

Issues and Opportunities in Measuring and Improving Healthcare Access and Quality

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Mental Health of Children and Adolescents

- 1 In the United States
 - 1 10% of children and adolescents suffer from mental illness severe enough to cause clinically significant impairment warranting treatment
 - 1 Most do not receive needed treatment
- 1 WHO predicts 50% rise in childhood neuropsychiatric disorders by 2020

WHO=World Health Organization

Brief notes on the mental health of children and adolescents.
[www.nimh.nih.gov/publicat/childnotes.cfm] Accessed 12/03.

Mental Disorders With Possible Onset in Childhood

- 1 Mood disorders (MDD), including bipolar disorder (BD)
- 1 ADHD
- 1 Anxiety disorders
- 1 Eating disorders
- 1 Disruptive behavior disorders, including Oppositional-defiant and conduct disorders
- 1 Autism and other developmental disorders
- 1 Schizophrenia
- 1 Tic and related disorders

Treatment of children with mental disorders. Available at:
www.nimh.nih.gov/publicat/childqa.cfm. Accessed 12/03.

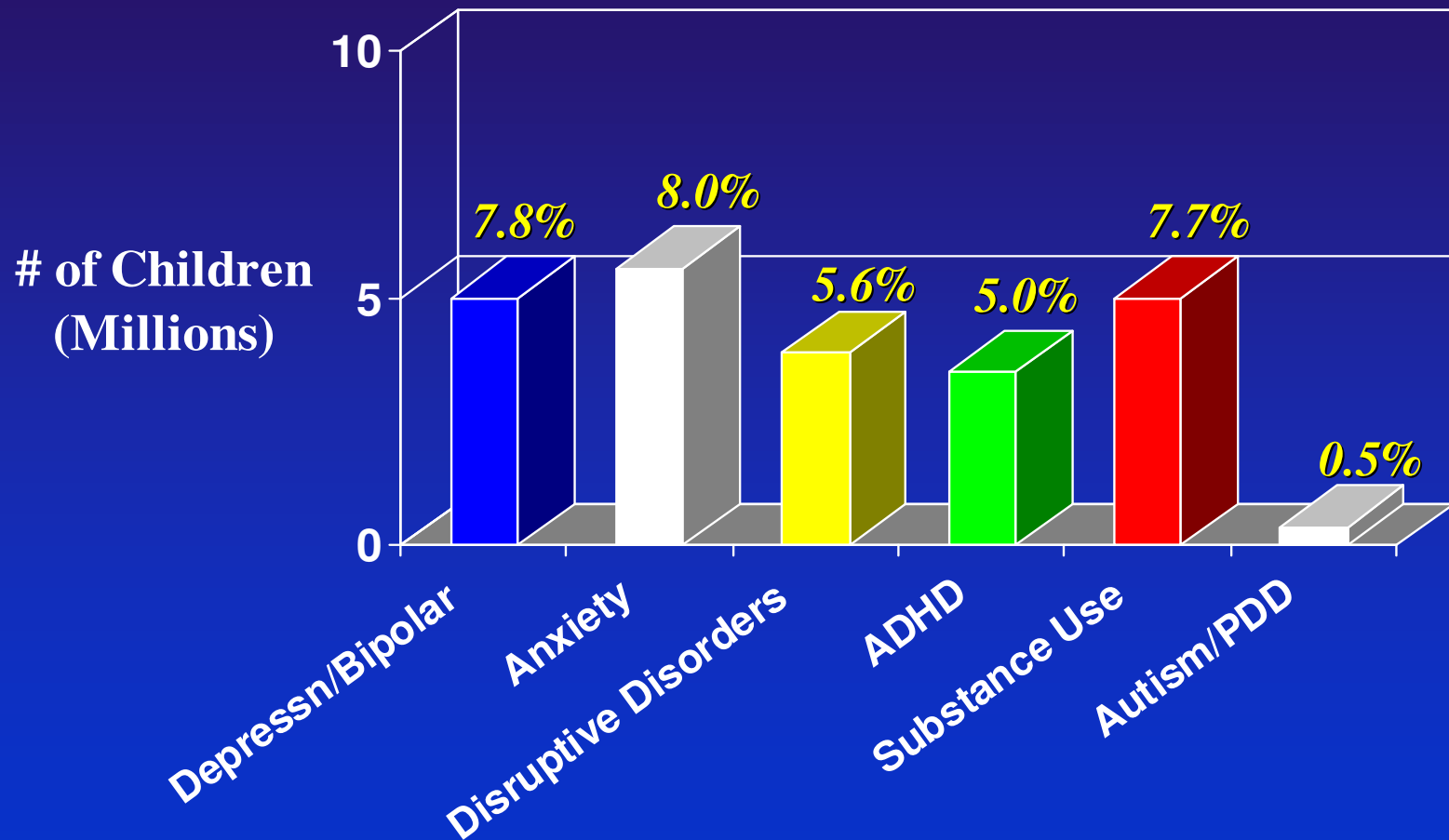
Special Concerns in Assessment and Treating Children/Adolescents

- 1 Children rarely seek help
- 1 Signs and symptoms may be different from adults (eg, rapid cycling in bipolar disorder)
- 1 Comorbidity is common
- 1 Youths may have difficulty expressing thoughts and feelings
- 1 Absolute need for multiple information sources
- 1 Treatments safe and effective in adults may be both, either, or neither in children and adolescents
- 1 Much less research than is available in adults

Barriers to Detection, Identification, & Diagnosis

- 1 Lack of Awareness of Frequency
- 1 Attitudes/beliefs/stigma: differs by disorder
- 1 Communication problems
- 1 3-23% variation in rates based on different definitions (Narrow et al., 1998; MECA Study)
- 1 Rates dependent upon population sampled (25% in primary care, 72% in protective service caseloads (Trupin et al., 1993))

Extent of Mental & Substance Use Disorders In U.S. Children and Adolescents



*Source: Office of the Surgeon General, and
National Institute of Mental Health, 1999*

Example #1: ADHD in US Children/Adolescents

- 1 Almost 7% (>2.6 million) US children (aged 6–11 yr) had diagnosis of ADHD in 1997–98¹
 - 1 3% had ADHD without learning disability (LD)
 - 1 4% had both ADHD and LD
- 1 Symptoms may develop before age 7²
- 1 More common in boys than in girls^{1,2}

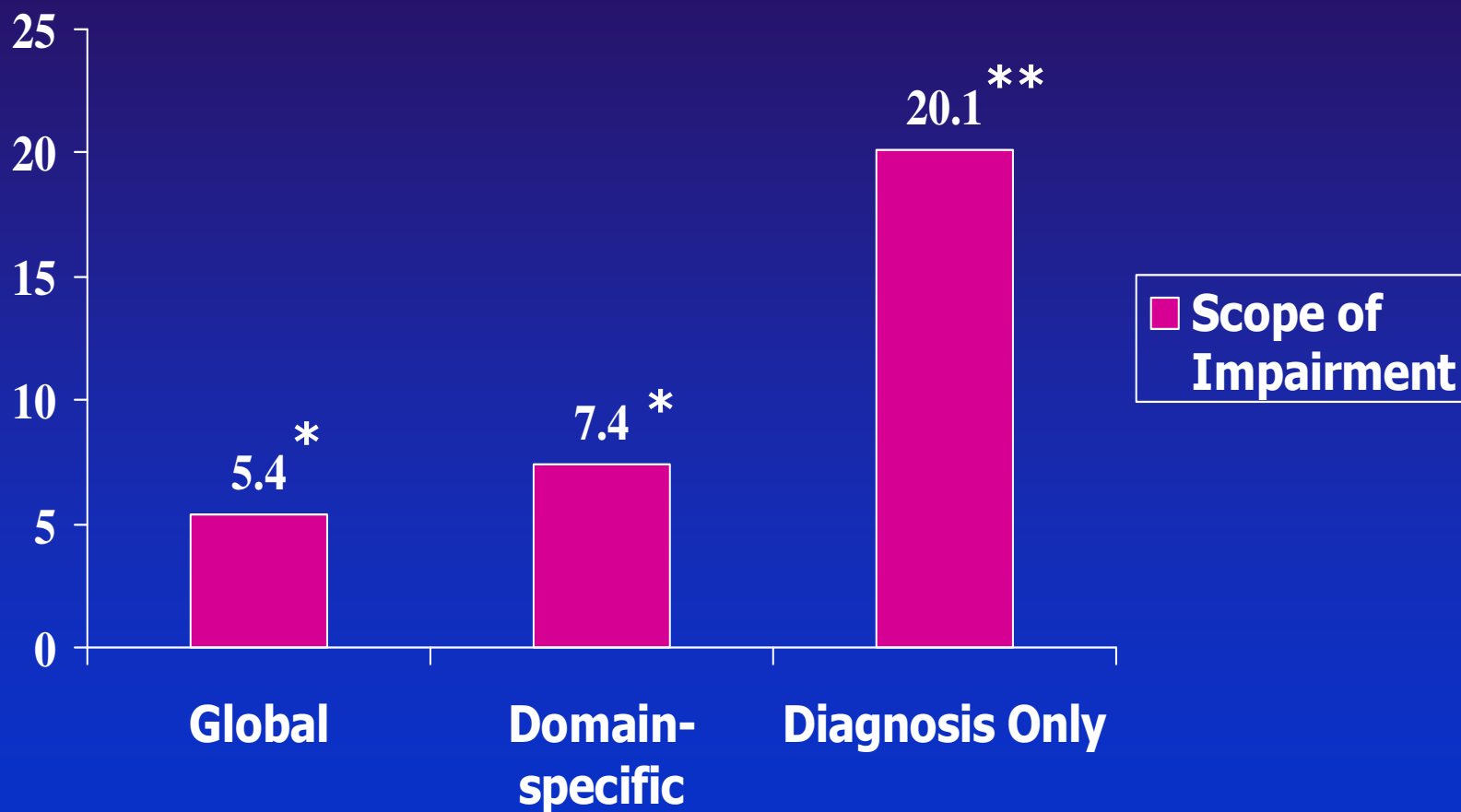
1. Pastor PN, Reuben CA. Attention deficit disorder and learning disability: United States, 1997–98. NCHS. Vital Health Stat 2002; 10(206).
2. *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition-text revision. Washington DC: American Psychiatric Association, 2000:39–134.

