Eliminating Racial/Ethnic Disparities in Health and Healthcare for Children with Special Healthcare Needs and Their Families

Glenn Flores, MD, FAAP

Chief Research Officer

Director, Health Services Research Institute

Connecticut Children's Medical Center

Professor of Pediatrics and Associate Chair of Research

University of Connecticut School of Medicine

Overview:
Goals of Today's Presentation

- Examine demographics of racial/ethnic minorities in America and Europe

- Briefly summarize variety of major racial/ethnic disparities in children's health and healthcare, especially for children with special healthcare needs (CSHCN)

- Delve into successful intervention for eliminating racial/ethnic disparities and achieving equity in pediatrics

- Finish with 7 steps to eliminate disparities and achieve equity for children with CSHCN

Background: Selected US & European Demographics

- Racial/ethnic minority children comprise 49% of US children, equivalent to 36 million
    - Census projections indicate that minority children will outnumber white children this year
- 26% of UK school children racial/ethnic minorities
- Non-German race/ethnicity comprises 20% of population in Germany, including 7 million people of Middle Eastern, African, or Asian race/ethnicity
    - With 12 million international migrants, Germany home to third largest number of immigrants worldwide
- France collects no census or other data on race/ethnicity of its citizens, due to 1978 law specifically banning collection of race-based data

Background

- Extensive body of literature (Flores G, Pediatrics 2010;125:e979-e1020) documents racial/ethnic disparities in children's health and healthcare extensive, pervasive, and persist over time

- Children's disparities occur across spectrum of health and healthcare, including in

  - Mortality

  - Access to care and use of services

  - Health status

  - CSHCN

  - Quality of care

Disparities for African-American (AA) Children

Mortality

- Overall childhood death rates consistently higher for AA children

- National US data for 43-year period revealed

  - Marked crude mortality disparities in young children 1-4 years old (twice that of white children) and older children 5 to 14 years old

 - Increases in mortality disparity ratio in most recent 10-year period

Mortality Disparities for AA Children

- Major disease-specific mortality disparities exist
  - Acute lymphoblastic leukemia (ALL)
  - Congenital heart defects (both fatality rate and lower average age at death)
  - In-hospital death after congenital heart surgery
- Example: compared with white children, adjusted odds of death for AA children after congenital heart surgery = 1.76 (95% CI, 1.2-2.5)

Mortality Disparities for AA Children

- Median age at death for AAs with Down syndrome substantially younger (25 vs 50 years old in whites)

- Substantially lower mean increase in median age at death for AAs with Down syndrome from 1968-97 (0.7 vs 1.9 vs. whites) (*MMWR* 2001;50(22):463-5)

FIGURE 1. Median age at death of persons with Down Syndrome, by race — United States, 1968–1997
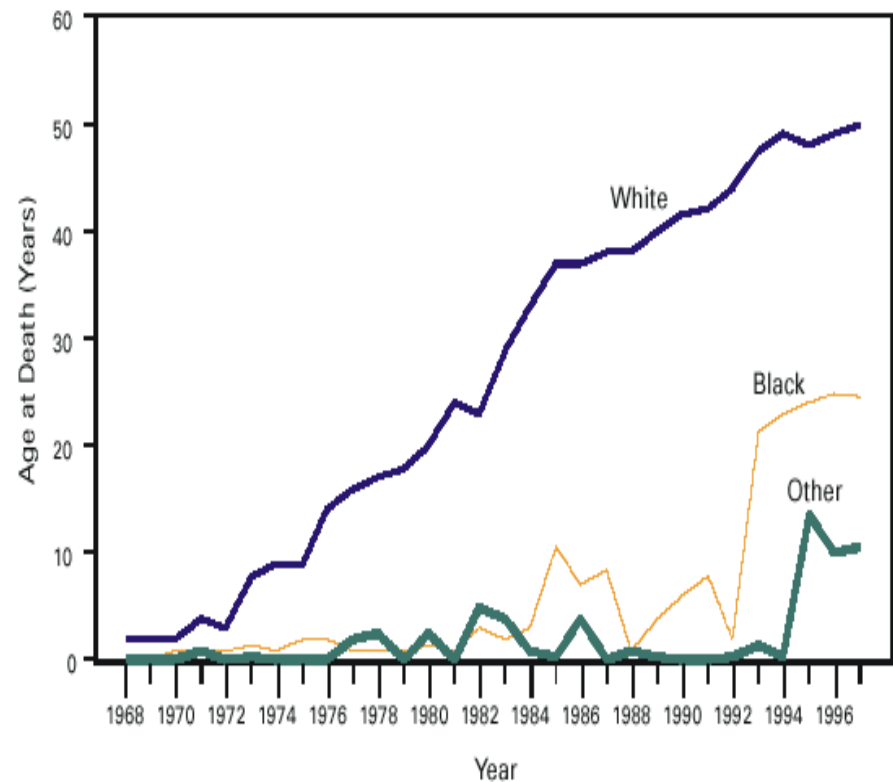
HIV and Asthma Disparities: AA Children

