

Packaged Lifespan Health Focus Group Materials

For the Facilitator:

Focus Group Introduction Script
Background Bullets
Parental Permission Signature Form
Assent Form
Consent Form
Lifespan Health Focus Group Questions
Note-Taking Templates (2)
Written Questionnaire
Payment Information for Research Participation Form
Facilitator and Note Taker Guide (3)

For the Focus Group:

Assent Forms (15)
Consent Forms (15)
Disparity Sensitizer Debriefs
Written Questionnaires (15)
Payment Information for Participation Forms (15)

Also Included:

Pens
Markers
Name Tags

Reminder: Please bring your audio recorder

FOCUS GROUP INTRODUCTION SCRIPT

Introductions:

Hi. I'd like to thank all of you for being here today and for your willingness to participate in our discussion. My name is [Facilitator] and with me today are [Notetaker 1] and [Notetaker 2]. We work with the ACT for Youth Center of Excellence.

Background:

We're here today to have a group discussion about health, and particularly about sexuality and health. I'd like to start by giving you some background information about why we're having this group discussion. The New York State Department of Health has asked us to help them learn about how people think about health across the lifespan. Generally, it's about things people do that affect their health, all throughout life. We really want to get the perspective of young people on this topic. So rather than us as adults trying to figure out the answers, we're going directly to the experts themselves....young people. We're meeting with young people, like yourselves, all across New York State asking you to share your knowledge and opinions with us. The information we get will help New York State plan how to better meet the health needs of young people.

Expectations for the Group:

So, I'd like to tell you what you can expect from today's session. We'll be here for about an hour and a half. During that time I'm going to be asking you a number of questions. I would like to stress that there are no right or wrong answers to any of the questions. We consider you to be the experts and we're here to learn from you.

We know that you all might have different opinions and different responses which is great. This is not a debate...we're interested in hearing all different points of views. Even if you think your experience or opinions are different from the rest of the group, please feel free to share. If someone says something that you agree with or disagree with, or that you'd like to talk about further, feel free to share your opinion. You can also talk directly to other participants in the group...you don't need to respond directly to me. But, I will ask that only one person in the group speaks at a time so everyone in the group can hear what's being said. I also ask that we be respectful towards each other. What being respectful means for this group is that we don't talk over other people, we don't argue with each other, and we don't make fun of anyone's answers or opinions. [Optional: I'd like everyone to take a look at the ground rules that we have posted and to observe them during our group discussion today].

Because everyone's responses are important to us, there might be times when I'll call on you if I notice that you're not saying much. If you're not comfortable responding you don't have to answer...you can just say "pass". There may also be times when I notice that you're saying a lot, and so I might ask you to let others in the group speak. Please don't be offended if I do that. Your opinions are still important to us, we just want to be sure that everyone has a chance to participate.

Recording and Confidentiality:

You might have noticed that [Notetaker 1] and [Notetaker 2] have pens and paper. They will be recording notes during the session so that we can capture all of your opinions and responses. We will not be recording any of your names. Everything that is said in this room will be reported anonymously. This means that we will not link any of your names to anything you might say today. Please remember that we're here to learn from you, so we'd really appreciate it if you would answer honestly.

If all of you give us permission to, we'd also like to record today's conversation with this [HOLD UP AUDIO RECORDER] digital recorder. When you read, ask questions about, and sign your consent forms, you'll see there's a separate line to sign if you agree to have our discussion audio recorded. The only reason we want to record today's conversation is to back up the notes that [Notetaker 1] and [Notetaker 2] take. If they miss something or want to hear something you said again, having the audio recording means we can play it back. If you don't want to have today's conversation recorded, that's fine. We can still talk and [Notetaker 1] and [Notetaker 2] will just take hand-written notes.

Everything said during this focus group needs to be kept confidential by you, too. You likely know some of the others here for this focus group. Please respect everyone's privacy and don't discuss what we talk about here today outside of this group.

