

**Mental Health Recovery: What Helps and What Hinders?**  
**A National Research Project for the Development of Recovery Facilitating**  
**System Performance Indicators**

**CROSS SITE CODEBOOK (Version Two)**

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**SECTION 1: SELF**

**SECTION 1.A: SELF – WHAT HELPS**

Internal States/Attitudes

- Confidence
- Dignity
- Sense of humor
- Self acceptance
- Self esteem
- Restoring or gaining hope
- Trust yourself
  - ❖ Learning to trust my intuition
- Reclaiming my strengths & passions
- Being comfortable with self
- Being forgiving
- Positive outlook
- Viewing self as whole/more than mental illness/full complete human beings
- Wisdom
- Self awareness
- Okay to grieve
  - ❖ Over trauma

Responsibility/Making Own Decisions

Self Reliance/ Personal Resourcefulness

- Perseverance
- Resourcefulness
- Self sufficiency
- Making lemonade out of lemons
- Adaptation

Self Determination/ Independence

Self Care

- Sleep
- Order & stability in daily living

- ❖ Structuring your day
- ❖ Establish a routine
- ❖ Someone to help
- ❖ Being directed
- Physical health activities
  - ❖ Yoga
  - ❖ Biking

## Self Advocacy

### **SECTION 1.B SELF – WHAT HINDERS**

#### Internal States/Attitudes

- Negative emotions
  - ❖ Shame
  - ❖ Self-loathing
  - ❖ Fear
- Self-stigma
  - ❖ Fear of not being accepted
  - ❖ We get in our own way
  - ❖ Don't see ourselves as worthy
  - ❖ Distrust themselves and others
  - ❖ Giving self negative messages
  - ❖ Secrecy
  - ❖ Seeing everything in life in terms of pathology
- Self-protection
- Hopelessness
  - ❖ Acceptance of stagnation
  - ❖ Pessimism
- Self-absorption
- Lack of motivation
- Disorganized thinking
- Believing don't deserve resources
- Fear of loss, that hope will go away

#### Not Taking Personal Responsibility

#### Unwilling to Take Risks

#### Disabling Conditions

- Physical ailments
  - ❖ Lack of knowledge about physical health
- Mental ailments
  - ❖ Medication dependency
  - ❖ Episodic nature
  - ❖ Not being able to work can be debilitating

- ❖ Killing hope – “will never recover”

Labeling

## **SECTION 2: BASIC MATERIAL RESOURCES**

### **SECTION 2.A: BASIC MATERIAL RESOURCES – WHAT HELPS**

A Livable Income

- Adequate incomes to pay for housing, car or public transit, medications, clothing, food and other basic necessities through a job and/or public subsidies
  - ❖ Control of own finances, including the option of services obtained by voucher or individual contracts with consumers
  - ❖ Discretionary money
  - ❖ Opportunity for economic self-sufficiency
  - ❖ Families, churches, peer groups and community organizations provide resources through natural mutual aid networks.
  - ❖ Advocacy groups
  - ❖ Low-income community organizing
- Opportunities to save and increase financial resources in order to expand choices in how to live
- The expectation of economic and social fairness, equity, as culturally developed within “The American Dream”
- Economic self sufficiency

Affordable Housing

- In safe locations, free of crime and street drugs
- Alternatives to long term hospitalization and involuntary outpatient commitment
- Transitional housing for persons being discharged from hospital, prison or jail and for the dually diagnosed
- Privacy from landlords, neighbors or persons sharing common space
- Outreach to prevent or reduce homelessness
- Own space, own apartment

Benefits and Entitlements

- Access to benefits and entitlements
  - ❖ Knowing what public benefit and service resources are available
  - ❖ Knowing eligibility requirements and procedures
  - ❖ Knowing your legal rights and entitlements to financial support, medical and mental health services
  - ❖ Peer and professional advocates to provide individualized aid in obtaining benefits and navigating the financial support systems of SSI, SSDI, Military pensions and Public Assistance
- Insurance coverage through Medicaid, Medicare or private health plans, including dental services

### Transportation

- Affordable and reliable public, private or program-sponsored transit

### Information and Access to Basic Material Resources

- Knowing what resources are available
- Help with navigating the systems involved

## **SECTION 2.B: BASIC MATERIAL RESOURCES – WHAT HINDERS**

### Income at or below poverty level

- Losing material support
- SSI and SSDI monthly rates are inadequate for one person or a family to live on.
  - ❖ Lack of control of existing financial resources due to conservatorship, representative payee or guardian relationships
  - ❖ Exploitation of consumers through excess reliance on volunteer and unpaid work
  - ❖ Disabling conditions caused by mental disorder and/or physical illnesses or a history of trauma and abuse.
  - ❖ Homelessness
  - ❖ Transportation barriers to access to employment, benefit and service sites, and peer support activities
  - ❖ Resource distribution needs to be more equitable and not reserved solely for the wealthy and/or the most severely disabled.