Example #2: Depressive Disorders in US Children/Adolescents

- 1 8% of children and adolescents (11–18 yr) met criteria for depression in one study¹
- 1 ~10%–15% of adolescents, ~30% of children with recurrent major depression will develop Bipolar I disorder²
- 1 Children and young adolescents with MDD have:
 - 1 Increased family history of depression
 - 1 Much increased risk for adverse adult outcomes

1. Shaffer D, et al. *J Am Acad Child Adolesc Psychiatry* 1996; 35:454–463.
2. Mood Disorders. In: *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition-text revision. Washington DC: American Psychiatric Association, 2000.

Prevalence Estimates of Serious Emotional Disturbance in C & A



* Rates based on reanalysis of 4 studies

** Based on MECA Study, 1996

Costello, Messer, Bird et al., 1998

Shaffer et al., 1996

How Many Children Need and/or Use Services across the US?

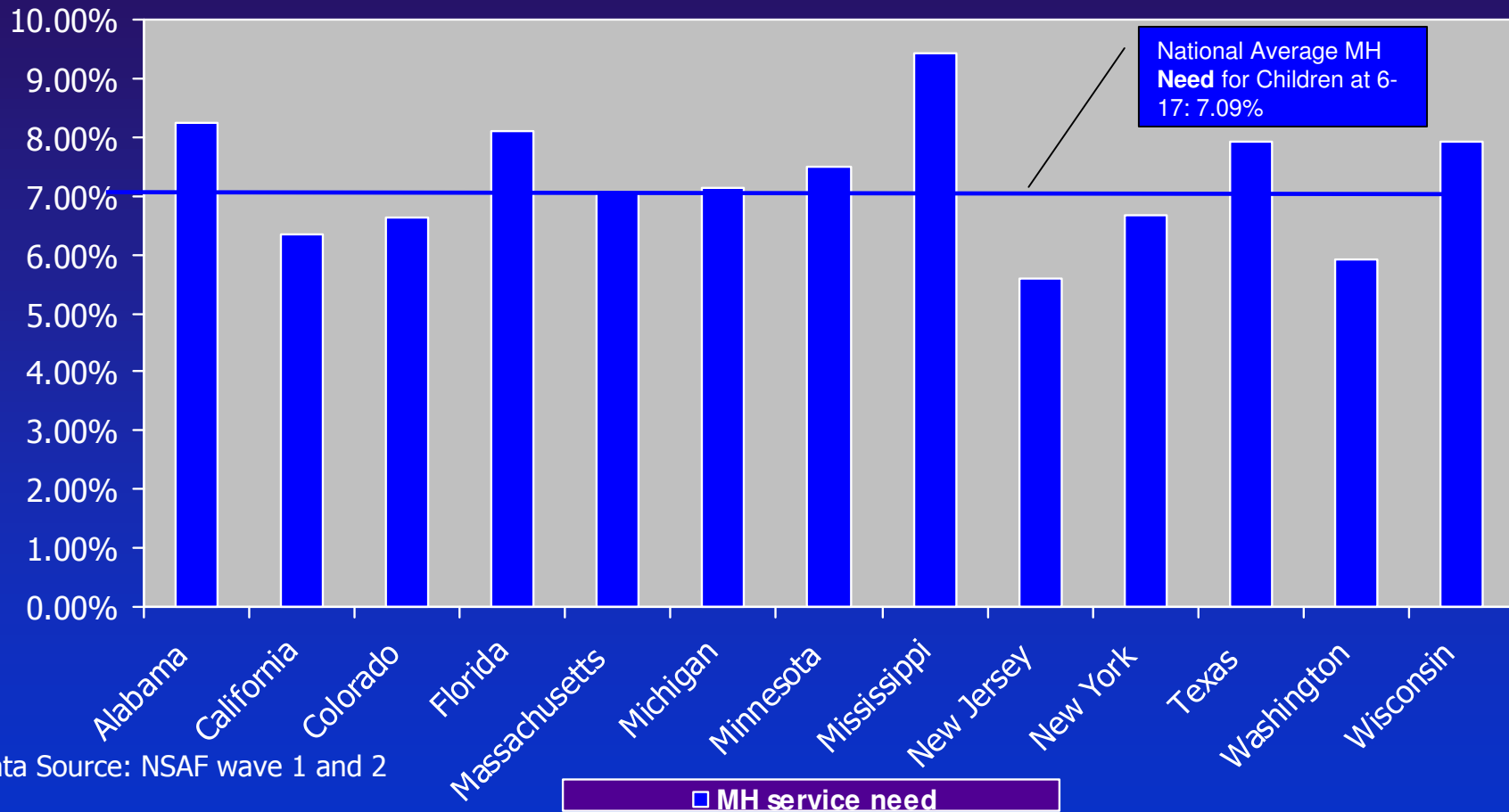
- 1 **Need for, Access to, and Use of Services:**
 - 1 How do these factors vary by insurance status, age, race/ethnicity, family structure, geographic area?
 - 1 Which characteristics are associated with mismatches between need and service use?

Rand Study: Data Sources

Sturm et al., 2002 (FAN)

- 1 No single comprehensive data source exists
- 1 Examined:
 - 1 National Survey of America's Families (NSAF)
 - 1 Community Tracking Study (CTS)
 - 1 Claims data bases – Ingenix, UBH
 - 1 Inventory of Mental Health Organizations (IMHO)
 - 1 Healthcare Cost and Utilization Project (HCUP)
 - 1 HCFA Medicaid Statistics
 - 1 State Mental Health Agencies
 - 1 And others