Questionnaire and Participant Honoraria

We'll end today's session at XX:XX. At that time we will ask you to complete a very short written questionnaire, and will give you \$20 to thank you for your time and participation today.

Before we get started does any one have any questions for me?

Also, please feel free to ask me to repeat a question if you didn't hear or understand it.

Participant Introductions / Icebreaker:

Okay, so let's begin. First we'd like to ask you to introduce yourselves. Let's go around the room and if you could please tell us just your first name and age, and something that you like to do for fun.

- Introduce self and notetakers
- Background:
 - Discussion about health, particularly sexuality and health, lifespan health
 - Want to talk to the experts – YOU!
 - NYS DoH want the info to better meet health needs of young people
- Expectations:
 - 1.5 hour long session
 - No right or wrong answers
 - Want to hear different perspectives and opinions
 - Can talk directly to each other – not just to me – but please one at a time
 - Be respectful of each other
 - Might call on you, but you can say “pass”
 - Might ask you to let others in the group speak
- Recording and confidentiality:
 - Note takers will record your opinions and responses
 - No names will be recorded
 - Please be honest!
 - Would like to audio record
 - Separate signature line on the consent form if you are ok with that
 - This will be back-up in case the note takers miss something
 - Everything said in this focus group needs to be kept confidential by you, too
 - Please don't discuss what was said here today outside of the group
- After the discussion:
 - We will end at XX:XX
 - We'll ask you to complete a short questionnaire
 - And give you the \$20 for your participation today
- Any questions?

ADOLESCENT HEALTH FOCUS GROUPS

Parental Permission Signature Form

(For Parents/Guardians of Participants Younger than 18 Years of Age)

We ask that you read this form and ask any questions you may have before agreeing to be in the project.

What the project is about: The purpose of this project is to explore young peoples' thinking about their current healthy behaviors and their connection to their future health and well-being in adulthood, especially as it pertains to potential future childbearing.

What we will ask your child to do: If you give permission for your child to be in this project, we will ask your child to participate in a discussion, or focus group. The group leader will ask questions of the group, and your child is encouraged to answer the questions and respond to the comments others in the group make. After the discussion, we'll ask your child to complete a short questionnaire to tell us more about your child. This will take about an hour and a half.

Risks and benefits of being in the project: Your child will not face any risks from participating other than those faced in day-to-day life. The survey questionnaire won't ask for names or other identifying information. The forms with names will be kept separate from the completed questionnaires and separate from the focus group notes. The benefits from participating in this project include learning more about how to maintain one's optimal health throughout life and about preventing risks. It also affords the opportunity to inform and influence the New York State Department of Health's initiatives and programs to promote adolescent health and well-being.

Compensation: Your child will receive \$20 as a "thank you" gift for participating in the focus group and completing the questionnaire.

Taking part is voluntary: Your decision about whether or not your child can participate will not affect your current or future relationship with Cornell University or with other organizations involved in the project. We will also talk to your child about participating and ask him or her to sign an assent form. If your child decides to participate, he or she is free to stop participating in the project at any time.

Your child's responses are confidential: The records of this project will be kept private. Only the Cornell University researchers responsible for the project will be able to look at the records containing your child's name, and to look at the notes, questionnaires, and other materials containing your child's comments. Your child's name will not be mentioned in any report about the project unless we obtain a separate signed permission form from you. Otherwise, the reports we may publish on this project will not contain information that would make identification of your child possible. In addition, even if you agree to have your child's name included in a report, we will make it impossible to tell which are your child's answers or comments, and which are someone else's answers. Surveys and consent forms will be kept in a locked file; only the researchers will have access to the records.

