



Adolescent and Parent Views on Health Care Quality

Standardized Measures, Quality Results, Status of Measurement and Research Needs and Opportunities

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Committee Questions

1. What are adolescent and parent views on the health care they receive and how does this vary among groups of adolescents? What do adolescents want from their health care?
2. What is the status of the development and use of patient-centered measures of quality?
3. What are opportunities and research needs to advance understanding of patient-centered care for adolescents?

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Question 1: Adolescent Views (Ages 12-17) Quality Topics With Standardized Measures

1. Communication with Providers (YAHCS)
 - explains clearly, listens carefully, respects you, speaks in language you understand, spends enough time
2. Helpfulness of Office Staff (YAHCS)
3. Private and Confidential Visits with Providers (YAHCS)
4. Provision of Recommended Counseling & Screening (YAHCS)
 - Risky behaviors (smoking/chew, alcohol/drunk driving, street drugs, steroids, sexual/physical abuse, violence, guns, seat belts/helmets)
 - Unwanted pregnancy and STDs
 - Diet, Weight and Exercise
 - Mental Health, Emotions and Relationships
 - Helpfulness of counseling/screening
5. Access to Care (problems getting needed care, know a place to go for private/confidential care) (YAHCS)
6. Receipt of Health Information (YAHCS)

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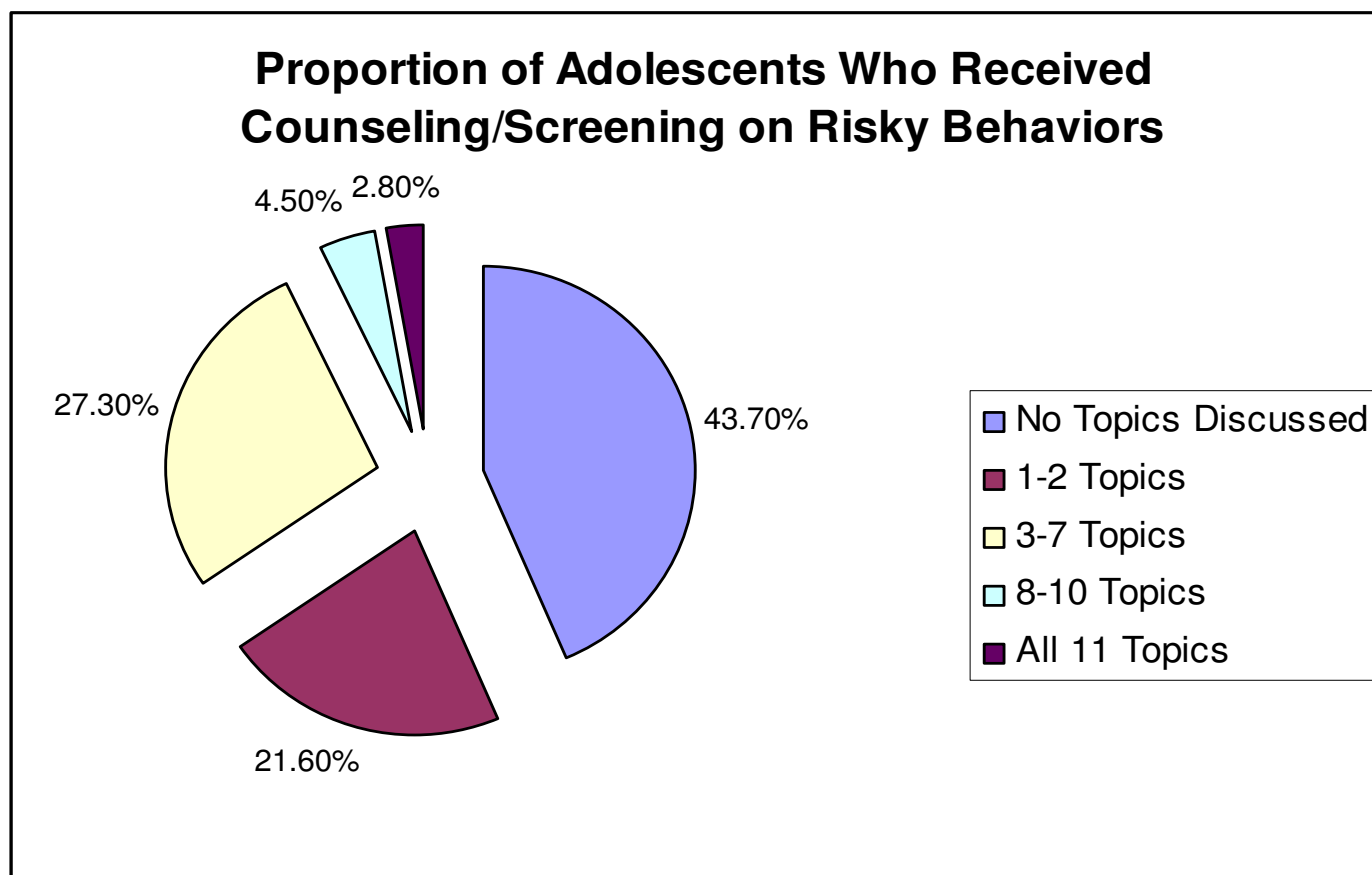
Question 1: Parent Views

Quality Topics With Standardized Measures

1. Medical Home for Adolescents (NSCH; NS_CSHCN)
 - Personal doctor or nurse
 - Communication with providers
 - Access to primary provider (phone and urgent care)
 - Care coordination to help access and follow-up on specialist care and other special services
2. Transition to adult health care for adolescents with special health care needs (NS_CSHCN)
3. Reports on adequacy of insurance (NS_CSHCN)
4. Reports mental health care (Child ECHO)
5. Reports on health needs, access and outcomes
 - Special health care needs status
 - Missed school
 - Met and unmet needs for medical, dental, mental health care (NS_CSHCN, NSCH)



