Utilizing Group Concept Mapping to define "recovery" and build self-assessment tools for mental health programs

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American Evaluation Association
October 17, 2014
Denver, Colorado

Today's Talk

- Define stakeholder engagement in the context of evaluation
- Describe Group Concept Mapping
- Construct a "voice-activated" framework
- Provide an example of Valuing Voice in Evaluation

Stakeholder Engagement in Planning and Evaluation

- Stakeholder Engagement
- Community-Based Participatory Research (CBPR)
- Participatory Action Research
- "Nothing About Us Without Us"

Stakeholder Engagement

- Corporate social responsibility, informs dialog and leads to sustainable shareholder value

- **Values:** Seeks feedback on opinions of those likely to be affected, or currently influenced by an issue

- **Benefits:** Can create greater transparency, justifiable decisions

- **Limits:** Often "top-down", seeking feedback on already asked questions, power gatekeepers

Community Based Participatory Research

- CBPR (CAPR, COPR, CCPR)
- **Values**: collaboration in and of communities; potentially higher uptake for community change
- **Benefits** : greater commitment to results
- **Limits**: Power sharing, "translation" of content, unbalanced representation; needs long term commitment to get impact

Viswanathan M, Ammerman A, Eng E, et al. *Community-Based Participatory Research: Assessing the Evidence*. Summary, Evidence Report/Technology Assessment: Number 99. AHRQ Publication Number 04-E022-1, August 2004. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/clinic/epcsums/cbprsum.htm

Participatory Action Research

- Partners researchers and participants, focuses reflectively on **problem solving**

- Iterative focus on **impact of change**

- Honors and reflects the **experiences of people** directly affected

- Useful when official information (government, academic) does not reflect population experiences

Setswe, G. Et al. Participatory Action Research and Community Participation: Developing a People's Policy for Health in South Africa. SA: Human Sciences Research Council, 2014.

Whyte, WF: Participatory Action Research, Thousand Oaks, CA: Sage Publications, 1991.

Viswanathan M, Ammerman A, Eng E, et al. *Community-Based Participatory Research: Assessing the Evidence*. Summary, Evidence Report/Technology Assessment: Number 99. AHRQ Publication Number 04-E022-1, August 2004. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/clinic/epcsums/cbprsum.htm

"Nothing About Us Without Us"

- Asserts critical role of persons to create, approve, design and evaluate research

- "Anti-research", combats the hierarchical paradigm that creates the "other"—the subject; seeks to support healing

- **Values:** Negotiates for values, control, ownership. Establishes primacy of the population, for equity

- **Benefits:** Redresses historical bias and hierarchy of knowledge and power in a system, can lead to greater more effective change

