# WHO DEFINES PEER SUPPORT?:

The Danger of Substituted Values & Voice

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# C/S/X MOVEMENT: A BIT OF HISTORY

1970s: users/survivors of psychiatry organized to: Protest inhumane treatment by institutional psychiatry

Protect & expand human rights

Demand an end to forced treatment and other abuses

Demand broad access to freely chosen alternatives

#### •Movement's organizing principles:

Freedom of choice

Voluntariness

Equality

Self-determination

Nothing
About
Us
Without
Us!

### PSYCHIATRIC ESTABLISHMENT RESPONSES

- •Harmful practices 'in the past; things are better now'
- Force unfortunate, but necessary & effective
- By virtue of diagnoses, survivors are incompetent to speak to their own needs

# CO-OPTATION:

The process by which a dominant group tries to absorb or neutralize a smaller, weaker group that poses a threat to its continued power.

Penney & Prescott, 2016

# CO-OPTATION TAKES MANY FORMS

Appropriate other group's language without adopting underlying values

Single out individuals from other group for recognition but no power

Articulate support for other group's goals while secretly working to undermine them

Appropriate other group's personal narratives & interpret them in ways that diminish their power

Penney & Prescott, 2016

# CO-OPTATION & THE MOVEMENT

•Survivors
invited to
policy
meetings but
disadvantaged
by:

- Included as tokens;
   insufficient numbers
- Lack of familiarity with bureaucratic procedures
   & unspoken codes

# NAMING OURSELVES

Naming oneself is fundamental to claiming one's identity

Around the world, we refer to ourselves by many names

Psychiatric survivors of psychiatry

Ex-patients

Ex-inmates

People with psychiatric labels/histories

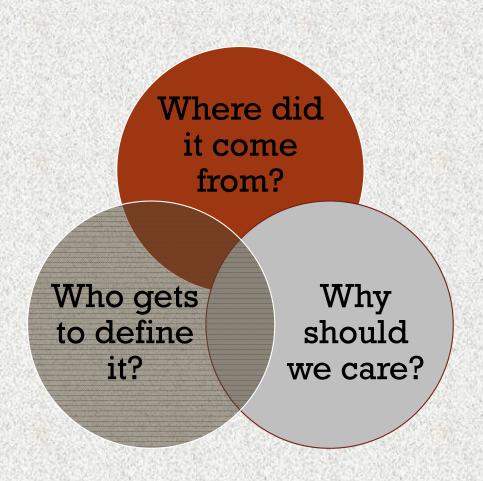
# BEING RE-NAMED BY OTHERS

■1980s: "CONSUMERS"

# 2010s: "PEOPLE WITH LIVED EXPERIENCE"



# WHAT IS PEER SUPPORT?



# SEEMS SIMPLE...

#### Peer

- An equal
- Shared demographic/ social position
- Similar life experiences/ challenges