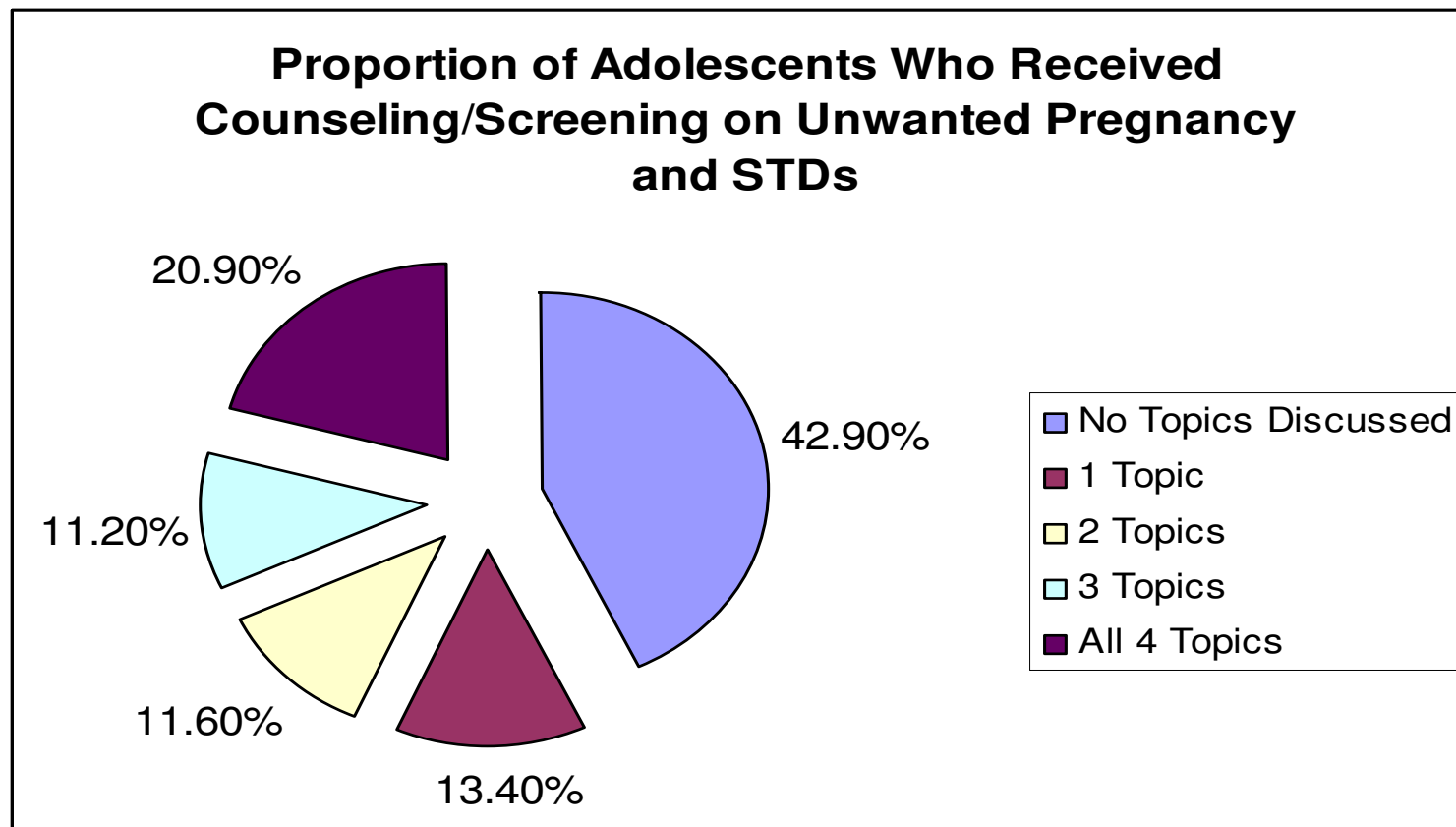
Adolescent Views (YAHCS) Counseling & Screening On Risky Behaviors for Adolescents With Qualifying Health Care Visits



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



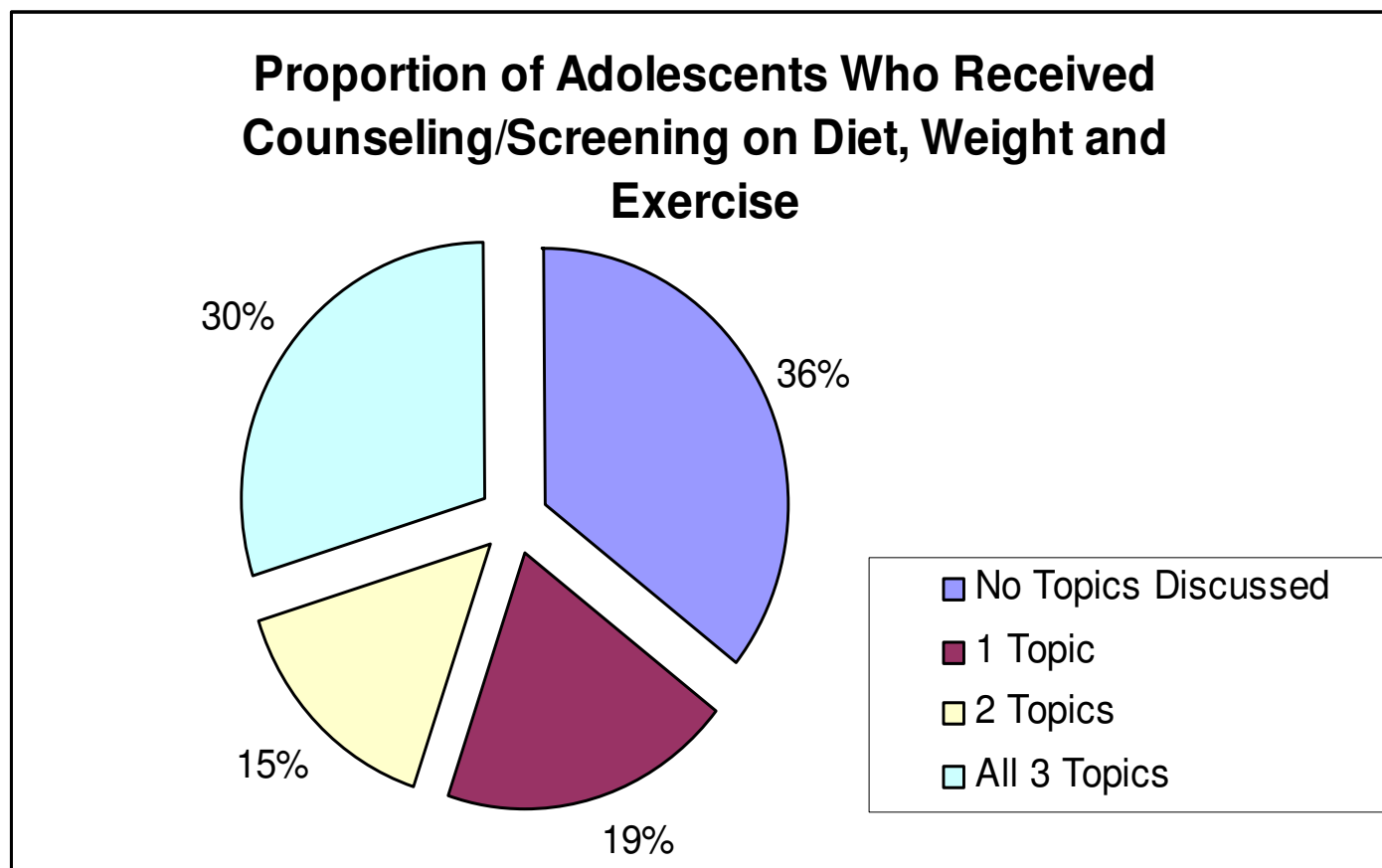
Adolescent Views (YAHCS) Counseling & Screening On Unwanted Pregnancy and STDs for Adolescents With Qualifying Health Care Visits



