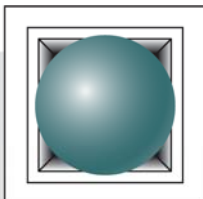




ARENTS' PERSPECTIVES ON HEALTH CARE FOR ADOLESCENTS

Parents have significant influence on the health outcomes of their adolescent children. Yet, their ideas about health and health care for teens have not been heard. This report presents findings from a focus group study conducted with parents of low-income adolescents in four cities -- Los Angeles, Miami, Chicago and Washington, DC -- about adolescent health care. English- and Spanish-speaking parents alike express concern about the many challenges today's adolescents face in maintaining their health and desire to play a supportive role in their teens' care. They offer suggestions for an ideal adolescent health care setting that is accessible and inviting and that provides teens access to knowledgeable and caring staff able to address a broad range of common health needs.

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*THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH*

Though perhaps not always acknowledged, parents play a critically important role in shaping the lives of their adolescent children and in assuring that they receive needed health care information and services. An extensive body of national survey literature, for example, shows that adolescents who report parental oversight,¹⁻³ connectedness,⁴ communication,⁵⁻⁷ or support⁸⁻¹⁰ are less likely to engage in various health risk behaviors. Yet, little information has been collected on parent views about teen health problems and the providers' role in addressing them, and even less has been collected on parent experiences in accessing health care for their teens or on how they think adolescent health services should be structured. Moreover, what we do know about parent perspectives is drawn from small-scale surveys or focus groups, some of which are fairly dated.

The available literature suggests that parents are generally aware of health risk behaviors and problems among the adolescent population -- including substance use, mental health problems, sexuality, and nutrition -- but that they are likely to underestimate the extent to which their own adolescent children may be involved.¹¹⁻¹² Nevertheless, parents, irrespective of race or income, value information from health care providers that can help them support their adolescents and better address their health care needs.¹³⁻¹⁷ In addition, they expect providers to engage in discussions with their teens directly about a broad range of health risk behaviors and problems.¹⁸⁻²² They also believe that teens need help on goal setting and conflict resolution.²³ And, while they recognize the adolescent's right to confidentiality, they expect providers to share information that is important to their child's health, believing that they are working together to keep their adolescent healthy.²⁴⁻²⁶ Some parents thought that this should be done without violating confidentiality;²⁶ others seemed to misunderstand the application of confidentiality protections.²⁷

Our report provides a comprehensive look on parents' perspectives on numerous topics, such as health problems facing teens, experiences obtaining health care for adolescents, parents' role in their teen's health care, and staff and services at an ideal health care site for adolescents. Using focus groups, our study documents the views of 61 parents of adolescent children from disadvantaged neighborhoods in Los Angeles, Miami, Chicago, and Washington, DC. Seven ethnically diverse focus groups of mixed gender were held in these cities. Three of the seven groups were conducted in Spanish with parents whose primary language is Spanish. Focus groups ranged in size from eight to ten parents each. Some lived in families with incomes between 100% and 200% of the federal poverty level, but most lived in families with incomes

below the poverty level. After discussing their experiences with health care, each focus group was broken up into teams of three or four parents to design their “ideal” health care site for teens and to report back to the group.

Concerns about Teen Health Problems

Parents were very concerned about the challenges confronting adolescents. When they were asked about the most important problems teens face, sexuality, sexual diseases, and drug and alcohol abuse were intensely discussed by all focus groups. Parents expressed frustration that outside the home environment, negative influences about sexuality, drugs, and alcohol were ubiquitous: near schools, in their neighborhoods, on television, and among their peers. Teens were continuously exposed, they said, to peer pressure and other influences that tempted them to make unhealthy decisions. In all groups, many parents linked drug and alcohol abuse directly to peer pressure and socializing. A few parents in different groups mentioned that peers introduced teens to new drugs and also made it easier for them to obtain familiar ones.

“I taught my children all I can about protected sex and taking care of themselves, and for some reason... having a baby seems to be a good idea and not a bad idea.”

– Miami Group, English Speaking

“I believe they are filling a hole with the sex and the drugs.”

–Los Angeles Group, English Speaking

“I think the drug problem comes in with the peer pressure too... you can't get away from it. You're trying to keep it out of the schools and you got the guy standing on the corner outside the school...”

–Chicago Group, English Speaking

Nearly every group addressed mental health as a problem for teens, emphasizing depression and anxiety. Within groups, many parents were concerned that teens seemed to face more challenging situations at earlier ages, including some issues that parents never dealt with when they were adolescents. A variety of stressors were brought up: sexual relationships, confusion

about sexual orientation, unhealthy home environments, partner abuse, changing hormones, and pressures at school. Parents in several groups worried about the physical and psychological impact of violence at schools and within gangs.

