

***Developing Local Systems
of Care
in Rural Areas***

**Wm. Martin Hydaker, M.A.,
Hydaker Community Consulting**

The Challenge

"The real difficulty in changing any enterprise lies not in developing new ideas but escaping old ones." John Maynard Keynes

The presentation has three parts:

- For background: System of Care History and Development
- Developing rural systems of care
- The national study to define community readiness (2008)

*System of Care
History and Development*

Where Have We Been?

- 1963 - Community Mental Health Act
- 1969 - Joint Commission of the Mental Health of Children published a landmark study showing that children are underserved or served in inappropriately restrictive settings.

Where Have We Been?

- 1982 - Jane Knitzer's book - *Unclaimed Children* highlighted the failure of public responsibility.
- 1984 - Child Adolescent Service System Program
- 1988 - Federation of Families founded

Federation of Families

1st Annual Conference

November 11, 1989

"It is not the child that creates undue stress on the family unit. We do not have dysfunctional families; we have dysfunctional systems that do not respond to families." Naomi Karp (founding member of the Federation)

Where Have We Been?

- MHSPY ~ RWJ Foundation 1989
- Comprehensive Community Mental Health Services for Children and Their Families ~ 1992

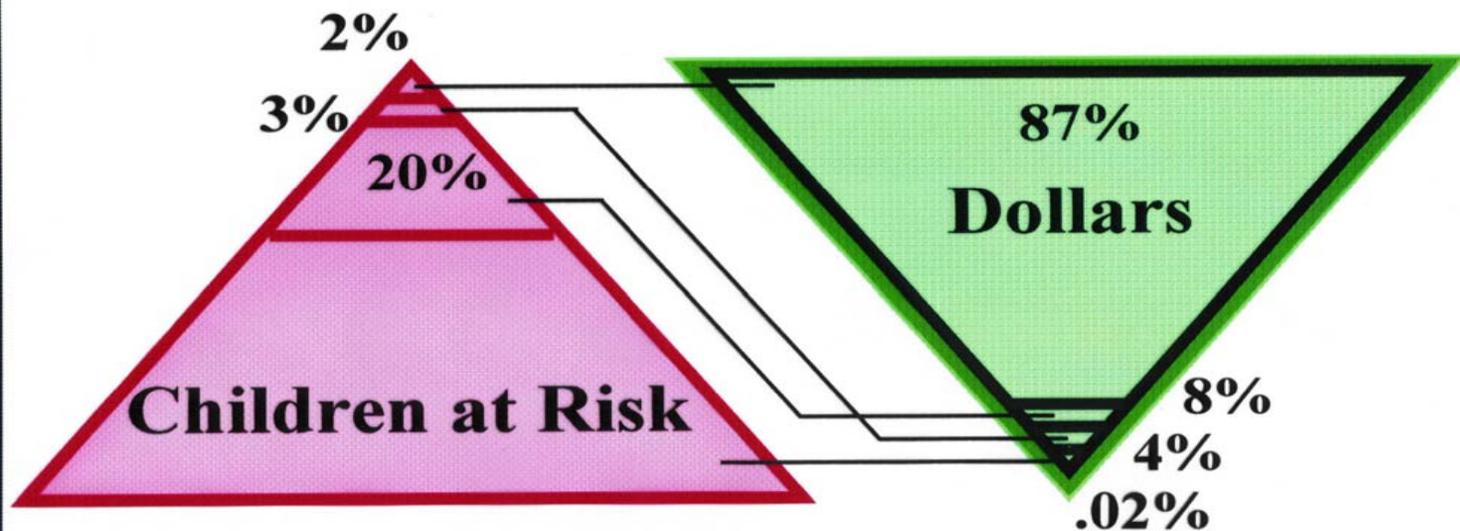
Categorical Approach

- Assess problems
- Look at services or programs that are available
- Plug child into existing programs

Where the Money Goes!

