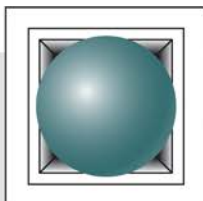


DOLESCENTS' EXPERIENCES AND VIEWS ON HEALTH CARE

Low-income adolescents are an underserved population with significant health needs. Although the design of new patient-centered models of primary care is receiving growing attention, the needs of vulnerable adolescents at risk of chronic conditions have not been addressed. This report provides the findings from a focus group study conducted with low-income adolescents in four cities -- Chicago, Los Angeles, Miami, and Washington, DC -- and shows the difficulties they face in obtaining needed care. These young people understand the many health needs of today's adolescents and offer suggestions for a health care setting that would provide greater access, deliver comprehensive teen-specific services, and help them to play a greater role in their own health care.

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HHealth care reform discussions have focused considerable attention on the design of improved models of primary care, but they have not addressed the unique health care needs of low-income and minority adolescents. This is due largely to the lack of relevant research. There are no large-scale studies showing the best ways to serve adolescents. In its recently released report, the Institute of Medicine concluded that there is a lack of evidence for effective models of adolescent health care and a need for further research.¹ This focus group study with adolescents offers additional information about health care for teens that can guide the direction of future studies.

Eliciting adolescents' own views can yield powerful information about their health care experiences and preferences. While adolescents are not usually asked directly about their health conditions or problems, a large body of national survey research with high school students has provided extensive data about their health risks and behaviors.^{2, 3, 4} Additional survey and focus group studies shed light on their health-seeking behaviors, including their reliance on family and friends for certain types of health information^{5,6,7,8,9} and the importance they place on providers who are competent,^{10,11,12,13} assure confidentiality,^{14,15,16,17,18} show them respect,^{19,20,21,22,23,24} are nonjudgmental,^{25,26,27} give them ample time to discuss concerns,^{28,29} and understand their cultural background.^{30,31} Others have shown that adolescents use various sites for care, depending on the nature of their problem,³² but also that they often lack information about where to go for needed services.^{33,34} Still others have shown that adolescents frequently are unable to have the kind of provider-patient relationship they want.^{35,36,37} This research, with only a few exceptions, is based on information from a single site, a small sample, or a particular adolescent subgroup, and it offers only limited insights into adolescent preferences about the design of health care services except that offices should be clean and comfortable,^{38,39} materials should be directed to adolescents,⁴⁰ waiting times should be short,^{41,42} and there should be opportunities for discussion groups.⁴³

This report presents findings from focus groups and supplemental questionnaires structured to learn about adolescents' perceptions of the health problems facing teens, their experiences receiving care, and their ideas about how best to structure care for the adolescent population. The study documents the perspectives of 204 young people ages 14 to 20 from disadvantaged neighborhoods in Los Angeles, Miami, Chicago, and Washington, DC. Focus groups organized by gender and age were held in these four cities, and nearly half of the participants were asked to fill out anonymous questionnaires after the group sessions. The groups were ethnically diverse

and representative of the demographics of the respective cities' low-income populations: 57% were African American and 32% were Hispanic. After a lengthy discussion about health care problems and experiences, each focus group worked in teams of three or four to design the "ideal" health care site for teens and present their ideas to the group. The National Alliance to Advance Adolescent Health worked with Philliber Research Associates and ICR to conduct the focus groups.

Recognition of Health Problems

Adolescents were astutely aware of the challenges they and their peers faced in their schools and neighborhoods. When they were asked about the most important problems, various health issues topped the list. Sexually transmitted diseases were mentioned by all focus groups and drugs and alcohol by all but one. Teen pregnancy, violence, negative peer pressure, and mental health issues were frequently cited as well. To some extent, answers varied by gender: females were more likely to mention abuse and obesity, and males more likely to discuss poverty, homelessness, or the economy -- all issues with direct or indirect health consequences. Mentioned also, but less commonly, were asthma, injuries, and concerns about family problems.

"...a lot of teens decide to have unprotected sex...and then they think, "Oh, I don't need to go get tested or anything"... HIV [or] AIDS is one of the biggest problems right now."

– Female (14-16) Miami Group

"There's some kids that get treated so bad that they think doing drugs is going to help them through it..."

– Male (17-20) Los Angeles Group

"A lot of teens – they're depressed."

– Female (17-20) Chicago Group

In response to a question about what "health care" means, nearly all focus groups cited health insurance and half mentioned cost or affordability as an issue. The topic reemerged twice more during discussion: when teens were asked about their experiences with the health care system and when they were asked if they sometimes did not get health care when they needed it.

