UPDATE:

Making Space for People with Lived Expertise project

Report to the
VC CoC Governance Board
January 10, 2024 meeting

OVERVIEW:

Values

Approaches

The Work

Findings

Concerns

Tools

Nothing About Us Without Us

Disability Justice

empowerment

human rights

independence

integration

self-help

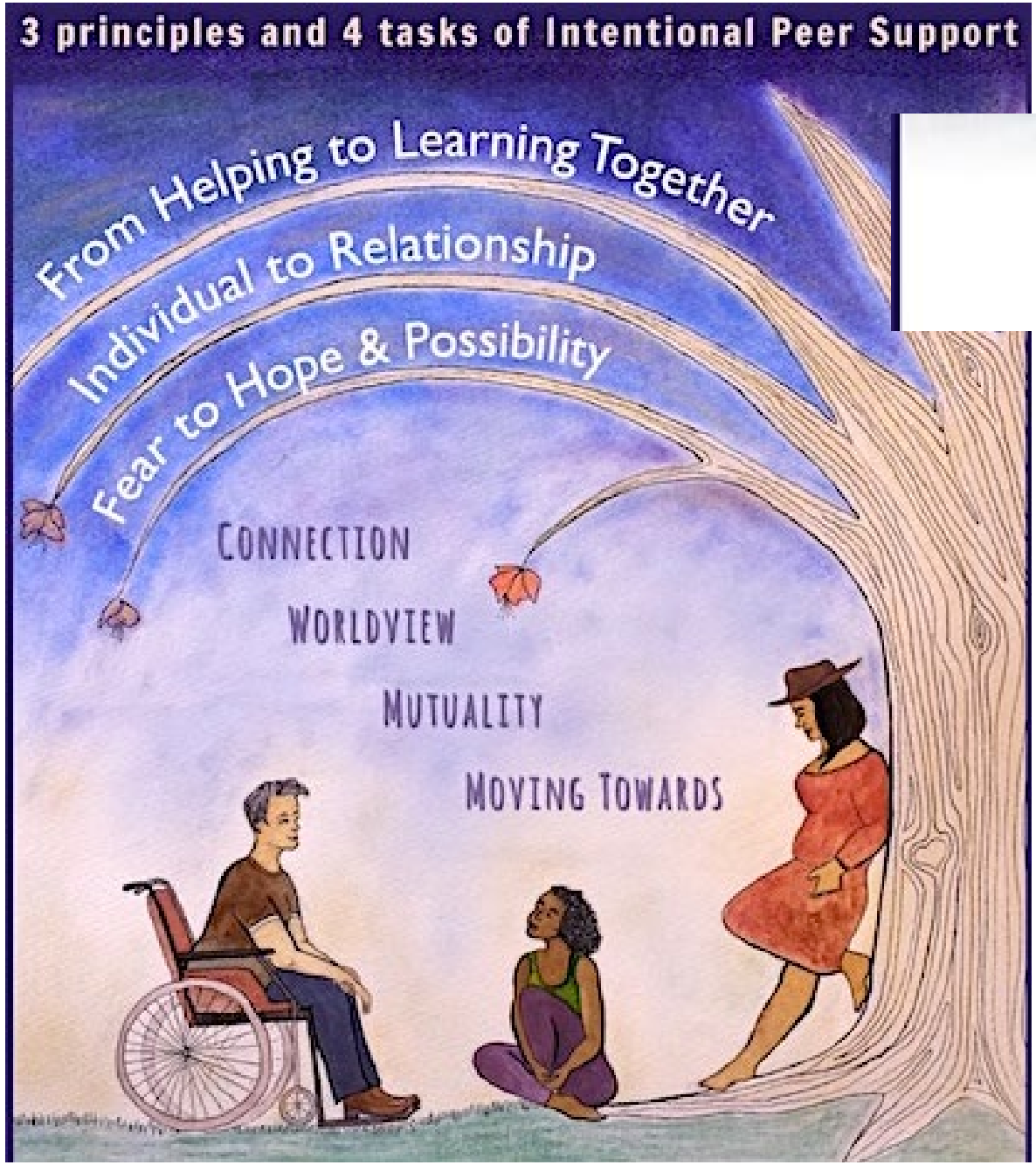
self-determination

- choice
- partnership

James I Charlton

Guided By Evidence-backed Practices

- ✓ Intentional Peer Support (IPS)
  (Shery Mead)
- ✓ Psychiatric Rehabilitation
  (Boston University, CASRA)
- ✓ 8 Dimensions of Wellness
  (Peggy Swarbrick, SAMHSA)
- ✓ True Livelihood:
  Workforce/Job Development
  (Denise Bissonnette)