- **Limits:** Capacity to translate research into tangible results for uptake; resource intensive
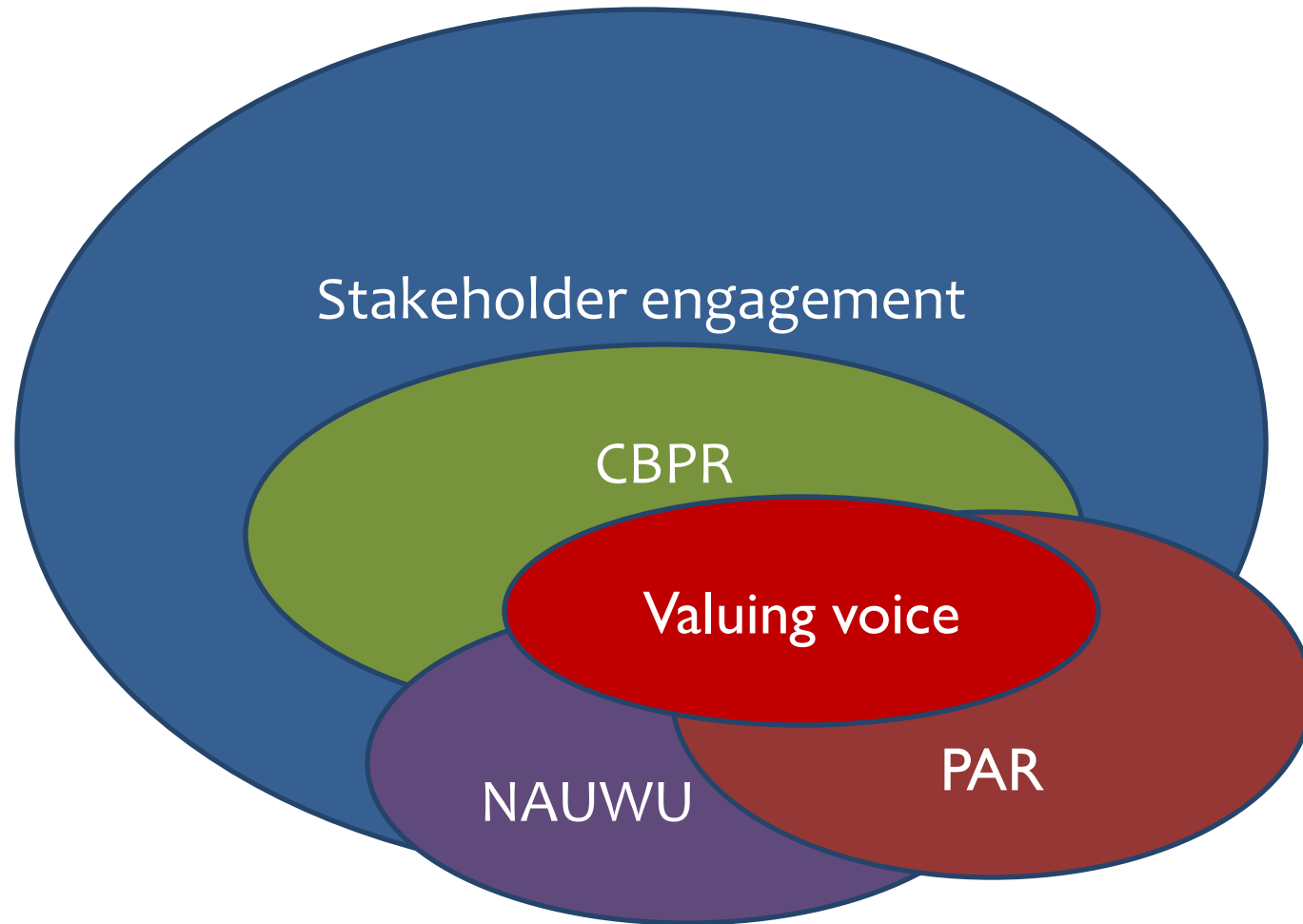
For example: Tuhiwai-Smith, Linda. Decolonizing Methodologies: Research and Indigenous People. 2nd edition, 2012. London: Zed Books.
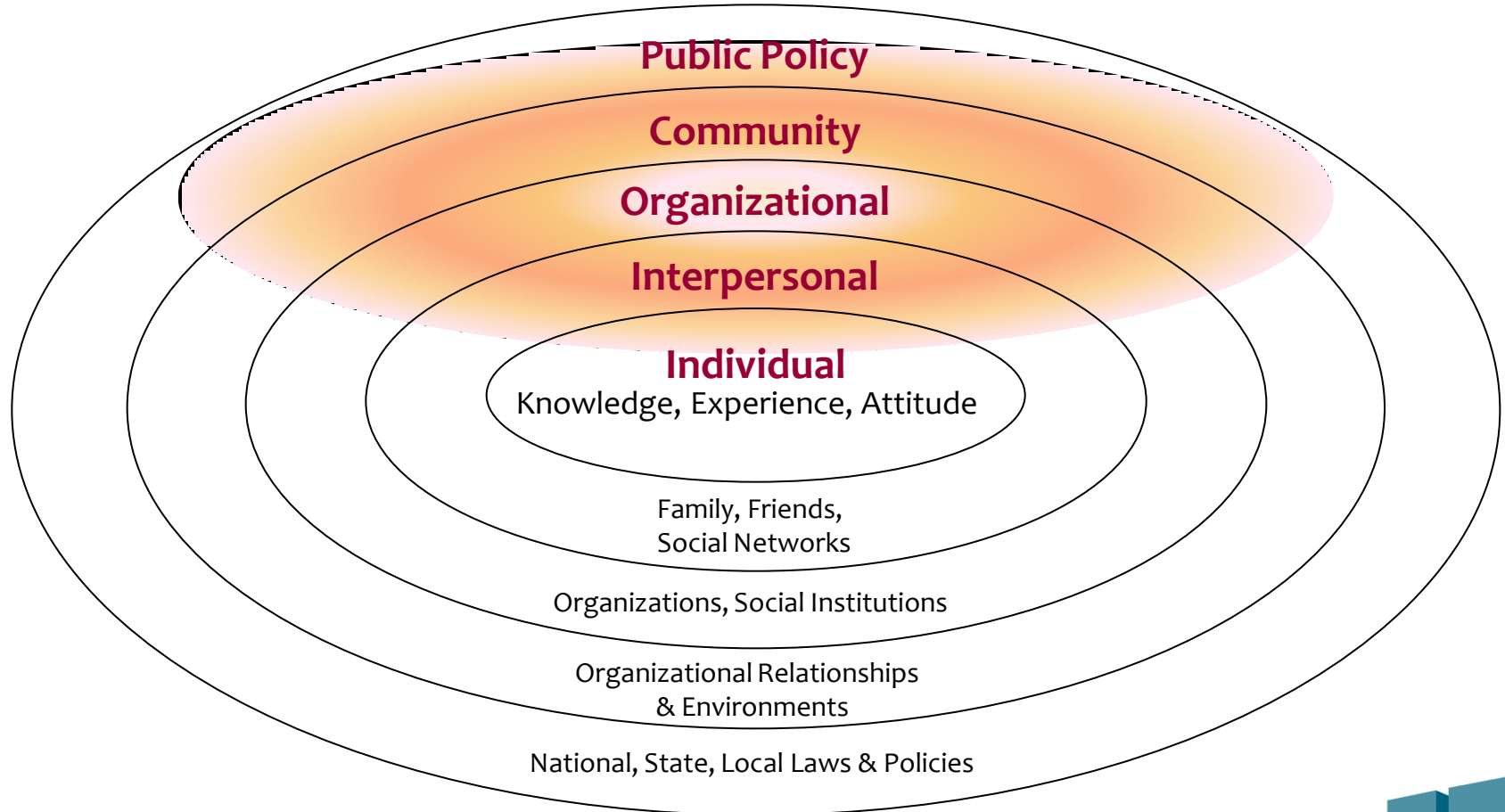
Valuing Voice