“So it could be that there are situations where they're being abused, their momma's being abused, their mom is on drugs, their dad is on drugs, someone's alcoholic. And...on top of having the issues in the house, they have to deal with what's outside in the world.”

–Chicago Group, English Speaking

“Instead of doing exercise, or running, or going to a gym or to the park, they're just playing [video games].”

–Los Angeles Group, Spanish Speaking

Parents in most groups also mentioned poor nutrition and lack of physical activity as major issues for teen health. They felt many teens were not educated on proper nutrition and had poor diets. Los Angeles parents were concerned about the lack of healthy options in school cafeterias and vending

machines. There was strong concern expressed by some parents in several groups that lack of good nutrition led to other problems, including diabetes.

Experiences Obtaining Care for Adolescents

When asked if they were able to get health care for their teenagers, most parents in all of the focus groups said they were able to do so. Among parents with insurance, most were satisfied with the care and treatment their teenagers received from their primary care doctors in office practices, which included pediatricians or general practitioners. Having known the physician for a long time, they trusted and valued what he or she had to say.

Spanish-speaking parents seemed to face unique difficulties obtaining health care for their adolescents. A Chicago parent said that there was a lack of information in the Latino community about where to go for care, especially among undocumented workers. Another spoke about the need for translators when parents don't speak English. Several parents in Los Angeles mentioned that they wanted to find health care professionals for their children once they entered adolescence and started going through changes, but they didn't know where to go.

Parents with insurance expressed a number of concerns about receiving care. In several focus groups, parents spoke about an inability to afford high co-payments. Many also said their plan did not cover some services, such as seeing a psychiatrist, counselor, or nutritionist. Parents in some groups expressed frustration with long waits for specialist appointments and a time-consuming referral process. They described waiting weeks or months for an appointment with a specialist while their adolescents' conditions changed or worsened.

Many groups said that parents who did not have insurance could use emergency rooms, health departments, or health clinics that offered affordable or free services, but they also spoke about significant frustrations in accessing these services. In emergency rooms, most parents said, they or their friends experienced long waits, unnecessary testing, or expensive treatment.

"Well, we just basically call our pediatrician and they tell us about you know, they'll say 'Oh go here or go wherever the hospital, this or that.' But [the information] is not something that's readily available."

– Miami Group, English Speaking

"I've found that a lot of my neighbors, and my kids' friends, their parents don't know about what to do... We don't have like a universal place where you can go and dial 911 and you get services for mental health, or substance abuse, or whatever."

– Miami Group, English Speaking

"It's easier to go to jail and get... psychological help than it is if you're a person out here going to school, and that's a shame."

– DC Group, English Speaking

"I had a problem with my brother. When he was young, he was into drugs...I would have liked to know where to go for help, but I never found information about where I could take him for rehabilitation and such. Now that I have my son, this is also something that worries me, in case I need something one day."

—Los Angeles Group, Spanish Speaking

Health clinics were described by parents in some groups as not always having the services their children needed, and some parents commented that it is difficult to find transportation to go to clinics in different sites. At these clinics, many parents said they waited in crowded rooms or felt rushed at the hands of busy providers.

Parental Responsibilities for Ensuring Care

Ultimately, parents in all groups believed it was their responsibility to keep their teens healthy and obtain care for them. Many parents felt that choices for care existed, but they acknowledged that some teens may not receive the care they need because of their parents. They mentioned that some parents have psychological or substance abuse problems, some do not believe in traditional forms of medicine, and some parents just do not care, while others have difficulty being absent from work. All parents agreed that open communication and honesty with adolescents about health issues was essential for adolescents' well-being, and many talked about the importance of engaging their teens in discussions about health, school, and peer problems.

Also, parents in every focus group were adamant about being involved in their children's health care. All seven groups mentioned making appointments and taking their teens to see a provider for routine checkups and physical exams, reproductive health, chronic conditions such as diabetes or asthma, and mental health, when necessary. Parents said that although they would take their child for care if they abused drugs or alcohol, none had personally dealt with that situation. Most parents in the focus groups said they were able to take time off work to bring their children to a health care professional, but some parents found it challenging to work around the standard weekday business hours that most offices and clinics were open. Many parents in all groups insisted they knew about health care visits of their teens or attended these visits. However, in a few groups, some parents acknowledged that they did not know when their teenagers went to get reproductive health care.

