Capabilities:
A Framework for Social Recovery in Public Mental Health

Mary Jane Alexander, Ph.D.
Nathan Kline Institute
New York University

April 30, 2013

The Center was supported by

- NIMH MH-078188 (P.I. MJ Alexander)
- Nathan Kline Institute - NYS OMH

The views expressed in this presentation are solely those of the presenter and do not represent the views of NIMH, NKI or NYS OMH

MANY, MANY PEOPLE MADE THE CENTER POSSIBLE

Center Leadership at NKI: Kim Hopper, Kris Jones, Christina Pratt

Community Partners: Isaac Brown, Amy Colesante, Tony Hannigan, Ellen Healion, Sophie Mitra, Phil Yanos

Center Staff: Seana O'Callaghan, Donna Brophy

Center Investigators: Carole Siegel, Beth Shinn, Sue Barrow, Ben Henwood, Lara Weinstein, Pathways to Housing CBPR Panel, Jacki McKinney, Jeanne Dumont, Lauren Tenney, Priscilla Ridgway, Eileen McGinn, Brandon Vick, Sarah Bergstresser, Alisa Lincoln, Boston CAMPH group Andrew Kirsch, Nora Kenworthy, Josh Koerner, Sarah Kopelivitch, Sarah Lewis, Elizabeth Austin, Molly Finnerty, Peter Stastny, Norma Ware, Pat Deegan, The Field School co learners and faculty

Webinar Outline

- Capabilities, Recovery, Public Mental Health
- The Center - In pursuit of Process & Opportunity Freedoms
- Selected Projects
  - Freedom Discussions - Valued Functionings:
  - Peer support: Agency and Activation
  - Alternatives to MH Crisis: social participation, social networks, agency, peer support
  - Contexts of Parenting: Expanding Opportunities

RE-THINKING RECOVERY

WHY APPLY CAPABILITIES TO PUBLIC MENTAL HEALTH?

Rethinking Recovery

Justice and Policy

- Advocacy: Service Users' press for human rights
- Justice: Full Community Participation by all members of a diverse society.
- Policy: Costs of unrealized lives

Evidence

Long on hope, under specified, short on operational detail

Social Science

Social Determinants evidence and CF accommodate expanded understanding of Recovery

Recovery: Personal & Social Meanings

Rediscovering meaning and purpose after a series of catastrophic events which mental illness is.

Deegan, psychologist & consumer activist

A personal journey of actively self-managing a psychiatric disorder while reclaiming, gaining & maintaining a positive sense of self, roles & life beyond the mental health system, in spite of the challenge of psychiatric disability.....Recovery is supported by a foundation based on hope, belief, personal power, respect, connections & self-determination.

Onken, Dumont et al, Mental Health Recovery

The process in which people are able to live, work, learn and participate fully in their communities

New Freedom Commission

A Lens on Human Development:
Behavioral Health Conditions

A Long and Healthy Life

Access to Knowledge

A Decent Standard of Living

Behavioral Health Conditions

Life Expectancy
25-32 years less than general population.

Marginal Literacy Rates
Half as likely as the general population to be at least marginally literate
[50% v 75%]

Income Below Poverty Line
3x more likely among Households where a member has a MH **Disability**

Sources
Health - Colton & Manderscheid (2006)
Literacy - Sentell and Shumway (2003)
Income - Vick Jones Mitra (2011)