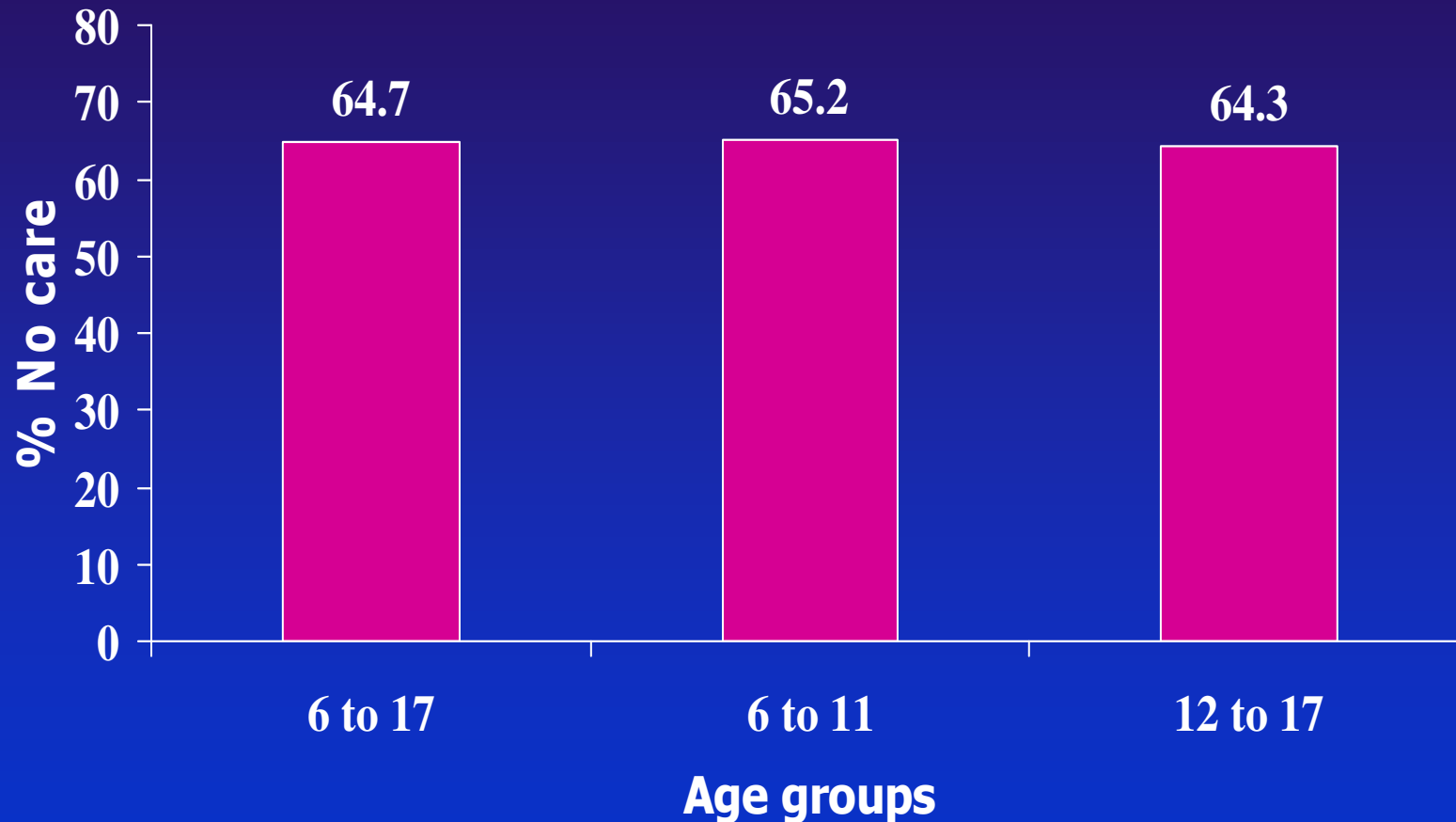
National Averages of Need



Data Source: NSAF wave 1 and 2

Sturm et al., 2002

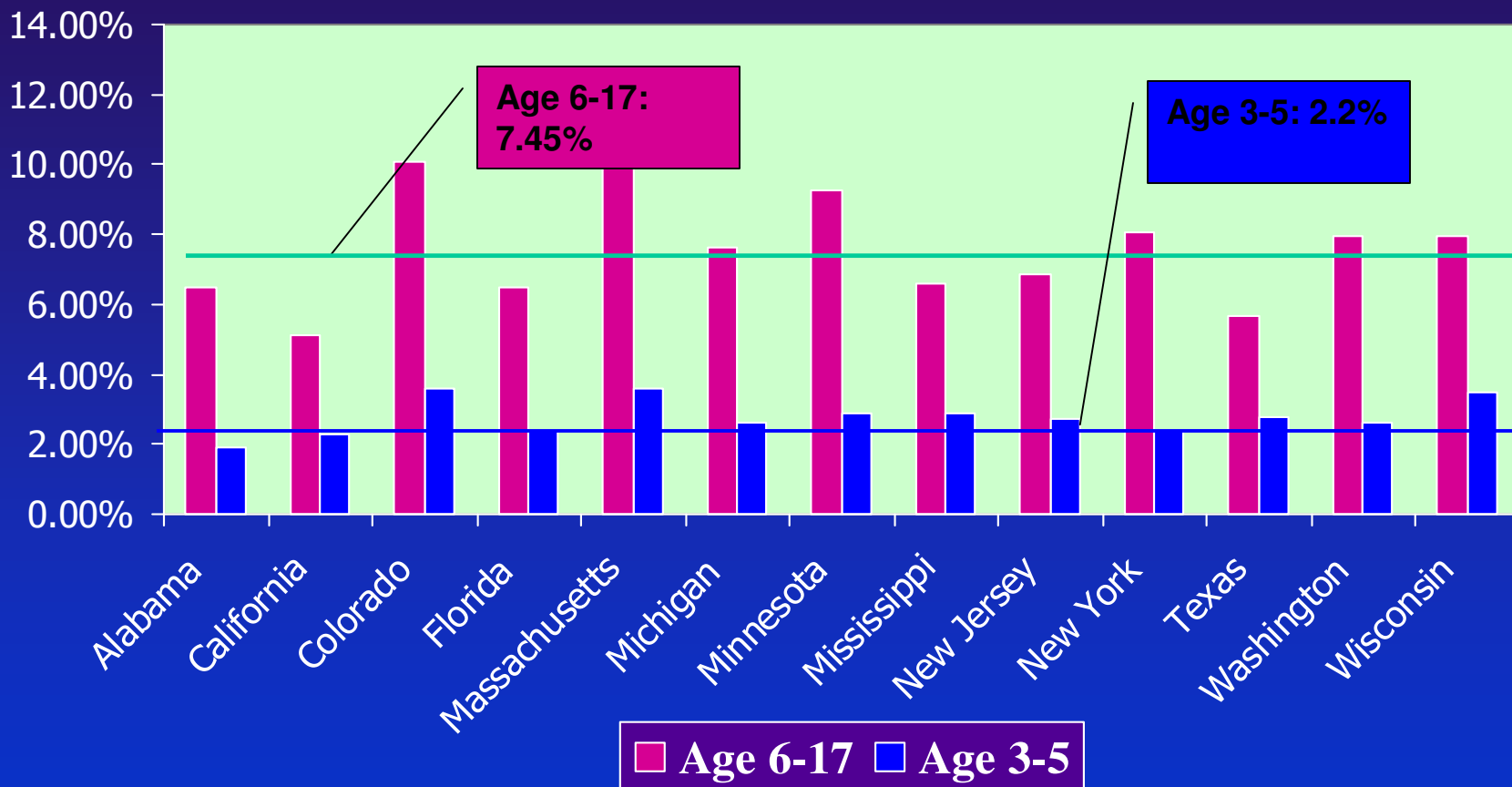
Unmet Need: No Differences by Age Groups