- Seeks, embraces knowledge of individuals to inform a big issue that affects many, to lead to group wisdom, in the owner's words
- **Values:** Assumes individual as a reliable unit of knowledge to inform the system
- **Benefits:** Mitigates hierarchical approach to social change evaluation, reduces reliance on advocates as voice
- **Limits:** Design challenges in capturing voice most efficiently and appropriately; obstacles to active participation
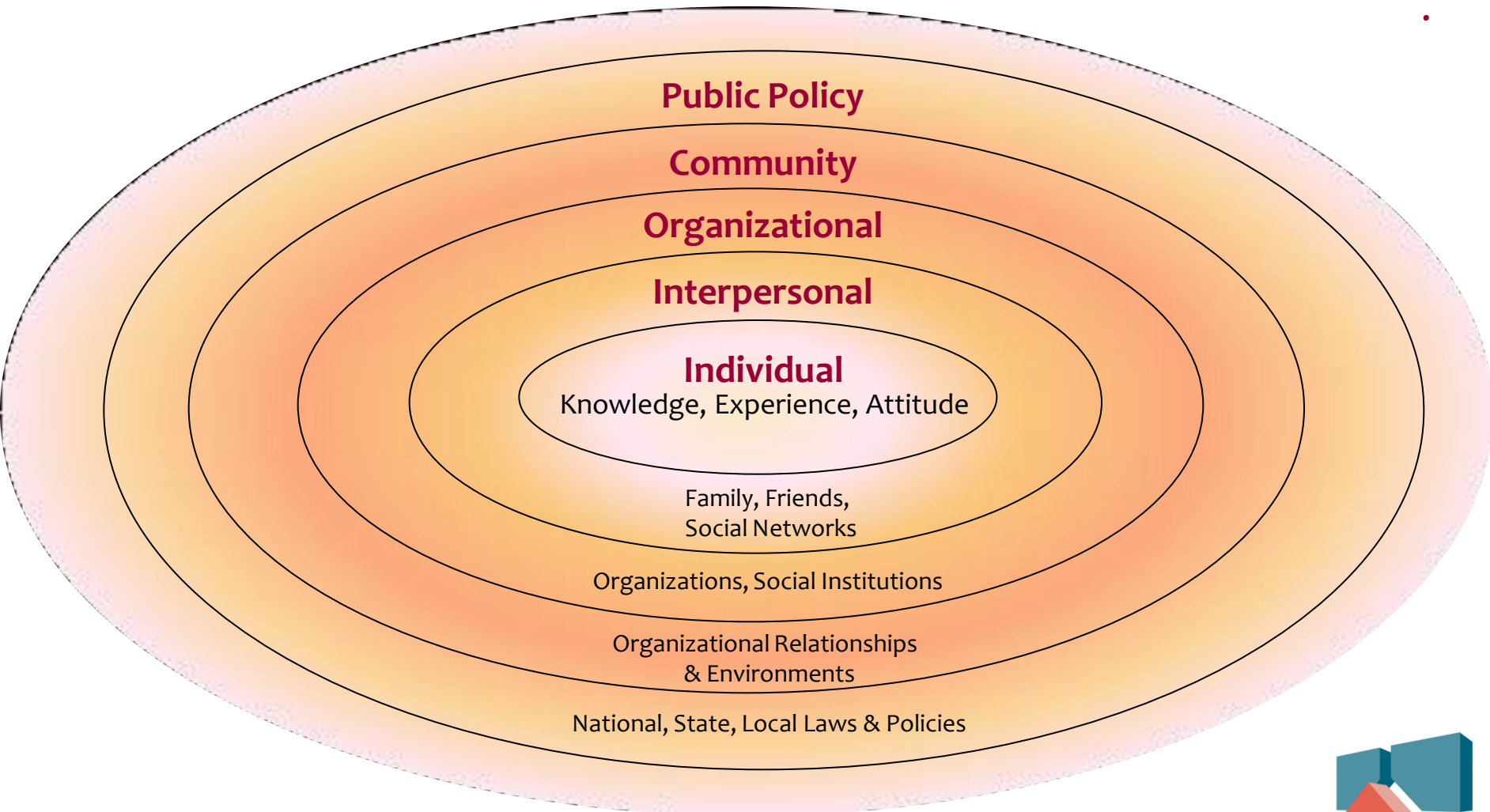- Uses: public health, mental and emotional health, people who have disabilities, aging/isolated populations