### Unsafe Neighborhoods

- Substandard and segregated housing, instability due to frequent and multiple moves

### Legal Status

- Discrimination and fears caused by uncertain legal status as an immigrant as to eligibility for benefits and services

### Gender Role Expectations

- Women to be full-time mothers and housewives and men to be bread winners

### Lack of Financial Opportunities to Make Choices

### Gross Inequities in the Societal Distribution of Resources for Mental and General Health

### Lack of Insurance

- Restrictions and gaps in insurance coverage

### “System is a Gatekeeper more than a Caretaker”

- Too much paperwork, too many forms and the consumer is required to jump through too many hoops in seeking benefits and entitlements.
- Have to go to too many places to get services

#### Access Barriers to Benefits

- Constrictive rules and regulations and a lack of parity for mental and physical health insurance coverage limits services
- Benefit and service access is limited to the wealthy or the severely poor, excluding the working poor.
- Disincentives to working due to the risk and fear of losing medical and other public assistance benefits (a Catch 22)
- Inadequate Medicaid benefit rates to cover provider costs, discourages the seeking of services by consumers and limits the number and quality of available service providers.
- Medicaid co-pays for prescriptions for psychotropic drugs are higher than for other medications; Medicare does not cover prescriptions at all.
- Timeliness: waiting lists and office waiting times
- Resources are limited to certain levels of functioning, disability or required level of care.
- Limited availability of means of communication, both by computer and telephone
- Lack of natural support networks and family support which is not controlling or dependency creating.

#### Consumer-Staff Relationship is Unequal in Power and Authority

- Staff does not know what it is like to be a consumer with limited resources and services.

#### Lack of Knowledge and Information about Basic Material Resources

- Withholding Information
- Lack of Practical Education

### **SECTION 3: HOPE/SENSE OF MEANING AND PURPOSE**

#### **SECTION 3.A: HOPE/SENSE OF MEANING AND PURPOSE – WHAT HELPS**

##### Hope/Sense of Meaning and Purpose

- Restoring or gaining hope
  - ❖ Hope must be tangible
  - ❖ Bootstrapping hope
- Purpose and meaning
- Positive attitude/positive outlook/optimism
  - ❖ Seeing that others are worse off
- Self-Acceptance/self-esteem
- Sense of humor
- Contributing/caring for something/someone/cause beyond oneself
  - ❖ Contributing to others/serving others/giving back/service to others/making a difference
  - ❖ Contributing to the community
  - ❖ Caring for animals
  - ❖ Caring for plants

- Telling stories of recovery
- Dignity
- Appreciating own strengths
  - ❖ Reclaiming strengths and passion
  - ❖ Acknowledging own strength
  - ❖ Appreciating strengths as a survivor
  - ❖ Appreciating own strengths and talents

#### Goals and Choices

- Dreams/goals (future-orientation)/goal setting
  - ❖ Having dreams
    - Allowing some “grandiose ideation”
  - ❖ Attainable goals/Setting achievable goals
  - ❖ Something to work towards
  - ❖ Having a long-term view
- Choices
  - ❖ Choices give life meaning
  - ❖ Services become meaningful when you choose them
  - ❖ Choosing my quality of life, how I want to live
  - ❖ Having opportunities and challenges

#### Spirituality

- Fellowship/church/spiritual community
- Spirituality
- Faith
- Connection to a higher power
- Spiritual practices

#### Personal Responsibility

- Self-Reliance
- Self-Determination
- Maintaining control over your life
- Independence
- Self-Sufficiency
- Motivation
- Confidence
- Taking responsibility for choices
- Trust
  - ❖ Trust yourself
  - ❖ Learning to trust my intuition

#### Active Coping

- Personal resourcefulness/resourcefulness
- Taking action
- Making lemonade out of lemons

### Perseverance

- Having a home of my own

### Others' Attitudes

- Having someone who believes in me
  - ❖ Encouragement
  - ❖ Validation
  - ❖ Positive feedback
  - ❖ Positive affirmations
- Positive expectations
- Having opportunities and challenges

### Gaining Knowledge/Becoming more Educated

- Learning about the disorder
- Intrinsic value of learning
- Advanced education

### Rejuvenation Opportunities

- Travel
- Nature
  - ❖ Sunshine

### Seeing Others Who are Worse Off

## **SECTION 3.B: HOPE/SENSE OF MEANING AND PURPOSE – WHAT HINDERS**

### Our Own Attitudes/Self Perceptions

- Self-Stigma
  - ❖ Fear
  - ❖ Fear of not being accepted/social rejection/fear of stigma
  - ❖ We get in our own way
  - ❖ Not taking personal responsibility for own recovery
  - ❖ Don't see ourselves as worthy
  - ❖ Shame
  - ❖ Self-loathing
  - ❖ Not trusting ourselves/unwilling to take risks
  - ❖ Giving self negative messages
  - ❖ Nondisclosure/secretcy
  - ❖ See everything in our lives in terms of our illness
- Hopelessness
  - ❖ Acceptance of stagnation
  - ❖ Pessimism
  - ❖ Hopelessness
- Lack of motivation
- Self-Absorption
- Self-Protection

