



# Quality of Health Care for Children and Adolescents: A Chartbook

**SHEILA LEATHERMAN | DOUGLAS MCCARTHY**

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THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL**

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**APRIL 2004**

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# Table of Contents

<b>Acknowledgments</b>	•	page 4
<b>Summary of Charts and Findings</b>	•	page 5
<b>Introduction and Overview</b>	•	page 15
The quality of children’s health care today	•	page 15
Defining quality of health care for children	•	page 17
Challenges and considerations in measuring quality of health care for children	•	page 19
A systems approach to improving quality of health care for children	•	page 21
Conclusion	•	page 24
<b>Methods and Organization of the Chartbook</b>	•	page 25
Development process	•	page 25
The conceptual framework for reporting on quality of health care	•	page 26
Scientific issues and terminology	•	page 29
<b>Charts</b>	•	page 31
Section 1. Effectiveness	•	page 32
Section 2. Patient Safety	•	page 52
Section 3. Access and Timeliness	•	page 58
Section 4. Patient and Family Centeredness	•	page 74
Section 5. Disparities	•	page 80
Section 6. Capacity to Improve	•	page 92
<b>Technical Appendix</b>	•	page 111
<b>References</b>	•	page 119
<b>About the Authors</b>	•	page 132

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The authors retain sole responsibility for any errors or omissions in the content of the chartbook.

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## Summary of Charts and Findings

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>EFFECTIVENESS: STAYING HEALTHY</b>					
<b>I:1 Receipt of Recommended Preventive Health Care Visits</b>	Early childhood to adolescence (3–17 years)	1999 National Survey of America's Families (Yu et al. 2002)	Nearly one-quarter (23%) of children and adolescents did not have an annual preventive health care visit at recommended ages. Adolescents were less likely to have preventive care visits than were younger children.	Lack of regular preventive care represents missed opportunity for prevention, early detection, and treatment of health and developmental problems, and is associated with more ER visits and hospitalizations.	32
<b>I:2 Immunizations for Young Children</b>	Early childhood (19–35 months)	2002 National Immunization Survey (CDC 2003b)	One-quarter (25%) of young children were not up to date on all recommended doses of five key vaccines nationally. Among the states, this gap ranged from one of seven children (14%) in Massachusetts to more than one-third (37%) in Colorado.	Unvaccinated children are vulnerable to infectious disease outbreaks, resulting in missed school and work days for parents and additional doctor visits, hospitalizations, and potential deaths.	34
<b>I:3 Guidance on Childrearing for Parents of Young Children</b>	Early childhood (0–36 months)	1995–1996 Commonwealth Fund Survey of Parents with Young Children (Schuster et al. 2000)	Many parents (38% to 77%) had not discussed one of six recommended childrearing topics with a health professional at appropriate child ages; more than one-third (37%) had not discussed any of the six topics.	Many parents (9% to 42%) had not discussed a topic <i>and</i> wanted more information about the topic. Unmet needs for information represent missed opportunities to promote child and family well-being and to build positive patient relationships.	36
<b>I:4 Speech and Language Development: Assessment and Guidance</b>	Early childhood (4–35 months)	2000 National Survey of Early Childhood Health (Halfon et al. 2002)	Up to one-third (21% to 32%) of parents reported that their child's health professional had not discussed how the child communicates; more than one-third (36% to 39%) said that the health professional had not discussed the importance of reading to their child.	Lack of discussion represents missed opportunities to address parent concerns about development, screen children for developmental delays, and promote early childhood literacy development, which is linked to success in school.	38
<b>I:5 Counseling Adolescents on Healthy Behaviors</b>	Adolescence (fifth through twelfth grades)	1997 Commonwealth Fund Survey of the Health of Adolescents (Ackard and Neumark-Sztainer 2001)	Less than one-half of adolescents reported that they had ever discussed most recommended health risk topics (e.g., eating, exercise, smoking, alcohol, STD, and pregnancy prevention) with their health professional.	The health system misses many opportunities to promote healthy behaviors and help prevent or reduce risky behaviors in teens. Many teens say they would like to discuss such information with their health professional.	40

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>I:6 STD Screening for Adolescents: Chlamydia Infection</b>	Adolescence (16–20 years)	2000–2002 HEDIS for private and Medicaid managed care plans (NCQA 2003a)	Among sexually active adolescent females enrolled in managed care plans, seven of ten (73%) with private insurance and six of ten (59%) with Medicaid coverage did not receive a test for chlamydia infection in the past year.	Chlamydia infection often goes undetected. Left untreated, it can lead to pelvic inflammatory disease and complications such as chronic pain, infertility, and problems in pregnancy.	42
<b>EFFECTIVENESS: GETTING BETTER WHEN SICK OR INJURED</b>					
<b>I:7 Inappropriate Antibiotic Treatment for the Common Cold</b>	Early childhood to early adolescence (0–14 years)	1991–1999 National Ambulatory Medical Care Survey (Steinman et al. 2003)	Clinicians reduced antibiotic prescribing at pediatric visits for the common cold by 50 percent from 1991 to 1999. Yet, they still prescribed antibiotics at one of five such visits (21%) in 1999 and more often prescribed broad-spectrum drugs.	Prescribing antibiotics when they are not necessary accelerates the spread of antibiotic resistant bacteria, potentially endangering all patients. Using broad-spectrum antibiotics inappropriately makes the resistance problem even worse.	44
<b>EFFECTIVENESS: LIVING WITH ILLNESS</b>					
<b>I:8 Prescription of Preventive Medication for Long-Term Asthma Control</b>	Middle childhood to adolescence (5–17 years)	2000–2002 HEDIS for private and Medicaid managed care plans (NCQA 2003a)	Among children and adolescents with persistent asthma enrolled in managed care plans, one of three (30% to 35%) with private insurance and two of five (38% to 40%) in Medicaid did not receive a prescription for an appropriate medication to control their asthma in 2002.	Underuse of recommended long-acting medication results in worse asthma control, which can lead to more asthma attacks, activity limitations, missed school and parent work days, ER visits, hospitalizations, and potential deaths.	46
<b>I:9 Antibiotics to Prevent Infection among Young Children with Sickle Cell Disease</b>	Early childhood (0–3 years)	1999 Medicaid administrative claims and encounter data for two states (Sox et al. 2003)	Low-income young children with sickle cell disease were dispensed an average of only 148 days (41%) of an expected 365-day supply of prophylactic antibiotics. One of ten (10%) received no antibiotics during the year.	Young children with sickle cell disease are highly susceptible to severe and potentially life-threatening pneumococcal infections. A randomized controlled trial demonstrated an 84 percent reduction in such infections when young children took daily penicillin.	48
<b>I:10 Monitoring and Evaluation for Cystic Fibrosis</b>	Early childhood to adolescence (0–17 years)	2002 Cystic Fibrosis Foundation Patient Registry Annual Data Report (CFF 2003b)	One of three children and adolescents (33%) with cystic fibrosis, a life-shortening genetic disease, did not receive all recommended monitoring visits, and up to one of five (4% to 19%) did not receive other recommended tests to help direct treatment and reduce complications.	In a comparison of process and outcomes of care across cystic fibrosis specialty centers, children who received care in accordance with guidelines had better lung function, an important outcome associated with survival.	50

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>PATIENT SAFETY: MULTI-PERSPECTIVE</b>					
<b>2:1 Patient Safety Indicators: Potential Medical Mistakes in Hospitals</b>	Early childhood to adolescence (0–17 years)	2000 Healthcare Cost and Utilization Project Nationwide Inpatient Sample (AHRQ 2003b)	Potentially preventable adverse events among hospitalized infants, children, and adolescents ranged from 0.003 per 1,000 patients at risk for transfusion reactions to 7.67 per 1,000 at risk for decubitus ulcers (bed sores).	Children and adolescents who experience potential medical mistakes detected by Patient Safety Indicators have 2 to 18 times higher hospital death rates and hospital stays that are 2 to 6 times longer and 2 to 12 times more costly.	52
<b>2:2 Pediatric Medication Mistakes in the Hospital</b>	Early childhood to adolescence (pediatric inpatients)	Clinician report and chart review at two hospitals during six weeks in 1999 (Kaushal et al. 2001)	Medication mistakes were detected in six of every 100 medication orders. One of every five medication mistakes either caused patient harm or had the potential to do so. The most frequent mistake was an incorrect medication dose.	The rate of potential adverse drug events was three times higher than for adults in a similar study, suggesting that children are at greater risk than adults from potentially harmful medication mistakes.	54
<b>2:3 Hospital-Acquired Infections in Pediatric Intensive Care Units</b>	Early childhood to adolescence (0–17 years)	National Nosocomial Infections Surveillance System (NCHS 2001; NCID 2001; 2003).	The risk-adjusted rate of certain infections acquired by patients in pediatric intensive care units declined by up to 36 percent among hospitals participating in a national surveillance system during 1995–2003 compared to 1986–1990.	Hospital-acquired infections can be reduced through ongoing monitoring and appropriate infection-control measures, which can improve patient survival, avoid unnecessary treatment, and reduce health care costs.	56
<b>ACCESS AND TIMELINESS: MULTI-PERSPECTIVE</b>					
<b>3:1 Parent Perceptions of Accessibility and Timeliness of Care</b>	Early childhood to adolescence (0–17 years)	2000 Medical Expenditure Panel Survey (AHRQ 2002b)	Parents reported that up to one in five children and adolescents (12% to 22%) had problems getting needed care and up to one-half (36% to 48%) did not always get care or appointments as quickly as the parent wanted.	Parents' perceptions of accessibility of care may affect care-seeking behavior, such as whether to use routine primary care or visit the ER, and decisions related to selecting or changing physicians and health plans. Accessibility is linked to health outcomes.	58
<b>3:2 Regular Source and Unmet Needs for Care</b>	Early childhood to adolescence (0–17 years)	2000 National Health Interview Survey (Blackwell et al. 2003)	Among uninsured children and adolescents, more than one of four (27%) did not have a regular source of health care, one of six (16%) delayed care because of cost, one of eight (13%) did not get needed health care because of cost, and one of five (19%) did not get needed dental care because of cost.	An estimated 7.3 million U.S. children and adolescents have unmet health and dental care needs—as perceived by parents—or delayed care because of cost. Unmet needs may have long-term effects on health and developmental outcomes, leading to more costly care later.	60

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>3:3 Unmet Need for Mental Health Care</b>	Middle childhood to adolescence (6–17 years)	1997 National Survey of America's Families (Kataoka et al. 2002)	Among children and adolescents with mental health problems severe enough to indicate a clinical need for mental health evaluation, four of five (79%) did not receive a mental health evaluation or treatment in the past year.	An estimated 7.5 million children and adolescents have unmet need for mental health care. Consequences include preventable suicide, poor academic performance, substance abuse, and future unemployment.	62
<b>ACCESS AND TIMELINESS: STAYING HEALTHY</b>					
<b>3:4 Time Since Last Dental Visit</b>	Early childhood to adolescence (2–17 years)	2000 National Health Interview Survey (Blackwell et al. 2003)	One of four children and adolescents (26%) did not receive dental care in the past year and one of seven (15%) did not receive any dental care in the past five years. Minority, low-income, publicly insured, and uninsured children are less likely to receive regular dental care.	Dental caries (tooth decay)—the most common childhood chronic disease—is largely preventable. Left untreated, tooth decay can lead to abscesses and infections, pain, dysfunction, and low weight. One third of children do not have any private or public dental insurance.	64
<b>3:5 Timely Initiation of Prenatal Care</b>	Prenatal development	2001 U.S. birth certificate data (Martin et al. 2002)	One of six mothers of live-born babies (17%) did not start prenatal care in the first trimester of pregnancy. Among the states, this gap ranged from one of eleven mothers (9%) in Rhode Island to three of ten (31%) in New Mexico.	Late or no prenatal care may lead to untreated maternal health problems and lack of timely advice and referrals for services such as smoking cessation that can help improve birth outcomes.	66
<b>ACCESS AND TIMELINESS / PATIENT AND FAMILY CENTEREDNESS: LIVING WITH ILLNESS</b>					
<b>3:6 and 3:7 National Goals for Children with Special Health Care Needs (CSHCN)*</b>	Early childhood to adolescence (0–17 years)	2001 National Survey of Children with Special Health Care Needs (CDC 2003d)	One-quarter to one-half (26% to 47%) of CSHCN lacked adequate access to or failed to receive well-organized, continuous, coordinated, comprehensive, and family-centered care. Most teens (94%) did not receive all recommended services to support their transition to adulthood.	Improvement is needed in serving CSHCN to catch health problems early, keep health problems from worsening, limit their adverse impact, maintain and restore normal functioning to the degree possible, and support successful transition to adulthood.	68
<b>3:8 Medical Home for Children with Special Health Care Needs (CSHCN): State Performance*</b>	Early childhood to adolescence (0–17 years)	2001 National Survey of Children with Special Health Care Needs (CDC 2003d)	Among the states, the proportion of CSHCN who did not receive coordinated, ongoing, comprehensive, family-centered care in a medical home ranged from two of five (39%) in Massachusetts to three of five (59%) in the District of Columbia.	CSHCN have more unmet health care needs and are less satisfied with their usual source of health care than other children, even though they are more likely to have insurance and a regular care provider.	72

\*Data represent children who have a chronic physical, developmental, behavioral, or emotional condition and who require health and related services beyond what is usual for children generally.

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>PATIENT AND FAMILY CENTEREDNESS: MULTI-PERSPECTIVE</b>					
<b>4:1 Parent Perceptions of Interpersonal Quality of Care</b>	Early childhood to adolescence (0–17 years)	2000 Medical Expenditure Panel Survey (AHRQ 2002b)	About one of three parents (32% to 35%) reported that the child’s health professional did not always communicate well. More than four of ten parents (44%) reported that the health professional did not always spend enough time with the parent and child.	The quality of parents’ communication with their child’s health professional may affect parents’ receptivity to receiving advice, how they oversee their child’s compliance with treatment regimens, perception of time spent with the clinician, and satisfaction with and outcomes of care.	74
<b>4:2 Parent-Reported Problems with Hospital Care</b>	Early childhood to adolescence (pediatric inpatients)	1997–1999 Picker Institute Pediatric Inpatient Surveys in 38 hospitals (Co et al. 2003)	Parents reported problems on 18 percent to 33 percent (average 27 percent) of the questions that they were asked within each of seven dimensions of patient-centered quality of care.	Parents’ overall rating of quality correlated most strongly with being provided information and partnership in care. Parents reported relatively more problems for children than adults reported about their own hospital care in a similar survey.	76
<b>PATIENT AND FAMILY CENTEREDNESS: STAYING HEALTHY</b>					
<b>4:3 Supporting Family Well-Being: Preferences and Practices</b>	Early childhood (4–35 months)	2000 National Survey of Early Childhood Health (Halfon et al. 2002)	The majority (56% to 94%) of parents of young children agreed that their child’s health professional should ask about six topics related to family well-being. More than three-quarters (77%) were asked whether a household member smoked tobacco. Less than half (10% to 44%) reported that health professionals had discussed the other five topics.	Parents potentially agree with a family-oriented approach to pediatric care, but it is not yet universally accepted in practice. Parent emotional support and economic concerns were the topics exhibiting the greatest divergence between parent endorsement and actual discussion.	78
<b>DISPARITIES: STAYING HEALTHY</b>					
<b>5:1 Differences in Receipt of Preventive Care Visits by Type of Insurance, Race, Ethnicity, and Income</b>	Early childhood to adolescence (3–17 years)	1999 National Survey of America’s Families (Yu et al. 2002)	Publicly insured, minority, and poor children and adolescents were more likely to receive recommended preventive health care visits than those with private or no insurance, white children, or those with family income above the poverty level (respectively).	More comprehensive coverage for preventive care by Medicaid and State Children’s Health Insurance Programs (SCHIP) probably accounts for higher rates of preventive care visits among publicly insured, minority, and poor children and adolescents.	80

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>5:2 Income, Racial, Ethnic, and Geographic Differences in Childhood Immunizations</b>	Early childhood (19–35 months)	1994–2002 National Immunization Survey (Eberhardt et al. 2001; CDC 2003e)	Poor, minority, and urban young children are less likely than nonpoor, white, and suburban young children (respectively) to be up to date on immunizations. Disparity has narrowed between poor and nonpoor children and between Hispanic and white children, but has widened between black and white children and between urban and suburban children.	Poverty and related factors are the “most powerful and persistent barriers to timely immunization” of children. Failure to ensure that vulnerable children were immunized was a major factor contributing to the severe measles outbreak of 1989–1991.	82
<b>DISPARITIES: LIVING WITH ILLNESS</b>					
<b>5:3 Racial and Ethnic Differences in Asthma Management</b>	Early childhood to adolescence (2–16 years)	1999 survey of parents of children enrolled in five Medicaid HMOs in three states (Lieu et al. 2002)	Compared to white children, black and Latino children had similar access to care. Yet, black and Latino children were less likely to be regularly using an inhaled anti-inflammatory medication when indicated for persistent asthma, even though they had worse asthma than white children.	Disparity in asthma medication use persists even when children are equally insured. Disparity may reflect deficiencies in prescribing and patient adherence as well as the effects of cultural differences in communication. Rates of medication use were unacceptably low among all children.	84
<b>5:4 Gender and Racial Differences in Evaluation and Treatment for Attention-Deficit/Hyperactivity Disorder (ADHD)</b>	Middle childhood (elementary school age)	1998 survey of parents and teachers of children in one school district (Bussing et al. 2003)	Most children with symptoms of ADHD were recognized by their parent as having behavior problems. Boys were more likely than girls and white children were more likely than African American children to have been professionally evaluated, diagnosed, and treated for ADHD.	Seeking professional evaluation is a key factor determining treatment for ADHD. Girls may be less likely than boys to manifest behaviors that prompt parents to seek evaluation. African American parents are more likely than white parents to face barriers to seeking help for their children.	86
<b>5:5 Effect of Family Income on Parent Perceptions of Quality of Care for Children with Special Health Care Needs (CSHCN)</b>	Early childhood to adolescence (0–17 years)	2001 National Survey of Children with Special Health Care Needs (van Dyck 2003; Blumberg 2003)	CSHCN with family income below the poverty level were three-and-one-half times more likely than those with higher family income to have an unmet need for health care (32% vs. 9%) and twice as likely to lack family centeredness (50% vs. 25%) in the care that they did receive, according to parent report.	Economically disadvantaged CSHCN experience the greatest difficulties with care. Inadequate insurance and other access barriers such as lack of transportation may be especially problematic for low-income families with special needs children.	88

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>DISPARITIES: MULTI-PERSPECTIVE</b>					
<b>5:6 Effect of Race, Ethnicity, and Language on Parent Assessment of Accessibility and Interpersonal Quality of Care</b>	Early childhood to adolescence (0–17 years)	1997–1998 CAHPS Benchmarking Database for children enrolled in Medicaid managed care plans in six states (Weech-Maldonado et al. 2001)	Compared to white parents, ratings were lower for African American and American Indian/Alaskan Native parents. Asian and Hispanic parents who did not speak English as their primary language gave significantly lower ratings than both white parents and their English-speaking Asian and Hispanic counterparts.	Language barriers and communication problems figure prominently in disparities for racial and ethnic minorities. Adverse consequences of cultural and language differences in health care for children may include misdiagnosis, misunderstanding of treatment instructions, and inappropriate medication, testing, and hospitalization.	90
<b>CAPACITY TO IMPROVE: STAYING HEALTHY</b>					
<b>6:1 Improving Primary Care Office Systems to Increase Preventive Care</b>	Early childhood (0–3 years)	1995–1998 random samples of medical records from eight group practices and clinics in one community (Bordley et al. 2001)	After the intervention, combined rates of preventive care increased for three of four goals: being up to date on immunizations (by 7 to 12 percentage points), screening for anemia (by 30 percentage points), and screening for lead poisoning (by 36 percentage points for performing a risk assessment or blood testing).	The practices established multi-disciplinary teams and received technical assistance to set objectives, monitor performance, and adopt or enhance quality improvement systems including chart prescreening, risk assessment forms, flowsheets, prompting and reminder systems, and patient education materials.	92
<b>6:2 Enhancing Primary Care Developmental Services for Young Children</b>	Early childhood (30–33 months)	Parent interviews and medical records at 15 primary care sites. Initial enrollment occurred during 1996–1998 (Minkovitz et al. 2003)	Compared to those with usual care, those in Healthy Steps were more likely to receive recommended preventive and developmental services, reported more patient-centered care, had greater continuity of care, and were less likely to engage in severe child discipline.	Healthy Steps integrates a trained child development specialist into primary care practices to enhance information and other services such as child development and family health checkups, home visits, a telephone hotline, parent support groups, and linkage to community resources.	94
<b>6:3 Promoting Lead Screening for Medicaid-Insured Young Children</b>	Early childhood (1 and 2 years)	1996–1997 medical records (Vivier et al. 2001); 1995–1996 Medicaid claims data (GAO 1999)	Four of five Medicaid-insured Rhode Island children (80%) had ever received a blood lead test by age 19–35 months, compared to only one of five children (21%) ages 1 and 2 years enrolled in traditional Medicaid in 15 other states.	A multifaceted educational and outreach strategy includes performance incentives for health plans and a statewide tracking system to notify health plans, health professionals, and clinics of children who are in need of screening.	96

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>6:4 Improving Delivery of Adolescent Preventive Care in Community and Migrant Health Centers (CMHCs)</b>	Adolescence (14–19 years)	1995–1997 surveys of poor and/or uninsured adolescents visiting five CMHCs for well-child care (Klein et al. 2001)	After CMHCs implemented the Guidelines for Adolescent Preventive Services (GAPS), rates of screening and counseling were higher (by 10 to 29 percentage points) than before the intervention for 19 of 31 content areas.	CMHCs received training and technical assistance and made improvements in care delivery including scheduling 30-minute well-child visits, encouraging confidential counseling time, using a patient questionnaire to screen for health risks, and enhancing patient education materials and referral networks when possible.	98
<b>6:5 Improving Screening for Chlamydia among Adolescent Girls Seen at HMO Clinics</b>	Adolescence (14–18 years)	2000–2002 patient encounter and laboratory data for visits to 10 pediatric HMO clinics (Shafer et al. 2002)	After the intervention, the proportion of girls screened for chlamydia infection increased significantly in the intervention clinics (from 5% to 65%) and was significantly higher than in the usual care clinics (21%).	The intervention included team development to identify and address barriers, performance monitoring, and clinical practice improvements such as flowcharts, universal urine specimen collection, and an educational campaign.	100
<b>CAPACITY TO IMPROVE: GETTING BETTER WHEN SICK OR INJURED</b>					
<b>6:6 Reducing Unnecessary Antibiotic Use Among Young Children in HMOs</b>	Early to middle childhood (3 months to 6 years)	1996–1998 pharmacy claims for children visiting 12 urban and suburban clinics affiliated with two HMOs (Finkelstein et al. 2001)	Among children who visited in both the baseline and intervention years, there was a relative intervention effect of 12 percent to 16 percent fewer antibiotics dispensed in the intervention practices, beyond the change in antibiotic use in the control practices.	The intervention involved peer-led physician education and performance feedback combined with educational materials mailed to parents and displayed in clinic waiting rooms.	102
<b>CAPACITY TO IMPROVE: LIVING WITH ILLNESS</b>					
<b>6:7 Education and Outreach to Improve Asthma Care and Outcomes at an Inner-City Hospital Specialty Clinic</b>	Early childhood to adolescence (2–16 years)	1999 interviews with parents and medical records of Medicaid-insured children at an inner-city hospital specialty clinic (Kelly et al. 2000)	Children in the intervention group were more likely than those in the control group to receive influenza immunization. Anti-inflammatory medication use increased and ER visits and hospitalizations decreased in the intervention group but not in the control group. Annual average health care charges declined \$543 more per child in the intervention group.	The intervention group children and their caregiver received individual asthma self-management education and a written action plan for exacerbations. An outreach nurse contacted children once a month to monitor their status, review medications, refill prescription, schedule follow-up care, and assist with transportation needs. The nurse also coordinated with school personnel.	104

CHART/TOPIC	DEVELOP. STAGE	DATA SOURCE	FINDINGS	IMPLICATIONS	PAGE
<b>6:8 Improving Diabetes Outcomes Through Coping Skills Training</b>	Adolescence (12–20 years)	1995–1998 clinical data and youth self-reports (Grey et al. 1999, 2000)	Teens in a coping skills training group achieved better blood sugar control and improvement in their quality of life as compared to a similar group of teens engaged in intensive diabetes management only.	Nurses led teens in social problem solving and cognitive behavior modification training to promote adherence to intensive therapy without compromising peer relationships. Each teen attended six small group sessions with monthly follow-up.	106
<b>CAPACITY TO IMPROVE: PATIENT SAFETY</b>					
<b>6:9 Decreasing Infections Acquired in the Neonatal Intensive Care Unit (NICU)</b>	Early childhood (neonatal period)	1994–1997 data from six neonatal intensive care units of the Vermont Oxford Network (Horbar et al. 2001; Rogowski et al. 2001)	The average rate of nosocomial coagulase-negative staphylococcus infections in very low birthweight infants declined to a level 44 percent lower than before the intervention. The change was significantly different from the trend at comparison NICUs and yielded \$9 in savings for every \$1 invested.	Multidisciplinary teams from the six NICUs engaged in a collaborative process that included training on quality improvement, agreeing on common goals and metrics, reviewing performance data, developing a list of “potentially better practices” for improvement, and site visits to benchmark performance and stimulate shared learning.	108



## Introduction and Overview

Advances in public health and health care have resulted in remarkable improvement in the health of America's children over the past century. To cite two telling examples: infant and child death rates have dropped dramatically (Brown et al. 2003) and advances in treatment mean that most children diagnosed with cancer now survive (Ries et al. 2003). Yet, serious challenges remain to improve health care for America's children.\*

### THE QUALITY OF CHILDREN'S HEALTH CARE TODAY

#### **A mixed picture emerges in comparisons to other**

**industrial nations.** U.S. children fare comparatively worse on measures of process and outcomes of care that depend on good primary care, such as timely immunizations (OECD 2003) and post-neonatal mortality (Starfield and Shi 2002). Children in the U.S. benefit from earlier introduction of some high-technology care, such as advanced cancer treatment (La Vecchia et al. 1998). Although the U.S. has more neonatal intensive care services per capita than three other highly developed English-speaking nations (Australia, Canada, and the United Kingdom), the U.S. does not achieve better comparative (birthweight-specific) neonatal mortality outcomes. Infant mortality is higher in the U.S. even among normal birthweight infants. Reducing the U.S. mortality rate among these infants to that of Canada would prevent 3,000 deaths annually (Thompson et al. 2002).

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\*For narrative simplicity, we use the term children generically in this introduction to mean both children and adolescents, unless the context indicates otherwise. This convention should not be interpreted to minimize the unique health care needs of adolescents, which are examined in several charts.

**One-quarter to three-quarters of children do not receive the health care that is scientifically proven and/or that experts recommend to prevent disease, reduce disease complications, and achieve optimal health and development.** For example: one-quarter of young children are not fully up to date on their immunizations (*Chart 1:2*), up to one-third of parents of young children are not asked about their child's speech and language development (*Chart 1:4*), less than half of adolescents discuss health behaviors with their clinician (*Chart 1:5*), up to three-quarters of sexually active adolescent girls do not receive chlamydia screening (*Chart 1:6*), one-third of children with persistent asthma do not get a prescription for long-acting medications to control their asthma (*Chart 1:8*), and low-income young children with sickle cell disease do not regularly receive antibiotics to help prevent serious infections (*Chart 1:9*).

**Up to one of five pediatric patients receives inappropriate care.** For example, 21 percent of pediatric patients visiting the doctor for the common cold are prescribed antibiotics (*Chart 1:7*). Several studies have found that 2 percent to 11 percent of pediatric hospital admissions and 4 percent to 22 percent of the days that children spent in the hospital were unnecessary (Kemper 1988; Kreger and Restuccia 1989; Payne et al. 1995; Waldrop et al. 1998).

**Some pediatric patients experience medical mistakes and acquire infections in the hospital that can result in harm** (*Charts 2:1 to 2:3*). These children have longer and more costly hospital stays and higher hospital death rates. Fortunately,

some hospitals have demonstrated improvement in patient safety over the past decade (*Chart 2:3*).

**Health care for many children is not always accessible, timely, or patient-centered.** For example, up to one of five children has problems getting needed care, one of four does not get annual dental care (*Chart 3:4*), four of five in need of a mental health evaluation do not receive any mental health care (*Chart 3:3*), and up to one-half of children with special health care needs do not receive well-organized, continuous, coordinated, comprehensive, family-centered care (*Charts 3:6 to 3:8*).

**Poor, minority, and/or uninsured children experience disparities in health care.** For example, poor, minority, and/or uninsured children are more likely than their counterparts to have incomplete immunizations (Klevens and Luman 2001)(*Chart 5:2*), inadequate dental care (*Chart 3:4*), unmet needs for care (*Charts 3:2, 3:3, and 5:5*), long waits at the doctor's office or clinic (Newacheck et al. 1996), and hospitalizations that might be preventable through better outpatient management (Parker and Schoendorf 2000). Minority children are less likely than white children to receive proven treatments, such as medications to control asthma and ADHD (*Charts 5:3 and 5:4*), anti-depressants and specialty care for depression (Richardson et al. 2003), and placement on the waiting list for a kidney transplant (Furth et al. 2000).

**Geographic variations have been documented in the provision, quality, and availability of several health care services for children**, including: immunizations (*Chart 1:2*),

neonatal intensive care resources (Goodman et al. 2002), tonsillectomy (Wennberg and Gittelsohn 1982), mental health services (Sturm et al. 2003), preventable hospitalizations (Parker and Schoendorf 2000), prenatal care for pregnant women (*Chart 3:5*), and a "medical home" for children with special health care needs (*Chart 3:8*). These variations appear to reflect factors unrelated to the need for services, such as differences in local practice style and the social, market, and policy environment.

**Systematic efforts must be directed toward improving the quality, availability, and equity of health care services for children to ensure continuing progress in improving their health.** Less attention has been devoted to measuring and reporting on quality of care for children than for adults. The quality of health care for adults is not necessarily a good proxy for the quality of health care for children, however (for examples, see narratives for *Charts 2:1 to 2:3*). Since measurement is a prerequisite to improvement, this discrepancy in quality measurement puts children at a relative disadvantage to adults in improving health care quality.

Children have unique health and developmental needs that can make them vulnerable to adverse effects of poor quality health care, which in turn has implications for their life course. Many health conditions that manifest in adulthood have their origins in childhood; likewise, health behaviors begun in childhood often persist into adulthood. Hence, it makes little sense to subordinate the quality of children's health care to that of adults, when the health of adults depends in part on the quality of health care that they received as children (Forrest et al. 1997).

Through this chartbook, we join with others in seeking to raise greater public awareness of the state of health care quality for children and adolescents. As a compendium of data and interpretation, it illustrates both successes achieved to date and gaps warranting improvement. We provide practical guidance, based on scientific evidence and expert recommendations, to help policymakers, health care professionals, and patient advocates consider what actions might be taken to better meet the unique needs of children and adolescents in the future.

## DEFINING QUALITY OF HEALTH CARE FOR CHILDREN

### Differences between children and adults. When

conceptualizing quality of health care for children, one must not think of children as simply “little adults.” Health and health care are different for children than for adults in numerous ways, with implications for quality measurement (Jameson and Wehr 1993; Forrest et al. 1997; Gidwani et al. 2003).

1. Children have **different demographics** than adults, which may accentuate socioeconomic, racial, and ethnic **disparities** in health care. Proportionally more children than adults are poor and of minority race and ethnicity, which puts them at a disadvantage in obtaining health care and achieving good health (Starfield 1997). Minority children—who represent one-quarter of all children today and are projected to comprise nearly half of all children by the year 2025—may face cultural and language barriers to care (Federal Interagency Forum 2003)(*Chart 5:6*).
2. Children undergo rapid and continuous **developmental change**—cognitive, emotional, social, and physical—such that

health issues and appropriate services change with age and general developmental stage. Although all children have inherent developmental vulnerabilities, some children face greater vulnerability from adverse social conditions (Halfon and Hochstein 1997). Many health promotion and preventive services are recommended for children to foster healthy development and to identify developmental vulnerabilities and risks warranting early intervention (*Chart 1:4*).

3. Children have **different disease patterns and manifestations** than adults. Children typically experience many short or recurrent illnesses, but most are generally healthy. Death is a relatively rare event, caused chiefly by injury and accidents. Whereas many adults are affected by a relatively small number of chronic conditions, a minority of children are affected by a relatively large number of rare diseases that are “usually related to birth or congenitally acquired conditions, rather than the degenerative conditions that affect adults” (Halfon and Hochstein 1997). Even when children experience the same diseases as adults, they do so in different ways requiring special approaches to diagnosis and treatment (Palmer and Miller 2001).

Changes in families and society are putting children—and especially adolescents—at risk of “new morbidities” such as alcohol and drug abuse, unsafe sexual practices, exposure to violence, and growing childhood obesity, with consequences for their long-term health and success in life (Carnegie 1995; Haggerty 1995). Addressing these issues requires coordinated and ongoing preventive effort among multiple sectors including but transcending health care.

4. Children are **dependent** on their parents or other caregivers to foster a safe and healthy home environment and to obtain health

care and adhere to treatment regimens. In many ways, the child's family can be considered the "patient" in child health care encounters (Szilagyi and Schor 1998). This dynamic creates challenges for including children appropriately in communication with health professionals and addressing parents' health problems that may affect children (Gidwani et al. 2003)(*Chart 4:3*).

Dependency decreases with age: adolescents need confidential time with a health professional to discuss risky health behaviors and their prevention (Klein and Auerbach 2002)(*Chart 1:5*).

5. Children often rely on **different sources of coverage and systems of care** than adults. Proportionally more children than working-age adults are insured by public programs such as Medicaid and State Children's Health Insurance Programs (Mills and Bhandari 2003). Nearly two-thirds of physician office visits by children and adolescents are with general pediatricians (Freed et al. 2004). Many also receive services through school-based and community clinics, public health agencies, children's hospitals, and an array of special federal and state programs that are often not well coordinated (Halfon et al. 2001). Children also may receive care in facilities or be treated with equipment that is not ideally suited or appropriate for children, potentially compromising the quality of their care (Palmer and Miller 2001).

**Typology of quality and quality measures.** Different stakeholders have varying interests and needs with regard to the definition of quality and application of quality measurement for purposes of accountability, improvement, and decision-making. At a fundamental level, quality can be conceived of and measured in terms of structure, process, and outcomes (Donabedian 1980).

**Structural quality** refers to the effect of health system attributes on the availability and provision of services. Attributes such as organizational leadership, culture, and information systems are important in determining the success of efforts at quality improvement (Ferlie and Shortell 2001). Other attributes, such as the availability and types of health care providers and insurance coverage, are the result of market forces and public policy. One important example in this chartbook shows that children (ages 3 and older) covered by public insurance such as Medicaid are more likely than privately insured children to receive annual preventive health care visits, probably because of more comprehensive coverage under Medicaid (*Chart 5:1*).

**Process quality** refers to the technical proficiency and the interpersonal facets of interactions with patients. To improve quality, physicians need to know what processes of care—diagnosing, treating, and educating patients—achieve better outcomes under given circumstances (Hammermeister et al. 1995). Establishing a firm cause-and-effect link between process and outcome of care is often difficult for children's health care, however. Ethical concerns and the small number of children affected by many conditions mean that randomized controlled trials are infeasible in many cases. Hence, many services or interventions for children must be evaluated in actual practice using nonexperimental study designs that are often challenging to conduct well (Kaplan et al. 2001).

**Outcomes** refer to the results of health care on children's development, well-being, and family satisfaction. Outcomes often are difficult to measure for children because of the natural range of developmental variability, the length of time before some

outcomes manifest, and, in some cases, their rare occurrence. Measuring proxy or intermediate outcomes—such as lost school days, activity limitation, changed behaviors, and preventable adverse events—is often necessary (Christakis et al. 2001b).

The Institute of Medicine has formulated a widely accepted definition of health care quality that integrates these concepts:

*“Quality of health care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (IOM 1990).*

**“Consistent with current professional knowledge”** means following “the best available scientific evidence concerning the processes of care that are likely to improve outcomes” (Palmer and Miller 2001). For children, lack of strong scientific evidence for the effectiveness of many health care services means that clinical quality measures must often rely on expert opinion (Schuster et al. 1997). **“Desired health outcomes”** means that both societal values and individual preferences must be considered in the context of children’s dependency. The former implies a duty of protecting children from harm and providing life-saving treatment when needed. The latter implies the need for good communication, shared decision-making, and cultural sensitivity in interpersonal interactions between the health professional and the parent and child, as appropriate to the child’s age and developmental maturity (Schuster and McGlynn 1999).

## CHALLENGES AND CONSIDERATIONS IN MEASURING QUALITY OF HEALTH CARE FOR CHILDREN

The issues described above have several consequences for conducting quality measurement for children.

**Lack of evidence raises questions about boundaries for quality measurement.** What level of evidence to require for a quality measure is a thorny issue for children’s health care. Quality measurement should be comprehensive to fairly reflect the current state of knowledge and practice. Quality measures must be based on scientifically sound evidence and professional consensus, be relevant to intended users, and feasible to implement with available data. These criteria cannot always be met for measures of child health care quality. For example, the National Committee for Quality Assurance recently abandoned its effort to develop a measure of appropriate treatment for childhood ear infection because the evidence was not sufficient to support it (Mangione-Smith et al. 2003).

The RAND *Quality Assessment Tools* used expert panels to rate the validity and feasibility of outpatient quality indicators (McGlynn et al. 2000). Less than one-fifth (18%) of the final indicators selected for children could be based on strong evidence. By comparison, two-fifths (40%) of indicators for women and nearly three-fifths (59%) for cancer and HIV care were based on rigorous evidence. The authors note that this approach “does not eliminate the goal of basing indicators on the strongest possible evidence, but it does suggest that it may be necessary to set more modest expectations for the level of evidence that will be available” (Schuster et al. 1997).

**Expert recommendations often leave questions of interpretation for quality measurement.** Expert recommendations for health supervision (well-child visits) specify many topics for behavioral counseling but not their relative importance or precise timing for discussion over a series of visits. Some topics may warrant repeated discussion with patients at each visit (e.g., current sexual activity for teens), whereas other topics might be tailored for discussion based on the needs and health risks of individual patients and families at particular visits (Epner et al. 1998; Downs and Uner 2002). This variability can make it difficult to interpret rates of discussion. Additional research is needed on the best way to measure quality of preventive services for children, such as whether to adjust rates to reflect patients' reported health risks and needs.

Many adolescents and parents say that they want more information from their health professional on recommended health behavior and childrearing topics, and many parents say they would be willing to pay more for it (Schuster et al. 2000; Klein and Wilson 2002)(*Chart 1:3*). This kind of feedback appears to validate expert recommendations from a patient- and family-centered perspective, but it must be interpreted with caution. Schuster and colleagues note that some individuals may have an "insatiable" demand for information. Hence, data that may reflect a desire for more information may not reflect inadequate discussions with a clinician.

**Quality measurement is influenced by policy and market issues.** For this chartbook, we take a broad approach to show where quality is falling short of an ideal, whether because of public policy or market constraints, insurance coverage and benefit limits, organizational management, or clinical practice.

The services available in a community and the time available for clinical encounters are to some degree a function of policy and market factors. Health systems and health care providers may reasonably argue that they should be held accountable only for the care that purchasers, consumers, and the community are willing and able to fund.

**Quality of personal health care services is too narrow a focus for children.** Addressing the needs of vulnerable children and those at risk of social and behavioral challenges requires a multi-sectoral approach involving health care providers as well as community organizations including schools, social services and public health agencies, and voluntary organizations. Hence, quality measurement for children needs to account for expected collaboration and coordination among various sectors. Several communities have produced community health report cards to promote a more comprehensive view of children's health needs (Halfon et al. 1998). An accepted set of standardized, systems-level community quality indicators is needed to encourage broader community accountability for children's health outcomes (DuPlessis et al. 1998).

**A paucity of representative data for children makes it difficult to report comprehensively on quality.** National and state-specific sources of data often do not provide data needed for quality measurement for the child population. For example, there are no nationally representative data to monitor diabetes trends and treatment among youth. Many quality measures and instruments have been developed for children's health care, but they are not evenly available across all quality domains nor are they regularly used (Beal et al. 2004).

Several promising efforts are under way to improve the data, tools, and methods of quality measurement for children, such as the Child and Adolescent Health Measurement Initiative (CAHMI), the National Initiative for Children's Healthcare Quality (NICHQ), the Pediatric Research in Office Settings (PROS), the Pediatric Prevention Network (PRN), and new national surveys on children's health and health care being fielded by the federal government. Better data should be possible going forward assuming adequate funding to repeat surveys on a regular basis and to analyze and report on the results.

**A condition-specific approach to quality measurement for children leaves many gaps.** Quality of care often cannot be validly measured or compared between different health care systems or providers for specific rare health conditions because of small numbers. One approach is to aggregate quality scores into composite measures of specific aspects of care across different clinical conditions (McGlynn et al. 2001). Another approach is to use noncategorical or generic measures of quality, such as unmet health care needs (*Charts 3:2 and 3:3*) and the degree to which children receive care within a "medical home" (*Chart 3:8*). There is growing interest in measuring child and family functioning and quality of life (*see Chart 6:8 for one example*). Two recent reviews identified a number of generic quality-of-life instruments for children and adolescents, though only a few have been tested adequately (Eiser and Morse 2001; Schmidt et al. 2002). The use of such outcomes measures in quality evaluation for children deserves further research.

**The child's perspective is often ignored, but is important to quality measurement.** Children often have a different

perspective on their health and health care than either parents or physicians, yet the child's perspective is often ignored, both in practice and in research, which may lead to biased information (Gidwani et al. 2003). Asking parents to rate the experience of care for adolescents is especially problematic, because adolescents may receive confidential care and care in school- or community-based settings about which parents may have limited knowledge. Health status measures have been developed that include the child or adolescent's perspective (Starfield et al. 1995; Landgraf et al. 1999; Varni et al. 2001). Additional research is needed on appropriate survey instruments that can be used to obtain the multifaceted perspective of parents, children, and health professionals regarding the quality of children's health care (Mangione-Smith and McGlynn 1998).

## **A SYSTEMS APPROACH TO IMPROVING QUALITY OF HEALTH CARE FOR CHILDREN**

Improving performance requires systematic approaches to evaluate and incorporate evidence into practice, more effective education for patients and practitioners, and more rigorous methods of assessment and accountability. As the Institute of Medicine reported, "no one clinician can retain all the information necessary for sound, evidence-based practice" (IOM 2001a). Effective quality improvement initiatives provide both feedback on performance and the tools needed by health care providers and systems of care to "close the gap" between current and desired level of performance.

There is a rapidly growing literature that identifies causes of poor quality and/or barriers to improvement and that recommends actions that may be effective in overcoming them.

**Lack of priority for children's health care quality.** A relative shortage of credible quality data on children's health may be explained by the common method of prioritizing quality issues based on cost and prevalence. Given that children suffer from many rare conditions and their expenditures per capita are less than for adults, issues related to child and adolescent health care may be undervalued. An alternative approach would be to prioritize based on "services that modify health states and behaviors that predispose individuals to future morbidity and mortality" (Forrest et al. 1997).

**Fragmentation of health care delivery and financing.** The current array of health care services and programs for children has been characterized as a "non-system" of care that is often difficult for families to navigate (Grason and Morreale 1997; Krauss et al. 2001). Improvement strategies proposed by experts (Halfon and Hochstein 1997; Halfon et al. 2001) include:

- decategorizing separate federal and state funding programs to promote greater integration of services;
- consolidating state programs to create a package of enhanced services that "wrap around" basic private and public insurance coverage for vulnerable children; and
- developing new integrated care models, such as a child-specific version of the social health maintenance organization.

**Lack of awareness or agreement.** Physicians may not follow guidelines for children's health care because few have been rigorously evaluated to establish their validity in improving outcomes (Cabana and Flores 2002). Even when a guideline is well supported by evidence (such as for asthma medications),

health professionals may not practice in accordance with the guideline because they lack knowledge of or are not in agreement with it (Cabana et al. 1999). Strategies to promote evidence-based guidelines include:

- developing more salient formats and using multiple modes for communicating guidelines (Flores et al. 2000);
- instituting one-on-one education and performance feedback delivered by peer leaders (Davis and Taylor-Vaisey 1997); and
- involving physicians in the change process, e.g., teaching quality improvement skills, educating about the problem to be solved, enlisting participation on teams (Greco and Eisenberg 1993)(*Charts 6:4, 6:5, and 6:9*).