If you have questions: Please ask any questions you have now, before you sign the form. If you have questions later, you may contact the Cornell University researcher responsible for this project, Jane Powers, by email at jlp5@cornell.edu or by calling 607-255-3993. If you have any questions or concerns regarding your child's rights as a subject in this study, you may contact the Institutional Review Board (IRB) at irbhp@cornell.edu or 607-255-5138 or access their website at <http://www.irb.cornell.edu>. You may also report your concerns or complaints anonymously through [Ethicspoint](http://www.ethicspoint.com) (www.ethicspoint.com) or by calling toll free at 1-866-293-3077. Ethicspoint is an independent organization that serves as a liaison between the University and the person bringing the complaint so that anonymity can be ensured.

If you agree to give permission for your child to participate, please sign and date this form. You will be given a copy of this form to keep for your records

Statement of consent:

I have read the above information, and have received answers to any questions I asked.

By signing below, I indicate I consent to participate in the project.

Please check one:

- I **DO NOT** consent to having the focus group audio-recorded.
- I **DO** consent to having the focus group audio-recorded.

Your child's name: _____

Your signature: _____ Date _____

Your printed name: _____

Printed name of person obtaining consent: _____

This consent form will be kept by the researcher for at least three years after the end of the study. It was approved by the IRB on XXXXXX XX, XXXX.

ADOLESCENT HEALTH FOCUS GROUPS

Assent Form (For Participants 13-17 Years of Age)

We ask that you read this form and ask any questions you may have before agreeing to be in the project.

What the project is about: The purpose of this project is to explore young peoples' thinking about their current healthy behaviors and their connection to their future health and well-being in adulthood, especially as it pertains to potential future childbearing.

What we will ask you to do: If you agree to be in this project, we will ask you to participate in a discussion, or focus group. The group leader will ask questions of the group, and you are encouraged to answer the questions and respond to the comments others in the group make. After the discussion, we'll ask you to complete a short questionnaire to tell us more about yourself. This will take about an hour and a half.

Risks and benefits of being in the study: You will not face any risks from participating other than those you face in day-to-day life. The survey questionnaire won't ask for names or other identifying information. The forms with names will be kept separate from the completed questionnaires and separate from the focus group notes. The benefits from participating in this project include learning more about how to maintain one's optimal health throughout life and about preventing risks. It also affords the opportunity to inform and influence the New York State Department of Health's initiatives and programs to promote adolescent health and well-being.

Compensation: You will receive \$20 as a "thank you" gift for participating in the focus group and completing the questionnaire.

Taking part is voluntary: Taking part in the project is voluntary. You may not answer or skip any questions during the focus group or on the survey that you do not want to answer. If you decide to take part, you are free to stop participating at any time. Nothing will affect your current or future relationship with Cornell University or with other organizations involved in the project.

Your responses are confidential: The records of this project will be kept private. Only the Cornell University researchers responsible for the project will be able to look at the records containing your name, and to look at the notes, questionnaires, and other materials containing your comments. Your name will not be mentioned in any report about the project unless we obtain a separate signed permission form from you. The reports we may publish on this project will not contain information that would make your identification possible. We will make it impossible to tell which are your answers or comments, and which are someone else's answers. Focus group notes, surveys, and consent forms will be kept in a locked file; only the researchers will have access to the records.

If you have questions: Please ask any questions you have now, before you sign the form. If you have questions later, you may contact the Cornell University researcher responsible for this project, Jane Powers, by email at jlp5@cornell.edu or by calling 607-255-3993. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) at (irbhp@cornell.edu) or 607-255-5138 or access their website at <http://www.irb.cornell.edu>. You may also report your concerns or complaints anonymously through [Ethicspoint](http://www.ethicspoint.com) (www.ethicspoint.com) or by calling toll free at 1-866-293-3077. Ethicspoint is an independent organization that serves as a liaison between the University and the person bringing the complaint so that anonymity can be ensured.

If you agree to participate, please sign and date this form. You will be given a copy of this form to keep for your records.

Statement of assent:

I have read the above information, and have received answers to any questions I asked.

By signing below, I indicate I consent to participate in the project.