- HIV/AIDS disparities substantial, including
  - Largest percentages and numbers of new diagnoses in every age group and via perinatal transmission
  - Longer adjusted length-of-stays for those hospitalized
- Highest asthma prevalence of any racial/ethnic group, and substantially higher than whites
  - Disparity has widened over time
- Substantially higher rates of asthma mortality, hospitalizations, ED visits, and office visits
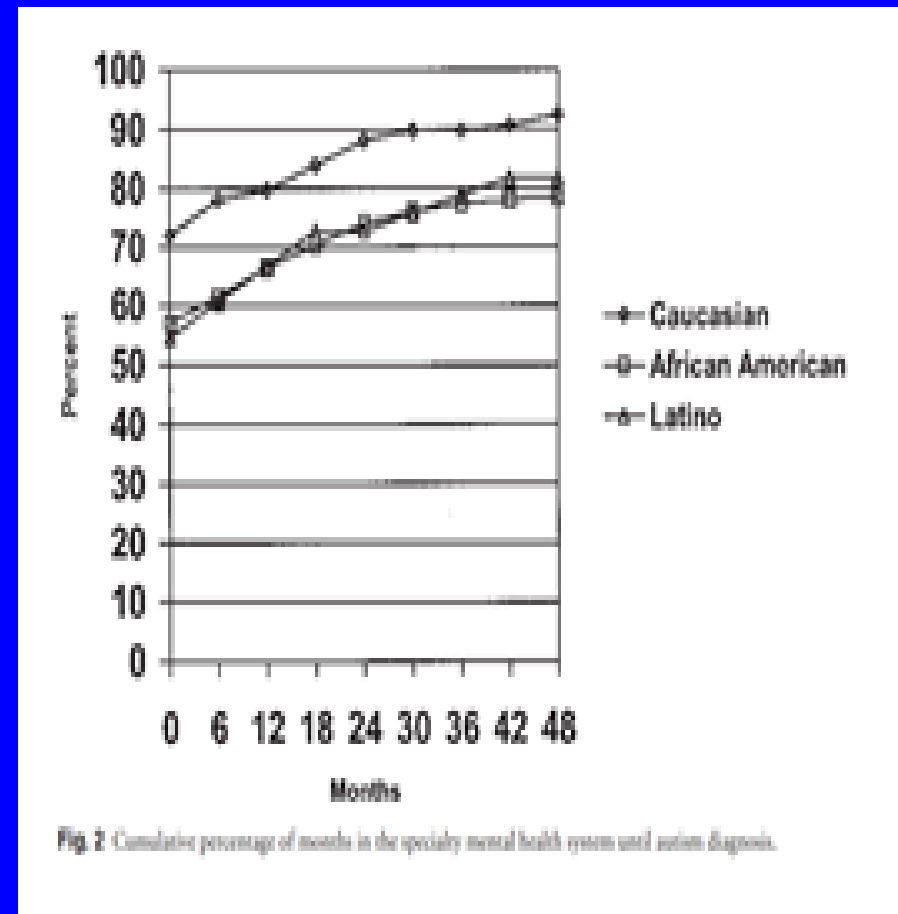 - Mortality and hospitalization disparities have worsened over time

