Parents’ Perspectives on Access to Child and Adolescent Mental Health Services

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Aim of Study

• To understand the perceptions of parents about accessing mental health services through California’s Children’s Health Insurance Program (CHIP), known as the Healthy Families Program (HFP)

• Part of a larger study on the utilization of mental health and substance abuse services in California’s HFP
Study Background

- Sponsored by the California Managed Risk Medical Insurance Board (MRMIB)
- Funded by a grant from the California Mental Health Services Act
- Collaboration with 21 health plans that provide HFP services in state
- Co-investigators from San José State University* and APS Healthcare, Inc. External Quality Review Organization**
  - Edward Cohen, Ph.D.*, Principal Investigator
  - Esperanza Calderon, B.A.**
  - Gerardo Salinas, M.S.W.*
  - Saumitra Sengupta, Ph.D.**
  - Michael Reiter, PharmD.**
  - Karen Parsons, M.S.W.*
CHIP Programs

• Very little published about mental health services in CHIP programs nationwide
• Almost all states offer low-cost CHIP insurance with MH and SA benefits
• CHIP programs generally offer full insurance benefits (health, dental, preventive, mental health and substance abuse) to targeted low income children not eligible for Medicaid
• Low monthly premium and low co-pays
Health Families Program

• Enrollment at time of study (2007-08) was over 850,000 children & youth
• 56% of parents described child as Hispanic/Latino
• Almost same number of parents primarily speak Spanish (46%) as English (47%)
• Families enroll in one of 21 health plans – most counties offered choice of more than two plans
• Mental health benefits:
  – Outpatient MH—up to 20 visits per year
  – Inpatient MH—up to 30 days per year
  – Substance abuse outpatient—up to 20 visits per year
  – Substance abuse inpatient—for detox only
## Selected Studies on Child/Adol MH Use

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Children’s MH Utilization Rate</th>
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<tbody>
<tr>
<td>National Longitudinal Survey of Youth(^2)</td>
<td>2,205 nationally representative sample (2000)</td>
<td>6.17% (any specialty MH treatment)</td>
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<tr>
<td>Impact of EPSDT Expansion(^3)</td>
<td>58 counties in CA between 1992 and 2001</td>
<td>3.91% after policy change</td>
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<td>National Survey of American Families(^4)</td>
<td>National household, 2002</td>
<td>Medicaid: 13%</td>
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<td></td>
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<td>Other insurance: 8.27%</td>
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<td></td>
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<td>Uninsured: 4.5%</td>
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<tr>
<td>National Benchmarking Study(^5)</td>
<td>20 states (Including CA), 2003</td>
<td>2%-16%</td>
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\(^2\) National Longitudinal Survey of Youth is a study conducted in 2000, which found that 6.17% of children utilized specialty mental health treatment.

\(^3\) Impact of EPSDT Expansion study examined the effect of policy changes on mental health utilization rates.

\(^4\) The National Survey of American Families, conducted in 2002, found that Medicaid covered 13% of children, and 8.27% had other insurance, while 4.5% were uninsured.

\(^5\) The National Benchmarking Study, conducted in 2003, reported a range of utilization rates from 2% to 16% across various states including California.
## Utilization of MH Services in the HFP

<table>
<thead>
<tr>
<th>Outpatient MH Services, CY 2007-2008*</th>
<th>MH utilization of subscribers</th>
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<tbody>
<tr>
<td>At least one outpatient MH visit</td>
<td>1.79%</td>
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<tr>
<td>By type of provider network:</td>
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<tr>
<td>Managed Behavioral Health Company (n=11)</td>
<td>1.20%</td>
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<tr>
<td>County administered plan or network (n=7)</td>
<td>2.28%</td>
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<tr>
<td>HMO or single provider network (n=3)</td>
<td>2.80%</td>
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<tr>
<td>By ethnicity of child:</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>5.34%</td>
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<tr>
<td>Black/African American</td>
<td>2.85%</td>
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<tr>
<td>Hispanic/Latino</td>
<td>1.81%</td>
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<tr>
<td>Asian groups</td>
<td>1.00%</td>
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<tr>
<td>At least one substance abuse visit</td>
<td>0.07%</td>
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</tbody>
</table>

*“Plan-provided services” only – not services for HFP children with SED which are provided by county MH"
Importance of understanding parents’ help seeking decisions

• Parents more likely to seek help the higher the perceived burden on family\(^7\)
• And higher perceived seriousness of the problem\(^8\)
• Role of pediatrician very important to most parents who have not yet accessed MH services\(^9\)
• Parents’ understanding of the nature of the problem and perceived barriers to getting care are also important factors\(^{10}\)
Methods

• Comprehensive evaluation was an effort to review current MH/SA utilization and contextual factors about access to care

• The comprehensive study involved:
  – Analysis of administrative service data
  – Parent focus groups
  – Key informant interviews with health plans
  – Review of health plans’ policies and procedures
Focus Groups: Sampling and Recruitment

• Three focus groups and individual phone interviews--drawing from Los Angeles, San Joaquin (Central Valley), Orange County and Riverside County

• Total sample: 25 adults and two youth
  – Parents recruited by health plans from lists having received at least one MH service in study year
  – Recruitment letters sent in English and Spanish
  – 16 parents Spanish speakers; one Vietnamese speaker
Focus Group Protocol

• Groups lasted 1 ½-2 hours
• Food and gift cards provided
• Staffing:
  – Principal Investigator
  – Student Research Assistant (Bilingual English/Spanish)
  – Notes Transcriber (Bilingual English/Spanish)
  – Spanish Interpreters (Vietnamese Interpreter in one group)
Sources of Thematic Domains Guiding Focus Group Questions

• Literature
  – Primary care interface
  – Extent of problem as seen by parent
  – Process of obtaining help
  – Response from initial visits

