

# What NYS Youth Say About Sexual Health: Implications for Planning Reproductive Health Programs

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Assets Coming Together (ACT) for Youth  
Center of Excellence  
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## Purpose of Project

- To learn more about how young people across New York State get information about sexual health and access treatment and services
- To obtain young people's ideas about improving adolescent sexual health care
- To inform and provide guidance to DOH planning efforts
- To bring additional youth voice to the Sexual Health Symposium

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## Research Process

- Developed research protocol and tool
- Built team of facilitators/recorders
- Obtained IRB approval
- Piloted tool and process
- Identified the sample:
  - Recruited through ACT for Youth sites & DOH providers
  - Offered \$20 incentive
  - Sought diversity: upstate/downstate, rural/urban/suburban, gender, race/ethnicity, sexual orientation, health and housing status

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## Research Process

- Conducting groups:
  - Most groups separated by gender
  - 1 moderator; 1-2 observers/note-takers
  - Self-administered demographic survey
  - Team debrief to correct notes
- Data gathering – October-December 2008
- Data analysis:
  - Conducted qualitative thematic analysis
  - 2,220+ “bullet points” from observers’ notes
- Involved 291 youth in 27 focus groups

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## Demographics – Pilot Groups (n=57)

- Age Range: 14 – 23 years
- Mean Age – 17.98 years (S.D. = 2.13)
- 59.6% Female, 38.6% Male, 1.8% Transgender
- 37% were not in school
- Ethnicity - 21% Hispanic
- Race
  - 53% Black or African American
  - 32% White

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## Demographics – Non Pilot Groups (n=234)

- Age Range : 13-21 y.o., Mean Age: 16.28 (S.D. 1.57)
- 48.3 % Female, 50.4% Male, 1.3% Transgender
- School:
  - Not in school – 5%, 8<sup>th</sup> grade – 3.4%, 9<sup>th</sup> grade - 17.6%, 10<sup>th</sup> grade – 18.0%, 11<sup>th</sup> grade – 26.2, 12<sup>th</sup> grade – 29.6%
  - 98% in public schools
- Ethnicity: 25% Hispanic
- Race (select all that apply):
  - 5.1% American Indian or Alaska Native
  - 3.4% Asian
  - 56.8% Black or African American
  - 23.5% White
  - 18% Other (includes multiracial and specific ethnic affiliations)

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## Focus Group Questions

- Education/Information
  - Where you get info
  - Best ways to learn about sexual health
  - Barriers to getting accurate information
  - Info needed now
  
- Access and Services
  - Where you go for condoms, birth control, and treatment
  - Barriers
  - Experience with services
  - Making it easier for youth
  
- Recommendations: How can we make things better?
  - Disparities and differences

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## Definition of Sexual Health



Adolescent sexual health poster designed by Kristy C. Jerkins and Kruti Sheth, based on NYS DOH Adolescent Sexual Health Working Groups definition of sexual health

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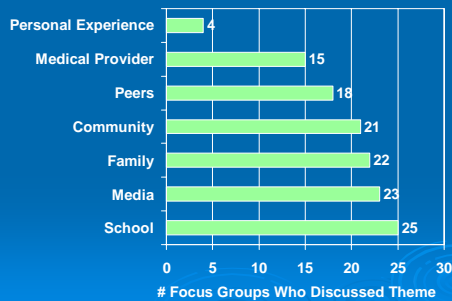
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## Where do you get information?




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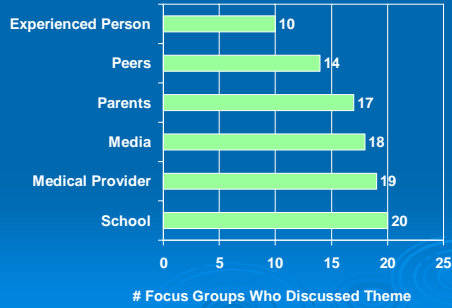
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## Best Source of Information