- ❖ Unwilling to take risk

#### External Stigma/ Prejudice/ Discrimination

- Being devalued/invalidated
- Being seen as untrustworthy/untruthful
- Not being listened to
  - ❖ Unrealistic goals set by others
- Killing of hope
  - ❖ Having dreams goals desires demeaned (e.g.. shot down/viewed as grandiose delusions)
  - ❖ Expert advice that fosters false hope
- Social stigma
  - ❖ Stigma of shock therapy
- Labeling
- Treated like a victim
- Treated like a child
- Low expectations
- Lack of challenge
- Lack of opportunity to give to others

#### Ignoring Spiritual Dimension

#### Interfering Disability Conditions

- Physical illness/poor health
  - ❖ Fatigue
  - ❖ Lack of sleep
- Mental disability
  - ❖ Relapse
- Trauma and losses

#### Unfulfilled Basic Needs

- Lack of money and finances
- Employment
  - ❖ Stagnant jobs

#### Lack of Information and Education

- Lack of illness education
  - ❖ Lack of information on diagnosis, help, and how to improve
- Lack of information on resources
- Lack of access to advanced education opportunities

#### Premature Letting Go of Supports e.g., meds and support groups

- Non compliance with meds

#### When Nature is Gloomy

- Cloudy days

## **SECTION 4: RELATIONSHIPS**

### **SECTION 4.A: RELATIONSHIPS/CONNECTIVENESS – WHAT HELPS**

#### Various Types

- Friends
- Family
  - ❖ The whole unit
  - ❖ Individual members
  - ❖ Extended family
  - ❖ Marriage/divorce
  - ❖ Family to family programs
  - ❖ Self-defined family
- Intimacies
- Co-workers
- Faith community
- Socializing/lightening up
  - ❖ Fun
  - ❖ Casual human contact

#### Connectedness is Gained or Maintained through

- It being my choice as to who I want to associate with
- Knowing your limits
  - ❖ Balance between connection & withdrawal
  - ❖ Having some downtime/ retreat
  - ❖ Letting go of people that pull you down
- Connecting with people based on affinity
  - ❖ Having similar likes and dislikes
  - ❖ Peer based affinity of shared experience
  - ❖ Sharing something in common (e.g., serving on mental health committees)
- Connecting with people outside the system/without disorders
- Characteristics of being supportive, including:
  - ❖ Being comfortable with others
  - ❖ Making friends that accept the illness
  - ❖ Being a trustworthy friend
  - ❖ A good personality
  - ❖ Being open to learning
  - ❖ Being connected to community
  - ❖ Feeling free to offer a compliment
  - ❖ Open to communication
  - ❖ Emphasize person's strengths
  - ❖ Mutual respect
- Regular contact with natural network
  - ❖ Outreach if isolating oneself
- Disclosure/openness

- Having a holistic view of ourselves
  - ❖ More than mental illness
  - ❖ Full complete human beings
- Participation in rituals & ceremony

#### Good Communication Skills/Open Communication

- Possessing good communication skills
  - ❖ Being verbal
  - ❖ Setting healthy boundaries
- Family communication is healthy
  - ❖ Open to learning
  - ❖ Family involvement in advanced planning for crisis

#### Having ways to get or keep in touch

- Telecommunication
  - ❖ Phone, computer, Internet, e-mail
- Publications
- Newspapers
- Conferences
- Meetings
- Groups

#### Expansion of Choices, Independence and Hope can Result from Relationship when

- People or one person believes in you
  - ❖ Positive expectation
  - ❖ Encouragement
- People believe you can recover

#### Community Integration/ Community Involvement

- Using regular community resources
- Social acceptance
- Putting down roots
- Neighborhoodliness

### **SECTION 4.B: RELATIONSHIPS/CONNECTIVENESS – WHAT HINDERS**

#### Lack of Informal Supports/Lack of Natural Support Network

##### Vulnerabilities

- Withdrawal
- Disabling conditions
  - ❖ Physical illness
  - ❖ Mental disorder
  - ❖ Substance abuse
- Trauma and abuse experiences
- Nondisclosure/secretcy

### Social Isolation

- Dislocation
  - ❖ Multiple moves
- Social mental health segregation
  - ❖ Stay inside insular world
  - ❖ Restricted post-inpatient contact with other inpatients

### Coercion

- Mandated connections
- Removing choices

### Power Inequities

### Family

- Uneducated about problem
- Controlling
- Dependency enhancing
- Overprotective

### Lack of Social Skills

- No place to practice

### Bad Experiences with Others (e.g. don't want to go back)

- Negative attitudes of others
- Unrealistic goals set by others
- Negative messages

### Immigrant Status

- Language barriers
- Substandard living

## **SECTION 5: CHOICE**

### **SECTION 5.A: CHOICE – WHAT HELPS**

#### Choice Process

- Knowledge
  - ❖ About what choices there are
  - ❖ About what choices aren't there
  - ❖ That have choice
  - ❖ That can make choices
- Timing
  - ❖ Time and patience to develop choice-making skills
  - ❖ My timing
- Choice skill building and practice

- ❖ Start small/progression of choices
- Support in making choices
- Having opportunities to make choices
- Right to make a mistake
- Who decides
  - ❖ We are or should be the choice makers
  - ❖ Freedom to choose (my, life, to be who I am)
  - ❖ Must take control of choices
  - ❖ Sharing/collaboration/partnering
- Finding purpose/seeing & choosing a path
- Choice makes meaning
  - ❖ Services become meaningful when you chose them
- Options are necessary to have choice/alternative paths
- Take responsibility for choices
- Learning to trust my intuition
- Being able to take risks, can make mistakes, right to fail
- Choice requires real options