**Insufficient time and reimbursement.** Adequate time and reimbursement are necessary but not sufficient to ensure that comprehensive, patient-centered care will be delivered. Increasing visit length was associated with increased preventive service delivery in the context of one quality improvement intervention (Klein et al. 2001)(*Chart 6:4*). Given current fiscal constraints, other strategies that experts (Berry et al. 2003) have proposed to address these issues include:

- redesigning care processes, appointment scheduling, and patient flow to use time more productively;
- making greater use of innovations to extend professional resources such as group well-child care and telephone and electronic communications to supplement face-to-face encounters; and
- expanding roles for mid-level practitioners as members of the care team (*Charts 6:2, 6:7, and 6:8*).

**Insufficient professional skill or confidence.** Physicians may recognize their responsibility for improved performance but lack the necessary skill or confidence that they can apply a skill (Cheng et al. 1999). Passive continuing medical education is rarely effective in changing outcomes (Davis et al. 1995). Strategies for improvement may include:

- enhanced medical education incorporating quality improvement skills as a core competency (IOM 2003b);
- interactive skills training that permits “skills rehearsal” (Clark et al. 1998; Thomson O’Brien et al. 2001);
- decision support tools and computerized prompts to help clinicians apply evidence (Balas et al. 2000; Bates et al. 2003); and
- quality improvement-focused peer review (Ramsey et al. 1993) and other opportunities for professionals to receive coaching and feedback.

**Insufficient systems and supports for improvement.** Small health plans, community hospitals, clinical practices, and solo practitioners may not have the operational capacity to implement changes in systems or practices (Dickey and Kamerow 1996; Ferris et al. 2001). Enablement strategies may include:

- providing technical assistance on quality improvement and information technology solutions (Chart 6:1);
- collaborating with other organizations to develop and test solutions (Kilo 1999)(Chart 6:9); and
- disseminating toolkits and templates that can be adapted for local use to improve the care process and support organizational assessment and change (Charts 6:2 and 6:4).

For example, the National Initiative for Children’s Healthcare Quality partnered with the Pediatric Research in Office Settings network to pilot test tools for improving the evaluation and management of children with asthma and ADHD. The American Academy of Pediatrics has incorporated these tools into an online learning program called *Education in Quality Improvement for Pediatric Practice* (McInerney et al. 2003). Through lessons learned from national implementation efforts, the American Medical Association’s *Guidelines for Adolescent Preventive Services* (GAPS) have expanded into a broader, adaptable model that includes a “train the trainers” program and tools to help local entities plan and implement improvement (Fleming et al. 2001)(Chart 6:4).

**Insufficient motivation for change.** Health plans and practitioners may lack incentives to adopt innovations and to improve their performance—or worse, may face perverse incentives that discourage them from doing so (Casalino et al. 2003; Leatherman et al. 2003). Potential solutions include:

- using innovative financial and contractual mechanisms to create incentives that reward improvements in quality (Shortell et al. 2001; Dyer et al. 2002);
- reporting publicly on quality to create market demand and accountability for improvement (Hibbard et al. 2003); and
- promoting organizational cultures that encourage and reward innovation (Berwick 2003).

For example, some Medicaid programs are combining public performance reporting with increased reimbursement for improved quality of care for children (Silow-Carroll 2003). Some insurers are paying pediatricians who complete the *Education in*

*Quality Improvement for Pediatric Practice* course described above (McInerny et al. 2003). The American Board of Pediatrics has adopted an emphasis on assessment and improvement of quality of care as a requirement for ongoing board certification (Stockman et al. 2003). Incentives for patients may include reducing out-of-pocket costs for preventive services such as immunizations (Briss et al. 2000).

**Evaluating and sustaining the gains.** Quality improvement interventions must be evaluated to determine whether and when they are cost effective in achieving their aims for improving outcomes and patient experience. Many interventions are evaluated on a relatively short-term basis; a critical challenge is to ensure that these gains are sustained over time through ongoing monitoring and reinforcement. Some examples in the *Capacity to Improve* section illustrate that gains may be variable in different settings, so interventions should be evaluated across multiple institutions or practices whenever possible (*for example, see Charts 6:1 and 6:9*). Such an approach also can help ensure that the intervention design is replicable by other organizations.

**Finally, several of the issues described above may be relevant to a particular quality issue.** For example, gaps in clinical quality for medications to control asthma (*Chart 1:8*) and antibiotic prophylaxis for children with sickle cell disease (*Chart 1:9*) appear related to both lack of professional compliance with evidence-based guidelines and lack of parent adherence to obtaining prescription refills or administering medications to their children. These gaps may reflect both potential access barriers and insufficient partnership to educate parents and children.

## CONCLUSION

Given society's collective aspiration to improve the well-being of children, optimizing health care for children must be a national priority. Efforts at quality measurement to date suggest that the health care system is missing many opportunities to do so. Although in some cases knowledge and tools remain limited and in need of advancement, in many other cases the nation is simply failing to apply what is known and to use the tools and strategies already available to improve care.

The examples in the *Capacity to Improve* section demonstrate that improvement and innovation in health care delivery are possible when health professionals, health plans, and others have the motivation and resources to apply the tools of quality improvement. The challenge is to provide the means and incentives for such improvement to occur as a matter of course.

Because good data often are lacking on quality of health care for children, this undertaking was a challenging exercise that undoubtedly leaves many unanswered questions. It is our hope that it will spur progress toward more robust research and reporting in the future. Research is urgently needed to establish the effectiveness of many recommended services for children, identify the processes and systems that promote improved outcomes, and expand the data, methods, and tools for measuring quality of care for children more comprehensively.

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*We'd like to know what you think about this chartbook. To take a short, anonymous user survey, click on the following link or copy the address into your Web browser: <http://64.73.28.22/s.asp?u=50446418798>. Or, e-mail [webeditor@cmwf.org](mailto:webeditor@cmwf.org) to receive an invitation to take the survey. You can also view and download the chartbook through the Commonwealth Fund Web site ([www.cmwf.org](http://www.cmwf.org)).*

# Methods and Organization of the Chartbook

## DEVELOPMENT PROCESS

The charts selected for this chartbook are intended to represent the best available published data in terms of relevance to policy, representativeness or generalizability of the results, scientific soundness of measures, balance in depicting various aspects of quality, and feasibility for presentation in chart format. Because of limitations in data (described in the previous section), the chartbook does not present a comprehensive picture. The number of charts was limited by our available resources and our sense for a manageable amount of information of interest to a wide audience. Our process was as follows:

1. We first reviewed the general literature on children's quality of care and synthesized available frameworks for organizing and presenting such information. We solicited feedback on our approach from a number of recognized experts and organizations involved in pediatric health care quality.
2. We conducted a literature review using PubMed and searches of bibliographies to identify potential studies of interest, focusing on relatively recent data published since 1998 (the ending date of a prior review conducted for the IOM *Crossing the Quality Chasm* report). Topics were drawn from several existing quality measurement frameworks including:
  - The RAND *Quality Assessment Tools* for children and adolescents, which were rated for validity and feasibility by a pediatric expert panel (McGlynn et al. 2000).
  - The Child and Adolescent Health Measurement Initiative framework and tools, developed by the Foundation for Accountability in collaboration with other organizations.
  - *The Pediatric Excellence in Health Delivery System Framework*, developed by the National Association of Children's Hospitals and Related Institutions.
  - *The Quality Framework for State Child Health Insurance Programs*, developed by the Foundation for Accountability, and the *State Children's Health Insurance Program Evaluation Tool*, developed by the American Academy of Pediatrics.
  - *The State of Managed Care Quality*, which presents HEDIS measures developed by the National Committee for Quality Assurance (NCQA 2003a).
  - The Institute of Medicine's report on *Priority Areas for National Action* (IOM 2003c).
3. From 500 studies identified, we selected a subset of 100 that we judged most relevant and feasible for presentation. Three pediatric expert reviewers prioritized this list based on the criteria described above and we made other adjustments based on considerations of balance.
4. The final form of charts and narrative was determined in consultation with quality experts (members of the Chartbook Advisory Board, project consultants, and other independent reviewers listed on the credits and acknowledgment pages).

## THE CONCEPTUAL FRAMEWORK FOR REPORTING ON QUALITY OF HEALTH CARE

In a recent, widely noted report, *Crossing the Quality Chasm*, the Institute of Medicine outlined six aims for improvement of the health care system: effectiveness, safety, timeliness, patient-centeredness, equity, and efficiency (IOM 2001a). A subsequent report, *Envisioning the National Health Care Quality Report* (IOM 2001b), adapted these aims as related components or domains constituting one dimension of a framework for publicly reporting on health care quality. To be consistent with this framework, we adapted these aims or domains for organizing this chartbook. We did not find representative national data to report on all aspects of this framework for children and adolescents.

### **Effectiveness: “providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse).”**

Given the focus on preventive and developmental services for children, most measures of effectiveness included in this chartbook report on underuse of services, which we define (in the context of children’s health care quality) as the failure to provide a service that would have been likely to produce a desired outcome. There is relatively less data showing that children overuse services, which means providing a health service when its risk of harm exceeds its potential benefit. Prescribing antibiotics for the common cold is one of the best examples of overuse in children (*Chart 1:7*).

### **Safety: “avoiding injuries to patients from the care that is intended to help them.”**

Safety issues include wrong diagnoses, medication mistakes, surgery performed on the wrong body part, and infections acquired in the hospital. Ensuring safety may require redesigning and improving faulty systems and processes of care, which may involve better staff training, communication, and coordination as well as standardization of equipment and procedures.

Relatively little national data are currently available to portray this domain for children. Different approaches to measuring medical mistakes offer strengths and weaknesses. Chart 1:1 depicts potential medical mistakes in hospitals based on billing records (administrative data), while Chart 2:2 uses a combination of medical records and reports by clinicians to depict medication errors. Another approach involves reporting to state and national databases (USP 2002). The “ideal reporting system may involve triangulation between administrative data, chart review, and voluntary self reports of critical incidents to maximize the ability to identify events” (Miller et al. 2003).

### **Timeliness: “reducing waits and sometimes harmful delays for both those who receive and those who give care.”**

The IOM *Envisioning* report expands the definition of timeliness to “obtaining needed care and minimizing unnecessary delays in getting that care” and distinguishes three aspects of timeliness: (1) access to routine primary and specialty care when needed; (2) timeliness in getting care for a specific problem once having accessed the system, including waiting time for an appointment and time from diagnosis to treatment; and (3) timeliness for an episode of care, including waiting time in the doctor’s office and coordination of care among multiple providers (IOM 2001b).

We refer to this domain as “Access and Timeliness” to emphasize the important link between these concepts. There is growing interest in the “medical home” as a concept for describing key aspects of quality of care for children spanning the access and timeliness and family-centeredness domains. We show data to illustrate this concept for children with special health care needs (*Charts 3:6 to 3:8*), although it is important for all children.

**Patient-centeredness: “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”**

The IOM *Envisioning* report distinguishes two aspects of patient-centeredness: 1) partnership in decision-making and 2) patient experience with care. This domain of quality is especially important because “what patients experience...as much as the technical quality of care, will determine how people use the health care system and how they benefit from it” (Gerteis et al. 1993). Partnership is perhaps even more important for children’s health care given the involvement of parents in the physician-patient relationship and the need to rely on family values to guide decision-making. Given the intermediary role that parents and other family caregivers play in health care for children, we refer to this dimension as “Patient and Family Centeredness” and include assessment of family well-being.

**Equity: “providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.”**

The IOM distinguishes equity at two different levels: 1) population level: “differences in access to health care services by

various subpopulations,” focusing especially on disparities between those with and without insurance; and 2) individual level: “differences in treatment received based on unrelated personal characteristics” (IOM 2001b). We highlight this concept in a section titled “Disparities,” but we also include data on disparities in other sections as appropriate.

Understanding the causes of disparities is important for determining changes that need to be made by the health care system or in wider social policies that influence health and health care. For example: socioeconomic factors such as income and education generally are stronger determinants of primary health care use than race or ethnicity alone (Fiscella et al. 2000), but racial and ethnic disparities remain in some studies even after controlling for socioeconomic factors (Flores et al. 1999; Elster et al. 2003). Moreover, disparities in access or treatment often remain among those who are equally insured, indicating that insurance coverage and ability to pay are necessary but not sufficient conditions for equal care (Rosenbach et al. 1999).

**Efficiency: “avoiding waste, in particular waste of equipment, supplies, ideas, and energy.”**

The IOM *Envisioning* report did not include this aim in its recommended framework for the National Healthcare Quality Report, on the grounds that it is a related but separate concept that demands additional research. For example, some research has found that improving the patient-centeredness of care has reduced costs (Tidikis and Strasen 1994). In other research, hospitals that scored higher on patient-centeredness tended to have better outcomes (rates of unexpected deaths and complications) but also had higher costs (Bechel et al. 2000). Research is needed to determine whether improved outcomes and patient-centered care

can be achieved at equal or lower cost for children. We acknowledge the importance of this domain but do not include it given limited space. We do cite information on costs, when available and relevant, in our narrative discussion.

### Capacity to improve: achieving the aims

We have adapted the IOM framework by including an additional section of charts intended to demonstrate the health care system's capacity to improve in achieving the aims described above. The IOM states that "[w]ithout substantial changes in the ways health care is delivered, the problems resulting from the growing complexity of health care science and technology are unlikely to abate; in fact, they will increase" (IOM 2001a). Thus, it is vital to find examples of change that can be replicated and adapted in local settings. The charts in this section are intended to provide a few such examples to stimulate interest; they are by no means a comprehensive treatment of this subject.

### Consumer perspective on quality

The IOM framework for the National Healthcare Quality Report incorporates a second dimension, adapted from the Foundation for Accountability's Consumer Information Framework. This dimension includes four perspectives representing different types of health care needs or reasons that people seek health care, reflecting the "life cycle of their involvement with the health care system" (IOM 2001b).

1. **Staying healthy** refers to "getting help to avoid illness and remain well." For children, this perspective must be broadened to include helping children achieve their developmental potential. Most nationally representative data on clinical quality for children fall into this perspective.

2. **Getting better** refers to "getting help to recover from an illness or injury." We denote this perspective as "Getting Better When Sick or Injured" for clarity. The only nationally representative data within this perspective are for antibiotic treatment of respiratory infections (*Chart 1:7*).
3. **Living with illness or disability** refers to "getting help with managing an ongoing, chronic condition or dealing with a disability that affects function." There was only limited nationally representative data to depict this perspective.
4. **Coping with the end of life** refers to "getting help to deal with a terminal illness." Although nationally representative data are lacking to illustrate this perspective, a recent Institute of Medicine report describes many deficiencies in supportive care for children with terminal illnesses (IOM 2002).

Quality measures and data (theoretically) can be subclassified along these four perspectives within each of the domains of quality described above. Some quality measures and data—particularly within the "Patient Safety" and "Patient and Family Centeredness" domains—cross multiple consumer perspectives and therefore cannot be classified within a particular consumer perspective (these are denoted "Multi-Perspective" in the titles).

### Developmental stage

Because children's needs for health care change as they develop, quality of health care for children must be measured and reported in developmentally appropriate ways. We have distinguished and reported on developmental stages as follows:

- Prenatal development (for charts depicting prenatal care);
- Early childhood (ages birth to 5 years) including infancy and the preschool years;

- Middle childhood (ages 6–10 years), corresponding to the elementary school years; and
- Adolescence (ages 11–17 years), corresponding to the middle and high school years.

The American Medical Association’s Guidelines for Adolescent Preventive Services (GAPS) subclassifies adolescence into early (11–14 years), middle (15–17 years), and late (18–21 years) stages. We defined the age range for this chartbook to include children and adolescents younger than 18 years, so we generally do not report on late adolescence except when it has been included in the same data on those younger than 18 years.

## SCIENTIFIC ISSUES AND TERMINOLOGY

**Generalizability.** We preferred studies using nationally representative data. When no national data were available on an important issue, we used studies of lesser scope to depict an important topic (such as medication errors) where the results are likely to be generalizable to broad segments of the population or other similar practice settings, health care providers, or plans.

**Strength of evidence.** The evidence base for children’s health care is variable. We included data in the Effectiveness domain for clinical services recommended by recognized national organizations, such as the American Academy of Pediatrics, when there was some evidence of efficacy to support the recommendation (described in the chart narrative). Evidence is strongest for immunizations (*Chart 1:2*), chlamydia screening (*Chart 1:6*), and antibiotics and asthma medications (*Charts 1:7, 1:8, and 1:9*). Compliance with the recommended schedule of preventive health care visits (*Chart 1:1*) is associated with reduced hospitalizations and ER visits, suggesting improved outcomes. For anticipatory

guidance on childrearing topics (*Chart 1:3*), we included all topics reported by the source so as to portray relative performance on the scope of recommended topics measured, although the evidence for different topics is variable. For anticipatory guidance for adolescents (*Chart 1:5*), we limited topics to reflect the consensus of recommendations of national organizations.

**Terminology.** We use the personal terms “health professional,” “clinician,” and “practitioner” when referring to individuals including physicians, nurses or nurse practitioners, and physician’s assistants. We generally reserve the use of the term “health care provider” to encompass a broader category including both individual professionals and institutions such as hospitals. We report on race and ethnicity generally following the terms (e.g., black or African American) reported in the original survey or publication.

**Statistical reporting.** We generally discuss differences only when they are statistically significant (i.e., 95 percent confidence or greater that differences are not due to chance), where significance has been reported or can be inferred based on large sample size. We use the term “significant” only in this context. In other cases, we describe what we considered to be meaningful differences. Percentages generally are rounded to the nearest whole number, except where rounding would mask significant or meaningful differences.

*Please see the technical appendix for details on study methodologies.*



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# Charts

## EFFECTIVENESS — STAYING HEALTHY — EARLY CHILDHOOD TO ADOLESCENCE — CHART 1:1

## Receipt of Recommended Preventive Health Care Visits

**Why is this important?** The American Academy of Pediatrics and the national *Bright Futures* initiative (sponsored by the federal Maternal and Child Health Bureau and supported by the Centers for Medicare and Medicaid Services and 31 professional and voluntary organizations) recommend a series of regular health supervision or well-child visits from birth to age 21 (AAP 1997; Green and Palfrey 2002). The schedule calls for nine visits from age 1 month through 2 years and annual visits from ages 3 to 21 years, skipping ages 7 and 9 years.

The purpose of these visits is to: “screen for disease, provide counseling about how to foster healthy development of the child and prevent disease and injury (anticipatory guidance), identify problems at a sufficiently early stage to intervene to prevent further problems, provide immunizations, answer questions, and allow a physician to become familiar with a child and his/her family” (Schuster 2000a).

Regular preventive care for children is associated with fewer adverse health care events, suggesting improved health outcomes (additional research is needed to establish these benefits more conclusively):

- Nationally, young children who received all recommended well-child visits had fewer emergency room visits (Hakim and Ronsaville 2002).
- Medicaid-insured young children in three states who received all recommended well-child visits had fewer avoidable hospitalizations (Hakim and Bye 2001).
- Medicaid-insured children of all ages in one state who received more preventive visits had fewer avoidable hospitalizations (Gadomski et al. 1998).

**Findings:** Nearly one-quarter (23%) of U.S. children and adolescents (ages 3 to 17 years) did not have an annual well-child visit at recommended ages, according to parent report in 1999 (data not available for children ages birth to 2 years). Adolescents were less likely to have a preventive health care visit than younger children.

Source: Urban Institute/Child Trends, 1999 National Survey of America’s Families, as reported by Yu et al. (2002).

**Implications:** Many children and adolescents are not receiving the preventive care recommended by experts to promote optimal health and well-being. In other studies of children younger than 3 years (not included in this chart), a range of 19 percent to 84 percent did not receive the recommended number of well-child visits (Freed et al. 1999; Ronsaville and Hakim 2000).

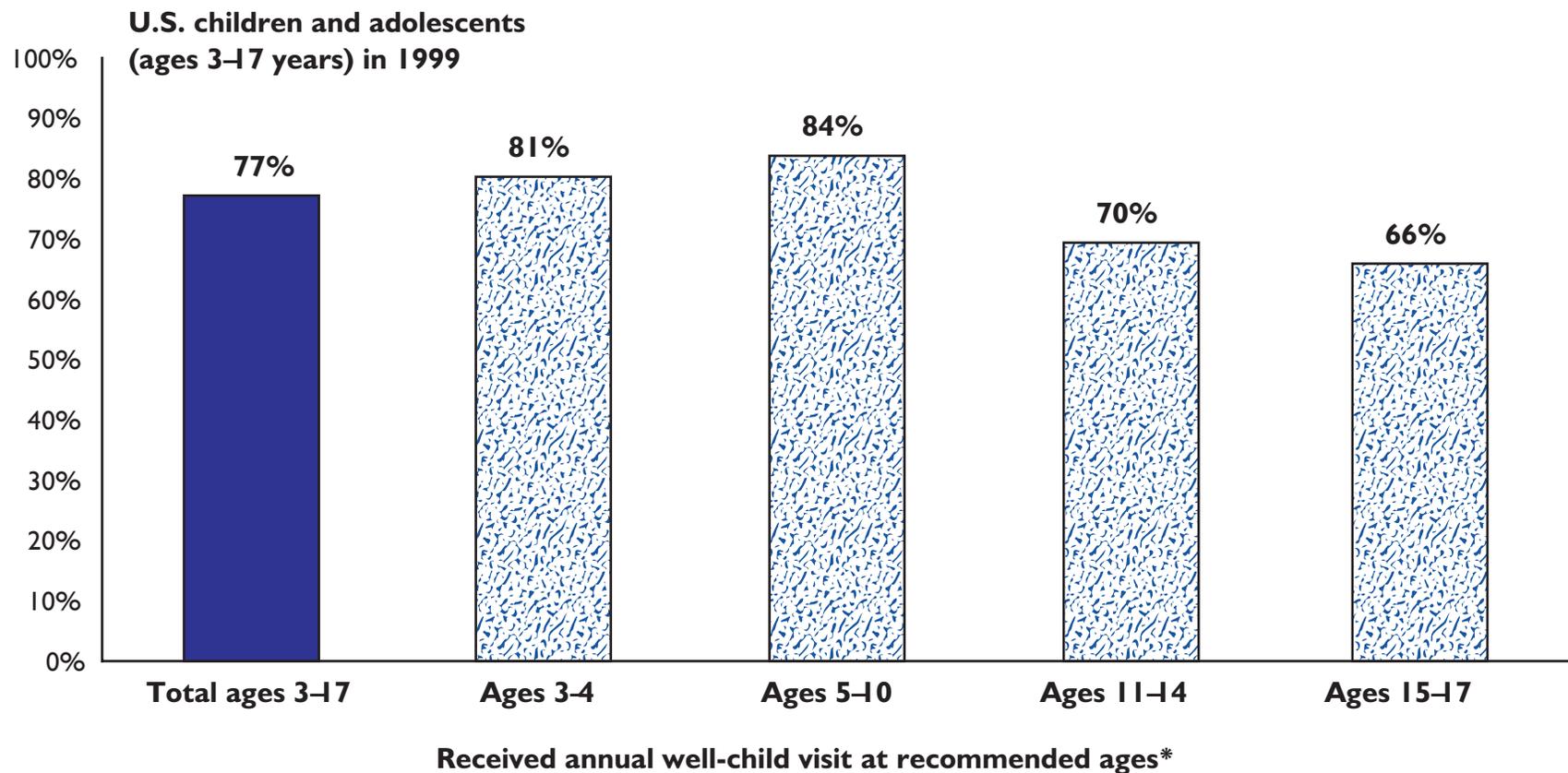
The potential for improved outcomes and the link between well-child visits and recommended preventive services such as immunizations argue for interventions to improve preventive care-seeking, such as parent reminders in combination with efforts to make primary care more accessible (Briss et al. 2000). For example, the San Mateo County, Calif., “Pre-to-Three” program has increased preventive care for low-income young children through assessment, case management, home visitation, and partnerships between community agencies to promote a “seamless network of services” (Cuellar et al. 2003).

See the narrative for Charts 1:2 and 3:1 for examples of other improvement interventions. See Chart 5:1 for disparities in preventive health visits.

## Receipt of Recommended Preventive Health Care Visits

Children who receive regular preventive care are less likely to have emergency visits and preventable hospitalizations. Three-quarters (77%) of U.S. children and adolescents received an

annual preventive health visit at recommended ages, according to parent report in 1999. Adolescents were less likely to have a preventive care visit than younger children.



Source: Urban Institute/Child Trends, 1999 National Survey of America's Families (N=35,938), as reported by Yu et al. (2002). \*Pediatric experts recommend an annual well-child visit at ages 3–6, 8, and 10–21 years; children ages 7 and 9 years were

considered compliant with the recommendations whether or not they received a well-child visit. Data were not sufficient to calculate compliance with recommendations for children ages 0–2 years.



## EFFECTIVENESS — STAYING HEALTHY — EARLY CHILDHOOD — CHART 1:2

## Immunizations for Young Children

**Why is this important?** Vaccination is a very cost-effective disease prevention strategy. High vaccination levels protect children against periodic outbreaks of infectious disease. For example, a measles epidemic in 1989–1991 resulted in 120 deaths, 11,000 people hospitalized, and \$100 million in medical costs (DHHS 2000a). More recently, nearly 8,000 cases of pertussis (whooping cough) were reported in 2000, resulting in 62 deaths (CDC 2002a). Vaccination also protects against mild illnesses that lead to absence from school and lost workdays for parents.

**Findings:** One-quarter (25%) of young children (ages 19 to 35 months) in the United States were not fully up to date on all recommended doses of five key vaccines in 2002. This combined coverage rate has changed little since 1999, when it was first reported.

The combined immunization rate for these five vaccines varied substantially among the states, from 63 percent in Colorado to 86 percent in Massachusetts. Only 11 states met the national *Healthy People 2010* goal of 80 percent coverage for the combined measure. However, two-thirds or more of the states and the nation as a whole met the goal of 90 percent coverage for four of the five specific vaccines included in this measure:

- 4 doses of diphtheria, tetanus toxoids, and pertussis vaccine, or diphtheria and tetanus toxoids only (82% national; state range 66% to 94%; 4 states met goal);
- 3 doses of poliovirus vaccine (90% national; state range 84% to 97%; 33 states met goal);
- 1 dose of measles-mumps-rubella vaccine (92% national; state range 85% to 96%; 41 states met goal);

- 3 doses of *Haemophilus influenzae* type b vaccine (93% national; state range 86% to 98%; 48 states met goal); and
- 3 doses of hepatitis B vaccine (90% national; state range 82% to 97%; 35 states met goal).

Source: National Center for Health Statistics, National Immunization Survey, as reported by the CDC (2003b).

**Implications:** More progress is needed to reach and sustain national immunization goals in every area of the country. The U.S. lags many other nations in timely vaccination of children: 63 countries exceeded the U.S. in reported rate of coverage for three doses of diphtheria-tetanus-pertussis vaccine in 2002 (WHO 2003). Steps to improvement include:

- public policies to ensure adequate vaccine supply and financing (several vaccines were in short supply during 2002) (IOM 2003a),
- improved tracking systems and participation in state and local immunization registries (Wood et al. 1999),
- multi-component community interventions that include education and outreach (Briss et al. 2000), and
- wider adoption of effective practices by health care providers, such as reminders for parents when immunizations are due, assessing the immunization status of all children, and prompts about needed vaccines during visits by children (Briss et al. 2000).

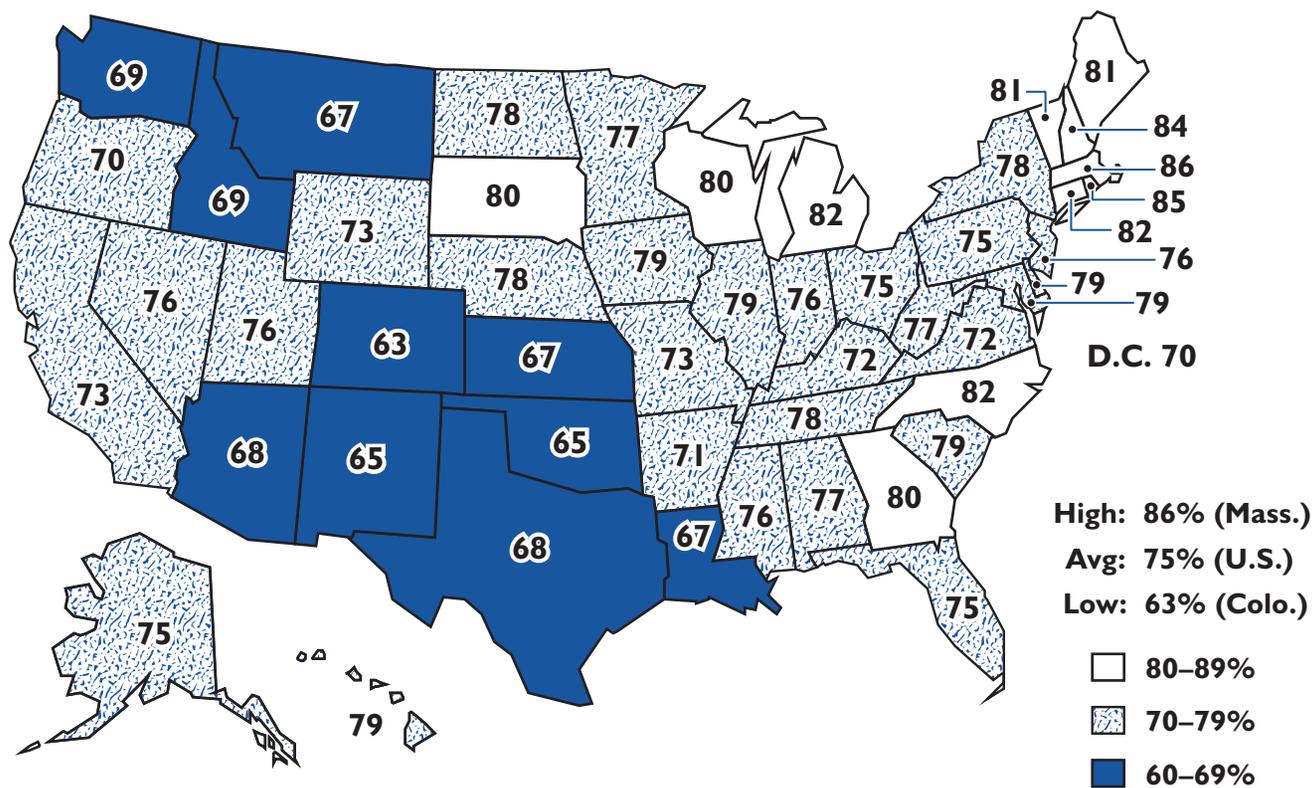
See Chart 5:2 for data on disparities and Chart 6:1 for an intervention that increased childhood immunization rates.

# Immunizations for Young Children

Only three-quarters of young children in the U.S. were up to date on their immunizations in 2002. Just 11 states met the

national goal of at least 80 percent coverage for this combined measure.

**Percentage of children (ages 19–35 months) who received all recommended doses of five key vaccines in 2002\***



Source: National Center for Health Statistics, 2002 National Immunization Survey (N=30,000+ households), as reported by the CDC (2003b). \*4:3:1:3:3 series = 4+ doses of diphtheria and tetanus toxoids and pertussis vaccine or diphtheria and

tetanus toxoids only, 3+ doses of poliovirus vaccine, 1+ dose of a measles-containing vaccine, 3+ doses of *Haemophilus influenzae* type b vaccine, and 3+ doses of hepatitis B vaccine.



## EFFECTIVENESS — STAYING HEALTHY — EARLY CHILDHOOD — CHART 1:3

## Guidance on Childrearing for Parents of Young Children

**Why is this important?** Parents often look to their child's doctor as a trusted source of information on child behavior and development. Both the American Academy of Pediatrics and the national *Bright Futures* initiative recommend a variety of age-appropriate topics that physicians should address to promote child development, effective parenting, and healthy family practices (Schuster et al. 2000; AHRQ 2002a).

Some evidence suggests that certain anticipatory guidance can have a positive impact on childrearing, such as increasing some child safety practices and use of nonviolent discipline, promoting positive mother-child interactions and parental understanding of child temperament, reducing infant crying, and improving infant sleep patterns (DiGuseppi and Roberts 2000; Regalado and Halfon 2001). Parents in three managed care plans reported more confidence in parenting skills and less concern about their child's behavior when they had talked to their child's health professional about such topics (Bethell et al. 2001).

**Findings:** Many parents (38% to 77%) of young children (ages birth to 36 months) in the U.S. reported in 1995–1996 that a health professional (such as a doctor or nurse) had not discussed one of six age-appropriate childrearing topics with them; more than one-third (37%) had not discussed *any* of the topics. Many parents (9% to 42%) had not discussed one of these topics with a health professional *and* wanted more information about the topic. Parents who had discussed more topics were more likely to report that they received excellent care.

Source: Commonwealth Fund Survey of Parents with Young Children, as reported by Schuster et al. (2000).

**Implications:** Health professionals do not always counsel parents on recommended childrearing topics, resulting in unmet needs for information, missed opportunities to help improve parenting skills and child and family well-being, and potentially lower satisfaction with care.

Parents with concerns about their child's learning, development, or behavior are more likely to get needed information when their child's health professional asks whether they have any concerns (Bethell et al. 2002). Parents of young children who visit the same practitioner for well-child care also report more discussion of these topics (Halfon et al. 2003), suggesting that continuity of care is beneficial.

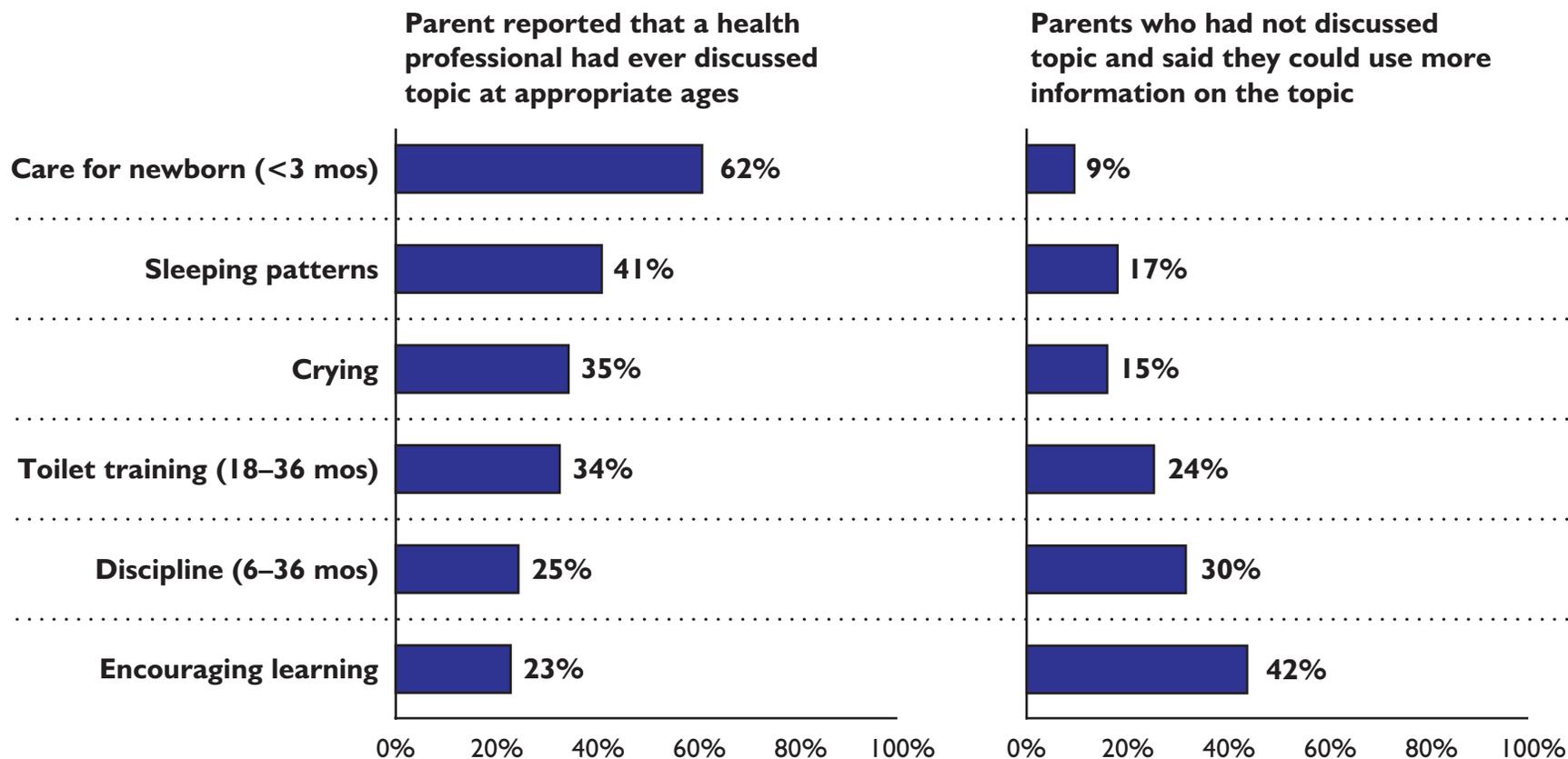
More structured approaches—such as the use of a questionnaire or checklist—may facilitate discussion of these topics, although additional research is needed about the best way to incorporate such approaches into clinical practice (Regalado and Halfon 2002). Providing printed materials to parents, or showing instructional videotapes in the waiting room, can reinforce discussions and facilitate parent recall and use of information (Glascoe et al. 1998).

System-level issues that may increase guidance for parents include assuring adequate time and reimbursement for these services and providing additional education and training for health professionals (Halfon et al. 2003). *See Chart 6:2 for an intervention that integrated a child development specialist into primary care practices to enhance information and other services for parents.*

# Guidance on Childrearing for Parents of Young Children

Less than half of parents of young children reported that they had ever discussed five of six age-appropriate childrearing topics with a health professional (such as a doctor or nurse)

during 1995–1996. Many parents had not discussed a topic and wanted more information about the topic, indicating unmet need.



Parents of U.S. children (ages 0–36 months) in 1995–1996

Source: 1995-1996 Commonwealth Fund Survey of Parents with Young Children (N=2,017), as reported by Schuster et al. (2000).



## EFFECTIVENESS — STAYING HEALTHY — EARLY CHILDHOOD — CHART I:4

## Speech and Language Development: Assessment and Guidance

**Why is this important?** Speech and language development is typically the most useful early indicator of a child's overall development and cognitive ability (Schuster 2000b). Early identification of children at risk for developmental delay or related problems can help the family prepare and seek intervention services to support the child from a young age when chances are best to effect change (Schuster 2000b). A systematic review of research found that speech and language therapy for children can be effective in improving expressive disorders (Law et al. 2003). Research suggests that eliciting parent concerns and reports about a child's skills is an effective way for physicians to screen for developmental problems (Regalado and Halfon 2001).

Reading aloud to young children helps children develop oral language skills and learn to read, which is important to success in school and life (Wells 1985; Bus et al. 1995; Mendelsohn 2002). Nationally, 6 percent to 16 percent of parents of young children report that they never read to their child and another 15 percent to 23 percent read only infrequently; half of low-income families with young children do not regularly read aloud (Young et al. 1998; Halfon et al. 2002). The American Academy of Pediatrics encourages physicians to promote early literacy development (AAP 1999), which can be especially beneficial among young children from disadvantaged backgrounds (High et al. 2000).

**Findings:** Up to one-third (21% to 32%) of parents of young children (ages 4 to 35 months) reported in 2000 that their child's doctor or other health professional had not discussed how the child communicates or about words and phrases that the child

uses and understands. More than one-third (36% to 39%) said that the doctor or health professional had not discussed the importance of reading to their child.

Source: National Center for Health Statistics, National Survey of Early Childhood Health, as reported by Halfon et al. (2002).

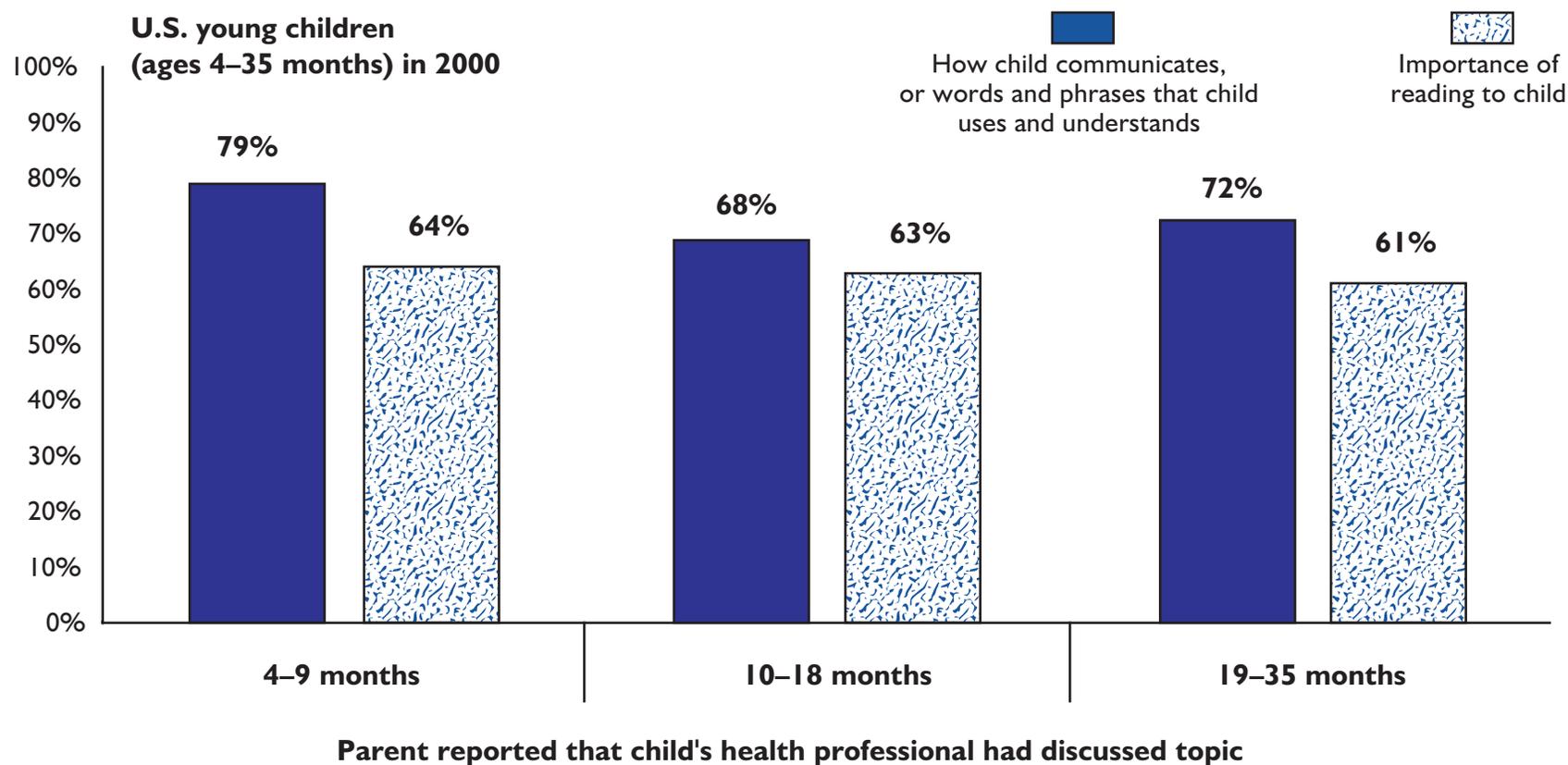
**Implications:** Although discussion of speech and language appears to be common, there is opportunity for improvement, especially concerning the importance of reading to children. The Healthy Steps demonstration program is one approach that has increased provision of developmental services to young children through enhanced well-child care services and the addition of a child development specialist to the care team (Minkovitz et al. 2001)(see Chart 6:2).

The "Reach Out and Read" initiative has engaged more than 1,400 physician practices nationwide in an intervention (during well-child visits) that encourages early literacy development through physician counseling and giving parents developmentally and culturally appropriate picture books (Reach Out and Read 2003). Evaluations in urban clinics serving low-income and multicultural families have found this intervention effective at encouraging reading and improving child language development (High et al. 2000; Mendelsohn et al. 2001; Sharif et al. 2002; Silverstein et al. 2002).

# Speech and Language Development: Assessment and Guidance

*About two-thirds or more of parents of young children reported in 2000 that their child's doctor or other health professional had discussed speech and language development*

*issues and the importance of reading aloud to their child to promote early literacy development.*



Source: National Center for Health Statistics, 2000 National Survey of Early Childhood Health (N=2,068), as reported by Halfon et al. (2002). See technical appendix for differences in survey wording by age group.