Please check one:

- I **DO NOT** consent to having the focus group audio-recorded.
- I **DO** consent to having the focus group audio-recorded.

Signature: _____ Date _____

Your Printed Name: _____

Printed name of person obtaining consent: _____

This consent form will be kept by the researcher for at least three years after the end of the study. It was approved by the IRB on XXXXXX XX, XXXX.

ADOLESCENT HEALTH FOCUS GROUPS

Consent Form *(For Participants 18 Years of Age and Older)*

We ask that you read this form and ask any questions you may have before agreeing to be in the project.

What the project is about: The purpose of this project is to explore young peoples' thinking about their current healthy behaviors and their connection to their future health and well-being in adulthood, especially as it pertains to potential future childbearing.

What we will ask you to do: If you agree to be in this project, we will ask you to participate in a discussion, or focus group. The group leader will ask questions of the group, and you are encouraged to answer the questions and respond to the comments others in the group make. After the discussion, we'll ask you to complete a short questionnaire to tell us more about yourself. This will take about an hour and a half.

Risks and benefits of being in the study: You will not face any risks from participating other than those you face in day-to-day life. The survey questionnaire won't ask for names or other identifying information. The forms with names will be kept separate from the completed questionnaires and separate from the focus group notes. The benefits from participating in this project include learning more about how to maintain one's optimal health throughout life and about preventing risks. It also affords the opportunity to inform and influence the New York State Department of Health's initiatives and programs to promote adolescent health and well-being.

Compensation: You will receive \$20 as a "thank you" gift for participating in the focus group and completing the questionnaire.

Taking part is voluntary: Taking part in the project is voluntary. You may not answer or skip any questions during the focus group or on the survey that you do not want to answer. If you decide to take part, you are free to stop participating at any time. Nothing will affect your current or future relationship with Cornell University or with other organizations involved in the project.

Your responses are confidential: The records of this project will be kept private. Only the Cornell University researchers responsible for the project will be able to look at the records containing your name, and to look at the notes, questionnaires, and other materials containing your comments. Your name will not be mentioned in any report about the project unless we obtain a separate signed permission form from you. The reports we may publish on this project will not contain information that would make your identification possible. We will make it impossible to tell which are your answers or comments, and which are someone else's answers. Focus group notes, surveys, and consent forms will be kept in a locked file; only the researchers will have access to the records.

If you have questions: Please ask any questions you have now, before you sign the form. If you have questions later, you may contact the Cornell University researcher responsible for this project, Jane Powers, by email at jlp5@cornell.edu or by calling 607-255-3993. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) at (irbhp@cornell.edu) or 607-255-5138 or access their website at <http://www.irb.cornell.edu>. You may also report your concerns or complaints anonymously through [Ethicspoint](http://www.ethicspoint.com) (www.ethicspoint.com) or by calling toll free at 1-866-293-3077. Ethicspoint is an independent organization that serves as a liaison between the University and the person bringing the complaint so that anonymity can be ensured.

If you agree to participate, please sign and date this form. You will be given a copy of this form to keep for your records.

Statement of consent:

I have read the above information, and have received answers to any questions I asked.

By signing below, I indicate I consent to participate in the project.

Please check one:

I **DO NOT** consent to having the focus group audio-recorded.

I **DO** consent to having the focus group audio-recorded.

Signature _____ Date _____

Your Printed Name: _____

Printed name of person obtaining consent: _____

This consent form will be kept by the researcher for at least three years after the end of the study. It was approved by the IRB on XXXXXX XX, XXXX.

Lifespan Health Focus Group Questions

Living a healthy lifestyle

1. What are some things you and your friends do now to be healthy?
[Prompts: Exercise? Play sports? Eat right? Avoid alcohol/drugs? Protected sex or abstinence? Encourage family/friends to engage in healthy behaviors?]
2. What are some ways you and your friends could be more healthy?
3. What makes you and your friends want to live a healthy lifestyle?
4. What makes it hard for you and your friends to live a healthy lifestyle?
5. How much do you and your friends talk about things related to health like exercise or nutrition? How much do you talk about these things with your family?