Distribution of Resources for Children's Mental Health Services

Allocation for a Composite State:



Serious Emotional Disturbance (SED)

- Federal Definition
 - Age - birth to 21
 - Diagnosis
 - Disability - functional impairment, multi-agency involvement
 - Duration - present for 1 year or expected to last 1 year

The Comprehensive Community Mental Health Services Program for Children and Their Families

Provides funds to

- States
- Communities
- Territories
- Indian tribes & tribal organizations

Government Investment

- Since 1993, 144 grants
- \$4-5 million per site, over 6 years
- Technical assistance, training
- Evaluation
- Currently, 59 funded sites, 83 graduated
- 2008-09, 18 new sites funded

Program Principles

- Services should be driven by the needs and preferences of the child and family
- Service planning should be strengths based
- Management of services should occur in a multi-agency collaborative environment

Program Principles-More

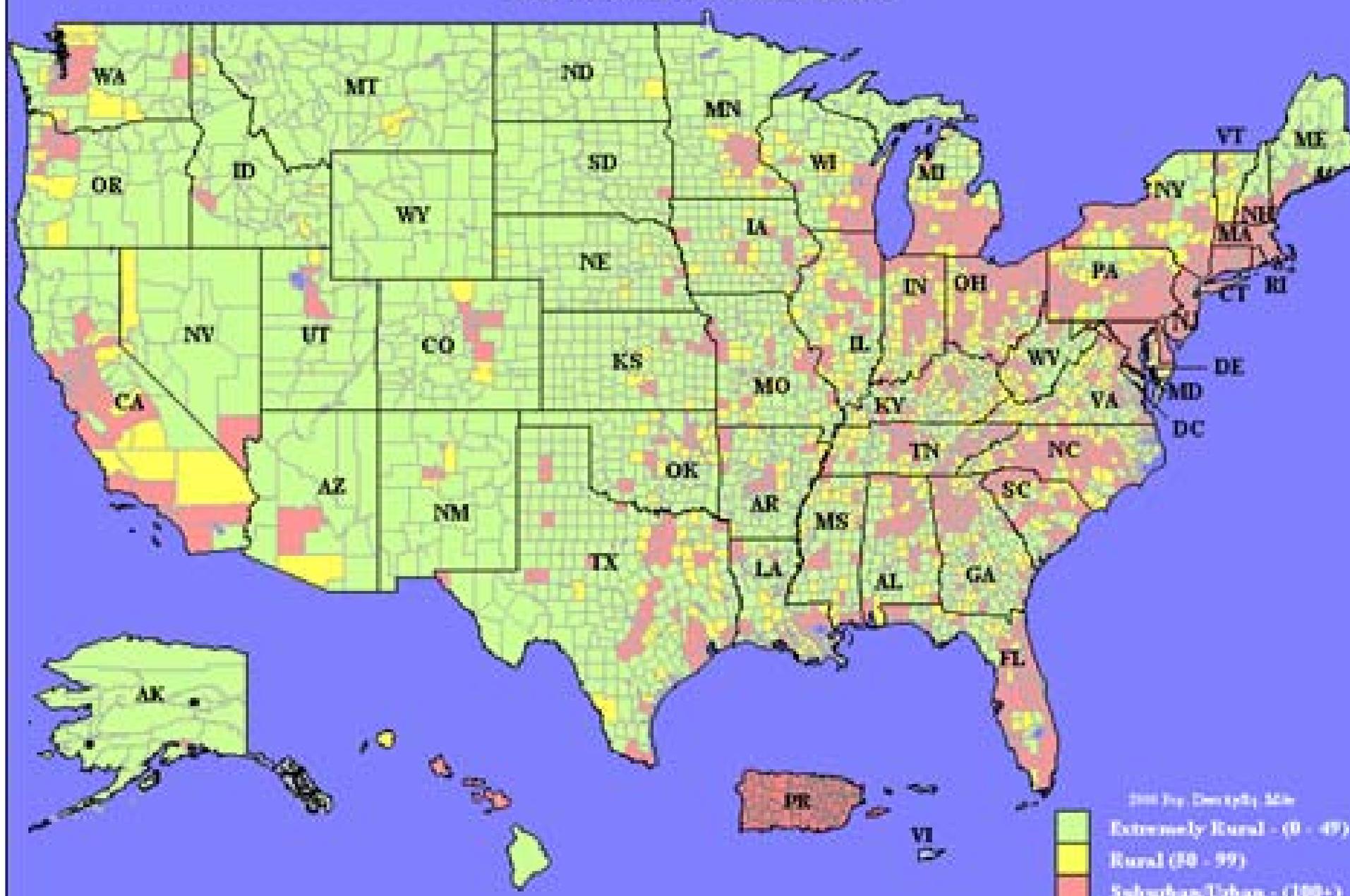
- Programs should be responsive to the cultural context of the population served
- Families should be the lead partners in planning and implementing the system of care.