Where Teens Get Their Care

Adolescents in our focus groups reported that they and their friends received routine and sick care from a variety of sources, including doctors' offices, community health clinics, and emergency rooms. According to the questionnaire administered at the end of each focus group session, slightly over a quarter reported using an emergency room when they were sick. Adolescents also reported that teens sometimes got care from mental health clinics, substance abuse programs, and family planning clinics.

TABLE 1: Questionnaire Responses: Where Teens Get Their Care (n=96)

Sources of Care*	Checkups or Preventive Care	Sick Care	Mental Health Care	Substance Abuse Care	Sexual Health Care
Doctor's office	70%	60%	27%	15%	33%
Community clinic	54	38	24	28	57
Hospital clinic	40	51	19	14	26
School nurse	12	17	6	6	16
Mental health clinic	NA	NA	52	14	NA
Substance abuse program	NA	NA	NI	68	NA
Family planning clinic	NI	NA	NA	NA	50
Emergency room	NA	27	NI	NI	NI
Don't know/no place	7	7	28	20	6

*Respondents could identify more than one source of care.

NA = Not applicable

NI = No information

did not report it as the usual site for care for mental health problems, 60% did not report it as the usual site to receive health education, and 55% did not report it as the usual site for sexual health issues. When asked if going to different sites to receive care was a good idea, most groups thought that it was not, but some thought that it was because they could protect their confidentiality, avoid overcrowded health centers, and assure that they would be able to see doctors who specialized in different types of health problems. In addition, they worried that if services for adolescents were all in one place, they would have to travel too far to get there.

Lack of knowledge about where to go for services presented an obstacle to receiving care, however. Questionnaire results showed that roughly half knew to use mental health clinics for mental health problems, but more than a quarter did not know of a specific place to go for these services. Similarly, more than two-thirds recognized the need to find a substance abuse program for drug and alcohol problems, but one-fifth did not know where to go. Only 6% of teens did not know of a place to go for sexual health services.

Adolescents who received sick care from a particular provider did not always receive other types of care from the same source. This was particularly true for those who received sick care from a doctor's office. An analysis of information from the questionnaires revealed that, among adolescents who reported people their age went to doctors' offices when they were sick, 83% did not report it as the usual site for drug or alcohol abuse problems, 62%

"They go to clinics, most of my friends do... they know if they go to their doctors, then it will come up on the health insurance bill..."

– Female (14-16) Washington, DC Group

"Like what if you're pregnant and you're worried you have an STD. You go to the STDs first and then travel across town and go to the pregnancy thing and then that wastes a lot of gas and time, and then by the time you get there, there's no people, you can't be seen and you have to wait until the next day. And some people just say forget it, you know."

– Female (14-16) Washington, DC Group

What else is preventing these young people from seeking more treatment for their health problems? Not having health insurance was identified as a major impediment, especially among older adolescents, as well as high copayments for covered services. In addition, adolescents noted that there was a lack of teen-specific information and resources and that they often have inadequate knowledge about where to go for needed services. Younger adolescents, in particular, claimed that many of their peers were uninformed about health risks, felt uncomfortable talking about their problems, or were afraid to find out if something were really wrong with them.

Experiences with Health Care

When the focus groups were asked about their experiences with health care, their answers were overwhelmingly negative. Teens most often cited two factors that affected their experiences within the health care system: long wait times and providers being too busy. A majority of the focus groups mentioned long waits in doctor's offices and in emergency rooms. They also recounted difficulties scheduling appointments.

Young people were most vociferous about inadequate attention and being rushed at the hands of busy health care providers. The wait to see the doctor was usually long, but the time spent with the doctor was short. They claimed that if the doctor spent more time with them, he or she could better assess what was wrong and provide better care. If the doctor just trusted the symptoms they mentioned without questioning and examining them, they said that it was possible to miss important information. Teens also reported that they sometimes forgot to bring up concerns because they felt hurried or the doctor did not have enough time to give a thorough explanation.

"I feel like they're trying to rush you out when you go. They have a schedule and they just attend to you and then just move you right out to the next person... You don't have the chance to ask what you need to ask."

– Female (14-16) Chicago Group

"You know I'm here to talk [to the doctor] about my health problems... So it's just too much for him to have different people in different rooms and for him to go in his office and sign papers and have me sitting there for 45 minutes... that's just too much."

– Female (17-20) Los Angeles Group

Questionnaire results showed that only 14% of focus group participants felt that their health care provider spent enough time with them "all of the time." A roughly equal percentage (16%) felt that their health care provider "never" spent enough time with them, and a much larger percentage of teens (43%) were satisfied only "some of the time."