People are the real wealth of nations…

Development Should…

…Enlarge Human Freedoms

…Expand People's Choices to Lead Full & Creative Lives

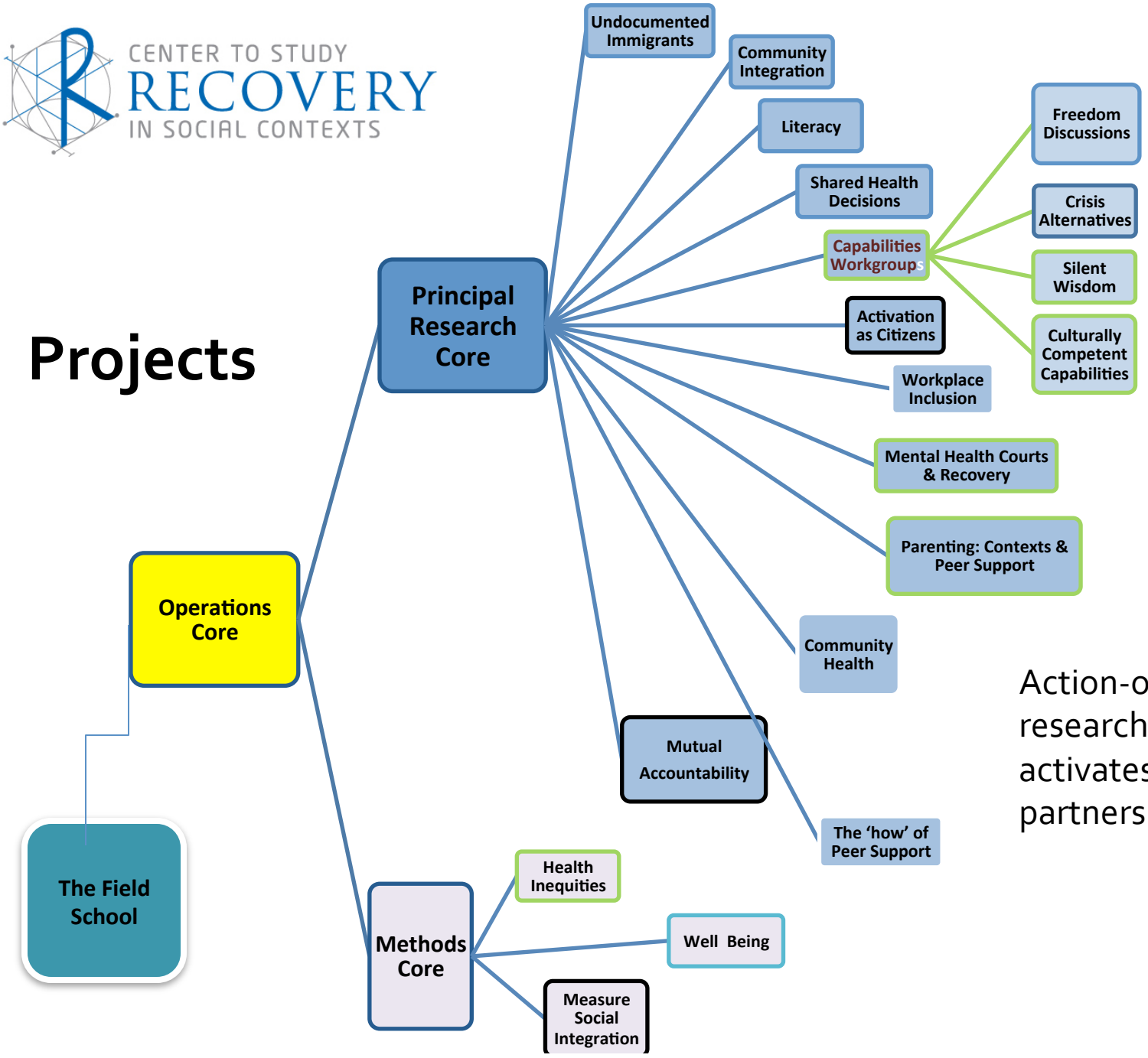
…Include people as Beneficiaries & Agents of its progress and change

…Build on the participation of each person

CENTER PROJECTS & PARTICIPATION

CENTER TO STUDY
RECOVERY
IN SOCIAL CONTEXTS

Projects



Action-oriented research that activates & supports partners' agency

CENTER TO STUDY RECOVERY IN SOCIAL CONTEXTS

Activities

Capabilities Seminars – monthly

Pro seminars – quarterly

Conferences – annual

Field School – ongoing, formal capacity building

Participation as Center Method

- Goals & Partnerships
  - Questions relevant to community values and answerable by empirical research. Access to make findings actionable.
- Core Elements/Process of CBPR
  - Mutual respect and trust
  - Capacity building (community empowerment, skills, ownership; researchers enhance questions, measures & methods; understand advocacy issues and impact of findings)
  - Accountability, transparency, sustainability
- Partnerships Add Value in all phases of Research & Action
- Ethical and Implementation Challenges

Hopper, Pratt,

BUILDING PARTICIPATION: THE FIELD SCHOOL

BUILDING PARTICIPATION
A Field School Pilot- Hopper, Pratt

Goal

- To build research & employment capacity for people with MH disabilities through intensive, combined didactic & experiential training

Curriculum

- Focus on models of critical thinking about community, participation, research
- Instruction in basic MHSR research design & analytic methods
- Field exercises in research design and methods
- Apprenticeships in ongoing Center projects

Process Evaluation

- Routine feedback, observation, documentation, interviews.
- Tracked research employment and education

Outcomes

- Enhanced participants' participatory capacity: voice, standing,presence
- Students obtained research employment, resumed or began formal degree programs; enhanced skills in current employment and advocacy
- Method closely documented; curricular materials developed
- Feasibility, difficulties and promise of the approach synthesized

FUNCTIONINGS: LOCALLY VALUED BEINGS & DOINGS

Lauren Tenney, MA, MPA, Psychiatric Survivor

FREEDOM DISCUSSIONS: AN EXPLORATORY, QUALITATIVE STUDY

Freedom Discussions

AIMS

- Conduct Survivor Research
- Values Clarification for Community and Center

ASKED PARTICIPANTS

- What is a decent life?
- What is a dignified life?
- What is a distinctive life?