#### Expansion of Choices

- Legal services
  - ❖ Enforcement
- Advocacy
  - ❖ More voice in legislation
- Exposure to healthy environment
- Services to others
- Travel
- Education
- Relationships
- Transportation
- Peer professionals
- Getting connected to help
- People who believe you can recover
- Money and financial resources

#### Important Choices

- Treatment
  - ❖ Freedom of whether and how to participate in program and services
  - ❖ Choice in staff
  - ❖ Choice in meds
  - ❖ Choice in services
  - ❖ Control of type of therapy
  - ❖ Voucher system
- Insurance
- Where you want to live/housing
- Living independently
- Finances

- Employment
  - ❖ Going to work
  - ❖ Where you work
  - ❖ Accommodations
- Personal living/daily routine
- Disclosure
- Choosing how I see myself, my disorder, my situation
- My quality of life/way I want to live
- Who I want to associate with
- Self management
- Right to take risks

Civil Rights/Human Rights

## **SECTION 5.B: CHOICE – WHAT HINDERS**

Coercion

- Coerced consent forms
- Court mandated services
- Controlling professionals
- Staff control
- Systems control
- Forced medication
- Forces treatment because of homelessness
- Denying choice in services

Limited Choices/Lousy Options

- Poor quality of life
- Lack of money and finances
  - ❖ Lack of control over
- Employment
  - ❖ Limited range of jobs
  - ❖ underemployed
- Housing
- Segregated settings/options
- Transportation
- Lack of skills
- Absence of holistic health alternatives

Disorder Itself

- Cyclic nature

Lack of Information and Knowledge regarding Choices

- Not enough information
- Not good information
- No options for getting information

- Absence of knowledge about your rights

#### Stigma, Prejudice and Social Control

- Discrimination in behavior and actions
- Invalidation (no recognition, criticism of choices)
- Exploitation of Consumers
  - ❖ Financial, e.g., over reliance on volunteer services
- Social isolation
- Family control
- Self-stigma
  - ❖ Self-absorption
  - ❖ Not seeing self as worthy
  - ❖ Lack of hope; hopelessness
  - ❖ Lack of motivation
  - ❖ See everything in your life in terms of your pathology
  - ❖ No belief in your rights

### **SECTION 6: INDEPENDENCE**

#### **SECTION 6.A: INDEPENDENCE – WHAT HELPS**

##### Defining Independence, What does It Mean?

- Freedom of speech
- Choice in relationships
- Self defined
  - ❖ Reframe independence to interdependence
  - ❖ Not reporting to anyone
- Consumer voice in mental health services

##### Basic Material Resources

- Money and finances
  - ❖ Economic self sufficiency
- Housing
  - ❖ Affordable
  - ❖ Privacy, own space, own apartment
- Transportation
  - ❖ Available
  - ❖ Dependable

##### Meaningful Activities

- Employment
  - ❖ Equal opportunity
  - ❖ Equal employment
- Volunteer work
- Systems advocacy
- General education

- ❖ Advanced education

Education & Information

- Learning about disorder
- Resources rights and procedures
- Learning independence

Hope/ Sense of Meaning/ Sense of Purpose

- Setting goals
- Restoring or gaining hope
  - ❖ People believing in you
- Spirituality

Personhood

- Self reliance/self responsibility/
  - ❖ Funding consumer to consumer teacher of self responsibility
  - ❖ Self directed care e.g., advanced directive
    - I don't want to report to anyone
  - ❖ Self advocacy
  - ❖ Allow for risk taking
    - Right and opportunities to fail
    - Validating you can make decision/ support for decision making
- Own attitudes/self perception
  - ❖ Self acceptance
  - ❖ Reclaiming my strengths and passions
  - ❖ Trust myself
- Disclosure/openness
- Skills
  - ❖ Social
  - ❖ Basic living
  - ❖ Self care
  - ❖ Self management of the disorder
  - ❖ Survival
- Physical health
- Avoiding unhealthy behaviors
  - ❖ Street drugs
  - ❖ Unhealthy relationships

Community Integration/Using Community Resources/Social Acceptance

- Natural networks
  - ❖ Friends
  - ❖ Family
  - ❖ Marriage/divorce
  - ❖ Co-workers
  - ❖ Faith community
  - ❖ Having fun

## Peers

- Mutual aid
- Peer Program
  - ❖ Warm lines, etc.
- Clubhouse

## Formal Services

- System
  - ❖ Orientation toward recovery model
  - ❖ Choice between public and private mental health system
  - ❖ Resource distribution needs to be more equitable (not just most severe)
- Services
  - ❖ Respected self directed inpatient care
  - ❖ Implementation of advanced directives
  - ❖ Access to medical records
- Staff
  - ❖ Qualities
  - ❖ Partnering/collaborative relationship with providers e.g., listened to, believed