Future health

6. What are some things you and your friends do now that might have an impact on your health in the future, say in 10, 20, or 30 years?
7. How much do think about how what you do now might impact your health in the future?
8. How much do you talk about your future health with your friends? With your family?

Future children

9. How much do you think about how your health behaviors now might impact any children you might have in the future? Do you talk about this with your friends? Your family?
10. What are some things a pregnant woman or a woman who might want to become pregnant **should do**? What are some things she **shouldn't do**?
[Prompts: use of folic acid supplements, healthy diet, exercise, avoiding substance use] How could these things affect the mother or baby?
11. What are some things a man who might want to become a father **should do**? What are some things he **shouldn't do**?
[Prompts: healthy diet, exercise, reading about pregnancy or babies]

Disparities

SENSITIZER – WHAT DO YOU THINK?

OPTIONS: TRUE FALSE DON'T KNOW

Tell the participants that you'll read a few statements and ask them what they think about each one. Ask the participants: "Stand up if you think this is true.... Okay. Sit down. [pause] Stand up if you think this is false... Okay. Sit down. [pause] Stand up if you don't know if it's true or false. [Alternate: Have the options printed on cards that are pasted on the wall in different parts of the room. Ask the participants to go to the card that reflects what they think about the statement.]

- The stress of inequality can have an impact on people’s health. What do you think? **True?** False? Don’t know?

DEBRIEF: 1) High school dropouts die, on average, 6 years sooner than college graduates.ⁱ

2) Research has shown that being exposed to stressful experiences even BEFORE pregnancy make it more likely a woman will have a premature or low birth weight baby.ⁱⁱ

- In New York state, the rates of infant mortality (infants who die) are about the same for all races and ethnicities. What do you think? True? **False?** Don’t know?

DEBRIEF: For example, in 2006, for every 1000 black babies born, 9 died before their first birthday. In the same year, for every 1000 white babies born, 5 died before their first birthday.ⁱⁱⁱ

- HIV/AIDS is known as an “equal opportunity infection.” This means that it has the same impact on all people. What do you think? True? **False?** Don’t know?

DEBRIEF: In 2006, HIV was the 3rd leading cause of death among Black women ages 25–44, compared to 5th for women overall in the U.S.^{iv}

- Women are more vulnerable to getting sexually transmitted infections when they are teenagers than when they are adults because their cervix is still maturing. What do you think? **True?** False? Don’t know?

DEBRIEF: This makes adolescent girls more likely to become infected with gonorrhea or Chlamydia than older women or males.

1. What is your first reaction to this information?
2. Why do you think these differences exist?

[IF THIS DOES NOT COME OUT IN RESPONSE TO QUESTION ABOVE:]

Statistics like this show that things that impact health aren’t just up to the individual person. Differences between groups of people, like structural or social inequalities, can impact health. Like:

- whether or not a person finished high school,
- a person’s gender or race, or
- age differences,

These can impact an individual person’s health in ways we might not think about very much.

3. What are some things you and your friends or family could do to change this?
4. What are some things you think people in power (such as the NYS DoH) could do to change this?
5. Here is an example of what people are doing: **EXAMPLE** What do you think? Do you know of other examples where young people are becoming activists?

EXAMPLE: In 2008 the Office of Minority Health launched a campaign called “A Healthy Baby Begins with You.” The campaign uses college students as peer educators to share information on college campuses as well as larger communities.^v During College to Community Outreach Week, the peer educators from local universities in Memphis, Tennessee participated in a number of events, such as youth training, door-to-door

canvassing, school visits, professional workshops, and a Community Baby Shower and Health Fair.^{vi}

Wrap up

Do you have any other comments you'd like to share?