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Social Research Model: Proxy Agencies as Focus

Public Policy

Community

Organizational

Interpersonal

Individual
Knowledge, Experience, Attitude

Family, Friends,
Social Networks

Organizations, Social Institutions

Organizational Relationships
& Environments

National, State, Local Laws & Policies

Social Research Model: Individual as Focus

Public Policy

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National, State, Local Laws & Policies

A Method for Seeking and Valuing Voice: Group Concept Mapping

"Concept Mapping is a methodology that creates a stakeholder-authored visual geography of ideas from many communities of interest, combined with specific analysis and data interpretation methods, to produce maps that can then be used to guide planning and evaluation efforts on the issues that matter to the group."
Kane & Trochim, 2007.

Two key attributes: active engagement of individuals and emergent rather than hierarchical structure
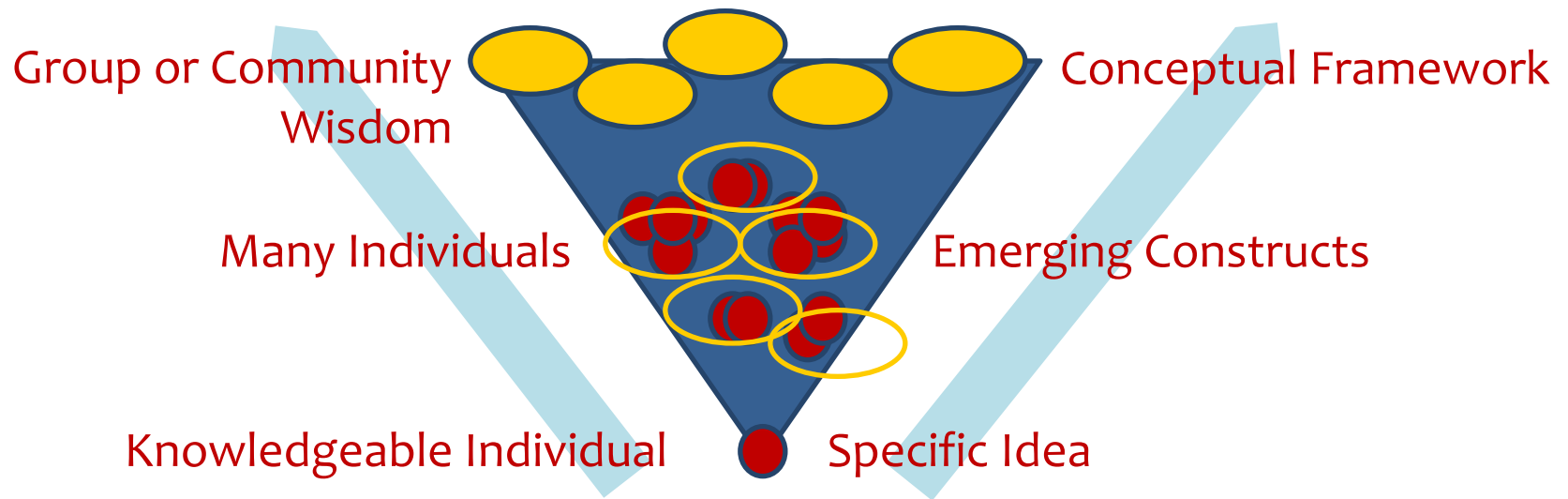
The Voice of the Person in the System of Inquiry