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



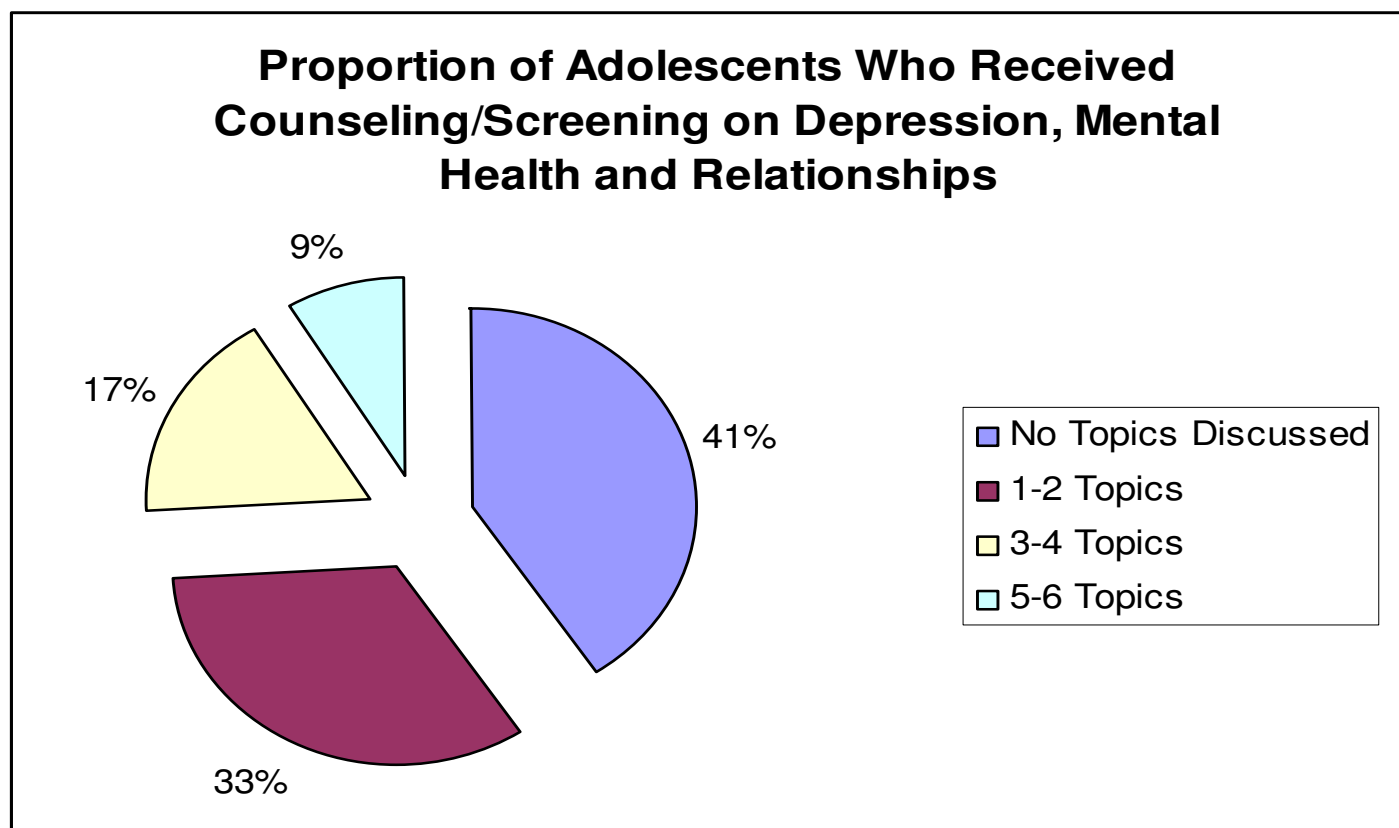
Adolescent Views (YAHCS) Counseling & Screening On Diet, Weight and Exercise for Adolescents With Qualifying Health Care Visits



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



Adolescent Views (YAHCS) Counseling & Screening On Depression, Mental Health and Relationships for Adolescents With Qualifying Health Care Visits



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



Adolescent Views (YAHCS) Counseling, Screening and Communication with Providers By Whether They Had a Private and Confidential Health Care Visit (Scored as "at least 50% of topics discussed")

Quality Measure Topic	Had Private and Confidential Visit	No Private and Confidential Visit
Risky Behaviors	25.0%	10.4%
Unwanted Pregnancy/STDs	55.3%	19.7%
Diet, Weight, Exercise	59.2%	38.2%
Depression and Mental Health	40.3%	14.0%
Usually or Always Had Good Communication	52.8%	39.2%



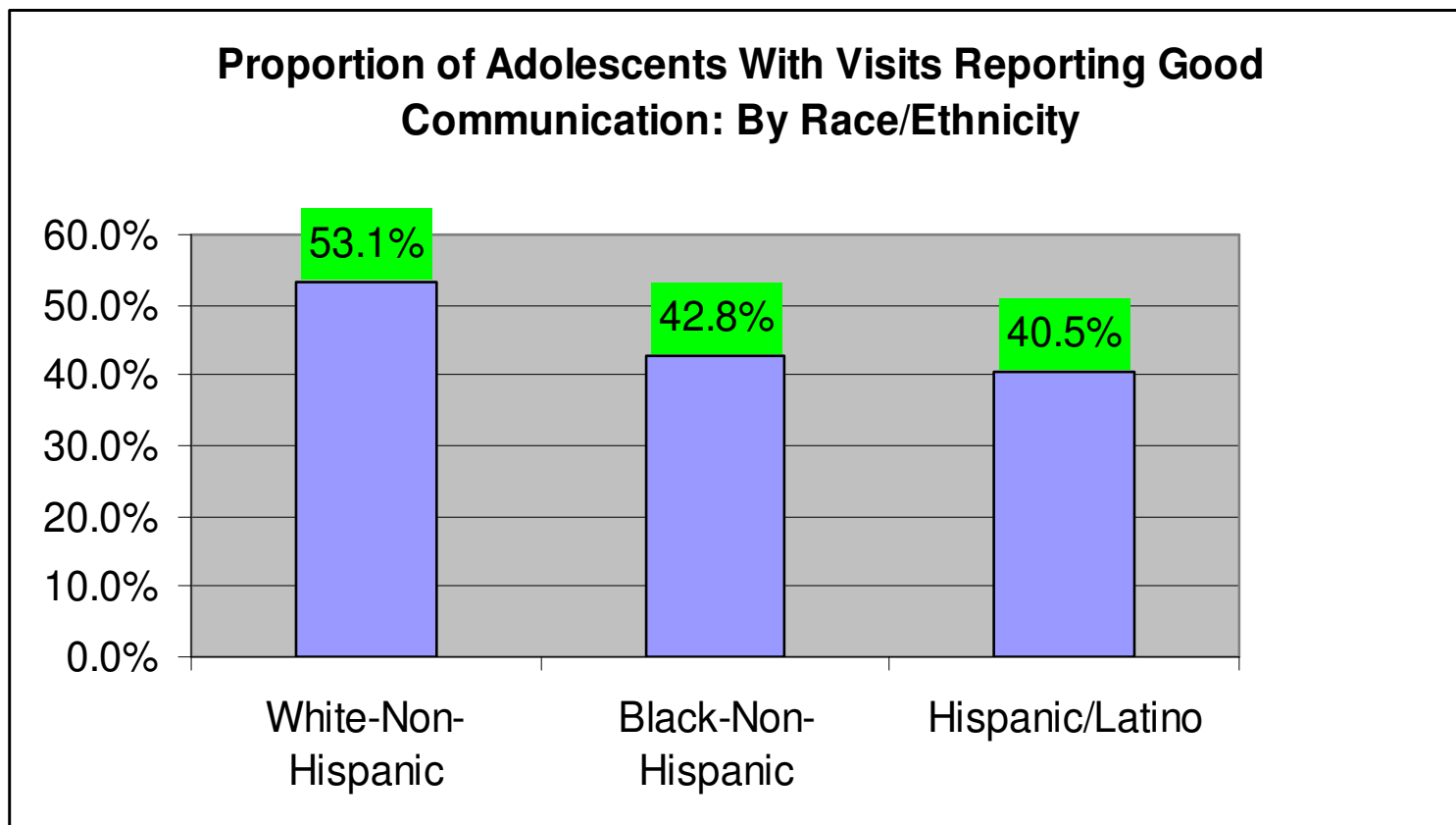
Adolescent Views (YAHCS) Significant Variations By Age, Gender and Race/Ethnicity

Quality Measure	Age (3 of 7)	Sex (5 of 7)	Race/Ethnicity (7 of 7)
Risky Behavior Counseling & Screening			
Unwanted Pregnancy/STDs Counseling & Screening			
Diet, Weight, Exercise Counseling & Screening			
Mental Health Counseling & Screening			
Had a Private & Confidential Visit			
Usually or Always Had Good Communication			
Helpful Office Staff			

Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



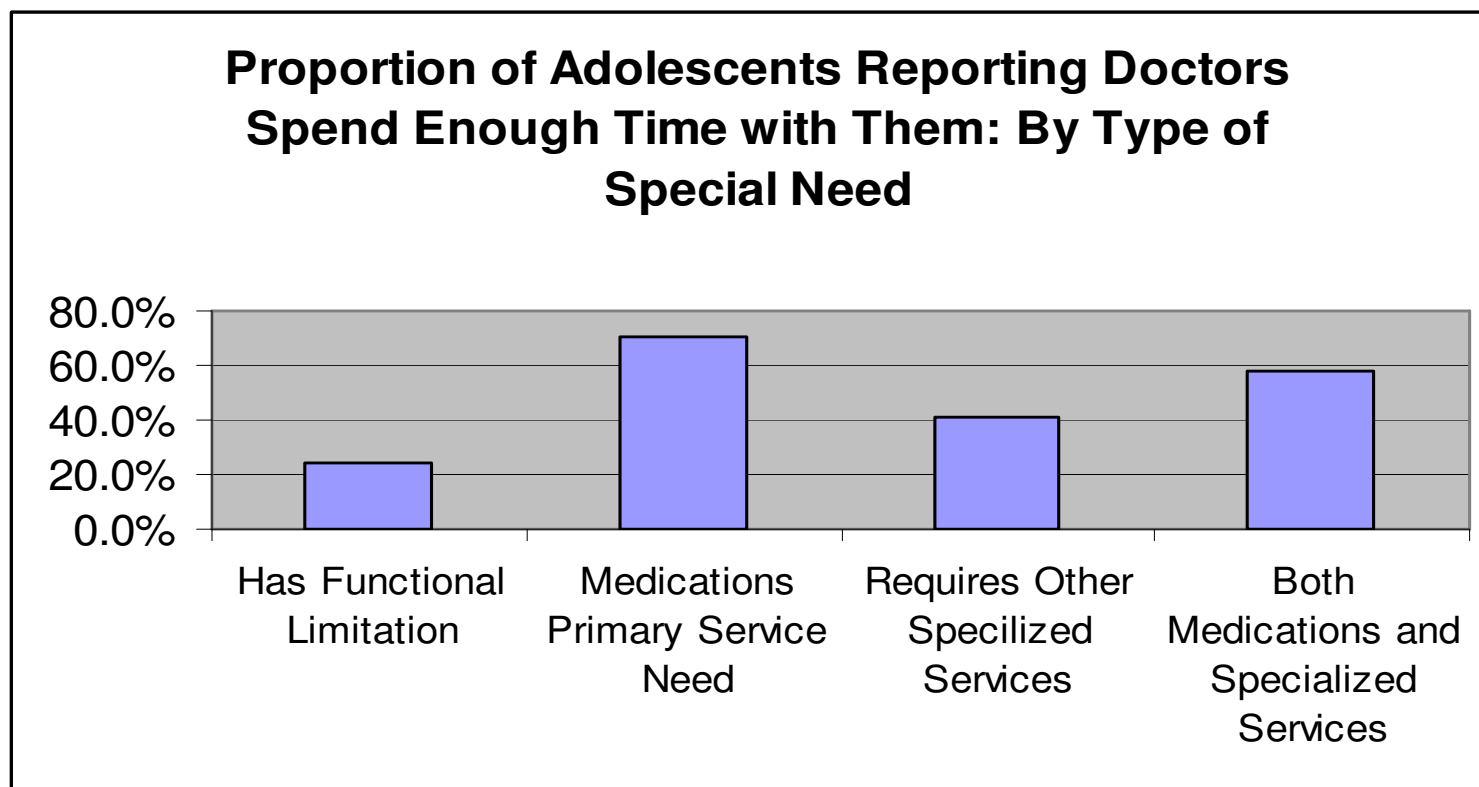
Adolescent Views (YAHCS) Adolescents With Qualifying Health Care Visits Who Usually or Always Experience Good Communication With Providers: **By Race/Ethnicity**



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007

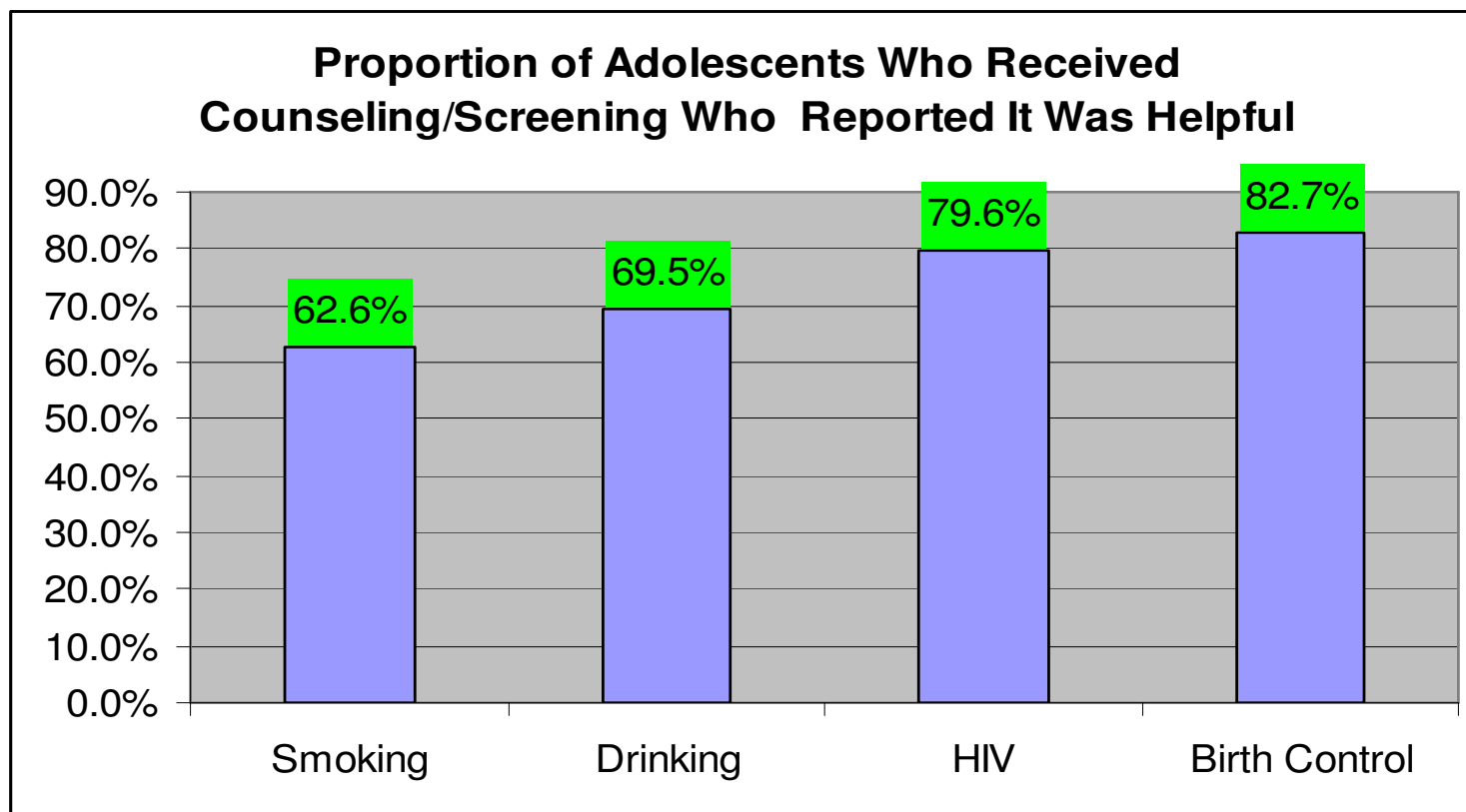


Adolescent Views (YAHCS) Adolescent With Special Health Care Needs Whose Doctors Spend Enough Time with Them





Adolescent Views-What Do They Want? (YAHCS) Reports on Helpfulness of Counseling & Screening Among Adolescents With Qualifying Health Care Visits



Source: The Child and Adolescent Health Measurement Initiative, Young Adult Health Care Survey (YAHHS) Benchmarking Database, January 2007



Adolescent Views –What Do They Want? (Focus Groups) Selected Comments from Focus Groups with Adolescents (Chicago and Denver, 2000)

Explain Clearly: “One thing that I don't like about some doctors is they try to get too technical They don't explain things to you so that you can understand them.”

