Lessons Learned from the National Evaluation

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National Evaluation Team
ICF Macro, WRMA, KAI, USF, FFCMH

Acknowledgements

ICF Macro
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National Evaluation Team
- WRMA, KAI, USF, FFCMH

CMHI National Evaluation

- Begun in 1993 with start of program
- Based on CMHI’s authorizing legislation
- Collects information at multiple levels from multiple sources at multiple waves
- Data collected on over 98,000 children and youth

Core Studies
- Cross-Sectional Descriptive Study
  Local data collection, National protocol
- Child and Family Outcome Study
  Local data collection, National protocol
- Service Experience Study
  Local data collection, National protocol
- Services and Costs Study
  National guidelines for data delivery
- System of Care Assessment
  National level
- Sustainability Study
  National level

Comparison Studies
- 5 paired sites, Service Experience substudy, Sector and Comparison Study

Treatment Effectiveness Studies
- BSFT, CSP, PCIT

Family Education and Support Study
- 3-tiered practice-based evidence study

Cultural and Linguistic Competence Studies

Provider Surveys
- Evidence-Based Practices, Provider Practices, Pediatrician Survey

Other Surveys
- Conflict Resolution Study (USF), Managed Care Study, case studies, ethnographies, State sustainability study

Researcher Secondary Data Analyses
- ongoing with NIMH-CMHS PA & Data Access Group

Evaluation Strengths

- Consistent data collected across years, as well as new data based on evolving needs
- Consistent core findings across program years
- Multilevel analyses of various types possible
- Creative and dedicated staff

Evaluation Best Practices

- Consistent data and data sources
- Responsiveness to changing program and grantee needs
- Participatory process
- Technical assistance
- Publications and presentations
### Evaluation Questions
- Are programs implemented according to goals and principles?
- Who receives services?
- What are the outcomes?
- What services are received and how?
- What are the costs?
- Do programs sustain and why?

### Evaluation Complexity
- Variability in characteristics of
  - Grantees
  - Communities, States, Tribal organizations
  - Children and families
  - Services and service experiences
  - Systems and partners
  - Technical assistance
  - Resources for sustainability

### Some Lessons Learned
- Children and families as a whole show improvement in consistent patterns
- *But variability masks specificity*
  - Outcomes relate to inputs
    - This makes sense for individualized services
- Services and fidelity to treatment impact outcomes

### Some Lessons Learned
- Site-level differences affect outcomes
- Cross-system data are needed to really understand costs of services
  - Complete cost data are often hard for communities to access, but are needed
- Most programs are sustained 5 years post-funding

### Some Lessons Learned
- Evaluation and data use are a participatory process
- Collaboration among evaluators, project directors, family members, youth, and social marketers improves investment in data and data use
- Evaluators and family members are good partners

### Focus of This Presentation
- Three system of care principles at the service level and outcomes
  - Youth guided
  - Family driven
  - Cultural and linguistic competence
Data Used for These Analyses

- Communities initially funded from 2002 to 2006
- Data collected from 2004 through December 2009
- Datasets for each analysis defined by data available for variables of interest

Demographic Characteristics of Children/Youth

<table>
<thead>
<tr>
<th>Gender</th>
<th>SOC Population(^a) 2004–2009</th>
<th>U.S. Population(^b) 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>62.9%</td>
<td>51.2%</td>
</tr>
<tr>
<td>Female</td>
<td>37.1%</td>
<td>48.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>SOC Population(^a) 2004–2009</th>
<th>U.S. Population(^b) 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 5</td>
<td>13.4%</td>
<td>26.0%</td>
</tr>
<tr>
<td>6 to 11</td>
<td>30.1%</td>
<td>25.0%</td>
</tr>
<tr>
<td>12 to 15</td>
<td>37.6%</td>
<td>17.8%</td>
</tr>
<tr>
<td>16 to 22</td>
<td>18.9%</td>
<td>31.2%</td>
</tr>
</tbody>
</table>

Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>SOC Population(^a) 2004–2009</th>
<th>U.S. Population(^b) 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaska Native</td>
<td>4.4%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Asian</td>
<td>1.3%</td>
<td>3.9%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>24.1%</td>
<td>14.6%</td>
</tr>
<tr>
<td>Native Hawaiian or other Pacific Islander</td>
<td>1.4%</td>
<td>0.2%</td>
</tr>
<tr>
<td>White</td>
<td>40.6%</td>
<td>57.7%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>24.0%</td>
<td>20.2%</td>
</tr>
<tr>
<td>Multi-racial</td>
<td>4.2%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

Federal Poverty Level

<table>
<thead>
<tr>
<th>Federal Poverty Level</th>
<th>SOC Population(^a) 2004–2009</th>
<th>U.S. Population(^b) 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below poverty</td>
<td>57.6%</td>
<td>17.4%</td>
</tr>
</tbody>
</table>

Living Situations at Intake

- Home 90.87\%
- Residential Treatment Center/Therapeutic Camp 2.04\%
- Foster Home 1.94\%
- Group Home 1.07\%
- Youth Justice Related 0.80\%
- Homeless 0.67\%
- Hospital/Psychiatric or Psychiatric Unit 0.60\%
- Emergency Shelter 0.58\%
- Therapeutic/Specialized Foster Home 0.53\%
- School Dormitory 0.14\%
- Hospital/Medical 0.09\%
- Camp 0.08\%
- Adult Justice Related 0.06\%
- Other 0.54\%

Mental Health Diagnoses

Most Common Diagnoses at Intake

<table>
<thead>
<tr>
<th>DSM–IV(^c)</th>
<th>SOC Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood Disorders</td>
<td>35.2%</td>
</tr>
<tr>
<td>Attention-Deficit/Hyperactivity Disorder (ADHD)</td>
<td>31.7%</td>
</tr>
<tr>
<td>Oppositional Defiant Disorder (ODD)</td>
<td>23.3%</td>
</tr>
<tr>
<td>Adjustment Disorder</td>
<td>13.9%</td>
</tr>
<tr>
<td>PTSD and ASD</td>
<td>8.7%</td>
</tr>
<tr>
<td>Anxiety Disorders</td>
<td>7.6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DSM–IV(^c)</th>
<th>SOC Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjustment Disorder</td>
<td>20.7%</td>
</tr>
<tr>
<td>Sensory Stimulation-Seeking/Impulse</td>
<td>17.0%</td>
</tr>
<tr>
<td>Anxiety Disorders</td>
<td>13.0%</td>
</tr>
<tr>
<td>Hypersensitive (Fearful/Cautious, Negative/Defiant)</td>
<td>10.0%</td>
</tr>
<tr>
<td>PTSD</td>
<td>6.7%</td>
</tr>
</tbody>
</table>

* Longitudinal Child and Family Outcome Study, Phases IV and V; aged 0–22 years.


* Revised Zero to Three’s Diagnostic Classification of Mental Health & Developmental Disorders of Infancy & Early Childhood (DC: 0–3R)
**System of Care Framework**

- **Infrastructure**
  - Governance
  - Management and operations
  - Service array
  - Quality monitoring

- **Service Delivery**
  - Entry into service planning
  - Service planning
  - Service provision and monitoring
  - Case review structure

**System-Level Characteristics**

- System change assessed in years, 2, 4, and 6 of funding
- Systems show improvement on all system of care principles at the infrastructure level
- Systems change more slowly at the service delivery level, except in providing least restrictive services

**Youth Service Experiences and Outcomes**

- Youth-Guided Services
- Youth Service Experiences and Youth and Caregiver Outcomes

**Measures**

- Youth Services Survey (YSS)
- Behavioral and Emotional Rating Scale (BERS)
- Child Behavior Checklist (CBCL)
- Columbia Impairment Scale (CIS)
- Reynolds Adolescent Depression Scale (RADS)
- Revised Child Manifest Anxiety Scale (RCMAS)
- Caregiver Strain Questionnaire (CGSQ)

**Youth Services Survey**

- Participation in treatment subscale
  - Three Items
    - I helped to choose my services.
    - I helped to choose my treatment goals.
    - I participated in my own treatment.