Developmental Shifts

- From:
 - Adversarial
 - Conflicting objectives
 - Deals
 - Categorical services
 - Provider driven
 - Lone Ranger
 - Value = \$s
- To:
 - Collaborative
 - Shared visions & goals
 - Partnerships
 - Flexible services
 - Family driven
 - Team member
 - Value = outcomes

Developing Rural Systems of Care

Substance Abuse & Mental Health Services Administration
Center for Mental Health Services
Rural Counties in United States



Rural/Frontier Strengths

- Community and connectedness
- Taking care of our own
- Lack of formal services (mixed blessing)
- Availability of natural & informal resources

Rural/Frontier Disparities

- Poverty
- Insurance
- Risky health behaviors
- Federal funding favors metropolitan over rural states
- Most rural Americans live in mental health shortage areas - 60%+

Rural/Frontier Challenges

- Distance and transportation
- Cultural issues
- Stigma
- Isolation
- Crisis services?

Is this a fair representation of the environment and the challenges you face?

*What makes a Systems of Care
Community a Systems of Care
Community?*

The system of care concept describes how the service delivery system might operate and is a framework and a guide, not a prescription. It is intended as an organizing framework and a value base. Flexibility to implement the system of care philosophy in a way that works for a particular community must be emphasized. Shelia Pires - 1992

*What is different in a rural area for
System of Care development?*

&

*How do you move beyond the
challenges and develop a System
of Care?*

Getting Started

- Identify collaborative partners
- Insure input from youth and families about the needs in the community
- Develop a commitment to System of Care values and principles

Getting Started

- Work towards a real commitment from key community stakeholders - people with the ability to influence attitudes and actions
- Organize a community team
- Create buy-in for a high fidelity wraparound approach

Collaboration is at the heart of system building. It takes time, energy, and attention to relationship building, trust building, capacity building, team building, conflict resolution, mediation, development of a common language and communication. (Shelia A. Pires in *Building Systems of care: A Primer*, Spring 2002)

Collaboration

- An unnatural act between non-consenting adults.
- A mutually beneficial and well-defined relationship entered into by two or more organizations to achieve common goals. (Weiner, M.)

Collaborating, Partnering & Integrating

- Behaviors cut across all agencies
- Wraparound and efforts to develop a single plan
- Wraparound when done well is a process of integration

Why a Partner with Systems of Care and Schools

- We have a fragmented and compartmentalized system
- We all have the same families in common
- We have to get everyone around the table at the same time
- We must work together on the system level to reach integration

Who is Wrap around for?

- Children with serious emotional and behavioral problems.
- Between the ages of 0 and 21
- For the entire family
- Having problems at home, school and/or the community (Multiple Agency Involved)

What about this community Team?

Local coalitions come together to:

1. Assess the most complex kids and get them to the right place
2. Oversee the wraparound project
3. Address integration and social service needs of the community

Where do I fit in?

- Connect with the local community team if you can
- Use the crisis plan or help create it
- Connect the treatment plan to the IEP
- Use for additional support and resources
- PBIS (Positive Behavioral Interventions and Supports)

Benefits to Schools and Families

- Parents supporting the IEP program
- Better communication with schools
- Involvement of the family
- Staying in school
- Being supported
- Multiple resources available to teachers with linkage provided by Care Coordinator
- Better accountability
- Better buy-in to the plan
- They feel better about the process

Great Smoky Mountain Study-1992 Caring for Children in the Community (1996)

- Funded by National Institute of Mental Health & The National Institute of Drug Abuse
- First of its kind study with children in the U.S.
- Focuses on co-morbidity of mental health and substance abuse in children
- Evaluates service use in 5 sectors; mental health, health, education, child welfare and juvenile justice

Study Sample

- Total sample 2342 children
 - Great Smoky Mountain (GMS), 1422 children - 349 Cherokee, 1073 remaining counties
 - Caring for Children in the Community (CCC),
 - 920 children

GSM & CCC Findings

- Five out of every 100 children will develop an emotional or behavioral disorder in childhood that meets the federal definition of a serious emotional disturbance, while another 20 to 25 will develop problems that are less severe, but still hold potential to disrupt their lives in childhood or adulthood.
- Twenty two percent of children with a severe emotional disturbance experienced a "derailment" such as expulsion from school. Unplanned pregnancy, conviction for a crime, or substance abuse, compared to 4.3 percent of children with mild mental health problems and less than one percent of children with few or no problems.