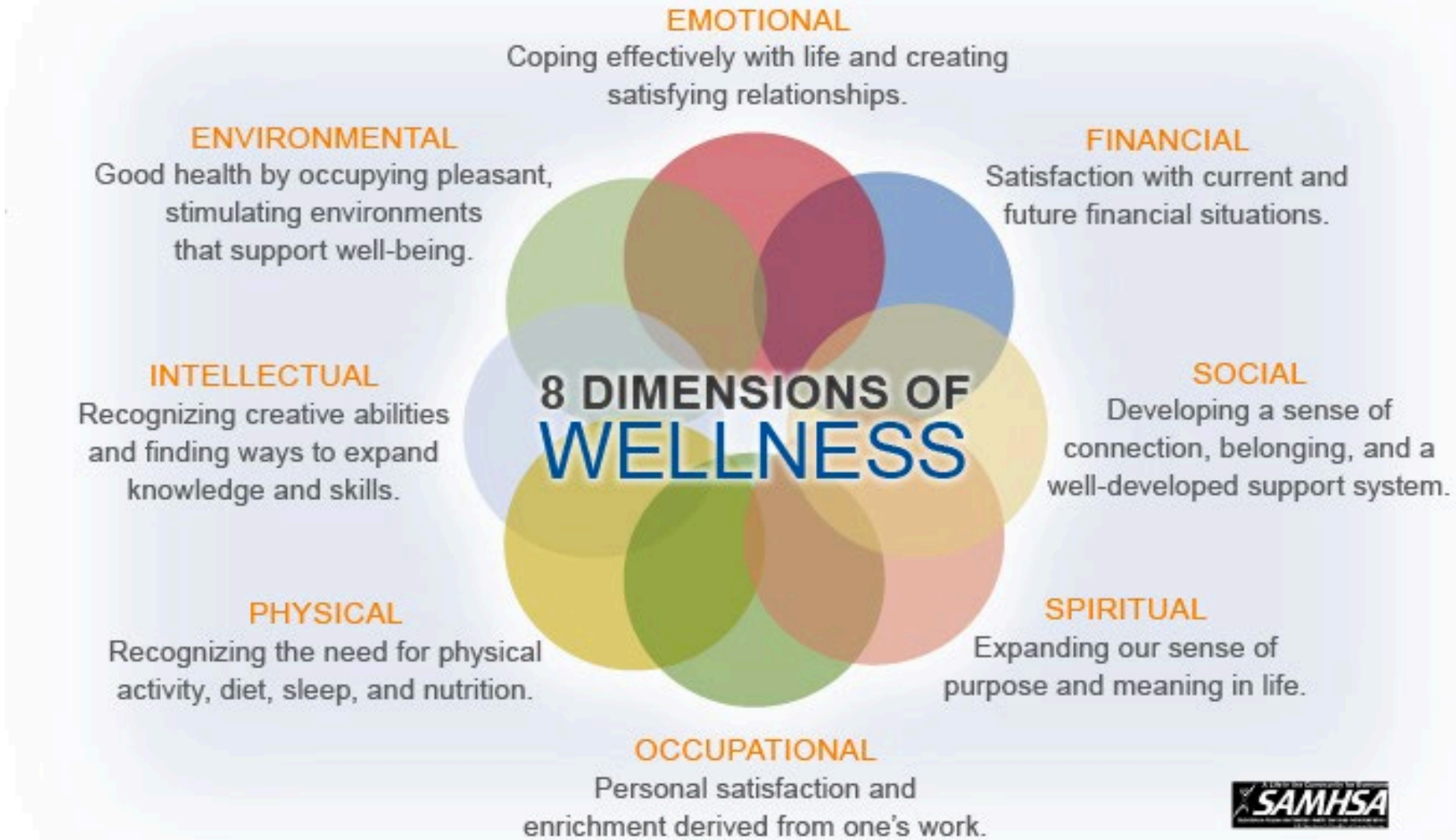


intentional PEERSUPPORT.ORG
Peer Support is about Social Change

Developed by
Shery Mead

intentionalpeersupport.org

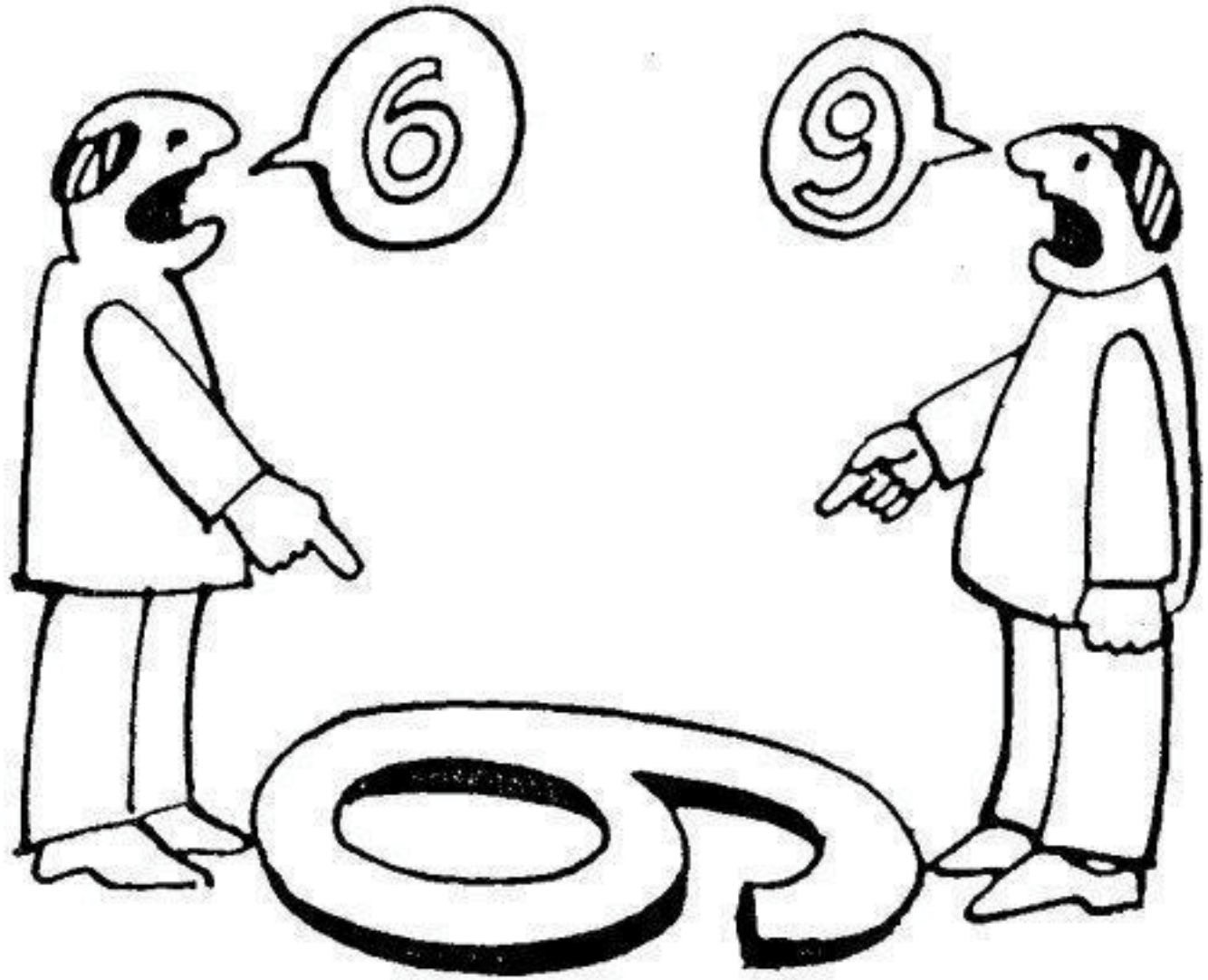
Much like improvisation in music, IPS is a process of experimentation and co-creation, and assumes we play off each other to create ever more interesting and complex ways of understanding



originally developed by:

Collaborative Support Programs of New Jersey

Institute for Wellness and Recovery Initiatives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The Clash of Perception

(from Pat Deegan)

Psychiatrist	Me (client)
You are getting better	Your cure is disabling me
Your symptoms are gone	My symptoms no longer bother you
You are more in control	Haloperidol is controlling me
You are stable	I can't think or feel
You are functioning again	My life is without meaning or passion