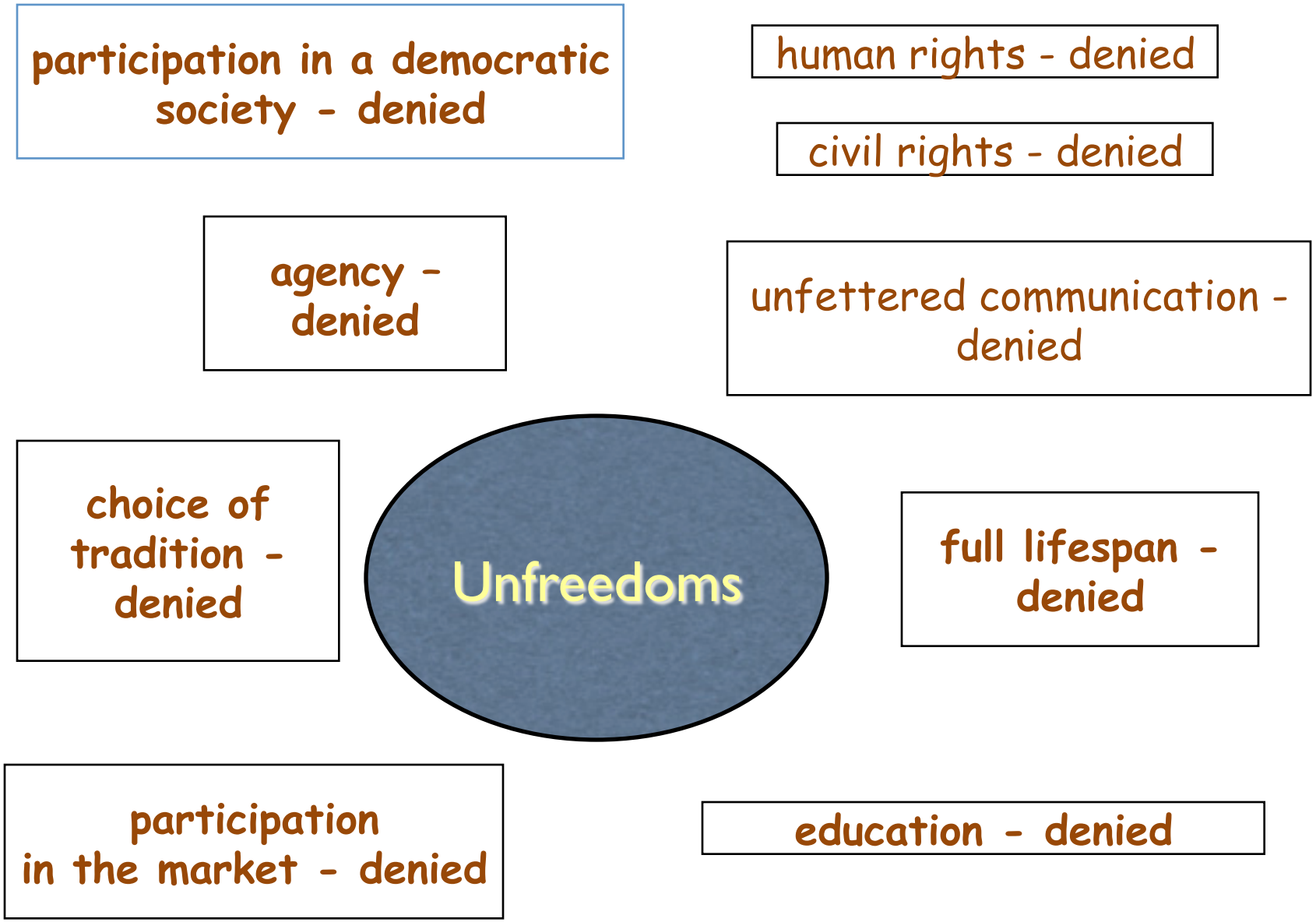
NOT DECENT	DECENT
Being trapped - locked up.	Your basic needs are met - food, clothing, shelter - *transportation was always a debate
Being raped and abused.	Not feeling stigma or discrimination.
Stressors from lack of money.	Having friends you can trust.
Not having any kind of community.	Being respected.
Not being able to be safe in your own skin.	Feeling like you have some power.
Being the life of the party and still wondering where the razor blades are.	Self-determination.