GSM & CCC Findings

- The risk of severe emotional disturbances escalates with each stress factor in a child's life, including poverty, violence in the home, and having a parent who has been arrested, has a drug or alcohol problem, has a mental illness, is unemployed, or has less than a high school education.
- A third of children have experienced a "traumatic" event, but only a small percentage develop post traumatic stress disorder. Of those, all experienced multiple traumas; the breakdown came after a last straw trauma, which could be quite mild in itself.

GSM & CCC Findings

- African-American and Native American children develop disorders at a similar rate as white children.
- Half of children prescribed Ritalin for Attention Deficit Hyperactivity Disorder have never had the disorder, and half of those who really do have it have never received the medication.

GSM & CCC Findings

- Children who had nine or more sessions with a mental health professional had significantly fewer emotional and behavioral problems following treatment. Children receiving fewer than nine showed no improvement.
- Each year, only one in five children with a diagnosable disorder saw a mental health specialist. More than 75 percent of those were seen by school counselors and psychologist - more than any other mental health professionals.

GSM & CCC Findings

- The risk of derailment among children with less severe disorders, while lower than youths with SED, was still eight times that of healthy children. Efforts to reduce risk in this group could have a substantial impact on outcomes for adolescents because they make up 20% of the population.
- <http://devepi.mc.duke.edu>

Study Conclusions

- Schools are already “involved” with most children who are experiencing diagnosable mental health disorders.
- On going efforts to enhance interagency relationships between specialty mental health and the schools is essential.
- We need to increase professional mental health resources in the schools where children can easily take advantage of them.

Hopeful Trends

- Technology
- Outreach Programs
- Evidenced based practices
- Wraparound and efforts to develop a single plan
- Police Pocket Guide
- Efforts to train first responders

Hopeful Trends

- Linking/integrating primary care and mental health
- Training/funding community professionals

*National Study to Define
Community Readiness*

Easy to believe in

Hard to do

Where to start?

Community Readiness

A Missing Piece

- Start by determining the areas of readiness and areas needing strengthening
- But first, how to define readiness

**DEFINING COMMUNITY
READINESS
for the
IMPLEMENTATION OF A
SYSTEM OF CARE**

Lenore B. Behar, Ph.D
William M. Hydaker, MA

Credits

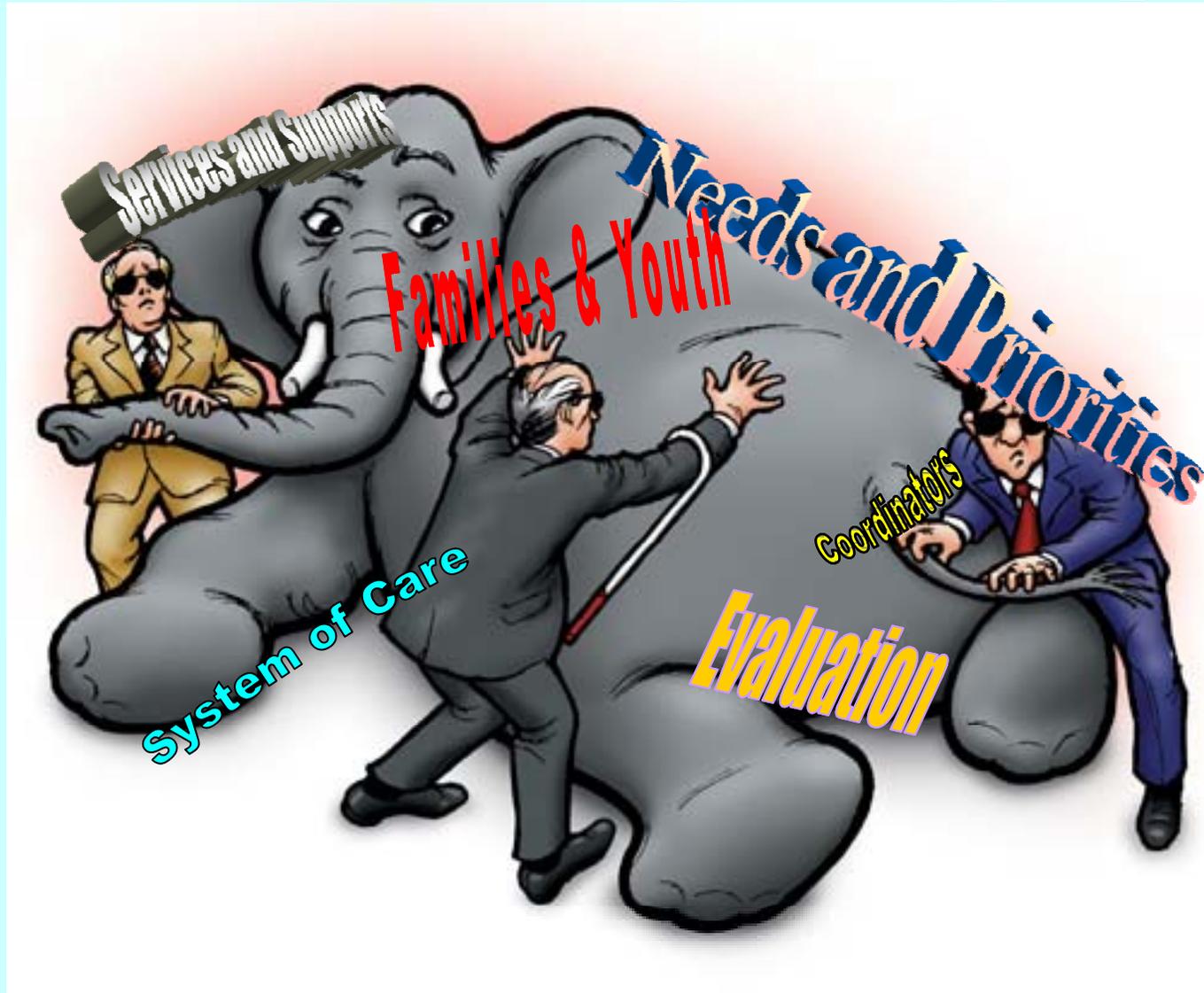
This study was developed under Contract 280-03-4200, Task Order Number 280-03-4200, funded by the Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services. The contents of this presentation do not necessarily reflect the views or policies of the funding agency and should not be regarded as such.