["thank you" ... brief survey]

ⁱ <http://www.groundreport.com/US/PBS-Series-Looks-at-How-Inequality-Is-Making-Us-Si/2858139>

ⁱⁱ <http://www.unnaturalcauses.org/assets/uploads/file/primers.pdf>

ⁱⁱⁱ <http://datacenter.kidscount.org/data/acrossstates/Rankings.aspx?ind=21>

^{iv} <http://www.kff.org/hiv/aids/upload/6092-07.pdf>

^v <http://minorityhealth.hhs.gov/templates/content.aspx?ID=6878&lvl=2&lvlID=117>

^{vi} <http://www.tri-statedefenderonline.com/articlelive/articles/3771/1/br-Memphis-ground-zero-in-war-on-infant-mortality/Page1.html>

Lifespan Health Focus Group Questions – FOR NOTE-TAKING

Group/Program: _____

Date: _____

Living a healthy lifestyle

1. What are some things you and your friends do now to be healthy?

[Prompts: Exercise? Play sports? Eat right? Avoid alcohol/drugs? Protected sex or abstinence? Encourage family/friends to engage in healthy behaviors?]

2. What are some ways you and your friends could be more healthy?

3. What makes you and your friends want to live a healthy lifestyle?

4. What makes it hard for you and your friends to live a healthy lifestyle?

5. How much do you and your friends talk about things related to health like exercise or nutrition? How much do you talk about these things with your family?

Future health

6. What are some things you and your friends do now that might have an impact on your health in the future, say in 10, 20, or 30 years?

7. How much do think about how what you do now might impact your health in the future?

8. How much do you talk about your future health with your friends? With your family?

Future children

9. How much do you think about how your health behaviors now might impact any children you might have in the future? Do you talk about this with your friends? Your family?

10. What are some things a pregnant woman or a woman who might want to become pregnant *should do*? What are some things she *shouldn't do*?

[Prompts: use of folic acid supplements, healthy diet, exercise, avoiding substance use] How could these things affect the mother or baby?

11. What are some things a man who might want to become a father *should do*? What are some things he *shouldn't do*?

[Prompts: healthy diet, exercise, reading about pregnancy or babies]

Disparities

SENSITIZER – WHAT DO YOU THINK?

OPTIONS: TRUE FALSE DON'T KNOW

Tell the participants that you'll read a few statements and ask them what they think about each one. Ask the participants: "Stand up if you think this is true.... Okay. Sit down. [pause] Stand up if you think this is false... Okay. Sit down. [pause] Stand up if you don't know if it's true or false. [Alternate: Have the options printed on cards that are pasted on the wall in different parts of the room. Ask the participants to go to the card that reflects what they think about the statement.]

- The stress of inequality can have an impact on people's health. What do you think? **True?** False? Don't know?
DEBRIEF: 1) High school dropouts die, on average, 6 years sooner than college graduates.
2) Research has shown that being exposed to stressful experiences even BEFORE pregnancy make it more likely a woman will have a premature or low birth weight baby.

- In New York state, the rates of infant mortality (infants who die) are about the same for all races and ethnicities. What do you think? True? **False?** Don't know?

DEBRIEF: For example, in 2006, for every 1000 black babies born, 9 died before their first birthday. In the same year, for every 1000 white babies born, 5 died before their first birthday.

-
- HIV/AIDS is known as an "equal opportunity infection." This means that it has the same impact on all communities. What do you think? True? **False?** Don't know?

DEBRIEF: In 2006, HIV was the 3rd leading cause of death among Black women ages 25–44, compared to 5th for women overall in the U.S.

-
- Women are more vulnerable to getting sexually transmitted infections when they are teenagers than when they are adults because their cervix is still maturing. What do you think? **True?** False? Don't know?

DEBRIEF: This makes adolescent girls more likely to become infected with gonorrhea or Chlamydia than older women or males.