## EFFECTIVENESS — STAYING HEALTHY — ADOLESCENCE — CHART 1:5

## Counseling Adolescents on Healthy Behaviors

**Why is this important?** Adolescence is a time of rapid change when youth experiment with and establish behaviors that can have both immediate and life-long consequences for their health. The Carnegie Council on Adolescent Development estimated that “nearly half of American adolescents are at high or moderate risk of seriously harming their life chances” (Carnegie 1995).

Several national organizations—including the American Medical Association, American Academy of Pediatrics, American Academy of Family Physicians, U.S. Preventive Services Task Force, and the Maternal and Child Health Bureau’s Bright Futures initiative—have recommended that primary care physicians screen and/or counsel as appropriate to help adolescents prevent injuries (such as through seat belt use), reduce the risk for future heart disease (such as through tobacco cessation, good nutrition, and adequate exercise), and prevent or reduce certain risky behaviors (such as alcohol use and unsafe sexual behaviors) (Elster 1998).

Some evidence suggests that clinical counseling can help adolescents make behavioral changes, such as decreasing alcohol consumption, increasing condom and contraceptive use, and increasing seat belt use (Klein and Auerbach 2002; Manlove et al. 2002). In other cases, recommendations may be extrapolated from studies showing the efficacy of counseling adults. Adolescent health care experts advise that counseling by health professionals should be part of a coordinated preventive effort involving family, schools, and the community (Santelli et al. 1999).

**Findings:** In 1997, one-half or less of surveyed adolescents (in the fifth through the twelfth grades in the U.S.) reported ever discussing most recommended health risk topics with their doctor or other health professional.

Source: Commonwealth Fund Survey of the Health of Adolescents, as reported by Ackard and Neumark-Sztainer (2001).

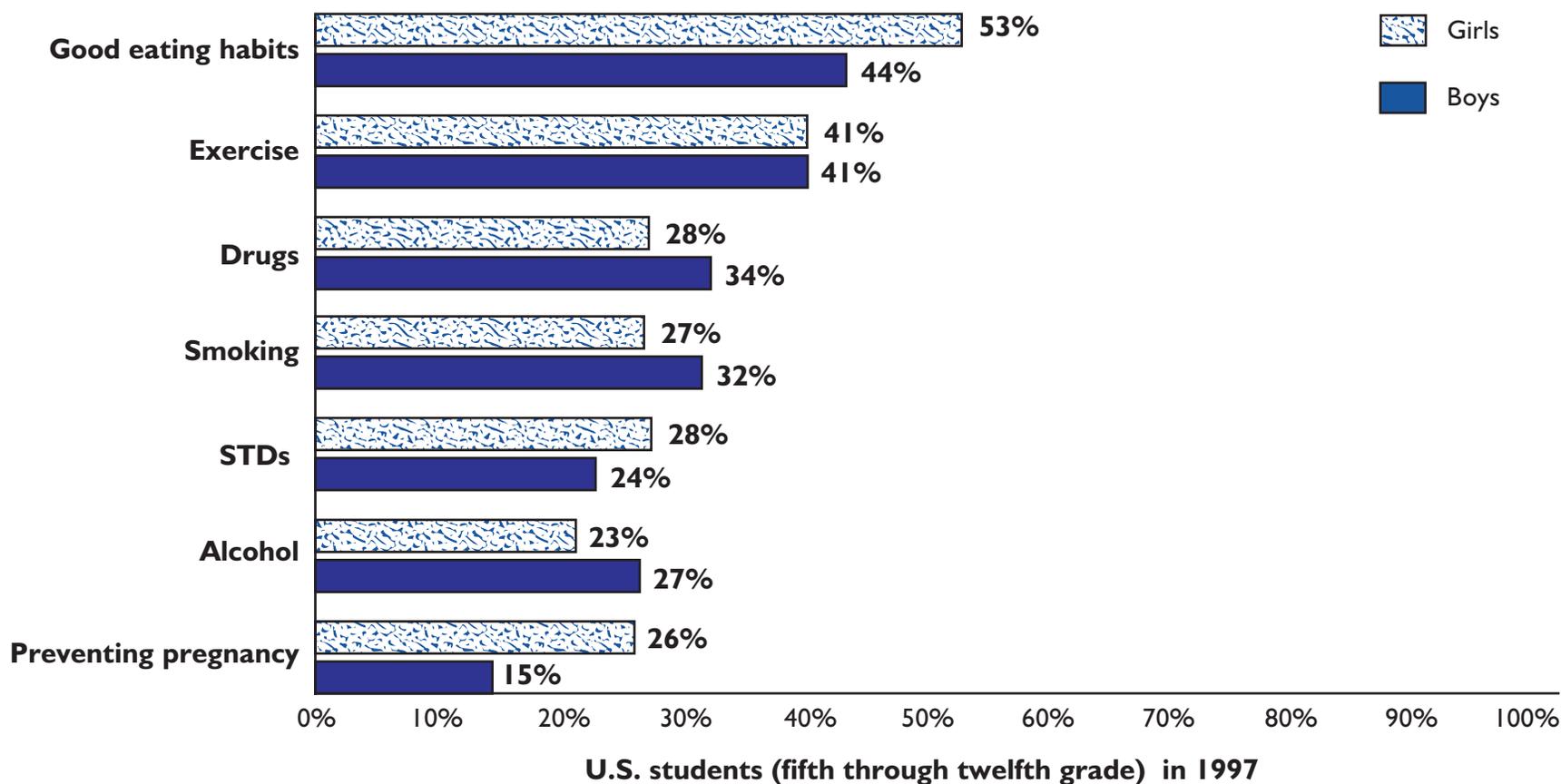
**Implications:** Although many adolescents say that they want to discuss health behaviors with a doctor or other health professional (Klein and Wilson 2002), health professionals miss many opportunities to do so. Reasons for this gap may include limited time during visits, lack of professional confidence, or skill deficiency to address teen issues (Park et al. 2001). Adolescents who have confidential time with their clinician and who visit teen health clinics are more likely to receive counseling (Blum et al. 1996; Klein and Wilson 2002).

Interventions that increase clinical counseling of adolescents (*see Chart 6:4*) include:

- skills-based training for health professionals (Lustig et al. 2001),
- use of structured risk assessments and supportive office systems (Boekeloo et al. 1999; Klein et al. 2001), and
- a combination of educational “priming” for patients and reminders for health professionals (Boekeloo et al. 2003).

# Counseling Adolescents on Healthy Behaviors

*In 1997, less than one-half of adolescents reported that they had ever discussed most recommended health risk topics with their doctor or other health professional.*



Source: 1997 Commonwealth Fund Survey of the Health of Adolescents (N=6,728), as reported by Ackard and Neumark-Sztainer (2001). Topics shown represent a subset of those included in the survey that matched the consensus of recommendations of

national organizations for screening and/or counseling adolescents at the time of the survey (Elster 1998). "Good eating habits" represents the highest rate achieved for any of the topics included in the survey.



## EFFECTIVENESS — STAYING HEALTHY — ADOLESCENCE — CHART 1:6

## STD Screening for Adolescents: Chlamydia Infection

**Why is this important?** Genital chlamydia is the most common bacterial sexually transmitted disease (STD) in the U.S., costing \$3 billion or more for treatment of complications. Nearly half (46%) of the infections newly reported each year occur in sexually active 15- to 19-year-old girls, among whom prevalence rates may reach 10 percent (CDC 2001).

Although chlamydia can be cured with antibiotics, most infected people do not have symptoms and remain unaware that they need treatment. When untreated, up to 40 percent of women with chlamydia develop pelvic inflammatory disease, which can result in chronic pelvic pain, infertility, or life-threatening tubal pregnancy (CDC 2001).

Screening females at risk for chlamydia reduces the incidence of pelvic inflammatory disease and is likely to be cost-saving (USPSTF 2003). The U.S. Preventive Services Task Force recommends that clinicians routinely screen all sexually active females age 25 and younger (evidence was insufficient to determine the effectiveness of screening men). The Centers for Disease Control and Prevention recommend annual screening for sexually active females younger than age 20—who are at greatest risk of infection (CDC 1993).

**Findings:** Among sexually active adolescent females (ages 16 to 20 years) enrolled in managed care plans, more than seven of 10 (73%) with private insurance and nearly six of 10 (59%) with Medicaid coverage did not receive a test for chlamydia infection in the past year. There was a small increase in rates from 2000 to 2002.

Source: National Committee for Quality Assurance, HEDIS, as reported by the NCQA (2003a). See technical appendix for a description of how sexually active women were defined. *Although this data source is not representative of all adolescents, it is the best available data on this topic.*

**Implications:** The rate of chlamydia screening remains very low in private health plans, although the higher rate in Medicaid plans is encouraging (the best-performing Medicaid plans achieved screening rates of 60 percent).

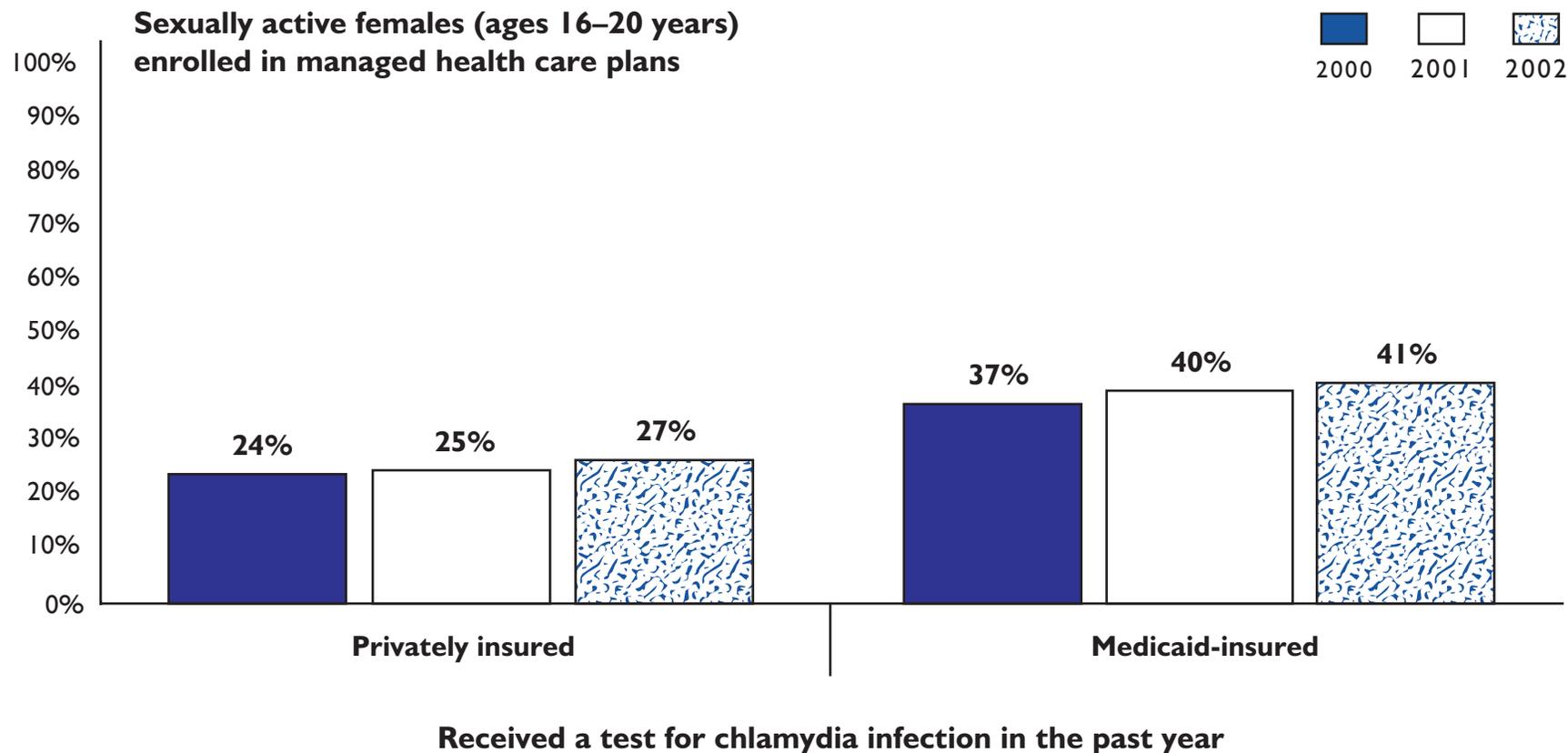
Only one-third to one-half of primary care physicians report regularly testing for chlamydia when they determine that an adolescent girl is sexually active. Factors associated with physician adherence to screening guidelines include: a sense of responsibility for STD prevention, confidence in addressing teen sexuality, and an understanding of the risk of infection and effectiveness of screening (IOM 1997; Torkko et al. 2000; Cook et al. 2001). Teens say that privacy and confidentiality are important to receiving STD screening (Blake et al. 2003).

A multifaceted intervention aimed at improving clinical practice substantially increased chlamydia screening rates in pediatric clinics of one HMO (Shafer et al. 2002)(*see Chart 6:5*). School-based STD screening programs also hold promise for reaching more youth (Nsuami and Cohen 2000).

# STD Screening for Adolescents: Chlamydia Infection

*Chlamydia—a sexually transmitted genital infection—often goes undetected and can lead to infertility or problems in pregnancy if left untreated. Among sexually active adolescent females enrolled in managed care plans,*

*less than three of 10 in private plans and four of 10 in Medicaid plans had been screened for chlamydia infection in the past year.*



Source: National Committee for Quality Assurance, HEDIS (N=282 to 334 private plans and 85 to 100 Medicaid plans), as reported by the NCQA (2003a). Used and adapted with permission from the National Committee for Quality Assurance.



## EFFECTIVENESS — GETTING BETTER WHEN SICK OR INJURED — EARLY CHILDHOOD TO ADOLESCENCE — CHART I:7

## Inappropriate Antibiotic Treatment for the Common Cold

**Why is this important?** Children use antibiotics at a higher rate than other age groups (McCaig and Hughes 1995). Widespread overprescribing of antibiotics contributes to the emergence of antibiotic-resistant strains of bacteria, which are increasing in prevalence (Whitney et al. 2000), potentially endangering all patients. Therefore, experts recommend limiting antibiotics to patients who are most likely to benefit (Dowell et al. 1998).

The common cold is caused by a virus, for which antibiotics are not effective and never indicated (Rosenstein et al. 1998). When an infection is caused by bacteria, then antibiotics may be appropriate, but experts recommend the use of narrow-spectrum antibiotics whenever possible to target specific bacteria. Using broad-spectrum antibiotics when they are not indicated makes the resistance problem even worse by unnecessarily exposing more diverse bacteria to antibiotics (Lewis 1995; CDC 2003a).

**Findings:** The inappropriate practice of prescribing antibiotics for children and adolescents (younger than age 15) suffering from the common cold (and other unspecified upper respiratory infections likely to be caused by a virus) decreased by 50 percent during the past decade, from two of five such visits (41%) in 1991–1992 to one of five such visits (21%) in 1998–1999. By the end of the decade, however, clinicians were more often prescribing broad-spectrum antibiotics at such visits (8% in 1998–1999 vs. 6% in 1991–1992).

Source: National Center for Health Statistics, National Ambulatory Medical Care Survey, as reported by Steinman et al. (2003).

**Implications:** Clinicians treating children have achieved the national objective of reducing antibiotic prescribing for the common cold by 50 percent. Further progress is needed to ensure that antibiotics are used appropriately so that they remain effective when truly needed.

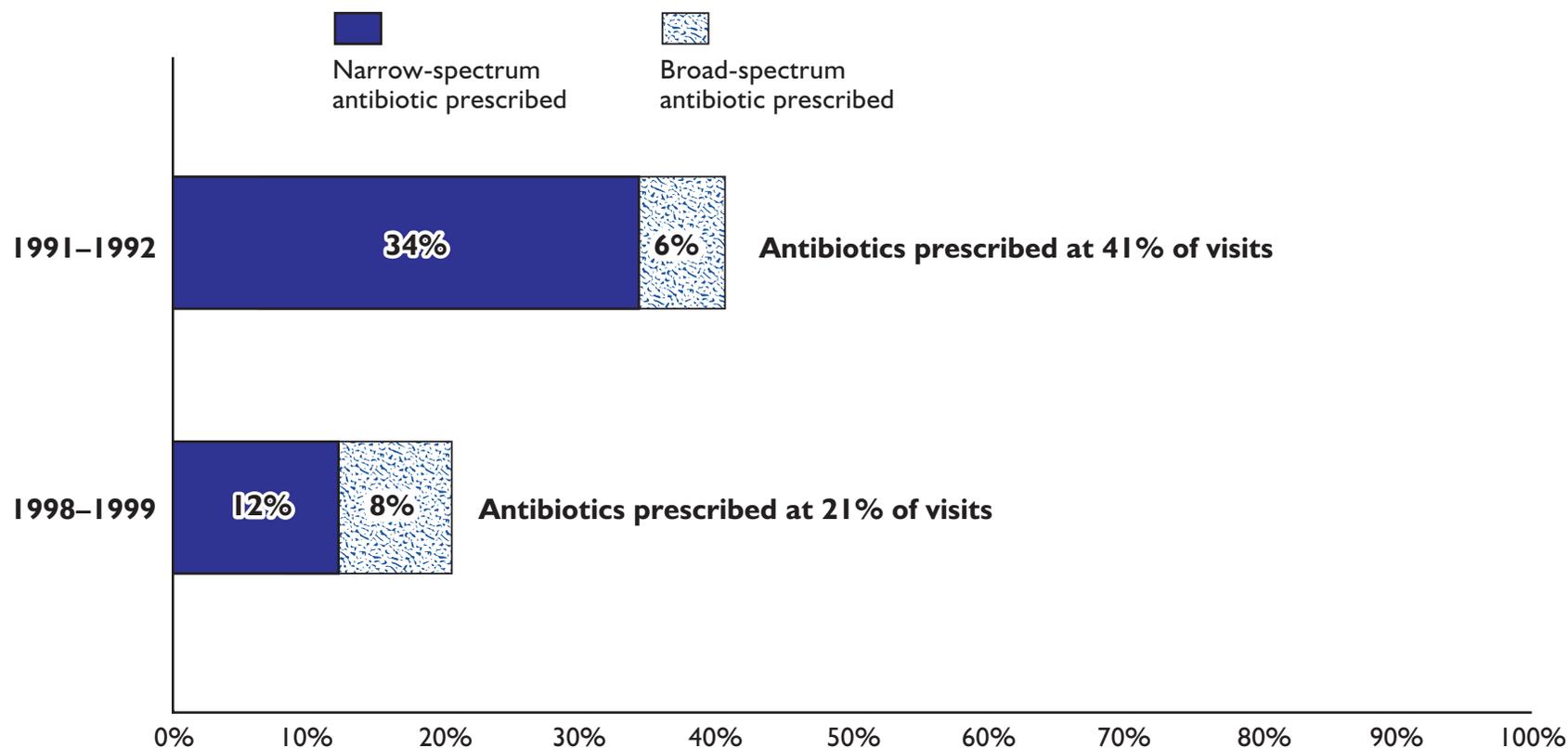
Parents often hold misconceptions about the proper use of antibiotics (Lee et al. 2003). Physicians may prescribe antibiotics for viral infections to meet perceived parental expectations or demands for antibiotics (Bauchner et al. 1999; Mangione-Smith et al. 1999; Stivers 2002), or based on a belief that antibiotics will prevent bacterial complications from developing (Pichichero 2002). These are not valid or effective reasons for using antibiotics, however (Rosenstein et al. 1998).

Research has found that parent satisfaction with the physician visit depends on meeting their expectations for good communication rather than on whether antibiotics were prescribed; this suggests that parent satisfaction can be maintained if physicians take time to explain the decision not to prescribe an antibiotic (Hamm et al. 1996; Mangione-Smith et al. 1999). Interventions that combine education for parents and physicians can decrease unnecessary antibiotic use among children (Finkelstein et al. 2001; Perz et al. 2002) (*see Chart 6:6*).

## Inappropriate Antibiotic Treatment for the Common Cold

Antibiotics are never indicated for treating the common cold. From 1991 to 1999, clinicians reduced—by 50 percent—the prescribing of antibiotics for children and adolescents with the

common cold (from 41 to 21 percent of visits). Yet, they more often prescribed broad-spectrum antibiotics, which risks spreading antibiotic resistance to more bacteria.



**Physician visits by children and adolescents (younger than 15 years) diagnosed with the common cold (and other unspecified upper respiratory tract infections likely to be caused by a virus)**

Source: National Center for Health Statistics, National Ambulatory Medical Care Survey (N=1,976 pediatric visits), as reported by Steinman et al. (2003) and personal communication with Michael A. Steinman (2003). Percentages do not add to 100

because of rounding. Adapted and republished from the *Annals of Internal Medicine* with permission of the American College of Physicians.



## EFFECTIVENESS — LIVING WITH ILLNESS — MIDDLE CHILDHOOD AND ADOLESCENCE — CHART I:8

## Prescription of Preventive Medication for Long-Term Asthma Control

**Why is this important?** Asthma—the most common childhood chronic health problem (after dental caries)—has increased in prevalence since 1980. Four million children suffered an asthma attack in 2000, resulting in 728,000 emergency room visits, 214,000 hospitalizations, and 223 deaths (CDC 2003c). One-quarter of children with asthma have symptoms severe enough to limit their activities (CDC 2002b) and 14 million school days are missed each year because of asthma (ALA 2003). Medical and societal costs of childhood asthma were estimated at \$3.2 billion in 1994 dollars (Weiss et al. 2000).

The National Asthma Education and Prevention Program has issued evidence-based guidelines for effective asthma management including patient education and monitoring, control of environmental factors, and appropriate drug therapy (NAEPP 1997; 2002). Children with asthma often overuse short-acting bronchodilators to relieve their symptoms, which can lead to poor outcomes (Lozano et al. 2003). Children with persistent asthma who use recommended long-acting medication (such as an inhaled corticosteroid) to control the inflammation that causes asthma achieve better outcomes, including fewer symptoms, emergency room visits, and hospitalizations (Calpin et al. 1997; Adams et al. 2001).

**Findings:** Among children and adolescents (ages 5 to 17 years) with persistent asthma enrolled in managed care plans, about one of three (30% to 35%) covered by private insurance and two of five (38% to 40%) covered by Medicaid did not receive a prescription for an appropriate medication to control their asthma in 2002. Performance improved from 2000 to 2002 for both private and Medicaid plans.

Source: National Committee for Quality Assurance, HEDIS, as reported by the NCQA (2003a).

**Implications:** National data show a substantial increase in the prescribing of medications to control asthma over the past decade (Stafford et al. 2003). Still, parents reported in 2000 that only two of five children (42%) who had an asthma attack in the past year used the recommended first-line medication (inhaled corticosteroid) to control their asthma (Krauss 2003). Further improvement is needed.

Although most pediatricians are aware of the medication guideline, some do not agree with it and therefore do not always prescribe medication as guidelines recommend (Cabana et al. 2001). Likewise, some parents and children report concerns or misunderstanding about these medications, resulting in failure to follow prescriptions about half the time (Bender et al. 1997; Leickly et al. 1998; Farber et al. 2003).

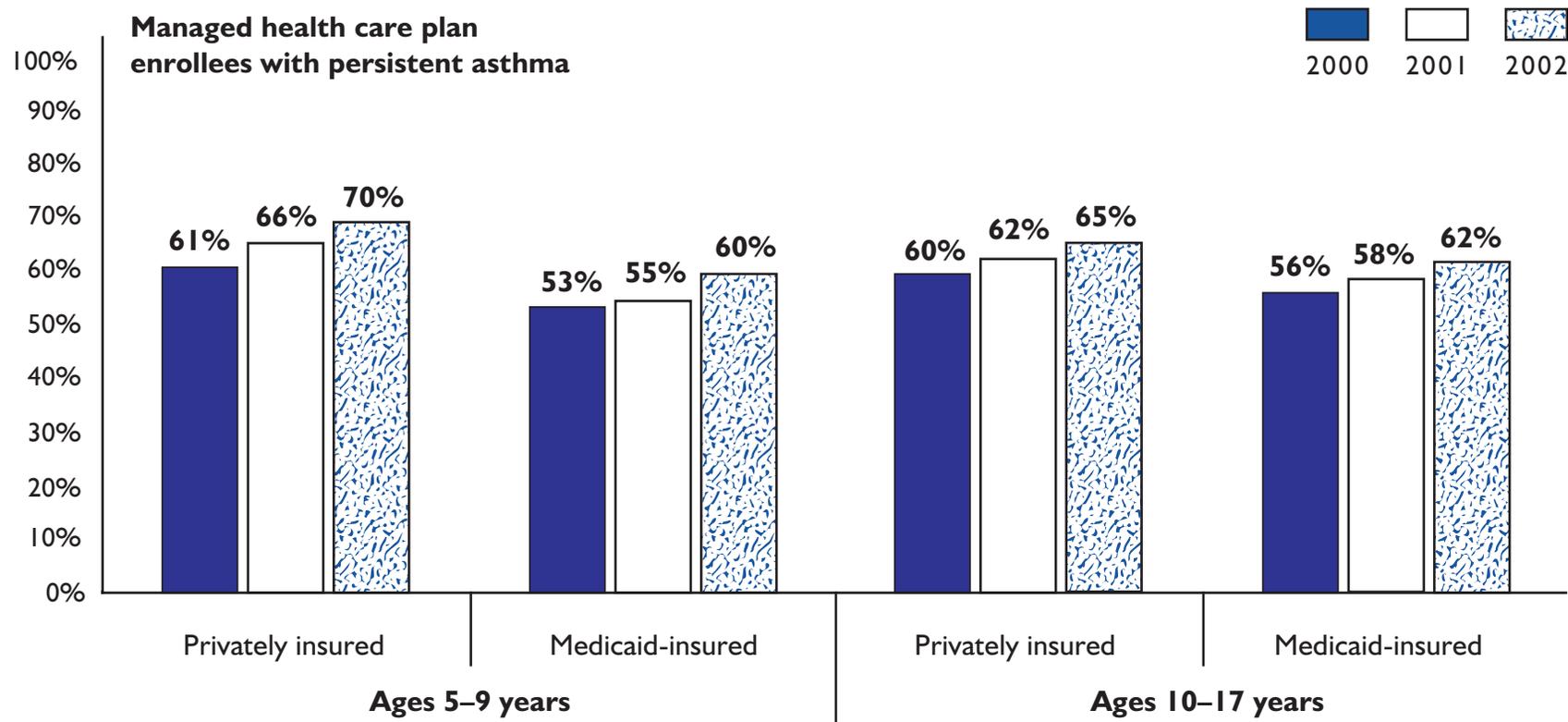
Improvement in asthma management will require a “planned asthma care approach” (IOM 2003c) that creates stronger professional partnerships with families to address concerns and support medication adherence (Bender 2002) (*see Chart 6:7*).

- An interactive professional training program improved physician communication with parents, prescribing of medications, and parent knowledge and satisfaction while lowering resource use (Clark et al. 1998).
- Asthma self-management education programs improve outcomes for children including fewer absences from school, activity restrictions, and emergency room visits (Wolf et al. 2003).

# Prescription of Preventive Medication for Long-Term Asthma Control

Only about two-thirds of children and adolescents with persistent asthma enrolled in managed care plans receive a prescription for a recommended medication to control their

asthma and prevent asthma attacks. Performance improved sequentially over the past three years.



**Received a prescription for an appropriate preventive medication for long-term asthma control**

Source: National Committee for Quality Assurance, HEDIS (N= 242 to 285 private plans and 53 to 90 Medicaid plans), as reported by the NCQA (2003a). Used and adapted with permission from the National Committee for Quality Assurance.



## EFFECTIVENESS — LIVING WITH ILLNESS — EARLY CHILDHOOD — CHART I:9

## Prescription of Antibiotics to Prevent Infection among Medicaid-Insured Young Children with Sickle Cell Disease

**Why is this important?** Sickle cell disease (SCD) is a genetic disorder that affects 2,000 infants born in the U.S. each year, predominantly African Americans (CORN 2002). Children with sickle cell disease require expert, comprehensive care in a medical home (a multidisciplinary team or a knowledgeable primary care physician who coordinates care with specialists) to prevent and treat complications (AAP 2002b). Chief among these is a high susceptibility to severe bacterial infection that can lead to meningitis, pneumonia, septicemia (the spread of pathogens and their toxins in the blood), and death.

Based on strong evidence from a randomized controlled trial (Gaston et al. 1986), experts recommend that children with two types of sickle cell disease (sickle cell anemia and S- $\beta^0$  thalassemia) receive prophylactic antibiotics (twice-daily penicillin or the equivalent) to prevent pneumococcal infection continuously from age 2 months until age 5 years, with pneumococcal vaccinations as a first line of defense and prompt treatment of suspected infections when they do occur (AAP 2000; NHLBI 2002).

**Findings:** During 1995–1999, children younger than 4 years with sickle cell disease who were continuously enrolled in Medicaid for one year in two states were dispensed an average of only 148 days (41%) of an expected 365-day supply of antibiotics of a type that could have prevented pneumococcal infection. (Antibiotics may have been prescribed for therapeutic reasons as well as prophylaxis.) The amount of antibiotics dispensed

varied greatly among children: 10 percent received no antibiotics and 22 percent received more than 270 days of medication. Children had an average of 13 outpatient visits during the year, suggesting that there were many missed opportunities to provide antibiotic prescriptions.

Source: Medicaid administrative claims and encounter data, as reported by Sox et al. (2003).

**Implications:** Even under generous assumptions, low-income young children with sickle cell disease went without antibiotics to prevent potentially life-threatening infections on three of five days during the year. Other research suggests that parents of children with sickle cell disease often fail to obtain antibiotic prescription refills on a timely basis (often due to transportation barriers) and frequently forget to administer these medications when they do have them (Elliott et al. 2001).

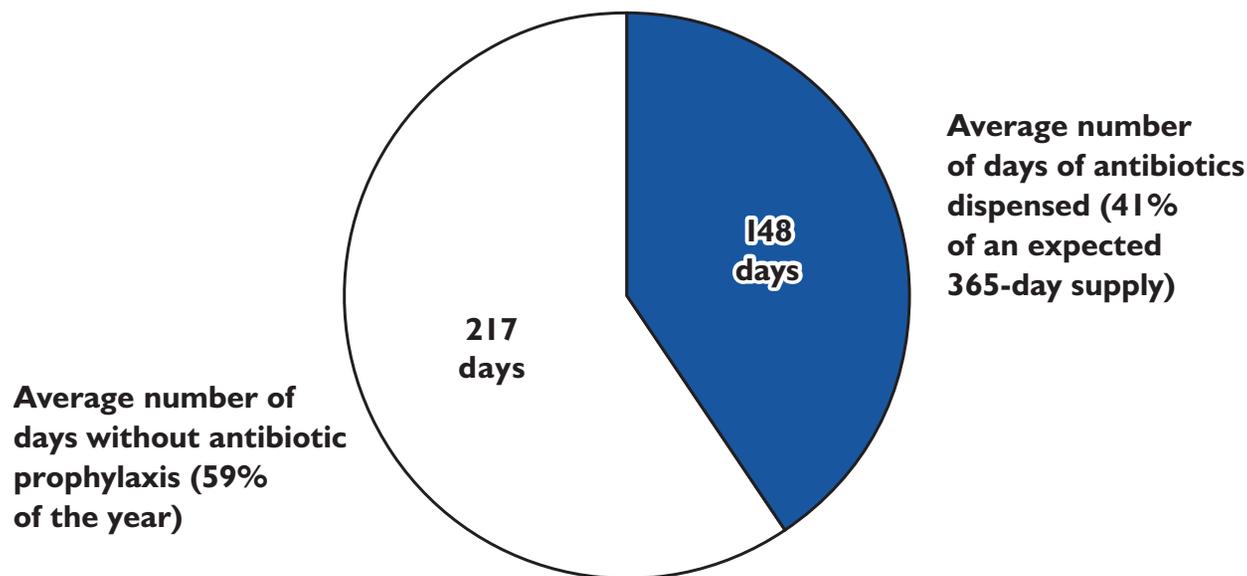
Interventions are needed to increase the prescribing of prophylactic antibiotics and encourage better adherence to prescriptions among these children. Some researchers recommend that clinicians monitor prescription adherence and review parental beliefs and barriers to achieving strict compliance (Elliott et al. 2001). Others have reported success with an intensive parent education program (Day et al. 1992). Survival has greatly improved for children with sickle cell disease in recent years (Davis et al. 1997) but could likely improve further with better care and medication compliance.

# Prescription of Antibiotics to Prevent Infection among Medicaid-Insured Young Children with Sickle Cell Disease

*During a one-year period, Medicaid-insured young children with sickle cell disease were dispensed an average of only 148 days (41%) of an expected 365-day supply of prophylactic*

*antibiotics to prevent potentially life-threatening pneumococcal infections.*

**Children (younger than 4 years) with sickle cell disease\* continuously enrolled in Medicaid in two states for a one-year period during 1995–1999**



Source: Medicaid administrative claims and encounter data (N=261), as reported by Sox et al. (2003). \*Diagnosis of sickle cell anemia (hemoglobin SS) or sickle-beta (S-β<sup>0</sup>) thalassemia.



## EFFECTIVENESS — LIVING WITH ILLNESS — EARLY CHILDHOOD TO ADOLESCENCE — CHART I:10

## Monitoring and Evaluation for Cystic Fibrosis

**Why is this important?** Cystic fibrosis (CF) is a life-shortening genetic disorder characterized by chronic respiratory infections and gradual loss of lung function, typically accompanied by digestive disorder and malnutrition (CFF 2003a). Cystic fibrosis is diagnosed in about 1,000 Americans each year, most frequently among white children. Through aggressive treatment, the average life-expectancy for people with cystic fibrosis has increased to more than 30 years today from less than five years in the 1950s (CFF 2003a).

The Cystic Fibrosis Foundation (CFF 1997) recommends that people with cystic fibrosis should receive:

- regular health care visits (at least four per year) to anticipate and treat physical and psychosocial problems,
- lung function measurements (spirometry) every three to six months to anticipate and treat complications and establish patterns of response to treatment,
- at least one respiratory tract culture annually to detect and treat respiratory pathogens,
- an annual chest X-ray to detect deterioration in lung structure (especially important for young children in whom lung function cannot yet be measured),
- an annual nutritional assessment to anticipate and treat nutritional deficits, and
- other annual routine laboratory tests for disease complications, such as cystic fibrosis-related diabetes.

In a comparison of process and outcomes of care across cystic fibrosis specialty centers, children who received care in accordance with CFF guidelines had better lung function, an important outcome associated with survival (Johnson et al. 2003).

**Findings:** Among children and adolescents (ages birth to 17 years) with cystic fibrosis, one of three (33%) did not receive the recommended four monitoring visits and one of 20 (4%) did not receive at least one respiratory tract culture during 2002. One of six of those ages 6 to 17 years (16%) did not receive at least two lung function measurements. One of five of those ages 14 to 17 years (19%) did not receive a blood glucose test for glucose intolerance or cystic fibrosis-related diabetes.

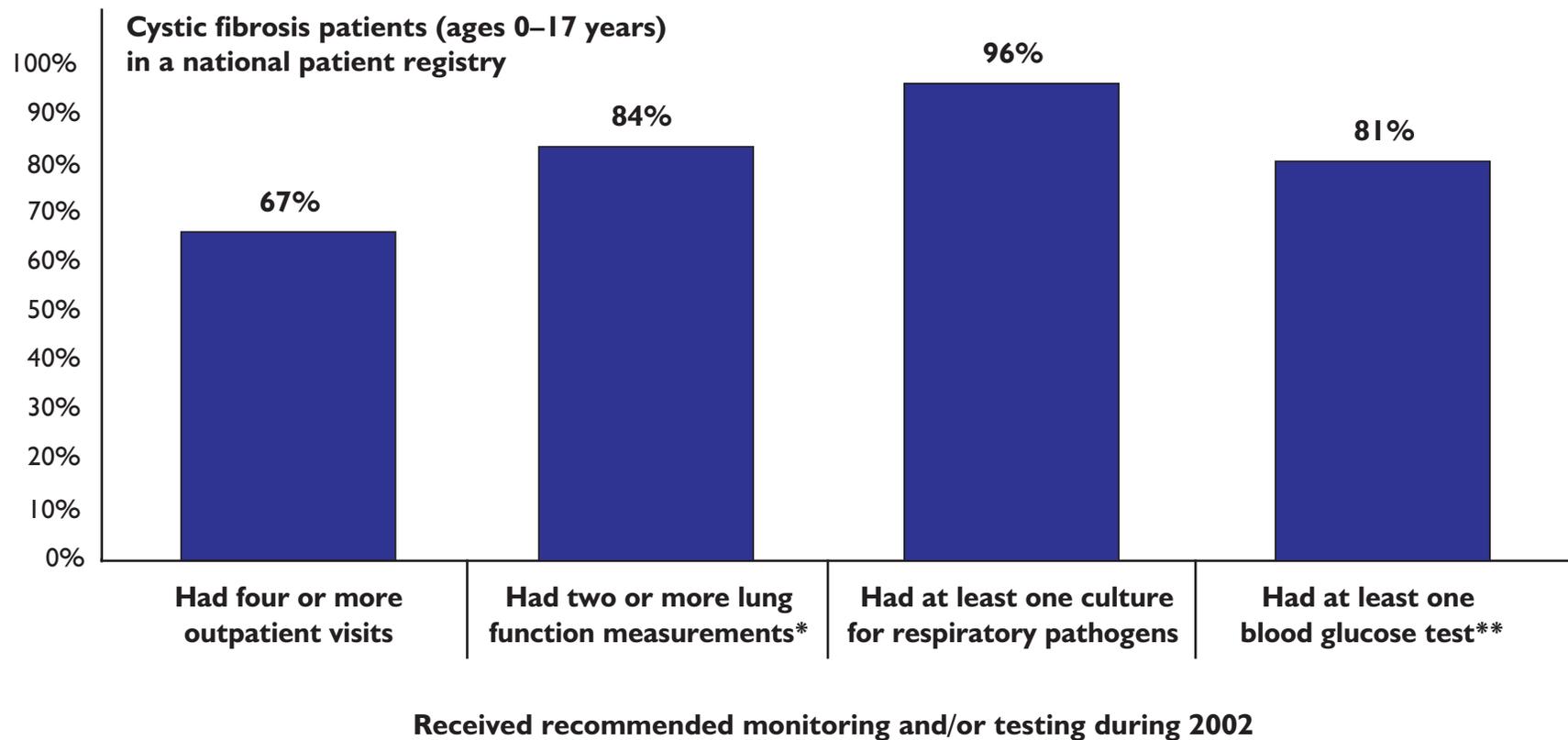
Source: Cystic Fibrosis Foundation Patient Registry Annual Data Report (CFF 2003b). (Data were not available on chest X-ray or nutritional assessment.)

**Implications:** Improvement is needed to ensure that all children and adolescents with cystic fibrosis receive recommended monitoring and evaluation that is associated with better outcomes. The Cystic Fibrosis Foundation is working with its network of care centers to identify and share best practices for improving processes and outcomes of care, such as earlier identification and management of cystic fibrosis-related diabetes (Marshall 2003). As part of this effort, the National Initiative for Children Healthcare Quality is working with several cystic fibrosis centers on a learning collaborative to improve the quality of care for children with cystic fibrosis. A toolkit has been developed to assist professionals and parents in good nutritional management and reducing children's exposure to environmental tobacco smoke (NICHQ 2003b).

# Monitoring and Evaluation for Cystic Fibrosis

Only two of three children and adolescents with cystic fibrosis, a life-shortening genetic disease, received all recommended monitoring visits during 2002, and about four of five received

recommended tests that can help anticipate problems and direct treatment to maintain better lung function and reduce the impact of disease complications.



Source: CFF Patient Registry Annual Data Report (N=13,817) as reported by the Cystic Fibrosis Foundation (2003b). \*Lung function was measured by spirometry primarily for patients ages 6 and older. \*\*Blood glucose test to detect glucose

intolerance or potential cystic fibrosis-related diabetes was measured for patients ages 14 years and older.



## PATIENT SAFETY — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 2: I

## Patient Safety Indicators: Potential Medical Mistakes in Hospitals

**Why is this important?** Medical mistakes—which represent “the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim” (Reason 1990)—are by definition preventable. They account for thousands of adverse events and deaths among hospital patients, including children, each year (IOM 1999). A national public opinion poll found that nearly one-half the public is very concerned about a medical mistake that could injure them or a family member during a hospital stay (KFF 2003).

The Institute of Medicine’s landmark 1999 report on medical errors has prompted national efforts to measure and diminish these threats to patient safety. As one response, the federal government created Patient Safety Indicators (PSIs), which use hospital billing records to “screen for problems that patients experience as a result of exposure to the healthcare system, and that are likely amenable to prevention by changes at the system or provider level” (AHRQ 2003a).

**Findings:** Patient Safety Indicators identified potentially preventable adverse events (potential medical mistakes) among newborns, children, and adolescents (ages birth to 17 years) during hospital stays nationally in 2000. They include a wide array of problems related to medical, surgical, and nursing interventions. PSI rates ranged from a low of 0.003 per 1,000 patients at risk for transfusion reactions to a high of 7.67 per 1,000 patients at risk for decubitus ulcers (bed sores).

Compared to adults (data not shown), children experienced lower or similar rates of complications for about half the

indicators. Children had higher rates of complications of anesthesia and postoperative physiologic and metabolic derangement compared to nonelderly adults (ages 18–64). Children had higher rates of accidental puncture or laceration during procedures, postoperative respiratory failure, and decubitus ulcers compared to younger adults (ages 18–44) only. Children’s rates exceeded those of elderly adults (ages 65 and over) only for infections due to intravenous lines and catheters.

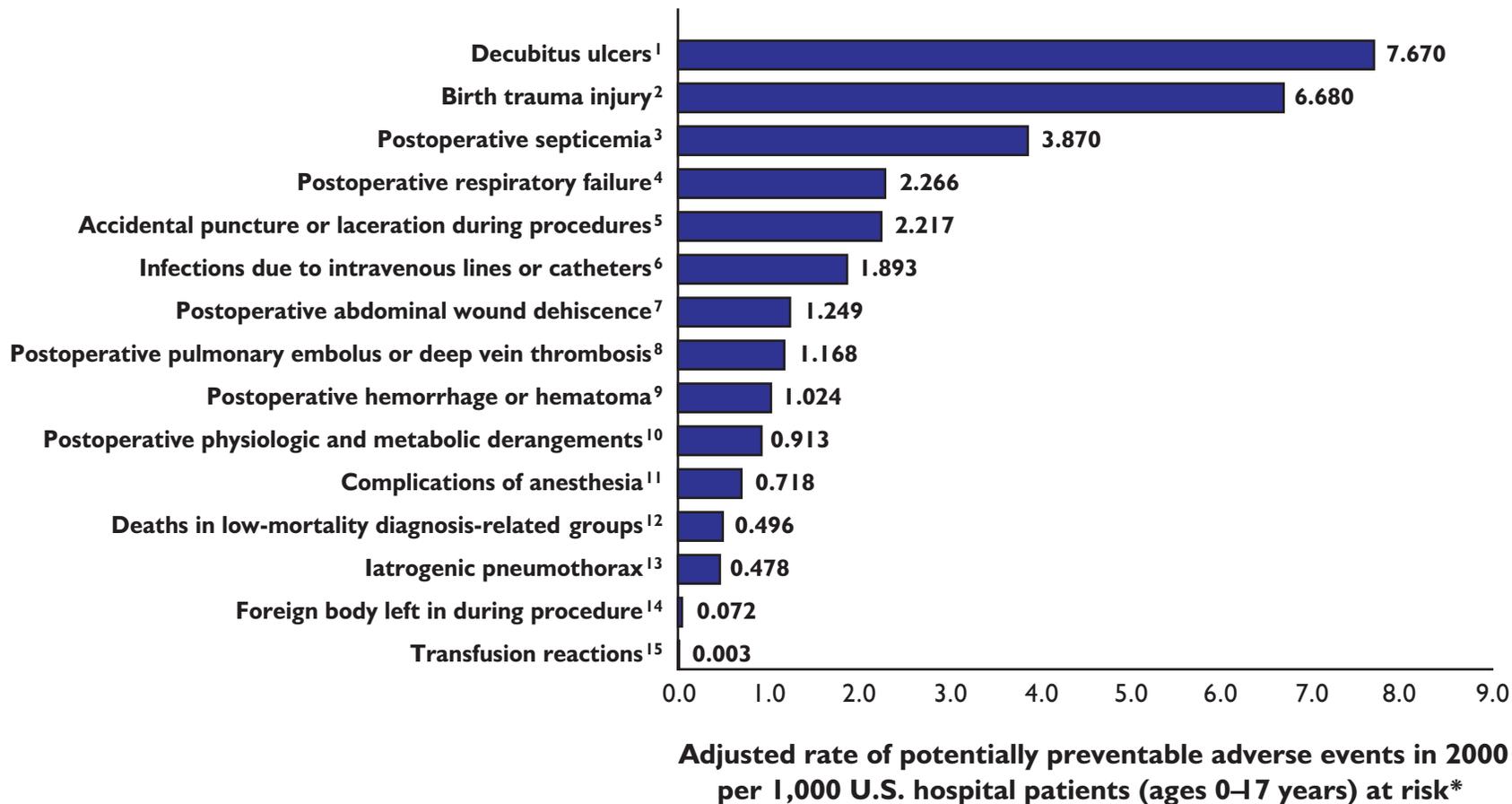
Source: Agency for Healthcare Research and Quality, Healthcare Cost and Utilization Project, Nationwide Inpatient Sample, as reported by AHRQ (2003b).