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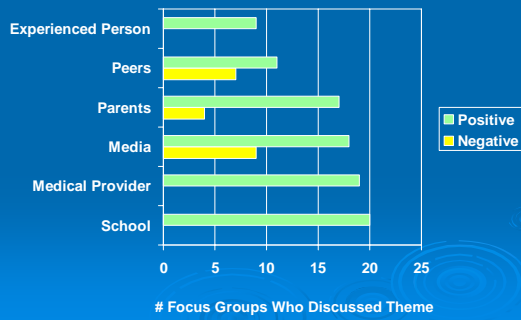
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## Best Source: Mixed Responses



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## Peers: Positive and Negative

*"Friends....can share your life"*

*".....you listen to them more"*

*"Peer educators know more than parents"*

*"Peers....even if they don't have all – or right information"*

*"You may believe it more but friends may not be accurate"*

*"They're going to tell you what you want to hear"*

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## Parents

*“....they have more experience and know you best so they know how to break it down”*

*“ Parents know you. They know how to talk to you.”*

### IT DEPENDS.....

- Comfort level
- If they know you are sexually active
- Only if you are close

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## Parents

➤ **Misinformed:** Sometimes parents give misinformation – *“if you have sex you’ll get cancer....”*

➤ **Uncomfortable talking:** *“so uncomfortable it makes you uncomfortable”*

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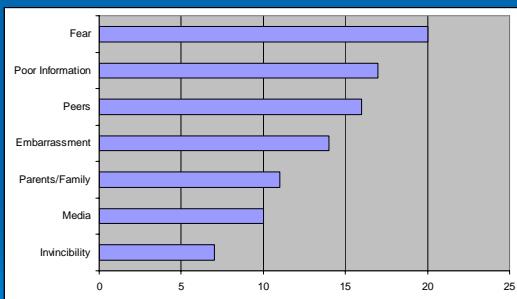
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## Barriers to Obtaining Accurate Information



# of Focus Groups Who Discussed Theme

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## Fear Themes

*"Being scared: what if I have something? 'I look too good to have it'"*

*"Youth don't want to get scolded by parents"*

*"Don't want everyone to know what is going on with you – want to handle it yourself"*

*"Afraid that if you're asking about it, you're doing it"*

*"People don't get tested because they might get judged"*

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## Poor Information Themes

*"People exaggerate: tell you they have big needles, it will hurt, HIV test is not 99% accurate so why take it? You can get poked the wrong way – get bad information this way."*

*"Incomplete information: Know that you need a condom, but may not know how to put it on"*

*"Getting very different information leads to confusion"*

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## Peer Themes

*"Peers: they go with what they think they know and it may not be accurate, they could give the wrong information."*

*"Peers – people you hang out with who think its cool to just go around and bang everyone but don't know nothing."*

*"Friends they lie, if you don't know the truth then you believe them"*

*"Your partner: say you don't know much about anything, and your partner doesn't know much—you'll believe what he says"*

*"They try to get you to 'come on' to be cool. You want to fit in with your friends, experience it and see what it is"*

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## Barriers to accurate info

### YMSM

"Stereotypes: when you try to get info, they think you already have a STD or are HIV+"

### LGBT:

"Friends don't know they are harming you by keeping you from getting certain information"

LGBT: People may not want to be your friend if they think you have an STD"

### HIV+:

"Language is important: STDs vs STIs: Using 'infection' makes it seem like I can get it treated by antibiotics – but they don't know the long-term effect – that they'll have to get warts burned off the rest of their life"

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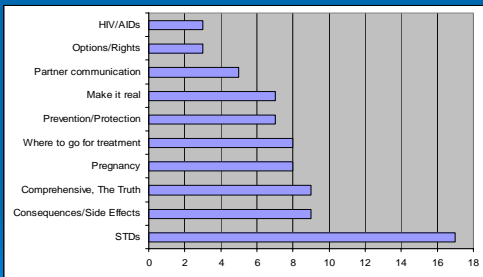
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## Information we need now



# of Focus Groups Who Discussed Theme

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## Information we need now!