Still, in almost all of the focus groups at least one adolescent spoke about positive experiences reflecting the adolescents' closeness with doctors or counselors. Some teens felt relaxed with their health care providers and trusted them.

Parental Involvement

Adolescents voiced mixed opinions about their comfort with having parents or guardians involved in their care. The consensus among focus groups with younger adolescents was that parents usually went with them for routine check-ups and physicals, which was also sometimes true for older adolescents who did not have transportation. For younger adolescents, parents often entered the doctor's office with the teen. Regardless of age or gender, if adolescents were sick or had to go to the emergency room, parents were usually present.

However, reproductive health and substance abuse issues elicited a different response among teens. The majority of adolescents, regardless of gender or age, did not want their parents to know about receiving birth control, STI or pregnancy testing, or if they abused drugs or alcohol. Some teens mentioned that they visited certain sites, such as free clinics or Planned Parenthood, so their parents would not know. They appreciated the clinics' confidentiality: the sites would not call their parents, and their visits would not show up on their health insurance bills.

"My parents don't come with me because they work and I am responsible. And I tell my parents, so is it not like I keep anything from them."

– Female (17-20) Washington, DC Group

"Yeah, it is kind of embarrassing, cuz like if they're in there with you, the doctor might ask you questions and you're uncomfortable answering in front of your mom or your dad. I think if they go with you, you could just tell them 'oh, could you wait in the waiting room while I go in here by myself. I think they'll understand."

– Male (17-20) Los Angeles Group

"My mom's going to already know... She's hip to you, you know. Can't hide too much from her. She'll be looking in your eyes."

– Male (17-20) Washington, DC Group

"I'd let the doctor [tell them]. Because, if my mom and dad are getting a professional point of view it'll be a lot easier and the doctor could probably break it down and explain it to them better than me trying to explain it to them..."

– Female (17-20) Washington, DC Group

Adolescents' preferences about whether to involve their parents in their health care seems to depend on the nature and severity of the problem and also on their relationship with their parents. Although adolescents tended to favor privacy for reproductive issues and STI testing, most wanted their parents to be directly involved in more serious health issues, such as HIV or pregnancy. According to the questionnaire results, only 13% never wanted their parents involved in their care.

When asked about health care providers communicating with parents if there were issues the adolescents themselves were not comfortable discussing, the focus groups varied in their answers. Some thought it would be easier and more efficient having a professional directly explain an issue to their parents, while others thought it would be worse and wanted the professional to talk to teens alone and recommend how to explain the situation to parents. Some thought that the provider, parents, and teen should all discuss the issue together. Questionnaire results showed that the majority of adolescents (64%) preferred provider communication with parents “some of the time” or “most of the time.”

The Ideal Health Care Experience

Each focus group was divided into teams of three or four individuals to discuss aspects of an ideal health care site: where it would be located, what it would look like, who would work there, and what services would be provided. Each team then presented their ideas to the larger focus group.

With respect to location, accessibility was mentioned by all focus groups as a key factor. They supported a site in a main area of town, perhaps near a shopping center, that everyone could reach. Some also gave suggestions of having several sites, one in each ward or neighborhood. The general theme was that it should not be a hassle to get there. According to results from the questionnaire completed after the focus group, 91% of adolescents felt that an easily accessible site was “important” or “very important.” To achieve this, teens suggested during the focus group sessions that such a site be on a public transportation route, close to their homes, or close to (usually not in) a school -- attributes that were deemed “important” or “very important” by 92%, 76%, and 71% in the questionnaire, respectively.

Adolescents in all focus groups also emphasized the importance of an inviting atmosphere, which according to the questionnaire, was “important” or “very important” to 82% of them. They preferred a clean, modern, attractive bright look in a safe neighborhood so they would not feel intimidated. They also expressed a desire for equipment to use while waiting, such as televisions, internet access, games, music, refreshments, posters, and a “chill” room. In addition, they spoke of wanting age-appropriate health information materials, and

“And they should have more advertisements so you can learn more about health while you’re there just sitting down there. Yeah, when you’re standing in the examination room, you know how you’re just waiting for the doctor? There should be like some signs up there like of different stuff, health stuff.”

– Male (17-20) Los Angeles Group

some groups suggested a resource room staffed with people to assist them. Questionnaire data showed that nearly two-thirds of adolescents favored an environment with just people their age.

Young people also mentioned that they wanted the site to accept both appointments and walk-ins; questionnaire data showed that 82% found the latter to be “important” or “very important.” Most focus groups mentioned that the health care site should be open 24 hours and have fast service. They did not want to feel lost in the shuffle. In fact, the questionnaires revealed that 24-hour availability and fast service were favored by 92% and 88% of adolescents, respectively. They also wanted care to be affordable; some thought it should be free; and others thought it should be low cost. According to the questionnaire results, affordability was important to 90% of adolescents.