**Implications:** Children and adolescents who experience potential medical mistakes identified by PSIs have 2- to 6-fold longer hospital stays, 2- to 18-fold higher rates of death, and 2- to 20-fold higher hospital costs compared to those who do not have such complications (Miller et al. 2003).

Data limitations mean that PSIs cannot offer definitive results, but they are relatively inexpensive to implement. Thus, they offer a good starting point to identify potential failures in processes and systems of care that hospitals should evaluate for quality improvement (Miller et al. 2003). Tools such as *Pathways to Medication Safety* (HRET 2003) can help hospitals plan appropriate changes—such as better organization, work environment, training, procedures, teamwork, and communication—to improve patient safety in the hospital.

# Patient Safety Indicators: Potential Medical Mistakes in Hospitals

*Infants, children, and adolescents hospitalized in 2000 experienced adverse events or complications that may be preventable with improved quality of care.*



Source: Agency for Healthcare Research and Quality, 2000 Healthcare Cost and Utilization Project, Nationwide Inpatient Sample, as reported by AHRQ (2003b). \*See technical appendix for footnotes defining populations at risk and rate adjustments, which vary by indicator.



## PATIENT SAFETY — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 2:2

## Pediatric Medication Mistakes in the Hospital

**Why is this important?** Mistakes often occur in prescribing, preparing, and administering medication for hospitalized patients and these mistakes sometimes cause patient injury (IOM 1999). Special procedures required for children, such as calculating medication doses based on the child's weight, may create additional chance for error (Fortescue et al. 2003).

This chart presents data on medication mistakes among pediatric patients at two Boston teaching hospitals, detected during six weeks in 1999 (Kaushal et al. 2001). *These data represent one of the most in-depth analyses among the few studies on this topic to date, although it may not be representative of all hospitals.*

**Findings:** Medication mistakes were detected in six of every 100 medication orders for pediatric patients, occurring at a rate of 55 per 100 pediatric admissions or 157 per 1,000 patient-days. About one of every five medication mistakes either caused patient harm or had the potential to do so.

*Preventable Adverse Drug Events:* One of every 100 medication mistakes resulted in patient injury. The rate of these events (0.05 per 100 medication orders) was the same as for adults in a similar study.

*Potential Adverse Drug Events:* Another 19 of every 100 medication mistakes had the potential to cause patient harm. Two of five (41%) of these mistakes were not caught before reaching the patient. Moreover, they occurred at the highest rate among "the youngest, most vulnerable" children in the neonatal intensive care unit. The rate of potential adverse drug events (1.1 per 100 medication orders) was three times higher than reported for adults in a similar study.

*Stage of medication process:* Nearly three-quarters (74%) of the pediatric medication mistakes occurred when physicians prescribed medication (data not shown).

*Types of mistakes:* Common mistakes were using an incorrect medication dose, giving medication via the wrong route of administration, failing to have full or accurate documentation, missing a date or using a wrong date, and giving medication at the wrong frequency.

Source: medical records, medication orders, medication administration records, and clinician self-reports (Kaushal et al. 2001).

**Implications:** The potential for harm from pediatric medication mistakes indicates an urgent need for efforts to examine and "error-proof" the medication process for hospitalized children. Attention also must be given to measuring and preventing mistakes that occur in primary care and other outpatient settings.

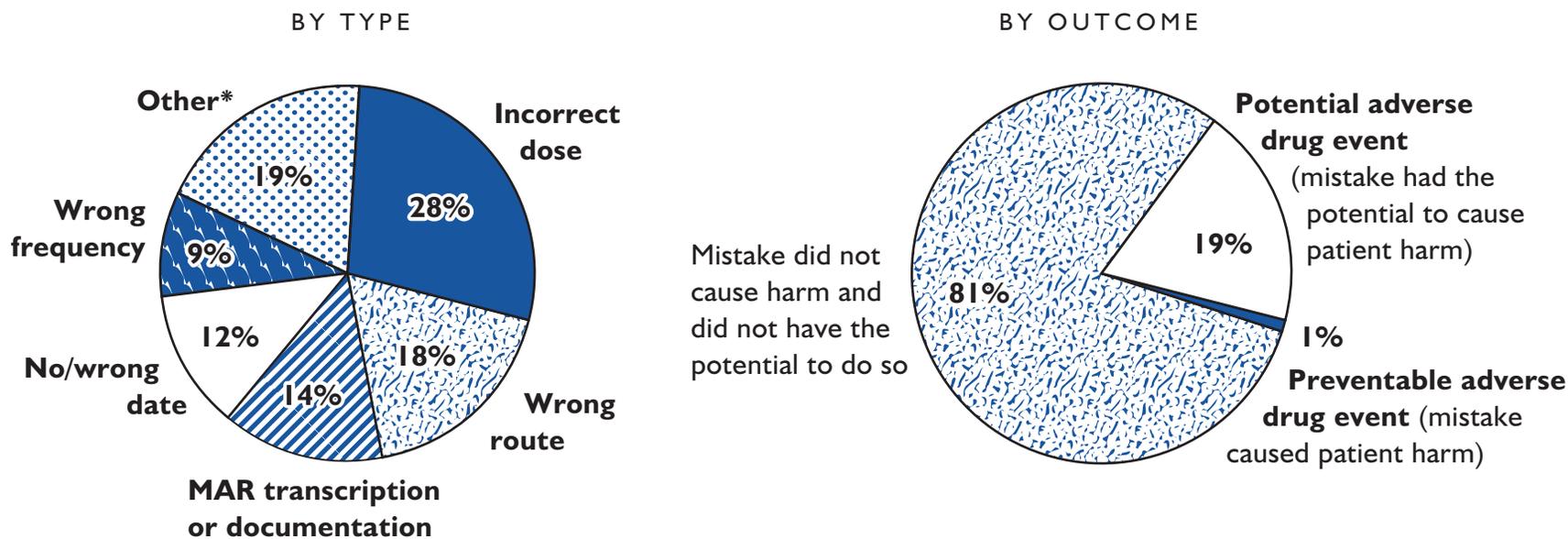
Researchers judged that most of the preventable and potential adverse drug events in these hospitals could have been averted by one of three interventions: (1) using a computerized physician order entry system with clinical decision support (such systems must be tailored to include weight-based dosing for children), (2) assigning full-time clinical pharmacists to support the medication process on patient wards, or (3) improving communication among physicians, nurses, and pharmacists (Fortescue et al. 2003). Simple tools also may be useful in reducing errors, such as checklists and precalculated dosing guidelines (Goldman and Kaushal 2002; USP 2002).

# Pediatric Medication Mistakes in the Hospital

Medication mistakes occurred in six of every 100 medication orders during a study at two hospitals. One of every five medication mistakes either caused patient harm or had the

potential to cause harm. An incorrect medication dose was the most common type of pediatric medication mistake.

**Pediatric Medication Mistakes Detected at Two Hospitals During Six Weeks in 1999**



Source: medical records, medication orders, medication administration records (MAR), and clinician self-reports (N=616 errors), as reported by Kaushal et al. (2001). May not be representative of all U.S. hospitals or of all pediatric medication mistakes.

Percentages may not add to 100 because of rounding. \*Other includes: missing or wrong weight (3.7%), illegible order (2.3%), wrong drug (1.3%), known allergy (1.3%), wrong patient (0.2%), and other (9.9%).



## PATIENT SAFETY — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 2:3

## Hospital-Acquired Infections in Pediatric Intensive Care Units

**Why is this important?** Hospital-acquired infections affect an estimated two million Americans—including 500,000 intensive care patients—each year (DHHS 2000b). Such infections result in longer hospital stays (10 days per patient on average), increased costs (\$39,000 per case on average), and higher in-hospital death rates (4 percentage points higher on average) (Zhan and Miller 2003).

Patients in intensive care units (ICUs) are at increased risk of acquiring infections because of frequent use of invasive medical technologies and procedures, which save lives but also carry an inherent risk for infection. A recent survey of 31 children's hospitals found that an average of 12 percent of patients being cared for in pediatric ICUs had hospital-acquired infections on a given day (Grohskopf et al. 2002).

**Findings:** Risk-adjusted rates of infection acquired by patients in pediatric intensive care units declined for two types of device-associated infection monitored by hospitals participating in a voluntary national surveillance system during 1995–2003 compared to 1986–1990.

- The rate of bloodstream infections associated with use of central intravenous lines decreased by 36 percent (from 11.4 infections per 1,000 device-days of use during 1986–1990 to 7.3 during 1995–2003).
- The rate of urinary tract infections associated with use of urinary catheters decreased by 19 percent (from 5.8 infections per 1,000 device-days of use during 1986–1990 to 4.7 during 1995–2003).

There was little change in the rate of hospital-acquired pneumonia associated with use of ventilators (4.7 infections per 1,000 device-days of use during 1986–1990 vs. 4.9 during 1995–2001). Compared to general medical and surgical ICUs, pediatric ICUs had a higher rate of bloodstream infections and lower rates of urinary tract infections and pneumonias (data not shown).

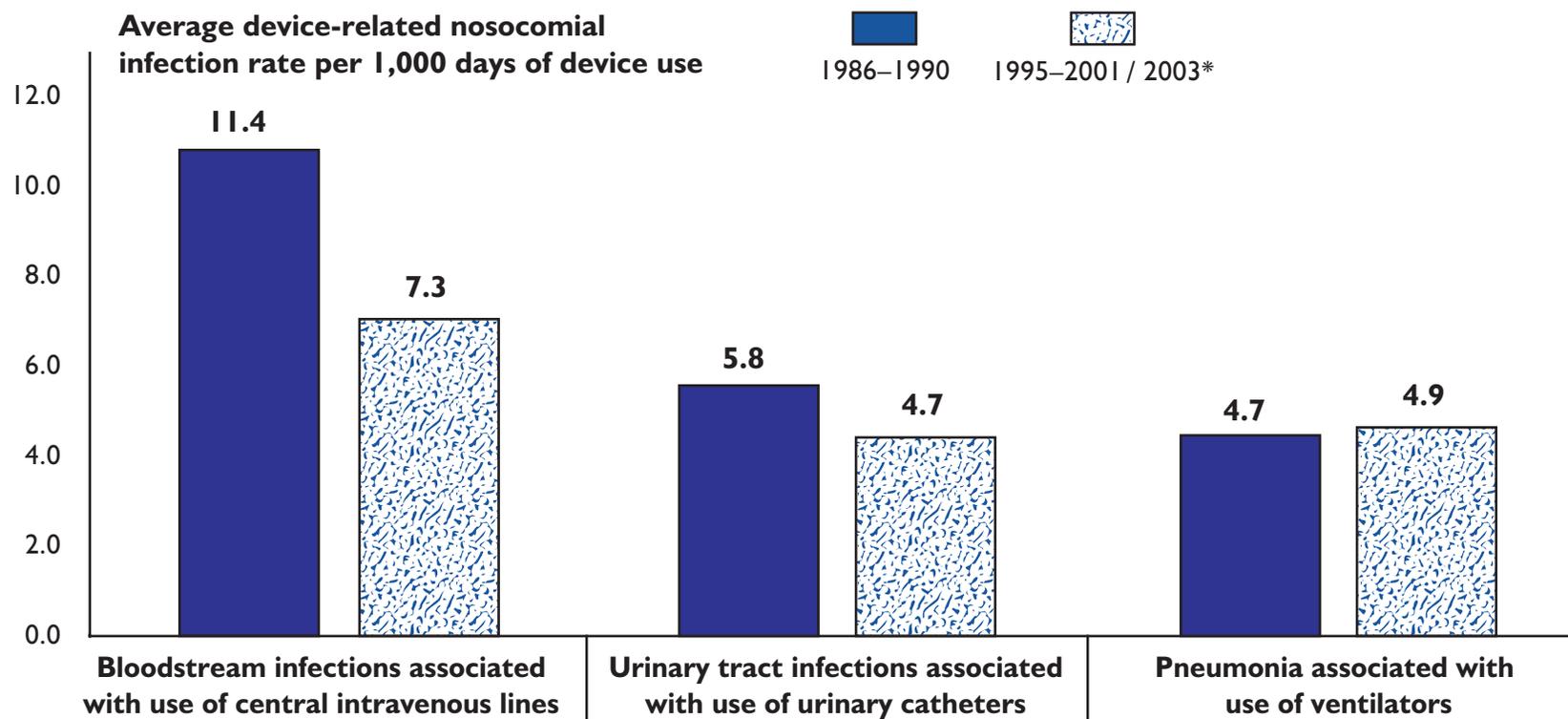
Source: National Center for Infectious Diseases, National Nosocomial Infections Surveillance System, as reported by NCHS (2001) and NCID (2001; 2003). Data may not be representative of all U.S. hospitals.

**Implications:** Hospital-acquired infections can be substantially reduced through ongoing monitoring and appropriate infection control measures (Rowin et al. 2003). Proper hand hygiene is perhaps the most important measure but is often not observed (Elward and McGann 2002). Differences between children and adults in factors such as immune system maturity, site and types of infections, process of care, and patient interactions mean that a child-specific approach often is necessary (Harris 1997).

Collaborative quality improvement initiatives such as the Pediatric Prevention Network, sponsored by the National Association of Children's Hospitals and Related Institutions (NACHRI) with support from the CDC, are studying pediatric hospital-acquired infections so as to identify and validate interventions to reduce their occurrence (Levine 2001). *See Chart 6:9 for a collaborative project that reduced hospital-acquired infections in neonatal intensive care units.*

# Hospital-Acquired Infections in Pediatric Intensive Care Units

*Hospitals participating in a national surveillance system have reduced the rates of two types of infections acquired by patients in pediatric intensive care units.*



Source: National Center for Infectious Diseases, National Nosocomial Infections Surveillance System (N=75 to 79 hospitals), as reported by NCHS (2001) and NCID (2001; 2003). May not be representative of all U.S. hospitals.

\*January 1995 to June 2003, except ventilator-associated pneumonia rate is for January 1995 to June 2001 (see technical appendix).



## ACCESS AND TIMELINESS — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 3:1

## Parent Perceptions of Accessibility and Timeliness of Care

**Why is this important?** Parents and other caregivers—especially mothers—typically act as intermediaries in health care for children, at least until the adolescent years. Parents' perceptions of the accessibility and interpersonal quality of care may affect their care-seeking behavior, such as whether to use routine primary care or visit the emergency room (Forrest and Starfield 1998; Doobinin et al. 2003), and decisions related to selecting or changing physicians and health plans (Kasteler et al. 1976; Hickson et al. 1988; Guadagnoli et al. 2000). Greater accessibility of primary care is associated with better health outcomes (Starfield 1985; Shi et al. 2002).

**Findings:** According to parents of U.S. children and adolescents (ages birth to 17 years) surveyed in 2000:

- One of eight (12%) children who had a doctor or clinic visit in the past year had *problems receiving care* that the doctor or parent thought was necessary.
- One of five (22%) children had *problems getting a referral* to a specialist in the past year when the doctor or parent thought the child needed to see a specialist.
- One of three (36%) children who needed care right away for an illness or injury in the past year *did not always get that care as soon as the parent wanted*.
- One of two (48%) children who had an appointment for routine care in the past year *did not always receive an appointment as soon as the parent wanted*.

Children and adolescents without insurance or covered only by public insurance (such as Medicaid or State Children's Health Insurance Programs) were more likely than those with any private

insurance to have a parent report gaps in access to and timeliness of care (data not shown).

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey (AHRQ 2002b).

**Implications:** Improvements are needed to better meet parent expectations for timely and convenient access to care for children and adolescents. Poorer ratings by parents of children without insurance or with public coverage may reflect numerous barriers such as concern about out-of-pocket costs, lack of geographically accessible providers, and language differences (*see Chart 5:6*).

Extending health insurance to the uninsured is the most important step to improving equitable access to health care (Hargraves and Hadley 2003). The President's Advisory Commission on Consumer Protection and Quality in Health Care (1997) recommended that children with chronic conditions who need frequent specialty care should be allowed direct access to specialists. Other interventions that experts (Berry et al. 2003) have proposed to improve accessibility and timeliness of care include:

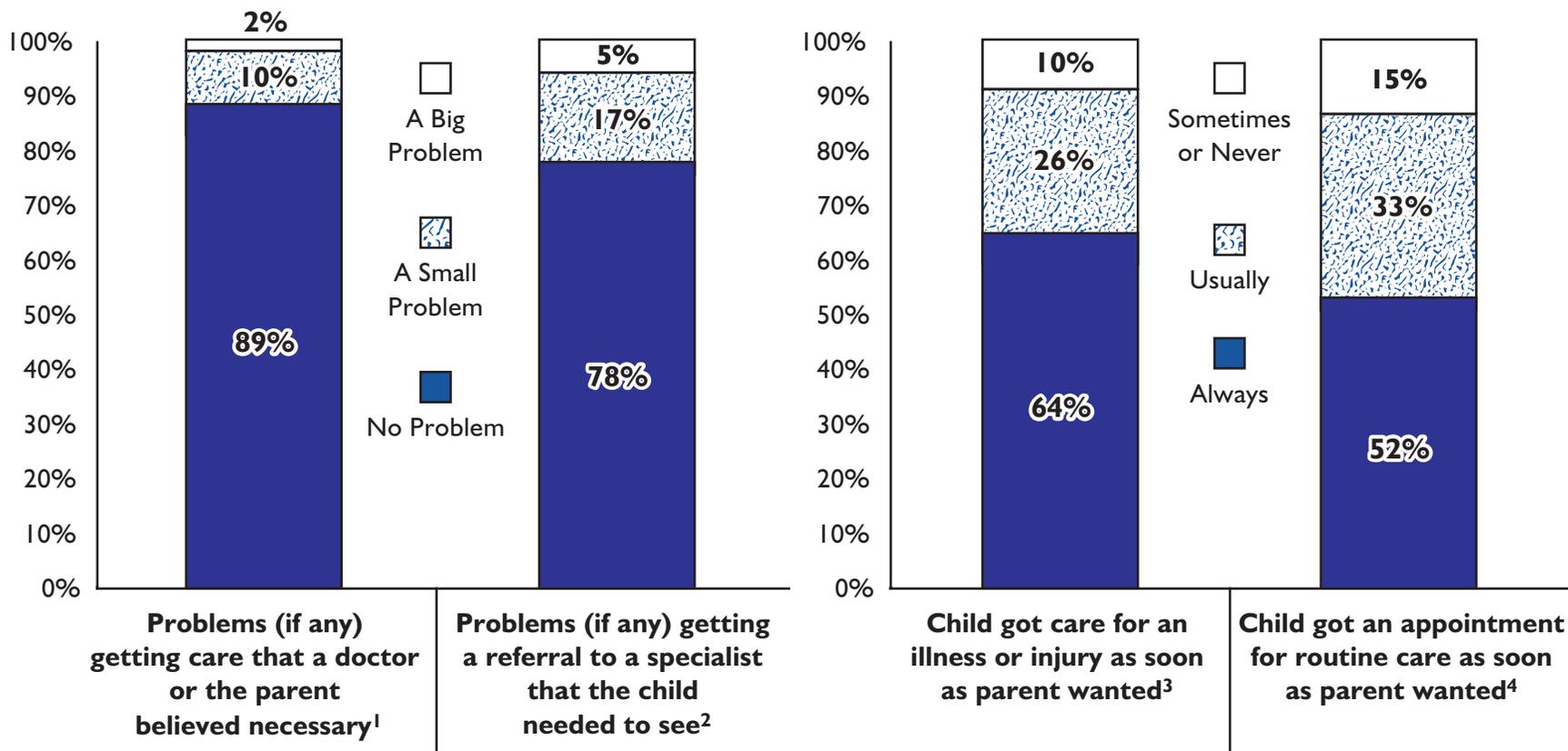
- making appointment scheduling systems more flexible,
- increasing the use of mid-level practitioners such as physician assistants and nurse practitioners,
- offering group appointments with team care,
- scheduling telephone consultations or using electronic communications (with appropriate reimbursement) to supplement face-to-face care, and
- extending after-hours (evening and weekend) care.

# Parent Perceptions of Accessibility and Timeliness of Care

In 2000, parents reported that up to one of five children and adolescents (12% to 22%) had problems getting needed care

and up to half (36% to 48%) did not always get care as quickly as desired.

## U.S. children and adolescents (ages 0-17 years) in 2000



Source: Agency for Healthcare Research and Quality, 2000 Medical Expenditure Panel Survey, Parent-Administered Questionnaire (N=6,577) as reported by AHRQ (2002b). Percentages may not add to 100 because of rounding.

Notes:  
 1. among those who had a doctor or clinic visit in the past year  
 2. among those whose doctor or parent thought they needed to see a specialist in the past year  
 3. among those who had an illness or injury that needed care right away in the past year  
 4. among those who had an appointment for routine care in the past year.



## ACCESS AND TIMELINESS / DISPARITIES — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 3:2

## Regular Source and Unmet Needs for Care

**Why is this important?** Twelve percent of U.S. children and adolescents—8.5 million—did not have any public or private health insurance during the year in 2002 (Mills and Bhandari 2003). Twenty-two percent of U.S. children and adolescents live in poverty or near poverty (up to 125 percent of poverty) (Proctor and Dalaker 2003). Although Medicaid expansions and the State Children’s Health Insurance Program (SCHIP) have covered millions more children and adolescents in recent years, one of five who live in poverty or near poverty remain uninsured. Three-quarters of uninsured children are eligible for Medicaid or SCHIP but remain unenrolled because of lack of parental knowledge or interest or burdensome enrollment procedures (Holahan et al. 2003).

The most important benefit of insurance is to facilitate having a regular source of care (Starfield 2000). Children without a usual source of care are more likely to have unmet needs for care (Newacheck et al. 2000a), more hospitalizations, and higher costs of care, and they are less likely to keep doctor appointments and receive preventive care (Starfield 1998). The extent to which children’s regular source of care is oriented toward primary care greatly determines the benefit that children derive from that care (Starfield 2000).

**Findings:** In 2000, U.S. children and adolescents (ages birth to 17 years) without insurance were much more likely than those with insurance to lack a regular source for care and to have unmet needs for health and dental care, as perceived by parents. Among the uninsured, more than one of four (27%) did not have a

regular source of health care, one of six (16%) delayed care because of cost, one of eight (13%) did not get needed health care because of cost, and one of five (19%) did not get needed dental care because of cost.

Source: National Center for Health Statistics, National Health Interview Survey, as reported by Blackwell et al. (2003).

**Implications:** An estimated 7.3 million U.S. children and adolescents have unmet health and dental care needs, as perceived by parents, or delayed care because of cost (Simpson et al. 1997). Unmet needs may have long-term effects on health and developmental outcomes (IOM 1998; Hadley 2003).

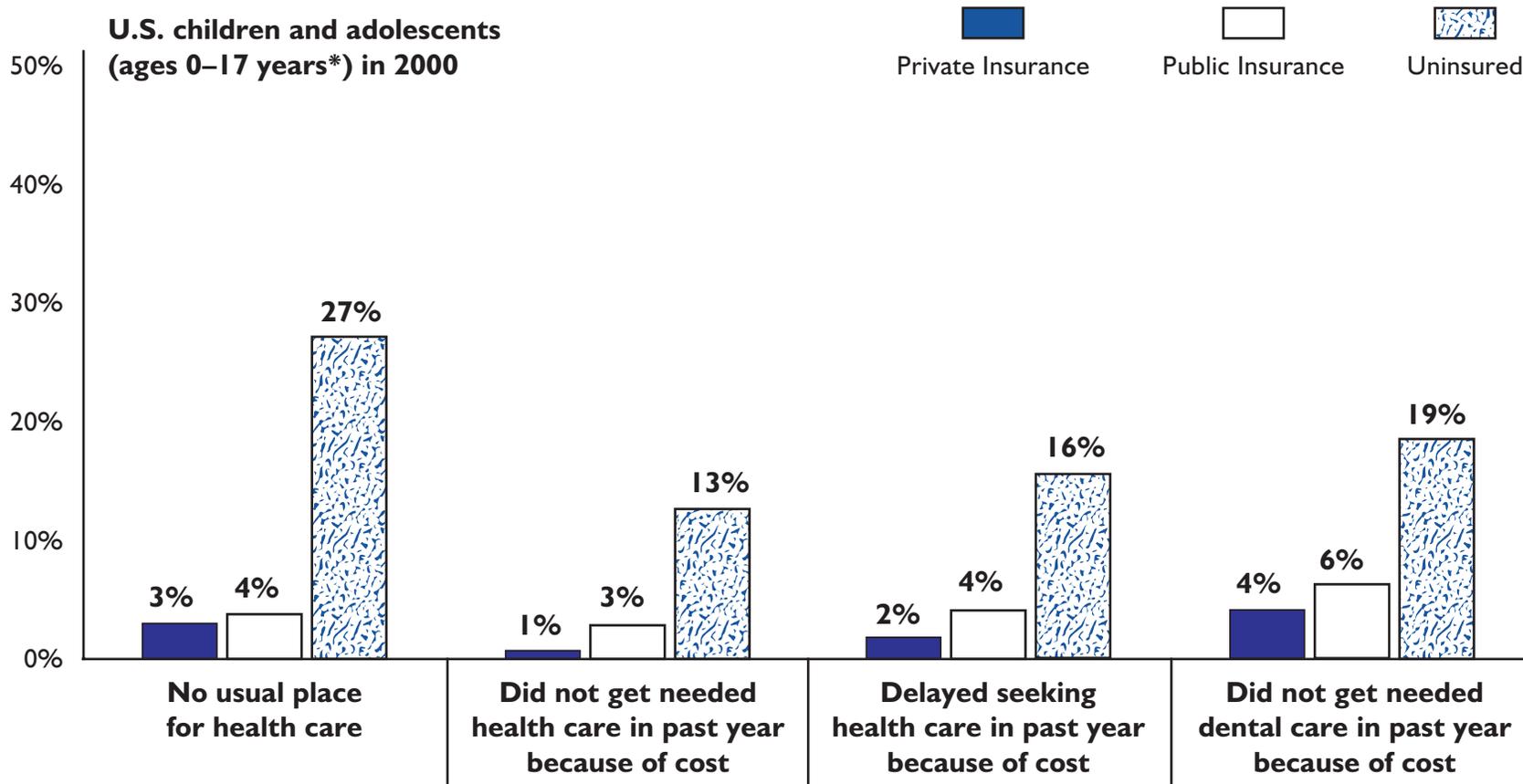
More effort and funding is needed to expand health insurance coverage for children and adolescents (Lewit et al. 2003), enroll those who are already eligible for Medicaid and SCHIP (such as through outreach and simplified enrollment and renewal procedures) (Ross and Hill 2003), and strengthen safety net providers such as community and migrant health centers that can help reduce disparities in access for those in underserved areas (Politzer et al. 2001).

Formerly uninsured children who gain coverage are more likely to have a usual source of care, fewer unmet needs for care, increased use of preventive care, and improved health status (Lave et al. 1998; Holl et al. 2000; Slifkin et al. 2002).

## Regular Source and Unmet Needs for Care

*In 2000, children without insurance were much more likely than those with private or public insurance to lack a regular*

*source of health care and to have unmet needs for health and dental care, as perceived by parents.*



Source: National Center for Health Statistics, 2000 National Health Interview Survey (N=13,376), as reported by Blackwell et al. (2003). \*Ages 2–17 years for dental care. “Other insurance” category omitted for clarity.



## ACCESS AND TIMELINESS / DISPARITIES — MULTI-PERSPECTIVE — MIDDLE CHILDHOOD AND ADOLESCENCE — CHART 3:3

## Unmet Need for Mental Health Care

**Why is this important?** One of five children and adolescents experience mental health problems severe enough to need mental health evaluation in a given year (Kataoka et al. 2002) and one in 10 suffer a mental illness that causes some level of impairment (DHHS 1999). Medication and psychosocial therapies are efficacious for treating many mental health disorders in children and adolescents such as attention-deficit/hyperactivity disorder, depression, and disruptive disorders. Identifying children at risk of developing psychosocial problems arising from factors such as parental depression, maltreatment, or other family dysfunction is important, because early intervention may prevent lifelong problems (DHHS 1999).

**Findings:** Among children and adolescents (ages 6 to 17 years) with mental health problems severe enough to indicate a clinical need for mental health evaluation, four of five (79%) did not receive a mental health evaluation or treatment in the past year, according to parent report in 1997. Children and adolescents of Hispanic ethnicity were more likely than white children and adolescents to have an unmet need for mental health care; children and adolescents covered by public insurance (such as Medicaid) were less likely to have an unmet need than those without health insurance.

Source: Urban Institute/Child Trends, 1997 National Survey of America's Families, as reported by Kataoka et al. (2002).

**Implications:** This data suggests that about 7.5 million U.S. children and adolescents have an unmet need for mental health services (Kataoka et al. 2002). Other research has found that the rate of mental health care services provided to children varies among

states but not in proportion to need (Sturm et al. 2003). Social consequences of this unmet need include lost opportunities to prevent suicide, poor academic performance, substance abuse, and future unemployment (DHHS 1999).

In a survey of pediatricians regarding depression in children, most agreed that it is their responsibility to recognize depression, but nearly half reported a lack of confidence in their ability to do so (Olson et al. 2001). Assessment tools are recommended to help primary care clinicians screen for mental health disorders in adults, but their effectiveness has not yet been established for children (USPSTF 2002) and they remain infrequently used at pediatric visits (Gardner et al. 2003).

Potential solutions recommended by experts (DHHS 1999; Wells et al. 2001; Farmer et al. 2003; Gilbody et al. 2003) include:

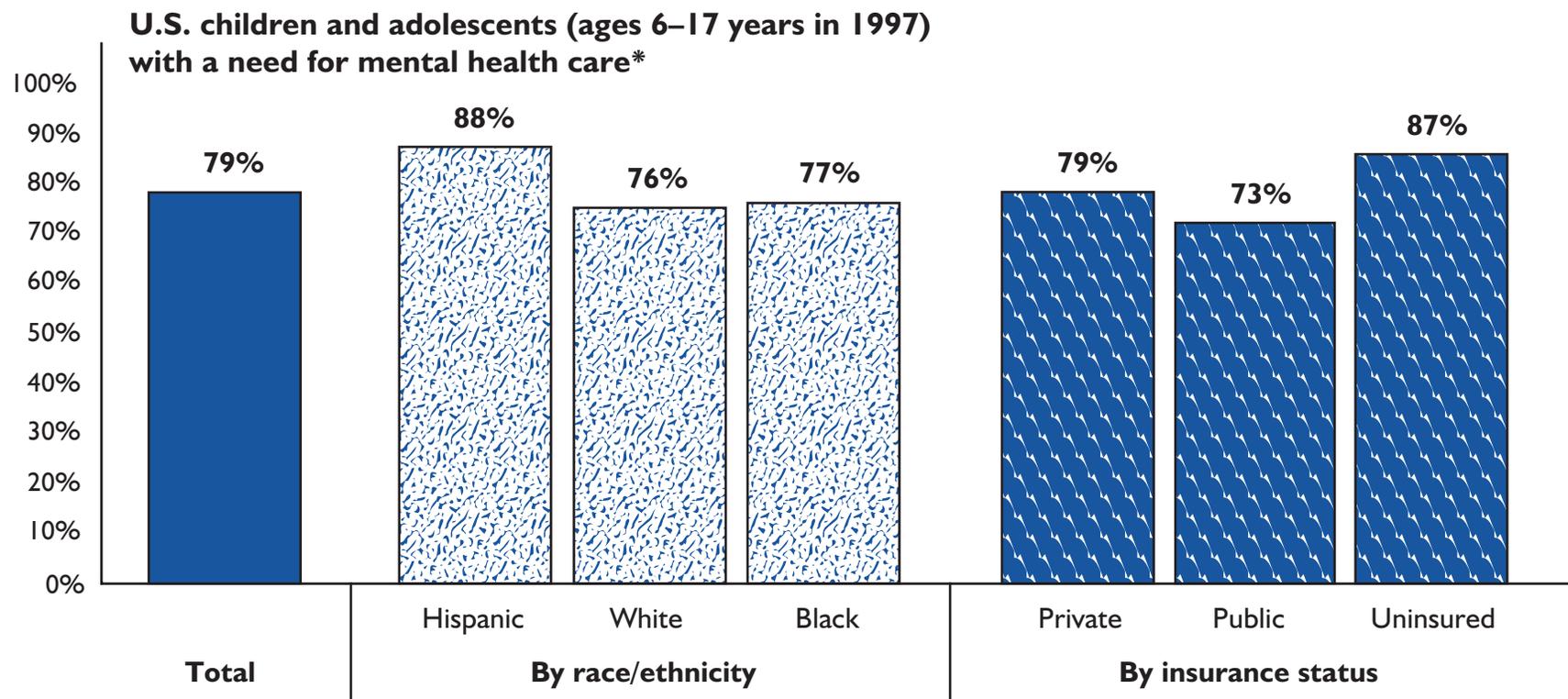
- improving coverage for mental health care services;
- coordinating resources among different sectors, programs, and systems of care;
- implementing systematic quality improvement interventions that include physician education, nurse case management, and enhanced linkages between primary care clinicians, schools, and mental health specialists; and
- increasing the availability of culturally competent care for ethnic minorities.

In a study at one school-based health center, screening adolescents for psychosocial problems resulted in decreased rates of school absence and tardiness among those who were referred for free mental health services (Gall et al. 2000).

# Unmet Need for Mental Health Care

Among children and adolescents with mental health problems severe enough to indicate a clinical need for mental health evaluation, four of five had not received any mental health

services during the past year, according to parent report in 1997. Children of Hispanic ethnicity and those without insurance were more likely to have an unmet need for care.



**Did not receive any mental health care services in the past year**

Source: Urban Institute/Child Trends, 1997 National Survey of America's Families (N=21,824), as reported by Kataoka et al. (2002). \*Need for mental health care was defined by researchers based on parent-reported child behavior (see technical appendix for methodology).



## ACCESS AND TIMELINESS / DISPARITIES — STAYING HEALTHY — EARLY CHILDHOOD TO ADOLESCENCE — CHART 3:4

## Time Since Last Dental Visit

**Why is this important?** Dental caries (tooth decay) is the most common childhood chronic disease—five times more prevalent than asthma. Yet, tooth decay is largely preventable with good oral hygiene, diet, and fluoride for parent and child. Once tooth decay occurs it does not improve without treatment. Left untreated, it can lead to abscesses and infections, pain, dysfunction, and low weight (NIDCR 2000).

The American Academy of Pediatrics and the American Academy of Pediatric Dentistry recommend that children have an early assessment to identify those at high risk for tooth decay and that all children establish a relationship with a regular dental provider by age one year (AAPD 2002; AAP 2003). The American Academy of Pediatric Dentistry and the federal Maternal and Child Health Bureau's *Bright Futures* initiative recommend two dental visits annually starting at age one year to provide education and services to prevent tooth decay, although a single annual dental visit may be a more customary practice (Yu et al. 2002).

**Findings:** Among U.S. children and adolescents (ages 2 to 17 years), more than one of four (26%) did not receive dental care in the past year and one in seven (15%) did not receive any dental care in the past five years, according to parent report in 2000. Minority children, children in families with lower income, and those with public or no insurance are less likely to receive regular dental care than white, nonpoor, and privately insured children (respectively). For example, only one-half of uninsured children and three of five Hispanic children had a dental visit in the past year and about one-quarter did not have a dental visit in the past five years. Although about four of five white, nonpoor, and privately insured

children had a dental visit in the past year, one of eight did not have a dental visit in the past five years.

Source: National Center for Health Statistics, 2000 National Health Interview Survey, as reported by Blackwell et al. (2003). (Visits may have included both preventive visits and visits to treat a dental problem.)

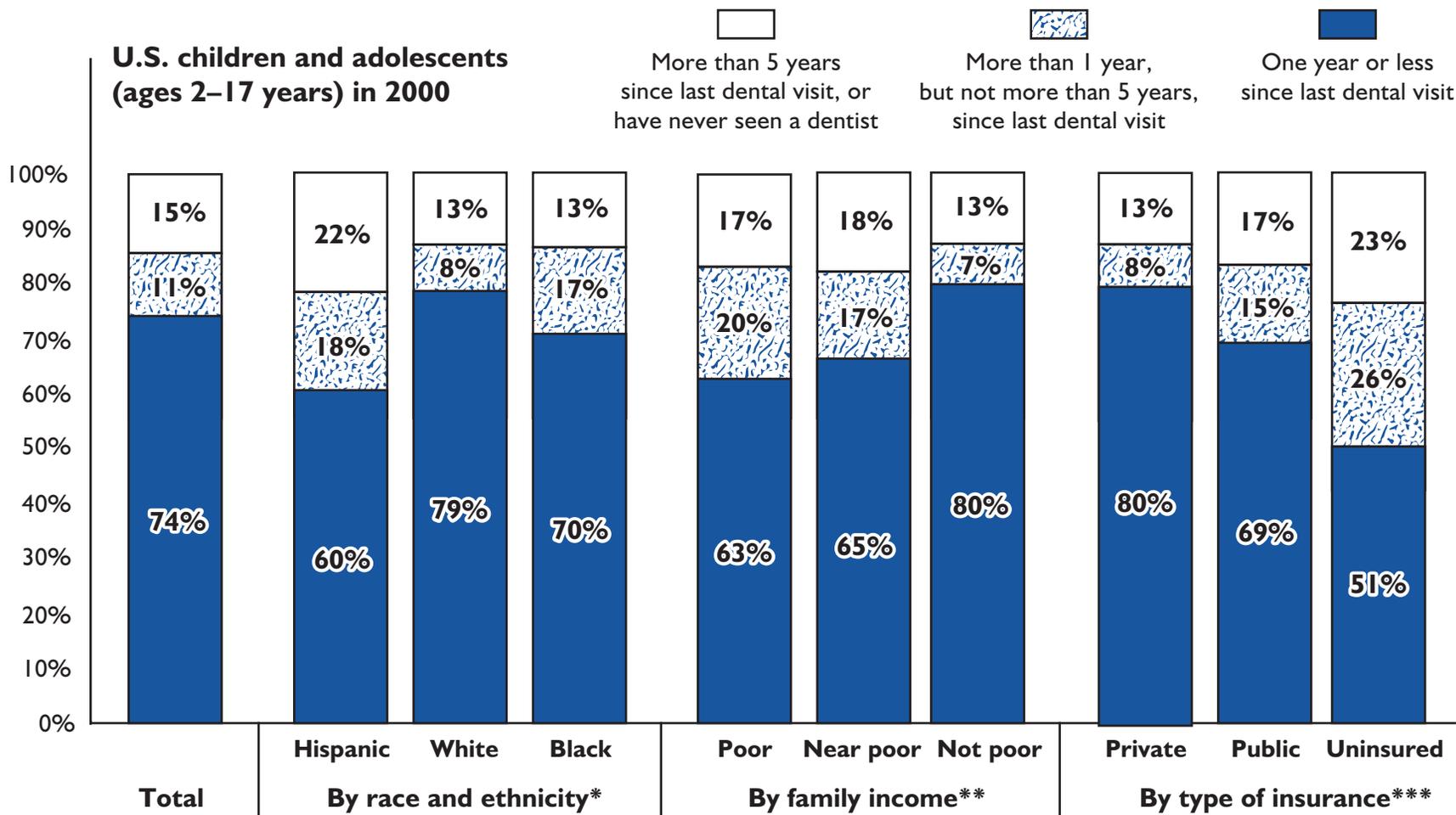
**Implications:** A substantial proportion of U.S. children do not receive regular dental care or any dental care, putting them at risk of serious tooth decay. One-third of children lacked any dental coverage in 1996 (Edelstein 2002). Those in low-income families are more likely to have dental coverage through enrollment in Medicaid and State Children's Health Insurance Programs (SCHIP). Yet, Medicaid-insured children are less likely to make preventive dental visits and more likely to have tooth decay (Colmers et al. 1999).

Medicaid spends just one-tenth of the national per capita average on dental services for children (Colmers et al. 1999). Few dentists participate in Medicaid because of low reimbursement and perceived administrative hassles (GAO 2000). Some Medicaid and SCHIP programs are increasing the participation of dentists through higher reimbursement and simplified administration, and improving availability and use of services through greater use of dental hygienists and outreach to beneficiaries (Almeida et al. 2001; Gehshan et al. 2001; Mofidi et al. 2002). Other barriers to care that need to be addressed for low-income families include lack of transportation and inability to get time off from work to take a child to the dentist (GAO 2000).

# Time Since Last Dental Visit

One of four children and adolescents (26%) did not receive dental care in the past year, and one of seven (15%) did not receive any in the past five years, according to parents in

2000. Minority children, children in families with lower income, and children with public insurance or without insurance are less likely to receive regular dental care.



Source: National Center for Health Statistics, 2000 National Health Interview Survey (N=13,376), as reported by Blackwell et al. (2003). Percentages may not add to 100 because of rounding. \*White and black race are non-Hispanic ethnicity. \*\*For family income, poor

means below the federal poverty level, near poor means 100 percent to less than 200 percent of the poverty level, and not poor means 200 percent of the poverty level or greater. \*\*\*Other insurance category omitted for clarity.



## ACCESS AND TIMELINESS — STAYING HEALTHY — PRENATAL DEVELOPMENT — CHART 3:5

## Timely Initiation of Prenatal Care

**Why is this important?** The American College of Obstetricians and Gynecologists recommends that women initiate prenatal care in the first three months of their pregnancy. Early initiation of prenatal care can be beneficial through early identification of risk factors and provision of preventive advice to encourage healthy lifestyle, treatment of conditions such as diabetes and high blood pressure, and referrals to services such as nutrition and smoking cessation programs (Alexander and Korenbrot 1995; McCormick and Siegel 2001). Prenatal care helps improve maternal health and survival and may contribute to improved infant survival by linking women with high-risk pregnancies to better obstetrical and neonatal care (Bronstein et al. 1995; McCormick and Siegel 2001; Vintzileos et al. 2002). Mothers who obtain adequate prenatal care appear to establish positive care-seeking behavior that makes them more likely to obtain preventive care for their infants (Kogan et al. 1998).

**Findings:** Among mothers of babies born live in the United States in 2001, one of six (17%) did not start prenatal care in the first trimester of her pregnancy—an improvement compared to 1990, when one of four (24%) mothers did not begin prenatal care early.

In 2001, state-specific rates of early entry into prenatal care ranged from 69 percent in New Mexico to 91 percent in Rhode Island. Only three states achieved the national Healthy People 2010 goal of 90 percent.

Source: National Center for Health Statistics, U.S. birth certificate data, as reported by Martin et al. (2002).

**Implications:** Access to prenatal care improved during the past decade as a result of expansions in Medicaid coverage for low-income pregnant women (Howell 2001). Yet, the women most likely to benefit from early and adequate prenatal care because of their higher risk of poor birth outcomes—teens, blacks, and those who are unmarried and have less education—remain less likely to receive it (Alexander et al. 2002). Moreover, some women do not receive all the content of prenatal care recommended by experts (Petersen et al. 2001) and these women are more likely to have worse birth outcomes (Kogan et al. 1994).

Half of women who started prenatal care late said they would have liked to start care earlier, but many didn't know that they were pregnant (CDC 2000). Commonly cited barriers to prenatal care include not being able to afford it, lack of transportation and child care, not being able to get an appointment, and negative attitudes toward health professionals or health care in general (Alexander and Korenbrot 1995; Sanders-Phillips and Davis 1998; CDC 2000).