Disparities in Quality of Care: AA Children

- AA heart-transplant patients have
  - Double the odds of transplant failure
  - Lower transplant survival rates
  - Median transplant survival time = 6 years lower
  - Median age at heart transplant = 5 years greater
  - Higher likelihood of HLA mismatch
- AA children with end-stage renal disease
  - More likely to receive inadequate hemodialysis dose
  - Substantially less likely than whites to be activated on kidney transplant waiting list
  - Less likely to receive preemptive kidney transplants
  - Receive fewer living & more cadaveric transplants

Disparities in Quality of Care: AA Children

Among those with autism:

- AAs receive diagnosis 1.4 years later than whites (after adjustment)

- In mental-health treatment mean of 13 months longer than whites before receiving diagnosis of autism (after adjustment) (*J Am Acad Child Adolesc Psychiatry* 2002;41:1447-53)

Fig. 2 Cumulative percentage of months in the specialty mental health system until autism diagnosis.

Mortality Disparities for Latino Children

- Puerto Rican children 1-4 years old have higher crude mortality rate than their white counterparts

- Latinos have higher drowning rate in neighborhood pools and pool drowning rates in general for male adolescents

- Higher adjusted risks of death for those with ALL and after congenital heart surgery

Disparities in Access and Use of Services: Latino Children

Multiple studies document wide range of disparities in access to care and use of services for Latino children, including greater adjusted odds of

- Uninsurance
- No usual source of care or healthcare provider
- No physician visit in past year
- Going ≥1 year since last physician visit
- Not being referred to specialist
- Perforated appendicitis
- Never/only sometimes getting medical care without long waits
- Getting timely routine care or phone help

Autism Disparities: Latino Children

Among ASD kids (Liptak '08), Ls more likely vs. whites to have:

- Had no preventive care visit: AOR=5.3 (95% CI, 5.1-5.4)

- Not used prescription meds in past year: AOR=2.7 (2.6-2.8)

- Had problems getting specialty care: AOR=3.8 (3.7-4.0)

- Not gotten timely acute care: AOR=18.6 (17.2-20.1)

Latino ASD kids with LEP parents more likely than whites (Zuckerman '17) to:

- Cite lack of parental ASD knowledge as care barrier: AOR=3.8 (1.8-8)

- Have unmet therapy needs: AOR=2.1 (1.2-3.7)

- Receive < 1 hour or no weekly therapy: AOR=4.5 (1.7-11.8)

Disparities in Mental Health and Healthcare: Latino Children

- Significantly higher unmet need for mental healthcare
- Lower odds of any mental-health visit, outpatient visits, antidepressant prescriptions, and receiving treatment from mental-health specialist for any condition, behavior problems, or depression
- Higher odds of developmental delays
- Lower odds of being diagnosed with externalizing behavioral disorders
- Lower odds of use of mental-health services among children being investigated for possible abuse or neglect and among Medicaid-eligible teenagers in substance-abuse treatment

Disparities in Prevention and Population Health: AI/AN Children

- Firearm injury rate more than 7 times higher than for white children

- Higher adjusted odds of overweight and obesity

- Birth rate for AI/AN female adolescents 2-3 times higher than that of whites

- Higher adjusted odds than white children of poor or fair health (highest of any racial/ethnic group)

- Within 6 months of new depression episode, lower adjusted odds than white children of any antidepressant prescription being filled

Parent Mentors Eliminate Children's Healthcare Disparities

- **Parent Mentor (PM)**: Special category of community health workers for children in which parents who have children with particular health conditions/risks leverage their relevant experience, along with additional training, to assist, counsel, and support other parents of children with same health conditions/risks

- Two rigorous RCTs by our team demonstrate PMs
  - Eliminate children's healthcare disparities
  - Improve children's outcomes
  - Empower parents
  - Reduce family financial burden
  - Save hundreds or thousands of dollars per child
  - Create jobs in areas with highest unemployment rates