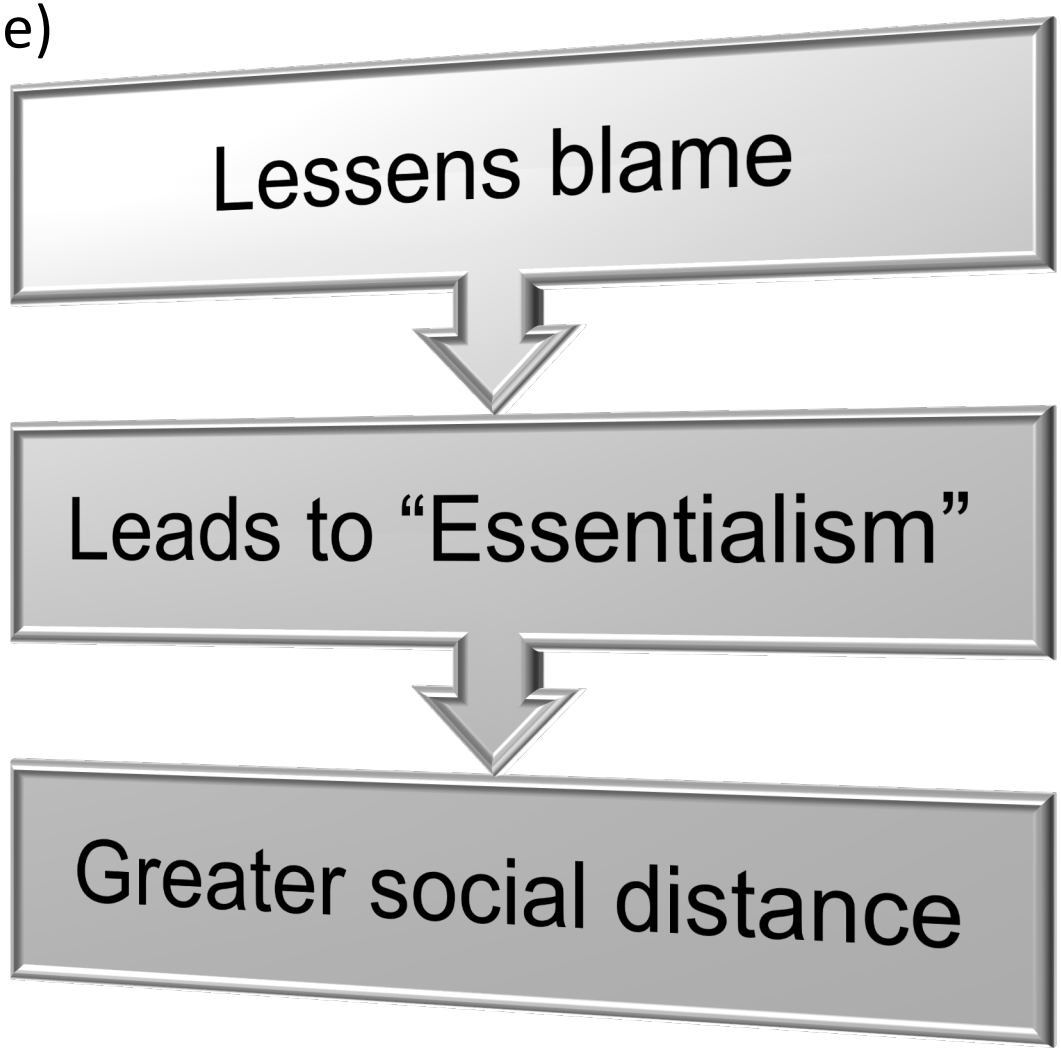
It is important to remember that this clash of perceptions I am describing went largely unspoken and unacknowledged. The psychiatrist and I did not sit down and have a thorough discussion of our divergent perspectives. It is also important to see there is a terrible power imbalance here. This clash of perception occurred between a psychiatrist and myself during one of my most vulnerable times.

Because of his enormous power in relation to me,
the psychiatrist's interpretation of me became the only valid story.
His story about me became the truth and my story,
my experience and my voice were silenced.

Why Can't You Understand I'm Trying To HELP You?

Brain disease model

(chemical imbalance)



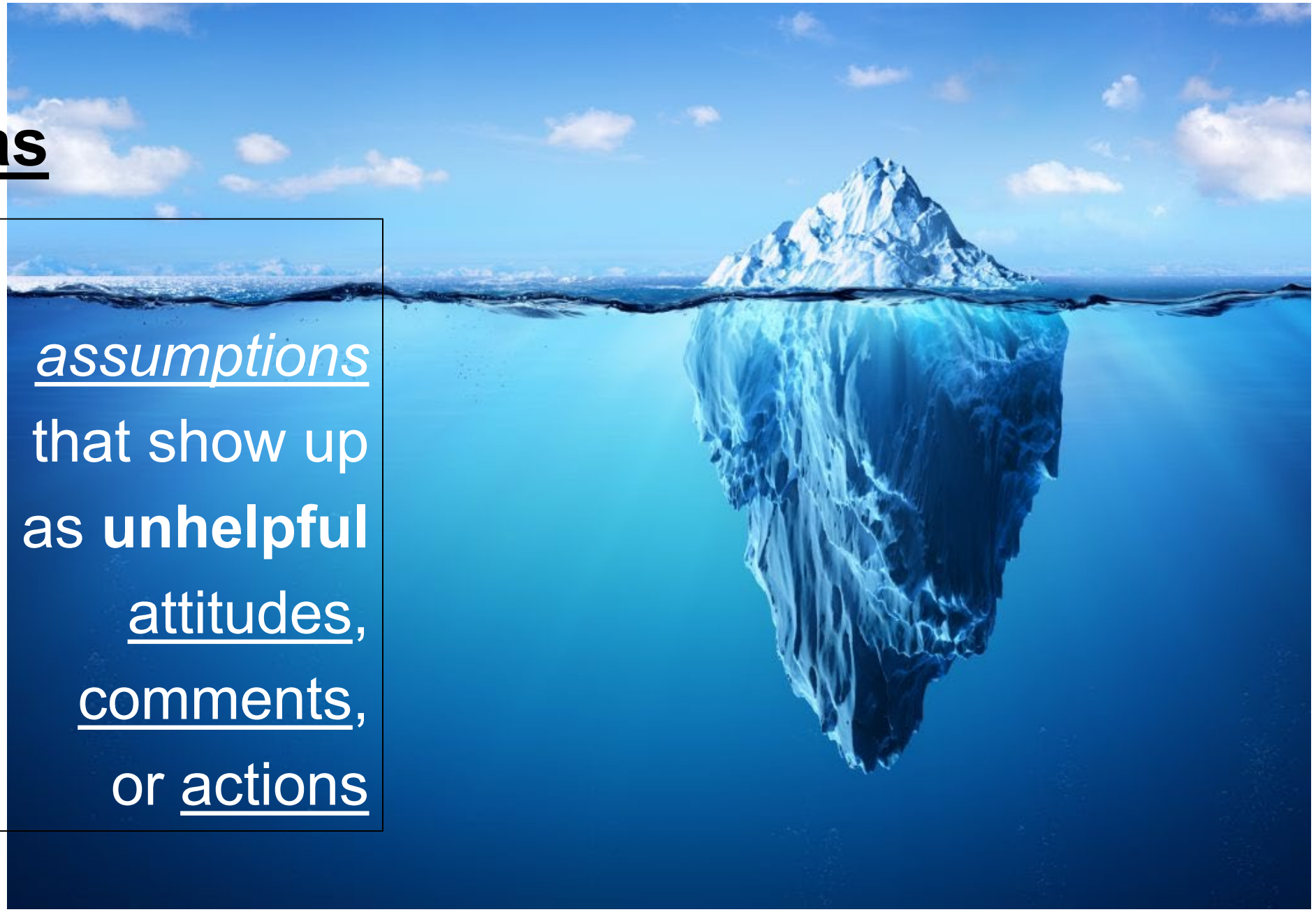
“Mixed Blessings” results
from good intentions, but …

You're Inappropriate

implicit bias

hidden

assumptions that show up as **unhelpful** attitudes, comments, or actions



Elizabeth R. Stone

MA

mother

PhD candidate

from New York

20+ years experience

peer/client/consumer

Epistemic injustice =

- Denial of rights
- Dismissal of perspective
- Ascribed disregard

Epistemic = ways of knowing

- What is known by individuals in a group that is viewed in a discriminatory manner, is *de facto* viewed as not valid, by virtue of membership in the devalued group.