- **Actively seeks and captures voice**: the opinions, knowledge and articulations of need of "community" members

- Visual outputs are representations of the community's co-authored framework, along with individual contributed details

- **Simple rules and processes** encourage knowledge contribution at each step

- Community and partners can agree on implementation and evaluation priorities; **a purposeful partnership.**

- Systematically **aligns evaluation** with the "voice-activated" priorities within and across the framework

Individual Knowledge to Group Wisdom

Group or Community Wisdom

Conceptual Framework

Many Individuals

Emerging Constructs

Knowledgeable Individual

Specific Idea

# Group Concept Mapping: Participants as Authorities

Planning: Planners and others needed to move the project forward develop a *focus prompt* and *identify participants*

Idea Generation: Open to engage individuals to contribute to the group knowledge via web, in person, any other means relevant to the context

Structuring: Individuals *sort and rate* the results of the idea development, jointly authoring the structure and value of the issue
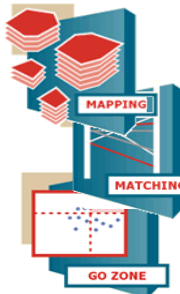
Analysis: Construct databases, produce results and compare analysis results options.

Representation: Compute the *maps, pattern matches and "go zones,"* and prepare them for interpretation by communities of interest.

Interpretation and Use: *Strategies and tactics for action* follow directly from the *interpretation* of the results. Pattern matches and go zones help build consensus on action.

Red=participant actions and contributions

Planning: Define the Issue

Determine Specific Aims:

- Seek the wisdom of the participants to describe what recovery feels like to them

- Inform program development, funding support for true recovery

Identify the Key Voices:

- Adults who have severe mental or emotional illness

- Staff and peer support

- 6 Locations

- Over 200 individuals

Develop Focus Prompt:

"A specific thing that makes this program effective in supporting a person's recovery is …"

Johnson et al. Utilizing Group Concept Mapping to Define Recovery Experientially. *Under Review.*

Idea Generation and Structuring: Record Knowledge and Opinion

Statement Collection

1. their investment in teaching citizens skills which help them stay motivated in their personal recovery process

37. that a person can have a bad day then leave and come back with a fresh start.

44. seeing the evidence of recovery through the recovery of others.

46. helps people learn to listen, and to be listened to.

84. classes help reclaim one's identity, self worth, self respect and dignity

90. getting to know an individual's immediate concerns and responding effectively from the first time someone comes here.

92. staff working here have similar experiences of mental illness and have recovered, which gives hope that each person can do it too.

1310

99
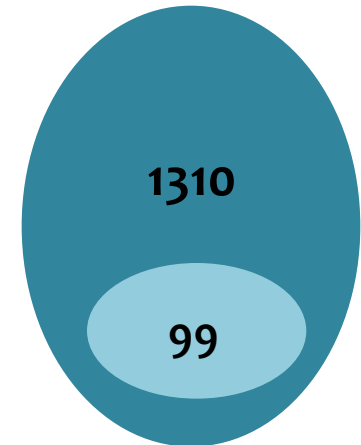
Sorting, Rating

- Individuals array items in unstructured sort that reflects their own thinking about meaning of issues and ideas to each other.

- Individuals rate each item (1-4) on **importance** and **evidence** at their location.

11. being part of this helps individuals connect to the community.
25. emphasis on diversity and individuals being integral to the community as a whole.
33. people connecting through activities and groups.

9. a nonjudgmental atmosphere that empowers people to speak while knowing that someone is listening to them.
48. practicing compassion for each other; accepting people right where they are.
57. Each person is treated with respect.

24. work at emphasizing health and unhealthy choices.
34. the education and tools to help considerably with social skills.
56. opportunities to develop physical fitness and healthy living skills at one's own pace and in one's own way.