Boundaries of Parental Involvement

When asked about the appropriate age for a teen to make and go to appointments by himself or herself, all focus groups agreed that there was no "magic number." The answer, they said,

depended on a child's maturity level, comfort with doctors, and personality. Most groups suggested the age of 18 as a natural point at which the teenager was an adult and could go to the doctor alone. In fact, in Miami, parents mentioned that if a child was under 18, he or she would not receive care without parental consent. Other answers included when the teen was 16 years old, when he or she was in college, when he or she left the house, or when he or she was "an adult." Several groups strongly expressed that they eventually wanted their children to have the opportunities to learn about health care by themselves and trust themselves to be independent, which would empower them to make their own healthy choices. All parents also said that if their child wanted them to be present for any reason, they would not say no. A few parents mentioned accompanying children into their twenties to appointments.

"I think it's when the kids trust themselves, because if they don't trust themselves... they get old and they still want you to be there with them. And I think it's when they decide, not when we decide."

– Chicago Group, Spanish Speaking

"I just think as a parent, you have to be comfortable with the values you've instilled in them. At that point, that's where that faith and trust, you just walk out [of the room] and let it go."

– Los Angeles Group, English Speaking

Parents in all groups voiced mixed opinions regarding their teens' feelings about their involvement in sexual and reproductive health care. In most focus groups, several parents said they understood that their teens felt uncomfortable sharing details about their sexual activity or about sexual health issues in general with them. All parents in each group said that if their adolescent wanted them to accompany them to appointments for sexual health, they would go. However, some parents in some groups acknowledged that their adolescents were probably seeking and receiving care without their knowledge. Some parents in a few groups also said their teenagers went alone to receive care but discussed it with them afterwards. Parents seemed to want to have more involvement in sexual health issues with teens. In all groups, however, most parents were unsure how best to have discussions with their adolescents and were divided in the extent to which they were able to communicate with them.

When asked how they felt about the idea of adolescents having private time with a health care provider, almost all parents in every focus group were familiar with the practice, but there was wide variation in their degree of comfort with this policy. Some parents in each focus group thought this was a good practice so adolescents would become more comfortable taking charge of their health and learn how to ask appropriate questions. They also believed that the adolescents would disclose information to the doctor they normally would not if the parent were present. In addition, they thought that if the health provider communicated with the teen alone, he or she might be more likely to listen. Other parents in each group did not feel comfortable

“Knowing my son, I know that if I’m standing there and he wants to ask a question, he may not ask it if I’m there. I’d rather step outside, let him ask the doctor, and then if there is anything, they can tell me later.”

–Miami Group, Spanish Speaking

“There may be things that they can tell the doctor because he or she is not their mom...What worries me is...sexuality, since they’re at that age. As much as one tries to explain and tell them, they don’t get it.”

–Chicago Group, Spanish Speaking

leaving their adolescents alone with a provider for several reasons: they believed an adolescent would not know which questions to ask, they wanted to know everything about their teens’ health and did not want information withheld from them, or they felt uneasy leaving adolescents with a provider they did not know. Although they desired more involvement, they also said they understood why the process exists. No parent could give a definite age when they felt it was appropriate to leave the room, and willingness to leave varied by age of adolescent; parents in a few groups talked about wanting to stay in the room for younger adolescents to ask questions or remember

symptoms to tell the doctor that the adolescent does not bring up.

Parents’ Desire for Support

Parents in all focus groups expressed a strong interest in health care providers’ support in parenting related to health concerns affecting their teens. Parents in several groups said it would be useful to have time to speak to the health care provider in private without their teen present but understood that doctors rarely had time to do this. Parents in most groups wanted guidance from the providers on how to open a dialogue with their teens about certain topics, particularly sexual and reproductive health, drugs and alcohol, nutrition, and mental health. They wanted to be able to educate their teens without being too intrusive. Parents in some groups suggested documents, like pamphlets or fact sheets, to hand out to assist them on how to broach specific topics, such as depression or obesity, with their teens. All groups also wanted information from their providers about spotting warning signs in adolescents. Parents wanted to be able to tell if teenagers are in trouble or at risk for certain behavioral problems, such as substance abuse. In addition, they wanted to be able to identify warning signs of conditions, like diabetes or depression.

“I’ve been told by my doctor that my son tells him that he wishes I was around more.... And he’s told me...kind of clue into this, and clue into that, how to treat him, and get him to open up to me more, and discuss more of his deeper feelings with me.”

– Chicago Group, English Speaking

“How to be able to identify when they’re into drugs. Because sometimes these kids are so smart and they do things and then come home looking normal...In my home, I don’t see anything, but outside, I don’t know.”