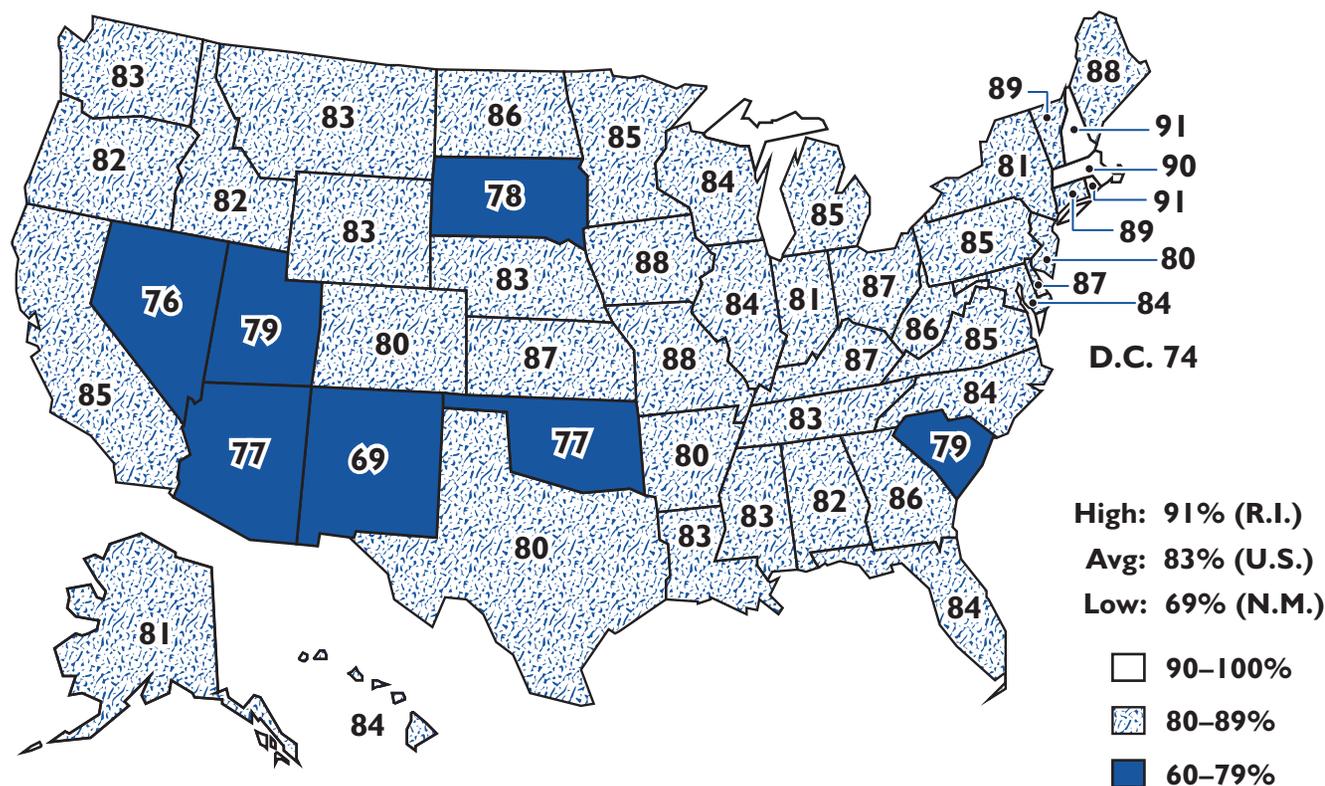
Despite increased access to prenatal care, rates of premature and low birthweight births have worsened during the past decade (Martin et al. 2002). This trend may be caused by multiple factors that adversely affect the health and well-being of disadvantaged women throughout their life-course (Lu and Halfon 2003). Further increases in prenatal care may have limited impact on birth outcomes unless effective medical and psychosocial interventions can be established and provided to those at need, both before and during pregnancy (Shiono and Behrman 1995; Alexander and Kotelchuck 2001).

# Timely Initiation of Prenatal Care

Five of six mothers (83%) began prenatal care in their first three months of pregnancy in 2001, up from three-quarters

(76%) in 1990. Rates varied among the states, and only three states met the national goal of 90 percent in 2001.

**Percentage of infants born live in 2001 whose mother began prenatal care in the first trimester of pregnancy**



Source: National Center for Health Statistics, 2001 U.S. birth certificate data, as reported by Martin et al. (2002).



ACCESS AND TIMELINESS / PATIENT AND FAMILY CENTEREDNESS — LIVING WITH ILLNESS —  
EARLY CHILDHOOD TO ADOLESCENCE — CHARTS 3:6 AND 3:7

## Progress Toward Implementing National Goals for Community-Based Systems of Services for Children with Special Health Care Needs

**Why is this important?** Children with special health care needs (CSHCN) are defined as those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998).

About 13 percent of U.S. children and adolescents have *existing* conditions that meet this definition (Blumberg 2003).<sup>\*</sup> These children are more likely than other children to be hospitalized, restricted to bed, and absent from school (Newacheck et al. 1998). Access to high-quality health care is important for these vulnerable children to catch health problems early, keep health problems from worsening, limit their adverse impact, and maintain and restore normal functioning to the degree possible.

The federal Maternal and Child Health Bureau has identified six outcome goals for community-based systems of services for CSHCN nationally and at the state level. These goals have been endorsed by over 70 professional and voluntary organizations (MCHB 2003).

**Findings:** During 2001, parents reported that about one-quarter to one-half (26% to 47%) of CSHCN (ages birth to 17 years) lacked adequate access to or failed to receive the kind of well-organized, continuous, coordinated, comprehensive, and family-centered care that experts believe is essential to promote their well-being. Most teens (ages 13–17 years) with special health care needs did not receive all the services recommended to support their

transition to adulthood. (See Chart 3:7 for performance on the specific components by which these goals were measured.)

Source: National Center for Health Statistics, National Survey of Children with Special Health Care Needs, as reported by the CDC (2003d).

**Implications:** There is substantial room for improvement in serving CSHCN, and especially for teens as they transition to adulthood. Other research has found that CSHCN have more unmet health care needs and are less satisfied with their usual source of health care than other children, even though they are more likely to have insurance coverage and a regular care provider (Newacheck et al. 1998; Silver and Stein 2001).

Improving community systems of care for these children requires collaborative effort among health professionals, families, health plans, and government and nongovernmental organizations (McPherson et al. 1998). Although the children represented in this data have greatest current needs for care, all children can benefit from the kind of community-based care described in the goals shown on these charts.

---

<sup>\*</sup> The National Survey of Children with Special Health Care Needs included nearly all children and adolescents with existing complex health conditions such as autism, cerebral palsy, cystic fibrosis, developmental delay, diabetes, Down syndrome, mental retardation, muscular dystrophy, rare metabolic and genetic disorders, sickle cell disease, and other rare disorders, as well as some children with more common conditions such as allergies, asthma, and ADHD who have a high need for services (Blumberg 2003). The survey did not include children at risk for developing special needs.

## Progress Toward Implementing National Goals for Community-Based Systems of Services for Children with Special Health Care Needs

Among six goals identified by the Maternal and Child Health Bureau to promote the health and well-being of children with special health care needs (CSHCN), four were achieved by

one-half to three-quarters of CSHCN, according to parent report in 2001. Very few teens received all the services needed to help them make a successful transition to adulthood.

**GOAL # 1: Families of CSHCN partner in decision-making and are satisfied with services\***



**GOAL #2: CSHCN receive coordinated, ongoing, comprehensive care in a medical home\***



**GOAL #3: CSHCN are adequately insured for services they need\***



**GOAL #4: All children are screened early and continuously for special health care needs**

(Data not yet available for this goal)

**GOAL #5: Services for CSHCN are organized so families can use them easily**



**GOAL #6: Teenage CSHCN receive services needed to support transition to adulthood\***



0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

**U.S. children with special health care needs in 2001\*\***

Source: National Center for Health Statistics, 2001 National Survey of Children with Special Health Care Needs (N=38,866 households), as reported by the CDC (2003d).

\*See Chart 3:7 for components of these goals. \*\*Ages 0–17 years for Goals #1–5 and ages 13–17 years for Goal #6.

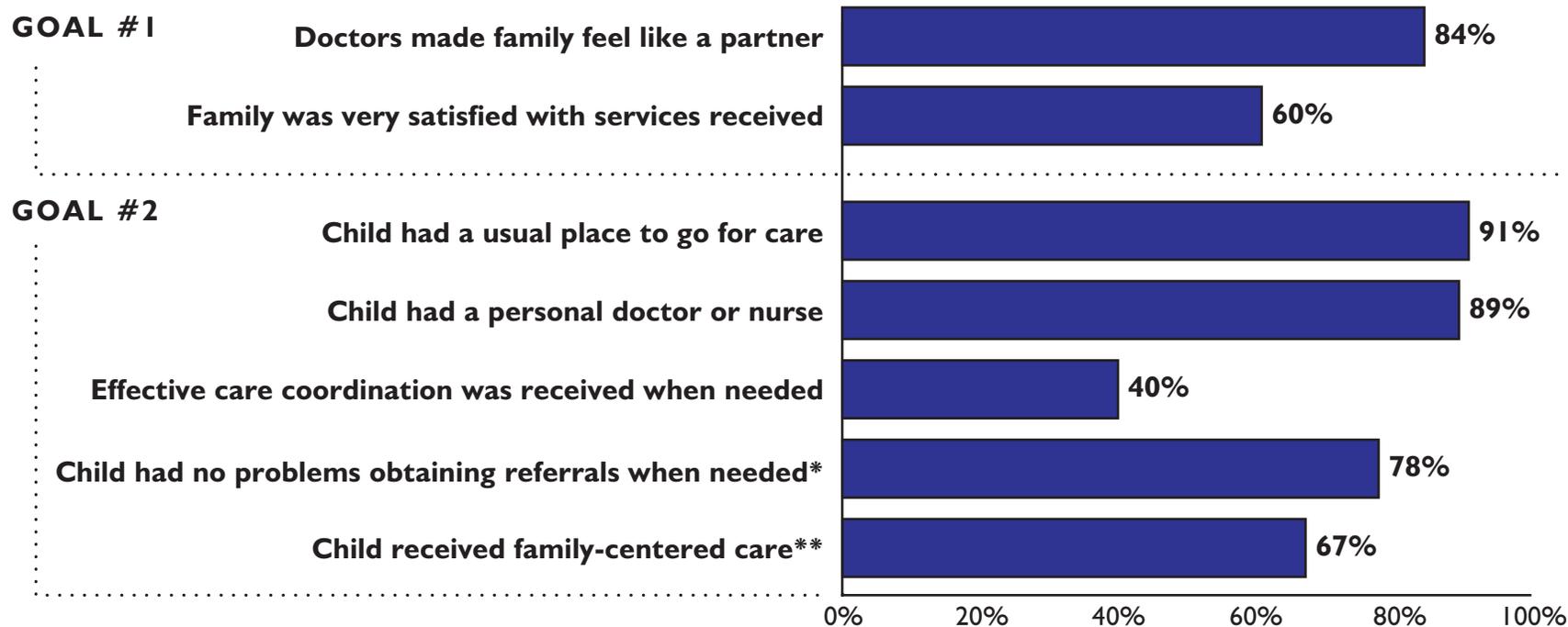


ACCESS AND TIMELINESS / PATIENT AND FAMILY CENTEREDNESS — LIVING WITH ILLNESS —  
EARLY CHILDHOOD TO ADOLESCENCE — CHART 3:7A

## Elements of Goals for Children with Special Health Care Needs

The Maternal and Child Health Bureau has identified six goals for community-based systems of services for children with special health care needs (CSHCN) nationally and at

the state level (see Chart 3:6). These charts show more detailed performance on the specific components of certain goals, based on a parent survey in 2001.



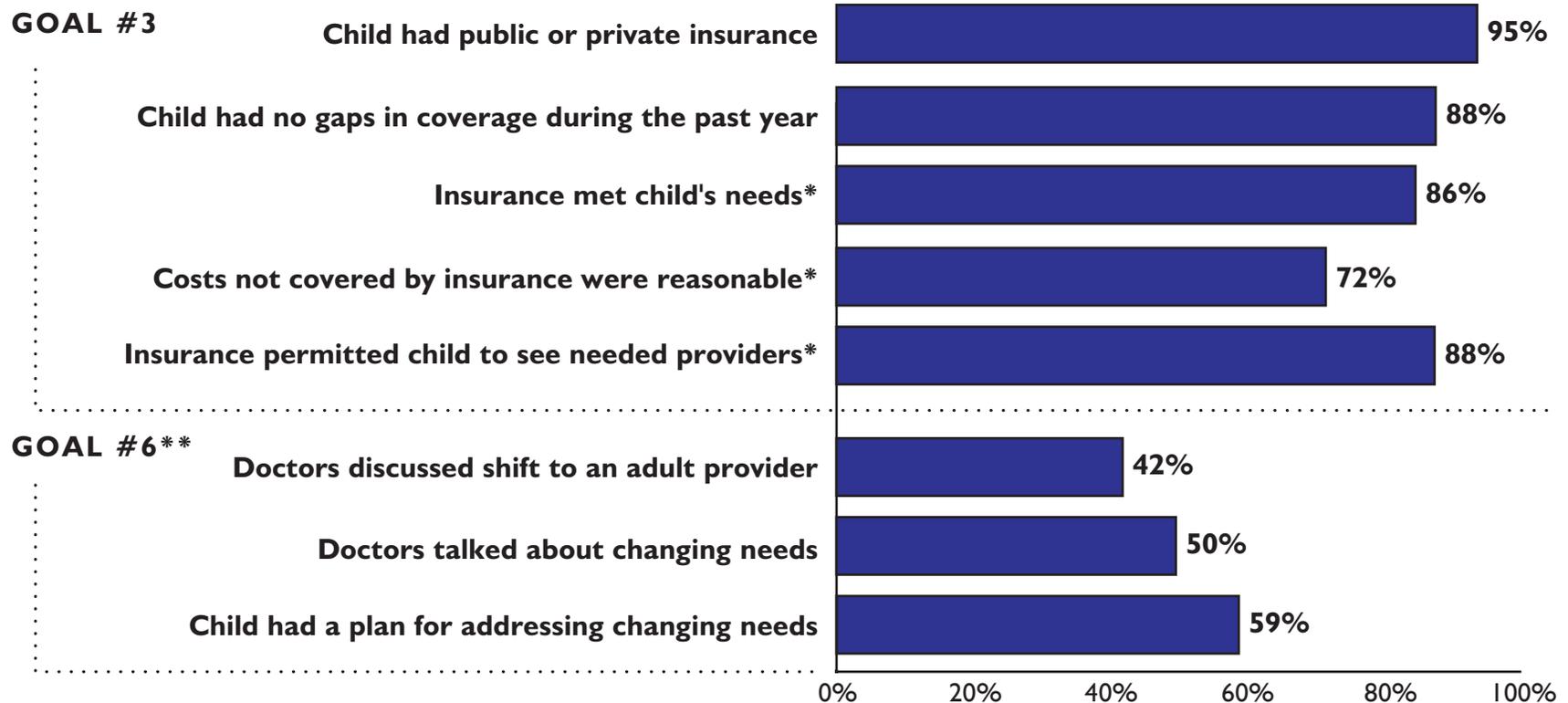
**U.S. children with special health care needs in 2001\*\*\***

Source: National Center for Health Statistics, 2001 National Survey of Children with Special Health Care Needs (N=38,866), as reported by the CDC (2003d). \*Among those who needed specialty care and a referral. \*\*Family-centered care means that the

doctor usually or always spent enough time, listened carefully, was sensitive to values and customs, provided needed information, and made the family feel like a partner. \*\*\*Ages 0–17 years for these goals.



## Elements of Goals for Children with Special Health Care Needs



U.S. children with special health care needs in 2001\*\*\*

Source: National Center for Health Statistics, 2001 National Survey of Children with Special Health Care Needs (N=38,866), as reported by the CDC (2003d). Goal #4 and Goal #5 do not have data components other than shown on Chart 3:6. \*Among those with insurance who answered "usually or always." \*\*Goal #6 includes a

measure of whether teens received vocational or career training, which is included in the overall performance shown on Chart 3:6 but is not shown here because performance is not under the control of the health care system. \*\*\*Ages 0–17 years for Goal #3 and ages 13–17 years for Goal #6.



ACCESS AND TIMELINESS / PATIENT AND FAMILY CENTEREDNESS — LIVING WITH ILLNESS — EARLY CHILDHOOD TO ADOLESCENCE — CHART 3:8

## Medical Home for Children with Special Health Care Needs: State Performance

**Why is this important?** The American Academy of Pediatrics recommends that all children and adolescents have a primary care professional (or a multidisciplinary team for children with severe chronic illnesses) whose practice serves as a “medical home,” to help ensure that health care and other needed services are accessible, continuous, comprehensive, family-centered, coordinated, culturally competent, and compassionate (AAP 2002a; 2002b). A medical home is especially important to children with special health care needs and their families, who often need help to access and integrate needed services from a complex web of providers and programs (Ziring et al. 1999; Krauss et al. 2001).

Research suggests that children who have good primary care have better outcomes (Starfield 1998). Children who have continuity with a regular practitioner are more likely to adhere to prescribed medication, receive preventive care and care that is well-coordinated, resource efficient, and family-centered, less likely to have ER visits and hospitalizations, and their physician is more likely to recognize problems and track information about the child (Starfield 1998; Christakis et al. 2000; 2001c; 2002; 2003). Some children seeing specialists as their regular source of care report unmet general and preventive care needs, indicating a need for coordination with primary care (Palfrey et al. 1980; Carroll et al. 1983).

**Findings:** Among the states during 2001, the proportion of children with special health care needs (ages birth to 17 years) who

received coordinated, ongoing comprehensive care in a medical home ranged from 41 percent in the District of Columbia to 61 percent in Massachusetts. (*The components of the medical home measure are shown on Chart 3:7A.*)

Source: National Center for Health Statistics, National Survey of Children with Special Health Care Needs, as reported by the CDC (CDC 2003d).

**Implications:** Many CSHCN do not receive care that meets the elements of a medical home. Barriers that must be overcome to achieve the medical home for all children include lack of adequate reimbursement for coordination services, lack of available community services, and fragmentation among different programs, health plans, and providers serving these children (Regalado and Halfon 2002).

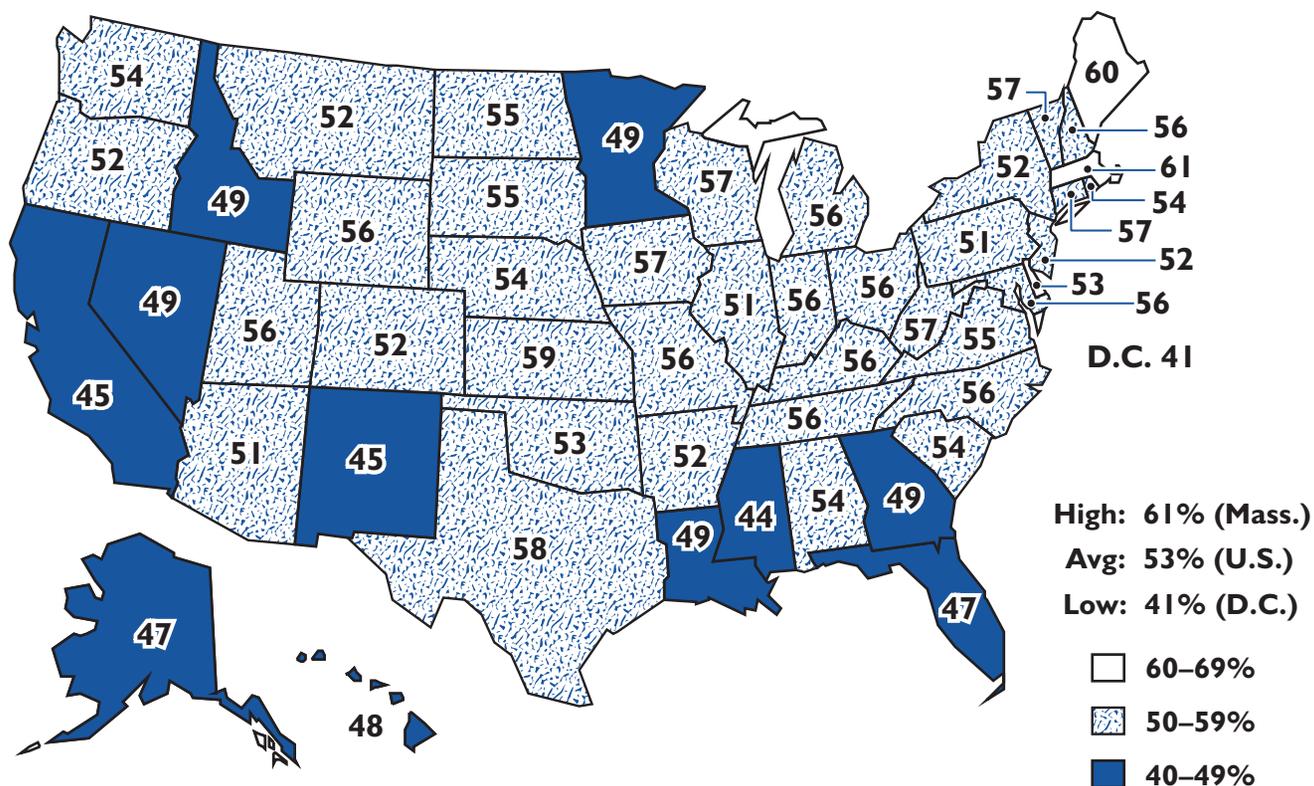
Some states are partnering with and providing resources to support health care providers and other community-based organizations to create integrated systems of care (Gillespie and Mollica 2003). Tools and resources are available to train and support physician practices in developing and improving their medical home for pediatric patients (Silva et al. 2000; CMHI 2003; NCMHI 2003). Improved coordination and coverage of services needed by children with chronic illnesses reduced hospitalizations and health care costs in one community (Liptak et al. 1998). Electronic records may help improve coordination and information tracking among different health care providers (Starfield et al. 1977).

## Medical Home for Children with Special Health Care Needs

Among children who have a chronic physical, developmental, behavioral, or emotional condition and who require health and related services beyond what is usual for

children generally, only one-half (53%) receive coordinated, ongoing, comprehensive, family-centered care from a health professional or team.

**Percentage of CSHCN (ages 0–17 years) who had an effective medical home, according to parent report in 2001**



Source: National Center for Health Statistics, 2001 National Survey of Children with Special Health Care Needs (N=38,866) as reported by the CDC (2003d). Components of this measure include: child had a usual source of care, child had a personal doctor

or nurse, effective care coordination was received when needed, child had no problems obtaining referrals when specialty care was needed, and child received family-centered care.



## PATIENT AND FAMILY CENTEREDNESS — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 4:1

## Parent Perceptions of Interpersonal Quality of Care

**Why is this important?** Parents have a substantial role in seeking and overseeing their child's health care. Parents' perceptions of interpersonal communication and time spent with health professionals are important indicators of patient and family centeredness and are closely tied to overall assessments of the quality of care (Gross et al. 1998; Homer et al. 1999; Darby 2002).

The quality of parents' communication with their child's health professional may affect parents' receptivity to receiving advice, how they oversee their child's compliance with treatment regimens, and satisfaction with and outcomes of care (Korsch et al. 1968; Francis et al. 1969; Stewart 1995). The amount of time that parents and pediatric patients have with clinicians may affect their ability to raise questions or address issues that fall outside the stated reason for a visit.

**Findings:** In 2000, among children and adolescents (ages birth to 17 years) who received health care in the past year:

- About one of three parents (32% to 35%) reported that the child's doctor or other health professional did not always communicate well (in terms of listening carefully, showing respect, and explaining things well).
- More than four of 10 parents (44%) reported that the doctor or other health professional did not always spend enough time with the parent and child.

Children and adolescents without insurance or covered only by public insurance (such as Medicaid) were more likely than those with any private insurance to have a parent report gaps in timely access to and quality of care.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey (AHRQ 2002b).

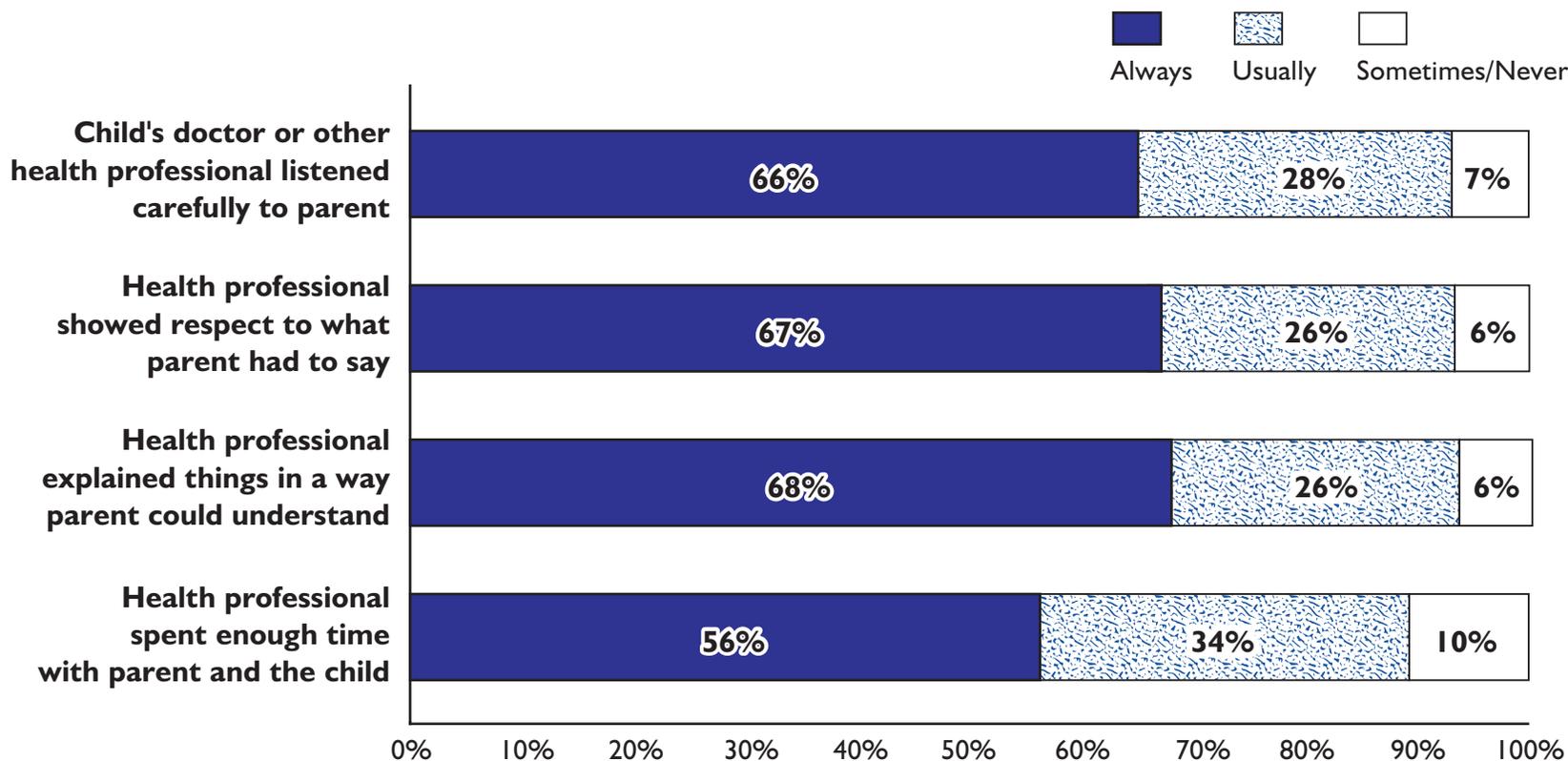
**Implications:** Improvements are needed to better meet parent expectations. Interpersonal deficits in care may account for some of the perception of inadequate time spent with the patient and parent (Gross et al. 1998). Greater attention also needs to be paid to the child's role in communications with health professionals (Tates and Meeuwesen 2001). Interventions that might address these gaps include:

- education and incentives for health professionals and their staff to help improve patient-centered communication skills (Lewin et al. 2001);
- formal or informal patient feedback to help professionals assess needs for improvement (O'Keefe 2001);
- culturally relevant questionnaires, written and audiovisual materials, and coaching in the waiting room to help prepare parents and children for effective health care encounters (Post et al. 2002; Ashton et al. 2003);
- interpreter services and teams of professionals that include at least one bilingual professional to overcome language barriers (Brach and Fraser 2000);
- use of mid-level practitioners (physician assistants and nurse practitioners) to increase time spent with patients during intake and follow-up care (Berry et al. 2003); and
- follow-up services such as telephone calls to determine how the child is doing post-care (Car and Sheikh 2003).

## Parent Perceptions of Interpersonal Quality of Care

*In 2000, just two-thirds of parents reported that their child's doctor or other health professional always communicated well*

*and little more than half reported that the doctor or health professional always spent enough time during the child's visit.*



**U.S. children and adolescents (ages 0–17 years in 2000) who received care in the past year**

Source: Agency for Healthcare Research and Quality, 2000 Medical Expenditure Panel Survey, Parent-Administered Questionnaire (N=6,577), as reported by AHRQ (2002b). Percentages may not add to 100 because of rounding.



## PATIENT AND FAMILY CENTEREDNESS — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 4:2

## Parent-Reported Problems with Hospital Care

**Why is this important?** Many hospitals are interested in learning about patients' experiences in an effort to promote patient-centered caregiving and to identify processes of care that they can take steps to improve. Hundreds of hospitals internationally use Picker Institute surveys to assess patients' impressions of specific aspects of hospital care, which are conceptually grouped into seven dimensions of quality (Cleary et al. 1991; Co et al. 2003). Example questions asked for the pediatric survey (several questions are asked in each of these dimensions) include:

- *Information to the child:* Was information discussed in a way that your child could understand?
- *Coordination of care:* Did one doctor or nurse say one thing and then another say something quite different?
- *Partnership in care:* How much did you participate in your child's care?
- *Information to parents:* When you had important questions to ask the doctors, did you get answers you could understand?
- *Confidence and trust:* Did you have confidence and trust in the doctors caring for your child?
- *Continuity and transition:* Did someone on the hospital staff tell you what you needed to know to care for your child at home?
- *Physical comfort:* Was the pain your child experienced more than you were told it would be?

**Findings:** Summing across 38 hospitals that used the Picker Institute Pediatric Inpatient Survey during 1997–1999 (primarily academic or teaching institutions), parents reported problems on 18 percent to 33 percent of the questions that they were asked within each of seven dimensions of patient-centered quality of care (multiple questions were asked within each dimension). Averaging across all seven dimensions, parents reported problems on more than one-quarter (27%) of the measures of hospital care for children who were treated for medical conditions (not surgical or intensive care) at these hospitals.

Source: Picker Institute Pediatric Inpatient Survey, as reported by Co et al. (2003). Results may not be representative of all hospitals.

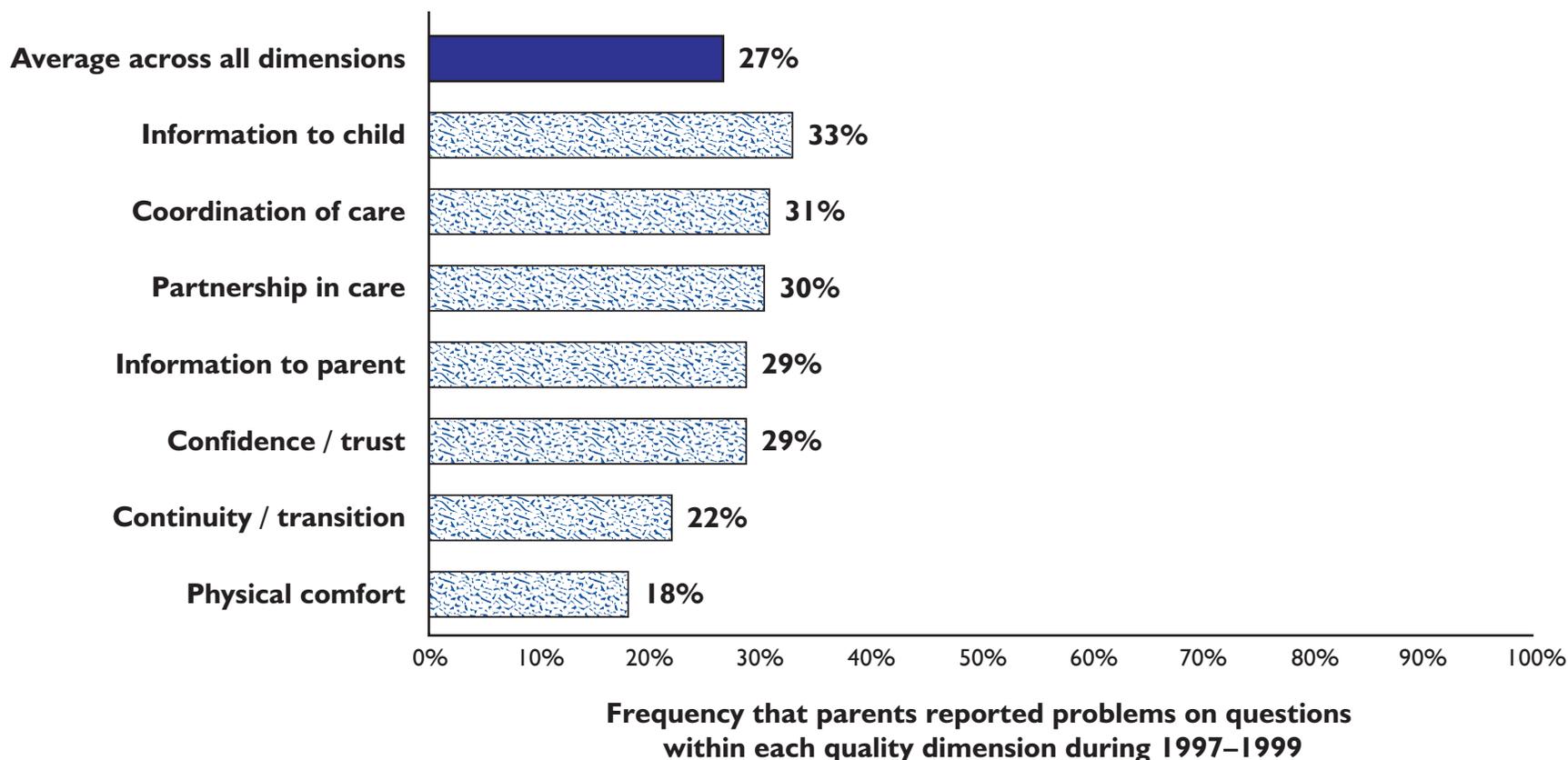
**Implications:** These data demonstrate the importance of asking specific questions to identify hospital care processes that warrant attention and improvement. Parents' overall rating of quality (not shown) correlated most strongly with being provided information and partnership in care, "indicating that parents view being kept informed and involved in the care of their child as the highest priority dimensions of patient-centered quality of care" (Co et al. 2003).

Compared to similar surveys measuring adults' perceptions of their own care in the hospital, parents reported relatively more problems for children in most dimensions, including coordination of care, information sharing, partnership in care (respect for patient preferences), and physical comfort. Adults reported more problems for continuity and transition (Coulter and Cleary 2001).

## Parent-Reported Problems with Hospital Care

Parents of children who were treated for medical problems at 38 hospitals during 1997–1999 reported problems on 18 percent to 33 percent of the questions that they were asked

about seven dimensions of quality. Averaging across all dimensions, parents reported problems on more than one-quarter (27%) of the survey measures of hospital care.



Source: 1997–1999 Picker Institute Pediatric Inpatient Survey (N=6,300 parents of children hospitalized for nonsurgical, non-intensive care unit medical conditions) as reported by Co et al. (2003). Results may not be representative of all U.S. hospitals.

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## PATIENT AND FAMILY CENTEREDNESS — STAYING HEALTHY — EARLY CHILDHOOD — CHART 4:3

## Supporting Family Well-Being: Preferences and Practices

**Why is this important?** Children's health and development depends heavily on family well-being (Schor 2003). Family stress or dysfunction from factors such as poverty, parental depression, and substance abuse in the home can disrupt parenting and put children at risk of developmental, behavioral, and emotional problems. On the other hand, parents who quit smoking not only avoid exposing their child to second-hand smoke but also reduce the likelihood that their child will take up smoking (Farkas et al. 1999).

To help children achieve better outcomes, the American Academy of Pediatrics' Task Force on the Family recommended that pediatricians "strengthen parental partnerships in different family types, screen for family circumstances that put children at risk, and help create family-friendly practice environments" (Schor 2003). Family-oriented care also is a core attribute of family practice as articulated by the American Academy of Family Physicians.

While most physicians say that they involve families in decision-making around children, family-oriented pediatric care goes further by addressing family issues that may affect the health and well-being of children—such as by providing brief counseling or referring a parent for treatment or services when appropriate (Schor 2003).

**Findings:** In a national survey in 2000, the majority (56% to 94%) of parents of young children (ages 4 to 35 months) agreed that their child's doctor or health professional should ask about six topics related to family well-being, including parents' health and

emotional support, violence in the community, difficulty providing for the child's needs, and substance abuse and tobacco use in the household. More than three-quarters (77%) of parents reported being asked whether a household member smoked tobacco. Less than half (10% to 44%) of parents reported that health professionals had discussed the other five topics with them. Parent emotional support and economic concerns were the topics exhibiting the greatest divergence between parent endorsement and actual discussion.

Source: National Center for Health Statistics, National Survey of Early Childhood Health, as reported by Halfon et al. (2002).

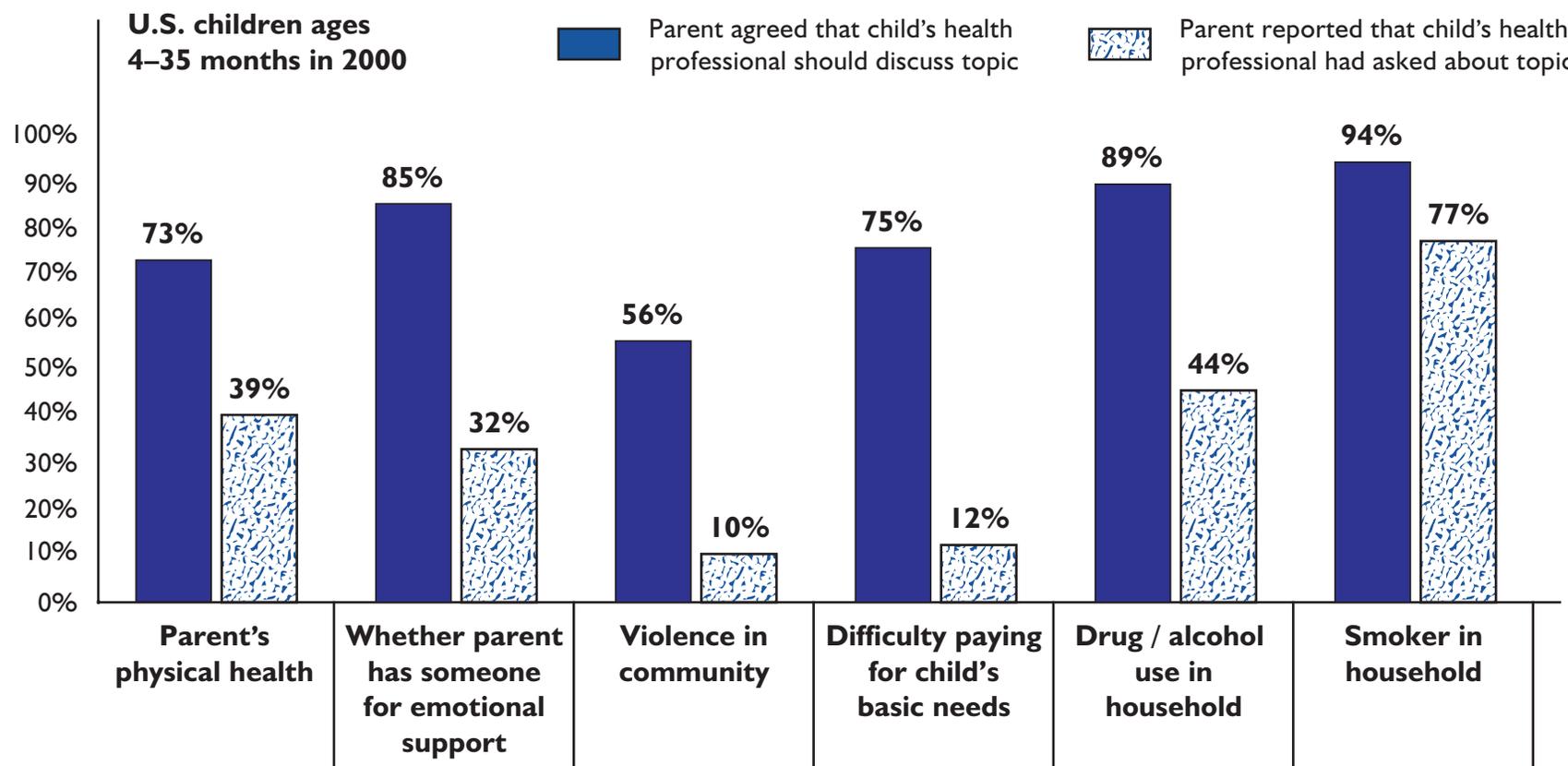
**Implications:** These data suggest that parents potentially agree with a family-oriented approach to pediatric care, but it may not yet be universally accepted in practice. In another study of primary care practices, two of three mothers of young children reported health behaviors or conditions (such as smoking or depression) that may affect children; most said that they "would welcome" or "would not mind" screening and referral for services at their child's visit (Kahn et al. 1999). Yet, a survey of pediatricians found that only one-third conduct family risk assessments (Minkovitz et al. 1998).

One study found that it is feasible to provide brief smoking cessation counseling and Nicotine Replacement Therapy for parents at pediatric visits along with referrals to primary care and follow-up telephone counseling (Winickoff et al. 2003). Greater knowledge is needed about other interventions to realize the goals of family-oriented care.

## Supporting Family Well-Being: Preferences and Practices

Most parents of young children want their child's health professional to ask about family well-being during pediatric visits. Although health professionals often asked about

smoking in the household, less than half (10% to 44%) of parents reported in 2000 that their child's health professional had asked about five other family well-being topics.



Source: National Center for Health Statistics, 2000 National Survey of Early Childhood Health (N=2,068), as reported by Halfon et al. (2002).



## DISPARITIES — STAYING HEALTHY — EARLY CHILDHOOD TO ADOLESCENCE — CHART 5:1

## Differences in Receipt of Recommended Preventive Health Care Visits by Type of Insurance, Race, Ethnicity, and Family Income

**Why is this important?** Without regular preventive health care visits for children and adolescents, immunizations may be delayed, health and developmental problems may go undetected, parents will not receive advice on child safety and childrearing, and adolescents will miss the opportunity for counseling to encourage healthy lifestyles and help prevent risky behaviors. Lack of preventive care is associated with more ER visits and avoidable hospitalizations among young children (Hakim and Bye 2001; Hakim and Ronsaville 2002).

**Findings:** Among children and adolescents (ages 3 to 17 years) in 1999, those with public insurance, minorities, and those with family income below poverty were more likely than those with private or no insurance, whites, and those with family income above poverty (respectively) to receive preventive health care (well-child) visits at recommended ages in the past year.\*

- One of three (32%) without insurance missed well-child visits, compared to one of four (24%) with private insurance and one of seven (15%) with public insurance.
- One of eight black children (12%) and one of five of Hispanic ethnicity (21%) or other race (22%) missed well-child visits, versus one of four white children (26%).
- One of six (17%) in families with income below the poverty level, versus one of four (24% to 26%) in families with income above poverty, missed preventive visits.

Source: Urban Institute/Child Trends, 1999 National Survey of America's Families, as reported by Yu et al. (2002).

**Implications:** The higher rate of preventive health care visits among minority and poor children probably reflects more comprehensive coverage of preventive care for low-income children enrolled in Medicaid and State Children's Health Insurance Programs (SCHIP). Federal standards for Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) require coverage of preventive health care visits in accordance with expert recommendations. Two-thirds of the states operate their SCHIP programs in whole or in part as a Medicaid expansion subject to the EPSDT requirements. Medicaid prohibits cost-sharing for categorically needy children and both Medicaid and SCHIP limit copayments for other children (Pernice et al. 2001).

Improving rates of preventive care for children requires expanding coverage for the uninsured and outreach to parents to encourage greater preventive care-seeking. Reducing patient out-of-pocket costs has been shown to increase immunization rates (Briss et al. 2000). Private sector purchasers and health plans should consider whether it would be cost-effective and feasible to reduce out-of-pocket costs to encourage greater use of preventive care among privately insured children. Primary care also needs to be made more accessible, especially for low-income families (Slifkin et al. 2002)(see Chart 3:1).