Shared Decision Making: “One of the things I appreciated from doctors has been that they give you a lot of options, like, cover all the bases and tell you what's something you can do or not do.”

Respect: “If they're talking about me or my sister, we can't be in the room to hear what they're saying about us.”

Trust: “If you don't like the person and, you know, what you're saying you wouldn't tell your parents . . . so you don't go back to them and you get worse and worse.”

Source: The Child and Adolescent Health Measurement Initiative, Consumer Focus Group Summary Report, 2000



Question 1: Parent Views

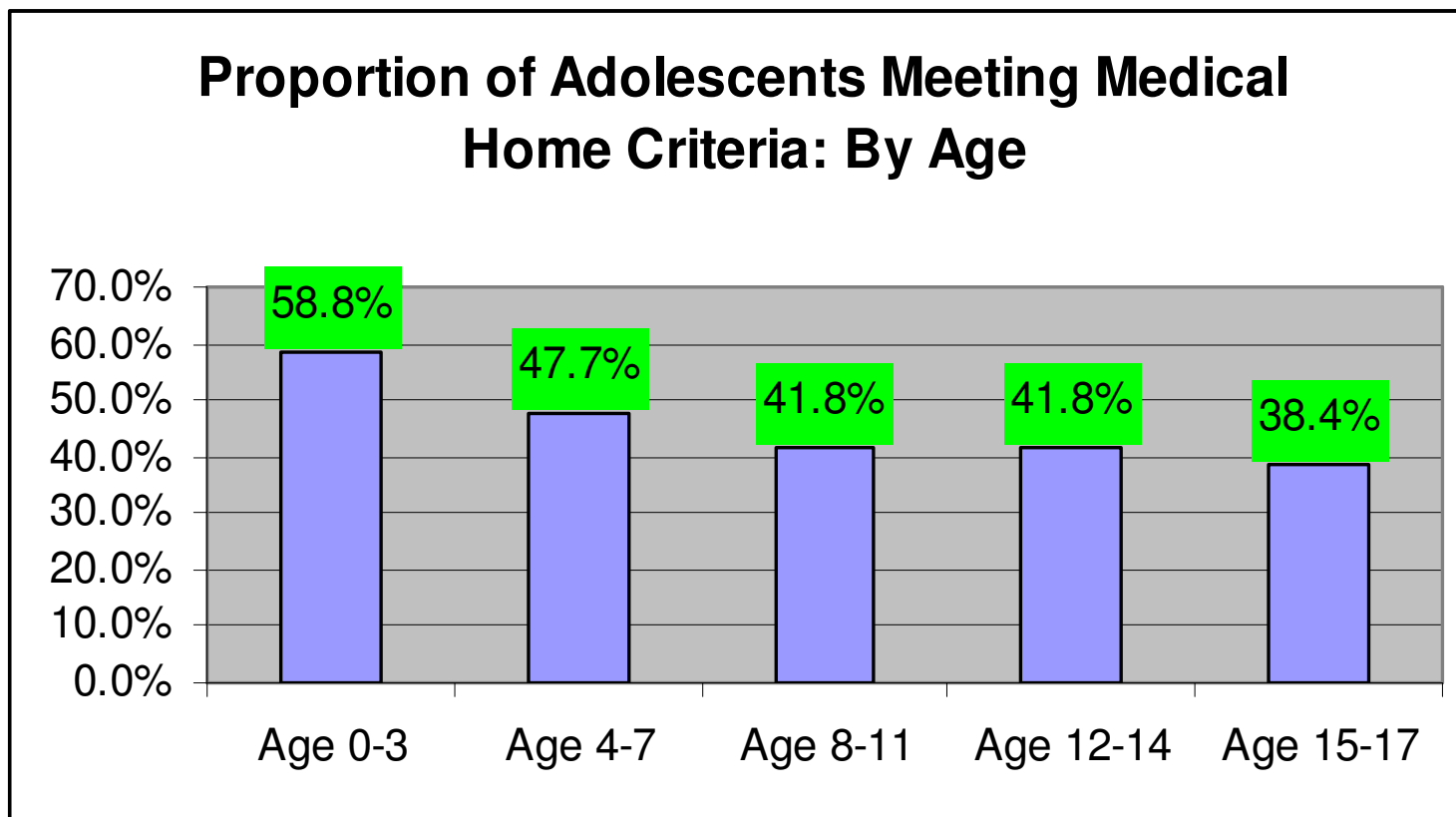
Quality Topics With Standardized Measures

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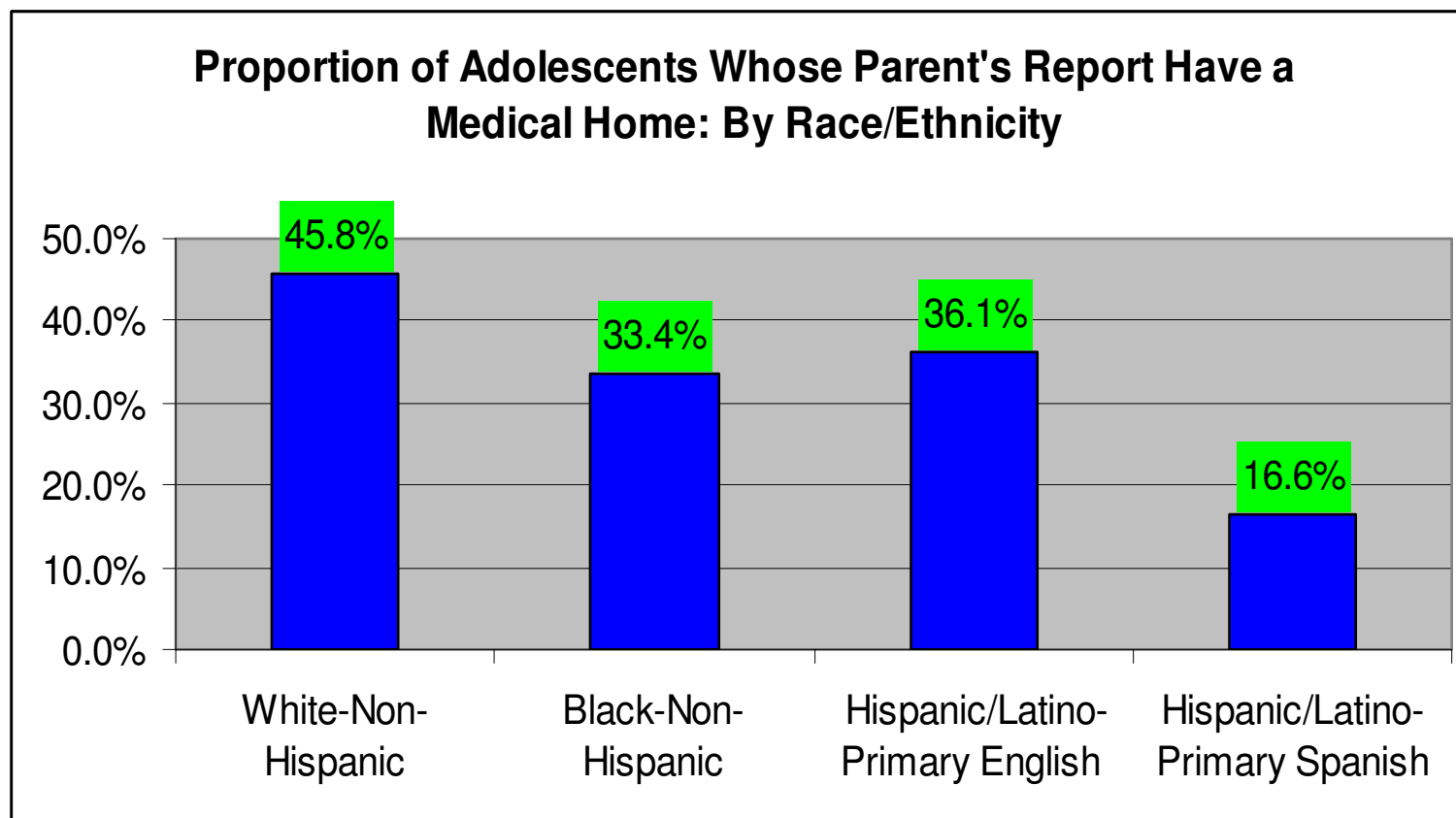
Parent Views (NSCH)