## **SECTION 6.B: INDEPENDENCE – WHAT HINDERS**

### Formal Services

- System
  - ❖ System bio-medical orientation
  - ❖ Paternalism
    - System encourages dependency
  - ❖ Incomplete oversight/accountability
- Services
  - ❖ Inappropriate (mis)diagnosis/treatment
  - ❖ Long term hospitalization
  - ❖ Lack of alternatives to involuntary treatment
  - ❖ Lack of meaningful access for but the wealthy or poor
  - ❖ Help available only in emergencies
  - ❖ Discontinuity in care
    - Loss of clinical supports/safety net
- Staff
  - ❖ Lack of up-to-date treatment information

### Lack of Public Awareness & Knowledge of Mental Disorder

- Social stigma
  - ❖ Psychiatric labeling
  - ❖ Treated as a victim
- Social isolation
- Discrimination
  - ❖ Employment

## Personhood

- Own attitudes/self perception
  - ❖ Fear
  - ❖ Acceptance of stagnation
  - ❖ Not taking personal responsibility
  - ❖ Not trusting myself
  - ❖ Not taking risks

## Disabling Conditions

- Physical ailments
- Mental ailments
  - ❖ Life long need for medication

## Lack of Natural Support Network

- Family
  - ❖ Uneducated about problem
  - ❖ Controlling
  - ❖ Dependency enhancing

## Lack of Basic Material Resources

- Lack of money and finances
  - ❖ Risk/fear of losing benefits
    - Disincentives
    - SS creates dependency
- Lack of transportation

## Lack of Respect for Experiential Knowledge

- Substituted judgment
  - ❖ Conservator
  - ❖ Representative payee

## Environment Stands in the Way

## **SECTION 7: MEANINGFUL ACTIVITIES**

### **SECTION 7.A: MEANINGFUL ACTIVITIES – WHAT HELPS**

#### Having/Gaining Meaningful Employment

- Meaningful work opportunities/career development
  - ❖ Important choices
    - Going to work
    - Where you work
    - Accommodations
- Ability to work
  - ❖ Development of job skills

- Equal employment opportunities
  - ❖ Employer respect and understanding
  - ❖ Accommodations
- No token jobs

#### Engaging in Volunteer Work

- Meaningful/purposeful volunteer activities
  - ❖ Doing something positive for others; helping others

#### Engaging in Advocacy Work (excluding self-advocacy)

- Systems advocacy
  - ❖ Advocacy groups
    - Lower income
    - Community organizing
  - ❖ Expansion of choices in advocacy
    - More voice in Legislation
  - ❖ Community involvement
    - Public issues
    - Schools
    - Community committee work
- Meaningful/purposeful advocacy activities
  - ❖ Doing something positive for others; helping others
  - ❖ Contributing/ helping others/ doing service/ making a difference

#### Involvement in Decision Making

- Being invited to the table
- Being able to say what you value
- Being able to give input in a forum
- Participating in focus groups

#### Engaging in Knowledge Development and Education Activities

- Intellectual stimulation, enhancement and enrichment
  - ❖ Taking a class
  - ❖ Reading
  - ❖ Self directed education
  - ❖ Community involvement
    - Arts and leisure
  - ❖ Intrinsic value of learning
- Advancing one's formal education
  - ❖ GED
  - ❖ Technical training
  - ❖ College education
- Expansion of choices in education
  - ❖ General education
  - ❖ Advanced education
- Having educational opportunities

## **SECTION 7.B: MEANINGFUL ACTIVITIES – WHAT HINDERS**

### Barriers to and within Benefits

- Disincentives to working & Catch 22's
- Risk/fear of losing benefits

### Stigma and Prejudice

- External/community stigma
  - ❖ Media messages focus on mental illness
  - ❖ Discrimination
- Fear of stigma/rejection
- Low job expectations
- Psychiatric labeling
  - ❖ Treated as a victim

### Limited Employment Choices/Lousy Options

- Limited range of jobs
- Underemployed
- Stagnant jobs
- Unemployment
- Lack of opportunity

### Exploitation of Consumers

- Financial e.g., over reliance on volunteer services

### Disabling conditions of Illness Itself

- Loss of identity when lose job
- Not being able to work can be debilitating

### Lack of Education Opportunities

- Lack of access to advanced education opportunities

## **SECTION 8: PEER SUPPORT/SELF-HELP**

### **SECTION 8.A: PEER SUPPORT/SELF-HELP – WHAT HELPS**

#### Peer Support Groups, includes:

- Peer directed support groups/ self-help groups/ ex-patient groups/ mutual aide groups
- Peers support groups without professionals
- Peer support groups with professionals
- Bipolar group

#### Peer Education/Peer Advocacy, includes:

- Advocacy groups
- Peer conferences/recovery conferences

- Funding consumer to consumer teaching of self-responsibility

Peer-Provided/Consumer-Run Services, includes:

- Drop-in centers
- Warm lines
- Social clubs
- Consumer dances

Peers in Helping Roles, includes:

- Employ more consumers/ higher proportion of consumers
- Peer professionals/ peer therapists
- Peer mental health department staff
- Office of Consumer Affairs
- Peer advocates
- Peer outreach workers
- Peer case managers
- Peer specialists
- Peer hospital care workers