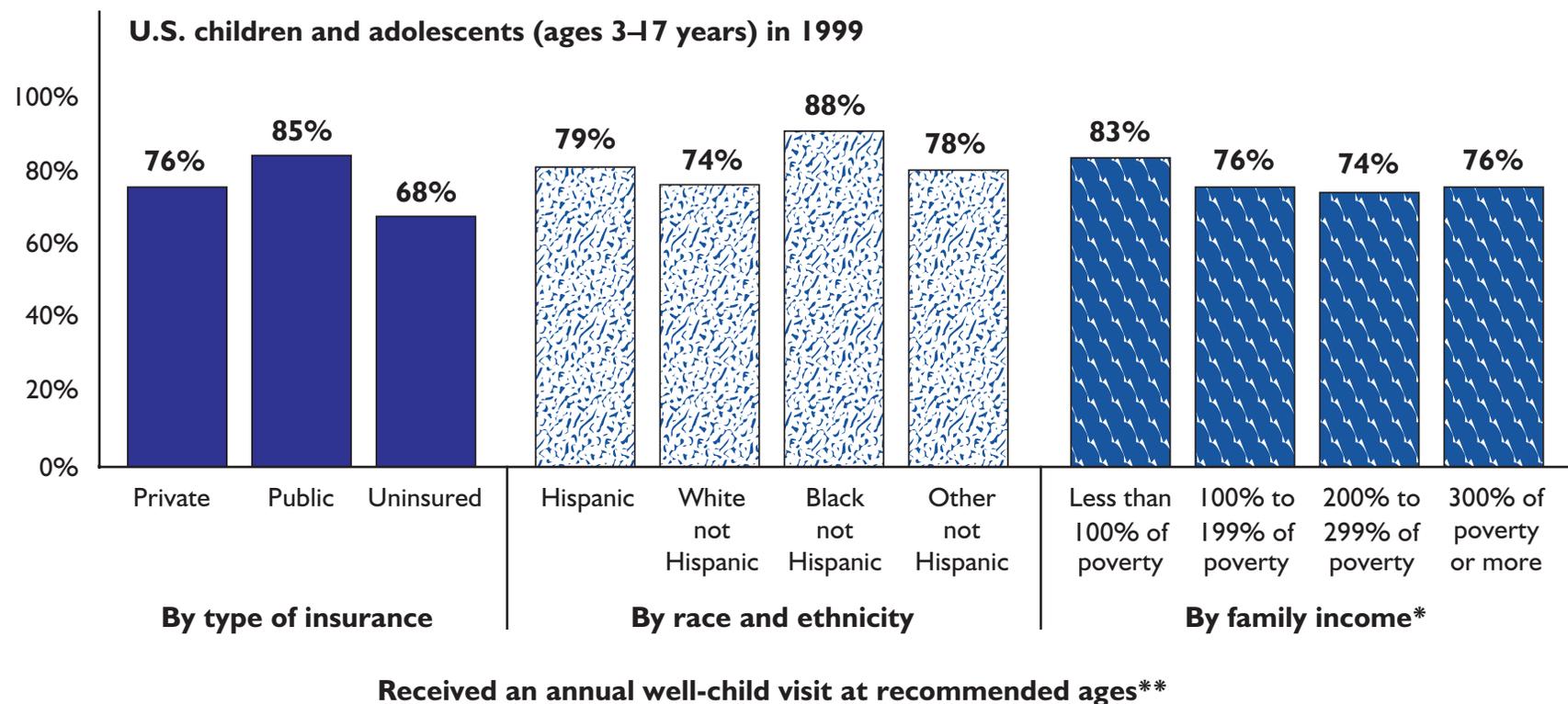
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\* Other research has found that minority and Medicaid-insured young children are less likely to receive recommended well-child visits than are white and privately insured young children (Ronsaville and Hakim et al. 2000; Thompson et al. 2003).

# Differences in Receipt of Recommended Preventive Health Care Visits by Type of Insurance, Race, Ethnicity, and Family Income

*Uninsured children and adolescents were least likely and those with public insurance were most likely to receive recommended preventive health visits, according to parent*

*report in 1999. More comprehensive public coverage probably accounts for higher rates of preventive visits among minority and poor children and adolescents.*



Source: Urban Institute/ Child Trends, 1999 National Survey of America's Families (N=35,938), as reported by Yu et al. (2002). \*Poverty means the federal poverty level. \*\*Pediatric experts recommend an annual well-child visit at ages 3–6, 8, and 10–21

years; children ages 7 and 9 years were considered compliant with the recommendations whether or not they received a well-child visit. Data were not sufficient to measure compliance with recommendations for children ages 0–2 years.



## DISPARITIES — STAYING HEALTHY — EARLY CHILDHOOD — CHART 5:2

## Income, Racial, Ethnic, and Geographic Differences in Childhood Immunizations

**Why is this important?** High rates of vaccination are needed to protect against periodic outbreaks of infectious disease. The measles epidemic of 1989–1991, which caused 120 deaths and 11,000 hospitalizations (DHHS 2000a), was associated with low vaccination rates among inner-city and minority preschool children (NVAC 1991; Gindler et al. 1992). A review of research by the National Vaccine Advisory Committee concluded that the “most powerful and persistent barriers to timely immunization are poverty and factors associated with poverty” (NVAC 1999).

**Findings:** Poor, minority, and urban children are less likely than nonpoor, white, and suburban children (respectively) to be up to date on recommended childhood immunizations. From 1994 to 2002, the disparity in combined coverage rate for four key immunizations among children ages 19 to 35 months:

- narrowed between poor and nonpoor children (from an 11 percentage point difference in 1994 to a 7 percentage point difference in 2002);
- narrowed between Hispanic and white children (from 10 percentage points in 1994 to 4 percentage points in 2002);
- widened between black and white children (from 5 percentage points in 1994 to 9 percentage points in 2002);
- widened between urban and suburban children (from 2 percentage points in 1994 to 5 percentage points in 2002).

Source: National Center for Health Statistics, National Immunization Survey, as reported by Eberhardt et al. (2001) and the CDC (2003e).

**Implications:** Actions to increase childhood immunizations must include ways to eliminate disparities for vulnerable children. Parents may face obstacles to obtaining timely immunization for their children, including inadequate clinic hours and convenient locations (Orenstein et al. 1990). Many parents cannot remember the immunization schedule (NVAC 1999) and many health care providers do not send parents reminders when immunizations are due (Tierney et al. 2003). Moreover, some eligible children are not immunized when they do have contact with the health care system (Szilagyi and Rodewald 1996).

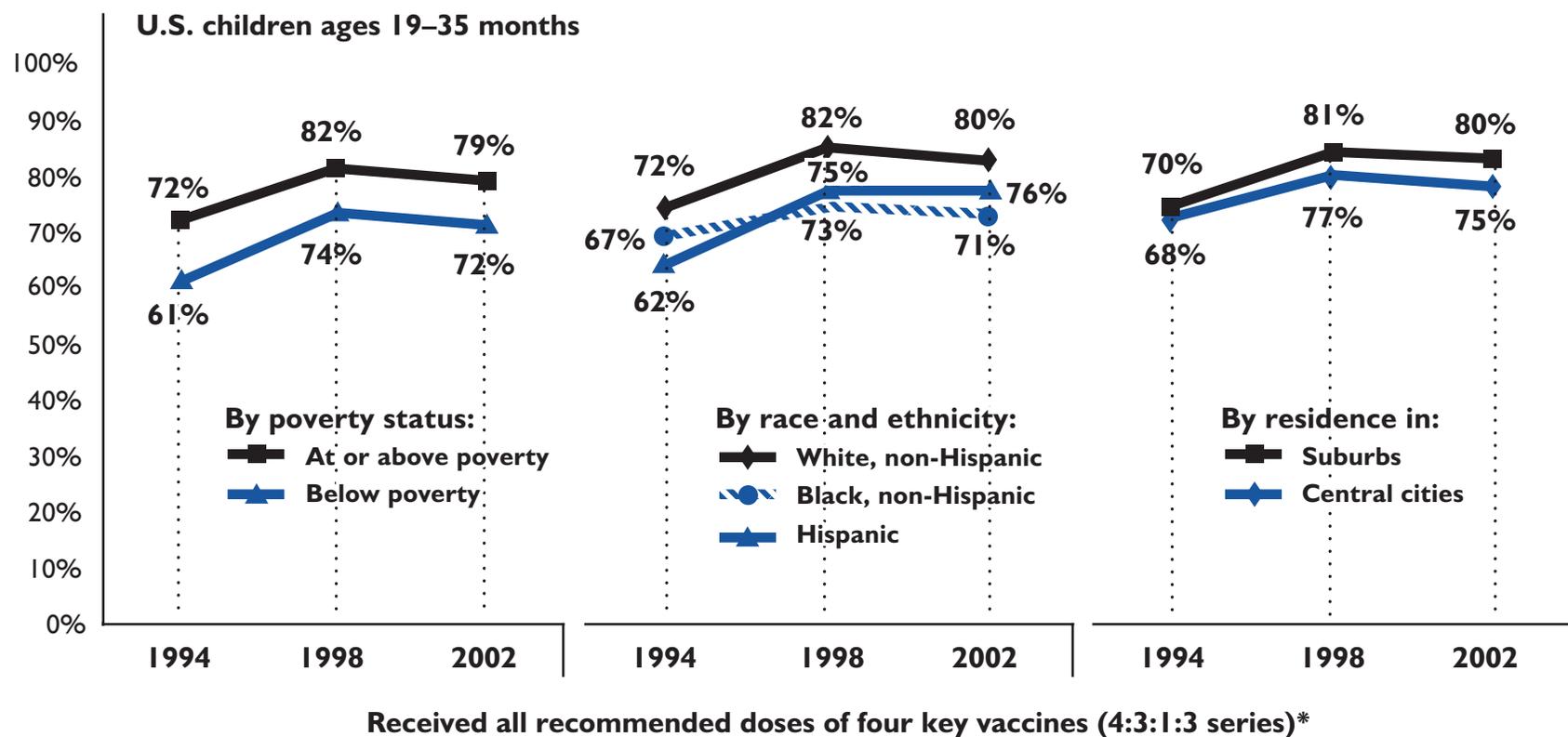
Initiatives to link immunization to the federal Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) have increased immunization rates up to 34 percentage points among low-income children. Interventions have included education, assessment, referral, and incentives (varying the frequency of required voucher pick-up based on immunization status) (Briss et al. 2000).

Several studies have found that home visiting programs can be effective in increasing immunization rates among hard-to-reach subpopulations (such as children living in public housing communities), although they can be resource intensive (Briss et al. 2000). One innovative program reduced disparities by assigning lay outreach workers to help inner-city physician practices track immunization status, contact families by mail, telephone, or home visits (for those with complex needs), and provide assistance with scheduling or transportation as needed (Szilagyi et al. 2002).

# Income, Racial, Ethnic, and Geographic Differences in Immunizations

Poor, minority, and urban young children are less likely than nonpoor, white, and suburban young children to be up to date on immunizations. Disparity in rates of immunization has

narrowed between poor and nonpoor and between Hispanic and white children, but has widened between black and white and between urban and suburban children.



Source: National Center for Health Statistics, National Immunization Survey (N=25,247 households for Apr.-Dec. 1994 and 30,000+ households for Jan.-Dec. of other years), as reported by Eberhardt et al. (2001) and the CDC (2003e). \*4:3:1:3: series = 4+

doses of diphtheria and tetanus toxoids and pertussis vaccine or diphtheria and tetanus toxoids only, 3+ doses of poliovirus vaccine, 1+ dose of measles-containing vaccine, and 3+ doses of *Haemophilus influenzae* type b vaccine.



## DISPARITIES — LIVING WITH ILLNESS — EARLY CHILDHOOD TO ADOLESCENCE — CHART 5:3

## Racial and Ethnic Differences in Asthma Management

**Why is this important?** Although the burden of asthma has been increasing among all children in the U.S, minority and poor children suffer disproportionately from asthma (Akinbami et al. 2002). For example, compared to white children, black children are 44 percent more likely to have an asthma attack, three times more likely to visit an emergency room and to be hospitalized, and four times more likely to die from asthma. Good asthma management in accordance with national guidelines—such as having a written plan to manage asthma at home and using anti-inflammatory medication when indicated to control underlying symptoms—can prevent asthma attacks and reduce adverse outcomes such as emergency room visits and hospitalizations (NAEPP 1997).

**Findings:** In 1999, rates of using recommended medication and having a written management plan were low among all Medicaid-insured children (ages 2 to 16 years) with asthma enrolled in five managed health care plans.

Compared to white children, black and Latino children were equally or more likely to have made a primary care visit for asthma care, to have seen a specialist for asthma care, and to have an asthma management plan, suggesting similar access to care. Yet, black and Latino children were less likely to be regularly using an inhaled anti-inflammatory medication when indicated for persistent asthma, despite having worse asthma than white children.

Source: parent telephone interviews and computerized medical records and claims data (Lieu et al. 2002).

**Implications:** Racial and ethnic differences in asthma anti-inflammatory medication use persist among low-income children even when they are equally insured with full prescription drug coverage. This disparity may reflect deficiencies in both physician prescribing and patient adherence.

Other research suggests that minority families are more likely than white families to view asthma as being uncontrollable and to have negative attitudes about anti-inflammatory medications (Yoos et al. 2003). Cultural and ethnic differences in communication between physicians and parents and older children may prevent the physician from making an accurate diagnosis and treatment plan as well as lead to poor understanding of the physician's recommendations and, thus, less adherence to treatment regimens (Flores et al. 2002).

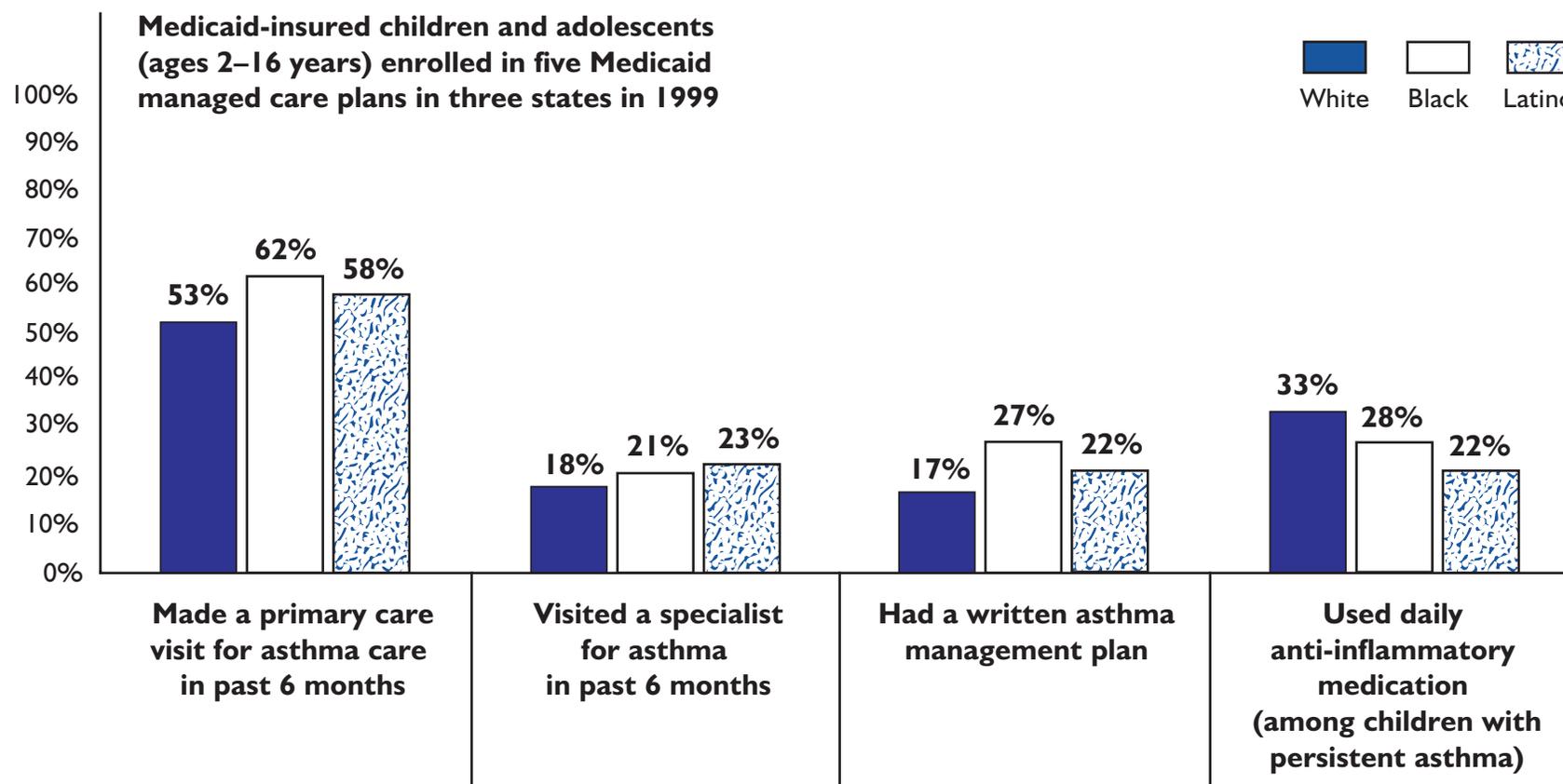
Several interventions have improved asthma care and outcomes for low-income and minority children living in the inner city, including use of:

- evidence-based professional education and supports for practitioners in inner-city public health clinics serving children (Evans et al. 1997),
- intensive patient and family education and outreach at an inner-city hospital specialty clinic (Kelly et al. 2000) (see Chart 6:7), and
- social workers to improve communication between inner-city children and their physicians (Evans et al. 1999).

## Racial and Ethnic Differences in Asthma Management

Among low-income children with asthma insured by Medicaid during 1999, black and Latino children were equally or more likely to have primary and specialty care visits and to receive a written plan to help them manage

their asthma symptoms compared to white children. Yet, black and Latino children were less likely to be regularly using preventive medication when indicated to control their asthma symptoms.



Source: 1999 Asthma Care Quality Assessment Project, telephone survey with parents (N=1,658) and computerized medical records and claims data, as reported by Lieu et al. (2002).



## DISPARITIES — LIVING WITH ILLNESS — MIDDLE CHILDHOOD — CHART 5:4

## Gender and Racial Differences in Evaluation and Treatment for Attention-Deficit/Hyperactivity Disorder

**Why is this important?** Attention-deficit/hyperactivity disorder (ADHD) is the most commonly diagnosed childhood behavioral problem in the U.S. (NIMH 1999). Seven percent of children and adolescents have been diagnosed with ADHD, according to parent report in 2000 (Blackwell et al. 2003). Treatment for ADHD—which may include medication and/or behavioral therapy—can improve symptoms and academic performance (Dulcan 1997; AHRQ 1999; AAP 2001).

Several studies have reported that girls and minorities are less likely to receive ADHD treatment; such disparities may arise from multiple factors including recognition by parents and teachers, care-seeking behaviors, barriers to accessing care, and actions of health professionals (Bussing et al. 2003).

**Findings:** In a 1998 study in one school district, most elementary school-age children identified by researchers as having symptoms of ADHD were recognized by their parent as having behavior problems. Among these children, boys were more likely than girls and white children were more likely than African American children to have been professionally evaluated, diagnosed, and treated for ADHD. Those with a regular source of health care were more likely to be evaluated (data not shown).

Source: parent and teacher surveys (Bussing et al. 2003).

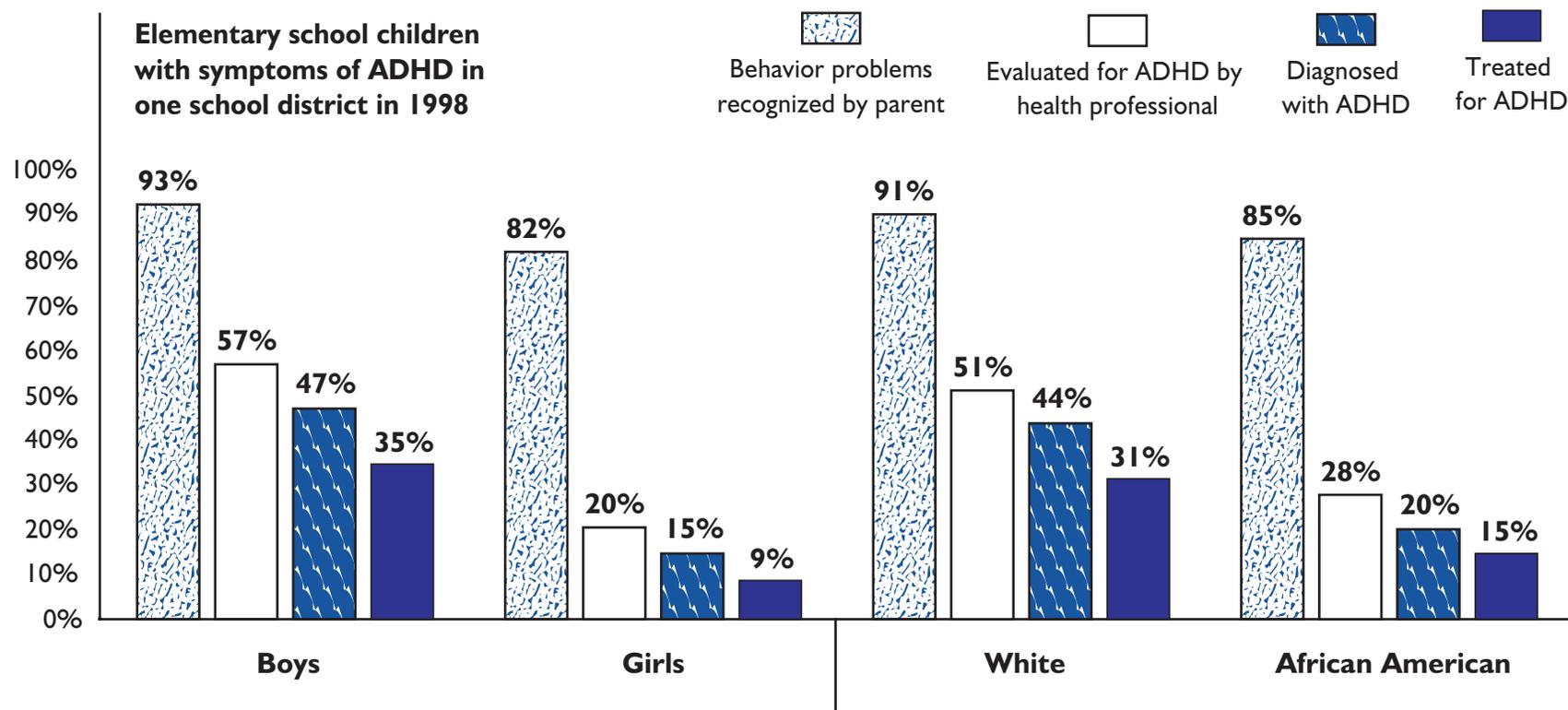
**Implications:** This study suggests that seeking professional evaluation is a key factor determining treatment for ADHD. Girls with ADHD may be less likely than boys with ADHD to manifest behaviors that prompt parents to seek evaluation (Gaub and Carlson 1997). African American parents are less likely than white parents to know about ADHD, less likely to receive information about ADHD from their child's health professional, and more likely to report low expectations for health care—all potential barriers to seeking help for their children (Bussing et al. 2003).

Providing education for parents of children with symptoms of ADHD, ensuring support from school personnel, and providing improved access to family-centered, routine pediatric care may help to reduce disparity in care-seeking (Bussing et al. 2003). The National Initiative for Children's Healthcare Quality has developed a toolkit—including educational resources for parents—to assist clinicians caring for children with ADHD (NICHQ 2003a), based on evidence-based guidelines developed by the American Academy of Pediatrics (AAP 2001). The AAP has incorporated these tools into an online learning program called *Education in Quality Improvement for Pediatric Practice* (McInerney et al. 2003).

# Gender and Racial Differences in Evaluation and Treatment for Attention-Deficit/Hyperactivity Disorder

*In 1998, most elementary school children with symptoms of attention-deficit/hyperactivity disorder (ADHD) were recognized by their parent as having behavior problems. Boys were more likely than girls and white children were more*

*likely than African American children to have been professionally evaluated and subsequently diagnosed and treated for ADHD.*



Source: 1998 teacher and parent surveys (N=1,615 children screened and 389 identified with symptoms), as reported by Bussing et al. (2003). Note: study did not assess the appropriateness of diagnosis or treatment.



## DISPARITIES — LIVING WITH ILLNESS — EARLY CHILDHOOD TO ADOLESCENCE — CHART 5:5

## Effect of Family Income on Parent Perceptions of Accessibility and Interpersonal Quality of Care for Children with Special Health Care Needs

**Why is this important?** Children living in poverty have worse health and greater disability than children in higher income families, even when they suffer from the same diseases (Starfield 1997). Families with low income are less likely to have health insurance and their children are less likely to get needed health care. Moreover, poverty is associated with other risk factors such as poor living conditions and inadequate nutrition (Starfield 1997).

Children with special health care needs (CSHCN\*) are more likely than other children to have unmet needs for health care across all income levels (Silver and Stein 2001). These children may be especially vulnerable to the effects of income disparities in access to care and in the degree to which services are tailored to meet the family's unique needs (Newacheck et al. 1998). *See Chart 3:6 for additional background on this population.*

**Findings:** In 2001, parents of children with special health care needs (ages birth to 17 years) with family income below the federal poverty level were three-and-one-half times more likely than those with higher family income (400 percent of poverty or higher) to report that their child had one or more unmet needs for health care (32% vs. 9%) and twice as likely to report a lack of family centeredness (50% vs. 25%) in the health care that their child did receive. \*\*

Source: National Center for Health Statistics, National Survey of Children with Special Health Care Needs, as reported by van Dyck (2003) and Blumberg (2003).

**Implications:** Children with special health care needs who “experienc[e] the greatest difficulties are concentrated among the most disadvantaged segments of [this] population” (Newacheck et al. 2003). Lack of or inadequate insurance coverage and other access barriers such as lack of transportation may be especially problematic for low-income families whose children have special health care needs.

Children with special health care needs insured by public programs such as Medicaid are more likely than those without insurance, but less likely than those with private insurance, to see a regular health professional and to have access to after-hours care (Newacheck et al. 2000b). These families may especially benefit from more comprehensive coverage, greater integration among health and social programs, improved community services, and culturally sensitive, family-centered assistance to navigate the health care system (Halfon and Hochstein 1997; Garwick et al. 1998).

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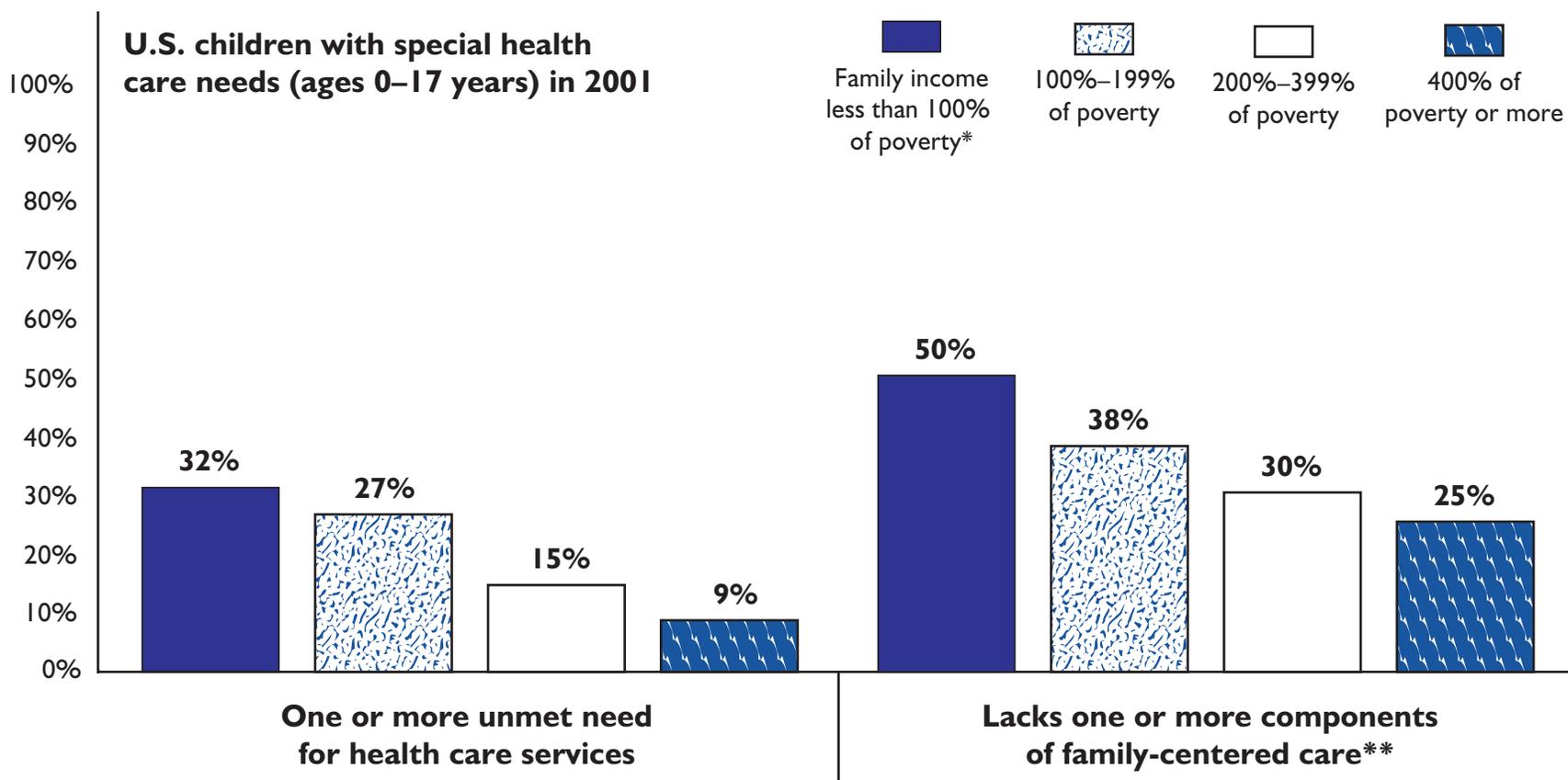
\* Children with special health care needs are defined as those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998). The survey identified only those with existing conditions, not those at risk of developing special needs.

\*\* Family-centered care means that the doctor usually or always spends enough time, listens carefully, provides needed information, is sensitive to the family's culture and values, and makes the family feel like a partner.

## Effect of Family Income on Parent Perceptions of Accessibility and Interpersonal Quality of Care for Children with Special Health Care Needs

Among children who have a chronic physical, developmental, behavioral, or emotional condition and who require health and related services beyond what is usual for children

generally, those with lower family income were more likely to have an unmet need for health care and to lack family centeredness in their care, according to parent report in 2001.



Source: National Center for Health Statistics, preliminary data from the 2001 National Survey of Children with Special Health Care Needs (N=38,866), as reported by van Dyck (2003) and Blumberg (2003). \*Poverty means the federal poverty level.

\*\*Components of family-centered care include: the doctor spends enough time with child, listens carefully, provides needed information, is sensitive to the family’s culture and values, and makes the family feel like a partner in the child’s care.



## DISPARITIES — MULTI-PERSPECTIVE — EARLY CHILDHOOD TO ADOLESCENCE — CHART 5:6

## Effect of Race, Ethnicity, and Language on Parent Assessment of Accessibility and Interpersonal Quality of Care

**Why is this important?** Racial and ethnic minorities may have unique cultural beliefs and practices as well as language differences that affect their access to and experience with health care (Flores and Vega 1998; Flores et al. 2002). “Ethnic and cultural norms influence a patient’s propensity to ask questions, express concerns, and be assertive during a medical interaction,” which may influence a physician’s propensity to share information and express empathy (Ashton et al. 2003). Adverse consequences of cultural and language differences in health care for children may include misdiagnosis, misunderstanding of treatment instructions, and inappropriate medication, testing, and hospitalization (Flores et al. 1998; 2002).

One of every 12 U.S. residents (8%) speaks a language other than English at home *and* does not speak English very well or at all (U.S. Census Bureau 2003). Courses in English as a second language typically do not teach the terminology needed to communicate well about medical care (Downing and Roat 2002). A national survey found that only half of Spanish-speaking Hispanics who needed an interpreter to speak with their doctor always or usually had access to one (Doty 2003). Another study found a high rate of errors in interpreting, especially by *ad hoc* interpreters, during pediatric visits at one hospital outpatient clinic (Flores et al. 2003). Only five states currently use federal-state matching funds to pay for language services as part of Medicaid and SCHIP programs (Andrulis et al. 2002).

**Findings:** Minority parents of children (ages birth to 17 years) enrolled in Medicaid managed care plans in six states, surveyed during 1997–1998, generally rated accessibility and interpersonal quality of care lower than did white parents. Most ratings were significantly lower for parents who identified themselves as black/African American or American Indian/Alaskan Natives (nearly all of whom were English-speaking). Those who identified themselves as Asian/Pacific Islander or of Hispanic ethnicity *and* who did not speak English as their primary language gave significantly lower ratings than both white parents and their English-speaking Asian and Hispanic counterparts.

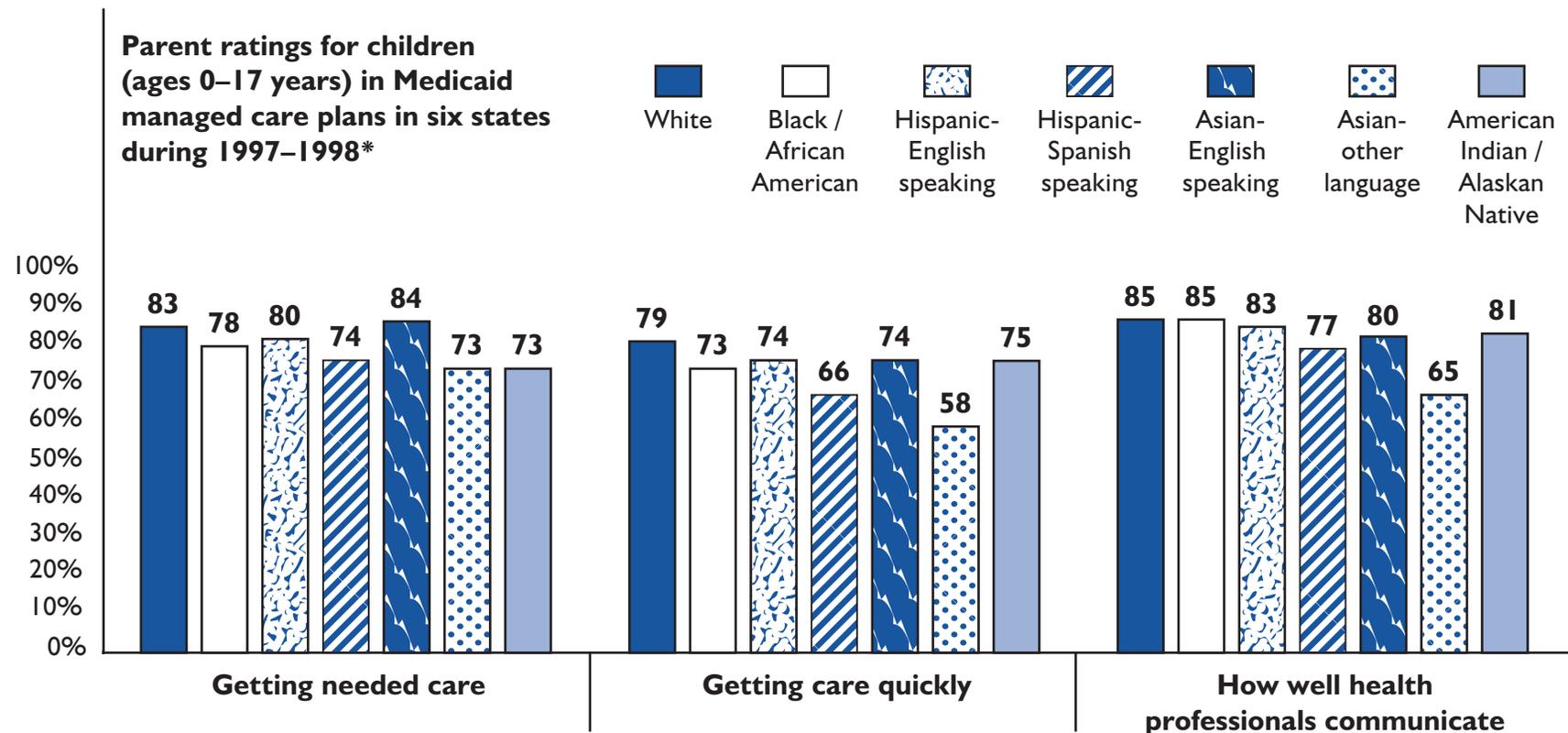
Source: Consumer Assessment of Health Plans (CAHPS) Benchmarking Database, as reported by Weech-Maldonado et al. (2001), and personal communication with Robert Weech-Maldonado (2003).

**Implications:** Language barriers and communication problems may figure prominently in disparities for racial and ethnic minorities (Ashton et al. 2003). Policy options for overcoming these barriers include increasing the availability of competent interpreter services (including appropriately trained and supervised volunteers) and of bilingual and minority health professionals and staff, and encouraging the use of culturally and language- and literacy-appropriate materials (Betancourt et al. 2002; Downing and Roat 2002). Experts recommend that doctors evaluate their communication competence and seek training when needed to improve culturally competent health care, such as by helping patients to ask questions and express concerns (Ashton et al. 2003).

# Effect of Race, Ethnicity, and Language on Parent Assessment of Accessibility and Interpersonal Quality of Care

Minority parents of children and adolescents enrolled in Medicaid health plans in six states rated the accessibility and interpersonal quality of their child's care lower than white

parents during 1997–1998. Language barriers were a major factor in disparity of ratings for Asian and Hispanic parents.



Source: 1997–1998 Consumer Assessment of Health Plans (CAHPS) Benchmarking Database (N=9,540), as reported by Weech-Maldonado et al. (2001), and personal communication with Robert Weech-Maldonado (2003). \*Scores were adjusted for differences in parent's age, parent's gender, parent's education, and child's health status.



## CAPACITY TO IMPROVE — STAYING HEALTHY — EARLY CHILDHOOD — CHART 6:1

## Improving Primary Care Office Systems to Increase Preventive Care for Young Children

**Why is this important?** Research indicates that primary care practitioners improve their ability to deliver preventive care when they adopt a systematic, organized approach—such as using information tools, improving office processes, and increasing teamwork among office staff (Dietrich et al. 1997; Dickey et al. 1999; Goodwin et al. 2001). Yet, less than half of primary care physicians report using such office systems (Dickey and Kamerow 1996). For example, only two of five pediatricians (38%) report assessing immunization performance and one of six (16%) report using systems to remind parents about upcoming or overdue immunizations (Tierney et al. 2003)—techniques that are effective and recommended for improving immunization rates (CDC 1999a).

**Intervention:** This study evaluated the impact of a year-long, community-wide collaborative effort to increase preventive care for young children (Bordley et al. 2001). All the major primary care group practices and clinics serving young children in Durham, North Carolina, established multidisciplinary teams and received technical assistance to set objectives, monitor performance, and adopt or enhance quality-improvement systems directed at one or more levels:

1. *patients*—educational materials and activation cards to prompt discussions with the doctor or nurse;
2. *practitioners*—post-it reminders on patient charts and risk assessments to prompt screening when appropriate; and
3. *the practice*—chart prescreening to identify needed services, flowsheets indicating recommended age-specific services, and tracking systems to identify patients in need of care.

**Findings:** After the intervention, the combined rates of preventive care provided to patients of these practices increased significantly for three of four project goals compared to preintervention rates:

- being up to date on immunizations (by 7 percentage points at age 12 months and by 12 percentage points at age 24 months),
- screening for anemia (by 30 percentage points), and
- screening (risk assessment or blood testing) for lead poisoning (by 36 percentage points).

Rates of screening for tuberculosis, the fourth goal, increased at practices that focused on this objective but not in aggregate (data not shown).

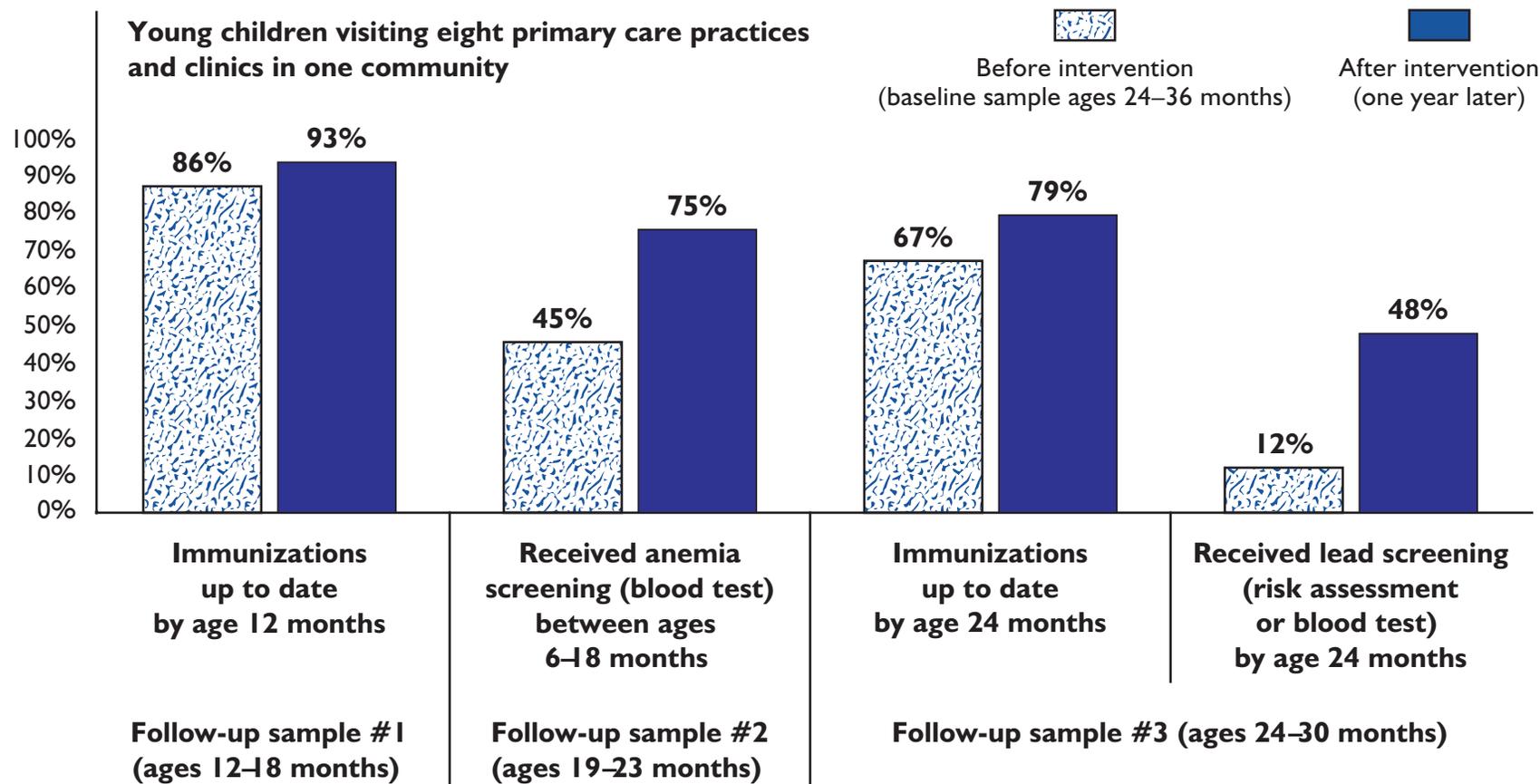
Source: random samples of medical records (Bordley et al. 2001).

**Implications:** With assistance, primary care practitioners can establish and improve office systems to increase preventive care for children. The degree of improvement achieved varied among practices depending on whether they targeted a particular service for improvement and based on their ability to successfully implement changes in office systems (Bordley et al. 2001). Controlled studies may be useful to verify the effectiveness of this approach and compare the relative effectiveness of different tools. Other research suggests that having an organizational “champion” is important to lead efforts at adopting such tools (Tierney et al. 2003).

# Improving Primary Care Office Systems to Increase Preventive Care for Young Children

Rates of preventive care increased among young children who were patients of primary care practices and clinics in one community that collaborated with researchers to adopt and

enhance quality-improvement systems, such as chart prescreening, risk-assessment forms, flowsheets, prompting and reminder systems, and patient education materials.



Source: random samples of medical records (N=339 in baseline sample and 285 to 300 in follow-up samples) as reported by Bordley et al. (2001). Samples were not the same children. Some results omitted for clarity.



## CAPACITY TO IMPROVE — STAYING HEALTHY — EARLY CHILDHOOD — CHART 6:2

## Enhancing Primary Care Developmental Services for Young Children

**Why is this important?** Recent research has led to new appreciation for the importance of early life experience in shaping children's intellectual, emotional, and social development (NRC 2000). Yet, changes in family and society are challenging parents and creating stresses that can harm children's life chances (Carnegie 1994). Reflecting this dynamic, many parents say they want more information about child development from their health professional (*see Chart 1:3*). Primary health care appears to offer an excellent opportunity to support parents in creating the environment for favorable developmental outcomes, since most young children already have regular contact with a primary care practitioner for immunizations and other well-child care (AHRQ 2002a; VanLandeghem et al. 2002).