Proportion of Children and Adolescents (0-17) Whose Parent Reports Indicate They Meet 4-Part "Medical Home" Criteria: By Age





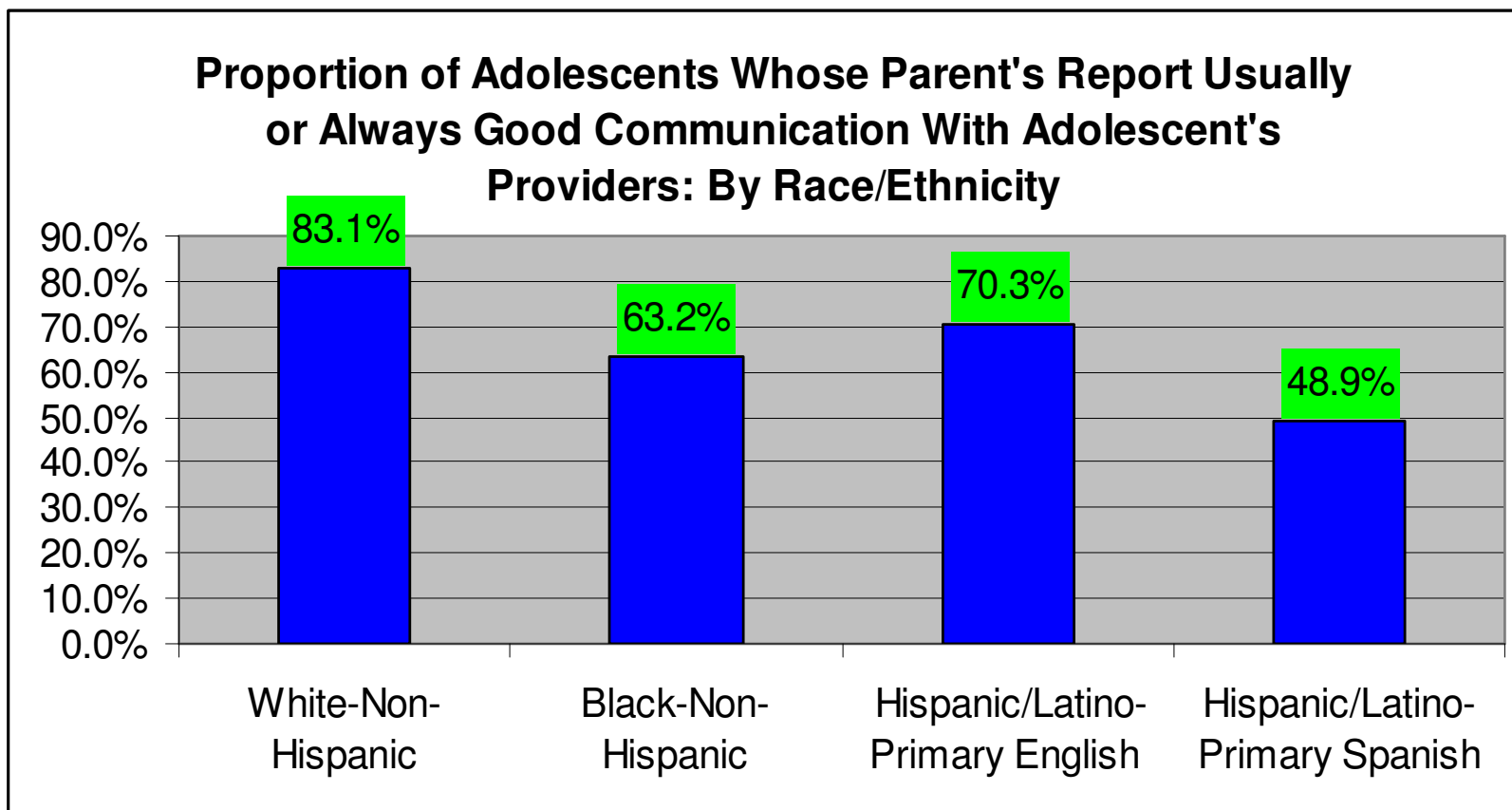
Parent Views (NSCH) Proportion of Adolescents (12-17) Whose Parent Reports Indicate They Meet 4-Part "Medical Home" Criteria: **By Race/Ethnicity**





Parent Views (NSCH)

Proportion of Adolescents Whose Parent Reports Indicate Good Communication (Usually or Always)
By Race/Ethnicity