Peer Recovery Role Models

- Role models
- Connecting with people like yourself/Connecting around shared experience/"If they could do it so could I"
- Role model of activists
- Being a role model/founding groups

Referral to Self -Help Options

Other Self-Help Options, includes:

- AA
- NA
- Double Trouble
- Having a sponsor

## **SECTION 8.B: PEER SUPPORT/SELF-HELP – WHAT HINDERS**

Lack of Peer Support/Self-Help Services

- Lack of referrals to peer support

Rank and File Apathy among Peers

Lack of Transportation to Peer Support /Peer Activities

Lack of Funding

- Infighting over limited funding

## Power Struggles

### SECTION 9: FORMAL SERVICES

#### SECTION 9.A: FORMAL SERVICES – WHAT HELPS

##### The Formal System Culture and Orientation

- Should be recovery oriented (recovery bigger than service system)
  - ❖ State level mental health advisory council should adopt a vision of recovery
  - ❖ Encourage people to grow
  - ❖ Foster interdependence (let go of dependency on the system, use it only for what is needed)
- Should be a holistic approach
  - ❖ See people as whole persons/unique
  - ❖ Tolerance
  - ❖ Medication management alone too limited a strategy
- Should be more proactive, less reactive
  - ❖ Avenue to accessing services shouldn't be for "worse off" problem
  - ❖ Support preventative measures
- Should a partnership, consumers partnering with professionals
  - ❖ Understand our experience
- System is responsive

##### Formal System Systemic Structural Characteristics

- Funding that is adequate
  - ❖ Resource distribution needs to be more equitable (not just most severe)
  - ❖ Reinvest monies in the community not forced outpatient treatment
  - ❖ Create a voucher system where consumer has vouchers to purchase what is needed
  - ❖ Monies follows the consumer
  - ❖ Fund from the bottom up, direct services funded first
- System is consumer driven
  - ❖ Employ more consumers
    - 51% of mental health department should consist of consumers
    - Make all positions in any provider agency, like case manager or counselor, 75% consumer positions
    - All levels from hospital care worker to policy maker
  - ❖ Be committed to consumer voice and participation
    - Involve consumers more in decision making
      - ❑ Being invited to the table
      - ❑ Being able to say what you value
      - ❑ Being able to give input in forum
      - ❑ Having focus groups
      - ❑ Allow consumers to demonstrate to decision makers what they are talking about
      - ❑ Include consumers in decisions to fire staff

- Have an Office of Consumer Affairs or ombudsman program
- Have consumer positions on the community service and mental health boards, committees and subcommittees
  - Mental health committees around peer advocates
- ❖ Be accountable to consumer-oriented results
- System encourages innovation
  - ❖ Give up ineffective practices/programs
  - ❖ Provide RFPs for new and innovative programs
- Choice in services
  - ❖ Who, what, where and what kind
  - ❖ Choice between public and private mental health services
  - ❖ Choices are particularly important in the areas of:
    - Freedom of whether and how to participate in program and services
    - Medications
    - Control of type of therapy and treatment
      - Having no case management
- System is coordinated
- High standards and accountability
- System takes care of its employees

#### Types of Formal System Services needed, including

- Psychotherapy
- Counseling
- Inpatient groups lead by staff
- Case management
- Vocational services and supports (e.g., supported employment)
  - ❖ Opportunities to learn job skills
- Crisis outreach and support
- Day programs
- Group therapy
- Psychosocial programs
- Transitional services
  - ❖ Housing
  - ❖ Release from prison
  - ❖ Establish peer services in hospitals and jails to help connect with peers outside
- Integrated dual diagnosis services
- Safety net services (housing, access to school)
  - ❖ Establish shelters for people w/ psychiatric disorders
- Improved inpatient services/hospitalization
  - ❖ As a last resort
  - ❖ Escape from pressure
  - ❖ Small unit personalizes it
- Alternatives to inpatient hospitalization
- Jail diversion alternatives
- Payee services
- Warm lines (i.e., support lines)

- Support groups
  - ❖ Double Trouble, NA, AA, bipolar group, family & consumer group together
  - ❖ Support groups in outlying and rural areas
- Doctor visits
- Medications
  - ❖ The right medication, right combination
  - ❖ Proper maintenance
  - ❖ Access to atypicals, to the newly released medications
- Respite care
- Holistic health alternatives
- Community support programs
- Partial hospitalizations

#### Formal System Services Helping Qualities

- Clean/modern
- Knowledgeable practitioners
- Understanding professionals preferably with personal experience
- Adequate funding for services
- Respected Self directed inpatient care
- Implementation of advanced directives
- Payee should have business background
- Access to medical records
- Reformed/good case management
  - ❖ Individualized and catered care; listen to you
  - ❖ More case managers/reduced caseloads
- Provided with more choices
  - ❖ Wide range of options
  - ❖ Tolerance for diversity
- More outreach to minorities
- Medication, when do right, can help consumers feel empowered
- Resources easy to access

#### Formal System Services Education and Information

- Patient education
  - ❖ Learning about disorder
  - ❖ Information on medications
    - Current advancements, improved information
    - Side effects
  - ❖ Existing resources and how to get them
  - ❖ The rights and procedures regarding treatment and services
- Family education
- Public awareness education
  - ❖ Increase public education to reduce stigma
  - ❖ Anti-stigma campaign