NOT DIGNIFIED	DIGNIFIED
People holding you back & making money off you.	Taking care of things & dealing with stress.
Being cut off from your family is awful.	Being able to help others.
Children on drugs. . . Schools controlling children.	Having meaningful employment/ volunteer work.
Being frustrated by frustrating situations.	Financially solvent.
People smiling while I talk about my pain - don't go there. I wasn't having a hallucination - she was laughing.	You learn from circumstances - gain a sense of maturity (which is **not** determined by age.
Court ordered to CDT - it's punishment.	To be able to self-advocate for myself as an adult.

NOT DISTINCTIVE	DISTINCTIVE
It keeps reverting back to money. If you're poor it's "mental illness" or "crazy" - if you're rich - you're eccentric.	Having a purpose - that your life has meaning.
Your family calling you crazy.	Having faith.
Adult Protective Services (APS) follow you and treat you like trash.	Being able to take a negative experience and turn it into a positive one - to find good in a bad situation.
You have to hide.	I start to help other people.
Heavy meds, sleeping and snoring in public.	I start asking for things.
Mental health retention court - to treat over objection.	Not using medicine. Thinking maybe I don't have to go there - program - If I stopped going would I be well?

WHAT MAKES A . . .

Decent Life?	Dignified Life?	Distinctive Life?
Your basic needs in life are met.	You have a little extra to get what you want.	You have enough for yourself and want to give to others.


participation in a democratic society - denied
human rights - denied
civil rights - denied
agency - denied
unfettered communication - denied
choice of tradition - denied
Unfreedoms
full lifespan - denied
participation in the market - denied
education - denied

The expanded "capabilities" version

- What really matters: real opportunities to achieve locally prized "beings and doings"

- Four domains for Public Mental Health
  - Basic securities
  - Treatment
  - Social participation + citizenship
  - Individual life projects

* NOTE: ignoring costs (equity).