Staff at an Ideal Health Care Site

All focus groups felt that being knowledgeable and caring were important characteristics for staff working at an ideal health care site. Adolescents wanted people who were smart and experienced to diagnose their problems. They wanted time with their doctors, an exchange of communication among doctors, and follow-up. They desired well-informed staff to answer whatever questions they may have.

“Well, I just think the doctors should be smart. They should know what they’re talking about. Be friendly and they should be able to break it down for you so you know exactly what’s going on.”

– Male (14-16) Chicago Group

“I mean, as soon as you go in there, you shouldn’t even get to ask ‘where do I go?’ there should be someone right there telling you ‘how can I help you?’ or ‘what do you need?’”

– Male (17-20) Washington, DC Group

“...people who are 18, they can work there... as maybe speakers so that people who actually went through this stuff, they could say how is your life going or whatever. And say what to look for or what to watch out for.”

– Female (17-20) Washington, DC Group

“Friendliness” was also mentioned frequently in group sessions, and according to questionnaire data, 93% and 87% of teens felt it was “important” or “very important” for doctors and staff, respectively. Friendliness included customer service, and teens spoke of having greeters and friendly receptionists.

Almost all focus groups agreed that they wanted staff that would be able to relate to and understand them without judging them. For this reason, many of the groups mentioned having young doctors. Adolescents also felt very strongly about the need for both male and female doctors as well as staff of diverse ethnicities and languages. They also felt it was important to have both peers their age and those a little bit older to help with various issues through teen groups, group discussions, or support groups.

Services at an Ideal Health Care Site

Within their teams, adolescents were nearly unanimous that the ideal health care site should have sexual and behavioral health services available. In fact, all but one group wanted sexual health services including STI testing, pregnancy testing, and free birth control and also wanted mental health services including counseling and therapy. Most of the groups also described the ideal site as having substance abuse services, drug testing, or rehabilitation programs.

Well over half of the groups felt that routine care such as physicals and check-ups were necessary. An equal proportion spoke about health and wellness services -- guidance on what to eat, fitness classes, and nutritional counseling. Additionally, they preferred having pharmacy and lab services onsite so they could fill prescriptions or get blood and urine work done immediately, rather than having to do it after their visits and not follow through. Dental care, vision care, and social services were mentioned by several groups as additional services needed at an ideal health care site.

“A doctor’s appointment should at least be 30 minutes and before you go in, it should be some kind of survey or questionnaires you can fill out. There should be a risk calculator to let you know what kind of things you’re at risk for based on you know your sexual habits, eating habits, family history, activities, no activities.”

– Male (17-20) Chicago Group

“It’s everything under one roof.”

– Male (17-20) Washington, DC Group

All but one of the groups agreed that most services needed by adolescents should be available at the site. While earlier discussion among these groups seemed to suggest less consensus on whether these services should be located in one place, the discussion changed when adolescents envisioned their ideal health setting. They wanted everything in the same location. They talked about the value of being able to conveniently access services and having providers who knew one another. A few groups even noted the importance of having their medical records in one place. Questionnaire data collected after the focus groups showed 83% of adolescents either “agreed” or “strongly agreed” that going to the same place for all health care was a good way to get health care needs met.

How to Bring Teens In and Keep Them Coming Back

Young people gave suggestions about what would encourage them to come into a health care site like this and keep returning. The most popular response was public relations and outreach. Most of the groups thought holding an event or advertising would help spread the word about the site. Ideas included teens doing community outreach, having a health fair, putting up posters, and advertising on television, radio, and the internet.

"...if you have something geared towards our age, I'd be more likely to go there."

– Male (17-20) Miami Group

"It doesn't make sense to turn down something that good."

– Female (14-16) Washington, DC Group

"You'd be happy to go and like...you'll be glad to take your time to go there instead of regretting like not wanting to go."

– Male (14-16) Miami Group

Other suggestions for reaching teens included connecting with schools and having free services available. Teens suggested that schools refer students to the health care site, pass out flyers, and inform students. Also, if students need sports physicals, schools could recommend the health care site. Adolescents also suggested having free or reduced fee services, giving a month of free services, or giving out something free as a way to bring teens in. Teens also mentioned that the environment of the center itself and the services offered would attract young people. Adolescents in the community would know there is a high likelihood that they would receive good service. If the health care site had all the

components that the teens suggested, then it would speak for itself. Survey data showed that 94% of adolescents were "likely" or "very likely" to use the ideal health care site they created, and over 90% felt their friends would use such a health care site.

