OTHER Side of the Desk

*Have you ever thought, just a wee little bit
Of how it would seem, to be a misfit
and how you would feel if YOU had to sit
On the OTHER side of the desk*



*Have you ever looked
at the man who
seems a “bum”*

*As he sat before you,
nervous... numb*

*And thought of the
courage it took him
to come*

*To the OTHER side
of the desk*

*Have ever you thought of
his dreams that went astray*

*Of the hard real facts,
of his EVERY day*

*Of the things in his life
that make him stay*

*On the OTHER side
of the desk*





Did you think to yourself, it could be I
If the good things in life had passed me by
And maybe I'd bluster and maybe I'd lie
From the Other side of the desk

Did you make him feel he was full of greed?

*Make him ashamed
of his race or his creed?*

*Or did you reach out to him
in his time of need*

From the OTHER side of the desk

A young boy and girl are shown from the chest up, looking down at something out of frame. The boy is on the left, wearing a white shirt with a blue grid pattern. The girl is on the right, wearing a dark top with a pink flower. The image is faded and serves as a background for the text.

*May God give us wisdom
and lots of it*

*And much compassion
and plenty of grit*

*So that we may be kinder
to those who sit*

*on the OTHER side of the
desk*

-Anonymous

“May your wounds be your *fuel*,
Your healing be your *center*,
And your wisdom be your *voice*”

-Cherene

“May your wounds be your *fuel*,
Your healing be your *center*,
And your wisdom be your voice



Thank You!!!!

Cherene Caraco

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