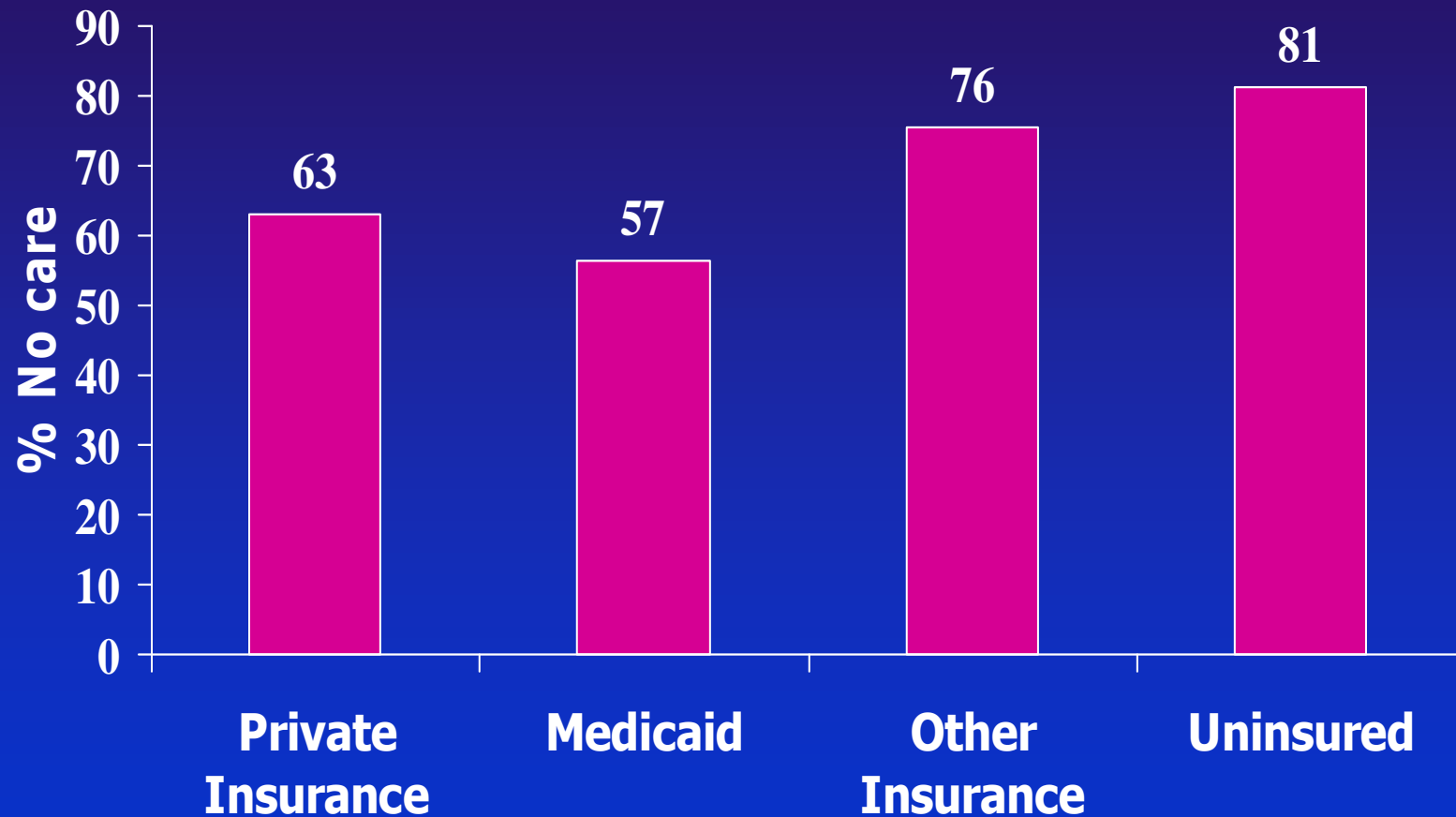
Data from NSAF

Sturm et al., 2002

The 3-5 age group has lowest usage rates and least variation by state



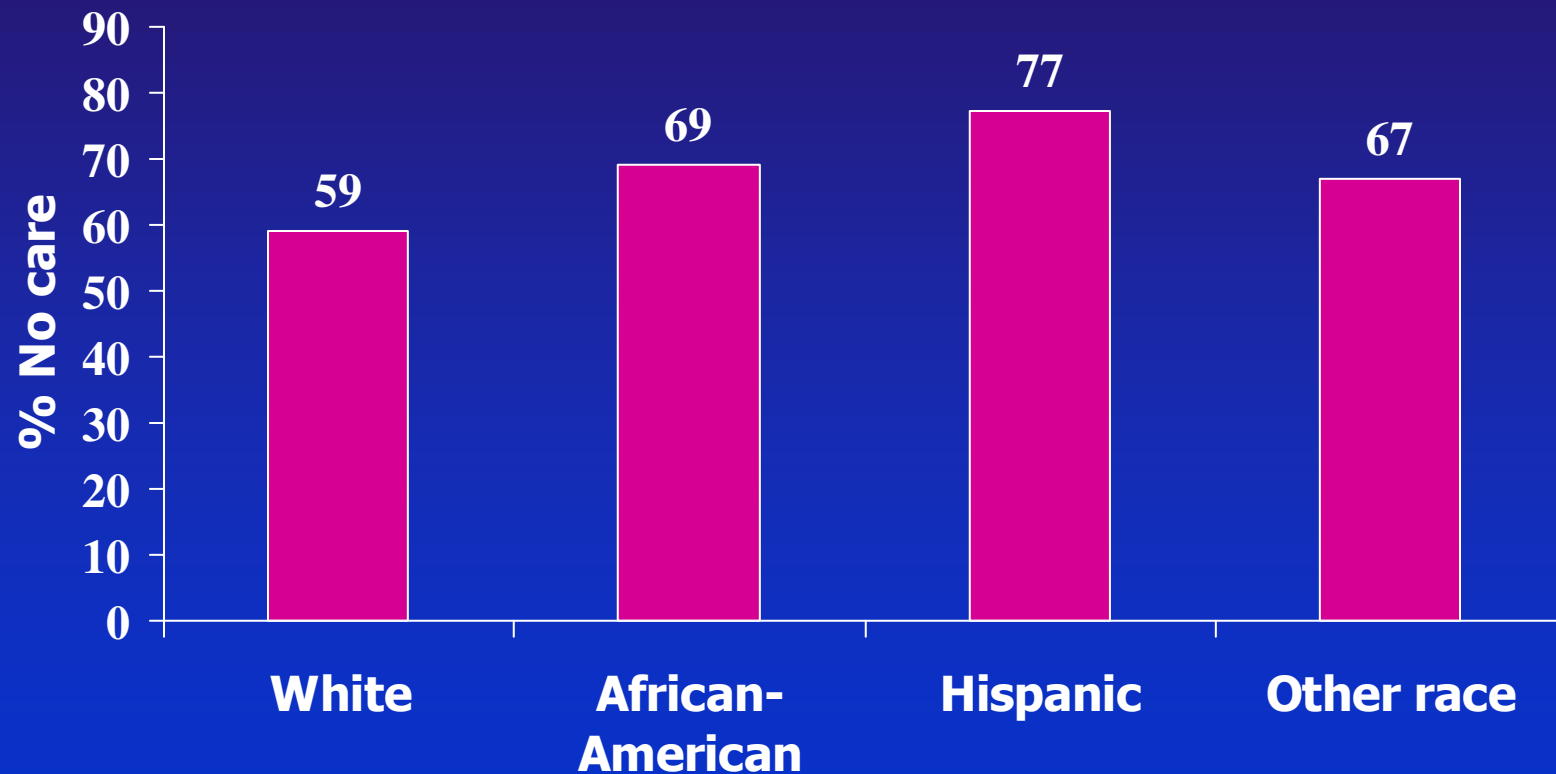
Uninsured children with MH needs least likely to receive any care



Data from NSAF

Sturm et al., 2002

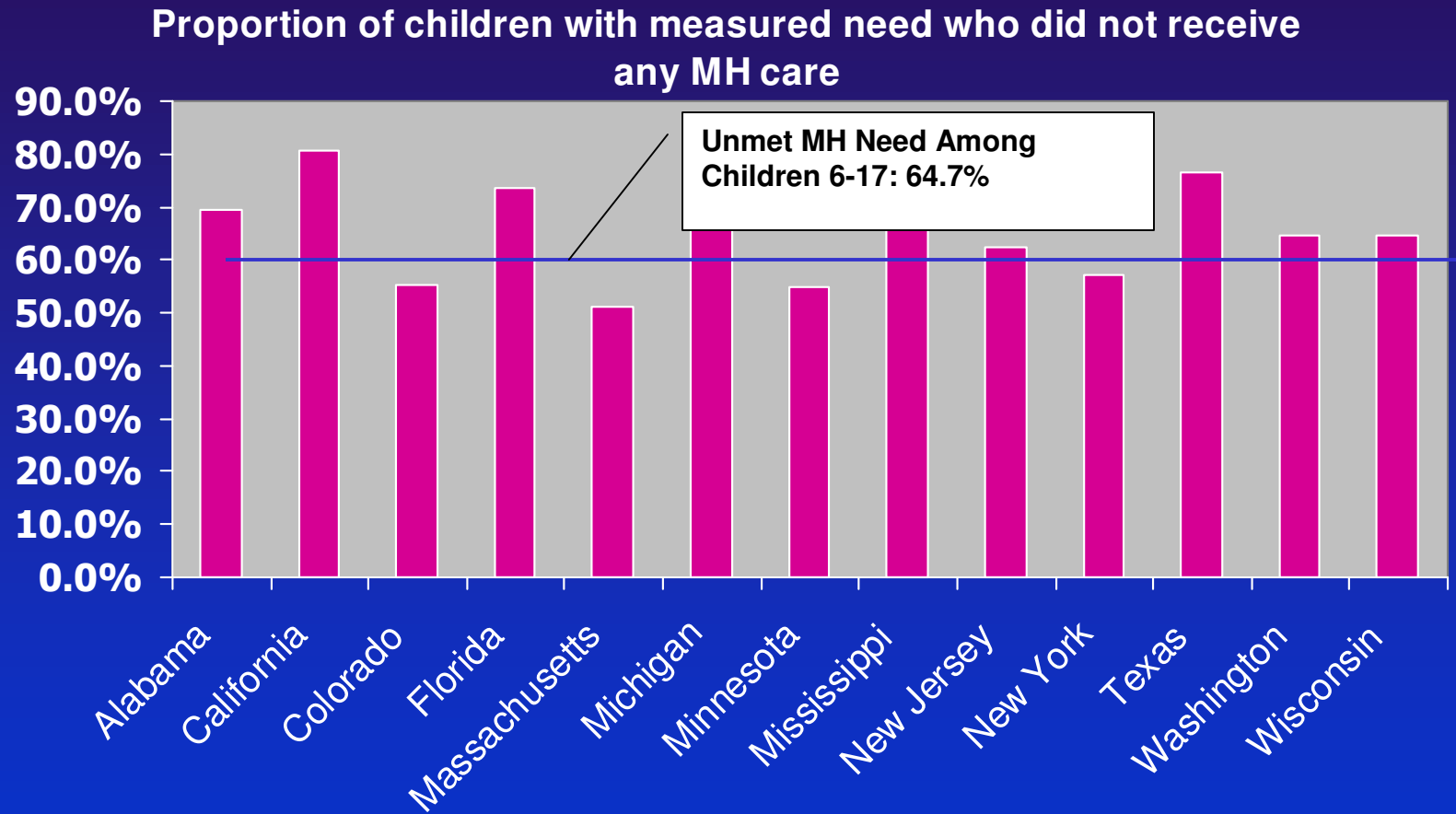
Minority children with MH needs least likely to receive care



Data from NSAF

Sturm et al., 2002

Geographic Variations in Unmet Need



Sturm et al., 2002

Geographic Variations Exceed Effects of Sociodemographics

- 1 **Rates of youth MH specialty care differ:**
 - 1 20-40% difference by race/ethnicity
 - 1 170% difference across CTS sites – from 5% in Phoenix to over 13% in Boston
 - 1 8 out of 12 sites are statistically different from the national average.
- 1 **No change when adjusting for age composition or race/ethnicity**