**Intervention:** The Healthy Steps for Young Children program promotes a new multidisciplinary model of pediatric care emphasizing "a close relationship between health care professionals and mothers and fathers in addressing the physical, emotional, and intellectual growth and development of children from birth to age three" (Healthy Steps 2003). The program integrates a trained child development specialist (nurse, early childhood educator, or social worker with experience in child development) into primary care practices to enhance developmental information and other services, including: enhanced well-child care, child development and family health checkups, home visits at critical developmental stages, telephone hotline for parents to discuss developmental concerns, parent support groups, written information materials, and linkage to community resources.

**Findings:** Parents of young children (ages 30 to 33 months) taking part in the Healthy Steps program at 15 primary health care sites were more likely than parents with usual care at the same or matched sites to report:

- receiving developmental information and services promoted by the program,
- being satisfied with support from the practice and communication with health professionals,
- engaging in nonphysical child discipline behaviors promoted by the program,
- discussing their own sadness with someone at the practice (among mothers at risk for depression), and
- maintaining continuity of care at the same practice after their child reached age 20 months.

Children enrolled in Healthy Steps were more likely to receive well-child visits at recommended ages and to be up to date on selected immunizations at age 24 months.

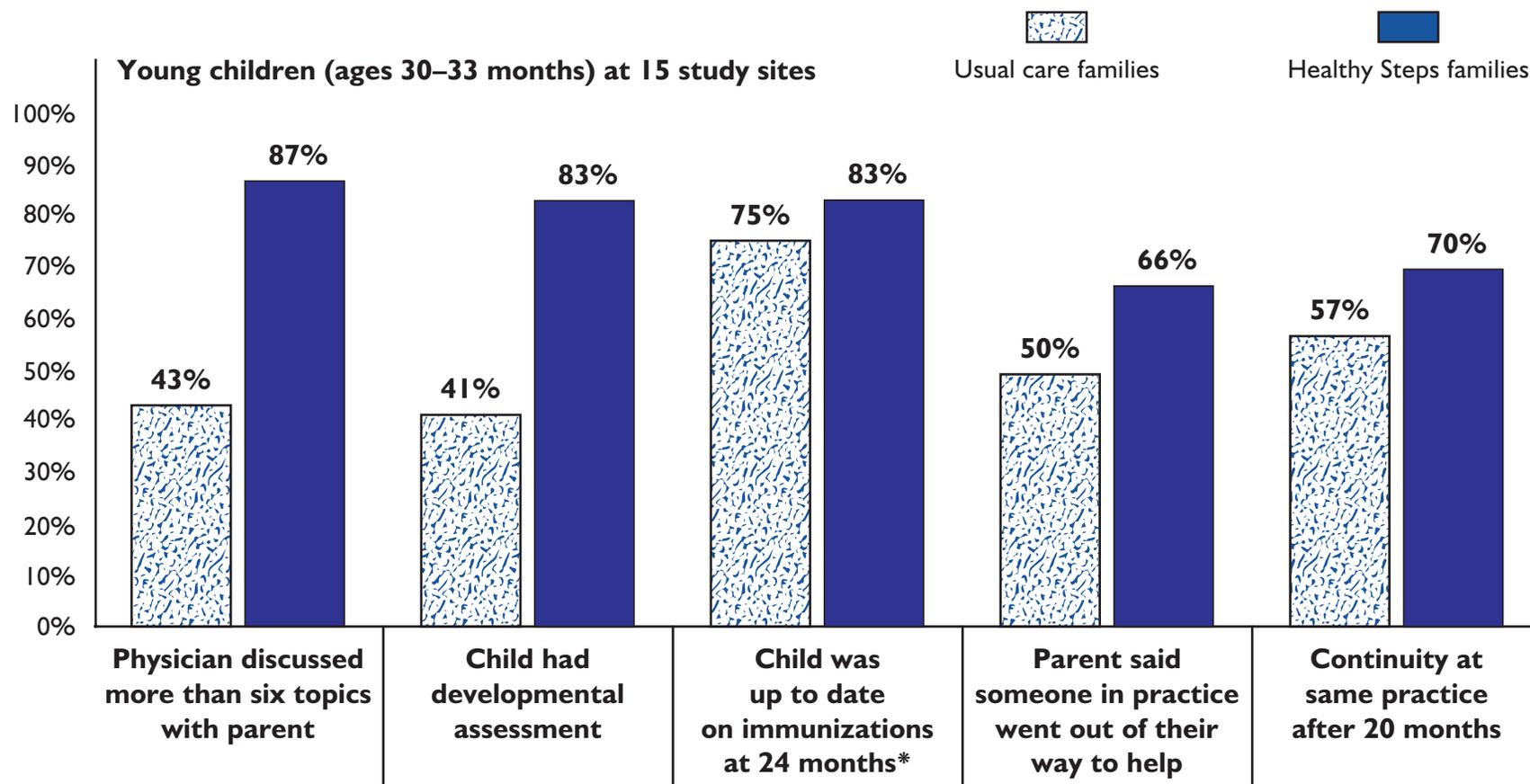
Source: Parent interviews and medical records (Minkovitz et al. 2003).

**Implications:** Enhancing early child development services in primary care will require structural changes in practice. Given current health care market constraints, the authors conclude, "it is unlikely that physicians will be able to extend the length of visits or provide more direct services to families without relying on other professional staff" (Minkovitz et al. 2001). The Healthy Steps program represents one model for accomplishing this goal, with an incremental cost ranging from \$402 to \$933 per child per year.

# Enhancing Primary Care Developmental Services for Young Children

The Healthy Steps program integrates child development specialists into primary care along with other enhanced services to promote the physical, emotional, and intellectual development of young children. Families taking part in

Healthy Steps were more likely to receive recommended preventive and developmental services and continuous, patient-centered care.



Source: Parent interviews and medical records (N=3,737), as reported by Minkovitz et al. (2003). \*4 doses of diphtheria-tetanus-pertussis vaccine; 3 doses of oral polio or inactivated poliovirus vaccine; and 1 dose of measles-mumps-rubella vaccine.



## CAPACITY TO IMPROVE — STAYING HEALTHY — EARLY CHILDHOOD — CHART 6:3

## Promoting Lead Screening for Medicaid-Insured Young Children

**Why is this important?** Young children are susceptible to lead poisoning when exposed to lead in their environment, especially deteriorating lead-based paint and paint dust in older housing (NRC 1993). Low-level lead poisoning typically does not manifest in medical symptoms and therefore cannot be detected without blood testing. Lead poisoning is associated with developmental delays, learning disabilities, and behavioral problems (AAP 1998a).

Lead poisoning has been declining in the U.S. since lead was banned in paint and gasoline. Yet, 8 percent of low-income young children (ages birth to 5 years) and 11 percent of young black children had elevated blood lead levels (greater than 10 micrograms per deciliter) in 1991–1994, compared to 4 percent of children generally (CDC 1997a). Three of five young children (62%) with elevated blood levels are enrolled in Medicaid (GAO 1999).

The Centers for Disease Control and Prevention recommend lead screening for young children at risk of lead poisoning—including all low-income children receiving public assistance—to identify those in need of interventions to lower blood lead levels (CDC 1991; 1997b). Interventions depend on severity of lead toxicity and may include follow-up testing, family education, abatement of the source of lead exposure, and medical management. The federal government has required since 1992 that all Medicaid-insured children receive a blood lead test at ages 1 and 2 years, and that children age 36 to 72 months be tested if they have not previously been screened. Only half the states had fully complied with this policy as of 1999 (GAO 1999).

**Intervention:** The State of Rhode Island requires universal lead screening of all young children and promotes screening through a multifaceted educational and outreach strategy (Rhode Island DOH 2003). A statewide public health tracking system is used to notify managed care plans, health professionals, and clinics of children who are in need of screening (AECLP 2001). Head Start providers and Women, Infants, and Children (WIC) nutrition clinics also check children's status and notify physicians when screening is needed (personal communication with Magaly Angeloni 2003). Medicaid managed care plans are eligible for state performance incentives for meeting goals including lead screening rates. The state offers bilingual case management services and an abatement program that funds replacement of lead-painted windows (Silow-Carroll 2003).

**Findings:** During 1996–1997, 80 percent of Rhode Island children (ages 19 to 35 months) who were enrolled in the state's Medicaid managed care program for at least one year had ever received a blood lead test. In contrast, only 21 percent of young children who were enrolled in traditional Medicaid in 15 other states for at least one year during 1995–1996 had received a blood lead test within six months of their first or second birthday (state rates ranged from 1 percent to 46 percent).

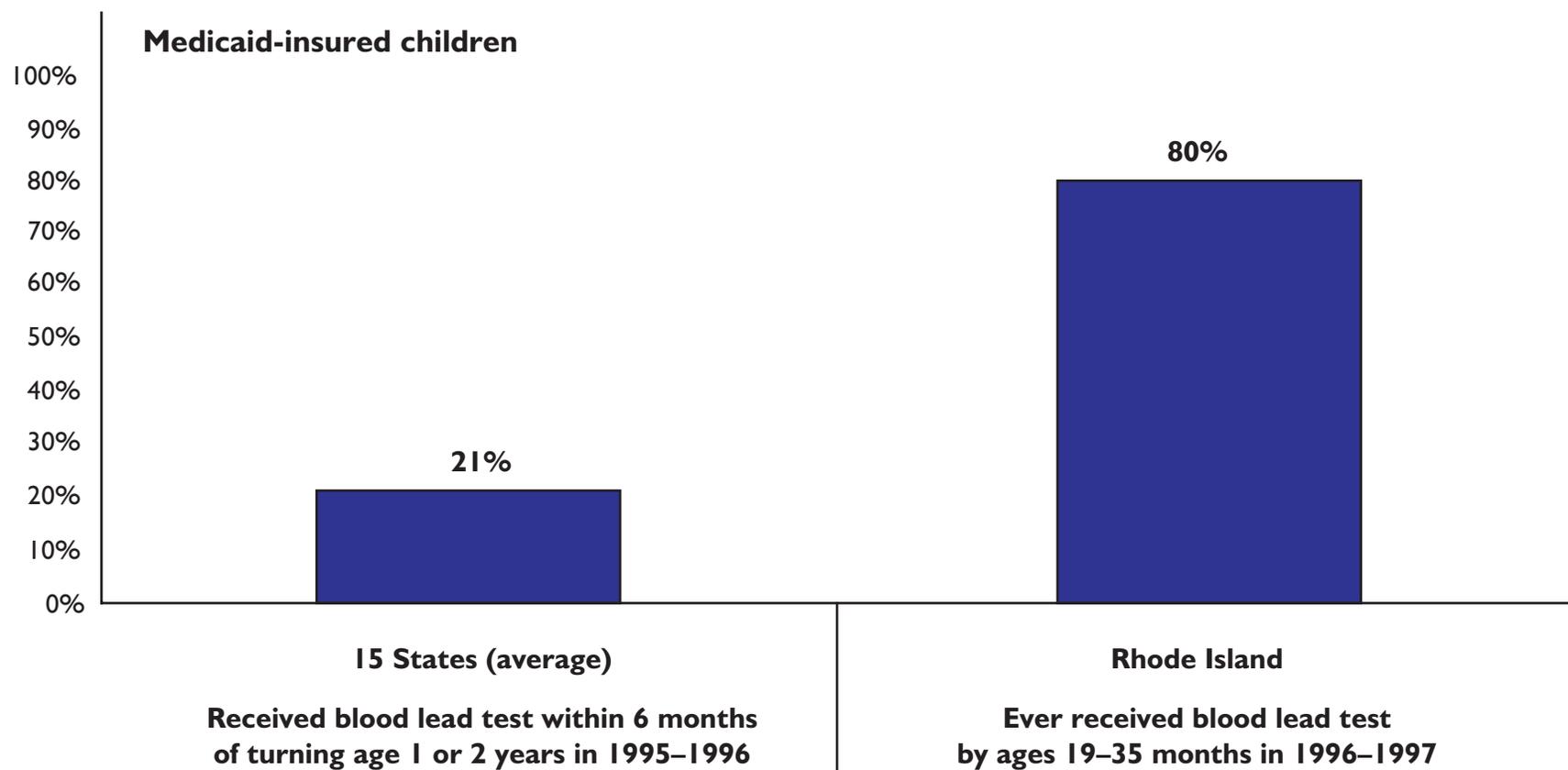
Sources: medical records (Vivier et al. 2001); Medicaid administrative claims data (GAO 1999).

**Implications:** A multifaceted statewide education and outreach intervention can increase lead screening rates to high levels among low-income young children.

## Promoting Lead Screening for Medicaid-Insured Young Children

*Lead poisoning remains a danger to low-income children who often live in older housing with lead-based paint. The CDC recommends (and federal policy requires) that all children insured by Medicaid be screened at ages 1 and 2 years to*

*detect lead poisoning, but rates have remained low nationally. Rhode Island has achieved a high screening rate among Medicaid children through a multifaceted education and outreach program.*



Sources: Medicaid fee-for-service claims data for 15 states (N=288,963), as reported by the GAO (1999); physician medical record audit for Rhode Island (N=1,988), as reported by Vivier et al. (2001).



## CAPACITY TO IMPROVE — STAYING HEALTHY — ADOLESCENCE — CHART 6:4

## Improving Delivery of Adolescent Preventive Care in Community and Migrant Health Centers

**Why is this important?** Adolescents face many behavioral and lifestyle choices—such as whether to use tobacco, alcohol, or drugs, eat healthy foods, get regular exercise, engage in risky sexual behaviors, and take precautions to prevent injury—that can have both immediate and lasting consequences for their health and success in life (Klein and Auerbach 2002).

The American Medical Association's *Guidelines for Adolescent Preventive Services* (GAPS) recommend that physicians provide guidance to adolescents to help encourage healthy lifestyles and screen for medical, behavioral, and emotional problems for which treatment, counseling, or referral to other services is indicated (Elster and Kuznets 1994). Many adolescents reporting health or behavioral risks say they would like to discuss these issues with a physician, yet most have not done so (Klein and Wilson 2002).

**Intervention:** This study evaluated the experience of five urban and rural community and migrant health centers (CMHCs) that received training and technical assistance to implement the American Medical Association's *Guidelines for Adolescent Preventive Services* (GAPS) among poor and uninsured adolescents ages 14 to 19 years (Klein et al. 2001). All five CMHCs made improvements in preventive care delivery including: scheduling 30-minute well-child visits, encouraging confidential counseling time, using a patient questionnaire to screen for health risks, and enhancing patient education materials and referral networks when possible.

**Findings:** Adolescents visiting for well-child care nine to 15 months after GAPS implementation were significantly more likely than those who had visited before the intervention to report receiving educational materials and discussing preventive topics with their health professional in 19 of 31 content areas. Rates of counseling were 10 to 29 percentage points higher for these 19 topics after the intervention. Rates of counseling did not increase significantly for topics that had relatively higher rates before the intervention.

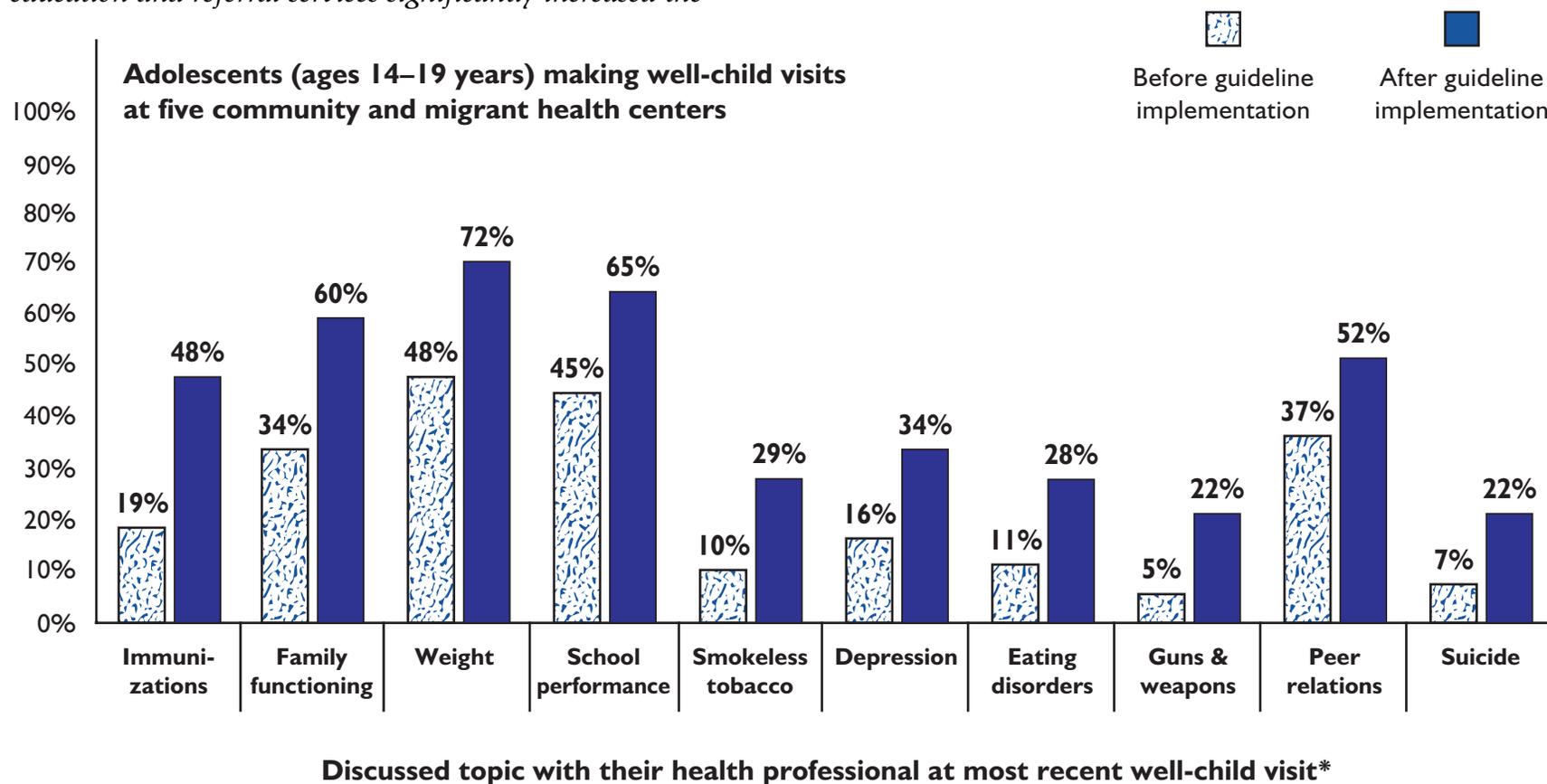
Source: patient surveys (Klein et al. 2001). (The chart displays the 10 topics with the greatest absolute increase in reported discussion.)

**Implications:** Health centers and similar clinical practice settings can improve preventive care for adolescents when they adopt guidelines along with a program of supportive practice improvements. Given limited time and the need to tailor screening and counseling to meet individual patient needs, rates of 100 percent would not be expected across all topics for every visit, but there is room for additional improvement. Effectively coordinating preventive care for adolescents requires commitment to recognize adolescents' unique developmental needs as well as the importance of providing adequate time and privacy for confidential screening and counseling (Klein et al. 2001).

# Improving Delivery of Adolescent Preventive Care in Community and Migrant Health Centers

Implementing adolescent preventive care guidelines as part of an intervention that included training, changes in scheduling policies, use of a risk-assessment tool, and enhanced education and referral services significantly increased the

rates at which poor and uninsured adolescents reported discussing several health- and lifestyle-related topics with their clinician.



Source: Patient surveys (N=260 pre-intervention and 274 post-intervention) as reported by Klein et al. (2001). \*Nineteen of 31 measured topics showed significant increase in

discussion; topics shown are the 10 exhibiting the greatest percentage point increase in reported discussion, arranged from left to right by magnitude of change.



## CAPACITY TO IMPROVE — STAYING HEALTHY — ADOLESCENCE — CHART 6:5

## Improving Screening for Chlamydia Infection Among Adolescent Girls Seen at HMO Clinics

**Why is this important?** Expert recommendations to screen sexually active adolescent girls for chlamydia infection are not widely followed in routine clinical practice (*see Chart 1:6*). This gap in quality results in many missed opportunities to treat patients who have contracted this sexually transmitted disease without knowing it and who remain at risk of developing potentially severe complications.

**Intervention:** This study tested the effectiveness of an intervention to increase compliance with screening guidelines for an ethnically diverse population of adolescent girls (ages 14 to 18 years) during checkup visits (Shafer et al. 2002). Ten pediatric clinics of a large health maintenance organization were randomly assigned to provide usual care or to implement the intervention. To reduce screening barriers, all clinics used a urine test (rather than culture obtained through pelvic exam). The intervention consisted of:

1. engaging clinic leadership and raising awareness of the gap in quality;
2. building teams at each clinic to implement the intervention, including identifying and addressing barriers to improvement;
3. developing clinical practice improvements such as customizing clinic flowcharts to summarize patient information from multiple sources, instituting universal urine specimen collection at patient registration (but only specimens from sexually active girls, as determined confidentially by the practitioner, were sent for laboratory analysis), and raising awareness about screening through an educational campaign; and
4. sustaining gains through continuous performance monitoring.

**Findings:** Before the intervention, the 10 clinics did not differ significantly in the proportion of sexually active adolescent girls screened for chlamydia infection at preventive health visits; both groups had very low rates of such screening. During visits 16 to 18 months after the intervention, the proportion of girls screened for chlamydia infection had increased significantly in the intervention clinics (from 5% before to 65% after the intervention) and was significantly higher than in the usual care clinics (21%).

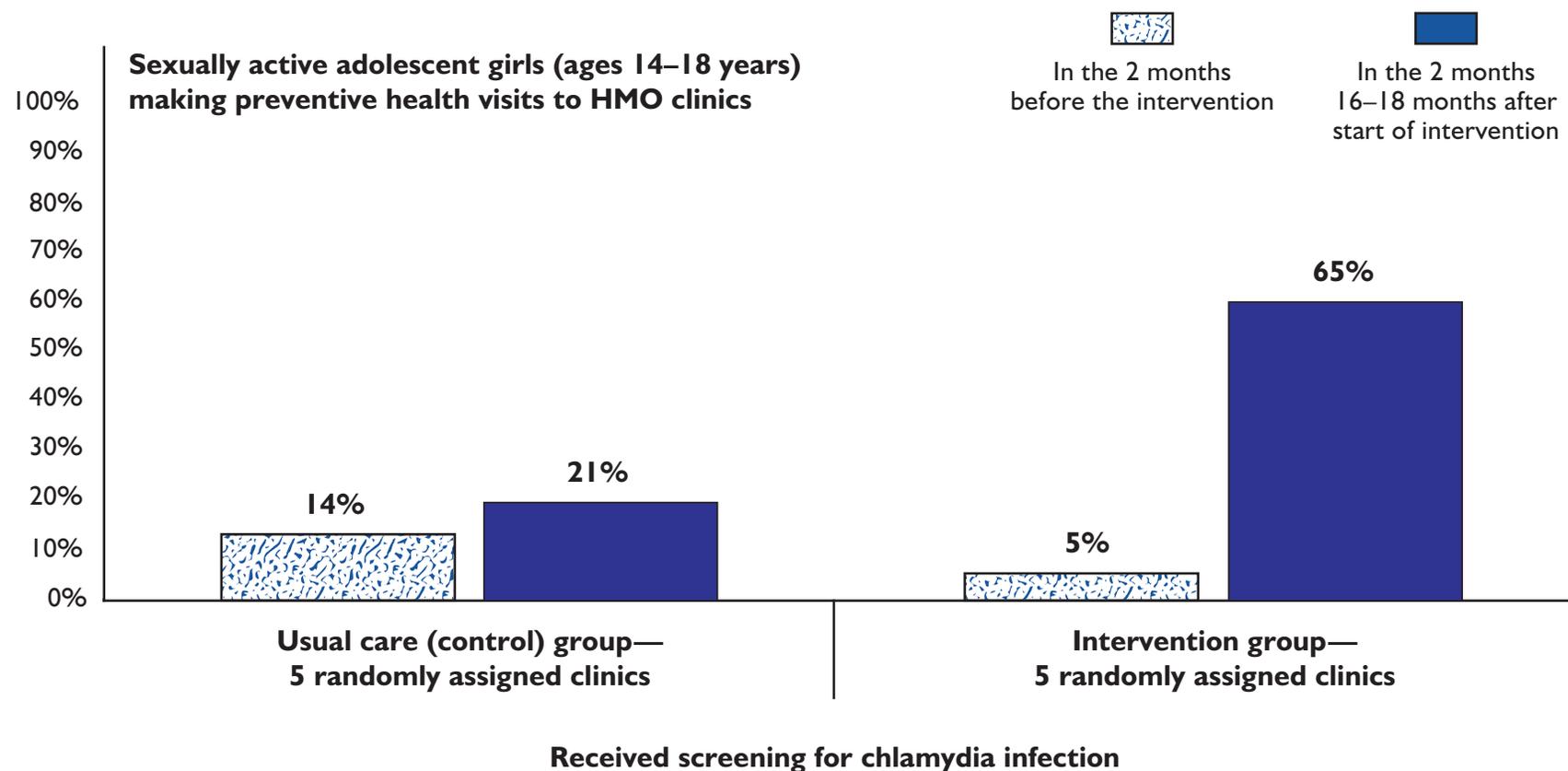
Source: Patient encounter and laboratory data (Shafer et al. 2002).

**Implications:** A multifaceted, systems-level intervention can increase rates of screening for chlamydia infection in organized group practice and may be replicable to other similar practice settings.

# Improving Screening for Chlamydia Infection Among Adolescent Girls Seen at HMO Clinics

*HMO clinics that implemented an intervention—including team development, performance monitoring, and clinical practice improvements such as flowcharts, universal urine*

*specimen collection, and an educational campaign—significantly boosted the proportion of adolescent girls screened for chlamydia infection.*



Source: patient encounter and laboratory data (N=7,920 routine checkup visits), as reported by Shafer et al. (2002).



## CAPACITY TO IMPROVE — GETTING BETTER WHEN SICK OR INJURED — EARLY CHILDHOOD — CHART 6:6

## Reducing Unnecessary Antibiotic Use Among Young Children Visiting Physician Group Practices and HMO Clinics

**Why is this important?** To curb the spread of antibiotic-resistant pathogens, unnecessary use of antibiotics must be reduced. This goal may be especially important among young children, who have a higher rate of infection with antibiotic-resistant pathogens than other age groups (Whitney et al. 2000). Although physicians have reduced antibiotic prescribing over the past decade (McCaig et al. 2002), further progress is needed (*see Chart 1:7*). Many physicians say that parents pressure them to prescribe antibiotics for a sick child when antibiotics are not clinically indicated (Bauchner et al. 1999). A multifaceted intervention to educate patients and physicians was successful in reducing unnecessary antibiotic use among adults (Gonzales et al. 2001).

**Intervention:** This study evaluated a one-year targeted educational intervention to reduce unnecessary antibiotic prescriptions for children (Finkelstein et al. 2001). Twelve urban and suburban group practices and multispecialty clinics affiliated with two geographically unique managed health care plans were randomized by matched pairs to intervention and control groups.

Parents of enrolled children receiving care at intervention practices were mailed a pamphlet on appropriate antibiotic use that was developed by the Centers for Disease Control and Prevention (CDC), with a cover letter signed by their physician. Additional CDC pamphlets and posters were displayed in intervention clinic waiting rooms. A CDC-trained pediatric peer

leader conducted small-group educational sessions with physicians in the intervention practices at the start of the intervention and again four months later, with the follow-up presentation including feedback on group and individual physician antibiotic prescribing performance.

**Findings:** Antibiotic dispensing decreased by 10 percent to 12 percent from the baseline to the intervention year among young children visiting control group practices, probably because of national public health initiatives. Antibiotic dispensing decreased significantly more, by 15 percent to 19 percent, in the intervention clinics. Among children who visited in both the baseline and intervention years (data not shown), there was a “relative intervention effect” of 12 percent to 16 percent fewer antibiotics dispensed in the intervention practices, beyond the change in antibiotic use in the control practices after adjusting for baseline use of antibiotics.

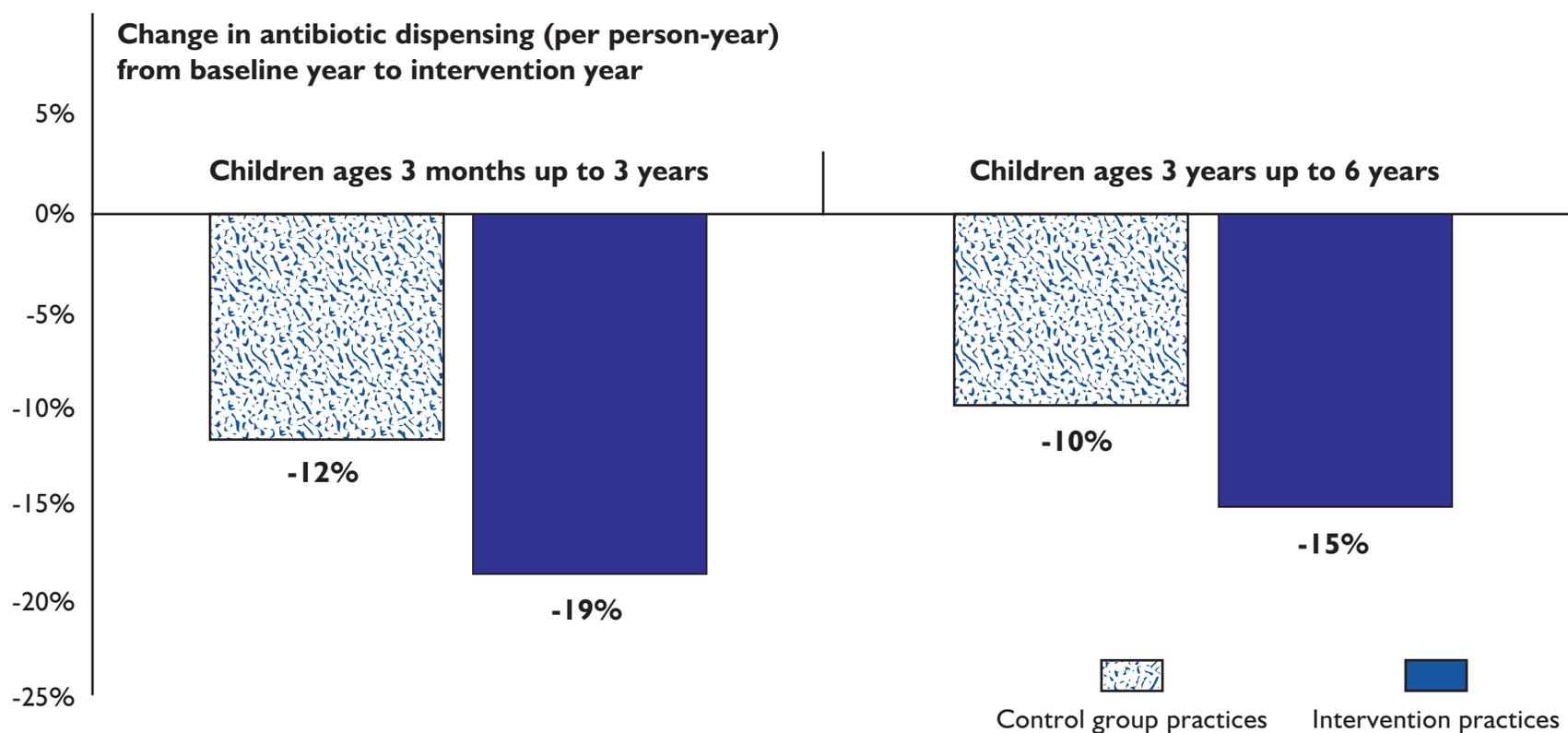
Source: computerized claims data (Finkelstein et al. 2001).

**Implications:** A multifaceted educational intervention directed at both physicians and parents was successful in boosting the reduction in antibiotic prescribing beyond the preexisting trend toward lower antibiotic use.

# Reducing Unnecessary Antibiotic Use Among Young Children Visiting Physician Group Practices and HMO Clinics

*An education and outreach intervention, directed at physicians and parents of young children visiting practices affiliated with two managed health care plans, reduced antibiotic dispensing beyond an independent trend toward*

*lower antibiotic use in control group practices. The intervention involved peer-led physician education and performance feedback combined with educational materials mailed to parents and displayed in clinic waiting rooms.*



Source: computerized claims data (N=14,468 and 13,460 patients in baseline and intervention years, respectively), as reported by Finkelstein et al. (2001).



## CAPACITY TO IMPROVE — LIVING WITH ILLNESS — EARLY CHILDHOOD TO ADOLESCENCE — CHART 6:7

## Education and Outreach to Improve Asthma Care and Outcomes at an Inner-City Hospital Specialty Clinic Serving Low-Income Children

**Why is this important?** Many children with asthma and their families are not practicing effective asthma management, including the regular use of anti-inflammatory medication when indicated to control asthma symptoms (*see Chart 1:8*). Poor and minority children suffer disproportionately from asthma and its consequences (Akinbami et al. 2002); hence, they may have even greater need for improvement in care and outcomes. Passive education alone is not enough to bring about change, but more intensive programs can be effective (Guevara et al. 2003).

**Intervention:** This study examined the effect of an intensive asthma education and outreach program at an inner-city hospital specialty clinic (Kelly et al. 2000). Medicaid-insured children and adolescents (ages 2 to 16 years) who had visited the emergency room twice or been hospitalized once in the past year, and who consented to participate, were alternately assigned to an intervention or control group. There were no baseline differences between the groups.

The intervention group children and their caregiver received individual asthma self-management education and a written action plan for exacerbations. An outreach nurse contacted these children once per month to monitor their status, review medications, refill prescription, schedule follow-up care, and assist with transportation needs. The nurse worked with school personnel on behalf of school-age children. Intervention group children could use the specialty clinic for care, but control group children were referred to their primary care physician for treatment.

**Findings:** During the intervention year, children in the intervention group received better quality of care, as measured by 95 percent who received an influenza immunization compared to 23 percent of children in the control group. Use of anti-inflammatory medication increased nearly three-fold (from 34% to 95%) among intervention children but did not change greatly in the control group (60% to 65%).

Adverse outcomes declined significantly in the intervention group (half as many emergency room visits and two-thirds fewer days in the hospital on average compared to the baseline year) but not in the control group. Intervention group children had a clinically meaningful improvement in their quality-of-life scores (data not shown).

Annual average health care charges declined \$543 more per child in the intervention group than in the control group in the intervention year.

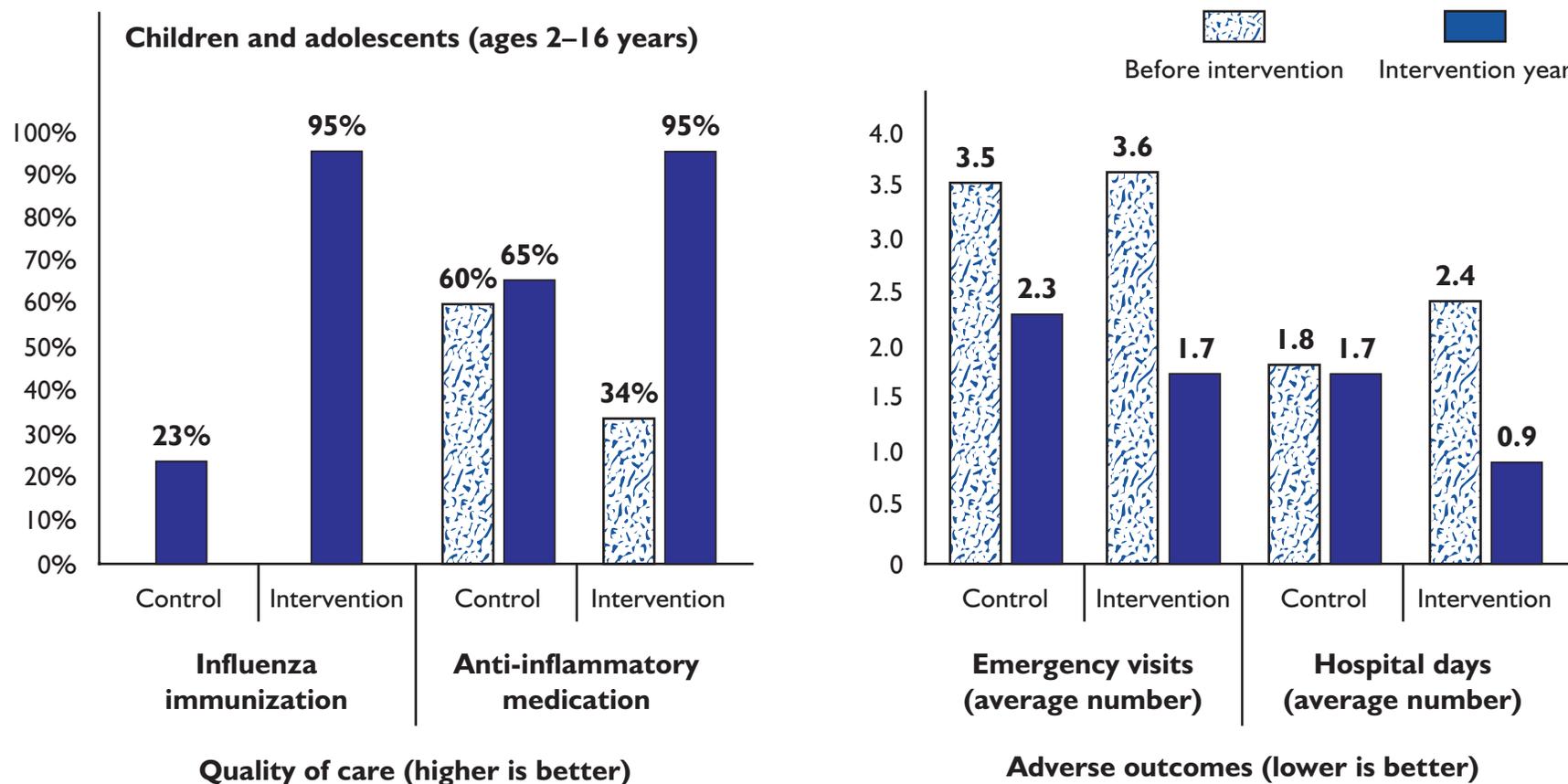
Source: parent interviews and medical records (Kelly et al. 2000).

**Implications:** An intensive education program combined with a series of outreach activities conducted by a nurse substantially improved quality of care and patient outcomes while also reducing treatment costs at an asthma specialty clinic.

# Education and Outreach to Improve Asthma Care and Outcomes at an Inner-City Hospital Specialty Clinic Serving Low-Income Children

A comprehensive asthma intervention that provided Medicaid-insured children with education, treatment, and

regular follow-up in an inner-city hospital-based specialty care clinic improved quality of care and outcomes.



Source: parent interviews and medical records (N=78) as reported by Kelly et al. (2000). Adapted and reproduced by permission of *Pediatrics*, Volume 105, Page 1032, Figure 1, Copyright 2000.



## CAPACITY TO IMPROVE — LIVING WITH ILLNESS — ADOLESCENCE — CHART 6:8

## Improving Diabetes Outcomes Through Coping Skills Training

**Why is this important?** Each year, about 13,000 children and adolescents are diagnosed with type 1 diabetes, in which the body does not produce insulin necessary to digest sugar and other food (LaPorte et al. 1995). An individual's ability to cope with a chronic disease like diabetes influences the success of treatment (Lazarus and Fokman 1984). The physical, emotional, and social demands of intensive diabetes self-management—which requires monitoring blood sugar, regulating diet and exercise, and making multiple insulin injections daily—are especially challenging for adolescents given developmental changes and stresses (Grey et al. 1999). As a result, adolescents with diabetes are at risk for poor disease control leading to hospitalizations and long-term complications, such as eye, kidney, and nerve damage.

**Intervention:** In this study, all 77 participating adolescents (ages 12 to 20 years) received intensive diabetes team management, including monthly visits at a specialty clinic and telephone follow-up. About half the teens were randomly selected to receive coping skills training during four to eight weekly small group sessions, followed by monthly booster sessions, to increase their “sense of competence and mastery by retraining inappropriate or non-constructive coping styles and forming more positive styles and patterns of behavior” (Grey et al. 2000). A nurse practitioner with experience in pediatric psychiatry and diabetes led teens in role-playing to model and give feedback on appropriate behavior in various social situations identified as problematic by youth, such as managing food choices with friends, decision-making about drugs and alcohol, and handling conflicts (Grey et al. 1999).

**Findings:** Glycosylated hemoglobin A1c test results (which give a three-month average reading of blood sugar control) were nearly identical at the start of the study among youth selected to receive coping skills training (intervention group) and those who did not (control group). One year after the start of the intervention:

- Average glycemic (blood sugar) control improved more in the intervention group than the control group (1.6 vs. 0.7 percentage point reduction in hemoglobin A1c level). A one percentage point reduction in this test is associated with a 15 to 30 percent reduction in risk of developing long-term diabetes complications (ADA 2002).
- Average quality of life impact score improved in the intervention group (13 percent lower perceived impact of diabetes) but worsened in the control group (9 percent higher impact), such that the average score was 14 percent better for teens who received coping skills training than the control group after one year.

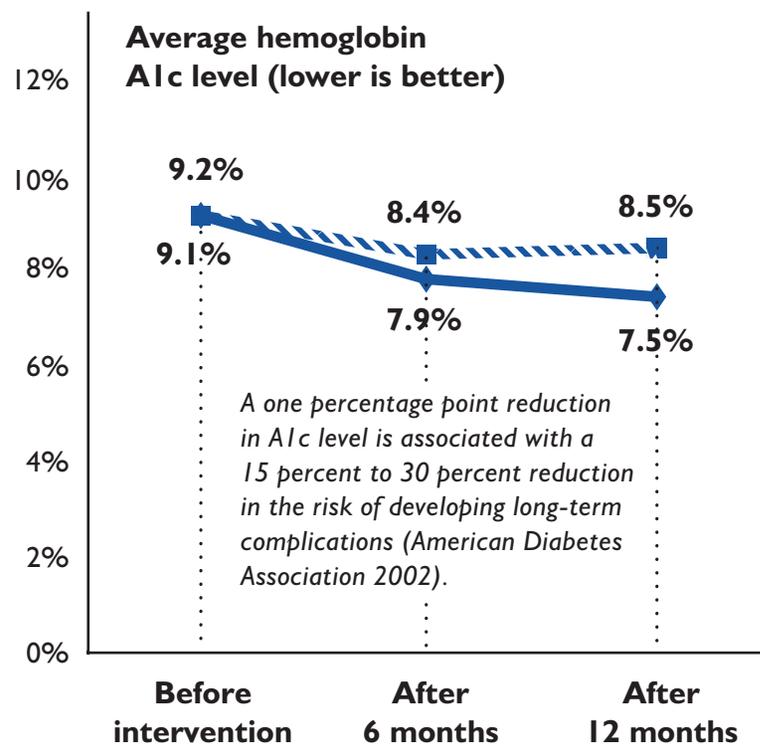
Source: ABCs of Diabetes Study (clinical data and youth self-reports), as reported by Grey et al. (1999; 2000); and personal communication with Margaret Grey (2003).

**Implications:** Adding a behavioral intervention to intensive diabetes management improves disease control and quality of life for adolescents. The Diabetes Complications and Control Trial demonstrated a 50 percent lower risk of developing eye disease after seven years among adolescents who reduced their average hemoglobin A1c level to about 8 percent (DCCT Research Group 1994).