The Capabilities Approach

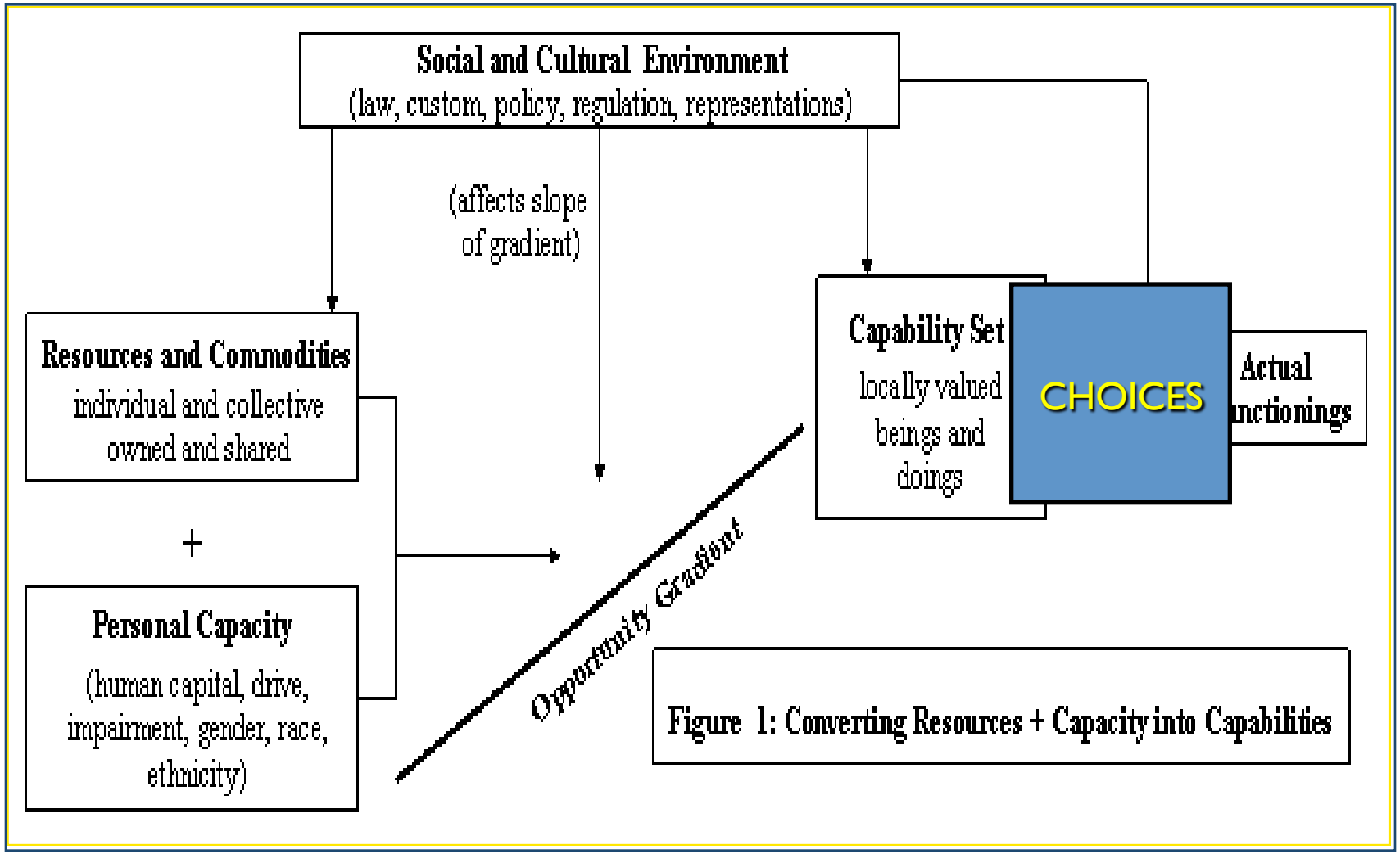


Figure 1: Converting Resources + Capacity into Capabilities

Elizabeth Austen, Isaac Brown, Sarah Lewis, Ellen Healion, Kim Hopper

MENTAL HEALTH PEERS – AGENCY & ACTIVATION

Peer Support

- Engages people in recovery
- Demonstrates that recovered identities are possible
- Works through trust, attuned support, nuanced understanding of capacity, and perspective
- Accountability is integral to providing support
- Takes place in the social world where people execute recovery
- Provides the supporting peers with opportunities to
  - Develop an identity beyond illness
  - Work for pay
  - Develop practical skills
  - Process and use their own MH history

Kim Hopper, Seana O’Callaghan, Pablo Sadler, Jody Silver, Deborah Layman, Kris Jones, Mary Jane Alexander

PARACHUTE NYC: AN APPROACH TO PSYCHOSIS RELATED CRISES

Mental Health Crisis Alternatives Developing Parachute NYC

- Center Conference provided a concerted opportunity for MH service recipients to voice their experience of unhelpful coercion, danger, trauma and disruption in standard Acute Inpatient hospitalization for psychosis related Mental Health crisis. Center commissioned papers on agency related to individual lived experience and to families' experiences. Current and historical alternative models presented and discussed.

- Center Capabilities Work Group comprised of NYC Director of Recipient Services, NYC DOHMH Medical Director, Community Psychiatrist, Center Investigators and support staff met for a year to develop a practical, alternative model based on Conference proceedings.