*"Need to be prepared for anything – need to know all information: how to get it, prevent it"*

*"EVERYTHING! – We don't want it sugarcoated. Sugarcoating leads to people ending up in situations where they don't know what to do."*

*"Heard you can't get pregnant in certain ways/places – e.g., hot tub, salt water, address all the myths"*

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*“Put pictures of diseases on a big screen on TV and be specific and scare people.... What your genitals will look like if you get a disease”*

*“Videos – They need to hear from people who have it and what they do to live with it, how it feels to have it”*

*“Know history of your [partner] before you have sex with them—need to know how to have that conversation”*

*“That they can meet with their doctor/pediatrician without their parents present.”*

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**YMSM:** *“Statistics: people need to know what the numbers are, e.g., 67% of the YMSM in my area are infected”*

**LGBT:** *“Prevention instead of treatment: people get caught up in the moment, but need to know how to protect themselves beforehand”*

**HIV+:** *“The facts -- What this STD will do to you – side effects, long term effects; “What your genitals will look like if you get a disease”*

**RHY:** *“Signs and symptoms of diseases; what to do/not to do if you have it”; “Show pictures of STD, use shocking/scare tactics like with tobacco use”; “How to protect yourself from STDS – condoms won’t prevent everything”*

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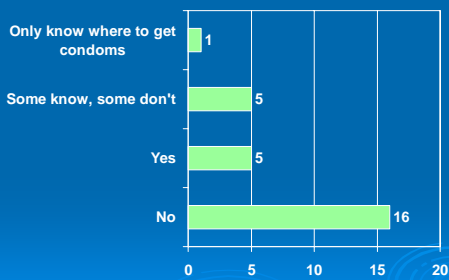
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### Do young people know where to go for sexual health care services?



# Focus Groups Who Discussed Theme

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*"I know how to roll blood – but not get HIV testing. Drugs and alcohol have a lot to do with this. You can buy drugs but can't get access to safe sex" (YMSM)*

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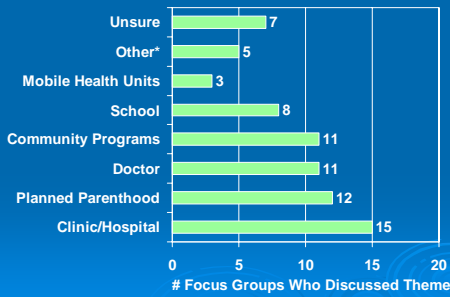
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### Where do young people go for HIV/STD tests and treatment?



\*Jail, Parents, Gay Clubs, Pharmacies and Stores

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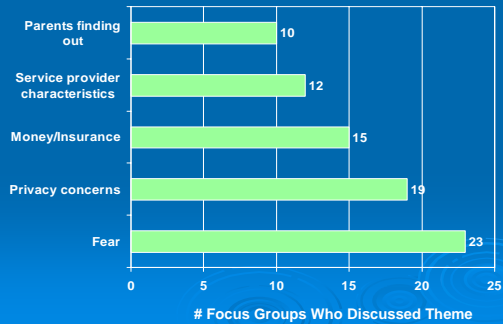
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### What might stop you and your friends from going to a doctor or health center?



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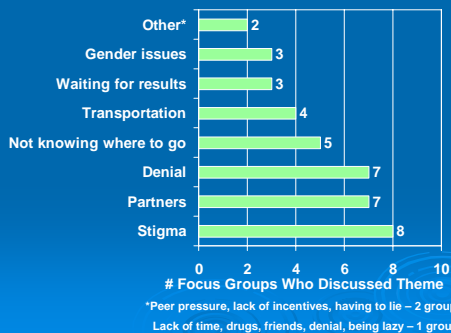
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## What might stop you and your friends from going to a doctor or health center?




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## Fear

- Fear of test results... *"If I have something, I don't want to know."* (10 groups)
- *"Fear of what to do if you find out—do I tell my parents, my partner?"*
- Afraid that the doctor will tell your parents or that information will somehow get to them
- Fear of what other are thinking (may think I am "dirty"), stereotypes and assumptions others have
- Fear that someone will "out" you regarding your status or visit to a clinic
- Fear of needles, getting inaccurate test results

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## Privacy concerns

- Seeing someone you know *"like your grandmother"* or knowing someone at the clinic
- Being seen (e.g., if testing is done at school)
- Rumors going around
- Confidentiality not being respected by service providers
- Parents finding out (e.g., when clinic calls people at home or sends things by mail)

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## Service provider concerns