These young people expressed a commitment to changing their health if a center like this existed. The vast majority of groups thought that if their ideal health site existed, they would be very likely to use it and return for visits. Also, they felt they would be more proactive about their health and get health care, which in turn, would mean taking better care of their bodies. Survey data showed that 88% of adolescents said they were "likely" or "very likely" to do things differently to improve their health if the ideal health care site they created did exist.

Conclusion

As the nation focuses on reforming health care, special attention should be given to health care for adolescents. Young people across the country are aware that sexual diseases, drugs and alcohol, teen pregnancy, violence, peer pressure, and mental health issues are problems for their age group. However, due to factors such as inadequate knowledge, lack of insurance, or negative health care experiences, many of them are not seeking or receiving the care they need.

"It makes you want to be careful, like, make better decisions."

– Female (14-16) Washington, DC Group

"People would probably be more educated...if they have a center like that, people would learn how to eat better. I think obesity would go down."

– Male (17-20) Los Angeles Group

"I think... there wouldn't be that many pregnancies, there wouldn't be that many diseases out here, 'cause they wouldn't want to do it, 'cause they would know what's going to happen. People ain't have nobody to talk to...then they wouldn't have that excuse..."

– Female (14-16) Chicago Group

The voices of these adolescents can help provide direction for a new model of health care for this age group. Regardless of ethnicity or location, disadvantaged adolescents voiced similar concerns about the quality of health care they received and how they thought care could be improved. To meet their needs, they recommend a health care site that is accessible and inviting, with knowledgeable and caring staff in an environment of trust and comfort. Most of them want comprehensive services in such a center, including services for sexual health, mental health, and wellness. The young people in these focus groups believe such a center would be widely used and that the welcoming atmosphere and high quality services of such a center would be the deciding factors in its success.

Methodology

This report presents the findings from a focus group study undertaken by The National Alliance to Advance Adolescent Health. A total of 204 adolescents from Chicago, Miami, Los Angeles, and Washington, DC participated in a total of 26 focus groups, which were conducted from the spring of 2008 to the spring of 2009. To obtain supplemental information for the study, an anonymous questionnaire was administered to 96 focus groups participants in 14 of the groups after the focus group sessions were completed. The focus groups were conducted by Philliber Research Associates and ICR.

Staff at local youth-serving organizations in each of the four cities recruited adolescents from disadvantaged neighborhoods to participate in the study. The groups were chosen to represent the ethnic make-up of each of the cities: overall, 57% of adolescents were African American, 32% were Hispanic, 6% were Caucasian, 3% were biracial, and 2% self-reported as "other." According to self-reported data provided prior to the sessions, most of the participants lived in families with incomes below the poverty level; some lived in families with incomes below 200% of the poverty level. The proportion of males and females was about equal.

The focus groups were comprised of males ages 14 to 16, females ages 14 to 16, males ages 17 to 20, and females ages 17 to 20. Twenty-six focus groups were conducted to achieve a sufficient number of participants overall and to ensure an adequate number of participants in each gender/age group in each city. The average number of participants in the 26 focus groups was eight, but ranged from five to 13. For the analysis, we combined smaller groups so that we were able to report on a total of 16 groups -- one of each of the four gender/age groups in each of the four cities -- with an average of 13 participants per group.

The groups lasted 90 minutes. Discussions were led by a moderator from the research firms, using a discussion guide that was prepared by The National Alliance and piloted with two groups in Washington, DC. Toward the end of each focus group session, participants were divided into teams of three or four and asked to identify the services and providers that would be part of an "ideal" health site and report back to the group. Audio and video recorders were used in each of the groups so that transcripts and DVDs could be used for the analysis.

Participants were offered a small gift for their time. Those 17 and younger were required to have a signed parent permission form prior to participating.

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The National Alliance to Advance Adolescent Health provides education, research, policy analysis, and technical assistance to achieve fundamental improvements in the way that adolescent health care is structured and delivered in the United States. Its mission is to enhance the physical and emotional well-being of adolescents, especially those who are low-income and minority, by improving the health care delivery model for adolescents and achieving the infrastructure changes needed to support it. The National Alliance seeks to promote comprehensive, interdisciplinary models of physical, mental, behavioral, and reproductive health care that incorporate a youth development philosophy and operate in collaboration with schools and other community-based programs. It also seeks to ensure that all adolescents have health insurance coverage for the services they require.

For more information about our work and available publications, contact Corinne Dreskin at The National Alliance to Advance Adolescent Health: cdreskin@TheNationalAlliance.org. Also visit our website: www.TheNationalAlliance.org.

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