Find the Balance between extreme attitudes

"running the person's life for him/her/them"

Get the person to do what I want or think is best

(Protect)

"letting the person do whatever he/she/they want/s"

Let the person do whatever he/she/they think/s is best

(Neglect)

Support & Empower

- ✓ Deep Listening
- ✓ Menu of Options
- ✓ Person Chooses
- ✓ Build Skills for Success

Dignity of Risk
&
Duty to Care

Patricia Deegan, PhD

Relationship :
The Most Important Tool

Instill Hope

Promote Full Participation

Respond to Crisis Differently

Uphold Informed Consent

Strive for Community Integration

Support Felt Needs

Honor the Power of Choice

Be Trauma Informed

Afford Dignity of Risk & Right to Try

Develop Self-Help/Peer & Natural Supports

Recognize the Power of Language

Guerilla Engagement =

attitude

invitation

curiosity

respect

irregular hours

incidentals

non-coercion

-> ***relationship-focused***

Could you help me understand what that means to you?

Critical Ingredients for Establishing *Mutually Responsible Relationships*

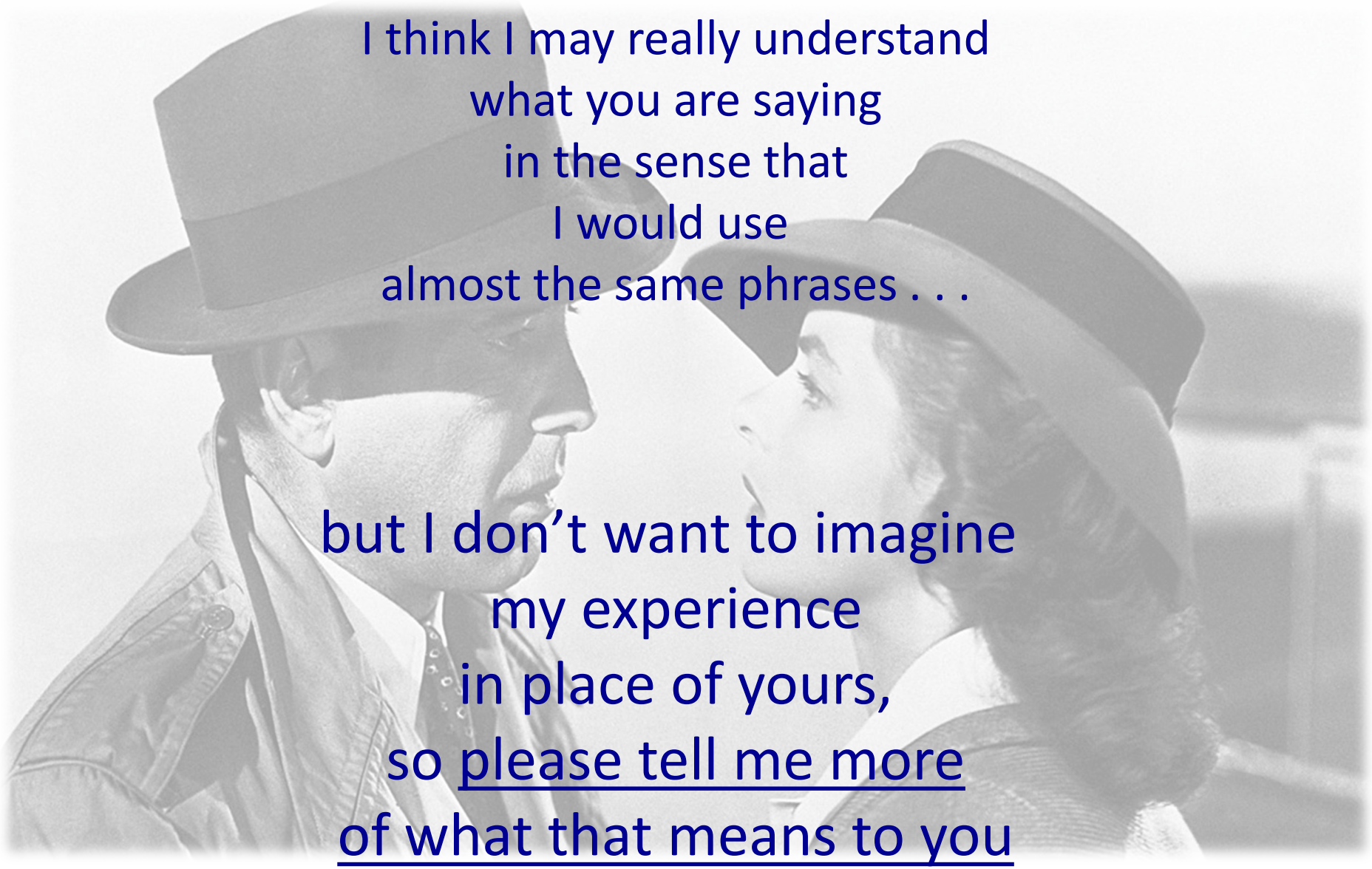
Being honest and direct about

- what I can do
- what I cannot do
- what makes me uncomfortable

Negotiating for needs and shared power

- Validating experiences
- Saying what I see and asking for clarity
- Saying what I feel and need
- Figuring out together what will work for both of us

from Shery Mead
Intentional Peer Support



I think I may really understand
what you are saying
in the sense that
I would use
almost the same phrases . . .

but I don't want to imagine
my experience
in place of yours,
so please tell me more
of what that means to you

Rogers, 1994, p. 11

Patterns in Paths to Homelessness

Childhood trauma/intergenerational homelessness

High amount of Child Support

Glamour of Lifestyle: camping, traveling, carefree

Limited Earnings Potential/History of Physical Labor

‘Break-up’ – Romantic, Friend, Family

Unanticipated Episode – Illness, Accident, Unemployment

Death of Homeowner

note correlates with poverty

Two Basic Paths Out:

- It has only been a short time, it was unexpected, **prior** to this the person had good ties to others, and had found **a solid spot in the mainstream of society**;

or

- Despite outward appearances and often quite clearly, the person has had **long-standing life experiences** most might label as traumatic and **learned to respond** to those difficult experiences in ways where the **main objective was avoiding further emotional pain**, but often ultimately was not safe nor was helpful in gaining a foothold to move forward.

constraints

- trauma histories
- distrust
- hatred of authority
- accommodated to discomfort
- personal benefits
  (e.g., friends, freedom, etc.)