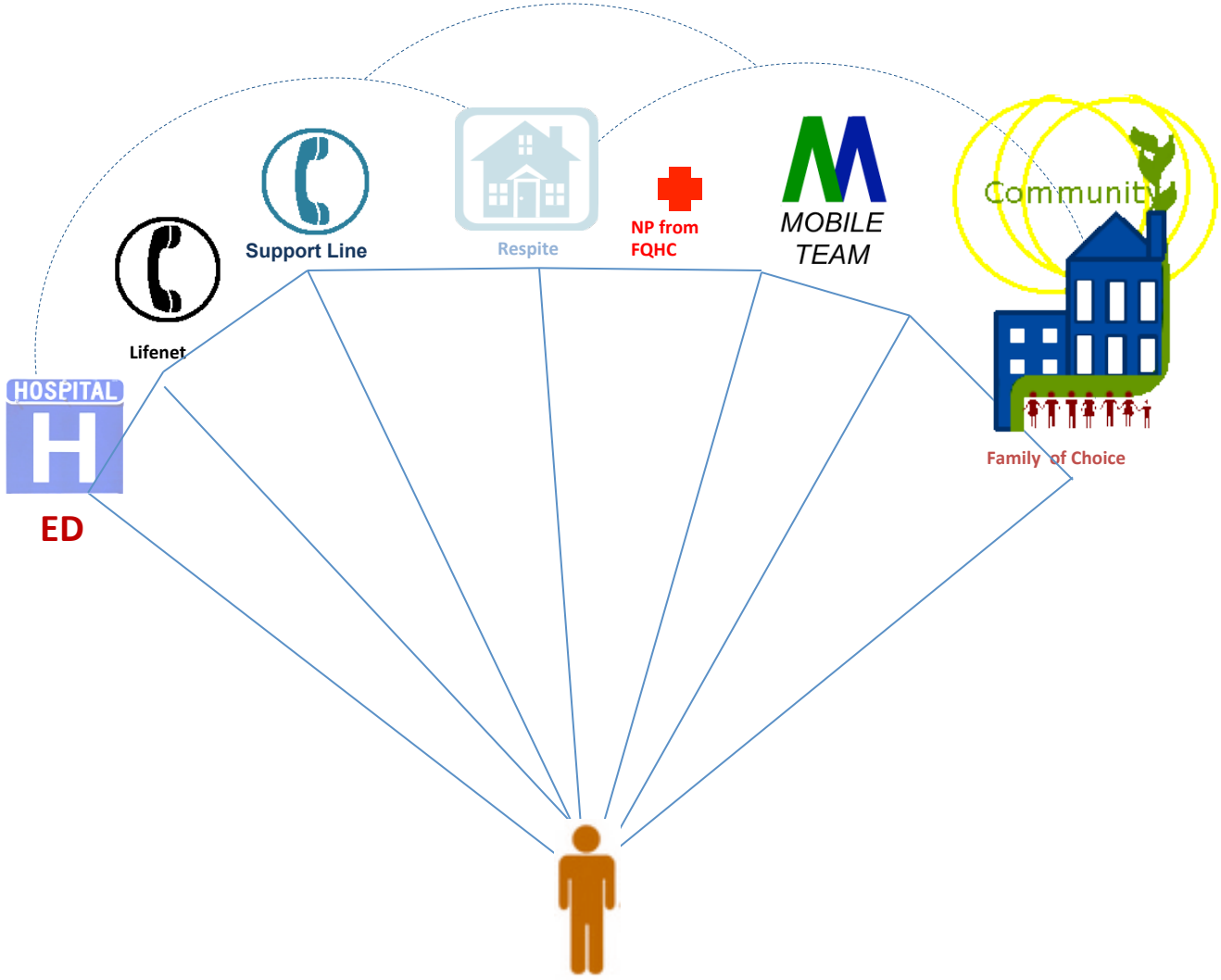
- [Several unsuccessful funding attempts]

- Medicaid call for innovative proposals to improve health, quality of life and decrease costs. NYC receives $17 million to launch Parachute.

The Voice for Crisis Alternatives

Un freedoms	Alternative
Coercion	Community treatment with full participation
Hospitalization	Peer supported Crisis Respite
Medications for psychotic symptoms	Medications for sleep, anxiety
Disrupted job, family, school, relationships	Sustain, call on, build networks
Isolation, stigma, alienation from self and others	Make meaning of crisis; Peers as 'like others' encourage mutual responsibility

Parachute NYC Components



Sue Barrow, Jacki Mckinney, Mary Jane Alexander, Deborah Layman, Christina Pratt

CONTEXTS OF PARENTING

Parenting & Mental Health Conditions

- One fifth of women, and one tenth of men with a 1-year (NCS-R) Mental Health condition are parents[1]
- 12% or about 2 million mothers living with youths aged 12 to 17 had a serious mental illness during the past year[2]
- 12% of youths aged 12 – 17 – about 3 million kids - lived with a mother who had a serious mental illness[2]
- About 3.4% of 12-17 year old youth lived with a mother who had both a Serious Mental Health Condition & a Substance Use Disorder[2]
- Parents with Mental Health Conditions are at high risk for losing custody[3]