• Contract with MRMIB
  – Client satisfaction
  – Quality of services
  – Timeliness and barriers to services
  – Suggestions for improvement
Analysis Plan

• Extensive field notes were taken
• Instances of anticipated and unanticipated themes were highlighted by individual researchers and then by team
• Team compared choices and came to consensus on main categories of thematic structure
Thematic Categories from Analysis

• Identifying the problem, and reactions from others
• Role of the primary care physician
• Administrative procedures in accessing care
• The first appointments
• The treatment process
• Culture, language, and stigma
• Parents’ recommendations
Identifying the problem, and reactions from others

• Problems noticed by parents early
  – Often before HFP enrollment
  – Some problems identified by school

• Hard convincing other professionals of seriousness of problem, or that it was something beyond the parent’s control

“I just felt something was wrong. I took her to see a counselor; I was so mad because the psychologist said I needed to learn to be a parent. I didn’t think so.”
Role of the primary care physician

• Primary care authorization for MH care is not required by HFP, but parents often discussed problem with PCP first
• Parents gave examples of both dismissive and empathic responses from PCP
  “The doctor didn’t want to refer him to a psychiatrist and just wanted to give him medicine. I said no. I felt he needed an evaluation first. I went for help at school.”
• The issue of medications came up frequently—a primary source of unresolved decisions or outright disagreement between clinicians and parents
Administrative procedures in accessing care

• Parents needed to make many phone calls to find clinicians, make appointments, repeat the history, and obtain approval for sessions

“Of the five [phone] numbers given [for mental health clinicians] only 2 called back. They only gave me 20 sessions and only gave me medication. I called to get more sessions. They said no. They said maybe she needs medication. I said no, I don’t want to give her medication. They gave her five more sessions. They said maybe another [clinician] can work well again.”
Administrative procedures: pre-authorization

• Key informant interviews with managed behavioral health care representatives confirmed they required pre-authorization
  – Not for gatekeeping, but to find a provider and monitor quality of treatment

• Parents experienced this differently
  “I had to call an 800 number for permission.”
  – Some parents were confused by this—it seemed to contradict the benefit description
  – It was out of context with their experience in community health settings
The first appointments

• There were delays in getting an appointment
  – Sometimes months, with a waitlist
• There was a learning curve for parents new to MH treatment
  – Different professionals may have different perspectives, especially during the assessment phase
  – Parents continually reported the need for basic information on what should be expected from MH treatment (early on they can’t be expected to ask all the right questions)
  – The need for assertiveness—most parents in our groups learned to be persistent
    “You have to do what’s right for you child. Insist, insist, insist!”
  – But—a clinician who was able to listen to concerns was considered effective, even when there were disagreements about the initial problem

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The treatment process

• The course of treatment went better when the parent felt the clinician was a good match

“I asked for good services, demanded it; when my son started in the beginning with MH, he had a good therapist. I had high expectations. I like the new guy, he had to work with teens who need more help…”

• Some practitioners were better than others in managing parents’ concerns, i.e. treading the line between disclosure to parents vs. confidentiality for youth

“I didn’t want to break the confidence (sic) but still needed to know what was going on with my son…”

• Discontinuity of care was a problem for some parents—shifting back and forth between HFP and Medicaid

“After I had to leave Healthy Families, my Medi-Cal doctor didn’t do the changes the other [HFP] doctor wanted, even though I explained that the changes were working.”
Culture, language, and stigma

• Cultural differences in understanding the role of treatment providers
  – U.S. laws, like mandated child abuse reporting
    “...other parents told me that they take your kids away if you get into treatment.”

• Stigma about mental health treatment
  “My son when he gets in trouble said he wants to see the counselor. I say no, you don’t want to become dependent on the counselor. You only get coverage till 19, can’t always have it”
  “I know other parents need help but they won’t do it--they don’t want that kind of help.”

  – But also:
  “I learned that getting what my child needs is more important than what other people think.”
Culture, language, and stigma

• Language
  – Urban health plan locations had a good distribution of Spanish speaking clinicians
    “I always look for Latino doctors. They just seem to understand my problem better.”
  – Health plans make extensive use of language lines and trained interpreters, though
    “I wasn’t sure my translator was saying the right things to the psychiatrist.”
Parents’ recommendations

• More outreach to school health clinics
  – Train health workers on HFP benefits and application process
  – Provide direct services for HFP subscribers

• Establish parent education & support groups
  – Parents used our groups for this

• Continue to elicit direct feedback from parents
Limitations of Study

• Despite one group in agricultural rural area, most respondents were from urban areas
  – Experience in rural area most likely different
• Recruitment was probably biased towards parents who had positive experiences
  – Response rate from initial recruitment was very small
  – Parents in our groups were also probably more assertive than most
• Always the potential for biased response about healthcare experiences\textsuperscript{11}, especially from selective memory
Implications—Primary Care

• Need for brief MH/SA assessment tools suitable for primary care
• Train primary care practitioners in how to talk to parents and youth about emotional problems
• Establish better referral tracking procedures to ensure smooth transitions to specialty care
• Pilot models of integrated MH/primary care for this population
• Continue monitoring quality of interpreting services and require the inclusion of training material about MH visits
Implications—Administrative Procedures

• Simplify pre-authorization procedures
• Analyze the cost effectiveness of such procedures given the benefit limitations
  – Consider limiting the requirement for such pre-authorization, i.e. for only >20 session requests
• Train phone response staff in MBHOs to better orient parents
Implications—Community Outreach & Education

• Take seriously parents’ recommendations about the school/HFP interface
• Locate important, culturally congruent community providers who can provide MH and SA information
• Establish ongoing parent information and support groups
• Establish a “parent mentor” program—recruiting parents to orient others


References