Sturm et al., 2002

Unmet Need “Indicators” Project

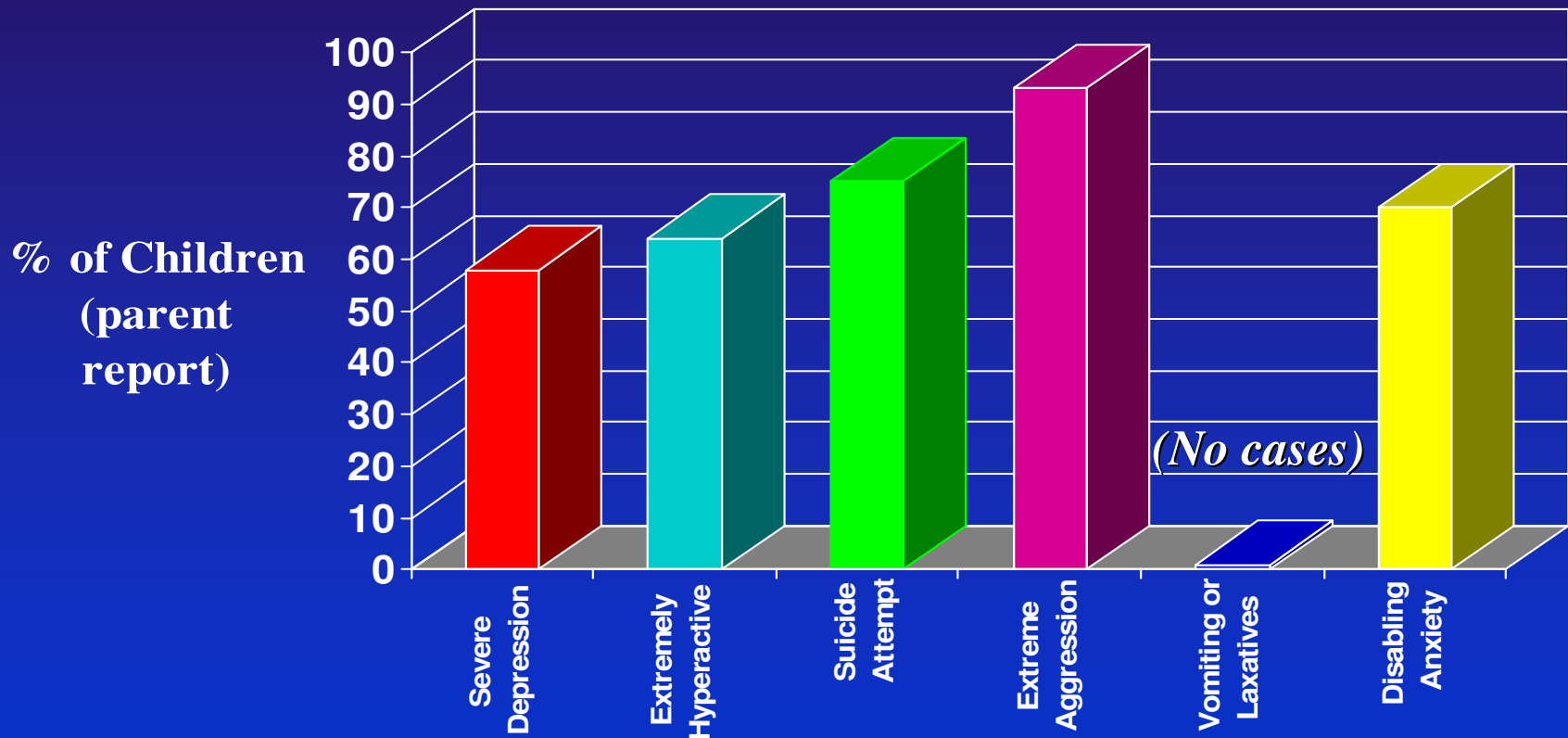
Jensen, Offord, Costello, et al., 2004

- 1 Federally Supported and Guided (CMHS, NIMH)
- 1 Scientific Approach to Determine Best Indicators of Current Unmet Need (considering age, gender, ethnicity, and cultural differences)
- 1 Use of Epidemiologic Data Sets and Collaborating Scientists
- 1 Input and buy-in from multiple focus groups, all major professional and advocacy organizations

Indicators

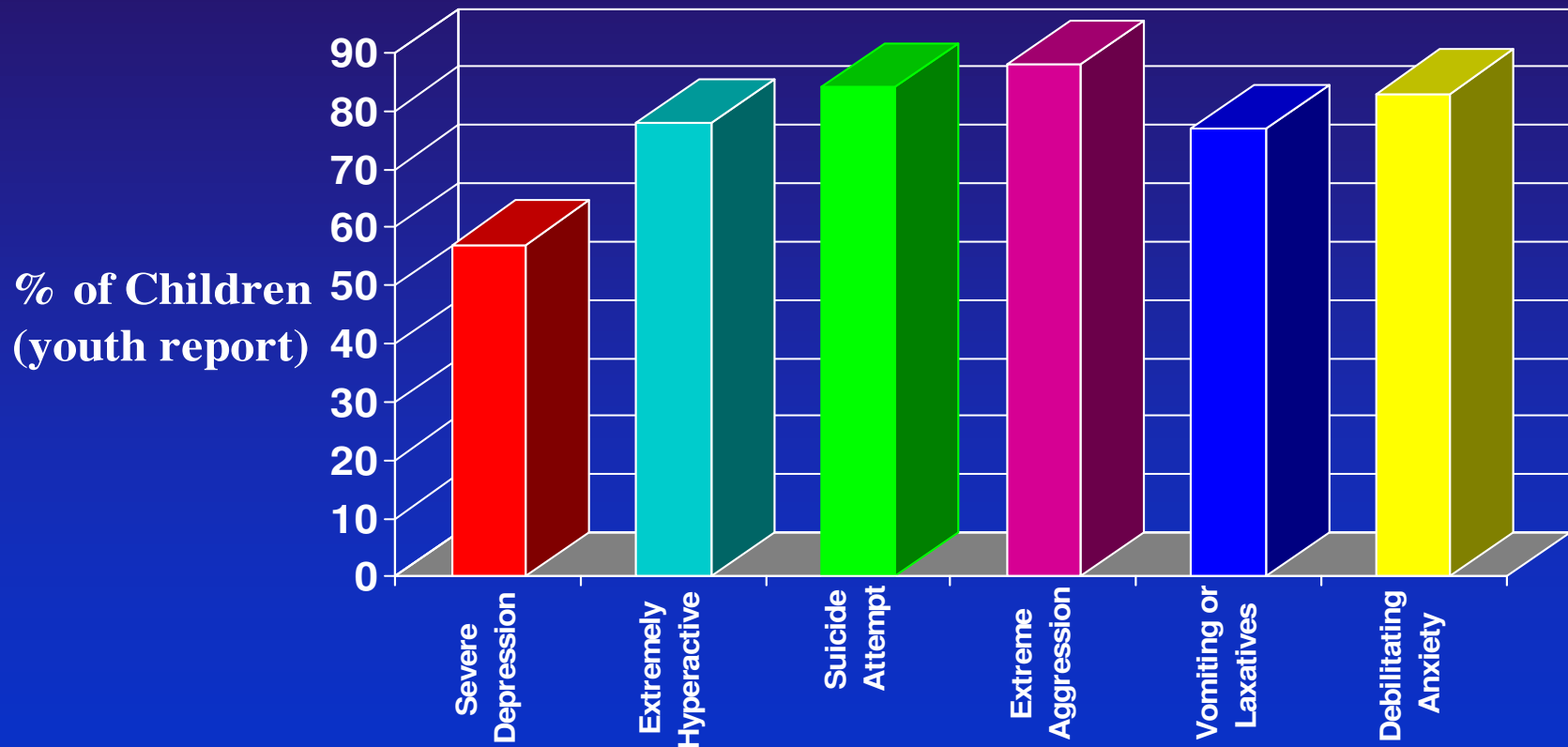
- 1 **Extreme Depression with impairment**
- 1 **Suicidal, with recent attempt or plan**
- 1 **Severe hyperactivity/impulsivity – resulting in physical danger**
- 1 **Disabling anxiety**
- 1 **Panic attack**
- 1 **Extreme aggression with impairment**
- 1 **Health-threatening eating problem**
- 1 **Severe mood instability**

Unmet Need by Indicator (Parent report, n = 2138)



*Source: MECA, Iowa-Conger, Texas-Roberts
Jensen, Offord, Costello et al., 2004*

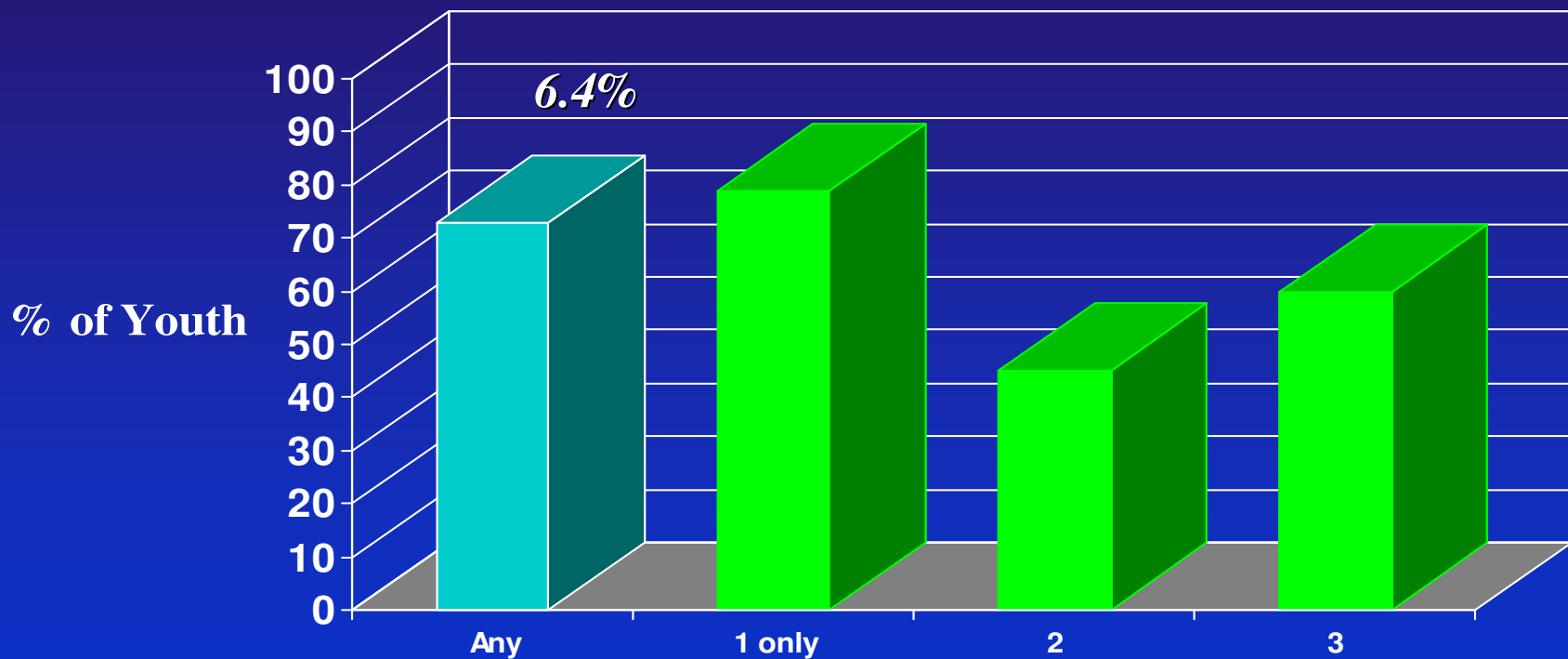
Unmet Need by Indicator (Youth report, n = 6348)