1. What is your first reaction to this information?

2. Why do you think these differences exist?

[IF THIS DOES NOT COME OUT IN RESPONSE TO QUESTION ABOVE:]

Statistics like this show that things that impact health aren't just up to the individual person. Differences between groups of people, like structural or social inequalities, can impact health. Like:

- whether or not a person finished high school,
- a person's gender or race, or
- age differences,

These can impact an individual person's health in ways we might not think about very much.

3. What are some things you and your friends or family could do to change this?

4. What are some things you think people in power (such as the NYS DoH) could do to change this?

5. Here is an example of what people are doing: **EXAMPLE** What do you think? Do you know of other examples where young people are becoming activists?

Wrap up

Do you have any other comments you'd like to share?

Other Notes/Special Characteristics

Lifespan Health Focus Group Questions – FOR NOTE-TAKING

Group/Program: _____

Date: _____

Living a healthy lifestyle

1. What are some things you and your friends do now to be healthy?

[Prompts: Exercise? Play sports? Eat right? Avoid alcohol/drugs? Protected sex or abstinence? Encourage family/friends to engage in healthy behaviors?]

2. What are some ways you and your friends could be more healthy?

3. What makes you and your friends want to live a healthy lifestyle?

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Future health

6. What are some things you and your friends do now that might have an impact on your health in the future, say in 10, 20, or 30 years?

7. How much do think about how what you do now might impact your health in the future?

8. How much do you talk about your future health with your friends? With your family?

Future children

9. How much do you think about how your health behaviors now might impact any children you might have in the future? Do you talk about this with your friends? Your family?

10. What are some things a pregnant woman or a woman who might want to become pregnant *should do*? What are some things she *shouldn't do*?

[Prompts: use of folic acid supplements, healthy diet, exercise, avoiding substance use] How could these things affect the mother or baby?

11. What are some things a man who might want to become a father *should do*? What are some things he *shouldn't do*?

[Prompts: healthy diet, exercise, reading about pregnancy or babies]

Disparities

SENSITIZER – WHAT DO YOU THINK?

OPTIONS: TRUE FALSE DON'T KNOW

Tell the participants that you'll read a few statements and ask them what they think about each one. Ask the participants: "Stand up if you think this is true.... Okay. Sit down. [pause] Stand up if you think this is false... Okay. Sit down. [pause] Stand up if you don't know if it's true or false. [Alternate: Have the options printed on cards that are pasted on the wall in different parts of the room. Ask the participants to go to the card that reflects what they think about the statement.]

- The stress of inequality can have an impact on people's health. What do you think? **True?** False? Don't know?
DEBRIEF: 1) High school dropouts die, on average, 6 years sooner than college graduates.
2) Research has shown that being exposed to stressful experiences even BEFORE pregnancy make it more likely a woman will have a premature or low birth weight baby.

- In New York state, the rates of infant mortality (infants who die) are about the same for all races and ethnicities. What do you think? True? **False?** Don't know?

DEBRIEF: For example, in 2006, for every 1000 black babies born, 9 died before their first birthday. In the same year, for every 1000 white babies born, 5 died before their first birthday.

-
- HIV/AIDS is known as an "equal opportunity infection." This means that it has the same impact on all communities. What do you think? True? **False?** Don't know?

DEBRIEF: In 2006, HIV was the 3rd leading cause of death among Black women ages 25–44, compared to 5th for women overall in the U.S.

-
- Women are more vulnerable to getting sexually transmitted infections when they are teenagers than when they are adults because their cervix is still maturing. What do you think? **True?** False? Don't know?

DEBRIEF: This makes adolescent girls more likely to become infected with gonorrhea or Chlamydia than older women or males.

1. What is your first reaction to this information?

2. Why do you think these differences exist?

[IF THIS DOES NOT COME OUT IN RESPONSE TO QUESTION ABOVE:]

Statistics like this show that things that impact health aren't just up to the individual person. Differences between groups of people, like structural or social inequalities, can impact health. Like:

- whether or not a person finished high school,
- a person's gender or race, or
- age differences,

These can impact an individual person's health in ways we might not think about very much.