– Los Angeles Group, Spanish Speaking

“I think that with teenage children, there is always some type of problem...it would be good to know how to handle that problem. If there were a group that I could go to so I can learn what I need to do to help my son, what I need to learn, how I need to react, something like that.”

– Los Angeles Group, Spanish Speaking

“I would say answer my questions...I know there are other patients there, but make the time to talk to me about my child’s health.”

– DC Group, English Speaking

“You know, 19, when they turn 19 the providers don’t even look at the parent anymore.”

– Miami Group, English Speaking

All three Spanish-speaking groups also thought that providing health information and support in school and community settings would be helpful. Some parents brought up the value of church and home support groups for dealing with substance abuse issues. Others wanted more classroom time for their teens educating them about sexual health and substance abuse. A few desired parent support groups for those whose teens were suffering from particular problems, such as abuse or mental health issues.

The Ideal Health Care Experience

Each focus group was divided into teams of three or four parents 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.

Parents in every focus group felt strongly that easy accessibility was important. There was some discussion on whether a health care site for adolescents should be near schools or in schools. Parents in one group believed that adolescents would be less likely to go to a center in a school for several reasons: other teens could gossip about visits, and most teens did not want to remain inside a school after the school day was over. Every group came to a consensus that the health care site should be near a school. Parents in several groups felt that a center could also be near places where teens tend to congregate, such as shopping malls or bowling alleys. Many parents brought up the importance of being in a safe neighborhood, on a well-lit or well-known street. Some parents in some groups felt that there should be several sites, one in each neighborhood, to make them easier to reach. All parents desired centers that were easily accessible by public transportation.

“Just like every neighborhood has its school, then there should also be a youth center in each neighborhood that provides all of these medical services, as well as educational, sexual, physical, and all of those things.”

– Miami Group, Spanish Speaking

“Where kids can also go and feel safe...”

– Los Angeles Group, Spanish Speaking

Parents described the aesthetics of an inviting atmosphere for adolescents, as well as flexible hours that would make it convenient for them to attend. All groups mentioned spacious, clean waiting rooms that had a separate area just for teens. They said that teens can often be intimidated by a doctor’s office, so it was important to have a comfortable, friendly setting.

“...within school [neighborhood] limits, either a bus ride or down the street, within walking distance for some people. Within that place, we would have a layout with couches, chairs; we would have televisions there that did loops of various video information, topics that were key in that particular area...”

– DC Group, English Speaking

“...you don't want a teen to finally get up the courage, the nerve or whatever to go and they say, 'Sorry we can't talk to you about this, you don't have an appointment you know.'”

– Miami Group, English Speaking

in one group suggested a 24-hour hotline for teenagers to call. All groups wanted the center to accept appointments and walk-ins.

Staff and Services at an Ideal Health Care Site

Parents wanted to have a variety of health professionals working at the site. All groups mentioned physicians, nurses, specialists (with one group specifying an obstetrician/gynecologist), and counselors and therapists. Most groups also mentioned wanting psychologists, nutritionists, and nurse practitioners as well. Parents in all focus groups felt that being knowledgeable and caring were important characteristics for staff working at this site. Many groups also wanted younger doctors that teens could relate to, but all groups agreed that the most important factor was experience with adolescent patients. Parents in most groups wanted professional staff with good communication skills who listened to adolescents' concerns and genuinely cared about their well-being. There was an interest in having racially and ethnically diverse staff, and Spanish-speaking parents in two groups also mentioned the need for staff who spoke different languages.

“Because I speak a little bit of English...I think I'm only going to understand 50% of it and I'm going to miss out on the other 50%. So for me, it is very important that I understand everything...”

– Los Angeles Group, Spanish Speaking

“The big one obviously for parents is highly qualified doctors, counselors and therapists in terms of their experience... you are going to make or break a teenager's life. That's where they're most influenced. That is where they need the most professional help at that age... and we trust those people that they're going to see.”

– Los Angeles Group, English Speaking

“And as far as the services, if you’re going to make it ideal for a teen, whatever services they need, the mental health, sexual health information, counseling...but if they just need to get something off their chest, they should just be able to go to talk to somebody, and then whatever medical things they need...”

– Miami Group, English Speaking

“...kids that have gone through those problems, or had a child when they young, or were involved in drugs, and they can give the example of what happened to them. So they can see that it’s not just their parents telling them not to do something because such and such is going to happen, but they can hear directly from that person what happened to them and the consequences they suffered.”