"A specific thing that makes this program effective in supporting a person's recovery is …"

Proximity = similarity

Analysis and Representation: Cluster Map
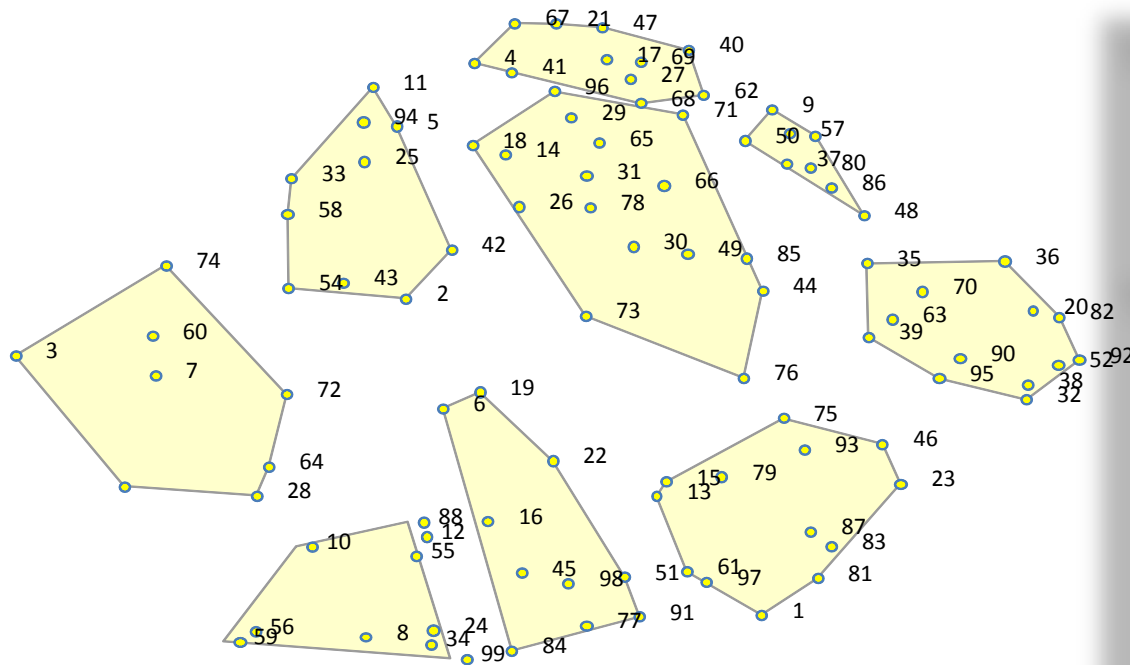
The Raw Materials:
- Statements
- Sort Input from each participant

The Tools
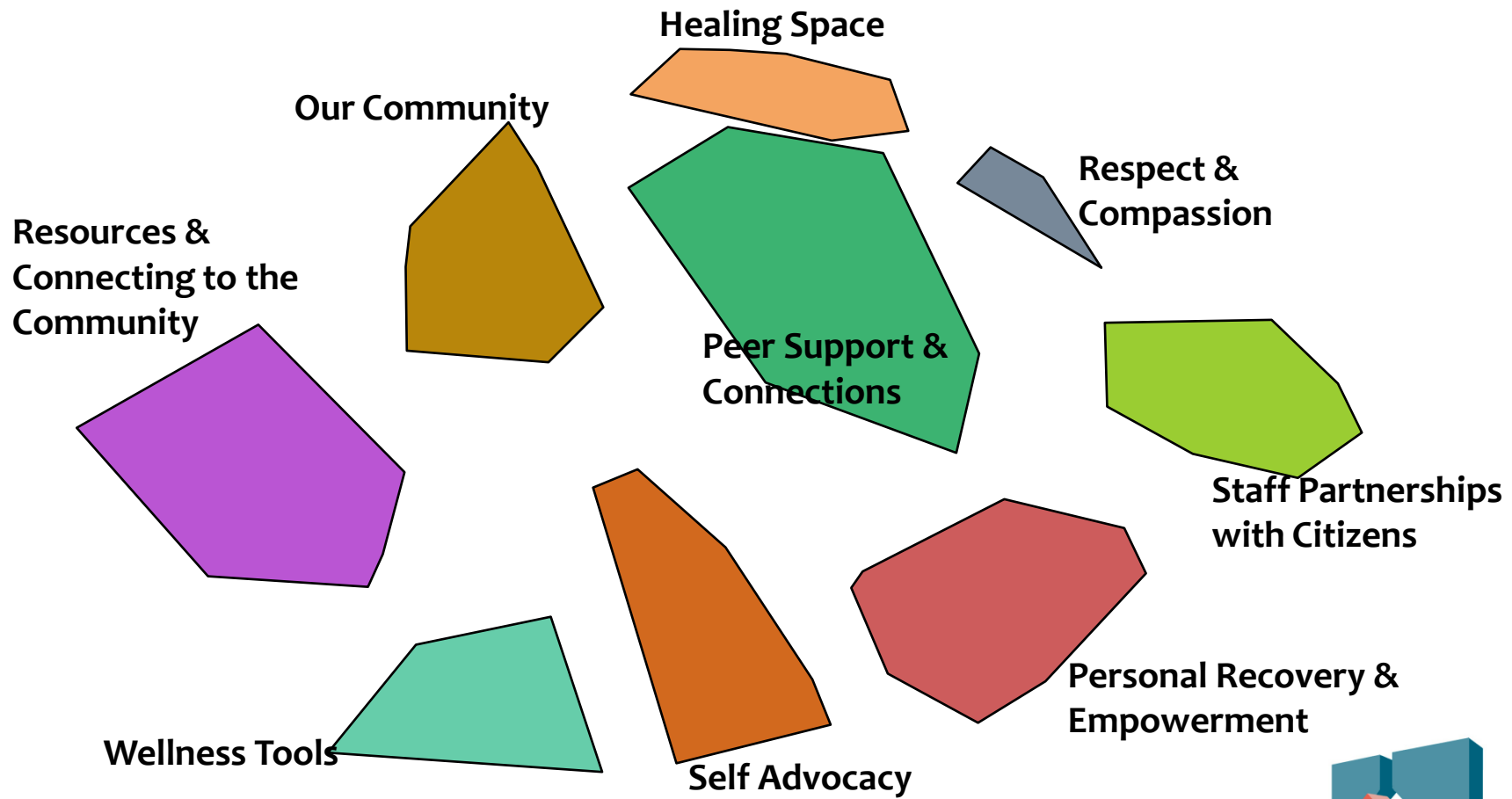- Aggregation of Sort Data
- Similarity Matrix
- Multidimensional Scaling
- Cluster analysis
- Anchoring/Bridging Analysis