Background: Kids' HELP Trial

Kids' **H**ealth Insurance by **E**ducating **L**ots of **P**arents

- 4.2 million US children (5.4%) uninsured

- 90% of uninsured US children (3.8 million) eligible for but not enrolled in Medicaid/CHIP

- Major racial/ethnic disparities exist

  - Only 4% of white children uninsured,
    vs. 6% of African-American and 8% of Latino children

- But not enough known about most effective ways to insure uninsured children

- No study had examined effectiveness of Parent Mentors (PMs)

- Aim of Kids' HELP (**Kids' H**ealth Insurance by **E**ducating **L**ots of **P**arents) trial: conduct randomized, controlled trial of effects of PMs on insuring uninsured minority children

Methods

- Design = randomized controlled trial
- Uninsured, Medicaid/CHIP-eligible Latino and African-American children recruited at community sites and randomized to:
    - PMs
    - Control group
- Subjects in both groups contacted monthly by blinded research assistant to monitor outcomes for 1 year
    - Additional participants followed for up to 2 years after trial ceased

Methods

- Setting: 7 Dallas communities with highest proportion of uninsured and poor minority children

- Recruitment of 237 participants occurred at 97 community sites, including supermarkets, department stores, libraries, Goodwill stores, food banks, health fairs, churches, schools, and housing projects
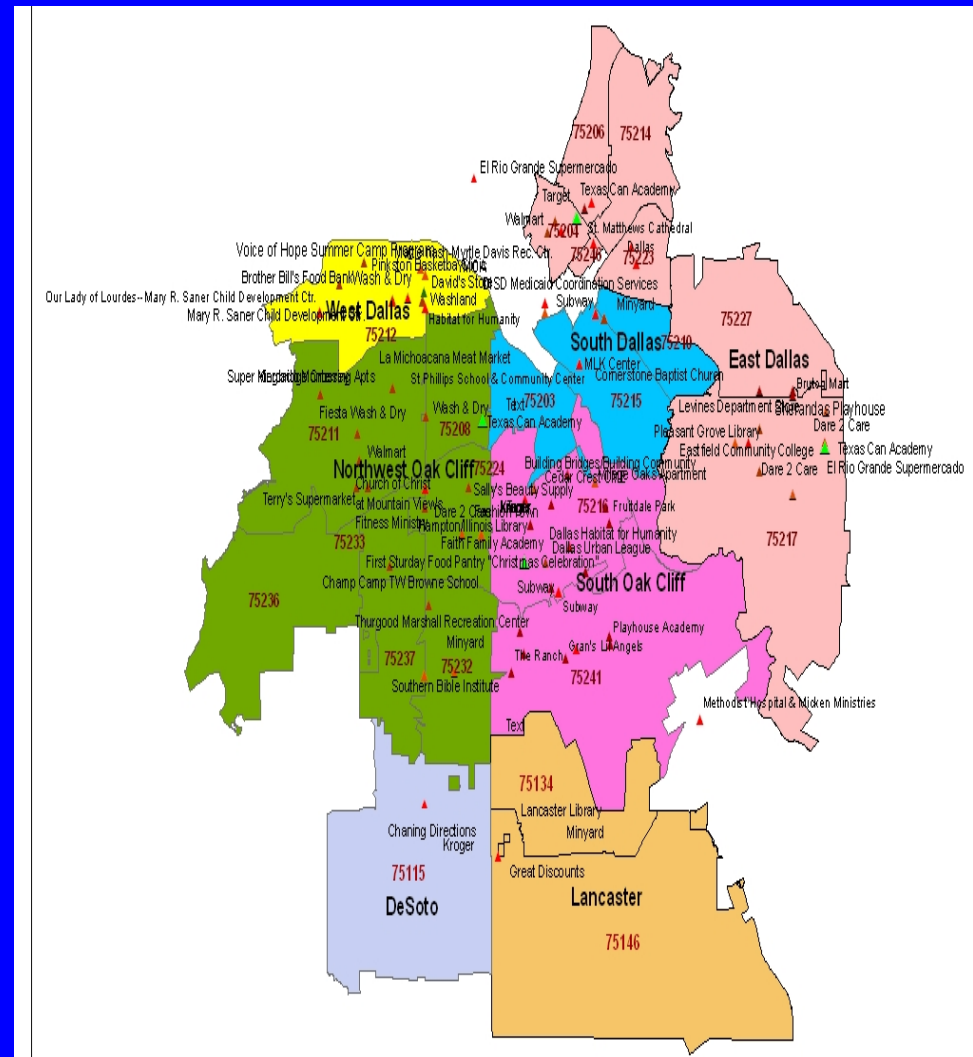
Methods: Intervention