Scale: Strongly disagree, disagree, undecided, agree, strongly agree
Participated in service planning?
- Slightly older, higher referrals from juvenile justice
- 2 or more living placements in past 6 months (39.2%/29.5%) more likely

Participated in treatment?
- No difference in age, gender, race/ethnicity, referral source, custody, number of living situations, poverty level, intake CBCL or CIS

Youth who participated in developing the service plan had
- Lower strengths at intake.
- Improved in strengths while those who did not participate made no change.

Rate of change did not differ for youth clinical or functional outcomes, or caregiver outcomes. Both groups improved.

Youth with high treatment participation show greater increase in strengths.

Youth with high treatment participation or satisfaction with treatment
- Had higher strengths at intake.
- Improved in strengths while those who were less satisfied made no change.

Caregivers agree.
Youth with high treatment participation improved in their functioning (CIS). Those with lower participation did not improve.

Caregivers of youth with high treatment participation had slightly greater reduced strain.

Differences in changes on CBCL, RADS, RCMAS were not significant. Both groups improved.

Higher externalizing problems and higher depression at intake among those with less treatment participation.

Youth who participate in treatment planning have lower treatment satisfaction at 6 months and their satisfaction increases to 12 months.

Youth who don’t participate in treatment planning have higher treatment satisfaction at 6 months and then dramatically reduce satisfaction to 12 months.
Youth strengths increase for those who participate in treatment planning and in treatment.

Youth functioning and caregiver strain improve for youth who participate in treatment.

Youth who participate in planning may be better able to assess the quality of their treatment.

Youth may be included in treatment planning, but substantive involvement in treatment may not follow.

Substantive involvement in treatment has a stronger relationship to some outcomes than participation in treatment planning alone.

Train service providers to better engage youth in services.

Develop or strengthen treatments that promote youth participatory process.

Ask youth about quality of services received along the way.

Family-Driven Services

Caregiver Service Experiences and Child/Youth and Caregiver Outcomes

Caregiver Service Experiences and Outcomes

1,195 caregivers of youth 11 and older from 2002–2004 grantee sites

Caregivers who did or did not participate in treatment planning

Caregivers who did (agree, strongly agree) or did not participate in treatment

Caregivers who were or were not satisfied with treatment.

Participation in Treatment Subscale

Three Items

I helped to choose my child’s services.

I helped to choose my child’s treatment goals.

I participated in my child’s treatment.

Scale: Strongly disagree, disagree, undecided, agree, strongly agree
Satisfaction with Services Subscale

**Six Items**

- Overall, I am satisfied with services my child received.
- The people helping me stuck with me no matter what.
- I felt my child had someone to talk to when he/she was troubled.
- The services my child and/or family received were right for us.
- My family got the help we wanted for my child.
- My family got as much help as we needed for my child.

Scale: Strongly disagree, disagree, undecided, agree, strongly agree

**Caregiver Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>High Treatment Participation n = 942</th>
<th>Lower Treatment Participation n = 253</th>
<th>Satisfied With Services n = 769</th>
<th>Not Satisfied With Services n = 423</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG age: M (SD)</td>
<td>42.0 (9.5)</td>
<td>42.5 (10.2)</td>
<td>42.1 (10.2)</td>
<td>42.1 (8.6)</td>
</tr>
<tr>
<td>Bio/foster/adoptive parent</td>
<td>88.3%</td>
<td>87.4%</td>
<td>86.5%</td>
<td>91.0%</td>
</tr>
<tr>
<td>Custody = One bio parent</td>
<td>55.4%</td>
<td>47.4%*</td>
<td>53.7%</td>
<td>53.9%</td>
</tr>
<tr>
<td>Female caregiver</td>
<td>93.4%</td>
<td>90.5%</td>
<td>92.8%</td>
<td>92.7%</td>
</tr>
<tr>
<td>Race/Ethnicity = White</td>
<td>42.5%</td>
<td>48.2%</td>
<td>41.5%</td>
<td>47.9%*</td>
</tr>
<tr>
<td>High school or less</td>
<td>54.2%</td>
<td>53.2%</td>
<td>57.2%</td>
<td>48.1%**</td>
</tr>
<tr>
<td>Below poverty</td>
<td>55.1%</td>
<td>51.1%</td>
<td>56.2%</td>
<td>50.6%</td>
</tr>
</tbody>
</table>