Concept Systems, Inc.

For the project discussed today, the methods and software developed by Concept Systems, Inc., Ithaca, NY was selected as the best approach.

The Concept System© software: Copyright 2004-2007; all rights reserved. Concept Systems Inc.

Why Concept Mapping ?



In Order to Avoid This



And Get Organized Input from Stakeholders



Why Concept Systems?

This system offers a next generation approach to data collection and management

- Moved concept mapping beyond focus group model
- Added web-based method to collect data
- Added statistical analyses, formerly subjective interpretation
- Added graphic presentations of finding
- Is flexible, applicable to many situations

Definition

- A structured process used to organize the ideas of a group that wishes to develop framework for planning and evaluation.
- The process is used to develop pictorial representations of the ideas generated by the group and the relationships of these ideas to each other.

Advantages

- Time efficient
- Easy to understand; no jargon
- Effective engagement strategy
- All participants have equal voice
- Supports ownership; empowers action

Advantages - - More

- Allows for assessing multiple dimensions, such as importance and feasibility
- Grounded by statistical analyses

Process - how does it work?

- Selecting a group
- Develop a focus prompt
- Brainstorming
- Sorting the responses
- Rating the responses

How the Data are Analyzed

- Data from the brainstorming, sorting and rating are statistically analyzed, using item analyses, hierarchical cluster analyses and multidimensional scaling

Design of Study to Define Community Readiness

Concept mapping fit the requirements to gather and organize information

- Needed to build consensus among diverse populations
- Participants were scattered across the country
- Wanted a transparent data driven and not subjective process

Study Design--More

- Used Concept Systems "Global" software to gather information
- Through e-mail invited participants, gave instructions, and link to website

Study Sample

- Selected participants experienced in implementing systems of care
- Invited two groups totally 223 people
 - Group 1: 151 representatives from 27 5th and 6th year sites
 - Group 2: 72 experts in systems of care (trainers, researchers, evaluators, consultants)

Phase 1: Brainstorming

Participants responded by entering statements online to:

“To be ready to develop a system of care, the following specific characteristics and functions are essential to be in place before an application for funding can be completed.”

Respondents to Brainstorming

- Responses from 115 people (52%)
- Broad representation across target groups, age, race, gender, ethnicity
 - 28% administrators (PIs, PDs)
 - 13% outside experts
 - 11% TA coordinators
 - 8% parent coordinators
 - 4% parents

Responses to Brainstorming

- 336 statements generated
- 109 unduplicated ideas
- "collaboration" was the most frequently misspelled word!