- PMs: minority parents in primary-care clinic who already had at least 1 Medicaid/CHIP-covered child who had coverage for at least 1 year

- PMs underwent 2-day training session addressing:
    - Types of insurance programs
    - Application process
    - Completing and submitting applications with parents
    - Being family liaison/advocate with Medicaid/CHIP programs
    - Renewing coverage
    - Obtaining pediatric and dental care and medical home
    - Helping families with food, clothing, and other social determinants of health

PM Intervention and Controls

- PMs met with families in their homes and at community sites and contacted them regularly via phone, e-mails, and texting
  - PMs followed up to 10 families at a time
  - Data document high levels of PM engagement with families, with means of 19.8 home visits and 161.4 phone/e-mail/text-message contacts/family/year
- Controls received Texas's traditional Medicaid/CHIP outreach and enrollment
  - Bilingual radio, TV, and newspaper ads; bus and bus-bench messages; websites with application links and order forms/materials for community-based organizations; and daycare-center outreach

Results: Obtaining Health Insurance Coverage

- Significantly higher proportion of PM group obtained health insurance vs. control group, at **95% vs. 68% (*P* < .001)**

- PM group had significantly higher adjusted relative risk (1.3; 95% CI, 1.2-1.3) and odds (2.9; 95% CI, 2.1-4.0) of insurance coverage

  - After adjustment for child's age and gender, parental citizenship and employment, and family income

Time to Coverage, Renewal Rates, and Long-Term Coverage

Outcome	Controls	PM Group	*P*
Median no. of days (IPR$_{95}$) to obtaining insurance	140 (10, 348)	62 (4, 289)	<.001
Renewed insurance	60%	85%	<.001
Two-year coverage rate*	76%	95%	<.001
Three-year coverage rate†	76%	100%	<.001

*One year after intervention ceased (N=135)

†Two years after intervention ceased (N=71)

Access to Care

Access Measure	Controls	PM Group	*P*
No PCP	39%	15%	<.001
No usual source of preventive care	7%	1%	.01
Different sources for sick and preventive care	27%	15%	.03
Never/sometimes gets immediate care from PCP	19%	0%	.03
Problems getting care from specialists	46%	11%	.03

Unmet Needs for Medical and Dental Care

Unmet Need: Didn't Receive All Needed…	Controls	PM Group	*P*
Healthcare overall	25%	13%	.02
Preventive care	22%	4%	<.001
Acute care	20%	3%	.04
Dental care	31%	18%	.03

Out-of-Pocket Costs of Care

Health Service	Mean Out-of-Pocket Cost (± Standard Error) for		P
	Controls	PM Group	
All doctor visits	$37 (±7)	$33 (±24)	<.001
Sick visits	$43 (±9)	$9 (±3)	<.001
Preventive-care visits	$27 (±9)	$5 (±2)	.09
ED visits	$94 (±33)	$81 (±93)	.22
Hospital stays	$25 (±0)	$0 (±0)	.25
ICU stays	$12.50 (±13)	$0 (±0)	.57