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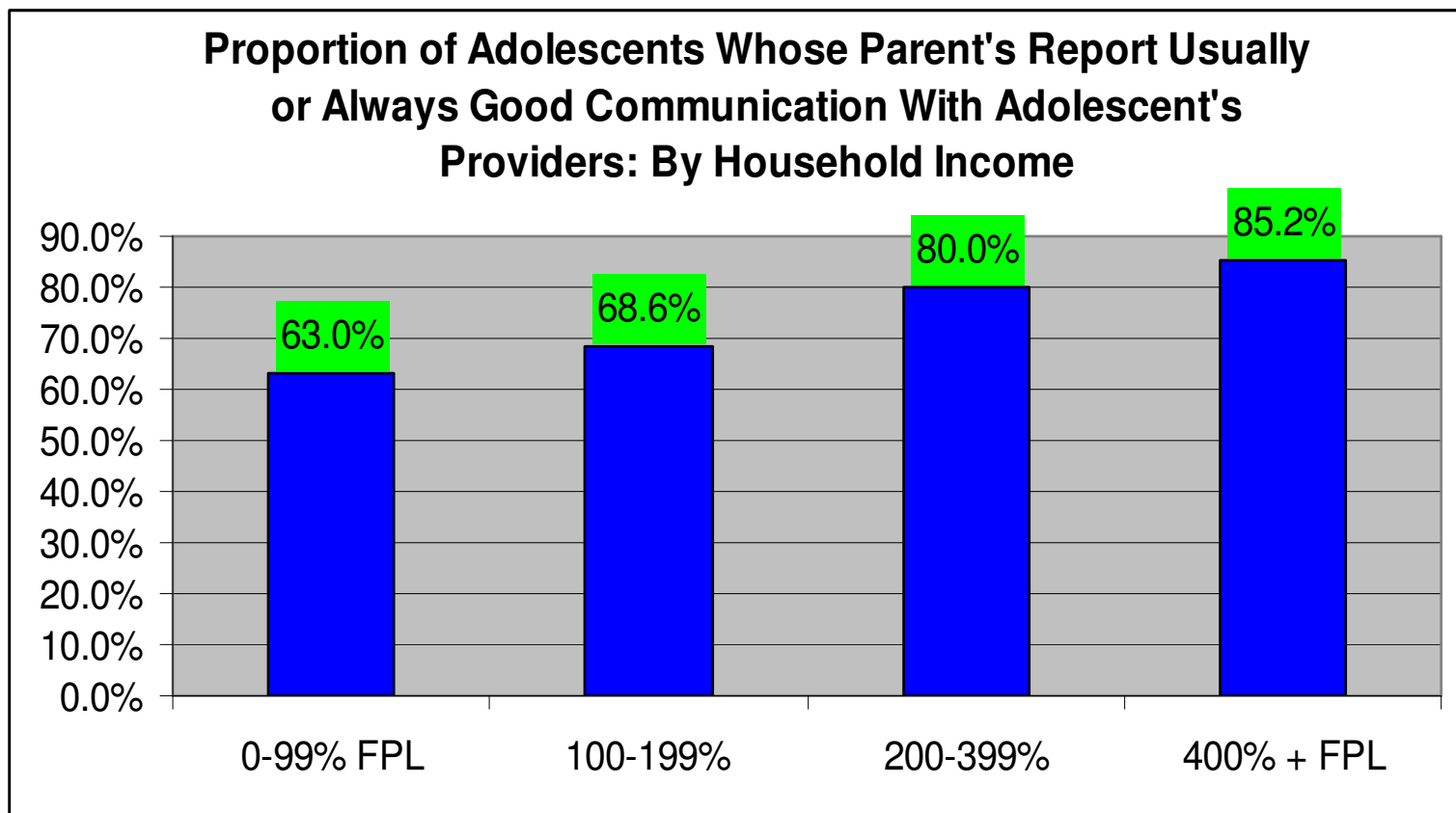
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Source: The Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health (www.childhealthdata.org), 2003 National Survey of Children's Health, January 2007





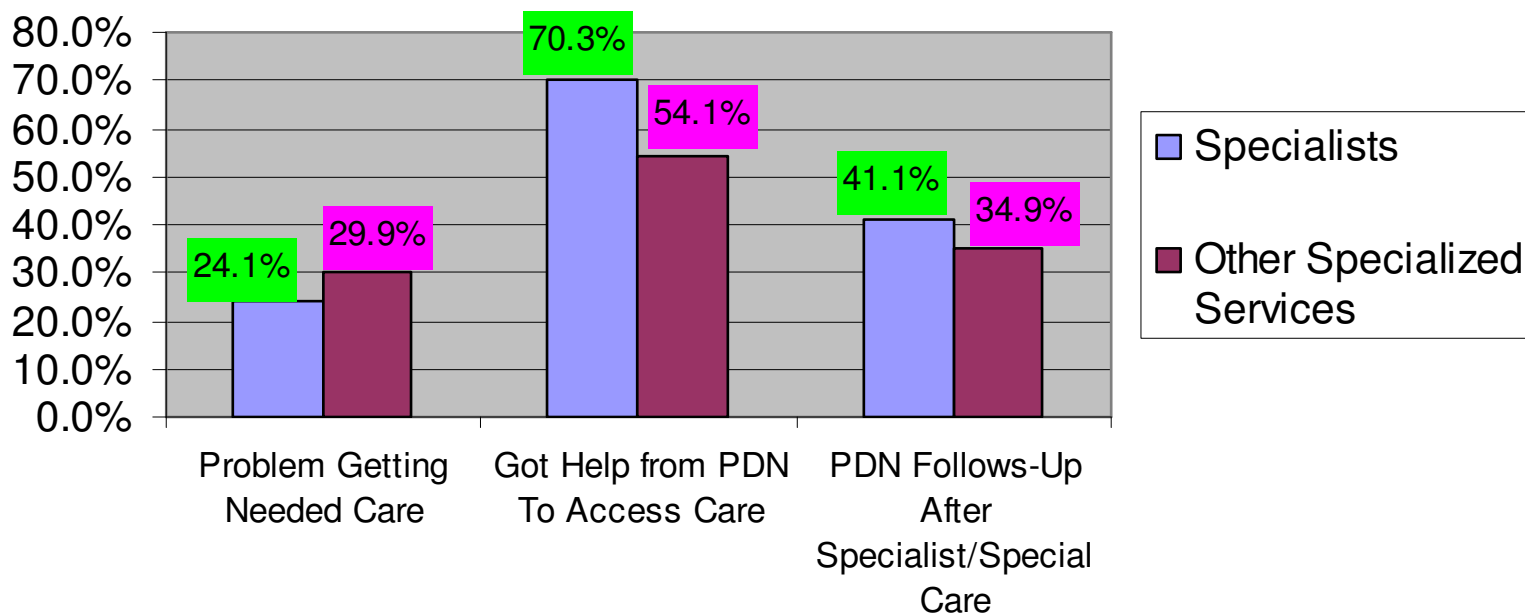
Parent Views (NSCH) Proportion of Adolescents Whose Parent Reports Indicate Good Communication (Usually or Always) **By Household Income**





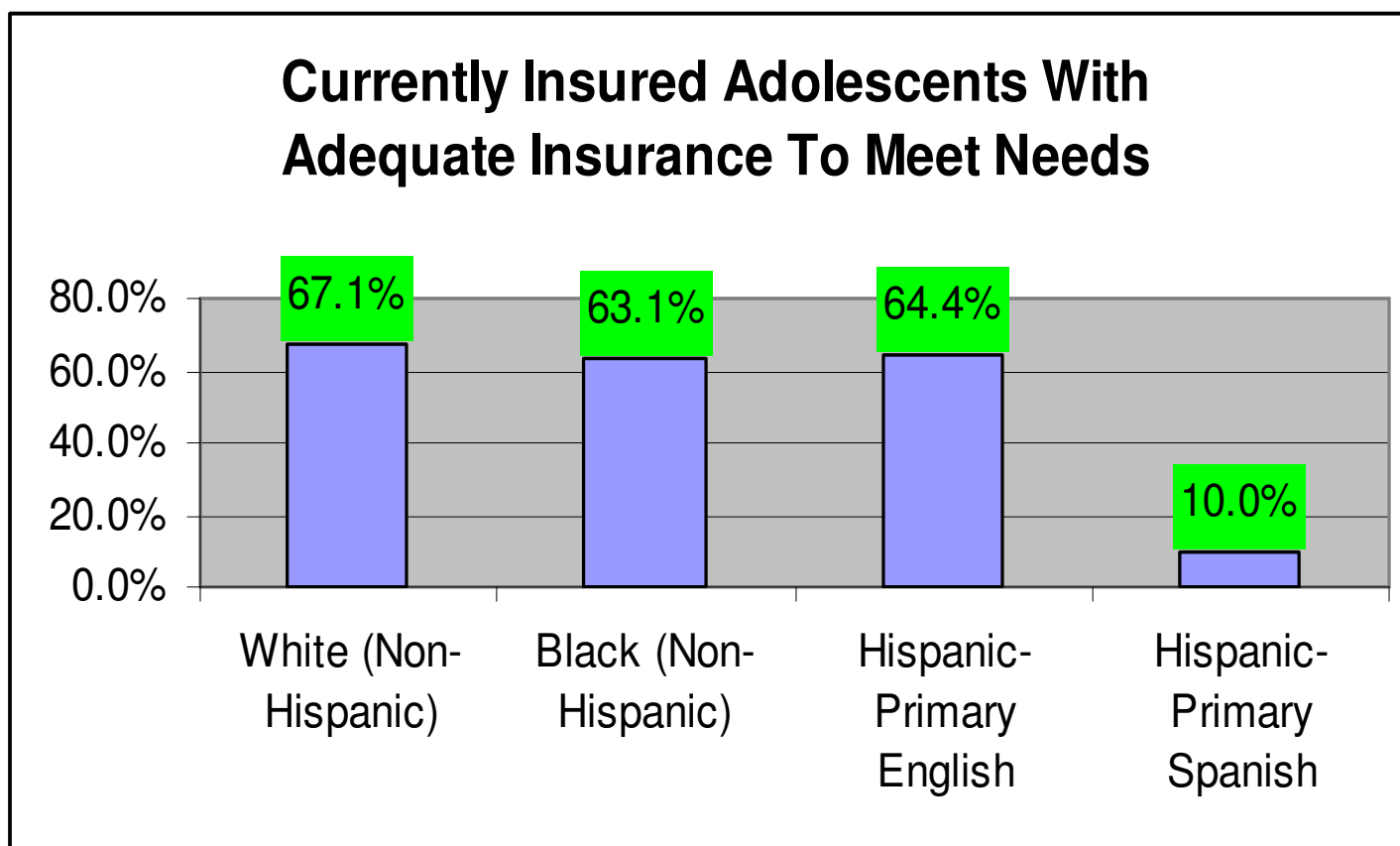
Parent Views (NSCH) Adolescents With Accessible and Coordinated Specialist Care and Specialized Services