Phase 2: Rating the Items

Invitations to participate were issued

Group 1 (27 sites) members were asked to rate the 109 items on a scale of 1-5

Ratings were for the Importance of the item and Difficulty of Implementation

65 of 155 members responded (42%)

Phase 2: Sorting the Items

Invitations to participate were issued

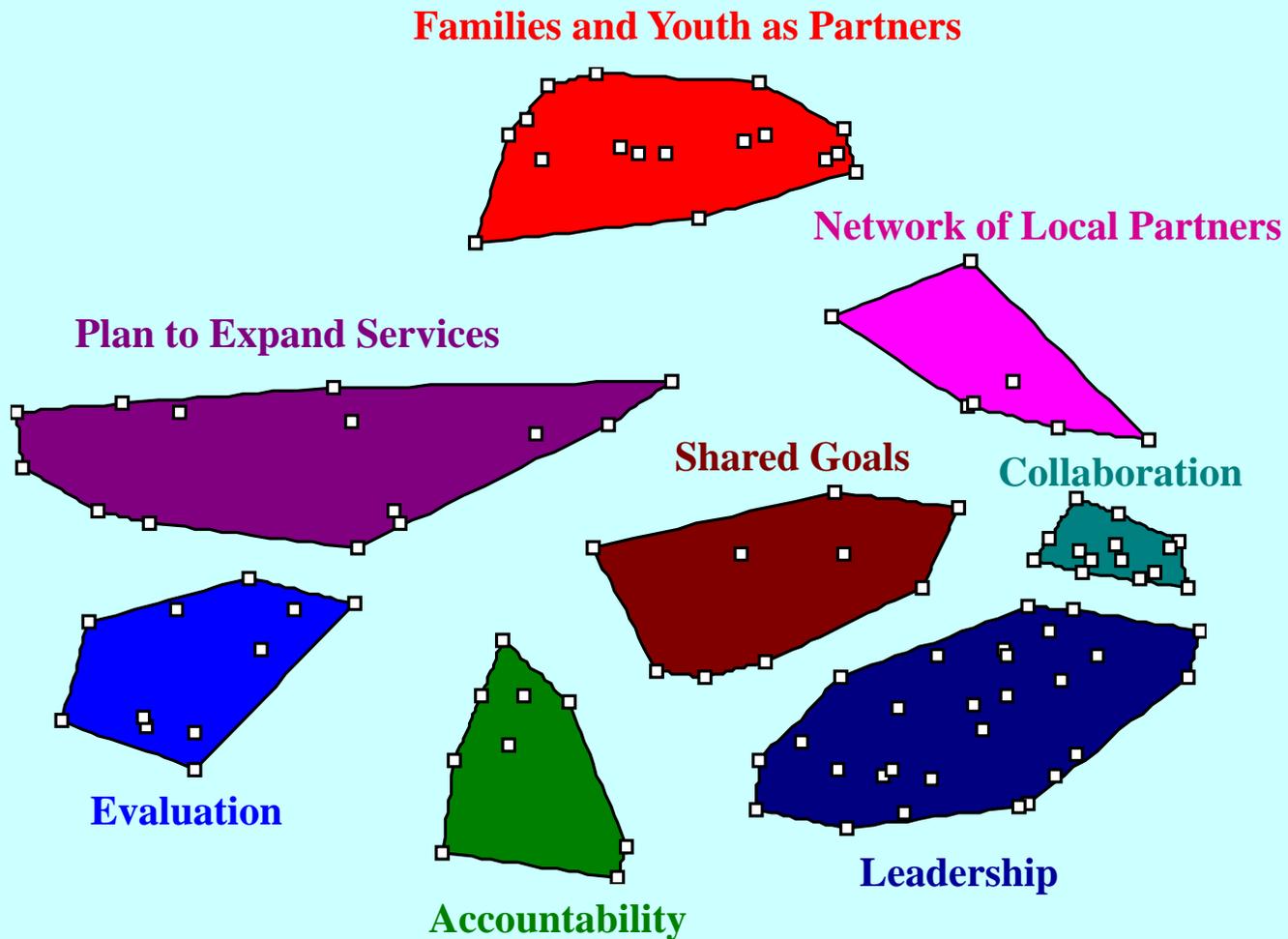
Group 2 (72 experts) members were asked to sort the 109 items into groups that went together