- Lack of services – too few, too far away
- Being judged by the service providers
- Location is too public: *“people see you coming and going”*
- Too kid-oriented (childish decorations, etc.)
- *“I want a place that can work with youth”*
- If not youth friendly, *“you don’t want to stay”*
- Dirty facilities
- Rude staff
- Providers that are not certified or licensed

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## Parents finding out

- Worried that medical providers would tell parents
- *“I will get kicked out if I have sex.”*
- Don’t want parents to know... *“I would be dead.”*
- Can’t ask parents for money... *“That’s why a lot of people run away.”*
- Hard to talk to parents about it
- Youth comments about insurance expressed worry that parents would find out

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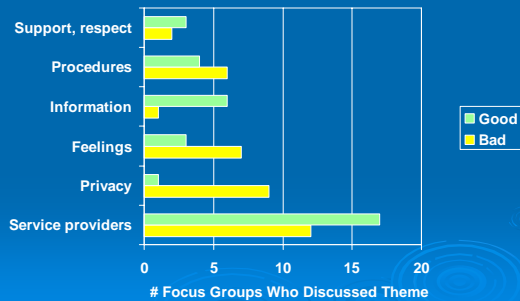
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## Experiences getting birth control, HIV or STD tests and treatment



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## Experiences getting services

*"Being sent out of the room scared me."*

*"Testing is so nerve-wracking; scary, waiting for yes/no."*

*"Clinic was kind to the girl but treated the boyfriend as if it were his fault."*

*"I don't like seeing different doctors at each visit."*

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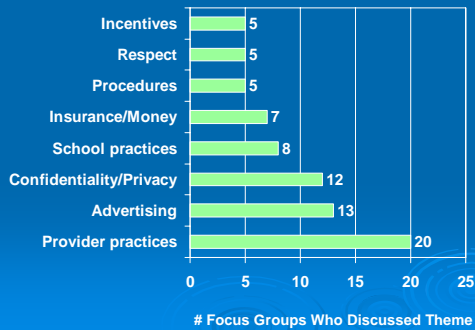
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## What might make it easier to get services?



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## Making access easier

- Extended hours (24 hour emergency access)
- Advertise location
- Free or low cost
- More local services especially in rural areas
- One-stop center for services
- Ensure parents don't have to pay for it
- School based services
- Integrate sexual health care into physicals
- Ensure privacy, show respect, welcome us
- Support and encourage us: *"Don't make me feel bad for wanting a test"* or for wanting information

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## Making Access Easier

### LGBT

- Not having to bring parents for treatment
- Confidentiality, respect
- Making me feel welcome

### HIV+

- Offer incentives to get tested
- Teens (not doctors) go out to encourage testing
- "It all comes down to – can you relate to the person: attitudes, tone – we have to stay interested"

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## Making Access Easier

### YMSM

- Schedule appointments for follow up
- Make services more available (e.g., have 24 hour clinic: what if you have a crisis in the middle of the night?)
- Tell you about other locations
- Don't make people feel bad if they want information or want a test
- Advertise more
- Insurance issues: e.g., red tape, don't tell me that Medicaid don't work or I need to change my HMO to get testing or that I've been sanctioned.....

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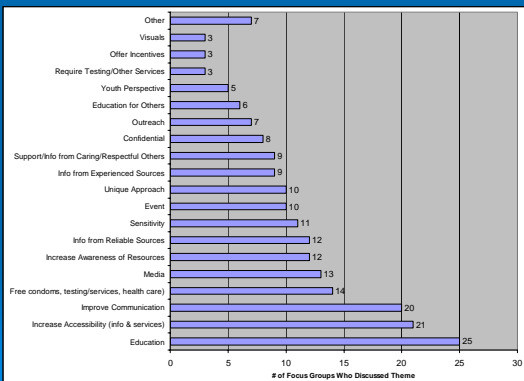
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## Recommendations



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### Offer more extensive sexual health education

- Increase the amount of sex education in the school (*"We should have health class every year – more in-depth info as you progress freshman to senior years"*).
- Provide sex education at earlier ages (*"More groups in schools – it's something you need to learn, school is a place to learn – start in elementary school – health class should be longer than 1 semester – sex was only 1 small section of the class"*)
- Make sex education a requirement for high school graduation (*"Should be education requirements for high school graduations and anyone who works with young people"*)
- Teach alternatives to sex (*"Know you don't have to have sex. You can hug and kiss to be intimate – you don't need sex to be intimate. People think if you're in a relationship you have to have sex."*)
- Utilize peer educators (*"Have young people come over and show them different methods --- use young people as the educators"*).