The Adverse Childhood Experiences (ACE) Study

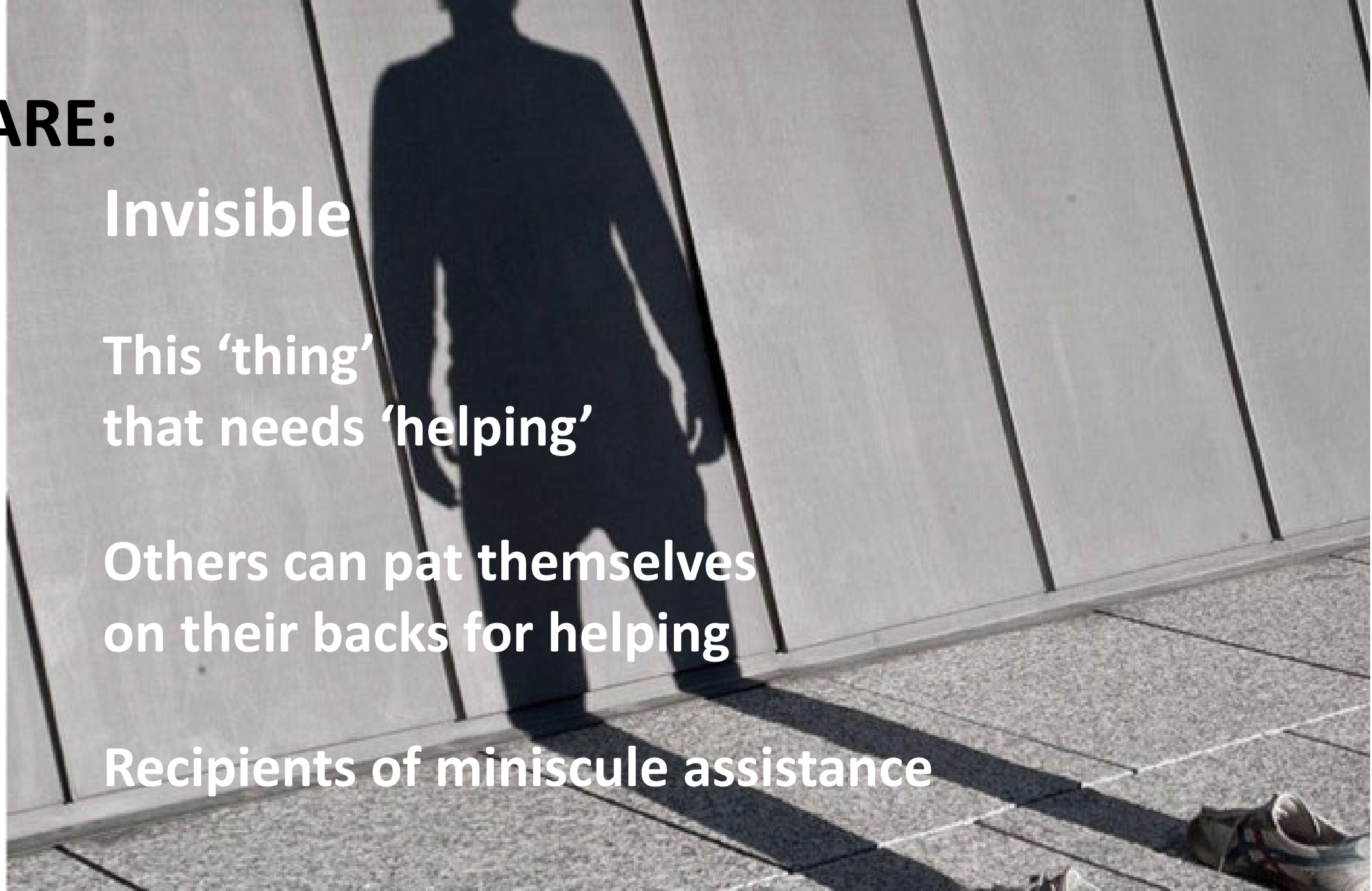
80% of people in psychiatric hospitals
have experienced physical or sexual abuse

66% of people in substance abuse treatment
report childhood abuse or neglect

90% of women with alcoholism
were sexually abused or
suffered severe violence from parents

64% of adult suicide attempts
are attributable to
childhood adverse experiences

WE ARE:



Invisible

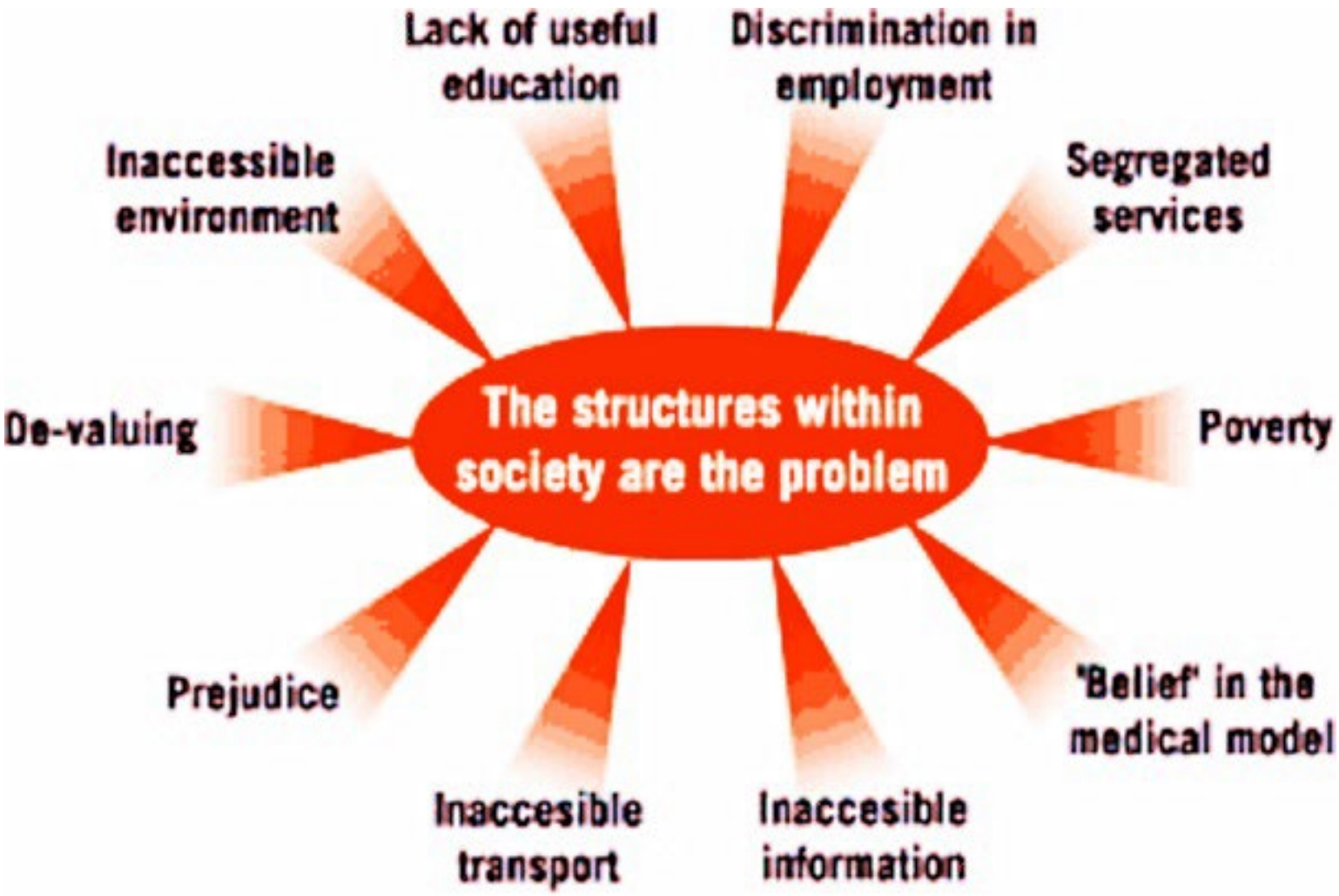
This ‘thing’
that needs ‘helping’