* p < .05; p < .001

**Participated in service planning?**
- Caregivers who did or did not participate did not differ on characteristics in table.

**Participated in treatment?**
- Youth more likely to be in the custody of one biological parent

**Satisfied with services?**
- Caregivers in the satisfied group were
  - More likely to be non-White, less educated, less likely to be working, less likely to work if youth did not have problems.

**Caregiver Treatment Planning Participation and Outcomes**

- Caregivers who did not participate in treatment planning was very small (n=83).
- Youth and caregivers in both groups improved on outcomes.
- Groups did not differ in change in outcomes.

**Caregiver Treatment Participation and Outcomes**

- Caregiver treatment participation shows similar pattern for change in strengths and functioning as for youth participation, but does not reach significance.
- Youth of caregivers who participated in treatment or who were more satisfied with services had higher strengths at intake.
- Caregivers satisfied with treatment made greater reductions in strain except subjective internalized strain (negative feeling such as worry, guilt, fatigue).

- Satisfaction with services is related to rates of improvement on youth strengths, functioning and problems, and caregiver strain.

- Improvement is greater among satisfied group on all measures.

- Youth strengths are higher, functional impairment and problems are lower, and caregiver strain is less severe at intake among those who are satisfied.

- How do satisfaction with services and participation relate to outcomes?

- Constructed four groups
  - Satisfied with participation and services
  - Satisfied with participation, not with services
  - Satisfied with services, not with participation
  - Not satisfied with services or participation
Four groups differ in outcomes.

Youth whose caregivers are satisfied with services and whose caregivers participate in treatment enter services with greater strengths.

Youth of caregivers dissatisfied with services enter services with lower strengths.

Caregiver Satisfaction With Participation and Services

Youth whose caregivers participated in treatment and were satisfied with services
• Entered services with the highest strengths and had the best outcomes.
• Youth whose caregivers were satisfied with services but did not participate in treatment made greater gains in strengths.

Youth whose caregivers were not satisfied with services
• Entered services with lowest strengths and made no change in strengths.
• However, if caregiver participated in treatment, there seems to be a slight trend in the positive direction.
• This pattern was similar for youth functioning and behavioral and emotional problems.
• Caregivers differed similarly in improvements in strain.

Summary

Most caregivers participate in treatment planning.

Caregiver assessment of treatment participation is probably not a sufficient assessment of treatment experience to understand the relationship of the role of caregivers in services and outcomes.

Satisfaction with services is highly related to outcomes.

Implications

More information is needed about
• The nature of caregiver involvement in treatment.
• The relationship of demographic characteristics and perception of services.
• Expectations may change with service involvement.
• More information about services may be needed by some caregivers.
Culturally Competent Services
Caregiver Preferences, Service Experiences, and Child/Youth and Caregiver Outcomes

- 3,872 caregivers and children/youth from 2002–2006 grantee sites
- Caregivers who considered cultural competence of service provider important (very, extremely) or less important
- Caregivers assessment of primary service provider’s as always or less than always culturally competent

Measures

- Cultural Competence and Service Provision Questionnaire (CCSP)
- Behavioral and Emotional Rating Scale (BERS)
- Columbia Impairment Scale (CIS)
- Caregiver Strain Questionnaire (CGSQ)

Cultural Competence and Service Provision Questionnaire

- Importance of cultural competence
  - Service provider who understands the customs, practices, and traditions of child’s racial or ethnic groups.
  - Beliefs, traditions, and practices of child’s racial or ethnic group be included in service planning and provision.
  - Provider seen most often is of the same racial or ethnic group as child.