#### Formal System Services Access

- Help with navigating the system
- Help with knowing what's out there
  - ❖ Knowing what resources are available
  - ❖ Having a resource list
- Extensive outreach efforts
- 24/7 telephone access to services in all spoken languages
- Access to records (ability to change erroneous information)
- Regular and frequent contact
- Evening services
- Parity in insurance

## **SECTION 9.B: FORMAL SERVICES – WHAT HINDERS**

### The Formal System Culture and Orientation

- Lack of holistic approach
  - ❖ System lacks orientation to build position of mental health, toward positive balance of living
  - ❖ Ignore spirituality/spiritual dimensions of psychosis
  - ❖ No attention to physical health
- Orientation overly medical/pathological/financing vs. consumer orientation
- Medical Model
  - ❖ Everything seen as an illness; illness orientation
  - ❖ We are not about symptoms only
  - ❖ Overmedication; over dependence on medication
    - Medication management alone too limited a strategy
- Crisis oriented v. rehab oriented – condition has to deteriorate to crisis before can receive help
- Infantilizing and dependency oriented
  - ❖ Does not support self responsibility
  - ❖ Learned helplessness
  - ❖ Paternalism
  - ❖ System encourages dependency
    - SS creates dependency
- Coercion/force
  - ❖ Coerced consent forms
  - ❖ Court mandated services
  - ❖ Systems control
  - ❖ Forced medication
  - ❖ Forced treatment because of homeless
  - ❖ Mandated connections
  - ❖ Removing choices
- Power inequities
  - ❖ Controlling professionals
  - ❖ Staff control
  - ❖ Role of consumer not valued
- Social control orientation

- ❖ Treatment/services/medication as means of control
- Stigmatizing
  - ❖ Attitude, culture, policies & tradition that the client is inferior to staff
  - ❖ Stigma in going for help
- Can be toxic

#### Formal System Systemic Structural Characteristics

- Lack of funding for effective programs, especially effective peer driven services
  - ❖ Funding cuts
- Incomplete oversight/accountability
  - ❖ Recipients viewed as source of billing vs. individual with freedom
  - ❖ Poor oversight of programs and systems
  - ❖ Lack of quality control of services
  - ❖ Inadequate/outdated state regs
- Inconsistencies, fragmentation (too many hurdles) and discontinuity
  - ❖ Differentiated rules and obstacles
  - ❖ Too much paper work, forms
  - ❖ Jump through too many hoops
  - ❖ Have to go to too many places to get services
  - ❖ Lose important services as your mental health improves
  - ❖ Withholding of information
  - ❖ Denied when seek help
  - ❖ Frequent changes of treatment providers (you never know who you will see, no one knows who you are)
  - ❖ Loss of continuity of services under managed care
- Inflexibility, Rigidity
  - ❖ Resources tied to certain levels of care, functioning, funding of programs
  - ❖ Over regulation that creates barriers, that doesn't contribute to quality
    - State regulation DMV licensing
  - ❖ Policies rigid on dual relationship (interactions with staff during off hours)
  - ❖ Innovation undermined by guidelines and funding stream attached to RFPs
  - ❖ Bending people to programs, not centered on person's needs
- Lack of choice and selection of services
  - ❖ System decides for you what you need
    - Hierarchical
    - Staff do not interview
    - Lack of partnership in decision making or treatment relationship
- Discrimination
- Providers rewarded for dependency
- System focused/system self-preservation rather than consumer focused/consumer driven
  - ❖ Lack of meaningful consumer voice in system
  - ❖ There is not an organized peer advocacy system for individuals/system
  - ❖ Tokenism in the use of consumer leader
  - ❖ No peer or consumer input in planning supportive housing
  - ❖ Consumers not employed or paid for their work

- ❖ Consumers not in loop to know about or compete for RFPs
- Payorship requirement/expectation that pay

#### Lack of Needed Formal System Services, including

- Lack of alternatives to hospitalization
- System doesn't know how to engage, support and respect families
- Lack of funding for supportive employment
- Lack of referral to self help options
- Don't promote peer support
- Lack of alternatives to involuntary treatment
- Loss of clinical supports/safety net
- Lack of specialized services for trauma survivors
- Lack of specific services, e.g., therapy, case management, psychosocial rehab
- No meds for indigent
- Lack of support for higher level of employment
- Lack of individualized services
  - ❖ Absence of ISP (individual service plan)
- Lack of program/treatment options
- Lack of places for dually diagnosed
- No outreach
- No alternatives to turn to when the public system doesn't help
- Lack of education on illness

#### Formal System Services Hindering Qualities

- Iatrogenic/adverse effects in treatment
  - ❖ Over medication
    - Wrong
    - Ineffective
  - ❖ Medication side effects
  - ❖ Tardive dyskinesia
  - ❖ Changing meds/No support as attempting to adjust
- Fragmentation of substance abuse and mental health services
- Records and treatment plans not shared with consumers
  - ❖ Faulty information
- Lack of confidentiality
- Services driven by insurance benefits
- Lack of service coordination
- Substandard service/Poor quality of care
  - ❖ Poor case management
    - High case load
  - ❖ Poor psychiatric services
    - Shock therapy
    - Short sessions
- Involuntary service termination
- Infantilizing e.g., day treatment that's like "adult babysitting"
- Hospitalization/Institutionalization, Long term hospitalization