Others can pat themselves
on their backs for helping

Recipients of miniscule assistance

rethinking “resistance” and “denial”

Social Model Of Disability



What Happens When People are Denied the Right to Make Choices?

Denial of
personal choice leads to
a syndrome called

learned helplessness…

profound depression

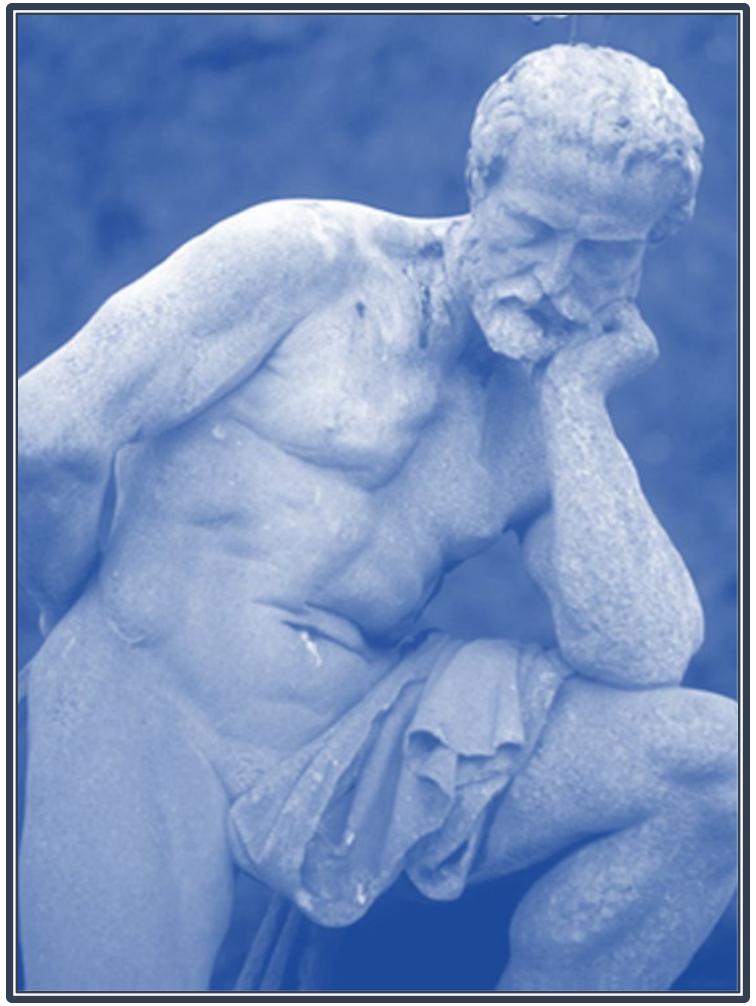
apathy

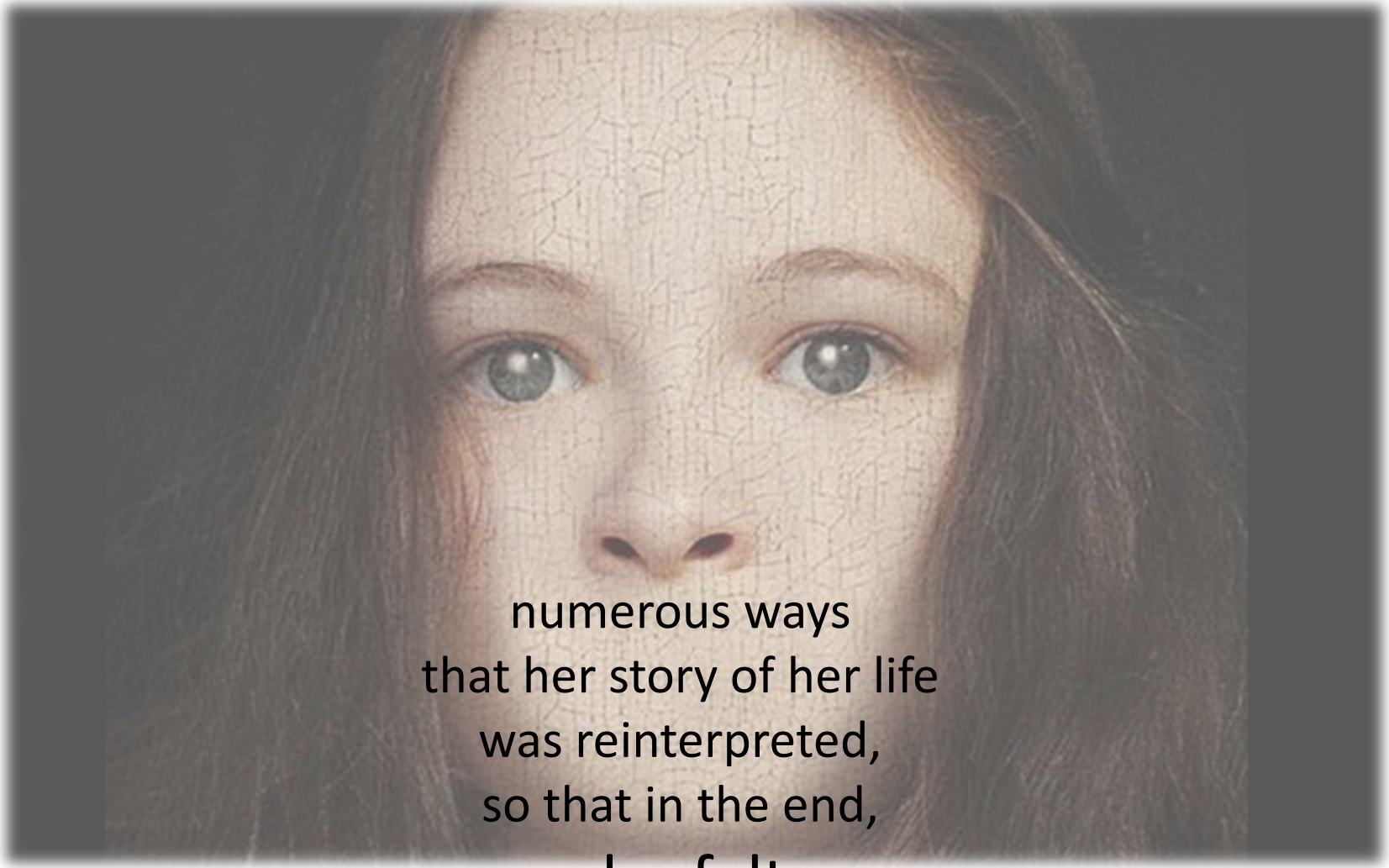
loss of self-esteem

indifference

cognitive deterioration

loss of sense of self





numerous ways
that her story of her life
was reinterpreted,
so that in the end,

she felt
she could not speak or be heard,
in effect she had no voice

Rogers, 1994, p. 12

Potential Blocks To Partnering

Listening

For

vs.