Caregiver Characteristics

- Caregivers who rated importance of cultural competence as high were more likely to be
  - Of a race/ethnicity other than White.
  - Speaking a language other than English at home.
  - Living in poverty.
  - Slightly older (but not significant).
  - Receiving services from a provider of the same race/ethnicity as child/youth.
**Group Differences**

**Provider understands child’s culture is important**

<table>
<thead>
<tr>
<th></th>
<th>Understand Child’s Culture High, Cultural Competence High ( n = 783 )</th>
<th>Understand Child’s Culture Low, Cultural Competence Low ( n = 1,032 )</th>
<th>Understand Child’s Culture Low, Cultural Competence High ( n = 515 )</th>
<th>Understand Child’s Culture Low, Cultural Competence Low ( n = 902 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG age: M</td>
<td>54.1</td>
<td>48.2</td>
<td>46.8</td>
<td>44.9</td>
</tr>
<tr>
<td>CG English*</td>
<td>86.2%</td>
<td>84.8%</td>
<td>95.1%</td>
<td>93.9%</td>
</tr>
<tr>
<td>Race/Ethnicity*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>29.4%</td>
<td>24.8%</td>
<td>57.0%</td>
<td>52.7%</td>
</tr>
<tr>
<td>Black</td>
<td>34.8%</td>
<td>40.1%</td>
<td>19.5%</td>
<td>20.2%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>22.2%</td>
<td>22.9%</td>
<td>14.4%</td>
<td>16.2%</td>
</tr>
<tr>
<td>Native American</td>
<td>3.9%</td>
<td>3.4%</td>
<td>2.7%</td>
<td>2.5%</td>
</tr>
<tr>
<td>API</td>
<td>4.5%</td>
<td>8.9%</td>
<td>1.6%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Below poverty*</td>
<td>62.8%</td>
<td>60.0%</td>
<td>51.2%</td>
<td>51.1%</td>
</tr>
<tr>
<td>Provider same race/ethnicity*</td>
<td>62.5%</td>
<td>54.8%</td>
<td>65.3%</td>
<td>61.9%</td>
</tr>
</tbody>
</table>

* \( p < .001 \)

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**Cultural Competence Importance and Youth Strengths**

**Caregivers rate importance of understanding culture and including culture in services similarly**

**Fewer caregivers endorse same race/ethnicity of provider as important**

- For those who do, groups differs from those constructed with the other two importance measures with an increase of children/youth who are not White, while White children/youth decrease
- If caregivers found services to be highly culturally competent, most had providers who were of the same race/ethnicity
- Those who rate importance and cultural competence as low were least likely to have providers of the same race/ethnicity.
Cultural Competence Importance and Experience and Youth Strengths

**Caregiver Report of Youth Strengths**

- Youth strengths differ at intake and show different rates of change to 6 months.
- Youth strengths make greatest gains when cultural competence is important to the caregiver and services are rated as highly culturally competent.
- Youth strengths are lowest when importance and experience of cultural competence are both lower.

**Within Subjects X Time:** $F = 5.916$, $p < .01$

**Between Subjects:** $F = 40.584$, $p < .001$

Strength index on the BERS–2C ranges from 38 to 161 with an average index between 90 and 110. A higher index indicates greater overall strengths.

While importance and experience of matching race/ethnicity of provider differentiates groups, the rates of change in strengths are slower for groups differentiated by importance of matching provider to child/youth by race/ethnicity.

**Implications**

- Assessing the importance of culturally based services to families at intake may assist in addressing potential challenges in outcomes.
- Understanding why culture is of low importance to some families may help in addressing service needs.

**What’s Next?**

- Examine how youth and caregiver participation, and cultural competence contribute together to outcomes.
- Apply evaluation findings to mental health treatment, services, and program development.
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- www.macrointernational.com/projects/CMHI
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