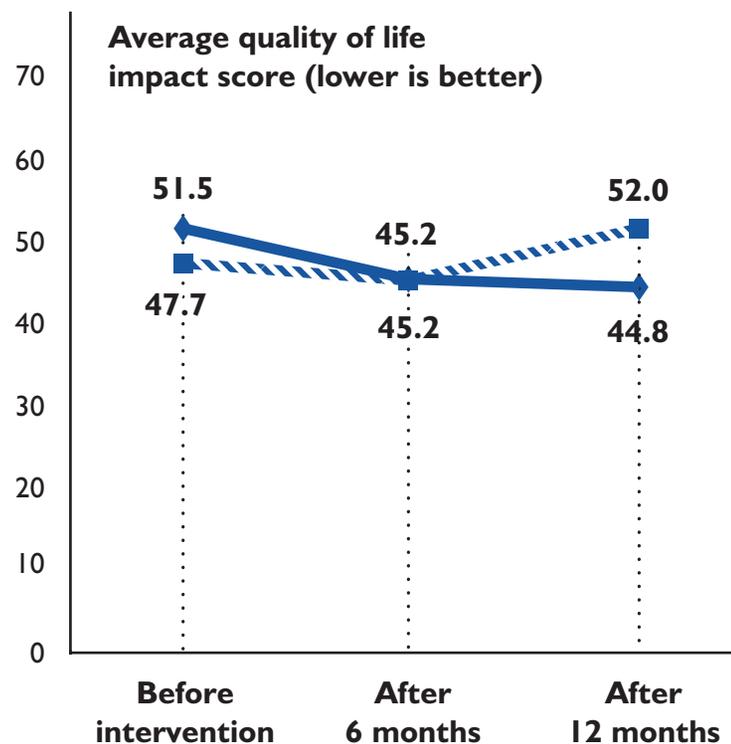
# Improving Diabetes Outcomes Through Coping Skills Training

A nurse-led behavioral intervention to teach coping skills for stresses associated with intensive diabetes management helped adolescents (ages 12–20 years) achieve better blood sugar

control and improvement in quality of life as compared to a similar group of youth engaged in intensive diabetes management only.



**Glycemic (blood sugar) control**



**Impact of diabetes on quality of life**

Source: ABCs of Diabetes Study (N=77), clinical data and youth self-reports, as reported by Grey et al. (1999, 2000), and personal communication with Margaret Grey (2003).

Adapted and reprinted from the *Journal of Pediatrics*, Volume 127, Margaret Grey et al., Coping skills training for youth with diabetes mellitus, Page 110, Copyright 2000, with permission from Elsevier.



## CAPACITY TO IMPROVE — PATIENT SAFETY — EARLY CHILDHOOD — CHART 6:9

## Decreasing Infections Acquired in the Neonatal Intensive Care Unit

**Why is this important?** Very low birthweight infants being cared for in neonatal intensive care units (NICU) are especially vulnerable to hospital-acquired (nosocomial) infections because of their immature immune systems and prolonged hospital stays (Harris 1997). Sepsis affects up to one of five very low birthweight infants in the NICU and is associated with substantially higher death rates and longer hospital stays (Stoll et al. 2002). The coagulase-negative staphylococcus (CONS) bacterium is the most frequent cause of such infections.

**Intervention:** Multidisciplinary teams from six NICUs engaged in a three-year collaborative process that included training on quality improvement, agreeing on common improvement goals and metrics, reviewing performance data, and developing a list of “potentially better practices” for improvement (Horbar et al. 2001). These practices were identified by sharing detailed analyses of care processes conducted by each site, reviewing the medical literature for evidence on prevention practices, and benchmarking the practices of participating sites and other superior performing NICUs through a series of site visits. Each NICU selected specific practices for improvement that its team considered most relevant, in the following areas: handwashing, nutrition, skin care, diagnosis, respiratory care, vascular access (intravenous line management), and organizational culture.

**Findings:** Among six NICUs participating in the improvement collaborative, the average rate of hospital-acquired CONS infections in very low birthweight infants decreased by 5.4 percentage points in absolute terms from 1994 (before the intervention) to 1996 (after the intervention). This change was significantly greater than a 0.9 percentage point decrease in the average infection rate among 66 comparison NICUs during this time. One year later (1997), the infection rate at the six collaborative sites continued to decline, to a level 9.7 percentage points lower than before the intervention, representing a 44 percent relative decrease since 1994. This change was significantly different from the trend at comparison NICUs. Infection rates improved at four of the six intervention sites, while worsening at the other two sites.

During the project, treatment costs were reduced by \$10,932 per infant among the six collaborating NICUs, representing average savings of \$2.3 million in annual patient care costs per NICU. Treatment costs rose at comparison NICUs. With an average resource commitment of \$68,206 per NICU, plus grant-funded support, the quality improvement produced \$9 in savings for every \$1 invested.

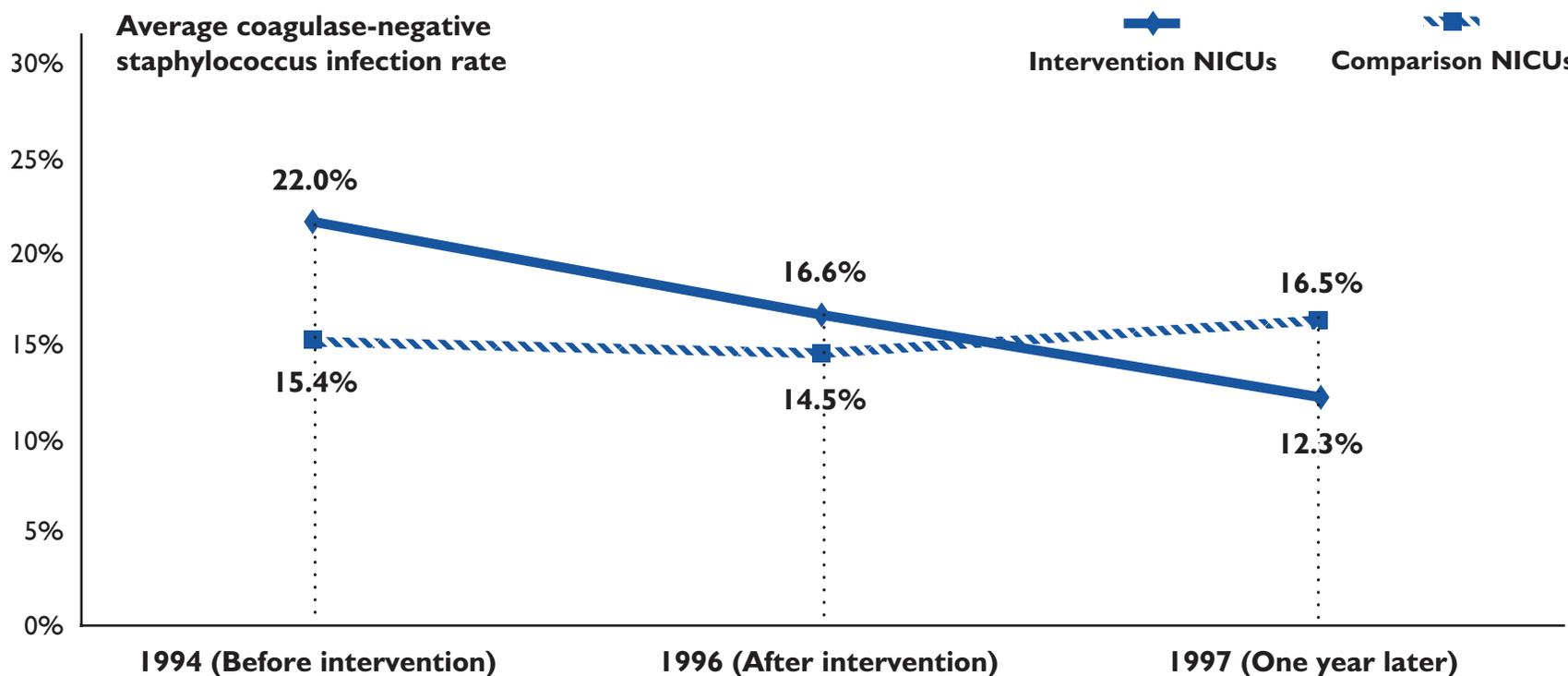
Source: Vermont Oxford Network, Neonatal Intensive Care Collaborative Quality Project, as reported by Horbar et al. (2001) and Rogowski et al. (2001).

**Implications:** An intensive, multidisciplinary, multicenter collaborative learning process conducted among highly motivated participants can support changes in local institutional practices that lead to improvement in average clinical outcomes and a reduction in patient care costs.

## Decreasing Infections Acquired in the Neonatal Intensive Care Unit

The coagulase-negative staphylococcus (CONS) bacterium is the most frequent cause of infections acquired by premature, very low birthweight infants in the neonatal intensive care unit (NICU). A collaborative quality-improvement project

among six NICUs resulted in a 44 percent lower incidence of CONS infection among such infants. This change was significantly different from the trend in infection rates among 66 other NICUs participating in a surveillance system.



Source: Vermont Oxford Network, Neonatal Intensive Care Collaborative Quality Project (N=745 to 789 infants at six intervention sites and 5,108 to 5,572 infants at 66 comparison sites, all with birthweight 501 to 1500 grams and admitted at or within 28

days of birth in each year), as reported by Horbar et al. (2001). Adapted and reproduced by permission of *Pediatrics*, Volume 107, Page 19, Figure 3, Copyright 2001.



*We'd like to know what you think about this chartbook. To take a short, anonymous user survey, click on the following link or copy the address into your Web browser: <http://64.73.28.22/s.asp?u=50446418798>. Or, e-mail [webeditor@cmwf.org](mailto:webeditor@cmwf.org) to receive an invitation to take the survey. You can also view and download the chartbook through the Commonwealth Fund Web site ([www.cmwf.org](http://www.cmwf.org)).*

## Technical Appendix

*This appendix provides information on data sources and study participants and methodologies. Since the chartbook presents data from many different kinds of sources and studies conducted by different researchers, methodologies differ from chart to chart. All differences described as significant reflect a 95 percent confidence level or greater.*

**Chart 1:1**—The National Survey of America’s Families is a random-digit-dialing survey of households with telephones and an area probability sample of households without telephones that provide national estimates for the civilian, noninstitutionalized population younger than age 65. Interviews for the 1999 survey were conducted in English or Spanish between February and October 1999 on behalf of the Urban Institute and Child Trends. Low-income families (under 200 percent of the federal poverty level) were oversampled. The 1999 Child Public Use File included 35,938 children younger than 18 years sampled from 44,499 households. Up to two children were sampled per household: one child age 5 or younger and one child ages 6 to 17 years. Information was obtained from the adult (typically a parent) who was most knowledgeable about the child. The 1999 response rate for child interviews was 81 percent. Child’s age was significantly associated with receipt of recommended well-child care in bivariate analysis (Yu et al. 2002; Safir et al. 2000).

**Chart 1:2**—The National Immunization Survey (NIS) has been conducted annually since 1994 by the National Immunization Program and the National Center for Health Statistics. The NIS provides national, state, and selected urban area estimates of vaccination coverage rates for U.S. children between the ages of 19 and 35 months at the time of the survey. The NIS combines two stages: 1) a random-digit-dialing telephone survey of nearly 1 million households conducted in English and Spanish (with interpreter services for other languages) to identify approximately 34,000 households with age-eligible children and obtain parent-reported vaccination histories based on written records whenever possible, and 2) a mail survey of all parent-identified child vaccination providers to validate the immunization record (the Provider Record Check Survey). Household and provider data are combined to produce provider-adjusted vaccination estimates. Provider vaccination record data was obtained for 21,317 children in 2002; the overall response rate for eligible households was 62 percent. Final estimates are weighted to represent all children ages 19 to

35 months and adjusted to account for nonresponse and households without telephones (Zell et al. 2000; CDC 2003b).

**Chart 1:3**—The Commonwealth Fund Survey of Parents with Young Children was a random-digit-dialing telephone survey of parents with children ages birth to 36 months. A nationally representative sample of 2,017 parents (response rate 68 percent) was interviewed from July 1995 to January 1996, including an oversample of African American and Hispanic households. One parent was randomly selected when two were present and one child was randomly selected when the household had more than one child ages birth to 36 months. Analysis for each topic was limited to parents of children between the ages for which that topic is recommended for discussion (N=170 parents of children younger than 3 months for newborn care, 1,645 parents of children ages 6 to 36 months for discipline, 1,011 parents of children ages 18 to 36 months for toilet training, and 2,017 parents of children ages birth to 36 months for all other topics). Analyses were weighted to reflect the overall distribution of parents in the U.S. with children younger than 3 years (Schuster et al. 2000).

**Chart 1:4**—The National Survey of Early Childhood Health is a telephone survey of a national random sample of 2,068 young children (ages 4 to 35 months), including an oversample of Hispanic and black children. The parent or guardian who is primarily responsible for the child’s medical care was selected for the interview. The survey was conducted in English and Spanish by the National Center for Health Statistics between February and July 2000, as a module of the State and Local Area Integrated Telephone Survey, which uses the National Immunization Survey sampling frame (see description of Chart 1:2 above). Results are adjusted to account for nonresponse and households without telephones so as to reflect the entire U.S. population of children ages 4 to 35 months. Only parents of children ages 4 to 9 months (N=432) were asked whether the child’s doctors or other health care providers had talked with them since the child’s birth about how the child communicates his/her needs. Only parents of children ages 10 to 18 months (N=674) and 19 to 35 months (N=962) were asked whether the child’s doctors or other health care providers had talked with them in the last 12 months (or since the child’s birth if the child was less than age 1 year) about words and phrases that the child uses and understands (Halfon et al. 2002; Blumberg et al. 2002).

**Chart 1:5**—The Commonwealth Fund Survey of the Health of Adolescent Girls and Boys was a nationally representative, stratified, school-based sample of 6,728 students (3,153 boys and 3,575 girls) in the fifth through the twelfth grades. A total of 297 public, private, and parochial schools (including an oversample of 32 urban schools) were randomly selected in accordance with their student representation in the population from a list maintained by the national Center for Educational Statistics. The survey was self-completed in the classroom setting during 1997. Results were weighted to reflect the U.S. population of in-school adolescents (Klein et al. 1999; Ackard and Neumark-Sztainer 2001).

**Chart 1:6**—National Committee for Quality Assurance (NCQA) Quality Compass data represent Health Plan Employer Data and Information Set (HEDIS) results submitted to NCQA for public dissemination by commercial and Medicaid health plans (NCQA 2003a). Data for this measure are collected from administrative claims data. The denominator includes female plan members ages 16 to 20 years by December 31st of the measurement who were continuously enrolled (no more than a 45-day gap) during the year and who had a visit code during the year for a service, procedure, or medication likely to be provided to sexually active females (such as pregnancy-related services, Pap smear, pelvic exam, screening and/or treatment for STDs, or contraceptive medications). The numerator includes those in the denominator who had at least one test for chlamydia during the measurement year (NCQA 2003b).

**Chart 1:7**—The National Ambulatory Medical Care Survey is an annual survey of office-based community physicians conducted by the National Center for Health Statistics. “Visits were sampled by using a multi-stage clustered probability sample design based on geographic location, provider specialty, and visits within individual physician offices.” Participating physicians (response rates 63 percent to 73 percent) complete a one-page encounter form for each patient visit during a randomly selected week, listing new or ongoing diagnoses and prescribed medications. Annual data were combined for 1991–1992 (60,252 visits) and 1998–1999 (37,467 visits). Visits to dermatologists and ophthalmologists were excluded. Antibiotics prescribed almost exclusively in topical or intravenous form and antimycobacterial medications were not counted. Patients diagnosed with more than one infectious disease were excluded from diagnosis-specific analyses. All rates were weighted to represent national estimates. The frequency of antibiotic prescribing and the use of broad-spectrum antibiotics were significantly different in 1998–1999 compared to 1991–1992 (Steinman et al. 2003).

**Chart 1:8**—National Committee for Quality Assurance (NCQA) Quality Compass data represent Health Plan Employer Data and Information Set (HEDIS) results submitted to NCQA for public dissemination by commercial and Medicaid health plans (NCQA 2003a). Data for this measure are collected from administrative claims data. The denominator includes health plan members with persistent asthma who were ages 5 to 9 years or 10 to 17 years by December 31st of the measurement year and who were continuously enrolled during the measurement year and the year prior to the measurement year (with no more than one 45-day gap in enrollment in each year). The numerator includes those in the denominator who had at least one dispensed prescription during the measurement year for a medication recommended for long-term asthma control by the National Asthma Education and Prevention Program: an inhaled corticosteroid, nedocromil, cromolyn sodium, leukotriene modifier, or methylxanthine (NCQA 2003b).

**Chart 1:9**—This study used administrative claim and encounter data from TennCare and Washington State Medicaid from 1995 to 1999. The study population included children ages 1 to 48 months at the start of a 365-day study period who were continuously enrolled during the 365-day study period and who had one inpatient or two outpatient claims or encounters with a diagnosis code for sickle cell disease (excluding codes for sickle cell trait and hemoglobin SC). Each subject’s 365-day study period began on the date of hospital discharge or the second outpatient visit. The outcome measure was the number of days during a 365-day period covered by prescription fills (regardless of overlap in dates) for a penicillin or macrolide antibiotic, or for trimethoprim-sulfamethoxazole (Sox et al. 2003).

**Chart 1:10**—The Cystic Fibrosis Foundation Patient Registry collected data in 2002 on 23,105 patients (including 972 newly diagnosed during 2002) with cystic fibrosis who received care at more than 115 Cystic Fibrosis Foundation–accredited care centers across the U.S. The registry thus includes about three-quarters of the estimated 30,000 people with cystic fibrosis in the U.S. Three of five (59.8%) of these patients (approximately 13,817) were younger than age 18 years in 2002. Rates reflect services received during 2002 (CFF 2003b).

**Chart 2:1**—The Healthcare Cost and Utilization Project (HCUP) Nationwide Inpatient Sample (NIS) is “the largest publicly available U.S. all-payer database, with data from nearly 1,000 hospitals in 28 states, approximating a 20 percent stratified random sample of nonfederal short-term, general, and other specialty hospitals.” All results were weighted to reflect the entire population of discharges from U.S. community hospitals. Patient Safety Indicators were developed

through a multi-step process including literature review of validity and reliability, expert clinician panel review, coding review, and empirical testing against medical records to ensure that the algorithm was more likely to identify process of care failures than a random sample of control cases. Rates were calculated using a beta version (dated July 2002) of the PSI software and were adjusted by age, gender, age-gender interactions, comorbidities, and diagnosis-related group (DRG) clusters, except as noted below. The denominator for each indicator is limited to the population most likely to be at risk for the complication, as described in the following footnotes to the chart. The hospital-level indicators shown in the chart generally use only secondary diagnoses to eliminate complications that were present on admission (AHRQ 2003a, 2003b):

- (1) decubitus ulcer per 1,000 discharges of length four or more days, excluding paralysis patients, patients admitted from long-term care facilities, neonates, and obstetrical admissions (N=364,783).
- (2) birth trauma injury (any diagnosis) per 1,000 live births, excluding preterm and osteogenesis imperfecta births; this rate was adjusted only for gender (N=4,056,052).
- (3) postoperative septicemia per 1,000 elective-surgery discharges of longer than 3 days, excluding patients admitted for infection, patients with cancer or immunocompromised states, and obstetric conditions (N=47,197).
- (4) postoperative respiratory failure per 1,000 elective-surgery discharges, excluding patients with respiratory disease, circulatory disease, and obstetric conditions (N=139,353).
- (5) accidental puncture or laceration during procedures per 1,000 discharges, excluding obstetric admissions (N=1,931,018).
- (6) infections due to medical care per 1,000 discharges, excluding immunocompromised or cancer patients and neonates (N=2,039,840).
- (7) postoperative abdominal wound dehiscence per 1,000 abdominopelvic surgery discharges, excluding obstetric conditions (N=125,313).
- (8) postoperative pulmonary embolus or deep vein thrombosis (DVT) per 1,000 surgical discharges, excluding patients admitted for DVT, obstetrics, neonatal, and plication of vena cava before or after surgery (N=371,850).
- (9) postoperative hemorrhage or hematoma with surgical drainage or evacuation, not verifiable as following surgery, per 1,000 surgical discharges, excluding obstetrical admissions (N=372,041).
- (10) postoperative physiologic and metabolic derangements per 1,000 elective-surgery patients, excluding obstetric admissions, patients with diabetic coma, and patients with renal failure who also were diagnosed with acute myocardial infarction, cardiac arrhythmia, cardiac arrest, shock, hemorrhage, or gastrointestinal hemorrhage (N=161,121).
- (11) complications of anesthesia per 1,000 surgical discharges, excluding patients who also had substance use disorders (N=400,278).
- (12) deaths per 1,000 admissions for low-mortality DRGs with a NIS 1997 benchmark of less than 0.5 percent mortality, excluding trauma, immunocompromised, and cancer patients (N=5,238,794).
- (13) iatrogenic pneumothorax per 1,000 discharges, excluding neonates, obstetrical admissions, and patients with trauma, thoracic surgery, lung or pleural biopsy, or cardiac surgery (N=1,866,063).
- (14) foreign body left in during procedure per 1,000 discharges, excluding neonates (N=2,128,169).
- (15) transfusion reaction per 1,000 discharges, excluding neonates; this rate was adjusted only for gender (N=2,128,169).

**Chart 2:2**—This chart presents data describing medication mistakes among hospitalized children at two Boston teaching hospitals, detected by querying and receiving voluntary reports from clinicians and by reviewing medication orders, medication administration records, and medical records during six weeks in 1999. At the first hospital, a freestanding children’s hospital, the study included randomly selected general medical, general surgical, and short-stay wards and pediatric medical/surgical ICU. At the second hospital, which treats both adults and children, the study included all pediatric wards, including general medical/surgical wards, pediatric medical/surgical ICU, and neonatal ICU. Data collectors were nurses, pharmacists, and physicians trained in an identical manner. Two physicians reviewers independently classified suspected and potential adverse drug events and rated the severity of any injury to the patient. Medication errors were defined as errors in ordering, transcribing, dispensing, administering, or monitoring a drug, excepting rule violations with little potential for harm that are usually interpreted correctly by pharmacy and nursing staff. Adverse drug events were defined as injuries that result from use of a drug (Kaushal et al. 2001).

**Chart 2:3**—The National Nosocomial Infections Surveillance (NNIS) System includes more than 300 participating hospitals that report data on certain

hospital-acquired infections to the CDC using standard protocols for at least one month each year. Accuracy of reporting is generally high (Emori et al. 1998). Participating NNIS hospitals must have at least 100 beds and meet minimum requirements for infection control staffing; they are larger on average but have similar geographic distribution compared to U.S. hospitals generally (Richards et al. 2001). The number of participating hospitals has increased since the mid-1980s (Sartor et al. 1995). Data includes only those pediatric intensive care units (PICUs) that reported at least 50 device- or patient-days (N=79 PICUs with 428,104 central line days for bloodstream infections during 1995–2003; 75 PICUs with 201,096 urinary catheter-days for urinary tract infection during 1995–2003, and 75 PICUs with 285,607 ventilator-days for pneumonias during 1995–2001). Ventilator-associated pneumonia was reported for January 1995 to June 2001 (rather than for January 1995 to June 2003 as for other infections) because the NNIS began using new criteria to define nosocomial pneumonia in January 2002 that would not be comparable to the 1986–1990 reference period shown in the chart (NCID 2001; 2003).

**Chart 3:1**—The Medical Expenditure Panel Survey (MEPS), sponsored by the Agency for Healthcare Research and Quality (AHRQ), collects nationally representative data on health care use, expenditures, coverage, and quality for the U.S. civilian, noninstitutionalized population. The household component is a subsample of participants in the prior year’s National Health Interview Survey (see Chart 3:2). Data shown were collected using questions derived from AHRQ’s Consumer Assessment of Health Plans (CAHPS®) survey asked on the MEPS Parent Administered Questionnaire (PAQ), a mail-back survey of parents of children ages 17 and younger. In 2000, the PAQ was completed by 6,577 respondents representing 90 percent of those eligible for the PAQ and an overall response rate of 63 percent (AHRQ 2002b; www.meps.ahrq.gov).

**Chart 3:2**—The National Health Interview Survey (NHIS) is an annual, nationally representative, multi-stage probability sample survey of the civilian, noninstitutionalized population of the U.S., conducted by the U.S. Census Bureau for the National Center for Health Statistics. Data on children are collected through face-to-face interviews with adults familiar with the health of one randomly selected child per family. In 2000, interviews were completed for 13,376 children, representing 91 percent of the children eligible for the child sample and an overall response of 79 percent (Blackwell et al. 2003).

**Chart 3:3**—The 1997 National Survey of America’s Families sampled 28,867 children in more than 44,000 households, with a response rate 65 percent (see

Chart 1:1 above for general information on this survey). “Children were categorized as having unmet need if they had exceeded a cutoff point on a mental health screening measure [the Mental Health Indicator] but had not received any mental health services in the past 12 months.” The Mental Health Indicator is a validated tool comprised of selected items from the Child Behavior Checklist that “best discriminated between demographically similar children who were or were not referred for mental health services, [and] is thus a measure of need for clinical mental health evaluation.” A stringent cutoff point was set to “avoid concerns about overinclusion of minor or transient symptoms,” resulting in specificity of 88 percent to 90 percent for each age-gender category. In both bivariate and multivariate analyses, Hispanic children had significantly greater odds of unmet need compared to white children, and publicly insured children had significantly lower odds of unmet need compared to uninsured children. There were no significant differences in unmet need by age category (middle childhood vs. adolescence), by gender, by income (poor vs. not poor), between children of white race and those of black or other race, or between uninsured and privately insured children. Multivariate analysis controlled for predisposing sociodemographic factors, enabling resources, and child’s mental health status (Kataoka et al. 2002).

**Chart 3:4**—The 2000 National Health Interview Survey is described above for Chart 3:2. Time since last dental visit was assessed with this question: “About how long has it been since [child] last saw or talked to a dentist? Include all types of dentists, such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.”

**Chart 3:5**—Birth certificate data provided to the National Center for Health Statistics include all of the 4 million births registered in the 50 states and District of Columbia in 2001. More than 99 percent of births in the U.S. are registered. The rate of first trimester prenatal care was computed using birth certificates that listed the month that prenatal care began (98 percent of all birth certificates in 2001) (Martin et al. 2002).

**Chart 3:6 to 3:8**—The National Survey of Children with Special Health Care Needs is sponsored by the federal Maternal and Child Health Bureau and conducted in cooperation with the National Center for Health Statistics (NCHS). Using the State and Local Area Integrated Telephone Survey (SLAITS) mechanism, a random-digit-dialing sample of 196,888 households with children younger than age 18 years in each of the 50 states and the District of Columbia was screened from October 2000 to March 2002. Among these households, 38,866 interviews

were completed (approximately 750 in each state) with a parent who was most knowledgeable about a child identified as having special health care needs. One child was randomly selected when there was more than one child with special needs in the same household. Children with special health care needs (CSHCN) were identified using the CSHCN Screening Tool, which asks whether the child: 1) needs or uses more medical, mental health, or educational services than usual for most children of the same age, 2) needs or uses prescribed medicine other than vitamins, 3) is limited in the ability to do things that most children of the same age can do, 4) needs or gets special therapy, or 5) has any kind of emotional, developmental, or behavioral problem needing treatment or counseling. Two follow-up probes ask whether the need for services is because of a medical, behavioral, or other health condition and whether the condition has lasted more than a year. The population at risk for developing special needs was not included because there is no currently accepted method for identifying such children using a survey questionnaire (van Dyck et al. 2002). The weighted overall response rate for special needs interviews was 61 percent (Blumberg et al. 2003). Results shown in the charts were compiled by staff of the NCHS Special Population Surveys Branch (CDC 2003d), based on specifications that are forthcoming (McPherson et al. 2004).

**Chart 4:1**—The 2000 Medical Expenditure Panel Survey and Parent Administered Questionnaire are described above for Chart 3:1.

**Chart 4:2**—The Picker Institute’s Pediatric Inpatient Survey was adapted from the Picker Adult Inpatient Survey and a quality of care survey developed by Children’s Hospital of Boston. Psychometric analysis indicates that the instrument is reliable and has high correlation with overall satisfaction and dimension problem scores. Survey item responses were dichotomized as “problems” or “not problems.” Each survey question was mapped to one of seven quality dimensions and a percentage of problem responses was calculated for each patient for each dimension. A problem score of 0 would mean no problems were reported and 100 would mean problems were reported on 100 percent of processes asked about in the survey. The overall problem score is an average of all the dimensions. Surveys were mailed to parents about two weeks after their child was discharged from one of 38 participating hospitals (primarily academic and teaching institutions) for a nonsurgical condition that did not require intensive care, followed by reminders to nonrespondents. Completed surveys were received from 12,600 parents, representing 48 percent of the surveys mailed (Co et al. 2003).

**Chart 4:3**—The 2000 National Survey of Early Childhood Health is described above for Chart 1:4.

**Chart 5:1**—The 1999 National Survey of America’s Families is described for Chart 1:1. In bivariate analysis, all independent variables shown in the chart were significantly associated with receipt of recommended well-child care. In multivariate analysis (after controlling for the child’s health insurance, family income, race and ethnicity, health status, and parent’s age and education), children who were uninsured or had poor health status or a parent with low educational attainment had significantly greater odds of not receiving recommended well-child visits. Children of Hispanic ethnicity or black race, covered by public insurance, or with a parent younger than 30 years, had significantly lower odds of not receiving recommended well-child visits. Differences in well-child visits by family income were no longer significant in multivariate analysis (Yu et al. 2002).

**Chart 5:2**—The National Immunization Survey (NIS) is described above for Chart 1:2 (which describes 2002 data). For the 1994 NIS, 25,247 household interviews were completed from April to December and 7,594 provider surveys were returned (41 percent of children eligible for provider follow-up) (CDC 1995). For the 1998 NIS, 31,664 household interviews were completed and 21,827 provider surveys were returned (67 percent of eligible children) (CDC 1999b). The 95 percent confidence intervals of the rates did not overlap for any of the comparisons shown on the chart for 1998 and 2002 (confidence intervals not available for 2004). Rates for rural areas (non-MSA) are not shown because their confidence intervals overlapped with those of urban and/or suburban areas. Data were not available in all years for other racial groups, which are not shown. The category “unknown poverty” was omitted for clarity. (See [www.cdc.gov/nis](http://www.cdc.gov/nis) for NIS data tables.)

**Chart 5:3**—The Asthma Care Quality Assessment Project involved five large health plans: three group model HMOs serving employer- and Medicaid-insured populations and two mixed-model Medicaid managed care organizations. Medicaid-insured children (ages 2 to 16 years) were included if computerized data indicated a physician diagnosis for asthma or a prescription for an asthma medication and a parent confirmed that the child had physician-diagnosed asthma (all eligible children were identified in four plans and a random sample was drawn in one large plan). A total of 1,658 interviews with parents were completed in English or Spanish during 1999 and included in the analysis (63 percent of those eligible). Interview

questions were based on previously validated instruments. Persistent asthma was defined as having five or more symptom days in past two weeks, using beta-agonist medications three or more times per week in the past two weeks, or using anti-inflammatory medications daily in the past two weeks. Compared to white children (31 percent of the sample), black children (38 percent of the sample) had worse asthma status, and Latino children (19 percent of the sample) missed more school days. In multivariate analyses that controlled for sociodemographic variables and asthma status, minority children had significantly lower odds of using inhaled anti-inflammatory medication in comparison to white children, while process of care measures were equal or better for minority children (Lieu et al. 2002).

**Chart 5:4**—The help-seeking analysis shown in this chart is derived from the first stage of a two-stage study. A gender-stratified random sample of 3,158 children (limited to one child per household) was drawn from children in kindergarten through fifth grade in one north central Florida school district who lived in a household with a telephone, were not receiving special education services for mental retardation or autism, and were white (reported as “Caucasian”) or African American (other minorities made up less than five percent of the student population). Parents of 1,615 children were contacted and agreed to participate in a telephone interview between October and December 1998. Mailed teacher questionnaires were completed with parent permission for 1,197 children. A total of 389 children were included in the help-seeking analysis if they had been diagnosed or treated for ADHD or scored two standard deviations above the norm by parent or teacher rating on a standardized screening measure, the SNAP IV. Estimates were adjusted for sampling and nonparticipation effects. All gender and racial differences in parent recognition and help-seeking were significant in bivariate analysis. Gender and racial differences in help-seeking remained significant in multivariate analyses after controlling for predisposing sociodemographic factors, enabling factors, and need for services. However, there were no significant differences by gender or race for parents’ recognition of behavioral problems after controlling for these factors (Bussing et al. 2003).

**Chart 5:5**—The National Survey of Children with Special Health Care Needs is described above for Charts 3:6 to 3:8.

**Chart 5:6**—The Consumer Assessment of Health Plans Benchmarking Database 1.0 included 9,540 children (younger than age 18 years) enrolled in Medicaid managed care plans in Arkansas, Kansas, Minnesota, Oklahoma, Vermont, and

Washington State in 1997 and 1998. Surveys were administered in English and Spanish by phone and mail with a 42 percent average response rate. Language for Hispanic and Asian parents was based on what she/he reported primarily speaking at home. Data for missing race and language and other race were omitted from the chart for clarity. The chart presents composite scores for three of five performance domains measured by the survey (see Charts 3:1 and 4:1 for examples of items included in these domains). After controlling for parent age, gender, and education and child’s health status, ratings given by African Americans, American Indians, and non-English-speaking Hispanic and Asian parents were significantly different from ratings given by white parents for most domains shown on the chart, except for “Provider Communication” among African Americans and “Getting Needed Care” among Hispanic Spanish-speaking parents. Ratings given by English-speaking Hispanic and Asian parents were not significantly different from ratings given by white parents (Weech-Maldonado et al. 2001).

**Chart 6:1**—This before-and-after study included all physician practices in Durham, N.C., that enrolled at least five patients per month: two family practice group practices, three pediatric group practices, an HMO pediatric clinic, a university medical center, and a federally qualified community health center. A random sample of 40 medical records was abstracted at each practice at baseline (N=339) and separate follow-up samples were abstracted 12 months after each practice’s office systems were operational. The follow-up samples consisted of 35 charts from each of three age groups at each practice: 12 to 18 months (N=289), 19 to 24 months (N=285), and 25 to 30 months (N=300). All rates of preventive services shown in the chart were significantly different at follow-up from rates at baseline. Longer time of exposure to the intervention was associated with a significant trend toward increased rates of preventive care. Logistic models accounted for clustering of patients within practices (Bordley et al. 2001).

**Chart 6:2**—This prospective controlled trial was conducted at 15 pediatric practice sites located in 14 states with enrollment staggered between Sept. 1996 through Nov. 1998. Newborns up to 4 weeks old were consecutively enrolled at birth or at their first office visit if they were not to be adopted or placed in foster care, were not too ill to make an office visit by age 4 weeks, their mother spoke English or Spanish, and the family intended to continue at the practice for at least 6 months. At each of six sites, 400 newborns were randomized to intervention or control groups (the same clinicians cared for children in both groups). At each of nine sites, about 200 newborns were

enrolled in an intervention practice and 200 at a matched comparison practice. Data was obtained from telephone interviews in English and Spanish when the child was 30 to 33 months (N=3,737 primarily mothers, representing 67 percent of 5,565 enrolled families), enrollment forms, and a random sample of medical records at each practice. In bivariate analyses of results from all sites combined, 21 of 24 quality of care outcomes measured in the study (only five of which are shown in the chart) were significantly improved for the intervention versus control group and comparison sites. These results were confirmed in multivariate analysis that controlled for site of enrollment and characteristics of the child, parent, and family, for the fact that families within sites tend to respond more similarly than those at different sites, and for nonrandom assignment at quasi-experimental sites or selective reporting of outcome data (Minkovitz et al. 2003).

**Chart 6:3**—This chart compares two separate retrospective data analyses. Rhode Island data were derived from a random sample of 2,000 children ages 19 to 35 months as of June 30, 1997, who were continuously enrolled (with no more than a 30-day gap) in the Rhode Island Medicaid managed care program from July 1996 through June 1997. Data on lead screening performed from birth to June 30, 1997, were available from the medical records of the primary care provider(s) for 1,988 of such children (Vivier et al. 2001). Comparison data were derived from Medicaid claims for 15 states that submitted complete 1994 and 1995 data to the federal government’s State Medicaid Research Files. The analysis was limited to young children who had an opportunity to receive a blood lead test paid for directly by Medicaid (N=288,963), specifically those that: 1) were enrolled in Medicaid for six months before and after their first or second birthday; 2) had their first or second birthday between July 1994 and June 1995; 3) had made at least one visit to a Medicaid provider; 4) had no evidence of ever being enrolled in Medicaid managed care; and 5) had no evidence of coverage by private health insurance before 19 months for one-year olds and 31 months for two-year-olds (GAO 1999).

**Chart 6:4**—In this before-and-after study, five community and migrant health centers (CMHCs) were selected for study participation based on diversity of geography, patient population, and clinician types; adequacy of information infrastructure; and stability and commitment of leadership. Data shown in the chart were derived from telephone interviews conducted by research staff with two independent samples of adolescent patients (ages 14 to 19 years) at pre-intervention (N=260) and nine to 15 months post-intervention (N=274). Adolescents and their parents seen at clinic visits were consented and enrolled

by clinic staff. Interviews, conducted two to four weeks after clinic visits, assessed whether adolescents recalled receiving each of 31 recommended counseling, screening, examination, or laboratory services. Differences in rates of screening (before versus after the intervention) were significant for all topics shown in the chart (Klein et al. 2001).

**Chart 6:5**—In this cluster-randomized controlled trial, the 10 largest pediatric clinics affiliated with a large HMO were selected for participation from those that were willing, had no adolescent-specific clinic, had a minimum of 500 sexually active adolescent girls (ages 14 to 18 years) visiting for routine checkups each year, and served an ethnically diverse population. Sites were randomly assigned to intervention or usual care; site staff were blinded to study conditions and assignment. Screening rates were determined using a patient encounter and laboratory database. Site-specific sexual activity rates were determined using an anonymous survey administered after routine checkup visits. Among adolescent girls ages 14 to 18 years who had 7,920 routine checkup visits during the April 2000 through March 2002 study period, 1,017 and 1,194 were estimated to be eligible for screening in the intervention and control sites, respectively. Estimated screening rates were calculated (number of chlamydia tests done divided by the product of the number of girls seen for checkups and the sexual activity rate) at baseline and six consecutive three-month periods during the intervention (only baseline and final rates are shown in the chart). The screening rate was significantly higher in the intervention clinics than in control clinics by the four- to six-month period after the start of the intervention and remained so throughout most of the post-intervention period. A statistical test (repeated measures analysis of variance) of time period by study group interaction effect found that the change in screening rates differed significantly for the intervention and control sites (Shafer et al. 2002).

**Chart 6:6**—In this cluster-randomized controlled trial, 12 clinical practices affiliated with two managed care organizations were stratified by size and randomly assigned (by pairs based on similar ranked baseline antibiotic prescribing rates) to intervention or control groups. Computerized claims data were analyzed for enrolled children ages 3 months up to 72 months if they had pharmacy benefits for at least three months during the study period and had a record of ambulatory visits and antimicrobial prescribing during the study period. There were 14,468 and 13,460 patients in the baseline and intervention years, respectively. Observation time in person-years was determined for each child as the period of membership in the age subgroup (based on age at the start of the intervention year) during the baseline and intervention years.

Baseline antibiotic use was significantly lower in the intervention sites. The change in unadjusted dispensing rates (shown in the chart) was significantly greater for intervention versus control sites. In a comparison of rates for 8,815 children enrolled during both years of observation (not shown), a significant intervention effect was confirmed after adjusting for each patient's antibiotic use in the baseline year, their age, and correlation between prescription rates for children in each practice site. This effect was confirmed in separate practice-level analyses, which found that the improvement was not attributable to extreme results at any one practice site (Finkelstein et al. 2001).

**Chart 6:7**—Participants in this controlled before-and-after study included Medicaid-insured children and adolescents, ages 2 to 16 years, who had visited an inner-city hospital emergency room two or more times or been hospitalized one or more times for asthma in the past year, had received primary care in the hospital's outpatient clinic, had not been evaluated by an asthma specialist in the past two years, and whose family consented to participate. Participants were alternately assigned to intervention or control groups (the family and interviewer were not aware of group assignment at recruitment), which were demographically similar at baseline. Most children continued to receive the majority of their care from the hospital's outpatient clinic during the intervention. Utilization data were collected through monthly telephone interviews with parents of children and verified by comparison to medical records. Data were obtained from hospital financial records on charges for outpatient medical care of study patients; charges for hospitalizations and ER visits that occurred in other institutions were imputed based on the study hospital's average charges. The cost of the outreach nurse (12 hours per week or \$15,000/year) was included in the cost of the intervention. In logistic regression analysis controlling for individual history of asthma outcomes in the prior year, children in the control group were significantly more likely than those in the intervention group to have an ED visit and to be hospitalized for asthma in the study year (Kelly et al. 2000).

**Chart 6:8**—Adolescent patients (ages 12 to 20 years) attending a university-affiliated diabetes clinic were invited to participate in this randomized controlled trial if they had no other health problems except for treated hypothyroidism, had been taking insulin for at least one year, had recent hemoglobin A1c between 7 percent and 14 percent, had no severe hypoglycemic events in the past six months, and were in school grade appropriate to their age within one year. Between November 1, 1995, and

December 1, 1997, 77 of 105 invited patients agreed to participate and were randomly assigned to control or intervention groups; there were no significant differences between participants and non-participants or between control and intervention groups on measured variables at baseline. Diabetes care providers and data collectors were blinded to study group assignment. Analysis of variance for repeated measures and simple post hoc contrast tests found that average hemoglobin A1c levels and quality-of-life scores (measured using the Diabetes Quality of Life: Youth instrument) improved significantly more over time and were significantly different at six months and 12 months for the intervention group compared to the control group (Grey et al. 2000).

**Chart 6:9**—This comparative before-and-after study involved six self-selected members of the Vermont Oxford Network, a voluntary group of professionals committed to research, education, and quality improvement. Data on project outcomes were derived from the Network's database of standardized information on infants weighing 401 to 1,500 grams at birth who were born at or transferred to participating NICUs within 28 days of birth. Nosocomial infection was defined as the occurrence, after the third day of life, of an infection from a predefined list of bacterial pathogens. "Coagulase-negative staphylococcal infection [CONS] required the recovery of the organism from blood or spinal fluid, signs of systemic illness, and treatment for 5 or more days antibiotics." The comparison group included 66 North American NICUs that contributed 25 or more cases to the Network database from 1994 to 1996 and were not participating in the intervention. Primary analyses compared change in average CONS infection rates from baseline (1994) to a predefined end-point (1996) with additional comparisons to 1997. The study included infants weighing 501 to 1,500 grams who were hospitalized more than three days at intervention sites (N=745 born in 1994, 772 born in 1996, and 789 born in 1997) and at comparison sites (5,108 born in 1994, 5,528 born in 1996, and 5,572 born in 1997). Significant differences in magnitude of change in average CONS infection rates at intervention and comparison sites (group-by-year interaction) were found using a logistic regression model that controlled for birth weight, location of birth, multiple birth, assisted ventilation, and year of birth. Secondary analysis (based on variable, year of birth) found a significant change in outcome over time among intervention NICUs from 1994 to 1997. There was also a significant decline in the average rate of all measured nosocomial infections at the intervention sites during this time, attributable to the decline in CONS infections (Horbar et al. 2001).

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**Sheila Leatherman** is a research professor at the School of Public Health, The University of North Carolina at Chapel Hill, and a Senior Associate of The Judge Institute of Management (1996) and Distinguished Associate of Darwin College at the University of Cambridge, England. She conducts research and policy analysis in the United States and the United Kingdom, focusing on quality of care, health systems reform, performance measurement and improvement, and the economic implications of implementing quality enhancing interventions in health care delivery.

In the United States, she conducted pioneering methodological research in quality measurement for managed care populations, resulting in a program that was awarded a U.S. patent in 1996. She was appointed by President Clinton in 1997 to the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, chairing the sub-committee to develop a national strategy for quality measurement and reporting. She subsequently served on the Strategic Framework Board of the National Quality Forum. She is the lead author of a series of chartbooks on quality of health care in the U.S., commissioned by the Commonwealth Fund. In the United Kingdom, she was commissioned by The Nuffield Trust to assess the British Labour Government's proposed quality reforms for the National Health Service in 1997–1998 and evaluated the mid-term impact of the 10 year quality agenda in the NHS, resulting in publication of the book, *Quest for Quality in the NHS*, in December 2003.

Professor Leatherman is an elected member of the Institute of Medicine of the U.S. National Academy of Sciences (2002), where she serves on the Health Care Advisory Board, and of the National Academy of Social Insurance (1997). She has a broad background in health care management in state and federal health agencies, as chief executive of an HMO, and as senior executive of a large national managed care company in the U.S. She is a senior advisor to The Nuffield Trust and to The Health Foundation in the United Kingdom, a member of the RAND Health Advisory Board, and serves on the board of directors of the international organization Freedom From Hunger.

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He was previously research director in a health services research center affiliated with a national health care company, where he researched health system performance and implemented quality evaluation tools in health plans nationally. He began his career as an internal consultant for a local government, where he supported quality improvement through operations research and information systems development.

He received his bachelor's degree with honors from Yale College and a master's degree in health care management from the University of Connecticut, where he was the Blue Cross Blue Shield of Connecticut health care management scholar. During 1996–1997, he was a public policy fellow at the Humphrey Institute of Public Affairs at the University of Minnesota. He serves on a local citizens' health care advisory committee working to improve the accessibility of rural health care in his community.



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