Parental Satisfaction with Process of Obtaining Insurance
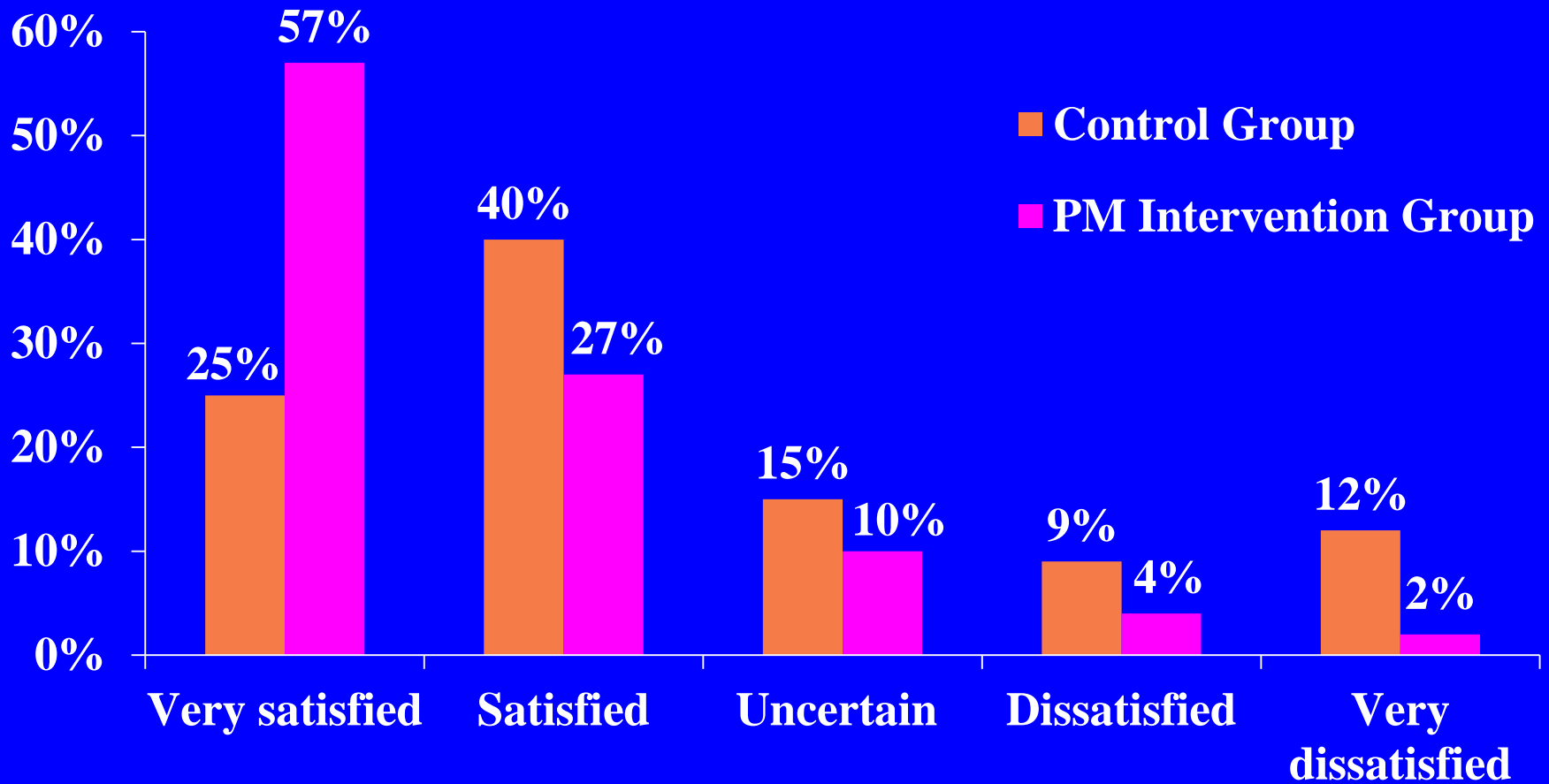
*P < .01 for comparison between controls vs. PM group