[1] From Nicholson (2001) using NCS; [2] NSDUH, 2002, 2003; [3] Burton, 2002

Questions posed

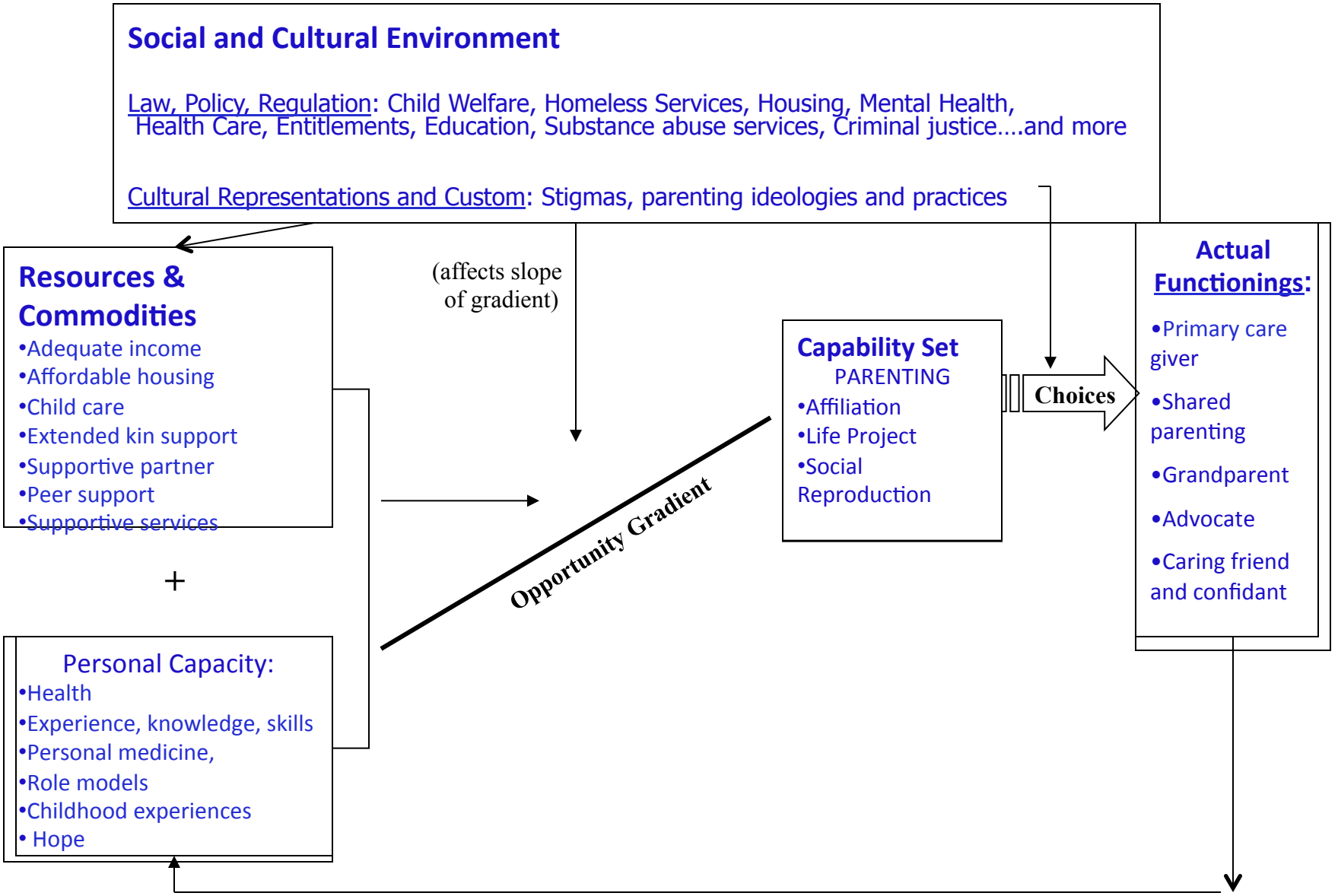
What are the life contexts of Mothers with Mental Health Conditions?

How do Mothers with Mental Health challenges interact with the social & cultural?

What do these Women value?

What do they need to support their ability to do and be parents?

A Capabilities Schema for Parenting



Contexts: Mental Health & Family Poverty

Medical Expenditure Panel Survey (2007)[1]

- Families that include a working age member with **any** MH diagnosis are 1.76x as likely as families with no MH diagnosis to be poor.
- All aspects of Poverty – rate, depth and severity - are significantly greater for these families
- These aspects of Poverty - rate, depth and severity - are higher for mood and psychotic disorders compared to other diagnoses

[1]Vick, Mitra, Jones, Alexander (2010) Social Indicators

Doing More with Less

ISSUES FOR ALL PARENTS

Finances

Housing

Food

Employment

Medical care

Childcare

Family supports

Balancing family needs

Transportation

ESPECIALLY CHALLENGING FOR WOMEN WITH MH DIAGNOSIS

Pregnancy

Family relationships

Social networks

Custody challenges or threats

Medical needs

Victimization and trauma

Limited finances due to discrimination, health issues single parent income

Children's emotional & behavior challenges

Homeless Women: Demographic and Clinical Profiles

Homeless alone

- 47% of all homeless women
- 25% of solo adults
- 59% Black or Latina
- 41% under age 35
- 30% disability income (SSI)
- 53% MH symptoms
- 47% any lifetime substance dependence [2]