- ❖ Lose living skills
- ❖ Retraumatizing
- ❖ Lose sense of being a citizen
- ❖ Detention/sentenced
- ❖ Abuse
- ❖ Abuse of power/authority in hospitals
- ❖ Seclusion /lack of access to the outside
- ❖ Restraints
- ❖ Hospital discourages continuing contact with other patients
- ❖ Locked away – “out of sight out of mine”
- Substituted judgment
  - ❖ Conservator
  - ❖ Representative payee
  - ❖ Payorship
- Help available only in emergencies
  - ❖ Termination without agreement e.g., doing too well
- Inappropriate (mis)diagnosis and treatment
- Invalidation (no recognition, criticism of choices)
- Exploitation of Consumers
  - ❖ Financial e.g., over reliance on volunteer services
- Social mental health segregation
  - ❖ Stay inside insular world
- Retaliation for filing grievance
- Lack of change and innovation
- When expert advice doesn't work
  - ❖ Expert advice fosters false hope

#### Lack of Education and Information regarding Formal System Services

- Withholding information
- Lack of practical education
  - ❖ Not good information
- Lack of illness education/patient education
  - ❖ Lack of information on diagnosis, help, and how to improve
  - ❖ Lack of information about service availability
- Lack of information on resources
- Not enough information
- No options for getting information
- Lack of knowledge of, and or belief in having, rights
- Lack of public awareness or knowledge of mental disorders

#### Barriers regarding Access to Formal System Services

- Lack of access to services and care
  - ❖ System is a gatekeeper more than a caretaker
    - Lack of meaningful access for all but the very wealthy or very poor
  - ❖ Resources tied to certain levels of functioning
  - ❖ Resources tied to certain levels of care

- ❖ Eligibility restrictions or limited eligibility, e.g., homelessness exacerbated due to housing policies
- ❖ Lack of access based on self defined need
- ❖ No movement off of waiting list
- ❖ HMO limitations
- Lack of timely access to services and care
  - ❖ Unresponsive staff
  - ❖ High caseloads
  - ❖ HMO procedures
  - ❖ Long delays, several steps before get services
  - ❖ No walk-ins
  - ❖ Waiting lists
- Transportation barriers
- Rejection of help seeking behavior
- Time limited services

## **SECTION 10: FORMAL SERVICE SYSTEM STAFF**

### **SECTION 10.A: FORMAL SERVICE SYSTEM STAFF – WHAT HELPS**

#### Staff-Consumer Relationship

- Partnering/collaborative relationship with providers
  - ❖ e.g., Listened to, believed, ask for our opinion
  - ❖ Equal
- Empowering relationship

#### Matched to the Right Staff

#### Staff Attitudes/Qualities

- Authentic e.g., trustworthy, honest, open,
- Respectful
- Positive expectations e.g., see recovery possible
- Supportive
- Caring
- Culturally sensitive e.g., to gays
- Humility
- Understanding the consumer experience
- Knowledgeable
- Innovative

#### Responsive Roles

- One on one relationship
- Teach self empowerment
- Provides multiple roles /Practical support
  - ❖ Stands by me with every type of problem
  - ❖ Calls to ask how feeling

#### Staff Availability/Access to staff

- Continuity of caregiver
- Great if can go in unannounced
- Reduced paperwork burden

#### Training & Education

- Improve training
  - ❖ Train ER
  - ❖ Training by consumers
- Doctors should be educated on medication interactions

### **SECTION 10.B: FORMAL SERVICE SYSTEM STAFF – WHAT HINDERS**

#### Staff-Consumer Relationship

- Power differential
  - ❖ Lack of consumer participation in treatment planning
  - ❖ Abuses of power
- Staff doesn't know what it is like being a consumer
- Paternalism
- Coercion
  - ❖ Staff control by pressure, threats and force
- Being treated based on preconceived notions based on diagnosis

#### Staff Attitudes/ Qualities

- Disrespectful attitudes
  - ❖ Condescension
  - ❖ Treat me like I am nothing
  - ❖ Don't listen to what you have to say
  - ❖ Patronizing
  - ❖ Dehumanizing
- Infantilizing
- Low expectations e.g., never get better
  - ❖ Don't believe in recovery
- Lack of trust
- Cultural insensitivity and incompetence
- Uncaring
- Untrustworthy/untruthful
- Devaluing/invalidation e.g., no one would listen
- Labeled as trouble maker; retaliation

#### Burnout/ Overworked

#### Role Issues

- Staying in formal roles e.g., detached, objectifying
- Rewarding dependency (conflict of interest)

- Burdened with paperwork

#### Inadequate Knowledge and Training

- Lack of up-to-date treatment information e.g., don't know meds
- Lack of professional training
  - ❖ Trauma services

#### Not Culturally Diverse Enough

- Not enough African American/Black staff