Adolescent Experience of Care: Accessible and Coordinated Specialist and Specialized Services





Parent Views (NS_CSHCN) Adolescents With Special Health Care Needs with Adequate Insurance: By Race/Ethnicity



**CYSHCN Adequate Insurance Among Currently Insured Adolescents (12-17): 20.2 point
State Range: 74.8 (RI) to 54.6 (MT)**

Source: The Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health (www.childhealthdata.org), 2003 National Survey of Children with Special Health Care Needs, January 2007



Development and Use of Standardized Adolescent and Parent Reported Quality Measures

1. **Adolescent-reported YAHCS** (with or without special health care needs screener) is standardized and available for health plan level assessment
2. Use of YACHS mostly isolated to **state Medicaid and SCHIP** (CA, NY, FL, WA, etc.) and is more limited than parent report data.
3. **Parent report more widespread** in national and/or state-level surveys (NSCH, NS_CSHCN, MEPS)
4. Some **non-standardized measures also available**, mostly for use in quality improvement and research.
5. **Adolescent report required** to achieve valid picture of needs and performance.
6. **Parent report also critical** to assess needs and performance.



Opportunities and Research Needs in Patient-Centered Care for Adolescents

1. Research needed to:
 - **Further develop and test** existing items on patient-centered care
 - Develop new items on **shared decision making, self-care management** and support, **coordination of care** and **transition to adulthood**
 - Further evaluate what is **best reported by adolescents vs. parents.**
 - Identify **aspects of adolescent-reported patient-centered care most predictive of outcomes and other aspects of quality.**
(Research to date supports high specificity, but low sensitivity of many measures of patient-centered care.)
3. **Transition to adulthood** an important area of focus for patient-centered care measurement. Research can be done on performance of new 2005/06 NS_CSHCN section on this topic and need for improvements and adolescent reported items.
4. Need to test YAHCS and other adolescent report **methods at the provider and office-level.**

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Opportunities and Research Needs in Patient-Centered Care for Adolescents

6. All standard self-report methods are likely to overestimate performance due to inherent challenges in gaining **responses from the most at-risk youth**. **Alternative/supplemental data collection** and measurement methods may be required.
7. Need for **national and state level adolescent survey**, preceded by careful development and testing process to ensure validity. **Online data collection** promising for adolescent population.
8. Consider integrating health care **quality survey items in the YRBSS** (Youth Risk Behavior Surveillance Survey) or otherwise integrating YAHCS into school based health center evaluations and other youth-focused health care systems.
9. Explore design and testing of an **integrated, multi-year quality measurement strategy** for states (and others) whereby a single consumer survey is implemented each year, with cycling sampling and administration modules for different populations that will allow subpopulation quality measurement over the course of several years. Could anchor to existing CAHPS child survey.



Opportunities and Research Needs in Patient-Centered Care for Adolescents

10. Emphasize and demonstrate the value of measurement methods that produce ***adolescent-centered profiles of performance*** that **link adolescent and parent reported quality information with other data sources** on access, quality, safety and outcomes of health care (e.g. administrative data, medical chart data).
11. Explore **value of engaging adolescents in defining and assessing quality in** the process of improving quality of care and outcomes. for improving (Patient Centered Quality Improvement).



Additional Slides for Reference Only





Parent Views (NS_CSHCN)

Experience of Care of Adolescents With Special Health Care Needs* Who Have a Personal Doctor or Nurse and Visited The Doctor

Experience of Care Topic	Usually Experience	Always Experience
Spends enough time with adolescent	27.0%	56.2%
Listens carefully	24.9%	62.3%
Parent gets information needed for child's health	28.3%	50.4%
Sensitive to family's customs and values	26.9%	59.5%
Talks about health care needs of adolescent as they become an adult	50.0%	
Adolescent has a health care transition plan	29.1%	

(*Adolescents Who Have Current Functioning and/or Above Routine Health Service Need Consequences Due to an Ongoing Condition)

Source: The Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health (www.childhealthdata.org), 2001 National Survey of Children with Special Health Care Needs, January 2007



Widespread Consensus on Components of Preventive Care

- Regular health care visits
- Private and confidential care
- Screening, early identification and referrals for behavioral, emotional and medical risks to health
- Counseling on behavioral, emotional and medical risks to health
- Culturally sensitive communication and partnerships with teens, families and communities

YAHCS

1. Young Adult Health Care Surveys (YAHCS)
 - **56 items**
 - **Mail or Telephone Administration**
2. Sampling algorithm to identify teens
 - Utilization-based
 - Enrollment-based
3. **Guidelines for scoring & presenting the YAHCS quality measures derived from the YAHCS survey results.**

Quality Measures

7 Sub Scales/ Measures Derived from the YAHCS

- 1) Counseling and screening to prevent risky behaviors
- 2) Counseling and screening to prevent unwanted pregnancy and STDS
- 3) Counseling and screening related to diet, weight and exercise
- 4) Counseling and screening related to depression, mental health and relationships
- 5) Care provided in a confidential and private setting
- 6) Helpfulness of counseling provided
- 7) Communication and experience of care



Overall Objectives

- Improve primary and secondary prevention services for adolescents
- Improve access and use of preventive care by adolescents
- Improve the content of care to include clinician screening for, and attention to, high risk behavior and conditions
- Reduce the gap between prevention recommendations and practice

Quality Improvement Opportunities

- Taking time with teens matters
- Repeated visits and trust matter
- Knowing a place to go get care without parents know matters
- Use of health surveys or checklists may improve quality of care
- Having a private visit matters the MOST!



Quality Improvement: Client Education

YACHS reveals opportunities for adolescent education:

- Inform teens about health care providers role
- Females 16-18 receive most counseling on STD/pregnancy prevention (although still low!)
- Start younger & include boys
- Teens need access to confidential health care
- Teens engaged in risky behaviors need counseling
- Teens need to talk about sadness/depression



Tough Issues

- Reimbursement/time pressures
- Confidentiality
- Physician discomfort
- Once you know, now what?
- Treatment resources for adolescents
- Perceived adolescent invulnerability
- Perceived physician powerlessness
- Cultural sensitivity and competence

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National Survey of Children's Health (NSCH), 2003



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