Analysis and Representation: The Emergent Structure

Healing Space

Our Community

Respect & Compassion

Resources & Connecting to the Community

Peer Support & Connections

Staff Partnerships with Citizens

Self Advocacy

Wellness Tools

Personal Recovery & Empowerment

Interpretation and Use:
Rating Importance and Evidence

Importance N=157   Evidence N=113

3.53   3.53

Personal Recovery & Empowerment
Respect & Compassion
Staff Partnerships with Citizens
Self Advocacy
Healing Space
Peer Support & Connections
Tools
Our Community
Resources & Connecting to the Community

Healing Space
Respect & Compassion
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3.06   r = 0.81   3.06

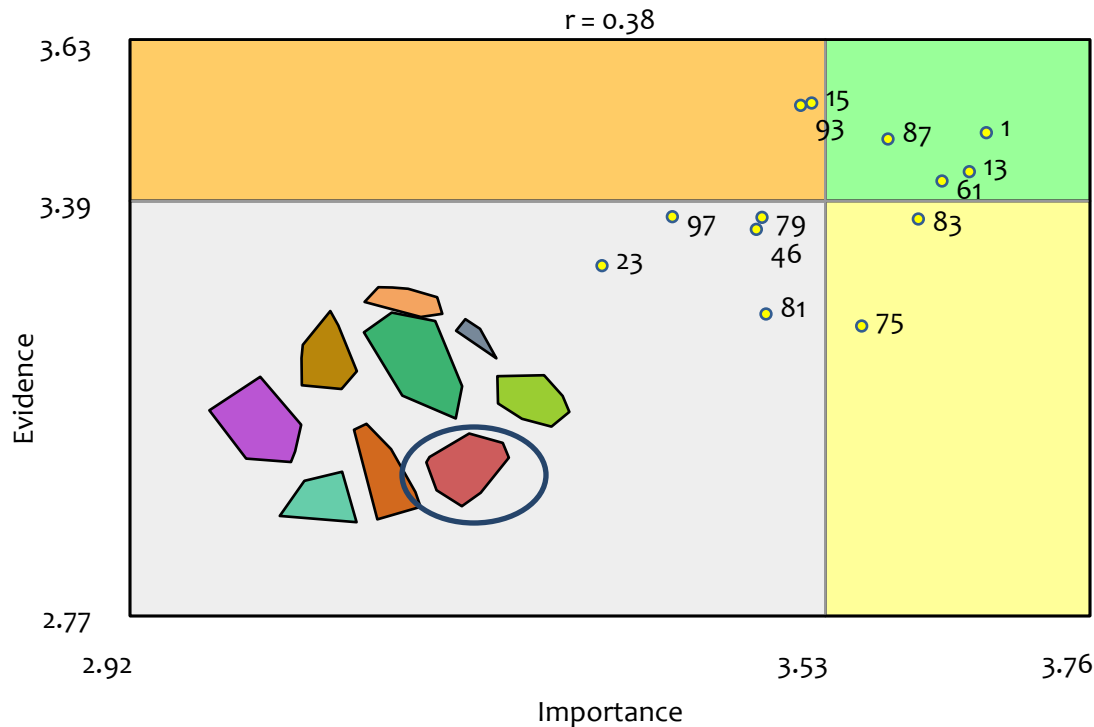# Analysis and Representation: Cluster Detail
Personal Recovery & Empowerment