Homeless with families

38% of all homeless women

- **84% of family heads**
- 62% Black or Latina
- **73% under age 35**
- 13% disability income (SSI)
- **36% MH symptoms**
- **28% any lifetime substance dependence** [2]

[1] Burt et al. 2001 (NSHAPC) except substance dependence
[2] Smith & North 1994

Parenting Capabilities: Formerly Homeless Mothers in supported housing

AIM 1 Explore mothers' parenting experiences & aspirations; parenting supports & barriers once housed

Method In-depth narrative interviews with 15 formerly homeless mothers - 8 living with, 7 living without children - in a range of supportive and subsidized housing settings

AIM 2 Explore how key stakeholders perceive needs and capacities of mothers dealing with MH, Substance Use and Housing issues - complex recovery trajectories

Method Group Discussions with

- Currently Homeless **Mothers** in a Singles Shelter
- **Grandmothers** caring for children of daughters with MH & SUD problems
- **Staff** at housing programs for single adults with mental illness
- MH **Policy Administrators**

Barriers to Parenting:

Navigating Multiple Systems

Systems in Conflict: Competing Agendas & Timetables

- Shelter system: intensive services to foster stable exits from homelessness; limited interest or expertise in family issues or housing options
- Treatment programs: "work on yourself" and defer parenting until in stable recovery; timeframes may be lengthy
- Housing programs: supportive housing for single adults as preferred post-shelter placement; admission requires drug free, on medication, work or benefits income
- Child welfare: protecting children, achieving permanence in 15 months (reunification or termination of rights to "free" child for adoption)

Mothers' Experiences, Perspectives, Aspirations…

- Mothers living alone and living with their children are at different points in their parenting trajectories.
  - Moms living alone were primary care givers in the past
  - Moms living with children had current or past separations

- Parenting is a primary identity and priority for both groups of mothers.

- Parenting goals of separated mothers were varied.
  - Reunification
  - Repairing damaged relationships with separated children
  - Building relationships with grandchildren.
  - Being friends & advocates for children cared for by others

Provider and System Perspectives

- Staff in single adult housing programs
  - limited knowledge of women's relationships, contact, or aspirations for reunification with children or grandchildren;
  - felt ill-equipped
  - lacked time
  - questioned the feasibility of addressing women's parenting issues
- State mental health policies
  - In contrast to Mothers' values, give no consideration to support for parenting
- Child welfare and child mental health policies
  - Mothers' issues and concerns are secondary to their focus on children. The two can conflict.

Wide Angle Lens: Parenting Contexts

A "wide angle" view of homeless women with MH Conditions reveals their connection to:

- Children who are not living with them.
- Complicated extended family networks caring for their children.
- Current and previous partners, spouses, and children's fathers with varied involvement with mothers and with children.
- Multiple institutional systems (homeless services, housing programs, child welfare, mental health, and substance abuse services, plus school and child health services). Their conflicting goals and timetables make conflicting demands on mothers.

Time lapse: Parenting Trajectories

A "time lapse" view of homeless women reveals recurring processes:

- Trajectories that tack between "regular" housing, doubling up with partners or relatives, family shelters, single adult shelters and single adult supportive housing as well as hospitals and residential treatment programs, with occasional incarcerations for some.

- A kaleidoscopic reconfiguration of their families over time as crises lead to dispersal and circulation of children within and outside family networks, and sometimes reunifications.

- Substantial periods of time when they lived with and cared for their own children and often those of others

Conundrums – of course

- Motherhood and family needs affect women's interactions with multiple systems but are supported by none.

- Women desire help with parenting issues but fear repercussions from seeking it (child welfare intervention)

- Tensions between professionally dominated discourse on child development (which guides assessments of adequate parenting) and the lack of resources and security of mothers trying to keep their children safe from physical and social hazards in low income communities without basic resources and supports

Implications: Recovery Approaches to Support Lives Women Value

- Service systems – Conflicting responsibilities
  - have failed to support women as parents
  - earned considerable distrust from many of the mothers they serve, despite their desire for support as parents.

- Motherhood – More than a set of skills
  - Motherhood is an identity that defines a meaningful life project for women whose mental illness, homelessness, and addictions have marginalized them from achieving valued social roles.

- More than Decent – Toward Dignified and Distinctive Lives
  - What approaches activate and support Parenting through engagement in community life?

Thank You!

CENTER TO STUDY
RECOVERY
IN SOCIAL CONTEXTS

http://recovery.rfmh.org

mja@nki.rfmh.org