3. What are some things you and your friends or family could do to change this?

4. What are some things you think people in power (such as the NYS DoH) could do to change this?

5. Here is an example of what people are doing: **EXAMPLE** What do you think? Do you know of other examples where young people are becoming activists?

Wrap up

Do you have any other comments you'd like to share?

Other Notes/Special Characteristics

Focus Group – Written Questionnaire

Directions: Please circle or fill in your answers for each question. This survey is confidential. Please do not write your name on this survey. Thanks again for your time.

1. How old are you? _____

2. What is your gender?

A. Male

B. Female

C. Transgender

3. What is your race/ethnicity? (check all that apply)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

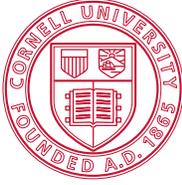
Hispanic or Latino

White

Other _____

4. What is your home ZIP code? _____

5. Is there anything you would like to tell us that you did not get a chance to share during the group discussion?



Cornell University

Kirstin Gasteiger
Accounts Rep
FLDC
Beebe Hall

PAYMENT INFORMATION FOR RESEARCH PARTICIPATION
Lifespan Health Focus Group Project

Please print clearly:

NAME: _____

ADDRESS: _____

I have received \$20 for participating in this research project.

SIGNATURE: _____

Citizenship (please circle one) USA Other: _____

FACILITATION

Three biggest things to keep in mind:

- Try to “stick to the script” as much as possible
 - This will make note-taking easier, ensure you get through all of the questions, and make synthesizing the notes easier
 - Even if it feels like the group has indirectly responded to a question in an earlier place, it’s worth it to directly ask the question
 - “I know we’ve already talked about this some, but...”
- Be comfortable with silence!
 - Only rephrase or restate a question if asked, or if there has been a LONG period of silence
 - It will feel uncomfortable sometimes, but people need to process the question, come up with a response, and take the time to come up with the courage to state their response
 - If need be, slowly tap out a count of 15 or 20 (or use some other aid) before restating the question or moving on
- You are in charge!
 - If someone is dominating the conversation, be prepared with ways to get back to group discussion
 - “You’ve had lots to share – do others have something to add?”
 - “I want to particularly ask those who haven’t had much to share up to this point to comment on the next question.”
 - If the response to a particular question is going on and on, you need to get back to the questions:
 - “I can see that there’s a lot to say about this, but in the interest of time, we need to move on.”

Other tips:

- Be sure to review the ground rules before starting
 - This might feel awkward, especially with a group of peers, but it’s valuable to get everyone on the same page, and gives you something to refer back to
 - “If you remember the ground rules we talked about, we want to make sure we give everyone a chance to speak...”
- Speak slowly and be brief in stating the questions (i.e., stick to the script) – participants need to hear and “digest” what you are asking.
- Don’t lead participants towards a certain kind of response when asking the question (again, stick to the script).
 - ONLY USE PROMPTS after participants have had a chance to respond to the open-ended question and when no one has more to say in response to that; prompts can then be used to cover topics/ideas that didn’t come up naturally in response to the open-ended question

- Remain neutral when hearing/affirming responses
 - “that’s one idea”
 - “What are some other ideas?”
- Think about your body language! You want to be a GREAT listener. This can encourage/discourage participation!
 - Look at the person speaking
 - Nodding is fine
 - Only look at your notes/scripts as needed, and avoid doing that while someone is speaking if at all possible.
- For the sections with scenarios, remind participants that the subquestions refer to the **hypothetical scenario**, not whatever personal experience they may have shared in response to the previous question – **keep bringing them back to the scenarios**.

NOTE-TAKING:

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- One note-taker should also act as timekeeper; somehow signal the facilitator when you are halfway through (about 45 min) and when you have 10 min left

AFTER THE FOCUS GROUP:

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