Satisfaction with Care, Quality, and Family Financial Burden

Measure	Controls	PM Group	*P*
Wouldn't recommend child's healthcare provider to friends	16%	6%	.01
Doctor never/sometimes respects you're expert on your child	23%	11%	.01
Mean overall quality score: child's well-care visit (0-10; 10=best)	8.6	8.9	.03
Need additional income to cover child's medical expenses	13%	6%	.04

Intervention Costs

Item	Mean Monthly Cost Per Participant
PM stipends	$33.20
Personnel	$15.60
PM travel costs	$2.13
One-time Supplies	$1.07
2-day training session	$0.70
PM meetings	$0.35
TOTAL	**$53.05**

Cost and Cost-Effectiveness Analysis

Expense	Controls (N=114)	PM Group (N=123)
PM and Program Coordinator costs	—	$85,795
ED visits	$62,730	$60,885
Hospitalizations	$81,234	$58,431
ICU stays	$277,094	$74,742
Wage loss and other costs of parents' missed work days due to child's illness	$33,589	$12,985
TOTAL	**$454,647**	**$292,838**

- Incremental cost effectiveness ratio per child insured = **-$6,045.22** (PMs **saved** $6,045.22/insured child/year)

Kids' HELP Feedback

Conclusions

- PMs significantly more effective than traditional Medicaid/CHIP outreach and enrollment in
  - Insuring uninsured minority children
  - Obtaining insurance faster
  - Renewing coverage
  - Improving access to medical and dental care
  - Reducing unmet needs and out-of-pocket costs of care
  - Achieving parental satisfaction and quality of care
  - Teaching parents to maintain children's coverage up to two years after intervention cessation
- PMs relatively inexpensive, at $636/child/year, but highly cost-effective, saving $6,045 per child insured/year

Implications

- Given that up to 3.8 million US children uninsured and Medicaid/CHIP eligible, and 53% Latino or African-American, findings suggest implementing PMs nationally for minority children could save over $12.3 billion

- If PM intervention shown to be effective for all racial/ethnic groups, findings suggest implementing PMs nationally for all uninsured children could save $21.7 billion

- PMs and analogous peer mentors for adults could prove to be highly cost-effective interventions for eliminating disparities and insuring all Americans

Translation Into Policy

- Based on our work, federal CHIP reauthorization legislation signed into law on 1/22/18 makes organizations that use PMs eligible to receive $120 million in grants for CHIP outreach and enrollment

- All 50 states and DC now have opportunity to apply for CMS funds to implement successful, evidence-based Kids' HELP PM model

JANUARY 16, 2018

RULES COMMITTEE PRINT 115-55

TEXT OF EXTENSION OF CONTINUING

APPROPRIATIONS ACT, 2018

[Showing the text of H.J. Res. 125, as introduced]

```
 4   SEC. 3004. EXTENSION OF OUTREACH AND ENROLLMENT
 5           PROGRAM.
 6       (a) IN GENERAL.—Section 2113 of the Social Secu-
 7   rity Act (42 U.S.C. 1397mm) is amended—
 8           (1) in subsection (a)(1), by striking "2017" and
 9       inserting "2023"; and
10           (2) in subsection (g)—
11               (A) by striking "and $40,000,000" and in-
12           serting ", $40,000,000"; and
13               (B) by inserting after "2017" the fol-
14           lowing: ", and $120,000,000 for the period of
15           fiscal years 2018 through 2023".
16       (b) MAKING ORGANIZATIONS THAT USE PARENT
17   MENTORS ELIGIBLE TO RECEIVE GRANTS.—Section
18   2113(f) of the Social Security Act (42 U.S.C. 1397mm(f))
19   is amended—
20           (1) in paragraph (1)(E), by striking "or com-
21       munity-based doula programs" and inserting ", com-
22       munity-based doula programs, or parent mentors";
23       and
24           (2) by adding at the end the following new
25       paragraph:
```

7 Steps to Eliminate Disparities and Achieve Equity for CSHCN

Race/ethnicity data (as self-identified by parent) routinely should be collected on <u>all</u> children by practices, health systems, insurers, managed-care organizations, and private insurers, so disparities can be identified, monitored, and targeted as part of QI efforts