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### Increase access to sexual health information and services

*"The best way is at school because a lot of people go to school. There should be a health center in school."*

*"Having [clinic] in nurses' office—including birth control—I'd feel comfortable with her, she'd keep it confidential, friends wouldn't know why you went to the nurse's office"*

*"Have places more accessible – make more places available where people live, in busy places"*

*"Have health clinics within programs/organizations that deal with the health side: exercise, nutrition, STD screening"*

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### Make resources more visible in the community

- *"Put the information where we are"*
- *"Have events (ex: basketball, BBQ, parties). Introduce sex ed during half time at games. Short brief messages. Maybe make a video to show during parties or the games. Have bowls of condoms at parties and other sexual health info. Make it fun to learn about AIDS. Have AIDS fortune cookies --- bite into it to get the FACTS. Have pamphlets on the table."*
- *"Something that moves around, telling us about it [mobile unit]"*

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### Improve Communication

“Start a group in school. Now they talk about it in health class but don’t do anything about it in school. They need to ask girls more, have more personal discussions, help them see future possibilities.”

“Groups like this talking together”

“Have more seminars like this – WOW – Adults are here! Have more people who are willing to listen to us: we are not being heard!”

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### Parent Communication Themes

“Offer a course for parents to help them talk with their kids”

“‘My child is too good to do that.’ Parents need to suck it up and realize they are doing it. Don’t be scared to talk about it – tell them about the birds and the bees early, everybody’s going to have sex at some point”

“Parents shouldn’t assume kids are having sex if they ask questions”

“One girl’s mother told her that she would get pregnant if you kiss a boy and the girl was torn up. Parent should be more open and honest even if it is awkward. There should be a parent workshop or send letters to the parents to tell them how to tell your children about sex education.”

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<b>LGBTQ</b>	Educate parents Increase media efforts (advertise on BET, MTV – role models Commercials introduce people playing basketball, dancing, going to school – we’re all HIV positive – decrease stigma/stereotypes Need to start hiring young people in positions of power – to work with other youth -- we should work for you
<b>YMSM</b>	Advertise more -- PSAs promoting testing, staying safe Make it feel more welcoming Increase sex ed in schools Have more incentives for testing
<b>HIV+</b>	Workers should do more outreach, door to door, pamphlets More education in schools – start early – require health class Parent education – passes down to generation
<b>RHY</b>	

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## Limitations and next steps

- Preliminary analysis – Limited ability to identify and validate differences among subpopulations of participants
- Have not yet fully integrated demographic information from self-administered surveys with the focus group data
- Anticipate conducting focus groups with parents/guardians in May-June 2009

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## With thanks to:

- Adolescent HIV Prevention Services Youth Leadership Retreat, Summer 2008
- ACT for Youth sites: Dutchess, Erie, Monroe, Orange, Queens
- Bronx AIDS Services
- CITY Project (NYC)
- Harvey Milk High School (NYC)
- Learning Web: Youth Outreach (Ithaca)
- Teens Against Violence (Corcoran High School, Syracuse)
- Youth Leadership Academy (NYC)
- Youth Advisory Group/AIDS Institute

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**Special appreciation to the youth  
who participated in the focus  
groups!**

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## ACT for Youth Center of Excellence Focus Group Team

- Cornell University:  
Kate Bubrick, Jane Powers, Amanda Purington, Karen Schantz, Jennifer Tiffany, Heather Wynkoop-Beach
- Cornell University Cooperative Extension/NYC:  
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- New York State Center for School Safety:  
Mary Grenz Jalloh, Beth Mastro
- University of Rochester:  
Hans DeBruyn, Jon Klein, Premini Sabaratnam

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We welcome comments, questions, and suggestions for further analysis.

Thank you!

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