*Source: MECA, Iowa-Conger, Texas-Roberts
Jensen, Offord, Costello et al., 2004*

Unmet Need by Any Indicator and Total # of Indicators (parent report)

n = 2138



*Source: MECA, Iowa-Conger
Jensen, Offord, Costello et al., 2004*

Modifications from Focus Groups: “Action Signs”

Extreme sadness and/or emotional withdrawal that lasts several weeks

Trying seriously to harm or kill oneself, or making plans to do so

Sudden overwhelming fear for no apparent reason, sometimes with racing heart or shortness of breath

Starting frequent fights, using a weapon, wanting to seriously hurt others

Frequent and severe explosive or out-of-control behavior that has harmed or threatens to harm others

Using laxatives or vomiting to make oneself lose weight

Extreme preoccupation with body image, exercise and losing weight that endangers one's health

Extreme worries or fears that interfere with daily activities

Severe mood swings affecting relationships with others*

Drastic changes in behavior or personality*

Extreme hyperactivity/impulsivity that puts the child in physical danger*

Repeated use of alcohol, drugs or other illegal substances

The Bottom Line: RAND and Indicators Studies

(Sturm et al., 2002, Jensen et al., 2004)

- 1 Most children with need do not receive any mental health services
- 1 Greatest disparities in unmet need among:
 - 1 minorities
 - 1 insurance status (uninsured)
 - 1 geographic areas
- 1 Even the most severely disturbed children are likely to not receive any services in the last year

Treatment Considerations

Scientifically Supported Treatments :

- 1 **ADHD: 200+ medication studies, 80+ psychotherapy studies**
- 1 **Depression: 1 medication (+/-), 2 forms of psychotherapy**
- 1 **Obsessive Compulsive Disorder: 4 medications, 1 psychotherapy**
- 1 **Anxiety Disorders: 2 medications, 1 psychotherapy**
- 1 **Conduct disorders: 2 medications, 1 psychotherapy**
- 1 **Autism: 2 medications, 1 psychotherapy**
- 1 **Schizophrenia: 2 medications**

Example #1:

ADHD Medications: What Works?

1 ADHD

- 1 Psychostimulants (MPH, dextroamphetamine, pemoline) - >200 DBRTs
- 1 NIMH-MTA Study shows that stimulant benefits persist up to 24 months, with increased effects with increased compliance
- 1 Controlled studies support efficacy of other medications
 - 1 TCAs (18 trials, e.g., Biederman et al, 1991)
 - 1 Bupropion (Wellbutrin)
 - 1 Atomoxetine (Strattera)

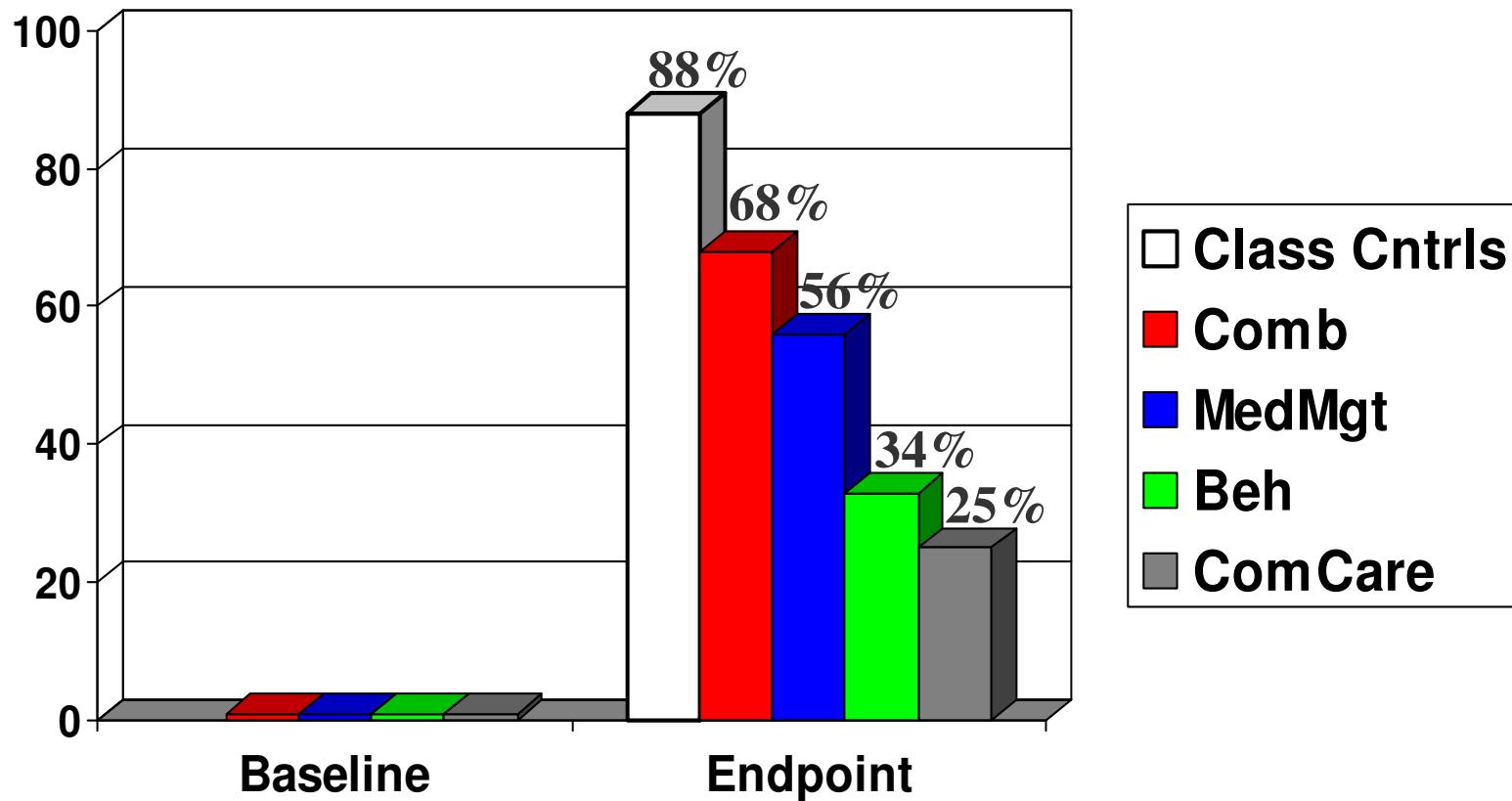
Example #1: ADHD Therapies What Works?

Well-established:

- Behavioral parent training
- Behavioral classroom interventions

- Family Therapy, Individual Therapy, and Cognitive Therapy neither well established nor probably efficacious

% “Normalized” at 14-month Endpoint MTA Groups vs. Classroom Controls



MTA N = 579

Classroom Cntrls N = 288

Example #2:

Depression Treatments: What Works?

- 1 Cognitive Behavioral Therapy (CBT)**
 - **> 18 studies demonstrate efficacy of group and individual CBT**
 - **Several *PV* studies demonstrate youth at risk for depn had only 20-50% expected depression rates**
 - **Large national trial underway comparing CBT, meds, & combination to placebo**
 - **More research support than any other treatment for childhood depression**

Example #2:

Depression Treatments: What Works?

1 **Interpersonal Therapy (IPT)**

- Several studies showing benefit of IPT with adults
- Two recent studies demonstrate efficacy w/teens
- IPT as effective as CBT in reducing sx of depression, but more effective than CBT in increasing self-esteem and social adaptation
- Another study how completed w/depressed youth in schools shows that outcomes can be improved in the “real world” (Mufson et al., 2004)

Example #2:

Depression Treatments: What Works?

Interventions w/Little-No Controlled Research w/Depressed Youth

- 1 Psychodynamic therapy
- 1 Play therapy
- 1 Unstructured short-term and long-term therapies
- 1 Family therapy
- 1 Alternative therapies (e.g., biofeedback, EMDR)

Future research may address these treatments

Example #2:

Depression Treatments: What Works?