Group 2 members were asked to label the groups

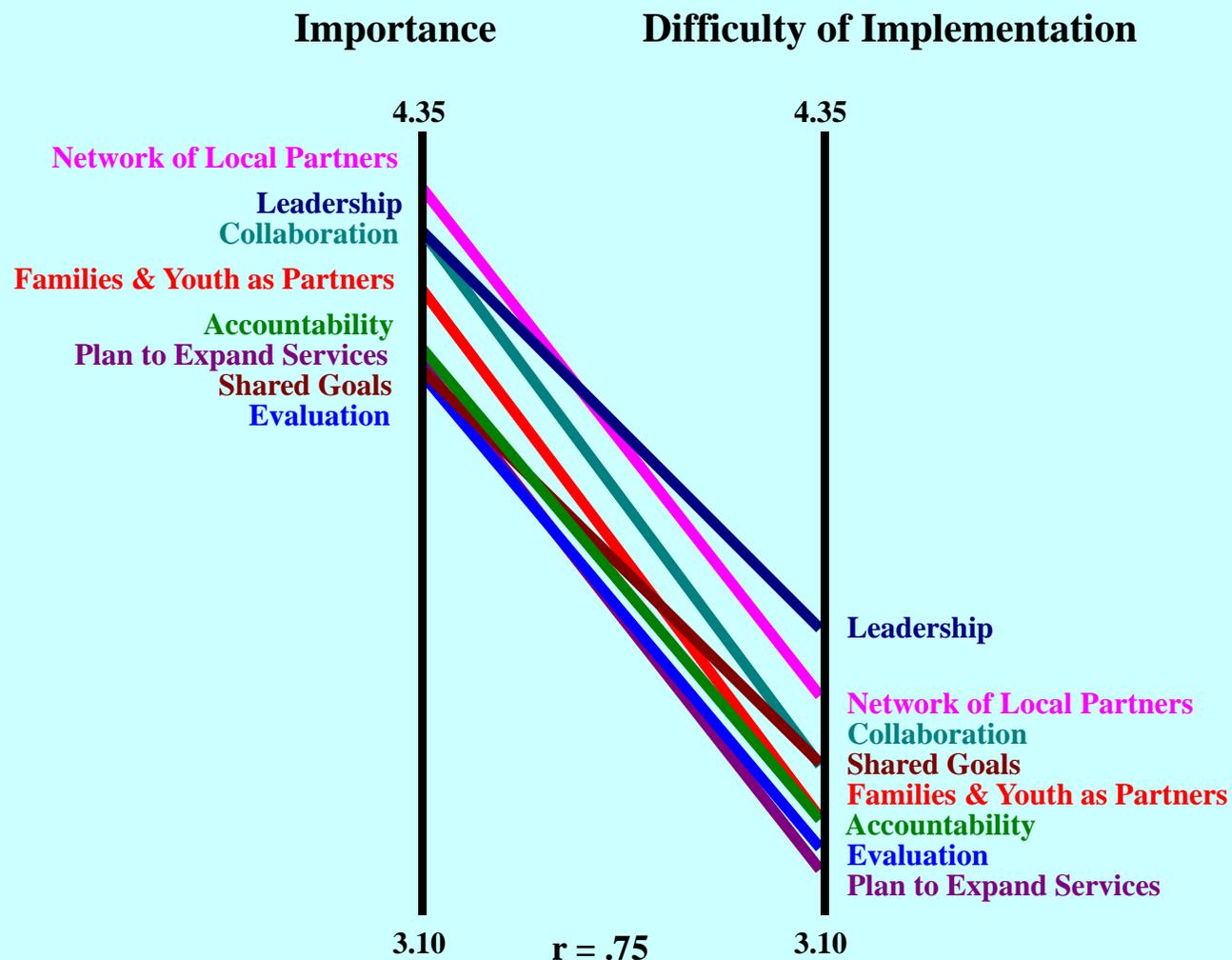
36 of the 72 members responded (50%)