1.   their investment in teaching me skills which help them stay motivated in their personal recovery process.

13.   empowerment to have your own voice, your own choice, to be in the driver's seat of your own recovery.

15.   it focuses on the person and his or her strengths as well as recovery.

23.   telling life experiences and sharing beliefs about recovery.

46.   helps people learn to listen, and to be listened to.

61.   learning to have a sense of personal responsibility.

75.   valuing each student's strengths and contributions.

79.   helps people see themselves in a commitment to recovery.

81.   to help a person get priorities in order at his or her own pace.

83.   it validates a person's strengths to find their own solutions.

87.   helps citizens understand how to make choices because they are the experts in their own recovery.

93.   that there is a high expectation for recovery.

97.   helps increase a citizen's communication skills.
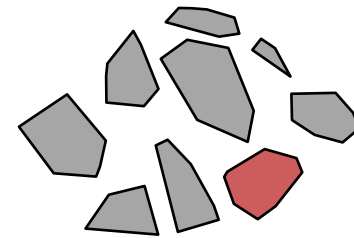
Interpretation and Use:
Go-Zones help build Consensus on Action

r = 0.38

Evidence (y-axis): 3.63, 3.39, 2.77
Importance (x-axis): 2.92, 3.53, 3.76

Plotted points: 15, 93, 87, 1, 13, 61, 97, 79, 46, 23, 83, 81, 75

1. their investment in teaching citizens skills which help them stay motivated in their personal recovery process.

13. empowerment to have your own voice, your own choice, to be in the driver's seat of your own recovery.

61. learning to have a sense of personal responsibility.

87. helps citizens understand how to make choices because they are the experts in their own recovery.

75. valuing each student's strengths and contributions.

83. it validates a person's strengths to find their own solutions.

15. it focuses on the person and his or her strengths as well as recovery.

93. that there is a high expectation for recovery.

23. telling life experiences and sharing beliefs about recovery.

46. helps people learn to listen, and to be listened to.

79. recovery language helps people see themselves in a commitment to recovery.

81. to help a person get priorities in order at his or her own pace.

97. helps increase a citizen's communication skills.

Voice in Group Concept Mapping: Other Examples

Organization	Focus prompt	Community
Jackson, Miss. Community Health	*A specific thing that causes African Americans to get sick sooner and die younger is…*	Residents, researchers, service providers
Institute for Optimal Aging	*One specific topic that should be examined to better understand what seniors need to live a healthy life is…"*	Elder residents in 3 community locations
NY Early Intervention Program	*As a result of early intervention services, children (families) will*	Parents, program designers, advocates
Toronto: Anishnabe Health Ontario	*What is a specific issue, feeling or thought, which occurs to you about living with diabetes?*	Residents in sharing circles
Albany NY: U Albany Medical School	*During the course of becoming a doctor, a variety of things occur that affect one's ability to be empathic. Please list all the factors you can think of.*	Medical students

Voice in Group Concept Mapping: Other Examples

Organization	Result
Jackson, Miss. Community Health	*Community development of health mall; local foods grocery and neighborhood gym in one location, developed food buying and preparation programs*
Institute for Optimal Aging	*Established prioritized research agenda to improve health in aging communities*
NY Early Intervention Program	*Established peer/parent education and support programs, with funding and evaluation*
Toronto: Anishnabe Health Ontario	*Established peer/parent education and support programs, with funding and evaluation*
Albany NY: U Albany Medical School	*Change in medical school curriculum*

Valuing Voice in Evaluation

- In Group Concept Mapping, **valuing voice is foundational**

- Using the results of Group Concept Mapping, a partnership can :

  – Articulate priorities for action or needed attention

  – Assign and integrate responsibilities among partners

- Valuing Voice supports the development of an **integrated planning and evaluation structure**, aligning evaluation needs with stated values at the outset

Thank you

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