# Support

- Empathy
- Encouragement
- Assistance
- Reciprocal relationship

Blanch, Filson, Penney & Cave, 2012; Penney, Prescott & Mead, 2009

# PEER SUPPORT IS...

Reciprocal process: people with something in common give & receive help

Mutual relationships based on shared experiential knowledge

Natural human tendency to respond compassionately to shared difficulties

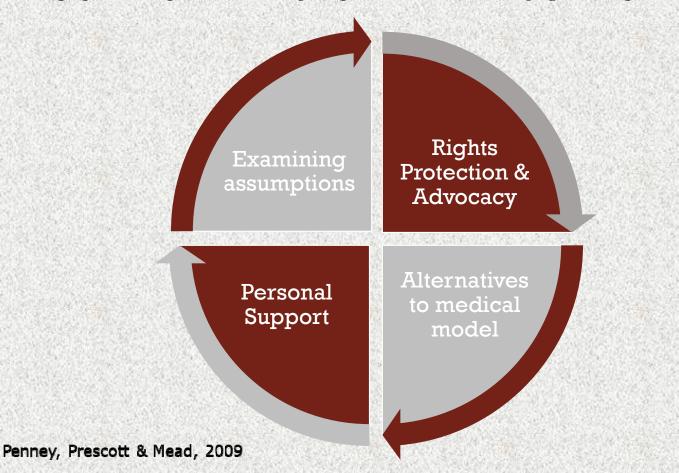
# THE PERSONAL IS POLITICAL

Powerlessness: result of mental health practices & social discrimination

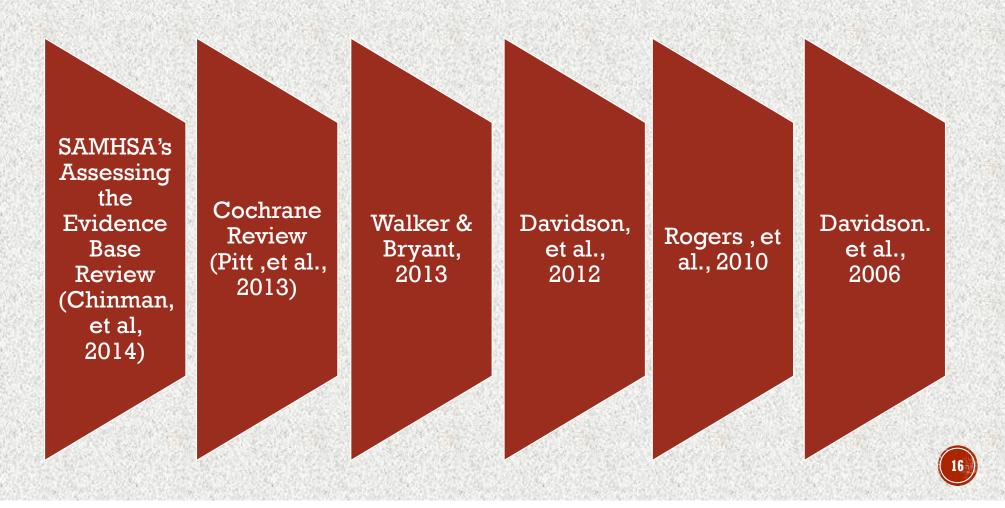
You are not to blame; you are not alone

Penney, Prescott & Mead, 2009

# COMPONENTS OF PEER SUPPORT



#### PEER SUPPORT IN US: MAJOR REVIEWS SINCE 2006



Studies used a range of confusing, incompatible definitions

No one questioned whether what was under study was, in fact, "peer support"

ALL conflated "peer support" with any service provided by someone working in a 'peer' job

#### DUELING "PEER SUPPORT" DEFINITIONS

System of giving & receiving help among people with shared experiences, based on:

Respect

Shared responsibility

Mutual agreement of what is helpful

NOT based on psychiatric models and diagnostic criteria Mead, 2008 Direct service delivered by a person with a serious mental illness to a person with a serious mental disorder

Chinman, et al., 2014

### **FINDINGS**

Minimal to moderate evidence that adding peerdelivered services to traditional mental health services may be effective on some outcome measures.

# **FINDINGS**

Staff with psychiatric histories:

- Work in para-professional roles in traditional programs
- Often perform the same tasks as non-peer staff

Job descriptions vary:

- clinical and/or para-professional services
- clerical staff; janitors; van drivers
- undefined roles that evolve based on perceived needs of the organization.

#### **FINDINGS**

# Most peer workers not trained in peer support values & skills

Assigned tasks may conflict with peer support values

- Pressuring clients for medication compliance
- Reporting clients' behavior to clinicians
- Keeping case notes

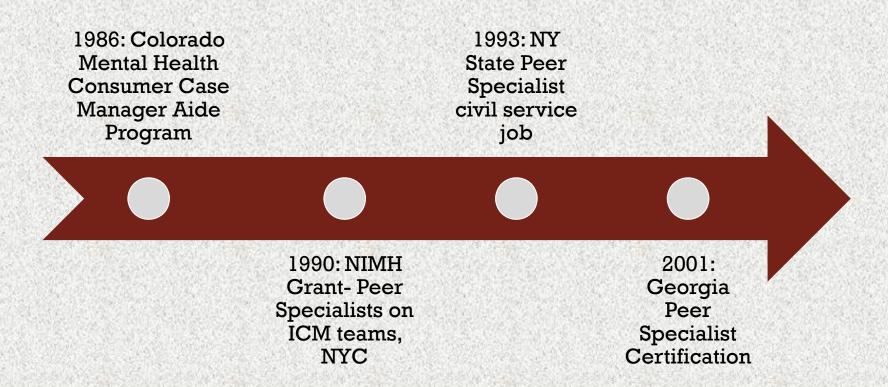
# METHODOLOGICAL PROBLEMS NOTED BY REVIEWERS...

Study design problems

Insufficient information about service models & context

Lack of clearly defined jobs & tasks

#### BEGINNINGS OF PEER SPECIALIST JOBS



# NY PEER SPECIALIST JOB, 1993

Developed by psychiatric survivors

Intent: bring genuine peer support to state-run programs

Undermined by administrators & clinicians

Some quit, others experienced crises, others "failed" probation

# CMS MEDICAID LETTER - 2007

Federal Center for Medicare and Medicaid Services defined reimbursable "Peer Support Services" as:

An evidence-based mental health model of care which consists of a qualified peer support provider who assists individuals with their recovery from mental illness and substance use disorders

# CO-OPTATION HAPPENED

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# CO-OPTATION: AN ON-GOING PROBLEM

#### Experience shows:

- Survivor voices & values are undermined
- Survivor influence is diminished

Issues of power & privilege must be addressed to enable survivors to work as partners with professionals

# LET'S BE CLEAR ON THE DISTINCTIONS

Genuine peer support promotes dialectical inquiry in a quest for healing and growth

Hiring peer staff as paraprofessionals within traditional agencies supports the status quo