– Miami Group, Spanish Speaking

Every focus group expressed a strong preference that all services be in one place and that they be covered by insurance or otherwise affordable. Within their groups, parents were nearly unanimous that the ideal health care site should have services for sexual health, mental health, nutrition counseling, and substance abuse. Common sexual health requests included sexual health education, STD testing and treatment, information on HIV prevention, obstetric and gynecological services, and family planning services. Parents in all focus groups suggested individual counseling and group therapy for mental health issues, most often for depression and anxiety. Parents in all groups also pointed out the importance of teaching teens about proper nutrition and offering them information about how to lead a healthier lifestyle, such as a diet plan. They believed that making available teen-specific informational pamphlets, holding

workshops or group discussions, and having guest speakers -- even older adolescents who faced similar challenges -- could help influence adolescents to make healthier choices. Parents in most groups also suggested services to deal with drug or alcohol abuse, such as therapy or support groups.

How to Bring Teens In and Keep Them Coming Back

Parents also gave suggestions on what would encourage adolescents to come in for care and keep returning if their ideal health site existed. Parents in several groups thought that providing a variety of services would give teens a reason to seek care at this center. Parents in some groups thought that a comfortable atmosphere and friendly, caring staff would encourage teens to keep returning after their first experiences. It was also commonly suggested that through word-of-mouth the number of teens interested in coming in would naturally increase. Parents in all groups expressed optimism that if their ideal center existed, teens would make use of it to make healthier lifestyle choices and improve their health.

“I think if they have people—positive people to encourage them... I think they would go.”

– Chicago Group, English Speaking

“I think they would be more involved in their health...”

– Miami Group, English Speaking

A Comparison of Parent and Adolescent Perspectives

Comparing the views of our parent focus groups with those of our adolescent focus groups²⁸, also conducted in Washington DC, Los Angeles, Chicago, and Miami, we found a remarkable degree of consistency. Parents and adolescents were in agreement about the major health issues confronting teens, emphasizing sexuality and mental health problems. Both talked about peer pressure with regard to drug and alcohol use, but parents expressed far more concern and were more likely to bring up abuse. Both parents and adolescents also expressed similar frustrations in obtaining health care, including busy providers and long waits. Most adolescents and parents said teens wanted parents involved in their health care if they had a serious problem, but they both voiced a wide range of opinions on how comfortable teens felt with parents' involvement in sexual health issues.

When asked about their ideas for an ideal health care site, the importance of knowledgeable, caring staff who could relate to teens was stressed by parents as well as adolescents. Both expressed a strong preference for all services at one site, and both wanted sexual and reproductive health care, mental health care, and substance abuse services. Perhaps predictably, all parent groups desired nutritional education and counseling, while this was a lesser concern to adolescents. Adolescent groups put a greater emphasis on the reassurance of confidentiality at such a center, while only a few parent groups mentioned it. Both parents and adolescents felt that good experiences with friendly staff and positive word-of-mouth would encourage teens to use the center and keep returning.

Conclusion

As research and demonstrations pertaining to primary care reforms continue, the delivery of care to adolescents should be given special attention. Parental input can help provide direction for thinking about a new model of care for adolescents. Regardless of ethnicity or location, parents in the focus groups express certain common negative experiences with the health care system for adolescents and were unanimous about many ways in which it could be improved. To meet their teens' needs, they recommend a health care site that is accessible and inviting, with knowledgeable and caring staff in a teen-friendly environment. They desire comprehensive services in such a center, including services for sexual health, mental health, nutrition, and substance abuse. They would also welcome more guidance and support for themselves. The parents in these focus groups believe that the environment and services of such a center would encourage adolescents to widely use the center and ultimately improve their health.

Methodology

This report presents the findings from a focus group study undertaken by The National Alliance to Advance Adolescent Health. A total of 61 parents from Chicago, Miami, Los Angeles, and Washington, DC participated in a total of seven focus groups, which were conducted from July to August 2008 by ICR. The parents all had children between the ages of 14 and 21.

Staff at local organizations in each of the four cities recruited parents from disadvantaged neighborhoods to participate in the study. The groups were mixed gender and represented the ethnic make-up of each of the cities. 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 between 100% and 200% of the poverty level. The proportion of males and females was about equal. Of the seven focus groups, three consisted of parents whose primary language was Spanish. A majority of the groups had eight participants, and sizes of the groups ranged from eight to ten.

The groups lasted 90 minutes. Discussions were led by a moderator from the research firm, using a discussion guide that was prepared by The National Alliance. Parents were asked to think not only about their situations and experiences but to reflect on those of their friends with adolescent children. 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. Transcripts from the Spanish-speaking parent groups were professionally translated. Participants were offered a small gift for their time.

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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 Aileen Collins at The National Alliance to Advance Adolescent Health: acollins@TheNationalAlliance.org. Also visit our website: www.TheNationalAlliance.org.

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