1 Evidence of the safety and efficacy of SSRI's (e.g., Fluoxetine – FDA Approved) (4 studies), 1 large NIMH trial in completion

1 Most SSRIs are prescribed by PCPs throughout U.S. and Canada, due to lack of specialists, geographic constraints, etc.

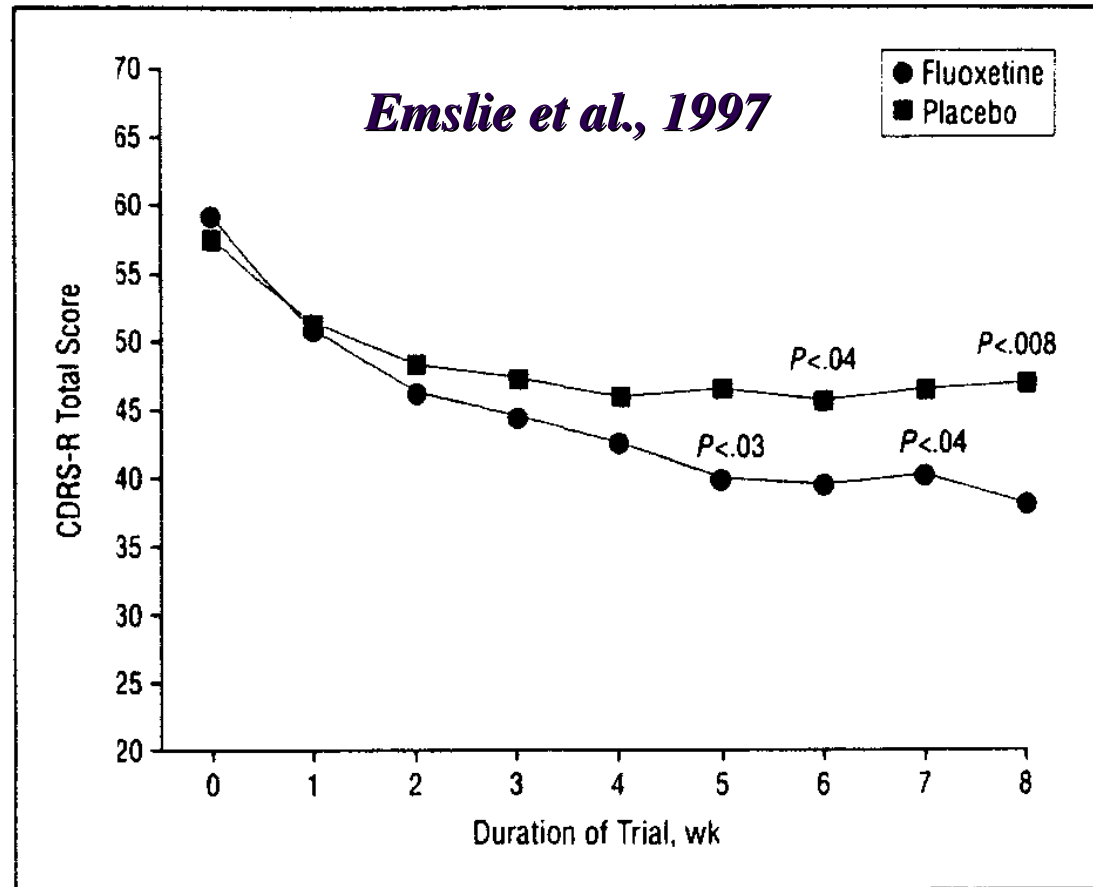


Figure 2. Weekly Children's Depressive Rating Scale—Revised (CDRS-R) scores (last observation carried forward) for fluoxetine and placebo.

***Our Task: Where and How are
We Going to Do Better?***

Example #1:
ADHD

Where We Might Do Better: Example #1

ADHD

- 1 **Some “overdiagnosis” of ADHD, but 1/2 of ADHD cases still missed in PC, special ed settings** (Bauermeister et al., 2002, Bussing et al., 1998, Olfson et al., 2003, Jensen et al., 1999, 2004)
- 1 **Only one-fourth to one-half of PCPs use DSM criteria, and many do not get data from school teachers** (Copeland, 1987; Wolraich et al., 1990, 1997; Moser, 1995; Sloan et al., 1998)
- 1 **Inadequate recognition of comorbid problems** (Jensen et al., 1989)
- 1 **Inadequate dosing** (MTA Cooperative Group, 1999a, 1999b)
- 1 **Inadequate follow-up (twice-yearly visits)** (MTA Cooperative Group, 1999a, 1999b)
- 1 **Only 1/2 of PCPs include any kind of therapy** (Hoagwood et al., 1998)

Teacher-Rated Inattention (CC Children Separated By Med Use)

Key Differences,
MedMgt vs. CC:

Initial Titration

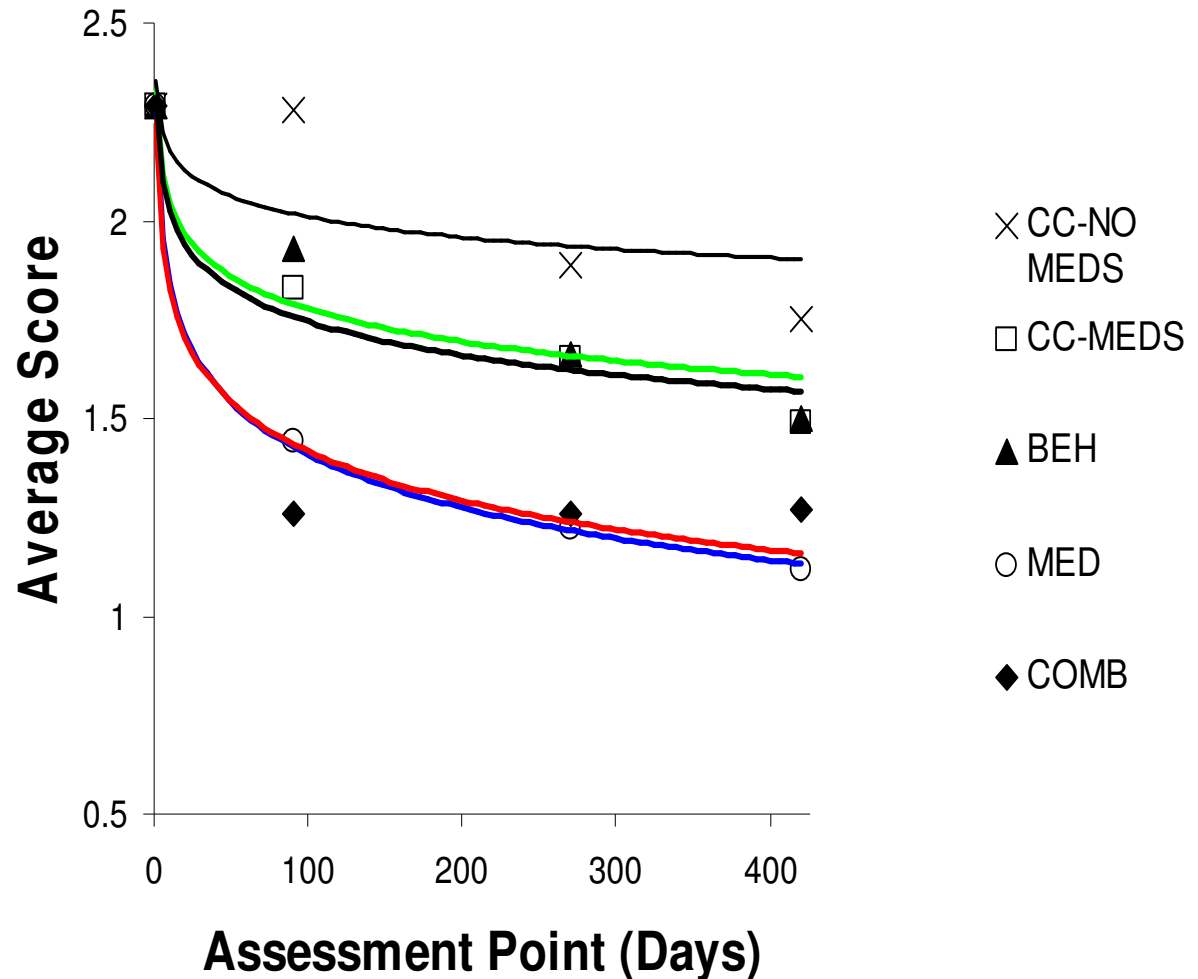
Dose

Dose Frequency

#Visits/year

Length of Visits

Contact w/schools



How We Might do Better: Example #1

AAP ADHD Guidelines: Assessment

- 1 Children 6-12 years of age who present inattention, hyperactivity, impulsivity, academic underachievement, or behavior problems should be evaluated by their PCP for ADHD
- 1 The diagnosis of ADHD requires meeting DSM-IV criteria
- 1 The assessment requires evidence obtained directly from parents/care givers regarding core symptoms, age of onset, duration of symptoms and degree of impairment

How We Might do Better: Example #1

AAP ADHD Guidelines: Assessment

- 1 The assessment requires evidence obtained directly from classroom teachers for core symptoms, duration of symptoms, degree of impairment and coexisting conditions
- 1 Evaluation should include assessment for coexisting conditions
- 1 Other diagnostic tests are not routinely indicated to establish the diagnosis

How We Might do Better: Example #1

AAP ADHD Guidelines: Treatment

- 1 Primary care clinicians should establish a treatment program that recognizes ADHD as a chronic condition.
- 1 The treating clinician, parents, and child, in collaboration with school personnel, should specify appropriate target outcomes to guide management.
- 1 The clinician should recommend stimulant medication and/or behavior therapy as appropriate to improve target outcomes in children with ADHD.

How We Might do Better: Example #1

AAP ADHD Guidelines: Treatment

- 1 When the selected management for a child with ADHD has not met target outcomes, clinicians should re-evaluate the original diagnosis, use of all appropriate treatments, adherence to the treatment plan, and presence of coexisting conditions.
- 1 The clinician should periodically provide a systematic follow-up for the child with ADHD. Monitoring should be directed to target outcomes and adverse effects, with information gathered from parents, teachers, and the child.