- Given lack of significant change over time in total number of disparities, together with appearance of many new disparities (Flores & Lin *Int J Equity Health* 2013 Jan 22;12:10)

- Recommendation consistent with 2 recent IOM reports, proposals by disparities experts, and ACA (Section 4302)

- Disparities monitoring and public disclosure at least annually should be considered by practices, hospitals, health plans, insurers, counties, and states

7 Steps to Eliminate Disparities and Achieve Equity for CSHCN Children

Ensure that every child has health insurance and medical and dental homes

- Because minorities children comprise 59% of uninsured children, although constituting only 48% of US children

- Latinos, AIANs, and African-Americans are significantly more likely to be uninsured and sporadically insured than white children

- Multiple disparities exist and have persisted in lack of personal doctor or nurse and in unmet dental needs

  - Underscores urgent need to ensure that every child has medical and dental home

7 Steps to Eliminate Disparities and Achieve Equity

Racial/ethnic disparities must be framed and addressed as <u>quality-of-care issues</u>

- Given substantial prevalence and persistence of children's disparities

- As pointed out by experts (Beal AC. *Health Affairs* 2004;23:171-9) and recent IOM report (IOM. Child and Adolescent Health and Health Care Quality: Measuring What Matters. 2011)

- So disparities can be eliminated via rapid-cycle QI and practice coaching

7 Steps to Eliminate Disparities and Achieve Equity

Ensure and advocate for <u>all children</u> to have access to needed subspecialty care

- Children who need and receive care from subspecialist have significantly fewer ED visits and hospitalizations and greater likelihood of healthcare consistent with national practice guidelines than children not receiving needed subspecialty care

- But minority children significantly more likely than white children to have problems getting subspecialty care

7 Steps to Eliminate Disparities and Achieve Equity

Aim to attain highest level of <u>cultural competency</u>

- Bias still exists in pediatric care
  - In children and adults hospitalized for limb fractures, whites received significantly higher doses of narcotic analgesics (22 mg/day of morphine equivalents) than blacks (16 mg/day) and Latinos (13 mg/day) (Ng et al. *Psychosom Med* 1996;58:125-9)
- But study of predictors of asthma-care quality for Medicaid-insured children (Lieu et al. *Pediatrics* 2004;114:e102-10) found patients of practice sites with highest cultural competence scores less likely to underuse preventive asthma medications (OR, 0.15) and had significantly better parent ratings of overall quality of asthma care

7 Steps to Eliminate Disparities and Achieve Equity

Pursue workforce diversity

- African-American (AA) patients with AA physicians more likely than those with non-AA physicians to rate physicians as excellent (AOR=2.4) and report receiving preventive care (AOR=1.7) and all needed medical care (AOR=2.9) during the previous year (Saha et al. *Arch Intern Med* 1999;159:997-1004)

- Latino patients with Latino physicians more likely than those with non-Latino physicians to be very satisfied with healthcare overall (AOR=1.7) (Saha et al. *Arch Intern Med* 1999;159:997-1004)

- Workforce diversity associated with nurse job satisfaction (*Res Nurs Health.* 2012;35: 265–76)

7 Steps to Eliminate Disparities and Achieve Equity

Leverage innovative, evidence-based interventions

- Rigorous evidence documents that intervening with community health workers (CHWs), *promotores*, or PMs can reduce or eliminate many barriers and threats to children's health and healthcare, through education, linking children and families to resources, providing social support, eliminating language barriers, and empowering parents; studies additionally indicate that such interventions cost effective

- As we've seen, RCTs document disparities actually can be eliminated, using innovative, family-centered, community-based interventions, which also create jobs and save money for society

Summary

- Racial/ethnic disparities in children's health and healthcare
  - Extensive
  - Pervasive
  - Persist over time
- Each racial/ethnic group has unique set of disparities
- Disparities occur across spectrum of health and healthcare
- Using 7 steps, we <u>can</u> eliminate disparities and achieve equity for CSHCN and their families worldwide