Results of the Study to Define Community Readiness

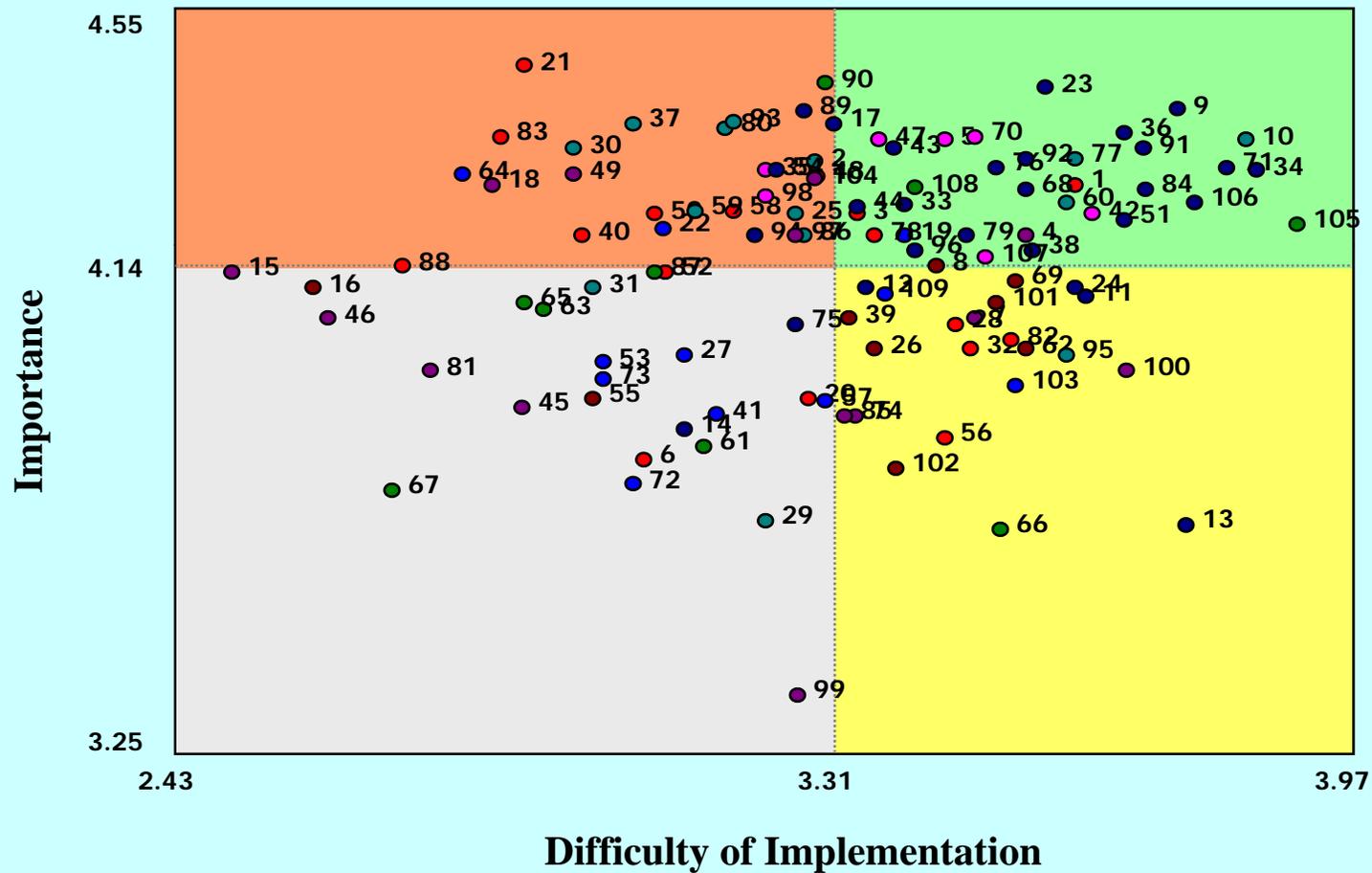
Eight Cluster Solution



Cluster Ratings on Importance and Ease of Implementation



Map of Focus Zones



Five Most Important Items

- #21 - There should be input from youth and families to determine the needs in the community.
- #90 - It must be understood that sustainability of services should be part of discussions beginning in the 1st year not waiting until the end.

Most Important Items--More

- #23 - It is important to have a real commitment to the effort from key community stakeholders - people with the ability to influence attitudes and actions of others such as elected officials, community champions, respected individuals, etc.

Most Important Items--More

- #9 - The concept of permanent system change needs to be understood and accepted as the end goal.
- # 89 - There must be a commitment from policy makers, community leaders, partners, and staff to the system of care values and principles.

Next Steps*

- Use the list of items as a basis for developing the Community Readiness Assessment Scale (CRAS)
- Work with new sites to assess readiness; report within 30 days
- Re-assess in 12 months to measure progress

*funded by CMHS

*The road to success is
always under
construction.*