How We Might do Better: Example #1 NICHQ ADHD Performance Measures

Measure	Population Statistic	Appropriate Goal
<u>Outcome Measures</u>		
Function*	Percent of children who maintain an appropriate level or improve functioning by 25%	80%
Symptoms*	Percent of children who have an acceptable symptom score or improve symptoms score by 25%	80%
<u>Balancing Measures</u>		
Family Satisfaction with Provider	Percent of families rating provider care as very good or excellent	90%
School Contact	Percent of patients for whom practice has a documented contact name from school	95%

Measure	Population Statistic	Appropriate Goal
Process Measures		
Use of Structured Diagnostic Assessment*	Percent of patients being treated for ADHD with structured diagnostic assessment documented in chart	95%
Use of Written Treatment Plan*	Percent of patients being treated for ADHD with written treatment plan in chart	80%
Individual Goals*	Percent of children who have identified current goals on their treatment plan	80%
Choice of Evidenced-based Treatment Options*	Percent of patients who have treatment options explained, and choose best option for family	95%
Appropriate Follow-up	Percent of patients with follow up provided at recommended intervals	80%
Continuation of Medication	Patients with prescribed medication following medication treatment plan evidenced by appropriate timing for refill request	80%

*Example #2:
Depression*

Where We Might Do Better: Example #2: Major Depressive Disorder (MDD)

- 1 High rates of MDD in PCP settings (up to 28%)**
- 1 4 of 5 Youth with MDD missed in PCP settings (Chang et al., 1988, Kramer & Garralda, 1998)**
- 1 Most PCPs think it is their responsibility to identify depression (Olson et al., 2001, Jensen, 2002)**
- 1 Most PCPs “intend” to screen for depression and suicide, but do it less often than other areas (sexual activity/birth control), only 15% and 17% do it **always** (Halpern-Felsher et al, 2000; Middleman et al., 1995)**

How We Might Do Better: Example #2: Major Depressive Disorder (MDD)

- 1 **Unstructured methods or mnemonics (HEADSS) while popular, don't get used consistently**
- 1 **Brief screening tools can increase rates of MDD identification** (Logan & King, 2002; Johnson et al., 2002; Walker et al., 2002)
- 1 **Most PCPs do not use systematic MDD screening tools; only 35% note they are “motivated” to change depression screening practices** (Olson et al., 2001)
- 1 **No guidelines and agreed-upon tools for identifying/managing adolescents w/MDD in PC**

How We Might Do Better: Example #2: Guideline Development of Adolescent MDD

- 1 Guidelines for Adolescent Depression – Primary Care (GLAD-PC)**
- 1 US-Canadian Steering Committee to evaluate evidence and make recommendations for screening, diagnosing, and managing Adolescent MDD**
- 1 AAP, AAFP, APA, APA, AACAP, AHRQ, plus depression and PCP experts**
- 1 Toolkit testing and development (DPS/PHQ-9M, algorithms, dosing charts, referral guidelines, etc.)**

How We Might Do Better: Example #2: Possible MDD Performance Measures

- 1 Proportion of well-child physical exam (and emergency visits?) where brief screen is done, OR
- 1 Proportion of providers' youth caseload where a screen is done at least yearly, OR
- 1 Proportion of depressed youth with documented follow-up in 2-4 weeks, OR
- 1 Proportion of depressed youth with appropriate care plan (EB intervention, patient self-management, documented parent- and youth information), OR
- 1 Proportion of providers (PCPs, MHPs, or both) trained in EB methods

*Earlier & Improved
Identification*

Where We Might Do Better: Earlier/Improved Identification

- 1 **3 in 4 kids with MH problems missed in PCP settings** (Costello, 1986, 1988; Dulcan et al., 1990; Chang et al., 1988, Kramer & Garralda, 1998)
- 1 **SGO, pediatric leaders, consensus panels, and President's New Freedom Commission acknowledge need to encourage MH screening and earlier identification of children and youth in PC-, school-, foster care-, and JJ-settings: "mental health check-ups"**
- 1 **Brief screening tools can increase rates of identification** (Horwitz et al., 1992; Jellinek et al., 1999, Murphy et al., 1996)

How We Might Do Better: Early Identification Strategies

- 1 Many states (nearly half – 23) are not addressing behavioral health issues in their EPSDT screening tools (Semansky et al., 2003)
- 1 Valid tools have been deployed locally and nationally, and are feasible in PC, EPSDT, and Medicaid settings (Jellinek et al., 1999; Murphy et al., 1996; Pagano et al., 1996)
- 1 Psychosocial Functioning/Impairment Screens
 - 1 Parent/Teacher Report: Pediatric Symptom Checklist, (PSC-35)*, less data on youth
 - 1 Child/youth report: Safe Times Questionnaire, Youth Outcomes Questionnaire; Problem-oriented Screening Instrument for Teens (POSIT), GAPS
 - 1 Clinician-administered: CAFAS, CGAS

* Tested, feasible, and valid in PC settings

How We Might Do Better: Early Identification Strategies

1 Comprehensive/Inclusive Mental Health Tools

- 1 Parent/Teacher/Youth Reports: CBCL/TRF/YSR, Behavioral Assessment System-Children (BASC), Ohio Scales, Strengths & Difficulties Questionnaire (SDQ-25)*, PSC-17*
- 1 Clinician: DICA, DISC, Kiddie-SADS, ISC, CAPA

1 Specialized Mental Health Assessment Tools

- 1 Multiple diagnoses (Substance Use, Anxiety, Depression, CD): VOICE DISC*, PHQ-A*
- 1 Depression: BDI-PC, BDI-Fast Screen 7, CDI, RCMAS, CES-DC, PHQ9-M*, VOICE DISC*
- 1 ADHD: Vanderbilt Scales, SNAP, Conners, etc.
- 1 Autism: Checklist for Autism in Toddlers (CHAT)*, Autism Screening Questionnaire (ASQ)*

* Tested, feasible, and valid in PC settings

How We Might Do Better: Performance Measures Generally Applicable to MH Problems

1 Patient/family involvement

- 1 % parental education in EB expectations
- 1 % provider training & application in motivational interviewing
- 1 % return visits/missed appointments
- 1 % parent-support systematically provided for chronic MH problems or whether it is a meaningful part of practice

1 Use of Identification and Tracking systems – chronic illness registries

- 1 % children/youth from caseload screened on yearly basis with EB tool
- 1 % children on meds w/initial and maintenance follow-ups < 2 weeks and 3 months, respectively

How We Might Do Better: Performance Measures Generally Applicable to MH Problems

1 Information profiling

- 1 % children/youth on psychotropic med with 1-2x yearly specialist visit
- 1 % abrupt stopping of meds (diabetes WebTV, daily meds f/u tool)

1 Decision support

- 1 Presence of automated pharmacy decision-support systems
- 1 Use of MH consultation/collaboration tools w/school, MH
- 1 Co-location of MH providers (e.g., Group Health of Puget Sound)
- 1 % trained/certified in EB assessments and treatments for specific conditions (US Aetna Healthcare, ADHD)
- 1 % MH Providers trained/certified in EB psychotherapies

1 Care coordination/continuity/communication

- 1 % w/plan for f/u; % w/delays > 3 months to MHS,
- 1 % w/PCP f/u of MHR
- 1 Use of MH-PCP-school tool

Ways to Make it Happen:

- 1 **Contractual requirements**
- 1 **Quality incentives**
- 1 **Co-location**
- 1 **Feedback/automated systems**

Parent Empowerment Training

- Promote parent/provider partnerships
- Increase parent knowledge about mental health needs and evidenced based service delivery options
- Increase parent self efficacy
- Improve parent communication and assertive skills
- Enhance the skills of parent advocates

STAR BINGO

Name _____
 3 mo period from _____ to _____

Directions: Place a star or your initials in each "Star box" that was completed for the 3 month period. Count up the total number of stars and refer to PRIZES.

<p>Child: _____ Brings home daily report card from school 4 days of 5 r r r r r r r r r r r r r r r</p>	<p>Parent: _____ Delivers Doctor's checklist to teacher for Completion r</p>	<p>Teacher: _____ Completes checklist, returns it to parent r</p>	<p>Other _____ _____ _____</p>
<p>Parent: _____ Completes own Checklist, gives Parent and teacher checklists to Doctor Writes down questions ahead of time for doctor r</p>	<p>Other _____ _____ _____</p>	<p>Child: _____ Follows family rules for r bedtime r TV r Other _____ r Other _____</p>	<p>Doctor: _____ Adjusts meds to "normalization" based on P/T checklists and other info</p>
<p>Child: _____ Participates in sport or other activity r r r r</p>	<p>Teacher: _____ Completes DRC (child prompts optional)</p>	<p>Doctor: _____ Follows H/W, r Monitors SEs r Elicits parent Qs r</p>	<p>Parent: _____ Remembers to bring Bingo card to Doctor's visit</p>

Training in E-B Psycho- and/or Pharmacotherapy

- CBT for anxiety, depression, trauma
- BT for ADHD, ODD
- E-B Use of Meds
- Briefer manuals (6-8 sessions)
- Same look and feel, common glossary
- Associated tools
- Integration w/Assessment and tracking procedures
- Initial workshop, year-long support/phone consultation
- Certification of clinics, providers, evaluation partners