Listening

To

10 Guidelines for Outreach Counseling From a Pretreatment Perspective

from: **Levy, J. S.** (2013)

Pretreatment guide for homeless outreach & Housing First:
Helping couples, youth, and unaccompanied adults

Meet clients (literally and figuratively) where they are at

The relationship is most important – promote trust and respect autonomy

Develop a common language of shared words, ideas, and values

Be goal centered – join the person in setting goals that resonate in his/her/their world

Mutually define or characterize particular difficulties to achieving goals and jointly develop strategies or plans

Carefully support transitions to new ideas, relationships (stages of engagement), environments (desensitization), resources, and treatment (bridge client language to treatment language)

Promote safety via harm reduction strategies and crisis intervention techniques

Utilize crisis as an opportunity to promote positive change

Respect the process of change – understand its stages and relevant interventions

Understand the person's narrative and integrate a process of 'meaning making' with movement toward positive change

Personal Medicine = Rediscovering Personal Interests…

- Volunteering
- Seeking employment opportunities
- Exploring nature
- Parenting
- Reclaiming a lost role
- Enjoyable activities/hobbies

A person's language reveals :
how one wants to be **perceived**
and by extension –
how one wants to be **treated**

identities
can be imposed
or resisted
or accepted
by *others* or *self*

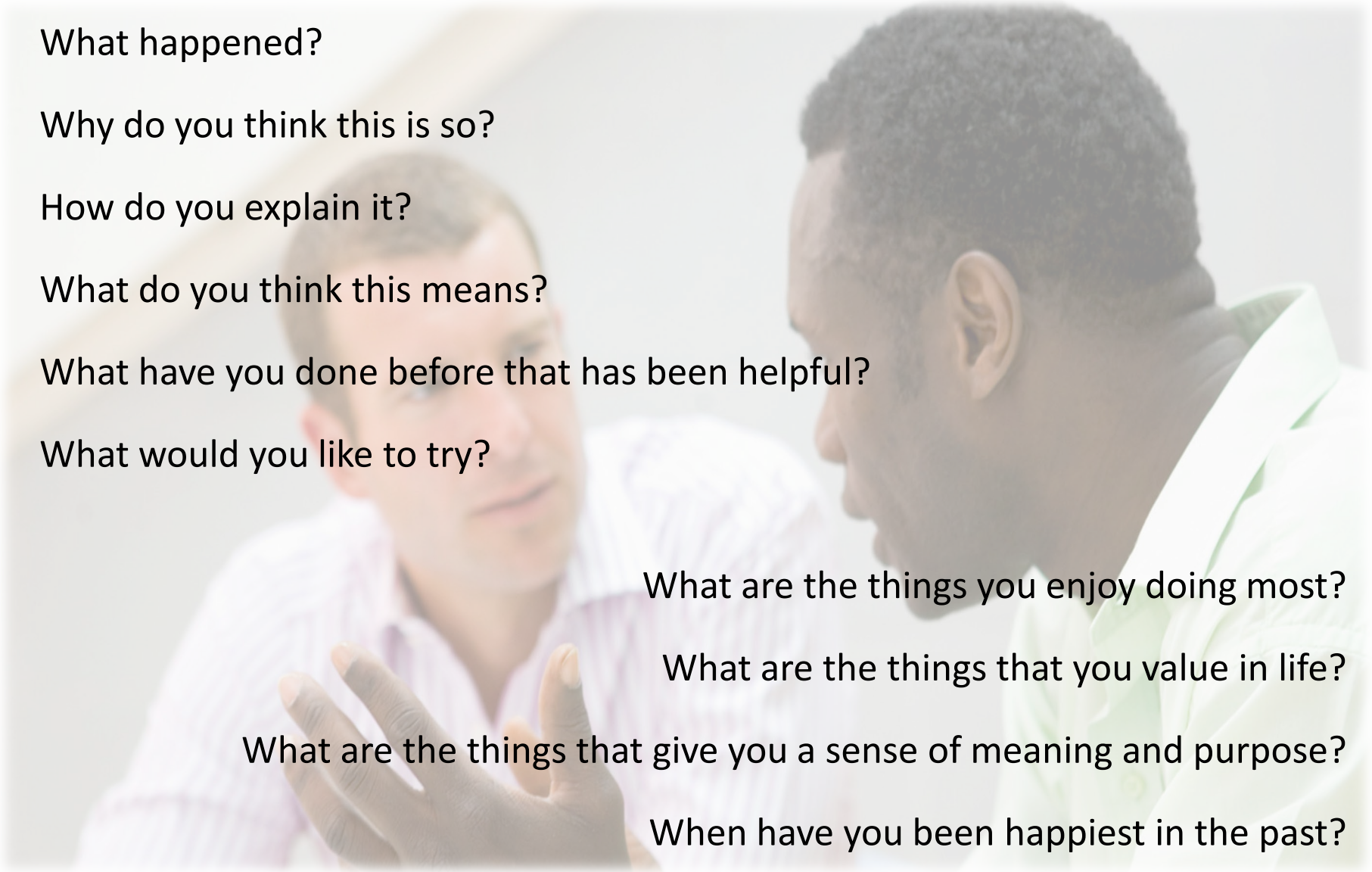
Worldview =>
Expectations about Support

Based on interviews that examined:
- Attributes of self
- Description of professionals
- Experience of decision-making processes
- References to subjectivity

FOUR TYPES emerged:

1. **Inward Expert**
2. **Outward Entrustor**
3. **Self-Aware Observer**
4. **Social Integrator**

From study interviews in Australia



What happened?

Why do you think this is so?

How do you explain it?

What do you think this means?

What have you done before that has been helpful?

What would you like to try?

What are the things you enjoy doing most?

What are the things that you value in life?

What are the things that give you a sense of meaning and purpose?

When have you been happiest in the past?

MISSION

FIND: A Friend in Deed

Bringing cutting-edge evidence-based practices grounded in lived expertise to recipients and providers of behavioral healthcare working at the intersections of mental health, substance misuse, justice-system involvement, and being unhoused.

What is a PAD?

A **Psychiatric Advance Directive** (**PAD**)
is a legal document
that documents a person's preferences
for future mental health treatment,
and allows appointment
of a health proxy
to interpret those preferences
during a crisis.

www.nrc-pad.org

Important Information

especially if a Person is Hospitalized

approaches that are helpful when having a hard time

pacing
taking a shower
punching a pillow
listening to music
writing or reading

touching - or not
talking
lying down
exercising
voluntary time-out

INCLUDE:

Actions that are not helpful
Preferences regarding physical contact by staff

Potential Challenges

- Facility limitations in service offerings.
- PADs are limited in emergency interventions based on "dangerousness to self or others" (5150). An individual **cannot direct whether or not to be hospitalized** in an advance directive.
- Stigma-based views (prejudice) that lead to the **discounting** (discrimination) of the perceptions, judgments and stated preferences of people with psychiatric disabilities.

State Initiatives

(Patricia Deegan, PhD)

What gives your life meaning?

Keep in Mind

Know yourself/know your lens

- ✓ Values
- ✓ Why you want to do this
- ✓ Your hopes
- ✓ How you see the world

How do you see others?

- ✓ Open curious perspective
- ✓ Embrace difference

Be Clear about . . .

- ✓ What you would like to see happen
- ✓ What you are willing to do
- ✓ What you can realistically expect from others

What I (*Elizabeth*) bring to this:

MA: Education (TESOL)

graduate studies in

- Social Work
- Psychology
- Community Psychology

Certified Addictions Counselor

Work in BH (25+ years)

- case manager
- residential counselor
- co-occurring disorders counselor
- trainer
- consultant
- advocate

'expert' via lived experience

- homeless with children
- multiple mental health diagnoses
- 6 voluntary psych hospitalizations
- 3 suicide attempts

for more information:

a.friend.in.deed.ventura@gmail.com

elizabeth r stone, ma :: 805-721-1124

A PERSON AND A MENTALLY ILL PATIENT

By Wally Kisthardt

We use words in many ways, to understand our being.
And we know our point of view affects what we are seeing . . .
A diagnosis is a powerful word, it's true.
For once a 'disorder' is defined, it's the lens that we look through.

A person gets excited; with a patient it is manic.
A person has concerns; with a patient it is panic.
A person is expressive; a patient's histrionic.
A person can get better; while a patient's often chronic.

A person may get angry; a patient becomes agitated.
A person is a creative thinker; a patient's thoughts are not related.
A person may be sad; a patient is depressed.
A person may be childlike; a patient is regressed.

A person may be cautious; with a patient it is guarded.
A person may change her mind; a patient must finish what is started.
A person tries to influence; a patient manipulates.
A person gets a second opinion; a patient triangulates.

A person is an activist; a patient's antisocial.
A person is a visionary; a patient is delusional.
A person lives in a home; a patient in a facility.
A person has many strengths; a patient has a disability.

A reminder to us all that mental illness does not nullify personhood.
And each and everyone we try to help may not behave as we think they should.
Don't let their illness shift our sights from the gifts that people possess,
And we will see the wonder in each life and the joys of each success.

from
You Validate My Vision: Poetic Reflections on Helping, Caring and Loving
by Wally Kisthardt

3 Realms of ACEs

Adverse childhood and community experiences (ACEs) can occur in the household, the community, or in the environment and cause toxic stress. Left unaddressed, toxic stress from ACEs harms children and families, organizations, systems and communities, and reduces the ability of individuals and entities to respond to stressful events with resiliency. Research has shown that there are many ways to reduce and heal from toxic stress and build healthy, caring communities.

PACEs Connection thanks **Building Community Resilience Collaborative and Networks** and the **International Transformational Resilience Coalition** for inspiration and guidance. Please visit **PACEsConnection.com** to learn more about the science of ACEs and join the movement to prevent ACEs, heal trauma and build resilience.

PACEs Connection

ACE Study — Five Important Findings

1. ACEs are surprisingly common — 64% of the 17,000 in the ACE Study had one of the 10 ACEs; 12 percent had four or more.
2. There's an unmistakable link between ACEs and adult onset of chronic disease, mental illness, violence and being a victim of violence.
3. The more types of childhood adversity, the direr the consequences. An ACE score of 4 increases the risk of alcoholism by 700%, attempted suicide by 1200%; it doubles heart disease and lung cancer rates.
4. ACEs contribute to most of our health problems, including chronic disease, financial and social health issues.
5. One type of ACE is no more damaging than another. An ACE score of 4 that includes divorce, physical abuse, a family member depressed or in prison has the same statistical outcome as four other types of ACEs. This is why focusing on preventing just one type of trauma and/or coping mechanism isn't working.

ACEs are just ONE PART of ACEs science. The Five Parts of ACEs Science:

- The ACE Study and other ACE surveys (epidemiology).
- How toxic stress from ACEs damages children's brains (neurobiology).
- How toxic stress from ACEs affects our short- and long-term health.
- How we pass ACEs from parent to child through our genes (epigenetics).
- And how resilience research shows our brains are plastic, our bodies can heal.

We're Not Doomed!

Our brains are plastic. Our bodies want to heal. To reduce stress hormones in our bodies and brains, we can meditate, exercise, sleep and eat well, have safe relationships, live and work in safety, ask for help when we need it.

We can build resilient families. Educating parents about their own ACEs helps them understand their lives and motivates them to become healthy parents to prevent passing their ACEs on to their kids.

For resilient families, we need healthy organizations, healthy systems and healthy communities. The frontier of resilience research lies in creating communities and systems that prevent childhood adversity, stop traumatizing already traumatized people, and build resilience.

Many people, organizations and communities are integrating trauma-informed and resilience-building practices based on ACEs science, including pediatricians, schools, juvenile detention facilities, businesses, social services, people in the faith-based community, health clinics, etc. For examples, go to **https://acestoohigh.com/aces-101/**.

<u>Relationship:</u>
The Most Important Tool

Instill Hope
Promote Full Participation
Respond to Crisis Differently
Uphold Informed Consent
Strive for Community Integration
Support Felt Needs
Honor the Power of Choice
Be Trauma Informed
Afford Dignity of Risk & Right to Try
Develop Self-Help/Peer & Natural Supports

Recognize the Power of Language

Critical Ingredients for
<u>Establishing Mutually Responsible Relationships</u>

Being honest and direct about

- what I can do
- what I cannot do
- what makes me uncomfortable

Negotiating for needs and shared power

- Validating experiences
- Saying what I see and asking for clarity
- Saying what I feel and need
- Figuring out together what will work for both of us

from Shery Mead - *Intentional Peer Support*

Approaches
that Incorporate Shared Decision-making

Common Ground
commongroundprogram.com

eCPR
emotional-cpr.org

Psychiatric Rehabilitation
cpr.bu.edu

Open Dialogue

Intentional Peer Support
intentionalpeersupport.org

Tools
for Incorporating Shared Decision-making

Psychiatric Advance Directives
www.nrc-pad.org

WRAP
wellnessrecoveryactionplan.org

Decision Aids

Organizations
with Additional Information

NEC:
National Empowerment Center
power2u.org

MFI:
Mind Freedom International
mindfreedom.org

MIA:
Mad in America
madinamerica.org